

## Konversation aus RareConnect, der internationalen online Plattform von und für Patienten, Ärzte und Wissenschaftlern

**Frage von Amy:** What do you find is the hardest thing about your Porphyria is?

**RareConnect Mitglied:** Hi Amy, the hardest thing? There are so many difficult challenges related to living with EPP and most of them have already been pointed out by others. Here 4 points I want to focus on:

1. A very difficult condition to grow up with - I vividly remember the pain I suffered as a child, the screaming, the crying, the feeling of injustice - Why me? - And the scorn from the other kids - You are the weirdo on the block, he wears gloves, large hats, he doesn't go to school outings, what's wrong with him. Even though as an adult you learn to somehow cope with the disease, it remains very challenging to live with EPP - You simply can't lead a normal life, you always live in fear of developing the painful EPP symptoms and when you do you have to retreat from life for a few days until symptoms subside. This has negative consequences on your family and professional life.
2. The helplessness of my parents, struggling to protect me from the painful consequences of the disease while trying to give me as normal a life as possible. And their desperation at the death of my brother who suffered fatal hepatic complications - Again, this strong feeling of injustice - Why our family?
3. People not believing the severity of the disease - What's your problem, you look normal, you don't have anything, you're exaggerating - While inside you are burning up in pain and you wish so much that you could just transfer the pain to them so that they can finally feel what you are feeling. I have sometimes wished my disease to be more visible - When someone sits in a wheelchair no one questions the severity of their condition...And the worse is when so-called healthcare professionals do not believe you, this is when I get very aggressive and I thank my mother for having taught me good manners which prevent my aggression from becoming physical.
4. Finally having a treatment that successfully addresses the symptoms of the disease and waiting for its marketing approval, knowing from your own experience and that of many others who have experimented it that the drug works while also knowing that it may never be approved because some health authority doesn't consider EPP to be serious enough to deserve such a treatment, because they don't believe EPP is severe enough, because they put a price tag on the quality of my life. This is tearing me apart inside - Thanks to the strong engagement of our doctor, Elisabeth Minder, and special Swiss legislation, I am under treatment now since 2006 and the drug almost made me forget I have EPP - It completely changed my life, I finally lead a pain-free, normal life - The thought that one day this may all end makes me very anxious. I simply cannot imagine going back to the life I had before...

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<https://www.rareconnect.org/en/community/porphyria/forum/topic/what-do-you-find-is-the-hardest-thing-about-your-porphyria-is>

**Sprache:** Die Übersetzung ins Deutsche kann auf der Plattform kostenlos beantragt werden und wird innerhalb eines Tages eingestellt. Antworten und Fragen stellen kann man auf u.a. Deutsch