

# Primary Immunodeficiency in South Africa: Challenges & Opportunities, a Patient Perspective

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PiNSA Chair



# Welcome to Sun City!



**Welcome**

# PiNSA: Some History

- \* Constituted in 2001 with seed funding from IPOPI
- \* Existed mainly as a patient support group for many years (volunteer based, limited capacity)
- \* Over the years has had funding support from the Jeffrey Modell Foundation, the Binding Site, Tristar, NBI and the IDF
- \* 2002 – 2014: Joy Rosario was elected to the IPOPI Board; Very important for PiNSA & PID medical community in South Africa



# PiNSA: Some History

- \* 2008: IPOPI 3-city tour of South Africa
  - \* Advocacy for PiNSA, PID awareness
  - \* Opportunity for IPOPI to experience the challenges of a developing country
- \* In 2009: Started publishing newsletter
- \* In 2001: 14 PID patients diagnosed
- \* In 2013: More than 200 Patients diagnosed

# PiNSA Achievements

- \* Constitution
- \* Strategic Objectives
  - \* Advocacy
  - \* Patient support
  - \* Lobbying
  - \* Medical Information
  - \* Fundraising
- \* Organisational Guidelines
- \* Website
- \* Toolkit of documents



# PiNSA: Achievements

## 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

**S**erious  
**P**ersistent  
**U**nusual  
**R**ecurrent



Contact our secretary on [pinsa.help@mweb.co.za](mailto:pinsa.help@mweb.co.za) for further information, alternatively go to the website on <http://www.pinsa.org.za>

- \* SPUR posters/flyers
- \* Newsletter
- \* Membership database





# PiNSA: Achievements

## Active FUNdraising in the Western Cape:



NEW

# PiNSA: Achievements

Afrikaans

## Our Immune System

A story for children with primary immunodeficiency diseases



Written by  
Sara LeBien

## Ukhuseleko Lwethu Ekosulelweni Zizifo

Ibali elilungiselelwe abantwana abanezifo ezikwisigaba sokuqala sokusilela kukhuseleko lokosuleleka zizifo ezosulelayo



Libhalwe ngu  
Sara LeBien

## Ons Immuunstelsel

'n Storie vir kinders met primêre immuungebreksiektes



## Ukuvikeleka Kwethu Ekusulelekeni Ngezifo

Matshana yezingane ezikwisigaba sokuqala eleki ekusulelekeni ngezifo ezithelalanayo



Zulu

Xhosa



# Challenges

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**"This is a major project of utmost importance, but it has no budget, no guidelines, no support staff, and it's due in 15 minutes. At last, here's your chance to really impress everyone!"**

# Challenges

- \* The need for local guidelines for diagnosis and treatment of primary Immunodeficiencies
- \* PID to be placed on the Chronic Disease List (CDL) so that it will be a defined prescribed Minimum Benefit (PMB) condition
- \* Immunoglobulin Therapy to be added to the Essential Drugs list (EDL)
- \* Access to SCIG in SA limited (no local product registered for this)

# Challenges

- \* Limited local donor pools: limited production of local IVIG product
- \* Funding
- \* PiNSA a volunteer organisation – limited capacity
- \* Want to move towards a viable business model
- \* PiNSA Secretary now pro-bono – a BIG thank you to Mariana!!

# Challenges



- \* Social media – an opportunity as well as a challenge
- \* Providing emotional support to patients and families without giving medical advice
- \* Refer to our Medical Advisory Panel doctors

"I know nothing about the subject,  
but I'm happy to give you my expert opinion."

# Challenges – Health Care Systems

- \* SA essentially 2 health care systems
  - \* PRIVATE
  - \* PUBLIC

Each has unique challenges for patients



# Challenges: Private Sector patients



**COSTS!!**

# Challenges: Private Sector patients

- \* Medical aids: poor administration, poor understanding of Medical Scheme rules, poor communication, delays in processing claims, denying funding for immunoglobulins  
= FRUSTRATION!!
- \* Many different schemes with different policies and rules – difficult for PiNSA to strategise to assist
- \* Doctors: too few PID specialists, underdiagnosis, lack of referral network

# Challenges: Public Sector patients

- \* Connecting with the patients in the public sector
- \* Limited treatment available, red tape!
- \* Due to cost of treatment, it can only be approved by certain approved specialists, or by a committee at the hospital
- \* Treatment delays
- \* Poor communication with patients
- \* Limited isolation facilities, poor hygiene
- \* Being relevant to these patients too!

# Opportunities for growth

- \* Growth in:
  - \* Influence
  - \* Effectiveness
  - \* Numbers



# Growth in Influence

- \* ASID Conference – increased awareness among medical practitioners of PID and the role of PiNSA
- \* PHANGO - Patient Health Alliance of Non Governmental Organisations
- \* IAPO – International Alliance of Patients' Organisations





# Growth In Effectiveness

- \* 5 Objectives:
  - \* Advocacy
  - \* Patient support
  - \* Lobbying
  - \* Medical Information
  - \* Fundraising

# Growth in active members

- \* More active members will lead to growth of the organisation and increase in reach

