



# ***Pathways to a Cure***

## *The CAA Newsletter*

### MESSAGE FROM THE DIRECTOR

Happy Spring from all of us at the Research Center! We would like to thank you for your continued interest and engagement in our newsletter. I am pleased to report that our newsletter email account, [PathwaystoACure@partners.org](mailto:PathwaystoACure@partners.org), has received many research study related inquiries and suggestions from our valued subjects. Please continue to reach out to us, review our website, [angiopathy.org](http://angiopathy.org), and send us your feedback.

I would like to take a moment to reflect on the annual International Stroke Conference that took place early February in sunny San Diego, California. I am happy to report that interest in small vessel disease and hemorrhagic stroke continues to grow each year. This year there were major symposia on all three major aspects of hemorrhagic stroke: prevention, early treatment, and rehabilitation. If you are interested in learning more about the highlights from the 2014 ISC, please visit [strokeconference.org](http://strokeconference.org).

In this edition of *Pathways to a Cure* we feature an article on our study Advanced Neuroimaging to Detect CAA. This study has been ongoing since 1996 and has enabled our research center to make important progress in imaging methods for CAA, based directly on data from our research subjects. It is gratifying to know that your participation in these studies creates a direct link to our rapidly advancing science. Please see our feature article for more information on this study. Also in this edition, we will be providing you with an update on our ongoing drug trial for Ponezumab (main article in our first edition), which is still actively recruiting new research subjects, and my personal favorite feature, our Patient Spotlight. We hope you will enjoy our third edition of *Pathways to a Cure*. Thank you for reading.

Sincerely,  
Steve



## **Advanced Neuroimaging to Detect CAA: What We've Learned**

**In this edition of *Pathways to a Cure***, we wanted to provide our readers with an update on our Advanced Neuroimaging to Detect CAA study. As a reminder, this study involves at least two years of MRI scanning, cognitive function and balance testing, as well as the optional components of a onetime PET scan and MRI scans on our higher definition MRI scanners. Each of these scans provides our physicians with a clearer image of the brain to better determine the course of CAA over time. Our site has been successfully enrolling subjects into the study since 1996, so we have collected quite a lot of data. Overall, we have enrolled 119 patients, 40 of which are currently in the process of completing the study. With over 50 scientific papers originating from this study, all published in first tier medical journals, our understanding of CAA has expanded considerably and increasing the number of participants has become a major priority in order to tackle the ultimate challenge of finding treatments to stop the progression of the disease.

Dr. Edip Gurol describes more of what he and his colleagues have learned from this study:

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## What We've Learned

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The first step was to form criteria for the diagnosis of CAA. Dr. Greenberg's landmark 2001 paper in the journal, *Neurology*, addressed this critical issue, thanks to the participation of our patients in a study using an MRI method that was new at the time. These Boston Criteria were validated and found to have very high accuracy in detecting CAA during life and are now used by all stroke doctors in the US and worldwide. Use of these criteria has facilitated subsequent research that helped us identify some of the most important clinical, radiologic, and genetic associations of CAA. These studies produced over ten newer advanced imaging methods and a wealth of data that help physicians take more accurate management decisions in CAA patients.

One of the results of our study is that CAA was shown to be among the most important risk factors for brain bleeding in patients using Coumadin as a blood thinner (anticoagulant). This important clinical information led to the widely accepted guidelines that recommend against the use of anticoagulants in patients with atrial fibrillation (a common heart rhythm disorder) who have sustained a brain bleed related to CAA. In fact, more

recent work showed that even use of a lighter blood thinner such as aspirin would increase the bleeding risk to some extent and that people with brain microbleeds without prior large bleed might be at higher risk of brain bleeding if Coumadin is used. These data resulted in more appropriate risk-benefit assessment in people who need to use blood thinners for prevention of blood vessel blockages or heart disease and decreased the risk of potentially fatal brain bleeds in many older adults.

Our CAA patients who have been able to participate to our ongoing imaging studies have contributed tremendously to our understanding of CAA pathology and its consequences, helping development of new diagnostic methods and potential treatments. These data already benefit millions of people around the world for very practical issues such as diagnosis of the cause of brain bleeds, as well as for choice of blood thinners, a very common need in older adults. The stroke community is indebted to our patients and we believe that our research will lead to efficacious treatments that will benefit all individuals with CAA.

## Ponezumab Study Update

**Between** August 2013 and April 2014, 16 patients have come to the **J Philip Kistler Stroke Research Center** for Ponezumab screening visits, 8 of whom have enrolled into the trial. Of those 8 enrolled, 5 have completed all three of their infusions and are in the follow-up phase of the study. It's been exciting to see such a high level of interest, and to be working with dedicated participants from all across the country.

The study enrolls patients who are:

- Diagnosed with probable CAA
- Between 55-80 years old
- Generally healthy
- Able to undergo multiple MRIs

If you are interested in learning more, please contact the study coordinator

Tom Gomes at [tgomes3@mgh.harvard.edu](mailto:tgomes3@mgh.harvard.edu) or call him directly at (617) 726-2941.



Tommy Gomes, Clinical  
Research Coordinator

## PATIENT SPOTLIGHT:

**This edition** of *Pathways to a Cure* features one of our very involved research participants, Rhonda Walker, mother of two grown daughters, living with her husband in Texas. Rhonda has participated in many of our studies, including Advanced Neuroimaging, Lumbar Puncture, and PiB-PET, and she is currently enrolled in our drug trial study, Ponezumab.

### **When were you diagnosed and what made you start participating in research with us here in Boston?**

I was diagnosed three or so years ago after experiencing bad headaches and tremors, but it took a while for my doctor to give me an MRI. After my doctor got the results and diagnosed me with CAA, I took to the internet to research CAA myself, and your center's website ([www.angiopathy.org](http://www.angiopathy.org)) was the first to pop up. I emailed asking for more information on the disease and one of your coordinators called me the next day, asking if I were interested in participating in studies. I figured that since it is relatively unknown what will happen down the line with my CAA, I should dedicate as much time and effort as possible to finding some treatment and helping others. Even if what I'm doing in these studies doesn't help me individually, my faith allows me to believe that I am here for a purpose, and that purpose is to help other people diagnosed with CAA, now and in the future.

### **How are you feeling since your diagnosis?**

I feel fine, overall. I still have some memory problems though, especially with finding the words I am looking for. For instance, I can look at a ball and know it's a ball, but I can't seem to find the word. That has seemed to clear up recently though and my neurologist here has also noticed some improvement with my 'word fumbling', so I'm happy about that.

### **What would you like to tell someone who has been recently diagnosed with CAA?**

When I was first diagnosed, I read some awful accounts of people with CAA saying that it's horrible and an immediate death sentence, but I would say to ignore that. Every person is different and every diagnosis is different. We don't know what's going to happen in our future and although it's easy to get upset about our luck, we should laugh when given the chance and live life to the very fullest. It is our responsibility to help others and we should do that as much as possible, so that's why I'm participating in research.

*Rhonda Walker is very interested in speaking to anyone who has questions for her, groups interested in learning about living with CAA, or anyone who would just like to reach out to another with CAA. If you would like to contact Rhonda, please call Clinical Research Coordinator Kathleen Macone at (617)643-2782, or email [kmacone@partners.org](mailto:kmacone@partners.org) for more information.*



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[www.angiopathy.org](http://www.angiopathy.org)

**Contact Information:**

Please send your comments, questions and recommendations to:  
[pathwaystoacure@partners.org](mailto:pathwaystoacure@partners.org).  
For more information on our CAA research and for FAQs, please visit: [www.angiopathy.org](http://www.angiopathy.org)

Please consider making a donation to the MGH Stroke Research Center in honor or in memory of someone special. Donations can be mailed directly to the MGH Development Office c/o Shawn Fitzgibbons, 100 Cambridge Street, 13th Floor, Boston, MA 02114. Please make your checks payable to Mass General Hospital with the memo: 1200-028184. You can also give online by visiting the “Support” section of our website [angiopathy.org](http://angiopathy.org). Thank you from all of us at the MGH Stroke Research Center!

Our dedicated Research Fellows enjoying their time in San Diego, CA during the 2014 International Stroke Conference.



**“Thank you for your commitment to CAA research!”**

From all of us at the J. Philip Kistler MGH Stroke Research Center