Envision the Cure - Embrace the Challenge

CADASIL Awareness Day was Nov 16!

Appreciate everyone in the community who supported this and past CADASIL Awareness Days. It is never too late to spread awareness, contact us about sharing cureCADASIL's 30 second Public Service Announcement with your local TV station, or have a family member join our mailing list. Spread awareness of CADASIL however you can throughout the month of November!

Pictured (top to bottom): Mills Family; Kennedy Family with US State Representatives

CADASIL at the Rare Disease Innovation and Partnering Summit

cureCADASIL partnered with Geisinger Health System to present on the ClinGen Data Sharing Program at the Rare Disease Innovation and Partnering Summit in Boston, MA on June 14, 2019. See the presentation on our website.

Patient data sharing of genetic test results is pushing the needle forward on research for rare genetic diseases like CADASIL!

Pictured (left to right): Juliann Savatt, MS, LGC and Sandra Talbird, MS

Have you always had questions regarding the genetics of CADASIL? Now is your chance to learn first hand from an experienced clinical geneticist!

Two CADASIL care webcasts are now available, explaining how changes in NOTCH3 impact health for families with CADASIL.
cureCADASIL Trustee, Jane Gunther attended the Global Genes Rare Patient Advocacy Summit in San Diego, CA September 18, 2019 and the Rare Entrepreneur Bootcamp prior to the Summit September 17, 2019

Thanks to amazing volunteers, donors and participants on Team CADASIL the 2019 Million Dollar Bike Ride event raised $51,000 for CADASIL research. These funds were matched by $30,000 from the Penn Medicine Orphan Disease Center (ODC) which was established to promote the development of therapies across a broad range of orphan diseases.

A grant for CADASIL research is being offered through the ODC for $81,000! Amazing impact on research by the CADASIL patient community! http://orphandiseasecenter.med.upenn.edu/million-dollar-bike-ride

The CADASIL research grant awardee will be announced by the end of the year.
Did you know there are currently 3 CADASIL studies in the US to join?

- A study at University of California at San Francisco (UCSF) developing novel neuroimaging and serological biomarkers to improve early detection and diagnosis of cerebrovascular disease including CADASIL
- A study at Mayo Clinic at Jacksonville, FL and now University of Utah assessing the cause of headaches or migraines among CADASIL patients
- ClinGen Data Sharing Program, an online study through Geisinger Health System, collecting NOTCH3 mutation data from your CADAIL genetic test to share in public databases

Patient shares her story for awareness

CADASIL patient actively sharing her journey to spread awareness and help others diagnosed with this rare disease. Read more about Barbara on our website.

cureCADASIL | info@cureCADASIL.org | Website

STAY CONNECTED