A Discussion on Environmental Health Tracking with Health Affected Groups
February 1, 2005
San Francisco Medical Society

MEETING SUMMARY

This discussion was co-sponsored by the San Francisco Medical Society (SFMS), Collaborative on Health and the Environment (CHE), and the California Environmental Health Tracking Program (CEHTP). There was a rich discussion about how to develop the Parkinson's registry, as well identifying health tracking issues for health outcomes that are not currently being addressed (such as infertility and learning and developmental disabilities). We also talked about what the groups would like to see from the current tracking program: better surveillance data to help examine the impacts of multiple exposures (especially including radiation and possibly EMF), more GIS and historical mapping, more information being pulled from existing databases and resources, the addition of biomonitoring to health tracking efforts and the ability to track disease recurrences. There was considerable interest in following up with this conversation, as well as supporting health tracking and biomonitoring legislation.

Thanks to all the participants for making this meeting a success! We had over 30 attendees with representatives from the following organizations:

- **National Brain Tumor Foundation**
- **American Heart Association**
- **Breast Cancer Fund**
- **International Dyslexia Association**
- **Central Brain Tumor Registry**
- **Marin Breast Cancer Watch**
- **UC Davis, Institute for Children's Environmental Health**
- **Parkinson's Action Network**
- **Breast Cancer Action**
- **Commonweal**
- **RESOLVE, the National Infertility Association**
- **American Cancer Society**
- **Learning Disabilities Association**
- **Children and Adults with Attention Deficit Disorder**
- **San Francisco Department of Health**

DISCUSSION NOTES

General Welcome and Introductions
- *Steve Heilig, San Francisco Medical Society*
- *Paul English, California Environmental Health Tracking Program*

Overview of Collaborative on Health and the Environment
- *Jeanette Swafford, Collaborative on Health and the Environment*

Overview of Environmental Health Tracking
- *Geoff Lomax, California Environmental Health Tracking Program*
- *Sharyle Patton, Collaborative on Health and the Environment*

Exposure and Disease Tracking: Opportunities and Challenges
- *Paul English, California Environmental Health Tracking Program*

Examples of Health Tracking in California's Pilot Projects
- *Eric Roberts, California Environmental Health Tracking Program*

Open Discussion (organized by general topics)

Cancer:

Exposure to electro-magnetic fields (EMF) is of concern to the cancer community. EMF exposure is mostly studied in occupational health. It is very complex and difficult to monitor. It is important to look at the biology of EMF exposure. The biologic impact should set the safety standards for EMF emissions. For brain tumors there is largely only anecdotal reporting of clusters and cases. There is very little data. Ionizing radiation which occurs during medical treatment for existing cancer (diagnostic exposure) may be a contributing factor to disease recurrence. Disease recurrence, particularly cancer, is not included in the Cancer Registry surveillance system. Studies in Europe that look at the synergistic or cumulative effects of EMF, metals and pesticides in regards to brain tumors should be replicated in the United States.

It is the hope of the Tracking Program that some day good surveillance data could be used to understand the impact of multiple chemical exposures on chronic diseases.

Brain tumor advocates are interested to know if there is a higher brain cancer rate in high pesticide areas like the Central Valley. There was interest in finding an opportunity to use existing tracking data from the Tracking pilot project to look at this question.

Breast cancer advocates are concerned about understanding and tracking voluntary exposures such as radiation therapy or medication (via primary prevention strategies) and their potential impact on disease recurrence.

Mapping:

Can the program incorporate topographic techniques in their mapping? This would allow the map review to examine surfaces for peaks and valleys in areas that could convey an elevation or decreased prevalence of the hazard or disease.

Yes, there are mapping programs currently available that include this approach. However, the smoothed mapping technique used in these demonstration projects was chosen because researchers believe this is the most effective way to communicate this information to a broad and often lay audience.

Maps are powerful, but it is important to recognize that they can be misinterpreted. It is important to have these maps to understand environmental and health trends over time and for possible reconstruction of historical exposures when possible. The environmental agent will dictate how far back you can look at potential exposures. It depends on the quality of the data. In some cases it makes more sense to use current data that has less reporting bias and is more complete—therefore making it more accurate. You can use this data to extrapolate exposures that occurred in the past. This is sometimes done because the historical data is not as good.

Infertility:

Is there any ongoing surveillance of miscarriage and genetic abortion?

Only after 20 weeks gestation. Also, infants who die right after birth would be included in vital records data.

There is some data on following pregnancy hormone levels in blood in early pregnancy.

It is important to use surveys in infertility tracking. But it will be critical to get the right questions onto these surveys. Also, geographic information of the respondent NEEDS to be included in the survey, otherwise environmental exposures cannot be assessed. "Time to pregnancy" is a useful indicator. Also, there is a higher risk of low-birth weight babies in women who had difficulty conceiving. It is important to mine existing clinical research studies and settings to understand infertility prevalence. There are significant ethnic differences in in vitro fertilization (IVF) outcomes. Asian women may not be as successful with IVF. There is concern that this is due to PCB and mercury exposure in women from consuming contaminated fish. Menarche or "time to cycle" may impact fertility. It maybe useful to coordinate with the California Health Interview Survey to look at fertility and puberty issues. This issue dovetails with developmental disabilities. It is necessary to broaden our thinking and not just think of the disease, but of a spectrum of outcomes that may be influenced by the environment. It is important to look at preconception exposures, birth outcomes, etc… in a combined way in order to have a more global view of how the environment is impacting our health. Men and women with impaired fertility are the "canary in the coal mine" in terms of environmental health issues and impacts.

Children's Health (learning and developmental disabilities)

Is the Longitudinal Children's Health Study an opportunity to have questions answered that would address some participant's health outcome issues?

There needs to be better planning with longitudinal studies to include biomonitoring, developmental and learning disabilities. With biomonitioring, cost is always an issue in the study design.

There is a need to advocate with federal and private funding institutions to assure that stakeholders will ultimate have access to data from case control or longitudinal studies.

For school data it is important to have a protocol for standardized questions for intake interviews with students to have more consistent data on learning and other developmental issues from children.

Environmental Health needs to include prevention and health promotion. It is important to consider behavioral and gene influences on health and disease.

Case control (and some prospective) studies should take blood and urine samples whenever possible. Biomonitoring is powerful but expensive. Cord blood, placenta samples and breast milk should be taken after delivery. This information is essential if we are to understand some of these environmental connections to health outcomes.

Parkinson's Disease:

Parkinson's disease advocates welcome input from the California Department of Health Services on designing an approach to tracking Parkinson's disease. With Parkinson's disease it is important to have surveillance in addition to research.

Privacy is a key issue for Parkinson's disease patients and advocates. The issues that surround the development of surveillance activities for Parkinson's disease can be seen as a model for understanding the strengths and limitations of registries and to identify the best methods of collecting tracking data that fits the health outcome of concern. Many Parkinson's disease

advocates understand that there is a difference between tracking and research and that both have a role in understanding environmental impacts on this disease.

The tracking program needs to be very strategic in their selection of pilot programs and where they are executed. We also need to connect with each other so that we can provide political help for tracking and registries in the state.

Overall:

Participants at this meeting that represent health-affected groups can be advocates for tracking and better research on these health outcomes. Advocates and patients need to tell the stories of those affected with chronic diseases so that key legislators and other decision-makers can become sensitized to these issues and in order to develop more political imperative for environmentally-related chronic diseases. The California-based Environmental Health Legislative Working group has lobby days and opportunities for tracking issues and legislation to be considered in their legislation disease matrix. Participants at this meeting were supportive of legislation to establish a state-wide office of tracking and believe it should be included in the legislation matrix. To learn more about the Environmental Health Legislative Working group and their lobby days, please contact Nick Guroff from the National Environmental Trust, nickguroff@earthlink.net .

It is important not to duplicate efforts but to draw on data that already exists and to this end it is important for advocates to support collaboration and data sharing across and within agencies.

Tracking should highlight cost issues. Policy-makers care about costs.

The next Planning Consortium meeting is Feb. 18th. If you are interested in attending, please contact Mimi Johnson.

A Discussion on Environmental Health Tracking in the Central Valley

January 24, 2005

Meeting Notes

MEETING SUMMARY

In order to learn more about the environmental health tracking needs in the Central Valley and to increase awareness of and participation in our program, the California Environmental Health Tracking Program (CEHTP) invited all interested stakeholders to an introductory meeting in Fresno. CEHTP staff presented information on the background, mission, and current activities of the program. Participants from a range of agencies and organizations provided insight into the current environmental health concerns and information needs for the region.

Key discussion themes included:

- Capacity of and access to data and tools created by CEHTP
- Importance of follow-up and action from data collection and research
- Importance of outreach to and inclusion of key impacted groups (e.g. Native Americans)
- Opportunities for CEHTP to facilitate partnerships and coordination/transparency of efforts/research
- Challenges for Tracking in the region, including politically-sensitive issues and population issues in rural areas
- Asthma as a priority concern for Tracking in the Central Valley
- Use of information to impact policy
- Inter-agency collaboration at the state level and how to work with data collection agencies

DETAILED MEETING NOTES

PRESENTATIONS

Overview of Tracking Mission and Program Goals- Eddie Oh described the gap in environmental health information and the role of Environmental Public Health Tracking (EPHT) in closing the gap. He also described the functions of a tracking system, the EPHT-related legislation and programs in CA, and the components of the California Environmental Health Tracking Program (CEHTP).

Presentation on Current CEHTP Activities- Eric Roberts described the two demonstration projects currently undertaken by CEHTP, highlighting the Central Valley/South Coast Children's Environmental Health Project and the resources under development through the two projects. These resources include remote address standardization and geocoding, community-driven information dissemination, and capacity for exchange of geography-oriented data.

Questions and answers during the presentations:

Are the smoothed maps adjusted for population density?
Yes- these are rates. Therefore if there is a dark spot, it is not because there are more people living there, but because the rate is higher. Also, these are residence addresses, not addresses of hospitals or clinics, so we are seeing where people live. Areas of the map with too few people to calculate small area rates are left blank.

Are the asthma numbers comparable to a national rate?
No, but the numbers are comparable within the sample. We can still show statistically significant differences and regional differences within the county.

Where did you get the asthma data?
Administrative records for Kaiser Permanente of Northern California and Medi-Cal (fee-for-service).

For CVSC, what kind of air pollution are you looking at?
Emissions include air toxics (from Cal/EPA) and pesticides (from the Department of Pesticide Regulation's Pesticide Use Reports). Note that emissions inventories are not measurements of pollutants in the air, so we will be using modeled concentrations of air toxics based on industrial sources.

Why industrial sources (for the example from CHAPIS)?
For this example, we only requested point (industrial) sources. Area and mobile sources are also available through CHAPIS (California Air Resources Board's Community Health Air Pollution Information System, online at http://www.arb.ca.gov/ch/chapis1/chapis1.htm).

Can you do temporal analysis- have you seen results?
We haven't had enough data (not enough years or numbers) to see temporal trends, but it is the goal of tracking in the future to compile data in a systematic and ongoing manner that would allow us to do such analyses..

Is the raw data from the CVSC project available?
Generally in Tracking, we try to learn the most useful ways to package data to maximize both confidentiality and utility. Rarely does this include "raw" data, but it depends on the circumstance.

Where are you getting your data for autism and mental retardation? Are you looking at school data?
We are using Department of Developmental Services data, which we can link to birth certificate records to obtain a geocodable address. We are no longer allowed to use Department of Education data due to FERPA (Family Educational Rights and Privacy Act), a Federal law that protects the privacy of student education records and has recently been interpreted to prevent the use of these records for public health purposes.

Are you coordinating with ARB to get closer estimates?
This is something we are interested in doing, although it may not happen through the CVSC pilot project. Right now, we are working with the Air Resources Board to help improve the functionality of CHAPIS, but it is always important to think about improving data quality. At the same time, we are not waiting for perfect data before moving forward.

QUESTION AND ANSWER/ DISCUSSION SESSION

These questions and comments serve as a reminder of the scope of the discussion following the presentations. Some of the discussion directly applied to the Central Valley South Coast pilot project, while other discussion (e.g. asthma surveillance in the Central Valley) related to the longer-term goals of the Tracking Program. Following are comments and questions grouped by general category.

Regarding regional environmental health concerns and needs/issues/concerns regarding data/ information:

- Overcrowded emergency rooms are a big problem. Fresno and Tulare have the highest ER visits in the state. Hope that project outcomes benefit everyone, not just research.
- A major issue is the politics around looking at the relationship between pesticides and health effects. There is a lack of willingness to push the envelope. The same people are always at the table.
- There will be challenges in replicating Bay Area studies here because it's a very different situation (e.g. rural, low population density).
- Software tools are useful (e.g. geocoding), but we are limited by money and resources.
- In Tulare, zip code analysis isn't that useful because zip codes are large but don't contain a lot of people. This is the challenge of low-population rural areas.
- There are concerns regarding association vs. causation
  - To some, association will indicate causation
  - Strategy- project stays engaged w/ community, provides training to community

Regarding the CVSC pilot project:

- Will there be replication of asthma surveillance from the Alameda Project in the Central Valley?
- Why wasn't asthma included in the CVSC project?
- The lack of asthma focus in the CVSC project indicates that stakeholder input was not present early on.
- Will birth outcomes from the Alameda County pilot project be replicated here?
- Why weren't Native Americans included in the birth outcomes analysis for Alameda County? Important to include in CVSC project.

Regarding the program:

- Who will be able to use the capacities that CEHTP is developing? (e.g. data exchange)

- Can CEHTP coordinate communication with the various (research) efforts here? There are so many projects happening in the region, but we often don't know about them until they're completed.
- A connection needs to be made regarding the impact of the environment on health. The government may not be the best vehicle for this.
- Is CEHTP collaborating with OSHPD (Office of Statewide Health Planning and Development)? State agencies should collaborate with each other as well as with communities.
- What are your considerations for funding (public, private)? CEHTP should be aware of who it gets money from.
- The GIS center in DHS is planning on geocoding all diseases. Are you aware of and what have you heard about this effort?

NEXT STEPS

Opportunities to participate/keep informed about CEHTP activities:

- Participation on the CEHTP statewide Planning Consortium and workgroups

  (contact Mimi Johnson at mjohnson@dhs.ca.gov or 510-622-4480)
- Participation on the CVSC Advisory Team

  (contact Michelle Wong at mwong@dhs.ca.gov or 510-622-4479)
- Quarterly newsletters
- Website: www.catracking.com
- Future funding opportunities

- ► We will include everyone on the email list for quarterly Tracking newsletter.
- ► We will email the meeting notes, a list of CVSC advisory team members, and the meeting roster to the group
- ► We will be in contact with those who are interested holding a repeat of this meeting in Kern County