Testimony of

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OVERSIGHT HEARING ON DISEASE CLUSTERS AND ENVIRONMENTAL HEALTH

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Thank you for the opportunity to submit written testimony to this Committee. I am Gina Solomon, a Senior Scientist at the Natural Resources Defense Council (NRDC) and an Associate Clinical Professor of Medicine at the University of California, San Francisco (UCSF) where I am also the Director of the UCSF Occupational and Environmental Medicine Residency Program. NRDC is a national, nonprofit, public interest organization dedicated to protecting human health and the environment, with over 1.2 million members and online activists in all 50 states. I am a practicing physician and am Board certified in both internal medicine and occupational and environmental medicine, and I have done research and education for over a decade on the links between disease and the environment.

Scientists estimate that of the 30 years added to our average life expectancy since 1900, 25 are attributable to public health programs -- primarily programs such as drinking water disinfection, sewage treatment, better nutrition, safer handling of food, and improved tracking of disease. Tracking of disease is fundamental to saving lives because it allows agencies to identify populations at risk and rapidly respond to outbreaks, clusters, and emerging threats. Investigation of disease and exposure allows scientists to establish relationships between hazards and disease, thereby guiding prevention strategies.

Since the conquest of old scourges such as smallpox, plague, polio, and leprosy, our national public health system has begun to stagnate. Our public health system needs to better address current threats such as chronic disease and environmental health. Currently the Centers for Disease Control and Prevention (CDC) tracks and rapidly responds to outbreaks of fifty acute infectious diseases. This is a fantastic tracking system, but there is no parallel for most chronic non-infectious diseases.

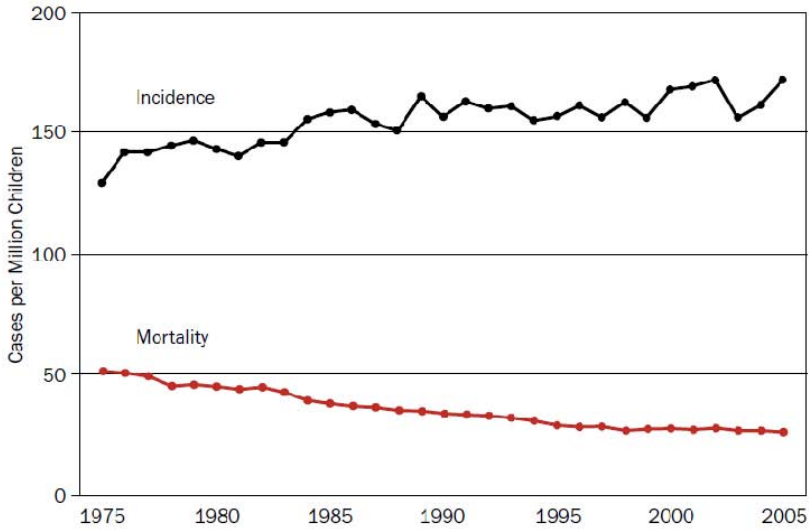
Chronic disease is responsible for four out of five deaths in the U.S. today, and the suffering of 133 million people per year in the United States. Asthma, developmental diseases such as birth defects or neurobehavioral disorders, degenerative neurological diseases such as Parkinson's and Alzheimer's, diabetes, and cancer are all chronic diseases. According to the U.S. Centers for Disease Control and Prevention (CDC), almost half of all Americans are living with chronic disease, which now accounts for 75% of U.S. health care costs.[1] Many chronic diseases are on the rise, and many are preventable. There is also increasing evidence that many of these illnesses may be linked to exposures in our environment.

Numerous chronic diseases and cancers are on the rise, including:

- Leukemia, brain cancer, and other childhood cancers, which have increased by more than 20% since 1975, even though – thanks to improved medical treatment – deaths have decreased (see Figure 1 below).[2]
- Breast cancer rates went up by 40% between 1973 and 1998.[3] While breast cancer rates have declined a bit recently, a woman's lifetime risk of breast cancer is now one in eight, up from one in ten in 1973.

- Asthma, which approximately doubled in prevalence between 1980 and 1995 and remains at the elevated rate.[4]
- Cryptorchidism (undescended testes) which has increased 200% during the 1970's and 1980's.[5]
- Autism, the diagnosis of which has increased by more than 10-fold over the last 15 years.[6]

FIGURE 1 **Cancer Incidence and Mortality for Children Under 20**



Cancer is the second most common cause of death for Americans under the age of 20. The incidence of childhood cancer increased more than 20% between 1975 and 1990. Since 1990, the incidence has remained roughly at this elevated rate. Although improved treatment options have led to a decline in the percentage of children who die from cancer, the percentage of children who are diagnosed with leukemia, brain, and other cancers has increased.

Source: U.S. EPA. America's Children and the Environment. *www.epa.gov/envirohealth/children*
Data: National Cancer Institute, Surveillance, Epidemiology and End Results Program

These nationwide statistics are alarming but can disguise the specific suffering experienced by individuals and communities. When I was a Clinical Fellow at Harvard in the mid-1990's, I learned of a major investigation into a childhood leukemia cluster in Woburn, Massachusetts. Twelve children in that small community developed leukemia over a period of ten years – an extraordinarily high rate of this rare disease. Did the state cancer registry identify this cluster of childhood leukemia, and link it to contamination of the water supply with the chemicals trichloroethylene and perchloroethylene? No. This cluster was discovered by mothers sitting with their children in the waiting room at the Dana Farber Cancer Center and recognizing other families from their neighborhood. Only later was this cluster confirmed and investigated by scientists at Harvard and state agencies.

This Senate Committee held a field hearing in April of 2001 in the town of Fallon, Nevada, where from 1999 to 2001, 11 children were diagnosed with leukemia. Scientists calculated that a cluster of this magnitude would be expected to occur in the United States by chance about once every 22,000 years.[7] The area had significant local environmental contamination with elevated levels of radioactivity, tungsten and arsenic in the water supply or in the community. The Fallon case came more than a decade after the Woburn case. This time, surely the public health system identified the problem?

Unfortunately, no. Nevada didn't even have a cancer registry at that time. Again, it was families in the town that first brought the problem to public attention.

In the summer of 2001, the Senate EPW committee again held a field hearing, this time on Long Island New York, to investigate the elevated rates of breast cancer in that area.[8] At that hearing, Senator Reid stated that "The time is long overdue for the Federal Government to craft an orderly approach for rapidly and effectively responding to the needs of communities for support and guidance in identifying and addressing disease clusters." (Transcript p.6) A full decade later, the time is even more overdue, and I am encouraged by Senators Boxer and Crapo's efforts to remedy this problem.

The last time I appeared before this committee, one year ago on March 17, 2010 at a hearing on children's health and the environment, Senator Bill Nelson came to the hearing to plead for help in the investigation into the causes of a childhood brain cancer cluster at The Acreage in Palm Beach County, Florida.

Although all of these high-profile cancer clusters were ultimately investigated, and various environmental problems were identified in most of the communities, the exact causes of all of these clusters were never fully understood. Disease clusters can be frustrating in that way. Scientists and researchers often have a hard time getting to the bottom of what's going on. Worse still, the well-known cancer clusters I have listed above are just the tip of the iceberg.

My colleagues and I just released an issue paper documenting 42 disease clusters in 13 states.[9] It is attached as part of my testimony. We documented confirmed clusters of:

- Testicular cancer in Prairie Grove, Arkansas, including three cases in 14 year-old boys, in a town of only 2,500 people.
- Birth defects in Kettleman City, California, including twenty babies born over less than two years with birth defects, and four children born with birth defects so severe that they have since died, in this town of only 1,500 people.
- Amyotrophic Lateral Sclerosis (Lou Gehrig's disease) – a very rare disease - in Herculaneum, Missouri, a town affected by a major lead smelter and decades of pollution.
- Multiple sclerosis (MS) in Wellington, Ohio, where residents are three-times more likely to develop MS than in the rest of the country, a disease whose causes are unknown but are thought to involve a combination of genetic and environmental causes.
- Polycythemia Vera, a rare and severe blood disorder, with four cases occurring on one road in Eastern Pennsylvania.
- Male breast cancer, childhood cancer, and birth defects in Camp Lejeune, North Carolina. More than 60 men who lived on that base have been diagnosed with breast cancer – an extraordinary finding, and one which deserves urgent attention.

Environmental Causes of Cancer

Although it is difficult to conclusively prove what caused any specific disease cluster, we can gather invaluable clues and hints from these tragic events. The Woburn cluster, for example, provided a key clue linking trichloroethylene (TCE) with cancer in humans – something that has since been confirmed in multiple studies. The cluster in Fallon, Nevada also provided important scientific clues. Biological sampling in Fallon revealed community-wide exposure to tungsten with almost 80% of the participants having urinary tungsten levels above the 90th percentile in the National Health and Nutrition Examination Survey (NHANES), and the median tungsten levels were almost 10-fold higher than the 1999 NHANES median level for tungsten. Tungsten was not previously thought to be carcinogenic, but had never been adequately studied. This same metal subsequently showed up at elevated levels in Sierra Vista, Arizona, another community affected by a childhood leukemia cluster. This tungsten is now undergoing testing by the National Toxicology Program to better understand its potential health effects.[10] Other disease clusters have revealed the cancer-causing properties of asbestos, the profound peripheral neuropathy caused by exposure to n-hexane, the complete wipe-out of sperm production from the pesticide DBCP (dibromochloropropane), and the liver cancers caused by vinyl chloride. All of these chemicals are now well-known to be human health hazards, and one of them – the pesticide DBCP – has been banned. The other chemicals, which fall under the purview of the Toxic Substances Control Act (TSCA), are still in widespread use today.

There is good reason to believe that only a small fraction of the links between the environment and disease has been revealed to date. Although there has been much focus on the genetic causes of disease, the scientific consensus has shifted to the position that most diseases are primarily caused by a combination of genetic and environmental factors. For example, a study of nearly 45,000 twins published in the New England Journal of Medicine evaluated the relative importance of genetic and environmental factors in cancer.[11] If the cancers were primarily genetic, identical twins (which share the same genome) would have more similar cancer patterns than fraternal twins (which only share the genetics of any siblings). The bottom line of this important study was that the vast majority of cancers are environmental rather than genetic. Statistically significant genetic effects were only seen for three cancers -- prostate, colorectal, and breast. In the case of breast cancer, less than one-third of the risk was due to inherited factors (potential range 4-41%); that means that about 70% of the remaining risk of breast cancer is due to environmental factors. For other cancers, the environmental component was even larger. The same principle is true for most other diseases, where environment is turning out to be more important than genetics.

Yet people keep citing a 30 year old paper from a British statistician that estimated that only 2 percent of cancers are environmental, and 4 percent are occupational.[12] That number was largely based on cancers from asbestos, and does not reflect the myriad other environmental causes of cancer and other diseases, nor does it reflect the knowledge from newer studies such as the New England Journal of Medicine twin study cited above.

If you ask me to tell you exactly what percent of cancers, birth defects, or neurological disorders are due to environmental factors, it would be difficult. That’s because there’s a

lot of work that still needs to be done to identify the list of specific environmental causes of cancer that go beyond the British statistician's narrow estimate and that add up to the 70 percent or more from the New England Journal of Medicine. Some of these factors are well-known (such as cigarette smoke), others are partially understood (such as the lists of carcinogens that occur naturally or that are in manmade substances), and others have yet to be discovered. In addition, because of the interactions between chemicals, as well as between chemicals and genes, the sum of causes will add up to more than 100 percent.[13] The big problem is that the rates of some cancers – including childhood cancers – and other diseases, are rising, so we don't have the luxury of a lot of time. People are getting sick and suffering, so we need to move quickly and use whatever clues we can to understand what's going on.

The President's Cancer Panel released a landmark report in April 2010 entitled, "*Reducing Environmental Cancer Risk: What we can do now*".[14] The report included the following statements:

> *Approximately 41 percent of Americans will be diagnosed with cancer at some point in their lives, and about 21 percent will die from cancer. The incidence of some cancers, including some most common among children, is increasing for unexplained reasons… A growing body of research documents myriad established and suspected environmental factors linked to genetic, immune, and endocrine dysfunction that can lead to cancer and other diseases.*
>
> *Action is possible at several levels: conducting scientific research to enhance our understanding and by extension, our ability to prevent and respond to environmental carcinogens; enforcing existing policies and regulations that protect workers and the public; implementing policy and regulatory changes that support public health and reduce the burden of cancer; and taking personal action.*"

Learning lessons from the disease clusters in communities around the country allows for the possibility of some good emerging from something that is otherwise very bad. I'm sure that every parent of a child with cancer would do whatever they can to help – not only their own child – but also help prevent other parents and children from having to go through such an ordeal by identifying causes and preventing future disease.

Difficulties Identifying Environmental Carcinogens

Most of the chemicals in use today are not tested for their potential to cause cancer or other diseases. Of the approximately 85,000 chemicals on the market today, an estimated 62,000 were 'grandfathered' in without any testing requirements under the Toxic Substances Control Act (TSCA). In the case of new chemicals, most have not been tested for toxicity, since the EPA cannot require testing without specific reasons, so the vast majority of chemicals that are introduced onto the market have not been tested in the laboratory.

For generations, there has been world-wide consensus that it is unethical to intentionally dose humans with toxic chemicals, if the exposures may be harmful. So the advancement of the science of human disease relies on so-called "observational studies" – studies of people who are sick with a given disease, compared with those who are not; studies of people who are more highly exposed to certain contaminants, compared with those who are not. These studies are difficult, often expensive, and they take time. Sometimes they get mired in uncertainty because there are simply not enough people in a given group to generate statistically significant findings; sometimes there are simply too many things going on at once, and it's not possible to tease apart all the potential factors; sometimes nothing turns up in the testing because we aren't testing for the right thing.

When you think about it, it's amazing that any environmental carcinogens at all have been identified from observational studies. Those that have are usually due to one of the following three factors:

1) Workers or communities who have been exposed to high doses of a few chemicals for years, and have experienced elevated rates of disease (such as diesel exhaust, trichloroethylene, benzene, and methylene chloride);
2) The disease is very rare (such as mesothelioma and asbestos, angiosarcoma and vinyl chloride, clear cell carcinoma and diethylstilbesterol);
3) The chemical is very potent (such as tobacco smoke, radiation, 2-naphthylamine, and dioxin).

Even if uncertainties remain in the analysis of the clusters, they contribute valuable information to better understand and prevent cancer. And that new scientific information is invaluable for protecting public health and preventing future disease.

Solutions and Recommendations

Fortunately, there are some tools that can help improve the science of cluster investigations, and that can also help engage communities in coming to a better understanding of the causes of disease clusters.

First, there are new scientific tools, including the rapidly advancing science of biomonitoring that allows detection of numerous chemicals in the human body; rapid improvements in toxicogenomics and metabolomics, that allow researchers to discern the effects of chemicals on the genes and metabolic systems within the body; and improvements in screening of chemicals that will help improve detection of hazards before they come on the market, and will allow further evaluation of agents of possible concern in clusters.

Second, there is the potential for greatly improved coordination between agencies. To date, cluster investigations have frequently been conducted by county or state health departments with limited assistance, or by the Agency for Toxic Substances and Disease Registry (ATSDR) which is expert at some aspects of this work but not others. Bringing agencies such as the EPA into the collaboration will be important to allow all areas of expertise to be brought to bear on the problem. Also, having a set of guidelines for cluster

investigations will help to assure that all communities that truly need assistance will get the attention they need, and will help to focus the federal efforts where they will be most useful.

Third, there is an opportunity to bring community resources into these investigations in a more formal way. As I noted above, the people who detected the problem in Woburn, Massachusetts were the parents of children with leukemia. The people who identified the testicular toxicity of DBCP were workers who realized that none of them had been able to father children. In case after case, the clues to help solve these mysteries have resided in the knowledge and experience of the affected communities. So the creation of formal Community Advisory Committees will be critical to gathering better information and to better communication and resolution of these difficult problems.

Disease clusters demonstrate the need for:

1. Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes. Good cluster investigations require the creation of consistent guidelines for a systematic and integrated approach to investigating disease clusters; improved coordination between various agencies at the federal, state, and local level; and local advisory committees that can help improve the outreach to and involvement of community members.
2. Reducing or eliminating known toxic releases into air, water, soil and food through strong science-based environmental controls and tough enforcement of those requirements; and
3. Requiring chemical manufacturers to ensure the safety of their products. Comprehensive chemical policy reform includes testing of all untested chemicals in commerce, requiring manufacturers to prove safety, and the use of an approach that protects children and other vulnerable populations from cumulative risks.

I am thinking of the residents of Woburn, MA, Fallon, NV, Tallevast, FL, Dickson, TN, Midlothion, TX, Camp Lejeune, NC, Prairie Grove, AK, Midland, MI, Kettleman City and Carlsbad, CA, Millsboro, DE, Amelia, LA, Herculaneum, MO, Libby MT, Clyde, OH, Wilkes-Barre, PA, and many dozens of other towns across the country. These people have suffered through illness and uncertainty, hope and disappointment. They have fought for answers, and in most cases, have not received them. It's not too late for these communities and others like them. There's still an opportunity to improve and systematize our approach to these disease clusters so these communities get the attention they need and maybe also the answers they seek.

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[3] Holly L. Howe, et al., "Annual Report to the Nation on the Status of Cancer (1973 through 1998), Featuring Cancers with Recent Increasing Trends," Journal of the National Cancer Institute, 93, no. 11 (June 2001): 824–42.

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