

HEALTH TRACKING & DISEASE CLUSTERS

*The Lack of Data on Chronic Disease Incidence
and its Impact on Cluster Investigations*

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Executive Summary

Each year, more than 1,000 calls are placed to public health officials regarding suspected local disease clusters. In many of these cases, investigators are called upon to determine whether rates of a disease in a particular community truly are excessive – and whether environmental exposures are to blame.

Requests for disease cluster investigations are just one sign of the broad public concern about the role environmental factors play in the development of chronic disease. Nearly 90 percent of Americans believe that environmental factors such as pollution cause disease or health problems.

Disease cluster investigations play an important role in responding to these concerns and protecting public health. Cluster investigations can help public health officials target resources for disease prevention and treatment, spur the discovery and cleanup of existing environmental hazards, and enable researchers to develop and test hypotheses about the possible links between environmental exposures and chronic disease.

Cluster investigations are notoriously difficult, even under the best of circumstances and with ample resources. However, in most states, the resources available for investigating disease clusters are extremely limited. In 1998, 26 states devoted less than one half-time person to cancer cluster investigations – a level of staffing virtually unchanged over the previous decade. States also demonstrate

varying degrees of vigor in their response to cluster reports, with some states resolving as many as 99 percent of all cluster investigation inquiries during the course of the initial phone call.

To succeed in cluster investigations, researchers need complete, up-to-date information on the incidence of disease in a community; data that are typically collected in a disease registry or other health tracking system. To be effective, health tracking systems must be statewide, detailed, up-to-date, utilize multiple sources of information, and include active surveillance by public health officials to ensure that all cases of disease are recorded.

In many states, however, accurate tracking systems for chronic disease do not exist. Only three states – California, Iowa and Massachusetts – possess both cancer and birth defects registries that meet the highest standards for quality and also report having any system at all for the tracking of asthma. And almost no states conduct systematic tracking of learning disabilities, neurological disorders such as Alzheimer's and Parkinson's, metabolic diseases like diabetes, or auto-immune disorders such as lupus.

This report details the real-life costs of this knowledge gap as it relates to the investigation of 14 suspected disease clusters over the past decade. A review of completed cluster studies and other literature and interviews with state public health officials reveal that lack of access to high-quality health tracking data:

1) Causes long delays in cluster investigations;

2) Prevents public health officials from identifying disease trends;

3) Inhibits the identification of true disease clusters;

4) Reduces the number of cluster investigations carried out by states, meaning that some clusters go uninvestigated; and

5) Deters communities from getting the information and help they need when a suspected cluster arises.

While most states lag behind in their ability to track and investigate disease clusters, several states have shown the potential benefits of chronic disease tracking.

- Researchers using data from the California Birth Defects Monitoring System have shown that maternal exposure to air pollution and residence within a quarter-mile of a Superfund site are related to the development of certain birth defects.
- Texas public health officials used their ongoing surveillance of birth defects data to identify a cluster of neural tube defects in Laredo just months after it emerged. The state is now targeting public health assistance to the area.
- New York state officials are using a first-of-its-kind cancer mapping system to identify potential cancer clusters. The state is now investi-

gating significantly elevated rates of breast cancer in seven Long Island zip codes.

With growing evidence that environmental factors play a significant role in the development of many chronic diseases – and with growing public concern over those links – the need to quickly and effectively identify and investigate disease clusters is greater than ever. The creation of a nationwide health tracking network would allow public health officials to conduct quicker, less resource-intensive, and more accurate investigations of disease clusters while providing researchers with the tools to better assess possible environmental links to chronic disease. Such a system would include:

- Tracking of cancers, birth defects, respiratory diseases such as asthma, neurological diseases such as Alzheimer’s and other chronic diseases in every state.
- Tracking of environmental exposures, such as exposures to PCBs, heavy metals and pesticides.
- An early warning system to alert communities to immediate health crises such as heavy metal and pesticide poisonings.
- Federal, state and local rapid response capability to investigate clusters, outbreaks and emerging threats.

In addition to establishing a national health tracking network, public officials should encourage the linkage of health data with existing data on environmental conditions, promote public involvement

in cluster investigations, and take an aggressive stance toward both the prevention of new environmental hazards and the cleanup of existing hazards nationwide.

Introduction

The mother of a young Ohio leukemia patient calls to offer support to the mother of another young leukemia patient who had graduated from the same high school as her daughter. During the conversation, the mother is told that a third young graduate of the high school has also been diagnosed with the disease. The two mothers decide to investigate, and within months find ten graduates who suffer from various forms of cancer. Environmental testing later uncovers evidence of toxic contamination on the grounds of the school, which was built on top of a former Army depot.

A woman diagnosed with scleroderma – an autoimmune disease that causes tightening of the skin and can attack vital organs – learns from a co-worker that another woman in her Boston neighborhood also has the disease. She begins asking questions around the neighborhood. When the number of local scleroderma patients hits six, she calls the state health department. Since that phone call, another 20 scleroderma patients in the neighborhood – along with 60 others who suffer from lupus, a related autoimmune disorder – have been identified. She and others in the neighborhood wonder if air or water pollution in the neighborhood could be responsible.

Doctors at a clinic in a Texas border town deliver three babies missing part or all of their brains over the course of just a few hours. They alert public health officials, but without information about other birth defects in the region, investigation is difficult. In the years since, clusters of similar birth defects have emerged on

other portions of the U.S.-Mexico border. Public health officials believe vitamin deficiencies are to blame while some community residents suspect that industrial pollution could play a role.

Concerned mothers. Curious patients. Alarmed doctors. When it comes to suspected clusters of cancer, birth defects, and chronic disease in the U.S., they are almost always the first to recognize a problem – and to begin the search for answers.

Each year, at least 1,000 calls are placed to state public health officials regarding suspected clusters of disease. These reports are just one sign of the broad public concern about the role environmental factors may play in the development of chronic disease. Nearly 90 percent of Americans believe that environmental factors such as pollution cause disease or health problems.¹

In many cases, concerns about a suspected disease cluster are unfounded. But in a significant number of cases, the possibility of a cluster is sufficiently real that public health officials feel compelled to investigate.

Cluster investigations are notoriously difficult, even under the best of circumstances. To succeed, researchers must have access to reliable, up-to-date information about the extent of disease within a community and solid information about potential environmental contaminants and possible routes of exposure.

Most Americans assume that such information exists. More than half of all Americans believe that the nation has a national system for monitoring exposures to environmental threats and tracking chronic disease.²

We don't. And the state-level chronic disease tracking programs that do exist often fail to provide researchers with the information they need to answer the most basic questions related to disease clusters: How many people are sick? Who are they? And where do they live?

The lack of chronic disease monitoring has impacts far beyond the investigation of disease clusters. While outbreaks of infectious diseases such as Legionnaire's disease or E. coli are often almost instantly identified (and bring about a prompt public health response), trends in the incidence of chronic diseases such as lupus or multiple sclerosis can go years without being identified by the public health system. Even statistics from registries for the most aggressively tracked diseases, such as cancer, may be two years or more out of date.

The result is a system that leaves citizens and public health officials largely in the dark about trends in chronic disease, and prevents the effective study of the degree to which environmental factors play a role in the development of those disorders. Delaying this understanding means public health officials and policymakers cannot act effectively to prevent disease.

Through case studies, interviews with state public health officials, and a review of existing literature, this report makes the case that the failure to adequately

track the incidence of chronic disease leads to costlier and less conclusive cluster investigations that often take longer to complete. In many cases, the lack of such data may result in worthwhile investigations never taking place at all.

To quickly and effectively identify and investigate disease clusters, the nation's public health system must have better information about where chronic disease is occurring in our communities and how individuals may be exposed to environmental contaminants. That information must be collected and stored in such a way as to be useful to researchers and be easily linked to other databases of exposure or health-related information. And state and federal officials must have the resources and the staffing to use that information to thoroughly investigate suspected disease clusters and the links between environmental contamination and public health.

Why Investigate Disease Clusters?

The causes of many cancers, birth defects and chronic diseases remain shrouded in mystery. While researchers have identified genetic, lifestyle and environmental factors that can contribute to the development of chronic disease, the exact interactions are poorly understood and other causes may remain unidentified.

Yet, there is growing awareness that environmental exposures play a significant role in the development of some chronic diseases. A 2000 study published in the *New England Journal of Medicine* found that environmental and lifestyle factors appear to play a greater role in the development of most types of cancer than genetics.³ Scientists estimate that about three percent of all developmental defects can be attributed to toxic exposures and, more generally, that environmental and lifestyle factors play a role in about 25 percent of developmental defects.⁴

The mystery surrounding the causes of many chronic diseases leads to concern when groups of neighbors, co-workers, or others who share a common bond contract the same disease at roughly the same time. Naturally, and justifiably, those affected by the disease wonder whether something more than chance – perhaps something to which they have been exposed in their air, water or food – could be responsible. And others in the community wonder whether they will suffer the same fate.

Public health officials have a responsibility to the community to respond to these

concerns with sensitivity – and a responsibility to the broader public to do so with efficiency. In some cases, this response will include a deeper investigation into the suspected disease cluster. These investigations can have direct public health benefits: the identification and closing of a contaminated well, the cleanup of a toxic waste site, the targeting of resources for disease prevention and treatment to those most in need. And in some cases, investigation of suspected clusters can shed light on the role environmental exposures play in the development of chronic disease – discoveries that can represent dramatic breakthroughs in public health.

What Is a Disease Cluster?

A disease cluster is defined as the occurrence of a greater than expected number of cases of a particular disease among members of a specific group, residents of a specific area, or over a specific period of time.⁵ This definition may appear straightforward, but a deeper reading tells a great deal about what clusters are and how they are viewed by scientists and researchers.

First, the word “cluster,” under this definition, simply means an excess of disease. Disease can cluster in an area for a variety of reasons, including demographics, lifestyle choices, occupational exposures and environmental factors – or for no reason at all. Just because a grouping of disease is called a cluster does not mean it has an environmental cause.

Second, the phrase “greater than expected number of cases” is often interpreted to mean a *statistically significant* excess of cases when compared to an established baseline. Even a random distribution of disease will result in some areas having more cases of disease than others. To be considered a cluster, an area must have such a high rate of disease that the elevation is unlikely to be explained by chance. However, the absence of a statistically significant cluster does not necessarily mean that there is no environmental link to the development of disease.

Finally, the phrase “particular disease” refers not to overarching categories of disease such as “cancer” or “birth defects” but to specific diagnoses within those categories. The term “cancer,” for example, is used to refer to more than 100 separate diseases. An increased rate of various forms of cancer within a community is therefore unlikely to be deemed a “cluster,” while an outbreak of a specific form of cancer is more likely to be given that designation.

The task of defining the existence of a cluster, therefore, is different from the task of assessing the role environmental factors may play in the development of a disease in a particular community. The task of defining a cluster is primarily a statistical exercise; the task of assessing the cause of a cluster is an epidemiological one. In the case studies that accompany this report, the term “cluster investigation” will be used to include both the statistical efforts made to define and assess the severity of clusters and the epidemiological studies that follow once a cluster has been identified.

How Common Are Reports of Disease Clusters?

State public health officials receive somewhere between 1,000 and 2,000 reports of suspected cancer clusters each year – a figure that does not include reported clusters of other diseases. About two-thirds of these reports come from individual citizens.⁶

The number of cancer cluster investigation requests varies widely from state to state, ranging from as many as 300 requests in California in 1997 to as few as two in small states such as North Dakota and Delaware. **(See Table 1.)**⁷

*Table 1: Requests for Cancer Cluster Investigations, 1997*⁸

STATE	INVESTIGATION REQUESTS	STATE	INVESTIGATION REQUESTS
CA	300	CO	9
NY	91	MD	9
NJ	71	VA	9
IL	64	MS	7
MA	59	AL	6
MO	43	FL	6
TX	43	NM	5
NC	30	UT	5
WI	29	KS	5
MN	29	ME	4
PA	25	AK	3
MI	24	MT	3
CT	20	IA	3
OR	20	WA	3
LA	18	ND	2
WY	12	DE	2
RI	12	NE	2
AZ	12	WV	2
NH	11	AR	2
ID	11	KY	2
SC	10	DC	1
IN	10	NV	0

Hawaii, Oklahoma, Tennessee and Vermont did not provide information. Georgia, Nevada and South Carolina reported that they do not conduct cluster investigations. Ohio refused to participate in the survey.

Of these reports, most are resolved immediately. Often, when citizens are made aware of the overall prevalence of cancer and the generally random nature of its distribution, their suspicions of a cluster are relieved. Even in cases where citizens' concerns are not relieved, public health officials may decide that the situation described is unlikely to constitute a true cluster and decline to launch an investigation.

Between one-quarter and one-third of all cancer cluster inquiries, however, progress beyond the initial phone call. Very few of these inquiries result in identification of a true cluster. State health departments report that less than five percent of all inquiries show sufficient evidence of a cluster to warrant a full-scale investigation.⁹ Of these investigations, only a few have ever succeeded in linking a specific outbreak of disease to a specific environmental cause. **(See "Historic Cluster Investigations")**

Why, then, do public health agencies focus scarce resources on the investigation of disease clusters? And why are such investigations important for public health?

Historic Cluster Investigations

Several investigations of clusters of rare diseases have yielded public health breakthroughs.

LEGIONNAIRE'S DISEASE – A mysterious outbreak of pneumonia at a 1976 American Legion convention in a Philadelphia hotel claimed 34 lives. Researchers traced the cause of the disease to bacteria in contaminated water used in the hotel's air conditioning system. The discovery has led to

increased attention to the maintenance of building water systems.¹⁰

RESPIRATORY CANCERS – The first atlas of cancer mortality in the U.S., published in 1975, showed clearly elevated rates of respiratory tumors in port cities. Subsequent studies linked the cancers to exposure to asbestos in the shipbuilding industry during World War II.¹¹ Asbestos use has dramatically declined over the last two decades and it has been removed from many public buildings.

BIRTH DEFECTS – During a two-month period in 1961, an Australian doctor delivered three babies with phocomelia – a rare birth defect in which the upper parts of the arms and legs are missing, resulting in the hands and feet being directly attached to the body. The mothers of all three babies had taken thalidomide, a popular tranquilizer. For much of the previous year, similar cases of the defect had been occurring in Germany, but doctors had failed to establish a pattern. Within months, thalidomide was withdrawn from the market.¹²

VAGINAL CANCER – A 1971 investigation of an unusual number of cases of a rare vaginal cancer among young women traced the cause to a drug, diethylstilbestrol (DES), taken by their mothers during pregnancy to prevent miscarriage.¹³ Physicians were subsequently advised not to prescribe DES to pregnant women.

LIVER CANCER – A 1974 study of a rare form of liver cancer contracted by four workers in the same Kentucky factory led to the identification of vinyl chloride as a potent carcinogen. Regulations adopted after the discovery reduced the level of vinyl chloride to which workers could be legally exposed by 99.8 percent.¹⁴

HIV – In the early 1980s, physicians began to learn of outbreaks of a rare form of cancer (Kaposi's sarcoma) and a rare pneumonia among gay men. The investigation into the cluster eventually led to the discovery of AIDS and its cause, HIV.¹⁵

Benefits of Cluster Investigations

Identifying a Cause of Disease

The greatest potential public health benefit that can arise from a cluster investigation is the discovery of a previously unknown cause of disease or a direct link between a specific environmental exposure and the development of disease. Such discoveries are rare, but when they occur, the benefits to public health are great.

Cluster investigations such as the inquiries into asbestos-related cancers and AIDS have the potential to bring about sweeping changes in lifestyles and medical treatment. Asbestos use, for example, has declined dramatically since the 1970s. The identification of AIDS and HIV – the direct result of inquiries into unusual cancer and pneumonia clusters among gay men in the early 1980s – have led to public health approaches designed to stem the spread of the disease and to new treatments that offer improved living conditions for AIDS patients.

For many reasons, the investigation of occupational or medical exposures is more likely to yield such a dramatic result than investigation of environmental exposures. First, in all but the most unusual cases, individuals are exposed to environmental contaminants at low levels over long periods of time. The long latency periods of many cancers, for instance, and inadequate understanding of how toxic exposures at low levels affect human health, make it difficult to identify the role such exposures could play in the development of particular cancers.

Second, people move into and out of

communities frequently, making it difficult to ascertain whether environmental exposures that took place in one location led to the development of disease.

Third, people are exposed to a multitude of toxic substances in a variety of settings throughout their lives. Sorting through the many possible exposures to determine the specific exposure that caused a particular disease is an extremely difficult task. While epidemiologic investigations (and common sense) sometimes suggest that residence near a toxic waste site or presence during a specific environmental release could be a cause for a given disease, such suggestions can rarely be proven to the high degree of certainty demanded by scientists.

While investigations of residential clusters are rarely sufficient to prove environmental causation, they can suggest hypotheses for further epidemiological study. By expanding the scope of a study to include several communities with common environmental exposures (for example, communities near hazardous waste sites), some of these concerns can be addressed, leading to the increased likelihood of significant findings.

Identifying Environmental Hazards

In many cases, the intense scrutiny caused by a cluster investigation has led to the identification of environmental hazards that may not have been identified otherwise.

Several of the most famous cluster investigations – such as those in Woburn, Mass. and Toms River, N.J. – were able to draw associations between disease outbreaks among certain populations and a

specific exposure pathway; for example, drinking water from certain town wells. From the point of view of identifying the cause of the cluster, these investigations did not prove with complete certainty that the contamination was the cause and thus were “failures” – expensive ones. But in the Toms River case, the investigation led to the identification of a previously unknown contaminant in the problem well. **(See "Case Study: Toms River, N.J." below.)** Both the Woburn and Toms River studies contributed to a scientific body of evidence identifying prenatal chemical exposures as a potential risk factor for childhood leukemia. And in both cases, the cluster investigations brought new momentum to efforts to clean up existing hazardous waste sites.

CASE STUDY: TOMS RIVER, N.J. (CHILDHOOD LEUKEMIA)

LACK OF UP-TO-DATE REGISTRY DATA SETS BACK AN INVESTIGATION

In the early 1980s, residents of Toms River began to suspect that environmental contamination could be responsible for what they perceived as an increase in childhood cancer in the community, which is located near a former dye and resin factory listed as an EPA Superfund cleanup site.

Despite the earlier suspicions, however, it was not until a Philadelphia nurse who had worked with many cancer patients from Toms River reported her suspicions to the EPA that an investigation took place. The request eventually made its way to the New Jersey Department of Health

and Senior Services, which conducted an incidence study based on registry data. That investigation was completed in 1995 and found a significant excess of child brain and central nervous system cancers in the community and in the surrounding county. However, the results did not become known to the public until the publication of a newspaper report the next year.¹⁶

The results of the initial study, while explosive, were far from definitive. The study was based on registry data that were four years old. As community groups and public officials plotted a response to the findings, one of the first orders of business was to update the cancer registry and re-create the 1995 study based on up-to-date data. The results of the second study, released in 1997, were illuminating: child cancer rates in Toms River and its surrounding township were again found to be significantly elevated, but those in the rest of the county were not. The elevation in total cancer cases was most apparent in girls under age 5.¹⁷

Investigators then began to look at possible environmental exposures that might have some relationship to the cluster. Based on the excess of disease that had been discovered and the existence of potential exposures that could be investigated, researchers opted to launch a case-control study.

The study included interviews with nearly 200 parents of children in the township, one-fifth of them parents of children with cancer. Birth records of township children were examined, computer modeling undertaken to reconstruct drinking

water conditions at various times over the previous three decades, and environmental monitoring was carried out of water supplies and local Superfund sites in order to determine any potential route of exposure the children may have had to toxic substances.

In December 2001, four years after that study was initiated, researchers released their results. The study found mothers of the female leukemia cases studied were six times more likely to have consumed water from one municipal well than were mothers of girls who did not contract leukemia. Female leukemia cases were also more likely to have been exposed to air emissions from the nearby Ciba-Geigy plant. However, investigators did not demonstrate conclusively that any one contaminant or source of exposure was responsible for the cluster.¹⁸

While the Toms River investigation took a total of six years and cost millions of dollars, it did breed some successes. A previously unidentified drinking water contaminant was found and new filtration systems installed. Measures were taken to limit the contamination of groundwater from toxic sites.¹⁹ And citizens settled a lawsuit with Ciba Specialty Chemicals, Union Carbide and the local water company, reportedly for more than \$10 million.

In addition, the Toms River case highlighted the importance of access to up-to-date cancer registry data, bringing about a long-overdue updating of the registry. Had those data been available earlier, researchers may have been able to save time

in their investigation. Also, had there been better public access to the registry and participation in the inquiry, there may not have been a year's lag time between the initial investigations and a public call for further work. And with consistent surveillance of those data, public health officials could have turned up evidence of a cluster long before it happened to be noticed by a nurse in a nearby state.

Marion, Ohio provides another example. Suspicions of elevated rates of leukemia among graduates of a local high school triggered environmental testing that located toxic substances on the school's athletic fields. While no study has conclusively linked the contamination with the leukemia cases, the revelations led to closing of the fields and, eventually, the construction of new schools for the district's children. (See "Case Study: Marion, Ohio," page 29.) Even when specific exposure pathways cannot be identified, cluster investigations often result in public officials taking added steps to monitor and remediate potential sources of environmental exposure. (See "Case Study: Atkinson, N.H.," below.)

CASE STUDY: ATKINSON, N.H. (CANCER)

CLUSTER REPORT BRINGS AWARENESS OF WATER CONTAMINATION

In January 2002, residents of Atkinson reported to state officials their suspicion that a small section of their town had elevated rates of cancer. Residents identified a total of 32 cases of various types of cancer diagnosed within a half-mile

radius of Providence Hill Road. Of those cases, at least 10 had been diagnosed within the past three years.²⁰

The New Hampshire Department of Health and Human Services investigated the claims using 1994-1998 data from the state's cancer registry. In late February, DHHS officials determined that the cases – which had been reported over a 22-year period and included several different cancer diagnoses – did not represent a true cancer cluster.²¹

However, the state's inquiry and the public attention focused on environmental conditions did bring about increased awareness of a potential public health concern in the town. The initial cancer reports prompted several area residents to have their private wells tested. Those tests revealed levels of radon in private wells more than 30 times higher than the concentrations at which the state of New Hampshire says well users should be concerned and more than 15 times higher than a proposed federal standard.²² A week after the state closed its cluster inquiry, test results from a public water system that serves 850 town residents were released, disclosing levels of radon up to 20 times the level of state concern.²³ Results of water tests at a local elementary school found similar levels of radon.

The EPA recognizes that radon in drinking water poses a risk of lung and stomach cancers. But, more than a decade after first proposing a drinking water standard for radon in public water supplies, the EPA has yet to finalize the rule. As a

result, state officials have no power to compel public water suppliers to install equipment to reduce radon levels in drinking water. However, state officials did offer well testing to neighborhood residents. In addition, the incident brought the lack of a national standard for radon in drinking water to the attention of the state's elected officials, who would be in a position to press EPA on the matter.²⁴

The Atkinson cancer cases may not have met the definition of a true cancer cluster. But the heightened community awareness that arose as a result of the cluster inquiry resulted in the identification of a potential health hazard, and may help motivate public officials to take long-overdue action to protect the public health.

Critics of cluster investigations sometimes suggest that the public health resources used for those investigations would be better spent on environmental cleanup. While citizens should not have to wait until health problems are documented in order for toxic threats in their neighborhoods to be cleaned up, history has shown that it has frequently only been the discovery of a disease cluster that has created sufficient urgency among public officials to spur cleanup activity. Moreover, the initiation of a cluster investigation has often led to the identification of local environmental threats that had previously been unknown or poorly understood.

Targeting Public Health Resources

The existence of a disease cluster can also help public health officials target prevention and treatment resources to the populations that most need them.

In Brownsville, Texas, for example, an investigation of a cluster of neural tube defects in the early 1990s did not conclusively link the cases to any known environmental exposure. The identification of the cluster, however, resulted in renewed efforts to educate women of child-bearing age in the border region of Texas about the importance of consuming multivitamins that include folic acid, which is known to reduce the risk of neural tube defects in newborns. (See "Case Study: Laredo, Texas," below.)

CASE STUDY: LAREDO, TEXAS (NEURAL TUBE DEFECTS)

AGGRESSIVE MONITORING CATCHES EMERGING CLUSTER

Within a 36-hour period in 1991, three babies were born with anencephaly (the absence of part or all of the brain) in a single clinic in Brownsville, Texas, on the Mexican border. Over the next few weeks, several other babies were born with the condition in Brownsville – highlighting a larger problem with neural tube defects (NTDs) in communities along the border.

The Brownsville cluster – and the lack of information about the prevalence of NTDs in the state – shocked Texans. In 1993, the state Legislature created the Texas Birth Defects Monitoring Division (TBDMD), a tracking system for birth defects in which state public health officials actively seek out cases of birth defects at local health care facilities. The benefits of that system were demonstrated in 2001 in another border community: Laredo.

In early 2001, as field staff from the division were collecting data from health care facilities, they noticed what appeared to be a high rate of anencephaly cases in Laredo. A subsequent review of data collected for the registry found that seven cases of anencephaly had occurred to babies born of mothers living in Laredo in late 2000 and early 2001 – a statistically significant excess of cases even when compared to other counties along the border. In May 2001, the division issued a memorandum about the high rates and laid out the public health response. That response included a campaign by the city of Laredo to encourage the consumption of multivitamins including folic acid, which has been shown to significantly reduce the risk of NTDs.²⁵

Meanwhile, state investigators are involved in efforts to determine the cause of the high rate of NTDs along the Texas-Mexico border. In conjunction with CDC and EPA, Texas health officials are conducting a case-control study, including surveys and laboratory testing of biological samples, in an attempt to narrow down the potential causes of the elevated rates.

The active surveillance done by TBDMD has also enabled the state to be more pro-active in the investigation of suspected birth defects clusters. Of the 76 cluster investigations the division has undertaken, more than 60 percent have been initiated by public health officials or health care providers. By way of comparison, less than one third of all cancer cluster inquiries nationwide are initiated by public health or health care professionals.

Moreover, the availability of registry data has eliminated the expense of attempting to track down and verify birth defects cases with physicians and the uncertainty of relying on birth certificates for investigations. One study mentioned by TBDMD staff found that only 40 percent of all Down's syndrome cases, for example, were noted on birth certificates.²⁶ Similar failings with birth certificates have been noted in other studies of birth defects clusters.

A senior epidemiologist at the division reports that the registry "has drastically increased the timeliness and also drastically increased the ease and accuracy with which we can do these investigations."²⁷ While the state still faces many challenges in NTD prevention – and in discovering why cases of the disorders tend to occur along the border – the state's birth defects registry has already proven itself to be a powerful tool in investigating community concerns, identifying problems as they develop, and helping the state focus its public health response.

Similarly, the identification of a cluster of pleural cancer cases in Charleston, South Carolina enabled state officials there to provide medical screening services to former shipyard workers and others at high risk in the community. **(See "Case Study: Charleston, S.C.," page 22.)**

Even when citizen reports of disease clusters are clearly incorrect, the ensuing interaction between the citizen and health officials provides the opportunity to spread important information about the prevention of disease. In their initial

response to cluster concerns, most state health departments provide general information about the disease in question and tips for prevention.

In short, while most cluster investigations "fail" to link a specific outbreak of disease to a specific environmental cause, the few that succeed can have dramatic impacts on public health. And those that succeed more modestly can result in improved environmental conditions and access to health resources that provide real health benefits to community residents.

How Disease Clusters Are Investigated

A Four-Stage Process

Inquiries into disease clusters are generally conducted at the state level – usually by state public health departments, but sometimes by state disease registry programs, state environmental officials or local health departments. In some cases, federal agencies, such as the Centers for Disease Control and Prevention (CDC), are called upon to lead or provide assistance with cluster inquiries.

The CDC and many states have established protocols that guide their cluster investigations. The CDC protocol, established in 1990, serves as the basis for many of the state protocols. This protocol breaks a cluster investigation down into four stages: initial response, assessment, major feasibility study and etiologic investigation (investigation into cause).²⁸

Stage 1: Initial Response

This stage begins at the moment public health officials receive a report of a suspected cluster. Public health officials gather identifying information and initial data on the cluster from the caller, obtain names and contact information for others with the disease, and share basic information about the disease. The CDC protocol requires that calls be tracked, preferably in a computerized database, and that each call receive a written response.

At this stage, public health officials must also make a determination as to whether to continue the investigation. Continuation is warranted under the

CDC protocol if the initial report describes a) a single and rare disease, b) plausible exposure to a source of environmental contamination, or c) plausible clustering. In the event none of these factors are present, a report is sent to the caller indicating that no further investigation is necessary.

Stage 2: Assessment

Once the decision has been made to move forward with an investigation, public health officials then carry out an assessment of whether the incidence of disease in the community constitutes a true cluster. This assessment takes place in several smaller stages moving from quick and general assessment of incidence rates to more detailed investigation, if warranted.

The first step in the assessment is to conduct a quick study from available data of whether a cluster may exist in a community. In some cases, this may include consulting data from a disease registry, where such data are readily available.

At this point, investigators must make a crucial decision; they must define the “community” to be studied – its geographic boundaries and population. Ideally, this decision will be made based on some hypothesis (or hypotheses) as to the cause of the cluster – for example, by analyzing disease rates in sections of a town nearest to a hazardous waste site or those parts of town receiving water from a suspect well. Investigators may also choose to narrow the time period being

studied to account for an environmental exposure of limited temporal scope.

In practice, however, decisions as to the boundaries of the population to be studied are often more arbitrary. First, community residents and researchers often do not have a good hypothesis when they begin an investigation. For example, a study of cancer cluster investigation requests found that residents did not specify a suspected cause in 40 percent of their initial reports.²⁹ Second, the way data are collected and stored in state disease registries often makes it difficult for researchers to break the data down into the smaller geographical units of interest in many cluster inquiries. As a result, many preliminary reports on clusters evaluate rates of disease based at a city or county level – levels that may not be appropriate for evaluating a suspected environmental exposure.

Once the boundaries of the study have been set and initial data on disease incidence collected, investigators must determine what rate of disease would be expected for a similar population and run a statistical comparison.

If the preliminary evaluation suggests that an excess may exist, investigators then must verify the cases by tracking down medical records or consulting a disease registry.

Finally, if the cases are verified and an excess confirmed, a thorough assessment of the potential cluster should take place. Elements of this assessment include: a) determining the most appropriate boundary for the study, b) identifying all cases within that boundary, c) identifying

the data that will be used for the study and the statistical and epidemiological procedures to be used in analyzing the data, d) performing an in-depth literature review and considering the plausibility of any association with an environmental factor, e) assessing the likelihood that an event-exposure relationship may exist, and f) assessing the community's perceptions, reactions and needs.

At this point, the investigation will likely come to one of three conclusions. If an excess of disease does not exist, the investigation will be terminated. If an excess does exist, but there is no plausible link to an environmental exposure, the investigation will also be terminated, but public health officials may advise the community of any risks they face and make recommendations for further disease surveillance, environmental monitoring or public health follow-up. If both an excess and a possible link to an environmental exposure exist, the investigation proceeds to the next stage.

Stage 3: Major Feasibility Study

At this stage, investigators reconsider the definition of the population being studied, re-evaluate the literature, and map out a plan – including costs – for conducting a major investigation. If a detailed investigation into cause appears warranted, investigators proceed to the final stage.

Stage 4: Investigation into Cause

In this stage, investigators embark on a quest to determine whether a particular environmental exposure can be linked to the disease in question. The CDC notes that the purpose of this investigation is

not focused on the cluster itself, but on the public health issues it raises.

Data for Cluster Investigations

One of the most important decision points in a cluster inquiry takes place at the beginning of Stage 2. It is at this point that public health officials must determine if there is significant likelihood of a cluster to merit further investigation. Poor decision-making at this stage can lead to the inappropriate expenditure of public health resources on investigations of unlikely clusters or, alternatively, the failure to fully investigate conditions that pose a risk to public health.

Information on the expected and actual incidence of a disease within a defined community is critical to this decision.

Sources of Information on Disease Incidence

Researchers generally have four options for assessing the number of cases of a particular disease in a community.

REGISTRY DATA – The most convenient and generally most accurate source of data on disease incidence is the centralized disease registry. While there are inconsistencies in the completeness and accuracy of such data from registry to registry, (see **"The Current State of Health Tracking Data" page 32.**) registry systems typically require systematic reporting of disease incidence by hospitals, labs or other health care professionals and subject such data to some form of quality assurance. In the best cases, researchers can, through a relatively straightforward query of a database,

derive detailed information about the number of cases diagnosed in areas as small as a census tract, along with demographic information that allows a more accurate comparison with similar populations elsewhere.

DEATH RECORDS – Mortality (or death) records typically play a role in investigations of cancer clusters. In areas with good cancer registries, mortality is tracked along with incidence, providing researchers with a picture both of how many people in a community have contracted the disease and how many have died from it.

Prior to the advent of cancer registries, death records were the only readily available source of centralized data to track cancer. Death records have the advantage of being complete – death certificates are filed in all jurisdictions and have been for generations. However, they have numerous disadvantages as an analytical tool. One obvious disadvantage is their inability to track chronic disease that results in disability but not death. Another potential problem is the possibility of inaccurate or incomplete descriptions of cause of death (See **"Case Study: Charleston, S.C.," below.**) A third problem is that mortality is not a true gauge of disease incidence. In some areas, people may live longer with a disease due to demographics or access to superior health care. Use of death records in those areas may mask the degree to which the disease is affecting the community.

**CASE STUDY: CHARLESTON, S.C. (PLEURAL
CANCER)
REGISTRY DATA SUCCESSFULLY IDENTIFY
AN OCCUPATIONAL CANCER CLUSTER**

In December 1998, residents of a Charleston neighborhood contacted the state of South Carolina with their suspicion that a nearby hazardous waste site was contributing to a perceived cancer cluster in their neighborhood.

The South Carolina Central Cancer Registry (SCCCR), which had been established three years earlier, took up an investigation. Using cancer incidence data for 1996, the registry found significantly elevated rates of five cancers – colo-rectal, stomach, lung, laryngeal and pleural. The rates of pleural cancer (a cancer of the lining between the lungs and rib cage) were particularly alarming, with three cases where only a fraction of a case would have been expected.

SCCCR staff expanded their investigation to include a study of mortality statistics from 1969 to 1995 and new pleural cancer cases identified in 1997. SCCCR also expanded the geographical scope of the inquiry to a three-county area – identifying a total of 19 cases of pleural cancer, a four-fold increase over what would have been expected. Further investigation determined that 12 of the 19 individuals had worked in the Charleston naval shipyard, where they were likely exposed to asbestos – one of the main risk factors for pleural cancer. A spatial study of the other cancer cases was also undertaken, but found no obvious clustering of the cancers.³⁰

In May 1999, less than six months after initiating its study, SCCCR issued a report determining that a cluster of pleural cancer did in fact exist, and recommending further surveillance of cancer rates in the area and other public health measures. Screening services have since been offered to local residents concerned about occupational exposure to asbestos and further studies have been undertaken of cancer rates in the region.

SCCCR staff report that it would have been difficult or impossible to confirm the pleural cancer cluster without access to accurate registry data.³¹ Without access to a registry, investigators would have had to comb death records, in which pleural cancer is often confused with lung cancer and other diseases as a cause of mortality.

The existence of the registry has also enabled SCCCR to conduct quicker and more numerous cancer cluster investigations. Previously, the state had relied on death records or on self-reporting from the community to investigate clusters. The advent of the central cancer registry in South Carolina has not only aided the discovery of a "true" cancer cluster, but enhances the ability of state officials to investigate other suspected clusters in the future.

PREVALENCE DATA – Another approach to investigating disease clusters is to use prevalence data – data that indicate the number of people living with a disease or experiencing specific symptoms at a particular moment in time. Unlike registry data, in which each new case of a disease is recorded at the time of diagnosis, prevalence is typically ascertained using

indirect measures, such as information on hospital admissions or discharges or physician caseloads.

Prevalence data – gathered through surveys of hospital discharges, emergency room visits, and individuals – are often used at the national level to ascertain general health trends. Their use at the local level, or in cluster inquiries generally, can be more problematic. As with death records, the number of hospital discharges for a certain disease can be as much a reflection of access to health care resources or willingness to seek treatment as it is an indicator of the degree to which a disease is affecting a community.

SELF-REPORTING/HEALTH SURVEYS – This is how nearly all disease cluster inquiries begin, with individuals or groups in a particular community reporting their own experiences with disease to local or state health officials. In cases in which incidence data are unavailable from a central registry and in which mortality or prevalence data are not sufficient, it is also the only way to determine the number of people within a community that suffer from a given disease.

Self-reporting can be encouraged by health officials through systematic health surveys of a community or by putting the word out through newspaper articles, mailings or other forms of public outreach. However, self-reporting creates a number of problems for investigators. First, a thorough accounting of disease incidence or prevalence requires aggressive public outreach, and even with the best of efforts some people are missed. Second, individuals may be reluctant to come forward due to concerns about

their privacy or may simply not bother to speak up, thus reducing the number of cases identified. Finally, a reliance on self-reporting requires that health officials expend the time and effort to verify each claim of disease. This process is both time- and resource-intensive. (See "**Case Study: South Boston, Mass.,**" below.)

CASE STUDY: SOUTH BOSTON, MASS. (SCLERODERMA AND LUPUS)

LACK OF REGISTRY DATA FORCES COSTLY HUNT FOR CASES OF DISEASE

In 1997, residents of South Boston, an urban neighborhood just south of downtown Boston, noticed that several women in the community had contracted scleroderma – an autoimmune disorder that can affect the skin or internal organs. Using word of mouth, residents compiled a list of current or former residents with the disorder, as well as a larger list of residents with lupus, another autoimmune disorder.

In 1998, South Boston residents contacted the Massachusetts Department of Public Health with their concerns. Department officials, recognizing the unusual concentration of cases, initiated an investigation. The progress of the investigation, however, when compared to more common cancer cluster investigations, has been slow. Massachusetts, like other states, does not support a central registry for autoimmune disease. As a result, investigators were forced to conduct extensive community outreach to identify cases – spreading word of the investigation through the

community and asking physicians at local health centers that treat autoimmune disease to alert their patients from South Boston about the study. Such outreach efforts, taking place over the course of several years, succeeded in identifying and verifying 26 current or former South Boston residents with scleroderma and 60 with lupus.³² Even so, the project manager for the study states that, due to the limits of self-reporting, "we can never be sure we got all the cases."³³ State officials report that the number of lupus and scleroderma cases represents a roughly two- to four-fold excess over what would be expected. But a lack of accurate baseline prevalence data for both diseases makes it impossible for state officials to pinpoint the exact degree of excess.

Investigators have extensively interviewed those patients and are now identifying a control population with which they will conduct similar interviews. The study is designed to determine what, if anything, those with autoimmune disorders in the neighborhood have in common in order to assess whether environmental exposures may be responsible for the cluster.

In many ways, the South Boston investigation is a positive model of a state taking aggressive action to investigate a suspected disease cluster. But it also shows that, absent the existence of readily available registry data, cluster investigations can be time-consuming and resource-intensive. It is questionable whether many states would be willing to commit four years and \$1 million, as Massachusetts has, to such an inquiry.³⁴

Establishing Expected Rates of Disease

Of equal importance to establishing rates of disease incidence is the process of establishing the "expected" rate of disease for a given community. For states with access to comprehensive disease registries, the task is relatively straightforward – one can calculate the rate of a given disease statewide or in a particular geographical area based on demographic criteria.

States without cancer registries can use the Surveillance, Epidemiology and End Results (SEER) database to establish expected rates of cancer incidence nationally. The SEER database is based on cancer registry data for a select group of states. SEER registries cover 14 percent of the U.S. population and are in the process of being expanded to cover 26 percent.³⁵

Investigators researching other chronic diseases typically do not have access to similar, comprehensive resources. Often, investigators must rely on published studies of disease incidence that may or may not reflect local conditions. In some cases, the task of determining the expected rate of a disease for a particular population can take years or become a major roadblock to a successful cluster investigation. (See "Case Study: El Paso, Texas," below; "Case Study: Dickson County, Tenn." page 34.)

CASE STUDY: EL PASO, TEXAS (MULTIPLE SCLEROSIS)

EXPECTED LEVELS OF DISEASE DIFFICULT TO FIND

In 1994, a former El Paso resident with multiple sclerosis contacted the Texas Department of Health (TDH) to report an apparent cluster of MS cases among people who grew up in one El Paso neighborhood from the 1940s through the 1960s. Of the 15 people in the neighborhood reported to have contracted MS, 14 attended a single elementary school. Former residents raised questions about the possible role a local metals smelter may have played in the outbreak.

In its initial 1996 evaluation, the health department determined that rates of MS among students at the school were approximately four times what would be expected, based on national prevalence rates. In 1997, the department received funding from ATSDR to conduct a more detailed investigation.

When completed in 2001, that study confirmed the existence of an excess risk of MS among students at the elementary school, but just how large that risk is remains unknown. Because no registry for MS exists in Texas, investigators were forced to undertake a survey of those who had attended the school – a survey with limited ability to identify all the cases of MS that arose within the community. The health department reported that they were unable to locate approximately 70 percent of the students who had attended the elementary school and that less than half of those who were located participated in the study. Among those

who refused to participate were at least two individuals with suspected cases of MS; those cases were excluded from the study.

Moreover, the investigation was hampered by a lack of data as to the rate of disease that would be expected in such a community. The health department determined in its final report that "current comparison MS prevalence estimates, appropriate for use with the El Paso school cohorts, were not available ..." The studies examined by the department to determine the expected rates of disease for the former students were either more than a decade old or based on self-reported, rather than medically confirmed, cases of MS. No prevalence statistics were available that were specific to Texas.

Investigators were somewhat successful in surmounting another data-related challenge: determining the levels of heavy metals to which students might have been exposed. Blood test results and hair samples from the time showed that students had been exposed to high levels of lead and other heavy metals.³⁶

In its final report, the Department of Health recommended that better prevalence data for MS be established for Texas, more study of the El Paso cluster be carried out, and a national study on the links between heavy metals exposure and MS be conducted. In 2000, the department launched an initiative to develop better baseline prevalence rates for Texas.

More than six years after the initial report of a

suspected cluster – and despite the investment of significant resources – investigators have still not fully identified the severity of the cluster – a determination that could have been made relatively quickly with the existence of good registry data for MS. However, the study has succeeded in focusing attention on the lack of good data on MS prevalence and has already sparked further investigation into the environmental links to MS.

Limitations of Cluster Investigations

A lack of data is not the only factor that inhibits the ability to establish the existence of disease clusters. The statistical methods often used to evaluate clusters – and the extraneous forces sometimes experienced by cluster investigators – impose their own limitations.

Methodological Limitations

As noted above, many cluster inquiries attempt to determine whether a statistically significant excess of disease exists in a community. The purpose of this inquiry is to rule out, to the extent possible, the possibility that the cluster could be the result of chance. However, standard statistical tools are generally most useful in cluster investigations if the community being studied is large.

In order for a true cluster to be diagnosed within a small community of a few hundred residents, the level of disease must not just be above the expected level, but *several times above the expected level* in order to meet the test of statistical significance. This criterion is rarely met. In addition, because common diseases have a high rate of incidence at baseline, it is unusual that elevations of those levels are

so great as to meet the test of statistical significance, unless the population being studied is large.

There are some notable exceptions. One study based on registry data has found that women in the metropolitan coastal region of the eastern U.S. are more likely to contract breast cancer than women in other parts of the country. A New York State project to map cancer rates statewide has also uncovered the existence of a potential breast cancer cluster on Long Island. (See "**Case Study: Suffolk County, N.Y.,"** below.)

CASE STUDY: SUFFOLK COUNTY, N.Y. (BREAST CANCER)

ACTIVE SURVEILLANCE PROVOKES INVESTIGATION

In 1998, following years of concerns about elevated breast cancer rates on Long Island, New York State became the first to initiate a cancer mapping program highlighting areas of the state with elevated rates of various cancers.

In May 2002, state officials used the data from the mapping project to initiate an investigation into elevated rates of breast cancer in seven zip codes in Long Island's Suffolk County. The area was the only part of the state to have breast cancer incidence more than 50 percent in excess of expected rates for the 1993 to 1997 period.³⁷

The investigation will examine factors – including environmental and lifestyle factors and variations

in medical treatment – that might be responsible for the excess. Community members will have the opportunity to express environmental concerns and epidemiological studies may take place.

State officials report that the Suffolk County investigation is the first of many that will result from the state’s Cancer Surveillance Improvement Initiative. The initiative also includes the mapping of possible risk factors, research on the causes of cancer and cancer prevention programs. The initiative demonstrates the promise that ongoing surveillance of disease registry data holds for prompting pro-active investigations of potential disease clusters and finding answers to pressing public health problems.

Generally, however, to successfully evaluate suspected clusters among small populations, researchers must rely on more than just a statistical comparison of disease incidence rates. They must also have a hypothesis as to the potential environmental or behavioral cause of the cluster as well as the means to evaluate that hypothesis – for example, detailed data on environmental conditions or exposures – through an epidemiological investigation. Such investigations, however, are expensive, and may be hindered by the lack of availability of good data on the degree to which individuals were exposed to the environmental contaminant in question.

Political Influence and Subjectivity

Finally, it is necessary to acknowledge the role of political forces in the conduct and design of cluster investigations. Political pressures may cut both ways – local citizens may clamor for more investigation

of a suspected cluster, while others may wish to avoid an investigation that could result in lower property values or harm the interests of a local industry. Further, public health departments face their own internal pressures caused by staffing, budgetary and other limitations.

As noted above, investigators must determine, at an early point in their analysis, the spatial and temporal boundaries of the “community” they intend to study. Where a hypothesis as to the cause of a cluster exists, health officials should use that hypothesis as the basis of their boundary setting decision. Yet, such decisions are inherently “judgment calls” and open the possibility for intentional or unwitting distortion. A cluster of disease that is limited to the area around a source of air pollution, for example, can be made to statistically “disappear” if public health authorities choose to use broad swaths of territory – such as an entire county – as the basis for their analysis. Similarly, studying too narrow a population base may exclude related cases in nearby areas or limit the possibility of developing statistically significant findings.

In addition, public health officials often determine which illnesses suspected by a community are studied, and which aren’t. Because many requests for cluster investigations include several diseases suspected to be in excess, limiting the number of diseases under study could lead to some potential clusters being ignored. **(See "Case Study: Fairfield, Maine," page 28.)**

CASE STUDY: FAIRFIELD, MAINE (BRAIN CANCER)

NARROW FOCUS LEADS TO QUESTIONS ABOUT CLUSTER INVESTIGATION

In February 1999, residents of rural Fairfield Center reported an alarming number of cases of brain cancer and other ailments, which they suspected could be linked to the illegal disposal of toxic paper mill waste in a local landfill. The Maine Cancer Registry (MCR) was called upon to investigate the claims, conducting interviews with Fairfield residents and learning about cases through word of mouth.

At the time of the investigation, the MCR was current only through 1995. Investigators found three brain cancer cases that were diagnosed after that year – cases that would not have been identified had MCR relied on registry data alone. In all, investigators found six cases of brain cancer that had been diagnosed in residents between 15 and 44 years of age – a rate five times the state average. In October 1999, the MCR confirmed that a cluster did in fact exist and the agency soon began a case series investigation to determine what, if anything, those with brain cancer shared in common.

The results of that investigation were published in 2001. It found that more than half the cluster cases simultaneously shared residence in Fairfield, spent time near the former paper company landfill, and were exposed to burning at a municipal dump. But because the study did not include a control group, it was unable to come to a conclusion

as to whether any of these possible routes of exposure could have been responsible for the cluster. Because the number of cases was so small, MCR concluded that such a study would not be possible, and that even if it were possible, MCR did not have the resources to conduct it. The report recommended that the state continue to conduct surveillance for additional brain cancer cases in the area and conduct a case-control study if more cases arise.³⁹

The conclusion of MCR's investigation has not resolved the issue, however. A group of 20 people or their survivors have filed suit against those allegedly responsible for the contamination at the landfill, claiming that chemicals at the site caused a variety of ailments. While MCR's investigation focused on brain cancer, plaintiffs in the case also claim to have suffered from elevated rates of lupus and lymphoma. A former director of the Massachusetts Cancer Registry who submitted documents on behalf of the plaintiffs noted that there were 10 cases of diagnosed lupus in Fairfield in 2000 where less than one case of lupus would be expected.⁴⁰

Maine public health officials responded promptly and aggressively to citizen reports of a brain cancer cluster in Fairfield. However, had it not been for the MCR staff's active case-finding, the cluster may not have come to light, due to the backlog in the state's cancer registry. Moreover, by focusing exclusively on brain cancer, public health officials may have missed out on other potential clusters within the community. Three years after the initial reports of a brain cancer cluster in

Fairfield, Maine's cancer registry still does not meet federal standards for timeliness.⁴¹

Decisions such as these are at the nexus where scientific and political concerns meet. Frequently, communities have significant concerns or complaints with the scope of a cluster investigation. Allowing community members to participate in the design of a study at an early phase of an investigation can mitigate these concerns.

In a few instances, cluster investigations have shown the potential to be overtly manipulated in response to political concerns. In 1998, for example, the individual in charge of the environmental cleanup of a former Army depot in Ohio linked to a school-based leukemia cluster was removed from his position. A federal administrative law judge later found that he was removed due to his insistence on an adequate investigation of the site. The judge cited in his ruling a 1997 memo from the man's superior to Ohio EPA staff: "The team has been instructed to work closely with ODH (the Ohio Department of Health) in seeking out information which can allow us to conclude that the existing 'environmental' conditions in the local community(s) do not pose a threat to human health." The memo came two weeks after ODH issued its first report highlighting potential increases in leukemia rates in the town.⁴² ODH subsequently concluded that there was an excess of leukemia among graduates of the high school but did not assign a likely cause. **(See "Case Study: Marion, Ohio," below.)**

CASE STUDY: MARION, OHIO (LEUKEMIA)

CLUSTER STUDY LEADS TO DISCOVERY OF CONTAMINATION, HINTS AT LINKS

In 1997, graduates of Marion's River Valley High School and a nurse at the school contacted Ohio public health officials with concerns about a potential leukemia cluster among graduates of the school. The high school had been built in the early 1960s on land purchased from U.S. Army that had been used as a depot for the cleaning and repair of vehicles and heavy machinery. Following the cluster report, the Ohio EPA investigated and discovered several carcinogenic substances at and near the site, some at levels above those thought to pose potential dangers to public health. Continued testing by the Army Corps of Engineers discovered additional toxic substances. In 1999, officials restricted access to the school's athletic fields, where toxic substances had been found.

The Ohio Department of Health began its investigation into the matter in 1997. First, it studied leukemia mortality rates in Marion County, discovering a sharp increase over time in the death rate from leukemia within the city of Marion, even as mortality rates in the rest of the county and the state overall declined.

The health department's next step was to conduct a review of registry data for leukemia for the years 1992 through 1996. The study ran into significant delays because Ohio's cancer registry was up to date only through 1992. State researchers were forced to pore through medical records to uncover every case of leukemia in Marion over the

1992 to 1996 period, a process that took nearly a year.⁴³ When finally completed, the study found significantly elevated rates of diagnosis in the city and county of Marion only among women 60 years of age and older.⁴⁴

However, the Department of Health had not yet initiated the study most wanted by residents – a detailed study of graduates. By 1999, local residents, working on their own, had identified more than 100 cases of cancer among graduates of the high school. They turned their results over to the health department, which initiated its own study.⁴⁵

That study concluded that rates of leukemia and esophageal cancer among graduates were significantly elevated. The health department also identified three cases of leukemia among high school attendees who did not graduate and one case among current students. Only about one-third of the graduates contacted responded to the survey.

Finally, in 2001, the Department of Health released a fourth study, this one a case review of leukemia among River Valley High School graduates and residents of Marion County. The study, which did not include a control group, concluded that a variety of factors may have resulted in the development of leukemia among the graduates. It also concluded that no further study of the cluster was necessary.⁴⁶

However, several of the study's findings placed that conclusion in doubt. Six of the nine graduates with leukemia had had extensive contact with the school's athletic fields. The average age of diag-

nosis among graduates (29) was far lower than that of Marion County residents as a whole (58), indicating that graduates may develop more leukemia in the future as they age. Moreover, one-third of Marion County residents (not just graduates) who had contracted leukemia had had some exposure to the depot grounds.⁴⁷

The study also failed to include three students who had attended River Valley High, but did not graduate. And it did not expand the pool of those studied beyond the eight graduates (and one current student) identified by the earlier cancer survey – a survey to which less than one-third of graduates responded.

The Marion case holds several lessons about cluster investigations. First, it demonstrates the importance of cluster inquiries in focusing attention on local environmental problems. Without the attention brought about by the inquiry, the scale of contamination on the school's grounds might not have been so quickly discovered. Second, it shows the potential costs of delay – throughout the investigation, students continued to attend River Valley High School.

However, the Marion investigation also shows the limitations of statistically based cluster investigations. The Ohio Department of Health's two initial studies, based on registry data, did not attempt to answer the central question of whether graduates of the high school – not residents of Marion – had suffered adverse effects. And the decision to cut off investigation after the case review study – despite the evidence of

potential links between exposure to contamination at the school site and leukemia – demonstrates the subjectivity of the decision to initiate or conclude a cluster inquiry.

In the end, the Marion investigation, while ultimately inconclusive, will have one definitive result: new schools for the district's children are under construction.

The availability of accurate, up-to-date registry data, therefore, is almost always necessary for the swift and effective investigation of disease clusters. But it may not always be sufficient. Additional information – particularly data on human exposures to toxic substances – appropriate study design, and the involvement of the public are often also needed to ensure successful cluster inquiries.

The Current State Of Health Tracking Data

The last decade has seen a substantial increase in interest in health tracking among both state and federal officials. Every state now has either an active statewide cancer registry or one in the process of implementation. Most states track at least some birth defects. And registries for selected other chronic diseases have been established in some locations.

Yet, in many states, the timeliness, accuracy and completeness of registry data still leave much to be desired. Even states that do track birth defects and cancer do so in ways that make analysis across state lines difficult. Moreover, such databases are often not linked to available data on sources of potential environmental exposures – such as data on drinking water contamination or air pollution.

These deficiencies can – and have – hampered cluster investigations, leading to the waste of time, money, and opportunities for protecting public health.

Cancer Registries

As mentioned above, every state now has, or is planning, a statewide population-based cancer registry capable of capturing all new cancer cases in the state.

The expansion of cancer registries demonstrates the positive impact the federal government can make in expanding opportunities for health tracking. While Connecticut established the first cancer registry before World War II, central cancer registries got their

first major boost with the inauguration of the SEER program in 1972. SEER, as noted above, encompasses several state and regional cancer registries covering approximately 14 percent of the U.S. population.

By 1994, 40 states had established central cancer registries. Most of these registries, however, were underfunded, many were years behind in the compilation and reporting of cancer information, and there was little standardization of registry data.

By then, however, the situation was beginning to improve. In 1992, Congress authorized the establishment of the National Program of Cancer Registries (NPCR) through the CDC. NPCR provided funding for states to initiate or improve central cancer registries in compliance with nationwide standards. The legislation required that, by 1998, cancer cases be reported to central registries within six months.

The federal involvement has led to significant improvements in cancer registries. In 1997, only 14 statewide registries met the minimum requirements for certification by the North American Association of Central Cancer Registries (NAACCR). In 2001, 26 statewide registries received NAACCR's "gold" certification, while another 10 received "silver" certification. In Fiscal Year 2002, the federal government allocated \$40 million to NPCR, which supports registries in 45 states. (The other five states are supported through the SEER program.)⁴⁸

Among the standards needed to receive certification are:

- **COMPLETENESS OF CASE ASCERTAINMENT**— Registries receiving gold certification must include 95 percent of expected cancer cases, while those receiving silver certification must be 90 percent complete.
- **COMPLETENESS OF RECORDS** — Registries must include, with few exceptions, all relevant information including age at diagnosis, sex, race, and county of residence at diagnosis.
- **TIMELINESS** — All information and corrections must be entered within 23 months from the close of the diagnosis year.⁴⁹

While the increasing number of cancer registries certified to NAACCR standards shows improvement in the system, there is still a long way to go. More than a dozen state cancer registries fail to meet even the NAACCR's minimum criteria for certification.⁵⁰

The lack of timely or thorough cancer registry data can have a major impact on the progress of cluster investigations. (See "Case Study: Toms River, N.J." page 14.) It can also make it difficult to conduct active surveillance to detect clusters as they are occurring. (See "Case Study: Fallon, Nev." below.)

CASE STUDY: FALLON, NEV. (CHILDHOOD LEUKEMIA)

WHEN TWO-YEAR-OLD DATA AREN'T GOOD ENOUGH

In late summer 2000, Nevada public health officials were alerted by local physicians to an unusual increase in diagnoses of acute lymphocytic leukemia (ALL) in and around the town of Fallon. Within the span of a few months, five children were diagnosed with the disease among a population where only one case would be expected to be diagnosed every five years. Subsequent investigation and diagnoses led to the identification of 15 cases of ALL and one case of another form of leukemia — all but two of them diagnosed between 1999 and 2001.⁵¹

Two months after the initial report of the cluster, state health officials began interviewing each of the case families to determine possible commonalities. Investigations of several potential sources of environmental contamination have taken place, environmental samples have been taken, and the Centers for Disease Control and Prevention have initiated biological testing of cases and controls. At least \$28 million in federal funds have been targeted to the investigation.⁵² The CDC is expected to release its report in the summer of 2002.

The Fallon case, while it was diagnosed as a cluster within only a few weeks, drew attention to weaknesses in the state's cancer registry system. An investigation by a Nevada newspaper found that the registry was more than two years behind in the collection of cancer data and does not have

the resources to examine the data to identify apparent cancer clusters.⁵³

However, even a registry that met federal standards (Nevada's does not) would have been unlikely to identify the cluster. Those standards require cancer cases to be filed with registries within six months and for registries to make the data available within two years. In Fallon, where the bulk of ALL cases were diagnosed in 2000, researchers may not have recognized the anomaly until 2002 at the earliest – if, that is, anyone was looking for it in the first place.

Birth Defects Registries

While the nation's cancer registries have their share of problems, accurate information on the incidence of birth defects is even harder to come by.

At least 34 states now track some birth defects, but the vast majority of those systems are inadequate. The Trust for America's Health reports that in 2000, more than 1 million births nationwide – approximately 25 percent of all births – were not covered by a birth defects monitoring program.⁵⁴ In many states that have registries, only the most serious defects are monitored, surveillance is limited to certain regions of the state, or the method of data collection is incapable of capturing all new cases of birth defects. In its analysis, the Trust awarded only eight state birth defects registries its "A" ranking, signifying that the registries engage in active case surveillance, rely on high quality data sources, and meet high standards for the accuracy of their data.

An additional 14 states received a "B" rating. Yet, even among the eight states that received an "A", two do not publish data in a timely fashion and two do not cover the entire state.⁵⁵

The lack of access to up-to-date registry data can make it extremely difficult for public health officials to investigate suspected birth defects clusters. (See "**Case Study: Dickson County, Tenn.**" below.) Conversely, access to such data can allow public health officials to conduct active surveillance of birth defects rates in specific regions of concern (See "**Case Study: Laredo, Texas,**" page 17.) and can support broader research into the causes of birth defects.

CASE STUDY: DICKSON COUNTY, TENN. (CLEFT LIP/CLEFT PALATE)

RELIANCE ON BIRTH RECORDS WOULD HAVE SHROUDED CLUSTER

In June 2000, the Tennessee Department of Health (TDH) was alerted by a local early intervention center to what appeared to be a cluster of cases of cleft lip and cleft palate in Dickson County. TDH enlisted the help of the Centers for Disease Control and Prevention in conducting a cluster study in the area.

Because Tennessee does not have a birth defects registry, TDH staff conducted active case-finding, searching birth records and local hospital discharge data to identify additional children born with cleft lip/cleft palate between 1997 and 2000. TDH eventually identified 18 infants born

with clefts in Dickson County. The decision to conduct active case-finding was essential: only three of the cleft lip/cleft palate cases between 1997 and 1999 were accurately recorded on birth certificates, compared to the 13 identified by TDH. Reliance on birth records alone would not have demonstrated the existence of a cluster.

While the rates of cleft lip/cleft palate in the county were significantly higher than would be expected, the lack of good baseline data on expected rates of clefts prevented investigators from drawing firm conclusions as to the severity of the cluster. Comparing local incidence of cleft lip/cleft palate to regional figures from Atlanta and to national estimates revealed rates approximately five times higher than expected.

Having proven the existence of a statistical cluster, CDC researchers surveyed 15 of the 18 mothers in an effort to determine whether the clefts had a common cause. Thirteen of the 15 mothers reported using a municipal water source; no other environmental exposures (with the exception of smoking and occupational exposure to chemicals) were included in the survey. The report concluded that no single factor appeared to be responsible for the cluster, but suggested that a more formal case-control study might be warranted if more children are born with the defect.⁵⁶

In the year and a half since the investigation was completed, the number of children being diagnosed with cleft lip/cleft palate in the area appears to have dropped.⁵⁷ However, the lack of good data to determine the expected rate for cleft lip/cleft

palate has left researchers and Dickson County residents to wonder whether the cluster of 1997 to 2000 was a statistical anomaly, the result of higher incidence rates for the disease in Tennessee as a whole, or the result of some unknown exposure that placed children at risk.

Other Chronic Diseases

While there are myriad problems with the nation's system of tracking cancer and birth defects, at least they are tracked. The same cannot be said for many other chronic diseases with suspected environmental links.

Consider asthma, a disease whose prevalence has increased dramatically in recent years (with the number of cases among children under four increasing 160 percent between 1980 and 1994), and which has well-known connections with the environment.⁵⁸ Yet, only 23 states and the District of Columbia had any system at all for tracking asthma cases in 2001, based on information reported by the states to the CDC. Many of those programs track asthma in only limited jurisdictions or among limited population groups.⁵⁹

The same is true of autoimmune disorders such as lupus and scleroderma, developmental disorders, learning disabilities, neurological disorders such as Alzheimer's and a host of other chronic diseases whose causes and potential links to environmental exposures are poorly understood or unknown. A 2000 report by the Pew Environmental Health Commission found that:

- Only eight states and the District of Columbia reported tracking at least some developmental disabilities such as autism and mental retardation.
- Only four states reported tracking autoimmune diseases such as lupus.
- Most states do not systematically track endocrine and metabolic disorders such as diabetes or neurological conditions such as migraines and multiple sclerosis.⁶⁰

Summary

Appendix A shows the status of cancer, birth defects and asthma tracking in the United States.

Of the 50 states, only three – California, Iowa and Massachusetts – possess tracking systems for both cancer and birth defects that meet the highest standards and also report that they possess any system for tracking asthma cases.⁶¹ In even these three states, the ability to track other chronic diseases with suspected environmental links is limited or non-existent.

The Impact of Health Tracking Data on Cluster Investigations: Lessons from the Case Studies

The case studies presented throughout this report represent a variety of cluster investigations and related studies, from common inquiries into local cancer rates to cutting-edge research into the links between environmental exposures and rates of disease. Each case, however, demonstrates the importance of high-quality data in the completion of prompt, thorough, and effective cluster inquiries.

Five general lessons can be derived from a close examination of the cases:

Lesson #1: Lack of Data Causes Delays in Cluster Investigations

Time and time again, investigations into disease clusters have been delayed by a lack of access to health tracking data. This is shown most clearly in recent investigations of clusters of non-cancer diseases – diseases for which registry data are completely lacking in most parts of the country.

Two investigations of non-cancer clusters – the multiple sclerosis cluster in El Paso, Texas and the scleroderma and lupus cluster in South Boston, Massachusetts – each took more than two years to identify cases of disease within the community; and in neither case are investigators certain that they have identified all cases.

Those studies also face another problem: the lack of good data on the expected

rates of disease in a community. Again, this is a question that could be easily answered with access to complete registry data.

With regard to cancer cluster investigations, the timeliness of cancer registry data is also critically important. The backlog in entry of new cases into the New Jersey Cancer Registry in the early 1990s, for example, initially forced researchers to use incidence data that were four years out-of-date in their investigation of the Toms River cluster, and then to re-do their analysis two years later once the data had been updated.

In cases such as the pleural cancer cluster in Charleston, South Carolina, access to timely and complete registry data led to relatively quick diagnosis of a cluster; in the South Carolina case, within six months of the initial report. Such prompt investigations of disease clusters and suspected environmental health threats should be the standard nationwide. Unfortunately, they are too often the exception.

Lesson #2: Lack of Data Deters Proactive Investigation of Potential Clusters

Many lament the low rate at which citizen-initiated cluster inquiries yield meaningful results. Yet few note that reliance on citizen reporting may *miss* many

potential clusters simply because individual citizens never become aware of other instances of disease within their communities. Active surveillance of high-quality health tracking data could catch these potential clusters while giving researchers more tools to analyze the links between environmental factors and chronic disease in a pro-active, rather than reactive, way.

Of the cluster inquiries studied, only three were initiated by public health officials. Most of the rest were initiated by individual citizens concerned about rates of disease in their communities. This is not a scientific sample, but the fact that most clusters are reported by citizens is well established. A 1998 survey of state health departments found that 65 percent of requests for cluster investigations came from the public and 10 percent from local health officials. The remainder came from individual physicians, the media, elected officials and other sources, many of whom no doubt also received their initial information about the cluster from the public.⁶²

In many cases – even where tracking data do exist – state public health officials do not have the resources to conduct active surveillance of disease patterns and initiate pro-active cluster inquiries. This represents a crucial missing link in the nation’s public health system.

In recent years, however, several states have begun to fill this gap. Texas officials used ongoing surveillance of birth defects rates in communities on the Mexican border to promptly identify a cluster of neural tube defects in Laredo. And New York officials used their exten-

sive new cancer mapping system to initiate an investigation into abnormally high rates of breast cancer in an area of Long Island. However, more states need to follow suit in order to ensure that unusual clusters of disease are promptly identified and, if warranted, investigated.

Lesson #3: Lack of Data Deters the Identification of True Clusters

The most damaging potential result of a lack of health tracking data is the failure to properly diagnose a “true” cluster of disease, or to discover an environmental link to a particular disease. In at least one case studied – the South Carolina pleural cancer cluster – state health officials reported that previously existing data, such as death records, would not have been sufficient to identify a true cluster.

Of similar importance is the role of health tracking data in determining the severity of suspected clusters. In numerous cases, lack of access to – or lack of confidence in – registry data has forced public health officials to rely on self-reports of disease, mortality records, or other less-comprehensive sources of information. Reliance on these data sets can inject uncertainty into cluster investigations or compel researchers to pour significant resources into case identification, as is occurring with the \$1 million South Boston lupus/scleroderma study.

Even where case-finding can be done, the lack of registry data can prevent investigators from understanding the true dimensions of a cluster due to the lack of information on the rate of disease that would be expected in a given community. In the Dickson County, Tennessee case,

for example, researchers were unable to confidently state the degree of excess in cleft lip/cleft palate cases due to a lack of good baseline data on disease incidence.

In a few cases – such as the Fairfield, Maine and Chesterfield County, Virginia cancer cluster inquiries – self-reporting is actually the *preferred* alternative for investigating a cluster due to severe weaknesses in state cancer registries. At the time of the 1999-2001 investigation of brain cancer rates in Fairfield, Maine’s cancer registry was only up to date through 1995. Relying on registry data alone would have caused investigators to miss three of the reported brain cancer cases. In Chesterfield County, health officials reported as a result of their case-finding that Virginia’s cancer registry could be underreporting cancer cases by as much as 23 percent.

CASE STUDY: CHESTERFIELD COUNTY, VA. (CANCER)

AFTER A DECADE OF STUDY, POOR REGISTRY DATA HAMPERS INVESTIGATION

In 1984, private drinking water wells in the Rayon Park residential neighborhood of Chesterfield County, Virginia were found to be contaminated with benzene, trichloroethylene (TCE, a common industrial solvent), and other volatile organic compounds leaching from the site of a military supply distribution center. Three years later, residents of the area were hooked up to a public water supply.

Residents of the area expressed concern about the

impact the contamination may have had on their health, specifically, the rash of kidney, liver and central nervous system disorders that seemed to plague the community. In 1993, ATSDR released a study of death records that found elevated cancer mortality among men in Chesterfield County as a whole between 1950 and 1979 (the last year analyzed). However, the study noted that there were no data available that would allow the analysis to be localized to the Rayon Park area. Virginia’s cancer registry began mandatory reporting in 1989 and data were not yet available. Similarly, the state’s birth defects registry had only one year of data at the time the study was conducted.⁶³

In 2001, amid consistent suspicions of high levels of cancer and other ailments in Rayon Park, state and local officials initiated a cancer cluster study. The study was based on a survey of cancer cases compared to expected rates for the county derived from Virginia’s cancer registry. Because of the small population involved (about 275 individuals), the study includes only an analysis of overall cancer rates. The study concluded that cancer rates in the neighborhood were not significantly different than those in the county as a whole.

Despite the cluster inquiry and the increased attention it has brought to Rayon Park, the area still faces its share of environmental problems. Since the ATSDR’s 1993 study was completed, groundwater contamination from the site has continued to spread beyond Rayon Park. In 2001, a newspaper investigation found TCE-tainted water pouring from a pipe at the site into a stream.⁶⁴

And in early 2002, a contractor cleaning up the site was indicted for illegally discharging contaminated groundwater into a local creek.⁶⁵

While local health officials conducting the cluster study report that the state's cancer registry was useful in determining expected rates of disease, the final report on the cluster investigation notes that, of 26 confirmed cases of cancer found in Rayon Park, six had not been reported to the Virginia Cancer Registry. As a result, the report estimates that registry may be underreporting cancer cases by as much as 23 percent.⁶⁶ Further, the cluster inquiry was limited to residents who lived in Rayon Park after 1985 – despite evidence of groundwater contamination prior to that date – because earlier cancer registry data were considered unreliable. The Virginia Cancer Registry does not meet national certification standards.

The inability of ATSDR to access reliable local registry data prevented the agency from investigating local health problems in 1993. A decade later, registry data continue to shape – and limit – how public health officials can investigate health conditions in Rayon Park.

Access to up-to-date, high-quality disease incidence data would eliminate or alleviate many of these problems, allowing researchers to more confidently determine when a cluster really is a cluster.

Lesson #4: Lack of Data Leads to Fewer Investigations of Potential Health Threats

Because the cases studied here largely

represent completed cluster inquiries, they do not answer the question of whether a lack of health tracking data results in some clusters not being investigated at all.

Research and common sense, however, indicate that the more investigations cost and the fewer resources states have to pursue them, the fewer investigations will be done. Cluster investigation protocols give states wide latitude to determine when a cluster is worth investigating and when it is not. Studies show wide variations in the percentage of investigation requests that are pursued beyond the first phone call, with some states satisfying as many as 99 percent of all inquiries at first contact and others satisfying as few as 10 percent.⁶⁷ **(See Appendix B.)**

A 1991 telephone survey of public health officials responsible for responding to cluster investigation requests documented the wide variety of approaches taken by state public health officials in response to cluster inquiries.

That study found that:

- Two states had no process for responding to cluster inquiries. When citizens with concerns about clusters called, “the officials assumed that they were routed around the agency until they gave up.”
- Several states actively discouraged callers from pursuing cluster inquiries, either by emphasizing the lifestyle causes of cancer or requiring citizens to fill out cumbersome forms with 10-20 pieces

of information for every cancer case. “Some respondents acknowledged that while the forms were imposing, the state did not have the resources to do the epidemiology themselves. In other words, if citizens did not do the work, the study would not be done.”

Some state officials contended “they would not follow-up unless people showed sufficient interest to return the forms or had their elected representative write or call.”

- Only five states clearly encouraged callers to pursue their request for cluster investigations.⁶⁸

It is unclear the degree to which this situation has changed in the last decade, but the results of a 1998 survey conducted by a Missouri School of Journalism researcher, when contrasted with the 1991 results, suggest that not much has changed at all. The 1991 study found that 27 states had less than one half-time person committed to cluster inquiries; the 1998 survey found 26 states with less than one half-time person. The 1991 study found that only two states had formally evaluated their communications with the community about cancer clusters; the 1998 survey found the same results. And only two-thirds of the states responding to the 1998 survey had standing protocols for handling disease clusters, nearly a decade after the CDC issued its own protocol.⁶⁹

The 1991 study concluded that states with the strongest overall commitment to environmental protection and public health were more likely to have a well-

developed capacity to respond to cluster inquiries.

A review of the case studies suggests similar conclusions. In several cases, an initial assessment was not begun until many years after citizens began to report their suspicions about the clustering of health problems in their community. In Chesterfield County, Virginia, for example, it took 17 years after the first detection of contamination in ground water to launch a study of Rayon Park residents. In other cases, public health officials responded promptly to citizen requests for investigations, often consulting registry data to make quick determinations of whether further study would be warranted.

Clearly, access to registry data can make initial investigations into clusters far easier and less resource-intensive, and thus more attractive to public health officials. The existence of registry data can also make it possible for citizens and independent researchers to conduct their own inquiries when public officials fail to take action.

Lesson #5: Lack of Data Leaves Community Concerns Unaddressed

Communities that suspect they are experiencing a disease cluster are often desperate for information and help. It is imperative that the public health system provide communities with as much information as possible promptly and with sensitivity, and that environmental and public health measures be taken quickly where they are needed.

CASE STUDY: HAZLETON, PA. (CANCER)

STUDIES' LIMITATIONS DEMONSTRATE IMPORTANCE OF EXPOSURE DATA

In the early 1990s, residents of Hazleton and neighboring Hazle Township began to complain of gasoline odors infiltrating their homes. Investigation by environmental officials discovered that approximately 50,000 gallons of gasoline had leaked from a series of underground storage tanks into the land underneath the homes, many of which sit atop abandoned mines. Several homes were evacuated and others monitored for levels of benzene and other pollutants.

In 1996, the EPA took over cleanup of the area, known as the Tranguch site, at the request of Pennsylvania environmental officials. EPA conducted its own residential air quality testing and determined that benzene levels did not warrant further action. However, EPA failed to communicate the results of the testing to residents.⁷⁰ Four years later, residents again began to express concerns about exposure to gasoline vapors. Hazle Township contracted with the University of Pittsburgh to conduct a health study of the area, while the Pennsylvania Department of Health launched its own study of the entire spill area.

The University of Pittsburgh study found statistically elevated rates of leukemia, prostate and stomach cancers among Hazle Township residents in the spill area. The study relied primarily on self-reporting, rather than registry data, to determine cancer incidence.⁷¹ Four months later, the state Department of Health released its own study,

based on registry data, which found statistically elevated levels of stomach cancer only (levels of leukemia were also elevated, but not statistically significant). The study suggested that the increase in stomach cancer could be linked primarily to the area's history as a coal mining center and not to any ongoing environmental contamination.⁷²

University of Pittsburgh researchers are continuing their study of the area, this time focusing on affected properties in Hazleton.

The Tranguch studies hold several important lessons. First, they demonstrate the importance of study definition. Because three of the four leukemia cases in the spill area took place in Hazle Township, the rate of leukemia there was judged statistically significant in the University of Pittsburgh study (which included only the township) but not in the state health department study (which included the entire spill area).

Second, both studies demonstrate the difficulty of relying on statistical methods to assess disease clusters in small geographical areas. The larger of the two studies – the Pennsylvania Department of Health investigation – included a base population of only 900 residents. The University of Pittsburgh study included only 207. Because of the small sample population, levels of leukemia incidence more than three times the expected rate (in the state study) still fail to meet the test of statistical significance.

Clearly, registry data have proven helpful in assessing the health problems affecting residents

in the Tranguch spill area. However, more information – such as historical information on benzene levels in the area or blood testing for evidence of benzene exposure – would be needed to draw a strong conclusion about the impact of the spill on residents' health.

The consequences of failing to do so can be severe. When a lack of data delays a cluster inquiry or results in unnecessarily vague or uncertain conclusions, the result can be the intensification – rather than the easing – of a community's fear and apprehension. In case after case, poorly conducted cluster inquiries have resulted in divided communities, eroded property values, and increased levels of stress, fear and frustration among residents – results that can have their own effects on public health and well-being.

In both Hazleton, Pa. and Toms River, N.J., the failure of public officials to share information with residents at an early stage of an investigation led to strained relations between public health officials and the community. In the Toms River case, public health officials responded by working to include local citizens in designing the public health response to the cancer cluster. However, in the Hazleton case, relations remain strained to the point where the communities of Hazleton and Hazle Township commissioned their own health studies, even as the Pennsylvania Department of Health conducted its cluster inquiry.

In addition, the inability to quickly identify clusters can lead to delays in the implementation of important public health measures – for example, folic acid educational efforts in areas plagued by

high rates of neural tube defects or environmental cleanups where suspected clusters led to the identification of contaminated sites.

While even the best cluster inquiries will not resolve every question in the minds of community residents, the existence of health tracking data can allow public health officials to quickly reassure residents of communities where clusters do not exist and speed the delivery of information and assistance to all communities with public health concerns.

A Sixth Lesson: Good Registries Are Not Enough

While access to complete, up-to-date information on disease incidence is essential to cluster investigations, the availability of such data does not guarantee that such investigations will be successful or that public health concerns will be addressed.

The Need for Tracking of Environmental Exposures

Investigations of suspected clusters of diseases that are common or occur in a small geographical area will not often be successful in identifying statistically significant levels of disease. Where environmental exposures can be plausibly linked to these cases, researchers must employ other methods – such as biological or environmental monitoring or epidemiological studies – to determine whether environmental factors can be associated with the outbreak of disease.

CASE STUDY: CALCASIEU PARISH, LA. (CANCER)

INQUIRY SHOWS NEED FOR EXPOSURE INFORMATION

Mossville, in Calcasieu Parish, is a small, predominantly African-American residential enclave in the shadow of a giant Condea Vista Co. chemical plant. Refineries and chemical plants have operated in the area since the 1940s.

In the 1980s, Mossville residents began to express concern about possible links between emissions from the chemical plant and their health. Ethylene dichloride, a suspected carcinogen, was found to have migrated into the soil beneath Mossville. Following a protracted legal battle, Condea Vista and the plant's former owner, Conoco, agreed to settlements totaling approximately \$47 million, including a voluntary buyout of some homeowners.⁷³

Around the time in 1997 that Conoco was settling its lawsuit, lawyers gathering information for a potential class-action suit tested the blood of 11 people around Calcasieu Parish. Three of the samples came back with unusually high levels of dioxin – one of the most highly toxic families of substances known to science. To confirm the results, the lawyers tested a pooled blood sample taken from a local hospital. That sample showed levels of dioxin that were at the high end of the national average and levels of one type of dioxin, TCDD, that were higher than average. The results of the tests were sent to Louisiana public health officials, who were asked to conduct an investigation. The Louisiana Department of Health and Hospitals declined.⁷⁴

Federal officials at the Agency for Toxic Substances and Disease Registry (ATSDR) did take up the investigation, however. In late 1998, they confirmed the earlier test results, and in late 1999, ATSDR released the results of follow-up blood testing that found average levels of dioxin three times the national average.⁷⁵ The levels were among the highest ever reported in the United States for a non-occupational exposure.

Louisiana state officials then embarked on their own study of cancer patterns in Calcasieu Parish. Based on data from the Louisiana Tumor Registry from 1988-1997, the study found that overall cancer rates in the parish were similar to those in other parts of Louisiana. But the study noted significantly elevated levels of lung cancer and soft tissue cancers, both of which have been linked to dioxin exposure.⁷⁶

While the Louisiana study hinted at the possibility that the elevated rates of some cancers could be the result of dioxin exposure, it stopped well short of asserting causation, largely due to the dearth of information about the nature of the exposures. Federal officials are currently conducting air monitoring to attempt to pinpoint the source of any ongoing dioxin releases. They have also launched another round of blood testing of area residents.

The existence of a tracking system to monitor dioxin exposures could have tipped off researchers to the problems in Calcasieu Parish years before they were discovered by the community. Four years after that discovery, the commu-

nity and state and federal officials are still working to ascertain how widespread the dioxin contamination problem is in the parish, whether exposure to the chemical is ongoing, and whether there is any link between the chemical and health problems among parish residents.

Biological monitoring of environmental exposures provides the most accurate information on the level of exposures to which residents of a community have been subjected. Yet the current availability of data on environmental exposures is extremely limited. A 2000 General Accounting Office (GAO) study found that federal exposure surveys measure in the general population only 6 percent of the more than 1,400 toxic chemicals thought to pose potential health problems. Even when exposure data are available, public health officials lack a clear understanding of the levels of exposure that would or should be expected in the general population.

About 90 percent of public health officials surveyed by the GAO reported that human exposure data from tissue samples was extremely or very important for addressing environmental health concerns. Yet almost two-thirds of those officials reported that they could include such data in less than half of the studies in which they deemed it important. Less than one-tenth always or almost always could include such data. Key barriers to the use of such data included a lack of laboratory capacity and a lack of knowledge for how to set the results of such testing in context.⁷⁷

In contrast to the scarcity of biological

exposure data, there is a significant amount of data collected by state and federal governments from environmental monitoring efforts. Most states regularly collect, track, and compile at least some information on the levels of various contaminants in drinking water, the application of pesticides, the discharge of toxicants from industrial facilities, or the levels of various pollutants in the air. Several studies have connected these databases with information from disease registries to achieve new insights into the environmental links to chronic disease. (See "Beyond Clusters," page 47.)

Better information on exposures and potential exposures, better training on how to use those data, and better linkages between health outcome and environmental databases are all of vital importance in investigating the links between environmental exposures and chronic disease.

The Need for Public Access, Involvement and Education

While the primary responsibility for investigating disease clusters remains with public health officials, individual researchers and citizens should have the tools to conduct their own assessments. Information collected through chronic disease tracking systems should be made readily available to researchers and the general public – provided that effective processes are in place to preserve patient confidentiality.

In addition, as noted above, decisions on the geographic and temporal scope of cluster investigations and the types of disease covered can have a direct impact on the results of a cluster investigation.

These decisions should be made with the participation of the affected communities. CDC and state investigation protocols allow for the inclusion of citizen advisory boards in the decision-making process for cluster investigations. These advisory groups should be constituted as early as possible in the process in order to build confidence with local residents and allow for the creation of studies that best serve the community's public health needs.

Finally, state disease registries should provide detailed annual information on cancer incidence in their states. Cancer-mapping projects such as the one in New York State have the potential to broaden public understanding of cancer trends in their communities.

The history of cluster investigations shows that trust and channels of communication between citizens and public health officials can easily break down. Where these breakdowns have occurred, the results have been damaging: reduced legitimacy for public health agencies; wasted time and money on suspect cluster inquiries and environmental remediation measures; anger, emotional stress and reduced property values for communities.

History also shows that, generally, the earlier and more completely information is shared with the public, the less likely it is that the crucial bonds of trust and communication will be broken. Involving the public in the design and conduct of cluster inquiries can be a useful tool for ensuring that such investigations lead to positive outcomes for public health and understanding.

The Need to Prevent and Clean Up Environmental Health Threats

While the investigation of suspected disease clusters is a matter of importance to public health, it should never interfere with or delay the cleanup of known or potential environmental threats. In many of the case studies presented in this report, local citizens have been forced to wage simultaneous battles to have their health concerns taken seriously and to clean up long-standing environmental problems in their communities.

In such cases, environmental and public health officials must take a precautionary approach by moving quickly to clean up sources of suspected environmental contamination and prevent future contamination – even in the absence of “proof” that such contamination has caused a specific disease.

In this regard, current proposals to reduce the number of Superfund hazardous waste cleanups conducted annually and ease New Source Review requirements for large industrial facilities under the Clean Air Act must be viewed with caution. Evidence from many studies suggests that exposure to toxic chemicals, air pollutants and drinking water contaminants play a role in the development of serious, chronic disease. Research into these links must continue, but it must be matched with aggressive action by the public health community and government to prevent pollution and clean up already contaminated communities.

Beyond Clusters: Investigating Environmental Links to Chronic Disease

As noted above, the investigation of localized disease clusters rarely results, in and of itself, in the discovery of a direct link between an environmental pollutant and the development of disease. Among the typical limitations of community-based cluster inquiries are small sample size and the presence of other, confounding factors that could be responsible for the increased incidence of disease.

Epidemiological studies that include multiple communities with similar environmental exposures can reduce the impact of these limitations and allow researchers to develop more informed hypotheses about the potential environmental links to chronic disease.

Disease registry data and information on environmental exposures are critical to such studies. Detailed and reliable data about who suffers from a disease, when combined with data on biological exposures or environmental conditions, can enable researchers to probe the connections between the environment and public health with greater precision than can often be obtained through inquiries into the cause of localized clusters.

Research activities in several states show the promise of this kind of research for documenting the environmental links to chronic disease.

The California Birth Defects Monitoring Program

Since its founding in 1982, the California Birth Defects Monitoring Program has played an important role in collecting information on birth defects in the state and in supporting research into the causes of birth defects. In several cases, case information drawn from the monitoring program has been used – in concert with interviews or environmental monitoring data – to probe the environmental links to birth defects.

- **PROXIMITY TO HAZARDOUS WASTE SITES** –

A 1997 study based on interviews with more than 2,000 women found that women who lived within a quarter-mile of a Superfund site during the first three months of pregnancy had a greater risk of having babies with heart and neural tube defects. Even with the large sample size, however, the study was limited by the small number of women who live in such close proximity to hazardous waste sites, reducing the statistical significance of the finding. The researchers recommended further studies based on measurement of actual environmental exposures.⁷⁸

- **EXPOSURE TO PESTICIDES** –

A 1999 study, again based on interviews with more than 2,000 women, found that women living within a quarter-mile of agricultural crops and those who engaged in household gardening

were more likely to give birth to babies with certain birth defects. Interestingly, no association was found between birth defects and self-application of pesticides inside the home or occupational exposure to pesticides. The researchers suggested further study based on actual exposure information.⁷⁹

• **AIR POLLUTION** – A 2002 study evaluated rates of certain birth defects along with air pollution levels detected by air monitors in Southern California in an attempt to determine whether exposure to air pollutants at key points during pregnancy was associated with birth defects. The study found links to various defects: exposure to carbon monoxide during the second month of pregnancy was associated with the development of ventricular septal defects and second-month exposure to ozone was associated with aortic artery and valve defects, pulmonary artery and valve anomalies, and conotruncal defects. No similar effects were found for other months during pregnancy or other air pollutants studied. The study was the first of its kind in the United States and researchers cautioned that the findings need to be confirmed by other studies.⁸⁰

The existence of complete, timely and detailed birth defects registry data was integral to all three studies, demonstrating the power such data can have for investigating the environmental links to chronic disease.

New Jersey Drinking Water Studies

Between 1979 and 1984, New Jersey created registries for both cancer and birth defects and began monitoring for the presence of 14 volatile organic compounds (VOCs) in public community water systems. In the 1990s, researchers combined the health tracking databases with information on drinking water contamination to explore the links between drinking water and health.

In the late 1980s, researchers with the state Department of Health compared data on leukemia incidence taken from the state's cancer registry with water testing results in a part of the state with a broad range of contamination. The study showed a significant association between concentrations of trichloroethylene (TCE) and perchloroethylene (PCE) and the overall leukemia rate among females in 27 towns.

In 1993, the state expanded its investigation to 75 towns with a total population of 1.5 million and also included non-Hodgkin's lymphomas as well as leukemias. The study also found an association between TCE and PCE in drinking water and certain kinds of leukemias and non-Hodgkin's lymphomas.⁸¹

Three years later, researchers examined the potential links between a variety of drinking water contaminants and adverse birth outcomes, including birth defects. The study – like the earlier studies of cancer – was based on a combination of water monitoring data and information from the state's birth defects registry. The researchers found associations between six types of drinking water cont-

aminants and defects, low birth weights, and small-for-gestational-age births.⁸²

The New Jersey studies, while not the final word on the link between drinking water contamination and cancer and birth defects, are part of a growing body of literature expressing concern about exposure to certain VOCs. The studies also demonstrate the potential benefits of linking environmental monitoring information with disease registry data.

Other States

Several other states have embarked on efforts to link existing information on environmental conditions to disease registries. Since 1987, for instance, Iowa has been regularly compiling information on drinking water contamination and investigating the potential health threats it may pose. In 2001, University of Iowa researchers compared data on contaminants in public drinking water supplies with information on cancer incidence from the state's cancer registry to explore the links between nitrate levels and cancer. Their research showed an association between long-term exposure to low levels of nitrates in water and the development of bladder cancer in women. Researchers suggested that the EPA's standard for nitrate in drinking water may not be adequately protective of human health but cautioned that more follow-up research is necessary to confirm the link.⁸³

The studies noted above demonstrate the potential of epidemiologic studies that span wider geographic areas in attempting to ascertain the links between environmental exposures and chronic disease. Clearly, more such research is needed to fill in the gaps in medical knowl-

edge about the environmental causes of cancer, birth defects and other conditions with suspected environmental links. However, to make that research possible, states must begin to compile accurate information on disease incidence, assemble good information on human exposure to environmental pollutants, and allow for the linkage of registry data to existing information on environmental conditions.

Policy Recommendations

Create a National Health Tracking Network

Regardless of what state they call home, citizens deserve swift and thorough evaluation of suspected environmental health threats in their communities. Researchers conducting those evaluations need timely, complete and accurate data to help make their work effective and affordable. And all of us deserve a public health system that works aggressively to probe the potential links between environmental exposures and chronic disease and protect us from exposures that may harm our health.

Creating such a public health system would require the commitment of new resources to tracking the incidence of chronic disease in our communities and our exposure to harmful substances in our environment. Public health organizations across the country have rallied behind proposals to create just such a nationwide health tracking network.

Such a network would include:

- Systems in all 50 states to track chronic diseases including: asthma and chronic respiratory diseases birth defects, developmental and other neurological disorders, cancers, neurological diseases such as Alzheimer's and Parkinson's, and other chronic diseases.
- Systems in all 50 states to track human exposures to environmental hazards, beginning with such priority substances as PCBs, dioxin, heavy met-

als such as mercury and lead, pesticide, and water and air contaminants.

- An early warning system to alert communities to immediate health crises such as heavy metal and pesticide poisonings. This system would be similar to current systems to alert communities to the outbreak of infectious diseases such as West Nile Virus.
- Up to 20 pilot programs to investigate clusters of disease and local health priorities not covered by the network. These programs could serve as models for later inclusion in the network and would allow states the capacity to track problems of particular concern. For example, Massachusetts could track autoimmune disorders such as scleroderma and lupus; lessons learned there could lead to nationwide tracking for these conditions.
- The creation of rapid response teams of federal, state and local officials to investigate clusters, outbreaks and emerging threats. The teams would be well-trained and have access to high-quality equipment and lab facilities that, in many cases, do not currently exist.
- The involvement of academic centers and local communities in environmental health research through the sharing of data and perspectives.

Creation of such a nationwide health tracking network would resolve several

problems that typically hamper disease cluster investigations. First, the network would expand tracking for cancer, birth defects, and other diseases into jurisdictions where existing registries are either nonexistent, incomplete, or of insufficient quality. The availability of such data would allow local and state public health officials to make determinations as to the validity of reports of disease clusters quickly and with little expenditure of additional public health resources. The likely result would be greater efficiency in the handling of cluster investigation requests and the provision of better information to the public.

Second, by creating nationwide tracking of chronic diseases – and by amassing data on human exposures to toxic substances in the environment – the network would provide researchers with important information with which to explore the environmental links to chronic disease. The availability of such data would allow researchers to compare rates of disease in communities with similar environmental exposures, conduct multi-community studies, and conduct more authoritative cluster studies in small communities where statistical methods alone are unlikely to be effective.

Third, by increasing the amount of resources devoted to investigating environmental links to chronic health problems, the network would reduce the pressure on state and local officials to minimize cluster inquiries due to staff and resource limitations. The result would likely be fewer delays in the investigation of potentially significant disease clusters.

Appendix A: Status Of U.S. Chronic Disease Registries

	CANCER (a,b)		BIRTH DEFECTS (c,d)			ASTHMA (e)
	First Year of Population-Based Data Collection (1)	NAACCR Certification	First Year of Available Data	Statewide?	TFAH Grade	Tracking?
AK	DNR	Gold	1996	Yes	B	No
AL	DNR	None	1998	No	B	No
AR	DNR	None	1980	Yes	A	Yes
AZ	1995	None	1986	Yes	B	Yes
CA	1988	Gold	1983	No (3)	A	Yes
CO	1988	Gold	1989	Yes	B	No
CT	1935	Gold	1993	Yes	C	Yes
DC	DNR	Gold	None		F	Yes
DE	1972	Gold	Collecting data	Yes	C	No
FL	1981	Silver	1996	Yes	B	Yes
GA	DNR	Gold (2)	1968	No	A	No
HI	1960	Silver	1986	Yes	A	Yes
IA	1973	Gold	1983	Yes	A	Yes
ID	1970	Gold	None		F	No
IL	1986	Gold	1988	Yes	B	Yes
IN	1987	None	None		D	No
KS	DNR	Silver	1985	Yes	F	No
KY	1991	Gold	1997	Yes	B	No
LA	1988	Gold	2003 (est.)	Yes	D	No
MA	1982	Gold	1998	Yes	A	Yes
MD	1982	Gold	1984	Yes	C	No
ME	1983	None	No data yet	Yes	D	No
MI	1985	Gold	1992	Yes	C	Yes
MN	1988	Gold	2002	Yes	D	No
MO	DNR	Silver	1980	Yes	B	Yes
MS	DNR	None	2001	Yes	D	No
MT	1979	Silver	No data yet	Yes	D	No
NC	1990	Silver	1989	Yes	C	Yes
ND	DNR	Gold	No data yet	Yes	F	Yes
NE	1987	Gold	1973	Yes	B	Yes

NH	1987	Silver	No data yet	Yes	D	No
NJ	1979	Gold	1985	Yes	B	No
NM	1973	Silver	1995	Yes	B	No
NV	1979	None	Collecting data	No	C	No
NY	1976	Gold	1997	Yes	B	Yes
OH	DNR	Silver	None		F	No
OK	DNR	None	1992	Yes	A	Yes
OR	DNR	Silver	None		F	Yes
PA	1985	Gold	Collecting data	Yes	D	No
RI	1986	Gold	1999	Yes	D	Yes
SC	DNR	Gold	1993	Yes	B	Yes
SD	DNR	None	None		F	No
TN	1989	None	Collecting data	No	C	No
TX	1992	None	1995 (4)	Yes	A	No
UT	1966	Gold	1994	Yes	C	Yes
VA	1990	None	1989	Yes	B	No
VT	DNR	None	None		F	Yes
WA	1992	Gold	1987	Yes	D	Yes
WI	1978	Gold	2003	Yes	D	Yes
WV	1993	Gold	1989	Yes	C	No
WY	1962	Gold	None		F	No

DNR= Did not respond.

(1) In many locations, hospital-based tumor registries had collected limited information on cancer prior to this date.

(2) Gold certification is for metropolitan Atlanta registry.

(3) California's registry, while not statewide, is designed to be representative of births in the state as a whole.

(4) Texas had collected statewide data for a time but has since discontinued collection in some areas due to budget cuts.

SOURCES:

(a) First year of population-based registry from Maria Hewett and Joseph V. Simone, eds., *Enhancing Data Systems to Improve the Quality of Cancer Care*, National Academy Press, 2000.

(b) Certification data from North American Association of Central Cancer Registries, "Cancer Registries Certified for High Quality 1999 Incidence Data," downloaded from <http://www.naaccr.org/Certification/1999Certification.html>, 24 April 2002.

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(d) Grade from Trust for America's Health, *Birth Defects Tracking and Prevention: Too Many States Not Making the Grade*, 2002.

(e) Trust for America's Health, *Short of Breath: Our Lack of Response to the Growing Asthma Epidemic and the Need for Nationwide Tracking*, July 2001. Asthma tracking data is based on information reported by the states to the CDC.

Appendix B: State Responses To Cancer Clusters

	CONDUCT INVESTIGATIONS?	HAVE STANDING RESPONSE PROTOCOL?	NUMBER OF STAFF AVAILABLE FOR CLUSTERS	ESTIMATED SATISFACTION OF COMPLAINTS (1=SATISFIED, 7=UNSATISFIED)	ESTIMATED % OF COMPLAINTS SATISFIED AT FIRST CONTACT (VIA PHONE)	INVESTIGATION REQUESTS IN 1997
AK	Y	N	0.25	2	75%	3
AL	Y	Y	0.5	4	50%	6
AR	Y	N	0.25	4	50%	2
AZ	Y	Y	0.5	5	70%	12
CA	Y	Y	1	4	DNR	300
CO	Y	Y	0.25	2	95%	9
CT	Y	Y	0.5	4	75%	20
DC	Y	N	0.25	4	50%	1
DE	Y	Y	0.25	2	75%	2
FL	Y	Y	0.75	2	10%	6
GA	N	N	NA	NA	NA	NA
HI	Y	N	1	6	0%	DNR
IA	Y	Y	0.25	2	20%	3
ID	Y	Y	0.25	3	75%	11
IL	Y	Y	0.25	3	50%	64
IN	Y	N	0.25	4	50%	10
KS	Y	Y	0.25	5	80%	5
KY	Y	N	1	DNR	DNR	2
LA	Y	N	1	4	50%	18
MA	Y	Y	>2	5	40%	59
MD	Y	N	0.25	4	55%	9
ME	Y	Y	0.25	2	99%	4
MI	Y	Y	0.75	2	75%	24
MN	Y	Y	1	DNR	95%	29
MO	Y	Y	1.5	DNR	60%	43
MS	Y	N	0.25	2	90%	7
MT	Y	Y	0.25	3	80%	3
NC	Y	Y	0.25	2	95%	30
ND	Y	Y	0.25	5	85%	2

NE	Y	Y	0.25	2	90%	2
NH	Y	Y	1.5	4	75%	11
NJ	Y	Y	1.5	5	75%	71
NM	Y	Y	0.25	3	50%	5
NV	N	N	NA	NA	NA	0
NY	Y	Y	>2	2	90%	91
OK	Y	N	0.25	4	90%	DNR
OR	Y	N	0.25	2	80%	20
PA	Y	Y	0.5	4	10%	25
RI	Y	Y	0.25	6	95%	12
SC	Y	Y	0.25	DNR	DNR	10
SD	N	N	NA	NA	NA	NA
TN	Y	Y	0.5	3	80%	DNR
TX	Y	Y	0.5	4	20%	43
UT	Y	Y	0.5	4	50%	5
VA	Y	Y	0.25	3	65%	9
VT	Y	N	0.25	DNR	DNR	DNR
WA	Y	Y	0.25	2	90%	3
WI	Y	Y	1	DNR	DNR	29
WV	Y	N	0.25	5	0%	2
WY	Y	Y	1	DNR	DNR	12

NA= Not Applicable

DNR = Did Not Respond

SOURCE: C.W. Trumbo, "Public Requests for Cancer Cluster Investigations: A Survey of State Health Departments," *American Journal of Public Health*, Vol. 90, No. 8, 1300-1303.

Appendix C: Glossary Of Abbreviations

- ALL:** Acute lymphocytic leukemia
- ATSDR:** U.S. Agency for Toxic Substances and Disease Registry
- CDC:** Centers for Disease Control and Prevention
- DES:** Diethylstilbestrol
- DHHS:** Department of Health and Human Services (New Hampshire)
- EPA:** Environmental Protection Agency
- GAO:** U.S. General Accounting Office
- MCR:** Maine Cancer Registry
- MS:** Multiple sclerosis
- NAACCR:** North American Association of Central Cancer Registries
- NPCR:** National Program of Cancer Registries
- NTD:** Neural tube defect
- ODH:** Ohio Department of Health
- PCBS:** Polychlorinated biphenyls
- PCE:** Perchloroethylene
- SCCCR:** South Carolina Central Cancer Registry
- SEER:** Surveillance, Epidemiology and End Results program
- TBDMD:** Texas Birth Defects Monitoring Division
- TCDD:** 2,3,7,8-tetrachlorodibenzo-p-dioxin
- TCE:** Trichloroethylene
- TDH:** Tennessee Department of Health
- TDH:** Texas Department of Health
- VOC:** Volatile organic compound

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