

Perinatal News

Winter, 2004

As I begin a New Year and think about goals for SCPA in 2004, one very important thing comes to mind. That is the passage by the South Carolina General Assembly of the South Carolina Birth Defects Act of 2003, House Bill 4115. SCPA, along with the March of Dimes, SC Department of Health and Environmental Control and other state organizations participated in a Task Force appointed by the South Carolina Legislature to develop a statewide monitoring program for all birth defects in our state. This legislation is a result of that work.

House Bill 4115 enacts the South Carolina Birth Defects Program to be established and operated under DHEC, establishes the purpose of the program and gives DHEC authority to carry out program activities and plan for the transition of the SC Neural Tube Defects system into the more comprehensive Birth Defects Program.

This entire Newsletter is dedicated to providing you with information about the importance of having a comprehensive system of birth defects monitoring and information in South Carolina. Congenital anomalies is the second leading cause of infant mortality in South Carolina. The South Carolina Birth Defects Program will provide vital information needed to better allocate resources, improve research and education on birth defects, enable us to identify trends over time, result in cost savings to our state and reduce infant mortality.

The passage of H-4115 is a priority for the SCPA/MOD Public Affairs Committee. The Committee is taking the lead on providing information to the SC Legislature, developing key contacts and sponsors for the bill and assuring passage in the 2004 General Assembly. We need you, as members of SCPA, citizens of South Carolina and advocates for mothers and babies to contact your local legislators and urge them to support the South Carolina Birth Defects Program H-4115. You will have an opportunity to do that face-to-face at the SCPA/MOD Legislative Breakfast on February 12, 2004. Plan to attend, call your legislator, tell him you will be there and would like to discuss the legislation with him. Grassroots advocacy works!

Jeannie Thompson

President



Annual Legislative Day, February 12, 2004

The South Carolina Perinatal Association and March of Dimes Public Affairs Committee will host its annual Legislative Day on February 12 at the Blatt Building in Columbia. Our key issues are support of the South Carolina Birth Defects Program, Bill H 4115, and support for Medicaid through increased cigarette tax.

SCPA members, March of Dimes advocacy network members, professionals, as well as, local and state leaders will receive an invitation to attend. The annual event provides an opportunity for you to meet and speak directly with your legislators. Never underestimate the power of your involvement in advocacy for mothers and babies. Your contact can make a difference. Legislators tell us for every call or letter they receive from a constituent, they assume there are ten people concerned about the same issue.

Information about the SC Legislature, including addresses and phone numbers, committees, and identifying your legislative district and representative, can be obtained from their website, The South Carolina Legislature Online ([http:// www.scstatehouse.net](http://www.scstatehouse.net)).

Please contact Kathy Ray, Public Affairs Committee, at 843-792-2602, or the March of Dimes, 803-252-5200, if you would like to become more involved in advocacy for mothers, infants, and families in our state.

Senator Smith Receives Award

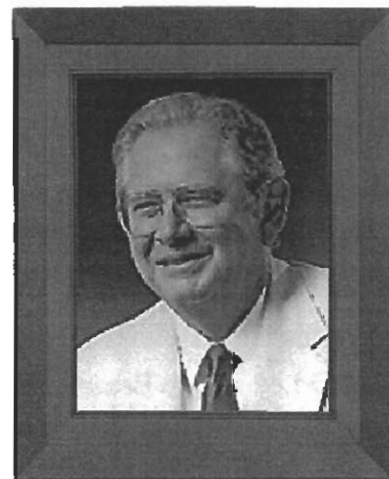
Senator J. Verne Smith is the 2003 recipient of the South Carolina Perinatal Association's Perinatal Achievement Award. Senator Smith was announced as the winner of this prestigious award at the 10th Annual South Carolina/North Carolina Perinatal Partnership Conference on September 21-23 in Greensboro, NC.

The Perinatal Achievement Award is given annually by SCPA to an individual or group who has made significant contributions to the improvement of health for SC's mothers and babies, through optimal care, education, advocacy, or research.

Senator Smith was recognized for his tireless efforts to improve health care for SC families. Senator Smith has served in Columbia since 1973, and has been a champion of legislation designed to help some of SC's poorest citizens. He supported the maintenance of regionalized perinatal care in South Carolina. Most recently, he has taken a strong leadership role to try to find permanent and stable funding for Medicaid.

Senator Smith is President of the Tire Exchange, Inc. He and his wife are long-time residents of Greer, SC, and are the parents of 2 grown children.

The South Carolina Perinatal Association thanks Senator Smith for his many years of hard work on behalf of South Carolina's mothers and babies, and for his continued dedication to improving the health and well being of our state's families.



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House Bill H-4115

A System to Identify the Incidence of Birth Defects in South Carolina

In the summer of 2002, a Task Force was appointed by the South Carolina Legislature to study the feasibility of a statewide monitoring program to capture information about birth defects in our state.

The task force was also given the assignment of determining how such a monitoring program should work. House Bill H-4115 is a result of that work.

Why H-4115 is Needed

1. **Information** Birth Defects information plays a key role in accurately identifying birth defect incidence, facilitating birth defect prevention and recurrence, and in improvement of health outcomes.

2. **Services** Monitoring programs enable referral of the child and family for clinical services, genetic counseling, early interventions, special needs programs, family support programs and other resources.

3. **Epidemiology** Accurate data, with statistical analysis, are the only means to know precise incidence, identify (or refute) clusters or "epidemics", assess geographic trends, and examine trends over time.

4. **Cost Savings** Each year's birth defects in South Carolina carry lifetime medical and educational costs of about \$100 million. The proposed Birth Defects Program, costing less than 1% of this amount, can favorably impact incidence, recurrence and outcomes with many birth defects. Our current SC Neural Tube

Defect system (1992-2002) costs approximately \$1.1 million annually, but saves approximately \$15-20 million in direct costs, aside from the indirect costs of lost productivity, and tragic human costs.

This system has been credited with reducing serious birth defects of the brain and spinal cord in South Carolina by 50% and is considered a national model.

5. **Research and Education** The program will facilitate education for both health care providers and families, and will be a resource for academic research into understanding birth defects.

6. **The National Standard** According to the Center for Disease Control and Prevention, about 2/3 of all states have a monitoring system. South Carolina has no system except for selected defects in the Neural Tube Defect system. North Carolina and Georgia have comprehensive systems similar to that proposed here.

What H-4115 Does

1. **Authorizes the South Carolina Birth Defects Program** to be established and operated under the Department of Health and Environmental Control (DHEC).

2. **Establishes the Purpose of the Program:** to monitor the occurrence of all major birth defects in South Carolina to determine rates and trends of birth defects; assess the efficiency of referral of affected children and families for services;

develop strategies for the prevention of birth defects; and promote research into the causes, distribution, and prevention of birth defects.

3. **Establishes DHEC's Authority to determine by Regulation** the staffing and procedures, develop linkages, partnerships, and agreements with agencies and organizations to carry out program activities, and plan for transition of the SC Neural Tube Defect system into the more comprehensive Birth Defects Program.

Fiscal Impact

There is no fiscal impact, as written. H-4115 establishes the structure of the program and initiates startup and transition planning. However, it is anticipated that in the future, the state would be requested to appropriate funds to assist in the operation of the program at about \$600,000 per year. The legislation would also allow DHEC to seek funding to support the monitoring program through federal grants (such as the CDC), private grants, approved fees and contracts.

Confidentiality

The legislation has the strongest possible confidentiality provisions, written in close collaboration with families and advocacy groups, to protect the privacy and rights of individuals with birth defects and their families.



If you haven't checked out the March of Dimes website lately, you are missing some great genetics information. The website is full of resources and continuing education to enhance your practice.

March of Dimes Fact Sheets cover a wide range of prenatal and genetic topics. They are available in printable format, in both English and Spanish. These are appropriate to share with families. The March of Dimes Online Catalog has many resources you can order for patient education. This includes the booklet, "Genetics and Birth Defects", which explains genetic counseling and who might benefit from counseling. The "Ask Us Now" feature allows you to ask questions of masters prepared specialists, by email or online chat. Both information and referral services are available. A wonderful continuing education program, "Genetics and Your Practice", is accessible through the website. There are also links to other genetic education or awareness sites on the internet.

WWW.MODIMES.ORG has so much more. Check it out the next time you are surfing the web or researching a genetics topic.

TIPS FOR A SUCCESSFUL LEGISLATIVE VISIT

1 **ARRANGE A VISIT.**

You should call or send a letter of introduction. Include information on your subject area and background on your organization. Request an appointment to discuss your ideas or explain why support on this issue is so important.

2 **PLAN FOR YOUR VISIT.**

Organize a short presentation before you go to the meeting. If you are going with a group, get together before the meeting to map out your strategy.

3 **PREPARE YOUR TALK.**

Expect only 5-10 minutes to make your case, or if you go with a group, 20 minutes total. Prepare a one-page fact sheet outlining your position.

4 **PRACTICE.** Have a friend critique your presentation and then share it with someone who knows very little about the issue.

Ask the person if they understand the points you are trying to make.

5 **AT THE MEETING.**

Bring copies of all important documents and duplicates of any information that you had sent out previously. Do not depend on them to have copies of your materials. Ask the legislator to use you as a resource on the issue.

He/she is not an expert on maternal and child health and will most likely appreciate your input.

6 **DON'T FUDGE ON THE**

TRUTH. If you do not know the answer, offer to get back with them about the correct information. By making this promise, it gives you a second chance to plug your issue.

7 **EDUCATE, DON'T PREACH.**

As an advocate, your job is to provide factual information that educates policymakers and/or

their staff about the benefits of allocating resources to your issue.

8 **DO NOT APPLY TOO**

MUCH PRESSURE. This is a sure-fire way to make a potential friend a definite enemy. First impressions are important. Be assertive, not aggressive or obnoxious.

9 **LEAVE INFORMATION.**

If you have one, leave a business card, or leave your name, address, and telephone number on the information that you are leaving for the policymaker or their staff.

10 **SEND A THANK YOU.**

A simple note of thanks goes a long way. In your letter of thanks, recap what was discussed, what was planned for or promised (if anything) and your willingness to provide additional information as needed.

From SCPA/MOD Legislative Manual - 2003

SC RATE OF NEURAL TUBE DEFECTS CONTINUES TO FALL

The provisional rate for NTDs in South Carolina has fallen below 0.7 cases per 1000 livebirths and fetal deaths. This is the lowest rate since surveillance for NTDs began in 1992. The rate represents a decrease of more than 60% over the past decade. In practical terms it means a healthy birth for 58 infants this year who 10 years ago would have had a serious birth defect of the spine or brain.

In 2003 spina bifida accounted for 55% (21 cases) of NTDs, anencephaly for 34% (13 cases), and encephalocele for 11% (4 cases). The cases were distributed throughout the state. Only 5% of cases are initially detected at birth. In most cases, the presence of an NTD-affected infant was found in the midtrimester by ultrasound or maternal serum AFP testing.

The NTD prevention effort in South Carolina, focusing on utilization of folic acid before pregnancy and during the early months of pregnancy, was initiated in 1992. Through physician offices and clinics and through a public awareness campaign, women of childbearing age were advised to take a multivitamin with 400 mcg. folic acid daily. In addition to this supplementation effort, the Food and Drug Administration mandated fortification of enriched cereal grain flours with folic acid. This was achieved in 1996.

This major prevention success can be attributed to the collaborative efforts of perinatologists, obstetricians, family physicians, pediatricians, nurses and other health care workers throughout the state who have helped spread the message that all women of childbearing years should take 400 mcg. folic acid every day. It also has been enabled by efforts and support of the SC Chapter March of Dimes, the state's 3 Regional Genetic Centers, Department of Disabilities and Special Needs, Department of Health and Environmental Control, Developmental Disabilities Council and Department of Health and Human Services.

A number of reports have suggested that folic acid use may also prevent other birth defects, especially facial clefting, conotruncal heart defects, limb defects and genitourinary defects. Further study is necessary to confirm these findings and if confirmed, to determine the magnitude of the protective effect.

Staff members at three regional offices of the South Carolina NTD Prevention Initiative are available to assist your office in any way to assure that your patients have information regarding prevention of these serious defects.

In the Piedmont Region (14 counties), contact Jane Dean, RN, Statewide Program Coordinator, Nancy Clary, the nurse caseworker or Dr. Laurie Seaver, the clinical geneticist at the Greenwood Genetic Center at 1-800-473-9411.

In the Midlands Region (16 counties), contact Carolyn Lovell, genetic counselor or Dr. Bob Best, head of the Division of Genetics, in the Department of OB/GYN, USC School of Medicine at (803) 779-4928.

In the Coastal Region (16 counties) contact Rene Betros, the nurse caseworker or Dr. Shashi Pai, head of the Genetics Division within the Department of Pediatrics at the Medical University of South Carolina at (843) 876-1514.

For any region in the state you may contact our office outreach representative, Dawn Delgado at (803) 315-0747 for folic acid materials to distribute to patients. Information about NTD prevention may also be obtained from the SC Chapter of March of Dimes (contact Karen Waldrop at (864) 235-8576).

TASK FORCE RECOMMENDS BIRTH DEFECTS PROGRAM FOR SC

Birth Defects continue to be the most common cause of death during infancy in South Carolina. Currently, only limited birth defect surveillance (for neural tube defects, cardiac malformations and limb reduction defects) is conducted in South Carolina.

A 21-member Task Force was established by the SC General Assembly to make recommendations regarding a comprehensive Birth Defects Program for South Carolina. The Task Force included representation from the Governor's Office, Senate, House of Representatives, state agencies, Greenwood Genetic Center, medical schools and advocacy organizations. The Task Force was asked to: 1) study birth defects surveillance methods, programs and procedures and 2) develop recommendations for establishing a statewide effective and comprehensive birth defects program for South Carolina.

Work on behalf of the full Task Force was carried out by five subcommittees dealing with:

1) Operations and Resources, 2) Data Utilization, 3) Advocacy and Family Issues, 4) Environmental Issues, and 5) Legislation.

Recommendations by the Task Force submitted to the General Assembly include:

- 1) The establishment and maintenance of a comprehensive program to monitor the occurrence of all major birth defects in South Carolina for the purposes of determining rates and trends of birth defects, assessing the efficiency of referral of affected infants and families for appropriate services, developing public health strategies for the prevention of birth defects, and conducting research on the causes, distribution and prevention of birth defects.
- 2) The identification of the program to be the South Carolina Birth Defects Program (SCBDP).
- 3) The location and operation of the SCBDP to be within the SC Department of Health and Environmental Control.
- 4) Appropriate measures be taken to protect the confidentiality and rights of

individuals with birth defects and their families.

5) Procedures be developed by which data are reported to or shared among appropriate agencies.

6) Procedures be developed for application, review, and utilization of the data for bona fide research purposes by governmental and nongovernmental institutions, agencies and organizations.

Legislation to establish the South Carolina Birth Defects program will be submitted for consideration by the 2004 General Assembly. Copies of the executive summary on the full report of the Task Force may be requested from the S.C. Chapter of the March of Dimes (Karen Waldrop, RN, Director of Program Services, March of Dimes, 37 Villa Road, Suite 317, B-123, Greenville, SC 29615) or the Greenwood Genetic Center (Dr. Roger E. Stevenson, Greenwood Genetic Center, 1 Gregor Mendel Circle, Greenwood, SC 29646)

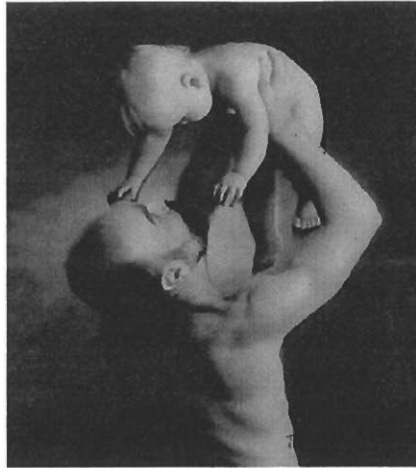
Submitted by
Greenwood Genetic Center

Alcohol, the Fetus and Fetal Alcohol Syndrome: An Education Misdirected By: Kirk Van-Beer

By the end of the 1970's, Fetal Alcohol Syndrome (FAS) was recognized as one of the three leading causes of mental retardation and had a prevalence that is comparable to Down Syndrome and spina bifida. Of the three, FAS was the only one known to be preventable. Further research recognized other characteristics in children that were not FAS but were linked to it and the term Fetal Alcohol Effects (FAE) was coined. Alcohol Related Neurological Defects (ARND) is a term now being recommended to replace FAE.

Fetal Alcohol Syndrome (FAS) is characterized by a cluster of congenital birth defects that develop as a result of exposure to alcohol before or during pregnancy. They are recognized by growth restriction, facial malformations, central nervous system dysfunction and major organ system malformations.

Fetal Alcohol Effects (FAE) or Alcohol Related Neurological Defects (ARND) is characterized by structural and functional defects



within the head attributed to prenatal exposure to alcohol. These defects include a small head size and abnormalities in the brain, which cause poor motor skills, poor eye-hand coordination, learning difficulties, behavioral problems and poor social interactions.

FAS/ARND are conditions seen by the majority of educators and clinicians as primarily caused by a mother's alcohol consumption either during or prior to pregnancy. However, work done by Gladys Friedler, Ernest L. Abel, and Theodore Cicero suggests that alcohol consumption can profoundly alter the reproductive chemistry in males.

The Alaskan Division of Alcohol and Drug Abuse, in admitting that alcohol is Alaska's number one health problem, advises men to stop using alcohol and drugs at least three months before attempting to have children, and staying that way throughout the pregnancy to support the mother.

Research on this subject appears to show that we are only just touching the edge of the iceberg of what there is to know on the subject. However, we are starting to acknowledge that alcohol does have an effect on the male's sperm by being a teratogen.

With FAS/ARND recognized as the leading cause of mental retardation among newborn children, and known to be preventable, the need for education of our families and children cannot be more important. We have missed the boat on the way we educate people. We need to focus more efforts on the effects of alcohol consumption by the male on FAE/ARND in children.

Summary by: Jeannie Thompson