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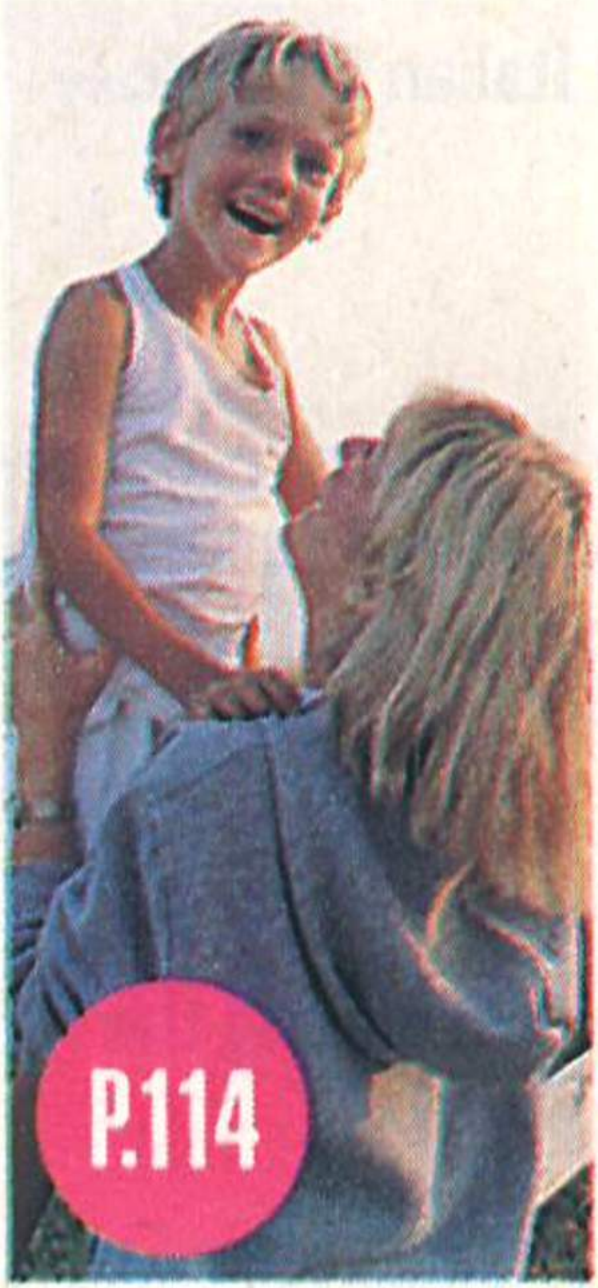


A Second Chance for Seth

One Family Battles Cerebral Palsy

By Laura Shapiro Kramer

Lying on the labor table in the hospital hallway, I was exhausted and bewildered. Where was my obstetrician? Was my baby all right? Why were things happening so fast? Painfully, I propped myself up and looked down at Seth. He was blue. What was wrong? Had he stopped breathing during delivery?

Immediately, we were swept into the delivery room, and a team of specialists arrived. They suctioned my baby's lungs, then whisked him away to the Neonatal Intensive Care Unit (NICU). For four painful days my obstetrician had been calling my contractions "false labor." Now nine hours of "real" labor—and a complicated, difficult delivery—were behind me. My doctor had arrived just an hour before the birth.

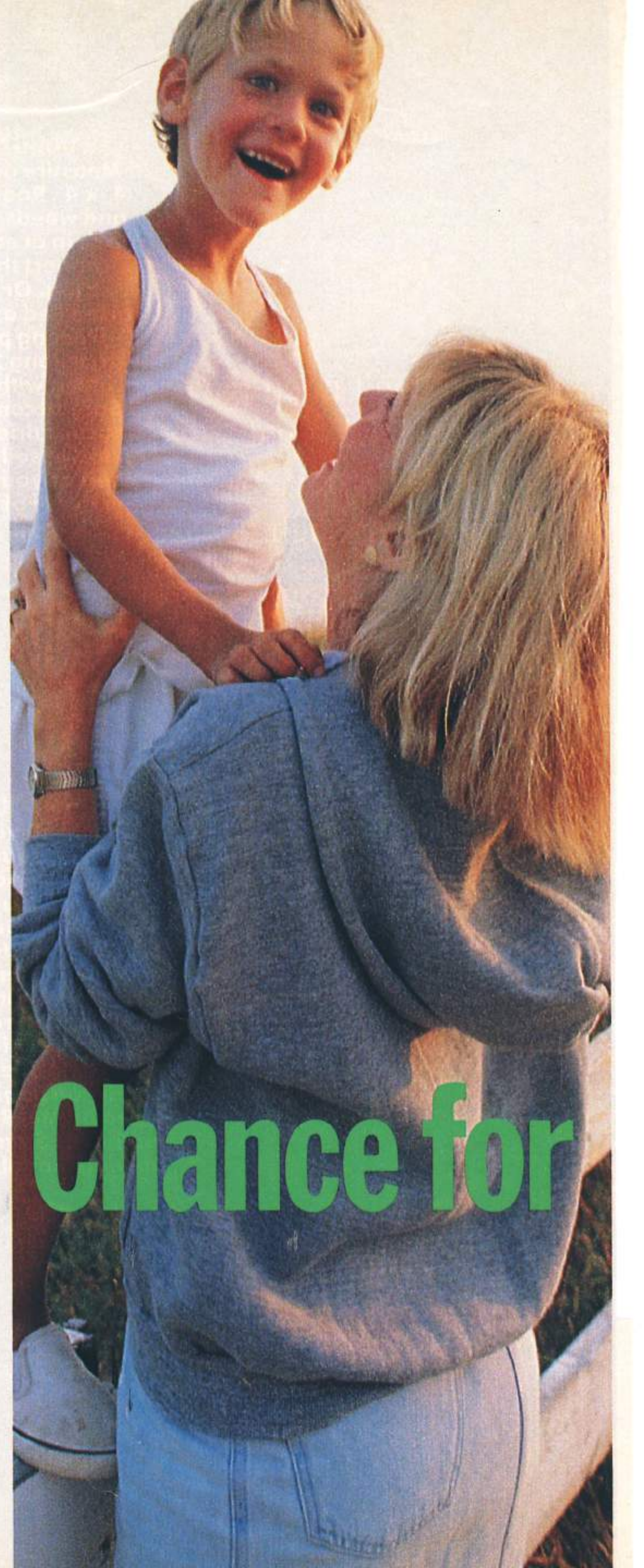
Sometime during the middle of the labor there was a disagreement between the resident physician and the nurse about whether the baby was getting enough oxygen. But this was our first child. My husband, Jay, and I were far too busy—and too tired—to ask questions.

We were assured everything was fine. Breast-feeding was difficult, but finally Seth did nurse, and four days after he was born, we were given a clean bill of health and sent home. The head nurse told me, "The girls will be crazy about your son." At 8 pounds 2 ounces he was the biggest baby the NICU ever had seen—and the most gorgeous.

In addition to being unusually beautiful, Seth was an easy baby. He slept through the night at 3½ weeks and was always smiling and happy. He looked around and followed me with his eyes. "He's a quiet baby, not too active," I remember telling my mother. "But he's very alert and intelligent. I can see it in his eyes." I loved him with the truest and purest feelings I'd ever known.

Then a friend came to visit with her son, who had been born a week after Seth. I was struck by Jonathan's hand-to-mouth coordination. At the time, Seth did not grasp anything or put anything into his mouth. I kept my obser-

Laura Shapiro Kramer has been a film and theatrical producer and is now a freelance writer in New York.



vations to myself, not even mentioning them to Seth's pediatrician at his regular checkups. She was always delighted with him, and the standard tests she ran never indicated anything wrong. "He's just fine," she told me after each visit. "A beautiful baby boy."

That fall Seth began to roll over, and soon afterward he would lie on his belly and try to pull himself forward "commando" style, but he did not get up on all fours. When he was 6 months old, Jonathan came to visit again. Jonathan was sitting unsupported. I became anxious. For days I surrounded Seth with pillows and encouraged him to sit. No success. But two or three weeks later Seth said, "Mama," very clearly. "Oh," I rationalized, "he's developing verbally instead of physically."

When Seth was almost 8 months old, Jay and I visited a highly regarded school to have a look at its day-care program. I observed a young boy exactly Seth's age who was not only sitting but crawling and climbing and starting to stand alone. As we left, I asked Jay, "Did you see what that boy was doing? Are you worried about Seth?"

"Don't be a worrywart," he replied. "Seth's just developing at his own pace. That's what the doctor says."

When I got home, I consulted every book I could find. Each one said, "Every child develops differently."

In April when we went for Seth's 10-month checkup, the doctor listened to my concerns and took special notice of his reflexes. "His reflexes are good," she said. "Let's wait until he's a year old before we get concerned." I trusted her, but I couldn't stop worrying. She agreed we should consult a neurologist—for my own peace of mind.

I would move mountains to give my baby a normal life. *Everything* would make a difference.

Our appointment was on a beautiful, cool, sunny day the last week of April. First the specialist asked a lot of questions: When did Seth hold up his head? When did he first smile, first roll over? He wanted to know about the pregnancy and the birth experience. I didn't remember much. I had forgotten that overheard conversation about adequate oxygen. And those four long days I had waited at home by the door with my suitcase, thinking Seth would be born any minute, seemed insignificant, not important enough to mention.

Then the neurologist examined Seth. Afterward, he spoke with us. The room was very still. I could hear birds singing outdoors. He spoke slowly and deliberately. "Your son will lead a normal life. He will feed and dress himself and probably learn to write somewhat legibly. And he may even climb stairs independently. He will not walk for a long time, and he will never walk normally. Later we might have to talk about seizures and learning disabilities. Your son has mild cerebral palsy."

I moved to the edge of the sofa, grasping for Jay, barely able to swallow. Cerebral palsy? That's a terrible condition—kids in wheelchairs in special vans . . . they can't hold their heads up . . . their speech is slurred. "What does it mean, he won't walk for a long time?" I managed.

Frank Siteman

Seth works on a science project at the Woods Hole Child Center.

"How long? What do you mean he won't walk normally?"

He couldn't say. He used a word we still hear: *developmental.* "Cerebral palsy is a developmental condition. You won't know what's in store until it develops."

We were numb. There was Seth sitting in his stroller, smiling. I fought back tears and hugged him, thinking I would never look at him the same way again.

Though the neurologist said there was little that could be done, I determined then and there that I would move mountains to give my baby a full life—a normal life. *Everything* would make a difference because I was going to see to it that it did.

Cerebral palsy is defined as any damage to the brain that is present at birth. What causes it? No expert we've consulted in five long years can answer that question. As I started my research, I discovered that cerebral palsy is a wastebasket term into which neurologists throw all kinds of disabilities. I looked, but I found no checklists, no guidelines and no context for the diagnosis. What does CP affect? All those qualities that in combination are uniquely human: mobility, speech, manual dexterity, sensory awareness and vision. The severity depends on how much and how well the individual can use his brain.

So we began with the best physical therapist we could find, who treated Seth three times a week for 16 months. Eventually there were weekly visits by two other therapists as well. But Seth wasn't catching up. As with most aspects of CP, there is disagreement among experts as to which approach is best—"neurodevelopmental" or "sensory-motor." The bottom line? There's no consensus.

I was determined to get all the help I could, so three days before Seth's first birthday, Jay and I took him to the Boston Children's Hospital for a second opinion. The doctor there said, "I consider your son more than just minimally impaired. He has a moderate, not a mild, CP." He demonstrated the way he believed Seth would walk: It was a gait typical of the way we think of CP—stiff in the hips, each leg dragged forward in an awkward way.

Left to right: **Seth working with Laura; playing with a friend; as Batman; Seth, Laura and Haya Kramer.**

Rather than being reassuring, this expert's opinion confirmed my worst nightmares, my secret, unspoken vision of Seth as a cripple. After I left his office and reached the street, I found myself howling with rage; I would *not* accept his diagnosis, his vision of Seth's future.

But at Seth's birthday party the guests saw only a strikingly handsome boy of exceedingly good cheer, with a winning smile and a delicious sense of humor. He sat up with some support, held his bottle, fed himself a little with his right hand and said a few words. The sensitive, remarkably intelligent boy already shone.

So what was wrong? There was a stiffness in his body when he attempted any complex motor skill, and there was the irregular motion of his left hand, which was often clenched. He drooled some. And, of course, there was his complete inability to walk—or even crawl normally.

Later, when I was feeling brave, I looked up the definition of *cerebral palsy* in Webster's. It said CP is characterized by an outward manifestation of muscular incoordination and speech disturbances. Speech? No one had mentioned speech impairment to us! So we had his hearing checked—it was fine— and then I hired a speech therapist. After working with Seth for a short time, she suggested he learn sign language. He was 15 months old. Wasn't he going to be able to talk either?

I felt totally frustrated. We were at sea, sailing in uncharted waters. Once, Jay admitted, "Don't you think I wonder if Seth and I are ever going to toss a ball back and forth together?" and I knew he grieved and was afraid, too. But he had no outlet for his frustration. And since no experts seemed to have answers, Jay just hoped I was doing all the right things.

And so did I. By now our list of consultants included two pediatricians, three therapists, an orthopedic surgeon, a podiatrist, and a specialist from the New York League for the Hard of Hearing. We had Seth's intelligence tested, and the results confirmed our conviction that he has exceptional abilities.

So we continued to weigh advice and make our own decisions. We chose not to teach Seth sign language, but we did have special casts built for his legs and feet, casts that the physical therapist said would help him learn to walk. By now, Seth was almost 2½. He did not walk. He did not stand alone. He talked, but since very young children are often hard to understand, there was no way of knowing how well he would be able to articulate as he grew older. He got around on his knees, knees calloused and hard from substituting for feet.

I wasn't satisfied with his progress, and I had a hunch there might be alternatives, experimental therapies—new, better ways to help him. A friend who was a physical therapist mentioned the Feldenkrais Method, which theorizes that the conscious brain can instruct the body to move in ways that are much closer to full potential—even if that body is handicapped by CP. Though a person may have moved the wrong way a trillion times, the brain can correct a move instantly.

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Although some medical professionals I asked dismissed Feldenkrais as "new-age mind/body drivel," it would prove to be the right answer for Seth.

On the phone, before we ever met, the therapist I found told me, "You will have to let all the other therapists go." I was dismayed. "Even speech?" I asked. "Everyone but me," Anat said firmly. "And the casts must be removed. He will never learn to walk as long as he wears them."

Terrified, I dismissed all of Seth's therapists. It was October 1985, 18 months after the initial diagnosis. He began to see Anat three times a week in a stark office with only a big table for furniture. She demanded his attention: She forbade us to give him applesauce, one of his favorites, unless he cooperated with her; she would put dabs of applesauce on the corners of his mouth, wanting him to use his tongue at each corner to help improve the clarity of his speech.

She expected him to take his sessions very seriously, and he did! "I am going to learn to walk," he told us. "Anat is teaching me." Less than three months later, Seth stood alone. In the spring before his third birthday, he took his first few independent steps. Soon he began to walk by pushing his stroller or holding hands. *(Continued)*

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A Second Chance

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Our hopes soared. Though doctors, parents and friends viewed our efforts as "hocus-pocus," no one could deny the exceptional progress Seth was making. But three weeks after he took those first independent steps, Anat abruptly quit.

We were alone again. Ultimately, though, it had always been up to us.

I sought out another Feldendrais teacher and arranged for Seth to begin work at the end of his summer vacation. I also enrolled myself in a three-year training program.

Soon after I began, we went away for the summer. Now Seth would be without therapy for an extended time. Obviously, I lacked the experience to give him any formal teaching, but I found I could "talk" to him with my hands. Maybe I couldn't teach him, but I could touch him as only a mother can touch her own child.

I could focus his attention on the left foot that wouldn't flatten on the ground, on the hand he clenched unconsciously, on the shoulder he hunched. I invented games: While he was lying on the floor, I'd say, "Close your eyes and imagine you're walking barefoot in the sand. *Feel* the sand between your toes." Right away, I could see his toes uncurl and his foot flatten. Later, standing, he could recapture that foot position by remembering walking in the sand.

We worked this way all summer. When we returned to the city in September, Seth began two weekly lessons with his new therapist, but I continued to work with him too. And one evening six months later, when he was 3½, I opened the front door of our house and watched him walk down the hall to greet me. He walked a little unsteadily, but proudly, using his arms for balance. His gait was fairly sure, scarcely resembling the picture painted for us by the expert in Boston. My heart pounded as I knelt down, waiting for him to reach me. He collapsed happily into my arms, and I burst into tears of joy. I controlled myself at once, though, lest Seth think I was unhappy with him. "That's my boy!" I shouted. "I'm so proud of you!" It had been a long trip from the labor table.

When Seth was almost 4, his baby sister was born. He continued to make progress with walking, but he moved very slowly and tired easily. I wondered whether I should get a double stroller, but discarded the idea. Seth wasn't a baby anymore, he was an accomplished little boy.

The battle with Seth's CP could have driven a wedge between my husband and me, but instead it drew us closer. But there are new worries. Will he learn to write? What about his vision? Are there changes in his bones? We have observed the beginning of some scoliosis and some atrophy in his left arm and hand. There is a good indication that he doesn't track well with his eyes. Now in the first grade, he exhibits many complex learning disabilities and requires tutoring and specially tailor-made programs.

The gaps between him and other children seem a bit wider now, and I observe some teasing by the other kids. Though I see him fighting back or charming his way into a playmate's favor, I feel angry—and like crying—when I witness a humiliation. I know how painful it will be—soon—when it's time for competitive sports, and I notice his growing awareness of his "problem." His little sister's agility and strength forever remind all of us of Seth's disabilities. She challenges him daily by her perfection.

Still, all the work he has to do to achieve what is so natural for everyone else has endowed him with high levels of concentration and self-discipline. He can't walk down stairs without some support, and climbing up is slow. But he runs with more exuberance than anyone I've ever seen. His knees knock against each other and he draws up his shoulders, but he has incredible stamina. I die inside every time he falls, often without apparent cause: He has no natural sense of balance. But he loves to run. And I love to watch him, the breeze ruffling his hair.

Along with his good looks and intelligence, I expect he will discover his potential with the *help* of his limitations. Don't we all? ■

WHAT IS CEREBRAL PALSY?

Cerebral palsy (CP) is a nonprogressive condition that results from brain damage and affects the motor functions. It may be mild, moderate or severe. Intelligence may be affected; if so, retardation usually parallels the degree of motor impairment. Seizures may or may not occur. Cerebral palsy is present in about 2 children per 1,000.

In most instances the cause is unknown. Significant head trauma and infections like meningitis can cause cerebral palsy *after* birth, as can complications of prematurity. Before birth, genetic disorders and brain malformations are thought to be responsible. During labor, diminished oxygen supply (asphyxia) has been considered a common cause. However, a large government-sponsored study of 50,000 pregnancies showed that the cases caused by asphyxia were far outnumbered by those caused by other factors during pregnancy. In fact, the study showed that the most important predictors of CP in children were: low birth weight (below three pounds), a malformation of any organ, breech presentation and maternal mental retardation.

Sometimes the condition may not be spotted until the second half of a child's first year or even later. Predicting the outcome is difficult: Of two children whose skills are similar at about 1 year, one may walk well at 3, the other barely walk at all. On the other hand, a child with mild CP may have little trouble learning to sit and walk, but problems may develop during the preschool period or even later. Nevertheless, many CP patients grow up to lead normal, productive lives.

Physical therapy appears to improve outcome, but not all children will show significant response. Much research still needs to be done, particularly on nontraditional therapies.

Ruth Nass, M.D., chief of pediatric neurology, New York Hospital-Cornell Medical Center, and Blythedale Children's Hospital, Valhalla, N.Y. □