

[About Epilepsy](#)
[Living With Epilepsy](#)

» [Research](#)

[Research Program
Overview](#)

[Grant & Fellowship
Opportunities](#)

[Epilepsy Research
Foundation New Therapy
Grant Program](#)

[Grant & Fellowship
Awardees](#)

[Clinical Trials](#)

[Phenome/Genome Project](#)

[AED Pregnancy Registry](#)

[Additional Resources](#)

[Advocacy](#)

[News](#)

[How to Give](#)

[About Us](#)

Research

[Epilepsy Foundation](#) » [Research](#) » [Epilepsy Phenome/Genome Project](#)

Epilepsy Phenome/Genome Project

The Epilepsy Phenome/Genome Project (EPGP) is the largest study ever created to understand how genetics influences epilepsy. Researchers from major epilepsy centers around the United States will collect blood samples and detailed seizure histories on a group of people with specific types of epilepsy. This information will be used to identify genes that contribute to a person developing epilepsy and the response to seizure medications. The hope is that this information will reveal new insights and improve diagnosis and treatment, and answer the troubling questions described above.

To understand the complex genetics of epilepsy, researchers need to enroll 1,500 pairs of siblings (i.e. brothers and sisters) who both have epilepsy not due to a known reason (like stroke, head injury, or brain infection). The study is also enrolling 750 participants who have seizures due to Infantile Spasms, Lennox-Gastaut Syndrome, polymicrogyria, or periventricular heterotopias. For this second group of people, a sibling with epilepsy is not required, although both biological parents (without epilepsy) are required to participate. Although the results of the study will apply to many different people with epilepsy, focusing this research effort on very specific types of epilepsy will allow the genetic analysis to be completed faster.

Bruce Hermann, Ph.D. Chair of the Epilepsy Foundation Professional Advisory Board, believes that “the EPGP study is a progressive approach in utilizing genetics research to solve some of the mysteries surrounding epilepsy. The results of this study may provide answers to many of the unanswered questions that our constituents have been asking for years about their treatments.” The Epilepsy Foundation encourages affiliate offices to share information on EPGP throughout their local communities.

Orrin Devinsky, MD, Professor of Neurology at the NYU School of Medicine views EPGP as “the opportunity of our generation to revolutionize epilepsy care. It could allow us to match safety and effectiveness of a drug to a specific person, focus research on new therapeutic targets, and crack the code on the causes of common forms of epilepsy.” He added, “we need siblings with epilepsy to answer these questions.”

Dr. Daniel Lowenstein, Professor and Vice-Chairman in the Department of Neurology at the University of California, San Francisco and a Principal Investigator on the study said, “Our dream is that, in the not-too-distant future, we will be able to do a gene profile before we ever make a decision about which drug to use on a patient.” This information would help guide doctors in choosing medications that are more effective and cause fewer, if any, side effects.

Participating in the study involves donating a blood sample and answering questions about your epilepsy. Numerous safeguards are in place to protect the privacy of participants, and the researchers will not share personal identifying information with anyone outside of their study center. Participation does not require travel to one of the study centers, and participants may receive a small compensation for their time.

This study is funded by the National Institutes of Health/National Institute of Neurological Disorders and Stroke.

EPGP will help shape the future of clinical care of people with epilepsy. For the project to be successful, it needs to be a huge collaboration among all of the people with epilepsy in our country. If you and your brother or sister have epilepsy, or if you meet the other criteria above, please consider being a part of this history-making research project!

If you would like more information, please contact EPGP at:

Toll-free phone: 1-888-279-EPGP

Website: www.epgp.org

E-mail: info@epgp.org



[printer friendly format](#) | [✉ e-mail page](#)

[About Us](#) | [Job Opportunities](#) | [Questions or comments about the website?](#) | [Disclaimer of warranties and liability](#)

8301 Professional Place Landover MD 20785 (800) 332 1000

Epilepsy Foundation of America®