

## CADASIL TOGETHER WE HAVE HOPE

### November 2nd, 2011 - Updates



Our website has an update section on the front page. We will immediately post information as it becomes available. Please check this section of the website each month for updates.

#### **November is Family Health History Month**

Collect your family's medical history and share it with your doctor at your next visit. With a detailed family medical history, a doctor can evaluate all of the factors that may affect your risk of some diseases and can recommend ways to reduce that risk.

The Surgeon General has provided a free tool "My Family Health Portrait Tool." <https://familyhistory.hhs.gov/fhh-web/home.action>. Enter your family's health history and share it with your family and your health care provider. Save the family health history so you can update it over time as talking about your history with your health care provider can help you better manage your health.

The CDC offers tips, on this podcast: <http://www.cdc.gov/Features/FamilyHistory/>

Other resources include:

A guide to family health history and a guide to genetics and health:

[http://www.geneticalliance.org/sites/default/files/ksc\\_assets/tools/book1ga\\_11022309.pdf](http://www.geneticalliance.org/sites/default/files/ksc_assets/tools/book1ga_11022309.pdf)

[http://www.geneticalliance.org/sites/default/files/ksc\\_assets/pdfs/Book2.GA\\_lowlitFHHT.pdf](http://www.geneticalliance.org/sites/default/files/ksc_assets/pdfs/Book2.GA_lowlitFHHT.pdf)

#### **To Assist Researchers and the Medical Professionals**

Please click on this link

<http://home.earthlink.net/~cadasil101/tracking/>

to provide your mutation (if you know it) and to update your current information on the registry. Remember, we respect your privacy and will not release your personal information to anyone. We are here for you!

#### **Do you wish to help others?**

Please e-mail us your experience with CADASIL. You do not need to provide your name in the article as we will be glad to use your initials.

We are **currently looking for** a French translator to assist us with CADASIL documents. Please let us know if you can lend a hand with this valuable service.

This month we are starting an **Awareness Campaign of educating medical school students** on CADASIL. As you are aware, it is difficult to locate doctors who know about CADASIL. A key solution to this problem is to educate medical students, particularly those in the field of neurology. If you wish to assist in this endeavor, please e-mail us the name and address of the medical school in your state or province as well as the name of any known contact person so we may send them the CADASIL Brochure. If you wish, we'd be glad to send you the materials so you may deliver them and offer that personal touch. Over 50 recent e-mail contacts (with many positive responses) have been made in this effort to educate medical students. Let's work together to educate medical students worldwide on CADASIL.

We were recently contacted by a person who is going through testing for CADASIL who told us the **American Stroke Association** gave her our telephone number. Their referral is awesome news and a credit to the awareness campaign CTWHH ran in 2006 asking patients and families to register with the American Stroke Association to highlight the existence of CADASIL. Developing and nurturing relationships as well as working collegially with various CADASIL organizations, doctors, researchers, and groups are things CTWHH holds dear. It's an honor to include the American Stroke Association to the list that recognizes our efforts.

### **Medicines and Procedures to Avoid**

It is important to tell the doctors you have CADASIL so that certain treatments or tests can be avoided. Thrombolytic and anticoagulant treatments, vasoconstricting medicines (issued from rye ergot or from Triptan) and products aimed at unblocking blood vessels (which is sometimes given after a stroke in CADASIL patients) are strongly inadvisable as there's a risk of bleeding in the brain. Likewise, cerebral conventional angiographies (examination which show blood flow through the arteries in the brain) should be avoided because they may cause a migraine which, in some cases, is very serious. Finally, you must tell the medical teams about current medications and the corresponding doses. This is a precaution so as to avoid the combinations of incompatible medication and any risk of overdose.

### **Visits to the CTWHH website:**

7,226 visitors so far in 2011

8,619 visitors in 2010

Thank you to everyone who has volunteered in the efforts to raise awareness.

Billie, Debby and Kalletta (Board of Directors)

CADASILtogether We Have Hope Non-Profit Organization

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Public Charity 501(c)(3)

