

# Trisomy 21 Symposium

**Saturday, May 19, 2018**

Ruth and Tristram Colket, Jr. Translational Research Building  
on the Raymond G. Perelman Campus



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## COURSE OVERVIEW

Trisomy 21 (Down syndrome) is the most common chromosomal condition in humans, occurring in one of every 700 to 800 live births. Trisomy 21 is also the most complex genetic condition, affecting many body systems, including brain development and variably affecting each individual.

Children with Trisomy 21 are at higher risk for vision and eye problems, ear, nose and throat problems including hearing loss, congenital heart disease, gastrointestinal and feeding problems, endocrine disorders, neurological and musculoskeletal issues, and developmental and behavioral challenges.

This one-day symposium will provide parents and healthcare professionals with up-to-date clinical information, therapeutic approaches and advice on a variety of topics affecting children with Down syndrome, covering ages from young children to young adults.

## GENERAL INFORMATION

The conference will be held in the Ruth and Tristram Colket, Jr. Translational Research Building on the Raymond G. Perelman Campus.

## REGISTRATION FEES

The registration fee includes registration materials, continental breakfast, lunch, breaks and parking. As part of our green initiative, syllabus material will be available online.

Conference Registration: \$50

To register, please visit [chop.cloud-cme.com](http://chop.cloud-cme.com).

## CANCELLATION AND REFUND POLICY

Children's Hospital of Philadelphia reserves the right to cancel or postpone any course due to any unforeseen circumstances. In the event of cancellation or postponement, the Hospital will refund registration fees, less a \$10 service fee, but is not responsible for any related costs, charges or expenses to participants, including cancellation charges assessed by airlines or travel agencies. In order to process refunds, cancellations must be received in writing by Friday, April 27, 2018. No refunds will be issued thereafter.

## SERVICES FOR PEOPLE WITH DISABILITIES

If special arrangements are required for an individual with a disability to attend this meeting, please contact the Continuing Medical Education Department at 215-590-5263 or via email at [cmeoffice@email.chop.edu](mailto:cmeoffice@email.chop.edu) at least two weeks in advance so that we may provide better service to you during the conference.

## PROGRAM — SATURDAY, MAY 19, 2018

- 7:45 a.m.      **Registration and Continental Breakfast**
- 8:20 a.m.      **Welcome and Introduction**  
*Mary Pipan, MD*
- 8:30 a.m.      **Making a Splash with Aquatic Therapy**  
*Helen Milligan, PT, MPT*  
*Aidan Milligan, Self Advocate*  
Learn how aquatic therapy can improve strength, oral motor skills, social interactions, balance, body awareness and activities of daily living for ALL individuals with Down syndrome. Benefits of pool therapy as well as the therapeutic goals of the group will be explained. Videos and pictures of the latest group will be shared during the presentation.
- 9 a.m.          **Down Syndrome and the Eye: What to Know About Eyes and Vision**  
*Stephanie Davidson, MD*  
This talk will discuss a review of pertinent ophthalmic conditions at every age, from birth to adulthood.
- 9:30 a.m.      **Questions and Answers**
- 9:45 a.m.      **Break**
- 10 a.m.        **Let Me Tell You About My Best Friend ...**  
*Patty and Lauren White*  
The bond between a mother and her daughter is a very special relationship. This mother and daughter will share their journey and will share some of the steps they have taken on that journey to make their relationship both healthy and happy.
- 10:30 a.m.    **Anatomical Differences in Down Syndrome: Ramifications for Chronic Ear Disease and Habilitation Options**  
*Robert Carlos O'Reilly, MD*  
This talk will address the underlying pathophysiology of ear disease in patients with Down syndrome and ramifications for treatment.
- 11 a.m.        **Sleep Disorders in Individuals with Down Syndrome**  
*Lisa M. Elden, MD, MSc*  
This talk will discuss airway and other breathing problems in individuals with Down syndrome.
- 11:30 p.m.    **Questions and Answers for Morning Session Speakers**
- Noon          **Lunch and Exhibits**

*continued >*

1:15 p.m.

### Breakout Sessions I

- A. **Title:** Let's Get Moving: An OT/PT Perspective on the First Years of Life  
**Presenters:** *Helen Milligan, PT, MPT; Heather Ruthrauff, MS, OTR/L, CBIS*  
**Target:** Young children  
**Description:** Discussion of the therapeutic principles behind treatment of the young child with Down syndrome and how to promote proper progression of skills. Discuss the interplay between gross and fine motor skills, visual motor skills, and sensory processing skills and how they all impact the development of a child with Down syndrome. Discuss equipment and other therapeutic interventions commonly used with children with Down syndrome.
- B. **Title:** Promoting Physical Activity and Exercise in Children and Adolescents with Down Syndrome  
**Presenter:** *Ann Tokay Harrington, PT, DPT, PhD, PCS*  
**Target:** School-aged children/adolescents  
**Description:** Many children in the United States do not meet the frequency and intensity of physical activity recommended for optimal health. Strategies to facilitate exercise participation through the application of health promotion theory will be discussed, as well as a review of the current literature on the recommendations for physical activity in school-aged children and adolescents with Down syndrome. Case study examples will be used to illustrate the principles presented.
- C. **Title:** Environmental and Behavioral Supports for Learning in Individuals with Down Syndrome  
**Presenter:** *Mary Pipan, MD*  
**Target:** Adolescents  
**Description:** Identify processing differences in individuals with Down syndrome that can impede the learning process. Present ideas for effective, proactive, preventative, educational strategies (positive behavioral support) that can enhance learning and minimize behavioral challenges.
- D. **Title:** Transition to Employment: Preparation, Process and Programs = Possibilities  
**Presenters:** *Symme Trachtenberg, MSW; Audrey Vincent, MSW, LSW; Jamie Dilanni, MS, CESP*  
**Target:** Adolescents and adults  
**Description:** Transitioning from pediatric to adult healthcare challenges youth to take charge and advocate for themselves. This session will include the timing for patient-family training about transition, the transfer of care, transference of medical records and the need for care providers to communicate effectively during the process.

2:30 p.m.

### Break and Exhibits

*continued >*

2:45 p.m.

## Breakout Sessions II

- A. **Title:** Practical Strategies to Promote Oral Feeding Skills in Children with Down Syndrome: From Bottle Feeding to Birthday Cake!  
**Presenter:** *Susan McCormack, MA, CCC-SLP, BCS-S*  
**Target:** Young children  
**Description:** This presentation will provide caregivers with information on the typical development of oral feeding skills, challenges in developing oral feeding skills in children with Down syndrome and strategies to promote bottle feeding, cup drinking and chewing skills.
- B. **Title:** Beyond the IEP: Developing the Foundational Skills Your Child Needs to Support a Successful Adolescence and Young Adulthood  
**Presenters:** *Mary Pipan, MD, Symme Trachtenberg, MSW*  
**Target:** School-aged children  
**Description:** Establishing nonacademic learning goals (your home-based IEP) to encourage independence, self-reliance and social competency.
- C. **Title:** Adolescent and Young Adult Healthcare Recommendations: Down Syndrome and Beyond  
**Presenter:** *Sheila Quinn, DO*  
**Target:** Adolescents and young adults  
**Description:** In this session, caregivers will learn about preventative healthcare standards and anticipatory guidance for all adolescents and young adults, including issues specific to young people with Down syndrome.
- D. **Title:** Tampon Toolkit  
**Presenters:** *Helen Milligan, PT, MPT; Heather Ruthrauff, MS, OTR/L, CBIS*  
**Target:** Adults and adolescents  
**Description:** Come learn about an exciting new project called the Tampon Tool Kit. This session is appropriate for parents and their adolescent girls who are interested in learning more about independence within self-care and puberty.

4 p.m.

## Program Adjourns

*Unless otherwise noted, faculty is from Children's Hospital of Philadelphia.*

## **COURSE DIRECTORS**

**Mary Pipan, MD**

*Director, Trisomy 21 Program*

*Attending Physician, Developmental Behavioral Pediatrics*

**Kim Schadt, CRNP**

*Trisomy 21 Program*

*Friedreich's Ataxia Program*

## **COURSE FACULTY**

**Stefanie L. Davidson, MD**

*Attending Surgeon, Division of Ophthalmology*

**Jamie Dilanni, MS, CESP**

*CHOP Career Path Program Manager*

**Lisa M. Elden MD, MSc**

*Attending Physician, Division of Otolaryngology*

*Surgical Director, Pediatric Sleep Center*

**Ann Tokay Harrington, PT, DPT, PhD, PCS**

*Physical Therapist, Center for Rehabilitation*

**Susan McCormack, MA, CCC-SLP, BCS-S**

*Senior Speech Language Pathologist, Center for Childhood Communication*

**Aiden Milligan**

*Son and Self Advocate*

**Helen Milligan, PT, MPT**

*Physical Therapist III*

**Robert Carlos O'Reilly, MD**

*Attending Physician, Division of Otolaryngology*

*Director, Balance and Vestibular Program*

**Heather Ruthrauff, MS, OTR/L, CBIS**

*Occupational Therapist*

**Shiela Quinn, DO**

*Fellow, Division of Adolescent Medicine*

**Symme Trachtenberg, MSW**

*Director, Community Education*

**Audrey Vincent, MSW, LSW**

*Social Worker, Trisomy 21 Program*

*CHOP Career Path Program*

**Patty White, RN and Mom**

*After Hours Program*

**Lauren White**

*Daughter and Self Advocate*

**Learn more: [chop.cloud-cme.com](http://chop.cloud-cme.com)**

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