VISION To be a proactive, supportive and nurturing patient organization, and to be a strong network of Filipino families and patients affected with primary immunodeficiencies.

MISSION To promote the welfare and quality of life of patients with primary immunodeficiencies.

GOALS

- To provide a strong and effective public awareness and education campaign about primary immunodeficiencies.
- To advocate and protect the rights of patients with primary immunodeficiencies, through policy formulation, government recognition and increase access to affordable medical care and treatment.

In 2017 the Philippine Patient Organization for Primary Immunodeficiencies (PhilPOPI) was established as a national member organization of the International Patient Organization for Primary Immunodeficiencies (IPOPI), with the Philippine Society of Allergy, Asthma and Immunology (PSAAI) as expert advisor. The organization is an associate member of the Philippine Society for Orphan Disorder Inc. (PSOD).

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Philippine Patient Organization for Primary Immunodeficiencies

Expert Advisory Group

PRIMARY IMMUNODEFICIENCY DISEASES (PID) are hereditary and genetic defects in the immune system that cause increased susceptibility to a wide range of infections. A PID often presents itself in the form of ordinary infection, which does not respond to treatment. Too often, physicians treat the infection, with repeated prescription of antibiotics, while missing the underlying cause, allowing the illness to recur, and leaving the patient vulnerable to vital organ damage, physical disability, and even death. Early diagnosis and access to appropriate treatment enable people living with PID to lead normal productive lives whilst significantly reducing healthcare expenditure. Lack of awareness of PID remains a major issue, and due to this problem, majority of patients are diagnosed too late. Unlike other rare disorders, there are many effective treatment options for PID patients, which would enable them to carry out a normal life.

PID FACTS

- PID affect at least 10 million people worldwide.
- There are currently 200 identified PID conditions.
- PID can affect anyone, regardless of age and sex.
- PID vary in severity depending on whether one or several parts of the immune system are affected.
- Current diagnosis levels suggest that around 1 in 8-10,000 people have a genetic primary immunodeficiency that significantly affects their health.
- It is estimated that 70–80% of PID remain undiagnosed globally.
- A simple and relatively inexpensive blood test, complete blood count (CBC), can identify over 95% of PID patients.

SYMPTOMS

- increased susceptibility to recurrent and persistent infections; these vary in severity, from ear and sinus infections to lung infections, meningitis and septicemia, amongst others
- patients may have abscess of the internal organs, such as liver, or infections of the blood; there are certain infections caused by germs that only afflict patients, therefore, the type of infection itself may serve as a red flag for PID
- patients may also present a variety of autoimmune or rheumatologic problems
- gastrointestinal (digestive) problems may also occur; in some cases it can be the result of an infection of the intestines, while in others it may be a reflection of an autoimmune or rheumatic disorder

Ten warning signs

1. *eight or more new ear infections within 1 year*
2. *two or more serious sinus infections within 1 year*
3. *two or more months on antibiotics with little effect*
4. *two or more pneumonias within 1 year*
5. *failure of an infant to gain weight or grow normally*
6. *recurrent, deep skin or organ abscesses*
7. *persistent thrush in mouth or elsewhere on skin, after age 1*
8. *need for intravenous antibiotics to clear infections*
9. *two or more deep-seated infections*
10. *family history of primary immunodeficiency*

DIAGNOSIS

The first step in diagnosing PID is a good evaluation. Pediatricians and immune system specialists (immunologists) can help with diagnosis and treatment.

Evaluation of the immune system

- ***physical exam***
- *blood tests*
- *vaccines to test the immune response*

If PID is suspected, a series of blood tests and vaccines may be required. Blood tests will show if any part of the immune system is missing or not working properly.

TREATMENT

At a minimum, the recurring infection can be treated with low or moderate doses of appropriate antibiotics. In at least 60% of cases, antibody deficiency is present, hence, requiring intravenous (recently subcutaneous) immunoglobulin. This has led the World Health Organization to include IVIg in the list of essential medicines. These can help prevent permanent organ damage, thus promoting the patient's long-term survival while improving the quality of life. Bone marrow transplantation and gene therapy are also used for more severe disorders. Advanced treatments such as the interleukins, PEG-ADA, and gamma interferon can also help in some complex cases.

Is nutrition important? *Good nutrition gives the body the energy and the resources to fight infections. Eating well always makes good sense,*

Is it possible to lead a normal life? *Thanks to new therapies, greater public awareness, and better access to information, many people with PID are leading normal lives - going to school, work, playing sports, and enjoying a better quality of life. There has never been more hope for people with PID.*