



CADASIL Together We Have Hope Newsletter

Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts and Leukoencephalopathy
www.cadasilfoundation.org

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CADASIL Together We Have Hope was established on May 10th, 2005, as a Non-Profit Organization, which was, will continue to work side by side with all CADASIL organizations, doctors, researchers and groups and not as a singular entity. Because the channels of communication need to be kept fully open for a treatment or cure for all CADASIL patients and their families.

CADASIL is a heredity disease that affects the muscle walls in the small arteries that provide blood flow to the brain. The gene prohibits the body from making a protein; this allows the small blood vessels to be defective. The blood vessels are so small they cannot be detected by the naked eye. (A layman's definition)

Our mission: We are devoted in promoting awareness, support and research for CADASIL patients, families, friends and healthcare providers. Creating a communication network among families and identifying sources of medical care and social services. Our vision: An environment where affordable diagnosis and up-to-date care is readily available with cost effective treatment for everyone. On the website there is a guest book. Through this we have over 200 confirmed cases of CADASIL and at least 58 doctors who have seen patients who have CADASIL. Please call 512-255-0209 or e-mail cadasil@earthlink.net if you would like to locate a doctor in your area or have any information concerning CADASIL.

Very Important New Study for CADASIL Patients:

The purpose of this study is to determine the safety, tolerability and effectiveness and side effects of an investigational drug compared to that of placebo in the treatment of subjects with mental decline associated with CADASIL. The diagnosis of CADASIL is established on brain MRI findings consistent with CADASIL, and: 1) Identification of a NOTCH 3 disease mutation, or 2) the presence of deposits (on electron microscopy of a skin biopsy).

Patients with CADASIL, who are between the age of 25 and 70 years, and have cognitive impairment, are eligible to participate. The study will take place over 18- weeks. Please if you or a relative are interested in further details or possibly enrolling in the study, contact the approved investigators listed below:

- New York, New York, NYU School of Medicine
Edwin H. Kolodny, M.D. or Gregory Pastores M.D.
Tel: 212-263-6589 or 212-263-8344
- Providence, Rhode Island, Brown Medical School,
Stephen P. Salloway, M.D., M.S.,
Tel: (401) 455-6403
- Professor Hugh Markus, St. George's Hospital School,
London Tel: 020 8672 9944

Please keep checking at back at the website for more approved investigators locations all around the world.

Testing for CADASIL diagnosis and prenatal

There are six testing sites for CADASIL diagnosis presently posted on the website. Human Genetics at Boston University School of Medicine has again made history in achieving the first ever-prenatal diagnosis of CADASIL. The scientific paper reporting this achievement has been

submitted for publication. Call 671-638-7083 for more information.

We are not in the medical field or claim to be a professional on CADASIL this newsletter is to help others and assist medical professionals.

Nitro Oxide:

No treatment has so far prospectively been studied in this disease. CADASIL tends to progress slowly. A number of patients are on an aspirin a day, or using a different form of nitric oxide supplement (tablet or powder form mix with water) with outstanding results. Currently there is no medical data that exists that proves that this supplement helps some of the symptoms of CADASIL. Thank you to Jack Shields for announcing this information at the First CADASIL Awareness Meeting in Newcastle-Upon-Tyne on January 18, 2005 and the Yahoo Support Groups. Nitric oxide plays a role in the dilation and constriction of small blood vessels in brain. Two references from the Internet about this supplement: Arginine may have a positive effect on cerebral circulation.

(<http://www.primev.com/Arginine.htm>), and the endothelium is deprived of Nitric Oxide, restriction of blood flow may occur. When blood doesn't flow freely through the arteries, poor cardiovascular health conditions may result. Nitric oxide is necessary to support and maintain a healthy cardiovascular system, (<http://www.cardiodiscovery.com/>)

The website has had **104,377 hits** so far from January 1st to May 31st. The search for CADASIL information has increased. Together We Have Hope is making a difference in the lives of people touched by CADASIL. Your donations would be a true blessing and support vitally important. Contributions will be used 100% towards making our mission and vision become a reality. Please remember every donation counts.

We will be attending the United Leukodystrophy Foundation International Conference In DelKalb, Illinois July 21 to 23rd. If you are interested in going please contact ULF at 1-800-728-5483.

Please Remember: Copy this newsletter and give or mail it to your doctors or anyone who is in the medical professionals so hopefully one day there will be a cure.

CADASIL Together We Have Hope Non-Profit Organization
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