

Registration of Expert Centres in Orphanet for Switzerland

A – Orphanet eligibility criteria

Orphanet includes **expert centres** dedicated to the medical management and/or genetic counselling for one particular rare disease or to a group of rare diseases:

The expert centres should deliver a service of indisputably higher quality than a standard hospital service in the relevant speciality. As there are no centres officially designated by the Swiss health authorities yet, the centres should fulfill most of the Orphanet eligibility criteria (see the registration form), adapted from the European Union Committee of Experts on Rare Diseases [recommendations](#).

The expertise has to be demonstrated by number of rare diseases patients seen, expert advice/second opinion provided, multidisciplinary facilities, referrals inside the country and from abroad, quality management procedures, collaborations and networking, implication in research and systematic data collection, and grants and publications.

Orphanet also includes **networks of expert centres** that are focused on a rare disease or a group of rare diseases and that are officially recognised as an international or national network of centres of expertise by Health authorities or which receive specific funding from a well established body.

Orphanet **does not register** an expert centre if it is a conventional specialised medical department without specific focus on rare diseases, even if it is a reputed one

B – Required information (mandatory*)

- Name of the expert centre in local language and in English*: *The name should include the disease/group of diseases covered by the centre (e.g. “Specialized clinic for rare epilepsies” or “centre for neuromuscular diseases”)*
- The disease(s) or group of diseases covered by the expert centre*: *you don't need to list all the diseases, the Orphanet Swiss team will send you a proposal based on the Orphanet classification.*
- Indication whether the expert centre is intended for children, adults or both*.
- Indication whether the expert centre is a genetic counselling clinic, a medical management clinic or both*.
- Name and details (email address and phone number, not mandatorily published online), of at least one expert centre coordinator*
- Team members: *a maximum of 3/4 professionals who are directly involved in the clinic.*
- Name and address of the hospital/institution and of the department/service responsible of the expert centre*
- Orphanet eligibility criteria form*
- Website of the expert centre

C - Steps to be followed to register an expert centre in Orphanet

1. Contact the Orphanet Swiss team through contact@orphanet.ch to receive a registration form.
2. Complete the form with the required information listed above.
3. Once the form completed, the Orphanet Swiss team will assess it and, if necessary, will contact you to clarify some data (particularly the list of diseases to be linked based on the Orphanet classification).
4. Once validated by the Swiss team, the form will be assessed by the Orphanet coordinating team.
5. Once validated by the Orphanet coordinating team, the centre will be published in the Orphanet website and you will be informed.

For more information:

- Orphanet procedure "[Data collection and registration of expert centres in Orphanet](#)"
- EUCERD recommendations "[Quality criteria for centres of expertise for rare diseases in members states](#)"