

Early diagnosis for rare diseases in Switzerland

29 March 2023, 17.00 – 18.30 CET

Program

- **Welcome and introduction**

Shayesteh Fürst-Ladani, RDAF President | Peter Löffelhardt, HOPOS | Nathalie Schober-Ladani, RDAF Secretariat

- **Journey to a rare disease diagnosis**

Susan Kuranoff, Global DARE Foundation

The presentation will dive into the journey to diagnosis for persons living with a rare disease and explore the impact of a late diagnosis for patients and their relatives, based on the experience with Refsum disease.

- **Challenges in early diagnosis**

Marianne Rohrbach, Children's Hospital Zurich

The presentation will provide perspectives on the role played by the reference centers for rare diseases recognized in Switzerland by kosek to facilitate access to diagnosis. It will also address key aspects for the diagnosis of rare diseases, such as newborn screening.

- **Situation of diagnostic tool reimbursement**

Daniel Lo Verdi, Swica

The situation for the reimbursement of rare disease diagnostic tools in Switzerland will be assessed, including the difference between the invalidity insurance and the compulsory health insurance and the impact of the coding of rare diseases.

- **Moderated discussion**

The co-moderators will lead a discussion with the speakers and the audience with the objective to identify and evaluate potential solutions to the challenges linked with rare disease diagnosis in Switzerland. Participants will have the opportunity to get additional insights from the speakers and share their view via an interactive setting.

- **Conclusion**

Peter Löffelhardt, HOPOS | Nathalie Schober-Ladani, RDAF Secretariat

The webinar is organized with the support of Alexion, Biogen, Ipsen and Roche.