



Pathways to a Cure

The CAA Newsletter

MESSAGE FROM THE DIRECTOR

Happy Spring, from all of us at the Research Center! Like many areas nationwide, it was uncertain if we would ever see the warm weather return after this historic Boston winter. Our spirits are lifted not only by the changing seasons, but also by exciting news in the CAA research community.

In early 2015, our research group closed enrollment to the CAA clinical trial of Ponezumab, which is aiming to determine whether this study drug can safely and successfully remove amyloid protein from blood vessels in the brain. This study is conducted by an international group of research centers that recruited CAA patients willing to participate in this exciting study. While we don't yet know if the results of the study will be positive, it has laid the groundwork for future scientifically driven treatment trials designed to improve quality of life for our patients. Trials such as these mark the beginning of a strong partnership of national and international groups who are all dedicated to continued collaboration on CAA research opportunities.

In this edition of *Pathways to a Cure*, we introduce another way our patients can help to develop these important clinical trials – brain donations. As you'll read, brain donations enable us to identify new imaging (MRI) markers that can serve as shortcuts to the development of future trials. These donations are part of a larger goal to complete a "chain of knowledge" by linking together the living functionality of our patients, research MRI scans during life, and examination of actual brain tissue with a microscope. As the final link in this chain, brain donations allow us to analyze and connect data in ways that would be otherwise impossible.

We hope you enjoy this edition, and as always, thank you for your continued interest in our newsletter!

Sincerely,
Steve Greenberg, MD, PhD



Brain Donation

Our research team is constantly searching for new ways to fight against CAA. In order to expedite this effort, we strive to get the most use out of the data we collect through MRIs, blood draws, cognitive testing, etc. One lesser known method through which we gather important data is by collaborating with The Brain Tissue Center at MGH in arranging brain donations.

Brain donation is one of the most meaningful and generous gifts a patient and family can give. When patients who've participated in CAA research make the decision for brain donation they complete the chain of research data. This final link allows for comparisons between a participant's research MRIs and the microscopic examination of his/her brain tissue. This ability to examine the brain microscopically is often the "missing link" in our research studies, so in many ways this is the greatest contribution a patient and family can make towards aiding the fight against CAA.

We recently spoke with June Reynolds, spouse of the late Edward Reynolds, about their experience with brain donation. Ed was a loving father and husband for 53 years, principal of several Massachusetts elementary schools, an accomplished watercolor painter, and a Deacon of the First Baptist Church in Dawson, GA. It is not surprising that he and June hadn't given much thought to brain donation during a lifetime full of impressive accomplishments!
(Continued on page 2)



Pathways to a The CAA Newsletter

— Brain Donation

(Continued from page 1)

Although the discussion itself is not an easy one to have, they appreciated the importance of considering such a donation. Knowing that the decision could help future generations, the two of them together ultimately agreed on Ed participating in the program as part of their deep commitment to CAA research.

When asked how she and her husband were able to make this decision, she simply replied, "It's not a huge thing ... it's not degrading to the person. It's not a loss of Ed." June also told us that their passion for donating to science was driven by a desire to both help other families avoid the hardships that Ed endured, as well as their wish to see science advance more quickly. "Towards the end of his life, he had been reduced to a horrible state ... that is where the passion comes from; something has got to be done. Some may think it's just a pebble on a beach ... what difference is it going to make? It's going to make a huge difference."

A common concern that we hear from patients and families is whether their intent to donate would result in a logistical burden during what would already be a very difficult day. In an effort to remove this pressure off of loved ones, Massachusetts General Hospital (MGH) coordinates all pertinent details and communications with the local hospital. As June explained, "I don't think I could have managed the whole operation of a brain donation. I wouldn't even know what I was talking about. Having all

the direction from MGH was phenomenal, and I know that's what made it happen."

We acknowledge there is still much to learn about CAA, and we are hopeful that supplementing our ongoing research with brain donation will expedite our efforts to better understand and develop effective treatments for CAA. In June's words: "Such a donation would not be the loss of a loved one, but a once-in-a-lifetime opportunity to help eradicate this disease and provide an enormous gift to others."

If you have any questions regarding brain donation, please contact our Research Coordinator, Grace Riley at 617-643-2782 or griley1@mgh.harvard.edu.



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<https://www.facebook.com/CerebralAmyloidAngiopathy>

PATIENT SPOTLIGHT:

This edition of Pathways to a Cure features Marie, a 62 year old woman from Beverly, MA. She and her husband Jim of 37 years have two sons, Jamie and Matt. She currently works as a reading interventionist with K-2 pupils at an elementary school on the North Shore, where she instills children with the same love of reading that she possesses. Marie has been very active with the J.P. Kistler Stroke Research Center, participating in GOCHA, Advanced Neuroimaging, PiB-PET, and Ponezumab studies.

What was a difficult aspect of receiving the diagnosis?

Initially, it was an incomplete understanding of what the future would bring. Could I have another stroke? Does CAA ever get better? Is it hereditary and could my sons have the condition? When I saw Dr. Greenberg, he comforted me by answering my questions with his extensive knowledge and expertise.

How did the diagnosis change your life?

Firstly, the initial stroke left me unable to drive, so I am not as independent as I once was. I rely on others for transportation, which can sometimes be burdensome. Secondly, I was very sensitive to lights immediately following the stroke. I have slowly improved and can tolerate indoor lights, although I still wear dark glasses when going outdoors. Lastly, it directly affected me as a classroom teacher. Initially I was unable to read (a big part of being a teacher), but my symptoms slowly improved over the years. Now, I have reached a point where I am again very much at home as a paraprofessional working with K-2 students on math and reading.

What inspired you to be so active in research?

I was impressed with the care I received at Massachusetts General Hospital and wanted to become part of any

research efforts that could help me and others with CAA. I hoped that my participation would lead to CAA-related medical advances such as better methods of detection, more accurate prognoses, and ultimately a drug therapy that would combat the disease.



Do you have a particular support structure you'd care to tell us about?

My sons and husband have been incredibly supportive and helpful. Having the ability to work in some capacity has also helped me retain my confidence and sense of purpose. Lastly, staying active and taking part in the studies with the Stroke Research Center team has made me feel like I am contributing to a worthy cause and helping fight this disease. From that, I also get the strength to cope.

Is there anything you know now, that you wish you had known sooner?

Surprisingly, I would say no. The facts have been presented by Dr. Greenberg and I don't have anything else I'm wondering about. I always look forward to hearing updates from your research team when they become available.

What would you say to others with CAA?

Try to maintain a positive outlook and do not dwell on the condition.

Our research participants are our greatest asset, and may be a valuable resource for anyone interested in, or living with, CAA. If you are interested in speaking with someone, please call Clinical Research Coordinator Grace Riley at (617) 643-2782, or email griley1@mgh.harvard.edu.

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www.angiopathy.org

Contact Information:

Please send your comments, questions and suggestions to:
pathwaystoacure@partners.org.
For more information on our CAA research and for FAQs, please visit: www.angiopathy.org

Please consider making a donation to the MGH Stroke Research Center in honor or in memory of someone special. All contributions directly support research on CAA and bleeding strokes.

Donations can be mailed to the MGH Development Office c/o Shawn Fitzgibbons, 100 Cambridge St., Ste. 1310 | 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. Best wishes to you and yours from all of us at the J. Philip Kistler Stroke Research Center!

2015 International Stroke Conference, Nashville, TN



Clockwise from top left: Abby (left) and Miriam (right) of MGH Stroke Research; Music City Center, Conference Venue; Conference Participants Gather for Keynote Presentation; Dr. Lee Schwamm, Director of TeleStroke and Acute Stroke Services at MGH



“Thank you for your commitment to CAA research!”

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