



“Physician testimony: Potential of patient organisations and working together”.

Dr. Nahla Erwa

Assistant Professor, Clinical Immunologist

University of Khartoum

Chairperson Clinical Immunology Specialty Council, SMSB

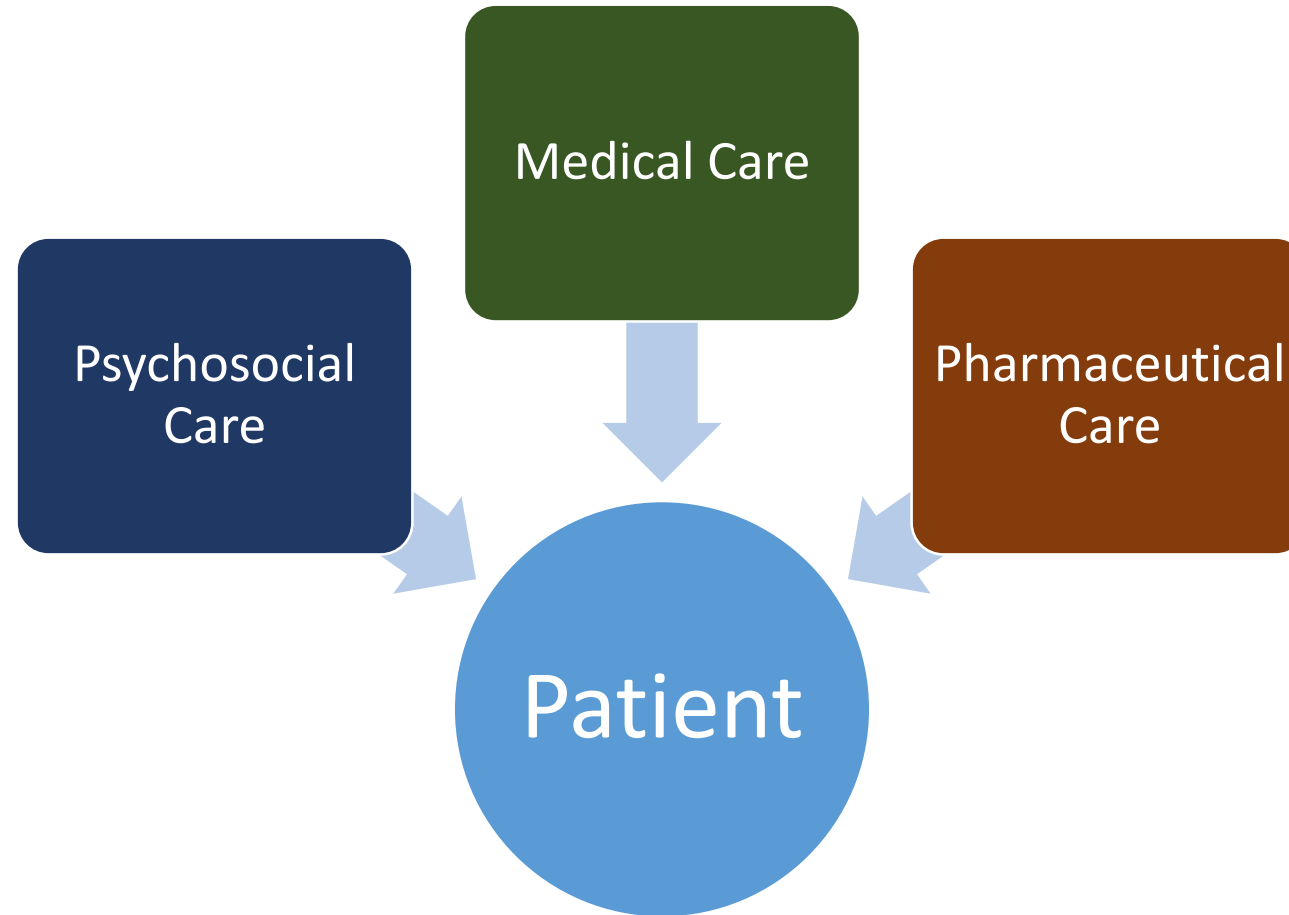
SUDAN

ASID Vice President

Senegal 12 April 2019



Patients are the Centre of Care (Main stakeholders)



What do we know about Africa?

- Vast Continent---*Continent of the Future*.
- Countries: 54.
- 5 Regions (political and geographical).
- Communication languages: English, French, Arabic, Portuguese and local languages.
- Population 1.3 billions with an estimate of about 370,000 PID patients.
- Average consanguinity rate of 35.5%

What do we know about PIDs in Africa?

- Most of the information is from North African Magrib countries, Egypt and South Africa.
- Registries available in the same countries.
- Lowest rate of diagnosis worldwide (90% still unknown)
- African PID mortality rate 25-34.6%
- *PID case recording doubled 2014 to date (2500 to 5000)!*

Reasons behind low diagnosis

- Reduced awareness at all levels:
 - Experience, knowledge and skills of healthcare professionals
 - Diagnostic and treatment facilities
- Distractions by more “urgent” healthcare problems (HIV, malaria, TB, Leishmaniasis...); ***BUT ARE THERE PIDs HIDDEN AMONGST THESE?!***
- Complexity of the diseases
- Heterogeneity and varied presentations (over 300 diseases)



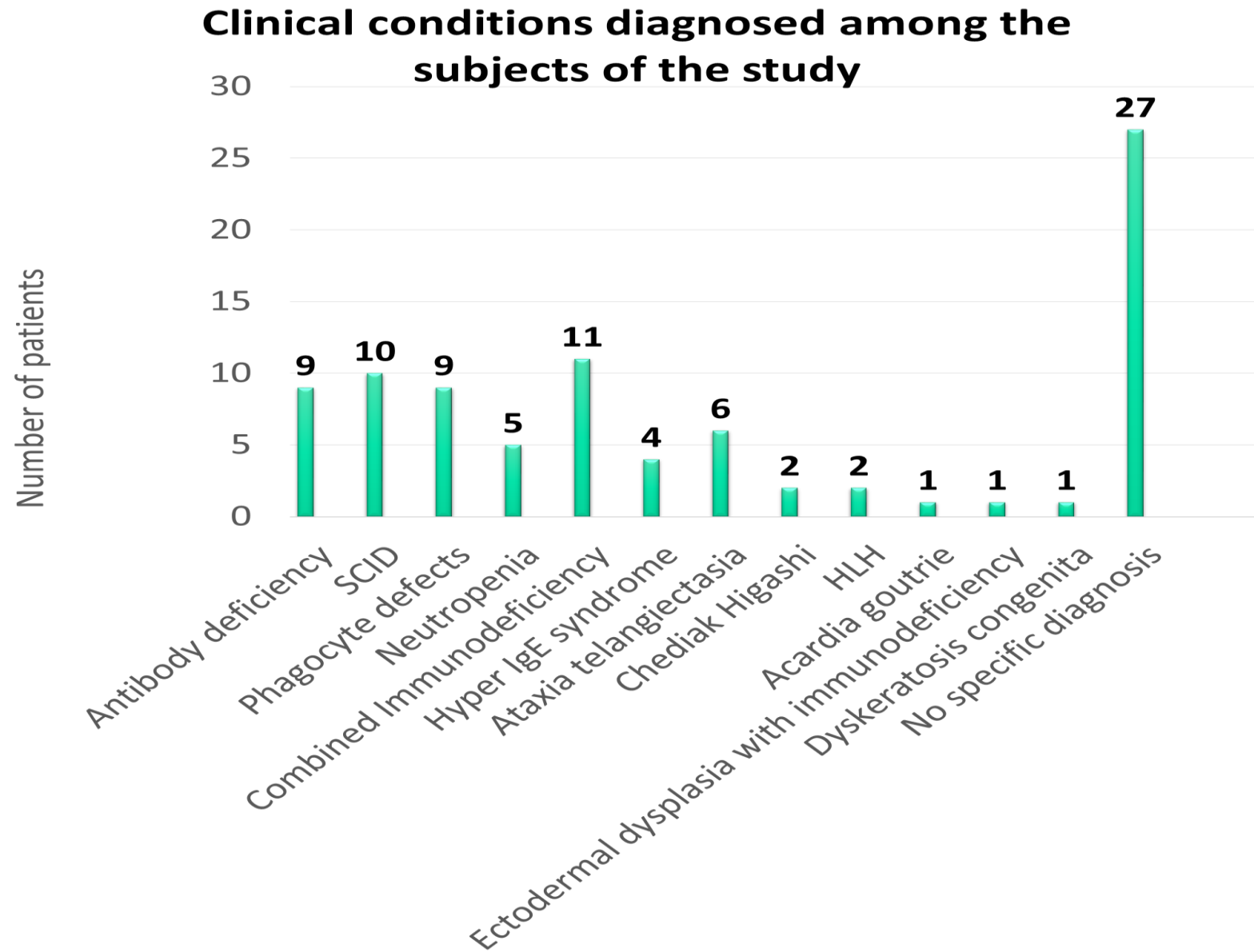
PIDs in Sudan

- Sudan is an African country with a population of over 37 million and high rates of consanguinity and intermarriages yet poor reporting of PID cases.
- Diagnostic and treatment facilities for PIDs are limited by the lack of awareness and low economic profile of the country.
- Following Sudan A-project in 2014, increased requests for the management of PIDs were noted (about 2-6 requests with 1-2 new PID diagnoses every month). Patients were mostly aged below 2 years and many died before being diagnosed, treated or registered as PIDs.



Soba University Hospital





Types of Treatment used & outcomes in the study population				
Treatment Modality	Total Number of patients	Deaths while on treatment	Number of known living patients while on treatment	Lost to follow up
IVIG (+/-other treatments)	13	7	5	1
Prophylactic Antibiotics+/_antifungal +/-vaccination	40	5	11	24
Immunosuppression/Immune modulation	4	0	4	0
GCSF + Antibiotics	1	0	1	1 (now seen in a different hospital)
Bone marrow transplantation	0	0	0	0
Total	58	12	20	26

Some Outcomes of study on PID's in Sudan

- Inadequate services and the lack of awareness affected both diagnosis and treatment.
- BMT was not used due to its unavailability.
- IVIG is underused due to high cost and perhaps inadequate diagnosis in some cases.

RECOMMENDATIONS

- 1. A patient registry is needed for accurate characterization of disease profile, demand management and research.**
- 2. Collaboration with stake holders and specialized centers will help further development in the field.**
- 3. Patient groups will help advocacy and awareness and hence diagnostic and treatment facilities.**



Sudanese Organization for Patients with Primary Immunodeficiencies

المنظمة السودانية لمرضى ضعف المناعة الأولي

How?



Sudanese Organization for Patients with Primary Immunodeficiencies
المنظمة السودانية لمرضى ضعف المناعة الأولي

1. SWOT analysis.
2. Standards of care
3. 1 + 2 to guide Constitution

Primary Immunodeficiencies Principles of Care (an IPOPI document and Implementation Package) # 4

- Interaction and getting involved with:

1. Decision makers.
2. Healthcare professionals.
3. Society
4. Industry

The need to work together (Why):

- Patients can form very powerful bodies to advocate for rights if they are empowered and **their health is kept well looked after.**
- They are THE STAKEHOLDERS so very powerful in fund raising.
- Patient groups can work through details of advocacy (eg our recent experience on WHO SDG search for opportunities in advocating and establishing PID care in Africa)...*Africa has so many other health priorities identified by the WHO and national Health authorities. In addition to poverty and instabilities in many countries.*
- Doctors are busy with many other conditions.
 - They need to be guided by patients to identify needs and priorities.....
 - They also require updating and refreshing their knowledge and skills...

How:

- Awareness campaigns (eg. WPIW)
- Patients support each other..
- Identify peculiarities of each disease profile
- Lobbying: Meetings; social, scientific..
- Fundraising, look for opportunities and identifying threats

WHO Strategic Development Goals

- WHO collaborations to pave the way for shaping standards of care to fit the purpose of National Health programs.
- SDG # 3: Good Health and Well being.
- SDG # 10: Reduced inequalities

Successful Examples from Home

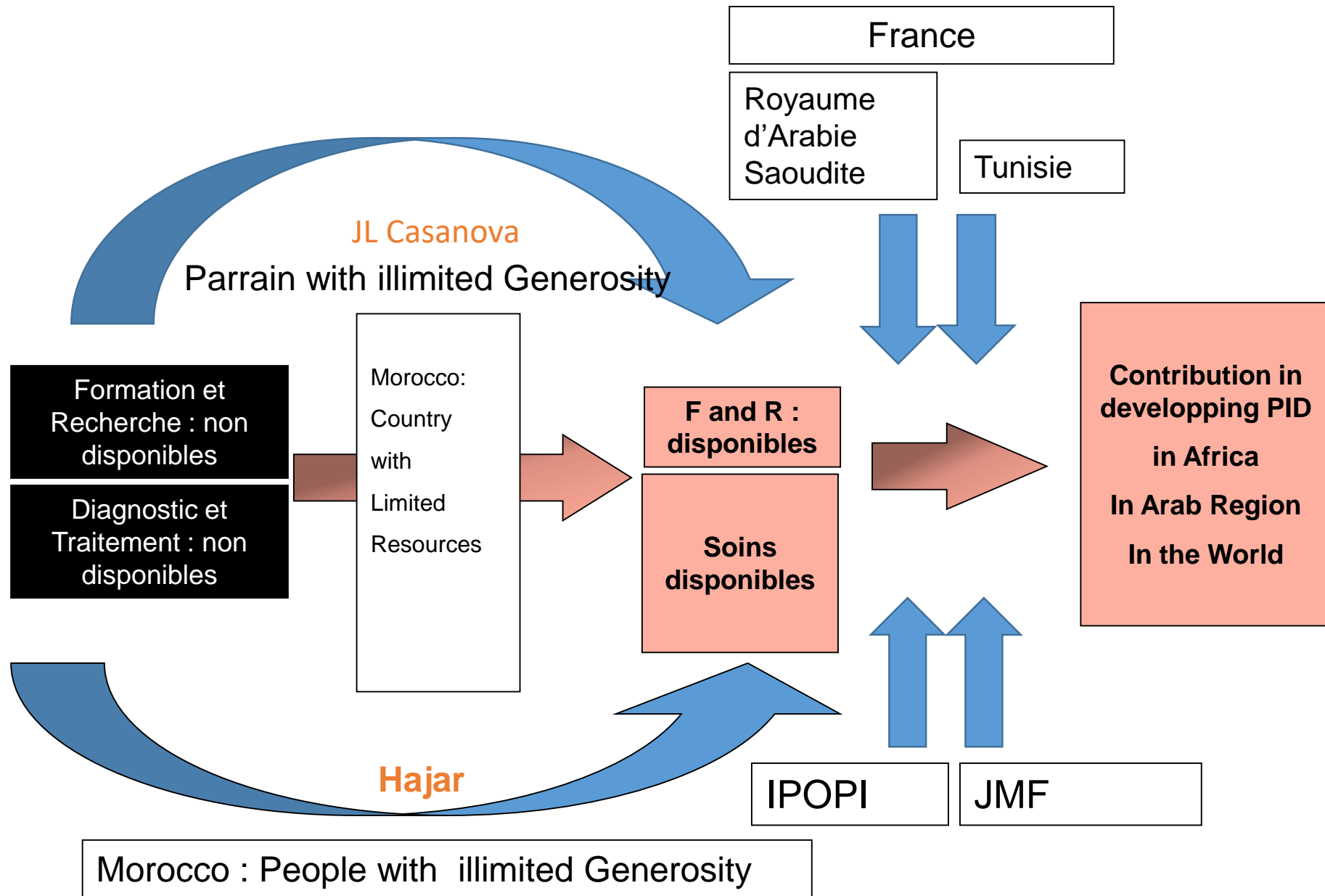
- Renal Patients Group (free and widely available renal dialysis and transplantation centres)
- Paediatric Diabetes Group (specialist centre)
- Haemophilia Group (Factor provision)
- SLE group (very successful annual awareness week)

Successful Examples from Home

- PID patients diagnosing relatives
- Others working to bring technology and raising awareness.

African PID groups

- Morocco
- South Africa
- Egypt
- Senegal
- Uganda
- Kenya
- Tunisia
- Sudan (active as a group but still awaiting formal registration).



THANKS 😊