

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

January 8, 2015

## Member Updates:

**Colleen Jackson-Cook, International Mosaic Down Syndrome Association (IMDSA)**, reported that IMDSA is in the process of preparing the agenda for the upcoming 321 econference in March 2015, a series of webinars that families can log into to get most up-to-date information on Down syndrome (DS). These are interactive sessions that will be archived so they can be viewed at a later time for convenience. IMDSA is also planning a Research Retreat Weekend for 2015 in New England. They would like to do some validations of DS-Connect<sup>®</sup> information by reviewing records.

**Michael Harpold, LuMind**, announced that LuMind had recently provided \$1.25 million in research grants for basic and translational research on DS, including behavioral and Alzheimer's disease research. They also hope to have a new clinical trial for an amyloid vaccine in DS individuals started in the near future. Recently, LuMind held a joint webinar that included a research update; the focus was research and awareness for DS-Connect<sup>®</sup>. He also highlighted the donation made to LuMind that provided an incentive for every registration on DS-Connect<sup>®</sup> during October 2014.

**Bob Schoen, Research Down Syndrome (RDS)**, announced that RDS awarded grants for more than \$1 million to six institutions last fall. RDS has been promoting DS-Connect<sup>®</sup> through its social media outlets. They are working to put together fundraising plans for this coming year.

**Sara Weir, National Down Syndrome Society (NDSS)**, reported that NDSS was busy all fall advocating for the Achieving a Better Life Experience (ABLE) Act, which was signed into law on December 18, and is currently working with Capitol Hill on implementation. NDSS will be holding an event July 15 at Eastern Market to support its work in establishing research infrastructure and science. They are also creating a road show to educate families about the importance of clinical trials and research participation. NDSS is building out the framework on a health disparities campaign. The Buddy Walk on Washington is scheduled for April 14 and 15. NDSS has continued to promote the registry and thinks the new video on signing up for the registry is great.

**Deanna Tharpe, Down Syndrome Affiliates in Action (DSAIA)**, reported that DSAIA is excited about its leadership conference from March 6 to 8, 2015, in Las Vegas. They plan to hold a "speed networking" session on that Sunday to connect people and talk about different topics related to DS. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) will have an exhibit booth on DS-Connect<sup>®</sup> at the conference. DSAIA has been using social media to promote DS-Connect<sup>®</sup> and explain why it's important to register. Ms. Tharpe shared that DS groups need information about DS-Connect<sup>®</sup> to answer questions and encourage potential participants, who don't think of it as a database of information; rather, they think it's another survey.

**Tom Blumenthal, Linda Crnic Institute**, described the Institute as a research organization, which is currently supporting about 20 labs at University of Colorado. It awards about \$1 - \$1.3 million each year. This year, the Institute expects to receive about 40 applications and hopes to fund 25-30%. They also have joint projects with Alzheimer's Association.

**Michelle Livingston, Global Down Syndrome Foundation (GDSF)**, said that GDSF had its most successful fundraiser in October 2014. They have a partnership with the Alzheimer's Association, and

they are jointly holding a May 2015 meeting in Chicago. GDSF recently launched a magazine, and they plan to promote DS-Connect<sup>®</sup> in an upcoming issue.

**Marilyn Bull, American Academy of Pediatrics (AAP)**, reported that she recently attended a national pediatricians conference in San Diego and was happy to see an increase in DS-specific offerings in the continuing medical education (CME) series, including one for primary care providers.

**George Capone, Down Syndrome Medical Interest Group (DSMIG)**, reported that the July 2014 symposium in Indianapolis was successful and that the CME offering helped draw people in. They plan to hold the next meeting in late June 2015 in Phoenix in conjunction with the National Down Syndrome Congress (NDSC) conference, with adult health care for people with DS the theme. In addition, DSMIG has plans to begin critically reviewing topics and maintaining a database of the literature and would also like to begin developing practical guidelines. Currently, DSMIG is updating its website to facilitate resource sharing.

**Kim Musheno, Association of University Centers on Disabilities (AUCD)**, reported that AUCD is getting ready for a new Congress. They are developing legislative and public policy goals with a priority on employment for individuals with intellectual and developmental disabilities (IDD), the reauthorization of the Elementary and Secondary Education Act, and the Workforce Innovation Act regulations. She announced the upcoming bus tour related to anniversaries of the Americans with Disabilities Act. There will be an interactive map for the bus tour, and other groups are encouraged to plan events that link to bus stops. The “6 by 15” campaign also will launch soon, which is an effort based on Senator Tom Harkin’s goal to increase the number of employed individuals with disabilities. Other goals for AUCD include health care, early intervention, and screening.

**Bob Riddle, National Institute of Neurological Disorders and Stroke (NINDS)**, reported that NINDS continues to support a broad portfolio of research on Down syndrome and Alzheimer’s disease. NINDS is also trying to revamp its translational research program to help investigators at specific points of the translational research pipeline.

**Laurie Ryan, National Institute on Aging (NIA)**, reported that NIA is engaged in active vaccine trials funded last year through a public-private partnership. NIA also is working on an initiative with the NICHD to develop biomarkers for DS. The letters of intent have been received, applications are due next week, and the study section review will be in the spring. The second level of review will likely be during the May council meeting, and grants will be funded by the end of fiscal year 2015.

**Lisa Gilotty, National Institute of Mental Health (NIMH)**, reminded everyone of long-standing Program Announcement 12-219 with the goal of supporting research into epidemiology, etiology, and treatment of mental disorders in those with IDD. NIMH participated and co-sponsored a workshop with the NICHD on co-occurring mental health conditions.

**Charlene Schramm, National Heart, Lung, and Blood Institute (NHLBI)**, announced two new research awards related to the heart defects associated with DS.

**Melissa Parisi, NICHD**, reported that the NICHD co-sponsored the previously mentioned workshop in June on mental health and IDD. The DS project group met in November 2014 with the National Center on Advancing Translational Sciences and received feedback about potential collaborations.

### **DS-Connect<sup>®</sup> Registry Update:**

- Launched Professional Portal in December 2014

- Hope to launch DS-Connect<sup>®</sup> in Spanish and for mobile devices in 2015
- Received TM classification
- Noted recent DS-Connect<sup>®</sup> efforts: LuMind Challenge (added 226 in October), advertisements in NDSC e-newsletter, NDSS website, GDSF magazine, and their new ad
- Current number of registrants is more than 2,600.
- Video testimonial has been posted to homepage.
- FAQs were updated.
- New survey modules on men's/women's health, leukemia, and deceased individuals

Consortium members discussed adding new testimonials to the registry site, and the suggestion was made that people in the community could answer the questions that groups often get. Consortium members could suggest possible speakers. The 321 e-conferences could also help answer questions from the DS community, and the NICHD could participate.

The Professional Portal is now live. The link can be found on the homepage. The DS-Connect<sup>®</sup> team demonstrated tiers of data access.

Consortium members had additional discussion on access to historical data and what researchers will receive if they perform certain data queries. The DS-Connect<sup>®</sup> team explained how the old surveys are archived and that certain research questions may require a little more input from coordinators. A participant's age is calculated by date of birth entered. A PDF is available on how to search registry data, how to view questionnaires and response options, and how to request level 2 or 3 access. Level 3 will be reviewed by the new DS-Connect<sup>®</sup> Registry Review Committee. Everyone is welcome to set up a professional account.

## **Other Updates and Discussions:**

**Lisa Kaeser, NICHD**, announced the publication of the updated Down syndrome research plan, [\*Down Syndrome Directions\*](#). The first major activity following the publication of the research plan will be to hold an outcome measures meeting in April 2015. She asked Consortium members to send ideas for additional members for the three working groups: cognitive, behavioral, and physical/biomarkers.

Dr. Parisi led a discussion of adding of other members to the DS Consortium. Consortium members noted how some of the suggested groups were involved in DS activities, such as World DS Day, communication, and education.

Dr. Parisi requested a motion to add Down Syndrome International to the DS Consortium. George Capone moved, and Colleen Jackson-Cook seconded. In a voice vote, there were unanimous ayes, no nays, and no abstentions.

Dr. Parisi also stated that the idea of adding a female self-advocate to the DS Consortium had been made, and everyone agreed. She requested that member organizations nominate a female self-advocate by January 16, 2015. They should submit a brief description and why the person would make a good member. The NICHD will then send a slate to Consortium members for a vote.

Another question was raised about the Consortium's activities. Now that DS-Connect<sup>®</sup> has been established and the research plan updated, what are its new goals, and how should it meet them? This will be the subject of an upcoming meeting.

The group discussed potential future meeting dates around the NDSS Buddy Walk in D.C. in April or the NDSC meeting in June. They agreed to hold a fall meeting as well.

## **Action Items:**

- Send ad to DSAIA for full-page advertisement
- Invite DS International to join
- Hold election for female self-advocate
- Finalize next meeting date/time

## **Attendees:**

**Sujata Bardhan**, NICHD

**Tom Blumenthal**, Linda Crnic Institute

**Marilyn Bull**, AAP

**George Capone**, DSMIG

**Leslie Cooke**, NICHD

**Lisa Gilotty**, NIMH

**Michael Harpold**, LuMind

**Colleen Jackson-Cook**, IMDSA

**Debbie Jae**, PatientCrossroads (guest)

**Lisa Kaeser**, NICHD

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

**Michelle Livingston**, GDSF

**Vanessa Rangel Miller**, PatientCrossroads (guest)

**Kim Musheno**, AUCD

**Melissa Parisi**, NICHD

**Bob Riddle**, NINDS

**Laurie Ryan**, NIA

**Robert Schoen**, RDS

**Charlene Schramm**, NHLBI

**Deanna Tharpe**, DSAIA

**Sara Weir**, NDSS