National Down Syndrome Society

21st Century Down Syndrome Research & Healthcare Symposium
Linking Research, Policy and Practice

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Vice President, Advocacy & Affiliate Relations
National Down Syndrome Society
Today’s Presentation: 
Down Syndrome Advocacy, Action & System Change

• **Why Advocate** – Does it make a difference?

• **NDSS DC** – What do we do?

• **NDSS federal legislative agenda and priorities**

• **Down syndrome research policy landscape**

• **How to advocate and get involved in our efforts at the national, state, and local levels**
Setting the Stage for Today

• How many of you...
  – Know who your Members of Congress are?
  – Have picked up the phone to call an elected official?
  – Written a member of Congress about an issue you care about?
  – Met with an elected official or attended the NDSS Buddy Walk on Washington?

• Why is this important? Does it make a difference?
  – You are a constituent
  – You are a voter
  – Our laws are outdated – systems change!
  – Legislators have the ability to put “our ideas” into action

• Met my friend, John Anton...
Why We Are Here?

Determination Trumps Down Syndrome

*No Limits for John Anton*

UPDATED 11:29 AM EDT Jun 28, 2012
What Does NDSS Do in DC?
Work with Congress and federal agencies to develop and improve laws, regulations and other policies

Train and educate parents, self-advocates and others to advocate on the local, state and national levels

Organize and participate in coalitions of national disability organizations

Lead national DS advocacy program
The mission of the Congressional Down Syndrome Caucus is to educate members of Congress and their staff about Down syndrome. The Caucus will support legislative activities that would improve Down syndrome research, education and treatment and promote public policies that would enhance the quality of life for those with Down syndrome.

**Ds Caucus Co-Chairs:**
- [Rep. Cathy McMorris Rodgers (R-WA)](mailto:rep.cathy.mcmorrisrodgers@mail.house.gov)
- [Rep. Pete Sessions (R-TX)](mailto:rep.petesessions@mail.house.gov)
- [Rep. Chris Van Hollen (D-MD)](mailto:rep.chrisvanhollen@mail.house.gov)
- [Del. Eleanor Holmes Norton (D-DC)](mailto:del.eleanorholmesnorton@mail.house.gov)
NDSS Legislative Agenda

- The legislative and policy priorities span the life experience of individuals with Down syndrome from birth through adulthood and range in issue from healthcare to asset development.

- These priorities have been shaped by self-advocates, families, affiliate leaders and others under the direction of the NDSS Board of Directors and the National Governmental Affairs Committee (NGAC).

- Improving Health Outcomes and Quality of Life for People with Ds
- Improving Education Opportunities for People with Ds
- Creating and Economic Future for Individuals with Ds
- Increasing Opportunities for Adults with Ds
Improving Health Outcomes & Quality of Life for People with Down Syndrome
- Down Syndrome Research Funding/Appropriations
- Legislation
  - Trisomy 21 Research Act Package
  - Kids Research First Act
- Congressional education and awareness of DS research needs
- Influencing Administration on DS research priorities

Improving Education Opportunities for People with Down Syndrome
- Elementary & Secondary Education Act (ESEA) reauthorization
- Preventing Restraints and Seclusion in Schools
- Postsecondary Education – Higher Education Act reauthorization
- Individuals with Disabilities Education Act (IDEA) reauthorization

Increasing Opportunities for Adults with Down Syndrome
- Transition Toward Excellence in Achievement and Mobility (TEAM) Act

Creating an Economic Future for Individuals with Down Syndrome
- Achieving a Better Life Experience (ABLE Act)
- 14C/Eliminating subminimum wage
- Workforce Investment Act (WIA) reauthorization

NDSS Legislative Agenda
• **ABLE: a New Tool for Individuals and Families**
  - Similar to Section 529 education savings plans for their college-bound children
  - That is easier to establish and less costly than typical special needs trusts
  - That will allow their adult children with disabilities to manage their own (or some of their own) funds

• Individuals with disabilities have been seeking a way to save that allows self-management of funds

• Traditional special needs trusts have not worked for all

• The ABLE Act is intended to offer another tool for individuals and families to consider in their planning
ABLE Act Congressional Background

- The bill has **overwhelming bipartisan, bicameral support**
  - 37 Senate cosponsors
  - 172 House cosponsors

- Bill is led by a bipartisan, bicameral set of Congressional champions, including:
  - Senator Robert Casey, Jr., (D-PA) and Senator Richard Burr (R-NC)
  - Congressman Ander Crenshaw (R-FL), Congressman Chris Van Hollen (D-MD), and Congresswoman Cathy McMorris Rodgers (R-WA)

- The bill has been scored
When it comes to improving the health and quality of life for people with Down syndrome, there are two important aspects that NDSS strives to address legislatively:

- Creating and maximizing research opportunities for Down syndrome
- Improving the quality of healthcare provided to people with Down syndrome
How Research on Down Syndrome Impacts Me
- David Egan, from a self-advocate perspective

• **Dispel Myths and Stereotypes** about who I am and my abilities

• Provide me and others with more informed and better **Health Care**

• **Prevent Alzheimer** or other conditions that limit my ability to contribute

• Improve my **Quality of Life** and that of more than 400,000 people living with Down syndrome in the United States and our families

• Research results will **help**:  
  – **Health Care providers** to respond to our special needs  
  – **Educators** to maximize our potential  
  – **Employers** to hire us  
  – Extend our **lifespan**  
  – **Help others** – Down syndrome could solve other medical issues
Congressional Action & Direction

Educating Members of Congress and Congressional Staff on our key research priorities and issues...
<table>
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<tr>
<th>Research/Disease Areas (Dollars in millions and rounded)</th>
<th>FY 2009Actual (Non-ARRA)</th>
<th>FY 2009Actual (ARRA)</th>
<th>FY 2010Actual (Non-ARRA)</th>
<th>FY 2010Actual (ARRA) 10/</th>
<th>FY 2011Actual</th>
<th>FY 2012Actual</th>
<th>FY 2013Estimated</th>
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<td>$79</td>
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<td>$4</td>
<td>$29</td>
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Down Syndrome Funding

• Challenges to funding levels
  – Sequestration – blunt instrument; 10 years
  – Private funding (between $10 - $15 million)
  – Lack of Down syndrome infrastructure (i.e., registry, biobank, clinical trials network)
  – Advocacy– attend Buddy Walk on Washington, join the NDSS DS-Ambassador program

• Opportunities
  – NCATS, CAN, other $ outside of NICHD – we need to take advantage of these programs!
    • NCATS: $639 million
    • NICHD: $170 million
  – Advocacy!
  – Down syndrome and associated conditions/co-morbidities (i.e., Alzheimer’s, Leukemia, Sleep apnea, etc.)
  – Large sums of monies for Alzheimer’s
  – Launch of Down syndrome registry in 2013
**Down Syndrome Research Legislation**

**Kids First Research Act**
- This legislation will expand pediatric research at the National Institutes of Health by $19 million. The bill does this by prioritizing resources for research for children with Down syndrome which are currently underrepresented in the NIH budget process.
- This bill will do this by re-directing federal dollars from presidential campaigns and party conventions.

**Trisomy 21 Research Package**
- The *Trisomy 21 Research Resource Act* would expand and intensify Down syndrome programs of the NIH and the Centers for Disease Control and Prevention (CDC) to create an infrastructure of Down syndrome tools, including a Down syndrome research database and Down syndrome biobank. The bill does not require any additional cost (i.e., appropriations) to the federal government. These research tools will further strengthen the research being conducted on Down syndrome across the country and better equip our research community with the tools necessary to facilitate their research.

- The *Trisomy 21 Research Centers of Excellence Act* would require the Director of the NIH to expand and intensify NIH programs with respect to research and related activities concerning Down syndrome. Additionally, the bill requires the Director of NIH to publish a research plan on Down syndrome and update it every five years. Moreover, the legislation would require NIH to award grants and contracts to public or nonprofit private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for centers of excellence regarding translational research on Down syndrome.
Alzheimer’s & Down Syndrome – The Administration

• Administration
  – Engaging the US Dept. of Health & Human Services (HHS) Alzheimer’s Advisory Council
  – Tracking the implementation of the National Alzheimer’s Plan - $100 Million for research, awareness, education and outreach, and caregiver support (FY 13 funding)
  – White House Brain Initiative - $100 Million (new $!)
  – Down Syndrome NIH Consortium
Down Syndrome & Alzheimer’s – Congress & Stakeholders

• **Congress**
  – Educating Members of Congress on scientific links
    • Congressional Down Syndrome Caucus
    • Alzheimer’s Task Force (bicameral)
  – Supporting legislation like HOPE Act, SPRINT Act, etc.
  – Submitted appropriations report language directly funding priorities to NIH
  – Hosting Congressional briefs (July 2013)

• **Coalitions**
  – Leaders Engaged in Alzheimer’s Disease (LEAD)
  – National Task Group (NTG)
  – Working with US Against Alzheimer’s and the Alzheimer’s Association
DS Infrastructure: If We Build It... They will Come!

• We need research tools:
  – Down Syndrome Registry
  – Down Syndrome Biobank
  – Down Syndrome Clinical Trials Network

• These research tools will:
  – Make it easier for patients to take part in clinical studies for new medications and other treatments for Down syndrome
  – Strengthen the research being conducted on Down syndrome across the country and better equip our research community with the tools necessary to facilitate their research
NDSS Down Syndrome Research Innovation & Discovery Fund (RIDF)

- RIDF will support research and clinical infrastructure needs for the Down syndrome scientific and research community by funding strategic priorities and initiatives that help advance the biomedical research field in Down syndrome.

- The goal of the RIDF is to improve the health outcomes, increase the quality and access to care, and develop new therapies and treatments for all people with Down syndrome.

- Governed by a set of advisors from research and scientific field.

- Launching in fall of 2013.
Examples of RIDF Areas

• **Establishing a National Down Syndrome Research & Clinical Trial Network:** Provide a vehicle in which NDSS, other national Down syndrome organizations, biomedical and clinical researchers, and local service providers can cooperatively develop the infrastructure for sustainable and continuous multi-institutional and state-of-the-art trials to develop, validate, refine, and deliver new treatments and therapies to people with Down syndrome.

• **Expanding the Congressional and Down Syndrome Affiliate Awareness of Key Research and Clinical Needs:** Support Down syndrome research advocacy efforts that highlight developments in the area of Down syndrome research and missing gaps

• **Funding Critical Down Syndrome Research Needs:** Establish funding mechanisms focused on translational research and public-private partnerships for researchers to spur innovation and research infrastructure for Down syndrome

• **Establishing a Formal Partnership with the Alzheimer’s Community:** Develop a formalized partnership with the Alzheimer’s community to continue engagement around the National Alzheimer’s Plan (NAPA), leverage funding opportunities, both public and private, for Alzheimer’s in Down syndrome, and educate and build additional support for this initiative among policymakers.
NDSS Advocacy Program

DS Government Affairs Committees

NDSS DS-Ambassadors (50 states)
NDSS Federal & State Advocacy

NDSS DS-Ambassador Program

NDSS GAC Program
Overall NDSS DS-Ambassador Program

Goals & Objectives

• Strengthen and organize the Down syndrome community grassroots network across the US

• Be more effective on Capitol Hill by building relationships in Washington, DC with Members of Congress and staff (voters count!)

• Engage more affiliates and advocates to provide valued input and feedback to NDSS on our advocacy efforts, programs, and key initiatives

• Encourage more advocates and self-advocates to become advocates for the Down syndrome community

• Grow the DS-Ambassador to 535 by 2014 (one for every single Member of Congress)... think about what we can do as the Down syndrome community!

"I am an NDSS Ambassador because I want people with Down syndrome, like my daughter, Rachel, to live 'real lives.' I value the great honor, privilege and responsibility of speaking with and on behalf of thousands of individuals with Down syndrome who need legislation to help them to be able to live their dreams."
— Jawanda Mast, NDSS DS-Ambassador, KS
NDSS DS-Ambassador Program

- Your chance to make a difference in a focused, structured way

- Who can join? Anyone!
  - Self-advocates, Parents, Grandparents, Siblings, etc.

“\“I am an NDSS DS-Ambassador because I have taught my children that in this great country they have a voice. I want to be an example to my children, especially Kelly, who has Down syndrome, that they each have a voice to change things in Congress. It doesn’t matter what color or size or shape or cognitive delay, we all have a voice. We just need to use it! Kelly now knows that she has the power to speak for herself to make her life better and to better the lives of others with Down syndrome.”

- Robbin Lyons, NDSS DS-Ambassador, WI
NDSS DS-Ambassador Time Commitment

- DS-Ambassadors commit 1-2 hours per month to the program

- DS-Ambassadors participate in “Business Meetings” every other month
  - All conference calls and webinars will be recorded

- DS-Ambassador receive “Assignments” in the “off” months

- While it’s not an obligation, DS-Ambassadors are also encouraged to attend the annual Buddy Walk on Washington in Washington, DC where you have the opportunity to meet your legislators and advocate with NDSS

- From time to time, NDSS will ask our DS-Ambassadors to weigh in on NDSS programmatic and initiatives to garner feedback from across the country

“I'm an NDSS DS-Ambassador because I believe in grassroots legislative efforts and being a champion of change. As an NDSS DS-Ambassador, I work tirelessly to bridge the gap of inequality experienced by my son, Carsen, and many like him who are not readily afforded the same social, educational, economic opportunities as his typical developing peers.”

– Cliff Stout, NDSS DS-Ambassador, MD
Buddy Walk® on Washington

• An annual two-day advocacy experience that brings the Ds community together to advocate for public policies that impact the lives of people with Down syndrome and their families

• Advocates come face to face with Members of Congress and their staff on Capitol Hill to advance education, research and healthcare for people with Down syndrome

• Attendees will participate in at least two webinars and an interactive advocacy training, attend a celebration and advocacy awards dinner and spend a day on Capitol Hill

• The experience is perfectly suited for self-advocates, family members, professionals, affiliate leaders and members and anyone else who wants to make a difference for people with Down syndrome
NDSS GAC Program

What DS-GACs do?

- Focus on developments and setting priorities in state legislatures

- Work in collaboration with the NDSS Policy Center to promote and pass state legislation and to influence the design of regulation and other policy
  - *DS Model Legislation*

- Work with state disability organizations and coalitions on key issues and priorities

- Participate in conference calls every other month led by Policy Center with all GAC-Co-Chairs to discuss pressing federal and state policy issues and priorities, opportunity to discuss best practices

GAC State Network

- DS Coalition of California (DSCCA)
- COLORADO (CO GAC)
- Florida Coalition for the Education of Individuals with Developmental Disabilities (FL CEIDD)
- Indiana DS Center for Public Policy
- LaGADS
- Maryland Down syndrome Advocacy Coalition
- MA Down Syndrome Congress Legislative Action Committee
- MISSOURI (MO GAC)
- NEBRASKA (NE GAC)
- OKLAHOMA (OK GAC)
- NEW JERSEY (NJ GAC)
- Ohio DS Advocacy Network (ODAN)
- DS Policy Network of Tennessee (DSPNT)
- Texas Down Syndrome Advocacy Coalition (TDSAC)
- Virginia Down Syndrome Alliance (VDSA)
- Wisconsin Down Syndrome Advocacy Coalition
How Can You Make a Difference!

• Follow NDSS on Facebook, Twitter, Pinterest
• Subscribe to our NDSS e-newsletter (click here)
• Subscribe to our NDSS Advocacy Alerts (click here)
• Attend the Buddy Walk on Washington
• Become an NDSS DS-Ambassador
“Nobody can do it alone. Having consumers, parents and other advocates working together with a key legislator or two is the only way to pass a bill. Legislators help with the process, and the stakeholders provide the passion.”

— The Honorable State Representative Judy Ann Buffmire from Salt Lake City
Utah State Legislature since 1992
Contact Me!

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sweir@ndss.org
What is advocacy?

Advocates ...

• Build relationships with others

• Plead the cause on behalf of others / are persuasive

• Give information to legislators, elected officials, and decision-makers in the hope that leaders will be influenced to support those viewpoints

• Identify problems that need to be addressed, contact legislators, and encourage them to guide the bill through the legislative process
Step 1: Know how decisions are made / bills become law

A bill is simply an idea that someone or a group of people would like to see become a law.
Step 2: Get acquainted with your Elected Officials

Do your homework online by reviewing their website:

- http://www.senate.gov

- **Political Life**
  - Who is this person as a representative? Geographic and demographic area they represent? Term in office? Platform? Major issues and concerns? Voting record? Committee assignments? Staff members?

- **Personal Life**
  - Who is this person? Spouse? Children?
  - Relate this information to our issues

Do your homework in person by meeting your representative to introduce yourself and build relationships

- Building relationships!
- Invite reps to DS events
- Engage self-advocates
Step 3: Know & Study the Issue(s)

- Study NDSS website, legislative websites, etc.
  - What has been tried before?
  - What are both sides of the issue?

- Talk to others
  - Who is affected by the issue or the solution?
  - Where do your advocates stand?

- Develop your “pitch” or “elevator speech”
  - Connect it to the representative’s life
  - Connect it to your personal story
Step 4: Decide your method for advocacy

- Email, fax, or letter
- Telephone call
- Social media
- In-person meeting
Email, Fax, or Letter

• Send hand written notes

• Communicate in multiple ways...

• Include these parts in your one-page letter
  – Your name, address, and telephone number
  – The issue that concerns you (Why and how it affects you?)
    • Refer to the bill number
  – Action that you want the representative to take

• Other ideas to remember
  – Keep it short, focused, positive, polite, business-like
  – Avoid educational jargon
  – Proof your letter and write well
  – Don’t go overboard with your passion and zeal
Telephone Calls

• Phone calls are quick and effective

• Your previous nurtured relationship with your representative will pay dividends

• Include these parts in your phone conversation
  – Ask to speak to the representative or staffer
    • Probably will speak to receptionist or aide, who is tallying constituents’ votes for and against an issue
  – Your name, address, and telephone number
  – The issue that concerns you (Why and how it affects you?)
    • Refer to the bill number
  – The action that you want the representative to take
Social Media

• Most representatives have an active social media presence

• Social media is an effective way to reach a large group of people

• Follow similar rules to email and phone contact
  – Focus on the issue
  – Include information for follow-up
    • Two-way communication
    • Let others know how they can learn more
  – Present a balanced view
Blog! Tie the message to an advocacy goal/message, then “share it!”

Follow Your Elected Officials and tell them what you want!
In-Person Meeting

• Visit with your elected officials at his/her home office
  – home office, town hall meetings, community functions
  – Consider inviting them to attend Buddy Walks, Local events, etc.

• Schedule an appointment and inform the office about the reason for requesting the meeting
  – Most meetings last 15 to 20 minutes

• Before the meeting
  – Dress professionally
  – Arrive on time
  – Greet the receptionist
  – Sign the guest book and include a short message about the issue
  – Ask to speak to the representative or the aide in charge of the key issues
  – Identify yourself as a constituent.
In-Person Meeting (Cont.)

• **During the meeting**
  – Introduce yourself and exchange business cards
  – State the issue that concerns you (Why and how it affects you?)
    • Refer to the bill number
    • Be prepared to educate the representative
    • Speak from personal experience when possible
    • Prepare a one-page letter to guide your discussion
  – State the action that you want the representative to take... Make the “Ask”
  – Thank the representative or staffer

• **After the meeting**
  – Follow up with a phone call, email, or letter thanking the representative for meeting with you
  – Offer another personal visit for more information
  – Address additional concerns or provide more information
Step 5: Join a Coalition or Group!

- **Reasons to join a group**
  - Amplifies your voice
    - Power in #’s!
  
- **Keeps you informed via websites and social media**

- **Ways to join a group**
  - NDSS
  - Others

*We each hold a piece to the puzzle*