

# Links to medical information on PID

## [www.ipopi.org](http://www.ipopi.org)

IPOPI was formed following a meeting between Bob LeBien from the US and Dr Helen Chapel from the UK in a London hotel in 1988. In 1990 a meeting in Oxford, UK, of the then existing national patient organisations representing people with primary immunodeficiencies, decided that an international organisation could well benefit people with primary immunodeficiencies around the world. At that time, not so long ago, there were thirteen organisations. Since then, through meetings in Switzerland, Spain, Sweden, Greece, Germany, France, Hungary and The Netherlands, the number of member organisations has more than doubled.

Everything that IPOPI does is driven by its Strategic Plan. This plan is based on solid research with all stakeholders – national member organisations, clinicians, nursing staff, industry, regulators and funders, and is revised on a regular basis.

## [www.primaryimmune.org](http://www.primaryimmune.org)

The Immune Deficiency Foundation (IDF) is the national (USA) non-profit health organization dedicated to improving the diagnosis and treatment of primary immune deficiency diseases through research and education. IDF is governed by a Board of Trustees, has an active Medical Advisory Committee comprised of prominent clinical immunologists, a nationwide volunteer support network, and a dedicated professional staff.

## [www.kinderimmunologie.de](http://www.kinderimmunologie.de)

The Working Group Pediatric Immunology (API) consists of doctors and scientists from Germany, Austria and Switzerland. They are all occupied with research and treatment of PIDs in children and young adults.

This website serves as an information-page for patients and their families and general practitioners (GPs) and is directed towards the German speaking audience.

(Language in the website is German)

Die API ist eine Arbeitsgemeinschaft von Ärzten und Wissenschaftlern aus Deutschland, Österreich und der Schweiz, die sich mit der Erkennung, Erforschung und Behandlung von Erkrankungen des Immunsystems bei Kindern und Jugendlichen beschäftigen.

Diese Homepage soll betroffenen Patienten und ihren Familien sowie interessierten Ärzten als Orientierung dienen, um sich über immunologische Erkrankungen und die Versorgungsmöglichkeiten im deutschen Sprachraum zu informieren.

## [www.esid.org](http://www.esid.org)

The European Society for Immunodeficiencies (ESID) is a non-profit organization having multiple aims. The main objectives are to facilitate the exchange of ideas and information among doctors, nurses, biomedical investigators, patients and their families concerned with primary immunodeficiency diseases and also to promote research on causes, mechanisms and treatment of these disorders. Recently ESID has initiated an educational program.

## [pin.info4pi.org](http://pin.info4pi.org)

Primary Immunodeficiency Network constitutes a physician platform serving investigators,

researchers, and other healthcare providers.

The patient platform will be for patients, family members and patient organizations.

Each platform is independent and protected, but both platforms will serve as a central resource to exchange ideas, provide updates, disseminate information on PI, and bring you breaking news.

There is also considerable information made available for the general public. Specifically, the platforms include:

- A message board to facilitate communication
- Disease specific survey results from JMF Centers worldwide
- Therapeutic protocols and best practices
- Latest developments in Newborn Screening
- Upcoming symposia and meetings
- Registries link
- Listings of specialized Referral and Diagnostic Centers and identification of disease-specific specialists worldwide
- Information on funding support and grant opportunities
- And Much More...

The sole mission of PIN is to serve both the physician and patient communities with an interactive platform, dedicated to research initiatives, innovative protocols, improved diagnosis, treatment, and quality of care. Patients will talk to Patients, and Physicians will talk to Physicians.

[www.xlpresearchtrust.org](http://www.xlpresearchtrust.org)

Aside from fundraising to support medical research, the charity also has two other key functions:

- To raise awareness of X-linked Lymphoproliferative Syndrom (XLP) amongst the medical and general public, and
- To act as a point of contact or a “hub” for families affected by XLP worldwide