



Lilly Jaffe

Lilly Jaffe, of Chicago, Illinois, was diagnosed with type 1 diabetes more than twelve years ago, at the tender age of one month.

What has happened to Lilly during her sixth year of life is remarkable.

In 2006, her parents Laurie and Mike—longtime JDRF volunteers—had attended the annual meeting of JDRF's Illinois Chapter, where Dr. Louis Philipson, of the University of Chicago, presented. He mentioned a study out of the U.K. that showed that some children diagnosed with diabetes in their first six months of life actually don't have type 1 autoimmune diabetes, but instead have diabetes characterized by a rare genetic mutation that can be treated with a common oral medication.

Mike approached Dr. Philipson and told him about Lilly—who had been on a pump for years by then. Since she fit the profile with her early diagnosis, she took a simple, saliva DNA test. The results came back in a few days—Lilly was positive for one of these rare mutations.

A month after that, Lilly was admitted to the University of Chicago's Clinical Research Center to begin a week-long program to see if the oral treatment could work for her. She began a small dose of the medicine and her insulin dose was cut in half. Over the course of the week, her oral medication was increased each day, and her insulin dose was decreased. After a week, tests began showing that, indeed, Lilly had begun to produce insulin on her own—for the first time in her six and half years of life!

The Jaffes left the hospital that night—with Lilly still on a pump, but using dramatically less insulin. About five days later, the pump came off, and Lilly had taken the last insulin shot she'll ever need.



Lilly's Law

After hearing the story about Lilly, Illinois Rep. Tom Cross (R-Oswego) worked with the University of Chicago to come up with legislation that sets up a 3-year pilot program that will create the neonatal diabetes mellitus registry program. "I want to commend U of C's Dr. Louis Philipson, Director of the Kovler Diabetes Center and his colleague Dr. Graeme Bell for all of their efforts in this cause and their tremendous help and expertise in this area," said Cross.

Lilly's Law will require physicians and other healthcare providers around the state to report certain information to the Department of Public Health regarding patients with diabetes mellitus with onset before 12 months of age. The information will be compiled in a registry for research.

"Monogenic diabetes is rare but life-changing when diagnosed. Helping people move from insulin to pills is incredibly satisfying and we hope a taste of things to come for the majority of people with diabetes" said Philipson.