A Journey; and a Child’s Cry for Change
Tom Karlya, DiabetesDad
Sunday, May 15th, 2016

Definition: Peds Endo Nurse

......is a specialty in nursing committed to the advancement of the art and science of pediatric endocrine nursing.
Definition: Peds Endo Nurse--Our House

A graduate of advanced Nursing School who chose to work in this specialty over a million other lucrative fields; to care for the needs of kids with endocrine issues. Clearly sent to us on a cloud from heaven to make sure our children with diabetes (and other endocrine issues) are tended to and live healthier lives while at the same time making sure they are not looked upon by others as being different; but rather able to excel despite the interference of over burdening parents who think that our health team’s life revolves strictly around, and only for, our child and at the same time manage all that with understanding, patience, a smile, and making every other parent feel the same way.

SO..........................Thank you.

How Did I Get Here???
(Subtitle----Why the heck should you listen to me?)

My story begins with.....

I was a working man
Having diabetes in our household made me no more an expert than standing in a garage made me a mechanic.
Diabetes Dad Guilty On ALL Counts!!

NO ONE HAS MADE MORE MISTAKES AT THIS THAN ME!!

I was determined not to make the same mistake twice.

We decided to immerse ourselves to learn everything we could...the more we became involved, the more we learned.
We learned about things that could help us on this journey.

The more you may have learned... about life with diabetes... there is always time to learn more?

Do what you can, where you are, with what you have.
---Theodore Roosevelt

If you're going through hell, keep going.
---Winston Churchill
The two biggest lessons we learned were that we could not stop…ever….and that no matter what we did or no matter where we ‘thought’ we might be making a difference……..

**DIABETES JUST DOES NOT CARE!!!!!!!**

...For us that day came March 20, 2009…….

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**Our Son Rob,**
Age 13  also diagnosed T1
March 20, 2009

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We Continued on Our Journey

It just seemed to me that more and more kids were being diagnosed with T1D……or more-so; in increasing numbers, kids’ diagnosis were being missed.
So we continue on........with matters which are important....... 

“PRIMARY CARE PHYSICIANS SHOULD ALSO TAKE PARENTAL CONCERNS SERIOUSLY AND DO URINE DIPSTICK TESTS DURING THE CONSULTATION FOR CHILDREN WITH SYMPTOMS OF T1D.”

Full study can be found: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3855567/pdf/bmjopen-2013-004068.pdf

Pediatrics; The Official Journal of the American Academy of Pediatrics wrote in the conclusion of their study on this subject matter:

CONCLUSION: The frequency of DKA in youth with type 1 diabetes, although stable, remains high, indicating a persistent need for increased awareness of signs and symptoms of diabetes and better access to health care........
Classic Symptoms of Diabetes

- Hunger
- Fatigue
- Frequent Urination
- Dry Mouth
- Itchy Skin
- Blurred Vision
- Unplanned Weight Loss
- Nausea/Vomiting
- Sweet or Fruity Breath

The Alarming Statistics

- It is estimated that half a million children worldwide suffer from T1D1.
- 40,000 people are diagnosed each year just here in the United States.2
- The incidences for T1D are rising sharply and between the years of 2001-2009, the prevalence in people under the age of 20 rose 21%3.
- Researchers in Colorado have documented a more than 50% increase in the incidence of diabetic ketoacidosis (DKA) at diagnosis of T1D in children between 1998 and 2012.
- A recent study in the UK documented that DKA was present in 25% of 2000 children newly diagnosed with T1D.


Philadelphia Pediatric Diabetes Registry

- Dramatic increase incidence of type 1 diabetes in youth in Philadelphia
- Marked increase in children under the age of 5 over the course of the registry
- Need for education to primary care providers and parents to prevent delayed diagnosis.

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Assistant Dean for Community Engagement
University of Pennsylvania School of Nursing
Impact of Diabetic Ketoacidosis (DKA) on Families

- Town hall study:
  - 556 responses—over 50% visited a professional—sent home as flu/virus
  - But know this—the parents missed it also
  - 330 families paid $3,038,200 (hospital Costs)/103 22 (State and Military which means the government paid for it)
  - A total 556 families lost 7289 hours of work and 18 stated they lost/left work completely after diagnosis.

Does it impact a community????

Utahns rallied around 5-year-old Erry when her undiagnosed Type 1 diabetes led to brain damage. A fundraiser, Kisses for medical expenses. However, a few months, the little girl lost her life died at home in the arms of her parents. She was buried at Tonaquint Cemetery in St. George. Family and friends attended the funeral for a touching and final goodbye.
Lives Impacted by Misdiagnosed Diabetes

In some cases it cost them their very lives.

Misdiagnosed Diabetes = Life Threatening

What Steps Can We Take To Save Lives?

Awareness Education Advocacy
WHAT CAN YOU DO????

Public Awareness—Communities—you are the expert
Education—education—EDUCATION
Community Alert ideas—lectures
In schools, communities, hospitals—just a start
Posters—Public Awareness Announcements—
School/Community projects—groups disseminate posters, etc.

REEGAN’S RULE
Reegan’s Rule became Law – North Carolina
Passed House: 111 Yay to 6 Nay/Passed Senate 47 Yay to 0 Nay/Governor Signed into Law

House Resolution 569 in PA

BE ACTIVE AND NOT IN THE STANDS