10th Annual
Trisomy 21
(Down Syndrome) Symposium

Saturday, May 7, 2016

Joseph Stokes Jr.
Auditorium
at The Children’s
Hospital of Philadelphia

Sponsored by the
Trisomy 21 Program

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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, endocrine disorders, epilepsy, musculoskeletal issues that affect motor abilities, hearing loss, speech apraxia, sleep disorders, feeding disorders and developmental disabilities, including learning disabilities, developmental delays 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 begin in the Joseph Stokes Jr. 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 Monday, April 25, 2016. Payment must accompany the registration form for it to be processed.

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 22, 2016. Refunds will be issued for the amount of registration minus a $25 administrative fee. No refunds will be issued thereafter.

Services for People with Disabilities

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.
Course Faculty

Course Directors

Mary Pipan, M.D.
Director, Trisomy 21 Program
Attending Physician, Developmental and Behavioral Pediatrics

Kim Schadt, C.R.N.P.
Co-director, Trisomy 21 Program

Faculty

Alan Babcock, M.Ed.
School Psychologist
Disability Services Coordinator
Penn State University Harrisburg

Alison Downes, M.D.
Attending Physician, Developmental and Behavioral Pediatrics

Anna J. Esbensen, Ph.D.
Research Director, Jane and Richard Thomas Center for Down Syndrome
Division of Developmental and Behavioral Pediatrics
Cincinnati Children’s Hospital Medical Center
Assistant Professor of Psychology
University of Cincinnati College of Medicine

Melissa Ferrello, Au.D., C.C.C.-A.
Audiologist, Center for Childhood Communication

Brad Hennefer
Self Advocate

Nancy Hennefer
Board Member, Bringing Up Down Syndrome

Susan M. McCormack, M.A., C.C.C.-S.L.P., B.C.S.-S.
Board Certified Specialist – Swallowing
Senior Speech Language Pathologist
Center for Childhood Communication
Pediatric Feeding and Swallowing Center

Helen A. Milligan, P.T., M.P.T.
Physical Therapist

Stephanie A. Pratico
Trisomy 21 Program Manager

Heather Ruthrauff, M.S., O.T.R./L.
Clinical Practice Coordinator
Occupational Therapy Department

Alyssa Siegel, M.D.
Attending Physician, Division of General Pediatrics

Ritu Verma, M.B.Ch.B.
Section Chief, Gastroenterology, Hepatology and Nutrition
Director, Celiac Center
Associate Professor of Clinical Pediatrics

Unless otherwise noted, faculty is from The Children’s Hospital of Philadelphia and the Perelman School of Medicine at the University of Pennsylvania.
Program – Saturday, May 7, 2016

7:15 a.m.  Registration and Continental Breakfast

7:50 a.m.  Welcome and Introduction
  Mary Pipan, M.D.

8 a.m.  The Journey through Pediatric Audiology for Individuals with Trisomy 21
  Melissa Ferrello, Au.D., C.C.C.-A.
  This session will review the significance of hearing loss in individuals for those with Trisomy 21, and review its impact on everyday life. The session will discuss the variety of methods utilized to diagnose hearing loss from birth through adulthood, and discuss some of the technology and interventions available for those diagnosed with hearing loss.

8:45 a.m.  Trisomy 21 and Gastrointestinal Issues
  Ritu Verma, M.B.Ch.B.
  This session will discuss gastrointestinal manifestations associated with Trisomy 21, review and discuss symptoms and management of gastrointestinal conditions, and discuss the impact of gastrointestinal symptoms on individuals with Trisomy 21 and their families.

9:30 a.m.  Break

9:45 a.m.  You and Your Pediatrician: A True Healthcare Team
  Alyssa Siegel, M.D., Stephanie A. Pratico
  This session will examine the relationship between parent and physician as a partnership, identifying the concerns, goals, responsibilities and expectations of each party involved. Through a series of patient scenarios, we will review and reconcile cases that demonstrate pitfalls in the parent-physician relationship.

10:45 a.m.  What Can I Do to Ensure a High Quality of Life for My Child/Young Adult?
  Alan Babcock, M.Ed.
  Alan will focus on what parents/guardians can do to obtain appropriate support from the professionals with whom they work. He will discuss the importance of parents being involved in developing and implementing a lifelong plan for their child/young adult, as well as effective communication strategies.

11:30 a.m.  Questions and Answers

Noon  Lunch and Exhibits

1:15 p.m.  Breakout Session I

A. Let’s Eat! Helping Children with Trisomy 21 Advance Feeding Skills
  Susan M. McCormack, M.A., C.C.C.-S.L.P., B.C.S.-S.
  TARGET: Young children — This session will describe typical oral feeding patterns and common feeding difficulties children with Trisomy 21 may demonstrate as they grow. Practical tips, activities and strategies to optimize oral feeding skills will be discussed and demonstrated.

B. Writing a Meaningful Individualized Education Program (IEP)
  Alan Babcock, M.Ed.
  TARGET: School-aged children — Alan will assist parents in understanding the IEP process. He will explain what they can do to be a participating member of the IEP team. Parents will learn how they can write IEP goals, objectives and specially designed instruction. He will also discuss the importance of inclusion and how to include it in the IEP.

continued
C. Healthy Food Choices and Active Lifestyles: Helping Children and Young Adults with Trisomy 21 Gain and Maintain a Healthy Weight

**CHOP Healthy Weight Program**

TARGET: Adolescents — Children with Trisomy 21 start showing a predisposition to obesity in the first 5 years of life. Obesity can negatively affect all aspects of life quality. In this workshop we will present the Healthy Weight Program’s approach to gaining and maintaining healthy weight including: how to be more aware of habits by tracking eating and activity, setting positive limits, problem solving, setting goals, talking about healthy behaviors, and staying motivated.

D. Understanding and Managing Behaviors in Individuals with Trisomy 21

*Anna J. Edsersen, Ph.D.*

TARGET: Adolescents and adults — This session will review the neurological etiology contributing to common behaviors exhibited by individuals with Trisomy 21. Behavior theory will be used to review common functions of behaviors, preventive and reactive techniques, and how these strategies can be used to manage common maladaptive behaviors exhibited by individuals with Down syndrome.

2:30 p.m. Break and Exhibits

2:45 p.m. Breakout Session II

A. Developing Motor Skills in the First Years of Life

*Helen Milligan, P.T., M.P.T.; Heather Ruthrauff, M.S., O.T.R/L.*

TARGET: Young children — At the end of this session participants will understand how Trisomy 21 impacts motor development in the 0- to 3-year-old population, understand and practice handling techniques specific to infants and children with Trisomy 21, and discuss foundational skills for activities of daily living (ADL), fine motor, gross motor and visual motor development.

B. Attention and Focus in School-age Children: When Is It a Problem and How Can We Help?

*Alison Downes, M.D.*

TARGET: School-age children — There are many factors that contribute to inattention in school-age children with Trisomy 21. Distinguishing ADHD can be challenging, but most important are the strategies for improvement in behaviors to allow for optimal success academically and socially. This session will aim to describe contributing factors to inattention in school-age children with Trisomy 21, explain the method for diagnosis and the diagnostic criteria of ADHD, and present behavioral, academic and pharmaceutical methods for management.

C. Increasing Socialization and Community Opportunities

*Brad Hennefer; Nancy Hennefer*

TARGET: Adolescents and adults — This breakout will discuss the importance of creating meaningful social relationships and cultivating social opportunities in a local environment. Brad and Nancy will share their top 10 tips of actions that all families can take to help prepare for a bright future. They will also share tips on how local parent affiliate groups can learn from BUDS and help their families have access to programs and services for all age groups.

D. Exploring and Supporting the Mental Health of Individuals with Trisomy 21

*Anna J. Edsersen, Ph.D.*

TARGET: Adolescents and adults — This session will identify how physical health problems common in Trisomy 21 may contribute to an individual’s mental health. The session will also address how the Trisomy 21 phenotype (common behavioral characteristics) relates to mental health. Case examples will be used to illustrate how families can help support the mental wellness of their relative with Trisomy 21.

4 p.m. Program Adjourns
Registration

10th Annual Trisomy 21 (Down Syndrome) Symposium
Saturday, May 7, 2016
Registration Deadline: Monday, April 25, 2016

Name ____________________________________________________________________
(One name per registration form)

Home Address _____________________________________________________________
_________________________________________________________________________
City ____________________________________________ State ______ ZIP ___________
Phone ____________________________________________________________________
Email ____________________________________________________________________

All above fields are required.

Registration Fee (per person) $50
Registrations will not be processed without form of payment. Faxed registration forms will be accepted for credit card payments only.

Breakout Sessions (please mark your selection)

Session I  ___ A  ___B  ___C  ___D
Session II  ___ 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

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