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June 2023



European
Reference
Networks



NEWSLETTER

Welcome to our next newsletter!

ERN RARE-LIVER
goes

Join our presentations:
Wednesday 8:30 - 10:00
at the Patient & Advocate Forum
Thursday at the Track Hub
exact time see program

See you in Vienna!
Visit us at our ERN RARE-LIVER booth PO 4

Dear ERN RARE-LIVER community,
Summer has arrived and we already had some very exciting workshops and meetings all across Europe in the previous months, we enjoyed again the pleasures of in person meetings and discussed new projects at scientific

dinners. Another important meeting lies ahead of us: the EASL in Vienna where we will meet for our get-together for members and partners of ERN RARE-LIVER on the evening of 22 June 2023.

We want to thank all our members for their support of our evaluation, monitoring and the new grant which was turned-in a couple of days ago. This year EASL offers a **Patient & Advocate Forum** on Wednesday 21 June in which we will participate. Our fellow Ida Schregel from Hamburg will talk about how we as ERN RARE-LIVER can improve the care of patients with rare liver diseases in Europe. On Thursday 23 June you can meet us at the **Track Hub**, please find the exact time in the scientific program of EASL. During the entire congress you can also find us at our **booth PO 4 in the industry section**.

The ERN RARE-LIVER Hamburg team is looking forward to exciting lectures, lively discussions and interesting talks about our Europe-wide network. If you have last minute questions, please don't hesitate to contact us.

For everyone who is unable to join EASL Congress, you will find a summary and pictures in our next newsletter as well as the slides of plenum sessions on the ERN website.

The ERN RARE-LIVER Hamburg team is looking forward to meeting you in Vienna.

[Email us if you have any comments or questions](#)

Report on the 5-year-evaluation

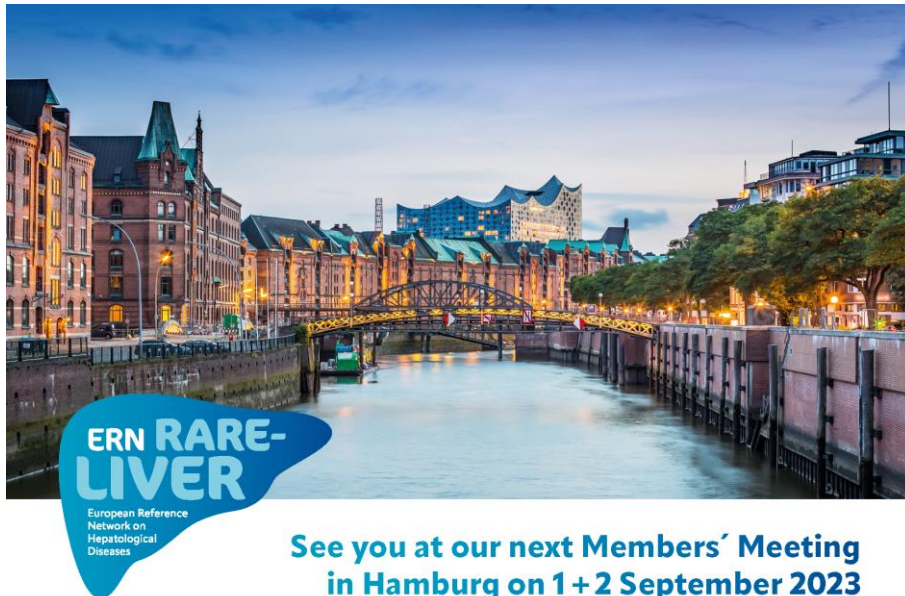


The network is delighted to announce receiving an excellent feedback in the 5-year-evaluation for its exceptional engagement in multiple ERN-related activities.

One of the most remarkable goals achieved is the high utilisation of CPMS activities which allowed all members to consult and exchange recommendations of care for a number of patients from different countries. Other outstanding achievements included the training of specialized nurses and the interchange of training fellows among centres, contribution to several

scientific publications and also the implemented communication and dissemination activities to improve patient knowledge and involvement.

Next Members' Meeting in September



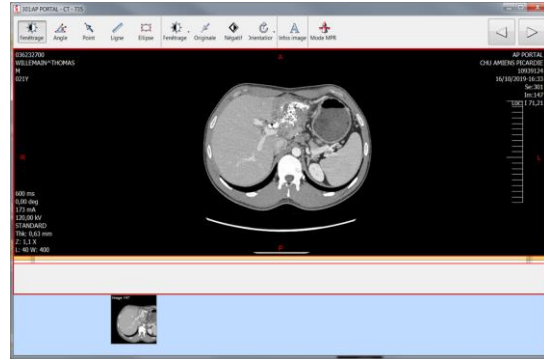
Please send us your nominations for the next **ERN RARE-LIVER Fellow Award** until the 31 July 2023. The winner will be announced at the Members' Meeting in September.

Please note that we will submit all relevant information on behalf of our Members' Meeting on our website soon.

ERN RARE-LIVER Scientific News

New Hepatic Alveolar Echinococcosis Working Group

After the foundation of the Swiss Echinococcosis Network in 2020 by Solange Bresson-Hadni and François Chappuis, Anja Lachenmayer and Annalisa Berzigotti are happy to have the opportunity to expand the disease profile of ERN RARE-LIVER and to build a “Hepatic Alveolar Echinococcosis” Working Group.



[Find the new working group](#)

ERN RARE-LIVER Scientific Publications

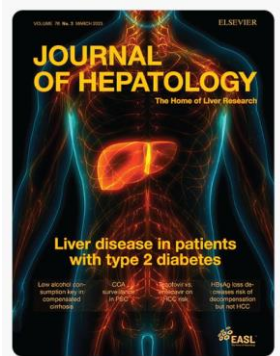
Aetiology and outcome of adult and paediatric acute liver failure in Europe

Via an online survey Dominic Lenz and many co-authors reached out to different European Reference Network Centres on rare liver diseases. Numbers and aetiology of ALF cases during 2020 were retrieved, diagnostic and treatment availabilities assessed. In total, 455 cases (306 adult, 149 paediatric) were reported from 36 centres in 20 countries.



[Link to Publication](#)

Paediatric Autoimmune Hepatitis: Time to change the textbooks?



New editorial by Ansgar Lohse (Hamburg) and Marianne Hørby Jørgensen (Copenhagen) published in the JOURNAL OF HEPATOLOGY referring to a French study on long-term outcomes of patients with type 1 or 2 autoimmune hepatitis presenting in childhood.

[Link to Publication](#)

Primary Budd-Chiari Syndrome

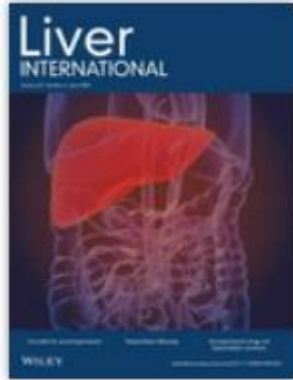
Congratulations to Juan-Carlos Garcia-Pagán and Dominique-Charles Valla from ERN RARE-LIVER Centres in Barcelona and Paris to their great review article on Primary Budd-Chiari Syndrome in the NEW ENGLAND JOURNAL of MEDICINE.



The NEW ENGLAND
JOURNAL of MEDICINE

[Link to Publication](#)

Results of the international autoimmune hepatitis group research workshop 2022



This review from different authors within various ERN RARE-LIVER Centres summarises the results of the latest workshop in Maastricht in 2022 and reviews the current challenges in adult AIH, particularly in relation to four important aspects of AIH: diagnostics; new immunomodulatory therapies; clinical trial design; and unmet clinical needs.

[Link to Publication](#)

Statement for ERN RARE-LIVER publications

We are happy to state that members and working groups of ERN RARE-LIVER are becoming more and more active, also causing an increasing number of surveys. While this is a very positive trend, there is an increasing need to motivate people to participate. To do this and to harmonize the way we deal with publications that come out of the scientific surveys, we would like to ask you to please include in your scientific surveys a statement with the main aim of the survey.

The statement below will let people know what they gain from participating: **If data are published, the paper will have the authorship of the core group, who will write the paper, and as final author the name of the (group) lead of the ERN RARE-LIVER, and all individual contributors will then be listed as part of this group or included in the acknowledgements.** Please always remember: Publications can only be counted as ERN RARE-LIVER publications when the following three criteria are fulfilled: Main authors come from at least two centres from at least two member states and the ERN RARE-LIVER is acknowledged.

If you have any interesting scientific news, we would be glad to share it in our next newsletter.

[Contact us](#)

LATEST SURVEYS

Controversies in the management of paediatric acute liver failure (PALF)

To those of you who have not responded to our survey on “Controversies in the management of paediatric acute liver failure (PALF)” — we have decided to **extend the deadline until 30 June**. We will be very happy to receive as many responders as possible. Akash Deep and Pierre Tissieres on behalf of Liver Failure Working Group- ESPNIC and Dominic Lenz and Marianne Hørby Jørgensen on behalf of ERN RARE-LIVER.



[Survey](#)

NEWS & EVENTS

Introducing our new Patient Representatives



ERN RARE-LIVER is happy to have **AIDA Regi Coscolluela**, from Mataró, Spain as a new Patient Representative on board our Wilson's disease working group. She was diagnosed with Wilson's disease with neurological symptoms at the age of 13 and now has 25 years of experience living with Wilson's disease. Aida is a Board member of the Spanish association of patients with Wilson's disease and their relatives.

[Read more](#)

Carmen Teemer from Engstingen in Germany is our second new Patient Representative. Working as a speech therapist, she is familiar with anatomy, medical terms and diseases that lead to speech and swallowing disorders. Carmen has been diagnosed with ADPKD and PLD in 2018 and since then helps other patients to get along with their diseases. **Welcome to our PLD working group.**



[Read more](#)



Sophie Hullin, from Paris, France works as an associate research professor in Mathematics for a cancer research institute in the United States and for a French university. Her research focuses on stochastic modelling in life science and more recently in oncology. Sophie is a Member of the patient's association AMVF (Association des Malades des Vaisseaux du Foie) since 2008 and a Member of the "EASL Clinical Practice Guidelines on Vascular diseases of the liver" Delphi panel, since 2019. ERN RARE-LIVER is very grateful for your support and welcomes you in our **Vascular Liver Disease working group**.

First Youth Panel established by ERN RARE-LIVER

On the joint Workshop Transition of Care from ERN RARE-LIVER and EJP RD in Ghent, Belgium paediatricians, hepatologists, nurses, patient advocats and 15 adolescents discussed possible improvements for transition of young patients. This is supposed to be the beginning of an impressive initiative.



[Read more](#)

Workshop on Liver Transplant for Inborn Errors of Metabolism



Thanks to all of our ERN RARE-LIVER members for the successful **Cross ERN Workshop on Liver Transplant for Inborn Errors of Metabolism** held in Coimbra, Portugal.

It was organised by ERN RARE-LIVER and financially supported by EJP RD. A wide range of topics was addressed, such as the current status quo, disease burden and timely decisions, medical and surgical care optimisation, quality of life and many more. Many participants reported fruitful discussions, interesting talks and excellent presentations. Special thanks go to Isabel Goncalves for her commitment and the organisation of this workshop.

[Find program](#)

**PLD Working Group Meeting
on June 6 in Nijmegen, the Netherlands**



The polycystic liver disease (PLD) working group met on June 6 in Nijmegen, the Netherlands. During the program physicians, researchers and patient representatives discussed the most recent PLD guidelines, the disease's impact on health-related quality of life (HRQoL) and the current management options with their limitations.

In addition, hybrid online discussion sessions were organized in which unmet clinical needs from the patients' perspective were discussed, new research ideas were presented and action points for the PLD workgroup were formulated.

The primary action point is to create structured 'care pathways' for PLD patients at first health care presentation. This will contribute to uniform PLD care across Europe and improves patient information.

[See program](#)

1st International Workshop on Future Therapies in Autoimmune Hepatitis

On 1 and 2 June this workshop brought together 30 international experts from 10 different nations and highlighted the role of ERN RARE-LIVER as a collaborative network and registry platform for rare diseases such as autoimmune hepatitis (AIH).

Thanks to the financial support of the Landesforschungsförderung Hamburg scientists, clinicians, biostatisticians, patient



representatives and regulatory authorities discussed how to design future clinical trials for AIH and thereby to improve its treatment. In addition to a focussed working group meeting to concretize the results, there are plans to establish the format as a permanent part of the AIH research community within the ERN.

[Read more](#)

Young Investigator Workshop on Basic Science and Translational immunology in PSC



At the Young Investigator Workshop on Basic Science and Translational immunology in PSC on 25 to 26 May in Hamburg, young researchers fruitfully discussed the latest cutting-edge research and ideas at a joint meeting with the international PSC study group.

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