

Down Syndrome Advocacy Conference Pre-Event Webinar



national down syndrome society®

**Down Syndrome
Advocacy
Conference**



2026 Down Syndrome Advocacy Conference

Welcome!



Madison Essig
Administrative Coordinator



2026 Down Syndrome Advocacy Conference



Welcome!



Kevin Ryle

Manager of Federal Government Relations

2026 Down Syndrome Advocacy Conference



Welcome!



Sean Feely

Director of Advocacy and Public Policy

2026 Down Syndrome Advocacy Conference





Agenda



Agenda

- Event Logistics
- Foundations of Government
- Legislative Priorities
- Preparing for Capitol Hill





Event Logistics



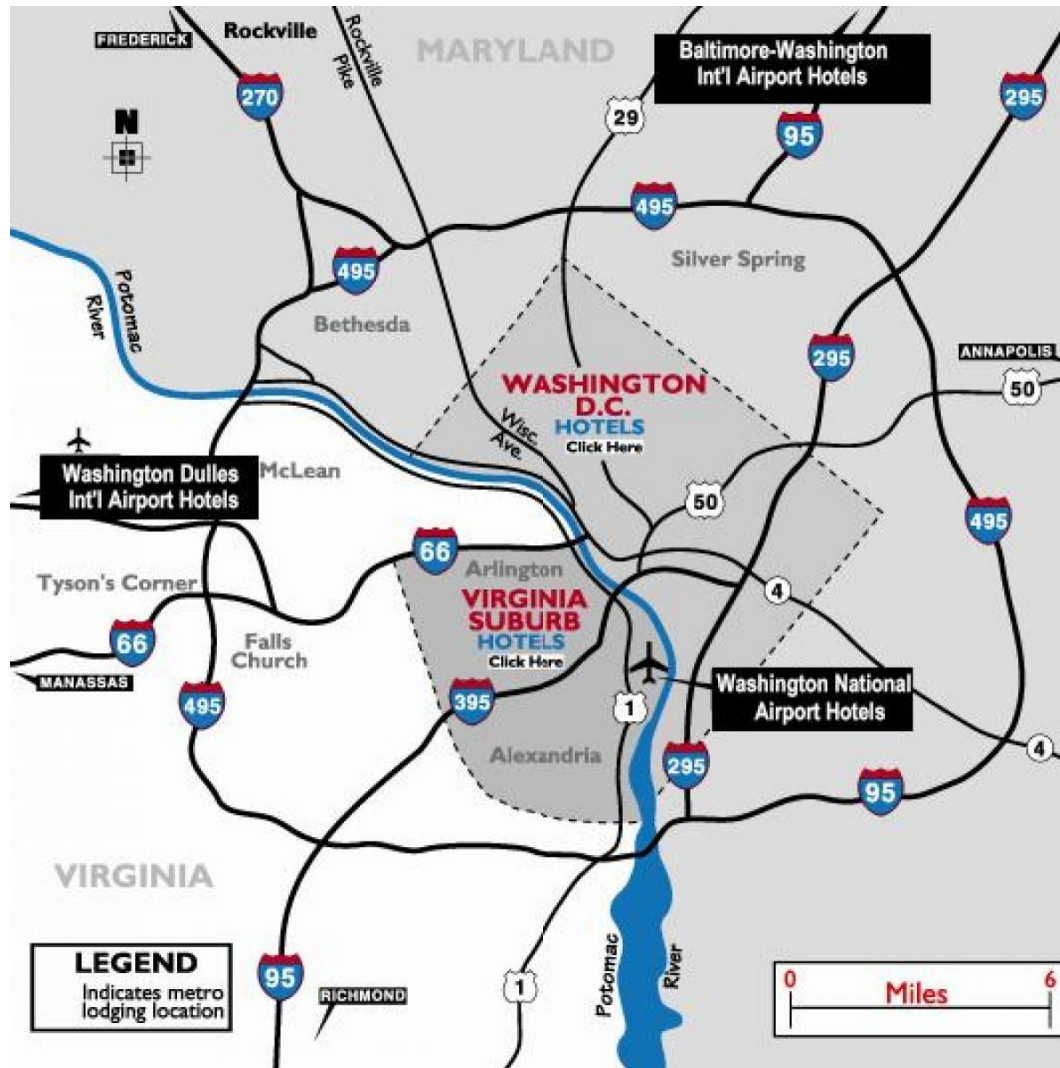
What do I pack?

- Conference training day = casual to business casual
- Evening reception = dressy casual
- Hill day = business professional

Bring comfortable walking shoes and check the weather!



How do I get to DC?



How do I get to the conference hotel?

- Reagan National Airport (DCA)
 - Free shuttle (look for hotel name)
- Baltimore Washington International (BWI)
 - Amtrak train (\$\$) or rideshare (\$\$\$)
- Dulles International (IAD)
 - Silver metro line (\$) or rideshare (\$\$\$)



Hotel and Venue

- Renaissance Arlington Capital View
 - 2800 S Potomac Ave., Arlington, VA 22202
- Check-in at 4 PM, Check-out at 12 PM



Which track is right for me?

Childcare:

- Recommended for all attendees ages 6 – 11

Modified Track:

- Recommended for youth advocates ages 12 – 17 and self-advocates who have never attended the conference before

General Track:

- Recommended for all other attendees



Conference Overview

Day #1: Monday, May 11th

Session #1	The Policy Landscape from 2025 to Today
Session #2	Powering Change with Research
Session #3	Sustaining Momentum in Advocacy
Session #4	Crafting Your Message for Impact
5:00pm	DS-Ambassador Happy Hour

Monday, May 11th

Dinner on Your Own

- Several restaurants in walking distance
- Consider getting dinner with your state delegation!

Conference Overview

Day #2: Tuesday, May 12th

2026 Conference Kick-Off and Skit

General Conference Programming

- General and Modified Tracks Available

Advocacy Workshop

Evening Reception & Dance Party

Tuesday, May 12th

Dinner on Your Own

- Several restaurants in walking distance
- Consider getting dinner with your state delegation!

Conference Overview

Day #3: Wednesday, May 13th

7:30 AM	Attendees take NDSS Buses to Capitol Hill
8:45 AM	Group Photo in front of the Capitol Building
9:00 AM – 5:00 PM	Attendees & NDSS Staff Attend Hill Meetings
5:00pm	Evening reception & Award Ceremony

Getting to Capitol Hill

- Buses – FREE!
 - Advocates can begin loading buses at 7:30 AM outside of the front entrance of the hotel
 - First bus **departs** at 7:45 AM
 - Last bus **departs** promptly at 8:00 AM
- Buses returning to the Hotel after evening reception on the Hill will have limited seats
 - Times of return buses TBD!



Getting to Capitol Hill

Alternate options:

- 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



Hill Day FAQs

- Who is scheduling meetings?
 - Advocacy Associates
 - No need to schedule your own meetings! You will get your schedule a few days before the event
- Who am I meeting with?
 - Members of Congress and their staff
 - Minimum of 2 Senate meetings, 1 House meeting
 - Potential for more meetings
- What will we discuss?
 - NDSS will provide talking points for legislative priorities and a leave behind folder
 - **Your personal story is the most important!**





Foundations of Government



3 BRANCHES *of* U.S. GOVERNMENT



 **Constitution**
(provided a separation of powers)



Legislative
(makes laws)



Congress



Senate



House of
Representatives



Executive
(carries out laws)



President



Vice President



Cabinet



Judicial
(evaluates laws)



Supreme Court



Other
Federal Courts

House vs. Senate

COMPARING THE HOUSE OF REPRESENTATIVES TO THE SENATE

House		Senate
435	Number of Members	100
2 Years	Term Lengths	6 Years
25	Minimum Age For Members	30
Many Rules, Formal	Organization	Few Rules, Less Formal
By Population	Representation of the States	Equal

Congressional Committees



UNITED STATES HOUSE COMMITTEE ON
WAYS & MEANS
CHAIRMAN JASON SMITH

U.S. SENATE COMMITTEE ON
**Health, Education
Labor & Pensions**

UNITED STATES SENATE
COMMITTEE ON FINANCE

Staff

- All members of Congress have staff. Some key staff include:
 - Chief of Staff
 - Legislative Director
 - Legislative Assistants
 - Legislative Correspondents
 - Staff Assistants
 - Schedulers
 - District staff
 - Interns





Legislative Priorities

2026 Down Syndrome Advocacy Conference

Legislative Priorities

- Charlotte Woodward Organ Transplant Discrimination Prevention Act (S. 1782 / H.R. 1520)
- SSI Savings Penalty Elimination Act (S. 1234 / H.R. 2450)
- Sustained funding for Down syndrome research
- Protecting and strengthening special education programs

Learn more [here!](#)

2026 Down Syndrome Advocacy Conference





Preparing for Capitol Hill



2026 Down Syndrome Advocacy Conference

Optional Prep Work

- Developing your story
 - Why did you choose to come to the conference?
 - How do the legislative priorities affect you?
 - What do you want your members of Congress to know about you/your experience/the Down syndrome community?



Optional Prep Work

- Member research
 - Who will you be meeting with?
 - What Committees are they on?
 - Have they supported the conference legislative priorities?
 - Use [Congress.gov](https://www.congress.gov) or your Members website to find this info!
 - You may have meetings with Representatives that are from your state, but not your district!



Optional Prep Work

- Self-advocate leave behinds
 - One-pager to leave with the member of Congress/their staff to remember you by
 - Resource to support self-advocates in meetings





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!



Jamie Dolan
1155 15th St NW, Washington, D.C. 20005
jdolan@ndss.org

My name is Jamie Dolan, and I am one of your constituents. I currently work part time at the National Down Syndrome Society (NDSS) as an Office Assistant, where I prepare information kits about the needs and abilities of people with Down syndrome. I have had the privilege to represent NDSS at the United Nations for the 2016 World Down Syndrome Day.

With the help of support programs, I also volunteer four days a week shelving return videos in the neighborhood library, delivering lunches to housebound people, and doing a variety of different tasks needed in a senior center.

I like helping people in my community and learning new skills so that I can work independently. I do a good job and I make people smile.

My dream is to be more independent, living in a home with friends (close to my family), now that my parents and I are all older.

Please support the Transformation to Competitive Integrated Employment Act which will help ensure that employers across the country pay workers with disabilities, like me, fair and equal wages and end subminimum wage. This bill will help me achieve my goals and create a pathway to greater financial and personal independence in my life.

Thank you,
Jamie Dolan





DS • AMBASSADOR[®] HAPPY HOUR

We invite you to join us

Monday, May 11th from 5:00 pm – 6:00 pm

We hope you can stop by to celebrate the work you do and enjoy some fun games to connect with advocates from across the country.

Interested in learning more about the DS-Ambassador program? All are welcome!





national down syndrome society®

Down Syndrome Advocacy Conference

May 11-13, 2026 | Washington, D.C.

If you have family or friends who are interested in attending, be sure they register before April 27th!

*For more information, scan the QR code or visit:
<https://ndss.org/down-syndrome-advocacy-conference>*



NYC Buddy Walk® 2026

NEW YORK CITY
SEPTEMBER 12, 2026



The NYC Buddy Walk brings together thousands of individuals, families, and advocates to celebrate and support the Down syndrome community.

REGISTER TODAY!





Questions?

policy@ndss.org

