Quarterly Webinar Series

Self-Advocates Win Landmark Federal Funding for Research: Join Global - Join the Movement

Michelle Sie Whitten, Co-Founder President & CEO
Kevin Brennan, Principal, Faegre Baker Daniels Consulting

Wednesday, May 1, 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
An Intro to Michelle

I am:

- **first and foremost a Mom! with...**
  - one awesome husband, Tom
  - two terrific kids, Sophia and Patrick
  - Sophia happens to have Down syndrome

- **first generation Italian-Chinese American**
  - My mother is from Italy and my father is from China - they met in NJ of course!
  - I am one of five kids and I was lucky enough to attend Tufts, Harvard and Peking Universities

- **a cable baby**
  - My dad worked in aerospace then became a cable TV pioneer - the father of “digital compression,” the founder of Starz/Encore channels and more
  - I worked in Asia in cable TV for 15 years!
  - We lobbied foreign governments for participation in cable TV and programming ownership

- **the founder and Pres/CEO of Global**
  - Global has a focus on research & medical care - including government advocacy for this area
Government Affairs Team

- **Faegre Baker Daniels**
  - 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>
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<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>
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The >300,000 Americans with trisomy 21 may hold the key to major medical conditions.
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!
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
Who are we? Why are we unique?

- **Global is a relative Newcomer!**
  - One of many national and international organizations

- **Our Primary Focus is Medical Care and Research!**
  **To this end we:**
  - Established and co-funded the first and only academic home for Down syndrome medical care and research
  - Lead government advocacy for medical care and research benefitting people with Down syndrome
  - Co-founded the T21 Research Society and the NIH DS Working Group
  - Are the largest funder of Down syndrome medical care and research after the NIH

- **We are Dedicated to BUILDING CAPACITY and a MORE STABLE Foundation!**
  - Global Membership Grants Program - Education and Employment Initiative
  - Global-NDSC Joint Medical Care & Research Roundtable and Prenatal Testing Pamphlet
  - Medical Care Guidelines for Adults with Down Syndrome

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Wednesday, May 1st, 2019

2019 Global Webinar Series
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

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<th>Mental Wellness</th>
<th>School Age/Education</th>
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<tr>
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<td>Infant</td>
<td>ENT</td>
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<tr>
<td>Telemedicine</td>
<td>Feeding &amp; Swallowing</td>
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Recent Publication's from the Sie Center:

1. Clinical Characteristics of Dysphagia in Children with Down Syndrome
2. Contributions to Racial Disparity in Mortality among Children with Down Syndrome
3. Understanding Hearing and Hearing Loss in Children with Down Syndrome
4. ENT/Audiology/Down Syndrome Database
5. Behavioral Characteristics of Individuals with Down Syndrome
6. Pediatric Comorbidities and Medical Complications Identified in Children with Down Syndrome

Publish the Prenatal Testing Pamphlet About Down Syndrome

- with the NDSC
- 100K distribution in its first year
- 3K distribution steady state
- Translated into Spanish & Icelandic
- Free downloads and free print
Medical Care Guidelines for Adults with Down Syndrome

- Recruited ECRI and 11 expert DS clinicians as authors and co-authors; Assisted to recruit 16 volunteer medical expert volunteers for each topic
- Finalized 9 topics for these initial guidelines
  1. Cardiac Metabolism
  2. Muscular Skeletal
  3. Thyroid-Immunology
  4. Bone Density
  5. Metabolic Disorders
  6. Behavior/Mental Health
  7. Dementia
  8. GI-Immune-Special Diets
  9. Obesity-Lifestyle Activity-Special Diets
- Collectively wrote and finalized 20 critical questions—key indicators of health for adults with Down syndrome
- ECRI reviewed hundreds of thousands of publications and vetted the small qualifying work for best practices and evidence associated with the 20 critical questions
- DRAFT summaries were drafted, consensus made and now being finalized
From Global’s Website
Dedicated to collecting detailed info on DS clinics across the U.S.

The Jane and Richard Thomas Center for Down Syndrome – Cincinnati

Affiliation:
Cincinnati Children’s Hospital Medical Center in the Division of Developmental and Behavioral Pediatrics

Summary:
Today, more than ever, families of children with Down syndrome can expect plan for a bright and productive future. The Jane and Richard Thomas Center offers an innovative approach to care. We aim to ensure the optimal health, developmental status, social-emotional functioning and adjustment of children with Down syndrome and their families now and in the future through:
- Structured evaluations and ongoing monitoring
- Individualized treatment planning based on best practices and standard of care
- Care coordination, support, and assistance throughout childhood to adulthood
- Education and advocacy
- Transition planning

The Thomas Center for Down Syndrome Services is located in the Division of Developmental and Behavioral Pediatrics and provides ongoing support and individualized therapies to help you and your child at home, in school, and in the community.

Ages Served:
Birth to adulthood

Hours and Days of Operation:
Monday – Friday 8 AM – 5 PM

Address:
3333 Burnet Ave, Cincinnati, OH 45229

Website:
https://www.cincinnatichildrens.org/services/down-syndrome

Email:
ThomasCenter@cchmc.org

Appointments:
513-636-4611

General Phone Number:
513-636-4611

Clinical Director:
Dr. Susan Wiley, MD

Services provided:

- Family Practitioner
- Psychiatrist
- Neuropsychologist
- Registered Dietician
- Physical Therapist
- Occupational Therapist
- Speech Language Pathologist
- Audiologist
- Social Worker

Other Services Provided:
Care coordination; Transition care for adolescents and adults to community care; Autism specialty; Board Certified Pediatrician in Developmental and Behavioral Pediatrics

Year Established:
The Down syndrome clinic at Cincinnati Children’s Hospital was established 1964 under the direction of Dr. Bonnie Patterson, MD. In 2001, thanks to the generosity of the Thomas Family, we expanded services and became “The Jane and Richard Thomas Center for Down Syndrome.”

Patients with Down Syndrome Seen Annually:
400+ individual patients served annually

Length of Waitlist:
Varied dependent upon appointment type

Medicaid Accepted?
Yes

Insurance accepted?
Yes

States in orange have at least one Down syndrome medical care center, while states in brown currently have none.
Global Down Syndrome Foundation: GROUNDBREAKING RESEARCH
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
Global - Proud of Our Accomplishments
40 Labs, 200+ Scientists Working on DS Research

Alzheimer’s Disease
- Bettcher
- 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

Wednesday, May 1st, 2019
The largest, most detailed study of the human population with Down syndrome

Employing the most advanced technology in precision personalized medicine to understand the multiple effects of Down syndrome

Goal - 1,000 people with Down syndrome and 500 typical “controls”; As of today, more than 500 volunteers have participated

Creating a biobank of samples from people with Down syndrome

- Will be able to find similarities and cohorts where you previously only had a single case study

Accessible for researchers and clinicians who have limited or no access to people with Down syndrome

Improving the lines of communication between practitioners and researchers
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.
EDUCATION & OUTREACH

- Largest Single Fundraiser in the world for Down Syndrome, *Be Beautiful Be Yourself Fashion Show*
- Award-winning magazine, *Down Syndrome World™*
- Life Skills & Health & Wellness Programs reaching 12K+ individuals with Down syndrome
- Quarterly webinars
- Uganda, Iceland, and Albania projects
- Research & Medical Care Roundtable at NDSC workshops and conferences
THE PROBLEM & GLOBAL’S LEADERSHIP TO SOLVE THE PROBLEM
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.
Down syndrome offers research opportunities across many of the 27 Institutes and Centers

- Significantly elevated risk for early-onset Alzheimer’s
- Much lower risk of stroke
- Much greater risk of diabetes
- High rate of dermatological disorders and arthritis
- Unique pattern of immune dysregulation
- ~30% experience mental illnesses such as depression or OCD
- >60% have vision problems
- >70% have hearing problems
- Protected from solid tumor cancers and greater risk for blood cancers
- Lower risk of heart disease and higher risk of congenital heart defects
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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).
Global’s Government Advocacy Goals

Legislation and Funding

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 President
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

The Sie Family Research Summit, from left to right: First row: Betsy Hoffman, John J. Sie, Tom Cech, Leslie Leinwand, Michelle Sie Whitten, John Sladek; Second row: David Braddock, Hans Lehrach, Mike Yarus, Larry Gold, Enid Ablowitz, Roger Reeves; Third row: Bill Strauss, Katheleen Gardiner, Mary Lou Oster-Granite; Top row: Michael Allshouse, David Solenger
Team Background

- Kevin Brennan
  - Arthritis Foundation
  - Amgen
  - Congressional Staff

- Client Representation
  - Patient Advocacy Groups
  - Biopharmaceutical & Diagnostic Companies
  - Digital Therapeutics
Background on 116th Congress

- Mid-Term Election Impact
- House and Senate Leadership
- Key Committees
- Global Legislative Agenda
2018 Election: Democrats Retake the House

U.S. House Election Results 2018

235
Democrats

Gained 40 seats
58,043,373 votes (52.5%)

1
Undecided

218 FOR CONTROL

199
Republicans

Lost 40 seats
50,595,506 votes (45.8%)

Key Races

80 Total

Dem. favored

Tossup

Rep. favored

Source: National Journal

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2018 Election: GOP Expands Senate Majority

U.S. Senate Election Results 2018

47 Democrats
23 Democrats not up for election
Lost 2 seats
53,085,728 votes (59.3%) 53

53 Republicans
42 Republicans not up for election
Gained 2 seats
34,987,109 votes (39.1%) 50

Key States
13 Total
Dem. favored
STATE LEADER MARGIN
Minn. Smith
W.Va. Manchin
Tossup
STATE LEADER MARGIN
Ariz. Sinema
Nev. Rosen
Mont. Tester
N.J. Menendez
Fla. Scott
Ind. Braun
Mo. Hawley
Tenn. Blackburn
Tex. Cruz

Rep. favored
STATE LEADER MARGIN
N.D. Grimmer
Miss. Hyde-Smith

1 Special election

Wednesday, May 1st, 2019
House and Senate Democratic Leadership

Speaker of the House
Nancy Pelosi (D-CA)

Democratic Leader
Chuck Schumer (D-NY)

House Majority Leader
Steny Hoyer (D-MD)

Democratic Whip
Dick Durbin (D-IL)
Key Senate Healthcare Committees

- Appropriations Committee
  - Draft Annual Federal Spending Bills

- Budget Committee
  - Write Annual Budget & Provide Reconciliation Instructions

- Finance Committee
  - Draft Tax Bills and Oversee Entitlement Spending (Medicare/Medicaid)

- Health, Education, Labor and Pensions (HELP) Committee
  - Authorize New Health Programs & Modify Current Programs (FDA/CDC)
Key House Healthcare Committees

- **Appropriations Committee**
  - Draft Annual Federal Spending Bills

- **Budget Committee**
  - Write Annual Budget & Provide Reconciliation Instructions

- **Energy and Commerce Committee**
  - Oversee Medicaid & Medicare
  - Authorize New Health Programs & Modify Current Programs (FDA/CDC)

- **Ways and Means Committee**
  - Draft Tax Bills and Oversee Entitlement Spending (Medicaid, Medicare & Social Security)
Senate Appropriations Committee Leadership

Appropriations Committee Chair
Richard Shelby (R-AL)

Appropriations Committee Ranking Democrat
Patrick Leahy (D-VT)

Approps. Labor HHS Sub. Chair
Roy Blunt (R-MO)

Approps. Labor HHS Sub. Ranking Democrat
Patty Murray (D-WA)
House Appropriations Committee Leadership

Appropriations Committee
Chair
Nita Lowey (D-NY)

Appropriations
Ranking Republican
Kay Granger (R-TX)

Approps. Labor HHS Sub
Chair
Rosa DeLauro (D-CT)

Approps. Labor HHS Sub
Ranking Republican
Tom Cole (R, OK)
Congressional Down Syndrome Caucus

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<th>Co-Chair</th>
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<td>Cathy McMorris Rodgers</td>
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<tr>
<td>Robert Casey</td>
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<td>Seth Moulton</td>
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<td>Stephanie Murphy</td>
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Launch of National Institutes of Health INCLUDE Initiative

Finalize FY2019 Down Syndrome Research Funding Level

Advocate for Down Syndrome Research Funding Increase as Part of FY20 Labor HHS Appropriations Legislation
President Delivers State of the Union - Feb 5th

White House Submits FY20 Budget to Congress - March 11th

NIH Director Collins Testifies Before Congress on FY20 Budget
  Frank Stephens Attended & Mentioned in House Hearing - April 5th
  Senate Hearing - April 12th

House Labor HHS Subcommittee Marked-Up Bill - May 30th
  House Appropriations Committee Mark-Up - May 8th

Senate Appropriations Committee Action Expected Soon

Next Steps on House and Senate Bills

New Fiscal Year Begins Oct 1
Why We Will Succeed!

- The MISSION of Global!
  - Leadership under Michelle Whitten, Dr. Espinosa and the entire team!
  - The Science, Medical Care, Outreach

- 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
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
There is a population explosion of people with Down syndrome in the U.S. that requires dramatically **more** funding not less

- Population - is estimated between 250,000 and 430,000
- Live Births - have increased to 1 in 691 today from 1 in 1,000 in 2002
- Lifespan - has more than doubled to 60 years from 28 years in the 1980s
- A Mini Population Explosion - will happen over the next several decades due to increased live births and lifespan
- Societal Trends - include a small but growing number of people with Down syndrome participating in college programs, choosing to get married, and living independently or semi-independently

There is a “eugenics framework” in countries like Iceland and Denmark...
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...
NIH & Congressional Meetings
- Global was the first to highlight the co-occurrence of Alzheimer’s disease in the Down syndrome (DS) population AND diseases people with DS are protected against
- 2004/2006 Dr. Elias A. Zerhouni (then director of the NIH) provided Global with the Disparity Funding #s for Down syndrome research at the NIH; Linda Crnic organizes a “State of the Union” for DS Research in DC

REPORT LANGUAGE & BRIEFINGS
- Since 2005 powerful report language inquiring into the disparity of NIH funding for Down syndrome research AND highlighting therapeutic leverage
- Briefings on DS and Alzheimer’s disease, Cancer, Research & Medical Care

FIRST DOWN SYNDROME CONFERENCE AT NIH
- (Dec 2010) NIH and Global co-hosted the first Down Syndrome Conference in NIH history that led to the creation of the DS-Connect patient registry
- Global’s investment in research was the catalyst for Patrick Kennedy and Pete Sessions to start the Congressional Down Syndrome Caucus (Task Force)
- Organized two national workshops with the national Alzheimer’s Association
Who 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
| 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         | 82. | KIIDS                          |
| 56. | Down Syndrome Network of Montgomery County | 83. | Little Leaf Learning Center     |
| 57. | Down Syndrome Network of Northern Nevada  | 84. | LuMind Research Down Syndrome Foundation |
| 58. | Down Syndrome of Louisville               | 85. | Madison Area Down Syndrome Society |
| 59. | Down Syndrome Partnership of North Texas  | 86. | Miami Valley Down Syndrome Association |
| 60. | Down Syndrome Society of Mobile County    | 87. | National Association for Down Syndrome |
| 62. | Downside Up, Inc                          | 89. | Northern Colorado Down Syndrome Association |
| 63. | East Texas Down Syndrome Group            | 90. | Ollie Webb Center, Inc.         |
| 64. | Eastern Idaho Down Syndrome Family Connect| 91. | Piedmont Down Syndrome Support Network |
| 65. | Eastern Pennsylvania Down Syndrome Center | 92. | Public Foundation of Parents of Children with Down Syndrome |
| 67. | Family Connection of South Carolina       | 94. | Rio Grande Down Syndrome Network |
| 68. | Foundation Ban Papia Aruba                | 95. | Rio Grande Valley Down Syndrome Association |
| 69. | Fun Coast Down Syndrome Association       | 96. | Rock the 21                     |
| 70. | Fundacion John Langdon Down A.C.          | 97. | Rosina Nanayakkara Charitable Trust Fund |
| 71. | Garrett's Fight Foundation                | 98. | Sharing Down Syndrome Arizona Inc |
| 72. | GiGi’s Playhouse Annapolis                | 99. | Southern Arizona Network for Down Syndrome |
| 73. | GiGi’s Playhouse                          | 100. | Sustainable Action Against Disaster |
| 74. | GiGi’s Playhouse El Paso                  | 101. | The Arc Down Syndrome New Mexico Fund |
| 75. | Gigi's Playhouse Milwaukee                | 102. | The Cedars of Marin             |
| 76. | Gold Coast Down Syndrome Organization     | 103. | The Up Side of Downs of Northeast Ohio |
| 77. | GraceSigns                                 | 104. | Triangle Down Syndrome Network  |
| 78. | Grays Peak Speech Services, LLC           | 105. | Wellspring Community            |
| 79. | International Down Syndrome Coalition     | 106. | Wisconsin Upside Down           |
| 80. | International Mosaic Down Syndrome Association | 107. | Yellowstone County's 'Extra' Special Kids (YES Kids) |
| 81. | Kern Down Syndrome Network                |
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 $77mil in FY2019
WATCH CLIP: 2017 CHAIRMAN TOM COLE (R-OK)
Congressman from Oklahoma, Ranking Member Labor, Health and Human Services, Education, and Related Agencies

WATCH CLIP: 2017 RANKING MEMBER ROSA DELAUNO (D-CT)
Congresswoman from Connecticut, Chairwoman Labor, Health and Human Services, Education, and Related Agencies

WATCH CLIP: Frank Stephens
Quincy Jones Advocate, Global Down Syndrome Foundation

WATCH CLIP: Michelle Sie Whitten
President & CEO Global Down Syndrome Foundation
Executive Director Anna & John J. Sie Foundation

WATCH CLIP: Joaquín Espinosa, PhD
Professor of Pharmacology, University of Colorado Denver School of Medicine, CeLead, Molecular Oncology Program and University of Colorado Cancer Center, Executive Director, Linda Crnic Institute for Down Syndrome

WATCH CLIP: Cathy McMorris Rodgers (R-WA)
Congresswoman from Washington, House Republican Conference Chair

WATCH CLIP: Bill Mobley, PhD
Executive Director, Down Syndrome Center for Research and Treatment, and Florence Riford Chair of Alzheimer’s Disease Research, UC San Diego

Watch the whole hearing!
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<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>
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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.”
YOU can make a difference in helping us elongate life and improve quality of life

JOIN GLOBAL, JOIN THE MOVEMENT!
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
How You Can Help!

- Sign Up! Become a member of Global
- Sign a petition and write letters for Global’s advocacy efforts
- Join Global’s NEW Advocacy Council or become a Global Advocacy Champion
- Join Global’s Research Council to fund life saving research at the Crnic Institute

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.

~ Martin Luther King Jr.
Become a Global Advocacy Champion!!

- **What you need to do**
  - Sign up! [advocacy@globaldownsyndrome.org](mailto: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