

Trisomy 21 Update

A Newsletter from the Trisomy 21 Program at The Children's Hospital of Philadelphia

Fall 2011



10TH ANNUAL CHOP The Children's Hospital of Philadelphia® BUDDY WALK® & FAMILY FUN DAY

October 2nd, 2011 marks the 10th Children's Hospital of Philadelphia (CHOP) Buddy Walk® and Family Fun Day sponsored by Northwestern Mutual – The Guinan Financial Group. The CHOP Buddy Walk® benefits the Trisomy 21 Program at CHOP. Nationally, the Buddy Walk®, a trademark of the National Down Syndrome Society, is one of the largest Down syndrome fundraising events, with more than 300 locally-organized walks around the world.

For the CHOP Buddy Walk® and Family Fun Day, approximately 4,500 moms, dads, grandparents and children from all across the tri-state region of Pennsylvania, Delaware and New Jersey will walk around the track together in the spirit of camaraderie, to promote acceptance and inclusion of people with Down syndrome and celebrate their many accomplishments. The Buddy Walk® and Family Fun Day is staffed by more than 150 volunteers and features a full slate of great activities, including food, music, moon bounces and mascots. In nine years, the CHOP Buddy Walk® and Family Fun Day has raised over \$1.9 million for the Trisomy 21 Program at The Children's Hospital of Philadelphia.

continued on page 4

The Trisomy 21 Program at the Children's Hospital of Philadelphia
is proud to host a

New Parent-Family Reception

October 22, 2011 • 9am-12pm
3535 Market Street, Philadelphia, PA

The New Parent-Family Reception will provide guidance to families with children less than 2 years of age, to assist them on this new journey.

According to Brooke Goodspeed, "Hearing unexpected news is a frightening and overwhelming experience". She and her husband, Jonathan, experienced this first hand after learning their second child had Down syndrome shortly after his birth. In an instant they found themselves thrown into a world of unknowns for which they were not prepared. "Pouring hours into reading books and talking to medical

continued on page 4

Occupational Therapy in the Pool

Wish summer could last all year long? It can! Enroll your child now for aquatic therapy at CHOP! Aquatic therapy is a fun, effective way to help your child build strength, coordination, and body awareness, while promoting water safety too. Caregivers will learn skills and techniques that they can use with their child on a daily basis to promote strengthening, problem solving, and acquisition of new developmental skills. Aquatic therapy sessions are held in small groups of 2-4 families and are lead by April Andrescavage, an occupational therapist in the Trisomy 21 Program. This special program for children with Down syndrome has been very popular in the past, so sign up now by contacting April at andrescavage@email.chop.edu.



Trisomy 21 Team

David Lynch, M.D., Ph.D.
Program director

Stephanie Rosati-Pratico
Program coordinator

Mary Pipan, M.D.
Clinical director

Kim Schadt, M.S.N., C.R.N.P.
Assistant director

Symme Trachtenberg, M.S.W.
Director of community education

Helen Milligan, M.P.T.
Physical therapist

Rita McGeever
Medical secretary

Tahira Adelekan, M.D.
Developmental pediatrician

Rosemary Eikov, C.R.N.P.
Nurse practitioner

Patty Huang, M.D.
Developmental pediatrician

Hillary Kruger, M.D.
Developmental pediatrician

Jaclyn Blady, P.T., D.P.T.
Physical therapist

April Andrescavage, OTR/L
Occupational therapist

Susan McCormack, M.A., CCC/SLP
Speech therapist

Amy Levin, M.A., OTR/L
Occupational therapist

Contact Information

The Children's Hospital of Philadelphia
Trisomy 21 Program
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Philadelphia, PA 19104-4399

Office voicemail: 267-426-5283

E-mail: trisomy21@email.chop.edu

Web site: www.chop.edu (In search box, type "Trisomy 21.")

Ask the Doctor

We welcome all questions! Please send to trisomy21@email.chop.edu.

Questions will be presented anonymously to our T21 team, and answers may appear in upcoming newsletters. Please submit your questions about caring for children with Down syndrome. Subjects can include child development, neurology or other issues.

Occupational Therapy Quick Tips:

It is easy and fun to make developmental toys from items that you can find around your house!

Creating a pegboard out of a parmesan cheese container! Clean out a finished cheese container making sure to keep the screw on lid with holes. Cut 3-4 straws into 3 inch pieces and slide them through the holes in the top of the cheese container. This toy can be use to develop hand eye coordination, grasp progression, and hand strength to open and close the container. Have fun!

Creating stacking cups out of plastic food containers! Instead of recycling that macaroni salad container, save it! Collect various size containers that can fit inside each other for fun stacking and nesting cup play. This toy can be used to develop problem solving skills, hand eye coordination, and controlled release. Get stackin'!

Working on pincer grasp at snack time using an egg carton! Put one small snack such as cheerios or gold fish into each hole of an egg carton and let your child use their fingertips to get the snack out. This can help to develop a pincer grasp which will enable your child to pick up small objects using the thumb and index finger. Enjoy!

Do you need more services or equipment for your child?

If you need a service or piece of equipment that is medically necessary for your child, and live in Pennsylvania, contact your Medical Assistance Health Maintenance Organization (MA HMO). Ask for the Special Needs Unit to discuss your child's needs. The number should be on the back of the card. Describe for the case manager all of your child's medical needs. If your concerns are mostly behavioral the behavior health insurance carrier will need to pay for it. Sometimes the Intellectual Disabilities (formally Mental Retardation) or Division of Developmental Disabilities service system in New Jersey can help. Ask for the Service Coordinator. Find out what services your child is eligible for.

If your request is medically based your doctor can write a Letter of Medical Necessity. You need to let your child's doctor know what you need, why, and for how long you think you will need it. Remember each state and each insurance company has its own rules and services.

Examples: diapers for a child over 3 years old, a home health aide to assist with mealtime, a wheelchair, etc.

Is your child 16 years of age or older? Are you wondering how to plan for the future, or have questions about your child's IEP? Please contact our social worker, Symme Trachtenberg, MSW, LSW at trachtenberg@email.chop.edu or (215) 590-7444.

Interview with:

Babette Zemel, PhD, Division of Gastroenterology, Hepatology and Nutrition

What is the Down Syndrome Growing Up Study?

The Down Syndrome Growing Up Study is a research project to develop new growth charts for children with Down syndrome. The current growth charts for children with Down syndrome are out of date and do not reflect the patterns of growth that we now see in children with Down syndrome. In order to create new growth charts, we need to measure the height and weight of hundreds of children with Down syndrome. We also need some additional information about health and factors that affect growth – like feeding problems.

The U.S. Centers for Disease Control (CDC) and Prevention is responsible for the growth charts for typically growing children that pediatricians use. A few years ago, the Down syndrome care community went to the CDC to express their concerns about the outdated growth charts for children with Down syndrome. As a consequence, the CDC decided to support researchers at CHOP to develop new growth charts and determine the best way to screen for obesity in children with Down syndrome.

It is very important for us to include as many children as we can in this research study, so that the new growth charts will describe how children with Down syndrome grow. The study visits take about half an hour and are conducted at all of the CHOP Specialty Care Centers. It will take a few years to gather all the information and create the growth charts. Once they are completed, pediatricians and other health care professionals will have the charts they need to assess growth in children with Down syndrome.

Why do children with Down syndrome need their own growth curves?

For all children, growth is measured at every visit to the pediatrician's office because growth is an important indicator of the overall well-being of a child. Growth problems can be due to nutritional issues and / or underlying health conditions. Sometimes, the change in a child's growth pattern is the first sign of a change in health.

It has been recognized for a long time that children with Down syndrome do not grow like typically developing children. They grow more slowly in length and height, and are generally short as adults. Although researchers do not know why their growth pattern is different, it is thought to be influenced by their genes. For this reason, it can be misleading to compare growth outcomes in children with Down syndrome to the growth charts for typically developing children. When the growth of a child with Down syndrome is measured in the pediatrician's office, it is most informative to know how their growth compares to other children of the same age with Down syndrome.

What have you learned so far?

So far, we have learned that children with Down syndrome are growing better than they did twenty years ago. At some ages, children are taller than they used to be. The rate of obesity has also been increasing, just as it has in typically growing children. However, there is still a lot that we need to learn about how children with Down syndrome grow and the factors that influence their growth.

How can families sign up to participate?

Families who would like to know more about the study or are interested in being a part of the Down Syndrome Growing Up Study can contact the study team at 215-590-2913, or email

hallw@email.chop.edu.

You can also talk to the Trisomy 21

Clinic about the study. We will tell you all about the study and schedule the study visit. Visits take about

30 minutes. There is a modest reimbursement for study participation.



New Parent Reception

continued from page 1

professionals was helpful in shaping our understanding of how best to provide for our new baby,” Brooke said. “However, reaching out to families that had been in our same shoes was like a much needed hug. Someone saying ‘hang on, I’ve been there’ is the comfort sometimes needed most during the early adjustment period. The comfort of understanding support, information, and advice-from someone who understands your perspective first-hand.” This inspired Brooke and Jonathan to work with the Trisomy 21 Program at CHOP to develop the New Parent-Family Reception.

For more information call, email
or go to our website:
[www.chop.edu/service/trisomy-21/
home.html](http://www.chop.edu/service/trisomy-21/home.html)

The Trisomy 21 Program

267-426-5283
trisomy21@email.chop.edu

Updated Car Seat Recommendation

In March 2011, the American Academy of Pediatrics updated their car seat policy, advising parents to keep their toddlers in rear-facing car seats until age 2, or until they reach the maximum height and weight for their seat. It also advises that most children will need to ride in a belt-positioning booster seat until they have reached 4 feet 9 inches tall and are between 8 and 12 years old. Children should not ride in the front seat of a car until they are 13 years old. This is a change from the 2002 policy that cited age 12 months and 20 pounds as a minimum before turning a child forward-facing.

The Automotive Safety Program at the Indiana University School of Medicine publishes information about transportation for children with special needs. It recommends that children with Down syndrome remain rear-facing as long as possible and suggests using a convertible car seat that allows children to ride rear-facing up to 30-35 pounds after the child outgrows the infant-only seat. Children with Down syndrome may have decreased muscle tone or unstable neck bones and a rear-facing car seat provides the most support to the head, neck and spine in the event of a collision. More information about transporting a child with special needs can be found at www.preventinjury.org.

Is your child’s car seat installed correctly? Have it checked by a child passenger safety technician! A list of local technicians can be found by searching “car seat check” at www.chop.edu or at www.seatcheck.org.

Additional information about car safety seats, including purchasing a car seat, can be found at www.healthychildren.org/carseatguide.

Buddy Walk

continued from page 1

Interested in getting involved? Here are some ways:

- Bring your family and friends to the Walk - Create a team – go to www.giftofchildhood.org/buddywalk to download to the team captain packet and learn more
- Need a service project? Contact Rebecca Elias at 267-426-6489 or elias@email.chop.edu to discuss ideas and how this would work
- We are always looking for raffle items or silent auction items for the raffle/silent auction tent
- Want to volunteer the day of the event? Contact Rebecca for more information

We look forward to seeing you there!

Introducing the
Trisomy 21 Parent Peer Program

**In collaboration with
Parent to Parent of Pennsylvania**

We want to tell you about an exciting new program that is being offered by the Trisomy 21 Program at The Children's Hospital of Philadelphia in collaboration with Parent to Parent of Pennsylvania. Together we will be developing a support network of parents, caregivers and siblings of individuals with Trisomy 21 (Down syndrome) through the creation of the "Trisomy 21 Parent Peer Program."

The purpose of the "Trisomy 21 Parent Peer Program" is to provide caretakers (parents, siblings and guardians) with much needed social, emotional and informational support. Research has demonstrated that support and practical guidance from experienced caregivers provides valuable assistance to fellow caregivers dealing with their child's special needs. We recognize the need for this type of support does not vanish with age. The "Trisomy 21 Parent Peer Program" is designed to support families of individuals with Down syndrome from infancy through adulthood living in the Pennsylvania area.

To implement the Parent Peer Program, the Trisomy 21 Program will utilize the current matching and follow-up structure provided by the Parent to Parent of Pennsylvania (P2P of PA) program.

Parent to Parent of Pennsylvania and the Trisomy 21 Program would like to take this opportunity to personally invite you to become a part of the first generation of "Trisomy 21 Parent Peers". It is our mission to recruit Parent Peers from each age group, from infancy through adulthood. If you would like to become a part of this program, your participation will involve additional training including a single instructional session lasting 2-3 hours that will provide formalized preparation in best practices allowing you to offer the unique one-to-one support that only a caregiver can provide. If you are interested in becoming involved in the "Trisomy 21 Parent Peers Program", please contact Kim Schadt at (267) 426-8627 or schadt@email.chop.edu.

Many thanks to the 30 families who have already signed up!

 **The Children's Hospital of Philadelphia®**

Hope lives here.



Community Resources for Families

The Community Resources database offers families and professionals the opportunity to see what resources are available in the region and, in some instances, across the country. To access the database, visit: www.chop.edu/crf

If you know of any resources not listed please let us know by sending an email to Trisomy21@email.chop.edu

Ask the Advocate

You are your loved one's best advocate

By Stephanie Rosati-Pratico, Trisomy 21 Program Coordinator

My daughter is in first grade and after only a few weeks of school she is having problems handling the work. It has gotten to the point where she doesn't want to go to school. The district is stalling on having her tested and in the meantime my daughter's frustration is growing. What can I do?

The Individuals with Disabilities Act 2004 (IDEA) ensures that all children with disabilities receive a free appropriate public education. IDEA includes the Child Find mandate which requires all school districts to identify, locate and evaluate all children with disabilities from birth to age 21. The mandate applies to all children who reside within a state. It does not depend on severity of the child's disability.

Write a letter to the Director of Special Education in your town. The Child Study Team has 20 days to notify you in writing of their decision of whether the child does or does not need an evaluation. If the determination is not favorable you have the right to file for mediation. If your daughter is evaluated and considered not eligible for services, you can request an independent evaluation at the districts expense.

Advocacy tip: Always put your requests/correspondence in writing. Date it and keep a copy.

I recently heard the term 'person first language' used in reference to those with Developmental Disabilities. Can you tell me what that means?

'Person first' language is a term used to describe the positive emphasis when referring to people with disabilities. As with all individuals, those with a disability deserve to be respected and valued as a person *separate from* their disability. The truth is that most people prefer to not have their disability mentioned at all. It is suggested that instead of referring to "an autistic child" you would say "a child with autism." Putting the disability before the person increases the stereotypical (typically negative) view that the disability defines the person. In fact, those with a disability tend to have more courage and endurance than most.

Advocacy Tip: 'Person first' language means to emphasize the person not the disability.

Submit your advocacy questions to Trisomy21@email.chop.edu. This column is not intended to take the place of a formal legal or medical consult.