

Kari Luther Rosbeck

Overnight Hope

Like so many of the mothers Kari Rosbeck works with today, she had a normal pregnancy. Her first child, a daughter named Noell, was born on December 19, 1993, healthy and happy. But two months and eight days later, Sudden Infant Death Syndrome (SIDS) mysteriously took the baby's life. Without warning, her life changed overnight.

Up to that point, her goal was to be an actress. She had always done theater administration, production, and acting, starting her own theater company at age 21. But when her daughter died, everything changed. "I had watched my father provide service to others through his whole life," she says today. "He's my hero and my role model, and those seeds he gave me about service to others started to emerge for the first time. Suddenly, the thing I always thought I wanted to do had no meaning. I wanted to take the feelings I had and use them to change the world, so other families never had to experience the loss I experienced."

Kari's pursuit of meaningful work ultimately landed her at the Tuberous Sclerosis (TS) Alliance, where she was named President and CEO in 2007. Through the organization, she met countless families who were forced to stand by helplessly as their children slipped away—a feeling she remembered all too well. At first, no treatments were available. But through methodical, persistent, unrelenting grit, Kari and the families she fights for changed everything. "It wasn't easy," she says. "We built the grassroots community and had volunteer branches in place. Then came the recession, and we were laying off staff, but we were still educating the community and supporting clinical trials. Finally, after years of pushing, the Food and Drug Administration approved the first drug ever to treat TSC. It was like overnight hope, transforming our organization in an instant. It was amazing."

Tuberous sclerosis complex (TSC) was

discovered in the late 1800s, afflicting 50,000 Americans and more than a million people worldwide. The genetic disorder, passed from parent to child in one-third of cases and the result of spontaneous mutation in two-thirds of the cases, causes tumors to form in vital organs, and is the leading genetic cause of epilepsy and autism. Afflicted children can face cognitive impairment that ranges from mild to severe, but life expectancy has been significantly extended and improved since the 1970s, when people only lived to age 20 or 30. "Now, people can live a normal lifespan, but there's the question of quality of life," Kari says. "We've come a long way with our treatments and our medication, but we still have a long way to go."



The TS Alliance was launched in 1974 by Adrienne Cohen, Susan McBrine, Debbie Castruita, and Verna Morris—four mothers from Southern California. At that point, not many medical professionals were working in the field of TSC, and the internet didn't exist yet, so it was hard to connect with others. "They were alone in this journey, but determined to create an enduring force for change and support," Kari says.

With the goal of making a dent in TSC research, the organization relocated to Washington, DC, for its proximity to Congress and the National Institutes of Health. The TS Alliance nurtured those relationships, and the genes responsible for TSC were discovered in the 1990s. Clinical trials for treatments were launched in the early 2000s, leading to the first FDA approval of a drug in 2010. "It's an incredible success story that connects directly with the individuals who lived with the disease and the family members who pushed the envelope," Kari affirms. "The Congressionally-Directed Medical Research Program began funding TSC research at the Department of Defense because a grandfather lobbied the Appropriations Committee Chairman

and got \$1 million set aside in the annual federal budget in 2002. We have to fight for this every single year, but since then, \$65 million has been appropriated for TSC research, and it's made a profound difference."

When Kari joined the TS Alliance, it was a \$2.1 million organization with large ambitions that demanded focus and energy, and through her work, Kari felt an angel nearby. "Going out and visiting with families in living rooms, church basements, and hospitals, it felt like my daughter was sitting on my shoulder the whole time," she says. "My job was to mobilize our community, start volunteer branches across the country, inspire them to fundraise, and really move the organization to the next level. And with blood, sweat, and tears, that's what we did together."

By the end of 2016, the organization closed out at \$5.2 million, a budget that had more than doubled with the help of her vision and tenacity. That means more grants to support groundbreaking discoveries, and more support for the TSC natural history database the nonprofit helped create in 2006, open to all researchers hoping to garner a better understanding of how the disease progresses over a lifetime. It also means funds to build a new biosample repository to house blood and tissue samples with matching clinical data records in the natural history database. "These initiatives give researchers the full picture of the person, which is a game-changer for them," Kari says. The TS Alliance also established a Preclinical Consortium that utilizes a multifaceted approach to bring new drugs to market and supports a Clinical Research Consortium that is now conducting the first-ever preventative study in epilepsy in the US.

Beyond research, the TS Alliance funds educational programs for those living with TSC, including meetings, regional conferences, and webinars hosted by its 37 volunteer branches nationwide. Its sophisticated website is an information repository for all things TSC, and the organization funds professional and public awareness campaigns to promote early diagnosis and treatment. Thirty-five percent of its budget comes from grassroots fundraising like walks and special events, and Kari relies on her own fundraising expertise paired with a dynamic team of seasoned professionals to meet the organization's goals. "I've found something that just clicks, and I know I'm exactly where I'm

supposed to be," she says.

Coming from the woman who moved eight times before the age of eighteen, that's saying something. Kari was born in Charleston, Illinois, where her parents grew up. Her father got his PhD in education from the University of Michigan and then landed the position of Dean of Students at Henderson State University in Arkansas, prompting the family to relocate to Arkadelphia when Kari was six years old. They moved again to Detroit, then back to Arkansas. More memorable than the constant upheaval, however, was the day her mother took her to see Pippi Longstocking. "At nine years old, I turned to my mother and told her that this was what I wanted to do for the rest of my life," she laughs. She would organize all the kids in the neighborhood to perform plays for their parents, and she loved singing with the children who lived next door. At the time, it seemed Kari was born for the stage, and she was cast in her first play, *Tom Sawyer*, when she was in sixth grade.

Kari's father also had a deep love of politics and decided to leave his post in academia when he was given the opportunity to run the Arkansas Republican Party. He was then hired as the Campaign Manager for Bob Eckelberry in Littleton, Colorado, so they moved again. "I spent that summer with my dad doing door-to-door visits, marching in parades, mobilizing grassroots, and fundraising," she says. "But Eckelberry didn't win, and when he lost, our family was lost too."

Stuck in Littleton, the family lived on her mother's temp salary which could only afford meals of hot dogs, eggs, and macaroni & cheese. Kari babysat to make extra money, and she still remembers vividly the year her family couldn't afford a Christmas tree during the holidays. Kari and her sister hung lights on the wall in the shape of a tree, and Kari was the one to buy presents for her family that Christmas. "Seeing my father vulnerable and knowing I could step up, be strong, and take care of things, was a defining moment for me," she says. "I was thirteen and my parents told me I didn't have to do it, but I wanted to. Everybody had a present that year even though we were going through hard times, and we still talk about that Christmas a lot as a family. I think when people struggle, they find their true integrity—what really matters and defines them."

Several months later, the family moved to Knoxville, Illinois, where Kari finished her seventh grade year and spent all of high school. She picked

up a newspaper route, and her father became Vice President of Student Affairs at a Community College. "His passion in those positions with community colleges was fueled by his strong belief in opening the doors of education to everyone," she says. "He dedicated his life's work to expanding the opportunity of education to people in prison, or people who couldn't afford it, or people who were down on their luck. He and my mom grew up with nothing, and he was fortunate enough to be able to get a college education on the GI bill. Education changed his life, and he wanted others to have that change."

With the glow of her father's example always visible, Kari flourished in high school. She landed her first lead role in a play, joined the cheerleading team, qualified for National Honors Society, and was friends with everyone, transcending all social circles. In her junior year, she got her first real job at Happy Joe's Pizza Parlor. "Nobody told me to work, but I saw my dad working, so I wanted to do it," she says. Balancing work with all her extracurricular commitments, she loved advanced math and graduated fourth in her class of 113 students. With dreams of becoming the next Demi Moore, she enrolled in Illinois State University for its strong theater program.

Her family, however, moved to upstate New York when her father became President of Columbia-Greene Community College. "I was a thousand miles away from my family for the first time, and I made the very hard decision to transfer there," she says. Over the next year and a half, she did all of their plays, building her resume until she took an internship at a regional theater. Having completed all her general credits by that point, she spent her last two years of college at the State University of New York at Albany in a conservatory-like setting. She returned to the regional theater the summer before her senior year, where they did a for-stage version of the film *Casablanca* that almost went to Broadway.

After graduating in 1988 and spending one final summer at the regional theater, Kari moved to New York to live with friends and audition nonstop. During the day, she worked at Theater Development Fund, where she honed her administrative skills and ultimately moved into their development department. In the evenings and on weekends, she worked at Riverside Shakespeare Theater and ultimately decided to

start her own theater company, where she could produce the plays she wanted to produce. Following the inspiration of the summer theater she had done through college, she developed a relationship with the Manhattan Church of Christ and rented space in their basement for \$25 a year. They performed summer readings in Central Park, children's plays at Lincoln Center Library, and produced two full-length plays.

After a whirlwind two years in New York City, Kari married a long-time friend she had met at the age of fifteen while on vacation in Arkansas. The following year, in 1992, they moved from New York to Minneapolis to start a family. She went to work at the Cricket Theater doing fundraising part-time and held various other odd jobs while taking acting classes and auditioning, until the death of Noell rocked her world and opened her eyes to the yearning for meaning she never knew she had. Fortunately, in time, a mentor—Mike Henley—asked her to work for him as the Development Manager at the American Refugee Committee (ARC). "I had always been completely dedicated to theater, and it meant having to give up my job at Playwright's Center, a touchstone of theater and influence," she recalls. "But it was the service piece I was looking for, so I took that step."

Over the next several years, Kari was promoted to Director of Corporate and Foundation Relations and traveled to Bosnia for her work with displaced and refugee populations. Her work also acquainted her with the second influential Mike in her life, Mike Coburn. He worked for the International Service Agencies (ISA), and he offered her a job that would allow her to telework from Minneapolis—an ideal arrangement since Kari was now the proud mother of two young sons. The arrangement worked very well for three years, allowing Kari time to give back even more by joining Rotary and leading a team to Ecuador.

In 2000, Mike Coburn decided to leave ISA to become the CEO of the TS Alliance, and he offered Kari the chance to come with him. "He's very mission-driven, and he saw the opportunity to turn an organization around," she says. "The TS Alliance was trying to reinvent itself after a rough financial time, and under his leadership, the growth was unbelievable. I joined him a year later, and as Director of Community Alliances, my job was to meet with families of children born with the genetic disorder and adults living with TSC. And since my job required travel all over the country, I

was still able to telecommute from Minneapolis – a great setup since I had two more sons.”

By 2007, Mike Coburn had moved on, and the CEO that replaced him was cycling out as well. Divisions within the community were thwarting the organization’s potential, and as Executive VP, Kari was asked to serve as the interim CEO while a search was performed. Her background and skill set, however, were exactly what was needed, and in the end, she was chosen to stay. “I remembered the stamina and fortitude that I had proven to myself during that Christmas when I was 13,” she says. “I knew I had the wherewithal to weather whatever storm came about in the transition.”

In April 2008 shortly after she became CEO, Kari received a phone call from Karen, a high school classmate whose adopted daughter had just been diagnosed with TSC. Kari reflected saying, “What were the odds, given that our hometown in rural Illinois had only 2,500 people? Again, I felt my daughter on my shoulder saying I was exactly where I was supposed to be.” Kari also knows she was exactly where she should be in 2010 when she married Chris, an accountant and former marine with an old soul and a brilliant, entrepreneurial spirit. “I admire him so much for what he’s made of his life,” she says. “He’s an amazing support system, sounding board, and partner.”

Now, as a leader, Kari focuses on teamwork, skills honed under her third mentor, Mike Harden. “We’ve built a culture of respect, creativity, and collaboration where everyone has a voice,” she says. “We are a ‘grass-up’ organization, and I learn so much directly from our community. Everything we do is mission-based, and everyone plays a role.” She also brought her own flare to celebrate the organization’s 40th anniversary by telling its story on Broadway. “Everyone thought I was insane at first, but it ended up being perfect,” she says. “We commissioned John Morogiello, a playwright I went to college with at SUNY Albany, who interviewed 22 families to tell the story through the eyes of the community. Our celebrity spokespeople flew from Los Angeles to donate their time and talents, and we hired other actors, some of whom I grew close with during my theater years. I so loved marrying these two things I love deeply.”

In advising young people entering the working world today, Kari urges them to set their goals high. “Map out your path to success,” she says. “No matter what challenges arise, get back

up the next day and keep your ultimate goals in mind.” This kind of grit was pivotal in landing the organization’s largest donation to date—a \$1.5 million gift that took fifteen years of building an organization worthy of the investment. She also praises the examples set by her parents. “My mother showed us ultimate love, sacrificing her own dreams and aspirations to support all of us,” Kari says. “Later, she started teaching continuing education to help people get their GEDs, continuing that commitment to service that runs so deep in our family. As well, my Dad taught me everything about leadership, entrepreneurship, fundraising, service to others, going for what you believe in, and believing that everything is attainable. It’s had a profound impact on what I’ve been able to accomplish.”

Now that she’s found the TS Alliance, Kari’s in it for life. “In the beginning, the organization couldn’t do much more than hold the hands of parents as they went through the struggle,” she says. “But today, we have drugs that shrink TSC tumors and are starting our first trial aimed at preventing epilepsy from ever developing in infants with TSC, which will completely alter the course and quality of life associated with this disease. We’re changing lives. To have been here for fifteen years to see this arc of progress, I can’t imagine any other organization where I would have gotten the chance to experience such an amazing journey. I’ve seen how hard work can create overnight hope, and I’m not going anywhere.”

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