

PARTNERSHIP FOR CHILDREN'S HEALTH AND THE ENVIRONMENT

MEETING NOTES

**Mt. Washington Conference Center
Baltimore, MD
April 26-27, 2004**

More than 50 members of the Partnership for Children's Health and the Environment, from 16 states and one Canadian province, gathered at Mt. Washington Conference Center in Baltimore, Maryland, for the third face-to-face meeting of the Partnership. The meeting was convened by Elise Miller, executive director of the Institute for Children's Environmental Health (ICEH), and co-facilitated by Miller and Janna Rolland, member of the Advisory Board of Directors of ICEH and former executive director of Community Toolbox for Children's Environmental Health. (*See Appendix A for a listing of acronyms and abbreviations.*)

The primary focus of this Partnership meeting was to identify policy priorities for children's environmental health (CEH) issues and determine how partner organizations might more effectively and collectively leverage these policies. Much of the discussion related to three CEH policy priorities: 1) The National Children's Study; 2) health tracking; and 3) mercury. In addition, time was spent highlighting current collaborative initiatives and discussing messaging and incubating new strategies and ideas about how to move CEH issues forward in general.

The goals for the Partnership Meeting, April 26-27, 2004:

General goals:

- 1) Evaluate where we have come as a field over the 18 months since we last met.
- 1) Find common ground and determine how we might work more effectively to complement, collaborate with, and leverage every organization's efforts.
- 1) Envision where we want to be in another three to five years as a field, specifically in terms of moving policy agendas.
- 1) Foster relationships between new participants and seasoned players in the field.

Specific policy-related goals:

- 1) Share information on new and ongoing collaborative initiatives in the children's environmental health field, particularly focused on policy, and solicit help from other partners for specific initiatives.
- 1) Determine state and national policies that seem particularly ripe for focused collaborative initiatives both in the short-term and long-term.
- 1) Identify gaps in the field and incubate new opportunities.
- 1) Discuss specific children's environmental health policies and programs with invited policymakers and other guests.
- 1) Review "Partnership Statement."

- 1) Build skills and messages to help move legislation forward and leverage all our efforts to better protect children's health.
- 1) Prepare for day in Washington, DC, meeting with Congressional and federal agency representatives.

Monday, April 26

Introductions

Because this meeting was focused particularly on policy directions for the CEH field, upon entering the room participants were asked to post their personal issue priority at the front of the room. These postings were clustered according to general themes. The purpose of the activity was to create a visual representation of the range of issues with which participants were already concerned. (*For a list of the issues that were posted, see Appendix B.*)

Miller next welcomed the group, appreciating the fresh energy of new people in the room. She commented that the Partnership meeting is an opportunity to build effective connections both with known colleagues and with new Partnership members. She outlined the goals of the gathering, including the chance to step back and reflect on each of our work, to share information on collaborative initiatives and to talk about gaps and opportunities. She noted this meeting will also focus specifically on policy issues and will be followed by a congressional briefing on Wednesday, April 28th. Senators Hillary Rodham Clinton (D), Olympia J. Snowe (R) and James M. Jeffords (I) will co-sponsor the briefing.

Rolland also welcomed the group and expressed excitement for the chance to meet all of the participants and to be re-inspired by their work.

A. Policies, Politics and Children's Environmental Health

First on the agenda were presentations by Joshua Sharfstein, MD, Minority Staff on the House Committee on Government Reform, representing the office of Representative Henry Waxman, and Damu Smith, executive director of the National Black Environmental Justice Network.

Joshua Sharfstein, MD – Uses and Misuses of Science in Policy:

Main Points:

Sharfstein began by listing some examples of the misuse of science in the federal government, including canceled or postponed conferences, rewriting of scientific reports for political reasons, and the failure to appoint the most qualified scientists to scientific advisory boards. Because of the increasing number of complaints of highly qualified scientists and the treatment of science and scientists by the current administration, Rep. Henry A. Waxman asked the minority staff of the Government Reform Committee to research the question of how scientific information is being used to inform decisions of the Administration. Last August, the minority staff released a report entitled *Politics and Science in the Bush Administration*. The report concluded that the Administration had changed procedures related to the use of science, altering the way that science is viewed and incorporated into policy as well as how scientific advisors are chosen. Sharfstein pointed out that the problem does not lie in the fact that advisors are "appointed,"

because every administration is required to make appointments. Rather, the problem lies in alteration of the process of appointment. Recommendations for science advisors have traditionally come from career scientists, such as those at the National Institutes of Health (NIH). The best advisors among those recommended would then be chosen. The process has been “flipped upside down” during the Bush Administration, and now nominations themselves also come from politicians.

Sharfstein then noted that the issue is not whether or not we agree with Bush’s policies and opinions—if any administration, Democrat or Republican, was manipulating the system in this way, we all would have a responsibility to speak out. One example he provided was regarding stem cell research: President Bush thinks that research with new lines of embryonic stem cells is not ethical based on his particular religious views and values, not scientific understanding. Whether or not this is true, Sharfstein stated it is wrong for the president to distort the number of existing stem cell lines and to give a misleading impression that this number is adequate for research. He argued that science should not be manipulated in an effort to support a religious belief. Considering the Bush Administration's statements to the public, advisory committee appointments, and treatment of scientific research, the minority staff's investigation has revealed that the process of involving science in policy making has fundamentally changed.

A discussion session followed Sharfstein’s presentation during which the question of the current policy and practical clinical impact of misuse of science was raised. Sharfstein answered that certain policy decisions may have been influenced, such as the decision by Centers for Disease Control and Prevention (CDC) not to lower standards for lead from 10 to 5 µg/dl despite very clear report of harm from a level of 5 µg/dl. He said that effects can be seen in clinical practice in the deletion of successful programs in areas such as sex education. Sharfstein also emphasized that Partnership members should feel free to contact him for help with keeping track of the progress of stalled reports or funding.

2) Damu Smith – Environmental Justice and Children’s Environmental Health Issues:

Main Points:

Smith first gave some background about the National Black Environmental Justice Network (NBEJN), a fairly new coalition of black community advocates for environmental justice (EJ) and public health. NBEJN was formed in response to right wing efforts to characterize EJ as an impediment to economic growth. The organization is largely focused on promoting safe communities, with a particular focus on the plight of black children, and works to ensure that the black community has a strong voice in public discourse on these issues. “Being noisy” is key if we are to move our work forward, he noted.

Smith asked meeting participants to consider why it is not acceptable to many in power to say publicly that black children are suffering the most from lead poisoning throughout the country. Black kids are also those with the highest incidence of asthma. In addition, Smith reminded the audience that communities of color and low-income communities are disproportionately located next to power plants and other polluting industry facilities. He emphasized how critical it is to recognize which populations are being more severely impacted and also how critical it is for the rest of the environmental health community to call attention to the issue alongside the minorities who are already speaking up.

Smith spoke about a cutting-edge use of the Civil Rights Act that may provide for increased protection of minority and low-income communities. He suggested the Environmental Protection Agency's (EPA's) current proposal on mercury which includes a "cap and trade" regulation is a violation of the Civil Rights Act: The impact of mercury emissions "credits" is that people living next to remaining plants are going to remain far more exposed to mercury. Section 2000d of Title VI of the Civil Rights Act states that: "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." There is ample evidence that dangerous plants are sited near communities of color at much higher rates than other communities, and the argument is being made that because permitting authorities receive federal funding to execute their work, this is a violation of Title VI of the Civil Rights Act.

Smith spoke about a recent attempt to use the Title VI argument to help an affected community, but the EPA ruled in favor of industry. The current thinking is that a community must be able to prove that specific health effects are directly linked to the presence of industry. Smith noted this is difficult, if not impossible, to do in many cases, and given this, government needs to shift to a policy of prevention. In further discussion, Smith and others at the meeting agreed that certain communities should be identified as "overburdened," and permits for placement of further sites nearby should not be considered.

He also expressed great interest in collaboration between NBEJN and the groups represented at the Partnership meeting. Along these lines, he mentioned that NBEJN is organizing five regional meetings with multi-stakeholders and hope that Partners would participate.

B. Partnership Policy Priorities: Overviews of Specific Concerns

After a short break, the group reconvened to hear presentations on three CEH policy priorities: 1) The National Children's Study; 2) health tracking; and 3) mercury. Before introducing the speakers, Miller mentioned the Partnership Statement developed on these issue specifically for this meeting (*See Appendix C.*)

1) Marion Balsam, MD, FAAP, Research Partnerships Program Director – National Children's Study

Main Points:

Balsam gave an overview of the National Children's Study (NCS) including its structure, research focus areas and funding concerns. She explained that the Children's Health Act of 2000 directed the National Institute of Child Health and Human Development (NICHD) to take the lead in developing a national, longitudinal study following 100,000 children from before birth to age 21. The study design will be representative of geographical, socioeconomic, racial and ethnic diversity. NICHD will be aided in this endeavor by EPA, the CDC and NIEHS. The purpose of the study is to compile extensive and comprehensive data about both short-term and long-term effects of factors affecting child health and development, including biological, physical, chemical and sociocultural aspects of a child's environment. She explained that the study plan is being developed by the Interagency Coordinating Committee of scientists from the four key

agencies as well as the NCS Program Office staff. There is also a Federal Advisory Committee of experts from around the country from academic, industry, nonprofit and research roles, as well as many working groups and a Study Assembly of more than 3000 individuals, including representatives of various interested organizations as well as parents.

Balsam gave a picture of the timeline. Funding needs will increase in 2005 when the serious implementation begins, including establishment of initial study sites. \$147 million is needed in 2006, when recruitment begins along with full implementation, in order to achieve the current timeline. The full 27 years of this study will cost a total of \$2.7 billion, but that will be offset by the expected health care cost savings generated by the NCS data leading to prevention of harmful environmental exposures. One of the challenges of the study will be to recruit 100,000 people and retain them for 21 years. Balsam emphasized that early results regarding exposures of pregnant women and early life exposures will be available in 2009.

Once the core study is funded, there will be opportunity for public-private partnerships to sponsor adjunct studies and other aspects of the study. These projects could use the infrastructure provided by the study, focusing on specific issues of interest to a particular group. In the time leading to the start of the study there are many additional workshops and pilot projects underway. Currently the study planning group is refining hypotheses as well as developing measures for exposures and outcomes..

In response to a question about whether funds for this study would displace other funding needed for children's environmental health research, which is already insufficient, Balsam responded that she thought the NCS would actually increase interest in additional funding for research on CEH issues by providing data which raises additional questions about environmental health.

2) Lois Banks, DMin, Director, State and Community Relations, Trust for America's Health; and Anna Dillingham, Community Health Associate, Trust for America's Health – Health Tracking Main Points:

Banks began by introducing the concept of nationwide health tracking. She shared the conclusion of the CDC that most chronic diseases could be prevented if a health-tracking network was well established in the United States. According to Banks, an effective health-tracking system would have five tiers:

- a) National baseline tracking of diseases and exposures, including asthma, chronic respiratory disease, cancers, neurological diseases, birth defects, and developmental disabilities. In addition, persistent organic pollutants, heavy metals, pesticides, air contaminants, and drinking water contaminants (including pathogens) will be examined.
- b) National early warning system.
- c) State pilot tracking systems.
- d) Public health investigative response – federal, state, and local rapid-response capability to investigate outbreaks.
- e) Support of community interests and scientific research to further health-tracking efforts

Dillingham spoke about the fiscal situation and current events in health-tracking work. She said that the momentum toward establishment of a national health-tracking system has been substantial during the past four years. The idea has grown and received federal financial backing.

In fiscal year 2002, Congress appropriated \$17.5 million to the CDC for this initiative, and from there the money was distributed to three state health departments, 17 states, and three universities. The universities where health tracking Centers of Excellence have been started are Tulane; University of California, Berkeley; and Johns Hopkins. The 2003 fiscal year saw an appropriation of \$28 million. Some states were re-funded, and four additional states were given money. With this money, local health departments are charged to focus on planning and building capacity or enhancement and demonstration projects. She mentioned California and Maine as two good examples of states that are developing model tracking systems and working to incorporate the voice of a wide range of stakeholders, including community members. Dillingham emphasized that health tracking is in its infancy, and that despite early progress, Congress must be continually urged to support the establishment of health tracking. \$100 million is needed in 2005 for health tracking, along with \$200 million to enhance infrastructure, \$10 million of which would be designated specifically for biomonitoring. The current pilot projects also need input from community and state groups, telling them which data would be most useful to track.

3) Kelly Heekin, Communications Coordinator, Health Care Without Harm – Mercury

Main Points:

Heekin started her presentation with a personal reflection on her recent experience at the March for Women's Lives which took place on April 25th at the Capitol in Washington, DC. She noted that much of the reason for the March's success was the accessible, personal message regarding choice, reproductive rights and human rights that resonates deeply with many women and men. She then made the connection between those fundamental values and her work eliminating toxic chemicals from the health care system. She noted that mercury is a great example of a contaminant that is threatening human rights. Heekin went on to list the known health effects of mercury, as well as the startling finding of the CDC that nearly 1 in 10 women already may carry enough mercury in their blood to endanger their children in utero. Heekin then presented some history, facts and figures related to mercury. She mentioned that waste incineration is one of the largest sources of mercury contamination in the environment, including incineration of health care products containing mercury. Some important legislation has been passed in an effort to control mercury emissions. In 1990, the Clean Air Act was amended to require all mercury-fired power plants to reduce output of mercury 90% by 2008. The Bush Administration has altered this ruling to require only 70% reduction of mercury emissions by 2018, and has also established that reductions will be made via a "cap and trade" strategy that leaves individual communities—often low-income and communities of color—highly contaminated. In conclusion, Heekin spoke very positively about the success achieved by Health Care Without Harm (HCWH). Because of the efforts of HCWH, many national pharmacies have stopped selling mercury thermometers. In addition, more than 50 hospitals have gone completely mercury-free and 2500 have pledged to do so by 2005. Only 115 medical waste incinerators are still in operation, and HCWH is working hard to shut down those that remain active.

Discussion

During group discussion, the most heavily debated topic was that of the connection between the National Children's Study (NCS) and health tracking. Concerns were raised about whether or not these two initiatives might compete for the same funding and undermine one another. Further,

concern was raised about the NCS being so broad and far-reaching that further research at other research and academic centers would then be erroneously deemed unnecessary. The notion that no more research is necessary could be perpetuated by constituencies interested in limiting data as a way of weakening the results of the studies.

Other concerns and questions included:

- Who will have access to data collected in the NCS? One answer is that there is a delicate balance of limiting access enough so that parents will feel that their child has sufficient privacy while still making the general findings useful and accessible to everyone who may be concerned about these issues.
- How can we better frame CEH issues so that messages can speak to people in a personal way? Through the discussion, the importance of connecting childhood exposure to adult illness was developed as a way that CEH issues might have more personal impact. Another suggested idea was framing these issues as “violence against children” to connect with broader concerns of abuse in society.
- How can we find the correct balance of short-term and long-term goals and priorities when developing next strategies? Several participants suggested the need for a specific strategy for both long-term and short-term considering the practical long-term application of whatever strategy is chosen.

C. New Children’s Environmental Health Caucus

George Lambert, MD, with the Center for Childhood Neurotoxicology and Exposure Assessment, Environmental and Occupational Health Sciences Institute, was invited to speak about the development of a Children’s Environmental Health Caucus.

Main Points:

Lambert began with a history of how the idea for a Children’s Environmental Health (CEH) Caucus came about. The objectives of the caucus will be to provide Congress with the best scientific information about CEH, to discuss sources of health risks and feasibility/costs of minimizing those risks, and to provide a forum to discuss current research and determine where more knowledge is needed. The inspiration came after a congressional briefing during which congressional staff expressed their interest in having an ongoing and unbiased source of information on CEH issues. Lambert then described the nascent CEH Caucus. It is currently cosponsored by three lawmakers from New Jersey, Lambert’s home state. In the Senate, Senator Jon S. Corzine (D) serves as the point person, and in the House, Representatives Jim Saxton (R) and Rush Holt (D) share the responsibility. The organizers are working to recruit up to 200 total participants. Some important issues coming up in the near future include perchlorate and Polybrominated Diphenyl Ethers (PBDEs). Some academic institutions and nonprofits alike have already agreed to participate in the caucus, including the American Academy of Pediatrics, Pediatric Environmental Health Specialty Units (PESHUs), the March of Dimes, American Public Health Association, and several NIH Children’s Centers. Lambert said that these groups were chosen because they are respected on the Hill.

Lambert was asked to clarify how scientific information would be prioritized for inclusion in briefings, and he shared that those involved in the caucus will gather information from their constituencies and design the caucus agenda. Following Lambert’s presentation there was some

discussion among the group about who would be included in planning. The question of involvement of industry representatives, such as the American Chemistry Council (ACC), was raised. Some felt that it was important to have them at the table if the CEH Caucus was to be taken seriously by “both sides of the aisle.” Others were concerned about the way that the ACC would present and potentially misrepresent information. Lambert emphasized that the CEH Caucus needed to be nonpartisan and science-based in order to be effective. He also welcomed all organizations interested in engaging with the caucus to contact him.

Tuesday, April 27

Miller opened the morning session by reflecting on the goals and results from the previous Partnership meeting. Miller first reminded the group of the most important gaps/opportunities in the CEH field that were highlighted in the Fall 2002:

- 1) Gap: lack of mainstream familiarity with CEH issues – Opportunity: unify a message and embed concepts;
- 1) Gap: dismal labeling of toxic chemicals in products – Opportunity: more right-to-know initiatives;
- 1) Gap: lack of positive ways of working with industry – Opportunity: engage them more effectively;
- 1) Gap: unwillingness of policy makers to implement the precautionary principle – Opportunity: use positive examples of its use to encourage further use.

She then noted the three priorities that participants in the 2002 meeting developed based on these gaps and opportunities: 1) environmental health literacy for policy makers, health professionals, teachers, teens and the general public; 2) incorporation of the precautionary principle into policy making; and 3) incorporation of environmental health into curricula and practice of health professionals.

The primary collective goal that came out of the meeting was to develop a long-term outreach and media campaign. Though Partners had several calls on this initiative, including a couple with a funder interested in this kind of campaign, this was ultimately not achieved due to several factors including the outbreak of the war in Iraq and the decision to focus energy and funding more specifically on the 2004 election.

Miller commented that though we have made some progress since 2002, we are still dealing with the priorities and concerns we articulated previously and will need to consider these in more depth later in the meeting.

Discussion about these past goals and priorities ensued. One participant urged everyone to keep those past goals in mind during brainstorming sessions at this meeting in order to build on previous work. Another mentioned that the CEH Caucus will be an effective tool if we make a point of helping it be successful. Finally, another participant commented that despite the lack of fruition of the media campaign, it is important to remember how much benefit we all receive in our individual and collective work by attending Partnership meetings and gaining new ideas and opportunities for collaboration. In this light, the Partnership continues to be of great value. Miller

reminded the group that part of the reason a messaging workshop was scheduled for this meeting was to help the CEH field in this area.

A. Collaborative Initiatives

Eight short presentations about collaborative initiatives were given, during which each presenter discussed the purpose and current activities of his/her organization's project. All also clearly stated what help each might need from other members of the Partnership to enhance their respective initiatives.

The speakers and their topics (in alphabetical order by organization) were:

- 1) Center for Health, Environment and Justice – Patrick Masterson (Childproofing our Communities Campaign)
- 1) Children's Health Environmental Coalition – Elizabeth Sword (First Strides Initiative on protecting children's environmental health in out-of-home licensed day care)
- 1) Clear the Air – Angela Ledford (campaign on mercury issues)
- 1) Healthy Schools Network – Claire Barnett (Coalition for Healthier Schools initiative)
- 1) Institute for Children's Environmental Health – Elise Miller (Learning and Developmental Disabilities Initiative)
- 1) Local Environmental Action Demanded (LEAD) – Rebecca Jim (Community initiative regarding a Superfund site)
- 1) Safe Tables Our Priority (STOP) – Karen Taylor Mitchell (Initiative on preventing disease from contaminants in food)
- 1) Women's Voices for the Earth – Bryony Schwan (Coming Clean campaign)

(See Appendix D for a brief summary of these presentations on collaborative initiatives.) (See Appendix E for a listing of additional collaborative initiatives and opportunities subsequently announced by meeting participants.)

B. Small Group Reports – Incubation of New Ideas

During the afternoon, participants gathered in five small groups to discuss current gaps in the CEH field and opportunities presented by those gaps. Three of the five groups were assigned specific conversation topics, reflecting the most important themes in discussion up to this point of the meeting. They were 1) literacy; 2) short-term versus long-term initiatives and goals; and 3) NCS and health tracking. The final two groups were open forums. Each group was asked to:

- Identify two to three gaps/opportunities
- Identify two to three steps to address above
- Embed environmental justice into all proposed opportunities
- Incorporate long-term and short-term strategies and at least consider the other if you choose to focus on one.
- Include ideas about how to build the field and the growing movement, including increasing CEH literacy and developing relationships with constituencies not currently engaged.

(For a summary of group reports, see Appendix F.)

C. Messaging Workshop – led by Amy Kostant, Environmental Media Services

After giving a brief overview of her work at Environmental Media Services, Kostant began by speaking about the confused messaging that has plagued the environmental health field. She used the example of the precautionary principle. She argued that public opinion research tells us that the public, as well as many reporters, say they do not know what the term “precautionary principle” means, but they agree with the concept. Kostant believes this disconnect is due in large part to counter-messaging by industry and general discomfort in talking about uncertainty in science.

Kostant then spoke about effective messaging techniques that the environmental health field can better harness in the future. She outlined the situation as follows: Environmental health advocates have evidence about the links between environment and health but because science is inherently based on hypotheses and not “proof,” the bottom line is that industry scientists are always going to be able to introduce doubt about the links in order to prolong research or stop appropriate action from being taken. The challenge, she suggested, is to narrow the information down to key messages that will communicate with and persuade the public to pay attention. Tell them what we know; tell them what we don’t know; tell them why we already know enough to take preventive action. Important elements of effective messaging:

- Standardize the message throughout the field because the average person must hear the same message six times from six different sources in a relatively short period of time before he/she will remember the content
- Keep those standard messages simple. It would be ideal, she said, to find no more than two umbrella themes that work universally throughout the field, for diverse audiences and organizational foci. Then, once any organization has opened a conversation with the standard message and caught the attention/recognition of the audience, more specific information can be presented more effectively.
- Wording of the message should be designed to appeal first to emotions in order to grab attention, and, second, to appeal on an intellectual level.
- Helpful questions to consider when brainstorming messages include what are solutions, what are obstacles to solutions, and how would things be different if they did what we said?

Kostant then noted that she had worked with Elise Miller, Susan West Marmagas, Aimee Boulanger and Kelly Rain to begin to develop messages based on the "Guiding Principles" drafted by the Partnership in 1999 as a starting point. These were handed out. She next instructed meeting participants to break up into small groups and come up with at least a couple of examples of a message that could serve as maybe three or four primary messages for the entire field of children’s environmental health. She also suggested that people refer to the spread of policy priorities that had been posted upon entrance to the room on the first day (*See Appendix B*), in addition to short-term versus long-term strategies and incorporating environmental justice.

(For a list of “messages” suggested by the groups, as well as discussion about the topic and a synthesis of messages following the Partnership meeting, see Appendix G.)

Wrap-up

The meeting concluded with a discussion about whether the Partnership has fulfilled its purpose or whether it continues to serve the field. The clear and unanimous response of the meeting participants was that the Partnership remains very useful. The general agreement was that Partnership meetings provide valuable and timely information and time to reflect on the larger picture of our collective work. Participants also noted that the Partnership provides a forum for collaboration between newly forming and/or small organizations and larger, nationally-established groups that would not necessarily come together otherwise, and it is critical to have this opportunity.

Feedback to help with planning the next meeting included:

- Consider the voice of participants in planning the schedule of the meeting.
- Ask participants to be in charge of recruiting new organizations and members. (In this context, the question of whether we want this to grow significantly was raised—if we double the numbers, it will change the dynamic of the conversation and become more “conference” like rather than “retreat” like, and we need to consider the implications of that.)
- Consider not starting things that we won’t have time to discuss sufficiently.
- Attract stronger ethnic, geographical, racial diversity.
- Have more time to reflect on the ideas and decisions that emerged from the last meeting and build on those.
- Try to meet in an environmentally healthy facility – for example, one that uses less plastic.
- Have more wilderness access (although it was noted that at the last meeting we meet in a more urban area to attract more people of color and make it more accessible to airports and train stations).
- Consider whether the Partnership might come under the umbrella of the Collaborative on Health and the Environment rather than remaining a separate entity, given the overlapping interests, values and mission.

(See Appendix H for Upcoming Events and Key Resources.)

Appendix A: Abbreviations and Acronyms

ACC	American Chemistry Council
CDC	Centers for Disease Control and Prevention
CEH	children's environmental health
CEHN	Children's Environmental Health Network
CHE	Collaborative on Health and the Environment
CHEC	Children's Health Environmental Coalition
EJ	Environmental Justice
EPA	Environmental Protection Agency
HCWH	Health Care Without Harm
HHPS	Healthy and High-Performance School
HSN	Healthy Schools Network
ICEH	Institute for Children's Environmental Health
LD	learning disability
LDD	learning and developmental disorders
LDDI	Learning and Developmental Disabilities Initiative
LEAD	Local Environmental Action Demanded
NAS	National Academy of Sciences
NBEJN	National Black Environmental Justice Network
NCS	National Children's Study
NICHD	National Institute of Child Health and Human Development
NIEHS	National Institute of Environmental Health Sciences
NIH	National Institutes of Health
PBDE	polybrominated diphenyl ethers
PESHU	Pediatric Environmental Health Specialty Units
REACH	Registration, Evaluation and Authorisation of CHemicals
STOP	Safe Tables Our Priority

Appendix B: Priority Issues posted by participants upon arriving at the meeting

The three main categories of policy priorities could be roughly grouped as concerns about: 1) toxics issues; 2) community capacity; and 3) system-wide approaches/policy ideas.

1) Toxics issues

- Reduce mercury contamination and emissions.
- Eliminate contamination of our food sources.
- Raise awareness of daily toxic exposures and minimize those exposures in schools, day cares and homes (e.g., lead in paint, mercury in food, pesticides, PBDE's cleaning chemicals, etc).
- Prevent chronic disease through reducing exposures.
- Determine safe levels of toxic exposures for kids of different ages.
- Stop the sale of toxic waste for unregulated "safe" purposes.

2) Community capacity

- Build and sustain the local infrastructures to advance and support CEH.
- Strengthen community-based organizations and connect them with larger state and national organizations.
- Develop community capacity to address local issues.

3) System-wide approaches/policy ideas

- Change the way government and private corporations currently use risk assessment and instead have regulations based on preventing harm (precautionary principle).
- Support government policies for children that are "pro-life" after birth.
- Ensure systems protect children with appropriate ways to prevent, track and intervene where necessary.
- Find alternative natural treatments for cancer.
- Change policies that discount people as they grow older and those that discount the future for children.
- Prevent chronic disease through health tracking.

Appendix C: Partnership Statement

Guiding Principles for Children's Environmental Health

The American Academy of Pediatrics and the National Academy of Sciences have found that children are uniquely susceptible to hazardous environmental exposures. In addition, they have determined that many of these exposures—exposures that may occur before conception and continue through late adolescence—can cause or contribute to disease and disrupt development, learning and behavior. Based on these scientific findings, the Partnership for Children's Health and the Environment unanimously supports the following Principles:

- All children have the right to clean air, safe food and drinking water, and consumer and commercial products free of environmental health and safety threats;
- All children have the right to healthy homes, healthy child care facilities, healthy schools and healthy communities;
- All children and adults have the right to know about proven and potential hazards to their environmental health and safety.
- It is our mutual responsibility to protect these rights and to act with precaution when making decisions that could affect children's health and development.

- Adopted December 1999

New Partnership Statement April 2004

Based on these Guiding Principles, the Partnership for Children's Health and the Environment asserts its support for three children's environmental health priorities: 1) implementing the National Children's Study; 2) developing a strong national health-tracking system; and 3) reducing mercury emissions.

1) Implementing the National Children's Study (NCS)

- Rates of asthma, learning and developmental disabilities, certain birth defects and childhood cancers are on the rise, and based on emerging scientific studies, environmental factors likely play a key role.
- The NCS would provide essential data identifying toxins and other environmental exposures that need to be removed from our environment to ensure children reach their full potential.
- Studying 100,000 children from fetal development to age 21 will significantly increase understanding of how the environment can affect health just as the longitudinal Framingham Heart Disease Study augmented our understanding of how to more effectively address heart disease.
- NCS would help save not only lives and the quality of life for thousands, it would help save money. For example, when lead was removed from gasoline and paint, billions of dollars were saved in terms of health care costs and lost income, according to the Centers for Disease Control. By removing other environmental toxins, we could experience significant cost savings as a society.

- We need \$27 million to \$50 million next year to ramp up the NCS, in addition to the \$12 million already allocated. These funds would in part need to be used to hire a laboratory large enough to store more than two billion anticipated biological and environmental samples—from participants' blood and DNA to dust from their houses, soil from their yards and air from their neighborhoods.

2) Improving Health Tracking

- Seven of ten deaths in the United States are attributable to chronic illnesses, many of which may be preventable, but there exists no coordinated, standardized, national system to track where and when they occur.
- Although some health tracking does occur at the state level, standards vary widely. Some states may have effective monitoring systems in place for certain illnesses, while other diseases may not be tracked at all. Without comprehensive health tracking, public health officials are missing important information that would aid them in improving the public health system and the overall health of the American population.
- Congress appropriated \$17.5 million in FY 2002 and \$28 million in FY 2003 to support a Nationwide Health Tracking Network in pilot states and cities, overseen by the CDC. While this is a step in the right direction, the cost of an integrated, comprehensive Nationwide Health Tracking Network is estimated to cost \$275 million a year. We recommend Congress provide the mandate, resources and support to establish a centralized disease tracking center within CDC for nationwide health tracking. This would include tracking animal-diseases, chronic diseases, such as cancer, asthma, events related to bioterrorism, and environmental risks.
- In addition, the federal budget must include \$200 million to enhance federal and state public health laboratories capabilities, including upgrading facilities and equipment and bolstering the workforce over the period of three years. This funding is essential if these laboratories are to conduct clinical testing for potential dangerous chemicals, such as ricin, cyanide, nerve agents and pesticides. After this period, laboratories should be sustained at a level of approximately \$100 million per year for rebuilding.
- To ensure an effective public health system we must include: More well-trained public health professionals; investment in a state-of-the-art early warning and communications network; tracking of diseases and monitoring of environmental exposures; and better equipped laboratories.

3) Reducing Mercury Emissions

- Mercury is a potent neurotoxicant and can affect the developing nervous system and brain. Eight percent of women have unsafe levels of mercury in their bodies, now placing over 600,000 babies born at risk each year. Mercury contamination in the food chain has steadily increased through recent decades. Between 1993 and 2002, advisories for mercury increased by 138%. 85% of total mercury released into the environment comes from coal burning power plants and municipal and hospital incineration of waste-containing mercury, contaminating the food chain.
- The Environmental Protection Agency in 2001 admitted using a so-called Maximum Achievable Control Technology (MACT) standard to enforce the Clean Air Act could cut

power plant mercury pollution by nearly 90% (from 48 tons per year today to about 5 tons by 2008).

- The EPA's current proposal to reduce mercury emissions by just 29% by 2010 and just 69% by 2018, resulting in needless and preventable mercury exposure for our next generation of children.
- The EPA's current proposal to subject mercury to a "cap and trade" system of controls is also contrary to well-documented science and public health principles. Because mercury is a potent and persistent toxin, local accumulation of mercury constitutes a significant health threat. The flexibility of a cap and trade system allows single facilities to purchase the right to continue or even increase mercury pollution, leading to greater contamination of surrounding areas.
- We recommend that Congress enforce the Clean Air Act as originally conceived in order to protect our children from mercury exposures.
- We also recommend the creation of indoor standards for mercury that would include: source reduction and elimination; required reporting of spills and testing; remediation post spills; and health testing of those exposed.

Appendix D: Organizational Presentations on Current Collaborative Initiatives

1) Claire Barnett, Healthy Schools Network (HSN) – Coalition for Healthier Schools

Barnett began with a timeline of the development of the Coalition for Healthier Schools:

1995-1997 – federal executive order, state activities, EPA initiates its IAQ-Tools for Schools Program outreach to states and schools

2000 – \$1.2 billion federal funding for school renovation grants

2001 – Healthy High-Performance School (HHPS) study and state initiatives

2002 – U.S. Senate hearing, EPA convenes schools work group to recommend improvements to EPA's programs and effectiveness

2003 – National Coalition for Healthier Schools meets in DC in January, reaffirms its mission and project goals, including developing a “platform” for school environmental health. In October, National Coalition “Summit” meeting in DC of state-based healthy schools groups, keynoted by Senator Clinton. National Healthy Schools Training Binder available.

2004 – Coalition releases its platform as “Position Statement 2004,” which can be found at <http://www.healthyschoolscampaign.org/action/pos-statement-apr2004.htm> to be used by federal officials

The coalition is trying to gain support and funding for the Healthy High-Performance School Act at the federal level. Barnett noted that many promises related to healthy schools have not been fulfilled. A study on healthy and high performance schools requested by Congress has not yet been completed. Federal funding for urgent repairs has not been renewed. The School Environmental Protection Act has not been enacted. Many organizations in this room have been involved in pressing to address these concerns.

Current Activities: Emphasis is being placed on short-term strategies leading up to the election, including strategies for individual states and developing effective back-to-school action in the fall. The Coalition is working with Environmental Media Services on media efforts, as well as the League of Conservation Voters, which has signed onto the Coalition's position statement. There are two main issue areas for healthy schools groups that have branched out in the states: 1) How do you “green up” new and existing school buildings in terms of siting, design, construction and maintenance practices; and 2) What are systems for protecting children? Barnett noted that we need a systems approach: There are no systems in place in schools that are actually protective of children.

2) Rebecca Jim – Local Environmental Action Demanded (LEAD) - Tar Creek Superfund site

Jim explained that LEAD is an organization founded to address concerns related to the first and largest Superfund site in the United States at Tar Creek, Oklahoma. Tar Creek is a huge mining area of lead and zinc. The site includes six towns and spans three states and several EPA regions, but Jim noted these entities are not generating real, permanent progress.

Jim was a high school counselor and became involved with environmental health concerns in Tar Creek because of the high incidence of learning disabilities that she observed among her students. LEAD is now working hard to educate the community and policy makers about ubiquitous contamination from mining waste containing lead. The tailings are under houses, tracked into houses, used in local sandboxes and are also sold around the country as sand and

gravel. With help from Harvard School of Public Health, they began to test lead levels in individuals in the six communities. Together they have developed a periodic table showing what is in the sand and are looking at the effects of multiple levels of exposure. Jim noted the “findings suggest we are very sick.”

Jim explained that LEAD has come to realize that only an act of Congress will likely lead to real change because there is not enough money in Superfund. Oklahoma Senator James F. Inhofe (R) is one of the key players in oversight and has developed a plan for the site that does not include buy-out and relocation of two of the towns that are most at-risk for exposure and cave-in. However, Oklahoma Governor Brad Henry has legislation allowing families with children under six to be moved out on a voluntary basis. There may be other organizations that would be willing to "adopt" other families with older children and even the elderly to help them with relocation. There is also a possibility of a disaster relief fund through the churches, but none of these options are clear-cut nor guaranteed. Jim closed by saying that Tar Creek is a major example of the problems that abandoned, contaminated communities are facing across the United States.

3) Angela Ledford – Clear the Air – Mercury Campaign

Clear The Air’s Mercury Campaign is dedicated to coordinating groups based in Washington, DC, around mercury issues and providing assistance to grassroots and national campaigns. To this end, Ledford gave an overview of activities and strategies that are employed by Clear the Air.

- a) Shift the way the mercury issue is framed from simply an environment/energy issue to the realm of health. The issue has to be about pregnant mothers and children so that people understand that they are being affected;
- b) Educate people better about the mechanisms by which mercury is released into the environment.

One way Clear The Air is working toward raising this issue to a higher profile by organizing a “stroller brigade” rally in Washington, DC, on May 6th, which is just before Mother’s Day. In addition, Clear The Air has been supporting the circulation of a “Dear Colleague” letter in the House of Representatives saying that the current mercury ruling is not adequate. Forty-five senators already sent a letter to EPA along the same lines. Something that Partnership members can do is to arrange formal meetings with the EPA and the Council on Environmental Quality at the White House to talk about our concerns. Ledford also mentioned that EPA Administrator Mike Leavitt has been more receptive to regional and local groups. This means that smaller, regional groups may be more effective than purely national groups, and we can all continue to work locally by writing opinion articles, letters to the editor and by talking with local, state and national policy makers.

4) Patrick Masterson – Center for Health Environment and Justice (CHEJ) – The Green Flag Program, part of the Childproofing our Communities Campaign

Masterson began with an overview of the Green Flag Program, one of CHEJ’s new projects. The program is designed to create environmental progress in schools through involvement of multiple tiers of teachers, students, and maintenance personnel. The program is designed to complement preexisting curricula and activities within the school and to support and enhance those activities with the knowledge that time and money resources are already overextended in most schools.

Schools join by completing a baseline survey, forming a group and picking one of four areas to work on. These areas are: a) recycling; b) non-toxic products; c) indoor air quality; and d) integrated pest management (IPM). Depending on the chosen focus area, a more in-depth survey is completed and experts in that area are brought in to talk with people at the school. A policy is developed for the school or for the school district if interested, and steps are outlined to achieve policy implementation. Once the policy is successfully implemented, the school receives an environmental leadership award. In the beginning, each school is given a “Green Flag” to hang in their hallway, and the environmental leadership award is added to the Green Flag in one of the four project areas. Throughout the process of designing and implementing a new environmental policy for the school, groups are involved in research and outreach to the community. Ways that other Partnership members could help in this effort include:

- Trying to get the program into schools. Interested school can access information from CHEJ’s web site or call staff directly; and
- CHEJ is looking for mentors that can bring the program down to a local/regional level. Mentors are people who want to help bring the Green Flag program to schools, to assist students, to ultimately give the award, to be that local connection for that particular school.

(Note: The new Coordinator for the Childproofing Our Communities and Green Flag program is Stacey Gonzlez. Questions should be directed to her at 703-237-2249 ext. 21 and not to Patrick.)

5) Elise Miller – Institute for Children’s Environmental Health – LDDI

Miller began by describing the formation of the Learning and Developmental Disabilities Initiative (LDDI) two years ago after the first meeting of the Collaborative for Health and the Environment (CHE) in response to concerns about rising rates of learning and developmental disorders (LDDs). LDDI brings together health-affected people along with researchers, health care providers and child advocates in an effort to leverage better public health policies that will reduce exposures to neurotoxicants. Work is still being done to identify and engage more groups interested in working on these issues. Collaborative programs are beginning to emerge, particularly with the Learning Disabilities Association, the American Association on Mental Retardation and The Arc of the United States. Other functions of LDDI include translating emerging science on neurotoxicants for lay audiences; analyzing information on neurotoxicants in the CDC biomonitoring reports; developing “Practice Prevention” columns to highlight what people can do at home to protect themselves and their families from exposures; supporting groups interested in pressing for stronger policies to reduce and eliminate neurotoxicants at the state and national levels; and disseminating pertinent articles, reports and other information. Miller asked interested organizations to sign onto the LDDI resolution. She noted it is important for key environmental health allies as well as LDD groups to be engaged in this initiative. Partnership members can also help by suggesting other groups, both locally and nationally, and sharing any information about neurotoxicants. Help in drafting letters to the editor on local, state and national levels would also be appreciated. The first major national meeting of LDDI will held on May 19th at the National Institutes of Health, and Miller invited all Partnership meeting participants to attend. The primary goal of the LDDI meeting will be to educate state and national LDD groups and other interested organizations about the current state of science.

6) Karen Taylor Mitchell – Safe Tables our Priority (STOP)

Mitchell came to this conference to share information about environmental contaminants in our food, including food-borne diseases. She said she was especially grateful; it has been challenging for her to find forums where she can present on these issues because it doesn't fall into what is traditionally considered "environmental health." She then described the breadth of the problem, which affects 76 million people each year, and the seriousness of the issue, mentioning that 325,000 hospitalizations result from food poisoning every year. Kids are particularly vulnerable to severe reactions. Many die, and long-term effects from food-related illnesses are common. Although food contaminants have not traditionally been thought of as "pollutants," the issue is fraught with the same challenges faced by the rest of the environmental health field, such as trade secrets and lack of access for consumers to get voices out there. Health departments may know where contaminated food went, but because of regulations they are not allowed to make that information public. Mitchell asked for help from Partnership members to get food safety and food safety policy on the environmental health agenda. Like other environmental health issues, much of the burden of this problem is being placed on the shoulders of parents and other individuals who feel responsible when their child gets sick or dies. In reality, the problem comes from the way the food industry is regulated and ineffectively monitored. Policy changes need to be made. Right now, 12 agencies oversee food. Mitchell noted that none has full responsibility for keeping food safe, and we need one agency overseeing safety.

7) Bryony Schwan – Women's Voices for the Earth – Coming Clean Campaign

The Coming Clean Campaign was formed to work on the chemical industry and is made up of 60 groups and five main projects. Focus areas include:

- Health and Beauty Products Campaign – Legislation has been passed in California and a consumer and corporate campaign has been initiated.
- Ad campaign – Ads have already been placed in a variety of media outlets.
- Dow Chemical Campaign – People from Bhopal, India, are also involved in this campaign which focuses on sites contaminated by toxic chemical emissions around the United States and the world.
- Biomonitoring/body burden working group – This group focuses on breast milk contamination and how to talk about that difficult issue with the public. A handbook will be produced on how you effectively utilize biomonitoring information on a local level to move issues forward. Soon the biomonitoring web site will be translated into Spanish. See <http://www.chemicalbodyburden.org>.
- Fenceline working group – Communities include Mossville, LA, Port Arthur, TX and Louisville, KY. Coming Clean offers technical and media assistance and also helps by writing letters of support for community initiatives. The hope is that current communities will win their fights and Coming Clean can then work with more affected communities.
- PVC working group – This group focuses on the entire lifecycle of PVC, from production to use and disposal. The goals are to eliminate incinerators and to get PVC out of the recycling stream. Coming Clean will soon produce a PVC toolkit.
- Policy working group – This year the policy group is focusing on toxins in dust, as well as other policy issues moving forward in the United States and internationally. These include PBDE legislation in several states as well as Registration, Evaluation and Authorisation of CHemicals (REACH) policy in the European Union.

8) Elizabeth Sword – Children’s Health Environmental Coalition (CHEC) – First Strides Initiative

Sword described the First Strides Initiative, noting it is focused on ensuring that day-care environments are safe for children. She explained that although there are 116,000 day-care centers in the United States, there are few policies that protect the children, as well as the day-care providers, from toxic exposures. Prior to starting kindergarten, children from dual-working households can spend up to 12 hours a day, five to six days per week in day care. The First Strides Initiative grew out of conversations with Claire Barnett of Healthy Schools Network about how to bridge the gap in protection between the home and kindergarten. Following from a Children's Environmental Health Network (CEHN) report that looked at two day-care centers in California, CHEC intends to study six to eight day-care centers throughout the United States, focusing on best practices, state regulations and common chemicals used in day-care facilities. We will also put together an advisory board. Ultimately, we will come up with a set of fact sheets to empower parents who leave kids in day care to ensure that their child is spending time in a healthy environment. Unfortunately, the initiative is still searching for funding. Once we get funding for the program, Partnership members can help tremendously by sharing information about day-care centers you know and “best practices” from your own experience.

Appendix E: Additional Collaborative Initiatives and Opportunities

Local/State:

- Initiate State Healthy Schools groups to push CEH in public agencies (including Departments of Health). Contact Claire Barnett at healthyschools@aol.com.
- Educate the Educators, such as National Association State Board of Education, National School Boards Association, Association of School Business Officials, Coalition Educational Facility Planners, Educational Reform Constituencies.
- New York City Asthma Partnership, <http://www.asthma-nyc.org/nycap/index.html>. Issues include diesel school bus conversion initiative, home assessments. Contact Marian Feinberg at sbcac@earthlink.net.
- Collaborative on Health and the Environment (CHE) Regional Meeting in Pittsburgh in March 2005. Contact Kathy Lawson at klawson@ldaamerica.org or see <http://www.cheforhealth.org/events/index.html>
- CHE-Northwest's Seattle Working Group on the Precautionary Principle. The group drafted a white paper on the precautionary principle and is now working to include language on the precautionary principle in the Seattle of Seattle and King County's comprehensive plans.. Contact Elise Miller: emiller@iceh.org or see <http://www.iceh.org/Pages/SeattleEfforts.html>.

National

- CEHN's Bush Report, released 4/5/04, <http://www.cehn.org/cehn/reportpressrelease.html>
- First Steps Initiative. Pre-natal outreach to parents on CEH. Contact Elizabeth Sword at elizabeth@checnet.org or see http://www.checnet.org/improve_firststeps.asp.
- Alliance for Healthy Homes works to increase federal funding for healthy homes. Contact Ralph Scott at rscott@afhh.org or see <http://afhh.org/>.
- Pass legislation to remove mercury from medical products, including vaccines. Send letters of support to members of Congress. Contact Sally Bernard at sbernard@safeminds.org or see <http://www.safeminds.org/>.
- American Public Health Association 2004 Annual meeting in Washington, DC in November will focus on the environment and public health. See <http://www.apha.org/meetings/>.
- New initiative to engage corporate investors on environmental health issues. Contact Rich.Liroff@wwfus.org.
- School pesticide reform strategy and national campaign led by Beyond Pesticides. Contact Kagan Owens at kowens@beyondpesticides.org or see <http://www.beyondpesticides.org/ToxicFreeSchools/index.htm>.
- Lawn/Landscape Pesticide Free Zones Campaign (modeled after Canadian local laws, ban aesthetic use of pesticides) led by Beyond Pesticides. Contact Kagan Owens at kowens@beyondpesticides.org or see <http://beyondpesticides.org/main.html>.

- “Healthy Hospital” report developed by Beyond Pesticides. Contact Kagan Owens at kowens@beyondpesticides.org or see <http://beyondpesticides.org/hospitals/>
- Mosquitoes/West Nile Virus initiative led by Beyond Pesticides. Contact Kagan Owens at kowens@beyondpesticides.org or see <http://beyondpesticides.org/main.html>.
- Federal PBDE ban bill (HR4076) Contact Yana Kucher at ykucher@environmentcalifornia.org or see <http://www.theorator.com/bills108/hr4076.html>.
- Environmental Justice – creating a grassroots-led children’s environmental health and justice network. Contact Deborah Berliner at deborah@communitytoolbox.org.
- Be Safe Campaign – contact Lois Gibbs at lgibbs@chej.org or see <http://www.besafenet.com/>.
- Pediatric Asthma Initiative – contact Leyla McCurdy at mccurdy@neetf.org.

International

- Commission on Environmental Cooperation report on “Toxics and Children’s Health.” This is a good report under siege by industry and needs to be supported. See <http://www.cec.org>.
- World Environment Day 2005 – June 5. Opportunity to help in the planning and execution. Contact parin@communitytoolbox.org or see <http://www.unep.org/wed/2004/>.
- REACH, European Union initiative. See <http://europa.eu.int/scadplus/leg/en/lvb/l21282.htm>

Appendix F: Results of Small Group Discussions

Five discussion groups focused on the following topics:

1) Literacy; 2) Short-term versus Long-term; 3) National Children's Study and Health Tracking. The final two groups were open forums. Each group was asked to:

- identify two to three gaps
- identify two to three opportunities (steps to address above)
- embed environmental justice into all opportunities
- Incorporate long term and short-term goals (and at least think about the other if you focus on one).
- Include ideas about how to build movement, including increasing environmental health "literacy" and building relationships with constituencies we're not currently engaging.

1) Literacy Group (Amy Kostant – amy@ems.org)

Gaps:

- a) People simply don't know about this – general public, policymakers, health care providers, other advocacy groups, media.
- a) No shared understanding or language – socioeconomic factors, race, gender, teenagers or women – is it speaking their language culturally, is it relevant to them?
- a) Need for messages with achievable goals/outcomes. Sometimes people are bombarded with negative messages – you can't do this, can't do that.

Opportunities:

- a) Use culturally appropriate strategies and tools.
- a) Create a centralized repository/database of successful and proven environmental health strategies from which to draw.
- a) Provide information about what people can do to affect change, such as writing to congressional representatives. Distinguish instances in which individual action will truly make a difference. Positive messages!!

2) Short-Term Group (Susan West Marmagas – swest@psr.org):

Gap:

Need for short-term action to make issues highly visibility.

Opportunities:

- a) Upcoming events that facilitate publicity
- a) Bring in other groups
- a) Use expertise of each individual group to lead multiple events, all with parallel messages.

Upcoming Events:

May – Stroller Brigade, EPA Change Rules, Fish Consumption/Voters

June – Endocrine Disruption Press Briefing (June 6)

July – Nuclear Weapons Action

Aug/Sept – Back to school issues

Sept – Food safety month

Oct – Children’s Health month, learning disabilities initiatives, Breast Cancer Awareness month

Additional Ideas and Activities:

- Monthly Day of Action building from the Stroller Brigade in May, focusing on issues such as Mercury, Schools (August), Pesticides, Lead, Food Safety and others.
- One-Page CEH overview will be drafted to provide a consistent messaging piece that can be used by organizations throughout the CEH field.
- Conference calls, coordinated by Lois Gibbs.
- Concept e-mail to be sent to group soon.

3) National Children’s Study and Health Tracking (Ruth Quinn – rquinn@jhsp.edu):

Gaps:

- a) Information and Communication about NCS and Health Tracking.
- a) Connection between NCS and Health Tracking – why the association important and how they complement each other.
- a) Lack of sufficient funding – concern that funding might get drained from other centers and research efforts.
- a) Include school/day-care environments
- a) Internal (federal) planning process needs external support and political will to achieve

Opportunities:

- a) Find private sector champion(s) for NCS on the model of Trust for America’s Health for Health Tracking.
- a) Organize regional joint briefings about NCS and Health Tracking.
- a) Strengthen language about the connection to environmental justice and minority populations.
- a) Strengthen role of environmental justice, minority and learning disabilities (LD) populations in sampling. This could involve intentional over-sampling of EJ, minority and LD populations.

4) Free-form Group 1 (Joy Carlson – carlsonj@rcn.com):

Gaps:

- a) Need to build broader and more constant constituency base.
- a) CEH policy approach has been inappropriately tackling issues on a "chemical by chemical" basis rather than focusing on the primary issue of prenatal health in general.
- a) Need to better incorporate precautionary principle.

Opportunities/Steps:

- a) Shift framing of CEH issues so that it is derived not from concern about specific chemicals but from a general concern about prenatal exposures and how they affect childhood and adult outcomes. Focus on bringing major national organizations like the National Academy of Sciences (NAS), NIH and National Institute of Environmental Health Sciences (NIEHS) on board with these concepts.
- a) Short-term Steps:
 - Institute partnerships

- Collect and translate science- Incorporate consistent framing and messaging into press conferences, mainstream books on pregnancy and other literature.
- a) Long-term Steps:
 - Build Broader Constituency Base.
 - Incorporation of the precautionary principle
 - Translate scientific information and make it more accessible. A CEH fact sheet in pregnancy kits would be a good idea. Important to work with major organizations like NAS, NIH and NIEHS
 - Frame research agenda for science.
 - Educate Health Care Professionals about environmental health issues and move toward greater environmental public health literacy in general.

5) Free-form group 2 (Sallie Bernard – Sbernard@safeminds.org):

Gaps:

- a) Lack of parent recognition of the injury to their children from environmental factors.
- a) Fragmentation of efforts on Capitol Hill, uncertainty about who is representing the children’s environmental health field.
- a) Lack of peer-reviewed science and scientists to speak on these issues.

Opportunities/Steps:

- a) In response to Gap #1:
 - Educate parents on reasons/causes.
 - Foster NIH openness to studies on environmental factors.
 - Advocate for increased prevalence of epidemiological studies by CDC, especially focusing on industry-influenced disease in communities.
 - Increase messages and research having to do with prevention.
- a) In response to Gap #2:
 - Increase communications with legislators.
 - Identify lead organization(s).
 - Successful example of the Consortium on Citizens with Disabilities, made up of 180 disabilities groups and 18 task forces.
- a) In response to Gap #3:
 - Increase NIEHS budget.
 - Pre-identify science experts.
 - Move toward better tracking of scientific literature as it is published, because the science may already be available but is simply hard to find.

Appendix G: Ideas for “Umbrella” Messages All Partners Might Use to Move the CEH Field Forward

The messages below are suggestions for basic statements that will work for most members of the Partnership. They are based on the PCHE Guiding Principles, which were co-drafted by Partnership members in 1999, and then further developed for the April 2004 PCHE meeting. Participants at that meeting elaborated on the suggested ideas, and the messages, as currently rendered, are a refinement and synthesis of our discussions at the PCHE meeting. They are intended to help all members of the Partnership have a common reference for articulating our concerns to the public.

While these messages can stand alone, they will be greatly enhanced by adding specifics from each group depending on the issue, policy agenda, or specific situation, region, chemical exposure and so forth.

Messages below are outlined as umbrella statements:

- Science/health message: The facts – what people need to know in order to care about this
- Moral message: The values– “we should do what’s right” message
- Advocacy message: The solution – “how we do what’s right” message

To be effective, expert messengers in each area should be determined to deliver messages:

- Science/health messages should be delivered by an expert in the field – a scientist or a doctor – preferably someone unaffiliated with your organization or campaign. Academic and/or those affiliated with a hospital are perceived by journalists as very credible.
- Moral message should be delivered by a member of the clergy, an affected parent, someone with moral high ground on the issue.
- Advocacy message should be delivered by someone who’s got a solution – someone who wants the listener to take action and is prepared to guide that action.

1. Research indicates that toxic chemicals significantly contribute to the rising rates of asthma, learning disabilities, behavioral disorders and childhood cancers.

- a. Children are particularly vulnerable to environmental contaminants because their biological systems are still developing and their size and behavior means they take in far more chemicals than adults. All children now carry toxic chemicals in their bodies—chemicals that didn’t exist 60-70 years ago.
- a. Poor children and children of color are disproportionately affected by toxic pollution because they often have to live in communities where there is greater pollution and contamination.
 - No one should have to choose between living with cockroaches and living with poisons that are known to cause cancer and other serious health effects.
- a. Health problems associated with environmental toxins cost us all: emotionally, physically, and financially.
 - Nationally, estimates of the environmentally attributable health care costs of chronic childhood illness are \$54.9 billion dollars (*Environmental Health Perspectives* 110:721-728 (2002)).

- As appropriate, include the names of states (and/or specific industries) in violation of policies that are supposed to protect children from toxic exposures.

1. Most chemicals used in areas where children live, learn and play are never tested for a range of significant health effects.

- a. The US EPA says of the 15,000 chemicals most widely used, only 43% have been tested for any kind of human health impact. Only 12 chemicals total have been tested for neurotoxicity.
 - We are all exposed to many chemicals at any given time through our air, water and food. Currently chemicals are only tested one at a time and actual life, long-range and synergistic effects are not considered. Many people think that products are adequately tested for human health impacts before they're put on the market. Since this is clearly not true, people have a false sense of safety concerning use of toxic chemicals.
- a. Products that have not been adequately tested or have been shown to be potentially harmful should not be used in areas where children and pregnant women are. This means we are doing a large-scale chemical experiment on our children. .
- a. We do not need to rely on dangerous chemicals to ensure we have enough food to eat and a high standard of living.
 - Less harmful alternatives exist and can be developed for toxic chemicals we currently use. In most cases when chemicals have been banned, forward-thinking industries have created less harmful substitutes that not only work well but are profitable for the company.
 - If safety standards are set to protect children, they will be stringent enough to protect everyone. If they are set at levels to protect an adult, which is currently the case in many sectors, they will leave children largely unprotected.
- a. Products should be tested for safety before they're allowed on the market.
 - Testing of products should begin with those we know are most toxic and in greatest use where children live, learn and play.
 - Testing for safety is the responsibility of the manufacturer and should become an automatic part of the product design process.
 - It would take too long and too many resources at this point to try to test to test them all one at a time and then synergistically. This is why:
 - Research should review whole classes of chemicals and those with similar molecular structures for human health effects in order to determine whether they should be on the market.
 - Industry and government should put their creative energy and resources towards developing alternatives for suspected toxic chemicals rather than trying to fight to keep those chemicals of concern in the market- People should try to minimize exposures by buying and using products that are the least toxic.

1. Parents have the right to know about threats to their children's environmental health and safety.

- a. Chemical companies do not have a right to trespass on our bodies without our permission.
 - We have a right to know about these toxic chemicals before they get into our bodies and our children's bodies.

- a. Products should be accurately labeled. Many parents, for example, assume that “non-toxic” means that it is safe for children. However, “non-toxic” does not necessarily mean that children are protected. This is, in part because standards for chemical safety often do not include children’s biological vulnerabilities. Plus some ingredients that are inert are not listed, but may still have health impacts.
 - Parents can’t protect their children if they don’t know what and where the dangers are.
- a. People not having information about chemicals used or stored in their communities puts our country at greater risk because determined terrorists can find out this information.

General Messages Rules:

Rule 1: Use only three main points.

Rule 2: Messages are ideas; they are not necessarily sound bites.

Rule 3: Messages are reinforced by sound bites, phrases, statistics and anecdotes.

Rule 4: Messages take time to create.

Rule 5: Once they are created, messages rarely change and must be repeated often.

Rule 6: Messages can be tailored for specific audiences.

Rule 7: Keep them simple.

The following message ideas were shared during the messaging workshop Tuesday afternoon:

- Children are more vulnerable to toxic exposures than adults.
- All communities have the right to equal protection from toxic exposures.
- We have the right to make decisions about what is happening in our community.
- Toxics are trespassing on our bodies—this is a human rights issue.
- Childhood illness is on the rise.
- Safer and viable alternatives exist.
- Children with health problems cost all of us— emotionally and economically.
- Our children have the right to good health.
- Ethical obligation to protect the health and safety of all our children
- We need to guarantee that our children are healthy, they need a healthier environment where they live, learn and play.
- We Americans have the ability and ingenuity to give our children healthy environments where they can live, play and learn, and where they can develop healthy minds to become tomorrow’s leaders [may not resonate with immigrant communities].
- We all share the responsibility for providing/ensuring a clean and safe environment to protect children.
- Your health is what you eat, breathe, drink and buy.
- Children should be guaranteed freedom from unsafe chemicals
- Are you safe from the pollution around you?
- Getting polluted is more than a drinking problem.
- All kids are exposed to environmental health threats; some are exposed more than others.
- Your body is your environment. It’s not just what’s outside of you.

- “Healthy environments = healthy children = healthy families = healthy communities”, e.g. you need healthy children to have healthy families and communities.

Further discussion centered on use of the “rights” terminology when speaking about CEH issues. Caution was urged when talking about sensitive prenatal and preconception issues in terms of rights. It was agreed that framing the issue as a human rights issue would resonate with some people and not with others. The suggestion was made that these issues deal not with “rights” but with more fundamental human “needs.” In general the group agreed that the best messages are those with which people make a personal connection. A few wording ideas were thrown out, including the idea that the word “our” makes any statement about children more personal. (We have a responsibility to protect OUR children, for example.)

Appendix H: Upcoming Events and Key Resources

Related Events:

- **Stroller Brigade**
May 6, 2004
sponsored by Clear the Air, <http://www.cleartheair.org>
- **World Environment Day**
June 5, 2005
http://sfgov.org/sfenvironment/articles_pr/2004/article/060404.htm
- **Endocrine Disruption Press Briefing**
June 6, 2004
amy@ems.org
- **G8 International Summit in Savannah, Georgia**
June 8-11, 2004
<http://www.savannahg8summit.org/>
- **The Annual Indoor Environmental Health and Technologies Conference**
June 23-25, 2004
www.leadmoldconferences.com/04pdfs/2004IEHTnationalconf.pdf
- **28th Annual Meeting of the Neurobehavioral Teratology Society, 44th Annual Meeting of the Teratology Society**
June 26-30, 2004
www.nbts.org/newframes.htm
- **35th National Conference on Autism Spectrum Disorders – "Soaring to New Heights", Autism Society of America**
July 7 - 10, 2004
www.autism-society.org/site/PageServer?pagename=2004_Conference&AddInterest=1062
- **The Center for Science in the Public Interest Second Annual Conference**
July 12, 2004
http://cspinet.org/integrity/conflictedscience_conf.html
- **Navigating the Future: Aligning Strategies and Science, CDC National Center on Birth Defects and Developmental Disabilities**
July 26-28, 2004
<http://www.cdc.gov/ncbddd/conference.htm>
- **Conference on Children's Health and the Environment**
September 11, 2004
<http://www.health-e-kids.org/>
- **Improving the Health of Women: Meeting the Challenges of the Rural Setting, National Rural Women's Health Conference**
October 28-30, 2004
<http://www.hmc.psu.edu/ce/RWH2004/index.htm>
- **Public Health and the Environment, American Public Health Association 132nd Annual Meeting and Exposition**
November 6-10, 2004
<http://apha.confex.com/apha/132am/techprogram/>

- **Learning Disabilities Association regional meeting of the Collaborative on Health and the Environment**
March 2005, Pittsburgh, PA
contact: Kathy Lawson klawson@ldaamerica.org
- **Children's Health Month, Environmental Protection Agency**
October 2005
<http://www.childrenshealth.gov/index.html>
- Regional meetings of the National Black Environmental Justice Network
contact Felicia Eaves feaves@AFHH.org, 202-543-1147

Recent Publications:

- Politics and Science in the Bush Administration, a report by the Minority Staff of the U.S. House of Representatives Committee on Government Reform.
- Fresh Choices: More Than 100 Easy Recipes for Pure Food When You Can't Buy 100% Organic, Published April 2004 by Rodale, written by David Joachim and Rochelle Davis
- Healthy Schools Network Training binders, published by the Healthy Schools Network at www.healthyschools.org.

Website Resources:

All the Partner member websites are posted on: www.partnersforchildren.org. These are some sites that were highlighted at this meeting:

Health Tracking

- <http://www.cdc.gov/nceh/tracking>
- <http://www.healthyamericans.org> (Trust for America's Health)

National Children's Study

- <http://www.nationalchildrensstudy.org> (National Children's Study official site)

US House of Representatives Committee on Government Reform

- <http://www.house.gov/reform/min> (many good resources on Lead)

Environmental Media Services

- <http://www.ems.org>
- <http://www.environmentalhealthnews.org>

ADDENDUM

Evening activities at the Partnership meeting:

Monday, April 26, 2004 –

A couple of participants shared videos on children's environmental health issues:

- 1) Nancy Evans presented a film she produced on children and asthma, the first in what she hopes will be a series entitled *Small Bodies of Evidence: The Toxic Lives of Children*. Afterwards, the group emphasized the importance of having this kind of film as a resource for all of us and discussed ways we might help Nancy get the additional funding she needs to complete this series. One suggestion was that all the (willing) Partnership groups might put in \$500 or \$1000 or whatever they could afford out of their budgets towards the creation of the film series since everyone would benefit.

- 1) Julia Earl then presented a short video, *Having Faith, Preventing Harm Minnesota*.

A number of viewers stayed to discuss both films and other issues related to getting information on children's environmental health highlighted in different media outlets.

Tuesday, April 27, 2004 –

Barb Sattler hosted the Partners at her home only two blocks from the Mt. Washington Conference Center. She hired a lively jazz trio to perform and offered an array of delectable desserts, cheeses and wines. All agreed this was a perfect way to wind down at the end of our meeting and connect with colleagues more informally. Much appreciation was expressed for Barb's generosity organizing this gathering for the Partnership.

Congressional Briefing:

Wednesday, April 28, 2004

The morning following the meeting in Baltimore, Partnership members attended the congressional briefing organized by the Partnership, in conjunction with the American Public Health Association and with the help of Physicians for Social Responsibility. The briefing was co-sponsored by Sen. Hillary Clinton (D-NY), Sen. Jim Jeffords (I-VT) and Sen. Olympia Snowe (R-ME) and was held in the Dirksen Senate Office Building in Washington, DC.

Objectives—

- 1) Introduce leaders in pediatric medicine, public and environmental health to legislative policymakers and staff.

- 2) Generate greater support for children's environmental health priorities in the 108th Congress.
- 3) Foster dialogue on core medical, public health and environmental health issues.

Moderator —

- 1) *Elise Miller, M.Ed.*, Executive Director of the Institute for Children's Environmental Health and National Coordinator of the Partnership for Children's Health and the Environment, Freeland, WA.

Speakers —

- 1) The National Children's Study: Improving Child Health in the 21st Century. Speaking: *Philip Landrigan, M.D., M.Sc.*, Professor and Chair, Department of Community and Preventive Medicine, Mt. Sinai School of Medicine.
- 2) Health Tracking and Childhood Chronic Disease: What We Don't Know Is Costing Us. Speaking: *Adrienne Ettinger, Sc.D., M.P.H.*, Assistant Professor, Bloomberg School of Public Health, Johns Hopkins University.
- 3) Mercury Exposure and Neurobehavioral Effects on Children: Getting Mercury Out of Our Kids As Soon As Possible. Speaking: *Lynn Goldman, M.D., M.P.H.*, Professor, Bloomberg School of Public Health, Johns Hopkins University.

Approximately 20 Partners and 30 congressional staffers and other interested colleagues attended. Afterwards, some Partners met with staff members in the offices of Sen. Edward Kennedy, Sen. Hillary Clinton, Sen. Patty Murray and others members of Congress to discuss these issues. Elise Miller and Michelle Gagnon also met with Al McGartland and Bill Sanders at the EPA to discuss EPA's current proposal on coal-burning power plants and mercury emissions.