



Ilyce Randell

Efforts to the max

By Pauline Yearwood

If you're looking for someone who exemplifies the adage that one person can change the world, Ilyce Randell is your woman.

She has, at least, changed the course of a disease and given dozens of Jewish parents hope where there once was none.

Randell's extraordinary efforts began eight years ago, shortly after she and her husband Mike had their first child. By the time baby Max was four months old, the Randells were seeing signs that something was wrong, and doctors put him into the hospital for a series of tests.

The results were devastating. Max had Canavan disease, a rare Jewish genetic disorder in which the body lacks an enzyme needed to create myelin, the substance that forms a sheath around nerve fibers. (Canavan can appear in non-Jews, but is far more prevalent among the Ashkenazi Jewish population.)

Doctors told the family that the disease "would literally destroy Max's brain until there's nothing left," Randell recalls. Max would "become a vegetable" and die before he was four years old, they said. The family was advised to consider placing him in a pediatric nursing home. Canavan, medical authorities said, was in "a class of disease so rare there's no treatment (research) going on. There's really nothing you can do," Randell recounts.

The next few months "were sort of a blur," she says. "I remember looking at our apartment building and wishing a bomb would hit it and everyone would be destroyed-that would be easier than the road we had ahead of us."

That mindset didn't last long. "We decided, if there was nobody doing any kind of work for this disease that we would raise money and find people, we would go wherever we had to go and do whatever was necessary," she says. Her efforts would not be focused on Max alone but on other families with children with Canavan and related disorders. Most of them, too, had lost all hope, Randell discovered through Internet forays.

She found a gene therapy trial that might have benefited Max and other Canavan children, but it was running out of money. "If we wanted Max to be treated, we had to raise enough money to keep the entire lab going, so that's what we did," starting with a fund-raising letter to friends and family members, Randell says. Those efforts raised \$50,000 and led to the formation of Canavan Research Illinois, a charity devoted to developing treatments and funding research for the disease as well as increasing public awareness. Randell continues to run the organization (www.canavanresearch.org), which has now raised more than \$1 million.

As for Max, he has had two gene therapy treatments-at 11 months, he was the youngest person in the world to receive the cutting-edge therapy for a brain disease-and has far surpassed his doctors' expectations. At eight, he attends special ed classes while spending part of the day in a mainstream classroom.

"Cognitively he is very very bright," his proud mother says, noting that he can operate a computer with his eyes, manipulate the joystick for his motorized wheelchair ("other kids think that's very cool") and communicate effectively by blinking his eyes and using them to "point" to what he wants. He can say a few words as well. Most importantly, Randell says, he is a happy, loving child with "a magnetic personality."

The Randells also have a three-year-old, Alex, who does not have Canavan but is a carrier of it. Randell has been instrumental in efforts to make sure that before they have children, Jewish parents are tested for Canavan and 10 other genetic diseases.

Today, Randell's days are filled with fund-raising, networking with other parents, lobbying and overseeing educational efforts, all designed to increase public awareness about Canavan and similar diseases. For her efforts, U.S. Sen. Dick Durbin called her a "profile in courage." And the impetus for her always comes from Max, who works so hard at all his tasks that a therapist once said that "if trying made it so, Max would be president."

"He makes me work harder," his mom says. "I think, if he can do this, I can certainly raise a million dollars. It can't be that hard."