Disclosure to Participants

• Notice of Requirements For Successful Completion
  - Please refer to learning goals and objectives
  - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours

• Conflict of Interest (COI) and Financial Relationship Disclosures
  - Presenter- Susan Weiner, MS, RDN, CDE, CDN, Editorial Boards: Endocrine Today, Diabetic Lifestyle, Endocrine Web; Advisory Board Livongo Health, Healthline, Diabetes Daily
  - Presenter: Tom Karlya, VP Diabetes Research Institute Foundation; Freelance/Contributing Writer Diabetic Lifestyle; Healthline

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• Off-Label Use
  - Participants will be notified by speakers to any product used for a purpose other than for which it was approved by the Food and Drug Administration.

Learning Objectives

• Identify 3 Specific Actions CDE’s Can Take to Educate the Community at Large on the Signs and Symptoms of Type 1 Diabetes
• Discuss the Alarming Rise and Human Cost of Misdiagnosed Type 1 Diabetes
• Discuss What Can Be Accomplished with other medical professionals, policy and legislation

What We Will Cover Today:

● The Overlooked Warning Signs of Diabetes
● The Alarming Rise of Misdiagnosed Cases of Type 1
● How a CDE Factors into this Equation
● Pro-Active Steps and Methodologies to Better Educate & Diagnose
● What We Can Do: Policies & Legislation
● A Parent's Journey

Diabetes: Missing the Diagnosis

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Diabetes in Real Life Columnist, Endocrine Today

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Diabetes: Missing the Diagnosis

Diabetic Ketoacidosis (DKA) is a serious complication of diabetes that occurs when your body produces high levels of blood acids called ketones because your body doesn't have enough insulin. DKA is a medical emergency that can lead to diabetic coma and even death if not treated promptly.

The Alarming Statistics

• 29 million people in the US have diabetes; 1 in 4 doesn't know.
• It is estimated that half a million children worldwide have been diagnosed with type 1 diabetes.
• 40,000 people are diagnosed each year just here in the United States.
• The incidences for type 1 diabetes are rising sharply and between the years of 2001-2009, the prevalence in people under the age of 20 rose 21%.
• In a recent study of a large, insured population of ~10 million children and adolescents younger than 18 years old, the annual prevalence increased 53% between 2002 and 2013, from 1.48 to 2.33 cases per 1,000 people.
• Researchers in Colorado have documented a more than 50% increase in the incidence of diabetic ketoacidosis (DKA) at diagnosis of type 1 diabetes in children between 1998 and 2012.
• Diabetic Ketoacidosis is a serious complication of diabetes that occurs when your body produces high levels of blood acids called ketones because your body doesn't have enough insulin.
• A recent study in the UK documented that DKA was present in 25% of 2,000 children newly diagnosed with type 1 diabetes.
Classic Symptom of Diabetes

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

In some cases it cost them their very lives

Philly Pediatric Diabetes Registry
Developed by Terri H. Lipman
- Dramatic increase incidence of type 1 diabetes in youth in Philadelphia in 20 years
- Marked increase in children under the age of 5 over the course of the registry
- Need for education of primary care providers and parents to prevent delayed diagnosis.
- Accounts for all cases of type 1 diabetes in children residing in Philadelphia

Dr. Lipman’s work is compelling and convincing. Why hasn’t it caught on?

One Man’s Journey & A CDI who Cared Enough...
A Child’s Cry for Change...

Definition: Describing Most of You
...in a specialty in the advancement of the art and science of endocrine and diabetes purposes for individual and public welfare.

Thank you!
Dramatic increase incidence of type 1 diabetes in youth in Philadelphia in 20 years

Marked increase in children under the age of 5 over the course of the registry

Need for education of primary care providers and parents to prevent delayed diagnosis.

Accounts for all cases of type 1 diabetes in children residing in Philadelphia

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

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

If you're going through hell, keep going.
--Winston Churchill

We learned about things that could help us on this journey.

We decided to immerse ourselves to learn everything we could...the more we became involved, the more we learned.

I was determined not to make the same mistake twice.

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.....

Know this MOST PARENTS ARE EAGER TO LEARN but we also learned.... DIABETES JUST DOES NOT CARE!!!!!!!!!

....For us that day came on March 20, 2009......
We Continued on Our Journey

As we grew we also learned of the impact of so much on those who were also on this 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.

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

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……….
A Patient’s Personal Journey

Reegan’s Rule legislation aims to prevent tragedies of undiagnosed diabetes.

Reegan’s Rule became law in North Carolina.

Passed House: 111 Yay to 6 Nay
Passed Senate: 47 Yay to 0 Nay
Governor Signed into Law

Misdiagnosed Diabetes = Life Threatening

What steps can we take to save lives?

Managing this disease IS NOT leading others to make a difference, make a change.

Change allows for the possibility of better outcomes.

Undiagnosed diabetes: Is it a Type 1 and Type 2 problem?

Detrimental Long Term Effects
Delayed Access to Health Care
Life Threatening Outcomes
Economic Consequences
“Don’t Do Nothing”  
~ Tom Karlya

I’ve Got Something to Say!!!!

The more we focused, the more people wanted to get involved......

Awareness, Education, Advocacy
• Legislative Agenda
• Policy
• Call to Action

How a Dad and a CDE Ended Up On the Same Track

Take Away
Spreading Awareness

- Conferences, Symposiums, Thought Leader Summits
- Educating Health Professionals
- Schools, Nurses, Staff, Parents
- Posters, Community Outreach, Engage

Making a Difference

- Contact Representatives
- d-PAC (Diabetes Patient Advocacy Coalition)
- Education now—download posters, community activism
- Letter to parents on the symptoms of type 1 diabetes
- Engage Community in awareness lectures; position yourself as THE expert in Diabetes you are.

Diabetes Awareness Program

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
- 556 hospitalized/547 survived/4 brain damaged/5 died
- 330 (families) paid $3,038,200 (hospital costs/133 22 (State and Military which means the government paid for it)
- A total 556 families lost 7,289 hours of work and 18 stated they lost/left work completely after diagnosis

DiabetesDAD

Tell us about your Type 1 Diagnosis

SURVEY GLU/T1D Registry TO ALL 27K REGISTRY PATIENTS

GLU/T1D Exchange Clinic Registry

- T1D Exchange was born out of the need to build a dynamic, multi-purpose, real-world patient data platform, including a large-scale T1D registry.
- T1D Exchange Clinic Registry includes patient-reported and electronic health record data from over 27,000 well-characterized type 1 diabetes patients. Participants:
  - Range in age, at the time of enrollment, from under 1 to 93 years.
  - Span a range of demographic parameters, socioeconomic statuses, and care regimens.

Patient-centric survey approach

- Survey developed with input from clinicians, statisticians, and people with type 1 diabetes
- 2,700+ participated in a survey about their diagnosis experience from Glu and the T1D Exchange clinic registry

*Increasingly, we hear of children and adults dying or suffering irreversible complications as a result of delayed or completely missed diagnoses and the resulting critical illness. But the scope of the problem is unknown.*
The Glu Community

- An opportunity to connect with others anonymously
- Open to all-patients, caregivers, siblings, clinicians, etc.
- Both patient insights through our “question of the day” feature and IRB approved studies paving the way for future research
- Robust content full of articles and action steps for all

Driving patient-centric research: DKA & Misdiagnosis

Current Events

Discussion with KOLs

Survey design & deployment

Raise awareness

Disseminate findings

Analyze to pinpoint predictor

Affect change & prevent tragedy

Current stage

The Impact on Healthcare Providers

- 35% of all participants report that they were not diagnosed until more than one month after they noticed symptoms
- 41% of participants report diabetic ketoacidosis at the time of their type 1 diabetes diagnosis
- 20% of participants report being admitted to the ICU at the time of their type 1 diabetes diagnosis

Older adults more frequently misdiagnosed

- 24% of participants report being misdiagnosed with another condition at symptom onset
- 16% of pediatric patients report being misdiagnosed initially, compared to 10% of those diagnosed over the age of 18.
- Analysis to better understand these findings is ongoing

The Impact on Healthcare Providers

Improving Lives for People with Type 1 & Type 2 Diabetes

- 24% of participants report being misdiagnosed with another condition at symptom onset
- 16% of pediatric patients report being misdiagnosed initially, compared to 10% of those diagnosed over the age of 18.
- Analysis to better understand these findings is ongoing

Room for improvement
“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:

Join Together

You Can Join

Just Some Initiatives

• DPAC
• MyGlu.org/Type1DExchange
• Beyond Type 1.org
• Child’s Cry for Change
• GetDiabetesRight.org
• Check Don’t Guess
• UP Rising Against DKA
• EASE T1D
• PA Residents for Diabetes Legislative Reform
• Test One Drop – T1D Awareness

Policies & Legislation

CDE

C Caring Enough to Do Something
D Detecting Symptoms of Diabetes
E Educating for Symptom Awareness

Let’s Do This Together!
Think About What You Can Do!

Questions?

Diabetes Resources

- For more information from Susan Weiner, visit: www.SusanWeinerNutrition.com
- T1D Exchange offers the online community Glu for people touched by type 1 diabetes so they can connect, share experiences and define and inform real-world research to address unmet needs. For more information from Henry Anhalt, DO, and T1D Exchange, visit: www.T1DExchange.org and www.glu.org
- Special thanks to Alexa Bickhart, RD

References

- 1: CDC, Diabetes Latest, June 17, 2014 http://www.cdc.gov/healthytype1/diabetesfactsheet/
- 3: CDC National Statistic Report, 2014
• Prior to 1980 only 12.2% were misdiagnosed vs after 1980 30.2% reported a misdiagnosis
• 52.8% of the people who reported they were misdiagnosed said it took over a month to be correctly diagnosed
• 20% of participants reported being admitted to the ICU and in pediatric 24% of those were unconscious (16% of adults)