

Episode 8 – Selective Mutism H.E.L.P. – Who am I?

Hello and welcome to the Selective Mutism HELP, Home Educational Learning Program, Podcast, my name is Kelly, and I will be your host. This podcast aims to give you the help you need to support the person in your life affected by Selective Mutism. In this episode, I'll be telling you about Selective Mutism H.E.L.P., who is involved, the purpose, and information available when it comes to learning about Selective Mutism. Let's get started.

Welcome to episode 8 of the Selective Mutism HELP Home Educational Learning Program podcast. My name is Kelly, and I am a parent of a child with Selective Mutism. Being that I am a parent and not a medical professional, this podcast is for informational purposes only. I wanted to take this opportunity to tell you all a little bit about myself and why I created Selective Mutism H.E.L.P. The quick version of who I am is, I am a mom who has a daughter with Selective Mutism. At the beginning of our journey, I struggled with figuring out what caused our daughter's SM. I put a lot of guilt and blame on myself. Maybe if I would have gotten the epidural during labor earlier she wouldn't have swallowed meconium. Since she swallowed meconium, the doctor didn't want her to aspirate it so they didn't want her to cry out when she was born. Did this lack of crying out prevent her from integrating primitive reflexes? Is that why she has SM? Or maybe it was because I used the ultrasound machine at work too many times to peek in at what she was up to while I was pregnant. Did this prevent areas of her brain to develop normally? Maybe we pushed her to walk too early, again not allowing her primitive reflexes to integrate. Maybe I was too anxious when she was young and my anxiety rubbed off on her. Did we do enough socialization when she was young? If only I knew what SM was earlier, I could have been aware of myself rescuing her and protecting her and maybe her SM wouldn't have been as severe as what it was. Maybe I should have snuggled with her more and not used the "cry it out" method. Maybe I shouldn't have swaddled her at bedtime and naptime so she could move more when she slept. All of these Maybes and What ifs were constantly circling through my mind. But, from those worries came action. I couldn't sit with those thoughts anymore – they weren't helping anyone! I needed to start taking action.

The first steps involved in me taking action was finding help, finding resources, and finding support. Here in the US, we have an organization called the Selective Mutism Association. They had a list of providers in each state that offered services for treating SM. Our state had one on the list, so that was where I started. We started therapy shortly after we found out what Selective Mutism was. The next part was finding resources. I started with an SM book by Dr. Aimee Kotrba that gave in-depth information about SM and how to go about treating it. I also got the children books that Lucy Nathanson with Confident Kids wrote to help our daughter understand what was going on and to let her know that she wasn't alone. I then found support. I found the Parents of Selective Mutism Facebook Group and put a post out there asking if anyone was from our state. I found someone who lived just 10 minutes from us and we met up at the park one day. I feel like this was the turning point for me. I no longer felt alone, I no longer felt responsible for causing my daughters SM, I had hope and guidance.

With the help I got from other parents, I was determined to pay it forward. I became one of the State Coordinators which was supported by the Selective Mutism Association and I began getting contacted from others that were experiencing the same things I had been experiencing. From there, I was able to get together a monthly parent support group. Once a month we would meet at a local library and discuss various topics pertaining to SM. It was a way for everyone to be real with what was actually going on. We could open up and share our stories,

give hope to others, and feel like we weren't alone. But, everything changed once Covid hit. We were unable to get together anymore for the support group and it was difficult to coordinate a zoom call while we were all at home because now we were at home with the kids. Most of our kids were little so we couldn't send them out of the room for an hour while we talked about their diagnosis without them hearing us. Therefore, I had to put the group on hold.

As the months went by, I felt like something was missing. I had grown almost dependent on these monthly meetings to be able to connect and without it, I felt empty. One day, I got an email with a subject line of "Do you have a passion you've put on hold" or something along those lines. I opened the email and it was a webinar with a tutorial on how to host an online summit. I don't think I even knew what an online summit was at that time, but I was intrigued. Come to find out, a summit is like a conference but it is online instead of in-person. My husband and I attended the SMA conference which was so helpful, so the idea of doing an online conference sounded very interesting. As I went through the webinar, I realized that an online summit about Selective Mutism could benefit so many people! Not just people near me, but people all over the world could have the same opportunity to learn about Selective Mutism. I wanted the information to come from professionals in the field of SM, as well as professionals from other fields like Occupational Therapy, and I wanted it to be information from those that have experience SM first hand. I also wanted it to be free to access, so there wasn't an excuse for anyone to not be able to learn about SM.

That is how Selective Mutism H.E.L.P. got started! In order to host a summit, you need a website, to have a website you need a business name. The acronym H.E.L.P. stands for Home Educational Learning Program. I wanted people to know they could learn about SM, find resources, and support all from the comfort of their own home. In the Fall of 2020, only three months after the life changing email, I hosted my first ever Selective Mutism H.E.L.P. online summit. I had a great team working on this project with me – it was me, myself, and I. Together the three of us, which was really just me, were able to reach out to various professionals and pitch the idea of having them be a speaker for the Summit. Talk about intimidating and scary! But, I did it, and I was blown away by the responses I got back from the professionals I contacted. They were onboard and excited to be interviewed. I had no idea what to expect as far as turn out for the summit, but I ended up getting 1200 people registered from around the world! I was amazed and humbled! So many people put their trust in someone they had never heard of to find out more information about Selective Mutism.

After I realized the effect this Summit had on so many people from around the world, I knew I had to keep doing them. So, I decided the 3rd weekend of May and October would be when Selective Mutism H.E.L.P. Summits would be available. In the Spring of 2021, I put on another summit with different presenters from the first one. For that Summit, I had even more people register. It was about 1800 people from over 50 different countries. Somedays I still don't believe that all of this has been real.

After the two Summits, a lot of the feedback I was receiving was that parents needed more information for their teens that had SM. Being that my daughter is still young, I knew I didn't have the knowledge or experience to help them. So, I decided to take a leap of faith and have all the topics for the third summit to be information for teens and adults with SM. At the time of this podcast recording, the third Summit is coming up on October 22-25th, 2021 and registration is now open! There will be 7 speakers – 4 professionals, one parent of SM teens

who is also an advocate for SM, and two adults with SM sharing their story of what life has been like for them. Usually in these summits there is a lot of back and forth conversation with me and the speakers, but in this one, I was just sitting back and listening to many of them. The information is helpful and makes you realize how different it is for a teen or adult with SM compared to a young child.

Now, I didn't record this podcast episode to toot my own horn or hope to get praised and commended for doing all this work. I wanted to share this information to let you all know that I am just a mom with an SM daughter. I am just a mom who doesn't want to have other kids suffer like our daughter did. I am just a mom who wants to spread awareness, have conversations, and help both parents and professionals understand Selective Mutism. For me it isn't about being better than another organization or making money or coming across like I know everything about SM. It's about just being a good, kind human. Too often kindness gets pushed aside. I want to be a good example for my kids and teach them that if they struggled with something, there may be someone else struggling too and you just maybe they can help some else struggle a little less.

I want to thank you for listening to my story and how Selective Mutism H.E.L.P. came about. I want to encourage you to try to find one way to spread awareness about Selective Mutism. Or see if there is a way you can start a parent support group or become a State Coordinator. I hope you will join me for the upcoming free online summit. You can get more information and register by going to www.smhelp.org/free-summit. Finally, If you are a parent or a professional or someone who has SM, please know that I am here for you. I will listen to your concerns, cheer with your successes, and share whatever information I can to help you. You can email me at smhelp2020@gmail.com or find me on Facebook and Instagram by searching for Selective Mutism HELP. Take care everyone!

Link to register for the free Online Summit: www.smhelp.org/free-summit

If you would like to contribute to the operating costs associated with the website, this podcast, and the free summit, visit <https://www.smhelp.org/awareness-merchandise.html>