State Medical Society of Wisconsin
Advancing the health of the people of Wisconsin

TO: **Senator Rodney Moen, Chair**
Members, Senate Health, Utilities, Veterans and Military Affairs Committee

FROM: **Kathy Andersen, Associate Director**
Colleen Wilson, Legislative Counsel

DATE: **December 8, 1999**

RE: **Senate Bill 290, Relating to Birth Defects Reporting**

The State Medical Society of Wisconsin is opposed to Senate Bill 290 because it requires physicians to send patient identifiable information to the state of Wisconsin without a parent's consent. This is consistent with the position physicians have taken on the collection of outpatient data by the state of Wisconsin without a patient's consent. The physicians of the State Medical Society strongly believe this is an intrusion into the patient-physician relationship.

Our principle objection to SB 290 could be addressed by requiring a parent's authorization before any patient identifiable information is released to the state. We believe that there should be a parent's signature on the form that is sent to the state. If a parent refuses to sign the form, a physician would send in the form, minus any identifiable information (i.e. name, address, phone number, etc.) A birthdate could be sent in to address the department's concerns regarding duplicative reporting. We respectfully request that the committee amend the bill so that confidentiality can be maintained if that is the parent's desire.

We also recommend that on page 6, line 8 the words "and treatment" be deleted from the bill. This goes beyond the scope of a registry set up to document a diagnosis and would require extensive work on the part of physician offices. Procedures performed in this state can be tracked through the mandated reporting system in the Bureau of Health Information.

Finally, we question on page 9, line 8 the addition of "and medical" to chapter 253.13 (2). It is unclear to us what "medical" services the department will be providing. This change should be further defined.

We appreciate the committee's consideration of our concerns.

330 EAST LAKESIDE ST. • PO BOX 1109 • MADISON, WI 53701-1109 • (800) 362-9080 • (608) 257-6781 • FAX (608) 283-5401 • www.wismed.com

Testimony in Support of Senate Bill 290
Senate Committee on Health, Utilities, Veterans and Military Affairs
presented by Amy L. Richardson, Regional Public Affairs Director
March of Dimes Birth Defects Foundation - December 8, 1999

Senator Moen and members of the Committee. I am Amy Richardson representing the March of Dimes Birth Defects Foundation in support of SB290. The March of Dimes is a national voluntary health organization with a mission to improve the health of babies by preventing birth defects and infant mortality. We are a unique partnership of scientists, clinicians, parents, business leaders and other volunteers who work together to accomplish our mission.

Consider these facts:
- This year in Wisconsin 65,000 babies will be born
- An estimated 2,000 babies will be born with birth defects
- 150 Wisconsin babies will die with birth defects as a cause

Anyone can have a baby with a birth defect. Similar risks are seen in parents of
- all ages
- all income levels
- all ethnic groups
- all parts of Wisconsin

The causes of most birth defects are unknown. They occur even if
- there is no one else in the family with a birth defect
- the mother gets good prenatal care
- the mother does not drink alcohol or take drugs

Very little is known about environmental causes of birth defects and what exposures are or are not safe. That's where birth defects surveillance becomes important.

What is Birth Defects Surveillance?
Birth defects surveillance is the collection and assessment of birth defects data to determine where, when and whom birth defects affect. It is important to note that the data is collected following the birth of the baby .Surveillance is the foundation for birth defects research and prevention activities and is not only important for detecting birth defects, but for
1) planning and evaluating the effectiveness of public health education and
2) ensuring that appropriate care is provided to families in need of ongoing services.

Brief History
Earliest legislative efforts requiring the reporting of birth defects in the United States date back to 1926 in New Jersey. However, widespread interest in surveillance was not generated until the early 1960's, when an epidemic of limb reduction deformities was associated with women's prenatal use of thalidomide. At the time few specific causes of

birth defects were known, yet patterns were suggesting that unidentified environmental factors were causing this particular defect. In 1978 only three state or local surveillance programs existed in the United States. Today at least 30 states have surveillance programs of varying degrees.

The Present

We know a lot more now than we did twenty years ago, and yet we know so little. When a cluster of birth defects that was discovered in Brownsville, Texas in the late 1980's, public health officials were alarmed. This cluster of neural tube defects – babies born with open spine or without part of the brain – went undetected for several years. From this tragedy came two important things:
1) federal legislation on birth defects surveillance and 2) the research that determined the role of folic acid in preventing this particular birth defect.

The Birth Defects Prevention Act of 1998 was passed with strong bipartisan support, led by Senate Majority Leader Trent Lott, Senator Kit Bond of Missouri, Senator Edward Kennedy and on the House side Representative J.C. Watts of Oklahoma and Solomon Ortiz of Texas. The bill establishes authority within the Centers for Disease Control and Prevention (CDC) to provide surveillance, research and services aimed at the prevention of birth defects. The act directs the CDC to support

- eight regional Centers of Excellence (MA, IA, CA, NY, TX, AR, NJ, GA)
- clearinghouse to provide public and professional education
- technical assistance to the states. 18 states out of 36 that applied received planning grants of $100,000 per year for three years.

The Brownsville, Texas tragedy is an excellent example of how research and public health education can work together to prevent birth defects. Now the CDC, the March of Dimes and other organizations are working together to educate women of childbearing years about taking folic acid prior to conception.

Pew Environmental Health Commission at Johns Hokpins School of Public Health (Baltimore). (news release)The Pew Commission provides leadership for strengthening the country's defenses against environmental health threats particularly as they relate to children's health. The recently released report calls for a national birth defects surveillance system and notes the inconsistent record-keeping among states. Futhermore, the report gives each state a grade on its surveillance system and Wisconsin very appropriately received a grade of "C."

Surveillance can facilitate the early detection of birth defects following birth that can lead to early intervention and treatment. Information identifying the family is important for connecting families to services. It is also important so that duplication of records does not occur. In states with fully functioning systems, it is not uncommon for a birth defect to be reported an average of four times from different sources. Great care has been taken in SB290 to ensure that the privacy of the individuals is protected. Birth

defects surveillance can be accomplished while protecting the privacy of individual families. It just needs to be a priority.

In closing, I remind the Committee that the Wisconsin Legislature makes decisions based upon what is important to us as a state. If we lose sight of the of fact that birth defects are a major public health issue, then we have lost part of the vision that has made Wisconsin a leader in health. What could be a better investment or more important than finding the cause of birth defects and improving all birth outcomes? March of Dimes is pleased to give its full support to this bill.

Thank you.

Milwaukee Journal Sentinel
November 26, 1999

Wisconsin infants lead nation in cleft palates

High rate could be part of recent rise in birth defects

By Neil D. Rosenberg
of the Journal Sentinel staff

Wisconsin has the highest rate of babies born with cleft palates, which may be part of a larger nationwide increase in birth defects, possibly linked to environmental hazards, a national report shows.

But because of a lack of adequate reporting systems for birth defects among most of the 50 states — including Wisconsin — the true extent of the problem and its causes remain elusive, according to the report.

Data from 29 states show that Wisconsin has 14.8 cases of cleft palate per 10,000 live births, or approximately 104 cases a year.

The report, issued last week, came shortly after state legislators from both parties sponsored a bill that would require hospitals and clinics to report all birth defects in Wisconsin. The bill, which is pending before the Legislature, would keep the names of the children confidential.

The current law requires only physicians to report cases "and very few of them ever do," said Russell Kirby, an epidemiologist and associate professor of obstetrics and gynecology at the University of Wisconsin Medical School's Milwaukee clinical campus at Sinai Samaritan Medical Center.

Clefting, which involves either the palate or the lip, occurs at different rates within various ethnic groups, said Arun Gosain, an associate professor of plastic surgery at the Medical College of Wisconsin, who performs cleft lip and cleft palate surgery at Children's Hospital of Wisconsin.

The incidence is about 1 in 500 among Asians; 1 in 1,000 among whites; and 1 in 2,000 among blacks. So, increasing numbers of Asian immigrants could raise a state's incidence of cleft palate and cleft lip, Gosain said.

Gail McCarver, a neonatologist and co-director of the birth defects research center at Children's Hospital of Wisconsin and the Medical College of Wisconsin, said she had no reason to doubt the study's findings concerning Wisconsin's ranking. Cleft palate is such an obvious birth defect that when it occurs, it most certainly would be entered on nearly all birth certificates, she said.

Please see **BIRTH** *page 10*

"That's probably accurate," she said. "There is reason to have concern."

But McCarver said she could not offer a reason as to why the cleft palate rate was so high in the state.

Clefting, whether of the lip, palate or both, generally is correctable with surgery.

"These children can get normal results, both in appearance and speech," Gosain said. "The important thing is early recognition and treatment.

The report, by the Pew Environmental Health Commission at the Johns Hopkins University School of Public Health, recommends that all states create "active" surveillance systems, in which staffers are paid to ferret out cases and carefully record them for later analysis. Only 10 states have such active systems.

Wisconsin received a grade of C for its birth defects monitoring system — it could have received an A, a B or an F for failing — because its system of birth defect surveillance is a passive one. That is, it does not actively seek out records and could result in cases being missed.

Because 15 states, as well as Washington, D.C., and Puerto Rico, have no birth defect reporting systems at all, the extent of the birth defect problem in the United States remains unclear, conceded Shelley Hearne, executive director of the Pew

Nationwide, other alarming trends included:

- The frequency of infants born with a hole in the wall separating the upper chambers of the heart has risen from 14.1 cases per 10,000 births in 1989 to 34.9 cases in 1996, a more than twofold increase.
- The frequency of infants born with complete or partial blockages of the urinary tract went from 9.7 cases per 10,000 births in 1989 to 15.5 cases in 1996, an increase of almost 60%.
- There also has been an increase in low birth weight and preterm infants, 6% higher in mothers ages 20 to 34 in 1997 compared with 1990.

What is clear is that there are at least 146,000 babies born each year with birth defects, which remain the leading cause of infant mortality in the United States with about 6,500 deaths a year, Hearne said.

Kirby said lack of resources has hindered the creation of an active surveillance system.

Things are improving, though, he said. With a $100,000 appropriation in this year's budget, the state Bureau of Public Health will have two full-time staffers devoted to addressing issues of birth defects in the state.

But Kirby, a central figure in efforts to beef up birth defect surveillance in Wisconsin, said it would require $500,000 a year for up to eight full-time employees, including those in the field securing data, a field supervisor, database technician and epidemiologist; and for necessary computer hardware and software.

That was requested in this year's state budget, but the allocation was reduced.

Sen. Kimberly Plache (D-Ra-

Birth/State's infants lead U.S. in cleft palates, report shows

"Our intent is to help the families of the infants get the necessary aid that they are entitled to ... and to obtain data for scientific purposes that could lead to the prevention, treatment or cure of birth defects."

Rep. Sheldon Wasserman

cine) and Rep. Bonnie Ladwig (R-Racine) are lead sponsors of the proposed bill.

Wisconsin was downgraded in the Pew study for not reporting birth defect data in a timely manner and having no capabilities to analyze the data that is collected.

That could be because one staff member is responsible for maintaining all such records for the state, said Rep. Sheldon Wasserman (D-Milwaukee).

The bill calls for establishing a special birth defect council, composed of medical experts and others who have experience with children born with birth defects, to increase the effectiveness of the registry. It also outlines who may have access to the information to eliminate possible exploitation of the families, Wasserman said.

"Our intent is to help the families of the infants get the necessary aid that they are entitled to by the state and federal governments," said Wasserman, who also is an obstetrician. "And to obtain data for scientific purposes that could lead to the prevention, treatment or cure of birth defects."

The United States has the worst infant mortality rate of any of the largest industrial nations in the world. Its infant death rate ranks 25th among all nations.

Hearne said 80% of birth defects have no known cause, but there are suggestions that environmental factors — diet, tobacco, toxins in water and air — may play a large part.

The report notes that studies have linked defects of the nervous system and heart in newborns to living close to a hazardous waste site. A New Jersey study found that mothers living closest to landfills were five times more likely to have babies of lower birth weight than other mothers.

An investigation of neural tube defects in newborns in Brownsville, Texas, ultimately led to the finding that lack of folic acid in the diet during pregnancy increased the risk of such defects, Hearne said. That led to the government regulation recommending increased intake of folic acid and allowing certain foods to be enriched with it.

With the link between the environment and birth defects still unclear, she said, an argument can be made for better birth defect reporting systems to recover the data necessary to undertake proper research to tease out the root causes of birth defects.

Part of the problem is that only $8 million out of $30 million authorized by Congress in the National Birth Defects Prevention Act of 1997 has been appropriated to date, Hearne said. That money would be used to upgrade surveillance programs among the 50 states.

As a result, 36 states applied for the funds but only 18 received them. Wisconsin was not one of them.

John Fauber and Kawanza L. Griffin of the Journal Sentinel staff contributed to this report.

Study finds rise in 2 birth defects, but numbers are suspect

Researchers call for national tracking system

By Anita Manning
USA TODAY

A survey of state and federal health statistics being released today finds a sharp increase in two specific birth defects between 1989 and 1998.

But researchers say they can't interpret the data because of inconsistent record keeping among the states.

The increases in the two defects, one involving the heart and the other involving the urinary tract, might reflect an actual rise in incidence, says pediatrician Lynn Goldman, who conducted the study, sponsored by the Pew Environmental Health Commission at Johns Hopkins School of Public Health in Baltimore.

But the increases also could reflect improved diagnosis or better tracking of the defects in states that keep records, she says.

"The problem is there is so much variability in how these state (reporting) systems operated," Goldman says. "As a pediatrician, I'm very concerned that you see these data and don't have a system in place to determine if they are accurate and what to do about it."

The survey found that between 1989 and 1996:

▶ The rate of atrial septal defects, a hole in the wall between the two upper chambers of the heart, grew from 14.1 cases per 10,000 births to 34.9 per 10,000 births.

▶ The rate of obstructive genitourinary defects, blockages in the opening of the urinary tract, rose from 9.7 cases per 10,000 births to 15.5 cases per 10,000 births.

▶ The incidence of low-birthweight and pre-term births has risen steadily since the mid-1980s, even in single births to mothers ages 20 to 34. From 1990 to 1997, 6% more babies born to those mothers were very low weight at birth — less than 1,500 grams, or 3.3 pounds.

Baby health starts before pregnancy

The March of Dimes says that to increase the chance of having a healthy baby, expectant mothers should:

▶ Take 400 micrograms a day of folic acid to prevent neural tube defects such as spina bifida. Begin before pregnancy because these defects occur during the first few weeks.

▶ Reduce exposure to pesticides. Wash fruits and vegetables before eating them, and don't use or apply pesticides.

▶ Don't take any drugs during pregnancy unless directed by a physician.

▶ Don't smoke, and avoid exposure to secondhand smoke.

▶ Avoid exposure to solvents, paint and other toxic substances.

▶ Avoid alcohol.

▶ Avoid stress.

▶ Eat a balanced diet, get plenty of rest and exercise, and get regular prenatal checkups.

For more information, call the March of Dimes (888-663-4637) or visit its Web site (www.modimes.com).

The report says a third of states, along with the District of Columbia and Puerto Rico, do not track birth defects, and 25 other states have inadequate monitoring systems.

Birth defects, the leading cause of death in the first year of life, kill 6,000 babies and cost the economy an estimated $8 billion annually, says Goldman, a former assistant administrator at the Environmental Protection Agency.

"We found only 20% (of birth defects) have known causes where there is enough information to take steps to prevent them," she says.

Many scientists suspect that exposure to environmental contaminants plays a significant role.

"We found that in our society, there is a lot of use of pesticides and chemicals known to be toxic to the developing fetus, but there is little data on exposures," Goldman says.

That may be surprising to the public "because everyone thinks, in this day of technology and the computer age, we know everything about everything," says Shelley Hearne, executive director of the Pew Environmental Health Commission.

"But we don't know fundamental information about the health of the citizens. We know more about the health of a fish than we do of the health of a child."

The commission plans similar studies on asthma and childhood cancer, Hearne says.

The report says that funding of the federal Birth Defects Prevention Act of 1998 falls $22 million short of what is needed to set up a national tracking system. The report urges full funding for such a system, along with a national effort to monitor exposure to environmental contaminants.

"The vision is there," Hearne says. "This is not rocket science. This is basic public health."

EMBARGOED FOR RELEASE
Until Noon EST Nov. 16, 1999

Contact: Donna Rohrer or Sara Sigelman
(202) 659-0330

Commission Study Finds Increases in Certain Birth Defects

Nearly 59 Million Americans Not Covered by Birth Defects Tracking

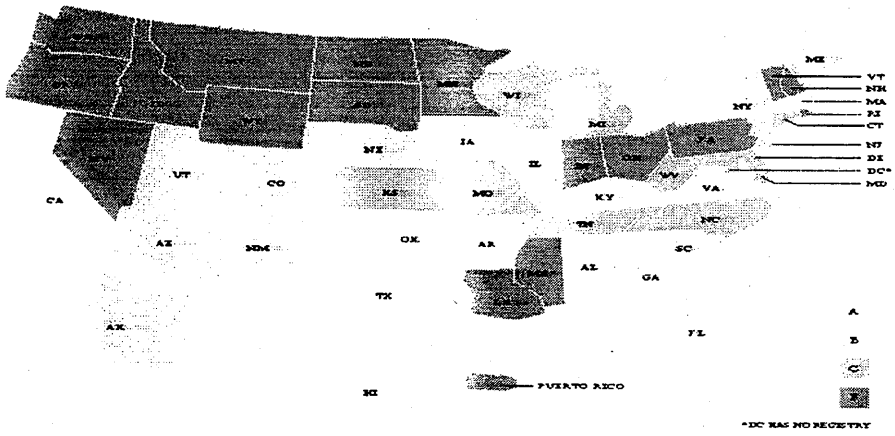
NEW YORK – Nov. 16, 1999 – A major analysis of national data on birth defects and the environment has found unexplained increases in certain birth defects and related conditions that point to the need for strengthening the public health system.

Even though birth defects are the nation's leading cause of infant death, one-third of the states, the District of Columbia and Puerto Rico – with a total population of nearly 59 million – fail to track birth defects, and 25 more states have systems that need improvement to better protect the public.

The study, conducted by the Pew Environmental Health Commission at the Johns Hopkins University School of Public Health, reported that only about 20 percent of birth defects have known causes, while the causes of the majority await further research. However, there is increasing evidence that environmental factors, including diet, personal behavior and exposure to toxic substances and pollutants, may play an important role in the development of birth defects and related conditions.

Commission researchers concluded that the unanswered questions about wide variations in certain birth defect rates reported over an eight-year period may be the result of improved diagnoses, variations in state tracking procedures or increases that are actual.

Researchers evaluated each state's monitoring effort and graded each on its quality. One-third of the states, the District and Puerto Rico – or 19 – received an "F" grade because they do not currently track birth defects at all. Only eight states were awarded an "A" for systems that can be helpful to future research on the causes of birth defects. The remaining 25 states have tracking systems that are in need of improvements.



SCORECARD OF STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS, NOVEMBER 1999
Detailed descriptions are available on the Commission's website: http://pewenvirohealth.jhsph.edu

"Without this information, public health officials are working in the dark," said Lowell Weicker, Jr., former Connecticut governor, three-term U.S. Senator and chairman of the commission. "We lack the key tool needed to identify emerging disease clusters and trends, making it tougher to tackle the environmental threats that may cause sickness and death in our children."

While federal and state investments in birth defects monitoring over the past two decades have produced some excellent systems, as observed in the commission's report, much more must be done.

"What we need is full funding of the Birth Defects Prevention Act of 1998," said Dr. Jennifer L. Howse, president of the March of Dimes and member of the commission. "This legislation called for more surveillance, research, education and services to prevent birth defects and protect children, but without full funding the job just won't get done."

The analysis examined data from the Centers for Disease Control and Prevention and states gathered from 1989-1996. Increases were found by analyzing information from those states with tracking systems for birth defects.

Among the study's findings about birth defects and related conditions:

- Rates of babies born with low birth weight and pre-term conditions have been rising steadily since the mid-1980s despite increased prevention efforts. Low birth weight and pre-term conditions in infants contribute to infant deaths and often accompany birth defects and related conditions such as cerebral palsy and mental retardation.
- The rate of infants born with one serious heart defect rose 2 _ times in less than a decade among states that track this defect.
- The rate of infants born with a blockage in the urinary tract rose more than 1 _ times in less than a decade among states that track this defect.

As a reflection of the variations in birth defects monitoring systems, researchers found inconsistencies even among the 33 states collecting data.

"Gaps in quality and consistency in state data prevent public health officials from answering the many disturbing questions raised by our analysis," said Dr. Lynn R. Goldman, principal investigator on the birth defects study.

"We know more about how much pollution we put in our physical environment than we know about the levels of those pollutants in our bodies and how they can affect the health of a developing baby," she said.

The Pew Environmental Health Commission was launched in May to develop recommendations to improve the nation's ability to track and prevent health problems linked to environmental conditions. Commission members include leaders from the public policy, health industry, government, academic and nonprofit communities.

In the coming months, the Commission will study two other children's environmental health issues, asthma and childhood cancers, and examine the quality of state tracking systems and other issues relating to the capacity of the public health system to combat new threats to health.

The Pew Environmental Health Commission is funded by a grant to the Johns Hopkins School of Public Health by The Pew Charitable Trusts. The Pew Charitable Trusts support nonprofit activities in the areas of culture, education, the environment, health and human services, public policy and religion. Based in Philadelphia, the Trusts make strategic investments to help organizations and citizens develop practical solutions to difficult problems. In 1998, with approximately $4.734 billion in assets, the Trusts granted over $213 million to 298 nonprofit organizations.

For the full report and state-by-state analysis, visit the Commission's website at http://pewenvirohealth.jhsph.edu

###

FACTS ABOUT BIRTH DEFECTS AND WISCONSIN'S ENVIRONMENT

1. Birth defects are the leading cause of infant death in the United States.

- Birth defects cause more than 20% of infant deaths in the U.S.
- In 1996, Wisconsin's rate of infant mortality was 7.3 deaths per 1000 live births.

2. Certain birth defects are rising and poor birth conditions such as preterm (less than 37 weeks) birth and low birthweight (less than 2,500 grams) are also problems.

- In 1996, 6.3% of all babies were born low birthweight in Wisconsin.
- Wisconsin has the highest prevalence of cleft palate among all states recording this birth defect. Between 1989 and 1996, Wisconsin's total rate of cleft palate was 1.48 cases per 1000 births.
- Changes in birth defects trends may be due to changes in reporting or diagnosis rather than actual increases in the defect itself.

3. The causes of about 80% of all birth defects are unknown.

- A study by the California Birth Defects Monitoring Program found that women living within one-quarter mile of a hazardous waste site were twice as likely to have babies with neural tube defects and four times as likely to have babies with serious heart defects. Also, a study by the New Jersey Department of Health and Senior Services found that mothers living closest to landfills were five times more likely to have babies of lower birthweight than other mothers.
- Wisconsin currently has 10 hazardous waste sites on the National Priority List.
- In 1998, scientists declared that the Great Lakes are still not clean. Chemicals remain in lake sediments and pollutants continue to enter the lakes' ecosystems from sources such as hospital incinerators and herbicide-treated farmland. Herbicides have been associated with birth defects.
- In May 1999, an environmental report noted that 330 of Wisconsin's lakes have consumption advisories warning residents of mercury-contaminated fish. Mercury has been linked to birth defects. The report also suggested that coal-burning power plants were the primary source of mercury contamination. The report suggested that coal-burning power plants are responsible for 39% of the mercury emitted into Wisconsin's air. Chemical companies and solid waste incineration also emit mercury.
- In 1998, Wisconsin had 447 fish advisories in effect (13 more than in 1997) according to the EPA. Fish advisories notify the public that local fish and wildlife have high levels of contaminants such as PCBs and mercury. Both PCBs and mercury have been linked to birth defects.

4. To strengthen efforts to prevent birth defects, the Pew Environmental Health Commission is recommending a national approach to monitoring birth defects and infant mortality in all 50 states.

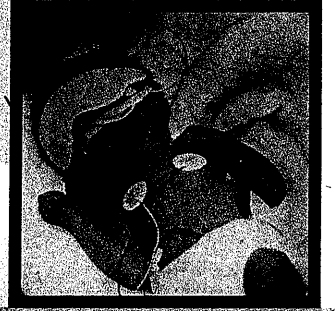
- State birth defects registries currently cover less than half the U.S. population.
- Research on the causes of birth defects and adverse health outcomes needs to be based on complete, accurate data.

5. Based on its birth defects surveillance program and compared to other state registries, Wisconsin's Birth and Developmental Outcome Monitoring Program (BDOMP) scores a C.

WISCONSIN VS. THE UNITED STATES—BIRTH DEFECTS MONITORING

An outstanding birth defects surveillance program scores an "A" because it satisfies the following scorecard categories, overall: statewide, covers all birth defects, counts fetal deaths (stillbirths), follows-up at least through the first year of life, is timely in its data production, actively searches out records, and has analytic capabilities. **Based on its birth defects surveillance program and compared to other state registries, Wisconsin's Birth and Developmental Outcome Monitoring Program (BDOMP) scores a C.**

- Wisconsin has a system that scores average in its capabilities. Its registry is statewide, covers all birth defects, follows-up at least through the first year of life, and includes fetal death records.
- However, Wisconsin's surveillance system is passive meaning that investigators do not actively search out records; therefore, many cases of disease or deaths may be missed.
- Also, Wisconsin's birth defects surveillance program is not timely in producing its data, and it does not have analytic capabilities.



Why America Needs

a Better System

to Track and Understand

Birth Defects

and the Environment

HEALTHY FROM THE start

COMPANION REPORT

THE PEW
ENVIRONMENTAL
HEALTH COMMISSION
at the Johns Hopkins School of Public Health

FOREWORD

by commission chairman Lowell Weicker, Jr.

For more than a quarter-century, we have made enormous strides in protecting our air and water quality and preserving areas of natural beauty and biological diversity essential to a healthy environment.

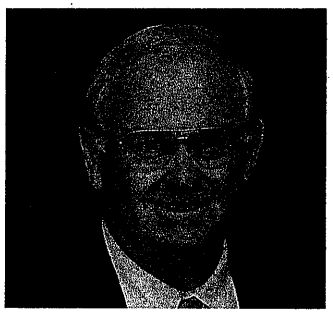
Despite this progress, and many public health breakthroughs over the past 100 years, we have lost our focus on protecting our children from health hazards arising from exposure to environmental contaminants.

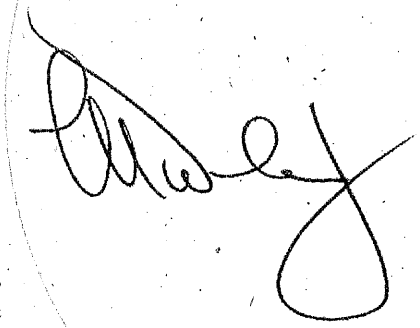
In the coming months, Pew Environmental Health Commission researchers will examine three serious health problems affecting thousands of American children: birth defects, asthma and childhood cancer. Unfortunately, one key finding will be the lack of health tracking information needed to understand and prevent these terrible killers and disablers.

These reports will not solve the problems of why too many American babies die each year of birth defects or why asthma among our children is at near-epidemic proportions or what causes childhood cancers. However they will raise scientifically valid questions aimed at redirecting our national will to solve this health crisis of chronic disease and disability.

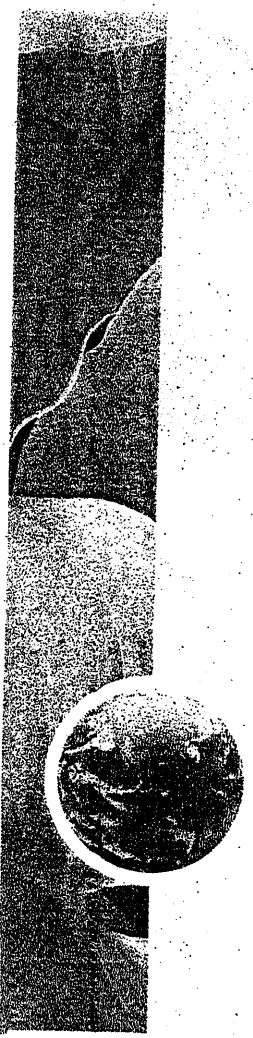
As a longtime advocate for our public health institutes, I am dismayed that we only track pollutants in air and water, but not the levels of exposure in our bodies.

The time has come to renew our investment in a public health system that will prevent the chronic diseases and disabilities that today afflict millions of Americans, especially our children.





The Commission will be providing policymakers, the public health community, and business and environmental organizations with a series of recommendations aimed at reshaping America's public health system.



The full text of Healthy From the Start is available on the Commission's website at http://pewenvirohealth.jhsph.edu

INTRODUCTION

Birth defects are the leading cause of infant mortality in the United States, about 6,500 deaths annually. For some groups in the United States, such as African Americans, preterm birth and low birthweight are the leading causes of infant mortality. Moreover, the reporting of certain birth defects and related conditions has increased over the past decade, according to an analysis of data collected from 29 states by the Centers for Disease Control and Prevention over the period from 1989-96.

The study analyzed a number of birth defects and several related conditions—preterm and low-weight births, and cerebral palsy, mental retardation and autism. While about 20 percent of birth defects have known causes, the causes of 80 percent of all birth defects and related conditions remain elusive, even as evidence mounts that environmental factors—including diet, personal behavior, and exposure to toxic substances and pollutants—play an important role in the development of these tragic and costly conditions.

The U.S. has the worst infant mortality rate among the G-7 industrialized nations and ranks 25th internationally, principally as a result of birth defects and related conditions.

What the analysis found is a wake-up call to strengthen and improve our nation's public health policy. The data show that despite much progress in clinical medicine, we know far too little about why rates of birth defects and related conditions remain stubbornly high and appear to be increasing in many instances.

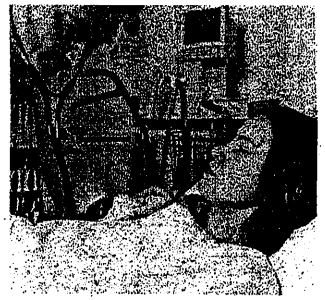
The good news is that much progress has been made in identifying environmental factors related to diet and personal behavior. For example, public health research helped to establish the detrimental effects of alcohol, caffeine and tobacco on a baby's development in the womb and the hazards posed by some medicines. Without public health research and education, American women might not have information about these threats, or the benefits of prenatal checkups, adequate diet, rest, exercise and avoidance of stress during pregnancy.

But despite all of these advances in medical knowledge and understanding–

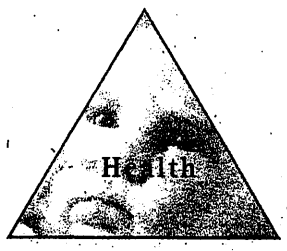
- The U.S. has the worst infant mortality rate among the G-7 industrialized nations and ranks 25th internationally, principally as a result of birth defects and related conditions.
- The costs also are tragically high, both for families and the nation. Recent estimates place the cost to the economy at $8 billion annually. In addition, the U.S. bears the burden of the direct costs of health care and disability and indirect loss of productivity related to low birthweight and preterm birth complications. Both contribute to infant deaths, and frequently accompany birth defects and such related conditions as cerebral palsy, mental retardation and autism.
- Despite the substantial gains that have been made in birth defects surveillance over the past two decades, public health researchers cannot pinpoint national trends because state tracking of birth defects remains inadequate. In fact, one-third of the states have no system for tracking birth defects at all.

The United States has an adequate network to capture important data on infectious disease in order to spot dangerous outbreaks before they spread. Certainly, we know how to build an effective mechanism that provides the consistency of reporting data and privacy protections. What is lacking is a national policy to guide state implementation of a comprehensive, modern tracking program that will help identify environmental and other preventable factors that contribute to birth defects and other disabilities and chronic diseases.

Addressing these tragic conditions and generating better information about environmental causes should be a national priority because birth defects and related conditions may be preventable.



While we as a nation have conducted considerable research on the role of social and biological factors, the adverse health effects of exposures to environmental toxicants are not receiving the attention they need. Against this backdrop, the Pew Environmental Health Commission urges a national review to reinvigorate the ability of our public health system to understand and prevent chronic disease and disability. Upgrading the system, with a special emphasis on improving and expanding what information is tracked on a nationwide basis, is crucial to meeting environmental challenges to a healthy society.



D E T E R M I N A N T S O F H E A L T H

BIRTH DEFECTS study

A birth defect is "any anomaly, functional or structural, that presents in infancy or later in life and is caused by events preceding birth, whether inherited or acquired."

—March of Dimes

The Pew Environmental Health Commission report on birth defects and related conditions covers low birthweight and preterm births, 20 different structural birth defects, and three developmental disabilities—cerebral palsy, mental retardation and autism. It has three objectives:

- Examine the quality and comprehensiveness of state tracking systems in order to assess the ability of researchers to answer questions about causes and prevention strategies;
- Examine existing data on state registries on births and birth defects to learn more about the rates and variations among states;
- Investigate the connection between exposure to environmental toxicants and birth defects and related conditions.

KEY FINDINGS on birth defects

- U.S. rates for a number of major birth defects are on the rise, and although these rates vary among the 29 states whose rates could be compared, there are some dramatic increases that deserve further study.
- Certain conditions in the analysis were increasing over time. We do not believe the reporting systems are reliable enough to conclude whether these increases are real or just changes in diagnosis over time. For example:
  - The increased rate in infants born with atrial septal defect, ASD (a hole in the wall between the two upper chambers of the heart) deserves further study. The analysis found that ASD rose from 14.1 cases per 10,000 births in 1989 to 34.9 per 10,000 in 1996, an increase of 2.5 times in eight years for states that track this defect.
  - The increased rate in infants born with obstructive genitourinary defects (complete or partial blockages in the opening of the urinary tract) also warrants more study. The analysis found that these defects rose from 9.7 cases per 10,000 births to 15.5 cases in the same time period, a 1.6-fold increase, for states that track this defect.
- States with more comprehensive tracking systems had significantly higher birth defect rates, most likely because better resources allowed for better data collection. For instance:
  - The average for states with the best tracking systems showed the rate of tricuspid valve atresia (an absent or restricted heart valve) was 870 percent higher than the average of states with less-effective tracking systems, over the period from 1989-96.
- Low birthweight and preterm births have been rising steadily since the mid-1980s despite increased prevention efforts. This trend is even found in single births to mothers ages 20-34. From 1990-97, 6 percent more babies born to these mothers were very low weight at birth (less than 1,500 grams). Even white single births showed the same trend, with a 4.6 percent increase in preterm births from 1989-96.

Summary Table of Birth Defects and Related Conditions

	Birth Defect	Dev. Disability	Birth Cond.	Definition	Suspected Enviro. Factor
Anencephaly	X			absence/near absence of brain	X
Atrial septal defect	X			opening(s) in wall between 2 upper heart chambers	X
Autism		X		limitations in social interaction, communication, imagination	X
Cerebral palsy		X		muscle impairment syndrome; abnormal body control	X
Cleft lip	X			failure of lip components to join	X
Cleft palate	X			failure of palate components to join	X
Common truncus arteriosus	X			fusion of 2 main arteries leaving heart	
Diaphragmatic hernia	X			hole in diaphragm between lungs and abdomen	
Down syndrome	X			genetic condition resulting in mental retardation, phys. markers	
Esophageal atresia/tracheoesophageal fistula	X			incomplete esophagus or hole between esophagus and trachea	
Gastroschisis	X			opening in wall of intestines	X
Hypospadias/epispadias	X			urinary outlet on males is in abnormal position on penis	X
Low birthweight			X	newborn less than 2500 grams at birth	X
Mental retardation		X		conditions characterized by thought, function limitations	X
Obstructive genitourinary defect	X			blockage or failure to form urinary tract outlet	
Preterm			X	newborn less than 37 weeks gestation	X
Rectal and large intestinal atresia/stenosis	X			blockage or failure to form rectum, large intestine or anus	
Reduction deformity, lower limb	X			absence of portion of lower limb	
Reduction deformity, upper limb	X			absence of portion of upper limb	
Renal agenesis/hypoplasia	X			failure of kidney development	
Spina bifida	X			failure of spinal cord to close	X
Tetralogy of Fallot	X			four serious heart defects combined	X
Transposition of the great arteries	X			heart defect; pulmonary artery, aorta switched	X
Tricuspid valve atresia and stenosis	X			heart defect; valve absent or restricted	
Ventricular septal defect	X			opening(s) in wall between 2 lower heart chambers	X

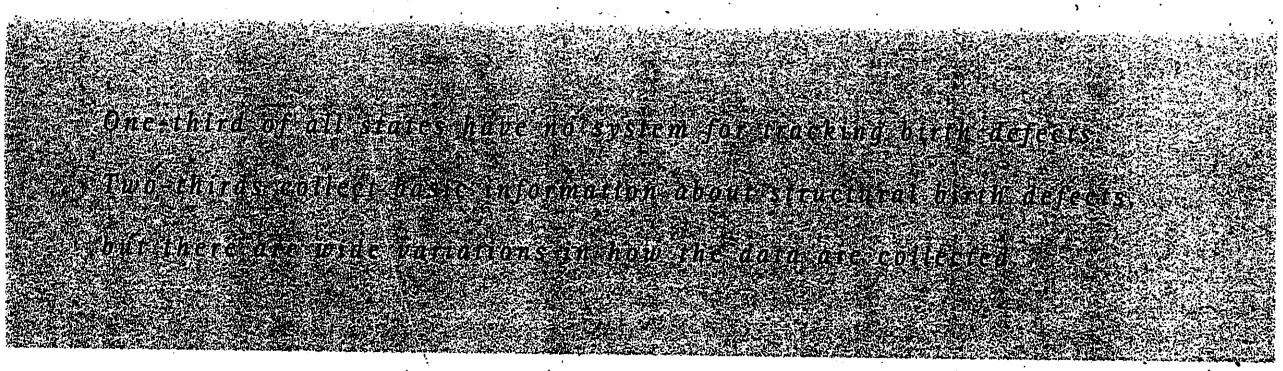
DATA

collection systems leave us in the dark

The study found that less than half the nation's population is covered in state birth defects registries. One-third of all states have no system for tracking birth defects. Two-thirds collect basic information about structural birth defects, but there are wide variations in how the data are collected. With the exception of some parts of California and metropolitan Atlanta, where a Centers for Disease Control pilot tracking program is under way, no state tracks related conditions such as mental retardation and cerebral palsy. Such disparities leave public health researchers in the dark in efforts to understand and prevent these tragic conditions.

A total of 33 states have some form of tracking system, but many use the "passive" method that relies on reporting by doctors and hospitals. Only 26 of the 33 had registry data available to review, principally because the data are not compiled. Of the 26 states, 16 rely on "passive" reporting by hospitals and doctors, which frequently underestimates cases.

Only 10 states use "active" methods, applying state resources to search out information about birth defects and related conditions in the general population. And finally, a total of 17 states, the District of Columbia, and Puerto Rico have no system at all.



FEW STATES make the grade

In order to highlight the seriousness of the problem, Commission researchers also evaluated each state's system against the Commission's model criteria, and gave each a letter grade from "A" to "F" to present a snapshot of the current situation.

Grade A: Eight states came close enough to model criteria to achieve the top grade. All 8 are active systems that extend through the first 12 months of life, assess fetal deaths as well as births, and have analytic capacity. They are not perfect; for example, several do not yet cover the entire state (California, Georgia and Texas).

Grade B-C: A total of 25 states have achieved some of the needed criteria to be effective. However, they fall short because of such shortcomings as: passive collection systems, failure to assess fetal deaths, and lack of analytical capability.

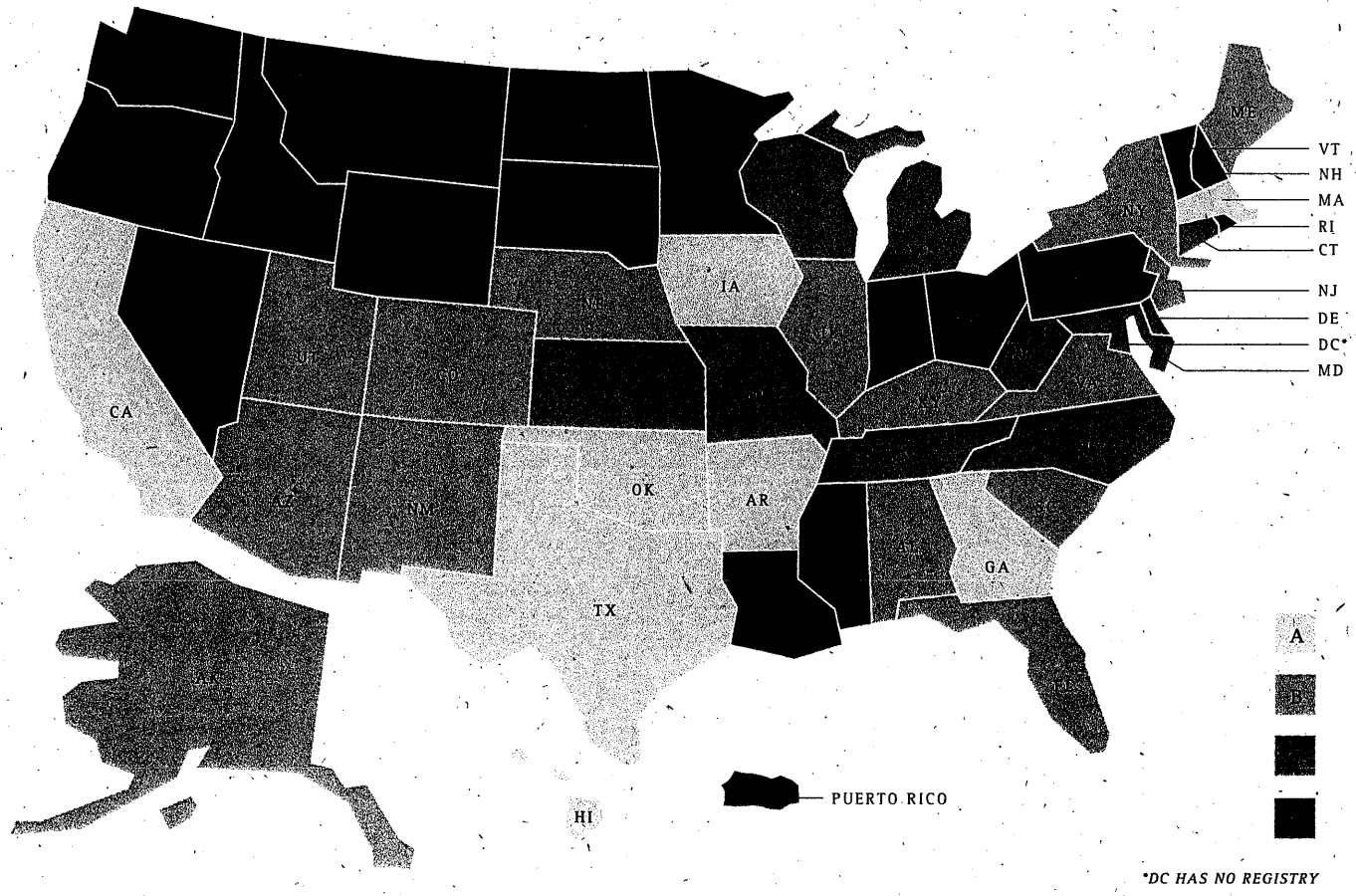
Grade F: A total of 17 states, the District of Columbia and Puerto Rico have no birth defects registries at all. However, several states recently received federal funds and report that tracking systems are being developed.

Conclusion: A national approach to build consistent, modern state tracking systems is essential if we are to develop prevention strategies that will alleviate suffering and deaths from birth defects and chronic disease and disability.

Criteria for Grading of State Birth Defects Tracking Systems

Grade	Type of Tracking	Comprehensive	Inclusion of Fetal Deaths	Timeliness	Analytic capability
A	Active	Yes/No	Yes	Yes/No	Yes
B	Passive/Active	Yes/No	Yes/No	Yes/No	Yes/No
C	Passive	Yes/No	Yes/No	Yes/No	Yes/No
F	NO TRACKING SYSTEM CURRENTLY IN PLACE				

Type of Tracking:
Active: Case investigators search out records
Passive: A report is to be filed to the government for tracking
Comprehensive: Statewide plus all birth defects as defined by CDC
Fetal Deaths: Includes deaths of developing babies of at least 500 grams and 20 weeks of age
Timeliness: Produce and release data in a reasonable amount of time
Analytic Capability: State analyzes its own data



SCORECARD OF STATE BIRTH DEFECTS SURVEILLANCE PROGRAMS, NOVEMBER 1999

Detailed descriptions are available on the Commission's website: http://pewenvirohealth.jhsph.edu

WHAT is the role of environmental exposure to toxicants?

Public health research has continued to identify factors in the environment that can affect children's health. Some of these factors involve personal behavior, such as consumption of tobacco and alcohol during pregnancy. But there are environmental factors, such as exposure to toxicants in the air, water or soil, over which individuals have limited or no control and which must be attacked on a community-wide basis.

There is little information on human exposure to the wide array of toxicants released into the environment in the U.S. every year. Most of the available information on exposure risks is based on results of animal testing. However, taken as a whole, the evidence suggests that exposures to these toxicants are likely to play an important role in birth defects and related conditions.

Many of the chemical compounds in use in agriculture and in our homes and gardens have been found in animal studies to cause birth defects, but there is little research on safe human exposure levels or adverse human health effects. Human studies are the most challenging, by far, in part because they require adequate tracking of diseases and exposures, and adequate funding of epidemiologic research.

There are a number of well-known environmental agents associated with harmful effects on a developing baby. These range from the mercury fish poisoning that led to Japan's outbreak of congenital disabilities and mental retardation known as "Minimata" disease, to the connection between folic acid deficiency and such neural tube defects as spina bifida in the United States. But much more information is needed if researchers are to identify other potential threats to children's health.

- Little is known about the human health effects of the estimated 15,000 chemical compounds produced in quantities of at least 10,000 pounds annually. Even more alarming, nothing is known about the human health effects of two-thirds of the chemicals produced in the U.S. in high volume (1 million or more pounds each year). However, based on animal and other studies, many of these chemicals are capable of causing developmental toxicity if exposure to sufficient dose occurs at a critical time.

- Gaps in tracking and research for both birth defects and exposures to developmental toxicants make it difficult to answer the questions raised by animal testing. Inconsistent state and national tracking data limit research into whether increases in birth defects are related to changes in environmental exposures, diagnostic improvements or other factors. It is very likely some increases are due to changes in diagnostic technology. But it is important to our children's future—and society's—to know for certain.

A national opinion survey conducted among registered voters by The Pew Charitable Trusts earlier this year found there is strong support among Americans to track health problems and environmental exposures, including birth defects. Other surveys found Americans understand there are many factors in the environment under personal control, such as maternal diet and use of drugs.

But nearly nine of 10 Americans surveyed for Pew also believe environmental factors are a major cause of health problems. Two-thirds said more should be done to protect public health, and by more than three to one, respondents favored increased federal spending on public health over tax cuts.

More than 90 percent of Americans believe we should do more research to learn about the health effects of environmental problems. Americans understand this approach represents our best opportunity for prevention.

Environmental agents associated with low birthweight and preterm births, and/or structural birth defects in human epidemiological studies

Agent/Exposure	Low Weight	Pre-term	Birth Defect
TOXIC SUBSTANCES			
Electronics assembly	X		
Hair dye			Cardiac defects
Lead	X	X	Total anomalous pulmonary venous return
Polychlorinated biphenyls (PCBs)	X		"Yusho" syndrome
Soldering			Cardiac defects
Solvents	X		Anencephaly, gastroschisis
Paint/paint stripping			Total anomalous pulmonary venous return, anencephaly
Benzene	X		Neural tube defects and major cardiac defects
Carbon tetrachloride	X		Central nervous system defects, neural tube defects, and oral cleft defects
Toluene	X		Microcephaly, CNS defects
Tetrachloroethylene			Oral cleft defects
Trichloroethylene			Central nervous system defects, neural tube defects, and oral cleft defects
Styrene monomer	X		
SOME PESTICIDES	X		Total anomalous pulmonary venous return, anencephaly
Agricultural work			Orofacial clefts
Triazine herbicides	X		
POLLUTANTS			
Carbon monoxide	X		
Chloroform and other trihalomethanes	X		Central nervous system defects, oral cleft defects, and major cardiac defects
Hazardous waste	X	X	Cardiac and circulatory defects, neural tube defect, hypospadias, gastroschisis
Methylmercury			Central nervous system defects, cerebral palsy, cleft lip and palate
Particulate matter (PM)	X		
PHYSICAL			
High altitude	X		
Ionizing radiation	X	X	Microcephaly, gastroschisis, eye malformations, CNS defects
Noise	X		
Work stress	X		

THE case of brick township

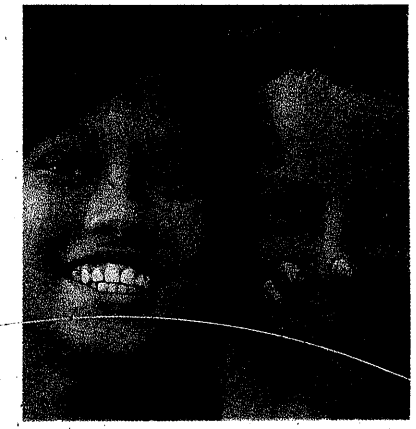
Tragically, there are many examples of reported clusters of birth defects and related conditions in communities around the country. So far, public health research has few answers to give us.

One of these is located in Brick Township, NJ. In 1993-97 concerned parents identified 53 cases of autism among 6,000 children between the ages of 3 and 10, and began asking questions about whether there is an increased risk in their community for autism due to environmental factors. Once believed to be a rare condition, autism is a complex developmental disorder that usually appears in the first three years of life. It is characterized by social aloofness, impaired verbal and nonverbal communication and imagination, and abnormal or limited activity. Some children with autism may function at below-normal intellectual levels, while others may do well in school but have severe social impairments.

Unfortunately, there are no answers at present as to the causes of autism, although research has identified suspected genetic and environmental factors. The unusual cluster of autism reported in Brick Township and in California, where the Department of Developmental Services recently issued a report showing a 210 percent increase in the number of autistic children entering its program over an 11-year period, must await the national baseline data that researchers need to answer such questions as:

Are these truly statistical excesses that should be studied further? Is evolution in the criteria used to diagnose autism responsible? Are more accurate diagnosis and reporting also factors? Are there environmental toxicants involved?

In Brick Township, investigators from the CDC and the state of New Jersey are examining a range of possibilities for environmental exposures, including air quality, a nearby landfill, and local drinking water supply. So far, there are no answers.



THE case of brownsville

However, history has shown that public health research into such questions is rewarded with advances in knowledge about health hazards and prevention techniques that work.

Just as Brick Township illustrates the human tragedy of unanswered questions, a preventive strategy that is now promoting healthy babies nationwide emerged from the study of another birth defect cluster in the Rio Grande Valley of Texas.

An unusually large number of cases of neural tube defects in Cameron County in the Brownsville area prompted state and CDC researchers to launch investigations into possible genetic and environmental factors. Although research was never able to answer the question of what had caused six babies to be born in a six-week period with a form of anencephaly, a neural tube defect in which all or part of the brain is missing, the effort led the State of Texas to begin a statewide program to monitor birth defects.

Texas is now one of the nation's leaders in developing a model system for tracking birth defects and related conditions. These cases, and the work of the Centers for Disease Control in assisting state health investigators, ultimately led to a preventive strategy that earlier research had identified as promising in protecting against this type of birth defect.

The role of the B vitamin folic acid as a protective factor against neural tube defects was initially suggested in the 1960s. In 1992, the U.S. Public Health Service recommended that all women of childbearing age take 400 micrograms of folic acid daily, starting before pregnancy. Folate, found in such foods as orange juice, is the naturally occurring form of folic acid. In 1998, the Food and Drug Administration determined that U.S. grain sold as *enriched* be fortified with folic acid at a level thought by some to be less than optimum.

The Texas cases provide an excellent example of the value of public health research and tracking, and why it should be continued. As a footnote, now that folic acid is being added widely to the grains most Americans consume, research needs to continue to determine the impact of this supplementation on other potentially sensitive populations, including young children and the elderly. In addition, continued tracking is needed to evaluate the results.

STUDY conclusions

The cost of these health problems is measured in family suffering and lifetimes of disability, as well as by the economic toll that is found in higher health and educational costs.

Birth defects are the no. 1 killer of infants in the United States, and certain birth defects and related conditions are increasing. The cost of these health problems is measured in family suffering and lifetimes of disability, as well as in higher health and educational costs.

Although exposures to environmental toxicants may play an important role, we have too little information at present on which to reach definitive conclusions. Addressing these tragic conditions and generating better information about environmental causes should be a national priority because birth defects and related conditions may be preventable.

There also are indications that certain birth defects, low birthweight and preterm births are increasing faster in some regions of the country than others. Yet we lack the information that consistent, nationwide tracking would provide to determine whether these variations are relevant and need more study, and if so, to develop prevention strategies.

The benefits to American society far outweigh the costs of improving our public health system and accelerating public health research to drive answers to the following questions:

- Why infant mortality rates due to birth defects and related conditions remain stubbornly high despite other improvements in the health of children and their mothers. There is much research suggesting environmental triggers, but the causes of the majority of birth defects remain unknown.
- What chemical toxicants are present in the environment and what are the exposure levels.
- What exposure levels to various environmental toxicants place developing babies at risk.
- Why the apparent increases in rates of certain birth defects or variations by state and region. These differences may result from changes in diagnostic technology and reporting, or may be linked to environmental exposures or something else we don't yet know about.
- What is responsible for unusual clusters of birth defects at some local levels, and how can they be prevented.
- What is responsible for the reports of increases in such developmental disabilities as cerebral palsy, mental retardation, and autism. Children with birth defects or who are born preterm or low weight are more likely to suffer from these tragic conditions. Research has linked them to a number of environmental factors, but causes are largely unknown.

But to answer all these questions, we must have good state systems that do a significantly better job of gathering information on the incidence and prevalence of such children's health problems. Some states are managing to do a yeoman's job of carrying out this important task, while others have done very little. We can remedy this situation, and this report lays out recommendations for that improvement.

The Birth Defects Prevention Act of 1998 was intended to provide the impetus and support. For 1999, Congress appropriated less than a third of the money authorized to implement national standards for state tracking systems. To compare the scale of public expenditure, the additional $22 million it would take to set up adequate databases on birth defects and related conditions would construct approximately 20 miles of a typical four lanes of interstate highway.

The federal government has failed to provide states with sufficient resources to track such health problems, and what is more, there is no policy framework to address exposures to environmental toxicants as a priority for public health investment.

For 1999, Congress appropriated less than a third of the money authorized to implement national standards for state tracking systems.

COMMISSION recommendations

We know how to create the public investment priorities and build the tracking systems that public health professionals need to address the social, biological and environmental factors that are contributors to chronic disease and disability in America. If we do not look for answers, we will never know the causes, and thus, will be unable to prevent these costly and life-threatening conditions.

Despite gains in treatment and clinical science, we have not made equal gains in prevention. In fact, prevention and prevention-based science–the analysis and the tracking systems that are discussed in this report–have been neglected. Prevention-based science must become an effective partner with research on diagnosis, treatments and cures if we are to move forward in improving the health of our children.

Just as we have made much progress in combating infectious disease, we have the greatest single opportunity we have had in generations to achieve a new, higher standard for public health, and to launch another leap forward in Americans' quality of life.

The foundation for a national effort to revitalize our public health system is leadership at the federal, state and local levels to ensure the health of our children is monitored and defended against potential environmental threats. With this national will, we can:

- See to it that every state has the commitment and resources to watch and protect public health. Full funding of the National Birth Defects Prevention Act is an important first step.
- Require and provide the resources for analysis of existing data on birth defects and the studies to do follow-up and identify risk factors.
- Work toward a national reporting system that allows researchers, policymakers and the public access to all relevant information, including developmental disabilities, via public databases that protect confidentiality and privacy, while improving the American people's knowledge of the health of their communities.
- Develop a national approach for monitoring exposures linked to the environment. We should not be ignorant of exposure levels in our bodies to environmental contaminants that are likely to be in our food, water, and air.

- Re-evaluate the federal policy framework for the nation's public health system to ensure not only capacity but also appropriate strategies for monitoring, evaluating and preventing chronic disease and disability.

The health of future generations of Americans depend on the choices we make today about the priority we give to attacking threats to public health. History has shown that a society's progress depends on its ability to maintain a healthy quality of life. Today we have more knowledge and tools to improve the determinants of health–biological, social and environmental–than ever before. The challenges are great, but so is our nation's ability to succeed.

ABOUT
the Pew Environmental Health Commission

The Pew Environmental Health Commission was created by The Pew Charitable Trusts to develop recommendations designed to bolster the nation's ability to track and prevent health problems linked to conditions in the environment.

The Trusts, along with the Johns Hopkins University School of Public Health, determined it was important to focus on the often-overlooked role of environment as a means to prevent chronic disease, the leading cause of death and disability in the United States today. The Commission believes the role of environmental health cannot be underestimated if we are to be successful in combating these new health threats. In the Commission's words, environmental health is "those aspects of human health, including quality of life, that are determined by interactions with physical, chemical, biological and social factors in the environment. It also refers to the theory and practices of assessing, correcting, controlling and preventing those factors in the environment that may adversely affect the health of present and future generations."

In the coming months, the Commission will be producing a series of reports on children's environmental health concerns—birth defects, asthma, and childhood cancer—that highlight the limitations of our present public health system in preventing chronic disease and disability, particularly those linked to the environment. This first report, on birth defects and related conditions, is intended to illustrate the gaps in our knowledge about birth defects and exposures to toxicants in the environment, and why it is so urgent that we strengthen our public health system to address these challenges.

Children's Environmental Health Investigative Team

LYNN R. GOLDMAN, MD, MPH
Principal Investigator

BENJAMIN J. APELBERG
Project Research Team Member

SUDHA KODURU, MHS
Project Research Team Member

CAROLYN E. WARD, MPH
Project Research Team Member

RICHARD SORIAN
Technical Writer

The Pew Environmental Health Commission Staff

SHELLEY A. HEARNE, DrPH
Executive Director

PAUL A. LOCKE, DrPH, JD
Deputy Director

THOMAS A. BURKE, PhD, MPH
Principal Investigator

NGA TRAN, PhD
Co-Investigator

JOAN LUCCO, PhD
Senior Research Assistant

JILL LITT, MPH
Project Manager

LOIS D. BANKS
Program Coordinator

NADIA SHALAUTA, ScD
Research Consultant

SHAWNISE F. SMITH
Administrative Secretary

Children's Environmental Health Working Group

The Pew Environmental Health Commission selected the Working Group members based upon their diverse viewpoints and technical knowledge. Most of these individuals have also provided peer review on the draft of this report.

SUSAN CUMMINS, MD, MPH
Chief, Childhood Lead Poisoning Prevention Branch, California Department of Health Services

DEVRA DAVIS, PhD, MPH
Senior Scientist, World Resources Institute

PEYTON EGGLESTON, MD
Professor, Department of Pediatrics-Immunology, Johns Hopkins School of Medicine

HENRY FALK, MD, MPH
Acting Assistant Administrator, Agency for Toxic Substances and Disease Registry

BERNARD GUYER, MD, MPH
Professor and Chair, Population and Family Health Sciences; Johns Hopkins School of Public Health

JOHN HARRIS, MD
Chief, March of Dimes, California Birth Defects Monitoring Program

RICHARD JACKSON, MD, MPH
Director, National Center for Environmental Health, Centers for Disease Control and Prevention

PHILIP LANDRIGAN, MD
Chair, Department of Community and Preventive Medicine, Mount Sinai Medical Center

JOHN PETERS, MD
Professor and Director, Division of Occupational and Environmental Health, University of Southern California

DON MATTISON, MD
Medical Director, March of Dimes

NEIL SCHLACKMAN, MD, FAAP
Senior Corporate Medical Director, Aetna US Healthcare

MICHAEL W. SHANNON, MD, MPH
Associate Chief, Boston Children's Hospital, Harvard Medical School

SHELIA H. ZAHM, ScD
Deputy Director, Division of Cancer Epidemiology and Genetics, National Cancer Institute

The Commission staff would like to acknowledge the assistance of staff of the Centers for Disease Control National Center for Environmental Health and members of the National Birth Defects Prevention Network and the California Birth Defects Monitoring Program, who generously gave of their time and advice in reading earlier drafts of this report. In particular we acknowledge: Adolfo Correa, Charlotte Druschel, Larry Edmonds, Judith K. Grether, Russell Kirby, Joe Lary, Angela Lin, John Meaney, Lisa Miller, Cynthia Moore, Len Paulozzi, Joann Petrini, Marsha Renwanz, Ed Sargeant, Lisa Schalick, Lowell Sever, and Marshalyn Yeargin-Allsopp.

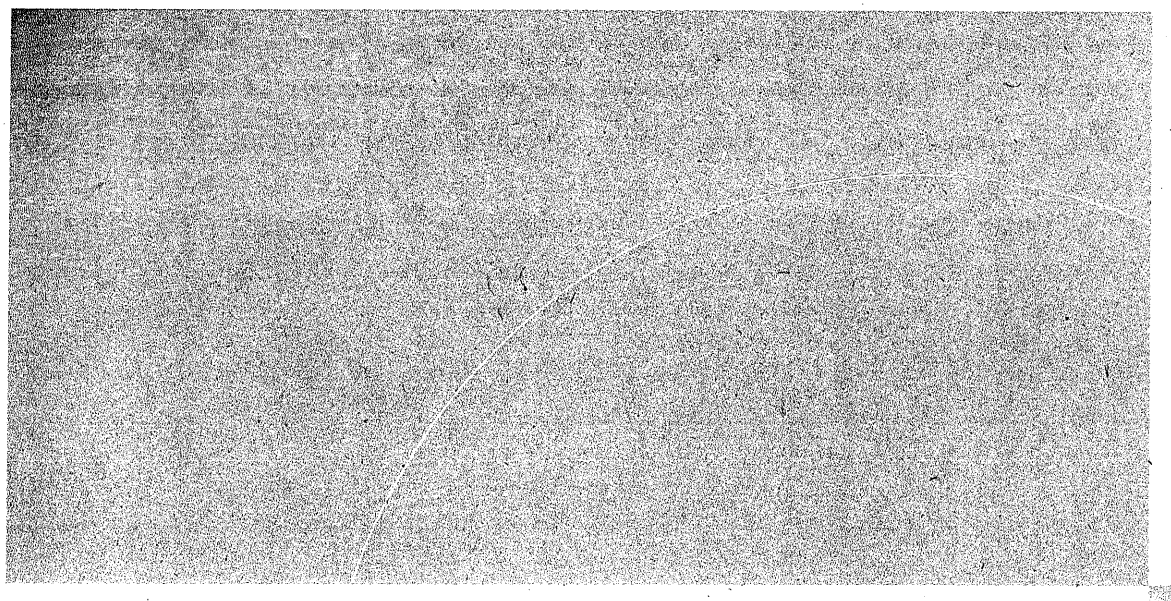
While these individuals have provided constructive comments and suggestions, it must be emphasized that responsibility for the final content of this report rests entirely with the Investigative Team and the Pew Commission.

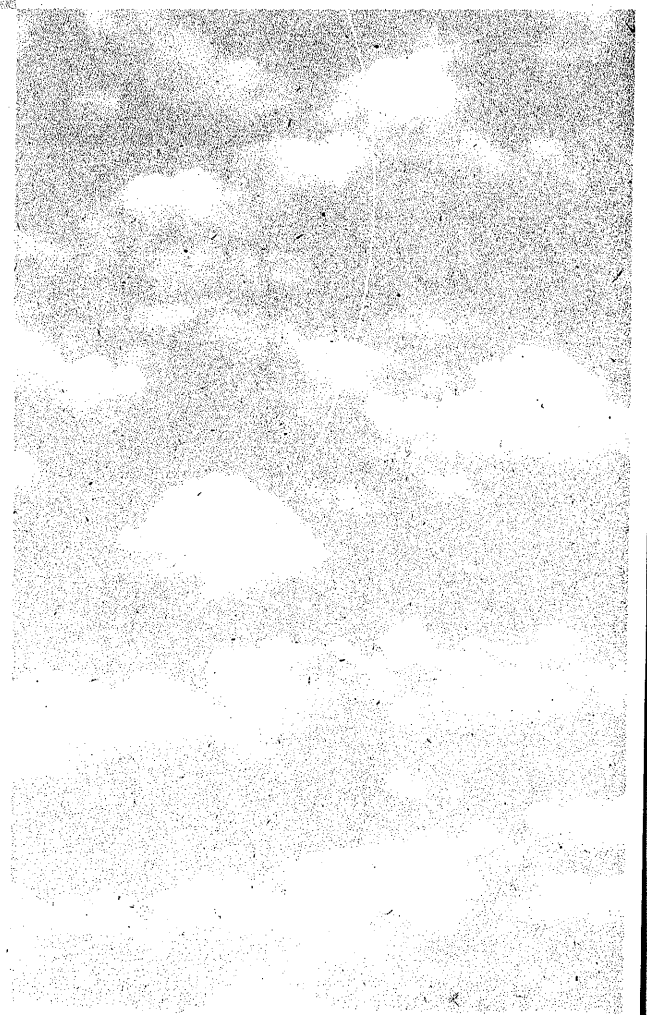
The Commission also wishes to thank the March of Dimes for providing photographs of children used in this companion report.

The Pew Environmental Health Commission at the Johns Hopkins School of Public Health is supported by a grant from The Pew Charitable Trusts. The opinions expressed in this report are those of the authors and do not necessarily reflect the views of The Pew Charitable Trusts.

Printed on chlorine free recycled paper.
Printed with soy-based inks.

Design: S K Designworks/Philadelphia





THE PEW
ENVIRONMENTAL
HEALTH COMMISSION

at the Johns Hopkins School of Public Health

111 Market Place - Suite 850
Baltimore, Maryland 21202

http://pewenvirohealth.jhsph.edu