

Driving Questions:

1. What is the prevalence of PID in different countries?
2. Which percentage of PID patients comes from consanguineous families?
3. Which percentage of PID patients has affected family members?
4. Does the patient's sex have an impact on the kind of first symptoms or on the onset of symptoms?
5. What is the distribution of PID among different subcategories?
6. Which individual genetic diagnoses predominate among the various subcategories in different countries?
7. Is the rate of neonatal diagnosis increasing over time?
8. Does the time lag between first symptoms and clinical or genetic diagnosis decrease over time?
9. What are the most frequent presenting symptoms of PID?
10. Is the rate of patients diagnosed in the absence of symptoms increasing over time?
11. What percentage of patients in the different subcategories undergoes stem cell transplantation (SCT) or gene therapy and how does this change over time?

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Plans for publication

Peer-reviewed publication on registry development and status every 2-3 years.

Source

<https://esid.org/Working-Parties/Registry>