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8 Keys Film Showings Around the State

In September 2023, the Alaska Center for Fetal Alcohol Spectrum Disorders (FASD) premiered the documentary film, *8 Keys for Adults with FASD*, by Dan Redfield, at the Beartooth Theatrepub in Anchorage.

The film features seven self-advocates who experience an FASD sharing their stories and the strategies that help them to be successful living with their brain-based difference.

The seven cast members developed the content of the film with support from Deb Evensen and Alaska Center for FASD founder Marilyn Pierce-Bulger. Anchorage filmmaker Dan Redfield filmed and edited the interviews and produced the animation that features Mario the narrator, throughout the film.

“I have never regretted getting an FASD diagnosis because it helped me put the pieces together and get answers for lots of unanswered questions I had about myself. The diagnosis has also helped me to be more gentle with myself and I now show myself more grace,” said cast member, Gina Schumaker.

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“The film is a powerful reminder that all is not as it appears when one looks or interacts with someone who may have a ‘hidden disability,” said co-producer Marilyn Pierce-Bulger.

“People perceive me to be higher functioning than I am, so it’s important for me to get people to understand that I do have limitations and I do have disabilities and that they do affect my day to day functionality ... [and] I require adaptations to be functional,” said cast member, Morgan Fawcett.

“This project has been eye opening in the sense of how many people are affected with FASD and how they display symptoms differently based on where they are in the spectrum ... These people are so strong and beautiful, they deserve to be celebrated. I’m so very grateful to have the chance to tell a small bit of their story,” said filmmaker Dan Redfield.

“This is a story of wisdom, strength, persistence, and hope. There is so much hope for individuals, families, and communities living with FASD and this film proves it,” said co-producer, Deb Evensen.

8 Keys For Adults With FASD was produced with generous support from the Alaska Department of Health FASD Program. The statewide showings in Anchorage, Mat-Su, Fairbanks, Juneau, Nome, Kenai, and Utqiagvik/ Barrow are supported by a grant from the Alaska Mental Health Trust Authority.

To learn more about the film, see the trailers, and track future showings, please go to:
<https://alaskacenterforfasd.org/8-keys-film>. ◇



Gina Schumaker, *8 Keys* cast member and Alaska Center for FASD board member, is a person with lived experience of FASD bringing her story and recommendations for success.



Janice Weiss: New Executive Director

In October 2023, Alaska Center for FASD Board of Directors enthusiastically welcomed Janice Weiss as the Center's new executive director.

Janice offers an extensive background in both public and non-profit organizational employment and volunteer work.

Most recently, she served as the Reentry Unit manager for the Alaska Department of Corrections (DOC), where she established the state's system for reentry case management and oversaw the educational and training programs for thirteen correctional institutions.

Before this, Janice served as the Reentry Coalition Coordinator for the Mat-Su Reentry Coalition, where she managed the coalition and established a case management program for successful reentry planning. She also organized reentry summits and served as the liaison between the Mat-Su community and DOC.

Janice has also served as president of the Board of Directors for the Alaska Center for the Blind and Visually Impaired, and as the executive director of the Alaska YWCA.

At one point, earlier in her career, she was the reentry program director for the Alaska Native Justice Center, and education coordinator for Hiland Mountain Correctional Center, where she received the honor of having the education and music building named after her. ◇

FASD United hosts Affiliates Summit in Washington D.C.

Alaska Center for FASD (AKCFASD) board members Mike Jeffery and Teri Tibbett attended the affiliate summit hosted by FASD United, in Washington D.C., between September 18-21, 2023. The summit was attended by 72 advocates representing 21 states,.

The agenda featured workshops, research, a Red Shoes Gala, and Capitol Hill visits with Congress members and staff in support of the FASD Respect Act.

The event opened with a networking opportunity and reception that welcomed FASD United affiliates, advocates, researchers, and leaders from across the United States.

The second day offered, "An Impactful Network: Widening the Circle," a workshop reflecting on innovative ways to interact and network.

That evening, FASD United hosted the Red Shoes Gala at the National Press Club, a fundraising event featuring speeches by members of Congress, FASD leaders, and presentations by people with lived experience of fetal alcohol spectrum disorders who shared their stories.

On the third day, affiliates participated in "The State of Science," a workshop highlighting current findings on growth and emerging trends in the FASD research field.

On the summit's final day, advocates visited the United States Capitol for meetings with policymakers in over 60 congressional offices.

AKCFASD board members met with the staff of Senator Lisa Murkowski and Representative Mary Peltola, and in person with California Representative Mike Thompson, to support the [FASD Respect Act](#) (S.1800/H.R. 3946), introduced by Senator Murkowski. Four new co-sponsors signed onto the bill as a result of these hill visits. ◇



Top to bottom: Representative Mike Thompson meets with AKCFASD board members Mike Jeffery and Teri Tibbett, and University of Rochester researcher Dr. Christie Petrenko; Teri and Mike pose in front of the U.S. Capitol; meeting with Senator Lisa Murkowski staff and FASD Advocate Susan Carlson.

Moving Ahead: Activities in 2024

The Alaska Center for FASD is undertaking an effort to increase access to diagnosis, supports, and services for individuals, families, caregivers, and professionals impacted by prenatal alcohol exposure in Alaska. The following activities, funded by grant through the U.S. Department of Health and Human Services, were secured for the Alaska Center for FASD by Senator Lisa Murkowski:

- 1. Develop and Coordinate a Pilot FASD Telehealth Diagnostic Team Delivered to Rural Areas in Alaska.** Assemble an Alaska telehealth diagnostic team--with medical and psychological professionals, occupational therapist, speech and language pathologist, navigator, and peer support specialist--to provide assessment, evaluation, diagnosis, and referral to supports and services for individuals, families, and caregivers impacted by PAE/FASD.
- 2. Identify, Catalog, and Promote Navigation of Existing FASD- and Culturally-Informed Resources (Supports, Services, Trainings) for Families and Caregivers That Are Effective Across the Lifespan in Both Rural and Urban Settings.** Identify existing resources and training opportunities for FASD case management and parent-family navigation resources at all phases of the diagnostic process (prior, during, post) regardless of diagnosis.
- 3. Expand Efforts to Engage, Support, and Empower Self-Advocates to Become Champions Locally, Regionally, and Nationally to Serve as Mentors, Trainers, Advisors, Advocates, and Peer Support Specialists.** Identify existing resources for individuals with PAE/FASD and promote efforts that engage adults with FASD to connect with peers for support and guidance.

People with FASD will guide leaders in the planning, implementation, and evaluation of supports for peers, demonstrating a commitment to the “nothing about us without us” philosophy.

4. Identify, Catalog, and Promote Evidence-Based FASD- and Culturally-Informed Services and Training Across Professional Sectors That Are Effective Throughout the Lifespan in Both Urban and Rural Settings. Identify existing resources and trainings for professionals across multiple disciplines, including medical and behavioral health, childcare and educators, legal and corrections, developmental-intellectual disability systems, foster and adoptive systems. This effort also includes coordinating FASD trainings for individuals, families, caregivers, and professionals in both rural and urban communities. If time and funding allows, the Center will coordinate an FASD conference in Alaska to include presenters, break-outs, training, and education beneficial to individuals, families, caregivers, and professionals.

5. Develop a Long-Term and Diverse Sustainability Strategy That Considers Financial, Social, and Environmental Capital. Identify potential sustainable funding resources, and leverage existing funds to bring more funds to the Center.

6. Continue to Participate with Other Stakeholders to Inform and Support Efforts and Responses to PAE/FASD in Alaska, Including, Sharing Resources, Developing Strategies, and Evaluating Effectiveness of Efforts. The Center will continue to collaborate with private, non-profit, state, and tribal partners on culturally-informed diagnosis, intervention, training, and education for individuals, families, caregivers, and professionals. The Center will continue to work with the Alaska Mental Health Trust, the State of Alaska’s FASD Program, and other stakeholders to continue focus on FASD diagnosis, prevention, navigation, peer support, and services. ◇



PAE/FASD Facts

- **Prenatal Alcohol Exposure (PAE)** is exposure to alcohol before birth. **Fetal Alcohol Spectrum Disorders (FASDs)** are a range of diagnoses that can result from PAE, including Fetal Alcohol Syndrome (FAS), Static Encephalopathy Alcohol-Exposed (SE/AE), and Alcohol-Related Neurodevelopmental Disorder (ARND). *Note: The term FAE (fetal alcohol effects) has been replaced with the term FASD.*
- With or without a diagnosis, the effects of PAE/FASD can present with physical, behavioral, and cognitive symptoms that range from mild to severe. Prenatal alcohol exposure most commonly impacts brain development, which controls behavior, memory, emotion regulation, attention, and impulse control.
- The impacts of drinking alcohol during pregnancy are unpredictable and depend on many variables—including how much alcohol was consumed, when in the pregnancy was it consumed, what was developing at the time the alcohol was consumed, the metabolism of the mother, and the metabolism of the developing baby, genetic, and other factors. There is no *known* safe amount of alcohol during pregnancy.
- PAE/FASD is often misdiagnosed as Attention Deficit Hyperactive Disorder, Autism Spectrum Disorder, and Oppositional-Defiant Disorder. A misdiagnosis can mean implementing the wrong interventions and exacerbating symptoms.

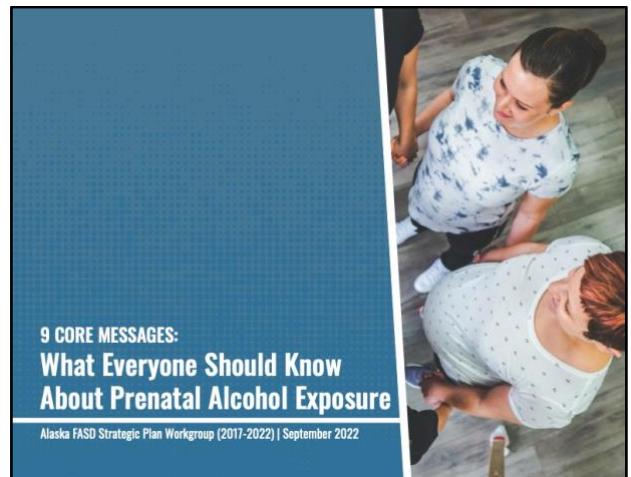
- 1.7 out of 1,000 live births in Alaska may experience FAS. This accounts for about 10% of the total diagnoses on the fetal alcohol spectrum.^[1] Individuals with other diagnoses are represented in far greater numbers, estimated at 65 per 1,000 (or 90% of the diagnoses).^[2]
- Up to 1 in 20 students in the United States may have an FASD (1.1% to 5%) according to a study of over 6,600 first graders in four U.S. cities.^[3]
- Only 1 of every 600 individuals impacted by prenatal alcohol exposure will receive an FASD diagnosis.^[4]
- To read more about PAE/FASD, see *9 Core Messages: What Everyone Should Know About Prenatal Alcohol Exposure* at: <https://health.alaska.gov/abada/documents/FASDCoreMessages.pdf>. ◇

^[1] *Health Impacts of Alcohol Misuse in Alaska*, Alaska Division of Public Health, (2018).

^[2] *Alaska Mental Health Trust, Drugs and Alcohol Report, FASD Summary*, (2020).

^[3] *May, Chambers, Kalberg; Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities*, JAMA, (2018)

^[4] *Fetal Alcohol Spectrum Disorder: Can We Change the Future?*, Alcohol, Clinical, & Experimental Research, (2020)



Top photo: FASD advocates Cheri and Justin Scott present on a panel at a Southeast Alaska FASD conference; Bottom: cover of the booklet, '9 Core Messages: What Everyone Should Know About Prenatal Alcohol Exposure.'



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Alcohol
Spectrum
Disorders**

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www.alaskacenterforfasd.org*



The FASD Respect Act
Building the Foundation for Change
#FASDRESPECT

FASD Has Action in Washington D.C.

The FASD Respect Act (S.1800/H.R. 3946) is federal legislation that addresses fetal alcohol spectrum disorders (FASD) and other prenatal substance exposure. The bill promotes education, aware-ness, and services for people impacted by FASD and other substances, and includes funding to promote alcohol and substance-free pregnancies, coordination with state and tribal systems, and interventions for individuals with FASD.

On Dec. 12, 2023, the bill cleared a major hurdle by passing the U.S. Senate Committee on Health, Education, Labor, and Pensions. The FASD Act was rolled into the Support Reauthorization Act (S.3393), which is now headed to the floor of the U.S. Senate for a vote.

This bi-partisan legislation is sponsored by Senator Lisa Murkowski (R-Alaska), Sena-tor Amy Klobuchar (D-Minn), Representative Betty McCollum (D-Minn), and Representative Don Bacon (R-Nebraska). Alaska's House member, Representative Mary Peltola, has also signed on as a co-sponsor.

About 300 organizations from 33 states have expressed support for the FASD Respect Act, including the Alaska Center for FASD.

To learn more about the bill, go here:
<https://nofaspolicycenter.org/the-fasd-respect-act>,