

BDSRA Board Member Spotlight | Fred Surrey

I am the father of two Batten Angels. Our daughters had CLN3. Our journey began back in 1996 when our oldest daughter Michele was in the second grade. She began to have trouble keeping up in school and we found out that she was losing her eyesight. We took her to eye doctors, and she received a couple of different diagnoses at first. Then in 1998, her eyesight greatly diminished, and we were sent to see a specialist in Mount Sinai in Manhattan. He said we needed to have Michele tested for Neuronal Ceroid Lipofuscinosis. We received the results in July of 1998 just before Michele's 9th birthday. From that point on, our lives changed.



Like so many others have said, the struggles began. Fighting with the education system, fighting with doctors, fighting with insurance companies. But at the same time, finding BDSRA! BDSRA became a bright spot in our lives. After feeling like you were alone in your battles, the BDSRA family brought us all together to make us realize we were not alone and to give us a place where everyone understood what you were going through. We began bringing our girls to the Annual Family Conference in 2000.

My wife Janet and I gained so many great friends at these conferences, and we remain friends with many of them to this day. The conference was a place of respite for us because the girls were taken in with the affected children and received great care and attention while Janet and I listened to updates on research and spoke to many of the doctors who attended over the years.



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Michele and Lauren were always included in any type of information gathering that the doctors set up at conferences. Blood drawings, behavior studies, disease progression studies, etc. Whatever the doctors were gathering information for at the conferences, we made sure that our girls were there to help gather the information needed to help the researchers towards a treatment or cure.

During that time, we met many board members and executive directors who would always ask me if I would like to get more involved with BDSRA. With two girls in the later stages of the disease, I saw no way at the time that I could get more involved. I had already co-founded and was an officer in the NY/NJ Chapter of BDSRA, spreading awareness and raising money with several different events we held in Staten Island, NY. Janet ran a yard sale for Batten disease for 15 years, and we made many friends through holding that event and spread awareness while still caring for our girls.

Even after Michele lost her battle with Batten in 2018, we didn't give up. We kept the yard sale going, still spreading awareness, and raising funds for research. After Lauren lost her battle with Batten in 2020, the COVID pandemic hit, and we could not have a yard sale.

It was after Lauren's passing that I was approached again and asked if I would like to help BDSRA continue and grow to help future families on their journey. I accepted and became a board member in January of 2021.

I know our girls are looking down and giving me guidance to continue the fight to find treatments and cures to eradicate this disease. I just hope I can do them and the BDSRA organization proud.

