



FALL 2020

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Pathways to a Cure

The CAA Newsletter

MESSAGE FROM THE DIRECTOR

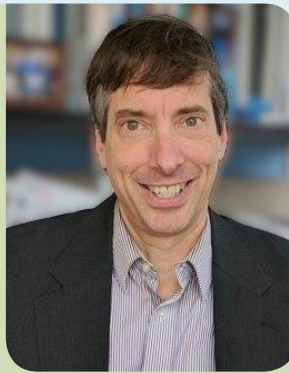
We did not plan on writing this edition of Pathways to a Cure on COVID-19. This pandemic has been a challenge on so many fronts to many people; it is hard to say when we will adjust to this new normal and what it will look like when we do. Nonetheless, the virus outbreak has forced us to find new ways to improve our research, and to keep our research participants safe. The good news is that our hospital and others have figured out ways to decrease virus transmission for both healthcare workers and patients.

I believe we can be confident that the steps we are taking are working and keeping us safe. Thanks to our great J. Philip Kistler Stroke Research Center team, we have identified a series of steps to ensure our participants and staff will be as protected as humanly possible. We are happy to return to making progress on finding a cure for Cerebral Amyloid Angiopathy and will continue to update our procedures as circumstances change.

On a much happier note, for those of us who are baseball fans, we remember the joy that Jim Bouton's **Ball Four** book brought to our lives. This book focused on Bouton's joyful and honest exploration of what it truly meant to find yourself while playing a kid's game for a career.

While Jim Bouton may have started as a ballplayer (we'll forgive him for starting with the Yankees) he grew to be far more than that, becoming a motivational speaker and inspiration to many. Sadly, Cerebral Amyloid Angiopathy is an equal opportunity disease and it struck Jim too early in life. The disease caused impairments to his speech, and eventually, premature death. His wife, Dr. Paula Kurman, has seized on these sad events to find a silver lining; to bring a spotlight to the devastating disease. We were elated to have her take part in this newsletter edition as a partner of a victim of this disease and are both honored and delighted to share Paula's story.

Sincerely,
Steve Greenberg, MD, PhD



COVID-19 Research Impact

Since its existence, a core value of the J. Philip Kistler Stroke Research Center program has been our research participants' health and safety. Prior to the pandemic, research participants were screened for general wellness, and equipment was sanitized during each visit.

During COVID-19, the safety and protection of our research participants has only become more critical. We have enhanced our previous practices with additional infection prevention methods— these include specific protocols around disinfection and sanitation of spaces and materials, maintaining social distancing, using hospital-grade Personal Protective Equipment, and screening both subjects and staff for symptoms.

In addition, we have worked to limit in-person interactions to only those necessary, and the use of technology has greatly aided in our ability to take these added precautions. Although COVID-19 disrupted our research this year, we have since safely and successfully reopened our CAA research studies and are continuing to work towards progressing medicines' understanding of this disease.

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— COVID-19 Research Impact

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As we look to the future, we understand COVID-19 has created unprecedented challenges for our patients, research participants, and the broader global community. Our team at the J. Philip Kistler Stroke Research Center knows the need for support has never been greater, and we want to assure participants that we are readily available to answer questions about our safety measures and how we are protecting participants coming on-site for study visits.

We welcome participants to reach out to a team member if they want to discuss their participation further. We want to thank all our research participants for their dedication and commitment during these trying times. Our top priority is the health and safety of our participants.

We will continue to follow CDC and Massachusetts General Hospital guidelines as we move forward and will continue to update as things change and progress.

Our JPK Coordinators are taking the additional following steps to ensure the safety of participants :

- ❖ **Study visit activities (MRI, PET scans, and neuropsychological testing) are being spread out on separate days to ensure a limited amount of contact with outside groups and adherence to proper social distancing.**
- ❖ **JPK coordinators and research staff are wearing MGH face masks and shields to prevent the spread of COVID-19.**
- ❖ **All surfaces are wiped down with Virex prior to, during, and after research activities.**
- ❖ **Staff and participants undergo a phone questionnaire to assess for COVID-19 symptoms before their visit takes place.**



Andrew Warren: Clinical Research & Data Coordinator II

Andrew joined the J. Philip Kistler Stroke Research Center in July of 2016. Andrew earned a degree in Cognitive and Brain Sciences from Tufts University with a minor in Computer Science. Andrew acts as JPK's data and imaging coordinator for a number of hemorrhagic and ischemic stroke studies and administers MRIs for Dr. Greenberg's and Dr. Viswanathan's outpatient neuroimaging studies. Andrew is excited to be back scanning at the Martinos Center for Biomedical Imaging after working from home due to COVID-19.



PATIENT SPOTLIGHT:

This edition of Pathways to a Cure honors American professional Major League Baseball pitcher Mr. Jim Bouton. Off the field, Mr. Bouton was a wonderful husband, keynote speaker and motivator. He is the author of the baseball book Ball Four and one of the creators of Big League Chew. Mr. Bouton battled Cerebral Amyloid Angiopathy and unfortunately passed away on July 10, 2019. In this edition of our Spotlight series, we asked wife, Dr. Paula Kurman, to share with us her experience and story with Jim.

My Husband, Jim Bouton, and Cerebral Amyloid Angiopathy

By Paula Kurman, Ph.D

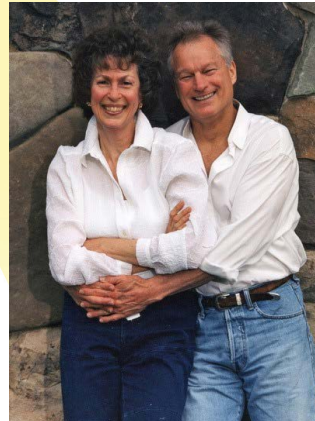
When did you start noticing changes in Jim?

Because of my professional background in human communication, I began noticing “soft signs” of change in Jim when he was in his late sixties. He was having difficulty dealing with numbers. And occasionally when speaking publicly, he’d loop around in a story and repeat himself. I began to hover when he made public appearances and join in with him as if it were planned. We had done public speaking together for years anyway, so no one seemed to notice anything wrong. And we enjoyed it. Jim’s quick wit was as entertaining as ever.

In the summer of 2012, Jim had a small but significant stroke. There were no physical signs, but he was speaking gibberish, so I knew the language center of his brain had been affected and I got him quickly to the hospital. At that point Jim knew he could not speak properly, nor could he write – because he tried. But he was fully aware of what was happening around him.

When did you first hear about CAA?

It was in the hospital that the serious trouble began. No one on staff considered the possibility of a vascular involvement, and at the time I did not know enough to raise the question. He recovered well over time, not surprisingly.



He was a man who was used to beating the odds. But a doctor put him on another blood thinner and suggested the possibility of Alzheimer’s disease. I changed doctors. That is when I first learned of CAA. Jim was finally taken off blood thinners, but much damage had been done. Comprehensive intellectual testing showed what he had lost,

and even more importantly, how much of him remained. We went everywhere together, until we no longer could. I took care of him myself until I needed help. Hospice was wonderful. Jim died at home on July 10, 2019.

What would you like to tell others who are going through something similar with a loved one?

Here are some things I’ve learned that I really want to tell others who are going through this with a loved one. It’s the hardest thing you’ll ever do, but worth doing. You’ll be good at it some days, but mostly not. You’ll have to forgive yourself when you’re not. Not all dementias are the same, and each person with dementia will be different. Forgetting is the least of it. Fear, and loss of comprehension, and loss of selfhood and autonomy are much more disastrous than forgetting. Be a good observer and learn all you can, not only from various sources, but from your loved one directly. There will be funny things that happen. It’s okay to laugh. Some moments will be so sweet they will take your breath away. Enjoy them. Love remains. The last word Jim spoke was three days before he died. He opened his eyes, put his hand gently on my face, and said “Beautiful.”

I am so thankful I was there for that.



In loving memory of Jim Bouton- July 10, 2019

J. Philip Kistler MGH Stroke Research Center

175 Cambridge Street, Suite 300

Boston, MA 02114



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Looking to support CAA Research?

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

**Wishing you a safe
and healthy end of
2020!**

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

❖ **Individual donations can be mailed to:** MGH Development Office c/o Elizabeth Barberio 125 Nashua Street, Suite 540 Boston, MA 02114

*Please make checks payable to Mass General Hospital, memo: #1200-028184

❖ **If you would like to learn** more about how to support CAA research at MGH, please go to: <https://giving.massgeneral.org/crowdfunding-community-fundraising/>

**For more information on our CAA research and for FAQ'S
please visit: www.angiopathy.org**

