

APDS Registry

an ESID Registry level 3 project



NEWSLETTER No. 3

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The ESID-APDS Registry:

Prospective observational study on natural history, treatment and outcome of patients with APDS

Dear colleagues and friends,

At the beginning of 2021 we would like to give you a short update on the activities in the APDS Registry. First of all, we say “thank you” to all of you for your continuous support since 2015. Meanwhile 40 study sites have contributed to the project and – in contrast to the announcement in the Newsletter 2019- the registry is still open for new patients thanks to the support of a further industry partner for the APDS registry: **Pharming Technologies**. This extended funding allows on the one hand the maintenance of the APDS specific online documentation section and the project management and on the other hand further reimbursement for the centers’ documentation efforts.

Here is where we stand:

There are:

- 175 patients documented with APDS1/2 mutation in the ESID registry, level 1
- 130 patients registered in the APDS registry, level 3
- 100 patients with level 3 baseline documentation (39 without GDPR-conform consent)
- 68 patients with at least 1 follow-up documented

The next goals of the registry are:

- to register all patients of level 1 also in level 3 (here the link how to include a patient: <https://esid.org/Working-Parties/Registry-Working-Party/Studies/APDS-Registry>)
- to document all patients registered in level 3, not only at baseline but also with yearly follow-ups (here the link to document your patients: <https://cci-esid-reg.uniklinik-freiburg.de/EERS/login/auth>)
- to make sure that all patients are consented according to the new General Data Protection Regulation (GDPR) (here the link to find the valid consent version: <https://esid.org/Working-Parties/Registry-Working-Party/Informed-Patient-Consent>)
If no action is taken (new consent or information on GDPR rights and documentation of this in the registry), the existing data have to be deleted by the end of February 2021.
- to publish an update of the entire cohort by the end of 2021 (goal: >120 completed baseline level 3 documentations)
- to support APDS-related scientific projects such as:
 - International retrospective study of allogeneic hematopoietic cell transplantation for activated PI3K delta syndrome (led by Mary Slatter, Jennifer Kanakry, Dimana Dimitrova, Zohreh Nademi): manuscript submitted.
 - APDS and growth disorders (led by Peter Olbrich and Olaf Neth): project ongoing.

We rely on your support to achieve these goals!

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Case payment

In March 2021 we will pay out the next batch of case payment. Only completely documented visits will be paid. Another motivation for filling in as much data as possible!

Do you want to register a new patient or need help regarding an already registered one?

Contact us:

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