EUROPEAN
HEALTH FORUM
GASTEIN

Röhl, Claas
Board Member - Pro-Rare Austria

Claas Röhl studied communication science at the University of Vienna after graduating from an engineering school in Vienna. He specialised in advertising and public relations and worked in film production and B2B-marketing. After the diagnosis of his daughter with Neurofibromatosis Type 1, a rare genetic tumour risk syndrome, he began his path into patient advocacy. He founded the Austrian patient organisation NF Kinder in December 2013. After completing several educational programmes for patient representatives on a European level (such as the EUPATI patient expert training course, EURORDIS summer school & winter school), and by continuously building a national and international network and investing in care and research infrastructures in Austria, NF Kinder managed to establish the first Austrian centre of expertise for Neurofibromatosis by forming a partnership with the Medical University of Vienna. At a European level Claas Röhl continued his ambition to create a better future for people living with Neurofibromatosis by co-founding NF Patients United, a European umbrella organisation for NF patient organisations.