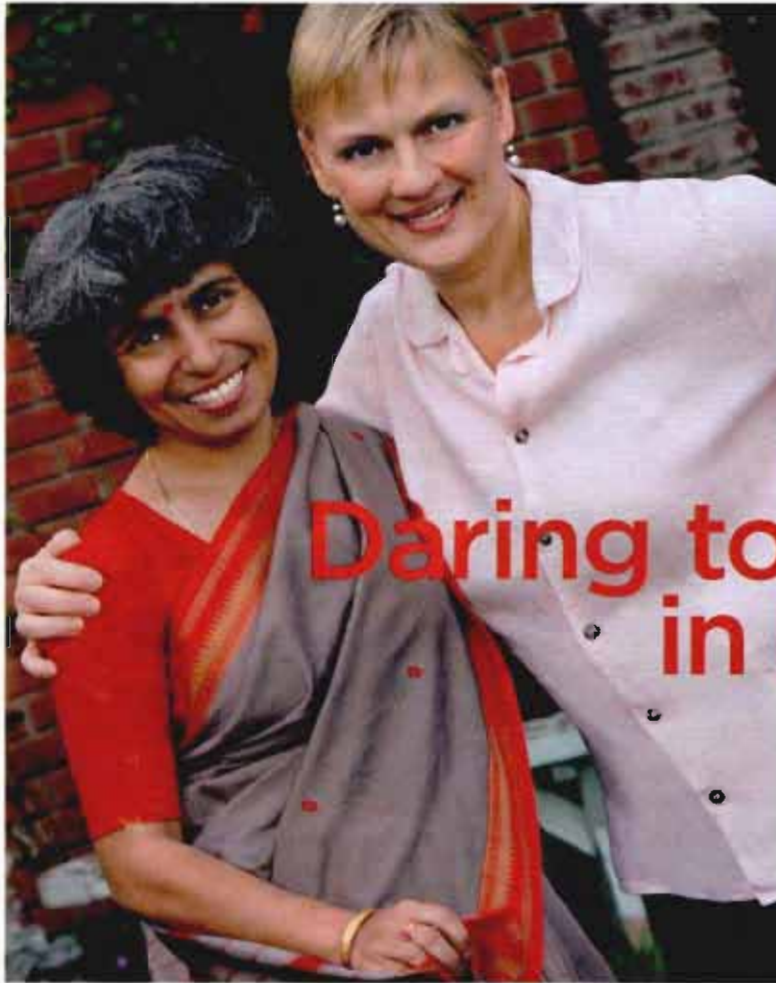


## IN THE NEWS



"We're soul mates," says Iversen (right), of her dear friend and colleague Mukhopadhyay

# Daring to Believe in Miracles

With autism cases on the rise, experts are working hard to unlock the mystery of this heartbreaking disorder. And now, two moms who refused to accept their sons' limitations have startled scientists with their breakthroughs **BY LAURIE DRAKE**

It's an unseasonably warm, sunny afternoon, and two boys are together in an Austin, Texas, backyard, though they are worlds apart. Tito Mukhopadhyay, 16, rocks back and forth, flaps his hands and groans softly, while Dov Shestack, 12, wanders through the family garden, squealing at a high pitch. Both suffer

from severe autism, a developmental disorder often characterized by uncontrolled body movements and an inability to communicate effectively and form social relationships.

But in fact, this scene is one of optimism. That's because Tito and Dov have been able to break through some of the barriers that confine

them, thanks to their exceptional mothers. Launching into an impromptu language lesson, Soma Mukhopadhyay, 42, hands her son a laptop and asks him to say hello to a visitor. After awhile Tito types out, "I feel lazy of writing," but Mom will have none of it.

Squirming, Tito responds to an inquiry about his native tongue: "I am usually taking English as my language although I am Bengali."

"Good, Tito!" says Mukhopadhyay warmly, in the British-accented English of her native India.

Then she sets her sights on Dov. "Dov, tell us about math," she says, only to be met with a string of nonsense words: "Alay alay alay alay!" She leads him to the laptop on the table. "Dov, tell us about math." After several minutes of encouragement, Dov types out, "I am the math-loving person." Then Mukhopadhyay hands him a laminated piece of paper with numbers printed on it **CONTINUED**

PHOTOGRAPHS BY KAREN FRENCH

and says, "Four times two, point!" Dov's eyes, obscured by long, dark lashes, dart around. "Come on!" she says, and Dov places his finger on eight. "Now, how many quarters make a dollar? Touch, touch! Come on, Dov!" He touches four. "Good, Dov!"

Mukhopadhyay's cheer is echoed by that of Dov's mother, Portia Iversen, 50, who looks on with pride. "For Dov to communicate this way is a tremendous accomplishment," she says. The credit, Iversen adds, belongs to her dear friend Mukhopadhyay. Until recently, many experts believed that the typical outward manifestations of severe autism—the head swiveling, rocking and other repetitive movements; the impaired language development and motor skills; the inability to make eye contact and relate to others—reflected serious emotional and cognitive disorders.

But Mukhopadhyay turned the theory upside down: Despite the neurological problems that cause those behaviors, she argued, the autistic child's ability to feel, think and reason remains intact. The key was finding a teaching method to help them bypass their "disobedient bodies," as her son, Tito, has described it, so they could communicate. Mukhopadhyay did. And Iversen, through her nonprofit foundation, Cure Autism Now (CAN), has raised millions to fund research and treatment, including Mukhopadhyay's groundbreaking techniques. In the process, they're offering new hope to parents who were once told their children would be forever imprisoned by their illness.

#### AN UNENDING MYSTERY

The women's timing could not have been better. Some 60 years after autism was first identified, it remains one of the most puzzling of childhood disorders. Forty years ago, most studies estimated that fewer than five of every 10,000 children in the United States were autistic; most experts now agree that the number has at least doubled, while some believe that as many as one in 166 children have the disorder to some degree. Boys are four times more likely than girls to be affected by it.

The reasons behind the rise in autism cases remain unknown. Some say it's simply the result of improved diagnostic techniques; others have explored links to environmental pollutants and food additives, though scientific studies have not proved any such connection. Just a few months after the Institute of Medicine rejected a link between childhood vaccines and autism last year, a new study

found that a mercury preservative used in vaccines can cause autism-like symptoms in mice. Researchers are looking for genetic roots: Last July, the National Alliance for Autism Research announced it was sponsoring a study involving 1,500 families with at least two autistic children to see if DNA mutations play a role. The latest research out of the University of California, San Diego suggests autism may be caused by abnormally rapid brain growth during infancy, resulting in other anomalies that affect the ability to process emotional and sensory information. That may help explain why the disorder is rarely detected in children younger than 2 years of age.

Whatever its cause, there is currently no cure, only therapy, to

which Mukhopadhyay's innovative methods are an invaluable addition—and all the more striking because she is not a medical expert of any kind. "She has provided another way to probe what nonresponsive autistic children do and don't know, understand and experience," says Michael Merzenich, Ph.D., a neuroscientist at the University of California, San Francisco who specializes in the development of children's behavioral abilities. "Her strategy can help these kids engage with the world they live in, and the people who love them."

#### NEVER GIVING UP

Sitting on the porch of her red-brick house, Portia Iversen muses on how fate brought the two mothers together. "We come from different uni-

verses, but we're soul mates," she says, glancing across the yard at Mukhopadhyay, whose petite frame is draped, as usual, by a traditional Indian sari. "We're both extremely stubborn, and we refused to give up on our children—that's why we met." Mukhopadhyay had completed a graduate degree in chemistry in Bangalore, in southern India, and her husband, Ram Gopal, was working as a chemical engineer when their only child, Tito, was diagnosed with severe autism at age 3.

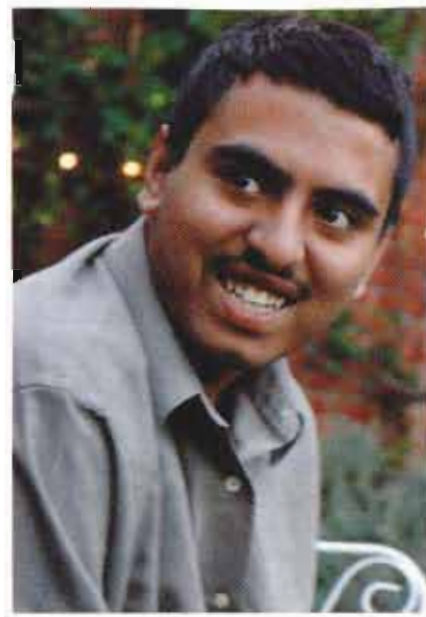
The toddler was mute and withdrawn yet capable of arranging matchsticks in elaborate patterns—and it was in that ability that Mukhopadhyay saw a glimmer of hope. "I asked myself, 'Is he really as hopeless as the

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doctors told me—or could he be as bright as I dare to believe?" She read Charles Dickens and Mark Twain to her son and began teaching him numbers and letters. By age 4, with a pencil tied to his hand (he didn't have the motor skills to hold one), Tito was scribbling and spelling; a few years later, he was writing poetry and prose—about nature, loneliness and pain.

In early 1999, Tito's accomplishments caught the attention of a visitor to India from Britain's National Autistic Society. The group sponsored a visit to London, where members were astonished to discover that the 10-year-old had an IQ of 185. Since he is nonverbal, Tito had to point or write his answers on a standardized test.

When Iversen heard about Tito through her colleagues at CAN, her own hopes were buoyed that Dov's mind could be similarly awakened. She had quit her job as a screenwriter and founded the organization with her husband, Jonathan Shestack, a film producer, soon after Dov was diagnosed with severe autism at age 2. Iversen arranged for Tito and his mother to participate in a CAN conference in Northern California in early 2000. As Tito responded to her questions by pointing to letters and by handwriting, Dr. Merzenich, who was in the audience, was stunned: "I was amazed that a child who would normally have been regarded as retarded revealed such knowledge and ability," he says. "Soma had opened the puzzle box, and there were re-



markable things inside."

For the next 18 months, he and a team of researchers at UCSF tested and interviewed Tito, who was able to describe his condition in precise, heartrending and extended detail.





Asked why he constantly rocks and spins and flaps his hands, Tito replied that he can't feel his body unless it's moving. The reason he has trouble maintaining eye contact, he explained, is that he can't always see

and hear at the same time. To researchers, his answers were revelatory—and confirmed theories that damaged brain circuits in severe autistics make them incapable of processing sight, touch, sound and

Opposite page: "If you read Tito's poems," says his mother, "every emotion—from sadness to joy—is mentioned." This page: "Dov likes to brag that he's more into girls than Tito is," says Iversen

movement normally; the result is chronic sensory overload, which prevents them from drawing together information in a coherent way.

#### BREAKING BARRIERS

While researchers were studying Tito, Iversen asked Mukhopadhyay if she would work with Dov. "We didn't have any great expectations, since she had never taught anyone but Tito and had worked with him for years," says Iversen. But after only a month and a half of one or two 30-minute lessons a week, the boy was able to **CONTINUED**

communicate by typing on a keyboard. "He was nowhere as good as Tito, but I saw what he and other severely autistic kids could become," says Iversen. Soon thereafter, CAN offered Mukhopadhyay a fellowship to teach Dov and nine of his classmates at the Carousel School, a private institution for special-needs children in Los Angeles.

During that year, Mukhopadhyay honed her teaching technique, which she calls the Rapid Prompting Method (RPM). Presuming a student's competence and comprehension are at or near age or grade level, RPM does not try to modify behavior with reward and punishment. Instead, Mukhopadhyay makes one or two instructional statements, then follows up with a question and asks for an immediate response, prompting the child if necessary. Speed is key because it helps the child bypass the impulsive behavior that might oth-

erwise distract him. "The goal is not to frustrate the child through another failure," Mukhopadhyay explains, "so the prompts have to be specifically tailored to the student—for some, it may be a hand movement, a gentle squeeze on the arm, a tap on the desk."

Dov and his classmates all progressed from preschool level to just below their respective grade levels within a year. The success led CAN to sponsor Mukhopadhyay and Tito's move to the United States in July 2001 so she could teach RPM to others. Mukhopadhyay, whose methods have already been adopted by schools in San Francisco and Philadelphia, continues to hold RPM workshops through her own nonprofit organization, Helping Autism through Learning and Outreach (HALO).

#### PROFOUND REWARDS

For both women, the days are long and demanding. When Mukhopadhyay comes home from her work at HALO ([www.halo-soma.org](http://www.halo-soma.org), or 866-465-9595) and Tito from school, he's usually eager to go out again. "Tito likes to go shopping and makes these big lists—Tic Tacs, candy, bar soaps and so on," she says. He also enjoys riding on buses, trains and escalators. "It's the movement he craves," says Mukhopadhyay. "We'll go to the mall just so he can ride up and down the escalators." After their field trips, she fixes dinner, then instructs him in the three R's before helping him reply to the many letters and e-mail he receives. Tito sometimes watches TV, "but he cannot keep eye contact for long," says Mukhopadhyay, "so he'd rather listen to the radio."

Iversen, who works full time at home for CAN CONTINUED

### THE HEART OF A BOY

An excerpt from Tito  
Mukhopadhyay's poem  
"The Blue Evening":

*Through in and through  
out was blue.  
Untouched by any touching  
thoughts  
Just touching the stretching  
loneliness  
Filling it with thoughts of you.  
Enchanting dream filled blue.  
Stealing my loneliness and  
my gloom,  
Making spaces in my heart  
While I walked through  
the dark  
Filled with dreams of you.*


([www.cureautismnow.org](http://www.cureautismnow.org), or 888-8-AUTISM), typically rises at 5 A.M. to get a head start before Dov, sister Miriam, 11, and brother Gabriel, 7, get up around 7. Dov has a full-time aide, but Iversen still finds dressing, feeding and driving him to school difficult and time-consuming. In the evenings she helps the younger kids with homework, reads to Dov, and makes sure there's lots of cuddling. He still struggles with such movements as tying his shoes, running, catching a ball, and giving a hug. But unlike many autistic children, "he has always loved being held and rocked," she says. "It calms him."

Life can sometimes be overwhelming, but neither woman ever despairs. "I do miss India," says Mukhopadhyay, "but I see a better future for Tito here, and I feel fulfilled teaching other children and uncovering their potential." Her husband, who now visits for a few months every year, plans to move to the United States once Mukhopadhyay, who has applied for resident alien status, receives her green card. Iversen, too, says that work keeps her going.

And the boys continue to thrive. Tito now attends a school that focuses on living and social skills, not academics. "Still, every day we practice speech and work on hand control," says Mukhopadhyay. "For example, I'll ask him 10 questions, like 'What day is it?' In the beginning, he would answer 'Sa-tuh-day,' but now he has learned to say 'Saturday' all together. Then we work on hand control with little plastic animals. I'll tell him, 'Pick up the green dinosaur and put it between the two horses.' Then I build on that and continue to make the instructions faster and faster so he has to follow several commands at a time."

Dov, who still attends Carousel, is also gaining more physical control—even enough to give his parents a peck on the cheek. "The goal now is to get him to type as fast as Tito can on the keyboard," says Iversen. "He has made progress, but not without an incredible amount of effort and patience on his part—and ours." The rewards, though, are profound. Since Dov learned to communicate by spelling words on an alphabet board three years ago—he points to the letters—he has been able to play with his siblings. "They even include him in their Kids Club, holding secret meetings where they converse with Dov for as long as 45 minutes at a time," says Iversen. "My husband and I just can't stand not knowing what he's saying in there!"

If the women have one regret, it is this—that Tito and Dov, who have so much in common, will never really be friends. "Because they're both so out of sync with their environment, there's almost no way for them to relate to each other when they're together," says Iversen, who sees Mukhopadhyay every few months. "Still, Tito is a big role model for Dov, but Dov likes to brag that he's more American and more interested in girls and clothes!"

The two friends laugh, then reach out to cuddle their sons. "Tito does allow me to hug him when he's open to touch, but sometimes he's not," Mukhopadhyay explains. Then comes another blessing. For the first time that afternoon, Tito and Dov actually sit still—and by doing so, seem to give back the love their mothers have showered upon them. 

 Connect with other special-needs moms at [www.lhj.com/parentcorner](http://www.lhj.com/parentcorner)