Get Engaged in NDSC’s Policy and Advocacy Efforts

Stephanie Smith Lee, NDSC Senior Policy Advisor
Overview of NDSC Policy Team & Priorities

• Who we are

• Current policy priorities
  – Education (K-12, UDL, Postsecondary)
  – Employment
  – Medicaid
  – Health Care
  – Other priorities

• National Down Syndrome Advocacy Coalition
NDSC Policy & Advocacy Center

- NDSC Policy Team
- NDSC Public Policy Advisory Council
- National Down Syndrome Advocacy Coalition (NDAC)
- Coalitions
  - Consortium for Citizens with Disabilities
  - Collaboration to Promote Self-Determination
  - National UDL Task Force & UDL Policy Council
  - Leadership Conference on Civil and Human Rights
  - Inclusive Higher Education Committee
  - HCBS Advocacy Coalition
  - Coalition to Promote Competitive Integrated Employment
  - Allies for Independence
Education (K-12)

• Every Student Succeeds Act (ESSA)
  – Work to retain accountability
  – Improve implementation through tools and technical assistance for stakeholders

• Individuals with Disabilities Education Act (IDEA)
  – Retain IDEA protections

• Inclusion
  – Increase inclusive opportunities for students with DS

• Universal Design for Learning (UDL)
  – Increase implementation of UDL
Postsecondary Education

• Retain and improve provisions in the Higher Education Act (HEA) that allow financial aid and authorize model programs and a national coordinating center for students with ID.

• Increase access to inclusive postsecondary opportunities for students with Down syndrome and other cognitive disabilities.

• Increase the quality of Postsecondary Education Programs through model standards.
Employment

- Retain Workforce Innovation Opportunity Act law, especially the definition of “competitive integrated employment”
- Phase out 14(c) subminimum wage in a responsible way (with capacity-building)
- Expand opportunities regarding apprenticeships as a pathway to employment for people with disabilities.
Medicaid

• Maintain current infrastructure framework of Medicaid and protect against cuts, block granting, and per capita caps.

• Maintain long term services funded by Medicaid, particularly Home and Community Based Services (HCBS) waivers that fund employment and residential supports. (The primary source of long-term employment support is Medicaid.)

• Increase public awareness of the importance of Home and Community Based Services and utilizing self-directed services with necessary safeguards.
Health Care

• Preserve key tenets of the Affordable Care Act that eliminate denial in coverage or charge higher rates based upon pre-existing conditions, prohibit annual and lifetime caps, and cover essential health benefits such as rehabilitative and habilitative services.
Other Priorities

- Financial Security & ABLE Accounts
- Housing
- Transportation
- Research
Workshops by NDSC Policy Team at NDSC Convention

• **Friday June 28**
  – 1:30 – 3:00pm: Town Hall meeting with Laurie VanderPloeg, Director of the Office of Special Education Programs
  – 4:00 – 5:00pm: Ask the Experts

• **Saturday June 29**
  – 9:30am – 11:30am: What’s Happening in Washington DC and What You Can Do
  – 1:30pm – 3:00pm: The Future of Inclusive Higher Education: Make Your Voice Heard
  – 4:00 – 5:00: Ask the Experts

• **Sunday June 30**
  – 8:30am – 10:00am: Your Story. Your Voice. You Make the Difference (grassroots advocacy)
  – 10:30am – 12:00pm: Introduction to Inclusive Higher Education
National Down Syndrome Advocacy Coalition

NDAC
National Down Syndrome Advocacy Coalition

A member service of NATIONAL DOWN SYNDROME CONGRESS
National Down Syndrome Advocacy Coalition (NDAC)

- Started in Fall 2017, NDAC is a member service of NDSC.
- Grassroots advocacy program to educate individuals with DS, family members and other allies about policy issues and give them advocacy tools to make their voices heard.
  - Active closed Facebook group
  - Quarterly update webinars and other resources

- 2 Types of NDAC Members:
  - **NDAC Members** - NDSC members of all abilities/levels of advocacy experience (anyone can join).
  - **NDAC Group Members** - NDSC Affiliate Program Subscribers who have opted to join the NDAC program, or other groups (cross-disability, other disability, statewide coalitions) who pay a $20 NDAC group membership fee.
By the Numbers

• NDAC Members: 269

States where we need representatives: Alaska, Rhode Island, South Dakota, Vermont, Wyoming

• NDAC Group Members: 35
  – Global/National/Statewide/Local Groups and Organizations
NDAC Group Members who are already working with us on outreach, messaging and sharing policy information with the families who they serve.
Sign up to stay up-to-date with NDSC Policy communications!

- **Monthly NDSC Policy & Advocacy Newsline emails**
  - [https://www.ndscccenter.org/stay-up-to-date-with-ndsc-news/](https://www.ndscccenter.org/stay-up-to-date-with-ndsc-news/)

- **Action Alerts**
  - [https://www.ndscccenter.org/political-advocacy/take-action-stay-informed/](https://www.ndscccenter.org/political-advocacy/take-action-stay-informed/)

- **Facebook**
  - [https://www.facebook.com/dsadvocates/](https://www.facebook.com/dsadvocates/)

- **Twitter**
  - [@policyupdates](https://twitter.com/policyupdates)
THANK YOU!

Stephanie Smith Lee
NDSC Senior Policy Advisor
stephanie@ndsccenter.org
Self-Advocates Win Landmark Federal Funding for Research: Join Global - Join the Movement

Martha Keele, Sr. Director of Community Development & Gov. Affairs

Thursday, June 27, 2019
What We Will Cover Today

- Welcome & Speaker Intros
- Global Down Syndrome Foundation (Global)
  - Catalyst - Lack of funding for Down Syndrome Research & Medical Care creates a life-threatening disparity
- What Global Does
  - Direct pediatric and adult medical care; Direct research with national and international reach
  - Lots of outreach, education, programs & events
  - National Government Advocacy
- Global is the Lead Government Advocacy Non-Profit for Research & Medical Care
  - Legislation + funding = success
  - What we do, why we are successful
- IMPORTANT NEXT STEPS!
  - Help Global MAINTAIN & INCREASE funding for FY2020 on
- Become a Global Advocacy Champion Member
- Q&A/Thank YOU
Global Down Syndrome Foundation

Faegre Baker Daniels Consulting
- Debra Lappin
- Kevin Brennan
- Lauren Bloch

Williams & Jensen
- Susan Hirschmann
- Cheryl Jaeger
- Laura Simmons
- Erin Book Mullen
## The Catalyst to Start Global

A life-threatening disparity of funding at the NIH

<table>
<thead>
<tr>
<th>Year</th>
<th>NIH Actual Total Obligations by Budget Mechanism (In Millions &amp; Rounded)</th>
<th>CF Research Funding (Dollars in Millions)</th>
<th>Fragile X Research Funding (Dollars in Millions)</th>
<th>MS Research Funding (Dollars in Millions)</th>
<th>Autism Research Funding (Dollars in Millions)</th>
<th>DS Research Funding (Dollars in Millions)</th>
<th>DS Research Funding to NIH Budget (Rounded)</th>
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</table>
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.
The Catalyst to Start Global

The Importance of Research & Medical Care

- 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
  - No current guidelines for adults with Down syndrome (Drs. William I. Cohen and David S. Smith); 2001 “Health Supervision for Children with Down Syndrome”; current ones are a “must” and provide a great check-list (Drs. Marilyn J. Bull, William I. Cohen, Nancy Rozien)

- People with Down Syndrome have a Different Disease Spectrum!

Research  Medical Professional  Patients  Medical Professional  Research
The Global Down Syndrome Foundation is part of a network of affiliate organizations that work closely together on a daily basis to deliver on our mission - Significantly improve the lives of people with Down syndrome through **Research, Medical Care, Education & Advocacy**:

- **Global**: fundraising, outreach, advocacy for Global and four Global Affiliates.
- **Sie Center**: over 1,700 unique patients from 28 states and 10 countries with 8 clinics (2 first in-kind)
- **Crnic Institute**: over 200 scientists working to elongate life and improve health outcomes for people with Down syndrome.
- **RMADC**: Leukine and other important breakthroughs.
- **Adult Clinic**: Pilot phase until June 2019. Goal is to have a world-class feeder for the Sie Center.
Global Down Syndrome Foundation: MEDICAL CARE INITIATIVES
Established and support the Sie Center
- One of the best/largest in the world
- 1,700+ unique patients from 28 states and 10 countries
- 14 FTE, 8 Clinics - two first-in-kind programs, full-time education specialist and mental wellness clinic
- Experts such as Dr. Fran Hickey, Dr. Lina Patel, Patricia C. Winders and Dee Daniels; M-F full days

Clinical Research Core Competencies
- DS and Aspiration, Infantile Spasms, Autism, Sleep Apnea, Morphine for Surgery, Behavior and Regression
- Other competencies - Physical Therapy, Educational Influences, Speech, Feeding and more

Specialty Clinic Offered

<table>
<thead>
<tr>
<th>Mental Wellness</th>
<th>School Age/Education</th>
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<td>Medical</td>
<td>Sleep</td>
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<tr>
<td>Infant</td>
<td>ENT</td>
</tr>
<tr>
<td>Telemedicine</td>
<td>Feeding &amp; Swallowing</td>
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</table>
Global Down Syndrome Foundation: GROUNDBREAKING RESEARCH
Global - Proud of Our Accomplishments
Crnic Institute for Down Syndrome Anschutz Medical Campus

❖ Dr. Joaquín Espinosa, Crnic Institute ED
  ➢ World-renowned cancer scientist; Howard Hughes Medical Investigator (HHMI)
  ➢ Ph.D. from the University of Buenos Aires in Argentina; post-doctoral training at The Salk Institute for Biological Studies in La Jolla, CA
  ➢ Professor in the Department of Pharmacology, Co-Leader of the Molecular Oncology Program, Founding Director of the Functional Genomics Facility, University of Colorado Denver School of Medicine

❖ Dr. Huntington Potter, Lead AD Researcher
  ➢ Discovered the mechanistic relationship between Alzheimer’s disease and Down syndrome; PROMISING LEUKINE TRIALS UNDERWAY
  ➢ Kurt N. and Edith von Kaulla Memorial Professor of Neurology, Director, RMADC, Vice Chair of Research Department of Neurology University of Colorado
  ➢ Graduated with a AB, MA and PhD from Harvard in Physics, Chemistry, Biochemistry & Molecular Biology; Professor at Harvard Department of Neurobiology from 1985 - 1998
  ➢ Professor and Eric Pfeiffer Chair of Research on Alzheimer’s disease and head of the NIH funded Alzheimer’s Center University of South Florida SOM 1998 - 2012
Alzheimer’s Disease

Bettscher, Dell’Acqua, Hoeffer

Kennedy, Potter, Xue

Cognition, Autism and Brain Function

Chen, Maclean, Jones, Maier

Mueller, Santos, Shaikh, Stitzel

Immunology

Lenz, Hsieh

Shen, Spritz

Sullivan, Yeager

Stem Cells and Development

Bilousova, Klymkowsky, Link, Old, Olwin, Pearson

Advanced Genetics and Genomics

Blumenthal, D’Alessandro, Dowell, Johnson, Liu, O’Connor

Leukemia

DeGregori, Espinosa, Yi
Everywhere we look, it is clear that trisomy 21 causes increased Interferon signaling. In typical people the Interferon pathway is lit up when fighting a virus or infection. In people with Down syndrome it is lit up 24/7...a huge taxation on the immune system.
THE PROBLEM & GLOBAL’S LEADERSHIP TO SOLVE THE PROBLEM
THE STRATEGY

Science
- Therapeutic leverage - Extreme predispositions (Alzheimer’s disease, autoimmune disorders) and protections (solid tumors, certain strokes & heart attack) BUT first and foremost people with Down syndrome.
- REBUILD the pipeline with excellent science

Medical Care
- Establish a world-class pediatric clinic and adult clinic providing excellent care, publishing best practice standards, and a bridging clinical and basic research.

Lobbying
- TRANSCENDS Global/Crnic Institute
- Congressional Champions
- Self-Advocates and Families
- Report Language every year
- Deep knowledge of the DS science and medical care nationally
- Hire the best lobbying/consulting firms in the biomedical field

Outreach & Education
- Organize conferences, workshops, and health & wellness programs that help people with Down syndrome directly in Colorado, the US and internationally
GLOBAL:

- Is the largest funder of Down Syndrome (DS) research after the NIH
- Supports over 200 DS researchers and 50 DS experts/clinicians; Supports excellent quality medical care to over 1,600 patients with DS
- Organizes quarterly medical and research webinars and publish on the topics in our award-winning magazine
- Organizes DS research and medical briefings in the Hill every year; We organize the Research & Medical Care Roundtable in conjunction with the NDSC each year
- Is spearheading the creation of sustainable Medical Care Guidelines for Adults with Down Syndrome
- Organizes workshops with the national Alzheimer’s Association and provides joint AD-DS grants; works closely with NIH
- Has collaborated with NDSC, DSAIA, LuMind IDSC, IMDSA and other orgs on specific research workshops
DS is one of the least funded genetic conditions by our National Institutes of Health

- **Low Government Funding** - Despite being the leading cause of developmental delay in the U.S. and the world, Down syndrome is one of the least funded genetic conditions by the NIH and has been since 2001.

- **Precipitous decline in funding** - From 2001 to 2006, NIH funding for Down syndrome research plummeted from $29 million to $14 million despite significant growth of the NIH budget.

- **Parity** - From 2001 to 2017, Down syndrome funding would have been $744 million - more than double the actual $356 million - had this research been funded in parity with the NIH budget.

- **Comparables** - Annual NIH research funding for Down syndrome is 2x to 45x less per capita compared to diseases with similar prevalence (e.g. Multiple Sclerosis) or chromosomal conditions and developmental disabilities (e.g. Fragile X or Autism).
Down syndrome offers research opportunities across many of the 27 Institutes and Centers

**National Institutes of Health:**

- 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
- Much greater risk of diabetes
- High rate of dermatological disorders and arthritis
- >60% have vision problems
- ~30% experience mental illnesses such as depression or OCD
- Unique pattern of immune dysregulation
- >70% have hearing problems
- Much greater risk of diabetes
- Large pediatric population and unique pattern of development
- Most prevalent chromosomal disorder
- ~30% experience mental illnesses such as depression or OCD
- Unique pattern of immune dysregulation

NIH Institutes and Down Syndrome

2019 NDSC Convention

Global’s Advocacy Strategy
1. Dramatically increase research funding at the National Institutes of Health (NIH) benefitting people with Down syndrome - this can also help millions without the condition

2. Move Down syndrome research from solely at the *Eunice Kennedy Shriver* National Institute for Child Health & Human Development to a Trans-NIH initiative under the Office of the Director
Why We Will Succeed!

- **It starts with YOU!**
  - Telling Your Story
  - A Unified Voice For Change

- **Congressional Advocacy**
  - Making New Friends
  - Mobilizing Our Allies

- **White House & Agency Engagement**
  - Offering Solutions
  - Pressing for Action
KEY TO SUCCESS IS PEOPLE and LOTS OF HARD WORK

- **Self-Advocates and Families**
  - Directly and through members/orgs

- **Scientists & Clinicians**
  - Directly and through DSMIG, T21RS

- **Congressional Champions**
  - Congresswoman Cathy McMorris Rodgers (R-WA)
  - Congressman Tom Cole (R-OK)
  - Congresswoman Rosa DeLauro (D-CT)
  - Congresswoman Cheri Bustos (D-IL)
  - Senators Roy Blunt & Patty Murray, and so many more...

- **NIH Champions**
  - Dr. Lawrence, Deputy Director NIH
  - Dr. Gary Gibbons, Director of NIHLB
  - Dr. Diana Bianchi, Director of NICHD and her team (Dr. Melissa Parisi, Lisa Kaeser, Sujata Bardhan)
  - Dr. Richard Hodes and his team at NIA (Dr. Laurie Ryan)
  - More every year...
Who’s else is in our Corner?
Global Members

- Global Members are KEY supporters of all our advocacy work
  - 1000+ individual members
  - 124 organizational members

- 4,000 National distribution to 49 states and growing!

- Only $20 for a full year’s individual membership; $150, $300, $500 sliding scale for organizational membership
GLOBAL Members
Over 1K individuals and 124 organizational members

1. 21 & Change, Inc.
2. 21_Connect
3. Adam’s Camp
4. Alaska Chapter National Down Syndrome Congress
5. All Around With Downs
6. Angel’s Center for Children with Special Needs
7. Arc Thrift Stores
8. Arkansas Down Syndrome Association
9. Association for Children With Down Syndrome (ACDS)
10. Bringing Up Down Syndrome (BUDS)
11. Capital Area Down Syndrome Association
12. Celebrate Differences
13. ChapTer 21
14. Chattanooga Down Syndrome Society
15. Chesapeake Down Syndrome Parent Group, Inc.
17. Designer Genes of North Dakota
18. Down Syndrome Advocates in Action Nebraska
19. Down Syndrome Affiliates in Action
20. Down Syndrome Albania Foundation
21. Down Syndrome Alliance of the Midlands
22. Down Syndrome Association for Families of Nebraska
23. Down Syndrome Association North Bay
24. Down Syndrome Association of Brazos Valley
25. Down Syndrome Association of Central Florida
26. Down Syndrome Association of Central Kentucky
27. Down Syndrome Association of Central New Jersey
28. Down Syndrome Association of Central Texas (DSACT)
29. Down Syndrome Association of Connecticut
30. Down Syndrome Association of Delaware
31. Down Syndrome Association of Greater Charlotte
32. Down Syndrome Association of Greater Cincinnati
33. Down Syndrome Association of Greater Richmond
34. Down Syndrome Association of Greater St Louis
35. Down Syndrome Association of Jacksonville
36. Down Syndrome Association of Memphis & Mid South
37. Down Syndrome Association of Middle Tennessee
38. Down Syndrome Association of Northeast Indiana
39. Down Syndrome Association of Northern Virginia
40. Down Syndrome Association of Tampa Bay - 21 Strong
41. Down Syndrome Association of the Hudson Valley
42. Down Syndrome Association of The Valley
43. Down Syndrome Association of West Michigan
44. Down Syndrome Association of Wisconsin
45. Down Syndrome Association of Wisconsin - Fox Cities
46. Down Syndrome Coalition of El Paso
47. Down Syndrome Community of Puget Sound
48. Down Syndrome Connection of the Bay Area
49. Down Syndrome Family Connection
50. Down Syndrome Foundation of Southeastern New Mexico
51. Down Syndrome Group of the Ozarks
52. Down Syndrome Guild of Dallas
53. Down Syndrome Indiana
54. Down Syndrome Information Alliance
| 55. | Down Syndrome Network of Arizona |
| 56. | Down Syndrome Network of Montgomery County |
| 57. | Down Syndrome Network of Northern Nevada |
| 58. | Down Syndrome of Louisville |
| 59. | Down Syndrome Partnership of North Texas |
| 60. | Down Syndrome Society of Mobile County |
| 61. | Down Syndrome Support Team |
| 62. | Downside Up, Inc |
| 63. | East Texas Down Syndrome Group |
| 64. | Eastern Idaho Down Syndrome Family Connect |
| 65. | Eastern Pennsylvania Down Syndrome Center |
| 66. | F.R.I.E.N.D.S. Support, Inc |
| 67. | Family Connection of South Carolina |
| 68. | Foundation Ban Papia Aruba |
| 69. | Fun Coast Down Syndrome Association |
| 70. | Fundacion John Langdon Down A.C. |
| 71. | Garrett's Fight Foundation |
| 72. | GiGi’s Playhouse Annapolis |
| 73. | GiGi’s Playhouse |
| 74. | GiGi’s Playhouse El Paso |
| 75. | Gigi’s Playhouse Milwaukee |
| 76. | Gold Coast Down Syndrome Organization |
| 77. | GraceSigns |
| 78. | Grays Peak Speech Services, LLC |
| 79. | International Down Syndrome Coalition |
| 80. | International Mosaic Down Syndrome Association |
| 81. | Kern Down Syndrome Network |
| 82. | KIIDS |
| 83. | Little Leaf Learning Center |
| 84. | LuMind Research Down Syndrome Foundation |
| 85. | Madison Area Down Syndrome Society |
| 86. | Miami Valley Down Syndrome Association |
| 87. | National Association for Down Syndrome |
| 88. | National Down Syndrome Congress |
| 89. | Northern Colorado Down Syndrome Association |
| 90. | Ollie Webb Center, Inc. |
| 91. | Piedmont Down Syndrome Support Network |
| 92. | Public Foundation of Parents of Children with Down Syndrome |
| 93. | Red River Valley Down Syndrome Society |
| 94. | Rio Grande Down Syndrome Network |
| 95. | Rio Grande Valley Down Syndrome Association |
| 96. | Rock the 21 |
| 97. | Rosina Nanayakkara Charitable Trust Fund |
| 98. | Sharing Down Syndrome Arizona Inc |
| 99. | Southern Arizona Network for Down Syndrome |
| 100. | Sustainable Action Against Disaster |
| 101. | The Arc Down Syndrome New Mexico Fund |
| 102. | The Cedars of Marin |
| 103. | The Up Side of Downs of Northeast Ohio |
| 104. | Triangle Down Syndrome Network |
| 105. | Wellspring Community |
| 106. | Wisconsin Upside Down |
| 107. | Yellowstone County's 'Extra' Special Kids (YES Kids) |
Global Down Syndrome Foundation Ambassadors

Sophia Whitten 2008
Chase Perry 2009
Katherine Winfield 2010
Alexander Sessions 2011
DeOndra Dixon 2011
Samantha Stevens 2013
Cole Rodgers 2013
Katherine Norton 2014
Steven Dulcie 2014

Global's Advocacy Strategy
Quincy Jones Exceptional Advocacy Award Recipients

Roy Blunt, 2019
Cheri Bustos, 2019
Zack Gottsagen, 2018
Colin Farrell, 2018
Eva Longoria, 2017
Madeline Stuart, 2017
Frank Stephens, 2016
Jamie Brewer, 2015
Anna and John J. Sie, 2015
Brad Hennefer, 2014
Beverly Johnson, 2014
Jerry Moran, 2014
Eleanor Holmes Norton, 2014
Tim Harris, 2013
Kyra Phillips, 2013
Cathy McMorris Rodgers, 2013
Chris Van Hollen, 2013
Jamie Foxx, 2012
Sujeet Desai, 2011
John C. McGinley, 2011
Pete Sessions, 2011
Tom Harkin, 2011
Karen Gaffney, 2010
Patrick J. Kennedy, 2010
Timothy P. Shriver, 2010
DeOndra Dixon, 2009
Quincy Jones, 2009
An Example of a MAJOR Breakthrough
As Global Champions for Down Syndrome Research we...

- Applaud the efforts of National Institutes of Health (NIH) to encourage research for Down syndrome by establishing the first Down syndrome patient research registry called DS-Connect®.
- Believe that Down syndrome, the leading cause of developmental delay in the world, deserves more research funding to explain why people with Down syndrome have a different ‘disease spectrum’ whereby they are highly protected from some diseases like certain cancers, stroke, and heart attack and are highly susceptible to other diseases such as Alzheimer’s disease and immune system disorders.
- Urge the White House, Congress, and NIH to make Down syndrome research funding a national priority so that we can discover therapies and cures to major diseases that could be life-saving to people with Down syndrome and millions of others suffering from the same life-threatening diseases.
On October 25, 2017, Global hosted the first-ever Congressional hearing on Down syndrome

“Down Syndrome: Update on the State of the Science & Potential for Discoveries Across Other Major Diseases”

Call to action for increased funding from the National Institutes of Health on Down syndrome research
Frank Stephens testifies Before Congress ... over 100M views resulting in a historic 71% increase of NIH’s Down syndrome research budget from $35mil in FY2017 • to $60 mil in FY2018 • to $80mil in FY2019
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<th>MS Research Funding (Dollars in Millions)</th>
<th>Autism Research Funding (Dollars in Millions)</th>
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INCLUDE (IN)vestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (E) Project Research Plan www.nih.gov/include-project

“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.”
Elongate life and improve health outcomes and quality of life for people with Down syndrome

- Assist to ensure the $77-$83M is reached for the FY2019 Down syndrome research budget at the NIH
- Assist to ensure that the FY2020 budget is at least $98M
- Assist to ensure annual increases and “never to have another year where there is less or flat funding...” using Report Language and Educational Outreach
- Sign up for NIH’s DSConnects patient registry and Global’s petitions
- Help GLOBAL be a “Watch Dog” for Down Syndrome Research and Medical Care Funding
- **Explore Centers of Excellence for Down Syndrome as a mechanism to ensure NIH Down syndrome research translates to actual patients/people with Down syndrome**
Become a Global Advocacy Champion!!

What you need to do

- Sign up! advocacy@globaldownsyndrome.org
- Petition or write to your Senators and Congressional Representatives and meet them
- Petition or write to the National Institutes of Health and other funding organizations that can help people with Down syndrome
- Drive/fly to Washington DC with us to meet government officials
- Like our social media, send to your network AND post your own advocacy social media

Can you do this?

- Becoming an advocate takes time and effort.
- How much time do you have?
- Can you do something once a week? Once a month? Once every three months? Once a year? ALL EFFORTS ARE IMPORTANT!
- Commit to and stick to a plan...

Become a Global Advocacy Champion!!

- You will make a difference and get funding for people with Down syndrome!
- You will be featured in Global’s award-winning Down Syndrome World Magazine!
THANK YOU from our GLOBAL ADVOCACY CHAMPIONS!

“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
Thank you for coming!

Special thanks to our sponsors.

GLOBAL DOWN SYNDROME FOUNDATION

PhRMA

RESEARCH • PROGRESS • HOPE

NATIONAL DOWN SYNDROME CONGRESS