

Support of grandparents crucial for families struggling to cope with autism

By Lindsay Pykosz
I&M Staff Writer

When a child is diagnosed with autism, the weight that bears down on his or her parents can be enormous. Suddenly, there are extra worries: Medical bills, doctor's appointments, special classes in school, and they begin reaching out to the people who have always been there for them in the past: Their own parents, the grandparents, for an amount of help that they may have never asked for before.

But it is these grandparents who begin to feel the same weight, many of them unaware of autism, its signs and symptoms, leaving them to do the research on the disorder that affects 1 in 110 children, 1 in 70 boys, to begin to help two generations all at the same time.

Kim Horyn, director of the Nantucket Autism Speaks Resource Center, said she is often visited by grandparents who feel they are at a loss because they don't know how or what they can do to help. She added that autism affects everyone in a family, not just the person diagnosed.

"They see their own child very overwhelmed, exhausted, distraught, and they see their grandchild behaving in unusual ways, and the sibling being overshadowed. They often come to see me to talk about the struggles and ask what they can do to improve the situation and alleviate some of the household stress. I always suggest that they try not to be judgmental, and that their support will mean the world to their family. If they can't handle the child on the Spectrum, maybe they can spend special time with the sibling, or cook a special dinner or clean the house, all of which would be much appreciated."

Sharon Lorenzo knows this struggle first-hand, as her grandson Otis began exhibiting signs of autism when he was 2, walking on his tip-toes and flapping his hands: two major signs of the disorder. Mercedes, Lorenzo's daughter, took her son to a diagnostic clinic in Chicago, where it was recommended that Otis enroll in speech therapy and physical therapy to get him up to speed.

After receiving a job offer to be a teen librarian in Bend, Ore. the



Sharon Lorenzo

family moved, only to be faced with the harsh reality that the state would not reimburse them for any of Otis' medical care expenses.

"Mercedes now has moved to Austin, Texas, where they have an excellent program," Lorenzo said. "He goes to a clinic and they approach it in different ways through physical therapy, speech therapy and swimming lessons, interaction and socialization. It's a skill set that he's opening up to."

As a grandparent, Lorenzo said her solution to most problem-solving is to do research. She's come to accept the fact that she has to financially and emotionally support her daughter and her husband and has become an advocate for research and funding to help find the cause and, ultimately, a cure for autism.

"You have to participate in the research of the disease," she continued. "They say something like 90-percent of cases are on the Y chromosome, but we don't know if it's intrauterine or post-birth. I also feel there is an environmental component, but the only way we're going to isolate that is through funding and research."

Now that Otis is 5, Lorenzo said the family's new home in Austin has been good for him and he has been getting the help he needs through special education classes. She was preparing all week for their arrival to the island yesterday, and said she has been brainstorming a variety of different activities for the family to do, especially since it's Otis' first trip to the island.

She participated in her first Walk Now for Autism Speaks on



the island last year, and said she is aware and thankful of the resources here that are available for children and families on the spectrum. This year's walk, scheduled for Saturday, Aug. 20, is just one of the many initiatives of Autism Speaks, founded in February 2005 by NBC Universal CEO Bob Wright and his wife Suzanne, who themselves are no strangers to the personal ramifications autism can have on a family.

Their own grandson Christian retreated into the darkness of autism when he was about 18 months old, and they began losing the grandson who was so special to them to the unexplainable illness.

"We had this little guy who was absolutely beautiful, meeting all of his developmental milestones, and at about 18 months he started losing everything," Suzanne said. "It was tragic for us, but what was even more tragic was when we found out it was autism. The avenue was not paved anywhere. There were no services we easily had access to. Kids had to move from one state to another because of the lack of services."

Bob recalled those days back in 2003 that were "truly heartbreaking" for the family.

"We lost a little boy," he said. "He was a little boy and he did all of the things he should have been doing. He was walking and talking and could recognize things. He pointed at things, and we had no experience with autism, in fairness, but he didn't seem right. I thought he was just precocious. His birthday is in August and in 2003, at the end of the year, he started to slip. He had a staph infection and had a terrible reaction to the vaccines, but past that time, he just seemed to lose his ability to communicate, and it took about four or five months and he lost

everything."

So their intuition as grandparents began to kick in. They knew something was wrong and something had to be done to help this little boy. Bob, who has since retired from NBC, and his wife began paying enormous medical bills for their grandson, and used their connections at Yale and Columbia—two major centers for pediatrics and "everything medical"—and New York Presbyterian Hospital, but there was no treatment.

"As grandparents, we were able to pull our own life experiences to try and help him," said Bob. "We had more connections in more areas than our children had. We used all kinds of connections to learn about how to bring treatment. We ended up, in the process, hiring a number of people to come over and provide speech occupational therapy. Grandparents can have an enormous impact."

Suzanne added that they are in the same boat as so many other grandparents are, but the bottom line comes down to helping out your kids.

"If we're going through this, these other grandparents are also faced with this enormous problem they have to help their kids," she continued. "They pay for what insurance can be paying for, young people move in with grandparents because they couldn't pay for their mortgage. It really does take a family to handle this problem. It affects all of their lives. It's really hard. Christian is a loving, beautiful little boy, and we accept him for what he is and try and pray that he's going to get somewhat better with all the therapy that he has."

Lorenzo added similar sentiments with regards to her family, referring to the fact that it takes an army to raise a child, especially a child with special needs.

"When you have an anomaly in a family, everybody is on the same boat to try and facilitate it," she said. "One of the things about this Nantucket community is everybody pulls together here to be helpful to families and to make you not feel that you're isolated."

TRANQUILLO, A PRIMA VISTA



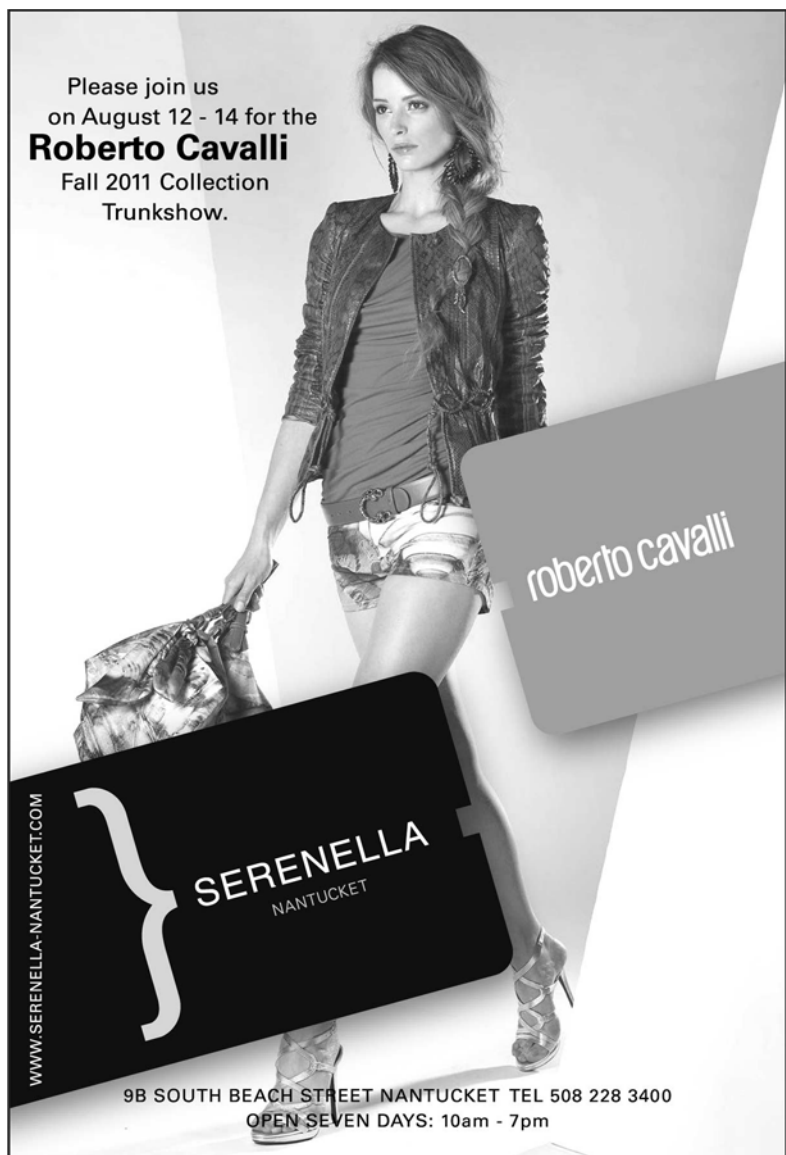
Southern Vistas

Fairhaven Hill
A Commanding Estate in Concord, MA

- 16 acres with views to Boston, Blue Hill, Mt. Wachusett
- Contiguous to Historic Walden Woods
- Privacy of Vermont, convenience of Boston
- 10 minutes to Hanscom FBO
- Elegant (envied!) home near excellent schools

Listed by: Brigitte Senkler 978-505-2652
Brigitte.Senkler@NEMoves.com

Please join us on August 12 - 14 for the **Roberto Cavalli** Fall 2011 Collection Trunkshow.



SERENELLA
NANTUCKET

9B SOUTH BEACH STREET NANTUCKET TEL 508 228 3400
OPEN SEVEN DAYS: 10am - 7pm



TOPPER'S DECK
CASUAL DINING

Bubble Brunch

Put some sparkle in your day. Our award-winning Sunday brunch now features the bubbliest drink menu on-island. Enjoy authentic and creative Prosecco cocktails, or choose from a fabulous array of champagnes.

THIS IS THE PLACE TO BE. BREAKFAST | LUNCH | COCKTAILS | DINNER | SUNDAY BRUNCH
508.228.8768 | toppersrestaurant.com | opentable.com | facebook.com/toppers

Located at The Wauwinet. Ample free parking and complimentary van service. Please dress casual.

LESLIE GREENE

TRUNK SHOW



Friday, 8/12
Saturday, 8/13
10 AM-8 PM

Don't forget:
Tax Free Sale!



SHREVE, CRUMP & LOW
FINE JEWELRY, WATCHES & GIFTS • SINCE 1796
0 MAIN STREET • NANTUCKET • (508) 228-6246
BOSTON • SHREVECRUMPANDLOW.COM