Improving Access to Care for Patients with Primary Immunodeficiency

22nd - 29th April 2016

Test - Diagnose - Treat
Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sudan
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional

WPIW 2016: An Expanding Community

Baxalta
Gold Sponsor

CSL Behring
Biotherapies for Life™
Silver Sponsor

3 New Member Organisations

Welcome to:
APSID
ARAPID
SEAPID

Click on organisations' logos to visit website
WPIW 2016: A Common Mission

Test. Diagnose. Treat.

- **Drive awareness** of Primary Immunodeficiencies (PI)
- **Increase understanding** of PI amongst GPs, nurses, parents, school teachers, day care employees, governments and the public
- **Encourage health authorities** to adapt and use WPIW materials for local health information campaigns to drive early diagnosis
- **Stimulate efforts** to improve diagnosis, treatment and QoL
- **Promote the model of combining physician education and global awareness** with the infrastructure to diagnose and treat PI
- **Stimulate national outreach** towards governments by promoting use of the PI ‘advocacy’ tool kit with key material and argumentation
WPIW 2016: The Website

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional

RAISING AWARENESS, DIAGNOSIS AND TREATMENT OF PI TOGETHER

World PI Week is a global campaign which aims to raise awareness and improve diagnosis and treatment of primary Immunodeficiencies (PI). Explore the website to learn how you can make a difference and ultimately improve the quality of life of people with PI worldwide. You can learn PI facts, sign the awareness petition, browse events or download resources.

Joanna Tierno
United States
Living with PI

"I lived with hypogammaglobulinemia since I was 6 months old but my road to proper diagnosis and treatment was long, painful and sometimes terrifying. Treatment with immune globulin has been the best thing that has happened to me and has given me a good quality of life and a chance to grow older."

Nicole Shearing
Australia
Living with PI

"34 years after having lived with constant shunt, ear, throat, chest, gut, bowel, bladder, kidney, skin infections and Golden Staph in my brain (dorsal root gangliitis anyone?) it’s such a joy as well as a placentation abortus at 27 weeks I was diagnosed with CVID. The journey is long but together we’re strong. Even stronger than Golden Staph!"

GET INVOLVED IN OUR 2016 CAMPAIGN

Add your story
WPIW 2016: Website - Key Features

Story book

The story book is the platform where patients become the protagonists of the campaign sharing their experience with the wider public.

Generated 108 stories to date!! Provides valuable insights into patients and their needs.

Local resources

Materials exist in increasing number of languages to support campaigns in local communities.

Materials produced in: Arabic, Danish, Farsi, French, German, Italian, Norwegian, Portuguese, Romanian, Serbian, Spanish, Swedish and Ukrainian.

Online presence

The website has direct links to WPIW Facebook, Twitter, Instagram and YouTube accounts as well as a live Twitter Feed.

Greatly increased global reach of the campaign!
WPIW 2016: Website - Key Features

The **Get Involved** section provides access to an online global map allowing to **promote events** and find information on what is happening during WPIW editions.

The **Get Inspired** section includes **practical toolkits for supporters** to organise their events, conduct media activities, reach out to local authorities, and showcase **best practice**.

The **mobile responsiveness** of the website allows access to the WPIW website from all smart phones / mobile devices.
A specific **Call to Action** was developed in line with WPIW 2016 theme: Improving Access to care for PI patients and was promoted on the WPIW website, inviting visitors to sign the petition.

**Call to Action**

```
World PI Week 2016: Improving Access to Care for patients with Primary Immunodeficiency.

Many countries and regions are taking advantage of the recent years to improve access to care for patients with PI. Many endemic diseases are on the increase, with HIV/AIDS being the most prominent, but other infectious diseases like Hepatitis, Mycobacterium Tuberculosis and many others are also on the rise. Even patients with primary immunodeficiency may experience symptoms that are similar to common or even serious infections.

This year, we are raising our voices to call on policymakers, health authorities, and healthcare funders to join in place the relevant mechanisms to ensure that PI patients receive the necessary treatment to improve access to care throughout the world.

More specifically, we call for treatments, health and medical policies to
```
WPIW 2016: New Materials

New Poster!
New eBanners!
Updated Infographic!

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sudan
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional

Improving Access to Care for Patients with Primary Immunodeficiency
22nd - 29th April 2016
Test - Diagnose - Treat

Test - Diagnose - Treat

Have a look at our campaign material online
WPIW 2016: Press Announcements

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sudan
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional
CAMPAIGN HIGHLIGHTS
“Stakeholders united under the World PI Week banner raise their voices this year again to call on decision-makers, health authorities, healthcare funders, and professionals to put in place the relevant mechanisms to ensure that all PI patients can receive safe, efficient and appropriate treatments and optimum care throughout the world, for both their own health benefit, and the long-term benefit of the health system”.

Publications

- Journal of Clinical Immunology (JOCI)
- LymphoSign Journal
- News and EFIS
- JMF Online
- PPTA Online
- Ongoing post WPIW submissions of the Editorial in other journals
Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional

World Pi Week 2016: Scientific Editorial

Ensuring patients with primary immunodeficiency have access to optimum care throughout the world: what remains to be done

World Pi Week
Test. Diagnose. Treat.
WPIW 2016: Translated Materials

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sudan
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional

Translated in more than 15 languages
WPIW 2016: Social Media Activities

- Platform of engagement for international scientific societies, nurses, patients’ group, industry and specialised media
- Dedicated hashtags: #WorldPIWeek, #WPIW, #Piawareness, #primaryimmunodeficiency @WorldPIWeek

World PI Week on Facebook, Twitter and Instagram

- 1000 likes on FaceBook
- 500 followers on Twitter
- On-going dialogue on the development of the campaign
- Ideal platforms for sharing pictures of activities during the week
- Driver for new petition signatures, event and story sharing
- Interaction amongst widespread local organisations
- Platform for updates on rare disease-related discussion
WPIW 2016: the Power of Social Media

World PI Week on Facebook, Twitter

Have a look at social media engagement around #WPIW

Argentina  Austria  Belgium  Brazil  Canada  Colombia  Egypt  France  Germany  Greece  Indonesia  Iran  Korea  Lithuania  Libya  Malaysia  Mexico  Netherlands  Poland  Portugal  Puerto Rico  Quebec  Romania  Russia  Spain  Sudan  Sweden  Turkey  Uganda  USA  Venezuela  International  Regional

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina  Austria  Belgium  Brazil  Canada  Colombia  Egypt  France  Germany  Greece  Indonesia  Iran  Korea  Lithuania  Libya  Malaysia  Mexico  Netherlands  Poland  Portugal  Puerto Rico  Quebec  Romania  Russia  Spain  Sudan  Sweden  Turkey  Uganda  USA  Venezuela  International  Regional
WPIW 2016: Media Coverage

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina  Austria  Belgium  Brazil  Canada  Colombia  Egypt  France  Germany  Greece  Indonesia  Iran  Korea  Lithuania  Libya  Malaysia  Mexico  Netherlands  Poland  Portugal  Puerto Rico  Quebec  Romania  Russia  Spain  Sudan  Sweden  Turkey  Uganda  USA  Venezuela  International  Regional
WPIW 2016: Call to Action and Petition Signatures

2016 Call to Action

- Dedicated 2016 Call to Action in line with 2016 Scientific Editorial
- Direct invitation to sign the online petition

Number of Signatures in 2016

- +256 signatures since January 2016
47 countries reported their involvement
Many more events taking place across the globe
WPIW 2016: Patient Stories

- 33 New Stories
- Patients from 4 Continents
- Increased interaction of patients with the campaign
- Increased global awareness of PI
- Increased recognition of the WPIW campaign
WPIW 2016: Promotion

<table>
<thead>
<tr>
<th>WPIW Official Press Release</th>
<th>Government Endorsement</th>
<th>Online Presence</th>
</tr>
</thead>
<tbody>
<tr>
<td>WPIW official PR used by NMOs to drive successful media activities</td>
<td>Greater involvement of health authorities and more outreach to government and policy makers</td>
<td>Increased recognition in the rare diseases campaign</td>
</tr>
<tr>
<td>WPIW supported Rare Disease Day through press release and social media</td>
<td>Targeted communication at local level for NMO engagement with policy makers</td>
<td>Broadened audience and reach through social media</td>
</tr>
<tr>
<td>WPIW logo included on the official ‘Friends of Rare Diseases Day 2016’ for the fourth consecutive year</td>
<td></td>
<td>Campaign anticipated and ‘rooted’ in NMOs annual activities</td>
</tr>
</tbody>
</table>
SNAPSHOTS OF EVENTS
Argentina – Training and Q&A Sessions

Who:
- PID patients associations from Argentina (AAPIDP)

Action:
Several events were held:
- A training workshop about immunoglobulin infusion conducted by two nurses from Prof Juan P. Garrahan Pediatrician Hospital specialised on PIDs
- A Q&A session “Talk with the specialists, questions and answers”, with 9 immunologist from different public hospitals of Argentina.
- A design art workshop and magic show for children.

Supported through IPOPI’s WPIW National Implementation Programme
Austria – Press Briefing

Who:

- Austrian self-help for Primary Immunodeficiencies organisation (Öspid)

Action:

- **Press briefing** to 10 Austrian Journalists about Primary Immunodeficiency.
- High caliber podium with national PI experts present and giving speeches and presentations.
- Information booth and presentation
- **Distribution of information materials** in hospitals
- Lecture in a plasma centre
Belgium – Family Day

Who:

- Belgian Primary Immunodeficiency Group (BOPPI)

Action:

- BOPPI organized its fourth national family day gathering many patients and their families.
- Medical workshops and open forums were held around the theme “Growing up with a PID”.
- Launched World PI Week with a balloon launch.

Find out more on the BOPPI website
Brazil – Conference

Who:

- Brazilian Group for Immunodeficiency (BRAGID)

Action:

- Launched balloons all around Brazil to raise awareness of primary immunodeficiency as well as promote World PI Week
- Organized and held the II BRAGID Meeting in Sao Paulo on 28-30 April to discuss and debate important topics in Primary Immunodeficiency
- Discussion at Pequeno Principe Hospital about warning signs, how to investigate and treat PI, etc. with emphasis on hematopoietic stem cell transplantation. The event gathered medical staff, nurses, residents and medical students.
Canada – 10 Warning Signs Video

Who:
- Immunodeficiency Canada

Action:
- **10 Warning Signs video** was produced and promoted all over the country (including via a press release) and picked up by 82 English media worldwide.
- **Video Release** at Hard Rock Café Toronto and played on large digital outdoor screen in public places from various cities in the country.
- **Balloons Toronto Tour**
- **World PI Week promotion** through advertisements, social media, online newsletter and website.
- **World PI Week promotional materials** distributed to 16 healthcare centres across Canada asking them to participate with local events.
Colombia – Symposium

Who:

- Fundación FIP

Action:

- Organized the **VI National Symposium on Primary Immunodeficiency**
- Launched balloons all around the country to raise awareness of primary immunodeficiency as well as promote World PI Week
Egypt – Balloons and Bubbles

Who:

- African Society of Immunodeficiencies (ASID) - NADA Society

Action:

- **Ceremony** at the Al-Azhar Park in Cairo
- **Balloons and bubbles launch** to raise awareness of primary immunodeficiency as well as promote World PI Week
- **Animations** with games for kids and students
France – Infographic

Who:

- Association de Patients Déficits Immunitaires Primitifs (IRIS)

Action:

- Produced a new infographic and shared it widely on social media

Supported through IPOPI's WPIW National Implementation Programme
Germany – 25th Anniversary

Who:

- German Patient Organisation for Primary Immunodeficiencies (DSAI)

Action:

- DSAI celebrated its 25th anniversary together with doctors, members, politicians and patrons
- A Medical education event was held
- DSAI held its annual meeting with the participation of the Bavarian Government Commissioner for Patient Affairs; magician and ringmaster André Sarrasani and actress Michaela Schaffrath
- A balloons launch was organised in Leipzig

Supported through IPOPI’s WPIW National Implementation Programme
Greece - Conference

Who:

- ARMONIA e.g the Association of Friends of Patients with Primary Immunodeficiency - Clinical Immunology in collaboration with the Immunology-Histocompatibility Department of “Aghia Sophia” Children’s Hospital

Action:

- Conference on Primary Immunodeficiencies Paediatric Immunology at the Museum of Cycladic Art in Athens to train doctors for early diagnosis and proper, lifesaving therapies for PI patients
- Scientific Symposium with physicians and patients with international experts
- Ceremony and lectures
- Information and distribution of PID leaflets

Supported through IPOPI’s WPIW National Implementation Programme
Indonesia – Doctors and Patients Meeting

Who:
- Indonesian PI Patients Society for Primary Immunodeficiency

Action:
- Organized a **doctor-patient meeting** to share information and answer questions from patients, carers and family members
- Organised a walk to raise awareness
Iran – Zebra Cake

Who:

- Immunology, Asthma and Allergy Research Institute - IAARI

Action:

- Celebrated World PI Week in Iran with a "Patient-Healthcare Providers" gathering with lectures and Q&A sessions.
- Organized fun activities for kids with puzzles, balloons, gifts and a cake.
- Organized the 8th International Conference on Immunodeficiency Diseases.
Korea – Awareness Raising

Who:

- PID Support Group

Action:

- Organized an awareness raising event on May 21st at the Samsung Medical Centre in Seoul
Lithuania – Awareness Raising

Who:

- Kaunas clinics

Action:

- Organized an awareness raising event with lectures from health professionals and discussions with patients, which ended with a balloon launch
Libya – Lectures

Who:

- The Arab Society of Primary Immunodeficiency - ARAPID

Action:

- Lectures at the Children’s Hospital in Tripoli entitled “A practical approach to a case of PID" and "Libya Experience of PID"
- The day was covered by the national TV channel.
Malaysia – Balloons and Bubbles

Who:

- MyPOPI - AMSA Malaysia

Action:

- Awareness raising event including a balloons launch, which Miss Malaysia (world winner) attended
- Blood glucose level testing
- Walk for hope

Supported through IPOPI’s WPIW National Implementation Programme
Mexico – Awareness Raising

Who:
- Fumeni

Action:
- Held a **Balloons Launch**
- A **Latin America Immunoglobulin Summit** was organized to discuss new facts of IgG replacing therapies for PID and as an immune modulator for other autoimmune diseases

Supported through IPOPI’s WPIW National Implementation Programme
Netherlands – Roundtable discussion

Who:

- Stichting voor Afweerstoornissen - SAS

Action:

- A Roundtable on Immune Disorders was organized gathering physicians, PI experts, researchers, nurses and family carers to discuss Primary Immunodeficiency treatments, around the “Burden of Treatment Study”
Poland – Celebrations with Games & Balloons

Who:

- ImmunoProtect

Action:

- Held a *balloon release* to raise awareness for primary immunodeficiency
- *Info session and games with kids*
- *PI Patients’ Day* in Krakow Children Hospital gathering some 80 guests and excellent speakers

Supported through IPOPI’s WPIW National Implementation Programme
Portugal – Family Day

Who:

- Portuguese Primary Immunodeficiency Patient Association (APDIP)

Action:

- Balloons launch
- Held two events: a Family Day and a Health Day:

**Family Day**: “V Meeting of Families with IDP” was held in Coimbra, at the Live Science Exploratory Centre

**Health Day**: “III Walk for Health” in Bélem and Lisbon.

Supported through IPOPI’s WPIW National Implementation Programme
Puerto Rico – 1st WPIW Celebrations

Who:

- Association for Immunodeficiency Patients in Puerto Rico (APIP)

Action:

- One day conference gathering physicians, government representatives, industry and APIP members
- April declared the official month of Primary Immunodeficiency in Puerto Rico.
- Patients and Family Education Event on Saturday, April 23 targeting both adults and children.

Supported through IPOPI’s WPIW National Implementation Programme
Quebec – ‘My Life is Better!’ Conference

Who:

- The Association des Patients Immunodéficients du Québec (APIQ)

Action:

- Organized a Free conference on "MY LIFE IS BETTER" which was open to anyone who wanted to attend. Aimed at promoting a better life for all Primary immunodeficiency patients
Romania – PID Hope Train

Who:
- Arpida Association – Rumanian Patient Association

Action:
- PID Hope branded train travelled around the city with kids and balloons
- Balloons launch took place in presence of patients, doctors, youth in town who tried to send a message of support to all those affected by PI
- Distribution of flyers and material on WPIW

Supported through IPOPI’s WPIW National Implementation Programme
Russia – Awareness raising

Who:
- Foundation for ‘Sunflower’

Action:
- **Bubbles and balloons launch** to promote a better life for PI patients
- Meeting between patients, doctors and scientists

Watch the video of WPIW 2016 in Yekaterinburg [here](#)
Spain – Gathering for PI

Who:
- Spanish Association of Primary Immunodeficiency (AEDIP)
- PID Foundation

Action:
- Held a balloon launch to make Primary Immunodeficiency visible worldwide
- One day medical event aimed to raise awareness of PIDs amongst physicians
- Games and awareness raising activities for children

Watch the Barcelona PID Foundation video

Section 1
Improving Access to Care for Patients with Primary Immunodeficiency

Section 2
Campaign Highlights

Section 3
Snapshots of Events

Argentina
Austria
Belgium
Brazil
Canada
Colombia
Egypt
France
Germany
Greece
Indonesia
Iran
Korea
Lithuania
Libya
Malaysia
Mexico
Netherlands
Poland
Portugal
Puerto Rico
Quebec
Romania
Russia
Spain
Sudan
Sweden
Turkey
Uganda
USA
Venezuela
International
Regional

Supported through IPOPI’s WPIW National Implementation Programme
Sudan – Educational Meeting

Who:

- Arab Society of Primary Immunodeficiencies (ARAPID)

Action:

- Lecture given in specialized medical building
- Educational meeting in immunology for physicians in various specialties
Sweden – Communicating on PI

Who:
- Swedish Patients Organisation (PIO)

Action:
- **Exhibitions** to raise awareness about PI in university hospitals
- **Press releases** in local media, posters, [interview](#) on the radio, social media campaign
- **Wide dissemination of the organization’s magazine** to Health Care Centers, hospital departments, government bodies
- Launch of a [revised website](#)
Turkey – Balloons

Who:

- IMYED - Medical community

Action:

- Held a Balloon release to raise awareness for Primary Immunodeficiency
Uganda – Balloons for kids

Who:

- UPPID

Action:

- Held a balloon Release
USA – Raising Awareness

Who:

- Immune Deficiency Foundation (IDF)

Action:

IDF Meetings & Events

- One-day education meetings
  - IDF Family Conference Days held throughout the US in April
- IDF Get Connected Groups meetings held throughout the US in April
- IDF Nurse Advisory Committee Meeting
- IDF Advocacy Day on April 21st in Washington D.C. 75 volunteers representing 35 States attended 160 meetings with legislators to promote PI awareness and advocate for community

CIS & IDF Partnership

- IDF educational materials mailed to all CIS members (more than 600)
- Joint Press release on partnership
- PI Awareness T-shirts distributed to participants of CIS Annual Meeting
USA – Raising Awareness

Who:

- Immune Deficiency Foundation (IDF)

Action:

Communications and Materials

- Featured WPIW on IDF Website which received 130,592 sessions/visitors in April 2016
- Created a new International Section on IDF website with IDF materials made available in various languages
- Published 4 blog features on IDF Blog throughout April and emailed more than 26,000 people to share how they could help spread awareness in just 5 simple ways
- Highlighted WPIW in IDF Advocate Newsletter and e-Newsletter, approx. 40,000 and 20,000 recipients, respectively
- Distributed WPIW Press Release in U.S
- Conducted very successful social media awareness campaigns on Facebook, Twitter, Instagram and LinkedIn

Other activities:

- IDF staff helped spread awareness in Towson, MD thanks to TZ the IDF Zebra, the official IDF mascot
- SCID Screening for newborns started in IDF home state Maryland
- Launch of IDF Plasma Partners Program
USA & International – Widespread Action

Who:

- Jeffrey Modell Foundation (JMF)

Action:

- Funded events in Centres in **110 locations, 45 countries**
- Held an “Uplifting” event in New York, USA
- Continued Social media action during the week through Facebook, Twitter and Instagram
- Distribution and coverage of World PI Week release
- Creation and delivery of dedicated communication and to raise awareness

Uplifting event, NYC

Happy Annual JMF WPIW Balloon Launch Day!

Learn more about JMF and its activities
USA & International – Widespread Action

Who:

- Jeffrey Modell Foundation (JMF)

Action:

- “Burst the bubble” for PI celebrations
- Simultaneous launch of thousands of specially designed balloons at Jeffrey Modell Diagnostic and Research Centers throughout Europe, Eastern Europe, Latin America, Asia, Africa, United States and Middle East
Venezuela – Sharing Information

Who:

- Asociación Civil Immunodeficiencias Primarias-Venezuela (AC IDP Venezuela)

Action:

- A series of conferences were held throughout the week to teach to evaluate, diagnose and treat primary immunodeficiency

- A launch of balloons took place and a party with the patients was organized

- Info sessions took place in hospitals to inform physicians, nurses, patients and the general public
**Venezuela**

**Who:**

- Asociación Civil Inmunodeficiencias Primarias Venezuela (IDPVenezuela)

**Action:**

- A *series of conferences* were held to teach to evaluate, diagnose and treat primary immunodeficiency

- A *launch of balloons* took place and a party with the patients was organized. Physicians, patients, friends and sponsors collaborated as one to spread all information available

---

Get more information on the campaign via website
International – Raising Awareness

Who:

- International Patient Organisation for Primary Immunodeficiencies (IPOPI)

Action:

- Provided support to 14 National Member Organisations (NMO) for local implementation of WPIW through family events, medical lectures, media outreach campaigns, information materials, etc.

- Launched Burden of Treatment Survey on 27 April.

- Released 3 new leaflets

- Recorded patient testimonials at NMO WPIW events in Spanish, Portuguese, German

- Communication and awareness raising on social media with great turn out
International – Raising Awareness

Who:

- **International Patient Organisation for Primary Immunodeficiencies (IPOPI)**

Action:

- Held IPOPI 2016 Asian Regional Patient Meeting gathering patients from 10 Asian meetings for the first time

- Held a specific workshop at IPOPI’s Asian Regional Patient Meeting to further disseminate the principles of care.

- Creation of an Implementation Package for principles of care

Action:

- Organized a policy event at the European Parliament with 3 Members of European Parliament from 3 main political groups and 12 patient and physicians from 12 different countries in Europe and Africa, joined by industry representatives and other interested stakeholders. The event ended with the signature of the 2016 Call for Action Improving access to care for patients with Primary Immunodeficiencies
International – Awareness Activities

Who:
- International Nursing Group for Immunodeficiencies (INGID)

Action:
- INGID is supporting nurses worldwide to promote primary immunodeficiency and world PI week awareness with educational activities
- Balloon launches in different locations
- Distribution of educational materials
- Strong presence on social media (Facebook, Twitter)
Regional – Raising Awareness

Who:
- European Federation of Immunological Societies (EFIS)

Action:
- Celebrated “The Day of Immunology” on 29th April with the theme: “The promise of Immunotherapy”
- Provided Members with campaign materials and support to organize local activities
- Organized together with International Union of Immunological Societies (IUS) an Award prize to reward best 2016 campaigns as per the “Dol Award”
THANK YOU

Test - Diagnose - Treat