



CADASIL TOGETHER WE HAVE HOPE NON PROFIT ORGANIZATION

WWW.CADASILFOUNDATION.ORG

Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts & Leukoencephalopathy



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Inside this issue:

- Research 2
- Anniversary Thanks 3
- Rehabilitation Resource 3
- Letter from Billie 3
- Visitors to website 4
- Registry 4
- Cases all over the world 4
- In Loving Memory 5
- Exercise the Brain 5

Special point 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 fifth anniversary!

July 1997 - 13 years ago CADASIL Together We Have Hope website was created.

CADASIL FAMILY CONFERENCE IN THE USA THIS YEAR

The Foundation is pleased to announce the **first ever CADASIL Scientific Symposium and Family CADASIL Conference** to be held in the USA. It's tentatively scheduled to be held at the end of July 2010 in Illinois. CADASIL Together We Have Hope will be co-hosting the conference with the United Leukodystrophy Foundation (ULF).

Prior to the conference, a Scientific Symposium on CADASIL will be convened. The participants of this event will be a distinguished list of physicians and researchers from across the globe conversant with the disease.

To ensure the event's success, the Foundation is accepting donations for the symposium and to celebrate our 5th anniversary. Any donations received by CADASIL Together We Have Hope by July 1, 2010 will be designated for the symposium and family conference. Please consider making a donation today. One hundred percent of your tax deductible donations will go directly towards ensuring a successful event. Look for developing details on this website.

Mail donations to CTWHH, 3605 Monument Drive, Round Rock, Texas 78681 or we accept donations through PayPal. We are a Public Charity 501(3)(c)

LOCATING A DOCTOR

The CADASIL Together We Have 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 our 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.



CADASIL RESEARCH/STUDY BY NEW YORK UNIVERSITY SCHOOL OF MEDICINE

Is conducting a research study for patients with CADASIL. 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. Continued on next page

CADASIL STUDY continued from front page—

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.

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.

CADASIL/RESEARCH INFORMATION

Paris France website is now translated into English go to www.cervco.fr and click on the British flag at the top left hand corner. It has their referral center for rare vascular disorders of the brain, retina and information on CADASIL. Professor Hughes Chabriat, Paris France

New article published February 2010**Cerebrovascular dysfunction and microcirculation rarefaction precede white matter lesions in a mouse genetic model of cerebral ischemic small vessel disease**

please go to the website to read this article @ <http://www.jci.org/articles/view/39733>

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Our laboratory is still focused on CADASIL research. We are studying the vessels involved in CADASIL and identifying proteins which interact with Notch3 in hopes designing disease modifying strategies in the future. I want to express my great of appreciation for the patients and families who have made important contributions to research. Michael M Wang M.D., Ph.D. Assistant Professor Department of Neurology, Molecular & Integrative Physiology Ann Arbor, Michigan

ANNIVERSARY THANKS!

CADASIL Together We Have Hope Foundation extends an enormous thank you to the following dedicated physicians and researchers who serve on the Scientific Advisory Committee.

Hugues Chabriet MD, PhD, Professor of Neurology de Neurologie, Hôpital Lariboisiere, Paris, France

Dr. James Grotta, Professor Neurology, University of Texas, Director of the Stroke Program Houston, Texas

Raj Kalaria, Professor of Neuropathology at the University of Newcastle upon Tyne, UK and the Institute for Aging and Health, Newcastle General Hospital England

Dr. Stephen Salloway, Director of Neurology and Director of the Memory Disorders Program and Professor of Clinical Neurosciences and Psychiatry at Brown Medical School, Rhode Island

Swati A. Sathé, MD, MS, Assistant Professor, NYU School of Medicine. Department of Neurology, Division of Neurogenetics, New York, NY

Former member:

Gregory M. Pastores, Associate Professor of Departments of Neurology (Genetics) and Pediatrics, New York, NY

STATE VOCATIONAL REHABILITATION AGENCIES

Education Resource Organizations Directory Please go to ed.gov @ http://wdcrobcolp01.ed.gov/Programs/EROD/org_list.cfm?category_ID=SVR#W
U.S Department of Education (Promoting educational excellence for all Americans Coordinates and provides counseling, evaluation, and job placement services for people with disabilities.

The goals of these programs are to help people be more independent in their homes and improve quality of live where ever possible. In Texas, my husband and I have already had an initial consultation with a case manager who explain the process and reviewed our needs. Steve is waiting for an occupational therapist to come to house to evaluate what is needed for him to live more independent and help me. They provide services both for the patient and caregiver.

A LETTER FROM BILLIE

I am delighted about the upcoming conference, a dream in the works for over twelve years. When my husband Steve was diagnosed then with CADASIL, there was no hope, web resources, or support. As a result, I created the "CADASIL Together We Have Hope" website. Then in 2005, the Foundation was formed. Our database grows weekly, with over 1,000 confirmed cases.

My heart felt thanks to patients, families, friends, and medical professionals for making this dream come true. Special thanks to my husband, Steve for his confidence in me: I will not stop until we find a cure or treatment.

Sincerely,

Billie

Billie Duncan-Smith

"The world breaks everyone, and afterward, some are strong at the broken places." - Ernest Hemingway

WEBSITE AVERAGE VISTORS PER DAY

from EarthLink Urchin tracking program

APR 2009	78	OCT 2009	64
MAY 2009	59	NOV 2009	59
JUN 2009	62	DEC 2009	58
JUL 2009	72	JAN 2010	70
AUG 2009	63	FEB 2010	68
SEPT 2009	70	MAR 2010	56

OUR REGISTRY

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.

47 years old average age of diagnosis 58% Females 42% 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

1005 confirmed cases in March 2010

CONFIRMED CASES AS REPORTED TO THE FOUNDATION FROM ALL OVER THE WORLD

1	Argentina	12	Germany	4	Portugal
48	Australia	1	Greenland	2	Puerto Rico
53	Austria	1	Holland	1	Saudi Arabia
2	Belgium	2	Hungary	13	Scotland
13	Brazil	2	India	4	South Africa
76	Canada	13	Ireland	3	Spain
1	Central America	5	Italy	3	Sweden
1	Chile	1	Korea	1	Switzerland
1	Costa Rica	2	Lebanon	1	Turkey
1	Cypress	1	Mexico	11	Unknown
59	England	4	Netherlands	691	USA
1	Finland	8	New Zealand		
5	France	6	Norway		



IN LOVING MEMORY
with prayers and thoughts
for families and friends



B. Fog

S. Klostermann

Mr. Lindahl

W. C. Regula Sr.

F. Tattleman

TOP 10 SIMPLE TRICKS TO EXERCISE YOUR BRIAN

By Mark Stibich, Ph.D.

Your brain's fitness depends on how much it is used. Every time you do something new or different, you create new neural pathways. These simple tricks will help give your brain a workout.

1. Use Your Opposite Hand

Spend the day doing things with your non-dominant hand. If you are left-handed, open doors with your right hand. If you are right-handed, try using your keys with your left. This simple task will cause your brain to lay down some new pathways and re-think daily tasks. Wear your watch on the opposite hand to remind you to switch.

2. Only Use Lists as Backup

Lists are great, but we can become too reliant on them. Make your grocery list, but then try to shop without it. Use the list once you have put every item you can think of in your cart. Do the same with your "to do" lists.

3. Learn Phone Numbers

Our modern phones remember every number that calls them. No one memorizes phone numbers anymore, but it is a great memory skills. Learn a new phone number every day.

4. Prepare One Story Every Day

Each morning think up one story that you will have ready to tell people. The story can be about something recent or from your past. Try to figure out the most entertaining way to tell the story. If someone calls or stops by, you will have something to talk with them about. It will make you more interesting while exercising your memory.

5. Observation Games

Each day pick a specific thing to observe. You may decide to pay attention to what people are wearing one day. Everywhere you go, and on TV, note how people dress and think about why certain people dress the way they do. Give your brain something to think about. The next day, choose something else to observe.

6. Go a Different Way

Drive or walk a different way to wherever you go. This little change in routine helps the brain practice special memory and directions. Try different side streets, go through stores in a different order -- anything to change your route.

7. Break the Routine

Do thing in a different order. Eat breakfast for dinner. Do your errands first thing in the morning. Drink coffee in the afternoon. Do your daily tasks in a new order. Notice how the change feels and what is good or bad about the new order.

8. Solve a Problem

Pretend you are starting a business and think about how you would solve a problem. What would you sell and to whom would you sell it? Who are your competitors and how would you beat them? Give your brain something to chew on. The next day, pretend your are starting an organization to fight hunger -- what new ideas can you come up with? Have fun with problem solving to make new connections in the brain.

9. Make Lists

Lists are wonderful. Making lists helps us to associate items with one another. Make a list of all the places you have travelled. Make a list of the most disgusting foods you have eaten. Make a list of the best presents you have been given. Make one list every day to jog your memory and make new connections.

10. Read a Book

Pick a book on an entirely new subject. Read a novel set in India. Learn about economics. There are many excellent popular non-fiction books that do a great job entertaining you while teaching about a subject.

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