

NATIONAL ORGANIZATION
ON
FETAL ALCOHOL SYNDROME

(NOFAS)

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Organization: The White House

FAX Number: 456 7028

From: Patti Munter

Date: 4/27

Number of pages:
(Including cover sheet) 8

COMMENTS:

Stu, I hope this is helpful. Please don't
hesitate to call if you have any other
questions.

The Washington Post

WEDNESDAY, APRIL 20, 1994

Sobering Look At Alcohol and Pregnancy

Doctors Face the Facts On Drinking's Effects

By Barbara Vobejda
Washington Post Staff Writer

The misshapen face of a child with fetal alcohol syndrome stares down from a projector screen at a roomful of medical students. Their lecturer, Thomas Pinckert, opens the course at Georgetown University's School of Medicine with a message as sobering as the image behind him.

"More than spina bifida. More than Down's syndrome. More than anything you're going to learn about. . . . This is a preventable cause," he said. "But look! It is the most common known cause of mental retardation."

For most of these students, Pinckert's lecture last week was the first detailed exposure to the set of devastating birth defects caused by drinking during pregnancy. Georgetown is only the second medical school in the country to offer such a course, which will be held over eight weeks.



Posters give the public a look at the dangers of fetal alcohol syndrome.

But for those who have fought for years to draw attention to fetal alcohol syndrome (FAS), the course is a long-awaited signal that the nation's medical establishment has begun to take the issue seriously. Northwestern University will begin offering the curriculum this fall and 16 other medical schools are asking for help in setting up similar courses.

There are also other reasons for optimism: Federal funding for FAS research and prevention is rising; a bill to help state and local governments address the issue is pending in the Senate; and celebrities such as singer Bonnie Raitt have drawn attention to the problem through televised public service announcements.

It has been a frustrating crusade for advocates like the National Organization on Fetal Alcohol Syndrome, who have seen massive media attention devoted to cocaine-damaged babies but slow recognition of the tragic effects of alcohol. Their efforts have been complicated, they know, by a culture that views drinking as an acceptable, often integral, part of American life.

"I think a lot of" specialists in obstetrics and gynecology (ob-gyns) "if they saw a pregnant patient with needle marks on her arm or cocaine on her nose, would have little hesitancy in addressing those issues," said Patti Munter, executive director and founder of NOFAS. "But if it's having a glass of wine with dinner, there is just a whole different dynamic. . . . I have friends who are pregnant now, who are going to the best ob-gyns, who are still being told if they need a couple of glasses of wine to relax, go ahead."

While attention to fetal alcohol syndrome has grown, it remains a serious public health issue. Estimates on the incidence of the syndrome vary, ranging from 4,000 to 8,000 babies born each year. The effects of alcohol on a fetus increase with the level of drinking, so the most serious cases are associated with the heaviest alcohol consumption.

As many as 55,000 babies are born each year with fetal alcohol effects, a less serious group of birth defects also caused by drinking during pregnancy. A study published by the federal government put the annual cost of treating fetal alcohol syndrome birth defects at \$1.6 billion.

The symptoms of fetal alcohol syn-

drome include damage to the central nervous system, facial malformations, developmental delays, maladaptive behavior and mental retardation.

"There are very significant pathological changes in many of these children," Pinckert told his students last week. "No amount of physical therapy, no amount of occupational therapy will change it. They didn't ask for it, but they're stuck with it."

Diane Malbin, the mother of a 14-year-old girl with fetal alcohol effects, argues that much can be done if parents and teachers learn new methods of working with the children.

"We're not making the kids all better, but we're making improvements," said Malbin, who is a clinical social worker in Portland, Ore.

Malbin was a "chronic, late-stage" alcoholic, she said, but knew nothing of FAS when she gave birth to Ariel. Later, as a graduate student, she realized why her child was having academic and emotional problems.

"She basically decided she couldn't read. . . . She was getting extremely frustrated, feeling bad about herself, exhausted, with headaches," said Malbin, now a recovered alcoholic.

Eventually, she enrolled Ariel in a school where students are taught in a hands-on, experiential approach. Her daughter is enjoying learning for the first time.

Kathleen Tavenner-Mitchell, a substance abuse counselor at Suburban Hospital in Montgomery County, said most teachers and counselors are ignorant about FAS and, as a result, many children diagnosed with learning disabilities or attention deficit disorder may be suffering from fetal exposure to alcohol.

Still, she is encouraged by the growing interest from medical schools.

After the class at Georgetown last week, Pinckert said he was approached by two other physicians, both urging that interns and residents at the medical school be lectured on FAS.

"The overall consensus is that maybe we don't do as good a job" informing future doctors about the problem, said Pinckert, who directs clinical genetics at Georgetown's Medical Center.

Pinckert echoed Patti Munter's concern that, while the medical community recognizes the risk for chil-

dren born to heavy drinkers, many doctors may still be telling their pregnant patients that occasional drinking is okay. Because there is no research showing what level of drinking is safe, he said, the best advice doctors can give their patients is to abstain completely while they are pregnant.

Anthony R. Scialli, a Georgetown teratologist, warned the students that the problem was not going to disappear quickly. Drinking is common—the federal Office of Substance Abuse Prevention estimates that 66 percent of women drink during pregnancy. And Scialli told the students they inevitably would have patients come to them worried because they had consumed low levels of alcohol while pregnant. "Without saying drinking is okay," Scialli told the students, "it is reasonable to say, 'Don't anticipate an adverse effect.'"

The heightened medical attention to the issue may be due in part to increasing federal funds for research and prevention, a figure that hit nearly \$12 million in fiscal 1993. But, said Laurie Foudin, director of the alcohol and pregnancy program at the National Institute on Alcohol Abuse and Alcoholism, "we're still behind."

"Compared to crack babies, it's been very slow," Foudin said of the country's response to FAS. "Partly because the media has given tremendous attention to drug exposed babies . . . and because alcohol is a legal drug . . . there's not been the realization of the devastating consequences of fetal alcohol syndrome."

Munter, who founded NOFAS four years ago after witnessing the problem in her work at a South Dakota Indian reservation, recognized the need to improve awareness among young doctors.

With funding from the Joseph P. Kennedy Jr. Foundation, and help from a Kennedy family member, William Kennedy Smith, a medical resident at Northwestern Memorial Hospital outside Chicago, NOFAS began working with physicians to develop a curriculum to offer to medical schools around the country.

"The hope is if you can hit people like doctors, you'll have a trickle down, then you have the potential for them to influence other groups," Smith said.

THE WHITE HOUSE

WASHINGTON

NATIONAL FETAL ALCOHOL SYNDROME AWARENESS DAY

February 2, 1994

My warmest greetings to all who are recognizing National Fetal Alcohol Syndrome Awareness Day.

As our nation strives to create a healthier society, we are becoming increasingly aware of ways to improve our well-being and that of our children. Part of this awareness requires us to ensure that as parents, we understand the consequences of our actions and the profound responsibilities of parenthood. Moreover, expectant mothers and fathers must know the dangers associated with alcohol during pregnancy. Medical research over the past two decades has made it increasingly obvious that alcohol consumption during pregnancy should be dramatically limited.

We now know that drinking as little as two alcoholic beverages a day during pregnancy may cause fetal alcohol syndrome, inflicting irreversible physical and mental harm upon the fetus. Infants born with FAS may suffer heart defects, stunted growth, and lower than average intelligence. While FAS can be prevented, as many as four out of every 100,000 newborn babies in this country suffer its terrible effects. Increasing public awareness of FAS is vital as we seek to educate expectant parents, prevent the disease's occurrence, and promote care for its victims.

I am pleased that Members of Congress are working to inform the public about this disorder and to stop its spread. Their efforts show a genuine dedication among public servants to educate constituents and to help the next generation of Americans. I look forward to working together in the months to come as we strive to prevent fetal alcohol syndrome.

Hillary joins me in saluting everyone working to fight FAS through patient care, research, and education. Best wishes to all for a successful campaign.



Lawmakers wage war on FAS

By Bunty Anquoe
Today Washington Bureau

WASHINGTON — Lawmakers have stepped up their efforts in the battle to end Fetal Alcohol Syndrome.

Fetal Alcohol Syndrome, known as FAS, are irreversible mental, physical and emotional birth defects afflicting children whose mothers drink alcohol during pregnancy. Fetal Alcohol Effect, or FAE, is a related disorder with similar, but less severe problems than individuals with FAS.

Sen. Tom Daschle, D-S.D., and other lawmakers last Wednesday reintroduced legislation to create comprehensive public education, prevention and research programs within the Department of Health and Human Services to reduce the incidence of the dis-



Daschle

vention of FAS and FAE.

■ Distribute diagnostic information to health care and social service providers.

ease.

The bill would:

■ Initiate a coordinated education and public awareness campaign to be conducted by several department agencies.

■ Establish grant programs to help state, local and tribal governments, as well as scientific and academic institutions to support research into the causes, treatment and pre-

■ Establish an interagency task force among all federal agencies that conduct or support FAS/FAE research.

Sen. Daschle, a longtime FAS activist, said the public education component of the bill is invaluable because many people don't realize the dangers of drinking while pregnant.

"The Office for Substance Abuse Prevention estimates that as many as 66 percent of all women drink while they are pregnant, endangering their infants' health and putting them at risk of being born with FAS or FAE," he said.

The National Council on Alcoholism and Drug Dependence has reported that the number of women who believe it is safe to consume up to three drinks

Please see **FAS/A2**

FAS: education is the key

FROM A1

per day while they are pregnant may be as high as one-third.

The toll on the cost of treatment is estimated to be more than \$1.5 million per individual over a lifetime, according to council figures.

About 5,000 children are born each year in the United States with FAS — approximately one out of every 750 births, according to a recent U.S. Surgeon General report. Almost 50,000 babies are born each year with evidence of Fetal Alcohol Effect.

FAS has been documented in most countries, among all races and all socio-economic groups. Its incidence is particularly high in Indian country where alcoholism is a major problem.

The rate of FAS among Indian people is about 30 times higher than the general population, according to Indian Health Service estimates.

"This means that one in 99 Indian children will be denied the opportunity to learn and grow as they should," said Sen. Ben Nighthorse Campbell, D-Colo., a co-sponsor of the bill. "They will be denied the opportunity to live their lives with healthy bodies and independent spirits and this nation will be denied their contributions to society...If my mother had been the drinker that my father was, I could have had FAS myself."

Further studies have indicated that the rate reaches as high as one in four children born with alcohol effects on the Pine Ridge reservation in South Dakota.

The Centers for Disease Control estimate that more than 8,000 alcohol-damaged babies are born each year, making FAS the leading cause of mental retardation at birth.

"The effects of FAS and FAE never go away," Sen. Campbell said. "There is no treatment or cure for this birth defect. But this condition is 100 percent preventable. It doesn't have to happen at all. The message is simple. If you are pregnant, protect your baby and don't



drink alcohol."

Physically, FAS babies are small and develop slowly. They often show facial abnormalities such as wide-set eyes and a flattened nose bridge. Major organ systems may be malformed and these babies usually have abnormally small heads and brains.

Psychologically, FAS babies have low intelligence levels, learning problems, poor coordination, short attention spans and behavioral problems.

Rep. Bill Richardson, D-N.M., and chairman of the House Subcommittee on Native American Affairs, is a primary sponsor of the bill's House version.

"Fetal Alcohol Syndrome is a frustrating problem in our society today," he said. "It is completely preventable. Very simple. No alcohol, no birth defects. It sounds like it would be easy to eliminate this problem, but it's not."

He said the incidence of FAS and FAE in his state is two to five times higher than the national average.

"The bill is an important step in the right direction towards eliminating this problem," he said. "The bottom line is that we must get federal funds to the areas that count — to schools, to community health centers and to clinics. In those

places, the funds can be used to spread the word about the dangers of consuming alcohol during pregnancy."

Rep. Joe Kennedy, D-Mass., has been active in the issue for years. He said the money invested in prevention will eventually save millions for taxpayers.

The Centers for Disease Control estimate that the total cost in terms of health care and social services to treat all Americans with FAS is close to \$1.6 billion each year.

"By just providing tens of thousands of dollars, using money to send a nurse to go to high schools and talk about this, a little action can go a long way to eliminate this terrible disease," he said. "This country spends about \$11 billion to \$12 billion each year on the war on drugs, but alcoholism affects almost every family in America. It's the number one addicting drug in America."

The bill does not ask for a specific dollar amount, but Sen. Daschle said, "there's no reason why we can't find the money to get these initiatives started." He said at least \$80 million is hoped for to get the bill's programs off and running.

Rep. Connie Morella, R-Md., said the bill will more than pay for itself in the long run.

"It will reduce medical costs," she said. "We have to look at cost reduction through prevention."

Patti Munter, president of the National Organization on Fetal Alcohol Syndrome, said public and medical education about FAS and FAE is critical.

"The dangers of FAS are not being taught in this country," she said. "Not even at many medical schools."

Her organization is spearheading a public awareness campaign and has helped to establish the first curricula to teach medical students how to properly diagnose FAS at the University of New Mexico Medical School and Georgetown University Medical School.

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(Goal I To provide comprehensive community based training in the prevention and treatment of ARDD.

(O)bjs.

- To increase ARDD awareness and knowledge among health and education professionals and community members and leaders.
- To identify, assess risks, and track pregnant women who are at risk for ARDD.
- To train health professionals and Community Health Representatives (CHR) in identification and management of ARDD.
- To provide community based training in ARDD for women of child bearing age and their spouses and their families.
- To train education professionals, including Head Start, infant, and toddler programs, in recognition and referral of ARDD.

Goals for the
"Northern Plains Interdisciplinary
Consortium for the Prevention
of Alcohol-Related-Developmental
Disabilities" Project.

2

G II To provide training for members of the Community Response Teams that will enable them to be fully aware of and actively involved in ARDD surveillance.

- O -To refer children at-risk for ARDD for surveillance and clinical evaluation.
- To assist families at-risk for ARDD to access the services that are available through the surveillance and tracking system.
- To identify and assist all women, at-risk for giving birth to an infant with ARDD, in finding appropriate support services and treatment.

G III To train Community Response Teams to be the primary community contact for the coordination of interdisciplinary educational interventions for children with ARDD.

- O -To coordinate the education resources for children with ARDD.
- To make available information on referral, curricula, and other resources for agencies and organizations involved in services for children and families with ARDD.
- To coordinate case management services for children with ARDD in the community.
- To coordinate transition services for children with ARDD in the community.

G IV To provide a system of follow-up and tracking on the inter-disciplinary needs of children with ARDD.

- O -To provide inter-disciplinary services to ARDD children and their families in the tracking system.
- To provide a community based resource center for persons working with children with ARDD.
- To provide support for infants and children who are receiving services through PL 99-457.

H 76

Fetal Alcohol Syndrome in Adolescents and Adults

Ann Pytkowicz Streissguth, PhD; Jon M. Aase, MD; Sterling K. Clarran, MD;
Sandra P. Randels, RN, MSN; Robin A. LaDue, PhD; David F. Smith, MD

Fetal alcohol syndrome is a specific recognizable pattern of malformation. Manifestations in 61 adolescents and adults suffering from alcohol teratogenesis are presented. After puberty, the faces of patients with fetal alcohol syndrome or fetal alcohol effects were not as distinctive. Patients tended to remain short and microcephalic, although their weight was somewhat closer to the mean. The average IQ was 68, but the range of IQ scores widely varied. Average academic functioning was at the second- to fourth-grade levels, with arithmetic deficits most characteristic. Maladaptive behaviors such as poor judgment, distractibility, and difficulty perceiving social cues were common. Family environments were remarkably unstable. Fetal alcohol syndrome is not just a childhood disorder; there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management.

(JAMA. 1991;265:1961-1967)

FETAL alcohol syndrome (FAS) now is recognized as the leading known cause of mental retardation in the United States,¹ surpassing Down's syndrome and spina bifida. Over 2000 scientific reports have now appeared, confirming that alcohol is a teratogenic drug capable of producing lifelong disabilities after intrauterine exposure. Fetal alcohol syndrome does not include all individuals affected by alcohol in utero, but rather it represents the severe end of the continuum of disabilities caused by maternal alcohol use during pregnancy.

From the Departments of Psychiatry and Behavioral Sciences (Drs Streissguth and LaDue and Ms Randels) and Pediatrics (Dr Clarran), Child Development/Mental Retardation Center and the Alcoholism and Drug Abuse Institute of the University of Washington Medical School, Seattle; and the Department of Pediatrics, University of Vancouver, British Columbia (Dr Smith). Dr Aase is in private practice in Albuquerque, NM.

Reprint requests to Department of Psychiatry and Behavioral Sciences, GG-20, University of Washington School of Medicine, 2707 NE Blakely, Seattle, WA 98195 (Dr Streissguth).

Fetal alcohol syndrome was independently identified in France² and the United States.^{3,4} Most of the patients described have been infants or young children.⁵ What the physical and mental manifestations of the syndrome in adolescents and adults are has remained an important unanswered question. Although isolated clinical reports of older patients with FAS have appeared,^{6,7} as well as follow-ups of primarily preadolescent children,^{8,9} to our knowledge this is the first systematic follow-up study that has examined adolescent and adult manifestations of this important cause of developmental disability. Some data from this overall project have been mentioned in the literature.¹⁰

METHODS

Patients who had been previously diagnosed as having FAS were eligible for this study if they were 12 years or older at the time of follow-up. Patients with

possible fetal alcohol effects (FAE) were seen as time permitted. Approximately half of the sample was clinically ascertained (patients of A.P.S., S.K.C., or D.F.S.) The rest were identified through an FAS screening study on four Indian reservations.¹¹ Original diagnostic examinations were conducted by three of us (J.M.A., S.K.C., D.F.S.) or our coworkers.

Fetal alcohol syndrome was diagnosed when patients had a positive history of maternal alcohol abuse during pregnancy and (1) growth deficiency of prenatal origin (height and/or weight); (2) a pattern of specific minor anomalies that included a characteristic facies (generally defined by short palpebral fissures, midface hypoplasia, smooth and/or long philtrum, and thin upper lip); and (3) central nervous system manifestations (including microcephaly or history of delayed development, hyperactivity, attention deficits, learning disabilities, intellectual deficits, or seizures).^{12,13} Patients exposed to alcohol in utero with some partial FAS phenotype and/or central nervous system dysfunction, but without sufficient features for a firm diagnosis of FAS or strong consideration of any alternative diagnosis, were identified as "possible FAE" for these analyses.

The follow-up examination occurred for the most part between 5 and 12 years after the original diagnostic examination and was conducted by three of us (A.P.S., S.P.R., and R.A.L.). It consisted of an intellectual examination (Wechsler Adult Intelligence Scale—Revised or Wechsler Intelligence Scale for Children—Revised^{14,15}), an academic

Ross Swimmer that the Oneida... tive of the Oneida Nation of New... protesters demonstrated in front of... refuse to con...
Indian Country Today 9/29/93

Daschle hailed for FAS work

By Bunty Anquoe
Today Washington Bureau

WASHINGTON — One more child born with birth defects caused by mothers who drink alcohol during pregnancy is one too many, says Sen. Tom Daschle.

The South Dakota Democrat is determined to stop the rising incidence of Fetal Alcohol Syndrome — the nation's leading cause of mental retardation. He has sponsored several pieces of legislation providing prevention programs for pregnant women and treatment for children suffering from FAS.

Most recently, the Senate Appropriations Committee, at the request of the senator, approved a \$3 million research and prevention program to be administered by the Centers for Disease Control in Atlanta, Ga.

"This \$3 million for the (program) represents a \$1.3 million increase over last year's funding and will help us combat the tragedy of FAS on our reservations, in our urban areas and rural communities in South Dakota," he said.

Fetal Alcohol Syndrome and its milder form, Fetal Alcohol Effect, are irreversible mental, physical and emotional birth defects that are caused by the use of alcohol during pregnancy.

Physically, FAS babies are small at birth and develop slowly. They often show facial abnormalities such as wide-set eyes and a flattened nose bridge. Major organ systems may be malformed and these babies usually have abnormally small heads and brains. Psychologically, FAS babies have low intelligence levels, learning problems, poor coordination, short attention spans and behavioral problems.

At least 5,000 infants are born each year with FAS — approximately one out of every 750 births, according to a recent Surgeon General report. Almost 50,000 babies are born each year with evidence of Fetal Alcohol Effect.

FAS has been documented in most countries, among all races and all socio-economic groups. Its incidence is particularly high in Indian country where alcoholism is a major problem.

The rate of FAS among Indian people is about 30 times the rate among whites, according to recent Indian Health Service estimates. Further studies have indicated that the rate reaches as high as one in four children born with alcohol effects on the Pine Ridge reservation in South Dakota.

The National Organization for Fetal Alcohol Syndrome recently honored Sen. Daschle for his dedication to combating the disease.

Patti Munter, organization president, said Sen. Daschle has been "tireless" in his efforts.

"His early and committed support has made a critical difference in allowing NOFAS to continue its work," she said. "His outstanding leadership is invaluable."

Sen. Daschle said his commitment to the issue is heartfelt and personal.

"It's been important to me because it affects the lives of so many people, especially in South Dakota," he said. "It's the single biggest cause of mental retardation and it's still a problem that we have yet to address comprehensively in national policy and I think it needs to be given the kind of national priority that it deserves. Fetal Alcohol Syndrome is a tragedy that is completely preventable, but only if we get help to the women who need it."

The senator also sponsored legislation to fight FAS that permits coverage of residential alcohol and drug treatment for pregnant women under the federal Medicaid program.

Ms. Munter stressed the importance Sen. Daschle's work.

"FAS babies do not get better. There is no cure and their physical and mental problems last a lifetime," she said. "We could eliminate this No. 1 known cause of mental retardation in this country if we educate women about the dangers of drinking while pregnant."

Her organization is spearheading a national public awareness campaign with the simple message, "A few drinks can last a lifetime. If you are pregnant... don't drink."

The group is also planning outreach through the medical community. Recently, the University of New Mexico Medical School, in conjunction with NOFAS, developed the first curriculum to teach students how to properly diagnose Fetal Alcohol Syndrome.

Georgetown University will also start teaching a similar curriculum in the spring of 1994.

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4/9/93

THE WASHI

Fetal Alcohol Damage Found to Persist

Many Physical Deformities Disappear but Emotional Problems Go On

Associated Press

LONDON, April 7—Babies born with fetal alcohol syndrome suffer long-lasting brain damage, though many physical deformities diminish over time, according to a 10-year German study.

Doctors have suspected that fetal alcohol syndrome—a condition associated with exposure to alcohol in the womb—causes chronic emotional and intellectual damage. But few scientists have traced affected children from birth to adolescence.

Fetal alcohol syndrome, which strikes one or two babies in every 1,000 live births worldwide, describes a collection of features including a small head, stunted growth and delayed mental development. Doctors do not know the precise level of alcohol that damages the fetus.

The new study shows that al-

though many of the physical deformities disappeared with age, an array of emotional disturbances persisted, said Hans-Ludwig Spohr, a pediatrician at Rittberg Hospital of the German Red Cross in Berlin.

The study is published in the April 10 issue of *The Lancet*, a British medical journal.

"This is an important study to document what's been reported anecdotally," said George Brennaman, a pediatrician at Johns Hopkins University in Maryland.

Brennaman is associate director of the Center for American Indian and Alaskan Native Health. Fetal alcohol syndrome is two to three times as common among American Indians as it is in the general population.

Although some doctors say women can safely have one or two drinks a week during pregnancy, Brennaman said he recommends

abstinence because the evidence is inconclusive.

German investigators traced 36 boys and 24 girls born with fetal alcohol syndrome between 1977 and 1979.

Doctors examined and scored babies according to the extent of physical and neurological damage shortly after birth and again about 10 years later.

In infancy, 45 percent were mildly affected, 30 percent moderately and 25 percent severely affected.

All of the children, even those severely deformed, eventually achieved normal weight and height. Microcephaly—an abnormally small head—persisted in 65 percent of the children, said Spohr.

Although two-thirds of the children lived with adoptive or foster parents in good environments, the majority continued to suffer from psychiatric problems.

A4 FRIDAY, MAY 7, 1993

THE WASHINGTON POST

Fetal Alcohol Syndrome Births Said to Rise Sharply

Associated Press

ATLANTA, May 6—Births of babies with health problems attributed to alcohol consumption by their mothers during pregnancy increased threefold from 1979 through 1992, federal health officials said today.

The increase in fetal alcohol syndrome may be even higher because the disease is difficult to diagnose in newborns, officials at the Centers for Disease Control and Prevention (CDC) said.

"It's likely that this rate that we're reporting is an underestimate, that the problem is of greater magnitude," said David Erickson, chief of the CDC's birth defects and genetic diseases branch. He added that he believes better reporting of the

syndrome by doctors is primarily responsible for the increased numbers.

The rate of reported fetal alcohol syndrome cases jumped from one per 10,000 births in 1979 to 3.7 per 10,000 births in 1992, according to the CDC.

A total of 1,782 cases of fetal alcohol syndrome were reported among the slightly more than 9 million births during the 14-year period—an average rate of just under two cases per 10,000 births.

Symptoms include mental retardation, abnormal facial features, central nervous system problems, behavioral problems and growth deficiencies. Newborns get the disease as a result of alcohol consumption by their mothers during preg-

nancy, but health officials do not know how much alcohol harms the newborn, Erickson said.

Many doctors advocate no drinking during pregnancy, and there is evidence that even small amounts of alcohol can harm the developing child, he said.

Some babies, he said, "don't have full-blown fetal alcohol syndrome, but they may have other problems of a less-pronounced nature."

Erickson noted that besides better reporting of the condition among doctors, more drinking among pregnant women may have contributed to the increased rate, but the CDC cannot be sure because investigators do not interview mothers of babies suspected of having the syndrome.

Doc: A 1

4/22

P. MONTNER

Opiled



P6(b)(6)

③ Nat'l Org for Fetal Alcohol
Syndrome

April
P6(b)(6)
P6(b)(6)

Shirley Poorlander

P6(b)(6)

Tony Podesta ↔ Bd Member

Indiana Health Service
(Rept of Romy Howe)
Dr. William Mason
FAS -- completely unstaffed
understaffed/underburdened

As ^{large} Federal Task Force (Nov 1990)
(1/2)

1 year
Head Start -- pilot
Project in S. Dakota
Especially for

Tribal Community Health
Abandon, SD
Family "community response teams"
-- preventive outreach

→ Epidemic levels (1-4 affected by alcohol)

→ Same as lower

→ WP → broader

→ 5000 babies born

55,000 Fetal Alcohol affects

- organ dysfunction
- hearing disability
- severe mental retardation

No 12 bottles

First Medical School
anniversary

April 92 TRMA

Leading Women Cause / MR

Training dentists in Pine Ridge

~~summary~~ Dennis Spadone
President

Labor Com -- Big game
Dorothy -- very committed
Patty Mitchell

MEMORANDUM

To: Stan Herr
From: Karen Goldmeier
Date: February 22, 1994
Re: Fetal Alcohol Syndrome -- Comparison of bills

Summary: Only Daschle's two bills describe substantive programs: S. 923 provides a comprehensive program for the prevention of Fetal Alcohol Syndrome, and S. 484 enhances services provided under Medicaid. No bills touch on mental retardation outside of their initial "findings" section. H.R. 3075 (Schroeder) and H.R. 3569 (Morella) only touch on Fetal Alcohol Syndrome only in the context of general funding for alcohol abuse among women. I have summarized them below, in order of relevance.

S. 923: Comprehensive Fetal Alcohol Syndrome Prevention Act (Daschle)

Establishes (1) a comprehensive program to prevent Fetal Alcohol Syndrome and Fetal Alcohol Effects and coordinate related Federal efforts; and (2) an Inter-Agency Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects.

Provides for related research, technical assistance, grants, cooperative agreements, and contracts, surveillance and prevention programs, professional and public education, and diagnostic criteria. It is especially heavy on prevention in the areas of public awareness, education, and the training of specialists. Finally, the bill also authorizes appropriations.

S. 484: Medicaid substance Abuse Treatment Act (Daschle)

Provides Medicaid coverage of Alcoholism & Drug Dependency Residential Treatment Services for women during pregnancy and for one year after giving birth, children of these women, and caretaker parents and their children (at state option).

Required services include: (a) counseling, addiction education and treatment; (b) parenting skills training; (c) room and board with twenty-four hour supervision; (d) child care and counseling; (e) facilitating access to education and health care for both mother and child.

H.R. 3075: Women's Health Equity Act (Schroeder)

Includes: (1) "Women and Alcohol Research Equity Act," which increases funding for research on alcohol abuse and alcoholism among women; and (2) "Adolescent Health Demonstration Projects

Act," which requires projects established under this Act to provide alcohol and drug abuse education and treatment. (This latter part of the bill does not mention Fetal Alcohol Syndrome specifically).

H.R. 3569: Women and Alcohol Research Equity Act (Morella)

- Increases funding for research on alcohol abuse and alcoholism among women.

Results: 12 items in BILLTEXT

Search criteria used:

FETAL ALCOHOL SYNDROME

Results are:

Ranked by probable relevance

1 S923 Daschle (D-SD) 05/07/93 (395 lines)
Introduced in Senate

To amend the Public Health Service Act to provide a comprehensive program for the prevention of Fetal Alcohol Syndrome, and for other purposes.

Item Key: 4280

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Introduced in House

To promote greater equity in the delivery of health care services to American women through expanded research on women's health issues and through improved access to health care services, including preventive health services.

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Introduced in Senate

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Item Key: 2337

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Introduced in House

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Item Key: 9119

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To require health warnings to be included in alcoholic beverage

advertisements, and for other purposes.

Item Key: 3220

6 HR2264 Sabo (D-MN) 05/25/93 (34440 lines)
Reported in House

To provide for reconciliation pursuant to section 7 of the
concurrent resolution on the budget for fiscal year 1994.

Item Key: 4800

7 HR2264 Sabo (D-MN) 05/27/93 (37335 lines)
Engrossed (passed) in House

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Placed on Calendar Senate

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9 HJRES230 Bacchus J. (D-FL) 07/14/93 (88 lines)
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To designate the period commencing on February 14, 1994, and ending
on February 20, 1994, as "Children of Alcoholics Week".

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To provide for budget reconciliation with respect to part B of the medicare program, the medicaid program, and other health programs within the jurisdiction of the Committee on Energy and Commerce.

Item Key: 4501

*** HISTORY REPORT -- ALL LEGISLATIVE ACTION, COSPONSORS, SPEECHES ***

MEASURE: S923

SPONSOR: Daschle (D-SD)

BRIEF TITLE: Comprehensive Fetal Alcohol Syndrome Prevention Act.

OFFICIAL TITLE: A bill to amend the Public Health Service Act to provide a comprehensive program for the prevention of Fetal Alcohol Syndrome.

INTRODUCED: 05/07/93

COSPONSORS: 10 (Dems: 8 Reps: 2 Ind: 0)

COMMITTEES: Senate Labor and Human Resources

LEGISLATIVE ACTION:

05/07/93 Referred to Committee on Labor and Human Resources (Text of bill appears on pgs. S5705-S5709 of the May 7, 1993 Congressional Record) (CR p. S5705-S5709)

05/07/93 DASCHLE, D-S.D., Senate speech: Introduces the Comprehensive Fetal Alcohol Syndrome Prevention Act. (Colloquy with BINGAMAN, D-N.M.) (Washington Post) (Text of bill) (CR p. S5705-S5709)

05/07/93 Original cosponsor(s): 7

Bingaman (D-NM)	DeConcini (D-AZ)	Stevens (R-AK)
Campbell (D-CO)	Inouye (D-HI)	
Conrad (D-ND)	Moseley-Braun (D-IL)	

05/21/93 STEVENS, R-Alaska, Senate speech: Supports the Comprehensive Fetal Alcohol Syndrome Prevention Act. (CR p. S6315-S6316)

05/21/93 Cosponsor(s) added: 1
Rockefeller (D-WV)

05/26/93 Cosponsor(s) added: 1

Wofford (D-PA)

10/25/93 Cosponsor(s) added: 1
Murkowski (R-AK)

Name Fri

record 1-25
Stan Herr - call me pls.

January 21, 1994

Chase
Requested for
& business
1-27



Health—A changing world
Office of Management and Budget
Executive Office of the President
Washington, DC 20503

Please route to:

Carol Rasco

Through: David Kleinberg **DKK**

Subject: Fetal Alcohol Legislation

From: Bill Dorotinsky **BD**

Decision needed _____
Please comment _____
For your information _____
Per your request
Take necessary action _____

With informational copies for:

Phone: 202/395-4926
Fax: 202/395-3910
Room: #7002

cc: NEM

Nancy-Ann Min requested we provide some follow-up information on current Fetal Alcohol legislation. Attached is a list of relevant legislation in the current session. None of the bills appears to be moving, and the Administration has not taken a position on any of the bills.

Please let us know if we can be of further assistance.

Results: 12 items in BILLTEXT

Search criteria used:

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