



General task description of the ESID Working Party (WP) Chair

- To act as an ESID Ambassador
- To oversee the WP Steering Group
- To design WP activities workplan, strategy, task development and execution and present these at board meetings and general assembly
- To work closely with the other ESID's WPs' Chairs and the President, Secretary and Treasurer
- To contribute to the mission of ESID through activities, ideas and innovation
- To attend the monthly Board meetings
- To contribute to ESID's quarterly newsletter content
- To liaise and collaborate with the ESID Executive Director
- To respond in a timely manner to Board/Society emails
- To ensure an efficient and complete transition for incoming WP Chairs

Job Description of the ESID Registry Working Party (WP) Chair

The ESID Registry WP is responsible for the maintenance and further development and promotion 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 online database for clinical and research data on patients with PIDs. 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 centres share their data with the ESID registry, thus providing an important backbone for this common European effort.

Main tasks and commitments:

- Elect and chair the Working Group (also known as the Steering Committee or SC).
- The ESID Registry team is guided by a Registry Steering Committee currently composed of 5 elected national representatives and the IPOPI chairperson. This group supports decisions regarding technical matters (thus supporting the local ESID Registry team located in Freiburg, Germany), conceptual changes in the database, evaluation of study proposals using Registry data, and is involved in fund raising. The Chair appoints the SC ensuring that it has balanced representation of countries, specialties, gender, and selects elected members from applications received via a public call. The Chair and SC review all research proposals and coordinates WP/SC responses, assesses study proposal' feasibility, and estimates potential scientific weaknesses and strengths. The Chair also ensures that the patient organisation (PO) representative takes the final decision should a proposal be deemed by the PO to be actually or potentially irrelevant, questionable, or unethical. The Chair supports assessments of costs regarding whether significant ESID/ outside funding may be needed to execute studies (together with the Registry Team and secretary).



- 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, assess potential additional fields that may be needed to ensure reliable data collection and remain responsive to current needs (e.g. pandemics, product errors)
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 relevant to the Registry WP.
- Stimulate development of new projects, aid running of studies and oversee that studies result in eventual publications.
- Explore and co-ordinate potential sources of funding, it is of primary importance to raise funds for the basic operations of the registry.
- Oversee, monitor and liaise with the ESID DPO and the GDPR implementation.
- Updates of publication rules, as needed.
- Arrange Registry sessions in biannual meetings.
- Aid in drafting and revising various patient consents, publication rules, documenting centre approvals and contracts and facilitate GDPR compliant approval processes (with Registry Team and DPO).
- In all matters needing further discussion and approval, alert the Board/President/Treasurer/Secretary, as appropriate.