



TRIGR USA

An NIH-Sponsored Primary Prevention Study for Type 1 Diabetes

Important TRIGR Updates

By Peggy Franciscus, RN Children's Hospital of Pittsburgh of UPMC TRIGR Coordinator

www.TRIGR.org
www.trignorthamerica.org

In 2008, the first children enrolled in the TRIGR Study will turn 6 years of age. This is an important milestone for the TRIGR study. When your child turns 6 years old and during the 6 year follow-up study visit, the study nurse or study doctor will discuss the autoantibody results with the families. Your child will also be scheduled to have an oral glucose tolerance test.

What are ANTIBODIES and what are AUTOANTIBODIES?

Antibodies are proteins produced by the body which react specifically with a foreign substance such as an infection, in the body. Normally, the immune system is able to recognize and ignore the body's own cells and to not overreact to non-threatening substances in the environment, such as foods.

Sometimes, however, the immune system ceases to recognize one or more of the body's normal constituents as "self," leading to production of autoantibodies. An **autoantibody** is an anti-body (a type of protein) manufactured by the immune system that is directed against one or more of the individual's own proteins. These autoantibodies attack the body's own cells, tissues, and/or organs, causing inflammation and damage.

Type 1 diabetes mellitus is the autoimmune form of diabetes. It is caused by the destruction of cells of the pancreatic tissue called the **islets** of Langerhans. The destruction of these cells is caused by an abnormal immune response creating autoantibodies. TRIGR is testing the autoantibodies which attack the insulin-producing cells in the pancreas. There are several different types of autoantibodies, which are called islet cell autoantibodies.



Jessica

The islet cell autoantibodies most associated with the development of Type 1 diabetes are: **IA-2A (Insulinoma-Associated-2 Autoantibodies)**, **GADA (Glutamic Acid Decarboxylase)**, and **IAA (Insulin Autoantibodies)**.

If one or more of these test results are positive or above normal, your child's risk for type 1 diabetes may be increased. This does NOT mean your child will definitely get diabetes. Sometimes a positive antibody test returns to normal. The results of the autoantibody tests will be discussed with you by the study coordinator or the study doctor.

WHAT IS AN ORAL GLUCOSE TOLERANCE TEST (OGTT)

The Oral Glucose Tolerance Test measures the body's use of glucose (sugar). Glucose is the body's main source of energy. Insulin, produced by the pancreas, helps people use glucose. People with certain disorders, such as diabetes, do not use or produce insulin well and therefore the body can not use it's glucose.

The test takes at least 3 hours. Some blood laboratory levels are affected by food. Your child will not be able to eat 8-12 hours before the test. They may have only water to drink. Your child will be given a special sweet drink. Blood samples will be taken before your child drinks the sweet liquid and then at 2 hours after the start of the test. It is important that your child drink the liquid within 5 minutes. When the test is finished, your child will be given a meal. Your child should not feel any side effects from the test. Your study coordinator will give you specific directions regarding diet, time, date of test, and when your child will need to stop eating, etc.

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TRIGR Tale From Charleston, West Virginia

For many years I had convinced myself that having a child was a bad idea-too risky for my own well-being (even though I have been on an insulin pump for almost ten years and am in great health) and I was afraid of having a baby that might have birth defects or develop Type 1. My husband is from a big family and has four siblings. I, on the other hand only have one brother so our ideas of "family" were very different. But despite having grown up with the happy chaos of a large brood, Larry was willing to forgo his dream of having children of his own, and had told me that he was willing to adopt if I decided I didn't want to have a baby.

By the time I was 35 years old though I could not deny the fact that I wanted a child of my own. And strangely enough, having a husband who was willing to give up children for me made me want to give him a child of his own even more. So I faced down my fears head on and decided that I could handle the risks, and so in the fall of 2005 Larry and I decided that we would try to have a baby. I had myself convinced that I wouldn't be able to get pregnant however. Living with Type 1 since I was seven years old gave me the attitude that my body would probably not cooperate. I had battled for control over this disease for years and I had no reason to anticipate getting a break on the fertility front, even though I had no other health problems that would prevent me from getting pregnant. I was shocked when I got pregnant the first month we tried to conceive. Shock gave way to panic. Keeping my Hgb A1C in the right range, not gaining too much weight, checking my blood sugar 12-14 times a day....it all seemed so overwhelming. But I took control of the situation and stayed on top of my blood sugar. In my second trimester I was reading a pregnancy magazine and saw a short article on the TRIGR study. I was intrigued and decided right away that I wanted to enroll our baby in the study. I was surprised to quickly receive a warm and friendly email from Peggy Franciscus from TRIGR telling me that they would type the baby's blood at birth to determine if she qualified for enrollment. I continued to have a happy, uneventful pregnancy until my last three weeks when I began to really feel badly due to serious pre-eclamptic symptoms. By that time I couldn't wait to have the baby. We knew we were having a girl and I was so anxious to find out if she was healthy.



Sophia Morgan Messina was born on August 4, 2006 and weighed 9 lbs, 3 oz. She was perfect and healthy and I was incredibly relieved and happy. About a week later Peggy contacted me and told me that Sophia had enough of a genetic predisposition to Type 1 that she would be accepted into the study. I cannot say that I was surprised by that news as my mother is Type 1 as well and I had been bracing myself to hear that she had inherited the genes for Type 1. The first year flew by and I have to say that it pained me to have Sophia's blood drawn so often-but she was a trooper and rarely ever cried. Also having the support of Peggy and Maryellen Dalmagro-Elias-the TRIGR nutritionist that I worked with so closely was so helpful to me.

Ultimately being in the TRIGR study gives me a sense of strength and control. I am not the type to put my head in the sand and avoid unpleasant situations. If Sophia ever begins developing antibodies I want to know right away. If she develops Type 1 we will deal with it. Having that information will help me face the situation head on and with strength and courage. I also like knowing that our family along with all of the other TRIGR families are doing something very important-

this study could possibly alter the course of treatment for children everywhere someday or even hold a key to a cure for Type 1. I like making that small contribution toward that goal-that is our gift to the world of research. When I think about what gifts I can give to my daughter I see that the best things I can offer to her are unlimited amounts of love and being a role model showing her that with or without Type 1, a positive outlook and determination can help you achieve anything your desire. I do know this. Every time that I look in her beautiful, curious, and joyful little face I see how worth it she is-regardless of what the future holds for our family.

Lesly Messina



Baby Get Up and Move!

Promoting Activity for Toddlers

By Marilyn Tanner-Blasiar, MHS, RD, LD
Washington University in St. Louis TRIGR Coordinator

When we think of toddlers, we often imagine them "toddling" around as they learn to walk. Yet according to recent figures from the CDC, today's toddlers aren't moving as much as they should, because 13.9% of 2-5 year olds are overweight, and approximately 26.2% are overweight or at risk for overweight.¹ More research and observational studies are needed, but to reverse this trend, current recommendations include eating healthy foods, limiting television time, and promoting daily activity.²

Over the years, the focus of pediatric nutrition has shifted from under-consumption and nutrient deficiencies to over-consumption and decreased energy expended in physical activity.³ Although there is insufficient evidence to recommend exercise programs or classes for toddlers as a means of preventing obesity in later years, the American Academy of Pediatrics does encourage parents to provide a safe, nurturing environment that allows the toddler to have supervised physical activity and unstructured exploration.

The National Association for Sport and Physical Education has created some guidelines to help answer questions regarding how much and what types of activity are recommended for this age group. (See "Activity Guidelines for Toddlers") These guidelines represent a total of 1.5 hours minimum of daily activity. Note that the converse is also true: parents should encourage a decrease of inactivity. There should be no more than 60 minutes of sedentary behavior at a time, except when sleeping.

In addition, studies have shown that screen time is already a concern at this young age. According to research by the Kaiser Family Foundation study, children between 6 months and 6 years of age are exposed to media on average of 2 hours a day.⁴ Thirty-six percent of these children have a TV in their bedrooms. A follow-up survey revealed that parents exposed their children to screen media intentionally because they believed it was "very important" for their children's intellectual development. For example, there are baby videos specifically aimed at children 1-18 months old. Currently, there is no evidence that these videos have positive effects on toddlers.⁵

The American Academy of Pediatrics is concerned with screen time in very young children. They recommend no TV at all for children 2 years of age and under, because of its potentially negative effects on development and physical activity. These early years are especially important in the growth and development of the brain. The AAP encourages more interactive activities with other children and adults to promote brain development. These include talking, playing, singing, and reading together.

Interactive behaviors help children learn by example (they then mimic sounds, movements, and words) and encourage participation versus the passive action of viewing the television.⁶ For children age 2 years and older, they recommend that screen time be limited to less than 1-2 hours of quality programming a day.

Recently, the University of Missouri-Columbia Extension health educators developed an expanded version of the MyPyramid food guide for kids for activity. The MyActivity Pyramid is a reminder for kids ages 6-11 of how to include physical activity in their lives.⁷ Although this is designed for older children, the concepts also apply to younger children, and include everyday activities such as active play, walking, or picking up toys; aerobic activities, running, play ground activities, or throwing a ball; and flexibility and strength activities such as stretching. Developing an interest in activity and movement in the toddler will instill healthy habits for the future.



A day at the park

(Additional information on Activity Guidelines for Toddlers on page 6).

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Prevent the "Travel Boredom Blues" on Your Next Family Vacation

Breinne Regan, MS, CCLS

With the warm weather approaching, you may be thinking, (or dreaming) of your next family vacation. A vacation can be a relaxing and enjoyable time for your family. Vacations are a time for your family to bond and to enjoy each other's company. Maybe you are traveling to another country or going to visit the grandparents. Whatever your destination may be, if the children are coming, you will want to keep them entertained during your travels.

This article will discuss several ways to keep your children amused while traveling. Whether your child is 6 months old or 10 years old, there are a variety of activities to help ease your children's "travel boredom blues." When planning travel activities, it is important to focus on your children's interests and create activities based on what they enjoy. Just remember to be creative; the possibilities are endless!

Here is a table of several activities based on the different development levels. These activities can be used whether you are traveling by plane, train, or car.

<p><u>Infants</u></p> <ul style="list-style-type: none"> Rattles Calming music Bright toys Toys with different patterns and textures Sensory toys Musical toys (not too loud!) Large blocks (different shapes) Pop-up toys A plastic mirror Blanket 	<p><u>Toddlers</u></p> <ul style="list-style-type: none"> Bubbles Silly songs Containers with lids Items to put into the containers Stuffed animal Blanket Busy boxes with pulleys, levers and bells A variety of sensory toys Picture books
<p><u>Preschoolers</u></p> <ul style="list-style-type: none"> Coloring books (washable markers or crayons work best!) Activity books Play sets Tic Tac Toe Draw pictures and have your child guess what it is Books Blocks Chalkboard Etch-A-Sketch Magna doodle Wooden puzzles Cars Dolls Puppets Disposable camera Tell a story or have your children make up a story 	<p><u>School-Aged Children</u></p> <ul style="list-style-type: none"> Activity books Drawing tablets Word guessing games I spy games Ad-Libs Books Walkman or an I-Pod Magna doodle Etch-A-Sketch Felt boards Card games Travel sized board games Hand held games Cars Yarn Lego sets 20 Questions Game

Other ideas:

- * **Scavenger Hunt:** Create a list of objects or items you know you will be seeing during your travels (rest stops, trees, different types of flowers, and signs). Create your list using words for older children and pictures for younger children. Have your children look for the items on the list during your travels.
- * **Photographs:** Provide your children with disposable cameras. Have the children take pictures while you are traveling. When you get home, your children can create their own scrap book to help them remember their vacation.

- * **The Alphabet Game:** While traveling, have your children name items they see that correspond with a certain letter of the alphabet. It may be easier to start at the beginning of the alphabet with the letter A and work your way to Z. Letter A could be an Airplane or an Apple tree, B could be a bird or bus. Allow your children to be creative with their answers. The game is not over until you reach the letter Z!
- * **Portable DVD Players:** Movies and shows are very popular with children of all ages. Many portable DVD players have head phone jacks so the movie will not disturb others.

Vacations can be a wonderful experience for the entire family. Keeping your children entertained during your travels is an important component to a happy vacation. Whether your family is traveling across the country or 100 miles from home, it is important to be safe, have fun, and enjoy the experience. Happy travels!

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Summer family fun at the beach



Two children watching a movie while traveling

For more information on the Child Life Profession please visit the Child Life Council's Website at www.childlife.org

TRIGR FAMILY ALBUM



Nia



Julia



Caitlin

Thank you for sharing your family pictures with us. We love to see how the children are growing up so quickly.

TRIGR FAMILY ALBUM Continued



Gracie's Birthday Party



Superman
Kyle



First eligible child in Pittsburgh

Additional information on Activity Guidelines for Toddlers

- * Toddlers should accumulate at least 30 minutes daily of structured physical activity.
- * Toddlers should engage in at least one to several hours per day of unstructured physical activity, and should not be sedentary for more than 60 minutes at a time, except when sleeping.
- * Toddlers should develop movement skills that serve as steps toward more complex movement tasks.
- * Toddlers should have indoor and outdoor areas that meet or exceed recommended safety standards for performing large muscle activities.
- * Individuals responsible for the well being of toddlers should be aware of the importance of physical activity and facilitate the child's movement skills.

Parents can try these activities for active fun with their children:

- * Pretend to be animals-move and sound like elephants, dogs, or bears.
- * Make picking up toys a fun activity by seeing how fast you can do it.
- * Throw a soft ball back and forth, or into a makeshift basket.
- * Make your own obstacle course using old boxes, blankets, and soft toys.

Source: National Association for Sport & Physical Education NASPE Guidelines for Toddlers and Preschoolers.
<http://www.aahperd.org/naspe/template.cfm?template=toddlers.html> accessed 6/29/2007.



News Briefs

Moving or Changing Your Phone Number?

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 want to be able to stay in touch with your family and want to make sure all of our information is current.

Is your family growing?

There is a research study that is now recruiting called TEDDY. Our Pittsburgh and New York sites are currently participating in this study.

TEDDY (The Environmental Determinants of Diabetes in the Young) is recruiting all newborns, under the age of 3 months with a family history of diabetes. For more information please contact either the Pittsburgh or New York site. Contact information on front page of this newsletter.

Picture from Puerto Rico



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