

Sharon's 2007 A Gift From Alexa Dinner Speech

The reason we are here tonight is because autism has reached epidemic proportions. It is damaging the brains of our children and depriving them and their families of the lives they deserve.

Not much more than a decade ago, the number of children struck by autism was 1 in 10,000. Last year I mentioned that that number had escalated to 1 in 166. Unfortunately, I have to update that statement as well. Since I stood here last summer, the statistics have changed again. 1 in 150 children is now affected by autism.

When Alexa was diagnosed on February 4, 2003 at 22 months old, not only wasn't I familiar with autism, I had never heard the word before. Like it was yesterday, I remember calling Aimee Shanker from the cold outdoors at LIJ. In tears I told her Alexa had autistic spectrum disorder because those were the neurologist's exact words and I didn't know what that meant. I didn't realize that meant autism. I thought it meant something like it with similar characteristics, and that I could fix it.

Today, only 3 ½ years later, it has become a common word. Most of us know families, other than mine, who are affected. Our children know their children. We read about it on the covers of magazines and hear about it on television. Yet very few people understand what it is and what it does.

I'll start with what it does. As a parent I can tell you it rips out the insides of your body. It breaks your heart in a way that can't ever be mended. It changes your whole life and everything you thought it would be. And it makes you stronger than you ever thought possible because you have no choice.

For her sister, she doesn't know what it is not to have a disabled sibling. She makes the sacrifices she needs to and finds the patience and understanding at 9 years old that most adults can't. She has become a role model for teaching and compassion because she loves her sister the way she is with all her heart.

And for Alexa, she was robbed of her childhood. Since 2 years of age she has been working more than the 40 hours a week most adults put in. She works in school, she works with therapists after school when the other children are on the playground or chasing the ice cream man, and she works through vacations. There is no Disneyland because she can't go for that long without regressing. And if we took her to Disney, she wouldn't understand where she is, couldn't wait on line or understand the concept of waiting in line, and would probably be so overwhelmed

by the noise and the crowd it would be a disaster. She'd be in a pull-up because while she was six on March 31st, she is not potty trained yet. And she doesn't understand that you don't run away from mommy. So chances are if you let her hand go for a second - to tie your shoe, to scratch an itch – it could be too late when you look up.

So instead of dwelling on what we can't change, we do what we can to live as normal a life as possible, and to honor our baby by running this charity.

Since autism has become so widespread and has no racial or socioeconomic barriers, there are other charities which now exist. My view is there are three major areas of need: research, supporting those currently affected and future planning. Research would be the most costly as the cause of autism is still a mystery. If I took all of the money we made here tonight and gave it to research it might only buy a few hours under a microscope. We are just too small to have a drastic impact in that area. Since the Hollywood set is now affected from the President of NBC to several celebrities and professional athletes, their organization which can raise millions needs to focus on research.

We, on the other hand, can affect the other two areas and make your money have life altering impact.

A Gift From Alexa supports many different schools throughout New York who would not have the resources to provide an appropriate staffing ratio or education without outside support. We provide supplies to the school district for which there is no budget. Half Hollow Hills is a leader in the State of New York and one of the largest districts with 144 autistic children. Yet there is not enough money in the budget for the supplies they need.

We contribute to another private organization to run a social development program through the school district which is 100% privately funded.

We had an organization in Vermont find our website and apply for a \$2,000 grant. They wanted to provide transportation for advocates to travel across the state to go to school board meetings and obtain benefits for children whose parents don't know what to do. Understanding what your child needs, what benefits you are entitled to, and fighting to get them is a challenge many emotionally drained parents can't handle. Some are not intelligent enough to figure it out; some don't want to face reality. And then who suffers? The child who needs appropriate services. And there are no second chances. By allowing these children to have advocates fight for them, they have a chance at a better life.

We will also provide resources to individual families in need should they have medical bills they wouldn't otherwise have if their child were not disabled. They should not be choosing between Christmas and the neurologist.

And lastly, my long term goal is to build a facility for the children when they age out of the school systems at 18 and cannot lead independent lives. Unfortunately many of the children will be in this category. Some of you may know someone who is a success story – a miracle. But unfortunately a childhood epidemic today will be an adult epidemic in 10 or 15 years, and someone needs to plan for that since the government isn't. And since no amount of exercise and antioxidants will keep me on the planet forever, there must be a plan. And even if I could live indefinitely, it would be a totally inappropriate environment for an adult, even though disabled, to continue living at home. They need to be with peers, in an appropriate residential facility with skilled staff. Many of these children are very intelligent as is Alexa who could read fluently at 4 years old. Her nonverbal IQ is in the 99th percentile. They will be able to contribute to society, but they will need to live in an appropriate environment with assistance to do that.

That gives you some idea what we are trying to do. I've been asked many times by good friends, what can they do? And I've reached the point where I am going to tell you.

By being here tonight, and making the sacrifice of time and money to do that, you have obviously done something substantial. And so many of you have been coming for three years. I don't know if it actually is or not, but three years feels like a milestone to me.

I said last year that life is more than big houses and Bryant and Cooper. And I say that because from running this organization, I have learned that for some that's what life is about. More disappointing is that those fortunate people actually think that's ok. But while I learned to accept that, I couldn't understand it. So in the search for a reason, I came to the conclusion that we influence our children more than we realize. So it is our job to instill in them just how lucky they are. Perhaps I am here doing this today in part because I was involved in fundraising since I was 9. Because I was lucky enough not to need a paying job, I was taught to donate my time. I started in 4th grade with the March of Dimes annual walk-a-thon. My father didn't think I'd do much more than a mile so he sponsored me \$1 per mile. I went 15 miles in my blue suede Pumas until I couldn't feel my legs. I was a candy stripper for three years through high school and continued from there.

Perhaps this is why it's natural for me to impress upon Dara how important it is to realize most of the world is not so lucky. Dara learned at an early age you don't say you are bored in my house. Because if you do, the activity for the day becomes packing your toys in bags to give to the children who don't have any.

In our neighborhood last year, a group of eight year old girls decided setting up a lemonade stand was a good idea. But in addition to their entrepreneurial spirit, their giving hearts decided to raise the money for A Gift From Alexa and so they brought me a bag of change with \$14. Several months later they had a talent show at my house, charging an entry fee for "Alexa's Charity." A few months ago a family was raising money for the Arthritis Foundation. The now business savvy group moved their lemonade stand to the community entrance for better traffic and raised substantially more.

I have to believe they do this because they know their parents are involved and committed. They have learned you don't need to keep all the money you make and sometimes there is something more worthwhile you can do with it.

If you bought a journal ad today, save the book for your kids to see so they understand you thought it was important enough to buy a page. And let them know you were here tonight and what a fundraiser is.

And then with the Grace of God they will grow up to be like all of you who gave up Bryant and Cooper or Blackstone to be here tonight.

There are several people I need to thank starting with my dinner chairperson, Melanie Muhlstock and the dinner committee. Aimee & David Shanker and Shari Plocker, you have been in this with me from the start. And this year I was lucky enough to add a few new, truly dedicated people. Gina Marshall, you are one. I couldn't imagine not having you. And from the ups and downs of a difficult year as life takes its unpredictable turns, I was lucky enough to find Rachael Ringold and Lori Fay. Thank you Rachael and Lori for your efforts, your commitment and your friendship. And to Mindy and Harry and the crew who caravans from New Jersey every year, thank you for making the trip.

To the merchants who donated services and merchandise for this event, thank you for believing in our mission. It is far more difficult than you might imagine to gather this amount of quality merchandise. Yes, we are a charity but many merchants are solicited constantly to the point where I sympathize with them because I am constantly solicited. Please save your journals so you can read

through them when you have more time. And remember who was willing to participate and patronize their businesses.

Thank you Doug Milo for donating your time to do all of our accounting with a smile.

Thank you to our three time sponsors who we have been able to rely upon since our inception: Fran and Scott Silverman, Chris and Ingrid Bragoli, Country Carpet/Harris and Geri Cohen, Jill and Ken Rosenberg, Shari and Craig Plocker, and Paul and Irene Doreste, and the law firms of Baker, Sanders, Barshay, Grossman, Fass, Muhlstock & Neuwirth, LLC and Parker Waichman Alonso, LLP.

And not to be overlooked, thank you to my incredible volunteer staff. All the ladies here tonight in staff shirts are unpaid volunteers with jobs and/or disabled children who made the time to come here to work to make your experience more pleasurable, so that the charity, in turn, can raise more money.

And to all of you, I know what it is to be over extended whether it be time or money or both. I know what it is to wish you didn't have to go to another fundraiser. So I have to be grateful that we are capable of filling a room with caring, dedicated people at least most of whom truly want to be here. And for the few who would rather be elsewhere, thank you for thinking it was important enough to be here anyway because you are making a difference. I could stand on my head and work 24 hours a day, but it wouldn't matter a bit if I could not fill this room. I need you all, so on behalf of the children thank you for being here.

And last but certainly not least, I have to thank Alexa. My sweet innocent baby...you are my angel. I don't see what you aren't...I see what you are. You are the warmth in my heart, my inspiration, my energy to keep going. You have the smile that makes everyday worth living and every battle worth the fight. You are responsible for making me a better person than I ever could have been and for aiding and saving all of the children we are able to reach. I stand here, in your honor, because we love you and thank you for being you.