

TEDDY Talk



Volume 9 Summer 2015

TEDDY Participants Have Easier Transition

You're enjoying a beautiful, breezy day at the beach, wading in the waves, feeling the warm sun on your face, and the sand shifting between your toes. A sudden wave surges up and heads for shore, and you can see it forming, hear it as it moves towards you. You can't stop it, but you *can* be ready for it and meet it as you choose.

Many families who have had a child diagnosed with T1D have described the experience like a sudden wave that

crashes over them, one they never saw coming and couldn't be ready for. There are almost 9000 children just like yours participating in TEDDY all around the world, and over 200 of them have developed T1D and made the transition into life with diabetes. Being part of the TEDDY study means that your child is being carefully monitored for the earliest

possible signs of T1D with cutting-edge testing that isn't available to pediatricians or family physicians.

Often, when a child begins to develop T1D, and cannot produce enough insulin to break down the sugars from the foods they eat, their body begins to break down fat as an alternate fuel. This is why a child developing diabetes often loses body weight despite having a good appetite. This process of quickly breaking down fats causes a buildup of

toxic acids in the bloodstream called ketones, which leads to a complication of T1D called diabetic ketoacidosis (DKA). DKA symptoms can develop very quickly, sometimes within 24 hours, and can result in excessive thirst, frequent urination, nausea and vomiting, abdominal pain, weakness, fruity-scented breath and confusion. If left untreated, DKA can be fatal.

TEDDY researchers have published findings that support

the statement that our TEDDY kids have an easier transition into diabetes, with fewer complications, and less hospital time. An article published in *Diabetes Care* describes how TEDDY kids had far lower rates of DKA when they became diabetic, as compared to children who were not in the TEDDY study, and therefore had no preparatory knowledge of genetic risk or an active

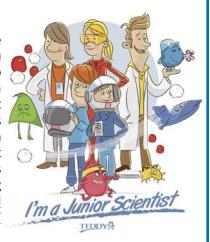
autoimmune response— the autoantibody testing results that TEDDY gets with every visit. The rates of DKA in 119 TEDDY children diagnosed with T1D before age 5 were significantly lower than those in children of comparable age and countries who were not participating in TEDDY.

There's nothing easy about having type 1 diabetes, but knowing what it is, and knowing that it may be on the horizon can make the transition into life with diabetes an easier one.



Hi Junior Scientists!

Right around the time you turn 10 years old, you will have the opportunity to go on an adventure with Will and Emma to meet some of the scientists working with TEDDY, learn about risk, and find out more about what TEDDY is looking for in a fascinating new book called Will and Emma Meet the TEDDY Scientists!



You will receive this book in the mail before your 10 year TEDDY visit, so you have plenty of time to read it.

New Questionnaire & Life Events

Turning 10 years old is very exciting, and it means something new at your TEDDY visits! TEDDY wants to know how 10 year olds think and feel, and we need you, our expert 10 year old TEDDY friends, to help us with this!

We will give you a questionnaire to fill out on your own at your visit, just like your parents do. The questions will ask about how you feel, what you think, and what kinds of things have happened since we saw you last.

No one knows more about being 10 years old than you, and we can't wait to hear what you have to say!





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TEDDY Store Success

Isabelle



Augusta, GA

Gainesville, FL

THE TEDDY STORE

Emma

Check Out TEDDY on YouTube

TEDDY's Washington site has posted several collaborative videos that our TEDDY families are sure to love! Search for "TEDDY Study- Washington".

- Food Record Jr. Scientist instructional video
- **TEDDY: The Blood Process**
- **TEDDY Around the World**



2014 Holiday Card Winner-

Katy Shreeve, of Cumming, GA, is an energetic 3rd grader with many interests. She loves to sew, garden, cook and is very active in Girl Scouts. Her favorite school activities are reading and art. She thinks that seeing her drawing on the TEDDY holiday card was thrilling!

Participants are Rejoining the TEDDY Study

Cloey Criggall is a TEDDY participant who has rejoined the study after having not participated for some time. Cloey originally joined the TEDDY study as a baby at our Gainesville, Florida site. Her last TEDDY visit before leaving the study was in June of 2009 at 33 months old. Cloey rejoined the study in June of 2014 for her 8 year visit. Cloey's mom, Casey Estep, answers our questions about why they came back to the TEDDY study in the Q&A below.

- Q) What challenges about TEDDY participation led you to withdraw from the study?
- A) At the time that I withdrew from the TEDDY study, the economy was in a downward spiral. Gas had gone up to almost \$4.00 a gallon, and I could not afford the 60 mile drive to and from the TEDDY visits. Also, my child had to go to the doctor often due to health issues, and she was very scared every time she had to return to the hospital for the TEDDY visits.
- Q) What led you to want to participate again?
- A) My daughter, Cloey, during the summer she was 7, had different and sporadic illnesses happen within a 2 month span. I thought to myself, "these events may be a key factor in helping the research for diabetes." It was the best decision I have made and wish I had never withdrawn from the TEDDY study years ago.
- **Q)** What options make TEDDY participation possible for you now?
 - A) Time, dedication, and also Cloey's readiness to complete the tasks that need to be completed for the TEDDY study.
- Q) What advice would you share with other families that are struggling with keeping up in TEDDY?
- A) Try to remember that the reason your child was selected for this study may be the key information your child can provide to the research being done. If I could go back to many years prior, I would tell myself no matter the struggles, no matter the time, it is worth every second given to help aid the TEDDY Study. The people are amazing to work with and are so eager to make the visits work on your time. These people are working together to try and help your child and catch the disease early enough to not have to go through heartache and pain watching your child go through the process diabetes does to their body.

Any child that joined the TEDDY Study as a baby can return to the study at any time before the age of 15 years at any of our TEDDY locations. We do yearly follow-up on families that no longer participate with a TEDDY Update Form, and this is the time when many choose to return. Some examples of reasons we've found that families choose to return to the TEDDY Study are a family member getting diagnosed with type 1 diabetes, an offer of home visit or satellite location close to home, a now older child that can participate on a different level than before, or a change in family circumstances.