

Collaborative on Health and the Environment (CHE)

**Environmental Contaminants and Fertility/Pregnancy Compromise
Discussion Group Call # 2**

March 8, 2004 9:00 am. PST

PARTICIPANTS: Alison Carlson, Michael Lerner, Jeanette Meyers, Frieda Nixdorf, Lois Shapiro-Canter, Rhonda Schlangen, Ted Schettler, Mary Lou Ballweg, Diane Clapp, Elizabeth Sword, Sharyle Patton, Linda Giudice, Shanna Swan, Nancy Hemenway, Edith Eddy, Susan West Marmagas. (Myriam Laura Beaulne? Maris Meyerson? Louise Mitchell? Becky Sander? Desiree Flores?)

UNABLE TO ATTEND: Pete Myers, Patricia Hunt, Karen Adams, Barbara Davis, Tina Eshaghpour, Lisa Rosenthal, Myrtis Sullivan, Michele Marcus, Laura Fenster, Kathy Toner.

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**ALISON CARLSON:** Welcome to the second meeting of this discussion group. If you are at your computer, you'll want to open up the CHE disease spreadsheet for which I forwarded the url: <http://www.protectingourhealth.org/corethemes/links/2004-0203spreadsheet.htm>

Most of us introduced ourselves during our first "meeting," and the transcript of that Dec. '03 call summarizes those introductions. You can use my call reminder email last week as a crib sheet to see the list of names and affiliations for everyone in this group as they speak. There are some very welcome and fascinating new participants since the new year. So, we'll start with one minute introductions of new participants (include who you are; what your affiliations are; and what motivates you to be a part of this group). Then some updates from a handful of members as outlined in my call reminder. Then we'd like to hear from any other participants who have an update that I have not been alerted to for today. These updates should generally take no more than 2-3 minutes (unless we've made prior arrangement for more time) so that there is space for any related questions or comment following each update. Toward the end of the call, I need to check in with everyone about some group process questions.

There's been interest expressed in a CHE call to discuss how to talk about scientific uncertainty in environmental health – and this may actually be the topic of a larger opt-in CHE National Partners call, so we aren't going to cover that today. Lastly, I have asked the Chair of CHE's Science Work Group, Dr Ted Schettler, if we could in principle initiate a practice on these calls of starting out with a science update in the event there is a study or note particular to fertility and environment we should all know about – so I hope to be starting that with our next call.

**NEW PARTICIPANT INTRODUCTIONS/MISSED INTROS FROM 12-08-03:**

**Mary Lou Ballweg** – Founder and President of Endometriosis Association, which is now 25 years old. Has had an interest in environmental issues since 1992 when strong connection was made between dioxin and endo. 30-40% of women experiencing infertility have endo. Endo Assn maintains the largest endo research registry, and funds research - including major research at Vanderbilt. 25 groups receive funding from Endo Assn Open Research Fund. EA is involved at American Society of Reproductive Medicine, and thinks this topic could possibly become the focus of a Special Interest Group there.

**Lois Shapiro-Canter** – President and CEO of Saratoga Foundation for Women Worldwide - an international women's and human rights organization with a program on environmental health. Joining this discussion group is a natural fit. The Foundation conducts local education programs for school children – and a primary effort is on environmental chemicals. The Saratoga Foundation received NGO

status at the United Nations a year ago, and recently established a 501 c. 4 sister organization to lobby NY State Legislature and conduct appropriate advocacy. The Foundation is also working on mercury contamination issues.

**Diane Clapp** – Medical Information Director at RESOLVE National, in its 30<sup>th</sup> year of existence, with 40 chapters around the nation. RESOLVE serves the infertile, both men and women, and those suffering miscarriages. Environmental issues are important to RESOLVE, which is very interested in preventive approaches to protect fertility. RESOLVE created a fact sheet on environmental toxicants [Ed note: See this organization’s 1995 booklet on the topic]. We publish Family Building Magazine and hope we will be able to include a good article on the key points for patients and practitioners about environmental influences on fertility and miscarriage.

**Ted Schettler** – Science Director for the Science and Environmental Health Network for last eight years. SEHN was founded in 1994 by a consortium of environmental organizations to promote the wise application of science to the protection of the environment and environmental health. SEHN works on topics related to science and ethics, the precautionary principle, the commons, and science in the courts, among other things. CHE is a project of SEHN (as is Health Care Without Harm), and as such, Ted is Chair of CHE’s Science Work Group. Ted is on the medical staff at Boston Medical Center, and has been active with Greater Boston Physicians for Social Responsibility. [Ed note: Ted is a co-author of *Generations at Risk: Reproductive Health and the Environment* and *In Harm’s Way: Toxic Threats to Child Development*.]

**Jeanette Meyers** – CHE Program Coordinator. Jeanette is personally interested in this group’s topic, having experienced endometriosis and a struggle with infertility, and is excited that a group of this caliber exists to move the dialogue forward.

**Frieda Nixdorf** – CHE Administrative Associate. Frieda is involved in particular to help support the group’s efforts and interests.

**Nancy Hemenway** - Executive Director and co-founder of the InterNational Council on Infertility Information Dissemination, which is a resource group dedicated to helping couples facing infertility. 40,000 registered members; 12M individual webpage hits a month. INCIID’s newsletter goes to 20,000 people – and Nancy is looking to include an article on environmental chemical influences on fertility in that. [Ed note: Nancy has also spoken also about potential for web forums and moderated discussion boards on the topic.]

**Edith Eddy** – Executive Director of the Compton Foundation [Ed note: Edith has had a longstanding interest in the reproductive rights field and promoting awareness of environmental chemical effects on fertility/fertility trends - and has written on the topic for the Population Coalition. The Compton Foundation sponsored a 1999 Commonweal meeting on environmental chemicals and fertility/reproduction.]

*(We’ll hope to hear introductions from others, not on call today, at some point in the future: Myrtis Sullivan, Barbara Davis, Michele Marcus, Laura Fenster, Michael Diamond)*

## **UPDATES AND DISCUSSION:**

~ **LINDA GIUDICE** - on Stanford conference proposal. The university’s president requested letters of inquiry from faculty for interdisciplinary research and conference forums as a part of the development of Stanford’s new Initiative on the Environment. The LOI was developed by Linda with input from members of this discussion group and was submitted February 15<sup>th</sup>. It was one of 13 chosen for submission of a full proposal by April 1. The title: “The Science, Economics, Policy and Education Behind the Effects on Reproductive Health of Environmental Exposures Across the Lifespan.” Content has to

be interdisciplinary, so it will involve a range of disciplines from science and medicine to economics and law. Three faculty members involved: Hank Greely from Stanford Law; Linda from Stanford Med, Reproductive Endocrinology and Infertility Clinic, and Women's Health; and CHE's Chairman Phil R. Lee, with Stanford Health Research and Policy.

Linda appreciated the input on the LOI from CHE partners and directors including Pete Myers, Ted Schettler, Michael Lerner, Edith Eddy, Phil Lee and Alison Carlson – and wants to include these and other members of our group potentially as a part of a planning committee should the full proposal be accepted. She hopes to integrate CHE as a potential co-sponsor of this conference as suggested by Michael Lerner.

Intended audience is national policy makers and thought leaders in medicine/repro endocrinology, science, law, ethics, economics. Goal is to bring to fore what the science currently is behind environmental chemical effects on repro health and to come to a consensus on what is known and what the gaps are. Some of the sub topics are: trends and epidemiology of enviro exposures; the effects of endocrine disruptors; effects of bis-A on gametogenesis; in utero vs. adult exposures; genes and the environment; the economics of reproductive disorders and environmental exposures; legal challenges; the education of policy makers; research and prevention.

Speakers have not been lined up yet. The budget is an issue, as it is more than 50k, while the suggested budget has been indicated at 25k. May need to come to a compromise or seek additional sponsorship. Idea is for this forum to lead to a proposal to the Institute of Medicine and professional/medical society annual meeting symposia.

**Q. from Mary Lou Ballweg:** Is there the thought of publishing these proceedings?

**Linda Giudice:** It's a good thought. Cost would be the issue. We could certainly do it internal to Stanford, a transcript at least.

**Q. from Edith Eddy:** I commend you, Linda, for this extremely well thought out effort. Very exciting. I hope there will be something published as a result. Is the cost issue an argument for narrower framing for this forum – or for getting more funding?

**Linda Giudice:** If there are other sources of funding to audiotape or publish proceedings, we're looking at 5-15k more to capture and transcribe and publish...

~ **TED SCHETTLER** - on CHE's new "disease spreadsheet" vis a vis reproductive health/fertility. See <http://www.protectingourhealth.org/corethemes/links/2004-0203spreadsheet.htm>. This spreadsheet was an attempt to put in a single excel format 200 diseases/conditions and then the known environmental contaminants that are thought to be connected. Categories of evidence are listed based on strength of the evidence as strong, good, and limited or conflicting. Sources are from major textbooks and in some cases supplemented by journal literature. The spreadsheet has limitations. It is not exhaustive. Doesn't include animal toxicology database. And there was no attempt to cover dose in terms of size, timing, duration or pattern of exposure. This is an important limitation.

Much of this sheet is from occupational literature but by no means all. Judgement had of course to be used about the weight of the evidence and which category evidence was then listed in. Ted noted that columns B,C and D on the sheet don't come up if you pull the file off the webpages, so they need to be "unhidden" using your toolbar menu. Those columns are important for seeing how the diseases are grouped. The argument has been made for establishing a grouping for reproductive health as its own category vs. the way repro-related diseases are currently scattered under, e.g. urogenital...

Ted then reviewed the sheet and pointed out specific repro related conditions, fetal toxicity, low birth weight, testicular atrophy, lost pregnancy and other. He welcomes comments and questions. CHE hopes to transfer the spreadsheet to a new format that will be more conducive to searching.

**Q from Diane Clapp:** This is an incredible resource and the implications for patients are important: We [Resolve] try to promote preventive approaches and also to address patients who are getting ready to try to conceive. A question in my mind is how to make all of this information more accessible. That is where I am coming from.

**Q from Lois Shapiro-Canter:** Couldn't we write regular op-eds or editorials on various environmental toxicants to begin educating the public? Should we all attempt to write in our own areas? Choose very specific area-relevant topics, like mercury and repro effects?

~ **MICHAEL LERNER** – on discussion among a smaller group of CHE partners about the value of a potential researchers forum on environment/fertility research gaps and directions. I am impressed with the forward momentum of this group. CHE's purpose is to bring together the patient and health professional community around these issues. CHE has over 800 Partners, some of whom are real pioneers and on this call. One is Mary Lou Ballweg of the Endometriosis Association, which charted the way in making the link between dioxin and endometriosis – and became a real leader in defining a research agenda, and funding research. When we think about the development of an environment and fertility research agenda, there are a number of different avenues – and there are people on this call who could create potential effect similar to that of the Endometriosis Association. There are a number of foundations looking for a right way to make contributions to infertility research. The dialogue process within CHE and among scientists helps us to talk about what the most important pieces of research are. It is important to foster development of funding strategies within patient groups. Patient groups are a major factor. A good example is in breast cancer and in getting federal funding for that. There's a whole set of ways in which it is worth scientists' time to help define what the next pieces of research should be in concert with patients and practitioners so it's not just a scientific agenda, but also reflects patient and practitioner input. The early steps are to define what we know; what we don't know; and ways to get that information out there. A model for that might be the debate about microwaves from cell phones vis a vis brain function and tumors in animals. Linkage between science and patient populations is an avenue for building a broader constituency to advocate for research and prevention. This kind of linkage is the basis of CHE.

**Q. from Alison Carlson:** Does CHE - do we – want to form a sub work group or planning committee to create a scientists and patient group forum to highlight important research and brainstorm research gaps? Or should that be folded into the Stanford proposal?

**Michael Lerner:** We could gather researchers and patient group reps in a call where they could decide how they would want to meet...

**Linda Giudice:** This is so important. I hope that if we succeed in doing a symposium at Stanford that CHE partners and this discussion group will play a part. Developing a critical research agenda is not just for scientists. It should be driven also by patients.

**Michael Lerner:** A key also is the promise of an IOM involvement, and our seizing the high ground – because this gives confidence to patient and doctor groups. CHE does best when it does not overstate.

~ **ALISON CARLSON** - introduced new participants not able to be on the call today:

Myrtis Sullivan – Pediatrician; faculty of UIC School of Public Health; involved in development of UIC Center for Study of Environmental Reproductive Health.

Barbara Davis – Acting Chief, Laboratory of Women's Health at NIEHS. Current research on phthalates and ovarian function.

Michelle Marcus – Repro and occupational epidemiologist at Rollin’s School of Public Health at Emory.

**Michael Lerner:** Shanna Swan has just joined this call. Can she take a moment to describe her very relevant research? Has she done that already for this group? [Ed note: yes; see transcripts of 11/15/03 CHE National Partner Call on Infertility and first teleconference meeting of this group on 12/08/03]

**Shanna Swan:** The research we’ve done showed statistical declines in sperm quality in the United States with links to pesticides. Whether these were real declines, we don’t know. May never. This led to geographic studies, which show that semen quality does vary from one location to another. The harder question is why, and that is what we’re now focusing on. Other people are coming out with evidence of environmentally-altered male fertility potential. The links are mostly with organochlorines and phthalates. It’s relatively new – the last few years.

**Michael Lerner:** Shanna has suggested in a different conversation the idea that it would be very useful to hire a scientist who could be dedicated to translating new, relevant studies and funneling them to the CHE network...

**Alison Carlson:** It’s a fantastic suggestion, and one that would combine well with our intended listserv for this group. It may be obviated by the potential availability of Pete Myers’ relational database service via [www.environmentalhealthnews.org](http://www.environmentalhealthnews.org) – but a scientist translator would be a critical service.

**Elizabeth Sword:** Based on the idea of collecting the surge of research data, what plans or mechanism would be appropriate to take that to a major publisher? Such as the New York Times magazine? Particularly on the male factor side where the data is gathering?

**Shanna Swan:** I work with Environmental Media Services to get that kind of information out. They do a fabulous job. The more the better. And I am pulling this together to propose a piece of writing about sperm as a sentinel biomarker...

**Michael Lerner:** Approaching the media is always strongest when the patient groups have worked strategically with the scientists and maintained a multiyear strategy for defining links. The media hits build on each other, as with the endo and breast cancer groups. It all comes together despite different foci to help drive a collective agenda.

**Nancy Hemenway:** Has there been any thought about making this discussion group more public? Inviting media, for instance? INCIID could provide a forum for a more public kind of approach...

**Michael Lerner:** It’s an interesting question. Some may want to be more private in their discussions and others more open.

**Alison Carlson:** I’d like to explore that idea more, but because we have run out of time, we’ll have to do this another time. We haven’t covered today a number of group process questions we meant to – and we ran out of time to get into your hopes for future call agendas and topics – so I will handle those questions and others by email for now. Thanks all for participating today.