

## Envision the Cure - Embrace the Challenge



“Restoring Cerebral Blood Flow in a CADASIL Model”

April 21, 2021, 12 p.m. ET, at your computer

Register here <https://attendee.gotowebinar.com/register/465948153137952014>

<http://www.curecadasil.org/cadasil-connection-speaker-series-webinar/>

Our speaker: Fabrice Dabertrand, Ph.D.

Associate Professor, School of Medicine

University of Colorado | Anschutz Medical Campus

Sponsored by cureCADASIL and the American Society for Neural Therapy and Repair

[www.cureCADASIL.org](http://www.cureCADASIL.org) [www.ASNTR.org](http://www.ASNTR.org)



### 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](http://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 (PIP<sub>2</sub>). 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 PIP<sub>2</sub> 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

## EMBRACE THE CHALLENGE. RIDE FOR A CURE.

Million Dollar Bike Ride · Virtual · 6/12/21  
Participate or Donate TODAY!



TEAM  
**CADASIL**



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](mailto:COVIDincommunities@nhlbi.nih.gov)

## COVID in Communities NIH Spring 2021 Newsletter

This collaboration is led by NIH scientists: Dr. Beth Koziel (NHLBI), Dr. Robert Hufnagel (NEI), and Dr. Tiffany Powell-Wiley (NHLBI) in collaboration with many NIH physicians/researchers and community groups.

### 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, Arterial Tortuosity Syndrome (ATS), Bronchiectasis, non-CF, CADASIL, Rare genetic eye conditions, Familial cancer syndromes (DICER1, Melanoma, Li-Fraumeni), Fragile X, g6PD deficiency, Hermansky-Pudlak Syndrome, Inherited bone marrow failure syndromes, rare immune deficiency syndromes, Loews-Dietz syndrome, Marfan syndrome, Neurofibromatosis, Non-syndromic aortopathy, Psoriasis, Sex chromosome number variation, Sickle cell disease, vascular Ehlers-Danlos syndrome, Williams syndrome, 22q11.2 deletion/duplication syndromes, and those without a rare disease

### Our early findings:

- COVID-19 frequency did not appear to be higher in any of the communities surveyed (average frequency 3.7%)
- Less than ten participants (0.4% of people surveyed) needed hospital or intensive care for COVID-19
- No disease community reported more than one member needing hospitalization for COVID-19
- No COVID-19 related deaths were reported in any of the disease communities surveyed
- *A follow-up survey is planned in the coming months to build on these initial findings*

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](mailto:COVIDinCommunities@nhlbi.nih.gov)

Image credit: NIAID-RML

## CADASIL Family Registry

Our Family Registry has over 400 CADASIL patients worldwide!

**PIN PARTICIPANTS**

Participant Map

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**SAVED FILTERS**

No filter published

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**COMPLETED SURVEYS**

- + Diagnosis
- + General Health
- + Family History
- + Medical Care Survey

# Participant Map

Navigate the map to view geographic distribution of PIN participants.

View by: Diagnosis

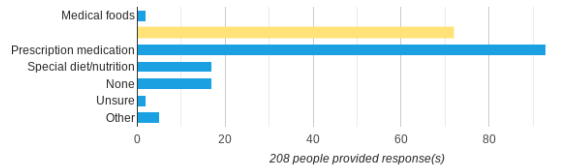


## About Survey Data

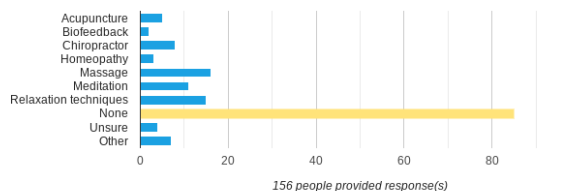
The [CADASIL Family Registry](#) is unique in that it gives all stakeholders, including researchers, physicians, pharmaceutical partners, patients, and family members a better understanding of CADASIL. By joining the registry and completing the health surveys online, you can increase understanding of 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](mailto:registry@curecadasil.org) to learn more.

Which of the following type of treatments does the participant use for the condition? (Select all that apply.)



Which of the following alternative therapies are currently used? (Select all that apply.)



[Join Registry](#)

cureCADASIL | [info@cureCADASIL.org](mailto:info@cureCADASIL.org) | [Website](#)

STAY CONNECTED

