SCR

16

STATE OF ALASKA
THE LEGISLATURE

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May, 1988

Copies of minutes listed below were originally included in this file. The minutes are available on the STAIRS database CMPR. In order to save space copies of minutes have not been left in the files.

Mary Van Nimwegen

H HESS 3-31-87 8:30 a.m.

HOUSE COMMITTEE REPORT

(7)

Date referred: 3/16/87

FURTHER REFERRALS:

DATE: 3-31-87

The Health, Education and Social Services Committee has considered CSSCR 16(Rls)

Relating to Fetal Alcohol Syndrome Awareness Week.

RECOMMENDS:

[ ] replace with ______________ [ ] the same title

[ ] attached amendment(s) [ ] a new title

[✓] do pass

[ ] do not pass

[ ] no recommendation

[ ] individual recommendations

[ ] additional referral to the ______________ Committee

ADOPTS: [ ] __________ letter of intent

ATTACHES NEW FISCAL NOTE(s):

[ ] fiscal impact

[ ] zero fiscal note

[ ] zero with analysis

[ ] same as previous fiscal note published ______________

[✓] same as previous zero fiscal note published ______________

SIGNING DO PASS:

Pell E. Pell[?]

Joyce Hanley[?]

[illegible] Ellis

Niilo Koponen

Bill Hudson[?]

Max F. Gruenberg

SIGNING OTHER RECOMMENDATIONS:

Dave Donley (NOREC)

[illegible] Ellis

Co-Chairman's signature

Niilo Koponen

STATE OF ALASKA

OFFICE OF THE GOVERNOR

BILL ANALYSIS

DEPARTMENT	DIVISION	BILL NUMBER	SPONSOR
Health & Social Services	Public Health	SCR 16	Binkely, Coghill, Josephson, Szymanski & Faiks

DEPARTMENT POSITION

Supporting

PREPARED BY	DATE	COMMISSIONER'S SIGNATURE	DATE
Elizabeth Ward, M.N.	2/26/87	Myra M. Munson	3/5/87

SUMMARY

OTHER AGENCIES AFFECTED BY BILL	CONSTITUENT GROUP(S) AFFECTED BY BILL
ORGANIZATIONAL SUPPORT FOR BILL	**ORGANIZATIONAL OPPOSITION TO BILL**

FISCAL IMPACT: ☒ NONE ☐ FISCAL NOTE ATTACHED

BACKGROUND/LEGISLATIVE INTENT

ANALYSIS OF BILL/PROGRAM EFFECTS

The Division of Public Health, Department of Health and Social Services, endorses and supports Senate Concurrent Resolution No. 16, Relating to Fetal Alcohol Syndrome Awareness Week. The bill is consistent with the educational and program objectives of the Division of Public Health; signature and enactment of the bill is recommended.

AMENDMENTS PROPOSED

PLEASE ATTACH A SEPARATE SHEET FOR ADDITIONAL COMMENTS OR ANALYSIS.

CS for SCR 16 Relating to Fetal Alcohol Syndrome Awareness Week

CONTENT SHEET

NATIONAL FETAL ALCOHOL SYNDROME AWARENESS WEEK

The joint resolution (S.J. Res. 373) designating the week beginning May 19, 1987, as "National Fetal Alcohol Syndrome Awareness Week," was considered, ordered to be engrossed for a third reading, read the third time and passed.

The preamble was agreed to.

The joint resolution, and the preamble, are as follows:

S.J. RES. 373

Whereas fetal alcohol syndrome is one of the three major known causes of birth defects with accompanying mental retardation in the United States, and the only preventable one;

Whereas fetal alcohol syndrome can result in such serious health problems as: deficiencies in prenatal and postnatal growth that are associated with mental retardation; developmental disabilities that may cause an infant to experience delays in learning to walk and speak; and heart defects, including defects in the wall between the pumping chambers of the heart;

Whereas in cases in which fetal alcohol syndrome is avoided, infants may still experience alcohol-related birth effects, known as fetal alcohol effects, which are a series of health problems that include increased irritability during the newborn period and hyperactivity;

Whereas the discovery of fetal alcohol syndrome as a major health problem is a recent occurrence, and many questions regarding the illness remain unanswered;

Whereas there has never been an infant born with fetal alcohol syndrome whose mother did not consume alcohol during pregnancy;

Whereas fetal alcohol syndrome can be prevented if pregnant women and women considering pregnancy abstain from alcohol consumption; and

Whereas the Surgeon General of the Public Health Service has issued an advisory stating that pregnant women and women considering pregnancy should not consume alcohol: Now, therefore, be it

Resolved by the Senate and House of Representatives of the United States of America in Congress assembled, That the week beginning May 10, 1987, hereby is designated "National Fetal Alcohol Syndrome Awareness Week", and the President of the United States is authorized and requested to issue a proclamation calling upon the people of the United States to observe such week with appropriate activities.

Mr. DOLE. Mr. President, I move to reconsider the vote by which the joint resolution was passed.

Mr. BYRD. I move to lay that motion on the table.

The motion to lay on the table was agreed to.

Official Business

COMMITTEE:
House HESS Committee

DATE: March 30, 1987

SIGN-IN

Subject of meeting:
HB 107 - Alaska Community Colleges
SCR 16 - Fetal Alcohol Syndrome Week
HB 113 - Approp: Pupil Trans/Tuition Sup.
CSSB 115 - Approp: Pupil Trans/Tuition

NAME	ADDRESS	PHONE	REPRESENTING	DO YOU WANT TO TESTIFY? & Which Bill
Brian Rogers	812 Gruening Bldg U of AK Fairbanks 99775	474 6490	U of A	HB 107 - will answer questions
Ralph McIntosh	5229 Kenyhill androge, AK 99504	562-2660	AFCFT	NO
Mary Shaw	205 N. Franklin	586-1736	Gov's Council on Voc. Ed.	
Dave Stivi		586-1756	HAA	NO
BOB ARNOLD	1802 Glacier Hwy Juneau Alaska	586-4372	self	no
Kurt Parkan	Boyer		Boyer	no
[illegible]	[illegible] Juneau	[illegible]	CBJ [illegible]	CSSB115 yes
Clark Gruening	217 Second Street Suite 204 Juneau	586-8110	CBJ Juneau	Specifically CCSB115

Drinking is harmful all through the pregnancy. It is especially harmful to the baby during the first three months, a time when many women do not know they are pregnant.

FAS is a totally preventable birth defect which only YOU can prevent.

FETAL ALCOHOL SYNDROME

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Alaska Native Health Board
[illegible] AVENUE, SUITE [illegible]

October 13, 1986

Vicki A. Hild
Alaska Area Native
Health Service
A-CHSB
P.O. Box 7-741
Anchorage, Alaska 99510

Dear FAS Networking Members:

Just a brief update. On September 29th I assumed the position of statewide FAS Coordinator with the Alaska Native Health Board and the Alaska Area Native Health Service. I feel it will be an exciting and challenging position that will enhance our FAS prevention efforts. I will be in contact with most members on specifics. My mailing address will remain the same. The new telephone number is 257-1709.

The North Pacific Rim's FAS Program, which started as a pilot project, will continue with emphasis on prenatal clinics at the Alaska Native Medical Center and on community education in their villages. Also, the Copper River Native Association has submitted a proposal for a FAS prevention program.

Results from the FAS diagnostic clinics held this past year throughout Alaska revealed a FAS rate for Alaskan Natives of 4.1/1000 live births. This is a conservative rate as some FAS children were unable to attend these clinics.

How does this rate compare? The rate of FAS in France and Sweden is 1.4/1000 live births, in the contiguous 48 states the rate is 1.7/1000 live births, and in Navajo the rate is 2.0/1000 live births.

For those who may not have heard about the case in California on Fetal Abuse, I have enclosed a copy of a newspaper article. Another interesting update is regarding the case in Canada where a woman who had given birth to a FAS infant was charged with child abuse -- she was found guilty.

Until the next update.

Sincerely,

Vicki

Vicki A. Hild, M.S.P.H.
FAS Coordinator

ALASKA NATIVE HEALTH BOARD
Alaska Fetal Alcohol Syndrome (FAS)
Fact Sheet

MAR 1 2 1987

* In 1985, all Alaskans consumed 4.35 gallons of absolute alcohol per capita.

* Alaska appears to have one of the highest recorded rates of FAS.

* The rate of FAS in Alaskan Natives is conservatively estimated at 4.2/1000 live births.

  How does this compare?

  France FAS rate - 1.6/1000 live births
  Seattle FAS rate - 1.7/1000 live births
  Navajo FAS rate - 2.0/1000 live births

* The rate of FAS in the Alaskan non-Native population is not yet known, but it is expected to also be high.

* A conservative estimate of new cases of FAS in Alaska is 10 per year.

* In the lower 48 it is estimated that for every child born with FAS, 10 are born with Fetal Alcohol Effects (FAE). FAE describes less severe damage due to alcohol. The extent of FAE in Alaska is not yet known.

* In Alaska, the dollar cost to care for one FAS child for his/her lifetime can be up to one million dollars or more.

* In Alaska, FAS may be the number one identifiable cause of mental retardation.

It's true that what a mother-to-be eats and drinks affects her baby. That's why pregnant women are advised not to drink alcohol because it can cause a BIRTH DEFECT called FETAL ALCOHOL SYNDROME (FAS). With FAS the baby is growth retarded, mentally retarded, has facial deformities and many other physical problems.

BUT THE FATHER'S DRINKING ALSO AFFECTS HIS CHILDREN:

It affects his ability to father children.
It increases the chance of other birth defects in his children.
His babies have low birthweight.

The father's support of the mother during the pregnancy is the most important action a man can do to have a healthy baby.

* Make an agreement that neither you nor the mother-to-be will drink alcohol, smoke cigarettes, marijuana or use any drugs during the pregnancy. This agreement makes it easier for a woman to maintain a healthy life style.

* Encourage regular prenatal care, and go with her to the checkups.

* See to it she eats a balanced diet, and takes prenatal vitamins and iron if prescribed.

* Remind her not to take any medicine during the pregnancy unless told to by her doctor.

IT'S YOUR BABY TOO!!!

ANHB/A-CHSB 1986

ALASKA NATIVE HEALTH BOARD

FETAL ALCOHOL SYNDROME (FAS) FACT SHEET

* Fetal Alcohol Sydrome (FAS) is a birth defect caused by the mother drinking during her pregnancy.

* FAS is probably the second most common birth defect.

* FAS may be the number one cause of mental retardation in the nation.

* Doctors Kenneth Jones and David W. Smith first identified and described the Fetal Alcohol Syndrome in Seattle, Washington in 1973.

* The complete syndrome is termed Fetal Alconol Syndrome (FAS) with milder forms of prenatal alcohol damage termed Fetal Alcohol Effects.

* Criteria for FAS
  1. Prenatal or postnatal growth retardation in height, weight, and/or head circumference.
  2. Altered morphogenesis (abnormalities) especially of the face.
  3. Central nervous system involvement, often with mental retardation.

  AND

  4. There must be a positive history of the mother drinking during the pregnancy.

* Facial abnormalities that are characteristics of FAS include:

  - small head circumference
  - small widely spaced eye openings
  - indistinct or no groove between the nose and upper lip
  - short nose
  - thin upper lip
  - flat midface

* FAS children are smaller than normal children in height, weight, and head circumference, usually below the third percentile, and they NEVER "catch up." They remain shorter. They remain thinner even with adequate nutrition. The head is smaller because when the alcohol affected the brain's development, it stopped growing. And when the brain stopped growing, so did the skull. The head remains smaller.

* The most devastating aspect of alcohol damage to the central nervous system is mental retardation. Alcohol "scrambles" the normal development of the brain so the children with FAS can be mildly to severely mentally retarded. The average I.Q. of 100 being normal. The range of I.Q. scores of FAS children is very broad with recorded scores of 15 to 105.

* Other problems seen with central nervous system damage due to alcohol include:

  - irritability in infancy

babies born to moderate (2 drinks per day) drinking mothers have FAS.

* Once a woman has an FAS child, and if she continues to drink, her future children will have FAS with increasing severity.

* Nursing mothers who drink are also passing alcohol to their infants. Alcohol level in the milk is about the same as her blood alcohol level. Heavy drinking while breast feeding may have deleterious effects including growth retardation (particularly of the brain) and decreased viability.

* Total Cost to Society of Fetal Alcohol Effects

  - lost productivity and potential
  - special care facilities
  - health care costs
  - special education needs
  - physical, intellectual and behavorial impairments
  - emotional burden on family and child

* Preventing FAS is EVERYONES' responsibility.

* Create an awareness about alcohol use and pregnancy with everyone you talk with.

* Support pregnant women in not drinking.

* Encourage the father to be supportive and make him aware of his responsibility in preventing FAS.

* Tell women who are planning to become pregnant to stop drinking alcohol at least one month before they expect to get pregnant. Maybe the rule should be, "No birth control, no alcohol."

* Offer alcohol-free drinks like alcohol-free beer and alcohol-free sparkling wine. Don't forget there are other fruit and vegetable juices that can be used in making tasty drinks.

* We all pay in one way or another for every FAS child born.

FAS High Risk Criteria

A woman is considered at risk for having a FAS infant if she reports one of the following:

1. Consuming two or more alcoholic drinks per day or a total of 45 drinks per month, or
2. Binge drinking (consuming five or more alcoholic drinks on any one occasion ranging from twice a week to two or three times a month), or
3. Previously delivered a FAS or FAE infant, or
4. If the patient identifies herself as being at risk because of drinking environment and lack of supportive environment in which to stop drinking during the pregnancy.

MEDICAL EVALUATION AND THERAPY OF FAS AND FAE CHILDREN

Among FAS and FAE children, there is considerable variation in the degree and types of anomalies present. Many of the anomalies are associated with functional deficits which may require immediate and long term medical attention. When FAS or FAE children are diagnosed they should be evaluated for these deficits and appropriate medical and rehabilitation services provided. Some of the anomalies, common in FAS and FAE children which will require further medical and or developmental evaluation and treatment are outlined below. This list is not intended to be a complete list of anomalies present in FAS or FAE children but should provide the health care provider with a direction in evaluating the medical and social needs of these children.

Area of Anomalies:	Evaluate for:	May Require:
- Growth	- Failure to thrive - Weak sucking ability - Other feeding dysfunction	- gastronomic or nasogastric feeding in infancy
- Head and Face		
Eyes	- Ptosis - Strabismus - Epicanthic folds - Micropthalmic - Nystagmus - Myopia - Estropia - Abnormal retinal vasculature	- thorough opthalmologic evaluation, glasses
Nose	- persistent rhinorrhea associated with a small nose and small nasal canals	
Ears	- recurrent otitis media - auditory deficiencies	- hearing aids, thorough hearing evaluation
Mouth	- cleft palate - cleft lip - poorly formed teeth - small trachea (may cause difficult intubation)	- surgery, orthodontic treatment, speech therapy
- Body Organs		
Heart	- cardiac defects (detected in 70% of diagnosed FAS cases): - septal defects - teratology of fallot - pulmonary valve stenosis - patent ductus arteriosus	- surgery
Kidney and Urogenital Tract	- hydronephrosis (dilation of the kidney, usually due to obstruction of urine flow) - hypoplasia (small kidney) - renal agenesis (absence of one or both kidneys) - obstruction of the Uthero-pelvic conjunction	- surgery, management of urinary tract infections

Medical Evaluation and Therapy of FAS and FAE Children (continued)

Area of Anomalies:	Evaluate for:	May Require:
Liver	- prolonged hyperbilirubinemia - abnormal liver functioning	
Genitals	- undescended testicles - hypospadias (abnormal urechral openings) - delay of menarche in girls	
- Skeletal		
Limb and Joints	- limited range of motion of hip, knees, elbows, and other joints - Clubfoot - radioulnar synostosis (fusion of elbow and forearm bones) - Klippel-feil anomaly - scoliosis - reduced skeletal age - shortened fingers - congenital hip dislocation - flexion contracture of the elbow - limited flexion of metacarpal phalangeal joints	- thorough orthopedic evaluation, physical therapy, surgery, occupational therap
- CNS		
Brain	- mental retardation - learning disorders - microcephaly - seizure activity - cerebral palsy	- IQ testing; educational diagnostic workup; management of behavior disorders, hyperactivity, seizures, etc.; special education; foster placement; complete developmental assessment.
- Other Behavioral Deficits	- delays in gross motor development - poor motor coordination - hyperactivity - poor eye-hand coordination - short attention span - variable social quotient - learning disabilities - school failures and conduct disorders - sleep disturbances - psychopathology	
- Other CNS Disorders	- neural tube defects	
- Other Health Problems	- recurrent infections - immune deficiencies	- special monitoring for high risk recurrent health proble
- Home Environment	- alcohol abuse - child neglect or abuse - proper nutrition - stimulating environment	- foster placement, pre-school attendance, public aid, family counseling/therapy

Alaska Native Health Board

Fetal Alcohol Syndrome - Cost Estimates in Alaska

1.	Neonatal Intensive Care	$1,300-$2,000 per day x 7 days = $9,100-$14,000
2.	Heart Defects surgical procedures	99% are done outside $20,000 and up for uncomplicated/non-emergency $50,000 for and up complicated/emergency
3.	Cleft Palate Surgery	Usually 4 surgeries, plus dental work and orthodontics = $50,000 - $75,000
4.	Speech Therapy	Initial Diagnostic $200 2-3 sessions per wk. at $90-$135 per wk. x 1 yr.= $9,360 - $21,060
5.	Kidney Defects surgical procedures	Approximately $1,500 per procedure
6.	Vision Defects	Surgery for strabismis or ptosis average $1,000 Exams and glasses $300 and up
7.	Special Education	1 child for 1 year average - $9,000 Preschool - $15,000 Multi-handicapped - $22,000 Deaf/Vision Impaired - $24,000
8.	Foster Care	$14 - $30 per day, yearly cost $5,110 - $10,950
9.	Residential Care	$100 - $150 per day, average stay 12 - 18 months= $36,500 - $82,125
10.	Day Treatment	$55 per day, average length 6 - 8 months= $9,900 - $13,200 (30-day month)
11.	Institutionalization	$230 - $280 per day $83,950 - $102,200 per year
12.	Travel Costs	Would vary, but if travel necessary, additional thousands of dollars would be added to cost of treatment/care.

1/86

Ideas For Community Activities
On The Prevention Of
Alcohol-Related Birth Defects
(ARBD)

* Make a written contract with pregnant client not to drink during the pregnancy.

* Offer pregnant clients a $100 off their total prenatal and delivery bill if they do not drink during the pregnancy.

* Offer pregnant clients a gift, such as an infant safety seat, if they do not drink during the pregnancy.

* Work with local taverns and restuarants to offer free non-alcoholic drinks to their pregnant customers.

* Work with local school board and teachers to incorporate a class on Alcohol-Related Birth Defects in junior and senior high schools. The class could be incorporated into a child development course, health course, science course.

* Work with schools to have special ARBD presentations made in the schools by the health aide, community health representative, public health nurse, or doctor.

* Arrange to have ARBD presentations made to the PTA.

* At local health fairs, have an ARBD display.

* Encourage Native Health Corporations, Indian Health Service and State Alcohol Programs to develop prevention and intervention programs for pregnant women.

* Launch an ARBD media campaign, including television, radio and newspapers, in your area.

* Contact local childbirth educators (LaMaze Childbirth Association) in hospitals and family planning clinics, and encourage and support their efforts by providing them with information on Alcohol-Related Birth Defects.

* Develop a one-hour ARBD presentation targeted to youth that can be presented to youth groups and clubs.

* Conduct ARBD presentation to women's groups in your community.

* Conduct ARBD presentation to men's groups in your community.

* Work with AA to have ARBD presentations made at regular AA meetings, and also at Al-Anon and Al-A-Teen meetings.

* Prepare educational display on ARBD for local clinic.

* Develop an ARBD prevention network in your own community/area by identifying persons who are interested in working to prevent Alcohol-Related Birth Defects.

* Adopt a pregnant woman and be her support person throughout the pregancy and postpartum period.

ALASKA NATIVE HEALTH BOARD/ALASKA AREA NATIVE HEALTH SERVICE
FETAL ALCOHOL SYNDROME PREVENTION PROGRAM

GLOSSARY OF TERMS

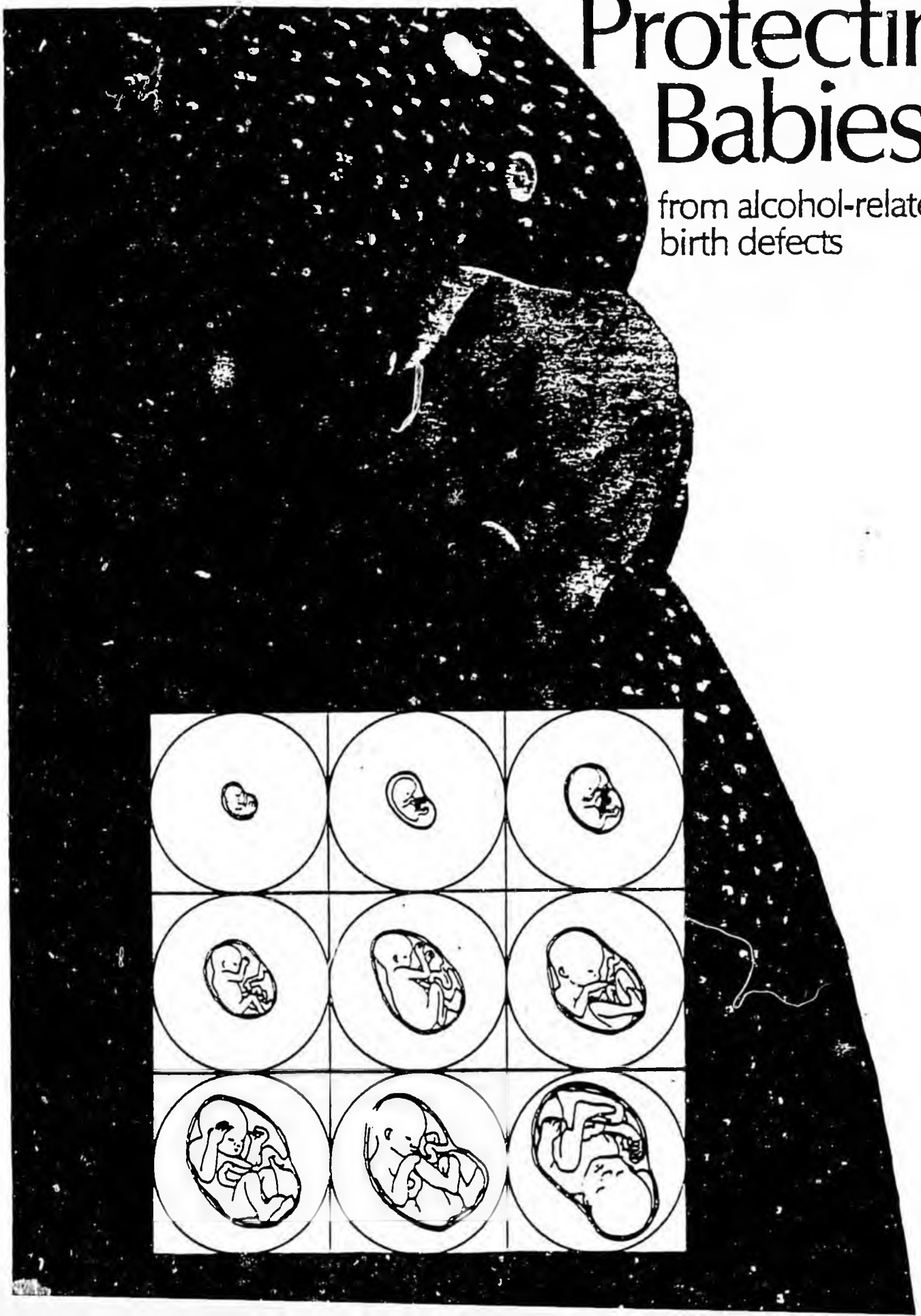
ABBERANT	-Wandering or deviating from the usual or normal course.
ACETALDEHYDE	-A compound formed by the action of enzyme systems on ethanol when it is metabolized by the body. It is further metabolized to acetic acid.
ANOMALIES (ANOMALY)	-Marked deviation from the standard, especially as a result of congenital or hereditary defects.
ANTABUSE	-The trademark for a preparation of disulfiram used to treat alcoholics. It is thought to interfere with metabolism of acetaldehyde, and its use results in temporary nausea, vomiting, palpitation, and other adverse effects.
APNEA	-Cessation of breathing.
CAMPTODACTYLY	-One or more fingers constantly flexed at one or more joints.
CLINODACTYLY	-Abnormal bending of fingers or toes.
CORPUS CALLOSUM	-An arched mass of white matter found in the longitudinal tissue that separates the two hemispheres of the brain. Transverse fibers connect the two hemispheres.
CYANOSIS	-A bluish discoloration of skin and mucus membranes due to excessive concentration of reduced hemoglobin in the blood.
CONGENITAL	-Existing at, or dating from birth.
DEFICITS	-A lack or deficiency.
DYSMORPHOLOGY	-The study of birth defects or malformation in a species.
ECCHYMOSES	-Blood under the skin--giving the appearance of bruises.
EMBRYO	-The fertilized ovum that eventually becomes the offspring during the period of most rapid development. In humans, this period is from 2 weeks after fertilization until the end of the 7th or 8th week, then it becomes a fetus.

MOTILITY	-The ability to move spontaneously.
NECROPSY	-Examination of a dead body to determine cause of death. Syn. - Autopsy.
NEONATE	-A newborn under 28 days of age.
PALMER CREASE	-Any of the normal grooves across the palm which accommodate flexion of the hand. In certain congenital anomalies, there is only a single transverse crease.
PALPEBRAL FISSURE	-The longitudinal opening between the eyelids.
PARITY	-The number of live births that a woman has delivered.
PERINATAL	The period shortly before and after birth generally considered to begin with completion of 28 weeks of gestation and ending 1 to 4 weeks after birth.
PHILTRUM	-The vertical groove in the middle of the upper lip.
PLACENTA	-An organ surrounding the fetus during pregnancy which joins the mother and offspring and supports growth and development during gestation.
POSTNATAL	-Occuring after birth.
PRENATAL	-Existing or occuring before birth.
PTOSIS	-Drooping of the upper eyelid.
STRABISMUS	-Deviation of the eye which the patient cannot overcome without treatment. The inability of both eyes to focus on one subject.
SYNDACTYLY	-Fingers or toes joined together.
SYNDROME	-A group of symptoms that characterize a disease or pathological entity.
TACHYCARDIA	-Accelerated pulse.
TERATOGEN	-An agent or factor that causes physical defects in the developing embryo.

Winter 1987

Protecting Babies

from alcohol-related birth defects



Expectant mothers who drink during their pregnancy may cause irreparable harm to their frail, delicate unborn babies. A major effort to reduce alcohol-related birth defects is under way in California.

Individuals and organizations concerned with the problem are active on a variety of fronts. Among their strategies

- Urging city and county governments to require that birth defect warning posters be displayed wherever alcoholic beverages are sold.
- Supporting state and federal legislation mandating that birth defect warnings be included on the labels of alcoholic beverages.
- Training medical practitioners to recognize symptoms of alcohol and drug abuse in women of child-bearing age so they can be referred to appropriate treatment.
- Making FAS an element in pre-natal counseling, with emphasis on educating fathers as well as mothers about the risks of alcohol and drug use during pregnancy.
- Creating new school curriculum materials for early education about the risks of using drugs or alcohol during pregnancy. As yet, barely five percent of California school districts include prevention of birth defects in their health classes.
- Improving programs for diagnosis of alcohol-related birth defects so that children with this disability may receive treatment that will help them develop to their full potential.
- Expanding research to determine exactly how a developing fetus is affected by the mother's alcohol and drug use, and to develop better modes of care for victims of alcohol and drug related birth defects.

Preventing birth defects associated with alcohol use was the subject of a national conference held in San Diego in 1986, sponsored by the Program on Alcohol Issues of the UCSD Extension. Research and treatment specialists from 15 states and Canada attended the conference, adopting a series of recommendations for new measures aimed at increasing public awareness of the danger of drinking during pregnancy.

Photo by Kurt Mulholland, NIAAA; drawing courtesy March of Dimes Birth Defects Foundation.

Dr. Gladden Elliott, president of the California Medical Association, told the conference that new knowledge is dispelling the notion that Fetal Alcohol Syndrome is relatively rare.

"We now know that the syndrome affects from one to 11 of every 1,000 births," he said. "For those women who have a drinking problem, it may strike as many as 29 infants per 1,000 births. This means that every year physicians are treating between 3,600 and 6,000 babies with fetal alcohol syndrome. And an additional 36,000 newborns each year show some signs of less severe alcohol-related birth defects."

More research is needed to determine what proportion of the 10,000 to 12,000 infants born each year with birth defects or developmental disorders are the victims of Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE).

Fetal Alcohol Syndrome is the most severe of these conditions and is associated with alcohol abuse or dependence by the mother, especially in the early weeks of pregnancy. FAS babies have decreased weight and head size, various degrees of mental retardation, and physical abnormalities most evident in facial features. The less severe Fetal Alcohol Effects are associated with drinking at any stage of pregnancy and include low birth weight, spontaneous abortion and some partial aspects of the Fetal Alcohol Syndrome.

The costs associated with Fetal Alcohol Syndrome are staggering. The direct costs of caring for affected children in the United States are estimated to be at least $2 billion a year. Institutional care for a severely retarded FAS child may run to $65,000 a year, or $2.5 million over its potential lifetime. In terms of human suffering, of course, the cost is incalculable.

A new study reported late last year in the British medical journal Lancet identifies Fetal Alcohol Syndrome as the leading cause of mental retardation in infants – ranking ahead of Down syndrome and spinal bifida. Alcohol use is the one cause of birth defects that is completely preventable.

Research has yet to establish exactly what mechanism is involved in causing harm to a developing fetus when the mother drinks. There is no known "safe" amount of alcohol that an expectant mother can drink, nor a period in her pregnancy that might be considered safe for drinking. Therefore pregnant women are urged to abstain altogether from alcohol when they are trying to conceive and throughout their pregnancy.

Programs to combat alcohol-related birth defects are being waged by public health agencies and medical organizations along with such private organizations as the March of Dimes Birth Defects Foundation and Healthy Mothers, Healthy Babies.

A special effort is being made to reach teen-agers with information about FAS and FAE. Dr. Mary Lu Hickman, a medical consultant to the state Department of Developmental Services, points out that one out of 10 girls will give birth before the age of 18.

"Teen-age mothers often don't realize they are pregnant until maybe the second or third month," says Hickman. "By that time, if they have had drinking episodes, the damage of FAS probably has already occurred. Major brain and organ systems are laid down by the eighth or ninth week."

Dr. Hickman chairs the California Prevention Task Force on developmental disabilities which is developing a plan called "Prevention 1990." The plan, she told the UCSD conference, will have a strong component dealing with both the prevention and treatment of alcohol related birth defects.

"The most important element of the plan is to get birth defects into the educational curricula," she said. "We want all students to have awareness and knowledge of the lifestyle necessary to prevent birth defects, including FAS and FAE."

She said the key to effective education about the risks of drinking and smoking during pregnancy must begin at an early age. "We feel very strongly that the knowledge needed to make a decision whether to drink or smoke should be given at least by grades three and four if it is going to be effective."

Future mothers and fathers are not the only target of education programs aimed at reducing alcohol-related birth defects. The California Medical Association recently inaugurated a

Chemical Dependency Education Program for physicians which hopes to improve their ability to detect drug and alcohol abuse in their patients and refer them to appropriate treatment.

Recognition of chemical dependency symptoms is especially important for obstetricians, who are in a position to help expectant mothers obtain counseling and treatment for alcoholism and other drug abuse which could jeopardize their unborn babies.

The CMA is also an ally of other organizations which are lobbying in Sacramento and Washington on behalf of legislation that would help inform the public about the link between alcohol and birth defects. Lawmakers at both the state and federal level are being urged to pass bills that would require warning labels on alcoholic beverage containers, and warning messages in advertising for the beverages.

State Sen. Gary Hart of Santa Barbara is sponsoring a 1987 version of a labeling bill that was effectively blocked in 1986 by heavy lobbying by the beverage industry. A coalition of organizations concerned about public health and child welfare is working on behalf of the legislation under the leadership of Consumers Union.

In Washington, the Center for Science in the Public Interest has been campaigning on behalf of federal legislation that would require a health warning label on alcoholic beverages.

The most successful battles on behalf of health warnings have been fought in local communities. More and more city and county governments are requiring that posters warning of the risk of birth defects from drinking alcohol be posted in all establishments where alcoholic beverages are sold.

Both the Los Angeles City Council and the Los Angeles County Board of Supervisors have adopted ordinances requiring such warning posters. (See accompanying article about how concerned individuals and groups in Los Angeles worked on behalf of the new regulations.)

In San Diego County, the Board of Supervisors voted favorably on a warning poster ordinance in October, 1986, and planned to lay down a procedure for implementing it in unincorporated areas of the county early in 1987.

"There is very little doubt at all that drinking alcohol in any form during pregnancy can cause birth defects," said Supervisor Susan Golding, who sponsored the San Diego County ordinance. Another supervisor, Brian Bilbray, said he was not impressed by the argument of opponents that it was up to doctors, not sellers of beverages, to warn women about alcohol and birth defects. Representatives of the restaurant and grocery industries opposed the ordinance.

"Maybe in your neighborhood you have pregnant ladies going to their physicians," Bilbray told the opponents. "A lot of my constituents never see a physician until they're ready to deliver."

The San Diego ordinance was supported by the March of Dimes Birth Defects Foundation, the National Council on Alcoholism and other public and private agencies concerned with maternal care, child welfare and prevention and treatment of alcohol and drug problems.

As proposed by Supervisor Golding, the San Diego posters would carry this message: "Warning. Pregnancy and alcohol do not mix. Drinking beer, wine or liquor while you are a pregnant or nursing mother—even in moderate quantities—can be harmful to your baby."

Georgia and South Dakota are now requiring warning signs statewide. Other cities which require the warnings include New York; Philadelphia; Washington, D.C.; Jacksonville and Leesburg, Florida; and Columbus and Lakewood, Ohio.

The Oklahoma Health Department has been circulating posters to liquor-serving establishment and asking that they be displayed voluntarily. A proposal still under consideration in Wisconsin would require that a pamphlet about Fetal Alcohol Syndrome be handed to all persons applying for marriage licenses in that state.

In most cases where posters are required, the warning deals only with the risk of birth defects. One community goes further, however. In Leesburg, Florida, the posters carry this message:

"Warning: Alcohol in Beer, Wine, and Liquor can cause intoxication, addiction, birth defects. Reduce your risks: do not drink before driving or operating machinery; do not mix alcohol with other drugs (it can be fatal); do not drink during pregnancy."

In Los Angeles, the California Restaurant Association filed a lawsuit challenging the constitutionality of the city's warning poster ordinance. However, a Superior Court judge rejected the argument that the ordinance infringes on the state's powers to regulate the sale of alcoholic beverages.

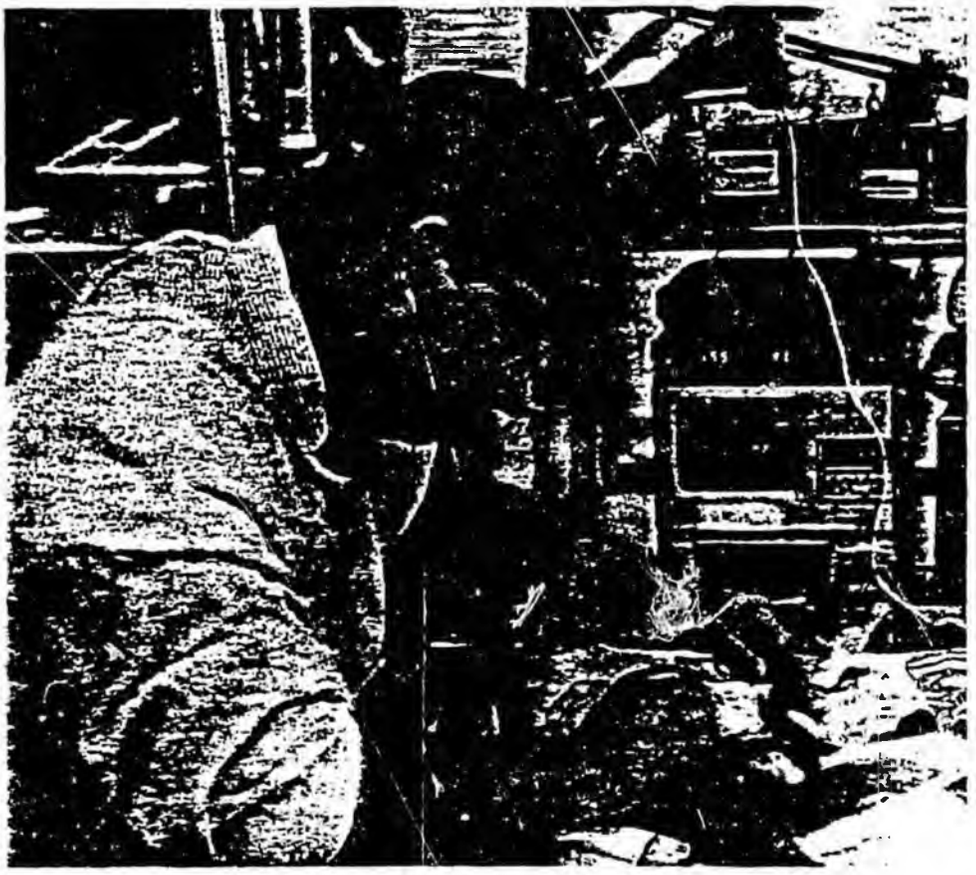


Photo by March of Dimes Birth Defects Foundation

Birth defects associated with alcohol use during pregnancy may affect as many as 6,000 babies born in the United States every year. A new study ranks alcohol abuse by the mother as the leading cause of mental retardation in America.

Warning Posters

—Persistence Pays Off in Los Angeles

Adoption of warning poster ordinances by the Los Angeles City Council and the Los Angeles County Board of Supervisors is a textbook example of how community concern about an alcohol problem can be translated into action by local governing bodies.

The successful campaign was guided by a Task Force organized by the Alcohol and Drug Dependency Council of Los Angeles County, which is the local affiliate of the National Council on Alcoholism.

The choice of leaders for the campaign showed an awareness of political realities. Co-chairing the Task Force were Mary Louise Frawley, who has the credentials of a conservative Republican, and Elizabeth Snyder, a prominent Democrat.

"Between the two of us, we had things pretty well covered," says Frawley. "There's a Democratic majority on the City Council, and a Republican majority on the Board of Supervisors."

The two chairpersons assembled a Task Force representing a dozen health and welfare organizations with a special interest in protecting mothers and children from the risk of alcohol-related birth defects. Members of the Task Force in turn reached out to other organizations that might be persuaded to join in the campaign. Eventually more than 35 public and private agencies were lending their names and influence to the effort. Frawley says the Task Force found valuable tips in a booklet on how to get local alcohol warning legislation passed, available from the Center for Science in the Public Interest, 1501 16th St. NW, Washington, D.C. 20036.

The Task Force lined up medical experts on the Fetal Alcohol Syndrome and Fetal Alcohol Effects to testify before the City Council's Health Committee about the importance of informing the public about the risks of drinking during pregnancy. By strategic timing, the Health Committee hearing was held during an observance of "Alcohol Awareness Week" in Los Angeles.

A favorable report by the Health Committee was followed by adoption of the warning poster ordinance by the full 15-member City Council. "We were surprised at the lack of opposition," says Frawley. "I think the beverage industry people were caught off guard."

This was not the case when the Task Force took the issue to the Board of Supervisors, seeking a similar ordinance to apply to the unincorporated areas of Los Angeles County. This time, representatives of the beverage and service industries were on hand to argue against the ordinance. The FAS Task Force made sure that its side was well represented, too.

"We had a fine turnout of our people for the county hearing," Frawley says. "We wanted to make sure the supervisors knew how many of us were in the audience, so we all wore 'Fight Birth Defects' ribbons."

The main argument made against the proposed ordinance was that it was unconstitutional – that only the state government was empowered to make regulations affecting the sale of alcoholic beverages. Legal scholars at the Prevention Research Center in Berkeley helped provide ammunition for an effective counter-argument in the presentation to the supervisors.

The supervisors adopted the ordinance. Warning posters now are required in 7,500 establishments selling alcoholic beverages in the city of Los Angeles, and in another 1,500 similar businesses in unincorporated areas of the county. Volunteers from the Task Force have been assisting city and county authorities in distributing posters to the affected businesses. Members of the Task force also hope to persuade other municipalities in the Los Angeles area to adopt similar ordinances.

In drafting a proposed text for the warning signs, the Los Angeles Task Force profited by the experience of others. In New York, similar warning posters refer only to the risk of birth defects from drinking "alcoholic beverages" during pregnancy. Surveys have indicated that some people believe the message refers to distilled spirits, but not to beer and wine. The Los Angeles posters state specifically that the risk lies in drinking "beer, wine and other alcoholic beverages."

What's the secret of a successful community effort to pass a warning sign ordinance? "Persistence," says Mary Louise Frawley.

"Liz and I spent a lot of time on the telephone, keeping after people to remind them of what we were doing and getting them to follow through on their promises to write letters or call a councilman or supervisor."

She had another tip for organizers of such campaigns. "We kept it as informal as possible. We tried not to have too many meetings. People shy away from commitments that mean sitting through a lot of dull meetings. Whenever you can, use the phone."

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National Institute on
Alcohol Abuse and
Alcoholism

U.S. Department of
Health and Human
Services

Public Health
Service

... Drug Abuse,
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NCALI

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National Clearinghouse
for Alcohol Information

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This infant is a low birth weight baby. State programs aim to increase awareness that maternal alcohol use can result in low birth weight and deleterious fetal effects.

project were to encourage women of childbearing age to avoid alcohol and unnecessary drugs during pregnancy; to urge women with drinking problems to seek and accept treatment; to influence health, social service, and education professionals to provide education on alcohol and drug effects to all patients, clients, and students prior to and during pregnancy; and to intervene with high-risk women (Yancosek 1982).

Target Groups

The education of women is vital regardless of the intensity of their drinking, to permit them the opportunity to make informed decisions about alcohol consumption during pregnancy. Becky Beardsley of the Nebraska LCAD Fetal Alcohol Syndrome Prevention Project has distinguished three subgroups of women as target audiences for information and intervention: high-risk, moderate, and low-risk (Table 1). Each of the cells in Table 1 describes a level of risk based on the drinking and/or pregnancy status of the individual. The low-risk cell, for example, describes the person neither currently drinking nor pregnant. Reinforcing the decision not to consume alcohol if pregnant is the thrust of prevention for the low-risk group. Public information efforts, school health education, and health professions curricula are also strategies for reaching women considered at low risk (Beardsley et al. 1985).

Program Structure

The Nebraska LCAD Fetal Alcohol Syndrome Prevention Project utilizes a program framework based on primary, secondary, and tertiary prevention modalities for each stage of the maternal-child health continuum (i.e., preconception, prenatal, intrapartum, and postnatal) (Table 2). Primary prevention encompasses activities that target low- and moderate-risk women. These efforts can include teacher training for junior and senior high school teachers, public information and education, and professional education for health and human service workers. Primary prevention may also entail curriculum development and consultation with curriculum developers associated with educational institutions.

Secondary prevention consists of professional training and consultation with health and human service workers. Training includes information and individual consultation on the identification of high-risk (alcohol- and drug-abusing) women, especially pregnant women, and intervention counseling techniques. Trained personnel may directly assist physicians and other health professionals in directing intervention efforts. Tertiary prevention consists of providing referral information and guidance for alcohol-abusing women and affected children. It might also include a support group for women with FAS/FAE children as well as legislative activities (Beardsley et al. 1985). The program components just identified will be discussed further in the article.

Caregivers in the intrapartum and postnatal periods may need to be reminded of secondary and tertiary prevention. Even a woman who has been drinking during pregnancy should stop doing so to protect her baby from further alcohol-related birth risk during the remainder of the pregnancy

Table 2. Target Groups of Women in Childbearing Years

Drinking	PREGNANT: Yes	PREGNANT: No
Yes	**High Risk** *Secondary prevention* (intervention aimed at alcohol/drug abstinence during course of pregnancy. *Tertiary prevention* (referral and support group) to minimize adjustment difficulty.	Appropriate referral would be made to existing agency.
No	**Moderate Risk** Since these women are currently pregnant, not using alcohol/drugs, *primary prevention* efforts aimed at reinforcing that as well as skill to maintain.	**Low Risk** *Primary prevention* efforts at reinforcing a choice of alcohol/drug-free lifestyle while pregnant if woman chooses to become pregnant

Health also conducted a statewide telephone survey of 300 randomly selected women of childbearing age. Only minimal costs, for computer time, were incurred (Nystrom 1983). The Pennsylvania Project for Prevention of Fetal Alcohol and Drug Effects used questionnaires mailed or directly administered to randomly selected women (Yancosek 1982).

In order to determine the extent and the nature of the problem and to obtain a base of information upon which a prevention program could be developed, Maine commissioned a study. The four objectives of the study were:

- ☐ To determine the state-of-the-art of the State and national level;
- ☐ To identify effective education and prevention strategies and activities;
- ☐ To develop a proposal for a long-term prevention model program; and
- ☐ To identify constituencies with the duties, responsibilities, or interest in prevention strategies (Mullen and Anderson 1985).

Existing statistics may also be useful in estimating the extent of the problem, although data about the incidence and prevalence of FAS/FAE are often flawed because of misdiagnoses. Information on demographic factors, births, infant deaths, fetal deaths, rate of alcoholism, number of women admitted for treatment, and other data is generally available through the State's division of statistics or a health planning agency. Such information should assist in understanding the effectiveness of current educational efforts and in identifying sources of information and advice related to the effects of drinking alcohol during pregnancy.

Professional Education

Many State FAS/FAE prevention programs have strongly emphasized professional education of physicians and other health care providers. Education of professionals is most effective when directed at both medical and nonmedical personnel concerned with the health and welfare of women and children. The overall goals of such education efforts are to increase knowledge of alcohol-related birth defects, to stimulate awareness and interest in the problem and prevention efforts, and to activate preventive and therapeutic behaviors such as:

- ☐ Patient or client education;
- ☐ History taking concerning alcohol and drug use;
- ☐ Diagnosis of maternal drinking and other drug problems;
- ☐ Intervention and and referral for alcoholism and drug treatment; and
- ☐ Diagnosis of FAS and other prenatal drug effects in children.

Many State programs have "kicked off" their professional education for physicians and other health professionals with a symposium, a workshop, or a conference. A forum that includes a local pediatrician, an alcohol/drug women's counselor, a family therapist with expertise in the areas of women's alcoholism and FAS/FAE prevention and, if possible, nationally recognized researchers in the field offers a valuable opportunity for introducing the many dimensions of this problem. Typically, physicians prefer to receive information from other physicians in the same specialty.

More extensive training sessions might be held at local hospitals, nursing schools, medical assistant training programs, and conferences sponsored by related organizations. Inservice sessions can be provided to Women, Infant, and Children (WIC) nutritionists, public school nurses, public school teachers, drug/alcohol counselors, Head Start staff, welfare caseworkers, and others concerned with maternal and child health.

As part of the New York State Division of Alcoholism and Alcohol Abuse (NYSDAAA) campaign in 1980, FAS information packets were mailed to 1,000 obstetricians and gynecologists. The packets contained a reprint from a prestigious medical journal describing FAS, an outline of the criteria for the diagnosis of alcoholism, photographs of FAS cases, patient brochures, posters in English and Spanish on drinking while pregnant, a patient alcohol and health self-test, a referral list for problem drinkers, a referral list for affected children, and patient pamphlets on alcohol abuse. In addition to mailing out the information packets, NYSDAAA-sponsored medical conferences and grand rounds around the State on FAS and alcohol-related birth defects. Over three-fourths of the physicians who reported receiving and reading the NYSDAAA FAS information packet considered the items useful. However, data on physicians' intervention efforts suggest that additional efforts are needed to motivate and assist many obstetricians and gynecologists with implementing a system for screening their patients routinely for problem drinking and to identify and refer those who are in need of special treatment for alcohol abuse (Russell et al. 1983).

Referral and Support Services

Once health and other professionals have received training about the problem of alcohol-related birth defects, they may need assistance in counseling, referring, and treating women and children. The Nebraska LCAD Fetal Alcohol Syndrome Prevention Program, for example, has responded to requests for assistance with designing screening and risk assessment tools. The services of qualified program staff have also been made available to assist with intervention and with counseling alcohol-abusing pregnant women. Referral information is provided to professionals who have identified either a woman abusing alcohol/drugs or affected children. A resource center providing up-to-date materials and information (e.g., audiovisuals, books) is also a service of inestimable value to persons in the field.

Offering consultation services to health professions educators interested in updating their curricula to include FAS/FAE prevention information is another support service provided by the Nebraska project. Some schools may want to include presentations by project staff as well (Beardsley et al. 1985). Nursing schools appear especially receptive and play a key role in disseminating current FAS/FAE information to health professionals.

To ensure that information is accessible, the North Carolina project operates a 24-hour telephone information service available to anyone with a question about FAS or about alcohol consumption during pregnancy. An answering machine records messages received when staff is not available to answer the hotline.

Community Education

Reaching the general public, especially women of childbearing age, with information about alcohol-related birth defects is a major thrust of most FAS/FAE prevention programs. Such public education campaigns should not be limited to women of childbearing age; informed mothers, friends, spouses may also serve as informal educators. Print materials, community education programs, and mass media are complementary and reinforcing modes of communication that reach a broad cross-section of the community.

Posters and pamphlets are the most common print materials developed and distributed by FAS/FAE prevention programs. Many States have received permission from existing programs to adapt materials and messages that have proved effective. The article in this issue on disseminating information (see page 54) suggests appropriate messages for women and physicians. Some excellent locations for placing such materials are doctors' offices, pharmacies, laboratories where pregnancy tests and premarital and pregnancy blood tests are taken, marriage license bureaus, social service agencies, church bulletins, maternity clothing stores, children's clothing stores, shopping mall displays, State liquor stores, supermarkets, family planning services, health clubs, WIC nutrition programs, laundromats, prepared childbirth classes, YWCAs, other women's clubs, beauty shops, and many other places frequented by women (Yanchek 1982).

Presentations that provide more detailed information through the use of speakers and audiovisuals are effective mechanisms for increasing awareness. Such programs can be offered to the membership of existing organizations, clubs, and groups such as childbirth education classes, LaLeche, PTAs, and YWCAs. All presentations should emphasize the positive aspects of healthy pregnancies rather than the negative aspects of birth defects. (Information about films, pamphlets, and other materials may be obtained from the National Clearinghouse for Alcohol Information.) Some communities have established a speaker's bureau composed of experts on various aspects of FAS/FAE who have indicated an interest in making presentations on the subject.

Newspapers, radio, television, and magazines are also useful channels for communicating information about alcohol-related birth defects. In 1982, the National Institute on Alcohol Abuse and Alcoholism (NIAAA) developed radio and TV public service announcements and distributed them nationwide to county drug and alcohol programs and radio and television stations. Newspaper sample articles and detailed talk show interview scripts were also distributed. Some of these materials are still available for distribution by contacting NIAAA. These and similar locally developed materials are the ingredients for a mass media campaign that might be conducted over a 3-month period every year or every other year. The Christmas-Hanukkah season and Mother's Day are particularly appropriate times for such campaigns.

School Programs

Drinking frequency and amount remains at alarmingly high rates among high school women as does the incidence of teenage pregnancy. To ensure that information on alcohol-related birth defects reaches teenagers before alcohol is a problem, it should be incorporated at all levels of education under the heading of preventing developmental disabilities. The Nebraska alcohol-and-drug school curriculum, as well as others in the Nation, includes junior and senior high school units on alcohol, drugs, and pregnancy. Most States, however, do not include such information in the elementary school curriculum. In school systems where alcohol-related birth defects are not addressed, the prevention program might encourage the department of education to develop such a component.

The Maine prevention program worked with four area institutions for higher learning. Activities included 10 FAS/FAE presentations; public service announcements through college radio stations and newspapers; and visual and narrative materials placed in health centers, dormitories, sororities, and fraternities. All human service programs sponsored by these colleges agreed to integrate information about FAS/FAE into their course materials (Mullen and Anderson 1985).

During the 1985-86 fiscal year, Pennsylvania will implement a comprehensive program aimed at increasing awareness among youth about the harmful effects of alcohol consumption during pregnancy. This initiative will include regional workshops for relevant school personnel, the development of a five-unit curriculum for grades 9–12, and a video training tape on screening and interviewing techniques for obstetricians, gynecologists, and nurses.

Conclusion

This discussion has provided an overview of the core activities of an FAS/FAE prevention program. As mentioned earlier, once training and inservices have been provided, a prevention program should continue to provide ongoing services as an information and referral source. Periodic training is, of course, necessary to reach newly identified providers. Those projects that emphasize the health of the mother as well as the fetus will have a full agenda.

Here is a sampling of activities for those interested in pursuing additional prevention strategies:

☐ Provision of technical assistance to the State Department of Education curriculum development task force and membership on the Department's task force on chemical dependency and special education;

☐ Recruitment, training, and deployment of a core group of physicians interested in the prevention and treatment of FAS/FAE to provide training to their colleagues through hospital departmental staff meetings, regional and State medical association meetings, etc.;

☐ Collaboration with the Developmental Disabilities Council to identify groups/agencies with the capacity to support effectively families who are experiencing the trauma of having a disabled child;

☐ Establishment of a diagnosis registry for FAS/FAE. ☐

Turn to page 76 for references.

***Laura Ronan, M.P.H.**, is the Coordinator of New Products for the National Clearinghouse for Alcohol Information.*

STEVE COWPER, GOVERNOR

DEPT. OF HEALTH AND SOCIAL SERVICES

OFFICE OF ALCOHOLISM AND DRUG ABUSE

POUCH H 05F
JUNEAU, ALASKA 99811
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1987

Dear Pediatrician:

Nationwide, the rise in Alcohol-Related Birth Defects, Fetal Alcohol Syndrome (FAS) in particular, has spurred the development of both prevention and intervention programs to combat this totally preventable birth defect.

The incidence of FAS for all populations in Alaska is not completely known, but it is expected to be high. Recent research clinics examined suspected cases in 12 locations throughout Alaska. The results confirmed our worst suspicions. We knew our FAS incidence had to be high because of our high per-capita consumption of alcohol. As one of the leading consuming states, we drink almost four gallons of absolute (pure) alcohol per person. In Alaska, the birth incidence rate of 4.2/1000 live births is the highest reported rate for any population thus far studied. For comparison, the rate in Seattle is 1.7/1000, in France 1.6/1000, in Sweden 1.7/1000, and 2.0/1000 on the Navajo Reservation.

The Alaska FAS incidence makes FAS the most common etiologically identifiable congenital cause of mental retardation in this population. The incidence of Down Syndrome, usually regarded as the most common cause of mental retardation, is 1.8/1000 in Alaska Natives.

I have taken the liberty of enclosing articles on FAS that I thought you might find interesting. If you would like more information, please feel free to contact me.

Sincerely,

Matthew C. Felix
Coordinator

Enclosures

mf2-26

5-F74LH

FACT SHEET: FETAL ALCOHOL SYNDROME (FAS)

compiled by Marcia Michel

FACTS

Twelve years of research have conclusively established that alcohol use during pregnancy poses a threat to the health of the child.

Fetal Alcohol Syndrome is a pattern of mental, physical and behavioral defects that may develop in the unborn child when its mother drinks alcohol during pregnancy. FAS is characterized by a cluster of congenital birth defects that include the following:

- Prenatal and postnatal growth deficiency, meaning low birth weight and failure to catch up
- A pattern of facial malformations, including small head size, misshapen eyes and midportion of the face
- Central nervous system dysfunction which can include mental retardation; brain damage resulting in difficulty with balance, coordination, learning or memory; alcohol withdrawal symptoms at birth; a poor sucking response and sleep disturbances during early infancy, restlessness and irritability; developmental delays; hyperactivity, short attention span and/or behavioral problems
- Varying degrees of malformations, particularly of the heart, joints, kidneys and genitalia.

Fetal Alcohol Effects (FAE)—less severe alcohol-related birth defects—have shown up in babies whose mothers drank smaller amounts.

According to current research, there is no safe drinking level for pregnant women.

In many cases, high levels of consumption will produce the full expression of FAS; but in some cases, moderate consumption is enough to produce FAS.

Researchers estimate that nationally FAS occurs in about 1 to 3 per 1,000 live births.

In Alaska, preliminary results indicate that FAS occurs in at least 3 per 1,000 live births among the Native population.

FAS has been found in virtually every ethnic and cultural group and in every social class.

For every child with FAS, as many as 10 other children may be born with FAE.

The severity of FAS seems to rise with each succeeding affected child born to a woman drinking alcohol.

FAS is the third leading cause of birth defects with accompanying mental retardation, and is the only preventable one among the top three.

Research shows there is no safe time to drink during pregnancy. The first trimester appears to be the interval when developing organs are vulnerable to damage.

Evidence supports an association between alcohol consumption and an increased incidence of spontaneous abortions found during the second trimester.

Alcohol exposure during the third trimester may interfere with the rapid growth that occurs during this time, including the growth of the brain.

The major effects of alcohol on developing tissues are slowing of growth and interference with cell migration.

Alcohol itself is the toxic agent, but other factors (nutrition, smoking, use of other drugs and other "unknowns") may enhance the effect of alcohol and influence the actual risk for FAS.

Cost of institutionalization for an FAS child in Alaska averages $90,000 per year. Travel and surgery on birth defects would be additional costs depending on amount and severity.

While all of the defects caused by drinking have not yet been identified, we do know:

- alcohol interferes with normal pregnancy
- effects on the fetus are permanent
- whether they occur or not is a matter of the basic metabolism of both the pregnant woman and the fetus

There is no treatment for FAS.

It is totally preventable.

In the absence of research establishing a safe drinking level, the U.S. Surgeon General advises women who are pregnant (or nursing or considering pregnancy) to refrain from drinking alcohol during pregnancy.

This information was compiled from several sources. For a complete listing of these sources, please contact Marcia at the Alaska Council.

ALASKA COUNCIL ON PREVENTION
OF ALCOHOL AND DRUG ABUSE, INC

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Unfortunately, at least in the near future, such systems are unlikely to be set up in many developing countries, partly because of lack of financial and human resources but largely because of lack of political will to face this problem. Creating this political will is the responsibility of the international obstetric community.

OUR PROPOSAL FOR IMPROVING MATERNAL HEALTH

At international meetings of obstetricians, where developing countries are well represented it is depressing to find that the emphasis is almost entirely on the high-technology subspecialties and that sessions on the social issues are usually attended by a small minority of physicians who are already knowledgeable about these problems.

Despite publications about the proportion of maternal deaths in hospitals due to haemorrhage, eclampsia, and so on, little thought seems to be given to the deaths from these causes that occur outside the medical-care system. The obstetric community should lead a review of the problem, in conjunction with government health departments and donor agency officials. Improvement of maternal care in developing countries is a long-term undertaking that will require national and international health planning to provide the necessary facilities, personnel, and supplies.

UNICEF has taken the lead in promoting effective primary health care for infants and young children; UNFPA in promoting family planning and population programmes for both demographic and maternal/child health purposes; and WHO in promoting overall primary health care. The World Bank has been a leader in describing the ways in which population growth hinders socioeconomic development. Some years ago the Bank established a department of population, health, and nutrition, to which it has committed sizeable resources, but programme and project developments have, in general, been difficult. In part this is because the Bank's programme is based on loans, an approach that has been successful for large capital projects such as road construction, industrial development, and dam building, but less so for social programmes such as population and health.

We suggest that the Bank makes maternity care one of its priorities. A programme for the prevention of maternal deaths could be built around the building of maternity centres in rural areas, the recruitment and training of staff for the centres, and the provision of supplies and drugs. The programme could be phased so that governments would take over these expenses in time. Loans for these purposes should be seen as an acceptable long-term investment in improving the health of women. In addition, because women receiving maternity care are an appropriate group to whom contraceptive information and services can be offered, our proposal provides an opportunity for the Bank to work toward its goal of reduced population growth rates. Leadership by the Bank, with its enormous resources, could, as an integral part of maternity care, considerably reduce maternal morbidity and mortality and perinatal mortality, and encourage contraceptive practice. In the socialist/communist countries of Cuba and the People's Republic of China, most women have ready access to maternity care, with effective referral systems for higher-level care. This has been accomplished through the allocation of the necessary resources. Such a system is not beyond the means of most countries, but it requires a dramatic shift in priorities.

Correspondence should be addressed to A. R.

References at foot of next column

Occasional Survey

NATURAL HISTORY OF THE FETAL ALCOHOL SYNDROME: A 10-YEAR FOLLOW-UP OF ELEVEN PATIENTS

ANN PYTKOWICZ STREISSGUTH
STERLING KEITH CLARREN KENNETH LYONS JONES

Department of Psychiatry and Behavioral Sciences, and Department of Pediatrics, Child Development and Mental Retardation Center and Alcoholism and Drug Abuse Institute, University of Washington, Seattle; and Department of Pediatrics, University of California, San Diego, La Jolla, California

Summary Of the eleven children who were the first to be diagnosed as having the fetal alcohol syndrome ten years ago, two are now dead, one is lost to follow-up, and the remaining eight continue to be growth deficient and dysmorphic. With menarche, which occurred with normal timing, the female patients developed increased body fat. The mothers were all severe chronic alcoholics. Four of the eight known survivors are of borderline intelligence and have needed some remedial teaching. The other four are severely handicapped intellectually and need complete supervision outside the home. The degree of growth deficiency and intellectual handicap was directly

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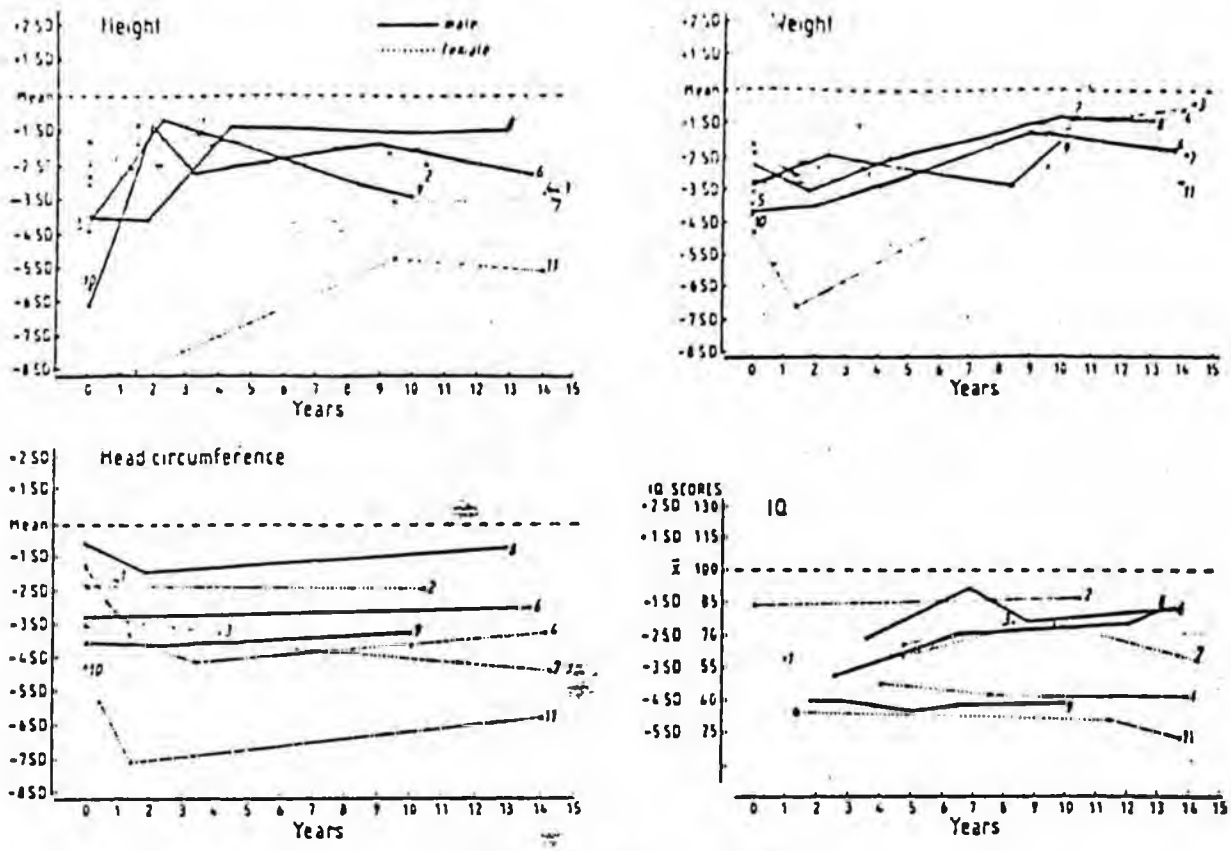

Fig 1—Growth and IQ curves with age.

Records taken at five ages are plotted when available. IQ scores are derived from individual age-appropriate tests of general intelligence and mental development, including the Wechsler intelligence scale for children (revised), the Wechsler preschool and primary scale of intelligence, the Stanford-Binet intelligence scale form L-M, and the Bayley scales of mental development. The Stanford-Binet scores reported in ref 1 have been revised according to norms published since then. The first IQ point for patient 11 is circled because it was measured from the Vineland social maturity scale and clinical observation.

and treatment with tympanic ventilatory tubes, has left her with a fixed 50 decibel conductive hearing loss in the left ear. She is undergoing standard orthodontic treatment for malocclusion.

Patient 3

She is a short, stocky, sexually-mature 14-year old girl who lives with her natural mother and several siblings. She is in the 7th grade but failing in examinations and not attending school regularly. Although she used to be cooperative and engaging, she has become suspicious, guarded, sullen, and a poor mixer at school. Family ties remain very strong, but the family is socially isolated and very poor yet steadfastly refuses help. The patient refused to be examined medically and psychologically but growth data were obtained.

Patient 4

She is a short, overweight, sexually mature 14-year-old girl (fig 2) who has lived in a stable adoptive home since she was 4½. She attends classes for the retarded and reads and spells at 2nd and 3rd grade level. She is a happy, outgoing, talkative child who has no inhibitions with strangers and is too immature to be left alone. She is no longer hyperactive but continues to have a short attention span.

The patient's facial features have not changed. Her palpebral fissures are short (2·2 cm bilaterally) but her inner canthal distance is normal (3·1 cm). The visual abnormalities include ptosis, strabismus, nystagmus, severe myopia, and bilateral optic nerve hypoplasia. She has a moderate class III malocclusion secondary to a flat midface and prominent mandible. She continues to have prominent lateral palatine ridges. Her external ears are prominent and of an odd shape. Her skeletal anomalies include bilateral radio-ulnar synostosis, brachydactyly, and camptodactyly of the fourth and fifth digits of both hands, and clinodactyly of the third and fourth digits of the left hand; an aberrant palmar crease pattern bilaterally; and bilateral syndactyly of the second and third toes. A cardiac murmur compatible with a patent ductus arteriosus was audible until she was 5. Since infancy, she has been in reasonable health although she has needed careful ophthalmological follow-up. Orthodontia with possible oral surgery is indicated.

Patient 5

This boy, who was 17 months old when first described, has been lost to follow-up for the past 10 years.

Patient 6

This short, thin pre-pubertal 13½-year-old boy has always lived with his natural parents and siblings. He is in the 8th grade and attends regular classes, with remedial teaching for mathematics and English. He is quiet, well-behaved, cooperative, and no longer hyperactive.

He has most of the facial features of the fetal alcohol syndrome except for a normal midface, which tends to make him look less typical than others with the syndrome. His palpebral fissures are short (2·1 cm bilaterally) while his

He has retained the typical facial features of the fetal alcohol syndrome. His palpebral fissures are 2·5 cm long while his inner canthal distance is 3·0 cm. Midline anomalies include epicanthal folds, a hypoplastic philtrum, and a thin upper lip. He has midface hypoplasia and micrognathia. The dental alignment is poor but there is no malocclusion. His mild skeletal anomalies include radioulnar synostosis and mild hip flexion contractures, camptodactyly of his fifth fingers, small toenails, and the presence of thirteen ribs bilaterally.

Patient 10

This patient died at age 5 days, after multiple apnoeic episodes; necropsy findings have been reported elsewhere.[11,12]

Patient 11

She is a very short, sexually mature but mentally retarded 14-year-old girl who has lived in a stable foster home since the age of 8. She is a quiet girl, is highly distractable but not hyperactive, and is totally trusting with strangers. She is obedient and compliant but too immature to be left alone.

She is in good general health but severely growth deficient. Midline anomalies include marked epicanthal folds, a hypoplastic philtrum, and a thin upper lip. Her midface is flat and she has some prognathism and a class III dental malocclusion. Her ears are prominent and have anomalous convolutions. Her skeletal anomalies include radioulnar synostosis, palmar crease anomalies, bilateral clinodactyly of the fifth digits, mild flexion contractures at the elbow and knee, and abduction contractures at the hips. Multiple small haemangiomas are still present on the trunk and there are striae atrophicae of unknown cause on the inner aspects of both legs. A systolic heart murmur, compatible with ventricular septal defect, resolved spontaneously by the age of 10. Her cleft palate was closed at an operation when she was 4. She has also undergone surgery for the reduction of prognathism of the mandible and is receiving orthodontic treatment.

DISCUSSION

Although we do not know how representative the eleven children we have followed up are of all those with the fetal alcohol syndrome, some of the features they have in common may be helpful in the planning for the future of affected individuals.

Growth

All the children remained growth deficient with respect to height, weight, and head circumference (fig 1). Although most of them showed some catch-up linear growth during the first years of life, weight and head circumference decreased relative to the norms during this time in most children. Thereafter, length and head circumference remained relatively constant with respect to the norms, while eight of the nine children on whom follow-up data were available showed some catch-up in weight with increasing age. The slow growth of the head after delivery may explain why in some infants the syndrome is diagnosed at 9–12 months of age instead of at birth.

The measurement which best summarises the appearance of children with the fetal alcohol syndrome is the weight for height age (table III). Initially the children were strikingly underweight for their height, with weight for height ages of from less than the 1st to the 15th percentile during the preschool years. However, at puberty the four females had weight for height ages ranging from the 50th to the 85th percentile (eg, fig 2). Neither of the boys who were between 13 and 14 years of age had reached puberty, and both continued to be underweight for height (eg, fig 3). The characteristic emaciated appearance in the young child (see fig 3) may not remain a salient feature in the affected adolescent, at least for females. This may help explain why new patients are rarely recognised during adolescence and adulthood.

TABLE III—WEIGHT FOR HEIGHT AGE AT THREE DIFFERENT AGES

Patient no	Pre-school (1·5–5 yr)	Pre-pubertal 9–10 yr	Pre-pubertal 13–14 yr	Puberty (13–14 yr)
Girls				
11	7·5%	5%		62%*
4	15%	37%	..	85%*
7	8%	50%	..	50%*
3	5%	15%	..	62%*
2	15%	38%	..	..
Boys				
9	3·5%	17%	..	..
8	3·5%	10%	20%	..
6	<1%	10%	17%	..

Height age represents chronological age on the growth charts at which the child's actual height fell at the 50th percentile (growth charts from National Centre for Health Statistics, National Institutes for Health).
Weight for height age is the percentile at which the child's actual weight fell when plotted against the height age.
Girls and boys have been rank-ordered separately by severity of dysmorphology.
*Menarche attained.

Pattern of Malformation

In the eight children for whom follow-up data are available, including the three who had undergone pubertal changes, the craniofacial features did not change over the 10 years, especially the short palpebral fissures, hypoplastic philtrum, thin vermillion border of the upper lip, and flat midface. However, the noses have taken on a new contour, with prominent growth of the nasal bridge, and subtle morphological changes in the nasal tip and/or ala nasi. The mandibles become relatively prognathic. Although the patients continue to resemble each other, the changes in the nose and mandible alter the overall facial phenotype substantially and may again explain why the syndrome tends not to be recognised in adolescents and adults.

Cardiac anomalies, which consisted of an atrial septal defect in one patient, patent ductus arteriosus in one patient, and grade 3/4 systolic murmur interpreted as representing a ventricular septal defect in six patients, have all resolved spontaneously or have become insignificant. Congenital hip dislocation has been managed successfully by the use of casts and/or abduction splints in two patients and by surgery in the third. Except for one case of severe scoliosis that had to be corrected by spinal laminectomy the other skeletal or joint anomalies, such as radioulnar synostosis, camptodactyly, and/or clinodactyly, have not had to be corrected by surgery and (with one exception) have not interfered with performance. The short palpebral fissures are thought to be secondary to decreased growth of the eyes. Frank microphthalmia observed at necropsy in patient 10 as well as optic nerve hypoplasia noted in two other children at their most recent follow-up visit tend to support this interpretation

craniofacial abnormalities (patients 4, 7, 9, and 11) have the most severe degree of microcephaly, the shortest stature, and the lowest intellectual function. Three of these four infants presented in a breech position, compared with none of the four moderately affected children.

The most predictive factor in the backgrounds of the four most severely handicapped children was the severity of maternal alcoholism. Three of them had mothers who died of alcohol-related causes less than 6 years after their births, which suggests that biological factors associated with the terminal stages of alcoholism may have contributed to the severe handicap. The quality of the later home environment did not counterbalance the severity of the prenatal insult. Two of the four severely affected children lived in the most stable foster homes, which suggests that the prognosis for the most severely affected children depends primarily on the extent and severity of the prenatal exposure to alcohol. However, improvement in social and emotional development was noted in patients whose home environments became stable, either because of reduction in maternal drinking, departure of the alcoholic mother, or placement of the child in a stable foster or adoptive home. The high frequency of abuse and neglect which characterised the first year of life for those who remained with alcoholic mothers who continued to drink indicates the need for intervention from birth.

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We gratefully acknowledge the following colleagues for their help: Dr Catherine Crowley, Dr Betty Darby, and Dr Cynthia Herman (clinical psychologists); Mrs Joan Rocheleau and Mrs Judith Furukawa (psychometrists); Miss Gail Yedinak, Miss Carole Grunta, Mrs Carol McMullen, and Mrs Therese Grant (clinic assistants); Mr James Parrish-Johnson (photographer); Mr Grey Owen (artist); Mrs Nydia Fabian (secretary). We also thank Dr Craig Weiss (ophthalmologist), who examined patient 4; Dr John Opitz who located patient 11; and the parents and caretakers for their cooperation.

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Round the World

From our Correspondents

United States

MALPRACTICE AGAIN

ON the day that several thousand physicians gathered from all over New York State to demand action over the medical malpractice crisis in the State, a new type of malpractice suit got underway in California. There, the plaintiffs are the parents of a young man who committed suicide in a state of depression, not having been cured by the ministers of the church of which he had become a member. On behalf of the pastors, it is stated that "the root of all depression is sin" and can be treated with advice based only on the Bible. Unhappily in this case the treatment was not successful, perhaps because the counselling of the church concerned reinforces feelings of guilt, which may already have reached a pathological degree. The outcome of the case, one in a growing number of such cases against churches and pastors, will be of interest.

If religious malpractice has not as yet reached a crisis, medical malpractice, at least in some States, has done so. Some ten years ago, most commercial insurance companies, faced with large increases both in the number of cases and in the size of awards, declined to give coverage. To cope with this crisis, the medical profession itself arranged mutual malpractice insurance coverage, and there are now some forty organisations, many of which face an uncertain future, especially since claims and costs have risen dramatically. In New York, the Medical Liability Insurance Company (MLIC), which insures about 35% of the doctors in the State, now finds itself short of over $750 million to pay future claims, despite a 55% rise in premiums. But what is making the situation more difficult is that the reinsurance companies, through which the costs can in part be "laid off", are also leaving the field, some backing out completely, others refusing to back certain groups within the medical profession. Some new insurance groups are confining cover to those medical practitioners with the smallest risks. As those concerned draw graphs predicting the future they arrive at quite horrifying figures. Something can be done to ease matters by changing from "occurrence" policies to "claims made" policies, the latter covering only claims made in the year in which the policy is in force. But this is only a small step.

Governor Cuomo of New York has suggested various legislative proposals, but it is very doubtful whether either he or the members of the legislature have anything like a full grasp of the problems. A decision to limit attorneys' fees would effect only a small saving. A ceiling could be put on damages for pain and suffering, but would not this infringe our constitutional rights? Would it not mostly concern the more severely injured? Perhaps all large awards should be terminated with the death of the injured party.

The spokesmen for the medical profession seem to be no more aware of the real problems and their ramifications than the legislators, and perhaps a lot less. What is alarming is the unwillingness of many physicians, and their organisations, to come up with the real solutions. For the plain fact is that there is a lot of real malpractice—some would say a horrifying amount. Incompetence, carelessness, laziness, indifference, and frank inhumanity are all too common. Practice and prescribing over the telephone all too often lead to disaster. Most problems are due to a small minority of individuals, but the profession and the hospitals have done little to rid themselves of these, often repeat, offenders. For years the profession has been denounced for the slackness and uselessness of its medical disciplinary actions. If, at last, the American Medical Association has started a drive to force incompetent physicians out of practice it is about 40 years too late.

But this is only part of the trouble. There are the notorious delays in settling suits (now more than eight years in New York), and there is a tendency in bad cases to add interest from the time of injury. Whence these delays? It is clear that the MLIC must have an enormous number of outstanding claims if its reserves are $115 billion and it is still $750 million short. Why are indefensible claims

Nutrition Today®

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ALCOHOL AND PREGNANCY

Characteristic Anatomical Defects that are Signs of the Fetal Alcohol Syndrome

Low nasal bridge

Short palpebral fissures, obscure the canthus. or inner corner of the eye, a normal feature in certain species of the Mongolian race

Indistinct philtrum, an underdeveloped groove in the center of the upper lip between the nose and the lip edge

Small hea
circumfere

Epicanthic
folds

Short nose

Small midfa

Thin reddis
upper lip

PHOTO COURTESY NEJM

Epicanthus is a characteristic of the eye where a vertical fold of skin extends from the root of the nose to the inner termination of the eyebrow, sometimes covering the inner canthus. Its presence is normal in certain of the Mongolian races but a telling deformity in FAS.

The Fetal Alcohol Syndrome is not always looked for nor is every physician and nurse familiar with its telltale manifestations. Hence, these figures are only estimates. The actual figures may be higher than we think.

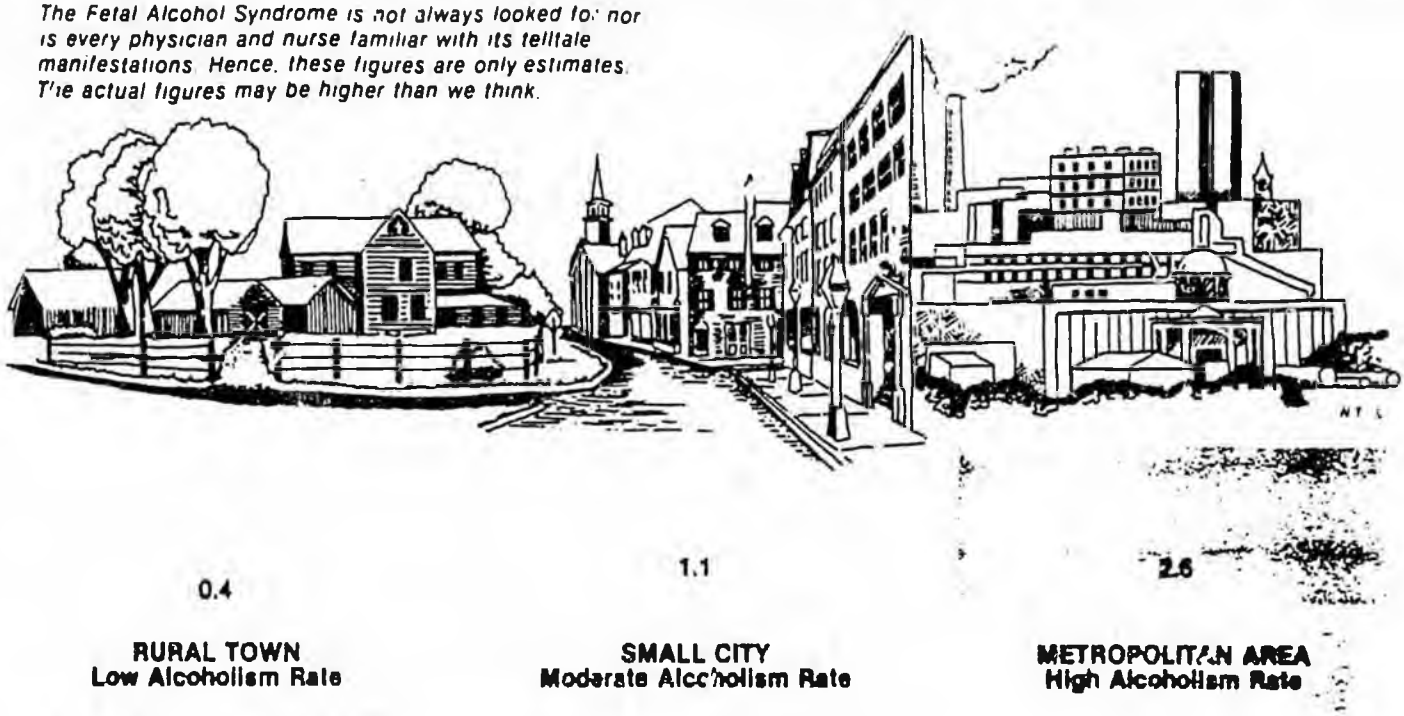


Figure 2. Incidence of the full fetal alcohol syndrome for each 1,000 live births in America

EFFECTS OF FAS

FAS in its most exquisite, full-blown development is revealed in a child by numerous defects in cranio-facial development, in prenatal and postnatal growth, and mental insufficiency. None of these defects correct themselves as the child grows older. Table 1 lists these major features.

This is the type of infant that is frequently born to women who, careful interrogation reveals, admit to having five or more drinks a day (i.e., 60 grams or more of alcohol) throughout pregnancy.

In twins born to alcoholic women some curious inconsistencies have been noticed. For example, three pairs of fraternal twins (those from separate eggs) have been observed in which one twin exhibited all of the physical deformities of the syndrome while the other twin was apparently normal. We do not know whether the second twin showed decreased mental acuity in later life. This suggests that the genetic susceptibility may be important. Otherwise at the present state of our knowledge this inconsistency defies explanation.

The only known affected identical twins, which is to say those from one egg, were equally deformed.

We do not yet know how prevalent the FAS is in America (fig. 2). The main reason is that recognition of the existence of the syndrome is so new that not all physicians have had time to become experienced in recognizing its signs and symptoms. In Seattle, where the syndrome was first defined, and pediatricians have been alert for the longest time, it is estimated that approximately one child is born with FAS in each nine hundred live births. Similar observations in New York City indicate that the incidence is one in each four hundred births. The data suggests that FAS occurs about as frequently as the trisomy 21 Down's Syndrome. Given the fact that it most usually causes mental impairment, the prevalence of FAS may make it the most common birth defect of which we are currently aware. For example, of over eighteen women in Brooklyn, New York, who were identified as having been heavy drinkers during pregnancy, twelve

TABLE 1

Major Features of Fetal Alcohol Syndrome
Observed in 245 Advanced Cases

FEATURE	MANIFESTATION	
	Present in over 90% of patients	Present in over 50% of patients
Brain injury		
Intellectual	Clear mental retardation	
Neurological	Too small head (microcephaly)	Poor coordination, hypotonia
Behavioral	Irritable in infancy	Hyperactive in childhood
Growth impairment		
Prenatal	Significant reduction in weight and height	
Postnatal	Significant reduction in weight and height	Disproportionately decreased fat stores
Facial Characteristics		
Head circumference	Too small	
Eyes	Short palpebral fissure	
Nose	Hypoplastic philtrum	Short upturned
Maxilla		Hypoplastic
Mouth	Thinned upper vermilion	Micrognathia or
	Retrognathia in infancy	prognathia in adolescence

FROM NEJM

·two grams of ethyl alcohol daily
se mothers in whom this intake
neasured reveals just how heavily
drink. In some other studies, the
e syndrome has been noted in
ho have four or five drinks a day
rage at least forty-five drinks a
These data should be no comfort
woman who may have three or
nks in one evening while she is
t and then no more for a day or
cause no data yet exists that in-
a safe level of alcohol consump-
ing pregnancy. It is quite clear
e animal data measuring im-
earning, and in laboratory spe-
have been observed, that injury
ven when lesser amounts of alco-
consumed than those needed to
the anatomical deformities of
and face.

syndrome in its full blown form
ır elements that are easily ob-
ld can be set forth in the accom-
figures and charts. To meet
uirements there must be present
of brain injury traceable to de-
in intellectual and neurological
These are clearly apparent at
and thereafter, but are not per-
n the first year of life. Even at
wever, it is easy to see that the
h FAS is too small, is not long
nor does it weigh enough for an
gestational age.
ircumference of its head is even
an it should be for the reduced
e are impairments that remain
it life. There is no such thing as
child catching up.

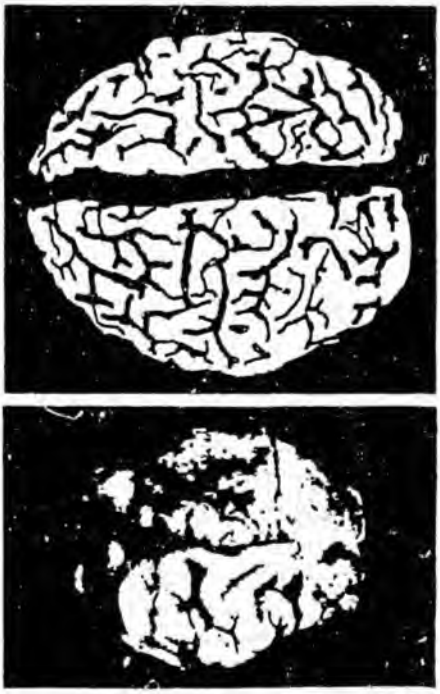
This is a teaching aid article. Price and delivery dates are available on request. For institutions and anti-alcohol programs, bulk prices will be available at a discount. Ordering information will be ready by January 1, for delivery after February 1.

Figure three shows a weight and height graph for the syndrome with data obtained during the first year of life in several of these children. In contrast to most other forms of low birth weight and height there is no postnatal catch-up growth. These infants are repeatedly evaluated for failure to thrive and at all times in subsequent growth they remain more than 2SD below the average, with weight usually being more severely impaired. The impaired adipose tissue deposits results in these children remaining skinny. Most studies of the reasons for the impaired size is a prenatal insult to cell proliferation leading to diminished numbers of fetal cells.

The best known symptoms of FAS are the abnormal features one can observe in the face (table 1). They are best understood by postulating that the brain and the part of the face dependent upon a brain of normal size just did not develop adequately to fill out the face. The eyes are too close together. There is the fold that covers the inner corner of each eye, a phenomenon that is normal in

NT E

PHOTO COURTESY S K CLARREN M D



Compare the size of the brain of a normal newborn infant with that of an infant with FAS who died five days after birth (lower specimen). The affected brain exhibits a gyral pattern obscured by a leptomeningeal neuroglial heterotopia.

How Alcohol Affects the Developing Fetus

Some observations about the normal and abnormal physiology of the pregnant woman who drinks. These reflections make it clear why we should all read the Holy Bible more carefully.

by CORTEZ F. ENLOE, JR., M.D.

When Dr. Iber wrote in the January/February, 1971 issue of *Nutrition Today* that "In Alcoholism, The Liver Sets the Pace," he helped us understand why drinking more than a moderate amount of alcohol causes the beverage to escape the detoxifying system of the liver and reach the developing fetus. The fetal alcohol syndrome or FAS, as it has since come to be known, had not been recognized at the time of Dr. Iber's report. There can be little doubt, however, that as he pointed out, the rate at which the liver can spare the body the damage of alcohol is "a linear function of time." He provided us with the clue to the fact that once alcohol consumption reaches a stage in which the alcohol blood level in the portal circulatory system between the digestive tract and the liver exceeds the capacity of the liver to detoxify it, trouble is sure to occur. The excess alcohol passes on into the general circulation and the person becomes drunk. And drunkenness is a primary cause of crime, of automobile accidents, of fatal crashes by private airplanes, and, now it seems, it may also be a principal cause of mental retardation and birth defects by making the fetus drunk. This then is reason enough to look at the pathologic physiology in the pregnant woman who drinks.

Dr. Enloe is the editor of Nutrition Today *magazine.*

At first blush one could easily be suspected of trivializing a serious matter when they observe that the pregnant woman who craves the psychologic release of a cocktail would do well to eat while she drinks. There is sound medical reasoning behind this advice because by eating as she sips, she slows the absorption of alcohol, or ethyl alcohol, or to be exact, ethanol, to use the contraction, from her stomach into the portal circulatory system. The slower the absorption rate, the better the chance that the liver will be able to break down the alcohol and keep it out of the general circulation.

As Dr. Iber pointed out, the moment one takes a drink, the alcohol that first reaches the stomach is quickly absorbed. However, if one then nibbles a bit of cheese or a mini-frankfurter hors d'oeuvre absorption is slowed. And the greasier the tidbit the better, because the presence of fat slows absorption of alcohol through gastric mucosa. By these willful acts—sipping drinks slowly and eating all the while—the liver, which has only a limited capacity to detoxify and metabolize any agent, is given an opportunity to reduce alcohol from the stomach into innocuous acetaldehyde and acetic acid, and these two substances subsequently break down into carbon dioxide and water. This chain of events is clearly established. It is only part of the routine activity of the liver, a large, busy factory alive with metabolic chemical reactions that break down nutrients and other chemicals absorbed from the stomach and intestine into less complex units so the body can use or dispose of them.

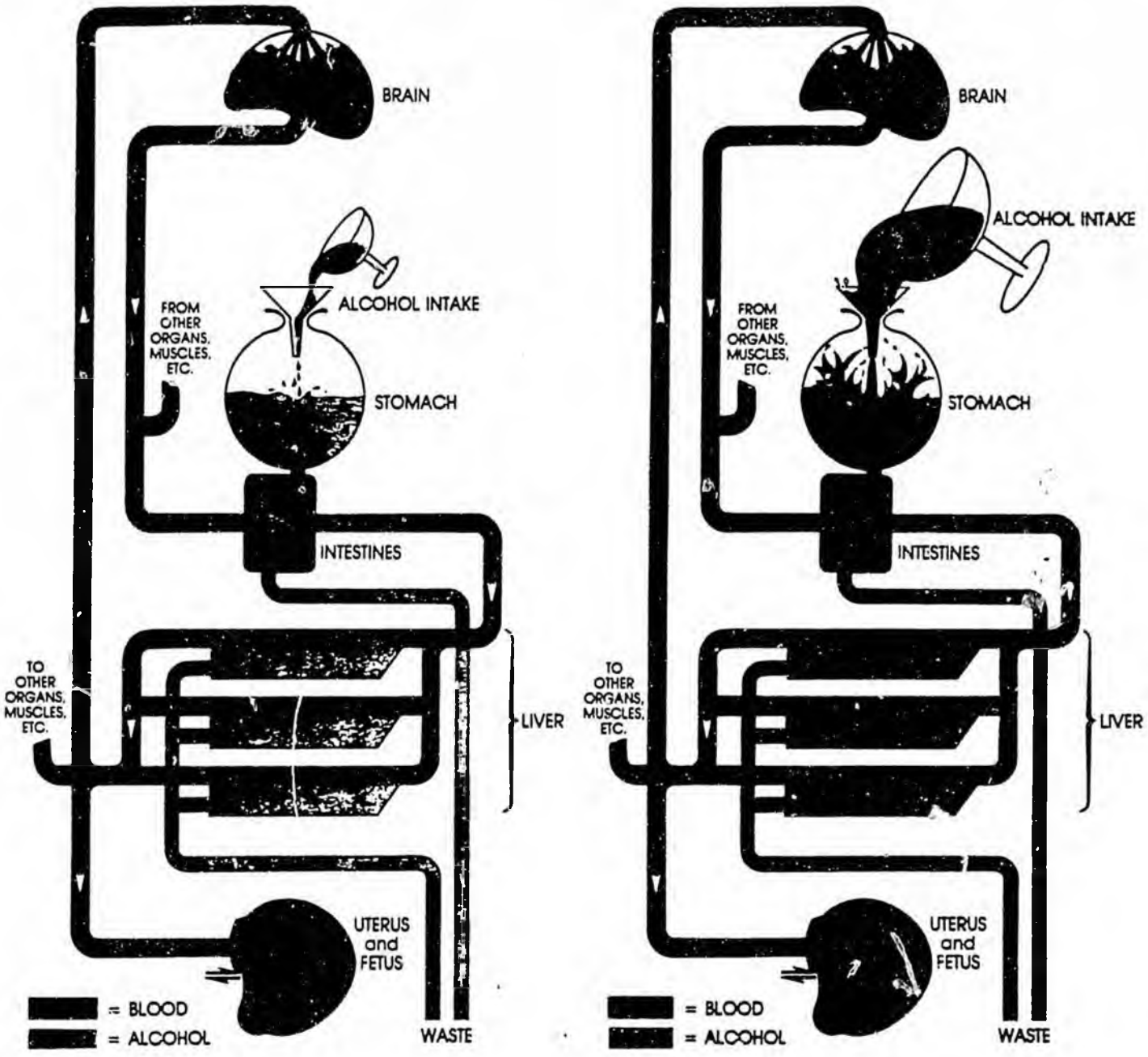
PORTAL PROTECTION

This emphasizes the virtues of the portal system because through its vessels everything that leaves the stomach or the small intestine must first go to the liver before it can pass into the body's general circulatory system. However, as Dr. Iber pointed out, the trouble is that the liver's capacity is limited and inflexible. As he told us, in the case of alcohol, the liver can handle about ten milliliters an hour. Or, to put it another way, it means that it will take the liver of the average person from five to six hours to fully oxidize the alcohol in four ounces of whiskey or two and one half pints of beer. This is why three drinks at lunch puts President Carter's mythical executive off his beat for the afternoon. This can only be avoided if one were to spread their alcohol intake of such drinks evenly over four hours' time, an unlikely event because then they would get little or no kick from drink at all.

The trouble begins when the liver receives more alcohol than it can handle. It simply lets the excess pass into the general circulation and picks out that which it can detoxify at its leisurely pace as it passes back through the liver. Thus it permits the host to enjoy the intoxicating pleasures of alcohol until the organ has time to pick it up and reduce it to carbon dioxide and water. If the amount is such that the transfer of acetaldehyde exceeds

Low rate of alcohol intake. The liver is able to "filter" the mother's blood, removing the alcohol before it can enter her circulatory system and affect her brain and the fetus.

High rate of alcohol intake. The threshold of the liver's ability to treat the continuing high level of alcohol in the blood is surpassed. As the blood enters the mother's circulatory system it continues to carry alcohol with it, suffusing her brain and the fetus with this toxic substance.



Schematic diagrams showing the threshold characteristic of the liver's ability to metabolize alcohol carried in the blood. When the threshold is exceeded—when the liver cannot cope—the alcohol carried through the mother's circulatory system suffuses her brain and the fetus.

female sex hormone over a period of time, then suddenly withdraw it, and it will be observed that the ovaries have ceased to produce their normal amounts of estrogen.

This habit of a cell to lose its basic function when that function is distorted or replaced by external factors, is one of the dangers of giving excessive amounts of cortisone to the person who still has a functioning adrenal cortex that manufactures the same hormone.

It is reasonable, therefore, to suspect when the cells of the developing fetal reticulum are bathed with desiccating alcohol they soon adapt to that state wherein the abnormal becomes to them the normal. This might be called the phenomenon of the wisdom of the cell.

The fact that the brain in both the adult and the developing baby has a rich supply of blood means that a majority of the alcohol-laden blood soon reaches the most easily damaged area. In the case of the fetus, we have known for some time that the alcohol in the blood of the mother easily crosses the barrier from the decidua (the temporary lining that forms in the mother's uterus to hold the placenta of the baby in place) into the placenta and thus heads for the organ that has the highest coefficient of affinity for alcohol of any organ in the body.

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Statewide FAS Coordinator

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ALASKA NATIVE HEALTH BOARD
Alaska Fetal Alcohol Syndrome (FAS)
Fact Sheet

* In 1985, all Alaskans consumed 4.35 gallons of absolute alcohol per capita.

* Alaska appears to have one of the highest recorded rates of FAS.

* The rate of FAS in Alaskan Natives is conservatively estimated at 4.2/1000 live births.

  How does this compare?

  France FAS rate - 1.6/1000 live births
  Seattle FAS rate - 1.7/1000 live births
  Navajo FAS rate - 2.0/1000 live births

* The rate of FAS in the Alaskan non-Native population is not yet known, but it is expected to also be high.

* A conservative estimate of new cases of FAS in Alaska is 10 per year.

* In the lower 48 it is estimated that for every child born with FAS, 10 are born with Fetal Alcohol Effects (FAE). FAE describes less severe damage due to alcohol. The extent of FAE in Alaska is not yet known.

* In Alaska, the dollar cost to care for one FAS child for his/her lifetime can be up to one million dollars or more.

* In Alaska, FAS may be the number one identifiable cause of mental retardation.

Alaska Native Health Board

Fetal Alcohol Syndrome - Cost Estimates
in Alaska

1.	Neonatal Intensive Care	$1,300-$2,000 per day x 7 days = $9,100-$14,000
2.	Heart Defects surgical procedures	99% are done outside $20,000 and up for uncomplicated/non-emergency $50,000 for and up complicated/emergency
3.	Cleft Palate Surgery	Usually 4 surgeries, plus dental work and orthodontics = $50,000 - $75,000
4.	Speech Therapy	Initial Diagnostic $200 2-3 sessions per wk. at $90-$135 per wk. x 1 yr.= $9,360 - $21,060
5.	Kidney Defects surgical procedures	Approximately $1,500 per procedure
6.	Vision Defects	Surgery for strabismis or ptosis average $1,600 Exams and glasses $300 and up
7.	Special Education	1 child for 1 year average - $9,000 Preschool - $15,000 Multi-handicapped - $22,000 Deaf/Vision Impaired - $24,000
8.	Foster Care	$14 - $30 per day, yearly cost $5,110 - $10,950
9.	Residential Care	$100 - $150 per day, average stay 12 - 18 months= $36,500 - $82,125
10.	Day Treatment	$55 per day, average length 6 - 8 months= $9,900 - $13,200 (30-day month)
11.	Institutionalization	$230 - $280 per day $83,950 - $102,200 per year
12.	Travel Costs	Would vary, but if travel necessary, additional thousands of dollars would be added to cost of treatment/care.

1/86

Costs will be updated as costs have increased since 1-86.

ALASKA NATIVE HEALTH BOARD

FETAL ALCOHOL SYNDROME (FAS) FACT SHEET

* Fetal Alcohol Sydrome (FAS) is a birth defect caused by the mother drinking during her pregnancy.

* FAS is probably the second most common birth defect.

* FAS may be the number one cause of mental retardation in the nation.

* Doctors Kenneth Jones and David W. Smith first identified and described the Fetal Alcohol Syndrome in Seattle, Washington in 1973.

* The complete syndrome is termed Fetal Alcohol Syndrome (FAS) with milder forms of prenatal alcohol damage termed Fetal Alcohol Effects.

* Criteria for FAS
  1. Prenatal or postnatal growth retardation in height, weight, and/or head circumference.
  2. Altered morphogenesis (abnormalities) especially of the face.
  3. Central nervous system involvement, often with mental retardation.

  AND

  4. There must be a positive history of the mother drinking during the pregnancy.

* Facial abnormalities that are characteristics of FAS include:

  - small head circumference
  - small widely spaced eye openings
  - indistinct or no groove between the nose and upper lip
  - short nose
  - thin upper lip
  - flat midface

* FAS children are smaller than normal children in height, weight, and head circumference, usually below the third percentile, and they NEVER "catch up." They remain shorter. They remain thinner even with adequate nutrition. The head is smaller because when the alcohol affected the brain's development, it stopped growing. And when the brain stopped growing, so did the skull. The head remains smaller.

* The most devastating aspect of alcohol damage to the central nervous system is mental retardation. Alcohol "scrambles" the normal development of the brain so the children with FAS can be mildly to severely mentally retarded. The average I.Q. of 100 being normal. The range of I.Q. scores of FAS children is very broad with recorded scores of 15 to 105.

* Other problems seen with central nervous system damage due to alcohol include:

  - irritability in infancy

babies born to moderate (2 drinks per day) drinking mothers have FAS.

* Once a woman has an FAS child, and if she continues to drink, her future children will have FAS with increasing severity.

* Nursing mothers who drink are also passing alcohol to their infants. Alcohol level in the milk is about the same as her blood alcohol level. Heavy drinking while breast feeding may have deleterious effects including growth retardation (particularly of the brain) and decreased viability.

* Total Cost to Society of Fetal Alcohol Effects

  - lost productivity and potential
  - special care facilities
  - health care costs
  - special education needs
  - physical, intellectual and behavorial impairments
  - emotional burden on family and child

* Preventing FAS is EVERYONES' responsibility.

* Create an awareness about alcohol use and pregnancy with everyone you talk with.

* Support pregnant women in not drinking.

* Encourage the father to be supportive and make him aware of his responsibility in preventing FAS.

* Tell women who are planning to become pregnant to stop drinking alcohol at least one month before they expect to get pregnant. Maybe the rule should be, "No birth control, no alcohol."

* Offer alcohol-free drinks like alcohol-free beer and alcohol-free sparkling wine. Don't forget there are other fruit and vegetable juices that can be used in making tasty drinks.

* We all pay in one way or another for every FAS child born.

MEDICAL EVALUATION AND THERAPY OF FAS AND FAE CHILDREN

Among FAS and FAE children, there is considerable variation in the degree and types of anomalies present. Many of the anomalies are associated with functional deficits which may require immediate and long term medical attention. When FAS or FAE children are diagnosed they should be evaluated for these deficits and appropriate medical and rehabilitation services provided. Some of the anomalies, common in FAS and FAE children which will require further medical and or developmental evaluation and treatment are outlined below. This list is not intended to be a complete list of anomalies present in FAS or FAE children but should provide the health care provider with a direction in evaluating the medical and social needs of these children.

Area of Anomalies:	Evaluate for:	May Require:
- Growth	- Failure to thrive - Weak sucking ability - Other feeding dysfunction	- gastronomic or nasogastric feeding in infancy
- Head and Face		
Eyes	- Ptosis - Strabismus - Epicanthic folds - Micropthalmic - Nystagmus - Myopia - Estropia - Abnormal retinal vasculature	- thorough opthalmologic evaluation, glasses
Nose	- persistent rhinorrhea associated with a small nose and small nasal canals	
Ears	- recurrent otitis media - auditory deficiencies	- hearing aids, thorough hearing evaluation
Mouth	- cleft palate - cleft lip - poorly formed teeth - small trachea (may cause difficult intubation)	- surgery, orthodontic treatment, speech therapy
- Body Organs		
Heart	- cardiac defects (detected in 70% of diagnosed FAS cases): - septal defects - teratology of fallot - pulmonary valve stenosis - patent ductus arteriosus	- surgery
Kidney and Urogenital Tract	- hydronephrosis (dilation of the kidney, usually due to obstruction of urine flow) - hypoplasia (small kidney) - renal agenesis (absence of one or both kidneys) - obstruction of the Uthero-pelvic conjunction	- surgery, management of urinary tract infections

Medical Evaluation and Therapy of FAS and FAE Children (continued)

Area of Anomalies:	Evaluate for:	May Require:
Liver	- prolonged hyperbilirubinemia - abnormal liver functioning	
Genitals	- undescended testicles - hypospadias (abnormal urethral openings) - delay of menarche in girls	
- Skeletal		
Limb and Joints	- limited range of motion of hip, knees, elbows, and other joints - Clubfoot - radioulnar synostosis (fusion of elbow and forearm bones) - Klippel-feil anomaly - scoliosis - reduced skeletal age - shortened fingers - congenital hip dislocation - flexion contracture of the elbow - limited flexion of metacarpal phalangeal joints	- thorough orthopedic evaluation, physical therapy, surgery, occupational therapy
- CNS		
Brain	- mental retardation - learning disorders - microcephaly - seizure activity - cerebral palsy	- IQ testing; educational diagnostic workup; management of behavior disorders, hyperactivity, seizures, etc.; special education; foster placement; complete developmental assessment.
- Other Behavioral Deficits	- delays in gross motor development - poor motor coordination - hyperactivity - poor eye-hand coordination - short attention span - variable social quotient - learning disabilities - school failures and conduct disorders - sleep disturbances - psychopathology	
- Other CNS Disorders	- neural tube defects	
- Other Health Problems	- recurrent infections - immune deficiencies	- special monitoring for high risk recurrent health problem
- Home Environment	- alcohol abuse - child neglect or abuse - proper nutrition - stimulating environment	- foster placement, pre-school attendance, public aid, family counseling/therapy

A Natural History of the Fetal Alcohol Syndrome

A 10-Year Followup of 11 Patients

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In 1973, 11 children with a similar pattern of altered body development and central nervous system function, all born to chronic alcoholic women who continued to drink heavily during pregnancy, were described in *Lancet* (Jones et al. 1973; Jones and Smith 1973). Subsequently, children with the fetal alcohol syndrome (FAS) have been identified in every racial group (Clarren and Smith 1978) and in many countries (Dehaene et al. 1977; Majewski et al. 1976; Degard et al. 1979). The teratogenicity of alcohol (the ability to induce malformations) has been confirmed in laboratory studies involving many different species of animals (Abel et al. 1983). However, the long-term outcome and the natural history of children diagnosed as having FAS have not been documented. We recently completed a followup evaluation of the initial 11 children diagnosed as having fetal alcohol syndrome. The purpose of this report is to set forth their present status in terms of mental development, academic performance, and physical condition; to follow their abnormally formed characteristics and their growth status across time; and to document their medical histories over the past 10 years.

The children in the present study (listed in Table 1) include the following: numbers 1 through 8 are presented in the same order as the 8 children described by Jones and colleagues (1973), and numbers 9 through 11 are the 3 children described by Jones and Smith (1973). The medical histories of these children are summarized in Table 2 and their growth curves intelligence quotient (IQ) scores are present in Figure 1.

Patient 1 drowned in the bathtub at age 3.5. She had been adopted when she was 15 months old and was reportedly easy to manage, seldom cried, and was neither fearful nor hyperactive. She had a heart murmur which was no longer audible at 15 months. In addition to a congenital hip dislocation, which was treated surgically and casted for one year, she was treated repeatedly for ear infections and had extensive physical therapy.

Patient 2 is a short, thin, prepubescent 10.5-year-old Native American girl who has lived in a stable adoptive home since she was 3 years old. She is in the fifth grade, attends regular clases at school that are supplemented with remedial reading. Achievement testing reveals grade level performance. She is self-sufficient, independent in urban life, and responsible for household chores and shopping. She reportedly has age-appropriate social interactions.

The features of the child's face and head have not changed significantly over the last 10 years. Her palpebral fissures (the length of the eyeslit) remain short (right 2.5 cm., left 2.4 cm.), while her inner canthal distance (the distance measured between the tear ducts of the eyes) is normal at 3.0 cm. Her nose is not disproportionately short, but the frontonasal region (the region of the forehead and nose) is abnormal in that there is deficiency in width and definition of the ala nasae (the "wings" of the nose) and a "teardrop"-shaped philtrum (the groove running between the nose and upper lip). Her midface is flat while her jaw appears clinically of normal size. This disproportion has led to a mild class III malocclusion (an underbite). Her external ears retain their mild irregular shape. The patient continues to have a low-grade heart murmur and has been diagnosed as having an atrial septal (heart) defect. The rest of her exam is normal except for a specific abnormal crease pattern of the palms of her hands which has been described as frequent in fetal alcohol syndrome (Jones et al. 1973; Tillner and Majewski 1978).

The patient had been in good health, although she has had chronic serous otitis media (middle ear congestion). Despite conscientious followup and treatment, she has a fixed 80-decibel conductive hearing loss in the left ear. She is currently undergoing standard orthodontic treatment for malocclusion with selected dental extractions and bracing.

Patient 3 is a short, stocky, sexually mature 14-year-old Native American girl who lives with her natural mother and several brothers and sisters. She is in the seventh grade at school but receiving failing grades and not attending school regularly. Although cooperative and engaging on earlier examinations, as an adolescent this patient is suspicious, guarded, and sullen. She is also a social isolate at school. Family ties remain very strong, but the family itself is socially isolated and very poor but steadfastly refusing help. This patient refused to be seen for an adolescent medical and psychological examination although growth data were available.

Patient 4 is a short, overweight, sexually mature 14-year-old black girl (Figure 2). She has lived in a stable adoptive home since she was 4-5 years old. She has always attended special classes for the re-

Table 1. Demographic and Growth Data: Original 11 FAS Children

Patient No.	Race	Sex	Alive in 1983		Birth Data					Follow-Up Data			
			Child	Mom	Gest. Age	Length	Weight	HC	Breech	Age	Height	Weight	HC
1	Am Ind	F	–	?	40	45.0	1850	32.0	+		deceased		
2	Am Ind	F	+	+	40	44.5	2500	31	–	10.7	130.0	26.36	50
3	Am Ind	F	+	+	38	47.0	2500	31	–	14.7	143.5	45.00	not taken
4	Black	F	+	–	36	42	1600	29	–	14.2	143.7	46.93	50
5	Black	M	?	?	38	43	1673	–	–		lost to follow-up		
6	Black	M	–	+	34	38	1550	30.5	–	13.9	145.1	31.14	50.6
7	White	F	+	+	44	45.7	2345	32	+	14.4	142.5	35.57	48.5
8	White	M	+	+	37	43.2	2250	35	–	13.2	145.2	32.39	53
9	Am Ind	M	–	–	38	43	2020	29	+	10.1	119.3	19.5	47.8
10	Am Ind	F	–	?	32	38.5	1300	27	–		deceased		
11	Am Ind	F	–	–	7 mos		964	–	+	14.0	129.5	25.85	47

tarded and reads and spells at a second- to third-grade level. She is a happy, outgoing, talkative child with no apparent stranger anxiety and no inhibitions. Because of her poor judgment, she is never left alone. Although she is no longer hyperactive, she continues to have a short attention span.

The patient's facial features are similar to those described in early childhood. The palpebral fissures are short (2.2 cm. bilaterally). She has numerous eye problems including ptosis (drooping eyelids), strabismus (crossed-eyes), severe myopia (nearsightedness), and defects in the optic nerves. She has a moderate malocculusion secondary to flat midface and prominent lower jaw. She continues to have palatine ridges. Her external ears are prominent and irregularly shaped. She also has numerous minor skeletal anomalies including radio-ulnar synostosis (fusion of the bones at the elbow), brachydactyly (abnormal shortness of the fingers and toes), camptodactyly (mild contractures of the fourth and fifth digits of both hands), clinodactyly (deflection) of the third and fourth digits of the left hand, and bilateral syndactyly (webbing) of the second and third toes). A cardiac murmur (compatible with a patent ductus arteriosus) was audible until 5 years of age. Since infancy, she has been in reasonable health although she has needed careful opthalmologic followup. Orthodontia with possible oral surgery is indicated but has not yet been undertaken.

Patient 5 was a 17-month-old black male who has been lost to followup for 10 years.

Patient 6 is a short, thin, 13.5-year-old black male who has lived with his natural parents and siblings his entire life. He is in the eighth grade and attends regular classes with remedial help in mathematics and English. He is quiet, well behaved, appropriate, cooperative, and no longer hyperactive.

The patient has most of the facial features of the fetal alcohol syndrome except for a normal midface which tends to make his face less typical of the syndrome. His palpebral fissures are short (2.1 cm. bilaterally) while his inner canthal distance is normal (3.3 cm.). He has the typical frontonasal features including epicanthal folds vertical folds of skin covering the inner corners of the eyes), short nasal tip, and a smooth philtrum. Although he has no malocclusion, he has a wide mouth with irregularly shaped and poorly aligned anterior teeth with an open bite. His external ears are prominent and oddly shaped. He has mild skeletal defects including radio-ulnar Synostosis (fusion) of the bones at the elbow and camptodactyly (mild contractures of the digits), and small toenails. He has been in reasonably good health although he is followed by an opthalmologist for strabismus (crossed eyes) and has allergies. He is currently in orthodontic treatment.

Patient 7 is a 14.5-year-old, short, microcephalic (a condition characterized by an abnormally small head), sexually mature white female who is quiet and compliant. She has lived in a stable adoptive family since she was 6. She has attended special classes for the retarded all her life, and her academic skills are at the first-to second-grade level. Because of her poor judgment and lack of inhibition with strangers, she is never permitted to go out alone in the neighborhood.

With the exception of normal palpebral fissure size (2.6 cm. bilaterally), she has most of the facial features of the fetal alcohol syndrome. Her inner canthal distance is 2.7 cm. She has mild epicanthal folds, a smooth philtrum, and a thin upper lip. Her midface is flat and she has a protruding jaw and a moderate dental malocclusion. She has had major skeletal problems, including bilateral congenital hip dislocations and scoliosis (curvature of the spine). In addition, she has small nails on her hands and feet. Multiple hemangiomas (birthmarks) present in infancy have resolved. A systolic murmur heard in infancy also resolved prior to a full diagnostic evaluation. She has had chronic serous otitis media (middle ear congestion) and still has a mild conductive hearing loss in spite of conscientious care.

Patient 8 is a short, thin, 13-year-old while male who lives alone with his natural father (Figure 3). Although school is becoming increasingly difficult, he attends regular classes with supplemental tutoring. Although his hyperactivity has gradually diminished, he continues to

Table 2. Frequent Medical problems: Original 11 FAS Children

Intraoral	8/6
Class III malocclusion 5/7; poor dental alignment 3/8; cleft plate 2/11	
Ears	5/9
Chronic otitis media 5/9; permanent hearing loss 3/8	
Eyes	4/8
Optic nerve hypoplasia 2/8; ptosis 2/8; strabismus 4/9; severe myopia 2/8	
Cardiac	8/11
Cardiac murmur interpreted as VSD 6/11; ASD 1/11; PDA 1/11	
Skeletal	9/11
Congenital dislocated hip 3/9; progressive thoracic scoliosis 1/8; radio-ulnar synostosis 3/9; flexion contractures 1/9; bilateral halluces valgus 2/9; minor hand anomalies 6/9	
Other	
Breech 5/11; weak suck 10/11; prolonged hospitalization after delivery 8/9; failure to thrive 6/9	
Behavioral	
Past hyperactivity 5/9; present hyperactivity 1/8; attention deficit 7/8	
Environmental	
Neglect 5/9; physical abuse 2/8; suspected sexual abuse 1/8	

Note: The denominator 8 represents the 8 long-term followup patients (Nos. 2, 3, 4, 6, 7, 8, 9, and 11)

The denominator 9 also includes Patient No. 1 who was followed until her death at age 3½ years

The denominator 11 is applicable for birth and neonatal data available on all patients

The denominator 7 indicates that Patient No. 3 was not examined for malocclusion

have an attentional deficit. He is currently repeating seventh grade because of refusal to attend school for 3 months. Present academic functioning is 1 to 4 years below present grade level. He is friendly, uninhibited, and self-sufficient but a loner, and he manifests poor judgment.

His facial features remain typical of the fetal alcohol syndrome. His palpebral fissures are very short (1.9 cm. on the right, 2.0 cm. on the left), while his inner canthal distance is 3.7 cm. He has a unilateral strabismus and the usual midline finding of epicanthal folds, short nasal tip, a smooth philtrum, and a thin upper lip. He has a mild malocclusion. Mild skeletal abnormalities include altered palmar creases, camptodactyly, and halluces valgus (mild anomalies of fingers and toes). Since 1 year of age, he has been healthy, although he was hospitalized for a hernia repair and surgical correction of undescended testis at the ages of 3.5 months and 6 months.

Patient 9 is a 10.5-year-old Native American male who is extremely thin and short (Figure 4). Hyperactive to the point of destructiveness, he is also outgoing and friendly to the point of intrusiveness. He has always attended classes for the trainable mentally retarded. He cannot read or write. He has lived in a single foster home where he has received excellent care. Seizures, triggered by both high-pitched noises and hyperventilation and followed by lethargy, were first noted at 8 months. They decreased in frequency and finally stopped by 4 years. A systolic murmur thought to be secondary to a ventricular septal (heart) defect also resolved by 4 years. He has had frequent viral illnesses and diarrhea as well as persistent otitis media (though his hearing is now considered normal). Dental restorative care and extractions preparatory to orthodontia have been performed. He has worn glasses since 3 years of age, is intolerant of light, and is virtually blind in the right eye.

The patient has retained the typical facial features of the fetal alcohol syndrome. He is near-sighted, has astigmatism, and has optic nerve atrophy. He has poor dental alignment, but no malocclusion. There are mild skeletal defects including radio-ulnar synostoses, camptodactyly, and small toenails. Thirteen ribs are present bilaterally (though normally there are 12 on each side).

Patient 10 died when he was 5 days old, after multiple apneic (breathing cessation) episodes. Detailed reports of the malformations and the medical condition of this infant have appeared previously (Clarren et al. 1978; Jones and Smith 1975).

Patient 11 is a very short, sexually mature 14-year-old Native American girl who has lived in a stable foster home since she was 8 years old. She is mentally retarded and does not speak spontaneously. She is highly distractable but not hyperactive. She is totally trusting and indiscriminate in relating to strangers. She is obedient and compliant but her judgment is too poor to permit her to remain alone.

Physical examination revealed a severely growth-deficient child in good general health. Midline features include marked epicanthal folds, a short nasal tip, a smooth philtrum, and a thin upper lip. Her midface is flat and she has a relative degree of jutting of the jawline with a resulting malocclusion. Her ears are prominent and poorly formed. She has multiple mild skeletal defects and small birthmarks. A systolic heart murmur, compatible with a ventricular septal defect, resolved spontaneously by the age of 10. Her cleft plate was closed at age 3 with a single operation and she is currently undergoing orthodontic treatment.

Discussion

Followup evaluation 10 years after initial diagnosis of the original 11 children with the fetal alcohol syndrome documents the long-term effects of prenatal exposure to alcohol. Although the degree to which these children are representative of all children with fetal alcohol syndrome is not known, certain generalizations regarding the natural history of the disorder have become evident. These may be helpful in planning for the future of affected individuals.

Growth

As depicted in Figure 1, all children remained growth-deficient over time with respect to height, weight, and head circumference. Although most children initially showed some catching up in linear growth during the first 1.5 years of life, there was a relative decrease in weight and head circumference for most of the children. The failure of the head to continue growing at a normal rate after delivery may explain why some infants who are undiagnosed at birth are later diagnosed at 9 to 12 months of age.

The statistic that gives the best single description of the particular appearance of these children and adolescents with fetal alcohol syndrome is the weight-for-height age depicted in Table 3. Initially, the children were all strikingly underweight for their height, with a weight-for-height age averaging between the 5th and 10th percentile during the preschool years. However, with the onset of puberty, the females developed a relatively more normal weight-for-height age relationship.

Neither of the boys who were between 13 and 14 years of age had reached puberty, and both continued to be underweight for height. The characteristically emaciated appearance of the young child with fetal alcohol syndrome may not be a salient feature in the affected adolescent, at least for females.

Pattern of Malformation

After 10 years, the 8 affected children for whom followup data are available, including 3 who have undergone pubertal

Figure 1. Growth and IQ across time in original FAS children. Height (a), weight (b), and head circumference (c) are reported in standard deviations from the mean. Girls are represented with dashed lines, boys with solid lines. Measurements from five ages were reported when available: birth and the last measurements and the measurements closest to the following ages: 1-1/2 to 2 years; 3-1/2 to 4-1/2 years, and 9 to 10 years. All available IQ scores (d) are reported from individual age-appropriate tests of general intelligence and mental development, including the Wechsler Intelligence Scale for Children Revised, the Wechsler Preschool and Primary Test of Intelligence, the Stanford-Binet Intelligence Scale Form L-M, and the Bayley Scales of Mental Development. Note that the original Stanford-Binet Scores (1) were re-calculated because norms applicable to 1973 were published after the 1973 *Lancet* paper was published. The first "IQ" point for Patient 11 is circled because it was estimated from the Vineland Social Maturity Scale and clinical observation.

Figure 1a. Height in Standard Deviations From the Mean: Original FAS Children

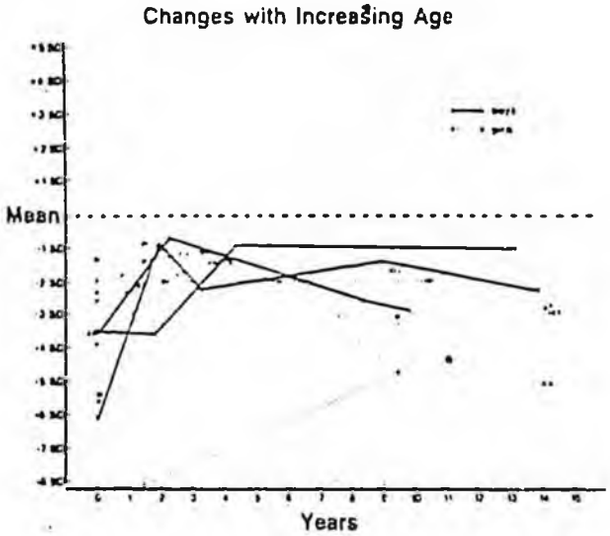


Figure 1b. Weight in Standard Deviations From the Mean: Original FAS Children

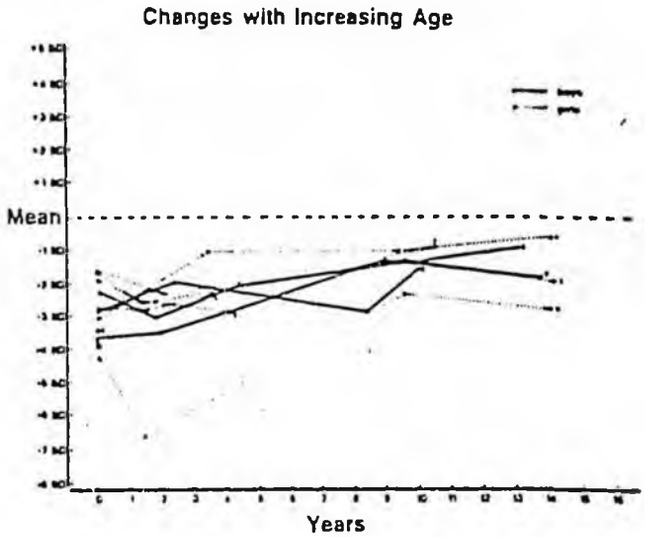


Figure 1c: Head Circumference in Standard Deviations From the Mean: Original FAS Children

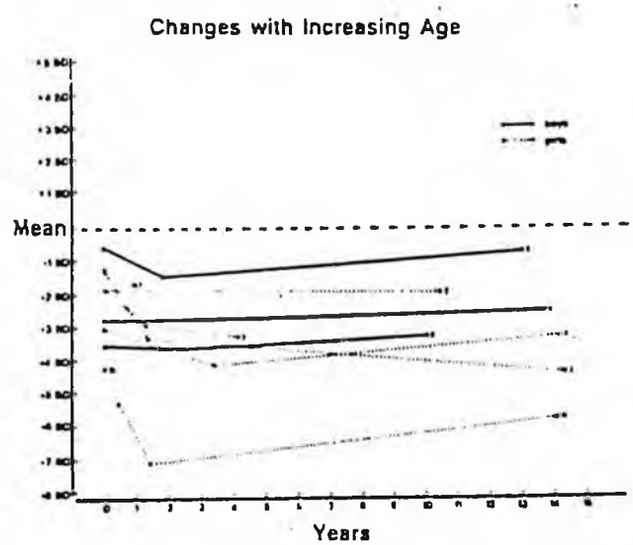
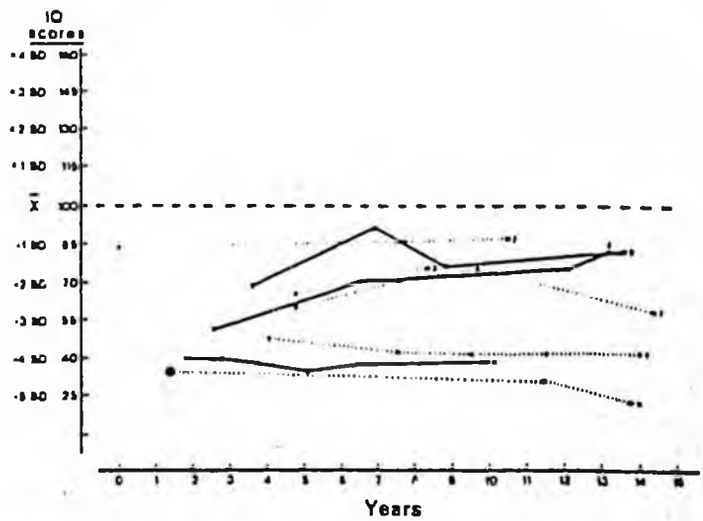


Figure 1d. Successive IQ Scores of Original FAS Children



Courtesy of Streissguth et al.

Courtesy of Streissguth et al.

Figure 2. Patient 4 at ages (a) 3 years, 9 months; and (b,c) 14 years, 2 months.

Figure 2a

Figure 2b

Figure 2c

Note the persistence across ages of the short palpebral fissures, hypoplastic philtrum, strabismus, and ptosis; the increased growth of the nose and mandible; and the short, stocky stature often associated with puberty in girls with FAS.

Figure 3. Patient 8 at ages (a) 2 years, 6 months; and (b,c) at 12 years, 2 months.

Figure 3a

Figure 3b

Figure 3c

Note the short palpebral fissures, epicanthal folds, flat midface, hypoplastic philtrum, and thin upper vermillion border. Note also the short, lean-pre-pubertal stature characteristic of young adolescent boys with FAS.

Figure 4. Patient 9 photographed at (a) birth, (b) 5 years, and (c) 8 years.

Figure 4a

Figure 4b

Figure 4c

Note the short palpebral fissures, epicanthal folds, short upturned nose, long and hypoplastic philtrum, thin upper lip vermillion, flat midface, hirsutism, and characteristic emaciated appearance of the pre-pubescent FAS child with minimal subcutaneous fat. (Photograph c from Streissguth et al, 1984, CIBA Foundation Monograph #105, Pitman Press, London.)

Table 3. Weight for Height Age at Three Different Ages: Original FAS Children

Patient No.	Preschool 1.5-5 years	Pre-pubertal 9-10	Pre-pubertal 13-14 yrs.	Puberty 13-14 years
Girls				
11	7.5%	5%	—	62%*
4	15 %	37%	—	85%*
7	8 %	50%	—	50%*
3	5 %	15%	—	82%*
2	15 %	38%	—	—
Boys				
9	3.5%	17%	—	—
8	3.5%	10%	20%	—
6	<1 %	10%	17%	—

Note: Height age of each child was determined by noting the chronological age on the growth charts at which the child's actual height fell at the 50th percentile (growth charts from National Center for Health Statistics, NIH).

Weight for height age is the percentile at which the child's actual weight fell when plotted against the child's height age.

In this Table, girls and boys have been rank-ordered separately by severity of dysmorphology.

*Menarche

changes, continue to have craniofacial features similar to those previously set forth as typical of the fetal alcohol syndrome. In particular, the short palpebral fissures, smooth philtrum, and flat midface remain constant. However, the patients' noses have taken on a new contour with prominent growth of the nasal bridge and jaw. The short eye openings in the fetal alcohol syndrome were initially interpreted as being secondary to decreased growth of the eyes. Optic nerve defects as well as other anomalies affecting the eyes of five other children at this most recent followup, tend to support this interpretation and are consistent with the work of Stromland (1981). Although the patients continue to resemble each other, the changes in nose and jaw alter the overall facial appearance substantially and may explain the general failure to recognize fetal alcohol syndrome in adolescents and adults.

Heart anomalies conisting of (1) an atrial septal defect in one patient, (2) patent ductus arteriosus in one patient, and (3) systolic murmur interpreted as representing a ventricular spetal defect in six patients have all resolved spontane-

y or are considered insignificant. Congenital hip dislocation has been managed successfully, with casting or splinting (two patients) while a third required hip surgery. With the exception of one patient with severe scoliosis requiring surgery, none of the other skeletal or joint anomalies has required surgery. With one exception, they have not interfered with performance.

Disharmonic growth of the midface and lower jaw has led to relative jutting of the jaws with malocclusion in five children, while dental malalignment was seen in all patients. Chronic ear problems required medical and surgical procedures in four children, three of whom have suffered permanent conductive hearing loss.

Since infancy, the children have all been in relatively good health. Although immunologic deficiency in children with fetal alcohol syndrome has been reported (Johnson et al. 1981), no obvious increase in the frequency of chronic or recurrent infections has been observed in these children. However, the present children were not evaluated from an immunologic standpoint.

Table 4. Severity of Diagnosis Related to IQ and Performance: Original FAS Children

Patient No.	FAS Diagnosis 1976	FAS Diagnosis 1983	Age 1983	IQ 1973	IQ 1983	Type of Instruction
11	Severe	Severe	14	30	20	Trainable mentally retarded
9	Severe	Severe	10	43	40	Trainable mentally retarded
4	Severe	Severe	14	47	46	Trainable mentally retarded
7	Severe	Mod/sev	14	60	57	Self-contained Special Ed Class
8	Mod/sev	Mod/sev	13	50	80	Regular Class + Special Ed
3	Moderate		(8)	66	(76)	Regular Class + Special Ed
6	Moderate	Moderate	13	68	81	Regular Class + Special Ed
2		Mod/sev	10	83	86	Regular Class + Special Ed
			$\bar{X}$ =	56	61	

Note: The patients were scored according to severity of diagnosis by Dr. David W. Smith in 1976 based on severity of dysmorphic characteristics and growth deficiency but without knowledge of IQ scores (16). Patients Nos. 2 and 11 were not included in the 1976 follow-up. Patient No. 3 was last seen at age 14 but the last available IQ exam was from age 8.

Patient 2, who had a hearing loss, was also given the Leiter International Intelligence Scale; a comparable IQ score of 86 was obtained.

The "1973" IQ scores for patients 9 and 11 were actually obtained in 1977 and 1975 respectively.

Four children (numbers 3, 4, 6 and 7) were given the Stanford-Binet form L-M IQ scale in 1973 before the 1972 norms were published. In Jones et al. 1973, their IQ scores were calculated with the old form, but in the above table their 1973 IQ scores have been recalculated using the more appropriate 1972 norm published in 1973. Later norms have the effect of decreasing an individual's IQ by approximately 10 points.

Performance

None of the eight children had normal intellectual development on followup (Table 4 and Figure 1d); four appeared to be mildly handicapped and four were seriously handicapped. The four mildly handicapped children had IQ scores in the borderline to dull-normal range, had gone through school with a combination of regular and remedial classes, and had academic achievement that was at least in line with their intellectual functioning. Two of these four had repeated one grade and were functioning at or below grade level. The remaining two were functioning several grade levels below their placement and were having increasing difficulty with school as they got older. All four of these mildly handicapped children lead relatively normal lives within their own social milieu, appearing to be independent, resourceful, and self-sufficient. Nevertheless, the discrepancy between their self-sufficient manner and their borderline to dull-normal intellectual skills may place them at risk for later social and academic problems. Further followup seems warranted. Two of these four children (both of whom remained with their natural families) already have social/emotional and school attendance problems.

The remaining four children were seriously handicapped, functioning intellectually in the mildly-to-moderately retarded range. They have never attended regular classes and are progressing through classes for the mentally retarded appropriate to their level of performance. Two of these children can read and write at a primary level, while the remaining two can barely write their own names. Although these latter children were all hyperactive when younger, those who are now adolescents are no longer hyperactive. They all continue to have attentional deficits and are all friendly, outgoing, socially engaging, and uninhibited. The youngest boy (Patient 9) is a severe management problem, but the three severely handicapped adolescent girls (Patients 4, 7, and 11) are compliant and obedient. All four of these latter children need constant surveillance and show little ability to differentiate among strangers and friends, being uncritically trusting in social interchange. They all continue to need sheltered environments.

The severity of diagnosis during the preschool years was highly predictive of the children's relative ranking on IQ scores at the last followup (Table 4). Thus, the children who were the most severely affected in terms of early facial features and growth deficiency had the poorest prognosis for later performance. Likewise, the children who were most mildly affected from the standpoint of growth deficiency and structural development and the best prognosis for later intellectual development.

Environment

The degree to which postnatal environmental factors have influenced the development of these children is difficult to assess. The first 2 years of life were not ideal for seven of these children. Six of them lived intermittently with natural mothers who continued to drink, or they were in temporary custody. The seventh was hospitalized. The one child who has remained in the same stable foster home since birth is among the most retarded. The four most severely handicapped children (whose mothers were unable or unwilling to care for them) have all been in conventional stable families who have provided stimulating and loving care for at least the past 5 years. Of the four mildly handicapped children, two remain with their natural mothers, one remains with his natural father, and one has been

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alcohol-related conditions at the time of both initial and followup interviews.

It is anticipated that future morbidity surveys of the United States directly related to collection of alcohol-related data will be able to use this instrument to diagnose clinically defined alcohol abuse and dependence. The demonstration of relative equivalence of method *and* results based on the ECA program's development of a viable standardized methodology for the epidemiologic study of psychiatric disorder has also set the stage for comparative studies of all sorts. To date, the DIS has been translated into 20 languages, and ongoing research using the DIS and ECA program methodology is being conducted on numerous special populations in the United States (e.g., diabetics, disaster victims, alcoholic patients) in addition to general population surveys in over nine countries including the Republic of China, Peru, Japan, Germany, and Canada. □

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A Natural History of the Fetal Alcohol Syndrome: A 10-Year Followup of Initial 11 Patients

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adopted. In this small sample, the differential effects of these diverse environments is not obvious in terms of intellectual development; but the caretaking environment does appear important in terms of social and emotional adjustment during adolescence.

The single most differentiating characteristic in the backgrounds of the four most handicapped children (Patients 4, 7, 9 and 11) is that three of their mothers were so severely alcoholic that they had died of alcohol-related causes within 6 years of the birth of these children (Table 1). Child neglect has been documented at least once during the early years in five of the nine children followed. Two appear to have been the victims of physical abuse (one in a natural home and one in a foster home), and one has been abused (Table 2). For those who remained with their natural mothers, the first years were always tumultuous, with a supportive relative or friend being particularly important as a refuge for the infant when the mother was drinking. Although the risks of child rearing in an alcoholic milieu are well known, these children were often particularly difficult to care for during their early years because of their failure to thrive, feeding difficulties, hyperactivity, and intrusiveness. On the other hand, of the three relinquished at birth by their mothers to state custody, one died in an apparent drowning accident in an adoptive home and another spent the first 1.5 years in a hospital and then had four different foster homes in seven years before finally getting into a stable home environment at 8 years of age.

Conclusions

Followup of these children over a 10-year period has suggested two factors that may well be helpful in predicting the ultimate prognosis for individuals with the fetal alcohol syndrome.

Of greatest predictive significance is the extent and severity of the pattern of malformation. In a previous study that included some of these children (Streissguth et al. 1978), severity of the pattern of malformation and growth deficiency was correlated with degree of intellectual impairment. In this study, the four children with the most striking craniofacial abnormalities (Patients 4, 7, 9 and 11) have the most severe degree of microcephaly (abnormal smallness of the head), the shortest stature, and the most impaired intellectual function. Three of these four infants presented in a breech position at birth, while none of the four moderately affected children did so.

The most predictive factor in the backgrounds of the four most severely handicapped children was the severity of maternal alcoholism. Three of these four mothers had died of alcohol-related causes within 6 years after the birth of the child, suggesting that biological factors associated with the terminal stages of alcoholism may be involved for the most severely handicapped children. Unfortunately, the quality of the later home environment could not overcome the severity of the prenatal insult. Two of the four most severely affected children lived in the most stable foster homes suggesting that the prognosis for children with the most severe fetal alcohol syndrome depends primarily on the extent and severity of the prenatal exposure to alcohol. However, improved social and emotional development was noted in all patients when home environments stabilized. This resulted from decreased maternal drinking, departure of the alcoholic mother, or placement of the child in a stable foster or adoptive home. □

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Training Professionals to Identify and Treat Pregnant Women Who Drink Heavily

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aged to discuss their responses to the counselor and her techniques. By comparing this patient with others, viewers are allowed to express frustration, anger, and concern towards patients. The goal is to recognize that the interviewer's unemotional, nonjudgmental, and supportive statements allow her to maintain communication with the patient.

Conclusion

Pregnancy is a time in a woman's life when changes in physiology and social role cause her to think and behave differently. The sense of responsibility for another life increases the mother's receptivity to assistance in overcoming problem drinking. Women are concerned about multiple health issues and will adopt a lifestyle consistent with total health. Professionals must develop new attitudes towards alcohol abuse by pregnant women. Treatment programs with pregnant women report that 60 to 80 percent of heavy drinkers reduce consumption before the third trimester.

The adverse effects of heavy drinking on fetal development have been demonstrated repeatedly in clinical, epidemiological, and experimental programs (Rosett and Weiner 1984). High blood alcohol concentrations represent a risk at all stages of pregnancy. There is no safe time for intoxication. Reduction of heavy drinking

has benefits for both mother and child. It is important to stop drinking heavily as early in pregnancy as possible; however, it is never too late. Some benefits can accrue whenever alcohol abuse ceases. Incorporation of treatment strategies into routine prenatal care represents an effective, low-cost method of preventing fetal alcohol syndrome and fetal alcohol effects. The Fetal Alcohol Education Program helps to improve the skills of health care professionals who can facilitate effectively the reduction in drinking among pregnant women. □

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An Evaluation of the Pregnancy Health Program

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ism, is unresponsive to treatment, is at risk herself, and is carrying an infant who is at very high risk. This type of patient, seen in all types of alcohol treatment programs, often receives extensive services without a corresponding change in her condition. The women in group 3 are typical of this prototype. All but one had at least four PHP appointments prior to delivery, and total service hours ranged from 4 to 47 without improvement. The vulnerability of the mother as well as the fetus is becoming evident. For example, a high death rate after delivery has been reported among mothers who have had FAS children (Beattie et al. 1983). The case histories of women in group 3 are consistent with a poor, possibly fatal, prognosis.

Only 10 percent of the cases in this study fit this bleak prototype. By the end of PHP contact, most mothers (86 percent) were judged by independent raters to have improved. This result underscores the importance of identifying women who drink too much and providing effective education and treatment for them before their problem becomes chronic.

Pregnancy is a time when most women seem to decrease their drinking easily (Hook 1978; Larsson 1983; Little et al. 1976) and generally respond well to treatment (Larsson 1983; Rosett et al. 1980), at least in the short run. The data from this study support these findings.

Conclusion

We suggest that pregnancy is an ideal time to intervene in heavy drinking. We have outlined a simple method of screening that will identify those patients at the first prenatal visit. We have also presented evidence that if a heavy drinker receives education, and treatment if needed, she is likely to experience a significant decrease in alcohol consumption beyond that normally expected. Finally, we have reported that women who are identified and treated early have healthier babies.

Prevention of fetal alcohol effects requires intervention in maternal alcohol use at all levels of drinking, from regular use to the most severe alcoholic drinking. But prevention efforts must start earlier and continue longer if they are to be maximally effective. True primary prevention requires women to decrease their drinking before conception. And resolution of any alcohol problem should endure after delivery so that decrease in drinking that occurs during pregnancy is the beginning of a long-term recovery that will benefit both mother and child. □

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