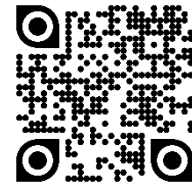




Hermansky-Pudlak Syndrome Network Inc.  
One South Road, Oyster Bay, NY 11771-1905  
1(516)922-4022 info@hpsnetwork.org  
www.HPSnetwork.org



We all have moments in our life that will be etched in our mind forever, you can recall exactly where you were, what you were doing and how you were feeling. Some of these memories are happy and exciting while others can completely derail your life's trajectory. For me, one of these moments took place on a September afternoon; I was standing in the kitchen cleaning up after lunch when that out of state number appeared on my phone, I quickly stopped everything I was doing and snuck away to the closest quiet room, shut the door, and sat tensely on the edge of the bed. I took a slow deep breath to try and calm my nerves because this was the phone call I had been anxiously waiting for. After his introduction I listened to the voice on the other end as he confirmed my worst fears, and told me: "Your daughter has HPS1"...

Time stood still and everything around me seemed to fall silent. I closed my eyes and bowed my head as I continued to listen to all he had to say. While I could feel my heart beating heavy in my chest, it also felt like it sunk to the pit of my stomach. I tried to conceal my tears and emotion as I finished the conversation and graciously said thank you for letting me know as an attempt to be polite. Now what... how do you process this life changing information. What was just a possibility a few minutes ago, had now become a reality. My mind was overwhelmed with so many thoughts, fears, and emotions; life was flashing before my eyes; how do we process this, how do we explain to our daughter and others around us, and what does this mean for her future?

While this is just one person's story, so many others can relate to the heart stopping moment of receiving their official diagnosis of Hermansky-Pudlak Syndrome.

The stories may be different, but the one thing is the same, we all turned to the HPS Network for guidance, support, and a sense of belonging. Those first moments of feeling hopeless, and alone fade when you connect with the HPS community and learn about the HPS Network's mission.

There is a defining moment after feeling so isolated and helpless when you finally connect with other people who truly understand the journey you have been on and the struggles you will face. I often recall the impact of attending our first HPS Family Conference, it was a therapeutic and inspirational experience to share stories, share laughter and tears and learn from the different generations on this voyage. It was at this first conference that I felt a sense of peace and my sadness had turned to **HOPE** because I knew we had found our place. I knew the HPS Network was the support system we needed, and these were the people that were going to help us survive this rare journey. This life-changing experience was possible because generous donors have continued to support the HPS Network!

Dare to dream with us; what if no HPS person was left undiagnosed searching for answers; if every person felt supported, had the education needed to advocate for their unique HPS needs and had access to knowledgeable providers and treatments. **Think of how your support could advance research to improve quality of life and one day a cure for this rare disease.**

This is all possible and you can be a large part of the journey that gets us there; your investment and dedication to the HPS Network guarantees that the next person who hears the words "you have Hermansky-Pudlak Syndrome" has a place to go, a community to be a part of and most importantly a sense of HOPE that research is being done to improve the future of this devastating rare disease.

On behalf of those with Hermansky-Pudlak Syndrome, I appreciate your time and invite you to join us on this mission by donating to the HPS Network! Your contribution makes it possible for the HPS Network to continue on their quest to raise awareness, provide support, find effective treatment and the dream of a cure can be a reality! Your actions today will have a positive impact on the future of Hermansky-Pudlak Syndrome!

Most sincerely,

*Kristen Brantner* (Mom of 2 children with HPS1)