



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAII 96813
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
February 24, 2023

The Honorable Representative David A. Tarnas, Chair
House Committee on Judiciary & Hawaiian Affairs
The Thirty-Second Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Tarnas and Committee Members:

SUBJECT: HB899 HD1 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS HB 899 HD1**, 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. Effective 6/30/3000. (HD1)

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.

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 HD1**.

Sincerely,

Daintry Bartoldus
Executive Administrator

HOUSE OF REPRESENTATIVES
THE THIRTY-SECOND LEGISLATURE
REGULAR SESSION OF 2023

COMMITTEE ON JUDICIARY & HAWAIIAN AFFAIRS

Rep. David A. Tarnas, Chair
Rep. Gregg Takayama, Vice Chair

Rep. Sonny Ganaden	Rep. Greggor Ilagan
Rep. Daniel Holt	Rep. Sam Satoru Kong
Rep. Troy N. Hashimoto	Rep. John M. Mizuno
Rep. Linda Ichiyama	Rep. Kanani Souza

NOTICE OF HEARING

DATE: Friday, February 24, 2023
TIME: 2:00 PM
PLACE: VIA VIDEOCONFERENCE
Conference Room 325
State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT HB 899 HD1**

Dearest Chair, Honorable Representative David A. Tarnas and Vice Chair, Honorable Representative Gregg Takayama, and Judiciary and Hawaiian Affairs 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 HD1**

I am again pleading and humbly requesting your VOTE, SUPPORT, and to PASS HB 899 HD1 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 to 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.

HB 899 Establishing an ANNUAL FASD AWARENESS and STRATEGIC CAMPAIGN aimed entirely to INCREASE PUBLIC VISIBILITY and AWARENESS OF THE INVISIBLE DISABILITY FASD. **HB 899 HD1** 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 **Guidance** to not drink while pregnant; it is **providing people with ACCURATE INFORMATION so they can make informed choices about their bodies is POWER.** This includes **boys and girls who are in non-childbearing years.** 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 world now recognize this 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 HD1**. 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.

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-1

Submitted on: 2/22/2023 5:14:02 PM

Testimony for JHA on 2/24/2023 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Louis Erteschik	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-1

Submitted on: 2/23/2023 8:42:55 AM

Testimony for JHA on 2/24/2023 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Cleota Brown	Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group	Support	Written Testimony Only

Comments:

Dear Representative Tarnas, Chair, Representative Takayama, Vice Chair and Members of the Committee on Judiciary & Hawaiian Affairs:

On behalf of the Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group's Board of Directors and 200+ volunteers, **we strongly support HB899 HD1** relating to health and designating the month of September as Fetal Alcohol Spectrum Disorder Awareness Month.

Daily news covers the opioid crisis and mental health conditions across the United States but fails to cover the missed epidemic, fetal alcohol spectrum disorders (FASD) which is a leading cause of both drug abuse, mental health and incarceration of youth. Prenatal alcohol exposure is the leading known cause of intellectual disability across our country with symptoms of ADHD, autism or organ failure as the diagnosis.

FASD's are a hidden crisis that is 100% preventable with education and awareness. It's estimated that 1 -5% of the population may be afflicted with an FASD. Of the estimated 17,000 babies born annually in Hawai'i, as many as 840 are estimated to have a FASD.

We can and must reduce these numbers and protect these infants. It requires awareness through education, public awareness campaigns, and training for the healthcare communities, particularly those in maternal healthcare and pediatrics. Our nonprofit has worked over the last decade as volunteers to train and educate across the State of Hawai'i with limited funding. We also have worked closely with Hawaii's Governors to declare September - FASD Awareness Month as it is across many states and countries including California, Minnesota, Washington State, Australia, Canada, New Zealand, United Kingdom, South Africa, to name a few.

Please help us reduce FASD in our State by voting to approve HB 899 HD1 to raise awareness for FASD in our communities and over time we can eliminate this hidden crisis.

We appreciate your support.

Cleota G. Brown, President

FASDHawaii.org

Date: February 22, 2023

To: Representative David A. Tarnas, Chair
Representative Gregg Takayama, Vice Chair
Members of the Committee on Judiciary and Hawaiian Affairs

From: Ann S. Yabusaki, Ph.D.

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

Fetal alcohol spectrum disorders (FASD) is a spectrum of disorders that affect individuals that often 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 to 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.

We will continue to bring FASD-informed assessment and interventions.

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 and support, despite being 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

HB-899-HD-1

Submitted on: 2/22/2023 9:10:30 PM

Testimony for JHA on 2/24/2023 2:00:00 PM

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

Comments:

Aloha Chairman Tarnas, Vice-chair Takayama, and Members of the House Judiciary Committee:

I fully support the passage of HB899 as it relates to making the Month of September Fetal Alcohol Spectrum Disorders (FASD) Awareness month. It is time for the State of Hawaii to recognize FASD as a public health concern. With approximately 18,000 births annually and a robust study in four (4) regions of the United States that has shown one in twenty first-grade children have an FASD, Hawaii alone projects nearly 900 individuals that will be affected by an FASD, annually. FASD is a life-long, permanent brain disorder caused when the human fetus is exposed to the metabolites of alcohol during pregnancy. Individuals affected by FASD impact every sector of our society (especially the schools, homeless, prison, and mental health insitutions). The costs to the State run in the millions of dollars annually. Hawaii must recognize FASD by making the entire month of September in perpetuity, FASD Awareness Month. In doing so, we can hopefully decrease the number of individuals affected by this condition and help those affected by FASD become productive members of our communities through early diagnosis and intervention programs. Those with FASD are born into an impossible world. It is our responsibility to make the world possible for them. I urge you to please pass HB899 and bring FASD to light.

Sincerely,

Kenichi Yabusaki, Ph.D.

HB-899-HD-1

Submitted on: 2/23/2023 4:37:39 AM

Testimony for JHA on 2/24/2023 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Lisa Smith	Individual	Support	Written Testimony Only

Comments:

I support HB899, HD1, because by providing the month of September as FASD Awareness Month, the people of Hawaii, along with the educational, business, public safety, and Judiciary agencies will be educated on a segment of the population which has been misunderstood - our FASD population, many of whom end up in jail, which may have been avoided if society provided this segment of our population the proper education and guidance to help them excel in life, rather than placing them in jail.

Education, Awareness, and Support Services will help this segment of Hawaii's people to thrive and this bill will help to accomplish these goals.

HB-899-HD-1

Submitted on: 2/23/2023 7:29:22 AM

Testimony for JHA on 2/24/2023 2:00:00 PM

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

Comments:

In support of HD1. Thank you.

HB-899-HD-1

Submitted on: 2/24/2023 2:55:43 PM

Testimony for JHA on 2/24/2023 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Dana Keawe	Individual	Support	Written Testimony Only

Comments:

support