

IPOPI

Awareness Campaign Workshop

Saturday 17th November 2012

Barcelona

Teresa Español



Awareness Campaign

Success Stories

from across the globe





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



FIRST PATIENT AWARENESS CAMPAIGN WORKSHOP 2011

- **BELGIUM JULY 2011**
- **BOPPI – BELGIAN PATIENT ORGANISATION**
- **WORKSHOP - OBJECTIVES**
 - 1. MEMBERSHIP STRATEGY**
 - 2. PUBLIC & POLITICAL CAMPAIGN**
 - 3. MEDICAL COMMUNITY OUTREACH**
 - 4. MEDIA OUTREACH**



FIRST PATIENT AWARENESS CAMPAIGN WORKSHOP 2011

- IPOPI Awareness Workshop Belgium July 2011
 - Raise PID awareness and BOPPI's profile and representation
 - Membership material developed and distributed by BOPPI & BPIDG
 - Public poster campaign during World PI Week 2012
 - Awareness event during World PI Week 2012
 - Raise Political awareness
 - Half day seminar with BOPPI and BPIDG in Belgium Parliament
 - Presentations: patients, immunologists,
 - expert on healthcare costs
 - Distribute call to action & press release
 - Follow up with local media



RUSSIAN AWARENESS CAMPAIGN

- IPOPI NMO Professionalization Programme Russia
 - First National PID Workshop in Russia October 2011
 - Creation of Russian PID Organisation November 2011
 - World PI Week awareness campaign
 - 10 Warning Signs media campaign with local TV stars support
 - Call to action Russian Ministry of Health to obtain support for distribution of key information materials to all hospital and medical centres
 - Letter signed by 1,000 signatories for recognition of rare diseases status in healthcare budget and policies



Dublin Workshop 2012

On Saturday 12 May 2012, a workshop was organised by IPOPI with PID patients and scientists in order to provide patients with:

- concrete examples of successful awareness campaigns
- overview of available IPOPI tools
- overview of the Irish environment in terms of patient awareness and advocacy from a key patient advocate with a wealth of experience in leading successful patient groups in Ireland
- Establish a stepwise awareness campaign plan



Dublin Workshop 2012 (cont.)

Local strategy – the way forward: Agreements on potential actions and timelines

Direct/Practical patient care issues

- Emergency medication
- Long-term illness card
- Affordability of the medication

Structural care issues

- Centres of reference
- Funding to hospitals/treatment units



Dublin Workshop 2012 (cont.)

Timeline and responsibilities

Activity	Deadline	Responsibility
NMO set-up: <ul style="list-style-type: none"> • Circulation of the statutes from the previous organisation to all the participants • Selection of a location for the next NMO meeting • Support in the organisation of the next NMO meeting • Provision of a strategy and information on Irish groups that the NMO should consider in their future activities 	23 June May-June May-June June-July	Maria Nolan All participants IPOPI RPP
Political awareness campaign: <ul style="list-style-type: none"> • Organisation of meetings with Irish MPs • Organisation of meetings with Irish MEPs • IPOPI PID Forum on Rare Diseases plans 	Oct-Nov 26 Sep	NMO IPOPI & RPP
Awareness raising campaign: <ul style="list-style-type: none"> • Discuss the possibility of developing a programme for the World PID Week 	June-April 2013	NMO with support from IPOPI



WORLD PRIMARY IMMUNODEFICIENCY WEEK

- First World Primary Immunodeficiency Week, April 2011
- IPOPI supported the organisation of 13
 - national World PI Week campaigns.
 - In 2012 IPOPI has supported 17 NMOs
- Media outreach campaigns
- Medical & public awareness campaigns
- Advocacy campaigns
- Targeted events
- Publications



WORLDWIDE

28 countries took part in 2011

80% of respondents used PI week materials:

PRESS RELEASE

PARENT/CARER TOOLKIT

SCHOOL TOOLKIT

PARLIAMENTARY TOOLKIT

POSTCARD

2012 A NEW POSTER translated in many languages





22nd - 29th April 2013

World PI Week

22 - 29. April 2013

Primary Immunodeficiency:
Turning Hope into Action!

TEST!

DIAGNOSE!

TREAT!



Europe

AUSTRIA - An awareness march in Salzburg and Graz. PID diagnosis low, flyers, posters in hospitals and pharmacies. Raise awareness among clinicians.

BELGIUM - Opening of a JMF diagnostic centre. Survey to establish knowledge of PID.

CYPRUS - Together with Rare Disease Organisation. Raising awareness amongst doctors, public.

CZECH REPUBLIC – 2day ESID meeting focus PID

ESTONIA - Members distribute leaflets to all related specialists such as lung, ENT, gastro etc.



Europe

FRANCE - Medical staff and nurses at hospitals, public and national press. DVD with testimonies of patient siblings.

GREECE - Media outreach and a concert in Athens to introduce PID to the general public.

HUNGARY - Program to educate medical students and health care professionals.

**IRELAND – 2012 ARTICLE IN IRISH TIMES. Ronan McGreevy's story.
Meeting at the European Parliament with Irish MEP's for the IPOPI EU Forum.**

ITALY - Book about the PID and NMO's work. Database with GP's and paediatricians and spread info PID groups.



Europe (Cont.)

NORWAY - Meeting at Bergen University, media cover

POLAND - Warsaw meeting with media, opinion leaders, industry, patients etc.

SERBIA - Distribution of brochures for children and parents. Summer camp for patients.

SPAIN - Awareness campaign in Barcelona, report on improvements for PID patients in Catalan. Website increased visitors.

SWEDEN - Patient organisation together with industry and Professors Hammarstrom and Palmblad produced an on line guided tour through the immune system. Family camps every year.

UNITED KINGDOM - Parliamentary Reception and promoting the SCID newborn screening programme.



OTHER COUNTRIES

- **SOUTH AMERICA - ARGENTINA, BRAZIL, CHILE, COLOMBIA, PERU, VENEZUELA**
- **NORTH AMERICA – CINCINNATI**
- **AFRICA - MOROCCO, SOUTH AFRICA**
- **MIDDLE EAST- UNITED ARAB EMIRATES**
- **ASIA - INDIA, IRAN, TURKEY**



Thank you to the workshop's sponsor

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