

# CADASIL SUPPORT GROUP NEWSLETTER

CADASIL - Cerebral autosomal dominant arteriopathy with sub cortical infarctions and leukoencephalopathy.

<http://home.earthlink.net/~cadasil/>  
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CADASIL is a diffuse disease of small arteries predominating in the brain. It starts during mid adulthood and is characterized by recurrent ischemic events (transient or permanent), attacks of migraine with aura, severe mood disorders, and sub cortical dementia and, at MRI, and a white spread leukoencephalopathy.

Please copy this newsletter out and give or mail to your doctors or anyone who is in the medical professionals, family and friends so hopefully one day their will be a cure for CADASIL.

## A NEW CHAPTER IN CADASIL

This is more than I could wish for. I feel like I am in a movie and waiting for someone to tell me cut, its over. Last Month, January 2005, I had the opportunity to attend the CADASIL Awareness Conference/symposium (First of its kind in the World)

10 years ago, when I started to research CADASIL, how I wished something would happen to make others be aware of CADASIL, which included a treatment or cure. I have been an advocate all the way. Telling everyone to be there own case managers and suggesting to print out the information from this website and inform your doctors or who would listen. I receive e-mails from doctors, patients, family members, etc. The worldwide support of the website has been unbelievable and no words could express the appreciation to everyone who

has ever gone to this site.  
(<http://home.earthlink.net/~cadasil/>)

Jack Shields who is a CADASIL sufferer he had a vision like me. Jack had organized the first ever CADASIL AWARENESS CONFERENCE/SYPOSIUM in Newcastle Upon Tyne at the International Center for Life On short notice, within 3 days, I flew to England on Wednesday, January 19, 2005. Jack and me did not stop working on the first ever CADASIL Research and Trust. More information from the conference/symposium will be published on this website and on the new website for the CADASIL Research and Trust.

## Summary of the conference/symposium:

Friday, January 21<sup>st</sup>, 2005 was the day of the conference/symposium. When I first walked into the building, on the door was a sign CADASIL AWARENESS CONFERENCE . I took a picture of the sign on the door as, I said to myself, this is finally happening, it's about time, as CADASIL if getting the support it needs. This was the right direction towards having CADASIL known worldwide through awareness of this disease. An office for the CADASIL Trust has been established at the International Center for life. Nick Athy is the office manger.

The first every CADASIL Research and Support Trust was announced at the beginning of the conference/symposium. Jack Shields is the managing director of the trust . Heart specialist,

Colin Doig is a trustee and the honorable MP Alan Beith from the House of Commons as patron.

## The agenda was as follows:

- Registration and coffee
- Introduction: Professor R. Kalaria
- Welcome: Professor John Goddard, Deputy Vice-Chancellor, University of Newcastle  
Professor Jim Edwardson, Director, Institute for Ageing and Health  
Patron: Right Honorable Alan Beith MP, House of Commons London
- Launch of the CADASIL Trust, International
- Tea Break
- Sessions: Clinical, Genetic and Pathological aspects of CADASIL
- Clinical Studies in CADASIL: Professor Hugh Marcus, London, England
- Genetics of CADASIL: Dr. Martin Dichgans, Munich, Germany
- Patient's personal account: John Shields, Northumberland how he is using a treatment that has stopped his migraines with aura for over 20 months now.
- Panel Discussion: Speakers and audience

- Wine and Cheese Reception
- Buffet Dinner (by invitation)

I talked with Doctors, Professors, Scientist, CADASIL patients, families of patients, etc. (Little o'le me from Texas). The conference/symposium was wonderful. Everyone knew of or had heard of my name, Billie, through my website. I was amazed, how one person could be known so much by so many.

I met at least 3 families that I have been e-mailing and assisted them in the beginning with CADASIL. One sufferer I e-mailed personally the week before the conference/symposium, without knowing I was going, and the gentleman came with his sister and could not believe I was there. I met two daughters, their mother a CADASIL sufferer whose father was an advocate for his wife and contacted me about eight years to find out what to do. It is a small world after all. During the evening meal, at the same table, I sat with the above families, Jack and Joan Shields family and a doctor from Germany. At the conference/symposium I found out the study which was posted on my website for "USA" only is not for USA. Dr. Martin Dichgans was the doctor who has involved the world on this study. Martin Dichgans who got interested with CADASIL right after Medical School and has not stopped since. Dr. Dichgans wants everyone to be encouraged to do the study on a drug for short-term memory loss. If you or one of your family members has CADASIL with short-term memory loss, please go to the page with the country you are from and contact them immediately. I had another volunteer to write articles on CADASIL to post on website. I couldn't eat as I was so excited to meet everyone and felt how honored to be there.

These are quick points from the conference/symposium, which I wrote down-

- Confirmed skin biopsy – specificity 100% correct
- LUCUNAR strokes – If you have genetic history of strokes, that if you smoke you increase your chance of having a stroke 10 years earlier than you should.
- Vascular Dementia study for cognitive impairments in CADASIL – Study of a drug for short-term memory loss is beginning in USA, Scotland, Japan, etc.
- Thrombolysis treatment not recommended
- CADASIL – onset average male 37 years old and average female 43 years old (5 to 6 years difference in gender)
- Cadasil is caused by notch 3
- Very unusually put patient can have CADASIL comma
- Embryo development in mice being studied
- What to do if patient has stroke - depends on servility of stroke, was suggested after stroke CAT scan should be done to see difference from one CAT scan to other.
- Eyes are effected with CADASIL patients as behind the eye you can have hardening of arteries

Jack Shields has worked very hard to establish the first ever CADASIL Research and Support Trust. He was done superb work on having established this trust and making CADASIL aware. This will be worldwide/international not only for UK. Jack has a son who will be

establishing the international website which I encourage everyone to join as this will have more impact than my website. It will have surveys, etc.

Before leaving, Jack and I plan to have video conferencing set up and keep closely in contact. This is the first (charity) Trust of its kind in the world. It is the result of Jack Shield's of three year battle with CADASIL, who decided to devote the rest of his days to helping other sufferers after finding there was so little help around except for my website.

Jack Shields is a retired chemical scientist and business owner, he decided to look at CADASIL and realized that he wanted to do anything to help CADASIL patients and families. He had to keep himself alive. He has been using a self-treatment for 20 months now. He has forged a partnership with stem cell research specialist Dr. Miodrag Stokjovic of Newcastle Life Sciences Center. I personally have met Dr. Miodrag Stokjovic and his wife who are supporting the treatment. I look forward to long-term contact with Dr. Miodrag, as he could be a great asset for all CADASIL patients. Dr. Miodrag did not have a clue about CADASIL until Jack had introduced him to this awful disease. Jack wants to encourage others with a treatment that has stopped his mini-strokes and migraines as he has done so for the last 20 months. This product is all natural and Jack has documentation on the study he did himself.

Jack is a Maverick just like me as his wife explained. It was so great to talk with Joan in person and others at the conference about CADASIL and what affects it has on everyone.

INTERNATIONAL CADASIL  
RESEARCH AND SUPPORT TRUST  
Registration Date: January 18<sup>th</sup>, 2005

**Objectives:**

To promote the relief of persons suffering from Cerebral Autosomal dominant Arteropathy with Subcortical infarcts and leukoencephalopathy. (An inherited condition with lead to blood vessels which are know to result in strokes and other changes to the brain and which is known as CADASIL) in such ways as the trust shall from time to time fit including with out limitation:

1. By conducting, promoting and encouraging research for the benefit of the public into the cause, management and cure of CADASIL and if considered appropriate by the directors of related condition and to disseminate the results of any such research
2. By establishing, maintaining and promoting the establishment of a international website (or any other appropriate medium of communication) to disseminate for the benefit of the public the latest authoritative technical information on diagnostic methods, research and evaluated clinical methods of treatment for any condition affecting person suffering from CADASIL.
3. By establish, maintaining or including, or by promoting or encouraging the establishment, maintenance and conduct of facilities for treatment, care, support or alleviation of symptoms of persons suffering from CADASIL.

Area of Operation: Worldwide – trust/charity operates inside and outside the United Kingdom.

If you would like to contact the trust please e-mail [contactus@cadasiltrust.org](mailto:contactus@cadasiltrust.org)



**Website:** <http://cadasiltrust.org/>

Online e-mail groups-

The purposes of these sites are to correspond with others who suffer from CADASIL or family and friends. Please remember if you post a message to either one of the groups will be seen by the members of the whole group.

Yahoo Groups was started in August 1999 by a CADASIL sufferer Dorene Nate. At present it has 161 members -  
<http://health.groups.yahoo.com/group/CADASIL/>

This message boards' intentions are to bring together friends and family of CADASIL, Cancer, stroke, Alzheimer's, dementia patients. At present it has 35 members - ezboard.com

**New Survey: PLEASE HELP!**

I am presently gather information on how many patients are diagnosed with CADASIL around the world. Please e-mail me at

[Cadasil@earthlink.net](mailto:Cadasil@earthlink.net) with the following:

male/female

age

area (city, state or county)

country

your initials – this way I won't duplicate the information AND if your doctor knows anything about CADASIL e-mail me his/her

name and phone number all this information will be kept confidential.

If you do not have access to a computer please call me at 512-255-0209. Please remember together we have hope!

**CADASIL STUDY - ONLY FOR PATIENTS WITH SHORT TERM MEMORY LOSS**

The purpose of this study is to determine the safety, tolerability and effectiveness, and side effects of an investigation drug compared to that of placebo in the treatment of subjects with mental decline associated with CADASIL.

Patients with CADASIL, who are between the age of 25 and 70 years, and have cognitive impairment are eligible to participate.

**USA** - The study will take place over 18-weeks .If your a patient or their relatives are interested in further details or possibly enrolling in the study, they may contact us by phone: (212) 263-8344, fax (212) 263-8310, or e-mail: [gregory.pastores@med.nyu.edu](mailto:gregory.pastores@med.nyu.edu)

Dr. Pastores called me to see if anyone would be interested in the study - I told him the Website Logo "TOGETHER WE HAVE HOPE" This is wonderful news - but remember only contact him if you have short term memory loss.

**ENGLAND** - CADASIL patients with short term memory loss at St George's Hospital Medical School in London, England will be under way soon.

The purpose of this study is to determine the safety, tolerability and effectiveness, and side effects of an investigation drug in the study of subjects with mental decline associated with CADASIL.

you will need:

1. Mutation proven CADASIL
2. Some cognitive symptoms
3. Referral from their family or hospital doctor.
4. Be able to attend our hospital in London

Any queries contact  
Professor Hugh Markus,  
Division of Clinical Neuroscience  
St George's Hospital Medical School  
Cranmer Terrace  
SW17 0RE

Tel: 020 8672 9944  
or e-mail: [hmarkus@sghms.ac.uk](mailto:hmarkus@sghms.ac.uk)

**Please Remember:** Copy this newsletter and give or mail it to your doctors or anyone who is in the medical professionals so hopefully one day their will be a cure for CADASIL.

**This newsletter is to help others and assist doctors.. I do not want to mislead anyone. I am looking for HOPE, link to others with CADASIL, find out as much about this disease as possible and hopefully a cure one day. I am not in the medical field or claim to be a professional on CADASIL.**

This newsletter goes out to people in America, England, Scotland, Sweden, France, Chile and Australia. If you know of anyone who is interested in this newsletter, please photo copy it, and pass it on. Also, contact me so we can add their name on the email lists or mailing address..

Please e-mail your updates on your progress with CADASIL. Also, if you would like to tell your story (we can leave out your names) please send this to me. It seems to help to tell others.

This is how I cope with my husbands illness. When produce these newsletters I sit at the computer and sometimes cry but it does seem to help the stress.

If anyone can help to clarify anything dealing with CADASIL, please let me know or provide any advise or help, please let me know.

### **What tests are done for CADASIL** MRI

A magnetic resonance scan (MRI) is usually performed and shows characteristic appearances with abnormalities in the deeper parts of the brain or white matter. This is a safe scan that involves no radiation but some people find it rather claustrophobic. This scan may be repeated to determine whether the disease is progressing.

Skin Biopsy  
CADASIL results in characteristic changes in the blood vessels. For obvious reasons we are unable to look at the blood vessels within the brain. However, even though CADASIL itself only produces symptoms within the brain, abnormalities within the blood vessels can frequently be seen elsewhere in the body. The easiest way to look for these is in the skin. A very small skin biopsy is easily performed under local anesthetic. It is important this is processed in a special way allowing it to be looked at under high magnification using an electron microscope. Under this magnification, one can frequently see abnormal collections of material, which we call GOM (granular osmiophilic material) as shown by the arrows in the figures. If these GOM are present we can be almost certain that the individual does have CADASIL.

I developed a web site for CADASIL in 1996 in hopes I could help others and find out more about this disease. The response has been fantastic. This went from helping others to a support group link. No words could express the

amount of thanks to everyone who has contributed to the web site and newsletters.  
<http://home.earthlink.net/~cadasil>.

Please remember "YOU ARE NOT ALONE  
AND TOGETHER WE DO HAVE HOPE"

Thank you for reading this newsletter.

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