# ADVANCED TRACK: DIABETES AFFECTS OTHERS: SUPPORTERS AND CAREGIVERS



Jane E-B Reusch MD Professor of Medicine, Biochemistry and Bioengineering Associate Director, Center for Women's Health Research University of Colorado SOM AMC Rocky Mountain Regional VA Medical Center



Brigitte I Frohnert MD, PhD Associate Professor of Pediatrics Barbara Davis Center for Diabetes University of Colorado SOM



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#### DISCLOSURES JANE EB REUSCH, MD

#### I am an adult endocrinologist

Research Support	CU Foundation CWHR Predoctoral Fellowship (Lilly)
Speaker's Bureau	
Advisory Panel/Consultant	Medtronics
Stock/Shareholder	
Other	ADA/AHA engagement with Know Diabetes by Heart



#### DISCLOSURES BRIGITTE I FROHNERT, MD PHD

Research Support	
Speaker's Bureau	
Advisory Panel/Consultant	PROVENTION BIO
Stock/Shareholder	
Other	



# Diabetes is not a death sentence: But it is usually for life



# What does this mean day-to-day?

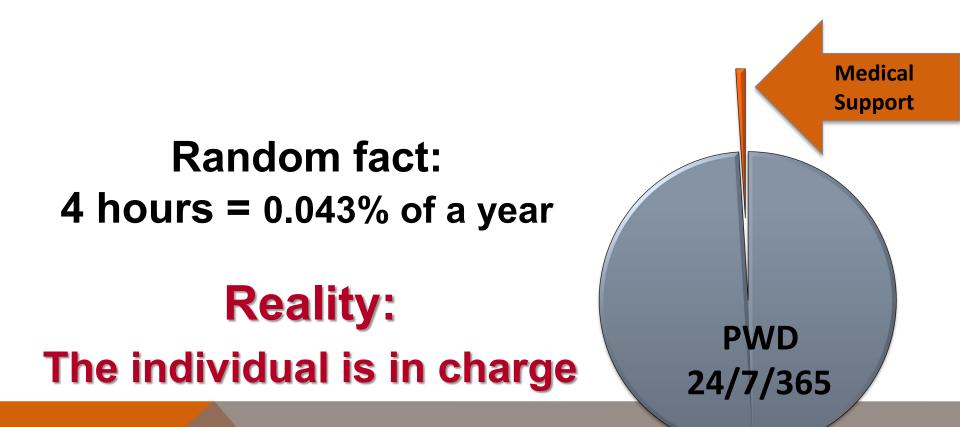
# **ANNIE'S STORY:**

# What is the story here?

# The urgency of finding a cure

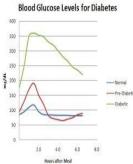


# THE INDIVIDUAL BURDEN OF DIABETES



# **INDIVIDUAL BURDEN** 24 HOURS A DAY = Decision point Glucose Breakfast Lunch Dinner

#### Individual And Family Burden 7 days a week









## **DIABETES DISTRESS**









Mental Health Provider Diabetes Education Program

# PARENTING AND DIABETES



# DOES DIAGNOSIS IMPACT ADJUSTMENT?

- Acutely symptomatic OR Identified by routine testing or in study?
- DKA OR no DKA?
- ✤ Age?
- ✤ Hospital OR ER OR ICU?
- How long was admission?





# TRAUMA AND GRIEF

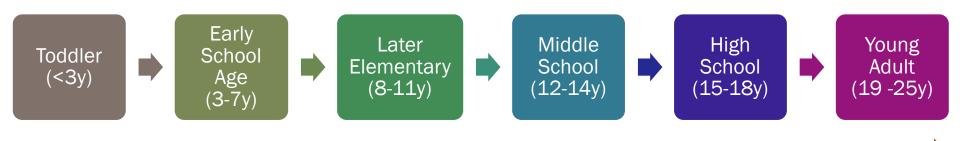
# KIDS GRIEVE DEVELOPMENTALLY...

- Different developmental milestones
- New and different impacts
- □ New grief response.





# **CHANGES IN ROLES AND CAPACITIES**



- Developing logic and abstract reasoning
- Increasing independence
- Decreasing parental supervision
- Changing role of peers



# CONSIDERATIONS AND BARRIERS FOR EARLY SCHOOL AGE (3-7)

#### Child:

- Concrete logic
- Self-centered
- Imagination and pretend play
- Does not understand time
- Variable hypoglycemia awareness

Challenges:

- Parental stress and burnout due to high care needs
- School and multiple caregivers with handoff of care.



# CONSIDERATIONS AND BARRIERS FOR LATER ELEMENTARY (8-11)

#### Child:

- Developing logic, still concrete
- More social and curious
- Developing athletic, cognitive, artistic, and social skills
- Peer group impacts selfesteem
- Recognizing hypoglycemia

Challenges:

- Beginning of puberty impacts on insulin resistance
- Limited insight about current behaviors' impact on future problems
- Increased activities, sleepovers
- Noticing differences from peers



# CONSIDERATIONS AND BARRIERS FOR MIDDLE SCHOOL AND HIGH SCHOOL

#### Youth:

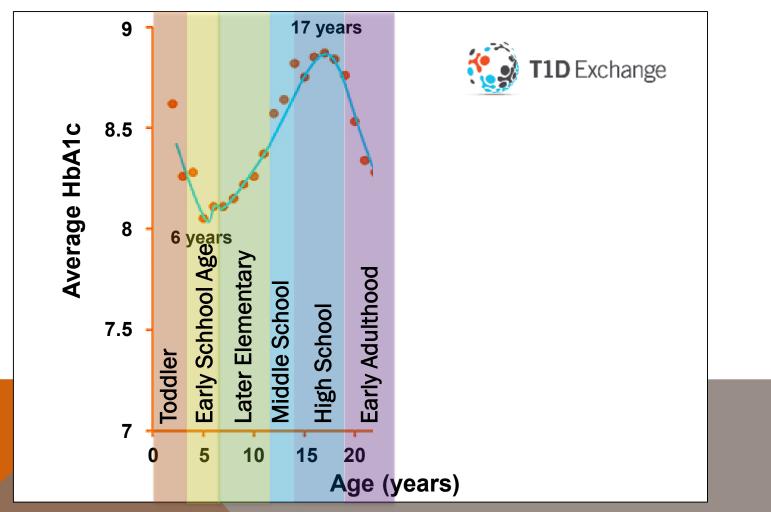
- Developing autonomy
- Developing insight on consequences, future
- Need for privacy
- Social concerns
- Body image concerns
- Peer and romantic relationships

Challenges:

- Ongoing hormonal impacts on insulin resistance
- Parents may place unrealistic expectations on self care
- Emotional impact of management: discouraged and overwhelmed.
- Driving
- Alcohol and other risk behaviors

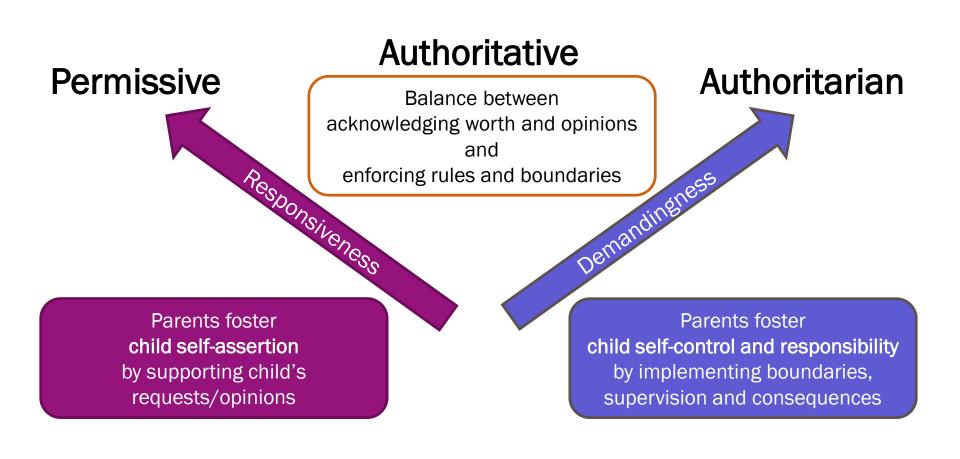


# DIABETES MANAGEMENT IS A CHALLENGE IN CHILDREN AND YOUTH



Adapted from Miller et al. Diabetes Care 2015 AND Gerstl et al. Eur. J. Pediatr. 2008

## PARENTING STYLE



# DIABETES BURN OUT: WHY DOES IT HAPPEN?

# KIDS

#### Too many tasks



# PARENTS

#### The nagging



# EMPOWERMENT

The granting of power or authority to oneself

People become empowered when they use all their resources to solve their own problems or achieve their own goals.

Strengths for Empowerment

- Awareness
- Choice
- Freedom
- Responsibility

Threats to Empowerment

- Fear
- Anger
- Ignorance
- Hopelessness
- Misguided Help

## **MODEL POSITIVE BEHAVIORS**



## SUMMARY

#### Grieving vs. Acceptance

Powerlessness vs. Empowerment

- Nurturing vs. Self Care
- Early recognition of problems coping
  Ack for bolp
- Ask for help

























