

Chair of ESID Registry Working Party – Job Description

The ESID Registry Working Party is responsible for the maintenance and further development of the ESID registry.

The aim of the ESID Registry is to build a common data pool and estimate the disease burden of primary immunodeficiencies (PID) in Europe and to provide an internet-based database for clinical and research data on patients with PID. This database is a platform for epidemiological analyses and can also serve as a tool relevant for the development of new diagnostic and therapeutic strategies or the identification of novel disease-associated genes. Most national registries and documenting centers share their data with the ESID registry, thus providing an important backbone for this common European effort.

Main tasks and commitments:

- **Chair the Working Group**
The ESID Registry team is guided by a Registry Steering Committee currently composed of 5 elected national representatives and the IPOPI chairperson. This group helps decide about technical (thus supporting the local ESID Registry team located in Freiburg, Germany) and conceptual changes in the database, evaluates study proposals using Registry data, and is involved in fund raising.
- **Work closely with the ESID Registry team in Freiburg**
Continuously updates the disease entities, current datasets and develops new clinical criteria for documentation and new datasets, while keeping the interface user-friendly and easy to fill.
- **Further develop the ESID registry**
Maintain and expand the activities of the Registry. Coordinate efforts with other registry entities within ERN RITA and the ESID Genetics and Clinical WPs, as well as international collaborators.
- **Update the ESID website sections and subsections**
- **Stimulate development of new projects**
- **Explore and co-ordinate potential sources of funding**
It is of primary importance to raise funds for the basic operations of the registry.
- **Attend the ESID Board meetings to update the Board**
- **Contribute to the ESID Newsletter**