



# **Pathways to a Cure**

## *The CAA Newsletter*

### MESSAGE FROM THE DIRECTOR

**We are thrilled** with the response we have received from the first edition of our CAA Newsletter, *Pathways to a Cure*. It brings all of us at the research center great pride to know that we are providing our patients with a source of information and opportunities to learn about our ongoing clinical trials. The Ponezumab trial, featured in our Spring edition, has brought multiple inquiries from our valued research participants and we are looking forward to further progress in our efforts to test this candidate treatment for CAA.



I have the privilege of chairing the program committee for the upcoming International Stroke Conference (ISC) to be held in San Diego, California in February 2014. This is the world's largest stroke conference and one of the major venues where investigators present cutting edge research for all forms of stroke. Over my years working with the ISC community, I've seen increased interest in the United States and internationally in CAA and the problems it produces, like hemorrhagic stroke and cognitive impairment. I am looking forward to new and exiting developments at this year's ISC. Please check our next edition for ISC highlights.

If you wish to learn more about the International Stroke Conference, please visit their website at [my.americanheart.org](http://my.americanheart.org).

Sincerely,  
Steve Greenberg, MD, PhD

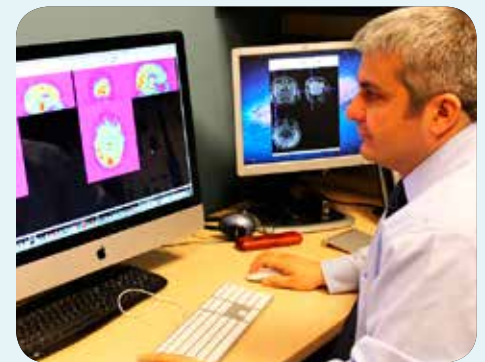
## **Diagnosing CAA Early and Accurately**

**Dr. Edip Gurol**, Neurologist and recognized expert in CAA, recently began an exciting study examining a novel way to diagnose CAA. Accurate diagnosis is an ongoing challenge as there are many causes for bleeding in the brain. A key step towards diagnosing CAA would be to measure amyloid protein in the brain, since this protein is a primary culprit in CAA. When amyloid protein accumulates in the blood vessels, it can cause vessel dysfunction and bleeding. If amyloid protein is present, then CAA is a likely diagnosis. If amyloid protein is not present, then other diseases may be to blame. This distinction is crucial for proper diagnosis.

In this new study, Dr. Gurol examines a specialized compound called

Florbetapir which is currently FDA-approved for other conditions such as Alzheimer's. Florbetapir is a nuclear medicine tracer that finds and attaches to amyloid protein in the brain. Subjects receive an intravenous administration of Florbetapir, and then undergo a 20 minute PET Scan. Any amyloid protein will show up in a bright orange and red color in the scan images. The diagnosis of CAA can then be supported or rejected based on these results.

*(Continued on page 2)*



Dr. Gurol reviewing PET scans



# Pathways to a The CAA Newsletter

## Diagnosing CAA

(Continued from page 1)

Florbetapir may prove to be a very safe and effective way of detecting amyloid protein in patients with CAA.

The compound is less expensive than other compounds previously studied for amyloid detection, and can easily be transported to hospitals around the country and world. Accurately diagnosing CAA may lead to better care, treatment, and early intervention in the future.

To become involved in clinical research at the Stroke Center, please contact Clinical Research Coordinator Thomas Gomes at 617- 726-2941 or [TGomes3@mgh.harvard.edu](mailto:TGomes3@mgh.harvard.edu).

### **In Memoriam: Research Participant and Friend**

**It is with the deepest sadness** that we remember the life, kindness, and generosity of our research participant and friend, Mr. Aram Avedisian. Mr. Avedisian passed away on September 10th, 2013. He was a beloved 59-year-old devoted family man who deeply loved his two children and wife Kathleen. He generously participated in our imaging and genetic research for several years and ultimately donated his brain for continued research. With heavy hearts, we offer our sincerest thanks to Mr. Avedisian and his wonderful family for their invaluable donations to CAA research over the years.



### **CAA Research participant**

Judy Copenhaver, photographed with her husband Albert, reflects on joining the CAA community and beginning to forge new connections with others. "I have been rather tight-lipped since I was first diagnosed with CAA two years ago. Recently, I have been inspired to take a little risk and start sharing just a little bit more. I have been amazed at what others are dealing with as well. Now, I feel much closer to them and conversation, though not dwelling on health issues, is much more open."

Photography provided by Steven Gardner, MD.

## PATIENT SPOTLIGHT:

**In this edition** of *Pathways to a Cure*, Mr. Jan Fens, President of the newly formed CAA Foundation and CAA Association, discusses his journey with CAA. He has taken unprecedented action to find a cure for this devastating disease and encourages each of us to become involved.

### **Would you share a little about yourself?**

I am a father of two children ages 18 and 20, and am a meat importer in the Netherlands. At age 52 I had my first severe headache, and was encouraged to see a neurologist. After MRI scans, a lumbar puncture, and blood work, they realized I had CAA.

### **How are you coping with your diagnosis?**

This diagnosis is very hard for me because everyone told me that this is how it is and there is nothing to do, however that is not the way I am built. That is not the way I see it. I want to fight this and I want to win the fight.

I found doctors in the Netherlands who are actively searching for a cure with Dr. Greenberg. To make a long story short, I realized we have to fund more research to find the right

treatment, and I began to sponsor research. I then started a foundation and an association to raise more money for research and awareness for this disease. Soon we are spreading worldwide.

### **What are some of your biggest challenges right now?**

Most people do not know what CAA means. What is Cerebral Amyloid Angiopathy? I have a saying to spread to the world; CAA also means Cruel As Alzheimer's. Everyone can understand this since Alzheimer's is so well known.

Fundraising is also a very big job. It is crucial for the CAA Association to reach worldwide so we continually connect with one another. I founded these organizations because CAA is a very big problem. Many people do not know that they have it, and they do not know that there is hope for the future. That is what I have to change.

### **What do you want to say to the CAA community?**

We are working very hard trying to find the right medicine and do everything we can to cure CAA. Please visit our websites to become involved:  
<http://internationalcaaassociation.org>;  
<http://dutchcaafoundation.nl>



Jan Fens and his children

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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)

In the spirit of giving this holiday season, 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). Happy Holidays to you and yours from all of us at the MGH Stroke Research Center!



Farewell Dinner for Departing Fellows, Liberty Hotel, Boston, MA

**The Fall** is a transitional time for the Stroke Research Center Fellowship Program. We say goodbye to some of our dedicated fellows and dear friends while welcoming our new 2013-2014 fellows. Every day, these talented young physicians and scientists dedicate their lives to understanding and treating CAA. We feel very fortunate to have worked with such a fine group of people and we look forward to the scientific advances of our new fellows in the coming year.

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

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