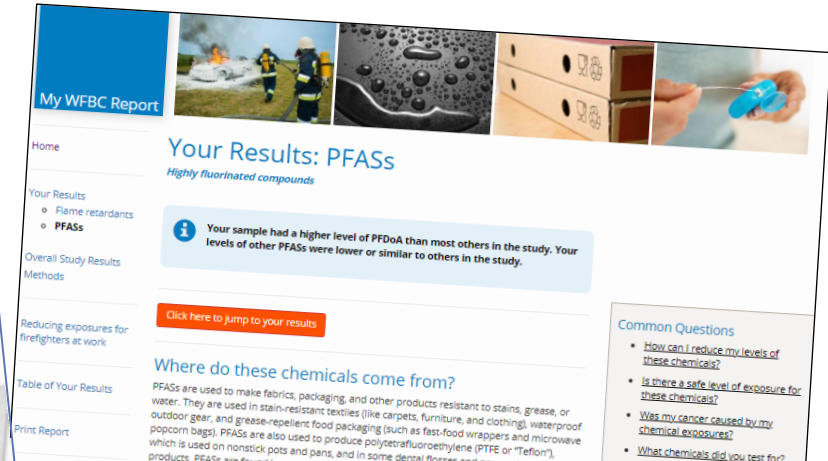
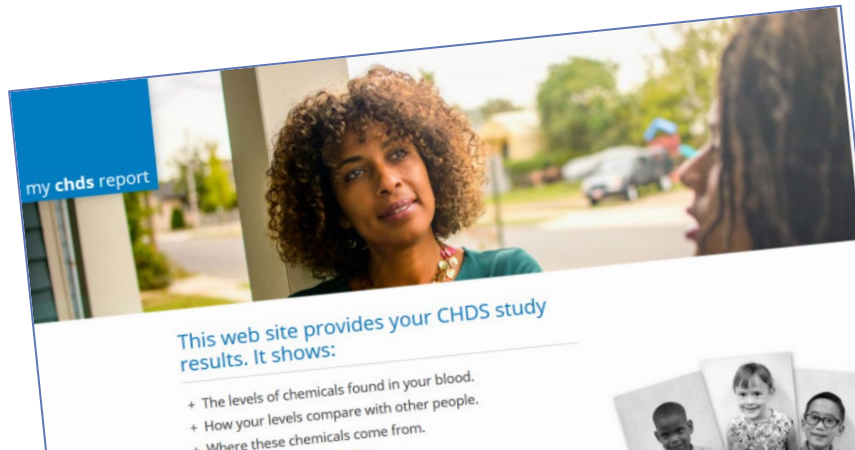


Communicating What We Do Know in Community Cancer Investigations

Julia Brody, PhD, Silent Spring Institute (brody@silentspring.org)

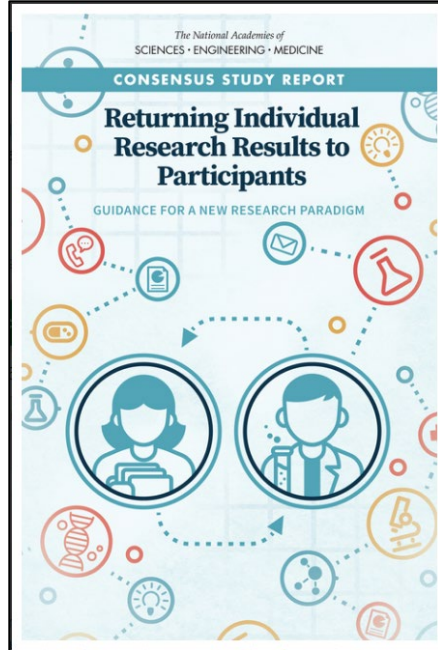
The Potential Contribution of Cancer Genomics Information to Community Investigation of Unusual Patterns of Cancer, Collaborative workshop convened by: National Cancer Policy Forum Roundtable on Genomics and Precision Health, April 2023



When people donate samples of blood, urine, dust, air, tap water... for research, they nearly always want to know what was found, even when health effects are uncertain.



NASEM 2018 consensus report

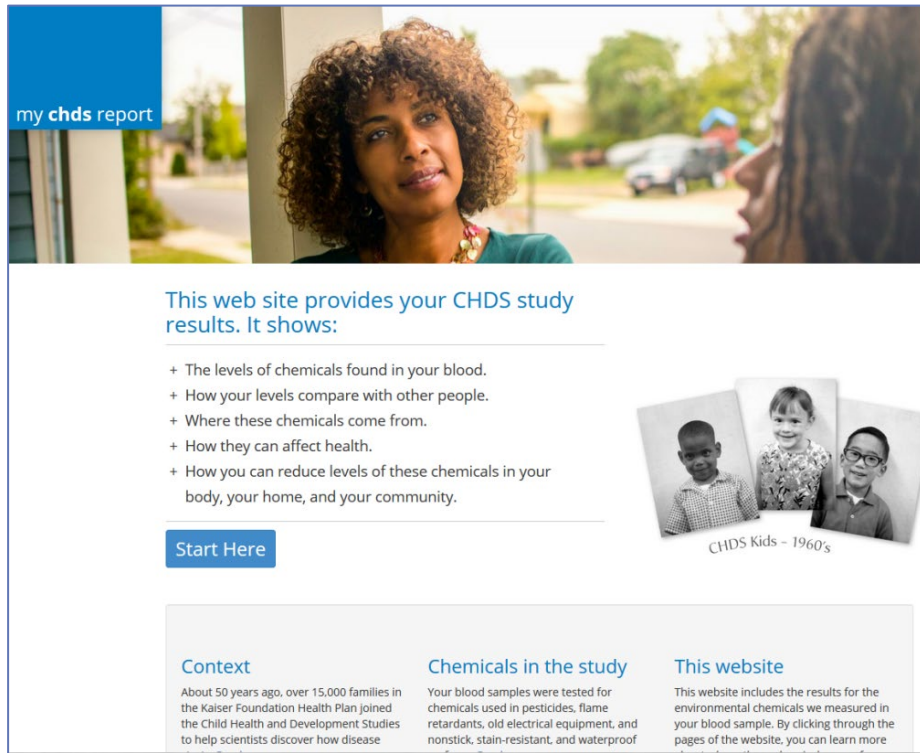


- Encourages return of individual results

“...as a matter of reciprocity, respect, transparency, and trust, the return of results should be routinely considered ...”

DERBI: Digital Exposure Report-Back Interface

- A software framework for generating personalized exposure reports -- for computer, smartphone, print
- Scalable to studies of all sizes
- Researcher dashboard to create reports – user-tested platform, adaptable to community context



The screenshot shows the 'my chds report' website. At the top is a header image with a woman looking out a window and the text 'my chds report'. Below this, a heading states: 'This web site provides your CHDS study results. It shows:'. A bulleted list follows: '+ The levels of chemicals found in your blood.', '+ How your levels compare with other people.', '+ Where these chemicals come from.', '+ How they can affect health.', and '+ How you can reduce levels of these chemicals in your body, your home, and your community.' To the right of the list is a photo of three children with the caption 'CHDS Kids - 1960's'. Below the list is a blue 'Start Here' button. At the bottom, there are three columns: 'Context' (describing the study's history), 'Chemicals in the study' (listing tested substances), and 'This website' (describing the report's content).

my chds report

This web site provides your CHDS study results. It shows:

- + The levels of chemicals found in your blood.
- + How your levels compare with other people.
- + Where these chemicals come from.
- + How they can affect health.
- + How you can reduce levels of these chemicals in your body, your home, and your community.

Start Here

CHDS Kids - 1960's

Context
About 50 years ago, over 15,000 families in the Kaiser Foundation Health Plan joined the Child Health and Development Studies to help scientists discover how disease

Chemicals in the study
Your blood samples were tested for chemicals used in pesticides, flame retardants, old electrical equipment, and nonstick, stain-resistant, and waterproof

This website
This website includes the results for the environmental chemicals we measured in your blood sample. By clicking through the pages of the website, you can learn more

Key report features

- Summary page with personalized “headlines”
- Individual & study-wide results
- Visualization of results and benchmark comparisons
- “Details on demand”

Results Summary

We found chemicals in every person we tested. Some people may want to make changes to reduce their chemical levels. We hope these results will help you make informed decisions.

Chemicals We Found

Your sample had a higher level of [a bisphenol](#) than 95% of Americans.



WHAT YOU CAN DO

Choose fresh or frozen instead of canned food or drinks. Be aware that plastics and food cans labeled “BPA-free” may contain BPS, BPF, or other chemical substitutes.

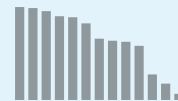
Your sample had a lower level of [a sunscreen chemical](#) than most others in the study.



WHAT YOU CAN DO

Choose shade, hats, and tightly woven fabric cover-ups for sun protection when you can.

Overall Study Results

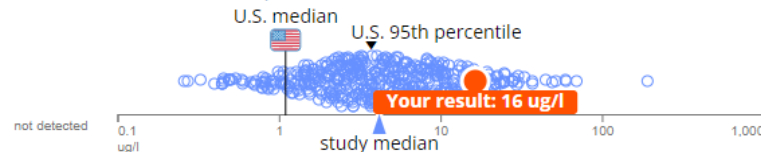


Detox Me Action Kit tested urine samples for 14 chemicals. The chemicals included preservatives in personal care products, chemicals added to plastics and food packaging, antimicrobials and pesticides, and flame retardants. [read more](#)

Action Kit participants tend to have lower chemical burdens than most people in the United States. Good job! [read more](#)

Although almost 90 percent of Action Kit participants report avoiding at least two chemical types, some chemicals—like the preservative methyl paraben and UV filter benzophenone-3—are still found in nearly all participants. [read more](#)

PFHxS (perfluorohexane sulfonic acid)



Boronow et al. EHP, 2017

- Chemical details
 - Sources
 - Health effects
 - Exposure reduction
 - Results graphs follow below text

[Home](#)

[Overall Study Results](#)

[Your Results](#)

- Antibacterials
- Bisphenols
- Parabens
- Pesticides
- Phthalates**
- Sunscreen Chemicals

[Community Action](#)

[Water](#)

[About PROTECT](#)

[More Resources](#)

[Common Questions and Contact Us](#)

[Table of Your Results](#)

[Print Report](#)

[Sign Out](#)

Your Results: Phthalates

Chemicals used in plastics and personal care products

Your samples had lower levels of 3 phthalates (BBP, DBP and DEHP) than most others in PROTECT.

[Click here to jump to your results](#)

What are they?

Some phthalates are added to polyvinyl chloride (PVC) plastics, like vinyl flooring, shower curtains, toys, and food packaging. They make plastic more flexible. Other phthalates are added to personal care products (like perfume and makeup) and printing inks. They help products hold fragrance and color. Some prescription medications have coatings that contain phthalates.

Watch this [video](#) to learn more!

How can they affect my health?

Many phthalates can harm the development of the reproductive system in baby boys and affect fertility in adults. Some phthalates are suspected to increase the risk of cancer. Some phthalates contribute to allergies and asthma.

How can I reduce my exposure?

- Avoid plastics in the kitchen.** Use ceramic or glass containers for food and drinks, and avoid microwaving food in plastic containers.
- Cook more meals at home with fresh ingredients.** Chemicals can get into food during processing and from packaging.

Common Questions and Contact Us

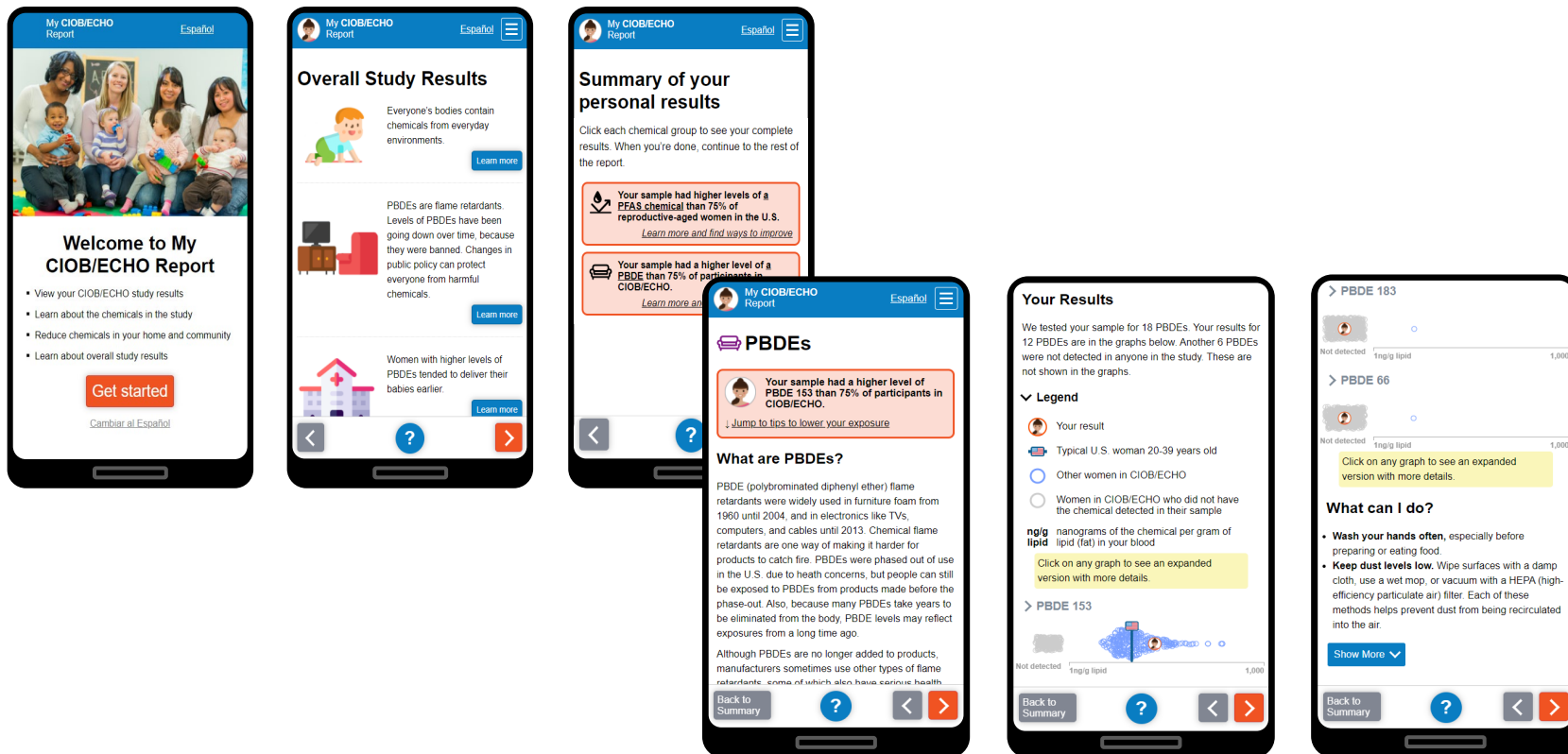
- Do the chemicals in my body mean that I'm going to get sick?
- Did the chemicals in my body affect my pregnancy?
- Why do I have multiple results for each chemical? Why do I only have one result for each chemical?
- When was I exposed to these chemicals?
- What does "not detected" mean?
- What do the units "µg/L" mean?
- What are the U.S. median and the 95th percentile mean?

Want to call us?

Do you want help interpreting your results? Feel free to call us at (787) 342-6131

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 Researching the Environment and Women's Health

Smartphone reports expand access



Reports support environmental health literacy

Transparency about uncertainty

Chemicals in the study “have been detected at different levels in people throughout the U.S. Detecting these chemicals ...doesn’t mean you will get sick.”

“So far, studies of people have found that higher levels of PFAS are linked to:

- Increased cholesterol levels
- Decreased vaccine response in children ...

Based on what we know now, we can’t link your results to specific health concerns for you or your family.”

“Since we don’t do experiments on people, we often learn how chemicals may affect health by testing in animals or cells, similar to the way we test new drugs for safety.”



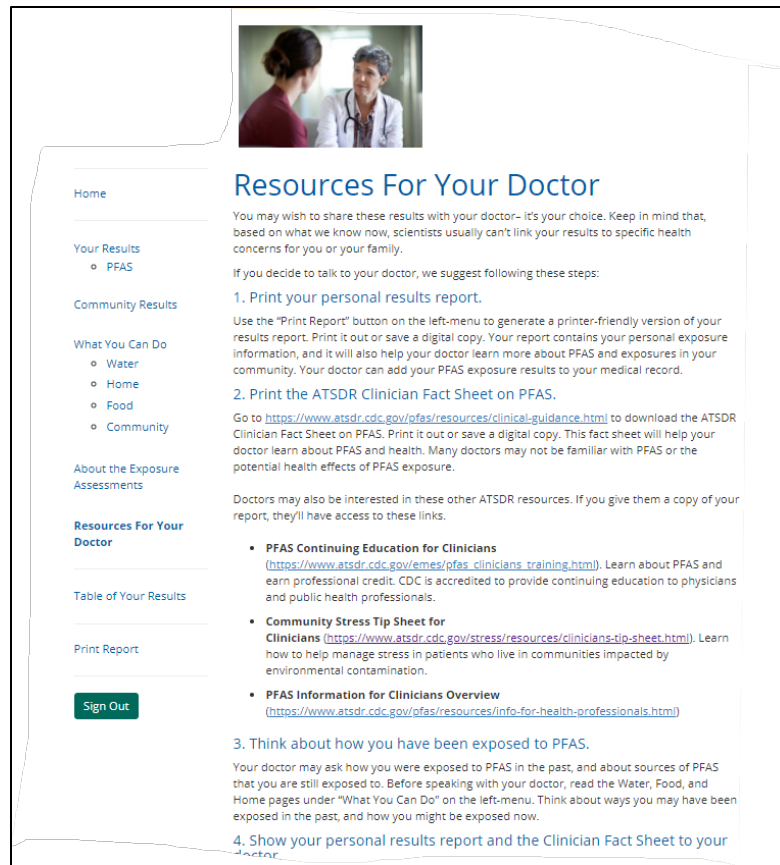
Community Context

- Meetings
- News media, social media
- Clinical care



Support for conversations with clinicians

DERBI reports can be
imported into EMR



The screenshot shows the 'Resources For Your Doctor' page on the ATSDR website. At the top right is a photo of a doctor and a patient. The left sidebar contains a navigation menu with links to Home, Your Results (PFAS), Community Results, What You Can Do (Water, Home, Food, Community), About the Exposure Assessments, Resources For Your Doctor (active), Table of Your Results, Print Report, and a Sign Out button. The main content area is titled 'Resources For Your Doctor' and includes an introductory paragraph, a list of steps for talking to a doctor, and links to various resources like the PFAS Continuing Education for Clinicians, Community Stress Tip Sheet for Clinicians, and PFAS Information for Clinicians Overview.



Resources For Your Doctor

You may wish to share these results with your doctor— it's your choice. Keep in mind that, based on what we know now, scientists usually can't link your results to specific health concerns for you or your family.

If you decide to talk to your doctor, we suggest following these steps:

1. **Print your personal results report.**

Use the "Print Report" button on the left-menu to generate a printer-friendly version of your results report. Print it out or save a digital copy. Your report contains your personal exposure information, and it will also help your doctor learn more about PFAS and exposures in your community. Your doctor can add your PFAS exposure results to your medical record.

2. **Print the ATSDR Clinician Fact Sheet on PFAS.**

Go to <https://www.atsdr.cdc.gov/pfas/resources/clinical-guidance.html> to download the ATSDR Clinician Fact Sheet on PFAS. Print it out or save a digital copy. This fact sheet will help your doctor learn about PFAS and health. Many doctors may not be familiar with PFAS or the potential health effects of PFAS exposure.

Doctors may also be interested in these other ATSDR resources. If you give them a copy of your report, they'll have access to these links.

- **PFAS Continuing Education for Clinicians** (https://www.atsdr.cdc.gov/emes/pfas_clinicians_training.html). Learn about PFAS and earn professional credit. CDC is accredited to provide continuing education to physicians and public health professionals.
- **Community Stress Tip Sheet for Clinicians** (<https://www.atsdr.cdc.gov/stress/resources/clinicians-tip-sheet.html>). Learn how to help manage stress in patients who live in communities impacted by environmental contamination.
- **PFAS Information for Clinicians Overview** (<https://www.atsdr.cdc.gov/pfas/resources/info-for-health-professionals.html>)

3. **Think about how you have been exposed to PFAS.**

Your doctor may ask how you were exposed to PFAS in the past, and about sources of PFAS that you are still exposed to. Before speaking with your doctor, read the Water, Food, and Home pages under "What You Can Do" on the left-menu. Think about ways you may have been exposed in the past, and how you might be exposed now.

4. **Show your personal results report and the Clinician Fact Sheet to your doctor.**

PFAS-Exchange.org

SILENT SPRING INSTITUTE

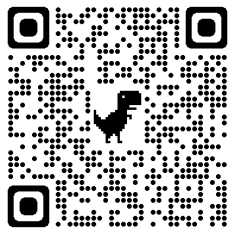
Home About Us What Are PFAS? News & Events Contact Search English (English)

PFAS Exchange

WHAT'S MY EXPOSURE RESOURCES CONNECTING COMMUNITIES CHILDREN'S HEALTH STUDY

The PFAS Exchange

An online resource center about PFAS contaminants in drinking water—helping communities understand their exposures and take action to protect their health.



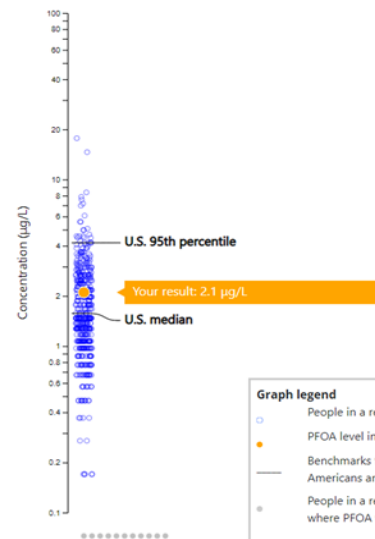
- Find community groups
- Enter personal results to get interpretive graphs

> PFOA (Perfluorooctanoic acid)

Your result: 2.1 $\mu\text{g/L}$



The level of PFOA in your blood is higher than 75% of Americans.



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Researching the Environment and Women's Health

Avoid False Reassurance

“There’s no proof...”

“What we do know...”



False Reassurance

- Even if a chemical is shown in a laboratory test to cause cancer, this does not necessarily mean it will cause cancer in people exposed to that chemical in the environment.

Source: National Cancer Institute, accessed Sept 2022

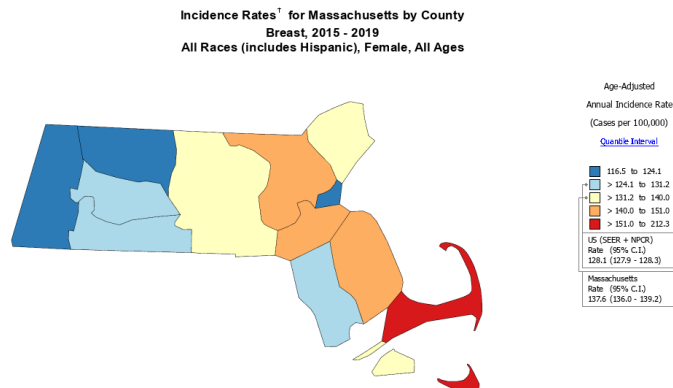
We do know...

#FTFY

Fixed That
For You

- Even if a chemical is shown in a laboratory test to cause cancer, this does not necessarily mean it will cause cancer in people exposed to that chemical in the environment. Often, chemicals that cause cancer in lab tests also cause cancer in people. US EPA and FDA use this information to make decisions to keep us safe.

Breast Cancer Incidence on Cape Cod, MA



- 1990s: MA DPH cancer rates by town showing elevated incidence of breast cancer on Cape Cod.
- Three datasets showed that established risk factors did not explain the risk
- Household Exposure Study led to the discovery of consumer products as major sources of exposure to endocrine disrupting compounds



Example Reports and Bibliography

- Links to example reports

<https://silentspring.org/derbi>

- Selected bibliography

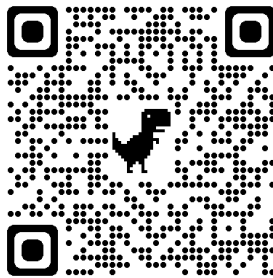
<https://silentspring.org/project/reporting-individual-exposure-results?pubs=all>



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[NIEHS](#), [NSF](#), [CDC/ATSDR](#), [CA Breast Cancer Research Program](#)

Silent Spring Institute is a mission-driven scientific research organization dedicated to uncovering the environmental causes of breast cancer



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