



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
March 13, 2023

The Honorable Senator Joy A. San Buenaventura, Chair
Senate Committee on Health and Human Services
The Thirty-Second Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Senator San Buenaventura and Committee Members:

SUBJECT: HB899 HD2 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS HB 899 HD2**, which designates the month of September as Fetal Alcohol Spectrum Disorder Awareness Month to promote public awareness of the risks of alcohol consumption during pregnancy.

As recognized by the Centers for Disease Control and Prevention and other national organizations, Fetal Alcohol Spectrum Disorder (FASD) awareness month is a powerful way to spread awareness. However, it is also important to use the month to highlight the individuals with FASD living in our community. Fetal Alcohol Spectrum Disorder month in September will allow us to celebrate the skills, talents, and abilities people with FASD contribute to Hawaii's future prosperity. It will also provide a venue to advocate on the behalf of individuals with FASD who may have unmet needs in our community.

FASD is the number one Developmental Disability that can be prevented. Awareness is the most effective way to create systems change to support this gap group in our community.

Thank you for the opportunity to submit testimony in **support of HB 899 HD2**.

Sincerely,

Daintry Bartoldus
Executive Administrator

THE SENATE
KA 'AHA KENEKOA

THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON HEALTH AND HUMAN SERVICES

Senator Joy A. San Buenaventura,
Chair Senator Henry J.C. Aquino, Vice Chair

NOTICE OF HEARING

DATE: Monday, March 13, 2023

TIME: 1:00 PM

PLACE: Conference Room 225 & Videoconference
State Capitol

415 South Beretania Street

POSITION: **STRONG SUPPORT HB 899 HD2.**

Dearest Chair, Honorable Senator Joy A. San Buenaventura and Vice Chair, Honorable Senator Henry J.C. Aquino and Health and Human Services Committee members.

I am Darlyn Chen Scovell, a volunteer advocate for families and children with FASD (Fetal Alcohol Spectrum Disorder) and the Hawaii FASD Action Group. Being the voice of children who have none and individuals with FASD who have been marginalized, unrecognized, and without help, attention, and services for many, many years. I am writing in **STRONG SUPPORT of HB 899 HD2.**

I am again pleading and humbly requesting your VOTE, SUPPORT, and to PASS HB 899 HD2 out of your committee. I am reaching out for your help in my fight for FASD Services and Community Awareness with a Noble Objective of *decreasing the number of babies born with FASD in Hawaii, spearheading the much-needed services and understanding of this invisible disability, FASD.* FASD diagnosis is a processing disorder, learning disability, and attention-deficit/ hyperactivity disorder, similar and **more prevalent than Autism Spectrum Disorders**, however distinctly VERY DIFFERENT. The NEURODEVELOPMENTAL IMPAIRMENTS associated with FASD came WITH SIGNIFICANT SOCIAL COST ACROSS THE LIFESPAN in increased medical, educational, and vocational support and lost productivity. I have worked with children with Autism as a Registered Behavioral Therapist under ABA Guidelines. In my observations, FASD is a Developmental Disability that is equally as severe as Autism, with the significant challenge that **FASD disability is NOT VISIBLE**; they look like you and me, and their IQ may pass as normal initially, but the damage is in the brain, neurological damage caused by ALCOHOL consumption during pregnancy. This is a CAUSE SPECIFIC AND PREVENTABLE.

HBB 899 HD2 - Establishing an ANNUAL FASD AWARENESS and STRATEGIC CAMPAIGN aimed entirely to INCREASE PUBLIC VISIBILITY and AWARENESS OF THE INVISIBLE DISABILITY, FASD. Aligning Hawaii with our Nation and Globally in the declaration of September as FASD Awareness Month.

HB 899 HD2 will allow for a **time-bound education campaign** to reach many professionals, families, children, men, women, and establishments regarding the responsible consumption of alcohol, its dangers, and neurological destruction in the brain when consumed during pregnancy. **The sad truth** is

that fetal alcohol syndrome is far more common than people think, and we cannot say accurately what level of alcohol consumption is risk-free. There have been many twists and turns in how we, medically and societally, view drinking while pregnant. There was a time when doctors recommended alcohol to pregnant women for relaxation and pain relief or even prescribed it intravenously as a tocolytic — meaning it stopped premature labor. Things began to change in 1973, when fetal alcohol syndrome, or FAS, was formally recognized after a seminal article was published in *The Lancet*, a medical journal. FAS is a constellation of findings that includes changes in growth, distinctive facial features, and a negative impact on the developing brain. We now know alcohol is a teratogen, which can cause birth defects.

The findings were staggering. The way we are consuming alcohol during pregnancy is resulting in a **conservative estimate of 1.1 to 5% of children — up to 1 in 20 — with FAS**. According to the American College of Obstetricians and Gynecologists, **Fetal Alcohol Spectrum Disorders are more prevalent than Autism**. And yet, at least 10% of pregnant women still drink during pregnancy. The **best analogy for the risk associated with alcohol consumption in pregnancy is driving with your newborn unbuckled in the back seat**. Maybe you'll get into a car accident, and maybe you won't. And if you do, maybe it will be a fender bender, or maybe it will be catastrophic. Driving is also not the only factor at play. In the same way, differences in body chemistry can play a role in who develops FAS. There is also the ability of your newborn to withstand an impact, the weather, the number of cars, and the state of mind of other drivers on the road. While the chances of getting in a car accident while driving home from the hospital with your newborn are very small, most parents will recall how much they stressed over installing the car seat correctly. **And yet, even with such limited risk, I doubt a single pediatrician would say: "Sure, drive unbuckled just this once. It's a celebration."**

Flooding our Communities with FASD AWARENESS is not only **Education and Guidance** to not drink while pregnant; it is **providing people with ACCURATE INFORMATION so they can make informed choices about their bodies is POWER**. The information is also beneficial to those with **undiagnosed FASD experiencing symptoms** and to **boys and girls still in their non-childbearing years to be well educated and informed about when they come to age and decide to become parents**. Children are experimenting with alcohol, and their ages are getting younger and younger each year.

Unfortunately, alcohol advertising fails to inform adequately about the dangers associated with alcohol use by childbearing-age consumers. The label adopted by the alcohol industry suggests that alcohol should be avoided during pregnancy because of the risk of birth defects, which may occur before a woman knows she is pregnant. Since many pregnancies are unplanned or mistimed, women may unintentionally expose their offspring to alcohol without realizing it. **Not all women have regular monthly periods**. Multiple organs of the fetus are at risk of damage from the teratogenic effects of alcohol crossing the placenta. The trajectory and long-term outcomes of those with **Prenatal Alcohol exposure (PAE)** were initially shrouded in mystery. Practitioners in the field then adopted the term invisible disorder for the consequences of Prenatal Alcohol Exposure. According to the *DSM-5*, the diagnostic terms fetal alcohol spectrum disorder (FASD) or neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE) describes the combined challenges and strengths common in people whose mothers consumed sufficient alcohol at the threshold known to be associated with adverse neurobehavioral effects. Individuals diagnosed with Neuro Developmental-Prenatal Alcohol Exposure suffer primarily from cognitive and intellectual deficits, including the areas of learning and memory, language, attention, executive functioning, and adaptive and social functioning (Mela, 2023). Experts estimated that 2% to 5% of U.S. schoolchildren—as many as 1 in 20—are affected by prenatal alcohol exposure, which can cause complications with growth, behavior, and learning (APA, 2022). The prevalence of fetal alcohol spectrum disorder (FASD) in the United States may be much higher than previous estimates have indicated. Researchers reported in the February 6 *JAMA* that in four

communities they studied, as much as 1.1 percent to 5 percent of first-grade children were affected, and those were conservative estimates (Moran, 2018).

Numerous scientific studies have shown that early diagnosis prevents secondary disabilities, such as school failure, juvenile delinquency, mental health problems, homelessness, and unemployability. Individuals with undiagnosed FASD often end up as recidivist clients in institutional settings, including jails, mental health programs, psychiatric hospitals, and homeless shelters. Do you know that we send our FASD Students needing care to the mainland, which costs us \$18,000.00 monthly, paid by the Hawaii Department of Education? Our very own Hawaii family is willing to come forward to provide details of this information. According to the Hawaii Department of Public Safety, the state spends about **\$140 per inmate per day**, which includes program services, food, health care, and administrative costs. When you add it up, that amounts to \$51,100 per year per prisoner locked up in Hawaii. This data was dated in 2016, and I am sure it is much more now. Our Hawaii State records show the cost to transport prisoners to and from the mainland — and to house them — have grown tremendously. In 2016, the state flew a total of 650 inmates to or from Saguaro at the cost of \$871,213, which works out to about **\$1,300 each way per inmate. There are current indicators that most of our inmates have FASD, most especially repeat offenders.**

The support for FASD research and services is limited. The National Institute on Alcohol Abuse and Alcoholism funds innovative research on FASD, said Christie Petrenko, Ph.D., a clinical psychologist and research associate professor at Mt. Hope Family Center, University of Rochester, and co-director of the FASD Diagnostic and Evaluation Clinic. Despite everything, the Substance Abuse and Mental Health Services Administration (SAMHSA)–funded FASD Center for Excellence program was shuttered in 2016, leaving a big gap between research and practical solutions for children and families affected by FASD. Currently, a bipartisan bill before Congress, the FASD Respect Act, would support FASD research, surveillance, and activities related to diagnosis, prevention, and treatment. (APA has endorsed this bill.) Our legislators have fully supported the FASD Respect Act from Hawaii to Washington, DC, which I was also involved in.

I am fortunate to have letters to the Congressional Delegation to Capitol Hill to seek all our Washington, DC representatives to Co-Sponsor the FASD Respect Act. ALL of our representatives in Washington DC signed and Co-Sponsored S.2238 — 117th Congress (2021-2022) and H.R.4151 - FASD Respect Act - 17th Congress (2021-2022) Advancing FASD Research, Services, and Prevention Act or the FASD Respect Act. With this in line, we need to have an action plan and services for our families and children with FASD in Hawaii. **Our Nation and the rest of the World- Globally now recognize FASD is an existing problem that needs action and support.** I hope you will be another Champion for this invisible disability population clouded by the stigma that their own mothers with guilt, shame, and fear of being judged, refuse to come forward to fight for these children. These children were said to have fallen into the cracks of our society, and I begged to disagree; they have fallen over the cliff and were forgotten.

Please help me help these children and families impacted with FASD. Please **VOTE to PASS HB 899 HD2.** Thank you so much. Please do let me know if there is anything else I can do to help this population who they say have fallen into the crack of our society and in my opinion, they fallen on the cliff and have been forgotten. FASD children who have an invisible disability – INVISIBLE NO MORE!

These children are born in an impossible world ~ Please let us make this world possible for them.

Thank you so much for your kind consideration, for the opportunity to advocate and testify.

Always with Gratitude.

Respectfully yours,

Darlyn Chen Scovell

Reference

American Psychological Association. (n.d.). *A hidden epidemic of fetal alcohol syndrome*. Monitor on Psychology. Retrieved January 14, 2023, from <https://www.apa.org/monitor/2022/07/news-fetal-alcohol-syndrome#:~:text=Experts%20estimate%20that%20%25%20to,growth%2C%20behavior%2C%20and%20learning>.

Mela, M. (2023). Patients with prenatal alcohol exposure frequently misdiagnosed, face multiple challenges. *Psychiatric News*, 58(01). <https://doi.org/10.1176/appi.pn.2023.01.1.12>

Moran, M. (2018). Fetal alcohol spectrum disorders may be more common than previously thought. *Psychiatric News*, 53(5). <https://doi.org/10.1176/appi.pn.2018.3a8>

Zagorski, N. (2017). Study estimates 630K infants born with FASD globally each year. *Psychiatric News*, 52(19), 1–1. <https://doi.org/10.1176/appi.pn.2017.9b19>

HB-899-HD-2

Submitted on: 3/12/2023 1:00:59 PM

Testimony for HHS on 3/13/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Cleota Brown	Testifying for Hawaii Fetal Alcohol Spectrum Disorders FASD Actio	Support	Written Testimony Only

Comments:

Dear Senator San Buenaventura, Chair, Senator Aquino, Vice Chair and members of the Committee on Health and Human Services:

On behalf of Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group **we offer our strong support for HB899 HD2 designating the month of September as Fetal Alcohol Spectrum Disorder Awareness Month to promote public awareness of the risks of alcohol consumption during pregnancy.**

Our 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. Currently there are no programs outside of the parent and caregiver support we provide through our 501 c 3. Annually our board directors and volunteers spend countless hours working directly with the Governor's Staff to obtain an annual proclamation for FASD Awareness Month in September. Approval and passing HB899 HD2 will formalize FASD Awareness Month and we can use this to develop and launch awareness campaigns.

Of the almost 17,000 babies born annually in Hawai'i, as many as 840 or 4.94% are estimated to have an FASD This is lifelong brain damage that is 100% preventable through education and awareness. **There is no safe amount or type of alcohol during pregnancy.**

Help us to help parents in Hawai'i to deliver healthy babies by passing HB899 HD2.

Sincerely yours,

Cleota Brown, President

fasdhawaii.org

HB-899-HD-2

Submitted on: 3/10/2023 7:15:28 PM

Testimony for HHS on 3/13/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	Testifying for Hawaii Disability Rights Center	Support	Written Testimony Only

Comments:

While symbolic, this could raise awareness of FASD and hopefully lead to actual services for this population.

HB-899-HD-2

Submitted on: 3/11/2023 9:56:46 AM

Testimony for HHS on 3/13/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Caroline Azelski	Individual	Support	Written Testimony Only

Comments:

In support of HD2. Thank you.

Date: March 12, 2023

To: Senator Joy A. San Buenaventura, Chair
Senator Henry J. C. Aquino, Vice Chair
Members of the Committee on Health and Human Services

From: Ann S. Yabusaki, Ph.D.

RE: I am writing in **full support of HB899 with change to HD1**

I fully support HB899 and request that amendment HD1, making it effective in 3000 be removed, and replaced with "immediately upon passage."

Too many babies are being born exposed to alcohol in utero, and too many children and adults are affected with behavioral, mental health and substance abuse, cognitive, disabilities that may have been avoided with aggressive awareness campaigns and education.

Fetal alcohol spectrum disorders (FASD) are a spectrum of disorders that affect individuals and are unrecognized by parents, providers, educators, probation officers, homeless advocates, and society in general. Since 2016 the Hawaii FASD Action Group was created to bring awareness to FASD and to develop prevention, assessment, FASD-informed interventions, surveillance, and bring ways to support individuals and their families affected by FASD.

By recognizing September, the ninth month of the year, as FASD month, we hope the State will create more awareness about the harms of drinking alcohol during pregnancy. No one deliberately harms their unborn child, and with education and awareness, we can prevent the occurrence of FASD. The Hawaii Fetal Alcohol Spectrum Disorders (FASD) Action Group will also be engaged in this educational effort.

I am a psychologist who works with individuals and families affected by FASD. I witness the devastation that occurs without FASD-informed interventions and supports. Many of the children and adults affected by FASD do not qualify for developmental disabilities services and without support, many fall into a gap of few to no services, despite affected by a developmental disability. An FASD month may help develop the services so desperately needed in Hawaii.

I greatly appreciate your consideration.
Ann S. Yabusaki, PhD

LATE

HB-899-HD-2

Submitted on: 3/12/2023 4:38:13 PM

Testimony for HHS on 3/13/2023 1:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Kenichi Yabusaki	Individual	Support	Written Testimony Only

Comments:

Aloha Senator San Buenavista, Chair, Senator Aquino, Vice-chair, and Members of the Health and Human Services Committee:

I fully support the passage of HB899, which declares the month of September as FASD (Fetal Alcohol Spectrum Disorders) Awareness Month. Hawaii currently has an unintended pregnancy rate of 50%, increases in binge drinking of alcoholic beverages by childbearing women, and potentially 900 added cases of FASD each year. FASD is a permanent brain disorder caused when the fetus is exposed to the metabolite of alcohol during pregnancy. Each year (based on a national study that showed 1 in 20 First grade children having an FASD, a conservative estimate). The consumption of alcohol during pregnancy is the leading cause of FASD, and making September FASD Awareness month will help decrease the number of those affected by FASD through PR campaigns on the dangers of in utero exposure to alcohol with the Department of Health taking a more serious role in this effort. Through this effort, we can decrease the number of individuals affected by FASD which affect every sector of our society (more notably, homelessness, mental health institutions, prison systems, our schools). I urge you to please consider passing HB899.

Thank you

Kenichi Yabusaki, Ph.D.