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## New Legislation Will Help Children and Adults Living with FASD, the Nation's Most Common and Preventable Developmental Disability

SENATORS LISA MURKOWSKI AND AMY KLOBUCHAR AND  
REPRESENTATIVES BETTY McCOLLUM AND DON YOUNG INTRODUCE THE  
FETAL ALCOHOL SPECTRUM DISORDERS RESPECT ACT

Indianapolis, IN, June 28, 2021 – The U.S. Senate and House have introduced matching bills to authorize comprehensive Fetal Alcohol Spectrum Disorders (FASD) support services, public health prevention, and research programs across agencies within the U.S. Departments of Health and Human Services, Education, and Justice.

The *Advancing FASD Research, Services, and Prevention Act*, (S. 2238, H.R. 4151), known as the FASD ReSPect Act, is cosponsored by Senators Lisa Murkowski (R-AK) and Amy Klobuchar (D-MN) and Representatives Betty McCollum (D-MN) and Don Young (R-AK), all dedicated champions of maternal and child health and support for individuals living with disabilities and addiction. Their home states of Alaska and Minnesota now lead the way in statewide efforts to respond to FASD.

FASD describes the range of lifelong physical, mental, and behavioral impairments that can occur in an individual prenatally exposed to alcohol. As reported in *JAMA: The Journal of the American Medical Association*, FASD affects as many as 1 in 20 school-age children in the U.S., and, according to a 2019 Centers for Disease Control and Prevention *Mortality and Morbidity Weekly Report*, 1 in 9 pregnancies are exposed to alcohol. The estimated annual cost for each individual with FASD, including health care, special education, residential care, lost productivity, and juvenile and criminal justice expenses, is \$30,945, for a total annual cost to society of \$205 billion.

Susan Elsworth, Executive Director of Indiana NOFAS states: “The passage of the FASD ReSPect Act is designed to transfer knowledge gained by research to usable insights for developing effective invention strategies and supports for individuals with an FASD and their caregivers. Additionally, states can use these funds to build diagnostic capacity and state infrastructure to address this vulnerable population.”

Challenges to addressing FASD:

- Complex spectrum disorder
- Often misdiagnosed
- Spans physical, mental, emotional and behavioral health for individuals
- Intersects all provider delivery systems

- Neurodiverse and affects are person specific
- Lack of awareness and education regarding FASD
- Stigma

Heather French, a family member of individuals with an FASD shared what the passing of the bill would mean to Indiana families: “With the passing of the FASD Respect Act I would hope to see access to diagnosis and support for families, as early diagnosis and supports allows people with FASD to reach their greatest potential and success. I would anticipate more awareness both in prevention and living with FASD. Our society needs to know that FASD is a possible outcome of drinking while pregnant and how that impacts that baby for their whole life. With awareness there can be knowledge, acceptance, and support of the struggles those with FASD face in receiving medical, education, therapy, and justice. FASD may be considered an invisible illness because you can not always tell some one has it by looking but it doesn’t need to be invisible to society’s awareness and support.”

Indiana NOFAS is a member of the National Organization on Fetal Alcohol Syndrome (NOFAS) Affiliate Network, a coalition of 33 FASD organizations working to disseminate information, provide referrals, and integrate FASD resources into local services. Susan Elsworth, Executive Director of Indiana NOFAS and the affiliate network coordinator, believes attention and investment for FASD is long overdue, “Families living with FASD seeking help are too often met with ignorance. They deserve medical and behavioral care and education and justice systems that recognize and meet their needs. The affiliates are on the front lines. They are prepared now to partner with state agencies, clinical networks, and service providers to prevent FASD and support families. Passage of this legislation will bring hope to our communities and meaningful resources that will improve their lives.”

The Mission of Indiana NOFAS is to prevent prenatal exposure to alcohol, drugs and other substances know to harm fetal development by educating, advocating and supporting professionals, policymakers, families and individuals throughout Indiana. Information regarding training and services provided can be found at [www.indiananofas.org](http://www.indiananofas.org).

To learn more about the FASD ReSPect Act visit the [NOFAS Policy Center](#) or contact NOFAS Policy Coordinator [Jennifer Wisdahl](#).

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