

# News & Updates from the Down Syndrome Clinic

at Kennedy Krieger Institute

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Summer 2011 • Vol. 2, Issue 1

## *Director's Update: A New Vision For A New Center*

### **Integrating patient care, research, professional training, and community programs to enhance understanding and improve outcomes**

Having a family member with Down syndrome can be a remarkable journey. Persons with Down syndrome invite us to reflect and examine our own humanity, and they inspire us to be better and do better ourselves. How fortunate we are to know them.

We believe the future is bright because of universal support for early childhood intervention while medical, educational, and social opportunities for persons with Down syndrome continue to expand beyond what we ever thought possible.

Yet despite these advancements there continues to be an unmet need to incorporate contemporary approaches in neuroscience, cognitive, and behavioral research in order to better understand and solve complex clinical problems that affect brain function in children and adults with Down syndrome. Research strategies addressing these cognitive and mental health conditions need to be continuously improved and shared with the biomedical research community. Even today many school-age children with Down syndrome still struggle with social-adaptive functioning and community integration.



Director, George Capone, MD

At the Down Syndrome Clinic at Kennedy Krieger, our vision is to provide seamless integration between clinical services and to promote research in the areas of clinical neuroscience, pharmacology, sleep medicine, and behavioral-educational interventions. We emphasize clinical care and research designed to explore and treat underlying cognitive and neurobehavioral dysfunction in persons with Down syndrome. We have a successful record of publishing original research and securing government and private funding to support our work. But that's not enough.

To accelerate the pace of research and enhance patient outcomes, we intend to create a center focused on advancing biomedical treatment through clinical service, training, and research. It is imperative that we engage young investigators in the search for solutions. But the struggle to attract and train a critical mass of talented researchers still remains one of the field's greatest obstacles.

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## Director's Update: A New Vision For A New Center

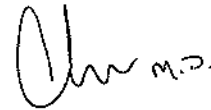
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In addition to providing clinical care, the center would function as a virtual laboratory for identifying, prioritizing, and shaping important research questions and their solutions.

However, the center cannot happen without your support and funding. Growth requires partnerships between parents, professionals, and philanthropists. Through these partnerships we can:

- Support families who wish to participate in our research studies
- Provide training to a new generation of medical and neuroscience investigators
- Create a personalized long-term vision of health and well-being for all persons with Down syndrome
- Share our clinical research findings with scientists, physicians, and healthcare providers around the world

To learn how you can help us make the Down Syndrome Clinic and Research Center a reality, please contact us at 443-923-9143 or email [downsyndrome@kennedykrieger.org](mailto:downsyndrome@kennedykrieger.org).



George T. Capone, M.D.

### Brightside Down Syndrome Mentoring Program Hold's First Fundraiser at Langermann's Restaurant



Supporters gathered to raise funds in support of Brightside Down Syndrome Mentoring program.

On April 15, 2011, the Brightside Down Syndrome Mentoring program held its first annual fundraiser at Langermann's restaurant in Canton. Approximately 100 people attended the fundraiser to support the program, which acknowledges the talents of teens and young adults with Down syndrome while promoting personal independence and fostering relationship development. Brightside volunteer Debbie Grimm, a facilities staff member at Kennedy Krieger and mother of Cheyenne and Dakota Grimm, attributes the growth and development of her once shy, reserved, and dependent daughters to Brightside's mission. "Because of programs like Brightside, the girls' social, emotional, and communication skills have soared. They're becoming independent away from me as they make new friends and look forward to seeing them. I love everything about Brightside and watching them grow into beautiful young ladies. I feel I've been blessed watching all this unfolding in front of me. That is a reward in itself."

The fundraiser was the idea of social work intern Megan Sullivan, who became committed to the program about six months ago, after first volunteering. "Volunteering for Brightside has been a pleasure and an amazing learning experience for me as a new social worker," she says.

The fundraiser, which included raffles and a silent auction, raised more than \$2,000, and good times were had by all! The highlight of the evening, however, was a selfless act by Jim and Darlene Wagner. The Wagner's made a bid on a silent auction item called the Rainy Day Basket, which was full of games, videos, and arts and crafts items. When they won, they unexpectedly handed the basket to Lavae Lee, one of the children in Brightside. After the initial shock of receiving such a great gift, Lavae jumped up and down with delight.

## Staff Interview: Rhonda Stallings

Rhonda Stallings has been a pediatric physical therapist since 1999. She works with individuals from birth through adulthood who have childhood onset disorders, including Down syndrome, cerebral palsy, neurodevelopmental, and congenital and acquired disabilities. She has been with the Down Syndrome Clinic at Kennedy Krieger since 2008. Here are some of the questions she most often hears, along with her answers.

### Q: When will my child walk?

A: The age range for independent walking in children with Down syndrome is very broad. While some children may walk as early as 11 months old, others may feel more comfortable by age 5. On average, children with Down syndrome start walking independently around 2 to 2 ½ years old. I often emphasize that while walking is important, the age at which that skill was attained will matter less than the quality of their movement when the child is 10 years old.

### Q: Will my child need orthotics?

A: There are many factors that affect the decision to use orthotics. I would recommend waiting until the child is comfortable standing or playing in standing position before considering the possible benefits of orthotics. Many times, it takes a while for children to get used to standing on their feet and using their little muscles for stability. If the foot and ankle are too unstable, I may recommend orthotics. However, whenever possible I like to wait until a child has been walking independently for about a month to give them time to develop some stability and balance on their own.

### Q: Why does my child sit with her back so rounded?

A: Because of low muscle tone and the tendency of young children to sit with their pelvis tilted back, these factors contribute to sitting with a rounded posture. Parents may need to reposition the child and use supports to help maintain proper posture. Also, it may help to elevate the playing surface about 2 to 3 inches above the belly button so that the child sits more upright.



### Q: My child won't ride the tricycle at home. Why?

A: There may be many reasons why your child won't ride the tricycle. It is often difficult to concentrate on the multiple tasks involved in learning to ride a tricycle. Here are just a few:

- Keeping feet on the pedals
- Using feet to propel the pedals
- Keeping bottoms on a slippery surface
- Maintaining upright posture
- Steering

It's important to adjust as many of these factors as possible to make it an enjoyable experience. I highly recommend using adapted pedals and nonslip material on the seat, especially if there is no support in the back. Parents may also have to use hands-on assistance for pedaling until the child is ready to take over.

## Recent Publications

J. Edgin, G. Mason, M. Allman, **G. Capone**, I. Deleon, C. Maslen, R. Reeves, S. Sherman, L. Nadel. (2010). Development and Validation of the Arizona Cognitive Battery for Down Syndrome. *Journal of Neurodevelopmental Disorders* 2:149-164

**G. Capone**. The Emergence of Pharmacotherapies for Cognitive Function in Down Syndrome. (2010). Invited Commentary appearing in *American Journal of Medical Genetics*. 152A(12):3026-7

Na Young Ji, **G. Capone**, W. E. Kaufmann, Cluster Analysis of Aberrant Behavior Checklist Items Supports Diagnostic and Statistical Manual of Mental Disorders Diagnoses in Down Syndrome. (2011). *Journal of Intellectual Disability Research*, in press

**G. Capone**. (2011). Pharmacotherapy for Children with Down Syndrome, in *Neurocognitive Rehabilitation in Down Syndrome: The Early Years*. (Eds. J. Rondal, J. Perera and D. Spiker). Cambridge University Press, Cambridge.



Kennedy Krieger Institute

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## Our Mission

We at the Kennedy Krieger Institute dedicate ourselves to helping children and adolescents with disorders of the brain, spinal cord, and musculoskeletal system achieve their potential and participate as fully as possible in family, school, and community life.

### Actively Recruiting Research Studies

*A 20-week double blind placebo controlled clinical trial to evaluate the safety and efficacy of rivastigmine in children and adolescents (ages 10 to 17 years) with Down syndrome.*

Kennedy Krieger Institute and Duke University are currently recruiting participants with Down syndrome (ages 10 to 17 years). The study is to determine whether an investigational medication (FDA-approved for Alzheimer's disease) improves memory, speech, and language functions in children and adolescents with Down syndrome. The study consists of four visits, and the participant's family will receive \$25 per visit to help with the cost of travel.

*For more information about the rivastigmine study, please contact Marie Andachter, research coordinator, at 443-923-7716 or [andachter@kennedykrieger.org](mailto:andachter@kennedykrieger.org).*

#### ***Down Syndrome Phenotype Project***

Kennedy Krieger Institute, Oregon University, Emory University, and Johns Hopkins University are recruiting children with Down syndrome, under age 18, to participate in the Down Syndrome Phenotype Project, which includes studies of the heart, cognitive function, and craniofacial anatomy. These studies are to help understand the genetic basis for certain physical characteristics associated with Down syndrome, including congenital heart disease and familiar facial features.

*For more information about the Down Syndrome Phenotype Project, please contact Kay Taylor, research coordinator, at 443-923-9143 or [taylork@kennedykrieger.org](mailto:taylork@kennedykrieger.org).*