

CADASIL Together We Have Hope Update – April 9, 2011

DO YOU KNOW HOW TO PRONOUNCE

Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts And Leukoencephalopathy?

We have a new video, [How to pronounce the full name for CADASIL - 2011](http://www.youtube.com/watch?v=n-dbdlt6lQ8) <http://www.youtube.com/watch?v=n-dbdlt6lQ8>

THE CADASIL REGISTRY NEEDS YOUR UPDATE. Please remember we do not share personal information with anyone. Thank you for helping by either updating your registry information or signing the registry if you haven't already.

To update your information: <http://home.earthlink.net/~cadasil101/tracking/>

If you have not yet completed the registry: <http://home.earthlink.net/~cadasil101/>

CANADIAN SURVEY/STUDY RESULTS. Thank you those of you who had participated in this survey.

<http://cadasilfoundation.net/Canadian%20CADASIL%20Survey%20Study%20Results%20-%20April%202011.pdf>

CADASIL FRANCE

I have been honored to be asked to link CADASIL France Association www.cadasil.com to our website. At the 2010 conference the foundation was also honored to link Cervo, Paris France <http://www.cervco.fr/pages/accueil.en.htm> to our website. Cervo is a reference centre for rare vascular diseases of the central **nervous system and the retina**. **Both websites have English translator for your convenience.**

CADASIL FUNDRAISER - JUNE 11, 2011- CADASIL Motorcycle Ride/Rally, Silent Auction, Spaghetti Dinner and Night Entertainment Fundraiser for the foundation. Thank you in advance to the Event Co-ordinator Bob Leslie and sponsors are: Hitching Post Motorsports, St. Paul, MN and South Saint Paul VFW Post 295, St. Paul, MN 55075. If you can't make this event, you can still make a donation on-line. www.cadasilrally.org

CADASIL WRISTBANDS FUNDRAISER

<http://cadasilfoundation.net/WRISTBANDS%202011.pdf>

UPDATED EDUCATIONAL MATERIALS

CADASIL Fact sheet: <http://cadasilfoundation.net/CADASIL%20FACT%20SHEET%202011.pdf>

CADASIL Definition Sheet <http://cadasilfoundation.net/CADASIL%20Definition%20Sheet%20.pdf>

EMERGENCY CARD

Don't forget about the emergency card for your purse, wallet and/or glove compartment. This card will inform the E.R. and medical community about CADASIL and the importance of not treating a stroke with anticoagulant treatments/products aimed at unblocking blood vessels as they increase the risk of a hemorrhage

<http://cadasilfoundation.net/2010%20Emergency%20Card.pdf>

LIKE YOUR DOCTOR

If you don't see your doctor listed on the physician's locator on the website and you think others would benefit from their expertise. Please complete this quick form so we can add them: <http://home.earthlink.net/~cadasil101/mag/>

SHARE YOUR EXPERIENCE

If you would like to write an article on how you or a family member copes with CADASIL, we are looking for up to date stories for the website. You do not have to use your name if you do not want to, just use your initial. This is a wonderful support for others.

E-mail us your article at info@cadasilfoundation.org