



THE THREE FIRST'S in DIABETES CARE, 21 YEARS BEFORE DCCT

"First to advocate and perform blood glucose self monitoring"
"First to use a blood glucose self monitoring and bolus/basal insulin dosing to achieve tight control"
"First to publish a paper on reversing complications by tight control"

Being the first for anything in the medical field is not the easiest. As you will see, it took a great commitment and a desire to help others to achieve what Dr. Bernstein achieved.

We are proud to be friends with Dick would like to thank him for providing us with the materials to write this feature. We know you will find it interesting and informative.

We have made it a 3-week series, discussing the 3 first's. Included is the actual article on how tight control can prevent complications, that was finally accepted by Diabetes Care and also the rejection letters from NEJM, ADA, AMA and Lancet which stated that:

"No physician or patient would ever be interested in such a time consuming program of using a device to check blood glucose multiple times a day and adjusting insulin doses"

Part 1 will be, "First to advocate and perform blood glucose self monitoring"

Part 2 will be, "First to use a blood glucose self monitoring and bolus/basal insulin dosing to achieve tight control"

Part 3 will be, "First to publish a paper on reversing complications by tight control"

If you have any comments, please email us at publisher@diabetesincontrol.com

Part 1:

"First to advocate and perform blood glucose self monitoring"

There are a number of myths surrounding diet and diabetes, and much of what is still considered sensible nutritional advice for diabetics can over the long run be fatal. I know, because it almost killed me. I developed diabetes in 1946 at the age of twelve, and for more than two decades I was an "ordinary" diabetic, dutifully following doctor's orders and leading the most normal life I could, given the limitations of my disease.

Over the years, the complications from my diabetes became worse and worse, and like many diabetics in similar circumstances, I faced a very early death. I was still alive, but the *quality* of my life wasn't particularly good. I have what is known as Type I, or insulin-dependent, diabetes, which usually begins in childhood (ifs also called juvenile-onset diabetes). Type I diabetics must take daily insulin injections just to stay alive.

Back in the 1940s, which were very much still the “dark ages” of diabetes treatment, I had to sterilize my needles and glass syringes by boiling them every day, and use a test tube to test my urine for sugar. Many of the tools the diabetic can take for granted today were scarcely dreamed of back then — there was no such thing as a rapid, finger-stick blood sugar—measuring device, nor disposable insulin syringes. Still, even today, parents of Type I diabetics have to live with the same fear my parents lived with — any morning they could try to wake up their child and discover him dead. For any parent of a Type I diabetic, this is a real and constant possibility.

Because of my chronically elevated blood sugar levels, and the inability to control them, my growth was stunted, as it is for many juvenile-onset diabetics, even to this day.

Back then, the medical community had just learned about the relationship between high blood cholesterol and vascular (blood vessel and heart) disease. It was then widely believed that the cause of high blood cholesterol was consumption of large amounts of fat. Since many diabetics, even children, have high cholesterol levels, physicians were beginning to assume that the vascular complications of diabetes — heart disease, kidney failure, blindness, et cetera — were caused by the fat that diabetics were eating. As a result, I was put on a low-fat, high-carbohydrate diet (45 percent of calories were to be carbohydrates) before such diets were advocated by the American Diabetes Association or the American Heart Association. Because carbohydrate raises blood sugar, I had to compensate with very large doses of insulin, which I injected with a 10 cc “horse” syringe. These injections were slow and painful, and eventually they destroyed all the fatty tissue under the skin of my thighs. In spite of the low-fat diet, my blood cholesterol remained very high. I developed visible signs of this state — fatty growths on my eyelids and gray deposits around the iris of each eye.

During my twenties and thirties, the prime of life for most people, many of my body’s systems began to deteriorate. I had excruciatingly painful kidney stones, a stone in a salivary duct, “frozen” shoulders, a progressive deformity of my feet with impaired sensation, and more. I would point these out to my diabetologist, but I was usually told, “Don’t worry, it has nothing to do with your diabetes. You’re doing fine:’ But I wasn’t doing fine. I now know that most of these problems are commonplace among those whose diabetes is poorly controlled, but then I was forced to accept my condition as “normal:’

By this time I was married. I had gone to college and trained as an engineer. I had small children, and even though I was not much more than a kid myself, I felt like an old man. I had lost the hair on the lower parts of my legs, a sign that I had developed peripheral vascular disease — a complication of diabetes that can eventually lead to amputation. During a routine exercise stress test, I was diagnosed with cardiomyopathy, which is a replacement of muscle tissue in

the heart with fibrous (scar) tissue — a common cause of heart failure and death among those with Type I diabetes.

Just as the disease had taken its toll on my parents, it also took its toll on my wife and children. Even though I was “doing fine,” I suffered a host of other complications. My vision deteriorated; I suffered night blindness, microaneurysms (ballooning of the blood vessels in my eyes), macular edema (swelling of the central portion of my retinas), and early cataracts. Just lying in bed caused pain in my thighs, due to a common but unpronounceable diabetic complication called ilio-tibial band/tensor fascia lata syndrome. Putting on a T-shirt was agonizing because of my frozen shoulders.

I had begun testing my urine for protein and found substantial amounts of it, a sign, I had read, of advanced kidney disease. In those days — the middle and late 1960s — the life expectancy of a Type I diabetic with proteinuria was five years. Back in engineering school, a classmate had told me how his nondiabetic sister had died of kidney disease. Before her death she had ballooned with retained water, and after I discovered my own proteinuria, I began to have nightmares of blowing up like a balloon.

By 1967 I had these and other diabetic complications and clearly appeared chronically ill and prematurely aged. I had three small children, the oldest only six years old, and with good reason was certain I wouldn't live to see them grown.

At my father's suggestion, I started working out daily at a local gym. He thought that if I were to engage in vigorous exercise, I might feel better. Perhaps exercise would help my body help itself. While I did feel slightly less depressed about my condition — at least I felt I was doing something — I couldn't build muscles or get much stronger.

After two years of pumping iron, I remained a 115-pound weakling, no matter how strenuously I worked out. It was at about this time, in 1969, that my wife, a physician, pointed out to me that I had spent much of my life going into, experiencing, or recovering from hypoglycemia, which is a state of excessively low blood sugar. It was usually accompanied by fatigue and headaches. During these episodes, I became confused and unruly and snapped at people. The strain on my family was clearly becoming untenable.

Suddenly, in October of 1969, my life turned around.

I had been the research director of a company that made equipment for hospital laboratories, but recently I had taken a new job as an officer of a housewares corporation. I was still receiving trade journals from my old field, and one day I opened the latest issue of a publication called *Lab World*. I came upon an advertisement for a new device to help hospital emergency rooms

distinguish between unconscious diabetics and unconscious drunks at night when laboratories were closed. Knowing that an unconscious person was a diabetic and not drunk could easily help hospital personnel save his life. What I stumbled upon was an ad for a blood sugar meter that would give a reading in 1 minute, using a single drop of blood.

Since I'd been experiencing low blood sugars, and since the tests I had been performing on my urine were wholly inadequate (sugar that showed up in the urine was already on its way out of the bloodstream), I figured that if I knew what my blood sugar levels were, perhaps I could catch and correct my hypoglycemic episodes before they made me disoriented and irrational.

I marveled over the instrument. It had a 4-inch galvanometer with a jeweled bearing, weighed 3 pounds, and cost \$650, which in those days could have been a month's salary. I tried to order one, but the manufacturer wouldn't sell it to patients — only to doctors and hospitals.

Fortunately, my wife, as I've said, was a physician, so I ordered one in her name. I started to measure my blood sugar about 5 times each day, and soon saw that the levels were on a roller coaster. Engineers are accustomed to solving problems mathematically, but you have to have information to work with. You have to know the mechanics of a problem in order to solve it, and now, for the first time, I was gaining insight into the mechanics and mathematics of my disease. What I learned in my frequent testing was that my own blood sugar levels swung from lows of under 40 mg/dl to highs of over 400 mg/dl about twice daily. A normal blood sugar level is about 85 mg/dl.* Small wonder I was subject to such vast mood swings.

In an effort to balance my blood sugar levels, I began to adjust my insulin regimen, and went from one to two injections a day. I made some experimental modifications to my diet, cutting down on the carbohydrates to permit me to take less insulin. The very high and low blood sugar levels became less frequent, but few were normal.

Although most medical journals and textbooks throughout the world measure blood glucose in mmol/l (millimoles per liter), most physicians, laboratories, and blood glucose meters in the United States measure blood glucose in mg/dl (milligrams per deciliter). Since you will be monitoring your own blood sugar levels with one of these blood glucose meters, blood glucose values in this book will as a rule be given in mg/dl. If you should need to translate from one to the other, 1 mmol/l = 18 mg/dl.

Three years after I started measuring my blood sugar levels, my diabetic complications were still progressing, and I was still a 115-pound weakling. My sense of gaining insight into the workings of my diabetes had diminished, and so I ordered a computer search of the scientific literature to see if exercise

could prevent diabetic complications. In those days, computer searches were not the simple, almost instant searches they are today. In 1972 you made your request to the local medical library, which mailed it to Washington, D.C., where it was processed. It took about two weeks for my \$75 printout to arrive.

There were quite a few entries of interest, and I ordered copies of the original articles. For the most part these were from esoteric journals and dealt with animal experiments. The information I had hoped to find didn't exist. I didn't find a single article pertaining to the prevention of diabetic complications by exercise in humans.

What I did find was that such complications had repeatedly been prevented, *and even reversed*, in animals. Not through exercise, *but by normalizing blood sugars!* To me, this was a total surprise. All of diabetes treatment was heavily focused in other directions, such as low-fat diets, preventing severe hypoglycemia, and preventing a potentially fatal extreme high blood sugar condition called ketoacidosis. Thus it had not occurred to me that keeping blood sugar levels as close to normal as possible for as much of the time as possible would make a difference.

Excited by my discovery, I showed these reports to my physician, who was not impressed. "Animals aren't humans' he said, "and besides, it's impossible to normalize human blood sugars:" Since I had been trained as an engineer, not as a physician, I knew nothing of such impossibilities, and since I was desperate, I had no choice but to pretend I was an animal.

Next week: Part 2: "First to use a blood glucose self-monitoring and bolus/basal insulin dosing to achieve tight control"