Attachment 5. Multi-site Study Recruitment Materials

- **Attachment 5a. Child invitation letter**
- **Attachment 5b. Adult invitations letter**
- **Attachment 5c. Multi-site Study Communication Plan Objectives**
- **Attachment 5d. Multi-site Study Overarching Communication Messages**
- **Attachment 5e. Multi-site Study Press Release – Launch**
- **Attachment 5f. Multi-site Study Website Flyer**
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Multi-site Study

Child Invitation Letter

Flesch-Kincaid Readability Score – 8.2
(delete authority; ATSDR spelled out)

Attachment 5a – Example - Child Invitation Letter

[ON LETTERHEAD]

[DATE]

[NAME OF ADULT]

[ADDRESS]

[CITY, STATE ZIP CODE]

Subject: Multi-site Study – Child Recruitment

Dear [NAME OF PARENT/GUARDIAN]:

Under the Section 316(a) of the 2018 National Defense Authorization Act (Public Law 115-91), Congress authorized the Agency for Toxic Substances and Disease Registry (ATSDR) to study if exposure to per- and polyfluoroalkyl substances (PFAS) in drinking water might affect human health. Thus, ATSDR is funding the Multi-site Study (CDC Protocol No. xxxx) conducted by [insert study investigators institution name].

ATSDR and [Insert study investigators institution name] will recruit at least 6,000 adults and 2,000 children who resided in areas served by PFAS contaminated drinking water or were exposed in utero or during breastfeeding when the mother consumed the contaminated drinking water. Drinking water exposure must have occurred within 15 years of the start of the study. Adults must be 18 years or older. Children must be 4 to 17 years old. Children whose birth mothers were ever employed as a firefighter, ever participated in fire training exercises using AFFF foam, or were ever employed at industrial facilities that used PFAS chemicals in the manufacturing process will be excluded.

[Insert site] was selected to be one of the study sites. Our records show that your child may be eligible take part in the Multi-site Study. If you and your child are interested, please call [insert study investigators institution name] directly at [study telephone number].

For questions about this research study, please call the study lead [insert name], at [study telephone number]. Please leave a message with your name, a telephone number, or an address.

Thank you for your interest.

[Insert Name]

[Insert Institution]

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~~Multi-site Study~~

Adult Invitation Letter

Flesch-Kincaid Readability Score – 8.2
(delete authority; ATSDR spelled out)

Attachment 5b –Adult Invitation Letter

[ON LETTERHEAD]

[DATE]

[NAME OF ADULT]

[ADDRESS]

[CITY, STATE ZIP CODE]

Subject: Multi-site Study – Adult Recruitment

Dear [NAME OF ADULT]:

Under the Section 316(a) of the 2018 National Defense Authorization Act (Public Law 115-91), Congress authorized the Agency for Toxic Substances and Disease Registry (ATSDR) to study if exposure to per- and polyfluoroalkyl substances (PFAS) in drinking water might affect human health. Thus, ATSDR is funding the Multi-site Study (CDC Protocol No. xxxx) conducted by [insert study investigators].

[Insert study investigators] will recruit at least 6,000 adults and 2,000 children who resided in areas served by PFAS contaminated drinking water or were exposed in utero or during breastfeeding when the mother consumed the contaminated drinking water. Drinking water exposure must have occurred within 15 years of the start of the study. Adults must be 18 years or older. Children must be 4 to 17 years old. Persons who were ever employed as a firefighter, ever participated in fire training exercises using AFFF foam, or were ever employed at industrial facilities that used PFAS chemicals in the manufacturing process will be excluded.

[Insert site] was selected to be one of the study site. Our records show that you may be eligible take part in the Multi-site Study. If you are interested, please call [insert study investigators] directly at [study telephone number].

For questions about this research study, please call the study lead [insert name], at [study telephone number]. Please leave a message with your name, a telephone number, or an address.

Thank you for your interest.

[Insert Name]

[Insert Institution]

Attachment 5c.

Agency for Toxic Substances and Disease Registry (ATSDR)

Multi-site Study

Communication Plan Objectives

Objectives	**Activities/Methods**	**Responsible participant**	**Timetable**	**Objectives achieved**
Objective 1:				
Identify and establish relationship with project stakeholders	• Establish and maintain collaborative partnership and alliances with local community groups and civic organizations • Develop plan to provide project updates • Establish and maintain links with community leaders and elected officials	Recipient, he Agency for Toxic Substances and Disease Registry (ATSDR)	Ongoing	Recipients met with community groups, ATSDR assist with setting up Community Assistance Panels CAP)
			Ongoing	Provided detailed information on planned study (developed research protocol, externally peer reviewed, revised – discussed content and changes).
			After Institutional Review Board (IRB) approval	Received extensive input from the community. Bi-monthly calls with recipients, site CAPs; in-person meetings as needed.

Objective 2:				
Develop and present project-related information	• Develop study-related information materials, forms, and reports for participants; submit materials, etc., for IRB and Office of Management and Budget (OMB) review • Describe planned activities for the study at informal meetings in Multi-site at civic or community clubs or other functions • Obtain comments on presenting study information from site CAPs, community groups, and others • Describe project activities at professional scientific meetings	ATSDR, Study investigators	Ongoing	IRB and OMB approvals pending.
			After the IRB approval	Set up additional meetings with site CAPs including representatives from local medical societies, school officials, and elected officials.
Objective 3:				
Develop and establish media relations	• Study PIs and staff should participate in local radio programs describing planned Multi-site Study • Use contacts from the site CAPs to contact local press • Publish information about upcoming health study • Record short video message from the ATSDR director and site CAP to introduce the study and encourage participation	Study PIs and co-PIs	Ongoing Ongoing After the OMB approval	Call or meet the press and local radio and television representatives at the site.

Objective 4:				
Organize community meeting for community members to announce the study	• Mail invitation letters and study fact sheet to recruits • Organize a public meeting at the appropriate/suitable venue • Use site CAPs and local contacts to distribute material about upcoming meeting to schools, employers, and other stakeholders.	Study PIs, study staff	After OMB approval 2 months after OMB approval	Provide a forum for potential participants to find out more about the study and have study investigators answer questions.

Attachment 5d

Agency for Toxic Substances and Disease Registry (ATSDR)

Multi-site Study

Overarching Communications Messages

- ATSDR and [insert institutions] are conducting the Multi-site Study:
    - To learn more about the human health effects of exposures to drinking water contaminated with perfluoroalkyl substances (PFAS), and

- The Multi-site Study will include children aged 4-17 years and adults aged ≥18 years who were exposed to the contaminated drinking water at the [insert site]. Persons will be eligible for the study if they lived in a home, worked or attended childcare at the site, were exposed in utero or during breastfeeding, that was served by a PFAS-contaminated public water system or private well.

- The Multi-site Study will recruit at least 6,000 adults and 2,000 children combined from the sites exposed to the PFAS-contaminated drinking water.

- The Multi-site Study will determine the participant's blood levels of PFAS as well as health indicators such as cholesterol levels, liver function, thyroid function and immune function. The participant's test results will be provided to the participant along with information on how to interpret the results.

Attachment 5e.

Agency for Toxic Substances and Disease Registry (ATSDR)

Multi-site Study

Press Release - Launch

For Immediate Release:

Contact: ATSDR Media Office

770-488-0700

The Agency for Toxic Substances & Disease Registry (ATSDR) is starting a study to determine the health effects of exposures to contaminated drinking water serving [insert site]. The public drinking water system at [insert site] was contaminated with perfluoroalkyl substances ("PFAS") from [insert as applicable].

The Multi-site Study will recruit at least 2,000 children aged 4-17 years and 6,000 adults aged ≥18 years who were exposed to PFAS contaminated drinking water. Birth mothers of eligible children cannot have a history of work exposure to PFAS.

"There is much that is unknown about the health effects of exposures to these chemicals," said Patrick Breysse, PHD, CIH, Director of ATSDR and the National Center for Environmental Health at the Centers for Disease Control and Prevention (CDC). "The Multi-site Study will advance the scientific evidence on the toxicity of PFAS and provide some answers to communities exposed to the contaminated drinking water."

Each participant will be asked to provide a blood and a urine sample for analysis of PFAS levels and health indicators such as cholesterol levels, liver function, thyroid function and immune function. The participant's test results will be provided to the participant along with information on how to interpret the results.

Attachment 5f.

Agency for Toxic Substances and Disease Registry (ATSDR)

Multi-site Study

Website Flyer

Multi-site Study

Under the Section 316(a) of the 2018 National Defense Authorization Act (Public Law 115-91), Congress authorized the Agency for Toxic Substances and Disease Registry (ATSDR) to study if exposure to per- and polyfluoroalkyl substances (PFAS) in drinking water might affect human health. Thus, ATSDR is funding the Multi-site Study (CDC Protocol No. xxxx) conducted by [insert study investigators institution name].

ATSDR and [Insert study investigators institution name] will recruit at least 6,000 adults and 2,000 children who resided in areas served by PFAS contaminated drinking water or were exposed in utero or during breastfeeding when the mother consumed the contaminated drinking water. Drinking water exposure must have occurred within 15 years of the start of the study. Adults must be 18 years or older. Children must be 4 to 17 years old. Children whose birth mothers were ever employed as a firefighter, ever participated in fire training exercises using AFFF foam, or were ever employed at industrial facilities that used PFAS chemicals in the manufacturing process will be excluded.

Frequently Asked Questions (FAQs)

1. Why is ATSDR doing the Multi-site Study?

ATSDR is conducting a health study to evaluate the health effects from exposures to PFAS-contaminated drinking water at number of sites around the country.

The purposes of the study are to:

- Learn more about the human health effects of exposures to drinking water contaminated with PFAS,
- Address some of the health concerns of the affected communities

2. How was the drinking water at this site contaminated with PFAS?

The source of the PFAS contamination is specific to the individual site. In general the source of PFAS could have been from the use of aqueous film-forming foam (AFFF), industrial PFAS production, or secondary use of PFAS in the production of consumer products which may have affected public or private water supply, or other waterways.

3. Who is eligible for the study?

Children aged 4-17 years and adults aged ≥18 years are eligible for the study if they worked or attended childcare at the site, were exposed in utero or during breastfeeding, or lived in a home near the site that was served by a PFAS-contaminated public water system or private well.

Persons with occupational exposures to PFAS (e.g., firefighters who used or trained with AFFF) and children whose mothers were occupationally exposed to PFAS are not eligible for the study.

Eligible females who are pregnant may enroll; however, the federal regulations say that people in prison, including those under house arrest, cannot take part in this type of study.

4. What is required in order to participate in the study?

Each participant (or the parent of a child participant) must sign a consent form. The consent form describes the study procedures and risks and benefits of participation. The consent form will request permission to obtain a blood and urine sample. These samples will be analyzed for PFAS and for health indicators such as cholesterol levels, liver function, thyroid function and immune function. The participant's test results will be provided to the participant along with information on how to interpret the results. The consent form will also request that the participant (or parent of the child participant) complete a health and exposure questionnaire. The consent form will ask permission to obtain body measurements (blood pressure, weight, height, waist and hip circumference). The consent form will request permission to obtain the participant's medical records and the child participant's special education records (e.g., individual education plan evaluation report or 504 Plan). Finally, the consent form for children participants will request permission to administer behavioral tests to the child and obtain information from the parent concerning the child's behaviors.

Attachment 5g.

Agency for Toxic Substances and Disease Registry (ATSDR)

Multi-site Study

Public Service Announcement

Under the Section 316(a) of the 2018 National Defense Authorization Act (Public Law 115-91), Congress authorized the Agency for Toxic Substances and Disease Registry (ATSDR) to study if exposure to per- and polyfluoroalkyl substances (PFAS) in drinking water might affect human health. Thus, ATSDR is funding the Multi-site Study (CDC Protocol No. xxxx) conducted by [insert study investigators institution name].

ATSDR and [Insert study investigators institution name] will recruit at least 6,000 adults and 2,000 children who resided in areas served by PFAS contaminated drinking water or were exposed in utero or during breastfeeding when the mother consumed the contaminated drinking water. Drinking water exposure must have occurred within 15 years of the start of the study. Adults must be 18 years or older. Children must be 4 to 17 years old. Children whose birth mothers were ever employed as a firefighter, ever participated in fire training exercises using AFFF foam, or were ever employed at industrial facilities that used PFAS chemicals in the manufacturing process will be excluded.

Each participant will be asked to provide a blood and a urine sample for analysis of PFAS levels and health indicators such as cholesterol levels, liver function, thyroid function and immune function. The participant's test results will be provided to the participant along with information on how to interpret the results.

Additional information on the study is available at http://www.atsdr.cdc.gov/pfas/index.html.