

# N.C. can act against birth defects

BY SHARON J. O'DONNELL

**CARY** — I've read with interest lately about couples planning the conception of their child so the birth will take place at the start of the new millennium. While I admire their enthusiasm, I'm hoping they haven't rushed into anything — and have given top priority to the health of their child.

For example, do they know that if women take a daily vitamin with folic acid for one to three months prior to conception, their baby's chances of being born with a neural tube defect will be reduced by up to 70 percent?

Neural tube defects (NTDs) are central nervous system closure defects.

## POINT OF VIEW

They are the second-most-common type of birth defect (after congenital heart defects). They include spina bifida, in which the spine doesn't close and sometimes develops into brain abnormalities. Though most people with spina bifida can lead productive lives, it is the leading cause of childhood paralysis.

Anencephaly, another NTD, is a fatal condition in which a baby is born with a severely underdeveloped brain and skull.

These defects originate in the first month of pregnancy — before many women even realize they are pregnant. Folic acid, a B vitamin contained in most multivitamins, is very effective in preventing NTDs, as well as cleft palate and lip, but it must be taken before conception and during pregnancy.

It is very difficult to obtain enough folic acid from diet alone, and the synthetic form found in vitamins is more easily absorbed by the body. Yet a 1997 March of Dimes survey showed that only 30 percent of women take a multivitamin containing folic acid before pregnancy.

Sadly, North and South Carolina lead the nation in occurrence of neural tube defects, according to Dr. Godfrey Oakley of the Centers for Disease Control. A state Department of Health Statistics report says one in 500 live births in North Carolina is affected by NTDs each year.

And each year between 3,000 and 5,000 babies are born in the state with birth defects serious enough to affect survival or the long-term health of the child. To prevent NTDs and other birth defects, more in-depth information is needed about the occurrence of certain types of defects. Valuable information is lacking.

The March of Dimes and other agencies are planning a Folic Acid Awareness Campaign to help reduce NTDs. But first these groups need to know where to target prevention efforts — which demographic groups, geographic regions and environmental factors.

A bill in the current session of the General Assembly, setting up a Birth Defect Monitoring Program, could provide the missing puzzle piece. It seeks an appropriation of \$325,600 for the state Department of Health and Human Services to establish a timely program to record the occurrence of birth defects in each region; to analyze birth defect data; and to use the information in the development of prevention programs. State Sen. William Purcell of Laurinburg and Rep. Mia Morris of Fayetteville are sponsoring this bill; it has been introduced in the Senate as Senate Bill 834. May 11 will be Lobby Day for the bill, a day on which the March of Dimes, the Perinatal Association and other supportive groups will talk to legislators about its importance and profound impact.

Birth defects are a leading cause of death in babies under 1 year of age. Unfortunately, North Carolina ranks 47th in infant mortality, and more babies die before their first birthday in our state than in almost any other. In 1997, 982 babies here died before their first birthday. In an average week, 18 babies under a year old die. This is nothing to celebrate.

In addition to the families' personal tragedies, there are huge financial costs. According to the 1998 state Center for Health Statistics report, hospital costs for children with birth defects total \$35 million each year in North Carolina, exceeding the costs for childhood injuries, infectious disease and cancer combined.

The real tragedy, though, is the many birth defects that could be prevented, the many lives that could be changed, if only there was a way to take full advantage of the prevention information we have.

It would be great to welcome one's child into the world as a new millennium is celebrated, but the most important thing to celebrate is the birth of a healthy baby. With the Birth Defect Monitoring Program and subsequent prevention programs like the March of Dimes' Folic Acid Awareness Campaign, there can be many more first birthday celebrations all over North Carolina. Saving North Carolina's babies is a fight we have to win.

*Sharon J. O'Donnell writes a family life column for The Cary News and is co-chair of the local March of Dimes Public Affairs committee.*





*I advise and enjoin those who direct the paper in the tomorrows never to advocate any cause for personal profit or preferment. I would wish it always to be "the tocsin" and to devote itself to the policies of equality and justice to the underprivileged. If the paper should at any time be the voice of self-interest or become the spokesman of privilege or selfishness it would be untrue to its history.*

— from the will of Josephus Daniels, Editor and Publisher 1894-1948

## An ongoing crisis

**Tragically, the rate of infant deaths in North Carolina is not declining, and health officials seem unable to respond. The governor can return action and coordination to the effort.**

More than 1,000 babies will die this year in North Carolina, a tragic fact that disturbs and seems to perplex those in the halls of officialdom who are charged with addressing and finding solutions to an unacceptable infant death rate. The state ranked third in 1998, behind only Mississippi and Alabama, in the number of babies who die soon after birth, and that represents a rate that is actually down 26 percent from 10 years ago. However, 1995 was the last year the death rate dropped.

The rate of babies born at drastically low weight, a leading cause of infant death, is up 9 percent in the last decade. And medical and public policy officials are at a loss to explain why the state can't increase the number of babies it saves, or why African-American babies die at a much higher rate than white and Hispanic infants.

Those are some of the facts in a recent report by The News & Observer's Trish Wilson. Wilson also reported that state officials put money and thought into the areas of maternal health and prenatal care after its woeful ranking in the early 1990s. Health officials settled on and pushed a campaign aimed at getting women into clinics as soon as they found out they were pregnant and regularly thereafter. Science joined the battle. Along the way, doctors learned that the rate of sudden infant death syndrome could be slowed if babies were put on their backs to sleep rather than on their tummies. New drugs kept tiny lungs inflated.

But the death rate wasn't tamed, and state officials don't seem to be reacting

fast enough now that they understand that their strategies aren't working. A simple program in next-door South Carolina (in which mothers-to-be take multivitamins containing folic acid) has cut neural tube birth defects — which strike in North Carolina at an alarming rate — by a remarkable 50 percent. State officials here, however, haven't touched the program. Nor have they been able to agree on a new strategy to attack infant deaths despite recommendations from two separate state task forces.

It is disgraceful that the state hasn't invested in the folic acid campaign, especially given the strong presence of the pharmaceutical industry in North Carolina. That is a job that properly belongs to Governor Hunt. The governor, in fact, needs to put some order into the new, scary realities of infant mortality rates by taking charge of the effort. At this stage, there is an obvious and acute need to coordinate the next steps. Low rankings on national scorecards sometime spur officials to action because of the embarrassment factor. No state wants to be at or near the top when it comes to the infant mortality rate. But shame is the least worrisome part of this.

Babies are suffering and dying, and North Carolina's effort to combat the problem seems well-intentioned but stymied. The governor has admirably made children — Smart Start being the best example — his main priority in his last two terms. It appears the youngest among us need his energy in getting a safe start, too.



# Saving babies, cheaply

Members of the General Assembly could become lifesavers, making a significant difference in the number of birth defects and infant deaths in North Carolina, at an almost absurdly low cost. This small miracle involves nothing more than a program getting women who have a reasonable chance of becoming pregnant to take daily doses of folic acid, a B vitamin, in the three months before pregnancy's onset.

The science is backed by the U.S. Centers for Disease Control and the March of Dimes, the respected group that fights birth defects. A folic acid program in South Carolina resulted in a 50 percent drop in the number of babies born with certain birth defects. Those defects, along with low birth weights, are the leading causes of infant mortality in North Carolina, which has one of the nation's worst records for infant deaths. Dr. T.W. Sadler of the UNC Birth Defects Center noted in a Point of View article for The N&O last Sunday that folic acid

has been proven to reduce the incidence of low birth-weight babies, too.

Another N&O correspondent, Dr. Godfrey Oakley Jr., a visiting professor in Emory University's department of epidemiology, said in a letter to The People's Forum published Wednesday that in North Carolina, \$2 million a year would pay for an effective program of encouraging folic acid use by women of child-bearing age.

That's cheap when North Carolina bears the death of 1,000 infants a year. So it would be negligent to pass up a proven method that saves lives, keeps children from crippling disabilities, and spares families and taxpayers from the big hospital bills that accompany birth defects. So here is the challenge for the legislature: Using the research already in hand about folic acid's benefits, authorize health officials to proceed with a program. And then make sure the funding is put into the impending budget.

# Attention: State can help babies

**M**emo to legislature: How to look like a George W. Bush-like compassionate conservative.

Subject: Babies dying.

The problem: North Carolina has one of the highest infant mortality rates in the country. The state was ranked 46th in the nation



**Rob  
Christensen**

in 1997, but preliminary figures suggest a drop to 48th in 1998.

While North Carolina's infant death rate of 9.3 deaths per 1,000 births is far better than Third World

countries (Kenya's rate is 55 deaths per 1,000 births), it trails most of the industrialized world (Japan's rate is 4 deaths per 1,000 births). North Carolina trails every European country except for those that once were part of the communist Eastern bloc.

The causes: Mainly premature births and birth defects. They are often caused by poor health and poor nutrition.

Who is affected: Everybody. But the state's infant mortality rate is twice as high for blacks as it is for whites — and it's not very good for whites. For blacks, the rate is 14.8 deaths per 1,000 births, but that is expected to rise to 16.3 for 1998. That is about the same rate as Bulgaria, Jamaica and Fiji.

History: Shocked by reports that North Carolina had the highest infant mortality rate in the country, Republican Gov. Jim Martin in 1988 formed a task force to attack the problem. (Actually, it turned out that when the final figures came in the state was only 49th.)

The infant mortality rate was sharply reduced for about five years. But by the mid-1990s, the attention of policy-makers began focusing on other problems, and the drive to reduce the infant mortality rate lost momentum.

Course of action: Provide \$350,000 per year to pay for a new birth defects monitoring program. The program would analyze data of babies born with health problems so doctors and researchers could help prevent deaths or birth defects in the future.

Who's pushing the legislation: The March of Dimes, the N.C. Perinatal Association, the N.C. Folic Acid Council and the Centers for Disease Control. The group held a breakfast for the lawmakers on Wednesday.

Status: The General Assembly last year provided \$350,000 for a birth defects monitoring program, but the money was frozen and used for relief for victims of Hurricane Floyd. Bills were reintroduced last week to fund the program.

Rationale: Help parents avoid the anguish of losing a child. Prevent the suffering of children born with birth defects such as spina bifida — a similar program in South Carolina cut the rate of babies born with spina bifida in half during the past seven years. Save the state a projected \$13.7 million over the next five years in reduced Medicaid payments — and that does not count the \$35 million spent each year on hospital care for children with birth defects.

A state that is becoming a national center for banking, computers and pharmaceutical companies ought not to have babies dying at a rate that no industrialized society should find acceptable.

Political pros: Would show sensitivity toward a health problem that disproportionately hurts the poor, while not costing much money. In fact, it might save the state money in the long run.

Cons: You got me.

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Want to talk Tar Heel politics? Call Rob Christensen at 829-4532 or e-mail him at [rob@nando.com](mailto:rob@nando.com)



# Infant death rate stumps officials

*Health community not clear on what direction to take after making no headway since 1995*

Associated Press

RALEIGH — Acknowledging that improved access to prenatal care has not solved North Carolina's infant mortality problem, health officials are trying to determine a new strategy for tackling the state's troubling infant death rate.

The mortality rate is down 26 percent from 10 years ago, when North Carolina reported the second-highest infant death rate in the nation. But health officials have made no headway since 1995.

In 1998, the latest year for which figures are available, infant death rates actually went up. Preliminary figures show North Carolina now has the third-highest infant death rate in the nation, after Mississippi and Alabama.

In a crisis, two separate bills introduced in the past month have prompted the General Assembly to consider new policies and pour more money into reducing the number of

infants, say health officials. The bills would funnel more money into prenatal care, and require more data and trying

other measures.

"It's a really tough area because the consensus has broken down," said Milton Kotelchuck, professor of maternal and child health at UNC-Chapel Hill. "The public health community is not clear on what is the right direction to go in."

Despite hundreds of studies, researchers still don't know what causes premature births, can't explain most birth defects, and can't pinpoint why black babies in North Carolina die at a rate nearly three times that of white babies.

Dr. Kevin Ryan, chief of the women's and children's health section at the state Division of Public Health, said the state is doing everything within its resources to combat infant deaths.

Mortality rates dipped significantly both in North Carolina and the nation in the 1990s, primarily as the result of new lung surfactant therapies that aid respiration in premature babies.

Medicaid eligibility for pregnant mothers was expanded to include those with incomes up to 185 percent of the poverty level, and Baby Love prenatal programs aimed at low-income mothers, were initiated across the state.

But officials and researchers are at odds over what to do next.

While some argue that the state should focus on preventing birth defects, others insist on finding ways to keep babies from being

born prematurely.

In 1998, 1,037 babies under age 1 died, accounting for two-thirds of all deaths to children under 18.

The leading causes of infant mortality are birth defects, which make up 19 percent of the deaths; premature births and the accompanying low birth weights, which account for 17 percent; and respiratory disease, 15 percent.

The problem of premature births is getting worse, particularly for black parents; the rate of low birth weights has grown 9 percent in the past decade.

Low birth weights often are associated with multiple births, which — with the increased use of fertility drugs — have increased 35 percent in the past 10 years.

Researchers say one reason that North Carolina and the Southeast in general have high infant death rates is that black babies die at a greater rate than white babies, and 26 percent of all births are to black mothers.

Some researchers once thought that higher rates of poverty among black women played a role in infant mortality, but studies didn't support that theory.

"If you compare even minority women who are very well educated who get very good prenatal care, they still have a much higher infant mortality rate than white women," said Docia Hickey, a Charlotte neonatologist.

Some researchers are examining whether the problem is linked to sexually transmitted diseases, the theory being that bacterial vaginosis, a general infection, deteriorates the tissue that connects the amniotic sac to the uterus.

Thirty to 40 percent of black premature births are linked to bacterial vaginosis, said Robert Dillard, a pediatrician at Wake Forest University.

But problems are not confined to the black population. Only seven states have higher infant death rates for white women.

Health officials say women can improve their chances of having healthy babies by starting to take prenatal vitamins at least three months before getting pregnant, and by waiting at least two years between births.

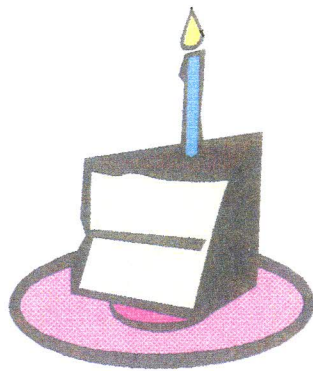
Doctors say taking a multivitamin with folic acid can reduce the risk of neural tube birth defects, such as spina bifida, by as much as 70 percent.

In South Carolina, an aggressive folic acid campaign lowered neural tube defects by 50 percent, said Dr. Thomas Sadler, director of the Birth Defects Center at the University of North Carolina at Chapel Hill.

North Carolina, where the rate of neural tube defects is among the highest in the nation, has no such program.



# North Carolina's Infant Mortality Rate



delivered  
to media,  
General Assembly,  
corporate leaders  
with cupcake  
with one candle -

## Is Nothing to Celebrate . . .

On an average day in North Carolina, three babies will die before they reach their first birthday. That means approximately 1,000 infants die each year in our state. As a matter of fact, North Carolina has one of the highest infant mortality rates in the nation, currently ranking 48<sup>th</sup>.

One main contributor to this high rate of young babies dying is birth defects, especially neural tube defects like spina bifida. North Carolina also has one of the highest neural tube defect rates in the nation, another fact that should be cause for alarm.

It's clear that our state desperately needs an active Birth Defects Monitoring Program so that data can be analyzed, causes can be determined, prevention efforts can be more effective, and therapy & services can be provided without delay. 35 states have such monitoring programs to save their children. Why doesn't North Carolina?

Hospital care alone for children under five with birth defects totals \$35 million each year in our state, exceeding the costs for childhood injuries, infectious diseases, and cancer combined.

Of course even more tragic than the staggering economic impact are the personal traumas families go through when dealing with a birth defect and possibly the death of an infant. The Birth Defects Monitoring Program would give more North Carolina families the chance to say two magic words to their beloved babies:

**Happy Birthday!!**



## Bill to Prevent Birth Defects Pending in Legislature

[Home](#) | [Local News](#)  
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**Wednesday**  
May 12, 1999  
11:00 AM

Send this  
to a friend 

DURHAM (WRAL) -- There are two bills in the [North Carolina legislature](#) aimed at preventing the birth defects that 150,000 children are born with in the United States every year.

The [March of Dimes](#) and other health organizations want to create a statewide registry so that birth defects can be studied. The immediate goal is to put resources to treat birth defects where they are needed most. Ultimately, the goal is to prevent birth defects all together.

Elizabeth Wagner is 10 and 1/2 months old and looks like any other baby, but she is one of 200 babies born in North Carolina every year with [spina bifida](#).



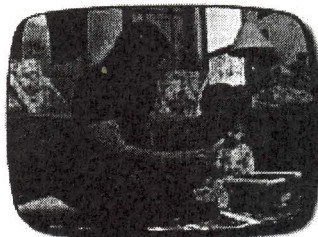
"We wouldn't trade her for anything, in our eyes she's absolutely perfect," says Elizabeth's mother.

"I think the hardest thing is waiting to see what she'll do next, trying not to get our hopes up too high, but also not to limit our expectations," says Jolyne Wagner, Elizabeth's mother.

[Representative Mia Morris](#) introduced [the bill](#) that would create a statewide Birth Defect Monitoring Program. The program would cost taxpayers \$325,000 a year.

"There is a lot of support," Morris says, "now whether or not there is the money to follow through is another challenge."

The money would also be used to create awareness. Researchers say [folic acid prevents birth defects](#), but too few women take it.



Jolyne Wagner says her daughter, who was born with spina bifida, "should walk with assistance, probably braces and crutches."

"We can prevent neural tube defects in 50 to 70 percent of women just by taking a multiple vitamin before the woman becomes pregnant," says March of Dimes Director Kay James.

Wagner believes the legislation would also help improve the quality of life for children like Elizabeth.

"These children can have productive lives and be independent with early intervention and medical care," Wagner says. Without the early care, their futures may not be quite as bright.

The cost of the program is comparable to the cost of treating one child with a birth defect in the first year. Lawmakers who support it say it is a small price to pay for healthy babies. The final decision will be made by the Appropriations Subcommittee on Health and Human Services.



Rep. Mia Morris hopes the bill she introduced to create a Birth Defect Monitoring Program will help improve the quality of life for children like Elizabeth.

Reporter: [Amanda Lamb](#)  
Photographer: [Keith Baker](#)  
OnLine Producer: [Julie Moos](#)

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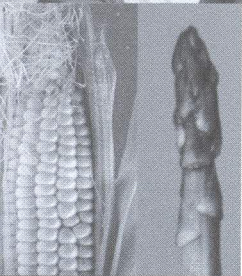
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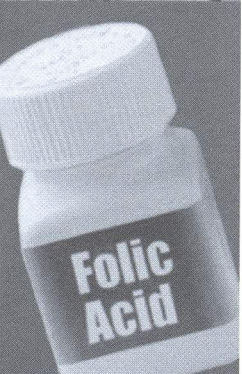


# FOLIC ACID . . .

*it's the stuff that healthy babies are made of.*



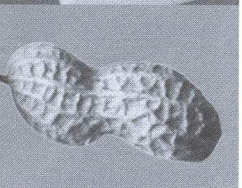
**Thank you for running this liner PSA. It's extremely important your listeners hear this message.**



## Public Service Announcement

To be run indefinitely

**The March of Dimes wants you to know multi-vitamins with folic acid can reduce certain birth defects. But these vitamins must be taken BEFORE as well as during pregnancy. For more information call toll-free 1-877-237-0085.**



## More information

Numerous studies have proven that folic acid, a B vitamin found in most multi-vitamins, can greatly reduce neural tube birth defects such as spina bifida. That's important information, particularly since North Carolina has one of the highest neural tube birth defect rates in the nation. The March of Dimes & the NC Folic Acid Council has begun a Folic Acid Campaign to get this vital message out to North Carolinians. Since neural tube damage occurs very early in pregnancy before some women even know they are pregnant, it is essential that ALL women of child-bearing age take a daily vitamin with folic acid – just in case. Unfortunately, studies show that only 25% of women in our state take a multi-vitamin. Call the NC Folic Acid Council's toll-free number at 1-877-237-0085 to find out more.



March  
of Dimes

*Saving babies, together*



# Simple pill could cut complex problems

North Carolina is among the worst states in the nation for neural tube defects, which kill or maim 200 children per year

*Duke nurse, husband understand pain of spinal cord defects*

**By JIM SHAMP**

*The Herald-Sun*

Medically speaking, Susan Gibbs didn't just fall off the turnip truck.

The 27-year-old bachelor's degreed registered nurse is coordinator of the myelodysplasia clinic at Duke University's Lenox Baker Children's Hospital. Myelo refers to spinal cord, dysplasia refers to something wrong. What's wrong with many of the people Susan Gibbs works with is called spina bifida and neural tube defect.

These are deformities of the skull, brain, spine or spinal cord that occur during the very early formation of a fetus. Some people with the problem are stillborn. Some live despite severe retardation



*NTDs could be slashed if women of child-bearing age took multivitamins*

**By JIM SHAMP**

*The Herald-Sun*

Front seat airbags have killed about eight children a year. Outraged government, industry and consumer protection types have, therefore, successfully rallied millions of dollars amid deafening demands for education and change.

An airplane crash off the coast of California recently killed 86 passengers. Government investigators, search crews, volunteers and industry representatives scrambled into an all-out offensive to find the black boxes, the wreckage, and answers to try to keep it from happening again.

During the past few weeks several Hispanic people have been found in the Triangle to have rubella.