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# Persistent chemicals, persistent activism: scientific opportunity structures and social movement organizing on contamination by per-and polyfluoroalkyl substances

Jennifer Liss Ohayon<sup>a</sup>, Alissa Cordner<sup>b</sup>, Andrea Amico<sup>c</sup>, Phil Brown<sup>d</sup>  
and Lauren Richter<sup>e</sup>

<sup>a</sup>Silent Spring Institute, Newton, Massachusetts, USA; <sup>b</sup>Department of Sociology, Whitman College, Walla Walla, Washington, USA; <sup>c</sup>Testing for Pease, Portsmouth, New Hampshire, USA; <sup>d</sup>Department of Sociology and Anthropology, Northeastern University, Boston, Massachusetts, USA; <sup>e</sup>Department of Sociology, University of Toronto, Mississauga, Canada

## ABSTRACT

Engagement with science is a prominent feature for many social movements, yet the dimensions of that scientific engagement and bidirectional relationships between science and advocacy are incompletely theorized in social movement scholarship. While social movement scholarship has previously demonstrated the importance of external political and economic factors for social movement processes and efficacy, we show that the emergence and success of environmental health activism is also dependent on dynamic relationships between scientific evidence and lay demands for particular types of knowledge production and application. Despite decades of industrial production and widespread contamination, per- and polyfluoroalkyl substances (PFAS) were a politically obscure class of chemicals until a recent spike in attention from activist, regulatory, and scientific circles. Drawing from in-depth interviews with activists of PFAS-impacted communities, we develop the *scientific opportunity* concept to examine how activists create and mobilize scientific factors to support their goals, and how scientific factors, in turn, support the emergence of further activism. Dimensions of scientific opportunity include availability of funding streams, openness and receptivity of institutionalized scientific spaces, presence of collaborative or community-led research, methodological and technological advancements aligned with activist demands, availability of relevant scientific findings and datasets, and presence of prominent scientific allies. We conclude by discussing the relevance of our concept to a wide range of social movements addressing science and technology.

## ARTICLE HISTORY

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## KEYWORDS

Social movements; activism; scientific opportunity; PFAS; environmental health movements

## Introduction

Across the United States, a social movement addressing significant contamination by per- and polyfluoroalkyl substances (PFAS) has emerged to target actions by government agencies and industry. Led by impacted community members who have successfully

**CONTACT** Jennifer Liss Ohayon  [ohayon@silentspring.org](mailto:ohayon@silentspring.org)  Silent Spring Institute, 320 Nevada Street, Suite 302, Newton, MA 02460

challenged policies of the U.S. government and production practices of some of the world's largest chemical companies, this movement demonstrates the complexity of relationships between scientific knowledge production and social movement mobilization. While previous literature has examined how movement efficacy is shaped by factors internal to a social movement, as well as external political, industry, and legal structures (Benford & Snow, 2000; Hilson, 2002; Kitschelt, 1986; McAdam et al., 1996; Schurman, 2004), we investigate the importance of *scientific opportunities* for the emergence and trajectory of social movements. As this case details, grassroots PFAS activist groups have not only made alliances with scientists and mobilized existing expertise, but effectively produced new knowledge and scientific infrastructures to significantly shift the research, regulatory, clinical, and manufacturing environments.

PFAS are a large class of over 12,000 fluorinated chemicals that are widely used in industrial processes and consumer goods, and are associated with a host of adverse health outcomes including hormone disruption, cancers, and reproductive, developmental, and immune toxicity (U.S. Environmental Protection Agency [EPA], 2021b; Agency for Toxic Substances & Disease Registry [ATSDR], 2019c). Exposure to PFAS is nearly universal through food and consumer products, and an estimated 200 million Americans receive PFAS-contaminated drinking water (Andrews & Naidenko, 2020). National testing by the U.S. Centers for Disease Control and Prevention (CDC) detected four PFAS in the serum of over 98% of Americans (Calafat et al., 2007). Community exposure to particularly high levels of drinking water contamination is generally linked to living in close proximity to industrial sites that manufacture or use these compounds; military, firefighting, or airport sites that use PFAS-containing firefighting foams for training or fire suppression; or wastewater treatment plants (Hu et al., 2016). There are no federally-enforceable regulatory standards for PFAS levels in drinking water, although the Environmental Protection Agency (EPA) announced in early 2021 that it would move forward with establishing standards for two compounds, PFOA and PFOS (U.S. Environmental Protection Agency [EPA], 2021c).

Despite industry knowledge of toxicological and exposure concerns regarding PFAS dating to the 1960s, evidence of risk was not made public and there was little regulatory or academic awareness of PFAS prior to the early 2000s (Lyons, 2007; Richter et al., 2018). The vast majority of U.S. PFAS activism mobilized only after 2016 and has subsequently helped focus significant regulatory attention on this class of chemicals. This class of chemicals remained relatively unknown to environmental health activists for so long because PFAS manufacturers, aided by a weak U.S. regulatory structure that privileges confidential business information and the rapid market entry of new chemicals, allowed human health and exposure data to remain 'unseen' outside of industry's institutional boundaries (Richter et al., 2020). Yet today, dozens of grassroots PFAS organizations participate in a national network of PFAS advocacy, and PFAS are a leading campaign issue for nationwide environmental organizations. How did a relatively obscure class of chemicals suddenly become one of the most important targets for environmental health activism? Why has this U.S. environmental health movement, constituted by both localized struggles and a cohesive, networked movement with unified goals, been so effective in channeling funding and regulatory action to this class of chemicals?

To answer these questions, we conducted interviews with activists from PFAS-impacted communities across the U.S. We show how the conditions for widespread activist organizing were created by key scientific events which were themselves instigated by lay discoveries. In turn, activists have strategically taken advantage of scientific opportunities when organizing around movement goals. Despite a robust literature that spans interdisciplinary social movement and science studies fields, the complex roles of social movements as strategic influencers of scientific fields are under-theorized and there is little explicit attention to the factors that aid a movement's influence. We present a three-category typology describing the main ways that PFAS activists influence the scientific environment in order to further movement goals: 1) creating new state-supported scientific programs, 2) establishing scientist-community collaborations and leading civic (citizen) research, and 3) strategically marshalling independent scientific research, technological advancements, and credentialed allies. Within these different categories, we elaborate on the dimensions of scientific opportunities that aid activists in leveraging science, including the availability of research funding, openness of institutionalized scientific spaces and the research environment, the presence of prominent scientific allies, and advancements in scientific methods, models, and knowledge that are aligned with activist demands. In doing so, we expand beyond existing scholarly attention to external political and economic factors and demonstrate the importance of dynamic scientific research and institutions for supporting the emergence, development, and outcomes of social movements.

### **Expanding social movement theorizing to scientific opportunities**

While a robust literature has underscored how political, industry, and legal structures shape social movement activities, these political, industry and legal-oriented concepts are insufficiently attentive to how scientific factors shape and explain movement emergence, and how activists, in turn, mobilize and produce science to achieve social movement goals. We therefore investigate the central role of science and scientific institutions in shaping (and being shaped by) environmental health activism.

The *political opportunity structure* approach developed in response to sociological analyses that focused on qualities internal to movements, such as resources, leadership quality, or issue framing (Benford & Snow, 2000). In contrast, the political opportunity structure argues that social movement campaigns and outcomes are largely shaped by political and historical factors external to organizations themselves (Kitschelt, 1986; McAdam et al., 1996). According to this approach, governmental responsiveness to movement goals and tactics (for example, the state's proclivity and capacity for repression, the presence or absence of elite allies) create conditions for more or less favorable movement outcomes (McAdam et al., 1996). The political opportunity structure is not fixed or static; rather it is dynamic and can be altered by activists (Meyer & Staggenborg, 1996). Despite the strengths and popularity of the political opportunity structure approach, it has been critiqued as being too fixated on offering invariant, universal models of social movements, defining political opportunities so broadly that the thesis becomes trivial or tautological, and displaying a structural bias by ignoring aspects like culture, strategy, or emotions (Goodwin & Jasper, 1999).

Furthermore, political opportunity structure focuses almost exclusively on how state and other political structures influence social movements, neglecting non-state targets (Armstrong & Bernstein, 2008). To expand the focus of previous work, Rachel Schurman (2004) developed the concept of *industry opportunity structures* to investigate how key industry relationships and weaknesses, as well as the nature of the goods or services, offer more or less favorable organizing opportunities for activists. Hilson (2002) also notes that a major weakness of political opportunity theories is the failure to treat law as a separate variable when explaining the development of social movements and their strategy choices, and identifies features of legal opportunity, namely access to laws on standing, availability of state legal funding, and judicial receptivity.

These opportunity concepts are useful but insufficient for the study of movements engaging with scientific issues because they fail to attend to the importance of scientific factors in shaping social movement organizing. While the rapidly developing PFAS social movement has targeted state actors (including legislative bodies, the military, and municipal water systems) and industry, the movement has also strategically engaged scientific findings, practicing scientists, and scientific institutions. Based on the PFAS case, we therefore develop the concept of *scientific opportunity* to examine the relationship of social movements to science, specifically identifying how activists employ and create possibilities opened up by scientific advances, the presence of collaborative research programs, the availability of relevant funding, and the support of credentialed individuals to drive changes in institutional policies and practices. Our intention is to introduce a concept that sensitizes social movement scholars to the importance of the scientific environment for the creation, trajectory, and influence of social movements, with elements of this environment acting in either enhancing or inhibitory ways. We use the terminology of scientific opportunity, rather than scientific opportunity structures, to recognize that not all opportunities are 'structural' (which may imply factors that are relatively stable over time and likely less modifiable by activists), but also encompass more process-based factors (for example, the receptivity of scientific institutions to activist input). Furthermore, some scientific opportunities are subject to interpretation (e.g., the ability to align a breakthrough scientific finding with demands for a class-based regulatory approach), and thus activists' own perceptions, rather than external structures, create new scientific opportunities. This also aligns with other literature shifting away from the language of 'structures' (e.g., 'political opportunity' in place of 'political opportunity structures'; Goodwin & Jasper, 1999; Hilson, 2002).

Our approach shares much with the work of other scholars in sociology and Science and Technology Studies (STS) who have examined the relationship between science and social movements. An extensive body of research has identified the impact of social movements on the structure of scientific fields, reconfiguration of technology, and research and medical practices such as clinical trial designs (Epstein, 1996; Hess et al., 2008). Work on scientific and intellectual movements as 'central mechanisms for change in the world of knowledge and ideas' documents how movements *within* scientific fields influence knowledge production and interpretation (Frickel & Gross, 2005). Studies of anti-toxics activism have examined local cases of activists collaborating with scientists and educating themselves on scientific findings in order to challenge dominant scientific paradigms (McCormick, 2007), and uncovered the various roles played by scientists as advocates (e.g., Moore, 2008), including *shadow mobilizations* of partially invisible

networks linking social movements with experts from government and academia (Frickel et al., 2015). Scholarship has also explored the process of knowledge co-production with activists, both through formal community-based participatory research projects (e.g., Wallerstein et al., 2008) and through the work of social movement scholars themselves (e.g., Lozano, 2018). Our innovation here is to expand the opportunities literature to explicitly theorize the important scientific factors that also undergird the creation, development, and effects of social movements.

The scientific opportunity concept examines how activists employ and recursively impact possibilities opened up by scientific advances, and by institutions and individuals that are using that science, similar to how political opportunity theorizing examines elements of the political environment that provide openings for and barriers to action. Our intention is not to diminish the power of the state or industry, but rather to recognize that scientific spheres are intimately entangled with politics and economics in ways that promote or constrain social change. Additionally, social movements have targets beyond the state and industry (Armstrong & Bernstein, 2008; Corder & Brown, 2015; Taylor & Zald, 2010), including clinicians, academic researchers, standards-setting organizations that use science, and research-focused organizations such as the National Academies of Sciences, Engineering, and Medicine (NASEM).

## Methods

This research is part of a larger project on PFAS regulation, activism, and industry behavior in the United States. For this article we analyzed 41 semi-structured interviews with activists representing 14 impacted communities. We conducted interviews between July 2015 and September 2020. We recruited interviewees through a mix of purposive sampling, relying on our multi-year research project on PFAS and our extensive networks with PFAS activism leaders, and snowball sampling, asking interviewees to suggest other potential participants. Interviews typically lasted an hour and questions focused on knowledge and perspectives, organizing strategies and tactics, and potential solutions to this issue. While most of our interviewees were comfortable calling themselves ‘activists,’ it was a contested term for a few individuals. We use the terminology of ‘activist’ throughout the article, although we recognize that some of our interviewees do not self-identify as such.

Many of the interviewees were located in the Northeast U.S., the site of much of the early organizing around PFAS, though other areas represented include Alaska, California, Colorado, Michigan, North Carolina, and Washington State. Many of the individuals we interviewed did not have any previous experience with activism and organized out of concern for their family’s exposure. We did not systematically collect demographic data on our interviewees. However, we know from our other interactions and observations that many of the activists interviewed for this article are White women, many are parents (including many who were concerned about their young children’s exposure to PFAS), and some have advanced degrees.

In addition, we attended government agency meetings, activist-organized meetings, and national PFAS conferences co-organized by academics and activists. We also attended town halls and planning sessions of NASEM’s Guidance of PFAS Testing and

Health Outcomes committee, which included reports and testimony from 43 activists (National Academies of Sciences, Engineering, and Medicine [NASEM], 2021).

Our study protocols were approved by Northeastern University's IRB, IRB # 18 July 2004, and we obtained informed consent prior to interviews. All interviewees are deidentified in this article and, following in-text quotations, we include the interview date to reflect shifting activism and outcomes over time. Whenever we use activists' real names, that data comes from other sources, such as public documents or media articles. Interviews were digitally recorded, transcribed, and coded in Dedoose. Following Ragin and Amoroso (2019) interpretive model of research, our analysis moved iteratively between interview data and theoretically informed analytic frames. We first generated codes based on questions from our interview protocol, and then created new codes that emerged from preliminary reading of interview transcripts.

Our author team includes both academics and an activist from a PFAS-impacted community. The academics on our author team collectively have over 50 years of experience conducting community-engaged research with environmental health activists. Elsewhere we have argued that public sociology that blends deep community engagement with rigorous social science methods is best suited to studying contemporary environmental issues, and that knowledge production should be aimed at improving health and justice outcomes (Cordner, Poudrier, et al., 2019a; Cordner, Richter, et al., 2019b). Our relevant experience includes organizing three national PFAS conferences in collaboration with PFAS activists across the U.S., collaborating on federal grants with impacted communities, and developing resources that have aided activist organizing (including a map tracking PFAS contamination sites nationwide and guidance documents for clinicians). This sustained, collaborative work facilitated our access to research participants and allowed us to become intimately familiar with the inner dynamics and evolution of PFAS activism. Simultaneously, our academic writing is committed to reflexive and theoretically-engaged scholarship that draws on our roles as scholar-activists but does not shy away from critique of the PFAS movement (Cordner et al., 2019b).

## Findings and discussion

In the first part of this article, we demonstrate how much of the initial public knowledge on the extent of exposure and health effects of PFAS was largely sparked because of instances of popular epidemiology (Brown, 1992) in which residents linked the illnesses of family members or livestock to suspected pollution sources. We show how a key scientific panel and a regulatory testing program that followed provided the framework for the emergence of PFAS activism across the U.S. We next discuss how activism has strategically targeted political actors to create new scientific mechanisms to advance movement goals, and document the importance of community-initiated scientific studies and scientist-community partnerships for advancing PFAS knowledge and action. Finally, we demonstrate how activists independently master scientific concepts and invoke the authority of scientific allies to challenge dominant approaches to PFAS regulation. Throughout, we elaborate on the dimensions of scientific opportunity that aid movement emergence and success, including scientific funding, scientific and technological advancements, openness and receptivity of institutionalized scientific spaces,

**Table 1.** Elements of the scientific environment that influence the emergence, development, and success of social movements.

Dimensions of scientific opportunity	Examples
Availability of funding for research, environmental monitoring, and biomonitoring	Established funding streams such as National Science Foundation and National Institutes of Health grants; appropriated government funding for state biomonitoring programs and federal health studies (e.g., Multi-Site Health Study)
Openness and receptivity of institutionalized scientific spaces	National Academies of Science, Engineering, and Medicine (NASEM) expert committee for developing guidance related to clinical testing and medical monitoring holding town halls for activists across the country
Presence or absence of research opportunities for activists to shape problem identification, design, data collection, and results dissemination	Community-led health survey in Merrimack, New Hampshire; Community-engaged ATSDR Multi-Site Health Study; Firefighter-academic partnership to test firefighter gear for PFAS and inform subsequent campaign for removal
Development of methodologies and technologies aligned with activist demands	Development of technology that achieves lower detection limits of PFAS; development of total organic fluorine approaches that account for total PFAS in products and support class-based approaches
Availability of relevant scientific findings and datasets	High-profile research that demonstrates the high persistence and hazards associated with PFAS compounds; EPA's publicly accessible Unregulated Contaminant Monitoring Rule dataset demonstrating extent of contaminated public water systems across the country.
Presence or absence of prominent and/or highly credentialed scientific allies	Scientists representing community-engaged science on Pease's community advisory board for the ATSDR study; NIEHS' former director arguing for a class-based approach in peer-reviewed articles and the media and sharing findings of low-dose PFAS toxicity at public conferences

and allied scientific experts (Table 1). We show that not only do science and scientific institutions influence the emergence, strategies, and outcomes of social movements, but scientific opportunities can also be a direct result of this grassroots activism, underscoring the reciprocal nature of the scientific opportunity concept.

### ***Scientific opportunity and the C8 study: creating the conditions for the rise in PFAS activism***

A key lay discovery established the scientific conditions needed for PFAS activism to emerge at distinct locations across the U.S. Specifically, we found a landscape amenable to social movement organizing was propelled by the C8 Science Panel, a court-ordered epidemiological study that resulted from an instance of popular epidemiology, and by a broad federal water testing program that followed.

In 1980, DuPont purchased 66 acres of rural land in Parkersburg, West Virginia owned by the Tennant family. In violation of the purchase conditions, DuPont dumped toxic sludge from its nearby factory into a landfill that drained into the Tennants' remaining property. In 1999, after the death of most of their cattle and years of unsuccessful outreach to DuPont and regulatory agencies, the Tennants enlisted attorney Robert Bilott to represent them in a lawsuit against DuPont. A resulting court order forced DuPont to share thousands of previously internal documents, including medical

reports and toxicological studies linking perfluorooctanoic acid (PFOA), a PFAS also referred to as C8 due to its eight-carbon chain, to cancer in factory workers and tumors in lab animals (Rich, 2016).

After the Tennant case was settled, Bilott organized a class action lawsuit representing approximately 80,000 residents from the Mid-Ohio Valley who had been exposed to PFOA in their drinking water (Bilott, 2019). In the resulting settlement, DuPont agreed to pay up to \$70 million for a court-ordered epidemiological study of impacted residents referred to as the C8 Science Panel. This study, which convened from 2005–2013 and ultimately enrolled 69,000 participants, identified probable links to PFOA exposure for six diseases and conditions: high cholesterol, ulcerative colitis, thyroid disease, testicular and kidney cancers, and pregnancy-induced hypertension (Science Panel, 2020b).

Despite the large number of impacted residents and increasing regional awareness of PFAS contamination, there was little local activism immediately following the released findings of the C8 Science Panel (Judge et al., 2016), though a Washington D.C.-based group representing local residents, ‘Keep Your Promises DuPont,’ formed in 2015 (Keep Your Promises, 2020). The class action lawsuit and associated C8 Science Panel, however, changed the landscape of knowledge on PFAS and created an amenable scientific opportunity framework for activists in other locations. Scientific publications on PFAS in peer-reviewed journals grew rapidly, from fewer than 300 total studies published before 2000 to over 3,000 studies by 2015 (Lau, 2015). Sixty-six scientific publications resulted from the Panel itself as of January 2020 and are available on the Panel’s website (Science Panel, 2020a).

In our interviews, activists were almost unanimously aware of the C8 Science Panel, frequently reporting the study as their first source of PFAS awareness, and several referenced how they mobilized its results to lobby health officials. As one activist stated, ‘When [state officials] say there’s no known health effects, we’re like, “Really? Look at this study of 69,000 people.” How can you say that?’ [4/24/2016]

In particular, the C8 Science Panel’s findings provided a foundation for a subsequent resident-led discovery of drinking water contamination in Hoosick Falls, NY. After resident Michael Hickey’s father, a longtime employee of a factory that made a substance similar to Teflon, died of kidney cancer, Hickey’s internet research led him to the conclusions of the C8 Science Panel linking PFOA to this disease. In 2014, he collected water samples from his tap and paid for them to be analyzed by the same Canadian lab used by the C8 Science Panel (Hickey, 2019). Hickey’s samples contained PFOA at concentrations that exceeded EPA’s then-provisional health advisory level for PFOA of 400 parts per trillion (ppt) for short-term exposure (U.S. Environmental Protection Agency [EPA], 2009). After over a year of unsuccessful outreach to local and state agencies, he found a sympathetic official, EPA’s Region 2 Administrator Judith Enck, who released a water advisory and lowered the Region’s provisional PFOA health advisory to 100 ppt in early 2016. In 2016, the New York State Department of Health performed blood testing and confirmed relative high exposures in Hoosick Falls (New York State [NYS] Department of Health, 2018). Since receiving their blood results, residents have organized for environmental remediation, policy change, and medical monitoring. In May 2016, the EPA established a long-term exposure guideline for PFOA and/or PFOS, another long-chain PFAS, in drinking water of 70 ppt (U.S. Environmental Protection Agency [EPA], 2016a, 2016b); a New York State Senate report attributes the

establishment of this guideline in part to heightened concerns in Hoosick Falls (New York State [NYS] Senate, 2017).

The Mid-Ohio Valley lawsuits also increased regulatory and public scrutiny of PFAS. In addition to setting health guidelines, the EPA added six PFAS to their third Unregulated Contaminant Monitoring Rule (UCMR3) program, requiring testing between 2013 and 2015 for these PFAS in public drinking systems. As a result of this testing, PFAS was discovered in drinking water systems serving at least 15.1 million U.S. residents (U.S. Environmental Protection Agency [EPA], 2018), although this underestimates actual population exposures as UCMR3 data only accounts for six PFAS compounds, has relatively high reporting limits, and primarily includes large water systems that serve more than 10,000 people (Hu et al., 2016). Nevertheless, many communities across the U.S. became aware of their PFAS contamination because of UCMR3 testing. One activist described how they began to organize in California after looking at UCMR3 data: ‘State agencies, water agencies, they’re all like, “This is not going to be a big problem in California.” That was their mantra, and I’m like, “Did you guys look at the UCMR data?”’ [11/14/2019] To complement UCMR testing, the EPA directed the Department of Defense to do testing at military sites which further increased community knowledge of contamination events.

In summary, the C8 Science Panel, itself arising from a lay discovery, raised public awareness of PFAS, spurred future studies, and supported further public-led investigations including a formative one in Hoosick Falls. Following this increased knowledge, new PFAS water testing regimes paved the way for activism across the country. From the scientific opportunity perspective, without the emergence of authoritative and accessible scientific findings that identify PFAS’ health effects (the C8 Science Panel) and broad-scale, publicly available datasets that profile high exposures (UCMR), it’s highly conceivable that lay people would never have known about PFAS (and thus could not have mobilized) nor would they have credible evidence to which they could link their claims of harm. From the standpoint of social movement emergence, not only do people use scientific studies as an opportunity for action, but scientific knowledge of PFAS itself constructs new categories of people (the PFAS-exposed), some of whom decide to mobilize collectively around that identity.

### ***The centrality of scientific research, institutions, and actors to the expansion of PFAS activism***

While key scientific events, namely the C8 Science Panel and EPA’s UCMR testing, provided important mobilizing opportunities for social movements, they did not initially translate to political structures more amenable to social movement demands. Government agencies at multiple levels often delayed action, citing scientific uncertainties concerning population-level exposures and environmental health impacts. In response, PFAS activists compelled government action by mobilizing the support of science, scientific institutions, and scientific actors in diverse ways. In this section, we describe the dynamic nature of the scientific opportunity concept, with social movements creating new opportunities to advance scientific knowledge that supports movement goals and extant science and scientific structures influencing strategies and outcomes. Specifically, we identify three ways that activists interact with the scientific

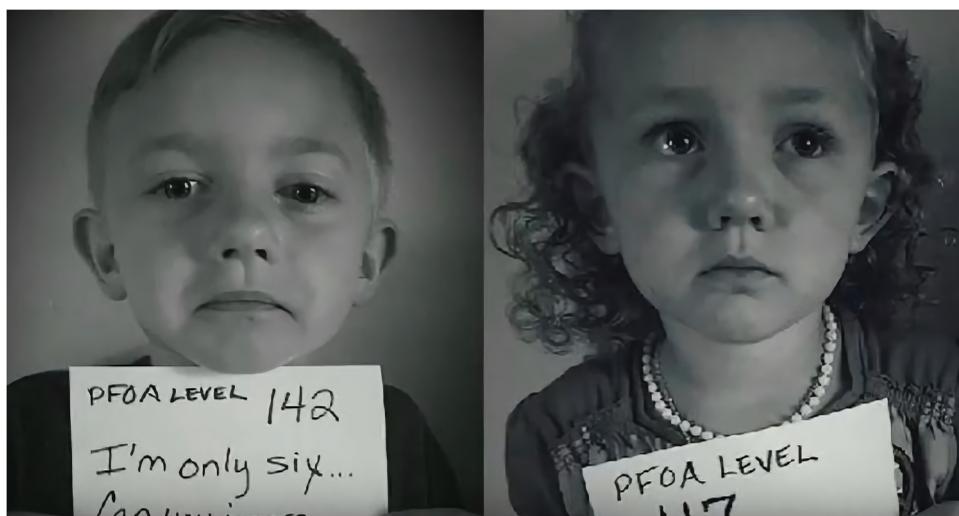
environment: 1) targeting institutions to create new scientific mechanisms and funding streams, 2) engaging in civic science and forming scientist-community partnerships, and 3) aligning existing science and scientific allies with movement goals. Within each of these categories, we outline the relevant dimensions of scientific opportunities that can influence the trajectory of social movements.

### ***Targeting institutions to create new scientific infrastructures and funding streams***

In the PFAS case, activists have targeted government and governmental-affiliated institutions to advance scientific knowledge that are responsive to their concerns. As examples, activists have pushed local and state officials to conduct water and blood testing, successfully lobbied to secure federal funding for a national health study, and pressured agencies and organizations to issue formal clinical guidance. These scientific infrastructures both aid movement mobilization (e.g., blood testing helps recruit additional activists and raises national attention) and are themselves a result of collective action. Whether activists can shape science-related goals is influenced by dimensions of scientific opportunity including availability of funding, relevant scientific findings, and datasets, and the openness and receptivity of institutionalized spaces.

As discussed, EPA's UCMR program is an example of a scientific opportunity; without this publicly available dataset of contaminants in drinking water systems across the country, many communities would not have known about their PFAS exposures and thus could not have mobilized. While UCMR3 testing raised public awareness, impacted residents were left unaware of PFAS levels in their own bodies. In response, many called on governments to institute blood testing programs. For example, one of the earliest PFAS community groups, Testing for Pease, formed in 2015, advocated for blood testing despite initial resistance from local and state officials who argued that there was not enough information linking bodily levels to adverse health concerns. As one activist said, "They keep saying it's inconclusive or there's not enough evidence. They're not taking any charge of trying to *make* the evidence . . ." [emphasis added; 4/24/2016] In this instance, state health officials translated scientific uncertainty into a tool that not only attempted to diffuse worry but also one that undermined actions that could advance scientific knowledge on links between exposure and health outcomes and thereby resolve that very uncertainty. Pease activists, however, continued to push for individual blood testing, and were aided in this goal by gaining the support of former New Hampshire Governor, now U.S. Senator, Maggie Hassan, who directed the New Hampshire Department of Health and Human Services to establish a blood testing program for community members.

Programs that make individual blood testing available to community members – and importantly returns their personal results – have been important organizing tools for activists. Blood testing of residents in impacted communities has increased local and national awareness, respected communities' right-to-know their exposures, provided helpful information for individuals who want to monitor their own health, and established the basis of concern for future regulatory demands. For example, Pease activists translated their blood testing results demonstrating high levels of PFAS, particularly in children, into political organizing, which in turn inspired other communities across the country to engage in this activist strategy. As noted by an interviewee from another New England PFAS-impacted community: "I went to the Testing for Pease website, looked at



**Figure 1.** Children from Hoosick Falls publicize their levels of PFOA exposure as part of a social media campaign. Included with permission from @pfoaprojectny1.

their timeline, worked my way backwards . . . Okay, now we need blood test[ing] . . . I'm not trying to reinvent the wheel.' [10/11/2017] Blood testing has also informed subsequent organizing on social media. Notably, #pfoaprojectNY, an activist group in Hoosick Falls, exposes contamination in their community by posting pictures of residents' blood results on Twitter (Figure 1). The photos of children, in particular, have been taken up by subsequent media coverage, including the New York Times.

While blood testing has been a central activist goal, not all impacted communities have successfully convinced their state government agencies to implement testing programs. In the absence of a consistent national regulatory approach, official responses have been uneven across space. For example, a community group in Westfield, Massachusetts tried unsuccessfully for years to convince the Massachusetts Department of Health to conduct blood testing. Blood testing was only made available (through federal, not state, support) when Westfield was included in a national health study, the ATSDR Multi-Site Study, described in the following paragraph. In some cases, state health officials may face financial constraints to conducting broadscale individual blood testing and prefer to extrapolate results from a small testing program to a larger population, rely on models for estimating population exposures, or do nothing at all. As we have emphasized, however, widely available blood testing programs that return individuals' personal results have been important mobilizing tools and activists have pushed government entities to support them. This underscores how the presence of particular types of scientific programs (e.g., ones that produce transparent and personalized data) can be a dimension of scientific opportunity, with both the programs themselves and the funding streams that establish them acting as scientific opportunities.

Similar to how PFAS activists expand the scientific opportunity landscape by increasing state biomonitoring (that then activates social movement actors and props up regulatory-related goals), activists have successfully advocated for government-funded health studies. Activists and their legislative allies were key players in securing

\$20 million in federal funding for the ATSDR to assess PFAS exposure at eight U.S. military bases, a PFAS health study at Pease, and additional funding for a \$7 million ATSDR Multi-Site Health Study of seven other sites (Agency for Toxic Substances & Disease Registry [ATSDR], 2019a). The ATSDR Multi-Site Health Study investigates the relationship between PFAS-contaminated drinking water and health, with the goal to enroll at least 7,000 adults and 2,100 children (Agency for Toxic Substances & Disease Registry [ATSDR], 2020). As ATSDR's director, Patrick Breysse, testified in Congress, this study may lead to ATSDR making 'recommendations to further reduce exposure' (Breysse, 2019). This federal funding, and the selection of Pease as a model site, was in large part due to legislative work from congressional representatives in states such as New Hampshire, who had been lobbied by community activists (McMenemy, 2018). The funding mechanisms require scientists to partner with community groups and were achieved through targeting the National Defense Authorization Act (NDAA), which annually authorizes all Department of Defense programs.

These cases underscore how scientific and political opportunities can interact. Social movement actors tied their activism to political openings, including receptive representatives and an annual budget appropriation process that Congress must pass (i.e., the NDAA), to achieve new scientific infrastructures such as the ATSDR Multi-Site Health Study and blood testing programs. Furthermore, there are instances of PFAS activists running for office themselves (for example, the mayor of Hoosick Falls is a PFAS activist). To be clear, however, the focus of the scientific opportunity concept is on illuminating openings and barriers for mobilization related to science, scientific infrastructures, and scientific figures. In this case, the availability of funding for scientific research – whether it is for blood testing, environmental monitoring, or a health study – is a dimension of scientific opportunity, and one that can be contingent on activists' perceptions of political opportunities.

In another example of activists targeting institutions to create new scientific infrastructures, they have advocated for translating the existing body of evidence on PFAS' health effects into physician guidance and medical monitoring. This is aligned with activist goals in that it would help community members and their doctors proactively identify and diagnose PFAS-associated health outcomes, as well as provide interventions to slow or stop the progression of diseases. As one activist stated with regards to the benefits of physician monitoring: 'I have this extraordinarily high level of PFAS in my blood. . . Because [my doctor] knows I have this PFAS level he kept checking my thyroid and just last week I was diagnosed with thyroid cancer.' [08/31/2020]

ATSDR eventually responded to activist petitioning for improved physician education by releasing a report with guidance for clinicians (Agency for Toxic Substances & Disease Registry [ATSDR], 2019b). Activists expressed disappointment, however, in the document's dismissal of blood testing and medical monitoring for asymptomatic individuals (Personal communication, 8 January 2020). In response to a climate of activist organizing, the National Academies of Science, Engineering, and Medicine created a Guidance on PFAS Testing and Health Outcomes expert committee to develop advice for clinicians about PFAS testing and strategies for exposure reduction. As part of this, the committee convened virtual town halls across the country, with dozens of activists and their scientific allies testifying at these town halls in support of access to blood testing, report-back of data, and medical monitoring. NASEM also appointed 41 community liaisons

(mostly activists) to advise the committee. The open nature of NASEM's town halls and the community liaison structure provide a scientific opportunity for activists to influence expert recommendations. ATSDR's guidance for clinicians was not developed with the open process that has defined NASEM's approach, and ultimately ATSDR's guidance was not aligned with activists' interpretation of the problem (with activist contempt for ATSDR's guidance in part inspiring the creation of NASEM's committee). In contrast, NASEM's final 2022 report was highly responsive to community concerns and recommended that physicians offer blood testing and medical monitoring for patients in exposed occupations or communities (National Academies of Sciences, Engineering, and Medicine [NASEM], 2022). NASEM's guidance was thus influenced by another important dimension of scientific opportunity: receptivity.

### *Participating in research*

Activists have also directly participated in the production of knowledge through civic (citizen) science, such as the resident-led water sampling in Hoosick Falls described earlier, and scientist-community partnerships. In civic science, individuals without formal scientific training collect and/or analyze data as part of scientific inquiries (Irwin, 1995). Through this production of previously undone science, they contribute to knowledge about PFAS exposure and health effects that can establish a stronger framework for regulations and medical treatments. From this perspective, the presence of research opportunities for activists to shape problem identification, research design, data collection, and results dissemination acts as an important dimension of scientific opportunity.

In an example of community-engaged research, academics at Bennington College in Vermont received two National Science Foundation grants to work with Hoosick Falls and Bennington residents on water testing and develop joint college-community courses to produce data that responds directly to their concerns about PFAS (Bennington College, 2020). As another example, researchers at Silent Spring Institute and activists are collaborating on a \$2.6 million grant from the National Institute of Environmental Health Sciences (NIEHS) that examines PFAS immunotoxicity in children (Silent Spring Institute, 2020). The ATSDR Multi-Site Health Study described earlier is another opportunity for activists to collaborate with academic, non-profit, and government scientists in advancing PFAS science, which may ultimately be translated into regulatory recommendations according to ATSDR's own director. In an example of community-based participatory research (Minkler & Wallerstein, 2011), an advocacy group in New Hampshire, Merrimack Citizens for Clean Water, carried out a community health survey in collaboration with researchers at the University of Vermont that documented elevated health concerns for several vulnerable populations and long-term residents (Panikkar et al., 2019). Activists have also effectively influenced academics to produce science that is responsive to their goals and frames. For example, a firefighter activist convinced an academic ally to test firefighter gear with the plan to publicize these results as part of a campaign to eliminate these uses of PFAS.

In these examples, the presence of community-oriented approaches to scientific knowledge production help mobilize movements and increase their influence, and allow for knowledge production responsive to activist concerns. In several of these cases, activists and their academic allies took advantage of research funding from

government agencies to form researcher-community partnerships. Some of this was already established funding streams (e.g., the Bennington College partnership leveraged the National Science Foundation's existing STEM grants), whereas other funding streams were established as a result of social movement organizing (e.g., the ATSDR Multi-Site Health Study).

### ***Mobilizing existing PFAS science and scientific allies***

In addition to directly altering scientific infrastructures, activists have also translated existing scientific discoveries, as well as methodological and technological advancements, into critical events for mobilization and influence. As has been the case in many other health-related social movements (e.g., Brown, 2007; Epstein, 1996), PFAS activists develop sophisticated knowledge of PFAS research and benefit from emerging findings that support movement goals. As such, PFAS activists demonstrate a high degree of scientific familiarity and reliance in their public advocacy work. Moreover, they invoke positions of prominent scientific figures to imbue their demands with increased legitimacy.

Just as political opportunity examines features of the political landscape that provide windows for action, scientific opportunities pave the way for social movement organizing. As discussed, the presence and accessibility of certain datasets aided movement mobilization: EPA's 2013–2015 round of UCMR was the first time that public water systems were monitored for PFAS and demonstrated the extent of contamination across the country, and the CDC's Fourth National Health and Nutrition Examination Survey (NHANES) report showed that nearly every U.S. resident had PFAS in their blood (Calafat et al., 2007). As demonstrated by our interviews and public observations, activists continually reference these findings in their organizing efforts.

As other examples, PFAS activists have on multiple occasions cited published research and the statements of prominent scientific figures when testifying at congressional hearings in Washington, D.C. For example, in a July 2019 testimony, Emily Donovan, co-founder of the North Carolina group Clean Cape Fear, referenced studies linking PFAS exposure with adverse health impacts, including preliminary research on pancreatic tumors in rats by the National Toxicology Program (NTP) that indicated that the safe exposure dose for PFOA is 700 times lower than the EPA's guideline (Lerner, 2019). This research was presented by Dr. Linda Birnbaum, then-Director of the NIEHS and NTP, at a NIEHS-funded PFAS conference that was co-organized by academics and community activists and allowed activists to learn more about the state-of-the-science and connect with scientists, while sharing their concerns (PFAS Project, 2020). Dr. Birnbaum has argued in other academic and public spaces for regulating PFAS as a class due to their shared persistence and toxicological properties (Birnbaum et al., 2021; Kwiatkowski et al., 2020); given Birnbaum's prominence and credentials, this lends additional fuel to the class-based approach that originated largely in activist discourses. Class-based approaches, which would shift from regulating chemicals one-by-one to acting on all members of the chemical family collectively, has been highly contentious. Industry has argued that this approach may lump non-harmful compounds together with hazardous ones, while activists have argued that the large size of the PFAS class (>12,000 compounds) makes it impossible to evaluate each individually and allows industry to continue to release less-studied replacement compounds that likely have similar hazardous

traits. When urging a class-based approach to regulation, activists frequently point to breakthrough research suggesting PFAS replacements for phased-out, long-chain PFAS (i.e., PFOA and PFOS; U.S. Environmental Protection Agency [EPA], 2021a) are not effectively removed by common water filtration devices, often directly identifying the study by the Principal Investigator's name, Christopher Higgins (Xiao et al., 2017).

In another prominent example, activists have mobilized an accumulation of scientific research that supports the establishment of stringent Maximum Contaminant Levels (MCLs), legal thresholds on the chemical concentrations allowable in public drinking water systems. While noting the need for federal action, activists in the last several years have predominantly targeted state governments given that this level provided a more amenable political opportunity structure. Activists' focus on MCLs helps protect public health by decreasing exposure to PFAS above levels of concern, while also creating future openings for mobilization by requiring routine water quality monitoring and public notification when detected PFAS compounds exceed standards or reporting limits. Given that the setting of regulatory water standards is a highly technical and bureaucratic process, PFAS activists have uniquely marshalled scientific findings to push for state regulatory standards that are significantly lower than EPA's health advisory. This includes the National PFAS Contamination Coalition, a group that coordinates grass-roots activism, campaigning for a federal MCL of 1ppt for all PFAS combined that was selected based on epidemiological research on immune effects in children (Grandjean & Budtz-Jørgensen, 2013).

At the time of writing, seven states have adopted MCLs for PFAS, many of them well below the EPA's health advisory level. In many cases, it is clear how community pressure helped focus attention on the need for standards and encouraged states to adopt precautionary-based MCLs based on scientific evidence of harm. For example, in Massachusetts, two nonprofit groups, Community Action Works (whose staff are now the new organization Slingshot) and Conservation Law Foundation, successfully petitioned the Massachusetts Department of Environmental Protection (DEP) to create a regulatory standard. They urged DEP's regulatory standard to be based on Vermont's health advisory limit of 20 ppt for the class as an interim step, and advocated for a final adopted level of 1 ppt based on the evidence of immunotoxic effects (Conservation Law Foundation, 2018). Massachusetts adopted an MCL of 20 ppt for the sum of the levels of six PFAS compounds (MA DEP, 2020), the largest number of PFAS compounds yet to be regulated by a state. As another example, New Hampshire's Department of Environmental Services (DES) developed MCLs for four PFAS following activist organizing in locations such as Portsmouth and Merrimack. Activists opposed New Hampshire's initial draft regulatory standards that were far higher than other states. In July 2019, in the wake of this public pressure and informed by a pharmacokinetic model developed by Minnesota state scientists that allows for an estimate of infant PFAS exposure from breast milk (Goeden et al., 2019), New Hampshire's DES adopted MCLs for four different PFAS at some of the lowest levels in the nation (New Hampshire Department of Environmental Services [NH DES], 2019). A New Hampshire activist explained how findings from the pharmacokinetic model complemented activist pressure on the state to lower their proposed legal threshold limit for allowable PFAS:

[DES] said a big piece of that was the Minnesota tool. That gave them the scientific evidence they needed. But I also feel that it was really strong community leadership . . . When those first numbers [for MCLs] came out, we really came back hard saying “this is not okay.” That’s important, especially when industry is trying to get it to go the other way [9/9/2019].

As other examples, advances in analytical chemistry allow for lower detection limits, new techniques of non-targeted analysis help identify more PFAS than previously known, and methodological advancements such as total organic fluorine measurements, a proxy for PFAS, can be used to estimate the sum of PFAS concentrations in environmental samples and consumer products. All of these analytical and methodological advances have been employed by activists in ways that align with strategic framing and movement goals, including adopting class-based regulations, avoiding problematic substitutions in product manufacturing, and eliminating PFAS in products. For example, an activist group, Toxic-Free Future, took advantage of the development of total organic fluorine analysis to test food packaging for PFAS and then target fast food retailers, and their upstream suppliers, to remove the chemistry from their products.

Finally, activists frequently consult with scientists when interpreting studies or seek their representation. As one New York activist stated when asked whether scientists have been helpful advisors for their organizing, ‘I can’t even list how many we’ve talked to.’ [3/17/2020] As a specific example, the early support of an academic scientist was key in supporting the emerging movement in Pease. As a Pease activist stated:

In the beginning, I was coming across scientific journals, articles, and I was doing my best to try to understand what they meant. So, [name of scientist] was a huge resource for me to say “You’re valid in sounding the alarm and pushing for blood testing because there is science to support that these chemicals could be harmful.” Where, in the beginning, our state health department was very much like, “Everything’s fine . . .” I’d leave a meeting where I felt like a whole panel of people made me feel like I was a crazy person for being worried. And if I didn’t have someone like [scientist] helping me to interpret the science . . . I maybe would have quit [9/9/2019].

In the cases highlighted, activists leverage opportunities such as relevant scientific findings, datasets, and tools, technological and methodological advancements, and allied experts to advance health-protective goals.

## Conclusion

Science and scientific institutions have been central to PFAS activism, both supporting and constraining social movement emergence, as well as shaping movement strategy selection and efficacy. For decades, industry circumvented public knowledge and action by concealing research on the concerning health effects of PFAS, an exploit made possible by inadequate chemical regulatory frameworks. Put simply, scientific ignorance of this chemical class among most regulators and the public precluded any activism. Key scientific studies and testing regimes, however, created space for increased social awareness and activist organizing, and themselves represent significant contributions of lay expertise to scientific knowledge. Without action by individuals such as a marginalized farmer in West Virginia or a bereaved son in Hoosick Falls, New York, PFAS’ health harms and extent of contamination might have remained obscured from public and regulatory view. Instead, PFAS has become a hot-button issue on Capitol Hill and in state

governments, the focal topic for millions of dollars of federal grant money, and the subject of a Hollywood movie, *Dark Waters*. This pattern warrants additional emphasis given that regulators and industry frequently dismiss community-identified health concerns.

This article emphasized the experiences of grassroots activists, who typically target government entities for improved regulation and monitoring of chemicals. Overall, however, activists leverage scientific opportunities for a diverse suite of goals across institutional spaces, including better practices among clinicians to monitor and respond to PFAS-related health outcomes, industry removal of PFAS from consumer products, and court-directed actions to create medical monitoring for victims of PFAS contamination.

We do not intend for the concept to be causally deterministic but rather hope that scientific opportunity acts as a sensitizing concept, drawing attention to the scientific factors that may undergird a social movement's emergence, trajectory, and success, something which has not been addressed in previous opportunity theories. The creation and success of social movements is not reducible to scientific opportunities, and social networks, cultural framing, strategy, emotions, and internal resources are also important factors affecting movement organizing (Goodwin & Jasper, 1999; Hilson, 2002). For example, many individuals became activists because of extreme worry about their children's PFAS exposures, and social media networks are important vehicles for recruitment, knowledge transfer, and strategizing; these emotions and mobilizing networks give rise to movements just as much as scientific opportunities. Furthermore, while there are some clear examples of instances in which activists leveraged scientific opportunities to achieve outcomes consistent with their goals, more research is required on how scientific opportunities have empirically influenced movement outcomes.

While not all social movements require scientific opportunities, the relevance of our concept underpins movements that address issues related to science and technology. For example, farmworkers leverage scientific studies and expert allies to demonstrate the toxicity of agrichemicals, as well as participate in scientific research to fill knowledge gaps (Kinchy, 2010). Similarly, breast cancer activists have deployed environmental and epidemiological evidence to break 'expertise barriers,' and have also targeted federal and state funding to create research programs that link environmental exposures to health outcomes with the hopes this will provide the future basis for stringent regulations (Brody et al., 2005; Parthasarathy, 2010). Moreover, AIDS activists challenged the slow and unethical design of clinical trials by recognizing opportunistic schisms in the research community and making themselves allies to particular sides (Epstein, 1996). With this case in mind, whether or not scientific consensus broadly exists can be added as another dimension of scientific opportunity, which is analogous to other opportunity theories' attention to relationships and conflict among actors (Meyer & Minkoff, 2004; Schurman, 2004). The concept is also applicable to seemingly disparate movements such as the animal rights movement, which can include dimensions of scientific opportunities such as technological and scientific advancements in line with activist goals (e.g., *in vitro* testing methods which can be used to pressure industry away from animal testing, new research that supports anti-meat health frames) and the presence of scientific allies (e.g., prominent physicians who lend support to arguments). Future research can investigate

the contours of scientific opportunities in different areas of activism and policy, attending to similarities and differences across cases.

While we underscore how particular configurations of science, scientific institutions, and scientific partnerships are important opportunities for activists, we do not argue that scientific knowledge, or the processes underlying its production, alone are sufficient for addressing environmental health problems. Adopting an excessively technocratic approach to policymaking for contentious and uncertain issues can exclude impacted, non-credentialed publics (Brown, 2007; Kinchy, 2010). Moreover, scientific knowledge production often operates on prolonged timescales incongruent with the urgent needs of contaminated communities. Finally, scientific knowledge can be a vulnerable object for basing activist demands, given how frequently industry and regulatory actors exploit scientific uncertainty to justify inaction. In response, activists call for regulatory overhauls that include shifting the burden of proof to chemical manufacturers.

Relatedly, while we highlight how activists successfully advance and benefit from PFAS science, communities face differences in their access to scientific knowledge, actors, and institutions. Our interviewees' positionality as primarily White can aid their political clout and ability to make claims on what constitutes authoritative knowledge. Also, they were often initially drawn into organizing around a single point source of pollution with identifiable origins in an industrial or military facility. Communities that face intersecting axes of oppression – for example, as a result of cumulative exposures from multiple polluting industries, and limited political, media, and academic attention due to racism, classism, geographical isolation, language barriers, and lack of legal status – can face nearly insurmountable barriers to achieving scientific recognition for environmental health harms (Richter, 2018). Environmental justice organizations, including WE ACT for Environmental Justice and Alaska Community Action on Toxics, have pushed for scientific and regulatory action on PFAS, opening up new opportunities to examine diverse activism and coalition formation.

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## Notes on contributors

**Jennie Liss Ohayon** is a Research Scientist at Silent Spring Institute, specializing in environmental policy and environmental justice. She researches the emergence of scientific and activist concerns around industrial chemicals with Northeastern's PFAS Project Lab. Her academic work is published in *Environmental Health*, *Environmental Research*, *American Journal of Public Health*, *PLoS*, and *Mobilization*, and her opinion pieces have been published in *The Hill*, *The Washington Post*, and *The Los Angeles Times*.

**Alissa Cordner** is an associate professor and Paul Garrett Fellow at Whitman College. Her research focuses on environmental sociology, the sociology of risk and disasters, environmental health and justice, and public engagement in science and policy making, and she is the co-director of the PFAS Project Lab. She is the author of *Toxic Safety: Flame Retardants, Chemical Controversies, and Environmental Health* (2016, Columbia University Press) and co-author of *The Civic Imagination: Making a Difference in American Political Life* (2014, Paradigm Publishers).

**Andrea Amico** co-founded the PFAS activist group Testing for Pease. Her family was exposed to contaminated drinking water at Pease Tradeport and she has worked tirelessly since learning of the contamination in 2014 to raise awareness, push for answers, and advocate for action on this class of chemicals. She testified at the first ever Senate hearing on PFAS in 2018 and gave a TEDx talk titled "PFAS and a Mother's Journey to Becoming A Clean Water Advocate" in 2019.

**Phil Brown** is university distinguished professor of Sociology and Health Science at Northeastern University, where he directs the Social Science Environmental Health Research Institute. He studies PFAS policy, activism, and governance. He directs an NIEHS T-32 training program, "Transdisciplinary Training at the Intersection of Environmental Health and Social Science," and is part of Northeastern's Superfund Research Program and Children's Environmental Health Center. He is a recipient of the Leo G. Reeder Award in Medical Sociology and the Fred Buttel Award in Environmental Sociology.

**Lauren Richter** is an assistant professor in the Department of Sociology at the University of Toronto, Mississauga. She focuses on US regulatory frameworks and scientific knowledge/ignorance production to understand how inequality shapes pollution exposure and recourse. She has published in *Environmental Sociology*, *Environmental Health*, *Environmental Science & Technology*, *Social Studies of Science*, *Organization & Environment*, *American Journal of Public Health* and *Journal of Exposure Science & Environmental Epidemiology*.

## ORCID

Alissa Cordner  <http://orcid.org/0000-0001-5223-2848>

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