

# Alaska Birth Defects Monitor

A publication of the Alaska Birth Defects Registry

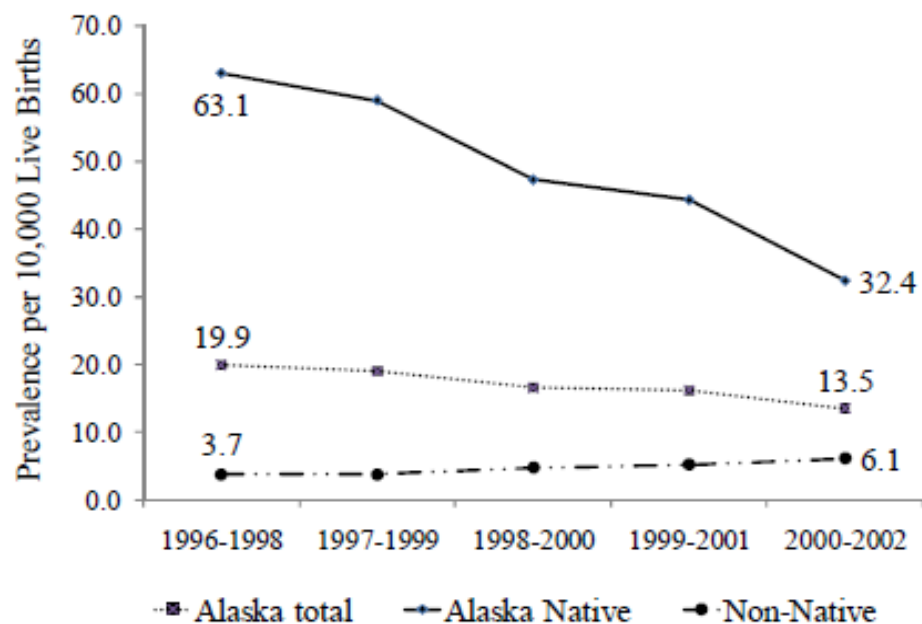
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## Decline in the Birth Prevalence of FAS in Alaska

A recent analysis of data from the Alaska Birth Defects Registry showed that for children born to Alaska-resident mothers during 1996-2002, Alaska experienced a significant 32% decrease in FAS birth prevalence from 19.9 to 13.5 per 10,000 live births ( $p=0.05$ ) (Figure 1) (Schoellhorn, 2010). Decline in the overall FAS prevalence was limited entirely to Alaska Native children who experienced a 49% decline from 63.1 to 32.4 per 10,000 live births ( $p=.003$ ). The prevalence among non-Native children showed a non-significant 64% increase from 3.7 to 6.1 per 10,000 live births ( $p=.18$ ). The prevalence ratio of Alaska Native to non-Native infants fell

Figure 1. FAS prevalence by three-year moving averages, Alaska Birth Defects Registry, birth years 1996-1998 to 2000-2002.



from 17 (95% confidence interval [CI]: 8 to 36) in 1996-1998 to 5 (95% CI: 7 to 16) in 2000-2002.

The observed decline occurred in association with a number of prevention activities: development and sustainability of a network of community-based FASD Diagnostic Teams; development of university-level FASD curricula and statewide training programs for educators and providers; a statewide multi-media public

awareness

campaign; and increased substance use screening in primary care settings.

The temporal association of declining FAS prevalence with these prevention activities suggests that some or all of these interventions played a role. Despite improvements for Alaska Native children, population-specific FAS rates remain higher for this group. It is unclear why FAS prevalence has

Source: Schoellhorn, 2010

**Decline in FAS** (continued from page 1)  
not declined among non-Native children.



*Recommendations for FAS prevention, treatment and reporting include:*

1. Health care providers should familiarize themselves with signs of alcohol abuse

and provide patient education and appropriate referrals for pregnant and other women of childbearing age.

2. Health care providers should familiarize themselves with the clinical presentation of FAS and provide appropriate interventions to affected children. Providers should evaluate children for FAS using standardized diagnostic criteria or refer patients to FAS diagnostic teams.

3. All health care providers should comply with the state's requirements for conditions reportable to public health.

4. Specialists should record diagnostic information in the child's medical record including specific information on facial dysmorphia, growth delay and central nervous system development.

1 Schoellhorn, J. Decline in the birth prevalence of fetal alcohol syndrome in Alaska. [http://www.epi.alaska.gov/bulletins/docs/b2010\\_03.pdf](http://www.epi.alaska.gov/bulletins/docs/b2010_03.pdf)

## Arctic Fetal Alcohol Spectrum Disorders Regional Training Center



The Arctic Fetal Alcohol Spectrum Disorders Training Center (Arctic FASD RTC) was established at the University of Alaska Anchorage's

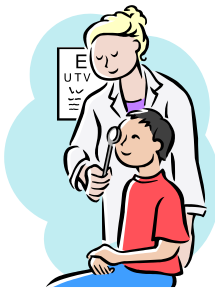
Center for Behavioral Health Research & Services (CBHRS) in October, 2008, following the award of a three year grant from the Centers of Disease Control and Prevention (CDC). Despite a remarkable and sustained effort by various entities in Alaska to increase awareness of FASD prevention and intervention strategies among all segments of the population, it was recognized that a more focused effort to educate health and allied health care professionals and students was needed. The Arctic FASD RTC is attempting to fulfill this need through targeted workshops and trainings that are sensitive to this rural and culturally diverse state.

*The Arctic FASD RTC has three primary goals:*

1. to increase awareness, knowledge, and behavior change among medical and allied healthcare practitioners and students, sensitive to a rural and cultural context;

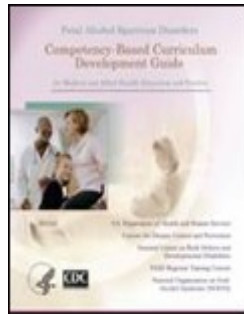


2. to develop rurally tailored and culturally competent educational curricula, materials, and campaigns that will lead to increased knowledge, changed behavior, and modified training and licensure guidelines, making FASD visible in training program and healthcare settings across this vast region;
3. to disseminate education and resources throughout the region to reach



a maximum number of stakeholders who can help us realize the prevention of FASD and reduction of FASD risk behaviors, with sensitivity to rural/frontier realities and an understanding of cultural diversity.

The Arctic FASD RTC uses a curriculum based on the CDC's *FASD Core Competency Curriculum Development Guide*, which outlines seven areas of FASD prevention and intervention knowledge and awareness in which practitioners should be competent.



[\[Read Guide\]](#)

These include screening and brief interventions for women regarding alcohol use, addictions, the biological bases of FASDs, the screening and diagnosis of individuals who experience FASDs, intervention and treatment strategies, and the ethical, legal, and policy issues concerning FASDs. Since its inception during 2008, the Arctic FASD RTC has trained 1,444 health and allied health professionals and students and provided 347 hours

of training on these areas of competency.

The Arctic FASD RTC has many workshop options – many of them free – to suit a variety of training and education needs. These options can be individualized to meet participant needs, interests, and schedules. If you have a specific training request or if you would like to know more about the Arctic FASD RTC, please email [arcticfasdrtc@uaa.alaska.edu](mailto:arcticfasdrtc@uaa.alaska.edu), visit the website at [www.uaa.alaska.edu/arcticfasdrtc](http://www.uaa.alaska.edu/arcticfasdrtc), or call Alexandra Edwards at (907) 561-2880. American Psychological Association continuing education credits may be available.

*Submitted by Alexandra Edwards*

#### **SPOTLIGHT ON THE COMMUNITY and FASD**



### **New FASD Diagnostic Team in Anchorage**

The non-Native community in Anchorage now has access to FASD diagnostic services modeled after the University of Washington standard of diagnostic evaluation for children affected by prenatal alcohol exposure. Over 10 years of work by concerned members of the professional and parent community and the Anchorage Council on FASD has resulted in the creation of the Anchorage FASD Diagnostic Team at Assets, Inc. Funding from the Alaska Mental Health Trust has supported start-up support and sustainable reimbursement will be provided via the State of Alaska FASD Diagnostic Team Provider Agreement.

The other active diagnostic group in An-

chorage, the Southcentral Foundation FASD Diagnostic team, has been providing diagnostic services to American Indian/Alaska Native children between the ages of 3-18 for about 10 years.

The client or family is supported by a parent navigator (a team member provided by Stone Soup Group) that supports the family during and after the diagnostic process. The comprehensive nature of the evaluation provides a 'road map' of how prenatal alcohol exposure has impacted the individual being seen. Every person who has had prenatal alcohol exposure has a different presentation because the dose of alcohol, timing of drinking during the pregnancy, and genetics of the mother and baby all interact to create an environment that is unique for each individual.

### ***Making a referral***

Agencies, clients or family members who know someone who *meets the criteria* for (and desires) referral to this diagnostic team, please go to <http://www.assetsinc.org> Click on the Services tab, then select the FASD Diagnostic Team box. Click the Referral Criteria choice. You will find a Referral Form link. Download and complete the form, then fax it to:

#### ***Assets, Inc.***

***FASD Diagnostic Team Coordinator  
(FAX) 907-274-0636***

The team coordinator will be in touch with you regarding next steps. For more information about the team and referral criteria please go to <http://www.assetsinc.org>

*Submitted by Marilyn Pierce-Bulger*

## **Stone Soup Group— Providing Support for Children, Teens and Young Adults with FASD and other Special Health Care Needs**



### ***What We Do***

**Stone Soup Group is a statewide nonprofit agency that helps families of children, teens & young adults with special needs.**

Each Stone Soup Group program is focused on different ways we can help families supporting children & youth with special needs to become informed, experienced, self-sufficient advocates for themselves and their children. Stone Soup Group is a great place to start if a family needs help, but doesn't know where to turn. There is no charge to families for most services. Any Alaskan family of a child or young adult with special needs is eligible to receive our help.

### ***Why Stone Soup Group is Unique***

Our Parent Navigators understand the journey - because they've been there. Stone Soup Group is made up of parents and family members of children and adults with special needs who know what it's like, and can draw on their own experiences to help other families.

### ***What is a Parent Navigator?***

A Parent Navigator is an experienced parent or family member of a person with special needs who helps other parents or families get connected to what they need. For example, a child's school might have referred her for a special education

evaluation, and the parents don't know what to do next. Stone Soup Group has a Parent Navigator that can help. Maybe families have heard about a Medicaid waiver, or a program that might help provide services for a relative with FASD, but it's unclear whether the child's eligible. Maybe a newborn has a cleft lip/palate or hearing loss and parents don't know what to do next. Even if families don't know exactly what to ask for, Stone Soup Group's Parent Navigators can help them through the entire process.

*A Parent Navigator can:*

- help a family in crisis
- help families address their children's medical needs
- assist families with special education issues
- listen to families' concerns; give support and advice
- make referrals for helpful services
- adapt to unique situations to help with all kinds of needs

### **Stone Soup Group Programs and Services**

In addition to general Parent Navigation support, Stone Soup Group offers the following programs:

#### **Cleft Lip/Palate Clinic Parent Navigation**

#### **Early Hearing Detection & Intervention (EHDI)**

#### **FASD Family Support Project**

Resources, information, and support for families raising children and youth with Fetal Alcohol Spectrum Disorders. Stone Soup Group also provides Parent Navigation support for families being seen by the new Anchorage FASD diagnostic team.

#### **Short Term Assistance & Referral (STAR)**

Emergency help for rural families in Anchorage

#### **Parent Training & Information (PTI) Center**

Special education assistance, training, and information for the state of Alaska

#### **Autism Family Support Center**

Support for families of children and youth with Autism Spectrum Disorders

#### **Newborn Hearing Screening Parent Navigation**

#### **AK 360° Military Family Support**

Support & help for military families of children & youth with special needs

#### **Family to Family Health Information Center**

A statewide information and networking portal for families raising children with special needs

#### **Positive Behavioral Support**

Training and assistance on evidence based methods of dealing with challenging behaviors in schools and at home, as well as special efforts focused on children birth to five years old

#### **AK Epilepsy AWARE**


Information and support for individuals with Epilepsy and their families

**Contact Stone Soup Group at** (907) 561-3701

<http://www.stonesoupgroup.org/index.html>

*Submitted by Becky Braunstein*

### **FASD Screening and Intervention Tools for Women's Healthcare Providers**

CDC has collaborated with the American College of Obstetricians and Gynecologists (ACOG) to develop a tool kit, [Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Tool Kit](#), for women's health care providers. The primary component in the tool kit is a CD-ROM that aims to teach women's health care providers how to properly screen and advise all of their patients of reproductive age about risky drinking and encourage the use of effective contraception among patients who continue to engage in risky drinking. It also addresses drinking during pregnancy. With information on screening, education, and counseling, this publication can help women's health care clinicians prevent FASDs when they encounter risky drinking, regardless of pregnancy status. This tool kit contains a brief guide, a laminated screening instrument for providers, resource information, and patient handouts that can be downloaded and printed. Continuing medical education credits are also available. The tool kit is available to download or to order from the [ACOG website](#) .

State of Alaska Department of Health and Social Services/Division of Public Health/Section of Women's, Children's and Family Health/Maternal and Child Health Epidemiology Unit  
<http://www.epi.alaska.gov/mchepi/ABDR/default.stm>

Sean Parnell, Governor  
 Bill Hogan, DHSS Commissioner  
 Ward B. Hurlburt, DPH Director  
 Stephanie Wrightsman-Birch, Section Chief



**Meet our Staff...  
 Jennifer Higby,  
 Medical Abstractor**

Jennifer returned to the MCH Epidemiology Unit in February 2009 after working in the private sector for almost 5 years. Jennifer previously worked in the unit as the PRAMS Data Manager for 2½ years. She came back to the unit as a Research Analyst supporting both the Childhood Understanding Behaviors Survey (CUBS) Program with data collection and the Alaska Birth Defects Registry as a part-time medical abstractor. Jennifer grew up in Wasilla and moved to Anchorage in 1999. She enjoys camping, fishing, four-wheeling, and target shooting. Jennifer is excited to be back working with the MCH Epidemiology Unit.

**Contact us!** If you would like more information on birth defects reporting in Alaska, a copy of our Birth Defects Surveillance Data Book, or if you would like a presentation on the prevalence and trends of birth defects for your agency or organization, please contact Sandy Collins, ABDR Coordinator.

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# Save the Date

September 27-29, 2010

Alaska Maternal Child Health and Immunization Conference  
 Hilton Hotel - Anchorage, Alaska

**What:**

This conference will provide opportunities to network and learn about best practices and tools on prevention, diagnosis and treatment of key women's, children's, and adolescent health issues in Alaska, as well as provide the latest surveillance data and research findings.

**Who:**

The conference will be of interest to physicians, private practice & public health nurses, nurse practitioners, midwives, immunization coordinators, social workers, community health aides, program managers and researchers among others.



Look for the registration forms to be posted in April, 2010 at: [www.confcoor.com](http://www.confcoor.com)

Or contact Bridget McCleskey at [confcoor@gqi.net](mailto:confcoor@gqi.net)

*This conference is sponsored in part by the Alaska Native Tribal Health Consortium EpiCenter, the State of Alaska Section of Women's, Children's, and Family Health, the Association of Women's Health, Obstetrics, and Neonatal Nursing (AWHONN), and The Children's Hospital at Providence.*

**Travel scholarships are available if you live outside of the Anchorage area. The deadline to apply is July 31<sup>st</sup>. Visit <http://www.confcoor.com/MCH%20Scholarship.html> for details!**

**The ABDR offices moved and our mailing address changed to:  
 3601 C Street, Suite 358  
 Anchorage, AK 99503**

## Folic Acid: Resources For Health Care Professionals

The National Birth Defects Prevention Network (NBDPN) offers free resources to support educational activities and promote professional understanding of the importance of folic acid recommendations. On-line CMEs are available, as well as toolkits for promoting folic acid education and healthy birth outcomes.

Check out: <http://www.nbdpn.org/current/resources/ntdresources.html>

