



Give **FASD** a seat at the table.

**March 2024
Policy Forum**

Wednesday
March 27th, 2024

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FASD United

THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS

Organization Update

9th International Research Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorders

Review, Respond and Relate
Integrating Research, Policy and Practice
Around the World



Registration is NOW OPEN!
April 11-14, 2024



FASD Respect Act 2.0

Bill Contents

- Education, Awareness and Services across community agencies
- Building State and Tribal Systems
- Centers for Excellence



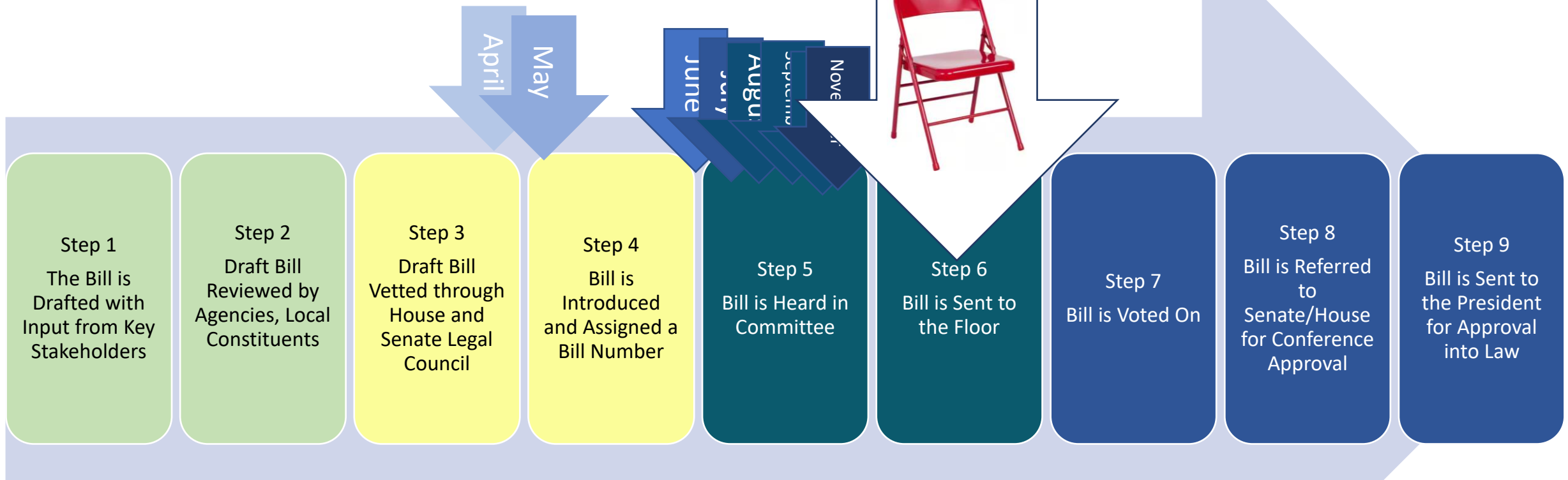
The FASD Respect Act

Building the Foundation for Change

#FASDRESPECT



Pathway to Law



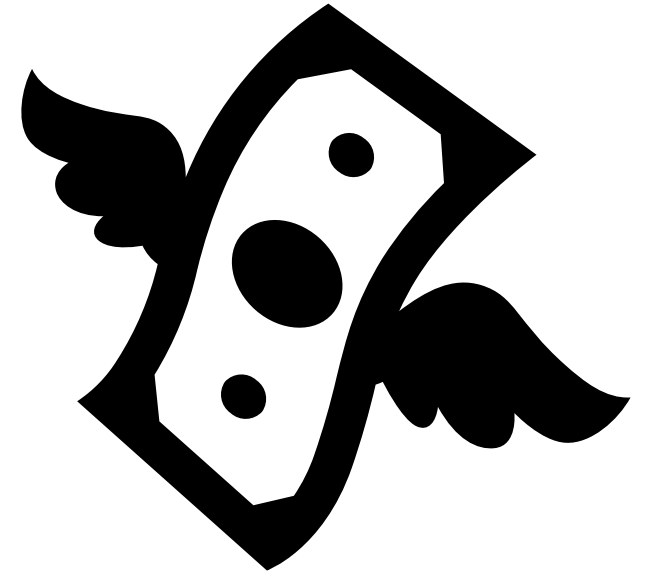
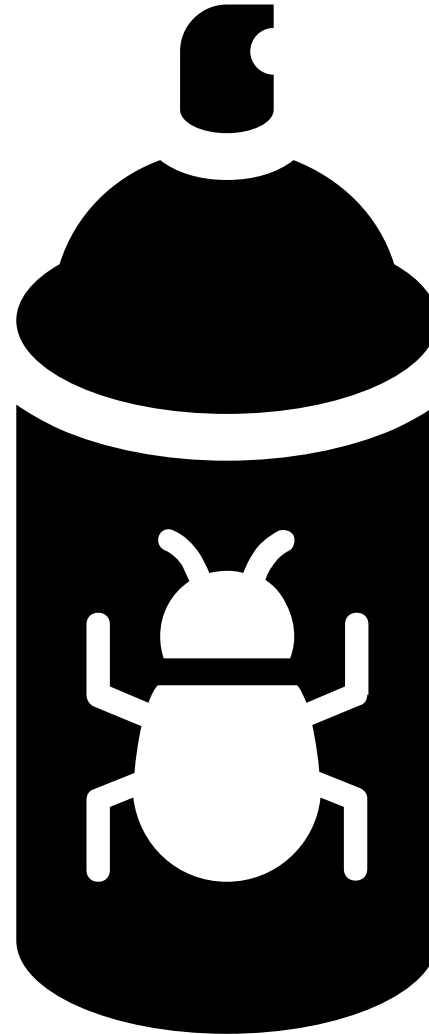
The 118th Congress Lasts for 2 years.
The 118th ends in December 2024.



The FASD Respect Act
Building the Foundation for Change
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Updates

- Appropriations
 - FY2024
 - FY2025
 - HHS
 - DOD
 - Agriculture???



What Happened in March



The FASD Respect Act
Building the Foundation for Change
#FASDRESPECT

Meetings

Rep. Don Beyer (D-VA-8)
Rep. Marc Molinaro (R-NY-19)
Rep. Debbie Dingell (D-MI-6)
Rep. Beth Van Duyn (R-TX-24)
Rep. Betty McCollum (D-MN-4)
Rep. Don Bacon (R-NE-2)
Rep. Henry Cuellar (D-TX-28)
Rep. Jake Auchincloss (D-MA-4)
Rep. Katherine Clark (D-MA-5)

Sen. Joe Manchin (D-WV)
Sen. Shelley Moore Capito (R-WV)
Sen. Lisa Murkowski (R-AK)
Sen. Amy Klobuchar (D-MN)
Sen. Jerry Moran (R-KS)



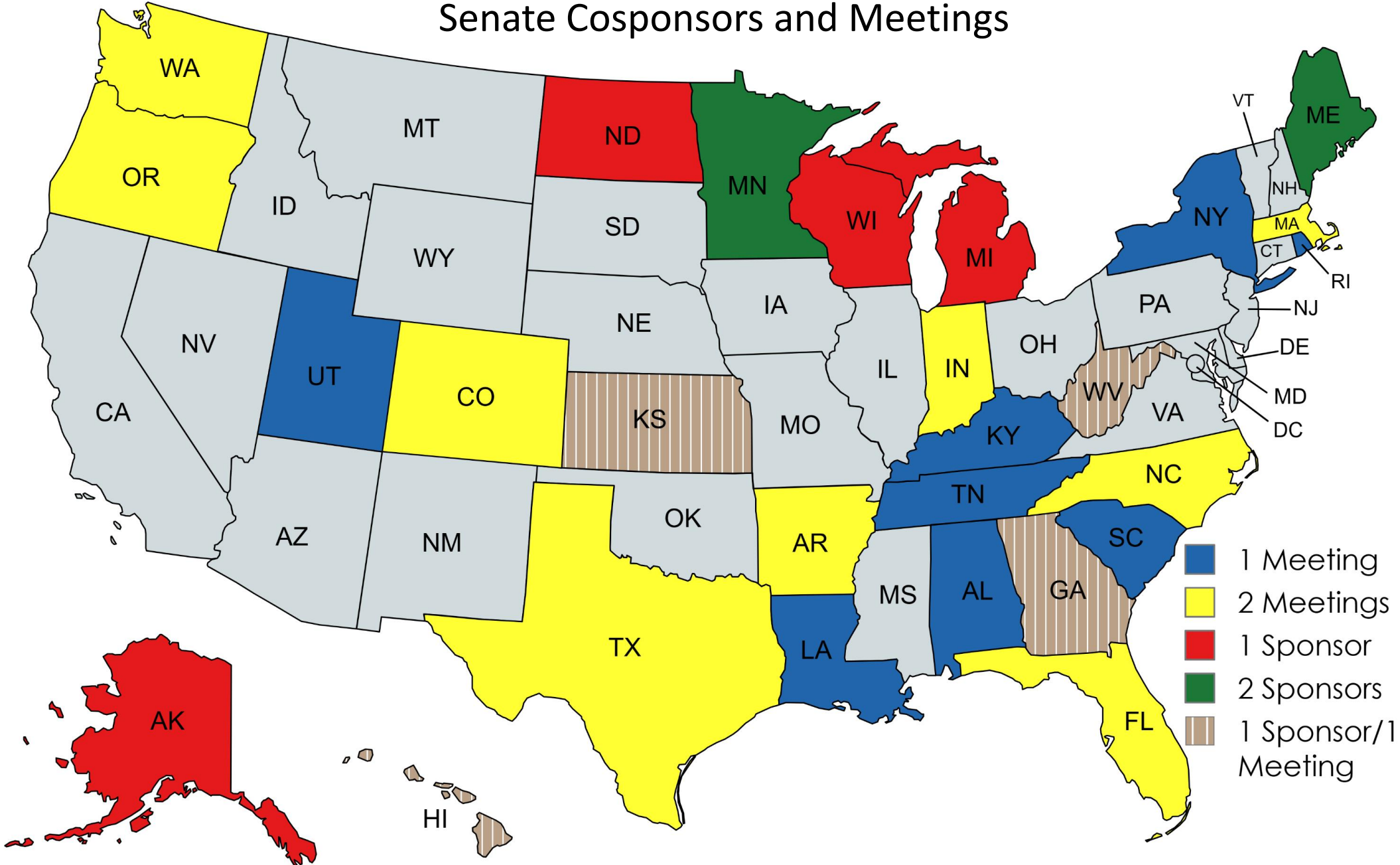
New Co-Sponsors

Rep. Jimmy Panetta (D-CA-19)

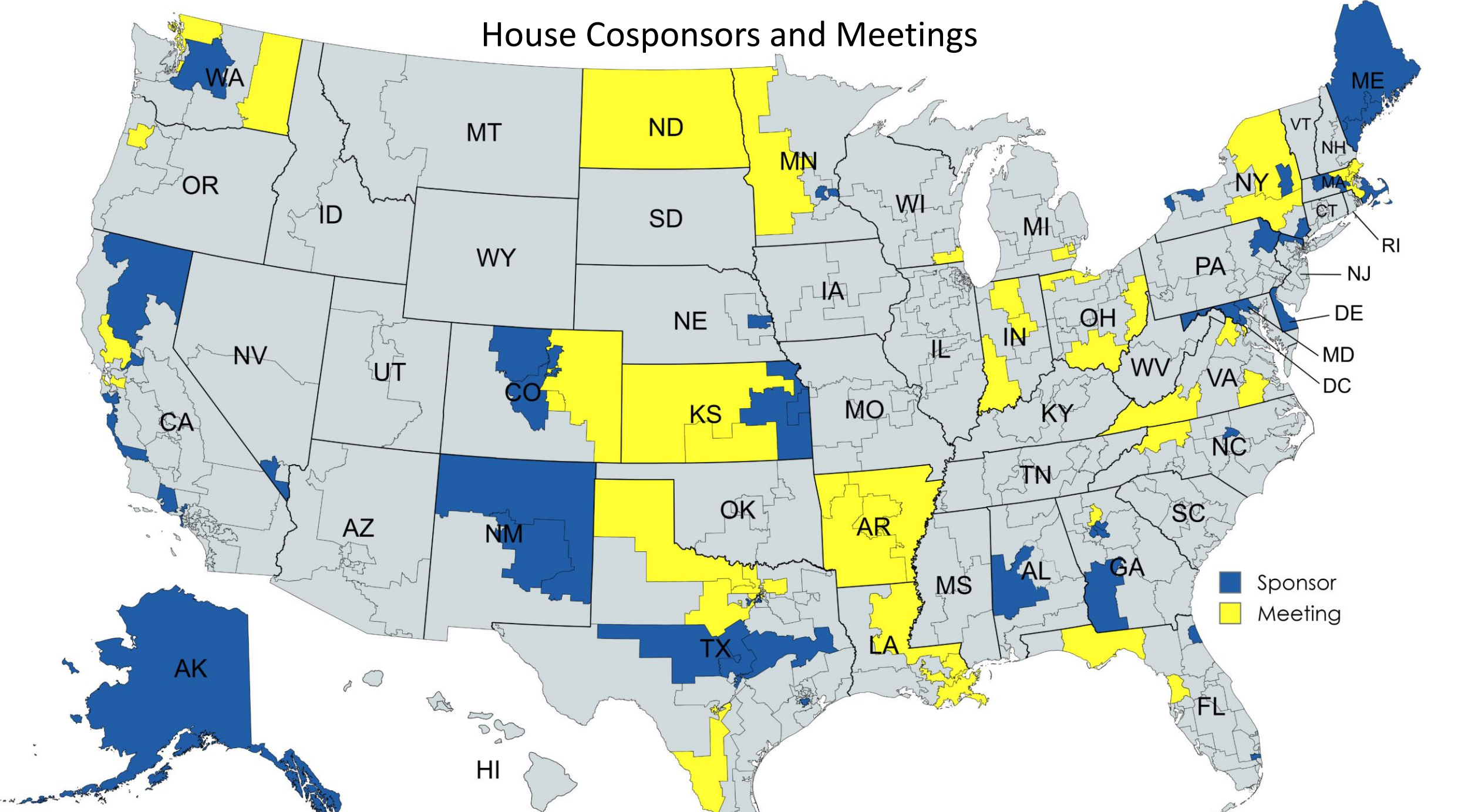
49 in the
House

11 in the
Senate

Senate Cosponsors and Meetings



House Cosponsors and Meetings



What do we do now?



- **Continue.** Keep asking for Co-Sponsors for The FASD Respect Act
- **Get Endorsements – Thanks AUCD!!**
- **Be active in your state.**



Capitol Hill Developmental Disabilities Resource Fair



Sponsored by Rep. Marc Molinaro (R-NY-19) and Rep. Debbie Dingell (D-MI-6). Hosted by the National Association of Councils on Developmental Disabilities.



Preventing Alcohol Misuse: Research to Improve and Save Lives

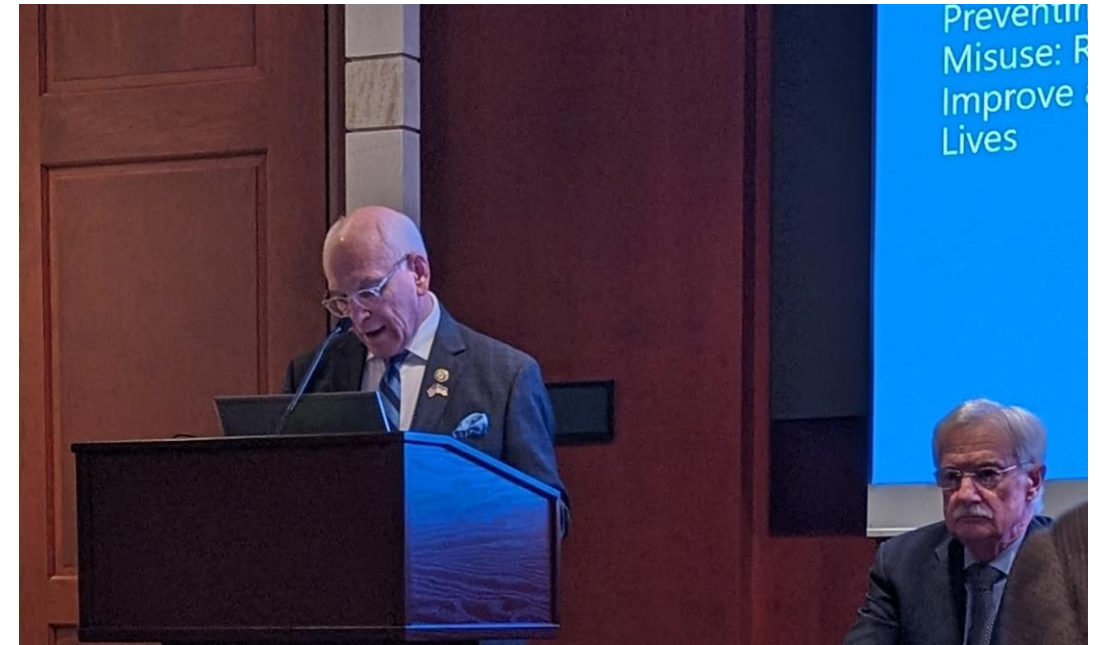
March 21, 2024 - 1:00 - 2:00 PM ET

U.S. Capitol Visitor Center
North Congressional Meeting Room (CVC 268)

Sponsored by Rep. Paul Tonko (D-NY-20), co-chair of the House Addiction, Treatment, and Recovery Caucus. Hosted by the Friends of NIAAA and the American Psychological Association.

Research Presentations on:

- Environmental Approaches to Prevent Alcohol Problems
- Prevention of Alcohol Misuse Among Cherokee Nation Youths
- Motivations for Alcohol Protective Behavioral Strategies Use



Rep. Paul Tonko (D-NY-20) and NIAAA Director Dr. George Koob

Resources

- Sample legislation for a State FASD Advisory Committee
- Template for a Governor's Executive Order creating a State FASD Advisory Committee



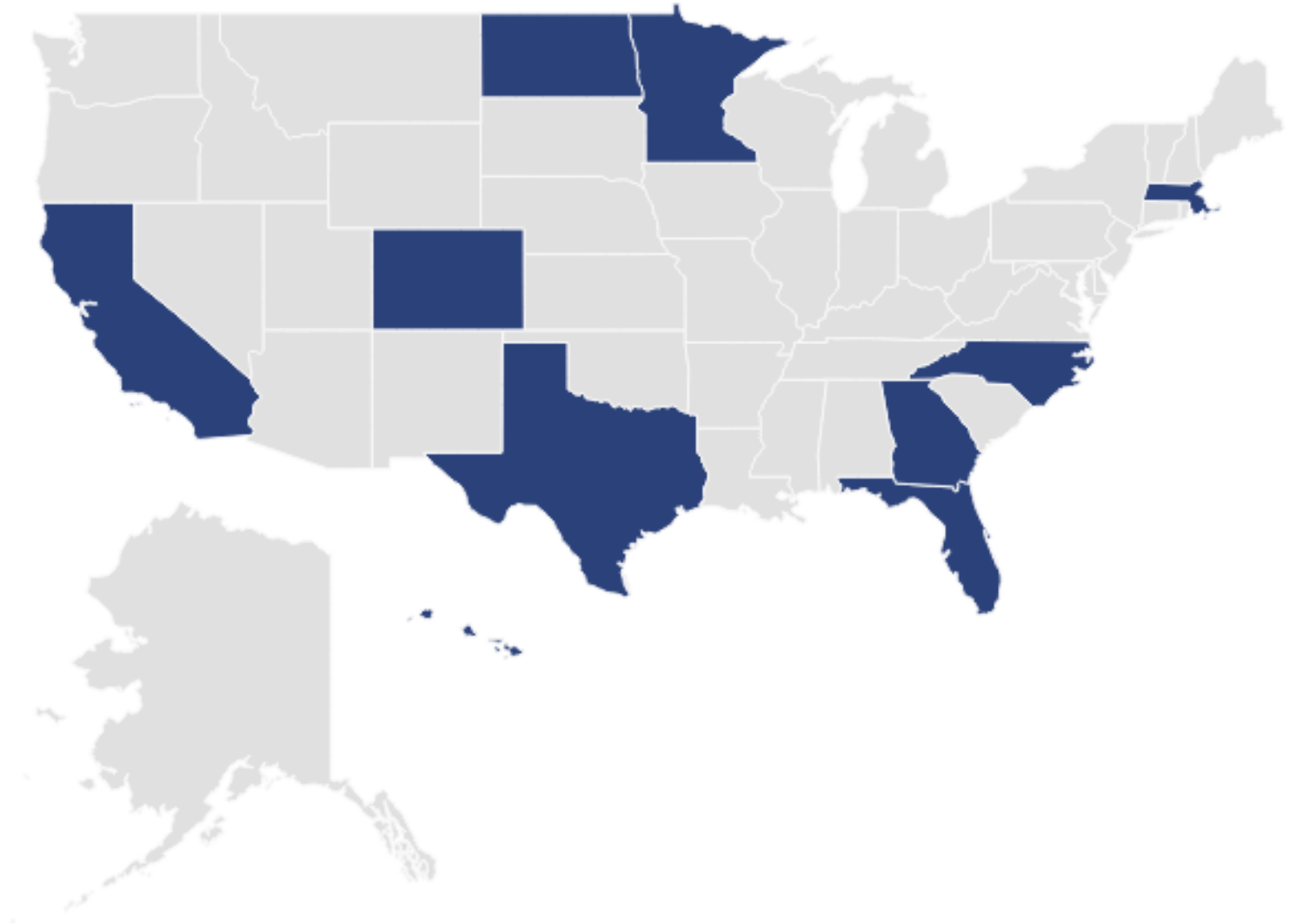
Guidance



- This is not a solo opportunity – check in and involve others in your state.
- Templates need to be customized to your state with data specific to your state
- Let FASD United know you are working on this so we can connect other interested parties to help.
- Start now. Do not wait for the FASD Respect Act to pass to start the work.

Email us if you want:

- Contact info for people working on state-level policy
- To be listed as a contact within your state



Program Contact: Melfi@fasdunited.org

www.nofaspolicycenter.org/state-policy-templates

State Information Sheets



How is FASD Recognized in the State of Alaska?



FASD is recognized by the State Department of Health

Information is available on the state department of health website and the state has an FASD specific program



The state includes FASD in its definition of Developmental Disability Alaska Stat. § [47.80.900](#)



People with FASD can qualify for waiver services without additional diagnosis.



Although FASD is not a named condition, a person with FASD could still qualify. There is no IQ cut off for waiver services and they would have to be diagnosed prior to age 22.



FASD is recognized by the state under IDEA for Special Education

FASD is listed as a named condition under OHI and the state has an online training program.



The state requires a warning sign for alcohol sales

Warning signs are required for both onsite and offsite alcohol sales.

Alaska Stat. § 04.21.065, Alaska Stat. § 04.21.080



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****This information has not been verified through the State of Alaska****

FETAL ALCOHOL SPECTRUM DISORDERS

IN WASHINGTON

Why The FASD Respect Act Needs Your Support

Fetal Alcohol Spectrum Disorders (FASD) are lifelong physical, developmental, behavioral, and intellectual disabilities caused by prenatal alcohol exposure

According to the CDC, FASD impacts as many as **1 in 20** in the US – **2.5x more than autism**

Of the over 84,890 babies born annually in Washington, **almost 4240 are estimated to have a FASD**, far in excess of current diagnostic capacity

Roughly 85% of children seen in diagnostic clinics are either adoptees or are in foster care, children living with their biological parents lack access to diagnosis due to **stigma and untrained medical staff**

Most people with FASD **won't qualify for disability services**, even with a diagnosis

Over 90% of individuals with FASD will develop co-morbid **mental health conditions**

High rates of older youth and adults with FASD **struggle with independent living and employment**

Individuals with FASD, with or without a diagnosis, face **high rates of incarceration and recidivism**

Even at lower prevalence rates, the estimated average annual cost to Washington for FASD is over **\$4.71 Billion** in health care, special education, residential care, productivity losses and corrections costs

Raising a child with FASD costs **30X more** than the cost of successful prevention efforts

Of the 1.09 Million students in Washington schools, as many as **54,700** may have FASD, yet far fewer are diagnosed

FASD is not tracked in special education under IDEA, and most **schools lack training** and supports for students with FASD

Without appropriate diagnosis and support, students with FASD face **higher than average school exclusion rates**

An estimated **380,700** of the 7.6 Million people living in Washington could be impacted by FASD

For more information go to www.nofaspolicycenter.org

State Information Sheets



-Streissguth AP et al. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, 25, 228-238.
-A Multi-country Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults (*J Addict Med* 2018;12: 466-473) – subscription required.
-MacLachlan K et al. (2020). Difficulties in daily living experienced by adolescents, transition-aged youth and adults with fetal alcohol spectrum disorder. *Alcoholism: Clinical and Experimental Research*, 44, 1609-1624.
-Astley SA. (2004). Fetal alcohol syndrome prevention in Washington State: evidence of success. *Paediatric and Perinatal Epidemiology*, 18, 344-351.

Making sense of the numbers on the economic cost of FASD

- ✓ Data on the economic burden of FASD are scarce
- ✓ Existing estimates likely underestimate the full economic impact of this disorder on the affected individuals, their caregivers, and society.
- ✓ Many costs are not easily identified because (1) the Federal programs that support FAS research and services are administered under the auspices of several departments of the Federal Government and (2) children with FAS often are not distinguished from other program recipients.
- ✓ However, the current research is sufficient to demonstrate that FASD is a serious public health problem associated with tremendous economic burden.



Economic costs of FASD- Center for Disease Control*

Cost of FASDs*

The lifetime cost of care for one individual with FAS in 2002 was estimated to be \$2 million. This is an average for people with FAS and does not include data on people with other FASDs. People with certain disabilities, such as profound intellectual disability, have much higher costs. It is estimated that the cost to the United States for FAS alone is over \$4 billion annually.

- ✓ **Does not include** the cost for loss of productivity, the cost of special education or expected additional costs for juvenile or criminal justice, substance abuse treatment, mental health care, or vocational services
- ✓ Dollar costs reported are expected to be underestimates of the true costs.
- ✓ All of the estimated dollars **are based on FAS alone**
- ✓ "Old data" – from the late Dr. Sally Anderson

* CDC website (<https://www.cdc.gov/ncbddd/fasd/data.html>) cited *Cost of fetal alcohol spectrum disorders, Lupton, Burd & Harwood*



Multi-country Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults – Greenmyer, Klug, Kambeitz, Popova, and Burd

- ✓ **Results:** Thirty-two studies from 4 countries met the inclusion criteria (United States [n = 20], Canada [n = 9], Sweden [n = 2], and New Zealand [n = 1]).
- ✓ Studies were NOT included **if they did not include costs for FASD**
- ✓ Included health care, special education, residential care, criminal justice system, productivity losses due to morbidity and premature mortality, productivity losses of caregivers of children with FASD, and intangible costs.
- ✓ Not included: corrections and intangible (due to unavailability)
- ✓ US cost studies (4) – \$68,151
- ✓ Estimates vary considerably due to the different methodologies used by different studies
- ✓ The mean annual cost for children with FASD was estimated to be \$22,810 and for adults \$24,308.

Date of published review: November/December 2018

Date range of studies: 1980 – 2013

Based on 20 studies





CALCULATING THE TOTAL ECONOMIC FASD COST

1) U.S. population*	335,893,238
2) Prevalence** (2% - average from May, et. al prevalence study)	6,717,865
3) Times per person costs***	23,804
with corrections ****	<u>31,000</u>
TOTAL	\$160B
(with corrections)	\$208B

*US Census, January 2024

**2% - average from May, et. al. prevalence study from JAMA 2018

****Multi-country Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults* – Greenmyer, Klug, Kambeitz, Popova, and Burd, November-December 2018 - converted to May 2017 currency values using online inflation calculators.

**** *The Economic Burden of Fetal Alcohol Spectrum Disorder in Canada in 2013 in Alcohol and Alcoholism* 51(3): 367-375 – Popova estimated cost of corrections at 30% of total cost of care.

State Proclamation Project

Give FASD a seat at the table by submitting Proclamation requests in all 50 states.

- What's the purpose of Ceremonial Proclamations?
- What can state advocates do?
- How can FASD United help?

www.nofaspolicycenter.org/how-to-issue-an-fasd-awareness-month-proclamation/





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