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To all Participants of the ESID Registry
and all those interested

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Newsletter ESID Registry December 2025

Dear Colleagues and Friends of the ESID Registry,

A few notes before everyone hurries away to family, friends, and hopefully ski slopes (or beaches?):

- In a few days from now you should notice upon login that the ESID registry has been set to „Live“, which means that really all migration work has been completed. It does not mean that there will not be any more amendments to be made in the future, but it does mean that we succeeded to implement most of what we had (and more features) in the new technical environment!
- A few **sub-studies** have already been launched, and more are to follow soon. Many of those will only be visible if certain criteria are met (e.g., the diagnosis FHL for the HLH Registry, etc.). Please note that **there are two new sub-studies** launching for the use of biologicals and for the disputed term "pediatric CVID“, see our [studies website](#) for more information also on many more approved studies still in preparation.
- Some centers (<80 of our >200 participating centers) will have received a notification from ERN-RITA about the **RITA registry**. Please be aware that the RITA registry was created purely as health care-focused basic one-time patient record, not to be confused with a longitudinal disease-specific data collection serving as platform for clinical studies like the ESID registry. Some people may get the impression it is redundant and unintentionally competes with the ESID registry (at least for documentation work time and patient consent), which I duly hope it will never be. Our 30 years report (*Kindle and Alligon et al. JHI 2025*; <https://doi.org/10.70962/jhi.20250007>) and success of many ESID registry-based publications speak for themselves. A plan for semiautomated data forwarding of common data elements from the ESID registry to the RITA registry (not the other way) is being developed, as it is possible with the ESID patient consent if point 1 is checked and data are double pseudonymized.
- With January 1st, the **new center report** should automatically appear in your Castor export box, a great interactive figure of all your most relevant data (an html file; which does not work on mobile operating systems, unfortunately) for your information and local use.

In that sense, let us use and improve the ESID registry further in 2026!

Happy holidays to all of you!

Best,

Markus Seidel

Previous Newsletters: if missed, please see: <https://esid.org/working-parties/registry-working-party/news-events/>