Envision the Cure - Embrace the Challenge

Save the Date!
cureCADASIL and the American Society for Neural Therapy and Repair (ASNTR) are co-hosting a series of webinars on recent CADASIL research. Reminder to join us tomorrow Wednesday, April 21, 2021 at 12 pm (noon ET)!

If you can't join live, the webinar will be recorded and available at cureCADASIL.org.

Dr. Fabrice Dabertrand will present his CADASIL study funded in part by the 2019 Million Dollar Bike Ride grant made possible by donations from CADASIL patients, families, physicians, and researchers, in partnership with cureCADASIL and Penn Medicine Orphan Disease Center.

Dr. Dabertrand, Associate Professor at the University of Colorado Anschutz Medical Campus, provided this summary of his research study: "Years before the emergence of strokes or mental decline, patients with CADASIL show a deterioration in the brain’s ability to increase blood flow in response to appropriate signals from the nervous system. Using a genetic mouse model of CADASIL, we determined the abnormality to be in cells lining the smallest blood vessels, or capillaries. We found that CADASIL is associated with reduced production of a lipid (PIP2). This prevents the cells lining capillaries from sensing brain activity and causing small arteries upstream to relax and increase blood flow locally. We found that injection into the blood stream of PIP2 corrects this the problem in CADASIL mice and restores blood flow to the brain in response to neuron activation."

Register at the link below to join the free, live webinar!

Register

Million Dollar Bike Ride for Rare Disease Research
cureCADASIL is thrilled to have Team CADASIL participating in the 2021 8th Annual Million Dollar Bike Ride for the 3rd year in a row!

Our goal is to raise $50,000 this year and we need your help! All funds go to CADASIL research and UPenn Med will match dollar-to-dollar up to $30,000! Donate Today and share with friends and family this amazing opportunity to support CADASIL research.

Limited Time! Team CADASIL t-shirts for the 2021 Million Dollar bike ride!

Buy T-shirt Now!

COVID Study

Some of you participated in a National Institutes of Health (NIH) research study, “COVID in Communities.” The results are out for the survey that will help NIH better understand how COVID-19 affects different health communities. The survey was conducted starting in October 2020 with 1,500 people representing rare and common conditions, including CADASIL.

A follow-up survey is planned in coming months to build on these initial findings. More information is available by emailing COVIDincommunities@nhlbi.nih.gov

COVID in Communities

Thank you for being a part of our COVID in Communities survey!

Our team greatly appreciates your time and willingness to fill out the survey. Your responses to the survey will help us better understand how COVID-19 affects different health communities.

Our first survey was open for two months, starting in October 2020. We were able to collect responses from over 1,500 people representing the following rare and common conditions:

Aplastic anemia, Ataxia Telangiectasia syndrome (ATS), Bronchiectasis, non-CF, CADASIL, rare genetic eye conditions, Familial cancer syndromes (Li-Fraumeni, Hereditary Non-Polyposis Colorectal Disease), hereditary bone marrow failure syndromes, iiea immune deficiency syndromes, Lowe-Deiters syndrome, Marfan syndrome, Neurofibromatosis, Non-syndromic arthrogryposis, Pseudoachondroplasia, Sex chromosome number abnormalities, Williams syndrome, X-linked ichthyosis, and those without a rare disease

Extra thank you to the members of the Williams syndrome, Neurofibromatosis, and Rare Genetic Eye conditions’ communities for returning the highest number of surveys. We appreciate your help with this important research!

For questions or comments, email COVIDinCommunities@nhlbi.nih.gov

CADASIL Family Registry

Our Family Registry has over 400 CADASIL patients worldwide!
The CADASIL Family Registry is unique in that it gives all stakeholders, including researchers, physicians, pharmaceutical partners, patients, and family members a better understanding of CADASIL. By joining the registry and completing the health surveys online, you can increase understanding of CADASIL, such as the type of prescription medications CADASIL patients take, and improve the lives of those living with CADASIL.

Researchers can contact registry@curecadasil.org to learn more.