

Preparing for Capitol Hill

April 18, 2023



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Down Syndrome
Advocacy
Conference

Hello!



Anna Fedewa
Manager of Public Policy
NDSS



Kayla McKeon
Manager of Grassroots
Advocacy
NDSS

2023 Down Syndrome Advocacy Conference



Session Agenda

- Federal Government Basics Review
- What to Expect
- How to be Effective
- Preparing for Capitol Hill Breakout #1
- Social Media and Communications
- Panel – Advocacy Tips and Tricks
- Preparing for Capitol Hill Breakout #2
- Reminders
- Soapbox Presentation
- Conference Closing



Federal Government Basics Review

The Cycle of Advocacy



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Congress - Reminders

- Meeting with **two Senators** and **one Representative**
- Staff are just as important as Members
- The committee your Member sits on could be key!





What to Expect

Craig Blackburn and Chapman Bryant



Craig Blackburn

- National Down Syndrome Congress Board Member
- Member of the National Down Syndrome Congress Advocacy Coalition (NDAC)
- New Orleans Saints Equipment Team
- Board Member of Louisiana Special Olympics and Gigi's Playhouse



Chapman Bryant

- Policy and Advocacy Associate at the National Down Syndrome Congress
- Former U.S. Senate Staffer for Senator Roger F. Wicker (R-MS)

Syndrome Advocacy Conference



Anatomy of a Hill Meeting

- Locate the building and room of your meeting (on your Soapbox schedule)
- Be sure to account for time to go through security! Prohibited items:
 - Aerosols
 - Pointed objects (including pocket knives)
 - Mace and pepper spray
 - Weapons of any kind

Anatomy of a Hill Meeting

- Advocates arrive 5 minutes early and are greeted by Congressional staff
 - Say hello, who you are, and who you are meeting with



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Anatomy of a Hill Meeting

- Advocates are escorted to a meeting room (conference room, Member's office, staff office)



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Anatomy of a Hill Meeting

- Meeting begins
- Introductions
 - Round robin
 - Include your name, where you are from, and your connection to the Down syndrome community
 - Keep it BRIEF!
 - Allow the Member or staff to introduce themselves too

Anatomy of a Hill Meeting

- Content begins – plan ahead!
- “I’d like to talk to you about...”
 - State the issue
 - Share the name of the bill and what it does
 - Share 1 – 2 brief stories
 - Ask the Member or staff if they have any questions

Anatomy of a Hill Meeting

- Content continues – plan ahead!
- Repeat!
 - Prioritize issues that your group has a personal connection to/story to share
 - Be mindful of the time
 - Let Member/staff know that there are other issues you are leaving behind information on

Anatomy of a Hill Meeting

- Wrap-up
 - Thank the Member/staff for their time
 - Give them the leave-behind folder and self-advocate one-pagers
 - Take a picture!



Anatomy of a Hill Meeting

- After the meeting
 - Complete the post-meeting survey on the Soapbox mobile tool (more on this later!)
 - Upload your picture to the mobile tool (more on this later!)
 - Begin walking to and preparing for your next meeting OR head to the hospitality suite on the Hill

Other Considerations



- Advocates must attend **all** meetings on their schedules
- If you are running late, please call the office to let them know
- Locations, times, and even who you are meeting with can change – **be flexible**
- Time is valuable – **be mindful of the time**
- **Make sure you leave the right information behind!**

Day in the Life of an Advocate

- Plan your travel to Capitol Hill
- Understand the layout of Capitol Hill
- Identify which buildings your meetings will be in
- Identify lunch and snack options
- Locate the Hill hospitality suite



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Traveling to Capitol Hill

- Metro
 - Most cost-effective
 - Take the blue line toward Largo Town Center and exit at the Capitol South stop
 - Refer to the event program for more details
- Uber/Lyft
 - Starts at \$12, surge pricing may affect cost
 - Consider splitting with other advocates
- Taxi
 - Available outside the hotel



First Street, NW

New Jersey Ave., NE

 Union Station
(Red Line)

Delaware Ave., NE

Russell
(SR-xxx)

First Street, NE

Dirksen
(SD-xxx)

Hart
(SH-xxx)

Constitution Ave.

7.5 min

N
↑

U.S. Capitol

Senate

House

Capitol Visitor Center
(HVC-xxx) (SVC-xxx)

Group picture here!

Maryland Ave.

Supreme Court

East Capitol St.

Library of Congress
Jefferson

Independence Ave.

First Street, SW

Rayburn
(RHOB-2xxx)

South Capitol St., SE

Longworth
(LHOB)-1xxx)

New Jersey Ave., SE

Cannon
(CHOB-xxx)

First Street, SE

Library of Congress
Madison

Capitol South
(Orange/Silver/Blue Lines)

Important Locations

- Hill hospitality suite
- Dining available
 - Russel Senate Office Building
 - Dirksen Senate Office Building
 - Hart Senate Office Building
 - Capitol Visitor Center
 - Longworth House Office Building
 - Rayburn House Office Building



Melissa Silverman and Jawanda Mast



Melissa Silverman
Self-Advocate - Maryland
National Down Syndrome Advocacy Coalition
Maryland Down Syndrome Advocacy Coalition



Jawanda B. Mast
National Down Syndrome Congress
Grassroots Advocacy Manager

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How to be Effective

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Storytelling

- Compelling stories prompt action
- Stories should be **clear, concise, and actionable**
 - How does a Member or their staff translate YOUR experience into action?
 - *They* are experts on policy, *you* are the expert on the lived experience of the Down syndrome community



Share Your Story

Your story is your most powerful tool!

Compelling stories personalize issues and prompt Members of Congress and their staff to take action. Your story should be clear, concise, and actionable. Use this storytelling template to build your story.

Consider

Before you begin crafting your story, it is important to understand key details that impact the narrative.

- What issue are you advocating on?

- When is a time this issue personally affected you or your loved ones?

- What is your goal in sharing this story? How do you want Members of Congress and their staff to respond? What do you want them to feel compelled to do after hearing your story?

Create

Follow the prompts from this bank to craft an effective story.

Set the Scene

- "I'd like to tell you about a time when I was personally affected by...."
- "_____ is an issue I really care about."

Explain the Situation

- "What happened was..."
- "I care about this issue because..."
- "I am affected by this by..."

Share the Impact

- "This made me feel..."
- "This hurt me because..."
- "This helped me..."
- "This impacted be by..."

Make the "Ask"

- "I am asking you to cosponsor (bill name) because...."
- "I am asking you to support (bill name) because..."

Closing

- "Thank you for your consideration. I hope more people have access to..."
- "Thank you for your consideration. I hope no one has to go through..."

Example - Charlotte's Story

Issue: Charlotte Woodward Organ Transplant Discrimination Prevention Act

Charlotte's Story: Organ transplant discrimination prevention is an issue I care about. I care about this issue because I received a live-saving heart transplant over 11 years ago. This transplant saved my life and made me feel very grateful that my doctors respected my life and did not let my diagnosis stand in the way of the care I needed. I am asking you to cosponsor the Charlotte Woodward Organ Transplant Discrimination Prevention Act because it would help ensure that people with Down syndrome and other disabilities are not discriminated against in the organ transplant system. Thank you for your consideration. I hope that all people with disabilities have access to healthcare that does not discriminate against them solely because they have a disability.

With Us Not For Us



Senator Ben Cardin



Congressman Jamie Raskin



Maryland Governor Wes Moore

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Our Strongest Voices

- Our strongest voices come from **self-advocates**
- Plan – How can you center self-advocate voices and experiences in your meetings?
- Don't forget about self-advocate one-pagers!



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Name
Address
Email

My name is (name), and I am one of your constituents.

I am currently in school at (school). Insert text here about your school, what you enjoy, and what you are involved in.

AND/OR

I currently work at (job) (X number of hours a week). Insert text here about what you do at your job, and what impact it provides to your life.

AND/OR

Insert text here about your interests, hobbies, and goals for the future.

Please support the (Insert bill name and number here). This bill would (briefly describe what the bill would do).

Describe how this law would impact you and why you think it is important for your Member of Congress to support this bill.

Thank you for your consideration!
(Name)

Insert a photo or two of yourself here!

Melissa Silverman
12103 Long Lake Drive
Owings Mills, MD 21117
magicbym@comcast.net
410-356-8496

February 22, 2022

Dear Delegate White,

My name is Melissa Silverman, and I am one of nearly 7,500 Marylanders who have Down syndrome. I live in Owings Mills, Maryland with my parents.

I wanted to take this opportunity to introduce myself to you. I graduated from Franklin High School in 2001, earning an academic diploma. I then went to CCBC in the Single Step Program and earned the 90-hour childcare certification. For the past 18 years I have been working in childcare with children from 2 years old through elementary school age. Presently, I work for Caliday in the before and after school care at Franklin Elementary School.



As a member of the Maryland Down Syndrome Advocacy Coalition and the National Down Syndrome Congress, some of the issues that are most important to me are the ability to make my own choices and have control over what I want to do through the self-direction program. Also, I want affordable housing options and transportation options.



I am writing to ask that you give a favorable report out of committee for HB294 County Boards of Education - Due Process Proceedings for Children With Disabilities - Burden of Proof. This bill would level the playing field for families and students who disagree with their school system about an important decision regarding the placement of their child or special education services their child needs to be successful. This bill will simply require school systems to defend their position first if there is a disagreement about a student's program, placement or services that cannot be settled at the IEP table. Right now, only parents who can afford expensive attorneys and expert witnesses have any chance of winning and even then they hardly ever do. This system isn't fair.

As one of your constituents, I want to thank you for your time and consideration, and for all that you do to improve the lives of individuals with Down syndrome throughout the state of Maryland. We appreciate you!

Sincerely,

Melissa

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Questions

- Create space for Members and staff to ask questions
- Ask the Member/staff your own questions
 - The best way to engage an unengaged participant
 - “Are you hearing this from your state or district?”
 - “Has your office worked on anything similar to this?”

Questions

- You are not expected to know the answer to every question!
- “That’s a great question. I am not too sure what the answer is. I am going to let the national organizations know you asked and someone will follow up with you.”
- Put the question in the meeting follow-up survey

Advocating to Champions

- “I know this is something you/your boss is already a sponsor of. I want to thank you/them for your/their leadership!”



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Advocating to “Adversaries”

- No one is truly an adversary
- Avoid preconceived notions or biases
- This is an opportunity to turn “adversaries” into champions through education and connection!



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Prepare, Prepare, Prepare!

- Member's party
- Member's committee assignments and leadership positions
- Personal connections to Down syndrome/disability/any of the legislative priorities
- Is the Member already a sponsor of any of the legislative priorities?
 - Has their state passed state-level legislation on the issue?
- Is the Member part of the Congressional Task Force on Down syndrome?

Do Your Homework

- Congress.gov
- Member's website
- Member's social media pages



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Member Research

It is important to research the Member of Congress you are meeting with before your meeting. Knowing who your Member is, what they care about, and what they support can help you tailor your message and have the most effective meeting possible!

To find this information, utilize Congress.gov, the Member's website, Member's social media, and other online resources.

Basic Information

Member's Name: _____

Member's State: _____

Member's District (if applicable): _____

Member's Party: _____



Committees, Caucuses, and Leadership Positions

Committee Membership: _____

Caucus Membership: _____

Leadership Positions: _____

Legislative Priorities

Bill: _____ Sponsor? _____ State legislation? _____

Bill: _____ Sponsor? _____ State legislation? _____

Bill: _____ Sponsor? _____ State legislation? _____

Bill: _____ Sponsor? _____ State legislation? _____

Bill: _____ Sponsor? _____ State legislation? _____

Important Personal Information

(connection to Down syndrome/disability, issues they support, other important information)



Member Research

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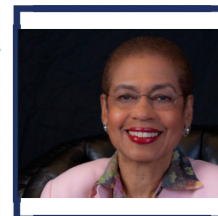
Basic Information

Member's Name: Congresswoman Eleanor Holmes Norton

Member's State: District of Columbia

Member's District (if applicable): At large

Member's Party: Democratic



Committees, Caucuses, and Leadership Positions

Committee Membership: Oversight & Accountability, Transportation & Infrastructure

Caucus Membership: Congressional Black Caucus, Congressional Task Force on Down Syndrome

Leadership Positions: Co-chair of CTFDS, RM of T&I Subco on Highways and Transit

Legislative Priorities

Bill: Charlotte Woodward Organ Transplant Sponsor? N State legislation? N/A

Bill: TCIEA Sponsor? N State legislation? N/A

Bill: NAPA Reauthorization Sponsor? N State legislation? N/A

Bill: INCLUDE Funding Sponsor? N State legislation? N/A

Bill: CTFDS Sponsor? Y State legislation? N/A

Important Personal Information

(connection to Down syndrome/disability, issues they support, other important information)

Congresswoman Norton has a daughter, Katherine (52), who has Down syndrome. She has been a champion for the disability community for many years including serving as a co-chair of the CTFDS in multiple Congresses. Focus issues include DC statehood, DC related workforce and environment issues, labor and wage issues, and issues relating to transportation and infrastructure. Congresswoman Norton has previously sponsored legislation in support of wage equity and would be a great addition to TCIEA.

Prepare, Prepare, Prepare!

- Creating a meeting “run of show”
 - What legislative priorities will we prioritize?
 - Who will share about each priority?
 - Which stories will be shared?
 - How will we center self-advocate voices and lived experiences?





Hill Meeting Run of Show

It is important to discuss and create the agenda for your meetings on Capitol Hill. This will help you facilitate the most effective meeting possible. Don't forget to review the run of show with all advocates who will be in the meeting and ensure that everyone feels confident in their assigned role!

Pre Meeting Logistics

Member: _____

Date: _____ Time: _____ Location: _____

Who you are meeting with: _____

Advocates attending: _____

Introductions

1) Advocates share:

- Name
- Where they are from
- Connection to the Down syndrome community

2) Member and/or staff introduce themselves

The Asks

You will likely only have time to discuss 2 – 3 legislative priorities but should have a plan for all five. Groups should plan for:

- Which advocates are responsible for each priority
- Which stories will be shared
- How self-advocate voices and experiences will be shared

1

Ask #1: _____

Advocate(s) responsible: _____

- State the issue
 - "We would like to speak to you about _____"
- Share bill details
 - "The bill is H.R. _____ or S. _____. The bill would help the Down syndrome community by _____"
- Share a story
 - "I'd like to tell you about a time when I was affected by _____"
- Take questions
 - "Do you have any questions for us about this issue?"

Ask #2: _____

Advocate(s) responsible: _____

- State the issue
 - "We would like to speak to you about _____"
- Share bill details
 - "The bill is H.R. _____ or S. _____. The bill would help the Down syndrome community by _____"
- Share a story
 - "I'd like to tell you about a time when I was affected by _____"
- Take questions
 - "Do you have any questions for us about this issue?"

2



Preparing for Capitol Hill Breakout #1

30 Minute Work Period

- Divide and conquer!
 - Member profiles
 - Meeting run of shows
 - Self-advocate one-pagers
 - Storytelling templates
- Questions?
 - Ask your state captains!



But first... leave behinds!

- Regional captains will drop them off!
- **One** for each House meeting and **one** for each Senate meeting
- Choose **one** person per meeting to be in charge of the leave behind
- Limited extras available



Social Media and Communications

Hello!



Michelle Sagan
Senior Manager of Communications
2023 Down Syndrome Advocacy Conference



General Info

- #DSAC2023
- Press release
- Storytelling
 - What is your "why"
- Personal and professional

ADVOCATE WITH ME AT THE



The Down Syndrome Advocacy Conference is an opportunity to advocate to Members of Congress on legislative priorities that impact the Down syndrome community. Learn more: www.ndss.org/dsac.



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Social Media

- Effective social media use (Do's)
 - Post, post, post!
 - Tag NDSS and partners
 - #DSAC2023
- Don'ts
 - Tag campaigns
 - Negativity
 - Use partisan language
 - Endorse a candidate or campaign

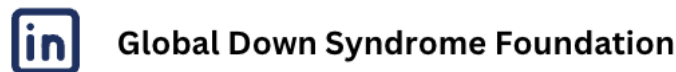




Follow NDSS on Social Media!



Follow NDSC on Social Media!



DOWN SYNDROME AFFILIATES IN ACTION



**Down Syndrome Affiliates
in Action**



@downsyndromeAIA



@downsyndromeAIA



**Down Syndrome Affiliates
in Action**



Down Syndrome Achievement Centers
educate. inspire. believe.



GiGi's Playhouse, Inc.



@gigisplayhouse



@GiGis_Playhouse



**GiGi's Playhouse, Inc -
Down Syndrome
Achievement Centers.**



LuMind IDSC Foundation



@lumindidsc



@LuMindIDSC



LuMind IDSC Foundation

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Panel – Advocacy Tips and Tricks

Thank you to our moderator, Debbie!



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Welcome to our Panelists!



Jen Alge - Ohio



Mary Borman - Arkansas



Kelly Lyons - Indiana



Robbin Lyons - Indiana

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Panel Questions

- Please introduce yourself, where you are from, and your experience with advocacy.
- What advice do you have for other self-advocates?
- What advice do you have for new advocates who will be going to Capitol Hill for the first time tomorrow?
- How can advocates best prepare for their meetings on Capitol Hill?

Participants – please hold your questions until the end.



Preparing for Capitol Hill Breakout #2

30 Minute Work Period

- Divide and conquer!
 - Member profiles
 - Meeting run of shows
 - Self-advocate one-pagers
 - Storytelling templates
- Questions?
 - Ask your state captains!





Reminders

Housekeeping

- Take ALL belongings, leave-behinds, worksheets etc. with you
- Make sure you are prepared for your meetings tomorrow
- Exchange contact information with your state delegation
- Dinner tonight is on your own
 - Refer to the event program for dining options
 - Consider coordinating with others from your state
- Questions?
 - Ask your state captain
 - Soapbox helpdesk

Tomorrow

- 6:30 AM – 8:00 AM: Breakfast
- 7:00 AM – Soapbox helpdesk opens
- 8:00 AM – 9:00 AM: Travel to Capitol Hill
- 9:00 AM – Group photo at the Capitol (meet on the House side)
- 9:30 AM – 5:00 PM – Hill meetings
- 12:00 – 1:00 PM – Alzheimer's briefing
- 5:00 – 7:00 PM – Congressional Reception (Rayburn 2045)

Alzheimer's Briefing



Congressional Briefing: The Intersection of Down Syndrome and Alzheimer's Disease

Our organizations, in cooperation with the Congressional Task Force on Down Syndrome and the Bipartisan Congressional Task Force on Alzheimer's Disease, invite you to attend a briefing on the intersection of Down syndrome and Alzheimer's disease.

When: Wednesday, April 19th, 2023, 12:00 PM - 1:00 PM

Where: Cannon House Office Building 401

Panelists:

- **Dr. George Capone**, Director, Down Syndrome Clinic and Research Center, Kennedy Krieger Institute
- **Dr. Matt Janicki**, Co-chair, National Task Group on Intellectual Disabilities and Dementia Practices
- **Dr. Huntington Potter**, Director, Alzheimer's Program, Crnic Institute for Down Syndrome; Director, University of Colorado Alzheimer's and Cognition Center
- **Dr. Michael Rafii**, Medical Director, Alzheimer's Therapeutic Research Institute; Professor of Neurology at USC Keck School of Medicine
- Moderated by **Dr. Bill Mobley**, Executive Director, Down Syndrome Center for Research and Treatment, UC San Diego

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





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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®



NATIONAL
DOWN SYNDROME
CONGRESS



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

Tonight

- Join us for the Champions of Change reception and dance party
- Drink tickets provided at registration
- Dessert provided
- Awards begin at 7:30 PM
- Dance party to follow!





Soapbox



Closing



Thank you!