Allyson Gordon
28 Sprague Avenue
Lincoln, RI 02865
(401) 787-0596
ally174@verizon.net

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The Honorable Susan Donovan
Chair, House Committee on Health & Human Services
State House
82 Smith Street
Providence, RI 02903
RE: H7075, H7188

Dear Chair Donovan and Members of the Committee:

My name is Allyson Gordon. I am the proud mother of a remarkable individual who has been fighting type-1 diabetes for the past 18 years after being diagnosed at 17 months old.

I am writing to seek your support of House Bill No. 7075, The Matthew Federico Diabetic Safety Act, as well as House Bill No. 7188. Both of these bills would allow those living with type-1 diabetes to access the vital supplies needed to maintain the daily care required of this chronic condition.

Type-1 diabetes is a relentless and cruel chronic disease. It is an autoimmune disease that renders those diagnosed completely reliant on outside insulin to survive. Before Frederick Banting and Charles Best produced what many had been working on for years, those with this disease were put on starvation diets that would eventually result in death within a few years. The discovery of insulin was truly the difference between life and death for those with type-1 diabetes. As remarkable as insulin is, however, type-1 diabetes still requires around the clock care and monitoring 24 hours every day. At any given point in time, severe low or high blood sugars could result in dangerous conditions. Luckily, advancements such as continuous glucose monitoring and glucagon have made it possible to safely manage such conditions. Unfortunately, such equipment is often unattainable due to cost.

When insulin was first developed, Banting sold its patent for $1. According to Banting, this was done because, " Insulin does not belong to me, it belongs to the world." Yet, as many advances as we have seen since that time, the reality has become that obtaining the necessary equipment to safely manage and survive type-1 diabetes no longer "belongs to the world", but instead belongs to only those who can afford it.

No one should be denied the right to obtain necessary equipment to safely manage this disease. Glucagon and continuous glucose monitoring are as essential to managing diabetes as insulin.

Living with type-1 is exhausting and relentless. Thanks to organizations such as Camp Surefire, which provided my daughter support, education, and resources at a critical time in her teen years, those with this disease understand they can live long, productive and rewarding lives. However, this is only possible with access to critical equipment. Over the course of the last 18 years of helping my child manage type-1, both of these things have been critical in allowing her to participate in society as a productive member and manage her condition without unnecessary trips to the ER. Such trips would only put a strain on an already overwhelmed health care system. Without access to such equipment, my daughter would have even greater risk of long-term complications down the road. Such complications would surely come with a cost, both a personal one to her and additional strain on our system.

Please help to pass those bills that would allow all of those diagnosed with type-1 to have access to critical devices such as continuous glucose monitoring and glucagon. After all, critical care in order to manage this disease should "belong to the world".

Sincerely,

Allyson Gordon

Former Outreach Coordinator for JDRF

Mother of 2011 Children's Congress Representative

Lincoln, RI