

REX'S STORY

For parents of disabled children, the joyful journey into parenthood may include an unexpected destination. Instead of a safe landing in the country of their dreams, they feel stranded on unfriendly foreign soil—a land filled with strange new terminology and heartbreaking diagnoses. But for Cathleen Lewis, the foreign land became home. It was home because Rex lived there.

Cathleen Lewis was a newlywed at age 36. After a successful professional life in France, she had moved back to the United States a year previously and had fallen in love with William Clack while he was in the States on business from South Africa. Los Angeles was now their home and a son would soon make the family complete. All was sunny, new and hopeful in their world. Then the fairy tale began to unravel.

Cathleen's pregnancy had been easy so a phone call from her doctor, announcing that the fetus had a suspicious mass on its brain, came as a shock. Delivered easily by c-section, Rex Lewis-Clack grew to a healthy ten pounds by eight weeks, and the surgeons deemed him ready for surgery. But the cyst was larger than expected and could only be fenestrated (deflated) rather than removed. Then at four months of age, another doctor made a devastating diagnosis: Rex was blind. The optic nerves had never developed for unknown reasons, perhaps due to Rex's brain cyst. Nothing could be done.

Still reeling from the diagnosis, Cathleen made an appointment for Rex at the Blind Children's Center. At a mere six months, Rex and Cathleen began attending the "Mommy & Me" class. Rex's first few months at the Center were very successful, but his parents were not doing as well. William was able to insulate himself from Rex's day-to-day challenges with professional life, but Cathleen had decided not to go back to work. The financial markets she had worked in before seemed futile in light of Rex's challenges. Instead she dedicated her time to helping Rex gain life skills. Even the simplest task, such as eating with a spoon, required numerous steps and endless repetition. Cathleen's workplace, home with Rex, was an emotional battleground.

By his first birthday, Cathleen began to believe that Rex's blindness could be overcome -- his joy and laughter were a good sign indeed. But three days later, an MRI revealed that Rex's brain cyst was growing again. This time, a shunt would be required. Rex's next year of life brought more troublesome developments: tactile defensiveness, little interest in food, extraneous body movements, noise sensitivity and irritability. By the time he reached 18 months, his reactions to sensory stimuli were out of control, a daily assault to his body and mind. One of Rex's teachers approached Cathleen with a possible explanation: Rex might be autistic.

Cathleen couldn't deny the obvious facts. Therapy was not helping her child rebalance his sensory system. But to have him face both blindness and autism? How could God have allowed this to happen to an innocent child?

Not only had Rex's progress come to a standstill -- he had gained no weight during his second year of life and still had not begun to walk or talk -- but his parents' marriage was in tatters. William asked for a divorce. Cathleen felt as if she were standing on the edge of a great precipice and the weight of her life (and Rex's) seemed unbearably heavy. She was on the verge of a breakdown.

It was at this fragile time that Cathleen and Rex made their way up the hill to Malibu Presbyterian Church a month before Rex turned two. Her brother had pointed her to God, and although Cathleen wasn't sure that God could offer much to her small family, they had nowhere else to turn. Over the next few weeks, they attended church and Cathleen began to pray, enlisting the church to pray for Rex as well.

Meanwhile, Cathleen had begun to notice how Rex responded to music, notably classical music. She knew of the theoretical link between music and brainpower, but this seemed more direct. When her son listened to great classical composers, there was a look on his face that seemed to say, "This I understand." Shortly after Rex turned two, his father came to visit. He had recalled Cathleen's mention of Rex's affinity for music, and so he brought with him a 48-key Casio piano keyboard and stand. The tactile sensation of touching the keys was unpleasant for Rex, but once he heard the notes the magic had been unleashed. Over the months that followed, it became apparent that the little piano hooked Rex into life like nothing else had. He would play the little piano until he dropped from pure exhaustion.

Rex's preschool classes continued at the Blind Children's Center, along with physical therapy, speech therapy and occupational therapy sessions. The specialists began suggesting that Rex may need a wheelchair soon, and the confusion over Rex's various medical diagnoses only increased his mother's concerns. One evening Cathleen called in a babysitter so she could have time to walk the beach and sort through the frustrations of their life. She cried out to God, "Don't you care?" His message to her was clear and unforgettable: Walk by faith, not by sight. Cathleen put her trust in God and just two days later, Rex said his first word. Several weeks later, he took his first steps—and he ran! Rex was finding increased freedom in his body movements, his piano music became infused with faster tempos, bolder tapestries and new, more vibrant melodies. During the Christmas season of his third year, he

began playing several holiday songs on the piano. For Rex, Christmas was music. For Cathleen it was a miracle. Rex added a second word to his vocabulary that season: piano.

Rex graduated from preschool at the Blind Children's Center at the end of his fifth year. He could now communicate with more words, often employing the echolalia that is characteristic of autistic children, but his limitations were numerous—especially his tactile and auditory sensitivities. Cathleen perused several private and public schools which might suit Rex. She finally settled on a specialized public school near their home. Rex was placed in a classroom for children with "multiple disabilities," where a vision specialist and a one-on-one aide helped maximize his education. Just as Rex's school life was dramatically changing, another discovery loomed ahead.

Just weeks into the new school year, Cathleen set up Rex's keyboard at their condo's Halloween party. Playing the piano gave Rex an entry point into the noisy environment, and the party gave Cathleen the chance to meet her neighbors. After the party a neighbor named Richard Morton invited Rex to come and play the full-size piano in his home; Rex was there within two days. The tonal quality and the light touch required for the keys captivated Rex and his improvisations took flight. Then Richard played a Bach Aria for Rex, and Rex played it back instantly—replicating hundreds of notes, complete with intricate trills. "How many times has he heard that piece?" Richard asked. "That was the first time," Cathleen answered. Five-year-old Rex began visiting Richard's piano every day.

Richard Morton had studied music and musical theory in depth, so Cathleen listened as he explained Rex's unusual gift. Not only did he exhibit perfect pitch and an exceptional memory, he could also transpose a song instantly from one key to another. "It means," explained Richard, "that Rex's musical brain is light years ahead of his motor, his technical ability to produce it." Richard was teaching Rex as time permitted and Cathleen asked the music director from the Lewis's church (Mr. Lynn Marzulli) to begin more consistent lessons with Rex on a twice weekly basis. Richard continued researching Rex's gifts and playing musical games with Rex at the piano. A few months after Rex turned seven, he announced that Rex was a prodigious musical savant—a scientific anomaly, causing an extremely rare island of pure genius to exist in a sea of disability.

Cathleen struggled to view her son in these new terms. Rex was an extremely rare and precious oddity? All she had ever wanted for her child was normalcy! But Mr. Marzulli helped her view Rex's savant abilities with new eyes. "When I watch Rex playing the piano, it's as close as I feel I've ever come to God. It's as if he has a direct connection to the Creator. Rex has a 'touch of the Divine.'"

Yet Rex continued to struggle in the classroom. His teacher labeled many of Rex's autistic reactions as "behavior issues" and began to punish him for behaviors he could not control. Cathleen observed the situation when she insisted on a classroom visit, to the lead teacher's annoyance. Rex's mother immediately insisted on an emergency meeting with all of his educational team—from the principal to the PE coach. Although she dreaded the confrontation, Cathleen knew she had to fight for Rex's education. The meeting could have resulted in greater animosity between parent and teachers, but it fortunately led to greater understanding and improved methods—and Rex's school life began to improve. Once he played and sang a Beatles tune ("Blackbird") at the school talent show, he was practically a rock star.

Rex was also forging into new territory with abstract thinking—a concept sometimes not possible for autistic children. One Sunday, while telling a story as they walked on the beach, Rex struggled to tell his mom what he was thinking. After working up his internal motor to get his thought out, Rex burst out with words he had never said before: "I love you, Mommy!" So many specialists had wondered about Rex's ability to feel complex emotions—the words took Cathleen's breath away.

Rex's musical talent was inspiring to Richard Morton, and he wanted the world to know about Rex. He spoke with producers at "60 Minutes" about his work with Rex, and informed Cathleen that the producers were very interested in meeting Rex. Cathleen was furious and refused the interview—until producer Shari Finkelstein called. Cathleen felt herself warming to this mother/producer who seemed to view Rex as an extraordinary child rather than a freaky science study. Rex was scheduled to play a concert at a fundraiser for the Blind Children's Center, so Cathleen allowed the "60 Minutes" team to attend as well.

As the big moment drew near, Cathleen grew nervous for her son. The diners were seated and the cameras were in place. What if seven-year-old Rex played half-heartedly? What if he froze before the large group? But the applause and laughter from the audience sparked him on and he played with even greater precision and vigor. He played the Beatles, he played Beethoven, and he laughed his way into the final notes as his face sparkled like a diamond. Though there were many external battles to be fought every day, Rex's greatest battle was internal—and the look on his face said he was winning. As Cathleen viewed Rex's "60 Minutes" profile, entitled "Musically Speaking," she was relieved to know she had made the right decision in allowing the interview. It beautifully captured the life and spirit of her son.

Rex's music teachers admitted he was moving beyond their skill level, so Sara Banta and David Pinto at Pepperdine University (near the Lewis's home) agreed to become Rex's new teachers. Rex was progressively overcoming his touch and sound aversions, and the world was becoming increasingly accessible. He and Cathleen were able to accept some invitations for Rex to perform at various educational and inspirational venues, requiring travel. His music became a connector to life.

Two years after the filming of "Musically Speaking," the mystery of Rex's gift and the fascination surrounding it, led to a follow-up profile by Lesley Stahl and the "60 Minutes" crew. Rex was nine years old, and the profile was simply called "Rex." The segment featured Rex as well as a 26-year-old British musical savant named Derek Paravicini. A British television series, "Extraordinary People," also profiled Rex and Derek—the duo even performed on dueling pianos. The collaboration with Derek opened an important door for Rex. Over the next months, his musical speech took on new depth as he added to his numerous solo performances, now collaboration with other musicians in his new middle school, meaning his school peers.

Today Rex continues to push back all the limits of his life in his time. He continues to perform his music and he loves his life—every second, minute, hour, month, year. He knows that it *is* a wonderful life. And through her faith and love for a little boy, so does Cathleen Lewis.

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