ACHONDROPLASIA

MULTIPLE EPIPHYSAL DYSPLASIA

LEBER CONGENITAL AMAUROSIS

LEBER HEREDITARY OPTIC NEUROPATHY

RARE DISEASES GUIDE IN ORDINARY EDUCATION

FACIOESCAPULOHUMERAL DYSTROPHY

Children with **R**ar**E**
Diseases and their
Inclusion in **B**asic
Learning **E**nvironments

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HIRSCHPRUNG DISEASE

EHLERS-DANLOS SYNDROME,
HYPERMOBILE TYPE

TEACHER'S GUIDE FOR INCLUSIVE EDUCATIONAL ACTIONS WITH CHILDREN WITH RARE DISEASES

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INTRODUCTION

This guide is the result of the coordinated work of the partners that make up the Erasmus + CREDIBLE project "Children with Rare Diseases and their Inclusion in Basic Learning Environments" (K201 2019-1-ES01-KA201-063925).

The world of rare diseases is enormously complex due to the large number of pathologies of this type that are described and catalogued, and to the dispersion and scientific-medical nature of the information related to them.

Teachers who work in the field of special education with children with rare diseases are very familiar with the problems that accompany the education and comprehensive care of these children, however, ordinary school teachers, since they interact with this type of children less frequently, they may find it more difficult to interact with them due to ignorance, fear and uncertainty.

It is accepted that the ordinary school is the area in which, beyond the family environment, social integration and autonomy begin to function. It would be desirable, therefore, that any child with a rare disease, whose characteristics do not determine the unavoidable need for special education, could access to it as one more step towards a full personal and social life.

The objective of this guide is to facilitate the inclusion of children with rare diseases in the ordinary school, providing teachers with support material with easy and quick access to specific and relevant information for them in the ordinary school environment.

This guide makes sense and is useful by itself, but its ideal use, in the context of the CREDIBLE project, as complementary material to the information available on the platform for exchanging teaching experiences, (https://credible.softspring.cloud/) which is the main objective of the project.

In this way, if a teacher needs information on a specific disease that has not been reported, the platform will still be able to consult the information available on the disease of interest in this guide, obtaining the guidelines for the basic approach to the challenge of that working with a student who suffers a rare dissease.

The first step in the development of this guide was probably the most complicated. Taking into account that there are about 7,000 rare diseases, and it is impossible to collect them all, and that we did not have specific prevalence data in ordinary schools, it was a priority to select those that, given their global prevalence and their characteristics, were more likely to be found in the mainstream schools.

It has been used as a starting point the document prepared by Orphanet "Prevalence and incidence of rare diseases: Bibliographic data" (2020) and began to work on its list of decreasing prevalence, applying the following exclusion criteria: that it was not, strictly, a rare disease (more than 5 people out of 10,000 suffered from it), that it exclusively affected adults, that there was a very high risk of causing death before 3 years of age or that it limitedly affected cognitive functions or required, in most cases, special schooling.

In this way, 31 rare diseases were selected and included in this first edition.

For each one of them, a card was prepared that contains specific information related to the relevant aspects of the pathological picture (symptoms, complications, treatments, emergency situations, etc.) in the ordinary school environment, expressed through a language adapted to the population. general and free of technicalities.

As it could not be otherwise, the specific and general pedagogical adaptations recommended were also specified based on the potential limitations that the presence of each of the rare diseases collected could imply for the children who suffer from them.

To ensure a successful learning process for students with rare diseases asks for careful attention, support, and encouragement from all the involved parties. Students with rare diseases have the same rights to education, social inclusion, support, and participation as all other students.

There are diverse rare diseases in the world. They can differ from each other in terms of their clinical picture, form, and severity. It is not expected that teachers become medical experts, however, they do need basic knowledge of each specific illness of a student they have in their lessons as it can help recognise the impact the rare disease has on the student's school life. Moreover, such knowledge may help find the most effective solutions for inclusive education. Having knowledge of rare diseases of their students, give teachers an opportunity to take care of students' need for autonomy and sense of belonging. It also allows these students concentrate on other matters not only their disease. A school that is inclusive pays attention to the individual needs of students with rare diseases. A deeper understanding of students' life in school and outside is of significance for all those involved, especially scool administration and teachers.

All parties involved have to keep in mind that each student reacts to one's disease and manages it differently. It should be noted that from an early age a lot of students have experienced what it is like to be 'different' thus finding out information about their disease. A lot of students are constantly faced with challenges, for example, various limitations of the disease and the treatment they need. It means tackling different exceptions in everyday school life and at home, desiring to be 'normal'. Every student wants to have great childhood and exciting youth.

Not all students with rare diseases need the same level of support. Sometimes it is only important that people around know about the student's rare disease and know how to act properly in emergency situations.

Rare diseases are associated with a variety of factors, such as adverse drug reactions, painful procedures, fear, need to stay in hospital, progression of a disease, discipline in therapeutic interventions. Moreover, these are existential aspects, such as hopelessness and invariance, dependence on prejudice, etc. The most common issues students with rare diseases face are the following:

- social risks if the student has had the disease recently, or this information has been kept secret;
- learning performance is rated lower than the student's actual ability;
- social exclusion: among peers students with rare diseases may be perceived as a 'disruptive factor' or 'burden', which can consequently lead to their low self-esteem;
- teachers may ignore students with rare diseases.

Any rare disease can cause particular stress, which can seriously affect a student's process of schooling.

- physical stress such as pain or discomfort, a lack of sleep;
- restrictions that impact the qulity of life;
- structuring one's day according to requirements imposed by the disease, for example, having special periods of rest, time for daily treatment procedures, frequent visits to doctors;
- work capacity restraints and the increased effort required to achieve the same results the classmates do;
- behavioural changes related to the use of medicine containing drugs;
- limited social contacts because of being stigmatised or adapting free time to requirements of the disease;
- being a burden to one's family;
- atypical life planning, for example, expecting limited future prospects;
- low self-esteem, peculiarities of psyche because of having experienced fear or constant confrontation with one's limitations;
- addictive relationships with adults because of feeling dependent on them.

What teachers can do Cooperation with parents

Parents of students with rare diseases are significant partners for teachers as they are the ones who can give all the necessary information about their child. This would include a medical diagnosis, situations and things causing stress and tension to their child, as well as information on necessary or desired aids. A successful learning process that meets the needs and wishes of the student requires mutual trust and regular exchange of information. It is important that the cooperation is focused and takes place even before any difficulties arise. Parents have to be informed of changes going on at school, for example, substitute teachers, student teachers, etc. It is recommended that school administration develop a detailed questionnaire for the student's parents so that the class teacher can successfully prepare for a conversation with them.

The specific way to plan, organise, and manage the learning process for students with rare diseases can only be chosen once information on the needs and interests of each child has been obtained, as each disease has its own peculiarities. It is also essential to communicate with the doctor of the student to find out how the disease may affect one's daily schooling, what possible side effects of medicine are and how to make daily routine at school easier for the student. However, the teacher needs a written permission of the student's parents to get in contact with the child's doctor.

Questions a teacher has to ponder over before the conversation with a student's parents

- What issues do I want to address?
- What goals do I want to achieve?

Questions a teacher may find useful to ask parents about a student's disease

- What kind of a disease is this one?
- How has the disease impacted the student's development and behaviour?
- What gives the most support in overcoming the challenges caused by the disease?
- How is the student's life at home organised?

Questions a teacher may find useful to ask parents about a student's current situation

- How does the student feel?
- What medical/therapeutic procedures/manipulations are performed on a daily basis?
- What is the situation in the family?
- Do siblings study at school?
- What should be taken into account in the learning process?
- How does the disease affect the student's daily life?
- What types of support are already available to the student and what additional solutions would be necessary?
- What are the student's strengths?
- Who should the teacher get in touch with in emergency situations? (It specifically applies to excursions or day trips as teachers and parents have to cooperate closely in these events.)

Questions a teacher may find useful to ask parents about setting goals?

- What will show that the things teachers and support staff do on a daily basis improve the student's situation at school?
- What does the student need in the elarning process?

Questions a teacher may find useful to ask parents about finding solutions?

- What can parents do at home to support the student thus indirectly promoting a positive organisation of one's school life?
- How can teachers facilitate the student's daily school life?
- To what extent and how should classmates be involved in supporting the student?
- What other school and out-of-school support measures are needed?

Questions a teacher may find useful to ask parents about reaching goals

- What are the tasks for the student, parents and the teacher?
- Should classmates (and/or classmates' parents) be informed? If so, in what form? Who will be involved in this process and how?
- How will the regular exchange of information between the school and the parents be organised?
- How often should meetings of teachers and parents take place? (It is necessary to agree on specific dates and times. Parents may be asked to put down information in a notebook on the time they spend doing school and out-of-school activities (homework, extracurricular activities, hobbies, etc.) together with the student.)

Cooperation with the medical staff

Communication among all the parties involved in the treatment and education of a student with a rare disease is a prerequisite for immediate and high quality support that is adapted to the student's needs and interests. To have such cooperation, written consent of the student's parents is necessary.

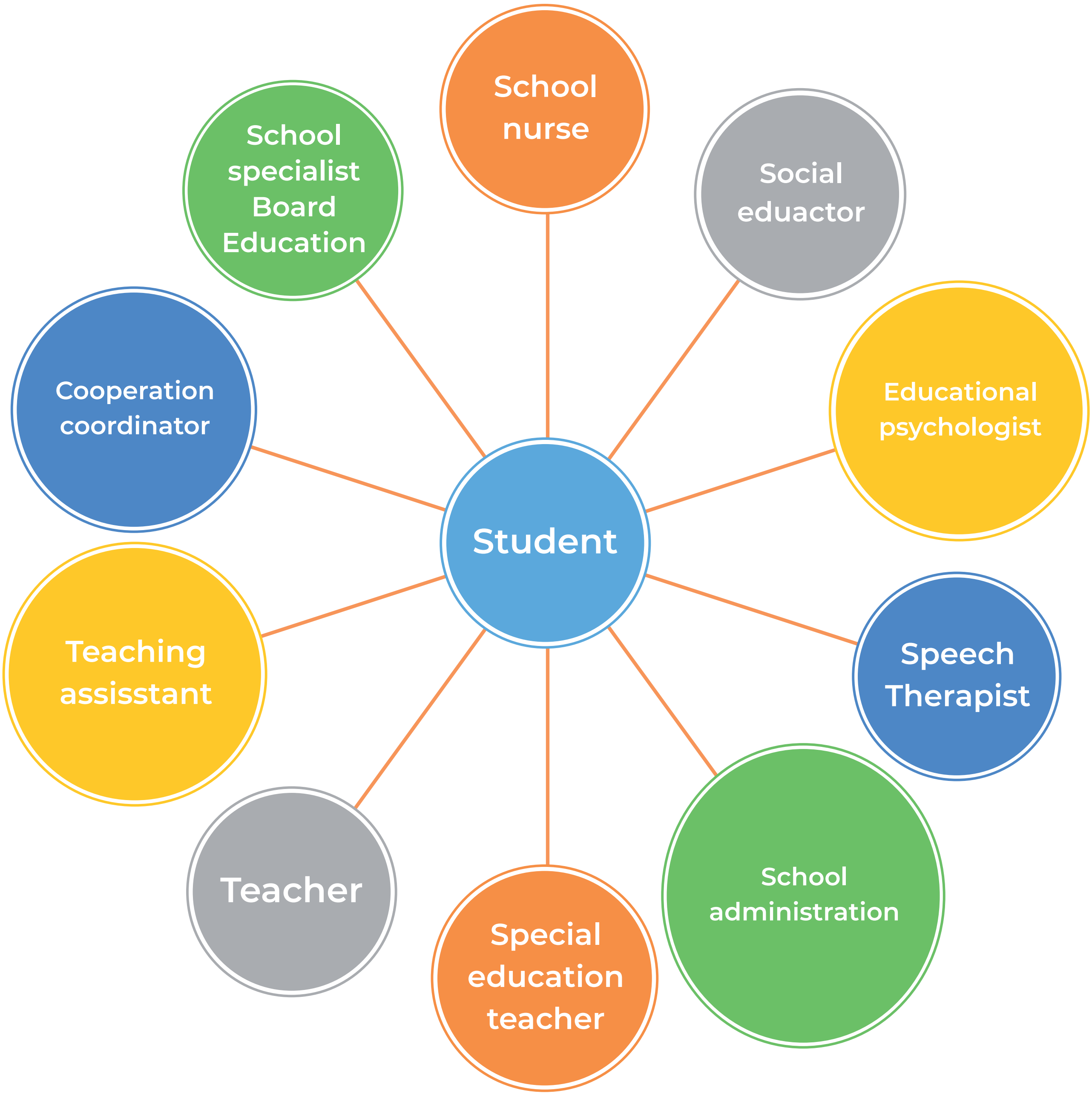
Support doctors can offer schools

- What essential knowledge about the disease of a student do school staff (teachers, school nurses, social educators, psychologists, etc.) need?
- Does the doctor of the student agree to cooperate with the school?
- Who will be the school contact at the medical institution (a hospital or clinic, a practice of a general practitioner)?
- How will the doctor support teachers and parents so that they can make relevant decisions on how to organise the student's learning?
- How will the school and the doctor work together or communicate when the student is in hospital?
- How will doctors be informed about the teacher's observations of the student's health in the learning process?
- What advice would the medical staff like to give to schools about the necessary support for the student at school?
- How to inform the student's parents about the goal of cooperation between the school and the doctor - that they want to provide the student with the most suitable conditions for learning?
- What kind of information exchange do the parents and the doctor agree to?

Cooperation among the school staff

The school support system for students with rare diseases may differ based on national regulations, the situation in the educational establishment and the partners the schools work with.

To support students with rare diseases, the school has to have one responsible person who acts as a coordinator for all the stakeholders in this situation.



The most important questions

- How is the school informed about the student's disease?
- How to pass on important information to the school without breaking the law of data protection and without compromising the student?
- How does the school ensure that all support measures taken at school are coordinated with the students's parents?
- How is it ensured that parents decide what kind of information is shared?
- How does the school raise awareness of the staff and other students about rare diseases and their consequences?
- What kind of activities does the school implement together with the parents?

The teacher is asked to count how much time the student needs to complete tasks, how quickly the student gets tired, to follow the student's emotional well-being, and to fix if any significant changes take place during the day. The teacher has to notice and document situations when the student is unable to complete tasks, for example, after therapy, procedures, etc. The teacher needs to be aware of one's emotional reactions to particular behaviour of a student with a rare disease.

Extracurricular activities

Participation in activities which take place out of school (for example, excursions, camps, international student exchange programmes) is important for every student. To avoid health hazard for students who have rare diseases, teachers who accompany these students have to consult the parents on the following issues:

The use of medication

- What medication should the student take and how often?
- Can the student take the medicine on one's own, or the teacher's help is needed?
- Is it necessary for a school nurse/doctor to accompany the student?
- Who should be called in emergency situations?

Ask the doctor to prepare an information file (information on the disease, medication and other therapeutic measures). If necessary, this file has to be translated into the language of the country the student is going to. If parents of the student do not accompany him/her, it is necessary to have a written authorisation from the parents letting the teacher accompany the student to the doctor or hospital.

If there is a student with a rare disease in a class, all the students should be involved in planning the trip - the location, activities and rules taking into account wishes and needs of the student with the rare disease. The classmates have to be informed about possible emergency situations and how to act in them.

Providing a digital learning process

When the student with the rare disease is at hospital or at home due to the one's health condition, the school may offer online learning so that the student can take part in classes, complete tasks and homework, or communicate with the classmates and teachers.

Before online learning

It is obligatory that parents, teachers and doctors discuss the organisation of online learning. The teacher responsible for the online learning process has to contact the parents and the doctor to find out which would be the most suitable time for the student with the rare disease to learn or communicate with the classmates or teachers.

Using medication at school

Medication can only be given to a student if there are a written request form the parents and written instructions from the doctor. As teachers are not trained to supervise the process of giving and taking medication, they are only allowed to help the student if the student cannot do it (for example, because of physical or cognitive development issues). If the teacher has any doubt, one must consult the parents or the doctor of the student. At school there have to be a person who is authorised to give medication to students and a person who supervises storage of the medication.

Emergency situations

A precondition for appropriate action in an emergency is its modelling, for example, under the supervision of the parents. It is the parents' responsibility to make sure that their child has necessary medication at school. Amount of the medication and expiry date have to be monitored regularly. It has to be clear who has to be contacted in emergency situations.

Assessment

Assessment has to be flexible, for example, in sports lesson it is advisable to assess only those exercises the student can do without assistance. Sometimes it is acceptable that the student with the rare disease take part in a sports lesson without being assessed.

If necessary, the amount of homework can be reduced.

Several breaks during the learning process have to be scheduled.

Class assignments can be done at different times or the time for completing a certain task can be prolonged.

Informing classmates

It is logical that classmates are informed about the situation the student with the rare disease is in, either a new class is formed or a new student joins the class. Students, who have not had any experience with diseases, often do not understand other people's pain and limitations.

One of the most important tasks of teachers is to create understanding among classmates about the situation of the student with the rare disease. The amount of information of rare diseases provided to classmates may vary from situation to situation.

There can be situations where the students with the rare diseases want to tell others about one's disease, its symptoms, needs, etc. It is believed that classmates should be informed to avoid rumours and false information because it can be traumatic. However, the situation should not be dramatised.

Only informed classmates are able to accept and understand that the student with the rare disease is 'different', reacts differently, needs medication, needs extra breaks or extra time, etc. If classmates are not informed, they may panic when, for example, they see a seizure or shock. However, there are cases when the parents of the student with the rare disease or the student oneself do not want to reveal this information to the classmates. Therefore before informing classmates, teachers have to discuss the situation with the student and one's parents.

The student

The student needs to be aware of one's disease and the risks and threats associated with it. For example, what one can or cannot do physically, what one is or not allowed to eat, what medication helps, etc. The student with the rare disease should be able to express their needs, issues, limitations, find solutions, ask for help from others when it is necessary, or talk to a teacher. This is significant support for the teacher. It allows the teacher to focus on one's work with the whole class, rather than constantly paying attention to or caring just for one student.

The student must be involved in taking care of one's needs if it is possible. The student's opinions have to be heard and incorporated in decision-making, according to one's age and the level of independence. It is important to remember to take medication to school or extracurricular activities, and take the medication regularly. The student should be able to notice the warning signs of an attack or exacerbation and respond accordingly. The student has to trust the teacher and ask for help in time. The student must learn one's behaviour control strategies. Teachers and classmates need to motivate students with rare diseases to participate and make them feel that they can meet the challenges.

ORPHA 15

Achondroplasia

DESCRIPTION OF THE DISEASE

Achondroplasia, formerly called "dwarfism", is a disease with characteristic physical features: short limbs with shortening of the bones closest to the body, long and narrow body, head large in proportion to the body, bulging of the forehead area, depressed nasal bridge and wide, short hands. The approximate height these people reach is 131 (± 5.6cm) in men and 124 (± 5.9cm) in women.

Acquisition of all motor-type skills is slower due to limb characteristics. In addition, chronic otitis often occurs, which can lead to the triggering of hearing problems.

Due to abnormalities in the joints, pain often occurs, which can cause difficulty in walking or holding objects.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR
MUSCULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SENSORY SYSTEM (PERCEPTION)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

They should not do physical exercises that involves extending the head back or arching the back, jumping should be avoided and, if they must lie down, it should not be on their stomach. When sitting on the floor, it should be with their legs crossed (Indian position) and not forward.

They usually need good hydration, so they must drink a lot of water, therefore, they will need a greater number of trips to the bathroom.

SPACE ADAPTATION - ERGONOMIC

Because of their short stature and walking difficulty, they may need extra support when climbing stairs, running, or walking. They may not be able to reach some objects on shelves or tables, use the door handles, etc. so it would be advisable to have a portable ladder in the classroom.

It is necessary to have chairs and tables adapted to a smaller stature. It would be convenient to have a platform on the chair for the student to get on and off it without help.

In addition, they must have a footrest so that their feet do not dangle during class hours.

A double set of books should be provided to avoid overloading the weight of the backpack. Also, pencils of a smaller size than usual should be used and a rubber adapter, to allow better graphomotor skills.

ENVIRONMENTAL ADAPTATION

If there is hearing loss, the noise level in the classroom must be controlled to avoid noise pollution. If their location in the classroom is frontal and close to the teacher, lip reading will be facilitated.

ACCESSIBILITY

There may be difficulties going up or down stairs so the use of an elevator will be facilitated.

INCLUSION STRATEGIES

Achondroplasia is a disease with a great psychological impact on the person, so help will be necessary to better manage the situation in which the person finds themselves. The adaptations that are made should not be obvious, or of different colors that could attract the attention of the rest, they should be aesthetically integrated in the center, such as, for example, if the height at which a hanger is located is decreased, the rest should also be decreased.

Autonomy should be encouraged, allowing the person to develop on their own, which will mean good autonomous development in the future.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

Many of the children who suffer from this disease suffer joint pain related to the morphology of their limbs and may require continuous analgesia for some periods. It may be necessary to administer/guard analgesic drugs to be administered on a prescribed schedule or on demand.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not anticipated than in the rest of the students. Reference is made to the reference protocols in each geographical area.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	As regular steps for short students' feet are too high thus increasing the risk of tripping and injuries. Therefore, rushing on stairs is not welcome, longer time is necessary to move from one place to another. Be aware of and analyse existing physical barriers and ways to overcome them with limited resources.
	Support provided by the teacher	Facilitate friendly atmosphere in the classroom. With other students talk about the words that have a negative connotation and can make short people feel bad (for example, a dwarf, a midget). Do not reduce learning performance requirements for short students as they tend to pretend to be helpless because this is a good way to avoid responsibilities and tasks. As short students may try to attract increased teachers' attention, rules of behaviour need to be discussed. Otherwise, the short student may develop a lack of self-confidence, dependence on adults, negative self-esteem, etc. Make sure that other students do not perceive the short student as 'the poor one' and if necessary remind that short students have to be treated according to the age, not height. Students have to understand that the short classmate is not 'sickk' but just different because of one's height. Explain to other students that in many cases misplaced help can hurt. Do not allow other students to take the short student on hands as it can injure the spine more easily than under ordinary circumstances. Provide extra time for WC and to change clothing. Take into account that short students quikly get tired from writing if the paper size is not appropriate (if they have to stretch their arm). Besides the obligatory set of books, provide an additional set of books so that the student has one at school and one at home to avoid the need for the student to carry a heavy schoolbag.

	Support provided by the teacher	Improve access to materials by providing steps (in the classroom, library, etc.). Promote the development of independent organisational skills, responsibility, fine motor skills. Work on developing healthy eating habits. Keep in mind that short students try to gain the attention and friendship of other students, so they can be very talkative and ignore the teacher's reprimands, as belonging to a group of friends will be more important than learning.
	Technical support	To help the student avoid backache, a horizontal legrest or a strap between the front legs of the chair should be added so that the student can rest one's legs. Special adaptations are necessary to make sure the student has access to a sink, WC, desks, materials, etc.

Used sources:

ALPE Achondroplasia Foundation.
Available at: *www.fundacionalpe.org*

ORPHA 65

LEBER CONGENITAL AMAUROSIS

DESCRIPTION OF THE DISEASE

It is an ophthalmological disease that affects the sense of sight and is caused by a malformation in the retina. It develops blindness and/or severe visual impairment.

Vision usually deteriorates over the years until reaching complete blindness.

MAIN ORGANS OR SYSTEMS AFFECTED

SENSORY SYSTEM (SIGHT)

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Adapt learning to the type of perception: use of relief models to work on shapes and structures, encourage the work of textures instead of colors, adapt the teaching process of the linguistic code in ink and/or Braille format, according to the prognosis of the affected students, and encourage mental math.

To facilitate the access of students with visual disabilities to the 2.0 domain, it is important to have screen review software that reads the screen and transforms it into sound, Braille or a combination of both.

If these difficulties are just in regard with reading due to reduced vision, large types and typescopes can be used.

SPACE ADAPTATION - ERGONOMIC

Difficulties in monitoring the class due to reduced visibility: place the student close to the teacher to facilitate visibility.

In case of absolute blindness, it should be studied whether the most advisable thing is to locate these students near the teachers. If the students have auxiliary teachers, it may be interesting to locate them in an area that allows them better interaction.

ENVIRONMENTAL ADAPTATION

Insufficient lighting for the range of vision: use cold fluorescent lights that allow lighting with the quality and intensity necessary to favor the vision of these students.

ACCESSIBILITY

Eliminate physical obstacles to facilitate accident-free traffic. Facilitate the use of auxiliary methods, such as walking sticks, considering that there may be difficulty in psychomotor coordination.

Place handrails in stairs, classrooms and hallways to facilitate ambulation. Place handles in toilets so that students can function with the greatest possible autonomy.

To facilitate orientation in the classroom, it is advisable not to make changes in the arrangement of the furniture, as well as to have plans and maps adapted to their visual impairment to improve their knowledge of the center.

INCLUSION STRATEGIES

Involve all the school's students in workshops about the senses, adapted to each age group.
Encouraging all classmates to act as guides when moving around the center, participating in physical activities (it may be useful for everyone to know how to be movements model) and assess the holding of workshops, adapted to the age range, on prevention and help in case of falls and collisions.

Make in the classroom, with everyone collaboration, the 3D models that are going to be used to facilitate learning in some subjects for students with visual impairments.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

There could be a slight increase in the risk of falls and shocks when travelling or during activities. Apart from these situations, a greater risk of emergency than for the rest of students is not foreseen. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Explain the school and classroom layout to a visually impaired / blind student or ceate a tactile map. Teach a visually impaired/blind student's classmates to be their guide while walking around the school or classroom. Explain other students they should allow the visually impaired/blind student to take a guide's hand to follow instructions. Explain to the personnel and other students that the visually impaired/blind student should first be asked if they need any help, and only upon an affirmative answer, they should be helped. In order to draw the visually impaired/blind student's attention, use a gentle touch (if the student's name is unknown). Create terrain guidelines both indoors and outdoors. Use plates at doors, have labels and signs in Braille. Do not change the placement of furniture and other objects in any room at the school. Use a contrasting design of environmental objects.
	Support provided by the teacher	Use everyday objects, 3D tactile objects to promote the student's development, senses, fine and gross motor skills, self-help and independence, as well as communication skills. Provide audio recordings of teaching and learning materials. If necessary, offer breaks in learning. Introduce and use labels and signs the visually impaired/blind student understands and remembers. If necessary, read instructions of tasks prior to their completion. Use available screen reading tools /apps. Provide relevant teaching and learning materials, such as audiobooks, books in Braille, online books with the option of increasing font size and choosing a background colour.

Individualised Education Plan (IEP) and 504 Accommodation Plan		
	Support provided by the teacher	Use built-in computer accessibility tools, such as magnifier and immersive reader, to make the information easier to see. Use bright, saturated, visible, or contrasting colours to highlight a particular object. Use Braille as an alternative means of learning. Use as simple letters as possible, such as Arial or Tahoma because they have no decorative elements being easier to understand.
	Technical support	Explain the classroom layout or create a tactile map. Apply labels and signs in all the rooms at the school because they make objects accessible to the visually impaired/blind student. Apply a labelling system accessible to all the students, for example, use different labels: print, Braille, talking recorder buttons, voice labelling system, images and objects, as it will help to find, implement and place materials appropriately. If you divide the classroom into learning stations or centres, the use of a clear and consistent labelling system will help the visually impaired/blind student to navigate the classroom and recognise names of the learning stations. Place labels at the students' eye level. Have labels in important for the visually impaired / blind student places. Make sure which lighting is best for different activities in the classroom, such as taking notes, watching a presentation or a video, and completing tasks. Remove all possible obstacles on the floor that may make it difficult for the visually impaired/blind studnt to move around the classroom. Do not use soft bean bags in the classroom as they may increase the risk of tripping. Ensure that there are no obstacles for the visually impaired/blind student's moving around the school.

Individualised Education Plan (IEP) and 504 Accommodation Plan

Technical support

Fig. 1 Voice Labelling System

(https://www.amazon.com/Reizen-Talking-Label-Wand-Labeling/dp/B085T731CV)

Talking Label System lets a person record one's own talking labels on items at the school and home. At first, put a self-adhesive label on the item and then record the message to identify it. To play the message, one should touch the label with a pen reader.

Talking Label System allows the visually impaired/blind student to identify their belongings and/or leave messages for themselves and/or others.

Overall, labelling helps to have order in the classroom and improves its accessibility thus encouraging independence of the visually impaired/blind student. Moreover, it enhances development of the reading skill.

Fig. 2 Bump Dots

Bump Dots of different colours and sizes are ideally appropriate for the visually impaired/blind student as they ensure simple identification of objects, for example, a keypad, board, switches, desks, tools, etc.

Used sources:

Perkins (2020). Elementary School Classrooms and Low Vision: Designing Accessible Classroom Series. Available at: *https://www.perkinselearning.org/technology/blog/elementary-school-classrooms-and-low-vision-designing-accessible-classroom-series*

Willings, C. (2017). Labeling System. Available at: *https://www.teachingvisuallyimpaired.com/labeling-system.html*

ORPHA 104

LEBER HEREDITARY OPTIC NEUROPATHY

DESCRIPTION OF THE DISEASE

Ophthalmological neurodegenerative pathology that affects the optic nerve and usually causes a loss of central vision. Usually this loss sets in progressively over weeks and in both eyes, until it stabilizes. Neurological signs may also appear such as motor disorders, involuntary muscle contractions, postural tremor, lack of muscle control and bad coordination of voluntary movements due to the cerebellum involvement.

MAIN ORGANS OR SYSTEMS AFFECTED

SENSORY SYSTEM (SIGHT)

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

NERVOUS SYSTEM (MOBILITY)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Adapt learning to the type of perception: use of relief models to work on shapes and structures, encourage the work of textures instead of colors, adapt the teaching process of the linguistic code in ink and/or Braille format, according to the prognosis of the affected students, and encourage mental math.

To facilitate the access of students with visual disabilities to the 2.0 domain, it is important to have screen review software that reads the screen and transforms it into sound, Braille or a combination of both.

If these difficulties are just in regard with reading due to reduced vision, large types and typescopes can be used.

In case of difficulty in coordinating voluntary movements, it is recommended to facilitate the functional use of the tools in the classroom or even to use adapted tools.

SPACE ADAPTATION - ERGONOMIC

It is recommended to place him near the teachers and with good visibility of the blackboard to facilitate them to follow the class. Since vision loss is central and lateral vision is maintained, it is recommended their seat to be placed to one of the walls of the classroom. The use of height-adjustable tables or lecterns may be helpful to enhance visibility.

ENVIRONMENTAL ADAPTATION

Insufficient lighting for the range of vision: use cold fluorescent lights that allow lighting with the quality and intensity necessary to favor the vision of these students.

ACCESSIBILITY

Eliminate physical obstacles to facilitate accident-free traffic. Facilitate the use of auxiliary methods, such as walking sticks, considering that there may be difficulty in psychomotor coordination.

Place handrails in stairs, classrooms and hallways to facilitate ambulation. Place handles in toilets so that students can function with the greatest possible autonomy.

To facilitate orientation in the classroom, it is advisable not to make changes in the arrangement of the furniture, as well as to have plans and maps adapted to their visual impairment to improve their knowledge of the centre.

INCLUSION STRATEGIES

Involve all the school's students in workshops on the senses, adapted to each age group. Encourage lateral interpersonal contact, avoiding frontal approaches.

Encourage all classmates to participate in physical activities, adapting activities and maximizing the use of lateral vision. At this point, it is important to take into account the possible motor problems that may arise and consider doing workshops, adapted to the age range, about prevention and help in the event of falls and collisions.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

There could be a slight increase in the risk of falls and shocks when travelling or during activities. Apart from these situations, a greater risk of emergency than for the rest of students is not foreseen. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Inform the school staff and students about the limitations the student suffering from Leber Hereditary Optic Neuropathy (LHON) has. Explain the school and classroom layout to a visually impaired/blind student or ceate a tactile map. Teach a visually impaired/blind student's classmates to be their guide while walking around the school or classroom. Explain other students they should allow the visually impaired/blind student to take a guide's hand to follow instructions. Explain to the personnel and other students that the visually impaired/blind student should first be asked if they need any help, and only upon an affirmative answer, they should be helped. In order to draw the visually impaired/blind student's attention, use a gentle touch (if the student's name is unknown). Create terrain guidelines both indoors and outdoors. Use plates at doors, have labels and signs in Braille. Do not change the placement of furniture and other objects in any room at the school. Use a contrasting design of environmental objects.
	Support provided by the teacher	Remember the visually impaired/blind student perceives information in a varety of ways. For example, in Braille, audio recordings or enlarged print. Note that reading a text in Braille can take up to three times longer than any other text. Plan additional time for activities, for example, if finding words in a text requires transition from one reading device to a different one. Try to assign tasks for which the student has necessary tools and technologies. Make sure the visually impaired/blind student does not feel isolated among classmates because it may affect their learning.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	The student who does not see body language and intercations of the surrounding people often finds it difficult to get involved and engage in learning activities. It is especially complicated to understand when a discussion needs to be interupted or changed. Plan time for breaks because the visually impaired / blind student may experience headcahes due to eye strain. Depending on the needs of the student with LHON, reduce the number or duration of lessons if necessary. Provide learning materials in an electronic format as it can greatly facilitate the visually impaired/blind student's accessibility to the materials. Provide a list of books to read and tasks to do in advance so that the student can prepare their work. Prepare tasks and their instructions in Braille. Add words to everything you do - verbalise your teaching to convey information about things going on in the classroom and what you are doing. Discuss each step that needs to be carried out to perform a particular action. Read all the printed information and describe any charts or diagramms that are being used. Inform the student if you plan to use videos, slides, etc. Discuss the alternative ways to present the required information. In case of any field trips or excursions, provide individual support to the visually impaired/blind student to reduce their anxiety that may arise in unfamiliar environments. Consider recording audio comments to complement practical work, for example, experiments or excursions. Agree with the visually impaired/blind student on alternative feedback because the student cannot read your handwritten comments. Make sure online learning materails and tools you use comply with the guidelines for accessible web design.
	Technical support	Explain the classroom layout or create a tactile map. Apply labels and signs in all the rooms at the school because they make objects accessible to the visually impaired/blind student. Apply a labelling system accessible to all the students, for example, use different labels: print, Braille, talking recorder buttons, voice labelling system, images and objects, as it will help to find, implement and place materials appropriately.

Individualised Education Plan (IEP) and 504 Accommodation Plan

Technical support

If you divide the classroom into learning stations or centres, the use of a clear and consistent labelling system will help the visually impaired/blind student to navigate the classroom and recognise names of the learning stations.

Place labels at the students' eye level. Make sure you have the labels in important places so that the visually impaired/blind student can examine them and remember.

Have labels in important for the visually impaired/blind student places.

Make sure which lighting is best for different activities in the classroom, such as taking notes, watching a presentation or a video, and completing tasks.

Remove all possible obstacles on the floor that may make it difficult for the visually impaired/blind studnt to move around the classroom.

Do not use soft bean bags in the classroom as they may increase the risk of tripping.

Ensure that there are no obstacles for the visually impaired/blind student's moving around the school indoors and outdoors.

Fig. 1 Voice Labelling System

(https://www.amazon.com/Reizen-Talking-Label-Wand-Labeling/dp/B085T731CV)

Talking Label System lets a person record one's own talking labels on items at the school and home. At first, put a self-adhesive label on the item and then record the message to identify it. To play the message, one should touch the label with a pen reader.

	Technical	Talking Label System allows the visually impaired/blind student to identify their belongings and/or leave messages for themselves and/or others. Overall, labelling helps to have order in the classroom and improves its accessibility thus encouraging independence of the visually impaired/blind student. Moreover, it enhances development of the reading skill.  Fig. 2 Bump Dots Bump Dots of different colours and sizes are ideally appropriate for the visually impaired/blind student as they ensure simple identification of objects, for example, a keypad, board, switches, desks, tools, etc.

Used sources:

ADCET (n.d.). Vision Impairment and Blindness. Available at:

https://www.adcet.edu.au/inclusive-teaching/specific-disabilities/blind-vision-impaired

Perkins (2020). Elementary School Classrooms and Low Vision: Designing Accessible Classroom Series. Available at:
https://www.perkinselearning.org/technology/blog/elementary-school-classrooms-and-low-vision-designing-accessible-classroom-series

ORPHA 251

MULTIPLE EPIPHYSAL DYSPLASIA

DESCRIPTION OF THE DISEASE

Multiple epiphyseal dysplasia is an alteration in the development of the bones and cartilage that affects mainly the epiphyseal area (the widest part of the bones, in the areas of the ends of the bones). These bone alterations cause joint deformities and osteoarthritis at an early age. Some of the problems these people face are: unsteadiness of gait, short stature that becomes more pronounced as the child grows, pain in the joints usually in the hips and knees. For these reasons, as the disease progresses, mobility may be affected.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

People who suffer from this disease can perform physical exercise, within limitations, but rest intervals should be allowed in case of discomfort or pain.

They do not require other measures of pedagogical adaptation.

SPACE ADAPTATION - ERGONOMIC

It is likely that you need some type of adaptation for writing and fine motor activities, such as adapted mice or keyboards (larger, smaller, ergonomic, tactile, ...) due to the fatigue or discomfort that these tasks can cause.

If they need aids for ambulation or a wheelchair, their position in the classroom should allow for their comfortable. A table adapted to be used with a wheelchair may be necessary.

The shelves, cabinets, desks, blackboards, hangers, work material, and chairs must also be placed at a height that allows their use. For this, the furniture can be adapted with small structural modifications.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

If mobility is greatly affected, the student will need crutches or a wheelchair, so ramps and/or elevators must be installed in the center and access to the chair adapted.

Also, there must be at least one adapted bathroom on each floor of the center with a toilet placed at the standard height of a chair, with folding handrails for support on both sides, as well as easily accessible sinks with chairs and a low mirror placement to be able to see themselves correctly in a sitting position.

INCLUSION STRATEGIES

Their participation in cooperative activities should be encouraged, so that their potential and abilities are reinforced, avoiding a situation of discrimination on the part of others. It is necessary to create an atmosphere of respect within the class, where each person is taken into account, so it would be beneficial to hold awareness talks so that the rest of the students know about the disease.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is possible that the student needs treatment to control pain in the hip or knees in certain periods (ibuprofen, paracetamol, for example) and that they must be administered (pills or syrups or creams) during the school day according to the specified guidelines that the responsible health personnel have given the parents or main care. It will be necessary to have the prescription in writing and as long as it is oral drugs.

If they wear any type of prosthesis, their proper fit should be assessed during the working day, if they show some kind of mismatch. For this, the responsible teaching staff will be in charge of repositioning according to the guidelines indicated by the family as per specialist health professionals.

POTENTIAL EMERGENCIES AND ACTION

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should bechecked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide an opportunity for the student to study in a wheelchair. Find alternatives to standard sports lessons
	Support provided by the teacher	Take into account that the student has to avoid sports that put a lot of strain on the joints, such as running and jumping. Preferred sports are swimming and cycling. Physiotherapy / therapeutic exercises and modified sports activities are required to meet the needs of the student.
	Technical support	Encourage the use of crutches or a wheelchair to prevent hip pain. Pain in hand while writing can be avoided if a wide-grip pen is used. 

Used sources:

Nemours Children's Health. About Multiple Epiphyseal Dysplasia. Retrieved (2022)
https://www.nemours.org/services/multiple-epiphyseal-dysplasia/about-multiple-epiphyseal-dysplasia.html

ORPHA 269

FACIOESCAPULOHUMERAL DYSTROPHY

DESCRIPTION OF THE DISEASE

Fascioscapulohumeral dystrophy is a progressive disease that produces generalized muscle weakness with 4% of diagnoses occuring in childhood. Normally, the first symptoms appear at the level of the face with difficulty in smiling, closing the eyes or whistling. So they usually have a diminished, depressed or angry facial expression. The main manifestation of this disease is shoulder involvement with difficulty in lifting the arms, reaching for objects, and drooping shoulders or scapulae that protrude more than they should. When the disease progresses, there is weakness in the abdominal muscles, in the movements of the wrist, feet and legs, which can interfere with the way of walking, resulting in a small percentage of people requiring the use of a wheelchair.

When this disease is diagnosed in childhood, hearing impairment or abnormal heart rhythms are possible, although it is rare.

MAIN ORGANS OR SYSTEMS AFFECTED

MUSCULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SENSORY SYSTEM (PERCEPTION)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

During physical education classes, it will be necessary for the child not to overexert themselves due to the muscular problems that it can cause, but moderate exercise is beneficial, so they should not be exempt from activities. Exercises that involve extra effort on the arms (climbing a rope or throwing balls, for example) are discouraged. Although they will present a fairly low ability in sports, due to low muscle strength and poor balance.

It should be understood that a facial expression may be different from the rest of the students and may not be indicative of problems or discomfort, since due to the disease they acquire a different expression than normal.

Due to pain, they may need to have rest intervals for certain activities. If there is a hearing loss, it is very likely that the child is a wearer of hearing aids. In this case, it is advisable to carry out good vocalization in case they need the extra help of lip reading.

SPACE ADAPTATION - ERGONOMIC

It would be advisable to provide the student with a second set of books so that the amount of weight in his / her portfolio is lightened. Shelves and hangers should be at a height for ease of use so that they do not have to raise your arms above shoulder level as this will be impeded or hindered.

If there is hearing impairment, it is recommended that their position in the classroom be in front of the teacher to facilitate lip reading.

In advanced stages of the disease, they may require aids for ambulation or a wheelchair, in which case their position in the classroom should be adapted to facilitate comfortable use and easy access. They may need a table adapted to be used with a wheelchair.

Due to the level of dependency and severity of the disease, it is possible that they wear prostheses somewhere on the body to support activities of daily living. It will be necessary to take this into account when adapting the living spaces (classroom, patio or school cafeteria).

ENVIRONMENTAL ADAPTATION

In case of wearing hearing aids, an appropriate tone of voice must be maintained in class, avoiding excessive noise, as it can cause added annoyance for the student.

ACCESSIBILITY

If it is the case of needing a tool for mobility such as crutches, a walker or a wheelchair, it will be necessary to remove architectural barriers throughout the center (inclusion of ramps, handrails, increase of the width of the doors if necessary, etc.). If a lift is available, they should be allowed to use it. In the case a lift is not available, the student's classroom must be lowered to an acces floor.

INCLUSION STRATEGIES

Autonomy should be encouraged by allowing activities to be carried out alone or alone when possible. In addition, the rest of the class should be made to understand that the person's facial expression and limitations are only due to the disease, so awareness talks can be a good method.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

Many of the children with this disease suffer from chronic pain and require continuous analgesia. It may be necessary to administer/guard analgesic drugs to be administered on a prescribed schedule or on demand.

Muscle weakness and instability can determine a greater risk of falling, making it necessary to avoid potentially dangerous situations.

Due to muscle weakness, it may be necessary to wear some type of prosthesis to ensure the correct placement of limbs. The support teachers or the classroom manager will have to ensure correct placement according to the indications of the boy or girl.

POTENTIAL EMERGENCIES AND ACTION

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	It is advisable to ensure the awareness of the involved people and the adaptation of the environment.
	Support provided by the teacher	**Difficulty in raising one's hand** Choose and use a way for the student to attract the teacher's attention without having to raise one's hand, for example, a sound button or a card which are located in a visible place. Pay more attention to the student to notice one's attention seeking signals. **Difficulty in standing for long periods of time** If there are activities in which the student has to stand for a long period of time, a high (bar) chair with a backrest is needed. **Difficulty in writing (by hand)** Use a computer for the student to write. Provide the student with written or printed notes, let make or use audio notes. Let the student take alternative tests, for example, oral or written on a computer, if handwriting causes problems. **Difficulty in concentrating because of pain and fatigue** Extended time limits for completing activities and tests. Avoid physical activities that cause overwork. If pain is the reason for reduced learning performance, discuss the situation with the support staff. The student's healthcare team can suggest methods for controlling pain. Choice of seating taking into account the needs of the student. Reduced amount of homework or class activities.

	Technical support	**Difficulty in sitting on a standard chair** Use alternative versions to standard ckairs and desks, for example, ckairs with additional support **Difficulty in raising one's hand** Use of interactive technologies, whiteboard, or computers which do not require raising one's hand higher than the waistline. Avoid writing on the board, posters or other surfaces if it is necessary for the student to raise one's hand above one's waistline. **Difficulty in writing** Speech recognition software can be used to reduce physical pain of writing. **Difficulty in concentrating because of pain and fatigue** Choose a chair with stable back support. Help the student choose a seat taking into account one's needs.

Used sources:

Padua, L. *et al*. (2009). *Quality of life and pain in patients with facioscapulohumeral muscular dystrophy*. Muscle and Nerve

Tawil, R. (2018). *Facioscapulohumeral muscular dystrophy. in* Handbook of Clinical Neurology

ORPHA 285

EHLERS-DANLOS SYNDROME, HYPERMOBILE TYPE

DESCRIPTION OF THE DISEASE

This syndrome includes several diseases that affect the connective tissue and supporting tissues of the skin, blood vessels, bones, and other organs. These people have a soft and very elastic skin, with dislocations, progressive degeneration of the joints, chronic pain and easy contusion, due to the latter, they usually present numerous scars on the elbows and knees due to the difficulty of healing. The face of these people has a characteristic appearance (acroheroic facies) with thin lips, a thin nose, thin cheeks and prominent eyes.

In addition, people who suffer from this disease may face digestive problems such as gastroesophageal reflux, feeling of fullness at the beginning of a meal, irritable bowel syndrome (with diarrhea or constipation, rectal mucus and abdominal cramps), heart problems, the mouth and teeth, emotional and problems in pregnancy and childbirth.

MAIN ORGANS OR SYSTEMS AFFECTED

MUSCULAR
CUTANEOUS- MUCOSOUS

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

CARDIOVASCULAR
DIGESTIVE

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

They can study normally. They will be able to participate in physical education class, but it is recommended to reduce the frequency and intensity of exercise. And that, in the case of contact sports or those with a risk of falling, protect themselves with elbow pads, knee pads, or wrist guards or a helmet if necessary.

SPACE ADAPTATION - ERGONOMIC

Extreme care must be taken with those materials that can be sharp (scissors, punches, ...) because their skin fragility is enormous and the healing time of the wounds is usually long. It is very easy to bruise with minimal blows. It is advisable to cover with soft materials those objects that can cause a bruise, such as the spikes of the table or the corners of a shelf.

It is important that the teacher controls some undesirable postures that children can adopt during the time they are in the classroom. To do this, they must be reminded that they do not sit with their legs in the shape of a W (W sitting), or hyperextend the knees or bend the feet inwards.

They may have certain problems related to writing due to the hyperextension of the joints of the hand that favor subsequent painful processes or during a prolonged period of writing. For this reason, the need to offer extra time to complete written exercises (assignments, exams) will be valued.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

It is recommended that the space in the classroom to reach the desk is wide and without obstacles. A placement will be sought that facilitates safe mobility around the classroom.

INCLUSION STRATEGIES

It is necessary to make the rest of the class understand what Ehlers-Danlos disease entails, emphasizing that blows to the student who suffers from it should be avoided. But always, urging that there is a non-discriminatory environment in the classroom, through cooperative games, awareness talks, etc.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It may be necessary to replace a dressing, if there are injuries in the healing process, it is advisable to have material in the classroom to carry out a simple cure and have basic notions of how to do it. The use of soft fixing tape or circular meshes is recommended to avoid damaging the skin. The indications set by the family or those responsible for the care will be followed. If you have any questions, it will be necessary to contact the nurse at the health center.

The prevention of bumps and falls is very important, and close vigilance is necessary, especially in risky situations (games, gymnastics, etc.).

POTENTIAL EMERGENCIES AND ACTION

In the case of a blow or fall, the risk of bleeding may be increased. In the case of affecting a large-caliber vein or arterial, the bleeding may require the intervention of the emergency service (according to current protocol).Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	If necessary, provide physiotherapy classes for the student.
	Support provided by the teacher	Keep track of the student's physical activity in the pedagogical process. As well as follow the student's well-being and possible pain. Adapt sports classes, physical activities to the student's ability (cooperation with parents, a school nurse, and medical staff). Help the student and peers find out information about the disease and understand why and what kind of support is required.
	Technical support	If necessary, provide the student with technical means for one's mobility in school and classroom. ICT.

Used sources:

Ehlers-Danlos Society: Parent's and Educator's Guide: Meeting the Needs of the Ehlers-Danlos Child. Retrieved (2022)
https://ehlers-danlos.com/wp-content/uploads/Educator-Parent-Guide-2016.pdf

ORPHA 388

HIRSCHPRUNG DISEASE

DESCRIPTION OF THE DISEASE

Digestive pathology that mainly affects the colon in relation to innervation defects of that organ, leading to reduced muscle mobility, as well as its chronic dilation. This dilation favors the accumulation of feces and gases, and the frequent appearance of intestinal obstruction.

MAIN ORGANS OR SYSTEMS AFFECTED

DIGESTIVE

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

METABOLIC (NUTRITIONAL-FOOD BASE)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Students with this pathology require medical monitoring, being able to suffer recurrent symptoms conditioning justified attendance absences.

Classes should be adapted to these absences, providing tutorials, private and online classes, or any other methodology that allows you to carry out the same academic follow-up as thier classmates.

They can present problems on the participation in games and the realization of physical efforts so they should be adapted to each student capabilities.

SPACE ADAPTATION - ERGONOMIC

Difficulties on controlling defecation and the appearance of nausea and vomiting: students suffering from this type of pathology should be located near the door to facilitate them to go to the toilet when necessary. Likewise, it will be ensured that the class is close to the toilets.

Access to changing rooms and showers in the centre will be provided whenever necessary to contribute to their comfort in the centre.

ENVIRONMENTAL ADAPTATION

Implementation of extraordinary measures is not required.

ACCESSIBILITY

Implementation of extraordinary measures is not required.

INCLUSION STRATEGIES

Due to the risk of stigmatization of this type of student, it is recommended to work in greater depth on the digestive system so that their classmates understand the consequences of their pathology. Promote that classmates to act as reinforcement in their learning process, so their socialization is facilitated while their academic learning is reinforced by collaborating with their peers.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is important an early detection of intestinal obstruction cases. The signs and symptoms that can be used to identify it are the appearance of intermittent pain that ends up becoming constant and intense, swelling, loss of appetite, vomiting and fever. The family should be informed immediately, and it is advisable to request urgent health care. During the wait, it is recommended to keep the students resting, lying down, calm and warm. Do not administer any type of oral medication, food or drink.

POTENTIAL EMERGENCIES AND ACTION

Beyond the intestinal obstructive condition, mentioned above, greater risks of emergency are not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Ensure the necessary care for the student with Hirschprung disease, especially for those students who have stoma. Provide frequent meals and regular options to drink. Plan meals in accordance with the expert device, as the student may have indigestion and a frequent risk of infection. Record lessons and provide electronic format materials on a certain learning platform because the student with Hirschprung disease is vulnerable to a lot of infections and viruses, resulting in frequent hospitalisations and / or prolonged school attendance due to the health condition.
	Support provided by the teacher	Keep in mind that students suffering from Hirschprung disease may have difficulty completing tasks, especially when there is a feeling of physical discomfort. Plan regular breaks in learning. Provide the student with alternative tasks if you notice the student is tired as some medications can cause apathy and difficulty concentrating. If so, the student will not be able to participate, for example, in a discussion actively. Provide video recordings of lessons, digitally available materials to help the student keep up with others in case of missed classes due to frequent and prolonged hospitalisations or after treatment complications. Extend the time the student can work on certain tasks or submit their work. Prepare a list of books and other materials, or the tasks to be completed in advance so that the student can start doing everything in time. Schedule individual consultations to compensate the student's absence from school. Help the student to divide their work in parts, set goals and encourage focusing on more realistic and achievable aims. Be precise in giving instructions. Send all required materials electronically if the student misses lessons.

	Support provided by the teacher	Having had consultations with the student's parents and the physician, carefully plan sports activities because too intensive activities can lead to the student's health problems. Sports activities must be appropriate to the student's abilities.
	Technical support	Provide an appropriate learning environment, such as regular ventilation of the classroom, lighting appropriate to the student's needs, as the student may be intolerant of heat or light, as well as some chemicals. Provide access to changing rooms and showers. If possible, create a small room where the student can take care of themselves and arrange their own clothes. Provide a seat for the student near the door of the classroom, to make it easier to go to the WC if necessary. Ensure that the classroom is close to WC.

Used sources:

ADCET (n.d.). Health Conditions. Available at:
https://www.adcet.edu.au/inclusive-teaching/specific-disabilities/health-conditions

ORPHA 418

CONGENITAL ADRENAL HYPERPLASIA

DESCRIPTION OF THE DISEASE

It consists of the enlargement of the suprarenal glands in connection with a deficient secretion of cortisol and aldosterone, in a vain attempt to compensate for this insufficient secretion, accompanied by an excessive release of androgens. Treatment with exogenous hormone administration usually keeps patients stable. The excess of androgens, induces accelerated growth and an excessive advance of bone maturation that can determine a short final stature. In addition, hormonal alterations can induce overweight or obesity. In girls, congenital genital malformations that require surgical interventions can be found, as well as a virilizing sexual maturation process and menstruation disorders.p

MAIN ORGANS OR SYSTEMS AFFECTED

ENDOCRINE-METABOLIC

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

GENITOURINARY

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Regular medical follow-up is necessary, which can promptly condition attendance at class. In the case of girls, if it were necessary to intervene surgically, it should be considered that they are delicate operations that require long recovery periods that justify, even, the loss of a school year.

Emotional stress and academic pressure can be poorly tolerated, so they should promote phycological care and avoid situations that boost the appearance of anxiety.

SPACE ADAPTATION - ERGONOMIC

It does not require the implementation of extraordinary measures.

ENVIRONMENTAL ADAPTATION

It does not require the implementation of extraordinary measures.

ACCESSIBILITY

It does not require the implementation of extraordinary measures.

INCLUSION STRATEGIES

Considering that hormonal alterations can induce the presence of certain physical traits, the risk of stigmatization is high, so it is recommended that effective socialization strategies and self-esteem reinforcement be implemented.

It may be useful to explain to the other students those aspects of the illness that do not violate the privacy of the student (secondary effects of the treatment, possible incidents, etc.) and that can improve the empathy of the group.

Encourage classmates to act as reinforcement in their learning process if there are prolonged periods of absence.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

The exogenous contribution of the deficient hormones must be rigorous, forgetting the medication or the excess in its administration can cause dangerous situations for the students affected by this disease.

One of the potential complications would be a high blood pressure crisis that could be detected by the appearance of severe headaches, nausea, nosebleeds or confusion. It is recommended to have, in the centre, a digital blood pressure monitor, and basic training in the use of it is necessary for the teaching staff. The family should be informed immediately, and it is advisable to request urgent health care and communicate the blood pressure figure by phone if we have it. During the wait, it is recommended to keep the student at rest, seated, calm and warm.

POTENTIAL EMERGENCIES AND ACTION

Beyond the situations described in the previous section, a greater risk of emergency is not foreseen than in the rest of the students. It refers to the reference protocols in each geographical area.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student with Congenital adrenal hyperplasia may have the following difficulties: long recovery after surgery, severe headache, high blood pressure, nosebleeds. Consult the student's parents on what suggestions an endocrinologist has and which people are considered as emergency contacts. The student requires constant medical supervision. Therefore, regular cooperation among the school staff, the student's parents and the doctor is necessary. The parents should always be available. The learning process should be adapted (tutoring, homeschooling, etc.) if school attendance is impossible. The school nurse should be specifically prepared to help the student. The teacher has to be aware of the student's medical condition. Inform the school staff and the student's classmates how they can help if the student has severe headache or one's nose is bleeding. In the learning process there have to be activities that boost the student's self-esteem.
	Technical support	There has to be a blood pressure monitor in the school premises. Make sure water is available in the school premises. There is a need for a special room for the student to stay in cases of health problems and where to wait for appropriate help to arrive.

Used sources:

What is CAH?
https://www.cincinnatichildrens.org/health/c/congenital-adrenal-hyperplasia (Last Updated 09/2021)

Fleming L, Knafl K, Knafl G, Van Riper M. (2017). Parental management of adrenal crisis in children with congenital adrenal hyperplasia. J Spec Pediatr Nurs. doi: 10.1111/jspn.12190

ORPHA 478

KALLMANN SYNDROME

DESCRIPTION OF THE DISEASE

It is a pathology characterized by a deficit in the production of sex hormones (hypogonadism) that is usually associated with an olfactory sensory deficit that can become total (anosmia). It causes late and incomplete or, even, non-existent puberty, determining the absence of sexual maturation. In boys it can be expressed in the lack of changes in the voice, growth of the genitals and the appearance of genital and facial hair. In girls it presents with absence of breast growth and alterations or absence of menstruation. The absence of sex hormones determines a greater growth, being able to reach a height superior to the average. Administration of sex hormones exogenously can minimize the condition. Other alterations such as defects in the palate, kidney problems, involuntary movement in hands and arms and, defects in the dentition.

MAIN ORGANS OR SYSTEMS AFFECTED

ENDOCRINE-METABOLIC

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SENSORY SYSTEM (EAR)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Regular medical follow-up is necessary, which can promptly condition attendance at classes.

This type of student may present speech difficulties (dysarthria) making it necessary to adapt the activities. It may be necessary to work on this aspect with specialist professionals and, in a complementary way, necessary auxiliary tools can be provided that allow correct communication with the teaching staff and with the rest of the students.

In case of hearing loss, the use of clear language, with vocabulary and simple and understandable syntactic structures, is recommended. Articulate clearly and speak at a leisurely pace.

SPACE ADAPTATION - ERGONOMIC

To minimize the impact of hearing loss, the student should face the teacher to facilitate lip reading. It is important not to obstruct the vision of the mouth and to be close to the person speaking, as well as to arrange the group in a way that facilitates the visibility of the face of the rest of the colleagues.

ENVIRONMENTAL ADAPTATION

Avoid environmental noise as much as possible to avoid distortion in the capture and understanding of information.

ACCESSIBILITY

It does not require the implementation of extraordinary measures.

INCLUSION STRATEGIES

Considering that hormonal alterations can induce the presence of certain physical traits, the risk of stigmatization is high, so it is recommended that effective socialization strategies and self-esteem reinforcement be implemented.

Sign language workshops in which students without hearing problems learn words or sentences that allow them to communicate more fluently with the affected students. Diction workshops are also useful to facilitate lip reading, as well as workshops on the senses, adapted to each age group.

The rest of the students should consider that people with hearing loss do not detect approaches of people or vehicles from the side or from behind them, trying to establish visual contact before starting the interaction.

It may be useful to explain those aspects of the illness to the other students that do not violate the privacy of the student and that can improve the empathy of the group.

Encourage classmates to act as reinforcement in their learning process if there are prolonged periods of absence.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

No special therapeutic support is foreseen.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not anticipated than in the rest of the students. It refers to the reference protocols in each geographical area.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student suffering from Kallmann syndrome may experience delayed/absent signs of puberty, and no / worsened sense of smell. There may be defects in palate, kidney problems, involuntary movements of the hands and arms, and defects in teeth that result in speech disorders, for example, dysarthria. The student requires constant medical supervision. Therefore, regular cooperation among the school staff, the student's parents and the doctor is necessary. The parents should always be available. The learning process should be adapted (tutoring, homeschooling, etc.) if school attendance is impossible. The school nurse should be specifically prepared to help the student. The teacher and the classmates have to be aware of the student's medical condition (they should know how to communicate with the student). Plan activities that can improve the student's self-esteem. Due to the student's speech disorders, the teacher should plan such communixation activities in which the student can participate. Additional to the school lessons, the student should work with a speech therapist. The student's learning process has to be adapted to one's impairement. Sign language can be considered as an alternative. The teacher has to give clear instructions. In the learning process there have to be activities that boost the student's self-esteem. When adapting the learning process, take into account that the student may have no smell or a worsened sense of smell. Adapt the classroom to minimise ambient noise.
	Technical support	Adapt the classroom so that it is appropriate for the student's hearing challenges. There is a need for a special room for the student to stay in cases of health problems and where to wait for appropriate help to arrive.

Used sources:

Kallmann syndrome. Retrieved (2022)
https://www.rch.org.au/kidsinfo/fact_sheets/Kallmann_syndrome_an_overview/

Maria I. Stamou, Ravikumar Balasubramanian, William F. Crowley, Jr., Daniel K. Podolsky, *Kallmann Syndrome*. Retrieved (2022)
https://rarediseases.org/rare-diseases/kallmann-syndrome/

ORPHA 664

ORNITHINE TRANSCARBAMYLASE DEFICIENCY

DESCRIPTION OF THE DISEASE

It is a disease caused by the inability to eliminate ammonia (a waste product resulting from protein metabolism). Environmental stressors (such as fasting, a high protein diet, an intercurrent illness or surgery) can trigger episodes of hyperammonemic encephalopathy (brain toxicity) that, if repeated throughout life, can leave neurological sequelae (the severe forms of these sequelae are not found in ordinary school). Long-term treatment involves restriction of protein intake for life and therapy with nitrogen-scavenging drugs.

MAIN ORGANS OR SYSTEMS AFFECTED

ENDOCRINE-METABOLIC

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

NEUROLOGICAL

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

This type of student requires continuous medical monitoring, which can cause recurrent absences. Classes should be adapted to these absences, providing tutorials, private classes, online classes or any other methodology that allows you to carry out the same academic monitoring as your classmates.

This disease can cause delay in neurological development that, in its mild / moderate forms, determine oral and written communication problems, being useful the use of elements that facilitate communication (pictograms, etc.) as well as applying strategies that help these students to develop their language in the classroom.

To help focus attention, these students can be placed close to the teachers, taking into account the spatial adaptations that they may require. Motivate their participation in class, propose activities that favour their attention.

Work memory from its different spheres, use tools such as puzzles to work visual memory, use strategies such as developing memory drawings after telling a story or viewing a video.

Adapt physical activities and physical efforts to their abilities.

SPACE ADAPTATION - ERGONOMIC

It may be necessary to adapt their position in the classroom to their psychomotor limitations, if any, being necessary to assess the suitability of the furniture they use. They may even need the help of specific reading and writing tools.

ENVIRONMENTAL ADAPTATION

It does not require the implementation of extraordinary measures.

ACCESSIBILITY

Depending on their psychomotor limitations, it may be necessary to review the accesses to the centre, the bathrooms, the school cafeteria, the classroom and their position within it.

INCLUSION STRATEGIES

Among the difficulties that students with this pathology may present is that of interacting with other people. Strategies should be developed to facilitate their development on a social level with classmates.

Promote that classmates act as reinforcement in their learning process, in this way socialization is facilitated for this type of student body and their academic learning is reinforced by collaborating with their peers.

It is recommended that their colleagues understand what this pathology consists of by stimulating their empathy. Workshops or activities can be developed to work with the rest of the students, which implies suffering from this pathology.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

An important part of the treatment consists in following a diet with strict control of proteins, therefore, both the teachers and the dining room staff must be aware of the need to maintain this restriction.

Excessive protein intake or failure to adhere to pharmacological treatment can lead to ammonium accumulation encephalopathy (brain toxicity) characterized by nausea, vomiting, headache, disorientation, and aggressive behaviour. This situation must be detected early to avoid the establishment of a coma.

The family should be informed immediately and request urgent health care. During the wait, it is recommended to keep the schoolchild at rest, awake, lying down, calm and warm. It is important to ensure their safety if there is marked disorientation as they could fall or hit themselve.

POTENTIAL EMERGENCIES AND ACTION

Beyond the situations described in the previous section, a greater risk of emergency is not foreseen than in the rest of the students. It refers to the reference protocols in each geographical area.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student suffering from Ornithine transcarbamylase deficiency may experience the following difficulties: writing issues, communication issues, headaches, disorientation, nausea, vomiting and headache.
		The student requires constant medical supervision. Therefore, regular cooperation among the school staff, the student's parents and the doctor is necessary. The parents should always be available.
		The learning process should be adapted (tutoring, homeschooling, etc.) if school attendance is impossible. It is important to remember that the student's state of health is not always predictable. The school staff and the student's parents should make a reasonable timetable to reintegrate the student back to school.
		It would be desirable to implement an effective socialisation and the student's self-esteem boosting strategy due to one's skin problems - dark colour on the face and hands.
		Inform the classmates.
		Help the student to focus of tasks, motivate to actively participate.
		Adjust the desk if necessary.
		Eliminate all activities and situations that can cause aggressive behaviour in the student.
		Use visual teaching and learning aids, specifically in writing and reading. Use memory games, exercises.
		It would be desirable to implement an effective socialisation and the student's self-esteem boosting strategy due to one's skin problems - dark colour on the face and hands.
	Technical support	If the student experiences health problems during lessons, the parents have to be informed immediately.
		There is a need for a special room for the student to stay in cases of health problems and where to wait for appropriate help to arrive.
		If necessary, adjust the desk and chair so that the student receives better information and is involved in the learning process.

Used sources:

Nicholas Ah Mew. Ornithine Transcarbamylase Deficiency. Retrieved (2022)
https://rarediseases.org/rare-diseases/ornithine-transcarbamylase-deficiency/

ORPHA 666

OSTEOGENESIS IMPERFECTA

DESCRIPTION OF THE DISEASE

Osteogenesis imperfecta, colloquially known as crystal bone disease, is characterized by brittle bones and low bone density, as well as hypermobility in the joints, that is, an abnormal extension of these. Therefore, these people are highly susceptible to bone fractures. There are 5 types of osteogenesis imperfecta, type I being the mildest.

In type I we find a normal height for his/her age or slightly shorter. In type II, some deformities and the longer bones are wider than usual. Type III has very short stature, a triangular face, and a deviation of the spine (severe scoliosis). Type IV produces moderately short stature and mild or moderate scoliosis. And finally, type V, in addition to being moderately short, causes dislocation in the elbow area.

A large percentage of patients with osteogenesis imperfecta have hearing impairments (decreased hearing or deafness).

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SENSORY SYSTEM (AUDITORY PERCEPTION)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

As for physical activities, extreme care must be taken with possible accidents, but always allowing the child to participate when the risk is minimal. Sports or exercises that pose a high risk of fracture should be avoided. It is advisable to ask the family before deciding to exclude the minor from the activities.

These people face multiple surgical operations, periods of convalescence, hospital visits, etc. Their schoolwork must be adapted to possible absenteeism, by prioritizing knowledge or including tasks that they can perform during their periods outside of class. The connection via telematics through streaming videoconference would be an option so that the child can follow the classes from home in the periods of convalescence.

If deafness or hearing loss occurs, it is necessary to use strategies such as good vocalization so that the student can lip read. Another method would be the use of sign language. In the case of wearing masks (due to pandemic status) in class, teachers may use a transparent mask to facilitate that the student can read lips without problems.

SPACE ADAPTATION - ERGONOMIC

A safe environment should be ensured avoiding anything that could lead to accidental trauma or contusion (lining table corners with foam, use of soft toys, etc.). Sometimes repetitive fractures can cause mobility difficulties that warrant the use of a wheelchair. In those cases, their position in the classroom will need to be adapted to allow for mobility and comfort. Shelves, cabinets, desks, blackboards, hangers, work materials, etc. must also be placed at a height that allows their use.

If there is a hearing deficit it may be helpful to place the student close to the teacher so that he / she can correctly lip read.

ENVIRONMENTAL ADAPTATION

In the event that the person must use hearing aid devices, it would be advisable to maintain a moderate tone of voice throughout the classroom, by all those present, avoiding excessive noise, in any case.

The parks or the schoolyard must be adapted to avoid unintentional injuries according to the recommendations set by the European Union.

ACCESSIBILITY

The person will need the help of a wheelchair in case of suffering a notable bone deformity that affects mobility or after periods of post-surgical intervention. Therefore, it will be necessary to install ramps and accesses for people with reduced mobility, if they do not exist, so that architectural barriers are eliminated. There must be at least one adapted bathroom on each floor of the center with a toilet placed at the standard height of a chair, with folding handrails on both sides, as well as easily accessible sinks with chairs and a low mirror placement to be able look properly in a sitting position.

INCLUSION STRATEGIES

Given the emotional and social repercussions that the disease can have, it is very important to work with the person to try to increase their self-esteem. In addition, school anti-bullying strategies should be encouraged, fostering relationships between equals. Also, it is necessary to use tools and activities that promote the autonomy of the person, increasing their feeling of independence.

Depending on the child's level of dependency, it will be necessary to have support staff (teachers) to facilitate the inclusion of the child in the classroom. Postural changes should be done by the child himself / herself in the wheelchair if he / she needs it, but it may be necessary to help him / her make them completely and safely to avoid blows.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is possible that the student requires treatment to control pain in certain periods (ibuprofen, paracetamol) and that they must be administered (pills or syrups or creams) during the school day according to the specified guidelines that the responsible health personnel have given to parents or primary caregivers. It will be necessary to have the prescription in writing and as long as they are oral medication. It will be necessary for teachers to be trained in the assessment of potential risk situations in the face of pain from a contusion. Teachers and cafeteria staff (if the child stays to eat) must recognize the signs of severity and possible fracture and notify family members and the health center if a fracture is suspected.

POTENTIAL EMERGENCIES AND ACTION

Bone fractures, especially of long bones (legs and arms), ribs, or vertebrae can occur from minimal trauma. Faced with a contusion situation, it will always be necessary to ask how they are feeling and if they have felt any kind of breakdown, functional decrease in any part of their body, especially the arms and legs. To detect the fracture, the teachers will observe if they have problems to carry out the classroom activities and if so, then the mobilization of the site in the classroom will be avoided until the appropriate health professionals come. Inspection with manipulation by teachers who are not qualified will be avoided due to the risk of producing an increase in the potential fracture.

If necessary, the emergency services should be alerted or the child should be transferred, if possible, to the nearest healthcare center. Above all, teachers must remain calm and ensure that the child is as relaxed as possible. Avoid sudden movements or repositioning of the fracture in case the bone is displaced from the site.

It is important to remember that, with any minor impact, a fracture or microfracture may occur, so in case of pain during school hours, the family of the minor and/or the corresponding medical center should be informed.

Another emergency situation can be a sprain (sprained joints, generally in the ankles, knees or elbows, which causes stretching of the ligaments with inflammation and hematoma and requires rest and partial immobilization, requiring the use of a wheelchair in the event of it occurring in the lower extremities), so that action will be taken as described above.

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference is made to the reference protocols in each geographical area.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Problem: physical (architectural) barriers that do not allow students to participate in school activities fully. The barriers students face most often: steps at school entrances or between floors; WC with a narrow or heavy door, high sinks; rooms for practical work (e.g. housekeeping or chemistry lessons) are not accessible to a wheelchair or a short student. Portable ramps and lifts for wheelchairs. Low lockers, shelves and soap dispensers. Low surfaces of desks. If necessary, ensure assistance of an adult in the WC. Slip-resistant flooring. Have a lift in multi-storey school buildings. If the student finds it problematic to move from one room to other (e.g., a gym or canteen, classrooms), give the student more time for that by, for example, letting the student leave the classroom a few minutes earlier thus giving one a chance to avoid a crowd. When arranging a classroom, pay attention to recommendations provided by the occupational therapist. Provide a quiet place where the student can be physically separated from others, can lie down because in case of pain those around can seem disturbing and annoying. When planning extra-curricular activities, sports lessons, and excursions, it is necessary to involve the students' parents to assess the involved risks. Make sure there are no objects in the classroom that could pose a risk of tripping.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	Problem: pain/joint pain and an increased risk of injuries/bone fractures Allow the student to use extra time to complete tasks. Pay attention to mobility of the student in the classroom making sure the student can avoid chaos and the risk of falling. The student will need special support to master the content of studies because of being absent, e.g. due to frequent medical visits. Encourage the student to try different pens and pencils for writing in order to find the most appropriate one. It is possibly that additional writing aids will be necessary. The student may be a slow writer Therefore it is good to provide one with relevant worksheets. Besides the obligatory set of books, provide an additional set of books so that the student has one at school and one at home to avoid the need for the student to carry a heavy schoolbag. Schedule regular breaks, ask the student to change posture and stretch every 30 minutes. The student may need to work in an online learning mode, require recordings of lessons, additional materials, and teachers' advice. Allow the student to use extra time to complete class activities or tests. Allow the student to leave the classroom to take medication on time. If the student has had a period of pain, allow one to submit the work, e.g. homework, later. Sports lessons and physical activities: Even though participation in sports lessons and other physical activities can be difficult, the student should be encouraged to take part in activities according to one's abilities and how one feels. Encourage the student to take part in most of contactless sports. To involve the student in the sports lessons and decide upon the most relevant exercises, consult a physiotherapist. Discuss modifications of the sports equipment, e.g., foam balls or spears, lighter sticks, bean bags, etc.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	Plan the use of time and space the way the student can participate in sports activities. Plan to have breaks for the student to rest if one is tired or in pain. Swimming and water therapy are especially suitable for the student as they allow one to move independently and have a low risk of fractures or injuries. Contact sports such as rugby, judo, etc. have to be avoided. Activities increasing a risk of falling have to be avoided. For example, skating, skiing or roller skating. Promote the acquisition of skills in different sports (including team sports) by involving the student in carrying out the duties of a judge or awarding points. If the student is not good at doing any activity, encourage one to think of alternatives.
	Technical support	Consultations with an occupational therapist about the most suitable seating and desk type for the student in the classroom. Consider using assistive technologies such as laptops, lightweight stationery and stationery with specific handles, Felt Tip Pen, and adaptive scissors. For a student in a wheelchair, it may be necessary to adjust the height of the desk to provide enough space for one's legs. To help the student deal with reading, use easels, portable reading stands, or adjustable desks.   Reference: *https://www.healthproductsforyou.com/p-bipgrip-pencil-pen-crayon-grip.html* *https://www.amazon.com/MaxiAids-Writing-Bird-Helper/dp/B00I5POPQW*

Used sources:

Brittle Bone Society. Including Children who have Osteogenesis Imperfecta in Mainstream PE Lessons. Available at:
http://redbridgeserc.org/uploads/factsheets/110798_Including_Children_In_PE_lores.pdf

Brittle Bone Society. Information for Schools.
https://brittlebone.org/support/information-for-schools/

ORPHA 701

UNIVERSAL ALOPECIA

DESCRIPTION OF THE DISEASE

This disease can appear at any stage of a person's life and causes hair loss in its entirety throughout the body due to inflammation of the hair follicle and subsequent hair loss. When personal image is damaged, these people suffer a great psychological impact due to the disease.

MAIN ORGANS OR SYSTEMS AFFECTED

CUTANEOUS- MUCOSOUS

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is not necessary to take any special pedagogical measures.

SPACE ADAPTATION - ERGONOMIC

It is not necessary to take any spatial and / or ergonomic measurements.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

There is no need to take any action regarding accessibility.

INCLUSION STRATEGIES

It is very likely that the child has low self-esteem due to their appearance and is likely to be shy in establishing relationships with other children. Therefore, it is advisable to encourage an inclusive and pleasant environment among students to avoid possible social exclusion inside and outside the classroom due to the physical appearance of the student.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It may be necessary to make sure that the student wears a cap to protect their head and to use sun cream when doing activities in the sun for a long time, since they will not have the protection from the sun that is normally provided by hair.

POTENTIAL EMERGENCIES AND ACTION

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should bechecked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

SUPPORTING THE STUDENT WITH **UNIVERSAL ALOPECIA** IN THE SCHOOL SETTING

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide an opportunity for the student to wear necessary headgear at school.
	Support provided by the teacher	Encourage positive collaboration and interaction in the classroom, at school. Organise activities showing students the importance of being empathic and understanding. Create a positive classroom environment and friendly atmosphere. The student may have low self-esteem. Therefore it is crucial to offer the student to complete self-esteem building activities. In case of outdoor activities on sunny days, make sure the student applies sunscreen on one's head or wears a hat.
	Technical support	Provide video materials, leaflets, or presentations on this disease.

Used sources:

National Alopecia Areata Foundation. Alopecia Areata School Guide. Retrieved (2022) *https://www.naaf.org/sites/default/files/documents/pdf/2014_new_school_pack_final.pdf*

ORPHA 705

PRENDED SYNDROME

DESCRIPTION OF THE DISEASE

It is a disorder that affects the ear leading to hearing loss of varying degree depending on the person affected, ranging from mild/moderate in some cases to severe/profound in others. These hearing problems can be associated with vertigo and 75% of cases present an enlarged thyroid gland (goiter) without affecting its hormonal function that usually develops in late childhood or early adulthood.

MAIN ORGANS OR SYSTEMS AFFECTED

SENSORY SYSTEM (HEARING)

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

METABOLIC-NUTRITIONAL

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Using a very clear language is recommended, with understandable vocabulary and syntactic structures for this type of student. Clear articulations, slow pace speaking and clear view of the teachers mouth is also crucial.

To avoid problems when following the lectures, notes or diagrams will be provided so that they do not have to take notes and can follow the class without interruptions. Shorten the theoretical explanations, pause and check that what has been explained so far has been understood. If necessary, doing individual tutorials to clarify doubts would be advidable.

Facilitate access to information and communication. Have the necessary technological and human means to facilitate communication with teachers and their peers.

SPACE ADAPTATION - ERGONOMIC

Place the affected students next to and facing the teacher, to make it easier for them to follow the lesson by lip reading. To promote interaction between the students, the group can be arranged in such a way as to facilitate the visibility of the face of the rest of the classmates.

ENVIRONMENTAL ADAPTATION

Prevent the existence of minimal background noise to avoid distortion of the capture and understanding of the information. These students work a lot with their eyes, as a way to compensate their hearing loss, so it is necessary that the classroom has adequate light that allows them to clearly see the blackboard and the face of the person speaking.

ACCESSIBILITY

Special measures are not necessary. If there are acoustic warnings for certain activities (end of class, end of playtime, etc.) it is important to consider alternative ones (flashing light, personalized warning, etc.). This will be also taken into account in evacuation warnings.

INCLUSION STRATEGIES

Sign language workshops in which students without hearing problems could learn words or sentences that allow them to communicate more fluently with the affected students. Diction workshops are also useful to facilitate lip reading, as well as workshops about the senses, adapted to each group age range.

All students should also be advised that people with hearing loss do not detect approaches of people or vehicles from the sides or from behind them, trying to establish visual contact before starting the interaction.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

No special therapeutic support is foreseen.

POTENTIAL EMERGENCIES AND ACTION

Greater risks of emergency are not foreseen than in the rest of the students.
Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	As the student with hearing impairement may feel isolated in the learning environment, provide different types of support for the student's socialisation at school. Create opportunities for social contact and interaction with other students because if these are limited, the student's learning could be affected.
	Support provided by the teacher	Encourage the student with audial impairement to sit in front of the classroom, where they will be able to see the teacher and interpreter, visual teaching and learning aids. This is especially important if the student has an interpreter or if they read from the lips, or rely on information from visual aids or use a hearing aid. Note if the student does not want to sit in fron of the classroom, there have to be other options. Respect the student's choice. Use hearning aids such as induction loops if possible. Hearing aids may have a transmitter/receiver systems with a clip-on microphone for the teacher. If the teacher uses such a microphone, one has to change their speaking or teaching style. Ensure that the background noise is kept to the minimum. Make sure your face is not covered. The student who reads lips cannot do that in dark rooms. Therefore, adapt the lighting in the elarning environment to the needs of the student. Ensure the information you give in speaking is also available in a form of a handout. These are materials for lessons, excursions, etc. Provide recordings of lessons. Make sure videos or movies used in lessons have subtitles. If that is not possible, think of alternatives. Observe the rule in lessons - only one person speaks at a time. Try not to talk when the student does not see your face. For example, while writing on the board or walking around the classroom.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	Minimase background noise because the hearing impaired student can be very sensitive to environmental (background) sounds which tend to stifle the student's speech. Speak naturally. Do not speak or read aloud too quickly so that the student or the interpreter can follow you. Plan breaks in learning. These are needed by the student and the interpreter as the process is mentally and physically tiring. Be aware that the perception of information visually can be tiring and cause eye strain for the student. If you turn off the light to use the projector, make sure that the lighting is sufficient for the audially impaired student see the interpreter. Remember that providing a good listening environment can have a significant impact on the student's performance. The audially impaired student rely on visual cues, such as body language and facial expressions, to obtain information. From time to time check the student's interpreter's notes to make sure the student receices sufficient and accurate information. Prepare written notes for your lessons. Encourage the use of technology, for example, the student may use a computer with a spell and grammar checker. Do not engage the student with the Prended syndrome in contact sports that may cause head injury.
	Technical support	In sports activities, for example, riding a bicycle or skiing, the student must wear head protection. The student with hearing impairement may need to use assistive technology to participate in a lesson. It can be a laptop, smartphone, etc., where the necessary software, such as spoken speech-to-written speech, can be used.

Used sources:

ADCET (n.d.). Deaf and Hard of Hearing. Available at:
https://www.adcet.edu.au/inclusive-teaching/specific-disabilities/deaf-hearing-impaired

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ORPHA 792

X-CHROMOSOME LINKED RETINOSCHISIS

DESCRIPTION OF THE DISEASE

It is a disease that affects vision and that causes a reduction in visual acuity as a consequence of the degeneration of the macula (a small area located in the center of the retina that allows the vision of details and movement, fundamental to distinguish faces and read). It appears in the first decade of life and develops symptoms such as decreased vision and reading difficulties. In severe cases, rapid and involuntary eye movements may also be observed and a retinal detachment may appear.

MAIN ORGANS OR SYSTEMS AFFECTED

SENSORY SYSTEM (SIGHT)

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Using large types and typescopes is recommended to counteract the loss of visual acuity.

To facilitate the access of students with visual disabilities to the 2.0 domain, it is important to have screen review software that reads the screen and transforms it into sound, Braille or a combination of both.

SPACE ADAPTATION - ERGONOMIC

There may be difficulties when following the classes, then locating the student close to the teachers will be useful and will help to improve their visibility of the blackboard. Using lifting tables and/or lecterns that allow the students to adapt the height of the reading/study material could also improve it.

ENVIRONMENTAL ADAPTATION

Insufficient lighting can worsen the problem, it is necessary that the classroom has adequate lighting that allows a clear view of the blackboard and the face of the person who is speaking. The use of cold fluorescent light tubes is recommended, cause this will them get an appropriate quality and intensity lighting, necessary to maximize visual acuity.

ACCESSIBILITY

To facilitate the orientation of the students in the classroom, it is advisable not to make changes in the arrangement of the furniture, as well as to have plans and maps adapted to their visual impairment to facilitate knowledge of the centre.

INCLUSION STRATEGIES

Involve all the school's students in workshops on the senses, adapted to each age group.

Encourage all classmates to act as guides when moving around the facilities. When it comes to participating in physical activities and games, it is useful for them that mates help them acting as model movements.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

No special therapeutic support is foreseen.

POTENTIAL EMERGENCIES AND ACTION

There could be a slight increase in the risk of falls and shocks when travelling or during activities. Apart from these situations, a greater risk of emergency than for the rest of students is not foreseen. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

SUPPORTING THE STUDENT WITH **X-CHROMOSOME LINKED RETINOSCHISIS** IN THE SCHOOL SETTING

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Inform the school staff and students about the limitations the student with X-Chromosome Linked Retinoschisis has. Make sure the student with X-Chromosome Linked Retinoschisis does not participate in such physical activities that may increase the risk of retinal detachment. Explain the layout of the school premises to the student suffering from X- Chromosome Linked Retinoschisis or create a tactile map. Teach a visually impaired / blind student's classmates to be their guide while walking around the school or classroom. Explain other students they should allow the visually impaired / blind student to take a guide's hand to follow instructions. Explain to the personnel and other students that the visually impaired / blind student should first be asked if they need any help, and only upon an affirmative answer, they should be helped. In order to draw the visually impaired/blind student's attention, use a gentle touch (if the student's name is unknown). Create terrain guidelines both indoors and outdoors. Use plates at doors, have labels and signs in Braille. Do not change the placement of furniture and other objects in any room at the school. Use a contrasting design of environmental objects.
	Support provided by the teacher	Advise the student with X-Chromosome Linked Retinoschisis to avoid contact sports as they may increase the risk of retinal detachment. Seat the student with X-Chromosome Linked Retinoschisis closer to a board / screen. Remember the visually impaired / blind student perceives information in a varety of ways. For example, in Braille, audio recordings or enlarged print. Note that reading a text in Braille can take up to three times longer than any other text.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	Plan additional time for activities, for example, if finding words in a text requires transition from one reading device to a different one. Try to assign tasks for which the student has necessary tools and technologies. Make sure the visually impaired / blind student does not feel isolated among classmates because it may affect their learning. The student who does not see body language and intercations of the surrounding people often finds it difficult to get involved and engage in learning activities. It is especially complicated to understand when a discussion needs to be interupted or changed. Plan time for breaks because the visually impaired / blind student may experience headcahes due to eye strain. Depending on the needs of the student with X-Chromosome Linked Retinoschisis, reduce the number or duration of lessons if necessary. Provide learning materials in an electronic format as it can greatly facilitate the visually impaired / blind student's accessibility to the materials. Provide a list of books to read and tasks to do in advance so that the student can prepare their work. Prepare tasks and their instructions in Braille. Add words to everything you do - verbalise your teaching to convey information about things going on in the classroom and what you are doing. Discuss each step that needs to be carried out to perform a particular action. Read all the printed information and describe any charts or diagramms that are being used. Inform the student if you plan to use videos, slides, etc. Discuss the alternative ways to present the required information. In case of any field trips or excursions, provide individual support to the visually impaired / blind student to reduce their anxiety that may arise in unfamiliar environments. Consider recording audio comments to complement practical work, for example, experiments or excursions. Agree with the visually impaired / blind student on alternative feedback because the student cannot read your handwritten comments. Make sure online learning materails and tools you use comply with the guidelines for accessible web design.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Technical support	Explain the classroom layout or create a tactile map. Apply labels and signs in all the rooms at the school because they make objects accessible to the visually impaired/blind student. Apply a labelling system accessible to all the students, for example, use different labels: print, Braille, talking recorder buttons, voice labelling system, images and objects, as it will help to find, implement and place materials appropriately. If you divide the classroom into learning stations or centres, the use of a clear and consistent labelling system will help the visually impaired/blind student to navigate the classroom and recognise names of the learning stations. Place labels at the students' eye level. Make sure you have the labels in important places so that the visually impaired/blind student can examine them and remember. Have labels in important for the visually impaired/blind student places. Make sure which lighting is best for different activities in the classroom, such as taking notes, watching a presentation or a video, and completing tasks. Remove all possible obstacles on the floor that may make it difficult for the visually impaired/blind studnt to move around the classroom. Do not use soft bean bags in the classroom as they may increase the risk of tripping. Ensure that there are no obstacles for the visually impaired/blind student's moving around the school indoors and outdoors.  Fig. 1 Voice Labelling System (https://www.amazon.com/Reizen-Talking-Label-Wand-Labeling/dp/B085T731CV)

Individualised Education Plan (IEP) and 504 Accommodation Plan	Technical support	Talking Label System lets a person record one's own talking labels on items at the school and home. At first, put a self-adhesive label on the item and then record the message to identify it. To play the message, one should touch the label with a pen reader. Talking Label System allows the visually impaired/blind student to identify their belongings and/or leave messages for themselves and/or others. Overall, labelling helps to have order in the classroom and improves its accessibility thus encouraging independence of the visually impaired/blind student. Moreover, it enhances development of the reading skill.  Fig. 2 Bump Dots Bump Dots of different colours and sizes are ideally appropriate for the visually impaired / blind student as they ensure simple identification of objects, for example, a keypad, board, switches, desks, tools, etc.

Used sources:

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Perkins (2020). Elementary School Classrooms and Low Vision: Designing Accessible Classroom Series. Available at:

https://www.perkinselearning.org/technology/blog/elementary-school-classrooms-and-low-vision-designing-accessible-classroom-series

Willings, C. (2017). Labeling System. Available at:

https://www.teachingvisuallyimpaired.com/labeling-system.html

ORPHA 823

ISOLATED SPINA BIFIDA

DESCRIPTION OF THE DISEASE

Spina bifida is a birth defect that causes improper formation of the spine and spinal cord. This disease can range from mild to severe. The child will have motor problems, which makes it very likely that there is muscle weakness in the legs or paralysis, even preventing them from walking. In addition, depending on the location of the problem, there may be orthopedic consequences, such as scoliosis (deviation of the spine), muscle contractures, deformations in the bones and joints, dislocation of the hip or abnormal growth. A malfunction of the nerves in the bladder or bowel is also very common, causing urinary and fecal incontinence. Another point to highlight are the skin problems that they usually have due to a decrease in sensitivity.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR
MUSCULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

DIGESTIVE
CUTANEOUS - MUCOSOUS
URINARY

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Before making pedagogical adaptations of the educational curriculum, it is necessary to know the limitations of the person and collaborate with the family for a correct exchange of information. The child should always start from the curricular normality and add the minimally necessary adaptations to avoid notable differences between the students.

SPACE ADAPTATION - ERGONOMIC

A class adapted to a wheelchair and of sufficient size for proper mobility will be necessary. In addition, the proximity of a toilet would be very suitable due to the need to empty the urine or faeces collection systems that may be carried due to incontinence.

It is likely that a table / desk is necessary that allows comfortable use with the wheelchair, ideally being adjustable in height.

Shelves, cabinets, desks, blackboards, hangers, work materials, etc. must also be placed at a height that allows their use.

ENVIRONMENTAL ADAPTATION

Children with spina bifida are usually allergic to latex so, if used in class, it would be advisable to use other materials since an attack situation may occur, allergic, being a life-threatening condition if not treated in time.

ACCESSIBILITY

The adaptations in terms of accessibility are aimed at the elimination of architectural barriers for the free use of a wheelchair. Therefore, it will be necessary to review all accesses, location of services and classrooms. Corridors and doors must be wide enough to allow for the smooth movement of a wheelchair. In the absence of an elevator, one must be installed and, if this is not possible, the student's class will be moved to the lower floor.

There must be at least one adapted bathroom on each floor of the center with a toilet placed at the standard height of a chair, with folding handrails on both sides, as well as easily accessible sinks with chairs and a low mirror placement to be able look properly in a sitting position.

INCLUSION STRATEGIES

Due to the social and emotional repercussions that the disease has, it would be very positive to work with the person to help them feel good and value themselves, in addition to implementing school anti-bullying strategies and fostering companionship through cooperative activities and games. The celebration of a thematic day in collaboration with the Association of Families of Students on the Disease with testimonies of related professionals and dissemination of knowledge adapted to the different ages of the classes can be a positive intervention to achieve a greater understanding of the disease.

In addition, tools and activities that promote the autonomy of the person should be used.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

In these children, the presence of support staff in the classroom is essential. It is not necessary for them to be there during the entire class period, but they must be there when necessary to support a need that the child cannot fulfill themselves.
It would be advisable for the teaching staff to become familiar with certain sanitary devices (urinary catheterization, urinary collectors ... etc) in order to be able to help in their management, if necessary. It is possible that a situation of fecal or urinary incontinence may occur so the intervention of the teachers may be required, trying to minimize the social and psychological consequences that the situation may cause. It is possible that the student may have periods of pain due to being in the same position or because of the deformity in the back. To do this, they may need to be repositioned in the wheelchair or adapt the seat where they are. In turn, they can have medication such as pain relievers (paracetamol, ibuprofen, for example). If so, the instructions of the prescribed medication should be provided by the family responsible.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not expected than in the rest of the students, as long as the recommendations on contact with latex are taken into account. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	**Problem:** motor problems - weakness of leg muscles, even the inability to walk; orthopaedic problems - based on the place of the problem, there may be scoliosis (a spine disorder), muscle contractures, bone and joint deformity, hip dislocation, or abnormal growth); bladder or bowel nerve disorders causing urinary and faecal incontinence; skin problems; a learning difficulty (however, these children usually have normal intelligence. **It is of utmost importance that parents, medical professionals and the school cooperate to help the student.** Provide the student with an individualised syllabus, additional support and extra time to do exercises because the student may be in hospital or home away from school for a long period of time. If there is a need to use latex in lessons, think of using other materials as the student may be allergic to it (they usually are). Using latex can be a reason for a seizure situation which is a life-threatening condition if not attended in time. Have an assistant or support staff in the classroom because even though the student might not need an assistant all the time, there may be critical situations when the student needs help. Get familiar with specific sanitary tools (for example, urinary catheterisation, urine collectors) to assist the student if it is needed. (It is possible that faecal or urinary incontinence situations may occur and you may need to intervene or reduce the social and psychological consequences.) If the student experiences periods of pain because of being in the same position or due to deformity of the back, help one sit in a wheelchair or adjust the seat. If the student has to take medicine, talk to one's family to get additional information.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be understanding if the student is late for a lesson as it may take more time to move because of technical devices that are used. Adapt physical activities taking into consideration advice given by the student's parents and medical professionals. Make sure that all the things needed for lessons are in the classroom so that the student does not have to carry them around. The student may need to work in an online learning mode, require recordings of lessons, additional materials, and teachers' advice. Do not lower the requirements, instead take into account the student's physical limitations. Emphasise the student's strengths.
	Technical support	The student may need leg mounts, walkers, or even a wheelchair therefore it is necessary to make sure that in the education establishment there is an elevator, lessons for this student take place in classrooms on the first floor, there are specific desks and chairs, etc. Classrooms, WCs, and other rooms have to be suitable for the student in a wheelchair to move around (spacious enough). WC has to be close to the classroom. It would be advisable to have a specially equipped WC or bathroom (a toilet placed at a standard chair height, with folding handrails on both sides, and easily washbasins with chairs and a low position for the mirrors) not far from the classroom. Shelves, whiteboards, hangers, work materials, and other things must be placed at a height that allows the student to access them. Additional space and time should be provided for the student to move around the school.

Used sources:

Gaintza, Z, Ozerinjauregi, N, Aróstegui, I. (2018). Educational inclusion of students with rare diseases: Schooling students with spina bifida. Br J Learn Disabil. 46: 250-527.

https://doi.org/10.1111/bld.12246

ORPHA 828

STICKLER SYNDROME

DESCRIPTION OF THE DISEASE

Pathology that causes various ophthalmological problems, the most frequent being high myopia, strabismus, juvenile cataracts, astigmatism, vitreous and/or retina detachment and glaucoma. Also, there may be abnormalities in the face and / or mouth, such as defects on the palate closure, double uvula, retraction of the cheekbones and/or the lower jaw. In addition, bone abnormalities such as spinal deviation, hump or hip problems may appear, even typical skeletal dysplasia (dwarfism) may occur.

40% of affected people suffer from deafness of varying severity.

MAIN ORGANS OR SYSTEMS AFFECTED

SENSORY SYSTEM (SIGHT)

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SENSORY SYSTEM (HEARING)

OSTEOARTICULAR

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

If there is difficulty in reading due to reduced vision, the use of large types and typescopes may be useful.

To facilitate the access of students with visual disabilities to the 2.0 domain, it is important to have screen review software that reads the screen and transforms it into sound, Braille or a combination of both.

In case of hearing loss, using clear language, with simple vocabulary and understandable syntactic structures is recommended, as articulating clearly and slow pace speaking.

SPACE ADAPTATION - ERGONOMIC

There may be difficulties when following the classes, then locating the student close to the teachers will be useful and will help to improve their visibility of the blackboard. Using lifting tables and/or lecterns that allow the students to adapt the height of the reading/study material could also improve it.

To minimize the impact of hearing loss, the student should face the teacher to let them do lip reading, with no obstacles that obstruct the vision of the mouth. Placing them close to the person speaking, as well as to arrange the group in a way that facilitates the visibility of the face of the rest of the colleagues is also recommended.

ENVIRONMENTAL ADAPTATION

The classroom should have adequate lighting that allows a clear view of the blackboard and the speaker's face. Using cold fluorescent light tubes is recommended, which allow lighting with the quality and intensity necessary to maximize visual acuity.

Preventing environmental noise as much as possible will avoid distortion in information capturing and understanding.

ACCESSIBILITY

Eliminate physical obstacles as far as possible to facilitate the transit of these students without accidents. Facilitate the use of auxiliary methods depending on the degree of limitation (walker, walking stick, crutch).

To facilitate the orientation of these students in the classroom, it is advisable not to make changes in the arrangement of the furniture and to have plans and maps adapted to the visual impairment to facilitate knowledge of the centre.

INCLUSION STRATEGIES

Teaching of sign language workshops for students without hearing problems could be promoted. Diction workshops are also useful to facilitate lip reading, as well as workshops about the senses, adapted to each group age range.

Encouraging all classmates to act as guides when moving around the center, participating in physical activities (it may be useful for everyone to know how to be movements model) and assess the holding of workshops, adapted to the age range, on prevention and help in case of falls and collisions.

Make in the classroom, with everyone collaboration, the 3D models that are going to be used to facilitate learning in some subjects for students with visual impairments.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

No special therapeutic support is foreseen.

POTENTIAL EMERGENCIES AND ACTION

There could be a slight increase in the risk of falls, shocks and blows when traveling or during activities. Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. It refers to the reference protocols in each geographical area.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	It is advisable to provide a special pedagogue who can help the student with hearning and/or visual impairement. To meet the needs of the student with Stickler syndrome, regular communication with the student's family is essential. As Stickler syndrome is a progressive disorder, parents can provide important information about the child's condition. Be aware that the student's parents and siblings may experience mental/emotional overload. It is of utmost importance to find out how vision/hearing/joint problems affect the student in the classroom or at home, how long the student can continue writing or can sit or stand comfortably. Make sure if the student has no objection that others students or staff know their condition and talk about it. To ensure learning of the student, find out what devices, teaching and learning aids have been successfully used. Find out information about the student's emotional and social needs because the student with Stickler syndrome may feel uncomfortable, isolated, or excluded from classmates and even the school staff due to physical differences and/or disabilities. Make sure what changes are necessary in the school or classroom to protect the student's eyesight and/or joints. Information on what to consider when organising trips or excursions is important. Find out how the school staff can help the student not to miss lessons or how the parents can help the student to study at home.
	Support provided by the teacher	Give the student an opportunity to move during the lesson, as their joints may become stiff because of prolonged sitting or standing. Invite the student to help you, for example, hand out worksheets, not to sit or stand for long periods. Make the student do tasks that do not require prolonged writing to avoid joint stiffness/pain.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	Plan breaks for stretching in any kind of learning activities. Allow the student to sit in a chair even if classmates in group work sit on the floor. Extend the time to complete written work. Use digital teaching and learning aids so that the student does not have to carry textbooks to the school.Also consider giving an additional set of books to the student not to carry a heavy backpack. Make sure the lessons are planned the way the student does not have to move a lot from floor to floor. Moreover, allow the student to move from one room to another one five minutes before the bell to avoid crowded halls. Provide large print books/materials. Provide and facilitate the use of assistive devices/communication devices where necessary. Provide the student with special pens and pencils. Allow the student to use the computer instead of writing by hand. Offer the student the most appropriate seating in the classroom for their visual/hearing/mobility challenges. Make sure the student sees you clearly, so they can see how the teacher speaks. Remember that turning a teacher's head while speaking can make their voice become muffled. When referring to a visual illustration or writing on a whiteboard, avoid using words like 'this', 'that', 'hear' and 'there'. Instead, use descriptive words such as 'calculations on the right side of the equation' to help the student focus better on visual aids. Speak directly to the class and say the words naturally because exaggerated pronunciation makes it difficult to read from lips. Avoid standing near a source of light, for example, a window, as the backlight obscures lips and facial expressions. Do not cover the mouth with a book or any other teaching and learning aid while speaking. Give the student more time to complete tasks or tests.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	When planning tests, keep in mind that, for example, joint inflammation often occurs on winter mornings, but fatigue occurs shortly after exercise. Provide instructions using hearing aids (ALD)/FM systems. Ensure modifications and adaptations in sports lessons for the student with Stickler syndrome. For example, give the student sports goggles during physical activity. Exclude any activities that may cause a blow to the head as it may cause retinal detachment. Physical activities and exercises that may cause joint pain should be avoided to protect the student's joints. Monitor the length of any physical activity so that the student does not suffer from joint pain and fatigue next day. In some cases, consider forbidding the student's participation in any physical activity due to the student's physical limitations. In this case, the student may need medical exercise instead of sports lessons. Before going on any excursion, think about the noise level and the duration of movement and standing. Do not consider amusement parks as an alternative for an excursion. Before any excursion, discuss it with the student's parents.
	Technical support	Due to the changing nature of Stickler syndrome, learning adaptations and modifications should to be planned based on the student's unique needs. In the classroom, provide a desk and chair whose height can be changed to reduce the student's joint stiffness. If the school has several floors, provide the student with access to a locker for personal belongings on each floor.

Used sources:

Stickler Involved People. Teacher's Help Page. Available at:
http://stickler.org/for-teachers/

ORPHA 930

IDIOPATHIC ACHALASIA

DESCRIPTION OF THE DISEASE

It is a digestive pathology characterized by the lack of mobility of the esophagus and difficulty in correct opening the sphincter that connects the esophagus and the stomach. It leads to difficult swallowing both solid food and drink, pain and frequent regurgitation, since the ingested food and drink do not get to the stomach and are accumulated in the esophagus. Weight loss is usually frequent and appears as a consequence of the limitation of food/drink intake. Some people also have symptomps as burning or heartburn in the esophagus (pyrosis).

MAIN ORGANS OR SYSTEMS AFFECTED

DIGESTIVE

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

METABOLIC (NUTRITIONAL-FOOD BASE)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

This type of student requires medical monitoring and may suffer from recurring symptoms, conditioning justified absences.

Classes should be adapted to these absences, providing tutorials, private and online classes, or any other methodology that allows you to carry out the same academic follow-up as their classmates.

They can present problems on the participation in games and the realization of physical efforts so they should be adapted to each student capabilities.

SPACE ADAPTATION - ERGONOMIC

Difficulties on controlling defecation and the appearance of nausea and vomiting: students suffering from this type of pathology should be located near the door to facilitate them to go to the toilet when necessary. Likewise, it will be ensured that the class is close to the toilets.

Access to changing rooms and showers in the centre will be provided whenever necessary to contribute to their comfort in the centre.

ENVIRONMENTAL ADAPTATION

Implementation of extraordinary measures is not required.

ACCESSIBILITY

Implementation of extraordinary measures is not required.

INCLUSION STRATEGIES

Due to the risk of stigmatization of this type of student, it is recommended to work in greater depth on the digestive system so that their classmates understand the consequences of their pathology.

It is also very advisable that the whole class knows the correct procedure to attend, in case of emergency, a choking or, at least, what should not be done.

Promote that classmates to act as reinforcement in their learning process, so their socialization is facilitated while their academic learning is reinforced by collaborating with their peers.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is important to pay attention to the moments in which these students ingest food or drinks since they could present a choking. The texture of food and beverages must be adapted to each person tolerance, for instance, thickening products can be used for liquids.

POTENTIAL EMERGENCIES AND ACTION

In the event of a choking episode, in relation to food/drink intake or regurgitation or vomiting, it is essential to act immediately using the following procedure:

> If you can see the object, try to remove it. Do not try to search blindly or repeatedly with your fingers. You can make things worse if you push the object further in and make it difficult to remove.
>
> If the student is coughing forcefully, encourage him to continue coughing and not stop.
>
> If the student's cough is not effective (it is silent or he cannot breathe well), yell for help immediately and assess if he is conscious.
>
>> If the student is still conscious, but is not coughing or his cough is not effective, hit/blow his/her back.
>>
>>> Lay the child facing down on your lap as you would do with a baby.
>>>
>>> If this is not possible, support the child in a forward lean position and give 5 blows/hits to the back from behind.
>>>
>>> If blows/hits to the back do not improve choking and the child is still conscious, perform 5 abdominal pushes. This will create an artificial cough, increasing pressure on the chest and helping to expel the object.
>>>
>>> Stand or kneel behind the child. Place your arms under the child's arms and around the upper abdomen.
>>>
>>> Clench your fist and place it between the belly button and the ribs.
>>>
>>> Grab this hand with the other hand and pull abruptly inward and upward.

Repeat up to 5 times.

Make sure not to apply pressure to the lower rib cage, as this can cause damage.

After chest or abdominal compressions, reassess the child as follows ...

If the object has not yet expelled yet and the child is still conscious, continue with the sequence of back blows/hits and chest or abdominal thrusts.

Call 112 or ask for help, if you are still alone. Never leave the child alone unsupervised.

If a choking child is unconscious or loses consciousness:

Place it on a firm, flat surface and cry out for help.

Call 112; put the phone on speakerphone so you have your hands free.

Do not leave the child at any time.

Open the child's mouth. If the object is clearly visible and you can easily grasp it, remove it.

Initiate CPR (cardiopulmonary resuscitation).

Workshops for teachers to learn and practice this procedure are highly recommended (simulation with maniquins).

Beyond the establishment of a choking box, which we have already commented, greater risks of emergency are not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

European Resuscitation Council Guidelines 2021: Pediatric Life Support. *https://cprguidelines.eu/assets/guidelines/European-Resuscitation-Council-Guidelines-2021-Pa.pdf.*

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide frequent meals and regular options to drink. Plan meals taking into account expert recommendations. Provide recordings of lessons and consider distant teaching and learning. Provide online materials so that the student can continue learning in the event of being in hospital or not being able to be at school.
	Support provided by the teacher	Keep in mind that some studnts may have difficulty completing tasks, especially when there is a feeling of physical discomfort. Plan regular breaks. Provide the student with alternative activities if you notice that the student is tired, as some medications can cause apathy and difficulty in concentrating. In such circumsyances, the student will not be able to participate in discussions. Provide recordings of lessons. Provide online materials in case the student has to be in hospital or experiences problems after treatment. Prolong the time for the student to complete tasks and submit work. Provide a list of books to read and tasks to do in advance so that the student can prepare their work. Plan individual consultations if the student has to be away from school and learning for a long time. Help the student to divide their work in parts, set goals and encourage focusing on more realistic and achievable aims. Be precise in giving instructions. Having had consultations with the student's parents and the physician, carefully plan sports activities because too intensive activities can lead to the student's health problems. Sports activities must be appropriate to the student's abilities.

	Technical support	Provide a relevant teaching and learning environment, such as regular ventilation of the classroom, lighting appropriate to the student's needs, as the student may be sensitive to heat or light, as well as certain chemicals. Provide access to changing rooms and showers. If possible, ensure a small room where the student can take care of oneself, arrange belongings, clothes. Provide a seat for the student close to the door to make it easier to go the WC if necessary.

Used sources:

ADCET (n.d.). Health Conditions. Available at:
https://www.adcet.edu.au/inclusive-teaching/specific-disabilities/health-conditions

ORPHA 1037

MULTIPLE CONGENITAL ARTHROGRYPOSIS

DESCRIPTION OF THE DISEASE

Arthrogryposis is a group of disorders characterized by contractures of the extremities, causing limited movement of the joints and muscle weakness. The 2 main types of arthrogryposis are the classic, which affects multiple limbs, and the distal, which involves the feet and hands.

Arthrogryposis multiplex congenita is not progressive, but many of the problems it causes can be progressive and worsen over time. The characteristics of this type of arthrogryposis are the forward inclination of the shoulders, extended elbows, with flexed wrists and fingers. The feet often have an "equine" appearance (ie, bent and arched inward) and the spine may be deviated.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR

MUSCULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is likely that the child requires palliative surgeries, so there may be recurrent absenteeism in certain periods. Therefore, a curricular adaptation is needed taking into account these absences, so that the person can advance academically like the rest. The teacher should always try to start from an ordinary curriculum, adding the minimum necessary adaptations possible to avoid differences between students as much as possible. The telematic connection via streaming video conference of the class would be an option so that the child can follow the classes from home in the periods of convalescence after the different surgical interventions carried out. Also, and as a way to increase the inclusion of the class.

SPACE ADAPTATION - ERGONOMIC

The means must be adapted to write by hand or by keyboard, draw, cut out, etc. due to the difficulty they present for actions that require fine movements of the hands and fingers. For this adaptation, ergonomic, joystick-type mice, push-button mouse emulators, virtual keyboards, extended or reduced keyboards, etc. can be used. The use of educational methodologies with virtual teaching resources that facilitate the achievement of teaching objectives could even be valued.

Depending on the characteristics of the student and their level of dependency, it will be necessary to have crutches or a wheelchair for their mobility. In turn, the shelves, cabinets, desks, blackboards, hangers, work material, etc. they must be placed at a height that allows their use.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

It is probable the person will need a wheelchair or crutches, so it will be convenient to adapt the entire center with ramps and access for people with reduced mobility (wheelchairs), such as a greater width of the doors, the installation of a elevator or, if this is not possible, the transfer of the class to the lower floor. Also, there must be at least one adapted bathroom on each floor of the center with a toilet placed at the standard height of a chair, with folding handrails for support on both sides, as well as easily accessible sinks with chairs and a low mirror placement to be able to see themselves sitting in the correct position.

INCLUSION STRATEGIES

It is necessary to promote the autonomy of the student, so that their self-esteem is not compromised, so it is convenient that they carry out the activities by themselves or alone, always within their capacities, trying to participate and perform the maximum activities proposed for all students, even if they take longer to complete or require rest intervals.

Involving the rest of the classmates and classmates in facilitating class assignments and increasing contacts via social networks can facilitate their inclusion and understanding of their disease.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is possible that the student requires treatment to control pain in certain periods (ibuprofen, paracetamol) and that they must be administered (pills or syrups or creams) during the school day according to the specified guidelines that the responsible health personnel have given to parents or primary caregivers. It will be necessary to have the prescription in writing and as long as they are oral drugs.

It is possible that, after a period of rest after an associated surgical intervention, the student will have a series of dressings placed over the surgical scar. These dressings can peel off or become stained, so there should be replacement dressings in the classroom itself, along with sterile gauze, antiseptic (chlorhexidine, for example) and gloves. Before changing and putting on the gloves, the teacher should wash their hands for 5 minutes with soap and water. If it is necessary to act quickly due to minimal bleeding, the teachers will put on the gloves and apply pressure to the area with the gauze to avoid it. At that time, a supporting teacher must be notified to facilitate the transfer or call the appropriate health resources.

In turn, teachers must be attentive to inappropriate postures adopted by the student in the classroom. The student will be provided with all kinds of pressure relief devices that allow greater comfort.

In the event of possible bruises, bumps or sprains, cold compact will be applied (using cold packs or with ice wrapped in a cloth). They will be left to rest and family members will be notified so that they can transfer them to the specific health center. If they cannot attend, then it will be necessary to notify the health center to claim a transfer for trauma care.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not anticipated than in the rest of the students.
Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide additional support staff and adapt the physical environment.
	Support provided by the teacher	**Problem: fatigue due to mucle weakness and limited joint movements** Encourage the student to use hands in the learning process, although it can be a big challenge. If necessary, ask for additional staff in the classroom. If the student is tired, written answers can be replaced by oral answers. Or ask the student write just the most essential information. If there is a student's assistant in the classroom, ask the assistant to put down the answers. If the student finds it problematic to participate in sports lessons, excursions or any other out-of-class activities, their importance has to be re-evaluated as the most significant thing is not to overload the student. **Problem: pain** Regular breaks, a chance to change posture, movements. Provide a place where the student can be physically separated from others, can lie down because in case of pain those around can seem disturbing and annoying. Help should be provided upon request not to make the student feel ashamed. Always ask the student for permission before helping. If you have to talk with the student about one's disease, do it when there are no other classmates around. If the student needs support, involve the student in its planning process. Keep in mind that students who suffer from this disease, are usually intelligent, their language and speech develop according to their age.

Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	Support may be needed to facilitate acceptance of the situation. To meet the needs of the student, it is necessary to provide physiotherapy or therapeutic exercises and modified sports activirties. Due to limited mobility, the student may need extra time for sports activities, before and after sports lessons. In case of pre-planned operations, it is necessary to involve the student in distance learning activities, provide lesson recordings, other materials, consultations. Extra time for completing tasks, tests, alternative types of assessment as there may be problems with writing. Consider using a computer for the student to write. Alternatives kinds of note-taking may be useful. Allow the student tp answer orally. The student needs more time to get from one room to a different room. Assistance with daily activities, such as taking books out of the school bag, etc. Reduce the amount of work done in the classroom and at home.
	Technical support	**The student's learning performance can be improved if:** one's place in the classroom is carefully selected; appropriate height and inclination of a table; appropriate writing tools; adapted aids, such as loop scissors; 

	Technical support	writing in the classroom is done on computers and laptops (a specially adapted keyboard and wrist supports); sometimes there is a need for personalised equipment, for example, voice recognition software, text translation/reading (also in foreign languages), touch screens, etc.; if the student has to move a lot, a wheelchair is a necessity, especially in older classes when the stduent's weight increases and it becomes more difficult to move; to avoid the student's discomfort, a wheelchair operated by the student is preferred.

Used sources:

The Arthrogryposis Group. Available at:
https://www.arthrogryposis.co.uk

ORPHA 1199

ESOPHAGEAL ATRESIA

DESCRIPTION OF THE DISEASE

It consists of a congenital malformation of the esophagus, so that a fragment of it, usually the central one, has not formed during pregnancy. In addition, very often, the existing portions of the esophagus communicate with the trachea (fistula), aggravating the condition. Given the severity of the condition, babies born with this malformation undergo surgery as soon as possible, and reoperations are also frequent. The child population that has been successfully operated lives with some limitations and a high risk of digestive complications (reflux, difficul swallowing, esophagus inflation, nausea, etc.), respiratory (frequent cough, risk of choking, recurrent respiratory infections, etc.). and even thoracic deformities as a consequence of the surgery.

MAIN ORGANS OR SYSTEMS AFFECTED

DIGESTIVE

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

RESPIRATORY
METABOLIC (NUTRITIONAL-FOOD BASE)
OSTEOMUSCULAR

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Students affected by this pathology are generally enrolled to the school later than children of the same age as a consequence of successive surgical interventions. In addition, they require medical monitoring and suffer from frequent complications that justify absences.

Classes should be adapted to these absences, providing tutorials, private and online classes, or any other methodology that allows you to carry out the same academic follow-up as their classmates.

Some people may present a delay in the acquisition of speech and present diction problems, in relation to the use of nasogastric catheters for long periods, in which case it should be assessed with the corresponding multidisciplinary team and the specific needs of each case should be analyzed.

They can present problems on the participation in games and the realization of physical efforts due to structural or functional problems in the thorax, low respiratory functional capacity or risk of expelling the nasogastric tube, if there is any.

SPACE ADAPTATION - ERGONOMIC

The appearance of nausea, vomiting and gastroesophageal reflux can be frequent, so students suffering from this type of pathology should be located near the door to facilitate them to go to the toilet when necessary. Likewise, it will be ensured that the class is close to the toilets.

Access to changing rooms and showers in the centre will be provided whenever necessary to contribute to their comfort in the centre.

It may be necessary to adapt the space that the student occupies (table and chair) in the classroom to minimize the discomfort that may be caused by structural and/or functional alterations that are consequence, at the thoracic level, of surgical interventions.

ENVIRONMENTAL ADAPTATION

It may be beneficial to maintain a correct environmental humidity to avoid tracheal dryness and promote the expectoration of respiratory secretions, especially if there is a persistent cough and/or recurrent respiratory infections.

ACCESSIBILITY

Implementation of extraordinary measures is not required.

INCLUSION STRATEGIES

It is important to take into account the delay in access to schooling, as well as possible problems in the vocal cords that determine speech problems since both circumstances can make it difficult to socialize in the school environment.

It is recommended to work on the digestive system in the classroom so that thier classmates understand the consequences of the pathology. In case of the affected person is using a catheter, it is also important that the group understand how it works and become familiar with the device.

It is also very advisable that the whole class knows the correct procedure to attend, in case of emergency, a choking or, at least, what should not be done.

Promote that classmates to act as reinforcement in their learning process, so their socialization is facilitated while their academic learning is reinforced by collaborating with their peers.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is important to pay attention to the moments in which these students ingest food or drinks since they could present a choking. The texture of food and beverages must be adapted to each person tolerance, for instance, thickening products can be used for liquids.

In case the student is using a nasogastric tube for feeding is necessary, they are usually taught to use it correctly and independently. If they require any kind of help, the teachers or the dinning room staff should have received, from their family, precise and written instructions. Anyway, it is important to avoid expelling or mobilizing the catheter, especially if there has been a recent surgery.

POTENTIAL EMERGENCIES AND ACTION

In the event of a choking episode, in relation to food/drink intake or regurgitation or vomiting, it is essential to act immediately using the following procedure:

> If you can see the object, try to remove it. Do not try to search blindly or repeatedly with your fingers. You can make things worse if you push the object further in and make it difficult to remove.

If the student is coughing forcefully, encourage him to continue coughing and not stop.

If the student's cough is not effective (it is silent or he cannot breathe well), yell for help immediately and assess if he is conscious.

If the student is still conscious, but is not coughing or his cough is not effective, hit/blow his/her back.

Lay the child facing down on your lap as you would do with a baby.

If this is not possible, support the child in a forward lean position and give 5 blows/hits to the back from behind.

If blows/hits to the back do not improve choking and the child is still conscious, perform 5 abdominal pushes. This will create an artificial cough, increasing pressure on the chest and helping to expel the object.

Stand or kneel behind the child. Place your arms under the child's arms and around the upper abdomen.

Clench your fist and place it between the belly button and the ribs.

Grab this hand with the other hand and pull abruptly inward and upward.

Repeat up to 5 times.

Make sure not to apply pressure to the lower rib cage, as this can cause damage.

After chest or abdominal compressions, reassess the child as follows ...

If the object has not yet expelled yet and the child is still conscious, continue with the sequence of back blows/hits and chest or abdominal thrusts.

Call 112 or ask for help, if you are still alone. Never leave the child alone unsupervised.

If a choking child is unconscious or loses consciousness:

Place it on a firm, flat surface and cry out for help.

Call 112; put the phone on speakerphone so you have your hands free.

Do not leave the child at any time.

Open the child's mouth. If the object is clearly visible and you can easily grasp it, remove it.

Initiate CPR (cardiopulmonary resuscitation).

Beyond the establishment of a choking box, which we have already commented, greater risks of emergency are not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

European Resuscitation Council Guidelines 2021: Pediatric Life Support. https://cprguidelines.eu/assets/guidelines/European-Resuscitation-Council-Guidelines-2021-Pa.pdf.

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student with Esophageal atresia may have the following difficulties: swallowing, frequent cough, nausea, risk of respiratory infections, choking. As medical supervision is required, it is necessary that the teacher works together with a school doctor. The student may miss school because of one's medical condition, surgeries. The student may have problems acquiring speech. Therefore, it would be important that a speech therapist consults the teacher. Sports activities or any other physical activity should be adapted to the strudent's abilities. It may be that the student cannot take part in sports lessons due to one's health issues. The teacher has to know what to do in situations where there is choking or the student has difficulty breathing. Explain to the classmates how they can help in emergencies. Be aware that the student may need to take medicine during the school day. The teacher has to make sure that the student can eat or drink at one's own pace. Small servings of food and beverages have to be consumed by the student. The school staff has to consult the student's parents about any risks the student may experience. It would be advisable that the classroom is close to the WC and the student sits close to the classroom door in case it is necessary to get to the WC quickly. These may be cases of nausea or vomiting. Adjust the desk and chair that the student can sit comfortably. It is necessary to maintain proper humidity in the classroom and the school to prevent the student from coughing or having a respiratory infection because of the dry air.

	Technical support	If the student uses a feeding tube, it is important to inform the school staff how they can help. Instructions have to be given accurately in writing. The school café staff has to be informed about the student's 'safe food' list. There is a need for a special room for the student to stay in cases of health problems and where to wait for appropriate help to arrive.

Used sources:

Esophageal atresia or tracheoesophageal fistula (EA/TEF) repair: How to help your child with eating. Retrieved (2022)
https://www.aboutkidshealth.ca/eatingwithtef

ORPHA 1656

HERPETIFORMAL DERMATITIS OR DURHING-BROCQ DISEASE

DESCRIPTION OF THE DISEASE

Dermatitis herpetiformis is an immune-type disease that produces red blisters that cause intense itching, normally distributed on the back of the forearms and buttocks. In children, palmar lesions can be observed. Also, hive-like swellings can occur in people with celiac disease. People with dermatitis herpetiformis often have celiac disease (digestive sensitivity to gluten). Despite its name, it is not related to the herpes virus.

MAIN ORGANS OR SYSTEMS AFFECTED

CUTANEOUS- MUCOSOUS

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

DIGESTIVE

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is very likely that the child will feel anxious or restless due to the itching caused by the injuries, so the situation should be understood and treated in the best possible way, avoiding taking measures that do not fit the situation of the student. In addition, they must be allowed to go to the bathroom or to see the school nurse in order to treat injuries and itching.

SPACE ADAPTATION - ERGONOMIC

The chair may need to be adapted using surfaces that minimize itching and pressure in the case of injuries to the buttocks. If this surface is not available, the student should be allowed to go to the nearest bathroom to hydrate the skin or get up from the seat, so as to avoid maintaining pressure and intense itching.

ENVIRONMENTAL ADAPTATION

During periods of intense heat, such as during spring or early summer, a good climate control of the classroom should be provided to minimize itching. In addition, if celiac disease occurs, the person responsible for the dining room must be notified since it is necessary for the child to have a gluten-free diet. The most common foods with gluten are those that have wheat, rye, barley, such as: pasta, couscous, bread, cookies, muffins, bread rolls, cakes, cereals, French fries, candies, rice, etc.

ACCESSIBILITY

There is no need to take any action regarding accessibility.

INCLUSION STRATEGIES

It may be necessary to explain to the rest of the students that the injuries and itching suffered by the person are not contagious, so the same physical approach can be given as would be given to a healthy student.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

Sterile substitution dressings must be available in the school medicine cabinet or in the classroom itself to cover possible wounds that occasionally need to be covered, as well as material to carry out a basic cure. The necessary material will be packages of sterile gauze, ampoules of physiological saline to clean the wounds and blood remains, as well as a bottle of antiseptic - preferably 1% chlorhexidine - and tweezers to extract foreign leathers embedded in the skin.

It is possible that the student requires treatment to control the itching in the acute phases (pills, syrups or creams) that must be administered during the school day according to the specified guidelines that the responsible health personnel have given to the parents or main care. Some of these drugs can cause drowsiness (pills or syrups) during the day or from the second hour of administration. The syrup will be administered by means of a 10 ml syringe that will be in the same box or in the medicine cabinet itself.

POTENTIAL EMERGENCIES AND ACTION

Given the possibility of bleeding -not controlled with the previous measures- from skin lesions or the rupture of any of the vesicles, especially in periods, gauze or sterile cloth dressings should be accessible to cover the wounds and refer to the infirmary, to the family or to the health center or hospital.

Associated with taking drugs for itching, although much less frequent, is nausea, malaise, dizziness or fever. If this is the case, the nurse, family or health center should be notified.

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

SUPPORTING THE STUDENT WITH **HERPETIFORMAL DERMATITIS OR DURHING-BROCQ DISEASE** IN THE SCHOOL SETTING

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide the student with appropriate nutrition at meals Inform the school nurse about the students' needs.
	Support provided by the teacher	Follow the healthcare provider's or the parents' instructions on the nutrition issues. If there is a need for the student to visit a school nurse, regularly remind the student of it. If necessary, make a special calendar of reminders.
	Technical support	Not necessary

Used sources:

Al-Toma A, Volta U, Auricchio R, Castillejo G, Sanders D, Cellier C, Mulder CJ, Lundin KAE. (2019).
European Society for the Study of Coeliac Disease (ESsCD) guideline for coeliac disease and other gluten-related disorders. United European Gastroenterol J. Doi: 10.1177/2050640619844125.

ORPHA 2440

ISOLATED SPLIT HAND-SPLIT FOOT MALFORMATION

DESCRIPTION OF THE DISEASE

This disease presents, in most cases, anomalies in the hands with a so-called “lobster claw” appearance. This problem randomly affects one to four fingers of the extremities, and can occur in both hands and feet. In addition, some of the described cases of this disease are associated with deafness and aniridia (it presents an absence of iris affecting visual acuity, even leading to total blindness).

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR
MUSCULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SENSORY SYSTEM (PERCEPTION)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

In the event of visual and / or hearing impairment, it is necessary to encourage the teaching resources to produce a great stimulation of the sense of touch. Such stimulation is key to proper intellectual and emotional development.

As for blindness, learning to read and write Braille should begin early, as should the assimilation of information from the environment through the intact senses (hearing, smell, touch, and heat). These children must learn to identify everything that surrounds them through the available senses, so that they can be located in the correct time and space.

If there is deafness, a correct use of sign language will be essential, in addition to vocalization by the teachers so that the person can lip read. To achieve optimal phonation, the student should be encouraged to ask the questions or any intervention aloud, in addition, they should be helped in the correct articulation and oralization of the words. In the case of wearing masks (due to pandemic status) in class, they should be transparent to facilitate that the student can read lips without problems. The use of an integrated visor can increase security in the necessary proximity that the student must have.

SPACE ADAPTATION - ERGONOMIC

They will need aids to write by hand or keyboard, draw and paint, cut with scissors, etc. due to finger abnormalities, if present. They can use special keyboards (virtual, finger pointers to press the keys, wide, etc.) and joystick-type, ergonomic, keystroke mice. In turn, augmented reality glasses-type display devices can be used to facilitate their interaction with the class work, as long as they do not present visual disturbances.

Visual aid will be necessary by increasing the size of the letters in written documents or using the magnifying glass tool on computers in case of decreased visual acuity. If total blindness occurs, the use of braille in written documents or screen readers in computer documents will be necessary. In the latter case, the arrangement of the classroom furniture must be stable, avoiding changes in the location of their position in the classroom and keeping access to it clear.

Regarding hearing abnormalities, the use of digital whiteboards and technological devices can be very useful since there are accessibility adaptations for people with these types of problems. It is recommended that the student is located close to the teacher to facilitate lip reading in the event that vision is preserved.

ENVIRONMENTAL ADAPTATION

Considering that there may be hearing loss or total deafness, it is recommended to minimize noise in the classroom to favor the reception of important messages.

ACCESSIBILITY

If there are malformations at the level of the feet, it may be necessary to install handles or handrails for a better movement of the person both in the classroom and in the different spaces used in the academic institution.

If vision is impaired, it is recommended that there be tactile position markers in the different spaces used by the student (bathroom, classroom, location in the classroom, corridors with normal traffic, dining room, etc.).

INCLUSION STRATEGIES

It is necessary to promote the autonomy of the student, so that their self-esteem is not compromised. They should carry out the activities by themselves or alone, always within their capacities, trying to participate and perform the maximum of activities proposed for all students, even if they take longer to complete or need adaptations.

An awareness is also required by the rest of the students, so that interpersonal relationships based on mutual respect are developed and situations of social exclusion does not occur.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is possible that the student requires treatment to control pain in certain periods (ibuprofen, paracetamol) and that they must be administered (pills or syrups or creams) during the school day according to the specified guidelines that the responsible health personnel have given to parents or primary caregivers. It will be necessary to have the prescription in writing and as long as they are oral drugs.

POTENTIAL EMERGENCIES AND ACTION

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	If possible, lessons have to be scheduled in nearby rooms. The student has to be provided privacy in a locker room.
	Support provided by the teacher	Although split hand/foot condition is not associated with cognitive impairement, some students may develop learning disabilities, emotional trauma, and/or mental instability due to the disease. It can be the result of surgery or chronic pain, or appear as side effects of certain medication. Give the student exrtra time to get from one classroom to another. Besides the obligatory set of books, provide an additional set of books so that the student has one at school and one at home to avoid the need for the student to carry a heavy schoolbag. Replace lengthy wriiten work with oral assignments. Reduce the amount of class work and homework. Allow alternative forms of assessment (for example, oral, computer-based, etc.).
	Technical support	Provide technical aids in the classroom so that the student can dictate answers. Use of a computer or any other relevant software to reduce the amount of writing. Offer distance learning and e-learning materials when the student is at home or hospital.

Used sources:

Haberlandt E, Löffler J, Hirst-Stadlmann A, Stöckl B, Judmaier W, Fischer H, Heinz-Erian P, Müller T, Utermann G, Smith RJ, Janecke AR. (2001). *Split hand/split foot malformation associated with sensorineural deafness, inner and middle ear malformation, hypodontia, congenital vertical talus, and deletion of eight microsatellite markers in 7q21.1-q21.3.* J Med Genet. Jun;38(6):405-9. doi: 10.1136/jmg.38.6.405. PMID: 11424924; PMCID: PMC1734906

ORPHA 2869

PEUTZ-JEGHERS SYNDROME

DESCRIPTION OF THE DISEASE

It occurs with the appearance of polyps throughout the digestive tract and may also appear outside the digestive system (kidneys, lungs, gallbladder, nasal passages, bladder or the tubes that connect the kidneys to the bladder (ureters). It can appear small dark spots around and inside the mouth, near the eyes, nose, around the anus, and on the hands and feet.

It can cause bleeding in the digestive system, with chronic anaemia as a consequence, and episodes of abdominal pain.

It is associated with a greater probability of suffering from some tumours.

MAIN ORGANS OR SYSTEMS AFFECTED

DIGESTIVE

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

RESPIRATORY
GENITOURINARY
CUTANEOUS- MUCOUS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Physical and recreational activity should be adapted to their respiratory capacities in the event that they are impaired by pulmonary involvement or by chronic anaemia in relation to recurrent digestive bleeding.

Continuous medical monitoring is necessary, and recurrent episodes of abdominal pain may occur, justifying absences. Classes should be adapted to these absences, providing tutorials, private classes, online classes or any other methodology that allows the children to carry out the same academic monitoring as their classmates.

SPACE ADAPTATION - ERGONOMIC

It does not require the implementation of extraordinary measures.

ENVIRONMENTAL ADAPTATION

It can be beneficial to maintain a correct environmental humidity to promote the expectoration of respiratory secretions, especially if there is a persistent cough and/or recurrent respiratory infections related to the presence of polyps in the lungs.

ACCESSIBILITY

It does not require the implementation of extraordinary measures.

INCLUSION STRATEGIES

It is recommended to work on the digestive system in the classroom so that your classmates understand the consequences of the pathology.

Promote that classmates act as reinforcement in their learning process, in this way socialization is facilitated for this type of student and their academic learning is reinforced by collaborating with their peers.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

Cases of moderate abdominal pain may appear that can be better managed if the student is provided with tools such as relaxation and controlled breathing. During these episodes it is important that they are in a comfortable and quiet environment.

It is important to detect a intestinal obstruction early. The signs and symptoms that can be used to identify it are the appearance of intermittent pain that ends up becoming constant and intense, swelling, loss of appetite, vomiting and fever. On the other hand, and since there is an increased risk of intestinal bleeding, one should be aware of the appearance of blood in the faeces or vomit, although on some occasions it manifests itself through less obvious symptoms (fainting, extreme fatigue, paleness, etc.).

In both situations, the family should be informed immediately, and it is advisable to request urgent health care. During the wait, it is recommended to keep the schoolchild at rest, lying down (raising her legs if they have fainted or are dizzy), calm and warm. Do not administer any type of medication by mouth, food or drink.

POTENTIAL EMERGENCIES AND ACTION

Beyond the situations described in the previous section, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student suffering from Peutz-Jeghers syndrome may have the following difficulties: severe abdominal pain, bleeding, fainting, vomiting, tiredness. Sport or any other physical activity must be adapted to the student's breathing ability. The student requires constant medical supervision. Therefore, regular cooperation among the school staff, the student's parents and the doctor is necessary. The parents should always be available. The learning process should be adapted (tutoring, homeschooling, etc.) if school attendance is impossible. Inform the student's classmates what to do in emergencies, for example, if the student are in severe pain. As regards the student's appearance, small dark spots on the lips, around the inside area of the mouth and near the eyes and nostrils can cause the student lose one's self-esteem. Therefore, support is essential.
	Technical support	Maintain proper humidity level indoors to prevent persistent cough and/or recurrent respiratory infections associated with polyps in the lungs. There is a need for a special room for the student to be in cases of health problems and where to wait for appropriate help to arrive.

Used sources:

Etienne Leveille, Thomas J. McGarrity, Milton S. Hershey Peutz Jeghers Syndrome. Retrieved (2022).
https://rarediseases.org/rare-diseases/peutz-jeghers-syndrome/

ORPHA 66627

PIGMENTED VILLONODULAR SYNOVITIS

DESCRIPTION OF THE DISEASE

Pigmentary villonodular synovitis is a disorder that affects the joints in such a way that their lining swells and grows, damaging the bone and making movement painful and limited. It usually occurs at the hip or knee level, although it can also occur at the ankle, elbow, hand, shoulder, or foot. In addition to pain and restriction of movement, the person notices warmth and tenderness in the area.

It is a disease in which symptoms can appear and disappear over time.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is very likely that the student will be absent in some periods due to the surgical needs of this disease, so the school curriculum should be adapted to absences (for treatment or diagnostic evaluation), so that they can progress academically with the rest of the students. It will possibly be required the prioritization of educational content for its evaluation in the case that the absences from the center are prolonged. However, it is best to continue with the ordinary curriculum for as long as possible to avoid differences with the rest of the students.

SPACE ADAPTATION - ERGONOMIC

Pressure relief on the joints may be necessary, so the use of crutches will be necessary, in the event that the hip or knee are affected, so that the joints rest. It may even be necessary to use a wheelchair in critical periods. Therefore, it would be necessary to adapt the classroom for this need, placing the child in an accessible area and with space and a desk adapted for their position in a wheelchair. They may also need to rest to relieve swelling and pain in the affected joints.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

If there are no handrails or handholds, they must be installed for the correct movement of the student if they do not need crutches. In addition, it is advisable to install folding handrails on the sides of the toilet in case the child has severe motor disorders, which prevent them from moving correctly without help. An emergency call system should be in place in the event of an accident in the bathroom.

INCLUSION STRATEGIES

Strategies should be applied to increase the autonomy of the student, despite their difficulties, enhancing their self-esteem. If it is possible, the student should carry out the actions by themselves, they must play with the rest of the class and carry out all the activities that are proposed in the classroom, even if it takes longer than the rest or the needed breaks.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It is possible that the child needs to take some anti-inflammatory and/or analgesic medication, in a timely manner and always in accordance with the guidelines established by the parents. The placement of bandages or stockings or prostheses will not be carried out. It will be sent to the Health Center for placement by qualified personnel.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not anticipated than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

SUPPORTING THE STUDENT WITH **PIGMENTED VILLONODULAR SYNOVITIS** IN THE SCHOOL SETTING

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Evaluate frequency and content of sports lessons and physical activities, their suitability for the student.
	Support provided by the teacher	Always make sure the student is not in pain. Pay attention to the student's physical activities during lessons and make sure there is no overwork.
	Technical support	If necessary, provide an opportunity for the student to use a wheelchair in the school's environment (the entrance of the school and classroom, ramps, floors, accessibility to desks and boards). Ensure access to ICT.

Used sources:

Willimon SC, Schrader T, Perkins CA. (2018). Arthroscopic Management of Pigmented Villonodular Synovitis of the Hip in Children and Adolescents. Orthop J Sports Med. Mar 21;6(3):2325967118763118. doi: 10.1177/2325967118763118. PMID: 29594178; PMCID: PMC5865515

ORPHA 73247

EOSINOPHILIC ESOPHAGITIS

DESCRIPTION OF THE DISEASE

It is a disease of allergic origin in which a chronic inflammation of the oesophagus occurs due to the proliferation and accumulation of immune cells (eosinophils) in the mucosa of the oesophagus. This hyper-immunity reaction is related to exposure to food and environmental agents. It can cause central chest pain, difficulty and pain when swallowing solid food, nausea, vomiting, heartburn, gastro-oesphagical reflux and even stopping of food in the oesophagus (impaction). These chronic symptoms, together with the dietary restrictions that are implemented to reduce the allergic reaction, can compromise a balanced diet and condition proper growth and development.

MAIN ORGANS OR SYSTEMS AFFECTED

DIGESTIVE

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

METABOLIC (NUTRITIONAL-FOOD BASE)

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Continuous medical monitoring is necessary, and recurrent symptomatic episodes may occur, justifying absences of assistance. Classes should be adapted to these absences, providing tutorials, private classes, online classes or any other methodology that allows they to carry out the same academic monitoring as their classmates.

SPACE ADAPTATION - ERGONOMIC

The appearance of nausea, vomiting and gastroesophageal reflux can be frequent, so students with this type of pathology should be located near the door to facilitate their exit to the toilet when necessary. Likewise, it will be ensured that the class has a location close to the toilets.

Access to changing rooms and showers in the centre will be provided whenever necessary to contribute to your comfort in the school.

ENVIRONMENTAL ADAPTATION

It does not require the implementation of extraordinary measures.

ACCESSIBILITY

It does not require the implementation of extraordinary measures.

INCLUSION STRATEGIES

It is recommended to work on the digestive system in the classroom so that their classmates understand the consequences of the pathology.

It is convenient that the whole class know the correct procedure to attend, in the first instance, a choking or, at least, what should not be done.

Promote that classmates act as reinforcement in their learning process, in this way socialization is facilitated for this type of student and their academic learning is reinforced by collaborating with their peers.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

Cases of moderate chest pain may appear that can be better managed if the student is provided with tools such as relaxation and controlled breathing. During these episodes it is important that you are in a comfortable and quiet environment.

It is important to pay attention when these students eat food as they could choke. The texture of the food should be adapted to the tolerance of each person, being very useful efficient chewing and drinking water with the food to minimize discomfort when swallowing.

POTENTIAL EMERGENCIES AND ACTION

In the event of a choking episode, in relation to food intake, gastroesophageal reflux or vomiting, it is essential to act immediately using the following procedure:

If you can see the object, try to remove it. Do not try to search blindly or repeatedly with your fingers. You can make things worse if you push the object further in and make it difficult to remove.

If the student is coughing forcefully, encourage him to continue coughing and not stop.

If the student's cough is not effective (it is silent or he cannot breathe well), yell for help immediately and assess if he is conscious.

If the student is still conscious, but is not coughing or his cough is not effective, hit/blow his/her back.

Lay the child facing down on your lap as you would do with a baby.

If this is not possible, support the child in a forward lean position and give 5 blows/hits to the back from behind.

If blows/hits to the back do not improve choking and the child is still conscious, perform 5 abdominal pushes. This will create an artificial cough, increasing pressure on the chest and helping to expel the object.

Stand or kneel behind the child. Place your arms under the child's arms and around the upper abdomen.

Clench your fist and place it between the belly button and the ribs.

Grab this hand with the other hand and pull abruptly inward and upward.

Repeat up to 5 times.

Make sure not to apply pressure to the lower rib cage, as this can cause damage.

After chest or abdominal compressions, reassess the child as follows...

If the object has not yet expelled yet and the child is still conscious, continue with the sequence of back blows/hits and chest or abdominal thrusts.

Call 112 or ask for help, if you are still alone. Never leave the child alone unsupervised.

If a choking child is unconscious or loses consciousness:

Place it on a firm, flat surface and cry out for help.

Call 112; put the phone on speakerphone so you have your hands free.

Do not leave the child at any time.

Open the child's mouth. If the object is clearly visible and you can easily grasp it, remove it.

Initiate CPR (cardiopulmonary resuscitation).

It is recommended that the school hold workshops among teachers to learn and practice the procedure (simulation with dolls).

Beyond the establishment of a choking box, which we have already commented, a greater risk of emergency is not expected than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

European Resuscitation Council Guidelines 2021: Pediatric Life Support.
https://cprguidelines.eu/assets/guidelines/European-Resuscitation-Council-Guidelines-2021-Pa.pdfATTRIGMENT PROTOCOL

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student with Eosinophilic esophagitis may have the following difficulties: allergic diseases, chronic inflammation of the oesophagus, chest pain, difficulty and pain when swallowing food that is hard to chew, nausea, vomiting, refusal to eat. The student requires constant medical supervision. Therefore, regular cooperation among the school staff, the student's parents and the doctor is necessary. The parents should always be available. The learning process should be adapted (tutoring, homeschooling, etc.) if school attendance is impossible. The school nurse should be specifically prepared to help the student. The teacher has to be aware of the student's medical condition. Inform the school staff and the student's classmates how they can help if the student is vomiting, fainting, or are in pain.
	Technical support	It would be advisable that the classroom is close to the WC and the student sits close to the classroom door in case it is necessary to get to the WC quickly. These may be cases of nausea or vomiting. There is also a need for a dressing room. Adapt the meals to needs of the student, coordinating the list of 'safe food' with the student's parents. There is a need for a special room for the student to stay in cases of health problems and where to wait for appropriate help to arrive.

Used sources:

Furuta GT. (2012). *Management of eosinophilic esophagitis from childhood to adulthood. Gastroenterol Hepatol* (N Y). Oct;8(10):683-5. PMID: 24683377; PMCID: PMC3969012.

ORPHA 85138

ADDISON DISEASE

DESCRIPTION OF THE DISEASE

It is an endocrine disorder that has its origin in the destruction of the cortex of the suprarenal glands in connection with an autoimmune reaction. The consequence is that there is a hormonal deficit (cortisol and aldosterone). The most common manifestations of affected people are: fatigue, weight loss, lack of energy, general malaise, nausea, lack of appetite, and muscle and joint pain. The darkening of the skin and mucous membranes is very characteristic. Treatment consists of exogenous replacement of deficient hormones.

MAIN ORGANS OR SYSTEMS AFFECTED

ENDOCRINE-METABOLIC

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

SYSTEMIC AFFECTION WITHOUT SYMPTOMS IF THERE IS EFFECTIVE TREATMENT

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

Regular medical follow-up is necessary, which can promptly condition attendance at class.

Emotional stress and academic pressure can be poorly tolerated, so situations that favour them should be avoided.

In properly treated people, there should be no limitations for carrying out normal physical activity.

SPACE ADAPTATION - ERGONOMIC

It does not require the implementation of extraordinary measures.

ENVIRONMENTAL ADAPTATION

It does not require the implementation of extraordinary measures.

ACCESSIBILITY

It does not require the implementation of extraordinary measures.

INCLUSION STRATEGIES

One of the manifestations of this disease is the darkening of areas of the skin such as the face or hands, which is why the risk of stigmatization is high, so it is recommended that effective socialization strategies and self-esteem reinforcement be implemented.

It may be useful to explain to the other students those aspects of the illness that do not violate the privacy of the student (secondary effects of the treatment, possible incidents, etc.) and that can improve the empathy of the group.
Encourage classmates to act as reinforcement in their learning process if there are prolonged periods of absence.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

One of the potential complications that can appear is hypoglycaemia (low blood glucose), which would be accompanied by dizziness, nausea, sweating and/or confusion. It is recommended to have a digital glucometer in the centre to be able to measure the blood sugar level, as well as a basic training of the teaching staff in the use of it and in the interpretation of the data it emits. Faced with the confirmation of hypoglycaemia, a sugary drink should be provided as soon as possible (if there is loss of consciousness, do not try to give anything by mouth). The family should be informed immediately and request urgent health care. During the wait, it is recommended to keep the schoolchild at rest, awake, lying down, calm and warm.

Another situation that could arise would be arterial hypotension (abnormally low blood pressure) that would manifest itself with dizziness, paleness, feeling cold and even fainting. It is recommended to have, in the centre, a digital blood pressure monitor, and basic training is necessary for the teaching staff in the use of it and in the interpretation of the data it provides. The family should be informed immediately and request urgent health care. During the wait, it is recommended to keep the schoolchild at rest, lying down (raising the legs above the level of the head), calm and warm.

The exogenous contribution of deficient hormones must be rigorous, forgetting the medication can cause dangerous situations for students affected by this disease, the most serious complication being acute adrenal insufficiency (Addison's crisis) that can cause a life-threatening shock. Signs and symptoms are severe weakness, disorientation, lower back or leg pain, vomiting, diarrhoea and severe abdominal pain, decreased consciousness or delirium, and low blood pressure. It may be necessary for the school to keep an injectable hydrocortisone preparation to be administered by qualified personnel or by any person who attends the affected person if they have a telephone order from the parents.

POTENTIAL EMERGENCIES AND ACTION

Beyond the situations described in the previous section, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Be aware that the student with Addison disease may experience the following difficulties: tiredness, weight loss, lack of energy, fatigue, nausea, loss of appetite, muscle and joint pain. Darkness of the skin and mucous membranes is very characteristic. The student requires constant medical supervision. Therefore, regular cooperation among the school staff, the student's parents and the doctor is necessary. The parents should always be available. The learning process should be adapted (tutoring, homeschooling, etc.) if school attendance is impossible. It is important to remember that the student's state of health is not always predictable. The school staff and the student's parents should make a reasonable timetable to reintegrate the student back to school. It would be desirable to implement an effective socialisation and the student's self-esteem boosting strategy due to one's skin problems - dark colour on the face and hands. The teacher should be patient as one of the most common student's disease symptoms is tiredness. Thus the student may not be able to participate in all school activities. The teacher should think of alternative ways how the student can contribute. Plan additional breaks in learning. During tests, the student with Addison disease may be restless and may need extra medicine. Breaks in tests and examinations should also be allowed.
	Technical support	The student with Addison disease has to wear a medical bracelet to inform others about one's health condition. It is advisable that there is a special person who help the student move from classroom to classroom in the crowded school halls. If possible, classrooms should be changed as little as possible. There is a need for a special room for the student to stay in cases of health problems and where to wait for appropriate help to arrive.

Used sources:

The Addison's Disease Self-Help Group. *When a student has Addison's: a guide for schools and parents. Retrieved (2022).*
https://www.addisonsdisease.org.uk/Handlers/Download.ashx?IDMF=a926f14a-fca1-4ff4-8629-b6246d933384

ORPHA 85410

JUVENILE IDIOPATHIC ARTHRITIS

DESCRIPTION OF THE DISEASE

Juvenile idiopathic arthritis encompasses a group of chronic diseases that are characterized mainly by inflammation of the joints, which prevents them from moving properly. Symptoms from one child to another with the same disease may vary and inflammatory crises may appear episodically, cyclically, or continuously.

The signs that the affected people present are: pain, inflammation and limitation of movement. It tends to present as morning stiffness, so the beginning of the day is usually quite hard, although it improves as the hours go by. In turn, they may present morning fever with an episodic duration for two weeks. In turn, a rash or red dots may appear during the fever period.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is necessary for the child to make regular movements during class hours, so as to avoid muscle stiffness and thus pain. It will make it easier for the student to get up or stretch during class hours to avoid joint stiffness or if there is pain related to sitting time.

In addition, during some periods the student may have difficulties when writing. For this reason, they will be allowed more time to perform the manual activities.

There may be times when the child uses joint splints to achieve a comfortable position of the joint and thus avoid pain, stiffness, muscle contractures and joint deformities. Depending on whether the affected limb is the dominant one, they will need help or support to complete the tasks. The girl / boy must play sports like the rest of the students. Although due to the pain that they may feel during sports practice, the necessary time of rest should be granted until the pain subsides. In this way, possible unintentional injuries of different severity related to sports practice will be avoided.

SPACE ADAPTATION - ERGONOMIC

The child may need a tool for mobility such as a crutch or wheelchair, so it is necessary to have enough space to maneuver in the classroom with a wheelchair and for a possible evacuation in case of emergency. They may need to use a chair/desk adapted to their joint limitations. In addition, it may be necessary to use ergonomic tools to write by hand or on a keyboard, using touch screens or joystick-type mice.

If they are a carrier of some type of splint in any joint, it will be necessary to provide a large and comfortable space to be able to carry out the adapted tasks.

ENVIRONMENTAL ADAPTATION

In pain crises it would be important to be able to isolate the person in a quiet space that had a bed or armchair where to place them so that they are comfortable and could be placed in the desired position.

To avoid mechanical stress on the joints derived from the practice of certain impact sports (football, basketball, racing, etc.), it is better to favor the practice of others where joint wear is absent or minimal, such as swimming or riding in bicycle. Therefore, it would be interesting to have sports elements (bicycle) and spaces that favor sports with low joint impact.

ACCESSIBILITY

The accessibility measures will be focused on the elimination of architectural barriers for the access and use of a wheelchair. There must be at least one adapted bathroom on each floor of the center with a toilet placed at the standard height of a chair, with folding handrails on both sides, as well as easily accessible sinks with chairs and a low mirror placement to be able look properly in a sitting position.

Shelves, cabinets, desks, blackboards, hangers, work materials, etc. must also be placed at a height that allows their use without the child having to force themselves excessively to be able to use it.

INCLUSION STRATEGIES

The child should be encouraged to be autonomous, since the disease can cause reduced mobility such as difficulty walking or less resistance to fatigue, stiffness or pain, and changes in height. But it is important for their self-esteem and their future adult life to feel like everyone else despite their limitations. An inclusive intervention would be to encourage the child to explain what their illness consists of and what they feel. In this way, teachers can explain why they are allowed more time to finish assignments or why they do not do certain exercises or are absent sometimes. This activity would be part of an informative school strategy where the entire school community would be involved with the family.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

The student may have pain, so after communication with the minor's family and the delivery of the drug, an anti-inflammatory may be provided (naproxen, ibuprofen are the most used) along with some food. The child will try to maintain a posture that does not cause pain in the joint, so they will maintain a semi-flexed position, this may indicate the time to ask them if they have any type of pain and they may need to be calmed down.

The child may receive other types of medications that make them unable to attend class regularly.

Certain medications associated with the disease can cause an increase in appetite and weight gain (for example, corticosteroids). It will be necessary to strengthen the recommendations to the family on food and promote a balanced diet either at school through those in charge of the dining room or at home.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not anticipated than in the rest of the students. Reference protocols in each geographical area should be checked.

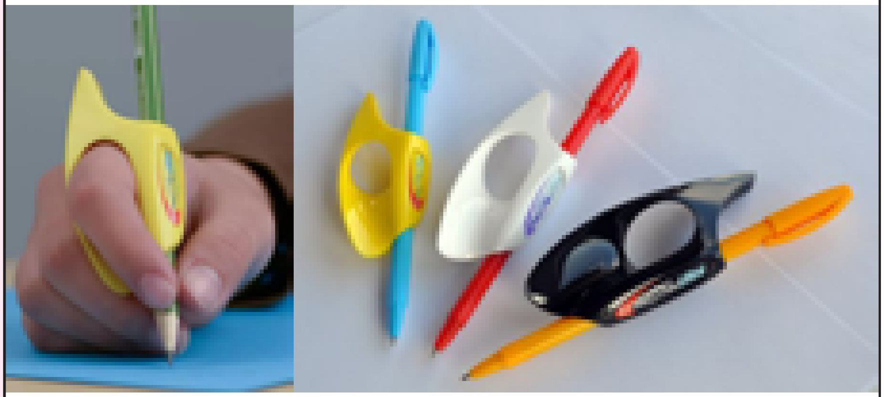
USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	**Problem: fatigue and morning stiffness, morning pain, pain in general, unpredictable pain, periods of pain** Remember that this health problem of the student may be externally unobservable. Take into account and be understandable that the student may experience morning stiffness after the night's sleep and be late for the first lesson. If the student's wrists are affected, one may find it difficult to hold stationery and perform long written tasks. Therefore the student should be given a chance to answer orally and encouraged to put down only the essentials. If the student's joints of knees are affected, it may be problematic to move from one room to other. Therefore allow the student to leave your lesson earlier to avoid the crowd and get to the next room. In sports lessons, offer exercises the student can perform and that do not cause discomfort or pain. Avoid involving the student in close contact sports as it can be dangerous. As carrying a schoolbag can be painful, besides the obligatory set of books, provide an additional set of books so that the student has one at school and one at home. If the student has limited options to participate in extra-curricular activities, sports lessons, and excursions, every situation has to be assessed to avoid the risk of overload. If there are lessons in which the student has to sit on the floor, make sure that one has a choice where to sit, for example, on a pillow or a balance ball, etc. Assess the student's ability to write. If necessary, ask for an assistant who will put down the information instead of the student. Schedule regular dynamic breaks for all the students in the class; ask them to change posture and stretch every 30 minutes. Not to attract attention of other students, ask the student to give out worksheets, or collect homework, etc.

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide a place where the student can be physically separated from others, can lie down because in case of pain those around can seem disturbing and annoying. To learn to notice the signs of exacerbations of the disease is a must as it helps the teacher adapt the tasks to the student's current situation. When there are no health problems, encourage the student to participate in all learning activities. Pay regular attention to how the student feels because if there is pain, the student may completely lose one's appetite and feel exhausted, every movement may be painful, for example, the student may find it difficult to raise one's hand or make any other small movement. In such a case, the teacher has to adapt the planned activities to the state of the student. Support has to be provided when there is a need for it not to make the student experience discomfort. Always ask the student for permission if you want to help. If the student needs to be supported, one has to be involved in its planning. The teacher should find out what makes the student experience discomfort/unexpected pain, what the most comfortable pose and for sitting is, etc. All the conversations about the student's health issues have to be conducted when everybody else has left the classroom. As the student wants to be the same as other students in the classroom, one may hide the health issues. To satisfy the student's needs, one has to observe recommendations given by a physiotherapist and attend modified sports lessons. The student may need to work in an online learning mode, require recordings of lessons, additional materials, and teachers' advice. Do not lower the requirements for the student, instead take into account one's physical limitations. Do not direct unnecessary attention of classmates towards the specific student.

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Emphasise the student's strength. Allow the student to leave the classroom to take medication on time. Allow homework to be submitted later if there has been a period of pain.
	Technical support	**It is possible to improve the student's learning performance if the following criteria are paid careful attention:** Relevant seating in the classroom, such as pillows on the floor. Relevant height and inclination of a desk. A standing desk might be necessary. Computers and laptops are used in lessons. Special keyboards and wrist rests might be necessary. Appropriate stationery.  Reference: *https://www.facebook.com/PencilGripsPlus/photos/4242464509112363*

Used sources:

Arthritis Foundation. Juvenile Arthritis: A Teacher's Guide. Available at: *https://www.arthritis.org/getmedia/4fee18c7-7c56-4bfa-8951-fccf7c16aad0/JA-teachers-guide-PDF.pdf*

KidsHealth (2020). Juvenile Idiopathic Arthritis (JIA) Factsheet (for Schools). Available at: *https://kidshealth.org/en/parents/jia-factsheet.html*

The National Rheumatoid Arthritis Society (2016). Managing JIA in School. Available at: *https://www.leedsth.nhs.uk/assets/e444607490/Managing-JIA-in-School-July-2016-V2-vmmcxw.pdf*

ORPHA 91378

HEREDITARY ANGIOEDEMA

DESCRIPTION OF THE DISEASE

Hereditary angioedema is a disease that causes swelling (edema) in some areas of the body, especially the skin and mucous membranes, such as the intestine or throat, temporarily and recurrently, causing an obstruction in the airways (inflammation of the throat and hoarseness), abdominal cramps, swelling in the arms, legs, hands, eyes, lips or genitals and skin irritation without itching. In this disease there is variability in the intensity and frequency of the episodes depending on the person or the situation. Episodes of bloating tend to become more severe during the late childhood and adolescence period. The problem with these attacks is the need for special medication, since they do not respond to medication that is usually used normally in situations in which the person suffers from edema (adrenaline, corticosteroids, etc.)

MAIN ORGANS OR SYSTEMS AFFECTED

CUTANEOUS- MUCOSOUS

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

RESPIRATORY
DIGESTIVE

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

No special measures are required.

SPACE ADAPTATION - ERGONOMIC

Some of the people who suffer from this disease may suffer swelling in areas that have been hit, so it is advisable to exercise caution when playing sports and with classroom objects (favor a wide space for placement of the desk, cover peaks tables, shelves, etc.).

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

There is no need to take any action regarding accessibility.

INCLUSION STRATEGIES

Students should be made aware of the disease so that they know that it is not a contagious condition. In addition, it is very positive to encourage relationships between students through cooperative activities and awareness talks.

In addition, it is necessary to carry out training and outreach activities regarding critical swelling processes. In this way, classmates can participate by sounding the alarm when detecting early signs of swelling, notifying the responsible teachers.

The affected child may have anxiety attacks related to previous experiences of bloating and shortness of breath (choking). To avoid this, it is necessary to create a safe environment where they realize that everyone in the school can help them overcome these critical experiences.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

In the event of a mild or incipient episode, the application of treatment may be necessary, the minor should be allowed to leave the classroom immediately to go to the nearest health center where they know how to treat them, and it is advisable to accompany them there.

In the case the child is trained and is able to self-administer the medication, the collaboration of the teacher, who should be familiar with the procedure, may be required. At the same time, they should have the necessary material and medication in the classroom, in a kit that is easily accessible to the teacher.

It is possible that the student requires treatment to control pain in certain periods (ibuprofen, paracetamol) and that they must be administered (pills or syrups or creams) during the school day according to the specified guidelines that the responsible health personnel have given to parents or primary caregivers. It will be necessary to have the prescription in writing and as long as they are oral drugs.

POTENTIAL EMERGENCIES AND ACTION

A severe episode can be life-threatening, as it can lead to suffocation. The child may warn of the sensation of a foreign body in the throat or tightness. They may also notice swelling of the tongue. Another way to recognize a throat attack are changes in the voice, which becomes more hoarse, difficulty swallowing or strange breath sounds.

These episodes must be treated without delay, if there is already obvious respiratory distress, it will be necessary to attend to them in the classroom to avoid mobilization and overexertion. The school nurse must be notified immediately to come with the prepared material and also notify an ambulance to transfer them to the emergency service of the nearest health institution as quickly as possible if the first intervention was not sufficiently effective.

In case the child is trained and is able to self-administer the medication, the collaboration of the teacher, who should be familiar with the procedure, may be required.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational	Provide appropriate acute AHE therapy. Provide a place where the student can be physically separated from others, can lie down because in case of pain those around can seem disturbing and annoying. Students with HAE can be active in the learning process if their needs are met.
	Support provided by the	Pay attention if you notice the stduent's discomfort, for example, fear, sadness, or anxiety. Talk to the student to find out the best type of support one needs at the moment. Encourage the student to tell you if there are any sympotms, especially if there there is something wrong with the throat. Encourage the student to have a positive attitude towards one's health condition. Reduce the amount of the work at class and home.
	Technical support	Not necessary.

Used sources:

HAEA. Available at: *https://www.haea.org*

Hereditary-angioedema. Available at:
https://www.thinkgenetic.com/diseases/hereditary-angioedema/living-with/61252

ORPHA
93402
93403
93404
93406

SYNDACTYLY

DESCRIPTION OF THE DISEASE

Syndactyly is a congenital malformation in which there is a fusion between two or more fingers or toes. It can be complete; affecting the total length of the affected finger or fingers, or it can be incomplete, joining the fingers only at a point or points. This condition occurs in several ways: with a fusion only of the membranes, that is, of the skin, which has an easy solution at the surgical level; a more complex fusion with the presence of more bones than normal; or an association with other types of abnormalities such as duplications or the incorrect position of the bones. Normally, in the mildest cases, it is cured by surgery for about 1 or 2 years. In more serious cases, it is usually expected a few more years, so cases may appear within schools, especially the more serious.

MAIN ORGANS OR SYSTEMS AFFECTED

OSTEOARTICULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is not necessary to take any action, since it is a person with limitations only in hands and/or feet, so the adaptations are fundamentally spatial and/or ergonomic.

SPACE ADAPTATION - ERGONOMIC

With an affectation of the fingers of the hands it is possible that the child needs special help when using different class instruments such as scissors or pencils. Therefore, it may be necessary to use special material ergonomically adapted for them.

When using computer keyboards, these can be replaced by applications that allow the use of office automation tools without a keyboard (ex: SOLCA), thanks to the use of cameras, touch screens, voice recognizers or joystick-type mice. It is also possible that alterations will need to be presented when walking or running if the malformations are at the level of the toes, so there will likely be a need for the use of crutches or a walker.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures beyond facilitating the comfort of the students with the footwear at some specific moments. There may be a need to reposition, accommodate or check the condition of the feet.

ACCESSIBILITY

There is no need to take any action regarding accessibility.

INCLUSION STRATEGIES

Positive feedback should be promoted regarding the self-esteem and emotional development of the students, carrying out activities that promote inclusiveness in the classroom to avoid displacement of the person due to their physical appearance, the rest of the children must understand that differences are produced by a disease.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

After some of the operations related to syndactyly, there may be scars that have bleed at some point. The only thing that should be done in these cases is to use a sterile gauze or cloth dressing to cover the wound. If the wound is dirty, it can be washed with water or saline solution before covering. Parents or primary caregivers will be notified and referred to the health center.

POTENTIAL EMERGENCIES AND ACTION

A greater risk of emergency is not anticipated than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Provide the student with necessary ICT.
	Support provided by the teacher	Whenever possible, provide the student with an opportunity to master the content of the curriculum using alternative methodologies (ICT). Create a positive classroom environment and friendly atmosphere. The student may have low self-esteem. Therefore it is crucial to offer the student to complete self-esteem building activities.
	Technical support	Provide the student with custom-designed stationary. Ensure access to specific audio materials, ICT.

Used sources:

Malik S. (2012). *Syndactyly: phenotypes, genetics and current classification.* Eur J Hum Genet. PMID: 22333904; PMCID: PMC3400728.

Jennifer M. Ty. *What Is Syndactyly?* Retrieved (2022).
https://kidshealth.org/en/parents/syndactyly.html

ORPHA 98896

DUCHENNE MUSCULAR DYSTROPHY

DESCRIPTION OF THE DISEASE

Duchenne disease is a neuromuscular disease that progressively causes muscle atrophy and weakness, causing the loss of muscle function and thus the independence of the person. This leads to the inability to walk and the need to use a wheelchair around the age of 12, with the first symptoms being weakness, clumsiness when walking or difficulty getting up from a lying position or climbing stairs. These people have a life expectancy of no more than 30 years. In addition to this loss of functionality, stiffness and contractures, thickening of the calf muscles, curving of the lumbar and cervical spine, together with scoliosis, weakness of the heart muscle and respiratory dysfunction appear in the child.

MAIN ORGANS OR SYSTEMS AFFECTED

MUSCULAR

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

CARDIOVASCULAR
RESPIRATORY

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is possible that the child will be absent during some school periods in the case of requiring palliative surgery. Therefore, the school curriculum should be adapted to absences, so that it can progress academically like the rest of the students. Perhaps the prioritization of educational content is required for its evaluation in case the absences from the center are prolonged, but always trying to start from the ordinary curriculum to avoid differences with the rest of the students for as long as possible.

SPACE ADAPTATION - ERGONOMIC

There may be an inability to run or jump in the case of children between 6 and 12 years old, from that age it is common for them to need to use a wheelchair so it will be necessary to make the necessary modifications in the classroom and in their position. Mobility and comfort should be facilitated. Just as there must be a wide area to have the different sanitary materials that you may need. Shelves, cabinets, desks, blackboards, hangers, work materials, etc. They must be placed at a height that allows their use.

It would be convenient for the classroom to be close to the treatment room or infirmary, where the sanitary material (oxygen therapy) would be kept if necessary.

ENVIRONMENTAL ADAPTATION

It is not necessary to take any environmental measures.

ACCESSIBILITY

In children under 12 - 13 years of age who retain a certain degree of mobility, although with limitations, there may be difficulty climbing stairs or frequent falls, so it would be advisable to have measures to stabilize their gait (grip on walls and on stairs). If they already need a wheelchair, it will be necessary to implement ramps and accesses for people with reduced mobility so that architectural barriers are eliminated in all areas of the school (entrance to the center, the classroom, the bathrooms, the playground, etc.). There must be at least one adapted bathroom on each floor of the center with a toilet placed at the standard height of a chair, with folding handrails on both sides,

INCLUSION STRATEGIES

It is necessary to apply strategies that promote the autonomy of the student, within their difficulties and abilities, enhancing their self-esteem. If it is possible they should carry out the actions by themselves, playing with the rest of the class and all proposed activities in the classroom, even if it takes longer compared to others or they need breaks.

Depending on the child's level of dependency, it will be necessary to have support staff (teachers) to facilitate the inclusion of the child in the classroom.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

In advanced stages of the disease, the child may require mechanical respiratory support, although the management of these systems and their maintenance require specific training in qualified personnel. It would be desirable for teachers to be familiarized with the equipment so that they could detect risk situations (accumulation of secretions, plugging, displacement of the cannula, etc.) in order to alert whoever corresponds. For this, it will be necessary for teachers to be trained in the assessment of these potential risk situations. Teachers and dinning room staff (if the child stays) must recognize the signs and notify family members and the health center in the event of a deterioration.

Making postural changes should be done by the child himself / herself in the wheelchair, but it may be necessary to help him / her make them completely.

POTENTIAL EMERGENCIES AND ACTION

One of the most serious threats of this disease is the possible heart failure due to the weakness of the myocardium (heart muscle), in this situation the emergency service should be called and the basic cardiopulmonary resuscitation maneuvers should be started (see current protocols).

Another possible emergency is respiratory failure, which, although it does not usually occur in spontaneously breathing children, can appear in relation to complications of mechanical respiratory support when required by students. In these cases, the teachers should immediately alert the school nurse of the center and collaborate in the maneuvers required by it.

It is necessary that the School Center has emergency medical supplies. For example, the presence of an insufflation mask for resuscitation would be desirable. Just as the presence of a secretion aspirator would make it easier for other professionals to assist you to act more quickly. The presence of oxygen bullets, nasal goggles or an oxygen mask would favor an early action on the respiratory failure derived from their disease.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	If necessary, it is advisable to recruit an assistant (for self-care).
	Support provided by the teacher	Extra time to complete in-class activities and tests. Keep track of the student's physical activity so that the student does not overwork. The student may have low self-esteem. Therefore it is crucial to offer the student to complete self-esteem building activities. As minor motor difficulties may be an issue, support for writing and sports activities is advisable. Offer the student an option to provide answers in writing on a computer as it may be difficult to understand one's spoken utterances. It is advisable for the teacher to look for solutions in an understanding and interested manner - to find the best and most appropriate solution for every student. Involving other professionals if necessary.
	Technical support	If necessary, provide an opportunity for the student to use a wheelchair in the school's and classroom's environment (the entrance of the school and classroom, ramps, steps, floors, accessibility to desks and boards, etc.). Appropriate seating in the classroom. Audio, video materials. ICT.

Used sources:

Mary L. Gavin. Muscular Dystrophy Factsheet (for Schools). Retrieved (2022).
https://kidshealth.org/en/parents/md-factsheet.html

ORPHA 238468

HYPOHYDROTIC ECTODERMAL DYSPLASIA

DESCRIPTION OF THE DISEASE

Hypohydrotic ectodermal dysplasia (HED) is a disease characterized by the malformation of structures such as hair, skin, teeth, and sweat glands. In patients with HED, characteristic features such as sparse hair (scarcity of hair and fine hair), abnormal teeth or lack thereof, as well as absence or decreased sweating due to the lack of sweat glands, which generates heat intolerance. They have a dry and fine skin. And, most of these people suffer from dry eyes and respiratory tract with symptoms similar to asthma.

Typical facial features that present are small jaw, wrinkles under the eyes, prominent forehead with thin, thin eyebrows and eyelashes, hyperpigmentation of the skin around the eyes, and saddle nose (raised tip).

MAIN ORGANS OR SYSTEMS AFFECTED

CUTANEOUS- MUCOSOUS

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is not necessary to take any specific pedagogical measures, the disease allows normal learning within the ordinary curriculum. It is only necessary to take into account the problems associated with dry eyes and lack of sweat, leaving them more time when performing classroom activities or exams. Regarding the physical activity subject, the exercises will be adapted so that they can be carried out without associated problems (lack of sweating and increased body temperature), facilitating their continuous hydration.

SPACE ADAPTATION - ERGONOMIC

Due to missing or abnormal teeth, problems can occur when eating. Therefore, it would be advisable to help the person if necessary and, in any case, supervise them to avoid choking. This information should be known to the school cafeteria staff in the event that they stay to eat at the school institution.

ENVIRONMENTAL ADAPTATION

It will be necessary to adopt physical cooling measures in case the child performs activities that cause an increase in body temperature (physical exercise) or on very hot days. Strenuous physical exercise should be avoided and adequate air conditioning of the room in which it is located should be sought to prevent possible complications.

It may be necessary to include humidifiers close to the student. It would also be necessary to have a weather station that provides the teacher with information about the humidity and temperature of the classroom.
Measures can be taken for outdoor activities such as using shade in recreation areas or humidifying the area using sprinklers.

ACCESSIBILITY

There is no need to take any action regarding accessibility.

INCLUSION STRATEGIES

It is possible that due to the physical appearance of the girl or boy there are cases of social distancing between their peers, so it will be necessary for the educational intervention by the teachers to their students so that they understand that they are a different person and that it should be respected like the rest. All cooperative-type activities can be a good tool to promote peer socialization.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

The teacher should ask the student how he or she feels with the current temperature or if there is a sudden change in the temperature marked by the portable weather station in the classroom.

It may be necessary for the student to apply moisturizing creams to avoid dry skin and mucous membranes. This application will be provided to them in an area that protects their privacy. It may be necessary to help position them in areas where they do not have access (eg, back).

In turn, it may be necessary for the teacher to help the student put eye drops in their eyes. If not necessary, they should be allowed some time to put them in. In turn, it will be necessary to take their temperature with a thermometer. If the temperature is above 37°C, it will be necessary to notify family members and place them in a heated room where there is a stable temperature and a certain humidity above 40%.

POTENTIAL EMERGENCIES AND ACTION

A situation of hyperthermia can cause fatal brain damage for the person, so, with the minimum of indication, the body temperature should be taken and if it is higher than normal (37°), cooling measures such as transfer to a heated room, cold drinks and even the use of ice, which should not be applied directly to the skin. To do this, it will be wrapped in a cloth and the student will be allowed to apply it to the neck or forehead areas. The school nurse will be notified for observation and surveillance in case it is necessary to adopt other measures such as transfer to a specific health center or the application of antipyretics.

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

Organisation of the learning environment at school

Individualised Education Plan (IEP) and 504 Accommodation Plan

Support provided by the educational establishment

If the student does not cooperate, you cannot cool one down or make one's temperature higher, call the parents! Meanwhile, do not leave the student unattended and keep in mind that if the student's temperature is too high, it may take up to 1-2 hours before it is possible to reach a temperature at a satisfactory level.

Regular wet cleaning of the premises.

On hot days, the student is allowed to dine together with a friend. It can be done only if there is an air-conditioner in the room.

The school nurse or trained staff will inform the parents/guardians in advance about any changes to the planned activities, such as gymnastics, activities on the playground, and excursions.

Each substitute teacher and substitute school nurse will be provided with written instructions for the care of the student's ectodermal dysplasia, as well as with a list of all the school nurses and trained staff.

Encouragement is essential. Emotionally, this disease can be challenging for many individuals who suffer from it. The emotional pain of ectodermal dysplasia can be overcome by exercising the student's own inner strength, by knowing medical facts and by getting support from others.

The school nurse, trained staff and other emplyees will the the confidentiality of ectodermal dysplasia, unless the student and one's parents / guardians decide to make the fact public.

As regards nutrition, it has to be taken into account that food is easily absorbed into the throat causing choking. Therefore, the student must avoid consuming dry food. There should always be some beverage available. All meal times have to be controlled.

Studentren suffering from extodermal dysplasia must be observed during the work with ICT, during sports lessons or any pysical activities.

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	The school should agree with the parents that a note signed by them is not necessary if the student decides not to participte in a sports lesson, other physical activities or games due to the heat. Instead of that the student should be allowed to engage in an alternative activity agreed upon previously. To try to pay as little attention as possible to the student's specific needs. For example, if there is a need to move the student away from a window or heater, make all the other students change places as well. Additional materials, explanations, recordings of lessons are advisable. Decreased ability to concentrate and insufficient learning performance due to fatigue and pain. The reason for it may also be simply feeling unwell. In swimming lessons, listen to the student's request either to stay in water or get out of the pool based on one's condition. Due to often being absent and experiencing decreased concentration levels, the student may end up having low self-esteem. One's self-value can also be diminished due to one's appearance and special needs. Communication with classmates should be encouraged. Provide additional support so that the student does not feel punished for having missed lessons due to ectodermal dysplasia. Sports lessons must not be forbidden for a student suffering from ectodermal dysplasia. On the contrary, the student should be encouraged to take part in these lessons. However, the student's temperature must be taken care of. The student must always have access to some beverage (water, juice). If sports lessons take place outside, a bucket of water must be available there. The student must be encouraged to gou outside every day. Be careful when it is hot/sunny outside - the student should be in a shadow. Moreover, if the temperature is rising, the student must be allowed to go inside. During winter, if it gets too cold, the child must be allowed to go inside to raise one's temperature. It is nothing unusual, if the student with ectodermal dysplasia in winter plays outside without a coat. It is because it is warm for them. But the coat must be left nearby in case it is necessary if it gets too cold for the student.

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the teacher	The student's temperature must be taken care of from the moment one enters the school until the moment when one leaves it. It is not advisable for them to get too warm as their concentration may decrease. Therefore the teacher should contact the parents/guardians to make sure that the student knows what has to be done at home.
	Technical support	Always make sure that the student does not sit by the heater in winter, but by the windows or in direct sunlight in summer. Ideally, in the summer months, the student should sit close to a fan, and in the winter months, if the central heating is turned on, a fan should be nearby as well. The student must be reminded to drink water, to turn on a fan and use a water sprinkler. There has to be cooling equipment, cooling gels, fans, sprinklers, medicine storage cabinet. If going on excursions in the warm period of the year, tthere has to be climate control in the vehicle. If it is not there, the parents have to be requested to provide an alternative means of transport for the student. In case the student has other health issues, additional problems may appear. If the student has a denture, it is necessary to rinse it after eating. If the student experiences overheating or needs to cool down during a test, one has to be allowed to complete it at any other time without being punished. Clothing of the student has to be checked - if the student feels cold or hot. Make sure that in case of emergency there is a water sprinkler, a heater, drinking water, cold gel nearby.

Used sources:

National Foundation for Ectodermal Dysplasias. Pieejams:
https://www.nfed.org/

Ectodermal Dysplasia Society. Pieejams:
https://edsociety.co.uk/

Canadian Ectodermal Dysplasia Syndromes Association. Pieejams.
https://ectodermaldysplasia.ca/

ORPHA 289390

PRIMARY SJÖGREN SYNDROME OR PRIMARY SJÖGREN-GOUGEROT SYNDROME

DESCRIPTION OF THE DISEASE

It is an autoimmune and systemic disease that manifests itself mainly through dry mucous membranes (mouth/eyes), but that can present many more symptoms at the level of the kidneys, lungs or even the whole body, although these are more common in adulthood.

The person may feel burning in the eyes or a sensation that there is a foreign object inside them, in addition to difficulty swallowing or eating dry food, pain or ulcers in the mouth, problems speaking, inflammation of the gums, etc.

This disease is not progressive, so the signs and symptoms remain stable over the years.

MAIN ORGANS OR SYSTEMS AFFECTED

CUTANEOUS- MUCOSOUS

OTHER FREQUENTLY AFFECTED ORGANS OR SYSTEMS

THERE IS NO AFFECTION OF OTHER ORGANS

POTENTIAL ISSUES IN THE CLASSROOM AND RECOMMENDED STRATEGIESED

PEDAGOGICAL ADAPTATION

It is not necessary to take drastic measures, since it is a disease that, generally, only causes difficulties at the level of hydration of the mouth and eyes, so the measures will be focused on alleviating symptoms. The student will be allowed to consume sugar-free candy or gum to stimulate saliva production if they have to speak during class or if feeling dry.

SPACE ADAPTATION - ERGONOMIC

It is not necessary to take any spatial and/or ergonomic measurements.

ENVIRONMENTAL ADAPTATION

Dry environments and air sources such as air conditioning, fans, or air heating should be avoided. For this reason, the use of tinted or dark glasses is recommended to protect the eyes from the wind and, also, from the sun, so as to reduce tear loss. The use of humidifiers is also recommended to increase ambient humidity.

It is preferable that the child has access to a nearby water source in case their oral hydration is necessary. If there is not have a nearby source, the student should be allowed a bottle of water to always have proper hydration. It is recommended to take sips of water throughout the day and chew gum or suck on candy (without sugar).

During dining and lunch hours, beverages that contain caffeine, foods with spicy or hot components, and sugary, dry and sticky foods should be avoided as they can aggravate the burning sensation in the mouth. In addition, the student should brush their teeth after each meal with a soft brush and use floss and mouthwash.

ACCESSIBILITY

There is no need to take any action regarding accessibility.

INCLUSION STRATEGIES

As in all diseases, it is necessary to make the rest of the students understand that it is a disease for which no student should be excluded. Therefore, it is recommended to carry out inclusive activities adapted to the age of the students (cooperative games, talks, etc.). In this way, discrimination on the basis of the disease will be avoided.

THERAPEUTIC SUPPORT IN THE ABSENCE OF A SCHOOL NURSE

It may be necessary to use artificial tears or lubricating ointments, provided by the teaching staff in accordance with the guidelines specified by the responsible health professionals to the parents or main caregivers, in the event of ocular dryness and discomfort.

Frequent nosebleeds may occur. It will be necessary to apply a pressure maintained by the outlet orifice. The child's head will be put forward and down and if it could be applied cold in the area by means of ice wrapped in a cloth.

The student may have frequent heartburn and regurgitation after meals. At certain times of the year it may be necessary to take gastric protectors according to the instructions of the parents or main caregivers based on the medical prescription. The time necessary for mouth washing and tooth brushing should be given after each meal (lunch, dinner and snack).

POTENTIAL EMERGENCIES AND ACTION

Beyond these situations, a greater risk of emergency is not foreseen than in the rest of the students. Reference protocols in each geographical area should be checked.

USED SOURCES

Orphanet pathology profile in https://www.orpha.net

OMIM pathology profile in https://www.omim.org

SUPPORTING THE STUDENT WITH **PRIMARY SJÖGREN SYNDROME OR PRIMARY SJÖGREN-GOUGEROT SYNDROME** IN THE SCHOOL SETTING

Organisation of the learning environment at school		
Individualised Education Plan (IEP) and 504 Accommodation Plan	Support provided by the educational establishment	Communication with a rheumatologist. Provide drinking water in the school's premises. Provide air control in the school's premises.
	Support provided by the teacher	Follow the healthcare provider's instructions (signs to be paid attention to: the student has a dry mouth, dry eyes). If the student talks for too long, offer some water, special sweets. If there is a need, send the student to a school nurse. Inform the school administration if the air in the classroom is too dry.
	Technical support	Ensure humidification if the air in the classroom is too dry. Increase indoor humidity and reduce exposure to air conditioning (climate control in the premises; help the student avoid sitting in fornt of a fan or air conditioner).

Used sources:

Thouret MC, Sirvent N, Triolo V, Monteilh C, Michiels J, Boutté P. (2002). *Syndrome de Gougerot-Sjögren primitif chez une fille de 13 ans [Primary Gougerot-Sjögren syndrome in a 13-year-old girl]*. Arch Pediatr. Feb;9(2):142-6. French. doi: 10.1016/s0929-693x(01)00722-9. PMID: 11915495.

Colin Tidy. *Sjögren's Syndrome Causes, Symptoms, and Treatment*. Retrieved (2022). *https://patient.info/doctor/sjogrens-syndrome-pro*

CREDIBLE

Children with RarE Diseases and their Inclusion in Basic Learning Environments

GENERALITAT VALENCIANA
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