



CADASIL TOGETHER WE HAVE HOPE NON PROFIT ORGANIZATION

WWW.CADASILFOUNDATION.ORG

Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts & Leukoencephalopathy

ORGANIZATION ATTENDING AND PARTICIPATING IN GENETIC CONFERENCE

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Inside this issue:

Hurricane Katrina Study Continues	2
Volunteer Page Magazine Article	2
ULF Conference Report	3
CADASIL Meeting Should I get tested?	3
Raising Awareness Health Care Providers	3
Donation Recognized by	4
Our Goals Charity Shopping	4

At the end of September we will be representing CADASIL and your organization at a National Organization of Rare Disease meeting in Rockville, Maryland. This conference is a collaborative effort of the National Institutes of Health, the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the American Society for Human Genetics, the American College of Medical Genetics, the Genetic Alliance, the Society for Inherited Metabolic Disorders, the National Organization for Rare Disorders,

and Emory University Department of Human Genetics to *address the growing public need for improvement in availability, accessibility, and quality of genetic and other diagnostic laboratory testing for rare diseases and conditions.*



WE HAVE A DOMAIN NAME: A special thanks to Teryn and Dean (from Oregon) for volunteering to set up our domain name for our organization @ www.cadasilfoundation.org. Their foundation is located @ www.mldfoundation.org (Metachromatic Leukodystrophy).

Special points of interest:

- CADASIL Together We Have Hope was established on May 10, 2005, as a Non Profit Organization
- The organization filed tax exempt paperwork 501 c-3 on June 29, 2005.

ESTABLISHING A SCIENTIFIC ADVISORY BOARD

An Associate Professor of Neurology and Pediatrics Director at Neurogenetics Laboratory and Department of Neurology volunteered to be on the scientific advisory board for the organization. This Professor is assisting us in the establishing the Scientific Advisory Board and we have approached a number of US and International Investigators.

FACT SHEET on our website for understanding the terms related to CADASIL, What other names are used for CADASIL? How to pronounce those names? Information about the genes that are related to CADASIL. Go to website and click on Fact sheet.

EMERGENCY CARE PLAN Developing an emergency plan is very important, be prepared and plan today. Cut out the business size card found in this newsletter and place in your wallet. Go to the website and click on emergency plans for more information and to print out more copies of the card.

HURRICANE KATRINA SLAMS GULF, AUGUST 29, 2005

If you are aware of any CADASIL families that have been effected in any of the Gulf states by this devastating catastrophe, contact CADASIL Help Hotline @ 1-877-519-HOPE.

Disaster officials recommend the following organizations if you could assist in anyway with this disaster:

American Red Cross 1-800-HELP-Now	Feed The Children 1-800-525-7575	Mercy Corps 1-800-852-2100
Salvation Army 1-800-525-7575	Operation Blessing 1-800-730-2537	The United Way 1-800-272-4630
ASPCA 1-866-275-3923	Samaritan's Purse 1-800-665-2843	Save the Children 1-800-728-3843
The Humane Society 1-888-259-5431	World Relief 1-800-535-5433	
Habitat for Humanity 1-866-720-2800	International Aid 1-800-251-2502	
MAP International 1-866-627-4483	International Medical Corps 1-800-481-4462	
Operation USA 1-800-678-7255	The Baton Rouge Area Foundation 1-877-387-6126	

CADASIL STUDY CONTINUES . . .

Please consider being in the study, as it could be a breakthrough to our families and the future of the next generation. If you don't think you have short-term memory problems but please remember changes are subtle in CADASIL and to let the researchers decide if you are a candidate for their study. Please locate the location near you and call them, as usually transportation and hotel costs are covered.

1. **New York, New York** - Dr. Edwin Kolodny (212) 263-6589 or 8344 e-mail: edwin.kolodny@NYUHEALTH.org or gregory.pastores@med.nyu.edu
2. **San Francisco, California** - Dr. Michael Geschwind (415) 476-6880 e-mail: mgeschwind@memory.ucsf.edu
3. **Little Rock, Arkansas** - Dr. James W. Schmidley (501) 686-5135 e-mail: SchmidleyJamesW@uams.edu
4. **Providence, Rhode Island** - Dr. Stephen P. Salloway (401) 455-6403 email: ssalloway@butler.org
5. **Calgary, Canada** - Dr. Michael D. Hill (403) 944-8065 Fax (403) 944-8065
6. **London, Ontario Canada** - Connie Frank RN (519) 663-3500 fax (519) 663-3196
7. **United Kingdom, London** - Professor Hugh Markus Tel: 020 8672 9944 e-mail: hmarkus@sghms.ac.uk
8. **Glasgow Scotland** - Dr. Keith Muir +44 141 201 2494 e-mail:k.muir@clinmed.gla.ac.uk

For up to date information please keep checking the website @ *CADASIL Study*

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. 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. The study will be ending towards the end of the year so please consider being a candidate.

VOLUNTEER PAGE

We established a volunteer page which is dedicated to everyone who has volunteered their time towards our mission, values and vision . Go to the website and click on the button *Our Volunteers*

MAGAZINE ARTICLE ON CADASIL

Men's Health Magazines, September 2005 Issue has an 9 page article on CADASIL **Hunting My Fathers Killer**, "A series of mysterious strokes killed my father and grandmother and her two brothers" by Deputy Editor William Phillips. Thank you to William Phillips for giving permission for our organization to post the story on our website at <http://home.earthlink.net/~cadasil101/mag/>

ULF CONFERENCE REPORT (www.ulf.org)

Attended the United Leukodystrophy Foundation conference the week of July 20 to July 24. It was a honor to attend and a wonderful experience. I have been enrolled with this organization for the past seven years.

There were some wonderful researchers, neurologists, and scientists, who presented at the conference. Some knew about CADASIL some did not. These professionals were so supportive of what CADASIL Together We

Have Hope (Foundation) is accomplishing.

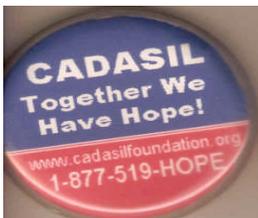
In addition to these valuable networking partnerships made, I was very fortunate and honored to meet and work with some of the leading pioneers in neurological disease. It was great to put a face to the names and voices of professionals I had corresponded with over the past ten years. A special thanks to Dr. Hugo Moser, Dr. Raphael Schiffman, Dr. Gregory Pas-

tures and too many other to name.

It is very important to identify the mutation of your affected gene. This determination must be made initially and for the future, as the doctors will only look for the defective mutation. There are over 50 mutations of CADASIL identified to date. This is the reason why it is so difficult to find a treatment or cure for CADASIL.



Send a self stamp address envelope to receive this free ribbon.



CADASIL MEETING During the ULF conference there were two people who were diagnosed with CADASIL whom were advocates for themselves and another person whose brother had been diagnosed. It was wonderful to meet everyone as we sat together and shared our information. This was probably the first official US CADASIL meeting as an

SHOULD I GET TESTED?

CADASIL is passed from parent to child through a mutation in a gene. Each offspring of a CADASIL parent has a 50% chance of inheriting the disease. If a person does not inherit the CADASIL gene, he or she will not develop the disease and cannot pass it to subsequent generations. A person who inherits the CADASIL gene will sooner or later develop the disease.

We have the dilemma of whether our CADASIL offspring should or should not be tested for CADASIL. There is a good article at <http://www.hdfoundation.org/testread/russroul.html> Genetic "Russian Roulette" The Experience of Being "At Risk" for Huntington's disease. Huntington's Disease is a 50% change of an inheriting disease like CADASIL. **WHERE TO GET TESTED** go to the website and click on the button Testing sites.

RAISING AWARENESS

Part of our mission is promoting awareness. Wear the colors of CADASIL (red, white and blue), Buttons add ribbons. Bumper stickers and pens are also available along with a ongoing fundraiser. Pass out to your doctors, friends and family. Go to the website and click the Awareness button. Keep checking back for more items.

Please Note: All items are low costs items to promote awareness!!!



HEALTH CARE PROVIDERS PAGE

For professional health care providers there is a separate web page, go to website and click the button on Health Care Professionals.

Please let your doctors know about this page as it contains the following:

- PowerPoint presentation on understanding CADASIL
- MRI films and reports
- Skin biopsy and reports
- Poster on understand vascular disease

DONATIONS Your donation would be a true blessing for this new organization and the support is so vitally important. You have a choice in how to make that gift, either as a one-time donation or by pledging to make regular, repeated donations throughout the year with no obligations. This organization depends solely on donations from the public. Questions call 1-877-519-HOPE or 512-585-2052. Together We Have Hope is making a difference in the lives of people touched by CADASIL. Please go to the website and click on donations, we accept checks and credit cards. Your contributions will be used 100% towards making our mission and our vision become a reality. Thank you to those who already have made a donation.

CEREBRAL AUTOSOMAL
DOMINANT ARTERIOPATHY WITH
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**CADASIL TOGETHER
WE HAVE HOPE
NON-PROFIT
ORGANIZATION**

**3605 Monument Drive
Round Rock, Texas 78681**

**Phone: 1-877-519-HOPE
or 512-585-2052**

Email: info@cadasilfoundation.org

WE'RE ON THE WEB!

WWW.CADASILFOUNDATION.ORG

THIS ORGANIZATION IS RECONIZED BY:



OUR GOALS: Develop and hold the first symposium on CADASIL in the U.S.A

Secure physicians and neurologist to be patrons of the organization and establish a scientific board

Educate doctors, radiologists, neurologist, and directors of strokes, and others who may well be presented with a person with symptoms of CADASIL, but fail to recognize them as such.

Keep up-to-date the internet website with CADASIL information, CADASIL studies, testing sites, news articles, newsletters, research, doctor pages and confirmed cases.

Reporting the outcome of the attended conferences.

Mailing out information packets to doctors, sufferers, etc.

CHARITY SHOPPING NETWORK Donate by shopping online, with charity shopping networks! Shop online and the vendors donation a portion of your purchases to the CADASIL Together We Have Hope (Foundation). If you already shop online with retailers such as Best Buy, Expedia, Home Depot, Old Navy, E-Bay, Dell Computers, Sears, Target, and many, many more, then why not have a portion of your purchases help us.

Your loyalty helps raise money for CADASIL, **without costing you anything extra... not even a penny.** There are hundreds of companies across a broad range of categories, which want to support you if you support them. By shopping at participating companies, your purchases can have a positive impact on CADASIL and helping to raise funds, which will be, used 100% towards our mission. Website located @ www.buyforcharity.com or <http://www.tricordia.com>

