

STORIES OF HOPE

Secrets of a 50-Year Survivor



Annette Richardson-Bienkowski

Annette Richardson-Bienkowski met about four dozen new friends two years ago when they all gathered in Boston to celebrate their shared accomplishment: surviving at least 50 years with type 1 diabetes.

"I looked at them all and almost cried," says Richardson-Bienkowski of New London, Conn. "The minute we met, it was so quiet. We just stared at each other and then some kept hugging each other. As kids in the 1940s or '50s, none of us knew anyone else with juvenile diabetes. We were treated as outcasts."

Now they are treated as living signs of hope and the source of possible answers to a cure for type 1 diabetes. Richardson-Bienkowski, like many of her new friends, has none of the complications associated with diabetes. Joslin Diabetes Center in Boston is studying 351 long-term survivors in the United States to determine genetic, environmental, psychological and physiological factors that may make them resistant to the destructive effects of diabetes.

"They're concentrating on us to find that magic thing that protected us for more than half a century," Richardson-Bienkowski says. "I want them so badly to find a cure. Not for me, but for the children with diabetes. I wouldn't know how to live without it."

She developed diabetes as a teen in England in 1958, taken by ambulance to a hospital with a prognosis of one day to live. When she didn't die, the doctors predicted a short life and advised that she live her remaining years in seclusion.

"I was told I should never leave my parents' home, I should never marry, I should never get pregnant," she recalls. "I broke all those rules. I wanted to do something in my short life."

Soon after her 21st birthday, she emigrated alone to America with one bottle of insulin, a glass syringe and the same stainless-steel needle she'd been using since the day of her diagnosis. She soon met an American man and decided to stay. She and her husband, John, have two daughters and three grandsons who would not exist if she had listened to doctors.

"God blessed me with two miracle drugs: insulin and laughter. Laughter has gotten me through an awful lot," she says.

In 2008 Richardson-Bienkowski received a 50-year survivor medal from Joslin, a teaching and research affiliate of Harvard Medical School, and joined its Medalist study. Joslin first began awarding 25-year medals to recognize individuals for their diabetes self-management in 1948. Joslin has presented 50-year medals to more than 3,000 people with type 1 diabetes since 1970 and 75-year medals to 34 survivors since 1996.

"As a Medalist, I like to tell what I call "The Other Side of the Story" because all one hears and reads about are the complications," Richardson-Bienkowski says. At last year's local Step Out: Walk to Stop Diabetes, she asked for a chance to speak after hearing a young girl with diabetes tell the crowd she wants a cure.

"I said, 'I am part of a study that is going to find a cure for you. I've had juvenile diabetes for 53 years, and it hasn't stopped me from living an active, adventurous life. I do everything I ever wanted to do.'

"The looks on their faces. They were stunned. They had no idea that someone could live that long with diabetes. Afterwards, parents and grandparents came over with tears in their eyes."

About 550 people who have lived with type 1 diabetes for 50 to 80 years have participated in the current phase of the Medalist study. Although the Medalists generally have good control of their blood glucose, it does not explain their remarkably low rate of complications:

- 43 percent had no advanced diabetic eye complications.
- 39 percent had no nerve disease.
- About 20 percent had no eye, kidney or nerve disease.
- 87 percent had no kidney disease.
- 52 percent had no cardiovascular disease.

The results suggest that other mechanisms may help protect Medalists from complications. Learning more about this group of people also may eventually help researchers develop ways to prevent diabetic complications.

Meanwhile, Richardson-Bienkowski is committed to spreading hope with her story, her participation in the Medalist study and her body, which she plans to leave to Joslin.

"I've already bequeathed every organ in my body to help figure out this miracle," she says. "That's my best gift to the children with diabetes." ▲

