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Down Syndrome Advocacy Conference

About the Conference

Hosted by the National Down Syndrome Society (NDSS), the annual Down Syndrome Advocacy Conference brings the Down syndrome community together to advocate for legislative priorities that impact them. This year we are thrilled to bring more than 350 advocates from 42 states and the District of Columbia to Capitol Hill!

This year's conference is presented in partnership with our advocacy partners, the National Down Syndrome Congress (NDSC) and the Global Down Syndrome Foundation (GLOBAL), as well as Down Syndrome Affiliates in Action (DSAIA), GiGi's Playhouse, and LuMind IDSC.

About NDSS

The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. Founded in 1979, NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming: Resources & Support, Policy & Advocacy, and Community Engagement. Within these focus areas, NDSS engages in various activities, events, and programs such as the National Advocacy & Policy Center, which seeks to create systemic change through engaged advocacy; the National Buddy Walk® Program, which honors and celebrates individuals with Down syndrome in local communities across the world, and other initiatives that provide support, informational resources, and community engagement opportunities for individuals with Down syndrome and those who support them. Visit www.ndss.org for more information about NDSS.

About our Partners

The National Down Syndrome Congress

The National Down Syndrome Congress (NDSC) is the country's oldest national organization for people with Down syndrome, their families, and the professionals who work with them. NDSC provides information, advocacy and support concerning all aspects of life for individuals with Down syndrome, and work to create a national climate in which all people will recognize and embrace the value and dignity of people with Down syndrome. Visit www.ndsccenter.org for more information about NDSC.

The Global Down Syndrome Foundation

The Global Down Syndrome Foundation (GLOBAL) is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome. GLOBAL has donated more than $32 million to establish the first Down syndrome research institute supporting over 400 scientists and over 2,200 patients with Down syndrome from 33 states and 10 countries. Working

closely with Congress and the National Institutes of Health, GLOBAL is the lead advocacy organization in the U.S. for Down syndrome research and care. GLOBAL has a membership of over 100 Down syndrome organizations worldwide and is part of a network of Affiliates – the Crnic Institute for Down Syndrome, the Sie Center for Down Syndrome, and the University of Colorado Alzheimer's and Cognition Center – all on the Anschutz Medical Campus. Visit www.globaldownsyndrome.org for more information about GLOBAL.

Down Syndrome Affiliates in Action

Down Syndrome Affiliates in Action is a membership association whose members are local, state, and regional Down syndrome associations. Long before there was DSAIA, staff and volunteers recognized how important it was to share experiences, exchange program materials, and find ways to learn from each other. In 2007, leaders from around the country gathered for the first conference which later became Down Syndrome Affiliates in Action. Today, DSAIA represents more than 2,000 leaders in the Down syndrome community. Visit www.dsaia.org for more information about DSAIA.

GiGi's Playhouse

GiGi's Playhouse is the only nationwide network of Down syndrome achievement centers. GiGi's Playhouse was founded by GiGi's mom, Nancy Gianni, in Hoffman Estates, IL. Through its first 18 years, GiGi's Playhouse has grown to 54 locations throughout the United States and Mexico and serves families in 71 countries. GiGi's offers over 50 different therapeutic, educational, and career development programs for individuals with Down syndrome of all ages, their families, and the community. The organization is 99% volunteer-run, and all programs are 100% free to families. From prenatal diagnosis through career skills, GiGi's Playhouse makes a lifetime commitment to families. With over 200,000 free program participation hours annually, GiGi's Playhouse helps participants thrive through building educational, developmental, fitness, fine and gross motor, social-emotional, and speech and language skills. Visit www.gigisplayhouse.org for more information about GiGi's Playhouse.

The LuMind IDSC Foundation

The LuMind IDSC Foundation (LuMind IDSC) envisions a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential. LuMind IDSC accelerates research to increase availability of therapeutic, diagnostic, and medical care options and provides resources, connections, and support to a vibrant community of individuals with Down syndrome and their families. Founded by two visionary families in 2004, LuMind IDSC has raised a total of $100M in funding for Down syndrome research to prevent the onset of Alzheimer's disease, improve sleep, and advance independence for people with Down syndrome. Visit www.LuMindIDSC.org for more information about LuMind IDSC.

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Charlotte Woodward Organ Transplant Discrimination Prevention Act

Legislative Request

Please cosponsor the Charlotte Woodward Organ Transplant Discrimination Prevention Act to prohibit discrimination against people with disabilities in the organ transplant system.

Background

Despite existing civil rights protections, individuals with Down syndrome and other disabilities continue to face both willful and unintended discrimination in organ transplantation which threatens their ability to access health care when they need it most. A 2019 report from the National Council on Disability (NCD), an independent federal agency that advises Congress and the executive branch on disability policy issues, found that people with disabilities, especially intellectual disabilities, have been denied access to organs because of subjective judgements about the value of a life with a disability, assumptions about their quality of life, and misconceptions about their ability to comply with post-operative care. Furthermore, the report found that some organ transplant programs have policies which exclude people with disabilities as candidates for a transplant – some with categorical exclusions based on disability, refusing to even evaluate a person's medical suitability for an organ transplant because of their disability.

Bill Summary

Introduced by Representatives Kat Cammack (R – FL) and Debbie Dingell (D – MI) in the House and Senators Maggie Hassan (D – NH) and Marco Rubio (R – FL) in the Senate, The Charlotte Woodward Organ Transplant Discrimination Prevention Act upholds, clarifies, and builds upon rights established in the Americans with Disabilities Act of 1990, Sec. 504 of the Rehab Act, and Sec. 1557 of the Affordable Care Act. The bill 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, or decline insurance coverage for a transplant or related service based solely on the fact that the individual has a disability. The bill also recognizes the importance of auxiliary aids and services, the ability of an individual's support network to help with post-operative care, and the need for reasonable modifications to policies and procedures to make organ transplant

systems and facilities more accessible to people with disabilities. At the same time, the bill respects the professional judgment of health care providers by clarifying how disability should properly be considered in an individualized treatment plan. Finally, this bill 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.

Impact

There have been several instances in which members of the Down syndrome community were unable to get the lifesaving transplants they needed and tragically passed away. This bill would ensure that individuals with disabilities have access to an organ transplant system free from discrimination. Furthermore, the bill provides those that feel they have been discriminated against the recourse they need to seek life-saving relief in a timely manner.

Important Information

- The bill is bipartisan in both chambers.
- The bill has no fiscal impact.
- This bill has the support of a growing list of disability and medical organizations.
- 36 states have passed state-level legislation prohibiting discrimination based solely on disability in the organ transplant system.
- The bill is named after Charlotte Woodward, an advocate with Down syndrome who received a life-saving heart transplant over a decade ago.

For more information, please contact Anna Fedewa, Manager of Public Policy, National Down Syndrome Society at afedewa@ndss.org.

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

Legislative Request

Please cosponsor the Transformation to Competitive Integrated Employment Act (TCIEA) (H.R. 1263/S. 533) to end subminimum wages and promote opportunities for competitive integrated employment for people with disabilities.

Background

The Fair Labor Standards Act of 1938 (FLSA) establishes minimum wage and other wage and labor practices. Under Section 14(c) of the FSLA, employers can apply for special wage certificates that allow them to pay employees with disabilities less than the federal minimum wage. A recent Government Accountability Office (GAO) report found that in 2019 close to 1,600 employers paid subminimum wages to about 120,000 employees with disabilities.[i] This same report found that the average wage of a person with a disability working under such certificates is $4.15 an hour. While 13 states have passed state-level legislation prohibiting the payment of subminimum wages to people with disabilities, legislation ending this provision of Federal law is needed to completely end the practice of paying people with disabilities subminimum wages.

Bill Summary

Introduced by Representatives Cathy McMorris Rodgers (R – WA) and Bobby Scott (D – VA) in the House and Senators Bob Casey (D – PA) and Steve Daines (R – MT) in the Senate and with the support of over 40 disability and employment focused organizations, TCIEA would prohibit the U.S. Secretary of Labor from issuing new 14(c) certificates and phase out the use of existing 14(c) certificates over the course of five years. This multi-year phase would help avoid job loss for workers currently employed under these certificates. The bill would also provide grant funding to states and employers currently holding 14(c) certificates to assist in transitioning toward paying at least minimum wage. Lastly, the bill would establish a technical assistance center to support employers in transitioning to competitive, integrated employment while still ensuring that individuals with disabilities receive the support they need to be successful.

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Impact

This bill would end the discriminatory practice of paying people with disabilities less than those without disabilities while also furthering the national goal of competitive, integrated employment where people with disabilities work alongside their colleagues without disabilities and are paid at least the minimum wage.

For more information, please contact Cyrus Huncharek, Director of Policy and Advocacy, National Down Syndrome Congress at cyrus@ndsccenter.org.

[i] Government Accountability Office. (2023). Subminimum Wage Program, DOL Could Do More to Ensure Timely Oversight. (GAO Publication No. 23-105116). Washington, DC.: U.S. Government Printing Office.

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

Legislative Request

Please support the inclusion of the Down syndrome community in Alzheimer's disease initiatives by:

- Cosponsoring the National Alzheimer's Project Act (S.133/H.R. 619) to build upon efforts to address Alzheimer's disease and related dementia through the coordination of federal planning and programs
- Supporting efforts to increase access to diagnostic care and treatment
- Supporting efforts to better support caregivers of individuals with Down syndrome and Alzheimer's disease by providing training and respite care

Background on Down Syndrome and Alzheimer's Disease

People with Down syndrome are uniquely situated in the Alzheimer's landscape because they have an extra copy of chromosome 21. The 21st chromosome carries the amyloid precursor protein (APP) gene, which is strongly associated with the formation of amyloid peptides and plaques, a hallmark of Alzheimer's disease. As a result, individuals with Down syndrome have an elevated lifetime risk for developing Alzheimer's disease, with the onset of symptoms coming earlier and progressing faster than in the general population. In fact, Alzheimer's disease is the number one cause of death for individuals with Down syndrome.

Unfortunately, Alzheimer's disease is commonly misdiagnosed in patients with Down syndrome due to some observable traits that are common to both conditions – an issue called diagnostic overshadowing. This issue, combined with a general lack of education about Down syndrome provided to our nation's medical professionals, makes it likely that individuals with Down syndrome will be left out of clinical trials for drugs to treat or prevent Alzheimer's disease.

Older Americans who develop Alzheimer's disease frequently receive care from their children, whereas people with Down syndrome are typically provided care by their parents. For parent caregivers, this reality can cause uncertainty of who will care for their children as they themselves also age. Many memory or long-term care centers will not accept individuals with Down syndrome due to the age of the person with Down syndrome and their Alzheimer's diagnosis. Siblings will frequently step in to provide care when their parents are no longer able,

but this transition often necessitates a move to a new state and can result in the loss of vital government benefits such as those for home and community-based services.

Policy Considerations

NAPA Reauthorization Act (S.133/H.R. 619)

Introduced by Representatives Paul Tonko (D – NY), Christopher Smith (R – NJ), and Maxine Waters (D – CA) in the House and Senators Susan Collins (R – ME), Mark Warner (D – VA), 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) in the Senate, the NAPA Reauthorization Act would to build upon efforts to address Alzheimer's disease and related dementia through the coordination of federal planning and programs. Additionally, NAPA must be updated to provide specific supports for the Down syndrome community.

Increasing Access to Diagnostic Care and Treatment

Congress must ensure that insurance coverage, especially at the Centers for Medicare & Medicaid Services, provides meaningful access to diagnostic care and treatment for individuals with Down syndrome, on par with care received by members of the general public. Since people with Down syndrome often show symptoms of Alzheimer's-related dementia earlier than others, threshold ages must be lowered as necessary, and key government healthcare benefits must be portable across state lines.

Supporting Caregivers

Congress must ensure that families have evidence-based training to provide high-quality care to their loved ones, community-based supports to allow them to care for themselves, and information necessary to prepare adequately for the financial impact of providing care. Congress should also consider ways in which memory care and long-term care centers can be more adequately supported in providing care to populations who experience Alzheimer's disease and related dementia at an earlier age and those with both Down syndrome and Alzheimer's disease.

For more information, please contact Anna Fedewa, Manager of Public Policy, National Down Syndrome Society at afedewa@ndss.org.

Support for the INCLUDE Project Research Plan at the National Institutes of Health (NIH)

Legislative Request

Please support the overall increase of the National Institutes of Health budget and a continued significant annual increase of the INCLUDE (**IN**vestigation of **C**o-occurring conditions across the **L**ifespan to **U**nderstand **D**own Syndrom**E**) Project Research Plan - a trans-NIH funding program under the NIH Office of the Director.

Background

Despite being the leading cause of developmental delay in the United States and worldwide, until recently Down syndrome was one of the least funded genetic conditions by our NIH. In October 2017 the first Congressional Hearing on Down Syndrome Research was organized for the House Labor, Health and Human Services, Education Appropriations Subcommittee where the shocking nearly two-decade long lack of funding for Down syndrome research was highlighted. In addition, the unique disease profile of people with Down syndrome was explained whereby they are highly predisposed to some diseases (e.g. Alzheimer's, autoimmune disorders) and highly protected from others (e.g. solid tumor cancers). Self-advocate, public speaker and actor Frank Stephen's five minute testimony received a congressional standing ovation and has gone viral to over 200 million views today.

With the increase in live births and the doubling of lifespan since the 1980s, there is a mini population explosion of people with Down syndrome in the United States. These next generations will be the first expected to outlive their parents.

Through robust Down syndrome research, and medical care informed by that research, we can (a) increase lifespan of our loved ones from 60 years (b) significantly improve health outcomes of people with Down syndrome - especially in the last twenty year of life and (c) understand and even treat many life-threatening diseases that affect the typical population as well as those with Down syndrome.

Ask Summary

House Representatives and Senators can support this initiative by supporting annual increases to the NIH budget and especially to the INCLUDE Project Research plan for Down syndrome research housed under the NIH Office of the Director. The estimated funding for FY23 is $130 million. Our goal is to eventually get to over $200 million more on par with autism and other diseases and conditions that have a similar estimated population.

Impact

This research will elongate life and significantly improve the health outcomes for people with Down syndrome. It also has great promise in discovery and treatment for major diseases that 60% of Americans die from. It will help correct a long-time discrimination against those with Down syndrome when it comes to both research and medical care.

Important Information

NIH INCLUDE funding for Down syndrome research has the support of hundreds of members and tens of thousands of individuals with Down syndrome and their family members. Prior to the establishment of INCLUDE, Down syndrome research at the NIH was primarily funded by just one institute. Because of INCLUDE there are now 17 institutes actively funding Down syndrome research with 11 clinical trials, early breakthroughs and so much promise.

For more information, please contact Michelle Sie Whitten, President & CEO, Global Down Syndrome Foundation at michelle@globaldownsyndrome.org.

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Congressional Task Force on Down Syndrome

Legislative Request

Please join the Congressional Task Force on Down Syndrome.

- **House**: Representatives may join the Task Force by contacting Liz Payne with Representative Cathy McMorris Rodger's office at liz.payne@mail.house.gov or Sullivan Gassmann with Congresswoman Eleanor Holmes Norton's office at sullivan.gassmann@mail.house.gov.
- **Senate**: Senators may join the Task Force by contacting Michael Gamel-McCormick with Senator Bob Casey's office at michael_gamel-mccormick@aging.senate.gov or Christiana Reasor with Senator Jerry Moran's office at christiana_Reasor@moran.senate.gov.

Background and Summary

The Congressional Task Force on Down Syndrome is a bipartisan, bicameral working group whose goal is to educate Members of Congress and their staff about Down syndrome and to advance legislation that benefits the Down syndrome community.

Established in May 2015, the Congressional Task Force on Down Syndrome, which is an expansion of the Congressional Down Syndrome Caucus originally formed in 2008, is made up of United States Representatives and Senators. The Task Force is led by Representatives Cathy McMorris Rodgers (R-WA) and Eleanor Holmes Norton (D-DC) and Senators Robert Casey (D-PA) and Jerry Moran (R-KS).

Bipartisan leadership in Congress has resulted in significant achievements for the Down syndrome community and the disability community at large. The Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and the Achieving a Better Life Experience Act (ABLE) illustrate what can be accomplished when Members work with each other to enact legislation that empowers individuals with disabilities.

The Global Down Syndrome Foundation (GLOBAL), the National Down Syndrome Congress (NDSC), and the National Down Syndrome Society (NDSS) partner together to jointly support the work of the task force.

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DOWN SYNDROME ADVOCACY CONFERENCE CONGRESSIONAL RECEPTION

Members of Congress and their staff are invited to join advocates from the Down syndrome community to celebrate their accomplishments and the completion of the Down Syndrome Advocacy Conference.

Wednesday, April 19, 2023
5:00 – 7:00 PM
Rayburn House Office Building 2045

Light refreshments will be served

GLOBAL DOWN SYNDROME FOUNDATION®

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NATIONAL DOWN SYNDROME CONGRESS

GiGi's Playhouse™ Down Syndrome Achievement Centers educate. inspire. believe.

Lumind IDSC DOWN SYNDROME FOUNDATION

This is a widely attended event in compliance with both House and Senate ethics rules.