

INTERGENERATIONAL RISK CONFERENCE REPORT

On April 27 and 28, 2016, a group of organizations including the Public Affairs Institute at Alma College, the Pine River Superfund Citizen Task Force (the U.S. EPA community advisory group for Superfund sites in the Pine River watershed), the Science and Environmental Health Network and the Student Congress at Alma College hosted a conference of Intergenerational Risks of Exposures to Environmental Contaminants. The Intergenerational Risk Conference (IRC) brought together environmental-health scholars, public officials working on environmental health policy, staff of elected officials, and especially citizens impacted by the contaminants produced by Velsicol and accidentally introduced into the food chain of the Upper Midwest in the 1970s. Core leaders in the conference included a group of students, faculty and staff from Alma College and from the Rollins School of Public Health at Emory University.

Much of the attention at the conference focused on what is known and what needs to be known about the intergenerational risks from exposure to polybrominated biphenyls (PBBs). The reason for this focus was that PBBs were the fire retardant accidentally mixed with animal feed in 1973-1974 and consumed by millions of residents of the Upper Midwest. However, the conference did not ignore the many other contaminants to which farmers, residents and especially former workers had been exposed. Velsicol produced many hazardous products, many of which were handled in ways that led to exposure to workers, worker families, residents near their old plant site in St. Louis, Michigan and others further from the former factory. The Pine River that flows past the 54-acre former plant site contained many of these contaminants, since the company long treated it as a free-sewer. People coming into contact with the river, fish from the river or other exposed animals could have been exposed far below the plant and into the Great Lakes. Although the unifying theme of the conference was the PBB exposures in Michigan and especially in St. Louis and the contamination in the adjacent Pine River, the goal of the conference was also to create a document that can be used as a cry for change in any community. Overshadowing the conference were the similar policy mistakes made in addressing the water problems in Flint, Michigan. Repeatedly, conference participants lamented that the mistakes in Flint seemed to demonstrate we had learned little from the PBB exposures in the 1970s and the precautionary lessons the PBB exposures made clear. Michigan's policy process seems mired in obliviousness to precaution and state government transparency as it was in the 1970s.

Conference Background:

In 1935, Michigan Chemical was founded along the Pine River in the small city of St. Louis, Michigan. The company quickly became one of the biggest employers in the watershed and prime source of environmental contamination. As early as the first year of operation, the downriver Saginaw City Council unanimously passed a resolution calling for the state to halt pollution from the plant. Documented complaints from watershed residents and foresighted public agency staff continued to arise over the next four decades.

In 1944, the factory began priority manufacturing DDT to protect military personnel in World War II from mosquito borne diseases in the South Pacific and southern Europe. As the war ended, production continued for use by the United Nations in dusting areas with large refugee

and homeless populations to protect them from body lice and other insects. As war related need for DDT declined, Michigan Chemical ramped up promotion of DDT as a miracle home and farm pesticide, sold under the trade name PestMaster. As criticism of DDT's negative impacts on environmental health increased, Michigan Chemical shifted to other agricultural and manufacturing chemicals, still using the word 'Master' in these other products. There was an animal feed supplement – NutriMaster. There also was a PBB based flame retardant developed in the late 1960s called FireMaster. By the time of commercial production of FireMaster, Chicago based Velsicol Chemical bought a controlling interest in Michigan Chemical. In turn, Northwest Industries, a Chicago conglomerate bought Velsicol. Later Northwest Industries reorganized and took the name of its large underwear subsidiary, Fruit of the Loom.

In May 1973, ten years after Michigan Chemical and Velsicol had fallen under the control of Northwest Industries, the company made a major shipping mistake, sending many bags of FireMaster to a Farm Bureau animal feed supply facility instead of NutriMaster. Unknown for a year, the PBB was mixed with animal feed and distributed across Michigan. Even after the accident was uncovered (much as would be repeated in 2014-2016 in Flint), state officials minimized the problem, put roadblocks in the path of investigators and allowed PBB contaminated milk, eggs and meat to be sold. Before rigorous control of PBB tainted food and farm animals was implemented, at least eight million people consumed at least some PBB.

In the mid-1970s, as complaints mounted about irresponsible delays in protection of public health, the state Department of Public Health [now Health and Human Services] launched the Michigan Long-Term PBB Study or the PBB cohort study of those exposed to PBB. Reaching out to 6,800 people, about 4,000 came forward to be enrolled in the study, mostly farm families with the highest exposure to PBB. Another 251 former workers and a few members of worker families were added to the PBB cohort after 1976 and then dropped in 1990 from follow-up. While the PBB cohort included nearly equal numbers of females and males and added children born to the 4,000, the worker group was overwhelmingly male, had much higher levels of PBB exposures and did not have children added. Consequently, the Department of Public Health dropped the worker group from follow-up in 1990. Much later, in 2011, the health department, at the time named the Department of Community Health, “discontinued any further activity to maintain [the] registry.” Emory University, which had been serving as a technical advisor to the state on the study now asked and received permission to continue follow-up. But, to do any follow-up, Emory needed permission from each member of the cohort.

Meanwhile, in St. Louis, Velsicol struck a deal in 1978 with state and federal environmental officials to shut the old factory and leave the state. If Velsicol absorbed the costs of tearing down and burying the old plant and stabilized two other waste dumps near the plant, they were allowed to walk away from the state with no further liability. As a result of this Consent Judgment finalized in federal court in late 1982, the plant was demolished and the new Superfund program became responsible for the plant site and the two waste dumps as parts of the national priorities list (NPL).

Fifteen years after the consent judgment, which supposedly assured proper remediation of the site, the EPA and state publicly returned to host a special community meeting to discuss the contamination in the Pine River and the effects it was having on the local fish population. In

1997, river fish were more contaminated than in the 1970s or earlier. EPA then began a process of returning to the community and removing more than 600,000 cubic yards of highly contaminated river sediment. To oversee this remediation, citizens in the watershed launched the Pine River Superfund Citizen Task Force. Since January 1998, the Task Force has pursued both full remediation of the site and sought, often unsuccessfully, to secure a comprehensive human health study related to the contamination. Environmentally, over \$100 million has been spent by EPA on river and residential property remediation. EPA also has completed plans for an additional \$350 million containment of contaminants at the old plant site and the waste dumps.

Beginning in late 1999, the Task Force, working with Alma College's Public Affairs and Environmental Studies programs and the Mid-Michigan District Health Department, repeatedly requested funds from the National Institute of Environmental Health Sciences (NIEHS) to support a "Community Based Participatory Research" study of the consequences of worker and resident exposures to Velsicol emissions. Repeatedly denied funding, the Task Force fought vigorously with its partners to force staff of the U.S. Department of Health and Human Services to come to the community with some success but, more often, with opposition. Beginning in 2013, the partnership between the Task Force, Alma College, the Mid-Michigan Health Department and Emory University's PBB registry has begun to produce results, as reflected in this conference.

In 2005, St. Louis learned from U.S. EPA that the city water system contained by-product of DDT production. Despite more than 40 years since DDT had been manufactured in St. Louis, and despite assurances in 1980 that the water system was uncontaminated by DDT, the city had to face replacing the water supply. Not only did Fruit of the Loom and Velsicol oppose being held liable for water system replacement, the U.S. Department of Justice and EPA's own attorneys opposed the city's request. With technical support of the Task Force, St. Louis eventually won \$27 million from the firms and additional funds from EPA to build a new water system with neighboring Alma. However as so often in the past, the human health consequences of this exposure remains unstudied by state and federal health agencies.

With collaboration between Dr. Michele Marcus at Emory, leaders of the PBB cohort, and the Task Force, Mid-Michigan Health Department and Alma College, a team of researchers from Emory gathered blood samples of more than 800 Michigan volunteers in 2013 and 2014. Remarkably, 500 of these volunteers came from St. Louis residents or former Velsicol workers and their families. Without the support of the St. Louis community, much of what already been done in PBB Registry follow-up would not have been possible. Some of the information that the Emory team gathered during two visits to the watershed has been interpreted for individuals but awaits collective assessment. Many of the presentations at the Intergenerational Risk Conference grow out of these initial analyses as well as the longer term work with PBB cohort records. Holding this conference is testimony to the cooperation of some of the North America's best environmental-health experts with concerned citizens, current officials, and institutions such as Emory University and Alma College. While the success of this cooperation is a positive story, the failure of earlier officials to launch such a forum, to support adequate funding for precautionary human health protection and to order prompt environmental remediation at the Velsicol sites in the watershed, remains a troubling example of irresponsible disregard by public officials for the Michigan citizens and their descendants, that officials are called to serve.

Conference Summary:

The conference began with a reception and dinner on the evening of Wednesday April 27th, 2016. Most of the 120 people who were to attend the conference were present. Those unfamiliar with the Superfund sites in the community were offered visits to the gates of the sites during the reception. After the locally sourced dinner, Carolyn Raffensperger, delivered the conference's keynote address on *The Precautionary Principle and Health Policy*. Executive Director of the Science and Environmental Health Network, Ms. Raffensperger, an attorney educated at Northwestern University, has written several books on the precautionary principle. Specifically related to EPA, she wrote *Precautionary Tools for Reshaping Environmental Policy* published in 2005 by MIT Press. She also was the convener of the Wingspread Conference on the Precautionary Principle. She forcefully reminded the conference attendees of the wisdom and need to fully understand the consequences of use of new substances before their widespread sale and use. She emphasized the wisdom of the Native-American concern with seeking practices that protected seven generations beyond the present. If we implemented the precautionary principle, incidents such as those that took place in St. Louis leading to the PBB mistake should not occur. The process for assuring protection of the seventh generation, she suggested, would be to appoint a spokesperson or legal guardian to act on behalf of future generations. Her remarks served as fitting start to the following day's discussions.

Thursday April 28th, 2016 was a day full of technical presentations, discussions between experts and citizens about those presentations, and concluding opportunities to propose outcomes. The day began with a panel featuring Dr. David Carpenter and Dr. Jonathan Chevrier. Dr. Carpenter is the Director of the Institute for Health and Environment at SUNY University at Albany and former Dean of the School of Public Health. Dr. Carpenter is a public health physician who has served as an advisor on environmental health for the World Health Organization and the U.S.-Canadian International Joint Commission. He is a world recognized expert of health risks from PCBs and other contaminants, including in remote locations, such as Inuit villages. He is editor in chief of *Reviews on Environmental Health* and on the editorial board of *Environmental Health Perspectives*. Professor Chevrier holds the Canada Research Chair in Environmental Health Sciences at McGill University and is an Assistant Editor of the *American Journal of Epidemiology*, one of the most prestigious journals in public health. Dr. Chevrier's work focuses on potential endocrine disrupting immunotoxic and neurodevelopmental effects of exposure to persistent and non-persistent chemicals, including DDT, flame retardants and dioxins. He is the Principal Investigator of the VHEMBE study, which investigates the health effects of exposure to public health insecticides used in malaria control efforts in Africa.

Dr. Carpenter questioned the traditional risk assessment methods and how ineffective they are, particularly looking at long term effects of chemical compounds like PBB, PCB, and DDT. He concluded by reminding the audience that until all the chemicals at the sites in a place like St. Louis are removed, a variety of health effects and outcomes will continue to present themselves and can do so for generations to come. Simply containing but not removing contaminants cannot assure outcomes will end. Dr. Chevrier built upon Dr. Carpenter's lead, emphasizing how little we know about the chemicals we use. Most strikingly, he explained to the audience that once chemicals are banned due to suspected harmful effects on human health, they are generally replaced by chemicals that have undergone very little testing in terms of health effects, and that

the pattern has been going on for decades. Because of this absence of toxicity studies, we should be extremely careful with how we use the many untested chemicals. This was a sobering warning about our current practices in using untested chemical. While there can be serious health consequences from exposures to any untested chemical, we should be especially troubled by lack of knowledge of the impact of harsh chemicals on childhood development as children are likely to be particularly sensitive to the adverse effects of chemicals. Evidence suggests that exposure early in life may have long-term impacts on health.

After the Carpenter-Chevrier panel, the focus shifted to a set of specific reports on the work of the Emory University team with members of the PBB Registry, St. Louis residents and former Velsicol workers. The first panel of presenters focused on the question of the *Importance of Community Engagement in PBB Research and Hearing Our Partners' Stories* and primarily included people representing locally exposed populations and the local health department. The panel was chaired by Dr. Melanie Pearson from Emory. Dr. Pearson is a Community Engagement Scientist with the Environmental Health Research Center at the Rollins School of Public Health. On a number of occasions, she has been to St. Louis and in other parts of Michigan with PBB exposure. Other than the PBB project, she has played a primary role in implementing and conducting community-based initiatives for three National Institutes of Health-funded research centers at Emory University. She has managed two longitudinal environmental exposures studies and has published scholarly articles on community-based health research. Dr. Pearson will coordinate the community-based initiatives of the newly established Environmental Health Research Center at Emory, which will involve communities and scientists working together on local environmental health concerns.

Providing the local health department perspective on the PBB project, Dr. Marcus Cheatham is the Health Officer of the Mid-Michigan District Health Department. The Mid-Michigan Health Department is a multi-county rural health department serving Gratiot County. Dr. Cheatham holds a Ph.D. from Michigan State University focused on public policy. As Health Officer, Dr. Cheatham is responsible for all administrative functions of local health department serving Clinton, Gratiot and Montcalm counties with 80 staff and six-million-dollar budget. He works with the Board of Health, oversees the budget and strategic planning process, and represents the Department in regional and state planning activities. MMDHD is nationally recognized for seeking innovative solutions to local public health challenges. He emphasized that the health department is fully supportive of working with both the people exposed to PBB and the team from Emory. He also serves on the Executive Committee of the Pine River Task Force.

Jane Keon is a life-long local resident whose residences for much her life have been adjacent to the Pine River. She is currently Secretary of the Pine River Superfund Task Force. For a number of years, she was Chair of the CAG. She is also an officer of another regional watershed group focused on agricultural run-off issues in the Pine River. She recently wrote a book on the first two decades of the CAG's efforts to oversee remediation of the Superfund sites along the river, *Tombstone Town*.

The fourth participant in the panel was Jane-Ann Nyerges, the leader of the PBB exposed farm family group. A Senior Information Architect/ Project Leader with Davenport Financial, LLC in Metropolitan Cleveland, she was a longtime Michigan resident. A graduate of Spring Arbor

University and Central Michigan University, where she studied therapeutic recreation, she brings special experience with the community of those exposed to PBB, having served on the PBB Registry Board.

The panel went into detail about how the various ‘PBB communities’ (farm families, former Velsicol workers and residents of St. Louis) really came together for the current PBB research and what the outcomes of the study have shown thus far. The panel gave the attendees, especially those from the ‘PBB communities,’ an opportunity to be updated on the status of monitoring of intergenerational impacts of exposures. Representatives of the various ‘PBB communities’ and the team from Emory University, felt it was important to start this section of the conference with this update from actual members of the communities such as Jane Keon, Jane-Ann Nyerges and a local health department official such as Dr. Cheatham. The local representatives emphasized that it was especially important to include people from the communities in order to keep the communities’ trust, as these communities have been through a tremendous amount of testing and otherwise subjects of health research but often without being included in planning of the research agenda and especially ignored in the dissemination of research findings.

Following the ‘PBB communities’ panel, there were responses from Dr. Michelle Marcus from Emory. Dr. Marcus is Professor of Epidemiology, Environmental Health and Pediatrics at the Rollins School of Public Health. She also has served as the Assistant Director of the Center for Health Research for Kaiser Permanente Georgia. She has published extensively on multi-generational health effects with both the Michigan PBB Cohort and the Avon Longitudinal Study of Parents and Children. Among her many special projects, she served on the National Academy of Sciences Institute of Medicine Committee on dioxin exposure among Vietnam Veterans. In reviewing the goals and progress thus far in follow-up of the PBB exposed populations, Dr. Marcus emphasized her commitment to continued consultation with the PBB Registry team being formed to include representatives of the ‘PBB communities.’

Dr. Marcus included in her remarks a summary of the project so far. She detailed the many frustrating problems in the state’s old PBB Registry data base. She reported that many people were dropped from the Registry by the state around 1990 and even those maintained after that period seem to have records with scrambled addresses and other scrambled information as a result of software changes and other factors. Until people in the old Registry give permission to the state to transfer their records to Emory, the research team has no knowledge of their identity. Finally, there are budgetary challenges to fully respond to the large numbers of former workers, residents of St. Louis and farm families who have come forward at the various samplings since 2013.

Following the presentation by Dr. Marcus, Dana Barr reported on *Dried Blood Spots for Retrospective and Prospective Exposure Assessment*. Dr. Barr is Research University Professor, Rollins School of Public Health, Emory University and Co-Director, Integrated Health Sciences, Hercules Health and Exposure Research Center. She is the author of more than 250 peer reviewed articles, 14 book chapters and other publications, spent 22 years at the Centers for Disease Control and Prevention, as head of the pesticide laboratory. She has served as an expert consultant in Canada, China, Israel, Japan, The Netherlands Thailand and elsewhere. From 2011-2012 she was President of the International Society of Exposure Science. She has had

previous contact with the Pine River Task Force, beginning in 2005 related to our desire to have infant blood spots tested for fetal exposure to DDT. She described the capabilities and limitations, mostly in workload, of the Exposure Research Center. The Center has a large backlog of work but has the ability to perform exceptionally precise work with small samples, such as the infant blood-spots.

After the presentations by Michelle Marcus and Dana Barr, a team of Emory researchers then explained the potential role of epigenetics in PBB exposure. The team described how epigenetics pertains to understanding the impact of contaminants altering gene expression and how this impact can be passed on to children of exposed parents. Dr. Alicia Smith began the series of presentations providing an *Introduction to Epigenetics: How Short-term PBB Exposure Might Result in Long-term Health Risks*. Dr. Smith is Assistant Professor of Psychiatry and Behavioral Science and Principle Investigator in the Human Psychiatric Genetics Laboratory at Emory University. Dr. Smith studies the role of genetic and environmental factors in the development of stress-related disorders across the lifespan. She holds affiliations in the Cancer Prevention and Control Research Program at the Winship Cancer Institute and the Children' Center for Neuroscience Research at the Emory Children's Pediatric Research Center.

Dr. Smith explained how the vast majority (99 percent) of the DNA sequence is the same for all individuals. Obviously, the small remaining differences in the DNA sequence are exceptionally important. But epigenetics focuses on changes of DNA that regulate gene expression without altering the DNA sequence – essentially inducing variations between genetically identical individuals. She added that epigenetic modifications are dynamic; that is, they can occur during development of the organism, as the organism ages, and may be reversible.

Focusing on PBBs, they can disrupt endocrine function by mimicking hormones. Among the glands that are part of the endocrine system which can be impacted by exposure to PBBs are the thyroid, parathyroid, pancreas, ovaries, testes, adrenal glands, the hypothalamus, pineal gland and the pituitary gland. All of these glands secrete hormones that regulate behavior of various target organs. She focused as an example on potential PBB disruption in estrogen among the 82 participants in the August 2012 PBB community sampling, of which 55 percent would have been exposed to PBB during adolescence (before age 17). Preliminary results indicate that the people exposed to PBB had different patterns of DNA responses to estrogen compared to unexposed populations. The consequences of that difference are not yet known.

Karen Conneely then added to Dr. Smith's presentation in her report entitled *Genetic and Epigenetic Variation in Individuals Exposed to PBB*. Dr. Conneely is Assistant Professor in Biostatistics and Bioinformatics in the Department of Human Genetics of the Rollins School of Public Health, Emory University. Dr. Conneely is an expert on biostatistics and has written peer reviewed articles on multiple correlation, especially related to type 2 diabetes. She is especially familiar with Michigan, having received her Ph.D. at the University of Michigan. The goal of her work is to gain insight into the biological mechanisms linking PBB exposure to endocrine-related health consequences.

Dr. Conneely, as Dr. Smith, explained at the start of her presentation the process of DNA methylation, during which methyl groups are added to DNA. This methylation modifies the

function of the DNA. Methylation often represses gene transcription. Dr. Conneely added that not all changes to the DNA methylation are bad. Some changes can help us adapt to our environment. Her work on PBB exposure, is looking at the impact of exposures for 671 individuals. Initially she wants to learn if there is a correlation between levels of exposure to PBB and DNA methylation. If so, she then wants to see the impact on the biological function of nearby genes. She also wants to investigate if there are genetic links to variations in storage or excretion of PBB. Essentially this work will look simultaneously at potential genetic and epigenetic impacts of PBB exposure. She concluded with a timeline, showing a final report goal of fall 2019.

The final epigenetic focused report was by Charles Easley who is studying the *Effects of Flame Retardant Exposure on Sperm and Future Generations*. Dr. Easley, formerly at the Department of Cell Biology at Emory University, recently moved to the University of Georgia. His overall research focuses on using pluripotent stem cells to model male factor fertility. He developed the first in-vitro model of human spermatogenesis using stem cells. His model allows for rapid and unbiased evaluation the impact of known reproductive toxicants on spermatogenesis. He is working on stem cell therapies to treat male factor infertility attributed to environmental toxicants.

Dr. Easley's presentation seemed to generate much interest in the audience, since he provided concrete examples of understandable outcomes which could be linked to exposures to flame retardants such as PBB. As we learned, PBB is one of a long chain of bromide based flame retardants, surprisingly one even continuing the use of the Velsicol trade name: FireMaster. Dr. Easley's work is focusing upon seeming decreases in sperm count and whether any declines can be tied to PBB exposure levels

Dr. Marcus brought the Emory team's set of presentations to a conclusion by reviewing carefully how each component of the Emory research will fit into goal of the 'PBB communities' to find comprehensive answers to concerns about human health consequences of exposures. She focused on the *Plans Going Forward* now that more funding has been received. She especially gave attention to the work of the PBB Leadership Team being formed to advise Emory on its work with the 'PBB communities.' The conference was informed that on the following day, Friday, April 29, 2016, there would be an initial meeting of the tentative leadership team including representatives of the farm families, the Pine River Superfund Task Force and the Mid-Michigan Health Department.

This topic made a natural lead into the luncheon address of Madeline Scammell on *The Community and Environmental Health Risk Process*. Dr. Scammell is Assistant Professor of Environmental Health at Boston University's School of Public Health and an Environmental Health Fellow at Harvard School of Public Health. She also leads the Superfund Research Program, Community Engagement Core at Boston University. Her work includes developing mechanisms to support long and short-term research relationships between community groups and scientists. She is principle investigator of an EPA study of cumulative risks in an environmental justice population. She chairs the Board of Directors of the Science and Environmental Health Network.

After discussing all of the possible factors of what these chemicals have been shown to do within the community and affected population, Dr. Scammell changed the conversation focus from what the health effects of exposures to the affects that a community can have once it learns of impacts and decides to act to respond to exposures. As if this were a rallying cry, her address pushed the audience into talking about what they are concerned about and what they are willing to do to assure their community is 'rid of the poisons.' This address really prepared the conference attendees for the next phase of the conference, where all attendees, except the expert presenters, were split into four groups of about 20-25 people and allowed to interact with the expert presenters.

Small Group Process

Four 30 minute sessions now took place with the four randomly selected groups of about 20 people interacting with four teams of rotating experts grouped into the following topics:

1. Fire Retardants and Endocrine Disruption;
2. Exposure Analysis and Cumulative Risks;
3. The Contribution of Epigenetics; and
4. Unaddressed Concerns – The Community Perspective.

Each group of experts was accompanied by a neutral recorder who kept records of the dialogue and folded the four sets of comments into a common list. After the four sessions, the members came back to the main hall and listened to the recorders list their group's outcomes. After this, there was a time allowed for everyone to clarify or correct the recorders lists of questions and comments.

The distinction between these two outcomes is that under 'Questions' we list concerns that called for expert answers. In many cases there were either full answers to these questions at the follow-up session. In other cases, the answer had to be found through further research. In contrast to 'Questions,' under 'Comments' were included other important statements that were made during the small group process that did not need expert answers but stood on their own, especially recommendations for further action.

Questions (A: = answer):

1. Is there a way to detox from Velsicol chemicals? A: Not that we know today; more research is required.
2. What is a half-life? A: It is the time required for the amount of something to fall to half its initial value, such as .28 parts per billion DDT to become .14 parts per billion.
3. How can those who have not yet joined the PBB Registry get tested for PBB? A: Right now we don't have the funding for adding more people. We need pressure to support further resources for PBB follow-up. We welcome support for finding more funding. At a minimum you should go to the PBB web site and sign up: https://docs.google.com/forms/d/e/1FAIpQLSd2d8NnptbpZyOrSA5zqx1Cqxz2vaFsT5DeqkmZ5_niqQsYIA/viewform. The quicker you get on the list the better the chance you will be added if more funding is received.

4. How can we educate physicians and other primary care providers of the need to understand PBB as a potential factor in patient health? A: We need to take control of our own health needs by educating our providers. There is a fact sheet prepared by the old Michigan Department of Community Health for physicians who might treat former Velsicol workers. The fact sheet can be used even if you are not a former worker but believe you were exposed to chemicals from Velsicol. The fact sheet is available at: http://www.michigan.gov/documents/mdch/Velsicol_MDandWorker_Factsheet_v2.1_183070_7.pdf
5. What is a high level of PBB? A: The average level for the U.S. population might be seen as a safe level. It was 0.014 ppb in a 2003 study; for the entire Michigan population the average is much higher at 0.265 ppb in 2012-2015. Is that safe? We need more research to answer that.
6. How can we stop future disasters involving industrial chemicals like those from Velsicol? A: This is a core question. Please look below for the discussion of next steps after the conference. One complication is the reduction in funding dedicated to such problems, growing from policy mistakes such as the abolition of the Superfund tax that 'paid' for much remediation of contaminated sites. Congress abolished that small tax on chemical production in 1995. It could be restored if Congress is pressured to do so.
7. What is the contamination risk today if you weren't previously exposed? A: The answer to this questions is one likely outcome of current research on intergenerational risks.
8. Why wasn't St. Louis evacuated? A: Repeatedly we were told the contamination was contained, only to find the problem was worse and extended into the wider community. The current EPA guided clean-up of residential properties and of contaminants in the three Superfund sites in town is guided by a determination to contain and remove all contaminants which could threaten human health. However, residents need to participate in the process, especially by attending Pine River Task Force meetings and letting their voices be heard.
9. Why do events like this still happen? A: Great question! In many cases, the public is unaware of the threat from various contaminants. Often when there is concern, we have been assured by those producing or using contaminants that all is well. We need to start demanding testing of all new and untested old contaminants – the precautionary principle described in our keynote address. We also are told there are economic and employment benefits from using some chemicals. The profits from Velsicol never equaled the cost of the current clean-up.
10. How can we inform and educate consumers about chemical products? A: The problem is the Toxic Substances Control Act of 1976 has any loopholes. First, there were 62,000 chemicals in use in 1976 that were grandfathered in as automatically safe. Because of low funding, EPA has a massive backlog in regulating untested chemicals. We need to insist/challenge/demand rules and regulations change such that this has to happen.
11. How do we know if there is PBB in the soil or when if it is gone if it once were in soil? A: PBB is known to persist in soil for a long time, but we don't know how long or what will keep it there. Only regular testing will determine if it is on a farm or at one of the animal burial sites.
12. Can someone pay to be tested? A: Emory has to test in groups and has a backlog of people wanting to be tested. You can donate to our project. For every \$250 in funding, one more person can get tested.

13. Is the PBB testing wait list first come first serve? A: Yes, unless you qualify as one of the original PBB cohort members we are searching for but have not found.
14. Do other labs test? A: Not many. Commercial labs normally do not test for PBB. There are some advanced research labs (usually at big universities) that may be willing to test.
15. Could we spread the funding for research and tests across more groups like different colleges? A: That's what we've done so far between Alma and Emory, and we can continue to do so if we get more funding. We need to find other institutions willing to be involved. We may take for granted Emory and Alma, but they have been uniquely interested. In various special project, we have received help from the University of Michigan Law School and other parts of the University of Michigan, Michigan State University, Central Michigan University. Wayne State University and Indiana University. We welcome other collaborators.
16. Can parents send blood spots to Emory? A: Not at this time. We'll include information on the blood spot research in later mailings.
17. Can we hold Velsicol accountable and get funding from them? A: We wish we could. The state in the 1970s and again in 1982 and 2002 with Fruit of the Loom gave legal protection to the companies in exchange for some funds for clean-ups. They foolishly never sought funding for human health follow-up studies. However, the State of Michigan cannot give away your rights to pursue personal damages from someone. The state and federal governments gave away their rights.
18. Is there a network of Superfund site communities? A: The Pine River Task Force and the City of St. Louis have made efforts to contact other similar communities. Few are as well organized as us. We welcome help on trying out-reach. We especially hope (see conclusion below) to find allies in Flint.
19. How do we address the fact that health issues are more widespread than originally admitted by the State of Michigan? A: That is one of the reasons why Emory University, Alma College, the Pine River Task Force and the Mid-Michigan Health Department are working together on this project. We welcome you supporting us by coming to meetings, etc.
20. How can we get those effected covered with better insurance? A: There are some special funds set up by Blue Cross, especially related to Blue Cross privatization, that should be approached about this issue. If you wish to work on health funding, contact Ed Lorenz at Alma College, Alma, MI 48801 (lorenz@alma.edu or call 989-463-7203).
21. How do we get our issue recognized on social media as Flint has done? A: See the discussion of next steps at the end of this report. People in Flint will point out, attention to their problems has been short lived and already is forgetting them. The Attorney General has pursued some 'show trials' of low level health and environmental officials but the same was done with Velsicol and the final results did not help most exposed people.
22. Are epigenetic effects reversible? A: Only in vitro (outside of the normal biological context) by changing methylation.
23. What do daughters' eggs look like if she was exposed via breast feeding? A: See next question's answer.
24. Has there been intergenerational research on eggs? A: No, eggs are valuable and not easy to donate.
25. How do we change global society and economy to move away from these chemicals?

A: This is a great question raised by the PBB accident and other environmental exposure problems across Michigan and the world. One step is to push for regulations that impose the precautionary principle.

26. What are the relationships between levels of PBB and autism, ADHD, other mental health concerns? A: This is an important research question. There is a recent statement on this issue drafted by some of the world's leading neuro scientists – the “Project TENDR: Targeting Environmental Neuro-Developmental Risks. The TENDR Consensus Statement” published in *Environmental Health Perspectives*. It can be read at: <http://ehp.niehs.nih.gov/EHP358/>
27. What is the broad consensus about ‘safe’ body burdens of PBB? A: See the answer to question 5. One hope of the current PBB Registry work is to find more information on correlations between levels of PBB and human health outcomes.
28. How have we adjusted policy to reflect our notions on body burden? A: Of course, one theme of this conference has been the value of precaution. Much work has been done on mean body burdens, as mentioned in the answer to question 5. However, we do not know if the population average for the U.S. of chemicals like PBB is a safe level.
29. What are the congeners (break down versions) of PBB and what are their implications? A: According to Specialty Analytical, “PBBs and PBDEs are manufactured by bromination of biphenyl and diphenyl ethers. . . . There are 209 theoretically possible congeners divided into 10 congener groups from mono- to deca-PBB or PBDE.” These substances have been linked to neuro-development impacts, possibly to breast and digestive system cancers, and endocrine disruption. See answer to next question.
30. What is the relationship between cancers, autoimmune diseases, nerve damage and thyroid issues to PBB? A: There have been a number of peer-reviewed studies of the possible health consequences of exposure to PBB. The PBB Registry website has a list of a number of these studies. Go to: <http://pbbregistry.emory.edu/Research/index.html>
31. How do socioeconomic status and poverty play a role in exposure to contamination and in responses to contamination? A: After the questions session we heard three presentations on what is called ‘environmental justice.’ We welcome your involvement in various environmental justice projects both in Michigan – there is a conference in September, for example – and nationally. See below for the names of three environmental justice experts – two from Michigan and one national.
32. What are the current risks of breast feeding, blood transfusion and organ donating in those with PBB today? A: We know PBB has been passed from mother to child by breast feeding. For a list of research reports on other consequences of PBB exposure go to: <http://pbbregistry.emory.edu/Research/index.html>
33. What is the status of my health records and tests conducted by the state? A: If you want personal information, please give us your name and we will try to give you information on whom to contact. We currently are seeking the full cooperation of the Michigan Public Health Institute in sharing information from the old PBB Registry. They have had many problems with handling and organizing PBB records. Their contact information is: MPHI, Central Administration, 2436 Woodlake Circle, Suite 300, Okemos, MI 48864; Phone: (517) 324-8300. We welcome pressure on them to fully cooperate with our work.
34. How have we learned and prepared ourselves after the Velsicol PBB mistake? A: This conference and its follow-up is one way. We hope you stay involved in one of the PBB related organizations to assure we follow the issues raised by Velsicol’s carelessness.

35. How do we get in the nation's eye again? A: We welcome your help in this. Please see the final part of this report which proposes ways to follow-up the conference.
36. Why don't states have departments for environmental justice? A: Great question. In so many policy areas lower income and otherwise less-powerful people do not have a voice. Establishing an environmental justice department might correct or overcome this trend.
37. How do I understand what my PBB level means? A: A good place to start is the PBB Registry website, especially their 'Frequently asked Questions' at: <http://pbbregistry.emory.edu/FAQ/index.html> Another place to turn is the Agency for Toxic Substances and Disease Registry ToxFacts website on PBB: <http://www.atsdr.cdc.gov/toxfaqs/TF.asp?id=528&tid=94> If you have problems with these sites, please call Ed Lorenz at (989) 463-7203 or email lorenz@alma.edu.
38. Who do I ask to look into health trends and environmental concerns? A: If you contact the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall) you can ask your questions and seek help.
39. How do we get more government transparency on these issues? A: Participation in Pine River monthly meetings is one way to influence transparency. See answer above. Also reach out to your elected representatives in the state legislature and the U.S. Congress. Ask why we don't have transparency!
40. How can we assure communities are included as stakeholders in decision making? A: Get involved in the environmental policy process. If you live in the Pine River Watershed contact the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall) you can get help and become involved.
41. Is the cleanup of Superfund sites monitored? A: Yes. To learn more, if you live in the Pine River Watershed contact the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall).
42. What's being done about other locations of contaminant concerns like Sumner, Michigan [10 miles southwest of St. Louis on the upper Pine River] where cows were buried and that have become residential areas? A: To learn more, contact the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall).
43. How is our food being protected- especially in shipping and handling at factory farms? A: You should contact Gary Rayburn, Healthy Pine River, at GaryRayburn@hotmail.com Gary attended the conference as an observer and can help with these issues.
44. How are dangerous levels of soil contamination discerned? A: To learn more, if you live in the Pine River Watershed, contact the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall).
45. How can we fund more health screening? A: A subcommittee of the PBB Leadership Team is working on this. We would be glad to get help. Contact Ed Lorenz at lorenz@alma.edu.
46. How can we avoid biased contamination testing? A: Get involved in the community advisory group process? To learn more, if you live in the Pine River Watershed contact

- the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall).
47. How can we learn and connect with what other, similar communities have done in these situations? A: Great question. The Pine River Task Force and City of St. Louis have been trying to build an independent network of groups near other Superfund sites. We would love to have help on this. To learn more, if you live in the Pine River Watershed contact the Pine River Superfund Task Force at P.O. Box 172, St. Louis, MI 48880 or attend the monthly meetings (3rd Wednesday, each month, at 7:00 p.m. at St. Louis City Hall).
48. Michigan does have an environmental justice plan, how do we enforce and use it? A: As a result of the discussions at the conference, we are getting involved in the Michigan Environmental Justice Coalition. More information on the Coalition followed this session.
49. How do we know if there is contamination when we're looking to purchase land? A: By law, "if known" contamination on property that is being sold is supposed to be identified to purchasers. But no test is required for unknown contamination.
50. How do we gain access to where hot spots of health issues arise in Michigan (without a subscription fee-hospital diagnosis data)? A: One approach for environmental contaminants is to use the Agency for Toxic Substances and Disease Registry website, Using the example of DDT, you can get a Michigan map for DDT hotspots by going to: <http://www.atsdr.cdc.gov/substances/SubstanceMapResults.asp> They have similar maps for all states and a host of contaminants, including PBB.
51. Why isn't the Farm Bureau held accountable for distributing contaminated feed and what did they do with the 1.7 million they received in 1973? A: Primary liability rested with Velsicol, which made the shipping error resulting in animal contamination. However, both the Farm Bureau and Velsicol used effective lobbying of state and federal governments to be exempt from most costs of the PBB accident. More general public involvement is the best way to confront this type lobbying.
52. How can we get public access to health records? A: Under HIPPA, the Health Insurance Portability and Accountability Act of 1996, only you or your personal representative has the right to access your records. If this question arises from the failure of the Michigan Public Health Institute to make PBB records available for the PBB research, complain to them: MPHI, Central Administration, 2436 Woodlake Circle, Suite 300, Okemos, MI 48864; Phone: (517) 324-8300. We welcome pressure on them to fully cooperate with our work.

Comments (R=response):

We classified under comments those statements that did not request an answer but that were statements of what someone wanted done. In a few cases, we have listed a response, not as an answer but to clarify the understanding of the conference staff of the context of the comment.

1. Knowing PBB levels helped me cope with and understand my health and diagnosis.
2. We need to study levels of PBB in women who were exposed while in the womb. Physicians should be informed about PBB and its effects as well as the environmental history of their patients. R: There is a fact sheet prepared by the old Michigan

Department of Community Health for physicians who might treat former Velsicol workers. The fact sheet can be used even if you are not a former worker but believe you were exposed to chemicals from Velsicol. The fact sheet is available at:
http://www.michigan.gov/documents/mdch/Velsicol_MDandWorker_Factsheet_v2.1_183070_7.pdf

3. The Superfund program is not funded by a tax to petroleum products or chemical companies but by tax payer dollars. R: The Pine River Task Force shares this concern and welcomes help in renewing the Superfund tax.
4. We need to get results of PBB testing results to the public? R: This is the goal of our work. However, there I a problem with the Michigan Public Health Institute blocking record access and otherwise cooperating in this project. Complain to them at MPHI, Central Administration, 2436 Woodlake Circle, Suite 300, Okemos, MI 48864; Phone: (517) 324-8300. We welcome pressure on them to fully cooperate with our work.
5. For change to happen we need economic incentives and disincentives without harming industries such as agriculture.
6. We know of 80,000 + chemicals in the environmental, but there are more we don't know of because it's not mandated public knowledge. R: You might check out problems implementing the Toxic Substances Control Act.
7. When a chemical is determined to be toxic, it's only slightly altered and manufacturing continues. R: As 6. above, check out problems with the Toxic Substances Control Act.
8. Should take a precautionary approach to the production of chemicals. R: Agree!
9. Lansing has Grand Rounds Program (conference of medical topics) and people are welcome to speak on the Michigan Department of Community Health not being cooperative in the PBB past (contact Dr. Carla Guggenheim, who attended the conference, if you want to work on this)
10. One PBB collection site, where 5,000 cattle were buried near a lake, has high level of people exhibiting cancer. R: Need some specifics. Send to Ed Lorenz at lorenz@alma.edu
11. Testing soil for PBB may require an entirely different methodology than testing people.
12. GoFundMe and volunteering could be arranged to increase funding for testing. R: Let's talk!
13. Media and social scene may increase interest in being tested for PBB, we could also prioritize people who can give a history of impacted family members. R: Good idea!
14. We could use Velsicol to educate in schools on epidemiology, history and effects of pollution. R: Fully agree. Maybe start with one of the books sold at the conference.
15. We can talk to the Alma College Board of Trustees about funding testing or funding lab at Alma to give medical students hands on training while benefiting the cause. R: Please do so, but please thank them for their current support.
16. Law suits are more successful when seeking money to go to community initiatives like the research rather than personal claims.
17. The demography institutes of U of M may be interested in a collaboration with Emory and have funding from NIA. R: Can you give us contact names?
18. We can talk to insurance companies since they bear a lot of the costs from health complications.

19. Even if PBB is not detected, complications can be passed along from epigenetic effects (effects have been shown to pass down in the generations following animals that suffered famine).
20. Subsequent pregnancies and nursing burns fat and could dilute amount of PBB. Weight loss leads to the release of PBB.
21. Regulations don't get implemented or enforced because it interferes with business.
22. Epigenetics will pass health issues to future generations and become a societal burden that continues to cost money.

Environmental Justice Discussion:

Following the small group process, the conference focus shifted to presentations and discussions of the concept of environmental justice and its relevance for the 'PBB communities' experiences, needs and expectations. There were three presenters during the environmental justice sessions: Jeremy J. Orr, Natalie Sampson, and during dinner Matthew Tejada. Jeremy Orr is the Environmental Justice Coordinator with the Wayne State University Law School's Transnational Environmental Law Clinic and with the Environmental Justice Coalition. A graduate of Michigan State University College of Law and with a bachelor's degree in public health from MSU, he previously served as the Executive Director of the Mid-Michigan Environmental Action Council in Lansing. For two years directed environmental justice projects in Kalamazoo for Gamaliel, the national coalition of faith-based community organizations.

Natalie Sampson is Assistant Professor of Public Health at the University of Michigan-Dearborn. She conducts community-based research to study social and physical environments and their effects on human health. Dr. Sampson is a steering committee member of the Detroit Climate Action Collaborative and the Healthy Dearborn Coalition, and works closely with the statewide Michigan Environmental Justice Coalition. As a Reach the Decision Makers Fellow, with community and academic partners, she advocates for evidence-based policy at the U.S. Environmental Protection Agency related to environmental reproductive health issues. She has special interest in translation of research into community and policy change.

Matthew Tejada is Director, Office of Environmental Justice, at the U.S. Environmental Protection Agency in Washington, D.C. Dr. Tejada is a graduate of the University of Texas at Austin with a Ph.D. in Modern History from St. Antony's College, University of Oxford. His office at EPA works on issues of community engagement and works closely with the National Environmental Justice Advisory Committee. He also encourages external partnerships of EPA with other federal, state, local and tribal agencies in support of community initiatives to protect our common environment. He spoke on *The Future of Environmental Justice at EPA and Beyond*. He welcomed the conference participants to follow-up with environmental justice concerns raised at the conference.

Conference Conclusion and Follow-Up Discussion:

The three related environmental justice presentations, from a local, state and national perspective helped shape the concluding discussions at the conference. Fairly quickly the environmental justice presentations and subsequent questions returned to the similarities between the long-term

problems of St. Louis and the wider PBB community of farmers and consumers of food contaminated with PBB, and the contemporary crisis in Flint, Michigan and wider Michigan and Great Lakes Region water contamination problems in both Canada and the U.S. Attendees of the conference expressed, without dissent, that it is the right time to show the nation that Flint is not the exception, but rather Flint needs to be seen as the final consequence of a long-term faulty environmental-health policy process. Solidarity is what members of the conference felt needed to be shown between exposed communities across the Great Lakes Basin. Attendees expressed concern that there is a danger that each environmental-health problem will be treated as distinct and as a nearly unique failure of an otherwise effective human health and environmental policy process. There also was concern that communities facing environmental-health policy failure will be pitted against each other for scarce resources, as currently under Superfund. An urgent need is for communities to form an alliance and commitment to stick together so that resources are made available to restore all environments and protect the human health of everyone, and especially future generations.

Attendees also emphasized that despite talk of love for the Great Lakes, there is a major, widespread problem with abuse of water resources throughout the Great Lakes Basin. The water problems have become especially acute for many lower income, rural, inner city and otherwise less powerful communities and people. If nothing else, those with adequate resources can move or buy pure water through expensive monitoring and filtration. To move forward in reversing policies that tolerate or welcome resource abuse in the name of 'development,' there were several proposed steps. These ranged from a joint letter from conference participants to state and federal officials. While perhaps necessary, some observed we need a larger effort such as the previously discussed formation of an alliance with a formal governance structure of all communities experiencing chronic environmental-health problems. While there is some sense Flint is getting all the attention at the price of the Pine River, commentators observed the effort already is underway in Flint to shift away from a comprehensive or adequate solution to the city's health problems, to a few dramatic or high profile lawsuits against low level officials. In addition to seeking to collaborate with Flint, others pointed out there are major water issues in the Detroit area growing from the unaffordability of city water. The unaffordability arises from the processing costs of Great Lakes Basin water. These and other contamination related water and environmental-health issues provide a motivation for creating a powerful regional coalition bringing together community organizations across the Great Lakes Region in both the U.S. and Canada. We need to recall that at the conference, we had both Canadian and U.S. participation and even attendance of staff from the International Joint Commission.

There were at least three other specific policy recommendations arising at the end of the conference. One suggestion was that the State of Michigan should create an Environmental Health Office whose sole function is to focus on protecting human health from contamination and with the responsibility to focus on intergenerational health protection and authority to override development schemes and order testing of contaminants and processes as originally envisioned in the federal Toxic Substances Control Act. There was criticism of the contradictory responsibility of the current state Department of Environmental Quality, headed by a former agri-business official and with a responsibility to promote economic development. Second, there was a recommendation that the PBB Leadership Group, working with Emory University become actively engaged in global discussion of fire/flame retardants, especially concerns about the

continued production, use and exposures to FireMaster derivatives. Third, we need to weave through all our recommendations, actions and expectations what might be called as a meta-goal the Precautionary Principle.

As we reached the end of the concluding discussion, a number of attendees noted that the Pine River Task Force, the participants in the PBB Registry, Emory University and Alma College should be thanked for launching this process which had already achieved its initial goal by educating about current understanding of health needs to address the legacy of Velsicol's mistakes. There was general appreciation of the process that had begun with expert presentations and yet transitioned into open citizen engagement with the experts. Both the initial keynote address on the Precautionary Principle and the final Environmental Justice Session served to empower attendees and give a concrete focus to expectations of ways to produce a positive outcome of the conference.

Already members of several groups in the Pine River watershed and the farm families exposed to PBB have found common ground. This conference purposes were to equip citizens with health knowledge, introduce key human health experts to the exposed population and their descendants and open the door to concrete positive action to address health problems, especially those that cross generational boundaries. As the conference ended, participants were hopeful, optimistic, and prepared to advocate significant policy change. However, the determination to bring needed change was informed by understanding and frustration both with how long it has taken to resolve the problems along the Pine River and now with the contamination of the people of Flint and with agricultural based contamination in the Pine River watershed above Alma. The participants' determination was that these new proofs that the policy process remains broken will become the straws that break the camel's back of resistance to precautionary based environmental-health policy.