



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 1, 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 Buenaventura and Committee Members:

SUBJECT: SB715 RELATING TO HEALTH.

The Hawaii State Council on Developmental Disabilities **SUPPORTS SB715 with a requested amendment**, 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.

Fetal Alcohol Spectrum Disorder is the one Developmental Disability that can be prevented. **We would like to request an amendment to add an appropriation of \$35,000** to the State Council on Developmental Disabilities. This is similar to what our Council spends on annual outreach for awareness events. This would ensure that an annual public awareness campaign preventing FASD can be established within our state. 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 SB715**.

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: Wednesday, March 1, 2023
TIME: 1:00 PM
PLACE: Conference Room 225 & Videoconference
State Capitol
415 South Beretania Street

POSITION: **STRONG SUPPORT SB 715**

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 SB 715.**

I am again pleading and humbly requesting your VOTE, SUPPORT, and to PASS SB 715 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.

SB 715 - Establishing an ANNUAL FASD AWARENESS and STRATEGIC CAMPAIGN aimed entirely to INCREASE PUBLIC VISIBILITY and AWARENESS OF THE INVISIBLE DISABILITY, FASD. Aligning Hawaii with the our Nation and Globally in the declaration of September as FASD Awareness Month.

SB 715 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 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 SB 715**. 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>

SB-715

Submitted on: 2/24/2023 6:59:06 PM

Testimony for HHS on 3/1/2023 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.

SB-715

Submitted on: 2/27/2023 4:35:35 PM

Testimony for HHS on 3/1/2023 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 Senate Committee on Health and Human Services:

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 disorders (FASD) on individuals, their families, and the communities of Hawai'i and our 200+ volunteers, **we strongly support SB 715.**

Designating the month of September as Fetal Alcohol Spectrum Disorder Awareness Month will demonstrate Hawaii's concerns about the impact and devastation of alcohol on unborn children.

US states such as Alaska, California, Minnesota, Washington and many countries e.g., Australia, Canada, New Zealand, United Kingdom, South Africa, etc. all designate September as International Fetal Alcohol Spectrum Disorders Month.

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 healthcare classes, etc. Few medical study courses include training for FASD.

We need your help in our efforts to educate and raise awareness for the prevention of FASD and SB 715 is the first step the State of Hawaii can easily take.

We sincerely ask for your support by passing SB 715.

With appreciation,

Cleota G. Brown, President

fasdhawaii.org



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

Re: Support of SB715, Relating to Health, Fetal Alcohol Spectrum Disorder Awareness Month

Hrg: Wednesday, March 1, 2023 at 1:00pm, Conference Room 225

Support

Due to the subtle and often undetectable nature of Fetal Alcohol Spectrum Disorder (FASD) diagnosis, many individuals go undiagnosed and do not receive the necessary treatment. This measure would help to create more public awareness to address the underdiagnosed disorder that plagues the lives of many individuals in our state.

Mahalo,

Rick Collins
Director
Hawai'i Alcohol Policy Alliance

SB-715

Submitted on: 2/24/2023 7:09:32 PM

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

Submitted By	Organization	Testifier Position	Testify
Cards Pintor	Individual	Support	Written Testimony Only

Comments:

Aloha,

I support this bill.

Mahalo nui,

Cards Pintor

Date: 2/26/2023

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

FROM: Ann S. Yabusaki, Ph.D., LMFT, psychologist

I am writing in **full support of SB715**.

By recognizing September, the ninth month of the year and recognizing the nine months of pregnancy, 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.

Fetal alcohol spectrum disorders (FASD) is a group of disorders that affect individuals that often are unrecognized by parents, providers, educators, probation officers, homeless advocates, and society in general. These lifelong brain-based disorders remain under diagnosed and without proper intervention, remain untreated, leaving individuals with FASD and their families without support.

The Hawaii FASD Action Group was created in 2016 to bring awareness to FASD and with education and support, develop prevention, assessment, FASD-informed interventions, surveillance systems, and other ways such as supportive housing, to support FASD affected individuals and their families.

The recognition of September as FASD month would help to bring awareness and understanding of this devastating condition. Many of my clients, both children and adults, do not qualify for state services and must flounder on their own. Designating September as FASD month may help develop the services so desperately needed in Hawaii.

I greatly appreciate your consideration and look forward to the passage of this bill into law.

SB-715

Submitted on: 2/27/2023 9:53:26 AM

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

Submitted By	Organization	Testifier Position	Testify
Tia Ikeno	Individual	Support	Written Testimony Only

Comments:

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

I would like to submit my written testimony IN SUPPORT of SB 715 where it would designate the month of September as FASD Awareness Month. The purpose is to bring more awareness into the community. As a juvenile probation officer, I see so many undiagnosed children who struggle with their day to day functioning because of the impacts alcohol on their brain in utero. Some things that may seem easy to grasp and understand takes FASD individuals significantly more time and specifics to process that information in their brain. If you add trauma to this invisible brain disability, it creates more struggle for this child to be successful in the justice system and throughout the rest of their life.

Many women are unaware of the impacts drinking has on their fetus when they are pregnant. Many women are unaware that they are pregnant and end up drinking causing unknown damage to their baby. Many individuals who take in FASD kids don't know what to do or how to help their child because often times they are misdiagnosed. So I believe it is our responsibility as a community to help bring more awareness about FASD in efforts to make life a little more manageable for these individuals and their families. An "invisible disability" is hard to treat but with more awareness and education, we can make this "invisible disability" invisible no more. So I encourage you to support this bill and help educate and bring more awareness to our community.

Mahalo,

Tia Ikeno, Juvenile Probation Officer - Girls Court

SB-715

Submitted on: 2/26/2023 11:24:23 AM

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

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

Comments:

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

I fully support SB715 which recognizes the month of September as Fetal Alcohol Spectrum Disorder (FASD) Awareness Month. Understanding and bringing forth awareness of FASD, a permanent life-long brain condition from prenatal exposure of the human fetus to the devastating and toxic effects of alcohol consumption during pregnancy, is of utmost importance.

From the standpoint that in Hawaii, 50% of pregnancies are unintended, increasing binge drinking among women of childbearing age and a national study that shows one in twenty first-grade children (5%) have an FASD, Hawaii must bring about more awareness about FASD. With an annual birthrate in Hawaii of approximately 18,000, nearly 900 individuals are potentially affected by FASD each year. In five years, more than 4,500 individuals will be affected by FASD.

The Hawaii FASD Action Group, since its inception in 2016 as an all-volunteer organization and is currently a 501(c) 3 (all volunteer) has via its speakers' bureau has given multiple presentations on FASD with two Proclamations about FASD in 2019 and 2021. Thus, making September FASD Awareness Month will contribute significantly to bringing about awareness and hopefully help reduce the number of individuals affected by FASD.

I urge you to please pass SB715 for a healthier Hawaii.

Sincerely,

Kenichi Yabusaki, Ph.D.

SB-715

Submitted on: 2/27/2023 10:32:47 AM

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

Submitted By	Organization	Testifier Position	Testify
Robert M Armstrong	Individual	Support	Written Testimony Only

Comments:

Aloha Chairperson San Buenaventura, Vice-Chairperson Aquino and Members of the Committee on Health and Human Services,

I strongly support SB 715 and urge its passage to begin placing attention and importance to one of our State's most insidious and under-reported concerns affecting some 71,000 residents.

Your actions will mitigate this tragedy and begin the compassionate and appropriate response needed in Hawai`i across all communities, institutions and populations.

In the end, passage will begin the process of saving taxpayers thousands of dollars in misdiagnoses and create an atmosphere where homelessness, substance abuse and other seemingly intractable issues can be addressed appropriately.

Mahalo for your concern and your vote.

SB-715

Submitted on: 2/27/2023 1:40:02 PM

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

Submitted By	Organization	Testifier Position	Testify
Candace Pang	Individual	Support	Written Testimony Only

Comments:

As a longtime employee in a substance abuse treatment program, I have seen the impact of prenatal alcohol exposure in the adult clients that we work with as well as for their children where now a second or third generation of family members are impacted. It can be overwhelming to look at the damage that this "legal drug"---- alcohol has on our community as it's just normalized in everyday life. But, starting with education, such as designating a month of awareness of fetal alcohol spectrum disorders to promote an awareness of the risks of alcohol use during pregnancy is a start. September is also National Recovery Month so how appropriate that would be to include both efforts!

SB-715

Submitted on: 2/27/2023 6:59:58 PM

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

Submitted By	Organization	Testifier Position	Testify
Sina P. Pili	Individual	Support	Written Testimony Only

Comments:

Aloha Chair, Vice Chair, and Committee Members,

I am in full support of SB 715 to designate the month of September as FASD Awareness Month. Recognizing FASD as an awareness month is a great way to bring greater understanding of FASD that affect women, children, and families. It is our societal duty to spread awareness to prevent & provide support for our community members who are affected by FASD.

Mahalo,

Sina P. Pili

SB-715

Submitted on: 2/28/2023 12:55:26 PM

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

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

Comments:

I support designating **the month of September as Fetal Alcohol Spectrum Disorder Awareness Month to promote public awareness of the risks of alcohol consumption during pregnancy.**