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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**

WASHINGTON, D.C., June 24, 2021 – The U.S. Senate and House introduced matching bills today 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). Alaska and Minnesota are at the forefront of the response to FASD, and the original bill coauthors are dedicated champions of maternal and child health and support for individuals living with disabilities and addiction.

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.

“FASD is an overlooked crisis affecting millions of children and adults,” said National Organization on Fetal Alcohol Syndrome (NOFAS) President Tom Donaldson, “this landmark bill will advance research, increase education, and most importantly provide access to critical services for individuals affected by FASD and offer them long overdue opportunities to succeed.” Board Chair Kate Boyce stated, “NOFAS and its affiliates across the globe applaud Senate sponsors Murkowski and Klobuchar and House sponsors McCollum and Young and urge prompt action to move this key bill forward.”

NOFAS Legislative and Policy Chair Susan Shepard Carlson, who led the effort to draft legislation that will build on the current federal response to FASD and meet the needs of families, added, “The FASD community thanks the Senate and House sponsors for leading the charge to enact this bipartisan FASD legislation to bring much needed focus and resources to a huge societal problem. For more than two decades, as Minnesota’s First

Lady, a Juvenile Court Judicial Officer, and a passionate advocate for the cause, I became convinced that the numbers of children born with FASD was a crisis affecting each and every one of us that, we as a nation, had failed to make a priority. S. 2238 and H.R. 4151 confront this crisis.”

Carlson added, “Existing FASD prevention and services are inadequate and too fragmented among federal, state, and local approaches. This new legislation provides a structure to develop well-informed public policy on FASD and creates a clear, ongoing societal commitment to advancing research and ensuring essential services for persons with FASD and their families.”

Helen Simpson, a young mother in Oregon who lives with the challenges and differences of FASD expressed relief and excitement, “This means I matter. Finally, the country and my community care about me. I have a family and a job, but things don’t come easy. The day I tell a doctor or disability services that I have FASD and I need help and they say, ‘I understand and I’m here for you’ might really happen!”

The 33 NOFAS affiliates serve as a vital national network for the dissemination of education resources and support services. Louse Brassard, NOFAS New Hampshire President knows passage of the legislation will not be easy, “Now the real work begins. We need to stand together. I believe once they understand the magnitude and the emotional and economic toll of FASD on the country, I don’t know how any member of the Senate and House could say no to children, adults, and families.” She believes building State and Tribal FASD systems is the cornerstone of the bill, “If we can connect each affiliate with the existing health, education, and disability services in their state and integrate FASD training and resources into all systems, NOFAS New Hampshire and my colleagues nationally can effectively support families with FASD.”

In addition to families living with FASD, the legislation will expand efforts to identify and help women at risk for alcohol use disorders. NOFAS Vice President and National Spokesperson Kathy Mitchell, a leading authority on FASD and the stigma surrounding the issue, commented, “If we are going to successfully address FASD we have to support women with substance use disorder, stop discriminating against people with addiction, and make diagnosis and treatment universal and accessible. This new legislation is the next step to taking FASD and prenatal alcohol exposure seriously.”

NOFAS is the only international public health advocacy nonprofit organization that works to prevent prenatal exposure to alcohol, drugs, and other substances known to harm fetal development. NOFAS works to raise awareness, educate, and support women before and during their pregnancy, as well as individuals, families, and communities living with FASD and other preventable intellectual and developmental disabilities. For more information, visit www.nofaspolicycenter.org.

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