

A letter to the ad hoc National Academies Committee on Guidance on PFAS Testing and Health Outcomes from the Community Liaisons

The National Academies of Science, Engineering, and Medicine (the National Academies) appointed the ad hoc committee on Guidance on PFAS Testing and Health Outcomes (the “Committee”) as a way for the National Academies to provide an authoritative and objective review of current evidence for human health effects of per- and polyfluoroalkyl substances (PFAS). The review will concern only those PFAS being monitored by the Centers for Disease Control and Prevention (CDC) in their National Report on Human Exposure to Environmental Chemicals and guidance will be provided to the CDC, the Agency for Toxic Substances and Disease Registry (ATSDR), and the National Institute of Environmental Health Sciences (NIEHS). The Committee also will provide recommendations regarding potential changes to CDC/ATSDR PFAS clinical guidance.

As Community Liaisons to this Committee, we represent communities impacted by PFAS contamination, advocate for management, remediation, and/or restriction of PFAS into the environment, study PFAS from a scientific perspective, or have been personally and/or professionally impacted by PFAS exposures. Our goal in writing this letter is to demonstrate our support for this Committee and its charge; as well as, highlight what we believe are critical actions needed for impacted communities which include, but are not limited to, PFAS blood testing and medical monitoring, improved education for healthcare providers, increased focus on environmental justice, extra attention to occupational exposures and vulnerable populations.

We appreciate the time the Committee took to hear our voices. The Town Hall meetings provided an opportunity for Community Liaisons and others to share their PFAS experiences with the Committee--which were often stories of deep trauma and stress, typically exacerbated by lack of access to quality health communications. We thank the Committee for their work and hope this letter affirms what the Committee heard and will use it to inform their review and recommendations. Multiple common themes emerged from these sessions. We see value in elevating them for further consideration.

PFAS blood testing and medical monitoring guidelines

Many communities have had PFAS in their drinking water for decades, unknowingly ingesting PFAS into their bodies with long-lasting consequences. Growing awareness of PFAS drinking water contamination has prompted some communities to advocate for and obtain PFAS blood testing, but the impacts of prolonged exposure to PFAS on health has not been addressed with any specific actions or recommendations. Additionally, PFAS blood testing has not been widely or easily accessible to all highly exposed communities.

At the very least, people deserve to know what PFAS are in their blood, and at what levels, using detection limits sensitive enough to completely capture exposures. The attitude of “you are better off not knowing” was described multiple times as a stressor for individuals and communities. Being armed with this basic level of information will at least give individuals baseline data about their internal exposures and the power to request preventive monitoring and testing for PFAS-linked diseases. One Liaison noted that “the only risk to testing is to the polluters.”

Improve healthcare provider knowledge and education

Healthcare providers do not receive extensive toxicological or environmental health education during their training. If training is provided, the emphasis is on safety concerns of pharmaceuticals. This lack of training is grossly apparent in how readily many healthcare providers dismiss patient concerns about health effects linked to PFAS exposure. Dismissals are further enabled by official health communications featuring outdated data and/or inadequate recommendations; as well as, health insurers limiting or refusing coverage related to PFAS exposures.

Additionally, many Community Liaisons expressed concerns regarding how the Committee will communicate and provide guidance surrounding the concept of uncertainty. For some health outcomes, there is substantial and repeated evidence for health outcomes across numerous human populations. There is also substantial and growing experimental evidence across species. However, epidemiological modesty and the desirability of more research often gets framed as universal doubt, and that framing has the potential to cause undue harm to patients who could benefit from proactive clinical interventions.

It is imperative healthcare providers are educated about the associated health risks linked with PFAS exposures. Clinicians should have access to regular updates regarding the best available summaries on recent findings and medical reviews to provide a solid knowledge base when addressing patient concerns about PFAS exposures. Clinicians should have guidance on how to competently request PFAS blood testing (if not already done by the patient), recommend additional screening tests to rule out, or proactively treat, emerging diseases linked to PFAS exposures, and inform interventions and policies to reduce and eliminate harmful exposures. One Liaison asserted that “knowledge is power” and that “if you don’t test, you don’t see a link.”

Environmental Justice

Many of the communities struggling with drinking water contaminated with PFAS face multiple challenges. These include exposure to complex PFAS mixtures, co-occurrences of other contaminants, employee exposure to multiple industries’ cross pollution, heightened exposure to PFAS spread in hurricane-prone communities, lack of access to healthcare providers, lack of access to insurance and preventative care, and lack of economic resources to implement filtration technologies at the household level. Environmental justice also means that some racial, ethnic groups and rural communities carry a disproportionately higher burden of PFAS exposures, including Indigenous peoples of the Arctic. Efforts must be made to equalize exposure reduction, remediation, monitoring, accessibility to alternative testing opportunities in areas considered medical & food deserts, and healthcare access across affected communities with the inclusion of free clinics and urgent care facilities. One Liaison indicated that many people in her community cannot afford to install filtration technologies in their homes and many people who live in rentals are unable to modify their water systems.

Occupational Exposure Risks & Vulnerable Populations

Extra attention must be given to occupations with higher risks of PFAS exposures, such as DoD firefighters, civilian firefighters at military bases, municipal firefighters, textile workers, food service employees, farm workers, franchise employees and contract staff, and industrial workers involved in the production and use of PFAS-containing products. Additionally, concern was expressed during the town halls surrounding health impacts from PFAS exposures for vulnerable populations such as pregnant women, newborns, infants, nursing/lactating mothers and the medically fragile or immune-compromised.

While most communities have only learned of their contamination in the last 5 to 10 years, PFAS contamination has been present for decades causing generational exposures within families. The committee should consider that some members of highly contaminated communities have suffered cumulative impacts of gestational exposures, as well as contamination through breastfeeding, and will continue to contaminate future generations given the persistent nature of this class of chemicals. Special focus should be given to health risks and communications for these vulnerable populations.

Impacted communities have lacked control in their exposures to PFAS and have been “contaminated without consent” and “poisoned without permission.” We were invited as Community Liaisons to this Committee because we represent the diversity of voices touched by PFAS contamination in some way. We therefore ask the Committee to consider the following recommendations in their final report:

- Epidemiological studies, including cross-sectional, case-control, nested case-control, longitudinal, and even clinical trials related to comorbid risk factors, have linked several diseases to PFAS drinking water

exposures in multiple populations and with repeatable dose-response across continents. Toxicological studies have strengthened the link between the epidemiological findings and diseases, and in vitro studies have provided clarifying pathways. While we acknowledge that findings among epidemiological studies can vary, when similar effects are seen across multiple observational studies and in toxicological studies, the strength of the association increases. The National Academies should emphasize these findings rather than minimize or discount them as currently done in the ATSDR PFAS Clinical Guidance document.

- The National Academies should recommend blood testing for PFAS as part of routine preventive health care in communities with known sources of PFAS contamination. At the very least, the list of PFAS should include those measured by the CDC through NHANES, including the sum of both linear and branched isomers, but the list also should reflect current state-of-the-art methods for detecting PFAS in biological fluids such as blood, at the lowest detection limit possible, as a growing number of PFAS are being discovered in the environment. Costs of PFAS blood testing should be covered by the polluter and/or the patient's insurance, not the patient. We note that New Hampshire already requires insurance coverage; that could be highlighted.
- The National Academies should acknowledge that specific health risks have been linked to PFAS exposure. Recommending avoidance as the only treatment option for patients is insulting and diminishes the very real fear that people have about their health and the health of their loved ones. At the very minimum, clinical guidance should recommend screening for those diseases for which probable links to exposure are strong and in individuals who have known PFAS exposures, elevated concentrations of PFAS in their blood, or additional risk factors that may be comorbid to those diseases linked to PFAS exposure. Medical screening guidance is available - <https://pfas-exchange.org/resources/> - from a team of academics, community groups, and physicians, and represents the approach that most affected communities endorse.
- The National Academies should acknowledge that subpopulations beyond just those with higher environmental PFAS exposure exist and have an increased risk of not only exposure but of PFAS-linked disease. Such subpopulations may require additional support and education and may not rely on traditional mechanisms, such as doctor's offices, for obtaining health-related information. In addition, these populations should receive blood testing with detailed individual report-back of results.
- The National Academies should acknowledge that the science surrounding PFAS is still emerging and that guidelines may need to be updated to reflect new evidence regarding exposure, health effects, and treatments.
- The National Academies should acknowledge that drinking water is not the only source of exposure to PFAS and impacted communities also may be exposed to PFAS via ingestion of contaminated food supplies such as fish, shellfish, wildlife and crops grown with contaminated soil, fertilizers and/or water, inhalation, and dermally. Indigenous peoples who are reliant on traditional diets of shellfish, fish, marine mammals, and other wildlife may have higher exposures. Cumulative exposures across these different sources is a growing concern.
- The National Academies should acknowledge that PFAS occur in the environment in complex mixtures and people are simultaneously exposed via multiple sources. The cumulative impact of exposure to myriad PFAS is a growing concern.
- The National Academies should recommend that physicians and other healthcare providers need more comprehensive education on environmental health to be able to answer patient questions, know what

health effects are associated with PFAS exposure, and establish a plan to monitor patient health (when indicated).

- The National Academies should provide recommendations on emerging concerns such as placental transfer of PFAS, PFAS contaminated breastmilk, and community concerns related to the association of PFAS exposure and reduced vaccine responses as it relates to infectious disease outbreaks.

In summary, we are grateful to the Committee for this opportunity and are hopeful that the Committee's recommendations will improve upon existing health advice that has not been responsive to the needs of communities contaminated with PFAS. The Committee is in a unique position to turn the current problem into a future model for health-protective guidance and communications.

Sincerely,

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