See the Unseen

World PI Week
TEST • DIAGNOSE • TREAT

- Claudia, Brazil
Living with a Primary Immunodeficiency

WHAT ARE PRIMARY IMMUNODEFICIENCIES?

Primary Immunodeficiencies are a group of over 550 conditions where part of the body's immune system is missing, does not function correctly or at all. These conditions leave individuals more vulnerable to infections, autoimmunity, and other complications. While some forms of Primary Immunodeficiencies are identified early in life, others manifest in childhood, adolescence, or adulthood, often after years of unexplained health struggles.

KEY FACTS

- **Over 550 forms** exist, affecting people of all ages.
- **Approximately 6 million people worldwide** live with Primary Immunodeficiencies, yet **70-90% remain undiagnosed.**
- **Not contagious** – these conditions are mostly genetic, meaning they are inherited, though some cases arise spontaneously.
- **Frequent infections** could indicate an underlying immune disorder.
- **Timely diagnosis** reduces hospitalizations, long-term complications, and improves quality of life.
- **Treatment options** vary and may include anti-infectious treatments, immunoglobulin therapy, targeted therapies, bone marrow transplant or gene therapy.
- **Quality of life** – with timely diagnosis and proper treatment, many can lead productive, fulfilling lives.

THE IMPACT OF DIAGNOSIS

A diagnosis transforms lives, enabling treatment and self-management.

Without a diagnosis:

- **Infants** with severe Primary Immunodeficiency may not survive past early childhood without extreme protective measures.
- **Children** may experience frequent illnesses, affecting education, social development, and overall quality of life.
- **Adults** may suffer from chronic infections and other manifestations that impact careers, family life, and mental health.

Listen here to real stories of resilience and fulfillment, celebrating dreams while uncovering unknowns.

Regardless of age or stage, a missing diagnosis brings isolation, fear, and anguish. We must unite so more dreams come true – like Maureen (Canada), writing her third novel, Vahid (Iran), pursuing a master's, Isabel (Spain), enjoying a vibrant social life, all while living with a Primary Immunodeficiency, and Claudia (Brazil), who says:

"I am capable, I am strong, and determined to achieve all my life goals, and nothing will stop me from being happy!"

PRIMARY IMMUNODEFICIENCY AND GLOBAL HEALTH GOALS

Aligning with the United Nations Sustainable Development Goals (SDGs):

SDG 3: Good Health & Well-Being
Early diagnosis and appropriate treatment reduce hospitalizations, complications and mortality rates.

SDG 10: Reduced Inequalities
Expanding access to diagnosis and care helps reduce health disparities worldwide.

World Health Organization (WHO) Initiatives:

Universal Health Coverage (UHC)
Ensuring affordable and accessible diagnosis and treatment supports global UHC efforts.

Global Action Plan for Immunization
Increasing awareness of Primary Immunodeficiencies ensures safer vaccination strategies for immunocompromised individuals.

Non-Communicable Diseases (NCD) Action Plan
Recognizing Primary Immunodeficiency as a chronic condition is essential for long-term healthcare planning and investment.

CALL TO ACTION

We are calling for collaborative efforts from the general public, healthcare professionals, policymakers and the Primary Immunodeficiency community.

To join the conversation, share the facts, stay informed and advocate for support. So that we can drive earlier diagnosis, effective treatment plans and ultimately, save lives.

Together, we must raise awareness, educate, and uncover the true stories behind Primary Immunodeficiencies.

-Marius, Belgium
Living with a Primary Immunodeficiency

Join us to

See the Unseen

Visit **worldpiweek.org** to learn more, access resources, and take action.

With thanks to IPOPI members for sharing their pictures and stories.