CADASIIL TOGETHER WE HAVE HOPE NON-PROFIT ORGANIZATION
MAY 2008 NEWSLETTER
VOLUME 11, ISSUE I

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First Placebo-Controlled Trail for CADASIL Published

The International CADASIL Donepezil Study Group led by Professor Martin Dichgans from Munich, Germany, Professor Hugh Markus from London, England, Professor Stephen Salloway from Providence, RI, USA, and Professor Hugues Chabiat from Paris, France has published the first placebo-controlled clinical trial for CADASIL in the international medical journal Lancet Neurology. The study exceeded the target enrollment of 150 patients, enrolling 168 CADASIL patients from Europe, the United States, and Canada. Patients had cognitive impairment on a the Mini-Mental State Exam, a cognitive screening test, or the Trail Making Test-Part B, a test alternating numbers and letters to measure speed of thinking and organizational skills. Study participants received donepezil (Aricept) 10 mg per day or placebo, an inactive medication, for 18 weeks. Neither the study team nor the patients knew whether they were receiving active medication. The results showed that patients on donepezil did no better on the VADAS-cog, a cognitive test similar to one used in clinical trials for Alzheimer's disease, but patients on donepezil did do better on three tests that measure cognitive speed and organization.

Thinking more slowly, difficulty concentrating, and staying organized are commonly seen in patients with CADASIL and other causes of stroke. Though there are no FDA-approved treatments for the CADASIL or vascular dementia, the results of this study suggest that donepezil may help treat some of these cognitive symptoms. The results are being presented at the International Stroke Congress in New Orleans, the American Academy of Neurology in Chicago. The European Federation of Neurological Disorders and Stroke in Nice, France, and the International Conference on Alzheimer's Disease in Chicago. The publication of the results and an accompanying editorial in a widely read international medical journal such as Lancet Neurology will bring much needed attention of the international medical community to help advance CADASIL research. The results of this study will help researcher's better design future clinical trials for patients with CADASIL and vascular dementia. Further, the ability of the International Study Group to meet and exceed the target enrollment is an encouraging sign that CADASIL future clinical trials will be successful.

References-Dichgans M, Markus H, Salloway S, Verkkoniemi A, Wang Q, Moline M, Posner H, Chabriat H. Donepezil in Subcortical Vascular Cognitive Impairment: a Randomized Double Blind Trial in CADASIL. Lancet Neurology 2008. Schneider L. Does donepezil improve executive function in patients with CADASIL? Lancet Neurology 2008.

Submitted by Stephen Salloway, M.D., M.S. Professor of Clinical Neurosciences
Alpert Medical School, Brown University, Providence, RI

Inside this issue

The foundation wants to thank everyone who was screened and participated in the CADASIL Study. Over 255 patients were screened worldwide to participate in the study; approximately 168 patients have completed the study. Also, thank you to the doctors and researchers for their dedication and hard work during the study and Eisai and Parexel companies.

Genetic Anti-Discrimination Bill Clears Congress

Statement from Francis S. Collins, M.D., Ph.D., Director, National Human Genome Research Institute, National Institutes of Department of Health and Human Services

Washington, Thurs., May 1, 2008 - The House passed today the Genetic Information Nondiscrimination Act (GINA) by a vote of 414 to 1. The act will protect Americans against discrimination based on their genetic information when it comes to health insurance and employment.

The Senate unanimously approved the legislation last week. It's anticipated that President Bush will sign the bill soon.

The long-awaited measure, which has been debated in Congress for 13 years, will pave the way for people to take full advantage of the promise of personalized medicine without fear of discrimination. Now they have it. This bill could just as well be known as the bill to protect people with DNA, and that would be all of us! Since each of us has dozens of genetic variations that may put us at risk for disease, we all would have had a reason to be concerned about the possible misuse of genetic information. With this act, Americans won't have to worry about their jobs or their health insurance being taken away because of the genes they inherited.

This is a momentous day. Thank you, members of the U.S. Senate and the U.S. House of Representatives, for giving a wonderful gift to the American people: protection from genetic discrimination.

QUESTIONS ANSWERED BY OUR SCIENTIFIC ADVISORY 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

CADASIL AROUND THE WORLD

UNITED STATES OF AMERICA

RHODE ISLAND
Dr. S. Salloway at Memory & Aging Program, Butler Hospital 345 Blackstone Boulevard, Providence, Rhode Island 02906 Telephone: 401-455-6403. Dr. S. Salloway in research they have the first tissue donated tissue bank in the U.S.A.

MASSACHUSETTS
Spyros Artavanis-Tsakonas, Ph.D. - Please contact his lab if you can help with funding Harvard Medical School, Department of Cell Biology 240 Longwood Avenue (LHRRB 410) Boston, MA 02115 USA 617·432·7048 CADASIL related research seems now to be extremely urgent. We are attempting to address this devastating disease in a systematic manner in a way that covers the entire spectrum of tools.

MASSACHUSETTS

Spyros Artavanis-Tsakonas, Ph.D. - Please contact his lab if you can help with funding Harvard Medical School, Department of Cell Biology 240 Longwood Avenue (LHRRB 410) Boston, MA 02115 USA 617·432·7048 CADASIL related research seems now to be extremely urgent. We are attempting to address this devastating disease in a systematic manner in a way that covers the entire spectrum of tools.

MICHIGAN

Michael Wang, MD PhD - Please contact his lab if you can help with funding University of Michigan Health System, 1500 E. Medical Center Drive Ann Arbor, MI 48109 734-936-4000 We are making some progress on studying the Notch3 gene. We're in the process of submitting papers on several proteins that bind to Notch3. These proteins unexpectedly alter the function of Notch3 and are also expressed in the blood vessels. Our next step is to investigate whether the proteins may play a role in CADASIL.

CANADA

Michael D. Hill, Assistant Professor, Department of Clinical Neurosciences - Director, Stroke Unit - Foothills Medical Centre, Rm 1242A, Foothills Medical Centre, 1403 29th Street NW, Calgary, AB T2N 2T9 CANADA PH: 403 944 8065 FX: 403 283 2270

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Pr. Marie-Germaine BOUSSER, Hopital Lariboisiere, Paris, France - Pr. Bousser is a professor of Neurology at Paris University and the Head of the Neurology department at Lariboisiere Hospital

Elisabeth A. Tournier-Lasserve, M.D., Professor of Medical Genetics, Department of Genetics Université Paris 7 - Denis Diderot, E365 Faculté de Medécine Lariboisiere

NETHERLANDS

Department of Clinical Genetics, Leiden University Medical Center, The Netherlands 071-526-8033

SCOTLAND

Dr. Keith Muir, Southern General Hospital in Glasgow, Scotland Telephone: 0141 201 2502 Pathophysiological relevance of acute post-stroke hyperglycemia in relation to brain perfusion and arterial patency 2006 – 2009

SWITZERLAND

PD Dr. Hans H. Jung, University of Zürich and Swiss Federal Institute of Technology Zürich, Zürich, Switzerland

WEST GERMANY

Prof. Dr. med. Martin Dichgans - Ludwig-Maximilians-University Munich, Klinikum Großhadern, Marchioninistr. 15, 81377 Munich, Germany Tel. ++ 49 89 7095 7801 Fax ++ 49 89 7095 7802

Please e-mail info@cadasilfoundation.org if you know of other locations.

Common Neurological Tests
American Academy of Neurology Foundation

Computerized tomography or computer assisted tomography (CT of CAT scan). This test uses x-rays and computers to create multi-dimensional images of selected body parts. Dye may be injected into a patient's vein to obtain a clearer view. Other than needle insertion for the dye, this test is painless.

Magnetic Resonance Imaging (MRI). An MRI is an advanced way of taking pictures of the inner brain. It is harmless and involves magnetic fields and radio waves. It is performed when a patient is lying in a small chamber for about 30 minutes. It is painless, but may be stressful for individuals with claustrophobia (fear of closed areas). A physician can offer options to help you relax.

Electroencephalogram (EEG). The EEG records the brain's continuous electrical activity through electrodes attached to the scalp. It is used to help diagnose structural diseases of the brain and episodes such as seizures, fainting, or blacking out. This test is painless.

Transcranial Doppler (TCD). This test uses sound waves to measure blood flow in the vessels of the brain. A microphone is placed on different parts of the head to view the blood vessels. This test is painless.

Neurosonography. This test uses ultra high frequency sound wave to analyze blood flow and blockage in the blood vessels in or leading to the brain. This test is painless.

Electromyogram (EMG). An EMG measures and records electrical activity in the muscles and nerves. This may be helpful in determining the cause of pain, numbness, tingling, or weakness in the muscles or nerves. Small needles are inserted into the muscle and mild electrical shocks are given to stimulate the nerve. Discomfort may be associated with this test.

Evoked Potentials. This test records the brain's electrical response to visual, auditory, and sensory stimulation. This test is useful in evaluating and diagnosing symptoms if dizziness, numbness, and tingling, as well as visual disorders. Discomfort may be associated with this test.

Sleep Studies. These tests are used to diagnose specific causes of sleep problems. To perform the tests, it is often necessary for a patient to spend the night in a sleep laboratory. Brain wave activity, heart rate, electrical activity of the heart, breathing, and oxygen in the blood are all measured during

MIND GAMES - 7 WAYS TO MAKE YOUR BRAIN BETTER, FASTER, AND SMARTER.
Reader's Digest By William Speed Weed

The No. 1 Thing You Can Do?

1. Move It
Quick -- what's the No. 1 thing you can do for your brain's health? Differential calculus, you say? Chess? Chaos theory? Nope, the best brain sharpener may be ... sneakers? Yup. Once they're on your feet, you can pump up your heart rate. "The best advice I can give to keep your brain healthy and young is aerobic exercise," says Donald Stuss, PhD, a neuropsychologist and director of the Rotman Research Institute at Baycrest Centre for Geriatric Care in Toronto. Mark McDaniel, PhD, professor of psychology at Washington University in St. Louis, agrees, but adds, "I would suggest a combined program of aerobics and weight training. Studies show the best outcomes for those engaged in both types of exercise."

As we age, our brain cells, called neurons, lose the tree-branch-like connections between them. These connections, or synapses, are essential to thought. Quite literally, over time, our brains lose their heft. Perhaps the most striking brain research today is the strong evidence we now have that "exercise may forestall some kinds of mental decline," notes McDaniel. It may even restore memory. Myriad animal studies have shown that, among other brain benefits, aerobic exercise increases capillary development in the brain, meaning more blood supply, more nutrients and -- a big requirement for brain health -- more oxygen.

The preeminent exercise and brain-health researcher in humans is Arthur Kramer at the University of Illinois at Urbana-Champaign. In a dozen studies over the past few years, with titles such as "Aerobic Fitness Reduces Brain Tissue Loss in Aging Humans," Kramer and his colleagues have proved two critical findings: Fit people have sharper brains, and people who are out of shape, but then get into shape, sharpen up their brains. This second finding is vital. There's no question that working out makes you smarter, and it does so, Kramer notes, at all stages of life. Just as important, exercise staves off heart disease, obesity, diabetes and other maladies that increase the risk of brain problems as we age.

2. Feed It
Another path to a better brain is through your stomach. We've all heard about antioxidants as cancer fighters. Eating foods that contain these molecules, which neutralize harmful free radicals, may be especially good for your brain too. Free radicals have nothing to do with Berkeley politics and everything to do with breaking down the neurons in our brains. Many colorful fruits and vegetables are packed with antioxidants, as are some beans, whole grains, nuts and spices. More important, though, is overall nutrition. In concert with a good workout routine, you should eat right to avoid the diseases that modern flesh is heir to. High blood pressure, diabetes, obesity and high cholesterol all make life tough on your brain, says Carol Greenwood, PhD, a geriatric research scientist at the University of Toronto.

If your diet is heavy, then you're probably also heavy. The same weight that burdens your legs on the stairs also burdens your brain for the witty reply or quick problem solving. The best things you can eat for your body, Greenwood notes, are also the best things you can eat for your brain. Your brain is in your body, after all. Greenwood's recommendation is to follow the dietary guidelines from the American Diabetes Association (available at diabetes.org).

STOP, BREATHE & RELAX

3. Speed It Up
Sorry to say, our brains naturally start slowing down at the cruelly young age of 30 (yes, 30). It used to be thought that this couldn't be helped, but a barrage of new studies show that people of any age can train their brains to be faster and, in effect, younger. "Your brain is a learning machine," says Michael Merzenich, PhD, a neuroscientist at the University of California, San Francisco. Given the right tools, we can train our brains to act like they did when we were younger. All that's required is dedicated practice: exercises for the mind. Merzenich has developed a computer-based training regimen to speed up how the brain processes information (positscience.com). Since much of the data we receive comes through speech, the Brain Fitness Program works with language and hearing to improve both speed and accuracy. Over the course of your training, the program starts asking you to distinguish sounds (between "dog" and "bog," for instance) at an increasingly faster rate. It's a bit like a tennis instructor, says Merzenich, shooting balls at you faster and faster over the course of the summer to keep you challenged. Though you may have started out slow, by Labor Day you're pretty nimble.

Similarly, Nintendo was inspired by the research of a Japanese doctor to develop a handheld game called Brain Age: Train Your Brain in Minutes a Day, which has sold more than two million copies in Japan. No software out there has yet been approved by the FDA as a treatment for cognitive impairment, but an increasing number of reputable scientific studies suggest that

programs like Merzenich's could help slow down typical brain aging, or even treat dementia. The biggest finding in brain research in the last ten years is that the brain at any age is highly adaptable, or "plastic," as neurologists put it. If you ask your brain to learn, it will learn. And it may speed up in the process.

To keep your brain young and supple, you can purchase software like Merzenich's, or you can do one of a million new activities that challenge and excite you: playing Ping-Pong or contract bridge, doing jigsaw puzzles, learning a new language or the tango, taking accordion lessons, building a kit airplane, mastering bonsai technique, discovering the subtleties of beer-brewing and, sure, relearning differential calculus. "Anything that closely engages your focus and is strongly rewarding," says Merzenich, will kick your brain into learning mode and necessarily notch it up. For his part, Merzenich, 64, has "4,000 hobbies," including a wood shop and a vineyard.

4. Stay Calm
So you may be saying to yourself, I have to sign up *right now* for Swahili and calculus and accordion lessons before my brain withers away! Stop! Breathe. Relax. Good. While challenging your brain is very important, remaining calm is equally so. In a paper on the brain and stress, Jeansok Kim of the University of Washington asserts, in no uncertain terms, that traumatic stress is bad for your brain cells. Stress can "disturb cognitive processes such as learning and memory, and consequently limit the quality of human life," writes Kim.

One example is a part of the brain called the hippocampus, which is a primary locus of memory formation, but which can be seriously debilitated by chronic stress. Of course, physical exercise is always a great destressor, as are calmer activities like yoga and meditation. And when you line up your mental calisthenics (your Swahili and swing lessons), make sure you can stay loose and have fun.

LAUGH YOURSELF WISE

5. Give It a Rest
Perhaps the most extreme example of the mental power of staying calm is the creative benefit of sleep. Next time you're working on a complex problem, whether it be a calculus proof or choosing the right car for your family, it really pays to "sleep on it." Researchers at Harvard Medical School have looked at the conditions under which people come up with creative solutions. In a study involving math problems, they found that a good night's rest doubled participants' chances of finding a creative solution to the problems the next day. The sleeping brain, they theorize, is vastly capable of synthesizing complex information.

6. Laugh a Little
Humor stimulates the parts of our brain that use the "feel good" chemical messenger dopamine. That puts laughter in the category of activities you want to do over and over again, such as eating chocolate or having sex. Laughter is pleasurable, perhaps even "addictive," to the brain. But can humor make us smarter? The jury is still out and more studies are needed, but the initial results are encouraging. Look for a feature on exciting new research about humor and intelligence in the September issue of *Reader's Digest*.

7. Get Better With Age
In our youth-obsessed culture, no one's suggesting a revision to the Constitution allowing 20-year-olds to run for President. The age requirement remains at 35. You've heard about the wisdom and judgment of older people? Scientists are starting to understand how wisdom works on a neurological level.

When you are older, explains Merzenich, "you have recorded in your brain millions and millions of little social scenarios and facts" that you can call upon at any time. Furthermore, he notes, "you are a much better synthesizer and integrator of that information."

Older people are better at solving problems, because they have more mental information to draw upon than younger people do. That's why those in their 50s and 60s are sage. They're the ones we turn to for the best advice, the ones we want to run our companies and our country.

Barry Gordon, a neurologist at The Johns Hopkins School of Medicine and author of *Intelligent Memory: Improve the Memory That Makes You Smarter*, puts it, "It's nice to know some things get better with age."

HELPFUL TIPS TO PREVENT, MINIMIZE OR OVERCOME EFFECTS OF DISABLING SYMPTOMS

CADASIL is a debilitating condition resulting in both emotional and physical disablement, thus restricting to our normal way of life. It affects the sufferer, family, caregivers, friends and many others in our lives.

The main symptom sources of CADASIL can best be described as: Medical, Environmental, Emotional and Physical
It cannot be the scope of this information to address the any possible medical treatments of this condition. That is a complex issue beyond the scope of anything. We do however attempt to address some of the disabling stressful consequences of symptom sources. The range of this information is to assist CADASIL patients and their caregivers to better manage environmental, emotional and physical forces affecting the patient's condition, well being and quality of life. Our objective is to find better ways of avoiding, reducing and minimizing the affect of symptoms upon our way of life, and restoring some of the daily activities we have taken for granted in the past, without adding to the list of medications, treatments and financial stress. As far as possible, we should not avoid a normal lifestyle for fear of injury or harm, but modify how and what we do to enhance our changed skills and abilities within safe limits.

Important Note: Please consider carefully any aids or modifications to ensure they are appropriate to your needs and condition. Consultation with your health care professional, physiotherapist, occupational therapist or other qualified adviser will assist to ensure your safety.

ENVIRONMENTAL SOURCES - Environmental factors affecting our lives include: Quality of foods consumed, A healthy diet is critical. If need be consult an appropriate health professional for advice. An adequate consumption of clean water is as important as a balanced diet, Air quality: e.g. smog, noise pollution, traffic induced pollution etc, Should these issues be identified to trigger adverse symptoms it may be worthwhile considering relocating. There may even be financial or family advantages to downsizing to a smaller country residence free of such hazards. Be aware this option may involve greater distances to travel for medical needs. Also, consider public transport availability.

EMOTIONAL SOURCES - Stress is probably one of the more significant triggers for adverse symptoms in CADASIL sufferers and should be avoided.

MEMORY - Memory difficulties can give rise to a great amount of unwanted stress. A good way of improving memory is to carry a pen and notebook and maybe a pocket diary. Often the act of writing something down is adequate to assist with the memory process. If something is forgotten it's a reasonably stress free task to refer back to your notes or diary. An early evening review of your daily notes and diary is a good idea.

WORK - Work stress can play a major role in ones health. Consider, is the stress worth it and can you find work, and financial and personal satisfaction in a different position or career.

HOME - Stress at home may be physical is the home suitable to your current situation, is it too large or a financial burden or maybe just not close enough to family.

RELATIONSHIPS - Stress in a relationship takes time and hard work to resolve. Consider if necessary consulting close family or friends as a mediator or even a professional counselor.

FINANCIAL - Probably one of the more difficult problems to resolve involving in many ways all facets of our way of life. Factors to be considered here are: Life changing and require very careful consideration and should be resolved while the capacities to make decisions still exist. Persons to be consulted may include spouses, partners, family and friends, business partners and professional financial consultants as an accountant.

POWER OF ATTONERY - Consider the establishment of an Power of Attorney. This will enable your Attorney, often a spouse or responsible adult child; To have the capacity to act on your behalf should you lose the capacity to manage your own affairs.

FINAL WISHES - The most difficult of all tasks is documenting and making known any “final wishes". This difficult task needs to be performed while you have the legal capacity to do so, to ensure the minimum distress to your loved ones. This normally involves consulting a lawyer.

PHYSICAL SOURCES - Physical restrictions upon the way we go about our lives can have a snowballing effect unless we are able to break the cycle. One way of helping break this cycle is to convert restrictions into a positive. It is important for us to maintain as active a life as possible both physically and mentally. For example if you have to cease work why not try and spend more time with the family doing things you were too busy to do earlier i.e. such as holidays. Maybe take up a hobby such as craft or furniture restoration or perhaps a sport such as lawn bowls, fishing or walking the pet.

Maybe your former employment skills are needed by a local charity. Charities are always in need of volunteers to perform a variety of tasks and fellow volunteers are an invaluable source of support. There is a saying "it’s better to work smarter than harder" and this applies even more to those with a disability. Remember it is better to take more time to complete a task in safety than to rush and fail due to error or worse suffer an injury.

HERE ARE SAMPLES OF HOW WE CAN PERFORM VARIOUS TASKS SMARTER

Clothing/footwear: Choose these carefully, they are expensive. Velcro clasps on shoes may be easier than laces. Avoid small buttons on clothing. Make sure clothing is of adequate size especially if the assistance of a helper is required. Clothing design will also influence the ease with which you can put clothes on and off.

Eating utensils: If hard to hold or twist in the hand, try taking a piece of dowel long enough and thick enough to fit comfortably in the hand. Drill a hole in one end, insert the utensil handle (e.g. fork or knife) and fix in place with suitable adhesive. Round the ends slightly. Remember the appropriate size of the dowel may well be different for different utensils depending upon the hand to be used and extent of disability.

Plates: If having difficulty carrying plates consider plates with a lip but be careful they are not too heavy.

Cups and saucers: A better option may be a mug provided it is not too heavy and the handle is large enough to grip comfortably.

Glasses: Drinking glasses are also available with handles. Pewter mugs of appropriate size are good alternatives, lighter than glass, don’t break if dropped and help keep drinks colder.

Pepper and salt: Twist mills may be difficult. Try the old-fashioned shakers.

Kitchen Utensils: When replacing consider carefully things such as weight, shape, style, size and ease of use with maybe one hand. It is best to keep uncomplicated by fancy electronics. Some second hand utensils are very functional, good quality and inexpensive. Secondhand shops are a good source.

Toothbrush: Toothbrushes may be purchased with a larger handle, if not try the wooden handle trick but be careful to keep well clear of brush head and round to avoid gum damage.

Soaps/shampoos: Liquid soap and shampoo dispensers can be easily glued or screwed to a shower wall and operated with one hand. An alternative but more expensive way is”soap on a rope"

Sink/faucets: Difficult taps may just need a new washer of appropriate style. There are also different styles of handles available and handle adaptors.

Shower area: A seat can prove useful with the use of a showerhead on a flexible hose and appropriately placed grab handles.

Toilet: A frame over the pan can often assist as well as grab handles. Consider the need to relocate the paper dispenser to the opposite side. If assistance is required, it may be worth considering having the toilet door swung outward instead of the traditional inward orientation. In event of a serious fall requiring assistance you do not become trapped in a difficult confined space making assistance difficult to reach you when the door slides or swings outwardly. You may also purchase a toilet, which sits higher for disabilities.

Bed: A firmer bed may be easier to get out of. In addition, a frame attached to the bed to grip may assist and would be inexpensive to make. If nausea or reflux is a problem, raise the bed head on a couple of house bricks. Depending upon the bed style appropriate size supports may be needed in the middle. An alternative is to have a foam wedge made about 6 inches (15cm) at the head to nil half way down the bed and place immediately under the mattress. If you have trouble sitting up in bed try a rope tied to the bed foot with well-placed knots. Use the rope to pull yourself up. Use a rope thick enough to be comfortable.

Chairs: Lounge chairs can be difficult to get out of. An additional foam cushion or timber slats under the original cushion may help. Also raising the chair with a wooden frame from underneath will also raise the chair. An excellent but expensive alternative is an electric "lift chair" although these may be purchased second hand at reasonable prices.

Aching feet: When sitting place your feet on a simple wedge about 18 inches (45cm) wide by 12 inches (30cm) ranging from 3 inches (8cm) at the back to nil at the front. It may help and can be made of all sorts of scrap. Try a couple of house bricks with a piece of stiff cardboard or plywood before making something more permanent.

Lighting: Ensure you have adequate lighting at all times. At night consider the use of a child's night-light to assist those late night trips to the toilet.

Garage: This can be a dangerous place; however with good work practices risks can be minimized. It is now imperative the garage be better organized, tools etc be put away after use with no refuse left around. Tools need to be kept in good order. Do not attempt tasks or use tools that are now beyond your capabilities. Think carefully there may still be an alternative way of achieving your objective. Maybe look at using a different type of material or tool. Try to remember how you achieved your goals before power tools. Those hand tools may well do the job again. Be extra careful of flammable and dangerous goods. Your reaction time to rectify an error of judgment may not be what it was.

Gardening: Gardening need not get out of hand. If needed you may wish to simplify your garden to within your new capabilities and by careful plant selection your garden will still be a valuable source of enjoyment. Choose plants that are low maintenance. Your nursery will advise you usually without cost.

Driving: If you are still able to drive be aware of any limitations you may have and drive well within those limitations. Do not drive if in doubt, stop and get help.

Special note to Caregivers: The role you play in the well-being of your loved one is critical. This in particular applies to the way you communicate and interpret what is being said or done.

Due to word selection problems what your loved one says may in fact not be that intended. They may have difficulty explaining symptoms due to a variety of reasons including poor word selection, fear, uncertainty that their symptom description is believable to themselves let alone others or difficulty remembering sufficient to give an adequate and reliable account, They my not want you to know there new symptoms or want you to be scared. You need to be observant. You may need to keep conversations in short sentences that are uncomplicated allowing for an uncomplicated reply if they become worst. Try to address one topic at a time.

Pressuring a love one for a reply to a complex question may have inapposite effect causing stress and loss of thread of the conversation. It may be better to wait and re-approach the subject later or re-wording of a question may assist also.
Your love one and moral support alone may help alleviate stress and in turn prevent or minimize adverse symptoms.

For resources on independent living aids, etc. go to the website.
Thank you to Allan Perry from Thorpdale, Victoria, Australia for writing this article. statesmanhman@yahoo.com
Please advise us if you have further tips or challenges to be included in this information. info@cadasilfoundation.org

CAREGIVERS RESOURCES

There are two Resources for Spousal caregivers:

Many members of Well Spouse, though not all, are caring for people with protracted neurological ailments, from stroke to Parkinson's to the family of dementias. www.spouse.org

The other is the Frontotemporal Dementia Association resource for those struggling with this group of little-understood diseases. www.ftd-picks.org

Thank you to Neurology Now Magazine Jan/Feb 08

SOCIAL SECURITY DISABILITY BATTLE WITH CADASIL

Your web site assisted me in successfully pursuing a Social Security disability appeal for a client with CADASIL. After a two year battle, benefits were granted.

A donation was made to continue with your fine efforts. Please feel free to refer anyone who needs legal assistance with efforts to obtain social security. We need to educate the agency as to the debilitation problems this illness causes.

Edward M. Pulaski, Esquire, Law Offices, Hazelwood PA 570-501-8133

MEDICAL NEWS - INTERNATIONAL SOCIETY FOR VASCULAR BEHAVIOURAL AND COGNITIVE DISORDERS MEETING - REPORT FROM VASCOG 2007 MEETING HELD IN SAN ANTONIO, JULY 2007

Members and friends of the International Society for Vascular Behavioural and Cognitive Disorders (Vas-Cog) representing 41 countries, met in San Antonio, Texas, USA, for the Third Vas-Cog International Congress (July 11-14, 2007). The countries represented included Argentina, Australia, Austria, Bolivia, Brazil, Canada, Chile, China, Colombia, Croatia, Denmark, Finland, France, Germany, Hong Kong, India, Indonesia, Israel, Italy, Japan, Republic of Korea, Mexico, Netherlands, New Zealand, Nigeria, Norway, Poland, Portugal, Russian Federation, Serbia and Montenegro, Singapore, Spain, Sri Lanka, Sweden, Switzerland, Taiwan, Thailand, Trinidad and Tobago, United Kingdom, United States and Venezuela. The Vas-Cog society members expressed their concern with the worldwide declining support and lack of interest of Public Health services, scientific funding agencies, and pharmaceutical industry on the brain at risk from vascular disease and stroke including CADASIL.

Despite the fact that prevention and early treatment of vascular disease are widely available at reasonable cost almost all countries face the more expensive option of paying the costs of hospitalization, nursing home, and loss of labour and life resulting from stroke, heart disease and dementia as a consequence of untreated vascular risk factors. They also concluded that vascular dementia is the second-most common form of dementia in the elderly after Alzheimer's disease but very few trials are being conducted on the use of existing and developing therapies for this devastating condition. It is the hope of the members of this international scientific society that Governments around the world, scientific funding agencies, and the pharmaceutical industry will recognize the importance of this problem and implement Public Health and research programs for the prevention and treatment of the deleterious consequences of vascular injury to the brain.

With respect the CADASIL and related small vessel diseases of the brain the audience were informed that several initiatives are underway to understand the mechanisms of how brain vessels degenerate and produce migraines and strokes leading to loss of function. It was interesting to learn that numbers of small strokes is related to degree of decline. CADASIL patients worsen in older age such that daily living activities and memory may be affected. Memory deficits may be attributable to loss of cholinergic neurons in CADASIL patients. Therapies for improvement in CADASIL have been slow; however it is encouraging that results from the trial of the cholinesterase inhibitor Aricept showed some benefits in taking the medication. The trial showed that there were Aricept may improve executive functions.

Two other topics of high interest that may affect brain health are type 2 diabetes and adiposity. Type 2 diabetes is rapidly emerging as a global epidemic and challenge to the public health system. This type of diabetes is associated with large and small vessel complications, including large artery stroke, coronary heart disease, retinopathy, peripheral neuropathy and albuminuria. Diabetes may also be associated with derangements in amyloid-beta processing, which characterize Alzheimer's disease. These pathologies not only result from hyperglycemia, but also from the common diabetic co-morbidities of hyperinsulinemia, hypertension, and dyslipidemia. One of the sessions presented overviews on the epidemiologic research that supports the hypothesis that diabetes is a major risk factor for dementia, insulin action and glucose action in the brain. The participants learnt about the complex of mechanisms underlying the cerebral damage diabetes can directly or indirectly cause.

Adiposity may be a marker for mental health disorders in late life. A lower body mass index (BMI) among demented has been observed in cross-sectional studies, potentially due to a greater rate of BMI decline that occurs during the years immediately preceding dementia. However, high BMI may also increase risk for dementia when measured prior to clinical dementia onset, perhaps via vascular effects or via the bioactive hormonal compounds that are secreted by adipose tissue. Understanding the life course of adiposity is relevant for shaping prevention efforts to decrease risk for mental health disorders in late life.

Psychiatric disorders, such as dementia and depression are common in small vessel diseases of the brain such as CADASIL and elderly populations. After the age of 85, the prevalence of dementia is 30% and of depression 10%. Hypertension may be related to both these disorders, as it is a risk factor for both stroke and ischemic (stroke) white matter lesions, which are known to increase the risk for dementia and depression. Hypertension is also a risk factor for Alzheimer's disease. Participants were updated on the intriguing relationship between blood pressure and late-life psychiatric disorders (mainly dementia and depression), and its role in the pathogenesis and clinical manifestations of these disorders. The general message from the above discussions was that much of the consequences of vascular disease may be prevented by altering life style behaviours.

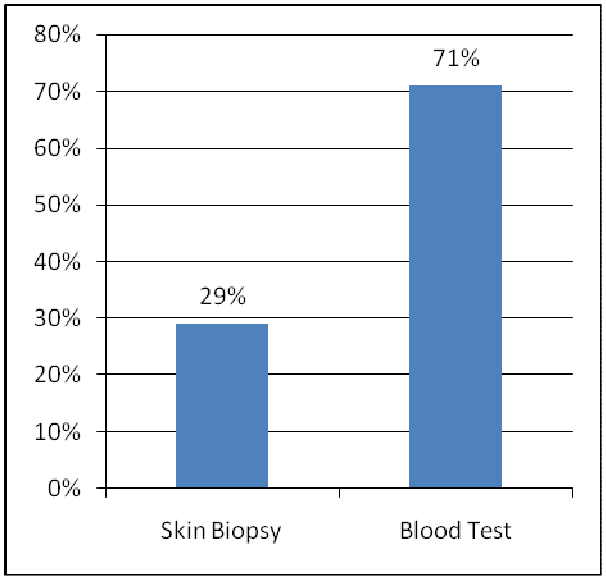
Submitted by: Professor Raja Kaleria, Professor of Cerebrovascular Pathology Institute for Ageing and Health, Wolfson Research Centre, Newcastle upon Tyne

Our CADASIL Registry

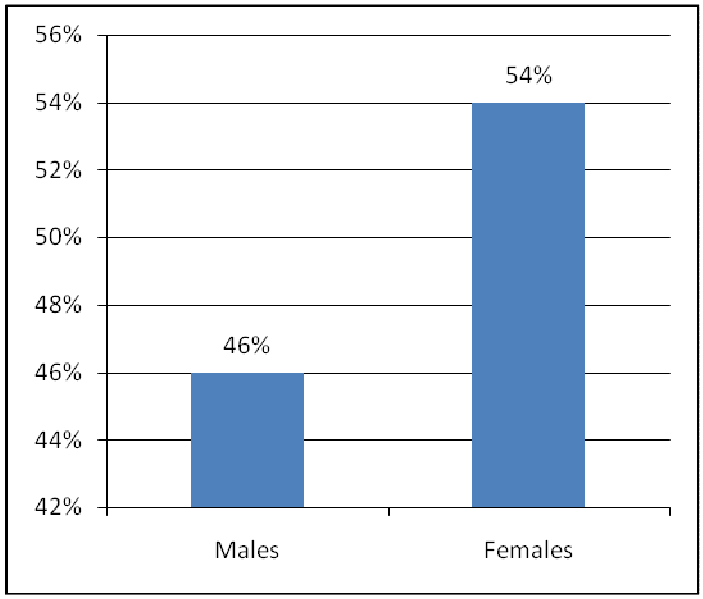
We have 836 confirmed cases worldwide. Average age of diagnosis 38 years old.

Our non-profit organization is the only one which holds the most comprehensive registry of affected individuals and families with CADASIL. Every number counts..... If you or someone in your family has CADASIL, please sign our registry and make your numbers known.

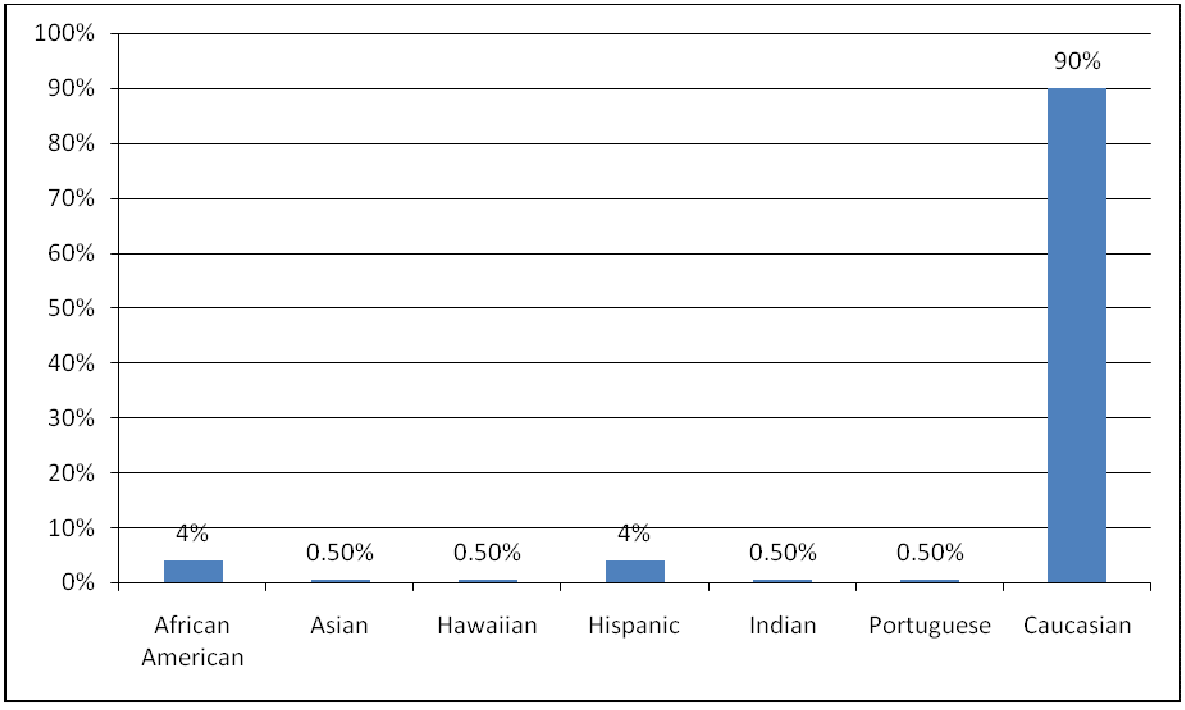
Testing



Sex



Ethnicity



YOU CAN HELP CADASIL TOGETHER WE HAVE HOPE AT NO COST TO YOU.

Below are Fundraiser which assists us 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).

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.

Scavenger Hunt at the American Museum of Natural History, In New York

Over 53 people attended the hunt and raised over $2,350.00 for the CADASIL TOGETHER WE HAVE HOPE.
A part of these funds were donated to research.

Thank you to Norma Howard for all her hard work and a big thank you for everyone who participated.

In loving memory of:

Duane Hoevenaar

Sharon Kirby

Ruth Northrop

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

3605 Monument Drive
Round Rock, Texas 78681

1-877-519-HOPE or
512-255-0209

E-MAIL:
info@cadasilfoundation.org

We're on the Web!
See us at
www.cadasilfoundation.org

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CADASIL Together We Have Hope is an all volunteer organization. We do not have any 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.

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