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Steven Jacquier

Judith Kleinfeld

David Gilliam

*University of Northern Colorado*

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# Prevention of Fetal Alcohol Damage in Northern Native Communities: A Practical School-Based Approach

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*Steven Jacquier, Judith Kleinfeld & David Gilliam*

**Abstract:** This article describes a Fetal Alcohol Syndrome prevention program, “FASD in Lab Mice,” that had a dramatic effect in increasing Alaska Native students’ understanding of the lifelong neurological and physical damage caused by drinking during pregnancy and, more importantly, led them to engage in active prevention efforts in their own and other Native communities. Informational programs typically used in the schools create little student interest and students often do not see connections between their own experience and the atypically extreme examples such prevention programs tend to emphasize. The “FASD in Lab Mice” prevention program, using actual experiments conducted by the students themselves, provides compelling evidence regarding the pervasive effects of alcohol on the developing fetus. The program received strong support from Native communities and incorporated community values of reverence for animal life with the use of animals for practical human purposes. Long-term quantitative as well as qualitative research on the effectiveness of this program model is needed.

## **Introduction**

In recent years a shift has occurred in the thinking regarding Fetal Alcohol Spectrum Disorders, FASD, an umbrella term encompassing a number of related and often overlapping terms specific to various forms of teratogenic alcohol injury (i.e., embryonic or fetal malformations caused by alcohol). The shift has been toward recognizing FASD as a significant brain injury where the injury itself is often invisible except as seen through its impact on behaviour.

The medical model describes four key criteria for a diagnosis of FASD: developmental exposure to alcohol, central nervous system impairment, growth deficiency for height or weight or both, and a specific pattern of minor

anatomical anomalies (Streissguth, 1997). A better description of FASD, in functional terms, is to say FASD is primarily a brain-injury based physical condition with serious behavioural symptoms such as problems in school, poor judgment, trouble with the law, difficulty in understanding rules, and often mental retardation. Happy and fulfilling lives may still be available as outcomes, with appropriate supports (Trudeau, 2005). The compromised potential of those with FASD together with the widespread failure of social institutions to recognize and deal effectively with this condition all too often results in a personal tragedy for individuals and a serious problem for communities (FADP, 2005; Lutke & Antrobus, 2004). Prevention of FASD should be a high priority but effective prevention strategies have proved elusive in remote northern communities such as Alaska Native villages and other remote isolated settings.

### **Causes of FASD**

Prenatal exposure via the mother consuming alcohol while pregnant is the causal pathway for FASD. Functionally, however, alcohol present in breast milk can cause outcomes identical to FASD but for the timing of the exposures. Concentration of alcohol in breast milk can be approximately the same as it is in the mother's bloodstream (Kesaniemi, 1974) and because the liver of the developing baby is infantile, the baby's developing organs and brain tissues will be exposed for an even longer period of time than if the baby were still in the mother's womb where the mother's mature liver would be at work breaking down the ethanol (American Academy of Pediatrics, 2005).

Alcohol administered directly to a baby or child—as when mixed with juice in a baby bottle, sometimes done in the naïve belief it calms a fussy infant without doing harm, or as when young children are directly given beer or mixed drinks—may also cause substantial permanent brain damage consistent with FASD (Diaz & Samson, 1980) though such damage may be referred to as “perinatal alcohol-related neurological injury” or by some similar term. If none of these pathways exposing the embryo, fetus, or infant to alcohol are present then FASD and similar manifestations of alcohol-related brain injury cannot occur; in this sense FASD and similar alcohol-related brain injuries are entirely preventable.

While there is some evidence from animal models and epidemiological research that paternal drinking and epigenetic factors may have some influence in the subsequent health of offspring (Abel, 2004, 1990, 1989a, 1989b, 1985; Cicero, 1992), the vast majority of FASD outcomes studied to date are directly linked to alcohol concentration in the pregnant mother's bloodstream. Indeed, in laboratory experiments with animal models even

one maternal exposure to alcohol has been demonstrated to have negative effects on the developing fetus (Persuad & Sam, 1992; Goedde & Agarwal, 1989; Clarren, 1990). The larger the dose and more prolonged the exposure, the more pervasive and severe the FASD damage is likely to be (Day, 2002; Jacobson & Jacobson, 1992).

The most severe organic damage occurs when the pregnant mother engages in heavy drinking, especially in binge drinking, during critical episodic stages of embryonic development. The higher the parity (number of times a woman has given birth) in a pregnant mother who has previously given birth to a child who suffers from FASD, the more likely she is to give birth to another child even more profoundly impacted by FASD. The liver is the only organ which can break down ethanol; with each additional child the mother's liver is older, has been exposed to more diseases and chemicals of various types, is under more strain, and is less able to as swiftly and effectively process alcohol and its toxic breakdown products out of the bloodstream. Since nerve tissue is particularly vulnerable to the effects of alcohol, CNS functions in particular (including judgment, language processing, and the visual system) are negatively impacted (Jaworski, 2002). While neurological damage both subtle and obvious is a hallmark of FASD, prenatal alcohol exposure can and does cause damage to a wide range of tissues and organs throughout the body, such as the heart, kidneys, and genitals (Coles, 1992; Hogan & Barnes, 1992; Jones, 1988; Moore, 1988).

In years past it was mistakenly thought that children who suffer from a characteristic facial pattern caused by alcohol exposure are more severely impacted than others in both the extent of brain damage and in how their lives are limited by FASD. Key defining features of "the FAS face" include a smaller than normal cranial circumference, thin upper lip, shorter than usual distance across the nose between the corners of the eyes, smaller eye openings, reduced or missing philtrum (the double ridged groove extending from the nose to the upper lip), epicanthal folds in the corners of the eyes in races for which this is not a normal feature, and a smaller than normal jaw. These ironically rather cute Cabbage Patch doll-like or elfin Kewpie doll-like FAS features tend to become much less recognizable after adolescence due to post-pubertal bone growth. This constellation of features, when present, is basically a consequence of the person with FASD having smaller brain size than would have been the case but for alcohol killing many neurons during development. The vast majority of people with FASD do not show the facial dysmorphology in a way anyone but an expert dysmorphologist using sophisticated tools would be able to detect, yet their brain damage is life-limiting.

In terms of practical effects, children with clearly observable alcohol-exposed faces tend to receive diagnosis and accommodations whereas those lacking “the face” but with behavioural challenges just as profound are under-diagnosed and tend to not receive many of the accommodations and allowances available to other people with FASD.

### **Prevalence and Economic Costs of FASD**

Ascertaining the prevalence of FASD—including Fetal Alcohol Syndrome (FAS) and Alcohol-Related Birth Defects (ARBD)—is difficult (Russell, 1994, 1992) and estimates vary depending upon the method used. In a review of the literature, May and Gossage (2009) concluded “the overall prevalence of FAS in the United States was estimated by the Institute of Medicine to be between 0.5 and 3.0 per 1,000 births. Based on the review presented here, which has the advantage of more recent studies, we believe that FAS prevalence in the general population of the U.S. can now be estimated to be between 0.5 and 2 per 1,000 births, and the prevalence of FAS and ARBD combined is likely to be at least 10 per 1,000, or 1 percent of all births.” Estimates of the prevalence of FAS/ARBD in Alaska Native American Indian populations range from 2.9 to 9.8 per 1,000 (May, 1983; Egeland, 1998; Chavez, 1988; Centers for Disease Control and Prevention, 2002; Cordero, 1992).

Debate exists as to the causes of such differences in rates of FASD between Native Americans and the general population. Differences in ethanol metabolism in particular racial groups may be one factor (Segal & Duffy, 1992; Edenberg, 1991; Schuckit, 1996, 1985). Greater vulnerability to ethanol acting as a teratogen and/or longer duration of fetal exposure before ethanol and its breakdown products are cleared from the system may be important. FASD may also be diagnosed more often in some ethnic groups because of “cluster” factors such as Native Americans tending to live in isolated locations and to be culturally distinctive and identifiable.

The demographic incidence of heavy drinking also varies between groups; partly in consequence of this it may be that certain groups, including some Native American, Irish, and Russian populations, may have a higher prevalence of FASD because they drink more frequently and binge more often than do some other groups (Alexander, 2007; Golden, 2005). One study found 60% of pregnant Latinas experiencing moderate to severe depression and told by their physicians to not drink, did so anyway to self-medicate against depression; 20% of pregnant English-speaking Latinas in the group studied were drinking before pregnancy and did not stop during pregnancy (O’Connor, 2008). Risk factors increase among populations with less education, more poverty, less high-quality prenatal care, and greater

numbers of children per mother. Indeed, among many Alaska Native villages drinking in general and binge drinking in particular have become normative behaviour among many young Native people, who thus become vulnerable to producing offspring impacted by FASD (Abel & Hannigan, 1995; Keen, 1992). The more risk factors present the higher the rate of FASD ranging from 2 percent for one factor to 85 percent when four risk factors are present; these factors measured by the Michigan Alcoholism Screening Test include such variables as life complications, percentage of drinking days, high parity, and racial background (Mulhauser, 2008).

Notable exceptions to the preceding generalization associating lower education and socio-economic status with increased drinking, however, are the current epidemic of binge drinking among American college women and evidence of alcohol use during pregnancy among professional women including physicians (NIAAA, 2008; DeJoseph, 2008). Indeed, a recent National Birth Defects Prevention Study (Ethan, 2008) found that drinking during pregnancy is fairly common nationwide and by no means only a problem among the poor, the educationally underserved, and minority groups.

The overall economic costs of FASD are staggering. Each FASD birth is commonly estimated to have direct taxpayer costs of \$1.4 million to \$3 million, largely through postnatal medical and early childhood care costs, special education, and other social services (Lupton, 2004; FASlink, 2008). This figure does not include costs of homelessness and incarceration, rates of which are believed to be extremely high among adults and adolescents affected by FASD, nor does it include economic quantification for the lost workforce productivity of people with FASD had they been born unimpaired. Approximately 60 percent of Alaska's homeless youth and youth sent outside Alaska for behavioural and mental health treatment, including many Alaska Native youth, are estimated to be impacted by FASD (Senner, 2008). A University of Washington study shows that among the population of people with FASD between age six and fifty-one, 60 percent of those twelve and over had trouble with the law, 79 percent of adults had employment problems, and 35 percent of adults and adolescents had been imprisoned (Streissguth, Bookstain & Barn, 2004; Bloss, 1992). Other studies have found a minimum of 23 percent of prisoners in Canada (Fast, 1999; Canadian Dept. of Justice, 2009) and 42 percent of prisoners in the US (Streissguth & Kanter, 1997) are affected by FASD. In Alaska it is acknowledged among mental health and criminal justice workers alike that the prison system is the state's predominant institution receiving adolescents and adults with brain injury incurred through developmental alcohol exposure. Indeed, the National

Crime Prevention Council states “more than 60% of prisoners are likely affected by alcohol *in utero*. It costs approximately \$120,000/year to ‘house’ a young offender and \$82,000 for an adult offender” (FASlink, 2008).

### **Social Consequences of FASD**

As they age, people with FASD find themselves increasingly marginalized by their condition and often come into more severe conflict with society. What does FASD mean in plain human terms? In brief, all too often FASD means frustrated and sad children and adolescents who feel bad about themselves as they slip ever farther behind unimpaired peers in practically every way: cognitive and physical progress, the ability to understand cause and effect relationships, emotional maturity, good judgment as regards when and where not to trust others, inability to succeed in work roles and in managing money, failure in romantic relationships, and trouble with the law — especially for sexual offenses (Kleinfeld & Wescott, 1993; Kleinfeld, Morse & Wescott, 2000; Dorris, 1989). FASD frequently means remorseful and guilt-ridden parents who all too often become worn down, emotionally and financially exhausted, and even divorced while simultaneously attempting to protect their brain-injured children and cope with their children’s organic and behavioural disorders. FASD means teachers who often do not recognize the many classroom problems created by these children actually result directly from their brain injury and is not at root wilful misconduct, do not know how to effectively manage or teach these brain-injured children, and find their jobs much more difficult in consequence. FASD means communities and government agencies that must deal with the problems created by FASD.

Teachers must be educated on effective teaching methods, such as more visual learning. Judges, probation officers, and the police must be educated on the problems of FASD, such as childrens’ special vulnerability to peer pressure. Special “mental health” courts must be developed and, in some jurisdictions are being developed, to deal with these problems. Lacking accurate identification and appropriate intervention these disappointed or angry young FASD-affected adults may be unable to assume fully independent and productive roles in society, drink heavily, and produce even more victims of FASD in the next generation (Kleinfeld, Morse & Wescott, 2000; Lesley, 2000).

FASD also contributes to infrastructural instability in local institutions of remote northern communities. Teacher turnover in Native village schools, for example, is notoriously high (frequently from one-quarter to over one-half the staff turning over each year); many departing teachers say this stems largely from their discouragement and burnout in coping with FASDs’ effects

in the classroom and community. A high incidence of FASD in an isolated population places strain upon the Village Public Safety Officers through higher levels of vandalism and general chaos, as well as increasing the strain on medical clinic staff coping with acute emergencies (such as accidents due to poor judgment) and chronic problems linked to the damage created by consumption of alcohol during pregnancy.

Discouragement and burnout stemming from constantly coping with a large burden of FASD behaviours is also a problem for village businesses dealing with such problems as shoplifting. Unfortunately, urban populations may misinterpret behaviours rooted in brain damage as a cultural marker, which stimulates racism. The degree of anti-Native bias in statements, mistrust of Natives, and ill treatment exhibited toward Native people in Alaska's urban centers is shocking and may be due in large part to unfortunate interactions people in town have had with Native people who cope with the difficulties of FASD.

### **Prevention of FASD**

Prevention programs informing women of developmental brain damage caused by alcohol are one component of the comprehensive approach needed to eliminate drinking during pregnancy and breastfeeding; prevention includes screening, identification, education, treatment, and follow-up as needed.

One would naturally think for well-educated, affluent, mature parents who are well-integrated in their communities and with good access to professional prenatal and perinatal care, the prevention of FASD may require only ongoing informational campaigns reminding parents of the risks to their children incurred by drinking during pregnancy and breastfeeding. This is sometimes true, but by no means always. Since the amount of alcohol which may be consumed during pregnancy with no detectable effects on the offspring varies from person to person (based on a complex interaction of many factors including genetics, age, weight, health, dose, timing of dose, and so on), FASD impacts may not always be detectable and correctly attributed as such when present. The conservative position is therefore the only absolutely safe amount of alcohol which may be consumed during pregnancy is none at all. This is a prevention message ideally but not in fact uniformly reinforced among educated and affluent parents by the monitoring of health professionals seeing them on a regular schedule and assisting in any needed substance treatment interventions. Not all health professionals understand or promote the "none for nine" message (a popular prevention awareness campaign slogan—no drinking for the nine months of pregnancy,

“not one drop”). While FASD can and does cause brain damage to the children of rich and poor alike, across all ethnicities and regions, in terms of group membership as a predictor it is statistically less likely to afflict the children of parents with more access to supports during pregnancy (Hogan & Barnes, 1992).

Effective FASD prevention has proven elusive and extremely difficult, particularly among heavy-drinking mothers (Russell, 1992; NIAAA, 1987; Eliany & Rush, 1992). Especially problematic is that FASD is commonly seen as being a problem of mothers, in contrast to being a problem of parents, families, and communities. The lone woman often stigmatized as “a mother drinking” did not become pregnant by herself, nor should she bear the entire burden of blame for drinking while unsupported by the baby’s father, the family, community, local institutions, and government programs. Far preferable is shifting away from “shame and blame” to a model recognizing alcoholism and substance abuse of alcohol in pregnancy as a serious disease in need of treatment, with multiple levels of both causation and cure (Malbin, 2002; May, 1995; May & Hymbaugh, 1989). Prevention research suggests the more stigmatized a pregnant woman feels the less likely she is to seek assistance and adopt healthier habits during pregnancy (Health Canada, 2008). In a similar vein, the more clearly the father’s role is identified and the more closely the father is involved with supporting a healthy pregnancy, the more likely a better outcome (Malbin, 2002).

Among communities in the Circumpolar North, especially isolated communities with large Native populations and a history of alcohol problems, mere informational campaigns alone are insufficient to accomplish effective FASD prevention. The typical informational campaign, relying on TV ads, magazine ads, newspaper ads, radio and television public service announcements, and flyers in public health offices (Hankin, 1992), is less likely to be effective when the target population’s first language is not English and where heavy drinking has become normative behaviour. In view of the debilitating impact and economic costs, effective FASD prevention efforts are crucial, particularly in underserved northern Native village communities.

### **The “FASD in Lab Mice” Project**

Relatively few institutions carrying out FASD prevention efforts exist in villages as compared to urban centers. The school may well have the most potential as a delivery vehicle for effective FASD prevention education given its stability in the community. Moreover, school program funding is not dependent upon boom and bust cycles of FASD prevention funding, unlike many efforts funded by erratic state and federal initiatives. Public schools

offer a promising intervention point although the onset of requirements for published community school scores in state benchmark testing, high stakes graduation qualifying exams, and the No Child Left Behind (NCLB) Act (with its associated mandate for publication of “school in crisis” and “failing school” status in statewide newspapers) has given rise to severe accountability pressures drawing attention away from FASD prevention. Administrative and instructional staff feel the need to focus narrowly on teaching to tested areas. An effective FASD prevention education program, therefore, must also accomplish the goals set forth and tested by these state and federal requirements, raising test scores in reading, writing, and math. The FASD in Lab Mice project targets the dual goals of emphasizing both prevention and the development of tested skills.

While the pressure is on in northern Native villages for students to pass various high stakes academic tests, parents are just as concerned that their children master these skills with content which is culturally appropriate, locally relevant, practical, and meaningful. Effective FASD education needs to use culturally appropriate methods while also simultaneously accomplishing effective reading, writing, and mathematics instruction in order for students to pass statewide exams.

Conventional approaches to FASD prevention education in the public school classroom generally involve one to several lessons connected to the health curriculum where students are lectured on the effects of alcohol—a tactic which sometimes has exactly the opposite of the intended effect by imbuing alcohol use with an aura of admirable rebelliousness or forbidden desirability (Ennet, 1994). Students are also shown photos of “the face of FAS,” given a reading on FASD, or perhaps shown a movie on FASD (such as “The Broken Cord”). Unfortunately, these approaches often fail to genuinely engage and hold student interest and relegate students to a passive role in receiving information (much of which they quickly forget). Such approaches also tend to present atypical examples, such as extreme cases, which students have not actually seen or only very rarely encountered in their own communities. Students thus tend to discount the relevance of such presentations and see FASD as being a problem “somewhere else, but not here” or only very rarely in their own community.

The contention that these approaches are generally ineffective—especially with subpopulations of students themselves most at-risk for producing offspring with FASD brain damage—is reflected by the continuing incidence of FASD in northern Native communities despite twenty years of this approach being used. Children, adolescents, and young adults suffering from FASD are particularly unlikely to absorb or translate into action information

presented in a didactic manner. Information in and of itself is not all that useful in prevention unless it changes learners' attitudes and behaviours and in so doing ultimately decreases alcohol-related brain damage.

Instead of using an informational approach to prevention, the FASD in Lab Mice project emphasizes direct, dramatic experience with the effects of alcohol on the developing fetus based upon lab mouse exposure research models (Gilliam, 1989, 1990, 1997) and building on other foundational animal model research (Randall & Taylor, 1979; Webster, 1983; Becker, 1992). The project dramatically demonstrates that alcohol is a teratogen pervasively producing a predictable variety of both subtle yet profound damage and less frequent but more visually dramatic forms of gross anatomically-visible damage—thus supporting rather than conflicting with what students observe from their own real-world local experience.

In brief, through this approach the students become junior scientists learning lab procedures, mathematics, science, health, social studies, basic economics (figuring budgets and the costs of both the project and of FASD to their community and society as a whole), practical job skills (such as measuring, logging data on forms, working and communicating cooperatively as members of a team), and English (both writing skills and reading) as they proceed to investigate the effects of alcohol on developing fetal mice. The students use the scientific method to design and perform a series of experiments with a control group and a treatment group of mice, changing one manipulated variable (alcohol) to test the outcome of exposure to alcohol on litters of mouse pups.

### **“FASD in Lab Mice” Prevention Project Implementation**

A typical community where this FASD in Lab Mice prevention project was implemented, which we will call Katamaita, resembles many Alaskan rural villages. Katamaita has a population of approximately 1,000 people year-round, with a seasonal fluctuation in the summer as some individuals and families depart for fish camps while others leave periodically for work elsewhere throughout the year. Somewhere between one-half and two-thirds of the adult population has graduated from high school, but actual functional literacy and numeracy varies widely. A small number of residents hold college degrees, generally occupying posts of civic importance in the community. Subsistence food-gathering and hunting are a significant part of village life. The traditional Native language is spoken mainly by grandparents and some parents, though most youth can understand and express themselves to some extent in the traditional language. Young people mainly use “Village English” for communication among themselves.

Alcoholism is a visible problem in the village and most of the law enforcement activity in the village stems from violence and accidents in connection with inebriation. Binge drinking is common among those who drink, of all ages; disruptive public drunkenness is common. While only a few of the children in Katamaita have an actual FASD diagnosis, the local teachers and itinerant clinicians often privately say they strongly suspect FASD in perhaps as many as half the population of both the school and the village as a whole; this is likely to be a substantial overestimation resulting from frustration. Katamaita is typical in that access to an FASD diagnostic team, while possible, is difficult to arrange and a diagnosis is expensive to obtain. Moreover, families and the community are not enthusiastic about obtaining a diagnosis because they do not see substantial benefits while the perception is such a diagnosis may stigmatize their children, themselves, and the community. An FASD diagnosis in a school child, for example, in and of itself does not qualify the student for receiving special education services. Contrary to common belief, special education services are available only when there is a certain degree of academic disparity between age, ability, and demonstrated performance; while sympathetic educators may attempt use an “other health impaired” work-around to obtain Special Education services for a student with FASD, their availability still ties to academic performance.

### **Materials and Methods of the FASD in Lab Mice Prevention Project**

The fundamental purpose of this school-based FASD prevention program is to involve students in discovering and proving for themselves—in a realistic and dramatically memorable way—what actually happens when a pregnant mother ingests alcohol and gives birth to alcohol-affected offspring.

A specific strain of lab mouse—black in color, very friendly in temperament, and easy to handle—is particularly useful for demonstrating both the subtle yet profound and visually dramatic effects alcohol has on developing offspring. These lab mice, the C57BL/6J strain (aka B6) from The Jackson Laboratory, in Bar Harbor, Maine, are ideal lab subjects for this learning demonstration experiment. They are small, hardy, have a short gestation period, are relatively inexpensively purchased, housed, and fed—and most importantly not only do their pups clearly show FASD effects but also the students are highly enthusiastic about working hands-on with these especially attractive and charismatic animals.<sup>1</sup>

Students ranging from middle school through high school form teams. Each team of two students is jointly responsible for one tub (an approved design of standard laboratory mouse cage, which is very easy to

clean) containing two identical female mice, called dams. These dams are genetically identical individuals of the same age and weight. The dams are maintained on chipped corn cob bedding (changed several times weekly) and given unrestricted access to water and a diet of Purina Mouse Chow. A coin is tossed to determine which shall be the treatment mouse and which shall be the control mouse, and the tails of both are marked with permanent ink to differentiate between the two. The dams are maintained and cared for in the same tub on the same bedding, eating the same food, drinking the same water, and experiencing all the same conditions (i.e., 12 hours light / 12 hours dark photoperiod, room temperature, ambient noise, and so on).

Students introduce a male C57BL/6J mouse into the females' tub under observation each day until successful breeding occurs. Once insemination has occurred the countdown begins; after nine days the pregnant dam will have gained at least 3.0 grams of weight (positively indicating she is indeed pregnant).

At day nine food is withheld from the control dam while her matching treatment dam is intubated. A feeding tube capped with a small hollow ball is placed in the mouth and gently maneuvered down the throat into the stomach, whereupon the measured dose is squeezed out of the syringe into the stomach. A dose of 20 percent ethanol in water solution is calculated and administered according to the exact body weight of the dam so that each treatment dam experiences the same blood ethanol level even if there are slight variations in the dams' body weights. The dose is 5.8 g/kg and produces a uniform 400 mg/100 ml of ethanol to blood titer equivalent to a 0.40 blood ethanol level among treatment dams.

The treated dam staggers, rubs her nose, and passes out for six to eight hours. Food is withheld from the control dam during this period to prevent her from accruing calories and nutrition denied to the treatment mouse during this same period; in one variation a calorically equivalent dose of sugar solution may be administered to the control mouse to insure isocaloric treatment. The treatment dam is maintained separate from all other mice while passed out and recovering, this in order to prevent cannibalism (the alcohol solution appears to produce a sweet scent or taste on the inebriated mouse's breath and mouth which is attractive to other mice).

The single dose administered to the treatment dam is roughly equivalent to one bout of binge drinking in a human. The timing of the dose for the treatment mouse is approximately comparable to this bout of binge drinking occurring in a human between days twenty-seven and thirty-three of human gestation.

Nine days later—just before giving birth—the dams are humanely sacrificed by cervical dislocation. The pups are removed by caesarian section and placed directly on a chilled watch glass sitting on ice. Control and treatment group pups are compared for number in each litter, individually weighed, measured with calipers for crown-to-rump length as well as cranial diameter, and examined for deformities.

Students examine the pups directly and also with the aid of magnifying glasses and high-powered dissection microscopes under strong illumination in order to better observe fine structures such as fused digits and size of the eyes. In one of several advanced extensions of the basic FASD in Lab Mice experiment, pups are preserved in fixative solution and then serially sectioned for ease in identifying abnormalities of internal organs such as the heart and kidneys; in another advanced variation (useful for working with Advanced Placement and Gifted & Talented students who wish to delve further than the basic experiment), skeletal deformities are made highly visible via differential staining.

The differences between robust, normal, control group pups and alcohol-exposed FASD pups are striking. There are sometimes significantly more pups in the control groups litters (spontaneous abortion and reabsorption accounts for the lower litter number in the treatment groups). Control group pups tend to be significantly larger than alcohol-exposed treatment group pups; generally the alcohol-exposed treatment group pups will be slightly smaller in all measures than the smallest of the control group pups and quite a bit smaller in cranial diameter. The dramatic measure to which students have the strongest immediate reaction is that of anatomical abnormalities: some alcohol-exposed mouse pups display fused digits, flipper limbs or missing limbs, small or missing eyeballs, and sometimes have their brains protruding from unsealed cranial crowns (exencephaly). The variation of two doses of 5.8 g/kg on days nine and ten in B6 mice tested in a clinical setting resulted in every litter showing malformations (Gilliam, 1989) and student replication in rural Alaska produced the same results. Numerical comparisons of control and treatment groups (graphed to show significant differences in count, length, weight, cranial circumference, and incidence of deformities), however, are ultimately the most compelling proof when all the data are displayed together. Students react with loud and excited exclamations, convinced they have definitively proven alcohol's role as a powerful teratogen in causing the observed pervasive differences and occasional birth deformities.

### **Reception and Response by Students with FASD**

A concern at the outset was how students who recognize themselves as having been prenatally and/or perinatally exposed to alcohol would react to the dawning realization that they may indeed have primary and secondary complications stemming from FASD. This was a topic openly acknowledged and treated with in a sensitive yet frank manner. While some students for whom this was indeed potentially the case never appeared to perceive themselves as possibly having FASD, others were quite sure they had at last found a valid, understandable, and solid explanation for their differentness, difficulties, and peculiarities. Understanding themselves not as “bad,” “evil,” “stupid,” “dumb,” “weird” or any other such pejorative but rather as people experiencing a brain injury was tremendously liberating for these students. Classmates understood other students in a more sophisticated way allowing them to interpret problems as rooted in FASD rather than as wilful misconduct. This was the case for parents as well.

### **Reception and Response by Native Communities**

The FASD in Lab Mice prevention education project was piloted throughout the school year in six Native villages located in two culturally different regions of Alaska. Students and communities were so excited about the project that they wanted not only to give presentations to other students and elders in their own communities, but also to communicate what they had found to other Native communities as well. They prepared posters and presentations, passed out test tubes showing defects in mouse pups, did slide shows and high-interest demonstrations. The project was demonstrated in this manner in an additional thirteen Native villages located in four different regions of Alaska, as well as at a number of statewide conferences, and to the state legislature.

Critical to the acceptance and subsequent success of this FASD prevention education strategy in all of the Native village settings in which it was actively being performed and demonstrated from 1991 through 2001 has been careful and respectful observance of village values and seeking and obtaining local permission at each site before proceeding. Visits were made to the local school advisory councils and traditional tribal councils to present the entire program and comments were sought for improvements or adjustments to cultural customs. These suggestions were incorporated. Additionally, in order to implement this FASD prevention education strategy, it was essential to first submit and obtain appropriate committee approval for an Institutional Animal Care and Use Protocol (via the University of Alaska Fairbanks Institutional Animal Care & Use Committee), and school

approval for lesson plans detailing curriculum objectives to be satisfied by student participation in the project.

This prevention education approach via an actual student demonstration of FASD in lab mice proved singularly well-suited, culturally, for implementation in Alaska's isolated rural village community schools. Though there were some initial doubts among outsiders about whether or not the project would be well received in Alaska's rural Native villages, every village offered the FASD in Lab Mice prevention education project (in either its full-term classroom instruction form or via a visiting team of student peer educators performing demonstration workshops) eagerly embraced the opportunity.

Generally speaking, Native people in Alaska's villages regard other living creatures—laboratory mice included—with both reverence and practicality. Accordingly, students realized the tremendous privilege they were being afforded in having this opportunity to work directly with the lab mice. Incidents of mouse mistreatment were very rare and were dealt with far more swiftly and harshly by peer discipline than by instructor intervention. The guiding principle with regard to the experimental animals is to treat them with the utmost respect and appreciation while minimizing discomfort at all times. The project did have one emblematic difficulty: on many occasions the building administrator came to the lab and shooed everyone out because the school day had long since ended but everyone was so engrossed in what they were doing that nobody had noticed the time.

### **Academic Outcomes**

The project is ongoing throughout the semester, re-exposing students to the issues at increasingly deeper levels, reinforcing learning gains and skill set acquisition through guided practice, discussion, reflection, and multiple project products. Students are kinesthetically involved with daily activities, physically picking up the mice; caring for them; measuring their progress both qualitatively and quantitatively; performing dissections and learning both anatomy and physiology of tissues, organs, and organ systems. The effects of drinking during pregnancy become "real" to them, tangible, concrete, and understood through multiple learning modalities. Students feel ownership of an authentic scientific experiment as a result of being personally responsible in caring for the lab mice, designing the experiment they will conduct, and assessing the outcomes. As students' understanding of the scientific method and insight into FASD grow, their convictions regarding alcohol use during pregnancy become distinctly stronger. Students know the only rational way to account for differences between the treatment and control pups is the

action of one single dose of alcohol they themselves administered with their own hands nearly halfway through the gestation period of the mice—there can be no other logical explanation.

Students not only learn about the effects of alcohol on outcomes of pregnancy via this prevention education approach, but also increase their mastery of significant content knowledge and skills more broadly in reading, writing, mathematics, social studies, economics, and science. Students prepare written products such as reports and posters incorporating the numerical summaries of their data along with descriptions of the process, outcomes, and their conclusions.

Students are much more interested in the lesson material—connected as it is to their lab mice and a topic of local significance—than to the average lesson material found in textbooks. Virtually all students showed greater gains on standardized tests (boys as well as girls) than comparable peers in neighbouring classrooms of the same schools and peers in villages located within the same school district but where the approach was not being used. Students also developed practical job skills and effective work habits: team planning, cooperative group effort in daily tasks, data collection and processing, report presentation, and public speaking. The project was enthusiastically embraced and the occasion of much thoughtful reflection among girls yet especially appealed to boys (who enjoyed the hands-on work with animals and also the “blood and guts” factor).

In sum, students commonly report that prior to their involvement with the FASD in Lab Mice project they had no idea whatsoever regarding these points:

- The type of alcohol in all forms of booze is the same: ethanol, the causal agent of FASD.
- The amount of ethanol in a beer is the same as in a glass of wine or shot glass of hard liquor (only the dilution factor with water and presence of congeners such as colour and flavourings differs between the various beverages).
- The strong solvent properties of ethanol in water allow this form of alcohol to pass throughout the body just as water does, and everywhere that water does, and so it acts upon and damages the central nervous system and virtually all other developing organs.
- The surprisingly large caloric energy in the ethanol in one drink.
- The teratogenic action is based on both dose consumed and developmental window of vulnerability (in other words, a person does not need to be an alcoholic in order to give birth to a baby damaged by FASD if the one exposure comes at just the wrong moment).

- The outcomes of drinking during pregnancy can be clearly seen and measured by contrasting an ethanol-exposed treatment group against a normal control group, and these outcomes range from pervasively subtle yet profound to shockingly obvious damage.

Students did not generally say they would eschew alcohol as a result of their experience working with the lab mice, though some did affirm this. What the young women did say quite emphatically was that they absolutely would refrain from any alcohol use during pregnancy and be much more aware and wary of the possibility of pregnancy. The boys said that they would avoid alcohol themselves during their partner's pregnancy, actively support a pregnant partner, and seek to prevent a pregnant partner from drinking.

### **Other Outcomes**

Students who participated in the project have travelled all around the state of Alaska presenting their research results to schools, tribal gatherings, and conferences. They have addressed committees of the Alaska State Legislature, have met with three different governors and a U.S. senator about FASD, and spoken on radio and television many times. Newspapers have reported the project not only in Alaska but across the U.S., in Canada, and even internationally overseas (the project and photo was "above the fold" in *USA Today* as published in Asia), a description was published in a nationally released book (Yow & Firstenberg, 2001), and the students have won recognitions and awards in abundance. The project itself has won endorsement, awards, and commendations from the Alaska State Legislature, Alaska governor's office, the Alaska Science & Technology Foundation, a Native corporation, rural school districts, rural school advisory councils, and traditional tribal councils of eight Native villages. As a result of the FASD in Lab Mice project the first author was recognized with both district and state educational awards and a national award for excellence in teaching.

Parents have commonly reported their children referring many months and even years later to something they learned from the FASD in Lab Mice project. Most significantly, there have been numerous accounts of an actual change in student attitudes and behaviours with regard to drinking during pregnancy. As one example, after participating in the project a teen girl was present at a party where a peer was handed an alcoholic beverage. The student knew her friend was sexually active with her boyfriend and felt concerned because her friend had missed her period the month before. The student obtained cups of orange juice and soda pop for herself and her

friend, then went to her friend and quietly said, “Let me tell you about some lab mice I worked with ...” gently supporting her friend in sobriety and a healthy potential pregnancy by swapping the non-alcoholic beverage for the alcoholic drinks throughout the evening. She supported her friend in having fun and remaining part of the group—but in a healthy manner. Her intervention was successful (this experience was first related by the proud mother of the student and then independently confirmed by the student herself later on).

The significance of project participation for male students as well as female students was distinct. While after their participation in the project students nearly all expressed strong attitudes against any alcohol consumption whatsoever during pregnancy, teenage males held this attitude as strongly as females and asserted their own responsibility. One boy, a high school sophomore, made the remarkably mature observation:

If a man does nothing else for his kid ever again in his kid’s entire life, but he successfully supports the mom in being alcohol-free through the nine months of pregnancy and breastfeeding afterwards, then he has been more of a real father to his kid—has given a greater gift to his kid—than guys who call themselves dads but who blow off supporting the mom during the pregnancy and only start showing real interest in the kid when it is time to start playing ball and going fishing or hunting together. That is way too late.

Male students’ self-recognition of the essential responsibility and importance of the father’s involvement in supporting a healthy alcohol-free pregnancy was commonly affirmed by project participants.

Students’ involvement has also made a difference for the better in their perception of the quality of their high school experience; a researcher from Old Dominion University (in Virginia) came across the first author one day in a school as he was washing lab mouse tubs after hours. She stopped and exclaimed, “You must be the lab mouse guy!” She went on to relate how for several years she had been periodically interviewing former students about their high school experience and found “the FASD in Lab Mice project” to be one of the more common (and puzzling, at the time) replies to the question “What was the single most memorable learning experience you had in high school?” in communities within a school district where the project had been active (personal communication, Seyfrit, 2000).

Indeed, even years later many students said “the FASD in Lab Mice project” was their single most memorable high school learning experience during encounters with them or their parents in chance locations such as airports (the students have grown and changed so much the first author might pass by without recognizing them, yet they step forward and say hello and almost always say how profoundly their participation in the project influenced them). At least two students chose scientific careers and attributed their decisions to their participating in the FASD in Lab Mice Project. One young man attended an advanced placement summer program at an MIT laboratory while still in high school, attended and graduated from Brown with honours in biological science, took a doctorate in pharmacology, and is now beginning a post-doctoral position at Sloan-Kettering—all in direct consequence, he and his parents assert, of his involvement with the FASD in Lab Mice project. Another student went on after high school to a job in a major Alaska state-funded FASD prevention project, working both as a designer and as the artist illustrating an animated FASD prevention computer game, *Decisionville* (RurAL CAP, 2005), then attended and graduated from the Savannah College of Art and Design.

It is to be hoped that far fewer among these at-risk youth will be producing offspring with FASD than would otherwise have been the case. Systematic research is needed on:

1. changes in knowledge and attitudes of students involved in the prevention project;
2. changes in test scores and engagement in school;
3. increase in interest in scientific, medical, and health education careers;
4. behaviour that would decrease incidence of FASD; and
5. long-term effects on number of FASD-affected births.

Obviously, such research would be methodologically difficult because of small sample sizes, the difficulty of locating comparison groups, and the difficulty of measuring outcomes over long periods of time. We realize that our evidence of program outcomes is anecdotal but school projects appearing to have dramatic effects on rural Native populations are rare and need to be reported, especially those targeting such a difficult problem as prevention of the devastating consequences of alcohol consumption by young pregnant women and their partners.

## Lessons Learned

The experience of this decade-long effort suggests the value of an FASD prevention effort in isolated rural schools in Native communities incorporating these crucial elements:

1. Kinesthetic involvement, rather than passive receipt of information: Students conducted a dramatic experiment themselves.
2. Emotional learning: Students cared for lab mice and saw the effects of alcohol on fetal development, a powerful emotional experience.
3. Meaningful and demanding academic learning: Students learned mathematics, English, science, economics, and social studies. The project met school goals of increasing performance on national and statewide standardized tests. Students also mastered a skill set valuable to their employability and knew it.
4. Local significance and practical application: Students understood why this project was relevant to themselves and their own communities. They were able to reconcile their previous observations that maternal drinking did not always cause obvious impairments with their own observations of the unpredictable effects of alcohol, wherein some mouse pups showed terrible and obvious damage while many others showed pervasive and profound yet less casually obvious damage.
5. Involvement of respected local elders and other community members in a school project that wedded western scientific methods with traditional cultural values: Students combined scientific methods with the reverence for life and gratitude for the contribution of animals to human welfare.
6. Shift from the role of learner to educator: Students presented their results to the community, younger students, conference attendees, legislators, and government officials.
7. Demonstration of achievement in ways that brought respect: Students did not just receive classroom grades. The community, their peers, and others applauded their achievements.

The FASD in Lab Mice prevention education project is relatively inexpensive in terms of the materials needed, but the amount of time required for teacher preparation as well as the time and energy required for properly insuring animal welfare on an ongoing basis is substantial and should not be underestimated. Time is also required to involve the community from the outset, showing how the project proposes to reinforce local values and

Native cultural traditions. The community must support the project before a lab mouse ever arrives at the school.

### **Conclusion**

While informational campaigns—such as including FASD prevention in health education programs, putting up signs and posters, and giving classroom lectures—all have their place these approaches are of limited effectiveness in isolated rural Native communities. The need for FASD prevention delivering results is clear and pressing; the type of approach described here holds promise. Weighing the personal, social, and economic costs of FASD against the comparatively modest expense of such a FASD prevention program, the potential community gains and economic savings far outweigh the expense and energy involved.

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### **Authors**

**Steven Jacquier** is a parent and educator active in FASD prevention education in Alaska, Hawaii, and developing nations including Indonesia and Nepal. StevenJacquier@gmail.com.

**Judith Kleinfeld** is co-director of Northern Studies at the University of Alaska Fairbanks, director of The Boys Project, and author of “Fantastic Antone Succeeds.”

**David Gilliam** is an experimental psychologist studying maternal genetic factors and prenatal drug effects at the University of Northern Colorado.

### **Notes**

1. Special notice should be taken that not just any mice will serve adequately for experimental subjects in this demonstration project, and furthermore, the Jackson Labs will not supply C57BL/6J mice without an Institutional Animal Care and Use Committee-approved protocol. Wild mice and pet store mice are not to be used for this project under any circumstances. Wild mice can serve as vectors of disease. Pet store mice are not intended for this purpose and at any rate are too genetically plastic to display the obvious outcomes predictably and consistently obtained by using C57BL/6J strain mice from Jackson Labs.

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### **FASD Resources**

Alaska State Office of Fetal Alcohol Syndrome	<a href="http://www.hss.state.ak.us/fas/">http://www.hss.state.ak.us/fas/</a>
Asante Centre for FAS	<a href="http://www.asantecentre.org">http://www.asantecentre.org</a>
Better Endings New Beginnings Publishing	<a href="http://www.betterendings.org/">http://www.betterendings.org/</a>
Centers for Disease Control: Reducing Alcohol-Exposed Pregnancies Through the Use of Community-Level Guided Self-Change Programs	<a href="http://www.cdc.gov/ncbddd/FAS/reduce.htm">http://www.cdc.gov/ncbddd/FAS/reduce.htm</a>
FAS Bookshelf	<a href="http://www.fasbookshelf.com/">http://www.fasbookshelf.com/</a>
FAS Community Resource Center	<a href="http://www.come-over.to/FASCRC/">http://www.come-over.to/FASCRC/</a>
FAS Link	<a href="http://www.faslink.org/fasmain.htm">http://www.faslink.org/fasmain.htm</a>
FASWorld	<a href="http://www.fasworld.com">http://www.fasworld.com</a>
FASD Connections supporting Adolescents and Adults	<a href="http://www.fasdconnections.ca">http://www.fasdconnections.ca</a>
Fetal Alcohol Spectrum Disorders Center for Excellence	<a href="http://www.fascenter.samhsa.gov/">http://www.fascenter.samhsa.gov/</a>
Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc.	<a href="http://www.fascets.org/">http://www.fascets.org/</a>
March of Dimes	<a href="http://www.marchofdimes.com/professionals/14332_1170.asp">http://www.marchofdimes.com/professionals/14332_1170.asp</a>
Minnesota Organization of FAS	<a href="http://www.mofas.org">http://www.mofas.org</a>
National Organization on Fetal Alcohol Syndrome	<a href="http://www.nofas.org/">http://www.nofas.org/</a>
Northern Family Health Society	<a href="http://www.nfhs-pg.org">http://www.nfhs-pg.org</a>
Stone Soup Group	<a href="http://www.stonesoupgroup.org/">http://www.stonesoupgroup.org/</a>
University of Washington Fetal Alcohol Unit	<a href="http://depts.washington.edu/fadu/">http://depts.washington.edu/fadu/</a>