



ENVIRONMENTAL HEALTH SERIES

Environmental Public Health Tracking: Connecting Health and the Environment

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Overview

Many of the nation's most serious health problems are the result of diseases and conditions for which science has not found a cause. Parkinson's disease, Alzheimer's disease, multiple sclerosis, autism, most birth defects and many types of cancer are some of the conditions that fall in this "unknown cause" category. Surprisingly, the information that could help prevent many of these health problems—data on the numbers and locations of disease cases and environmental factors that may influence them—is not collected in a way that can help researchers discover ways to prevent these illnesses. Policymakers and public health agencies are working to improve environmental public health tracking. Two states have passed legislation to gather data on environmental factors that may influence disease development. The federal government, through the Centers for Disease Control and Prevention (CDC), also is working to improve environmental public health tracking efforts, mainly through support for the creation of tracking systems by state and local agencies.

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Background

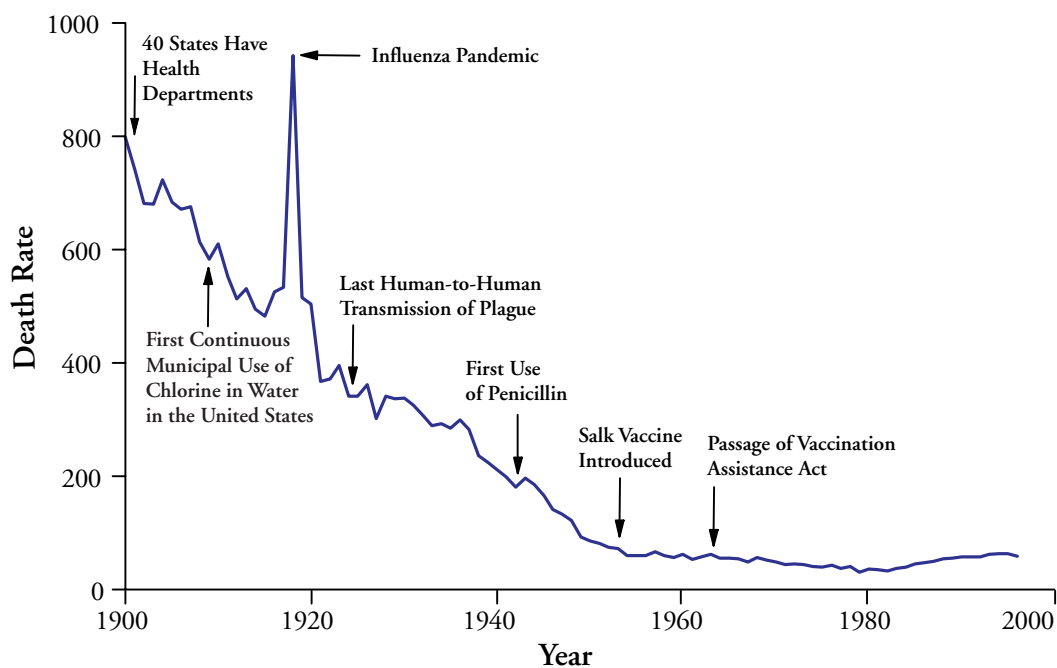
A child born in the United States in 1900 could expect to live to age 47. Today, a newborn can expect to live nearly 77 years. This near 30-year leap in life expectancy is due primarily to public health efforts that prevented infectious disease—improved sanitation and hygiene, food safety, chlorinated drinking water, and vaccinations. See figure 1.

The public health successes of the 20th century have increased life spans and eliminated infectious disease as the leading cause of death. Pneumonia, tuberculosis and diarrhea were the leading killers in 1900. Today, chronic diseases such as cancer and heart disease are the leading cause of mortality—four of every five deaths in the United States are the result of chronic disease. Chronic diseases also carry a tremendous price—annual health care and lost productivity cost the United States \$325 billion each year.

The rates for a number of chronic diseases have increased during the past two decades. Some of the most profound increases have occurred with asthma—rates have more than doubled, and asthma-related emergency room visits and deaths have increased significantly. Rates for some types of cancer—including childhood brain cancer, testicular cancer, non-Hodgkin's lymphoma and several types of tumors—also have increased. Although the rising rates for many types of cancer have been attributed to better detection methods, researchers say that this alone does not explain the rise in the cancer. The rate for a birth defect called



Figure 1. Decline in Infectious Disease Deaths, 1900-1996.



Source: *Morbidity and Mortality Weekly Report*, July 30, 1999.

hypospadias, a genital malformation in boys, has doubled. In California, autism rates doubled between 1987 and 1998, and the state Department of Developmental Services reports that its autism caseload doubled between 1999 and 2003. Some experts also believe that rates for developmental disorders, such as attention deficit disorder and learning disabilities, are on the rise, but good information on these conditions is not available because no national registries exist.

An essential tool for combating chronic and other noninfectious diseases, conditions, and health effects is tracking, which provides information that is essential to prevention efforts. Lynn Goldman, a professor of public health at Johns Hopkins University, says, "As a nation, we have not invested in preventing chronic diseases. Even though we know about the increasing importance of chronic diseases and the staggering human and financial toll they have on our country, we have no systems in place to track chronic diseases nor do we have the capability to respond to these health crises."

Environmental Public Health Tracking: Part of the Answer?

Environmental public health tracking is the process of 1) tracking environmental hazards, which involves gathering

data about human exposure to environmental factors—including air pollution, pesticides, waste sites, weather extremes, water pollution and many others, 2) assessing human exposure to those hazards, and 3) gathering health-effects information through disease registries and other sources.

Tracking Environmental Hazards

An environmental hazard is an agent or factor in the environment that is capable of causing human illness or injury. People can be exposed to environmental hazards through air, water, soil, food and other sources. Some examples of environmental hazards include mercury, pesticides, air pollution, and temperature extremes. The U.S. Environmental Protection Agency (EPA) collects monitoring data for many environmental hazards for the purpose of regulation. EPA is working with the states to build a comprehensive data exchange network, which will aid in environmental information sharing between states and jurisdictions. Other government agencies, such as the National Aeronautics and Space Administration (NASA), also collect data on environmental hazards that may affect health. Since existing data are incomplete and are not collected specifically for environmental public health tracking, CDC is working with other government agencies and partners to utilize existing information sys-

tems for environmental public health tracking and to identify information gaps.

Assessing Human Exposure: Biomonitoring

The best method of ascertaining human exposure to environmental factors is through biomonitoring—a direct measurement of environmental chemicals in the human body, often through the use of blood, urine or hair samples.

CDC currently is collecting data on human exposure to 116 chemicals in the environment, including pesticides, polychlorinated biphenyls (PCBs) and environmental tobacco smoke (also called second-hand smoke). The overall purpose of the report is to provide unique exposure information to physicians, scientists and health officials to help prevent disease that results from exposure to environmental chemicals.

Some of the specific public health uses of the exposure data are to:

1. Determine which chemicals get into the population and at what levels;
2. Determine the prevalence of people with levels of a chemical that are above known toxicity levels;
3. Establish reference ranges that can be used by physicians and scientists to determine whether a person or a group of people has an unusually high exposure to a chemical;
4. Assess the effectiveness of public health efforts to reduce exposure of Americans to specific chemicals; and

5. Set priorities for research on human health effects.

When this data is combined with hazard and health tracking information, it will eventually help physicians, researchers and public health officials prevent diseases that are caused or influenced by exposure to chemicals in the environment.

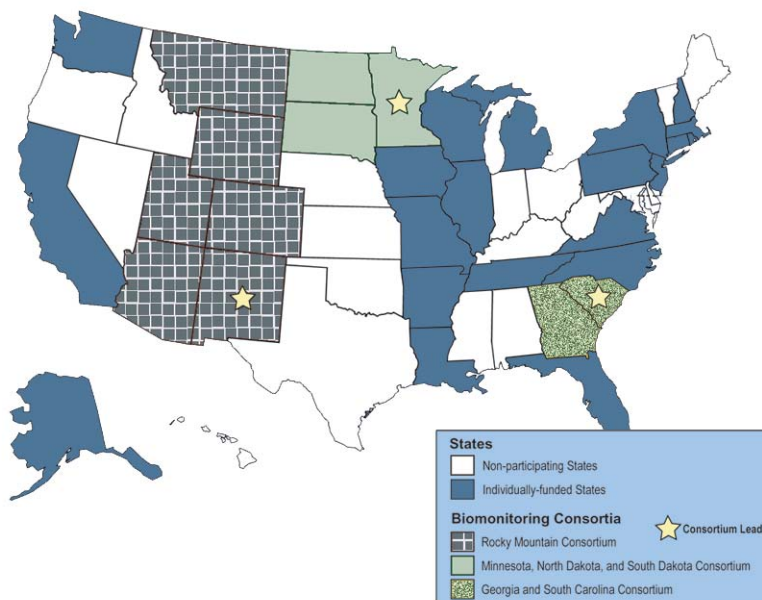
To determine the hazard exposure levels at the state, city or community level, states will need to implement their own biomonitoring programs. CDC currently is working with state laboratories to enable them to conduct their own testing. Figure 2 indicates which states currently receive funding to plan biomonitoring programs.

Tracking Conditions and Health Effects

In order to prevent chronic disease and other negative health effects, it is necessary to obtain basic tracking information about those health effects. This includes knowing how many people have the condition, where the cases are located and how the rates are changing over time. Many of the health effects that may be associated with the environment—birth defects, developmental disabilities, cancer, chronic respiratory disease, asthma and neurological diseases such as multiple sclerosis, Parkinson's disease and lupus—are tracked poorly, if at all.

Tracking helped public health officials to eliminate many of the infectious diseases of the 20th century, including cholera, typhoid fever and yellow fever. “What are the

Figure 2. Biomonitoring Planning Grantees.



Source: Division of Laboratory Sciences, National Center for Environmental Health, CDC, August, 2003.

lessons we learned from the war with infectious disease? Track, respond, prevent,” says Shelley Hearne, executive director of Trust for America’s Health. “But with chronic diseases, we don’t even track. It’s hard to respond and prevent when you don’t do the basics.”

Some health tracking systems already are in place in many areas nationwide. These include cancer registries, birth defects registries and asthma tracking systems. In many instances, however, the data is not collected in a standardized way or is incomplete, meaning that it cannot be compared with data from other states or regions.

The Pew Environmental Health Commission at the Johns Hopkins School of Public Health produced a report assessing the quality of the nation’s tracking systems in 2000. The report found a number of deficiencies:

- Currently, very few states have made any attempt to track autism, mental retardation or cerebral palsy.
- Cancer registries in many states have been neglected for years. In some states that do collect data, resources are not available to perform analysis and respond to incidents such as cancer clusters.
- Many states have no birth defects tracking, or their tracking attempts are inadequate. Birth defects are the leading cause of death among infants, and some birth defects, such as hypospadias, have increased dramatically during the past few decades.
- Twenty-one states do not have internal programs to specifically track asthma. It is nearly impossible to compare data between states since the quality and detail of the data vary tremendously.

Chronic Diseases, Unknown Causes

Asthma

Asthma—a chronic disease that inflames the airways and lungs, causing shortness of breath, wheezing and, in extreme cases, death—afflicted approximately 7 percent of the population in 2001. Rates have more than doubled since 1980, and asthma’s economic toll is also on the rise: in 1990, estimated asthma-related costs totaled \$6.2 billion. By 2002, the figure had grown to \$14 billion.

In a report released in May 2000 by the Trust for America’s Health, researchers used CDC data to determine that most states have no ongoing asthma monitoring program. The study found that 30 states have no timely information that describes asthma within their borders and that only

seven states have “ready access” to statistics on emergency care for asthma. It also found that, among the 23 states that track asthma, uncertainty exists as to the adequacy of the tracking efforts.

Developmental Disabilities

Developmental disabilities such as mental retardation, autism, cerebral palsy and attention deficit hyperactivity disorder (ADHD) affect 17 percent of U.S. children under age 18. Between 5 percent and 10 percent of children who attend public schools have learning disabilities, and ADHD affects another 3 percent to 6 percent. According to CDC, the causes of birth defects and developmental disabilities are unknown in about 75 percent of cases. It is known that some environmental hazards—such as PCBs, lead and mercury—are associated with developmental disabilities.

Most developmental disabilities, such as ADHD and autism, are not systematically tracked. For most states, this means that researchers cannot say with confidence what the rates are for these diseases or whether they are increasing or decreasing.

Cancer

According to the American Cancer Society (ACS), more than 500,000 Americans will die of cancer in 2003—more than 1,500 people per day—meaning that one of every four deaths in America is from cancer.

A growing body of evidence indicates that environment plays a much larger role than heredity in the development of cancer. Research on identical twins demonstrates that genetics is less important than environment when it comes to cancer—between 52 percent and 82 percent of cancers, depending on the type, are caused by environmental factors. Environmental factors in this case include many things, such as chemicals in the environment, solar radiation and secondhand smoke. Exposures that result from personal behavior—tobacco, alcohol and poor diet, for example—also are considered environmental factors.

Birth Defects

Birth defects are the leading cause of infant mortality in the United States, accounting for 20 percent of all infant deaths. One in 33 babies born in the United States has a birth defect. Although doctors know that exposure to certain medications and alcohol can cause birth defects, the causes of approximately 70 percent of all birth defects remain unknown. Some birth defects—such as hypospadias, a malformation of the male genitals—have increased significantly in the United States during the last 20 years.

Autism: A State Concern

Autism rates are climbing throughout the United States and in countries around the world.¹ Autism is a developmental disability that significantly impairs an individual's ability to communicate and interact socially. The California Department of Developmental Services found that the rate of autism diagnoses in California has risen from 1 in every 2,500 children born in 1970 to 1 in every 323 children born in 1997, an almost eightfold increase. Researchers note that, between 1985 and 1995, the prevalence of autism increased by 269 percent.² Studies conducted in other states also have found substantial increases.

The burden on California's health system also is growing. The autism caseload increased threefold from 1987 to 1998, and the costs of treatment and care are overwhelming the system.³ Autistic children require increased medical care, special education and constant lifetime supervision. The California Department of Developmental Services estimates that autism costs taxpayers at least \$2 million for each new child who requires a lifetime of care.

Scientists agree that some of the increase probably is attributable to better diagnosis and increased awareness of the disease; however, many feel that improved diagnostics cannot explain the increase.

¹ *Autism Spectrum Disorders* (California Department of Developmental Disabilities, April 2003).

² *ibid.*

³ Aurelio Rojas, "Major rise in autism hurts disabled centers," *Sacramento Bee*, March 7, 2003.

Disease Clusters

"The bane of a public health officer's existence is a birth defect or cancer cluster," says Dr. Richard Jackson, former director of the CDC's National Center for Environmental Health. "You can't deal with these kinds of events without good health data and good environmental data." Unfortunately, good health data and good environmental data often are lacking.

A recent federal study of an autism cluster in Brick Township, New Jersey, demonstrates how this lack of information can hinder an investigation. The study, conducted by CDC and the Agency for Toxic Substances and Disease Registry, found that autism rates in the community were higher than normal, but concluded that not enough data on autism exists to determine whether these rates reflect a "cluster" relative to the rest of the United States,

since autism is not commonly tracked and reported to a registry. The study did not find a link to chemicals present in soil or water.

Unfortunately, of the many cancer cluster investigations CDC has conducted during the past 30 years, causes have not been found for most of them. In many cases, investigations show that rates are not out of the ordinary for the population being studied. In those cases where rates do prove high, a cause generally is not found. Although random chance is likely to play a role in the occurrence of some cancer clusters, some may be the result of environmental exposures.

A major challenge that confronts researchers is the tremendous number of variables involved in an investigation, including long latency periods between exposure and disease appearance, the high number of chemicals to which people are exposed, and the tendency for people to move from place to place. The lack of reliable environmental and disease tracking data compounds this already complex job, usually leaving residents of the investigated town or region without satisfactory answers about the cause of the disease cluster in their community.

Information gathered from an environmental public health tracking system would help in two ways:

1. It would aid in identifying clusters of health effects, such as autism, asthma, or cancer.
2. It also would allow researchers to design good studies to help identify the cause of the cluster and to prevent similar cluster events in the future.

Federal Efforts

In March 2002, both the U.S. Senate and House of Representatives introduced legislation (S. 2054 and H.R. 4061) to create a Nationwide Health Tracking Network. The legislation would track where and when chronic diseases occur and examine their relationship to environmental factors.

Many support the creation of an environmental public health tracking system to prevent disease and solve cluster investigations. Supporters include the American Medical Association, the American Public Health Association and the American Chemistry Council. These groups make the case that tracking diseases along with environmental factors can provide more and better scientific data to help doctors, researchers and public health officials improve treatment plans and prevent the disease. Better information also will help policymakers improve policy. Supporters contend that the tracking approach, although it will cost an estimated \$275 million a year, will save the

nation billions in the long run, given the enormous, spiraling costs of chronic disease and health care. Supporters say the price of the system is small compared to the \$375 billion per year spent nationally on chronic disease-related treatment and care.

CDC is working to create a standardized national tracking network that allows direct reporting and linkage of health effect, exposure and environmental data. The planned tracking system will:

- Allow ongoing monitoring and dissemination of information on levels of environmental contaminants and trends in disease occurrence;
- Facilitate research on the relationship between environmental factors and disease; and
- Measure the effects of regulatory and prevention strategies.

To allay concerns related to medical privacy and confidentiality, the tracking system will implement security safeguards that are consistent with the U.S. Department of Health and Human Services' (HHS) regulations on medical privacy, which went into effect on April 14, 2003.

This effort requires close involvement with the states. In fiscal year 2002, CDC distributed approximately \$14.5 million to 17 states, three local health departments and three schools of public health to initiate the development of an Environmental Health Tracking Network (see figure 3).

Money also has gone to help states with biomonitoring—CDC awarded \$10 million in planning grants to states between 2001 and 2003, with implementation of plans to begin in October 2003.

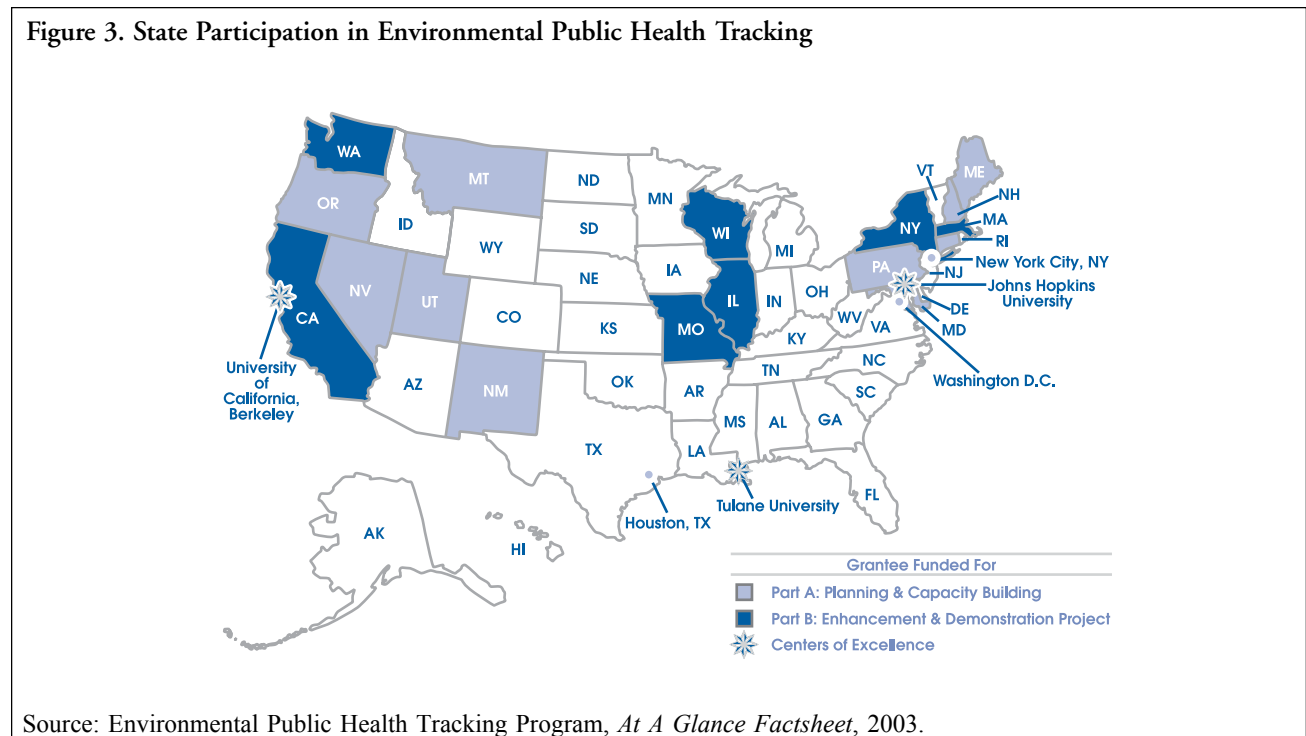
State Efforts

Because states bear a large burden when it comes to chronic diseases, they are integral to creating systems that track health and environmental factors at the local level. A number of states have begun to improve their tracking systems and to consider implementing statewide environmental public health tracking networks.

In 2001, California enacted Senate Bill 702 (Cal Health & Saf Code §104324-104324.5) establishing the intent of the legislature to create an Environmental Health Surveillance System. The legislation created a working group to study setting up a system to track conditions such as asthma, birth defects and cancers of unknown origin. Senator Martha Escutia, who introduced the bill, said the goal is to provide communities with reliable information about chronic disease and its relationship to the environment. In February 2003, Senate Bill 189, the California Health Tracking Act, was introduced. This bill states the intent of the legislature to implement the recommendations of the working group for establishing the Environmental Health Surveillance System.

Montana passed a bill (H.B. 582) on chronic disease tracking in 2001 that requires the state health department to

Figure 3. State Participation in Environmental Public Health Tracking



Source: Environmental Public Health Tracking Program, *At A Glance Factsheet*, 2003.

convene a task force and perform a feasibility study on the creation of a chronic disease registry. The task force was required to consider a host of technical issues related to such a system and to take into account recommendations by the Pew Environmental Health Commission and the CDC.

In response to the disease cluster in the small town of Fallon, Nevada, where 16 children came down with leukemia, the Nevada Legislature passed Assembly Bill 315, which the governor signed in May 2003. This law requires the state health officer to analyze data from health facilities to determine whether trends exist in cancer incidence and to perform an investigation if a localized increase in rates is detected.

Both Massachusetts and New York introduced bills in 2003 to implement health tracking. Massachusetts Senate Bill 695 requires the creation of an environmental illness registry to record the incidence of asthma, lupus, lead poisoning and other environmental illnesses. New York Assembly Bill 4295 sets up an environmental health tracking system within the Department of Health in cooperation with the Department of Environmental Conservation and Labor to correlate environmental data with disease data.

California is the only state to introduce legislation on the biomonitoring component of environmental public health tracking. In May 2003, Senator Deborah Ortiz introduced Senate Bill 689, the Healthy Californians Biomonitoring Project. The legislation calls for creation of a pilot program to monitor breast milk for signs that environmental contamination plays a role in the development of diseases such as autism, which has increased dramatically in California. It also calls for the creation of other pilot projects to use blood and urine to test for environmental exposures.

Resources

Centers for Disease Control and Prevention, Environmental Public Health Indicators: Details on CDC's and the Council of State and Territorial Epidemiologists' (CSTE) work in identifying environmental public health indicators:

<http://www.cdc.gov/nceh/indicators/default.htm>.

Centers for Disease Control and Prevention, Environmental Public Health Tracking: Information on CDC's work in environmental public health tracking:

<http://www.cdc.gov/nceh/tracking/>.

Centers for Disease Control and Prevention, National Report on Human Exposure to Environmental Chemicals: Information on CDC's biomonitoring activities:

<http://www.cdc.gov/exposurereport/>.

U.S. Environmental Protection Agency, Information Integration Initiative: Provides information on work that EPA and the States are doing to develop a comprehensive data exchange network that will provide a wide-range of shared information among states and EPA, tribes, localities, the regulated community and other data partners: <http://www.epa.gov/oei/iilive.htm>

Trust For America's Health: Provides information on how to strengthen the nation's public health system and nationwide health tracking: <http://healthyamericans.org>

Notes

- ¹ Johns Hopkins School of Hygiene and Public Health, *America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*, (September 2000).
- ² Ted Schettler, "Toxic Threats to Neurologic Development of Children," *Environmental Health Perspectives* 109, Supplement 6 (December 2001): 813-816.
- ³ Lynn Goldman, Testimony before the Senate Environment and Public Works Committee Field Hearing, June 11, 2001.
- ⁴ Interview with Shelley Hearne, "The Environment and Disease: Tracking the Health Connection," *State Health Notes* (National Conference of State Legislatures, June 18, 2001), 3.
- ⁵ *America's Environmental Health Gap*.
- ⁶ National Health Interview Survey, National Center for Health Statistics, 2001.
- ⁷ K.B. Weiss and S.D. Sullivan, "The health economics of asthma and rhinitis. I. Assessing the economic impact." *Journal of Allergy and Clinical Immunology* no. 107 (2001): 3-8.
- ⁸ National Heart, Lung and Blood Institute. *Morbidity and Mortality: 2002 Chart Book on Cardiovascular, Lung, and Blood Diseases* (May 2002).
- ⁹ P. Lichtenstein, N.V. Holm, P.K. Verkasalo, A. Iliadou and J. Kaprio, "Environmental and heritable factors in the causation of cancer—analyses of cohorts of twins from Sweden, Denmark and Finland," *New England Journal of Medicine* 13, no. 343 (July 2000): 78-85.
- ¹⁰ Centers for Disease Control and Prevention, *Birth Defects: Frequently Asked Questions*, www.cdc.gov/ncbddd/bd/faq1.htm.
- ¹¹ L.J. Paulozzi, "International trends in rates of hypospadias and cryptorchidism," *Environmental Health Perspectives* 107 no. 4 (April 1999): 297-302.
- ¹² Richard Jackson, Director of the National Center for Environmental Health at CDC, interview with author, Feb. 1, 2002.
- ¹³ *America's Environmental Health Gap*.
- ¹⁴ Ed Fletcher, "State May Test Pollution in People," *Sacramento Bee*, May 5, 2003.

The *Environmental Health Series* is produced by staff from the Environmental Health Project at the National Conference of State Legislatures in Denver. The Centers for Disease Control and Prevention (CDC) reviews each issue for accuracy and scientific integrity. For more information, visit www.ncsl.org/programs/esnr/toxics.htm or call (303) 830-2200.

This issue of the *Environmental Health Series* was researched and written by Glen Andersen.