



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 15, 2023

The Honorable Representative Della Au Belatti, Chair
House Committee on Health & Homelessness
The Thirty-Second Legislature
State Capitol
State of Hawai'i
Honolulu, Hawai'i 96813

Dear Representative Belatti and Committee Members:

SUBJECT: HB899 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS HB 899**, 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.

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**.

Sincerely,

Daintry Bartoldus
Executive Administrator

HB-899

Submitted on: 2/11/2023 9:42:02 AM

Testimony for HLT on 2/15/2023 8:30:00 AM

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

Comments:

Dear Representative Belatti, Chair and Representative Takenouchi, Vice Chair and Members of the Health and Homelessness Committee:

On behalf of the Board of Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group, a 501 c 3 with a **mission 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 and our 200+ volunteers, we strongly support HB899.**

Annually our Founders and volunteers have worked with the Governor's office to designate September as Fetal Alcohol Spectrum Disorders Awareness Month to promote public awareness of the risks of alcohol consumption during pregnancy.

Throughout many countries e.g., Australia, New Zealand, United Kingdom, South Africa, Canada, etc. September is and has been for many years designated International Fetal Alcohol Spectrum Disorders Month.

Despite public health efforts, prenatal alcohol exposure (PAE) remains the leading preventable cause of neurodevelopmental disorders [1]. Alcohol (EtOH) exposure during pregnancy can result in Fetal Alcohol Spectrum Disorders (FASD) [2,3,4], which together have a prevalence of approximately 2–5% in the United States alone [4, 5]. FASD can present with a wide range of symptomatic severity, from neurobehavioral abnormalities to embryonic lethality. Primary cognitive and behavioral deficits can underpin secondary disabilities, such as mental health problems, disrupted school experience, addiction, sexually deviant behavior, and dependent living [3, 6,7,8,9]. The resultant clinical profile appears to be influenced by the fetal brain's stage of development at the time of exposure and pattern of maternal EtOH consumption [10,11,12,13,14,15,16]. [Impact of alcohol exposure on neural development and network formation in human cortical organoids Oct. 28, 2022](#)

FASD is 100% preventable and it is our firm belief that no mother or parent holds the intention of inflicting lifetime harm to their unborn child. Mothers and fathers simply do not recognize the impact of alcohol on their unborn fetus. There is no education provided in high schools, universities, maternal classes, etc. Few medical study courses include training for fetal alcohol spectrum neurological disabilities.

Research on the number of women who drink alcohol during pregnancy is simply a hit and miss effort in Hawaii which is strictly on a voluntary basis. The data is outdated with the last major report in 2020 tracking the number of women who abstained from alcohol during pregnancy [Hawaii Health Matters, Maternal, Fetal & Infant Health](#)

We strongly encourage you to pass this legislation HB 899 and ensure every year in September we join with our colleagues across the nation to raise awareness for FASD. We assure you, as the only community based organization in Hawaii who's mission is focused entirely on fetal alcohol spectrum disorders, we will be doing our best to raise awareness every day of the year. Visit our website FASDHawaii.org, or our social media pages [Facebook @hawaiifasd](#), [Instagram #hawaiifasd](#) and [Linkedin #Hawaii FASD Action Group](#)

Thank you for this opportunity to submit our written testimony.

Sincerely yours,

Cleota G. Brown, President

FASDHawaii.org

(808) 235-5874

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

COMMITTEE ON HEALTH & HOMELESSNESS

Rep. Della Au Belatti, Chair
Rep. Jenna Takenouchi, Vice Chair

Rep. Terez Amato	Rep. John M. Mizuno
Rep. Greggor Ilagan	Rep. Scott Y. Nishimoto
Rep. Bertrand Kobayashi	Rep. Diamond Garcia

NOTICE OF HEARING

DATE: Wednesday, February 15, 2023
TIME: 8:30 AM
PLACE: VIA VIDEOCONFERENCE
Conference Room 329
State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT HB 899**

Dearest Chair, Honorable Representative Della Au Belatti and Vice Chair, Honorable Representative, and Health and Homelessness 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**

I am again pleading and humbly requesting your VOTE, SUPPORT, and to PASS HB 899 out of your committees. 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** 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**. 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

Submitted on: 2/13/2023 10:51:18 AM

Testimony for HLT on 2/15/2023 8:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Robert M Armstrong	Hawai`i Fetal Alcohol Spectrum Disorders (FASD) Action Group	Support	In Person

Comments:

Aloha Representatives Belatti, Takenouchi and members of the Health and Homelessness Committee,

On behalf of the Hawai`i Fetal Alcohol Spectrum Disorders Action Group, I am in STRONG SUPPORT of House Bill 899 designating September as Fetal Alcohol Spectrum Disorder Awareness Month and promoting greater awareness and information about this frequently overlooked and misdiagnosed issue.

For those of you who know me, I have worked tirelessly on homelessness in the Downtown-Chinatown neighborhood and helped to organize the first O`ahu Summit on Homelessness for then Governor Ige and Mayor Caldwell more than six years ago. I serve on the Neighborhood Board there and was recently a Democratic House candidate for District 28. My commitment is real and my dedication is strong to solving this---plus other issues---that plague our island and State.

In the course of this work and through my involvement with founding the Ohio chapter of Mothers Against Drunk Driving some thirty years ago, I have seen the tragedy of how substance abuse affects individuals and for our purposes, the community.

Whether we're talking homelessness, drunk driving, or fetal alcohol disorder syndrome, we are only now understanding the toll and cost substance abuse has on society. House Bill 899 helps add awareness by spotlighting a month-long period for education, research, advocacy and unity in helping to eliminate this scourge from society.

In particular, the impact of Fetal Alcohol Spectrum Disorder, similar to what we're learning about autism, can have a wide variety of human and cultural consequences on the child and his or her ability to learn and positively function in society; on families and their ability to identify, cope and resolve internal challenges and issues; on law enforcement from policing bullying and impulse control to larger issues such as domestic violence, homelessness and even more serious crime, and of course on non-profits and governments who eventually must find the money to deal with the impacts of FASD, from traffic accidents and homelessness, to depression counseling and dysfunctional families, lost wages and workplace incidents, more instructional, counseling and educational services in schools to more policing efforts, court cases and social

service providers. We all eventually pay the cost of fetal alcohol syndrome disorder either directly or indirectly.

Many of us believe FASD is perhaps the linking component to the myriad of issues that continue to vexes modern society. It needs to be talked about, identified and resolved and that all begins with HB 899 and the awareness it would permit. For the many volunteers working on this cause, from those of us in the medical field to educators to public relations and marketing professionals, this Bill's passage would also help us gain legitimacy, funding and the ability to better position this cause now and in the future.

I sincerely thank you for your kind consideration and approval of this effort.

Robert M. Armstrong

HB-899

Submitted on: 2/10/2023 7:26:12 PM

Testimony for HLT on 2/15/2023 8:30:00 AM

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.

Dear Chair Au Belatti, Vice Chair Takenouchi, and members of the Health and Homelessness Committee,

I am writing in full support of HB899.

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 find ways to support FASD affected individuals and their families.

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.

I am a psychologist who works with individuals and families affected by FASD. I witness the devastation that occurs without FASD-informed help. Many of the children and adults affected by FASD do not qualify for developmental disabilities services and having an FASD month may help develop the services so desperately needed in Hawaii.

I greatly appreciate your consideration.

Ann S. Yabusaki, PhD

HB-899

Submitted on: 2/13/2023 8:34:59 AM

Testimony for HLT on 2/15/2023 8:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Cortney Gleaton	Individual	Support	Written Testimony Only

Comments:

I am the adoptive mother of three (3) children that were in the custody and care of the Office of Children's Services in Alaka for eight (8) years. During this time, one (1) of the children, who is now 16 was given a full scare Fetal Alcohol Syndrome diagnosis in 2016. This diagnosis was swept under the rug by OCS and her theraputic foster agency and none of the 23 recommended services were ever established. Upon adoption at the age of 14 and in the recent months of my husband and I doing a deep dive we have discovered that for 7 years our child has had an FASD diagnosis, yet she was not provided any intervention or services. We are now racing against time to try and get her the proper services that she needs in an effort to hope that she can gain the basic life skills to have a productive adult life. We moved to Hawaii 6 months ago and have found that the resources are more scarce and limited here than in Alaska, partially I believe because practitioners know little about FASD and are scared. We have been unable to find ONE therapist that is willing to work with her on her trauma, as everyone has told us that she "needs more help than they can provide". As soon as any practitioner on island finds out that she has an FASD diagnosis the immediate reply is that they are not equipped to handle her.

By declaring Septemner FASD awareness month in Hawaii the hope would be that FASD is no longer something that very few know about, but that the awareness is able to spread and more people become educated on FASD. Hopefully be declaring September FASD awareness month mothers will have better access and education on what can happen if you consume alcohol during your pregnancy an expose your baby in utero. FASD is a silent disorder that too many children and adults suffer with alone, because professionals do not know how to approach or treat persons with FASD.

I urge the legislature to declare September FASD awarness month.

HB-899

Submitted on: 2/13/2023 11:31:39 AM

Testimony for HLT on 2/15/2023 8:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Kathy Dougherty	Individual	Support	Written Testimony Only

Comments:

FASD, a diagnosis more common than all of the developmental disabilities COMBINED, yet also gets misdiagnosed 80% of the time.

There needs to be more awareness about it and recognizing September as FASD Awareness Month is a nice start.

HB-899

Submitted on: 2/14/2023 4:24:25 PM

Testimony for HLT on 2/15/2023 8:30:00 AM

Submitted By	Organization	Testifier Position	Testify
Choon James	Individual	Support	Written Testimony Only

Comments:

[HB899](#)

Aloha State Legislators,

HB899 is a good exercise to shed light on this perennial societal problem. We need more education and awareness. Infants are born into this world with NO choice to choose who their mothers and fathers are.

It's most tragic when innocent infants are born to bear burdens from irresponsible adults who abuse alcohol, drugs or other toxic substances. Innocent infants are forced to deal with these negative consequences throughout their lifetime, whether they like it or not. This is very unfair and can be minimized with education and discipline from responsible adults.

Mahalo,

Choon James

Measure Title: RELATING TO HEALTH.

Report Title: Fetal Alcohol Spectrum Disorder Awareness Month

Description: Designates the month of September as Fetal Alcohol Spectrum Disorder

Description: Awareness Month to promote public awareness of the risks of alcohol consumption during pregnancy.

HB-899

Submitted on: 2/14/2023 8:19:37 PM

Testimony for HLT on 2/15/2023 8:30:00 AM

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

Comments:

Dear Chair Belatti, Vice-Chair Takenouchi and Members of the Health and Homelessness Committee

I strongly support HB899 relating to making the month of September "Fetal Alcohol Spectrum Disorder (FASD) Awareness Month." FASD is a permanent brain condition manifested by behavioral symptoms (after birth) when a fetus is exposed to toxic metabolites from alcohol consumption during pregnancy. A nationwide study covering four regions of the US showed that one in twenty (5%) first-grade children have an FASD (conservative estimate). With approx. 18,000 births in the State of Hawaii alone, nearly 900 individuals are affected by an FASD annually. Hawaii must become more aware of FASD as individuals affected by this condition impact every sector of society; especially in schools, homelessness, incarceration, and mental health institutions, etc., and costs Hawaii millions of dollars annually. Aside from previous Proclamations addressing FASD for the month of September, Hawaii should permanently declare the month of September "FASD Awareness Month." By doing so, we can create more awareness through Public Service Announcements, Ads, and via all forms of Media to decrease the numbers of those affected by an FASD. I urge you to please pass HB899 for the health of the State of Hawaii.

Sincerely,

Kenichi Yabusaki, Ph.D.