

Trisomy 21 Update

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

Fall 2006



Buddy Walk 2006

Thanks to everyone who made the 2006 Buddy Walk a success! The walk, which raised almost \$200,000 for the Trisomy 21 Program at The Children's Hospital of Philadelphia, was held Sunday, Oct. 1 at Villanova University Stadium. The morning was filled with activities including musical entertainment, kids' contests, raffle prizes, food and mascots, all while participants walked for a good cause. NBC 10 News anchor Vince DeMentri returned to serve as master of ceremonies as other local celebrities stopped by throughout the morning. More than 4,000 people came out to enjoy this wonderful day.

We welcome our trisomy 21 fellow, Patty Huang, M.D.

In recognition of the importance of training more doctors specializing in care for children with developmental disabilities, the Friends of Trisomy 21 and the Commonwealth of Pennsylvania have provided financial support for a developmental-behavioral pediatrics fellow.

We welcome our first trisomy 21 fellow in this field, Patty Huang, M.D. Dr. Huang became interested in developmental disabilities while attending college at Rice University. She volunteered as a "best buddy" to an adult woman with cognitive disability.

"Over four years, I got to know that individual, her friends and family, and learned first-hand about her community, work and everyday life," she says. "I knew then that I wanted to find a medical specialty in which I could work with children with developmental disabilities."

Dr. Huang attended Baylor College of Medicine and completed her residency at Cornell University. She will be involved in direct patient care as well as research and program development in the Trisomy 21 Program during her three years at CHOP.

Note from the Editors:

Welcome to the first official newsletter of the Trisomy 21 Program! We are delighted to embark on this new journey and invite all of you to help guide our way. Please feel free to submit suggestions, feedback or questions to trisomy21@email.chop.edu.

~Team T21

Support Group

CHOP's support group for trisomy 21 patients and families meets Mondays from 6 to 8 p.m. at 3535 Market St., Philadelphia, 16th floor, conference room C.

- Monday, Oct. 23
Back to School: Maximizing Your Child's Education
- Monday, Dec. 11
Holidays: Handling the Stress

R.S.V.P. one week before each meeting to Dorothy Brightcliffe, R.N., and parent, at 267-426-5360 or trisomy21@email.chop.edu.

Please contact us if you need special assistance.

Trisomy 21 Team

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

Mary Pipan, M.D.
clinical director

Kim Schadt, 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

Dorothy Brightcliffe, R.N.
family consultant

Rosemary Eichov, 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.

Social Work and Community Education

In order to get the best care for children with Down syndrome, families need to be proactive in pursuing information about services and develop partnerships with healthcare providers, educators and the community. The Trisomy 21 Program's social worker, Symme Trachtenberg, M.S.W., provides supportive counseling and resource information to families who have children with Down syndrome. She helps families navigate a complex range of options and encourages families to learn about the wide array of programs, entitlements and services available to them and their children from infancy through adulthood. In addition, Trachtenberg is involved with schools and community agencies working toward social and educational inclusion for children with Down syndrome.

Physical Therapy

The Trisomy 21 Program offers physical therapy evaluations with Helen Milligan, M.P.T., to help people with Down syndrome achieve their full potential in activities throughout their lives. The evaluation includes an assessment of flexibility, strength, balance and function at home and in the community. Recommendations may include stretching or strengthening exercises, orthotics, taping and special equipment. During the evaluation, parents also can ask questions about their children's development and therapy. The goal in physical therapy is to help patients with Down syndrome remain active without having the physical challenges of decreased strength, increased joint flexibility, decreased balance or pain.

Challenger Day Participants Try Sports, Activities

Challenger Day, held Sept. 10, was an opportunity for people with disabilities, and their families, to try out new sports and other activities. Participants in the event, which took place at Upper Merion High School in King of Prussia, Pa., were matched with buddies to accompany them to various events, including swimming, football, baseball, cheerleading, basketball and lacrosse, all hosted by local sports teams and coaches. Art activities also took place. Celebrities and the local fire department made appearances, and several organizations offered educational information for families. Children's Hospital's Trisomy 21 Program distributed its own recreation directory, printed by the Upper Merion Parks and Recreation Department.

Spotlight on Otolaryngology

Interview with Udayan K. Shah, M.D., director, Otolaryngology Innovative Technologies Program

How did you first become interested in children with Down syndrome?

Kids with Down syndrome epitomize why pediatric otolaryngology needs to get involved with their care — you can't think about the ear, nose and throat separately in children with trisomy 21. It's very satisfying to be able to follow them long-term and see the gains they make following intervention.

At what age should a pediatric otolaryngologist (ear, nose and throat, or ENT physician) initially evaluate a child with Down syndrome?

We often need to get involved in the newborn period, especially if there is a failed hearing screen or if there are any airway concerns. After infancy, an ENT physician may be involved if the primary pediatrician needs assistance in managing ear wax, middle ear effusion caused by dysfunction of the eustachian tube (a tube that links the pharynx to the middle ear), frequent ear or sinus infections, or breathing concerns. In my experience, most children with Down syndrome require regular evaluation by an ENT doctor.

How often do you see kids with trisomy 21, and how frequently do you follow up?

I see approximately three to four children with Down syndrome each day I have clinic. For children with ear infections or hearing loss, I see them about every three to four months until about age 6 or 7, due to the narrowness of their ear canals and the need to keep on top of eustachian tube dysfunction or ear fluid.

Are there more complications associated with tympanostomy (PE) tubes for kids with Down syndrome?

Tympanostomy tubes (a tiny ventilation tube surgically inserted through the ear drum) may be necessary to treat ear infections and manage hearing loss. Kids with Down syndrome have more episodes of drainage from ear tubes than children without Down syndrome, according to the medical literature. The procedure of placing a PE tube

should be undertaken with an anesthesiologist and an otolaryngologist, both experienced in caring for children with Down syndrome. The procedure itself is somewhat technically difficult due to the narrowness of the ear canals.

Many children with Down syndrome have large tonsils and adenoids. Doctors often recommend surgical removal, but there can be some complications. How do you decide whether surgery is necessary?

Frequently, children with trisomy 21 have *obstructive sleep apnea* (a temporary stoppage of breathing during sleep). These children often have difficulty using noninvasive therapies, such as continuous positive airway pressure, so most of the time, they benefit from a removal of the tonsils and adenoids to treat their upper-airway obstruction. Removal of tonsils and adenoids may be necessary as well for Down syndrome children with recurrent strep throat, and the adenoids may need to be removed for recurrent ear or sinus infections.

What is the relationship between gastroesophageal reflux and sinus infections and airway problems?

Gastroesophageal reflux (acid reflux) contributes to sinus infections and ear infections. An evaluation for this may require diagnostic studies or consultation with a pediatric gastroenterologist.

Many children with Down syndrome have a hoarse voice quality, and parents often don't notice it. What do you recommend?

Assessing hoarseness in Down syndrome kids may be done in the office or in the operating room, using a small fiberoptic scope to look at the larynx, or voice box. You can assess the surface of the vocal folds for irregularities, either due to nodules or to thickening from inflammation. You can assess the motion of the vocal folds as well. If they have a breathy or weak voice, then assessing the vocal folds for strength and mobility is important, particularly in children who have had thoracic or cardiac procedures, during which the nerves that control the voice box may be affected.

Thank you, Dr. Shah; we appreciate this chance to talk with you. And thank you for your interest in and clinical care for children and families with Down syndrome.

Resources Available Through the T21 Program

Educational consultant

Our consultant is a parent advocate who can assist in the process of creating an individualized education program (IEP).

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 or shred and how to maintain records on an ongoing basis. Contact us at 267-426-5360 or trisomy21@email.chop.edu.

Symposium

The symposium takes place each year in March to inform families and professionals about current trends that will benefit people with trisomy 21.

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 resources directory is under “Downloadable Material.”

Support group

The group meets five times a year and is led by our family consultant, Dorothy Brightcliffe, R.N. Each session has a particular topic and includes time to chat. For more information, see Page 1.