

Proponent Testimony

For

Ohio HB 37

134th General Assembly

Thank you to Chairman Lippus, Vice Chair Holmes, Ranking Member Russo, and members of the House Health Committee.

My name is Mirna (Malinar) Funkhouser. I am the mother of a type 1 diabetic, who was diagnosed at the age of 10 in 2011, on Veterans Day. I always find this almost like a sign from above, that day honors our warriors and veterans, but we celebrate the yearly anniversary and that my son Justin is still alive.

Being a parent is difficult enough and a job of its own. Having a child with type 1 diabetes is a 24 x 7 x 365 days a year job keeping them alive. Many families have multiple. The day Justin was diagnosed our lives changed forever. My career as a prominent business consultant was done, and my children were put first, Justin has 2 older brothers. Divorce was another challenge. The last numbers I saw from 2018 Ohio ranks as one of the highest states in divorce, and 70% of the children are male between the ages of 13-18 years old. I mention this because 59% of T1D families divorce because of the financial burdens and losses of home, retirement and savings, and they lose more the time with the family. Your life becomes obsessed, many parents suffer PTSD. And we have nothing left. We are officially in the poorest of all poverty levels.

Now bring into the mix all of the external challenges; bullying at school, many children have a second dx of being in the quadrant ADHD or Aspergers; siblings take a second seat, groceries increasing by \$200 a week for special low or high snacks, insurance OOP increase. One parent typically will go part time and eventually just work at home if they can.

We as parents **must follow state law** and protect our children otherwise, we can be charged with domestic violence, medical neglect, medical assault and in the middle of an CS investigation. Notably Ohio law note INSULIN an no other medication in law for Medical assault, and neglect or domestic violence. I find this interesting, that this is law, yet we have a HB37 which needs passed to enforce that law on others in this state. If not, then everyone who is against the law or does not enforce it would in fact be charged with the above charges.

INSULIN...a very powerful word. It is life and if given too much it is death. Without it you die. There is NO middle ground at all. It does not go away. So the same drug to save your life can also kill you.

We started “The Be A Part Of It Foundation” and “Camp Time Kids” program in Ohio and now sitting in the US with 17 sites. We are not funded by the government it is all volunteer. Our goal is to reach this generation right now and bring them to a level that they can advocate for themselves. Help others who are diagnosed later in life after college or during college, these kids had camp and a second family.

They have parents who work together for the same common cause. To keep our children alive and without any complications from this disease fill of insulin. To build a structure of support for them and with their testimony today we all arrive at the same conclusion...there is no debate it must be done to protect our future generations.

Kevin’s law protected us in a high level that we could get a prescription for 72 hr emergency use That is a current miracle I have yet to see in Hb188 Kevin’s Law, give a 72 hr amount of insulin from a vial or pen to the patient, absolutely impossible I have brought an example of a pen and vial. I also, if you can see this picture (I show the boxes stacked in various arrays) these are the insulin’s that are available, the more common ones. This pile you see here is enough to buy a house at sheriff auction and refurb it, pay for 4 people on a trip around the world or purchase a brand new Ford Escape for cash. This very small pile.

The cost of insulin and supplies to keep our children alive is more than a mortgage with interest 4.25%, property taxes and property insurance on a 42000 square feet , 5 bedroom home on prime acreage. That is just not right, ad they need this

protection from when they graduate college, they will have student loans, a house or apartment and insulin to pay for. Guess which gets paid for first.

They are afraid, and you hold that fear in your hands. As representatives that we voted in, your duty is to protect the future generations. I hope you take the time to get to know the sampling we have here today. Watch video we have from their scholarship applications. Note: get a hanky out.

The proposed HB 37 allowing 3 months during a 12 month period for an emergency insulin refill is a minimum at best that you as our representatives should approve. I highly doubt that you can put a price on the head of a person to keep them alive when the alternative is millions in long term care dialysis, coma, brain trauma, loss of executive functions, and then death. Reduce long term complications and care in the billions that are being paid out now when insulin rationing occurs.

I can run off the top of my head a situation that you would ask and bring back why that would not work. Do you know why I know these answers., Because it takes after an insurance change to move everything over and get pre approvals and new prescriptions and overrides 30 days; that is 8 hrs a day on the phone (they close at 4) between, the Endo, DME, Old insurance and New insurance. That is one month alone NO INSULIN. One year I had to do this 7 times in one year. I have a flow chart on my wall, because it is a repeat every day. I then decided to get my Ohio insurance license for health, Life and accident and medical to get the skinny. Boy did I find out the waste.

First, the commissions paid are 50-70% of the premiums to the salespeople. One way to cut.

Second, the State of OHIO has sued Caremark and the PBM's that robbed Medicaid and Medicare and over charged for these into the upper 6 figures, hence the contract with CareMark in Ohio was cancelled for state programs. Use the lawsuit money put it into a program for and disease management code and they can use those funds to pay for this SO CALLED free insulin.

Many people say just go to the ER and get insulin, well that is true they will put you on a drip, then send you home and throw away the vial that was left over from your

hospital visit, then bill \$18k to the insurance. Now does anyone here not see where this is going. (stop and breathe)

Third, make each company establish a portion of their profits (insurance MCP's inclusive), that allocates a percentage of their funds for these medications to be used to offset the cost of the emergency refills. They will still be millions in the plus.

In Closing

We owe this next generation of leaders, individuals who do not let Type 1 diabetes stop them. They carry more on their shoulders than any child or young adult should. But the weapon of fear that has been placed into their minds because of the need to ration insulin, it is absolutely the worst torturer this state could put a child through. It stops them from moving out of the own, getting a decent job they work several, being independent. The fear needs to stop so they are on equal ground and can afford an education home, and a family one day; without rationing and dying from DKA.

There are many reasons an emergency refill of 3 months is needed:

1. No insurance
2. Insurance changes so down one month
3. New job 60 day holding many going to 1 year before benefits
4. High Out Of Pockets for the formulary
5. A reduced insulin prescription
6. Broken insulin vial
7. Stolen insulin and emergency pack and pump (this is a big bully thing in schools and a federal crime since the value is over \$15000 of equipment they wear on their body)
8. Travel forget at home on counter
9. Needing to keep one vial and 2 pens at school per your 504 plan, in cases of lockdown or you pump stops working or you forgot the pack, Backups are

everywhere in the house, school, all cars and the bag on the back of the child. Some also on boats and in second homes they may frequent like grandparents for overnight.

10. Split families require supplies to each house

11. Homelessness

12. Death in jail because the insulin is in the car and the jail houses do not carry and are not trained.

13. Your luggage is lost for days when travelling

14. Forgetting at home before going for visitation to your other parent who has no supplies.

15. Sudden increase in insulin needs you run out sooner, usually because of growth spurts or being sick

As a passionate advocate for these children and a proud Ohio resident of 57 yrs. We have the strongest protections in school, we have law protecting these kids, we have BCMH, now we need to protect the families and these children when they become adults. Please DO NOT forget about our seniors, who are told sorry the insulin will be in in 2 weeks and it went up an additional \$400 a month. Medicare anything close to what Medicaid does for insulin.

You as a committee can stop this. You can save lives. Kevin's legacy and the work of the Houdeshells we can never be thank full enough for, it has eased some fears, We offer a \$20,000 4 year scholarship to a student in Ohio under Kevin's name, asking each applicant to commit to being part of the change, Now we are asking you to do the same it is your.

Thank you for your time, I want to thank the Southern JDRF and also Ohio #insulin4all for joining up with us as a team today and the families and young men and women starting their next journey in life for being here and sending in written testimony.

It was my pleasure to represent our future.

Best Regards,

Mirna (Malinar) Funkhouser

