

HEALTH SENSE

Autism continues to confuse scientists, parents looking for treatments

By Judy Foreman
The Boston Globe

Parker Beck, now 5, seemed normal when he was born, say his parents, Victoria and Gary Beck of New Hampshire. He grew, learned a few words, did all the usual "toddler things."

Then, at 15 months, he suddenly stopped speaking. He developed chronic diarrhea. Most bizarrely, he began spinning in circles.

He had brain scans, allergy assessments, blood work. The Becks suspected autism — a disorder once deemed rare but now known to be common, affecting 1 to 2 in every 1,000 people.

But first they needed to rule out a digestive disorder. So Parker had an endoscopy, a test for which he was given Secretin, a drug approved to help diagnose pancreatic cancer.

Afterward, he began speaking again and had "incredible leaps of development," says his mom, whose scientific sleuthing rivals that in the film "Lorenzo's Oil."

Was it the Secretin? The Becks began begging researchers to find out. They spread the word to other parents, and wrote a book.

Soon, the Internet crackled with questions from parents, including Eileen and Sean Martin of Massachusetts, who generally spend 5 hours a day online seeking help for their autistic children.

Recently, when a Secretin story aired on TV, the Becks got 800 calls in two days and thousands of letters. "I can't answer them," Victoria says. "I'm a regular mom with two kids."

Welcome to the desperate world of autism.

Resources on autism

The following organizations have information about autism:

- National Alliance for Autism Research, (888) 777-6227.
 - Autism Society of America, (800) 328-8476.
 - Cure Autism Now, (213) 549-0500; CAN has started a gene bank for families with more than one member affected by autism.
 - Autism Research Institute, (619) 281-7165, which has compiled information on Secretin.
 - The Giving Back Fund, (617) 556-2820, which manages the Doug Flutie Jr. Foundation for Autism, a resource for low-income families of children with autism.
 - Language and Cognitive Development Center in Boston, (800) 218-5232, a school for children with autism.
 - National Institute of Child Health and Human Development, (800) 370-2943.
 - National Autism Hotline, (304) 525-8014.
 - National Organization for Rare Disorders, (800) 999-6673.
 - The Option Institute, (800) 714-2779.
- "Unlocking the Potential of Secretin," a book by Gary and Victoria Beck, is available for \$15 through the Autism Research Institute. Proceeds go to the institute. Send a check to: Autism Research Institute, 4182 Adams Ave., San Diego, Calif. 92116.

Years ago, autism — a developmental disorder characterized by language problems, social withdrawal, learning disabilities and repetitive behavior — was presumed caused by bad mothering.

Now, researchers think autism — which affects 400,000 Americans, four times as many males as females — may be caused by defects in two to seven genes, environmental factors such as viruses, chemicals or vaccines, an autoimmune abnormality or a combination of these.

Some children develop a type of autism if they get an extra piece of chromosome 15 from their mothers, but not an extra piece from their fathers, says Dr. Edwin Cook, director of developmental neuroscience at the University of Chicago.

Unlike mental retardation, autism can strike people of normal or high intelligence, says Marie Bristol-Power, an autism specialist at the National Institute of Child Health and Human Development, which is part of the National Institutes of Health.

It also affects several brain areas, including the cerebellum (which helps maintain attention), the amygdala (important for memory and emotions) and the hippocampus (crucial to memory).

Though some children aren't diagnosed until they are 3 — and some, like Parker Beck, lose language and other skills they had developed — autopsy studies suggest the initial damage can occur prenatally, before the 30th week of pregnancy, possibly preventing key brain areas from maturing

normally.

Even kids who appear normal at birth may not be, say researchers who've looked at videotapes of first birthday parties for kids later diagnosed with autism and have found subtle clues that others missed.

Those who think a virus is the cause note that years ago, before vaccines dramatically reduced the incidence of rubella (German measles), autism was high among children born to women who had rubella during pregnancy.

Many cases of autism are prevented by immunization against rubella, notes Cook. But some blame the vaccines themselves. Parker Beck's cognitive skills regressed after his immunization at 15 months against measles, mumps and rubella, his mother says.

So far, there's "no strong scientific evidence that would cause you to say there's a link, but there are enough scientific questions remaining that you also cannot say there is none," says Kathleen Stratton, a pharmacologist at the Institute of Medicine who has held workshops on the vaccine-autism issue.

There's also no cure. But 30 years of research supports the efficacy of applied behavioral analysis, a painstaking method by which a tutor teaches a child one skill at a time. And drugs, especially antidepressants, can also help, especially in children and adults who are anxious and frustrated. This year, researchers showed an antipsychotic drug called Risperidone reduced aggressive symptoms in autistic adults. Trials are now under way to see if it works in kids, too.

Some researchers think vitamin B6

supplements may also help.

But the big buzz is over Secretin, a hormone made by Ferring Pharmaceuticals in Tarrytown, N.Y. Because it is FDA-approved to diagnose pancreatic problems, it is not illegal for doctors to prescribe it for other purposes.

By Victoria Beck's estimate, 1,000 autistic kids have tried Secretin. In fact, there's been such a run on the drug that the manufacturer says it will be in short supply into this year.

The child health institute has received so many questions that it has posted a statement on the Web (www.nih.gov/nichd) saying it has no position on Secretin because there's so little data.

In fact, the only published research was a report a year ago by the researchers who treated Parker Beck. They found Secretin was linked to a "dramatic improvement" in behavior, eye contact, language and alertness in Parker and two other children.

That's not overwhelming, and even Victoria Beck guesses Secretin may help less than half the time. Nor is it clear whether it has side effects, though none have surfaced so far.

The answers will come only with clinical research and researchers, including the University of Chicago's Cook, are about to get placebo-controlled, double-blind trials of Secretin under way.

Until those data are in, he says, "it is cruel to wave the flag of cure before there's more certainty."

True, but that could be months or years. In the meantime, the families of autistic patients can at least raise the issue with doctors, and learn all they can from those who've tried it.