

Subject Line: An Invitation to Participate in an Online Study from the University of Pittsburgh

FOUNDATION FIGHTING BLINDNESS



**My Retina
Tracker[®] Registry**

January 22, 2024

**The University of Pittsburgh is Conducting a Survey
Study to Gather Patient Input Before Developing
Information Resources for People with Inherited
Retinal Dystrophy (IRD)**

**From the Foundation Fighting Blindness
My Retina Tracker Registry**

You are being contacted because you are a member of the Foundation Fighting Blindness sponsored My Retina Tracker Registry[®].

In your Registry profile, you and/or your doctor or genetic counselor have indicated that you or someone close in your family has a clinical diagnosis of inherited retinal dystrophy.

If this is not correct, please contact Coordinator@MyRetinaTracker.org.

Attached is a recruitment announcement from the University of Pittsburgh. A University team is hoping to develop information resources for people living with inherited retinal diseases (IRD). At this time, the University of Pittsburgh is seeking participants for an online survey study. The goal of the study is to learn more about the patient community understanding of the clinical trial process. The survey will also ask about how affected people would like to receive information about the clinical trial process.

Please read the attached announcement from the University of Pittsburgh carefully. If you would like more information, please reach out directly to the contact provided.

From University of Pittsburgh (A plain text copy of the attached flyer from the University of Pittsburgh follows for your convenience.)

Do you have an inherited retinal dystrophy (IRD)?

We want to hear from you!

Help us create resources for people with IRD who want to learn more about clinical trials by participating in an anonymous online research survey.

Access the survey using the QR code or URL below.

https://pitt.co1.qualtrics.com/jfe/form/SV_ezJADoLaSbN0TKm



You are eligible to participate if you:

Are 18 years or older

Are fluent in English

Have an IRD

Questions? Contact Alex Larson, B.S. larsonaj@upmc.edu

A Reminder from the Foundation About Participating in Research

The Foundation Fighting Blindness is providing this notification to you for information only. If you, or someone you know are interested, you must make arrangements directly with the investigator who is responsible for the conduct of the research project. The Foundation Fighting Blindness makes no representations regarding the safety, efficacy or research results of any project. If you choose to participate in a study, you should do so only after careful consideration on your part and without reliance in any way upon the Foundation Fighting Blindness.

The Foundation Fighting Blindness is not legally responsible for or to any person who decides to participate in a research study.