

Primary Immunodeficiency Disease (PID)

occurs in people born with an **immune system** that is either absent or hampered in its ability to function

Whilst not contagious,

these diseases are caused by hereditary or genetic defects and can affect anyone.

PID causes children and adults to have

infections

that come back frequently or are unusually hard to cure.

The consequences of not considering the diagnosis can be severe.

People with a Primary Immunodeficiency Disease (PID) live their entire lives being more susceptible to infections, enduring recurrent health problems and often developing serious and debilitating illnesses. Fortunately, with proper medical care,

many patients live full and independent lives.

If you or your child is affected by illnesses that are Severe, Persistent, Unusual or Recurrent, speak to your doctor about the possible presence of a Primary Immunodeficiency.

REMEMBER THE WARNING SIGNS

Serious **P**ersistent **U**nusual **R**ecurrent



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Contact our secretary on pinsahelp@mweb.co.za for further information, alternatively go to the website on <http://www.pinsa.org.za>

What is PiNSA?

The Primary Immunodeficiency Network of South Africa (PiNSA) is a Non-Profit Organisation (NPO) for people in South Africa dealing with Primary Immunodeficiencies (PID).

PiNSA exists to fulfil the following objectives:

1. Provide support to patients, including adults, and their families
2. Provide information to patients, their families and the medical fraternity including nurses and doctors
3. Advocate for awareness to ensure early diagnosis and timely treatment
4. Lobby key stakeholders in government and industry in order that PIDs are formally recognised and appropriate treatment is made available
5. Ensure sustainability of the association through strong governance and a fundraising programme

What is Primary Immunodeficiency Disease?

Primary Immunodeficiency Disease refers to a group of over two hundred genetic disorders affecting the immune system. Many of the disorders result from a single gene defect that affects one or more components of the immune system. These can lead to a greatly increased susceptibility to recurrent and persistent infections.

An undiagnosed or misdiagnosed primary immunodeficiency can lead to illness, disability, permanent organ damage or even death. Most disorders can appear at any age and are chronic but, with early diagnosis and adequate treatment, the majority of affected people live a near normal life style.

PID is not HIV/AIDS. As an inherited condition, i.e. passed down from one or both parents, it is not infectious. Although both types of disorders affect the immune system, HIV/AIDS is acquired. As PID symptoms can present themselves as a common infection, many patients with a PID often go undiagnosed.

How is PID diagnosed?

Many primary Immunodeficiencies can be diagnosed with a simple and inexpensive blood test, but some need more specific investigation. Warning signs of PID are infections which are serious, persistent, unusual and recurrent. Early diagnosis of PID can mean a reduction in costly hospital stays and with appropriate treatment, improved quality of life.

What treatment is there for PID?

At present there is no cure for PID and the only hope of a normal infection controlled life is an infusion, either by intravenous (in the vein) or by sub-cutaneous (under the skin), of safe, fractionated blood products, alongside high and constant doses of antibiotics. Fortunately, with proper medical care, many patients live full and independent lives.

How will people know about PID?

Doctors and nurses both in training and in practice, need to be made aware of the existence of PID through a strong advocacy programme. Similarly the general public should be made aware of PID especially as diagnosis can be easily missed. Finally, key stakeholders in government and medical aids need to be aware of PID, in order to ensure required financial and medical support. An example is that PID is on the list of Chronic Diseases and the treatment protocol included on the list of essential medicines, as is the case with the World Health Organisation.

The World Day of Immunology is on the 29th April, and is an internationally recognised day. PiNSA is keen to increase awareness across Sub-Saharan Africa and more importantly South Africa, and will thus be celebrating this day each year. Posters, flyers, press releases, television, radio and print media (e.g. newspapers and magazines) will all be used to bring about awareness.

What support is there?

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