**Petition**

European Reference Networks (ERNs) for rare diseases covering 24 thematic areas were established in March 2017.

1. **Scope of the ERNs**

In order to review and / or improve a patient’s diagnosis and treatment, healthcare providers / members of an ERN consult, exchange information and share knowledge with other members in their network. Coordinators and other network leaders convene ‘virtual’ advisory boards of medical specialists across different disciplines, using a dedicated IT platform and telemedicine tools.

1. **Treatment of patients with rare or complex diseases**

ERNs are not directly accessible to individual patients. However, with the patients’ consent and in accordance with the rules of their national health system, the patient's case can be referred to the relevant ERN member in their country by their healthcare provider.

1. **Collaboration beyond treatment**

* Development of guidelines, training, and sharing of knowledge;
* facilitation of adequately powered natural history or clinical studies to improve understanding of diseases and to develop treatments such as new drugs or medical devices;
* development of new care models, eHealth solutions and tools.

Unfortunately Swiss Health Providers were unable to participate due to the prevailing political conditions.

Within the Swiss National Concept for Rare Diseases, Swiss Reference Centres for rare diseases are to be officially established. It is therefore absolutely vital that Swiss Centres for Rare Diseases are also able to participate in the European Reference Networks and, concretely, to answer to the next call to be released by the EU in December 2017.

Being part of the European Reference Network will allow Switzerland to uphold and improve the quality of care and also research and avoid duplication of work. Should Switzerland continue to be excluded from these evolving networks, we are greatly concerned that rare disease research in Switzerland will suffer, the attractiveness of Switzerland to researchers, especially research clinicians will suffer, and consequently clinical care for rare disease patients in Switzerland will suffer.

Therefore we call on the Swiss authorities to do all that is in their power to enable Swiss participation in European reference networks. We wish to point out that this is of outmost urgency, since future research calls within Horizon 2020 within the rare disease area will be built on the European Reference Networks.