

A Simple Matter of Life

The importance of the early diagnosis of Primary Immunodeficiency also known as Inborn Errors of Immunity (IEI's)



Inborn Errors of Immunity, also known as Primary Immunodeficiency, is a genetic condition affecting the efficiency of the immune system

Over 480 different PID's have been identified ranging from the very rare SCID (Severe Compromised Immunodeficiency Disease) to relatively common selectively IGA deficiency

Overview

- Background
- Challenges
- PiNSA
- Way forward

Background

- 62 million people (Stats SA 2022)
- 11 official languages
- 29 years of democracy
- 9 provinces
- 2.5 million taxpayers pay 84% of personal income tax (2022/2023 financial year)
- Private healthcare versus state healthcare
- Estimated at ? undiagnosed patients

Constitution of South Africa

The Constitution of South Africa (1996) says the following about Human Rights

27.1 Everyone has the right to have access to healthcare services

28.1 Every child has the right to basic nutrition, shelter, basic healthcare services and social services

Challenges

- Socio-economic
- Language
- Connectivity
- Exchange rate
- UNDER DIAGNOSIS



1% of PID patients in South Africa have been diagnosed and are receiving some sort of treatment or support



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

If you want to know more about PINSA and how we can help you, please e-mail info@pinsa.org.za or visit our website <https://www.pinsa.org.za>

P / N S A
PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA



To ensure that people with Primary Immunodeficiency in South Africa receive optimal treatment and support

History of PiNSA

- Constituted in 2001
- Registered Non Profit Organisation (NPO)
- 14 patients diagnosed
- Voluntary group parents and patients
- Committee: Chair, Vice Chair, Treasurer and Secretary
- Medical Advisory Panel (MAP)

Strategic objectives

- Patient support
- Medical Advisory Panel (MAP)
- Advocacy and awareness
- Training
- Lobbying

Website

[Home](#) [Member Home](#) [About Us](#) [Contact Us](#) [Log Out](#)



[Make a Donation](#)

PRIMARY IMMUNODEFICIENCY

Members Portal

[Healthcare Professionals](#)

[What is PID](#)

[Living with PID](#)

[Our Stories](#)

[Conferences and Events](#)

[PID Kids and Teens](#)



Dear PiNSA members, this site is for you, welcome!



Members Information:

[Members Home](#)

[Healthcare Professionals](#)

[What is Primary
Immunodeficiency](#)

[Living with Primary
Immunodeficiency](#)

[Our Stories](#)

[Conferences and Events](#)

[PID Kids and Teens](#)



World PI Week

TEST • DIAGNOSE • TREAT

#WorldPIWeek

22 - 29 April 2023



info@pinsa.org.za



PiNSA strongly recommends that necessary measures be taken at national level to ensure PID patients can have continuous and equal access to the widest range possible of safe and effective IG therapies. Prescribing physicians should always have the flexibility to choose the most appropriate therapy for their patients.



You are welcome to contact us at info@pinsa.org.za