facing SCHOOL

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MODULE PARENTS AND ADMINISTRATION

ACTIVITY 4. RAISING AWARENESS & BEING HEARD. ACTIVISM FOR PARENTS.

- **TIME:** 30m.
- **RESOURCES:** PDF Guide on how to use social media and contact with actors of influence to give more visibility to the reality lived by families with children with RD.
- **LANGUAGES:** ENG / SPA

DESCRIPTION:

Having a kid with a rare disease can present multiple challenges that might not be known by the people surrounding us, which can lead to isolation for the families living in this situation.

Being more visible in our societies is a tool to create a positive change in the lives of families and children with rare diseases, since it starts the conversation, not only in the classroom and our neighbourhoods, but also in our local administrations and even in the government.

Nowadays social media and technology have brought the potential to expand our barriers and create a global change in favour of people with rare diseases. Parents and young people with rare diseases can be powerful actors in this change, using the right tools to share their stories to be heard louder and further than ever.

Additionally, reaching out to groups of influence such as media and politicians can also amplify the scope of action.

OBJECTIVES:

Being more visible in our societies is a tool to create a positive change in the lives of families and children with rare diseases, since it starts the conversation, not only in the classroom and our neighbourhoods, but also in our local administrations and even in the government.

LESSON OVERVIEW:

A guide on how to use social media and contact with actors of influence to give more visibility to the reality lived by families with children with RD.

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Share your story:

You can share your children's stories and their experience with the disease through blogs, social media, interviews in the media, etc. You can tag policy makers, governments and relevant organizations on your posts to reach out to them and make your struggles visible by them.

Participate in events and conferences about rare diseases, disability and children's rights:

Do some research and find out when and where these events will take place to organize your agenda. Inform yourself on the topic before going to take the most advantage of the experience. It is the perfect place to connect with other families in the same situation and important actors such as healthcare professionals, politicians, etc.

Organize your own fundraising events and activities:

Like sports events, contests, lotteries, concerts, etc. You will kill two birds with one stone; on the one hand you will make your children's disease more visible and known, and on the other hand you will be able to raise funds to invest them on organizations that help improve the quality of life of people with rare diseases such as organizations working to ensure their rights or to researchers looking for a treatment. You can also use the funds to keep campaigning and raising awareness, investing it on a new website or on new events and activities!

Reach out to the media:

Get in touch with original journals, magazines, and television programs, participating your stories and requesting media content on rare conditions.

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Reach out to policymakers:
Including local agents, members of congress, and government officers. Request meetings to partake your perspectives, give data and substantiation, and advocate for policy changes that can ameliorate the lives of affected families.

Attend policy forums and meetings:
Find out how you can participate in policy forums, public hearings, and community meetings where decisions regarding healthcare and rare diseases are discussed. Share your personal experiences and advocate for policies that address the needs of children with rare diseases and their families.

Reach out to experimenters:
Find the experimenters or exploration groups that are probing the complaint your family is affected by. Together you can work to find ways to finance exploration to keep moving towards a treatment, or to share in clinical trials.

Join associations and organizations:
If none of the above convinces you because you lack the time, the energy or the means to carry them out, you can join an organization that follows your same goals. There, you will meet other families experiencing similar situations and you will have the opportunity to participate in the campaigns organized by the association, thus being part of the change but without having to dedicate so much time and effort, nor displaying your life in mainstream or social media.