

# Hope, Gratitude, and Empowerment

By Savannah Lillywhite

Hope, gratitude, and empowerment. Those were my biggest take-aways from attending the 9<sup>th</sup> International Congress on Schwachman-Diamond Syndrome last April.

My story is a little unique in that I have had a child pass away from complications of having SDS and then a few year later having another child with SDS. In 2012, my husband and I had a beautiful baby boy named Andrew who spent his entire action-packed 3 ½ months of life in the hospital until he passed away due to respiratory distress as a result of Schwachman-Diamond Syndrome. Fast forward through about four years of trying to remember Andrew without thinking of SDS as much as possible, a failed IVF attempt, and then having Lincoln, who has the same syndrome, the summer before conference. I share this only to convey that I went into this conference having fully experienced what SDS can cost families but also with hope for Lincoln and other children and adults with this disease, as well as a desperate need to not feel powerless.

Hope, gratitude, and empowerment came hand in hand from witnessing some of the brightest minds in the world gathered together to share their treatment goals and research progress specifically related to Schwachman-Diamond Syndrome. Being present for the conference gave a unique opportunity to ask general questions after presentations as well as specific questions related to my child during break times. For example, not only was I able to visit with my son's gastroenterologist who was in attendance, I was also able to ask opinions from another gastroenterologist who had flown in from Australia! Beholding brilliance combined with devoted empathy and kindness, knowing that they truly care about the lives of individuals and families fighting this all-encompassing disease, and are working hard to improve patient outcomes, nearly overwhelmed me with gratitude. I was able to extend heartfelt gratitude to doctors and researchers from across the United States, Canada, France, England, Italy, China, and more for all they are doing to help find better treatment and a cure for SDS.

It is important for individuals and families dealing with SDS to continue to give a face and heart to this syndrome at these conferences, so that the most important reasons for research, our children, parents, siblings, etc. are never forgotten. What was most meaningful to me, were the relationships formed at the conference. I was blessed to become friends with not only some of the brightest minds in the world, but with some of the biggest hearts. When speaking with an incredible doctor and researcher from the UK about Andrew, I in turn was able to learn about his life. Through the opportunities to have conversations in between sessions and on the planned excursion to the NASA space center, I gained an unexpected, treasured friendship. I also was able to make and deepen friendships with individuals and other families living with SDS. Some, I previously had the privilege of befriending on social media and were finally able to meet in person. This was huge for me. When Andrew was alive, I had not yet found the Schwachman-Diamond support group on Facebook and had felt very alone. Having the love and support of others dealing with SDS is invaluable and any opportunity to gather together is one to be cherished.

Empowerment also came from being able to gain a deeper understanding of Schwachman-Diamond Syndrome as I listened to the presentations, asked questions, and looked up concepts I did not understand. Admittedly, there was much that went over my head. However, each exposure to the medical terminology associated with SDS provides another chance to deepen understanding. Additionally, a congress program and abstract book of presentations given was provided, so I can go back and review and study what was discussed. An online copy of this can be found on the SDSF website.

Moreover, attending the conference empowered me to put more effort into fundraising. While this is something I still need to improve upon, seeing in person that experts around the world are actively working on finding better treatments and a cure, and that SDSF helps bring them together and helps fund these goals, was powerful for me. At the end of each presentation, the presenters would thank various organizations, and SDSF was frequently on the screen being thanked for their support.

In conclusion, I left the conference with more hope and empowered than I expected to; for that I am forever grateful. Though there were times I felt a little

overwhelmed by all of the information being given, being able to talk with doctors, researchers, and families about SDS helped me come away with not only a better understanding of the disease, but also with cherished friendships, renewed determination as my son's advocate, a larger understanding of the importance of fundraising and motivation to support the Schwachman-Diamond Syndrome Foundation hoping that one day we will have our cure.