



4TH HAWAI'I CONFERENCE ON FASD

FASD Across the Lifespan: *Addressing the Challenges*

**FRIDAY, SEPTEMBER 15, 2023
8:45AM TO 4:00PM**

**O'AHU VETERANS CENTER
1298 KUKILA ST. HONOLULU, HI 96818**

(IN-PERSON ONLY)

WWW.FASDHAWAII.ORG

MAHALO NUI LOA TO OUR GENEROUS SUPPORTERS!



Angela Mariamu Smith Trust
Darlyn Chen Scovell
Ember and Alan Shinn
Ken and Ann Yabusaki
Central Pacific Bank, Kaneohe Branch
Brian Lee



WELCOME

Dear 2023 Conference Delegates:

On behalf of the FASD Action Group, we welcome you to this year's conference focused on ***"FASD Across the Lifespan: Addressing the Challenges"***.

We've made wonderful progress in our mission to raise awareness and develop informed care and services for fetal alcohol spectrum in Hawai'i. Here's the highlights and you'll hear more details during the conference.

- In 2022 we were awarded a \$300K Grant in Aid in support of The FASD Social Laboratory, a one year pilot program in partnership with Lanakila Pacific and the Salvation Army Family Treatment Services to train and offer an FASD evaluation using the Life History Screen. This program will run through April, 2024.
- On April 21, 2023 Governor Josh Green signed Act 012 from HB899-SD2 enacting September as FASD Awareness Month in the State of Hawai'i.
- On July 3, 2023 Governor Josh Green signed Act 192 from SB318-SD2 enacting a 5 year pilot program through a designated task force to be set up by the Department of Health to implement a co-management system of care for the diagnosis and treatment of individuals with fetal alcohol spectrum disorders.
- 2023 was a banner legislative year across the nation. Sixty-one bills focused on FASD were introduced in states with fourteen enacted into law achieving a 23% legislative success rate.

To continue this progress, we need each and every one of you to assist us with these critical success factors:

1. Identifying people with an FASD who need support:
 - a. Help make this invisible disability visible in Hawai'i through an introduction to FASDHawaii.org where we can work to develop informed support services and programs.
2. Help us gather data on FASD in Hawai'i:
 - a. Without data, we will continue to lag behind in our ability to develop programs and services in Hawai'i.
 - b. Without data, the DOH FASD Task Force will not be successful.

Mahalo nui loa,



Cleota G. Brown
President

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Email: hawaiifasdactiongroup@gmail.com Ph: 808-258-5874



CONFERENCE DESCRIPTION

Fetal alcohol spectrum disorders (FASD) refer to a collection of diagnoses that represent the range of effects that can happen to a person who was exposed to alcohol before birth. The effects are lifelong and can include physical, behavioral, and learning challenges. These conditions can affect each person in different ways, and can range from mild to severe.

Based on the National Institutes of Health-funded community studies, experts estimate that the full range of FASDs in the United States and some Western European countries might number as high as 1 to 5 per 100 school children (or 1% to 5% of the population)¹ and recognized as a worldwide public health issue and a growing epidemic.

This year's conference focuses on the lifelong challenges of people and families affected by FASD. Our goal is to increase the community's support, understanding, and response to those affected by FASD and to prevent FASD altogether. FASD affects all of us and our systems of care. Collectively, we can make a difference.

GOALS: On the premise that every person deserves the right to a purposeful and meaningful life, the goals of this conference are to:

1. Develop an FASD-informed workforce in all sectors of the state
2. Create multidisciplinary teams to provide a comprehensive assessments, diagnoses, interventions, and support system for individuals and families affected by FASD.
3. *"Be the change that you wish to see in the world."* Mahatma Gandhi

TARGET AUDIENCES: Everyone: parents, medical, mental health, and substance abuse professionals, administrators, personnel at DOH, DHS, DOE, and the Judiciary, legislators, and anyone willing to help people with FASD reach their highest potential.

CONTINUING EDUCATION: ADAD has approved 6.0 credits for full attendance at this conference. There is no charge for these CE hours.
ADAD CE Registration Approval #ADAD-24-008.

¹ <https://www.cdc.gov/ncbddd/fasd/data.html#ref>, download 6/28/2023



CONFERENCE PROGRAM

8:00 AM - 8:45 AM

Registration

8:45 AM - 9:00 AM

Welcome and Housekeeping: Ann S. Yabusaki, Ph.D., LMFT

9:00 AM - 9:15 AM

Opening Pule and Blessing: Kahu Lāhela Johnson is a native Hawaiian spiritual healing guide from Hawai'i on the island of O'ahu.

9:15 AM - 10:15 AM

Keynote: Parent Panel with Terra and Jeremy Daniel, Gene and Ginny Wright, Sina P. Pili, Terra Daniel, moderator.

Description: Our parent panel will address the highs and lows of raising an individual with an FASD. Our panel covers experience with raising children from birth to early childhood to young adults and will share what has worked in finding success for our entire families. We will share what we wish others knew about our lives and how they can help support families like ours in their respective professions. Those in attendance will take home ideas and plans to be able to make a positive change in their communities – both personal and professional.

Objectives:

- 1. To give others an honest look into what it is like to raise an individual with an FASD.**
 - 2. Share experiences on how parenting using “brain first” interventions and preventions help everyone in the family succeed.**
 - 3. Inspire others to see what individuals with an FASD teach us on a daily basis and how they make us better people.**
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10:15 AM - 10:30 AM

Break



CONFERENCE PROGRAM

10:30 AM - 12:30 PM

Keynote: Paul D. Connor, Ph.D., Clinical Neuropsychologist Private Practice and University of Washington. Joanne Sparrow, Ph.D., Clinical Psychologist, Private Practice and Seattle Children Research Institute Families Moving Forward Program

Description: Using a case study format, this presentation will acknowledge the challenges of access to diagnosis across the lifespan. Screening tools and red flags that can help identify individuals who may benefit from more formal assessment and the assessment process will be discussed. This presentation will also highlight interventions developed specifically for children with FASD and offer ideas for modifying existing non-FASD focused approaches for adolescents and adults.

Objectives:

1. Understand the cognitive and behavioral red flags that may indicate the possible impact of prenatal alcohol exposure.
2. Understand the process involved in diagnosing FASD.
3. Understand the ways in which red flags and screening tools can help caregivers and providers view the individual differently, adjust expectations, and adapt the environment and services (when a formal diagnosis is not available).
4. Identify services and supports currently available for individuals impacted by prenatal alcohol exposure and their families.

12:30 PM - 1:15 PM

LUNCH and Mahalo Recognitions

- Darlyn Chen Scovell, MA, RBT, CSAC recognizes seven legislators instrumental in helping to pass legislation for FASD.
 - Ann S. Yabusaki, Ph.D., LMFT. The Hawai'i FASD Action Group recognizes Cleota "Cleo" Brown as the volunteer of 2023 for significantly advancing the mission of the Hawai'i FASD Action Group.
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CONFERENCE PROGRAM

1:15 PM - 2:30 PM

“Learning Circles” Activity. Joanne Sparrow, Ph.D. and Ginny Wright, Parent, Facilitators.

Description: Participants will break into groups to deepen their understanding of and become resources for individual and families affected by FASD. Please summarize the group discussion by identifying two big takeaways and action steps the group will take and share them in the larger group.

Before beginning, Kahu Lāhela Johnson and Ann Yabusaki will introduce the Ho'olauna.

Objectives: Participants will:

1. Identify at least two of their unique gifts and talents that can have a positive impact on a) a person with FASD and their family and b) the system(s) in which they are involved.
 2. Identify two strategies that they can begin using to have a more positive impact on a) a person with FASD and their family and b) the system(s) in which they are involved.
 3. Make a connection with at least two others with whom they can partner to have a more positive impact on a) a person with FASD and their family and b) the system(s) in which they are involved.
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2:30 PM - 2:45 PM

Break

2:45 PM - 3:00 PM

Joanne Sparrow, Ph.D., and Ginny Wright, Parent. Facilitators.

Reconvene with everyone to share the takeaways and action steps from each group.

3:00 PM -3:30 PM

Ann Yabusaki, Ph.D., LMFT, Moderator: Q&A session with all presenters.

3:30 PM - 4:00 PM

- Evaluations
 - Announcements: Lydia Hemmings, FASD Project Lead
 - Closing Pule: Kahu Lāhela Johnson
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CONFERENCE PRESENTERS



**Kahu Lāhela
Johnson**
*Spiritual
Healing Guide*

Kahu Lāhela Johnson is a native Hawaiian spiritual healing guide from Hawai'i on the island of O'ahu. She teaches healing through forgiveness in a practice she calls Hana I Ka Pono, which helps you to align with your Divine Soul Self and release connections to past hurt, trauma, old beliefs, and patterns that may have been inherited through multiple generations. Profound change, healing, clarity, balance, harmony, inner peace, and a sense of lightness occurs as a result of daily practice and reminds us that we are not separate from Source, but that we are each an integral cell within the body of the whole!



**Jeremy and
Terra
Daniel**
*Parents and
FASD Advocates*

Jeremy and Terra Daniel entered the world of FASD when their second daughter was diagnosed at 14 months with partial Fetal Alcohol Syndrome (pFAS). Since that day, they have dedicated much of their lives to raising awareness and advocating for their daughter and others impacted by prenatal alcohol exposure. They are the founders of HOAPILI, a non-profit organization that provides monthly parties and year-round sports clinics for anyone needing a place to belong. They live on the North Shore of O'ahu with their four children and service dog, Pineapple.



CONFERENCE PRESENTERS



Ginny Wright

*Parent and
FASD Advocate*

Ginny Wright and her husband Gene have been married for 47 years. All their children are adopted and six of the children have special needs. Their challenges include ADD, ASD, complex and fragile medical conditions, Fetal Alcohol Spectrum Disorders, PTSD, Cognitive Disabilities. They have also been foster parents to more than 2 dozen children - many with disabilities. Raised in Kailua, Ginny graduated from Weber State University in Ogden, Utah with a B.A. in Early Childhood Education and taught in Utah for several years before returning home to Hawai'i. Upon returning, she switched careers and established an association management firm and currently manages four nonprofit trade associations in Hawai'i. Before her youngest child's medical condition made travel challenging, she had traveled extensively throughout the world and visited every continent except Antarctica. Nowadays, she enjoys the K-pop group BTS, painting, cooking, and family activities.



Gene Wright

*Parent and
FASD Advocate*

Gene Wright hails from Ogden, Utah but has called Hawai'i home for almost 40 years. He has worked at Bellows Air Force Base for 37 years. He was active in Boy Scouting for many years. Gene has written and published 3 books on religion. He enjoys being outdoors and playing the banjo. An avid adventure traveler, Gene hiked throughout the world and, at age 63, climbed the summit of Mt. Kilimanjaro. Shortly after his Kilimanjaro descent, Gene was diagnosed with a genetic kidney disorder. His health quickly declined. After years of in-home dialysis, Gene received a kidney transplant in September 2022. His donor was his daughter's very best friend Elizabeth Casken who died unexpectedly. Liz was an individual with Fetal Alcohol Syndrome and served as a greeter at the Hawai'i FASD Conference in 2019. Today Gene is a healthy and active father of eight and grandfather of 3 - #BecauseOfLiz.



CONFERENCE PRESENTERS



Sina P. Pili

*Parent and
FASD Advocate*

Sina P. Pili is a Pacific Islander woman of Native Hawaiian and Samoan ancestry raised in La'ie on the North Shore of O'ahu. Married to Davis Pili and together they have five precious children. With over ten years working in the social work and behavioral health field, Sina has experience working with children, youth, adults and families. Sina is a Behavioral Health Specialist for the Department of Education. She is an advocate for FASD awareness and informed services within the school systems. She has participated annually in the summer academy statewide training for the School Based Behavioral Health Department presenting on FASD informed services and strategies to work with students diagnosed with FASD. Sina received a Bachelor of Arts in Psychology from the Brigham Young University-Hawai'i and then a Masters in Social Work from the University of Hawai'i. She is a student in the PhD Social Welfare program at the University of Hawai'i with research interests in Prenatal Alcohol Exposure, Fetal Alcohol Spectrum Disorders, and FASD Behavioral Health informed services in school systems.



**Paul D. Connor,
Ph.D.**

*Clinical
Neuropsychologist*

Dr. Paul D. Connor is a clinical neuropsychologist from Washington State. He obtained a bachelor's degree from the University of Washington and a Ph.D. in clinical psychology and neuropsychology from Brigham Young University. He received post-doctoral training in neuropsychology and Fetal Alcohol Spectrum Disorders (FASD) at the University of Washington. As a faculty member at the University of Washington, he conducted research on the effects of prenatal alcohol exposure on neuropsychological and mental health functioning as well as structural and functional brain anomalies. Dr. Connor has authored or co-authored multiple peer reviewed manuscripts and book chapters focusing on the long-term effects of prenatal alcohol exposure into adolescence and adulthood. In addition, he has presented and consulted internationally about assessment and diagnosis of FASD in adulthood. He is currently in private practice, conducting neuropsychological evaluations in clinical and forensic settings, specializing in the diagnosis of adults with potential FASD.



CONFERENCE PRESENTERS



**Joanne
Sparrow, Ph.D.**
*Clinical
Psychologist*

Dr. Joanne Sparrow is a clinical psychologist in private practice currently licensed in Washington and Colorado; she holds a Ph.D. in clinical psychology from Seattle Pacific University (2018). Originally from Toronto, Canada, she obtained a bachelor's degree in psychology and cultural anthropology from York University followed by a post-graduate Diploma in Child Study from the University of Toronto (where her interest in FASDs first began). After completing her master's degree in clinical/ counseling psychology at San Jose State University, Dr. Sparrow spent several years working in the field of community mental health before becoming a case manager for a birth-to-three program where she worked with families with children diagnosed with a variety of developmental disabilities. Dr. Sparrow has been working with Dr. Heather Carmichael Olson (developer of the Families Moving Forward Program at Seattle Children's Research Institute) for over a decade and offers FMF to families in her private practice. Dr. Sparrow recently became president-elect of FASD Focus NW (the Washington state affiliate of FASD United) and is a member of the Executive Committee of FASD United.



DISCLOSURES

LOCATION: O'ahu Veterans Center
1298 Kukila Street
Honolulu, Hawai'i 96818
(808)422-4000

PARKING: Free parking is available at the Center. Overflow parking is available in the neighborhood.

CONFLICT OF INTEREST: In keeping with the accreditation guidelines, presenters participating in this event have been asked to disclose to the audience any involvement with industry or other organizations that may potentially influence the presentation of the education material. Disclosure has been done in written form prior to the presenter's participation.

AMERICANS WITH DISABILITIES ACT: The Hawai'i Fetal Alcohol Spectrum Disorders (FASD) Action Group and the O'ahu Veterans Center comply with the Americans with Disabilities Act. All meeting areas are accessible. Those with additional special needs please contact Lydia Hemmings via email: fasdprojectlead@fasdhawaii.org

REFUND AND CANCELLATION POLICY: The Hawai'i Fetal Alcohol Spectrum Disorders (FASD) Action Group reserves the right to cancel or move this conference if acts of nature or conditions beyond our control prevent it from taking place. In the event of cancellation refunds will not be issued.

GRIEVANCES: Participants may contact Lydia Hemmings via email: fasdprojectlead@fasdhawaii.org



A NOTE OF GRATITUDE TO THE VOLUNTEERS

ACKNOWLEDGMENTS

Conference Committee:

- Almedo "Junior" Pamintuan, Hawai'i State DOH, Alcohol & Drug Abuse Division
- Alysa Makahanaloa, Adult Client Services Branch, First Circuit Court
- Amelia Kyewich-Kaneholani, M.Ed., Hawai'i State Council on Developmental Disabilities
- Angela Bolan, Hawai'i State DOH, Alcohol & Drug Abuse Division
- Angela Smith, Parent and Advocate
- Anisa Pacapac-Marquez, Hawai'i State DOH, Alcohol & Drug Abuse Division
- Ann S. Yabusaki, Ph.D., LMFT, Chair
- Cheryl Kameoka, Coalition for a Drug-Free Hawai'i
- Gigi Davidson, Parent and Advocate
- Ginny Wright, Parent and Advocate
- Joanne Sparrow, Ph.D., Clinical Psychologist
- Kathy Dougherty, School Psychologist
- Ken Yabusaki, Ph.D., Retired Biochemist
- Sina P. Pili, Parent and Advocate
- Susan Oka, Coalition for a Drug-Free Hawai'i
- Susan Yoo Kim, Hawai'i Zero to Three Court
- Terra Daniel, Parent and Advocate

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- Program Designer: Lee Yabusaki
 - Audio video Specialist: Sean Yabusaki
 - Registration: Cheryl Kameoka, Susan Oka, Lee Yabusaki, Lydia Hemmings (FASD Project Lead)
 - Displays and Room set up: Ken Yabusaki, Susan Oka
 - CE application: Alysa Makahanaloa

