

Inaugural Joshua Kurby Charge for CHARGE 5K

CHARGE Accounts interview with Sandy Kurby, who organized an event in memory of her son, Joshua

CA: What is your connection to CHARGE syndrome?

Sandy: I first became aware of CHARGE syndrome after my twin boys were born on July 3, 2008. A few days after their birth, Joshua was diagnosed with CHARGE syndrome, although he never tested positive for the gene. Within moments of hearing his diagnosis, we were in the NICU on a laptop looking up CHARGE and came to the CHARGE Syndrome Foundation website. We had the nurses print out the manual, and the entire site, Foundation, and members have been the best support ever since.

CA: Why did you decide to do a fundraiser?

Sandy: On March 14, 2009, my son Joshua passed away at 8½ months of age. While he did not die because of CHARGE syndrome, it was considered a secondary cause because of his compromised system. I had been an avid runner for years before Joshua and Joseph were born and wanted to do something in honor of Joshua while raising awareness about CHARGE. It wasn't until the very end of March that I decided to commit to hosting the 5K event.



CA: Tell me about the event, how did it go?

Sandy: The Inaugural Joshua Kurby Charge for CHARGE 5K was a run/walk event held in our local park. We had many volunteers helping out with water stations, start/finish, registration, etc. We came up with the course; got permits for the race and for sound amplification since we had a DJ there as well; got sponsors to donate bagels; got other food, water, and Gatorade; designed and printed t-shirts and bib numbers; and made signs to direct participants on the course, thank our sponsors, and inform others about what CHARGE syndrome is. The event went really well. There were many CHARGE families, Josh's NICU nurses, friends, neighbors, and people

we didn't know who attended. Some of our greatest compliments were from people we didn't know:

– I wanted to take a moment and thank you for the Charge 5K event. I enjoyed the course immensely, rarely do you have an opportunity to run a path that doesn't end up as an out-and-back or a twice-around. I didn't become bored or impatient and was able to relax into a great run. The bagels were a nice touch. Please tell Panera 'thank you' from me. I appreciate that they would support their community in such a generous fashion. The bagels were wonderful. I have always been a Panera patron, and now I like them even better.

Kind regards,

— Rebecca

Just wanted to take a moment and thank you for the wonderful event you hosted this weekend. My girlfriend and I were in town on business and chose your event because we liked the cause and the location. You and your volunteers did a great job with sponsorship, registration, course layout, timing, and all the small things that make for a pleasant event. Most important, your group created a welcome atmosphere with lots of friendly, smiling faces eager to help in any way they could. Congratulations on a successful inaugural event. Hope you were able to further the CHARGE



cause, and thanks for educating us and letting us help support this worthy endeavor. I hope you will sustain it for years to come. And, I hope I will be able to attend again.

Thanks again, and well done.

— Rob

P.S. As a result of their sponsorship of your event, Panera Bread has gained a fan as well as a customer. I will make it a point to stop at one of their shops whenever I can.

I had a great time. I would have liked to have stayed and talked more, but I had to get my son to Taekwondo lessons. I am glad the rain held off for most of the event to make it easier on everyone. I hope your sister felt it was a success. I certainly did. I hope she is able to have it again next year. Since I am not very familiar with CHARGE, I don't know the details of how it affects kids and families, but given the mortality rate associated with it, I am surprised it hasn't received more media attention. Hopefully, with awareness events like this, it will get more attention, funding, and research. Please let your family know it was a great inaugural race.

— Ryan

Thanks, Sandy. It was a nice race, and I'll be looking forward to doing it again next year.

— Rock (a gentleman that placed in the race)



CA: What advice would you give to others trying to plan a fundraising event?

Sandy: The advice I'd give others trying to plan a fundraising event is to think about your personal interests and experiences and go from there. I had been a runner for several years, ran eight marathons before my twins were born, and felt like I knew what necessities are a part of holding a run/walk event. I learned that there was more that goes into hosting a race than I thought. The other piece of advice is to pick your event and commit to it. The hardest step for me was setting the date: calling the village and park district to make sure the date was OK, and contacting our race timing company to ensure the

date would work for them as well. Once I made that first commitment and wrote that first check, it was scary. You wonder if you'll make the money back that you are putting in (next year I would like to get sponsors to make the event cost free to us, but given our short time to really plan, I couldn't seek sponsorships like I would have liked), you wonder if anyone will show up, and you wonder if you are crazy for doing it. It is well worth it. Everyone had a great time—participants, volunteers, those who just came to cheer others on. It is a great way to raise awareness and raise money for the Foundation. I think the first year is the hardest, but there are people willing to help, willing to sponsor, and willing to make your event the best it can be. All you have to do is start the process.

CA: Would you do this event again?

Sandy: Definitely! I am going to make this an annual event. I decided before the race that I would take a month off before thinking about or planning for next year, but I can't help but let the wheels spin in my head while I come up with ways to improve or things to change for next year. It was such a worthwhile event, and most of the volunteers have already told me to count them in for next year.