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SPECIAL REPORT: THE LATEST ON AUTISM

Supermodel Carolyn Murphy in Ralph Lauren Black Label
AUTISM'S
ANGELS

The devastating disorder is inexplicably on the rise, and some visionary families have joined forces to promote awareness—and to find answers. By Diane Guernsey

DAVID SLATKIN is irresistible: a meltingly adorable seven-year-old who, with his thick, golden-brown hair and angelic face, might have stepped out of a Ralph Lauren ad. Take one look at his photograph and thoughts bubble up—maybe someday he'll play soccer or lacrosse, he'll love math or music or computers. Maybe someday he'll go to one of the Ivies or take a year off before college to travel. Maybe someday...

Learn more about David and those thoughts die away.

David has autism.

"David doesn't talk; he's never said Mama or Daddy," says his mother, Laura, a thoughtful, soft-spoken woman who is the founder and president of the Candela Group, a New York–based home-fragrance manufacturer. "And he doesn't understand language; we talk to him, but he doesn't comprehend it. He's very hyperactive. His twin sister, Alexandra, sits on the bed while I put on my makeup, and we're together. But if David is in the room, he's jumping all over, climbing on everything and putting things in his mouth that he shouldn't. I love him so much, but I can't be with him unless I'm devoting all my attention to him."

David's father, Harry, who is the president of home design for Limited Brands, joins in, speaking with the total honesty that he and Laura have chosen to use when they talk about David. "We're lucky—at least he's not eating his feces or smearing them on the wall. But he wanders off at the drop of a hat. We've put locks on all the doors, high up so he can't reach them. One night we forgot, and the next morning the kitchen door was open, and all the glasses were smashed on the floor."

When David was diagnosed, at seventeen months, his parents responded with textbook-perfect swiftness. They immersed him in an intensive, fifty-hour-a-week home-based educational program called Applied Behavioral Analysis, or ABA (see "Education and Treatments," page 98), along with other therapies, hoping that this multifaceted approach would help him, as it does many children, to overcome his cognitive and behavioral limitations and regain a more normal developmental path.

"I call that first year our year of hope," says Laura. "Harry and I took a journey to lands we'd never been to, reading, talking to so many wonderful doctors and therapists, learning about all
Laura Slatkin (left) and Ilene Lainer, both parents of autistic children, cofounded the New York Center for Autism Charter School at P.S. 30 in Manhattan; it opened last September. Opposite: A five-year-old boy with autism gets a hug from Carolyn Ryan, director of education at the NYCA Charter School.
the educational methodologies and therapies. We brought in a number of different doctors and groups to oversee his programs. After nine or ten months, I said to one doctor, 'It's been a while now; where would you say David fits on the spectrum of autism? Is he more challenged or less?' And he said, 'I would say that your son is severely autistic.' Laura pauses, then says, 'That was a dagger through my heart. That was the day when I knew we weren't one of the lucky ones. It rocked my world. I had to leave the room and go cry. When you have a child, you have all these hopes and dreams—and that's when it all unraveled.'

Even with his intensive programs, it took David three years to learn to dress himself, and he still needs supervision to do so. On weekly supermarket trips, he picks up cans as Laura points to them, then bites them instead of putting them in the cart.

Basic communication is a struggle. Unlike many nonverbal children, David doesn't understand how to use picture cards to convey his wishes. His parents have taught him hand signals—"I'm hungry" is touching his lips with two fingers; "I'm thirsty" is rubbing his throat with one hand; "I need to use the bathroom" is tapping the knuckles of both hands together. But the system isn't foolproof. "Someone still has to take him to the toilet every thirty minutes," says Laura. "And if we're on a trip and he has to go, he doesn't signal. We're hoping that, maybe three years from now, he'll be able to signal 'bathroom.'"

This is a crucial goal, not just for David's future but also because when he gets frustrated by his inability to communicate, he will bite his hand viciously—or he may turn on others.

"One day at the supermarket, he was in such a vile mood, lunging and scratching," Laura recalls. "When I leaned down to pick him up, he bit my shoulder really, really hard. I couldn't disengage him except by doing the most effective thing—which was to grab his hair at the back of his head and pull very hard. People saw that, and you can imagine the looks they gave me! We had to give up and leave."

Even when David is calm, it's a double-edged sword. "David

At the NYCA Charter School, instructor Erin Bajornas assists a five-year-old boy, one of the first students fortunate enough to win a place in the lottery for attendance. The intense one-on-one partnership is a hallmark of the Applied Behavioral Analysis teaching method.
can walk along with us in New York, and he looks like a normal kid," says Harry. "We try to project that, because we don’t want him flapping his hands and howling as he goes down the street. Our friends say, ‘Oh, he looks so great and normal!’ But he’s not. How many times has it happened that we’re standing with David on a corner, and he’ll put his hand up a lady’s dress? Those are the things that we live with all the time.”

The Slatkins do everything they can to help Alexandra, David’s sister, cope with his disorder. Since she was eighteen months old, she’s been seeing a psychologist to help her articulate her responses and feelings. “We wanted her to be proud of David for who he is but also to know that it’s okay to feel angry when she has friends over and he starts to scream and howl,” Harry says.

When Alexandra tries to hug David, he pushes her away unless the Slatkins hold him. “Recently he’s been very lovey-dovey, and if I walk into a room, he’ll come over and kiss me,” says Laura. “That’s when our whole world changes. Harry and I live off those snapshots of reality, when we see what he’d be like if he were a normal kid.”

Does she ever imagine how different their lives would be if autism could be cured? “It would mean the world to have my son back—not ‘back,’ because I never had him, but to have David turn and say, ‘I love you, Mom,’ or ‘I want chicken for dinner,’” says Laura. “It’s crushing; it just takes a huge chunk out of you not to be able to communicate with your son.”

At times the pain has been almost unbearable. In a documentary entitled Autism: True Lives, Harry describes the very large pond next to their house in the Hamptons. “We put locks on all the doors leading outside because we didn’t want David possibly going into the pond. But there were times when”—he stops, then talks through his tears—“you hoped he did, because you wouldn’t want him to suffer like this all his life.”

Everyone urged the Slatkins to cut this from the documentary, Laura says, but they left it in. “Since then, we’ve spoken to many families who say, ‘We all share that hidden, dark thought.’”

Later in the documentary, Harry describes coming to terms with David for who he is and no longer feeling so tormented. What haunts the Slatkins now, they say, is fear for the future: “We worry all the time, How are we going to take care of David when he’s twenty or thirty?” says Laura. “We can’t talk about it; it’s too painful.

“Autism is so devastating,” she says quietly. “People really don’t understand.”

**A Terrible Mystery**

Autism (a group of traits and behaviors known clinically as autism spectrum disorders, or ASD) is a developmental disorder that emerges in infants and young children. It is shattering

**Signs and Symptoms**

Parents and caregivers should learn the typical developmental milestones and the signs of autism. If you have any concerns, speak with your doctor about having your child screened as soon as possible. Do not be lulled into taking a “wait and see” approach; early intervention can make a profound difference in an autistic child’s progress.

**Early Signs of Autism (infancy to age two):** Child does not babble, point or make meaningful gestures by one year of age; does not speak single words by sixteen months; does not combine two words by two years; loses language or social skills; avoids eye contact; doesn’t know how to play with toys (particularly dolls); obsessively lines up toys or other objects; is overly attached to a particular toy or object; doesn’t smile; at times seems to be hearing-impaired.

**Ages Two to Five:** Child does not respond when name is called, though tests show that hearing is normal; does not use an index finger to indicate objects; avoids eye contact; dislikes being hugged, cuddled or touched; does not speak or stops speaking; speaks in a monotone, without much facial expression; speaks oddly or repetitively; endlessly echoes words or phrases or makes unusual sounds; is physically hyperactive or underactive; flaps hands, flicks fingers, spins; shows a lack of sensitivity or an oversensitivity to sound, touch or visual stimuli; has unusual sleep patterns; eats a very limited range of foods; regresses from previously learned social or play behaviors; has severe mood swings or extreme tantrums; has poor physical coordination; stares fixedly at objects such as bright lights or door hinges; seems highly distracted or daydreamy; becomes overly attached to objects; obsessively opens and closes doors, turns lights on and off, ritualistically lines up objects; engages in very little imitative play or make-believe; shows no interest in playing with peers; shows no separation anxiety; engages in self-injurious behaviors (head banging, hand biting); shows no fear of danger or pain.

*Detailed checklists are available on the Web sites of Autism Speaks, First Signs and the National Institute of Mental Health (see “Where to Get Help,” page 101) and in The Autism Sourcebook, by Karen Siff Ekorn.*
Autism's Angels

Chuck and Sarah Gardner, two MIND Institute cofounders, at their Sacramento home with their son, Chas, who is autistic, and their daughter, Ginny. Because it targets the very traits that we intuitively link with being human—the ways in which we learn, speak and relate to other people, moment by moment. In place of these, autism causes actions ranging from the bewildering to the bizarre.

Whereas a typical two-year-old boy would smile at his parents or romp with a playmate, a child with autism might rock back and forth, twirl in circles, flap his hands, bang his head against a wall or sit for hours lining up toy cars or spinning their wheels. At two, an age when most youngsters pick up new words almost daily, an autistic child may be mute; “speak” in squeaks, grunts or gestures; robotically repeat a word or phrase; or stop speaking altogether. His temper tantrum might be an hours-long shriek-fest set off by bright lights or an unfamiliar situation, and his eating and sleeping patterns may be chaotic or rigidly ritualistic (see “Signs and Symptoms,” page 99).

Autism has many faces. Some 60 to 75 percent of autistic children are also mentally retarded to a degree (with an IQ of 70 or lower), but a smaller subset of children on another part of the spectrum have Asperger’s syndrome, which is marked by high intelligence, verbal dexterity and an inability to read social cues. (Boys are ten times as likely as girls to have Asperger’s.) These children can talk fluently and at length about, say, train timetables while remaining oblivious to their listeners’ boredom or impatience.

Wherever a child falls on the spectrum, the disorder can be supremely challenging to his or her parents, family, teachers and doctors—especially since we still know frustratingly little about what causes it. “At this point, there are no medical tests, like X-rays or blood work, that we can use to make a diagnosis,” says pediatric neurologist Gary Goldstein, M.D., president of the prestigious Kennedy Krieger Institute, in Baltimore. Diagnosis, which takes considerable clinical skill, is based on a battery of behavioral observations and developmental assessments. (Mentally retarded children tend to score poorly across the board on intelligence and developmental tests, while autistic children often score lower on language and abstract reasoning but higher on visual-spatial and rote-memory tasks.)

And the number of diagnosed cases of autism has leaped alarmingly in recent years.

Autism on the Rise

Autism is the nation’s fastest-growing developmental disorder. Twelve years ago, 1 child in 10,000 was diagnosed with it; now 1 in 166 children will fall somewhere on the autistic spectrum, with boys outnumbering girls four to one. “Our center has gone from treating only a handful of children with autism to treating a thousand,” says Goldstein. Currently 1 million to 1.5 million people
are diagnosed with autism in the United States—a number that could reach 4 million within a decade if the trend continues.

Much of the increase occurred when clinicians adopted a new and broader set of diagnostic criteria in the mid-1990s; today many children are diagnosed with autism who would previously have been labeled mentally retarded or otherwise learning disabled. Still, says psychiatrist Thomas R. Insel, M.D., director of the National Institute of Mental Health (NIMH), “I’m not convinced that this increase can be explained by differences in diagnosis. My own opinion is that there’s been a very real increase in the last ten to fifteen years.” And the latest governmental figures bear him out. “If you don’t know someone who is affected by autism, you will,” warns one expert. “It’s just a matter of time.”

Rebirth of a Movement
At this frightening juncture, there is also cause for hope. Parents and advocates express a sense that our understanding of “the world of autism,” as they often call it, is poised for a great leap forward. A new group of activists (including the Slatkins), scientists and educators has emerged in recent years, bringing fresh energy, financial clout and the latest scientific methods to the quest for answers.

Not only that, but they are building collaborative networks with one another, and throughout the field, in the service of one goal: to understand, treat and ultimately cure autism. Ambitious, yes—but if they succeed at saving thousands of children, they will have pulled off one of the greatest rescue missions in history.

This new crusade builds on the decades-long work of the pioneering autism organizations, notably the Autism Society of America (ASA) and Cure Autism Now (CAN), as well as high-caliber specialized schools such as the Eden Institute, in Princeton, New Jersey; and the Alpine Learning Group, in Paramus, New Jersey. And the new advocates, like their predecessors, have been spurred into activism by the personal pain of having a child or grandchild with autism.

When David Slatkin was a toddler, his parents looked for quality schools dedicated solely to autistic children (something they feel is every autistic

“Ten years ago, you rarely heard about autism,” says David G. Amaral (below), the research director at MIND. “Now there are hundreds of scientists in the field.”
NIH), they met the NIMH’s Tom Insel, who summarized the current state of research, its possible future directions and areas of need. The Slatkins came away sobered. “We realized how little is known,” Laura says. “It was clear that although CAN and NAAR [the National Alliance for Autism Research] had done a fantastic job of building the foundation, hundreds of millions of dollars were needed to make more progress.”

The “aha” moment came that night, as the Slatkins and Insel attended an NIH dinner celebrating the Human Genome Project. “Tom looked around the room, which was full of these brilliant, brilliant scientists,” Laura says. “He told us, ‘If you can get the greatest scientists in the world to focus on autism, you’ll get where you need to be much faster.’ We were very excited; it gave us a direction and a sense of how we could help.”

Coincidentally, the next day they met billionaire Jim Simons, founder and CEO of the hedge-fund-management company Renaissance Technologies Corp., and his wife, Marilyn, whose family had been touched by autism. Over the next two years, the couples discussed how to act on Insel’s advice. Laura also introduced the Simonses to NBC Universal chairman Bob Wright and his wife, Suzanne, who were feeling their way through the landscape of autism after their two-year-old grandson’s diagnosis. “Both families were very committed to moving the field forward; they wanted results and answers,” Laura says. “I thought it would help to establish strong lines of communication.”

Thereafter, as the three couples pursued their separate advocacy efforts—the Slatkins through NYCA, the Simonses through their foundation and the Wrights with their fledgling organization Autism Speaks—they also strategized on how to work together. Last year, this synergy bore its first fruit: a two-day autism think tank cochaired by the Slatkins and the Simonses in collaboration with Columbia University and cosponsored by the Wrights, the NIH, CAN, NAAR and others. “We invited twenty of the brightest scientists in the world—Nobel laureates, scientists who were not focused on autism—to brainstorm with autism experts, advocacy groups and individuals,” Laura says. “Tom Insel spoke, and the Simons Foundation offered six grants of $120,000 each to researchers who would enter the field. There was a lot of good energy in the room, with scientists talking to philanthropists and the government talking to private foundations. Conversations took place that shaped the future direction of autism.” Clearly, a new guard of advocates had emerged, determined to take the battle to new heights.

Autism Speaks

For Bob and Suzanne Wright, the first response to the riddle of autism was to raise awareness—and dollars. They founded Autism Speaks in 2005, their decision fueled by seeing their daughter Katie struggle to cope as her son, Christian, lost his 800-word vocabulary and displayed horrific tantrums, and by witnessing medical science’s helplessness. “We went to Columbia University Medical Center for a complete diagnosis, which took several days and cost $10,000,” says Bob. “They said, ‘We’re sorry; we can’t find a medical abnormality that we can treat.’ Almost as the good news, they added, ‘Many of these children develop medical problems, and we’ll be happy to treat those if that happens.’”

“We were shocked,” he says. “As we learned more, we realized we’re in an epidemic—people are wandering around looking for help, and doctors are saying, ‘There isn’t much research, and, sorry, you can’t get insurance reimbursement for this.’”

After the Wrights started to speak openly about their grandson, Home Depot cofounder Bernie Marcus (who is a longtime childhood-disabilities philanthropist) jump-started the new organization with a $25 million donation.

The two aims of Autism Speaks are to raise autism awareness hugely by shining a megawatt spotlight on it and to fund scientific and biomedical research. Build awareness, say the Wrights, and the funding will come. “Out of the $29 billion NIH budget, autism gets only $102 million,” says Bob. “AIDS gets $2.9 billion, and breast cancer gets $700 million, as they should, but people need to understand that this is the most prevalent childhood developmental disorder in the United States.”

In its first year, Autism Speaks raised more than $40 million— as well as untold levels of awareness. After the Today show aired a five-part series called “Autism: The Hidden Epidemic,” Bob and Suzanne were invited to speak on the show. Suzanne has discussed the issue on The View, as has Bob in an interview with Charlie Rose. The couple have also been guests multiple times on Don Imus’s radio show. This year, Autism Speaks launched a three-year public-service ad campaign in partnership with the Advertising Council. (One full-page ad features a ponytailed little girl playing the piano and reads: “Odds of a child performing at Carnegie Hall: 1 in 73,000. Odds of a child being diagnosed with autism: 1 in 166.”)

Last February, in a major step, Autism Speaks merged with NAAR, a nonprofit organization that funds scientific research on autism. “One big goal is to search for biomedical causes so that we can develop treatments,” says Goldstein. As chair of the Autism Speaks scientific-affairs committee, he oversees research programs such as the ongoing Baby Sibs Project, which monitors the neurological development of infant sib-
lings of autistic children; he’s also managing Autism Speaks’s launch of the Interactive Autism Network, a national registry and database that helps connect families with one another and with researchers.

The Wrights are now lobbying for the Combating Autism Act, which would authorize nearly $1 billion for research over the next five years. “Not enough studies are done on children with autism to draw conclusions about its causes, and that’s extremely frustrating to parents,” says Bob. While he urges families to get involved in raising consciousness, he also acknowledges a sad truth: “Autism is a 24/7 problem. The children have to be looked after all the time, and the parents tend to be exhausted and broke. They don’t have the time or the resources to do many things, so we are trying to speak for them.”

Funding Frontier Science

Jim and Marilyn Simons, also catalyzed by Insel’s advice, have pledged to pay out an astounding $138 million for autism research over the next five years. One of the Simons Foundation’s first, widely trumpeted grants was $13 million for a five-year genetics study by Michael Wigler, Ph.D., and Jonathan Sebat, Ph.D., at Long Island’s prestigious Cold Spring Harbor Laboratory (home to one of DNA’s decoders, James Watson). They are using a cutting-edge technology to do genome scans of autistic children’s nuclear families and compare them with normal genomes, seeking out autism-linked mutations.

In another example of the new synergy at work in the field, Wigler and Sebat are studying DNA that was procured by L.A.’s Cure Autism Now, founded by film producer Jon Shestack

Possible Causes

Over the past fifteen years, science has moved from blaming autism on emotionally remote “refrigerator mothers” to seeing it as a complex interplay between genes and the environment. But we still don’t know with any certainty what leads to the wide range of behaviors on the spectrum of autistic disorders.

“We have to ask what has changed in the last ten or fifteen years that could account for it,” says the NIMH’s Insel. “There are so many things, from diet to vitamins to different kinds of prenatal care, cell phones, computers—it’s endless. Whatever it is, it probably occurs prenatally, because most parents say that they knew something was wrong at birth or shortly after.”

Brain Circuitry: A vast amount of research into the neurology of autism is going on. Children with autism have been shown to have a smaller head size at birth, then experience a period of excessive head growth by age two. The different areas of the brain vary in size from those in a typical brain and tend to function in isolation from one another, rather than coordinate their efforts.

Child psychiatrist Fred Volkmar, M.D., of the Yale Child Study Center, pinpoints another key difference: “Typically, we process faces in a certain part of the brain, but people with autism use a different area—the area normally used for processing objects. Here at Yale, we’re experimenting with ways of getting the face-processing part of the brain to wake up.”

Genetics: “There’s a strong genetic component to autism,” says the Kennedy Krieger Institute’s Goldstein. “It’s found in 1 percent of boys and 0.25 percent of girls. And it runs in families: if you have identical twins and one has it, it’s very likely that the second twin will too. If they’re fraternal twins, there’s a 10 percent chance that the other twin will have it, and this is also true of subsequent siblings. If you have one child with autism, the risk is tenfold that you’ll have another—that’s why many families choose not to have more.”

The consensus is that several genes are involved.

Environment and Immunizations: The possibilities include viral infections, exposure to environmental chemicals like lead and mercury, metabolic imbalances and immunizations—the last being the most divisively and hotly debated issue of all. Many parents and some experts suspect that thimerosal, a mercury-containing preservative once commonly used in childhood vaccines but now phased out for most, is to blame in some cases of autism. (The book Evidence of Harm, by David Kirby, outlines the history of the controversy.)

“I think the evidence is pretty solid that vaccines are probably not contributing, by and large, to the increase in autism,” David G. Amaral, Ph.D., research director of the MIND Institute, says carefully. “But it’s probable that, in a small percentage of kids, the immune system can’t clear out toxins efficiently, and when they get vaccinated, that may cause them to become autistic.” Genetic vulnerability and other factors may play a part, since most children who received thimerosal-laced vaccines did not develop autism.

The case is far from closed: Congress recently earmarked $15 million for the Centers for Disease Control and Prevention (CDC) to conduct more studies.

Immune System: There is some evidence that autism may be immune-based; the MIND Institute found that some autistic kids have irregular levels (either low or high) of cytokines, which influence immune response, mood and behavior. Another MIND study detected atypical antibodies in the blood of autistic children and their mothers; these antibodies may affect fetal brain development, leading to autism. If this turns out to be so, it paves the way for a diagnostic test and possible prevention.

Pregnancy Stresses: There is some speculation that pregnant women who have yeast infections or a poor diet or who experience hormonal or immune-system changes are more likely to have autistic children.
Education and Treatments

Here are a few of the best-known and best-substantiated methods in use.

**Applied Behavioral Analysis (ABA):** Devised by psychologist Ivar Lovaas at UCLA in the mid-1960s and based on the behavioral work of B.F. Skinner, ABA uses rewards (a favorite food or toy, a hug, a word of praise) when a child completes social, behavioral or academic tasks such as saying hello, making eye contact or pointing to pictures or numbers as his parent or teacher names them. Its hallmarks are Discrete Trial Teaching, which breaks complex skills into small, manageable steps, and Speech and Language Therapy and Verbal Behavior (see below).

**Chelation:** A medical procedure using oral or intravenous medications that makes the body excrete any stored heavy metals and toxins. Preliminary testing for mercury toxicity is required.

**Denver Model:** A family-based treatment created by developmental psychologist Sally Rogers in the early 1980s, this model combines intensive teaching with relationship-building and social-communicative skills. Parents determine the child’s treatment objectives and receive training to help their child meet these goals in one-on-one work at home and within a typical classroom setting.

**Dietary Interventions:** Children with autism are prone to allergies and gastrointestinal problems; gluten- and casein-free diets are common treatments.

**Floor Time:** Developed by child psychiatrist Stanley Greenspan, this is also called the DIR (Developmental, Individual Difference, Relationship Based) approach. It’s rooted in the premise that people learn best when emotionally engaged. In spontaneous, unstructured sessions, twenty to thirty minutes long, the parent, therapist or teacher literally gets down on the floor to interact and play with the child. This helps to facilitate back-and-forth communication and personal involvement.

**Integrated Play Therapy:** A social intervention in which a child with autism plays in a small group with typical children and an adult facilitator, using toys and games that promote imagination and social interaction.

**Picture Exchange Communication System (PECS):** A system that uses pictures and ABA methods to help children learn colors and numbers, form sentences and keep to scheduled activities (a picture of someone sleeping can cue a child that it’s nap time). Nonverbal children often use PECS to communicate their wishes and needs.

**Speech and Language Therapy:** This helps a child to communicate more effectively, using words and/or body language. Therapists show the child how to initiate and sustain a conversation and how to read body language.

**TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children):** This method, developed in the 1970s by the University of North Carolina School of Medicine, in Chapel Hill, is widely used and incorporates a variety of approaches, including ABA.

**Verbal Behavior:** A component of ABA, this method emphasizes repetition and rewards to reinforce desired speech patterns. The child learns “echoics” (imitative words and language), “mands” (statements of what he wants), “tacts” (descriptions of things in the environment) and “intraverbals” (engagement in conversation).

and his wife, Portia Iversen, in 1995. Not only did the couple go public about their son Dov’s autism, but their organization also funded research and sent clinicians into the homes of families with more than one autistic child in order to collect blood samples and create a gene bank. “The first giant ‘eureka’ moment that will make the big pharmaceutical companies feel there’s something there has not come yet, but I’m confident that it will,” says Shestack. Until that time arrives, everyone agrees that early diagnosis and intervention—the earlier, the better—are the keys to a brighter prognosis.

**Treating Autism Early**

As limited as our biomedical understanding of autism still is, the supporting evidence for some educational and therapeutic approaches has been gathering for decades. At this point, it’s clear: intensive therapy, begun when a young child’s brain has maximum “neuroplasticity” and most easily rewires itself, can lead to profound improvements in speech, relating and learning.

“With early intervention, we’re seeing many more kids doing much, much better,” says leading researcher and child psychiatrist Fred Volkmar, M.D., of the Yale Child Study Center. “Right now, getting a diagnosis and early intervention for a child of three is a big deal; but eventually, we’re going to get these services at six months.” He offers this ringing testament to the power of early intervention: “In March I gave a conference on how to help autistic kids who go to college. Ten years ago, I’d never have thought it would happen.”

For a handful of children, early intervention has led to the almost unthinkable: actual recovery. (Although, technically, autism is not curable, a child can advance to the point where he or she no longer meets the clinical diagnostic criteria for the condition.) This happened for Jake, the son of Karen Siff Exkorn, a former management consultant. In her book *The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing*, Exkorn describes how Jake, diagnosed with autism at two, recovered after several years of intensive ABA and other therapies. (Now nine, he appeared last September on *Good Morning America.* “I recognize that the
Autistic teen Jason McElwain ("J-Mac") at Greece Athena High School, in Rochester, New York, after scoring twenty points in the last four minutes of the final home game of the season.

recovery rate is only 5 to 10 percent, but I'm hoping that with all of the research going on now, this rate will increase," says Exkorn. "One of my goals in writing the book was to offer parents hope—not false hope, but hope. Everyone says knowledge is power, but knowledge is also hope."

Given her philosophy, it's no wonder that Exkorn is on the board of the New York Center for Autism and enthusiastically supports its Charter School.

NYCA: Building From the Ground Up

After the Slatkins decided to create the school, Laura joined forces with Ilene Lainer, an employment attorney whose second son, Ari, aged ten, is autistic, to research and write the school's charter application. It was a tedious, two-year process, but it paid off. Last September the NYCA Charter School, on the second floor of P.S. 50, on East 100th Street in Manhattan, opened its doors to its first class: four boys, aged five through nine, with moderate to severe autism. (Adding about one new student per month, the school will reach its full capacity, twenty-eight, by 2008.) A sad but not unexpected irony is that neither David nor Ari is a student at the school (Ari didn't win a place through the lottery, and David was never entered), nor is there much chance that either child will gain admission in the future. David is now enrolled in a school in Queens; Ari is being homeschooled. For its founders, the NYCA Charter School is truly a labor of love.

The school undoubtedly meets a need: some fifty families applied for the first twelve openings, says Lainer, who, having resigned her partnership at the law firm to care for Ari and help launch the school, is now president of its board. In contrast to the public schools' special-education classes, the NYCA Charter School has a one-to-one teacher-student ratio for its ABA curriculum, which its advocates say is optimal for most autistic children. "The instructors rotate among the kids every half-hour or so to ensure that a child learns to generalize, which is one of autistic children's challenges," Lainer says. "A child with autism might learn something from you, but if he doesn't practice it with other people or at home, he might never apply it in a more general way." The one-on-one ABA approach, in which a teacher guides a student through a series of steps to learn social, educational and life skills (anything from making eye contact or sitting quietly to saying hello or learning numbers and reading), can be grueling, but it is undoubtedly effective at drawing autistic children out of their isolation. The students also interact with the typically developing students who throng P.S. 50's downstairs halls and classrooms, reflecting the NYCA vision of giving autistic children the education they need while integrating them into the larger community as much as possible.

"We've married public education and a state-of-the-art school, but it's a very expensive methodology," says Laura Slatkin. (The city spends about $62,000 a year on each NYCA student.) "Our next question is, How do we educate 4,500 children in a cost-effective manner and maintain the program's quality?"

Ilene Lainer and Laura Slatkin are not alone in their crusade for top-quality schooling for autistic children: on Long Island, the Child Development Center of the Hamptons (CDCH), for children from birth through age five, was founded in 1996 by Dawn Zimmerman Hummel, whose son, Jon, now sixteen, is autistic. In 2000 Hummel added the CDCH Charter School for grades K–8. With 210 students enrolled, the CDCH is now raising money for an impressive new preschool facility. And two veterans in the field, the Eden Institute and the Alpine Learning Group—founded in 1975 and 1988, respectively, and long considered the gold standard in autism education and services—will soon launch capital campaigns to develop new
NBC Universal chairman Bob Wright and his wife, Suzanne, who have a grandson with autism, were shocked to find so little help or information, and no insurance reimbursement for diagnosis or treatment. They founded Autism Speaks in 2005 to raise awareness and dollars.
programs. In the past decade, the number of schools devoted to autistic children has mushroomed.

Crunching the Numbers
No matter how much is done, everyone agrees that more services are desperately needed. Autism is a lifelong disability. When students “age out” of school at twenty-one, the state no longer pays for educational services—aides, transportation, intensive ABA. Their families must apply to the state disability fund for aid, which, even if granted, falls far short of previous help.

“One thing that no one has taken into account is the vast socioeconomic impact of autism,” says Shestack. “Looking ahead, just as society is hit with the Alzheimer’s crisis, there will also be 1.5 million people with autism who are no longer part of the school system. The burden will fall on the state and federal government. It’s huge. Autism costs society close to $90 billion a year in education and services, and it will just get worse. Right now a lot of it is borne quietly by the families, but that can’t go on forever.”

Autism’s financial toll is truly catastrophic. Therapies for a child with autism can run more than $70,000 a year. Parents take out second and third mortgages, and marriages buckle under the strain: it’s been speculated that the divorce rate among parents of autistic children is 80 percent. Whatever else autism means to parents, it usually means the end of their dreams for a normal life.

The MIND Institute: Only Connect
While the East Coast autism community has been gathering steam, equally big things have happened out West—thanks especially to Chuck and Sarah Gardner, of Sacramento, California, who with four other families founded the Medical Investigation of Neuromedical Disorders (MIND) Institute at the University of California, Davis, in 1998.

The road to MIND began much earlier, in 1994, when the Gardners’ son, Chas, was two. “We took him to be assessed,” recalls Sarah, a news anchor with KCRA-TV (owned by the Hearst Corporation, Town & Country’s parent company). “The specialist, who is one of the field’s top experts, said that he was severely autistic and that we should enjoy him while we had him, because we’d be institutionalizing him by the time he was eight.” For a moment, her eyes tear up. “It was a very long drive home.”

“That declaration made us take action,” says Chuck, who owns a construction-management company. “To say, when a child is only two, that this is his future—we just couldn’t accept that. It was the wrong answer.”

The Gardners leaped into gear: Sarah ransacked educational materials while Chuck delved into autism research. He soon discovered the gaping voids in the field’s biomedical data—and in its cross-disciplinary network. “The researchers weren’t talking to the clinicians, and they weren’t talking to the educators, which was where most of the work was being done.”

The Gardners began to advocate for more biomedical research and for a place where parents, educators and scientists could meet on common ground to share ideas and information. They brainstormed with other families who had children with autism, including four fathers Chuck calls the stakeholders: government consultant Rick Rollens, state investment officer Rick Hayes, businessman Steve Beneto and cardiologist Louis Vismara, M.D.

Meanwhile, chaos raged at home. Chas suffered from severe gastrointestinal problems and insomnia. “At night he’d lie on the floor and roll around like a fish out of water, screaming and flailing his limbs, and we’d sit there and go, ‘What do we do?’” says Sarah. “We would sleep in shifts, one to two hours at a time. Sometimes it was so stressful, we’d both stay up because we didn’t want to leave the other one alone. Even our doctor couldn’t tell us what was going on. It got to the point where Chuck and I were walking zombies because we were so exhausted. We were going through life, and in a sense we still do, with a white-knuckle grip on the day.”

Sympathetic to the Gardners’ plight and intrigued by their idea of a new research center, a friend introduced Chuck to Hibbard Williams, M.D., dean emeritus of the UC Davis School of Medicine, and Tom Anders, M.D., executive associate...
Autism’s Angels

dean of the medical school. They, in turn, arranged a meeting with a panel of UC Davis scientists, who heard Gardner out, then attached a price tag to his dream. “Rick Rollins asked, ‘How’d it go?’” recalls Chuck. “I said, ‘It went great! All we need to do is raise $5 million!’

In what Chuck calls “a really big team effort” and anyone else would call a miracle, the “foundling fathers” pooled their skills and Belodexos and, aided by UC Davis’s matching grant of $1.5 million, did in fact raise $5 million—within four months. “We adopted the mind-set, as did the university, that we didn’t care who got the credit, we just needed to get to the finish line,” says Chuck. “We raised it really quickly, we built the facility, and the program was off and running.”

The MIND Institute itself, a stunning 100,000-square-foot complex of stone, wood and skylights located in Sacramento, is indeed a place where scientists, educators, parents and children come together, literally through the same front door. “It’s intentionally designed to facilitate interaction,” says Chuck.

“This is a very goal-centered program,” says research director David G. Amaral, Ph.D., a neuroscientist who got involved when the institute was still a gleam in its founders’ eyes. “The founders said, ‘Why don’t you develop a plan that will take the fewest steps from our lack of knowledge to prevention, treatments and cures?’ We’ll always go with the project that gets us on the road to helping the kids much faster.”

One such project, CHARGE (Childhood Autism Risks From Genetics and the Environment), a five-year study, is compiling the medical, neuropsychological and environmental-exposure profiles of 1,000 to 2,000 children, with and without autism, to sift through them for common genetic or environmental factors.

The institute, whose multidisciplinary staff includes more than 200 researchers and clinicians, is also studying the immune system of children with autism. “We’ve pushed this because parents brought us the concern that vaccines were causing autism,” says Amaral. This is a hotly contested question, with parents and reputable scientists ranged on both sides (see “Possible Causes,” page 97).

MIND’s most ambitious project is also its newest: the five-year Autism Phenome Project. “We want to raise $15 million to do this huge battery of tests—the largest ever given to kids with autism,” says Chuck Gardner. The researchers will gather biochemical, physiological and developmental data from 1,800 autistic children and use it to answer the vital, building-block questions about the nature of the disorder.

“It’s become clear that autism is not autism; it’s autism—a variety of different disorders, all with different etiologies,” says Amaral. “This project is big and costly, but we think that by doing it, we’ll be able to identify autism Type A, B and C. I think we’ll find that different things are causing autism, some of which may be preventable.

“This is going to be like the Human Genome of autism,” he continues. “I’m very optimistic because our biomedical research techniques are so much more sophisticated now. The amount that we’ve learned about Alzheimer’s in fifty years, we’re going to learn about autism in ten, if not sooner, because the technologies are so much better and faster.”

He’s talking the kind of talk Chuck Gardner likes to hear. “If I could say one thing that I’m most proud of, it’s that we—the collective we—have changed the paradigm,” says Chuck. “Before, none of the doctors wanted to talk about curing autism, but we fought to put it in our mission statement. Now, it’s not if autism can be cured, but when. That’s a big shift, and when you get people thinking differently, different things start to happen.”

Does the Gardners’ son, Chas—now a lively fourteen-year-old who remains severely autistic despite intensive, ongoing ABA therapy—participate in the MIND Institute studies?

“Yes,” the Gardners say together.

Sarah reflects for a moment, then cuts to the heart of a parent’s experience with autism—and to the core of the autism advocates’ mission. “When I was pregnant, Chuck wanted a boy, because in his mind, that boy was going to be a major-league ballplayer,” she says. “When you’re handed the diagnosis of autism, you see all those hopes and dreams go away. And you realize that, whether the loss is being a major-league ballplayer or having a child of his own so someday Grandma can hold it, your child might pass through this world…without having an impact.”

Again her eyes well up. “Through the work at the MIND Institute, we’re going to see to it that these kids have an impact on this world. These children who are in the studies, whose parents help with time or money—these kids are going to help find a treatment. They’re going to find a cure. That’s what people need to know when they think about the MIND Institute—that we’re going to do great things.”

She concludes, “Chuck and I laugh sometimes when we talk about Chas. Someday we’ll be able to say, ‘He might be the strong, silent type—but he helped cure autism.’”