

## THE FAMILY STUDIES RESEARCH COLLABORATION PROGRAM

David A. Greenberg, Ph.D. is directing **The Family Studies on the Genetics of Epilepsies Research Program** at the New York Presbyterian Medical Center, Columbia University Mailman School of Public Health in New York City. Dr. Greenberg is also collaborating with other physicians and neurologists at various hospitals, clinics and private practice offices. The purpose of this research study is to find the causes of the following epilepsies that begin during childhood or adolescence and have no known causes:

**(JME) Juvenile Myoclonic Epilepsy.** In this form of epilepsy the patient has myoclonic (muscle) jerks usually of the arms and shoulders. These jerks occur shortly after awakening in the morning or after a nap. Patients also may have grand mal seizures and absence (petit mal) seizures.

**(JAE) Juvenile Absence Epilepsy.** In this type of epilepsy the patients have brief spells of staring, each lasting a few seconds. These patients also can experience grand mal seizures.

**(CAE) Childhood Absence Epilepsy** also called "petit mal" affects children starting around 4-8 years of age. Absence seizures occur many times a day.

**(AGM) Epilepsy with Grand Mal Seizures upon Awakening** is unusual in that patients have most seizures in the morning shortly after awakening or on awakening from a nap.

**(RGM) Random Grand Mal** is a form of epilepsy in which grand mal seizures can occur any time of day (not night).

**(BRE) Benign Rolandic Epilepsy** is a focal type of epilepsy that affects children around 7 years of age. In a BRE seizure, the child often awakes making grunting noises and has difficulty speaking for a few minutes. A grand mal seizure sometimes follows.

**Family members** with or without symptoms of epilepsy are also invited to participate because they provide useful information for understanding how genes are involved in the expression of epilepsy

**For our web page, please visit: <http://geneticsofepilepsy.org/>**

**What do participants have to do:** Participants will have an interview and asked for a sample of saliva. Time invested will be less than 2 hours. Study participation will not interfere with participant's medical care. All testing is free of charge and no medical treatment is offered.

If you would like to be contacted by a member of our research team, please fill out the spaces below. Sign where indicated and leave this form with your physician. If you received this information by mail, please return in the enclosed prepaid, pre-addressed envelope. You may also contact: Dr. Greenberg at telephone 212-342-0488 or [dag2005@columbia.edu](mailto:dag2005@columbia.edu); Irene S. Klotz, LMSW, Director of Recruitment at 212-342-0489 or [isk2001@columbia.edu](mailto:isk2001@columbia.edu); Nicole Iorillo, BA, Research Associate 212-342-0482 or [ni2148@columbia.edu](mailto:ni2148@columbia.edu); Janine Rose, BS, Research Associate 212-342-0481 or [jr2780@columbia.edu](mailto:jr2780@columbia.edu)

You can also fax this form to 1-212-342-0484.

*All study information is confidential to the extent of the law*

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Name (print) Signature Date

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If minor: parent/guardian (print) Relationship Signature

\_\_\_\_\_  
Address Telephone #

\_\_\_\_\_  
Email address

Institutional Review Board (CPMC IRB)	
IRB # <u>AAAA0217</u>	Approval Date <u>3/25/10</u>
Initials <u>JK</u>	Expiration Date <u>3/24/11</u>
Columbia Presbyterian Medical Center	

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Name of collaborating physician