IPOPI WPIW NMO Support Programme Report

2026

World PI Week
TEST • DIAGNOSE • TREAT

IPOPI

Algeria

Algerian Association of People with Primary Immunodeficiency

Project:

- Organised and participated in several events for World Primary Immunodeficiency Week, starting in the central provinces (Setif Province), then moving to the Kabylie region (Tizi Ouzou Province).
- Have another event scheduled in the capital on June 12, 2026.
- Distributed leaflets about diagnosis, treatment, and the rights of this group.







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Argentina

Asociación Ayuda al paciente con Inmunodeficiencia Primaria (AAPIDP)

Project: *Social media campaign "What is it like to live with a PID"*

- The project carried out on social networks was based on demonstrating to the community in general what it is like to live with a PID and why patients and their families should not have to wait to receive their medications on time and in the proper manner, that they are not denied, shortened or changed by brand or type of administration and in turn be able to access genetic studies, advanced therapies, to study and work. It had a very positive impact and garnered many views. Patient testimonials were presented, addressing specific cases of why we cannot wait. The main platforms for dissemination were Instagram and Facebook.



Australia

Immune Deficiencies Foundation Australia (IDFA)

Project: *Think PI Sooner*



IDFA delivered a successful campaign focused on promoting earlier diagnosis of primary immunodeficiencies (PI) through the "Think PI Sooner" initiative. The campaign combined digital communications, healthcare professional engagement, patient storytelling, media outreach, partnerships, and educational activities to reach diverse audiences across Australia. Key achievements included reaching more than 12,000 people through social media, generating over 1,700 views of the campaign video ‘I Don’t Feel Alone’, distributing a new healthcare professional resource, and delivering targeted healthcare advertising. The campaign also included a webinar attended by patients, families, and healthcare professionals, as well as media coverage highlighting the challenges of delayed diagnosis and the importance of early recognition of PI. Strategic partnerships with healthcare and rare disease organisations significantly expanded campaign reach, while patient stories remained central to raising awareness and fostering community connection. Overall, the project strengthened awareness of primary immunodeficiencies, promoted earlier diagnosis, and increased engagement among patients, healthcare professionals, policymakers, and the broader community.





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Bolivia

FIDEP Bolivia

Project:

In April 2025, FIDEP organised an educational dinner meeting in La Paz, Bolivia, with the support of IPOPI and in collaboration with Laboratorios Bagó. The event brought together 30 pediatricians, who are often the first point of contact for patients with Primary Immunodeficiencies (PIDs). Two immunologists delivered presentations on the diagnosis, management, and early recognition of PIDs, generating active participation and discussion among attendees. Educational and awareness materials were also distributed to healthcare professionals to support earlier detection and referral of patients. The meeting was further enriched by the participation of patients and patient representatives, who shared the importance of timely diagnosis and comprehensive care. Thanks to IPOPI's support, this activity contributed to increasing awareness of PIDs and strengthening collaboration between healthcare professionals and the patient community in Bolivia.









Brazil

Eu Luto Pela Imuno Brasil (ELPIB)

Project:

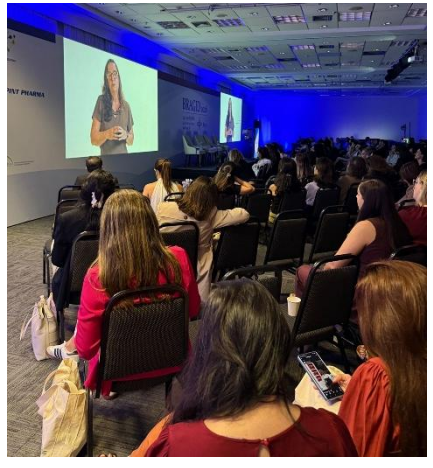
The project was carried out during the BRAGID Meeting 2026 (Brazilian Immunodeficiency Group), which took place on April 24th and 25th, 2026. The event focused on Clinical Immunology and Inborn Errors of Immunity, bringing together national and international specialists at the Blue Tree Premium Faria Lima hotel in São Paulo.

A video presentation was shown to the doctors, in which our vice-president presented a journey through plasma collection around the world. There was also a room for patients who heard the opening and welcome address by Dr. Ekaterini, the current president of BRAGID, followed by a presentation by volunteer Cláudia on ELPIB's activities, and a presentation by pharmacist Cristina Fortunato explaining an overview of immunoglobulins, from plasma collection to the finished medication. Finally, a delicious coffee break was served, allowing patients and doctors to connect and exchange ideas. It was a success!









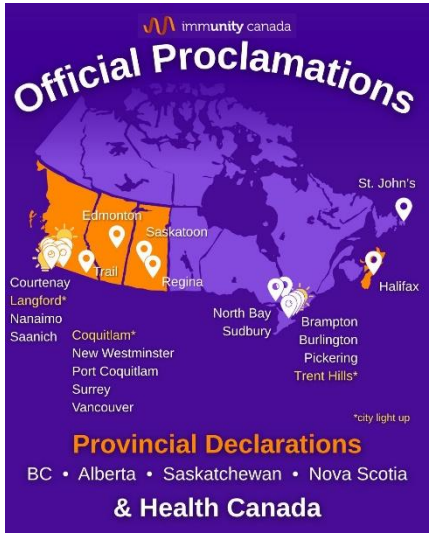
Canada

ImmUnity Canada

Projects:

- This WPIW, Immunity Canada had 4 provinces and 20 municipalities across Canada officially declare and recognize World PI Week in their legislature. We also received an official proclamation from Health Canada. Three cities also lit up main monuments purple and orange in recognition. Several city mayors met with members of Immunity Canada who are patients and families (from Halifax, NS who met with 5 members for an hour and included children's storytime, to Vancouver, BC who met with four adult patients to hear about their journey).

- They also created and posted a different patient story video every day on our social media, highlighting the theme of WPIW. It was very popular and they had people reaching out asking to share their stories and wanting to create their own videos and share their stories as well.











Chile

Fundación IDP Chile

Projects:

Last April, they carried out the following awareness campaigns about people with intellectual disabilities (PIDs):

1. An animated video was created about the story of Sofia, a young woman with a PID, and how she copes with it in her adult life.
2. A virtual meeting was held with a leading nurse specialising in our Ricarte Soto Law to explain how this law works for people with PIDs.
3. Materials were distributed to various hospitals throughout the country to raise awareness about PIDs.
4. A breakfast was held with some members and their families.









China

PID Care China

Project: *Multi-stakeholder collaboration*

Highlighted a growing multi-stakeholder collaboration within the primary immunodeficiency community in China. The project brought together leading medical institutions, physicians, universities, patient families, corporate partners, and social supporters to jointly raise awareness of PID and advocate for earlier diagnosis, timely treatment, and long-term patient support.Throughout the campaign, a series of nationwide activities were carried out, including public awareness initiatives, charity runs, patient storytelling, online and offline educational outreach, and community engagement programs. These activities helped improve public understanding of PID while amplifying the voices and real-life experiences of patients and families.

One of the key highlights of the project was the increasing participation of healthcare professionals and medical centers in promoting standardized diagnosis and disease management, alongside stronger involvement from patients, caregivers, and social partners in advocacy and support efforts.The campaign also demonstrated the importance of collaboration between the medical community, patient organizations, academia, industry partners, and society in building a more supportive ecosystem for individuals living with PID in China.



Ecuador

Fundación PIDE

Project: *Suspicion, diagnose and treatment*

- Open House: To educate patients, healthcare personnel, and the general public on important aspects of Inborn Errors of Immunity
- Outreach workshops in tertiary specialty hospitals in four cities: Manabí, Quito, Cuenca, and a symposium in Guayaquil. The PIDE Foundation is working directly with academia and immunologists in all four regions of the country.
- Online national workshop for patients and their families.
- IV National Symposium Talking about Inborn Errors of Immunity in Ecuador.- activity that involved medical and nursing students, specialist doctors, people suffering from PID, and their families.
- Impactful work on social media, using printed and digital dissemination material. We have attracted the interest of tertiary hospitals and important universities in the Coastal Region.











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Estonia

Estonian Patients Organisation for Primary Immunodeficiencies

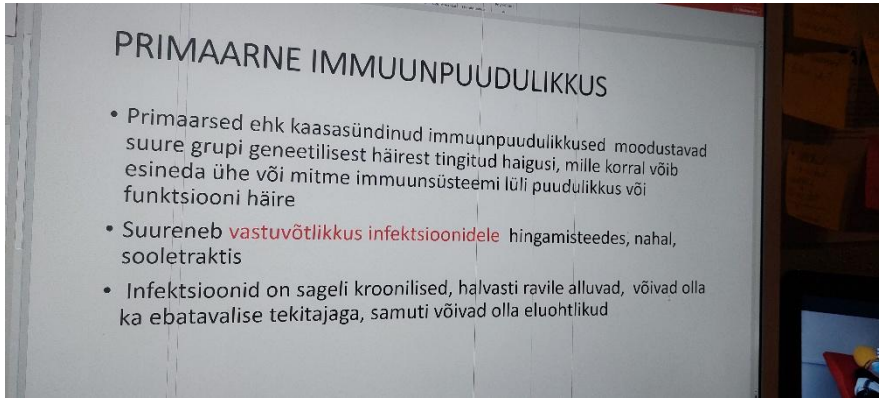
Project:

During PI Week, Kersti, Chair of the Estonian Primary Immunodeficiency Patients Association, visited family medicine centres, particularly in rural areas, to raise awareness of PI warning signs and early recognition.Drawing on her experience as a patient representative, mental health nurse, and patient experience advisor, she facilitated engaging discussions on vaccination, prevention, early diagnosis, and newborn screening.

IPOPI educational materials received very positive feedback and were widely appreciated by healthcare professionals.

The campaign's impact has continued beyond PI Week, with ongoing enquiries from healthcare professionals and plans to continue awareness activities throughout the year.

They now plan contribute to discussions with the Social Affairs Committee of the Estonian Parliament regarding the implementation of the SOHO Regulation from the patient perspective. As part of ongoing doctoral research, a scientific article will be prepared focusing on the importance of raising awareness among family medicine centres to support the early recognition of rare diseases, including primary immunodeficiencies.



France

Immuno-Deficience Primitive: Recherche, Information, Soutien

Project: *IRIS Courage Festival*

The first IRIS Courage Festival took place in the city of Toulouse at the end of April. For an afternoon, children and adults alike came together for a moment of laughter and sharing. On the programme: games, creative workshops, a treasure hunt, and a wonderful afternoon snack. This initiative was born from the desire of a mother of a patient to pay tribute to the courage of children and families living with PID.



This celebration was also an opportunity to gather children's quotes about courage:

- "Courage is when you do things that aren't easy."
- "Courage is when put up things we don't like."
- "Courage is like a door thet opens up for us to see."
- "Courage is like being able to lift something really heavy, like a house."
- "Courage is when we face our fears."
- "Courage is like seeing someone eat your favorite food and choosing not to eat it yourself."

Following this successful day, the plan in to spread it nationally next year to other cities in France!.









Ghana

Ghana Patients Organisation for Primary Immunodeficiencies (GhanaPOPI)

Project: GhanaPOPI Inaugural Event & World PI Week 2026

- On April 22 - Official launch of **GhanaPOPI** at Korle Bu Teaching Hospital, establishing a national platform for PID awareness, advocacy, and patient support.
- Conducted **nationwide awareness and health education activities** in hospitals, reaching patients, caregivers, healthcare professionals, and the public.
- Organised a **national virtual symposium** for healthcare workers on “Primary Immunodeficiencies in Ghana: Bridging Awareness, Care, and Support,” promoting early diagnosis, referral pathways, and multidisciplinary care.
- Initiated discussions on **research collaboration, patient registration, and data collection** to strengthen evidence generation and policy planning.






GAF launch Burma Camp redevelopment project to tackle housing deficit

Patient Organisation for Primary Immunodeficiencies launched

Hungary

Hungarian Organisation for Patients with Immunodeficiency (HOPI)

Project: *Educational and community day*

- HOPI marked World Immunology Day 2026 with an educational and community-focused event in Nyíregyháza. Under the theme “No Time to Wait”, physicians, patient representatives, and individuals living with primary immunodeficiency shared their knowledge and personal experiences, emphasizing the importance of early diagnosis, awareness, and access to appropriate medical care.

- The event brought together patients, family members, and healthcare professionals, providing an opportunity to exchange experiences, strengthen community connections, and raise awareness of primary immunodeficiency. All presentations were recorded and will be made available online to reach a wider audience.

- Following the lectures and a shared lunch, participants visited Nyíregyháza Zoo, where they met the pair of hyacinth macaws symbolically adopted by HOPI. The adoption reflects the values of hope, strength, and togetherness that unite the immunodeficiency community and served as a memorable highlight of the day.







Iceland

LIND Iceland

Project: Family Day

Family day with the PID families in Iceland. Due to the weather in Iceland they had to wait until June, the Family day took place in 21th of June in a national park. It was a great turn out with completely sold out tickets and lovely weather. Families and members came together to enjoy the day, and the atmosphere was truly special. It was wonderful to see so many people connect, share moments, and take part in the activities.



India

Indian Patients Society for Primary Immunodeficiency (IPSPI)

Project:

- IPSPI in collaboration with AMSA INDIA organised a Walkathon at CP Inner Circle, Connaught Place,New Delhi on 25th April,2026.IPSPI distributed pamphlets on 10 Warning signs of PID . Certificates of participation, T.shirts, Medals,Bags, Diary and Pen and Refreshments were given to all Participants.Professor Dr. LH Ghotekar,Medical Superintendent, LHMC,New Delhi was Guest of Honour of the event.
- IPSPI in collaboration with AMSA INDIA and Butterfly organised Free General Health Checkup Camp and Awareness on IEI for Children and Parents in South Delhi on 26th April,2026.
- IPSPI is honoured to be awarded appreciation Trophy from Ministry of Health and Family Welfare, Government of India.
- Due to extremely hot weather in Delhi and other places in India, CMEs on IEI has been postponed to July 2026



Indonesia

Indonesia Primary Immunodeficiency Patients Society (IPIPS)

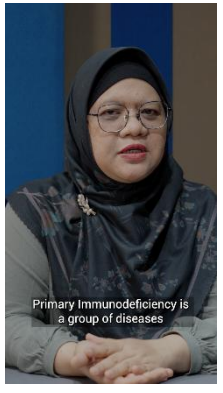
Project: Digital Awerness Campaign

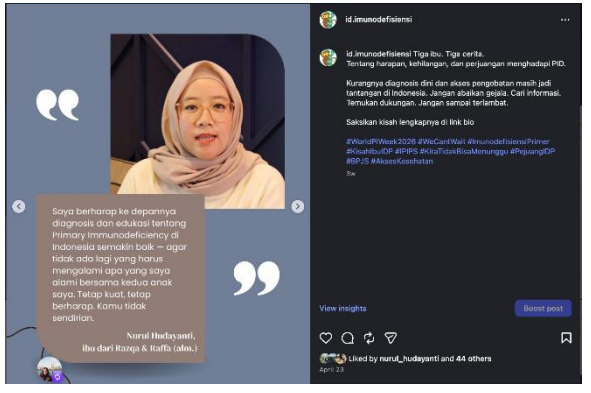
- IPIPS carried out a digital awareness campaign through its social media platform @id.imunodefisiensi to increase public understanding of PID.

- A key activity was the launch of a video campaign featuring three parents of children with PID alongside medical professionals explaining the disease and the importance of early diagnosis. The campaign gained strong engagement, reaching more than 89,000 views across platforms and receiving coverage from major national media outlets.

- The activities also generated interest from healthcare stakeholders, including a government-owned hospital in Jakarta. As a follow-up, IPIPS organized offline PID awareness sessions for healthcare professionals, where the organization shared the 10 warning signs of PID and distributed IPOPI PID educational booklets. Additional initiatives included preparation for future doctor webinars and collaboration with hospitals to expand educational outreach and advocacy efforts in Indonesia.









Ireland

Primary Immunodeficiency Support Ireland (IPIA)

Project: *Toolkit*

- The IPIA project https://ipiainfo.org/toolkit/ achieved several important milestones. IPIA advanced its Toolkit project, including a domain change, website updates, and improvements to create a more user-friendly patient experience. A key highlight was the inclusion of a new Mental Health Support section https://ipiainfo.org/toolkit/mental-health-support/within the IPIA Toolkit, reflecting a growing recognition of the psychological challenges faced by individuals living with Primary Immunodeficiency. This addition is hoped to strengthen the toolkit as a comprehensive resource for both patients and healthcare professionals.
- To expand awareness and utilization of the toolkit, IPIA actively promoted it through a targeted newsletter campaign distributed to members and healthcare staff. This effort it's hoped to help increase engagement and accessibility of the available resources.
- In addition, IPIA participated in the Cost of Disability Summit, contributing to broader discussions on the financial and social impacts of living with chronic conditions. This engagement further reinforced IPIA's commitment to advocacy, awareness, and holistic support for the Primary Immunodeficiency community.









Israel

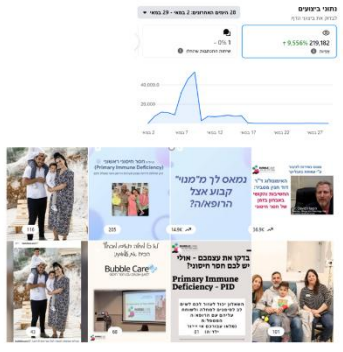
Bubble Care

Projects:

• Shared PID awareness materials throughout April and May, including patient stories, educational videos, podcasts, hospital case studies, advocacy updates, and international World PI Week content.
• Advocating for the widening of newborn screening to include lack of B cells. In Israel, there is a newborn screening program to identify babies with lack of T cells (SCID).
• Implemented a two-week paid social media awareness campaign across Facebook, Instagram, TikTok, and YouTube, featuring patient and family stories, educational content on PID warning signs, expert videos, and self-assessment questionnaires. From Facebook from May 2 to May 27: 219,182 exposures were made.
• Approached a well-known podcast group in Israel that tells in English to the world about Israel's health issues and innovations lead by Prof. Bruce Rosen. He will interview Prof. Raz Somech, an immunologist, about babies' screening in Israel for severe PID disease
• Will prepare a short video of an Immunologist explaining how to diagnose and treat PID diseases and what are the signs for it.







Italy

Associazione Immunodeficienze Primitive (AIP) APS

Projects:

- AIP APS carried out activities designed to move from awareness to concrete advocacy and dissemination actions.
- The data collected through the national survey “PIDs and Work” were scientifically analyzed, resulting in an article prepared for publication by Dr. Pulvirenti. This represents an important step in generating robust evidence on the challenges faced by people living with primary immunodeficiencies (PIDs) in the workplace.
- On April 21st, AIP APS organized the national webinar “Working with a PID – A Possible Challenge”, moderated by Filippo Cristoferi, AIP Director. The event featured key contributions from Prof. Alessandro Aiuti, President of ImmunITA, and Dr. Pulvirenti, who presented the survey results. Included direct discussion with policymakers from different political parties, including Members of Parliament Discussion highlighted several priority areas requiring stronger protection and legislative action: the right to work and equal access to education, safeguarding employment for both patients and caregivers, improved awareness and understanding of rare and invisible diseases from employers and colleagues.
- In parallel, a targeted digital communication campaign across its social media channels was implemented to raise awareness about PIDs, the Association, and the significance of World PI Week.









Kenya

PID Kenya

Project: National Webinar

- In collaboration with Kenyatta National Hospital and the University of Nairobi, PIDs Kenya hosted a national webinar on 29 April 2026 under the World PI Week theme “We Can’t Wait,” titled “Strengthening Early Recognition and Comprehensive Care for Primary Immunodeficiencies in Kenya: From Clinical Suspicion to Access to Lifesaving Plasma Derived Therapies,” bringing together over 1,100 healthcare professionals and clinicians.

- Expert speakers and patient advocates highlighted the importance of early recognition, the reality that a substantial number of individuals with PIDs remain undiagnosed or misdiagnosed, and the need for a national patient registry.

- Key recommendations included strengthening the diagnosis process; standardizing initial evaluation and referral supporting and using a PID patient registry; advocating for access to diagnostics and therapies; adopting family-centred, communication-focused care; and strengthening professional networks and ongoing learning.



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Lebanon

Association of Lebanese Patients with Primary Immunodeficiency (ALPPI)

Projects:

- Worked to raise awareness, share knowledge, and bring people together through a series of meaningful activities: April 18, SCID and other PIDs event at Hotel Dieu de France Hospital, dedicated to doctors, with the aim of supporting better understanding and care.
- April 22 - Nourish to Protect: Everyday Nutrition for Better Immunity reaching patients and the general public to encourage healthy habits to support the immune system.
- April 25 - Wellness Day a warm gathering that brought together patients, families, and friends to strengthen connection and support.
- April 28 - Advancing Early Diagnosis and Timely Care for Primary Immunodeficiency, in collaboration with the Order of Pharmacists, focusing on pharmacists to promote early recognition and better care. Through these efforts, ALPPI aimed to touch different communities with one shared goal: improving awareness, early diagnosis, and quality of life for those living with primary immunodeficiency because PID can't wait!







Malaysia

Persatuan Pesakit Imunodefisiensi Primer Malaysia

Projects: *Blood donation and public awareness*



The MYPOPI Xpodium & MYPOPI OCS Blood Donation Campaign 2026 was successfully conducted on 25 April 2026 at CrossFit Eren Kota Kemuning and on 13 May 2026 at UOA Business Park, Shah Alam. Organized by MYPOPI in collaboration with Xpodium, Koha Digital, and OCS Malaysia, the campaign combined blood donation activities with public awareness initiatives on Primary Immunodeficiencies (PIDs).

The project featured educational exhibitions, awareness materials, distribution of leaflets on the 10 Warning Signs of PID, and awareness-sharing sessions with blood donors. An additional online PID awareness talk was conducted for approximately 80 Koha Digital agents, further extending the campaign's outreach.



Both blood donation events exceeded the targeted collection goals, demonstrating strong community participation and support. More than 100 volunteers contributed to the success of the campaign, which helped increase public understanding of PIDs, promote the importance of blood donation, and strengthen collaboration among patient advocacy groups, corporate partners, and the wider community.







Mexico

Asociación Mexicana para pacientes con imunodeficiencias primarias (AMPIP)

Projects:

- They carried out a week of virtual activities focused on the overall well-being of people living with PIDs, their families, and caregivers. The project included talks delivered by healthcare professionals and a pedagogue, addressing topics such as emotional well-being, early palliative care, early detection, and the role of play in learning and emotional support. In addition, digital challenges, educational materials, and community activities were developed to strengthen self-care, family interaction, and support networks. As part of the project, board games were provided to children and families, promoting spaces for connection, learning, and emotional well-being.







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Morocco

Hajar Association



Project:

- April 25-26 – Organised “Sharing Joy” - an innovative therapeutic, educational and inclusive initiative.The project brought together more than 50 children with PID, particularly Ataxia Telangiectasia, and their families from 9 cities across Morocco for a unique two-day experience focused on inclusion, emotional well-being and dignity.
- The programme combined therapeutic workshops, psychological support, creative and recreational activities, and parent discussion groups, all delivered by a multidisciplinary team of 20 healthcare professionals and volunteers. For many children, it was the first opportunity to play outdoors, interact freely with peers and experience moments of joy and belonging. Beyond recreation, the project created a strong sense of community among families living with rare diseases, reduced isolation, strengthened self-confidence and promoted awareness about PID and the importance of paramedical care.
- Through media coverage and educational materials distributed to families, the initiative also contributed to increasing national awareness and supporting earlier diagnosis. What makes “Sharing Joy” particularly impactful is its holistic and human-centered vision of care, recognising that children with PID need not only medical treatment, but also emotional support, inclusion and the right to fully experience childhood. The project represents a replicable model of multidisciplinary and community-based care for the global PID community.





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Nepal

Nepal Primary Immunodeficiencies and Inborn Errors Initiative

Project: *Orientation program*





- An orientation program was organized in Nepal on the occasion of World PI Week in the presence of health workers, school principals, and educational stakeholders. The program was organized with the aim of raising global awareness about Primary Immunodeficiency (PI).
- The orientation focused on raising awareness about primary immunodeficiency, including discussions on the importance of early diagnosis, testing, and available treatment options for primary immunodeficiency. The key message of the program emphasized that primary immunodeficiency is treatable and encouraged participants to take early steps with the slogan “Treatment is possible, let’s start today.”
- The session was facilitated by Mr. Sandeep Poudel, President of NePOPI Nepal, who highlighted the importance of awareness, timely identification and collaborative efforts to support people affected by PI. The participants actively participated in the discussion and shared their views, which made the event informative and effective.







The Netherlands

Stichting voor Afweerstoornissen (SAS)

Project: *40th Anniversary*

From April 17 to 20, the SAS celebrated a truly special event: its 40th anniversary!

We are happy and grateful to have reached this milestone and to have been able to celebrate it at Center Parcs De Eemhof with 29 families.The weather cooperated; we enjoyed dry weather and the sun even made an appearance.

The good atmosphere was already evident during the bingo and games night on April 17; members enjoyed seeing each other again and exchanging experiences. There were handmade bingo prizes, signed by a creative SAS member who offered her artwork in honor of the bingo. The plush toys from Giant Microbes were popular.

Naturally, an extra prize was awarded for the lucky number 40. During the SAS Family Day with 125 visitors, informative presentations were given by several experts.





Peru

No somos Invisibles - IDP Perú

Project:

- Development of an awareness video that encouraged the public to reflect on how their lives would change if they could no longer perform everyday activities they often take for granted. Through authentic and relatable real-life situations, the campaign drew a parallel between daily life and the challenges faced by people living with PIDs. Rather than relying on complex production or special effects, the project focused on simplicity and realism to create an emotional connection with viewers.
- The initiative successfully promoted empathy, increased awareness of PIDs, and reinforced the importance of visibility, understanding, early diagnosis, and support for patients and their families. The campaign also strengthened the advocacy efforts of No Somos Invisibles – IDP Perú by giving a voice to individuals living with invisible conditions and encouraging broader community engagement during World PI Week.

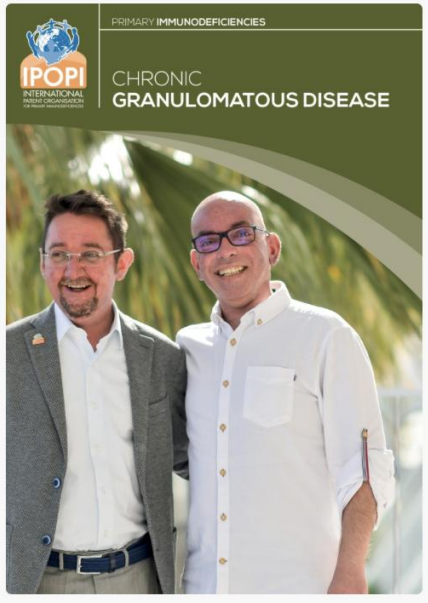


Poland

Association for Patients with Primary Immunodeficiencies (IMMUNOPROTECT)

Project: Translated Leaflets

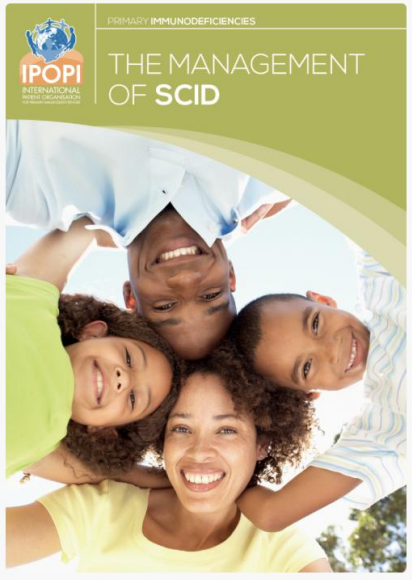
The project was devoted to diagnosed PID patients. There were IPOPI leaflets translated into Polish. The main goal was to educate PID patients in the matters they have to deal with or they have some doubts about. Educational material is in progress, so there aren't final versions of leaflets in Poland. As soon as the leaflets are ready, they will be sent to IPOPI.



PDF | eBook



PDF | eBook



PDF | eBook

Portugal

Associação Portuguesa de Doentes com Imunodeficiências Primárias (APDIP)

Project: *Family Day*

- APDIP did their Family Day that took place on April 25 at the Pousada Convento de Évora, bringing together patients and families for a walk to the Roman Temple in Évora, a lunch, and educational sessions, including the Crescer com IDP project for younger patients and talks by an immunoalergologista and a nutritionist. Portugal also contributed to the global campaign through Ricardo Pereira, who represented the country in the Rare for Real video series. APDIP also promoted the Portuguese version of MAPPA Survey (https://www.aip-it.org/i-nostri-progetti/mappa-survey/), an initiative monitoring patient pathways with Primary Immunodeficiencies, inviting patients and caregivers to share their experiences..









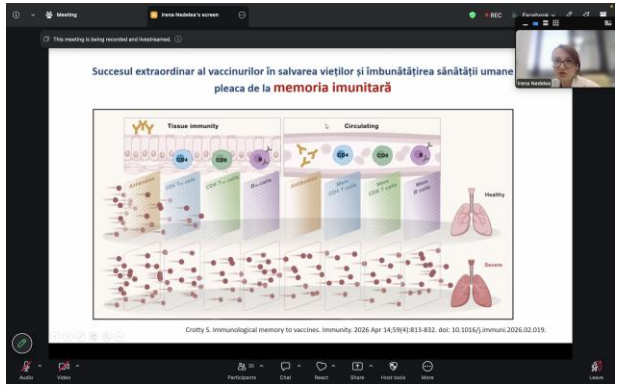


Romania

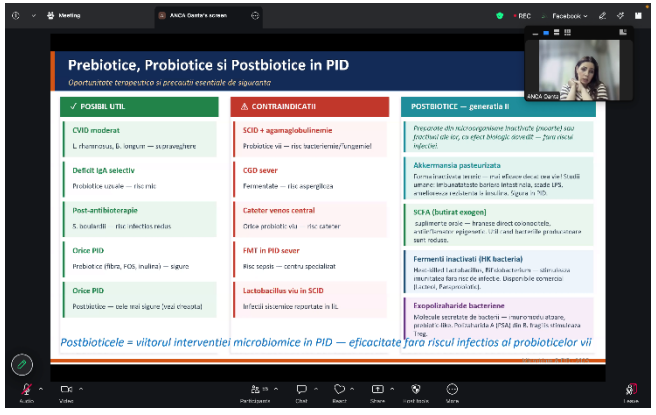
Romanian Association for Patiens with Primary Immunodeficiencies (ARPID)

Project: National Campaign with educational events and awareness material

- On 28 April 2026 ARPID organized an online webinar dedicated to healthcare professionals focusing on the role of genetic testing in the diagnosis and management of primary immunodeficiencies. The webinar emphasized the importance of early identification of patients, appropriate referral pathways, and the impact of genetic diagnosis on treatment decisions and patient outcomes.
- On 7 May they did their Annual Conference for Patients, bringing together patients, caregivers, healthcare professionals and partners for an afternoon of education and discussion. 62 on site and 172 online.
- Throughout World PI Week, ARPID developed and shared a series of infographics based on the campaign message..









Senegal

l'Association Sénégalaise de patients atteints de Déficits Immunitaires primitifs (ASDIP)

Project:

The project highlights the importance of effective patient reception and orientation. It emphasizes the strong motivation of all stakeholders involved in patient care. It also underlines the moral and psychological support provided to patients by healthcare professionals. Additionally, the project benefits from the availability and commitment of healthcare professionals working with ASDIP.









Spain

Asociación Española de Déficits Inmunitarios Primarios (AEDIP)

Project: *Community Walk*

AEDIP organized the forth edition of our "Caminata Solidaria" for WPIW on May, the 23rd in Gavilanes (Ávila). It counted with 80 people and 100 inscriptions in total, in a small village of 500 inhabitants. This year it couldn´t be done in the WPIWeek because of logistic problems with the town hall, but seeing the number of incriptions, it has been a total success. It has served AEDIP as an opportunity to make the NMO known in the community and to inform of the importance of plasma donation for the PID patients´ treatment, which were the main objetives of the event.







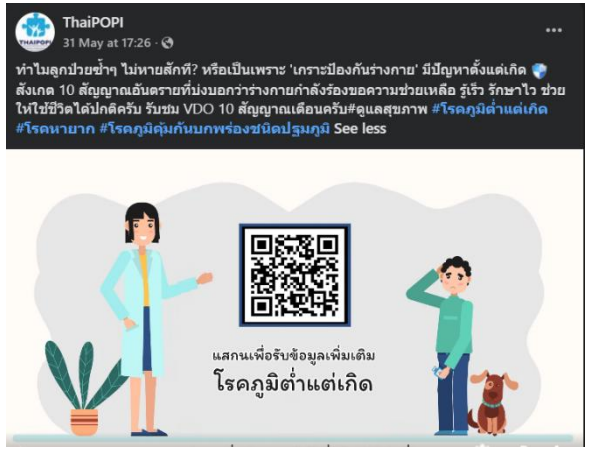
Thailand

Thailand Patient Organization for Primary Immunodeficiency (ThaiPOPI)

Project: Searching for new members

- Members of the ThaiPOPI attended a allergy doctors' meeting and gave the membership application form to the doctor so they can recommend PID patients to join ThaiPOPI.
-10 Warning Signs VDO. We posted a video about 10 warning signs of the PID disease (Only Thai language) on social media such as facebook page, Line application (Only ThaiPOPI member in group). Hopefully, they will help share the information so that people can get knowledge PID disease.







Tunisia

ATUN-DIP

Project:

- April 18 - A Family Awareness Day on PIDs was organised in Mahdia, Tunisia, in collaboration with clinicians from Tahar Sfar Hospital, the National Center for Bone Marrow Transplantation in Tunis, and immunologists from the nationwide reference laboratory for PID diagnosis at the Pasteur Institute of Tunis.
- The event raised awareness among patients, families and the wider public on PIDs, early diagnosis, and the impact of consanguinity on the recurrence of these rare diseases.
- Educational sessions covered the immune system, the “10 Warning Signs” of PIDs, genetic counselling, adapted vaccination strategies and individualised therapeutic approaches.
- Experts presented available treatment options in Tunisia, including immunoglobulin replacement therapy, haematopoietic stem cell transplantation and supportive medical care.
- Patients and families shared personal experiences, highlighting the daily challenges of living with PIDs and the need for continuous medical and psychosocial support.
- The day concluded with a roundtable on therapeutic education for children with PIDs, reinforcing the importance of empowering families and improving long-term care.









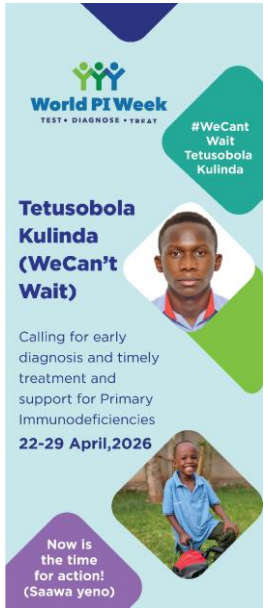
Uganda

DOVE Primary Immune Deficiency Patients Organization

Project:

- Awareness was one of our main highlights from the grassroots level. Diagnosis, a lot of people are misdiagnosed. Availability of treatment centers, availability of practising immunology. Lastly was government international.









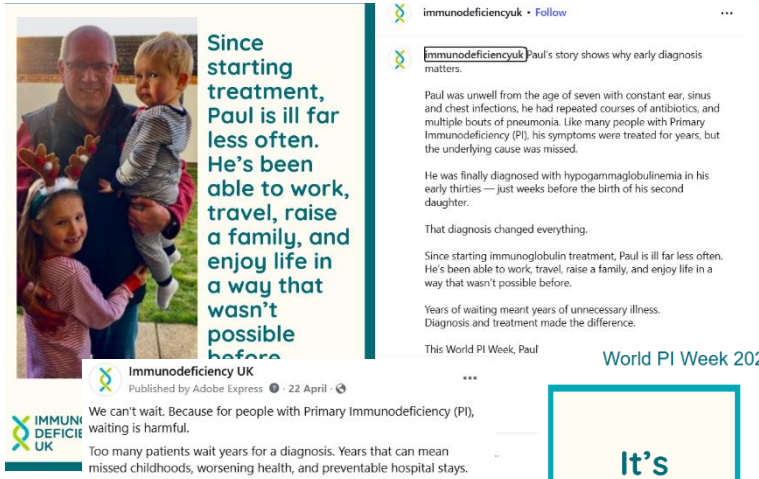
IPOPI INTERNATIONAL PATIENT ORGANISATION FOR PRIMARY IMMUNODEFICIENCIES

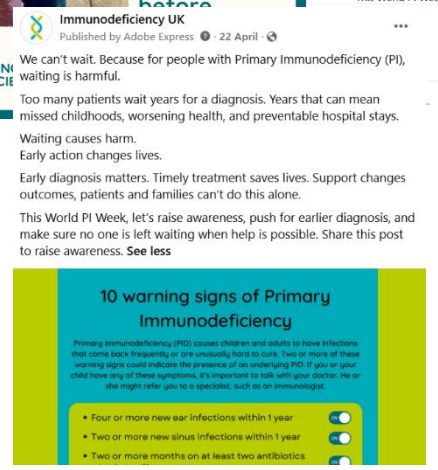
United Kingdom

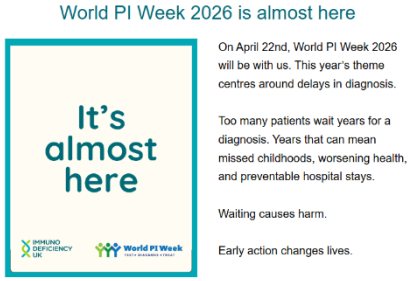
Immunodeficiency UK

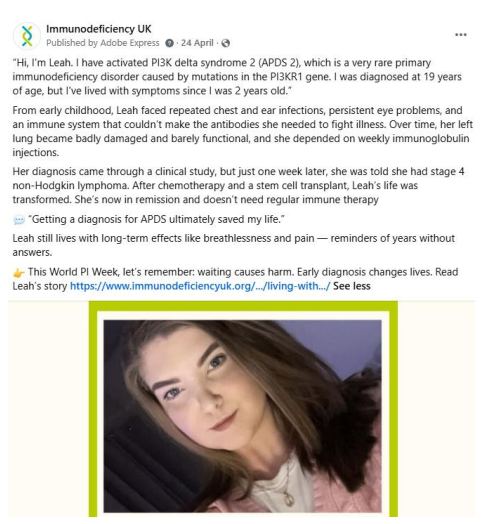
Project:

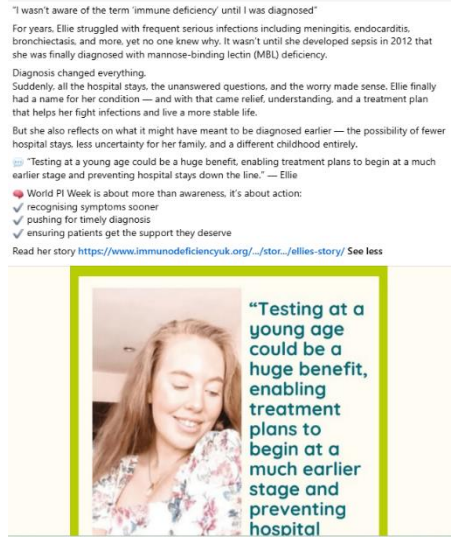
A multi-channel digital advocacy and storytelling initiative raise awareness of the impact of delayed diagnosis for people living with primary immunodeficiencies (PI). Running across digital and social media channels, the campaign featured powerful patient stories, educational content on the signs and symptoms of PI, and clear calls to action. Through compelling testimonials and evidence-based messaging, the campaign contrasted the devastating cost of delayed diagnosis with the positive outcomes of early detection and treatment. The campaign engaged patients, families, healthcare professionals, policymakers, and the wider public, encouraging greater awareness, earlier recognition of symptoms, and support for systemic change. Our campaign reached over 18,500 people and received over 700 content interactions (the number of likes or reactions, saves, comments, shares and replies) across Facebook, LinkedIn and Instagram. It also generated 64 new followers.











Venezuela

Immunodeficiencias Primarias Venezuela (IDP)

Projects:

The WPIW 2026 was characterised by different activities: a walk commemorating that week, The VII symposium on IEI was held, conferences and meetings with pulmonologists, nurses, pediatricians and medical students were made. A video made by patients about their life with IEI was also presented. The most notable activities are shown in the photos:

1. Photo 1: Hike to commemorate the start of the WPIW.
2. Photo 2: VII symposium on IEI with more than 100 attendees and 14 speakers.
3. Photo 3: Meeting with the nurses to talk about IEI.
4. Photo 4: Meeting and conference with pediatricians to highlight the early diagnosis of IEI.
5. Photo 5: Activities and conference with medical students. It was a successful week with new plans to continue working in this area. Thanks for your support











IPOPI wishes to thank

GRIFOLS

Takeda

for their support towards this IPOPI Programme, which helped enhance the impact of the global momentum through concrete NMO national activities

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