

# IPOPI WORLD PI WEEK GRANT REPORT

2024



# Argentina

## The Immune Deficiency Foundation of Australia (AAPIDP)

### Project: 4th Virtual Congress

- On 5 June AAPIDP carried their 4<sup>th</sup> Virtual Congress, conducted by specialist in the field of PIDs. Vaccines, talking with specialists & guaranteeing access to health care in current times.
- Media Campaign from April 22 to 29, AAPIDP carried out a strong campaign on social networks with a new video of warning signs, QUIZ, key testimonials from patients, caregivers and also educational awareness material.

**Congreso Virtual**  
para Pacientes con Inmunodeficiencias Primarias

MIÉRCOLES  
05 DE JUNIO  
18 A 20 HS.

EN VIVO  
YouTube - Facebook LIVE

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

#MiHistorialDP

Fui diagnosticada 35 años tarde, perdi mucha calidad de vida por eso es esencial el diagnóstico precoz.

**Alvarez Mónica**  
Inmunodeficiencia Primaria (déficit de interleuquina 17 F)

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

#MiHistorialDP

Tenemos una IDP, hemos tenido por suerte una vida plena hoy los dos estamos en la Facu, practicamos deportes y tenemos muchos amigos. A mí, Joaquín me diagnosticaron la IDP a los 3 años de edad por un problema en un pulmón, mi hermano que nació después fue diagnosticado cuando nació. Creo que hemos tenido y tenemos una vida normal gracias al diagnóstico correcto y temprano y el tratamiento sostenido en el tiempo. Para resumir, tenemos que tener un diagnóstico temprano y tratamiento médico sostenido en el tiempo.

**Joaquín y Simon Asprea**  
Inmunodeficiencia Primaria

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

#MiHistorialDP

El mayor desafío para las personas que vivimos con inmunodeficiencia primaria es recibir la medicación correspondiente en tiempo y forma para poder cumplir mi tratamiento.

**Ayelén**  
Inmunodeficiencia Común Variable

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

#MiHistorialDP

Hola Somos Mateo y Agustín. Fuimos diagnosticados con una i.d.p hace 12 años una inmunodeficiencia primaria, es una enfermedad poco frecuente. O sea... Somos INVISIBLES AL MUNDO. Por eso... Tenemos el derecho y el deber de darles visibilidad, para que las enfermedades poco frecuentes no sean más invisibles! La vida y la salud no se negocian!

**Mateo y Agustín**  
Inmunodeficiencia Primaria

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

#MiHistorialDP

Hace 15 años que me diagnosticaron luego de haber padecido muchas infecciones recurrentes, pero por suerte con el tratamiento adecuado mejoró mi calidad de vida. Llegar al diagnóstico certero y tener la medicación adecuada tiene que ser un derecho para todos. Gracias al apoyo incondicional de la Asociación puedo llevar adelante todo con bastante normalidad.

**Ofelia**  
Inmunodeficiencia Común Variable

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

¿Cuáles son los **SIGNOS Y SÍNTOMAS** de las inmunodeficiencias primarias?

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

¿Cuánto conocés sobre las **inmunodeficiencias primarias**?

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

Se estima que **6.000.000** de personas en todo el mundo **viven con inmunodeficiencia primaria**

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

Las **inmunodeficiencias primarias** son **defectos hereditarios** del sistema inmunológico

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

Hay más de **485** formas de **inmunodeficiencia primaria** que varían ampliamente en gravedad

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

**70-90%** de las personas con **inmunodeficiencias primarias** aún **no se diagnostican** en **todo el mundo**

World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

**Varios signos y síntomas** pueden ayudar a detectar **inmunodeficiencias primarias**. Infecciones de oído, sinusitis o infecciones de la piel, así como inflamación en los pulmones, el hígado y los intestinos

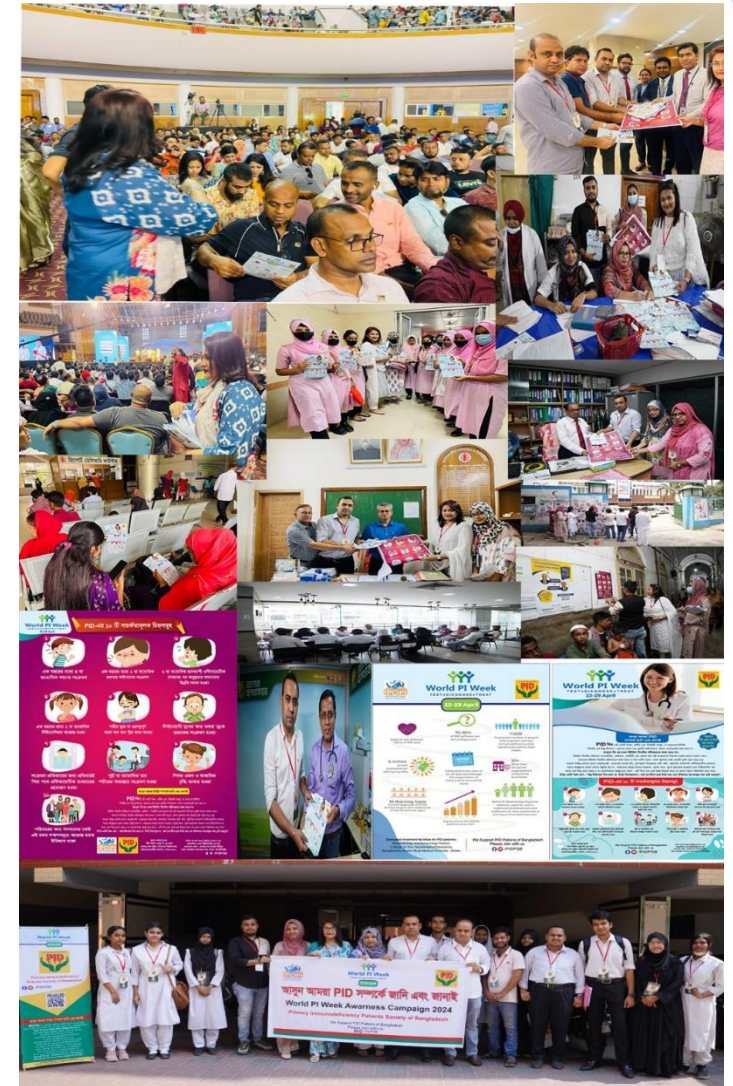
World PI Week  
AAPIDP Asociación de Pacientes con Inmunodeficiencia Primaria

# Bangladesh

## Primary Immunodeficiency Patients Society of Bangladesh (PIDPSB)

### *Project:* Know & Tell, 50 Hospital & 50K People

- Visited 52 Hospitals with 3000 flyers 1000 Posters for Indoor/Outdoor.
- Campaign in an event of 2000 professionals of Bangladesh (98<sup>th</sup> Batch Reunion).
- Produced More than 10 Contents of Doctor, Artists & PID Patients Story for YouTube & Facebook page of PIDPSB.
- Regularly Posting Photos and videos on social media.
- Print & Publication- 6000 copy of 10 Sign in Bangla Language flyers & Posters (Hard Copy Distribution & Online Distribution).
- Series Discussion with Media/Influencer, Doctors & Nurses On PID Topic.



# Belgium

## Belgian patient organisation for primary immunodeficiencies (BePOPI)

### *Project:*

- Held the #Burstthebubble campaign. Joined patients, medical staff, friends and family in blowing bubbles in 6 Belgian hospitals: Antwerp, Brussels, Charleroi, Gent, Leuven and Liège.
- Sharing videos on their social media blowing bubbles. Piloted their first PID Café in Brussels, patients and their entourage received accurate information about PID, both through lectures and in writing.
- Chat group for supporting each other, and they started the first close-knit offline PID-community in Belgium.

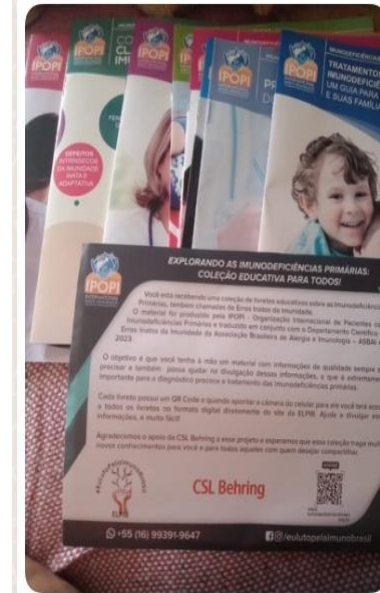


# Brazil

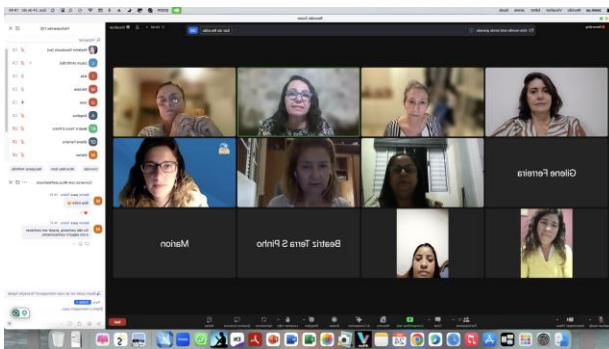
## Eu Luto Pela Imuno Brasil (ELPIB)

### Project:

- Sent each member of the association a set of 10 IPOIPI educational booklets translated into Brazilian Portuguese. Booklets also available on their website. For the new members, the mascot Lina was also sent
- Held an online meeting to inform patients about the association's activities and the importance of actively participating in it.
- Great movement on social media throughout April with informative posts and publications of testimonials from patients about what their life is like with PID.



Bom dia !!! Gratidão acabei de receber 🥰



# Canada

## ImmUnity Canada

### *Project:*

- Worked with volunteers to obtain official declarations of WPIW in 13 cities and one province across Canada (Pictured on the right: member Suzanne receives a provincial declaration of from David Pankratz, MLA, in Manitoba).
- ImmUnity Canada Executive Director, Whitney Goulstone (pictured on below right) hosted a webinar on advocacy and getting involved.
- Began a campaign for members to talk about the importance of access to them (pictured below on the left). This campaign will continue throughout the year at our regional education events and Walks for Immunodeficiency.



# Chile

## Fundación IDP Chile

### *Project:*

- Held a virtual meeting with patients and doctors, with the foundation.
- Distributed IPOPI flyers in different hospitals in Santiago and made a box for the patients where they created a medical agenda along with an informative pamphlet on PID. Also organised an in-person meeting for the patients.



# China

## PID Care China

### Project: Exploring PID through Art

- Public education campaign on PID: Hosted at China Pharmaceutical University (CPU).
- Keynote speech by Mr. Huang Rufang, Director of the Chinese Organization for Rare Disorders, and talks by industry experts and PID specialists, such as Dr. Yang Yong, Vice President of CPU.
- Art exhibition: Featured interactive experiences of student volunteers and PID patients entered transparent spheres, recreating the "bubble boy" living conditions. Traditional music performances by PID child patients.
- Quiz: 10 questions about PID, encouraging audience participation and knowledge. Attendees who answered correctly were rewarded with gifts.
- Initiatives: The Student Union of CPU designated PID promotion for university public welfare campaigns, aiming to educate medical students and faculty about PID. Media outlets showed strong interest in advocating for human immunoglobulin as the primary indication for PID treatment in China.
- Impact: Positive coverage by 15 Chinese media outlets, with interest from other organizations in replicating the event. Industry support was evident.





# Cyprus

## The Association of People with Primary Immunodeficiency and Friends of Cyprus

### Project: Together we can

- The adult ensemble of their conservatory together with the host of the Music Café organised an event to support the association. Playin nonstop for six hours, and everyone still begged them to go on. Prokopis Band had a beautiful music program with selected Greek songs, enchanting the world to sing along with them.
- Informing People passing by taking their leaflets and asking questions.
- Social media: Rare Diseases Patient Experiences, by the Organisation Cyta. Thanks to this event, the speakers were able to capture the current situation surrounding rare diseases in Cyprus.



# Ecuador

## Fundación PIDE

### Project:

- Short Films: Activity conducted with medical students from the Central University of Ecuador, involving nine people with PID.
- Dissemination Workshops: Conducted in third-level hospitals and universities in four cities (Quito, Cuenca, Portoviejo, Guayaquil). Fundación PIDE is working directly with academia.
- II National Symposium "Talking about PID in Ecuador": Activity involving medical students, specialist doctors, people with PID and their families, and personnel from the Ministry of Public Health of Ecuador.
- Social Media Impact Work and Use of Dissemination Material: Attracted the interest of major universities in the country and are working on important visibility projects.



# Estonia

## Estonian Association of Patients with Primary Immunity

### Project:

- A display promoting World PI Week in four libraries with the aim of raising awareness of PID.
- Social media campaign about immunodeficiency.
- 6 presentations about PID in two Estonian higher education institutions teaching healthcare workers. The head of Estonian association, Kersti Urbala, was as always very welcome to share her personal experience with primary immunodeficiency to the future medical professionals.
- Important meeting with the Social Committee of the Parliament, where the supply of medicines and the treatment of each PID patient were discussed. The meeting was constructive and highlighted important issues and ways to address them, emphasising the right of every PID patient to receive timely and adequate treatment.



# Greece

## Immune Deficiency Association of Greece (Galinos)

### **Project:** Conference “Patients Are Central To the Solution”

- Over 60 patients and their families participating, keynote physicians, pharmaceutical representatives, local government representatives
- Six keynote speakers from various specialities spoke on the following topics, such as the value of genetic testing in PID patients, to how to live with a PID – psychological implications and tools for coping.
- Local TV coverage with interviews
- Community and support for patients and their families and a raised familiarity with the physicians present
- Comprehending PIDs from a patient’s perspective. Patients and physicians.
- Educating on the warning signs and importance of early diagnosis and treatment.
- Understanding how PIDs affect different and are treated by different specialities
- Networking with key stakeholders and physicians to secure participation in future medical specialty conventions to speak about and raise awareness on PIDs.



# Hungary

## Hungarian Organisation for Patients with Immunodeficiency (HOPI)

### Project: Access to Care for all PID patients in Hungary

- Educational material made with the aim of introducing treatment in clinics and centers in the different regions of Hungary.
- Introducing doctors who take care of patients with PIDs.
- Filming a series of videos on multiple PID related topics with specialists and publishing it on Youtube (4 videos published, 2 in post-production, 4 more scheduled to film later)
- Connecting the community of patients to doctors via Q&A part of the interviews.



# Iran

## Iranian Primary Immunodeficiency Association (IPIA)

### Project:

- The 15<sup>th</sup> International Congress of Immunodeficiency Diseases (ICID)\_for pediatric immunologists, pediatricians, nurses, students, patients and their families.
- 51 lectures in two full days, most important part of the event was the ceremony for the patients and their families.
- Celebrating the 25<sup>th</sup> year of IPIA, 400 delegates attended. Full of fun, music, and art to improve the mental health of patients with PIDs and their families.
- The new head of the Iranian PiA was announced during this event.



**15<sup>th</sup> International Congress on Immunodeficiency Diseases (ICID)**

April 25,26- 2024  
Children's Medical Center,  
Tehran, Iran

*In-person Congress*

Research Center for Immunodeficiencies (RCID)

rcidcong.tums.ac.ir  
info.rcidcong@gmail.com  
+98 (21) 66129187

# Iceland

## Lind Iceland

### **Project:** Educational meeting for practical nurses

First session:

- Dr. Solrun Melkorka Maggadottir
- What is Immune system and how does it work

Second session:

- Thorunn Larusdottir and Hrefna Jonsdottir nurses
- Treatments and care

Publishing the brochure guide for schools

- Distributed to all school nurses and childrens departments at hospitals



# Italy

## Associazione Immunodeficienze Primitive (AIP)

### Project: The Adventures of Lino Globulino

- A new comic episode of The Adventure of Lino Globulino was created: «[Lino Globulino e la diagnosi precoce](#)» (Lino Globulino and the early diagnosis). In this latest story, Globulino, together with his friend Battista, connects to his fans to explain the simple functioning of Newborn Screening, and the precious benefits it can bring on the therapeutic path for patients with rare or ultra-rare diseases.
- The comic was published on [AIP website](#) and it was communicated through a news in the [website homepage](#)
- 5 posts were shared on [Facebook](#) and 1 post was published on [Instagram](#)
- The episode was uploaded on AIP [YouTube Channel](#)
- A newsletter was sent to AIP's associates and contacts and published on the AIP WhatsApp groups reaching a total of 4350 contacts
- A [press release](#) was spread through emails and the AIP website





# Ireland

## Irish primary immunodeficiencies association (IPIA)

### *Project:*

- Both children and adults seen by their immunologists at Main Dublin Hospitals
- Activities in a stand in James's Hospital. The Main Concourse Promotional. Distributed promotional items including tattoos, treats, brochures, balloons, and posters.
- Similar Activities in the children's hospital. A stand and distributed promotional items
- Different Approach in Beaumont Hospital, distributed promotional items without a stand

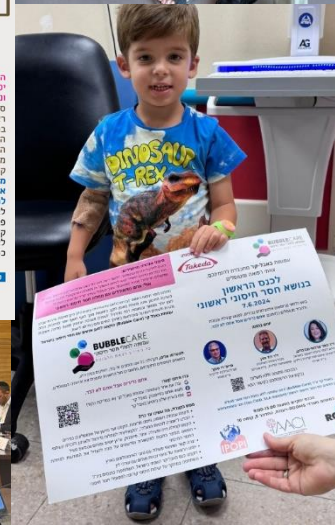
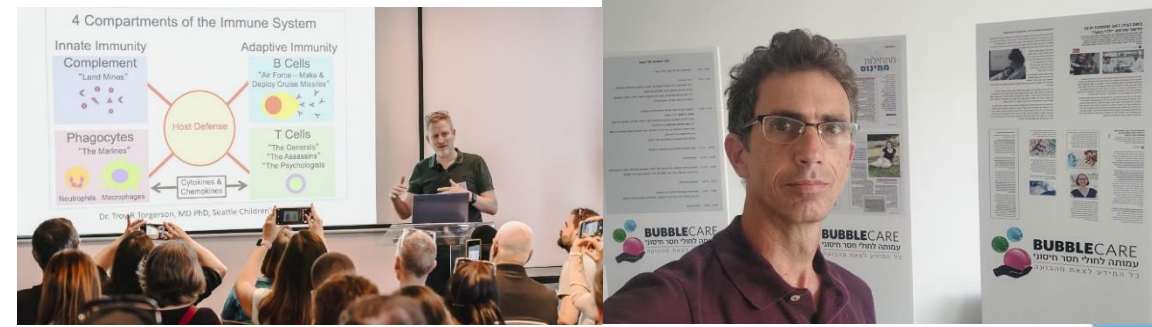


# Israel

## Bubble Care

### Projects:

- First-ever PID patients' conference - 70 people participated, including immunologists. 3 leading immunologists presented lectures and answered questions, 2 PID patients and a mother of a 3 year old born with SCID told their personal stories. Posters and flyers were sent to 15 hospitals that treat PID. The conference was endorsed by the society of Allergy and Immunology doctors. The lectures were filmed and will be available online. 4 articles we published in the media were printed for the conference.
- Adding to the [website](#) and [facebook](#).
- Created Bubble Care YouTube presence:
- IPOPI campaign for encouraging plasma donations.
- They are partners in the coalition for rare diseases: Lobbying for national policy.
- Articles in media: Article in a popular magazine also online. 3 PID patients and a doctor.

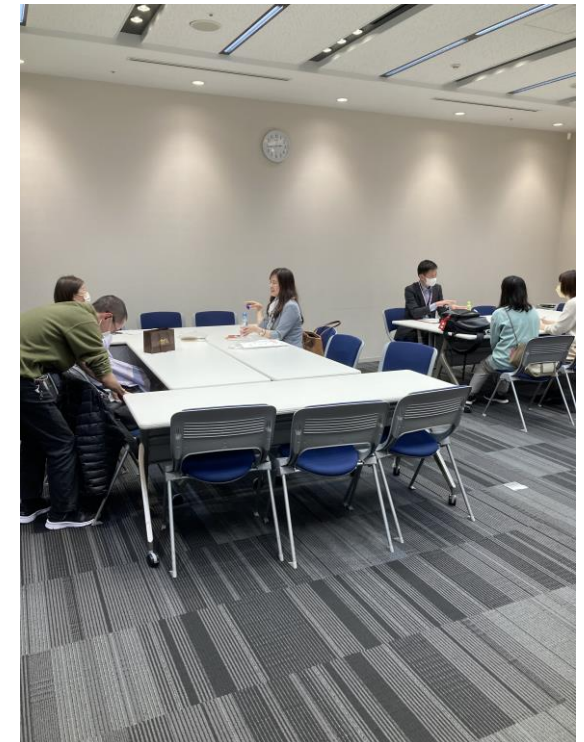


# Japan

## PID Tsubasa-no-Kai

### *Project:* Patients and family members meeting

- Held a family day “in person” on 24 Mar 2024, for the first time since May 2019.
- Attended by 12 participants including adult and child patients as well as family members, mainly from nearby areas.
- The event was small but a success with positive feedback!
- Online patients and family meeting to share insights from the in-person meeting and to keep in close touch between the members.



# Lithuania

## Lithuanian society for primary immunodeficiencies (IMUNAS)

### *Project:*

- Live press conference “Primary immunodeficiencies – a verdict or a possibility? With Prof. Laura Malinauskienė, assoc. Prof Edita Gasiūnienė, Imunas board member Laurynas Ramanauskas.
- Press release sent to mass media.
- Wide media coverage followed press conference and press release: Delfi, Kaunodiena, Irt.lt, Ink.lt
- Prof Laura Malinauskienė interviewed at the TV show “Good morning” at the state TV channel LRT
- Radio show “Experts suggests” at the most popular radio station for our target population News radio” participants: Prof Laura Malinauskienė
- Annual patients’ meeting in Vilnius. Lectures held by Imunas medical advisors: assoc. prof E. Gasiuniene and assoc. prof A. Blaziene



# Malaysia

## Persatuan Pesakit Immunodefisiensi Primer Malaysia (MYPOPI)

**Project:** In collaboration with the Ministry of Health Malaysia and IPPT USM Bertam, Penang

MYPOPI E-Book "Meniti Perjalanan Kehidupan Bersama Penyakit Immunodefisiensi Primer" (Living with PID – English Translation) posted by MoH on their official social media account on 21 Apr 2024

PID Awareness Story shared in MoH's e-magazine published on 01<sup>st</sup> June 2024

MYPOPI – IPPT USM and patients & families during WPIW2024 Public Awareness Program held on 24 – 26 April 2024

# Mexico

## Asociación Mexicana para pacientes con inmunodeficiencias primarias (AMPIP)

### *Project:*

- Continued to provide knowledge about PID to the population of Mexico.
- Conferences and experiential talks given by patients, family members, and a multidisciplinary team focused on understanding PIDs.
- Helped patients have a realistic and positive view of themselves and their possibilities, fostering group responsibility by sharing personal experiences.
- A family meeting with PID patients to encourage mutual support, beneficial for coping with difficult situations. Specialists including pediatricians, psychologists, thanatologists, and nurses provided valuable advice.
- Patients and their families shared the vulnerable aspects of the disease through talks.
- The president of the AC and her administrative team handled the logistics of the event, including the closing ceremony.



# The Netherlands

## Stichting voor Afweerstoornissen (SAS)

### *Project:* Family Day

- An educational and enjoyable day for the members of the Stichting voor Afweerstoornissen.
- The SAS Family Day was filled with interesting presentations by health care professionals and interactive sessions about, for example, living with PID.
- Visitors could visit the PID information market where various organizations could offer their products or services.
- Of course there was also plenty of time to exchange experiences and children's activities were organised.



# Poland

## Association for Patients with Primary Immunodeficiencies (IMMUNOPROTECT)

### *Project:*

- Camera covers with Immunoprotect logo and 10 warning signs of PID distributed in Polish medical centres during Word PI Week.



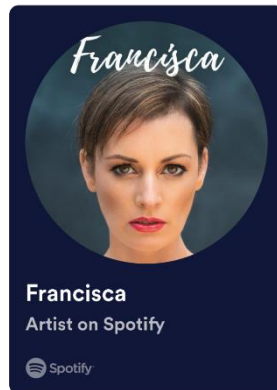


# Portugal

## Associação Portuguesa de Doentes com Imunodeficiências Primárias (APDIP)

### *Project:* Family Day

- Event fostering community bonding, shared experiences and unity among members.
- A guided tour of the UNESCO World Heritage site, Convento de Cristo, provided a cultural appreciation and enlightenment.
- A lunch at the convent's offered nourishment joyous conversations and laughter.
- A acoustic concert by Francisca, created an intimate and heartfelt atmosphere in one of the convent's historical rooms.



# Romania

## Romanian Association for Patients with Primary Immunodeficiencies (ARPID)

### Project:

- 2nd regional patient-doctor-nurse meeting. Educating healthcare providers from newer PID centers and establishing connections. Primary goal ensuring better care for PID patients. A very successful event.
- The 7th Romanian Patient Conference, virtually with 7 distinguished doctors and around 50 patients from Romania and Moldova. Platform for sharing insights and advancements in the diagnosis and treatment. Dynamic interactive sessions and in-depth discussions. Broadcasted social media platforms, accessible for further viewing, [here](#).
- Press campaign to highlight the challenges faced by individuals living with PIDs. Raise public awareness about these conditions and support for PID patients, the importance of understanding and addressing their unique needs. Published in all the relevant media at a national level, can be found on the following platforms:

**Agerpres:** The official press release, detailing the challenges faced by PID patients and emphasizing the importance of public awareness and support, is available [here](#).

**360 Medical:** This source covered the press release, focusing on the advocacy for equal access to medical care for patients with primary immunodeficiencies. You can read the article [here](#).

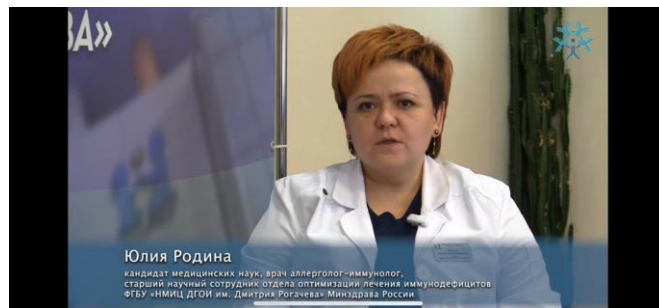
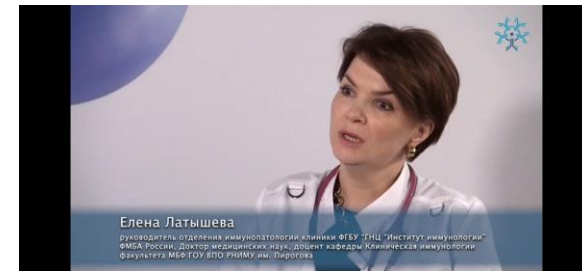
**Medical Manager:** This publication also featured the press release, highlighting ARPID's efforts to improve care and support for PID patients. More details can be found [here](#).



# Russia

## Association for PID patients (OPPID) Project:

- Immunology experts broadcasts (22-28 of april 2024):
  - 22.04.2024 Dr. PhD Anna Scherbina (PID - inborn errors of immunity)
  - 26.04.2024 Dr. PhD Andrey Prodeus PID diagnostics for children
  - 28.04.2024 Dr. PhD Elena Latisheva adult PID patients
  - 24.04.2024 Dr. PhD Yulia Rodina SCID cases
  - 28.04.2024 Dr. PhD Yulia Rodina SCIG use practice
  - 27.04.2024 Dr. PhD Dmitriy Balashov HSCT for PID patients
- Children's drawings competition 22-28.04.2024
- Joint press conference both OPPID (Natalia Berseneva) and Russian State Foundation "Circle of kindness" (Alexander Tkachenko) in The Civic chamber of Russian Federation 26.04.2024.
- The link to the videos is available [here](#).



**Всемирная неделя  
Первичных иммунодефицитов  
22 - 29 апреля 2024 года**

Выступления экспертов в области иммунологии

Сербина А. Ю.    Продеус А.П.    Родина Ю. А.  
Дерипапа Е.В.    Латышева Е. А.    Балашов Д.Н.

Творческий конкурс    «Круг добра»

# Spain

## Asociación Española de Déficit Inmunitarios Primarios (AEDIP)

### Project: II Community Walk

This community walk focused on recruiting participants and giving them more information.

- Gathering people from nearby villages and NMO members.
- Set up an information stand with at least four members providing details about the illness.
- Created and distributed a new pamphlet with four themes:
  - What is a PID? Importance of donating plasma; the Importance of early diagnosis; and the importance of equality.
- Distributed the pamphlet to every participant when delivering t-shirts



# Sweden

## Primär immunbristorganisationen (PIO)

### **Project:** Zebra get-together in Jönköping

- Three lectures, for a live audience and people joining online
  - “The immune system and primary immunodeficiencies“ *Åsa Nilsson, chief physician, clinic for infectious diseases, University Hospital Linköping*
  - “Person centred care from the nurses’ perspective” *Ramona Fust, nurse, clinic for infectious diseases, University Hospital Linköping*
  - “Structured and empowering nurse dialogue with PID patients” *Carina Hagstedt, nurse, clinic for infectious diseases, Regional Hospital Ryhov*
- Discussions and conversations amongst patients and family members
- Interviews on the local radio station
- An important and nice evening with new knowledge, new acquaintances, shared stories, laughter and tears



# Uganda

## Dove Primary Deficiency Patients' Organization limited (DPIDPO)

### Project:

- Media collaborations through interviews, panels and discussion on local TV as well as national.
- Social media engagement on different channels to amplify campaign message.
- Stakeholders meeting including patients, government representatives and professionals.
- PID Awareness walk on April 28 to raise awareness and show solidarity.
- DPIDPO have raised awareness, engaged stakeholders, and advocated for improved support for individuals with PID within the Ugandan context. Through strategic collaborations, innovative outreach efforts, and grassroots mobilization, the campaign has effectively amplified the voices of affected families and contributed to positive change in Uganda's healthcare landscape.
- A main topic of discussion was to make immunoglobulin available and at lowest price for our patients

NBS TV INTERVIEWS, UGANDA.



PIDD AWARENESS WEEK.



# Ukraine

## Rare Immune Diseases (RID)

### *Project:*

- Flyers and an animated film with features of PIDs were distributed and broadcasted in regional hospitals of Ukraine.
- The NGO RID took part in the all-Ukrainian conference for doctors with the report "Patient Stories".
- A flyer on neonatal screening with information for mothers was printed.
- The video clip about PIDs was supplemented with subtitles for broadcasting in public places.



# Venezuela

## Immunodeficiencias Primarias Venezuela (IDP)

### Project:

1. Distributing campaign material on Otorhinolaryngology unit and Pediatric service
2. Conference "We can do more to identify patients with primary immunodeficiency" for health workers.
3. V Annual Meeting on IEI, on April 26-27
4. Distributing campaign material to medical students, in the Faculty of Medicine.

1.



2.



4.



3.





IPOPI thanks their support, which enabled the funding of numerous outstanding initiatives during World PI Week 2024.

**CSL Behring**

**GRIFOLS**

