

Dear Friend of Angioma Alliance,

Each year, our Angioma Alliance members select a word to reflect their intention for the year. The 2019 word was **BRAVE**, and our members demonstrated their bravery in so many of their actions.

Our first **clinical drug trial** for symptomatic hemorrhage began enrolling in late 2018 at the University of Chicago. This year, 28 brave Angioma Alliance members with recent hemorrhage signed up to test the medication, atorvastatin, to determine whether it is effective at preventing hemorrhage. This is the first year of a two-year enrollment period, and we are awaiting some preliminary results shortly. In Europe, 79 brave patients have enrolled in a separate trial to test the effectiveness of propranolol in treating cavernous angioma.

On November 6<sup>th</sup>, six brave Angioma Alliance members **testified at the United States Food and Drug Administration** to share their experiences. Their impact was profound – FDA staff were in tears as they listened. Cavernous angioma is complicated; understanding the illness will help FDA guide future treatment trial designs. In fact, we may see the beginning of a Phase II trial of a medication currently known as REC-994, which is being specifically developed to treat cavernous angioma, begin as early as next fall. The FDA Listening Session preceded our **15<sup>th</sup> Annual International CCM Scientific Meeting** and our **National Patient Conference**, making for a huge week of learning and sharing.

This year, more than a thousand brave members registered in the newly upgraded **Susan Sukalich International Cavernous Angioma Registry**, allowing us to reach the goal we'd set. We launched a major upgrade of our registry early this year that allows researchers direct access to de-identified data. We also use the registry to inform and recruit our members and to provide a picture of the community to researchers and companies exploring the possibility of developing treatments.



In December 2016, our 4-year-old son Elan had a sudden episode of dizziness and headache, and he couldn't walk straight. After two frustrating hospital trips, Elan had a CT scan and was found to have a golf ball-sized cavernous angioma in his cerebellum. He was admitted to our children's hospital and had brain surgery the next morning.

While we were in the waiting room during his surgery, we searched the internet, desperate for more information. Luckily, we stumbled across Angioma Alliance. The support and hope we have found here continue to keep us going.

Elan's journey hasn't been easy. He now has too many lesions to count, and he had a second surgery for a different cerebellar lesion in 2017. We are constantly worrying. What's going to happen next? Is Elan going to have another bleed? Is he going to get more? We have no idea.

I have been working with Angioma Alliance since Elan's diagnosis, first as a volunteer founding member of the Southern California Community Alliance and now as a part-time staff member, overseeing the activities of Community Alliances in the western US. I can't think of anything more meaningful that I can do to help my family. I believe in a future with a cure for cavernous angioma, and I know that Angioma Alliance is an essential part of turning that belief into reality.

*Lindsay Ramirez*

Hundreds of other brave members **shared their stories with the public** in legislators' offices as they explained the federal CCM-CARE Act of 2019, during hospital grand rounds, on social media, and at fundraising events around the country. We now have 8 regional **Community Alliances** with 6 others nearing formation, as well as 8 **Angioma Alliance-recognized CCM Centers of Excellence** around the country. We are grateful that our members and their care providers have stepped forward to speak on behalf of all affected families.

Finally, 130 brave families participated in Angioma Alliance's **free genetic testing** program. They were able to discover their particular mutation to make better decisions about their and their extended family's healthcare. They also are now ready to participate in any research for which they qualify.

There were far more activities that required the bravery of our community including our major New Mexico **Baca Family Historical Project**, the **member-driven genealogy project among those with the CCM2 Exon 2-10 Deletion** that has led to the discovery of a new founder mutation dating back to 1760, and the creation of a **CCM-healthy cookbook**. Globally, we've seen our affected families organize a **consortium of 10 European patient organizations** as well as **Brazil's first ever national CCM science, care, and patient meeting**.

Moving into 2020, our word is **BELIEVE**. We believe in **real treatments**. We are moving toward a package of interventions that can stem the progression of the illness. Every day we learn more about the positive effects of Vitamin D, a preservative-free diet, and treating sleep apnea. We are excited that potentially effective medications are in trials, and we look forward to even more powerful treatments to come.

We believe in the power of **our stories**. Our stories are changing the future of care as we share them with legislators, the public, medical providers, and each other.

We believe in the power of **joint action**. When we come together in Community Alliances or as a community of researchers or medical providers, we can have an impact far beyond that of any individual.

We believe in **Angioma Alliance**. Our mission is to inform, support, and mobilize those affected by cavernous angioma and drive research for better treatments and a cure. Our staff, Board of Directors, advisors, and hundreds of volunteers have been the driving force behind much of the progress we've seen. Keeping Angioma Alliance strong through volunteer efforts and financial support is how we will all move forward to a cure.

We believe in **YOU**. Join the patient registry, call a legislator, start a Community Alliance, host a fundraiser, offer online support – please make a difference in all the ways you can.

During this giving season, please join us in ensuring that 2020 is another landmark year by making a **tax-deductible year-end donation**. You can send in a check using the enclosed donor envelope or make a donation online at [Angioma.org/donate](https://Angioma.org/donate) or [www.Facebook.org/AngiomaAlliance](https://www.Facebook.org/AngiomaAlliance).

Thank you again for your support of a momentous 2019. Remember, without you, there can be no cure.

With Gratitude,

Connie Lee, Psy.D.  
President and CEO



## Ways to SUPPORT

\$50

PROVIDES PATIENT BOOKLETS TO 15 AFFECTED FAMILIES

\$100

PROVIDES UP TO DATE INFORMATION ON ANGIOMA.ORG FOR ONE MONTH

\$250

SUPPORTS THE CENTER OF EXCELLENCE PROGRAM FOR ONE MONTH

\$500

SUPPLIES TISSUE TO ONE CCM RESEARCH FACILITY

\$1,000

PROVIDES GENETIC TESTING AND COUNSELING FOR ONE INDIVIDUAL

\$5,000

FUNDS A REGIONAL PATIENT MEETING