

Guest Editors' Note: *Edwin Jacob "Jake" Garn is a man who has many titles. He is a graduate of the University of Utah, a Navy Pilot, a former Mayor of Salt Lake City, a Retired Brigadier General in the Air National Guard and a three term United States Senator (retired). His newest title is Vice Chairman of Huntsman Corporation. However, of all of his titles, there are two that he values the most. They are astronaut and kidney donor. In 1985 he orbited the Earth 109 times as a crew member on the Space Shuttle Discovery. The following year, he donated a "space" kidney to his daughter, Susan, who suffered from diabetic nephropathy. He always emphasizes that the one title he does not have is doctor. Nevertheless, during his life he has learned a great deal about medicine, especially nephrology. Senator Garn discussed his unique experience and perspective on diabetes and kidney disease, in a talk to the Forefronts audience, entitled "What doctors don't know about kidneys." His remarks were so well received that we included an abbreviated version in the proceedings of this Symposium issue.*

What doctors don't know about kidneys

SENATOR JAKE GARN

In the summer of 1969, my wife and I were concerned about our daughter. She had been sick for several days and, at first, we thought it was just the flu, so we were not very worried about her. However, on a Sunday evening she became very ill in church. We took her home and decided that this was something more serious and that we should take her to the doctor. My wife took her the next morning. I was at work when the phone call came. She said, "Honey, you've got to come and meet me at Primary Children's Hospital immediately." I said, "What's wrong?" She said, "Sue has diabetes." I said, "I hate to admit my ignorance, but I'm really not sure what diabetes is all about." She said, "I don't have time to talk to you. We don't have time to go home. Meet me there!"

I'll never forget walking into the hospital—scared, not quite knowing what was going on—walking up to the admitting desk and saying, "Here is my insurance card. What forms do I fill out to get her admitted?" This woman said to me, "Mr. Garn, don't you think you ought to be with your daughter?" I said, "Well, yes, I do." She said, "Go with her. She's only ten years old and she needs both her mom and dad with her."

We had quite an education about diabetes during those few days in the hospital. We learned about its causes, the problems that go with it and, most importantly, how to treat a diabetic and how to give insulin shots. Even with all the explanations in the hospital, I'm not sure we were really quite prepared for what was going to take place in the future. I'll never forget one doctor who said to us, "Well, you don't need to worry about the side-effects of diabetes with this child. She's ten years old, and by the time she is an adult, I feel certain we will have a cure. We'll be able to handle it so that, even if we don't have a cure, we'll be able to prevent the side-effects of diabetes." So we really weren't concerned about the long-term future for Sue.

We had her under good control through the first few years. Then she reached a point, which we were warned about, of denial, when she didn't want to be different anymore. She would cheat, and didn't want to tell her friends that she had diabetes, so she would eat things that she should not and not be as precise about her testing as she should be. So we went through a period of diabetic comas and insulin shock. We were in and out of the hospital occasionally to get her regulated.

Those teenage years were very, very difficult, but by the time she was in her late teens, of course, she realized her health was much

more important than what her friends thought. She brought herself under good control. She took responsibility for always giving herself shots, testing often, etc. However, even though she was under very good control during her early twenties, she started to have problems both with her eyes and with her kidneys. Eventually, she lost the sight of one eye as well as having both her kidneys fail. I was very grateful that I was found compatible and for the opportunity that afforded me to donate a kidney to her.

I'm often asked what is the most important thing that I've ever done in my life. People almost always assume that it is either being a United States Senator or having been an astronaut. Believe me, being an astronaut is far more important than being a United States Senator. I spent five months at NASA with people who knew what they were doing and then I had to return to the U.S. Senate. But both of those achievements in my life fade into absolute meaninglessness compared to the opportunity I had to give my kidney to my daughter. She does have the only transplanted "space kidney" on earth. No one else has one. When I look at her . . . when I look at her children sitting on her lap and realize what a fine mother she is . . . and think that my kidney is keeping her alive, *that* is the most important thing this human being has ever done in his life.

I feel badly that we haven't made more progress in curing this disease. I realize that there are a lot of great people who are doing research in trying to solve these problems with diabetes. Sometimes I feel like it's academic to them and I hope they can understand, in their labs, what they are doing for the patients and for the families of the patients. They don't meet them face-to-face the way a clinical person does. They don't see or experience the agony we go through: not just the patient, but the brothers, sisters, parents, and grandparents. It's a disease that affects everyone.

So, I hope all you professionals in research understand what your work can mean to the patients, to the practicing physicians who treat them, and also to the families who live with this kind of disease, difficulties and problems day after day. It is work that I encourage you to pursue so that someday kidney transplants are not necessary anymore, that eyes and sight are not lost, that we reduce the death rate and come to the promise that doctor made me 27 years ago as a young father, that we wouldn't have to worry about the side-effects of diabetes anymore and, more importantly, someday to find the cause of diabetes and prevent it from happening.