

# **8<sup>th</sup> Meeting of the Down Syndrome Consortium: A Public-Private Partnership**

February 26, 2014

**6100 Executive Boulevard  
5<sup>th</sup> Floor Conference Room  
Rockville, Maryland**

## **Welcome and Introductions**

*Yvonne Maddox, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)*

## **Presentations Attached**

1. Resources for Down Syndrome Biobanking: The National Institutes of Health (NIH) NeuroBioBank and DS-Connect™
2. DS-Connect™: The Down Syndrome Registry Update

## **Updates**

**Dr. Colleen Jackson-Cook, International Mosaic Down Syndrome Association (IMDSA)**, reported that the organization was born out of her research and is now showing promise.

**Michelle Livingston, Global Down Syndrome Foundation (GDSF)**, reported that the GDSF board meeting was yesterday. The board is putting a lot of its focus on research into Alzheimer's disease and Down syndrome (DS). Dr. Huntington Potter is applying for center status, as GDSF is the only Alzheimer's center within a 500-mile area and the only one that looks at DS. The University of Colorado and the Linda Crnic Institute for Down Syndrome continue to provide grants for research. Children's Hospital Colorado has 800 patients in its Sie Center for Down Syndrome. GDSF plans to start an adult care center in partnership with the Sie Center, to launch in 2015. GDSF will hold a Be Beautiful Be Yourself gala on May 7 in Washington, D.C., and one in October in Denver.

**Dr. Marilyn Bull, American Academy of Pediatrics (AAP)**, reported that parent-friendly guidelines were published in September 2013 and can be found on [www.healthychildren.org](http://www.healthychildren.org). The National Down Syndrome Congress (NDSC) Convention is the major focus for the summer and is actively trying to recruit as many DS individuals and DS families to attend. It also offers some funding to ensure that people who want to attend can do so.

**Deanna Tharpe, Down Syndrome Affiliates in Action (DSAIA)**, reported that DSAIA held its leadership conference Thursday night.

**Jon Colman, National Down Syndrome Society (NDSS)**, reported that NDSS is working hard on its Hill Day and Buddy Walk as well as expanding advocacy efforts. Working with Rep. Pete Sessions, NDSS raised \$100,000 last year, looking to have \$200,000 this year for filling gaps in NICHD infrastructure.

**Lisa Kaeser, NICHD**, reported that the Research Plan is nearly finished and should be posted for public comment by end of week on the NICHD website and the Down Syndrome Consortium (DSC) website.

**Vittoria Aiello and Maria Monaco-Kushner** attended as Down Syndrome Network of Montgomery County board members.

**Dr. Michael Harpold, Down Syndrome Research and Treatment Foundation (DSRTF)**, reported that DSRTF is holding a series of events to promote research, starting soon and continuing throughout the year, including the first international DS conference in England. It has given out more than \$1 million in 2013. DSRTF has seen very good results in the last 5 to 7 years in research on cognitive function. It has started three clinical trials since 2011, two on developmental intellectual disabilities and one on Alzheimer's, with more pending.

**Mitchell Levitz, self-advocate at the University Center for Excellence in Developmental Disabilities at the Westchester Institute for Human Development**, reported that the Westchester Institute is developing Web-based training on intellectual disabilities and research.

**David Tolleson, NDSC**, reported that NDSC is holding the DS Congress this year in Indianapolis. Registrations are filling up; it has two hotels and is fielding support questions from 10 different countries. NDSC is expanding its work to reach underserved populations, including bringing in Spanish speakers and translation capabilities.

Dr. Michael Harpold, DSRTF, commented that one question for the group is "Why is the life expectancy in the African-American population still so low, and what is being done to improve that?"

**Deanna Tharpe, DSAIA**, noted that we need better information delivery and recruitment of cultural sectors.

**Mark Bradford, Jérôme Lejeune Foundation (JLF)**, noted that this is the foundation's 20<sup>th</sup> anniversary year. On March 18 in D.C. and March 20 in New York City, JLF will hold a conference on the beatification of Jerome Lejeune. The next international conference is September 18 and 19, 2014, in Paris, focused on the evaluation of clinical trials. JLF has had two funding cycles; the first closes on March 16, focusing on accelerated brain function in DS and its relation to Alzheimer's. JLF has funded \$22.5 million in grants. Its clinic has 55 patients, and it is working with the University of Chicago to start a center in the United States to enroll more patients and export the Parisian model.

**Dr. Yvonne Maddox, NICHD**, requested that each organization report how much money goes toward DS research each year so that the DSC can show the combined effort.

**Dr. Laurie Ryan, National Institute on Aging (NIA)**, reported that NIA is focusing heavily on Alzheimer's, with \$130 million in grants, a portion of which is used for looking at DS and its relation to Alzheimer's. NIA wants to create more trans-NIH opportunities and collaborations.

**Kim Musheno, Association of University Centers on Disabilities (AUCD)**, reported that AUCD will hold a disability policy symposium in April, with 2 days of training, and then go to Capitol Hill to talk about intellectual disabilities (approximately 600 people). Ms. Musheno noted that the Combating Autism Act is scheduled to lapse in September unless it is reauthorized.

**Dr. Bob Riddle, National Institute of Neurological Disorders and Stroke (NINDS)**, reported that there is much promise in the NINDS Alzheimer's and DS research.

**Dr. Melissa Parisi, NICHD**, gave an update on DS-Connect™: The Down Syndrome Registry. Currently, 1,384 people have registered; the goal is 10,000. So far, 1,084 of the registrants are under the age of 30, which shows a great need to recruit older individuals with DS. The website now has a DS radio link, which includes a podcast featuring Lisa Kaeser. The *Down Syndrome Quarterly* update will go out next week.

## **Discussion on Outreach Efforts**

**Kerri Childress, NICHD**, presented current outreach materials for DS-Connect™ and reported on social media activity and the importance of linking with the organizations involved. Discussion continued on keeping connectivity with research groups, advocacy groups, and self-advocates. Other suggestions included using self-advocate videos on the website, using conventions to register individuals, and incorporating concerns of the community in the frequently asked questions.

## **Attendees**

**Mark Bradford, JLF**

**Marilyn Bull, AAP**

**Kerri Childress, NICHD**

**Jon Colman, NDSS**

**Michael Harpold, DSRTF**

**Andrew J. Imparato, AUCD**

**Colleen Jackson-Cook, IMDSA**

**Lisa Kaeser, NICHD**

**Mitchell Levitz**, self-advocate, University Center for Excellence in Developmental Disabilities at the Westchester Institute for Human Development

**Michelle Livingston, GDSF**

**Yvonne Maddox, NICHD**

**Kim E. Musheno, AUCD**

**Maggie Nygren**, American Association on Intellectual and Developmental Disabilities

**Mary Lou Oster-Granite, NICHD**

**Melissa Parisi, NICHD**

**Bob Riddle, NINDS**

**Laurie Ryan, NIA**

**Deanna Tharpe, DSAIA**

**David Tolleson, NDSC**

**Vittoria Aiello**, Down Syndrome Network of Montgomery County (guest)

**Maria Monaco-Kushner**, Down Syndrome Network of Montgomery County (guest)