

Mother of autism advocate visits Portland

When Temple Grandin was growing up in the 1940s, both her doctor and her father pushed for her to be institutionalized. Her mother, Eustacia Cutler, had other plans, teaching her daughter social skills and arranging speech therapy for her by age 2.



JACKIE FARWELL

Now 68, Grandin went on to become one of the world's foremost advocates for people with autism, known for promoting more humane treatment of livestock at ranches and slaughterhouses and profiled in an Emmy Award-winning HBO film in 2010. Grandin, who teaches at Colorado State University, spoke in Maine in May 2012. Her mother — a Harvard University graduate, singer, actress, and playwright who authored a book about raising Grandin called "A Thorn in My Pocket" — visited Portland Friday. She discussed Grandin's upbringing and her own documentary, "Challenged and Emotionally Disquieted Children."

Cutler was joined by Dr. Jed Baker, whose latest book explores anxiety, and Sean Barron, who co-wrote a book with Grandin about how the two came to understand "social mysteries" through their per-

spectives of autism. I spoke with Cutler last week, ahead of her visit to Maine. Below is an edited transcript of our conversation, which ranged from her reflections on Grandin's youth to society's discomfort with people with autism.

As a baby, Grandin failed to speak or look her mother in the eyes, detesting being touched or held.

My pediatrician said, "Oh, I think you're just an anxious mother." I think go straight to an authority. For Temple, it meant by two she was having speech therapy. It made all the difference in the world. Not only was she learning how to speak, but there were other little children there and she learned you have to take into account other children around you. You've got to sit in your little chair and wait your turn. This, for all children, is a lesson in how you have to behave, but it's critical for those on the autism spectrum that they learn that very young.

Grandin attended school with other neighborhood children, an integration Cutler says more children with autism need.

By five, when Temple could talk and she had learned how to get along with other children, she was integrated into the little local country day school where the other children went. We're not doing this at a lot of schools.

That same school today will not take a child on the spectrum. How are you going to teach this child to join the world if you don't put the child into the world? They said, "We will work with you but you've got to work with us." We did it together. Schools that do this succeed the best.

Cutler is writing a social history of autism, exploring a lack of understanding between people who have autism and those who don't.

We talk about our children being special and that they have special gifts. This is very confusing to somebody from the outside. In a sense they do, but they also are not easy for the outsider.

We're very busy addressing autism and we're not looking at us. It has a long history of bothering us, and I think we have to address this. Families are in great distress. Then it spreads out to the community surrounding the family, to the school. Nobody has been informed in the community so they don't know.

I keep saying to mothers: There are no answers, there are only choices. But choices can be changed. The neighborhood needs to understand that too, if they're suddenly faced with one of these children in a store or in neighborhood games or in school.

For children with autism, changes in routine can be deeply upsetting.

You and I are talking now on the telephone and we un-



COURTESY OF EUSTACIA CUTLER

Eustacia Cutler, mother to autism awareness advocate Temple Grandin, visited Portland on Friday to speak about her reflections on Grandin's youth and society's discomfort with people with autism.

derstand each other. It feels social and it feels conscious, but actually most of it is neurological. We take this incredible gift for granted. Autistic children don't have it, in varying degrees. The old saying is, if you know one autistic child, you know

one autistic child. They can only see things from a literal point of view, what is physically around them.

[Other people] feel hurt and insulted. They need to understand that it's not a deliberate fault, the child simply cannot ad-

just to the difference. **Parents often approach Cutler after her presentations to privately ask questions they're afraid to pose publicly.** They worry about siblings. It's very hard on siblings. We have to remember they're children, too. Don't turn the siblings into little helpers. I also recommend that they try to save a little piece of the day to have alone with that sibling. It doesn't have to be anything sensational, it's, "Everybody out of the kitchen, you and I are going to make dinner together." The other thing that's valuable is a counselor. Children will tell a counselor what they won't tell their mother because they know their mother is troubled. Sometimes they don't even have the words for it. The other question that comes up is always adolescence, which is the hardest of all. Everybody's worked hard, the children, the parents and now all of a sudden Mother Nature says, "Well throw away the rule book! I'm going to give you a new body, new feelings, new clothes, new friends."

The Temple Grandin & Eustacia Cutler Autism Fund offers free webinars to parents, including conversations with Grandin, Cutler and autism authorities.

Read BDN Health Editor Jackie Farwell's blog, Vital Signs, at vitalsigns.bangordailynews.com.



BRIDGET SHARKEY (LEFT), 14, AND HER FATHER, MIKE SHARKEY, ARE TRYING TO RAISE AWARENESS ABOUT THE CONDITION CALLED MISOPHONIA, AN UNDERSTUDIED CONDITION IN WHICH REPETITIVE NOISES, SUCH AS CHEWING, SEND A PERSON INTO FLIGHT OR FIGHT MODE.

Sounds

Continued from Page C1

spine. Imagine that amplified a hundredfold. Imagine that happening for 10 to 15 minutes and you're trapped."

Previously, misophonia was lumped into a more general category of sensory processing disorder, Brout said, although neither condition is recognized by the Diagnostic and Statistical Manual of Mental Disorders. In the early 2000s, Pawel and Margaret Jastreboff of the Emory University School of Medicine, working with patients with hyperacusis, a disorder in the perceived volume of sounds, noticed there was a subset of patients with different symptoms. Those patients were reacting to repetitive trig-

gers, not when sounds were merely too loud.

Misophonia could be a matter of the brain's failing to filter out unnecessary stimulation, Brout said.

When a sleeping dog hears a noise, it will prick up its ears in alert. But if the noise keeps repeating, there's less sense of danger, and the dog will stop pricking up its ears.

"It's the same with people," Brout said. "The auditory stimuli travels the quickest to the fight-or-flight center."

Most people can filter sounds out, Gould said. "But when you have misophonia, you do the opposite. You zoom in on those sounds and filter everything else out."

This theory about the underlying basis of misophonia is not embraced by all, however; researchers are not sure what the underly-

ing basis is.

Misophonia likely has both a genetic and environmental component, Brout said. Perhaps environmental factors are merely a trigger for a genetic predisposition.

Rosenthal agreed. It's important "not to make false dichotomies — either nature or nurture," he said. No matter what the label, he said, the cause is fundamentally both.

Dahlsgaard said she tries to educate her patients about the brain's capacity to become less reactive to perceived threats. She teaches her patients "better coping strategies than escape, such as by refocusing their attention at the dinner table towards pleasant things and rewarding them for doing so."

Dean McKay, professor of psychology at Fordham Uni-

versity, agreed it was helpful to come up with a way to tolerate the sounds. His lab is developing a treatment program that would use recordings of certain trigger noises, such as chewing sounds, so patients can practice enduring the sounds at low volume and work their way up.

Those with misophonia say one of the most important things is to realize they have company.

"It's not a good feeling to think you're the only one," said Gould, who is making a documentary called "Quiet Please ... " to help others feel less isolated.

Bridget once wrote that she "felt like an outcast."

But now that she's getting help, and with the support of her family, she feels ready to tackle a new challenge: starting high school in the fall.

the U.S. from 1968 to 1982, with over 2 billion tablets sold in 1978 alone) appears to have caused far more problems than it has solved.

Our desire for a quick, easy fix, and the pharmaceutical industry's willingness to provide it, has led us to where all short cuts lead us — less healthy than we were to start with. Next week I will cover the nondrug treatment options for these conditions.

Dr. Michael Noonan practices chiropractic, chiropractic acupuncture and other wellness therapies in Old Town. He can be reached at noonanchiropractic@gmail.com.

FBI mum on cruise passenger who fell overboard, died

BY RAY LAMONT
GLOUCESTER DAILY TIMES

More than week after a woman fell from a luxury cruise ship and died off Cape Ann, Massachusetts, authorities still have not released her name.

As responders in the Sept. 11 incident, police from Rockport, Massachusetts, confirmed the 59-year-old woman who fell from the 650-foot Seabourn Quest some 10 miles off the coast of Cape Ann was from Palm Desert, California. The woman's body was first located by Rockport, Massachusetts, fishermen and recovered from the sea by the town's harbor masters.

But Officer Mark Rowe on Friday said he was advised not to release the woman's name as an FBI investigation into the case continued.

The FBI took over the case from the U.S. Coast Guard as the investigative agency handling a death in international waters. Lt. Wade Thompson of Coast Guard Sector Boston said Friday that any release of the woman's name would have to come from the FBI.

Kristen Setera, speaking for the FBI on Friday, said only that, because of the "ongoing investigation," she and the agency would continue to have "no comment at this time" including any identification of the passenger.

Felix Browne, a spokesman with the Massachusetts Executive Office of Public Safety, which includes the Office of the Medical Examiner, said he was not told as of that afternoon whether a planned autopsy on the woman had been completed or not by the medical examiner. He also noted that while the medical examiner's task is basic — determining a cause of death — it can take longer and prove far more complex in some cases than others.

Meanwhile, local responders who located and recovered the woman's body said Friday they had not been contacted by the FBI or anyone else in connection with any investigation.

Mike Burbank, fishing aboard his F/V Kaybur Too for bait off Thacher Island with plans to go on a tuna trip the next morning, answered when he heard the "man overboard" call from the Sea-

bourn Quest around 7 p.m.

Tracking about a mile southwest of responding U.S. Coast Guard vessels and the giant ship — in the wake of the cruise ship — he was the first to locate the woman's body floating in a tide rip at the surface. He then radioed Rockport harbor masters Rosemary Lesch and Scott Story, who also responded, and they recovered the woman's body, bringing it back to Rockport where they were met by town police and other agencies.

"I've heard from nobody — nobody," Burbank said Friday. "You'd think that someone investigating would want to talk to us if we were right there, but I've heard from nobody." Burbank said the initial call from the Seabourn Quest that night indicated the overboard passenger was in the water for 23 minutes at the time of the first report.

Lesch said Friday the harbor masters had not been called, either. She told the Gloucester Daily Times last weekend the woman's body had been clad in a "summer outfit" when she was hauled from the water.

"Scott (Story) and I were talking about it," she said. "You would think that somebody would have gotten back to us, but nobody has."

Officials from Seabourn Quest, a luxury cruise line that is an affiliate of Holland America under the corporate umbrella of Carnival PLC of London, have not responded to numerous calls or messages for comment.

Seabourn's U.S. headquarters are in Seattle, but the line operates regular luxury cruises out of Boston. The Seabourn Quest, with 11 decks and a capacity of 458 passengers in 247 suites, sailed out of Boston at the time of the incident, embarking on a 12-day cruise around New England, the Canadian Maritimes and then up the St. Lawrence River.

After the incident off Cape Ann, the Quest continued on to its first stop at Bar Harbor, Maine. The vessel's online tracker as of late Friday placed the Seabourn Quest — with 450 passengers — off Ville Saguenay, Quebec. The tracker notes the ship had traveled 1,294 nautical miles since leaving Boston.

Noonan

Continued from Page C1

stages. Patients who have been on the meds for more than a few months typically worsen when they try to reduce the dose (and often end up in a hospital if they try to stop suddenly). This is taken as a sign that the drugs are working. But it may also mean the patient's brain is showing the effects of withdrawal.

A key concept in the promotion of these drugs is the idea that they correct a chemical imbalance in the brain; patients are told the

medications are like insulin for a diabetic. But the research does not support this theory. Rather than rebalancing brain chemistry, these drugs create a new dysfunction. This change does suppress the original problem, at least temporarily, but it does not correct it. After long-term use, these chemical changes in the brain become permanent, making it difficult or impossible to get off the drugs.

Even more problematic is the "prescribing cascade" that is triggered. Like any drugs, this class of meds has side effects, and many of them are neurological. Unfortunately,

these new symptoms are not recognized as side effects but are seen as signs of a deeper, more serious form of mental illness. The patient is then told they were "latent bipolar" all along. This new diagnosis is then treated by stronger meds, usually an antipsychotic. These "gateway drugs" are typically either meds for depression or a stimulant for ADHD.

The research does suggest that some patients benefit from long-term use of these drugs; this is especially true of the most severe cases. But the indiscriminate use of these meds (Valium was the No. 1 prescription drug in