

Improving Access to Care for Patients with Primary Immunodeficiency

22nd - 29 th April 2016



Test - Diagnose -Treat

WPIW 2016: An Expanding Community

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Foundation



jm
Jeffrey Modell
Foundation



PPPTA
Plasma Protein Therapeutics Association



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

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World PI Week
Test. Diagnose. Treat.

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22nd - 29th April 2016

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 world-wide. 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."

Share this story: 

Nicole Shearing

Australia

Living with PI



"34 years after having lived with constant sinus, ear, throat, chest, gut, bowel, bladder, kidney, skin infections and Golden Staph in my brain (Encephalitis anyone? It's such a joy!) as well as a placental abruption at 27 weeks I was diagnosed with CVID. The journey is long but together we're strong. Even stronger than Golden Staph!"

Share this story: 



 Add your story

GET INVOLVED IN OUR 2016 CAMPAIGN



 Live Twitter feed

World PI Week What did you do on #WPIW? Share your events on <https://t.co/lwRpfk6QW2> #PrimaryImmunodeficiency #WPIW #piawareness

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WPIW 2016: Website - Key Features

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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!

 Visit our Website

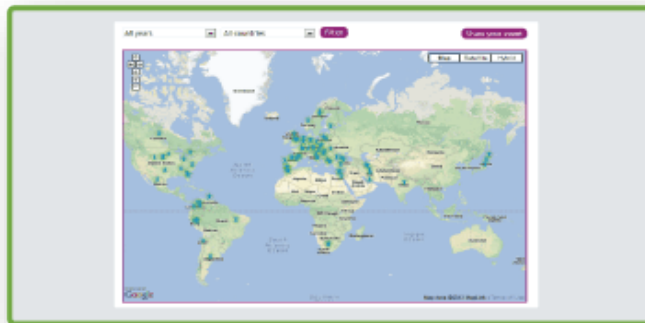
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Share your event

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



Get Inspired

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



Mobile Responsiveness

The **mobile responsiveness** of the website allows access to the WPIW website from all smart phones / mobile devices.



WPIW 2016: Website - New Features

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Sample tweets and posts

A new social media section provides advice on how to engage on social media and list a series of sample tweets and posts and references key hashtags to be used.



Call to Action

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

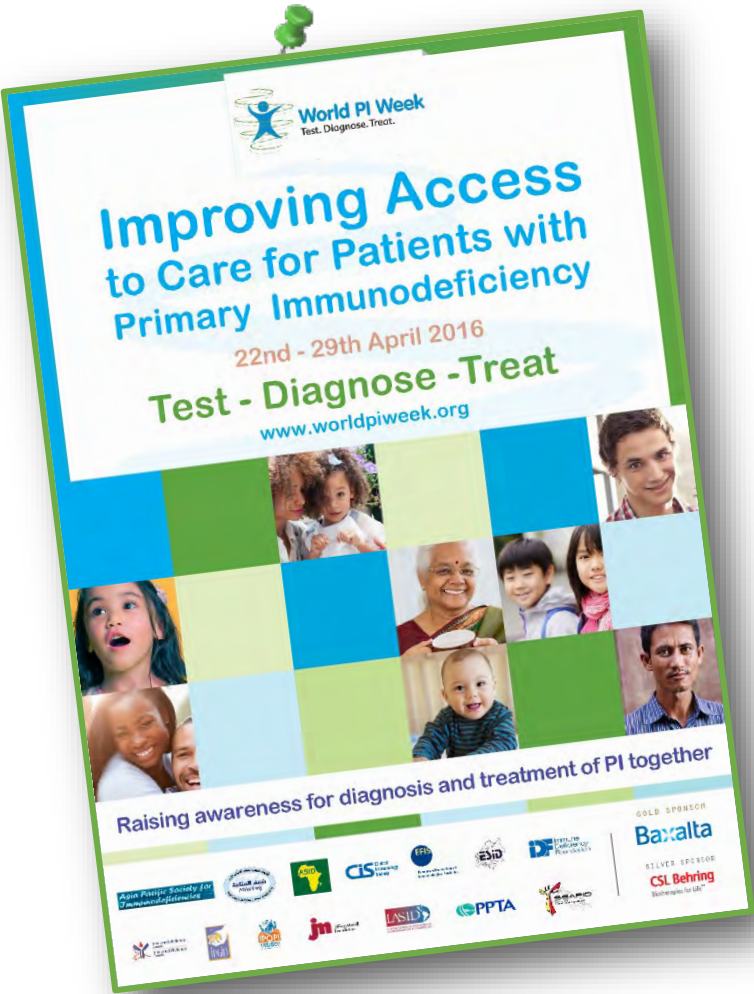
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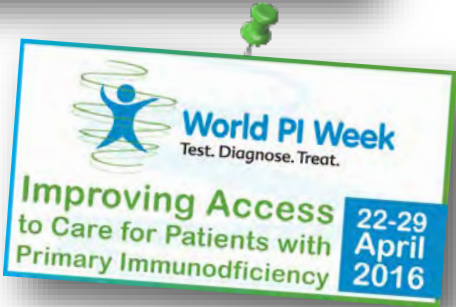
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[New Poster!](#)
[New eBanners!](#)
[Updated Infographic!](#)



Have a look at our campaign material online



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Primary Immunodeficiency Community Supports Rare Disease Day

Brussels – 29 February 2016

Accounting for about 250 of the 6,000 recognised rare conditions, Primary Immunodeficiency (PI) affects more than 50 million people worldwide. United under the “World PI Week” banner, the PI community, from patients to healthcare providers and family carers, express its affinity with the broader rare disease community today, to continue raising awareness about orphan diseases. Alongside the Rare Disease community, PI advocates call for a coordinated approach, research cooperation and scientific knowledge sharing around these disease towards improved therapeutic and diagnostic processes.

As with other rare diseases, daily life for patients diagnosed with PI is fraught with challenges. Primary immunodeficiencies are disorders in which part of the body’s immune system is missing or does not function properly and can, if not treated, be chronic, serious and even fatal. Thanks to research and medical progress over the last decades, most of these conditions are now manageable, yet because symptoms are those of common and recurrent infections, PI often remains undiagnosed, misdiagnosed, or late-diagnosed.

The theme of this year’s Rare Disease Day is “Patient Voice”, recognising the crucial role that patients play in voicing their needs and in initiating change that improves their lives and the lives of their families and carers. Just like World PI Week, Rare Disease Day amplifies the voice of orphan disease patients to collective that it is heard all over the world.

In line with Rare Disease Day, patients, parents, carers, health care professionals and politicians will organise hundreds of events around the world on 22–29 April to raise awareness on Primary Immunodeficiency and how to improve its diagnosis and treatment.

By bringing patients’ lives into the spotlight, the rare disease community hopes to contribute to bringing about change and achieve equal access to quality treatment and care at local, national and European levels for patients – a goal that is equally high for PI patients and advocates as illustrated by WPIW 2016 theme “Improving Access to Care for Patients with Primary Immunodeficiency”. Indeed, despite life-saving treatments having been developed for patients affected with PI, access to care can vary significantly across continents and even countries of the same region.

For more information on **Rare Diseases Day 2016**: www.rarediseaseday.org

For more information on **World PI Week**: www.worldpiweek.org

Like World PI Week [Facebook page](#)
Follow World PI Week on Twitter: [@WorldPIWeek](#)

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Bronze sponsor: **CSL Behring**

Press release on
Rare Disease
Day 28 February
2016



PRESS RELEASE

World PI Week: 7 days to raise awareness on Primary Immunodeficiency (PI)

From 22-29 April 2016, the global Primary Immunodeficiency community - including patients, nurses, physicians, scientists, family carers and industry – organizes awareness raising activities around the world to celebrate the “World Primary Immunodeficiency Week”.

Started in 2010, the World PI Week aims to raise awareness of this devastating condition and to ensure that primary immunodeficiency is taken out of the shadows and into focus as a health priority.

Primary immunodeficiency (PI) diseases occur in people with an immune system that is either absent or deficient in its ability to function. Because PI often presents in the form of “common” infections, physicians can sometimes treat the infections while missing the underlying cause, allowing the illnesses to reoccur, and leaving the patient vulnerable to vital organ damage, physical disability, or even death.

Thanks to research and medical progress over the last 60 years, life-saving treatments have been developed, including immunoglobulin replacement therapies, bone marrow transplantation, gene therapy, antimicrobial and antifungal and prophylactic antibiotics, and emergency medicine.

However, access to these treatments vary significantly across continents and even countries of the same region: access to bone marrow transplantation and gene therapy for severe types of immunodeficiencies is the rule in most countries in North America and Europe, whereas it is available only in a very small number of centers in Latin America, Asia and Africa. Likewise, while national health systems cover treatment with intravenous or subcutaneous immunoglobulin (IgG) in most European countries, these treatments are not always reimbursed in poorer regions of the world despite extensive evidence that early diagnosis and proper treatment are life-saving, life-enhancing and always cost-saving, as they prevent unnecessary co-morbidity for PI patients.

For this reason, in 2016, the PI community raises its voice to call on policymakers, health authorities, payers, healthcare professionals and the general public to put in place the relevant mechanisms to ensure that all PI patients can access the care they are entitled to in order to live normal and productive lives.



Official press
release World PI
Week 2016



Editorial
World PI Week (WPIW) 22-29 April 2016

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Into action: Improving access to optimum care for all primary immunodeficiency patients

Primary Immunodeficiency (PI) is a group of over 300 inborn defects of the immune system, both in its hematopoietic as well as in its non-hematopoietic components. They can present with a broad spectrum of clinical features, either with infections (recurrent common or common life-threatening or rare life-threatening), autoinflammation, autoimmunity, malignancy, and/or allergy. Previously classified as “rare diseases” PI are no longer as rare as previously thought: today, it is estimated that PI affects more than six million people worldwide, with no gender, age or geographical boundaries.

Because PI can present in the form of “common” infections, lack of awareness means that between 70 to 90% of PI sufferers remain undiagnosed, with their healthcare practitioners treating PI related infections as some other “common infection”. Reacting to the urgent need to raise awareness on this condition, concerned organisations such as the African Society for Immunodeficiencies (ASID), the European Society for Immunodeficiencies (ESID), the Latin American Society for Immunodeficiencies (LASID), the Clinical Immunology Society (CIS) and Foundations devoted to PI such as the Immune Deficiency Foundation (IDF) and the Jeffrey Modell Foundation devoted to PI (JMF) have over the last two decades, implemented and supported awareness campaigns and activities all over the world towards physicians and the general public, to improve early diagnosis, appropriate treatment and management of PI with a view to reducing morbidities and mortalities related to PI.

New Scientific
Editorial on
improving access to
optimum care for PI
patients

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CAMPAIGN HIGHLIGHTS

WPIW 2016: Scientific Editorial

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“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



WPIW 2016: Scientific Editorial


Translated in
French, Spanish,
Arabic

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Editorial
Semaine mondiale des Déficiences Immunitaires Primaires (DIP) 22-29 avril 2016

Auteurs
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Comment permettre aux patients atteints d'un déficit immunitaire primaire (DIP), à travers le monde, d'accéder à une prise en charge optimale


Les déficits immunitaires (DIP) sont un groupe d'environ 300 maladies d'origine génétique, dues à différents dysfonctionnements du système immunitaire. Considérés comme des maladies rares, les DIP sont finalement moins rares que ce que l'on pensait : on estime aujourd'hui qu'elles concernent 6 millions de personnes dans le monde, sans considération de sexe, d'âge ou de zone géographique.

Les DIP s'expriment souvent à travers des infections « communes ». De ce fait, elles restent méconnues, ce qui fait que 70 à 90% des patients restent non diagnostiqués, et sont traités par leur médecin au regard des symptômes exprimés lors de ces infections et non de leurs causes. Face au besoin urgent de sensibilisation à ces pathologies, les organisations concernées, telles que l'Association Africaine pour les DIP (AAID), la Société Européenne pour les DIP (ESID), la Société Latine Américaine pour les DIP (LASID), la Société d'immunologie clinique (CIS), des fondations dédiées aux DIP, comme la Fondation pour les DIP (FIP) et la Fondation Jeffrey Modell (JMF), ainsi que l'Association Internationale de Patients pour les DIP (AIPD) ont, durant les deux dernières décennies, développé et soutenu des campagnes de sensibilisation et des activités à travers le monde, en direction des médecins et du grand public, afin de favoriser un diagnostic précoce, un traitement approprié, et une prise en charge globale des DIP dans le but de réduire la morbidité et la mortalité liées à ces pathologies.

Depuis 2011, une campagne mondiale de sensibilisation aux DIP – la Semaine mondiale des DIP (WPIW) – existe sous la signature « Test, Diagnose, Treat » (tester, Diagnostiquer, traiter). Elle se déroule chaque année en avril, avec le soutien du réseau international des acteurs des DIP (www.worldpiweek.org), afin d'encourager chaque groupe actif dans ce champ à participer à cette plateforme commune, et ainsi renforcer l'impact de leurs initiatives à l'échelle locale.

Grâce à ces activités et aux traitements vitaux qui ont été développés ces 60 dernières années, le nombre de DIP diagnostiqués et de patients traités a cru chaque année.

Néanmoins, en dépit de ces résultats positifs, force est de constater que l'accès aux traitements varie considérablement selon les continents et même significativement selon les pays dans une même région du monde. Par exemple, l'accès précoce à une greffe de cellules souches hématopoïétiques, ou à la thérapie génique, pour les DIP les plus sévères, est la règle dans la plupart des centres de santé d'Amérique du Nord, d'Europe, mais n'est possible que dans un tout petit nombre de centres en Amérique latine et en Afrique. Est-ce acceptable ? De même, alors que les systèmes de santé nationaux prennent en charge le traitement substitutif en immunoglobulines par voie intraveineuse



الأسبوع العالمي لنقص المناعة الأولي
من 22-29 إبريل 2016

World PI Week
Test. Diagnose. Treat.

الأعمال الواجب القيام بها لضمان حصول مرضى نقص المناعة الأولي على الرعاية المثلى في جميع دول العالم

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

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ترجمة: الطبيب الأستاذ مهدي العادلي، أستاذ الطب الباطني، جامعة القاهرة، مصر

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Translation: Mehdi Adeli, Assistant Professor, Well Come Medicine - Qatar

الطبيب الأستاذ مهدي العادلي
أستاذ الطب الباطني، جامعة القاهرة، مصر

ARAPid.org



En acción: mejorando el acceso a la atención óptima para todos los pacientes con inmunodeficiencias primarias
Semana mundial de las Inmunodeficiencias Primarias (WPIW)
22-29 de abril, 2016

In action: Improving access to optimal care for all patients with primary immunodeficiencies
Global Week of primary immunodeficiencies (WPIW)
April 22-29, 2016

Las inmunodeficiencias primarias constituyen un grupo de más de 300 defectos innatos del sistema inmunitario, tanto en sus componentes hematopoyéticos como en los no-hematopoyéticos. Dichos defectos pueden presentarse con un amplio espectro de manifestaciones clínicas, ya sea con infecciones (comunes recurrentes, comunes graves, o raras y graves), autoinflamación, autoinmunidad, malignidad y/o alergias. Anteriormente clasificadas como "enfermedades raras", las inmunodeficiencias primarias no son tan raras como se pensaba: hoy en día se estima que afectan a más de seis millones de personas alrededor del mundo, sin distinciones geográficas, de género o edad.

Debido a que las inmunodeficiencias primarias pueden presentarse bajo la forma de infecciones "comunes", la falta de conocimiento y familiaridad genera que entre 70 y 90% de personas afectadas se quede sin diagnóstico, lo cual que sus profesionales de la salud tratan dichas infecciones como cualquier otra "infección común". En respuesta a la necesidad urgente de despertar conciencia acerca de esta condición, organizaciones preocupadas como la Sociedad Africana para las Inmunodeficiencias (ASID), la Sociedad Europea para las Inmunodeficiencias (ESID), la Sociedad Latinoamericana para las Inmunodeficiencias (LASID), la Sociedad de Inmunología Clínica (CIS) y funda-



WPIW 2016: Translated Materials

Translated in
more than 15
languages

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World PI Week
Test. Diagnose. Treat.

Βελτιώνοντας την Πρόσβαση
στη Φροντίδα των Ασθενών
με Πρωτοπαθείς Ανοσοανεπάρκειες
22 - 29 Απριλίου 2016
Έλεγχος - Διάγνωση - Θεραπεία
www.worldpiweek.org

World PI Week
Test. Diagnose. Treat.

بهبود دسترسی بیماران نقص
ایمنی اولیه به خدمات مراقبتی
۲۲-۲۹ آوریل
آزمایشات، تشخیص، درمان
www.worldpiweek.org

World PI Week
Test. Diagnose. Treat.

Bolji pristup lečenju
za pacijente sa primarnom
imunodeficijencijom
22-29 april 2016
Istraži-Dijagnostikuj-Leči
www.worldpiweek.org

World PI Week
Test. Diagnose. Treat.

Øget adgang til
behandling for patienter med
primær immundefekt
22-29 april 2016
Test - Diagnose - Behandling
www.worldpiweek.org

World PI Week
Test. Diagnose. Treat.

Améliorer la Prise en Charge
Patients atteints de Déficits
Immunitaires Primaires
22-29 avril 2016
Tester – Diagnostiquer – Traiter
www.worldpiweek.org

World PI Week
Test. Diagnose. Treat.

Migliorare l'accesso
alle cure per i pazienti affetti
da immunodeficienza primitiva
22 - 29 Aprile 2016
Test-Diagnosi-Trattamento
www.worldpiweek.org

Favoriamo insieme la consapevolezza dell'importanza di una
rapida diagnosi ed un corretto trattamento delle PID

WPIW 2016: Social Media Activities



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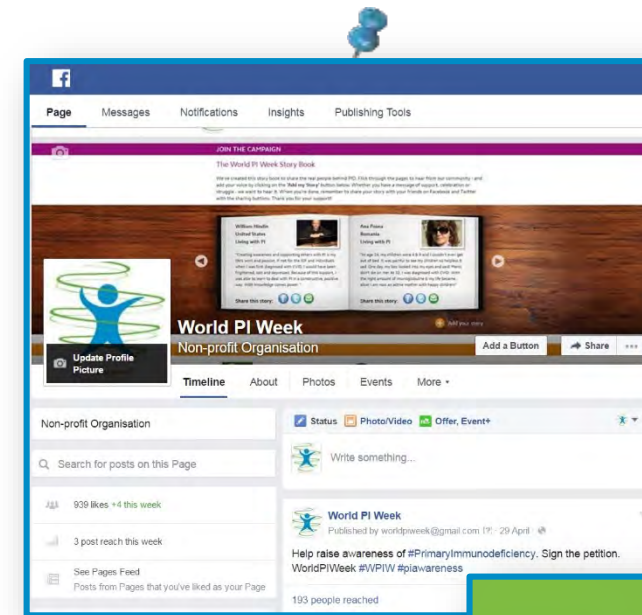
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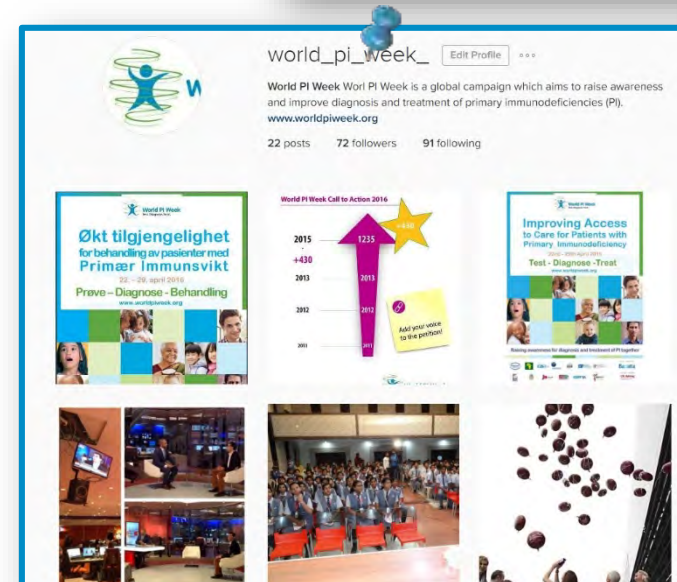
- Platform of engagement for international scientific societies, nurses, patients' group, industry and specialised media
- Dedicated hashtags: #WorldPIWeek, #WPIW, #Piawareness, #primaryimmunodeficiency @WorldPIWeek

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



Follow us
Facebook,
Twitter &
Instagram!



WPIW 2016: the Power of Social Media



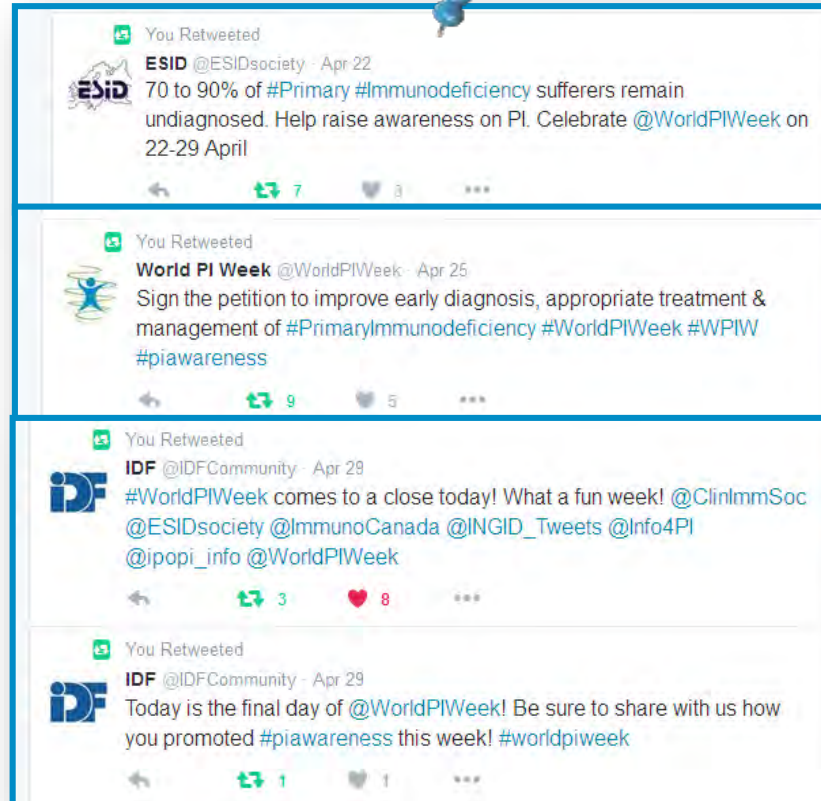
World PI Week on Facebook, Twitter

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Have a look at social media engagement around #WPIW [here](#) !



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WPIW 2016: Call to Action and Petition Signatures

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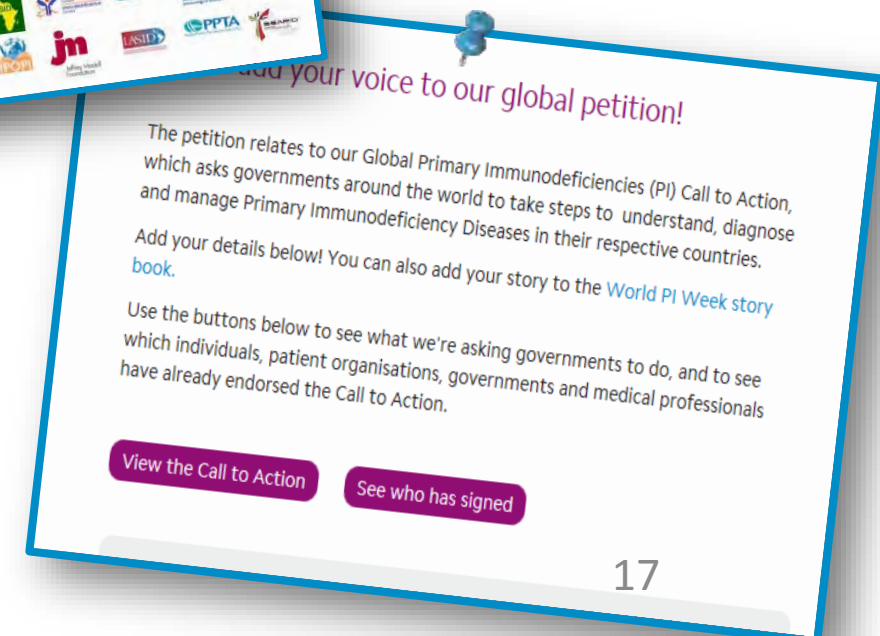
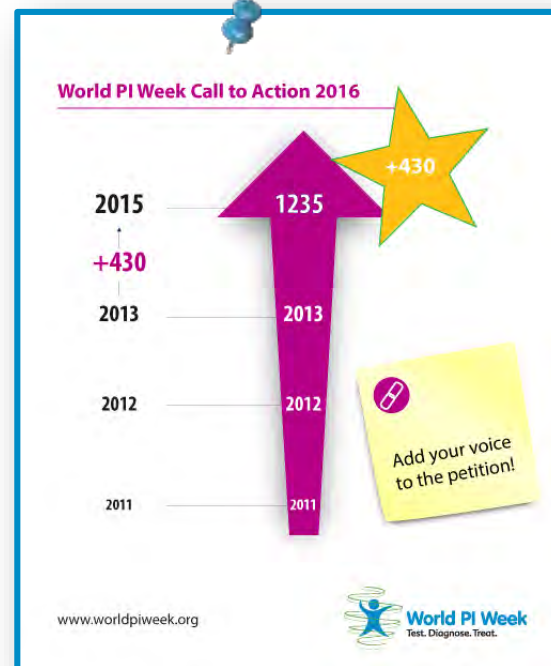
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2016 Call to Action

- 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



WPIW 2016: Country Involvement

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47 countries reported their
involvement

Many more events taking place
across the globe



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Australia
Argentina
Azerbaijan
Belgium
Bosnia
Brazil
Bulgaria
Canada
Chile
Colombia
Czech Republic
Egypt
France

Germany
Greece
Hungary
Iceland
India
Ireland
Iran
Italy
Israel
Kazakhstan
Japan
Lithuania
Malaysia
Mexico

Morocco
Norway
Peru
Poland
Portugal
Romania
Russia
Serbia

Slovakia
Slovenia
South Africa
Spain
Sweden
Switzerland
Taiwan
Turkey

United Kingdom
Ukraine
United States (appr 25 States)
Venezuela

WPIW 2016: Patient Stories

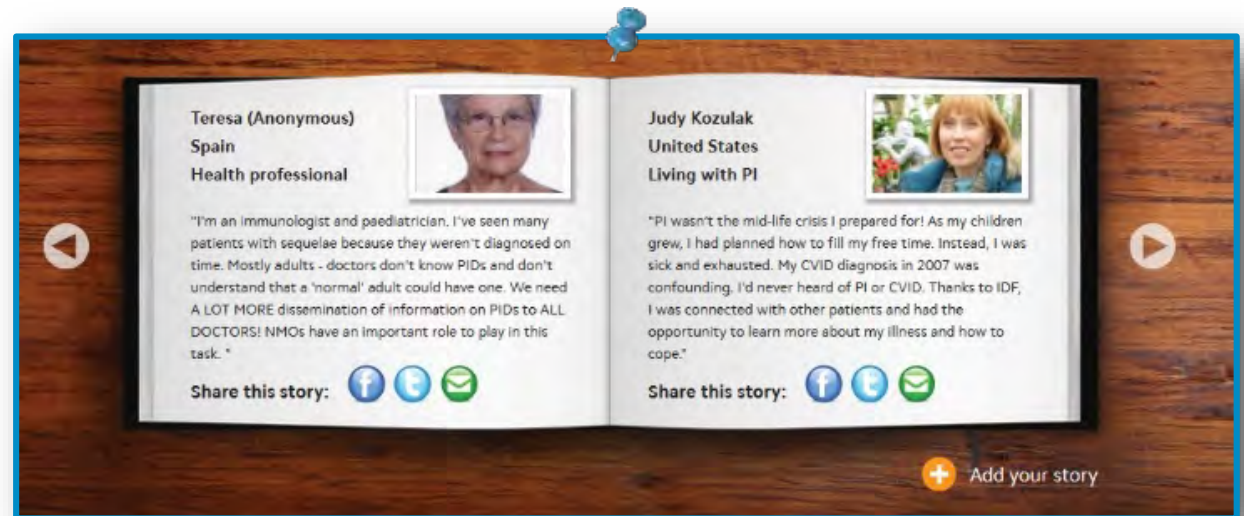
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- **33 New Stories**
- **Patients from 4 Continents**
- Increased interaction of patients with the campaign
- Increased global awareness of PI
- Increased recognition of the WPIW campaign



WPIW 2016: Promotion

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WPIW Official Press Release

- WPIW official PR used by NMOs to drive successful media activities
- WPIW supported Rare Disease Day through press release and social media
- WPIW logo included on the official **'Friends of Rare Diseases Day 2016'** for the **fourth consecutive year**

Government Endorsement

- Greater involvement of health authorities and more outreach to government and policy makers
- Targeted communication at local level for NMO engagement with policy makers

Online Presence

- Increased recognition in the rare diseases campaign
- Broadened audience and reach through social media
- **Campaign anticipated and 'rooted' in NMOs annual activities**

SNAPSHOTS OF EVENTS

Argentina – Training and Q&A Sessions

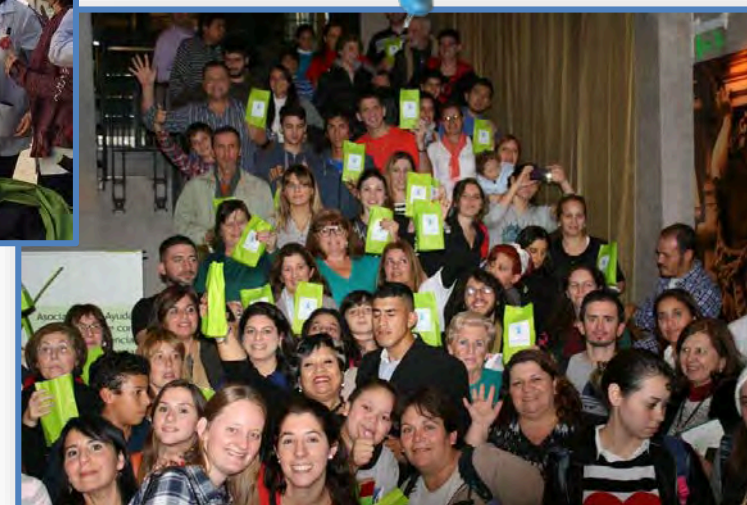
Who:

- 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.



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



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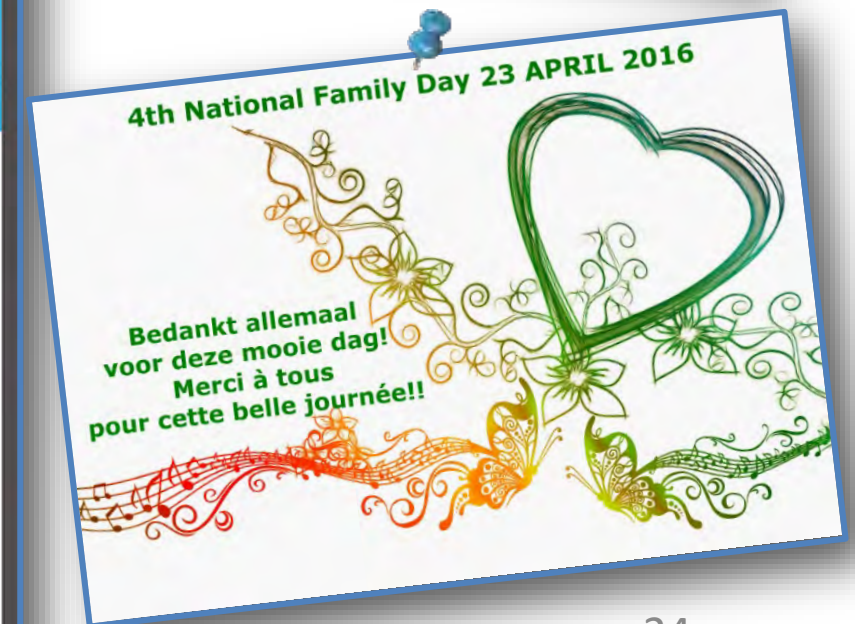
Belgium – Family Day

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**.



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

Watch the video [here!](#)

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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



Semana Mundial de las Inmunodeficiencias Primarias
Abril 22-29, 2016

VI Simposio Nacional de Inmunodeficiencias Primarias
Avances en Diagnóstico y Tratamiento para el personal del área de la salud
Abril 30 de 2016

Invitan: LASID, ACIN, Asociación Colombiana de Alergia, Asma e Inmunología, jmcn, ACOI, FECOER.

Apoyan: Baxalta, Biotoscana Colombia, KEDRION BIOFARMA, GRIFOLS, octapharma, Biospitar, jmcn Jeffrey Modell Centers Network, IPOPI, FIP 10 años.

Hotel NH Collection Smartsuites Royal
Calle 80 No. 51B-25, Gran Salón Smart
8:00 am - 5:00 pm
Barranquilla Colombia

Informes: fundacionfip@gmail.com
Tels: (4) 311-8121 • (314) 864-6956
Entrada libre con inscripción previa en www.fundacionfip.org

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



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France – Infographic

Who:

- Association de Patients Deficits Immunitaires Primitifs (IRIS)

Action:

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



Depuis près de 20 ans,
IRIS agit au côté des patients
atteints de déficits immunitaires primitifs (DIP)

iris SOUTIENT les
DIP c'est
DANS SES GÈNES

L'INFORMATION **LA RECHERCHE** **L'ACCOMPAGNEMENT**

4 000 enfants et adultes concernés
Agréée par le ministère de la Santé
Membre fondateur
du Centre de Référence des Déficiences Immunitaires Héritaires (CEREDIH)
Partenaire de l'EFS

iris
ASSOCIATION DE PATIENTS
DÉFICITS IMMUNITAIRES PRIMITIFS

Agir, soutenir IRIS, devenir bénévole... Contactez-nous.
associationiris.org Tél. 03 83 64 09 80

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



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**



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



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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



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Korea – Awareness Raising

Who:

- PID Support Group

Action:

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



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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



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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.



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Malaysia – Balloons and Bubbles

More on their
[Facebook page](#)

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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**



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



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Netherlands – Roundtable discussion

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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



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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: “Ill Walk for Health” in Bélem and Lisbon.



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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.



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**



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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](#)



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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](#)



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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



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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

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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**

Watch the [video](#)



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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



IDF Get Connected Group meeting in Burke, VA



Advocacy Day, Washington DC

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USA – Raising Awareness



Watch the IDF
Thank you
video [here](#)

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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



IDF staff, Towson, MD

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:

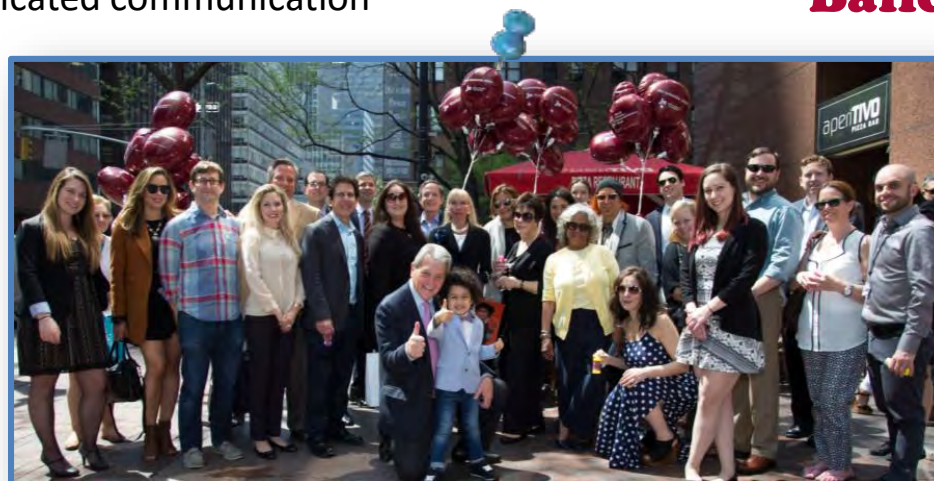
- Jeffrey Modell Foundation (JMF)

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



**Happy Annual JMF WPIW
Balloon Launch Day!**



Uplifting event, NYC

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



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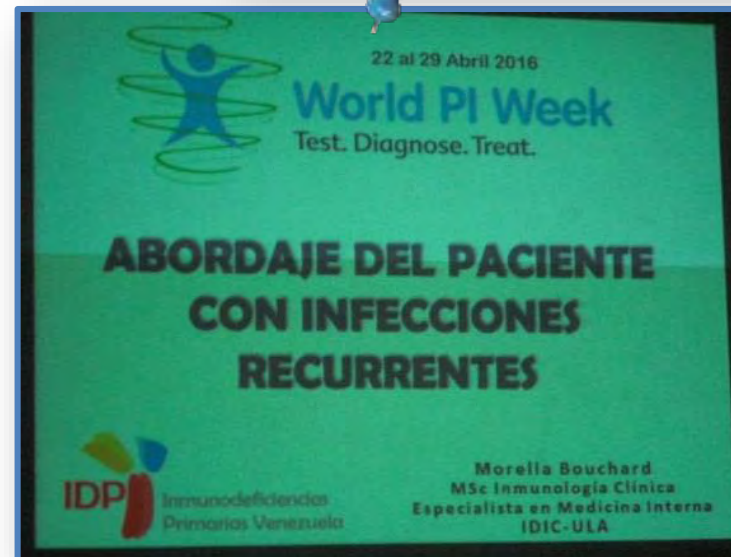
Venezuela – Sharing Information

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



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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

Malaysia



Portugal



Puerto Rico



Argentina



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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



Asian Regional Patient Meeting



Learn [more](#) about the activities of IPOPI



Policy event at European Parliament

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](#)**

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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

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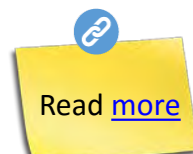
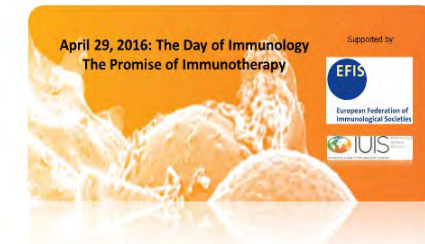
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Who:

- **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 (IUIS) an Award prize to reward best 2016 campaigns as per the “Dol Award”





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