Q&A with Erica Hahn

Interviewed by Joelle Seligson

It’s any parent’s worst nightmare. When her son, Spencer, was nine months old, Erica Hahn learned he had had a stroke in utero. Doctors believed he would never walk or talk. Exhausted, devastated, and needing to get out of the house, the single mom began bringing her baby to the Children’s Museum of Indianapolis, an outing the pair has taken two or three times a week ever since. Spencer not only took his first steps and said his first word at “his” museum, as he calls it, but has now marched in more than 200 of the museum’s End of the Day parades. Hahn spoke with Dimensions about her now 10-year-old son’s remarkable progress and why the museum means so much to both of them. You can learn more about their story at astc.org/myscimuseum and www.facebook.com/200parades.

Erica, tell me just a little bit about Spencer.

OK, well, he just turned 10 years old, and in so many ways he is a typical 10-year-old boy. He is into the Teenage Mutant Ninja Turtles and magic and theater and drawing. He is somewhat of an old soul in that he is addicted to B.B. King music—he actually met B.B. King, he’s the only child to ever wish to meet him from Make a Wish, and they met and became friends—so, yeah, in many aspects he’s just like a—he has some challenges, but he’s happy and he is well adjusted, and he is learning new things every day, just like every other kid.

And when did the two of you begin going to the Children’s Museum of Indianapolis?

I started taking him to the museum when he was probably around eight or nine months old. And honestly, I did it—I wasn’t, at the time, there weren’t a lot of—people walked in the mall for exercise, things like that. And I did it honestly as a way just to get out of my house and to kind of—it turned out to be a great plan, but in the beginning, it really just started as, Mom needs to get out of the house, how can we do this and have some stimulation for the child as well?

What do you remember about his first visit?
Again, I remember—we had just had some extremely unfortunate, heart-wrenching news about his health, a stroke that had occurred in utero, and we had received the MRI results back, which showed that over two-thirds of the left side of his brain never formed, just did not exist. And so I think if I remember anything, I remember him feeling comfortable, and I didn’t honestly know if he would. Stimulation in children, especially children with special needs, can be very overwhelming, can be extremely irritating to their sensory systems, and it’s just—it can be too much. I definitely remember him not showing signs of that. I remember personally having just had this devastating news and not knowing what the future held—I remember feeling overwhelmed myself, because I saw all the typical children, or what looked like typical children, I guess, playing, all different ages, and at a point in our lives when I was so—I didn’t know what his future was going to hold, and I was sad by that, to be completely honest.

**From there you started going pretty frequently, right? Two times a week?**

Yeah. We really were like two to three times a week for the last 10 years.

**Wow. And why do you think Spencer was so drawn to the museum?**

His love affair really started with Rex, the museum mascot, it’s a dinosaur, and if you go when the museum opens, Rex is out, and then Rex also leads the End of the Day parade when the museum is closing. And that was really his first—he was too young to really be interested in the exhibits and what was going on, but he loved Rex. And he wanted to be around Rex all of the time, for sure. He would just light up. I have pictures of him when he was tiny with Rex, and he loves him.

**Why do you think so?**

You know, it’s funny, and again, when it was happening I don’t think I had a conscious thought, but if I look back throughout the years—Spencer was never—the language center of his brain was destroyed. And he was never supposed to speak. And I honestly think that he is drawn to Rex because Rex is the ideal friend, right? He doesn’t pressure him to speak; Rex does not speak himself. Rex communicates with high-fives and hugs, and those things are very comforting to Spencer. As he has grown up and started to realize that there are actors in the actual costume, he’s kind of become fascinated with the ability to be something different than what you are. And I think again, it wasn’t conscious in the beginning, but I think looking back, that is what defines their friendship, is that here was this amazing creature
that placed absolutely no pressure on him and just loved him for who he was, and he responded to that.

**How else do you think the museum has affected Spencer’s life and your own experience?**

I can honestly say with 100% certainty that neither one of us would be where we are today without them. For Spencer, he learns something new every time he goes there, and again, this is two or three times a week for 10 years, and you would think at some point that, you know, you stop learning or you’re not as enthused. But we’re literally there from open to close, and he’s learned something new. The employees, one of the employees is a teacher, she’s a concierge at the museum, she makes flash cards for reading, because he’s learning to read now. She taught him how to tie a tie this weekend. So he’s learning—initially, he used and I used the *Playscape* portion, which is for children under five, for therapy. And I know in those early days for me—I’m a single mom, I don’t have help, and didn’t have the income for expensive therapy equipment and things like that. But going to the museum, I looked around and I thought, wow, this stuff looks exactly like what his therapists bring over to my house. So I used the equipment there as an extension of therapy. He thought we were playing, of course, which is what—he didn’t look at it as work, but I was able to use that, and that would’ve been—I never would’ve had that resource on my own. And so, it’s made such a—a—he took his first steps there, he spoke his first word there, I taught him sign language there, and again like I said, he learned to tie a tie just two days ago there. So it literally has grown with him, and that’s what I love and what I’m forever grateful for, for the museum.

**How do you think the two of you have in turn affected the museum and its staff?**

You know, it’s funny because—I live—being a mom of a kid with special needs, you tend to only think about what is going on—you just don’t have a lot of energy, I guess, for other things sometimes. What I’ve loved over the past couple of years is seeing employees that have, again, watched him grow up and hearing them say things to me or to him that knowing him has changed the way that they may respond to another visitor that has a special need, whether it’s with more patience or with more understanding. I wholeheartedly believe these people are the cream of the crop, and I think they would be amazing to anyone, I’m sure they are. Amazing to anyone, but just to hear that knowing Spencer has made them even more amazing and made them want to learn more, that’s a big deal, and that’s kind of an education that they may not have gotten without seeing him progress.
That’s pretty great. I know that this is something that has been a private thing between the two of you and the museum for the past 10 years—or I guess eight years, and then over the past two everything blew up and went very public. So what was your reaction when AAM [the American Alliance of Museums] nominated Spencer as a Great American Museum Advocate?

Well, first off, I had to keep this secret. The whole time—any mom wants their kid to be a champion, you place them on sports teams or on school projects, and you live for those moments where this crowd is cheering for your child. Sometimes as a special needs mom, you worry about whether or not you’ll have those opportunities, and even something as simple as just like a kindergarten graduation, you may not necessarily get the experience of. So I was told that they had nominated Spencer, and I was asked some questions and went through some history with them, and honestly kind of just didn’t really think about it again. And I don’t know if I didn’t understand the magnitude of what they were nominating him for or I was just in my own bubble, but I remember getting the call that not only had the nomination been completed, but he had been chosen as the first-ever Great American Museum Advocate, and then I had to keep the secret for probably a month because I knew he would want to go right away. So it was amazing. And then again, the museum going above and beyond—one of the greatest moments of my life was, we were at the ceremony, and again I knew the secret ahead of time, but I had given my speech, and Spencer came up, and he was really nervous to give his speech, he didn’t know if he wanted to talk, and at the end he finally said just a few sentences. Then I was able to announce to him that Rex had come all the way from Indianapolis to Washington, D.C., to greet him and to congratulate him on his award. He had just had surgery on both legs, he was in a wheelchair, and this child is jumping up and down, there’s not a dry eye in the house—just that moment, the culmination of it all. Here was his first true friend and probably his oldest and dearest friend, and he’d come all the way to say thank you. It makes me want to cry now just thinking about it. It was beautiful.

What a great moment. And it sounds like he’s really taken it all in stride.

Yeah, he has no concept—he understands that—he calls himself an ambassador for the museum, so he understands—and I use that sometimes, if we are nearing—he has autism, so if we are nearing a meltdown, we are nearing some sort of uneasiness, I like to remind him that he needs to maintain his best behavior at the museum because he now kind of represents that. He wants to work there, so we talk a lot about what it means to work there, what it would be like for him to wear the Rex costume, which is what he hopes to do when he grows up. He’s paralyzed
on his right side so he’s terrified that his right arm is not going to fit correctly into the suit, and another amazing everyday memory that I hold really close to my heart was one of the employees sat down with him for probably 20 minutes on a break and went over exactly what the costume—how you put it on, how the costumer could make adjustments and fit it so that if in fact he does work there and become Rex, he can wear the costume just like everybody else.

Is he still working on a book on his experience at the museum?

He wrote a book right around his 100th End of the Day parade. These End of the Day parades have become really his new fascination—when I say “new,” it’s probably been going on for four and a half years now. When he completed his 100th, he wrote a book, and he is working on a book because he did just complete his 200th parade, and the great thing about this one is that he can read and write now. The first one, he pulled out the pictures that he wanted and then he told me what he wanted to say and I typed it into the computer, but this one he’s actually writing with his own handwriting.

It’s incredible. And he was recently raising money with his End of the Day parades for other children and families with disabilities, is that right?

It is, yeah. So for the 100th parade—I like to give—I feel like he has been so blessed by the museum, not just in the awards and the accolades—we went to the White House and met [U.S. First Lady] Michelle Obama [when the Children’s Museum of Indianapolis received a 2014 National Medal for Museum and Library Service], the things he has done are amazing. But I like to use every experience as a learning experience. So around the 100th parade, we started talking about how he could give back. At the time he was very interested in the Lilly Theater, which is the children’s theater in the museum. He loves all the actors and we see—there’s a 1:00 and 3:00 show, and we’re at both every weekend during the run of the play.
And we wrote—he raised money for the 100th parade for the Lilly Theater, and he raised over $1,000. This time, for the 200th parade, we talked a little bit more, because he’s older now and he can kind of understand that there is a difference between him and other children, and just how he can give back to help kids access the museum in the way that he was able to. So he raised money for the 200th, and it’s going to go into a fund for kids with special needs, into things like sensory bags that are available at the concierge for kids who may need earphones or some sort of tactile, sensory thing to play with, maybe their parents didn’t bring it with them—just so they have, so they can enjoy the museum even though it could be overwhelming. I’m very proud of him. The other thing I’m really proud about with the 200th is in talking about giving back and our journey with a decade at the
museum, he decided that he wanted to introduce his friends at the museum to everyone. So the museum literally gave us access to interview—he chose 25 employees, and he interviewed each one of them, and then for each parade from 175 to 200, he highlighted—we posted on the Facebook page his interviews with the employees [www.facebook.com/200parades]. And I was so proud of him for wanting to introduce these people and to champion these people because again, so many of them have been with us for 7, 8, 10 years—it’s really amazing how long they have been on this journey with us. So I was really proud of him for being able to not make it all about him—that he wanted to share that with other people.

Well, he probably has a few years before he can officially start as Rex, right? So where do you see him going from here?

Well, we just completed parade 203, so he is on track to get to 300. [Laughs.] We are still going—I bought him for Christmas, interestingly enough, an art set, and he started drawing pictures of him and Rex, so that’s kind of expanding his creativity. I think that he—some downtime is good, obviously, but I know that he’ll continue to grow there, I know that when we get to 300, I will have an entire new list of things he has accomplished there. We’re in an exciting time, because I spent so much time at the beginning talking about first steps and speaking and all of this, but what I love is, as he gets older now, he is interested in the exhibits, and he’s learning from them, and I think he’s going to continue to grow, and I hope that the people there continue to grow as well from knowing him.

And you mentioned for yourself as well that now that you’ve spent all this time with museums, you might pursue it professionally. Where do you see yourself going?

It’s kind of something that I’m just kind of thinking about. When you have your story, you don’t necessarily think it’s a big deal. At the time, I didn’t set out to have all of these first things accomplished at the museum. I remember receiving his diagnosis and honestly crying in a corner for days. And now, seeing where we are 10 years later, I feel like I really want to help give back to other parents who may be in the same situation that I am or was, whether that be without the financial means to do the therapies or the equipment needed, and just let them know that there is this amazing place where you can have access to all of these things. And I think that to just be able to give back in that way, because our story could’ve had a horrible ending, and it didn’t, and I believe that is due in such large part to the museum and what they have gone through and been through with us over the years. So I would love to—you know, it’s funny, because your child should really learn from you, and to be entirely honest, I learn from him more than he probably
will ever learn from me, and to take his cue and want to give back to other people the way he is.

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