



national down syndrome society®

Down Syndrome
Advocacy
Conference

2023

Legislative Priorities

April 18, 2023



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Session Agenda

- Charlotte Woodward Organ Transplant Discrimination Prevention Act
- Transformation to Competitive Integrated Employment Act
- National Alzheimer's Project Act (NAPA) Reauthorization
- Increased Funding for the INCLUDE Project
- Congressional Task Force on Down Syndrome
- A Conversation with Congressional Staff



Charlotte Woodward Organ Transplant Discrimination Prevention Act

Hello!



Anna Fedewa
Manager of Public Policy



Charlotte Woodward
Education Program
Associate

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Organ Transplant Discrimination

- 2019 National Council on Disability (NCD) report found:
 - People with disabilities frequently denied access to organ transplants because of their disability



Organ Transplant Discrimination

- 2019 National Council on Disability (NCD) report found:
 - Some medical professionals refused to evaluate a patient's medical suitability for an organ transplant because of their disability



Charlotte's Story



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Charlotte Woodward Organ Transplant Discrimination Prevention Act

- House Energy and Commerce Committee, Subcommittee on Health
- Senate Health, Education, Labor, and Pensions (HELP) Committee



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Charlotte Woodward Organ Transplant Discrimination Prevention Act

Lead Sponsors – Senate



Senator Margaret (Maggie) Hassan
D – New Hampshire



Senator Marco Rubio
R – Florida

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What is the bill?

- **Upholds, clarifies, and builds upon** rights established in civil rights law to **prohibit discrimination against people with disabilities** in the organ transplant system



What does it do?

- Prohibits covered entities from:
 - determining that an individual is ineligible to receive a transplant
 - deny an organ transplant or related service
 - refuse to refer the individual to an organ transplant center
 - refuse to place an individual on a waiting list
 - decline insurance coverage for a transplant or related service

based solely on the fact that the individual has a disability

What does it do?

- Provides access to **expedited review** through both the Office of Civil Rights at the Department of Health and Human Services and in a federal district court.



How does it impact the Down syndrome community?

- Increased rate of heart conditions which may lead to need for transplant
- Preventing organ transplant discrimination can save lives



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FAQ – 37 State Bills

States with Organ Transplant Discrimination Prevention Laws

Arkansas
Arizona
California
Colorado
Delaware
Florida
Georgia
Illinois

Indiana
Iowa
Kansas
Kentucky
Louisiana
Maryland
Massachusetts
Michigan

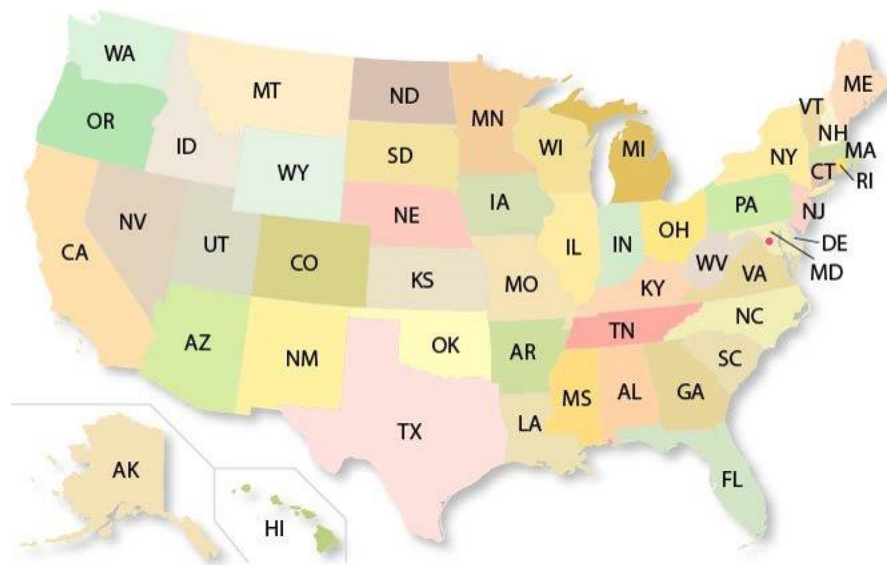
Minnesota
Mississippi
Missouri
Montana
Nevada
New Jersey
New Mexico
North Carolina

Ohio
Oklahoma
Oregon
Pennsylvania
Rhode Island
South Dakota
Tennessee
Texas

Virginia
Washington
West Virginia
Wisconsin
Wyoming

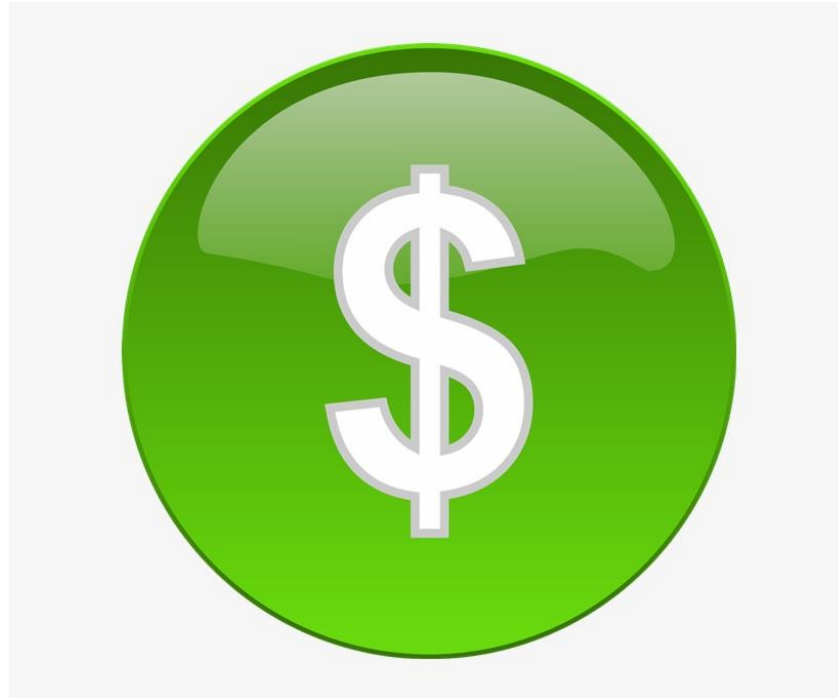
FAQ – Interstate Commerce

- The organ transplant system is a system of **interstate commerce** (a federal responsibility!)



FAQ – Cost

- The bill has **no cost**.



Summary

- Prohibits discrimination based solely on disability
- Does not limit physician autonomy or discretion
- Traction at the state-level
- Organ transplant system is interstate commerce = need for federal action
- Bill is bipartisan, bicameral, and has no fiscal impact



Transformation to Competitive Integrated Employment Act (S. 533/H.R. 1263)

Hello!



Ryan Rotundo
Director of Programs



Matthew Schwab
Matthew Schwab Speaks

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Subminimum Wage

- Section 14(c) of the Fair Labor Standards Act of 1938
- 120,000 workers with disabilities paid less than minimum wage
- Average earnings = \$4.15 an hour
- Sheltered workshops

Matthew's Employment Story



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Transformation to Competitive Integrated Employment Act

- H.R. 1263/S. 533
- House Education and Workforce
- Senate Health, Education, Labor, and Pensions (HELP) Committee

U.S. SENATE COMMITTEE ON
Health, Education
Labor & Pensions



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Transformation to Competitive Integrated Employment Act

Lead Sponsors – House



Representative Cathy
McMorris Rodgers
R – Washington – 5



Representative Robert
"Bobby" Scott
D – Virginia – 3

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Transformation to Competitive Integrated Employment Act

Lead Sponsors – Senate



Senator Robert "Bob" Casey
D – Pennsylvania



Senator Steve Daines
R – Montana

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What is the bill?

- Creates a pathway toward **competitive integrated employment** through the elimination of subminimum wage
- Competitive integrated employment (CIE)
 - Paid at or above minimum wage
 - Same benefits as nondisabled colleagues
 - Interaction with nondisabled colleagues
 - Opportunities for advancement

What does it do?

- Prohibits the issuance of new 14(c) certificates
- Provides grants to states to or subminimum wage employers to transition to CIE over 5 years
- Technical assistance to employers



How does it impact the Down syndrome community?

- Higher unemployment rates for people with disabilities
- Higher poverty rates for people with disabilities
- Sheltered workshops are segregated
- Employment is the basis for financial independence and security

FAQ – State Level Impact

States with state legislation:

Alaska
California
Colorado
Delaware

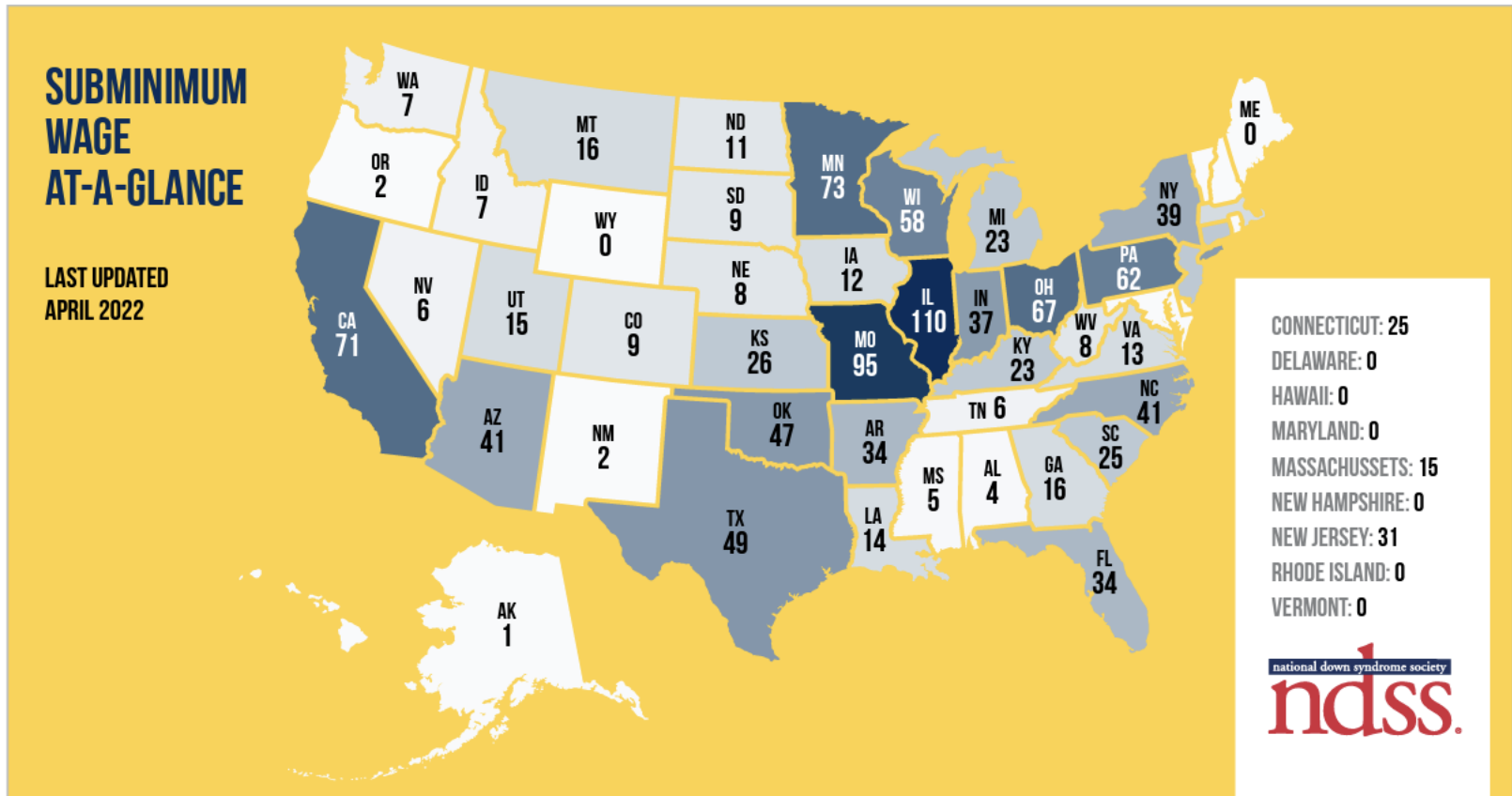
Hawaii
Maine
Maryland
New Hampshire

Oregon
Rhode Island
South Carolina
Tennessee
Washington

NEW! Virginia!

FAQ – How many people does it impact?

This map shows the number of active and pending Section 14c certificates by state.



To view active and pending certificates in your state -

<https://www.dol.gov/agencies/whd/workers-with-disabilities/section-14c/certificate-holders>

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FAQ – Where do people go?

- **Discovery** – Service that supports person in learning about job and other interests.
- **Supported employment** – Service that supports person in finding and learning about how to do the job. This support can also help your employers learn what individuals need to be successful.
- **Customized employment** – Supports that work hand-in-hand with employers to identify parts of tasks that individuals can do well.
- **Education** – Post-secondary education, technical school, community college, and other training programs
- **Transportation** – Services that support person in getting to and from job, education, etc.
- **Assistive technology** – Funding for technology to support person in achieving job goals.
- **Benefits counseling** – Support to help person understand how the money earned through employment may affect social security income and health care.

FAQ – SWTCIE Grants

California
Connecticut
Florida
Georgia
Illinois

Iowa
Minnesota
New York
North Carolina
Ohio

Pennsylvania
Texas
Virginia

Summary

- Prohibits new certificates
- Grants to transition employees to CIE
- Technical assistance to employers
- Traction at the state-level
- Combination of grants, collaboration, and evidence-based programming and practice to ensure people with disabilities have meaningful opportunities



Inclusion of the Down Syndrome Community in Alzheimer's Disease Initiatives

Hello!



Anna Fedewa
Manager of Public Policy



Alex Bolden
DS-Ambassador

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Down Syndrome and Alzheimer's Disease

- Individuals with Down syndrome have an increased risk for developing Alzheimer's disease
 - The 21st chromosome carries a gene strongly associated with the formation of plaques that indicate Alzheimer's disease
- Alzheimer's disease is the leading cause of death for the Down syndrome community

Self-Advocate Perspective



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National Alzheimer's Project Act (NAPA) Reauthorization

- H.R. 619/S. 133
- House Energy and Commerce Committee
- Senate Health, Education, Labor, and Pensions (HELP) Committee



National Alzheimer's Project Act (NAPA) Reauthorization

- Builds upon efforts to address Alzheimer's disease and related dementia through the coordination of federal planning and programs
- NAPA must be updated to provide specific supports for the Down syndrome community!

National Alzheimer's Project Act (NAPA) Reauthorization

Lead Sponsors – House



Rep. Chris Smith
R – New Jersey – 4



Rep. Paul Tonko
D – New York – 20



Rep. Maxine Waters
D – California – 43

National Alzheimer's Project Act (NAPA) Reauthorization

Lead Sponsors – Senate



Senator Mark Warner
D – Virginia



Senator Susan Collins
R – Maine

Original co-sponsors: Shelley Moore Capito (R – WV), Edward Markey (D – MA), Jerry Moran (R – KS), Robert Menendez (D – NJ), Lisa Murkowski (R – AK), and Debbie Stabenow (D – MI)

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Increasing Access to Diagnostic Care and Treatment

- Congress must ensure insurance coverage (such as at the Centers for Medicare & Medicaid) provides access to high-quality diagnostic care and treatment
- Lowering of threshold levels
- Portability of healthcare benefits across state lines

Supporting Caregivers

- Training
- Respite care
- Financial planning
- Accessibility of memory care and long-term care centers



Summary

- Individuals with Down syndrome have an increased risk for developing Alzheimer's disease
- NAPA Reauthorization Act (H.R. 619/S. 133) must include the Down syndrome community
- Congress must ensure access to diagnostic care and treatment
- Congress must ensure caregivers are supported



Increased Funding for the INCLUDE Project at NIH

Advocating for Down Syndrome Research Funding at our National Institutes of Health (NIH)

Michelle Sie Whitten, President & CEO
Global Down Syndrome Foundation



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Why We Advocate



“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” - Margaret Mead

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People with Down Syndrome Have a Radically Different Disease Spectrum



The ~400,000 Americans with trisomy 21 may hold the key to major medical conditions

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Research & Medical Care Go Hand-in-Hand

- **Excellent, Appropriate Medical Care is Important!**
 - It increases the length of life
 - It improves the quality of life
 - It allows people with Down syndrome to reach their true potential
- **Scientific Research Directly Influences Medical Care!**
 - Research can help us create excellent guidelines for medical care
 - Research can help us solve the worst medical ailments that are more common in people with Down syndrome - Alzheimer's Disease, Immune System Disorders, certain Leukemias
- **People with Down Syndrome have a Different Disease Spectrum!**



Research



Medical
Professional



Patients



Medical
Professional



Research

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A Life-Threatening Disparity of Research Funding at NIH

Year	NIH Budget (Millions)	CF Research Funding	Fragile X Research Funding	Autism Research Funding	Ds Research Funding	Ds Research Funding to NIH Budget
2000	17,840				27	0.0015
2001	20,459				29	0.0014
2002	23,321				28	0.0012
2003	27,166				23	0.0008
2004	28,037				19	0.0007
2005	28,594				15	0.0005
2006	28,560				14	0.0005
2007	29,178				16	0.0006
2008	29,607				17	0.0006
2009	30,545				18	0.0006
2010	31,238				22	0.0007
2011	30,916				20	0.0006
2012	30,860	86	27	192	20	0.0006
2013	29,129	78	30	186	18	0.0006
2014	30,019	77	36	186	18	0.0006
2015	30,293	80	38	208	24	0.0008
2016	30,293	83	40	216	25	0.0008
2017 Est	30,293	83	40	216	25	0.0008

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What is NIH?

- The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the nation's medical research agency – making important discoveries that improve health and save lives.
- The National Institutes of Health is made up of 27 different components called Institutes and Centers. Each has its own specific research agenda, often focusing on particular diseases or body systems. All but three of these components receive their funding directly from Congress, and administrate their own budgets. NIH leadership plays an active role in shaping the agency's research planning, activities, and outlook.
- The Office of the Director is the central office, responsible for setting policy for NIH and for planning, managing, and coordinating the programs and activities of all the NIH components.

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Lower risk of heart disease and higher risk of congenital heart defects



Significantly elevated risk for early-onset Alzheimer's



Protected from solid tumor cancers and greater risk for blood cancers



Much lower risk of stroke



National Institutes of Health:

Down syndrome offers research opportunities across many of the 27 Institutes and Centers



Large pediatric population and unique pattern of development



Most prevalent chromosomal disorder



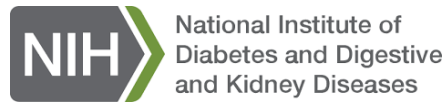
>60% have vision problems



~30% experience mental illnesses such as depression or OCD



>70% have hearing problems



Much greater risk of diabetes



High rate of dermatological disorders and arthritis



Unique pattern of immune dysregulation



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What is INCLUDE?

- INCLUDE (**I**nvestigation of **C**o-occurring conditions across the **L**ifespan to **U**nderstand **D**own syndrom**E**) Project Research Plan
- *“Down syndrome. The agreement directs the NIH Director to develop a new trans-NIH initiative – involving, at a minimum, NICHD, NIA, and NCI – to study trisomy 21, with the aim of yielding scientific discoveries to improve the health and neurodevelopment of individuals with Down syndrome and typical individuals at risk for Alzheimer's disease, cancer, cardiovascular disease, immune system dysregulation, and autism, among others. This initiative shall bring together research results that will be available to academic researchers, nonprofit organizations, and industry researchers. Funding for this trans-NIH initiative will supplement, not supplant, existing NIH funding levels for Down syndrome research.”*



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What Research is INCLUDE funding?

Applying the expertise and resources from multiple NIH Institutes and Centers, INCLUDE will:

- **Conduct targeted, high-risk, high-reward basic science studies on chromosome 21.** Past research has shed light on the complex biology that results in three copies of chromosome 21 (trisomy 21) present in individuals with Down syndrome compared to the usual matched pair. Increased funding toward basic research on chromosome 21 will improve understanding of the biology of Down syndrome and support development of new treatments for health conditions experienced by individuals with Down syndrome. With advances in technology, researchers can further explore the effects of multiple genes on chromosome 21 and identify genetic pathways that may be most responsive to new therapies.
- **Assemble a large study population of individuals with Down syndrome.** A large study population, called a cohort, of individuals with Down syndrome is essential for following development of the condition over time and fully characterizing condition traits at different stages of development. Several smaller cohorts composed of this population currently exists. INCLUDE aims to connect these existing cohorts and enroll new participants at different ages to create one large cohort to study the full range of conditions experienced by individuals with Down syndrome across the lifespan. INCLUDE will supplement extensive data collected from the cohort with information from registries and other data sources to provide a rich resource for studying the condition more broadly.
- **Conduct clinical trials research inclusive of individuals with Down syndrome.** Currently, there are numerous clinical trials that study conditions and diseases that disproportionately affect individuals with Down syndrome but exclude this population from participation. Additionally, there are few clinical trials focused primarily on individuals with Down syndrome despite their relative frequency in the general population. INCLUDE will identify clinical trials that seek to address conditions common in the Down syndrome population and bolster recruitment and inclusion of people with Down syndrome, develop meaningful standards for inclusivity of individuals with Down syndrome in trials, and establish measures specific to individuals with Down syndrome for evaluating clinical success. These efforts should support development of new and existing therapies for co-occurring conditions in Down syndrome and establish a clinical trial infrastructure to support trials of these therapies.

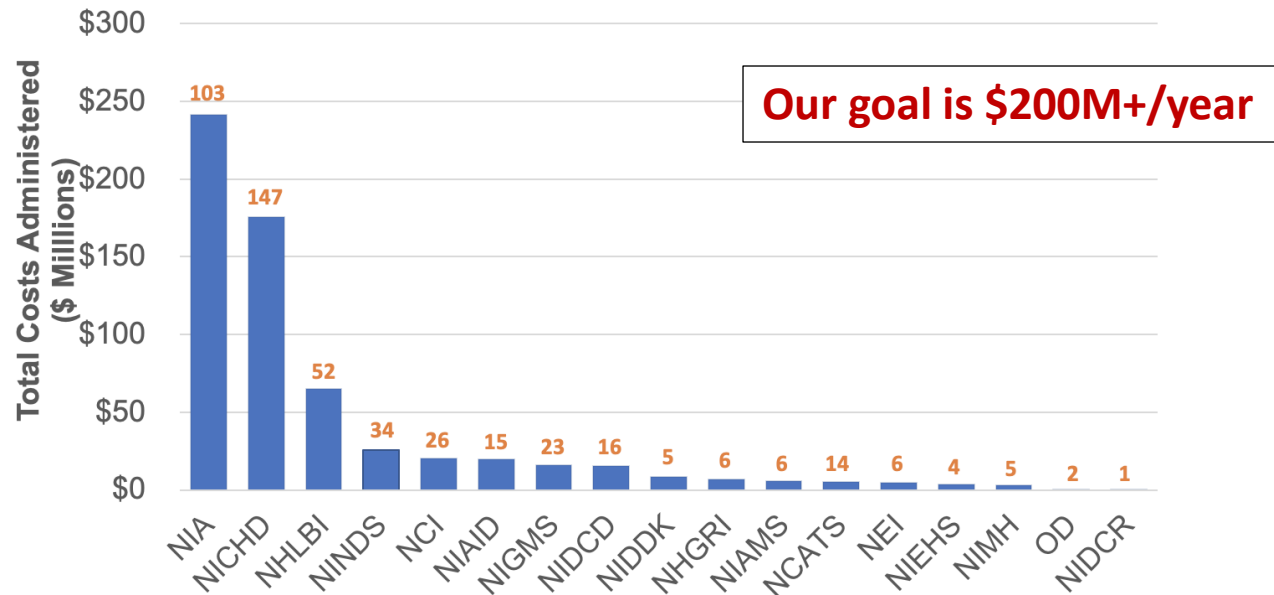
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Our Advocacy is Working! But We Still Have Work To Do...

\$200M+ of NEW NIH DS funding over five years! FY2023 \$130M Anticipated

465 unique awards involving 17 Institutes



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You Can Track Every NIH INCLUDE-Funded Research Project!

Improving the **quality of life of people with Down syndrome**

The INCLUDE Data Coordinating Center (DCC) is making it easier for scientists and the Down syndrome community to work together. Matching the latest technology with shareable resources, researchers use the Data Hub to enhance healthcare and change lives.

[Learn More](#) [Contact us](#)

Enabling discovery through collaborative resources, data integration and open science.

The INCLUDE DCC has created a cloud-based, open, digital platform to easily access and share Down syndrome resources to maximize and accelerate research.

[Data Hub](#)

Explore
View and explore available data and

Build
Search and filter available studies and

Integrate
Integrate with other data analysis

Publications

The scientists who have led studies supported by the INCLUDE program are already making important discoveries in co-occurring conditions that affect people with Down syndrome. Here are some of the scientific papers that have been published in leading academic journals around the world.

As we complete our list of publications, we invite those featured to review and provide feedback at info@includedcc.org

Publication Year:

<p>Clinical Linguistics & Phonetics 2019</p> <p>Speech and motor speech disorders and intelligibility in adolescents with Down syndrome.</p> <p>Apraxias, Dysarthria, Language Development Disorders, Speech Delay, Speech Disorders</p>	<p>Journal Of Speech, Language, And Hearing Research : JSLHR 2021</p> <p>Auditory-Perceptual Features of Speech in Children and Adults With Down Syndrome: A Speech Profile Analysis.</p> <p>Speech Disorders</p>
<p>American Journal Of Speech-Language Pathology 2019</p> <p>Estimates of the Prevalence of Speech and Motor Speech Disorders in Youth With 22q11.2 Deletion Syndrome.</p> <p>Apraxias, DiGeorge Syndrome, Dysarthria, Fragile X Syndrome, Galactosemias, Language Development Disorders, Neurodevelopmental Disorders, Speech Delay, Speech Disorders, Speech Sound Disorder, Velocardiofacial Syndrome</p>	<p>Clinical Linguistics & Phonetics 2019</p> <p>Estimates of the prevalence of speech and motor speech disorders in adolescents with Down syndrome.</p> <p>Apraxias, Ataxia, Dysarthria, Language Development Disorders, Speech Delay, Speech Disorders</p>
<p>Journal Of Speech, Language, And Hearing Research : JSLHR 2022</p> <p>Observational Study to Preliminarily Characterize the Audiological Profile of Children With Down Syndrome.</p> <p>... profiles in children with Down syndrome, including the use of extended high-frequency sensitivity and speech intelligibility index assessment. Participants were 18 children with Down syndrome between 5 and 17 ...</p>	<p>American Journal Of Speech-Language Pathology 2021</p> <p>Maternal Use of Decontextualized and Contextualized Talk: An In-Depth Investigation of Early Parent-Child Interactions in Down Syndrome.</p>

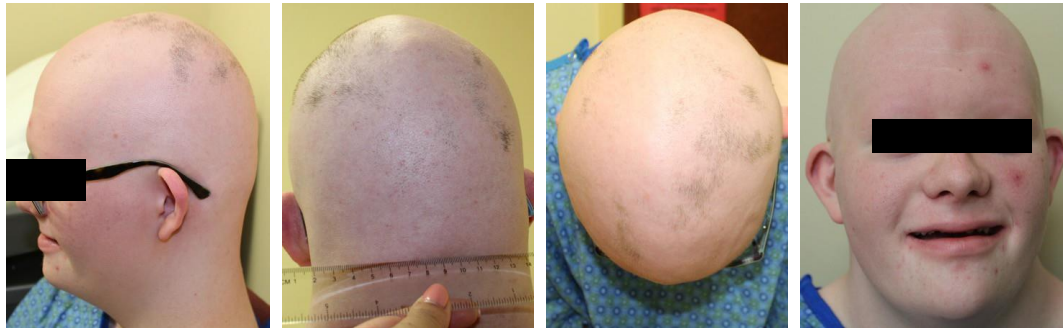
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Elongating Life & Improving Health Outcomes *is* Achievable

NIH INCLUDE-FUNDED CLINICAL TRIAL TREATING ALOPECIA AREATA IN PATIENTS WITH DOWN SYNDROME

Baseline
SALT = 86



Week 16
SALT = 4



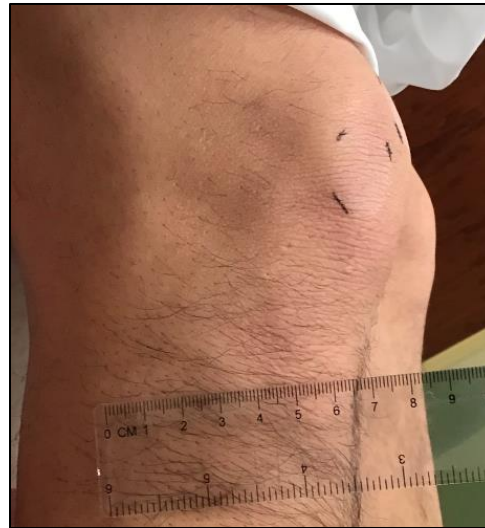
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Elongating Life & Improving Health Outcomes *is* Happening!

NIH INCLUDE-FUNDED CLINICAL TRIAL TREATING PSORIATIC ARTHRITIS



Screening



Week 8

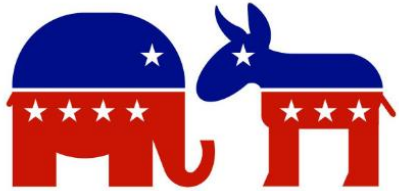


Week 16

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Self-Advocates with Down Syndrome

YOU are the KEY



- Tell your Representative and Senators this is important to you
- Write to your Representative and Senators
- Sign petitions of support
- Attend and/or speak at DC or local briefings where research and medical care are key topics
- Testify before Congress and receive a standing ovation and 200M internet views 😊!

THANK YOU! AND THANKS TO NDSS FOR ORGANIZING THIS CONFERENCE

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Congressional Task Force on Down Syndrome

Hello!



Colleen Hatcher
NDSS



Jordan Kough
NDSC



Michelle Sie Whitten
GLOBAL

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What is the task force?

- Bipartisan, bicameral working group of Members of Congress
- Goals:
 - Educate Members of Congress and their staff about Down syndrome
 - Advance legislation that benefits the Down syndrome community

Why is it important?

- Bipartisan leadership in Congress has resulted in significant achievements for the Down syndrome and disability community including:
 - Americans with Disabilities Act (ADA)
 - Individuals with Disabilities Education Act (IDEA)
 - Achieving a Better Life Experience Act (ABLE)

National Support

- The task force is jointly supported by the Global Down Syndrome Foundation (GLOBAL), the National Down Syndrome Congress (NDSC), and the National Down Syndrome Society (NDSS)



Congressional Leadership



Congresswoman
Cathy McMorris
Rodgers
R – Washington



Senator Robert
"Bob" Casey
D – Pennsylvania



Congresswoman
Eleanor Holmes
Norton
D – DC



Senator Jerry Moran
R – Kansas

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Members

House

Representative Barry Moore (R – AL)

Representative Pete Sessions (R – TX)

Representative Andrew Garbarino (R – NY)

Senate

Senator Roger Marshall (R – KS)

Increased Membership

- Invite your Members of Congress to join the Congressional Task Force on Down Syndrome!
- Contact information for the co-chair offices is in the leave behind folders





Effectively Advocating for the Down Syndrome Community

Welcome to our guest!



Grace Hart

Disability Senior Policy Aide
Senator Bob Casey, Senate Special
Committee on Aging

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