Testimony of

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From

New York, New York

At the Hearing entitled:

"Redefining Reality: How the Special Diabetes Program is Changing the Lives of Americans with Type 1 Diabetes"

Wednesday, July 10, 2019, at 9:30 a.m.

Before the

United States Senate Special Committee on Aging

Dirksen Senate Office Building, Room 106

Washington, D.C.

Chairman Collins, Ranking Member Casey, and members of the Committee, thank you for inviting me to testify today. It's an honor to be here with delegates from the JDRF 2019 Children's Congress.

I was diagnosed with Type 1 Diabetes when I was 11 years old. It's been nearly 60 years, but I remember vividly that my diagnosis was a traumatic event for my family, and especially for my mother. I have a distinct memory of her standing on the porch as my father drove me to the doctor. The fear and desperation in her eyes remains an indelible image in my mind.

Whenever I meet the mother of someone with Type 1, I am brought back to that moment, to that confusion, panic, and uncertainty, which is why I am so determined to do everything I can to help find a cure for this disease. I am here today, with these amazing delegates, to implore you to keep supporting advances in Type 1 research, by supporting a long term renewal of the Special Diabetes Program.

After my diagnosis, I was kept in the hospital, where I learned to inject oranges with insulin syringes, until I was brave enough to try it on myself. My new, and confusing diet consisted of weighing food, on a small scale, and deciphering carbohydrate ratios, which I'm still guessing at today. In those days, we had to boil syringes to ensure sterility, and test blood sugar levels, with urine in a test tube. We've come a long way.

And as I adjusted to my new reality, I was determined that I would not be deterred from living the life I envisioned. When I was 16, I left home to pursue my show business dream. I was a folksinger, dishwasher, and played tiny parts on TV shows and movies. Hard enough for any teenager, but balancing blood sugars, with inexplicable highs and lows, making healthy food choices, getting proper rest, could take its toll. I can only say, that determination, and will, kept me from giving up.

Thanks in large part to the Special Diabetes Program, living with Type 1 Diabetes today is very different than back when I was a teenager. My access to amazing diabetes technology, like a continuous glucose monitor, that can be used with different types of insulin pumps, gives me constant information to help avoid blood sugar highs and lows, and I'm so fortunate to be able to afford insurance that allows me to choose the best insulin pump and glucose monitor for my specific lifestyle.

My anxiety level has decreased somewhat since those days. Living an erratic life in movies, television and theatre has become more manageable thanks to funding for the Special Diabetes Program which made all these things possible. However, it is imperative that Congress provides a long term renewal of the program, which will ensure that critical research can continue unimpeded and enable more life-changing breakthroughs for the children you see here today.

Finally, I would be remiss if I did not tell you how concerned I am about the skyrocketing cost of insulin. The idea that someone has to ration insulin in 2019, due to greed and avarice, is unconscionable. No mother in the U.S. should lose her son due to insulin

rationing, and no father should have to rely on buying insulin from Canada to keep his child alive. I am lucky to have good health insurance, but I am still paying far more than I should be, for the life-saving drug that I would die without. Senators, this is simply unacceptable. Dealing with Type 1 Diabetes is already hard enough. Chairman Collins, Ranking Member Casey, Senator Shaheen, and others of this committee, I want to thank you for addressing the insulin pricing issue head on, and beg you to keep up the fight to bring down these costs.

As you do, please keep up your commitment to the research, our community desperately needs to find a cure for Type 1 Diabetes. We need you to keep the momentum going by renewing the Special Diabetes Program before it expires at the end of September, and put it on stable funding for years to come. If you do that, you will make it easier for all these delegates to live their dreams and enable them to thrive without the fear of Type 1 Diabetes holding them back.

Thank you Chairman Collins, Ranking Member Casey and Members of the Committee for your support and your time today.