

Follow Up Participant  
5000 Street Address Road  
Somewhere, VT 00000

Postage

Barbara Davis Center  
1775 Aurora Court F527  
Aurora, CO 80045



# Follow Up

Follow Up of Children Diagnosed with Diabetes Study

## Welcome Follow Up Study Families!

The **Follow Up of Children Diagnosed with Diabetes** study began in February 2012. This is a joint effort with the TEDDY Study Group and the JDRF to learn more about the early development of type 1 diabetes. Clinics in Sweden, Finland, Colorado and Washington monitor children starting just a few weeks after their diagnosis. So far, over 110 families have enrolled.

One key goal is to find out how long kids still make insulin after getting diabetes. We also want to know if how sick they are at diagnosis changes their short and long-term insulin needs. We are learning a lot about the different ways children present with diabetes, and their long-term treatment. Your testing and questionnaires help us understand these differences. We hope this data can help lead to better care for all kids with type 1 diabetes.

Things we have learned so far:

7.5

The average age of the children in the study

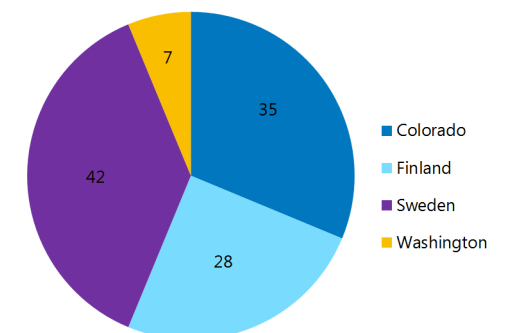
64

Active & still producing c-peptide at 12 months.

50 boys/ 52 girls

Enrolled in the study

## Follow Up Study Sites

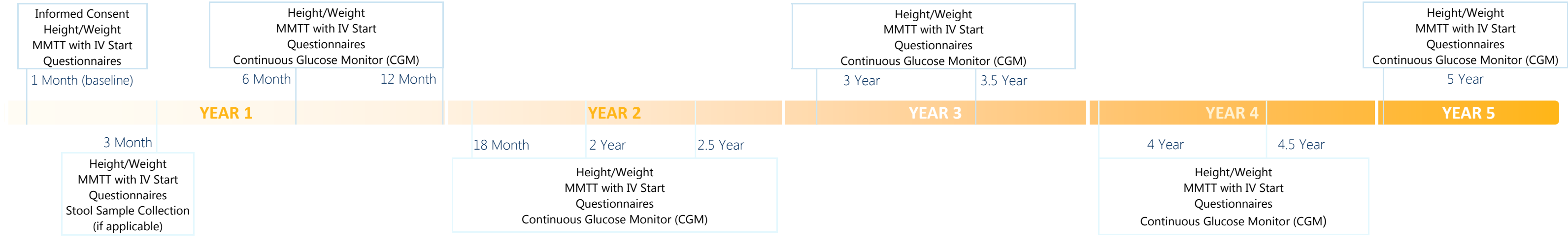


Participants by study location

# Follow-Up Study Protocol Updates

The Follow Up Study has recently made a few updates to the protocol. When we began enrolling subjects in 2010, the group had developed the protocol for the study visits up to 3 years post-diagnosis. Since we are now seeing children post-diagnosis with c-peptide production at 3 years and beyond, we have added visits so we can continue to monitor the subjects until 5 years.

## Schedule of Visits



We will also be asking our participants if they would like to wear the continuous glucose monitor (CGM) at each visit starting at 6 months. The data you are sharing from the CGM is very useful to the study. We hope to present some of this data to you in a future newsletter. Please remember, the CGM is an optional part of the study. You can still participate if your child is not interested in wearing the CGM. If you have any questions, please contact your study nurse or coordinator.

## A Parent's Perspective

*Mom of Brian (10 years old, Parker, CO, JDRF study participant since Jan 2014) has been kind to participate in an interview about Brian's diagnosis.*

### Tell us about your diagnosis

Finding out my son had type I juvenile diabetes was a scary time. It was hard to understand why a healthy active child would come down with this diagnosis. I think media and the stigma behind diabetes is that of unhealthy, older people. It happens to young, old, healthy and unhealthy people, but at the time it was very confusing as to why my son was diagnosed with it. Especially because I didn't know anyone who had it, nor did I have any family that had it either.

### What was your biggest challenge at diagnosis?

My son Brian handled the diagnosis very well! Way better than I did to be honest. He just wanted to know and understand it better. The finger pokes and correction shots were the hardest part for him. Now that he has a pump it is just a way of life and it doesn't interfere with any daily activities. He is very responsible and sometimes I forget he is living with diabetes

### What surprised you most at diagnosis?

My biggest surprise at diagnosis was that healthy children can have diabetes. That at such a young age their pancreas would stop producing insulin.

### How do you currently manage your child's diabetes (CGM, pump, etc.)?

Brian is currently on a Medtronic pump. He is very knowledgeable in regards to using it. He is not using a CGM at this time but I do see that in our future.

### What has been your biggest triumph since diagnosis?

My biggest triumph since diagnosis was letting Brian out of my sight and knowing he will be ok living with diabetes. At first I would sneak in his room and watch him sleep. Making sure he was breathing and doing well. It consumed my thoughts and I was always worried that he would go "low". As time [went] by, I realized that he has become a stronger individual because of this disease. He is very responsible and it has been very rewarding watching my son grow up and know that he will be ok. Living with diabetes isn't a life sentence, but that he is stronger because of it.



## Mixed-Meal Tolerance Test (MMTT)

### What is an MMTT and what do the results mean to you?

An MMTT is a Mixed Meal Tolerance Test. It is a test that measures how well your beta cells are working. We give you a milkshake type drink as a meal. We test your body's ability to produce insulin by measuring the c-peptide level in the blood.

As you digest the shake you drink, your blood sugar goes up. This causes the beta-cells in your pancreas to produce insulin. When children with type 1 diabetes are diagnosed, they can usually still produce some of their own insulin. In fact, after starting insulin treatment, beta-cell function can actually improve for some time. This is called the honeymoon period. This test will tell us how much insulin your body is producing and how your body is able to respond to rising blood sugar levels.

### Why are the MMTTs done?

You do MMTTs because we want to know how well your beta-cells are working. The test tells us how much insulin they are making right after you have been diagnosed with type 1 diabetes. If we know how long the beta-cells are able to produce insulin, it may help us find ways to improve the ability of the beta cells to make insulin, and increase the length of the honeymoon period.

### Does it matter that the blood sugar levels increase with the MMTT?

The shake you are given at your MMTT is designed to mimic any other meal you might have. It contains fats, proteins, and carbs. We are giving all the study children the same shake so the results can be compared to each other. Your blood sugar will go up after you drink the shake just like what happens after you eat. We know this will happen, and we monitor you to make sure that it never gets too high. The test can be stopped at any time if there is a problem. Over time, your body will produce less and less insulin. We will stop doing MMTTs when your body is no longer making very much insulin.

### Why the schedule of 0, 3, 6, 12, etc. months?

Your beta-cells will continue to produce insulin for some time after you are diagnosed with diabetes. Because this time varies from person to person, it can be difficult to predict how long your body will continue making insulin. We test every person in the study several times so that we can see when their body stops making insulin.