Ali Carlson: How CHE Fertility Came into Being, and How It Helped Shape the Reproductive Health & Enviromental Health Fields

CHE's Fertility/Pregnancy Compromise Work Group (its name back then) was founded in late 2003. All the conditions turned out to be ripe for forming this formidable and influential group, and it just blossomed, from the get-go.

The original impetus was two-fold. First, when CHE was newly launched, some colleagues expressed concern about the possible impact chemical contaminants can have on fertility and suggested this might be a priority focus for CHE's efforts. Second, two of the co-authors of *Generations at Risk: Reproductive Health and the Environment* [MIT Press, 1999], Dr. Ted Schettler, science director at the Science and Environmental Health Network, and Dr. Gina Solomon, then-senior scientist at the Natural Resources Defense Council and assistant clinical professor of medicine at the University of California at San Francisco, had just published one of the first peer-reviewed papers on chemicals and infertility: Environment and health: 6. Endocrine disruption and potential human health implications. The CHE directorate was considering how best to organize around that science.

At the same time, I had just concluded four years as an assisted reproductive technologies patient. I was also a Stanford human biology graduate working at the intersection of academia, business, science, medicine and sports, and knew something about the nascent research on chemical exposures and challenged fertility. In fact, I had grown up and later coached tennis for 16 years in a New York town on the Hudson River where (it turns out) barrels of illegally buried PCBs riddled the land around my tennis facility. Learning subsequently – when I was trying to get pregnant with assisted technology – that PCB exposures were associated with egg damage and impacts on fertility, I became vocal about the lack of attention among medical professionals to environmental chemical risks to fertility and reproductive health. My doctors had no knowledge of this – nor any clue about how to address environmental risks. To me it felt like a black hole in awareness among health professionals of an important and growing body of scientific research.

Given my background and interest, I was asked to serve as a Senior Fellow at Commonweal in order to develop and facilitate a CHE work group on links between toxic chemicals and fertility/reproductive health concerns. The group launched with the core goals of highlighting and disseminating the emerging science in this budding field and organizing scientists, medical professionals, professional societies, health advocates, funders, government agency staff and concerned individuals to advance the science and bring attention to these issues. Five months of initial scoping had made clear that there was growing, but yet-to-be-focused, interest among the many stakeholders. And CHE's mission of "setting the table" for interdisciplinary science-based collaboration and education turned out to be the perfect forum to pull everyone together in a concerted effort.

Two among over 100 exploratory conversations turned out to be highly propitious. An interview with the executive director of the American Society of Reproductive Medicine, Dr. Robert Rebar, revealed that ASRM, the largest professional association in its sector, was receptive to input and assistance in creating "reproductive environmental health" materials and training programs for its 10,000+ members. Concurrently, then-head of Stanford School of Medicine's Women's Health and Reproductive Endocrinology departments, Dr. Linda Giudice, admitted during a scoping interview that she and her colleagues were, "frankly, disturbed that [they] had no training or informed counsel to offer patients

regarding environmental chemical risks." Giudice, a widely respected clinician, biochemist and reproductive endocrinologist with research focus on the endometrium (who was also an Institute of Medicine fellow, and soon-to-be board member of ASRM and the Society for Gynecological Investigation), signed on as a founding CHE Fertility "partner" to lend her heft and expertise to the Collaborative's purpose. The work group very quickly gained momentum with her leadership.

Other critical mentors and founding partners included Drs. Pete Myers, Michael Lerner and Ted Schettler; research scientists Drs. Shanna Swan, Lou Guillette, Theo Colborn, Patricia Hunt, Tracey Woodruff; agency leaders Drs. Jerry Heindel (National Institute of Environmental Health Sciences – NIEHS), Germaine Buck Louis (National Institute of Child Health and Development –NICHD) and Sally Perrault Darney (then with the US Environmental Protection Agency); and environmental health nongovernmental organization (NGO) leaders Sharyle Patton and Charlotte Brody. Key associations also joined CHE Fertility's brain trust, including the Association of Reproductive Health Professionals, Planned Parenthood Global Partners and the Reproductive Health Technologies Project, as did a number of prescient health/environment and reproductive health and rights funders, such as Edith Eddy of the Compton Foundation; Sophia Kohlemainen of the Cedar Tree Foundation; and Marni Rosen of the Jenifer Altman Foundation. Mary Wade, Eleni Sotos and Julia Varshavsky with CHE were also instrumental in organizing and supporting CHE Fertility's efforts over the years of its growth.

This mix of leading stakeholders developed what is now standard fare at CHE: science-focused teleconferences; an interactive listserv; a carefully culled and tailored scientific abstracts database; regular newsletters; and expert resources for media. They also created an informally managed "speakers bureau" for stakeholder meetings and programs, Congressional testimony, etc. The pioneering actions that made CHE Fertility so successful included:

- Organizing a range of stakeholders around credible science, in particular establishing partnerships between federal agency leaders, advocates, scientists and doctors.
- Bringing heft and validity to the concerns raised by the science, signaling its importance to decision-makers in medicine, policy and funding.
- Propagating the logic and far greater efficiency of investing in upstream disease prevention as an important complement to the 96% of dollars invested in disease in the US going toward treatment.
- Galvanizing a large choir of sophisticated messengers and catalysts who inform policy debates, influence research agendas and funding priorities as well as clinical care.
- Engaging a set of leading professional associations until they paid attention. Those societies upped the ante, becoming critical voices in health care sector and on Capitol Hill, with the steady assistance from CHE Fertility partners.
- Providing an important platform for nurses, who became some of the most proactive and effective voices for improved understanding and practice.
- Pressing for research agendas (and funding) to fill critical knowledge gaps.

Notable Accomplishments of CHE Fertility:

- CHE Fertility organized what turned out to be a seminal meeting in 2005, known as the "Vallombrosa Workshop on Environmental Contaminants and Human Fertility Compromise: Science and Strategy." It was attended by attended by 45 leaders from medicine, science, advocacy, government and philanthropy. The gathering resulted in the landmark Vallombrosa Consensus Statement, which synthesized and prioritized the weight of scientific evidence linking toxic chemicals and compromised fertility. It was later published in *Seminars in Reproductive*

Medicine and widely disseminated. The Vallombrosa process also served as a model for organizing CHE's future efforts to bring attention to the emerging science on other health problems in which the environment played a role.

- The Vallombrosa Workshop and Consensus Statement in turn emboldened the American Society of Reproductive Medicine (ASRM) to invite Dr. Giudice and me to start an Environment and Reproduction Special Interest Group (ERSIG), a three-year process to get formal approval and official status that allowed the group to issue calls for abstracts for ASRM annual meetings, award research prizes, develop training courses, issue statements and policy recommendations, provide expert testimony – all critical to raising the profile and credibility of reproductive environmental health concerns. ERSIG and Vallombrosa were the basis for scaled attention to REH also at Association of Reproductive Health Professionals (ARHP), The Endocrine Society, the American College of Obstetricians and Gynecologists (ACOG), Society for the Study of Reproduction (SSR) and other professional associations.

- Vallombrosa also inspired a call for a much larger and broadly inclusive gathering, which turned into the 2007 "Summit on Environmental Challenges to Reproductive Health and Fertility." This meeting was organized by CHE and the University of California at San Francisco (UCSF). Twelve months in the planning, this three-day conference convened over 400 participants from around the world for a comprehensive program using a unique, participatory approach combining science presentations with breakouts and "town halls" exploring the implications of the science and data gaps. The conference also featured a particular emphasis on the developmental origins of adult disease. The 2007 Summit marked ACOG's first significant engagement in reproductive environmental health issues. A few years later, ACOG released a major statement on REH.

- The 2007 Summit in turn spawned the University of California at San Francisco's Program on Reproductive Health and Environment (PRHE), the first of its kind in a major medical/health sciences university. In addition, the summit led to another expert workshop in 2008, chaired by Drs. Giudice and Guillette (subsequently known as the G2 Workshop). They were charged with shaping and promoting a comprehensive women's reproductive environmental health research agenda focused on a hypothesis posited at the summit around ovarian dysgenesis syndrome (akin to the far more examined testicular dysgenesis syndrome hypothesis that had been generated by Danish clinical researcher Niels Skakkebaek and colleagues, in 2001). The G2 Workshop resulted in a widely cited publication, Female reproductive disorders: the roles of endocrine-disrupting compounds and developmental timing, published in the journal *Fertility and Sterility* in 2008. That publication and subsequent research then guided CHE Fertility's ongoing efforts.

- In 2007-2008, as I shifted into the philanthropic sector (launching Passport and Forsythia Foundations), Julia Varshavsky ably stepped up to the plate to move CHE Fertility's agenda forward. After Julia went on to do her doctoral research, Karin Russ, RN, MS, took over the CHE Fertility Work Group, which had grown from 20-30 "partners" at its founding to over 400 by 2009. They both deftly helped to enhance and scale collaborative, interdisciplinary research as well as clinical and consumer education and outreach.

CHE Fertility's Impact and Legacy

CHE Fertility's collaborative work essentially defined the field of reproductive environmental health. Without CHE and the expertise of the pioneering researchers, health professionals and advocates that it attracted, the emergence of what is now a highly robust field would likely have taken years if not possibly decades more to develop. In short, CHE Fertility was at the center of launching an effective, multidiscipline endeavor that bridged science with medicine, health advocacy and policy that ultimately put reproductive environmental health on the map of priorities for scientists, health professionals and concerned citizens alike. Its legacy lives on to the great benefit of women and men in their childbearing years who long to bring a healthy child into the world.

At the end of the Vallombrosa workshop, Dr. Russ Hauser from the Harvard School of Public Health made a moving statement that seemed to resonate particularly with other researchers and serve to inspire our collective next steps: "This was one of my first experiences interacting with NGOs and advocacy groups. This is a new thing for me. In the past [I thought] of the public and these groups as 'consumers of the science.' Now I think of us more as partners, working together to do better science, bring it to the public, and make it affect policy and regulations. I hope to be able to bring more to the table in the future. I'd like to help draft the consensus document. And I will join CHE and CHE Fertility."