

Envision the Cure - Embrace the Challenge

CADASIL clinical roundtable meeting held in Philadelphia

cureCADASIL hosted the first US Roundtable of CADASIL clinical researchers in conjunction with the 2019 American Academy of Neurology (AAN) annual meeting in Philadelphia, PA on Monday May 6.

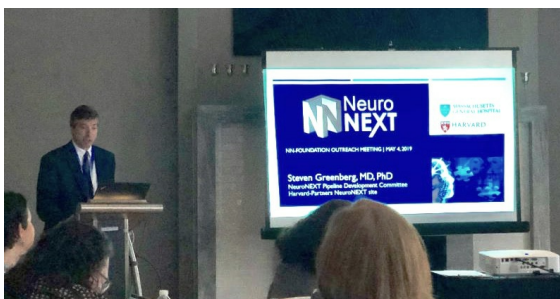
The objectives of the meeting were to discuss recent advances in CADASIL research, identify research gaps and funding opportunities, and potential future collaborations based on common research interests.



Pictured (left to right): Karen Orjuela, MD; Jane Paulsen, PhD; James Meschia, MD; Jennifer Majersik, MD; Nancy Maurer, RN; Elisa Ferrante, PhD; Dorothee Schoemaker, PhD; Jose Biller, MD; Mitch Elkind, MD; Stephen Salloway, MD; Michael Geschwind, MD; Fanny Elahi, MD; Sandra Talbird, MS

Have you always wanted to participate in research, but traveling is too difficult? Now is your chance!

A [CADASIL care webcast by a genetic counselor](#) is now available, explaining how to join ClinGen in less than 5 minutes.



Pictured: Steven Greenberg, MD, PhD

 **LET'S ROLL.** 

Million Dollar Bike Ride . Philadelphia . 6/8/19
Participate or Donate TODAY!



In less than a month amazing individuals will be riding in the 2019 Million Dollar Bike

Attending and presenting at the NeuroNEXT Foundations Outreach May 4 meeting was exciting and informative. There are many possibilities for CADASIL partnerships, and we must all continue to advocate for rare disease. To learn more about NeuroNEXT visit neuronext.org

Ride for their loved ones living with CADASIL - Will you join these families & help us reach our goal? Donate today at <http://givingpages.upenn.edu/CADASIL> to have your donation doubled for CADASIL research!

Donate Now

New research to be presented in May at ISPOR and CCG conference

New research will be presented at the 2019 ISPOR conference May 20-22 in New Orleans entitled "*Treatment Patterns, Health Care Resource Use, and Financial Impact of CADASIL in the United States*"

Thanks to over 30 individuals who have joined the ClinGen study, new CADASIL variants (mutations) not previously in the ClinVar database have been identified. Results of this research will be presented at the 2019 Curating the Clinical Genome (CCG) conference May 29-31 in Washington, DC



CADASIL community word art

Thanks to all who participated in creating CADASIL word art for Rare Disease Day 2019!



Patient educates others on CADASIL

Last Fall, patient Laura Luhrsen connected with cureCADASIL to prepare for a presentation she volunteered to give to Physical Therapy students on CADASIL. Telling your story and educating others is a great way for individuals to spread awareness of CADASIL! [See more](#)

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