



# Community Newsletter

#2 | February 2023

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Who  
are  
we?

**CAMK2 Therapeutics Network** is a family-led, scientifically supported international collaboration working to improve the lives of individuals with CAMK2 genetic mutations. The rare gene mutations result in severe neurodevelopmental disorders that affect our loved ones and pose extreme challenges for family life.

We aim to nurture a strong CAMK2 community and, in partnership with our medical and scientific colleagues, to work toward developing near-term treatments by repurposing medications. Our long-term goal is to use precision genetics to develop a cure.

See [CAMK2.org](https://CAMK2.org). Direct questions to [info@camk2.org](mailto:info@camk2.org).



## Latest News



### On 14th January we had our 2nd online Community Meeting.

It was a great opportunity to learn more about CAMK2 - simplifying a lot of the scientific language. We shared the network's achievements so far and what we expect as next steps. It was an important moment to strengthen the community and reinforce the importance of everyone fundraising efforts.



### We created a Welcome Kit for new CAMK2 families!

This is an effort to make all information about CAMK2 accessible and easy to navigate, especially for those who are diving into the subject. We want new families to be able to have things a little bit easy. The kit is available on request and will soon be available for download on CAMK2.org website



## Donation Status



**Total Raised:** **\$65,866.83 USD** (as of 31/11/22)

**First Goal:** **\$150,000 USD** to support research for drug repurposing

**Help Us With Our Goal!**



**Donate Now**



## Fundraising Ideas



Don't know where to start? Here are some ideas...

**Birthday Voucher** - suggest your friends and family do make a donation instead of the traditional gift... who needs more stuff anyway?! =)

**Setup a recurring donation (weekly or monthly)** - Rather than making a large donation, or feeling pressure to do so, anyone can set up a recurring donation for the amount they are comfortable with and can afford. These can be set up on

**Employee/Company Match Program** - This is one of the easiest ways. Companies financially match donations that their employees make to non-profit organizations. Check with your employer for specifics of their program.

**Yard Sale** - Declutter and sell things you no longer need! You can also offer to take things that others would like to donate or get rid of and add that to your yard sale inventory.

# What I have learned from Fundraising

I wanted to share with the CAMK2 community what I have learned. I think I am supposed to say, **"I am humbled by the support of my community and friends." That is actually true.**

And, I am actually awed by the guy I had a crush on sophomore year in high school (but did not really know) who sent in money to support CAMK2 Therapeutics Network. We flirted in chemistry class. He was the Judd Nelson type in the era of *The Breakfast Club*—and I was not that type at all. He now lives in Florida and I in California. We re-connected because I simply joined the "People who grew up in University City, Missouri" Facebook group and he performed an act of kindness.

In order to help my daughter and children like her, **I had to get up the guts to share my heart and my vulnerabilities.** On Facebook, on email, and in person, I have shared my deepest sorrow and greatest hopes with long lost friends, new friends, close friends, work colleagues, and family. And I have asked for help. I was raised to be self-reliant. Asking friends, family, and people I barely know for money may not seem like a big deal, but to me, it was.

The goal of "The Network" is to provide information on this rare disease to families and doctors, but also to provide funding to support science to research treatments and cures. For me, co-founding the CAMK2 Therapeutics Network was not only a way to help my daughter and children like her, but also a way for me **to cope—a way to stay positive and work for hope. For me, there is something therapeutic just in the art of trying.** My primary lifetime coping mechanism is to "try very hard." Consequently, I am a very good "trier." Call me PollyAnna, but I truly believe that if we try hard enough, we will win against this disease. That is my other vulnerability. I actually believe that. I know this leaves me bare not only to disappointment but also to derision of others.

So we founded the CAMK2 Therapeutics Network and the Network forged relationships with physicians and scientists who could help us. And then we built a website. And then we had to fundraise. When we got to this point, I had a panic attack. I was going to actually have to ask for money—and in doing so share my vulnerabilities. I said this to my husband the night before the fundraiser went live. He said to me, **"Do you want to be 'cool' or do you want to help these kids?"**

Well the answer was obvious. So I took a deep breath and actually posted on Facebook outside the CAMK2 group, emailed my friends, and posted to work colleagues. And yes, cliché to say, **I received tremendous support even from people from whom I did not expect it.** Through this effort, I have been embraced by my close friends, reconnected with old friends, and made new friends. Some of the support is in the form of donations and some of the support is in the form of a "thumbs up" or a comment "Thank you for educating me about CAMK2. I have learned so much from you." Another prior classmate shared with me her own hardships regarding her own daughter with a more common genetic illness. Another friend threw a fundraiser on my behalf. She asked all of her friends for money! Translation: **She was willing to perform her own act of courage in support of my daughter and me**

Turns out, all of us as humans have deepest sorrows and greatest hopes. As grown ups, we can see this in each other. It is no longer important to be "cool," it is only important to find connection and to help each other. **I was scared I would be pitied or my optimism mocked. I have instead been embraced.**



Bonnie Dwyer