Comprehensive Care Models
A look at Primary Immunodeficiencies

Johan Prévot
Executive Director
IPOPI

NRBDO Fall Conference 2017
Toronto, Canada
18 November
(by video conference)

IPOPI
INTERNATIONAL
PATIENT ORGANISATION
FOR PRIMARY IMMUNODEFICIENCIES

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IPOPI

- 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

IPOPI has 63 National Member Organisations

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

www.ipopi.org

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IPOPI strategic objectives

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Primary Immunodeficiencies (PIDs)

- Over 300 different PIDs defined in 9 different groups
- Occur in persons born with failed immune systems
- Hereditary or genetic defects,
- Can affect anyone, regardless of age or sex.
- Vary in severity whether one or several parts of the immune system are non functional (innate or adaptive)
- Considered rare disorders but taken as a whole = significant number of patients whose lives are profoundly affected by their condition
- Est. 80% patients no access to adequate care

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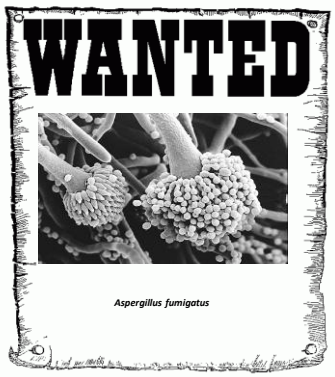
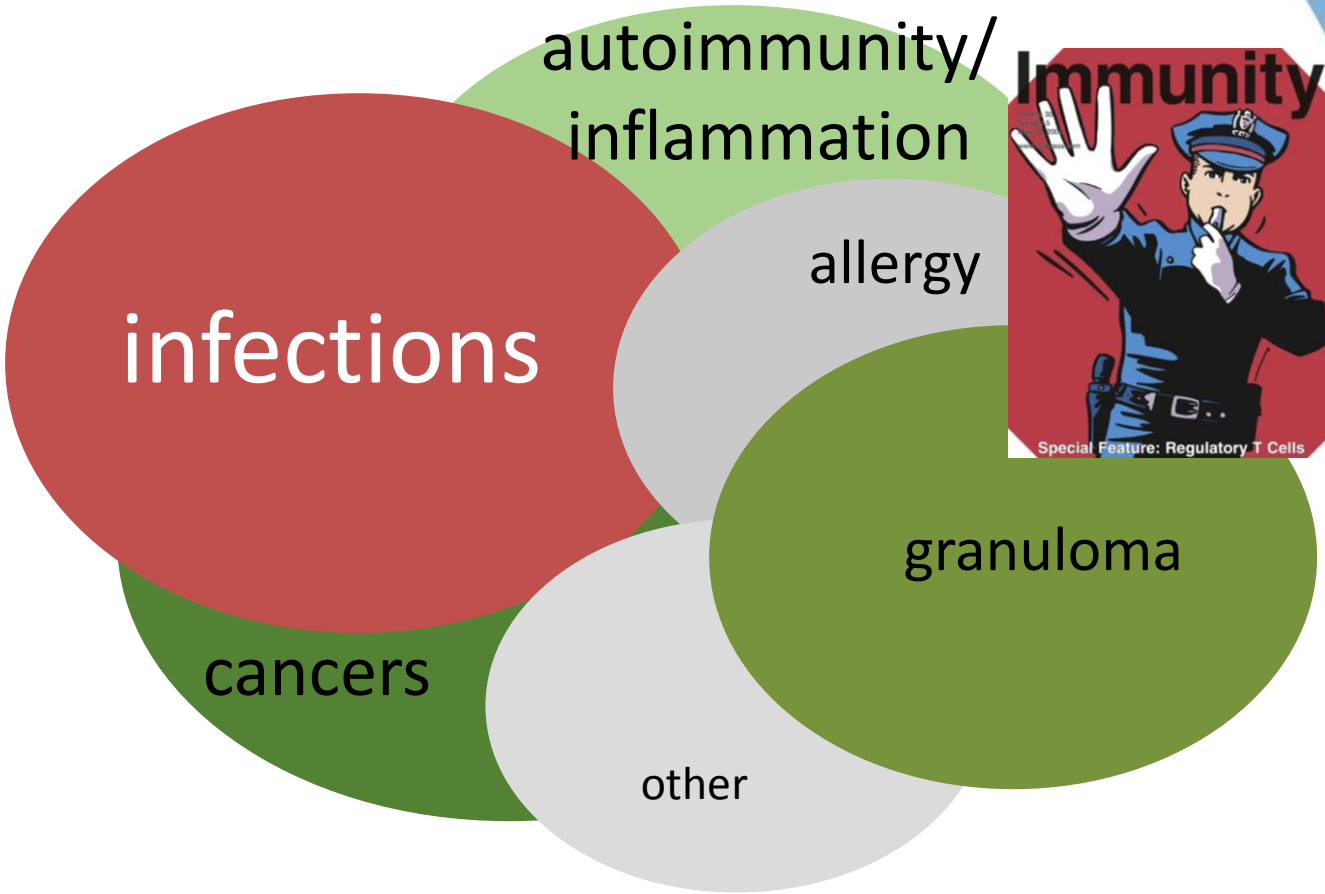
A diversity of manifestations





Pediatric Medical Centers → **Transition** → Adult Medical Centers

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Key challenges for patients

- Misdiagnosis and late diagnosis
  - Newborn screening
  - Genetic testing
- Access to & choice of treatment
  - IG therapies are not generic medicines
    - IVIG, SCIG, FSCIG – administered hospital/home
  - BMT/Gene Therapy
  - Many Others
- Transition care
- PIDs in adulthood / ageing
- Financing / reimbursement → HTA assessments

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PID Principles of Care

Published in Frontiers Immunology

Launched at European Parliament December 2015

frontiers in IMMUNOLOGY

HYPOTHESIS AND THEORY ARTICLE
published: 15 December 2014
doi: 10.3389/fimmu.2014.00627

Primary immune deficiencies – principles of care

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Primary immune deficiencies (PIDs) are a growing group of over 230 different disorders caused by ineffective, absent or an increasing number of gain of function mutations in immune components, mainly cells and proteins. Once recognized, these rare disorders are treatable and in some cases curable. Otherwise untreated PIDs are often chronic, serious, or even fatal. The diagnosis of PIDs can be difficult due to lack of awareness or facilities for diagnosis, and management of PIDs is complex. This document was prepared by a worldwide multi-disciplinary team of specialists; it aims to set out comprehensive principles of care for PIDs. These include the role of specialized centers, the importance of registries, the need for multinational research, the role of patient organizations, management and treatment options, the requirement for sustained access to all treatments including immunoglobulin therapies and hematopoietic stem cell transplantation, important considerations for developing countries and suggestions for implementation. A range of healthcare policies and services have to be put into place by government agencies and healthcare providers, to ensure that PID patients worldwide have access to appropriate and sustainable medical and support services.

Keywords: primary immunodeficiencies, awareness, diagnosis, management, treatments, worldwide

INTRODUCTION

WHY A PRINCIPLES OF CARE DOCUMENT/CALL TO ACTION

Primary immune deficiencies (PIDs) are a large and growing group of over 230 different disorders, caused when some components of the immune system (mainly cells and proteins) are defective. While PIDs are generally recognized as rare disorders, some are more common than others. Taken as a whole, they represent an important group of conditions that, if not treated, can be chronic, life-long, serious, and even fatal. The lives of patients with PIDs are profoundly impacted by their condition. The immune system normally helps the body to fight infections caused by germs (or "micro-organisms") such as bacteria, viruses, fungi, and protozoa. Owing to defective immune systems, people with PIDs are more prone to infections. In addition, a poorly regulated immune system may start to attack tissues, leading to inflammation, and autoimmunity (1, 2). When PIDs are left undiagnosed or are misdiagnosed, chronic illness and disability take a heavy toll on healthcare resources (3, 4).

The immune system is divided into two parts, each of which contains two components: on the one hand, soluble proteins may be particular for one germ (antibodies) or non-specific (complement). The other components are cellular – those that are specific for one germ only (lymphocytes) and innate cells that are involved in clearing all types of infections (such as phagocytes including macrophages and neutrophils).

Primary immune deficiencies are currently classified into groups, depending on the part(s) of the immune system affected. Over half the affected patients have antibody deficiencies and their treatment consists of replacing the missing antibodies (5). Cellular defects of lymphocytes are more severe and require replace-

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6 key principles

- Principle 1: The role for **specialised centres**
- Principles 2 : The Importance of **Registries**
- Principle 3: **International research collaborations**
- Principle 4: The role of **patient organisations**
- Principle 5: Management and **treatment options**
- Principle 6: Managing PID diagnosis and care in **all countries**

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PID comprehensive care models

Comprehensive care for PIDs

- From the foetus to the elderly
  - Transition care & ageing
- Diagnostics including genetic testing
- Individualized patient approaches
- Diverse treatment options including PDMPs, gene therapies, BMTs and other specialist treatments
- Choice of treatment
- Site of treatment
- Multidisciplinary, holistic care – need for specialist centres
- Patient-centredness
- Patient & family support

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CEREDIH

- French national reference centre for primary immunodeficiencies
- Funded through French national rare diseases programmes
- Highest number of registered patients in the EU
- Availability of whole range of diagnostics and specialist treatments

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CEREDIH : objectives

1. Organise and structure PID care in France
   - Ensure patients benefit from a holistic approach to care, including appropriate transition care & improve proximity care
   - Improve coordination between different structures

2. Improve knowledge and practises
   - Educate, train and inform
   - Epidemiology
   - Develop projects focusing on clinical research, therapeutics, public health and physiopathology

11 ans plus tard…

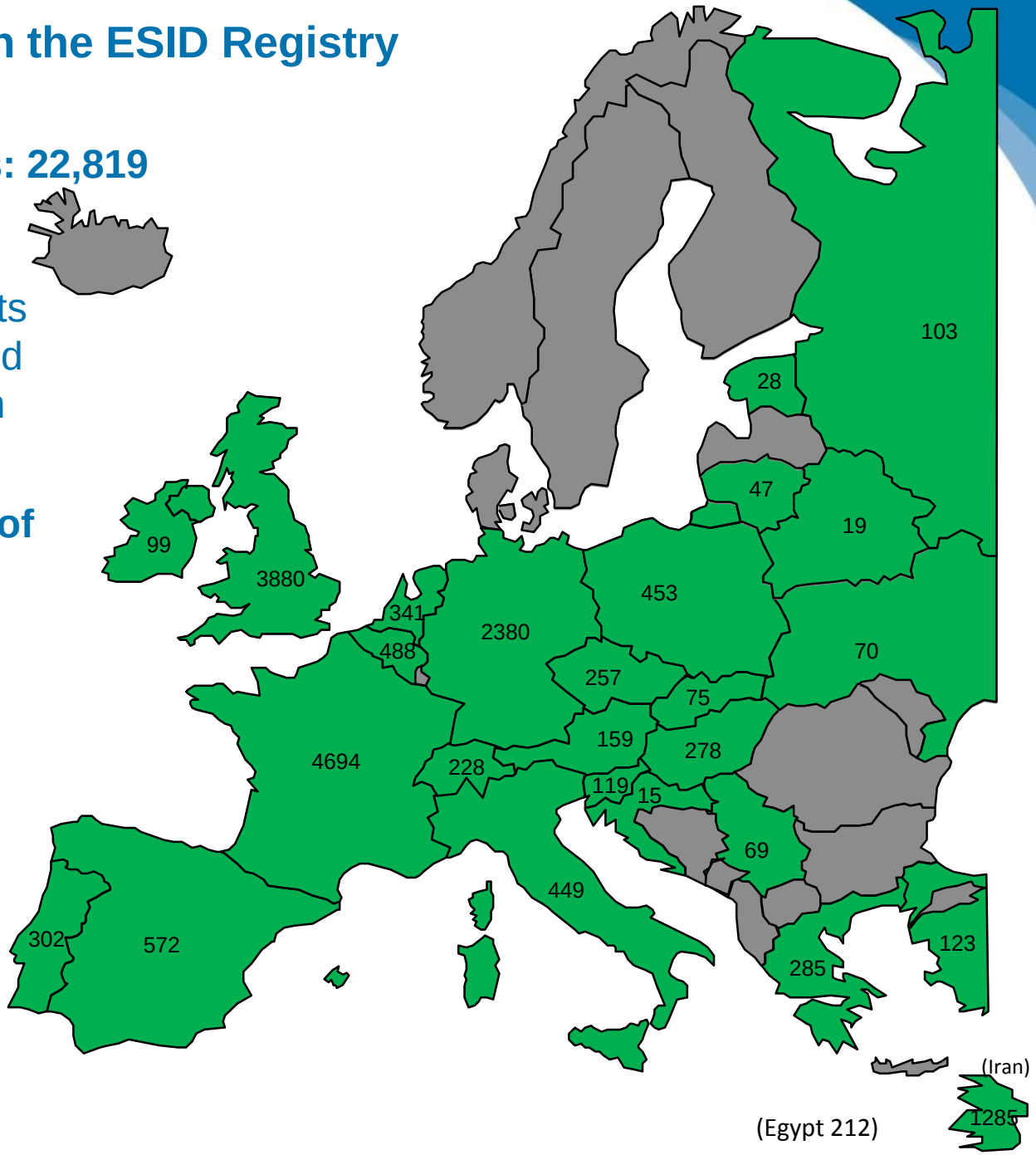
Registered patients in the ESID Registry

as of March, 17, 2017

Total number of patients: 22,819

Thereof number of patients with data Imported from old Registry that has not been verified yet: 5789

Map shows distribution of verified data only!



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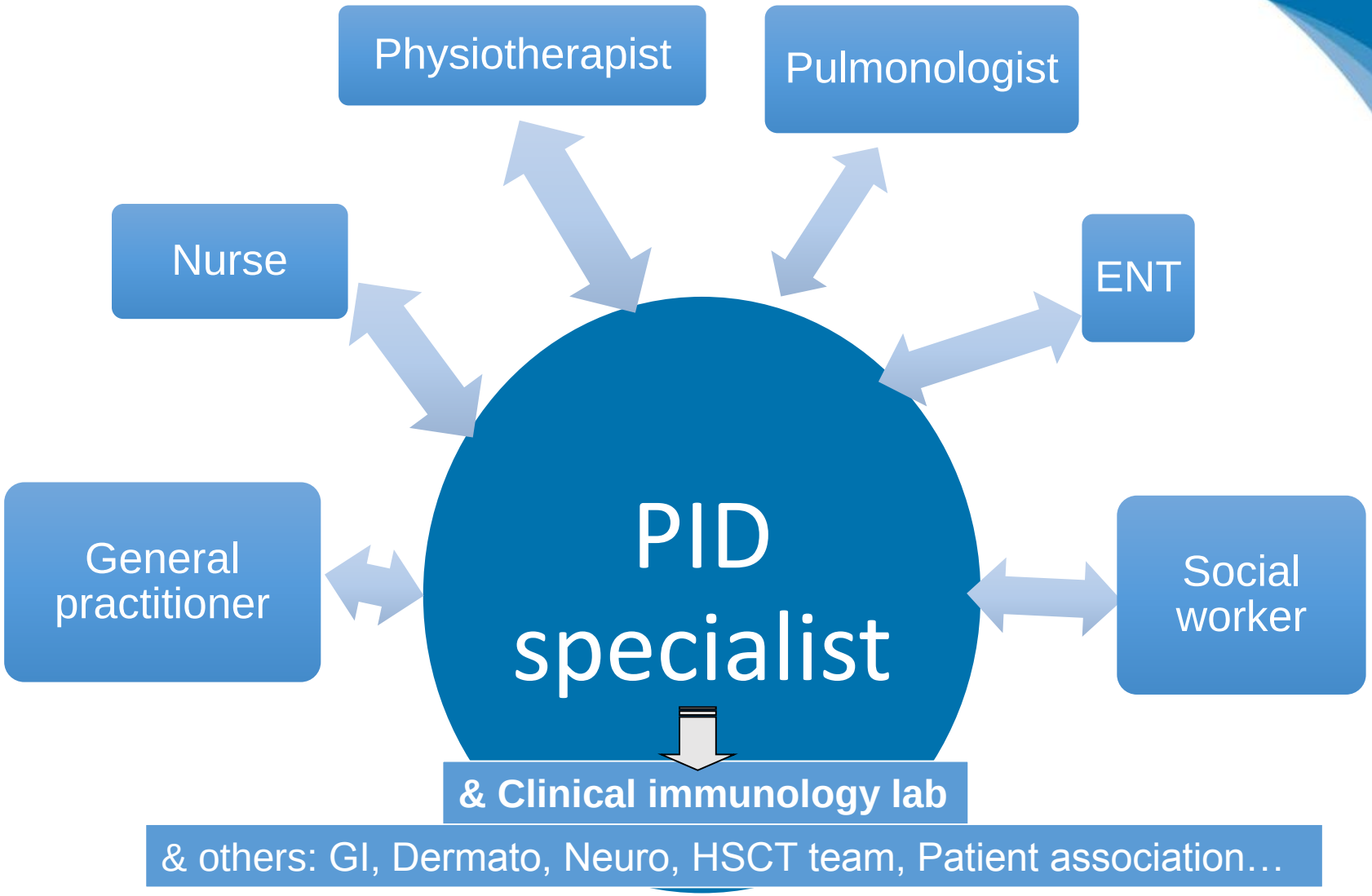

Keyword: NETWORKING
Tools: Monthly meetings, Visioconferences, Multidisciplinary consultations,…

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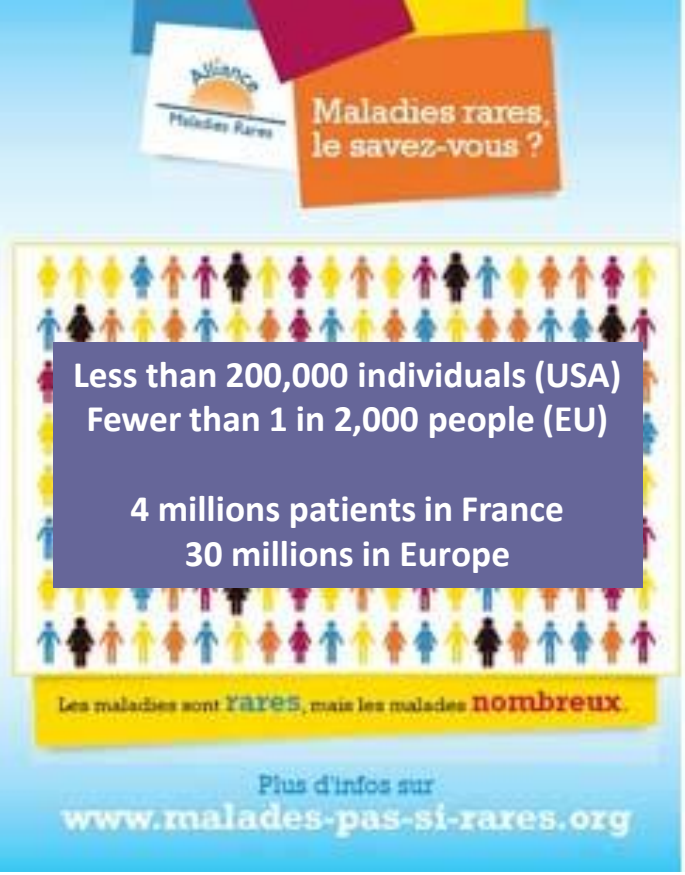
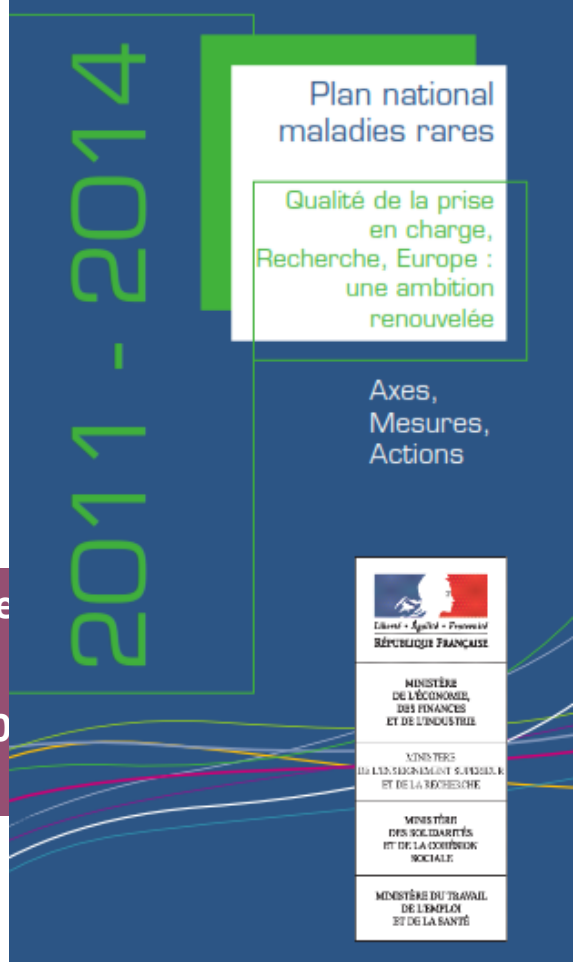


Less than 200,000 individuals (USA)
Fewer than 1 in 2,000 people (EU)

4 millions patients in France
30 millions in Europe

Ensure equity in the access to me
care and therapy
(Public Health Law, 09/08/200



Partnership with industry
Unrestricted annual grants to support research efforts (human resources and functioning)
See last slide

CEREDIH

Created in Nov 2005

Financing mechanisms

- Crédit MR : 213.000 Euros / (
  - Réévaluation par le PNMR3

Liberté • Égalité • Fraternité
RÉPUBLIQUE FRANÇAISE
Ministère de la Santé et des Solidarités

- Partenariats privés : 150.000 Euros/an

LFB L'ENGAGEMENT ÉTHIQUE · CSL Behring Biotherapies for Life™ · octapharma · Shire · Binding Site · gsk

- Soutiens associatifs : 10.000 Euros/an

ATEurope.org · Trophée Guillaume

- Salaires, Fonctionnement (déplacements,..)

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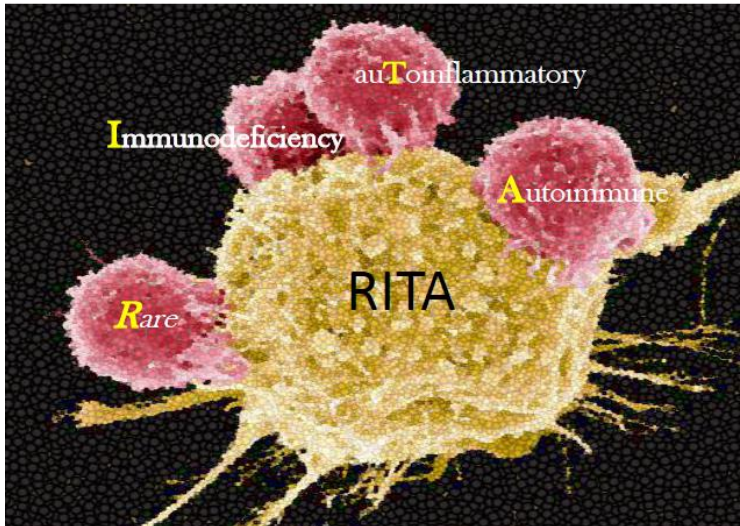
ERN Rare Immunological and Auto-Inflammatory Disorders (RITA)

- IPOPI involved in European Reference Network Board
- Higher visibility, including with health authorities and policy makers
- Clear, EU-endorsed framework to optimize cross border collaboration and care
- Patient-centred approach
- Funding opportunities for research and clinical projects
  - EU
  - National



European Reference Network
for rare or low prevalence complex diseases

Network
Immunodeficiency, Autoinflammatory and Autoimmune Diseases
(ERN RITA)

ERN RITA :
Rare Immunodeficiency, Autoinflammatory and Autoimmune Diseases

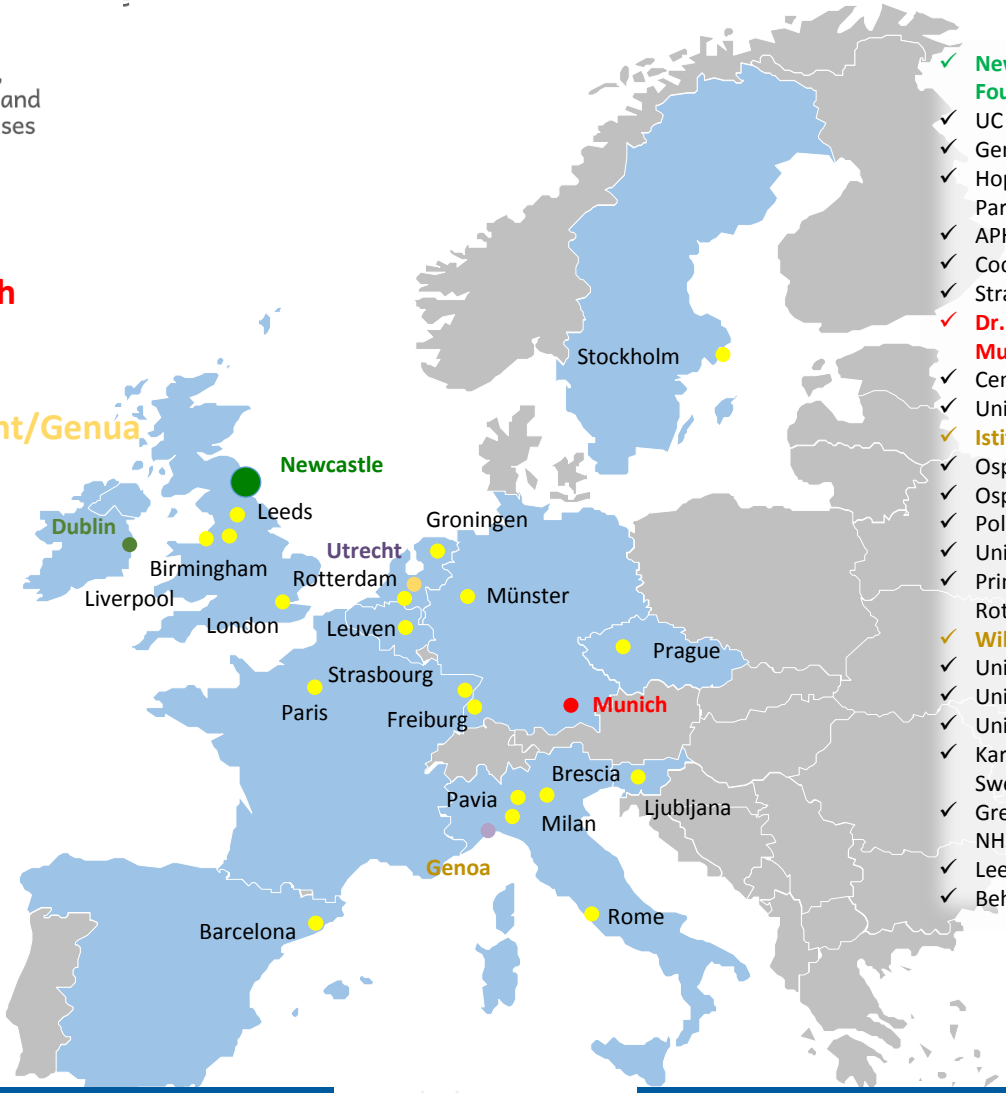
European Commission

Coordinator Newcastle
Coordination Unit Munich

PID Munich
Autoinflammation Utrecht/Genua
Autoimmunity Dublin

24 Health Care Providers

10 Member States



- ✓ **Newcastle upon Tyne Hospitals NHS Foundation Trust**
- ✓ UC Leuven
- ✓ General University Hospital, Prague
- ✓ Hopital Universitaire Necker Y Enfants Malades, Paris
- ✓ APHP Bicêtre hospital, University of Paris
- ✓ Cochin Hospital, Paris
- ✓ Strasbourg University Hospital, Strasbourg
- ✓ **Dr. von Hauner Children's Hospital, LMU, Munich**
- ✓ Center for Chronic Immunodeficiency, Freiburg
- ✓ University Children's Hospital Muenster
- ✓ **Istituto Giannina Gaslini , Genova**
- ✓ Ospedale San Raffaele Milan
- ✓ Ospedale Pediatrico Bambino Gesù Roma
- ✓ Policlinico San Matteo, Fondazione IRCCS Pavia
- ✓ University of Brescia
- ✓ Primary Immunodeficiency Center Erasmus MC, Rotterdam
- ✓ **Wilhelmina Children's Hospital, Utrecht**
- ✓ University Medical Center Groningen
- ✓ University Medical Centre Ljubljana
- ✓ University Hospital Vall d'Hebron , Barcelona
- ✓ Karolinska University Hospital Stockholm, Sweden
- ✓ Great Ormond St. & Royal Free Hospital London NHS Foundation Trust
- ✓ Leeds Teaching Hospital NHS Trust
- ✓ Behcets UK (London, Birmingham, Liverpool)

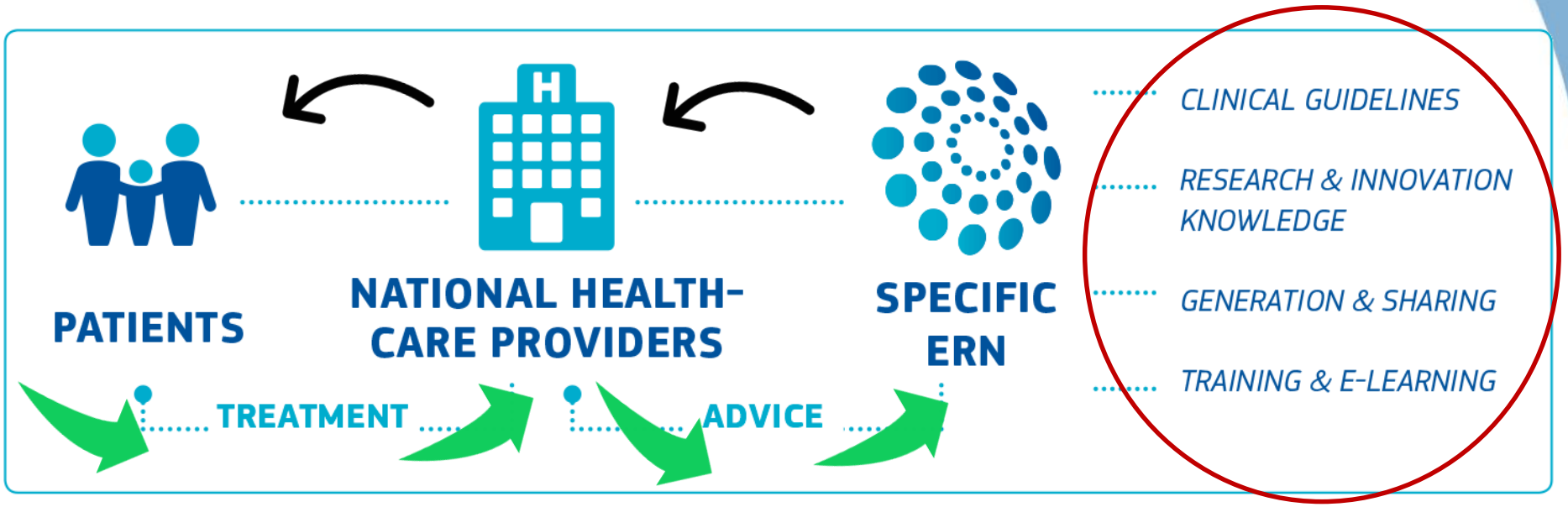
Rare Immunodeficiency auToinflammatory Autoimmune

European Reference Network

European Reference Network
for rare or low prevalence complex diseases

Share. Care. Cure.

European Commission



Clinical virtual care

Remote monitoring & follow-up

Remote guidance and diagnosis

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Source: Enrique Terol, DG Sante, EC

IPOPI and EU Consortia SCIDnet & Recomb

SCIDNET

DEVELOPING GENETIC MEDICINES FOR SEVERE COMBINED IMMUNODEFICIENCY

- Multi-stakeholder consortia for the research and development of gene therapy for SCID
- EU grants (Horizon 2020)
- IPOPI's role: represent SCID patients' views on the research and development process, incl. clinical design, review of trial protocols, patient/parent information
- Consortium of university hospitals, associations, SME and patient organisation from different European Union countries and Switzerland

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Gene therapy in inherited bone marrow disorders

- Cures now available for specific SCID and metabolic conditions (and encouraging early results in hemoglobinopathies)
- First ever cures with Gene Therapy
- Morbidity and mortality still low compared to other treatments and previous innovations
- New effective safer vectors are being used
- Each disease should be considered individually (gene regulation, expression, tissue specificity)

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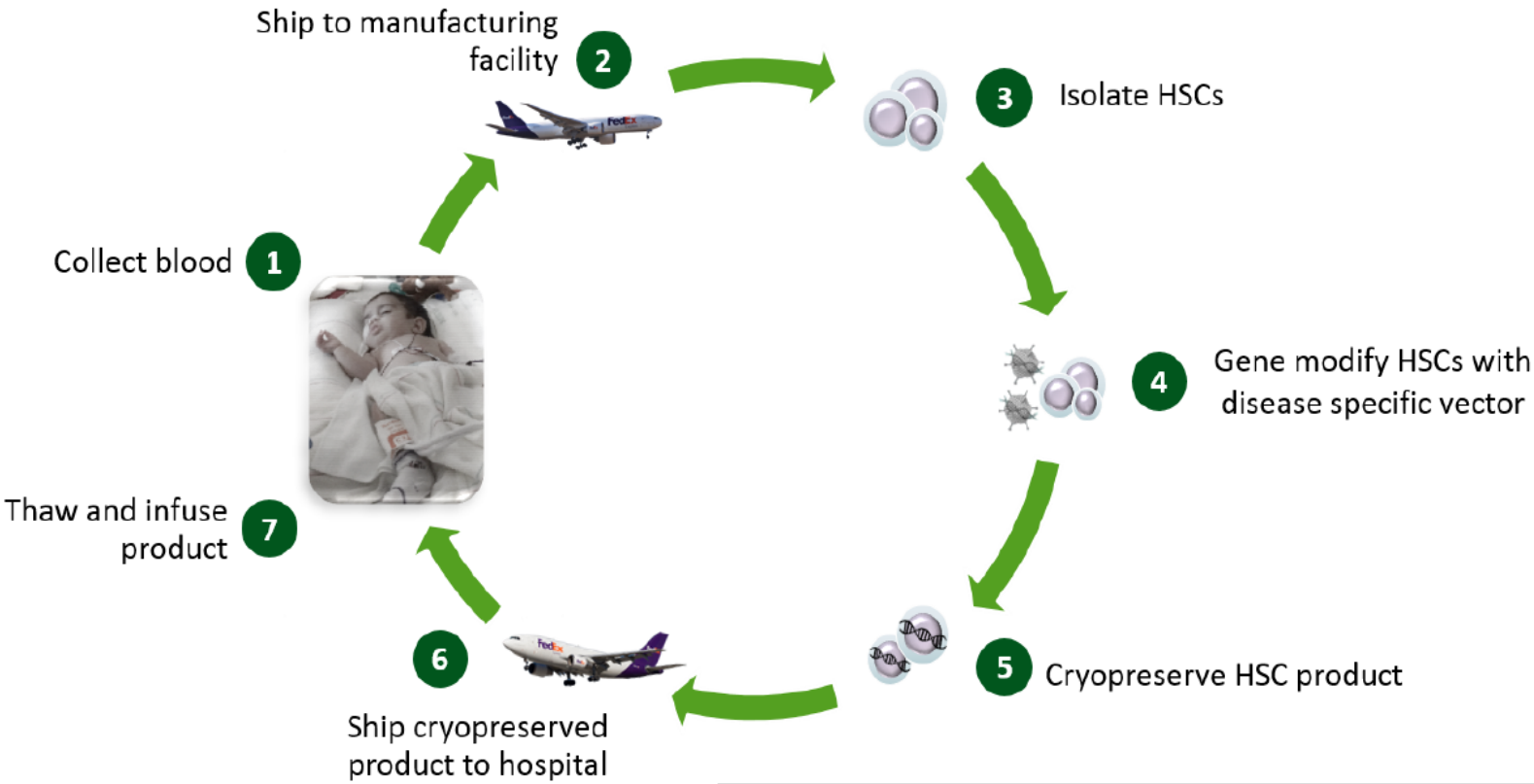
GMP cell product manufacturing platform

One platform, multiple products



GSK receives positive CHMP opinion in Europe for Strimvelis™, the first gene therapy to treat very rare disease, ADA-SCID

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The role of patient organisations…

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Advocacy

IPOPI PID Forums – Brexit impact for RDs/PIDs & Ageing with PIDs

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Growing older with a PID: transition of care and ageing

Recommendations of the International Patient Organisation for Primary Immunodeficiencies (IPOPI)

July 2017

Introduction

The International Patient Organisation for Primary Immunodeficiencies (IPOPI) is the association of national patient organisations, dedicated to improving awareness, access to early diagnosis and optimal treatments for people with primary immunodeficiencies (PIDs) worldwide.

PIDs are a group of more than 300 genetic rare disorders in which the immune system does not work adequately or at all. PIDs are often regarded as a group of conditions typically observed in paediatric age. However, PIDs affect patients throughout their life, and with increasingly more knowledge and awareness about rare diseases, more

IPOPI

Don't Brexit on rare disease patients – the case of PIDs

Recommendations of the International Patient Organisation for Primary Immunodeficiencies

March 2017

Introduction

IPOPI is the International Patient Organisation for Primary Immunodeficiencies. As the association of national patient organisations, it is dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide.

Following the United Kingdom's (UK) vote in the Brexit referendum, both the EU and the UK are currently preparing for the formal negotiation process. The potential consequences of the UK leaving the EU are still unknown. However, patients with primary immunodeficiencies (PIDs), healthcare professionals working in the field and other stakeholders involved with rare diseases have expressed serious concerns about the consequences this political withdrawal from the EU will entail for patients, as well as healthcare professionals, researchers and other stakeholders.

SCID NBS Campaign

EUROPEAN PARLIAMENT 2009 - 2014

Committee on the Environment, Public Health and Food Safety

08.2.2013

NOTICE TO MEMBERS

(0001/2013)

Question for Question Time in committee 0001/2013
under Rule 197 of the Rules of Procedure
by Glenis Willmott, Frédérique Ries, Miroslav Mikolášik

Subject: Oral question on "Newborn screening for rare diseases"

change.org Start a petition Browse Log in

Petitioning UK Newborn Screening committee

Stop the unnecessary deaths of babies. Include SCID in the UK new-born screening programme!

Susie Ash London, United Kingdom

Sign this petition

24,917

24,917 have signed. Let's get to 25,000.

Last name

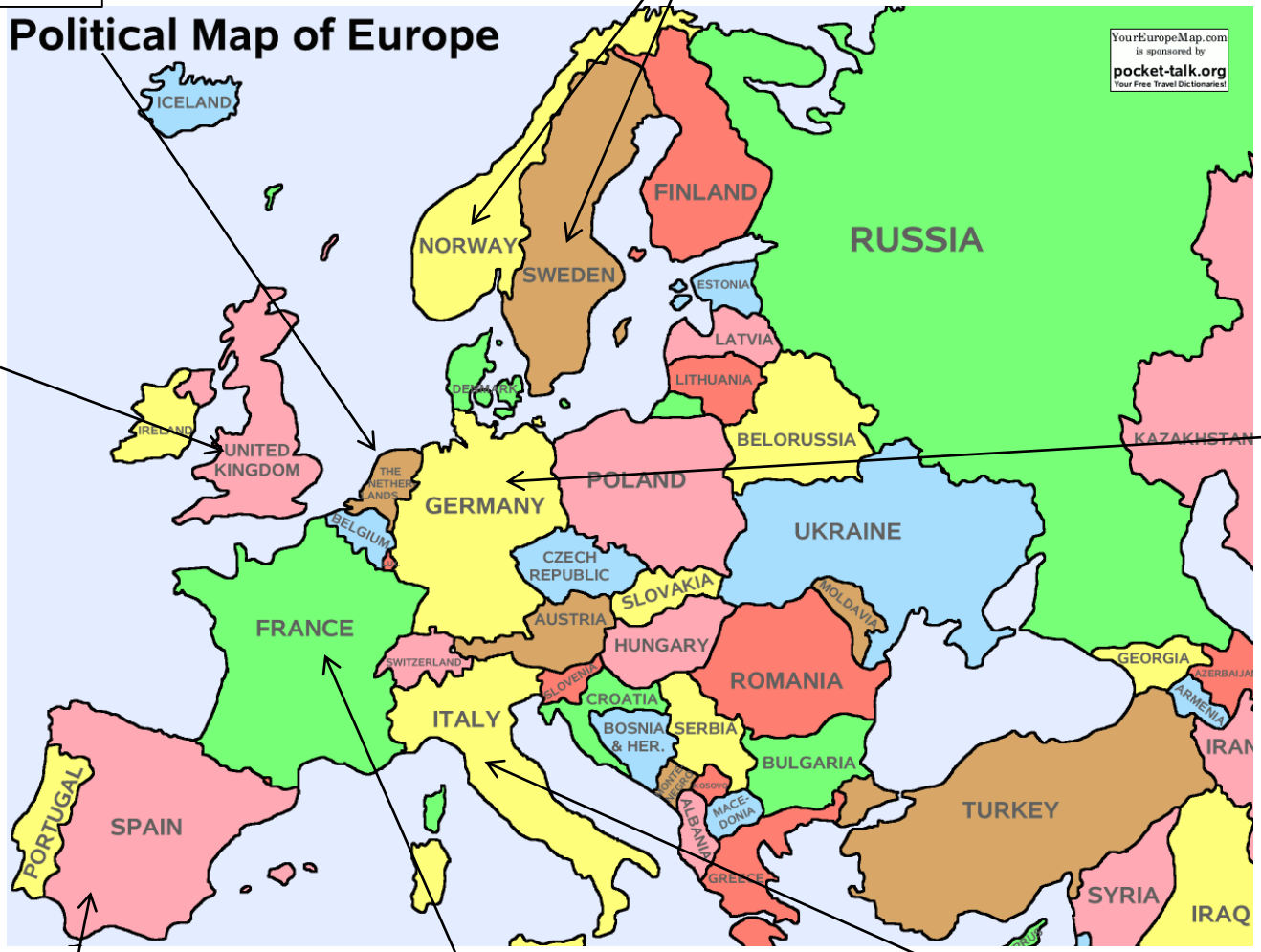
Email

TRECS
program
Ongoing
discussion

TRECS/KRECS
Prospective screening

TRECS
Ongoing
discussion

TRECS/KRECS
Prospective
screening



TRECS/KRECS
Pilot program

TRECS
Pilot program
Due to start

Mass spec screening
For ADA

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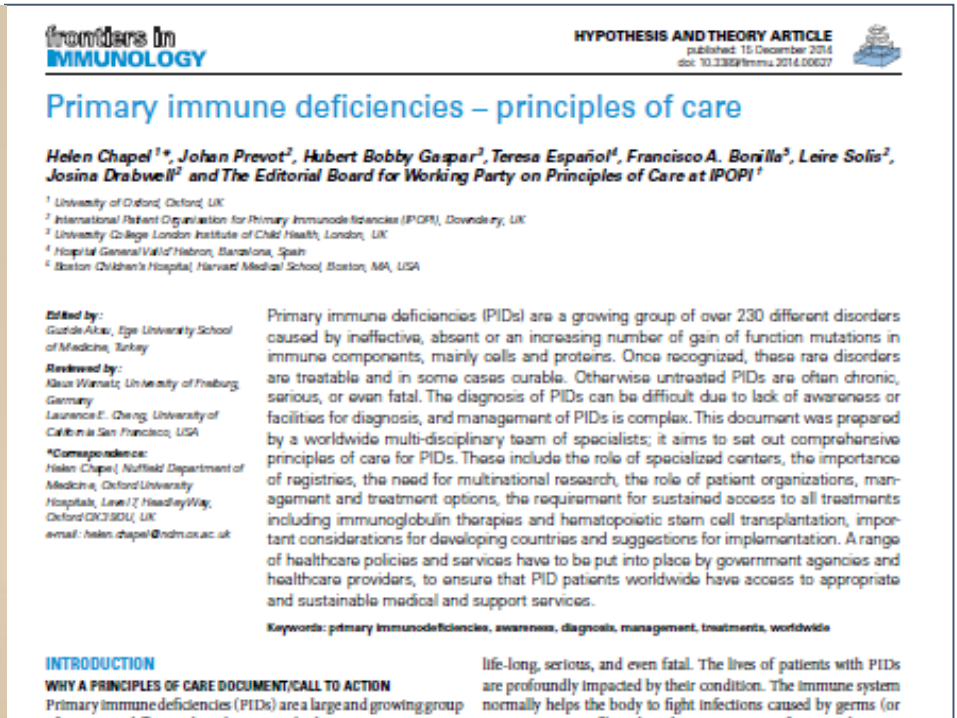
Implementation of PPLs of Care

- NMO workshop – Interactive Session with all NMOs
- Distribution of PPLs of Care Implementation Package
- Started working on implementation survey
- Used by doctors in Latam, Asia, Europe, Africa



frontiers in IMMUNOLOGY

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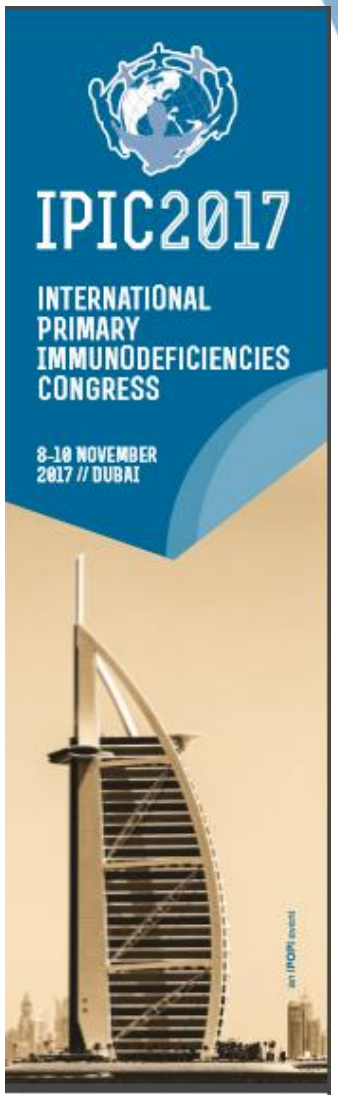
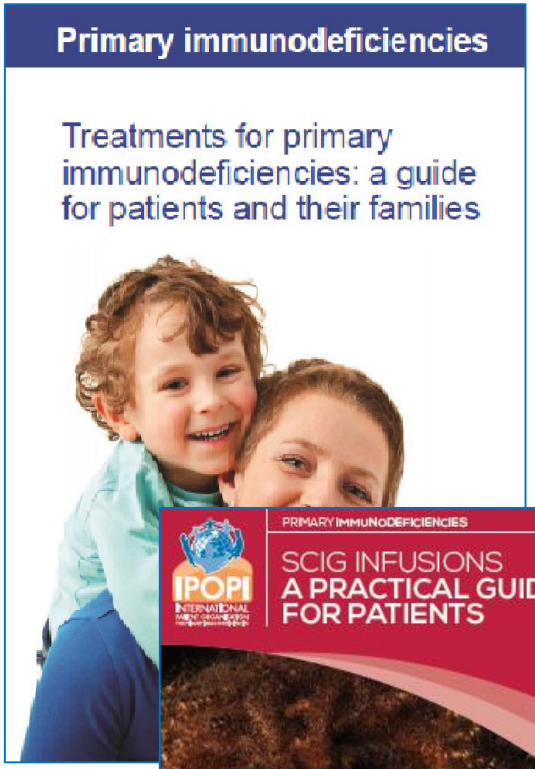
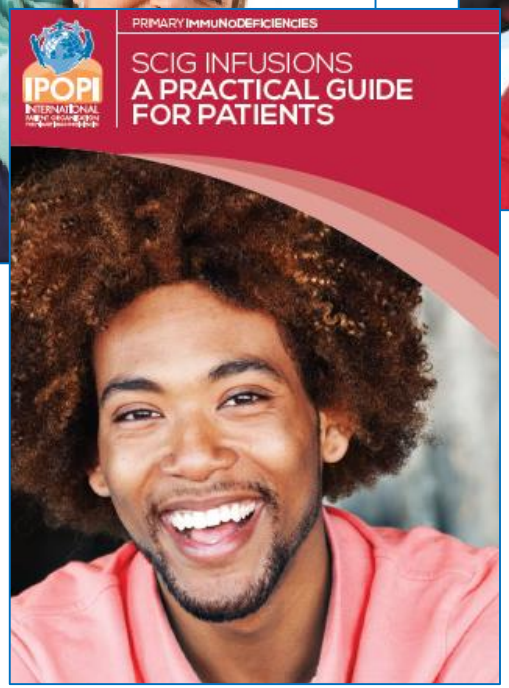
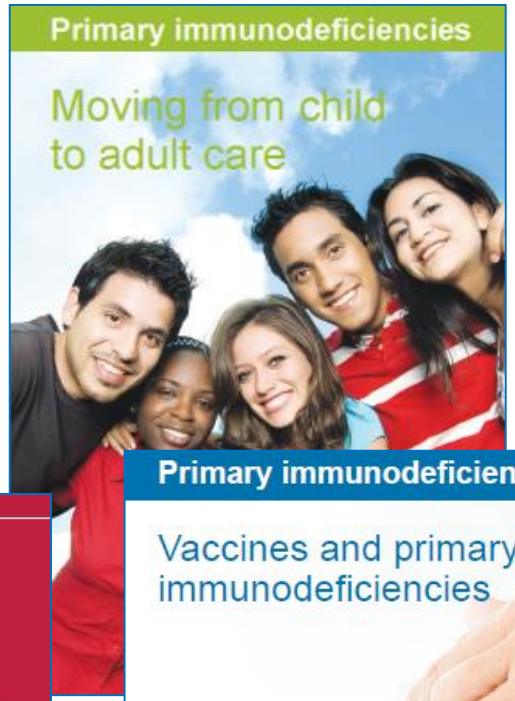
Driving clinical care

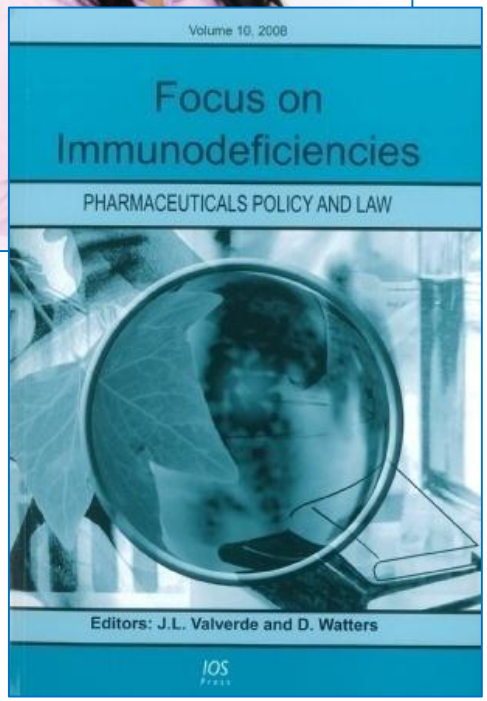


Education









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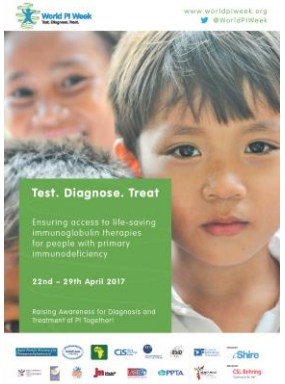
Awareness – World PI Week

22-29 April every year

- **IPOPI Supports local implementation of WPIW** through IPOPI NMO Support programme
- **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
- Since the inception of the campaign IPOPI has supported **103 NMO national campaigns**



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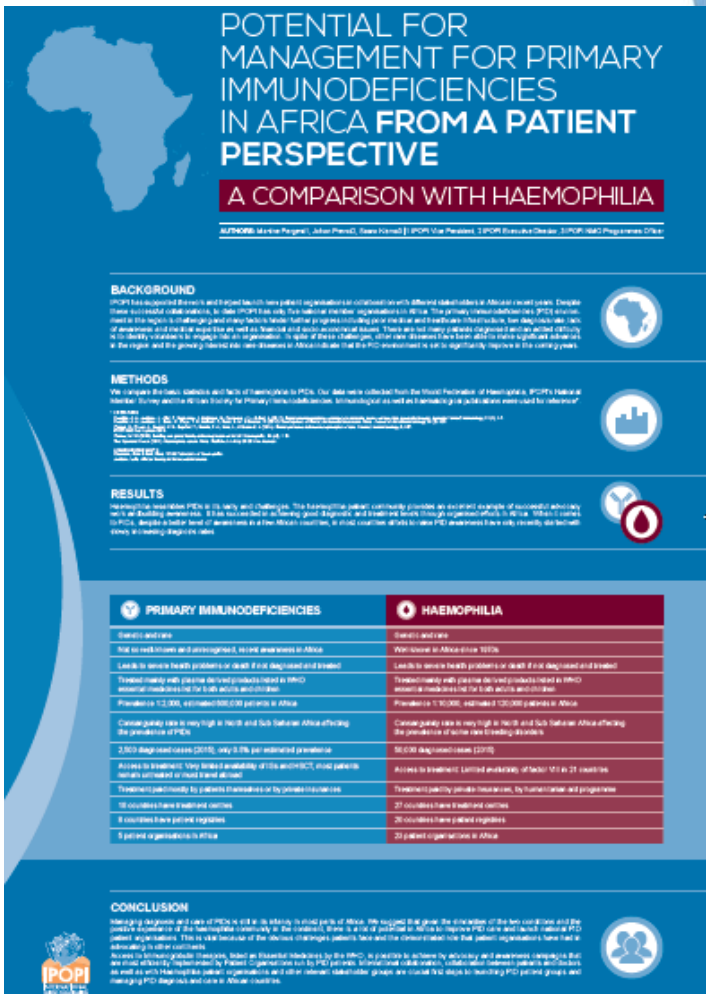
Working with others

PLUS
PLATFORM OF PLASMA PROTEIN USERS

- PLUS Stakeholders Consensus Meetings
- Organised since 2010 in either Dublin or Estoril



POTENTIAL FOR MANAGEMENT FOR PRIMARY IMMUNODEFICIENCIES IN AFRICA **FROM A PATIENT PERSPECTIVE**

A COMPARISON WITH HAEMOPHILIA

BACKGROUND

METHODS

RESULTS

PRIMARY IMMUNODEFICIENCIES	HAEMOPHILIA
Genetic and rare	Genetic and rare
Not so well known and unrecognised, recent awareness in Africa	Well known in Africa since 1970s
Leads to severe health problems or death if not diagnosed and treated	Leads to severe health problems or death if not diagnosed and treated
Treated mainly with plasma derived products listed in WHO essential medicines list for both adults and children	Treated mainly with plasma derived products listed in WHO essential medicines list for both adults and children
Prevalence 1/2,000, estimated 500,000 patients in Africa	Prevalence 1/10,000, estimated 120,000 patients in Africa
Consanguinity rate is very high in North and Sub Saharan Africa affecting the prevalence of PIDs	Consanguinity rate is very high in North and Sub Saharan Africa affecting the prevalence of some rare bleeding disorders
2,500 diagnosed cases (2015), only 0.5% per estimated prevalence	50,000 diagnosed cases (2015)
Access to treatment: Very limited availability of IVIg and HSCT, most patients remain untreated or must travel abroad	Access to treatment: Limited availability of factor VIII in 21 countries
Treatment partly by patients themselves or by private insurances	Treatment partly private insurances, by humanitarian programmes
18 countries have treatment centres	27 countries have treatment centres
8 countries have patient registries	26 countries have patient registries
5 patient organisations in Africa	29 patient organisations in Africa

CONCLUSION

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Conclusions

- Few (none?) are the countries where fully effective comprehensive care models have been implemented
- The funding mechanisms involved in the financing of such frameworks are country/region dependent
- HTA assessments must take into account rarity of disorders
- The vast majority of patients affected with a PID worldwide still do not have access to their life saving and/or life enhancing treatment
- The situation is improving
- IPOPI is committed to further develop as an international advocacy organisation on behalf of PID patients worldwide through collaboration with other PID stakeholders

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