# Interview with Claas Röhl

## Transcription

My name is Claas Röhl. I'm from Vienna, Austria. Two and a half years ago, I founded the patient organisation NF Kinder, and we fight for people who have neurofibromatosis, which is a rare genetic disease. We try to help them get better access to healthcare, proper healthcare. We try to start research projects and to connect patients and help them, also, with psycho-social activities.

We try to get information to Austria, because there's a lack of information among doctors. We go to the international conferences. I bring along doctors from the University Clinic in Vienna, which wouldn't have gone there without me. So I even paid them the … or, offered travel grants so that they really can get access to the latest information and bring that know-how back to our home country in order to treat the patients right. We offer scholarships for young investigators or young doctors and psychologists. We want to really boost the awareness about this disease and have young talents to focus on this disease, because there's a lack of information among professionals but, of course, also among patients.

### WHAT KIND OF TRAINING HAVE YOU HAD TO HELP YOU WITH YOUR PATIENT ADVOCACY WORK?

Three years ago, when I made the decision that I want to found this organisation, do all this work, the first step for me was I got in contact with the national fundraising association and did a fundraising training, because that's just such an essential part. In order to do something and make something happen, you need to have some funds. That was really important for me. Then, I've done that. The last year in summer, I did

the EURORDIS Summer School, which is a training for rare disease patient representatives, also on research and development. That was my first introduction into the professional research and development process and what patients can do. I was really happy that I've done that. When I heard that I could apply for EUPATI, I was so happy and entered there immediately and was very lucky and happy to got into second course. Now, I even have the chance to go even deeper into this very interesting field of research and development. These three educational courses are like my basis that I really can use in everyday work.

On the one hand side, I really know now the procedures and, also, the terminology, so, when I'm talking to a researcher, academic researcher or to a doctor or to some people in the regulatory office or from a pharma company, I can understand where they come from, what their perspectives are, and I can have a conversation on eye level so that they, also, notice that I know what I'm talking about, and they take me seriously, which they might not have been doing before. That's one crucial part about it. If you know about the procedures and how things are really going and being developed, you have an understanding, also, and that's an essential part of EUPATI where you can get involved.

My goal is to, really, get involved at the earliest stage possible so that I can discuss with researchers what questions do we need to ask, what should research focus on, because, for example, we did a survey among German speaking patients. About 300 patients took part in this survey, and we asked them, among other questions, "What do you think should research really do?" Because the symptoms in our disease are such a large variety of symptoms, so you need to focus on something. It turned out the two most important symptoms for patients are the most neglected one in research, so that's a really good basis to start a conversation and tell them "Well, you're not really tackling the patients' needs here, so let's discuss

what we should do in the future.”

That’s one very important part, and, so, we’ve been involved from the beginning, and we ask the right questions, and, then, we design the study in a way that patients really feel “Yeah, this is something important for me, and I want to be a part of it.” When it comes to clinical trial, we have less trouble to recruit patients, and they’re already being informed by the patient organisation, which has been a part of this whole process from the beginning, so there’s another level of trust here, which is very important, I think. At the moment, often the patient involvement only starts when there’s a clinical trial, and it ends after the clinical trial, but we want to stay involved, because it’s very important that we are involved in the health technology assessment process and with the regulatory offices so that we, also, can convince the people up there that we need this drug on the market and that it is, for example, being reimbursed for patients so that they have access.

## WHAT ARE SOME OF THE CHALLENGES AND BARRIERS THAT YOU ARE FACED WITH IN YOUR PATIENT ADVOCACY WORK?

On the one hand side, it’s a daily struggle to raise funds. I could spend my whole day doing nothing else than that, but I have so much more important work to do than the fundraising. It’s essentially, in Austria, we don’t get governmental support for an NPO, so we are 100 percent financed by donations and companies that sponsor us, but that’s really important and takes a lot of time. I wish it wouldn’t be like that. There’s some other European examples that get support by the government.

Challenges are to really get people together, because, at the moment, we don’t have a working European patient organisation, so we just started with that, and I was selected to be the

European coordinator for this big task. It’s very important that patients, especially for rare disease, understand that we all face the same challenges, so we all have the same goals. We have to understand that we reach those goals far more earlier if we work together and combine our efforts, because it’s just a waste of money and time and resources if every country reinvents the wheel again and again.

Not just the patients need to work together. We need to work together with academic research but, also, of course, with pharma companies and with the authorities. That’s a big task, because I think patient involvement is just about to start. The concept is, people understand that it’s important, but it’s …in practic life it’s not really there, yet. What I experience is a big challenge, because there’s no drug on the market for my disease at the moment at all. Pharma companies don’t really talk to me that much, because they say, “Due to our compliance guidelines, we can only support you when we are active in your disease area.” That’s one big problem, because how can we be innovative and start something new if you don’t get together at this stage. That’s, maybe, one big challenge. Yeah, and just to get people to work together, because academic research is so competitive. They’d rather not work together and publish their own data than see the whole picture and say “Okay, if we join forces, then we reach our goal more early.” They don’t do that at the moment, so they … Yeah. I don’t want to be too specific and say that they’re more focused on their own careers than on patients, but, at the moment, the system is not focused on the patients but on publishing papers.

I think that EUPATI gave me the basic knowledge to set up a proper strategy to tackle the many, many problems that our disease group is facing. I hope that I will be able to use this knowledge and gather around the necessary people to reach that goal and work together. I think that’s the key to success, work together and know what you want to do and how to

do it.