



May 23, 2006

Dear Member of the ALS community,

Our ALS research program is continuing a study involving sporadic (or non-inherited) ALS that we thought might interest you. As you know, the cause of sporadic ALS is unknown. We are interested in determining whether genetic and environmental factors may "predispose" an individual to developing sporadic ALS. In the past, research has looked at cause and effect in sporadic ALS one variable at a time. We suspect that sporadic ALS may be the result of several factors, some genetic and some environmental, coming together. Recent advances in the field of statistical genetics make it possible to answer such questions if there are sufficient study participants available.

Blood samples from ALS patients and their living parents and brothers and sisters are needed for this study. We need a minimum of 400 sets of samples from a patient and both of that patient's parents, of which we currently have 240. Additionally, we need an additional 400 sets of samples from a patient and that patient's brother or sister, who is preferably at least as old as the patient was when he or she first noted symptoms of ALS. We currently have about 340 of those sets.

We need slightly less than 3 teaspoons of blood from each participant. We will supply the needed tubes and instructions for returning the samples via Federal Express without charge to the participants. Most physicians and labs will draw the samples without charge, but we will pay for drawing of samples if applicable.

Additionally we request that patients complete a questionnaire that addresses potential environmental influences on development of ALS.

Obviously there will not be an immediate benefit to patients, but an understanding of the causes of ALS may eventually benefit patients with the disease.

Anyone willing to participate in this study or wishing to discuss it, please contact us. We look forward to working with you on this endeavor.

Nailah Siddique RN MSN  
Clinical Nurse Specialist  
(312) 503-2712  
e-mail: nsiddique@northwestern.edu

Elena Zvirbulis MS  
Genetic Counselor  
(312) 503-0154  
e-mail: e-zvirbulis@northwestern.edu

Teepu Siddique MD  
Director, Neuromuscular Disorders Program  
Les Turner ALS Foundation/Herbert C. Wenske Foundation Professor  
Professor of Neurology  
Professor of Cell and Molecular Biology