



Pathways to a Cure

The CAA Newsletter

MESSAGE FROM THE DIRECTOR

Happy winter from all of us at the MGH Stroke Research Center and best wishes for a joyful and healthy 2018.

Our patients with CAA often ask about treatments for CAA. Our answer is that though there is great promise for eventually finding treatments to slow or stop CAA progression, we cannot yet offer disease-modifying treatments. Our ability to diagnose the disease has nonetheless made a difference in our patients' lives, as it allows us to predict risk of intracerebral hemorrhage and balance the need for different blood-thinning medications. In this edition of Pathways to a Cure, we have chosen to focus on the most common of these situations: patients who have both CAA and Atrial Fibrillation (AFib).

This presents a classic "between a rock and a hard place" dilemma where patients have good reason not to be on blood thinners (to limit their risk of bleeding stroke), but also have good reason to be on them (to limit risk of blood clots coming from the heart causing a blocking stroke). This is an important and high stakes decision, as both types of strokes can be devastating. We put every effort behind finding a solution that minimizes the risks of both.

I cannot emphasize enough that these decisions are best made by patients and doctors taking an individualized approach to finding the safest solution. There is no "one size fits all" answer, but general approaches and principles exist that we will try to lay out for you in this issue. You will also hear from a patient of ours who has experienced this dilemma first hand. We hope you enjoy this edition and as always, thank you for your continued interest in our newsletter and all that we do here!

Sincerely,
Steve Greenberg, MD, PhD



The complicated relationship between CAA and AFib

Through research spearheaded by the J. Philip Kistler Stroke Research Center, we have not only learned more about CAA, but also about other diagnoses that commonly occur alongside it. When a person is diagnosed with two chronic diseases or conditions, each with their own unique risk factors, this is defined as a "comorbidity." One common comorbidity among patients who have CAA is Atrial Fibrillation (also known as "AFib").

A diagnosis of AFib means that the individual has an arrhythmia, or an irregular heartbeat. Having AFib significantly increases one's risk of blood clot formation in the heart, thereby increasing the risk of ischemic stroke. Ischemic strokes occur when blood clots block a vessel supplying blood to the brain. In patients with AFib, it occurs when a blood clot forms in the heart and travels to the brain vessels. These blood clots deprive the brain of oxygen and nutrients, causing damage to the affected area. In the CAA population, many patients have a co-occurring diagnosis of AFib.

AFib is commonly treated by a class of medications called anticoagulants. Anticoagulants thin the blood to reduce the risk of blood clot formation. The purpose of this is to minimize the potential for ischemic stroke. A well-known anticoagulant (Continued on page 2)



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— The relationship between CAA & AFib

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anticoagulant is warfarin (also known by its brand name Coumadin), but there are also newer anticoagulants like dabigatran (Pradaxa), rivaroxaban (Xarelto), apixaban (Eliquis) and edoxaban (Savaysa). These drugs thin the blood and make it less likely to clot— which is helpful in preventing ischemic strokes, however decreasing the blood's ability to clot means increased risk for bleeding. This is understandably a major concern for people with both CAA and AFib.

Anticoagulation medications are one of two FDA-approved treatment options for patients diagnosed with AFib. The second treatment option is not a medication, but a surgical procedure: placement of the WATCHMAN device. This device also works to decrease the risk of ischemic stroke, however in a way that is different from an oral anticoagulant medication. The WATCHMAN device decreases stroke risk by closing off the left atrial appendage (an area of the heart unused after birth, where blood clots commonly form). By blocking these clots from entering the blood stream, it prevents them from travelling to the brain where they may cause an ischemic stroke. Patients treated with the WATCHMAN device undergo a procedure where they have a small puncture made in their upper thigh, and the device is inserted into the heart through a catheter. There is a short recovery period, and the WATCHMAN device remains in the left atrial appendage permanently. This is another treatment that may be considered for some individuals diagnosed with both AFib and CAA and, like anticoagulant medications, there is

exclusionary criteria and risks to consider. Patients should speak with their doctor to better understand treatment options and discuss what type of treatment plan will be safest and most effective for them.

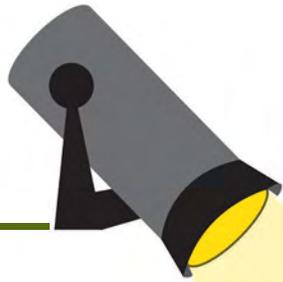
Physicians at the J. Philip Kistler Stroke Research Center have been leaders in developing methods to help patients make informed decisions about their treatment options. One of these methods is the idea of shared decision-making. The goal of shared decision-making is to enable the patient to weigh the potential risks and benefits of different treatment options and become fully informed so they can work with their physician to be an active part of their treatment decision. This method can also be applied when considering how to treat other conditions. Participants in our research have been crucial in helping us collect the data and information about CAA and bleeding strokes that has allowed us to develop this shared decision-making approach. This is yet another reminder of how important our research participants are, not only in understanding CAA as a disease, but in how physicians can continue to improve its treatment and management on a daily basis.

When making any medical decision, we encourage all patients to engage in this shared decision-making process. Discussing the risks and benefits of different management approaches with your physicians and family allows you to understand your options and select the best care approach for you. If you would like to better understand your risk for stroke and other comorbidities, please consult with a stroke neurologist so you can be prepared to handle future medical decisions.

Sarah Grill: Clinical Research Coordinator

Sarah joined the J. Philip Kistler Stroke Research Center in July of 2017. Sarah holds a Bachelor's degree in Psychology and a Master's degree in Child Development and Clinical Psychology. At JPK, Sarah coordinates Dr. Greenberg's study examining people who have probable CAA and hemorrhagic stroke. In her role, Sarah enjoys working with the study participants and helping them navigate the research activities. If interested in learning more about this study, contact Sarah at sgrill@mgh.harvard.edu





PATIENT SPOTLIGHT:

This edition of Pathways to a Cure features Mr. David Arsenault. He lives in Essex, Massachusetts with his wife, 2 cats, and 2 standard poodles. Mr. Arsenault enjoys acting on stage in front of a live audience, recently performing in the play, Inherit the Wind. He previously worked as a welder, has served in the U.S. Military and has been an enthusiastic participant in the JPK research program since 2015.

Q: How did you come to find out about your diagnoses of CAA and AFib?

A: I received my diagnosis of AFib before being diagnosed with CAA. My diagnosis of AFib came about when I was recovering at Massachusetts General Hospital after having a heart attack at work in 2011. Nearly six years later, I was brought to Lahey Clinic for a stroke and then transferred to MGH. Shortly into my stay at MGH, I met Dr. Edip Gurol who discussed the findings of my brain MRI and I was ultimately diagnosed with CAA. We also spoke about my pre-existing condition of AFib and Dr. Gurol informed me that the two can be related.

Q: What did you find to be most challenging about receiving these diagnoses?

A: Initially hearing of my diagnoses, I was extremely frustrated and felt that nothing could be done. There were no treatments or medications available for CAA, and I learned that CAA cannot even be confirmed without autopsy, which frustrated me even more. When I learned of my AFib diagnosis, I just wanted to treat it in whatever way possible.

Q: What was your decision-making process like when choosing treatment?

A: When I was first diagnosed with AFib, I wanted to treat the disease in any way I could, so I chose to be on Coumadin. Treatment options became more complicated when I received my diagnosis of CAA. Dr. Gurol, my Cardiologist and I discussed whether I should continue to take blood thinners and ultimately, we decided that I should go off Coumadin after sealing off my left atrial appendage. I felt confident making this decision because I trusted my



Mr. David Arsenault (Left) with Dr. Edip Gurol (Right)

doctors and they engaged in a shared-decision making process with me, so I felt that I understood why this was the best choice for me.

Q: What advice would you give to others who have CAA and AFib?

A: I would tell others that they should trust their doctor's advice, and do the best that they can to follow it. Ultimately, trusting my doctors helped motivate me to improve my health so that I could continue living my life. My Neurologist, Dr. Gurol, has helped me realize that these diagnoses are not 'the end', and the end may actually be a long way away.

Q: What inspired you to become active in research?

A: Part of why I take part in research is because I believe in helping others who have been diagnosed with CAA. The other part is because I want to learn as much as I can about CAA in hopes that treatment becomes available.

Q: In what ways do you feel supported in dealing with CAA and AFib?

A: My wife is my biggest supporter; she encourages me to keep up my healthy behavior. I am glad she is there to support me so that I can keep living my normal lifestyle despite these diagnoses. I also feel very supported by the doctors at MGH who have always been very understanding and kind to me.

J. Philip Kistler MGH Stroke Research Center

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WINTER 2018

www.angiopathy.org

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 wonderful 2018!

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

Individual donations can be mailed to:

MGH Development Office c/o Shawn Fitzgibbons
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/>

**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**

