Cancer Clusters: Findings Vs. Feelings

Prepared for the American Council on Science and Health
by David Robinson
American Council on Science and Health

*Project Coordinator*
Ashlee Dunston

*Art Director*
Yelena Ponirovskaya

*President*
Elizabeth M. Whelan, Sc.D., M.P.H.

March 2002
THE AMERICAN COUNCIL ON SCIENCE AND HEALTH (ACSH) APPRECIATES THE CONTRIBUTIONS OF THE REVIEWERS NAMED BELOW.

Michael Bracken, Ph.D., M.P.H.  
Yale University School of Medicine

Sir Richard Doll, M.D., D.Sc., D.M.  
University of Oxford

George Ehrlich, M.D.  
University of Pennsylvania School of Medicine

Sander Greenland, Dr.P.H., M.S., M.A.  
UCLA School of Public Health

Clark Heath, M.D.  
American Cancer Society

William Jarvis, Ph.D.  
Loma Linda University Schools of Medicine and Public Health

Alan Kristal, Dr.P.H.  
Fred Hutchinson Cancer Research Center

Steven Rosen, M.D.  
Northwestern University Medical School

Gilbert Ross, M.D.  
Medical Director, ACSH

Wallace Sampson, M.D.  
Stanford University School of Medicine

David Schottenfeld, M.D., M.SC.  
University of Michigan School of Public Health

Michael Simon, M.D., M.P.H.  
Barbara Ann Kamanos Cancer Institute, Wayne State University

Mark Utell, M.D., University of Rochester Medical Center

Elizabeth Whelan, Sc.D., M.P.H.  
President, ACSH

ACSH accepts unrestricted grants on the condition that it is solely responsible for the conduct of its research and the dissemination of its work to the public. The organization does not perform proprietary research, nor does it accept support from individual corporations for specific research projects. All contributions to ACSH—a publicly funded organization under Section 501(c)(3) of the Internal Revenue Code—are tax deductible.

Individual copies of this report are available at a cost of $5.00. Reduced prices for 10 or more copies are available upon request.

Copyright © by American Council on Science and Health, Inc.
This book may not be reproduced in whole or in part, by mimeograph or any other means, without permission.
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>5</td>
</tr>
<tr>
<td>Introduction</td>
<td>6</td>
</tr>
<tr>
<td>What Is A Cancer Cluster?</td>
<td>6</td>
</tr>
<tr>
<td>How Common Are Cancer Clusters?</td>
<td>7</td>
</tr>
<tr>
<td>Why Are Investigations of Potential Environmental Cancer</td>
<td></td>
</tr>
<tr>
<td>Clusters So Often Inconclusive?</td>
<td>9</td>
</tr>
<tr>
<td>The Bull’s-eye Problem</td>
<td>9</td>
</tr>
<tr>
<td>Public Pressure</td>
<td>11</td>
</tr>
<tr>
<td>Problems with Data Collection</td>
<td>13</td>
</tr>
<tr>
<td>Chance</td>
<td>15</td>
</tr>
<tr>
<td>Geography as Symptom</td>
<td>15</td>
</tr>
<tr>
<td>Proving a Negative—Never Say “Never”</td>
<td>15</td>
</tr>
<tr>
<td>A Case in Point—Long Island and Breast Cancer</td>
<td>16</td>
</tr>
<tr>
<td>Conclusion</td>
<td>20</td>
</tr>
<tr>
<td>A Checklist: ACSH Recommends</td>
<td>21</td>
</tr>
<tr>
<td>References</td>
<td>22</td>
</tr>
</tbody>
</table>
Executive Summary

The issue of cancer clusters, which has been in the spotlight recently, is plagued by a wide disparity between public perceptions and scientific findings. Movies like Erin Brockovich and A Civil Action have led the public to think that industrial pollution in the environment is causing local “cancer clusters” where cancer cases are more prevalent due to cancer-causing chemicals.

There are many scientifically documented instances in which chemical exposure has caused cancer in humans, but these have generally not been purely environmental. Contamination in the water supply or air causing residents of a neighborhood to develop cancer, although popularly thought to be a common occurrence, has rarely been documented through scientific investigation. Instead, the clusters that scientists have been able to attribute successfully to a particular cause have been occupational—such as workers in a factory developing a particular type of cancer as a result of exposure to one of the chemicals they handle every day—or have been linked to a particular medicine, or to behaviors such as smoking or sunbathing. The evidence for environmental contamination causing cancer, however, is sparse. There is some indication that chemicals dissolved in drinking water may elevate the risk of gastrointestinal and bladder/urinary tract cancers, and that living next to a smelter or other “point source” of air pollution may elevate risk of lung cancer. The many efforts that have been made to demonstrate links between other types of cancer and environmental contamination have not conclusively identified such links.

Science does not support the popular image of traces of chemical contamination elevating the cancer risk of everyone who lives in a neighborhood regardless of where they work, what sort of lives they lead, and what hereditary influences may predispose them to cancer. The absence of conclusive scientific evidence in this area may be partially explained by the myriad challenges that bedevil cancer cluster investigations—challenges that are explored in this report.

This report discusses the potential cancer clusters in Toms River, New Jersey and Long Island, New York, because they contain many elements typical of cancer cluster investigations and have received considerable media attention.
Introduction

The fear that industrial pollution, present in trace amounts in the environment around us, may be causing “cancer clusters”—local areas where cancer is more prevalent as a result of cancer-causing pollutants—has received a great deal of attention recently. Films such as *Erin Brockovich* and *A Civil Action* have helped bring clusters to the forefront, and community concern over possible clusters has led to congressional mandates, federal investigations, and an increase in public sensitivity to the issue. In this report, ACSH provides a concise introduction to the issue, to help journalists, public officials, and members of the public understand both the science and the beliefs that drive the discussion.

What Is a Cancer Cluster?

Cancer clusters are a frequent topic of media attention, and have come to have two different meanings, one for the public and one for scientists. While the public typically thinks of cancer clusters in terms of cancer caused by industrial pollution, scientists tend to see the issue differently. Robert N. Hoover, M.D., Sc.D., Director of the Epidemiology and Biostatistics Program in the Division of Cancer Epidemiology of the National Cancer Institute (NCI) defines a cancer cluster as a geographic area, time period, or group of people with a greater than expected number of cases of cancer.¹ Epidemiologists—scientists who study the causes and distribution of human diseases—expect cancer rates to vary slightly from year to year and use statistical tests to determine whether or not a given rate is different enough from the average to qualify as unexpected.² Proving that a cluster exists entails a rigorous statistical analysis, in which the number of cases observed in some area over a specified interval of time is compared to the expected number of cases for that time period and area.

Scientists can use clustering as a way to learn about associations between cancer and any external agent, not only pollutants. For example, much of the scientific literature on clusters involves the evaluation of hypotheses that attribute the spread of cancer to infectious agents. The U.S. Centers for Disease Control and Prevention has conducted cancer cluster investigations for over 20 years.
G. Caldwell, of the Arizona Department of Health Services, reviewing this body of work, explained that “the original plan was to investigate such clusters to determine if they were a phenomenon indicative of cancer transmissibility.” Likewise, the 1982 edition of Schottenfeld and Fraumeni’s authoritative textbook *Cancer Epidemiology and Prevention* begins its chapter on clustering by explaining that it is “especially directed towards examining more localized variations in the incidence of cancers in space and time that might suggest that the cancers are induced by infectious agents.”

The realization that smoking elevates the risk of lung cancer is described in much of the early (pre-1970) scientific literature as an analysis of clustering—nations and areas with more residents who smoke evince higher rates of lung cancer. Such instances demonstrate that the term “cluster” can be used on a very large scale, to refer to an elevated incidence of cancer in the entire population of one nation as compared to that of another, or to similarly large groups. It is more commonly used, however, to describe elevated rates in more localized areas, such as a single town or neighborhood.

The public and the media, on the other hand, often use the term “cancer cluster” in a more general way. When members of a community believe that the number of cancer cases in their community is abnormally high, they will often seek an explanation for the “cancer cluster.” The media may then report on efforts to explain the cluster, before a statistical analysis has verified that the rates of cancer in the community are actually elevated. Thus, the term “cancer cluster” is often used by the public and the media to refer to the perception of an elevated number of cancer cases, and by epidemiologists to refer to confirmation of this perception. The community perception may reflect an elevated rate of cancer, or it may not.

**How Common Are Cancer Clusters?**

Scientists and researchers have verified a number of cancer clusters. Diethylstilbestrol (DES), a drug used during the 1940s and 1950s to prevent premature labor in pregnant women, is the cause of one such cluster. Because a prestigious group of Boston physicians advocated the use of DES, many of the women who used it
Cancer Clusters:
Findings and Feelings

lived in the Boston area. Fifteen to 20 years after these women had used DES, doctors noticed a miniature “epidemic” of vaginal cancers among their daughters. The specific form of cancer observed—adenocarcinoma—is so rare that the hospital where eight of the daughters were treated within the space of a few years had never encountered any cases of it before. Physician concern over the cancer led to an investigation that linked the vaginal cancers to DES. Most observers might not call this a “cluster” because it does not involve supposedly carcinogenic conditions in the environment where people live, but it is considered one by epidemiologists since a large number of rare cancers in one area (Boston) prompted the study.

Other cancer clusters have been found in occupational settings. One example concerns the material polyvinyl chloride (PVC), more commonly known as vinyl. PVC is one of the most widely used synthetic compounds in the world. It is an important material for construction and siding, a common insulator of electrical and other wiring, and a common material for making shower curtains. At factories around the world, workers were exposed to very high concentrations of one of the ingredients used to make PVC, a volatile chemical known as vinyl chloride monomer (VCM). VCM is not used directly by the public, but it is a key part of the PVC manufacturing process. The workers who handled VCM, it was observed, had elevated prevalence of a rare liver cancer, hepatic angiosarcoma. Rigorous investigations eventually proved that VCM elevated the risk of hepatic angiosarcoma in these factory workers.

The public expresses concern over many possible clusters each year. In most cases, the perceived increase in the prevalence of cancer that has generated alarm is not in fact an increase in prevalence at all. According to public health officials, 85 percent or more of the possible clusters reported to them by concerned community members are in fact not statistically significant elevations of cancer rates. Many of these supposed clusters include whatever types of cancer have been diagnosed in the area. This ignores the reality that different cancers are really different diseases.

As noted, cancer clusters have been reliably linked through controlled studies with specific medicines, like DES, and with occupational exposures to chemicals like VCM. Scientific findings do not, however, match up with public perceptions about localized elevations in prevalence of many different cancers as a result of industri-
al pollutants in the environment. To quote from the most recent edition of *Cancer Epidemiology and Prevention*, “Overall, there are a sufficient number of point source studies to conclude that excess lung cancer risk was very likely caused by large, relatively uncontrolled sources of community air pollution, particularly arsenic-emitting smelters…. However, the risks for community exposure are likely to be quite small, between 1.5 and 2.0 [times the normal rate] and will require substantial study populations and careful assessment of other known lung cancer risk factors.” Thus, ambient air pollution in non-occupational settings may be linked to lung cancer—not to the wide range of other cancers for which it is often blamed. At present, lung cancer is the only cancer that has been scientifically tied to ambient air pollution.

As to pollution in drinking water, the evidence is similarly lacking compared with public fears. There is a complex mixture of trace elements present in drinking water, usually at levels of 10 or fewer parts per billion. *Cancer Epidemiology and Prevention* reviews several suggested cancer links—including possible carcinogenic effects of arsenic and organochloride compounds with bladder, GI tract, and other cancers. It does not identify any chemicals about which the body of evidence is large or consistent enough to support the conclusion that they increase cancer risk in the amounts that are present in U.S. drinking water.

Some clustering should be expected as the result of chance alone. Wherever this chance clustering occurs, it is reasonable to expect that people will want to know why it has happened—and equally reasonable to expect that no cause will be found.

**Why Are Investigations of Potential Environmental Cancer Clusters So Often Inconclusive?**

*The “Bull’s-eye” Problem*

A variety of factors often work together to create the appearance of a cluster where nothing abnormal is occurring. Looking for clusters is analogous to drawing a bull's-eye after you have thrown darts at the wall at random. In this situation, there is possibly a place in which a bull's eye can be drawn that will leave multiple darts in
close proximity to some common center. According to the American Cancer Society, cancer will be diagnosed in an estimated 1,268,000 Americans in 2001. Finding clusters in cancer data is thus something like looking for patterns in the location of over a million darts thrown at a dartboard the size of the United States.

The definition of what geographic area is to be investigated in a cancer cluster study is often problematic. If the hypothesis that cancer rates in a certain area may be elevated provides the initial impetus for the study, the natural temptation is to study only the area that includes the cases that inspired the study. This problem is called “pre-selection bias” because it involves researchers pre-selecting the geographic area of a study based on what they already know an investigation of certain areas would reveal. In much the same way as gerrymandering—to include certain voters in an electoral district—can shape the outcome of elections, pre-selection bias—to include certain patients in the geographic area of a study—can shape the outcome of cancer cluster investigations.

The problem of “drawing the bull’s-eye” applies not only to space, but also to time. A study of two clusters in one Ontario town noted that “…the tendency is to include all years in which cases were reported [in the date range chosen for analysis], thereby maximizing, and magnifying, any effect which may be present.”

A third way in which the bull’s-eye problem can skew results is in the selection of which cancer to include as part of a possible cluster. In the case of possible pediatric cancer clustering in Toms River, New Jersey, investigators began by looking at every category of childhood cancer and included in their investigation those categories of cancer whose rates were significantly elevated in Toms River. The threshold of significant elevation that was used meant that for every twenty cancer categories examined, one would qualify as significantly elevated.

These sorts of expansions are problematic because the greater the number of possible cancers, areas, and time periods that are evaluated as potential clusters, the greater the chance that randomly distributed cases will appear as a cluster. In addition, the links that have been proven between exposure to carcinogenic chemicals and elevated incidence of cancer have entailed elevated rates of extremely specific cancers: DES, in high doses, elevates risk of vaginal adenocarcinoma, exposure to VCM elevates risk of hepatic angiosarcoma. One thing these documented instances of elevated
prevalence have in common is that the chemical agent consistently elevates risk of a specific cancer, not of all cancers equally.

Often in these debates, however, a burgeoning set of effects is putatively linked to a single cause. This is aptly illustrated through one of the most widely publicized cancer cluster cases in recent years, the Erin Brockovich case. Dramatized in a major film with Julia Roberts portraying Ms. Brockovich, an overworked paralegal, the case dealt with the release of chromium-6 into the Hinkley, California water supply by Pacific Gas and Electric. The suit blamed the chemical for dozens of symptoms, from nosebleeds to breast cancer, miscarriages, Hodgkin’s disease, and spinal deterioration. Workers who inhale large amounts of chromium-6 over long periods have been shown to be at elevated risk of developing lung and sinus cancers. But chromium-6 has never been shown to be related to any other human cancer, or to be carcinogenic to any degree when dissolved in drinking water.

Public Pressure

Sometimes, public pressure can impel public health officials to undertake an investigation they do not believe is warranted. Investigations undertaken after experts have concluded that nothing out of the ordinary is occurring are unlikely to produce noteworthy results.

Community members who raise concerns about possible clusters will frequently explain themselves in terms of a “common sense” feeling that something is wrong. Often, they are not inclined to wait patiently for an in-depth, methodical investigation by public health authorities.

An investigation into childhood cancer in Toms River, New Jersey, provides insight into the pressures that can work against balanced scientific inquiry. Toms River is the location of two “Superfund” sites, places the Environmental Protection Agency (EPA) has designated as a high priority for clean-up due to the presence of hazardous waste.

A nurse in a Philadelphia pediatric oncology ward noticed that many of her patients were from the Toms River area, and speculated that an environmental cause might be elevating the pediatric cancer rates in Toms River. When parents brought their concerns to the attention of state authorities, in 1996, the state evaluated the cancer
rates and found no cause for alarm. A spokeswoman from the New Jersey Department of Health explained that the state, based on existing data about cancer rates, did not think a comprehensive cluster investigation would be economical or useful, because the numbers of childhood cancers were “not statistically meaningful.”

 Nonetheless, the state moved to address community concern with a series of investigations into possible sources of cancer risk, including the Superfund sites. The parents brought a sense of urgency to the discussion. “This is a terrible disease, and these kids suffer…. These kids don’t have time to wait. I have two other children, and I’m scared to death,” said one mother of a childhood cancer victim.

 “In my heart and in my mind, I have no question. Now, it's up to the scientists to use logic and common sense to get at the truth,” said Linda Gillick, chairwoman of a citizen's committee organized to address the issue and the mother of another cancer victim.

 Where parents were certain, scientists were not. The data on cancer rates that was available when community members first raised concerns did not show more cancer than scientists might have expected to be found in a random distribution in Toms River. Residents prevailed on their congressional representatives to ask federal officials for an investigation that state health officials said would be futile. Ultimately, the study was undertaken as a joint effort between state officials and the federal Agency for Toxic Substances and Disease Registry.

 As part of her group’s effort, Linda Gillick traveled to Washington, D.C. to defend a special line-item allotment of $1 million for the Toms River study in one of Congress’s annual appropriations bills. Ultimately, Congress passed the item.

 Concerned citizens thus had a doubly decisive impact on the issue. After convincing Congressional representatives to circumvent state cancer experts and launch a federal investigation, the citizen activists intervened again to increase the funding for the study over the amount allotted it in the normal budget process. At both junctures, public concern and fear overrode the decisions of administrators charged with setting public health priorities based on scientific findings.

 The study, which took more than five years to complete, concluded that “no single risk factor evaluated appears to be solely responsible for the overall elevation of childhood cancer incidence
in Dover Township.” The study found that most of the childhood cancer cases in the area have no explanation; the only supportable environmental link was that between prenatal exposure to contaminated drinking water and pediatric leukemia in girls.

Dr. Eddy Bresnitz, a New Jersey state epidemiologist, explained that even the narrow relationship found in the study might be a fluke. “Due to the relatively low number of study subjects and other factors, chance cannot be excluded as a possible explanation for the findings.”

“You can't have a child with leukemia living two houses down from a child with a tumor, drinking the same water and breathing the same air, and tell me they didn't get cancer from exposure,” Linda Gillick told the New York Times. “That's my common sense speaking.”

**Problems with Data Collection**

Scientific studies linking elevated cancer risk to environmental causes have generally involved years-long latency periods between exposure to carcinogenic factors and development of cancer. The DES cases did not become obvious until more than 10 years after its use, and exposure to VCM in vinyl plants takes years to cause cancer. Even smoking and sun exposure, the two most widely documented avoidable cancer risk factors, can take half a lifetime to make their effect apparent. The latency problem surfaces in two ways in community-inspired cancer cluster investigations.

First, some of the people who were exposed to the environmental chemical under investigation may have moved away from the area before the investigation began. If they subsequently develop cancer in their new homes, their absence diminishes the perceptibility of the cluster. If they remain healthy, their absence from the area effectively increases the apparent magnitude of the cluster.

Second, it is possible that some of the cancer cases that occur within the investigated area may not be attributable to the local environment. If some of the people who are diagnosed with cancer moved into the area shortly before being diagnosed, steps must be taken to assure that their cancer cases are not attributed to local causes.

The most significant problem plaguing data about possible cancer cases is that cancer is typically not a reportable disease.
Cancer Clusters: Findings and Feelings

government keeps extensive, complete records of the incidence of many infectious diseases—such as tuberculosis and venereal disease—in order to track and counter potential outbreaks. For cancer, however, no such record exists. Recently, several states have begun statewide cancer registries. These are helpful to some degree, but they lack historical data, are plagued by physician compliance problems, and may not be able to keep accurate account of diagnoses made out of state. This last issue is particularly problematic, since many definitive cancer diagnoses are made at major medical centers for patients who come from out of state in search of top expertise.

In the absence of reporting requirements, the NCI runs a program called SEER (Surveillance, Epidemiology, and End Results), which documents cancer prevalence in a sample of the U.S. population to determine the baseline levels of various cancers. The program uses information from hospitals, pathology laboratories, physicians, and death certificates to determine who has cancer, supplemented by population surveys. The SEER program has been in operation since 1973 and has quality control procedures in place that maximize the accuracy and completeness of its results. In addition, many states provide additional support for the maintenance of cancer registry information beyond that provided by SEER.

These programs are helpful, but long-term historic information about cancer incidence is only available for some parts of the country. The population surveyed by SEER—a subset of the total US population—is designed to be a representative sample of the national population. If the local area in which a cancer cluster investigation is conducted differs demographically from the national population, the expected cancer levels established by SEER may not apply to the area being studied.

The data collection problem is significant because the only way to determine whether or not the cancer rate in a community is abnormally high is to compare it to an expected rate. Expected rates determined with reference to populations different from the one under study in the area of a potential cluster may not provide a reliable guide as to how much cancer should be expected in the area under study.
**Chance**

As discussed above, the nature of random distributions is such that some amount of clustering may be expected to occur simply by chance. It is conventional among scientists to regard an elevated cancer rate as “statistically significant” if chance alone would produce as much or more elevation less than 5% of the time. This is commonly written in the scientific literature as “p<0.05”, where \( p \) is the probability of seeing such an elevation if only chance is at work. With this criterion, if one examines the cancer rates in 100 neighborhoods, and cancer cases are occurring randomly, one should expect to find about five neighborhoods with statistically significant elevations.

Any unusual amount of cancer will tend to provoke concern, regardless of whether it stems from chance or a more concrete cause. As a result, the finding that there is a substantial elevation in cancer rates suggests that further investigation into possible causes may be warranted, but does not in itself establish that any particular cause is at work.

**Geography as Symptom**

When a group of people who live in geographic proximity to one another exhibit an elevated rate of cancer, the rate may reflect characteristics other than geography that those in the affected area share. Characteristics like similar diets and exercise patterns may tend to be geographically “clustered” because low-income people who eat disproportionately more fatty foods live near one-another, because health-conscious suburbanites live in the same neighborhood, or because rates of smoking tend to differ from one community to the next. In any of these cases, a geographic cluster might be proved to exist even if there were no chemical carcinogen in the environment.

**Proving a negative—Never Say “Never”**

No matter how many possible environmental cancer causes are contemplated, it will always remain possible that some heretofore ignored chemical in the environment is elevating cancer rates. Thus, investigations of possible environmental causes for cancer can be
Cancer Clusters: 
Findings and Feelings

extended almost indefinitely, as more and more possible carcinogens are examined.

For all these reasons—the many ways in which a “bull’s-eye” can be drawn, problems of latency, the lack of reportability of cancer, the similar behaviors and backgrounds of people who live near one another, and the vagaries of chance—investigations into proposed environmental cancer clusters are unlikely to confirm environmental hazards as a source of human cancer.

A CASE IN POINT—LONG ISLAND AND BREAST CANCER

One example of how science can be overtaken by public concern can be found in the ongoing investigation of breast cancer rates on Long Island. Several advocacy organizations have sprung up to urge public health authorities to take action regarding a perceived breast cancer “epidemic.” The oldest of these groups is 1 in 9: The Long Island Breast Cancer Action Coalition. Operational since 1990, 1 in 9 (along with the similar groups that have since been created) serves as a highly effective force in the public debate. 1 in 9’s website explains: “We have organized and participated in trips to Albany and Washington to educate our legislators about the need for action that will help prevent the breast cancer epidemic.”

1 in 9 has tenaciously supported the idea that industrial pollution is elevating the rates of breast cancer on Long Island. Geri Barish, the group’s president, wrote an instructive editorial in response to claims that her group was doing more to stoke fears than to support science:

As activists, we are motivated by an absolute and unflinching commitment to examine every possible scenario for the unacceptably high levels of cancer in our midst. While we recognize that many factors, including genetics, diet, and poor health practices contribute to the rates of the disease, we believe that industrial chemicals, such as pesticides and other environmental contaminants, may also play a role.
One breast cancer victim, voicing concerns typical of those recorded by news media, seems convinced that pesticide use on neighboring lawns caused her cancer. Noting that her neighbors want “their lawns green and bug-free,” she feels the fact that three women on her block have died from cancer is “not a coincidence. It can’t be.” Concerns like these highlight the quandary in which public health officials find themselves—they cannot, no matter how much they investigate, prove that the elevated rate is a coincidence, even if that is the real explanation, because it is not possible to prove a negative.

Ms. Barish and her colleagues do not appear to consider it a possibility that, when known breast cancer risk factors such as Jewish ethnicity, bearing a first child later than usual in life, socioeconomic status, early age at menarche, and late age at menopause are considered, the rates of cancer on Long Island might be no higher than should be expected. Geography might be symptom rather than cause, because people who live on Long Island tend to share other characteristics beyond area of residence. Any cancer, anywhere, deserves the attention of medical professionals. The question is whether the number of breast cancer cases on Long Island suggests that Long Island should get more attention than other localities, breast cancer more attention than other diseases, or the environment more attention than other potential risks. The answers to these questions might be no—a possibility that 1 in 9 does not consider.

1 in 9’s legislative activism, combined with that of other Long Island breast cancer groups, succeeded on June 10, 1993, when the U.S. Congress passed a bill mandating an investigation into possible environmental causes for breast cancer on Long Island by the NCI. The bill, which was supported by then-New York Senator Alfonse D’Amato, explicitly required the NCI to examine five possible environmental risk factors—“contaminated drinking water, sources of indoor and ambient air pollution, electromagnetic fields, pesticides and other toxic chemicals, and hazardous and municipal waste.”

Thus, the power of public pressure was responsible for getting an investigation launched. This intervention by activist groups is often counterproductive because it has the effect of circumventing the normal mechanisms that guide scientific inquiry. By creating a narrowly tailored federal mandate to investigate putative environmental causes of breast cancer, advocates and legislators have taken over a task for which scientists are the most qualified—deciding how lim-
Cancer Clusters: Findings and Feelings

ited research and public health dollars ought to be spent.

The Long Island breast cancer issue also provides a demonstration of the “bull’s-eye” problem. An article in Newsday entitled “Waiting for Science Can Cost Lives” celebrated the day when “the determined and creative women of Long Island went door-to-door and began plotting cases of breast cancer in the area.” As discussed above, the increased scrutiny to which the area under study is subject may create an inaccurate impression of an elevated cancer rate.

The mandated investigation, called the Long Island Breast Cancer Study Project (LIBCSP), is ongoing. The findings released thus far, available to the public at the Project’s website, do not seem to bear out the fears of community activists.

One of the questions at the core of this debate is whether or not breast cancer rates on Long Island are elevated at all, and if they are, whether or not this elevation can be explained in terms of non-environmental risk factors like those outlined above. The LIBCSP has just released a comprehensive Geographic Information System designed to help researchers investigate the situation. Meanwhile, using already available tools, a group of researchers at the NCI completed a study, “Breast Cancer Clusters in the Northeast United States: A Geographic Analysis.” Taking pains to avoid the bull’s-eye problem discussed above, the researchers used a computer modeling system to scan the study area for significant clustering. They found that “there is a statistically significant and geographically broad cluster of breast cancer deaths in the New York City-Philadelphia, Pennsylvania, metropolitan area” and noted that within this large cluster are four smaller clusters, each significant in its own right—Philadelphia with suburbs, central New Jersey, northeastern New Jersey, and Long Island. The researchers explain: “The elevated breast cancer mortality on Long Island may be viewed less as a unique local phenomenon and more as part of a more general situation involving large parts of the New York City-Philadelphia metropolitan area.” This study thus confirms that rates on Long Island are elevated, but does not do so in a way that lends support to theories about localized pollution causing cancer, since it examines such a broad area. Whether the use of pesticides in a neighborhood, or proximity to power lines or to a factory (or any similar situation) is responsible for the elevated rates cannot be determined from a study that considers such large aggregates of people. It is worth noting, however, that the cluster identified by the study
extends well beyond Long Island. The area of the cluster does not share proximity to any single source of industrial pollution. Many activists have pointed to the Long Island aquifer, which is the source of drinking water for all Long Island residents, as a potential risk because of seepage of chemicals into the aquifer from the ground. The identified cluster, however, includes many sources of drinking water other than the Long Island aquifer, suggesting that water contamination is likely not the reason for the increased risk.

Looking at these data, the researchers conclude that the high breast cancer risk is likely due to one of the factors that they were not able to incorporate in their study. “The several known and hypothesized risk factors for which we could not adjust that may explain the detected cluster are most notably age at first birth, age at menarche, age at menopause, breastfeeding, genetic mutations, and environmental factors,” they wrote. They group “known and hypothesized” risk factors together, but it is important to differentiate between the two—environmental factors are a “hypothesized” source of risk. For example, the author of a paper entitled “Epidemiology of breast cancer: an environmental disease?” explains that the goal of the paper is to consider “potentially controversial conditions which could in the future be recognized as new risk factors.”

An in-depth study of the two most frequently blamed chemicals, the pesticide DDT and a now-banned industrial insulator called PCBs, investigated Long Island women and concluded that increased risk of breast cancer does not appear to be associated with past exposure to these compounds. Further, the study’s authors found that “breast cancer risk among Long Island residents was not elevated compared with residents of the adjacent New York City borough of Queens.” Some smaller-scale studies completed in the early 1990s had indicated that PCBs might be a cancer risk, but these results were not confirmed by this LIBCSP study.

The investigation mandated by the 1993 law funded five separate large U.S. studies of women located mainly in the northeastern U.S., to evaluate the association of blood and serum levels of DDE (a chemical produced as DDT breaks down in the environment) and PCBs with breast cancer risk. In a review of these five studies published in the Journal of the NCI, researchers conclude that “combined evidence does not support an association of breast cancer risk with plasma/serum concentrations of PCBs or DDE. Exposure to these compounds, as measured in adult women, is unlikely to
Cancer Clusters:
Findings and Feelings

explain the high rates of breast cancer experienced in the north-eastern United States.”

Another area which the LIBCSP is investigating in response to the congressional mandate is the possibility of carcinogenic effects from electromagnetic fields. A research group at the State University of New York at Stony Brook conducted a review of occupational studies evaluating correlation between women’s workplace exposure to electromagnetic fields and the incidence of breast cancer. They report that eleven such studies have been conducted. Six of the studies found no association between cancer and workplace exposure, three of the studies found an association for the whole group studied, and two of the studies revealed associations only in subgroups of the population under study. These studies show a fairly typical distribution of positives and negatives that are found when there is no association. When an association represents a causative relation, studies are much more consistently positive.

The LIBCSP’s largest, definitive report has yet to be published. Based on the findings released thus far, however, it seems that the political impulse to tie breast cancer on Long Island to industrial pollution is not being validated by science.

Conclusion

Based on the data available today, there is no firm evidence that traces of industrial pollution diffused in the environment are causing cancer clusters. This could change as the issue receives continuing scientific scrutiny. For now, however, there is a substantial gap between scientific findings on this issue and public perceptions. Science continues to indicate that the primary sources of cancer risk are obesity, diet, exercise, smoking, alcohol, sun exposure, occupational chemical exposure, genetic familial cancer syndromes and susceptibility risk factors such as infectious agents—and not environmental chemical exposure. Beyond these, chance (random case clustering) is a major predictor of perceived cancer clustering. Citizens, journalists, and public officials share in the responsibility for accurate and fact-based discussion.
A Checklist: ACSH Recommends

For members of the community:

• Be skeptical. “Common sense” does not trump science in this realm.
• Know your sources: Activists and experts often disagree when it comes to cancer clusters.
• Remember the bull’s-eye effect: Check for bias in the way statistics are organized or calculated.

For journalists:

• Help consumers differentiate among suspected clusters in which incidence is actually not increased, clusters in which incidence is increased, and clusters for which a cause other than chance has been identified or is at least strongly suspected on good scientific grounds.
• Put community concern in context—use information like that contained in this report to ensure that the science of cancer clusters gets covered along with the human side of the issue.
• Clearly distinguish between helpful actions that people can take to reduce cancer risk—frequent checks for early detection, a healthy diet and exercise, and in some cases chemoprevention—from steps like filtering the water that are not proven ways of reducing cancer risk.

For politicians:

• Focus on measures that are both popular and proven—like mammograms and chemoprevention when appropriate for breast cancer, and frank but well-informed discussion of confirmed lifestyle risks for all cancers.
• Explain the facts about environmental clusters—we may have nothing to fear but fear itself.
• Maximize the efficacy of cancer research and epidemiology dollars by allowing public health officials and scientists to direct and manage the details of research efforts.
References


2. Typically, the statistical threshold p<0.05 is used.


5. p. 305 in Cancer Epidemiology and Prevention.


10. Schottenfeld and Fraumeni, 2nd ed. ch. 20—“Water Pollution”.

11. Fleming testimony (ibid.).


17. “TRACKING DOWN A CAUSE; Lawmakers pledge fund to better assess child cancer cluster.” Asbury Park Press. 3/19/96.


19. “State says Toms River water supply is OK now, but studies continue.” AP Newswire. 11/16/99.

20. TRACKING DOWN A CAUSE, *ibid.*


36. *ibid*.

