

daniel's success story

A DETERMINED MOTHER
DEMONSTRATES
THAT FULL RECOVERY
FROM AUTISM
IS POSSIBLE.

BY MARY ROMANIEC

Once diagnosed with autism, Daniel (4 ½), shown here with his sister, Theresa (6), now lives a normal life.

imagine

that your child has been diagnosed with cancer.

The fear and dread are overwhelming. The physician sitting across the desk proceeds to cover in detail the prognosis, options, and course of treatments she would prescribe. She then offers you information about where to find support and resources as you begin the journey toward your child's wellness.

Now imagine that your child has been diagnosed with autism, the neurological disorder that, in epidemic proportions, is robbing kids of a childhood, destroying families, and threatening the possibility of these children becoming fully functioning adults. This time, the physician probably gives you neither information nor hope. He is more likely to say something like "There's no cure," or "You will eventually have to institutionalize your child." You leave his office stunned, only beginning to grapple with the loss of your child's imagined childhood and to cope with the enormity of the diagnosis and its awful prognosis.

Parents of autistic children can each tell the story of when and how they discovered that something was wrong. They might have had a happy, healthy, normally developing baby, until a round of antibiotics or vaccines (MMR in particular) sent the child into a world all her own—a world the parents could not enter. The shock of how drastically a child can change in such a short period can send parents reeling in a spiral of emotions and desperation as they struggle to help their child. Sadly, many parents choose not to deal with the possibility that their child may have fallen within the spectrum of autistic disorders. I have heard parents say that they didn't want "the label" of autism affixed to their child, as though making such a choice might eventually make the symptoms go away. I also know of parents who excused their child's odd behavior in a sincere belief that he or she was merely misunderstood. Other parents knew something was wrong early on but could not convince doctors to examine their children thoroughly enough to make the correct diagnosis. For the lucky

minority, a diagnosis of autism is made before the child is two years old, and proper treatment is begun immediately.

The story of my son, Daniel's, autistic symptoms began before he was born. I had received a measles vaccine just after the birth of my daughter and just prior to Daniel's conception (my two children were born 14 months apart), and I took a flu vaccine in my second trimester. I had a difficult pregnancy. When I tell doctors or other parents about the vaccines, many are astounded that I was not told of their possible side effects or complications in the context of conception and the well-being of an unborn child. I took for granted that the medical community would inform me of such possibilities. These were only the first of many things I took for granted, only to later learn how painfully misplaced my trust had been.

Daniel was born with bilateral clubfoot, a broken collarbone, and a high, piercing scream. When he was seven months old, I emphatically told our pediatrician that I was concerned about his development—he could not even lift his head. Once the pediatrician had confirmed that Daniel had a problem, he prescribed immediate physical therapy. The orthopedic physician got quickly on board and recommended a pediatric physical therapist who lived in our area and would come to our home. I am eternally grateful that he sent Charlotte Feichtmann into our lives: her patient, caring, understanding demeanor had a great impact on Daniel and on me. After carefully taking notes at our first meeting, she got to work helping Daniel roll over and lift his head. He made steady progress with her, first rolling over, then sitting up, then crawling. Finally, he could stand on his own. Each milestone was an event for Charlotte, for Daniel, and for me.

Then things got a bit tricky. Daniel had received all of the recommended vaccinations, including his MMR at the one-year mark. Our pediatrician's records indicate that, two days after Daniel received the MMR vaccine, I called to say that he



Daniel at five months (left), and showing signs of delayed development at seven months.

had terrible green diarrhea. Two days after that, I called to tell the doctor that Daniel had developed a fever of 105. When Daniel was about 15 months old, we began to notice a regression in behaviors that he had already learned. He stopped playing peekaboo or wanting to walk. Charlotte could get him walking during a therapy session, but when the session was over and she'd left, he quickly reverted to crawling.

My first thought was that these regressions meant I was neglecting to do something necessary for Daniel's continued development. I asked Charlotte to come twice a week and put the pressure on Daniel. After a month of twice-weekly sessions and little progress, Charlotte began to ask me about Daniel's other behaviors. Yes, I told her, he did often close doors. I'd thought that was just a weird quirk of

his. Yes, he did line up his blocks in a row, not a column. Was that abnormal? Charlotte pointed out Daniel's sensitivity to textures, particularly those of raw pinto beans and Styrofoam. Merely touching either made him gag.

It was odd to watch what had seemed a relatively normal child be identified as "abnormal." The catalyst for me, however, was when, at 18 months, Daniel could still not understand me when I spoke to him. I began to accept that he was autistic. Oddly enough, my first reaction was "Let's fix this." The only alternative to this internal battle cry would have been to say, "There is no cure," which would have about killed me.

We knew there had to be an explanation for the green diarrhea. Our pediatrician made the usual recommendations: bland diet, applesauce, etc. In desperation, we also consulted a practitioner of contact reflexology, a branch of chiropractic. I was and remain unsure about the merits of this modality as a treatment for autism, but it did point us in the right direction: diet intervention. The contact reflexologist had me hold Daniel on my lap, then had me hold out my left arm parallel to the floor. She placed vials of powdered versions of various foodstuffs around my son, then pressed down on my arm to see if "energy" was lost. When she tested for milk, my arm went down like a lead balloon—this, she said, indicated that Daniel was allergic to milk. Wheat produced the same reaction, but a number of other allergens did not. She concluded that I should stop feeding Daniel milk right away, and wheat shortly thereafter.

I thought milk would be relatively easy to eliminate from Daniel's diet, but

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I was skeptical about wheat. Actually, I was more concerned about the inconvenience to me of feeding Daniel a wheatless diet. And what if this contact reflexologist was a crackpot?

But in less than a week of eating

What is IVIG THERAPY?

Intravenous immunoglobulin (IVIG) is a treatment commonly used for people with severe immune suppression. While treating a severely immune-suppressed child who was also autistic, Dr. Sudhir Gupta realized that, as the child's immune system improved, his symptoms of autism decreased as well. Encouraged by the possibility of treating autism by improving immune-system function, Dr. Gupta began to treat and study autistic children.

IVIG treatment is seldom covered by health insurance, unless the child's immune dysfunction indicates an established significant medical disease treatable only by gamma globulin infusions.

Otherwise, the costs can be prohibitive for many parents who seek such treatment for their children.

Immunoglobulin is derived from human blood. Blood must be taken from thousands of human blood donors in order to isolate the small number of grams of gamma globulin to be infused. Though this treatment is not without risks—of side effects such as nausea and headache, as well as the risk, however minimal, of infectious disease from any blood-donor product—parents facing the possibility of their children suffering a lifelong autism disorder often take the gamble.

— MARY ROMANIEC

no dairy products, Daniel stopped waking up screaming after his naps. Inspired, I stopped feeding him wheat as well, though only half-heartedly. But the green diarrhea never stopped, and now Daniel was banging his head against the wall and writhing on the ground—clear symptoms of autism.

Watching Daniel do that was the worst part. It didn't seem to matter what the diagnosis was as I changed yet another diaper of loose green stools. I was angry and frustrated by what we had not been told after the diagnosis—information I had to discover on my own.

Thank God for the Internet. I sat crying in front of my computer, prayerfully begging for an answer, any answer. Finally, I typed in “dietary intervention autism.” Up popped two books: *Special Diets for Special Kids*, by Lisa Lewis, PhD, and *Unraveling the Mystery of Autism and Pervasive Developmental Disorder*, by Karyn Seroussi. I ordered them right away and read them as soon as they were delivered. Once I thought I understood the reasons for a gluten-free/casein-free (GF/CF) diet, I began in earnest. I wrote down the names of all the weird flours in the recipes I read, then went shopping. But there was still so much I didn't know.

For one thing, I hadn't fully grasped the concept of cross-contamination: that gluten-free foods could be contaminated merely by touching foods containing even just a few particles of gluten. Nor was the overuse of soy an issue at the time—until Daniel got worse. Finally, we buckled down, committed 100 percent to Daniel's new diet, and saw a huge change in his behavior. But after three weeks on the diet, we blew it, vacillating a little here and a little there. After a few weeks of this, Daniel was in full regression. I will never forget Kim Courtney, the occupational therapist who worked with Charlotte, looking at me in desperation as Daniel screamed and flailed. He'd lost six months of progress overnight, and when Kim asked if we'd put him on some new drug, I cried. “It's the diet,” I said. “He is on drugs, and the drug is food.” I cried some more in a phone call to my husband. I swore that I would get better at this, but I needed his help. Our son's recovery depended on our getting good at this.

A few months later, Daniel's diarrhea worsened to the point that he fell off the growth curve. An endoscopy revealed that he had erosion of the esophagus, stomach, and upper intestine. The gastroenterologist could offer no explanation for this, although she knew about our excessive use of soy. We discovered that when we ran out of soy yogurt, his diarrhea disappeared. Then came the publication of Lisa Lewis's second book, *Special Diets for Special Kids Two*, which explains in detail how too much soy can cause this type of erosion. We stopped giving Daniel soy, and the diarrhea began to clear up.

We had been fully on the GF/CF diet for six months when we met Dr. Sudhir Gupta, an immunologist at the University of California, Irvine. Dr. Gupta is known for his studies regarding treatment of autism with immunoglobulin to build the immune system and help heal the brain. After running lab tests on Daniel, Dr. Gupta concluded that he might benefit from an intravenous infusion of immunoglobulin (IVIG). We began a month later, not really caring whether or not our

Diagnosis: Autism

now what do I do?

Yes, children can recover from autism.

And to varying degrees, and depending on the individual child, there can be a lessening of autistic symptoms. Most often this process will require extraordinary effort by the parents to turn over every stone in the quest to help their child. What follows is a brief list of where to begin.

1. Begin the education process.
2. Find an autism doctor.
3. Read these books:
 - Lewis, Lisa, PhD. *Special Diets for Special Kids*. Future Horizons, 1998.
 - Lewis, Lisa. *Special Diets for Special Kids Two*. Future Horizons, 2001.
 - Maurice, Catherine. *Let Me Hear Your Voice*. Ballantine Books, 1994.
 - Seroussi, Karyn. *Unraveling the Mystery of Autism and Pervasive Developmental Disorder*. Broadway Books, 2002.
4. Educate yourself about the GF/CF diet.
5. Become a good GF/CF cook.
6. Educate your spouse.
7. Attend a conference on autism.
9. Look into biomedical treatments.
10. Supplement, supplement, supplement.
11. Start a behavior-therapy program.

In summary, you are about to begin an odyssey that will change your life in ways you never dreamed of. There will be days when you cry in frustration over the setbacks, and days when you dance for joy on the successes. Especially in the beginning stages, expect to take one step back for every two steps forward. This is still progress, however slow.

None of these therapies comes with a predictable rate of improvement. Many believe that you need three months to a year before you can accurately monitor the success of your efforts. You might feel that real progress has been made when, one day, your child passes some important developmental milestone—or simply when you have the overall feeling that your daily family life now has an element of normalcy.

— M . R .

For the unabridged version of this article, please see www.mothering.com/10-0-0/html/10-8-0/diagnosis-autism.shtml

health insurance would cover the treatment. We knew we were battling time to save our son.

The infusions' effects were dramatic. Our son went from two words in January 2002 to full sentences by July 2002. His lab results improved dramatically as well. When we saw Dr. Gupta in June for a follow-up visit, he was looking at a different kid from the one he'd met in January, and he was all smiles at Daniel's progress. In August 2002 we met with an autism specialist to review Daniel's lab results and progress. She joyfully concurred that he'd won the autism lottery and would fully recover. Even in the worst moments of pure hell, we had been convinced that this would eventually happen, but still it was good to hear—especially when the specialist told us that she hoped we had not touched his college fund, because he was going for sure. In December 2002, Dr. Gupta declared Daniel to be one of his recovery kids.

The autism specialist asked me why I thought we'd been blessed with this set of circumstances while others were still struggling to help their own children. I had to believe that it was because I was meant to help the parents of the next autistic child, but I would not be able to do this if we were still working on Daniel's recovery. We continued his IVIG treatment until just after his fourth birthday, in June 2003, when his pediatrician proudly proclaimed that he no longer saw in Daniel any trace of autism. It was at this point that I felt comfortable telling others that Daniel had recovered. I knew that with autism comes a life of gut issues, immune challenges, and a genetic predisposition to other autoimmune disorders. Still, it was good to know that Daniel would be a taxpayer, not a tax burden.

Recovery for Daniel would have been virtually impossible without my husband's involvement. Rich is, by profession, an engineer, and he's a stickler for details. As I pursued the medical evidence and made doctors' appointments, Rich encouraged or challenged my efforts. He provided the much-needed

balance to the sense of chaos I might otherwise have created. He also found ways to pay for whatever treatments or therapies Daniel needed. His financial prudence paid off and allowed us to do what we considered best for Daniel.

Once we understood that Daniel was recovering, I knew it was time to reach out to the next parents by helping them in the ways I had most needed but had never received. I wrote checklists of what to do when your child has been diagnosed as autistic. One is a basic checklist: finding an autism doctor, buying helpful books, getting educated, starting the GF/CF diet, etc. (see sidebar, "Diagnosis: Autism: Now What Do I Do?"). I've sent these checklists to parents all over the US and abroad. I've been asked so often for my telephone number and e-mail address that I've had business cards printed.

Since appointing myself a parent mentor, I have been introduced to some

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of the most amazing parents. They are at first panicked, but are hopeful that they can help their children recover from autism. I first explain to them that there *is* recovery from autism, or at least a lessening of symptoms. I then explain that they have the ability to research and implement themselves whatever treatment their child needs.

I also coach them in how best to change their child's diet without killing themselves in the middle of the grocery store. I'm a big believer in ready-to-eat foods, especially early in the GF/CF diet, when parents are likely to be most stressed from dealing with the overwhelming facts of their child's diagnosis and behavior. I encourage them to take a gradual approach: first eliminate dairy foods for two weeks, then eliminate gluten one meal at a time, finding five

items for each meal that the child will eat. I then point them in the direction of websites where they can order foods and supplements. Bag mixes can be added once they've gotten beyond ready-to-eat foods; finally, they should branch out and try some recipes from scratch.

The grassroots effort of such parent-to-parent connection is what can debunk the myth that autism is "untreatable" or "incurable." As more and more parents hear that autistic kids are actually recovering, those efforts grow.

This fall will mark another milestone: Daniel will start kindergarten on time. He will need nothing other than a bit of speech therapy as he continues to improve his articulation. My appreciation of the milestones of normal childhood development has been greatly enhanced by the gift of his recovery. The final milestone will be when Daniel graduates from college. I will be the mom with the biggest tears of joy, which are the gift of hope.

For more information about chronic illnesses and autism, see the following articles in past issues of *Mothering*: "The Flu Vaccine and You," no. 125; "Vaccines and Autism," no. 115; "Show Us the Science," no. 105; and "Diagnosis Autism: What Families Can Do," no. 100. Go to www.mothering.com for more related material.

FOR MORE INFORMATION

Book

Marohn, Stephanie. *The Natural Medicine Guide to Autism*. Hampton Roads Publishing Co., 2002. (See sidebars for other selections.)

Organizations

Families for Early Autism Treatment (FEAT)
PO Box 255722
Sacramento, CA 95865-5722
916.843.1536
www.feat.org

National Autism Association (NAA)
PO Box 1547
Marion, SC 29571
877.NAA.AUTISM; 877.622.2884
www.nationalautismassociation.org

Talk About Curing Autism (TACA)
PO Box 12409
Newport Beach, CA 92658-2409
949.640.4401
www.tacanov.org

Treatment Centers

Dr. Buttar Clinic
Rashid A. Buttar, DO
20721 Torrence Chapel Road #101
Cornelius, NC 28031
704.895.WELL

www.drbuttar.com/about/about.asp
help@drbuttar.com

Dr. Sudhir Gupta
University of California, Irvine
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International Child Development
Resource Center
Jeff Bradstreet, MD
1688 W. Hibiscus Boulevard
Melbourne, FL 32901
321.953.0278
www.icdrc.org

Pfeiffer Treatment Center
William Walsh, PhD
4575 Weaver Parkway
Warrenville, IL 60555-4039
630.505.0300
www.hripte.org

True Health Medical Center
Anju Usman, MD
603 E. Diehl Road, Suite 135
Naperville, IL 60563
630.505.4040

University of California Davis
The MIND Institute
2825 50th Street
Sacramento, CA 95817
888.883.0961
www.ucdmc.ucdavis.edu/mindinstitute/

Websites

Autism One
Presentations from the Autism One 2004
Conference can be downloaded from this site.
<http://64.202.165.26/autism1/homepage.asp>

Autism Research Institute
Dr. Bernard Rimland's organization. Many excellent articles, information, and a link to the Defeat Autism Now! conference; also information on subscribing to the institute's newsletter. www.autism.com/ari

Center for the Study of Autism
Many good links and valuable information.
www.autism.org

Gluten-Free/Casein-Free Diet
A wealth of information on the gluten-free/casein-free diet, a protocol that helps approximately 70 percent of children with autism. www.GFCFDiet.com

Yahoo Autism Groups
There are more than a thousand groups on Yahoo devoted to autism. Most are parent-driven with extremely knowledgeable members. Ask any question, and chances are you will have several excellent answers within 24 hours. <http://groups.yahoo.com> (type "autism" in the search field).

The books listed above can be purchased by clicking on the Powell's button on Mothering.com

Mary Romaniec is the mother of two children, Theresa (6) and Daniel (5). She has written several articles, appeared on radio shows, and discussed the practical steps parents can take to aid in their children's improvement or recovery from autism. She is available for parent-to-parent consultation.

The Defeat Autism Now! Approach

Most pediatricians, child psychiatrists, and neurologists have been trained to believe that little or nothing can be done to bring about major improvement in autistic children. Conventionally trained physicians typically tell parents to, in effect, "Keep them warm and dry, and if they get out of hand, we'll give them drugs."

This is bad advice. Due largely to the Defeat Autism Now! (DAN!) Project, initiated in 1995 by the Autism Research Institute (ARI), thousands of formerly autistic children are now no longer considered autistic, or are well on their way to being mainstreamed.

Early intervention is important. Since its founding in 1967, the ARI has recommended both early behavioral intervention, now referred to as ABA (applied behavior analysis), and early biomedical intervention. The biomedical intervention is best achieved by physicians trained in the DAN! approach.

Doctors who subscribe to the DAN! philosophy recognize that:

- Autistic children have biomedical problems that cause their autism. If these problems are identified and corrected, the result in most cases can be the child's functioning at normal or near-normal levels.
- Many biochemical problems may cause autism, and no two autistic children are alike in their configurations of causal problems.
- Unlike most conventional doctors, DAN! doctors consider using psychiatric drugs—all of which have serious side effects—only as a last resort.
- Many clinical laboratory tests are useful in determining the optimal treatment regimen for each child. The four books listed below are the best sources of information about these tests and treatments. The first three are more "parent-friendly"; the last is a technical book for physicians and research scientists.

Edelson, Stephen M., PhD, and Bernard Rimland, PhD, eds. *Treating Autism: Parent Stories of Hope and Success*. Autism Research Institute, 2003.

Hamilton, Lynn M. *Facing Autism*. Waterbrook Press, 2000.

McCandless, Jaquelyn, MD. *Children with Starving Brains*, second ed. Bramble Books, 2003.

Pangborn, Jon, PhD, and Sidney Baker, MD. *Defeat Autism Now! Biomedical Assessment Options for Children with Autism and Related Problems*. Autism Research Institute, 2002.

Unfortunately, there are too few DAN! doctors, and most of them have waiting lists, sometimes long ones. However, there are safe and frequently effective treatments that parents can use on their own, without the need to consult a physician. Parents can get a head start by trying these treatments while they wait for an appointment. Especially recommended are:

- High doses of vitamin B6 and magnesium
- High doses of dimethylglycine (DMG)
- The gluten-free/casein-free (GF/CF) diet

For information on these treatment modalities, see the ARI's website and/or the books *Treating Autism*, *Facing Autism*, and *Children with Starving Brains* (listed above). These and other books, articles, and tapes are available from the Autism Research Institute, 4182 Adams Avenue, San Diego, CA 92116; 619.563.6840; www.autism.com/ari/

For a list of doctors who subscribe to the DAN! philosophy, go to www.autism.com/ari/dan/contents.html and click on one of the lists of DAN! physicians: "United States" or "Outside the US."

The best results are seen in children who receive both early behavioral intervention and DAN!-type biomedical treatments. We always advise parents to refrain from telling the child's behavioral therapists, teachers, friends, and relatives when the vitamin and/or other biomedical treatments are begun, so that parents can get unbiased comments about any changes in their child's behavior. Over the years, we have heard from hundreds of parents the same encouraging story: A teacher says, "Your child has suddenly shown great improvement! He has made more progress in the past week than in the past month! You must be doing something different." Such words are music to any parent's ears.

The next DAN! conference, for parents and professionals, will be held in Los Angeles, October 1–3, 2004. Write to ARI or visit the ARI website for more information.

— BERNARD RIMLAND, PHD