

# Meeting our full potential...

Sponsored by: The Down Syndrome Advocacy Foundation and  
The Center for Community Inclusion, LIU Post

## The 11th Annual Conference on Best Practices in the Education of Children with Down Syndrome December 5 & 6, 2014 LIU Post

The Tilles Center Atrium, 720 Northern Boulevard  
Brookville, New York 11548

### KEYNOTE SPEAKERS

*Jon Anton  
Self-Advocate*

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

*Helene Fallon  
Long Island Parent Center*



*Marisa Paravani Self-Advocate*



### SATURDAY A DAY FOR THE WHOLE FAMILY



#### Directions to LIU POST

From the West: L. I. Expressway to Exit 39 (Glen Cove Rd). Go North to Northern Blvd. (Route 25A). Turn right. Go 2 miles to L.I.U., Post Campus (Tilles Center) – West Gate. Turn right onto Post Lane, the Tilles Center Atrium will be on your left.

From the East: L. I. Expressway to Exit 41N (Rte. 107). North on 107, bear left at fork where 106 & 107 split. Turn left onto Northern Blvd. (Rte. 25A). At first light, turn left into L.I.U. (East Gate). Immediately turn right onto University Dr. At 2nd stop (West Gate), turn left onto Post Lane - follow directions above.

# Meeting our full potential...

## Friday, December 5th

8:00 AM – Registration ~ Refreshments will be served - Tilles Center Atrium

## Keynotes

9:00–11:00

9:00 AM – Keynotes Begin...

“My Journey to Self-Advocacy” by Jon Anton, Self-Advocate

“Healthy Students with Down Syndrome: All the Medical Updates that Educators Need to Know”

by Brian Skotko, M.D., M.P.P.

How might behavior problems in the classroom be the result of an underlying medical issue? How do the conditions that go along with Down syndrome affect learning? In this presentation, Dr. Brian Skotko reviews all of the questions and concerns that educators most often have about their students with Down syndrome. He provides the answers and action steps, stemming from the latest clinical research on people with Down syndrome. Based on his clinical experience in the Down Syndrome Program at Massachusetts General Hospital, Dr. Skotko provides suggestions on how educators can collaborate most effectively with parents and clinicians to maximize students' potential.

“The World of Common Core”

by Helene Fallon, M.Ed., Director of the Long Island Parent Center and Long Island Communities of Practice

Feeling overwhelmed, thinking about "opting out" of testing, having a difficult time with Common Core in your classroom or district? Learn how to better understand the theory and concepts behind Common Core standards. The more you understand, the easier the implementation will be.

## Session One

11:00–12:00

1. Keeping Children and Adolescents with Down Syndrome Healthy:

All the Medical Updates that Parents Need to Know – Brian Skotko, M.D., M.P.P.

2. Including Technology to Facilitate Independence – Randy Young, MS Ed.

3. The Importance of Physical Development Early in Life to Reach Maximum Potential –

John E. Hofmayer, M.S., P.T., PPT Therapies

## Box Lunch (Hillwood Commons) 12:00–12:45

## Session Two

12:45–1:45

1. Adult Brothers and Sisters who have Siblings with Down Syndrome – Brian Skotko, M.D., M.P.P.

2. Enhancing Your “Modifications Tool Box” – Diane Ripple, M.A.

3. Developing Language and Speech in Early Learners – Marian B. Boehm, MS, CCC-SLP

## Session Three

2:00–3:00

1. Navigating the Systems – Stacey Astachovsky, MSW

2. Barriers to Life-Long Inclusion: The Problem with “Problem” Behavior – John Innis, M.A., BCBA

3. Starting on the Right Path for Educational Success – Kathleen M. Feeley, PhD, BCBA

# Meeting our full potential...

## Saturday, December 6th

9:00 AM – Registration

## Keynotes

10:00–12:00

10:00 AM – Introduction by Mike Hoffman, D.A.D.

“Meeting My Full Potential” by Marisa Paravani

“A Parent’s Perspective” by Mary DeBernardi-Paravani

“We have a few things to say” ~ Siblings of Children with Down Syndrome

“How to prevent the need for legal representation”

Lunch Provided (Top of the Commons) 12:00–12:30

## Session One

12:30–1:30

1. Critical Components of Intervention for Infants and Toddlers with Down Syndrome – Nicole Neil, M.A.
2. ABA Discreet Trial Training/Skill Development – Jennifer Hawthorne, M.S. Ed, BCBA
3. Teaching Sexuality and Abuse Prevention to Young Adults with Special Needs – Tracy E. Murphy, Special Education Consultant, MS

## Session Two

1:40–2:40

1. Transition to Preschool and Kindergarten – Kathleen M. Feeley, PhD, BCBA
2. Strategies for Enhancing Community Inclusion – Randy Young, MS Ed.
3. Transition Panel to Prepare for Adult Services – Marlene Rosenson

## Session Three

2:45–3:00

## ZUMBA SHOW

*The children and young adults with and without Down syndrome who participate in the Saturday program will be performing*

# Meeting our full potential...

## Saturday, December 6th

A great opportunity for families of children with Down syndrome and the professionals who serve them.

While parents and professionals attend informative workshops, children with and without Down syndrome will be engaged in educational activities, will come together for lunch, and have an afternoon of recreational activities organized by LIU Post's athletes. This is a wonderful opportunity for families to connect, and it provides children with and without Down syndrome an opportunity to build relationships with other children with Down syndrome and their siblings.

On both days of the conference, for a nominal fee, families can enroll their children 12 months and older in our Building Blocks Play Group which will last the length of the conference

\*\*\*Must Reserve a spot by calling 516-299-3812 no later than November 30th \*\*\*\*No walk-ins

### **SIBLINGS AND CHILDREN/INDIVIDUALS WITH DOWN SYNDROME**

#### **Morning Program**

- Creative Arts, Literacy Project, and Making Music
- Sibling Empowerment Sessions — Lead by a Denise Mussler, NYS Certified School Counselor ~ Siblings will meet in small groups to discuss the triumphs and challenges of being a sister/brother to someone who has Down syndrome.



#### **Pizza Lunch at the Pratt Center**

#### **Afternoon Program**

- "Sports, Sports, Sports" Led by LIU Post's Athletes
- Zumba



## Keynote Speakers...

**Jon Anton, Self-Advocate**, John Anton is a Legislative Specialist with the Massachusetts Down Syndrome Congress, an Intern for Representative Tom Sannicandro at the State House in Boston, Chairperson for MASS Advocates Standing Strong, and a dedicated self-advocate. Advocating for people with developmental disabilities and empowering them to have their voices heard is his dream. John was also honored by the National Down Syndrome Society as "Advocate of the Year" for his work with legislators, policy makers, and disability advocates to support legislation that improves and protects the lives and rights of people with Down syndrome and other disabilities. He also worked tirelessly, along with many others, to change the name of the Department of Mental Retardation to the Department of Developmental Services. This passed in July of 2010. John lives in his own apartment with supports and continues to share the message that people should be heard, taken seriously, and have respect and dignity as citizens of the United States.

**Brian Skotko, M.D., M.P.P.**, A Board-certified medical geneticist and Co-Director of the [Down Syndrome Program at Massachusetts General Hospital](#), Dr. Skotko has dedicated his professional energies toward children with cognitive and development disabilities. In 2001 he co-authored the national award-winning book, *Common Threads: Celebrating Life with Down Syndrome*, and most recently, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. He is a graduate of Duke University, Harvard Medical School, and Harvard Kennedy School. Dr. Skotko authored major research on how physicians deliver a diagnosis of Down syndrome to new and expectant parents. He has been featured in *The Wall Street Journal*, *The New York Times*, *The Washington Post*, *The L.A. Times*, NPR's "On Point," and ABC's "Good Morning America." Dr. Skotko serves on the Honorary Board of Directors for the [Massachusetts Down Syndrome Congress](#), the Board of Directors for the [Band of Angels Foundation](#), and the Professional Advisory Committee for the [National Center for Prenatal and Postnatal Down Syndrome Resources](#).

**Helene Fallon, M.Ed.** has a background in social work and education with extensive training in education and improving outcomes for children and young adults with disabilities. She is the parent of two children with special needs. Working nationally as a professional development specialist, she conducts trainings on many topics, always focusing on collaboration and effective communication in education.

**Mike Hoffman, D.A.D.**, the President of the Down Syndrome Advocacy Foundation and father of Matt, a high school junior will be sharing tips for change. Mike and his family have paved the way for other families with Down syndrome in this region and have done so by changing the perceptions of others so that their son Matthew was afforded equal opportunities.

**Marisa Paravani** is a young woman who is Self Determined. Marisa graduated high school after participating in collaborative classes. She has gone on to explore work in retail fashion and works with young children in a community program. She recently received her driver's permit and soon will be exploring a driver's education class. Marisa utilizes OPWDD's Consolidated Support Services (CSS) program to self-direct her services. She enjoys socializing with friends in her community, going to the gym, and doing volunteer work. When asked about CSS Marisa says "I feel this is a great opportunity to interact with new people and I love CSS!"

## Breakout Sessions, Friday 12/5...

**Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know** — **Brian Skotko, M.D., M.P.P.** In this presentation, Dr. Brian Skotko reviews all of the questions and concerns that parents most often have about their sons and daughters with Down syndrome. He provides the answers and action steps, stemming from the latest clinical research on people with Down syndrome. Based on his clinical experience in the [Down Syndrome Program](#) at Massachusetts General Hospital, Dr. Skotko makes sure that every parent can anticipate medical conditions so that the potentials of all people with Down syndrome are maximized.

**Including Technology to Facilitate Independence** — **Randy Young, MS Ed.** Assistive Technology (AT) is any device or service that increases, maintains, or improves the functional capabilities of individuals with disabilities. AT devices and services make it possible for individuals with disabilities to work, play, attend school and be more independent in their communities. This workshop provides an overview of the role that AT plays in a student's "IEP" Individualized Educational Plan and examines questions that should be considered in the assessment process. This workshop will highlight examples of AT which are used to help facilitate independence both at school and in the community.

**The Importance of Physical Development Early in Life to Reach Maximum Potential** — **John E. Hofmayer, M.S., P.T., PPT Therapies** There is no greater time in a family's life than the early stages of their child's development. It is during this time that a child's neurological system, regardless of capability, is its most susceptible toward growth and maturity. Science has proven this theory and as a result families are more aware than ever of this critical period in the life of a young child. There are ample resources for family's raising a child with a "typical" neurological and physical system but until recently there have been limited resources for families faced with the challenges of raising a child with a neurological and physical system that is "atypical." In this brief talk, Mr. Hofmayer will elaborate on how the human body first learns to interact with the environment. It is through this interaction that we set the foundation for physical development for the rest of life. He hopes to also shed light on the resources available to families raising infants and children of all ability levels in the earliest stages of development, in particular the Early Intervention Program.

## Breakout Sessions, Friday 12/5...

**Adult Brothers and Sisters who have Siblings with Down Syndrome – Brian Skotko, M.D., M.P.P.** In this workshop, Dr. Brian Skotko will discuss the most commonly raised questions and concerns by adult brothers and sisters who have siblings with Down syndrome. Using national research about siblings, he tackles questions about medical decisions, living arrangements, guardianship options, financial questions, and lifestyle choices. Also, he draws on questions and research in his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brother and Sisters*.

**Enhancing Your “Modifications Tool Box” – Diane Ripple, M.A.** This interactive, hands-on workshop will allow participants to explore everyday challenges in making modifications for students. Strategies for some common classroom situations will be discussed. Participants will also have the opportunity to ask questions and leave with specific strategies to try right away!

**Developing Language and Speech in Early Learners – Marian B. Boehm, MS, CCC-SLP** Notice that language comes first in this presentation. This session will examine the relationship between language, speech and motivation in young children. We will discuss misconceptions and best practices in intervention and present methods to help develop intentional communication and improve speech production.

**Navigating the Systems – Stacey Astachovsky, MSW** Learning and understanding how to navigate the New York State governmental systems for children and adults with intellectual and developmental disabilities is essential. What is OPWDD, the Front Door Initiative, and Self-Determination? Learn the difference between Medicaid and Medicaid Waivers. Understand when to apply for Social Security Supplementary Income, and the importance of Special Needs Trusts and Guardianship.

**Barriers to Life-Long Inclusion: The Problem with “Problem” Behavior – John Innis, M.A., BCBA** Obvious “problem” behavior such as causing injury to one’s self or others, property destruction, or extreme tantrums are cause for concern and immediate and appropriate intervention. Less obvious behavior can also be a “problem” if it leads to social isolation, lowered expectations and feelings of esteem for the individual. This talk will highlight the obvious, and not so obvious, aspects and consequences of behavior and what constitutes a “problem,” while encouraging a life-span view and a functional approach to addressing “problem” behavior.

**Starting on the Right Path for Educational Success – Kathleen M. Feeley, PhD, BCBA** From a very young age, families and professionals should be preparing the young children with Down syndrome to meet with optimal success within school settings. During this sessions, several strategies will be presented that can be implemented to enhance behavior, communication skills, and instructional readiness.

## Breakout Sessions, Saturday 12/6...

**Critical Components of Intervention for Infants and Toddlers with Down Syndrome – Nicole Neil, M.A.** Young children with Down syndrome show an early developing pattern of relative strengths and weaknesses. This behavioral phenotype is characterized by impairments in foundational skills including communication, motor, and cognitive development, but relative strengths in social development. These early impairments may be pivotal behaviors that, when improved through intervention result in changes in related skill areas. Empirically based interventions to address these areas involve relatively intense procedures. We will discuss potential interventions for early communication, motor and cognitive impairments and review current research reflecting optimal intervention intensity conditions to employ when implementing these interventions.

**ABA Discrete Trial Training/Skill Development – Jennifer Hawthorne, M.S. Ed, BCBA** This presentation will discuss Discrete Trial Instruction and how it is used to teach new skills. Discrete Trial Instruction may be used to teach social/play skills (i.e. imitative play, turn-taking and imitating peers, receptive and expressive language, self-help skills (i.e. toileting, dressing and undressing and oral hygiene), academics (i.e., matching identical items, identifying shapes, colors, letters, and numbers). She will discuss how goals are customized to meet the needs of each child.

**Teaching Sexuality and Abuse Prevention to Young Adults with Special Needs – Tracy E. Murphy, Special Education Consultant, MS** Individuals with disabilities are three times more likely than without disabilities to be victims of sexual abuse, and the likelihood is even higher for individuals with certain types of disabilities, such as intellectual or mental health disabilities. Educating yourself about the dangers and signs of abusive situations should be your first step toward preventing abuse with your developmentally disabled child/student. There is an alarming lack of primary prevention efforts geared to preventing sexual abuse of children with disabilities. This workshop will ALSO focus on the strategies to create specific resources that will be helpful for particular concepts addressed by YOU! Personalize your visual ‘Circle of Concepts’ grid, develop skills and strategies to create a visual storyboard/social story, as well as developing a video modeling plan. Bring your iPad to explore additional resources.

**Transition to Preschool and Kindergarten – Kathleen M. Feeley, PhD, BCBA** It is important for families and professionals to plan early regarding the path they want their child with Down syndrome to take during the preschool and kindergarten years. Options for programming and strategies for collaboration will be the focus of this workshop, in addition an overview of strategies to address skill acquisition will be provided.

**Transition Panel to Prepare for Adult Services – Marlene Rosenson** Transition to adult services can seem like a daunting task. But when well prepared, it can be a smooth process. During this workshop, there will be a panel of individuals with disabilities, families, and service providers who will present on important factors to consider as one transitions to adult services. There will be time for the panel to address questions.

**Strategies for Enhancing Community Inclusion – Randy Young, MS Ed.** Research shows that people with disabilities participate in fewer community activities and are less satisfied with their community participation than people without disabilities. This workshop will focus on a variety of community inclusion strategies for people of all ages with disabilities. Particular emphasis will be placed on how assistive technology can be used to help foster community integration.

# Best Practices in the Education of Children with Down Syndrome Conference Schedule and Registration

## Registration Fee Friday Conference

- \$85 Professionals (by November 21st) -->  \$100 (after November 21st)
  - \$60 Parents/Students (by November 21st) -->  \$75 (after November 21st)
- \*Lunch included. Those with dietary restrictions are kindly asked to bring their own food.*

## Registration Fee Saturday Conference

- \$60 Professionals (by November 21st) -->  \$75 (after November 21st)
  - \$35 Parents/Students (by November 21st) -->  \$50 (after November 21st)
  - \$15 Per Child/Individual with a disability (by November 21st) -->  \$25 (after November 21st)
- \*Lunch included. Those with dietary restrictions are kindly asked to bring their own food.*

**\*DSAF members for the 2014 calendar year receive a 10% discount\***

**Please indicate the Friday workshops you would like to attend:**

Friday, Session One (11:00–12:00)	Friday, Session Two (12:45–1:45)	Friday, Session Three (2:00–3:00)
<input type="checkbox"/> 1. Brian Skotko, M.D., M.P.P. <input type="checkbox"/> 2. Randy Young, MS, Ed. <input type="checkbox"/> 3. John E. Hofmayer, M.S., P.T.	<input type="checkbox"/> 1. Brian Skotko, M.D., M.P.P. <input type="checkbox"/> 2. Diane Ripple, M.A. <input type="checkbox"/> 3. Marian B. Boehm, MS, CCC-SLP	<input type="checkbox"/> 1. Stacey Astachovsky, MSW <input type="checkbox"/> 2. John Innis, M.A., BCBA <input type="checkbox"/> 3. Kathleen M. Feeley, PhD, BCBA

**Please indicate the Saturday workshops you would like to attend:**

Saturday, Session One (12:30–1:30)	Saturday, Session Two (1:40–2:40)
<input type="checkbox"/> 1. Nicole Neil, M.A. <input type="checkbox"/> 2. Jennifer Hawthorne, M.S. Ed, BCBA <input type="checkbox"/> 3. Tracey E. Murphy, Special Education Consultant, MS	<input type="checkbox"/> 1. Kathleen M. Feeley, PhD, BCBA <input type="checkbox"/> 2. Randy Young, MS Ed. <input type="checkbox"/> 3. Marlene Rosenson

**Saturday**     Number Adults \_\_\_\_\_     Number Children/Individuals with Down Syndrome \_\_\_\_\_

Number Siblings/Friends \_\_\_\_\_

Financial Assistance is available for a limited number of families –

Large groups eligible for group rates –

***Certificates of Attendance will be provided on-site***

**\*\*Information: Call 516-299-3812 or Email: [conferenceonbestpractices@gmail.com](mailto:conferenceonbestpractices@gmail.com)\*\***

If you are traveling, we will have a block of rooms available at the Executive Inn Woodbury  
 Phone 516-921-8500, ask for the Conference on Down Syndrome - Address: 8030 Jericho Turnpike  
 Woodbury, New York 11797 (for the reserved group rate you must respond by November 5th)

Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_

E-mail Address \_\_\_\_\_

Payment \_\_\_ Visa \_\_\_ MasterCard \_\_\_ Discover \_\_\_    We accept purchase orders.

Check (Checks payable to Long Island University)    Total \_\_\_\_\_

Credit Card # \_\_\_\_\_ Three/four digit security code \_\_\_\_\_

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

You may send this form via:

Email: [conferenceonbestpractices@gmail.com](mailto:conferenceonbestpractices@gmail.com)

Fax: 516.299.4167

Mail: To LIU Post –College of Education and Information Technology

Attention: Grace Gazzo

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