Dear Down Syndrome Advocates:

On April 11-12, almost 300 advocates from across the US participated in the NDSS Buddy Walk® on Washington advocacy conference in Washington, DC. The event included a day of advocacy training and a day of meetings with Members of Congress and their staff on Capitol Hill focused on three of NDSS’ federal priorities (or "Asks"). We are writing to encourage those who were not able to attend the Buddy Walk® on Washington to contact your Members of Congress to advocate for our three Asks. The Asks are:

1. Co-sponsor the ABLE to Work Act (HR 4795 / S 2702) - The landmark Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act passed at the federal level in December 2014 and states will soon launch ABLE programs. The ABLE Act allows people with disabilities to set up tax-free savings accounts without losing eligibility for federal benefit programs like Medicaid and supplemental security income (SSI). The ABLE to Work Act would improve upon the ABLE Act by increasing the annual contribution limit for ABLE accounts, which is currently $14,000. Specifically, an ABLE beneficiary who earns income from a job (and does not have another retirement account) could save up to the Federal Poverty Level (currently $11,770) in addition to the $14,000 annual maximum contribution.

   Click here to see the sponsors and co-sponsors for the Senate version of ABLE to Work
   Click here to see the sponsors and co-sponsors for the House version of ABLE to Work

2. Join the Congressional Task Force on Down Syndrome - The Congressional Task Force on Down Syndrome is made up of US Representatives and US Senators who work with NDSS to educate Members of Congress and their staff about Down syndrome, and to promote legislative activities and public policies that would enhance the quality of life for those with Down syndrome.

   Click here to see the current members of the Task Force

3. Co-sponsor the Accurate Education for Prenatal Screenings Act (HR 3441) - This legislation would complement an FDA oversight framework by requiring the Centers for Disease Control (CDC) to create and maintain education programs for patients and health care providers. Specifically, it requires that accurate and up-to-date information be provided to patients about the clinical features, prognoses treatments of Down syndrome and other conditions according to relevant national disability organizations and medical professional societies. These provisions also complement the Prenatally and Postnatally Diagnosed Conditions Awareness Act, signed into law in October 2008, and legislative efforts at the state level to require that accurate information about Down syndrome be provided to patients by their health care providers. This bill has been introduced in the US House of Representatives only, not in the US Senate.

   Click here to see the sponsors and co-sponsors for the bill

To learn more about these Asks, see the leave-behind packet that the Buddy Walk® on Washington participants gave to their Members of Congress during their meetings on Capitol Hill.

The Buddy Walk® on Washington participants were very successful in promoting these Asks. Since the Buddy Walk® on Washington, 24 Members of Congress have become co-sponsors of the ABLE to Work Act, 14 Members of Congress have joined the Congressional Task Force on Down Syndrome and 4 Members of Congress have become co-sponsors of the Accurate Education for Prenatal Screenings Act. These are wonderful accomplishments but more needs to be done and we need your help. Please find out if your US Representative and US Senators have supported these Asks. If they have, please thank them! If they haven't, please urge them to do so!
Here are the steps to take:

1. If you aren't sure who your US Senators and US Representative are, type in your home address on this page to find out their names.

2. Click on the links above to see if your Senators and Representative have sponsored or co-sponsored the bills mentioned above and whether they have joined the Congressional Task Force on Down Syndrome.

3. E-mail and call your Members of Congress to either thank them for their support or to urge them to support these issues. Let them know that you are a constituent and briefly explain why these issues matter to you. (To find contact information for Members of Congress, go to the individual Members' websites. Most Members' websites have e-mail forms to use when contacting them.)

4. Stay in touch with NDSS to let us know what kind of response you receive.

Taking these actions will continue the momentum of the Buddy Walk® on Washington and will bring us closer to making important gains for people with Down syndrome at the federal level.

Thank you for your advocacy and support!

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