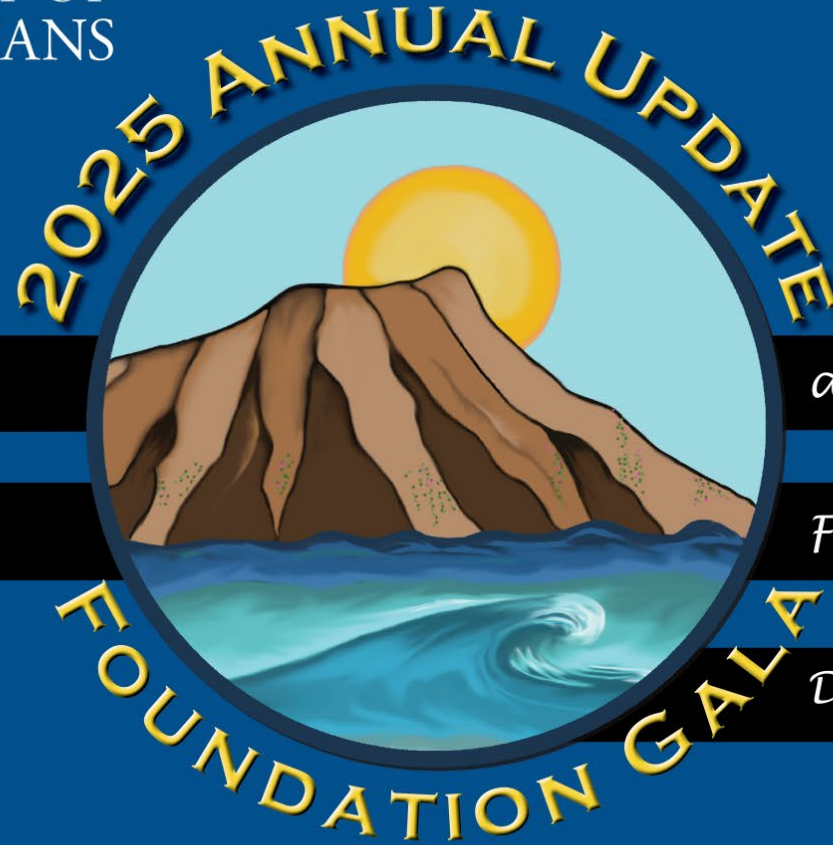




HAWAII ACADEMY OF
FAMILY PHYSICIANS



February 7-9, 2025

and

February 8, 2025

Doubletree Alana - Waikiki

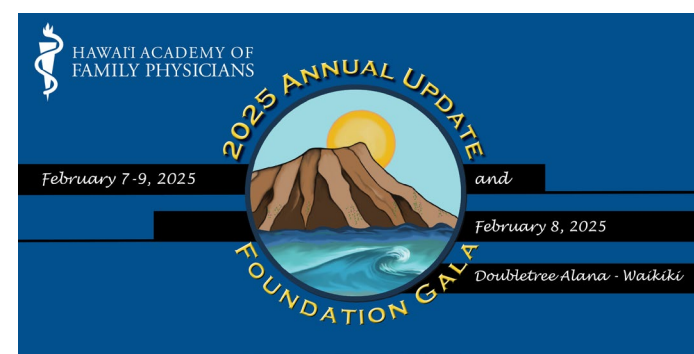
FASD IS A KĀKOU THING

Amanda Luning, LMCH, IECMH-E®

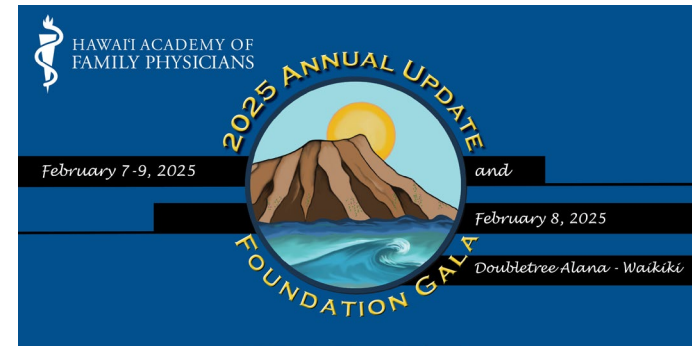
Executive Director/DrPH Candidate

This presentation may...

- Leave you feeling uncomfortable or overwhelmed
- Leave you with more questions than answers
- Ask you to explore ambiguity
- Encourage you to remember why you chose to be in a helping profession and remind you that you are a part of a community of helpers.

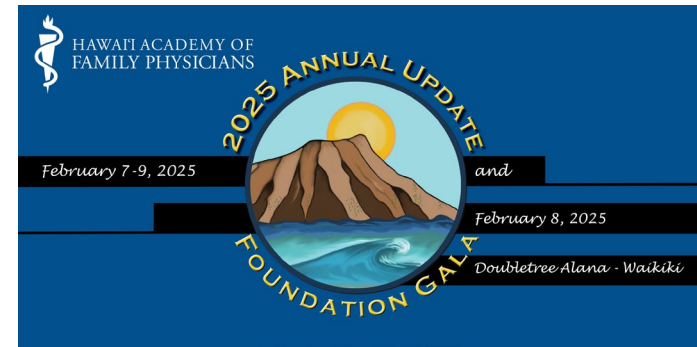


"Do the best you can until you know better.
Then **when you know better, do better.**"
—Maya Angelou.



**“As a collective we
commit to giving the
benefit-of-the-doubt that
each of us here to be of
help and service and is
doing the best we can
with what we have.”**

-HI FASD AG GROUP TENET



THE HAWAI'I FASD ACTION GROUP

Our Mission:

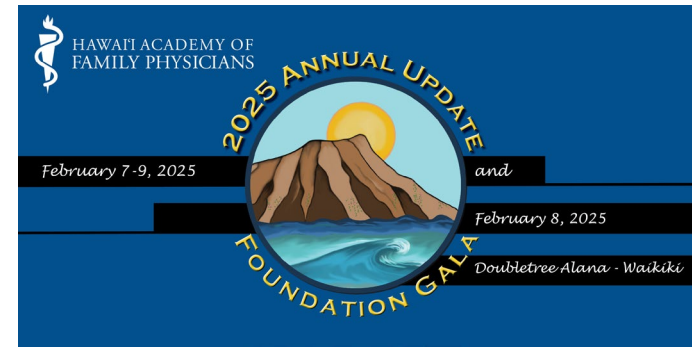
The Hawai'i FASD Action Group's primary mission is to raise awareness through education, advocacy, and research on the impact of Fetal Alcohol Spectrum Disorder (FASD) on individuals, their families, and the communities of Hawai'i.



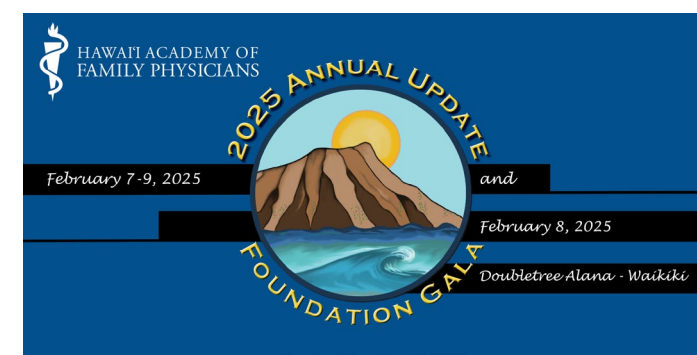
Together...let's make FASD "Invisible No More"

Presentation Objectives:

- Recognize fetal alcohol spectrum disorders (FASD) as a complex set of conditions that can be assessed for throughout the lifespan.
- Identify some of the interdisciplinary work happening in this area and learn more about some Hawai'i-based risk data.
- Feel empowered to take the information back to your practice and support community initiatives to increase overall awareness and systems of support for patients with these conditions.



ABOUT FASD



Fetal Alcohol Spectrum Disorders (FASD) are a spectrum of diagnosable conditions, ranging from the most serious Fetal Alcohol Syndrome (FAS), with a range of health conditions such as heart defects and visual and hearing impairments, to the often “hidden” lifelong neurological and neurodevelopmental disorders due to prenatal alcohol exposure. These can cause more subtle issues such as sensory sensitivities and other functional, social, memory, and communication impairments. ^{3,4,9}

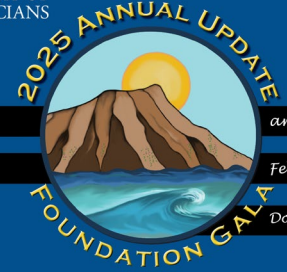
What are the spectrum of conditions?

The term fetal alcohol spectrum disorders (FASD) refers to a range of physical, cognitive, and behavioral abnormalities caused by prenatal alcohol exposure. Depending on the features identified, the disorders categorized as FASD include:

- Fetal alcohol syndrome (FAS)
- Partial fetal alcohol syndrome (PFAS) *moving away from this*
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects
- Neurobehavioral disorder associated with prenatal alcohol exposure ¹



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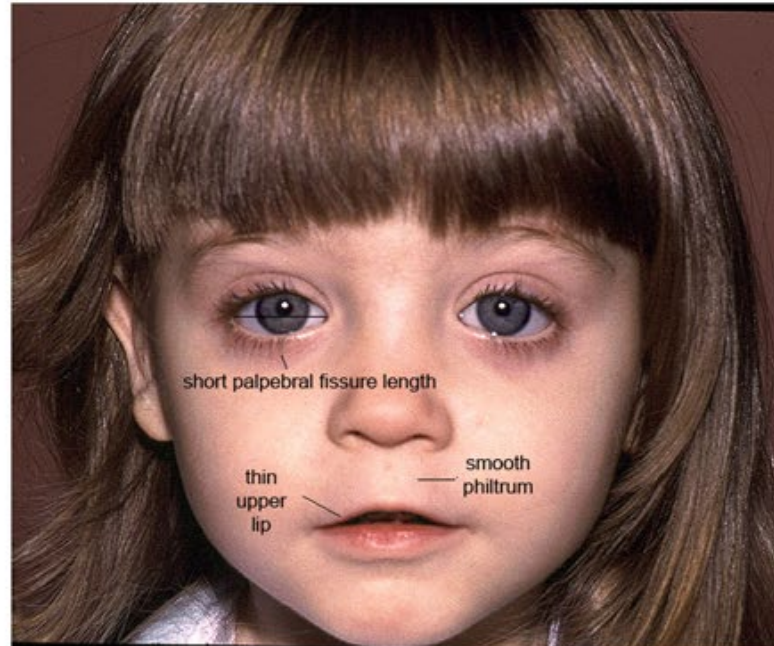
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February 8, 2025

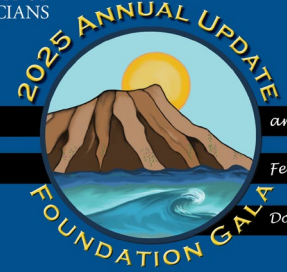
Doubletree-Alana - Waikiki

Characteristic Facial Features

- Short palpebral fissures
 - Thin vermillion border
 - Smooth philtrum
-
- There are other features that occur with increased frequency in individuals with an FASD.
 - Visit AAP.ORG/FASD, [Fetal Alcohol Spectrum Disorders Assessment](#) or the [FASD Diagnostic and Prevention Network](#) by University of Washington.



Source: Dr. Noemi Alice Spinazzi, MD, FAAP
UCSF Benioff Children's Hospital – Oakland



Minor Anomalies

- Hypoplastic midface – 58%; Flat nasal bridge – 48%
- Epicanthal folds – 55%; Ptosis – 17 %
- Decreased interpupillary distance ($\leq 25^{\text{th}}$ percentile) – 55%;
Decreased intercanthal distance ($\leq 25^{\text{th}}$ percentile) – 28%
- Altered palmar crease (eg, "hockey stick" configuration of the upper palmar crease)– 47%; 5th finger clinodactyly – 40%;
camptodactyly – 31%
- "Railroad track" ears (ie, a prominent horizontal crus and prominent and parallel inferior crus of the anthelix) – 15 %
- Long philtrum ($\geq 90^{\text{th}}$ percentile) – 33 %
- Anteverted nares – 32%



Source: Dr. Noemi Alice Spinazzi, MD, FAAP
UCSF Benioff Children's Hospital – Oakland

Central Nervous System (CNS) Involvement

- Required for the diagnosis of FAS, pFAS, ARND and ND-PAE
- Can be structural, neurologic, or functional
- Structural: decreased head circumference ($<10^{\text{th}}$ percentile for age/sex or, if height/weight also $<10^{\text{th}}$ percentile, HC $<3^{\text{rd}}$ percentile); abnormalities on MRI
- Neurologic: abnormal reflexes, abnormal tone, cranial nerve deficits, recurrent seizures
- Functional: Cognitive, executive function, memory, motor, social skills

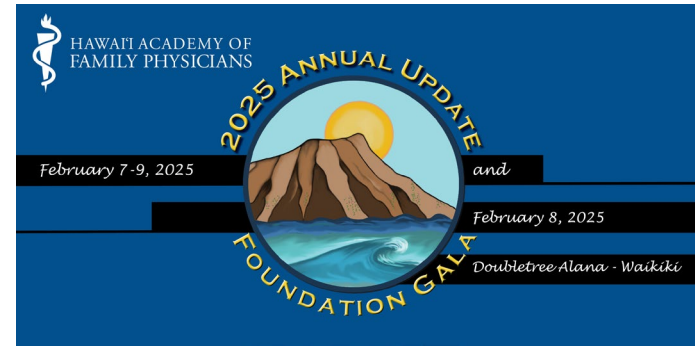
Source: Dr. Noemi Alice Spinazzi, MD, FAAP
UCSF Benioff Children's Hospital – Oakland

There is currently no specific or sensitive screening tool (ex: no M-CHAT for FASD).

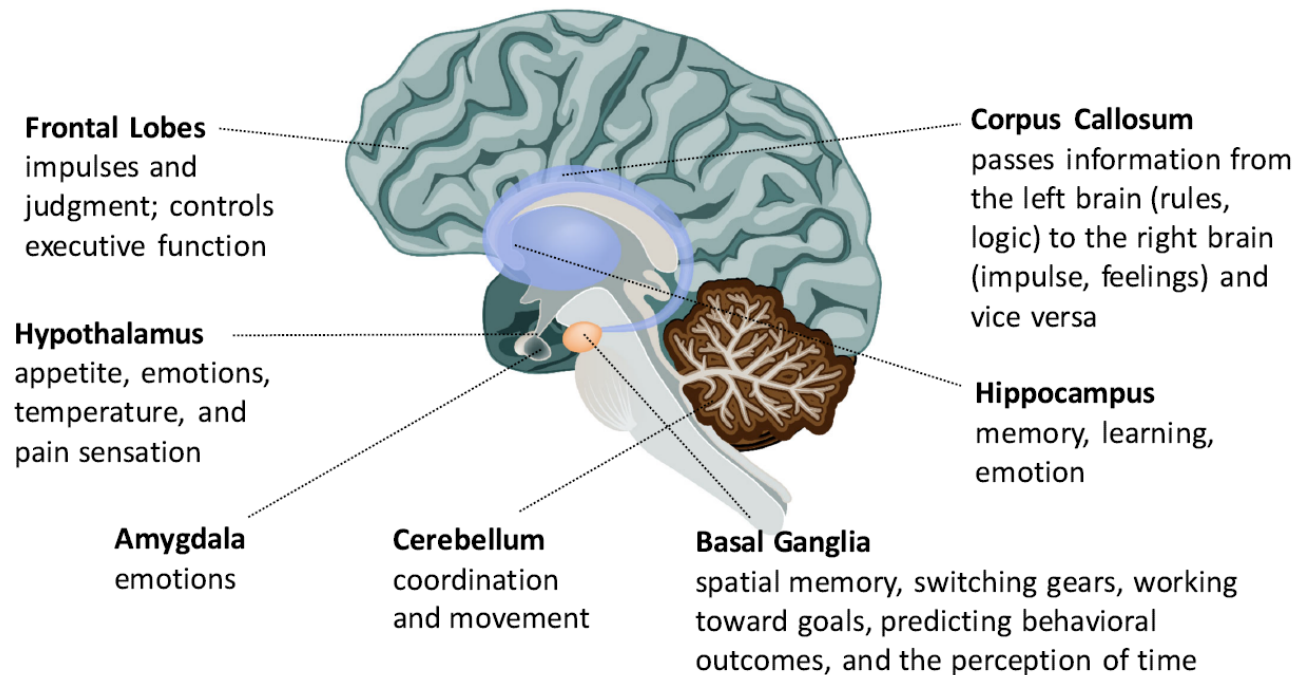
Only 10%-20% of kids with an FASD have facial or observable structural features.

So, what about the rest?

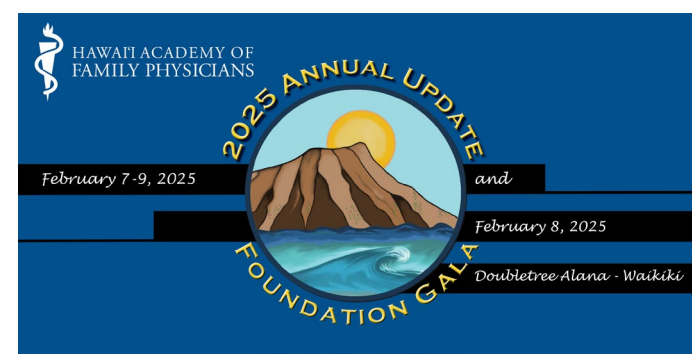
Brain-Based Neurobehavioral Disorder



Areas of the Brain Affected By Prenatal Alcohol Exposure



Source: Dr. Sarah Mattson, UCSD



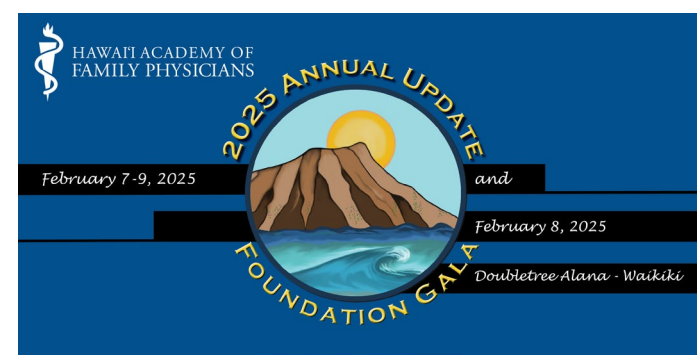
Things to “Keep in Mind”

- Any developmental, cognitive, or behavioral concerns (especially those that present as difficult to “treat”)
- Complex medical concerns
- Growth deficiencies
- Maternal history, including alcohol or substance use, as well as any available information on prenatal care
- Sibling or family member diagnosis
- Family history of adoption, foster care, or child welfare services involvement
- Exam features associated with an FASD

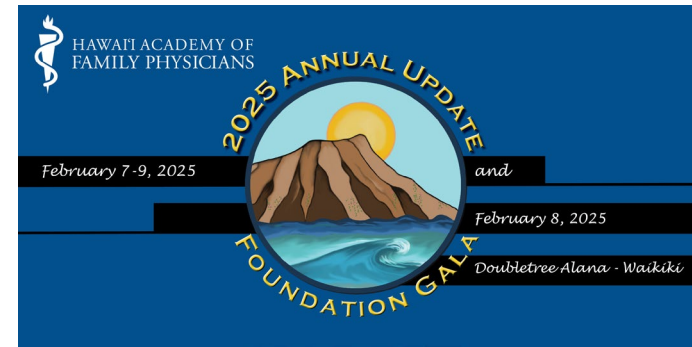
Not a “One and Done”

Ask objectively, document objectively...be kind and real.

Getting REAL about FASD



- It is more prevalent than Autism Spectrum Disorders, as high as 1 in 20 first graders ^{2,7}
- Pregnancy and alcohol statistics in Hawai'i are indicative of even higher rates ^{5,6}
- It is currently NOT screened for throughout the lifespan



Why “Kākou Thing”?

- Alcohol use is ubiquitous in our communities, and not just a women’s or pregnancy issue
- We ALL have a responsibility to talk about alcohol use and its effects...*past, present, and future*
- Public awareness messaging has historically been oversimplified

(ex: DOH flyer from 2013)

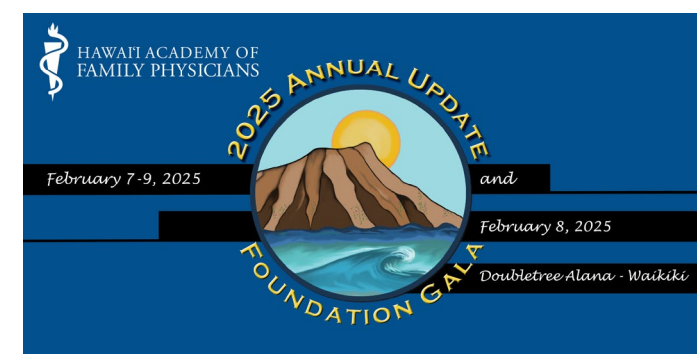
Why “Kākou Thing”?

FASD is VERY often undiagnosed or misdiagnosed.

The effects of an FASD, especially when unidentified, significantly increase:

- School, behavioral, and learning challenges
- The likelihood of mental and health and substance use disorders
- Involvement in public safety and our court systems ¹⁰
- Vulnerability in unsafe situations and with unsafe people

What can I do as a Family Physician?



LEARN MORE

FASD UNITED Spotlight on AAFP

<https://fasdunited.org/fasd-npn-spotlight-american-academy-of-family-physicians-aafp/>

<https://fasdunited.org/> (*resources, interventions, parent and family supports, social and health justice*)

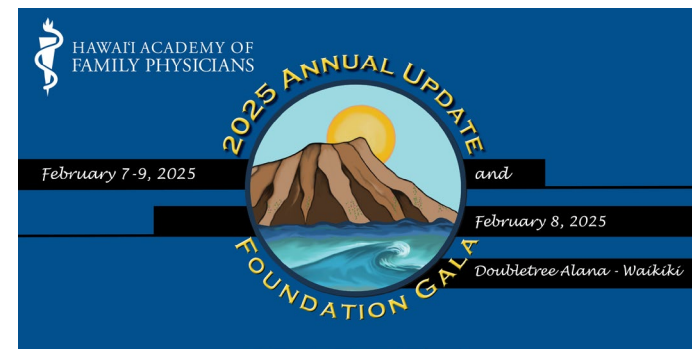
SCREEN MORE

<https://www.aafp.org/pubs/afp/issues/2017/1015/p515.html>

<https://www.aap.org/fasd>

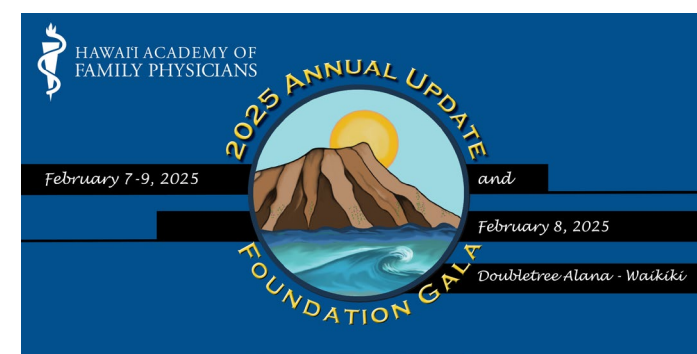
TALK MORE...

TALK ABOUT IT



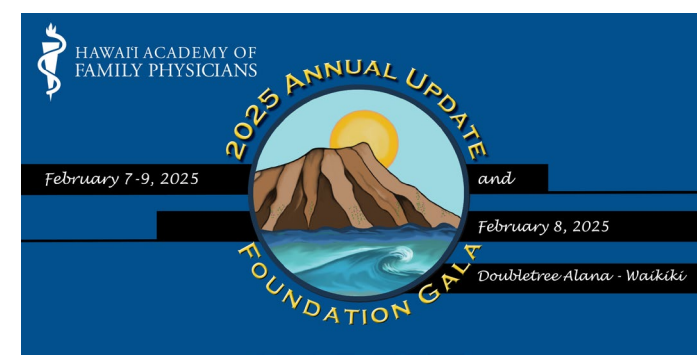
- “Each body is different. Sometimes women don’t know they’re pregnant right away.”
- “Alcohol use is legal for adults, socially acceptable, and culturally encouraged. It is used very frequently in regular social interactions, ceremony, and celebration.”
- “There are a lot more of us affected by alcohol than we know.”
- “The effects of alcohol on fetal development are unique, and while no amount is truly safe, each person may have different needs and conditions, the more information the better the care and supports people can receive.”

Exploring “FASD-Informed”?

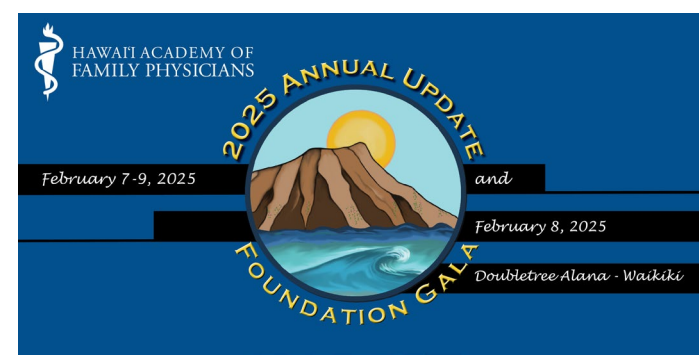


- Understanding that we may never get accurate or direct information about alcohol use and/or exposure, but it can still be considered.
- Making brain-based considerations in understanding and responding to the “meaning” of all behavior (vs. non-compliant, defiant, resistant, willful, intentional, etc.).
- Slowing down, trying something new, allowing for differences in a very fast-paced world.

We CAN all make a difference



- Check our BIAS
(then check it again...and again, and again, and again...)
- Who are we screening...when, why, and how?
- Family Physicians are uniquely positioned to know FAMILIES and can take a multigenerational approach to care.
- CONNECT with other types of providers!



Efforts here at HOME...

- Department of Health

https://health.hawaii.gov/about/files/2013/06/Brochure_Alcohol_Can_Hurt.pdf (AND SO CAN THIS BROCHURE ☺)

- Hawai'i FASD Action Group

<https://fasdhawaii.org/>

- September Awareness Month

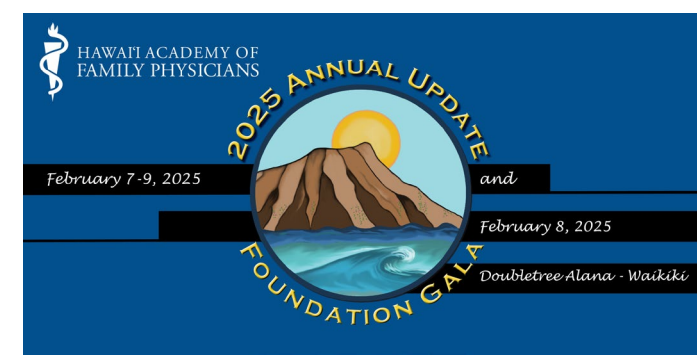
<https://governor.hawaii.gov/wp-content/uploads/2017/12/170908-Proc-FASD-Awareness-Month.pdf>

- Social Laboratory Project

<https://fasdhawaii.org/wp-content/uploads/2024/12/Hawai'i-FASD-Action-Group-Executive-Summary-FASD-Social-Laboratory-Project-Awared-no.-OCS-GIA-23-87.pdf>

- Act 192 (2023)...

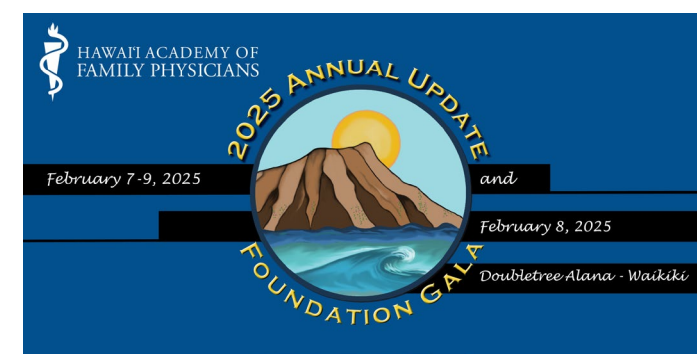
Act 192: Co-Managed System of Care



From the Statute:

“The primary provider shall refer the patient who screens positive for a Fetal Alcohol Spectrum Disorder to a Fetal Alcohol Disorder Specialist...”

2025 Hawai'i FASD Workforce Survey

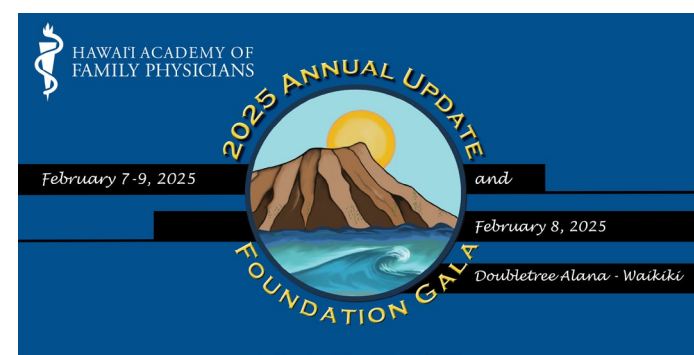


Because prenatal alcohol exposure is a complex public health issue that often evokes a broad range of unique experiences, a well-trained, nuanced, and connected workforce is especially important.

This survey is designed to help develop a better understanding of current professional knowledge and education in Hawai'i in this area:

Survey Hopes

- To learn about prenatal alcohol exposure awareness across sectors and disciplines in Hawai'i
- To learn about places where people are learning (education, training, etc.)
- To learn about local screening familiarity and availability
- To learn about Hawai'i's formal FASD diagnostic capacity



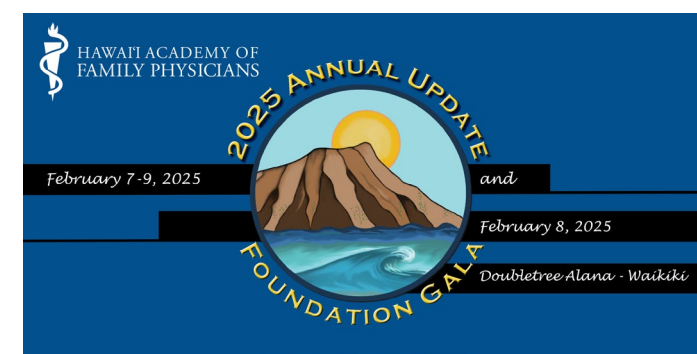
Want to get involved?

Please take the SURVEY

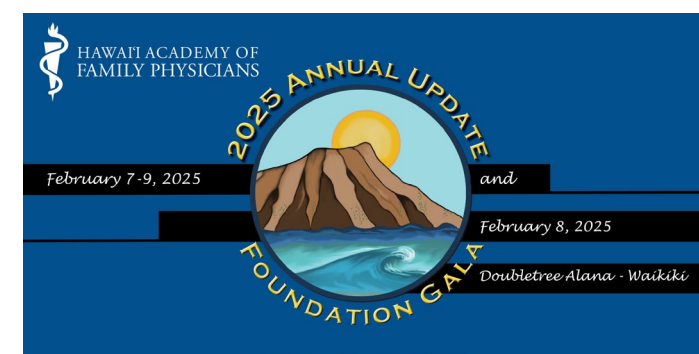
Join a WORKGROUP



TELL your colleagues, family, and friends!



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