

News & Updates from the Down Syndrome Clinic

at Kennedy Krieger Institute

801 North Broadway, Baltimore, Maryland 21205

www.downsyndrome.kennedykrieger.org

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From the Director


This is an exciting time for the families of children and adults with Down syndrome. Recently, Down syndrome has reached high visibility in the national and international advocacy community, with increased research opportunities and calls to fully fund research for Down syndrome. In September 2011, the National Institutes of Health (NIH) announced the formation of the NIH-NICHD Down Syndrome Research Consortium, designed to share research initiatives and ideas for potential research with the Down syndrome community. And this July, the National Down Syndrome Congress (NDSC) will celebrate its 40th annual convention in nearby Washington, D.C. The NDSC conference represents the most spirited gathering of families touched by Down syndrome in North America, and offers an unparalleled opportunity for professionals and family members to network and reconnect.

There are more opportunities than ever for continuing advocacy by parents, professionals, and persons with Down syndrome. Visit the Kennedy Krieger Institute Down Syndrome Center website to learn more about the opportunities for participation in person-centered research and new initiatives with our partners around the USA.



Director, George Capone, MD

Take care,



George T. Capone, MD

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NIH-NICHD, Down Syndrome Consortium, established in September 2011

Dr. Capone is a member of the newly created Down Syndrome Consortium. According to Yvonne T. Maddox, deputy director of the NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)—the agency that will chair the new consortium—"The idea is to have an open channel of communication between the NIH and those organizations intimately involved with Down syndrome. The consortium will allow NIH to inform the Down syndrome community of advances in the field, ongoing studies, and potential avenues for future research. In turn, those who work in Down syndrome research and patient care can share their experiences and ideas for potential research opportunities with NIH."

Press release available at <http://www.nih.gov/news/health/sep2011/nichd-29.htm>



Kennedy Krieger Institute
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Upcoming Events

The National Down Syndrome Congress (NDSC) Annual Convention in Washington, D.C.

The 40th annual NDSC Convention will be held in Washington, D.C. this year from July 20th-22nd. The convention will feature workshops for parents, a youth and adults conference, the sibling gathering, and a kids' camp. Experts from around the world will be speaking on best practices, family life, educational, and social topics. Dr. George Capone, a member of the NDSC Board of Directors and Professional Advisory Committee, will be a presenter. The Down Syndrome Center will have an exhibitor display where families can receive information on current clinical initiatives and research announcements.

Please join us as we "embrace all individuals with Down syndrome as they live the dream." We hope to see you there!
Visit: <http://convention.ndsccenter.org/>.

The Down Syndrome Medical Interest Group (DSMIG-USA) Annual Meeting & Clinical Symposium is held in conjunction with the NDSC Convention

The DSMIG-USA represents a group of medical and allied healthcare professionals working in clinics for persons with Down syndrome. Since 2009, DSMIG-USA has met in conjunction with NDSC to host its membership meeting and clinical symposium. Dr. Capone has been a member of DSMIG-USA since its inception in 1996 and currently serves on the board of directors and conference planning committees.

BWI Airport Annual Down Syndrome Family Run and Walk

The BWI Airport Annual Down Syndrome Family Run and Walk will be held on September 30, 2012. It's a 5K run or 2K walk benefiting the Down syndrome clinic and local Down syndrome parent groups. To register, visit www.es.northropgrumman.com/airportrun.



Brightside Save the Date

Join us on Saturday, September 8, 2012 from 5 - 9 p.m. for the Brightside Dance and Carnival. The event will be held at the Joppa Magnolia Fire Hall. More information will be coming soon.

SUPPORT OUR DOWN SYNDROME CLINIC & RESEARCH CENTER

Having a family member with Down syndrome is a unique and very personal journey. Your financial gift in support of our work helps our patients and their families unlock their greatest potential. Your financial support ensures that children and young adults with complex conditions can participate in clinically meaningful studies to advance the treatment options we offer.

Staff Interview: Trish Shepley, LCSW-C

Q: Why might counseling be recommended?

A: In coordination with Dr. Capone, our mental health counselors consider issues specific to persons with Down syndrome that may be impacting physical, emotional, social, and spiritual functioning. Most persons are seen at the request of their parents or caretaker.

Q: How is the need for counseling determined?

A: Our mental health counselors develop an assessment and care plan to help sort out the factors contributing to the patient's concerns or condition, and determine the need for further medical and counseling support.

The assigned therapist will create a counseling plan with the family that may include individual, family, or group sessions. Family members and caregivers are encouraged to participate, to support the patient's success in using specific strategies at home, school, work, and community settings.

Q: Are there specific considerations within the context of Down syndrome?

A: We will integrate our experience and knowledge about persons with Down syndrome along with the specific

needs of each individual to ensure the most effective method of therapy. Having an understanding of people's life experiences based upon their particular communication, learning, and memory style assists in developing a practical and effective intervention.

Q: What is an example of an individualized intervention?

A: People with Down syndrome tend to have strong visual memories that have been described as "photographic" or "like a movie." Because linking sequence and timeframe of events presents a challenge, a distant memory may be incorporated with a more recent memory, or connected by similarity to a present event. Individuals may relive or replay strong memories—both positive and negative.

The therapist works with the patient and family to discover how factors and events in the patient's life are related in their understanding of presenting problems. The therapist will develop visual materials and concrete strategies to support the use of coping strategies. The plan typically includes support from caregivers to provide cues or reinforcement, while building the individual's capacity to independently use tools and strategies to achieve a desired outcome.

New Articles/ Recent Publications

G. Capone, J. Aidikoff, P. Goyal (2011) Adolescents and young adults with Down syndrome presenting to a medical clinic with depression: phenomenology and characterization using the Reiss scales and Aberrant Behavior Checklist. *Journal of Mental Health Research in Intellectual Disabilities* 4:244-264

Capone, G., McConnell, K. (2011) Health supervision for children with Down syndrome 2011 –Revisited. *Pediatrics*, published online October 5, 2011

M. Truitt, Biesecker, B., **Capone, G.,** Bailey, T. and Erby, L (2011) The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling*, published online September 19, 2011

Oster-Granite ML, Parisi MA, Abbeduto L, Berlin DS, Bodine C, Bynum D, **Capone G,** Collier E, Hall D, Kaeser L and others. (2011) Down syndrome: National conference on patient registries, research databases, and biobanks. *Molecular Genetics and Metabolism* 104(1-2):13-22.

IN THE NEWS

"Autism can be diagnosed in Down syndrome", by Heidi Splete. Interview with Dr. Capone, In: *Pediatric News*, November 2011 and *Psychiatry News*, November 2011. Read about it: [http://www.pediatric-news.com/index.php?id=7791&cHash=071010&tx_ttnews\[tt_news\]=79038](http://www.pediatric-news.com/index.php?id=7791&cHash=071010&tx_ttnews[tt_news]=79038)



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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

Clinical research study (BP25543) for adults (18-30 years) with Down syndrome

Roche Pharmaceuticals is sponsoring a study at Kennedy Krieger Institute and the Johns Hopkins University for adults with Down syndrome between 18 and 30 years of age. The purpose is to study the safety and tolerability of a new drug that has been developed to improve attention and memory. The study is free, and you will be paid to participate. For more information, please contact Carrie Blout, MS, CGC at 410-502-7535.

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

Kennedy Krieger Institute and Duke University are currently recruiting participants with Down syndrome (ages 10-17) to determine if an investigational medication (FDA-approved for Alzheimer's disease) helps to improve memory, speech, and language function 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. The study is free, and you will be paid to participate. For more information, please contact Cathleen Weadon at 443-923-9140.

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