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facing
SCHOOL

TESTIMONY AND EXPERIENCES GUIDE

INDEX:

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Carolina

"During my education, I had to overcome many physical barriers. I am in a wheelchair and some classrooms were not accessible".

Education: University graduate
Disease: Friedreich's Ataxia

During my education, I had to overcome many physical barriers. I am in a wheelchair and some classrooms were not accessible. Sometimes, it was decided to move the course to the ground floor. But other times, I was suggested to drop out of school. Teachers and school have always been aware of my disease. In Spain it is mandatory to submit a medical report during the registration process. However, there was not an active communication between school and family.

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The school did not implement any methodologies or activities to promote and enhance the inclusion in the classroom or to raise awareness about my diseases either. Anyway, my classmates always supported me and helped me when I needed it. In my case, I suffered discrimination mainly from the school and some teachers. Regarding my treatment, I could always leave class when I had a medical appointment.

I believe there are pros and cons when we talk about digitalization. In one hand, it gives you the possibility to organize your time as you like. But, at the same time, you can feel isolated when studying from home. Anyway, I have studied from home, and I am very happy with the results.

Laura

"Most of the times, teachers and the school board have shown interest in my disease and had helped me on everything".

Education: Masters degree
Disease: Arthrogryposis multiplex congenita

In my case, schools were always adapted to my necessities. There were not physical barriers. Besides, the school provided me with a personal assistant. Most of the times, teachers and the school board have shown interest in my disease and had helped me on everything. The school did not have any information about my diseases beforehand. However, they were willing to know more about it. There has always been a fluid communication between the school and my family aiming to guarantee my wellbeing.

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The school decided to organize a calendar, so I always had a classmate by my side to help me if necessary. I also participated in extra-curricular activities. However, if we talk about trips and excursions, I always had to travel by myself, which made me felt a little excluded. My desk was always adapted to my condition, according to my necessities at the time. My classmates were more or less aware of my disease. They were nice, but they did not show so much interest. In fact, any of my classmates are currently a friend of mine. I felt isolated at times, but there were not any solutions implemented. Nonetheless, teachers and school staff always helped me whenever I had a medical appointment. They were open to change the date of an exam, lend me class notes or schedule a support class.

I believe that digitalization of education is very useful. Back then, when I was student, blended learning was not very common. But I truly think that it would have improved my school performance. At University, I found very useful devices such as the voice scrambler, which allowed me to take notes with my voice.

CAIXAFORUM

May 3rd 2023, Madrid

On Wednesday, May the 3rd, 2023, Fundación Isabel Gemio presented the projects co-funded by the European Union which currently coordinates and the documentary «Manual Básico de Resiliencia» at CaixaForum Madrid, thanks to the very special collaboration and support of the Fundación «La Caixa».

Isabel Gemio, hostess of the event, explained to the over 200 people gathered for the occasion the details of the Erasmus+ THE VALUE OF FACING SCHOOL. People affected by rare diseases, families, journalists, and representatives of the Comunidad de Madrid's government were informed that this project will allow us to help students suffering these pathologies to achieve educational success. In the meantime, the consortium of the project will promote social awareness on rare diseases and the need for everyone to contribute to their scientific research.

After the screening of the documentary, many people approached the team of Fundación Isabel Gemio to show interest on the project. It was also a great opportunity to build up our network of volunteers and gather opinions and inputs from people affected and professionals from the education system.

Rosália

"Respect for and responsibility for the full well-being of students with degenerative and/or rare diseases requires a multidisciplinary team whose aim is always unrestricted inclusion in the life of the person/student".

Special Education Teacher

Throughout my professional life, 35 years of service in special education, 16 of which have been spent running the Évora ICT Resource Centre, I have always prioritized observing the student as a whole person, looking for solutions and/or content that promote development and active participation in society, using all the «participants» in their lives.

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Respect for and responsibility for the full well-being of students with degenerative and/or rare diseases requires a multidisciplinary team whose aim is always unrestricted inclusion in the life of the person/student. It is, therefore, essential that the student is listened to, both orally and in their non-verbal expressions, to find solutions that allow all contexts to be adapted to their characteristics.

Daniela

“My son Lorenzo attends a public elementary school that follows the "without backpack" model in which teaching is organized in groups and there are many hands-on activities. Just the type of model is very inclusive in itself because each child's time is more easily respected”.

Mother of Lorenzo

Lorenzo attends a public elementary school that follows the «No Backpack» model in which teaching is organized in groups and there are many hands-on activities. Just the type of model is very inclusive because each child’s time is more easily respected. The teachers have always been very welcoming and inclusive. Lorenzo has not encountered any particular barriers or obstacles, except for the difficulties and slowness related to the mild impairment of executive functions related to Duchenne. His increased slowness in learning was accommodated within the normalcy of the teaching rhythms of the backpack-free method.

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Since Lorenzo knows the name of the pathology and that he has a difficulty in his muscles that involves weakness, but he does not yet know how much it may impact his life, we made the choice not to make the pathology explicit to his other classmates yet but only his muscle difficulties. It is our intention to carry out an outreach, with the support of the association, next year when he starts secondary school and the signs of the condition will be more evident. Lorenzo is averagely accepted in the class group, likes to be in small groups, and, where activities become too strenuous or «fidgety,» he still manages to find his own compensatory strategies for being in the group.

Teachers were involved in a meeting with the Parent Project psychologist at the beginning of the school cycle and were always willing to consult descriptive materials made available. There has never been any problem or hindrance on days when Lorenzo has been absent for visits/exams. Teachers have always been very welcoming and when they have seen the need, they have always implemented distance learning lessons.

RARE 2023 CONFERENCE

October 3rd & 4th 2023, París

The Rencontres RARE has become a not-to-be-missed event for all those involved in the rare disease community: public decision-makers, patient representatives, health and research professionals, and pharmaceutical, medical device and health technology companies. Held every two years, the conference provides a forum for reflection, with a particular focus on research into all aspects of the patient journey (diagnosis, development of therapeutic solutions, organisational and social innovations, etc.) The central theme of this year's event is «From Territory to Europe» and «The Care-Research Link», i.e. how to strengthen coordination and collaboration between local and European players, while reinforcing the vital link between care and research. The congress had three key places:

- the auditorium, hosting the talks of the speakers.
- the agora, where speakers could describe their mission in the rare disease field.
- the poster session.

The role of the Foundation For Rare Diseases in the project tis to develop digital educational material and resources to facilitate the teaching action of teachers and allow them to carry out their daily work in normally and with a greater inclusion of the student in classroom dynamic. To develop these resources, we took advantage of the collaboration of some researchers funded within the context of our national call in Social Science and Humanities, of the AFM Telethon and of the INSHEA (Institut national supérieur formation et recherche – handicap et enseignements adaptés).

Rachele

"Until the third year of high school, the attitude of classmates towards my situation was, with a couple of exceptions, completely negative. I found myself living daily episodes of bullying through messages in which my pathologies and their severity were diminished".

Education: University student
Disease: Ehlers-Danlos syndrome, Chiari malformation type 1, Spontaneous Liqueur Hypotension Syndrome, Trigeminal Neuralgia, Gastroparesis, autoinflammatory disease with periodic fever, benign chronic intestinal insufficiency

There have always been multiple and diverse obstacles in the classroom: mainly physical barriers. Teachers have always been informed about my health condition. The school itself required medical certificates in order to attest to the veracity of my health. However, no methodologies or outreach activities have been implemented to improve classroom engagement, nor a protocol for an emergency related to my illness. No changes were made to the class to fit my situation either. Often, I was forced to leave the classroom, missing part of the lesson or even the whole lesson, in case I needed it (e.g. persistent cough, syncope, etc.).

The classmates were also aware of my pathologies. Until the third year of high school, the attitude of classmates towards my situation was, with a couple of exceptions, completely negative. I found myself living daily episodes of bullying through messages, in which my pathologies and their severity were diminished. This also happened in the presence of the professors, who did nothing to protect me. Fortunately, during the last two years something has changed, perhaps the fact that my health had drastically deteriorated and was much more evident at the physical level, purely external (although my pathologies are part of the so-called «invisible» because they mainly affect the internal organs). Therefore, during this period, the attitude became more understanding and collaborative.

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Xénia

“With a few years' hindsight, my recommendation is to anticipate schooling and all the changes as far as possible, not to hesitate to communicate with the teaching teams and to reassure, as it's often the difference and the unknown that scare people”.

Mum of Joany

My son Joany, aged 9, suffers from a very serious neurological condition known as Ondine syndrome: he suffers from periods when he can’t breathe, so he has to be tracheotomised and hooked up to a respirator when he needs it, particularly at night but also sometimes during the day. When he enrolled in school, we greatly anticipated the exchanges both with the school and with the administration.

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We knew that we would have to go through a process with the MDPH (Maison Départementale pour les Personnes Handicapées), recruit and train an AESH (Accompagnant des Elèves en Situation de Handicap), inform the school, and that all this would take time. We started the process 10 months before the first day of the nursery school.

In particular, we made sure that the school and the whole teaching team were well informed about the disease and its constraints, while at the same time trying to be reassuring: we understood that it could be very stressful to welcome a child with a very specific rare disease and we made sure that we prepared Joany's arrival at school as much as possible so that the burden on the school wasn't too heavy.

With a few years' hindsight, my recommendation is to anticipate schooling and all the changes as far as possible, not to hesitate to communicate with the teaching teams and to reassure, as it's often the difference and the unknown that scare people.

DMD & BMD MEETING

October 1st 2023, Treviso

On Sunday, October 1, in Treviso, Parent Project presented the Erasmus+ project 'THE VALUE OF FACING SCHOOL: the inclusion of youth with neuromuscular diseases, muscular dystrophies and other rare diseases in education co-funded by the European Union.

The Project, which aims to promote the inclusion and school integration of youth with neuromuscular diseases, was presented as part of the territorial meeting on Duchenne and Becker muscular dystrophy organized together with the municipality of Treviso.

The event was attended by many families, patients, clinicians as well as the institutional realities of the area. It was an excellent opportunity to bring patients, but not only them, closer to this issue common to all children. Each of them has a story to tell and life experiences to share, and this can be a further starting point to raise even more awareness of the issue of rare diseases and school inclusion.

Begoña

"For me, as a mother, the most important thing is to create an educational route together with the school, to know the student's situation in all the processes and above all to ensure that the student has all the needs covered, both in terms of human resources like technical support".

Mother of a child affected by DMD

The main obstacle that prevented the development of my child's education with normality was making my son's needs and support visible, and the evolution he was going to suffer over the years. Accessibility, the need for educational support, for example, in the first instance of the Educational Technical Assistant (ETA). We as a family at the time of schooling put pressure and sought support so that our son had all the necessary resources...it was not an easy process. However, some accessibility improvements were made at school: ramps, adapted bathrooms, elevator.

The ETA and other educational supports such as the Therapeutic Teacher, Hearing and Language assistance was also requested. From the first moment both the teachers and the staff of the centre knew about the pathology. We decided from the first moment to normalize the situation and try to make things as easy as possible for all parties. In the same way, every time a teacher joins the different educational cycles, information on the pathology was sent to him and also the current moment in which my son was found and any change in his health was always communicated. The communication with the centre, in addition to being fluid, was both ways, being very participative as a family in the Educational Centre. Methodologies were also implemented to achieve the best adaptation at each moment, and they were increased when the symptoms were getting worse. As an example: Adaptation of exam time, and tasks as adaptation of homework.

Besides, activities were carried out to raise awareness of its pathology and people with disabilities and the school participates every year in the Solidarity Race to raise awareness of Neuromuscular Diseases. In the classroom, where the Tutor or Tutor was studying, they also had my direct telephone number, an identification card with the pathology and dangerous medications, as when he began to have heart problems, he had information on how to act through medical reports. The students also knew his pathology and as they grew up together they were aware of the changes he suffered year after year, and whenever any student or family was interested, we had no problem answering so they could learn about this rare disease. We wanted to teach, not hide. Fortunately, he did not suffer discrimination beyond something very specific.

As to digitalization, I consider it difficult, but it is clear that it is useful. The difficulty lies in the choice of devices and programs. The computer and the Tablet have facilitated his learning, but in a very limited way. For me, as a mother, the most important thing is to create an educational route together with the family in order to maintain a dynamic relationship with the families, to know the student's situation in all the processes and above all to ensure that the student has all the needs covered, both in terms of human resources like technical support.

Maria

"In the school context, we must focus on abilities, not deficits. We have to work on children's self-esteem and help them realise it's OK to ask for help. We all need help sometimes".

Former student with muscular dystrophy

When I went to primary school, I realised something was wrong with me when I started to fall several times while walking or running; I was six years old. When I was 10, I stopped walking and started using a wheelchair, and then the difficulties with architectural barriers arose. My schoolmates helped me a lot and played with me. Even though the teachers knew I had this illness, sometimes they didn't know what to do with me. Teachers don't always have the necessary tools and knowledge to deal with children with these illnesses.

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Most importantly, they are available to include the students, which is different from just being in the classroom. All children can participate in lessons with the appropriate adaptations and accessibility resources. All children can learn together with their peers.

Muscular dystrophy is a progressive disease, so we must adapt daily. The body is changing. It's important to value what you can do and your potential. We are no longer in the medical model, so we must focus on abilities, not deficits. We have to work on children's self-esteem and help them realise it's OK to ask for help. We all need help with something.

ASEM NETWORK

September 29th 2023, Madrid

Last September 29, Federation ASEM presented to the network of professionals of the associative movement of neuromuscular diseases the Erasmus+ project THE VALUE OF FACING SCHOOL , co-funded by the European Union and coordinated by Fundación Isabel Gemio (Spain), and with the following partners: Uniamo Federazione Italiana Malattie Rare (Italy), Parent Project per la Ricerca sulla Distrofia Muscolare (Italy), Universidade de Évora (Portugal), Foundation for Rare Diseases (France) and CEIP Clara Campoamor (Spain).

The Erasmus+ Project THE VALUE OF FACING SCHOOL is aimed at the creation of a network for cooperation, improvement of working methodology, activities and practices of organizations and institutions specialized in rare diseases. In addition, the initiative will develop the capacity of organizations to work in a transnational and multisectoral context, to address different priorities and needs, and to generate a change in educational methods for students suffering from these pathologies.

Federation ASEM presented this initiative to its member entities in the last ASEM Network Meeting held in Madrid, where professionals and representatives of the federated entities were able to learn first-hand about the objectives and activities being developed through this European project in which we participate together with Fundación Isabel Gemio and other European entities that make up the partnership.

Julie

"The inclusive school is an opportunity for Romane, who defies all the odds, but it's also an opportunity for everyone around her, children and adults alike, who learn from her about difference, tolerance and respect".

Mum of Romane

When a rare disease is diagnosed, as was the case for our daughter Romane, who has PACS1 – Schuurs-Hoeijmakers syndrome, the world stops, we have to mourn the life we had imagined and the questions about the future begin. School is the first big step in a child's life and it was our biggest source of worry: when should our daughter go to school? How often? Will she fit in? Is the mainstream school right for her?

#facingschool

We are lucky that Romane goes to a school where inclusion is not just a word, but a daily challenge, a value shared by everyone. Romane started the nursery school like all the other children, surrounded by a caring and attentive staff, and she has never stopped progressing and blossoming. The inclusive school is an opportunity for Romane, who defies all the odds, but it's also an opportunity for everyone around her, children and adults alike, who learn from her about difference, tolerance and respect. With her smile and her joie de vivre, Romane is changing the way we look at illness and disability.

María Teresa

"An advisory and monitoring team should be created for students, families and teachers. Besides, education centers must have health and support personnel".

Mother of a child who suffers from spastic paraparesis type 7

The main obstacles for the correct development of my child's education were physical (muscular weakness and exhaustion) auditory (neurosensory hypoacusis) visual (diplopia) receptive dysphasia, dislalias, epilepsies (absence crisis). Some solutions were adopted: in primary PT and physiotherapy, speech therapist. In secondary, adaptation of access to the subjects, test-type exams, analysis before the beginning of the class, computer to facilitate your tasks and more time during the exams.

#facingschool

The teachers knew about my son's disease. But there were no methodologies implemented or awareness activities carried out to improve my child's inclusion in the classroom. The only emergency protocol was to call us and call 112 and transfer him to your referral hospital. My son has suffered a lot of discrimination, but eventually, his classmates left him aside. Teachers also complained that my son missed a lot of classes.

Schools must incorporate an assistant in class to help people affected take notes, assignments etc.. Also flexibility in attending or not classes and exams is necessary and respond and analyse the needs of each student.

“Donne, Salute e Rarità”

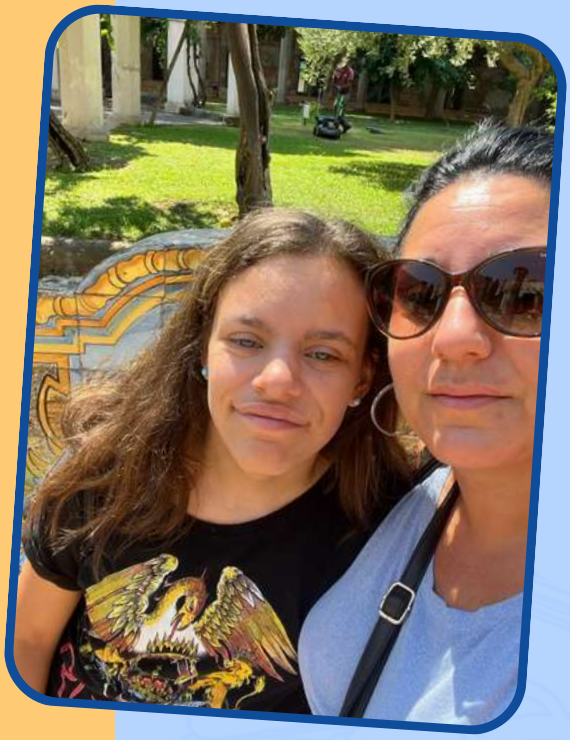
November 23rd 2023, Rome

ÜNIAMO
Federazione Italiana Malattie Rare

On 23rd November 2023 UNIAMO, during the press conference of the project “Donne, Salute e Rarità”, presented his role in the project Erasmus+ The Value of Facing School the inclusion of youth with neuromuscular diseases, muscular dystrophies and other rare diseases in education’ co-funded by the European Union.

The press conference has started a project that will continue in 2024 and that focuses on the importance of prevention for the female world and gender medicine. During the event, UNIAMO presented some projects that involve it including the Erasmus+ project and highlighted what has been done so far and the resources that have been implemented.

Paola



"The preparation and specialization of support teachers make the difference of a good path but unfortunately, very often happens to have non-specialized teachers and good will is not enough".

Mother of Sarah,
affected by Williams syndrome

The continuous change of support teachers does not allow to guarantee continuity to the educational and didactic project. Having to start every year with the knowledge of the problems and the potential of the girl wastes a lot of time and the forces invested every year are likely to be in vain. The preparation and specialization of support teachers make the difference of a good path but unfortunately very often happens to have non-specialized teachers and good will is not enough.

#facingschool

Compared to the problems mentioned earlier, because of the regulations on school contracts, the family can not do much. Thanks to the association, every year we try to get new support teachers and information material on pathology. We have always tried as a family to explain the condition, with all its variables and asking for more meetings during the year to monitor school performance, not only in consideration of a teaching performance but also to take stock of the situation of inclusion with classmates.

During the primary school period, Sarah has always been involved in all activities with involvement in small groups and with the mediation of adults or parents. During the course of secondary school, there was no particular attention from teachers to inclusion, especially now in high school, where several times we had to ask that Sarah could have a classmate nearby instead of just having the support teacher. Sarah has a differentiated program, she does not have a short time and follows all the subjects but everything adapted to her times. We often use Erickson material, applications of dyslexia association that help Sarah study on maps and simplified texts.

Marco

"At first, my classmates knew nothing about my disease, and after I got to know them a little better, I started telling them about Duchenne. Their attitude has been welcoming and they are all always willing to help me".

Disease: Duchenne muscular dystrophy

I am Marco, and I am in the second year of middle school. My school experience is positive. When I started attending sixth grade, I encountered the first difficulties regarding access to my classroom as I would have to a step too high for my electronic wheelchair to reach it, but with the help of my professors, we identified an alternative route to reach my classroom without architectural barriers.

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To learn more about all the issues related to Duchenne muscular dystrophy, My professors and classmates joined an activity organized by the Duchenne Listening Center of the Parent Project association. At the moment, it was not necessary to change my classroom as my professors had identified a very large and spacious classroom. The school purchased an ergonomic desk suitable for my electronic wheelchair, a laptop computer, and for music lessons a keyboard that I could play instead of a flute.

Initially my classmates knew nothing about my disease, and after I got to know them a little better, I started telling them about Duchenne. Their attitude has been welcoming and they are all always willing to help me. School inclusion is a very important issue, and I think digitization can be very helpful in facilitating it. In my case at the moment, we use the interactive whiteboard and laptop that I use during class. I would add that technology can be increasingly helpful for those who have physical or even cognitive deficits.

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