Proponent Testimony on SB 37 – Lisa Boley Sponsors: Senators Craig, Manning Cosponsors Thomas, Yuko, Antonio

Chairman Hackett, Vice Chair Romanchuk, Ranking Member Craig, thank you for the opportunity to share proponent testimony on SB 220. I am for SB 220 that prohibits a health plan issuer from imposing cost sharing on a prescription insulin drug in an amount that exceeds \$35 for a 30-day supply.

My name is Lisa Boley. I am a mom to a type 1 diabetic child diagnosed at the age of 10. My husband is also a type 1 diabetic diagnosed at the age of 11. The cost of insulin is astronomical from approximately \$300 for a vial of insulin such as Humalog/Novolog or Lantus to approximately \$600 per box of insulin pens. I am reaching out to you regarding the high cost of insulin that can occur for the now standard workplace high max OOP insurance plans, for us that is \$13,000 a year since 2016. *From Wharton, "The share of employers offering only high-deductible coverage increased markedly from just 7% in 2012 to 24% in 2016.*¹ "Also key findings from Value Penguin, "Fifty-one percent of the workforce nationwide was enrolled in a high-deductible health plan in 2019²."

From T1international's 2018 access and supply survey found that 1 of every 4 US respondents have rationed insulin due to cost³. DKA, diabetic ketoacidosis is unavoidable if a T1D goes without insulin or not enough insulin with dehydration, ketones and high blood glucose unaddressed. The summer before my son was diagnosed with type 1 diabetes, flyers had gone up at my work. These flyers on the walls were for raising money for an employee's 13 yr. old son who had died. His son was a type 1 diabetic. This hit me hard as my husband is a type 1 diabetic and little did I know my son would be diagnosed that October. Insulin is life for a diabetic. Without insulin or even just the lack of enough insulin, diabetic ketoacidosis, DKA will be quick and can be deadly. For our situation with DKA, it took just 3 hours (9am to noon) sleeping in on a summer day and not eating for my son to go from being perfectly fine with good glucose readings at 9am to him needing help at noon with high glucose number and vomiting. We were able to push some fluids and insulin but still not enough that his breathing changed and was admitted to the ER at Rainbows Hospital for Children. It is scary to think that in just those few hours of not having enough insulin and being dehydrated how serious the situation became.

Rather than rationing insulin or going without insulin the cost of insulin should be addressed to avoid DKA. No child or adult T1D should die from DKA because they cannot afford insulin.

Sincerely, Lisa Boley

1: Types of insulin and Walmart regular insulin:

Physicians prescribe today certain types of insulins. There are reasons for the types of insulin, such as Humalog and Novolog and certain types of basal insulin. The reasons include reducing low blood sugars hypoglycemia (can lead to coma and death), better control of BG mg/dL standard deviations and better long-term health consequences.

When not being able to afford insulin, one might just say go get a bottle of Regular insulin from Walmart. It is extremely dangerous to switch types of insulin such as a rapid acting insulin to regular insulin or NPH for cost without serious understanding and knowledge of dosing. Each insulin type has a different peak, duration and onset that affects ICR insulin carb ratio, ISF insulin sensitivity factor, and basal dosing amounts of that specific insulin along with changing prebolus timing and on top of that the 42 plus factors impacting a T1Ds blood glucose on a day to day basis. Regular insulin is best for keto type diets such as 6-12 grams of carbs per meal Dr. Bernstein.

Types	of	Insu	lin
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Insulin type	How it is delivered	Expiration when opened	Onset	Peak	Duration
Rapid Acting					
Admelog	Pens and vials	28 days	15-30 min	30 min-2 ½ hours	4-5 hours
Afrezza inhaled powder	4, 8 and 12 unit Cartridges	3 days	3-7 minutes	12-15 min	1 ½-3 hours
Apidra	Vials and pens	28 days	10-20 min	30 min-1 ½ hours	2-4 hours
Fiasp	Vials and pens	28 days	15-20 min	1 ½- 2 hours	5 hours
Humalog, U-100 and U-200	Vials, pens, cartridges for refillable pen	28 days	10-20 min	30 min-1/12 hours	3-5 hours
Novolog	Vials, pens, cartridges for refillable pen	28 days	10-20 min	1-3 hours	3-5 hours
Short Acting **					
Regular	Vials and pens	31-42 days, depending upon brand	15-30 min	2 ½-5 hours	4-12 hours
U-500 (5x the concentration)	Vials and pens	28 days	30 min	4-8 hours	18-24 hours
Intermediate acting **					
NPH (created in 1946)	Vials and pens	31-42 days, depending upon brand	1-2 hours	4-12 hours	14-24 hours
Long acting					
Basaglar	Vials and pens	28 days	3-4 hours	No peak +	11-24 hours
Lantus	Vials and pens	28 days	3-4 hours	No peak +	11-24 hours
Levemir	Vials and pens	42 days	3-4 hours	No peak +	6-23 hours
Toujeo, U-300	Pen only	42 days	6 hours	No peak	24-36 hours
Tresiba, U-100 and U-200	Pen only	56 days	1 hour	9 hours	36-42 hours
Combination					
NPH/Regular 70/30	Vials and pens	31-42 d vial 10 d pen	30 min	50 min- 2 hours and 6-10 hours	18-24 hours
Rapid acting 70/30	Vials and pens	28 d vial 14 d pen	15-30 min	1-4 hours	18-24 hours
Rapid acting 75/25	Vials and pens	28 d vial 10 d pen	15-30 min	1-6 ½ hours	12-24 hours
Rapid acting 50/50	Vials and pens	28 d vial 10 d pen	15-30 min		

Endocrineweb.com



https://health.ucdavis.edu/livinghealthy/topic/diabetes/index.html



2: Why do the programs in place do not work to address the cost of insulin?:

Have you ever been to the pharmacy for prescriptions and been told that the costs are \$900 and \$1200? And have you ever walked away? I have.

- Two major pharmaceutical companies base their insulin assistance programs on FPL thus many people who work will never qualify.
- For another pharmaceutical company, a \$100 discount card on a \$300 monthly insulin prescription through insurance results in a cost of \$200 per month for only one type of insulin at \$2400/yr. My son is on two types of insulin, one is for basal and one is for boluses. Usefulness of discount cards depends on the negotiated rate with the insurance/PBM and the type of card whether it limits max cost or is a deduction.
- Discount cards and coupons are temporary but T1D is not temporary for my child.
- COVID assistance programs are temporary. (\$35 copay card or \$99 coverage for loss of insurance during COVID). For the first time we qualified for a discount card from one of these pharmaceutical companies.
- Discount cards cannot be used for government programs.
- We have had discount cards denied at the pharmacy over the years because of insurance or prescription.
- Coupons for example, GOODRx for Humalog are based on vial not monthly prescription. For Walgreens with GOODRx coupon, the cost goes from \$166 down to \$56.68 then times 3 for the number of vials at \$170.04/month. Or Walmart from \$165 to \$141.04 times 3 at \$423/month. Toujeo Max pen with GOODRx for CVS goes from \$613 to \$478.
- There are also requirements for 340B program. We go through UH regional which is part of Rainbows and have never been offered the 340B program but why would that happen if we are not uninsured or low income.
- I have bought insulin from Canada before at \$45 a vial of Humalog. Our Physician was kind enough to write the prescription 4 to 5 times trying different brands, different discount savings cards, different coupons, different durations as well as paper prescription to buy ultimately from Canada. We found insulin pens though to be just as expensive through Canada and not an option.
- Insulin Pens are even more expensive. We use vials for boluses and pens for basal in order not to mistakenly give the wrong insulin especially at 5 to 8 or more shots a day.



Factors That Affect BG

Food	Biological
↑↑ 1. Carbohydrate quantity	↑ 20. Insufficient sleep
→↑ 2. Carbohydrate type	↑ 21. Stress and illness
→ ↑ 3. Fat	22. Recent hypoglycemia
→ ↑ 4. Protein	→ ↑ 23. During-sleep blood sugars
→↑ 5. Caffeine	124. Dawn phenomenon
↓↑ 6. Alcohol	↑ 25. Infusion set issues
↓ ↑ 7. Meal timing	26. Scar tissue and
↑ 8. Dehydration	lipodystrophy
? 9. Personal microbiome	↓↓ 27. Intramuscular insulin delivery
Medication	↑ 28. Allergies
→↓ 10. Medication dose	↑ 29. A higher glucose level
↓↑ 11. Medication timing	↓ ↑ 30. Periods (menstruation)
↓↑ 12. Medication interactions	↑↑ 31. Puberty
↑↑ 13. Steroid administration	32. Celiac disease
14. Niacin (Vitamin B3)	↑ 33. Smoking
Activity	Environmental
→ ↓ 15. Light exercise	↑ 34. Expired insulin
↓ ↑ 16. High-intensity and	↑ 35. Inaccurate BG reading
moderate exercise	↓↑ 36. Outside temperature
→↓ 17. Level of fitness/training	17. Sunburn
↓↑ 18. Time of day	? 38. Altitude
19. Food and insulin timing	Behavioral & Decision Making
diaTribe	 ↓ 39. Frequency of glucose checks ↓↑ 40. Default options and choices ↓↑ 41. Decision-making biases ↓↑ 42. Family relationships and social pressures

3. **DKA**

Acidosis in **DKA** is due to the overproduction of β-hydroxybutyric acid and acetoacetic acid. At physiological **pH**, these 2 ketoacids dissociate completely, and the excess hydrogen ions bind the bicarbonate, resulting in decreased serum bicarbonate levels. Ketone bodies thus circulate in the anionic form, which leads to the development of anion gap acidosis that characterizes DKA<u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC151994/</u>National Center for Biotechnology Information

Note: Table below the β -hydroxybutyric acid μ mol/L level in DKA is 30 times higher than normal with a standard deviation of 850 μ mol/L. The acid which measured in the blood is traveling through the veins, organs and brain.

DIABETIC KETOACIDOSIS AND THE HYPERGLYCEMIC hyperosmolar state are the most serious complications of diabetic decompensation and remain associated with excess mortality. Insulin deficiency is the main underlying abnormality. Clinical diagnosis is based on the finding of dehydration along with high capillary glucose levels with or without ketones in the urine or plasma. The diagnosis is confirmed by the blood pH, serum bicarbonate level and serum osmolality. Treatment consists of adequate correction of the dehydration, hyperglycemia, ketoacidosis and electrolyte deficits.

The **acidity** or alkalinity of any solution, including **blood**, is indicated on the **pH** scale. The **pH** scale, ranges from 0 (strongly acidic) to 14 (strongly basic or alkaline). A **pH** of 7.0, in the middle of this scale, is neutral. **Blood** is **normally** slightly basic, with a **normal pH range** of about 7.35 to 7.45. <u>https://emedicine.medscape.com/article/118361</u>

	Normal range	Condition; mean (and SD)		
Parameter		DKA	HHS	
Sodium, mmol/L	136–145	134 (1.0)	149 (3.2)	
Potassium, mmol/L	3.5-5.0	4.5 (0.13)	3.9 (0.2)	
Blood urea nitrogen, mmol/L	2.8-7.9	11.4 (1.1)	21.8 (3.9)	
Creatinine, µmol/L	38-110	97.2 (8.8)	123.8 (8.8)	
Free fatty acids, mmol/L	0.4-0.7	1.6 (0.16)	1.5 (0.19)	
β-Hydroxybutyric acid, µmol/L	< 300	9100 (850)	1000 (200)	
Lactate, mmoi/L	0.50-2.2	2.4	3.9	
Insulin, pmol/L	35-145	90 (10)	270 (50)	
C-peptide, nmol/L	0.26-1.32	0.25 (0.05)	1.75 (0.23)	
Glucagon, ng/L	50-100	580 (147)	689 (215)	
Growth hormone, µg/L	< 5	7.9	1.1	
Cortisol, nmol/L	140-690	1609 (345)	1539 (490)	
Catecholamines, ng/mL	0.150-0.750	1.78 (0.4)	0.28 (0.09)	

"From 2000 to 2009, the age-adjusted rate of DKA hospitalizations among persons with diabetes fluctuated but declined at an average annual rate of 1.1%. During 2009–2014, however, the rate increased 54.9%, from 19.5 to 30.2 per 1,000 persons, at an average annual rate of 6.3%.⁴"

One sign of DKA is Kussmaul breathing which is "using deeper, longer breaths, the lungs can expel more acidic carbon dioxide than normal. Because Kussmaul breathing is a sign of severe metabolic acidosis, which is life threatening condition, hospitalization is usually necessary⁵." You can enter the world of a

T1D parent and child through viewing the training video below on Kussmaul breathing from Augusta University Medical College of Georgia for doctors and nurses. This is a courageous mom to allow others to learn. Warning it is upsetting to watch as a parent but this is DKA, this is T1D. https://www.youtube.com/watch?v=raEKXVfuWTo

¹ https://knowledge.wharton.upenn.edu/article/high-deductible-health-plans-pros-and-cons/

² https://www.valuepenguin.com/enrollment-changes-to-high-definition-health-insurance-plans#:~:text=%20Fifty-

one%20percent%20of%20the%20workforce%20nationwide%20was,in%20the%20percentage%20of%20workers%20enrolled%20in%20HDHPs 3 https://beyondtype1.org/type-1-diabetes-statistics/

⁴ Trends in Diabetic Ketoacidosis Hospitalizations and In-Hospital Mortality — United States, 2000–2014 | MMWR (cdc.gov)

⁵ Kussmaul breathing: Symptoms, causes, diagnosis (medicalnewstoday.com)