Do you want to help advance research in primary immunodeficiency?

Here’s how!

USIDNET was developed to advance research in primary immunodeficiency (PI). The cornerstone of this initiative is a registry of patient information, and the strength of this registry lies with individuals with PI. Please consider joining so each and every person is counted!

Patient enrollment is simple, secure and cost-free. See reverse for more information.

www.usidnet.org | 866-939-7568 | contact@usidnet.org
Why Join the USIDNET Registry

More than 4,000 patients with PI have enrolled in the USIDNET Registry. Every patient’s participation is critical to expand enrollment so an understanding of each disease is possible.

Living with PI makes your life experiences unique. However, when your experiences and those of other patients are examined collectively, common findings can help develop vital research and improve the quality of life for the entire PI community. And as a rare disease community, it’s essential that individuals come together—there is power in numbers!

How to Consent into the USIDNET Registry

Enroll Online
You can join the USIDNET Registry online through PI CONNECT, the IDF Patient-Powered Research Network. PI CONNECT brings together the clinical data from healthcare providers in the USIDNET registry and the patient-entered information from IDF ePHR, the electronic personal health record designed for the PI community.

You create an IDF ePHR account at www.idfephr.org, and you may choose to consent into PI CONNECT. By consenting, your de-identified information will become a part of the USIDNET registry. Your health information will help give researchers a better understanding of the true patient experience.

Paper Enrollment
Enrolling through IDF ePHR is not the only way to join the registry. The USIDNET team can mail you a packet which contains all necessary forms to get started. If you prefer this method or have any questions about USIDNET, please contact us: contact@usidnet.org.

Through USIDNET, you help to build a valuable resource and contribute to a brighter future for the PI community!