

The Rare Disease Action Forum welcomes the Rare Disease Day

While rare means rare for each individual disease, “rare” is actually many across all the approx. 6,000 diseases that affect 300 million people and their families worldwide who have to cope with these diseases and their impact on life expectancy and quality of life.

This year’s World Rare Disease Day takes place on 28 February 2021. On this occasion, numerous events are organized throughout the world with the common objectives of raising awareness about rare diseases.

The Rare Disease Action Forum (RDAF) joins in and shares the message of the rare disease community to raise awareness for patients with a rare disease in Switzerland. As a multi-stakeholder organization, we unite different actors such as industry, healthcare professionals, patients and research organizations in their common goal to improve access to the diagnosis, treatment and care of patients with rare diseases through dialogue with other stakeholders such as regulators and payors. Thanks to our unique institutional set-up, the RDAF provides a reliable and neutral platform to foster dialogue and define common solutions for action.

OUR MISSION

We address rare disease specific challenges related to the Swiss regulatory environment, value assessment of orphan drugs and other processes impacting patients with rare diseases, with the aim to:

- **Raise awareness about rare diseases in Switzerland and foster dialogue about patients’ needs:** Patients with rare diseases face specific challenges and the RDAF is committed to increase decision makers’ awareness about the specificities of rare diseases.
- **Assess and adapt the regulatory environment to the needs of patients with rare diseases:** We are committed to assess key areas of rare disease related policies, regulations and processes, and actively shape the framework to improve access for patients with rare diseases in Switzerland.
- **Adapt the standards to enable equal and fair treatment for patients with rare diseases:** We work towards a timely and predictable value assessment process for orphan drugs.

RDAF ACTIVITIES

The RDAF:

- **Organizes regular multi-stakeholder workshops including roundtables** to discuss key issues related to the development of orphan drugs and the access to diagnosis, treatment and care for patients with rare diseases in Switzerland.
 - ⇒ *Our last workshop focused on [registries](#) for rare diseases in Switzerland. Participants outlined the main benefits for patients as well as the challenges, including the maintenance of such registries and data protection in small populations.*
- **Assesses policy developments and engages in dialogue and outreach activities with public authorities and other key stakeholders.** The RDAF monitors legislative and regulatory developments and regularly submits proposals to improve orphan drug development and access for patients with rare diseases.
 - ⇒ *Read our [statement](#) for the public consultation about the revision of the Swiss Federal Health Insurance Act concerning package 2 of the cost containment measures.*