CADASIL TOGETHER WE HAVE HOPE NON PROFIT ORGANIZATION
WWW.CADASILFOUNDATION.ORG

Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts & Leukoencphalopthy

CADASIL RESEARCH/STUDY BY NEW YORK UNIVERISTY SCHOOL OF MEDICINE

Volume 12, Issue 1

APRIL 2009

Inside this issue:

New York University of Medicine, Division of Neurogenetics

is conducting a new research study for patients with CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy).

The purpose of this study is to better understand the early symptoms of CADASIL so the medical profession may learn to diagnose CADASIL early and may help them in developing awareness and guidelines for appropriate diagnosis and management of CADASIL

As you are aware, CADASIL is often misdiagnosed due to lack of awareness of this condition among healthcare providers and because the disease can closely mimic other neurological conditions. People with CADASIL struggle to find a doctor who has knowledge about this condition.

Please call New York University @ 212-263-8344 to find out more. NYU will mail a questionnaire for you or your caregiver to complete and mail back to them with a stamped return addressed envelope. The responses and questionnaire are very valuable. If possible, NYU School of Medicine asks if you could get copies of your medical records and mail these to them separately. Your medical records are not needed to participant. NYU School of Medicine may contact some candidates for a more detailed telephone interview.

Together We Have Hope endorses this study and the more participants NYU School of Medicine has will make this important study a success for CADASIL patients and the professional community.

If you wish to participate in this study, please call NYU@ 212 263 8344. **This study is open so far for U.S.A, Canada, Scotland, Ireland and England.**

Special points of interest:

- May 2005 CADASIL Together We Have Hope was recognized by the IRS as a 501 3(c) organization. We are fortunate to celebrate our ***fourth year.***

LOCATING A DOCTOR

The CADASIL Together We Hope Foundation continues to create a list of physicians who has seen at least one or more patients with CADASIL. If you are a patient who would like to have his/her doctor listed or if you are a doctor who would like to be placed on this list, please contact us at info@cadasilfoundation.org If you locate a doctor from this list, please be sure to let them know that the foundation referred them to you and let them know about out website.

Please Remember: Copy this newsletter and give or mail it to your doctors or anyone who is in the medical profession so we can raise awareness which is much needed.

INDIVIDUALS NO LONGER HAVE TO WORRY ABOUT DISCRIMINATION AGAINST THERE GENETIC DISEASES.

United States citizens are now protected by the USA legislation against genetic discrimination by health insurers or employers by:

- Prohibiting group health plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.

- Prohibiting issuers of Medigap policies from adjusting pricing or conditioning eligibility on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.

- Prohibiting employers from firing, refusing to hire, or otherwise discriminating with respect to compensation, terms, conditions or privileges of employment. Employers may not request, require or purchase genetic information, and may not disclose genetic information. Similar provisions apply to employment agencies and labor organizations.

President Bush Signs Landmark Genetic Nondiscrimination Information Act Into Law , May 21, 2008. Washington, D.C. – May 21, 2008 – The Coalition for Genetic Fairness (http://www.geneticfairness.org/) commends President George W. Bush for signing into law today the first civil rights legislation of the new millennium, the Genetic Information Nondiscrimination Act (GINA). GINA is the first and only federal legislation that will provide protections against discrimination based on an individual's genetic information in health insurance coverage and employment settings.

"This is a tremendous victory for every American not born with perfect genes – which means it's a victory for every single one us," said Representative Louise Slaughter (D-NY). "Since all of us are predisposed to at least a few genetic-based disorders, we are all potential victims of genetic discrimination."

"Individuals no longer have to worry about being discriminated against on the basis of their genetic information, and with this assurance, the promise of genetic testing and disease management and prevention can be realized more fully.

For more information, please go to Genetic Alliance (http://www.geneticalliance.org/)."

SUPPORTING RESEARCH

CADASIL Together We Have Hope board of directors are pleased to announce donations have been made to:

New York School of Medicine to assist with the new CADASIL Study

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

WE NEED YOUR SUPPORT!

CADASIL Together We Have Hope is an all volunteer organization. We have no paid employees. Your donation is tax deductible and will be used to further the goals of CADASIL Together We Have Hope. We are devoted to promoting awareness, support and research for this rare genetic disease working with patients, families, friends and healthcare providers. We have created a communication network among families and continue to identify sources of medical care and social services . Please go to www.cadasilfoundation.org and use the Donate Button to go to the PayPal. You may take the donation automatically from your checking account or credit card. You do not have to open an account to donate. When donating through PayPal, your transaction is secure and none of your personal financial account information is shared with the Foundation. We are a 501(c)(3) non-profit and tax exempt organization per IRS code. Your donation is fully tax deductible.

If you would like to volunteer please contact us at 1-877-519-HOPE or e-mail us at info@cadasilfoundation.org

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CADASIL
TOGETHER WE HAVE
HOPE NON-PROFIT
ORGANIZATION

3605 MONUMENT DRIVE
ROUND ROCK, TEXAS 78681

E-mail: info@cadasilfoundation.org

WE'RE ON THE WEB!
WWW.CADASILFOUNDATION.ORG

PARTNERSHIP FOR PRESCRIPTON ASSISTACE PROGRAM OVERVIEW (U.S.A)

Who We Are The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or nearly free. Among the organizations collaborating on this program are the American Academy of Family Physicians, the American Autoimmune Related Diseases Association, the Lupus Foundation of America, the NAACP, the National Alliance for Hispanic Health and the National Medical Association. To access the Partnership for Prescription Assistance by phone, you can call toll-free, 1-888-4PPA-NOW (1-888-477-2669).

Our Mission Our mission is to increase awareness of patient assistance programs and boost enrollment of those who are eligible. The Partnership for Prescription Assistance offers a single point of access to more than 475 public and private patient assistance programs, including more than 180 programs offered by pharmaceutical companies.
Help is Here Express Find out more about the "Help is Here Express" Bus Tour - visiting communities across the country.
Medicare Prescription Drug Coverage - Starting January 1, 2006, Medicare offered prescription drug coverage to people with Medicare. To find out more about this program, go to the website.
What We Offer - *Help for Those in Need* - Many people have difficulty affording health care, including prescription medicines. A number of patient assistance programs provide help to patients who lack prescription drug coverage and earn less than 200% of the federal poverty level (approximately $19,000 for an individual or $32,000 for a family of three). In 2003, more than 29 million people in the United States make less than 200% of the federal poverty level and have no health insurance.
Access to the Medicines They Need Patients will be directed to the public or private programs most likely to meet their needs. The Partnership for Prescription Assistance helps qualifying patients without prescription coverage: Enroll in more than 475 patient assistance programs, Access more than 2,500 medicines, Learn how to contact government programs for which they may qualify, such as Medicaid, Medicare, or the State Children's Health Insurance Program. ***Help with Insurance Premiums and Co-pays*** Co-Pay programs provide financial assistance for pharmaceutical products and health insurance premiums to Americans who financially and medically qualify. Qualifications vary by programs. Income levels vary by state.
Go to their website: https://www.pparx.org/SelectMedication.php

QUESTIONS ANSWERED BY OUR SCIENCTIFIC COMMITTEE

Can a CADASIL Patient donate blood?
CADASIL patients should be able to donate blood. Patients who have had a stroke should check with their local blood center about policies regarding donating after stroke. Some blood centers asks that people be stable for one year after a stroke before donating but policies differ from one center to another.

Are doctors generally aware of CADASIL, and is it easy for them to differentiate CADASIL from other diseases causing dementia? The neurologists and particularly those involved in stroke neurology should be aware of this disorder. It is more difficult for a general practitioner because of the rarity of CADASIL.

Can CADASIL be sporadic, or is it always inherited? *Yes, the disease can be sporadic due to the possible occurrence of sporadic mutations in the Notch 3 gene. In this case, the two parents do not have the mutation but a mutation appears in one of their children. This occurs extremely rarely. Today, we do not have therapy with proven efficacy for slowing the progression of CADASIL? Additional basic researches and analysis of follow-up data are needed to better understand the exact mechanisms underlying the vascular wall alterations and factors influencing the progression of the disorder*

Is this statement true? 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 mutation gene will sooner or later develop the disease
The above statement is true: CADASIL is passed as a dominant mutation and offspring have a 50% chance of developing the disease. All mutation carriers develop some form of the illness (complete penetrance) though the timing and severity and symptoms may vary in family members with the same mutation. Women with CADASIL live longer than men on average. So there are other genetic and environmental factors, yet to be identified, that modulate gene expression. A de novo mutations (A de novo mutation is a new mutation) can rarely occur in exceptional isolated cases without a prior family mutation.

Should a cadasil patient take aspirin?
Yes, There is no scientific evidence that aspirin plays a preventive role in CADASIL, however, based on what is currently known in stroke patients, we usually recommend this treatment if there is non contra-indication and the occurrence of a first ischemic event. The tough decision is deciding what to do when patients have TIA's and strokes despite treatment with aspirin. Because of the risk of hemorrhage and lack of evidence, blood thinners such as warfarin and clot busters like TPA are not recommended.

How much aspirin should be taken?
The dose of aspirin most currently evaluated in therapeutic trials is between 75 mg to 325mg. Asymptomatic CADASIL patient should have a low dosage of aspirin and a patient with a history of TIA's or stroke could be given a higher dose of aspirin per day. It is recommended to take coated aspirin.

CADASIL is a vascular disease leading to only brain symptoms without lesions in other organs. This is mainly related to the fact that the angioarchitecture (distribution of microvessels) is different in the brain compared to other organs and that the granular osmiophilic material deposits occurring with the disease are more important in cerebral vessels.

CADASIL TISSUE BANK

Why is brain donation important? A brain autopsy is the only way to confirm the cause of dementia. Researchers rely on information from autopsies of donated brains to learn how CADASIL and other dementias affect the brain. By understanding these diseases better, researchers hope to develop better treatments and cures for them

Dr. Salloway, one of our Scientific Advisory committee members, has established a CADASIL tissue bank in collaboration with colleagues in the pathology department at Brown Hospital in Rhode Island. Studies with CADASIL brain tissue are leading to advances in understanding the molecular causes of small artery degeneration in CADASIL, which will hopefully lead to new treatments in the future. This Bank is supported by brain and tissue donation by surviving families of CADASIL patients.
For more information please contact

Memory & Aging Program
Butler Hospital
345 Blackstone Blvd.
Providence, RI 02906
Phone: 401-455-6403
Fax: 401-455-6405

For general information go to
http://www.memorydisorder.org/braindonation.htm

RAISE FUNDS FOR CADASIL NO COST TO YOU

The following Fundraisers assists in with raising funds to support our mission, vision and values.
RECYLE INK http://empties4cash.com/index.html
Recycle your ink cartridges no cost to you and request the checks be mailed to CADASIL Together We Have Hope at 3605 Monument Drive, Round Rock, Texas 78681

- 100% profit to our organization
- No selling required
- Completely **FREE** to participants
- Minimal work to be done
- No obligations and no hassles
- Recycle Ink provides shipping materials and they pay for shipping at no cost to you.
- This program was designed to raise funds for nonprofit organizations.
- There will not cost you to help them! Everything will be provided at no cost to you. We will send you the supplies and we will pay for the shipping.
- Spread the word. Let friends, family and nearby businesses know of your recycling and fundraising efforts.
- Pass out baggies to your supporters so they can send cartridges directly to us from home. Recycle, reuse and reduce. Stress the importance of the program for the environment and help reduce millions of pounds of landfill. So enroll today to help us at http://empties4cash.com/index.html

SHOP ONLINE at http://www.igive.com/welcome/

Donate by shopping online, with charity shopping networks! Shop online and have a portion of your purchases donated to the CADASIL Together We Have Hope (Foundation). http://www.igive.com/welcome/

If you already shop online with retailers such as Best Buy, Expedia, Home Depot, Old Navy, eBay, 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, who 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.

SEARCH ENGINE - GOODSEARCH.COM

- Search the Internet (powered by Yahoo) Raise money for CADASIL without spending a dime. Part of the ad revenue for every search will go to our cause! Set GoodSearch as your homepage or bookmark the site to use as your search engine. To set as your homepage on your internet search engine, go to "Preferences...", and change your homepage address to WWW.GOODSEARCH.COM

At the GoodSearch page, select CADASIL TOGETHER WE HAVE HOPE as your charity of choice. From then on, with every search you conduct on the internet, 50% of Good Search's advertising revenue, estimated to be about a penny per search, will go to us. The more people who use the site, the more money that will go to providing information, education and support to persons with CADASIL.

Just 500 of us searching four times a day will raise about $7300 in a year without anyone spending a dime. Spread the word to your friends, family and business associates. and make WWW.GOODSEARCH.COM your homepage.

CADASIL REGISTRARY

Please sign the registry as we need to have everyone with CADASIL documented for research, etc. and make your number count.
All information provided to us is kept strictly confidential!
Go to the website and click on Registry.

858 Confirmed Cases Worldwide

49 years old average age of diagnosis

56% Females
44% Males

How our database has grown since June 2005 to present.

200 confirmed cases in June 2005
523 confirmed cases in July 2006
568 confirmed cases in January 2007
702 confirmed cases in August 2007
796 confirmed cases in May 2008
858 confirmed cases in April 2009

CASES BY COUNTRY

Austria	0%	Portugal	0%	New Zealand	1%
Belgium	0%	Spain	0%	Puerto Rico	1%
Central America	0%	Sweden	0%	South Africa	1%
Holland	0%	Switzerland	0%	Ireland	2%
India	0%	Turkey	0%	Scotland	2%
Italy	0%	Brazil	1%	Australia	6%
Korea	0%	France	1%	Canada	7%
Netherlands	0%	Germany	1%	England	7%
				USA	70%

THE FOUNDATION IS CURRENTLY

- Disseminating and sharing the latest information through the internet website (e.g., information, studies, testing sites, new article, newsletters, research, doctors pages and database for confirmed cases.
- Working closely with CADASIL Research/Studies.
- Providing awareness on the disease through conference attendance and sharing of information by reporting the outcome of the attended conference.
- Members of the American Brain Coalition, which is comprised of some of the United States leading professional neurological and psychiatric associations and patient organizations. Through involvement we seek to understanding the functions of the brain, and to reduce the burden of brain disorders through public advocacy.
- Members of the Coalition for Genetic Fairness, which was founded in 2000 to address the growing concern, surrounding the misue of genetic information in insurance and employment decisions. We worked closely with the Coalition and the GINA bill. The final bill finally passed and to ensured that no genetic discrimination with insurance companies and employers will discriminate against you.
- Members of the Genetic Alliance is a 501 (c)(3) not-for-profit organization that transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making.
- Members of the United Leukodystrophy Foundation is dedicated to helping children and adults who have leukodystrophy and assisting the family members, professionals and support services that serve them. The ULF is committed to the identification, treatment and cure of all leukodystrophies through programs of education, advocacy, research and service.
- Recognized by the National Organization for Rare Disorders (NORD), a 501(c)3 organization, is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Founded in 1983.
- Recognized/Respected all over the world by leading experts on CADASIL.

HAVE FUN IMPROVING YOUR MEMORY

Knowing how you recall different types of information offers a hint on how to recall all types of information. Remembering that your most vivid memories are emotional memories, find a mental and emotional connection to the items you want to remember. For example, remembering names is difficult for a lot of people. Try associating the person's name with a characteristic or physical attribute. If the person's name is Diane and she has an outgoing personality, you could label her in your mind as "Dynamic Diane." By personalizing the information, you are creating an emotional connection rather than just factual information. No one has to know the secret names you have for people. Only you will know that the guy down the hall with the boisterous laugh is really Giggling George.

Use acronyms to remember longer strings of information. Robert Murray, a high school math and science teacher in Los Angeles, introduced every student to "Roy G. Biv" when trying to teach them the colors of the spectrum. Remarkably it only took one class session for most students to list red, orange, yellow, green, blue, indigo and violet when trying to recall the natural colors. By Stephanie Tallman Smith

IN LOVING MEMORY

With prayers and thoughts
for the families and friends.

Minister Connie Mack Farmer

Evelyn McCoy

Rex Sanders

Linda Bordelon

Richard Ray Dale

DONATIONS

Your donation would be a true blessing for this 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. 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 becomes a reality. Thank you to those who already have made a donation.

WHAT IS THE DIFFERENCE BETWEEN A STROKE AND A TIA

Stroke is a brain injury that happens when the blood supply to a part of the brain is interrupted. Without blood and oxygen, the brain tissue starts to die, and the functions controlled by the affected brain cells – such as speech, muscle movement and memory – become mildly to severely impaired. Most strokes are caused by a blood clot blocking an artery leading to the brain. These are called *ischemic* strokes. A smaller percentage of strokes are caused when a blood vessel in the brain bursts open, spilling blood into the brain and damaging the surrounding tissue. These are called *hemorrhagic* strokes.

TIA (transient ischemic attack, also sometimes called a "mini-stroke") begins just like an *ischemic* stroke; the difference is that in a TIA, the blockage is temporary and blood flow returns on its own. Since blood flow is interrupted only for a short time, the symptoms of a TIA don't last long – usually less than hour.

Even though TIA symptoms go away, you should *never* ignore a TIA; it is often a warning sign that a major stroke may happen soon. A person experiencing signs of a TIA should call 9-1-1 and get to an emergency department at once. This preventive measure could help prevent a fatal or disabling stroke.

EMERGENCY CARE PLAN

Developing an emergency plan is very important, be prepared and plan today.
Make sure the written emergency plan should be placed in a secure safe place, i.e., in the car glove compartments, by your phone, etc. The emergency plan should include the following:

- Age
- Allergies,
- Medical condition (diagnoses and relevant past medical history),
- Medications currently taking,
- Caregiver's information (names, phone numbers, addresses, etc.),
- Insurance information,
- Primary care physicians and specialist's information (name, phone numbers, etc),
- And avoid the following medicines for CADASIL

Medications to avoid with CADASIL
such as Thrombolyisis & anticoagulant treatments, Arteriography, Vasoconstricting medicines (issued from rye ergot or from Tripoptan) and Products aimed at unblocking blood vessels as they increase the risk of a hemorrhage.