

Collaborative on Health and the Environment (CHE)
Environmental Contaminants and Fertility/Pregnancy Compromise
Interest Group Call # 1 December 8, 2003 9:00 am. PST

WELCOME:

ALISON CARLSON: Our agenda today is to get to know who our group members are; to end up with a sense of how participating in this interest/discussion group could be of benefit; and how we'd like to move things forward. Everyone should take two minutes to introduce yourself and capsulize your interests, constituencies (if any), priority agendas, and challenges related to this topic. Open discussion will follow to identify themes, potential paths toward goals, and an agreement on reconvening.

CHE, host of this forum, is a national partnership of patient and health professional organizations, scientists, environmentalists and other concerned groups and individuals interested in disease prevention through safeguarding the environment. CHE's goal is to raise the level of public and scientific dialogue regarding links between health and the environment, and also to create the shared space to do that and encourages effective collaboration.

If you haven't already read the CHE science webpages at www.protectingourhealth.org, we recommend you do. There are sections on Infertility and Endometriosis (and other health endpoints). There are a peer-reviewed analysis and "What We Know" pages that group member Ted Schettler put together and for which he would welcome feedback.

Biomonitoring studies show that the average American has a "body burden" of contaminants including a significant number of known reproductive toxicants. Human and animal studies show links between these and male and female reproductive system misdevelopment and dysfunction; decreased sperm quality, number and genetic integrity; egg quality and genetic damage; time to pregnancy; spontaneous abortions; miscarriage; and other repro health issues. We also know that some human health conditions undermining fertility, like endometriosis, have been increasing in incidence in recent years.

At his talk at a 2000 plenary session of the Planned Parenthood Political Academy, Pete Myers asked if we weren't seeing fertility becoming a "choice" issue – in this sense of *others'* choices "to allow untested or poorly tested chemicals into the environment" – and at what point we could as a result expect to find reproduction becoming a privilege - for "those who can afford a technological fix?" Pete points up here the important matter of policy choices and therefore *also* the possibility of precaution and prevention. The anguish and costs of infertility, assisted reproduction, preterm birth and birth defects are already high in so many dimensions that it's hard to see any justifications for *preventable* causes of those costs.

INTRODUCTIONS:

LINDA GIUDICE: Reproductive endocrinologist at Stanford with a large patient base. Linda treats, for the most part, women with endometriosis, PCOS (polycystic ovarian syndrome), ovarian failure, fibroids, and infertility. She is interested in being part of this group as a way of learning more about the effect of the environment on reproductive health and to help in initiating objective evaluation of environmental influences on reproductive health with the goal of setting a national research agenda for the benefit of women and men in the US. On the November CHE Partners call, Linda offered the suggestion that the Institute of Medicine could be a good vehicle for a conference or workshop. Over the last 2-3 years the

IOM has had a Roundtable on Environmental Health Sciences, Research and Medicine that spins off workshops. Ones Linda knows of, which can be found on the IOM website, were:

- 2001 – Rebuilding the Unity of Health and the Environment: A New Vision of Environmental Health for the 21st Century
- 2002 – Health and Environment in the Southeastern United States
- 2002 – Cancer and the Environment: Gene-Environment Interactions
- 2003 – Ensuring Environmental Health in Post-Industrial Cities
- 2003 – The Role of Environmental Hazards in Premature Birth

Her cursory review of the IOM pages suggests they haven't had a focus narrowing down the effects of environment on fertility. So, Linda posed a question that might help define our group's purpose and agenda: *If we were to propose a conference or workshop, what would its title be?*

PATRICIA HUNT: Reproductive geneticist at Case Western Reserve [NB: Pat is a full professor at CWRU; contact list identified her as associate professor] drafted into this issue “unwittingly.” Her research has focused on looking for mechanisms for why there is an increased risk of chromosomal abnormalities in offspring as maternal age increases. She's looked at this question using mouse models and where she was finding genetic abnormalities in the eggs. There was a dramatic change in the data that was very unexpected. It turned out to be because of Bisphenol-A. She published last April describing this study, and is continuing with other related studies on genetic quality of gametes. Pat now finds herself immersed in the arena of toxicology – and one problem she sees is that reproductive biologists and toxicologists speak different languages. And, her studies have been in mice, so the question is how do we do definitive studies in humans? Her fear is that if we wait for proof in humans it will be too late. Pat's work has convinced her that it is important to pay attention *now* – and she is fully dedicated to focusing on issues of environmental assaults on human fertility. [Pat added a post-call addendum that she thinks it would be very useful to have a face-to-face meeting of this group, and that it is possible a number of group members might be able to fund their own trips to such a meeting.]

SHANNA SWAN: Reproductive epidemiologist, formerly at the California Dept. of Health, where she was focused largely on miscarriage and menstrual function in relation to solvents and chlorinated byproducts. She was appointed to the National Academy of Sciences Committee on Endocrine Disruptors. As a statistician and epidemiologist, for several years she has worked on the question of whether sperm counts have been declining. She published several papers on this which indicated stronger declines in Europe than the US, with insufficient information to draw a conclusion about other areas. But Shanna was dissatisfied with the quality of the data from these historical studies, and wanted to look at the question differently. So she started the Study for Future Families, which includes pregnant women and their partners in four US cities and examines semen quality and time to conception. Shanna is also working on a still-unpublished study of worldwide trends in time to conception, in particular, one measure of time to conception: waiting more than 12 months to conceive. This is a good measure for prospective studies, but less helpful when doing the kinds of studies that involve long recall of time to pregnancy. She is very interested in teasing out the differences between causes of voluntary and involuntary infertility.

TINA ESHAGHPOUR: Program Officer with the Women's Foundation of California. Trying to explore the links between environment and the broader women's health arena, and to explore the nexus between women's health and the health of communities and where those meet. Tina worked on the Foundation's October 2003 report: *Confronting Toxic Contamination in Our Communities* (see www.womensfoundca.org). This has opened dialogues with legislators and community groups – and women's health advocates are becoming environmentalists. These groups have typically not been communicating. So her hope in participating in this interest/discussion group is to encourage greater

discussion of these issues and the related science, and to learn how to translate the science so it is accessible, promoting community activism. Helping communities make sense of it and then share that information with policymakers.

SHARYLE PATTON: Director of Commonwealth's Health & Environment Program. Attended the Beijing Women's Conference and UN conferences on women's health issues. Sharyle has been very involved working on the Stockholm Convention POPs Treaty and the International Persistent Organic Pollutants Elimination Network (IPEN}, and is interested questions related to linkages between environmental threats and health outcomes. Also in how to deal with uncertainty in policy work, given that proof of the mechanisms of cause and effect may not always be forthcoming. CHE works to raise the level of public dialogue about these connections and to bring diverse groups together in this discussion. Community-based work is important as are women's health issues worldwide.

SUSAN WEST-MARMAGAS: Director of Environment and Health Programs at Physicians for Social Responsibility national office. PSR is an association of physicians, nurses and other health practitioners. It tries to mobilize health professionals and policymakers, and advocates for policy changes to improve environmental health. PSR has a history of interest in toxics issues and repro health - most recently, a strong focus on fish contamination and communicating about that with health practitioners. PSR has 25 active chapters across the US. Susan's primary interest is in learning more about the related science around the issue of environment and infertility and how to communicate about it to health professionals and the public.

MYRIAM LAURA BEAULNE: Biologist and environmental health organizer with Clean Water Fund and Clean Water Action. Myriam does research as a biologist, and coordinates the Senior Advisory Council of the Alliance for a Healthy Tomorrow in Massachusetts, a broad based coalition of over 120 groups and 1000 individuals – health workers, environmental justice advocates, scientists, educators, and parents. AHT has had an interest but not a previous focus on fertility. The main benefits of a group like this is being able to find out what other groups are doing and try to collaborate. AHT can also help with local access to researchers doing work on this topic, and distribute the information to its large constituency.

MICHAEL LERNER: President of Commonwealth. Michael reiterated CHE's purpose and method, and said the area of fertility is a critical one among the hundred or so diseases and conditions where links to environmental contaminants are either known or suspected. He's glad all these callers have begun this conversation. If you look at the history of the field, it's been the health-affected groups – such as with endometriosis, autism, asthma, breast cancer, learning disabilities – that have been asking rigorous scientific questions and playing a rigorous role in pushing the science. This group provides a framework, an opportunity to promote rigorous science and a shared space. He endorses Linda Giudice's point about the IOM, as it would establish “bona fides” we need to bring to this effort.

LOUISE MITCHELL: Physical therapist who also promotes conferences and seminars on alternative medicine and cancer, nutrition, and environmental issues. She represents three constituencies: 1) Campaign for Better Health, a recently launched integrative health effort with the goal of educating congress, the media and the public on low cost health solutions; 2) New Day Farms, focused on growing mineral-rich food by increasing soil fertility 3) the Weston A. Price Foundation, where Louise is a publicist. The Foundation educates people about Dr. Price's research linking nutritional deficiencies to various health conditions, including infertility. Louise described Dr. Francis Pottenger's research on cats (on nutrient depletion and the health of subsequent generations of offspring, with increasing miscarriage and infertility rates). Weston Price studied indigenous cultures and their diet changes, and found the same results in offspring that Pottenger did. Louise's goals are to understand the significance of toxics as compared to

nutritional deficiencies in the causes of infertility, and the possibilities of using nutritional and detoxification approaches to protect ourselves from toxins and to prevent, minimize and reverse infertility.

LISA ROSENTHAL: Educational coordinator for the American Infertility Association. AIA has been trying to access this kind of information for a while, but has had a hard time. AIA advocates for the infertile, and has a quarterly magazine called *In Focus*. The next issue is on health and fertility. AIA is participating because they want to see environmental health information get to infertility patients. AIA can provide vehicles for information transfer, such as web pages, conferences and a magazine. [Lisa emailed an addendum that in her searches as editor-in-chief of *In Focus* for experts in the field of repro health, she has rarely come across a more extensive group of knowledgeable key professionals in one place as on this call – and that AIA can become a funnel for different organizations and individuals to use as outreach. Lisa wants to know what she can do to facilitate the AIA getting and publishing important related information and articles, especially in regard to their February *In Focus* issue.]

MARIS MEYERSON: President of Resolve of Northern California, one of the largest of Resolve chapters. Maris was an infertility patient herself, and feels this information could have had relevance for her personally. She and Resolve are most interested in getting fertility relevant environmental information out to patients and doctors. [NB: Maris called with an addendum that she hopes the group will discuss the answer to Linda Giudice’s query as to what the title of would be if we were to propose a workshop to the IOM. Maris feels this question/answer could focus all of us. Resolve and other patient groups sometimes face the skepticism of doctors about new science and approaches. An example is alternative medicine approaches to fertility enhancement/treatment. So Resolve needs to handle the issue of environment and fertility with this in mind. Resolve does a series of conferences, symposia and workshops. Maris sees potential for some kind of forum regarding this issue. Resolve sponsors National Fertility Awareness Week every September, for which there is a central theme chosen. Maris advises an approach to the national office of Resolve to propose this topic for 2004 or 2005. Fact sheets and other materials would support such an approach.]

RHONDA SCHLANGEN (not able to make this call; intro read by Alison, at Rhonda’s request): Planned Parenthood Global Partners has incubated the issue of endocrine disruptors and reproductive health within Planned Parenthood Federation of America for the past several years. Beginning March 1999 when Valerie DeFillipo (PPGP prog dir) and Rhonda (then with National Audubon Society’s Population and Environment Program) joined other members of the population, reproductive health, and environment community in a small consultative meeting organized by the Compton Foundation at Commonweal. Thereafter, Rhonda joined PPGP, and with Valerie has worked to advance this issue within the organization, and explore how Planned Parenthood as a reproductive health provider/advocate can shape the growing national and international debate about how the chemicals humans have created are impacting our reproductive health and capacity. In November 2000, they included a presentation on Environment and Fertility in the Planned Parenthood Global Partners Advisory Group’s semi-annual meeting (PP affiliate CEOs and senior national staff). The reaction was enthusiastic and a recommendation was made that the issue be introduced to a wider PPFA audience. PPFA then included a session on endocrine disruptors and reproductive health at a January “2025” visioning meeting. Finally, Dr. Pete Myers presented the plenary speech on endocrine disruptors and fertility at the July 2000 Planned Parenthood Political Academy’s international luncheon. Most recently endocrine disruptors and reproductive health was adopted as one of a small set of “emerging issues” to be tracked by working groups within Planned Parenthood. Given the competing reproductive health and policy issues – particularly in today’s intense political environment – it is difficult to generate the energy and resources to engage in a “new” issue. However, there is significant interest in this issue among both national staff and our affiliates. Rhonda believes PPFA’s reproductive rights mission should ethically extend to *all* the reproductive health services a woman seeks – the same woman seeking contraception to limit child

bearing; the same woman seeking prenatal or obstetric care for herself and her child; the same woman trying to get pregnant.

ELIZABETH SWORD: Executive Director of the Children’s Environmental Health Coalition. CHEC was founded to inform parents about environmental health risks to children. In the past two years, CHEC heightened its focus on new parents. A year ago, CHEC began a broader primary focus on pregnant women. It launched “First Steps,” a monthly online email program where enrollees receive emails on the monthly anniversary of the baby’s due date or birth date covering a range of educational topics. It’s one topic a month, breaks down the “giant” problems into manageable pieces and allows internalization of the issues. It has just started and now has 5,000 participants. This program is supported online by CHEC’s HealthHouse at www.checnet.org. Offline, CHEC also produced the Household Detective handbook, a Children’s Environmental Health reference book, and Not Under My Roof, Protecting Your Baby From Toxins at Home, a video with Olivia Newton-John and Kelly Preston. Elizabeth and CHEC are most interested to collaborate in 2004 to promote upstream environmental protection of children.

MARY WADE: Health Educator and journalist (15 years as a childbirth educator; masters degree in journalism with specialization in medicine/science); affiliated with CETOS Safe Pregnancy Initiative, a community based model for upstream enviro health education and advocacy. Mary worked with Commonweal for four years as administrator of Dr Rachel Remen’s institute. Mary’s interest as a CHE partner is in integrating environmental health and prenatal education – and in developing educational curriculum/materials for those who are pregnant and young people entering childbearing years. She thinks materials need to be clear, provide for simple implementation and sensitive to the emotional responses evoked when information about harm to the fetus and children is presented. Equal attention must be paid to the emotional and scientific components in developing prenatal exposure education materials.

MISSED INTRODUCTIONS (apologies from the moderator):

JEANETTE MEYERS: Coordinator of the Collaborative on Health and the Environment. Jeanette has a degree in health education, and brings to this discussion as well a personal interest in infertility issues.

FRIEDA NIXDORF: CHE Administrative Associate. Jeanette and Frieda do critical work to further CHE’s mission and effectiveness in all of the arenas in which CHE is focused.

GROUP MEMBERS NOT ON THIS CALL:

Ted Schettler

Karen Adams

Becky Sander

Pete Myers

Nancy Hemenway

Rhonda Schlangen

DISCUSSION:

ALISON CARLSON: Let’s open up discussion to see if we can articulate some themes. It sounds like those mentioned today relate to identification, translation and communication of the science: Creating a space to get perspective on the science; dealing with scientific uncertainty; promoting educational forums (both for patients and practitioners); a need for expert guidance concerning what to communicate; looking at models for creating awareness; highlighting critical research; assessing industry inputs. Specific action oriented themes included approaching the IOM, Stanford University and the American Society for Reproductive Medicine.

ELIZABETH SWORD: A general question: What successes can we identify as models for communicating environmental health information?

SUSAN WEST-MARMAGAS: PSR has recently reached out to the Association of Reproductive Health Professionals about fish and mercury. We're excited about the program, but there is no "conclusion" yet. Reaching out to pediatricians is easier than reaching OBs. Why? There is so much information that an OB is responsible for communicating to patients, and most prefer to stick with known science where they feel causality has been proven. And of course time is a challenge. It would be great to do focus groups with OBs. Could it maybe also be a malpractice concern? Concerns about differentials in information delivered, or not delivered? This brings up a whole set of questions for docs.

ELIZABETH SWORD: CHEC recently sent a letter signed by Dr. Phil Landrigan at Mt Sinai to 5000 OB/GYNs telling them about CHEC's free "First Steps" program. CHEC heard back from two dozen doctors. Those two dozen were very enthusiastic about having a place they could refer patients about environmental contamination.

SHANNA SWAN: What resonates with me is not just fertility and not just endocrine disruption. The sad fact is that most epidemiologists don't believe this. And we face the broader problem that we're discussing very low dose exposures, with diverse health endpoints. Without dead bodies or missing limbs, it's just harder to believe.

LISA ROSEMTAL: I had the same reaction when AIA has approached reproductive endocrinologists about this topic. We got lots of skepticism. As patient advocates, we need help and information sent to us – because AIA would be glad to communicate the issues through our variety of communications forums, like our newsmagazine.

LINDA GIUDICE: In terms of getting on radar screens of OBs, the IOM would be very useful. In general, there is almost nothing on repro tract abnormalities, for instance, at national forums for practitioners. There should be forums at practitioner association meetings like ASRM and the Society for Gynecology. The folic acid model is a successful one. And there are fact sheets coming from practice committees. Those are helpful in limiting liability, too.

MARY WADE: I've spent a lot of time reaching out to childbirth educators. You need to be careful to give out usable information. Pregnant women are given so much important information, and they are anxious anyway. Some we have to be conscious of simplifying and careful use of language to address the emotional component as well as the science.

MICHAEL LERNER: Has Linda had a chance to review the peer-reviewed infertility piece created by Dr. Schettler on the CHE science webpages? Because I see that as usable as a basis for ASRM and other societies, the IOM, etc. The strength of CHE is that it encourages people such as those on this call from a broad range to do what they do best in their own arenas. It is exciting that we have such a set of group members. Can we follow up and create a disciplined process. Perhaps create subgroups, for instance one focused on the IOM endeavor and mainstream medicine, developing panels at key meetings?

LINDA GIUDICE: I've not yet had a chance to read that piece yet, but will. There's also the Gordon Research Conferences on Environmental Endocrine Disruption.

SHANNA SWAN: I was an organizer for that and have some access there...

PATRICIA HUNT: I want to address Linda's comment about there being almost no data in humans. That makes it easy to dismiss, especially when you hear it's a contentious issue. When I started with Bisphenol-A, I knew it was a contentious issue. But you have to be aware of the "long arm of industry." Industry tries hard to suppress the information. I am not saying all industry studies are wrong, but there

are two very different sets of data. And this poisons colleagues and creates skepticism. We need to help people look at the data objectively. Reaching out to the mainstream is a framing issue.

SHANNA SWAN: Today there was an article I saw on Pete Myer's website (www.environmentalhealthnews.org) about how a great percentage of journal articles are ghostwritten by pharmaceutical industry reps. It says that almost half of journal articles are ghostwritten by industry.

MICHAEL LERNER: It is true that industry has played a confusing role, but we also know that patient groups bring a great capacity to break through the noise, if their efforts are added to rigorous science. Patient groups have done terrific jobs helping patients discriminate. We also have the conservation biology field, and environmentalists, professionals and researchers – and the funder community paying attention. This is a powerful combination developing. It is worth the effort. We all know the obstacles. We must identify others who are not yet involved in the conversation but should be.

ALISON CARLSON: Out of respect for everyone's time, we promised this call would be no more than an hour. So I need to ask how you as a group would like to go forward. Should we schedule quarterly calls for the whole group, and split into subgroups to work on specific efforts? Do we want to set a time now for mid-March for another discussion? And what topic do we want to focus on for that call?

MICHAEL LERNER: I suggest we make the next call a report-back session. For instance, perhaps Linda could report back on the steps being pursued to get an IOM study. Perhaps Lisa and Maris could outline next steps for their groups, and Alison can work with them to promote that. There is the ASRM piece. So the call could serve as a target date to discuss what we've been able to move forward. I also want to propose to Linda that there would be value in holding a conversation at Stanford, either generally or specific to the IOM piece. It is possible that CHE could provide some travel money for key people to come to Stanford for that. We need to "seize the heights" to continue to establish credibility.

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*NB: Alison will distribute call notes and a group contact list with full contact info – as well as an alert for the date and time of the next call in mid-March. There will likely be a number of new people joining this group in the meantime. You are encouraged to be in touch with Alison and other group members regarding thoughts and needs for specific efforts that potential subgroup "committees" might pursue.*