

The High Cost of Insulin and Diabetic Healthcare - How to Navigate the Financial Barriers - A Mother's Perspective.

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Terminology

- Short-acting insulin- Humalog, Novalog, Apidra, Fiasp, Afrezza, **Novolin-R**
- Long-acting insulin – Lantus, Basaglar, **Novolin-N**
- Basal – background insulin, insulin your body needs to keep you alive
- Bolus – dose given for food
- Correction – dose given to correct for a high blood sugar
- Insulin Pump - Delivers continuous dose of short acting insulin. Allows for auto-calculated dosing after eating based on individual set ratios
- Continuous Glucose Monitor
 - Dexcom – Sensor that is inserted under the skin, measures glucose levels every 5 minutes, transmits to a receiver/phone, transmits to parents
 - Allows for identification of trends, if high every night, adjust pump to administer more basal
 - Libré – sensor inserted under the skin

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- Bolus insulin

- Correction factor

- Insulin pump
- Automatic bolus

- Correction factor



to administer more basal

- Libré – sensor inserted under the skin

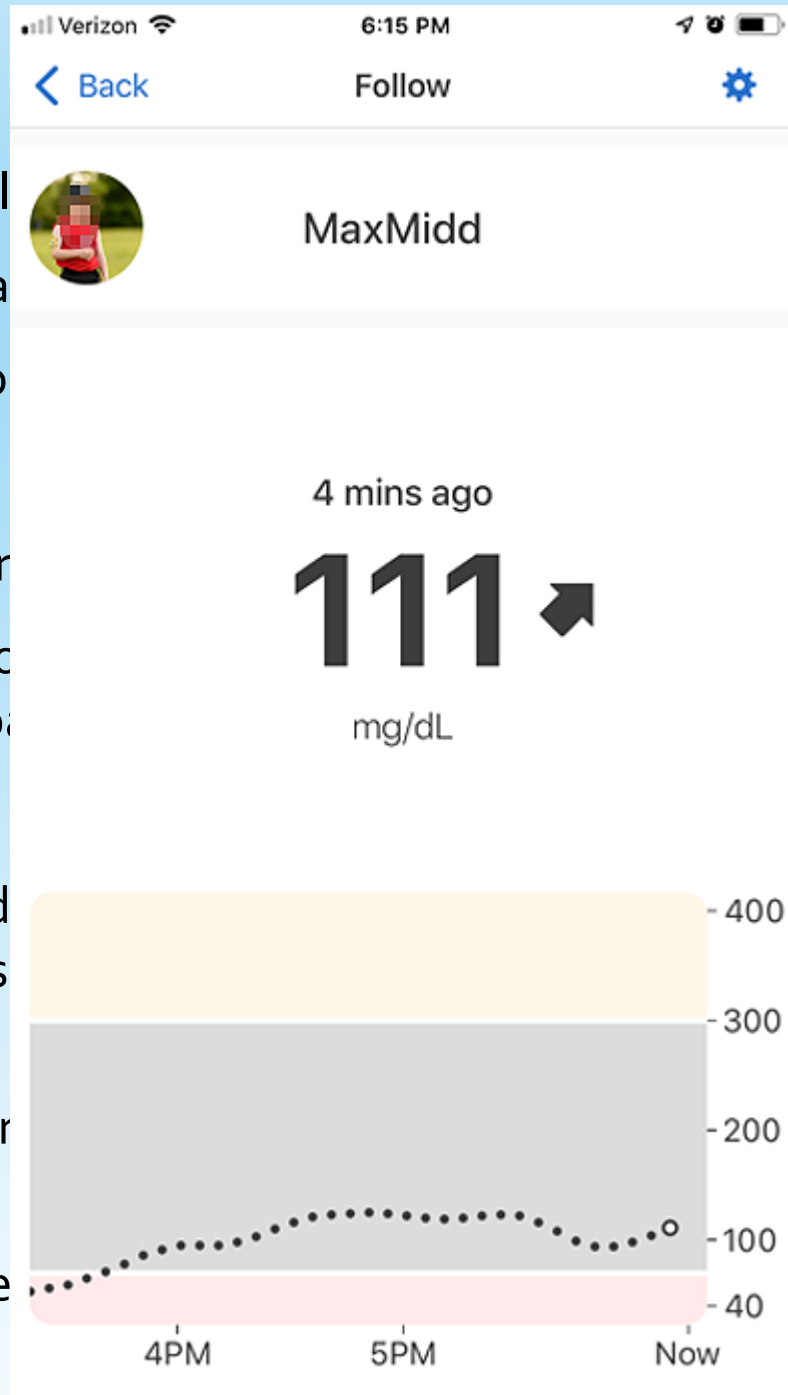


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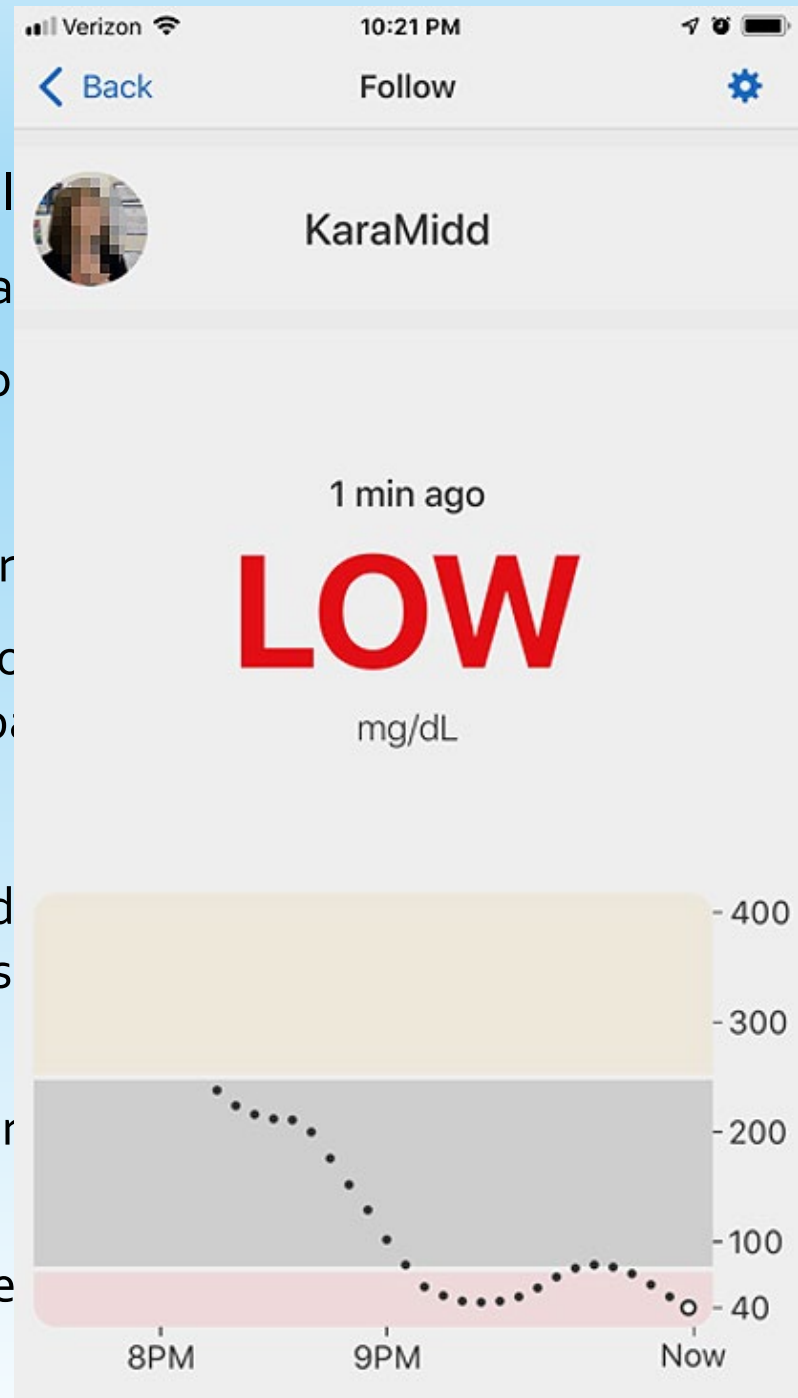
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What are the Known Financial Barriers?

- Insulin
- Test strips
- Blood glucose meters
- Lancets
- Alcohol swabs
- Syringes
- Glucagon (Baqsimi®)
- Insulin Pump
 - Pump Supplies (sites and cartridges)
- Continuous glucose monitor
- Doctors visits
 - Every 3 months to Pediatric Endocrinology, A1C, reading of CGM data, blood work, time off from school & work to attend



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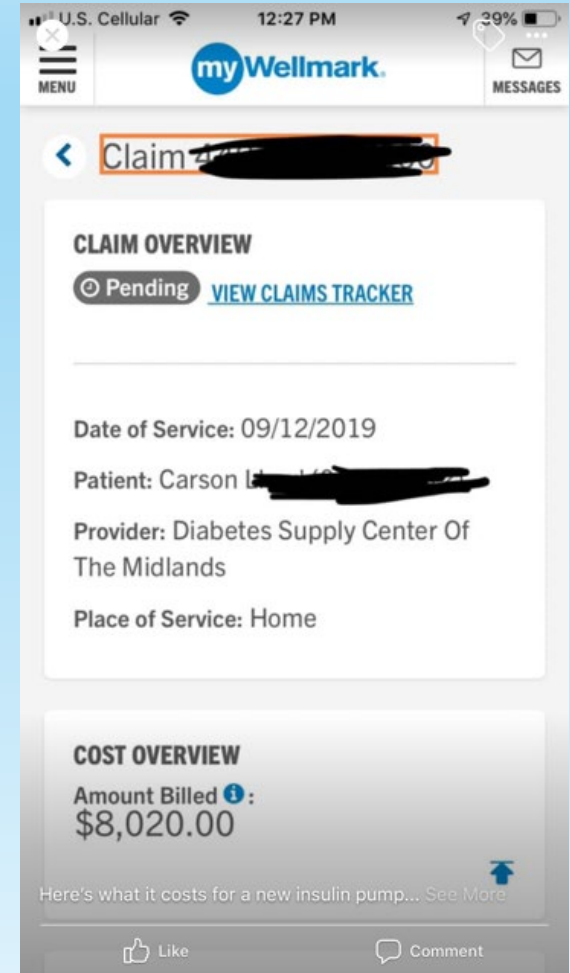
Cost of Insulin Pens:

- Norway: \$0
- Scotland: \$0
- Thailand: \$5
- Australia: \$28
- Mexico: \$35
- Taiwan: \$40
- Greece: \$51
- Italy: \$61
- Canada: \$70
- Germany: \$73

• **United States: \$700**

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Product	Time in Use	Cost
Insulin Pump	1-4 years	\$8,000
1 Box Pump Infusion Sets	1 month	\$150
1 Box Pump Reservoirs	1 month	\$60
1 Vial Apidra Insulin	1 month	\$400
CGM Transmitter	3 months	\$1,800
CGM Sensors	3 months	\$900
CGM Receiver	1 year	\$500
1 Bottle SkinTac	1 year	\$20
Humalog Kwikpen	3 months	\$700
Tresiba Kwikpen	3 months	\$500
1 Box Pen Needle Caps	1 month	\$60
Metformin	1 month	\$20
One Drop Chrome Kit	1-3 years	\$0
One Drop Premium	1 month	\$45
1 Glucagon Emergency Kit	1-time-use	\$300



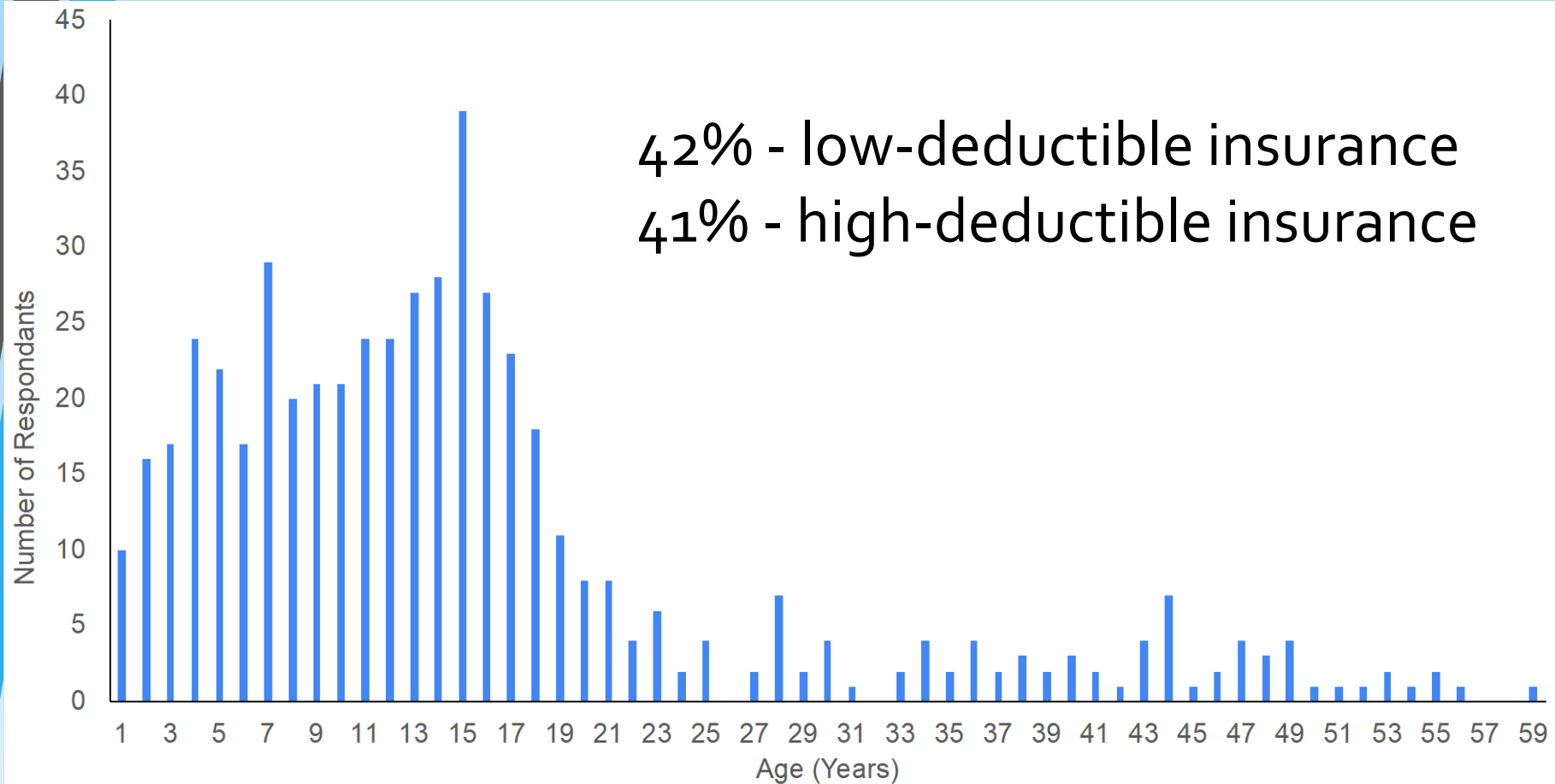
Retail: \$1889.99



Financial Barriers

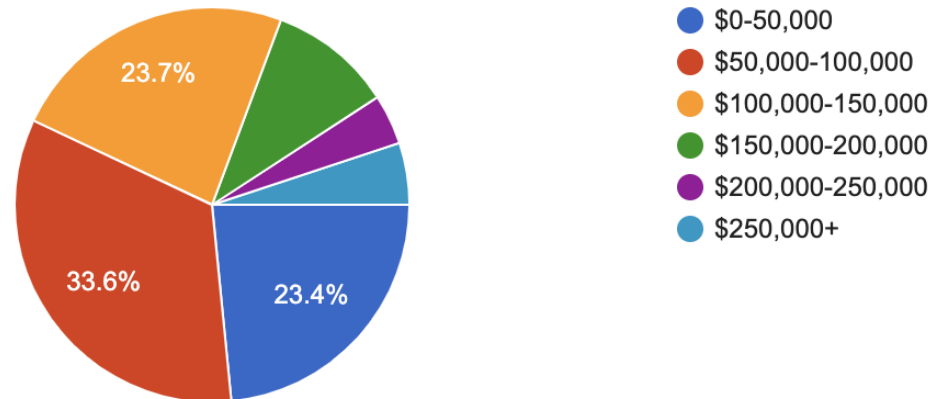
- Administered a Google Doc survey
- Facebook Groups
 - Type 1 Families of the Bluegrass (180)
 - Parents of T1 Diabetics (22,024)
 - Diapers & Diabetes (3,286)
 - You know you're a T1 diabetic when... (27,862)
 - CGMitC off topic (6,230)
 - T1 Mod Squad Open (9,421)
- Collected data from 478 Type 1 (T1) families/individuals
 - 45 US States
 - 3 Countries

Demographics

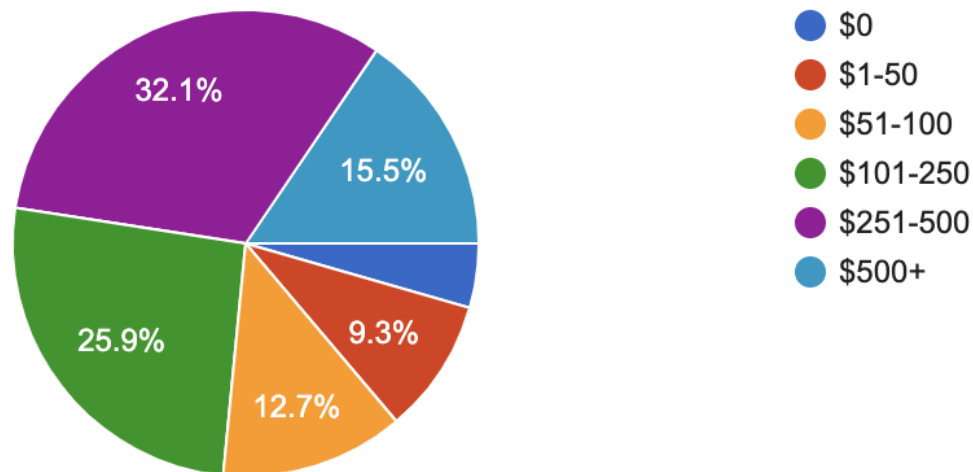



2 T1 in household - 57
3 T1 in household - 3
4 T1 in household - 1

Household Income




Average Amount Spent per Month on Diabetes Supplies





Availability of Insulin Pumps and CGMs

- 71.6% indicated that the T1 in the household had a pump
 - Of the remaining, 26.9% state a financial barrier is preventing them from getting a pump
- 87.7% indicated that the T1 in the household had a CGM
 - Of the remaining, 37.1% state a financial barrier is preventing them from getting a pump



What other expenses (outside of pumps/test strips/glucose monitors/insulin) do you encounter for diabetes care?



Expenses – The Real Story

- Tape/Patches
- Supply boxes for school
- Ketone strips
- Food/Drinks
- Cold packs
- Cell phones
- Travel/Gas
- Adhesive removers
- Ointments
- Batteries
- Pump belts
- Water bottles
- Backpacks
- Adhesive
- Higher cost of childcare
- Bills from diagnosis
- Better insurance
- Counseling
- Overnight diapers
- Medical alert bracelets, car seat medical alerts
- Diabetes books
- Time off work when kids are ill
- Diabetes camps
- Loss of income
- Flonase
- Anxiety medication
- For those that Loop – apple developer account \$100/year, RileyLinks (\$150/year)
- Storage bags for low snacks
- Waterproof storage for pumps/dexcom receivers/phones
- Diabetic alert dogs (~\$25,000)
- Attorney fees to fight school districts
- What is your time worth?
- Fundraising
- Extra refrigerator
- Sleep aids for parents
- i-port
- Set of supplies for home (with backup), emergency, school
- Zofran
- Shipping costs
- Missed work to attend field trips with kids
- Sharps containers
- Caffeine for days following hard diabetes nights
- Long term the addition of other specialist doctors visits (GI, Eye, Neuro, Heart, Kidney)
- Generator to save insulin in case of emergency (e.g., hurricane)



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Expenses – The Real Story

- Food (228)

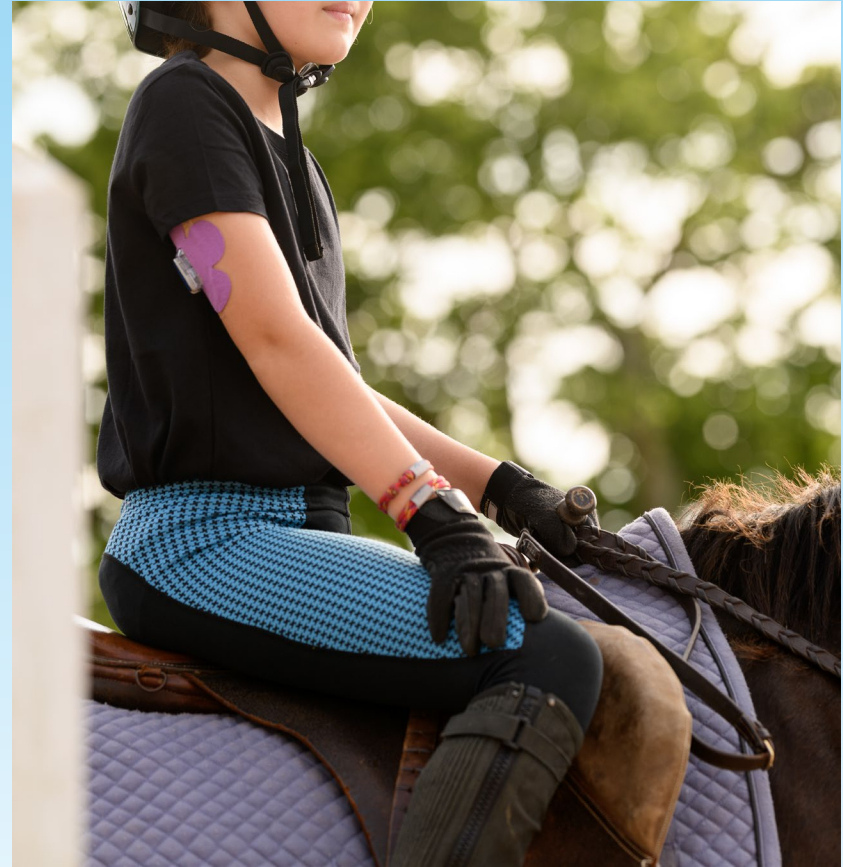
- “Food. OMG how much we spend on food.”
- Low carb diets (e.g., Fairlife milk)
- Health food
- Low supplies (glucose tabs, juice boxes, candy, glucose gels/frosting/honey)
- School supplies (emergency kits in each room at school)

- Time and Travel (47)

- On phone with insurance companies and suppliers
- Time off work for doctors visits or sick kids
- Educating teachers and school staff, time on phone and text with school each day
- Gas
- Parking fees at doctor or hospital



Expenses – The Real Story



Expenses – The Real Story

- Tapes/Adhesives/Adhesive Removers (105)
 - Lidocaine – Numb the area before insertion
 - Flonase – Prevent allergic reactions to adhesive
 - Patches
 - Tapes
 - Unisolve/Oils – solution to take tapes and patches off
 - Skin tac – additional measure to help device stick to the skin
 - Cotton swabs – cleaning up residue
 - Ointments to treat skin after removal
 - Arnica
 - Aquaphor




Expenses – The Real Story

- Ketone strips- Must check for ketones when sustained high blood sugars and while sick
 - Urine sticks - \$7/100
 - Blood ketone meter - \$35-70
 - Blood ketone test strips - \$21 for 10 strips
 - Critical for kids that aren't potty trained or anyone too sick and dehydrated to urinate on a stick
- Pump belts
 - On average, \$25 each
- Diabetes camps
 - \$550 for one week, a reduced rate due to the amazing fundraising by the camp



Impact of these Barriers

- We can't get the newest and highest tech equipment because our insurance will only approve a new pump every 4 years (and even then they expect the pump to break before they agree to a new one)
- Decreased blood sugar control, which could ultimately lead to complications as the T1 ages
- Death
 - 2019: Jesimya David Scherer, Jada Renee Louis, Josh Wilkerson, Kayla Davis
 - 2018: Meaghan Carter, Micah Fischer, Jesse Lutgen, Harold Kefauver
 - 2017: Alec Raeshawn Smith, Antavia Lee Worsham, Shane Patrick Boyle



How are T1 Diabetics Navigating these Financial Barriers?

1. Change Lifestyle

- 84.1% of surveys state that the household has had to change lifestyle after diagnosis
- Dropping cable, eliminating extra curricular activities, eat out less, pick up extra jobs, quit work to stay home with T1 child, loss of house, nothing spontaneous, credit card debt
- “How has it not changed?” “Everything”
- “T1D changes your whole life. All routines are gone. Every meal, every bite is a consideration. There is a profound loss of sleep and security. You live in uncertainty, where you never know what might happen to your child.”
- “I can meet my kids needs but after medical supplies for my child I go without for the things I need”

How are T1 Diabetics Navigating these Financial Barriers?

2. Traveling to and ordering from a different country

- Including the cost of travel, still cheaper to purchase out of country
- This is still a relatively new concept that is gaining in popularity (Bernie Sanders)
- Only 6.8% of responses have purchased from a different country
 - For those based in the US, Canada and Mexico are the target countries
- 37.6% have explored healthcare in other countries
- 22.7% have considered moving to a different country for better healthcare

How are T1 Diabetics Navigating these Financial Barriers?

3. Moving to a new state

- Colorado has placed a cap on how much individuals can pay for insulin a month (\$100)
- Minnesota in progress
- Some states (e.g., Michigan and Massachusetts) have special insurance care for children covering at 100%

4. Rationing doses

- 13.3% of responses have rationed insulin or skipped dosing due to insulin costs
- Re-using insulin from leftover pump cartridges
- Skipping meals so you don't have to dose
- Partial dosing

How are T1 Diabetics Navigating these Financial Barriers?

5. Eliminating use of insulin pumps or CGMs

6. Using equipment (like CGMs or pump sites) for longer than they are intended


- Insulin intended to be used 28 days after it's been opened, use until empty

7. Re-use lancets and syringes for up to months at a time

- Trade syringes in at needle trade-ins for drug users?
- 57.1% of responses have run out of supplies before they were able to refill

8. Fighting

- protests at Eli Lilly, vigils, lobbying at all levels of government



How are T1 Diabetics Navigating these Financial Barriers?

9. “Looping” -Bypassing the programming of the pumps and CGM and creating a DIY closed loop system (pump and Dexcom speak to each other, dose when high, suspend when low)

- But requires the upfront money to purchase the appropriate equipment and computer savvy to set up the appropriate programming

10. Patient assistance programs

- Kept very quiet, if not for this survey and Facebook I wouldn't know they existed
- 80% of survey responses did not know of any patient assistance programs
- Coupon cards, test strip programs, Will's Way



How are T1 Diabetics Navigating these Financial Barriers?

11. “Walmart Insulin”

- Different time profile, cannot be used in pumps
- “Walmart Insulin is NOT the answer to UNAFFORDABLE Insulin!!! It’s like putting dirty gasoline into a new Maserati” (Facebook User)
- Ultimately can lead to death if not under doctor’s supervision



Final Thoughts

"Insulin pumps and CGM should not be considered optional. I hate when people say that I could reduce my costs for managing my diabetes by switching to MDI. I should not have to choose between being financially stable and staying out of debt and having the best treatment for my diabetes. The standard of care for diabetes needs to be updated so that insulin pumps and CGM are affordable and available to everyone. The long term benefits to better coverage for the technology will drastically reduce the financial impact of treating complications that arise from improperly managed diabetes throughout life."



Final Thoughts

- ❖ “That the cost of type 1 is more than just insulin, and needles. Some things like CGM's cost more upfront, but save hundreds of thousands in the long run when you look at the long term cost of kidney failure, eye sight loss, and neuropathy. The health of the primary care giver is just as important as the health of the diabetic. Especially when the T1 is under the age of 6.”
- ❖ “It’s hard EVERY MINUTE of EVERY day.... I can see why people don’t take Insulin because of the cost. They need to eat and live first.”

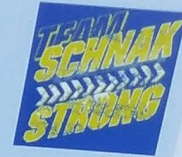


Final Thoughts

- ❖ The cost is ridiculous, especially with two Type 1s in the household. Between insulin, doctor visits and insulin pumps, we spend at least \$12K a year
- ❖ “Take 30% of your gross pay, that is what we spend every year on T1 care. The cost of insurance and our out of pocket max is 29.7% of our gross yearly income.”
- ❖ “It sucks”



TYPE ONE DIABETES



**Occurs when the immune system attacks
and destroys the insulin-producing beta cells in the pancreas.**

SYMPTOMS:

**Extreme Thirst
Frequent Urination
Sudden Weight Loss
Change in Appetite
Vision Changes**

**Strong Fruity Breath Odor
Nausea or Vomiting
Feeling Tired, Drowsy, Lethargic
Rapid, Deep Breathing
Weakness, Confusion
Unconsciousness**

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