

International Patient Organisation for Primary Immunodeficiencies

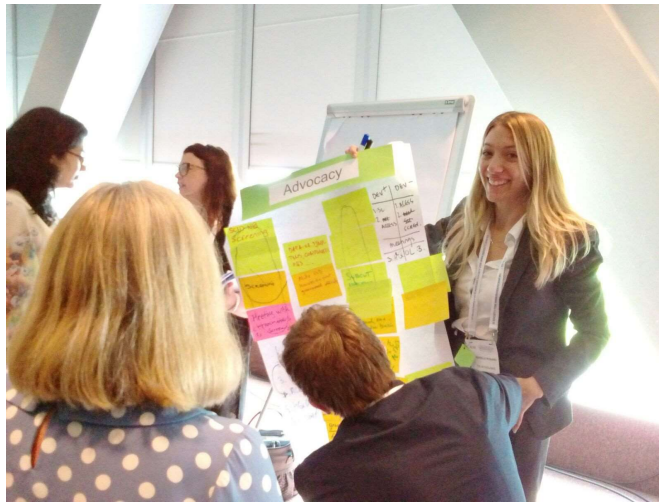
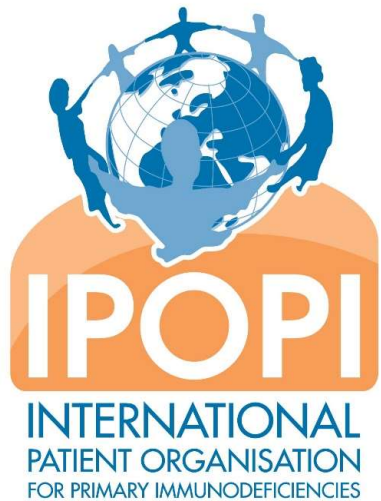
Overview of key achievements
&
what lies ahead...



24 October 2018
XVth IPOPI Global PID Patients Meeting
Lisbon, Portugal

Welcome to the XVth Global PID Patients Meeting

A place to interact, exchange ideas,
share and learn from others!



Welcome to the XVth Global PID Patients Meeting

A place to celebrate our community and
remember how and why we are all here!

Luciano Vassalli Award
LeBien Award



IPOPI's Mission

- IPOPI is the association of national patient organisations dedicated to improving:
 - awareness
 - access to diagnosis and optimal treatments
 - worldwide for primary immunodeficiencies
- Established in 1992 and growing year after year!





THE GLOBAL ORGANISATION WORKING TO **IMPROVE**
THE QUALITY OF LIFE FOR PEOPLE WITH PRIMARY IMMUNODEFICIENCIES

www.ipopi.org



Structure

Board of Directors

Jose Drabwell, Chair (UK)
Martine Pergent, Vice-Chair (France)
Christine Jeffery, Treasurer (Australia)
Andrea Gressani (Italy)
Dragana Koruga (Serbia)
Violetta Kozhereva (Russia)
Bruce Lim (Malaysia)
Roberta Pena (Argentina)
Annie Pienaar (South Africa)
John Seymour (USA)

Staff

Johan Prévot Executive Director
Clare Glynn, Finances
Saara Kiema, NMO Programmes Officer
Magda Lourenço, Communications Manager
Carla Morgado, Executive Assistant
Leire Solis, Health Policy & Advocacy Manager
Carol Tavener, Administration

Medical Advisory Panel

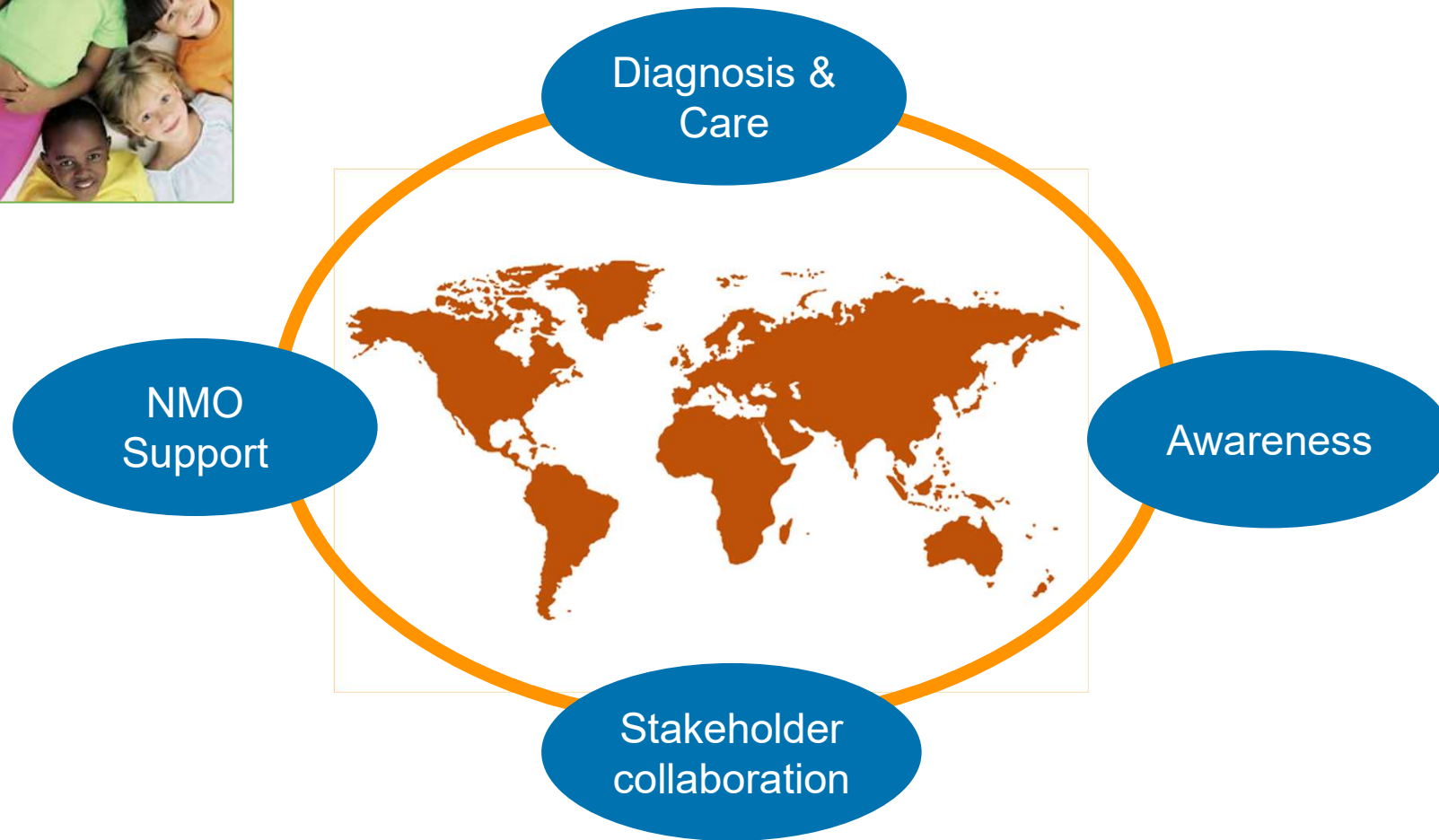
Dr. Nizar Mahlaoui, Chair (France)
Prof. Martin van Hagen, Vice Chair (NL)
Dr. Adli Ali (Malaysia)
Dr. Tadej Avcin (Slovenia)
Prof. Aziz Bousfiha (Morocco)
Dr. Charlotte Cunningham-Rundles (USA)
Dr. Monika Esser (South Africa)
Prof. Alain Fischer (France)
Dr. José Franco (Colombia)
Prof. Isabelle Meyts (Belgium)
Prof. Antonio Condino Neto (Brazil)
Dr. Olaf Neth (Spain)
Prof. Surjit Singh (India)
Dr. Joanne Smart (Australia)
Prof. Klaus Warnatz (Germany)

Special Adviser

Prof. Bobby Gaspar (United Kingdom)



IPOPI strategic plan 2016-2020



Strategic Plan 2016-2020

1. To promote early diagnosis & ensure optimal access to care

Advocacy at the international level:



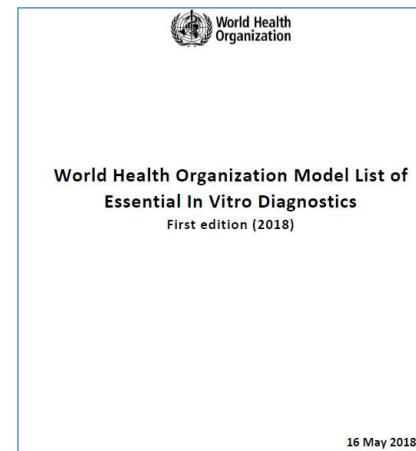
**World Health
Organization**



IUUIS

International Union of Immunological Societies

*Immunology
without
Borders*

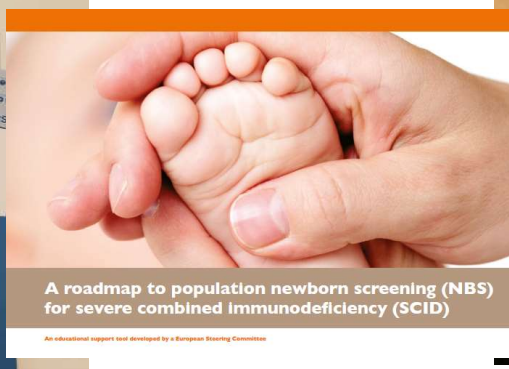


**RARE
DISEASES
INTERNATIONAL**

Strategic Plan 2016-2020

1. To promote early diagnosis & ensure optimal access to care

Advocacy at the Regional & National level:



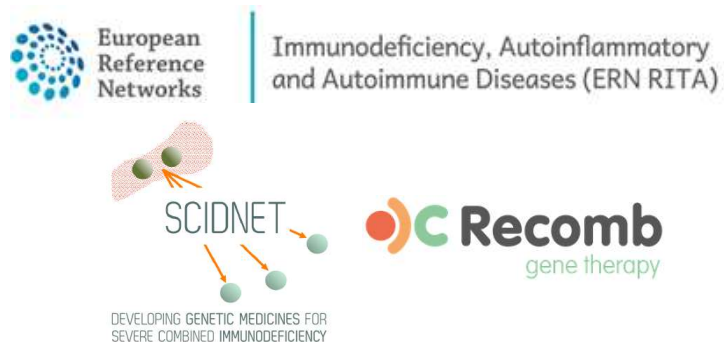
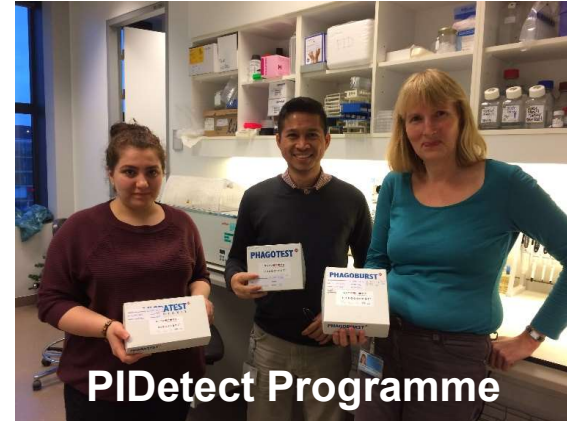
Strategic Plan 2016-2020

1. To promote early diagnosis & ensure optimal access to care

Monitor developments and advance clinical care



Promote early diagnosis globally



Advocacy at the Royal Level...



Strategic Plan 2016-2020

2. To develop, strengthen and support national member organisations (NMOs)

Support the launch of new NMOs



Information & skills building



Strategic Plan 2016-2020

2. To develop, strengthen and support national member organisations (NMOs)

Provide Support to NMOs

Financial support to NMO campaigns and events



Strategic Workshops



And other ways!



Strategic Plan 2016-2020

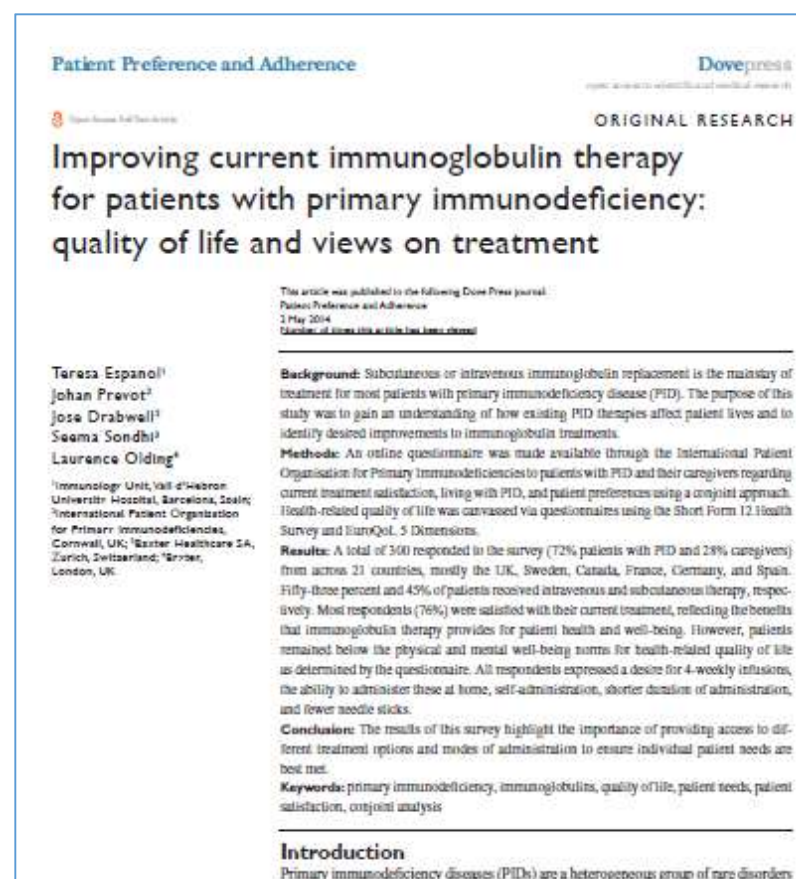
3. To raise PID awareness globally Implementing awareness campaigns at various levels



Strategic Plan 2016-2020

3. To raise PID awareness globally Compile and promote data

IPOPI surveys



Strategic Plan 2016-2020

4. To stimulate stakeholder collaboration

Secure patients interest through global stakeholder collaboration



Strategic Plan 2016-2020

4. To stimulate stakeholder collaboration

Diversification of stakeholder collaborations – societies & others



Strategic Plan 2016-2020

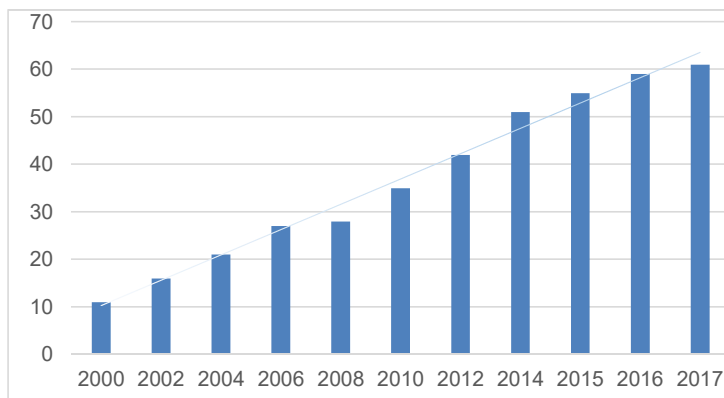
4. To stimulate stakeholder collaboration

Diversification of stakeholder collaborations – corporate partners

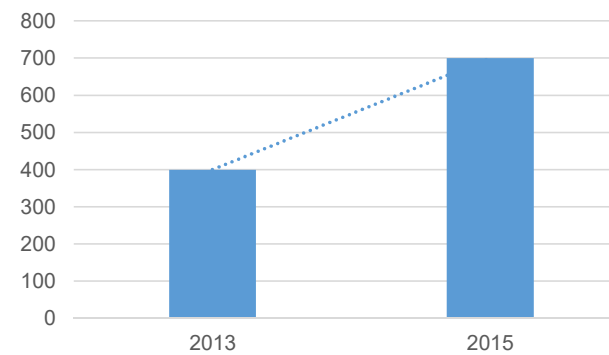


IPOPI on the move

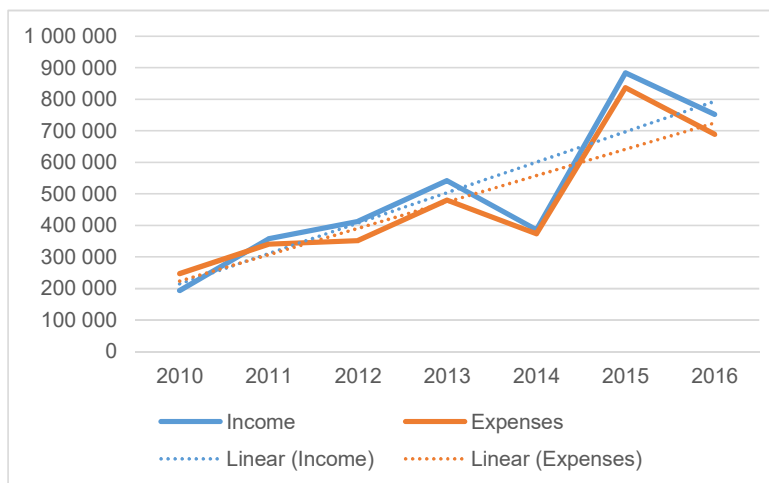
Number of National Member Organisations



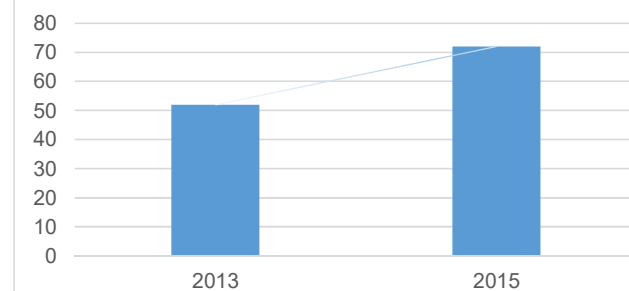
IPIC Participants - over 70% increase



Income and Expenses GBP



IPIC - Countries represented 40% increase



What lies ahead

- The vast majority of patients affected with a PID worldwide still do not have access to their life saving and/or life enhancing treatments
- Put PIDs and PID patients on the map is a top priority
- Huge disparities between and within regions in terms of diagnosis and access to treatments
- Many countries do not have active NMOs yet
- Continue and increase support to our existing NMOs!
- We need to be proactive but also vigilant and reactive whenever needed
- IPOPI is committed to further increase its actions through a strategic, focused approach in unison with its stakeholders

4th IPIC, Madrid

an IPOPI event



IPIC2019

INTERNATIONAL PRIMARY
IMMUNODEFICIENCIES
CONGRESS

6-8 NOVEMBER
MADRID, SPAIN

www.ipic2019.com

Biennial Meetings

Next stop: Birmingham 2020



Past Meetings:

1992 Lugano, Switzerland
1994 Sitges, Spain
1996 Goteborg, Sweden
1998 Rhodos, Greece
2000 Geneva, Switzerland
2002 Weimar, Germany
2004 Versailles, France
2006 Budapest, Hungary
2008 Den Bosch, Holland
2010 Istanbul
2012 Florence
2014 Prague
2016 Barcelona
2018 Lisbon

Upcoming Meeting:

2020 Birmingham

