

Back from

# Autism

Many children with autism make tremendous improvements after undergoing intensive training with behavioral therapists. It's a form of treatment that University of Minnesota psychology students working with autistic children are learning. And Duluth campus graduate **Joe Mohs** says he is living proof that the therapy works.

**A**t 25, it still upsets Joe Mohs (B.A. '08 UMD) to see home movies of himself as a sad-eyed toddler staring blankly at the family Christmas tree, barely noticing his big sister sitting next to him, or looking vacant and frightened at a party, where all around him kids are smiling and laughing. Joe was 15 months old when his mother, Kay, began tiptoeing up behind her blue-eyed little boy as he watched cartoons to bang two pan lids together and gauge his reaction. Crash! Nothing. Joe wasn't startled; he didn't even turn around. ¶ Though he walked before his first birthday, Joe babbled only a short time before becoming nearly silent. Unlike his sister, Mary Kay, about two years older, Joe didn't like to be touched or cuddled. He walked on his toes and stared off at nothing in particular. He didn't play with much besides a wooden toy hammer to pound pegs through holes in a board.

Anxiously wondering why their son seemed to be slipping away, Kay and her husband, Bob (B.A. '71, B.S. '73, D.D.S. '75), took their son to his pediatrician, a family friend who told them to be patient, that "all kids develop at different rates." But Joe's condition got worse. He abandoned the toy pegs altogether, preferring to wave the hammer back and forth for hours at a time.

While Bob worked at his dental practice in Alexandria, Minnesota, where the family lived, Kay stayed home with the children, trying to find ways to draw out her youngest. Finally, in 1986, when Joe was 22 months old, Minneapolis Children's Hospital diagnosed him with infantile autism. Bob will never forget the advice one psychiatrist gave them. "He warned us not to get too attached to Joe because he would probably have to be institutionalized before he was a teenager."

He was wrong, however, and it's important to Joe that people know that. Although he's nervous about revealing publicly that he was once diagnosed with autism, Joe is telling anyone who will listen about the intensive behavior therapy that helped him. That same therapy is being taught to psychology students by professors Gail Peterson

and Eric Larsson at the University of Minnesota and is available in the Twin Cities. Joe hopes that by talking openly about his experiences he can help others get the assistance they need.

## UNDERSTANDING AUTISM

Referred to as part of a group of autism spectrum disorders (ASDs) that includes Asperger's syndrome and pervasive development disorder, autism is a developmental disorder, and every person who has it suffers from varying difficulties with language, communication, and social skills. Boys are more likely to be autistic than girls; this, scientists believe, may be the result of exposure to high levels of testosterone when in the uterus. In most cases, symptoms appear between the ages of 1 and 3 and usually develop gradually, though in cases of "regressive" autism, symptoms appear suddenly, with children losing skills they had previously attained, like speech, within days or weeks.

*Autism* literally means "self-focused," and children with the disorder are often described as retreating into their own worlds. To varying degrees, they may suffer any number of problems, including an inability to talk or understand language; heightened

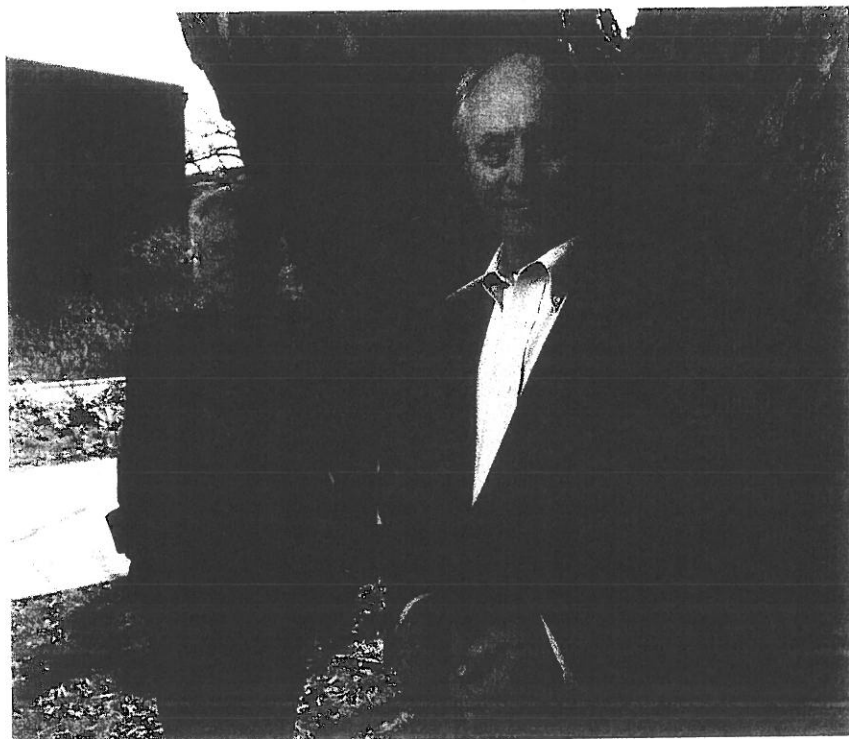
**Joe Mohs and his father, Bob, are spreading the word about the intensive behavior training that helped Joe overcome autism.**

BY MELEAH MAYNARD

PHOTOGRAPHS BY MARK LUINENBURG

sensitivity to sound, taste, and light; a lack of interest in interacting with others; outbursts over disruption in routines; a tendency toward repetitive behaviors like lining up toys; and self-stimulatory behaviors like hand-flapping, excessive eye blinking, and rocking.

It was Johns Hopkins University psychiatrist Leo Kanner who first used the term *early infantile autism* to describe the behavior of 11 socially withdrawn children in his 1943 paper, "Autistic Disturbances of Affective Contact." Though some professionals assumed these children, and children with similar symptoms, were mentally deficient, Kanner observed that they all appeared to be quite intelligent and had excellent memories. Kanner



**Adjunct professor Eric Larsson, left, and associate professor of psychology Gail Peterson teach Applied Behavior Analysis courses to U students who want to work with autistic children.**

also pointed out that while a few of the children had been diagnosed with some form of schizophrenia, he questioned that diagnosis. He believed these children had been born without the ability to connect with others and the world around them.

But it was psychologist Bruno Bettelheim's theory—that autism was caused by "refrigerator mothers," emotionally cold women who drove their children to develop strange behaviors and an inability to communicate—that became widely accepted. First described in the late 1960s, the "refrigerator mother" theory prevailed through the 1970s and into the '80s, with some Freudian psychologists still supporting it today.

Children were sometimes placed in hospital-based programs where they were cared for by adults whose job it was to give them love and attention. Others were institutionalized. Doctors routinely prescribed medications for anxiety, depression, psychosis, and mood disorders—and continue to do so today.

In the 1960s, O. Ivar Lovaas, a young psychologist at the University of California, Los Angeles made headlines by essentially ignoring the reasons for the condition. Instead, he focused on

changing the behaviors associated with it. He rewarded desirable behavior (like speaking and responding to requests) with favorite foods, toys, and hugs and deterred undesirable behavior (tantrums and self-harm, such as head-banging) by yelling, shaking, slapping, and, in a few cases, giving mild electric shock.

In a 1965 interview with *Life* magazine for the article "Screams, Slaps & Love: A Surprising, Shocking Treatment Helps Far-Gone Mental Cripples," Lovaas explained his therapy, which was lauded for helping autistic children improve. "You have to put the fire out first before you worry how it started," he said. But readers thought his methods were unnecessarily harsh. And although Lovaas later refined his therapy, eliminating the use of shock and physical punishments to develop what is now known as Applied Behavior Analysis (ABA)—the treatment that helped Joe Mohs—his reputation was irreparably damaged by the article, which critics of ABA still cite when decrying the treatment as cruel.

### CAUSES AND TREATMENTS DISPUTED

In the 1980s, an estimated 1 to 2 in 10,000 children in the United States were affected by ASDs. In 2006, the Centers for Disease Control estimated that number to be an average of 1 in 110. Theories about the reasons for the increase and the causes of autism vary widely, but most credible researchers agree that environmental pollutants, specifically toxins that impair children's immune systems and could damage developing brains, may play a role.

Others say autism's rise may be exaggerated because checklists, developed in the 1990s, have made it easier to diagnose autism and related disorders. Eric Larsson, an adjunct psychology professor at the University, is in the former camp. "Visit any school and it's obvious that there are many more children these days with major language disorders and severe impairments than there used to be," he says. "I believe that compares directly with the rise in pollution."

The theory that childhood vaccines cause autism was born in 1998 when Andrew Wakefield, a British surgeon, published the results of a study suggesting a possible link between the MMR (measles, mumps, and rubella) vaccine and the onset of autism. Though Wakefield wrote that research had not proven there was a connection between the two, the paper did discuss parents' assertions of behavioral changes in their children following immunization. He advised that, to be safe, the vaccines should be separated.

After years of controversy, in February of this year the medical journal *The Lancet*, where Wakefield's study had originally appeared, retracted his paper and the British General Medical Council ruled that Wakefield's study was flawed. But the vaccine theory lives on.

Others wonder whether thimerosal, a mercury-containing preservative used in vaccines, might cause autism. Though studies have found no causal link between autism and thimerosal, the FDA began working with manufacturers in 2001 to create thimerosal-free vaccines. Perhaps, Larsson and others say, children who are genetically predisposed to autism or have already been exposed

to too much mercury are “pushed over the edge” neurologically when mercury enters their system. Bob Mohs believes this may have been the case with Joe, since he seemed to become more withdrawn after his vaccinations.

ABA itself is often misunderstood too. Lovaas was well-versed in the work of B.F. Skinner (the father of behavior analysis and a professor at the U of M in the 1930s and '40s) when he began work on what would become his Applied Behavior Analysis treatment model. His work was inspired in part by Anne Sullivan, Helen Keller's teacher, who made tremendous strides with her unsociable deaf, blind, and mute pupil using behavior modification techniques. Lovaas wondered whether that could work with autistic children too.

Today, ABA is the treatment for autism most solidly backed by scientific data. Yet the treatment remains plagued by attacks from critics who contend it's wrong to make demands on autistic children and “force” them to become different. And disagreement persists between supporters of a behavioral approach to treating autism, like ABA, and those who believe in psychoanalytic treatments focused on understanding and analyzing the origins of the disorder.

All debates aside, say Larsson and Peterson, Applied Behavior Analysis's biggest obstacle is misunderstanding over how it works. All ABA programs are not equal. While studies show 45 percent to 50 percent of autistic children who receive ABA therapy overcome their symptoms sufficiently to function independently in school, this level of benefit is greater for children who receive ABA services in the intensive way Lovaas intended. Parents of autistic children are routinely informed of ABA programs in public schools, but most schools lack the staff, training, and funding to provide ABA at the intended level of intensity.

Instead, they offer what they can, Larsson explains: part-time classroom aides, weekly home visits, special education classes using behavioral therapy principles. Because these programs are often unsuccessful, many parents and educators believe ABA doesn't work. “We get special education directors telling horror stories about how bad ABA is because what they've seen is poorly trained staff doing their best to blunder through the treatments in too little time,” Larsson says.

## LEARNING ABOUT LOVAAS

ABA was just emerging when Bob Mohs happened to hear about it one evening while watching TV. It was 1987, and by that time he and Kay had crisscrossed the country to help Joe with speech and occupational therapy, special diets, vitamins, and sensory integration therapy. Nothing had worked. And then the answer came into their living room. “I remember Dan Rather saying how, in a moment, they were going to talk about a new program at UCLA that was helping children recover from autism,” says Bob, who quickly popped a tape in the VCR to record it.

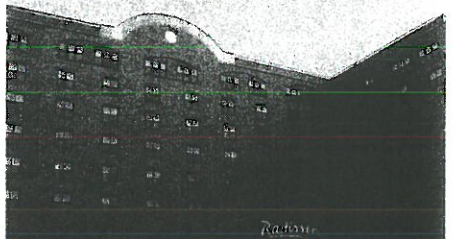
The story explained how psychologist Lovaas had just released the findings of his study of 19 children with autism who participated in an intensive behavior therapy program. Nine of the children had “recovered,” meaning they were able to enter school and function as any other child their age. The rest had improved to varying degrees, but not as significantly. The report made clear that children treated as early as possible had the best chance of getting better. Bob immediately called Lovaas's clinic in Los Angeles and scheduled Joe for an evaluation.

Soon he and Kay were watching 3-year-old Joe through a two-way mirror as he sat across the table from two psychology students in a UCLA lab. Joe responded immediately, and in 10 minutes he was stacking blocks in patterns and matching colors, “things we had no idea he could do,” says Bob. The Lovaas team agreed to work with Joe, but the family would have to relocate to Los Angeles for two years of intensive, eight-hours-a-day treatment. Kay packed Joe and Mary Kay, 5, and moved a few months later, accompanied by Cathy Mattheisen, a family friend and teacher who took a leave of absence from work to help out. Bob stayed behind in Minnesota to work but visited his family on weekends. At last the Mohses felt there might be some hope for their son.

Tammy and Jeff Meyer (B.A. '82), of Minneapolis, were not so lucky when they were trying to get help for their son Max in the mid-1990s. Tammy remembers the second of their three children as a model baby who was off the charts physically and mentally. He was active and happy and loved to be cuddled. Looking back later, though, she realized there were signs that something was wrong. He didn't talk and

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increasingly began going off by himself. "It seemed like the joy had gone out of him," Tammy recalls. And then came the moment that seemed to push Max to a place where he became unreachable.

He was about 18 months old and had recently gotten his MMR vaccines. Tammy's sister was babysitting and called, frantic, saying something was wrong with Max. Tammy rushed over and found her son covered in a red rash. Doctors diagnosed a yeast infection and prescribed an antibiotic. "That's when he started really slipping away," says Tammy. "He became a different child. His personality changed, and little by little the sparkle just went out of his eyes."

Desperate for help, they took Max to Park Nicollet Clinic in St. Louis Park but got no answers. Tammy began researching

ABA therapy with Peterson, Larsson is also the executive director of the Minneapolis-based Lovaas Institute Midwest. Unlike the many treatment centers around the country operated by the Los Angeles-based Lovaas Institute, the Lovaas Institute Midwest is a separate entity. Opened in 2003 with help from Lovaas, with whom Larsson collaborates regularly, it provides in-home early intensive ABA therapy to children with autism.

University psychology majors interested in working with autistic children often work at the institute as behavior therapists after completing Larsson and Peterson's courses, some taking a semester-long internship working directly with autistic children and their families in their homes. "The work is not for everybody,

because with these children you have to be very explicit," Peterson explains. "If a child doesn't touch people, you reach out and take his hand and touch it and praise that, and you might spend weeks doing one thing." Peterson has taught psychology at the U since 1973 and has been involved for 20 years with local and national organizations that serve autistic children and their families, including a stint on the board of Families for Effective Autism Treatment (now the Minnesota Autism Center).

Before working on long-term goals like helping children learn to communicate and interact, most parents want help with things that would make life immediately easier for everyone, like potty training or getting kids to dress themselves. From the outset, therapists also work to stop autistic children from having the "meltdowns" that commonly accompany the disorder.

"Because these kids can't talk, they cry, throw things, or scream when they want a

toy or a treat, and their parents rush to get them what they want," says Larsson. Changing this pattern involves some training of the parents, and it's one of the toughest parts of the therapy. Kids with autism learn that doing the wrong thing gets them what they want. "It's hard because we have to get parents to stop responding to crying," Larsson continues. "If their child wants a French onion potato chip because that's their favorite food, they need to give them some only when they aren't crying so eventually the child learns how to get what they want in an acceptable way."

It's a matter of figuring out the motivation behind a behavior and then finding ways to change it, says Kristy Oldham (B.S. '98), who first worked as a behavioral therapist at the Lovaas Institute Midwest before becoming a program director there. Oldham has worked with many children over the years and they are all motivated by something. "Our job is to help them get back to their parents and siblings and stop sitting and staring at the mini blinds. We have to find ways to transfer their motivation away from the blinds and get them to engage with us."

How? By rewarding desirable behavior in order to promote more of it. Children with autism seldom learn by watching others. That's why therapists use imitation to get kids to understand how to do just about everything, including play. First the therapist claps, then the child claps and is rewarded with a bit of food, a hug, or a few minutes



**Kristy Oldham (B.S. '98), left, a program director at the Lovaas Institute Midwest, and U psychology student Nadhia Fuentes work with Malcolm Dawson-Moore in his home using Applied Behavior Analysis.**

his symptoms and was horrified to realize that her son seemed to have many of the classic signs of autism. She called Fraser, a Minnesota nonprofit that provides autism services, to schedule an evaluation, and in 1994, just after his second birthday, Max was diagnosed with autism. Like Joe's parents almost a decade earlier, Tammy and Jeff were told there was little hope for

their son and that speech and occupational therapy were among the few treatment options available.

They tried both, along with special diets and sensory integration, just as the Mohs family had. Nothing helped until Tammy met a woman whose son also had recently been diagnosed with autism. Hoping to find answers, the two women went to hear a lecture by Bernard Rimland, the psychologist credited with overturning the theory that bad parenting was the cause of autism. There, Tammy heard about Eric Larsson and ABA therapy. Max was now 4 years old, already past the window of time when treatment was likely to be most effective.

### **IMITATE, REWARD, REPEAT**

In addition to co-teaching University of Minnesota courses on

with a favorite toy. The therapist touches her nose then tries to get the child to touch his nose. Success earns another reward. Heads are patted, tummies are rubbed, mouths are formed into smiles and frowns, and, eventually, something clicks and the learning process moves forward, sometimes smoothly, but often accompanied by frustration, outbursts, and tears—especially in the beginning.

But in this tightly controlled environment, autistic children are able to learn in ways they can't in the loose settings other children thrive in. It is painstaking and exhausting. In a typical eight-hour-day of treatment, two to three therapists will work with a child in shifts.

was in tears all the time too.”

“It was pure and unfiltered desperation all the time,” she says. “Unless you're a parent with a critically ill child, you don't know what it feels like to feel desperate for someone to tell you what's wrong, desperate for information and answers, and desperate for your child to be able to tell you how they're feeling. It was all-consuming. Nothing else mattered.”

Though Joe Mohs was not symptom-free when his mother brought everyone home after only one year in Los Angeles, Kay and Mattheisen had learned so much during their training at the Lovaas Institute, therapists there felt they could continue



**Max Meyer, 18, didn't begin Applied Behavior Analysis until he was 4, past the age that treatment was likely to be most effective. Still, he overcame many of his autism symptoms and continues to work on his social skills.**

Teaching an autistic child to speak takes time and almost unimaginable patience. Some children, particularly those who don't speak at all, can't make sense of the words being said around them or incorporate them into speech like other kids do. For reasons that are not understood, many children with autism hear only sounds that are unconnected to

meaning, so before they can learn to talk, they must understand what they're hearing. Again, this begins with rewards. Long before a child learns to say, “Daddy, I love you,” a therapist teaches how to imitate the smacking of lips and then to make sounds (blowing out a match makes a sound like who). Once words are learned, therapists attach meaning to them so that a picture of a ball doesn't elicit a cry of “banana” or “cow.” It may take thousands of trials, but this is how children with autism learn to talk.

Tammy Meyer remembers this time in Max's treatment well. “The only words he understood were *nook, mom, dad,* and *juice,*” she says, adding that she spent weeks just getting Max to sit in a chair and pay attention to her for three seconds, then five seconds. Recalls Jeff: “He cried and screamed, it was terrible, and Tammy

Joe's treatment back in Minnesota. Supported by regular phone conversations with staff at the UCLA clinic, Kay and Mattheisen trained special education instructors at a local school and others they hired to work with Joe over the next year and a half. Therapy ended just before kindergarten and Joe, who was 6, joined his classmates unassisted.

It wasn't long before teachers were telling Kay and Bob that he was the best reader in his class. But that didn't stop the Mohses from worrying and watching Joe constantly. “We were overprotective,” Bob says. “But we were so afraid he would revert back to swinging that little hammer.”

### PRICELESS PROGRESS

One of the requirements of ABA therapy is that a parent or other caregiver must always be present during therapy. Consistency is critical to success, so treatment doesn't stop when the therapists go home. That means family members have to know how to keep the intensive training going seven days a week, even in subtle ways that children may not even be aware of. Sessions are heart-wrenching for parents, particularly early on when children are enraged over being forced to sit and do things they've never been asked to do before.

As a clinical supervisor at the Lovaas Institute Midwest, Adrienne Turzynski (B.S. '03), who studied ABA at the University, listens to parents talk about how hard it is to watch what's going on. "People don't like the idea of behavior modification," she says. "They don't like the way that sounds, but when you work with kids with autism you have to do things in a very precise way." Turzynski has heard critics claim that the therapy's rigorous exactitude turns children into "robots." But she doesn't see it that way. For her and others who have seen the changes ABA can bring about, the therapy is a way to give children back the normalcy that the disorder has taken from them.

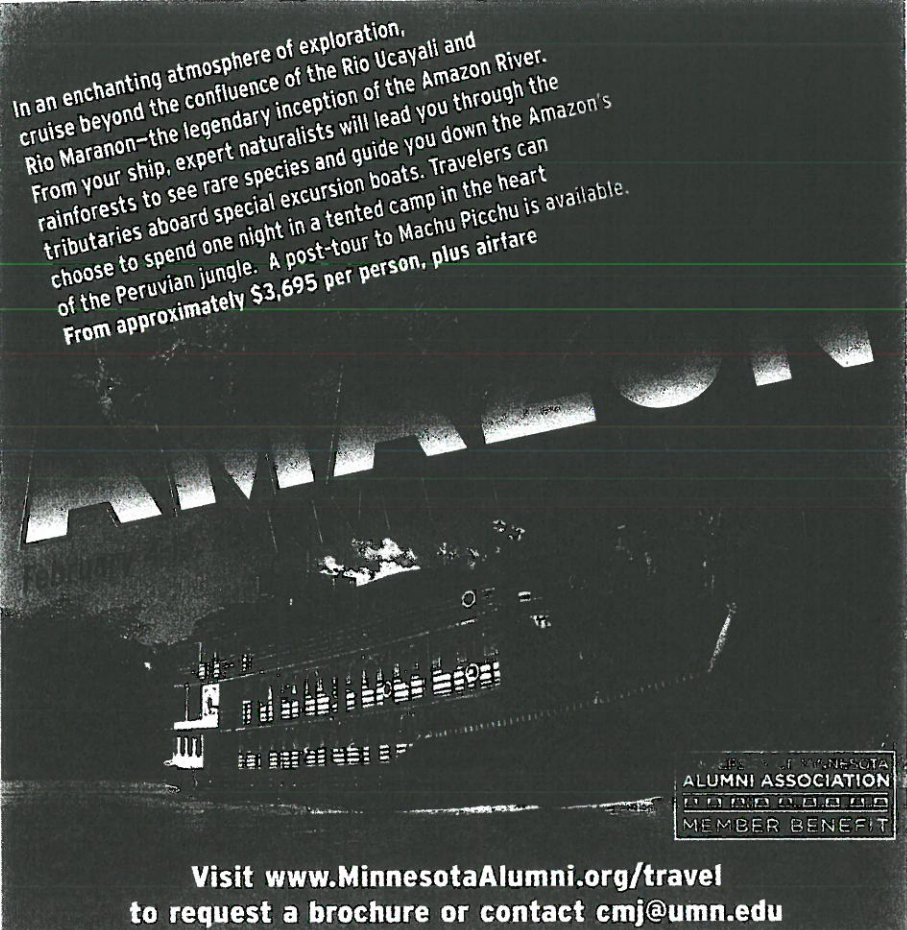
Take an aggressive boy who bangs his head on the television to get attention from his mom, she says. A therapist watching closely for a few minutes will see that every time he does it, mom yells his name and asks him to stop. So they set up a system where the mom comes in and hugs, kisses, or praises him when he isn't hitting his head. "It's unbelievable how fast this works," she says. "We definitely can't claim to recover every child we work with, but I've been here nine years and I've never seen a case where we didn't make some progress."

Researchers continue to explore why ABA therapy is more successful with some children than others. But it appears that the reason children who get treatment early have the best outcomes may be found in research into the genetic underpinnings of autism, says Travis Thompson (B.A. '58, M.S. '61, Ph.D. '61), a psychologist at the University of Minnesota and author of several books on autism.

Although some people with autism consider themselves to have recovered from the disorder, Thompson opposes using the term *recovery*, calling it controversial in professional circles. Most people with autism will always struggle with social and coping skills, he says, adding that he believes the term is misleading to parents and a disservice to people with autism. "I don't believe that many of these kids won't feel lonely and need some support in their lives," he says. "They need to know it's quite normal and quite OK that they need this."

Numerous genetic defects have already been associated with autism, but a paper published in the journal *Science* in 2008

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by researchers at Children's Hospital Boston and members of the Boston-based Autism Consortium identified five new autism-related gene defects that have helped researchers discover some common patterns. Essentially, Thompson explains, the newly identified defects seem to play a role in learning by disrupting the development of synaptic pathways in the brain. This means the genes for building synapses simply don't "turn on" like they should, says Thompson, who has been working with autistic children since the early 1960s. If this is the case, he continues, early intervention therapy based on Applied Behavior Analysis may work because the intensive instruction in speech and social behavior literally puts cells in "overdrive," causing them to produce the proteins needed to make the synapses needed for learning.

As Tammy and Jeff Meyer watch Max enter adulthood, they can't help thinking that their handsome 18-year-old son might have overcome far more of his symptoms had they been able to start ABA treatment sooner. Even after they talked with Larsson, who was an independent psychologist at the time, they soon discovered their insurance wouldn't cover the cost of ABA therapy, which can run as much as \$60,000 per year. (Scientific evidence confirming ABA's results and lobbying by families and advocates have led to mandated coverage in several states, as well as payment by Medicaid, but many families still can't get adequate financial help.)

So the Meyers hired Larsson, whose services insurance would pay for, to train them to provide the therapy themselves. Once trained, they hired and trained college students, neighbors, anyone who was willing to help them provide the intensive hours of treat-

ment Max needed. Still in diapers at age 4 and unresponsive, Max began making progress almost immediately.

"Dr. Larsson told us there were no guarantees and I had to remind myself of that all the time because the therapy was painfully difficult," she says. "But then after one month Max was out of diapers and then he started making eye contact. He learned how to write his name, and then he called me mom. So even though we used up all of our financial and emotional resources, it made it all worth it."

After being home-schooled for most of his education, Max is now in high school at a St. Paul charter school where he does well and has made a few friends, though he doesn't see them outside of class. At home, Max prefers to spend time alone, so Tammy and Jeff prompt him many times a day to come upstairs and be with the family. When Max graduates in June, he may take some community college courses in addition to working his part-time job at a local bakery.

When people ask Tammy about Max's future, she isn't sure how to answer. A talented artist, Max has retained the remarkable visual memory he displayed as a child that enables him to do things like watch a complicated karate move and then replicate it without further instruction, or use sheet music once to play an unfamiliar song on the guitar and never need to see the music again. Tammy is teaching him to drive, though the abstract thinking driving requires has her worried about his safety.

"He's always worked so hard," she says. "When other kids were outside playing in the summer, he was inside learning how to have a conversation. He's working even when he isn't aware of it."



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## A SECOND RECOVERY

By the time Joe Mohs entered high school, his autism symptoms were practically a distant memory. Surrounded by friends, he enjoyed the attention he got as a championship swimmer on his school's team. Kay continued to be his biggest supporter, including when he sometimes struggled with understanding social cues like facial expressions and body language, especially from girls.

Then, in February 1999, Kay was diagnosed with breast cancer and died 15 months later, in May 2000. The entire community reached out to support Joe and Bob in their grief, but it wasn't enough to save Joe from becoming depressed and belligerent. "Something happened when she died," Joe recalls. "I was devastated and something changed inside of me."

To cope with his grief, Joe tried marijuana and it became a habit he couldn't break. Promises to quit stretched into years of drug treatment before things got so bad Joe began having psychotic episodes and had to be admitted for a short time to a state hospital. Bob remembers thinking how he and Kay had worked so hard to keep their son from being institutionalized and somehow he'd ended up there anyway.

After his hospitalization, however, Joe made a commitment to work hard to reclaim the life his parents had fought so hard for him to grab hold of as a child. He describes his family's struggle to help him overcome his autism in "Autism Is Treatable," a short video posted on YouTube (see it at [www.MinnesotaAlumni.org/autism](http://www.MinnesotaAlumni.org/autism)). Joe and his dad made the video last year with Gail Peterson, introduced to the Mohses by Larsson in 2009. Peterson had long been interested in finding new ways to raise awareness about

autism treatment, and the University had just announced a new Imagine Fund grant through which Peterson was able to finance the bulk of the cost to produce the video.

"Autism is such a traumatic experience for most families who go through it, they just want to move on once their children have improved to the point where they don't need special attention anymore," says Peterson. "I thought it was remarkable that Joe wanted to do this."

A college graduate working as an auditor for a Duluth company, Joe was feeling grateful and optimistic about his future when he decided to call Peterson. He hoped that by talking about his treatment, he might be able to help others get better too.

Today, when he isn't working, Joe likes to play video games at home in his apartment or watch videos with his roommate. He spends a lot of time with his dad, and last year the two of them started a new web-based project together, [www.joeslivingproof.com](http://www.joeslivingproof.com). Designed by Joe, who has a degree in graphic design, the site tells the story of how he is proof that autism treatment works. Father and son are hoping that through the site, and by sharing their story at speaking engagements, they can help strengthen and inspire others to seek answers and treatment for autism and other challenges, like addiction.

But mostly, Joe says, he wants to do something for Kay. "Honoring my mom was the motivation for the video and the stories I'm telling about my life," he says. "I've come so far and I couldn't have done that without her. She would be so proud of me." ■

*Meleah Maynard (B.A. '91) is a Minneapolis-based freelance writer.*

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