

**The Meister Advocacy Fund:  
Every child with Down syndrome deserves an education that will help them to thrive**

Learn More and Donate at: [bit.ly/meisteradvocacyfund](https://bit.ly/meisteradvocacyfund)

**“You know your son the best.”**

That is what the nurses kept telling us when Charlie went to the NICU at 1 day old with emergency surgery scheduled for the next day. We’d have to advocate for him because we knew him best. What did they mean? He was two days old. All I knew was that he had the hiccups for the past 6 months in my belly and gave me horrible heart burn? How did we know him best? But they were right. We knew when things were not right and when to speak up for him.



That medical advice has proven valuable over the last 12 years with him going through at least 19 surgeries and medical procedures. It is same piece of advice I give to other parents facing surgery for their children.

That advice came back to me in the fall of 2022 as Charlie went back to school in person for the first time since March 2020. He went back to the same small private school he had attended since kindergarten.

He knew most of the kids and faculty and was excited to go. But something had changed. The small school had grown. His original class of 15 was now 25. And the classrooms designed to teach 15 kids were now outfitted to hold 25. So, when our outgoing kid who loves to learn, started to refuse to do his work, we knew something was wrong. This wasn’t the same kid. And we had to advocate for him. That included pulling him out of the only school he’d ever known and having our mothers, both retired teachers, homeschool him. That also meant that we would spend the next 9 months looking for a school for our outgoing, smart, charming kid who loves to learn.

**That search [for a school program] was long and painful.**

**It included blatant discrimination based on his medical, not educational, diagnosis of Down syndrome. It involved antiquated stereotypes that “He must be a sweetheart.” It involved more tears than I care to remember.**

**It isn’t something I’d wish upon anyone else. Ever.**

So, when my sister and brother-in law offered to make a donation in Charlie’s name to our charity of choice, it was pretty clear we wanted to direct it to the world of education in some way.

We had been hearing more and more stories of other Down syndrome community families struggling with schools during COVID-19. Many were looking to get what they were entitled to under IDEA. Others, like us, were looking for other options and didn’t know where to look or how



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to start the process. The advice I kept getting was “Get an advocate.” This was new territory for me. I could find someone to help us advocate for him. We weren’t going to have to go at this all alone. And if that was the case, then nobody else should go at this alone.

That is how the Meister Advocacy Fund came about. Upon hearing that my sister and brother-in-law were donating, our parents immediately decided to contribute. Chris and I were able to make our own donation, and use our company match to increase it.

***The Meister Advocacy Fund is there to help families advocate for their children with Down syndrome. Parents know their children best. But, if families cannot afford the advocacy that they need, the fund is there to support them.***

Charlie helped come up with the name, a play on our last name, and one of our many nicknames for him. He said, “Meister Advocates, because Meister means ‘Master’ and we want advocate masters.” So, there you have it. We are proud to announce the formation of the Meister Advocacy Fund, run by the Down Syndrome Association of Maryland. And we invite you to invest in families who have a child with Down syndrome by making a tax-deductible gift to the Fund today.

- Karen, Chris, and Charlie and family

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**Questions? Let’s Connect:**

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