The Trial to Reduce IDDM in the Genetically at Risk

TRIGR USA

An NIH-Sponsored Primary Prevention Study for Type 1 Diabetes

www.TRIGR.org **Important News TRIGR Milestone** www.trigrnorthamerica.org This year in Pittsburgh, the first child to be enrolled at this site and the first Fall 2012 eligible TRIGR child turned 10 years of age. To mark this special occasion, a Volume 9 plague was presented to each child to thank them for their dedication to diabe-Issue 1 tes research. **TRIGR Investigators** Lauren and TRIGR Staff. First and Coordinators eligible child at the Pittsburgh site. Children's Hospital of Pitts-burgh of UPMC Dorothy Becker, MD Peggy Franciscus, RN m_franciscus@yahoo.com Columbia University 1 Medical Center Robin Goland, MD Ellen Greenberg, MS emg25@columbia.edu ☆ Mattel Children's Hospital at UCLA Uday Devaskar, MD Heather Horowitz, RD hhorowitz@mednet.ucla.edu * Ponce School of Medicine Brandon and Mom. First mom Jose Torres, MD to enroll at the Pittsburgh site Roxana Colon Roxana.colon@yahoo.com ☆ University of Washington Jerry Palmer, MD Patty Malone, RN malonep@uw.edu Washington University in St. Louis Neil White, MD Marilyn Tanner, MHS RD

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TRIGR

Gifts

Small gifts in life are special. They are not wrapped but presented to be seen in all their glory and given in joy. In our travels for the TRIGR Study we have received some special gifts from the heart. So thank you to all the givers of these gifts:

Original artwork

Craft projects. Sometimes I was not sure of what they are Homemade buns for the cold and weary travelers who had not eaten all day Hand cream made with bee's wax and honey from a 4 H bee keeping project Coupons for needed items such as candy, Gatorade and batteries A medal to keep us safe on our journey Two rocks and a stick chosen with care from their garden The offers of drinks, food and a comfortable place to rest during our visits The warm welcomes into your homes Flowers picked from the garden A much needed bathroom Suggestions for places to eat. Some of the best pancakes ever! An umbrella on a rainy day Photos of the children Hugs and smiles. The greatest gift of all!

Have you ever wondered where other TRIGR families live?

We have two links that you can go to and look at where other TRIGR families are in the United States and the world. These were made by Randi Shannahan from our TRIGR site in LA.

 The first link is a map of USA participant locations. <u>http://batchgeo.com/map/</u> <u>eb7d48c878018d1b3d12bc4f94182ebe</u>. Map #1 shows the locations of all TRIGR study participants in the U.S. Each location marker is color coded by study center (key at bottom). Red- Pittsburgh, PA; Navy Blue- Seattle, WA; Green- St. Louis, MO; Yellow- Los Angeles, CA; Purple- Ponce, Puerto Rico; Light Blue- New York, NY.

2. The second link is a map of all TRIGR international study centers. <u>http://batchgeo.com/</u> <u>map/5b2417dc9806c7a76d848f7b6c1571ef</u> Red- Canada; Navy Blue- Czech Republic; Green- Finland; Yellow-Poland; Purple- Sweden; Light Blue- USA; Orange- all others (Australia, Estonia, Germany, Hungary, Italy, Luxembourg, Netherlands, Sardinia, Spain, Switzerland).

If viewing the maps online, click on the marker on the map to view specific city & TRIGR study center info.

EXTENSION OF THE TRIGR STUDY

The TRIGR team would like to express our sincere gratitude to your family for your commitment and participation in TRIGR. We know how much effort you have put into it and we greatly appreciate this.

Every child and family who takes part in TRIGR plays an important role to further our knowledge of the process that might lead to diabetes. Our goal for TRIGR is to study whether early nutritional intervention would prevent or delay the development of diabetes in children, like yours, who are genetically at risk.

Our initial plan was to follow your child until 10 years of age. However, it is not well known how puberty may affect the development of diabetes-associated autoantibodies and diabetes, and therefore we would like to continue the observation of all TRIGR participants till the youngest child reaches the age of 10 years in 2017. The oldest participant will then be 14-year-old. Your child will have one to four additional visits, if he/she is born between May 2002 and February 2006. Once the study is completed in 2017, you will be informed of which study formula your child received during the intervention period.

The additional annual follow-up visits after the 10-year visit will be similar to the current annual TRIGR visits including measurement of height and weight, physical examination and blood sampling. An additional 2-hour oral glucose tolerance test will be performed at the last visit.

We are also interested in obtaining a one-time sample for further genetic testing. This sample will be used to analyze new types of genes that may be associated with the risk of developing type 1 diabetes. This blood sample would be obtained with your child's annual blood draw. We hope that you will be interested in continuing in the study with us. For your child to be entered in this extension phase of the study you will be asked to sign a revised Informed Consent at your next study visit.

On behalf of the study group, we again thank you.

TRIGR Family Highlight from Germany

Hi, I'm Anouk. I live on a farm in a small village near Wolfsburg in Lower Saxony. I am 9 years old and in fourth grade. I have a small pony named "Flecky". Santa Claus brought it me three years ago. I take riding lessons with my friend every Friday. My hobbies are riding, vaulting (sport with horse) and drawing. I go to art school (the "Mice-Workshop" in Sülfeld), where I have done etchings. Etchings are complex prints. First we scratch our designs into a metal plate then paint them with different colours before printing them. Our class has already made beautiful calendars with our pictures and have won prizes. Here is a picture of one of my etching. When I grow up I would like to become an artist. During my free time, I play with my brothers, sisters and friends. We have lots of hiding places in our yard where we sometimes secretly eat candies or just laze around. Of course I have to look after my pony too. Every day it has to be taken out of the paddock to be cleaned then we have to clean the horse stable. I walk to school every day with my friends Jacob and Pauline. Our small village school is fun. We have only 16 pupils at our class. This year we have started to learn Spanish. We also had a great class trip to the Altenhausen castle. So, that's about me - and what do you do?

Yours, Anouk





TRIGR Family Highlight from United States



My name is Sophia and I am six years old. I am in the first grade and live in Charleston, West Virginia with my mom and dad and my dog Lulu. I also have two African Dwarf Frogs and I really want a guinea pig! My mom says that I will have to wait until I am older to have one so I am trying to be patient. My mom has Type 1 Diabetes and she said she has had it since she was seven years old. She said that back then she had to take shots every day but now she can use an insulin pump and that it is much better. My family told me that I am in the TRIGR study to try to help doctors understand why kids get diabetes. The arm sticks hurt a little but it's ok.

The last time Peggy came to my house to do the test and brought me a present and a great t-shirt. The TRIGR people are really nice and they always remember my birthday. I don't mind the study because I want to help and maybe someday people like my mom will

get better. Plus my mom lets me get a treat after the tests. I LOVE sweets. My mom says they are ok "in moderation" which means just sometimes. I told her that I didn't have a sweet tooth. I have sweet TEETH!

My mom and dad have taught me a lot about eating healthy and getting lots of exercise. My dad is a really great cook and makes good food for us every day. I love to exercise because it makes me healthy

and I want to be fit and strong! I have been taking horseback riding lessons since I was four and I also started Aikido this year and I love it. It makes me feel strong and I will be getting my yellow belt soon. I am really excited about it. I will also be moving out of the little kids "lead line" at our horse shows next spring and will get to ride alone in the ring. I love horses and I think riding is really fun. I love my family very much and I know that they love me too because they tell me everyday that they do and that they are proud of me. I think that we make a great team.



TRIGR Family Highlight from Australia



My name is Alissa. I am 6 years old. I live in Cootamundra, Canberra, New South Wales, Australia.

I like ice-cream, chocolate and lollies. My favourite toy is my big and small pigs. I like school and playing soccer. I like to eat meat. I like to play with animals. I like fruit and vegetables. I love swimming in summer.

I love going to Nan and Pop's farm and my Uncle and Auntie's farm.

My mum has Diabetes. Dad likes going to the beach. I like music and dancing. I also like watching TV. I made the front cover to the TRIGR Calendar this year! Hope you like it.



TRIGR Family Album



Angelic Ava on her first communion.



We love the creative costumes. Matt The Rockstar, Gracie the cat and our John Deere Service Tech Sam.



Beautiful fall day for Abigail to be rock climbing.



Emily at National Hip Hop Dance competition in Pittsburgh

News Briefs

<u>TrialNet</u>

TrialNet is screening relatives of people with type 1 diabetes to find out if these family members are at risk for developing diabetes. Screening involves a simple blood test. Screening can be done on first degree relatives (mom, dad, sibling) of a person with type 1 diabetes if they are between the ages of 1 and 45.

Relatives (cousins, uncles, aunts, nieces, nephews, and half siblings) can be screened if they are between the ages of 1 to 20 years. If you are interested

in participating in the TrialNet study, please go to the website for more information at <u>www.diabetestrialnet.org</u>.



Moving or Changing Your Phone Number or Email?

Please let your TRIGR site coordinator know ahead of time if possible of your new address and any changes in your home or cell phone numbers. We also like to keep a current email address since many of the families like to communicate with the site staff via email. We want to be able to stay in touch with your family and want to make sure all of our information is current.