Envision the Cure and Embrace the Challenge

Announcing new webinar

Just released is a recorded webinar by CADASIL expert Saskia A.J. Lesnik Oberstein, MD, PhD of Leiden University Medical Center in the Netherlands.

Presentation title: CADASIL and NOTCH3: genotyping, phenotyping and exon skipping

Learn more about research in the Netherlands here

Webinars Highlight Research

Did you know there are five CADASIL Connection research webinar recordings available for viewing on the cureCADASIL website? Each webinar is a unique topic given by a physician or researcher in the CADASIL field. We hope you enjoy these webinars and share with your care providers!

cureCADASIL Family Registry

The CADASIL Family Registry has grown from 100 participants in 2015 to almost 300 today!

Have you updated your surveys since you joined? The Registry has a new website and the ability to update your surveys. It’s important to update your General Health and Medical Care survey once per year to ensure your health status is up to date.

Thank You to the Carney Family
The Invitae/cureCADASIL Registry Team is implementing reminder emails to remind you again next year! Look for emails from coordinator@pin.invitae.com.

Thank you to the Carney Family for their SUCCESSFUL fundraiser! They hosted an amazing weekend of events in Cedar Falls, Iowa. One unique event was a car shine and show that included riding in a car of your choice with a donation!

We cannot express our gratitude enough!

What about my genetic information?
The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment. Learn more here.

Consider sharing your story to increase awareness and to potentially help many others cope as they become diagnosed or at hereditary risk for CADASIL.

Specific ICD-10-CM code for CADASIL, effective October 1, 2018

If you have not yet heard, read our press release on the new ICD-10-CM code for CADASIL that will become effective October 1, 2018 in the United States.

This could not have been possible without Dr. Swati Sathe, cureCADASIL Scientific Advisory Board member, hours of dedication from cureCADASIL volunteers, and 100s of letters of support from CADASIL families, doctors, researchers
Thank you!
Additional information is also available on the cureCADASIL website.