



PID in Africa: challenges & opportunities - Physician perspective



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OUTLINE of challenges

Many **Other Health issues** in (South) Africa

Lack/Other **distribution** of Available resources

Obstacles **Implementation**

Opportunities

The Right to PID care

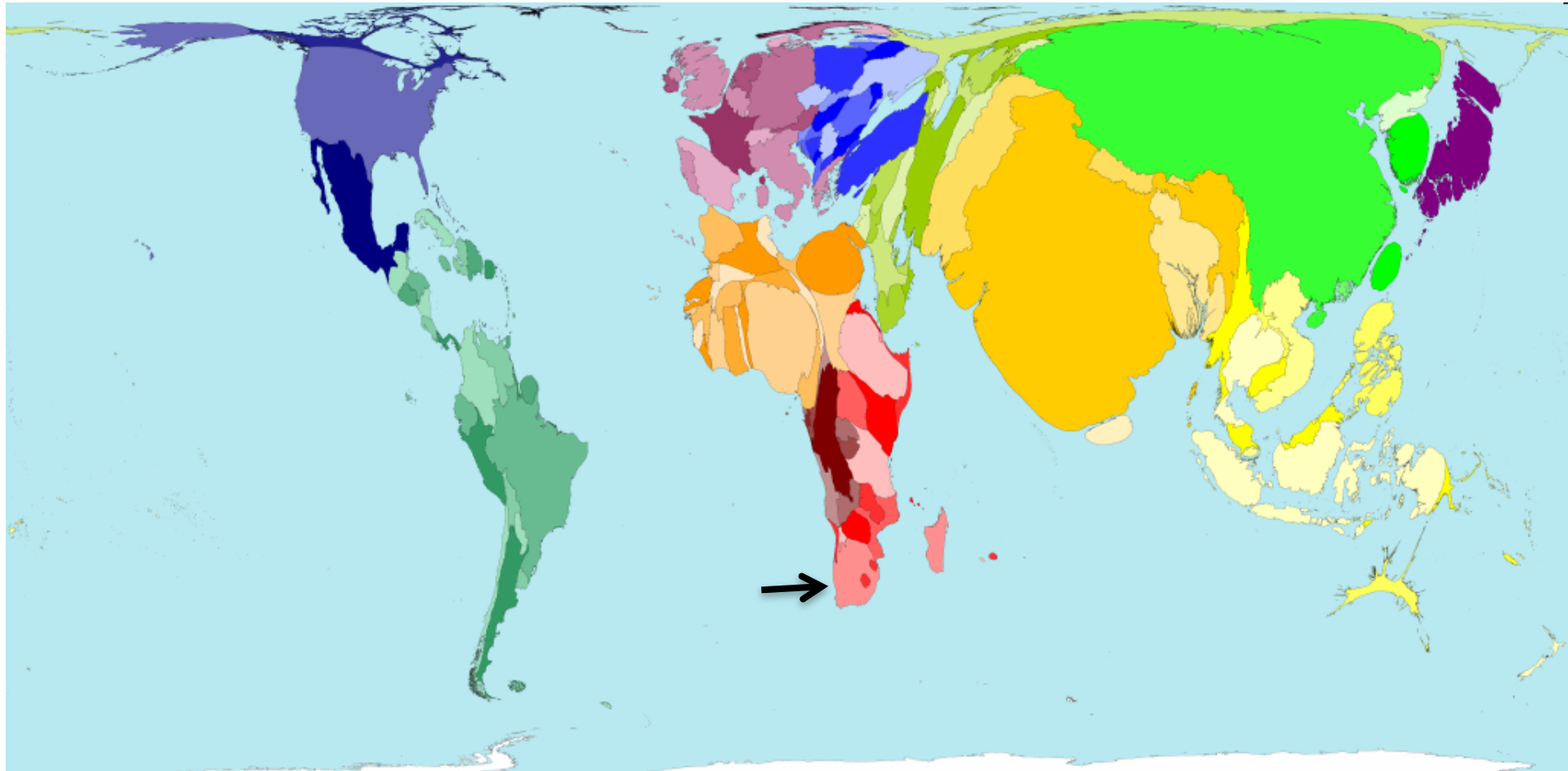


Other Health Issues and other...



- Malaria
- Tb
- HIV

Global population distribution

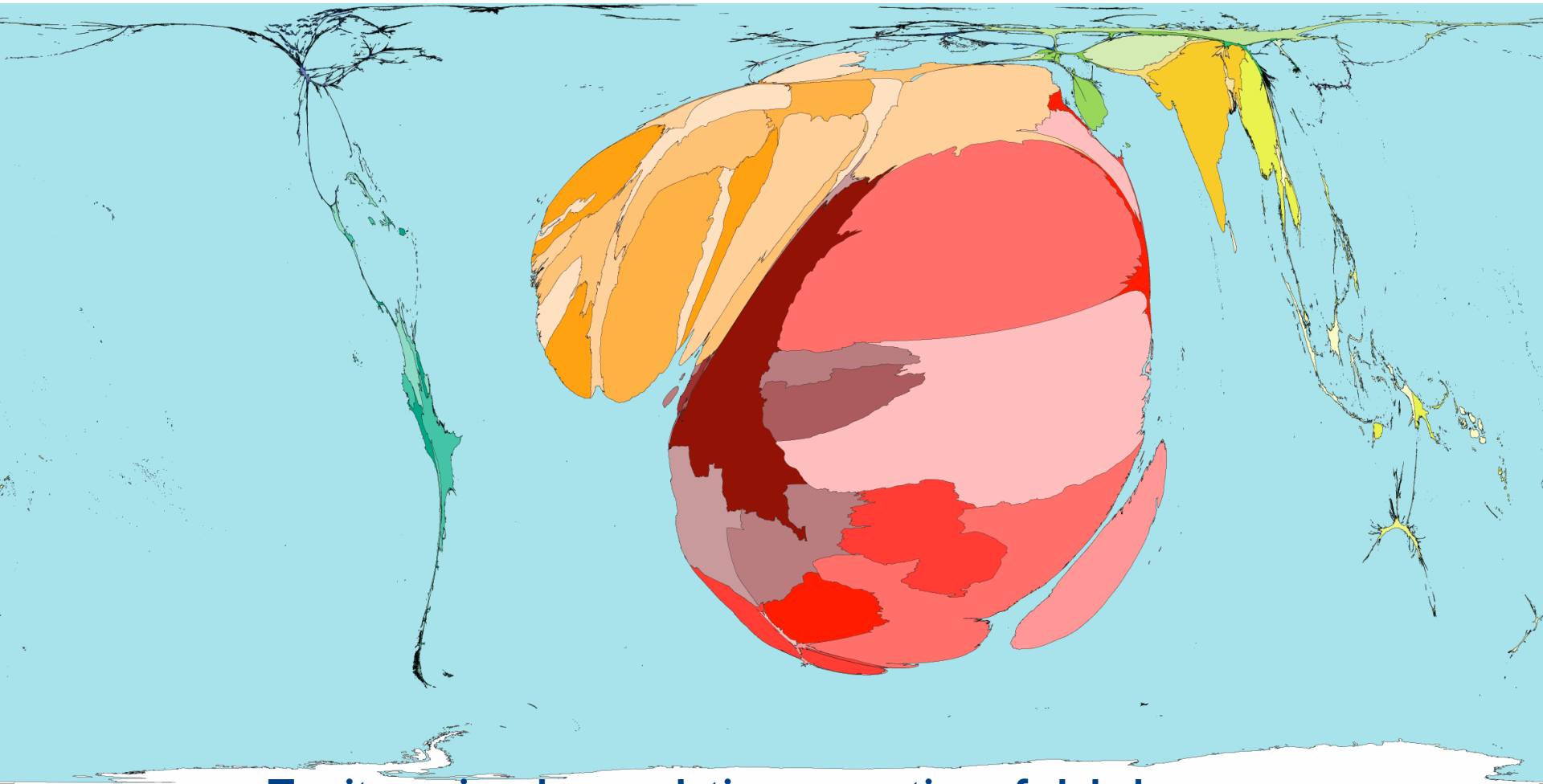


**Territory size shows relative proportion
of the world's population living there**

Source: www.worldmapper.org



Malaria — the biggest cause of death for African children <5yrs

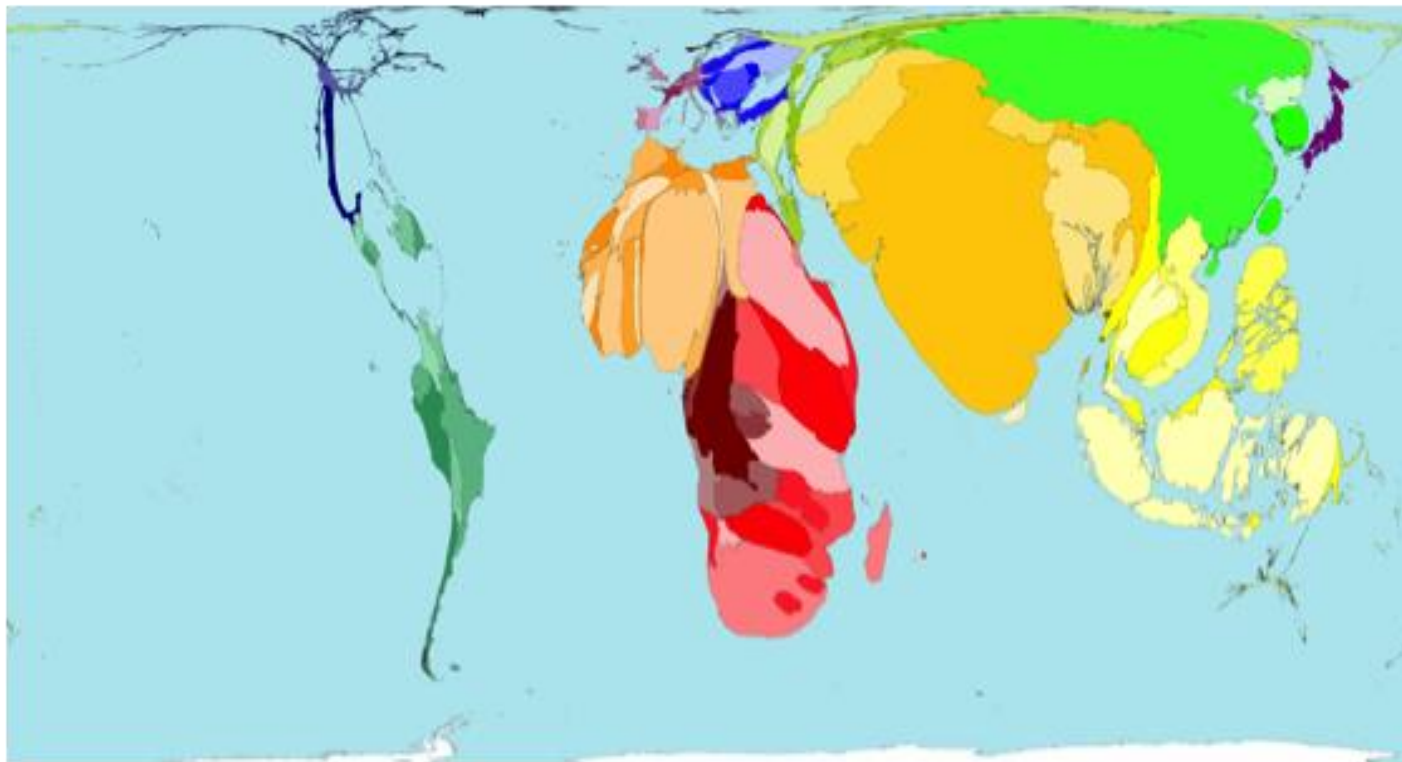


**Territory size shows relative proportion of global
Malaria-infected population (aged 15–49 yrs) living there.
92% of malaria cases are living in Africa, 72 million new cases in 2003**

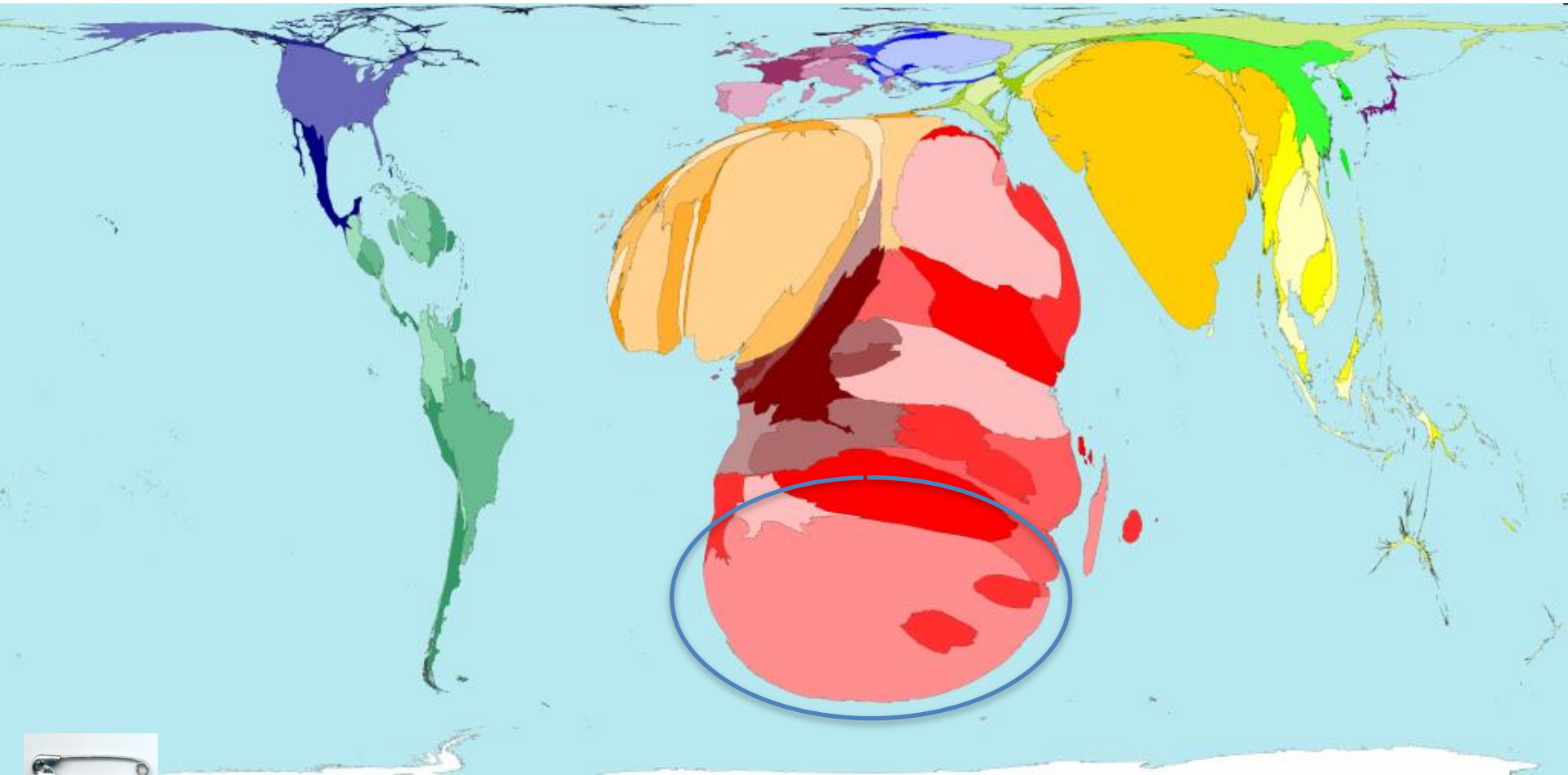
TB

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Global distribution of HIV



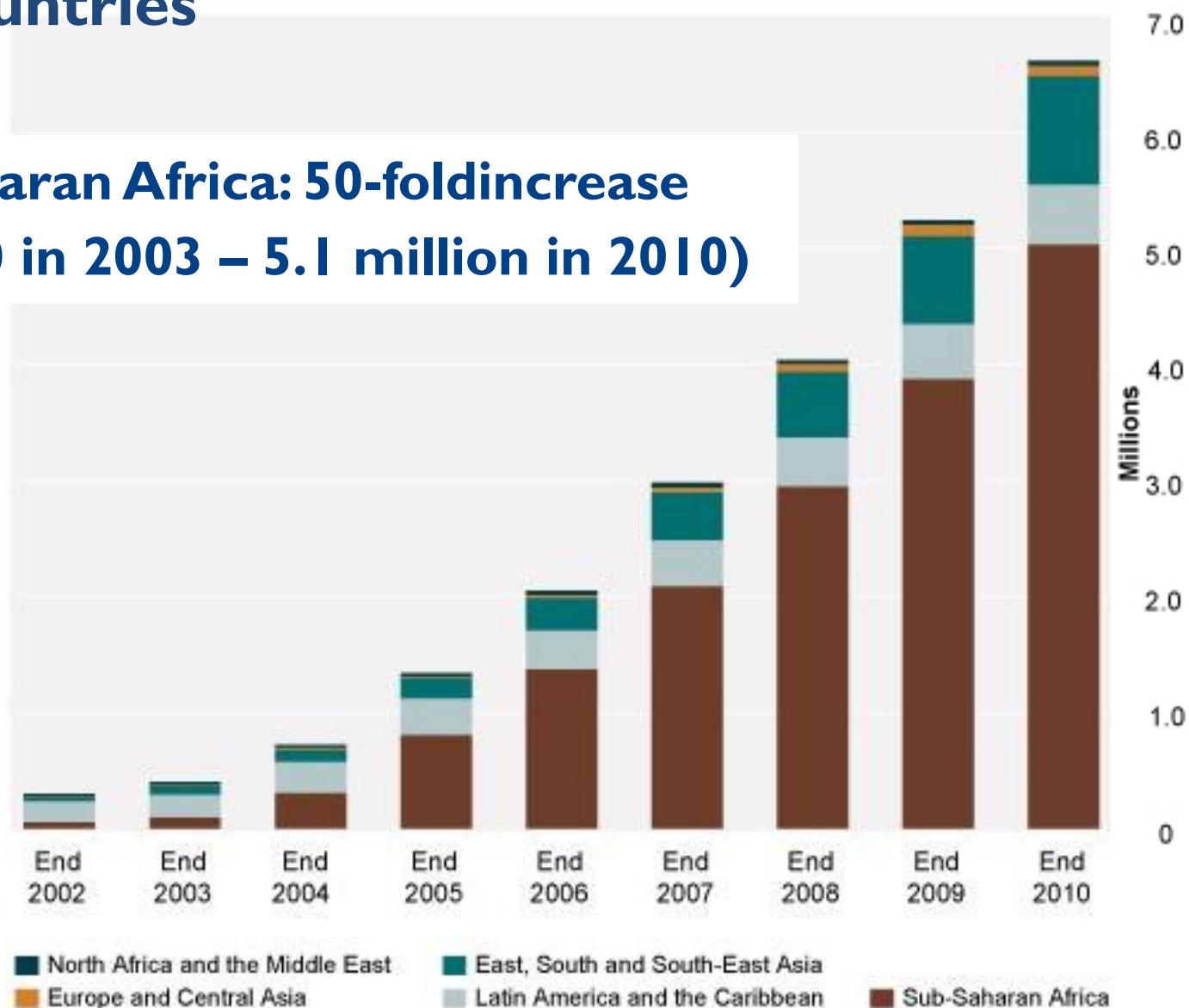
Territory size shows relative proportion of global HIV-infected population (aged 15–49 yrs) living there

Source: www.worldmapper.org



Patients on ART in low- and middle-income countries

**Sub-Saharan Africa: 50-fold increase
(100,000 in 2003 – 5.1 million in 2010)**



Primary immunodeficiency diseases worldwide

[Bousfiha AA, Jeddane L, Ailal F, Benhsaien I, Mahlaoui N, Casanova JL, Abel L.](#)

[J Clin Immunol. 2013 Jan;33\(1\):1-7. doi: 10.1007/s10875-012-9751-7. Epub 2012 Jul 31](#)

Africa : 902,63 I PID



Faculty of Health Sciences,
University of Stellenbosch



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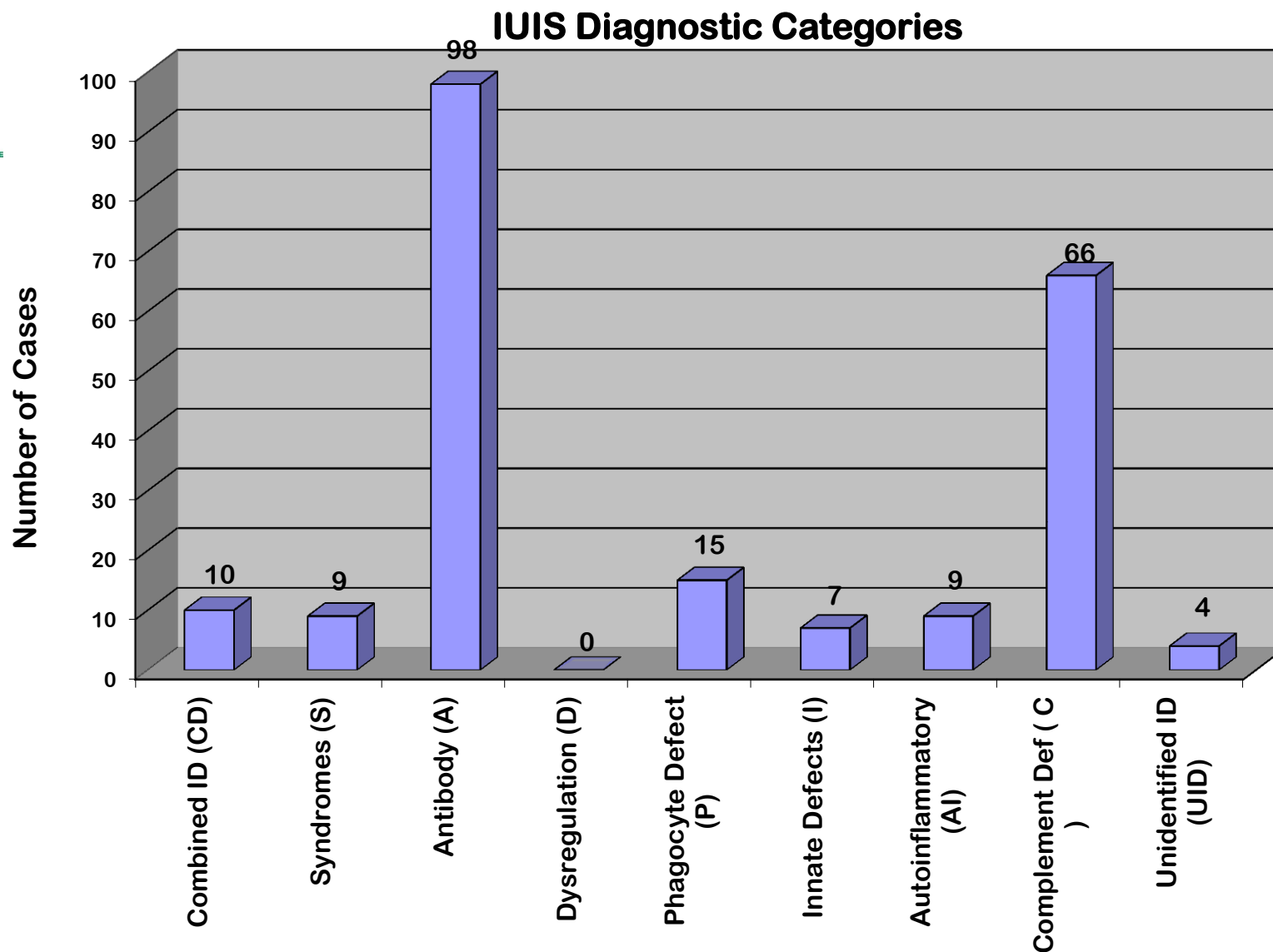
South African Data

Universities of Stellenbosch, Cape Town and Witwatersrand



NATIONAL HEALTH
LABORATORY SERVICE





Lack of resources not always.....

- True lack of resources - ??
- Misallocation – arms budget, administration
- Fraud, theft, lack of accountability
- Lack of training
- Lack of appropriate training
- Avoidance/Lack of awareness – the SA HIV pandemic example

RURAL African Realities of access to care - Bush Ambulances



**ISSUES ON ACCESS
TO TREATMENT &
CARE (J Emmanuel)**



Bicycling Empowerment Network
Namibia (BENN) to help get people
to medical aid before it is too late.

Obstacles - Implementation

The Right to PID Care and implementation issues

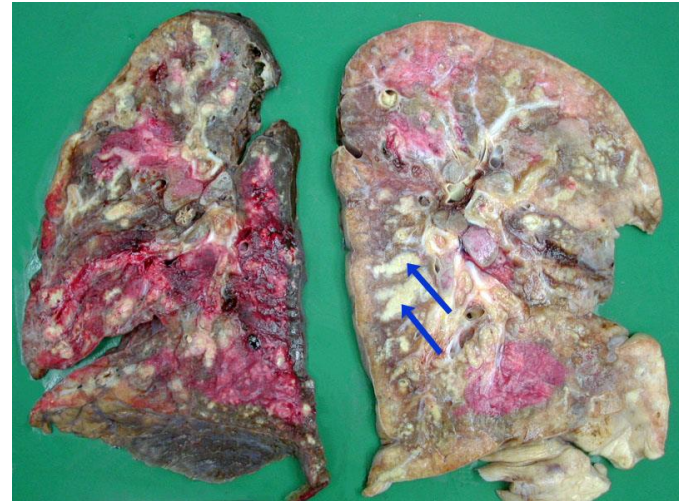
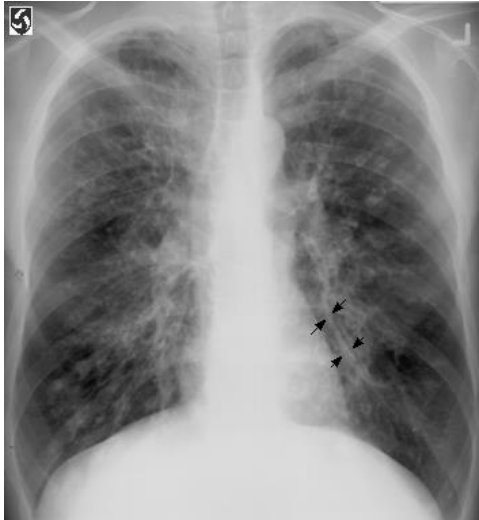
Case 1

- 21 year old girl with Hypogammaglobulinaemia on IVIG since age 13, financial difficulty – comes off Medical Aid, struggles for months to access Ig **treatment** in **SA** public health sector –
- **Reasons :**
- Resistance to patient “Dumping” from private to state sector
- Lack of knowledge of condition by attending physician despite referral
- Budget constraints of provincial hospitals for “non” PMB medication

Case 2

- 21 year old XLA referred by his family to PI clinic for review. On IMI/IVIG since age 4 years. Subsequent to transfer from specialized Paediatric to general adult care at provincial hospital , developed growth failure, bronchiectasis, renal and hepatic failure. Dies 3 years later despite optimized Ig therapy and multiple admissions for infections.
- **Reasons :**
- Failure of transitioning
- Lack of dedicated follow up
- Social issues

Bronchiectasis complication



Case 3

- 6 month old infant in Intensive Care diagnosed with SCID at provincial hospital in the Western Cape – cannot access BMT because sibling is not matched and subsequently dies.
- **Reasons :**
- Late Diagnosis : already has BCG dissemination
- Resource limitations at academic hospitals for BMT and to accept patient (competition)
- Lack of funding module for BMT in PID

GLOBAL including AFRICAN
ACTION

OPPORTUNITIES

Organization

2008 :ASID Founded

2012 :ASID **Call for ACTION**





Collaboration

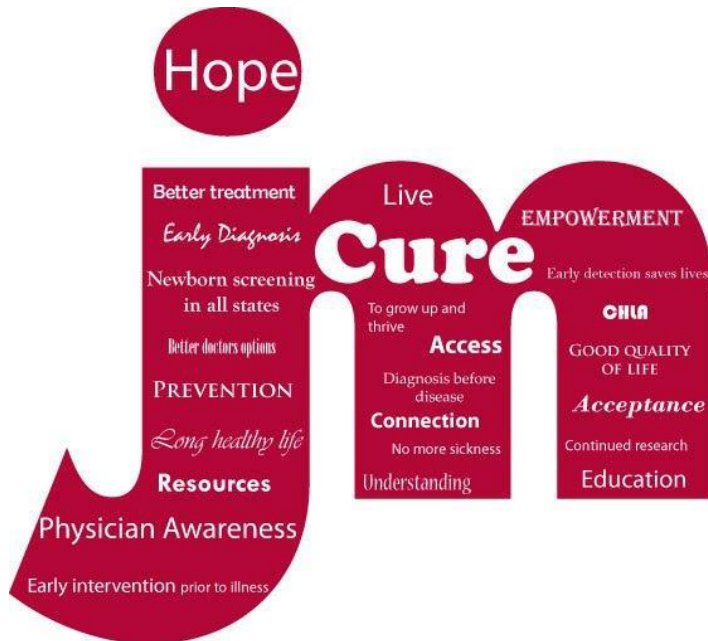
- Angola
- **Botswana**
- Burkina Faso
- Burundi
- Cameroon
- Congo/DRC
- Ethiopia
- **Ghana**
- **Kenya**
- **Nigeria**
- **Malawi**
- Mozambique
- **Namibia**
- **Rwanda**
- **Tanzania**
- **Uganda**
- **Zambia**
- **Zimbabwe**



Primary Immunodeficiencies (PI) – Call to Action - Driving Diagnosis for Optimal Care

- **Appropriate awareness raising for Primary Immunodeficiencies (PI):**
 - ☐ Encourage and support governments to implement targeted campaigns to increase recognition of PI amongst the medical profession, parents, schools, researchers and nurses, with the objective to increase understanding of the disease, knowledge of the '10 Warning Signs', SPUR and available testing methods and treatments.
- **Foster Education of Health Professionals:**
 - ☐ Work together with medical specialist's organizations, such as ASID and academia, to encourage and support basic and applied immunology teaching into educational programs for medical students, generalists, pediatricians, and subspecialists including: rheumatologists, pulmonologists, neonatologists and nurses.
 - ☐ Develop initiatives to allow the exchange of expertise and education, including networking with immunology centers and representatives in other countries.
- **Research, Data Collection and Collaboration:**
 - ☐ Encourage input into the ASID Registry, which will enable future processes to improve diagnosis and treatment through networking.
 - ☐ Continue to expand Centers of Excellence with advanced technology to promote best practice in terms of disease classification, treatment outcome measures, assessment of costs, and an integrated approach to PI recognition throughout Africa.
 - ☐ Establish and encourage a working network in each of the African countries, bringing together the best quality research and care in both the public and private healthcare systems.
- **Identify through Early Diagnosis and Screening:**
 - ☐ Encourage and support African countries to develop clinical protocols to reliably identify all forms of PI.
 - ☐ Support availability of specialized testing facilities to ensure provision of wide-spread use of simple diagnostic tests for PI at regional level.
 - ☐ Support implementation of newborn screening programs ensuring better coverage for screening/diagnostic tests by both governmental and private health plans.
- **Comprehensive and Appropriate Treatment:**
 - ☐ Encourage the development of Centers of Excellence with advanced technology and regional services specialized in the care of PI patients.
 - ☐ Encourage African governments to facilitate an equal access to adequate support services both in the public and private hospital systems; as well as choice of site of care, whether it is in hospital, or clinic, physician office, or home.
 - ☐ Ensure the inclusion of PI in the list of standard of care programs.
 - ☐ Encourage and secure high quality supply of human plasma and safe and appropriate immunoglobulin treatments (including: intravenous (IV), Ig, or Subcutaneous (Sub-Q) Ig).
 - ☐ Encourage African governments to develop and utilize a standard VIS (Vaccination Information Sheet), to reduce potential adverse events in the childhood vaccination program.
 - ☐ Ensure appropriate reimbursement for life sustaining, lifesaving treatments.
- for...**AFRICA**

JMF –HOPE –ADVOCACY -ACTION



Thank you