Rare Disease and the Coronavirus Pandemic

The NIH is interested in how COVID-19 is affecting people with CADASIL. The survey is 30 minutes long and is for individuals with CADASIL who either have or have not had COVID-19. To participate before the study ends on Oct 31, please visit:

https://redcap.link/covid_in_communities

The survey is in both English and Spanish. If other languages are needed, please email COVIDinCommunities@nhlbi.nih.gov. Additional information about this rare disease study can be found on the NIH website. Dr. Kozel and her team hope to have 500 CADASIL participants!

Million Dollar Bike Ride 2020 results in $82,000 CADASIL research grant! CADASIL Community is amazing!

The Penn Medicine Orphan Disease Center 2020 Million Dollar Bike Ride was a virtual event this year due to COVID-19. That did not stop Team CADASIL participants and supporters from raising over $50,000 to support CADASIL research! In addition, UPenn matched $30,000 dollar-for-dollar and they are in the process of reviewing CADASIL grant applications for the 2021 $82,000 CADASIL research grant! Thank you!

Meet Dr. Beth Kozel, MD, PhD, a clinical geneticist and principal investigator of the COVID-19 Rare Disease study currently looking for CADASIL patients to participate in their research study. Watch this CADASIL care webcast by Dr. Kozel on genetic testing for CADASIL on our website.
the ClinGen Data Sharing Program? Encourage them to join today! Getting involved in research matters! [www.cureCADASILFamilyRegistry.com](http://www.cureCADASILFamilyRegistry.com)