

STARTING A NOT-FOR-PROFIT ORGANIZATION

Local founders describe motivation, successes

By KRISTEN D'ANDREA



Behind every not-for-profit organization there is a story. The story of how it came to be. The story of what motivated its founders. And the story of how an idea goes from conception to fruition.

In the majority of cases, the founders of local not-for-profit organizations who we spoke with didn't set out to start a foundation. In fact, the primary motivator behind those we spoke with was to help others. In doing so, many times the founders ended up helping themselves—an end result that was just icing on the cake. Here are some of their stories.

■ Helping children with cancer

At just two years of age, before she could read, play on a soccer team or go to school, Morgan Zuch was diagnosed with Acute Lymphoblastic Leukemia. At one point during her 31-day hospital stay, Morgan didn't walk, talk or eat for 10 days. "We didn't know if she was going to make it," said her dad, Rod Zuch.

Sitting in a chair in her small hospital room one evening, Zuch said he began to pray. Ironically, he had recently left a job in the not-for-profit sector and in his sleep-deprived state considered that his

daughter's illness could be God's way of punishing him. "I said, 'Listen, God, I promise that if you make my daughter better, I'll find a way to give back.'" The next morning, Zuch awoke to his daughter standing in her crib, pointing at some men outside cleaning the window, saying, "Guys!" "I jumped up and started yelling, 'Yes, guys, guys.' We were both waving at the men saying, 'Guys, guys, guys, over here' and they were waving back," Zuch said.

Two years later, Nancy Lee Zuch came to her husband with an idea: "Let's start a pre-school for kids with cancer," she said, and I said, 'What a perfect way

to give back.'" Within a year, The Morgan Center opened its doors in Plainview.

■ The Morgan Center

The impetus for the creation of The Morgan Center began shortly after Morgan was diagnosed with leukemia in October 2000. Every Tuesday, Morgan and her mom would drive to Schneider Children's Hospital. On their way to the hospital where Morgan would encounter doctors, needles, shots and medications, they would pass the preschool that Morgan had planned to attend. As her friends turned left into the parking lot,

Morgan and Nancy kept going, on a path that had been predetermined for them.

Due to her chemotherapy treatments and suppressed immune system, Morgan could not socialize or interact with other children. "Morgan couldn't go to school because it could kill her," Zuch said, noting that even a simple childhood illness or infection could be life-threatening for his daughter.

"The Morgan Center was really conceived in our home," Zuch said. "My wife began teaching Morgan in our kitchen." While cultivating their daughter's cognitive development, the Zuchs still felt Morgan was being deprived of socialization and companionship with children her own age.

During a visit to the hospital one day, Morgan was playing with another child as they both waited to see doctors. "My wife suddenly realized that children with suppressed immune systems might not be able to go to school with other children, but they could go to school together, with each other," Zuch said.

From Conception to Reality

New Year's Eve 2002: The Zuchs put the kids to bed and sat down to write their business plan.

"We had a good idea but we also had a lot of good people willing to step up and help us," Zuch said. "Our board was made up entirely of our friends and we met in our kitchen. We were only able to accomplish this because we were surrounded by so many good people."

After writing the business plan, establishing a board and getting 501(c)(3) status, money had to be raised if the The Morgan Center were to open its doors by that September. Zuch met with Vytra's CEO Tom McAteer and explained what he and his wife were trying to do. "I said, 'I need a first donor to get this thing going.'" Once Vytra committed to "a sig-

nificant amount of money over three years," Zuch approached The Miracle Foundation. "I was able to say to them, 'Look, I already have Vytra as a major donor, would you like to come on board?'" By May, he had commitments of \$40,000 but was coming up significantly short on his projected budget of \$100,000 for the first year.

Ironically, Rod Zuch was turning 40 that year, but instead of throwing a big birthday bash, the Zuchs decided to hold a cocktail party in honor of their two major donors. They invited 200 friends, as their guests, and by the end of the evening, had raised another \$25,000. "There were raffles and a silent auction," Zuch said. "Some people were just coming up to us giving us checks. After that, I knew I could raise the rest—and we did."

The Future

Today, Morgan is 11 years old and "doing great," said Zuch. She visits the Center, named in her honor, often and was recently as assistant teacher for the day. Morgan's 14-year-old brother, who was five when his sister was diagnosed with leukemia, is also actively involved with the Morgan Center. He has gone into the classroom and played his guitar for the children. "If you're going to start a not-for-profit organization, you should definitely take a survey of the entire family, because it is a lot of work," Zuch said. "But the return—you may not see it in dollars, but you will definitely see the impact it makes."

In addition to his full-time marketing job, Rod Zuch is president, co-founder and volunteer at the Center. Nancy Lee Zuch, who was the executive vice president of her family's realty appraisal company before starting the Morgan Center, has since left the company with her family's blessing. Today, as co-founder, director and teacher, she is the only full-time employee at the Center.

The Morgan Center currently has four part-time teacher aides and three volunteers. "Our teachers get paid a modest per-diem salary, but most donate it back," Zuch said. "They're not in it for the money."

In its short, seven-year history, The Morgan Center has helped nearly 100 families and held six graduations. Every year, enough money is raised so that all of the children who attend the Morgan Center can do so for free.

Zuch said he is currently working on a plan to take the Morgan Center, which is the first and only such program for pre-school children with cancer in the country, national.

"When all is said and done, between the families you help and the people who help you, you get so much more out of it than you put in—and I put a lot in," Zuch said. "It's very gratifying. And if that doesn't motivate you, than don't start a not-for-profit, because there is no money in it. Anyone who does it for the money is in the wrong field."

Breast Cancer Awareness

Lorraine Pace knows all too well about getting more out of something than you put in. In 1992, after she and several of her friends and neighbors had been diagnosed with breast cancer, she began to suspect an environmental cause near her West Islip neighborhood. "I said to my oncologist, 'Look at all of these women in Suffolk County being diagnosed with breast cancer. And, we have a higher mortality rate than Nassau County. Maybe it's because we have no awareness,'" Pace said. "I wanted to do a survey, so I set up a meeting with the health commissioner and my oncologist said he would help."

After getting Good Samaritan Hospital in West Islip on board, Suffolk Life agreed to run a survey for West Islip res-



idents on the cover of their paper, free of charge. More than 1,000 people, 68 percent of the population, responded. "At the time, however, there were 8,650 households in West Islip and we were told that in order for the survey to be understood—since it wasn't scientific—we needed $\frac{3}{4}$ of the population to participate," Pace said. "So we started going door to door."

In 1992, long before breast cancer was spoken about as openly as it is today, Pace and her friends were bringing the topic to the forefront of conversation. "Many of the women we spoke with filled out the survey saying they didn't have breast cancer," Pace said. "But then they would make a doctor's appointment only to find out after having a mammogram that they did in fact have it."

Soon, other towns heard about the mapping Pace was doing through the creation of the West Islip Breast Cancer Coalition. She assisted in starting 25 other breast cancer coalitions across Long Island and the country. CNN, 60 Minutes and Primetime Live were among several media outlets that reached out to Pace, as well. "I was getting calls from all over the world from people wanting to start mapping in their area," she said.

In 1994, she left the West Islip Breast Cancer Coalition to start Breast Cancer HELP (Healthy Environment for Living Planet), Inc. Since its inception, the group's goal has been to raise awareness and promote education for the cause, treatment, and cure of the disease; while maintaining a focus on action and advocacy to eradicate breast cancer.

Breast Cancer Help, Inc. has helped to ensure that Long Islanders have access to the best possible diagnosis and care through the purchase of cutting-edge medical and research equipment. In 2003, Breast Cancer Help opened its Long Island Cancer Help and Wellness Center in Bay Shore to provide increased cancer awareness to promote education and early detection while providing patients and survivors with much needed support.

■ Life comes full circle

"We raised money for the first digital mammography system on Long Island at Stony Brook University Medical Center," Pace said. In a bizarre twist of fate, three years ago, after having a mammography, Pace was told that her cancer had come back. "Because of the digital mammography, it was caught very early and I only needed surgery, no radiation or chemotherapy," she said. "I was told a regular mammography might not have caught my recurrence right away."

"When you do things for other people, sometimes you end up helping yourself—even though that was not my original intention," Pace said.

Her advice to others who may be contemplating starting a not-for-profit: "You need determination and some help."

"If you truly believe in something, or if you see something that's in need or going wrong, don't think about it, just go for it," Pace said.

■ Advancing research into the lymphatic system

Wendy Chaite discovered the need for more research into the lymphatic system shortly after her daughter was born with systemic lymphatic disease and lymphedema. "I spent the first few years of my daughter's life trying to find medical care and scientific answers," Chaite said. "I kept coming up empty-handed; it was very frustrating." Realizing what was needed; she left her job as a successful attorney on Wall Street and began advocating to advance the field of lymphatic research.

"Research funding by our government was nearly non-existent," Pace said, noting that the lymphatics were being sorely neglected in both medical school curricula and research institutions. Ironically, science has now recognized the importance of the lymphatic system on virtually every function of the human body in health and illness, she said.

Pace began by meeting with different physicians and scientists to identify the obstacles and challenges in the field. She interviewed the executive directors of other organizations who served as her mentors. "I assessed

their situations and the framework in which they had created things," Pace said. "I asked them if they had it to do over again what they would do differently." She quickly found that there was no "cookie cutter" way of starting a foundation. "The critical part was in assessing what the needs are for your particular issue," she said. "In our case, we were dealing with a blank slate. It was particularly challenging because I had to create that slate."

■ The Lymphatic Research Foundation

Through the creation of the Lymphatic Research Foundation (LRF) in July 1998, the field of lymphatic research has significantly advanced both in this country and internationally. Among the organization's accomplishments in its short 11-year history: LRF helped to establish the first-ever Endowed Chair of Lymphatic Research and Medicine at Stanford University School of Medicine; successfully advocated Congress for recognition of lymphatic research and diseases as a higher national medical research priority; started the international peer-reviewed scientific journal, *Lymphatic Research and Biology*; and, launched the first-of-its-kind patient registry and tissue bank for lymphatic diseases.

"We really have changed history," Pace said.

In July 2008, Pace stepped down as executive director of the Lymphatic Research Foundation with the intent of focusing on research and public policy for the organization. "Unfortunately, my daughter's health changed fairly dramatically at that same time" and she's since become a full-time caregiver.

Pace's daughter recently began a clinical drug trial for her disease. If it hadn't been for the work of the LRF during the last 11 years, Pace said she's confident she wouldn't even be talking about potential drug therapy at this time.

