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- [→ Feature Articles](#)
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- [→ Glossary](#)
- [→ Epilepsy Talk Radio](#)
- [→ Help Center](#)
- [→ Links](#)
- [→ Multimedia Center](#)
- [→ PubMed Journal Articles](#)

[Home](#) > [Resources](#) > [Feature Articles](#)

## The Epilepsy Phenome/Genome Project: Together We Can Find an Answer

By Kristen Schardein, RN, MS; Clinical Research Nurse, University of California - San Francisco Epilepsy Center



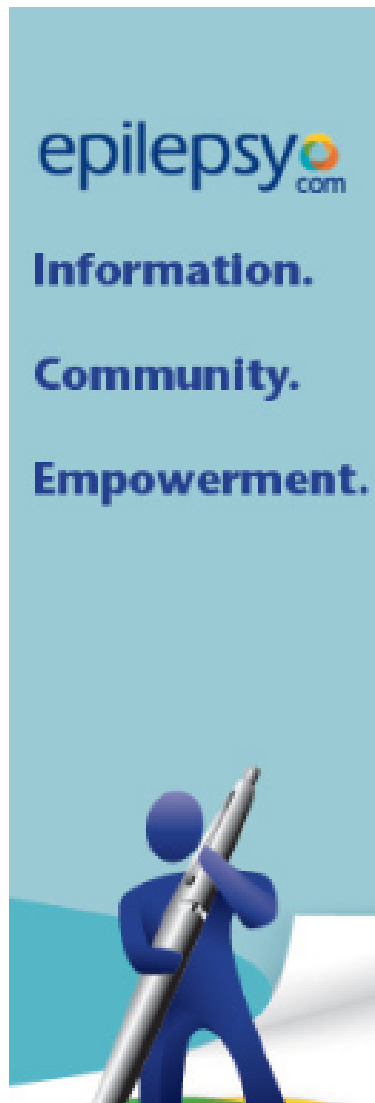

When a person is diagnosed with epilepsy, important questions arise: *Why did this happen? Which treatment (or no treatment) is best for me? How long will the epilepsy last? Will any of my children or relatives be affected?*

The Epilepsy Phenome/Genome Project (EPGP) is the largest research study ever created to understand how genetics influences epilepsy. Researchers from 13 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.

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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 of the UCSF Department of Neurology 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 for specific patients.

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). Although the results of the study will apply to many different people with epilepsy, focusing this research effort on brothers and sisters with epilepsy will allow the genetic analysis to be completed faster because siblings share some of the same DNA.

Participating in the study involves donating a blood sample and answering questions about a person's 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 would like more information about EPGP:

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

Website: [www.epgp.org](http://www.epgp.org)

E-mail: [info@epgp.org](mailto:info@epgp.org)