



Press release

Collaboration between Pro Rare Austria and Salzburg University of Education becomes a cornerstone of the global 2023 Rare Disease Day campaign

13 January 2023, Paris – A joint project between the Pädagogische Hochschule Salzburg and Pro-Rare Austria, the Austrian national alliance for rare diseases, received international recognition through Rare Disease Day.

As part of the global Rare Disease Day campaign, EURORDIS alongside its partners has developed a school toolkit for pupils aged 7 to 8 to start a conversation about rare diseases from an early age.

It introduces a basic understanding of life with a rare disease and aims to provoke empathy for children with a rare condition. Equally important, it invites school students to think about how they can include their peers who might be isolated in the class or feel or seem different.

The lesson plan has been adapted from a resource created by the Austrian teacher Manuel Preishuber, as part of the collaboration between the Pädagogische Hochschule Salzburg and the Austrian national alliance of rare disease patient organisations, Pro-Rare Austria.

It has received high praise from an international expert panel of educators and scientists, in particular, due to its ease of use and implementation in any classroom worldwide.

“I’m so impressed with Manuel’s heart-warming lesson plan, which gently guides children to a stronger understanding of rare diseases. I love the beautiful classroom display that collects the learning points together at the end to remind children about how to be a good friend to somebody with a chronic illness.”

- **Geoff Case, Digital Editor of RARE Revolution Magazine and a former teacher**

“I was very impressed by the lesson plan entries for this year’s RD campaign. Introducing rare diseases to children of this age is very important, and doing so in a fun and engaging way in a classroom is a brilliant initiative. I hope that we can adapt it to classrooms across the world. It is never too early to encourage awareness and thoughts about rare diseases and those living with rare diseases.”

- **Prof Shahida Moosa, Stellenbosch University.**

To help teachers and student teachers understand and navigate better through the challenges of living with a rare disease, Pädagogische Hochschule Salzburg has also provided a dedicated course for educators.

“School plays an important role for children and adolescents with diseases in terms of recovery and social inclusion. Therefore, it is particularly important to offer courses and training for teachers that

enable them to deal with the topic of rare diseases. Through the online seminar on rare diseases, participants should be able to acquire and develop theoretical and practical skills in dealing with affected students. It is very gratifying that a lesson plan created by a participant during a course is now made available in every classroom around the world.”

- **Prof Nicola Sommer, Pädagogische Hochschule Salzburg**

“This easy-to-implement school kit is not only intended to provide more knowledge or raise more awareness for teachers and students but above all to help the students to treat a classmate with a rare disease with understanding and empathy and accept them as a full member of the class community.”

- **Ulrike Holzer, Pro Rare Austria**

EURORDIS hopes that this school toolkit can be used as a starting point for a better understanding of the health and equity issues some children might be facing, regardless of where they live.

Each of us can contribute by connecting with others and helping break the isolation some people might feel. You can download the lesson plan by following [this link](#).

About the Rare Disease School Toolkit

Raising awareness of rare diseases among young people is critical, as rare diseases disproportionately impact children and are often little understood by patients, peers, and educators alike. EURORDIS together with its partners has developed a classroom curriculum and toolkit to address the issue of misunderstanding and to foster dialogue and exchanges among students about ways their school can be more inclusive and accommodating for people living with a rare disease.

This project was made possible by a dedicated grant from Fondation IPSEN under the aegis of Fondation de France.

About Rare Disease Day

Rare Disease Day is the globally coordinated movement on rare diseases, initiated in 2008 and led by EURORDIS and 68 national alliance patient organisation partners working towards equity in social opportunity, healthcare, and access to therapies for people living with a rare disease. Over the last 16 years, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, multicultural, and multi-lingual – but united in purpose.

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease patient organisations from 74 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

About rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date affecting an estimated 30 million people in Europe and 300 million worldwide. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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