

Attachment 9c.

**Agency for Toxic Substances and Disease Registry
Pease Study Fact Sheet**

What is this new study about? The Agency for Toxic Substances and Disease Registry (ATSDR) wants to learn how per- and polyfluoroalkyl substances (PFAS) in drinking water may have affected the health of Pease residents. We also want to see if PFAS levels in people have changed over time.

Who wants to know these things? Researchers from ATSDR are conducting this study. The New Hampshire Department of Health and Human Services (NH DHHS) is helping to recruit people for the Pease Study.

Why does ATSDR want me to join? ATSDR is inviting adults, ≥ 18 years, and children, 4-17 years, with their parent, to take part in the Pease Study. ATSDR is inviting two groups of people.

First, ATSDR wants to enroll 1,000 adults and 350 children who worked at, lived at, or attended daycare at the former Pease Air Force Base or the Pease International Tradeport. ATSDR will start by enrolling people who took part in the 2015-7 Pease PFC Blood Testing Program. If there is space, ATSDR will invite people who drank PFAS contaminated water from Pease, including private wells, but didn't take part in the Blood Testing Program.

To compare, ATSDR wants to enroll a second group of 100 adults and 175 children from the Portsmouth area who never drank water from Pease. For Portsmouth children, their birth mothers also must never have drunk water from Pease.

If you fit into one of these two groups, ATSDR invites you to join the Pease Study. For either group, it is best if the mother takes part with her child. That is because we will ask lots of questions about her child's exposures, especially about her pregnancy and breastfeeding. If another parent enrolls with his or her child, that is OK. We might need to ask a few more questions about the mother's history.

You might be eligible to take part as both an adult and as a parent. As a parent, you also might be eligible to enroll with more than one child. Either is OK for ATSDR.

If I decide to take part in this study, how can I join? We invite you to call ATSDR at [xxx-xxx-xxxx] to let us know you want to take part. Trained ATSDR staff will ask you a few questions to make sure you are eligible. Since this is a study only about PFAS in drinking water, people who ever worked with PFAS chemicals at their jobs cannot take part. If we find you eligible, ATSDR will make an appointment for you. We will mail you an appointment packet to help you get ready.

Where will I go to take part? We are offering appointments at our central study office at [xxxxx address]. The appointment will take about 45 minutes for adults and about 2 hours for children.

It is hard for me to come to the office. Can I still take part? If your house is within a one-hour drive from the study office, we can set up home visit.

How do I get ready for my appointment? We will provide a packet with instructions on how to prepare for the appointment.

- On the morning of the appointment, we request that you collect a clean first morning voided urine sample. Bring it to the appointment.
- We also request that you not eat for at least 8-hours before your appointment so that we can collect a fasting blood sample.
- If you are taking any medications or dietary supplements, we request that you bring them to the appointment. For your child, we will ask the dates of his or her vaccinations.
- If you were a past participant, we request that you bring your Pease PFC Blood Testing Program results. If you arrive at your appointment, and do not bring the results, we will ask for permission to get your results directly from NH DHHS.

Why do I have to sign the consent form? By signing the consent form, you agree to be part of this study. We are required to have your signed consent form before we start any part of the study.

In addition to doing the parts of the study, you may have a health condition that we would like to ask your doctor to verify. ATSDR would also like to check a child's school records to compare to the child's assessments. We'd like your consent for ATSDR to get this additional information. This will improve the quality of the study results.

What will happen at my appointment? After you consent to take part in the Pease Study:

- We will measure your height, weight, waist, hip, and blood pressure.
- We will take in your urine sample, which you collect that morning.
- We will collect a fasting blood sample. A trained phlebotomist will draw a small amount of blood from a vein in your arm (about 5 teaspoons for children and 7 teaspoons for adults). We will label your samples with a study ID only.

If we find that you have of a medical condition that will interfere with a blood draw or blood test, you may not be able to take part in all parts of the study. However, you can still do the interviews and have a weight, height, waist, hip, and blood pressure measured.

- The questionnaire about your exposure and medical history should take about 30 minutes to complete. If you are a parent who also enrolled as an adult, ATSDR will give you a 15-minute questionnaire about your child.
- If you are a parent, we will also ask you to complete an assessment of your child's attention and behaviors. It should take about 15 minutes.
- Trained professionals will give your child the behavioral assessments. Although some age groups will only need 30 to 60 minutes, the testing will take about 90 minutes for most children. The tests will be paced and should not be tiring for your child.

Can I do the interview by telephone? No. All parts of the study must be done face-to-face. We need to interview everyone the same way.

Can someone else interview for me? No. It is important that we interview only people who are eligible. Of course, ATSDR will ask parents to answer questions about their children. If you are having trouble speaking, a household member may assist you.

What questions will I be asked? We will ask about your health in general, your family health history, your jobs, and about other ways that you might be exposed to PFAS. For adults, we will also ask about health behaviors such as use of alcohol and tobacco. Parents and children will complete their behavioral assessments as well.

This is personal. Why do you need this information? Your personal information will be kept private. The research staff will combine your answers with everyone else's. We want to know if the health status and blood PFAS are different between groups of people.

What if I don't know how to answer the questions? If you do not know or do not remember the answer, you simply say so.

Will you measure PFAS in my blood? Yes. We will test your blood for the PFAS. We will let you know what your PFAS levels are. If you were part of the 2015-7 Pease PFC Blood Testing Program, we would like to compare those results to the Pease Study results.

Will you do other blood tests? Yes. We will test your blood for health markers like cholesterol, liver enzymes, kidney function, sex and thyroid hormones. These markers will help us learn more about how PFAS affect health. Doctors use most of these markers to assess health.

Will you measure PFAS in my urine? Scientists are learning more about PFAS every day. Your urine specimen will be stored until lab methods are developed and the scientific evidence shows which PFAS tests will yield useful results. It might be a year or more before ATSDR decides if and which PFAS tests in urine should be done as part of this research study.

How will I learn about my test results? We will send your test results to you in a letter. We think it will be up to two years from the time of your blood draw when we finish all of the tests and send the letters. If one of your test results means you might have a health problem, we will contact you when the laboratory sends us the result.

How are you going to use my information? We will write reports or scientific articles about the study results. We will combine everyone's results to get a picture of the health issues of people in Pease and how they relate to PFAS. These reports or articles will be made public after the study is finished. The results in these reports will be presented in a way that people who take part cannot be identified.

What are the risks of taking part in the study? Your only risk from taking part in the study are from having your blood drawn. It may hurt a little when the blood is drawn and you may have some bruising afterward where the blood is drawn. We will do our best to avoid these problems.

Are there any costs to my taking part? You do not have to pay to be part of this study. The blood tests are free.

What benefit do I get for taking part? While there are no direct benefits for taking part in the study, we will give you the results of your blood PFAS and health tests that you may find helpful to share with your child's doctor. We also think that the study will help the Pease community better understand the connection between PFAS and health.

Will I be paid to take part? The study has different parts. We will give you a \$25 gift card if you complete the questionnaire. We will give you a \$25 gift card if you complete your body and blood pressure measures and donate blood and urine. If you are a parent with a child who completes a battery of assessment tests, we will give you a \$25 gift card. This is our way of thanking you for taking part in the study.

Can I change my mind about taking part after I start? You can always choose whether you want to be part of this study, or not. You can stop at any time by telling the study staff that you do not want to go on. You also can refuse to answer any question or to have your blood drawn or donate urine. There is no penalty for refusal or withdrawal from the study.

Are you trying to sell me something? This study does not have anything to sell or buy. This is a study paid by ATSDR at no cost to you.

How will you protect information I provided? This research is covered under a Certificate of Confidentiality. That means that courts cannot compel ATSDR to reveal your identity, unless you consent to it.

All of the information that you give us will be kept private to the extent allowable by law. We will use a code number instead of your name for your answers and test results. We will keep your records under lock and key at the study office in Pease. ATSDR will protect any computer files with your information and keep them secure. Only study staff with a need-to-know will have access to your information and test results. Other scientists may request information from this study. If we share the information with them, we will first make sure that you cannot be identified.

How can I get more information about the study? To ask questions about the study call Dr. Marian Pavuk at [xxx-xxx-xxxx]. For questions about your rights related to this study, contact the CDC/ATSDR Human Research Protection Helpline at (800) 584-8814. Please leave a message about the CDC Protocol No. xxxx, and a brief message about your concern of question.