



TRISOMY 21
Down Syndrome in the 21st Century

CONFERENCE SCHEDULE

8:00 am - 8:45 am	Registration / Continental Breakfast		
8:45 am - 9:00 am	Welcome / Opening Remarks (Kristin Tassin)		
9:00 am - 9:30 am	Keynote Speakers: Siblings Christopher Scott and Lori Wyatt		
Tri-Strand Topics	Educational Strand	Medical Strand	Parental Strand
9:45 am - 11:00 am	“Honey, I Blew Up The Curriculum” - Part 1 Nancy & Bridget Brown, Butterflies for Change	Legal, Ethical and Medical Considerations for Delivering Diagnoses (1 hour CME credit available)* Kathryn K. Ostermaier, MD, Down Syndrome Clinic of Houston Anne Bernay, President, Families Exploring Down Syndrome Kristin Tassin, Director/Co-Founder, Father’s Joy	What Your Children Without Down Syndrome are Thinking: Sibling Issues Brian Skotko, MD, MPP, Genetics
11:15 am - 11:30 am	Pick Up Lunch		
11:30 am - 12:45 pm	Keynote Address: Celebrating Life with Down Syndrome Brian Skotko, MD, MPP, Genetics		
1:00 pm - 2:15 pm	“Honey, I Blew Up The Curriculum” - Part 2 Nancy & Bridget Brown, Butterflies for Change	Alternative Treatments For Children with Down Syndrome (1 hour CME credit available)* Nirupama Madduri, MD, Pediatric Developmental Behavioral Health	Parents Supporting Parents: A Shared Journey Jeanine Pinner, Training and Outreach Coordinator, Texas Parent to Parent
2:30 pm - 3:45 pm	“Lights, Camera, Action”: Using Scripting, Acting, Video Modeling, and Role Playing to Teach Social Skills Joanie Garro, MA, BCBA, CT	Pulmonary Issues and Sleep Apnea (1 hour CME credit available)* Ellen M. Friedman, MD, FAAP, FACS, Pediatric Otolaryngology George B. Mallory, Jr., MD, Pediatric Pulmonology	Q&A Panel Kathryn K. Ostermaier, MD, Down Syndrome Clinic of Houston Jan Stailey, Director, The Rise School of Houston, Diagnostician, and Educator Kristin Tassin, Director, Father’s Joy, Attorney, and Parent Nancy Brown, Inclusion Specialist
4:00 pm	Conference Ends		

Booths Open

EDUCATIONAL STRAND:

1. **“Honey, I Blew Up The Curriculum” - Parts 1 & 2**, Nancy & Bridget Brown, Butterflies for Change

Adaptations and Accommodations: The IDEAL Method of Adapting Curriculum

In this workshop participants will learn how to adapt curriculum to meet the needs of a diverse classroom. Parents will learn how to help their children at home and make easy adaptations that will help children access the general education curriculum and be a full participant in the educational process.

Participants will:

- Learn how to look at the learner, curriculum and environment
- Learn how to find the essential and enduring concepts of a lesson unit using the curriculum planning pyramid
- Learn how to all students can have access to the general education curriculum and the learning standards.
- Learn the 8 types of adaptations
- Learn how to authentically assess a student who has academic challenges
- Learn simple, easy-to-use tools and strategies that include: mini books, previewing, auto summarizing, graphic webs, picture/photo stories and books, read please, using technology and adapting to maintain the integrity of the curriculum and reduce density
- Learn about the concepts of backward design and universal design
- Learn how a student with a disability used all the adaptations to be successful in general education from pre-school - High School
- Learn simple ideas and programs that help students support each other in collaborative groups
- Learn about environmental structures that support all learners: co-teaching models, stations, and cooperative groups
- Learn how to communicate effectively with general education teachers, special education teachers, and parents
- Learn how to involve parents in the process

2. **“Lights, Camera, Action”:** Using Scripting, Acting, Video Modeling, and Role Playing to Teach Social Skills, Joanie Garro, MA, BCBA, CT

Video modeling interventions involve a child watching videotapes of positive examples of adults, peers, or him or herself engaging in a behavior that is being taught. Research suggests that video modeling interventions are effective in teaching a variety of skills to children with autism and other developmental disabilities. Participants will learn how to use video modeling to teach social skills to individuals of all ages and ability levels.

The presenter will also discuss the success of FILM CLUB, an inclusive social skills class using scripting, acting, video-modeling, film editing, and directing for children in elementary, junior

high, and high school, and adult ages. FILM CLUB was created by Ms. Garro because she saw a need in the community for children and adults to develop their social interaction skills by using this fun technique.

MEDICAL STRAND (3 hours CME credit available)*

*This activity has been implemented in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of Advanced Health Education Center and Greater Clear Lake Families Exploring Down Syndrome. The Advanced Health Education Center is accredited by the ACCME to provide continuing education for physicians.

1. **Legal, Ethical and Medical Considerations for Delivering Diagnoses**, Kathryn K. Ostermaier, MD, Developmental Pediatrician, Down Syndrome Clinic of Houston; Anne Bernay, President, Greater Clear Lake Families Exploring Down Syndrome; Kristin Tassin, Director/Co-Founder, Father's Joy

This presentation will provide participants with the following information:

- Research demonstrating that the manner in which doctors deliver diagnoses can be harmful to parents and children;
- An outline of current legislation (The Prenatally and Postnatally Diagnosed Conditions Awareness Act) that requires doctors to give balanced and scientific information and resources to parents;
- A prescription for doctors on how to deliver a diagnosis positively, supportively, and informatively;
- A demonstration through the lives of people with Down syndrome of the opportunities available to them and the full lives they share with their families, friends and others in their communities; and
- Resources available to doctors and families that provide support, information and an understanding of the diagnosis.

2. **Alternative Treatments For Children with Down Syndrome**, Nirupama Madduri, MD, Pediatric Developmental Behavioral Health

This workshop will provide a discussion of Complimentary and Alternative Treatments and their role in management of children with Down syndrome, examining the medical research and also a discussion of the most common therapies.

3. **Pulmonary Issues and Sleep Apnea**, Ellen M. Friedman, MD, FAAP, FACS, Pediatric Otolaryngology; George B. Mallory, Jr., MD, Pediatric Pulmonology

This workshop will provide a discussion of Obstructive Sleep Apnea in children with Down syndrome, focusing on medical/pathological findings, medical complications, therapeutic management, clinical presentation, surgical management, and unique anatomical features for children with Trisomy 21 compared to the general population.

PARENTAL STRAND

1. **What Your Children Without Down Syndrome are Thinking: Sibling Issues**, Brian Skotko, MD, MPP, Genetics

Through 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. Parents and/or professionals will come away with practical answers to commonly raised questions. This presentation draws upon Brian Skotko and Sue Levine's publication in *American Journal of Medical Genetics* and their new book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*.

2. **Parents Supporting Parents: A Shared Journey**, Jeanine Pinner, Texas Parent to Parent Training and Outreach Coordinator

At some point, most of us have needed the support of another parent who's "been there." Then we are ready to "pay it forward" by providing support to another, it is crucial that we know what skills are necessary to support another parent. Among these skills are supportive communication and an understanding of the stages of adaptation that we all go through after learning that our child has a disability, chronic illness or other health care need. This session provides basic information that will assist in taking that first step toward "paying it forward." Components: Stages of adaptation, listening, supportive communication, confidentiality, limit-setting/self-determination.

3. **Q&A Panel**, Kathryn K. Ostermaier, MD, Developmental Pediatrician, Down Syndrome Clinic of Houston; Jan Stailey, Director, The Rise School of Houston, Diagnostician, and Educator; Kristin Tassin, Director/Co-Founder, Father's Joy, Attorney, and Parent; Nancy Brown, Inclusion Consultant

T21 has gathered a panel of experts including a medical doctor, educator/diagnostician, attorney/parent, and inclusion specialist. Participants will be provided an opportunity to ask the panel questions related to a broad range of medical, educational, legal, and parenting issues.