Red Hill Registry:

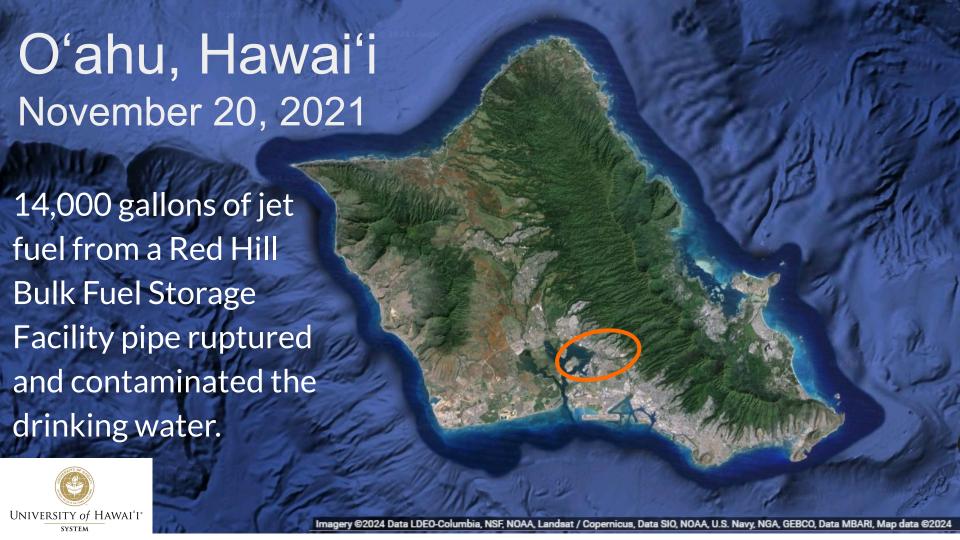
A community-engaged approach to identifying and addressing community needs from the 2021 jet fuel spill at Red Hill

Presented by Rosana Weldon, PhD, MPH and Aimee Grace, MD, MPH

National Academies of Science Engineering and Medicine Committee Meeting Session II: Public Health Response and Recovery February 20, 2025



UNIVERSITY of HAWAI'I®



JP-5 (jet propellant-5)- A Total Petroleum **Hydrocarbon (TPH) TPH Component**

- Used as military aircraft fuel
- Colorloss liquid is flammable

Coloriess liquid is flammable and smells like kerosene	Xylenes	3.5%		
and sinchs like kerosene	Methylnaphthalenes	4.6%		
Made in oil refineries from	Naphthalene	3.0%		
hydrocarbons	C5-C8 Aliphatics	12%		
Additives	>C8-C18 Aliphatics	68%		
 Thousands of components 	>C18-C32 Aliphatics	0.0%		
	>C8 Aromatics	9%		
University of Hawai'i*	Credit: Diana Felton, Hawai'i Department of Health			
SYSTEM				

Benzene

Toluene

Estimated % of TPH

0.2%

0.1%



5775 Analytes Exceeding Screening Level Analyte Name

Screening Min Level

Total

Samples

8071

Exceedance Exceedance 20.30 82.70

Max

Exposure Assessment

Sampling Month LTM A1 Zone Resi

No environmental samples concurrent with exposure Sampling Month LTM A1 Zone Resi Sampling Month 2

No biological samples drawn at the time of exposure

Needs to consider human behaviors and exposure setting

Locations

Sampled

Exceedance Analyte concentration exceeds lowest regulatory screening level

Analytes

Tested

444.0K

3.90 130.00

UG/L Not Detected

UG/L Not Detected

UG/I Not Detected LIG/L Not Detected

Detected Above

Screening Level

32

Count of

Exceedances

4

26

d Units Screening











							OUL	Not Detected
							UG/L	Not Detected
A I-ALUIT TUUU	1000 Alolia Avellue	10/11/2023	MI-188-0001301-7313-3-18	i, i-Dichioroethene	1	טוו	UG/L	Not Detected
A1-ALOH1600	1600 Aloha Avenue	10/17/2023	A1-TW-0001561-23139-N	1,2,4-Trichlorobenzene	70	ND	UG/L	Not Detected
A1-ALOH1600	1600 Aloha Avenue	10/17/2023	A1-TW-0001561-23139-3-N	1,2,4-Trichlorobenzene	70	ND	UG/L	Not Detected
A1-ALOH1600	1600 Aloha Avenue	10/17/2023	A1-TW-0001561-23139-N	1,2-Dichlorobenzene	600	ND	UG/L	Not Detected
A1-ALOH1600	1600 Aloha Avenue	10/17/2023	A1-TW-0001561-23139-3-N	1,2-Dichlorobenzene	600	ND	UG/L	Not Detected

UNIVERSITY of HAWAI'I*

LTM A1 Zone Resi

Sampling Month

LTM A1 Zone Resi

Total

Zone All

Find Address

Analyte Name

Screening All

All







Reported Health Effects







Study	Dates	Sample size	Data collection
ACE 1	Jan 7–Feb 10, 2022	2,289	survey/interview
ACE 2	Sep 2022	986 (from ACE 1)	survey
ACE 3	Feb 2023	653	Medical records
UHERO	Jan 2024	174 (from ACE 1 & 2)	survey
DCPH-P-EDC	Nov/2020 - Dec/2023	44,373 (Red Hill), 59,499 (Comparison)	Medical Records

Abbreviations: Assessment of Chemical Exposures (ACE), The Economic Research Organization at the University of Hawai'i (UHERO), Defense Centers for Public Health-Provisional-Epidemiology Data Center (DCPH-P-EDC)

Reported Health Effects



Brain/Central Nervous System



Brain fog, difficulty concentrating, fatigue, headaches, dizziness, memory loss reintention.

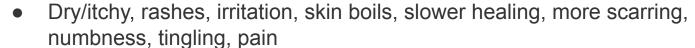
System

Gastrointestinal System

• Diarrhea, N/V, abdominal cramps, heartburn, eosinophilic esophagitis



Skin





Ear, Nose, And Throat



Runny nose, nose bleeds, burning nose/throat, hearing loss

Mental Health

Anxiety, depression, sleep issues, stress, fear, trauma/PTSD



Eyes



Redness, irritation, pain, burning

Respiratory System



 Difficulty breathing, feeling out of breath, coughing



Long-term Health Effects

- Somewhat unknown
- Many people experiencing symptoms 2+ years after the incident
- Seem to be similar to other complex health problems such as long COVID, chronic fatigue syndrome, or autoimmune issues
- Congressional report on the Health Effects of Jet Fuels

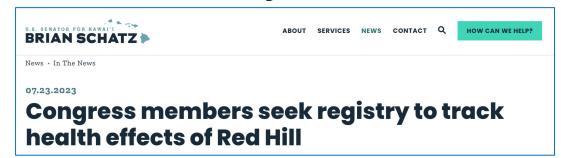
Actions Due to Health Study Results

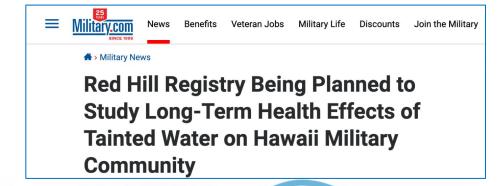
- Red Hill Clinic established
- DOD established a roster of exposed people
- Additional Epi Data Center Studies
- Additional support for medical providers
- National Academies of Science,
 Engineering and Medicine Consensus
 study on the potential health
 implications of the Red Hill fuel leak



An independent, third-party Red Hill Registry has been called for by...

- Congress
- Centers for Disease Control and Prevention (CDC)/ Agency for Toxic Substances and Disease Registry (ATSDR)
- Hawai'i State Department of Health (HDOH)
- Defense Health Agency (DHA)







UH NEWS Press Release June 20, 2024

UH entered agreement to establish Red Hill Independent Health Registry







News release headline: UH awarded grant to establish Red Hill Independent Health Registry

UH News story headline:

Red Hill health registry to support individuals exposed to fuel

The University of Hawai'i is creating a health registry to provide support and resources for anyone directly impacted by the Red Hill water crisis. The Red Hill Independent Health Registry (Red Hill Registry) is a UH Office of Strategic Health Initiatives project funded by a five-year, \$27.2-million federal grant.

"The Red Hill Registry will be a tremendous step forward in serving the tens of thousands of individuals who were exposed or placed at risk of exposure to fuel releases from the Red Hill storage facility," said UH President David Lassner. "The selection of UH to lead this major initiative is a testament to our expertise across multiple disciplines, our scientific independence, and our proven, widely understood ability to execute large complex programs that serve the people of Hawaii."

The opt-in, third-party registry will be co-developed with the community to provide connections to services and educational programs, while tracking participants' health status and gathering information on how fuel exposures may impact health. In its first year, the project will also include a Congressionally mandated feasibility assessment for an epidemiological outcomes study to further advance the understanding of the long-term health effects related to the Red Hill fuel soill.

Stay informed

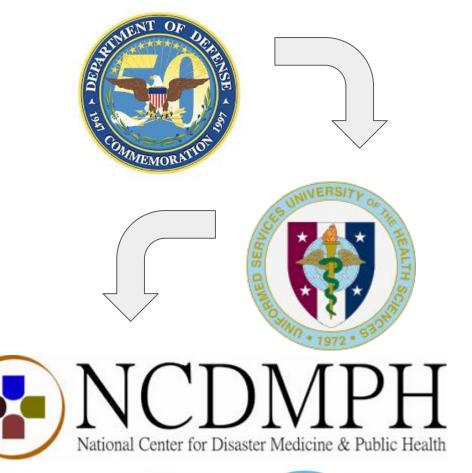
In the coming months, the registry team will host community listening sessions and establish a community oversight working group to ensure that community voices are included at every step of the process. To support these efforts, the team will also seek to hire local community members, including individuals directly affected by the crisis, to support outreach, enrollment and referral services. A formal online registration portal for the registry is anticipated to launch in fall 2025. For now, individuals who are interested in receiving updates on the registry's development and community engagement efforts are encouraged to sign up at this website.

"The health and social-emotional implications of the Red Hill water crisis on individuals and families, in addition to the environmental impacts, are critically important," said Aimee Grace, principal investigator and director of the UH Office of Strategic Health Initiatives. "We see this registry as providing an important opportunity for individuals and families to share their stories and be linked to services, and be able to monitor their health over time."

Funding was provided through the National Center for Disaster Medicine and Public Health at the Uniformed Services University of the Health Sciences. The registry was recommended and will be supported by the Hawaii State Department of Health, the Agency for Toxic Substances and Disease Registry at the Centers for Disease Control and Prevention, and the Defense Health Agency. Participating units across UH include the Thompson School of Social Work and Public Health, John A. Burns School of Medicine, Water Resources Research Center and University Health Partners of Hawaii.

Funding Structure

- Award executed June 11, 2024
- Total Funding \$27.2M across5 years
 - \$4M in first year (Planning Year)
 - Significant funding for hiring staff and community incentives





What is a Registry

- A database
 - To collect, store, and handle data for analysis
 - Data are used to answer questions about exposure and health effects
 - Knowledge gained can help both the Red Hill-affected community as well as other communities that are exposed to hydrocarbons
- A guide for
 - Referral system
 - Education programs

Most importantly... a Registry is about PEOPLE!





Goals of Red Hill Registry

- Connect the community to needed services through a referral program
 - Health services, social services, housing referrals
- Provide educational programs for healthcare providers and community members
- Track participants' health status over time and gather information on how fuel exposures may impact health



UH Red Hill Registry Team











Year One: Planning Year

- Community Engagement and Co-Creation of Registry
 - Most important!
- Registry Infrastructure
- Congressional Feasibility Assessment Report
- Recruitment and Enrollment
- Communications and Media
- Scientific Planning
- Referral Program
- Education Program



Registry Infrastructure

- Hiring
 - Seeking to hire from the impacted community
- Website
- IT Setup
- Consent Management Platform
- Managing Incentives



Congressional Feasibility Assessment Report

- Submitted 09/23/24 (on time!)
 - Background & literature review
 - Recruitment strategies
 - Methods for assessing health outcomes
 - Data analysis methods
 - Identifying exposures and eligibility
 - Providing information on resources and services
 - Repository for research

Report to the Committees on Armed Services of the Senate and the House of Representatives



Feasibility Assessment Regarding a Potential Red Hill Epidemiological Health Outcomes Study

Prepared by the University of Hawai'i

September 23, 2024



Recruitment and Enrollment

- Sign up for updates
- DOEHRS Registry data sharing agreement with DoD
- Pre-enrollment survey
 - Basic exposure, geography, contact information
 - Beginning December 2024
- Enrollment baseline survey
 - Detailed exposure, health, referral needs information
 - Beginning July 2025











Communications and Media

- Social Media
 - Instagram, Facebook, X, Threads = @RedHillRegistry
- Press Releases
- Logo Planning
- Podcasts, videos and more



Scientific Planning

- Literature review of impacts of jet fuel on health
 - Determining links between exposure and outcomes, identifying gaps in knowledge
- Provided scientific expertise for the pre-enrollment screening questionnaire (launched December 2024)
- Developing a full baseline questionnaire with community input
- Convening a Scientific Advisory Workgroup in February
 - Gathering experts on exposure science, toxicology, and epidemiology



Referral Program

- Considering and selecting referral platforms to connect future enrollees to services/resources
- Meeting with other National Registries to learn about their referral programs and best practices (Ex: Flint Registry; World Trade Center Health Registry; Katrina Registry)
- Clinical input and leadership
- Listening and honoring the community's needs based on focus group and survey responses







Education Program

- Updating UH Red Hill Information Hub https://redhill.hawaii.edu/
- Conducting preliminary analysis of patterns of contaminant movement
 - Developing a qualitative analyses and maps showing patterns of potential exposure
- Creating an interactive StoryMap to visually present the history, context, exposure timeline, and response efforts



Community Engagement: Outreach

Neighborhood Board Meetings





Shut Down Red Hill Mutual Aid Kapilina water jug exchange



Navy Closure Task Force Open House



Community Representation Initiative (CRI)

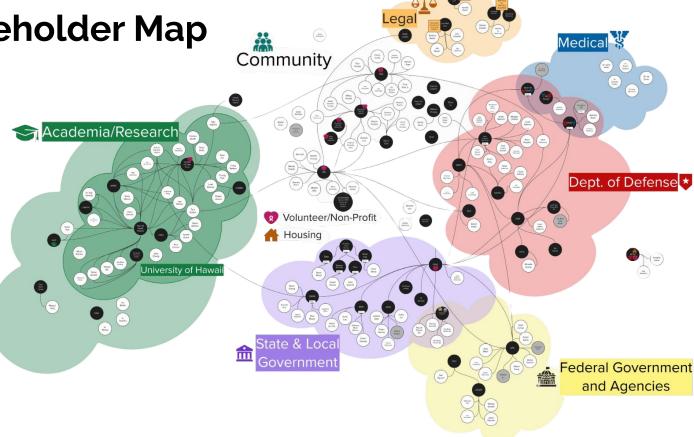






Red Hill Stakeholder Map

Building relationships within the Red Hill community that will solidify a foundation for the Registry





Co-Create with the Community



Focus groups to gain insight from:

- Impacted water users (those with military affiliation and civilian)
- Professionals and advocates
- Concerned residents (not directly exposed)
- Online surveys
- Pre-enrollment opportunity
- Community Advisory Workgroup





What is the Community Saying

- Just glad this is happening
- TRANSPARENCY
- Honesty
- Leave no one out
- Do what you say you're going to do without overpromising
- Independence from military
- Trauma informed; mental health referrals and support
- Hiring impacted community
- Continued education on needed topics from health to environmental, for the community and healthcare providers



Referral Needs Reported from Community (1/2)

- Healthcare Topics (Head to toe symptoms/issues referenced by community)
 - Ex: toxicology, dermatology, neurology, endocrinology, gastrointestinal, mental health, genitourinary, ENT
- Social Issues
 - Health advocacy, legal aid, counseling, community trauma specialist, health insurance, cultural trauma, trust/transparency, talk story/community building



Referral Needs Reported from Community (2/2)

- Employment Topics
 - Employee rights; career change: due to lifestyle change,
 relocation, or illness/disability; re-entering the workforce
- Housing Topics
 - Water utility maps, water filtration systems, landlord/tenant rights, maintaining a safe home environment
- Education-related Needs
 - Learning/behavioral difficulties, financial assistance (adult & children's education), reentering education (adults)



Education Needs

- Community
 - Podcasts, videos, radio, social media, media engagement, support groups
- Health care providers
 - Fact sheet for participants to take to appointments and/or QR code linked to information sharing the 5 W's of the Red Hill water crisis
 - Training programs for continuing education for HCP's
- Topics
 - Cultural education, history of Hawai'i and militarization of Red Hill, environmental health awareness, legal protections/support, crisis management, pet health, sharing ongoing research



Challenges

- Military and civilian impacted individuals
 - Various health care systems and insurance plan coverages
 - Potential global dispersion of the affected community today
- Trust / Institutional Betrayal
 - Fear of retaliation
- Eligibility questions around geography and time frame of exposure
- Time: With each passing day, we risk losing reach to some impacted community members as they travel far from Hawai'i
- Healthcare Providers in various locations of the world where community now lives may be unaware of RH water crisis
- Limited research on long-term health effects of jet fuel ingestion





Thank you!

On behalf of the Red Hill Registry, we want to acknowledge the Red Hill community and people of Hawai'i who recognized a problem and fought for answers!!

