

# Communicating Breastmilk Biomonitoring Results to Project Participants

*The Moms and POPs Project promotes discussion of best protocols for biomonitoring breastmilk, so that communication of results to participants and the general public will result in better toxic chemicals policies and healthier personal choices, rather than a decrease in the number of women committed to breastfeeding. MaPP is a joint project of Making Our Milk Safe (MOMS) and the Commonwealth Biomonitoring Resource Center. The following article is presented with the hope that this information will bring value to discussions concerning best biomonitoring protocols when breastmilk is the biospecimen of choice.*

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## Introduction

This report explores different protocols for communicating results from breastmilk biomonitoring projects to project participants. This report is based on interviews carried out by the Moms and POPs Project (MaPP) with key researchers whose work demonstrates a diversity of approach to data communication.

The report includes:

1. A brief overview about biomonitoring and the concerns about making public information resulting from breastmilk biomonitoring;
2. A set of preliminary observations based on these reports about efficacy of data communication;
3. A list of those interviewed followed by descriptions of each of their projects.
4. A set of questions for those groups or individuals interested in breastmilk biomonitoring as a public health tool.

Each project description includes recruitment methods, communication protocols, and project outcomes and is categorized by whether the project was designed and implemented by a toxic chemicals policy advocacy group, or by an academic or government researcher, or by a combination of the two.

Each of the case studies demonstrates some of the options available in biomonitoring breastmilk. Each was designed within a particular context, and each represents a diversity of decisions among researchers about communicating data to project participants. We hope that these case studies will provide useful information. Please consider the following question while reading each of the case studies.

Which of the following biomonitoring project components are the best models for your country or community, should biomonitoring be initiated? What components need to be adapted so that cultural traditions are respected and informational needs of biomonitoring participants and their respective communities are addressed?

- a. Recruitment
- b. Counseling
- c. Data communication
- d. Follow-up

MaPP hopes that this report will be useful to groups designing breastmilk-monitoring projects. There are no answers that apply to every biomonitoring project, but by sharing ideas, we can deepen our insight about what kinds of communications protocols will be most suitable. At the end of this report is a set of questions concerning breastmilk biomonitoring. To discuss these and other questions, please consider becoming a MaPP partner. The MaPP website sponsors a discussion forum for those considering the implementation of breastmilk monitoring as a public health tool. We look forward to receiving comments and suggestions about how we might make this report more useful. (Contact [spatton@igc.org](mailto:spatton@igc.org) Sharyle Patton – MaPP Co-coordinator)

### ***Overview of the Issue***

The communication of information about the presence of toxic chemicals in human bodies raises many questions for those who conduct human biomonitoring projects and for the biomonitoring participants. Historically, biomonitoring projects were designed to assess human exposures to toxic chemicals to inform public health policy, or for the purposes of possible medical or other interventions. The use of biomonitoring for these and other purposes has increased in the past decade, and biomonitoring projects are currently being designed and implemented by health and environmental activists to raise public awareness about the need for toxic chemicals policy reform.

Whether a biomonitoring project is a research or advocacy tool or a combination of both, there is a growing trend to communicate biomonitoring results to project participants for a variety of reasons. Among these is a belief on the part of researchers or participants that the participants have a right to know their personal chemical body burden results, in the same way as they are routinely given results from other kinds of medical tests such as dental X-rays or mammograms. In some projects, participants themselves have designed the project explicitly to learn about the concentrations of toxics in their bodies, so that they might make healthier food and product choices or might more effectively engage in campaigns restricting the production and use of toxic chemicals. Others request the information so that they can

speak publicly about their results for purposes of creating discussion about prevalence and significance of toxic chemicals exposures.

However, there have been limited efforts to determine how researchers have developed biomonitoring data communication protocols, how well they believe these protocols have worked, and how they might change these protocols in future projects. Knowing about toxic chemicals in one's own body can be profound, perplexing, or dispiriting, or it can catalyze curiosity, a determination to make healthy choices or a commitment to engage in the political arena. These questions are especially important in projects where breastmilk is the biospecimen of choice.

Breastmilk, because of its high fat content and because of its relative ease of collection, is an ideal biospecimen to test for levels of a class of lipophilic, or "fat-loving" chemicals called persistent organic pollutants (POPs). Assessing the levels of POPs in breastmilk can help establish baselines of exposure to these toxic chemicals as well as help determine the effectiveness of regulations that ban or severely restrict their use. But does the publicizing of information about toxicants in breastmilk scare women away from breastfeeding, or create fear or denial? Breastfeeding is even more important in a contaminated world, because of the enormous health benefits that breastmilk conveys to the nursing child, but there are difficulties in transmitting simultaneously two seemingly competing messages, one stating that breastmilk contains industrial or environmental chemicals considered to be toxic to humans and ecosystems, and the second stating that breastmilk remains critically important for the health of the child despite the presence of these toxins.

In order to explore answers to some of these questions, the Moms and POPs Project (MaPP - a project of the Commonwealth Biomonitoring Resource Center and Making Our Milk Safe) interviewed a selected group of researchers and project coordinators about their studies and projects. We wanted to explore the range of protocols used in breastmilk monitoring to learn more about what processes were more effective in support of breastfeeding, more responsive to women's concerns about toxic chemicals exposures and health outcomes, and more adept at publicizing biomonitoring data in ways that informed individuals, communities and public health officials about toxic chemicals exposures.

Our fundamental question has been, "Is it possible to monitor breastmilk, an ideal food for babies, in ways that will ultimately lower the levels of toxic chemicals in all our bodies without lowering the number of women who chose to breastfeed? A first step in this inquiry is exploring how information about toxicants in breastmilk affects the commitment to breastfeed by those who have contributed breastmilk in biomonitoring studies. *MaPP will continue to interview additional researchers over the next year, and will include interviews with participants in biomonitoring projects. Please look for updates on the MaPP website.*

### ***Project Observations***

Each biomonitoring project discussed below was specifically designed for a unique set of circumstances, and drawing general conclusions is difficult. However a few important observations stand out concerning the necessary components in biomonitoring projects to ensure that breastfeeding is supported.

1. Information about personal levels of toxic chemicals in breastmilk did not discourage breastfeeding when the biomonitoring project was designed and implemented by a self-identified and cohesive community, when there existed well-developed plans for the use of the biomonitoring results which were shared with participants, and when biomonitoring project participants were well informed about the benefits of breastfeeding and strongly committed to breastfeeding.
2. Ample counseling throughout the biomonitoring project, including during the recruitment period and continuing after results are communicated, was critically important in alleviating participants' concerns about toxicants in breastmilk and the safety of breastfeeding.
3. Advocacy projects that biomonitor breastmilk in order to support political activities or campaigns tended to provide more information, counseling, and follow-up activities for participants than did those researches engaged in biomonitoring activities as part of epidemiological studies, and more dialogue between academic researchers and advocacy researchers could be mutually beneficial.

### ***List of Interviewees***

1. Sonya Lunder, MPH, is a research scientist at the Environmental Working Group, a public interest organization based in the United States. EWG is a recognized leader in scientific research in support of toxic chemical policy reform. Lunder was the principle investigator for a project in 2003 that measured the levels of flame-retardants called PBDEs in the breastmilk of 20 American women from 14 states within the United States. Type of Project: Advocacy
2. Nerissa Wu is a research scientist at the California Department of Public Health. In 2007, she was conducted a biomonitoring project that measured the levels of flame retardant's (PBDE's) in the breastmilk of 46 women in Boston, Massachusetts. Type of Project: Academic
3. Clark Williams-Derry oversees research programs for Sightline Institute, a private non-profit research and communication center in the Pacific Northwest United States. He was the main researcher for a Sightline project that looked at levels of flame-retardants in the breastmilk of twenty women living in the Pacific Northwest. Type of Project: Advocacy and Research
4. Sherry Hatcher, PhD, is a psychology professor at the Fielding Graduate Institute. In 1974, cattle feed in Michigan was accidentally contaminated with high levels of Polybrominated Biphenyl's (PBB's). Due to this accident, people in Michigan were exposed to high levels of PBB's through their consumption of contaminated meat and dairy products. Hatcher conducted a study with 90 nursing mothers about the "psychological experience of nursing mothers learning about the presence of a toxin in their breast milk." Type of Project: Research
5. Katsi Cook, a midwife and healer in the Mohawk community in Akwesasne, New York, helped design and implement a project that analyzed the breastmilk of Mohawk women for the presence of PCBs. Because of environmental contamination, the community was

concerned that breastmilk might have become unsafe. Type of Project: Advocacy and Research

6. Henk Bouwman, PhD, is a researcher and professor at the School of Environmental Sciences and Development in South Africa. His research focuses on assessing levels of DDT and pyrethroids in breastmilk of women in rural areas where these chemicals are sprayed regularly to prevent malaria. Type of Project: Research

7. Janna Koppe, PhD, is a neonatologist and university professor in Holland. Aware of environmental contamination by dioxins from incineration, Koppe and her research team conducted a study to test the levels of dioxins in new mothers to explore levels of human exposure to dioxins. Type of Project: Research

### ***Interview Protocol***

Each researcher participated in a one-hour phone or face-to-face interview about their experience conducting a breastmilk biomonitoring study or project. The questions were designed to obtain information about each phase of the study, including the processes for recruitment and the protocols for communicating information about both personal and pooled information from the project. We also asked each researcher to assess the success of their protocols and describe how they might improve upon them in subsequent biomonitoring projects. Each of the interviews was recorded, transcribed, and summarized for major findings of the study. The set of interview questions is included in the appendix.

### ***The Studies***

#### **1. Environmental Working Group: USA**

In 2003, the Environmental Working Group (EWG) tested the levels of flame-retardants (polybrominated diphenyl ethers PBDEs) in the breastmilk of 20 American women in 14 states.

EWG staff scientist Sonya Lunder believes biomonitoring projects that communicate individual results to participants can be especially effective in telling the story of toxic chemicals contamination in all our bodies. She states, “Biomonitoring is less about testing my body and protecting my kid and more about bringing all of us together as a community to advocate for change.” She believes that mothers who know about the levels of toxic chemicals in their own breastmilk are passionate messengers, who can deliver information about toxic chemicals body burdens in ways that will attract the attention of community members and which will ultimately lead to reform and to ensuring that “breast milk, nature’s perfect food, will remain the best food for babies.”

Flame retardants (PBDE’s) belong to a set of chemicals called Persistent Organic Pollutants or POPs. All POPs are lipophilic, or fat-loving, and their presence is easily measured in breastmilk because of its high fat content. Although legislation has banned the production and use some forms of PBDEs in the EU and in some states in the United States, PBDEs continue to be found at levels of concern in human bodies. The highest levels globally are found in breastmilk of women in California.

## **Recruitment**

In 2002 -2003, EWG recruited women through environmental health networks, word of mouth, and through other informal networking, including an Internet web-based sign-up. Participants were selected from various geographic locations throughout the United States and all were fluent in English, well educated, and relatively affluent. Most participants were women who regularly explored the Internet for health information, and many were members of public interest organizations concerned with health and the environment issues. At least half of the women recruited had a high level of awareness about contaminants in breastmilk, and EWG discussed with participants the strong possibility that analysis would indicate detectable levels of flame-retardant in their breastmilk.

Ms. Lunder says that it was important to discuss one important drawback of participating in the project, which has to do with the burden of information. Once an individual learns about the levels of toxic chemicals in her body, she carries this information with her daily and forever. The information cannot be “unlearned.” Each individual’s reaction to learning about toxic chemicals in her or his body is unpredictable, and may change over the course of time. Given these concerns and their own objectives, the EWG decided after this project to focus on the testing of cord blood, the analysis of which gives a picture of in utero exposure, a key concern for exploring how in utero exposure to toxic chemicals is linked to adverse health outcomes later in life.

## **Protocols**

Women were selected who were preparing to give birth to their first child and who were committed to breastfeeding with relatively few concerns about contributing the amount of milk required for analysis. Samples were collected within a few months of giving birth. Factors such as exhaustion, health problems and post-partum recovery prevented some of the women recruited from later participation, and many women found the actual collection process, which required hand-pumping, to be difficult. The amount of breastmilk required for analysis proved to be problematic for some as well.

## **Materials and Information**

At the time of sample collection, participants completed an exposure assessment questionnaire to provide information about their lifestyle and home and work environment. Participants were given fact sheets about the importance of breastfeeding which specifically addressed concerns about toxic chemicals exposures, information about how to hand pump, contact information for a lactation consultant to help with breastfeeding and the collection process, and information about the toxic chemicals found in the average human body. After the results were communicated, participants were given general information about how to avoid exposures to PBDEs. Throughout the project, EWG continually offered support to encourage breastfeeding, depending on individual participant needs.

## **Communication of Results**

Flame-retardants were found in the breastmilk of all twenty women. Individual results were given to each participant by telephone, and Ms. Lunder organized a subsequent, optional

conference call for participants that provided an opportunity for further questions as well as a sharing of reactions to the biomonitoring project results.

Results communications brought a range of reactions from participants, and reactions were unpredictable. One participant with high levels of PBDE's in her breastmilk was very "nonchalant" when she received her results. Another woman was dismayed that her personal PBDEs levels were high because she had taken extensive precautions to protect her daughter from toxic chemical exposures. One woman said, "I would definitely choose to do this again but I was totally unprepared for how I felt about it." Women tended to have stronger reactions to their results when they started comparing their results to the rest of the group. Lunder strongly believes that it is important for the researcher to be prepared for a variety of reactions from participants upon receiving their results and to be as available as possible to address participant's concerns.

Because results were received up to nine months after samples were collected, some women had already ceased breastfeeding. There is no evidence that anyone ceased breastfeeding in reaction to learning about the levels of PBDEs in their breastmilk; but because breastfeeding had ended for some participants well before they received their personal data, the impact of the results on the commitment to breastfeed was difficult to assess.

### **Project Outcome**

About half of the women who participated in this project were a part of the project release effort in the media, which included broadcasting the findings on national news. These women appeared on camera breastfeeding their babies to emphasize how important breastmilk is for the health of the baby, while simultaneously talking about the need to get toxic chemicals out of the environment and out of all our bodies. Some of these same women also engaged in community outreach by talking to their local legislators or moms' groups about the importance of addressing breastmilk contamination through legislation and policy change.

Following the release of the report, state legislation was introduced in California, Maine, and Michigan that would restrict the use of several types of flame-retardants. In May 2003, the Maine legislature passed a bill requiring electronics manufacturers to phase out all brominated flame retardants. In July 2003, California banned Penta and Octa-BDEs but did not ban Deca-BDEs, which is the most widely used flame retardant.

Ms. Lunder believes that breastmilk biomonitoring is best conducted within the context of advocating for policy change to protect our health and our environment. The burden to prevent children from exposure to toxic chemicals shouldn't fall on parents alone. She emphasized that "it's important that parents have the time, energy and willingness to explore how to keep their children healthy and strong, but in the long term, it will be more effective for parents to also work with their communities to remove bioaccumulative and persistent chemicals from consumer products altogether." Ms. Lunder believes that mothers who participate in a breastmilk biomonitoring project are extremely credible messengers about the toxic chemicals found in all our bodies because their personal stories concerning the sensitive

issue of contaminants in breastmilk captures attention in ways that everyone can understand and be concerned about.

An executive summary and full report of this project are also available to the public on the EWG website at <http://www.ewg.org/reports/mothersmilk/es.php>

## **2. Dr. Nerissa Wu, Boston, Massachusetts, USA**

Dr. Wu was lead investigator in a study conducted by the Boston University School of Public Health in cooperation with other academic institutions that documented relationships between levels of fire retardants (Polybrominated diphenyl ethers, or, PBDEs) in breastmilk with food consumption patterns and with house dust concentrations. The breastmilk was collected from 46 first-time mothers, 18 years or older who had lived in the Greater Boston area for over three years at time of delivery. Household dust in commonly used areas was also tested in the homes of a subset of participants. The study concluded that there was a significant, positive association between levels of PBDEs (with the exception of PBDE 209) found in breastmilk and PBDEs found in dust as well as with dietary habits, particularly the consumption of dairy products.

### **Recruitment**

Participants were recruited during the second trimester of pregnancy at three sites: a health center in Lowell, Massachusetts that serves an ethnically diverse, working class community; a private obstetrics office in Cambridge, Massachusetts; and a maternity center in Brookline, Massachusetts. The Cambridge and Brookline facilities serve similar populations, predominantly white and highly educated. Dr. Wu was breastfeeding at the time of recruitment and actively breastfed her baby while recruiting participants in the Lowell center, in an attempt to raise awareness about the value of breastmilk and to encourage project engagement. Many of the young mothers encountered at the Lowell Center were adverse to breastfeeding and considered it “something only poor people do.” The study was committed to economic diversity; however, the study team was able to recruit five participants from the Lowell Center.

### **Protocols and Educational Materials**

All participants were given information about PBDEs and biomonitoring as a means to assess levels of PBDEs. Extensive materials about the benefits of breastfeeding, many of which had been developed by Physicians for Social Responsibility, were distributed with the recruitment materials. Because breastfeeding rates in the area were low in the community served by the Lowell Center, the research team provided a lactation consultant who was available to the participants throughout the study, as was the research staff. Participants were given a questionnaire intended to assess exposure pathways. Participants were asked to indicate in the questionnaire whether they were interested in receiving personal results. All participants were given a small stipend in exchange for breastmilk samples.

### **Communication of Results**

When results were available, participants were sent a letter, along with a personal code, which could be used to access personal results by calling Dr. Wu. In addition, two physicians from Physicians for Social Responsibility were available for further consultation. Those who

requested results were given comparison data from other studies, and the communications team prepared materials that would explain such terms as “mean,” “median,” “ppb,” etc. The project coordinators also discussed with participants current animal studies that link PBDE exposures to health outcomes, and how this information is relevant to health outcomes in humans.

Only 35% of participants initially called to request results. In subsequent follow-up calls, 60% of participants requested results, and researchers concluded that results needed to be more easily accessible.

Reactions to results were varied. Some women with low levels felt that had their levels been higher, they might have reconsidered breastfeeding. Those with higher levels felt that the ongoing support of research staff during the project made a substantial difference in their decision to continue to breastfeed. But most women were deeply committed to breastfeeding from the very beginning of the project. All those who received personal results felt that the ongoing support from the researchers during the project was critically important. None of the women said that learning about their personal levels of PBDEs caused them to cease breastfeeding.

### **Project Outcomes**

The study found statistically significant, positive associations between PBDE concentrations in breastmilk and house dust as well as with reported dietary habits, particularly the consumption of dairy products. Due to low detection rates, it was not possible to draw conclusions about the association between BDE-209 in milk and dust. The results do support the hypothesis that the indoor environment and diet both play prominent roles in adult human exposure to PBDEs.

Dr. Wu stated that the majority of participants were highly educated and deeply committed to breastfeeding, which helped them assess information about toxic chemicals and about the importance of breastfeeding in ways that didn't move them away from their original decisions to breastfeed. The breastmilk study was a very good tool to educate participants about toxic chemicals and environmental health issues, and all participants who received personal results were interested in making personal choices based on the information from the study. However, the source of PBDEs in household dust is uncertain, and information about avoiding exposures could only be presented in terms of suggestions.

The continual encouragement by researchers and their availability to answer questions and to discuss the significance of findings was enormously important throughout the course of the project, and Dr. Wu believes that any breastmilk monitoring project needs to incorporate a similar level of support, although the extent and scope of information will need to be different depending on cultural traditions and community values, as well as on levels of education of participants. Many of the participants in this project reported that the “breast is best” logo, the context in which results were provided and the manner in which results were personally communicated were all key to their commitment to continue breastfeeding.

Dr. Wu points out that most physicians know little about toxic chemical body burdens or the levels and significance of toxic chemicals found in breastmilk, and are therefore generally unprepared to respond to questions women may have about breastfeeding.

Human Exposure to PBDEs: Associations of PBDE Body Burdens with Food Consumption and House Dust Concentrations: Nerissa Wu,<sup>†</sup> Thomas Herrmann,<sup>‡</sup> Olaf Paepke,<sup>‡</sup> Joel Tickner,<sup>§</sup> Robert Hale, Ellen Harvey, Mark La Guardia, Michael D. McClean,<sup>†</sup> and Thomas F. Webster\*<sup>†</sup>

Boston University School of Public Health, Eurofins ERGO Research, Center for Sustainable Production, University of Massachusetts Lowell, and Virginia Institute of Marine Science Environ. Sci. Technol., 2007, 41 (5), pp 1584–1589

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Participant experiences in a breastmilk biomonitoring study: A qualitative assessment: Nerissua Wu, Michael D McClean, Phil Brown, Ann Aschengrau, and Thomas F Webster Department of Environmental Health, Boston University School of Public Health Environmental Health, 2009

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### **3. Katsi Cook, Akwesasne Mohawk Tribal Community, New York, USA**

#### **Project Description**

Katsi Cook is an educator, midwife and community health expert who has worked and lived for decades with the Mohawk tribal community in upstate New York. She is known globally for her work in promoting good community health practices.

In the 1980's Ms. Cook became deeply concerned about the possibility of PCB contamination of breastmilk after research indicated that three companies, Alcoa, Reynolds and General Motors had been discharging toxic wastes into the Racquette, Grasse, and St. Lawrence rivers. By the late 80's, turtles, fish, and frogs were all found to contain toxic chemicals, some at levels that would qualify them as toxic waste. Today two Superfund pollution clean-up sites have been identified close to reservation lands. Because tribal members depended on fish for a large part of their diet, Ms. Cook was concerned that high fish consumption might have made breastmilk unsafe for use. She approached the New York State Health department about conducting a biomonitoring project, and over a million dollars was raised to conduct a series of studies, which would assess dietary patterns of Mohawk women, and the PCB concentrations in breastmilk and in serum.

#### **Protocols**

Ms. Cook worked with tribal councils to discuss the project and to develop an agreement with researchers delineating responsibilities and a decision-making process that would

respect the cultural traditions of the Mohawk community and ensure that the tribe was an equal partner in the project. The Mohawk tribe was adamant that researchers were not invited to play an “outsider” role, i.e., collecting samples for analyses with no responsibility towards the goals and needs of the community regarding the project process.

Ms. Cook stated in our interview, “In small communities people remember everything and therefore it is important to look at social, ecological and the political climate in the community where you are conducting a biomonitoring study.” Within the Mohawk community women’s lives are lived out in concentric circles of family, church, environment, and cultural traditions, and biomonitoring processes needed to be carefully attuned to the complexity and interrelatedness of tribal institutions and to the relationships among tribal women themselves. Encouraging mutual support among the women based on their close relationships as they participated in the project was important.

From the beginning, Ms. Cook framed the project as a tool that community women could use to make change. Giving breastmilk was seen as a “badge” of women’s commitment to a healthier environment. The presence of toxic chemicals in breastmilk was seen as a violation of body integrity and participants actively engaged in planning the project to ensure that it would be conducted in ways that would allow them to reclaim authority over their own bodies, connecting each step of the project to the idea that every mother has a right to breastfeed her baby and that every baby has the right to receive clean milk.

Ms. Cook recruited 97 participants from 1986 through 1992 for a series of testing projects that measured levels of contaminants in both women and men in the Akwesasne community. A population of 154 Caucasians was recruited as a control group. Throughout the project, the community and researchers all promoted breastfeeding and promoted a positive image of mothering. Each participant was given a \$20 voucher to buy baby supplies from a local store. The New York Health Department provided hand pumps for breastmilk collection, and Ms. Cook instructed participants in their use.

## **Results**

Once the project was completed and results analyzed each woman was given her results in a private meeting. Subsequently the tribe conducted a community meeting to discuss overall results and to plan next steps, based on results of the study. The results from 1986-89 indicated that Mohawk women had levels of PCBs in breastmilk approximately twice as high as the levels found in the control group and suggested that these levels were the result of eating PCB-contaminated fish from local lakes. Subsequent decreases measured in testing done 1990-92 were linked to lower fish consumption, likely based on fish consumption advisories for pregnant or nursing woman. Ms. Cook reported that the community was both grateful for the information about their body burden levels and angry that a nearby industry had poisoned the land, fish, and the bodies of community members.

## **Outcome**

Most tribal members decreased consumption of fish. The tribe used the biomonitoring results for political advocacy campaigns, including asking for remediation of the contaminated rivers and tribal lands.

There was no follow-up to determine if there was a decrease in rates of breastfeeding as a result of the study.

Ms. Cook pointed out during the MaPP interview that change is most likely to occur when it called for from within a committed and cohesive community able to utilize tools such as biomonitoring to support advocacy activities. To help guide community-based biomonitoring research practices, the Akwesasne developed a protocol that outlines the components of good relationship between a community and outside researchers, one that ensures equal partnership in all aspects of the project. This protocol has served as a model for other communities across the United States that have an interest in initiating research projects using outside expertise. See: Protocol for Review of Environmental and Scientific Research Proposals; Akwesasne Task Force on the Environment (ATFE) Research Advisory Committee (RAC) copyright 1996 <http://www.northnet.org/atfe/Prot.htm>

Katsi Cook stressed that a sense strong responsibility of stewardship for their land and a shared knowledge of tribal traditions and history among the Mohawk tribal community framed how the biomonitoring study was carried out, and how the resulting information was shared among tribal members and later used to demand cleanup of the waterway and of the adjoining dumpsites.

Katsi Cook said, “Our grandmas tell us we're the first environment, that our babies inside of our bodies see through the mother's eyes and hear through the mother's ears. Our bodies as women are the first environment of the baby coming, and the responsibility of that is such that we need to reawaken our women to the power that is inherent in that transformative process that birth should be.”

We have so much toxic contamination of our environment, we can't eat the fish anymore. It's really stressful to live in a place where your teachings, your traditional teachings, have been violated in this way. Your very identity as Kanienkehaka or Mohawk people has to do with keeping the agricultural cycle alive. That cycle of continuous creation is the very basis of what we know as human beings. That's why we're here on this planet as Kanienkehaka, to keep the way of the teachings of our original ancestors alive, to continue to do those things, our original instructions. Birth is a part of all of that, and all the things we choose to work on as human beings.”

Am J Epidemiology. 1998 Jul 15;148(2):164-72: Fish consumption and breast milk PCB concentrations among Mohawk women at Akwesasne.  
Fitzgerald EF, Hwang SA, Bush B, Cook K, Worswick P.  
Bureau of Environmental and Occupational Epidemiology, New York State Department of Health, Albany 12203, USA.

#### **4. Dr. Sherry Hatcher, Michigan, USA**

Sherry Hatcher, PhD, a psychology professor at the Fielding Graduate Institute, conducted a study that explored how women who had been exposed in 1973 and 1974 to high levels of Polybrominated Biphenyl (PBBs) reacted to learning about levels of PBBs in their breastmilk

and whether their reactions affected their ability or decision to breastfeed. The biomonitoring study had been conducted by Michigan Public Health Department.

In 1973, cattle feed in Michigan was accidentally contaminated with high levels of Polybrominated Biphenyl's (PBB's), manufactured chemicals that are used to fireproof products such as computer monitors and televisions, when PBB was mistakenly substituted for magnesium oxide, a dairy cattle nutritive supplement. Once the accident was discovered, 800 farms were quarantined and tens of thousands of cattle were destroyed. However, by the time such measures were taken, Michigan residents had been consuming contaminated meat and dairy products for nine months. (Chen 1979)

An independent lab, the Environmental Research Group, tested 2000 women for the presence of PBBs, and in 1976 the Michigan Public Health Department reported that 96% of the breastmilk samples from a representative population of nursing mothers in the lower peninsula of Michigan showed detectable levels of PBB. State agencies were uncertain about what this data meant in terms of possible harm to the nursing infant and stated that they were "unable to specify a 'safe' level of PBB in breastmilk or to otherwise to advise mothers on the relative risks and benefits of breastfeeding at various PBB levels." (Brilliant, et al, p.4.)

Researchers and medical professionals were divided about the significance of these high levels for the health of the nursing infant and the safety of breastfeeding. Some believed that there was indeed danger, given that PBBs are considered a carcinogen. Others felt the enormous benefits of breastmilk for the infant far outweighed the danger of exposing a nursing infant to PBBs. The Michigan press publicized this debate, and other information about the accident including the diseases exposed cattle were suffering from, including weight loss, anorexia, skin lesions, birth defects and decreased milk production. PBBs are considered toxic to humans and ecosystems.

Hatcher was a nursing mother herself in Michigan and she was interested in how those women whose milk was analyzed reacted to contradictory information about the safety of breastfeeding, and whether their reactions had an effect on their ability to breastfeed or their decision to continue to breastfeed. To explore these questions, she conducted a study with 97 nursing mothers. Her hypothesis was that the higher the level of PBBs in an individual's breastmilk, the more likely the woman would be in denial about the problem.

### **Protocols**

Unfortunately the state delayed informing citizenry about the PBB contamination of food products following the accident, and as a consequence, people were unable to take any preventative measures to avoid exposure. When information began to circulate about food contamination, arrangements were made to test breastmilk. Several thousand women willing to pay the \$25 testing fee were tested, and results were returned to those who requested this information.

Dr. Hatcher wanted to find out how women were coping with the ambiguity and whether women would report any stress resulting from receiving biomonitoring results and other information from the state, which included a summary of the findings but contained

contradictory and inconclusive information about the safety of breastfeeding, especially when exposures were high. Dr. Hatcher also thought those tested might find it useful to have an outlet to express their concerns and confusion. She was able to contact by mail every tenth women who had been tested, working in cooperation with the ERG lab, and she then sent a questionnaire to all those who responded. Dr. Hatcher sent the results of her research compiled from the questionnaires to all who had participated. Dr. Hatcher made no direct contact with any of the biomonitoring participants.

None of the women who filled out the questionnaire contacted Dr. Hatcher for more information, even though this had been offered as a next step.

### **Project Outcome**

Dr. Hatcher found that among the women she surveyed, 67% did not remember their biomonitoring data, lost the letter giving their results, or misremembered their data. Only 38% understood that PBB would be in the breastmilk fed to their nursing infant. 52% felt that PBB would have no effect on their baby, and only 3% thought PBB might have an adverse effect. Most did not have a clear understanding about what PBB is, how it was used, and how they might have been exposed. Only 15% changed their decision to nurse their infants and switched to bottle-feeding instead. But most women said they would advise friends to have breastmilk tested, which indicates some ambivalence.

Interestingly, women with higher levels tended to be in denial about the toxics in their breastmilk. But there were other responses indicating concern. Some women tended to attribute any health outcome, such as a cold, to PBB exposure, whereas others indicated discouragement about breastfeeding, when, in filling out the questionnaire, they inadvertently misspelled key words, writing for example “brat milk,” instead of breastmilk, or “oxytoxin” instead of oxytocin. Some women reported that their breastmilk had dried up upon hearing the news about PBB contamination.

### **Conclusions**

Dr. Hatcher is concerned about psychological reactions in general, as the increase of information about toxic chemicals in food and products continues to raise public awareness about the linkages between health and toxic chemical exposures. She states in her report, “a mother’s psychological reaction to the chemical contamination of her breastmilk could have lasting developmental effects on her child.”

Hatcher, SL (1982). The Psychological Experience of Nursing Mothers upon Learning of a Toxic Substance in their Breast Milk. *Psychiatry*, 45, 172-181.

## **5. Northwest Environment Watch, Pacific Northwest and Montana, USA**

### **Project Description**

The purpose of this project was two-fold: the researchers were interested in comparing levels of PCBs and PBDEs in breastmilk. Previous research had measured levels of PBDEs in North American residents at ten to forty times higher than levels found in Japanese or European residents. The advocacy groups’ representatives were interested in using the

resulting data to create public awareness about the need for improved toxic chemicals regulation. By personalizing environmental pollution through biomonitoring individuals in the Pacific Northwest and Montana, advocacy groups wanted to highlight the need to restore and maintain some of the previously pristine qualities of an area long proud of the health of both its ecosystems and its human inhabitants.

### **Recruitment**

The Northwest Environment Watch (NEW), a public interest group working in Oregon, Washington, Montana and British Columbia, recruited participants by placing ads in local newspapers and by personal recruitment through a lactation consultant. Forty participants were recruited, with ten each coming from the greater metropolitan areas of Seattle, Portland, Vancouver and Missoula. NEW originally intended to recruit participants from a wide range of socio-economic and ethnic backgrounds, but recruiting women from lower-income communities was difficult. Attempts to recruit women through Women, Infants and Children (WIC) clinics were not possible, because WIC clinics were concerned that the project would deter women from breastfeeding.

### **Protocols**

NEW used the collection and analytic protocols recommended by the Environmental Working Group, who had conducted a breastmilk monitoring project previously. The project organizers worked closely with a pediatrician who had an interest in breastmilk and toxicants issues in designing and implementing the project. The pediatrician reviewed all results from the laboratory analysis before information about individual results was sent to participants.

### **Materials**

Following recruitment, the lactation consultant was able to meet with each of the Washington, Oregon, and British Columbia participants in their homes. She was able to personally distribute information about the substances being tested for and about the benefits of breastfeeding, and respond to questions.

### **Results Communication**

Once the data had been received and analyzed, the lactation consultant called each participant personally to say that the individual results were being sent and to suggest that each participant consult with the project pediatrician with questions or concerns. Two mothers from the forty participants contacted the pediatrician. The project staff felt that the continual and personal support provided by the lactation consultant for participants throughout the duration of the project was key to the success of the project. It is likely that most participants had few questions upon receiving results because of ongoing support and opportunity to discuss issues surrounding the contamination of breastmilk.

### **Results**

The results from the project were presented at an international scientific conference in Toronto. Findings of the project indicate that thirty percent of the women tested had higher levels of PBDEs than PCBs. In each of the regions, advocacy groups released information about the project in press conferences, featuring project participants who spoke about their reactions to learning about toxic chemicals in their bodies. In Washington, local toxics

organization utilized the report and the testimony of the participants to pass one of the strongest anti-PBDE legislation in the country, banning all PBDEs from commerce.

### **Conclusions**

Because the results became available up to a year after breastmilk collection, and often well after many of the participants had ended breastfeeding, there was no possibility to determine whether personal information about breastmilk contamination affected decisions to continue breastfeeding. The project staff did encourage participants to breastfeed their next child, given the benefits of breastmilk. No follow-up was carried out to evaluate participants' reactions to the project process and the information received about personal body burdens of PBDEs and PCBs.

The advocacy members of the project team recommend that others engaging in breastmilk monitoring projects include professional backing from a physician educated in toxic issues, and ongoing verbal contact with participants to prepare them for receiving personal results, since both of these components helped maintain a sense of trust and community within this project.

Toxic Flame Retardants Found in Puget Sound Women.

[http://www.sightline.org/press/releases/rel\\_pbdes\\_feb04\\_wa/?searchterm=contaminants](http://www.sightline.org/press/releases/rel_pbdes_feb04_wa/?searchterm=contaminants)

PBDEs Greater than PCBs in 30% of Breast Milk Samples from the Pacific Northwest. Jianwen She. Arthur Holden. Margaret Sharp. Clark Williams-Derry 2, and Kim Hooper1  
1Hazardous Materials Laboratory. California Department of Toxic substances Control, Berkeley, CA 94710. U.S.A.  
2 Northwest Environment Watch, Seattle, WA, USA

## **6. Dr Henk Bouwman, South Africa**

### **Project Description**

Because of resurgence in cases of malaria due to a resistance developed by disease vector mosquitoes to pyrethroids, DDT was reintroduced as an anti-malarial agent in South Africa. Dr. Henk Bouwman analyzed breastmilk for the presence of DDT and its metabolites and for the presence of pyrethroids.

### **Protocols**

152 breast-milk samples were collected from three towns in KwaZulu-Natal, in South Africa. Women were recruited from health clinics in the towns of Jozini, Mkuze and Kwaliweni. The first two clinics serve people from areas where malaria control is endemic. Breastmilk is the primary food for infants and many women breastfeed their children up to two years, which can lead to a significant transfer of pollutants to infants.

Women were given stipends of food for contributing samples, because male family members or male villagers would quickly steal any money given them. Women in rural South Africa

have little political power, are not engaged in community decision-making, and are considered to be, at best, “second class citizens.” (Dr. Bouwman)

Currently DDT is in use in agriculture and as a pesticide in household gardens and for internal spraying of walls and in bed nets, but in the five year period between 1995 and 2000 a synthetic substance, deltamethrin, a pyrethroid, was introduced. DDT was reintroduced and used to spray the interiors of houses, after a malaria outbreak indicated that pyrethroids were no longer successful in halting the spread of the disease. The mothers therefore experienced five years of no DDT for malaria control, with pyrethroids used instead, followed by exposure to a single application of DDT.

Women were asked to give breastmilk samples and most women agreed to contribute, expressing milk manually. Both first time mothers and mothers with more than one child were asked for breastmilk samples. A total of 152 mothers were enrolled in the study. Many of the women were teenagers with first or second children, because women are given stipends for each child born. Each woman signed a consent form and a translator was available to make sure each woman understood the purpose of the monitoring study and their rights to decline participation in it.

### **Materials**

DDT is considered beneficial in South African rural communities as a substance that leads to good health, since it does prevent malaria. Most women tested knew very little about the health effects associated with DDT or with pyrethroids, and the project investigators distributed no information about pesticides with the women, given the high incidence of malaria in much of the area, the high rate of poverty, and the likelihood that many of the women may have been HIV/AIDs positive. All these factors make breastmilk monitoring a complex issue, and the problems of survival in general are overwhelming. Dr. Bouwman suggests that the short-term use of a pesticide known to cause harm to humans but with the capacity to stop the transmission of a deadly disease, at least until malaria-bearing mosquitoes develop immunity, may be the best decision. Certainly this is the decision made by the South African government in the case of this community. There is no health service or public interest group within this community mobilized to halt the use of DDT or to push for alternative measures to roll back the malaria, nor are there government resources that would support such alternative measures.

### **Data Communication**

Most of the women who gave samples had no known home address and there was no way to locate them to deliver results. Neither were results given to the communities where the women were likely to reside. Researchers were aware that formula was financially out of reach, access to clean water was limited, and the women recruited have no choice other than to breastfeed. Therefore there was no concern about data discouraging women from breastfeeding, whereas there was concern that women would likely find the information irrelevant or possibly consider the information simply another burden to bear.

However, results of this project were published in a scientific journal and publicized in the print and television media. Information about the toxic chemicals found in breastmilk was

balanced with information about the importance of breastfeeding, with the concern voiced about the need to explore possible long-term health effects of exposures to both pyrethroids and DDT to nursing infants.

### **Results/Conclusion**

DDT and pyrethroids were found in all samples tested. First-time mothers had higher levels of these toxic chemicals in their breastmilk than did mothers with more than one child. The researchers are concerned about the long term effects on infants, given exposures to both DDT and pyrethroids, and the long duration of breastfeeding for most children. Dr. Bouwman is hopeful that the Stockholm Convention, a globally binding United Nations treaty which permits the use of DDT only for use in health emergencies, will help guide government measures that will eventually reduce the use of both DDT and chemical alternatives that may be equally harmful to human and ecosystem health.

Bouwman, H., Sereda, B. and Meinhardt, H.M. (2006). Simultaneous Presence of DDT and Pyrethroid Residues in Human Breast Milk from a Malaria Endemic Area in South Africa. *Environmental Pollution*, 144, 902-917.

## **7. Dr. Janna Koppe, the Netherlands**

### **Project Description**

In the late 1970's in the Netherlands, government studies indicated that industrial and municipal waste incinerators were emitting high levels of dioxin. Comparison studies showed that the inhabitants of the Netherlands were being exposed to dioxin levels twice as high as those found in most other European countries, because of differing technologies for limiting incinerator emissions. Dioxin exposure occurs largely through diet, and many suspected that the consumption of fish and dairy products in the Netherlands might be linked to concentrations of dioxin that researchers were beginning to find in the breastmilk of Dutch mothers in 1984. The Dutch incinerators were apparently responsible for the spread of dioxins through air currents across pastures where cattle were grazing, and dioxin was likely entering the food chain through dairy products.

In 1987, Janna Koppe and research team designed a study to test for both the levels of dioxins in the breastmilk of first time mothers and for levels of dioxin in cord blood samples as an indicator of prenatal exposure. The project also assessed neurodevelopment and hormonal levels of babies born to the recruited mothers.

### **Protocols**

Originally 120 women in their last trimester of pregnancy were recruited from a regional maternity hospital, but only 44 women continued for the duration of the study because women in the Netherlands at that time tended to stop breastfeeding after two months.

Research staff made the attempt to recruit women from another hospital serving mostly immigrants from the West Indies, but such efforts were refused, because of ethnic practices prohibiting breastmilk collection, which was considered to be deprivation of nourishment to

the newborn. As a result, most of the recruited participants had typically lived their whole lives in the Netherlands and tended to occupy a higher socio-economic level.

In the Netherlands most births are delivered by midwives, unless the pregnancy is high-risk, and the midwives at the regional hospital, all deeply interested in the project, took on the task of recruitment. They were responsible for describing the project and its importance to participants, for explaining the contents of consent form, and provided breastfeeding support and project information throughout the duration of the project.

Multiple samples of breastmilk were collected over a 24-hour period from each woman two to four weeks after giving birth.

All women tested were interested in receiving their individual biomonitoring results when offered this opportunity. Individual data and information comparing individual levels to levels for the entire cohort became available approximately a year after samples were collected.

The women in the cohort were acquainted with each other and were invited to join group discussions after receiving results. The discussion group shared concerns about results, consulted with researchers about the implications of their results, and discussed what actions each might take based on their own results to avoid further exposures. Participants were encouraged to choose healthier diets by increasing consumption of fruits and vegetables and avoiding high fat foods, including red meat and dairy products.

No participant stopped breastfeeding upon receiving results; all participants had been supported in breastfeeding and given a consistent message about the importance of breastmilk and its nutrients for the health of the baby. Participants were encouraged to maintain their body fat and to avoid losing weight in order to limit any release of dioxin from adipose tissue, which would make dioxin more bioavailable in the production of breastmilk. All the participants' children were born healthy and well developed.

### **Outcome**

The results from breastmilk analysis indicated that dioxin levels were quite high, and researchers were concerned about whether women should be encouraged to breastfeed. Dr. Koppe's strongly supported the continuance of breastfeeding despite these high levels, given that breastfed babies tend to be healthier than those fed on formula.

Some of the babies of the mothers from the initial study were followed into their teens. Some exhibited toxic effects from dioxin, such as lower insulin levels, but such effects may have been due to prenatal exposures. All 18 of the girls who consented for follow-up into teens had delayed breast development.

During the years of high public concern about incinerator dioxin emissions, there was a small decline in breastfeeding, but as more public information about breastmilk was distributed and as more stringent regulations were enforced regarding permissible emission levels, breastfeeding rates increased.

The Netherlands initiated a breastmilk-monitoring program that tests ten women from ten different regions every five years for levels of dioxins, PCBS, and DDT. By the late 80's and early 90's levels of dioxin in breastmilk had declined by 50%, and levels continue to decline.

Although dioxin levels are declining, dioxin exposure remains a problem in the Netherlands because incineration of waste continues, better regulated, with improved emissions filters, but small levels of dioxins continue to be emitted.

### **Conclusions**

In terms of lowering levels of dioxins in breastmilk without ultimately lowering the number of women who breastfeed, the study was successful. Dr. Kappa believes that the support of midwives, a traditional source of trusted information in the Netherlands, accompanied by consistent messages from the midwives about the nutritional values of breastmilk and discussions among members of the tested cohort were key to continued breastfeeding. Participants were able to express concerns and ask questions throughout the study so that emotional reactions such as fear or doubt were allayed and participants were supported in choosing better diets for themselves and their families.

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Breast milk, dioxins and the possible effects on the health of newborn infants

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1. How might it be appropriate or useful to inform breastmilk project participants about their personal levels of contaminants? Are there cultural constraints or public health concerns that might indicate the need for limits concerning data communication?
2. What factors should inform the decision about communicating biomonitoring results to project participants? Should participants be included in making this decision? What information about formula, breastmilk, use of data and personal choices should inform the decision to communicate data?
3. Is it possible to release publicly monitoring data indicating the presence of toxic chemicals in breastmilk in ways that do not discourage women from making unhealthy choices about breastfeeding?
3. In poor or marginalized communities with few resources and with no available alternatives to toxic chemicals use, should biomonitoring data be communicated by researchers to the community and to the project participants? Who should make that decision? When the decision is made not to communicate data, do the researchers

have an obligation to engage in public policy work that this community might take on, were resources and information available?

4. What are your thoughts about creating caring communities for breastfeeding mothers, at local and national levels? Such communities of concern might develop methods for enhancing the practice of breastfeeding and would encourage public discussion about the significance of toxic chemicals found in breastmilk, knowing that such information might help all of us make better choices, and support our promotion of public health policies more protective of human health. How can breastmilk monitoring be best implemented so that the public communication of results ultimately reduces the levels of toxics in all our bodies, rather than the number of women who breastfeed?

Please consider becoming a MaPP partner and posting your thoughts about the above questions on the MaPP website. [www.momsandPOPsproject.org](http://www.momsandPOPsproject.org)

For more information about the above projects or about breastmilk monitoring, please consider becoming a partner in MaPP. Contact: Sharyle Patton, MaPP Co-coordinator at [spatton@igc.org](mailto:spatton@igc.org)