

19th Meeting of the Down Syndrome Consortium: *A Public-Private Partnership*

October 7, 2020

Roll Call

Rachel Goldman, NICHD

Welcome

Dr. Melissa Parisi, Chair, NICHD – NIH allocated \$60M for INCLUDE funding in DS Research in 2020. Dr. Bianchi has written this month's NICHD Director's blog about INCLUDE. We want to continue to ensure that this project is truly "trans-NIH," and we will be incorporating many new due dates in FY21 and FY22, many of which are still open. We funded 42 total awards in FY20, included a new funding opportunity for COVID-19-related supplements. We are sponsoring a workshop on November 9-10, and the registration will be sent out on 10/9 from Rachel Goldman.

Outreach

Dr. Sujata Bardhan, NICHD/DS-Connect® Coordinator – We just launched the clinical trial page on DS Connect; **please give us feedback**. The function allows participants to search for clinical trials by location and by age range. We received many great comments from the community about ideas for outreach, such as a link to DS-Connect on the Consortium page. GDSF, NDSS, and NDSC are planning a virtual webinar in November to promote research in the DS space, spearheaded by David Egan. Advocates and self-advocates will be joining. The DCC Administration and Outreach Core will enlighten the community about DS research via "listening sessions." We are aiming to increase the number of underrepresented minorities in research. Many investigators are trying to do studies virtually with creative approaches to ensure that people can participate in research. We will be including a calendar of upcoming events on the DS-Connect home page.

RFI Results and Research Plan Update

Lisa Kaeser and Rachel Goldman, NICHD – Thank you to all who responded to the RFA. The RFI responses are now posted on the INCLUDE website: 11 responses, 154 pages of feedback. We will organize the research plan into 5 categories. We are aiming to post a draft research plan for public comment by December 31st. We will be including a portfolio analysis of research to date in Down syndrome, pulling together all the publications from the past 7 years and looking for potential research gaps we may not have identified.

Round Robin

Kandi Pickard, NDSS – NDSS participated in the recommendations for the RFI. They held a virtual adult summit in May, with over 65 sessions on employment, healthcare, and research in adults with DS. Planning a smaller scale adult summit in April 2021. Please see website for resources and handouts from the first adult summary, in addition to some presentations. NDSS recently hired a public health advisor to stay focused on aging and the adult population, as well as prioritize health altogether

Down Syndrome International, Jessamy Tang – Working on COVID19 responses with countries around the world such as Nigeria, Uganda, and Bangladesh. World Down Syndrome Congress has been postponed with no rescheduled date yet. Other projects include advocacy, inclusion, employment, self-advocacy. Published education guidelines on website. Health guidelines are under development.

Kristen Hughes, Special Olympics – All of our activities have moved from in person to virtual. We are promoting physical activity and fitness, as well as providing advocacy training for self-advocates and family members. HCP trainings are now being done virtually – see learn.specialolympics.org.

Roger Reeves, T21 Research Society – The 4th International T21RS will be virtual, hoping to have an in-person meeting in 2022. T21RS-sponsored survey on COVID-19 in DS. Update infographic for COVID-19 is being developed.

Joaquin Espinosa, Linda Crnic Institute – Excited about the INCLUDE awards to the University of Colorado investigators. You will be hearing from us about our role in the DCC. Joaquin will be leading the administrative and outreach core.

Melissa: we hosted a workshop a year ago on Cohort development, which resulted in 6 working groups to work on specific projects. These activities will be informing the data coordinating center.

Michelle Whitten, GDSF – The NDSC Roundtable on treatment and vaccines panel was successful. We repeated with DSDN and will do with DSAIA and other organizations. JAK inhibition as a treatment for COVID-19 in DS. We have been able to implement emergency relief grants to 140 families for food, rent, and medical costs, with another round pending. We offered to 118 local DS organizations who are members of Global, as well as bridge grants to 20 small groups. We have made sure that every ward of the state is geared up with PPE; families get 1 weeks' worth of PPE so they can make visits in the hospital. Be Beautiful Be You Fashion show will be virtual, tickets are \$25. In person Acceptability Gala planned for May 2021 in DC. Global medical care guidelines for adults will be published this year. Self-advocate committee and club will be launched in January.

David Egan, Self-Advocate – Happy “World Down Syndrome Day” to everyone! New book: More Alike Than Different: My Life with Down Syndrome. See website: davideganadvocacy.com.

Mitchell Levitz, Self-Advocate – Worked on guidelines and protocols for medical professionals to use. Collaborating on other projects. Will reach out to NIH about feedback on Center for dignity and healthcare, which was sent to everyone. Please send feedback by the end of October.

David Tolleson, NDSC – congrats to David on his book! Pivot with “convention on your couch,” number of attendees like Sacramento convention. NDSC Convention in 2021 will be in Phoenix in July, plan is to be hybrid virtual and in-person. Hosted summer learning series in Spanish that reached 1500 people. International lack of information. Work with colleagues to provide information on COVID-19, working with families on educational rights for families with

children in the hospital. Fall learning series specific to different ages of life. Virtual gala on October 22: Tim Tebow, Ludacris, “Born this Way” cast, free to attend and there is a dance at the end. Register at the NDSC website.

Matthew Janicki, NTG – transitioning from being under American Academy of Developmental Medicine and Dentistry to being their own not-for-profit organization. Now a new partner in CDC-funded University of Illinois brain health 5-year grant on IDD and dementia. Workplace enhancement workshops will begin October 19th and take place every 2 weeks, using ECHO framework (hub site and spoke sites to share info from experts). Participate in T21RS study on COVID. Will look at data during meeting tomorrow, specifically, how people with DS are affected by COVID, including comparison of incidence rates between DS and other IDD groups (new).

Nicki Baumer, DSMIG – DSMIG collaborated on efforts related to COVID-19 and DS/hospitalizations and DS. Virtual meeting June 2020, not sure about July 2021. During DSMIG conference—1st Town Hall on COVID-19 and DS—will repeat same format in a few months. Tackle SES, diversity, race, inequalities in clinical care, adverse childhood experiences. Will send out survey for input.

Heather Snyder, Alzheimer’s Association – Executive Committee of Professional Interest Area (PIA) of iSTAART—connect DS and Alzheimer’s communities. Scientific researchers to look at intersection of DS and AD. 2nd webinar last week: AD and EOAD and DS; scientifically focused. DS-Connect is similar to Alzheimer’s Association CT matching service: “trial-match” to make it more user-friendly. Includes trials for those with DS; 7 trials listed on alz.org for DS and AD. Happy to share information: can send them INCLUDE RFAs to post on website.

Colleen Jackson-Cook, International Mosaic Down Syndrome – Awareness campaign in October. New social media card every day to focus on awareness raising and fundraising, both educational and foundational. Undecided what will happen for 2021 research retreat in the summer, current plan is to hold it in California. Creating a new documentary film about mosaic DS – resource for families.

Hampus Hillerstrom, Lumind IDSC – We are involved in COVID-19 Q and A; T21RS survey distribution. Observational study of adults in DS—paused in March, restarted end of summer. Bringing in assessment scale for validation developed by Andre Strydom—will be submitted very soon for publication. Interim analysis of first 100 participants: blood biomarker data will be presented on a poster at CTAD meeting; novel biomarkers. New England DS symposium with MIT, Alana Foundation, and Massachusetts DS Congress: Nov 10th, 8:45 am- 4 pm. We will notify NIH next year to avoid conflict with NIH workshops. Different topics: basic science, OSA, AD, self-advocates. My DSC with community members—opportunities for research from home. “MapHabit” visual maps for AD initially—tool for independence in children. Goal Attainment Scale for AD in DS: DGI clinic?

Maggie Nygren, AAIDD – submit proposals for our 2021 conference. Involved in hosting 2020 Reinventing Quality Conference, find at reinventingquality.org, all 45 min long. Topics include decision-making using technology, and grief and loss in the time of COVID.

Members Present

Sujata Bardhan, *NICHD*
Nicole Baumer, *DSMIG*
Sarah DeMaio, *AUCD*
Tara Dutka, *NIMH*
David Egan, *Self-Advocate*
Joaquin Espinosa, *Linda Crnic Institute*
Rachel Goldman, *NICHD*
Jim Hendrix, *Lumind IDSC*
Hampus Hillerstrom, *Lumind IDSC*
Kristin Hughes, *Special Olympics*
Colleen Jackson-Cook, *IMDSA*
Lisa Kaeser, *NICHD*
Erica Landis, *OD*
Mitchell Levitz, *Self-Advocate*
Huiqing Li, *NHLBI*
Maggie Nygren, *AAIDD*
Melissa Parisi, *NICHD*
Kandi Pikard, *NDSS*
Roger Reeves, *T21 Research Society*
Robert Riddle, *NINDS*
Charlene Schramm, *NHLBI*
Michelle Sie Whitten, *GDSF*
Malcolm Smith, *NCI*
Heather Snyder, *Alzheimer's Association*
Nathaniel Stinson, *NIMHD*
Jessamy Tang, *Down Syndrome International*
David Tolleson, *NDSC*
Christy Weir, *Special Olympics*

Chat

From Margaret Nygren to Everyone: 03:31 PM

Hello from Silver Spring, MD!

From Sujata Bardhan-NICHD to Me: (Privately) 03:40 PM

Are we going to record this meeting?

From Debbie Jae to Everyone: 03:42 PM

I don't see the slides advancing. Can others see something other than the title slide?

From Global Down Syndrome Foundation to Everyone: 04:14 PM

So impressive. Very grateful to NIH and NICHD's leadership on INCLUDE that will truly improve the lives of people with Down syndrome in a real and immediate way!

From Joaquin Espinosa to Everyone: 04:30 PM

I have to join another call, thanks everyone for your hard work for people with Down syndrome

From Kathleen Egan to Everyone: 04:51 PM

I am looking forward to working with Global, NDSC and NDSS and NIH on the outreach project to have more families and individuals with Down syndrome to volunteer in research. I also have

a chapter on Research participation in my book. We are hoping to make a difference in numbers for DS Connect

From Lisa Kaeser to Everyone: 04:51 PM

It would mean so much, thank you!!!

From Heather Snyder- ALZ to Everyone: 04:56 PM

Thank you everyone! I have to get off but it has been great to hear everyone's updates!

From Sarah - AUCD to Everyone: 04:57 PM

I'm going to have to hop off for a 5pm commitment, but I can send a written update.

From Melissa Parisi to Me: (Privately) 04:58 PM

can you save the chat?

From Sarah - AUCD to Everyone: 04:58 PM

Great to hear about all of the good work happening!

From Roger Reeves to Everyone: 05:00 PM

Off to the next meeting! Nice to hear from you all.

From Global Down Syndrome Foundation to Everyone: 05:01 PM

Thanks everyone for your impactful and continued work during this challenging time.

Appreciate you all and looking forward to working with many of you on exciting 2021 initiatives!