



March 30, 2023

Re: Assembly Bill 116

Members of the Nevada Legislature:

As the leading human rights organization for all individuals with Down syndrome, the National Down Syndrome Society (NDSS) supports the passage of AB116, which will allow individuals diagnosed with Down syndrome and their families to obtain the most accurate and up-to-date information regarding Down syndrome.

AB116 would require providers to distribute widely accepted information based on peer-reviewed medical literature and research. Families deserve the most accurate information possible from their health care providers when receiving a diagnosis of Down syndrome.

Health care providers often distribute outdated information to patients who receive a Down syndrome diagnosis. Receiving a diagnosis of Down syndrome can be a very complicated time for individuals and families; ensuring they receive the most accurate and current information is a critical step. Another issue facing individuals with Down syndrome and their families is the lack of information provided on local support groups and resources, which are so important to those navigating a recent diagnosis. Assembly Bill 116 would provide information on hotlines specific to Down syndrome, relevant resource centers and contact information for Down syndrome organizations.

Federal legislation, the Prenatally and Postnatally Diagnosed Condition Act (PL 110-374), was enacted in 2008. Unfortunately, the federal law was never funded. In the absence of funding, Delaware, Florida, Idaho, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Nebraska, New Jersey, Ohio, Oklahoma, Pennsylvania, Tennessee, Texas, Utah, Virginia and Washington have passed legislation to ensure those diagnosed with Down syndrome receive the information and resources they need. Now is the time to pass AB116 and add Nevada to this list. Thank you for your leadership on this important piece of legislation.

Sincerely,

Nick Leto

National Down Syndrome Society

Manager of State Government Relations

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