



Dear PVNH affected persons and/or family members;

We are researchers from the Research Institute of McGill University Health Centre in Montreal, Canada who broadly study seizures, epilepsy and associated genetic causes. We are currently partnering with PVNH Support & Awareness to recruit participants for a new study that we are conducting on periventricular nodular heterotopia. The purpose of our study is to develop a comprehensive picture of the phenotypic spectrum of epilepsy in people with PVNH and to identify causative gene defects. Our ultimate long-term goal is to determine the underlying causes of PVNH in order to improve treatment outcomes and quality of life for affected persons.

For the study, we will be conducting a 30-minute phone interview with each participant/parent or guardian, where we will complete a questionnaire to obtain all relevant medical information. We will also request to have access to medical records to obtain the results of MRIs, EEGs, genetic testing and other studies.

If you are interested and willing to take part in our study, please contact us by email or by telephone (listed below). We look forward to hearing from you.

Sincerely,



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