

Dear Colleagues,

Please consider completing an electronic survey being conducted as part of an AAP grant funded project focused on the prevention, early identification and care for children who have or may have one of the Fetal Alcohol Spectrum Disorders (FASDs).

Survey Link https://uwmadison.co1.qualtrics.com/SE/?SID=SV_5tj8ewogdGRUk1T

Purpose: The intent of this survey is to gather information about pediatric primary care and sub-specialty care attitudes and practices regarding the identification of children who have or may have one of the FASDs as well as corresponding care management, care coordination and care planning for children who were prenatally exposed to alcohol.

Eligible Participants: All pediatricians and pediatric subspecialists are welcome to complete the survey. Questions will be most applicable to primary care and subspecialty pediatricians who provide well-child care in an out-patient or ambulatory care setting.

Time: The survey will take approximately 5-10 minutes to complete.

All surveys will be anonymous. Survey results will be used to inform the development of education, awareness and practice-based resources for pediatricians and other pediatric clinicians. Please contact the AAP Program Manager, Josh Benke, at 847/434-7863 or jbenke@aap.org if you have questions about the survey and/or its results.

Thank you in advance for the time you take to https://uwmadison.co1.qualtrics.com/SE/?SID=SV_5tj8ewogdGRUk1T complete this survey.

Best regards,

Vincent C Smith, MD, FAAP

Medical Director

AAP FASD Prevention, Early Identification and Management Program

Public reporting burden of this collection of information varies from 5-10 minutes with an estimated average of 7 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).

SURVEY OF PEDIATRICIANS: FASD PREVENTION, EARLY IDENTIFICATION AND CARE FOR AFFECTED CHILDREN

1. Do you currently provide primary or specialty medical care to pediatric patients?
 Yes No

2. Are you currently in a pediatric residency or fellowship training program?
 Yes No

3. Do you feel it is important to inquire about prenatal alcohol exposure in your patient population?
 Yes No

4. Please check which of the following two statements below best corresponds with your personal viewpoint. Please check only ONE box

 Occasional consumption of alcohol (one standard drink per day or less) during pregnancy is not harmful to the mother or the fetus.

 Pregnant women or women who are trying to become pregnant should completely abstain from consuming alcohol.

5. Please indicate to what extent you agree with the following statements about alcohol consumption during pregnancy:

Alcohol consumption during pregnancy...	<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Neither Agree nor Disagree</u>	<u>Agree</u>	<u>Strongly Agree</u>
a. Is more prevalent in women with lower incomes	1	2	3	4	5
b. Is more prevalent in women with higher incomes	1	2	3	4	5
c. Does not vary between income levels	1	2	3	4	5
d. Is more prevalent in women with lower levels of education	1	2	3	4	5
e. Is more prevalent in women with higher levels of education	1	2	3	4	5
f. Does not vary between education levels	1	2	3	4	5
g. Is more prevalent in African-American women	1	2	3	4	5
h. Is more prevalent in American-Indian women	1	2	3	4	5
i. Is more prevalent in Anglo-white women	1	2	3	4	5
j. Is more prevalent in Asian-American women	1	2	3	4	5
k. Is more prevalent in Hispanic/Latina-American women	1	2	3	4	5
l. Does not vary between ethnic or racial groups	1	2	3	4	5

6. To what extent do you agree that fetal alcohol spectrum disorders (FASD) are more likely to occur in children from certain racial or ethnic groups?

<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Neither Agree nor Disagree</u>	<u>Agree</u>	<u>Strongly Agree</u>
1	2	3	4	5

7. To what extent do you agree that making a diagnosis of one of the fetal alcohol spectrum disorders (FASDs) stigmatizes the child and/or the family?

<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Neither Agree nor Disagree</u>	<u>Agree</u>	<u>Strongly Agree</u>
1	2	3	4	5

8. To what extent do you agree that concerns regarding stigma contribute to pediatricians' reluctance to identify the physical and behavioral health concerns that could lead to a diagnosis of one of the fetal alcohol spectrum disorders in their patient?

<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Neither Agree nor Disagree</u>	<u>Agree</u>	<u>Strongly Agree</u>
1	2	3	4	5

9. Which of the following are the primary dysmorphic facial features associated with prenatal alcohol exposure? (Check all that apply)

- Wide inner canthal distance
- Short palpebral fissures
- Full lips
- Smooth philtrum
- Thin upper lip
- Flaring nares
- Don't know/unsure

10. Which of the following could indicate that a child may have been exposed to alcohol prenatally? (check all that apply)

- Growth deficiencies
- Clinically significant abnormalities on neuroimaging and/or a history of seizures
- Cognitive/developmental deficits or discrepancies
- Executive function deficits
- Delays in gross/fine motor function
- Problems with self-regulation/self-soothing
- Delayed adaptive skills
- Confirmed history of alcohol exposure in utero
- Don't know/unsure

11. The diagnosis of “neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)” as identified in the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5):
- Requires recognition of neurocognitive impairment, impaired self-regulation, and deficits in adaptive functioning
 - Can be diagnosed without knowledge of confirmed prenatal alcohol exposure
 - Includes recognition of the 3 primary morphologic features of prenatal alcohol exposure
 - Is the least common manifestation of prenatal alcohol exposure
 - All of the above

12. During the past two years, did you diagnose any children with fetal alcohol syndrome (FAS) or any of the fetal alcohol spectrum disorders (FASDs)?
- Yes No

If YES, which diagnostic schema (if any) did you use to support your diagnosis:

- Institute of Medicine criteria
- American Academy of Pediatrics algorithm and/or toolkit
- Seattle 4-digit diagnostic criteria
- Diagnostic and Statistical Manual of Mental Disorders (DSM-5)
- Other schema (please specify) _____
- I did not use any particular schema

13. During the past two years, did you refer any children for assessment for one of the fetal alcohol spectrum disorders?
- Yes No

14. In the past two years, have you participated in any training on fetal alcohol spectrum disorders (e.g., residency training, CME training)?
- Yes No

15. In the past two years, have you used, referenced or been made aware of the following fetal alcohol spectrum disorders (FASDs) resources?
- American Academy of Pediatrics FASD Online Toolkit
- Centers for Disease Control and Prevention FASD Webpage
- FASD Center for Excellence SAHMSA Webpage
- NOFAS Website
- Other reference or resource (please specify) _____
- I did not use any particular FASD resources in the past two years

16. How prepared are you to identify children who have or may have one of the Fetal Alcohol Spectrum Disorders?

<u>Not at all prepared</u>	<u>A Little Prepared</u>	<u>Moderately Prepared</u>	<u>Prepared</u>	<u>Completely Prepared</u>
1	2	3	4	5

17. How willing are you to diagnose and/or refer for further evaluation and possible diagnosis children who may have one of the fetal alcohol spectrum disorders?

<u>Not at all Willing</u>	<u>A Little Willing</u>	<u>Moderately Willing</u>	<u>Willing</u>	<u>Completely Willing</u>
1	2	3	4	5

18. Are you aware of clinical guidance on screening for prenatal alcohol exposure in pediatric patients?

Yes No

If "yes," please specify: _____

TELL US A LITTLE ABOUT YOURSELF AND YOUR PRACTICE

19. During a typical workweek, how many hours do you spend in the following professional activities?
If you do not spend any time in a particular activity, please enter zero (0) hours in the appropriate space.

<u>Activity:</u>	<u>Hours:</u>
Direct patient care	_____
Administration	_____
Academic Medicine	_____
Research	_____
Fellowship training	_____
Other (specify) _____	_____
TOTAL HOURS/WEEK	_____

Are you currently in a pediatric residency training program? Yes No

20. Approximately what percentage of your time is spent in the following areas?

General pediatrics _____ %
 Other specialty/subspecialty area (specify - please print) _____ %
 _____ **100%**

21. Please indicate your primary employment site setting, that is, the setting where you spend most of your time. Please indicate only ONE response.

- Self-employed solo practice
- Two physician practice
- Pediatric group practice, 3-10 pediatricians
- Pediatric group practice, >10 pediatricians
- Multispecialty group practice
- Health maintenance organization (staff model)
- Medical school or parent university
- Non-profit community health center
- Non-government hospital or clinic
- City/county/state government hospital or clinic
- US government hospital or clinic
- Other: _____

22. Please describe the community in which your primary practice/position is located?

- Urban, inner city
- Urban, not inner city
- Suburban
- Rural

23. In what year were you born? 19_____

24. How many years have you been in practice (do not include formal training)? _____
(number of years)

25. What is your gender? Male Female Transgender

26. With what racial or cultural group(s) do you identify yourself? (Indicate all that apply)

- White, non-Hispanic/Latin@
- Hispanic/Latin@
- Black/African American, non-Hispanic/Latin@
- Asian
- Native Hawaiian/other Pacific Islander
- American Indian/Alaska Native

Thank you for taking the time to complete this survey!