

Georgia/
Florida

TEDDY Talk



Volume 5
Fall 2011

TEDDY Update: GA/FL and Worldwide

The GA/FL TEDDY Study's youngest children just celebrated their first birthday a few months ago as our oldest children started first grade this past August.

Here are just a few exciting things that have happened: We had a fun time at the Atlanta TEDDY Fall Festival at Roswell Park on October 8. We want to congratulate Christopher from the Atlanta TEDDY site, who won the worldwide TEDDY Holiday Card Contest for 2011.

Worldwide, 356 TEDDY children are currently positive for the autoantibodies against the pancreas: the first sign that the immune system is attacking the body's insulin producing cells.

Worldwide, there have been 95 TEDDY children diagnosed with type 1 diabetes and 176 children diagnosed with celiac disease. Of those diagnosed with type 1 diabetes, 31 have a close relative with type 1 diabetes and 64 do not.

All your hard work moves us closer to an eventual cure or prevention for type 1 diabetes. Thanks for all you do!!

Ella's Story:
One TEDDY mom's interview about her child's diabetes diagnosis
Read her family's story about getting diagnosed with Type 1 diabetes and her experience with the TEDDY study in the insert to this newsletter.



Meet a fellow member of the TEDDY Florida Family:

Kylie
Age 2

Get children involved in stool collection!



Kylie

From Atlanta TEDDY

If your child is in a daycare or even just a play group, you can see how quickly illnesses go around. Many viruses and bacteria don't cause children to get sick but are still in the stool for a short time. TEDDY has an amazing resource in the hundreds of thousands of stool samples collected by parents. TEDDY will be able to test those samples for viruses and gut bacteria. Stool is TEDDY's best option to try to answer the question: Do viruses or bacteria protect against or cause someone to develop type 1 diabetes?

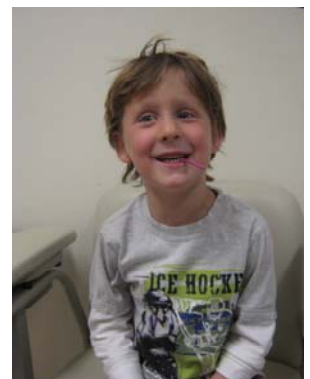
As children grow older, we'd like to encourage them to be more involved with stool collection. Teaching children to help can be an easy way to get them more excited about TEDDY. Children can help close the baggies, put on the mailing label, or even remind you to collect the sample. Please remember, TEDDY would like stool collected once a month until the age of four, and then four times a year after 4. If you are struggling with collecting stool and would like advice, please let us know at your next visit or call your TEDDY office. If you have tips that have worked for you, let us know so we can pass it along to other TEDDY families.

What's new with TEDDY?

Accelerometer. Starting at age 5, we will ask our TEDDY kids to wear an accelerometer for the week following the annual visit. It is a small device that your child will wear on a stretchy belt. It measures physical activity.

Urine samples. We will ask for urine samples at TEDDY visits. We are looking for metabolites and protein in the urine.

Cortisol samples. This will be done at the visit using a mouth swab. Cortisol is a way for us to measure stress. TEDDY researchers want to know if stress can contribute to the development of Type 1 diabetes in some children.



TEDDY Fall Festival

TEDDY 

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GA/FL TEDDY STUDY

TEDDY Family Fun!

Georgia Aquarium

Has your family visited the Georgia Aquarium? We want your TEDDY visit day to turn into a Family Fun Day. We are partnering with different attractions to bring you family fun at a discounted price. For a discount on Georgia Aquarium attractions, buy your tickets at:

www.georgiaaquarium.org/ourteddyfamily



We had fun time at the Atlanta TEDDY Fall Festival. We met at Roswell Area Park on Saturday, October 8, 2011. We had a great turnout. A total of 228 people attended including 55 TEDDY kids, their families, and TEDDY staff. The star of the show was Mr. Greg of Mr. Greg's Musical Madness. He had us dancing, clapping, and singing. We also enjoyed festival games including a throwing footballs, creating spin art, and the Potty Toss. I think the Potty Toss was the favorite because the prize was a toy potty filled with colorful slime! The TEDDY families and staff enjoyed spending time together without blood draws, poop samples, and diet records!



Mr. Greg performing



The Potty Toss game



Mr. Greg's biggest fans enjoying the show

What is celiac disease?



Celiac disease is an autoimmune disease that damages the lining of the small intestine causing poor absorption of food. The immune system reacts to gluten in food. Gluten is a plant protein found in grains like wheat, barely and rye. Just like type 1 diabetes, both genes and environment play a role in celiac disease.



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A gluten intolerance, or sensitivity, is not a wheat allergy. Children and adults with celiac may have diarrhea, constipation, gas, bloating, stomach pain or anemia. Some people report no symptoms but have damage to the small bowel from celiac disease.

About 1 in 100 children in the US will develop this disease. The genes that increase a person's risk for type 1 diabetes also increase the risk for celiac disease. TEDDY tests children yearly, starting at age two, for an antibody to transglutaminase. This is an enzyme found in the intestines. When these antibodies are found it usually means there is damage to the small bowel. This may or may not lead to celiac disease.

Celiac disease is diagnosed with a small bowel biopsy. It can be controlled by following a gluten-free diet, avoiding wheat and other gluten in all foods and drink. Living gluten-free is much easier today than many years ago. Most food labels list wheat and gluten and there are many resources on the internet including websites with recipes, how to eat out at restaurants, gluten-free bakeries and how to help children stay gluten-free at school.

Gluten Free Corn Bread

2 cups stone ground yellow cornmeal
1 cup corn flour (*Note: corn flour is **NOT** corn starch*).
1 tablespoon baking powder
1 teaspoon sea salt
1 teaspoon baking soda
1/2 cup sugar
2 cups of buttermilk
4 eggs

Preheat oven to 400 F.

In a large bowl stir together corn meal, corn flour, sea salt, baking soda, baking powder and sugar until incorporated. Next add eggs and buttermilk and stir until completely mixed.

Pour into a 13 X 9 inch baking dish that has been sprayed with non-stick spray. Bake for 25-35 minutes until golden brown and done through. Slice and serve immediately.

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Ella's Story

A Former TEDDY mom shares her family's story of getting diagnosed with Type I diabetes

What were your thoughts when your child was first screened and found to be high risk for type I diabetes?

We thought it was a mistake at first, since there is not a family history of Type 1 diabetes. After listening to Dr. Muir discuss how our daughter qualified and hearing the advantages of the study, there was no question we would participate.

Tell me about your child's experience with the blood draws at the TEDDY visits?

For the first two years, the blood draws were not fun for any of us. My daughter was very young, and she did not like having her arm held still. Our daughter would cry until it was finished. The TEDDY personnel were very considerate; for example, the numbing cream helped with the "pain."

How old was your child when she became antibody positive? What was your response?

Our daughter became antibody positive around two years old. The anxiety came back. The praying began, hoping she would not get diabetes.

What did you do to monitor your child once she was persistently antibody positive?

Around age 3, we were given a glucose meter to test her blood sugar periodically and when she was sick. This testing helped us to help keep her healthy. Our daughter did not always understand this and sometimes did not respond well.

Tell me about her diagnosis of celiac disease.

At age 4, with the help of TEDDY, our daughter was diagnosed with celiac disease. Our pediatrician told us to wait until symptoms occurred; he did not want our child to have endoscopies unless necessary. I called Leigh (study coordinator) to let her know what our doctor said. The TEDDY endocrinologist called our pediatrician to discuss this new information. Within 24 hours, our pediatrician called us and recommended a GI doctor. When our GI doctor saw the numbers, he could not believe she did not have any symptoms of celiac. Luckily, being diagnosed early was an advantage because removing gluten from her diet was not as challenging as it was for my husband and me to remove it from our diet. In today's world, being gluten free is not difficult.

Tell me about her diagnosis of Type I diabetes.

Leigh (the study coordinator) found Ella's elevated blood sugar during a TEDDY visit. She explained it to me and told me to contact my pediatrician. Holding back tears, I called my husband to tell him the news. Unfortunately, my pediatrician's nurse was unaware of

the TEDDY study, so she told us to make an appointment for the next day. I called Leigh, and we got a call back from the study endocrinologist explaining the procedure and importance of getting down to the children's hospital. We registered our daughter at the front desk. The nurses looked at us as if we were crazy. Our daughter was in no pain, talkative, and had absolutely no symptoms of diabetes. The doctors shockingly diagnosed her with Type 1 diabetes. Every medical personnel asked us how were able to determine this diagnosis without ANY symptoms. The most difficult part was watching our hungry, crying child go through testing and not feeling an inch of illness. She had not eaten since lunchtime and had to wait until tests were given before eating.

How did your family handle the diagnosis?

The next two days consisted of monitoring and a crash course on Type 1 diabetes. The next three months were extremely stressful and tearful for all of us. Once we realized there was a community out there to help, we started to relax. It took me about 6 months to feel comfortable living our life again. We still have days of worrying about finding babysitters and wondering how she will be emotionally as a teenager. Our daughter still says, "I wish I did not have diabetes." Overall, she handles the dual diagnosis VERY well. She will not eat anything before asking if it has gluten. She enjoys showing others how she takes her blood sugars independently and gets her insulin ready for us. Our daughter definitely has had to mature a little faster than other children her age, but that does not stop her from being a fun child.

How was your experience with TEDDY?

Our daughter misses seeing the TEDDY staff every three months, and still asks about going to TEDDY. We cannot say enough about the good things the TEDDY study did for us. Of course, the staff is amazing. It has grown since we left. It was difficult to receive a diagnosis, but it has helped to have the three TEDDY ladies (Leigh, Kate, and Michelle) continue their involvement. I have received several e-mails and phone calls just checking on our family since our diagnosis.

