

*Eighth Annual*  
**Trisomy 21**  
**(Down Syndrome) Symposium**



**Saturday, April 9, 2011**

Sponsored by the  
Trisomy 21 Program at  
The Children's Hospital of Philadelphia

**cme.chop.edu**



The Children's Hospital  
*of Philadelphia*<sup>®</sup>

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# Course Information

## Course Overview

Trisomy 21 is the most frequently occurring chromosomal abnormality, found once every 800 to 1,000 live births. However, both pediatric and adult clinical care continues to present significant and unique challenges.

Children with Trisomy 21 are at higher risk for congenital heart disease, gastrointestinal abnormalities, endocrinologic disorders, epilepsy, musculoskeletal issues that affect motor abilities, hearing loss, speech apraxia, sleep disorders, feeding disorders, and developmental disabilities including learning disabilities, mental retardation and autism. Deficits in any of these areas can adversely affect the child's development and adaptive behavior.

This one-day symposium will provide parents and healthcare professionals with up-to-date clinical information, therapeutic approaches and current research being conducted in the field of Trisomy 21.

## General Information

The conference will be in the Stokes Auditorium located on the first floor of The Children's Hospital of Philadelphia. Registration begins at 7:15 a.m.

## Registration Information

Attendees may register by mail or fax. Please see the registration form for the address and fax number. Preregistration is required; the registration deadline is Friday, March 25, 2011. Payment must accompany the registration form for it to be processed.

## Services for the Disabled

We encourage participation by all individuals. If arrangements are required for a person with special needs to attend this meeting, please contact the CME Department at 215-590-5263 at least two weeks in advance so we may provide better service to you during the conference.

## Cancellation and Refund Policy

The Children's Hospital of Philadelphia reserves the right to cancel or postpone any conference due to any unforeseen circumstances. In the event of cancellation or postponement, The Children's Hospital of Philadelphia will refund registration fees but is not responsible for any related costs, charges or expenses to participants, including cancellation charges assessed by hotels, airlines or travel agencies.

In order to process refunds, cancellations must be received in writing by Friday, April 1, 2011. Refunds will be issued for the amount of registration minus a \$25 administrative fee. No refunds will be issued thereafter.

# Program – Saturday, April 9, 2011

7:15 a.m. Registration and Continental Breakfast

7:50 a.m. Welcome and Introduction  
*David Lynch, M.D., Ph.D.*

8 a.m. Celebrating Life  
*Brian G. Skotko, M.D., M.P.P.*

9 a.m. The Hip and Other Orthopaedic Issues in Individuals with Trisomy 21  
*Wuddhav N. Sankar, M.D.*

10 a.m. Break

10:15 a.m. Allergic Rhinitis  
*Terri Brown-Whitehorn, M.D.*

11:15 a.m. Panel Discussion

Noon Lunch and Exhibits

## 1:15 p.m. Breakout Session I

### A. Progressing Feeding Skills in Children with Trisomy 21

*Susan M. McCormick, M.A., C.C.C.-S.  
Dawn R. Sampson, M.S., C.C.C.-S.*

#### TARGET: Young Children

*This lecture will provide an overview of typical feeding challenges in children with Trisomy 21. Information on evaluation and management with emphasis on practical strategies caregivers can implement.*

### B. Waivers and Resources

*Symme Trachtenberg, M.S.W., L.S.W.  
Jennifer Plumb, M.S.W., L.S.W.*

#### TARGET: School-aged Children

*This session will provide parents with the updated information on all the services your child is entitled to receive. The Community Resources for Families database will be demonstrated.*

### C. What Your Other Kids Without Down Syndrome are Thinking: Sibling Issues for Parents

*Brian G. Skotko, M.D., M.P.P.  
Sue Levine, M.A., C.S.W.*

#### TARGET: Adolescents

*Through discussion and a series of interactive exercises, parents will explore what questions, needs and concerns are often raised by children who have a brother or sister with Down syndrome.*

### D. New Perspectives on Neurochemistry of Trisomy 21

*David Lynch, M.D., Ph.D.*

#### TARGET: Adults

*Review of the neurochemical and neuroanatomical features of Trisomy 21 emphasizing how they are related to the clinical issues of Trisomy 21. Highlights will include new discoveries that expand our understanding of the brain of individuals with Trisomy 21.*

2:30 p.m. Break and Exhibits

## 2:45 p.m. Breakout Session II

### A. Care Notebooks

*Symme Trachtenberg, M.S.W., L.S.W.  
Jennifer Plumb, M.S.W., L.S.W.*

#### TARGET: Young Children

*Participants will receive a CHOP Care Binder and training in how to keep it current. Participants are encouraged to bring Early Intervention and physicians' reports to get started.*

### B. Easing into Independence: Developing Self-Care Skills Through Encouragement

*April Andrescavage, O.T.R./L.*

#### TARGET: School-aged Children

*This breakout session will address helping children develop increased independence in areas of self-care. Tasks such as personal hygiene, privacy, bathing, dressing and grooming will be explored through creative adaptations and teaching methods.*

**C. Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know**

*Brian G. Skotko, M.D., M.P.P.*

**TARGET: Adolescents**

*This session will review questions and concerns that parents most often have about their sons and daughters with Down syndrome.*

**D. Research Regarding Fitness in the Down Syndrome Population**

*Helen A. Milligan, M.P.T.*

**TARGET: Adults**

*Individuals with Down syndrome should remain fit and active throughout their life span. There are many reasons that make exercise and fitness challenging. This session will review the research on exercise and fitness and discuss how to design and implement a training program for individuals with Trisomy 21.*

**4 p.m. Breakout Session III**

**A. Beginning a Lifetime of Learning: Early Intervention in Children with Trisomy 21**

*Mary Pipan, M.D.*

**TARGET: Young Children**

*Parents play an essential role in a child's learning, from infancy forward. Early intervention programs aim to guide parents in this teaching role. This session will discuss how parents can make early intervention part of their everyday lives, building foundational skills that will support later development and prioritizing goals that fit the needs of the child and family.*

**B. Information/Orientation Session for It Takes Two to Talk® – the Hanen Program® for Parents**

*Elaine Tirello, M.A., C.C.C.*

*Maryellen Aland, M.S., C.C.C./S.L.P.*

**TARGET: School-aged Children**

*It Takes Two to Talk is a research-based, family-focused language intervention program for parents of children with expressive language delay, aged 18 months to 6 years. This session will provide an overview and information on the program.*

**C. Social Skills**

*Symme Trachtenberg, M.S.W., L.S.W.*

*Jennifer Plumb, M.S.W., L.S.W.*

**TARGET: Adolescents**

*Learn ways to improve your adolescent's social skills. Techniques, handouts and resources will be provided.*

**D. Diagnosis and Treatment of Psychiatric Disorders in Individuals with Trisomy 21**

*Andrew Levitas, M.D., M.P.P.*

**TARGET: Adults**

*Individuals with Down syndrome may suffer from a range of psychiatric disorders that make up the behavioral phenotype of the syndrome. This range of disorders and their psychopharmacologic treatment will be described.*

**5:15 p.m. Program Adjourns**

# Registration

**Eighth Annual Trisomy 21 (Down Syndrome) Symposium**  
**Saturday, April 9, 2011**

**Registration Deadline: Friday, March 25, 2011**

Name \_\_\_\_\_  
*(One name per registration form)*

Home Address \_\_\_\_\_  
\_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ ZIP \_\_\_\_\_

\*Phone \_\_\_\_\_

\*E-mail \_\_\_\_\_  
*\*Required field*

## **Registration Fee (per person) \$45**

*Registrations will not be processed without form of payment.*

*Faxed registration forms will be accepted for credit card payments only.*

**A limited number of scholarships will be available to parents. Please e-mail [utsch@email.chop.edu](mailto:utsch@email.chop.edu) for details on applying for a scholarship.**

## **Breakout Sessions (please mark your selection)**

Session I \_\_\_ A \_\_\_ B \_\_\_ C \_\_\_ D

Session II \_\_\_ A \_\_\_ B \_\_\_ C \_\_\_ D

Session III \_\_\_ A \_\_\_ B \_\_\_ C \_\_\_ D

## **Method of Payment**

Personal Check  Institutional Check  
*(payable to The Children's Hospital of Philadelphia)*

MasterCard  American Express  VISA  Discover

Credit Card # \_\_\_\_\_

Exp. Date \_\_\_\_\_

## **Mail or fax the completed registration form with payment to:**

Ms. Micah Holliday, Continuing Medical Education Department  
The Children's Hospital of Philadelphia  
34th Street and Civic Center Boulevard  
CHOP-North, 1220, Philadelphia, PA 19104-4399  
215-590-5263 / Fax 215-590-4342 / [Hollidaydm@email.chop.edu](mailto:Hollidaydm@email.chop.edu)

# Course Faculty

## Course Directors

**David Lynch, M.D., Ph.D.**

*Program Director, Trisomy 21 Program  
The Children's Hospital of Philadelphia  
Associate Professor of Neurology  
University of Pennsylvania School of Medicine*

**Mary Pipan, M.D.**

*Clinical Director, Trisomy 21 Program  
The Children's Hospital of Philadelphia  
Clinical Associate Professor of Pediatrics  
University of Pennsylvania School of Medicine*

**Krista Ruiz, B.S.N., R.N.**

*Program Coordinator, Trisomy 21 Program  
The Children's Hospital of Philadelphia*

**Kim Schadt, C.R.N.P., C.C.R.P.**

*Nurse Practitioner, Trisomy 21 Program  
The Children's Hospital of Philadelphia*

**Symme Trachtenberg, M.S.W., L.S.W.**

*Director, Community Education  
Trisomy 21 Program Social Work Consultant  
The Children's Hospital of Philadelphia*

## Course Faculty

**Maryellen Aland, M.S., C.C.C./S.L.P.**

*Speech Language Pathologist  
Co-founder – A & T Family Language  
Consultants  
Part-Time Clinician  
Project Child, Mercer County Special Services  
School District*

**April Andrescavage, O.T.R./L.**

*Occupational Therapist  
The Children's Hospital of Philadelphia*

**Terri Brown-Whitehorn, M.D.**

*Attending Physician  
Division of Allergy and Immunology  
The Children's Hospital of Philadelphia  
Assistant Professor of Clinical Pediatrics  
University of Pennsylvania School of Medicine*

**Sue Levine, M.A., C.S.W.**

*Co-founder and Social Worker  
Family Resource Associates Inc.*

**Andrew Levitas, M.D.**

*Medical Director  
Center of Excellence for Mental Health  
Treatment of Persons with  
Intellectual Disabilities  
Associate Professor of Psychiatry  
University of Medicine & Dentistry of  
New Jersey/School of Osteopathic Medicine*

**Susan M. McCormick, M.A., C.C.C.-S.**

*Speech Language Pathologist  
Pediatric Feeding and Swallowing Center  
Center for Childhood Communication  
The Children's Hospital of Philadelphia*

**Helen A. Milligan, M.P.T.**

*Physical Therapist, Trisomy 21 Program  
The Children's Hospital of Philadelphia  
Early Intervention in Delaware and  
Montgomery Counties*

**Jennifer Plumb, M.S.W., L.S.W.**

*Social Worker  
The Children's Hospital of Philadelphia*

**Dawn R. Sampson, M.S., C.C.C.-S.**

*Speech Language Pathologist  
Pediatric Feeding and Swallowing Center  
Center for Childhood Communication  
The Children's Hospital of Philadelphia*

**Wudbhav N. Sankar, M.D.**

*Attending Surgeon, Division of Orthopaedic  
Surgery  
The Children's Hospital of Philadelphia  
Assistant Professor of Orthopaedic Surgery  
University of Pennsylvania School of Medicine*

**Brian G. Skotko, M.D., M.P.P.**

*Clinical Fellow in Genetics  
Children's Hospital Boston  
Massachusetts General Hospital  
Brigham and Women's Hospital  
Dana-Farber Cancer Institute*

**Elaine Tirello, M.A., C.C.C.**

*Speech Language Pathologist  
Co-founder – A & T Family Language  
Consultants  
Private Practitioner  
Speech-Language Consultant to Local Preschools*

### Acknowledgements

The conference organizers would like to thank and acknowledge the Friends of Trisomy 21 and the Auto Dealers CARing for Kids Foundation for their generous support of this symposium.



Friends of Trisomy 21



**Continuing Medical Education Department**  
**CH** The Children's Hospital of Philadelphia  
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