Be a Part of Research!

An added benefit for users of IDF ePHR is the opportunity to be a part of research by consenting into PI CONNECT, the new IDF Patient-Powered Research Network.

PI CONNECT joins the information you enter in your IDF ePHR, the online personal health record for patients with primary immunodeficiency (PI) with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains clinical data on several thousand patients with PI. Bringing together this information through PI CONNECT gives researchers valuable insight into the patient experience. Rest assured, your information is safe, secure and de-identified.

IDF was approved for a funding award for PI CONNECT from the Patient-Centered Outcomes Research Institute (PCORI). PI CONNECT is a part of PCORnet: the National Patient-Centered National Clinical Research Network. PCORnet aims to advance the shift in clinical research from investigator-driven to patient-centered studies, giving patients “a seat at the research table.”

PCORI envisions PCORnet to be a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research.

PI CONNECT along with all networks in PCORnet will form a new national resource with the goal to boost the efficiency of health research.

Share Your Research Ideas

You can feel great about contributing your information to research to help improve care of patients with PI, but have you ever had an interesting idea for researchers to investigate?

PI CONNECT gives you access to an exclusive research forum where you will be able to:

- See research questions as they are posed and offer your opinions about them.
- Propose your own research questions that matter to you.
- Track your own data and see how you compare to others with the same disease.
- Have your ideas heard and translate them into actions!

You can help guide research, and the information you share provides real-time information, giving researchers a better idea of the patient experience.

FAQ’s

1. **What is PI CONNECT?**

   PI CONNECT is the new IDF Patient-Powered Research Network. PI CONNECT connects the information you enter in your IDF ePHR, the online personal health record for patients with primary immunodeficiency (PI) developed by the Immune Deficiency Foundation (IDF), with the United States Immunodeficiency Network (USIDNET) patient-consented registry, which contains clinical data on several thousand patients with PI.
2. **Why should I join PI CONNECT?**
   It’s a great way for you can be a part of research! Bringing together your information from your IDF ePHR through PI CONNECT gives researchers valuable information about the patient experience. You can also join the research conversation in the discussion forum.

3. **What is PCORnet?**
   IDF was approved for a funding award for PI CONNECT from the Patient-Centered Outcomes Research Institute (PCORI). PI CONNECT is a part of PCORnet: the National Patient-Centered National Clinical Research Network. PCORnet aims to advance the shift in clinical research from investigator-driven to patient-centered studies, giving patients "a seat at the research table." PCORI envisions PCORnet to be a secure, national data network that improves the speed, efficiency, and use of patient-centered comparative effectiveness research. PI CONNECT along with all networks in PCORnet will form a new national resource that aspires to boost the efficiency of health research.

4. **Is my information safe?**
   Rest assured, your information is safe in PI CONNECT. We use the latest health information technology to ensure your information is secure, including adhering to federal and state regulations, and maintaining comprehensive standards, frameworks and security controls.

Create Your IDF ePHR Account and Join PI CONNECT in 4 Easy Steps!

1. **Create Your IDF ePHR Account**
   Go to www.idfephr.org and click “New User” and create an account. You’ll be asked to enter your basic information. IDF ePHR is an easy way to safely and securely store your information in one place.

2. **Begin Your First Record**
   You can create records for your whole family, but the first record you begin with should be for the person with PI. All other records that follow do not require a PI diagnosis. Make sure to enter all required information, and accept the terms and conditions. Those who have a PI will be asked to consent into PI CONNECT.

3. **Join PI CONNECT**
   Join PI CONNECT, the IDF Patient-Powered Research Network, and be a part of research! You will be asked to join, or consent into, PI CONNECT, which allows patient-entered data from your IDF ePHR to enter into the United States Immunodeficiency Network (USIDNET) patient consented registry. Once you join, you can participate in research conversations on the PI CONNECT forum.

4. **Start Using the IDF ePHR**
   Your IDF ePHR is your personal health record. Record your medications, track your infusions, set goals, reminders and notifications - make it work for you. Customize your ePHR and sync with Microsoft HealthVault to access information from various labs, pharmacy systems, personal health devices and health resources. Make time with your clinician more beneficial by sharing organized, comprehensive information from your ePHR. Most importantly, use IDF ePHR to help you live a healthy life!

For more information, e-mail piconnect@primaryimmune.org or call 800-296-4433.