### EMBRACE Newsletter Vol. 2 June 2020



# **Envision the Cure - Embrace the Challenge**

#### Rare Disease Resources for Coronavirus Pandemic

While everyone is affected by the coronavirus pandemic, we understand those with CADASIL and other underlying diseases may have extra concern. Although there is not specific research or guidance for CADASIL, we hope these <u>rare disease resources</u> from our partner Global Genes are helpful. Please stay healthy.



#### Million Dollar Bike Ride 2020 goes virtual!

After much deliberation, the Penn Medicine Orphan Disease Center has decided to host a virtual Million Dollar Bike Ride, instead of gathering face-to-face on June 13th. Their efforts to support rare disease is ongoing and they remain committed to the 2020 MDBR Research Grant Program. Team CADASIL will participate in the virtual event and continue to raise up to \$30,000 to be matched dollar for dollar by UPenn to support a CADASIL research grant.

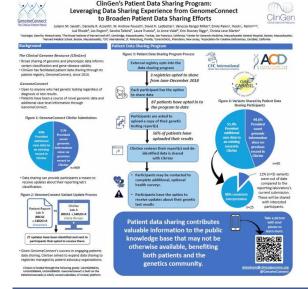
Ride, run, or walk the week of June 8th and post your picture on social media with the hash tags #cureCADASIL #PennMedMDBR2020 Your support is appreciated!

Do you have loved ones who have not joined the CADASIL Family Registry and the ClinGen program? Encourage them to join today! www.cureCADASILFamilyRegistry.com

#### **CADASIL Poets and Authors**

Families affected by CADASIL have amazing ways of expressing themselves and making a difference for this rare disease. A New Jersey couple has been writing and performing poetry for many years. Please visit our website to learn more about <u>David and Eloise's use of poetry</u> during their journey with CADASIL.

CADASIL champion Michael
Kennedy has authored two books
whose proceeds support CADASIL
awareness, education and research.
Michael has hosted numerous
fundraisers, co-chairs Team
CADASIL in the Million Dollar Bike
Ride and amazingly finds time to



write wonderful children's books with a purpose.

Thank you Eloise, David, and Michael!

## cureCADASIL Leadership Expansion, with a Focus in Drug Development

It is with great pleasure that the Board of Trustees announces the appointment of 2 new Trustees. Joining the <u>Board of Trustees</u> are Lisa Pugliese (Board Member, expertise in clinical trial development and management) and Debra Robinson (Board Member, expertise in global drug program development).

In addition to the transition of Jane Gunther from Trustee to President, this expansion represents a shift for cureCADASIL, bringing drug development talent, expertise, and energy to the table that will support and focus our research and clinical initiatives. Thank you for your support as our organization continues to evolve to envision a cure for CADASIL and take the necessary steps to make a cure a reality!



# **2019 MDBR Research Grant: Pericyte Contractility in CADASIL**



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

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!

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