



2024 Down Syndrome Advocacy Conference Legislative Priorities

The NDSS Down Syndrome Advocacy Conference brings advocates from across the nation together to advocate for priorities that impact the Down syndrome community. The 2024 conference will be held on World Down Syndrome Day, March 20 – 21, in Washington D.C. For more information and to register, visit www.ndss.org/dsac.

The legislative priorities for this year's conference include:

Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 2706/S.1183)

The Charlotte Woodward Organ Transplant Discrimination Act, named after NDSS staff member, self-advocate, and transplant recipient, Charlotte Woodward, would prevent discrimination based on disability in the organ transplant system. Additionally, it would establish an expedited review of claims of discrimination at the Office of Civil Rights at the United States Department of Health and Human Services that would give timely relief to those who have been discriminated against.

SSI Savings Penalty Elimination Act (H.R. 5408/S. 2767)

The SSI Savings Penalty Elimination Act would increase the allowable asset limitation to remain eligible for supplemental security income (SSI) from \$2,000 to \$10,000 for individuals. It would also eliminate the marriage penalty by increasing the allowable asset limitation for couples from \$3,000 to \$20,000. The limits would be indexed and adjusted annually for inflation.

Inclusion of the Down Syndrome Community in Alzheimer's Disease Initiatives/the NAPA Reauthorization Act (H.R. 619/S. 133)

Given the genetic connection between Down syndrome and Alzheimer's Disease, it is imperative that the Down syndrome community is included in all federal initiatives related to Alzheimer's Disease. Specifically, the Down syndrome community must be included in the National Alzheimer's Plan Act (NAPA) Reauthorization Act which would continue the important work of the NAPA Council.



Legislative Priorities FAQ



How are the annual priorities chosen?

The legislative priorities are carefully chosen by the NDSS Advocacy and Public Policy team based several factors including constituent and community input, the current political climate and balance of power in Congress, and the likelihood of movement/progress on the chosen priorities. Our team's goal is to maximize your efficacy and impact by choosing priorities that are meaningful to our community and have a clear path toward passage in the United States Congress.



A priority I really care about or have previously advocated for is not on this year's list! What happened?

In order to maximize impact, the number of priorities that can be discussed in a single meeting is limited. Therefore, there may be priorities that are important to you or that you have advocated for previously that were not chosen to be part of this year's conference priorities. This does not mean that NDSS and our grassroots advocates are not actively engaged with these issues! In fact, there are several events, advocacy campaigns, and grassroots activations NDSS leads throughout the year in support of priorities other than those chosen for the conference. If you are interested in staying connected with this work, please consider joining the NDSS [DS-Ambassador grassroots advocacy program](#).



I am not familiar with one or more of the chosen priorities. What should I do?

The Down Syndrome Advocacy Conference is open to advocates of all ages and all experiences! You do not need to be an experienced advocate to attend. The first full day of the conference (March 20) will be devoted to educating attendees on the priorities as well as how to effectively advocate on Capitol Hill. NDSS also provides numerous pre-conference trainings and resources to help advocates familiarize themselves with the issues.



Will I be able to advocate on priorities other than the three chosen while I am on Capitol Hill?

Attendees are asked to only address the three legislative priorities above during their time on Capitol Hill for the conference. This helps contribute to a unified, and ultimately the most impactful, voice on Capitol Hill. Additionally, members of Congress and their staff are sent notice of the priorities and supplemental materials ahead of their meetings with constituents to ensure that the most productive meeting possible can occur. If advocates discuss priorities outside of those identified by the conference, members of Congress and their staff may be unprepared or unable to meaningfully discuss these additional priorities. Attending the conference is a great way to build a relationship with your members of Congress and their staff so that you may approach them with additional requests or priorities in the future!



Who should I contact if I have questions about any of the legislative priorities or the conference?

Please contact conference@ndss.org with any questions.