

Dear Friend of Angioma Alliance,

COVID-19 has changed the face of this year, but it hasn't changed our determination to improve the lives of cavernous angioma patients and their families. You make this possible. With your support, we've made great progress in 2020, and we're planning ambitious new initiatives as we enter 2021. This year, to advance research and care, we:

Began a COVID-19 registry, the only registry in the world tracking CCM patients who test positive for COVID. So far, we've learned that our members do not seem to be more seriously affected as a result of COVID infection than the general public, which is heartening. We should have more data in the coming months. In the meantime, we've offered our members regular webinars with our scientific advisors to keep them up to date on the latest recommendations for our patients.

Created a strong virtual community with support groups meeting at least weekly and countless webinars and informational meetings. Our community is strong and thriving, even though we can't be together in person.

Hosted our annual International Scientific Meeting in a unique format, with pre-recorded presentations and live discussion sessions. Research progress continues apace with some COVID impacts, but so far very little momentum has been lost.

Testified in two critical FDA Meetings to advance the development of the CCM-Health Index as a qualified tool for measuring the effectiveness of treatments.

Inaugurated a virtual poster session series. In these quarterly meetings, research trainees present their work to expert scientists for feedback and critique. We are keeping scientific discussion alive around the year.

Recognized a new CCM Clinical Center at the University of Miami/Jackson Health System, offering an opportunity for multi-disciplinary expert care to those who live in the southern US.

Completely updated our website with a new look and even more comprehensive information for patients, their families, medical providers, and researchers.

Continued our New Mexico program, where we have made such a difference, and geared up our **genealogy work with the CCM2 community**, an effort that will help us find patients and raise awareness.

Continued supporting multiple clinical drug trials as well as the development of other forms of treatment and prevention. We are very excited about the possibilities as we move forward into 2021.



Ben Clayton came to his CCM diagnosis after a long journey with other health issues, some of which led to invasive procedures. When he was finally diagnosed with CCM, he also received genetic testing where it was determined that he carries a CCM3 genetic mutation. At that time, he and his wife Nicole also found Angioma Alliance.

After several conversations with Connie Lee to better understand the illness and the resources available, the family knew they needed genetic testing for their 3 daughters. Angioma Alliance was able to arrange and subsidize their testing. Fortunately, their older twin daughters do not carry the mutation. Unfortunately, their youngest daughter Mary Ellen does, although she is asymptomatic so far.

Through Angioma Alliance, the family has learned about emulsifier-free eating. Nicole has made it her mission to keep the family's diet clean. For CCM3 patients, this is especially important as their gut lining is inherently more compromised. Ben has been able to find support in our weekly Zoom support group. To give back, the family has reached out to their circle to raise funds through Facebook fundraisers, paying forward toward a cure.

"Without Angioma Alliance, I don't know where our family would be now," says Nicole. "These last few years have been a roller coaster, and Angioma Alliance has been our source of information, comfort, and hope."

Accelerating Cures in 2021

In 2021, in addition to our existing programs, we plan to launch an exciting new initiative to Accelerate Cures. It has taken researchers and the patient community years to develop all the pieces needed for a successful drug trial. Within the next few years, we will have everything in place: a robust and eager patient community, tools like validated surveys and biomarkers that will measure the efficacy of a medicine, a network of Centers of Excellence to host trials, and a large pipeline of potential treatments. **We now need to attract the attention of treatment developers** (the pharmaceutical industry and others) in what is a very competitive field among rare diseases. **We need to convey the message that we are ready, that a drug trial is feasible, and that developing treatments for CCM would bring a good return on investment.**

To that end, in 2021, we plan to launch an initiative to accelerate cures. We will be hiring an individual who can coordinate a critical examination of our current resources in order to address any deficiencies, craft a white paper delineating our strong position, and **engage in outreach to prospective industry partners**. The individual will be familiar with business development in the pharmaceutical sector and will have a mission-driven mindset. We have no doubt this initiative will increase both the number of treatments and speed of development for CCM. We ask for your support to launch this critical initiative.

In 2021, we also will be assisting with existing clinical trials and improving care in a myriad of ways. We are **broadening our patient base** with a new **Breaking Barriers initiative** that will offer outreach and connection to Black patients. We will be supporting the start of **Phase 2 trials of Recursion's medicine REC-994** which is being developed specifically for CCM. Our support of this trial includes attending FDA meetings, consulting on trial design, and recruiting. We will finish **recruiting for the atorvastatin trial** at the University of Chicago. We intend to expand our **DNA/Tissue Bank and our patient registry**, and we hope to recognize additional **Centers of Excellence** if travel allows.

During this giving season, please join us in ensuring that our dream of accelerating cures in 2021 comes true by making a **tax-deductible year-end donation**. You can send a check using the enclosed donor envelope or make a donation online at [Angioma.org/Donate](https://www.angioma.org/Donate).

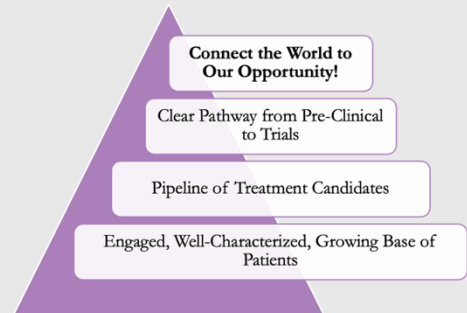
Thank you for your support through this unusual year and for the trust you place in us. We will find a cure together.

With Gratitude,



Connie Lee, Psy.D.
President and CEO

What's Needed For A Cure?



Important CARES Act Tax and Alternate Gift Information

Even if you are not itemizing your 2020 taxes, the CARES Act allows for an additional, “above-the-line” deduction for charitable gifts made in cash, up to \$300, this year only. This means your donation could reduce your adjusted gross income (AGI) dollar-for-dollar.

If you are itemizing, the AGI limit for cash contributions was increased for individual donors. For cash contributions made in 2020, you can now elect to deduct up to 100 percent of your AGI (increased from 60 percent).

Angioma Alliance is able to accept gifts of stock. This allows you to receive two tax benefits: the charitable donation tax deduction and the avoidance of incurred capital gains tax. Please contact our treasurer Karen Buck at karen@angioma.org to discuss specifics.

Finally, please consider donating your old car to Angioma Alliance. More information about car donation can be found on the Angioma Alliance website at:

<https://www.angioma.org/ways-to-give/donate-your-car/>