Volunteer Spotlight: Kathy Borello

Our daughter Hannah was born in December 2000 & was diagnosed with Tetrasomy 18p at 5 months old. After Googling her diagnosis, we found the Chromosome 18 Registry & Research Society. Upon meeting with Hannah's doctor, we expected some great revelation. We did… what we received was a packet of information from the Chromosome 18 Registry & Research Society!

I've volunteered for years. All for organizations, that enhanced Hannah's life in some way. But, I realized none of them would ever CHANGE her life. Only the Registry could do that. So, our involvement with the Registry grew, as we realized the life-changing impact it has. From 2013 to 2017, I served as a volunteer on Executive Board as the V.P. of Member Relations & was Co-Chairperson for the 2017 Chromosome 18 Decoded – Annual Family Conference, held in Naperville, IL. My husband Jeff currently volunteers as the Director of Technology, since 2015. In 2018 I resigned my board position, to join our Grants Committee and Conference Committee.

During my term on the Executive Board, I got a behind the scenes look and how much funding is needed to support the research and the families we serve. I saw the hard work and dedication of Dr. Jannine Cody and our clinical research team, Neale Parker and our Registry office team. I saw the need for funding for the clinical research & Registry. So, I decided to focus 100% on fundraising, because "funding equals research."

In April our family helped organize the Starfish Crawl in Normal, IL This month I'm hosting a Yankee Candle fundraiser. In November we are organizing a Starfish Scramble in Naperville. The clinical research & work of the Registry is so important to our affected individuals and families. I truly believe the research can be life-changing; leading to treatment of the conditions caused by chromosome 18 syndromes. As Hannah gets older, I see the need even more. Our research can lead to proactively treating conditions caused by chromosome 18 syndromes, rather than reacting to them. Other groups have seen how beneficial proactive treatment is, in treating people affected by Down Syndrome, Cystic Fibrosis and more. Treating the conditions caused by chromosome 18 will lead to longer, healthier lives for those affected. But, we cannot treat the conditions, unless we identify them. That's why we need more clinical research and the Registry. That's why volunteer. To make a difference to my one Hannah... and to all the others like her.