



- Our Vision
- Background of PiNSA
- Challenges
- Relationships
- Support
- Working with Rare Diseases Group
- Communication Tools

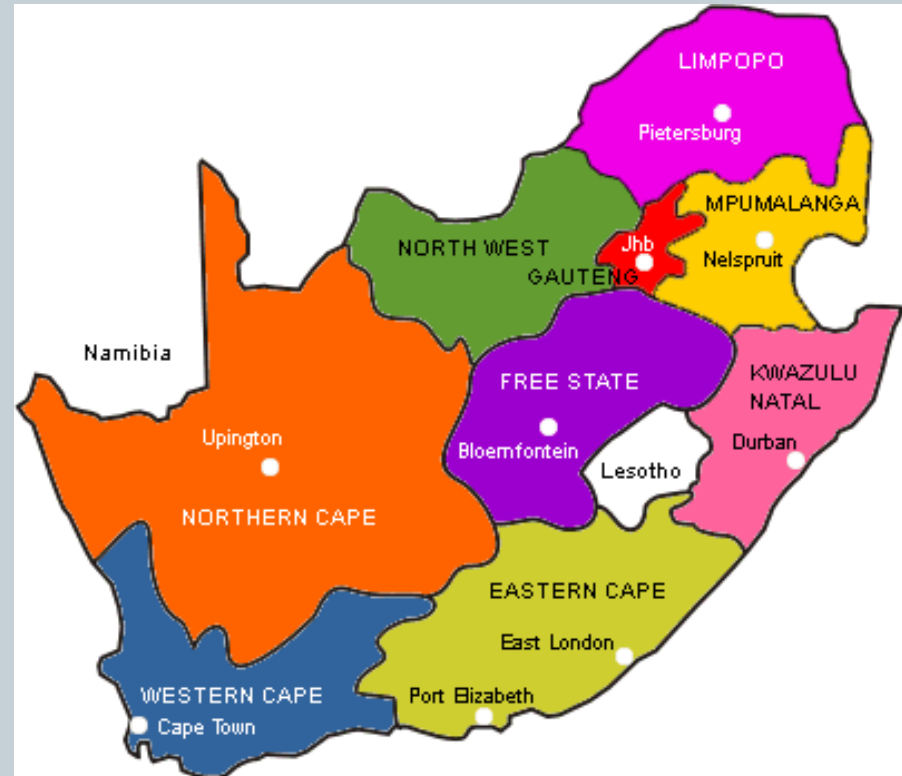


PiNSA was established with help from the International Patient Organisation for Primary Immunodeficiencies (IPOPI)

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

- 57 million people (approx 350 on registry, 130 on Support Group PiNSA)
- 80% were diagnosed before age of 10
- PiNSA tend to have a growing group of teenagers now after 16 years, young adults
- 11 official languages
- 9 provinces
- +/- 4000 undiagnosed patients

- Distance
- Terrain
- Language
- Health system
- Regulatory Authorities
- Exchange rate
- Under-diagnosis

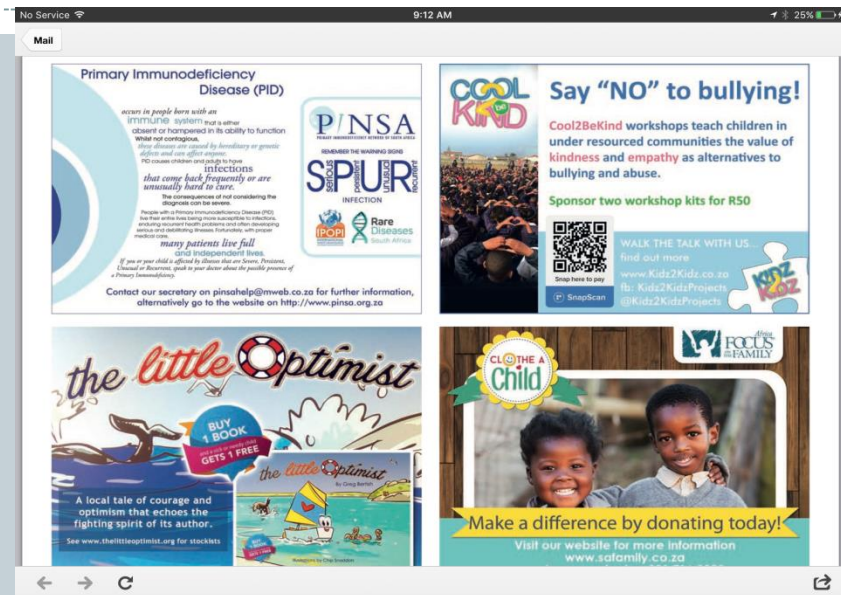


- Medical Advisory Panel with 3 professors each in a different field:
  - Immunology – Prof Jonny Peter
  - Pulmonology – Prof Andre Van Niekerk
  - Rheumatology – Prof Monika Esser
- International Patients Organisation for PID (IPOPI)
- International Nurses Group for Immunodeficiencies (INGID)
- Immune Deficiency Foundation (IDF)
- Rare Diseases South Africa (RDSA)
- Medical Aid Schemes
- Product manufacturers
- Plasma Protein Therapy Association (PPTA)
- International Plasma Fractionation Association (IPFA)

- Telephonic support
- e-Mail support
- Flyers and newsletters
- Regional meetings
- International conferences
- Patient Advocacy



Annie Pienaar – ASID 2019



Advertisement in ChildMag 2018

RareX 2018

# Collaborate with Support Groups

22q11.2 Deletion Syndrome Foundation South Africa / DiGeorge Syndrome  
Rare Diseases Foundation – Zimbabwe  
Rare Diseases Foundation – Lesotho  
Rare Diseases Foundation – Uganda  
Rare Diseases - South Africa  
Rare Diseases Foundation – Botswana  
Haemophilia Foundation - Namibia

The PASSION that the Rare Diseases Groups in Africa shows gives me hope for PID in Africa. We just need passionate doctors that can assist our groups to grow. They are young, vibrant and create awareness everywhere they go.



# Working with a Rare Diseases group

9

- Collaboration
- Share information
- Continuous interaction
- Share congress/conference ideas
- Collaborate in stakeholders meetings/Rare Days



[About Us »](#)[What are PID's »](#)[Make a Donation](#)[Contact Us](#)

Search For

[SEARCH](#)

## WHERE TO FIND HELP

[COMMUNICATIONS](#)[RESOURCE LIBRARY](#)[PATIENT STORIES](#)[PID KIDS & TEENS](#)[USEFUL LINKS](#)[PARTNERS](#)

# Conclusion

## Remember:

There are always someone with more knowledge than yourself  
Be humble and prepare to learn every day from others

Every organisation must have a back up plan  
Anything can happen and you need people you can rely on.

Know that you will make mistakes: That's part of life  
Acknowledge and carry on with the good work

The more you talk about PID – the more you will know about PID