



Fatemeh Mollet

President of NBIA Suisse

Since 2016, I have been volunteering as the president of the NBIA Suisse association dedicated to patients affected by neurodegeneration with brain iron accumulation. My commitment stems from personal experience, as three of my nieces are affected by this rare disease. As an aunt witnessing their daily life, I felt a moral duty to get involved in this cause, not only to support my own family but also all the families affected by this ultra rare disorders.

Being in good health, I feel privileged to have the energy and resources needed to represent the interests of patients and their families and to be their voice. My goal is to advocate for better access to care, appropriate treatment and, above all, to actively contribute to the advancement of medical research in the hope of a future where the quality of life for patients is improved. Our work at NBIA Suisse is purely voluntary. It is driven by the hope and the belief that research will one day lead to therapeutic solutions, a cure.

Our association is a true pillar of support for families, while working closely with researchers and healthcare professionals to further the understanding of NBIA. We believe together we can help make hope more tangible and that is what motivates me everyday.

NBIA Suisse contributes to

- Raise public awareness about NBIA by organizing events among the public and healthcare professionals
- Connect with the scientific and medical community to promote the research in these little-known ultra rare disorders
- Support research projects by organizing Fundraising events for NBIA
- Break the isolation that families face by establishing support groups to create a space for sharing and supporting families
- Collaborating with researchers and doctors to promote the development of new therapies