The PFAS Health Study

Participant Information Sheet

Per- and Polyfluoralkyl Substances (PFAS) were, for many years, important components of aqueous film forming foam (firefighting foams). They also had many other uses in food, makeup, sunscreen, clothes, paints, leather coatings, household products such as protective coatings on furniture, and non-stick surfaces on some cookware and food packaging. They are very stable chemicals, persist for a long time in the environment and, once absorbed, are only cleared slowly from the human body. They may have harmful effects on human health. Detailed information on what is known about the health effects of exposure to PFAS is available on our website (pfas.anu.edu.au).

Researchers at the National Centre for Epidemiology and Population Health, Research School of Population Health, Australian National University (ANU) are conducting The PFAS Health Study.

Outline of the Study

This Study is part of a larger research project about health effects of living in a PFAS contaminated area. We will analyse blood samples and conduct a survey of people in several towns that have high levels of PFAS contamination of the environment from firefighting foams — Oakey (Queensland), Williamtown (New South Wales) and Katherine (Northern Territory) — and compare them with people who live in several similar towns that have not had a source of high exposure to PFAS. We will analyse these samples for PFAS chemicals, and common blood chemicals (uric acid, creatinine and blood fats (cholesterol and triglycerides)). The survey will gather information about participants’ exposure to PFAS, health conditions, health concerns, and levels of distress and anxiety. You can complete the survey on behalf of your child online or in a paper format.

We aim to find out how blood PFAS levels compare between residents of contaminated areas (PFAS Investigation and Management Areas) and residents of non-contaminated areas, and to find out what factors might influence a person’s PFAS level, what health concerns might be linked with blood PFAS levels, and how blood PFAS levels influence other chemicals in blood, specifically cholesterol and uric acid, which have been linked with PFAS exposure. Your child's blood sample will only be tested if you provide consent for additional testing.

The Study's findings will be made available through the Study's webpage (pfas.anu.edu.au) in mid-2020, and published in scientific journals. The results will give a broad overview of health impacts, if any, of living in a PFAS Investigation or Management Area.

The Australian Government has commissioned this Study. No personal information we collect will be given to the Australian Government.

Taking part in the Study is entirely voluntary; your child is not obliged to take part, and choosing not to will be no disadvantage to you or your child. You can withdraw your child from the Study at any time without disadvantage and without giving a reason. If you choose to withdraw your child we will destroy data already collected from you if you ask us to.

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1 Official Project Title: The Per- and Polyfluoroalkyl Substances (PFAS) Health Study: Cross-sectional Survey and Blood Serum Study

This is for you to keep
Participant Involvement
Here is what we would like you to do:

1. Complete the enclosed consent forms. You will only need to complete the consent form that is inside the survey, the loose consent form is for you to keep;

2. Complete the health and lifestyle survey. The survey will ask you about your child’s possible PFAS exposure, health complaints and concerns, levels of distress and anxiety, and some background information. You can choose not to answer some questions if you wish. The survey will take 30-45 minutes to complete. Further details on how to complete the survey online are available in the letter of invitation.

If you provide consent for additional testing on your child’s blood sample that was sent to the ANU, your child’s sample will be tested in early 2020. You will be provided with your child’s results and the normal range of blood chemicals in a letter at this time. If you consent, we will also send your child’s results to their regular doctor. If any of the results are abnormal, the letter that you receive will include a recommendation for your child to attend their usual medical provider to discuss these results and arrange further review. Abnormal findings are common in the general community, even when the person is not aware of them. The study staff will not be able to provide a clinical interpretation of these results because interpretation requires a full medical history and examination. Your child’s usual medical provider will be able to interpret this information for you. It will be your responsibility to seek further medical follow-up and and there may be costs associated with this. It will be your responsibility to fund all costs related to any medical or clinical follow-up after you receive these results.

While it is unlikely that your child, as an individual, will gain personal benefit from having their blood sample tested or in completing the survey, there will be benefit to your wider community, and other communities in Australia and worldwide that are concerned about PFAS contamination in their environment. Exposure pathways, health effects, and levels of anxiety and distress regarding PFAS exposure will be documented and the results will be given to government and freely available to participants, the general community, and other researchers.

Your privacy
Your child’s privacy is important to us. We will not tell other people that your child has taken part. Only members of the research team will have access to the information you give us. Personal identifying information will not appear in any reports, it will only be used to contact you about future studies relating to the PFAS Health Study if you agree to us doing this. When your child’s information is being analysed, people doing the analysis will not see any information that identifies you.

The ANU Privacy Policy can be found at https://policies.anu.edu.au/ppl/document/ANUP_Q10007 and contains information about how you can:

• Have access or seek correction to your personal information; and

• Complain about a breach of any Australian Privacy Principle (APP) and how ANU will handle the complaint.

Data Storage
Your child’s data will be stored securely on password protected ANU data servers during the collection and analysis stages of the Study. It will be stored on password protected ANU servers for five years from the date of any publication arising from the research, and then archived at the ANU. Information about your child will always be stored separately from anything that can identify them. Your child’s data may be used for future ANU analyses of the health effects of PFAS exposure. Any future such analyses would require additional ethical review and clearance. Access to the archived data will be limited to named staff working on the Study. Your child will not be identifiable in any archived data.

This is for you to keep
Blood Storage

If your child had their blood tested for PFAS through the Voluntary Blood Testing Program and you agreed for their blood to be sent to the ANU, their blood sample has been stored at ANU in a secure freezer. All study staff have made a written commitment to keep your child's information secure at all times. They will not be used for any other purpose than this Study without your consent. You can consent to have your child's blood included in future PFAS research by the ANU by ticking the box on the consent form. Future research will not include genetic research.

Research Team

Professor Martyn Kirk (ANU) leads the PFAS Health Study. Professor Adrian Miller from Central Queensland University provides advice on working with Aboriginal communities. Dr Miranda Harris (ANU), Emeritus Professor Bruce Armstrong (University of Sydney and Western Australia), Professor Jochen Mueller (University of Queensland), Professor Cate D’Este (ANU), Professor Robyn Lucas (ANU), Professor Archie Clements (Curtin University), Associate Professor Rosemary Korda (ANU), Associate Professor Philip Batterham (ANU), Dr Jennifer Bräunig (University of Queensland), Professor Cathy Banwell (ANU), Dr Tambri Housen (ANU) and Dr Aparna Lal (ANU) advise on the content and methods of the Study. Ms Hsei Di Law (ANU) advises on data analysis of the Study. Ms Sue Trevenar (ANU), Ms Kayla Smurthwaite (ANU), and Ms Anna Rafferty (ANU) coordinate the Study's operations.

Questions and Answers

Ask us at 1800 430 903, pfas.anu.edu.au or pfas.health.study@anu.edu.au

Concerns or complaints

The Human Research Ethics Committees (HREC) of the Australian National University (ANU), the Northern Territory Department of Health and Menzies School of Health Research (NTDoH and MSHR) have approved the Study (ANU HREC protocol 2018/651, NTDoH and MSHR HREC protocol 2018-3226). If you have concerns regarding the way this research is conducted please do not hesitate to contact the researchers or the the ANU or NT Ethics Administration:

**Human Research Ethics Officer**
The Australian National University

T: (02) 6125 3427
E: Human.Ethics.Officer@anu.edu.au

**Ethics Administration**
Human Research Ethics Committee of the NT Department of Health and Menzies School of Health Research

T: (08) 8946 8600
E: Ethics@menzies.edu.au

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