

**3rd Annual Town Hall Meeting**  
**Translating Breast Cancer and Environmental Research into Action**

*The Right to Know in an Era of Toxic Ignorance*  
*Ethical and Scientific Challenges for Reporting Back Personal Exposures to*  
*Environmental Chemicals*

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Referring to the study of which Carla Perez spoke in the previous presentation, Rachel Morello-Frosch approached the research results from a different perspective - that of the research participants' right to know about chemical burdens.

Dr. Morello-Frosch provided a historical framework for the concept of biomonitoring and health surveillance, indicating some of the positive outcomes that followed such activities. In the past, lead testing and biomonitoring in homes and workplaces indicated high exposures to lead, with African American children bearing the highest burdens. By utilizing the knowledge to effect change, lead exposure has diminished. This has been the traditional use for biomonitoring.

Now, she explained, we have better and less expensive testing techniques that are becoming more available and can test for lower levels of more chemicals. However, Morello-Frosch elaborated, this has created another dilemma. Now it is possible to test for more chemicals and emerging pollutants in order to look for trends and disparities, but it is not necessarily known from where these chemicals are coming. They have "no return addresses".

There are approximately 100,000 chemicals registered for commercial use in the United States, but only about 10% have been tested for things like cancer or developmental and reproductive impacts. The current capacity to detect chemicals is better than the capacity to know what it means for health.

The environmental justice community considers issues related to biomonitoring, yet there is also some concern that biomonitoring may make stakeholders focus myopically and "over-scientize" issues of environmental health disparities and prevent researchers and advocates from looking for the causes of those disparities.

Dr. Morello-Frosch continued, saying that some scientists are thinking about report-back issues from a clinical and ethical perspective. When should researchers report back the study levels to participants? Often report-back doesn't happen or only happens when there is a regulatory benchmark to say that there may or may not be a problem. This may then preclude the ability of the community to take precautionary action. Since

people are becoming more proactive in directing their own health care, it is suggested that they be told their levels even if there is not a clinical benchmark. This may give them the ability to take precautionary action to reduce their exposures, even if it is not known exactly what it means for their health.

Another report-back issue Morello-Frosch discussed was advocacy science linked with biomonitoring. Groundbreaking studies in the Bay Area have spotlighted the idea of toxic trespass and its affects on people's bodies. This has pushed a new era of research ethics by getting research participants to talk publicly about their experiences and share their results with the community at large.

"We don't need a lot of epidemiological studies before we begin to act," she said. "The fact that chemicals are turning up in people's bodies should be sufficient to push the regulatory arena to take action, even before the impact of the substances is definitively known." She spoke of specific policy goals: "to build constituencies, to promote environmental health, to improve chemicals policy and to expose the inadequacies of current regulatory policies in the US and push for bans of certain chemicals like brominated fire retardants."

In her collaborative research, Dr. Morello-Frosch said she uses the participatory research model as described by Marion Kavanaugh-Lynch in a previous presentation and works closely with community members for report-back. It begins with reporting back to individual participants, then in community meetings, and to both English and Spanish media outlets.

It has been said that reporting back to participants will "stress them out" and "paralyze them" because there's nothing they can do to change the outcomes. In Morello-Frosch's experience, nearly every participant wanted their results even though it was made clear to them that it was not known how these chemical burdens might affect their health. Many people are simply curious; others want to use the information as part of their advocacy strategies. Either way, Dr. Morello-Frosch affirms that she has taken a right-to-know approach in her report-back strategy.