



IPIC2023

INTERNATIONAL
PRIMARY
IMMUNODEFICIENCIES
CONGRESS

DIAGNOSIS
AND CLINICAL CARE

—
ROTTERDAM
THE NETHERLANDS

—
NOVEMBER 8-10, 2023

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an IPOPI event

ASID Success and challenge in Africa

Jeddane Leïla

African Society for Immunodeficiencies (ASID)

Regional Diagnosis and Clinical Challenges

November 9, 2023

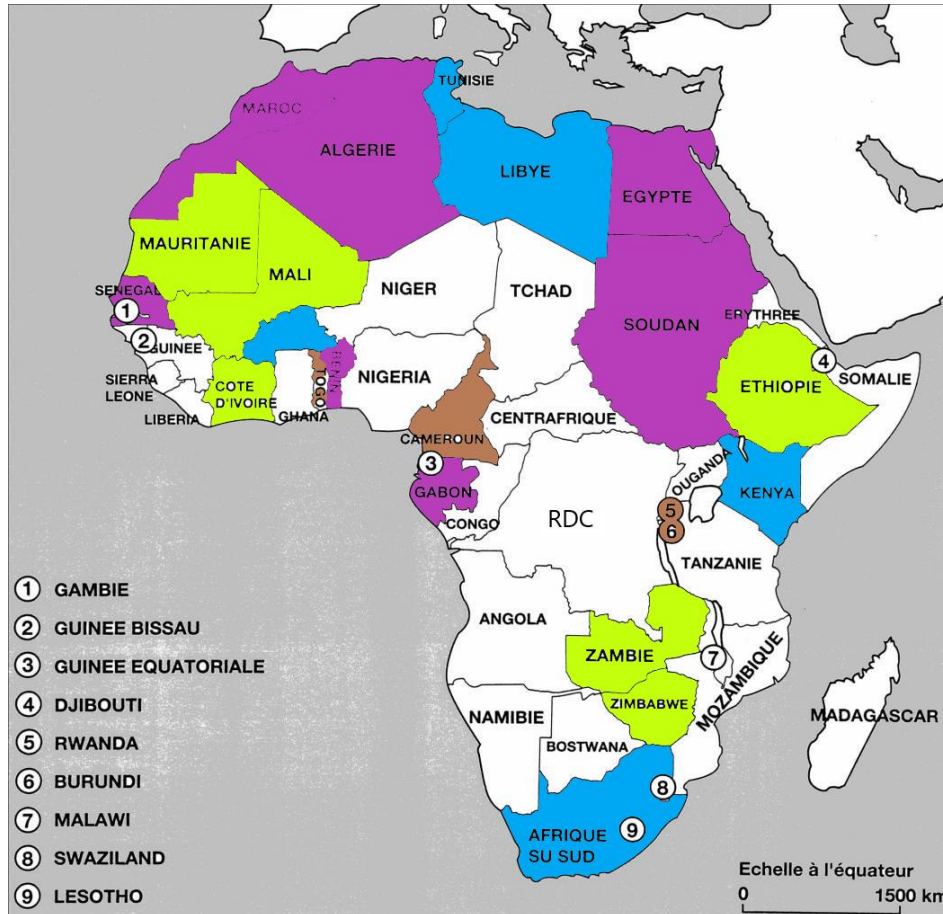




INTRODUCTION

- “Primary Immunodeficiencies” (PID) or “Inborn errors of Immunity” (IEI): 482 disorders
- Global prevalence:
 - 86.3/100,000 (Boyle JM, Buckley RH. JoCI, 2007)
 - 29.1 /100,000 (US: Kobrynski et al, 2014)
 - 11/100,000 (France: Mahlaoui N, et al. JACI, 2017)
- Estimation in Africa (1,44 milliard):
 - 158,438 – 419,142
 - Registries: 2,250 (publications)

PIDs in Africa: Where are they?



- Many gaps throughout the continent:

- Diagnosis
- Management
- Awareness
- Involvement



A successful story: the A-Project

- One Day in One Country with One Expert
- Training program developed by ASID since 2013
- Further declined in several type and levels:
 - Clinical A-Projects Level 1, 2 and 3
 - Nurse A-Project
 - Biological A-Project



Portugal 2013



J Clin Immunol (2015) 35:517–518
DOI 10.1007/s10875-015-0179-8

ANNOUNCEMENT

A-Project : a Training Program from ASID

Nahla H. H. Erwa^{1,3} • Leïla Jeddane³ • Maroufou J. Alao³ • Monika Esser³ •
Tandakha N. Dieye³ • James Chipeta³ • Ahmed Aziz Bousfiha^{2,3}

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1st A-Project: Benin (2014), then...

1st A-project Benin
 African Society for Primary Immunodeficiencies
 En partenariat avec
 La Société Béninoise de Pédiatrie

Un Workshop sur les Déficiences Immunitaires Primitives

Institut des Sciences Biomédicales
 Appliquées (ISBA)
 October 2014
 4 Mars 2014

Local Organizers:
 Pr. AA BOUSFIHA (Benin)
 Dr. MJ ALAO (Benin)

Participating Countries:
 Benin, Gabon, Maroc et Togo

LFB
 Gold Sponsor

Sudan A-project
 29 April 2014

Towards Better PID Awareness and Care
 (Workshop and Conference Centre, Soba University Hospital)

Local Organizers:
 Nahla H H Erwa
 Wesal M Abbas
 Nagwa M Elbeshir

ASID nominated trainers:
 Monika Esser South Africa
 Sheram M Reda Cairo, Egypt

Baxter
 Gold Sponsor

3rd A-project : Gabon

Workshop sur les Déficiences Immunitaires Primitives

Centre de Recherches de Service de Santé Infantile
 24 septembre 2014

Local Organizers:
 Pr. Jean-Marie Njagu
 Dr. Mylene Verbeke

ASID nominated trainers:
 Pr. Aziz Bousfiha

SAHAR
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Zambia A-project
 8th October 2014
 4th A-Project

TOWARDS BETTER PRIMARY IMMUNODEFICIENCY (PID) AWARENESS AND CARE

Local Organizers:
 Prof. Shikwaza
 Prof. Paul Kanyo
 Dr. Prosper Mwaanga
 Dr. James Chipea

ASID nominated trainers:
 Dr. Monika Esser

LFB
SAHAR
 Gold Sponsors

5th A-project : Cameroun
 21 et 22 novembre 2014
 Palais des Congrès de Yaoundé

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 Gold Sponsor

6th A-project SENEGAL & 1st Biol A-project
 Atelier sur les déficits immunitaires primitifs

CHNU A. Le DANTEC
 Unité d'Immunologie
 Laboratoire Bactériologie-Virologie
 C.N.T.S.
 25 - 26 FEVRIER 2015

Local Organizers:
 Tandakha Ndlaye Dieye, Prof, PhD (Sénégal)
 Aziz Bousfiha, Prof, MD (Maroc)
 Indou Deme Ly, MD (Sénégal)

LFB
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7th A-project : Ethiopia
 Department of Paediatrics and Child Health Auditorium, CHS-AAU

18 February 2015

Local Organizers:
 Dr Amha Mekasha (MD, MSc),
 Prof Asrat hailu Mekuria (PhD)

Trainers:
 Professor Reinhard Sezer
 Dr Nahla Erwa

octapharma
 Gold Sponsor

Uganda A-PROJECT & World PIDs Week

Theme: Primary Immunodeficiency Diseases (PIDs); Causes, Diagnosis and Management

Venue: Hotel Africana, Kila Date: April 24, 2015

Test Treat

MAKCHS
 Gold Sponsor

9th A-project : Casablanca
 A l'hôpital des Enfants Abderrahim El Harouchi

28 Avril 2015 à 12h

ANIMATEURS:
 Prof Aziz BOUSFIHA
 Prof Fatima Akil
 Dr Ibtihal Benbrahim
 Dr Leila Jedane

World PID Week
 Gold Sponsor

Rwanda A-project
 22nd September, 2016

TOWARDS BETTER PRIMARY IMMUNODEFICIENCY (PID) AWARENESS AND CARE IN AFRICA

UMUBANO HOTEL, KIGALI, RWANDA

Local Organizers and Speakers:
 Prof. James Chipeta (ASID; Zambia)
 Dr. Lisine Tuyisenge (REAA; Rwanda)
 Dr. Tanya Rogo (RPA; Rwanda)

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A successful story: Senegalese A-Project

- Combined Clinical A-Project with 1st Biol A-Project
- To identify clinicians to involve in further training programs
- Initiative to create a patient support association
- Four years later (2019):
 - Dakar hosted the 6th ASID meeting
 - ASDIP participated to WPIW
- Now:
 - Specific consultation for IEI in Dakar
 - Basic diagnosis available


 Société Sénégalaise d'Immunologie (S.S.I)
 et la Société Sénégalaise de Pédiatrie (S.O.S.E.P.E.D)
 En partenariat avec

 African Society of Immunodeficiencies (A.S.I.D.)

**6th A-project SENEGAL
 & 1st Biol A-project**
Atelier sur les déficits immunitaires primitifs

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 Tandakha Ndiaye Dieye, Prof, PhD (Sénégal)
 Aziz Bousfiha, Prof, MD (Maroc)
 Indou Deme Ly, MD (Sénégal)

Pays participants :
 Mauritanie, Côte d'Ivoire, Sénégal








Kenya A-Project: same story



1st Kenya A-Project

White Sands Hotel,
Mombasa City
9th April 2019

Speakers :
- Monika Esser
- James Chipeta
Local Organizer :
- Angela Migowa



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KENYA
PAEDIATRIC
ASSOCIATION

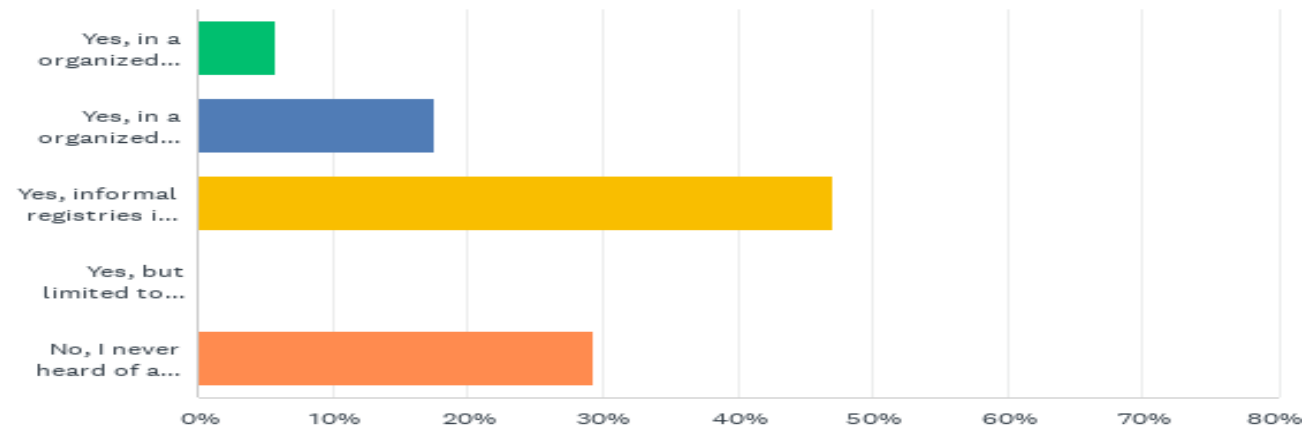




Challenge(s) in Africa

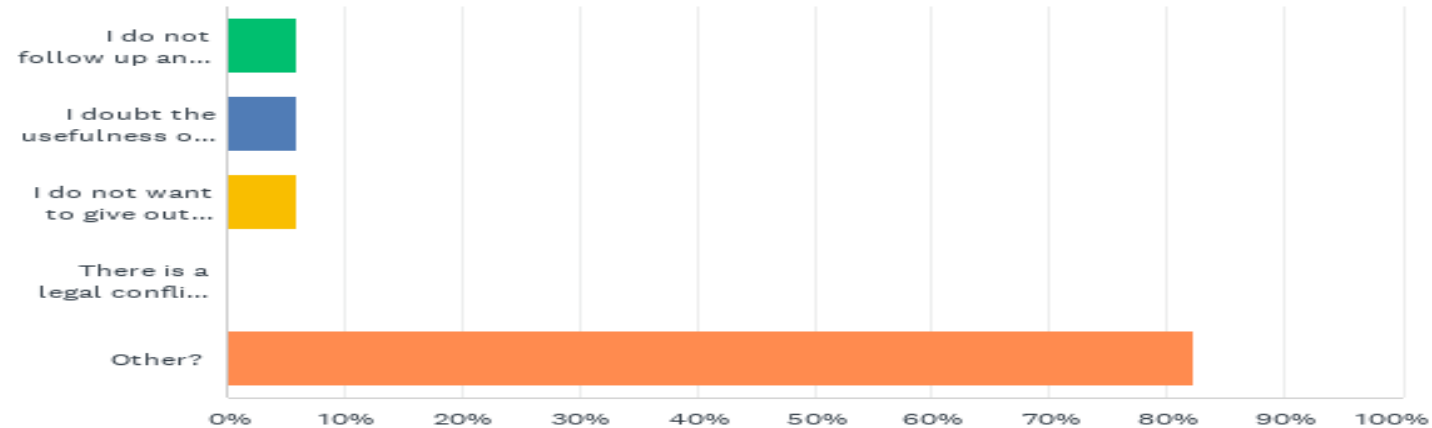
- Closing the gaps furthermore!
- Getting data for Africa: striving to set up a registry since ASID creation!!
- Diagnosis: Availability of genetic diagnosis
- Management:
 - Availability of (affordable) IgG replacement therapy
 - HSCT: training and networking

Q5: Did you hear about a PID patient registry/data collection in your country?



CHOIX DE RÉPONSES	RÉPONSES	
Yes, in a organized format (database) at the national level	5.9%	1
Yes, in a organized format (database) in an unique center	17.6%	3
Yes, informal registries in one or several center	47.1%	8
Yes, but limited to specific diseases (recurrent fevers, cystic fibrosis, ...)	0.0%	0
No, I never heard of a registry on IEI disorders in my country	29.4%	5
TOTAL		17

Q7: If you are not participating in a registry, what are the main reasons?



Other reasons:

- Registry not available (3)
- No cooperation in collecting data (1)
- Lack of human resources (1)
- Lack of communication (1)
- Legislation on Data protection (1)

CONCLUSION

ASID is still young (15 years) and has a long way to go...
... But we already get this far, thanks to networking, patient associations,
constant training and perseverance!





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