

[Title, name]

[Address]

Subject: Become an ambassador for the World Primary Immunodeficiency Week 2024

Dear Mr / Ms,

I am writing to you on behalf of the [World Primary Immunodeficiency \(PI\) Week](#) campaign to invite you to **support the movement and become an ambassador of the primary immunodeficiency cause**. Every year since 2011, groups of individuals and organizations including patients, healthcare professionals, specialist clinicians and nurses, researchers, industry and advocates from around the world gather to celebrate the lives of those affected by primary immunodeficiency, call for greater recognition of the diseases and for changes in policies and practices to address remaining unmet needs, during World Primary Immunodeficiency (PI) Week (22-29 April).

Primary immunodeficiencies (PIDs) are a group of genetic, hereditary diseases whereby the body's immune system is missing or does not function properly, leading to an increased susceptibility to infections affecting different parts of the body and which are recurrent, severe and sometimes fatal.

World PI Week offers a crucial and visible opportunity to inform and educate policy-makers, schools, hospitals, families, and the general public about primary immunodeficiency diseases to drive the earliest possible diagnosis and optimal treatment. Celebrations aim at uniting people to bring about positive changes in healthcare systems and practices around the world in support of patients.

World PI Week 2024 is excited to share with you its new theme: Access to care for all PID patients, everywhere: *Let's make early diagnosis & timely access to quality treatment a reality worldwide.* Around the world, 80% of primary immunodeficiency patients do not yet have access to adequate care. Lack of knowledge around PIDs, gaps in the availability and accessibility of diagnosis and treatments, lack of specialists & multidisciplinary care or shortages of the source material necessary to produce treatments leave individuals and families vulnerable. It's time to shatter these barriers. Let's make universal access to early diagnosis & quality treatment a reality for all those living with PIDs. Together, we can raise awareness and bring about change.

That is why this year we are highlighting the importance of reaching equitable diagnosis, achieving universal access to specialised care and, ultimately, ensuring quality treatments for all.

We are writing you to **encourage you to support our efforts this year**. It is important to our cause to count on the support of policymakers to rapidly and effectively bring attention to the disease and contribute to driving improvements and collaboration at a global level. World PI Week operates globally and has events in over 82 different countries with a strong network. **Your advocacy for primary immunodeficiency awareness, work at policy level and public renown has the potential to reach large numbers of people and policymakers** in these countries and beyond and enact concrete advances.

The extent of your engagement is up to your discretion, but any contribution would be greatly appreciated. For instance:

- helping us raise awareness of PIDs on social media by sharing some of our posts with a support message, or publishing a support message of your own on your channels.
- providing a quote or a video message for use on World PI Week website and communications collaterals

- contributing to the “Strike a Y” campaign by sharing a picture of yourself striking a “Y” pose on social media during the campaign Week (22-29 April), using #PictureAwareness
- giving an interview in the media be it on TV, radio or in printed media outlets
- hosting an event or generating policy conversations on the role of data in PID care
- following and sharing with your communities our initiatives of the 2023 campaign like the communities’ videos or the campaign kick-off coffee talk (see our website for more information)
- sharing your thoughts on “Why data changes lives” through our [“Data for PIDs” online campaign](#)

Our team and the estimated 10 million people affected by primary immunodeficiency across the world would be honored to build on your support for World PI Week. We remain available to discuss further how you could get engaged in the campaign and encourage you to read some of the personal testimonies of those effected by primary immunodeficiency available on our webpage to understand what keeps us going and why we are so passionate about the cause. These stories, are inspirational and the reason our organizations continue to advocate for those living with primary immunodeficiency.

We look forward to hearing from you and remain at your disposal should you have any questions.

Thank you in advance for any type of support you may wish to offer.

Best Regards,

[Insert name of your organisation and representative signing this letter]

The World PI Week Steering Committee is composed of the following organisations:

APSID, Asia Pacific Society for Immunodeficiencies
 ARAPID, Arab Society for Primary Immunodeficiencies
 ASID, African Society for Immunodeficiencies
 CIS, Clinical Immunology Society
 EFIS, European Federation of Immunological Societies
 ESID, European Society for Immunodeficiencies
 Immunodeficiency Canada
 INGID, International Nursing Group for Immunodeficiencies
 IDF, Immune Deficiency Foundation
 IPOPI, International Patient Organisation for Primary Immunodeficiencies
 JMF, Jeffrey Modell Foundation
 LASID, Latin American Society for Immunodeficiencies
 PPTA, Plasma Protein Therapeutics Associations
 SEAPID, South-East Asia Primary Immunodeficiency network

About World PI Week:

World PI Week is a global movement to raise awareness of primary immunodeficiency and related challenges; promote quality of life, early diagnosis, availability and access to treatment and care worldwide; and stimulate communication and advocacy around primary immunodeficiency. Learn more [here](#).



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