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# The Psychological Impact of Learning You or a Loved One is At-Risk for Type 1 Diabetes

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# Presentation Overview



- Psychological Impact of Genetic or Antibody Testing for T1D Risk
  - Emotional Impact
  - Cognitive Impact
  - Behavioral Impact
- Will be highlighting early results coming out of the TEDDY study

# Genetic and Autoantibody Testing for T1D



- Often controversial
  - No prevention is available
  - Usually done with children who do not have the cognitive capacity to make their own decisions
  - Usually provides a crude probability estimate of T1D
- Best done in research centers where psychological impact can be monitored and privacy protected



# Psychological Impact of Genetic of Antibody Testing



- Most studies have been conducted with mothers of children tested for T1D risk
- Most studies have focused on emotional impact
  - These have used the State component of the State Trait Anxiety Inventory (SAI)



# Emotional Impact: Maternal SAI scores over time



Genetically at-risk	Country	Pre-test	Post-test	4-6 mos post-test	1 year post-test
Johnson (2004)	US		37	31	28
Carmichael (2003)	US		36	32	30
Johnson (2007)	Finland		36	32	
	Germany		38	39	
	Sweden		40	36	
	US		41	39	
<b>ICA+</b>					
Johnson (1995)	US		55	39	
Hummel (2004)	Germany	43	51		

# Emotional Impact: SAI scores for ICA+ children and adults and their parents

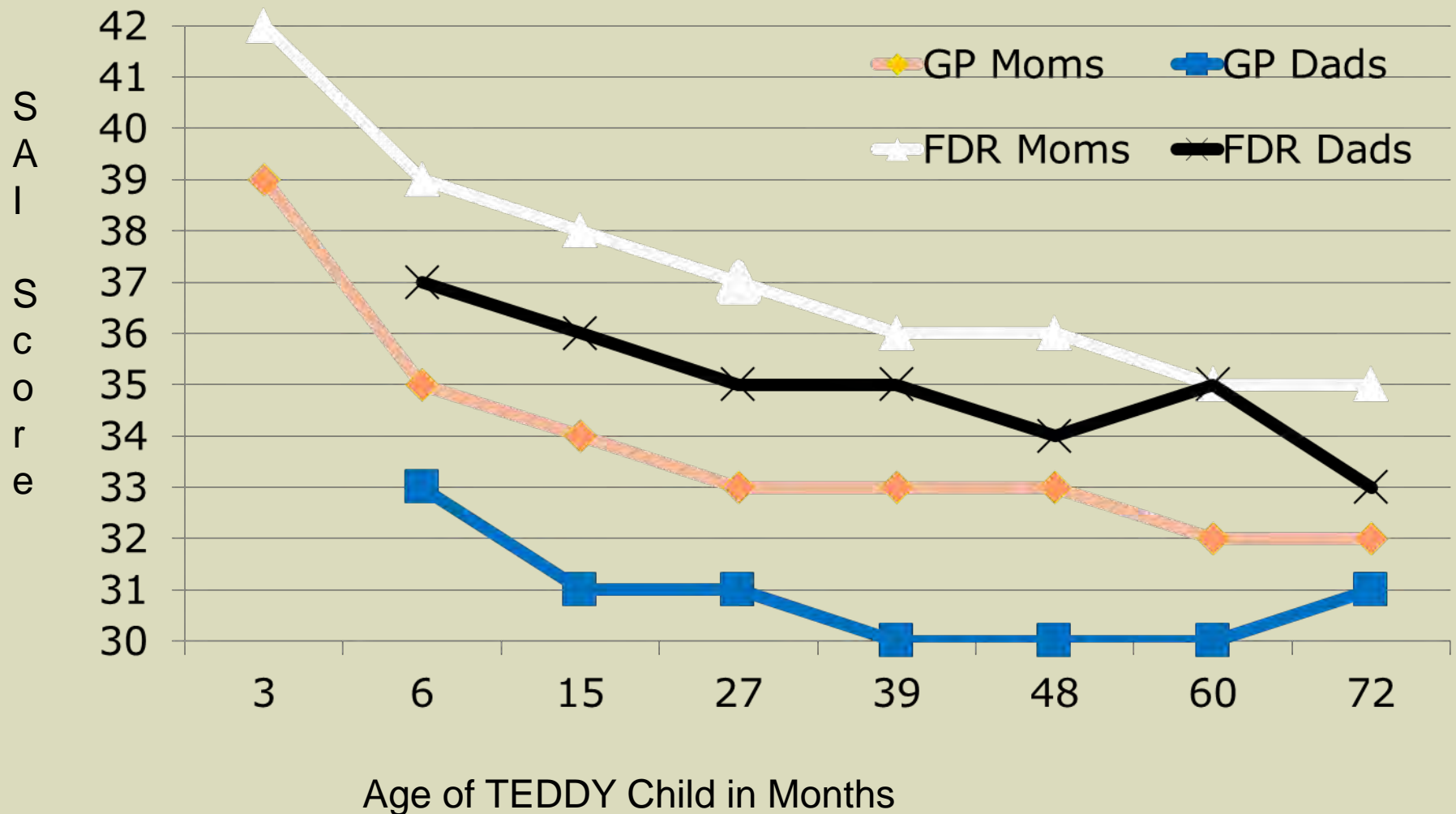


ICA+ adults	Country	Pre-test	Post-test	4-6 mos post-test
Johnson (1990)	US		52	35
Johnson (1995)	US		45	34
ICA+ children				
Johnson (1990)	US		44	33
Johnson (1995)	US		42	32
Mothers				
Johnson (1995)	US		55	39
Hummel (2004)	Germany	43	51	
Fathers				
Hummel (2004)	Germany	39	44	





# Emotional Impact: SAI scores for TEDDY Moms and Dads Across Time by GP/FDR Status





# Emotional Impact: Predictors of TEDDY Moms' SAI scores

- Country
- Family history of T1D
- Ethnic Minority Status
- Younger Maternal Age
- Lower Education
- Post Partum Depression

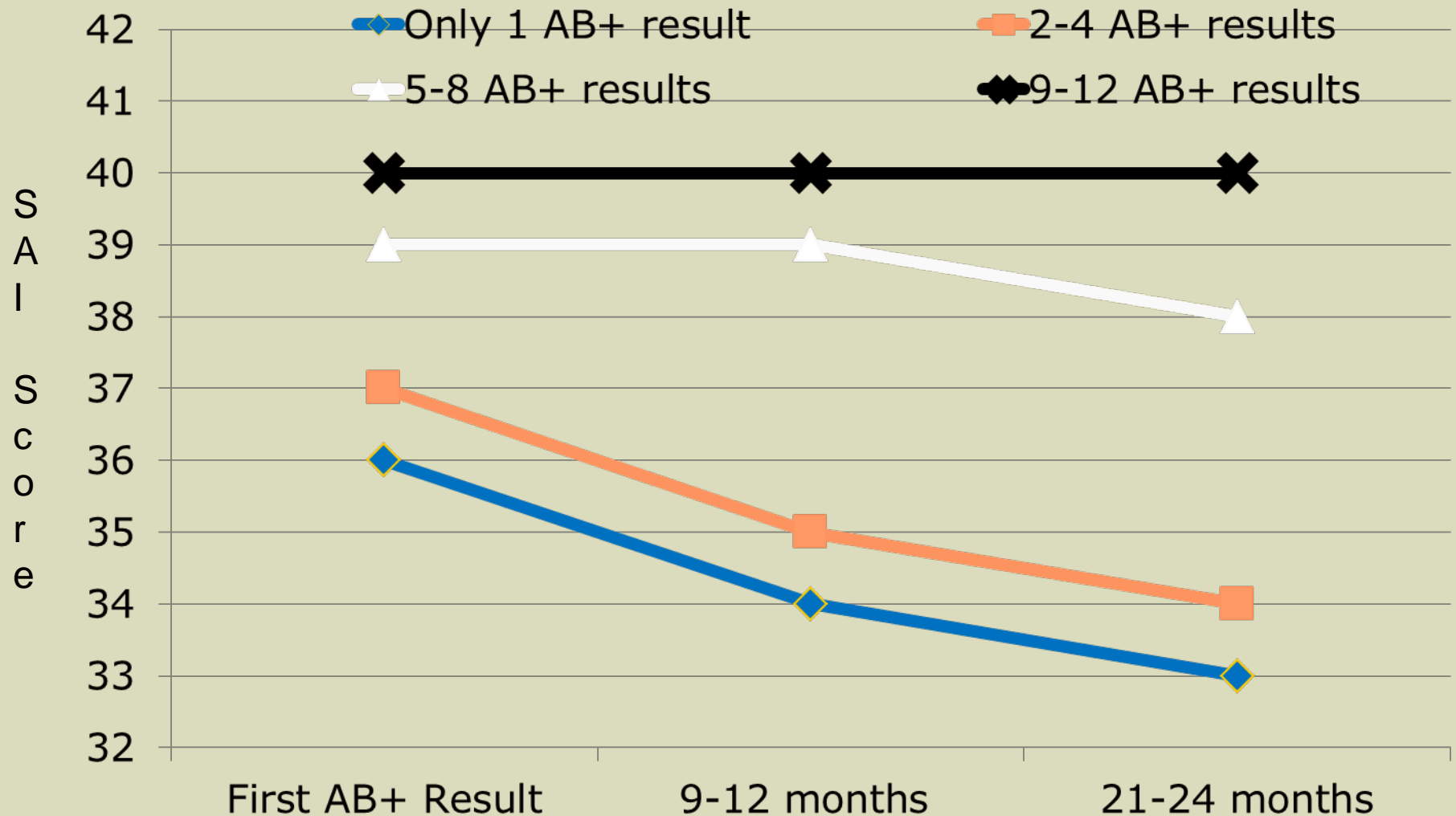




# Emotional Impact: What Happens When a TEDDY Child Becomes Antibody Positive?

- Moms and dads SAI scores increase
- In moms, the increase in SAI scores is greater in:
  - Moms with a higher previous SAI score
  - Older moms
  - Moms with accurate perceptions of their child's risk for T1D

# Emotional Impact: What Happens to Moms' SAI Scores When TEDDY Children Have Multiple AB+ Results?





# Emotional Impact: SAI scores differ by



- Time since risk notification
- Country
- Role
  - Child versus adult
  - Parent versus child
  - Mother versus father
- Family history of T1D
- Ethnic minority status
- Age and Education
- Prior adjustment history (post partum depression)
- Genetic Risk versus Antibody Positive status
- Evidence of disease progression (multiple AB+ results)



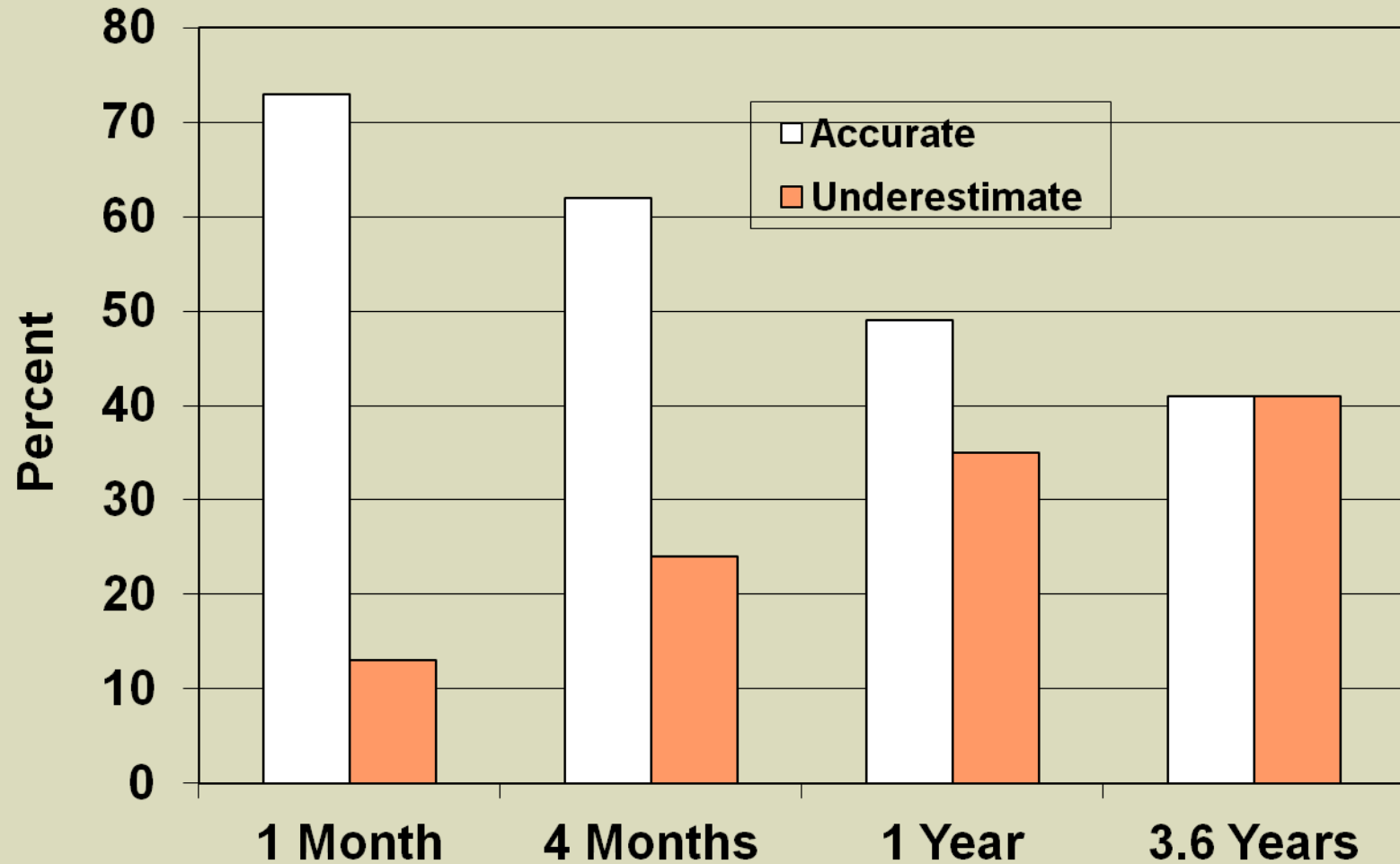
# Psychological Impact of Genetic and Antibody Testing: Cognitive Impact

- Some studies have examined whether participants understand the risk information provided
- Most have been conducted with parents, usually mothers





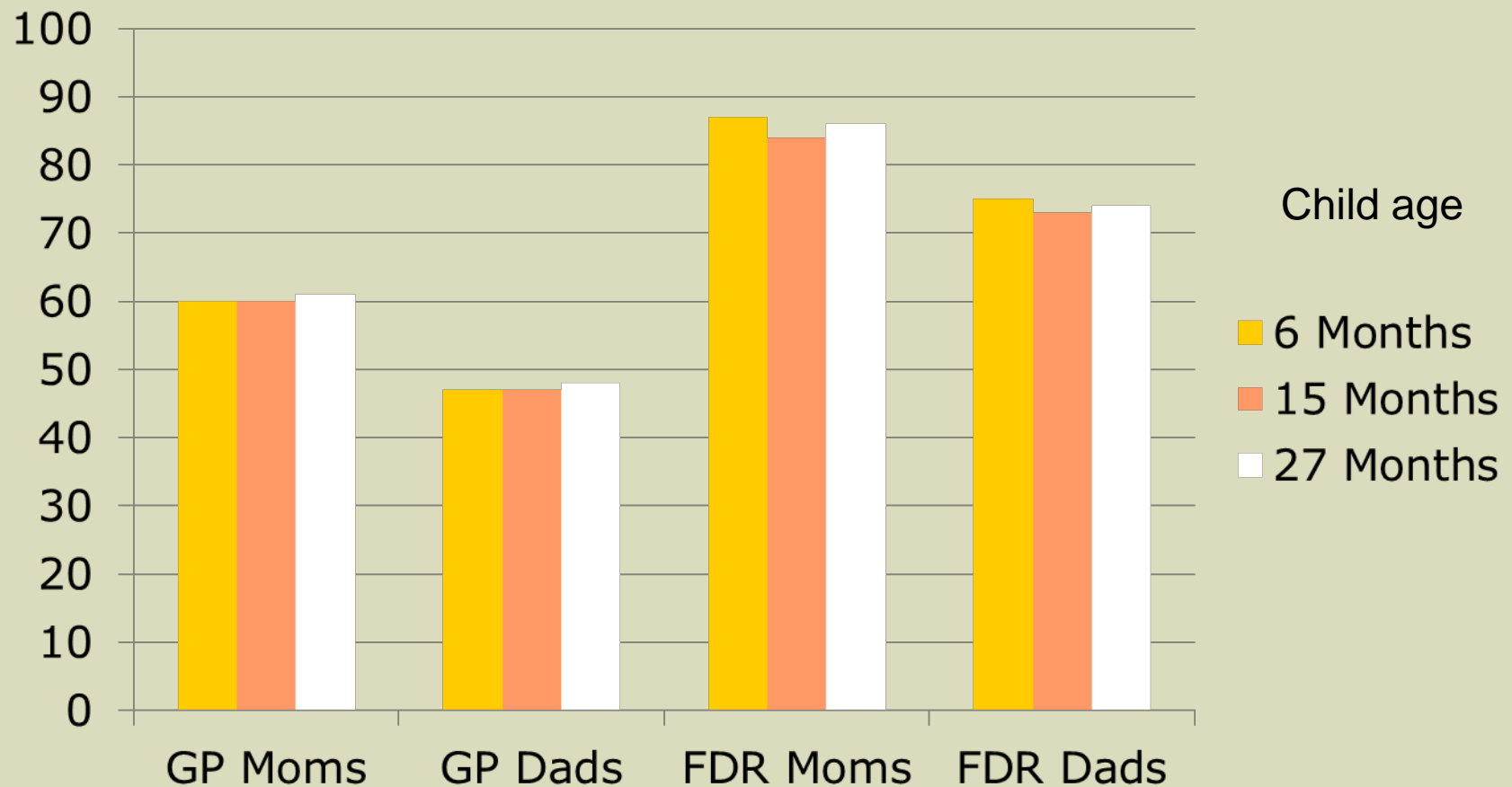
# Cognitive Impact: Risk Perception Accuracy Over Time of Mothers of Genetically At-Risk Children



(Johnson, 2006; Baughcum, Johnson et al, 2007)



# Cognitive Impact: Percent of TEDDY Moms and Dads with Accurate Risk Perceptions Over Time







# Cognitive Impact: What Predicts Risk Perception Accuracy in TEDDY Moms and Dads?



- Country
- Family history of T1D
- Higher SES
  - Majority culture
  - Greater education
  - Less crowded household
- Lower locus of control (belief that something can be done to prevent T1D)

# Psychological Impact of Genetic and Antibody Testing: Behavioral Impact



- A small literature suggests that many with positive screening results report behavior changes in an effort to prevent T1D
- T1D monitoring behaviors, changes in diet and exercise are common
- Potentially harmful behaviors (limiting contact with other children, delaying immunizations) are rare **FSU COLLEGE OF MEDICINE**



# Behavioral Impact: Many Mothers Report Behavior Change in Response to Child's Increased T1D Risk



- 67% mothers reported behavior changes
- Most common behaviors reported:
  - Monitoring behaviors (59%)
  - Dietary changes (34%)
  - Physical activity changes (14%)
- If the at-risk child was a FDR, mother was 19 times more likely to report behavior changes
- Mothers who were more anxious and who had accurate perceptions about the child's T1D risk were more likely to report behavior changes

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(Baughcum, Johnson et al, 2005)





# Behavioral Impact: Percent Reporting Efforts to Prevent T1DM in DPT-1 and TEDDY



Study/Respondent	Percent Reporting Behavior Change to Prevent T1DM
DPT-1 Oral Insulin Trial	(Johnson et al, 2009)
Parent	38
Participant	48
DPT-1 Parenteral Insulin Trial	(Johnson et al, 2007)
Parent	57
Participant	48
TEDDY year 1	(Smith et al, in press)
General Population Parent	42
FDR Parent	51

# Behavioral Impact: What Predicts Prevention Behaviors in TEDDY Moms?



- Family history of T1D
- Higher maternal education
- TEDDY child is an only child
- Higher SAI score
- Accurate risk perception
- Belief that something can be done to reduce the child's risk for T1D

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Smith et al, Diabetes Care, in press



# Summary: Emotional Impact



- Anxiety is common and is associated with increased risk (antibody positive status versus genetic), less time since risk notification, country, role (adult versus child; parent versus child; mother versus father), family history of T1D, ethnic minority status; younger parental age and less education, prior adjustment problems (post partum depression), and evidence of disease progression (multiple AB+ results)



# Summary: Cognitive Impact



- Diabetes risk is difficult to communicate
- Risk underestimation is common and may increase over time
- Accurate risk perception is associated with country, maternal role, family history of T1D, higher SES (majority culture, greater education, less crowded household), lower locus of control (belief you can do something to prevent T1D)

# Summary: Behavioral Impact



- Prevention behaviors are common in both natural history and intervention trials - threatening study validity
- Dietary prevention behaviors are most commonly reported
- Prevention behaviors are associated with family history of T1D, higher maternal education, only child status; higher SAI score, accurate risk perception, belief that something can be done to reduce risk for T1D





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