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A glimmer of hope

The Sacramento area now has its own support network for parents of Down syndrome babies

By Cynthia Hubert -- Bee Staff Writer



Toby Linn, 2, has Down syndrome, which occurs in about 1 in 800 births.

Sacramento Bee/Anne Chadwick Williams



Michael Linn gives his son a high-five in the Folsom family's kitchen.

Sacramento Bee/Anne Chadwick Williams



Elaine Linn and her son express their affection. "I know that if Toby has cognitive ability and the ability to speak, he will be able to do just about anything," she says.

Sacramento Bee/Anne Chadwick Williams



Dorina Martin, an occupational therapist, works with Toby Linn earlier this month in Folsom. The toddler has Down syndrome.

Sacramento Bee / Anne Chadwick Williams

Mere minutes after Toby William Linn came into the world on an August morning in Sacramento, his joyful parents announced his arrival in an electronic message to friends and family.

"We have a healthy baby boy!" they wrote.

Less than 24 hours later, Elaine and Michael Linn sent out a second, more somber note.

"This morning, we learned that Toby has Down syndrome," they said. Their baby was, in fact, precariously ill with a congenital heart defect and other problems related to his genetic condition.

The next year was a blur of medical crises, surgeries and doctor visits. Toby faced a major heart operation, and he had feeding and digestive problems. He had a weakened immune system that forced him, his parents and their toddler son, Jake, to be virtually housebound.

After overcoming the shock of Toby's diagnosis, Elaine and Michael Linn, more than anything, wanted to know how it would affect his future. How could they give him the best life possible? Who were the local specialists? What about the latest research? Schools? Financial planning? Family support?

The answers were elusive, the Linns found. Other than an informal support group, the Sacramento area offered little in the way of resources for youngsters with Down syndrome and their families, Elaine Linn said. "Nothing was available to us," she said. "So I just started digging."

Along the way, Linn met other parents of children with Down syndrome. They created the Down Syndrome Information Alliance, a nonprofit group made up of patients, parents and caretakers who work together on behalf of youngsters with the condition. The new group is linked with, among others, UC Davis' MIND Institute, and has ties with two national Down syndrome organizations.

"I needed to do this for myself, and for other parents, so that our kids with Down syndrome can be as independent as possible and live full and productive lives," Linn, an energetic public relations specialist, said on a recent day at the family's Folsom home.

"For a long time, I was in a fog," she said, seated in front of a wall decorated with portraits of Jake and Toby, including a bare-chested shot of the younger boy with a jagged scar from his collarbone to his navel. "It was, 'Why me? Why us?' Then I started to see some glimmers of light, and I got going."

Linn, her friend Heather Prieto and recent Ohio transplant Rich Bermudez were the main forces behind the Down Syndrome Information Alliance.

Prieto realized what Sacramento was missing, she said, when she contacted a group in Texas that offered forums and seminars for parents, sponsored social events for children, and lined up speakers such as medical specialists, lawyers and therapists.

"I was so inspired," said Prieto, whose daughter Gabby, 3, has Down syndrome. "It was such a great community. I wanted that to happen here."

The Down Syndrome Information Alliance is off to a promising start. The nonprofit group meets monthly, has launched a Web site and is planning its first major fund-raising event. Working with area hospitals, it offers new parents of Down syndrome babies a thick binder of information about everything from how to handle birth announcements to the latest research to when and how to seek certain types of therapy.

"I'm very hopeful about it," said Joseph Pinter, a UC Davis neurologist associated with the MIND Institute, which studies and treats disorders including autism and Down syndrome. Pinter, who uses brain imaging to research the neurology of developmental disorders, is serving as the new alliance's medical adviser.

"Locally, we have some good pediatricians and other specialists but there has not been an organized presence to keep people on the cutting edge and to encourage family participation," the doctor said. "My hope is that we can all help one another. It doesn't always start with doctors. When parents start organizing, inevitably they make things happen."

Elaine and Michael Linn had no reason to believe that Toby, now 2, would be anything other than healthy. Elaine was 31 when she gave birth to him, and no one in her or Michael's families had a history of Down syndrome. Her pregnancy was uneventful, and Toby arrived two weeks early.

He was 7 pounds, 12 ounces and 19 inches long, with a shock of sandy brown hair. He looked "perfect," his mother said. But some disturbing signs soon surfaced.

Toby refused to eat during his first 24 hours of life, and his body temperature was dangerously low. His doctor called in a specialist, who asked some telling questions. "Does Toby look like everyone else in your family? Are there any medical conditions we should know about?"

When the neonatologist told Linn he suspected Down syndrome, "I was shocked beyond belief," she recalled. "I walked out of the room. I broke down crying." She phoned her husband, a teacher, at school, and he rushed to join her at the hospital.

The Linns knew next to nothing about Down syndrome, a chromosomal disorder that occurs in about 1 in 800 births and is one of the most common causes of mental retardation. Alta Regional Center, which serves developmentally disabled people in Sacramento and surrounding counties, has about 900 clients with Down, said medical director Terry Wardinsky.

People with Down syndrome have some common physical characteristics, such as flat faces and an upward slant to the eyes. They also commonly suffer from heart disease, hearing loss, seizure disorders and poor muscle tone that makes sucking and swallowing difficult. Most are developmentally delayed, and babies are slow to sit, stand, walk and talk.

Toby's first year was a monumental struggle. He underwent major heart surgery in San Francisco and was slow to recover from the operation. "He was this close to dying one day," Linn said, holding her thumb and forefinger about an inch apart, tears welling in her eyes. Once released from the hospital, Toby's fragile immune system made the risk of taking him out in public too great, so the family became virtual prisoners of their home. "No church, no grocery store, no mall," Linn said.

Toby's mom did "a lot of crying," she said.

In their hours at home, the Linns used the Internet and telephone to research ways to give their son a head start in what undoubtedly would be a difficult life. They wanted to start working his muscles, from his mouth to his legs, as soon as possible. They wanted him to learn basic skills that would allow him to live independently some day. They wondered how they could bring music into his life. Today, Toby's schedule is packed with seven therapy appointments a week.

The Linns believe strongly that early intervention has given their son an upper hand. Though Toby was slow to learn to walk and can speak only a few words, he is good-natured, active and responsive. He "understands everything," his mother said, including the soothing tones of his favorite song, "Itsy Bitsy Spider."

According to the National Institutes of Health, it remains unclear whether early intervention can remedy developmental delays in children with Down syndrome. "Information is limited and contradictory," the agency has reported. Pinter agreed, but added that "it makes sense" for parents to check out all possibilities.

Elaine Linn is determined to ensure that parents in the Sacramento area have the opportunity to do just that. Her work with the alliance has given her hope for Toby and for numerous other children whose parents otherwise might have never explored the possibilities.

Occasionally, Linn has her moments of doubt, when someone's comment about a "really pretty" little girl or a "super smart" boy make her worry and wonder.

"I ask myself, 'Are the girls going to like Toby? Will he go to the dances? Will he do well in school?'

"I also have times when I think, 'Are we going to be able to retire and also allow Toby to live independently?'

Then she finds her strength.

"No one dreams of having a child with Down syndrome," Linn said. "That isn't society's idea of perfection. But I know that if Toby has cognitive ability and the ability to speak, he will be able to do just about anything.

"So what I dream for Toby is what I dream for both of my children. I want him to live on his own, have a job, get married, be happy. I not only dream it, I expect it. I plan to give him every chance."

A Celebration of Hope

WHAT: First major fund-raising event planned by the Down Syndrome Information Alliance

WHEN: 6:30 p.m. March 23

WHERE: MIND Institute, UC Davis Medical Center

PROGRAM: Guest speaker Karen Gaffney, an accomplished athlete and college graduate who has Down syndrome

INFORMATION: (916) 658-1686 or www.downsyndromeinfo.org

