

## “It All Adds Up” CHARGE Fundraiser

By Julie Brandrup

Writing an article about fundraising is only slightly less intimidating than my initial thoughts on actually having a fundraiser for the CHARGE Syndrome Foundation. But now that it is over, I realize how much fun we had raising \$10,000 (and counting) for the Foundation, and it is so exciting to think how the funds can benefit people with CHARGE. I hope sharing what we did will encourage other parents to give it a try.

First of all, fundraising has always felt a little uncomfortable to me. I don't like to ask people for money, especially when it feels a little self-serving (since my daughter, Adele, has CHARGE syndrome). But at the Chicago CHARGE Conference, Jay and I started to feel the pressure to raise money. And by pressure, I don't mean peer pressure; I mean the internal feeling that if we weren't willing to do something, who else could be expected to? One of the conference presentations that year gave us a better understanding of how the Foundation uses the money, and even more impactful to us was learning what would not get done if the Foundation were left without more support. Research grants were of particular interest to us, especially with the attention sparked by the discovery of the CDH7 gene. I remember hearing that some researchers merely ask the Foundation to help with their postage costs and wouldn't it be nice not to have to turn them down ever again?

That's when our idea was planted, but we waited for a specific milestone in our own life to make it happen. Some of you may know that Jay and I are exactly the same age, literally born on the same day and year—so we are always looking for creative ways to celebrate the unique occasion. We decided to make our 40th birthday a fundraiser for CHARGE syndrome. It seems fairly common to throw a party for your spouse on the big 4-0, so we decided to do it for each other and ask for donations to CHARGE in lieu of gifts. To help people understand they were being invited to more than a birthday party, we gave it the theme: “It All Adds Up.” We hoped this was a clever way to explain that the party was for both of our birthdays and was also a fundraiser.



Our first step in planning was to contact some fundraising superstars, the Bluestones in New York and the Wolfe family in Chicago, to help us with how to word the invitations and handle the

donations. They were all so helpful and inspiring. We used the Foundation's website to start our own "Charge It for CHARGE" webpage for online donations. To tell our story, we made a custom webpage that explained more about the event and why the Foundation is so important to us. See the webpage at <http://www.brandrup.com/40>. (Something similar could possibly be done on Evite.com or a blog site.) From there, we linked the "Charge It for CHARGE" donation page.



We received more than half of the donations before the actual party, and with each new e-mail telling us of a new donation, our excitement and enthusiasm for fundraising was growing. The night of the party, our daughters Adele and Margo put on new outfits, and we all went to celebrate not only birthdays but also the love and support being shown to us by our friends and family. Having Adele there allowed everyone to see for themselves how much progress she has made and hopefully was inspiring to them. Additionally, the party venue had a view

of our Children's Hospital so we were able to reference Adele's time there. We took a few minutes to toast our family and friends and say a few words about how "It All Adds Up." Afterwards, everyone sang "Happy Birthday" to us, and we blew out our "80" candles atop a four-layer cake decorated for each decade of our lives. I wish we had a photo of Adele's face when she saw her name next to the ASL sign for "I Love You"—it was a priceless moment.



Going into it, Jay and I had a good idea that celebrating our birthday with friends and family would be fantastic fun, but I think we both were a little surprised by how enjoyable the fundraising portion was. What's more, because the webpage and "Charge It for CHARGE" page could stand alone as a virtual fundraiser, we have received donations in honor of our birthdays from friends and family from all over the country who weren't at the party. Some of those donations, whether large or small, made us realize that even people who are not in our everyday lives are still very in touch with our story and want to contribute. People really do want to give, and sharing a little of our personal story made for an extremely meaningful event. It felt like a huge success, and it certainly helped take the edge off turning 40.

*Excerpts from party speech:*

*“In planning this night, we wanted to make it bigger than ourselves. And have long wanted (and needed) to raise more money for the CHARGE Syndrome Foundation.*

*To be honest, it has always felt a little awkward to ask for donations to something that affects what sometimes feels like **only us**. But over the last 7½ years, we have learned CHARGE syndrome affects people in all parts of the world, and most of them are in desperate need of information about this complex and sometimes overwhelming syndrome. Starting with Adele’s diagnosis at 5 days old, the CHARGE Syndrome Foundation has been our primary source of support and, to this day, no single organization has done more for us. But in a kind of twisted vice versa, it is the families affected by CHARGE who end up financially supporting the Foundation, and that only goes so far.*



*There’s a running joke among CHARGE families that we need a celebrity to have a baby with CHARGE to get some serious financial backing and attention. If it’s 1 in 10,000, it might as well be a celebrity. We mean no harm, but can you imagine the publicity if (insert current celebrity) had a child with CHARGE syndrome? In the meantime, we’ve realized that it’s just the immediate CHARGE families and the people who care about them...to raise the needed funds.*

*There is a lot the Foundation wants to do, including being able to provide research grants to the medical communities, which is one of the things we are most excited about.*

*Adele is doing better than almost anyone imagined. We get a lot of credit for her progress, but we can say most everything we do has started from the CHARGE Syndrome Foundation—someone’s story in the newsletter, a piece of research, a posting on the website, a conference presentation, so many little things that we would not have known about without the CHARGE Syndrome Foundation. They provide an incredible amount of information that allows us—and families like us—to give our child every possible advantage.*

*We are grateful to be in the position to have caring, generous, and supportive friends—and what can sometimes seem like an “only us” situation, doesn’t feel like it at all tonight. What you have given—and will give—will make a significant difference. It is an overwhelming night of gratitude and joy.*