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JULY 2006

Arteriopathy with Subcortical Infarcts and Leukoencephalopathy

CADASIL

Cerebral Autosomal Dominant

TOGETHER WE HAVE HOPE

www.cadasilfoundation.org

WWW.CADASILFOUNDATION.ORG

CADASIL Together We Have Hope Non-Profit Organization

SCIENTIFIC ADVISORY COMMITTEE ESTABLISHED FOR OUR ORGANIZATION

CADASIL Together We Have Hope Scientific Advisory Committee is comprised of respected practitioners, researcher and leading experts who are knowledgeable about CADASIL disease and similar disorders.

Gregory M. Pastores MD is an Associate Professor of Neurology and Pediatrics at the NYU School of Medicine in New York, and Director of the Neurogenetics Laboratory for the Department of Neurology at NYU. He graduated from the University of Sto. Tomas in Manila (1983) and received his training in Pediatrics and Genetics at the Mount Sinai Medical Center in New York (1989) and at the Mayo Clinic in Minnesota (1991). He is Board Certified in Pediatrics (1989) and in Clinical Genetics (1993) and Clinical Molecular Genetics (1993). Dr. Pastores has extensive clinical and research experience in the diagnosis and management of patients with lysosomal storage disorders, CADASIL and with inherited diseases that primarily afflict individuals of Ashkenazi Jewish ancestry. He has also been engaged in the development and testing of treatment for Gaucher disease, MPS I and VI, Pompe disease and a late (adult)-onset form of Tay-Sachs disease (GM2-gangliosidosis). His current interest lies in the molecular genetics of inherited diseases that involve the nervous system.

Hugues Chabriat MD, PhD is Professor of Neurology at the University Paris VII in France. He received his MD from the Medicine Faculty "Cochin-Port Royal" and his PhD in Neuroscience from the Faculty of Science "Jussieu" at the University Paris VI. Dr Hugues Chabriat is working with Professor Marie Germaine Bousser and collaborates with Professor Elizabeth Tournier-Lasserve and with Dr Anne Joutel within "the French CADASIL team" for many years. He participated in the discovery of CADASIL and the identification of the mutated gene performed by the geneticists in France. His main research focuses on the imaging features of stroke particularly in small vessel diseases. He has made multiple contributions on the clinical, neuropsychological and imaging features of CADASIL and works on the dismantlement of small vessel diseases of undetermined origin.

Dr. James Grotta is Professor Neurology, Director of the Stroke Program and named the American Heart Association Physician of the Year 2006. He occupies the Roy M. and Phyllis Gough Huffington Distinguished Chair in Neurology, is funded by the National Institutes of Health with grants to

INSIDE THIS ISSUE:

carry out research from the laboratory to the bedside and to train new fellows in the field of stroke. Dr. Grotta received his training at the Universities of Virginia and Colorado, and the Massachusetts General Hospital, and first joined the University of Texas Houston Medical School faculty in 1979. His research focuses on development of new therapies for acute stroke patients. This includes experimental laboratory studies on the biology of brain injury and recovery after stroke, and other approaches to reducing brain damage and improving recovery after stroke. He has also orchestrated the development of a collaborative network between University of Texas, Memorial Hermann Hospital, Houston Fire Department-Emergency Medical Services, and other regional stroke centers to increase the delivery of appropriate therapy to a larger number of acute stroke patients. Dr. Grotta, Chairman of the Department of Neurology at the Memorial Hermann Hospital in Houston has an active clinical practice based at Memorial Hermann Hospital focused on stroke treatment and prevention, and is a frequent invited lecturer at national and international meetings and symposia for the work he and his team have done in Houston.

Dr. Stephen Salloway is Director of Neurology and Director of the Memory Disorders Program. He is a Professor of Clinical Neurosciences and Psychiatry at Brown Medical School. He received his MD from Stanford Medical School and completed residencies in neurology and psychiatry at Yale University. Dr. Salloway has published more than 160 scientific articles, book chapters, and abstracts including 3 books. He is the Past President of the American Neuropsychiatric Association a fellow of the American Academy of Neurology, and a member of the American Neurological Association, and he serves on national and international committees to develop criteria for stroke and vascular dementia. He is a scientific reviewer for the National Institutes of Health and for more than 25 journals, universities, and research foundations. Dr. Salloway is the Brown Combined Residency in Neurology and Psychiatry and co-Director of the NIH-sponsored Brown Dementia Research Fellowship Program. He lectures widely on CADASIL, dementia, and neuropsychiatric disorders. Dr. Salloway has received numerous grants for his research which focuses on a) clinical trials for prevention and treatment of vascular dementia, Alzheimer's disease, and mild cognitive impairment, b) studies of genetic and sporadic forms of microvascular brain disease and c) assessment of frontal behavior and executive function. Under his direction the Butler Memory and Aging Program has become a national referral center for the study of CADASIL. Dr. Salloway has established a CADASIL tissue bank in collaboration with colleagues in the pathology department at Brown. 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. Dr. Salloway recently collaborated with an international group of CADASIL researchers to design and conduct the first controlled trial for CADASIL.

Raj Kalaria is Professor of Neuropathology (Cerebrovascular Pathology) at the University of Newcastle upon Tyne, UK and the Institute for Ageing and Health, Newcastle General Hospital. He obtained his doctoral qualifications from King’s College, University of London, and the Royal College of Pathologists, UK, before completing his training in the USA. Professor Kalaria’s main scientific interests lie in risk factors and the neuropathologies of vascular dementia including CADASIL and Alzheimer’s disease. Professor Kalaria has published over 200 peer-reviewed articles and is editor of two books. He also serves as associate editor on the editorial boards of Alzheimer Disease and Associated Disorders and NeuroReport journals. He has been past Honorary Secretary of the British Neuroscience Association (2000-2004). He presently serves on the executive and scientific boards of the International Society for Vascular Cognitive and Behavioral Disorders, the International Brain Research Organization and the Alzheimer’s Research Trust (UK).

We wish to thank the above scientific advisory committee members volunteering their time towards our mission!

VOLUNTEER OPPORTUNITIES

We are an all volunteer organization with non-paid staff which operates totally within our mission, vision and values statements. We need collaboration, cooperation and commitment. Please help us to help you.

- Write articles for our newsletter
- Researchers for monitoring new information on CADASIL
- Coordinators for monitoring the CTWHH online forum
- Caregiver yahoo group volunteer
- Conference Volunteers
- Sponsor Volunteers
- Fundraising Volunteers
- Coordinators for telephone conference calls
- Coordinators for Raising Awareness
- Proof reader for the website
- Publisher - Writer
- CPA, Accountant
- Lawyer or a Para legal
- Tax consultant
- Grant Writers

For more information or to volunteer please go to the website at www.cadasilfoundation.org and scroll down and click on Volunteers.

CADASIL PHYSICIAN LOCATOR NOW ON OUR WEBSITE

We have been creating a list of physicians who have seen at least one or more patients with CADASIL. Before we asked you to e-mail us or contact us to locate a doctor in your area. Now we have the list on line. This Doctors list contains doctors from the following countries so far: Australia, Brazil, Canada, England, Finland, France, Germany, Ireland, Italy, Japan, Netherlands, Portugal, Puerto Rico, Scotland, Switzerland and USA. If you locate a doctor from this list, please be sure to let the doctor know that the referral came from CADASIL Together We have Hope. As well, let them know about our website. 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. Please remember even though CADASIL Together We Have Hope has made every effort to keep this list current, some doctors provided on this list may not be as knowledgeable about CADASIL as others. It is still important for patients and physicians alike to understand that every case of CADASIL is different and patients need to develop a good doctor/patient relationship utilizing all of the testing, diagnosing and treatment of symptoms that arise. If any questions arise about any physicians listed on this list please do not hesitate to contact us at: info@cadasilfoundation.org or 1-877-519-HOPE

DEFINITION OF CADASIL FROM THE ONLINE MEDICAL DICTIONARY

CADASIL: Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy. An inherited form of vascular dementia that strikes relatively young adults of both sexes and is characterized by multiple strokes, dementia, migraine-like headaches, and psychiatric disturbances. CADASIL is due to mutation of a gene called NOTCH3 located on chromosome 19. Also called hereditary multi-infarct dementia. www.Medterms.com dated July 13, 2006.

CADASIL STUDY ENDED

Thank you to everyone who was screened and participated in the study. The Study has been closed to any new participants. Over 255 patients were screened worldwide to participate in the study; approximately 168 patients have completed the study. The study final results should be out around December 2006. The foundation also personally wants to thank the Eisai and Parexel Companies and the doctors and researchers for their dedication and hard work during the CADASIL study to make it a success.

SHOP FOR CHARITY (NO COST TO YOU)

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). 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 that 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 at www.igive.com or http://www.tricordia.com

CADASIL TISSUE BANK

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.

NEUROCHEMICAL IMBALANCES IN CADASIL

(CADASIL) is likely the most common form of hereditary small vessel disease which leads to cognitive decline and dementia. MRI has enabled quantification of the burden of small strokes in deeper structures including the white matter of the brain. Little is known about the chemical abnormalities and consequences in CADASIL patients. A previous single case report indicated that substantial cholinergic nerve cell loss may occur in CADASIL. Using quantitative morphological methods we have recently confirmed profound loss of cholinergic nerve cell fibres in a larger number of CADASIL subjects. In the absence of any Alzheimer's disease type of pathological lesions, these observations suggest that therapeutic strategies to replace the lost acetylcholine should be developed for CADASIL patients. Thus, clinically approved aceytlcholinesterase inhibitor drugs (used for Alzheimer patients) such as Aricept, Galantamime and Rivastigmine could be useful for CADASIL sufferers. However, loss of other neurochemicals including dopamine from the deeper grey brain structures may also occur. Irrespective, it is clear there is cholinergic nerve cell impairment and cholinomimetic therapy is implicated for CADASIL sufferers. Such an approach could even be useful for sporadic cerebrovascular disease characterised by small vessel disease abnormalities like Binswanger's disease (hypertensive encephalopathy).
Prof RN Kalaria, Newcastle General Hospital, UK, July 2006

HARVARD MEDICAL SCHOOL TO TEACH A NANOCOURSE ON CADASIL

Fall 2006 Course Titled:
A Notch Signaling Disease
Course Description: CADASIL Notch signaling disease including ischemic stroke and neural degeneration.
Course director: Spyros Artavanis-Tsakonas
Course Lecturers: Spyros Artavanis-Tsakonas and Mike Moskowitz

This course is an educational tool meant to bring students and other interested individuals in the Harvard community up to date on a particular field, to provide insight into the current problems in that field, and to, in general, define a solid basis for further study in that field, in a short time period.

IS INADEQUATE FAMILY HISTORY A BARRIER TO DIAGNOSIS IN CADASIL?

Article from Medline.com (ISSN: 0001-6314) http://www.medscape.com/medline/abstract/16218915?queryText=cadasil Acta Neurol Scand. 2005; 112(5):323-6
Razvi SS; Davidson R; Bone I; Muir KW, Department of Neurology, Institute of Neurological Sciences, Southern General Hospital, Glasgow, UK
Cerebral autosomal dominant arteriopathy with subcortical infarcts and leucoencephalopathy (CADASIL) has typical clinical features t include stroke, migraine, mood disturbances and cognitive decline. However, misdiagnosis is common. We hypothesized that family history is poorly elicited in individuals presenting with features of CADASIL and that enquiry into family history of all four cardinal manifestations of CADASIL is superior to elicitation of family history of premature stroke alone in raising the diagnostic possibility of CADASIL. MATERIALS AND METHODS: Retrospective review of family histories at presentation in 40 individuals with confirmed CADASIL was performed through structured interview in a Neurovascular Genetics clinic (182 first-degree and 242 second-degree relatives identified). Family history obtained from structured interview was compared to family history initially documented at presentation. RESULTS: At initial presentation, 30% of individuals were inaccurately documented to have no family history of significant neurological illness. Thirty-five per cent of patients had an initial alternative diagnosis. Initial inaccurate documentation of negative family history was more frequent in individuals with an initial alternative diagnosis. After structured interviews, 34% of 182 first-degree and 35% of 242 second-degree relatives of CADASIL patients had history of stroke (16% of first-degree relatives had stroke before the age of 50 years). Forty-three per cent of first-degree and 28% of second-degree relatives had migraine, mood disturbance or cognitive decline. CONCLUSIONS: A false-negative family history was commonly documented in individuals presenting with features of CADASIL and was associated with initial misdiagnosis. Restriction of family history to premature stroke alone is probably inadequate to identify affected CADASIL pedigrees.

OUR FAMILY HISTORY, YOUR FUTURE

Your family history holds key information about your past and clues to your future health. Many of your physical traits (such as eye color, hair color, and height) are inherited. So, too, are risks for certain genetic conditions and health problems such as heart disease, diabetes, and some cancers. You may have noticed that some of your relatives are healthier and live longer than other relatives. You may also have noticed that some relatives have the same health problems. By collecting your family's health history, you can learn what health problems you may be at increased risk for in the future and how to reduce your risks. For instance, people at increased risk for heart disease may be able to reduce their risk through not smoking, regular exercise and diet. Finding out your family history can benefit both you and your relatives ... and it can be fun too!

How to Collect A Family History

You can collect your family history by talking to your relatives. Start with your parents if they are living. Older relatives are often good sources of information. Some relatives may not want to share their medical histories or they may not know their family history. However, whatever information you discover will be helpful. Vacations, holidays and family reunions can be good times to collect this infor-

mation. As each generation ages, important information can be forgotten or lost - so now is the time to start your project! If you are adopted, you may be able to learn some of your family history through the parent(s) that adopted you or from adoption agency records.

How to Record Your Family History
Begin by writing down the medical and health information on: yourself, your brothers and sisters, your children and your parents. Once completed go back a generation at a time. Include: nieces and nephews, aunts and uncles, grandparents and cousins. For each relative, try to write down as many of these items as possible: Age or date of birth (and, for all family members who have passed on, age at death and cause of death). When you find information is unavailable, write down your best guess (e. g., "40s"). Document Medical problems such as: Cancer, Heart disease, Diabetes, Asthma, Mental illness, High blood pressure, Stroke, Kidney disease, Alcoholism and others. Try to note the ages at which the conditions occurred. Did Uncle Pete have his heart attack at age 42 or age 88? Did your mother develop diabetes in childhood or as an adult? Record Birth defects such as spinal bifida, cleft lip, heart defects, others. Note learning problems, mental retardation, vision loss/hearing loss at a young age (remember to record the age it began). For family members with known medical problems, jot down if they smoked, their diet and exercise habits, and if they were overweight (for example: you could note that your brother John, who had a heart attack at age 40, weighs 300 lbs and smokes 2 packs a day). Above your mother's side of the family tree write down where her family members came from (for example, England, Germany, Africa, ...); then do the same for your father's side of the family. This information can be helpful because some genetic health problems occur more often in specific ethnic groups. You should keep your family tree in a safe place and update it every couple of years (or update it at a regular family gathering, such as Thanksgiving). You can share a copy with your doctor, who may find it helpful in caring for your health.

This link http://www.hhs.gov/familyhistory/download.html is for My Family Health Portrait download page from the U.S. Surgeon General's Family History Initiative. From this website page, you can download the My Family Health Portrait software and install it on your home computer, or you can use the new Web-based version. Thank you to the genetic alliance website for the above information.

WHAT IS AN EMERGENCY CARE PLAN

Developing an emergency plan is very important, be prepared and plan today. Written emergency plans should include brief but specific information about the person's medical condition, including physical and mental state. 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.

OUR FIRST ANNIVERSARY

Thank you to everyone who participated in celebrating our first anniversary. Our Bumper sticker celebration raised over $ 900.00. Please if you received a bumper sticker and have not yet made a donation, don't forget to mail it to us or go online to make a credit card donation. If you did not receive a bumper sticker, please e-mail us your mailing address and we will be glad to put one in the mail to you with information on how you can make a donation.

LETTER WRITING CAMPAIGN

Below is a list of places to write to inform others about CADASIL. Please share how you coped or learned about CADASIL. In the next coming newsletters we will print additional addresses for everyone to write to raise awareness for CADASIL.

Don Nash
Supervising Producer (NBC)
30 Rockefeller Plaza
Rm. 374 E
New York, NY 10112

USA TODAY
Editor
7950 Jones Branch Drive
McLean, VA 22108-0605

Reuters Health Information
Editor
3 Times Square, 3rd Floor
New York NY 10036

Newsweek
Editor
251 W. 57th St.
New York, NY 10019

Good Morning America
Producer
147 Columbus Ave
New York, NY 10023

48 Hours
Producer
524 West 57th St
New York, NY 10019

INCREASE AWARENESS WITH THE AMERICAN STROKE ASSOCIATION

In our last newsletter we asked everyone to sign the American Stroke Association registration and ask that information on CADASIL be provided on there website. We appreciated everyone who did so. We also wrote the American Heart/Stroke Association requesting to raise awareness by providing information brochures about CADASIL in neurologist's offices.

This was the response we received through e-mail: "Thank you for contacting us in your efforts to raise awareness of CADASIL. After speaking with several internal constituents including staff from our Patient Education and Science departments, we've agreed that, although at this time we will not be able to accommodate your request to produce a brochure specific to CADASIL, we will begin to look for opportunities to include information on CADASIL on our websites as appropriate. Again, thank you for contacting us in your efforts to raise awareness on this important condition, and we wish you the best of luck on your endeavor." If you have any additional questions, feel free to contact me. Thanks, Erin Moyer, Manager, Marketing & Development, Patient Education American Heart Association and American Stroke Association

NEW ONLINE AWARENESS FUNDRAISING PAGE

CADASIL postage stamps, clothing, hats, stickers, a teddy bear and other fun items. All items are shipped directly to you! A percentage of the funds are donated directly to our foundation! Wear, display, and give these items for gifts to raise awareness for CADASIL. Please go to the website and scroll down on the left side and click on awareness or go directly to the link http://www.cafepress.com/cadasil Check it out!

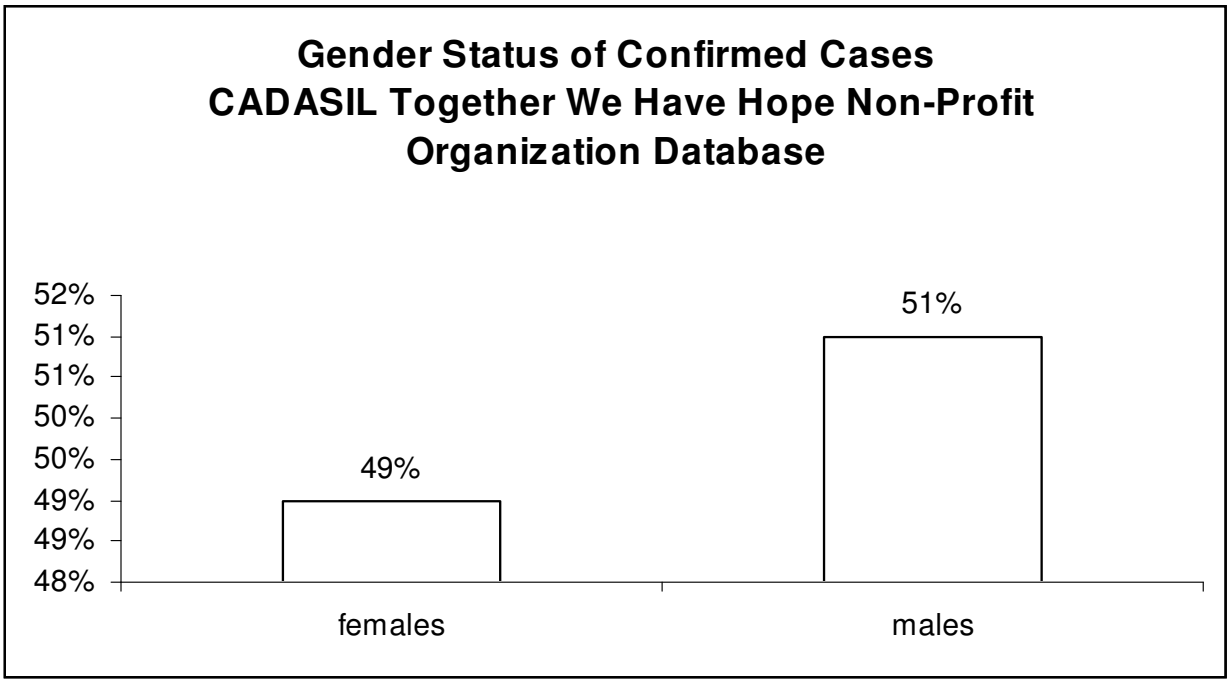
UPDATE ON GENETIC INFORMATION NONDISCRIMINATION ACT OF 2005

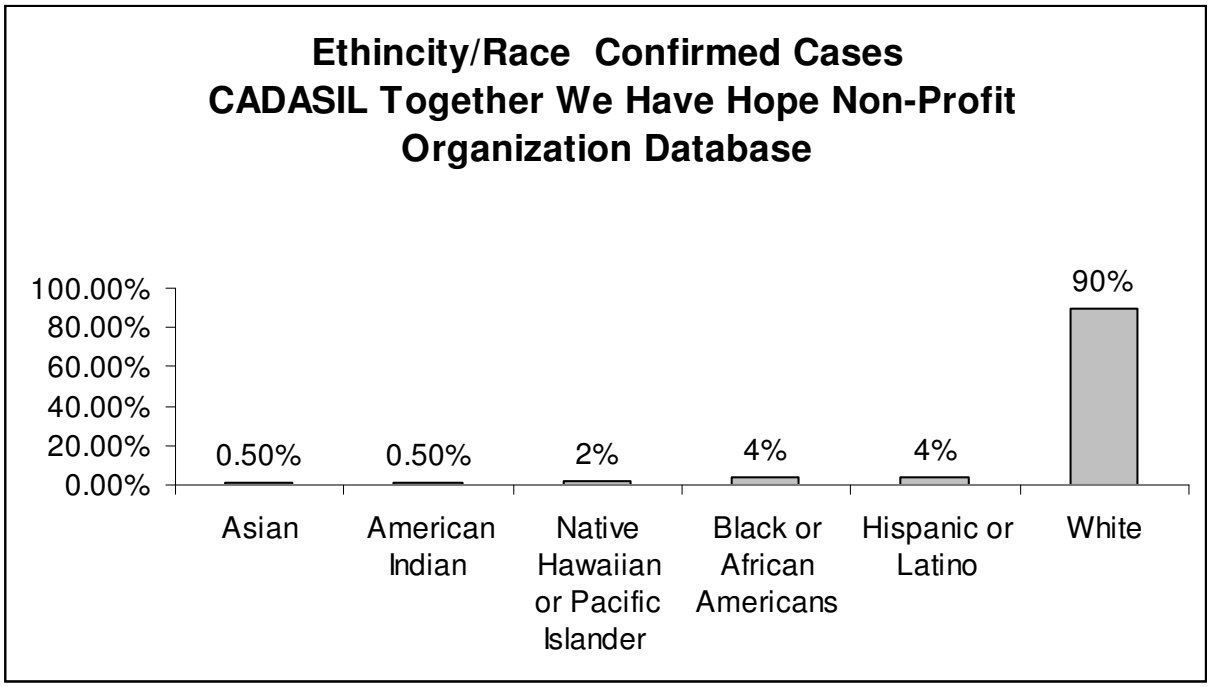
The Coalition for Genetic Fairness' June 29th, 2006 Genetic Information Nondiscrimination Act of 2005 (H.R. 1227) (GINA) briefing with Representative Judy Biggert was a tremendous success. Approximately 50 Coalition members, congressional staffers, and industry representatives assembled in the Rayburn House Office Building on Capitol Hill, along with filmmakers from Kartemquin Films who captured the event as part of an upcoming documentary.

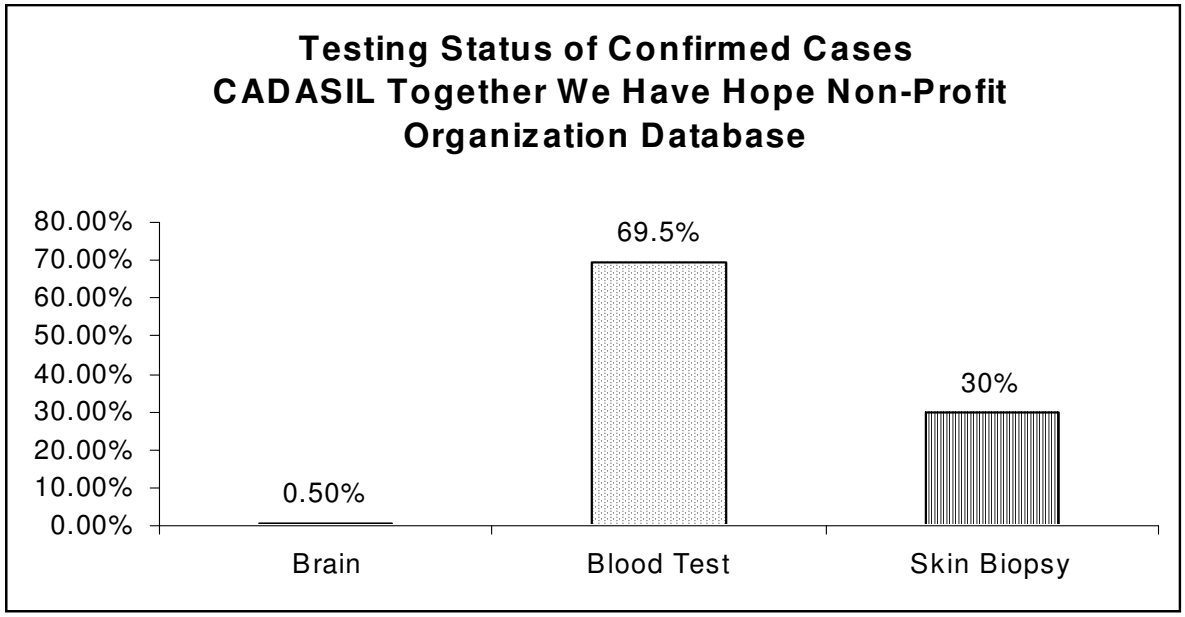
CADASIL Together We Have Hope receives e-mails wanting to have their family members tested but due to genetic discrimination are scared about the future, our own family is affected with this discrimination also. The voices of a few should not dominate this discussion. Cases of discrimination—and the very real concerns associated with the possibility of discrimination—are already affecting the quality of our health care and clinical trials. Please check on our website under Genetic Information Nondiscrimination Act of 2005 to volunteer to helps us pass this bill for all of us.

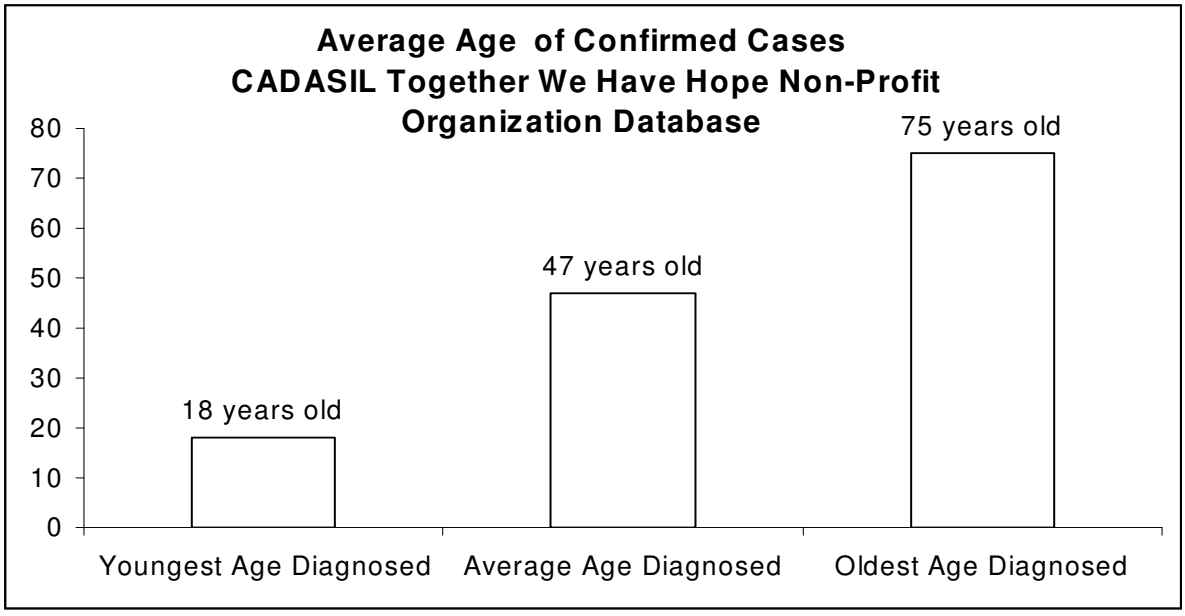
WHY SIGN OUR GUESTBOOK?

Make sure you have signed the guestbook online. Every number counts. We would like to mail you a welcome packet, keep you up to date with the most current information on CADASIL and you become part of the CADASIL Family. Once you have signed the guestbook and, your information is transferred to our database, which tracks the number of confirmed cases all over the world. The foundation does not require membership to join and all personnel information provided is kept strictly confidential. Occasionally we will publish new charts in our newsletters with the most current information on our database. As of July 20, 2006 we have 523 confirmed cases on our database.









MY HUSBAND HAD CADASIL

As some of you may know, I recently lost my beloved husband to CADASIL. It was the most exasperating, confusing, frightening 3 years of my life. Phil apparently had this disease for about twenty years, but we were totally unaware that the strokes he was having, balance problems and the mood swings were all symptoms of this strange illness that we had never heard of. In 1986, Phil had his first stroke at age fifty one. At that time, no one could tell us why he had a stroke; he had none of the usual problems that lead to a stroke. However, we accepted this and were determined he would not have another stroke. For the next fifteen years, we walked, exercised, watched his cholesterol and did everything we could to keep the wolf from the door. During this time, he had several MRI's and each time we were told that he had brain damage, but no one seemed to know what had caused it. At first we were told it was MS, but the Neurologist ruled it out because he had no other symptoms. When Phil turned 66 years old, things started to happen that no one could explain. He started limping and dragging one

leg. He also became very moody and was making a lot of mistakes driving. The children became very concerned and we started making the rounds of neurologists. The answers were always the same. "There appears to be damage to the brain, which is causing some of his problems, but we don't know what is causing the damage." After about 18 months of this, I decided to be an advocate and made an appointment with Mayo Clinic in Jacksonville, Florida. On the day of his appointment, he had another stroke and was in the hospital. When he came out of the hospital we did go to the Clinic where he was finally diagnosed with CADASIL. Since that day, our lives have been turned upside down. Trying to find information, trying to find out what to expect, and finally trying to cope with the changes in our lives became our main focus. Each time Phil would go downhill was very traumatic for me. I would have to learn how to cope with another problem and figure out a new routine to cover the new problem. My biggest fear was that he would be a vegetable and suffer a great deal when the end was near. I guess in some ways we were fortunate that we never had to cope with that. He was only unable to eat for one day when he developed pneumonia and ended up in the hospital. He passed away four days later without ever recovering at the age of 71 years old. A part of me is grateful that he didn't suffer, but I am still very bitter that there is still nothing that can be done for people like Phil diagnosed with CADASIL.

My thoughts and prayers are always with our CADASIL family. I feel as though we are a very special group of people who only gain strength from each other. God Bless You All, Jo

CADASIL A RARE, OFTEN MISDIAGNOSED, GENETIC DISEASE

These are excerpts from Alice Lindahl story. You can read the full story online. Go to our website and stroll down on the left hand side until you come to *how others cope with CADASIL*

One day, in 1982, Wayne developed numbness and slurred speech. He was 45 years old at the time. The doctors as first thought he was having a stroke, but test could not confirm this. They eventually determined that the symptoms were caused by an allergic reaction to epoxy glue with which Wayne works. We accepted this explanation and thought little about it until other episodes started happening. I remember one day, Wayne wanted to make a telephone call. He stood with the receiver in his hand and didn't know how to dial the number. He knew he wanted to call, but couldn't dial. By the time he was 50, I knew there was something very wrong. Wayne's personality changed. He became increasingly angry over many things and was very hard to get along with. There were other times when he would become quiet and withdrawn. Some days it seemed that he just wasn't thinking right. At the end of 1992, Wayne had another of his stroke-like episodes. He had blurred vision, drooped mouth and lost his speech. By he time we arrived at the hospital, all of those symptoms has vanished! Nevertheless, I insisted that he be admitted. I needed answers. There has to be a reason for theses continuous problems. The doctor ordered an MRI and the results were stunning. They should Wayne's brain to be deteriorating in an extraordinary way. As a matter of fact, upon meeting Wayne in persons, the doctor expressed shock at Wayne's abilities. Clinically speaking, he had expected someone that would not be early as functional as Wayne was. Although he could not give a reason for this, the doctor did say that he damage was irreversible and would likely continue to get worse. There were man good times when I almost thought this wasn't happening. Things would be so normal and then something would happen to remind me of the reality. I had no name on the condition. In 1994, our new neurologist was interested in Wayne's condition and ordered another MRI. After reading it he commented that after practicing for twenty-five years, he had never seen anything like this. In 1997 I received a letter from the doctor who Wayne had seen in 1992. With it he included an article, written by a French doctor, about CADASIL. The letter said that he believed this disease may e that Wayne was suffering from. My only response at that time was ---GENETIC? Our children? It can't be true. What was true was that Wayne's younger brother was showing any of the same symptoms at that time.

The genetic part of CADASIL hit home hard in October 2000 when our then 39 year old son was diagnosed with CADASIL and then again our oldest son, 43 years old, got the same horrid diagnosis. My entire world was crashing. Wayne passed away peacefully on August 5, 2004. His younger brother also

diagnosed with CADASIL, passed way six months later at the age of 63.
Over the past several years I have made contact in writing and by telephone to doctors all over the world in a quest for information and support for CADASIL patients. My hope has been to find someone who would be interested in my family and CADASIL – possibly for research.
Since December 2003, I had been in contact with Dr. Stephen Salloway and Dr. Stephen Correia with the Memory and Aging Program at Butler Hospital in Providence, Rhode Island. Plans were made to have Wayne's brain was sent to Rhode Island after his death and we also donated Wayne's brother's brain when he passed away. My life goes not, but I go to sleep each night and awaken each morning with those seven letters in the front of my face "CADASIL".I now worry about my other family members affected. I now worry about my other three children and all of my grandchildren. It has been tracked by to my husband's grandfather, who died young of stroke-like symptoms. Wayne's father, who died at the age of 56, was diagnosed with MS, but the diagnosis has now become suspect. Wayne's uncle died of similar symptoms in his early 60's.
Presently we have six living family members that have been clinically diagnosed with CADASIL. These include my two oldest sons, Wayne's other uncle, nephew, and two cousins. All these people are between the ages of 42 and 70. I would be greatly appreciative if somehow our family would be contacted for research purpose relating to CADASIL. The author can be reached at matti_cadail@msn.

MOTIVATION STORY - YOU HAVE TWO CHOICES BY AN UNKNOWN AUTHOR

Jerry is the manager of a restaurant. He is always in a good mood. When someone would ask him how he was doing, he would always reply: "If I were any better, I would be twins!" Many of the waiters at his restaurant quit their jobs when he changed jobs, so they could follow him from restaurant to restaurant. Why? Jerry was a natural motivator. If an employee was having a bad day, Jerry was always there, telling him how to look on the positive side of the situation. Seeing this style really made me curious, so one day I went up to Jerry and asked him: "I don't get it! No one can be a positive person all of the time. How do you do it?" Jerry replied, "Each morning I wake up and say to myself, I have two choices today. I can choose to be in a good mood or I can choose to be in a bad mood. I always choose to be in a good mood. Each time something bad happens, I can choose to be victim or I can choose to learn from it. I always choose to learn from it. Every time someone comes to me complaining, I can choose to accept their complaining or I can point out the positive side of life. I always choose the positive side of life." "But it's not always that easy," I protested. "Yes it is," Jerry said. "Life is all about choices. When you cut away all the junk every situation is a choice. You choose how you react to situations. You choose how people will affect your mood. You choose to be in a good mood or bad mood. It's your choice how you live your life."
Several years later, I heard that Jerry accidentally did something you are never supposed to do in the restaurant business. Jerry left the back door of his restaurant open. In the morning, he was robbed by three armed men. While Jerry was trying to open the safe box, his hand shaking from nervousness slipped off the combination. The robbers panicked and shot him. Luckily, Jerry was found quickly and rushed to the hospital. After 18 hours of surgery and weeks of intensive care, Jerry was released from the hospital with fragments of the bullets still in his body. I saw Jerry about six months after the accident. When I asked him how he was, he replied, "If I were any better, I'd be twins. Want to see my scars?" I declined to see his wounds, but did ask him what had gone through his mind as the robbery took place. "The first thing that went through my mind was that I should have locked the back door," Jerry replied. "Then, after they shot me, as I lay on the floor, I remembered that I had two choices: I could choose to live or could choose to die. I chose to live." "Weren't you scared" I asked? Jerry continued, "The paramedics were great. They kept telling me I was going to be fine. But when they wheeled me into the Emergency Room and I saw the expression on the faces of the doctors and nurses, I got really scared. In their eyes, I read 'He's a dead man.' I knew I needed to take action." "What did you do?" I asked. "Well, there was a nurse shouting questions at me," said Jerry. "She asked if I was allergic to anything." 'Yes,' to bullets, I replied. Over their laughter, I told them: "I am choosing to live. Please operate on me as if I am alive, not dead." "Jerry lived thanks to the skill of his doctors, but also because of his amazing attitude. I learned from him that every day you have the choice to either enjoy your life or to hate it.
The only thing that is truly yours - that no one can control or take from you – is your attitude, so if you can take care of that, everything else in life becomes much easier.

In Loving Memory of . . .

Philip DiGioia, 71 years old of Port Orange, Florida, USA. Our thoughts and prayers are with his wife, Josephine and their family.

Tena (Kroonenberg) Hoevenaar, Laurels of Sandy Creek Nursing Home in Wayland, Michigan (for the past 18 years), prior to that she lived in Caledonia, Michigan . Our thoughts and prayers are with her daughter, Dorene Natte and her family. Tena is survived by her husband of 62 years, Herman (age 91), 3 sons and 1 daughter, 9 grandchildren, and 6 great-grandchildren.

Thank you to both families for sending memorials gifts to the foundation in loving memory of their loved ones.

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IMPORTANT MESSAGE:
CADASIL Newsletter will be published twice yearly with news bulletins mailed to you when important information becomes available and can't wait.

Thank you for those who contributed to this newsletter.

Billie Duncan-Smith, Director

CADASIL Together We Have Hope and please remember you are not alone!