



Bob Inglis
Islet Transplant Recipient

Life on Thin Ice

Midday on a sunny September afternoon, Bob Inglis and his wife Cathy are relaxing in the lounge area of 3G2, the transplant ward at the University of Alberta Hospital. Bob is looking positively chipper.

This wouldn't be particularly startling—Bob happens to be a gregarious, upbeat guy—except for the fact that he underwent a transplant procedure less than 48 hours ago. And two days before that, he was at his home in Halifax, completely oblivious to the series of circumstances that was about to hijack his life.

That day, around 4:00 p.m., Bob received a call from Edmonton, saying that there was a potential donor match for his second pancreatic islet transplant (he had been on a waiting list for several months). Six hours later, at 10:00 p.m., the Edmonton clinic called again to confirm the match. At 6:45 a.m. the next morning, Bob and Cathy were on a plane.

"We didn't go to bed that night," Cathy laughs. "It was just a whirlwind."

Their hectic preparations didn't prevent them from taking some time to reflect, however. Like any transplant recipient, Bob is keenly aware that his own good fortune came at the price of someone else's devastating loss. "You're excited to get the call, but you also have to consider that another family is grieving."

In the past year-and-a-bit, Edmonton's islet program has provided a 180-degree turn to what had been, up to then, an arduous journey for the Inglis family.

Type 1 diabetes was formerly called "juvenile diabetes," but Bob was a man in his early 20s when he was first diagnosed, in 1986. From the very beginning, he learned to take his condition very seriously. "When they stick you in a room, and the elderly guy next to you is blind, and the guy across the room from you is an amputee, you go, Oh, my, my," he recalls.

Bob did everything he could to correctly monitor and manage his disease. But, despite his best efforts, he eventually developed severe hypoglycemic unawareness—the complete inability to sense the often wild fluctuations in his blood sugar levels.

In the midst of a karate class (Bob is a martial arts enthusiast), the instructor might abruptly shut

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the class down. "He'd say, 'Everybody stop. We're not moving on until Bob checks his blood sugar.' I'd lie, I'd say, 'I'm fine—you guys are crazy!' I'd go check, and I'd be 1.1 [perilously low]."

The implications were much more ominous when Bob was alone. One day, he rolled his car, and was later unable to recall the events leading up to the accident.

Even though Inglis tested his blood sugars relentlessly—often 15 or 20 times a day—he still couldn't keep his diabetes under control. The stress became unbearable. "When you have hypoglycemic unawareness for a long time, it psychologically affects you—it has to."

Inglis uses a metaphor to describe his former life. "Every day I had to cross a frozen lake. The ice would be cracking under me and I didn't even know it. I would fall through—sometimes I could pull myself out, other times I had to rely on friends and family to help me. I would test and test and test, checking for cracks. There were always cracks and I felt I was always on thin ice. My diabetes was my life. Every minute, every day."

Even bedtime didn't bring respite. "My wife would go to bed beside me, not knowing if I would wake up."

Inglis had been reading media coverage of the Edmonton Protocol, but in the early years it was only available to local candidates. When the program expanded to include out-of-province patients, Inglis managed to pay his way to Edmonton for an assessment—and made it onto a waiting list.

By the time the call came for his first transplant—on June 23, 2010—Inglis had neared the end of his rope. In the previous month alone, he had had 13 hypoglycemic unawareness episodes. The first transplant produced virtually instant results. "I received close to 700,000 islets," he says. "Right away, my insulin intake went down, and my blood sugars began to level off. I went from 8–10 needles a day to about 3."

More importantly, Inglis noticed an abrupt change in his state of mind. "It's not the number of needles you take. It's about the quality of life and the freedom of not having to do that. "After a week, then two, then three, it was, like, this is incredible. I don't remember this, because it's been so long. I don't remember this feeling."

He also discovered his new membership in a very exclusive club. "I was number 127—the 127th person to receive the Edmonton Protocol," he says. "When I was in Edmonton, I met some amazing people—number 7, number 25. Everybody I spoke to was so passionate, and so overjoyed and overwhelmed by the procedure. Most of us, by the time we got our transplants, were close to death."

Now, fresh from his second transplant, Inglis is more grateful and enthusiastic than ever. "I sailed right through it this time," he says. "I'm feeling phenomenal."

Inglis feels particularly privileged to have received the procedure in the place where it began—complete with personal attention from a central figure in the Edmonton Protocol, Dr. James Shapiro. "Dr. Shapiro, and the whole team here in 3G2—they're all amazing."

Unfortunately, the treatment came at a price—literally. Unable to secure coverage from the Nova Scotia government, the Inglises had to foot the bill themselves. "The trip, when we add everything up, will probably cost us \$20,000," Bob says. Adds Cathy, "And that's with the medication being covered by my insurance."

Although he doesn't regret a penny he spent, Inglis recognizes that many other Canadians could never afford a similar outlay. Because of that, he and Cathy intend to continue the battle for government funding.

"It's one thing to celebrate what happened for us," says Cathy. "But if we're the only ones who can benefit, it's kind of unfair."

"I can't imagine not having the option of this treatment," Bob declares. "Without it, I wouldn't be here today."