Front Burner

IN THIS SECTION

GUEST OF HONOR

MOTHER COURAGE

Tracy Seckler is on a life-saving mission—for her son, Charley, and thousands of other boys with Duchenne muscular dystrophy

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Hands cupped around a mug of hot tea, strawberry blond hair brushing her slender shoulders, Tracy Seckler sits in her cozy farmhouse living room and recalls the day in July 2004 that her family's life forever changed: the day her three-and-a-half-year-old son Charley was diagnosed with Duchenne muscular dystrophy (DMD), a fatal genetic disorder.

"We were shocked," she says. "Shocked."

From the beginning, Charley had experienced minor physical challenges—when raising himself from a sitting position or climbing stairs, for example—but Tracy and her husband Benjamin were psychologically unprepared for the horrifying news they received nearly four years ago, after Charley's blood was analyzed at a specialized New England lab. Like an estimated 20,000 other boys in the United States who suffer from DMD, Charley was destined for a debilitating descent into a wheelchair and a much-abbreviated lifespan; boys with DMD typically survive only into their late teens or early twenties.

Determined not to let this happen to their son, the Secklers charged into high gear. Benjamin, a radiologist, pored through medical journals every night and spoke with physicians and scientists who were involved with biomedical research. Tracy contacted muscular dystrophy organizations and parents of other boys with DMD. "It became obvious pretty quickly there was a void that needed to be filled to make a difference in this disease," Benjamin explains.

Four months after the diagnosis, the Secklers launched Charley's Fund, a nonprofit organization dedicated to finding a cure for DMD. What differentiates Charley's Fund from similar organizations—the Muscular Dystrophy Association, for example—is its singular commitment to putting as much money as possible into the hands of researchers who are focused on finding therapies for DMD.

In just three years, Charley's Fund has raised six million dollars, which it has funneled to carefully selected university labs, research institutions, biotech companies, and individual scientists around the world. In 2008, Tracy says, the foundation is committed to raising two and a half million more.

Tracy insists, however, that collecting money is only part of their goal. "We're a nonprofit turned on its head a little bit," she says. "Our goal is to develop a product and see it to market. The product just happens to be the therapy for a disease which will hopefully save our son's life and thousands of others."

A former teacher, Tracy heads the day-to-day operations and directs fundraising efforts from her home office in South Egremont, Massachusetts. She's both attractive and articulate, and radiates a gentle confidence that is not only captivating but central to her newfound mission. Benjamin, a full-time radiologist with a practice in Poughkeepsie, New York, serves as the foundation's president.

The Secklers have assembled an all-volunteer scientific advisory board as well as a loosely knit group of subspecialty physicians, attorneys, financial advisors, and other business people who offer their expertise as needed.

Tracy admits at first she was somewhat skeptical that they could make a real difference. "When we started this foundation, nagging in the back of my mind was the question: 'If there could be a treatment, wouldn't there be?'" she confesses. But as she began to understand more about the drug research and development process, she became convinced that Charley's Fund could help bring the medical goals within reach.

THE SECKLER FAMILY, CLOCKWISE FROM TOP; BENJAMIN, CHARLEY, MAISY, AND SAMMY, WITH TRACY IN THE CENTER.

CHARLEY SECKLER

"What we learned is that the science is there," she says brightly, "but it needs focus and oversight and money. We just put together the pieces."

The Secklers—no strangers to success, as evidenced by their Ivy League backgrounds and professional achievements—are taking aim at their target from a number of different directions. "You don't need to be a professional darts person to hit the bull's-eye if you throw fifty-thousand darts at once," Benjamin reasons.

But the darts aren't free. To boost the research momentum, the Secklers look continually for ways to attract donors and dollars. Besides more common fundraising tools such as letter-writing campaigns, dinners, and sales of logo-imprinted clothing and accessories, their strategy has included some innovative and high-yield twists. Charley's Fund, for example, co-produced *Darius Goes West*, an award-winning documentary by Logan Smalley about a boy with DMD who leaves his southern hometown for the first time to travel across the United States with a group of college-aged friends. The film has garnered critical attention as well as more than $100,000 for Charley's Fund; all proceeds from benefit screenings and DVD sales go directly to the foundation.

Special events have spawned a significant portion of contributions. But for a while after Charley's diagnosis, Tracy says, she and Benjamin couldn't picture themselves attending a glossy, upbeat event to raise money. "I remember saying to Benjy, 'Can you imagine going to a party with smiles on our faces?'" Tracy recalls. "It seem[ed] very contradictory."

But Berkshire neighbors—who happened to have a world-class art collection—quickly came to the rescue. They hosted a private dinner party for fifty people, inviting an art historian as well as the Secklers to speak to the guests. At the end of the evening, the Secklers were approached by people who wanted to make contributions. It was a "seamless and comforting way," says Tracy, to ease the couple into the special-events circuit. Since then, the Secklers have headed a series of events on both East and West coasts, including jewelry and accessories sales; an auction; concerts; dinners and cocktail parties; benefit film screenings; and family fun days, among others.

Karen Climo, secretary of the Charley's Fund board of trustees, is "amazed" by the Secklers' drive and stamina. "It takes an enormous will to do what they're doing, to get up every day and put one hundred ten percent of their energy into fundraising," she says. "Fundraising is hard."

Prior to Charley's diagnosis, Tracy had no fundraising experience whatsoever. This, Climo says, makes their success even more remarkable. She says about Tracy, whom she also views as a highly engaged mother and household organizer: "She's a brilliant girl, and that really shows in the way she manages this."

Three major Charley's Fund events (the "Gems for Duchenne" jewelry sale, the "Wish I Could" auction, and a *Darius Goes West* film screening) have so far been held in the Berkshires; attendance and contributions have been impressive. Tracy points out that from the beginning she and Benjamin found inspiration and support not only from friends and neighbors in the region, but also from local institutions and the community at large. "On an Obama level of fundraising, where everyone comes together and does what they can, we've raised tons of money from people in the Berkshires," she says.

Unexpected contributions have rolled in from local sources. Pam Fink, the owner of Good Charma, designed bracelets to be sold for the benefit of the foundation; sales have already yielded more than $50,000. The bracelets are available at Gatsby's in Great Barrington, Massachusetts. The Sinai Academy of the Berkshires, the school in Pittsfield, Massachusetts, attended by the Seckler boys—Charley and his older brother Sammy—promotes Charley's Fund in each issue of the parents' newsletter, and last summer the school donated ten percent of the proceeds from its annual gala to the foundation. Area high school students have donated money earned by babysitting and other odd jobs. Children have requested that their bar or bat mitzvah gifts go directly to Charley's Fund.

One of the foundation's major supporters is Mel Zuckerman, founder and chairman of the Canyon Ranch resorts. As a grandfather, he says, he is "particularly taken" with children's diseases, especially those with no cure. "You hear of a child who never had a chance to prevent something . . . something they were born with," he muses. "How can you not have compassion for that?"

Chris Barash, head of school at Sinai Academy, has observed a "great outpouring of support" in the local community. She says Tracy and Benjamin have galvanized people with their energy and confidence. "I think if any two people can run a successful campaign against DMD, it's the Secklers. The combination of the two of them is extraordinary."

The Secklers met at Harvard College—Benjamin majored in biology, Tracy in American history and literature—but they didn't become romantically involved until after graduation, when they were both living in New York City. Tracy was employed by the city government to investigate crime in the city school systems. Benjamin was attending medical school at Mount Sinai.

After working for the city for two years, Tracy jettisoned her plans for law school and decided instead to become a teacher. After securing a master's degree in education from Columbia University, she accepted a teaching job in Scarsdale, New York. When Benjamin, who became her husband in September 1995, decided to complete his residency at Mass General, the couple moved to Cambridge,

How Tracy Does It

What is your favorite productivity tool?

"I have to say the BlackBerry has definitely changed my life. It makes me a lot more productive. It has these handy-dandy organizers that are color-coded for kid and business-related commitments. Everything's in there."

What book had the greatest impact?

"Two, really. *The Blessing of a Skinned Knee: Using Jewish Teachings to Raise Self-Reliant Children* by Wendy Mogel—it's a fantastic parenting book—and *When Bad Things Happen to Good People* by Harold S. Kushner."

What books have you read that influenced how you conduct your business?

The Cure: How a Father Raised $100 Million—And Bucked the Medical Establishment—In a Quest to Save His Children by Geeta Anand.

What business-oriented website do you regularly read?

Philanthropy News Digest (www.foundationcenter.org/pnd/)

What business publications do you read regularly?

"*Chronicle of Philanthropy* and *Contribute* magazine. And, thanks to Google alert, I'm notified any time there's any news at all related to DMD."

TRACY AND CHARLEY SECKLER

Massachusetts. There, Tracy cofounded and taught at a charter school in Dorchester, and the couple's oldest son, Sammy, was born.

A year later, in 2000, when she was pregnant with Charley, the young Seckler family moved to the Berkshires, a place to which they both had lifelong connections. Tracy was teaching English part time at Berkshire Country Day School in Lenox, Massachusetts, and was pregnant with Maisy (now three) when Charley was diagnosed. She resigned to focus on Charley's medical needs.

Today, seven-year-old Charley downs twenty-eight pills each day and wears leg braces at night. He goes to physical therapy and is often fatigued. By his parents' careful design, however, he's not aware of the tragic fate that has inevitably befallen other boys with DMD. With the same intellectual vigor that jump-started a successful foundation, Tracy and Benjamin mapped out a strategy for what and how to tell their children about Charley's disease. They decided, Tracy says, to "unfold information as necessary."

"We didn't want our kids to wake up one day and have the same experience we did on the day we found out," she says. "We wanted it to be part of their lives, so we started saying 'muscular dystrophy' from the beginning." From the children's perspectives, Tracy says, having muscular dystrophy is like needing glasses: a condition that affects ability and requires correction.

Tracy is essentially a full-time-plus volunteer for Charley's Fund, a role she tries constantly to balance with being a mother of three. After she puts their kids on the bus in the morning, she climbs the stairs to her home office—a converted guest bedroom—and works until five o'clock. After they put the children to bed, she says, she and Benjamin "go right back to the computer. We work on this every free second we have."

In October 2007, Charley's Fund committed $2.5 million to AVI Biopharma in Portland, Oregon, to accelerate the development of new therapeutics for DMD. If everything goes as planned, Benjamin says, it's likely that a phase one clinical trial will start within a year.

Eric Hoffman, the molecular biologist who in 1986 identified the gene whose mutation causes DMD and who now heads the Research Center for Genetic Medicine at the Children's National Medical Center in Washington, D.C., believes that parent-led foundations like Charley's Fund can indeed help to harness worldwide medical advancements. Foundations are "critical," he says, in fostering coordination of all the players—major corporations, private companies, government institutions, and other research organizations. "People in the hub of this monster . . . make sure [the efforts] are collaborative and cooperative instead of competitive," he says.

TAKEAWAY

BE INNOVATIVE:
Creating unusual fundraising events has been successful for Charley's Fund: The "Gems for Duchenne" jewelry sale, the "Wish I Could" auction, and a *Darius Goes West* film screening, all held in the Berkshires, garnered impressive attendance and contributions.

BE FOCUSED:
The Secklers believe in focus. Charley's Fund is unusual in its singular commitment to putting as much money as possible into the hands of researchers who are working on finding therapies for Duchenne Muscular Dystrophy.

NONPROFITS PLAY A ROLE:
Nonprofit foundations like Charley's Fund can be critical in coordinating efforts between major corporations, private companies, government institutions, and other research organizations.

Citing the AVI Biopharma deal, Hoffman says Charley's Fund has taken a lead in getting promising drugs closer to the clinical trial stages. In fact, he says, he's more optimistic than he's been in twenty years. "You really need a well-functioning bicycle wheel to win the race," he says. "Charley's Fund is a really important translational spoke in the whole wheel."

Buoyed by this kind of positive feedback from the scientific arena as well as by their expanding donor base, the Secklers remain resolute and confident. "This is a real goal, an achievable one," says Tracy. "We're near the finish line of what's been developed for a long time." BBQ

Christine Hensel Triantos is a freelance writer who lives in Richmond, Mass., with her husband and two children.

THE RECIPE

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