

## **Keynote Speaker, Carrie Bergeron-Desai:**

### *The Journey to “Carrie” On*

Carrie is a thirty-three year-old with Down syndrome from upstate New York where she lives alone in a cozy apartment. She radiates joy and warmth, a trait that has been evident since she was a hypotonic infant with a wobbly head! She is presently in a NYS Self-Determination plan. Staff supports her in her daily routine.



Carrie graduated from her local high school with an IEP diploma when she was twenty-one years old. A post-graduate year was spent at Herkimer County BOCES where she received a certificate in Early Childhood Education. She then went on to receive a two-year degree (obtained in four and a half years) from Herkimer County Community College as a teacher’s assistant in 2003.

She has been volunteering at the Upstate Cerebral Palsy Center for over four years, helping with the toddler programs. She also volunteers at the local hospital assisting in a Tai Chi program on the geriatric floor which she will soon take over when the present instructor retires.

Physical fitness is maintained by daily workouts at the YMCA, two weekly classes in Tae Kwon Do and lifetime membership at Weight Watchers. Her interests are: sign language, reading, karate (black belt status), music, and dancing.

She is a former board member of the National Down Syndrome Congress (NDSC) and currently serves on the Self Advocates Committee. She loves to share her experiences as a young person with Down syndrome. Carrie is a current member of the local Speakers Bureau. In October 2008 she was honored with an Accent on Excellence award. She was one of ten recipients out of seventy-five applicants for the award which recognizes the efforts of outstanding young leaders in the Mohawk Valley where Carrie lives.

Carrie received the 2007 “Voices” award from the National Down Syndrome Society (NDSS) in New York City. She also was the recipient of the Christian Pueschel Memorial Citizenship Award in 2005 at the annual National Down Syndrome Congress (NDSC) convention. Both awards celebrate the distinguished achievements of young people. Carrie truly believes that ALL children with Down syndrome should be given every opportunity to meet their potential and have success and happiness.

Down Syndrome Parent Group of WNY  
222 Culpeper Lane  
Williamsville, NY 14221

# **Empowering Ourselves for a Brighter Future**

*A Conference for  
Community & Family Supporting Individuals  
with Down Syndrome*

**Keynote Speaker:  
Carrie Bergeron-Desai**

brought to you by



**Saturday, May 1, 2010  
8:00am – 3:00pm**

St. Mary’s High School  
142 Lavarack Avenue  
Lancaster, New York 14086

## AGENDA

- 8:00 – 8:30 Registration & Refreshments**
- 8:30 – 8:45 Welcome, Introduction & Slide Show**
- 8:45 – 9:45 Keynote Speaker:  
Carrie Bergeron-Desai**
- 10:00 – 11:00 Session 1 Workshops (Choose one)**

**A) Guardianship, Wills & Trusts, Lisa Allen, Esq. of Harris Beach PLLC and Dan Kautz, Financial Planner, Independent Retirement Advisors**

Discussion of unique financial issues encountered by parents of children with special needs including Medicaid and SSI eligibility and maximizing Social Security benefits. Life insurance and retirement questions to explore with your personal financial advisor will be covered.

**B) Passing on the Gift of Faith, Sandra Rice, Parish Ministry Consultant for Bethesda Lutheran Communities and Sharon Urbaniak, Associate Director in the Lifelong Faith Formation department for the Roman Catholic Diocese of Buffalo**

Discussion of effective ways to share your faith with your child with Down syndrome as well as ways to succeed at inclusion in a community of worship.

**C) Medicaid: What Services Do We Need?, Christina Williams-Wood, Medicaid Service Coordinator and Susan Lichtenthal, Executive Director of the Lutheran Service Society of New York**

Overview of services available to individuals with developmental disabilities. Discussion of a variety of services and funding sources including OMRDD, Medicaid, and private sources. There will be time at the end of the session for questions and answers.

**D) Raising a Child or Family Member with Down Syndrome: A Male Perspective, Facilitated by members of the Bornhava Men's Forum**

Intended for fathers and male adult relatives of children and young adults with Down syndrome. Open dialogue and discussion on those issues relating to raising a child or young adult with Down syndrome in a relaxed atmosphere. Facilitators from the Bornhava Men's Forum will be on hand to help get the discussion started.

### **11:15 – 12:15 Session 2 Workshops (Choose one)**

**A) Guardianship, Wills & Trusts, Lisa Allen, Esq. of Harris Beach PLLC and Dan Kautz, Financial Planner, Independent Retirement Advisors**

See description in Session 1.

**B) Attention Problems in Children with Down Syndrome: Could It Be Sleep Apnea?, Linda Brodsky, MD, FAAP, FACS**

Discussion of the current information available about the link between cognition/ attention/behavior problems in Down syndrome and sleep disordered breathing (sleep apnea). Evaluation and treatment options will be discussed.

## Session 2 Workshops (continued)

**C) Special Education: What's It All About?, Vickie Rubin, Director, Early Childhood Direction Center, Trainer, Parent Network of WNY & Stacie Ricioppo, Education Coordinator, Early Childhood Direction Center, Trainer, Parent Network of WNY**  
Brief overview of the special education system. Participants will learn what to expect at a Committee on Special Education (CSE) or Committee on Preschool Special Education (CPSE) meeting and receive tips on advocating for their children.

**D) Humoral Immunodeficiency in Pediatric Down Syndrome Patients: Overview of Study Results, Dr. Heather Lehman, Research Assistant Professor of Pediatrics & Anita Shvarts, MD, Pediatric Resident / Women & Children's Hospital of Buffalo**  
Presentation explaining the components and cells that make up our immune system. Also includes a summary of the results from a recent study investigating antibody-based immunity in children with Down syndrome from Western New York.

### **12:15 – 1:15 Lunch & Resource Area**

### **1:30 – 2:30 Session 3 Workshops (Choose one)**

**A) PROMPT Speech Therapy, Leah Blum & Susan Pisarek-Freatman, Speech Language Pathologists, PROMPT Certified**  
PROMPT Speech Therapy – a hands-on approach to help train/retrain motor speech pathways in individuals of all ages.

**B) Why Children with Down Syndrome Have an Excuse Not to Listen - Hearing Problems, Christopher Poje, MD, FAAP, FACS**

A review of the many reasons children with Down syndrome have more ear disease and what can be done to identify and prevent it. Recommendations to screen for hearing problems as children get older will also be reviewed.

**C) Letting Go: Empowering Young Adults with Disabilities, Vickie Rubin, Director, Early Childhood Direction Center, Trainer, Parent Network of WNY & Stacie Ricioppo, Education Coordinator, Early Childhood Direction Center, Trainer, Parent Network of WNY**  
Discussion of the challenges involved with the transition from childhood to adulthood for students with special needs and their parents. Tools to deal with the emotional issues will be shared. Participants will also acquire resources for effective transition planning.

### **2:30 – 3:00 Q&A Session with the Keynote Speaker & Wrap Up**

**\*\* Please register by April 1 so we can plan for refreshments and handouts. \*\***

**Boxed lunch included with registration.**

**\*\* Childcare will not be available.\*\***

## REGISTRATION FORM

Please complete this form by April 1 so we can plan for refreshments and handouts. The registration fee of \$15 per person or \$20 per couple includes refreshments during registration, a boxed lunch and handouts. We are regrettably not able to provide childcare for this event, so please plan accordingly.

Name(s) \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Total # attending \_\_\_\_\_ Amount enclosed \_\_\_\_\_

I am a: \_\_\_\_\_ person with Down syndrome  
\_\_\_\_\_ parent / family member  
\_\_\_\_\_ teacher / staff  
\_\_\_\_\_ agency / provider

Do you need accommodations? (i.e. interpreter, Braille)  
\_\_\_\_\_

### Workshop Choices

Session 1 \_\_\_\_\_ A \_\_\_\_\_ B \_\_\_\_\_ C \_\_\_\_\_ D

Session 2 \_\_\_\_\_ A \_\_\_\_\_ B \_\_\_\_\_ C \_\_\_\_\_ D

Session 3 \_\_\_\_\_ A \_\_\_\_\_ B \_\_\_\_\_ C

### Lunch (Choose one)

\_\_\_\_\_ Ham \_\_\_\_\_ Turkey \_\_\_\_\_ Vegetarian

*Mail this form and checks made out to DSPG to:*

DSPG 2010 Conference

222 Culpepper Lane, Williamsville, NY 14221.

For more information contact  
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