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To all Participants of the ESID Registry
and all those interested

Graz, February 6th, 2026

Newsletter ESID Registry January 2026

Dear Colleagues and Friends of the ESID Registry,

We would like to share several important reminders and updates regarding ongoing ESID Registry activities.

1. Reminder: ADA SCID Study - Data Completion Deadline (15 February)

We kindly remind all of you who have patients diagnosed with ADA-SCID to participate in the study currently open “Evaluation of immune reconstitution of patients with adenosine deaminase deficiency treated with enzyme replacement therapy - a joint ESID-IEWP study.” Once the relevant diagnosis is entered, the ADA SCID study forms become visible on the platform and you can complete the information directly there. Please add the required patient information ultimately **by 15 February**.

We also remind you to review and consider participation in the other ongoing studies, including:

- [HSCT indications and outcome of HSCT for Ras-Associated Autoimmune Leukoproliferative Disorder \(RALD\) - a joint ESID/EBMT IEWP study](#)
- [STAT6GOF - Clinical Cohort Study](#)

as well as the remaining studies listed on the [ESID Registry studies page](#).

2. Update on Cross Platform Collaboration with the ERN RITA Registry

We are currently in close communication with both the platform provider and ERN RITA to identify the optimal solution for semi-automated data forwarding of common data elements from the ESID Registry to the RITA Registry (one-way transfer only). The idea is the ESID Registry to remain the primary data entry platform, with the possibility to transfer relevant data to the RITA Registry with just a few mouse clicks and without the need for additional patient consent. Work on this solution is ongoing, and we will provide a further update in the coming months.

3. Update on the Quarterly Center Report in Castor

In our previous newsletter, we informed you that as of 1 January, the new center report, an interactive overview of your most relevant center data, would automatically appear in your Castor export box. There was a one-week delay in its delivery; however, we hope that by now everyone has received the report and had the opportunity to review it. The center report will continue to be generated and sent on a quarterly basis.

Thank you for your continued engagement and contributions to the ESID Registry. Should you have any questions, please do let us know.

With kind regards,
Prof. Markus Seidel

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