

BDSRA Board Member Spotlight | Donna Fogle

As a newly single parent, once I pulled myself together from the shattering angst of my daughter's Batten diagnosis, this unimaginable journey began. I had absolutely no clue how much life was going to change after I heard those dreaded words. She was only two years old, and I had never even heard of Batten Disease. Without giving it a second thought, I did what I had to do. I started fighting for my child in the most unthinkable ways. I became an advocate without even realizing it. Advocating at school, with doctors and therapists, with the insurance company, pharmacists, the legislature, etc. Advocacy became a near daily task as did dispensing medication and operating medical equipment that I felt inadequate to do. I researched endlessly for what possible treatments may be available to her here and abroad. I made modifications to my home to accommodate all her new special needs. I did things I never imagined that I would do in my lifetime. All the while, I still had the responsibility of caring for my healthy and active son as well as maintaining my career in the insurance industry. It wasn't easy. But there were lots of wonderful people who made sure I wasn't all alone in this. Strangers literally came out of nowhere who provided me with guidance, resources, support, and hope. Those were things that I needed more than I could ever comprehend. They helped to sustain me, along with my faith, through my greatest challenge in life -- the anticipation of and eventual realization of losing a child.



After a valiant 7-year battle, Kourtney's time on earth came to an end. I chose to try to channel my pain into purpose in her honor and her memory. One of the ways that I could do that was to join the BDSRA board, so I did. My work already had me talking with state and federal legislators regularly about health insurance. Now, I had another more important message to share with them. A very heartfelt

story about a near perfect baby girl who showed no signs or symptoms of any illness whatsoever at birth but who's life was taken by an ugly disease with no known treatment or cure – yet.

That continues to be one of my greatest passions in life is to advocate. I strive to advance the awareness, education and understanding of the needs of families with Batten Disease with the legislature. I also engage with pharma, with researchers, and with anyone trying to help make a difference for the rare families of today and in the future. In 2017 I had the immense honor of sharing my angel's life story with the Florida legislature to help pass RUSP alignment legislation for Newborn Screening. That was a feeling I simply cannot articulate sufficiently with words. I've gone to Capitol Hill in Washington D.C. many times and shared hers and other Batten children's stories with more legislators and staffers than I can count. What I have discovered in this process is that there are some of the best, most phenomenal family advocates exist in our very own Batten community. Batten parents are some of the strongest, most determined people of all. It has been a privilege to be a small part of the big things that are happening in the rare disease space. There are some truly remarkable parents doing some unfathomable things. Miraculous things have happened. I've seen lots of them occur in a relatively short span of time since our diagnosis in 2004. But there is still much work to be done. We need more folks to join us to accomplish our many goals.

I'm currently serving as the BDSRA Board Secretary and chair the Advocacy Committee. I would encourage those who have an interest and passion for serving to consider contributing in some way. Either applying for the board or volunteering to serve on one of the many committees if they are able. If the time isn't right to serve fully on the board now, we completely understand. Perhaps consider committee participation as it is nearly all virtual and the time and travel commitments are minimal but impactful. Our board is currently made up of some talented, caring, and knowledgeable folks who each bring something unique to enrich BDSRA. I trust that there are others within our Batten community who have special skills that would also be beneficial to the board. It would be great to have someone multi-

lingual or a trained clinician/physician or an accomplished fundraiser or a computer programmer/coder, join us - just to name a few. The possibilities for helping are endless. If it is on your heart to do so, I would encourage you to get plugged-in in some way.

Some of the best friendships and greatest bonds I have ever known have occurred within this incredible circle of people that I never wanted to know. People who get it – like no one else really can. People who, just like me, have taken this very journey. People who were also dealt the devastating blow of a Batten Disease diagnosis. People who have lost a child and shown that life can and does go on. People who are unaffected carriers/siblings who have healthy children of their own. People who raise and/or donate money faithfully to make research efforts possible. People who have committed their entire professional lives to the tireless pursuit of developing treatments and finding a cure for us. People who refuse to accept that there is nothing more that can be done -- because there's lots more that can be done!

Without a doubt, some of the most meaningful times of my life have come through serving as a Batten advocate. It helps to give those who follow behind me more hope than what we were given all those years ago. It helps to bring about positive change. It helps to keep Kourtney's memory alive, and it helps to give purpose to my tremendous pain. I also like to think it makes my daughter proud that I am not living a life of sadness since she went to heaven. Instead, I continue to be inspired by her and remain a mom on a mission, unwilling to give up until there is a cure.