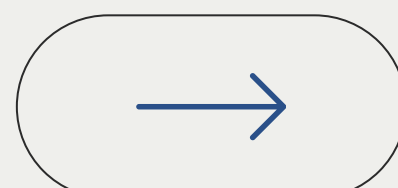


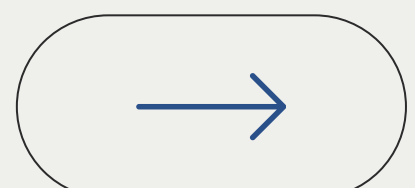
VOICES OF OUR YOUTH PANEL

ERN RARE-LIVER

# *Our Stories*

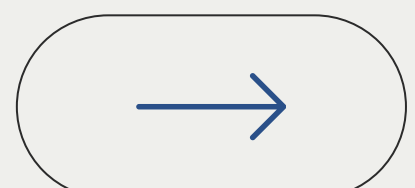


I think that my illness does not affect my youth much. The biggest difficulty I experience is dealing with tiredness or some symptoms that arise associated with the disease. And sometimes, it's difficult to realize that being so young, I have a disease that will stay with me for the rest of my life.



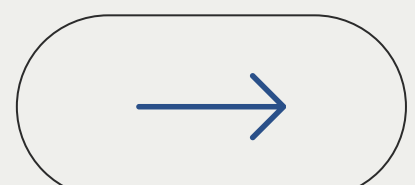
There is always the "Why me" questioning once in a while.

Yet, this experience has also shaped my perspective and made me more resilient. It's taught me to prioritize what truly matters.

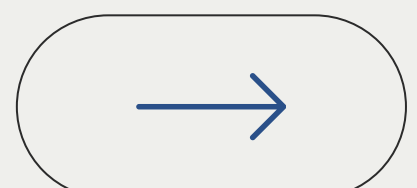


Personally, I don't feel like my condition has a significant impact on my ability to be young. I can still pursue all my hobbies, study, and enjoy fun activities with friends or family. However, it does make me feel tired a bit quicker, but it's not too bad in my case. At parties, you see everyone around you drinking, which can be a bit limiting because of the condition.

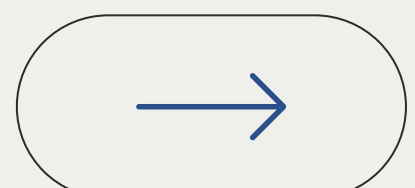
For me personally, though, I don't feel like I'm missing out. In fact, I see it as an advantage, as I only see downsides to drinking alcohol (even for people without a condition). Taking my pills in the morning takes me no more than half a minute a day, so no, I don't feel like my condition has a big impact on my youthfulness.



My advice for doctors who frequently work with young people is to treat your patient as a person, not just as a patient. The person sitting in front of you has their own personal history that can impact their life and their condition. They are in a phase of life with many changes that can cause stress. See the person in front of you as more than just symptoms and a condition. See them as someone experiencing life for the first time, unsure of what the future holds.



I would suggest that clinicians listen to their patients and show them that they are not alone. Show them that, as doctors who observe different cases every day, you know how difficult it is to have a chronic illness and have to take medication for the rest of your life. Present reality and the positive side



My main advice is to be aware that the young patient need to be very much encouraged to have projects. Care is successful if it becomes a means, not an end—taking time to hear concerns without rushing. Asking open-ended questions helps us feel we're partners in decisions about our care. Clear explanations and honest conversations about what to expect can also build trust.

