



TESTING *for* PEASE

Patient Perspective on PFAS Testing & Health Outcomes

National Academies Committee on Guidance
on PFAS Testing and Health Outcomes

July 13, 2021 | Andrea Amico, Co-Founder

Introduction



www.testingforpease.com
www.pfasproject.net
https://www.ted.com/talks/andrea_amico_pfas_and_a_mother_s_journey_to_becoming_a_clean_water_advocate

My Story

Water contamination shuts down well at Pease



Mother's PFAS exposure



Michelle Dalton of Durham, a member of Testing for Pease, speaks during the public comment portion of a pediatric cancer meeting Wednesday at the Portsmouth City Hall. [Rich Beauchesne/Seacoastonline]



Sophia & Vinny Amico after having their blood drawn for PFAS in 2015

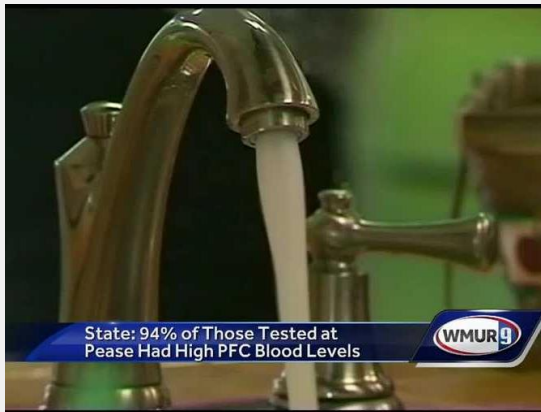
Benefits of PFAS Blood Testing at Pease



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From left to right: Alayna Davis, Andrea Amico, & Michelle Dalton



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Questions from PFAS communities

- Will my health be negatively impacted because of my PFAS exposure?
- Are my current health issues related to my PFAS exposure?
- What health effects are related to PFAS that I should watch for and what are their symptoms?
- Is there anything I can do now (ie run a test, draw labs, physical exams, more frequent doctors visits, etc) to monitor for health effects?
- How can I have my blood tested for PFAS? And what do the results mean?
- Is PFAS exposure the reason I cannot become or stay pregnant?
- Should I become pregnant knowing I have been exposed to PFAS?
- Should I breastfeed my baby knowing I have been exposed to PFAS?
- Are my child's behavioral or developmental issues related to PFAS? Or will their development be impacted because they were exposed to PFAS?
- Is my water safe to drink? Should I filter my water?
- Should I eat local produce from my garden or local farms?
- Should I eat local wildlife (chicken eggs, fish, shellfish, deer, game, etc)?
- Should I quit my job (if occupation is the PFAS exposure pathway)?
- What can I do to stop my exposure?
- How long will it take for PFAS to leave my body?
- Is there anything I can do to decrease the current PFAS levels in my body faster?
- Is my immune system compromised?
- Are my vaccines still effective? Should I be re-vaccinated?
- Will the Covid-19 vaccine be effective in me if I have high levels of PFAS in my body?
- What other sources of PFAS am I being exposed to?
- Why can't I find PFAS labeled on consumer products, clothing, personal care products, etc?



Challenges faced by PFAS communities

- Communities have been exposed to a mixture of PFAS for decades
- Lack of federal regulations for PFAS = ongoing exposure to a mixture of PFAS
- PFAS blood testing is expensive, difficult to access, and testing capabilities can vary from lab to lab
- Communities bear many costs from PFAS exposure (health, financial, emotional) due to no fault of their own
- PFAS has been given the benefit of the doubt over public health for far too long

Mixed Messages Raise Anxiety For Those Dealing With Pease Water Exposure

By EMILY CORWIN • SEP 28, 2015

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Shari and Brooke Piper are among almost 1000 community members to get their blood tested after exposure on Pease.

CREDIT EMILY CORWIN, NHPR

People exposed to contaminants in well water on the former Pease Air Force Base say the state's information about health risks has been insufficient. While the state says no conclusions can be made about the science, scientists say more is known that the state is letting on.

Challenges faced by PFAS communities

- Physicians in general receive minimal training in environmental health

Are Healthcare Providers Asking about Environmental Exposures? A Community-Based Mixed Methods Study

Kristina M. Zierold¹ and Clara G. Sears¹

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Academic Editor: Terry Tudor

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Abstract

People living near environmental hazards may develop symptoms and health conditions that require specialized monitoring and treatment by healthcare providers. One emerging environmental hazard is coal ash. Coal ash is comprised of small particles containing heavy metals, polycyclic aromatic hydrocarbons, and radioactive elements. The overall purpose of this study was to explore whether healthcare providers ask patients if they live near an environmental hazard like coal ash storage sites and to assess what health conditions prompt a provider inquiry. Focus groups were conducted in 2012 and a cross-sectional survey was administered in 2013. Overall, 61% of survey respondents reported that their healthcare providers never asked if they lived near an environmental hazard. One focus group member stated "No, they don't ask that. They just always blame stuff on you..." Respondents with asthma and other lung conditions were significantly more likely to be asked by a healthcare provider if they lived near an environmental hazard. Due to the unique exposures from environmental hazards and the low prevalence of patients being asked about environmental hazards, we recommend that healthcare providers take environmental health histories in order to understand patients' exposures, to monitor symptoms of exposure, and to assist with education about reducing exposure.

1. Introduction

People who reside near environmental hazards face unique exposures that complicate health. Due to the potentially chronic exposures associated with living near environmental hazards, healthcare providers need to know and understand their patient's exposures in order to monitor symptoms of exposure, provide appropriate treatment of health conditions, and assist with education about reducing exposure. Asking patients if they live near environmental hazards and taking an environmental health history should be a standard component of a patient's health history.

There are limited studies conducted among healthcare providers regarding training in

What Do FM Residents Know About Environmental Health?

Canadian Survey Compares Knowledge, Attitudes, Practices

July 17, 2019 08:48 am [News Staff](#) – Because they often serve on the front lines of health care, family physicians play a crucial role in identifying potential environmental hazards, educating the public about sources of environmental exposures and treating patients who have environment-related illnesses.

All that knowledge requires considerable training, however. The results of [a survey](#) in the June issue of *Canadian Family Physician* suggest that substantial gaps exist between what family medicine residents know, what they consider valuable, and how they are being trained to effectively assess and manage patient concerns related to environmental health.

Study Design

The study was conducted in two parts. First, a team composed of team of Canadian family medicine program directors and several environmental health experts developed [a comprehensive 93-question survey](#) that measured knowledge of, attitudes toward and clinical practices related to environmental health.

Once the survey received ethics approval from all participating institutions, an invitation was sent to every first-, second- and third-year family medicine resident at four training programs in Ontario between November 2015 and January 2016. Each resident received three reminders over a six-week period. Ultimately, 203 residents responded.

Key Findings

Several questions asked residents about taking an environmental exposure history. While 92% of those surveyed thought that taking an exposure history was important, just over 18% reported having specific training in how to take one. Another 48% of residents agreed that "taking an exposure history takes up too much time in office practice."

Story Highlights

A survey of more than 200 family medicine residents in Canada found gaps in knowledge and training related to environmental health.

More than 90% of residents thought taking an environmental exposure history was important, but less than 20% received such training.

The researchers recommended that environmental health be considered a high priority in postgraduate family medicine education.



Environmental health: a survey of Texas primary care physicians

Winifred J Hamilton¹, Daniel J Ryder, H Paul Cooper Jr, Darryl M Williams, Armin D Weinberg

Affiliations + expand

PMID: 17094519

Abstract

Although the role of environmental health hazards in cancer and other diseases is increasingly appreciated, most physicians have had little or no training in environmental health or in integrating exposure histories into their clinical practice. As part of the Texas Medical Association Physician Oncology Education Program, we mailed a questionnaire to 350 Texas primary care physicians (PCPs) to evaluate their attitudes, practice, training, and preferred sources for information regarding environmental health issues. Of the respondents, 86.1% reported that they had never received specific training in environmental health history-taking and 91.7% indicated a desire to learn more about environmental health hazards. The data also revealed that patients regularly raise questions about environmental topics that PCPs do not routinely discuss. Our findings identify a need for more environmental health education for Texas PCPs, and we suggest several possible mechanisms by which this might be accomplished.

<https://pubmed.ncbi.nlm.nih.gov/17094519/>

<https://www.hindawi.com/journals/jeph/2015/189526/>

Challenges faced by PFAS communities

- Association of American Medical Colleges article:
 - 1 in 5 pediatricians received training in environmental history taking.
 - Medical students received just seven hours of environmental content training.
 - Nearly one-quarter of schools surveyed did not require any environmental content.
 - AAMC's 2013 survey of medical school graduates found that more than one-third of respondents said they received "inadequate instruction in environmental health."



Challenges faced by PFAS communities

- Current ATSDR Physician Guidance is too long, dismissive, contradictory, and unhelpful to communities and providers.
- No clear guidance on breastfeeding and pregnancy for women in PFAS impacted communities
- Healthcare providers are often dismissive of community questions and concerns. And lack the education, guidance, and resources to adequately address their patients PFAS related questions/concerns and develop a plan to monitor their patients health.

Doctors don't know how to discuss environmental risks with pregnant patients: study

REUTERS | JUN 26, 2014 AT 10:50 AM



Half of the doctors surveyed said they rarely take an environmental health history from patients. (byryo/Getty Images/Stockphoto)

Obstetricians recognize that exposure to chemicals and metals can affect a pregnancy, but said in a new survey that they face barriers to counseling patients about environmental hazards.

The first of its kind study found that U.S. obstetricians and gynecologists feel they lack the medical education and training, evidence-based guidelines and tools for communicating potential environmental risks to patients.

Solutions needed by PFAS communities

- Recommending clear, concise PFAS medical monitoring guidelines such as those issued by the PFAS-REACH team in June 2021
- Access to PFAS blood tests to all community members in highly exposed areas or occupations at no cost to the community or worker. More commercial labs need to offer these tests to improve accessibility and affordability
- Improved physician outreach, materials, and education by public health agencies in PFAS impacted communities with accurate information
- Increased environmental health and exposure education at the medical school level
- Clear counseling and education for pregnant and breastfeeding women to make individual, informed decisions
- Awareness that subpopulations and environmental justice communities may require additional support and education and may not rely on traditional mechanisms, such as doctor's offices, for obtaining health-related information, and may need additional support
- Establishing a plan for ongoing education to healthcare providers and local communities as science evolves.
- We must act with a sense of urgency based on the science we have today!



Jun 29, 2021

Improved medical screening in PFAS-impacted communities to identify early disease

People highly exposed to PFAS often face significant hurdles in getting screened for potential health effects from the exposure. That needs to change.

Isabella Raponi , Phil Brown and Alissa Cordner

https://wordpress.silentspring.org/pfas-exchange/wp-content/uploads/sites/2/2021/06/PFAS-REACH-Medical-screening-guidance_clinicians.pdf

https://wordpress.silentspring.org/wp-content/uploads/2021/06/PFAS-REACH-Medical-screening-guidance_PFAS-impacted-communities.pdf

Conclusion

- Thank you to NASEM, the Committee, and sponsors for convening this panel and working to address this issue
- The three community town halls had excellent representation of impacted communities and allowed for many points of view to be expressed
- Millions of Americans have been exposed to a mixture of PFAS (some people for decades and some families for generations)
- Current lack of federal regulations mean communities continue with ongoing exposure
- Access to local healthcare providers who are knowledgeable on environmental exposures, PFAS blood tests, and clear medical monitoring guidelines are a significant gap in PFAS impacted communities that needs to be filled immediately
- PFAS have been given the benefit of the doubt for far too long and it is time to prioritize human health based on the science we know now



- This Committee has the power to make recommendations that will improve the quality and quantity of PFAS impacted community members and will save lives!
- Thank you for your time and work on this very important public health issue

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.”

~ Margaret Mead

For more information, please visit:

www.testingforpease.com



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