EMBRACE Newsletter Vol. 1 February 2020



Envision the Cure - Embrace the Challenge

cureCADASIL Transitions Leadership

After 4 years of leading and growing cureCADASIL, our dedicated and tireless President, Nancy Maurer, has transitioned from President to Trustee. We thank Nancy for her dedication and vision that she brought to our patient organization! Trustee Jane Gunther has stepped into the role of President, and we look forward to her new ideas and energy!



RARE DISEASE DAY 29 FEBRUARY 2020



Rare Disease Day is Feb 29

Rare Disease Day is February 29, 2020, the rarest day of the year! Spread awareness and support for CADASIL during Rare Disease Day with a Twibbon frame on your FaceBook profile

https://twibbon.com/support/cadasil-awareness-day-2



Registration is also open to attend RDLA's Rare Disease Week #RAREDC2020 on Capitol Hill! Join more than 800 advocates and register here to raise awareness for

CADASIL and all rare diseases: https://bit.ly/36nAAmS

Do you have loved ones who are not on social media or Facebook but would still like to receive updates? You can now text to join our contact database!

Dr. Joe Arboleda Lab -CADASIL Blood Biomarker Analysis

Thanks to your continued support, cureCADASIL has provided research funding to Dr. Joe Arboleda since our inception and every year since 2016.

Learn more on how the latest funding was used to support blood biomarker analysis with post-doc Dorothee



Schoemaker, PhD and to learn what types of studies we have funded:

cureCADASIL Funded Research page

An interview with Jane Gunther, new President of cureCADASIL

Jane Gunther, PhD was recently interviewed by Lauren Fang, a patient advocate associate for Rare Genomics, at the Global Genes Summit last October. Learn more about Jane on the Rare Genomics Institute blog.







We need you! Team CADASIL has been selected to participate in the 2020 Million Dollar Bike Ride to raise money for a CADASIL research grant! If you are interested in joining Team CADASIL as a rider registration is now open!

2019 MDBR Research Grant: Pericyte Contractility in CADASIL

Read details provided by Dr. Fabrice Dabertrand (University of Colorado at Denver) on his research grant titled *Pericyte Contractility in CADASIL*.

This research grant was funded by the CADASIL community, cureCADASIL, and the Penn Medicine Orphan Disease Center through the 2019 Million Dollar Bike Ride.

Let's do it again in 2020!! Donate to Team CADASIL and help us reach \$30,000 to be matched dollar for dollar by UPenn!

Donate to Team CADASIL

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