

Connection and Inspiration at the 2019 PFAS Conference

From June 10-12th, 2019, over 250 community activists, government officials, state legislators, scientists, journalists, lawyers, academics, and students all convened on the Northeastern University campus in Boston for the **2nd National Conference on Per- and Polyfluoroalkyl Substances**. The purpose of the conference was to foster alliances across sectors (government, academics, NGOs, and community groups) to better support communities impacted by per- and polyfluoroalkyl substances (PFAS) contamination. Like the 1st National PFAS Conference held in June 2017, this was a unique meeting, bringing together different stakeholders to address an expanding public health and environmental crisis.

The three-day long conference was hosted by the Social Science Environmental Health Research Institute (SSEHRI) at Northeastern University. The conference Organizing Committee was composed of academics and advocates from SSEHRI, PROTECT (Puerto Rico Testsite for Exploring Contamination Threats—Northeastern’s Superfund Research Program), the Harvard T.H. Chan School of Public Health, Testing for Pease, STEEP (Sources, Transport, Exposure and Effects of PFASs - the University of Rhode Island’s Superfund Research Program), Michigan State University, Whitman College, and the Environmental Protection Agency (EPA).

Conference presenters, panelists, and workshop participants discussed the significant growth in the number of known sites contaminated by PFAS since 2017, as well as the corresponding rise in community organizing, public awareness, scientific research, and regulatory action. The event provided a forum for diverse stakeholders to come together to share and discuss their experiences addressing PFAS contamination across the US and internationally.

Attendees~ The conference was attended by over 250 people from the US and several other countries, including residents and activists from PFAS-impacted communities; scientists from a range of disciplines and from academia, government, and independent research organizations; municipal, state, and federal regulators; lawyers; journalists; firefighters and fire safety experts; and environmental and public health organization leaders. Federal and state regulatory agency representation included the EPA, the National Institute of Environmental Health Sciences (NIEHS), the Agency for Toxic Substances and Disease Registry (ATSDR), the National Institute for Occupational Safety and Health (NIOSH), and the US Department of Defense (DoD). Also in attendance were representatives from numerous environmental advocacy groups, including the Environmental Working Group (EWG), the Green Science Policy Institute, Union of Concerned Scientists, Clean Water Action, and the Natural Resources Defense Council. Most crucially, the community members and activists, and firefighters from across the country as well as internationally that were in attendance traveled from Hoosick Falls, New York, Laurence County, Alabama; Oscoda, Rockford, and Belmont, Michigan; Tucson, Arizona; Merrimack, Rye, Portsmouth, and Hollis, New Hampshire; Fayetteville and Cape Fear, North Carolina; Buxmont, Pennsylvania; Westfield, Hyannis, and Ayer, Massachusetts; Anchorage, Alaska; and Fountain Valley, Colorado. Two presentations were given by activists from outside the US—one by a firefighter from South Australia’s Metropolitan Fire Service and another from “Mamme No PFAS”, a community group battling drinking water contamination in the Veneto Region of Northern Italy.

Keynotes

Two keynote speeches were delivered on the first and third days of the conference, by Dr. Linda Birnbaum (Director of the NIEHS) and Gina McCarthy (Harvard T.H. Chan School of Public Health and former EPA Administrator), respectively.

Dr. Linda Birnbaum discussed the growing awareness of the diversity of sources that contribute to one's PFAS exposure—i.e. sources other than drinking water. Birnbaum identified three urgent areas of PFAS research: the need to develop a robust, sensitive tool capable of measuring total organic fluorine content, deciding whether PFAS should be studied as a single class or as a number of subclasses, and finally, the question of essentiality (i.e. “where do we really need these chemicals?”), including a call to reject the status quo practice of regrettable substitution. Birnbaum's keynote drew substantial media attention when Sharon Lerner, a conference attendee and investigative journalist, published a piece in *The Intercept* (“Teflon Toxin Safety Level Should be 700 Times Lower than Current EPA Guideline”) highlighting the alarming figure presented by the “nation's top toxicologist” that the safety threshold for PFOA in drinking water should be reduced to 0.1 parts per trillion in light of a recent study linking PFOA exposure to pancreatic cancer in animals.

Gina McCarthy (former head of the EPA and current faculty at the Harvard T. Chan School of Public Health) kicked off the final day of the conference with a thoughtful and inspiring keynote reflection on the dismantling of the EPA under the Trump administration. She urged attendees to be “relentless” in their organizing efforts to keep their communities healthy in the context of PFAS contamination. In her discussion of climate change and the fossil fuel industry, McCarthy spoke about the need to “personalize” climate change in a manner that will give people pause (e.g. “we are talking about our health and our children's health”) rather than continuing to center images of polar bears and melting glaciers. McCarthy also encouraged the audience to “do more conferences like this” and to cultivate more spaces where scientists have to engage directly with the public and explain their research in non-technical language that is accessible to the communities impacted by their work.

Brief Highlights

Brenda Hampton (Concerned Citizens of West Morgan-East Lawrence Authority, AL) described decades of community mobilization against the health and environmental impacts of major PFAS production and industrial chemical pollution in Alabama, stating that clean water is a right, not a privilege. **Mark Favors** (Fountain Valley Clean Water Coalition, CO) spoke about the challenges facing communities impacted by PFAS water contamination from military sites. In the context of Fountain Creek Colorado, Favors discussed the blatant lack of transparency from the US Department of Defense and the need for a comprehensive congressional investigation. **Krystle Mitchell** (South Australia Metropolitan Fire Service) recounted her experience discovering elevated levels of PFAS in firefighters, and tracing the likely source of exposure to eggs laid by chickens raised at fire stations and consumed by the firefighters. **Dr. Rebecca Altman**, an independent science writer, recounted the history of fluorochemicals, tracing their military origins in the Manhattan Project that developed the atomic bomb (1942-45) up through their global dispersion by way of Scotchgard fabric protector, non-stick Teflon Pans, and firefighting foam. Activist **Laura Facciolo** (Mamme No PFAS) presented data on the extremely elevated PFAS blood levels of residents living in the Veneto Region of Northern Italy and the huge demonstrations of resistance led by local mothers. Journalist **Sharon Lerner** (*The Intercept*) delivered what she referred to as a “what if talk,” invoking moments in the history of PFAS chemical manufacturing when she suggested things could have been handled differently,

based on close analysis of internal industry documents. **Dr. Laura Rabinow** (Rensselaer Polytechnic Institute) presented on the culture of regulatory minimization and inaction and presented her concept of “incommensurate science”.

Ohio Attorney **Rob Billot** (Taft Law) spoke to a packed room and reflected on the current state of affairs weighed against the backdrop of his nearly two-decades long career litigating on behalf of PFAS-exposed communities. Billot emphasized the ways in which decades of corporate information sequestration and secrecy by chemical manufacturers dug the graves of so many workers and community members. He reminded the audience that in the year 2019 there are still no federally enforceable standards for “safe” levels of PFAS in drinking water. In a similar vein, **Ken Cook** (of the Environmental Working Group) opened his presentation with a call to consider what federal laws for MCLs would look like if they were established in the public interest (i.e. to fully protect public health).

A number of conference posters and presentations provided insight into the latest scientific research on the human health effects of PFAS exposure at various doses and life stages. One study conducted by **Dr. Amalie Timmermann** (University of Southern Denmark) in Guinea-Bissau, West Africa examined a possible link between the PFAS blood levels of exposed children and a weakened vaccine immune response. **Dr. Phillip Grandjean** (Harvard T.H. Chan School of Public Health and the University of Southern Denmark) presented his work on the relationship between PFOS body burden in children and breastfeeding duration, specifically how prenatal PFOS exposure and exposure during infancy may contribute to vaccine failure and infectious disease in early childhood. **Dr. Graham Peaslee** (University of Notre Dame) discussed the extensive use of aqueous film forming foams (AFFF) by the US Department of Defense, noting that as recently as ten years ago people were told that AFFF is as safe as soap. After being contacted by a firefighter who was curious about exposure via turnout gear, Peaslee conducted total fluorine measurements with a particle accelerator and found that turnout gear was indeed treated with PFAS (mostly to keep it water resistant), including PFOA. To the extent that turnout gear constitutes a serious exposure route for firefighters, Peaslee stressed the need for a larger occupational health study. **Dr. Suzanne Fenton** (NIEHS, National Toxicology Program), who has been studying PFOA and its effects on breast, obesity, liver function, and maternal/fetal transport since the early 2000s, presented preliminary data on the effects of GenX exposure (the “safer” alternative to PFOA and PFOS introduced about a decade ago) in rats.

All of the presentations given by community members and activists were extremely powerful and impactful. We encourage those who were unable to attend the conference to watch their presentations on our website, as each of them sheds important light on community mobilization happening against PFAS contamination in a variety of contexts. On this point, **Dr. Jamie DeWitt** (Eastern Carolina University) prefaced her presentation on the immunotoxicological findings of PFAS with the following personal reflection: “As a result of being part of this conference I’ve made a little personal commitment...that when I go back [to Eastern Carolina University] all of my graduate students who receive training in toxicology are going to meet at least one person in their career who has been affected by the contaminants that we study”. DeWitt went on to say that hearing from impacted community members at the conference spurred her and a colleague to reconsider how they teach toxicology to medical students: “my colleague and I, based on what I’ve seen here at this conference, are going to redesign some of our toxicology materials...we’re gonna give them cases—[e.g.] we’re gonna show them levels of PFAS in people’s blood from Wilmington [NC] and say, ‘Tell us what you would do with a patient who comes to you with this concern’”.

We are grateful to all of the community members and groups who traveled to speak and share their experiences, as well as their affiliated organizations: Laurene Allen (Merrimack Citizens for Clean Water, NH); Andrea Amico and Alayna Davis (Testing for Pease, NH); Jenny Carney, Tobyn McNaughton, and Sandy Wynn-Stelt (House Street Community, MI); Bob Delaney (MI); Emily Donovan (Clean Cape Fear, NC); Laura Facciolo (Mamme No PFAS, Italy); Mark Favors (Fountain Valley Clean Water Coalition, CO); Brian Grubb (International Association Fire Fighters Local F88, OH); Brenda Hampton (Concerned Citizens of WMEL Water Authority, AL); Michael Hickey (Hoosick Falls, NY); Mindi Messmer (New Hampshire Safe Water Alliance); Krystle Mitchell (South Australian Metropolitan Fire Service); Cheryl Osimo (Massachusetts Breast Cancer Coalition); Anthony Spaniola (Need Our Water, MI); and Joanne Stanton (BuxMont Coalition for Safer Water).

POSTERS~ Two time blocks were devoted to viewing **31 scientific posters**. Poster topics were international in scope and showcased a range of cutting edge research areas pertaining to the consequences of PFAS contamination on a global scale. They provided attendees with additional insights into PFAS chemistry and detection at AFFF impacted sites, new research on health and toxicity concerns (including decreased vaccine response, impaired lactation, and prenatal PFAS exposure), the effects of PFAS on wildlife and ecosystems, PFAS hazardous waste disposal, filtration techniques, and many others. A full roster of poster presentations and abstracts displayed at the conference is available on the [PFAS project website](#).

WORKSHOPS~ Day two of the conference included an afternoon breakout sessions in which attendees could participate in one of six workshops.

Sharon Lerner (*The Intercept* and Type Investigations) and Kyle Bagenstose (*Bucks County Courier Times*) co-lead a workshop for community members interested in media engagement, titled **“Working with the Media to Tell Your PFAS Story.”** Lerner is a prominent investigative journalist who has authored over thirty articles on global PFAS contamination since 2015. Shaina Kasper of the Toxics Action Center facilitated the workshop.

Two workshops focused on PFAS drinking water contamination. Dr. Gloria Post of the New Jersey Department of Environmental Protection led the **“State Water Advisories and Regulations”** workshop, facilitated by Dr. Alissa Corder of Whitman College. Participants learned about how drinking water guidelines are derived and the particular regulatory considerations that are unique to the PFAS chemical class. Drinking water guidelines that have been promulgated for PFAS across the US so far were compared and analyzed. A related workshop on existing drinking water filtration methods, **“Drinking Water Contamination and Remediation,”** was led by Chris Higgins (Colorado School of Mines), Hans Keijser (Hyannis Water System) and Laurel Schaidler (Silent Spring Institute). This session included a discussion of the range of PFAS contamination issues in drinking water, various treatment technologies, and analytical methods for detecting and monitoring PFAS levels.

The **“Living with PFAS: Community Experiences”** workshop was facilitated by Ben Gerharstein (of ATSDR) and Andrea Amico (of Testing for Pease). Community members split up into small groups to share their stories. The workshop was part of a larger ATSDR project on understanding and addressing “community stress” related to PFAS.

The **“Federal Agency Research Overview”** workshop was led by representatives from six different federal agencies (EPA, USGS, DOD, ATSDR, NIEHS, and NTP), each of whom provided an overview of their particular agency’s initiatives related to PFAS. Session attendees

questioned agency representatives directly and discussed which agency initiatives they considered to be highest priority.

Finally, the “**Considerations for Local Health Studies**” workshop was designed to assist community members interested in initiating a health study in the context of local PFAS contamination. It was facilitated by Laurene Allen (Merrimack Citizens for Clean Water), Sylvia Broude (Toxics Action Center), and Courtney Carignan (Michigan State University). This workshop included discussions of existing health studies and the strengths and limitations of health studies for impacted communities.

Summary Themes ~ Setting aside the diverse and sometimes conflicting interests of individual stakeholders who spoke at the conference, several cross-cutting themes repeatedly came up over the course of the three days: questions about essential use (e.g. how water resistant does my raincoat ACTUALLY need to be? What about allowing select fires to burn instead of immediately dousing them in foam?); uncertainty surrounding exact levels of toxicity and doubts about the best way to measure toxicity; and questions about who should be held responsible, to what degree, and how.

Participant Feedback - We distributed an online feedback form two days after the conference ended, and left it open for responses for two weeks. Approximately a third of attendees completed the survey, providing us with feedback on their overall conference experience as well as suggestions for improvement in future years. The survey form included multiple choice as well as open-ended questions.

When asked, “How satisfied were you with the conference schedule and content overall?”, the vast majority of respondents (92.6%) indicated that they were overall satisfied (i.e. responding with 4 or 5 on a 1-5 scale, with 1 being least satisfied) with the experience. Additionally, 95% of respondents indicated that the conference was both “relevant and helpful” to their “job, work, and/or advocacy”. Among the many thoughtful comments and points of constructive criticism that we received were the following suggestions: more content from workers involved in handling PFAS during the manufacturing and remediation process, include the perspectives of more medical professionals who treat patients ill from PFAS contamination, more networking opportunities and spaces for policy brainstorming, and more content on hazardous waste cleanup and contamination prevention.

Additional Information: Several online media outlets have published their coverage of the conference. Among them: [The Intercept](#), [Bloomberg Environment](#), [The Intelligencer](#), [Bridge](#), and an [excerpt](#) from the forthcoming documentary, “GenX: A Chemical Cocktail”, by Ethereal Films.

Presentation slides, recordings, and poster abstracts of all consenting participants have been made available on the [PFAS project website](#). The conference Organizing Committee may be reached by email for follow up at pfasproject@gmail.com.

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