Chas Gardner’s parents want to give him a normal life. But first they have to do just one thing: cure autism.

by Nell Bernstein
photography by Angela Wyant

A Father’s Fight

A MISSION AND A LIFE: Chuck Gardner plays with his son at their home near the institute he helped create.
Chuck Gardner remembers the day his son, Chas, was diagnosed with autism. Chuck and his wife, Sarah, had known for more than a year that something was wrong. They’d noticed that Chas didn’t seem to respond to his name the way other babies did. In preschool, while the other children chased each other around the playground, laughing and shouting, Chas sat in the corner by himself, endlessly spinning the wheels of an upended fire truck.

The director of the preschool agreed that he was not developing normally. So in 1995, when Chas was 2½, the Gardners took their son to a specialist.

By then the couple had done some reading about autism. Much of what they had learned sounded a lot like Chas—he wasn’t pointing or imitating or picking up language the way most toddlers did. On the other hand, Chas was affectionate, unlike the emotionally distant children the literature described. Chuck and Sarah were anxious when they entered the doctor’s office, but not without hope.

They left in a state of shock. The specialist had watched through one-way glass as the Gardners played with their son. Then she told them not only that Chas had autism but that he had a severe form of the disorder. At 2 years old, Chas had no verbal ability. The doctor told his parents he probably never would. And while therapy helped some autistic children, she said, it was unlikely to be useful for Chas.

The message, says Chuck: “This is a write-off. Cut your losses and try again.”

More than once during the session, the doctor mentioned that Chas had never given his parents a toy during the observation. But that afternoon, when the Gardners returned home, the boy toddled to his toy box, took out a toy, and gave it to his mother. The gift felt like a message, a plea.

“At that moment,” Chuck says, “we became resolved that we were going to do something. We weren’t accepting this judgment. We wanted to make sure that we left absolutely no stone unturned in trying to help our son.”

Chuck and Sarah flew Chas all around the country to see specialists. In Chicago, a doctor put the boy on steroids. In Denver, a faith healer prayed over him. Some of the treatments seemed to help a bit, but the improvement never lasted. Chas was so hyperactive that his tiny body seemed to vibrate. He had chronic abdominal pain and constant diarrhea. He would scream and cry for hours on end. And he had a permanent bump on his forehead from his habit of banging his head on the floor.

Chas never slept for more than an hour straight, so Chuck and Sarah stayed up most of each night, stealing sleep in brief shifts, then stumbled through their days like “walking zombies,” Sarah recalls.

Chuck, a general contractor, started his workday at dawn. Sarah, a television newscaster, worked from 2 in the afternoon until 11 at night. As Sarah drove home, her dread would intensify as she approached her family’s comfortable residence in Sacramento, California’s capital.

“I knew when I rounded the corner—if Chas’ light was on, it had already begun,” she says. It was wild screaming fits that could last all night while Chuck and Sarah kept an anxious vigil.

Finally came one particularly grueling midnight session during which Sarah and Chuck looked on helplessly, heads in their hands, as Chas screamed and wailed, balled up on the floor. The little boy was obviously in pain, but he would not allow his parents to hold him. The Gardners couldn’t soothe their son, much less heal him. By that time the family had seen more than 30 different doctors, and Chas was still in anguish. Letting things continue as they were seemed impossible; putting their child in an institution went against their deepest parental instincts.

Chuck and Sarah concluded that there was only one thing left to do: cure autism.
REACHING FOR THE SKY:
It’s just as well that the Gardners were naïve about the way science works, Chuck says. It kept him from realizing how tall a mountain he’s chosen to climb.
For reasons that no one fully understands, autism has gone from a rare disorder to a seeming epidemic. California reported a 273 percent jump in cases between 1987 and 1998; in some states, the number of cases over the past decade has increased by as much as 1,000 percent. Yet nothing about autism is certain; it’s unclear, for instance, if such increases are due to changes in the way the condition is diagnosed or a true rise in frequency. If the incidence is increasing, scientists aren’t sure why. And parents are still told that little can be done to treat the disorder.

Autism covers a wide range of symptoms and behaviors, but autistic children typically have a hard time communicating and forming relationships. Easily overstimulated, they are prone to repetitive behaviors like rocking or flapping their hands. Many suffer from sleep disorders and painful gastrointestinal problems. Medication and behavioral therapy can help some symptoms. But Chuck Gardner felt the message he got was that his son had “somehow slipped beyond the bounds of hope.”

He couldn’t accept that. Maybe Gardner couldn’t fix his son’s autism, but he wasn’t going to just stand by and do nothing. So with no scientific background, he joined with four other fathers—government consultant and lobbyist Rick Rollens, state investment officer Rick Hayes, businessman Steve Beneto, and cardiologist Louis Vismara—to found the M.I.N.D. Institute.

The Medical Investigation of Neurodevelopmental Disorders Institute at the University of California, Davis, was launched in 1998 and last year moved into brand-new 100,000-square-foot headquarters. It’s now one of the biggest autism centers in the country and a leading funder of autism research outside the National Institutes of Health. Its staff of 76 includes pediatric neurologists, child psychiatrists, molecular geneticists, and speech and occupational therapists.

What makes the M.I.N.D. Institute truly remarkable, though, is not just its size but its guiding spirit. In a field where parents, researchers, and clinicians have often been at war, this is an organization based on collaboration. The “founding fathers” raised $4 million to get the center off the ground and tens of millions more to keep it going. Their aim was to create a place where top-notch research was conducted, but also where their concerns could help guide the research. That combination is unusual in mainstream science, and it doesn’t make for a sedate environment. But it does, by all accounts, make for a productive one.

Autism may be the most hotly contested ailment since AIDS. Years ago, conventional wisdom held that it was caused by “refrigerator mothers” who stunted their kids’ development by withholding affection. That analysis has long been discredited, but doctors and parents have remained at odds. Many parents believe vaccinations triggered their children’s affliction, for instance; researchers say it looks less and less likely that vaccines have anything to do with most cases of the disorder (see “Do Vaccines Cause Autism?” at right).

It hasn’t been a polite disagreement. The advocacy group Moms on a Mission for Autism posts a Hall of Shame at its Web site, reserving places of honor for scientists who have challenged the notion that immunizations cause the condition. Last year, U.S. Rep. Dave Weldon, M.D. (R-Florida), suggested that researchers had manipulated data to make a connection between vaccines and autism disappear.

These fathers raised the money to start the M.I.N.D. Institute—$4 million, to be exact. In return for their efforts, they wanted a hand in guiding the center’s autism research.
For their part, many scientists say that parents and advocacy groups, in their quest for answers, sometimes hinder research that could improve treatment. Several recent studies came about because parents vigorously advocated them, not because the treatments under examination were a logical next step, says psychologist Bryna Siegel, Ph.D., director of the Autism Clinic at the University of California, San Francisco (UCSF).

In 1998, for instance, the mother of an autistic child began telling other parents that after her son received an enzyme called secretin during a test of his pancreas, his diarrhea cleared up and he began to speak. Before long, her story had made its way into newspapers and onto TV, and a black market for the drug developed. UCSF clinicians started getting a barrage of calls—as many as 30 a day—from parents asking about secretin infusions. Researchers, including Siegel, launched a study assessing a group of autistic children before and after they were given the substance. The results: Not one of the 20 children in the study showed significant improvements in language. But 15 of the 18 parents who filled out surveys believed that their children had in fact improved. Another study, reported in The New England Journal of Medicine, reached a similar conclusion: Secretin brought no more benefit to the children who received it than a placebo did. Even then, the majority of parents told the researchers they wanted the enzyme for their children. [continued on page 178]

Do Vaccines Cause Autism?

Scientists who look at the question in different ways come up with the same answer. by Kathleen M. Wong

GIVE THE SHOT—OR NOT? That decision worries parents who have heard of a possible connection between childhood immunizations and autism.

The concern has focused on the measles-mumps-rubella (MMR) vaccine and thimerosal, a preservative once used in a number of vaccines. But many studies have been completed since the link was first proposed, and their results are reassuring. In the overwhelming majority of cases, it seems the connection is more apparent than real: Affected children simply receive the vaccine around the time their disorder is recognized.

Epidemiologists have tackled the question en masse. For instance, researchers in Denmark studied immunization records and autism diagnoses for every child born in that country between 1991 and 1998, and found that unvaccinated children were just as likely to be diagnosed with autism as those who had gotten the shots. Evidence also points away from thimerosal: In Denmark and Sweden, autism diagnoses have continued to climb for as many as 6 years after the chemical was eliminated from all childhood vaccines.

Other research shows that signs of autism can appear well before a child is old enough for the first MMR shot. By studying home videos of children later diagnosed with autism, psychologist Geraldine Dawson, Ph.D., of the University of Washington, has detected autistic behavior in babies as young as 8 months (the first MMR shot is generally given between ages 12 and 18 months). At bath time, mealtime, or first-birthday parties, Dawson says, these children fail to make eye contact with others, don’t look at what others are pointing to, and don’t turn their heads when parents call their names. “We seem to come into the world wired to know that people are special and to want to capture their attention. In autistic babies, this [capability] seems not to be there,” Dawson says.

Neuroscientist Eric Courchesne, Ph.D., of the University of California, San Diego, has demonstrated that brain growth in autistic children may go awry shortly after birth. In his study, the heads of youngsters who were later diagnosed with autism began to grow at an abnormally fast rate at about 2 months of age. Brain scans showed that the overgrowth is concentrated in areas of the brain that go to work when a person perceives and understands facial expressions, deciphers emotions, and interprets tone of voice. These are abilities that autistic children profoundly lack.

“At the moment that babies ordinarily begin to learn these very important skills, their brains are clouded by this sudden overgrowth,” Courchesne says. “Because this growth process likely begins at birth or soon after, we have to look at an earlier time frame than vaccines to find what’s responsible.”

Kathleen M. Wong is senior editor of California Wild magazine.
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“The moral of the story is that hope springs eternal,” Siegel says. “It quantifies the magnitude of parental hope.” It also shows the way such hope can obstruct the very science on which the future of autistic children may depend, she says. Money that goes into pursuing a far-fetched cure might serve these youngsters better if it were used to study treatments with a stronger scientific rationale, Siegel suggests.

On the parents’ side, distrust; on the scientists’, frustration. Out of this contentious context, the M.I.N.D. Institute was born.

In their travels around the country to meet with doctors and researchers, Sarah Gardner says, it struck her and Chuck as ludicrous that parents had no place to go for help with the full range of problems their kids were experiencing. Medical centers didn’t offer help with behavioral issues typical of autistic children. The Gardners were appalled to find that some scientists had never met an autistic child. What’s more, Sarah says, “researchers were not talking to clinicians and educators. One didn’t know what the other was doing.” Worst of all, no one was offering the Gardners much in the way of hope. They were clutching at straws, but straws were not enough.

At a local support group for parents of autistic children, Chuck Gardner met Rick Hayes, an investment officer for the state of California. The two men had secured the promise of a $20,000 donation for the organization, only to have the money held up by red tape. “Rick and I just went, ‘Oh, this is crazy! Why are we wasting our time on this?’” Gardner says.

He and Hayes remember that moment as a turning point. The donation was relatively small, and their children’s needs were overwhelming. Gardner was a builder who worked on large projects, Hayes a business planner and investor who understood what it took to make an enterprise succeed. Both men knew something about scale. “Unless groups around the world started pulling together in common cause, we were never going to reach scale,” Hayes says. “That was the vision-thinking big.”

So the two men started sketching out a plan for the organization they wanted to see. It would combine research and treatment under one roof; it would bring disciplines together with the goal of understanding and curing autism; it would include parents as equal partners.

Excited, the Gardners described the concept to some well-connected friends. A short while later, the couple were heading off to dinner with Thomas Anders, M.D., then chairman of the psychiatry department at UC Davis. The Gardners told Anders about their son’s pain as families endure. He promised to arrange a meeting with a group of UC Davis scientists so Chuck Gardner could pitch his plan.

“I really wanted it to go away,” Anders admits. “I thought my scientific colleagues would confirm my view and it would go away.”

Anders had miscalculated. Most of the research to date had been done by psychiatrists, psychologists, and, to a lesser extent, neurologists. Gardner was proposing widening the circle to include geneticists, pediatric clinicians, and immunologists. The researchers were intrigued.

There was just one hitch, they told Gardner: He would need to raise $6 million. “That’ll slow him down,” Anders thought.

By then, however, Gardner and Hayes had assembled a group of fathers who not only were motivated but who knew just how the system worked and how they could tap into it. When Anders met with Gardner and Hayes a few months later, the duo had $4 million to put on the

The goal was a cure in 10 years. “Chuck was very enthusiastic,” notes one researcher, “and somewhat naïve.” Science, he says, doesn’t work that way.

Well as their vision for an institute that would both study and treat the mysterious illness that afflicted him. Their goal, Chuck announced, was a cure in 10 years.

“Chuck was very enthusiastic,” Anders recalls, “and in my view somewhat naïve.” After all, science doesn’t really work that way, Anders says. Serious research takes as long as it takes, and it is driven by data, not a father’s dreams.

But Anders liked the Gardners, and his years as a child psychiatrist had made him keenly aware of the suffering autistic children and their table. Several dads had pulled an all-nighter at the Gardners’ kitchen table writing a grant to the California Department of Developmental Services, which brought in the first $250,000. The group had scared up another $2 million-plus in private donations, and they got the rest from the UC Davis Medical Center.

Then Rick Rollens joined the group. Once secretary of the California State Senate, he had retired to devote more energy to advocating for his autistic son, Russell. In less than a year, Rollens was able to get a state bill passed that gave the
M.I.N.D. Institute $1 million a year; eventually, Rollens got the appropriation raised to its current level of $4 million a year.

Rollens exemplifies many of the opposing forces contained within the walls of the M.I.N.D. Institute. As much as anyone, he is responsible for the center’s very existence. But he still sees himself as an outsider fighting a hostile medical establishment.

Rollens believes that his son’s autism was triggered by a vaccination. He uses terms such as “sordid history” to describe the medical profession’s track record on the illness, and words like “betrayed” when he talks about his own experience.

“It became clear to me that we as parents had to take things into our own hands and push science forward,” Rollens says. “If we waited for mainstream science, there was little doubt in my mind that Russell’s fate would be sealed.”

The M.I.N.D. Institute has a single front door that opens onto a large atrium, so that researchers never lose sight of the children for whose sake they are peering into petri dishes. Offices that house representatives of various disciplines are dispersed throughout the building to encourage casual talk. And the moms and dads are everywhere, from the lunchroom to the boardroom.

The single-minded intensity of parents struggling to rescue their children is both inspiring and exhausting for the representatives of mainstream science and medicine who staff the institute. The parents are equally likely to find themselves frustrated with the slow pace and measured tones of the scientific process. But so far, parents and researchers say, the differences have been productive.

“The parents encourage us to think outside the box,” says osteopathic physician and executive director Robert Hendren. “Encourage” may be a polite word for what the parents do. Hendren says he spends a good part of his time responding to e-mails from parents who want the M.I.N.D. Institute to look into one theory or other about what causes autism—telephone lines, power lines, medication administered to induce labor. One mother, Hendren recalls, read him the riot act because she felt the center had spent too much on invitations for its grand opening, money she felt should have been put into finding a cure for her child.

Hendren’s tone makes clear that he’d rather be streamlining the lab than arguing over paper stock. But without the founding fathers, there would be no state-of-the-art lab.

The remarkable labors of parents involved with the M.I.N.D. Institute are fueled in great part by their children’s suffering. But these dedicated moms and dads are motivated by something else as well, what they call glimpses or flickers, those moments that convince them that their children can understand more than they are able to express, that there is a healthier child struggling to get out.

“We look at these kids, and they look normal,” Gardner says. “It’s like looking through a department store window at something. It’s there but you can’t touch it. But because you can see it, you’re driven to find some way to grab it.”

That fundamental parental instinct, to rescue one’s child, has inspired what may be the most controversial element of the organization’s mission: its
emphasis on a cure. It has been 9 years since the specialist told the Gardners their son would likely show little improvement, 9 years since the boy seemed to try to prove his doctor wrong by handing his mother a toy. Chas Gardner is now 12.

Today, thanks to a combination of medication and behavioral therapy prescribed by M.I.N.D. Institute medical director Randi Hagerman, M.D., the Gardners’ house is calmer than it was when Chuck and the founding fathers dreamed up the institute, but it’s still far from serene.

Curled up on the floor of the den while daughter Ginny, 9, turns somersaults beside her, Sarah speaks in 2- or 3-minute bursts between getting up to check on Chas. Unsupervised, he can get into trouble fast. A

backyard. On weekends they go fishing. At some point they have a conversation about the time when Chas was autistic and what his parents did about it. Chuck imagines apologizing to his son for not having been able to rescue him sooner. Sarah believes no apologies will be called for; she imagines Chas thanking his parents for loving him, for “having the drive to do this.”

This kind of vision contributes to what Gardner diplomatically calls the “creative tension” between the parents who conceived the M.I.N.D. Institute and the scientists who run the facility. Executive director Hendren recalls arriving in the fall of 2001 and being shocked at the expectations of the parents. Today, he says cautiously, “I can say ‘cure’ with

denial, anger, bargaining, depression, and, finally, a measure of acceptance. Some, Siegel says, get stuck in denial. Instead of accepting their child’s limitations and making the most of his or her gifts, parents often focus on what Siegel sees as an unrealistic and self-damaging conviction that if they just try hard enough, their children will one day be normal.

The center’s scientists are necessarily more circumspect, but they gently raise a similar point. “Their passion has been helpful, but they don’t always bring a full medical or scientific background,” Hendren says of the parents. “So some of the things they hope for are kind of naïve, and it takes some time to explain that to them.”

In this context, the real test of the M.I.N.D. Institute may not be whether its researchers can come up with a cure in the next 10 years, but whether the unique collaboration on which the enterprise is founded can sustain itself if they don’t.

There is no question that its mission is of growing urgency. Nationwide, as many as 3 in 500 children have the disorder, estimates the U.S. Centers for Disease Control and Prevention. And in May 2003, California’s Department of Developmental Services, which helps people with autism, released a startling new finding: The number of kids who came to the state needing help for the disorder had leapt again, doubling in the previous 4 years alone.

In a public statement, Director Cliff Allenby acknowledged that the state couldn’t explain the increase. But he did reassure Californians that officials were doing something about it: collaborating with the M.I.N.D. Institute to find out what was going on.

Chuck and Sarah imagine the future: Their son talks about what he learned in school that day and thanks them for loving him, for rescuing him.

gorgeous boy with big hazel eyes, Chas wanders in and out of the den, climbing onto his mother’s back, his face impassive as he bursts into shouts that are comprehensible only to his family.

In many ways, Chuck acknowledges, the specialist who diagnosed Chas was right. His progress has been slow. He has limited language skills; if he wants something to eat, he grabs his parents by the hand and pulls them to the refrigerator.

And yet Chuck still feels that the doctor will be proved wrong. Chuck does not accept that Chas will always be as he is today. Chuck holds on to an elaborate scenario of life with the boy behind the window.

In this picture, Chuck comes home from work to a son who is eager to tell his dad what he learned in school that day. The two play catch in the

out choking because I think of it as a preventative cure, or very early intervention.”

But when it comes to visions like the one of Chuck and Chas playing catch and having discussions, Hendren remains skeptical. “The notion that you take some person who has had autism all his life,” he says, “do a procedure or give him a pill, and presto, he’s transformed into a normal person—that’s not possible.”

Chuck Gardner thinks his colleagues are underestimating themselves. “I expect to cure autism,” he says. “I absolutely do. I’m prepared for the outcome if we don’t, but that is my expectation.”

Bryna Siegel has a psychiatric term for this kind of relentless optimism: pathological grief. The parents of autistic children, she notes, typically go through the classic stages of grieving:

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