



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

**September 2024
Policy Forum**

Wednesday
September 25th, 2024

Program Contact: Chris Melfi
Melfi@fasdunited.org
202-785-4585

Jenn Wisdahl
wisdahl@FASDUnited.org
202-601-2530



FASD United

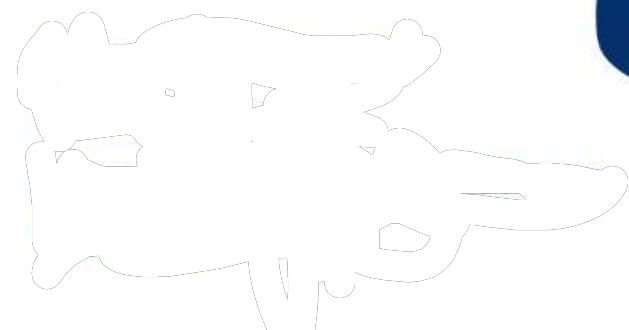
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS

Organization Update

Affiliate Update



FASD United
Affiliate Network





9TH INTERNATIONAL RESEARCH CONFERENCE ON

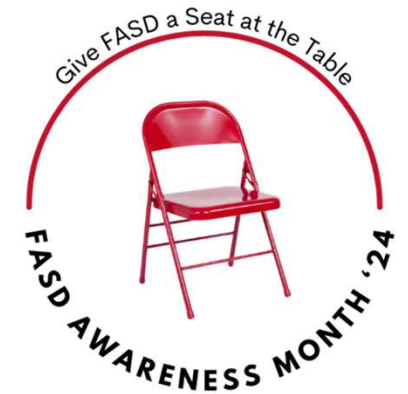
FETAL ALCOHOL SPECTRUM DISORDERS

MARCH 20 - 23, 2025
HYATT REGENCY, SEATTLE, WA

Call for Abstracts:

Extended submission date

FASD
AWARENESS
Month
RESOURCES



Website Available

<https://fasdunited.org/fasd-awareness-month-2024/>

September is FASD Awareness Month

Create a Press Release

Customize/Copy this
Press Release template
and submit it to your
local paper.

Our hope is that letters
like this encourage
members of your
community to raise
awareness about FASD
in September.

You can even add
specific events taking
place around the
community to the
letter.



FOR IMMEDIATE RELEASE
September 9, 2024 \

Contact: (name of person submitting)
(phone) – or – (email)

(your city, your state) – (your organization) is joining the cause to celebrate September as FASD Awareness month and to increase awareness and support for people with Fetal Alcohol Spectrum Disorders (FASDs). FASD is a spectrum disorder describing the range of effects that can occur in an individual who was exposed to alcohol before birth.

Prenatal alcohol exposure is associated with an increased risk of miscarriage, stillbirth, prematurity, sudden infant death syndrome (SIDS), and a range of lifelong physical, behavioral, and intellectual disabilities. FASDs can impact physical, mental, behavioral, or cognitive development as well as cause growth deficiencies, central nervous system disabilities, and, in only about 10% of people diagnosed, specific facial characteristics. Studies show that up to 1 in 20 U.S. school children may be on the FASD spectrum, a rate more than double that of autism.

Unfortunately, FASD is under-recognized, with supports and services not widely available and far too few diagnostic and treatment services currently available. In addition to public health messaging on the importance of avoiding alcohol while pregnant, it is crucial to bring recognition and awareness of children and adults with FASDs and their need for services and support.

Individuals with FASDs benefit from structure, support, understanding, and most importantly, early diagnosis, early intervention, and FASD-informed medical and mental health care. Recognizing the strengths, talents, and gifts that individuals diagnosed with FASD bring to our communities is a great way to celebrate FASD Awareness Month.

Human service organizations, health care professionals, educators, and the public are called to action to work together to support the FASD community by increasing awareness, becoming educated, and supporting broader efforts to bring FASD-informed services, interventions, and supports to those with this disability. For more information on FASD or alcohol use during pregnancy, visit www.fasdundited.org or www.cdc.gov/fasd.

Sample Social Media Posts

For an Individual



- September marks the 51st FASD Awareness Month in the #US, join me in giving FASD a seat at the table and advocating for increased education and supports for those living with this common disability. #1in20

For an Organization

- The FASD community is stronger together, which is why (organization name) is shining a light onto those living with this prevalent disability during FASD Awareness Month 2024.



FASD Respect Act 2.0

Bill Contents

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

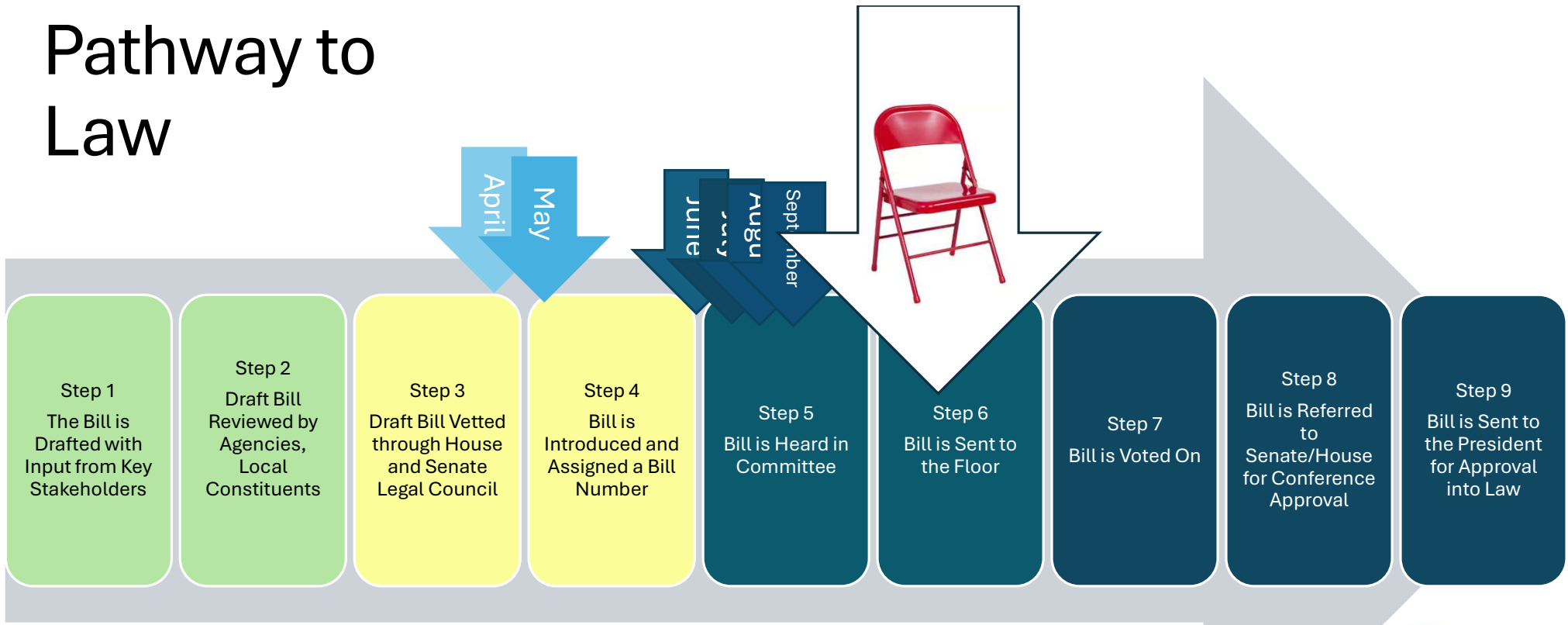


The FASD Respect Act

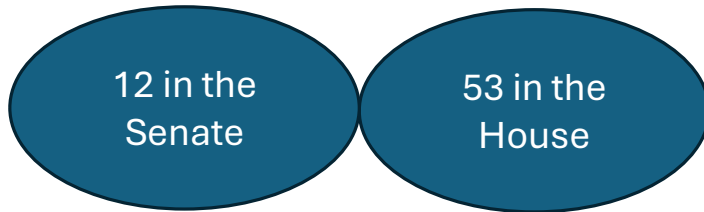
Building the Foundation for Change

#FASDRESPECT

Pathway to Law



Cosponsors



The FASD Respect Act
Building the Foundation for Change
#FASDRESPECT

What Happened in September



Meetings

- **Arkansas**
 - Rep. Hill
- **California**
 - Rep. Costa
 - Rep. Pelosi
 - Rep. Peters
 - Rep. Garcia
 - Rep. DeSaulnier
 - Rep. Calvert
 - Rep. Thompson
 - Rep. Valadao
- **Colorado**
 - Rep. Crow
 - Rep. DeGette
 - Sen. Bennet
- **Florida**
 - Rep. Dunn
- **Hawaii**
 - Sen. Schatz
- **Indiana**
 - Sen. Braun
- **Kansas**
 - Rep. LaTurner
 - Sen. Marshall
 - Sen. Moran
- **Louisiana**
 - Rep. Johnson
 - Rep. Carter
 - Sen. Kennedy
 - Rep. Scalise
- **Massachusetts**
 - Sen. Warren
 - Rep. Clark
- **Maryland**
 - Rep. Raskin
- **Maine**
 - Rep. Pingree
- **Michigan**
 - Rep. Huizenga
- **Minnesota**
 - Rep. Craig
- **Mississippi**
 - Rep. Guest
- **North Carolina**
 - Rep. Ross
 - Rep. Hudson
- **New York**
 - Rep. Morelle
 - Rep. Nadler
 - Rep. Williams
- **Oregon**
 - Rep. Bonamici
- **South Dakota**
 - Sen. Rounds
- **Tennessee**
 - Rep. Rose
- **Texas**
 - Rep. Fletcher
 - Rep. Luttrell
 - Rep. Veasey
 - Rep. Weber
 - Rep. Pfluger
- **Virginia**
 - Rep. Connolly
- **Washington**
 - Rep. Schrier
- **Wisconsin**
 - Rep. Steil
- **West Virginia**
 - Sen. Capito
 - Rep. Miller

What Happened in September

12 in the Senate

53 in the House



Cosponsors

- Rep. Eric Swalwell [D-CA-14]
- Rep. Brandon Williams [R-NY-22](INSTANT IMPACT!)

What Happened in September



The FASD Respect Act
Building the Foundation for Change

Slate of 9 Health Bills Passed in House

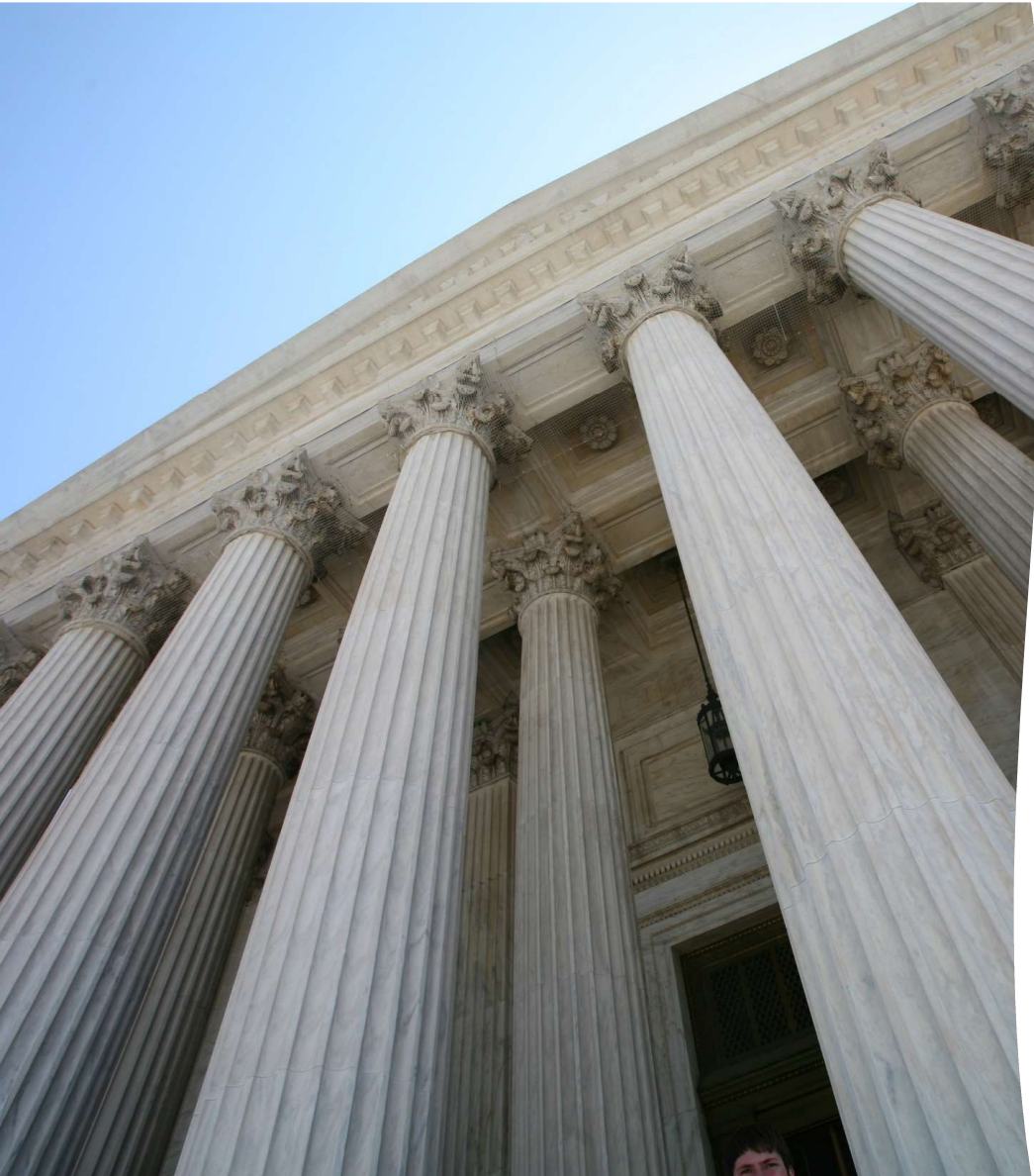
- **S. 133** – *NAPA Reauthorization Act*
- **S. 134** – *Alzheimer's Accountability and Investment Act*
- **H.R. 6829** – *HEARTS Act*
- **H.R. 3884** – *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act*
- **H.R. 2706** – *Charlotte Woodward Organ Transplant Discrimination Prevention Act*
- **H.R. 3433** – *Give Kids a Chance Act*
- **H.R. 7189** – *Congenital Heart Futures Reauthorization Act*

HR. 7213 Autism CARES Act Reauthorization

- Rep Smith (R-NJ) and Rep. Cuellar (D-TX)
- Passed through House last week (402-13)
- Strengthen whole government response to ASD through 2029
 - Ensure research reflects whole of ASD community
 - Increase the number of NIH Centers of Excellence
- 46 cosponsors have not signed onto FASD Respect Act

End of 118th Congress

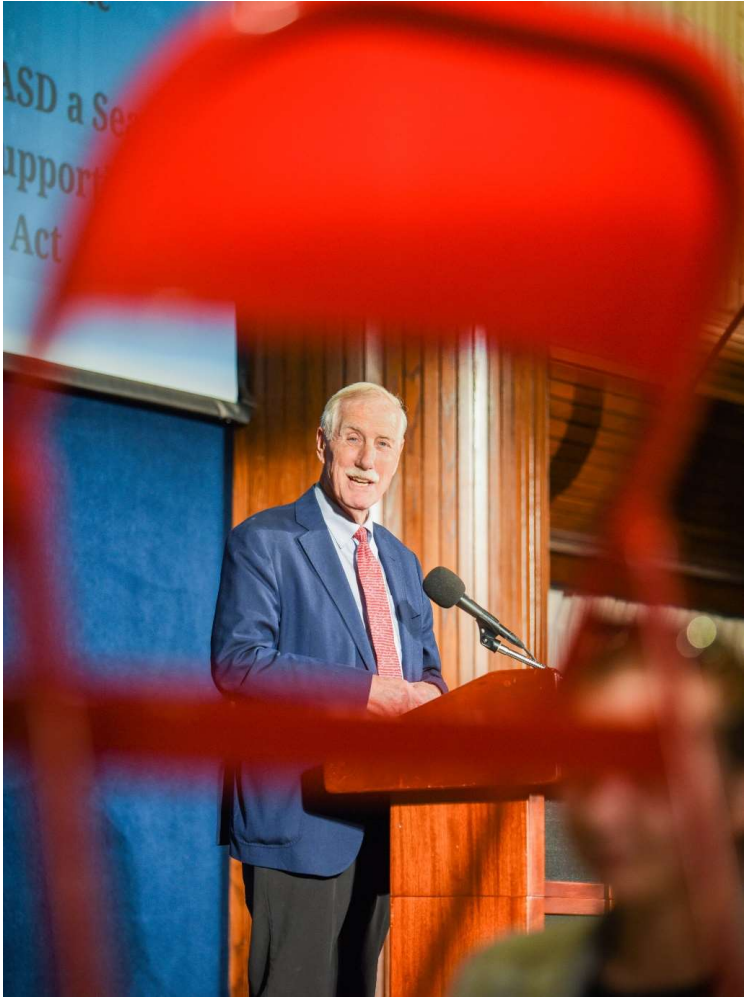
- Session officially ends Jan 3rd, with the last legislative session happening Dec 20th
- Need to push for meetings to socialize bill
- Meeting with House Authors to discuss inclusion in other House bills
- Drafting letter from House and Senate authors to House Energy and Commerce Committee urging them to include FASD Respect Act in the final version of SUPPORT Reauthorization



Virtual Hill Week- November 12th-15th

- A chance for the entire community to connect with their lawmakers
- Can serve as follow-up for those who attended Hill Day
- Contact Chris Melfi (Melfi@fasdunited.org) to coordinate meetings





Sen. Angus King (I-ME) speaking at the Red Shoes Gala



Sen. Lisa Murkowski (R-AK) with Tracey Perez Koehlmoos and Susan Shepard Carlson



Dr. Heather Carmichael Olson speaking after receiving honor at the Red Shoes Gala



Sarah Hamersma, Barb Clark, Michelle Worman, Angela Freeman, and Ryan Jolly during Hill Day



Rep. Bryan Steil (R-WI-1) with Guida Brown



Robin Burgamy meeting with Rep. Huizenga's (R-MI-4) Legislative Aid, Alec



Krista James and Phil Wilson with Alphonse in Sen. Kennedy's [R-LA] office



Krista James and Chris Melfi on the Speaker's Balcony





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Building the Foundation for Change
#FASDRESPECT

Know

- Meetings make a difference
- This is crunch time

Feel

- Empowered to connect
- A sense of urgency
- Power in community

Do

- Book meetings
- Ask to cosponsor
- Ask to pass

