

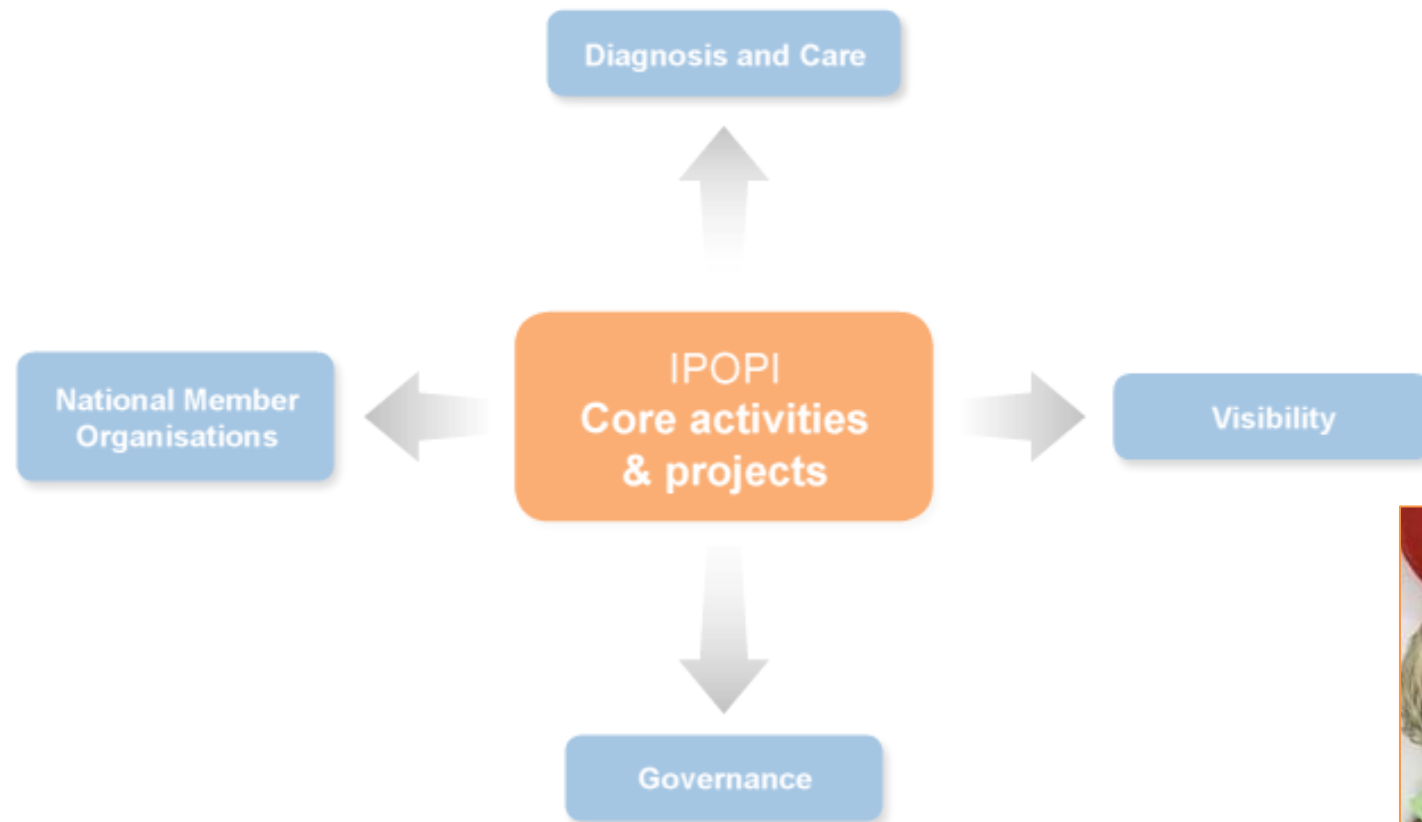


# IPOPI

## Review of Key Activities & Achievements 2013-2014

Johan Prevot  
30 October 2014

XIIIth IPOPI Biennial Meeting  
Prague, Czech Republic





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



- 2012: National Rare Diseases Plans Implementation
  - Carving out PID recognition as important group of rare diseases in national plans -Recommendations , Report & Follow up campaign in France





- **2013: Cross Border Healthcare & PIDs**
  - Inclusion of PIDs in cross border healthcare policies: Recommendations, Parliamentary Questions, and National follow-up campaign in Ireland



- 2014: Comprehensive Framework of Care and Policy for PIDs
  - Branding event – PIDs are a key subgroup of rare diseases deserving specific attention
  - Profiling of IPOPI and PID community – New MEPs
  - Positioning IPOPI as key interlocutor on upcoming dossiers (Blood Directive, Paediatrics, ADMPs etc)
  - Building political momentum around PID issues
  - Planned follow up campaign Romania



## • From EU to National Level

**Phase I – preliminary policy positioning of need for EU action on SCID NBS, which included the following milestones:**

- PID Forum SCID New born Screening, 15 June 2011, EU Parliament, Chaired by Socialist MEP Glenis Willmott. First policy positioning of SCID at EU level
- Set of EU Recommendations agreed June 2011
- Willmott Parliamentary Question on SCID NBS 20 July 2011
- EU Commission response 30 August 2011 (encouraging but more data needed)
- SCID NBS Follow Up UK East Midlands Meeting with Glenis Willmott – BBC and media coverage . First positioning of SCID NBS in UK (agreement on actions in UK and continuation of EU campaign) Nov 2011
- PLUS Meeting with Commissioner Dalli, Oct 2011 – Need for EU action on SCID NBS discussed & promoted
- Meeting with Mrs Willmott and Commission Head of Unit S Schreck Jan 2012 – Need for EP Resolution or Oral Question to influence upcoming Commission policies on NBS identified



**Phase II – advocacy campaign for Rare Diseases NBS Oral Question and/or resolution using SCID as case study, which included the following milestones:**

- Technical / expert policy support to Glenis Willmott office started Q2 2012
- Call to Action launched at EU Parliament to gather wide r support and stir the debate on European guidelines for rare diseases NBS
- Cross-party political support obtained Q3 2013
- Meeting with Socialist ENVI Coordinator L McAvan Sep 2012. McAvan support obtained.
- Meetings with Christian Democrat and Liberal ENVI Coordinators Q4 2012. Support obtained.
- ENVI Coordinators Meeting Jan 2013 – request for more information
- ENVI Committee Meeting 24 January – Support obtained & decision to table Oral Question
- Oral Question tabled 8 February 2013 – Key achievement
- ENVI Meeting 25 April 2013 – EP supportive, EC cautious and referring to NBS as national matter
- Next steps: HFE -Meeting with Commission to reposition topic (EU) and National Policy Events

- National Actions (France)
  - First Event December 2013
  - Advocacy campaign led by IPOPI in collaboration with IRIS
  - Endorsement by key politicians incl Marie-Françoise Clergeau (MP) and Michelle Meunier (Senator)
  - Collaboration with French PID Reference Centre and leading doctors
  - Policy Event - 22 October in French Senate
- To fasten the Implementation of SCID NBS in France





## • PID Political Campaign

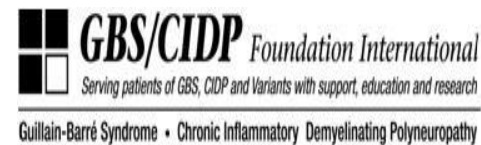
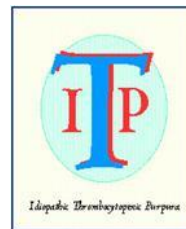
- Objective 1: Establish a clear policy to increase early diagnosis of patients with a PID
- Objective 2: Establish a clear policy to support patients with PIDs to have access to the appropriate treatment and care they need, promote importance of patient choice.
- Objective 3: Support the establishment of a national registry for PIDs
- **Inclusion of specific provisions on PIDs in new RDs strategy**
- **Creation of specific PID advisory committee in MoH**
- **Project of law to promote need for wider access to Igs**
- **Political event in Brasilia planned for November 2014**



- Activities undertaken with 

Platform of Plasma Protein Users

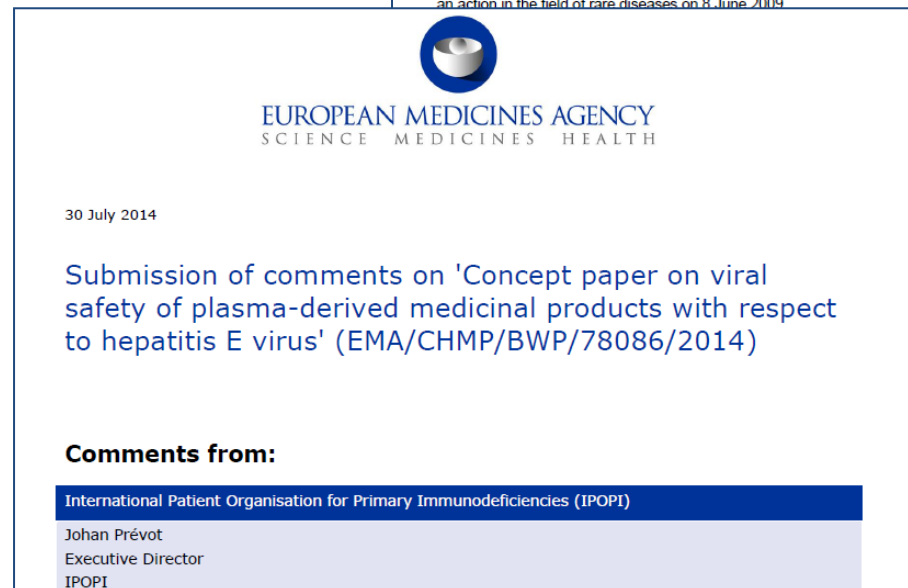
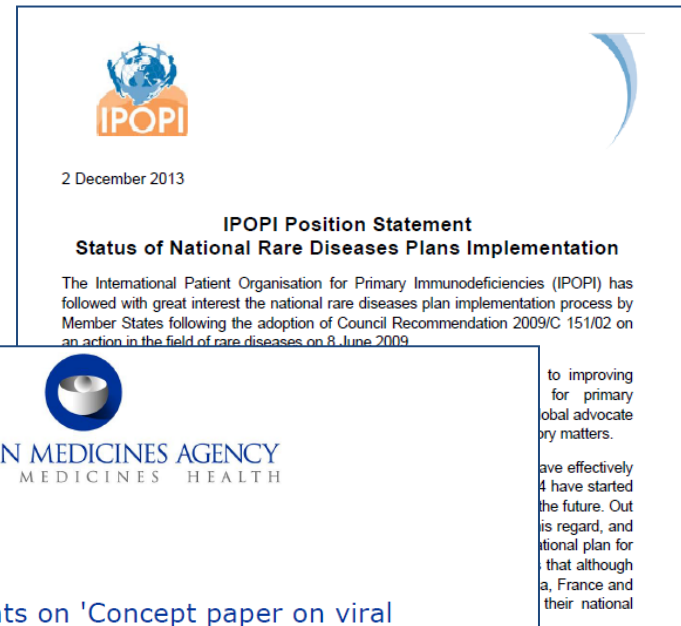
  - Meeting with Health Commissioners
  - Formal Meeting with EU commission services (17 June '14)
  - Consensus stakeholder meetings (Dublin & Estoril)
  - Joint Meeting with ABO Risk-Based Decision Making, London, 10 June 2014
  - Formal response to WHO Rome Declaration



# Advocacy – Other actions



- WHO
- EMA/FDA
- European Commission & Parliament
- Council of Europe
- EURORDIS
- PPTA Stakeholders Group
- IPFA
- Health First Europe
- EPPOSI
- IAPO
- EPF



## • PID Principles of Care

H. Chapel; J. Prevot; J. Drabwell; T. Español; Y. L. Lau; S. Sánchez Ramon; B. Gaspar; J. Puck; B. Egner; D. Edgar; G. Spicket; A. Symes; J. S. Orange; N. Mahlaoui; K. Sullivan; S. Ehl; C. Picard; F. A. Bonilla; J. Kerr; M. Ballow; J. Litzman; R. E. Schmidt; C. Kinnon, A. Gardulf; A. Gennery; H. J. Longhurst; M. Esser; B. Tavares Costa-Carvalho; S. Singh

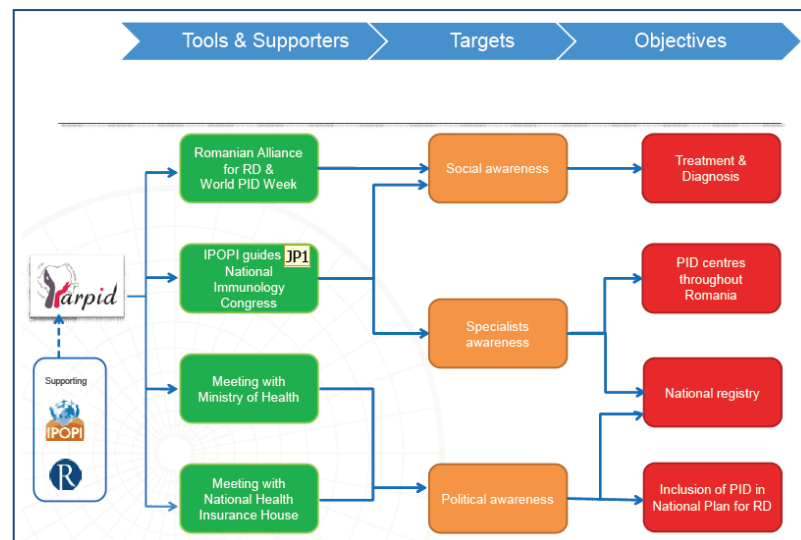
- IPOPI-led project
- Publication as tool for political advocacy
- Tool for all stakeholders to advocate for access to early diagnosis and appropriate treatment
- Involvement of international key opinion leaders
- Lays out fundamental principles of care that should be met to reach gold standard care for PIDs
- Publication aimed for end of 2014
- Promotion in 2015



# Awareness – National Workshops



- Spain (Nov 2012) and Romania (Oct 2013)
  - Elaboration of national PID awareness action plans
  - Improved NMO Skills set & know how
  - Strengthened network of NMOs/national stakeholders
  - Case study reports



# Awareness – National Workshops



- Brazil (2013)
  - 1st joint meeting of two key patient groups and doctors
  - Decision on joint national PID awareness campaign:
  - Strengthened network of stakeholders & unified approach



## Awareness – Regional Meetings



- **Antalya, Turkey, 15 March 2014**
  - Held in collaboration with J-Project conference
  - Involvement of key regional patient leaders and doctors
  - Involvement of key European PID doctor
  - Endorsement of Antalya declaration
  - Discussion of Eastern European environment
  - Identification of priorities for attending countries
  - Follow up of implementation



## Awareness – Regional Meetings



- **LASID/ IPOPI Meeting –Chile Oct 2013**
  - Regional priorities identified
  - Regional patient advocacy campaigns
  - Strengthened NMO network
  - Launch of new NMOs

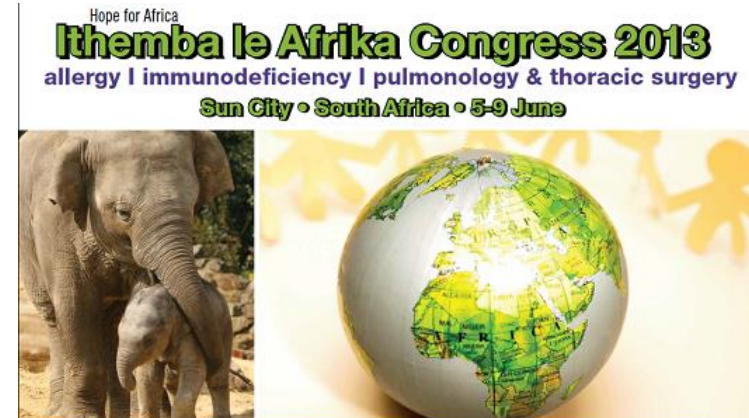




## Awareness – Regional Meetings



- IPOPI - ASID Meeting: Sun City, South Africa, June 2013
  - New NMO's since meeting – Uganda, Egypt. Next: Senegal & Zambia



# Awareness – Bob LeBien Asian Programme

- Thailand, Malaysia, Hong Kong (2013)
  - First ever meetings between doctors, patients and other stakeholders
  - Co-organized with doctors societies
  - Involvement of key PID doctors from the region & EU
  - Malaysian NMO – February 2014
  - Thai NMO – June 2014
  - Hong-Kong NMO – August 2014



# Awareness – Bob LeBien Asian Programme

- Latest event in Singapore, September 2014
  - First ever meeting between doctors, patients and other stakeholders
  - Co-organized with doctors societies
  - Follow up meeting held on 16 October 2014
  - Decision to launch group
  - Group expected to apply for IPOPI membership soon





# Awareness – WPIW Support Programme



- 22-29 April, every year
  - Supported local implementation of WPIW through IPOPI NMO Support programme in **49 countries** since 2011
  - Dissemination of IPOPI Patient Information Materials and WPIW support materials through network of NMOs
  - Promotion of World PI Week through IPOPI's Social Media Tools including Facebook and Twitter
  - Participation of IPOPI Staff, Board Members and Medical Advisory Panel in selected events





# International Primary Immunodeficiencies Congress (IPIIC)



## 1st IPIC – Key Measurables



- Clinical programme
- Key Opinion Leaders involvement
- 400 participants
- 52 countries
- 15 supporting medical societies
- 7 sponsors and 8 exhibitors
- 60% of delegates = doctors
- Other delegates included:
  - Patient Organisation Leaders
  - Nurses
  - Industry
  - Others



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**Biotest**  
From Nature for Life

**octapharma**  
For the safe and optimal use of human proteins

**bpl**  
Bio Products Laboratory



**PerkinElmer**  
For the Better

**CANE**  
MEDICAL TECHNOLOGY

**Binding Site**  
THE BINDING SITE

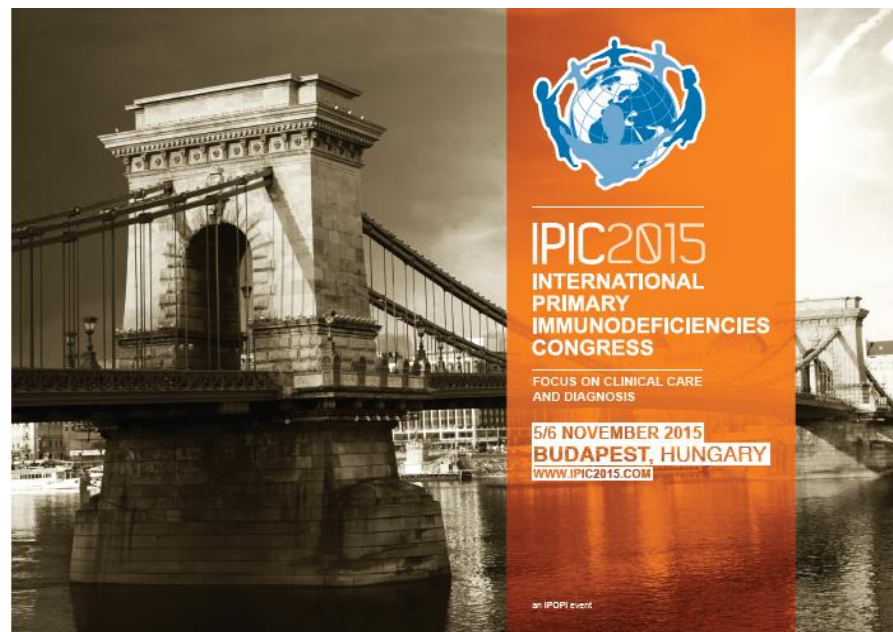
**KEDRION**  
BIOPHARMA

**IFTA**

## 2nd IPIC, Budapest, 5-6 November 2015



- 13 supporting medical societies already confirmed
- Programme will look at sessions on:
- Gastro Intestinal issues
- Auto-immunity
- SCID
- Infectious complications
- Immune dysregulation
- New genetics
- Registries to advance clinical care ...among others!



*“The uniqueness of IPIC comes from the fact that its programme is clinically orientated and prepared with the input from the key PID stakeholders: doctors, patients and nurses”.*



# IPOPI Biennial Meetings every other year!



- Next stop: Barcelona



## Past Meetings:

1990 Oxford, UK  
1992 Lugano, Switzerland  
1994 Sitges, Spain  
1996 Goteborg, Sweden  
1998 Rhodes, Greece  
2000 Geneva, Switzerland  
2002 Weimar, Germany  
2004 Versailles, France  
2006 Budapest, Hungary  
2008 Den Bosch, Holland  
2010 Istanbul  
2012 Florence  
2014 Prague

## Upcoming Meetings:

2016 Barcelona





Thank you for your attention!