

Why You Need to Be at the HPS Family Conference

My first conference was in 2013. I was a scared 28-year-old mom who had just received her 18-month old's HPS diagnosis two weeks prior. We had zero expectations of what conference would be like, what the agenda was, and we did not know a single soul.

But if that is where information and researchers were going to be, then that's where I was going to be too.

I'm not going to lie, that weekend was ROUGH. Like, crying in my hotel room for a couple of hours rough. But it was also something else, something very much like hope.

After taking an emotional beating throughout the Saturday sessions, we attended the Saturday night dinner. If you've never been, it is an experience. At this dinner, there are parents, adults with HPS, kids with HPS, a whole community. They come together to CELEBRATE. Can you imagine? I had just had my heart torn out and they were having a party! But it's not just the HPS community, our researchers are there too, celebrating with US. It's a beautiful sight to behold.

As the night wore on, I got it. I could stew, sulk, and be angry at the world, or I could do what our Executive Director and Founder frequently says and said that night: I could learn to dance in the rain, and so we did.

Sunday was critical for me. Doctors and researchers way smarter than I gave their talks. I scribbled furiously, planning to google what I didn't understand or ask my sister, a nurse. I saw the value of these doctors looking at the patients and parents in the eye while they delivered updates. Our bodies in those seats are their motivation.

My first conference, we were a family of four, with Leanna recently having had strabismus surgery and only 18-months old. She's now a tween of 12, and we've added two more siblings to the mix. What we've also added was hope and optimism. We have seen the progression of the research, the movement of the needle, but most importantly, we have gained a place where we belong. A place where everyone understands the worry of a bleed that won't stop or a funny bruise story. A place where it may be the only place Leanna sees another person with HPS. It's more than just a place, it is home, it is sanctuary, it is family. And it is worth every sacrifice to be there.

I hope to see you there to welcome you to the family or to catch up like only family can. Let's GO!

Becky