



September 12, 2015

The Honorable Jamie Herrera Beutler
The Honorable Lucille Roybal-Allard
U.S. House of Representatives
Washington, D.C. 20515

Dear Representatives Herrera Beutler and Roybal-Allard:

On behalf of the National Down Syndrome Society, I am writing to express our support for H.R. 3441, the Accurate Education for Prenatal Screenings Act. We commend you for your leadership in sponsoring this legislation.

NDSS is the largest nonprofit organization dedicated to advocating for people with Down syndrome and their families at the federal, state and local levels of government. With a network of 375 NDSS affiliate groups spanning all 50 states and representing over 400,000 people in the United State with Down syndrome, we envision a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. NDSS is at the forefront of efforts to develop and encourage government health agencies and health care providers to distribute accurate, up-to-date information about Down syndrome to patients who receive a prenatal or postnatal diagnosis. Such information is necessary to address the pervasive problem of patients receiving inaccurate, outdated and offensive informational materials following a diagnosis.

As such, we have significant concerns over the Non-Invasive Prenatal Tests (NIPTs) that are on the market today, and which are not regulated by the U.S. Food and Drug Administration (FDA), the leading U.S. regulatory body responsible for protecting and promoting public health through the regulation of foods, drugs, and devices. Problems have been identified with these tests such as: claims that are not adequately supported with evidence, lack of appropriate controls yielding erroneous results, and falsification of data. Furthermore, these tests are not being coupled with the necessary and adequate information and genetic counseling that women and families require when going through testing and screening for Down syndrome.

H.R. 3441 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 about the purposes, risks, benefits, accuracy and limitations of the NIPTs. This bill would also require these education programs to include information about the conditions such screenings may detect, including 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. Thank you for your leadership and support on this important issue.

Sincerely,

A handwritten signature in black ink, appearing to read "Sara Hart Weir".

Sara Hart Weir, MS
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