

Advocacy - Pediatric Stroke Awareness

Mary Kay Ballasiotes, mother of a pediatric stroke survivor and advocate

Did you know that strokes can happen in babies, children and teens? If not, unfortunately you are not alone. I remember attending my first meeting with SSEEO back in 2005 and sharing the story of my daughter Michelle's stroke before birth. No one at SSEEO had heard about it either, but they were interested in helping raise awareness. That was how I became a SSEEO board member in 2005. I also became a volunteer for the American Heart Association/American Stroke Association (AHA/ASA) and over the past 12 years Michelle and I have been actively speaking out about strokes in children at many events.

When we lived in the Chicago area, there really wasn't any local support for families like us, so I founded a group for children impacted by stroke. We had quarterly meetings and get-togethers where parents could meet healthcare professionals, and share resources. The kids loved meeting other children who were "just like them". We partnered with SSEEO for events like the Strike out Stroke baseball games. Michelle and I also have had many opportunities to raise awareness for pediatric stroke with the AHA, including forming a heart walk team in Glen Ellyn with 24 little survivors, 200 of their friends and family and SSEEO members. We also attended AHA National Lobby Day events along with members of SSEEO. Once we moved to Georgia in 2008, Michelle was chosen to be the AHA National Youth Advocate of the Year in 2009 and the Augusta, GA Stroke Hero for the Heart Ball and Heart Walk.



Mary Kay and Michelle

The highlight of our advocacy work was our trip to Sharjah, UAE. Michelle and I were honored to be selected as delegates for the first [Global NCD Alliance Forum](#) in November 2015! It was an incredible opportunity and experience to meet advocates from around the world and put pediatric stroke on the global stage. All of these opportunities have allowed us to educate and raise awareness that strokes can happen at ANY age!

Since moving to Charlotte, NC in 2010 there hasn't been an opportunity to form a local group, but I was able to put together a global organization, [International Alliance for Pediatric Stroke](#), dedicated to advancing awareness, education and research for babies and children impacted by stroke. We have partnered with the AHA and University of North Carolina in Chapel Hill to create fact sheets, videos, a healthcare providers' learning module, a Patient and Family booklet, and medical brochure. I encourage you to visit our website learn more about pediatric stroke and how you can make a difference for this population!

[Click here to learn more about perinatal stroke](#)
[Click here to learn more about childhood stroke](#)

This Month's Book Recommendation

The Luckiest Girl in the World: My Story of Struggle and Hope in Overcoming Pediatric Stroke

by Jamie Lee Coyle

"Growing up, everyone would always say how lucky I was, but at the time I was not sure what they meant. I was just doing what I always loved; skating and playing ice hockey. Everything seemed to go my way, from winning virtually every raffle I entered to scoring the game-winning goal whenever my team needed it.

As I got a little older, I could feel these things before they happened, as if I knew that I was going to catch the corner of the net to get the puck past the goalie as time expired. I felt like the luckiest girl in the world. Becoming an Olympian was something I thought about as far back as I could remember. By the time I was twelve, I was well on my way to living my dream.



Then, on August 9, 2008 I suffered a stroke during a hockey game. No one suspected that such a thing could happen to a twelve-year old, but as the reality of pediatric stroke turned my dream into a nightmare, the journey back to skating and playing hockey again showed me just how much I could accomplish with the love and support of my family and people all around me who cared. And I came to realize that I truly was the luckiest girl in the world."

Available at local libraries and Amazon.

Resources



The International Alliance for Pediatric Stroke (IAPS)

A stroke can happen to **anyone** at any **age**, including babies, children, teens, and even before birth. Unfortunately, there is very little information, support, and research for this population. The International Alliance for Pediatric Stroke (IAPS) was created to bring together global pediatric stroke communities, uniting in a common effort to advance knowledge, awareness and research for these children.

Our mission is proudly supported by leading pediatric neurologists and all of our information is approved by the physicians on our board. Our website provides extensive, comprehensive, and reliable resources for pediatric stroke. You can Get the Facts, share our Fact Sheet, connect with other organizations, get access to many publications and much, much more.

IAPS's grassroots efforts are already making a difference, but we have a long way to go. Your support through donations and raising awareness are greatly appreciated! Check out our [How You Can Help](#) page to find easy ways you can make a difference for children who have been impacted by stroke. Sign up for our newsletter to stay up-to-date on the latest information about strokes in children.

IAPS welcomes your comments, suggestions and questions. Please join us on this mission! We want to hear from you, so if you need help navigating the uncharted path of your pediatric stroke journey, contact us. Together we will make a difference for all children who are impacted by strokes! To learn more about IAPS visit us at iapediatricstroke.org.

Survivor Story

Lori Malawski, mother of Alex and Amanda Malawski, pediatric stroke survivors

Our life has been one adventure after another since our twins were born. Both children were born 11 weeks premature and subsequently suffered strokes after they were born. As a result of their strokes, they have cerebral palsy. Amanda is affected on the right side of her body and Alex is affected on the left side of his body. Now 16 years old, they are active teenagers with very busy schedules.

My husband and I have always wanted to travel and now our summers are filled with one track meet after another across the country. The children are a part of the Great Lakes Adaptive Sports Association (GLASA) which specializes in sport activities for people that have a physical or visual disability. They have participated in track, field, swimming, water skiing and triathlons. This year will be their eighth year of participating in the Adaptive Sports USA Junior Nationals which occurs in Madison, WI. Athletes up to the age of 23 attend from all over the country and we have become great friends with many of the families.



Alex



Amanda

Amanda has excelled at track and is hoping to make the Paralympics in 2020. She participated in the trials for Rio last summer in North Carolina and is on her high school track team. She has also represented the USA by competing internationally in England and in the Netherlands. Alex has a love for movies and writes movie reviews for his school newspaper and has an online blog for all of his film reviews. He recently received an adaptive three-wheel bike and has spent the summer on many bike trails.

Although we spend a lot of time watching and participating in sporting events, we still make time to share our stroke message. One of our first presentations was at a SSEE annual stroke conference. Amanda, Alex, my husband and I shared our stroke story along with our love for sports and involvement in adaptive sport programs.

We continue to publicly speak about pediatric stroke and are determined to get the message out about stroke, pediatric stroke and that stroke can happen at any age.

NEW.....SSEE Photo and Video Gallery



See the many faces of SSEE at our newly updated Photo and Video Gallery. Take a moment to explore the newest additions at sseeo.org.



Toll Free Teleconference Series: Tuesday, August 8th, 2017

**STROKE RESEARCH STUDIES
AND WHY YOU SHOULD PARTICIPATE**

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