

DOES EPILEPSY RUN IN YOUR FAMILY?



The Epilepsy Family Study of Columbia University is seeking volunteers for a study of the role of heredity in epilepsy. Right now we are focusing our research on a particular form of epilepsy, in which people have changes in their hearing associated with their seizures.

You may be eligible if you or someone in your family has (or used to have) epilepsy or seizures associated with one or more of the following symptoms:

- ❖ **Hearing sounds that aren't really there, such as buzzing, ringing, humming or other sounds**
- ❖ **Hearing distortions of actual sounds, such as changes in volume (growing louder or softer)**
- ❖ **Seizures triggered by sounds such as the phone ringing or music playing**
- ❖ **Any other types of changes in the hearing or auditory symptoms associated with seizures**

How to Learn More or Volunteer for the Study

Please call or write to the address shown below, or send email to the project director, Kay Kamberakis. Thank you for your help! This research would not be possible without you.



Epilepsy Family Study of Columbia University

G.H. Sergievsky Center, P&S Box 16
Columbia University, 630 West 168th Street
New York, NY 10032

Telephone: 1-877-EPI-GENE or 212-305-9188, E-mail: kk765@columbia.edu

☞ Check out our website at www.epilepsygenetics.org ☛

What Participation Would Involve...

If your family is found to be eligible, you will be asked to contact some of your relatives to invite them to participate also. (None of your relatives will be contacted unless you speak to them first.) Family members who decide to participate will be interviewed (usually over the telephone), and may be asked to donate a small blood sample (approximately 2 Tablespoons). A routine neurological examination of approximately 15 minutes, an electroencephalogram (EEG), or magnetic resonance imaging (MRI) may also be included for those who have had seizures. Naturally, there is no charge for the neurological examination, EEG, MRI or any other aspect of the study. Participation is completely voluntary, and all of the information collected will be kept strictly confidential.

Description of the Research Team

This study is directed by **Ruth Ottman, Ph.D.**, Professor of Epidemiology at Columbia University and Deputy Director for Research at the G.H. Sergievsky Center. Dr. Ottman is a geneticist and epidemiologist who has studied the genetic contributions to epilepsy for over 20 years. The study co-investigators include **Melodie Winawer, M.D., M.S.**, Assistant Professor of Neurology, **W. Allen Hauser, M.D.**, Professor of Neurology and Epidemiology, and **Timothy A. Pedley, M.D.**, Professor and Chair, Department of Neurology. Dr. Winawer is an epilepsy expert who researches the genetic contributions to the disorder. Drs. Hauser and Pedley are both world-renowned experts on epilepsy, and are responsible for all of the clinical diagnoses in the study. The project coordinator for the study, responsible for the day-to-day operations, is **Kay Kamberakis**. She is experienced in recruitment and data collection for research studies and is currently pursuing a Master's Degree in Public Health.

Important Findings from Our Previous Study

- ❖ In the close relatives of people with generalized epilepsy, the risk of epilepsy is about four times as high as in the general population, whereas in the close relatives of people with localization-related (partial or focal) epilepsy, the risk is about two times as high as in the general population.
- ❖ Genetic risk does not play a significant role in causing epilepsy in people with serious brain injuries that occurred after birth (e.g. severe head injuries, brain tumors, stroke, etc.).
- ❖ The genetic influence on the risk of epilepsy decreases as people get older.
- ❖ In most families, the pattern of risk does not fit any simple genetic model (dominant, recessive, etc.), so it is difficult to predict how many, and which family members will develop epilepsy.
- ❖ In many families in which several people have epilepsy, the clinical form of epilepsy (seizure type, age at onset, etc.) varies among different individuals.
- ❖ A form of epilepsy, called "autosomal dominant partial epilepsy with auditory features" is sometimes caused by a gene, *LGII* (Leucine-rich Glioma Inactivated gene), which is found on chromosome 10. People who are affected frequently report changes in their hearing before their grand mal seizures, such as volume changes or hearing sounds such as buzzing, ringing, machine sounds, etc.

This study is funded by a research grant from the U.S. Department of Health and Human Services, National Institute of Neurological Disorders and Stroke (NIH R01NS36319). Solicitation of subjects for the study is approved by Columbia-Presbyterian Medical Center Institutional Review Board.