

Trisomy 21 Update

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

Fall 2007



The Children's Hospital of Philadelphia Buddy Walk and Family Fun Day

Sunday, September 30, 2007



Save the date for The Children's Hospital of Philadelphia Buddy Walk and Family Fun Day on Sunday, Sept. 30, 2007 at 10 a.m. at Villanova Stadium on the campus of Villanova University.

The walk raises funds for patient care, research and education for the Trisomy 21 Program at Children's Hospital. Trisomy 21, or Down syndrome, affects more than 350,000 people in the U.S. This event is great fun for the whole family and includes a walk, food, music and activities for all.

We hope to see you there! For more information, please visit www.tri21center.org, or contact Rebecca J. Elias at 267-426-5600 or by e-mail at events@email.chop.edu.

Spotlight on:

Tabira Adelekan, MD

Dr. Tahira Adelekan is a developmental behavioral pediatrician who has recently joined the T21 team. After attending the University of Texas Medical School at San Antonio and completing a pediatric residency at Downstate Medical Center in New York City, she came to The Children's Hospital of Philadelphia for fellowship training in developmental behavioral pediatrics.

Dr. Adelekan became interested in children with special needs during residency, when she noticed that medical issues of children with special needs were often not detected as early as other children. One of her goals in working with children with the T21 program is to help general pediatricians create optimal medical homes for children with Trisomy 21 and other special needs, encompassing both their medical and developmental issues.

From her experience with working in our T21 program thus far, she says "I've learned to focus on the child and the child's strengths, more than the IQ (intellectual quotient) or the DQ (developmental quotient)."

T21 email list

If you would like to be added to the Trisomy 21 program email list, please send an email to us at trisomy21@email.chop.edu.

DufferFest 2007

Congratulations to the family and friends of Kara Kenney who successfully hosted the first annual Dufferfest on 6/23/07. This all day family-fun music festival helped to raise more than \$20,000 for our Trisomy 21 Program. **Thank you to everyone who supported the event and contributed to its success.**

Upcoming Educational Sessions:

The next educational session will be held on Saturday, 11/3/07 from 9am-12pm. Topics will include sexuality, a father's perspective on T21, preparing for adolescents and beyond, and transition 101. Look for further information on our website.

Trisomy 21 Team

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

Mary Pipan, M.D.
clinical director

Kim Schadt, R.N., B.S.N., C.C.R.P.
program coordinator

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

Dorothy Brightcliffe, R.N.
family consultant

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

Patty Huang, M.D.
developmental-behavioral pediatrics fellow

Hillary Kruger, M.D.
developmental pediatrician

Contact Information

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(In the 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.

Information on Local Down Syndrome Interest Groups (DSIGs)

In an attempt to provide information without duplicating the efforts of local Down syndrome interest groups (DSIGs), we will be highlighting area DSIGs in our program newsletter. By drawing attention to these various groups we hope to provide parents an opportunity to become involved locally, while also offering group contact information, website access, and the ability to sign up for any electronic newsletters, resources or information they may offer. DSIGs wishing to be highlighted in upcoming issues of our newsletter can contact us by emailing trisomy21@email.chop.edu.

Bucks County DSIG: Diana Santoro

The Bucks County Down Syndrome Interest Group (BCDSIG) is a community organization dedicated to providing resources and support to families, therapists, physicians, educators and others affected by Down syndrome in Bucks County, PA. New parent outreach is a top priority.

We are:

- Dedicated to improving access to the most advanced and innovative care to promote health, education and independence
- Working together to raise awareness and communicate issues related to Down syndrome and the rights of those with disabilities
- Providing support and information to our members and those interested in Down syndrome
- Advocating the needs of people with Down syndrome

The BCDSIG is comprised of more than 70 families who share resources and actively participate in monthly informational meetings and social events throughout the year. To find out more about BCDSIG meeting dates, locations, events and information, please visit our web site at www.bcdsig.org or call 215-766-0890. To subscribe to our weekly eNewsletter, please email Diana Santoro at dgsantoro@gmail.com

Montgomery County DSIG: Chris & Rose Townsend

When our family was faced with the diagnosis of Down syndrome, our first priority was to speak to someone who had experienced this diagnosis themselves. We found the support needed from a member of the Montgomery County Down Syndrome Interest Group (MCDSIG). Through MCDSIG we have met many families with children of all ages, both typically develop-

Interview with:

Frances Rosenblum, MD, General Pediatrics

Dr. Frances Rosenblum graduated from Medical School in 1975. She moved to Lansdale, Pennsylvania in 1979 to practice general pediatrics and has been with the same pediatric group, now called Kids First Highpoint, since then.

How did you become interested in caring for children with Down syndrome?

My interest came from a more general interest in children with special needs which came from having a son with ADHD. My practice became a 'medical home' for children with special needs a few years ago. Over the years I have come to really nurture and to enjoy my experiences seeing special needs children."

What is a medical home?

A medical home is a general pediatric practice that is designated to provide primary pediatric care for children with special health care needs by facilitating subspecialist referrals and educational, social, and nursing care and really encouraging the family to become proponents of their child's care from birth into adulthood. The medical home is part of a nationwide American Academy of Pediatrics initiative. As a medical home, our practice has a parent group that meets every few months to discuss ways to enhance our care for children with special needs. These parent partners are not only used as consultants but if we have a child who is identified with a certain diagnosis, e.g. child with Down syndrome, we try to get them in touch with another family with similar issues. We have a special education teacher on our parent committee as well. Sometimes we have questions about IEP's or where to go next and I will call one of my parents and ask questions.

Many children with Down syndrome could benefit from having a medical home. What do you do differently as a medical home practice for routine general pediatrics visits?

We explain to the family what the medical home is. We have a nurse who is a clinical coordinator who spends 8-10 hours per week talking to our families. She tries to call each

family of our special needs children the week before the appointment to go over questions in order to enhance our visit. This makes the visit more streamlined and efficient. We set aside a half-hour for our routine exams with all of our special needs children. The questions parents bring up to the nurse are reviewed. To improve continuity of care, our special needs children are assigned a primary physician who sees that patient for all of their well child visits, and when possible, problem visits as well. We now have several hundred children with special care needs and are developing better means of communicating with them. When it's time for the flu vaccine we send out questionnaires to those children so they get priority for flu vaccines. We are trying to develop a newsletter for our families as well.

In children with Down syndrome during well child visits what areas do you stress from birth to 6 months?

We have families call Early Intervention. I think the Early Intervention people do a wonderful job of providing support and help and they are usually very very enthusiastic about the children. Of course we have to be concerned that children do not have any underlying conditions associated with Down syndrome. Most families are thrilled and delighted with their babies, and don't have a lot of other problems or concerns. I have had very few parents that are devastated that the child has Down syndrome.

What common medical conditions do you need to watch for in the early months, and are there areas to which general pediatricians need to pay more attention?

We see a lot of feeding issues. We have several babies who have nursed well but sometimes babies don't latch on and suck well and moms will need to pump or give formula by bottle. We find that a lot of babies with Down syndrome, because of their low tone, have gastroesophageal reflux and also there is always the concern for aspiration and chronic cough. They have tiny ear canals and often I can't see their eardrums so I frequently send these children to see ENT to look at their ears to make certain that they do not have fluid or infection behind their eardrums which can lead to hearing loss. They can be congested a lot so it can be hard

to tell if they have upper respiratory infection (a cold). Children may also have partial upper airway obstruction causing snoring and apnea (an interruption of breathing in sleep). If this is the case then I refer them for a sleep study. Babies with Down syndrome often will have constipation issues.

As babies with Down syndrome become toddlers what areas do you stress in well child care visits?

We always track the patient's growth on Down syndrome charts. There are often feeding issues as children transition from baby food to table food. Some won't start self-feeding, or don't take strained foods readily. If they have a hard time with a cup and solid food I usually let these children stay on formula and a bottle for a longer period of time; 18 months to 2 years if needed. I really encourage parents to spoon feed after 6 months and by one year to be feeding more solid foods such as cheerios or puffs. The children tend to do a little bit more gagging, and spit out food, but I think most of our families persevere. Of course, we do recommend parents brush the baby's teeth regularly. We usually have them see a pediatric dentist by 18 months of age.

They should see an Ophthalmologist at one year of age. We get yearly thyroid function tests. Hearing tests need to be done every 6 months until 3 then every year.

I am amazed again how much Early Intervention has helped these children acquire their milestones sooner. It's been wonderful. If the child is progressing nicely with Early Intervention, then I do not think it is necessary to get additional services through private therapists. However, if the child is really lagging behind then I will refer for additional services. I find some families try to do too much and then we say back off a little bit. We also counsel families to avoid daycare situations until 3 years when possible. They tend to be more susceptible to getting sick, and tend to get sicker when they do get a virus.

As toddlers become preschoolers what areas do you stress in well child care visits?

Toileting is certainly a little bit later, usually at 4 or 5 years old. I have the names of some great therapists that will

come in and actively train the child. Behavior issues also become more of a problem at these ages, including atypical behaviors, oppositional behavior, and ADHD behaviors. It's sometimes hard to tell how much is the child's personality or if another diagnosis should be considered. When behaviors are a problem we usually refer to a child psychiatrist or developmental behavioral pediatrician.

I continue to be concerned that they receive the educational services and therapies they need to maximize their potential. It's also important to ask the family if they are pleased with their child's development and relationships with peers and siblings, and screen for significant stress.

What about the medical issues common in preschoolers?

Sleep apnea in this age may require the tonsils and adenoids be removed. Constipation can also be an issue. And of course annual thyroid tests, hearing tests, dental checkups. Tests for Celiac disease and a neck x-ray are also recommended.

At school age, how does your role as a pediatrician change?

Parents often have concerns about school placement and some of our families want children to be in regular classrooms. I really don't feel comfortable in the role of educational consultant, so rely on our parent-partners and organizations like The Parents Education Network. In general, my feeling is the child should be happy and not feel frustrated in his schooling. They need to continue to get speech, OT and PT.

We usually don't see children with DS as often in school age because many of their health issues have resolved, or are being followed. We continue to watch their growth, and to follow hearing, vision, thyroid tests, as recommended in the medical guidelines for children with Down syndrome.

Many parents worry about children starting to gain weight at this age.

There are some really wonderful physical education programs in the area that I refer to that have programs for children with special healthcare needs, such as Autism

and Down syndrome. A lot of the churches have inclusive activities such as Girl Scout troops or bowling clubs. There is also horseback riding, which I think is a wonderful activity for any child with special needs.

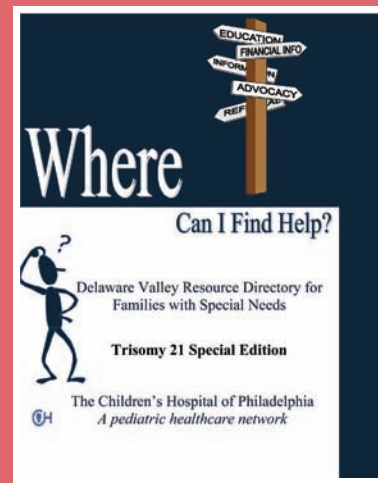
It sounds like the focus on preventing too much weight gain is activity?

Absolutely. If the families have healthy eating habits and healthy lifestyles, then their children are naturally going to follow that. So I try to get the family involved in making this change. I frequently will send them to see a nutritionist to learn how to eat healthier.

What suggestions do you have for parents to get the most out of their visits with their pediatrician?

I would suggest that they come with a written list of questions to be addressed. I would also encourage families to ask questions of their therapists and teachers and become involved in parent support groups.

Resource directory



The resource directory, updated each year, is on the Trisomy 21 Program Web site. Go to www.chop.edu and type

“Trisomy 21” in the search box and choose the first option. Then choose “Resources for Families” from the list on the left side of the page. The resource directory is under “Downloadable Material.”

Local Down Syndrome Interest Groups (DSIG's), *continued*

ing and those with Down syndrome. It was encouraging to see so many loving families who had overcome the initial shock and confusion of the diagnosis and who were busy enjoying life with their children. With each family we met, we learned something new about our son, his care, his development, his education and the opportunities available to him. We found other parents to be our best resources and are thankful to be part of providing resources to new parents as our son grows and we learn more.

Initial and continuing family support is what MCDSIG offers families through the exchange of ideas and information through presentations, social functions and welcome folders. The group holds meetings three times a year on important topics presented by speakers who are experts on various issues

pertaining to people with Down syndrome. Members are kept informed of pertinent information and events by other organizations that may be of interest through frequent email newsletters. The group also holds three large social events, a Spring Fling, a fall pizza party and a Winter Holiday Party. At other times throughout the year, there are age appropriate socials and events where families can socialize. Most importantly the group exists to help new families who have just received a diagnosis. The group distributes New Parent Packets to hospitals and OBGYN offices so that families can get in touch with the group when they are ready.

MCDSIG is free and open to all. If you would like more information visit the website www.MCDSIG.org or contact Rose Townsend by phone at 610-754-1483 or email at rosetownsend@yahoo.com.

Resources Available Through the T21 Program

Care Notebook

This is an organizational tool to keep all medical and educational materials in one place, making it easy to retrieve the right piece of information for the doctor, the school, the babysitter and the rest of the family. Call or e-mail to sign up for a one-on-one or group session, at which you will learn how to use the notebook, including which records to keep in the notebook and how to maintain records on a continuing basis. Contact us at 267-426-5360 or trisomy21@email.chop.edu.

Symposium

Mark your calendars! The 5th Annual T21 Symposium will be held on Saturday April 12, 2008. Look for details on our program website.

Educational Sessions:

These half day sessions will be held on Saturdays from 9 a.m.-12 p.m. and will include a variety of educational topics specific to T21. Look for details on the upcoming November session on our program website