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## **Tracking Disease Clusters And Environmental Health**

Law360, New York (April 6, 2011) -- On March 29, the U.S. Senate Committee on Environment and Public Works held a hearing entitled "Oversight Hearing on Disease Clusters and Environmental Health." Committee Chairwoman Barbara Boxer, D-Calif., and Senator Mike Crapo, R-Idaho, ranking member of the Superfund, Toxics and Environmental Health Subcommittee, introduced the Strengthening Protections for Children and Communities from Disease Clusters Act (S. 76), also known as Trevor's Law, on Jan. 25, 2011. The bill would require the U.S. Environmental Protection Agency to:

- 1. Develop, publish and update guidelines on an approach to investigate suspected or potential disease clusters, environmental pollutants, or toxic substances associated with such clusters, or potential causes of such clusters;
- 2. Establish and operate Regional Disease Cluster Information and Response Centers and Regional Disease Cluster Information and Response Teams;
- Ensure that the Office of Children's Health Protection has a prominent role in developing and updating such guidelines and in establishing and operating such Centers and Teams;
- 4. Establish Community Disease Cluster Advisory Committees to provide oversight, guidance, and advice relating to such investigations;
- 5. Provide support to individuals on such Teams and Committees through grants and cooperative agreements with institutions of higher education;
- 6. Compile and update a publicly available, online database that provides information relating to disease clusters; and
- 7. Use available authorities and programs to compile, research, and analyze information generated by actions authorized under the act.

Under the bill, any person could petition the EPA, the Agency for Toxic Substances and Disease Registry (ATSDR), and the National Institute of Environmental Health Sciences (NIEHS) to request that a Response Team conduct an investigation or take action to address the potential causes of disease clusters. The EPA would be authorized to make grants to any group of individuals that may be affected by such clusters.

During her opening statement, Senator Boxer stated that, according to the EPA, from 1975 to 2007, rates of childhood cancer have increased by more than 20 percent. According to the National Cancer Institute, leukemia is the most common form of childhood cancer, accounting for 20 percent of the incidences. The greatest number of childhood cancers occurs during infancy — the first year of life.

Senator Boxer also referred to the 2010 report by the President's Cancer Panel, which stated that it was "particularly concerned to find that the true burden of environmentally induced cancer has been grossly underestimated." Senators Boxer and Crapo intend their bill to increase coordination, transparency, and accountability when federal agencies work to investigate and address potential disease clusters.

Senator Frank R. Lautenberg, D-NJ, chairman of the Subcommittee on Superfund, Toxics and Environmental Health and a co-sponsor of Senators Boxer and Crapo's bill, stated that he intends to introduce "soon" an updated version of the Kid-Safe Chemical Act. The updated version of the bill will incorporate feedback that he received last year.

The most recent version of the bill, introduced in the 110th Congress, would amend the Toxic Substances Control Act to require each manufacturer of a chemical substance distributed in commerce to submit to the EPA: (1) a statement certifying that the substance meets required safety standards or that there are insufficient data to make such determination; and (2) all reasonably available information concerning the substance not previously submitted.

The bill would require manufacturers to update such information at least every three years or at any time new information becomes available on a substance's toxicity.

The witnesses included:

- Trevor Schaefer, youth ambassador and founder, Trevor's Trek Foundation
- Erin Brockovich, president, Brockovich Research & Consulting
- Dr. Richard Belzer, Ph.D., president, Regulatory Checkbook
- Dr. Gina Solomon, M.D., MPH, senior scientist, Natural Resources Defense Council (NRDC)

The witness statements are available online.

Schaefer testified regarding his experience of being diagnosed with brain cancer at age 13 and how he was not the only child in his small town to be diagnosed with brain cancer. Schaefer described the importance of Trevor's Law in providing people in small communities an opportunity to have their voices heard regarding environmental impacts on their health.

Brockovich testified that each month she has 45,000 to 60,000 visitors to her website, of which "thousands" contact her to report issues ranging from environmental pollution, cancer and other diseases resulting from contamination of their property and environment, worker injuries and illnesses, and more.

According to Brockovich, these people make up whole communities that are witnessing first-hand the harmful health effects from exposure to toxic chemicals. Brockovich reiterated the President's Cancer Panel's finding that the number of cancers caused by toxic chemicals is "grossly underestimated."

Brockovich has begun to record on a map the location of Americans contacting her about unexplained diseases and she brought the map with her to the hearing. Senator Boxer noted that the fact that Americans were turning to Brockovich, a private citizen, rather than their state or federal government, demonstrated the need for S. 76.

Belzer focused on four issues with S. 76: 1) how disease is defined; 2) how disease cluster is defined; 3) how potential cause of a disease cluster is defined; and 4) the subordination of science to politics. According to Belzer, the bill does not define disease, although it defines disease cluster and potential cause of a disease cluster.

Belzer testified that a good definition of disease cluster would be both sensitive, to pick up all cases, and selective, to ensure there are no false positives. According to Belzer, the bill's definition would be only sensitive, not selective. Senator Boxer disagreed with

Belzer's remarks, but asked him to work with her to strengthen the bill.

Solomon noted that, on March 29, the NRDC and the National Disease Cluster Alliance released an issue paper documenting 42 disease clusters in 13 states. The paper, entitled Health Alert: Disease Clusters Spotlight the Need to Protect People from Toxic Chemicals, calls for better documentation and investigation of disease clusters to identify and address possible causes.

The paper also states that toxic chemicals should be identified and controlled through TSCA reform, so these chemicals do not pollute communities and sicken people. The paper is available online. Solomon praised S. 76, which would direct and fund federal agencies to assist state officials in investigating disease clusters and would create consistent science-based guidelines for the investigation and identification of disease clusters.

Sens. Boxer and Lautenberg agreed that Trevor's Law and the Kid-Safe Chemical Act are different, but complimentary approaches to the same issue. While Sen. Boxer's bill would address the problem after the fact, Sen. Lautenberg's bill would shift the burden to manufacturers to prove the safety of their chemicals before using them in products. Sen. Boxer noted that Trevor's Law is not an EPA bill. Instead, it calls for the federal agencies to cooperate.

Assuming contamination is found in water, soil or air, however, the EPA is the agency with the authority to require cleanup, and that is why it is the primary agency. Sen. Boxer repeatedly asked both senators and witnesses to work with her to address any perceived shortcomings in the bill.

## Commentary

The concept of disease registries to track the incidence of disease by geography or demographic data is sought by many different constituencies (e.g., those seeking stronger environmental laws as well as many advocates of health care reform). If some kinds of registries are created, many immediate issues will flow from the data, such as which federal agency is appropriate to analyze any data and which agency is expected to be responsible for acting on any results.

Those who believe that some or much onset of disease is due to environmental factors will look to the EPA as the lead agency, while others might argue that agencies with more familiarity with health issues would be more appropriate (e.g., the Centers for Disease Control and Prevention).

One additional factor comes from the jurisdictional turf of congressional committees based on which member of the House or Senate sit on which committee. Senators on the Committee on Environment and Public Works will look to the EPA since, among other reasons, they will have a greater ability to shape any final legislation relating to EPA activities, even if the larger well of expertise might lie outside of the EPA.

It should also be noted that TSCA legislation from the last session of Congress included requirements for the EPA to analyze and address both "toxic hotspots" and communities that had disproportional exposures to environmental pollutants. If Sen. Lautenberg reintroduces legislation, as he indicated in today's hearings, it would likely be similar, if not identical, to those provisions from legislation in the last Congress.

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