

European Reference Network RARE LIVER Special Interest Group

Terms of Reference (Version 3; March 6, 2019)

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Definition of the group:

The European Reference Network (ERN) RARE LIVER is a special interest group (SIG) at ESPGHAN in which 13 European pediatric liver centers are represented. ESPGHAN members detached from these individual ERN member centers form the steering committee of this ESPGHAN SIG.

ERNs were implemented through an EU initiative to improve care for rare diseases throughout Europe. ERN RARE LIVER is the European Reference Network for rare liver diseases, a Europe-wide network of paediatric and adult hepatologists from expert centres. It's focus is on improvement of clinical management and research of rare liver disease in adults and children with special focus on transitional care for young adults. It presently covers 12 different rare liver disorders, addressing autoimmune liver disease, metabolic, biliary atresia and related liver disease, and structural liver disease. ERN RARE LIVER's vision is to improve access to the health care throughout Europe for all rare liver diseases. It now consists of 28 (+3) expert centers. The network is in close collaboration with a large number of patient organizations and groups, at the moment totaling 37.

Specifically, ERN RARE LIVER aims at the following:

1. Generate clinical guidelines and care pathways with implementation across Europe in collaboration with the European Association for the Study of the Liver (EASL) and the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN).
2. Develop patient registries, bringing together a critical mass of data for the rare liver disease community.
3. Use telemedicine systems for multidisciplinary teams.
4. Develop unique training and knowledge sharing resources for professionals and patients.
5. Driving forward the pace of research, ultimately resulting in novel therapies.

The aims of ERN RARE LIVER are in line with ESPGHAN's mission to promote the health of children with special attention to the gastrointestinal tract, liver and nutritional status, through knowledge creation, the dissemination of science based information, the promotion of best practice in the delivery of care and the provision of high quality education for paediatric gastroenterology, hepatology and nutrition professionals in Europe

Presently, pediatric activity in ERN RARE LIVER focusses on two activities:

1. Improvement of quality of care for children with biliary atresia. Member centers will be asked to register incident cases in a database and update the following quality metrics annually.
2. Implement the telemedicine system CPMS (<https://cpms.ern-net.eu/login/>) to serve as a platform to discuss challenging cases starting in two areas: 1. Vascular malformations of the liver and 2. Neonatal Cholestasis.

Rules and Regulations

1. The Steering Committee of the ERN RARE LIVER-SIG is a board composed of a closed group of delegates from EU certified ERN RARE LIVER pediatric centers. No time limits apply for serving in the Steering Committee. A representative from a patient organization (approved by ERN RARE LIVER) is also member of the steering committee.
2. All ESPGHAN members with a proven interest in pediatric liver disease, confirmed by a short CV and verified by the SIG steering committee, may apply to become a member of the SIG. They are invited to attend open meetings and to propose projects to the steering committee. They can be invited to collaborate in ongoing or new activities led by delegates from ERN RARE LIVER centers. As representatives of their center they may apply for ERN RARE LIVER collegiate membership and thereby become full members of the ERN RARE LIVER-SIG steering committee. New members will be welcomed during the open SIG meeting at the annual ESPGHAN meeting. An updated member's data base (SIG-MDB) will be maintained by the ERN RARE LIVER-SIG secretary.
3. The steering committee is chaired by the ERN RARE LIVER pediatrics coordinator who is appointed by the ERN RARE LIVER board of pediatric representatives together with the ERN RARE LIVER management board. The ERN RARE LIVER *pediatrics* coordinator represents ERN RARE LIVER in the ESPGHAN council and the Hepatology Committee and reports on activities and activities linked to the (ESPGHAN funded) budget. The ERN RARE LIVER- SIG's chair and secretary term lasts three years with the option of a one-time renewal defining the maximum term at six years. The positions of the SIG's chair and the ERN RARE LIVER pediatrics coordinator may be held by different individuals.
4. A member of the steering group will take over the following secretarial responsibilities in SIG administration:
 - a. Day to day management of the SIG
 - b. Maintenance of updated Members data base
 - c. Updated registry of the SIG activities and publications
 - d. Regular updating (at least once a year) of the SIG area on the ESPGHAN website (members section)
5. Budget: an annual budget will be allocated by the Hepatology Committee to the ERN RARE LIVER SIG upon presenting an annual action plan.
6. At least one closed annual meeting will be held where ongoing activities are reviewed. This can eventually be scheduled during the ESPGHAN Annual meeting. Active core members will be asked to participate.
7. One open meeting of the ERN RARE LIVER-SIG during ESPGHAN Annual Meeting for all ESPGHAN members with an interest will be offered.
8. Additional ad hoc meetings can be scheduled according to needs and work development for specific activities such as guidelines or position papers. Sufficient ESPGHAN funding for ERN RARE LIVER SIG provided, attending costs of delegates will be partially covered.

9. On-line meetings and Teleconferences will be held to promote and facilitate ERN RARE LIVER SIG initiatives
10. All members of the ERN RARE LIVER SIG will be informed 3 monthly by a newsletter authored by ERN RARE LIVER delegates of adult and pediatric liver centers or other ERN members (e.g., patient representatives)
11. A brief annual report concerning financial issues (related to ESPGHAN funds), registry and research activities is to be published under the responsibility of the ERN RARE LIVER pediatric coordinator in the ERN RARE LIVER SIG section of the ESPGHAN member's website.
12. These terms of reference will be published in the ERN RARE LIVER SIG section of the ESPGHAN member's website. Proposals to modify these terms of references are discussed on an annual basis during the SIG steering group meetings. Modified versions will be forwarded to the Hepatology Committee and council of ESPGHAN for approval.