

TRUTH AND  
CONSEQUENCES OF

# FETAL ALCOHOL SYNDROME:

WHY NEW JERSEY  
SHOULD BE  
CONCERNED



The Governor's Council On Prevention Of Mental  
Retardation And Developmental Disabilities  
*And*  
The New Jersey Task Force On Fetal Alcohol Syndrome

# FETAL ALCOHOL SYNDROME:

## WHY SHOULD NEW JERSEY BE CONCERNED?

Fetal Alcohol Syndrome (FAS) and Alcohol Related Neurological Developmental Disorders (ARND) are a cluster of serious birth defects caused by alcohol that is consumed while women are pregnant.

While FAS may be diagnosed during infancy or early childhood, the problems last throughout a person's life.

- ▶ FAS is a cluster of permanent, non-curable brain disorders, including mental retardation.
- ▶ ARND are also characterized by organic brain damage and some physical malfunctions, but mental retardation is not always present. However, the behavioral disorders associated with FAS are similar.
- ▶ Risk factors for frequent drinking during the periconceptual period included one or more of the following:
  - ✓ Living in poor socio-economic environments
  - ✓ Being college educated
  - ✓ Being employed
  - ✓ Being unmarried
  - ✓ Smoking
  - ✓ Having an annual household income over \$50,000. (Ebrahim et al: 1998) (Floyd et al: 1999)



## HOW COMMON IS FAS AND ARND IN NEW JERSEY?

*On any given day in the US 10,657 babies are born*

*1 baby will be born HIV positive*

*3 babies will be born with Muscular Dystrophy*

*4 babies will be born with Spina Bifida*

*On any given day in the US 10 babies will be born with Down Syndrome*

**BUT**

*20 babies will be born with Fetal Alcohol Syndrome (FAS)*

**AND**

*100 babies will be born with Alcohol Related Neuro-developmental Disorder (ARND)*

Recent research suggests that FAS affects 1-3 infants out of every 1,000 (Abel & Sokol 1991). This is comparable to the incidence of Down's syndrome and spina bifida, the two most commonly recognized birth defects (Warkany, J., 1971). ARND is far more common with as many as 3 or 4 infants affected out of every 1,000. These are conservative numbers. With an average birth rate of 110,000, this translates to at least 11 children being born with FAS and about 30 to 40 children being born with ARND in New Jersey every year.

New Jersey law mandates that all children with the diagnosis of FAS be reported by physicians to the Birth Defects Registry, housed in the Department of Health and Senior Services.

However, very few cases of FAS are actually reported to the Birth Defects Registry. This situation exists because few physicians are trained to recognize and diagnose FAS/ARND. In addition, if they do suspect these disorders, many physicians are reluctant to "label" these children as such. As a result, it is not possible to provide definitive estimates of the prevalence of FAS/ARND. In addition to the immeasurable toll they take on children and their families, FAS and ARND pose extraordinary financial costs to this country. These include the costs of health care, education, foster care, job training and general support services for affected individuals. The total cost to the economy due to FAS was greater than \$2,500,000,000 in 1995. The health care costs are estimated to be at least \$1,400,000 over the lifetime of one person with FAS (U.S. Department of Health and Human Services).

## WHAT IS FAS?

Fetal Alcohol Syndrome (FAS) is a life-long birth defect caused by maternal consumption of alcohol during pregnancy. FAS is the most commonly known preventable cause of birth defects that result in mental retardation. FAS is 100% preventable if a woman does not drink alcohol while pregnant.

Damage to the fetus from exposure to alcohol can occur in varying degrees. At the most severe end of the continuum is FAS. Babies born with FAS usually show evidence of anatomical abnormalities. The most common are:

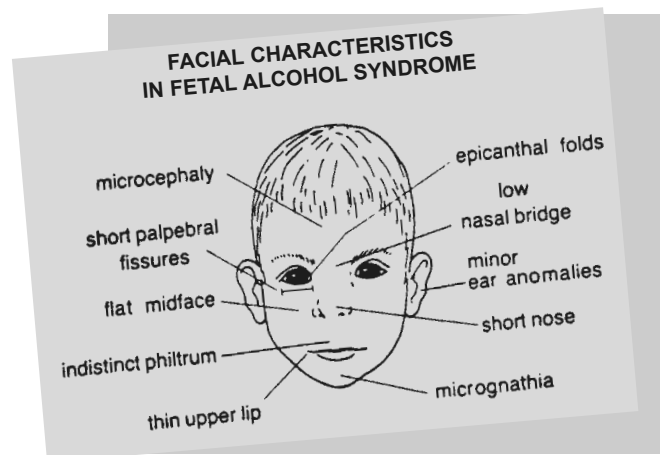
**Growth Retardation:** Babies are abnormally small at birth and usually remain so throughout life.

**Facial Anomalies:** Babies may have a cluster of facial characteristics, including small, widely spaced eyes; a short, upturned nose; small, flat cheeks; a smooth philtrum, or no groove between the nose and upper lip; and an abnormally thin vermilion ridge or upper lip.

**Central Nervous System Abnormalities:** Infants may have mental retardation, developmental delays, short attention span, hyperactivity, impulsivity, perceptual problems, poor coordination and learning disabilities.

In addition to the above major signs, children with FAS also may be born with a variety of physical and organ malformations, including heart and kidney defects, bone, joint, eye, ear and liver problems. They may suffer more frequently from illnesses, such as colds or ear infections.

Mental retardation, operationally defined as an IQ below 70 and functional limitations, is observed in approximately 50% of FAS children (Mulvihill, J.J.; and Yeager, A.M.; 1976). The severity of intellectual deficits is positively correlated with the severity of anatomic defects in these children (Streissguth, AP, et al; 1978).



However, the classic FAS child represents only a portion of a greater number of children who have been exposed to alcohol prenatally. Alcohol Related Birth Defects (ARBD), Fetal Alcohol Effects (FAE), and Alcohol-Related Neurodevelopmental Disorders (ARND) are synonymous terms used to describe less obvious, but not always less severe, degrees of FAS. Currently ARND is the encompassing term used to describe this syndrome. There is no exactly defined set of findings that confirms a diagnosis of ARND. These children typically have some behavioral and learning abnormalities and/or developmental delays without necessarily exhibiting the entire spectrum of craniofacial and other teratogenic (a substance that causes developmental malformations) effects of prenatal alcohol exposure. However, studies have shown that the learning and behavioral difficulties can be as severe as in FAS and often translate into maladaptive behavior, as illustrated below.

<b>Behavior</b>	<b>Outcome</b>
Poor judgment	Easily Victimized
Attention deficits	Unfocused and distractible
Problems with arithmetic	Cannot handle money
Memory problems	Does not learn from experience
Abstraction problems	Does not understand consequences
Disoriented	Social misfits
Poor frustration tolerance	Quick to anger and give up

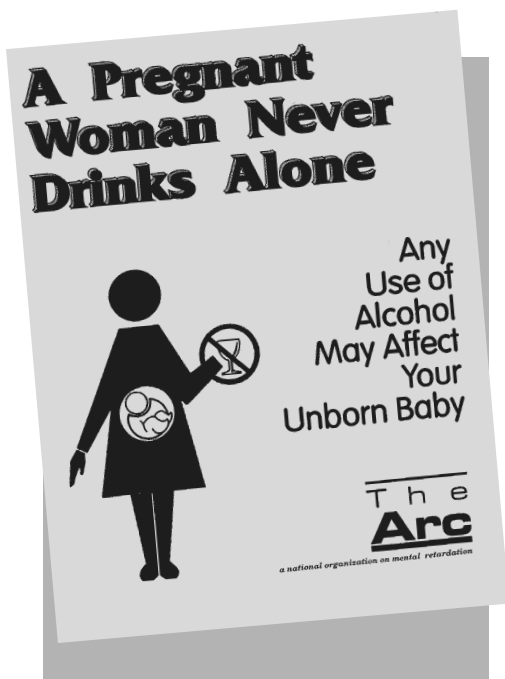
These types of problems are subtle, so that children with ARND are often misdiagnosed or considered to be “bad seeds.” Rather than receiving the educational and behavioral supports needed to help to compensate for the disabilities, these children believe that they are just “school failures and troublemakers.” Depression and low self-esteem are common in children with ARND. In addition, the desire to be accepted by peers combined with their impaired decision-making abilities, often lead these children into compromising situations. As a result, a great many children with ARND experiment with drugs and alcohol and get in trouble with the law at an early age.

## ***IF FAS IS SO EASY TO PREVENT, WHY DOES IT HAPPEN?***

Unfortunately, too many young women and men are not educated about the possible dangers of drinking alcohol during pregnancy. The common thought is that only alcoholic women can give birth to a child with FAS or ARND. Too often, the pregnancy is not planned, and because the woman is not aware that she is pregnant, she continues to consume alcohol during the early months of her pregnancy, unaware that the fetus may sustain permanent organic damage. In addition, very little information is included about the teratogenic effects of alcohol upon embryonic and fetal development in medical and nursing education. As a result, it is still common for physicians to tell pregnant women that it is all right to have an occasional drink.

## ***WHAT HAS NEW JERSEY DONE TO ADDRESS FAS?***

New Jersey has taken some steps to address the issues of prevention, education, diagnosis and treatment of FAS. Several of these efforts are discussed here. Some have been ongoing and have been quite effective, while others have been one-time events. One overriding factor in nearly all of these efforts is the lack of a long-term,



comprehensive system for prevention, diagnosis and treatment of FAS. Instead, prevention programs and projects have been carried out in a piecemeal and fragmented fashion.

Prior to 1981, very little was known about FAS in New Jersey. In 1982, the first statewide conference on FAS was held for perinatal professionals. The first New Jersey Task Force on Fetal Alcohol Syndrome was established in 1983 by the Governor’s Advisory Council on Alcoholism within the NJ Department of Health (now the Department of Health and Senior Services). Over the next five years, the Task Force designed and conducted several programs and activities to increase public and professional awareness about the effects of alcohol on the developing fetus. Enough interest was raised through the media, the public education network and groups, such as the March of Dimes, that in 1993, the New Jersey State Legislature passed Public Law 1993 Chapter 43. This bill requires that warnings regarding the dangers of drinking during pregnancy be posted in all establishments in New Jersey that sell or serve alcoholic beverages.

During the 1980’s, however, few direct services were available to address the specific issues of pregnant women who used or were addicted to alcohol. Systems to identify, manage and provide follow-up of these women and their infants were needed. In 1985, the Governor’s Council on the Prevention of Mental Retardation published its report, Programs for Preventing Causes of Mental Retardation. This report summarized the status of prevention efforts in New Jersey at that time and presented recommendations on what the State needed to do to improve prevention efforts. One of the recommendations was the development of a more substantial systematic statewide approach to address FAS. Consequently, the FAS Prevention Project was approved for funding in 1988.

The New Jersey Department of Health and Senior Services (DHSS) administers the FAS Prevention Project. Its primary mission is to provide a coordinated, statewide network of regionalized services to prevent the adverse effects of alcohol and substance use on the developing fetus and to promote healthy pregnancy outcomes. Hospitals and other agencies provide direct drug and alcohol intervention and addiction treatment referrals to pregnant women. A recent mandate requires hospitals to have available a Risk Reduction Specialist. This individual provides drug and alcohol assessments and screening, education, counseling and referrals to addiction treatment programs for pregnant women.

In its twelve years of operation, the FAS Prevention Project has served literally thousands of women. However, despite its effectiveness,

the FAS Prevention Project focuses primarily on women who are pregnant already and who use clinic-based services for their health care. Very few services are available for women who receive health services through private venues. In addition, an evaluation conducted by the Center for Alcohol Studies at Rutgers University in 1996, showed that there was no link between risk reduction services and the infants’ health, both at birth and during development. As a result, it was not possible to determine how many children were born with FAS or ARND.

*And there was a certain man of Zorah...whose name was Manoah; and his wife was barren and bore not. And the angel of the Lord appeared unto the woman, and said unto her: 'Behold now, thou art barren, and hast not borne; but thou shalt conceive, and bear a son. Now therefore beware, I pray thee, and drink no wine nor strong drink, and eat not any unclean thing...'*

*Judges 13:2-4*



The DHSS, in partnership with other state departments, sponsored a workshop on Fetal Alcohol Syndrome for New Jersey Family Court Judges in 1993. The program included topics on recognizing FAS in teen defendants; sentencing issues for teens identified with FAS; and techniques for communicating with persons affected by FAS. This was a well-received and effective technique for educating members of the criminal and juvenile justice systems about FAS and its impact on these systems.

The Governor's Council on Prevention of Mental Retardation and Developmental Disabilities also allocates funding for FAS education through the Office for Prevention of Mental Retardation and Developmental Disabilities in the Department of Human Services. These funds provide grants to non-profit agencies and organizations to educate the public about ways of preventing Fetal Alcohol Syndrome (see addendum for grantees and project descriptions). The programs focus on women who are not yet pregnant, with particular emphasis given to adolescents in their schools. However, the greatest shortcoming of this effort is the lack of funds to implement FAS prevention education programs on a statewide basis. For the most part, projects have been implemented in only a few municipalities or counties and only for a maximum of three years. The lack of on going support has generally resulted in the cessation of FAS community education, once the grant period has ended. As a result, it has not been possible to measure the impact of these programs upon the individuals' behavior in the long term.

"Pregnant Pause" events have been held around the state for the past three years. Pregnant Pause is a fun-filled and informative event, organized by a collaboration of various county organizations to encourage alcohol serving establishments to offer non-alcoholic drinks to pregnant women. Pregnant Pause is also used to educate the community about FAS. Under the auspices of Local Chapters of The Arc of New Jersey, Pregnant Pause has grown from two events held in Monmouth and Ocean Counties in 1997, to events in fifteen counties in 2000.

The Department of Education recently drafted the Comprehensive Health and Physical Education Core Curriculum Standards. These stipulate what must be taught in New Jersey's public schools, in order to enable students to meet those standards. The words "fetal alcohol syndrome" and "alcohol-related neurodevelopmental disorders" do not appear in the standards. However, several suggested activities at each grade level do include information and exercises to educate students about the physical and behavioral effects of alcohol and its actions on the body.

Most school-based alcohol and drug programs emphasize the dangers of under-age drinking, while the focus of most Family Life Education is on the physiology of procreation, interpersonal skill development and improved decision-making. Rarely do school-based programs merge their alcohol and drug programs with their Family Life Education classes to instruct students about the detrimental effects of alcohol on fetal development.

*In 1627, Francis Bacon observed that wine and strong drink taken during pregnancy were known to endanger children to "become lunatic, or of imperfect memory."*



In January 1999, a survey was conducted in each of the three state medical schools of the University of Medicine and Dentistry of New Jersey (UMDNJ); the School of Health Related Professions (six programs); and 43 nursing programs. Each was asked if information about FAS was included in its curriculum and to specify the amount of time devoted to the subject.

The results of the survey indicated that most medical students and residents receive from 1 to 1.5 hours of instruction during their entire medical school training. Of the 23 nursing programs that responded to the survey, 21 indicated that information about FAS was covered in their curriculum. However, most devoted less than a total of 60 minutes of instruction to FAS (see addendum for report by Anthony Garro, Ph.D.). Nearly every program indicated an interest in receiving more information about FAS/ARND.

## **WHY WAS THE TASK FORCE ON FAS ORGANIZED?**

In 1996, Ann P. Streissguth, Ph.D., a nationally acclaimed FAS/ARND researcher, published the results of her study that documented the long-term affects of prenatal exposure to alcohol. For the first time, there was conclusive evidence that prenatal exposure to alcohol caused organic damage in specific parts of the brain that resulted in mental retardation and severe behavioral disorders. These findings provided the impetus to sponsor a major conference in New Jersey in 1998 that included Dr. Streissguth as the keynote speaker. The purpose of the conference was to educate allied health, educational, child welfare professionals and policy-makers about these new findings. In addition to presenting data on the intellectual deficiencies and behavioral problems associated with FAS/ARND, Dr. Streissguth also addressed important family factors that either mitigate or aggravate the long-term detrimental effects of prenatal exposure to alcohol. These family issues are called protective and risk factors and include:

<b>FACTORS INFLUENCING FAS CHILD'S SOCIAL DEVELOPMENT</b>	
<b>PROTECTIVE</b>	<b>RISK</b>
Stable family	Dysfunctional family
Early diagnosis	No diagnosis
Educational supports	School problems
Mental health services	Undiagnosed mental health problems
Family support system	Substance abuse
Community services	Juvenile delinquency

Dr. Streissguth's findings demonstrated that, while the Protective Factors do not "cure" a child with FAS/ARND, a warm, loving and stable family environment serves to lessen the ill effects of the alcohol exposure. However, risk factors almost always resulted in the child with FAS/ARND having mental health problems, disrupted school experiences, early and sustained substance abuse problems, unemployment, problems with independent living, and involvement with the juvenile and adult criminal justice systems. Dr. Streissguth's research also documented the astronomically high costs associated with the behaviors caused by FAS/ARND.

A meeting was held with interested participants at the conclusion of the conference that resulted in the establishment of the New Jersey State Task Force on FAS. The Honorary Chair of the Task Force is former State Assemblywoman Barbara Wright. Members of the Task Force include representatives from the State Departments of Human Services; Health and Senior Services and Education; The Arc of New Jersey; allied health professionals; organizations with an interest in FAS; parents of children with FAS; faculty of the UMDNJ-NJMS and School of Osteopathic Medicine (SOM) and numerous other agencies. The Task Force met throughout 1998 and 1999 for the purpose of determining the issues that needed to be addressed and goals that needed to be established in order to prevent, treat and ameliorate the effects of FAS.

## TASK FORCE RECOMMENDATIONS

### COMPREHENSIVE FAS SYSTEM

- 1.) Prevention, education and outreach
- 2.) Risk reduction and treatment services for women and children
- 3.) Diagnostic, treatment and case management services
- 4.) Surveillance and research



While New Jersey has taken some active steps to prevent FAS/ARND, these actions have been incremental. Education about FAS/ARND is key to preventing these disorders and to reducing the high costs associated with them. Therefore, it is recommended that comprehensive educational systems be implemented to insure that all of New Jersey's young adults and allied health care professionals are well informed about the dangers of drinking alcohol while pregnant.

## PREVENTION EDUCATION AND OUTREACH

### **EDUCATION in the SCHOOLS**

*Children with FAS/ARND don't remember  $A+B=C$*

All schools in New Jersey must include specific health curriculum standards about FAS for all students.

All school faculty members should receive yearly FAS education and materials.

Information about FAS should be presented annually at the New Jersey State Education Association Conference through the Department of Education and FAS materials should be made available at the Educational Resource and Training Centers.

The Department of Education should provide support and cooperation in providing continuing FAS education for school nurses.

University and college orientation programs should provide information about FAS to all new students.



## **COMMUNITY EDUCATION**

All Division of Youth and Family Services' (DYFS) caseworkers and substance abuse resource workers should receive annual training about FAS.

All foster parents should receive training about FAS.

All Municipal Alliance plans should include FAS prevention objectives.

All Drug Awareness Resistance Education (D.A.R.E.) officers should receive FAS education through the New Jersey Officers Association and include this information in their student presentations.

The Center for Alcohol Studies at Rutgers University should offer comprehensive training about FAS.

FAS educational materials and speakers should be publicized and an ongoing media campaign with a universally recognized logo should be implemented throughout the state. Particular attention should be placed on reaching the following:

- ✓ Community organizations, agencies and civic groups such as Rotary Clubs, Kiwanis, Chambers of Commerce
- ✓ Faith communities
- ✓ Addiction treatment centers and youth and adults incarcerated in jails and detention centers

## **PROFESSIONAL EDUCATION**

All schools and universities that train physicians, nurses, mental health professionals and other allied health care professionals should include a comprehensive curriculum for educating about FAS, along with other preventable causes of developmental disabilities.

All hospitals should mandate FAS and addiction training as part of the Joint Commission on Accreditation of Health Organization process.

Continuing education for all health and allied health professionals about FAS should be required.

New Jersey licensing requirements for social workers, Certified Alcohol and Drug Counselors, Licensed Professional Counselors, and Substance Abuse Counselors and licensed professional counselors should include knowledge about FAS.

## **CORPORATE EDUCATION**

All Employee Assistance Program (EAP) counselors should provide FAS education to their corporate employees and clients. Information and activities should be made available to employees and to the public through various methods, including, but not limited to:



- ✓ FAS informational inserts included with driver's license renewals, utility, cable T.V. and telephone bills, restroom stall stickers and lunchtime videos and presentations
- ✓ Collaborations between the FAS Task Force, corporations and businesses should be established to develop and make available information for customers and for the public
- ✓ EAP training should include FAS education as part of the regular curriculum

These recommendations are planned as an ongoing program that will continue to identify and to reach out to diverse populations. As these recommendations are implemented, they will be evaluated routinely for their effectiveness in educating people about FAS/ARND and in encouraging them to change at-risk behaviors.

## RISK REDUCTION RECOMMENDATIONS

Risk Reduction Services are defined as the provision of alcohol and substance use/abuse screening, assessment, client education and intervention counseling. When appropriate, addiction treatment referral, follow up and overall case management of clients at risk are also included. Professional training and community education regarding the dangers associated with prenatal use of alcohol and other substances may be provided as well. Recommendations are to:

1. Ensure the implementation of the perinatal regulations N.J.A.C. 8:33C, adopted February 1, 1999, requiring the delivery of Risk Reduction Services at 13 Regional Perinatal Centers in the State.
2. Ensure the provision of/or access to Risk Reduction Services for all women at sites where prenatal and family planning services are provided.



## DIAGNOSIS AND TREATMENT RECOMMENDATIONS

The birth defects and developmental disabilities associated with FAS/ARND can be prevented by primary prevention measures; i.e., educating young adults about the importance of preconceptional health and avoiding alcohol during pregnancy, as well as providing treatment for high-risk women. Unfortunately, when primary prevention efforts are not supported, children are more likely to be placed in the double jeopardy situation of sustaining both developmental disabilities and severe behavioral problems. However, early identification and diagnosis of children with FAS/ARND can help to mitigate some of the more severe behavioral effects of prenatal exposure to alcohol (Streissguth AP, 1978). A comprehensive system to identify, diagnose, and treat children who were exposed to alcohol should be developed and institutionalized as a statewide resource. Much of the expertise needed to operate a FAS Diagnostic and Treatment Center already exists in New Jersey at the UMDNJ. The FAS Diagnostic and Treatment Center should have 6 components, each of which is described on the next page.



# 1. IDENTIFICATION - OUTREACH AND REFERRAL

FAS/ARND identification of children should begin at the time of birth, if possible. Obstetricians should ensure that all-high risk women be linked to a risk reduction program. In addition, the Primary Care Physicians of the children born to these women must be informed of the possibility of FAS so they can monitor development. Should children display the dysmorphic features associated with FAS/ARND or show evidence of developmental delays with no genetic basis, they should be referred to the FAS Diagnostic and Treatment Center.



The FAS Diagnostic and Treatment Center should have a case management system that includes outreach and referral services. On an annual basis, case managers will contact all entities providing alcohol services, prenatal services, and/or child health services to inform them of the FAS Diagnostic and Treatment Center services. Particular emphasis will be given to programs that provide prenatal and/or treatment services to high-risk women so that a system of identifying infants at birth can be established. These include Risk Reduction Specialists in prenatal clinics, hospitals with maternity wards, health care organizations and treatment centers, and individual medical practitioners. Outreach efforts should be directed toward early intervention programs, Special Child Health Services, foster family and adoptive family organizations, pre-school programs, special education study teams and regional offices of the Division of Youth and Family Services and the Division of Developmental Disabilities.

# 2. DIAGNOSIS

A team of specialists should complete diagnoses of infants and young children. These include a Geneticist, Pediatric Neurologist and/or Developmental Pediatrician and other therapeutic specialists. If a diagnosis of FAS/ARND is made, a developmental/educational plan will be developed in collaboration with the family and education and/or community resources. In addition, with a policy of insured confidentiality, NJ mandates that the diagnosis must be reported to the Birth Defects Registry.



# 3. CASE MANAGEMENT

A core of FAS case managers of the Diagnostic and Treatment Centers will provide on going consultation and advocacy for each child who is diagnosed with FAS/ARND. Case managers will interface with the primary health care providers, early intervention programs, school study teams, and state and local agencies. They also will serve as a referral resource to community services; e.g., alcohol and drug treatment facilities for mothers.

# 4. FAMILY SUPPORT

The educational and behavioral problems of children with FAS/ARND are generally severe and families often feel isolated and at a loss about how to manage their child. The case managers will organize and lead family support groups at sites that are accessible throughout the state. The purpose of the family support groups will be to provide a forum for parents to share their concerns and experiences with each other and to obtain guidance from professionals.

## 5. PSYCHIATRIC SERVICES

Many children with FAS/ARND experience psychiatric problems, particularly depression. Psychiatric services should be available to evaluate children who are exhibiting the abnormal mental health symptoms associated with FAS/ARND and behavior analysts should assess those individuals with treatable behavior disorders. A consultation system should be established to provide continuous psychiatric services to persons with FAS/ARND and their families.

## 6. CONTINUING ALLIED HEALTH EDUCATION

The FAS Diagnostic and Treatment Center should serve as the locus of continuing education for the allied health professional community.

### SURVEILLANCE AND EVALUATION RECOMMENDATIONS

The design of the FAS Diagnostic and Treatment Center provides an ideal means to improve data collection on the incidence of FAS/ARND, including demographics of affected children. In addition, education of primary health care providers about FAS/ARND should result in an increase in reporting of these disorders to the Department of Health and Senior Services. Increased reporting will provide the data necessary to evaluate the effects of primary prevention, as well as information required for program and service planning. In addition, it may be possible to conduct cost-benefit analyses for prevention of prenatal alcohol damage. Such research could include the reduced costs to the social/health care system by early and accurate identification. In addition, it provides researchers with the ability to determine the most successful interventions and medications for impacting the behaviors and consequences associated with FAS/ARND. Therefore, surveillance and evaluation must be an integral part of the design of the FAS Diagnostic and Treatment Center.



The principal design of the FAS Diagnostic and Treatment Center is drawn from the highly successful Huntington's Disease Clinics and Support Service. Originally initiated at the Department of Genetics at UMDNJ-SOM, the service is now available at all three campuses of UMDNJ-SOM, with support groups held at additional sites throughout the state. The program has become self-sufficient through third-party reimbursement, as well as by a state appropriation of \$250,000. Similarly, the services of the FAS Diagnostic and Treatment Center will be extended to other campuses, over time. Systems for third-party reimbursement will be established for both private providers and health care organizations, as well as for the Division of Medical Assistance and Health Services. The potential will be assessed for receiving state and/or federal support to sustain and to expand the Center.

*The cost to American taxpayers for FAS is estimated to be \$5 million each and every day!*

At this time, initial funding in the amount of \$500,000 is requested to put in place the components of the Diagnostic and Treatment Center and to begin a statewide FAS/ARND pre-

vention and education campaign. This comprehensive approach will move New Jersey into the nation's forefront of FAS/ARND prevention and treatment.

## References

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# TASK FORCE QUESTIONNAIRE - UMDNJ

Department	Discussed in Program?	If yes, what Areas?	How much time devoted to topic?	Exposed to patients or simulated pts. w/FAS?	Counseling for Pregnant Women?	Advice to Pregnant Women?	Interested in Educational Materials?
<b>NEW JERSEY MEDICAL SCHOOL</b>							
NJMS Family Medicine	No			No	Yes	Stop	Yes
NJMS Medicine	Yes	Clin. Clerkship Residency	15-30 min 15-30 min	Yes	Yes	Stop	No
NJMS OB/GYN	Yes	Clin. Clerkship Residency	15-30 min 15-30 min	Yes	Yes	Stop	Yes
NJMS Pediatrics	Yes	Clin. Clerkship Genetics Residency	15-30 min > 60 min 30-60 min	Rarely	Yes	Stop	Yes
<b>SCHOOL OF OSTEOPATHIC MEDICINE</b>							
SOM Family Medicine	Yes	Clin. Clerkship	15-30 min	No	Yes	Stop	No
SOM Medicine	Yes	Clin. Clerkship Sub Internship Residency	<15 min <15 min <15 min	No	Yes	Stop	Yes
SOM OB/GYN	Yes	Clin. Clerkship Residency	<15 min > 60 min	No	Yes	Mod & Stop	Yes
SOM Pediatrics	Yes	Clin. Clerkship Sub Internship Residency	<15 min <15 min 15-30 min	Yes	Yes	Stop	No
<b>ROBERT WOOD JOHNSON MEDICAL SCHOOL</b>							
RWJMS Family Medicine	Yes	Residency	30-60 min	No	Yes	Stop	Yes
RWJMS Medicine	No			No	No		
RWJMS OB/GYN	Yes	Clin. Clerkship Residency	15-30 min 30-60 min	Yes	Yes	Stop	Yes
RWJMS Pediatrics	Yes	Clin. Clerkship Residency Elective	Assigned reading 15-30 min 15-30 min	No	Yes	Stop	Yes
<b>SCHOOL OF HEALTH RELATED PROFESSIONS</b>							
Nurse Midwifery Program	Yes	Lecture/Seminar Clinical Rotation	30-60 min 30-60 min	Yes	Yes	Stop	Yes
Physicians Assistant Program	Yes	Lecture/Seminar Clinical Rotation	30-60 min 30-60 min	Yes	Yes	Stop	Yes
Masters Physicians Assistant Program	Yes	Lecture/Seminar Clinical Rotation	30-60 min 30-60 min	Yes	Yes	Stop	Yes
Masters in Clinical Nutrition	Yes	Elective	15-30 min	No	Yes	Limit	Yes
Dietetic Internship Program	Yes	Lecture/Seminar	< 15 min	No	Yes	Stop	Yes
Diagnostic Medical Sonography	Yes	Lecture/Seminar	30-60 min	Yes	No	Stop	Yes

## TASK FORCE QUESTIONNAIRE - SCHOOLS OF NURSING

Institution	Discussed in Program?	If Yes, What Areas?	How Much Time Devoted to Topic?	Exposed to patients or Simulated Patients w/FAS?	Counseling for Pregnant Women?	Advice to Pregnant Women?	Interested in Educational Materials?
Atlantic Community College Mays Landing, NJ	Yes	Associate Degree-Maternity portion-pregnancy	15-30 min	Yes	Yes	Stop	Yes
Bayonne Hosp. School of Nursing Bayonne, NJ	Yes	Diploma Schools of Nursing: Parent Child Health Nursing-High Risk Section	< 15 min	Yes, if patient census allows	Yes	Stop- and also refer to specialist for assistance	Yes
Brookdale Community College Lincroft, NJ	Yes	Assoc. Degrees Pgm; Maternal/new-born rotation; teratogenic effects discussed- Impact on fetus & on neonate discussed	15-30 min	Yes	Yes	Stop- but don't feel guilty about having 1-2 drinks during course of pregnancy	Yes
Bloomfield College Bloomfield, NJ	Yes	Bacc. Degree; Health Promotion II - Pathophysiology and Nursing Practice in Secondary & Tertiary Prevention	30-60 min	Yes, if available	Yes	Stop	Yes
Burlington County College Pemberton, NJ	Yes	Assoc. Degrees Pgm: OB & Peds	15-30 min	Sometimes	Yes	Stop Refer to Specialist	Yes
Charles E. Gregory School of Nursing, RBMC Perth Amboy, NJ	Yes	Diploma Schools of Nursing – Family-Child Nursing Course	15-30 min	Yes If available in OBS/nursery & Peds Clin. experiences	Yes	Stop Refer to Specialist (if unable to stop drinking)	Yes
Christ Hospital School of Nursing Jersey City, NJ	Yes	Diploma Schools of Nursing-Fundamentals, Substance Abuse, OB, Fetal Development	15-30 min	Yes	Yes	Stop	Yes
The College of New Jersey Ewing, NJ	Yes	BSN Program: Growth & Development (Freshman), Childbearing course (Junior); Master Degree: Women's health & child care.	30-60 min each	Yes, MSN-FNP program	Yes	Stop	Yes
College of St. Elizabeth Morristown, NJ	No			No	Yes	Stop	Yes
County College of Morris Randolph, NJ	Yes	OB/ Assoc. Degree Nursing Program	15 -30 minutes	No	Yes	Stop	No
Elizabeth General School of Nursing Elizabeth, NJ	Yes	Diploma School of Nursing- Maternal/Child Health	15-30 min	Yes	Yes	Stop & Refer to Specialist	Yes

Essex County College Newark, NJ	Yes	Assoc. Degrees Pgm: Maternity Nursing (Nursing IV)	15-30 min	Yes	Yes	Stop Refer to Specialist	Yes
Fairleigh Dickinson University, Becton School of Nursing Teaneck, NJ	Yes	Baccalaureate Degree	15-30 min	sometimes	Yes	Stop	Yes
Holy Name Hospital School of Nursing Teaneck, NJ	Yes	Diploma Schools of Nursing During the Parent-Child Health Nursing course	30-60 min	Yes (as the clinical situations present themselves)	Yes	Stop if possible, or at least moderate their intake	Yes (educational materials)
Kean University Union, NJ	Yes	Baccalaureate Degree Pgm- Upper Division Nursing Completion Program- Course on Chronic Illness Administrative Masters	30-60 min	Yes Some-not all	Yes (done so in wellness course)	Stop	Yes
Mercer Med. Ctr. School of Nursing Trenton, NJ	Yes	Diploma School of Nursing Fresh Yr. - visit development day care centers. Nursing III, Placentation Class; Nurse IV, Subst. Abuse in Preg Both classes during clin exp	>60 min	Yes	Yes	Stop Refer to Specialist Other; No safe level of alcohol has been determined, therefore abstinence is best	No  (School situated next to Mercer Council on Alcohol and they provide speakers, literature, and films.
Middlesex County College/UMDNJ Joint Pgm Edison, NJ	Yes	Associate Degrees Nursing Pgm - OB	15-30 min	No	Yes	Stop	No
Monmouth University Long Branch, NJ	Yes	Baccalaureate Degree Nursing Prog. Master's Degree Nursing Prog.	30-60 min (as appropriate)	If clinical situation arises	Yes	Moderate Stop Refer to Specialist	Yes
Mountainside Hosp. School of Nursing Montclair, NJ	Yes	Diploma Schools of Nursing Peds/Comm. Health	30-60 min	Yes	Yes	Stop; Other, this is standard "antepartal" teaching; however, alcohol addiction is discussed in community/ mental hlth	No
Muhlenberg Reg School of Nursing Plainfield, NJ	Yes	Diploma Schools of Nursing - OB, Peds and Perioperative Nursing	15-30 min	Yes	Yes	Stop, and Refer to specialist for assistance	Yes
New Jersey City University Jersey City, NJ	Yes	Bacc. Degree Nursing Pgms- Under high risk pregnancy and newborn	15-30 min	Yes, varies with clinical group & opportunity	Yes	Stop, and refer to specialist for assistance	Yes
Ocean County College Toms River, NJ	Yes	Assoc. Degree of Nursing - Maternal Child Health course & mental health course	15-30 min	Yes, if seen clinically	Yes	Stop and/or refer to specialist	Yes



Passaic County College Paterson, NJ	Yes	Assoc. Degree of Nursing - Maternal/Child course Med/Surgery course	30-60 min	Yes	Yes	Stop, and refer to specialist	Yes
Raritan Valley Community College Somerville, NJ	Yes	Assoc. Degree of Nursing - Nursing of the Childbearing Family	15-30 min	Yes, if time show a video	Yes	Stop	Yes
Rutgers, The State University Camden, NJ	Yes	Baccalaureate Degree Pgm Peds and Maternity Nursing	15-30 min	Yes	Yes	Stop	Yes
Rutgers College of Nursing Newark, NJ	Yes	Baccalaureate Degree Pgm	30 - 60 min	Yes	Yes	Stop	Yes
Seton Hall University, College of Nursing So. Orange, NJ	Yes	Baccalaureate Degree Pgm - Nursing Care of Childbearing Family	30-60 min	Yes	Yes	Stop	Yes
St. Francis School Hospital School, Jersey City, NJ	Yes	Diploma School of Nursing 2 <sup>nd</sup> yr. of program	30-60 min	Yes	Yes	Stop	Yes
St. Francis Hospital School Trenton, NJ	Yes	Diploma School of Nursing & Assoc. Degree. Prenatal nutrition	< 15 min	Yes	Yes	Stop	No
St. Peter's College Jersey City, NJ	No						Yes
UMDNJ School of Nursing Newark, NJ	Yes	Assoc. Program	30-60 min	Yes	Yes	Stop	Yes
William Paterson University Wayne, NJ	Yes	Baccalaureate Degree Pgm on maternity nursing	< 15 min	No	Yes	Stop	No



State of New Jersey  
DEPARTMENT OF HUMAN SERVICES  
OFFICE FOR PREVENTION OF  
MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

## fy 2001 public education grants

The Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities has made Fetal Alcohol Syndrome (FAS) prevention a priority. The following projects were awarded funding based on their ability to educate about FAS. These diverse programs will be conducted throughout the State of New Jersey and will reach thousands of citizens during their implementation.

The following programs have received first year funding from the Office for Prevention of Mental Retardation and Developmental Disabilities for Fiscal Year 2001 (July 1, 2000 through June 30, 2001). These three-year projects encompass prevention education for many audiences, including allied health professionals, school children, adolescents, parents and other community entities. Programs focus upon Fetal Alcohol Syndrome and Alcohol Related Birth Defects (ARND). FAS is caused by exposure of fetuses to alcohol. A broad range of disabilities may result that include central nervous system damage, mental retardation, growth deficiency and anti-social behaviors. It is a profound, lifelong disability that is **100% preventable** if a woman does not drink while pregnant. Since there is no known safe amount of alcohol consumption during pregnancy, it is recommended that women who are pregnant or who are planning a pregnancy abstain from drinking entirely.

A requirement of grant funding is an evaluation of each project by the agency conducting the program. Evaluations are both process and outcome oriented. Approximately 20 per cent of the total grant funds during the last year of the project must be devoted to conducting the evaluation. Depending upon the nature of the project, evaluations range from written pre and post surveys to observations of behavioral change in the project participants. In addition, a comprehensive demographic survey of the project participants is completed prior to the development of the evaluation. Quarterly reports are submitted to the Office for Prevention by each grantee that outline the progress of the project and the development and administration of the evaluation. A final oral presentation and written report of each project is also required as part of the funding process.

### FAS PREVENTION FOR FAITH-BASED ORGANIZATIONS

*The Arc of Atlantic County, Inc.*

Deborah Davies, CEO  
101 Shore Road  
Somers Point, NJ 08244  
(609) 926-0800

The primary goal of this program is to prevent FAS by increasing awareness among the congregations of faith-based organizations throughout Atlantic County. Faith-based organizations cut across all levels of economic, social, health and educational status. The Arc of Atlantic County will recruit and train adult and youth representatives from the various faith communities for the purpose of establishing FAS education programs in their respective congregations.

### REMeDy: THE FAS RESOURCE CENTER OF NJ

*Central NJ Maternal & Child Health Consortium, Inc.*

Denise Stickle-Peronti, Executive Director  
501 Hoes Lane, Suite 206  
Piscataway, NJ 08854  
(732) 699-0944

REMeDY stands for **R**eferral, **E**ducation, **M**aterials, **D**irectory. The FAS Resource Center of New Jersey will provide community, professional and paraprofessional education utilizing a variety of strategies. These include a) the distribution of FAS/ARND

information to couples seeking marriage licenses; b) the development of an FAS/ARND professional educational program and instructor's guide; c) a regional FAS/ARND conference for health care professionals and d) the publication of an edition of Clinical Updates, a regional publication for health professionals, that will be dedicated to FAS.

### **FAS-PREVENTION-EDUCATION IN MONMOUTH/OCEAN COUNTIES**

*Preferred Children's Services*

Evelyn Sullivan  
P.O. Box 2036  
Lakewood, NJ 08701  
(732) 367-4700

Preferred Children's Services (PCS), a community based behavioral health agency serving Ocean County and surrounding areas; Substance Abuse Resources (SAR), a Monmouth County prevention services provider and the Alcoholism and Drug Abuse Council of Ocean County (ADACO) will collaborate on the implementation of this project. Together, they will use a variety of strategies to educate about FAS for staff, treatment providers, adolescents and high-risk children and their families in Monmouth and Ocean counties.

### **PRESCRIPTION FOR A HEALTHY PREGNANCY**

*UMDNJ-New Jersey Medical School*

Anthony Garro, Ph.D., Vice Dean  
185 South Orange Avenue, Room C-671  
Newark, NJ 07103-2714  
(973) 972-7691

Providers of health care to pregnant women are the target audiences of this project. A tool resembling a physician's prescription pad, called a "Prescription for a Healthy Pregnancy", will be given to each patient. The prescription pad will facilitate the discussion of alcohol consumption, along with other issues affecting pregnancy outcomes. A study is planned that will ascertain current health provider practices regarding advice given to women about alcohol use. This advice will be contrasted with other advice given regarding diet and smoking. It also addresses practitioners' perceptions of barriers that impede discussing alcohol use with their patients.

### **FETAL ALCOHOL SYNDROME TRAINING TRACK (FASST)**

*UMDNJ-University Behavioral Healthcare*

Ann Hummel  
671 Hoes Lane, P.O. Box 1392  
Piscataway, NJ 08855-1392  
(732) 235-4376

The FASST program is designed to reach Mercer County pregnant and post-partum women, adolescents involved in the criminal justice system and Work First New Jersey recipients at sites where Mercer Trenton Addiction Science Center (MTASC) is currently providing addiction prevention/intervention services. An educational component will consist of FAS presentations with clients who present as high risk for alcohol abuse at the clinics. In-service training for professional staff at MTASC sites and a series of brown-bag lunches will serve to increase staff awareness of FAS.

# ***NJ TASK FORCE ON FETAL ALCOHOL SYNDROME***

Former Assemblywoman Barbara Wright, Honorary Chair

Deborah E. Cohen, Director  
Office for Prevention of Mental Retardation and Developmental Disabilities

Lynn Spatzer, Task Force Coordinator  
Office for Prevention of Mental Retardation and Developmental Disabilities

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Glenna Gundell, Director Emeritus, Coalition for Prevention of Developmental Disabilities

Ruth Hladyk, Northern Region Children's Coordinating Council, NJ Parent's Caucus

Brian Illencik, The Arc of Atlantic County

Ronnie Jacobs, Council of Alcoholism/Drug Abuse of Bergen County, Inc.

Carol Kaslander, Division of Family Health Services, Maternal, Child and Community Health

Marilyn Kent, DOE, School Health Services Specialist

Mary Knapp, DHOSS, Birth Defects Registry

Patti Lucarelli, Regional Perinatal Consortium of Monmouth & Ocean Counties

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**Fetal Alcohol Syndrome (FAS)** is a cluster of permanent, non-curable brain disorders and physical malformations, including mental retardation, that is caused by women drinking alcohol during pregnancy. **FAS is 100% preventable** if the woman does not drink during pregnancy. The effects of FAS are life-long. It is the most commonly-known preventable cause of birth defects that result in

mental retardation. **Alcohol-Related Neurodevelopment Disorders (ARND)** or **Fetal Alcohol Effects (FAE)** are also characterized by organic brain damage and some physical malformations, but mental retardation is not always present.

The **FAS Info Center** is a statewide resource library that contains videos, newsletters, monographs, studies, posters, and Internet links on FAS. All the materials are available for loan. **Click here** to see a list of our resource materials.

Great Prevention related links:

<http://depts.washington.edu/~fadu>

[www.arcnj.org/html/pregnant\\_pause.html](http://www.arcnj.org/html/pregnant_pause.html)

[www.ncadd.org](http://www.ncadd.org)

[www.nofas.org](http://www.nofas.org)

[www.beintheknownj.org](http://www.beintheknownj.org)

<http://www.fasdcenter.samhsa.gov/index.cfm>

<http://www.cdc.gov/ncbddd/fas/default.htm>

[www.samhsa.gov](http://www.samhsa.gov)

Contact: Ann Wilson, The Arc of New Jersey/ Coalition for Prevention of Developmental Disabilities at 732.246.2525, or e-mail at [awilson@arcnj.org](mailto:awilson@arcnj.org)



New Jersey  
Department of Human Services



March  
of Dimes  
*Saving babies, together*