

Claas Röhl



Member of the IMI Scientific Committee

President NF Kinder

President EUPATI Austria, President NF Patients United, board member ERN GENTURIS, board member Pro Rare Austria, member of different working groups in REiNS (Response Evaluation in Neurofibromatosis and Schwannomatosis)

After I received the diagnosis Neurofibromatosis Type 1 of my first child and after I was the main care giver during her 18 month of chemotherapy, my journey of becoming a patient advocate began. It was obvious that the circumstances for NF patients in Austria, but also all over the world, have to improve. Participating in the EURORDIS summer

school, the EURORDIS winter school, the EUPATI patient expert training course and also the ESO masterclass for cancer patient advocacy, helped me to learn about research and development of drugs, but also about patient advocacy. It also helped me to build an international network, to register at the EMA as a patient expert for Neurofibromatosis. My goal is to optimize care for NF patients and contribute to NF research, by generating data with the NF communities all over the world, on patient priorities, unmet needs, patient relevant outcomes and by acting as a gateway to the patient community and assisting in communication and patient recruitment for clinical trials.

Previous positions

- advertising & marketing consultant until 2012
- care giver 2012-2013
- foundation of NF Kinder Dec 2013
- foundation of EUATI Austria 2015
- foundation of NF Patients United 2017

Fields of expertise

- Neurofibromatosis Type 1, Neurofibromatosis Type 2, Schwannomatosis
- fundraising College of Austrian Fundraising Association
- EUPATI fellow
- EURORDIS summer school fellow
- EURORDIS winter school fellow
- ESO masterclass cancer patient advocacy