

Mom Searching For Diabetes Cure

By JACOB GOLDSTEIN

Here is Dr. Norman Kenyon, retired surgeon, president of the University of Miami medical school's first graduating class, volunteering to operate on lab animals at UM's Diabetes Research Institute.

Here is Kenyon's 12-year-old diabetic granddaughter Laura Mauriello, padding



Dr. Norma Sue Kenyon, left, shows the insulin pump of her diabetic daughter, Laura Mauriello, which helps regulate her blood sugar.

barefoot across her living room floor, insulin pump clipped casually to her jeans. And here is Dr. Norma Sue Kenyon, daughter of Norman, mother of Laura, a senior scientist at the Diabetes Research Institute: now flying to California to court a corporate research partner, now pulling sterile blue paper slippers over pumps as she walks into her UM lab, now home in Pinecrest leaning over Laura's back, changing the needle that delivers her insulin.

Three generations, with Norma Sue Kenyon at the center -- the doctor's daughter, the diabetic's mother, the hard-driving scientist driving science to find a cure for the disease that nearly killed her baby daughter.

"I see everything in Norma Sue's life as it has evolved as being what it should be - what was meant to be," says Dr. Daniel H. Mintz, founder of the DRI and one of Kenyon's longtime mentors. "When Norma Sue speaks, she's speaking from the heart about her work and the hope that she'll change the future for her child and for other children."

'ALARMS WENT OFF'

Kenyon's daughter is diagnosed with Type-1 diabetes

Kenyon was born on Sept. 1, 1957, at Jackson Memorial Hospital, where her father was a surgical resident and her mother was a nurse. She went from Palmetto High to Duke University. She was married in 1985 -- it would end in divorce 10 years later -- and in 1986 finished a Ph.D. in immunology at the Medical College of Virginia.

She returned to Miami to do a fellowship with Mintz at the DRI, then went to work as a researcher at Coulter Corp. in Hialeah. By 1993, Kenyon had two daughters: Laura, 1, and Caroline, 4. She left Coulter that year and took a job as an associate professor at Duke.

Shortly after accepting the job, she flew from Miami to North Carolina for a weeklong trip to scout out her future lab; her kids stayed with family in Miami. On the last day of her trip, Kenyon learned Laura was in the intensive care unit and had been diagnosed with Type-1 diabetes.

"All my alarms went off," she says. "I knew that meant she was in a coma."

Before Kenyon boarded the plane to Miami, she called Mintz to tell him what had happened to Laura.

"Norma Sue," he said, "come home and help us find a cure for your daughter."

Six months later, she did.

A BIG LEAP

Lab work: Dr. Norma Sue Kenyon studies insulin-producing cells at the University of Miami.



Kenyon will head UM's translational research center

Kenyon's career has been, among other things, a 20-year effort to unite the intellectual challenge of academic research with the satisfaction of finding real-world uses for scientific advances.

"A lot of ideas die," she says. "You aren't trained as a scientist to take your idea, pursue it, prove it and then make it a product."

To save some ideas -- not just in diabetes, but throughout the university -- Kenyon has been appointed head of the new \$13-million Coulter Center for Translational Research at UM. The center, slated to open later this year, will house lab space and hire experts in subjects like regulatory affairs and clinical trials to help researchers steer their work from lab bench to bedside.

"It's really a huge leap from that mouse to a person, and getting there is more complicated and expensive than a lot of people realize," she says.

It's a leap Kenyon has come to know well as the DRI's director of pre-clinical research.

There are two main forms of diabetes. Type-2, also known as adult-onset, affects about 16 million Americans and is correlated with obesity and a high-sugar diet. Type-1, also called juvenile-onset, affects one million to two million and has not been connected to diet or weight. The work at the DRI focuses on Type-1.

In Type-1 diabetes the body, for reasons no one understands, begins to attack itself. The immune system destroys the insulin-producing pancreatic cells known as islets, leaving the body unable to metabolize sugar. As in Laura's case, the onset of the disease often goes unrecognized until the patient -- usually a child -- enters a critical state that can end in a coma or death.

After the initial crisis, the disease can be treated by injecting insulin one or more times a day. But, as the Lance Armstrong-esque wristbands now in vogue at the DRI say, insulin is not a cure. Decades of insulin therapy leave many patients with problems like deteriorating vision, nerve damage and kidney disease.

The grand project of the DRI is to cure Type-1 diabetes by giving diabetics islet-cell transplants from organ donors (and, perhaps ultimately, from stem cells).

The transplanted cells ideally begin producing insulin on their own, relieving the patient of the need to constantly monitor blood-sugar levels and inject insulin, and eliminating the long-term health problems of diabetes.

More than 30 patients have received transplants at the DRI in recent years, and many have remained off insulin injections. But getting a transplant carries a steep price: Taking powerful drugs that suppress the immune system to prevent it from attacking and destroying the new islets. The drugs, which must be taken for life, carry risks, including kidney and liver damage and susceptibility to illness and infection.



Research: Dr. Camillo Ricordi injects solution into an animal pancreas at UM's Diabetes Research Institute.

For most patients, including Laura, the risks of immunosuppressive drugs outweigh the risks of insulin therapy.

Kenyon studies ways to make immunosuppressive therapy more effective and easier on the body. Five years ago, a study she did in monkeys suggested a new drug might work much better, with fewer side effects. The research made national news; one headline called it the "best transplant news in 20 years."

"I honestly believed Laura would be transplanted soon," she says.

But months later, early trials in humans were halted abruptly when researchers realized the drug sometimes caused potentially fatal blood clots.

"That was like a train wreck," Kenyon says. "We were going 100 mph. I saw Laura getting transplanted at the end of the line. Then we got diverted."

IN A BETTER MOOD

Laura wished for death; now she wishes for horse camp

Laura, a precocious, articulate girl with long brown hair like her mother and a deep desire to go to horseback-riding camp this summer, doesn't seem to mind that her mother has yet to cure her disease.

"Diabetes isn't that bad," she says, listing her diabetes-management tasks like most kids list household chores -- check blood sugar every few hours, change the needle that supplies her insulin every few days.

It hasn't always been that easy, of course. The summer when she was 9, she began to realize what it meant to have diabetes.

"I wish I were dead," she told her mother again and again.

Kenyon could do little but hold her daughter in her arms.

"We'd cry together," she says.

Laura no longer tells her mother she wants to die. Instead, she tells her mother she wants to go to horse camp.

There are some camps for diabetics, but Kenyon hasn't found any that are horse camps. There is a place in Vermont, a horse camp run by a woman whose daughter has diabetes. That might be OK -- the woman would know what to look for, how to keep an eye on Laura.

But when Kenyon talks about sending her child to a camp 1,500 miles away, she's worried. Not worried like a high-powered diabetes researcher, or even worried like the parent of a diabetic, but simply, finally, worried like a mother whose baby girl is going out into the world.

"Vermont is so far away," she says.