

The Rides of His Life

By Dan D'Ambrosio



Greg Crawford feeling strong on his way across the country in 2013. The University of Notre Dame dean raised half a million dollars for research into Niemann-Pick Type C Disease on the ride.

Greg Crawford, dean of the College of Science and a professor of physics at The University of Notre Dame, is riding his fifth cross-country tour in five years in 2015, averaging — at age 48 — 100 to 150 miles a day on trips approaching 4,000 miles in length.

He is motivated to push himself so hard because he's riding to find a cure for a rare disease, Niemann-Pick Type C (NPC), that strikes children typically at four or five years of age. Most children live only a few years more.

Growing up in Ohio, Crawford was into BMX bikes.

"When I was a teenager, we rode our bikes everywhere," Crawford said. "I got my first real road bike in college and did a trip from Cleveland to Pittsburgh. That was my first long-distance ride, about 150 miles one way."

Crawford is a physicist, getting both his undergraduate degree and his Ph.D. at Kent State University in Kent, Ohio. He rode to Pittsburgh because he wanted to go to the big city.

When Crawford accepted an offer to become a dean at Notre Dame in South Bend, Indiana, in 2008, he continued

to ride almost every day, commuting on his mountain bike to work through the winter as long as there was no snow on the ground.

"It's a form of transportation for me," Crawford said.

At Notre Dame, he was put in charge of every facet of the College of Science, including biology, chemistry, math, applied math, and physics. He soon learned that the entire campus, including students, staff, and many of his professors in the College of Science, shared a passion to find a cure for NPC, which had taken the lives of three of the four children of Michael and Cindy Parseghian, the son and daughter-in-law of legendary Notre Dame football coach Ara Parseghian.

In a person who has NPC, fats and cholesterol, essential to the healthy functioning of cells, are trapped in harmful amounts in the spleen, liver, lungs, bone marrow, and brain. Children afflicted with the disease generally do not live past early childhood.

"I wanted to do something for the cause because everyone was so passionate about it," Crawford said. "I couldn't do the science because that's not the

science I do. I decided to raise funds and pay other scientists to do it."

Crawford settled on bike rides as a way to raise money for research into NPC. Bikes had always been a part of his life, and it seemed natural to rely on them for this purpose as well.

In his fourth bicycle tour last year, Crawford rode 3,700 miles from Los Angeles to San Diego, across Arizona and New Mexico to Houston, then to Charleston, South Carolina, and up to Baltimore, raising \$500,000 for the Ara Parseghian Medical Research Foundation — the most he has raised to date. His first three tours all raised in the neighborhood of \$100,000 each.

Crawford's wife joined him on his first two tours, but she has fallen back into a support role since then, along with his two daughters, who are 15 and 19 years old. His 19-year-old daughter attends Notre Dame and on one of his rides drove the support van supplied by the university for two weeks.

"My wife retired on me, but we always have people join us along the way, often Notre Dame alumni who want to ride a leg or two," Crawford said.

Crawford explained that the fund-

raising is necessary because Niemann-Pick's rarity makes it unattractive for both industry and government agencies to fund research. There's no revenue model for industry, and the constituency for governmental intervention is too small.

Depending on ethnicity, the incidence of the various forms of Niemann-Pick Disease range from 1 in 40,000 to 1 in 250,000, with the latter being the most common. Only individuals of Jewish descent in eastern and central Europe exhibit the more frequent incidence of the disease.

Cindy Parseghian calls Crawford a "remarkable man."

"He's always thinking of ways to get more for us, more dollars, more research," she said. "I've never seen anybody as active as him."

Slow speech, slow vision

Cindy Parseghian was a member of the second class of women to enter the University of Notre Dame in 1973. Notre Dame had been exclusively male until the previous year. Parseghian grew up in western Colorado, but her father always had a passion for the midwestern school. Although he had not attended Notre Dame himself, he wanted Cindy and her brother to go there.

Parseghian's father died when she was 10 years old, but both she and her brother did attend Notre Dame.

"I entered as a naïve freshman," she said. "As I look back on life, it was probably one of the best three decisions I ever made."

During her junior year at Notre Dame, Cindy met her future husband, Michael Parseghian, son of the school's legendary football coach, Ara Parseghian.

"This is corny, but we studied in the same section of the library," Cindy said of her husband. "We were such nerds."

The two were married three months after graduation and moved to Chicago where Michael entered medical school and Cindy went to Northwestern University for her MBA.

"Mike asked where I wanted to go for his residency if we left Chicago," Cindy said. "We talked about the Southwest with my family in Colorado."

Michael landed one of two residen-

cies available in Tucson, and the couple found the place where they would put down roots.

"We absolutely fell in love with Tucson," Cindy said. "There's lots of winter cycling. So many people come here to train."

As they settled into their life together, the Parseghians had four children: son, Ara, born in 1984, Michael in 1987, Marcia in 1988, and their youngest, Christa, in 1991.

"If you were to ask me at that time as a parent what was our biggest goal, first I would have said we were the luckiest people alive," Cindy said. "We had four beautiful children who appeared to be perfectly healthy. Raising happy, loving, giving, responsible children was our biggest goal."

The Parseghians had about a year with their four children when everything seemed perfect. Then Michael, four or five at the time, started having

pediatrician, the doctor asked him to perform a couple of small tests like jumping on one foot. He concluded that Michael was clumsy.

Visits to more pediatric specialists and an ophthalmologist brought no answers. Frustrated, the Parseghians decided to take Michael to Columbia University Medical Center.

"They took a three-minute look and said, We think it's Niemann-Pick Type C Disease," Cindy remembered.

Why? Two reasons. Michael had an enlarged spleen, and the horizontal and vertical gaze palsy — his slow eye movements — were symptomatic of the extremely rare disease.

Stolen lives

Niemann-Pick is an inherited disease that requires both parents to carry a recessive gene. Typically, the parents show no signs or symptoms of the



Writing messages of encouragement on Greg Crawford's Notre Dame-themed support van.

trouble keeping up physically with the other children on the playground.

"Other kids were developing more dexterity, and he wasn't gaining skills," Cindy said. "His speech became slow."

Something was also going on with Michael's vision. His eyes seemed to move much slower than his head when he turned to look at something. Meanwhile, Ara was developing normally. When Cindy took Michael to the family

disease.

In the summer of 1994, the Parseghians had a skin biopsy done on Michael to determine if his skin cells could process cholesterol. Michael tested positive for Niemann-Pick disease.

"After Michael tested positive, we had our other children tested, and much to our disbelief, our two daughters also tested positive," Cindy said. "We screamed and yelled. I'm not em-

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barrassed to say that I cursed God. As a parent, it was out of the realm of what you could conceive of. Three beautiful children were going to have their lives stolen from them in a horrendous way.”

Cindy explained that the progression of NPC is similar to the progression of Alzheimer’s disease. The children lost their ability to walk and talk, although none of them developed dementia. Their inability to swallow properly led to pneumonia. Seizures were common as cholesterol clogged up their systems.

On March 27, 1997, Michael had a seizure in bed and suffocated.

“We thought we had years left with him,” Cindy said.

The Parseghians’ youngest child, Christa, wasn’t as physically strong as the others and died in October 2001 of pneumonia. Marcia died four years later in 2005 — another case of acute pneumonia.

Through it all, Ara helped to take care of his younger siblings.

“When he was a young teenager, he knew how to change a feeding tube and what to do when they had seizures,” Cindy said.

In 1994, within six weeks of their girls being diagnosed with NPC, the Parseghian family had a foundation up and running, named after the children’s legendary grandfather. It was called the Ara Parseghian Medical Research Foundation.

“Since then, we’ve raised \$40 million, and I don’t even know how many researchers we’ve funded,” Cindy said. “In the early years, we concentrated on the basics of what was going on with the disease. Nothing was known about it. Now we have a pretty good idea of what’s happening and why the cholesterol is getting stopped.”

Parseghian said people ask her why so much money should be spent on such a rare disease. Her answer is to point to Dr. Joseph Goldstein and medical researcher Michael Brown at Texas University’s Southwestern Medical School. The two scientists conducted research on another rare disease that afflicted children that led to the development of statins, the most prescribed drugs in the world, which received the 1985 Nobel Prize in Medicine.

A lot of hope

As part of the Parseghians’ extended Notre Dame family, Greg Crawford has never questioned why so much money should be spent on research on Niemann-Pick Disease.

Crawford’s biggest year of fundraising ever in 2013 — \$500,000 — went toward funding a clinical trial being conducted by the Mayo Clinic and the National Institutes of Health on a new drug, Zavesca, that has proven to be effective in slowing the progression of NPC in mice. Notre Dame researchers were also involved, funded by the Ara Parseghian Medical Research Foundation. The trial is now progressing to children and adults with the disease, and it is showing some promise.

“Like anything else, there’s a lot of hope,” Crawford said. “If you have a child with the disease, you hang onto anything. I’m very proud of the trials and proud of all of our scientists. It’s pretty amazing for Notre Dame to be a part of it.”

Crawford rode a Specialized S-Works carbon-fiber frame outfitted with top SRAM components on last year’s tour. The bike was donated by a Notre Dame alum named Jeff Shupe, a co-founder and chief operating officer of SRAM.

“It cooks. It’s fast,” Crawford said of the S-Works bike. “Jeff donated the bike and all of the parts. SRAM is an amazing company. I know he started it when they got out of college. 25 years later, it’s nearly a billion-dollar company.”

Crawford’s tours are planned by Destination Cycling (destinationcycling.com) in Boston, which specializes in organizing charity rides. Unlike the routes across America far from the beaten path developed by the Adventure Cycling Association, Crawford plans his routes to take advantage of the most publicity possible.

“I want to make sure I hit media to promote the cause and meet with Notre Dame alumni,” Crawford said.

Crawford tells Destination Cycling which cities he wants to hit for the maximum fundraising effect, and they do the rest.

The Destination Cycling website describes how in 2010 and 2011 Crawford and his wife took a 2,300-mile “Desert to Dome” ride from Tucson to the steps

of the Golden Dome on the Notre Dame campus. On the second ride, the couple traveled 2,200 miles on the “Road to Discovery” from Boston to Dallas, and in 2012, Greg Crawford, riding now without his wife, rode 3,250 miles from Boston to Pebble Beach, California, “visiting alumni clubs and families affected by NPC along the way.”

Team Parseghian

Following his blockbuster tour last year, which raised five times as much money as he had on previous tours, Greg Crawford was still planning this year’s tour at press time. He wants to raise even more money this year than he did in 2013 to support the clinical trials at the Mayo Clinic and National Institutes of Health. He’s training, as he always does, in flat Indiana, riding intentionally against the wind whenever he has the opportunity.

“People say, ‘How do you feel riding so many miles?’” Crawford said. “After a week, you get into shape anyway. There’s no way to really prepare. You

know it’s going to be hard no matter what, the psychological aspects are more demanding than the physical aspects.”

Some days, Crawford said, stretch into very long hours, and weather and altitude have their ways of making things harder.

“You just remember why you’re doing this mission you’ve been called to do and the responsibilities you have trying to raise money for the fight against this disease,” Crawford said.

Although he hits many big cities along the way on his fundraising tours, Crawford does allow himself the luxury of staying outside the city and driving in to meet with the media so he doesn’t get stuck riding on busy downtown streets in Houston, for example.

“It’s worked out quite well,” he said.

Crawford said the senior Ara Parseghian, although 91 years old, still fires up the troops.

“He works with us every year,” Crawford said. “We have a conference for the scientists working on the disease, and he

comes in and gives a pep talk to them like they’re a football team. It’s great.”

The younger Ara Parseghian, 30, is serving an anesthesiology residency in Portland, Maine, as he pursues a medical career like his father. Michael Parseghian works at an orthopedic clinic in Tucson where the younger Ara shadowed him for a couple of days last year in surgery.

In her role as president of the Ara Parseghian Medical Research Foundation, Cindy Parseghian is inspired by the role Greg Crawford has played in her family’s struggle against an implacable disease.

“He’s always on to the next thing,” she said. “I think he sleeps three hours a night. This army of volunteers and supporters have made this effort viable. What I learned is that people want to help. They just want to know how.” **AC**

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