



DS-Consortium Meeting

◆ January 8th, 2015

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
National Institutes of Health (NIH)



Eunice Kennedy Shriver National Institute
of Child Health and Human Development



Agenda

- ❖ Round Robin: Updates from Consortium members
- ❖ DS-Connect® Updates: Outreach, Video testimonial, New surveys, Glossary
- ❖ Professional Portal Demonstration
- ❖ NIH Research Plan on Down Syndrome
- ❖ Outcome Measures Workshop
- ❖ Adding New Members



A Brief History of DS-Connect[®]

- ❖ 2010: Meetings were held to discuss a registry...
- ❖ 2011: DS Consortium founded by NIH
- ❖ 2012: Contract awarded to PatientCrossroads
- ❖ Sept. 2013: DS-Connect[™] launched
- ❖ Oct. 2014: Registered trademark approved (from DS-Connect[™] to DS-Connect[®])
- ❖ Dec. 2014: Professional Portal launched!!!
- ❖ 2015: Coming soon: Spanish DS-Connect[®], Mobile App



Outreach

❖ LuMind Challenge: 226 signed up in the month of October



A no-cost way to raise funds for Ds cognition research - take the LuMind/DS-Connect® Challenge!

To celebrate Down Syndrome Awareness Month, our co-founder offered a challenge. For every person who registers with DS-Con during the month of October, they will donate \$100 to LuMind Fo They've also offered an additional challenge if more than 125 join Progressing research takes more than time in the laboratory, it n support of the Ds community. ... [See More](#)



DS-Con Syndr

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Newsflash: Happy Down Syndrome Awareness Month!

Donate

In this issue:

- The LuMind DS-Connect® Challenge
- Year End Donors
- Annual Appeal and Giving Tuesday
- Affiliate profile: DSACT
- Research Webinar
- Meet Our Friends
- Follow Us Online

LuMind/DS-Connect® Challenge Raises \$40K and Moves the Needle on Research - Thank You!

You rose to the challenge! Thanks to the more than 200 people who signed up with **DS-Connect®** during October, LuMind is receiving over \$40,000 for cognition research.

You literally moved the needle on NIH's gauge - it is firmly pointing to the next tick mark. But it is still a long way from the Registry's 10,000 person goal, so sign up if you haven't already!



Outreach

❖ NDSC e-Newsletter

[National Down Syndrome Congress](#) | [NDSC Convention](#) | [More Alike Than Different](#)

e-newsletter of the National Down Syndrome Congress

Down Syndrome E-News

News for Members and Friends

October 16, 2014

What Else Should We Do in October?



Join DS-Connect™: The Down Syndrome Registry today. DSconnect.nih.gov

Make this the month you join DS-Connect™, the registry for people with Down syndrome!

DS-Connect™ is a voluntary, confidential, online survey tool to collect basic information about people with Down syndrome. This information can help connect people with DS to scientists who study DS; promote research by collecting information that scientists can use; help health professionals improve how they treat people with DS; help scientists develop new treatments that may improve the quality of life for people with DS.

This is our opportunity to show the world that funding for research is important! To do that, you have to be counted in the registry. Take part to advance knowledge and research about Down syndrome. [Get all the details here!](#)

Outreach

❖ NDSS website



The National Advocate for People with Down Syndrome Since 1979

[down syndrome](#)[resources](#)[ways to give](#)[my great story](#)[buddy walk®](#)[advocacy](#)[about ndss](#)[donate](#)

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DS-Connect™: The Down Syndrome Registry

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NDSS is excited to be a part of DS-Connect™: The Down Syndrome Registry, the new Down syndrome registry hosted by the National Institutes of Health (NIH) and the Down Syndrome Consortium. The goals of DS-Connect are to gain a better understanding of Down syndrome, to learn more about the health issues associated with Down syndrome, to develop new treatments for Down syndrome and to improve care for people with Down syndrome. NDSS is encouraging all self-advocates and their families to learn more and [join the registry](#). All information is available below in a letter from Self-Advocate Advisory Board Member Mitchell Levitz.

Dear Down Syndrome Self-Advocates, Families, and Friends:

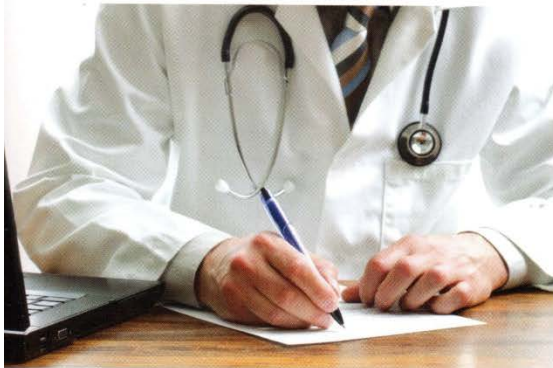
My role as a self-advocate involved with the Down Syndrome Consortium is to make sure that people with Down syndrome are encouraged to participate in any research projects that may come up. You may remember that some of us went to the Buddy Walk® on Washington in Washington, DC this year to advocate and speak with our senators and representatives, asking for their support for additional funding for the National Institutes of Health (NIH) to do research. Participating in research is important because it allows us, as self-advocates, the opportunity to communicate what is important to us and our health. We can learn from each other with the information that we provide.

Resources

- » [New & Expectant Parents](#)
- » [Helpline](#)
- » [Local Support](#)
- » [Publications](#)
- » [Health Care](#)
- » [Therapies & Development](#)
- » [Wellness](#)
- » [Education](#)
- » [Caring for Your Family](#)
- » [Transition & Beyond](#)
- » [Aging Matters](#)
- » [Research](#)
 - [Research & Down Syndrome](#)
 - [DS-Connect™: The Down Syndrome Registry](#)
 - [Guide to Clinical Trials & Research Studies for People with Down Syndrome & Their Families](#)
 - [Directory of Current Studies](#)
- » [NDSS en Español](#)

Outreach

❖ GDSF magazine: “Down Syndrome WORLD”



NIH Launches Important Registry for People With Down Syndrome

THE EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD) TAKES ON THE LACK OF RESEARCH FUNDING FOR DOWN SYNDROME.

SINCE 2001, RESEARCH funding for Down syndrome has plummeted, making it one of the least-funded genetic conditions at the National Institutes of Health (NIH). But the NICHD, under the NIH, plans to change that with the launch of DS-Connect™: The Down Syndrome Registry. DS-Connect provides a way for individuals with Down syndrome and their families to take part in medical studies and help researchers develop new treatments for associated conditions, such as autoimmune disorders and Alzheimer's disease.

Though taking part in studies is optional for people who sign up, the registry provides doctors and researchers with a wealth of information about cognitive issues and medical conditions that profoundly impact people with Down syndrome. The information, kept secure and confidential, is used to support ideas for research, drug treatments, behavioral programs, and educational services for people with Down syndrome. Members are free to opt out at any time.

Those who register receive updates and news about ongoing research. They're asked to update their profiles annually in order to

provide researchers with the most up-to-date information possible.

DS-Connect was created through the efforts of the NIH Down Syndrome Consortium, a public-private partnership of medical and advocacy groups. It grew out of a national conference cosponsored by the NICHD and the Global Down Syndrome Foundation in December 2010. Currently, over 2,000 people have registered, with a set goal of 10,000 members.

Join DS-Connect today at dsconnect.nih.gov.

New Ad



DS-Connect®

The Down Syndrome Registry

Share health information simply and securely.

<https://DSConnect.nih.gov>

Down Syndrome Consortium Member Organizations

NIH National Institutes of Health
Down Syndrome Working Group

American Academy
of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™



aaidd
American Association
on Intellectual and
Developmental Disabilities

AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DOWN SYNDROME
RESEARCH, EDUCATION, SERVICE

**DOWN SYNDROME
AFFILIATES IN ACTION**

DSMIG-USA
Down Syndrome Medical Interest Group-USA

**GLOBAL
DOWN SYNDROME
FOUNDATION™**

**International
Mosaic Down Syndrome
Association**

**Jérôme Lejeune
FOUNDATION**
research, care, advocacy

Down Syndrome Cognition Research
Wmind
Age Partnership Ltd

**NATIONAL
DOWN SYNDROME
CONGRESS**

ndss
National Down Syndrome Society

**Research
Down Syndrome**

**Special
Olympics**



NIH National Institutes of Health
Turning Discovery into Health

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
National Cancer Institute (NCI)
National Heart, Lung, and Blood Institute (NHLBI)
National Institute of Mental Health (NIMH)
National Institute of Neurological Disorders and Stroke (NINDS)
National Institute on Aging (NIA)
National Institute on Minority Health and Health Disparities (NIMHD)



Other Outreach Activities

❖ Attended Conferences, webinars:

- September 18-19: International Clinical Conference Jérôme Lejeune, Paris, France
- October 3-5: IMDSA Meeting, Williamsburg, VA
- October 11: DSNMC Buddy Walk, Rockville, MD
- October 15: Webinar for LuMind Challenge

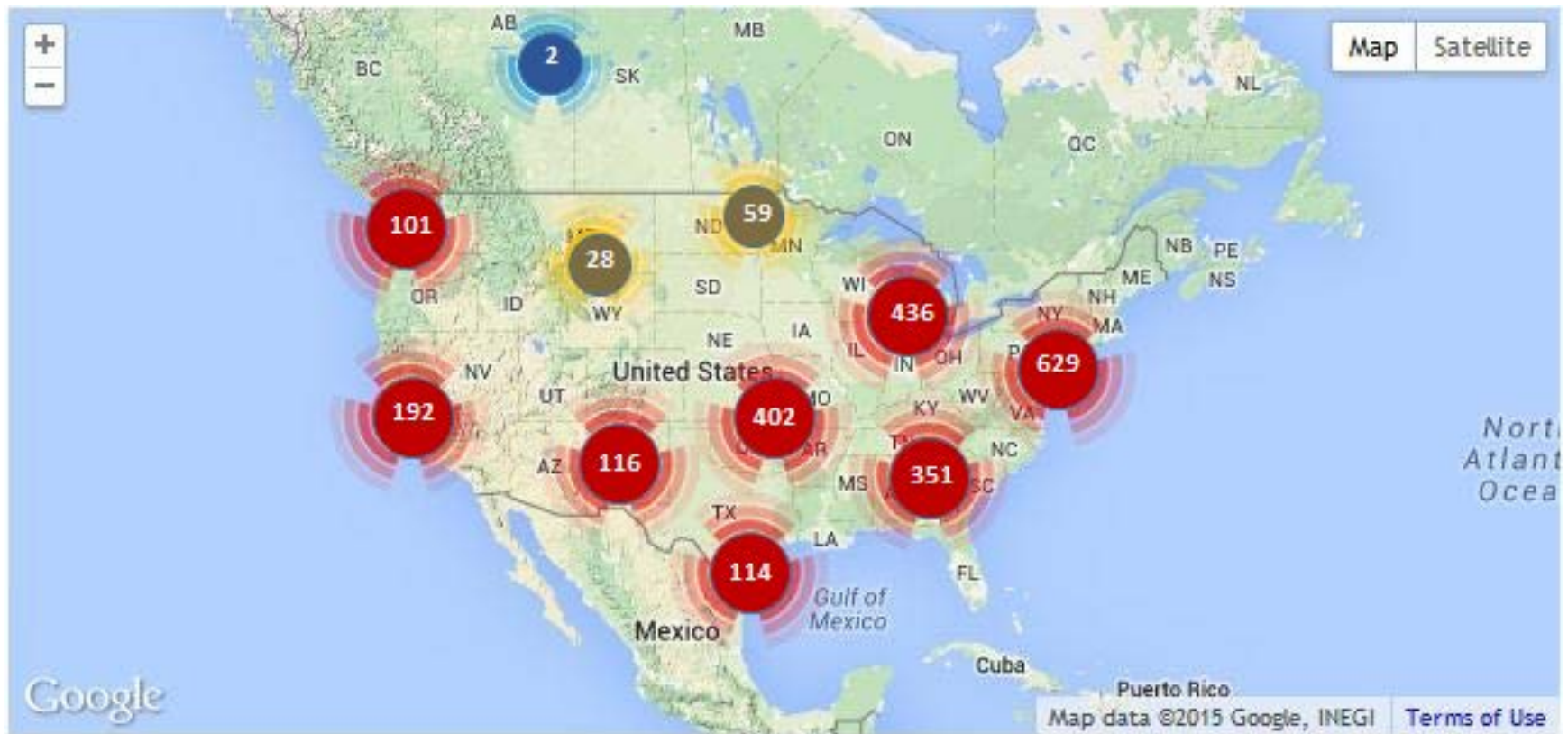
❖ Upcoming Conferences, webinars:

- March 5-8: DSAIA Leadership Conference, Las Vegas, NV
- March 21-23: 321 econference webinar
- March 25-27: American College of Medical Genetics Meeting (ACMG), Salt Lake City, UT
- May 19: Down Syndrome Alliance of the Midlands, Omaha, NE
- June 25-28: NDSC Annual Convention, Phoenix, AZ

❖ **Other opportunities to partner?**

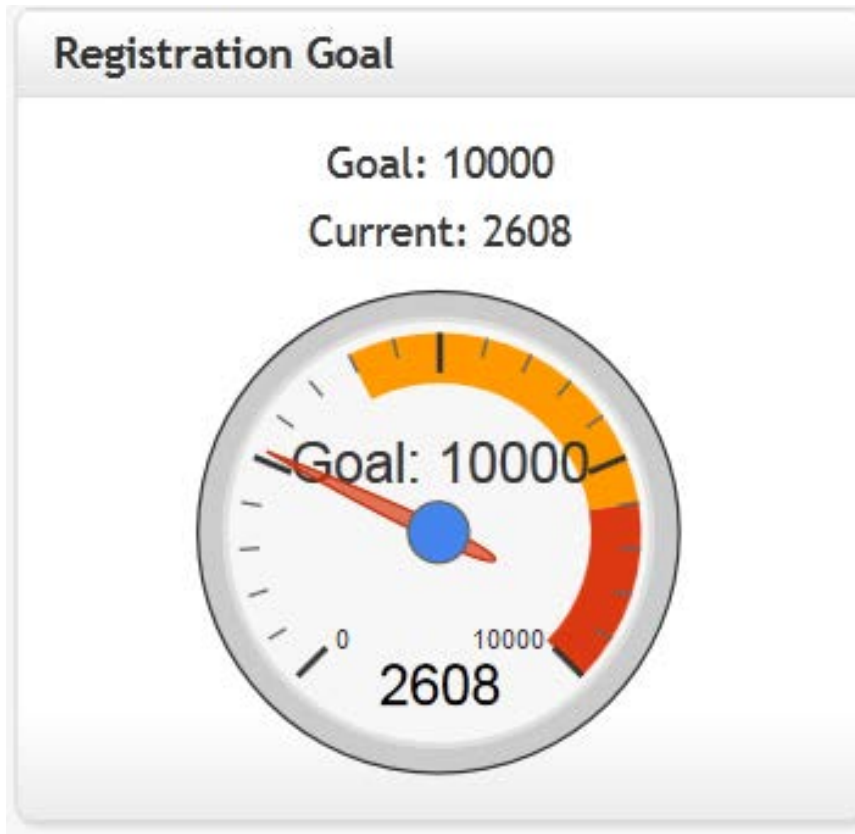


Participants in North America





Goal Gauge



January 6th, 2015



DS-Connect[®] Video Testimonial

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DS-Connect[®]: The Down Syndrome Registry

“The new registry provides an important resource to individuals with Down syndrome and their families,” said Yvonne T. Maddox, former deputy director of the NIH’s Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), which is funding the registry. “The registry links those seeking volunteers for their research studies with those who most stand to benefit from the research.”

[Join the Registry](#)

Available on YouTube



New Survey Modules Developed

Initial Health Survey with
“Trigger Questions” that lead
to other surveys:




- Initial Health Questionnaire
- Thyroid Questionnaire
- Heart Questionnaire
- Sleep Questionnaire
- Skeletal Questionnaire
- Gastrointestinal Questionnaire
- Adulthood Questionnaire
- **Men’s Health Questionnaire**
- **Women’s Health Questionnaire**
- **Leukemia Questionnaire**
- **Deceased Questionnaire**
- Diabetes Questionnaire
- Celiac Disease Questionnaire
- Development Questionnaire
- Prenatal and Birth Questionnaire

Available to all registrants





New Items Added to the Top Menu



National Institutes of Health
Turning Discovery Into Health

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❖ **DS-Connect®: Who We Are**

❖ **Glossary**

❖ **For Professionals**



Portal for Professionals-LIVE!!

Professional Portal-Now Live



Researchers, clinicians and other professionals can access de-identified aggregate data in DS-Connect™ to identify target populations for study or trial planning or recruitment. You can also contact the [DS-Connect™ Coordinator](#) to communicate with registrants on your behalf regarding potential candidacy for clinical trials and research studies.

Set up a Professional Account

Explore the Data



Remember, this is your registry and you're in charge of the information in it. Check out how to explore the information you and others have provided to learn more about Down syndrome and its impact on other community members. [Log into your account](#) today and start exploring the data.

Registry Updates



Get information on the latest registry-related news, including ongoing efforts to advance research discoveries, develop treatments, and improve the quality of life for people living with Down syndrome.

- No direct access to Registry participants
- Registry Coordinator will contact eligible families about the study or trial
- Participants can choose whether to contact investigators to join



Professional Portal: Tiers of Access

- ❖ Access Level 1: View data identical to Registrants' view and can perform more detailed searches of de-identified data
- ❖ Access Level 2: More complex searches, de-identified row-level data, or to collect new data
- ❖ Access Level 3: For study posting or recruitment



Future Developments

- ❖ Spanish language version
- ❖ Mobile Device Compatibility
- ❖ Expanded resources section:
 - ClinicalTrials.gov and About Clinical Trials
 - Healthychildren.org information for families by AAP
- ❖ Customizable functions on participant account:
 - Educational component
 - Health care reminders
 - Messages about the Registry
- ❖ Link to biospecimen repositories via GUID

Down Syndrome Directions

**The National Institutes of Health
Research Plan on Down Syndrome**

- ❖ Original NIH Research Plan released in 2007
- ❖ 2014 revision: update the goals and objectives for NIH-supported research on Down syndrome
- ❖ Led by NIH DS Working Group (Lisa Kaeser and Mary Lou Oster-Granite) with input from the scientific, family, advocacy communities, including the DS Consortium
- ❖ Extensive bibliography of NIH-funded research

5 major sections:

1. Pathophysiology of DS and Disease Progression
2. Down Syndrome-Related Conditions: Diagnosis, Screening, and Functional Measures
3. Treatment and Management
4. Down Syndrome and Aging (*new*)
5. Research Infrastructure

Just published in November!

https://www.nichd.nih.gov/publications/pages/pubs_details.aspx?pubs_id=5865



Outcome Measures in Down Syndrome

- ❖ Significant need in DS research community
- ❖ NIH-sponsored workshop:
 - April 23-24, 2015
 - Washington, DC area
- ❖ Modeled off comparable Fragile X activity





Get DS Connected!

**Advance science,
improve lives.**



Join DS-Connect™: The Down Syndrome Registry today.
Get DS-Connected: **DSconnect.nih.gov**



Eunice Kennedy Shriver National Institute
of Child Health and Human Development

**Share her health information—
help others.**



Join DS-Connect™: The Down Syndrome Registry today.
Get DS-Connected: **dsconnect.nih.gov**



Eunice Kennedy Shriver National Institute
of Child Health and Human Development

<https://DSConnect.nih.gov>



Acknowledgments

- ❖ External Scientific Reviewers
- ❖ Registry Governance Board
- ❖ Registry Operations Board
- ❖ Down Syndrome Consortium
- ❖ Families and individuals with DS
- ❖ NIH Down Syndrome Working Group
- ❖ DS-Connect® development team:
 - Sujata Bardhan, PhD
 - Aubrey Callwood
 - Debbie Jae, MS
 - Lisa Kaeser, JD
 - Vanessa Rangel Miller, MA, MBA
 - Christina Stile

Consortium Members



Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)



National Cancer Institute (NCI)

National Heart, Lung and Blood Institute (NHLBI)



National Institute of Mental Health (NIMH)



National Institute of Neurological Disorders and Stroke (NINDS)



National Institute on Aging (NIA)



National Institute on Minority Health and Health Disparities (NIMHD)

