

[Title, name of Government official]

[address]

**Subject: Taking action to respond to Primary Immunodeficiency in [insert country] - World Primary Immunodeficiency Week (World PI Week), 22-29 April 2018**

Dear Mr / Ms ……,

I am writing to you on behalf of [insert National Member Organisation name] to **draw your attention to the challenges faced by people living with Primary Immunodeficiency (PI)** in [your country] and **urge you to recognise the importance of early diagnosis and appropriate treatment.**

PI is a growing category of over 350 forms of rare, genetic deficiencies of the immune system which increase susceptibility to a wide range of recurring, life-impairing and sometimes life-threatening infections that affect different parts of the body. It is estimated that PI affects over six million people worldwide and [insert number] people in [your country], yet the political attention is limited.

Therefore, we call on you to be proactive in taking steps to respond to PI. This starts with ensuring access to early diagnosis and appropriate care. Among other actions, ensuring that PI is properly addressed in the national rare disease plan, enhancing awareness and education, setting up regional specialist centres, promoting expert treatment centres, and establishing patient registries are vital in tackling those challenges in [your country].

Early testing and diagnosis of PI are crucial, yet complex and many patients can go on being treated for significant periods of time for their symptoms rather than for the underlying cause of their condition, resulting in repeated hospitalisation and unnecessary medical expenses. Around 70-90% of people living with PI remain undiagnosed worldwide. The relatively low awareness of PI, the lack of diagnostic facilities and the wide variety of types of PI often lead to diagnostic delays or incorrect diagnosis. Ensuring early diagnosis and access to appropriate treatment for patients is therefore a priority for the PID patient community. Several studies have shown the significant benefits this will bring to patients and to society in socio-economic terms. Importantly, PID patients who receive optimal treatment will also be able to contribute productively to society.

Since 2011, World PI Week has been raising awareness of PI and stimulating efforts to improve diagnosis, access to treatment and quality of life for people with PI. This year, over 60 countries will join the campaign under the theme *“My future starts with early testing and diagnosis of Primary Immunodeficiency*”.

On the occasion of World PI Week, there is no better time for you to take action, to the benefit of PI patients in [your country]. Greater action is needed by the government to ensure that patients can be diagnosed early-on and have access to optimal care.

I hope we will be able to count on your support towards this important initiative. [Organisation name] would welcome the opportunity to meet with you to discuss further what steps can be taken, to ensure that persons with PI can have continuous and equal access to their life-saving treatments in [your country].

Yours sincerely,
[Name, Title]

For more information about **Primary Immunodeficiencies:** [add link]
For more information about ***World PI Week***: [www.worldpiweek.org](http://www.worldpiweek.org)
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