FAMILY & COMMUNITY
Planning for the Holidays
A Very Special Bat Mitzvah
Advice: Self-Acceptance for Parents

MLB to Special Needs Parent—Shonda Schilling Talks to EP

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EARLY INTERVENTION
Tele-Intervention

UNITED STATES MILITARY SECTION

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I have known Shonda Schilling since 1995. She and her husband, retired professional baseball pitcher Curt Schilling, were in Washington, D.C. advocating for ALS (Amyotrophic Lateral Sclerosis—also known as Lou Gehrig’s Disease). My late husband Kevin O’Donnell (who had ALS) and I were also there advocating for the disease when the four of us had the chance to meet. We were all approximately the same age. Kevin and I had our young daughter Alina, then two years old, with us. The Schillings had their infant son Gehrig with them. Curt Schilling was pitching for the Philadelphia Phillies and ALS was their designated charity. What I remember most about that initial meeting was the enormous warmth and humanity bestowed on us by the Schillings. They were sincerely concerned about our well being as a young family fighting a terminal illness. In fact, their dedication was evident when they named their first child Gehrig.

Kevin was an amazing, funny, loving man. He and I had several opportunities to attend the Schilling’s holiday parties because of our common fight against ALS. Kevin bravely faced ALS until 2001, when he succumbed to the disease at 36 years old. The Schillings moved around with Curt’s teams and were busy raising four children. We lost touch.

While on vacation, I saw The Best Kind of Different in a small bookstore. I immediately contacted Shonda to share my feelings of inspiration and gratitude.

Her first book and a New York Time’s Bestseller at that, The Best Kind of Different is a true account which documents life before Grant’s diagnosis and after. It also touches upon how most members of the Schilling family struggle with Attention Deficit Hyperactivity Disorder (ADHD). It’s brutally honest, touching, intelligent and easy to read. It’s the perfect gift for any family facing challenges.

I met Shonda in Riverton, NJ, at Orchard Friends School to hear her speak on the spectrum of autistic disorders.

To onlookers, Shonda Schilling is strikingly beautiful, poised, and impossibly fit for a mother of four. Her four children, Gehrig (15), Gabriella (13), Grant (11), and Garrison (9) are very lucky because they have an incredible mother. In addition to her role as mom, advocate, and author, Shonda is also a melanoma survivor and the Founder of Shade (http://www.shadefoundation.org), a non-profit organization dedicated to eradicating melanoma through the education of children and the community in the prevention and detection of skin cancer and the promotion of sun safety.

In the gym of Orchard Friends School, Shonda and I had a chance to catch up. After hugs, we got right to my questions.

JA: Thank you for writing this book! It’s an honest portrayal that will help other families better cope with the challenges of AS. I was thinking back to when we met as advocates for ALS and was wondering if your role as a young wife with the Phillies prepared you for this role?

SS: Yes, my role as an advocate for ALS (through the Phillies) as well as for Shade have both prepared me for my role as advocate to Grant. They both taught me how important it is to raise awareness and funds for the causes in which we believe.

JA: I have read that when a child is sick or disabled, marriages are stressed far more than usual and the divorce rate is higher. What is your advice to parents in this situation?
My advice is to go back to the basics. Be on the same page. Listen, really listen, to each other. Communication is so important in all marriages, especially in those with special needs children.

For parents of a recently diagnosed child, what would you tell them?

Take a deep breath; it’s going to be ok.

What have you implemented into your daily schedule so that your family runs more smoothly under the circumstances?

Preparation. Nothing’s a surprise. We have lists and remind all of our children, especially Grant, what will happen each day. Regarding behaviors, we follow up on our rules and consequences - that’s extremely important, specifically with Grant. He does not understand consequences, so following up is key.

Are you currently raising funds for AS research?

Yes. All of the funds we raise implement services, not research. I want to take care of the needs of the children with AS first.

I read in your book that Grant is in a public school. How is he doing there and is this the norm for most children with AS?

How children with AS are educated varies with their needs and the school system in place in their communities. Grant is doing well in our public school. His teachers and support system are amazing. If sending your child to a public school, be sure to establish and maintain open communication with all teachers and staff members. And thank them! Grant is confident and happy to have a voice! He knows that he is helping to teach adults that it’s ok to be different and he’s proud of who he is.

As an advocate and voice for Asperger’s, maybe you and Grant can write a book from his perspective one day… about life with AS?

He’s definitely not ready for that now, but maybe someday.

Why did you choose to write about your family’s experience?

When Grant was first diagnosed, I was in shock. I was given a name of another mother in the same situation and my thought was not to label Grant and not to go public with his diagnosis. I cried hysterically and felt guilty that it took me seven years to learn of his condition. I was numb and mad that I did not trust my motherly instincts. I knew something was wrong but doubted myself. Eventually, I contacted the mother nearby and was encouraged and supported. I decided to give Grant the label along with his story and a voice. My memoir is the story of love - the love for a child who’s different. It provides the dignity he deserves.

In your acknowledgments, you mentioned and thanked the Asperger’s Association of New England (www.aane.org). Is there a national group also?

Yes, the US Autism and Asperger’s Association (http://www.usautism.org).

Your memoir has been well received and is a necessary addition to every bookshelf. Thank you for your enormous efforts! I will watch and cheer on The Best Kind of Different, and mom too! •
The Best Kind Of Mom Raise A Teacher. More Shirts (Click on image below): *JUST RELEASED*, Limited Time Only This item is NOT available in stores. Guaranteed safe checkout: PAYPAL | VISA | MASTERCARD Click BUY IT NOW To Order Yours! (Printed, Made, And Shipped From The USA). Additional Styles. Unisex Tee - $22.50 Women's Tee - $23.50 Hoodie - $37.50 Unisex Tank Top - $19.95 Women's Tank Top - $19.95 Premium Tee - $24.00 Sweatshirt - $29.95 V-Neck Tee - $22.95 Long Sleeve Tee - $24.50.