
NEWSLETTER

February 2023



European
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Welcome to our next newsletter

**Dear ERN RARE-LIVER
community,
members and friends,**

dear

Today is Rare Disease Day! We take this for an occasion to inform you about the latest activities within our ERN RARE-LIVER community.

We would like to draw your attention on the new Survey HCC immunotherapy in AILD and invite you to contribute cases.

Our PBC working group developed a new patient-friendly PBC leaflet, which is online now. And we want to remind you to submit data for the whole year 2022 for our yearly monitoring.

There is a lot to do for all of us.

But we are happy to help you - just let us know.

Your ERN RARE-LIVER team in Hamburg.

[Contact ERN office](#)

SCIENTIFIC NEWS



Survey HCC immunotherapy in AILD

Immuno-oncology (IO) in patients with autoimmune liver disease

The safety of immuno-oncological therapies for patients with autoimmune liver disease has not been adequately studied. To demonstrate the safety of these revolutionary therapies for our patients, we are conducting a retrospective multi-centre study.

We would invite you to contribute cases of patients with autoimmune liver disease (AILD) who received checkpoint inhibitor therapies.

Even if you have not yet treated AILD patients with such agents, please provide this information in our online survey.



[Find more information](#)

GENERAL NEWS & EVENTS

New PBC patient leaflet online



Thanks to the tireless efforts of the PBC working group we now have an new PBC patient leaflet online. Through the participation of Adriaan van der Meer (ERASMUS UMC, Netherlands), Alessio Gerussi (Azienda Sanitaria Socio Assistenziale (ASST)-Monza, Ospedale San Gerardo, Italy), Frederik Nevens (University Hospital KULeuven, Belgium) and our patient representative Angela Leburgue from Paris this cooperation is a successful example of the excellent work across different borders.

[Download PBC Leaflet](#)

Reminder!

Yearly Monitoring of ERN activities is coming up

It is time again for the yearly data collection for the European Commission, called Monitoring. All Full Members and Affiliated Partners are required to hand in their data for the whole year of 2022. Our new Full Members that joined in 2022 will participate for the first time. Please fill in the attached form and send it back to us until **12 March 2023** at the latest.

You may notice that we are not asking you for publications this time. This is because we will filter for publications on our side and can therefore save your time for this point. Should you have a publication that was published at the end of 2022 and has not yet appeared on PubMed, please send us the reference, so that we can complete our list.

Please be so kind as to pre-filter your activities according to the criteria given in the form before handing in.

We would like to ask all centres to participate in this data collection exercise. The continuation of the ERNs is dependent on their development, so we need to monitor the activity of our members regularly.

Should there be any questions, please feel free to contact us.

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