

IPOPI

**International Patient Organisation for
Primary Immunodeficiency**

2nd Symposium for Primary Immunodeficiencies
Paediatric Immunology
Aegli Zappiou
Athens, Greece

The global organisation working to improve the quality of life for people with primary immunodeficiencies



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IPOPI
INTERNATIONAL
PATIENT ORGANISATION
FOR PRIMARY IMMUNODEFICIENCIES

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WHAT IS IPOPI?

The global patient organisation working to
improve access to early diagnosis
and optimal treatment of primary
immunodeficiencies

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What are the purposes of IPOPI?

- To work to improve access to early diagnosis and optimal treatment and care
- To promote the establishment and support the work of National Member Organisations
- Be a strong, efficient and reliable global patient organisation

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WHAT has IPOPI achieved?

- A European Consensus Conference funded by the European Commission
- The re-instatement of immunoglobulins to the WHO Essential Medicines List (EML)
- Brought together 29 national patient organisations – Belgium could become number 30!
- Produced an excellent website and regular electronic newsletter
- Organised an Global Leaders forum in Primary Immunodeficiency

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- Produced an on-line directory of immunoglobulins available in countries around the world
- Developed an effective Strategic Plan which is reviewed each year
- Developed a pattern of regional meetings bringing together patients, nurses, doctors, regulators and industry
- Become a member of the World Health Organisation Global Collaboration on Blood Safety (WHO – OMS - GCBS)
- Established an office as a resource to members

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Biennial meetings with ESID and INGRID

Rhodes Greece	1998
Geneva Switzerland	2000
Weimar Germany	2002
Versailles France	2004
Budapest Hungary	2006
Den Bosch Netherlands	2008
Istanbul Turkey	2010

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Consensus Conference



European Primary Immunodeficiencies
Consensus Conference
19 – 20 June 2008
Paul Ehrlich-Institut, Langen, Germany



Conference under the
auspices of the
European Commission
of the EU



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Immunoglobulins reinstated on the WHO list



WORLD HEALTH ORGANISATION

Essential Medicines List (15th List , March 2007)

Application for the inclusion of Polyvalent Human Immunoglobulins in the WHO Model List of Essential Medicines

Submitted by:




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www.who.int/medicines/publications/essentialmedicines/en/index.html



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First Global Leaders meeting 2009



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WHY have a national patient organisation?

- It brings people together
- It enables patients to share problems and ideas
- It can be a powerful force for improving diagnosis and achieving better management
- It enables the patient community (together with doctors) to engage with political decision makers locally and nationally...

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WHY become a member of IPOPI?

- Your NMO becomes part of a global organisation which is particularly relevant and useful in the EU community
- You can share the experience of others who have faced problems with diagnosis, management and supply of safe and effective therapeutic materials
- It makes your own NMO more powerful – strength in numbers!

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PiNSA

PRIMARY IMMUNODEFICIENCY NETWORK OF SOUTH AFRICA



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Personal background



It is my hope that all children who are born with a primary immunodeficiency will have the opportunity to live a full and healthy life. I am grateful to the people who have helped me along the way and to the doctors who have helped me understand my condition. I am also grateful to the people who have helped me to live a full and healthy life.

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The present situation

- Support:** telephonic, e-mail
- Advocacy:** website, newsletter, regional meetings
- Information:** website, IPOPI
- Fundraising:** IPOPI grant, WIN grant, Binding Site, NBI
- Lobbying:** essential medicines list, posters in clinics

"SPUR" severe persistent unusual recurring

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PiNSA Website

- Who we are
- What is Primary Immunodeficiency
- 10 Warning Signs and "SPUR"
- Frequently Asked Questions
- Patients Stories
- Information Links
- Helpline
- Credits

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Ongoing relationship with IPOPI



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IPOPI Three City Advocacy Tour 2008

Purpose:

- raise awareness
- give support
- feedback to Board

Itinerary:

- Cape Town
- Durban
- Johannesburg
- Paediatric Congress Sun City



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Efharisto
Joy Rosario
IPOPI Board

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