ENRICHING LIVES
Actors Chris and Marianne Cooper Help Improve Education for Kids with Disabilities

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Jesse’s WORLD

Ten years after their son died from sudden unexpected death in epilepsy, actors Chris and Marianne Cooper continue to fight for the education rights of kids with disabilities.

BY COELI CARR

Marianne and Chris Cooper were busy working actors before they contemplated having their first child. Marianne was shooting The Thin Blue Line and Chris had just wrapped Matewan when Marianne became pregnant, and they moved to a more spacious apartment in Hoboken, NJ, to prepare for their baby’s arrival in January 1988. For the first seven months, Marianne’s pregnancy was uneventful. Then, in her 30th week, she suddenly developed a high fever and went into labor, delivering Jesse 10 weeks prematurely. Three days later, her son sustained a massive grade 4 intraventricular hemorrhage (IVH)—bleeding in the nervous tissue of the brain and the spaces, or ventricles, containing cerebrospinal fluid. Infants born more than 10 weeks prematurely are at the highest risk for IVH, according to the National Institutes of Health.

“Type of bleed, deep in the white matter of the brain, injures the tissues that contain the motor fibers, which, in turn, damages the ability to control muscle movement,” says William Graf, MD, FAAN, a pediatric epileptologist, developmental pediatrician, and professor of pediatrics and neurology at Yale School of
Medicine in New Haven, CT. "The extent of the disability correlates with the severity of the injury. With a grade 4 IVH—the most severe level of hemorrhage—seizures are also typical."

**A WILL TO SURVIVE**

Doctors didn't think Jesse would live out the week. But he survived and remained in neonatal intensive care for nearly three months. It was another two months before the Coopers could hold their son unfettered by tubes. Finally, on December 8, 1987, the couple took Jesse home. They had been given no diagnosis, but they left the hospital that day with antiseizure drugs that had been prescribed because an electroencephalogram, a test of brain wave activity, had detected seizure activity.

Over the next four months, the Coopers suspected Jesse had other medical problems in addition to seizures. "He wasn't meeting developmental milestones," says Marianne, recalling that his body was rigid when he rolled over and he had difficulty holding up his head. The Coopers eventually traveled to Boston Children's Hospital, where Jesse was officially diagnosed with cerebral palsy and severe spastic quadriplegia. Cerebral palsy is a condition in which brain damage affects normal muscle function; spastic quadriplegia means the muscles of all four limbs are stiff or permanently contracted. A common cause is an injury to the brain in the early stages of its development, such as Jesse's IVH, says Dr. Graf.

Jesse's inability to speak or walk was challenging, but his parents were most concerned by his daily seizures, which ranged in length from two seconds to two minutes. The Coopers took him to a series of neurologists, each of whom recommended antiseizure drugs that either stopped working after a time or produced unacceptable side effects. "Because of Jesse's profound sensitivity to these drugs, it was dangerous to have him on medication," Marianne says. But it was equally dangerous to take him off. By the time he was 3, Jesse was having intense tonic-clonic seizures—episodes marked by stiffening of the muscles followed by jerking movements—several times a day despite medication.

**A PLAN FOR SCHOOL**

The Coopers continued their acting careers (Chris' film credits include The Muppets, August: Osage County, and Adaptation, for which he received an Academy Award for Best Supporting Actor; Marianne played the mother of Christopher Moltisanti on The Sopranos) when Jesse was a baby and toddler, but scaled back as their son got older.
A neurologist told them their son would never be "intellectually normal," but the Coopers felt otherwise. They noticed that Jesse responded appropriately to comedic gestures, and he fully engaged with toys Marianne adapted for him. Based on these interactions, the Coopers had every expectation that Jesse would attend the local public preschool in a regular classroom. After all, the Individuals with Disabilities Education Act, passed in 1975, had guaranteed a “free and appropriate public education” in a regular classroom with an aide and a curriculum adapted for the child’s disability.

Marianne reached out to the New Jersey Statewide Parent Advocacy Network (SPAN), a parent-run organization devoted to children with special needs. She also researched the Individualized Education Program (IEP), a blueprint designed by parents and school administrators that details the educational goals of students with disabilities and how those goals will be achieved. If both parties don’t agree to the terms, such as allowing a student to bring an adapted computer or some other educational aid into the classroom, mediation and even a lawsuit may follow.

"Despite the parents’ right to be equal members of the team, the IEP can sometimes be a battleground," says Marianne—especially when parents believe the curriculum doesn’t sufficiently challenge their child intellectually. The Coopers’ case was no exception. The study team proposed that Jesse attend a preschool for children with disabilities that was an hour away by school bus. After a week, the Coopers pulled their son out. Since Hoboken had no public preschool that included children with special needs, the Coopers chose a private one. For kindergarten, the Coopers reluctantly enrolled Jesse in a public school exclusively for children with special needs.

Their frustration at the lack of mainstream public school options made Chris and Marianne rethink their plans for Jesse’s future education. In the summer of 1994, the family moved to the South Shore of Massachusetts, which, at that time, had more success integrating students with special needs. But, as the Coopers quickly learned, each school district decides how to provide education for children with disabilities, and the differences in those provisions can be vast, even between adjacent school districts.
Play It Safe to Avoid SUDEP

When Jesse Lanier Cooper died from sudden unexpected death in epilepsy (SUDEP) at age 17, his mother, Marianne, was shattered but not surprised. That possibility had haunted her from the time of his birth, when an electroencephalogram showed seizure activity. As a young child, Jesse’s daily tonic-clonic seizures were intense and uncontrolled by medication. The fact that he had cerebral palsy and spastic quadriplegia exacerbated his risk. “People with treatment-resistant epilepsy tend to have SUDEP at a rate of between 3 to 4 per 1,000, with the majority of fatalities occurring in young people,” says Daniel Friedman, MD, a SUDEP expert at New York University Langone School of Medicine.

Despite being a leading cause of premature death in people with epilepsy, SUDEP was a relatively understudied—and controversial—phenomenon for many years. In the past, some physicians argued that the risk of SUDEP was so low that mentioning it would cause parents and caregivers undue stress. Today, advocacy groups and families who have lost relatives to SUDEP are raising public awareness and encouraging openness about the phenomenon, even helping to spearhead further research. Professional organizations like the American Epilepsy Society (aesnet.org) suggest that any conversation about epilepsy with parents and caregivers should include a discussion about SUDEP.

SEIZURE CONTROL IS CRITICAL

To avoid SUDEP, older children must understand and carefully manage their seizure triggers. “This means taking medications as prescribed and limiting or eliminating the factors that lower the seizure threshold, such as not getting enough sleep or ingesting drugs or alcohol,” says Dr. Friedman. He adds that research has not yet established a clear link between diet and SUDEP, and that patients may experience their own idiosyncratic and individualistic triggers.

Parents of young children may consider seizure-detection devices, which use sensors placed under mattresses or in wristwatches to pick up the shaking movements associated with seizures. These devices do not prevent SUDEP, says Dr. Friedman, but they can alert a caregiver to respond. Even just repositioning or touching the person during a nighttime seizure may avert SUDEP. And because sounds and vocalizations often accompany these seizures, some parents use baby monitors to be alerted to cries or groans.

Devices, however, are not the primary focus of efforts to reduce SUDEP. “Because of increased public awareness, many parents now know the best weapon against SUDEP is improving seizure control,” says Dr. Friedman. “There’s no better protection than that.”

Parents and caregivers can learn more about SUDEP through the SUDEP Institute at epilepsy.com/sudep-institute.

A TOUGH TRANSITION

By the time he was ready for first grade, Jesse could recognize words. Chris and Marianne had always read to him, and not just children’s books. They read the sacred poetry of Rumi and Khalil Gibran, the speeches of Martin Luther King Jr., Greek myths, and Bible stories. “There was a huge disconnect between Jesse’s inability to move on his own and his fluid mind, and our goal was to narrow that gap as much as possible,” says Marianne.

Given her son’s aptitude and curiosity, Marianne felt hopeful when he was integrated into a regular classroom in South Shore. But he was the only child with severe disabilities who was non-verbal and in a wheelchair, and he cried a lot. Marianne believes that’s because he was ignored and excluded. His teacher, who had no previous classroom experience, told the Coopers that Jesse was manipulative, refusing to do what didn’t please him. But Marianne discovered that the classroom aide was abusive, keeping Jesse in his leg braces longer than was appropriate and, as reported by a neighbor, feeding him improperly by not allowing him to breathe between bites.

There were other problems, too. Jesse was a reader, as measured through his use of eye-gaze technology, but the rest of the students were still being taught the alphabet. When Jesse had trouble holding a crayon, the teacher offered no alternative activity or solution. “I realized that full inclusion would not happen on its own. I would have to become relentless to get the results I wanted,” says Marianne. Following the advice of an advocacy mentor, Mary Somozia (see “6 Tips from an Advocacy Pro” on page 32), who has two children with cerebral palsy, Marianne began keeping a meticulous paper trail, recording every time the school didn’t return her calls and saving every shred of correspondence in case legal action might prove necessary.
The Coopers offered to provide a classroom aide for Jesse at their own expense, but the school insisted it was the sole decision maker. The situation went from bad to worse when Marianne was told to “let go” and that her son didn’t belong in the school. The Coopers finally hired a lawyer and took their case to mediation, where they successfully won the right to have a say in choosing an aide for their son and adapting the curriculum to suit his needs.

**DISABILITY CAN MASK ABILITY**

The challenges the Coopers faced are not unusual, says Dr. Graf. People often don’t understand that cerebral palsy doesn’t progress and mostly affects the motor system. “Seeing children in wheelchairs, people assume they have a cognitive disability, especially if they also have a hard time speaking or are nonverbal,” he says. But only about 30 to 50 percent of children with cerebral palsy also have an intellectual disability.

Despite his physical limitations, Jesse proved to be intellectually gifted, making the honor roll nearly every semester. He wrote poetry, played video games, and used a computer to speak with friends and classmates. When his intelligence was assessed through the use of an adapted computer, Jesse scored in the 99th and 79th percentiles on different parts of the test.

**SUDDEN LOSS**

By all measures, Jesse was thriving in his senior year of high school, but his seizures continued unabated—a constant worry for him and his parents. In fact, Marianne was haunted by the idea of waking up one morning to discover that Jesse had died in his sleep from a nighttime seizure. And then, one cold January morning in 2005, Marianne’s worst fear became a reality. Her 17-year-old son had died from sudden unexpected death in epilepsy (SUDEP).

SUDEP occurs at a rate of 3 to 4 per 1,000 people with treatment-resistant epilepsy, says Daniel Friedman, MD, an assistant professor of neurology at New York University Langone School of Medicine and an expert in SUDEP. The overall rate of SUDEP in children under the age of 18 is very low—about 2 per 10,000 children. “But people whose epilepsy began before the age of 18 are at a higher risk for SUDEP in adulthood,” he says. “Death typically occurs between the ages of 20 and 40.”

The Coopers were devastated and nearly undone by grief. “The threat to both Chris and me—and perhaps to other grieving parents—was the danger of grieving alone, each partner nursing a private agony and perhaps blaming the other for not experiencing the same grief at the same time,” says Marianne, who tried to remind herself that grief is different for everyone. “Grief is like a sniper. It comes out of nowhere, and neither Chris nor I expected the other to be at the receiving end of that shot simultaneously.”

**HONORING JESSE**

Two years after their son’s death, the Coopers launched the Jesse Cooper Foundation, a small nonprofit group that supports two Massachusetts organizations, the Jesse Advocacy Fund and

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**6 Tips from an Advocacy Pro**

Mary Somoza fought hard to get the best education possible for her twin girls, who both have severe disabilities. Now she helps other parents do the same for their children.

Aiba Somoza is an accomplished painter and art teacher. Her identical twin sister, Anastasia, is an advocate and consultant for people with disabilities. These 31-year-old professionals both have cerebral palsy and spastic quadriplegia. The relentless, driving force who helped them fulfill their innate potential? Their mother, Mary Somoza.

Mary gave birth prematurely after experiencing polyhydramnios, a condition that significantly increases amniotic fluid levels, in her third trimester. The girls’ lungs were undeveloped at birth, which resulted in a lack of oxygen to their brains. The twins were kept in intensive care for three months, and the Somozas’ medical costs mounted. The process of applying for Medicaid helped Mary hone her advocacy skills.

By the time the girls were 9 years old, Alba, who cannot speak and uses a computer to communicate, had been enrolled in a special education class with other students with various disabilities. Anastasia was in a regular classroom. Dissatisfied with what she called the “education warehousing effect” that discourages true learning, Mary asked to have Alba transferred to an integrated classroom. The school district considered Alba’s disability too severe and turned down the request. Somoza sued, and her efforts attracted national attention. The Somozas had the support of the advocacy organization United Cerebral Palsy and
My best dream is to fly, soaring through the air."
—JESSE COOPER

AccesSportAmerica. The Jesse Advocacy Fund, housed within the Federation for Children with Special Needs (fcsn.org), is an educational group that helps low-income bilingual parents of children with disabilities hire advocates to fight for full inclusion in the classroom. AccesSportAmerica (accessportamerica.org) uses sports and physical activity to improve fitness and overall functioning in children with disabilities. “We keep it at a local level because we believe it’s easier to see results through direct involvement,” says Marianne. In its eight years, the foundation has helped nearly 300 families.

Also in 2007, when Jesse would have turned 18, Marianne got a tattoo on the inside of her wrist of her son’s name with an infinity symbol beneath it. She considers it “an exuberant shout, a testimony to Jesse’s being in the world, an affirmation of his own wish to proclaim it, and a reminder that I was and will be his mother every day for the rest of my life.”

In his last poem, “I Am,” written in 2004, Jesse wrote: “My best dream is to fly, soaring through the air.” Through their organization and advocacy work, the Coopers are helping other children like Jesse to soar as well.

Even of President Bill Clinton. “At that time, ‘inclusion’ was a hot-button issue,” Mary explains. When Alba entered fourth grade, she became the first student with significant disabilities to be enrolled in a general education classroom in the New York City public school system.

Since then, Mary has helped families who have children with neurologic disabilities, including the Coopers, get the social services they need. Since 1993, she has also served on the advisory council of the New York State Office for People with Developmental Disabilities, which provides services both directly and through a network of about 750 nonprofit agencies.

Mary believes parents have more power to advocate than they realize, and she offers these tips to help them get started.

1. **Don’t take no for an answer.** “Belief in your child’s potential and the right course of action ensures you’ll never back down,” she says. When Alba was 4, Mary applied for a communications device through Medicaid. The program turned down her request, defining the item as an educational tool rather than a health care need. When Mary appealed her case through a Medicaid arbitrator, she brought Alba with her to the Medicaid office. “I described how the device allowed for communication that was vital to Alba’s health,” she says. Mary’s request was approved, and she became the first person in New York State to receive this Medicaid-funded device for health reasons.

2. **Stay on top of afterschool programs.** Any child with a disability who attends regular classes in a public school can participate in any afterschool program offered to students without disabilities. If your school is unable to provide an aide for your child, your school district, if you request it, must fulfill that obligation. “My daughters weren’t necessarily ‘invited’ to take these afterschool classes,” says Mary. “But I kept abreast of the afterschool offerings on the school’s calendar, and so we invited ourselves.”

3. **Join support groups.** “The best source of advocacy-related information comes from other parents who’ve been through it,” says Mary. “Joining the parent grapevine is the best way to avoid reinventing the wheel.”

4. **Be an efficient letter writer.** If your school district isn’t satisfying your child’s needs, write a letter to the local superintendent of schools and copy as many higher-ups as possible, says Mary. Then, for good measure, copy the editor of your local news outlet. “I learned this highly effective 10-letters-in-one trick the hard way,” she says.

5. **Document everything.** Keep backup copies of all emails and letters. Create a print file of all communication, or convert all paper communication into a PDF format and save it electronically in a well-organized folder system.

6. **Contact your local Parent Center.** The US Department of Education provides grants to Parent Centers throughout the country (parentcenterhub.org). There, advocates and advisers help educate parents on their rights within the school system and, if necessary, how to address school districts’ denials of parental rights.

Mary acknowledges that some parents fear the repercussions if they rock the boat with too many demands. “What you do to help your disabled child today will have ramifications 10 years from now,” she says. “Remember: It’s the squeaky wheel that gets the grease.”