



Pathways to a Cure

The CAA Newsletter

Message from the Director:



It is a pleasure to reach out to the CAA and hemorrhagic stroke community again this year.

As you'll see later in this edition of Pathways to a Cure, many of my colleagues and I are just back from the 8th International CAA Conference, held in 2022 in Western Australia, which is the first time it has been hosted outside of North America or Europe. For many of us, this was one of the first opportunities we've had to be in face-to-face contact with our colleagues in the CAA community since the outbreak of the COVID-19 pandemic. It served as a great reminder to all of us of the value of interpersonal interactions. Many of the new ideas that come out of these conferences occur in the hallways in between sessions or over dinner, which are experiences that cannot be duplicated by virtual meetings.

The conference also served to demonstrate all the progress we've made both in understanding CAA and in organizing the worldwide CAA community. Some of the tangible benefits from our international collaborations are the recently updated Boston Criteria for defining CAA, a new set of diagnostic and treatment guidelines that we hope to release in the upcoming 6 months, and a new and substantially upgraded website for the International CAA Association. One exciting feature of the website will be a listing of healthcare providers around the world who have registered themselves as having expertise in CAA, which we hope will be a great resource for the many patients who struggle to find a clinician familiar with the disease. Please see the adjacent section "International CAA Conference Recap" for more details about this exciting conference.

I know you will all join me in taking pride in the progress we've made, and in recognizing how far we still must go. On that humbling note, I send my new year wishes to you and your families.

International CAA Conference Recap

By Susanne van Veluw, PhD



The 8th International Cerebral Amyloid Angiopathy (CAA) Conference took place on November 3-5, 2022.

The 8th International CAA Conference took place on November 3-5, 2022. It was a unique meeting in several regards. This was the first time that an International CAA Conference was held on the beautiful continent of Australia. We gathered at the University Club of Western Australia, in Perth. Not only was this the first in-person meeting after the Covid-19 pandemic – which meant reconnecting with old friends and establishing new friendships – the scientific program was also excellent. A broad range of topics was discussed, including novel insights related to iatrogenic CAA, Dutch-type CAA, perivascular amyloid clearance, biomarker research, and Amyloid-Related Imaging Abnormalities. The new Boston Criteria version 2.0 were presented by one of our online participants.

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International CAA Conference Recap *(Continued from page 1)*

Another 'first' was an up-date on the development of the International CAA Association clinical guidelines. The goal of these guidelines is to provide clinicians worldwide with evidence-based recommendations for the diagnosis and management of CAA. To facilitate the discussion, several working groups had convened prior to the meeting to draft recommendations regarding the diagnosis, testing, and management of CAA and CAA-related inflammation. Each working group reported initial findings and recommendations, followed by a productive discussion with input from the audience. The guidelines will be finalized over the coming months and disseminated via the official website of the International CAA Association, www.caaforum.org.

the International CAA Association board has made many website updates over the past year, and these were launched at our meeting in Perth. The goal of the platform is to serve patients, clinicians, and scientists worldwide, and one particularly exciting new feature is the 'for patients' page, including FAQs and an interactive map listing CAA experts across the world. The map was incorporated as a response to requests from patients all over the world seeking physicians with expertise in the diagnosis and management of CAA in their respective geographical areas. We hope that this and other new features will be helpful to many and invite you to visit the website at www.caaforum.org.

The conference was concluded by a public forum which brought researchers and patient advocates from three continents (Australia, USA, and Europe) together in one room to talk about CAA, including Dutch-type CAA, and attendees heard a moving personal account by a patient advocate who shared first-hand experience of the challenges of having Dutch-type CAA in her own family. This forum provided the unique opportunity to inform Australian members of Dutch-type CAA families about the research progress that has been made over the past couple of years and the plans in place to move towards treatment trials.



CAA Conference attendees reunited in-person for the first time since the COVID-19 Pandemic.



Group photo at the welcome reception for conference attendees.

Overall, the 8th International CAA Conference in Perth was a huge success. This meeting could not have been made possible without the dedication and hard work of the local organizers: Drs. Hamid Sohrabi, Ralph Martins, Kevin Taddei, and Samantha Gardener.



Patient Spotlight: Rick Tomkinson

*Kate Tomkinson on behalf of
her husband and CAA research
subject, Rick.*



In the spring of 2015 while visiting a daughter in college, Rick started having difficulty with balance and was unsteady. We thought he had vertigo and perhaps some dehydration as often he was most unsteady when it was hot outside. We made an appointment with a neurologist and after a battery of tests, there was no conclusive diagnosis. He began drinking copious amounts of Pedialyte, however his symptoms remained.

After several MRIs over a 2-year period we decided to go to the Mayo Clinic with a referral from his original neurologist. More MRIs were taken as well as an overnight stay to test for epilepsy. The report after the visit was again inconclusive, but the last sentence suggested that perhaps he had CAA.

We saw more neurologists in Montana, where we now lived full time. I then took the initiative to send the MRIs to several neuroradiologists in Denver and Salt Lake and that is when we got the confirmation that Rick indeed had CAA. It was at this point that I began researching CAA in earnest and found out about the research going on at Mass General.

After sending Rick's MRIs and joining the research study at MGH, Rick and I began to have the difficult discussion about what we could expect from the disease and the fact that at this time there was no treatment available. At no point did we ever doubt being involved in clinical research, as even in the early stages we knew that anything we could do to help find a cure and hopefully help others with this disease, we were going to do it!

With any disease that involves the brain and dementia there is no straight path and no timeline to follow. It was at this point that we decided to just enjoy every day as best we could. The hardest part for both of us, but especially for me as the caretaker, is how to address the changes that are happening as the disease progresses. How do you tell someone they can no longer drive? How do you help someone deal with the fact that they can't play their favorite sports? Then when they can no longer work their phone and insist it is broken and you must gently continue to "fix" it.

Making your loved one feel relevant and empowered is a struggle. Unfortunately living in rural Montana there were not many available resources or any support groups. And as the disease progresses you can leave your loved one alone for shorter and shorter periods of time and that just further isolates the caretaker. It can feel like you are in a never-ending spiral, trying to keep a love affair alive and be a spouse instead of a nurse.

Toward the end of Rick's 7-year battle I did find support through the local (1 hour away) hospice group. They gave me more relevant information than I had received throughout our journey, and I was very grateful for their support. I would suggest others diagnosed with CAA reach out to a Hospice group for information on the stages of dementia, so they have some milestones to look for.

After our first visit to MGH, we learned about the option to donate his brain for research, and we looked at each other and decided we would do whatever it takes to do make that happen. I will say I was happy the decision was made early on, as there is some preparation particularly when you do not live close to a large hospital.

Choosing an experienced funeral home was important as they helped facilitate getting the brain removed and worked closely with MGH to ensure it got delivered in a timely manner. Dr Greenberg and the staff of MGH CAA Research Program were very helpful.





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Meet the Coordinators: Erin Dixon and Christopher George



Erin Dixon joined the CAA Research Program at the J. Philip Kistler Research Center in June 2022.

Erin is the lead coordinator for studies led by Dr. Anand Viswanathan aiming to understand differences between individuals with mild cognitive impairment (MCI), and individuals with both MCI and CAA. Erin also coordinates the CAA Brain Donation program. In her role, Erin enjoys working with participants enrolled in imaging studies, and helping patients and families understand the brain donation process. To contact Erin, email erdixon@mgh.harvard.edu.



Christopher George joined the CAA Research Program at the J. Philip Kistler Stroke Research Center in June 2022.

Christopher is the lead coordinator for a study led by Dr. Edip Gurol, aiming to learn more about individuals with cerebral small vessel diseases (cSVD), including CAA. In his role, Chris enjoys learning from the world-class physician-scientists at MGH, and most of all, working with the research participants who so generously donate their time to the studies. To contact Chris, email cdgeorge@mgh.harvard.edu.

Looking to Support CAA Research?

Many patients and families have lent their time and energy to finding a cure for CAA by helping raise funds for our research program. The CAA Research Team at MGH encourages your interest in hosting a charity event or fundraising among friends and family and appreciate the efforts many of you have already made to this end!

To learn how to support CAA research at MGH, visit this link: <https://giving.massgeneral.org/crowdfunding-community-fundraising/>

Or scan the QR code:



Individual donations can also be mailed to:

*MGH Development Office c/o Kylie Baruffi
125 Nashua Street, Suite 540 Boston, MA 02114*

*Please make checks payable to Mass General Hospital, memo: #1200-02818

Visit the MGH CAA Research Program on the Web:
www.angiopathy.org.

We've made significant changes to our website. We hope you'll enjoy its new content, updates, and design! welcome your questions, comments, or feedback – get in touch with us on the “Contact” page, or by emailing Erin Dixon erdixon@mgh.harvard.edu.