



Policy & Training Center



Monthly Forum

Wednesday, January 27, 2021

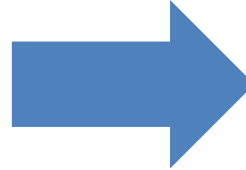
National Organization on Fetal Alcohol Syndrome (NOFAS)

30th Anniversary



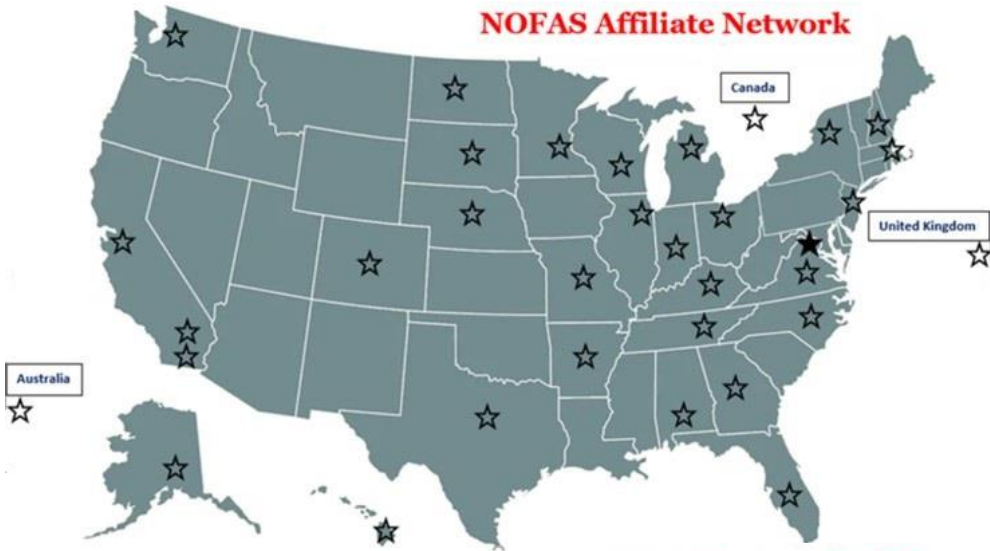
National Organization on Fetal Alcohol Syndrome

1990 - 2020



- Awareness and Education
- Support and Advocacy





N.O.F.A.S. Weekly Roundup
National Organization on Fetal Alcohol Syndrome

News Resources Policy Events Webinars DONATE

NEW AT NOFAS

November 30, 2020

Tomorrow is Giving Tuesday. Join NOFAS!

Tomorrow is Giving Tuesday when you can be part of the global movement to support the causes and organizations you believe in. This year, NOFAS is asking you to make a difference for families and communities by contributing \$30 or more in recognition of 30 years of NOFAS service to the FASD community. Your contribution counts double as the first \$30,000 raised will be matched dollar for dollar by the members of the NOFAS Board of Directors.



Collaborative for Alcohol-Free Pregnancy



Justice Task Force

NABCA



CIFASD Collaborative Initiative on Fetal Alcohol Spectrum Disorders



NOFAS Policy & Training Center

Susan Shepard Carlson

Purpose:

Lead the effort for the “wide” FASD community to achieve desirable public policy outcomes on behalf of individuals living with FASD and their families.

Goals:

- Develop and disseminate a FASD public policy agenda and call to action
- Pursue public policy outcomes that benefit the FASD field on global, federal, state and local levels
- Establish and maintain productive relationships with key partners, public officials and their staff
- Build a coalition of knowledgeable, active policy leaders

Monthly Forum

The forum is a regularly-scheduled monthly virtual meeting (held the last Wednesday of each month at 2:00 p.m. ET) to brief advocates and guide policy outreach.

Monthly Agenda

- Congressional update
- Federal agency update
- FASD legislative strategy and status
- Training, tips, and materials for advocates
- Coordination of outreach
- Q&A

Federal Response to FASD

Tom Donaldson

National Institute on Alcohol Abuse and Alcoholism

FASD FY2020: \$29.4 million



Collaboration on FASD Prevalence (CoFASP) consortium

ICCFASD
Interagency Coordinating Committee
on Fetal Alcohol Spectrum Disorders

Federal Response to FASD

Centers for Disease Control and Prevention

FASD FY2020: \$11 million

Collaborative for Alcohol-Free Pregnancy



MMWR | Screen and Intervene to Reduce Binge Drinking

| | | |
|---|--|--|
| Binge Drinking Can Cause Injury, Disease, Death | More Intervention Is Needed | Primary Care Providers Can Make a Difference** |
| <p>Binge drinking is defined as</p> <p>on an occasion, in about 2-3 hours</p> | <p>4 in 5 adults who binge drink were not advised to reduce drinking by a healthcare provider*</p> | <ul style="list-style-type: none"> <input checked="" type="checkbox"/> SCREEN all adults <input checked="" type="checkbox"/> PROVIDE FEEDBACK about health risks <input checked="" type="checkbox"/> WORK TOGETHER to reduce drinking if patient desires |

*At least once checkup within the past 2 years. **The US Preventive Services Task Force recommends alcohol screening for all adults and brief counseling for those who screen positive. Screen which includes binge drinking. 2017 data from the BRFSS, 12 states and the District of Columbia, as reported in McHugh et al., MMWR. © 2018 CDC. All rights reserved.

www.cdc.gov



Federal Response to FASD

Health Resources and Services Administration

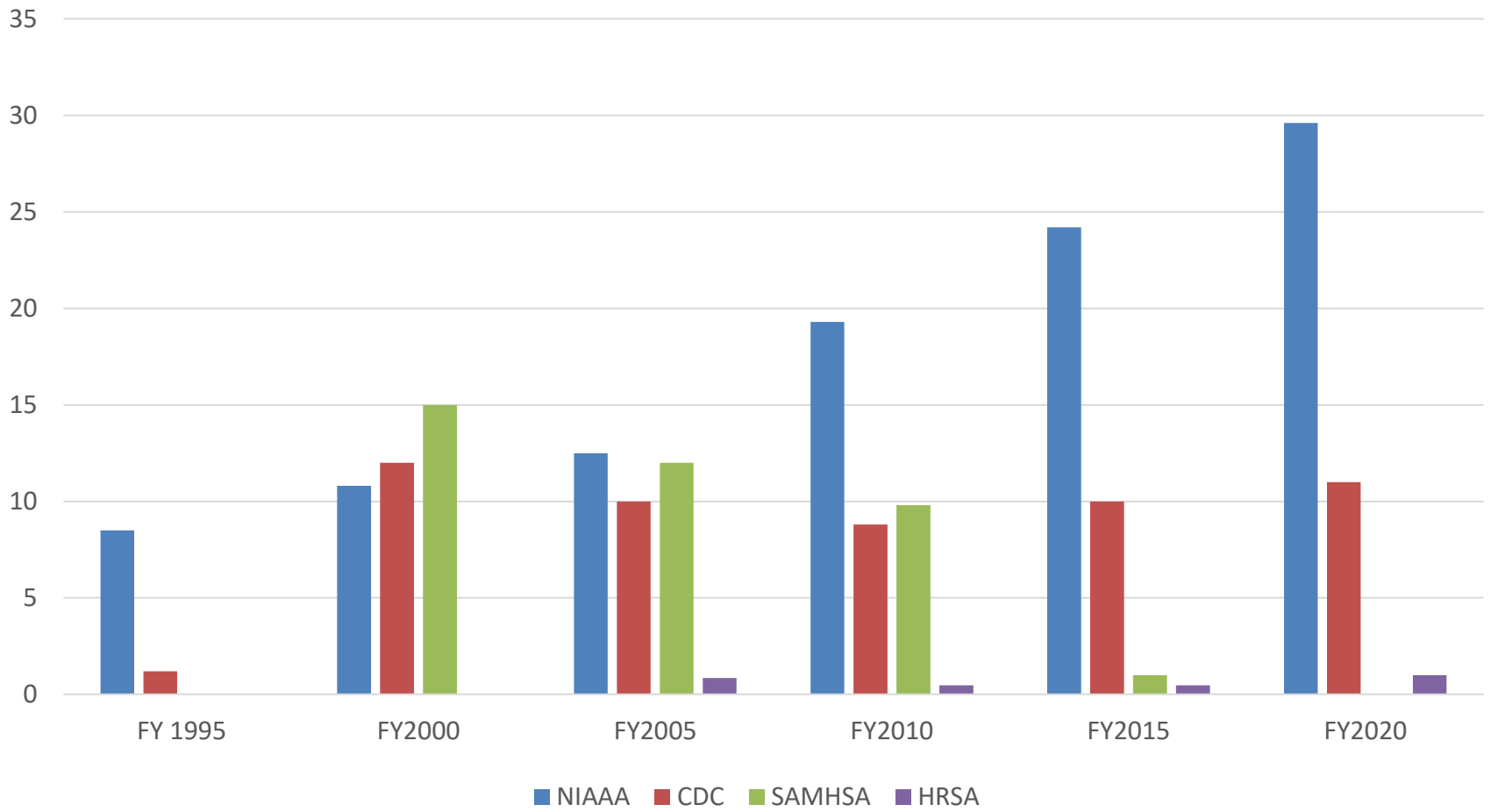
FASD FY2020: \$1 million

Supporting Fetal Alcohol Spectrum Disorders Screening and Intervention program

- 1) to improve the ability of primary care providers (PCPs) serving pregnant women, to screen their patient population for alcohol use, provide brief intervention, and refer high-risk pregnant women to specialty care; and,
- 2) to improve the ability of PCPs serving children and adolescents to screen their patient population for prenatal alcohol exposure among those suspected of FASD, and manage and provide referrals to necessary services for those identified with FASD

FASD Federal Funding

(numbers in millions of dollars)



Overview of the 117th Congress and the Legislative Process

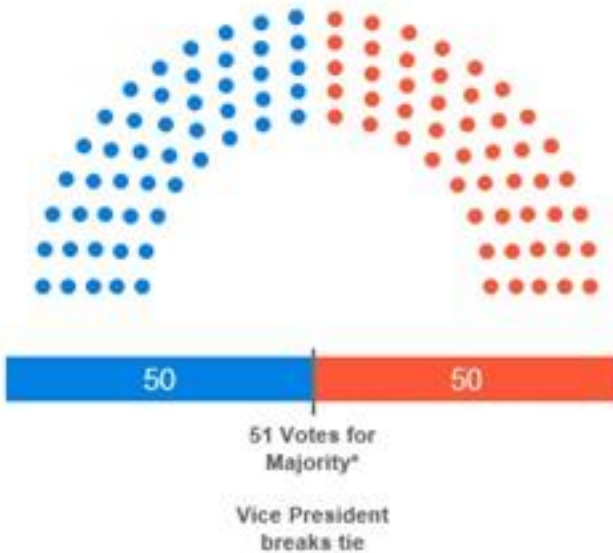
Kate Boyce

U.S. Senate

Democrats: 48

Independents: 2

Republicans: 50

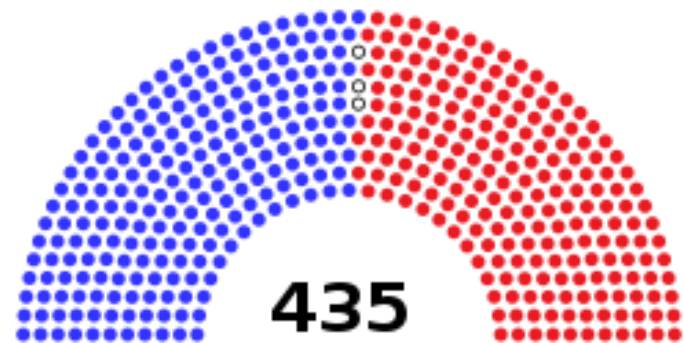


U.S. House of Representatives

Democrats: 221

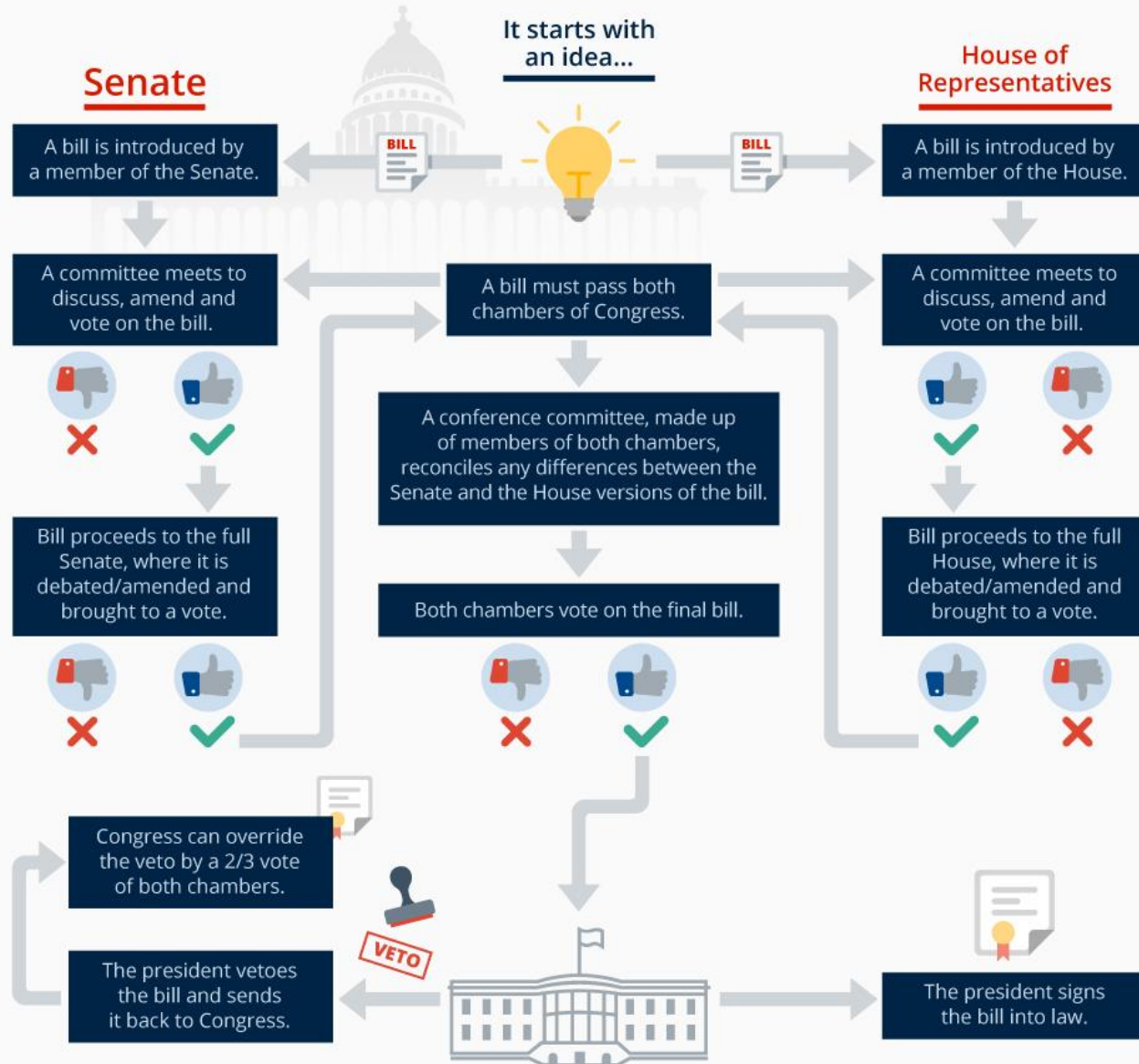
Republicans: 211

Vacancies: 3

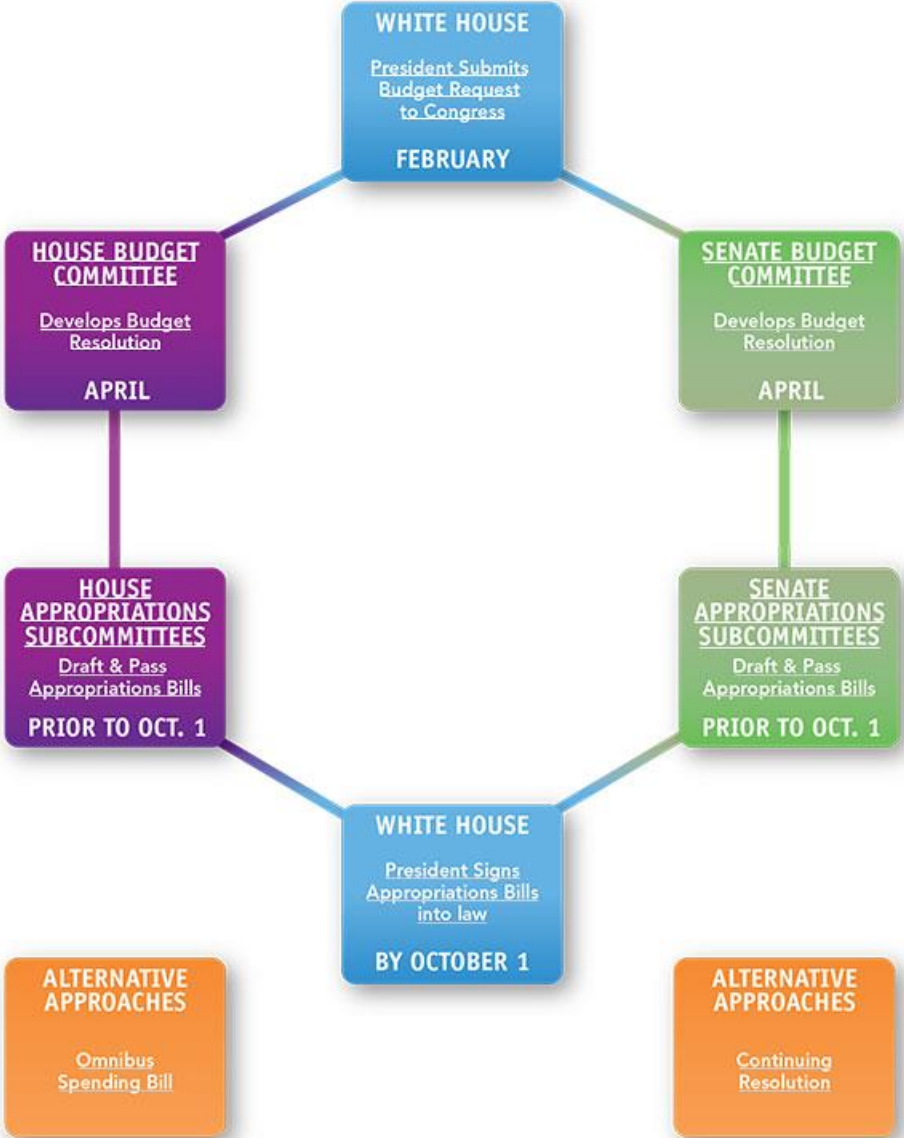




The U.S. Legislative Process



Federal Budgeting and Appropriations



Committees of Jurisdiction for FASD Legislation



US SENATE
COMMITTEE ON
**HEALTH
EDUCATION
LABOR &
PENSIONS**

HOUSE COMMITTEE ON
ENERGY & COMMERCE

CHAIRMAN FRANK PALLONE, JR.

United States Senate Committee on
APPROPRIATIONS
Labor, Health and Human Services, Education, and Related Agencies



**SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES**

Summary of FASD Legislation

Susan Carlson

SECTION 1. SHORT TITLE - “Advancing FASD Research, Prevention and Services Act”.

SECTION 2. PROGRAMS FOR FETAL ALCOHOL SPECTRUM DISORDERS.

(a) Amends Part O of Title III of the Public Health Service Act by adding the following:

(a) DEFINITION.

(b) RESEARCH ON FASD AND RELATED CONDITIONS (NIAAA). The

(c) SURVEILLANCE, PUBLIC HEALTH RESEARCH, AND PREVENTION ACTIVITIES (CDC).

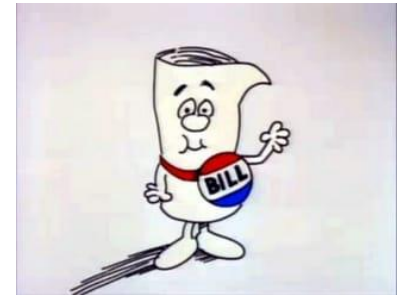
(d) BUILDING STATE FASD SYSTEMS (HRSA).

(e) PROMOTING COMMUNITY PARTNERSHIPS (HRSA).

(f) DEVELOPMENT OF BEST PRACTICES (HRSA).

(g) TRANSITIONAL SERVICES (HRSA) – SERVICES FOR ADULTS.

(h) AUTHORIZATION OF APPROPRIATIONS. Authorization of expenditures for fiscal years 2022 through 2027.



FASD Legislation

SECTION 2. PROGRAMS FOR FETAL ALCOHOL SPECTRUM DISORDERS. (Continued)

(b) SERVICES FOR INDIVIDUALS WITH FASD.

(c) PREVENTION, IDENTIFICATION, INTERVENTION, AND SERVICES IN THE EDUCATION SYSTEM.

(d) PREVENTION, IDENTIFICATION, INTERVENTION, AND SERVICES IN THE JUSTICE SYSTEM.

(e) SUNSET PROVISION. Requires the Secretary of HHS to make recommendations to Congress whether programs shall continue no later than four years after appointment of members to the National Advisory Council on FASD.

116TH CONGRESS
1ST SESSION

S. 2879

To amend the Public Health Service Act to reauthorize and extend the Fetal Alcohol Spectrum Disorders Prevention and Services program, and for other purposes.

FASD Legislation

SECTION 3. NATIONAL ADVISORY COUNCIL ON FASD.

The Secretary shall establish a 17-member advisory council to be known as the National Advisory Council on FASD to foster coordination and cooperation among all government agencies, academic bodies and community groups that conduct or support FASD research, programs, and surveillance, and otherwise meet the general needs of populations actually or potentially impacted by FASD.

SECTION 4. INTERAGENCY COORDINATING COMMITTEE ON FASD.

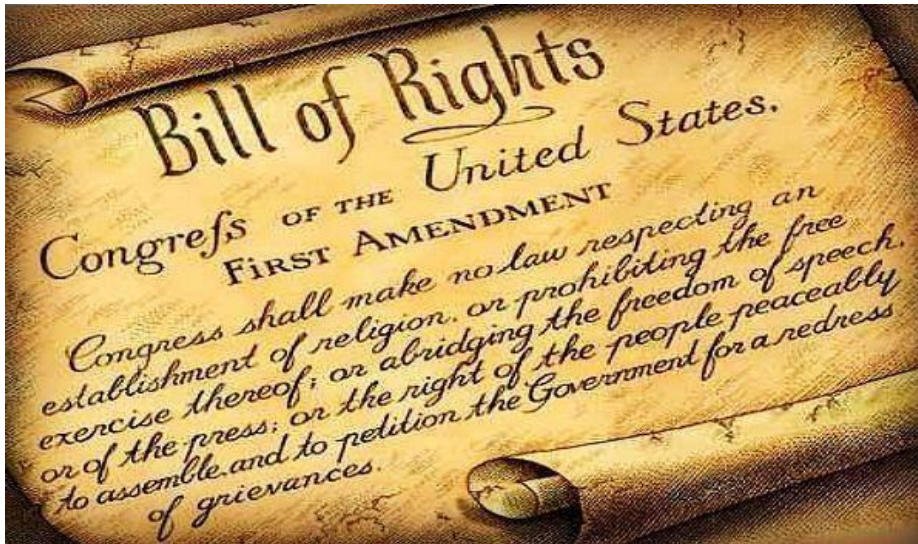
SECTION 5. FASD CENTER FOR EXCELLENCE.

SECTION 6. APPROPRIATIONS

Authorizes appropriations for each year \$50,000,000 for FY2022 and such sums as may be necessary for each of fiscal years 2023 through 2027. Funding for the National Advisory Council on FASD shall not exceed \$2 million and for the Interagency Coordinating Committee on FASD shall not exceed \$1 million.

Advocacy – It's a Right

Mike Anderson

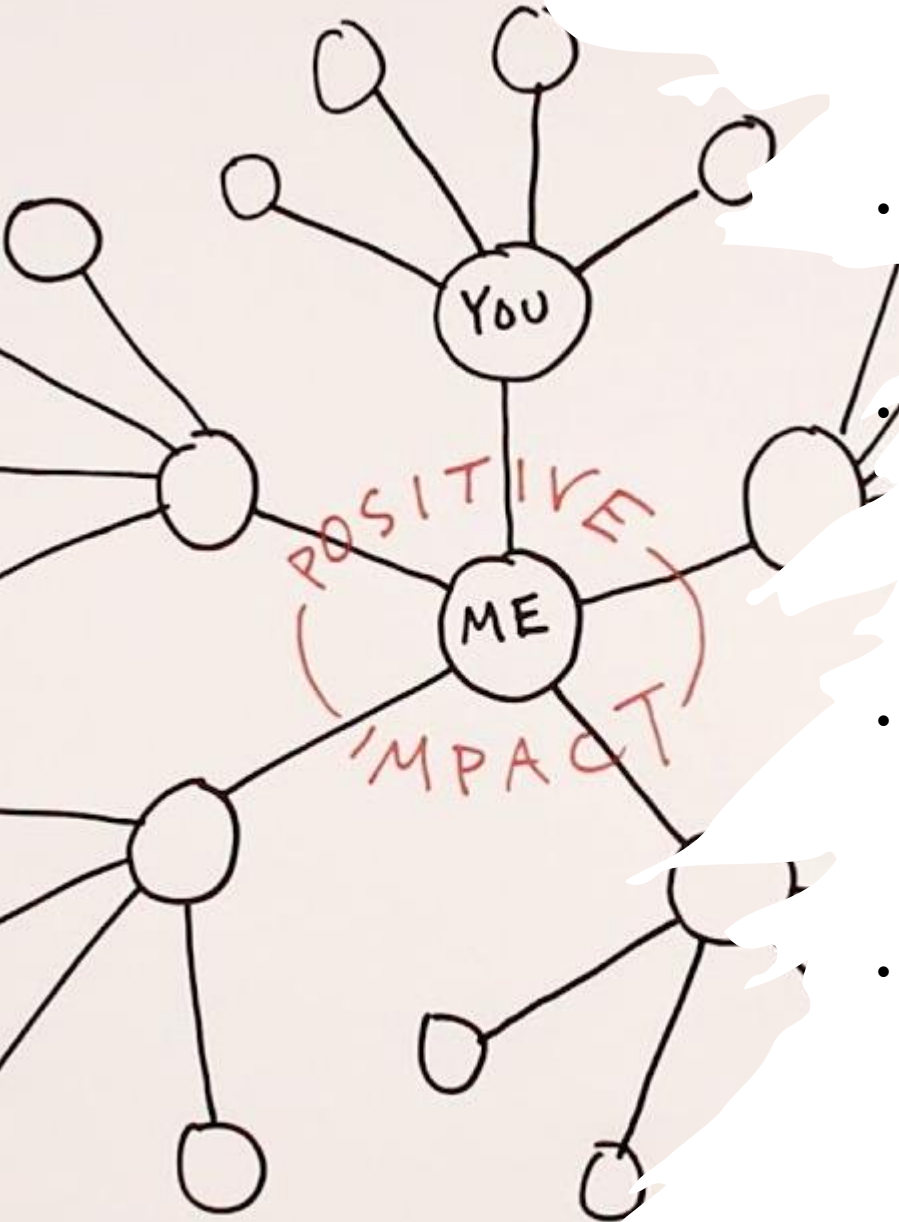


Advocacy - Attempts by an individual or group to bring about change on behalf of a particular goal, program, interest, or population. Advocacy includes educating policymakers and the public about evidence-based policy.

Lobbying - Attempts to influence a legislative body through communication with a member or employee of a legislative body, or with a government official who participates in formulating legislation. Lobbying can include written and oral communication for or against specific legislation. Grassroots lobbying consists of efforts to influence legislation by encouraging the public to contact legislators about legislation.



Your Role as an Advocate



- **Tell your story!** Describe how you are affected by FASD; why it is important to you
 - Maintain an up-to-date and accurate knowledge of FASD
- Contribute your perspective to our FASD national policy agenda and legislative proposals
 - Help document the significance and impact of FASD in your state
 - Stay connected with NOFAS; follow the status of active legislation
- Grow your expertise on proposed legislation, policies and the talking points and materials to be shared with policymakers
 - What's the overall, unified message (hint: national agenda for FASD)
- Establish and nurture relationships with your elected officials and their staff
 - Contact and follow-up with legislative staff – let others in our FASD network know who you visited, what your message was, what the result was, what the next action is
- Recruit other advocates to join our cause

Let's get started!

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Let's get started!

Let's get started!

Create, advance, and fund a National FASD Agenda

SENATE

- Likely Sponsors: Murkowski (R-AK) and Klobuchar (MN)
- Targeted Co-Sponsors in key states: WA, CA, NC, NH, MO, IN
- ☐ **Ask your Senator to co-sponsor**
 - Contact their health assist by email/call
 - Nature of FASD in your State
- **By When: mid February**
- What you should send them
 - Tailored Leave Behind (latest, specific)
 - Copy of Legislation
 - Summary of legislative provisions
- When should you follow up (a week later)
 - Did you get my email?
 - Do you have any questions I can answer?
 - When should I contact you next?
 - Are there other offices I should contact to help?
- Follow w/"No Asks." Just send updates

HOUSE

- Likely Sponsors: McCollum (D-MN-04) and Young (AK-00)
- Targeted Co-Sponsors in key states: (e.g., WA, CA, NH, MN, FL, IL)
- ☐ **Ask your Representative to co-sponsor**
 - Contact their health assist by email/call
 - Nature of FASD in your State
- **By When: mid February**
- What you should send them
 - Tailored Leave Behind (latest, specific)
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- Follow w/"No Asks." Just send updates

Questions about the process? Mike Anderson, akahellellc@gmail.com, 571-481-7148

How do I...?

1. **Know your audience.** Research bios, positions, staff, past votes. Anticipate questions that could be asked.
2. **Know your ask, your message, your story.** Organize, practice, refine.
3. **For multiple advocates, assign each a role to speak to.**
4. **Prioritize your ask and message up front.** Be prepared for interruptions, shorter time than anticipated.
5. **Send a meeting request at least 2-weeks in advance** to both the scheduler and staffer. Follow up on your request after two days.
6. **Email meeting materials in advance to the staffer,** thanking them at the same time for the opportunity to meet with them at XX O'clock on XXX day.
7. **“Standard” approach**
 - **Lead Advocate. Thank you for meeting today**
 - Recognize Member’s help and staff’s help (as applicable) in the past
 - Introduce advocates – some small talk will ensue
 - Ask if they have the materials you sent them on hand
 - **Roles as assigned**
 - Make your ask, tell your story, make your case
 - Assign a note taker!!
 - **All**
 - Listen, ask questions, seek to understand while increasing awareness
 - **Lead Advocate. Thank you for meeting today**
 - Feedback what you heard you can expect from the staffer and Member
 - If they need more info, what is it and when will you have it back to them
 - Who else should we be speaking to? Can you help introduce us to them?
 - Can we keep the staffer in the loop on this issue as we advance this legislation?

1/10/10



Thank You!



National Organization on Fetal Alcohol Syndrome