

A 'Sweet Victory' in the Fight Against Autism

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Not even a minute after Marguerite Kirst Colston walks into her quaint Bethesda, Md., home, her 6 1/2-year-old son, Camden, without saying a word, grabs her hand and pulls her into the kitchen and toward the refrigerator. She opens the door, and Camden gestures toward the blueberry cottage cheese.

What happens next is unexpected.

Camden is hoisted into a wooden high chair so his mother can spoon-feed him. Restless, he pulls on his green right sock, then his left sock, which is white. And he belts out a deafening squeal.

Colston knows the sound. It is the only sound her son makes. No consonants, no words, only the loud, drawn-out single syllables.

"Eeeeeeee, eeeee!"

It's sometimes accompanied by hand gestures or the repetitive slapping of his hands against his brownish-blond-crowned head.

'WE'VE COME A LONG WAY'

At age 3, Camden was diagnosed with autism, to the shock of his mother, who at the time was working as vice president of financial services consulting firm BCK International. Colston soon learned that there was little support for families with autistic children, so she decided to do something about it. Colston now serves as director of communications for the [Autism Society of America](#), a nonprofit dedicated to increasing treatment and services to the autism community.

Recently, the society collaborated with more than a dozen autism-related organizations as well as D.C. lobby shops and a group of parents of autistic children in Texas to push for the first piece of autism-specific legislation that authorizes \$945 million over five years to be spent on federal research and education about autism.

The [Combating Autism Act](#) passed Dec. 6, after intense lobbying and wrangling over whether funding and other mandates for autism research and programs should be included in the budget for the National Institutes of Health. The bill is scheduled to be signed into law by President George W. Bush this week.

The bill requires the director of the NIH to increase, intensify, and coordinate autism research, such as looking at environmental causes of autism. It also expands the duties of

the [Interagency Autism Coordinating Committee](#), established in 2000 to coordinate autism research and other efforts within the Department of Health and Human Services.

Autism is a disorder characterized by repetitive behaviors and severe impairment in social interaction and communication. As many as 1.5 million people in the United States have autism, and it is the nation's fastest-growing developmental disability.

“The bill is about getting people, parents, and doctors involved and educated about autism,” Colston says. “We’ve come a long way.”

Camden’s wide, deep-blue eyes are alert as he runs through the downstairs family room. His movements become somewhat calm only after he joins his mother on the couch. Just as quickly, he’s up again and walking to an open space in the room, where the 32-pound, 3-foot-6-inch kindergartner sits down, legs folded, toy in hand. He faces the wall with his back toward his mother. Camden attends Luxmanor Elementary School in Rockville, Md., where he is enrolled mostly in special-education classes.

Camden’s not aware that his mother was part of a frustrating fight on Capitol Hill that resulted in victory for the millions of parents who have children just like him.

“He just likes to be in his own world sometimes,” says Colston, a single mother of two. Camden’s 8-year-old sister, Theresa, is not autistic.

According to the [Centers for Disease Control and Prevention](#), the prevalence of autism spectrum disorders has increased to about one in 166 births. Despite the growing number of autistic cases, autism research has been one of the lowest-funded areas of medical research.

That is, until parents like Colston got fed up and became determined to lobby long and hard, both on Capitol Hill and on a grass-roots level around the country.

“With the rate that autism is growing and affecting our children, it’s so hard to believe that nothing has been done about it,” says Colston.

A TAKEDOWN IN TEXAS

In March, autism groups approached Sens. Rick Santorum (R-Pa.) and Christopher Dodd (D-Conn.) and asked them to draft the legislation. They were determined to force Congress into action.

Sen. Mike Enzi (R-Wyo.) then told the groups to unify and present themselves as one voice. “[He] said, □ You have to get the community behind you and come to me in one voice,” Colston recalls.

So the Autism Society of America called on Autism Speaks, Cure Autism Now, and other autism-related organizations. A total of 14 groups banded together, set aside differences,

and came up with one goal: More education, more research, more services. Syndicated radio host Don Imus, a staunch supporter of autism research, joined the battle and lobbied hard on air for the bill.

The Senate passed the bill with unanimous consent on Aug. 3. The groups thought it would get through the House just as smoothly.

Not so.

The real, hard-fought battle began when Rep. Joe Barton (R-Texas), chairman of the House Energy and Commerce Committee, initially blocked the bill, refusing to mandate how the NIH should conduct its research. Barton believed that disease-specific decisions should be left to scientists rather than politicians. He wanted to be careful not to inject political leanings into significant medical research.

Lobbyists and parents in his home state began to rally around the cause. In Arlington, Texas, they met with Barton.

At that meeting, a few parents recall the congressman saying he had never met anyone with autism. During an October luncheon at the Renaissance Hotel in Richardson, Texas, where outgoing House Speaker Dennis Hastert (R-Ill.) and other lawmakers had gathered, about 200 parents demonstrated against the blockage of the bill.

Kristi Hammer, the mother of a 4-year-old autistic child and one of the parents who attended the meeting with Barton, helped lead the Texas demonstration. She says Hastert's office contacted her before the rally, asking if the group would call it off if he agreed to meet with them. When Hastert's office refused to give her confirmation that they would meet, the demonstration went on.

"It was just a bunch of us parents who really care about all children with autism," says Hammer from Plano, Texas, where she resides.

Neither Barton nor his staff returned numerous phone calls.

While spearheading the National Institutes of Health Reform Act of 2006, Barton said the autism bill conflicted with his proposal to bring change within the NIH. One of his goals was to increase the NIH budget next year by \$1.4 billion, to \$29.7 billion. Another was to reorganize the NIH, the primary research arm of the federal government comprising 27 institutes and centers, in a way that would make it more efficient.

In passing the NIH bill, Barton stated, he wanted to improve medical research by removing politics from the process.

"One of the primary objectives of the bill is to get the politics out of research and let the experts at the NIH be the ones to decide their priorities, rather than have politicians tell them what they should be," Barton stated in a press release issued in October.

Sharon Scribner, managing director at Sonnenschein Nath & Rosenthal, who lobbied hard for the autism bill, says the autism organizations “pounded the pavement, visited Congressman Barton’s office trying to get to him.”

Nearly 35,000 e-mails supporting the bill were sent to Barton and his committee. One after another, lobbyists and parents shared their stories with Barton.

Barton eventually led the bill out of committee this month and to the House floor, where it passed.

“The passion, the emotion, and the commitment and willingness to work with him, I think, made him realize the impact of the bill,” Colston says. Though the final bill cut out some of the groups’ initial desires, such as funding for more services, the autism community sees it as a “sweet victory,” she says.

“One in 100 boys now develop autism. If this were some pandemic flu affecting one in 100 people, everybody would be doing everything to fight it,” says Hammer. “This bill is the first acknowledgment by government that this is a national issue.”

Jon Shestack, co-founder of Cure Autism Now, calls the bill “a federal declaration of war on the epidemic of autism.”

ONE GREEN SOCK, ONE WHITE

Every morning, Camden picks out his own clothes — right down to his socks. His closet consists of mostly green- and blue-colored clothing. Colorful photos hang on wooden cabinets. The faces of his friends — Kyman, Justin, Spencer, Kayshawn, and Tony — are stuck to a yellow plastic school bus that adorns the family’s refrigerator.

Camden picks out his own clothes, often choosing mismatched socks, before heading to school. Though most children Camden’s age are at the point where they know their colors and can feed themselves, he still struggles.

When Camden was born, he was only four pounds, three ounces. When he ate, his heart rate plummeted. He was placed in the neonatal intensive care unit at Georgetown University Hospital for three weeks. Doctors said Camden was born with Noonan Syndrome, a developmental disorder often associated with heart disease. He was referred to a program in which a variety of therapists made weekly visits to his home. It was a few years later that he was diagnosed as autistic.

“The journey took 2 1/2 years before diagnosis, but the intervention was there. Many children don’t have those opportunities,” Colston says.

For many families, mostly minorities, diagnosis comes much later in the child’s life because of a lack of educational and medical services.

Part of the newly authorized funding will go toward more aggressive outreach in minority communities, Colston says.

She calls the success of the Combating Autism Act a start. The hope, she says, is to assist adults with autism in areas like education and employment and have that assistance covered by insurance.

After all, Camden won't be a child forever.

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