

Information Event SRDR 01. September 9:00-11:30

Please see below the program of the information event Swiss Rare Disease Registry. The presentations will be held in English. In addition, you have the possibility to register for one of the workshops and you can choose in which language you want to attend the workshop (German, French, or English). The organization of the workshops and the language in which the workshops are held depends on the number of participants.

The event is free of charge, please register [here](#) until **25 august 2021**. After we have received the registrations, we will inform you if and in which language the workshops will be held. And we will send you the zoom link to participate in the event.

Program (subject to change)

9:00-9:05 **Welcome**

9:05- 10:00 **Presentations**

- The Swiss Rare Disease Registry (SRDR): Vision and Design
Michaela Fux, Project manager SRDR
- The Patient Organizations' View on SRDR
Alfred Wiesbauer, Vice president Proraris
- The National Coordination Rare Disease, kosek's Perspective on SRDR
Agnes Nienhaus, Executive director kosek
- The Orphanet Nomenclature and ORPHAcodes: The Advantages and Challenges
Martin Arles, Project manager Orphanet
- The Modalities of Data Exchange, Storage and Access
Adrian Spörri, Head of SwissRDL - Medical Registries and Data Linkage
- From Diagnosis to Data Exchange: An Experience Report from Kispi ZH
Kathrin Weber, Clinical study coordinator at Children's hospital Zurich
- The SRDR: Future Perspectives
Claudia Kühni, Co-Project leader SRDR

10:00-10:15 **Coffee Break**

10:15- 11:00 **Workshops** on goals, expectations, and concerns

- **The Data Providers View: From Diagnosis to Data Exchange** (Chair Michaela Fux, Project manager SRDR): What are goals, expectations, and concerns

about the data preparation, and data transfer, the ORPHA coding, and the obtaining of the informed consent from the perspective of the data providers?

- **Patients and Patient Organizations as the Voice of the Concerned** (Chair Alfred Wiesbauer, Vice president Proraris): What are expectations and concerns about the SRDR from the patient's perspective? How can the experiences of the patients and patient organizations contribute to the registry?
- **The Registry as a Platform for Research** (Chair Claudia Kühni, Co-Project leader SRDR): What contribution can the SRDR make to research? What are goals, expectations, and concerns from a research perspective?
- **How Can the Pharmaceutical Industry and the SRDR Interact?** (Chair Matthias Baumgartner, Co-Project leader SRDR): What is the value of the registry for the pharmaceutical industry? What are expectations and concerns from the perspective of the pharmaceutical industry?

11:00-11:25 **Wrap-Up and Questions**

11:25-11:30 **Closing remarks and Farewell**