

## Webinar report

### “Access to diagnosis and treatment of rare diseases in Switzerland Current status, challenges and initiatives”

**25 March 2021, 08:30 - 09:30 am**

The Rare Disease Action Forum (RDAF) organized a free webinar on 25 March 2021 on the topic “Access to diagnosis and treatment of rare diseases in Switzerland – Current status, challenges and initiatives”. The webinar was presented by:

- Shayesteh Fürst-Ladani (RDAF President, SFL Pharma),
- Jacqueline de Sá (ProRaris),
- Elisabeth Minder (Swiss Society of Porphyria),
- Corinne Wenger-Kundert (Roche),
- Anja Bühler (SFL Pharma),
- Andreas Uttenweiler (Takeda),
- Juan Gomez (Vertex) and
- Rea Lal (Pfizer).

#### PRESENTATIONS

RDAF president, Shayesteh Fürst-Ladani opened the webinar and welcomed the participants. She introduced the RDAF to the audience and provided an overview of the RDAF’s most recent initiatives to raise awareness about rare diseases in Switzerland and improve patients’ access to diagnosis, treatment and care.

The presentations provided an overview of the following topics:

- **Rare diseases in Switzerland from the patients’ perspective**

Jacqueline de Sá gave participants an introduction to rare diseases in Switzerland. She highlighted main challenges faced by patients living with rare diseases such as the diagnostic delay or unclear reimbursement of costs by the health insurance. Furthermore, she presented important milestones in the Swiss landscape for rare diseases like the organization of the Rare Disease Day in Switzerland by ProRaris or the National Rare Disease Concept. Elisabeth Minder presented the symptoms and treatment options for patients with porphyria in Switzerland, as well as the challenges in this context. She shared insights into the conditions for access to orphan drugs for patients and underlined the high variability in approval rate and delays for reimbursement requests under art. 71a-d KVV (Verordnung über die Krankenversicherung, Swiss Ordinance on compulsory healthcare).

- **Regulatory framework for orphan drugs in Switzerland**

Corinne Wenger-Kundert laid out the detailed criteria and the regulatory pathways for the orphan drug designation (ODD) for medicines in Switzerland. Furthermore, she gave an overview of applicable timelines for ODD application as well as related obligations. Anja Bühler presented the benefits of obtaining an ODD and compared the incentives for the development of orphan drugs in Switzerland and in the EU. She also shared insights into the regulatory strategy for marketing authorization application in Switzerland.

- **Access to treatment for rare diseases in Switzerland**

Andreas Uttenweiler presented recent data on the approval and the reimbursement of orphan drugs in Switzerland from his [CAS thesis](#) “Orphaned patients: Swiss access to orphan drugs is insufficient”. The collected data show that a high percentage of orphan drugs is not on the Swiss specialties list (SL) and that the inclusion into the SL list takes over 2 years for orphan drugs. Juan Gomez presented a case study on the access to treatment for cystic fibrosis in Switzerland and highlighted the shortcomings of the current reimbursement system for orphan drugs. In this context, he emphasized the existing bias against less well-established rare diseases and outlined potential solutions.

## PANEL DISCUSSION

Rea Lal moderated the panel discussion addressing following topics:

- The institutional set-up of the RDAF, which provides a unique neutral platform for different Swiss stakeholders across the field of rare diseases to define solutions for united action,
- RDAF towards shaping the regulatory environment in Switzerland,
- Potential solutions to improve the reimbursement regime for orphan drugs which are not on the SL,
- Current RDAF initiatives to improve access to orphan drugs in Switzerland, such as the ongoing dialogue with the Swiss society of medical and insurance examiners (SGV) to better reflect the specialties of rare diseases.

## CONTACT

Visit our website or contact the RDAF Secretariat to find out more about the RDAF and its initiatives and how to become a member.

- **RDAF website**

<https://www.rda-forum.org>

- **RDAF Secretariat**

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