TB Cultural Profiles: A Model for Enhancing Medical Understanding Through Community Engagement

Value in Cancer Care Summit 2024
15 November 2024

Duncan Reid, MD, MS

Medical Director of EthnoMed
Clinical Assistant Professor
International Medicine Clinic
Harborview Medical Center
University of Washington

EthnoMed.org social: @EthnoMedUW
UW Medicine HARBORVIEW MEDICAL CENTER
TB ELIMINATION ALLIANCE
Firland Foundation & Workshop
TB FREE KING COUNTY

Relevant Financial Disclosures

- I have nothing to disclose

Outline

Case Presentation 1

- Brief Background of the Marshall Islands
- TB in King County

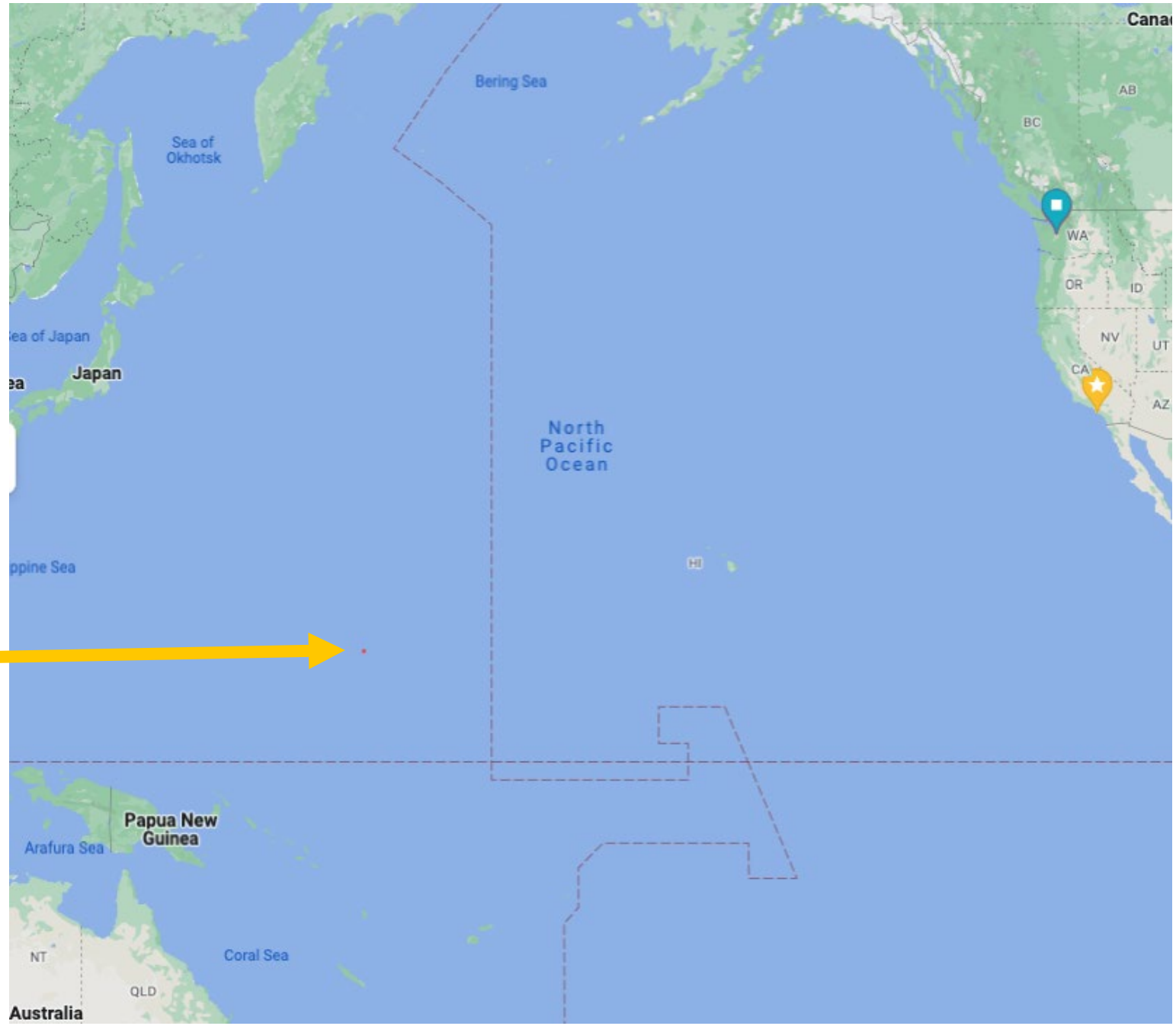
TB Profile Project Overview

- Current lessons from selected immigrant communities
- Relevance of approach for other diseases, such as cancer

Case Presentation 1

- 60 year-old man with Stage 4 Chronic Kidney Disease and type 2 diabetes who recently developed a productive cough, night sweats, and weight loss. He is Marshallese-speaking.
- What do you know about the Marshallese community? **How could historical and geographic context help inform your care?**

Nickelodeon


Bering Sea
Sea of Okhotsk
Sea of Japan
Japan
North Pacific Ocean
Papua New Guinea
Arafura Sea
Coral Sea
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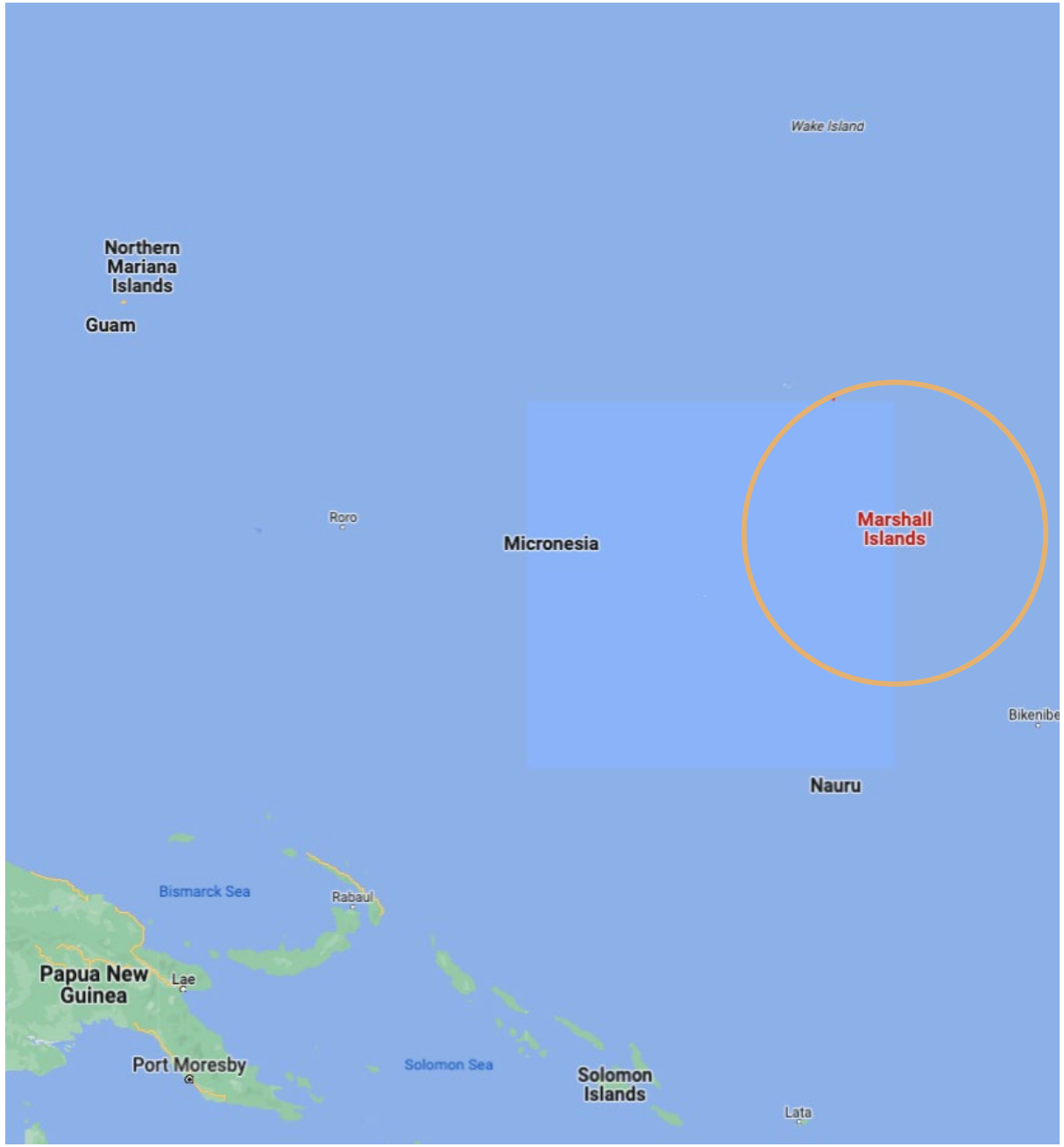
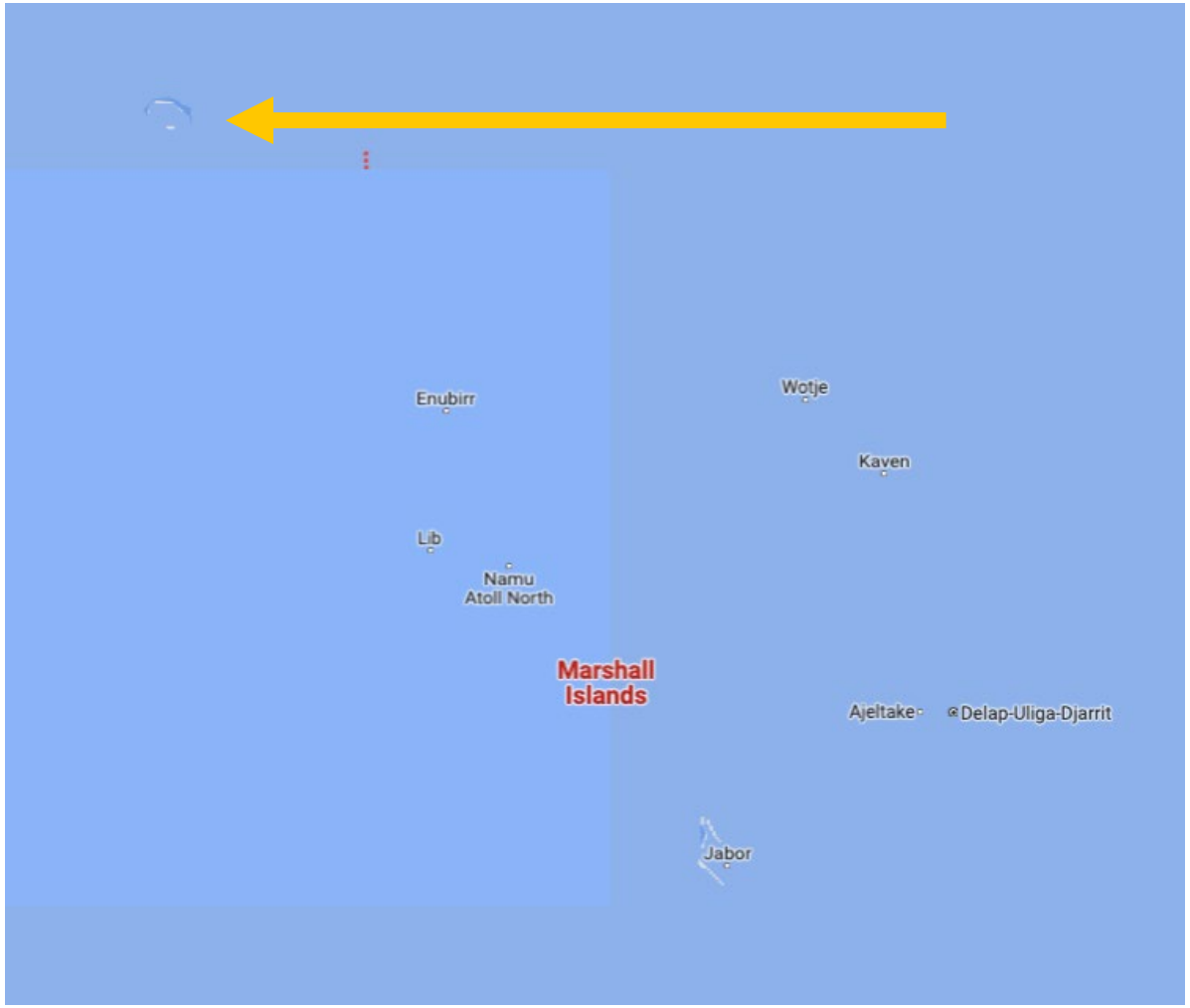
Google Maps





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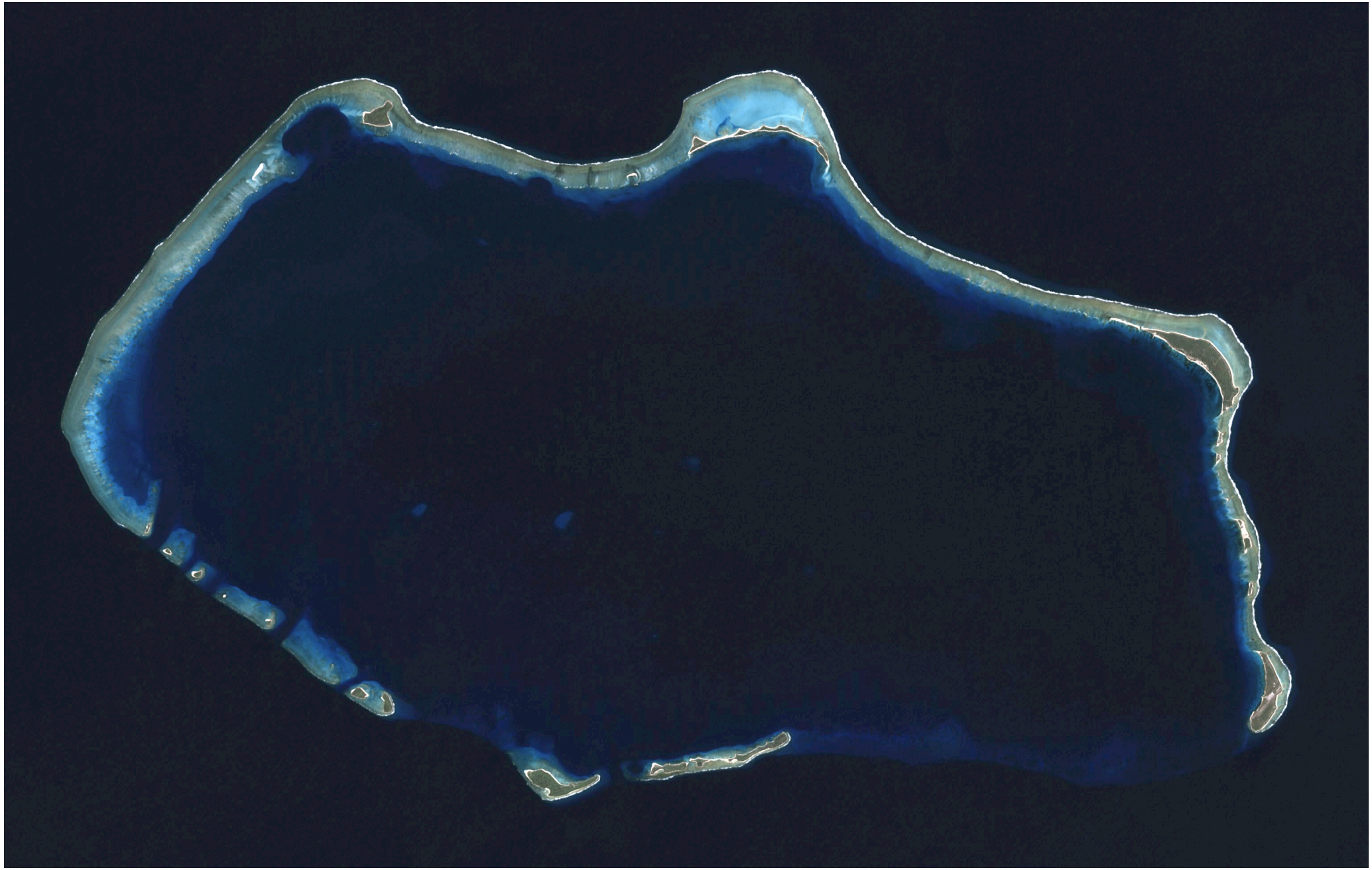

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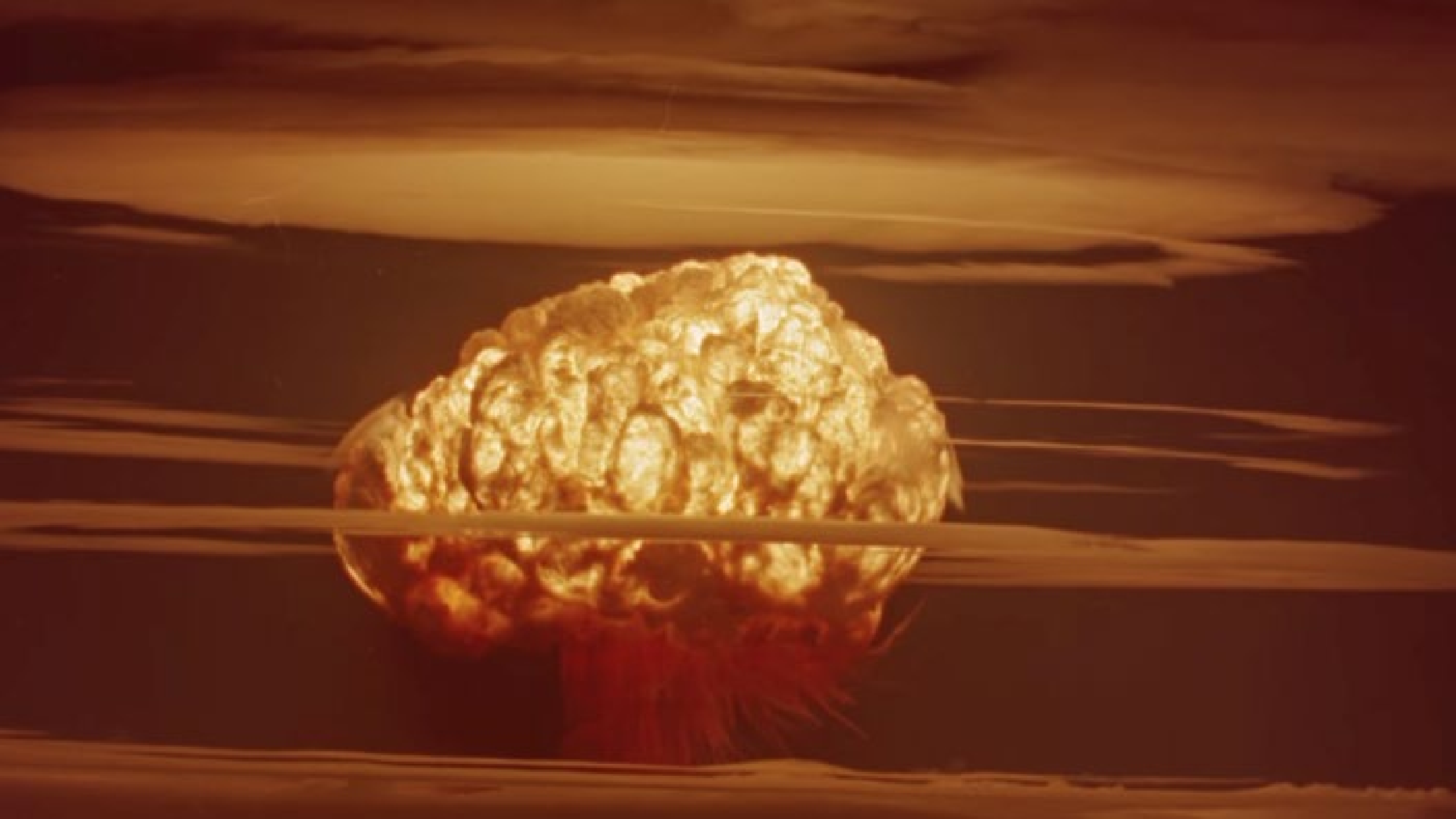


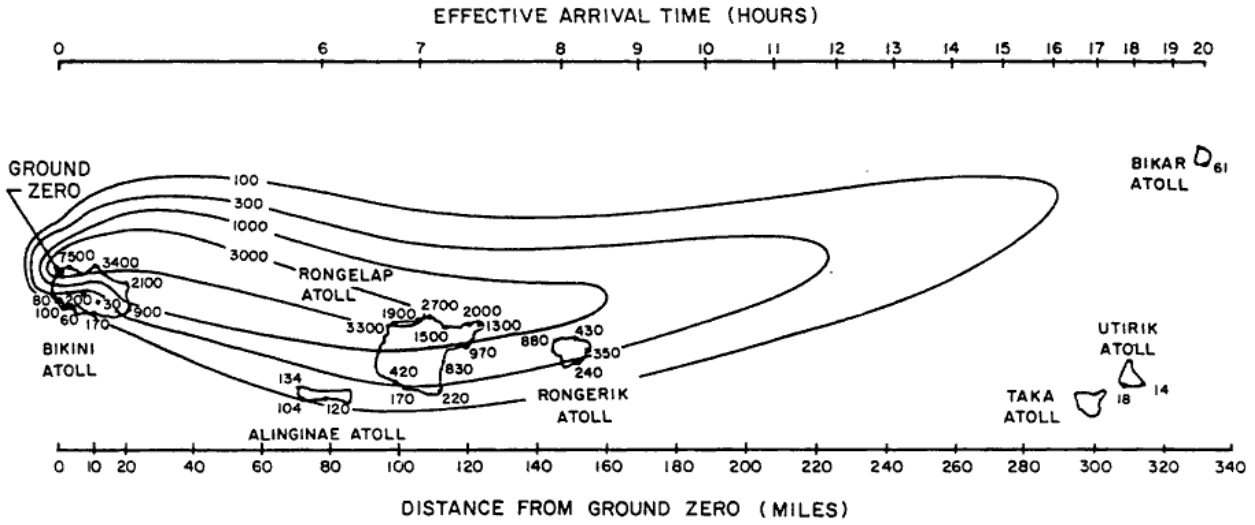
- Chosen by the U.S. military as a nuclear testing site, over 60 nuclear tests through 1958, 20 of which deposited significant fallout
- The Marshall Islands is a high-TB burden country with an estimated TB incidence of about 500 cases per 100,000 population per year in 2019 (WHO).
- 23% of the population estimated to have Type 2 Diabetes
- **Cancer: limited screening and diagnostic facilities**

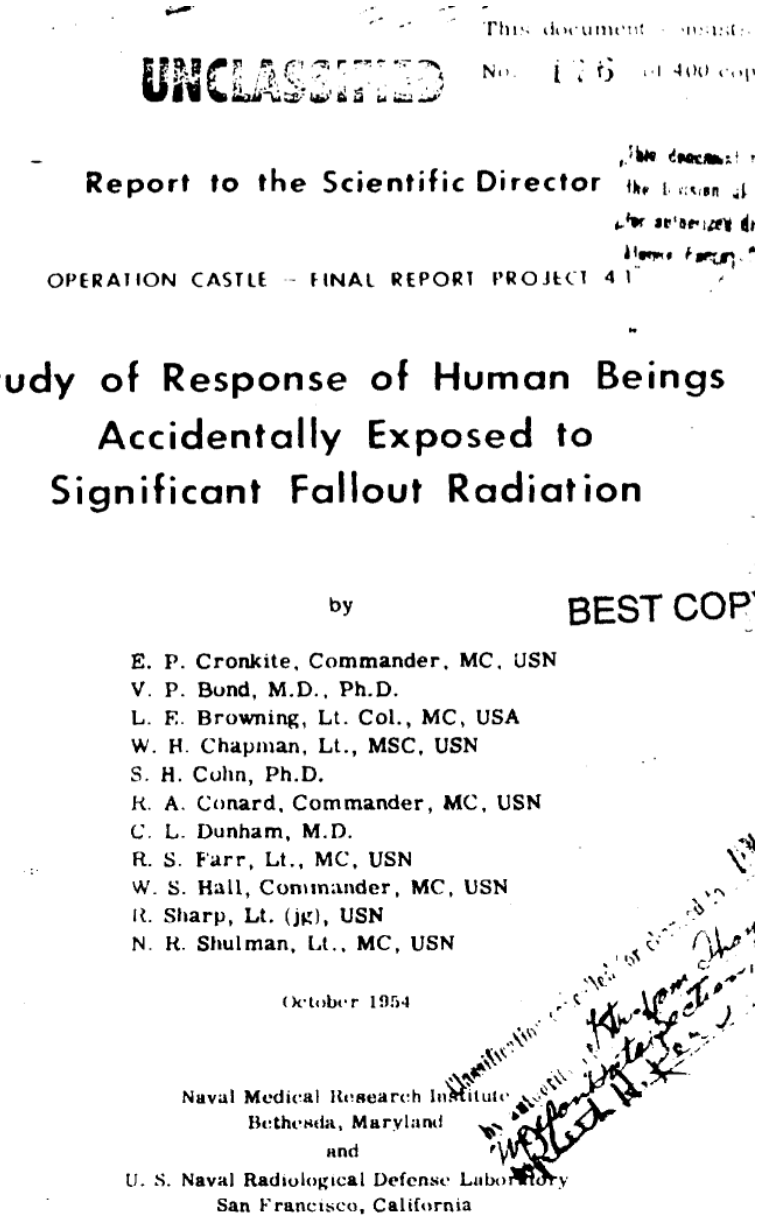
https://diabetesatlas.org/data/en/country/124/mh.html

Health Phys. 2010 August ; 99(2): 105–123. doi:10.1097/HP.0b013e3181dc523c.

Project 4.1:

- Medical study and experimentation of Marshallese accidentally exposed to fallout from the *Castle Bravo* test
- The primary study was completed 75 days after the time of exposure
- No informed consent obtained
- Classified results, released in 1970s
- Legacy of distrust





UNCLASSIFIED

Report to the Scientific Director

OPERATION CASTLE – FINAL REPORT PROJECT 4.1

Study of Response of Human Beings Accidentally Exposed to Significant Fallout Radiation

by

BEST COP

E. P. Cronkite, Commander, MC, USN
V. P. Bond, M.D., Ph.D.
L. E. Browning, Lt. Col., MC, USA
W. H. Chapman, Lt., MSC, USN
S. H. Cohn, Ph.D.
R. A. Conard, Commander, MC, USN
C. L. Dunham, M.D.
R. S. Farr, Lt., MC, USN
W. S. Hall, Commander, MC, USN
R. Sharp, Lt. (jg), USN
N. R. Shulman, Lt., MC, USN

October 1954

Naval Medical Research Institute
Bethesda, Maryland
and
U. S. Naval Radiological Defense Laboratory
San Francisco, California

Health Phys. 2010 August ; 99(2): 105–123. doi:10.1097/HP.0b013e3181dc523c.

- Images from Project 4.1:

Plate 3.1 Early hyperpigmented maculopapular neck lesions at 15 days. Case 39, age 15, F.

Plate 3.2 Neck lesions at 28 days. Wet desquamation. White color is calamine lotion. Case 78, age 37, F.

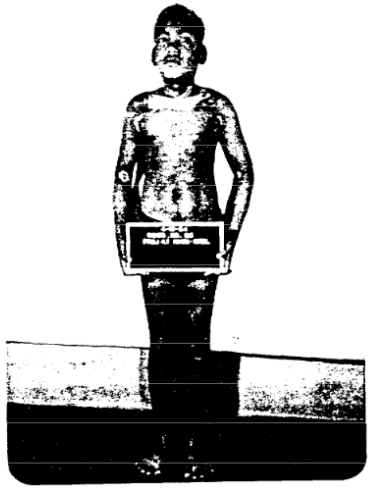


Plate 3.3 Repigmenting superficial neck lesions at 40 days. Hyperpigmented areas not completely desquamated. Case 24, age 15, F.

Plate 3.4 Healed neck lesions at 77 days showing dusky pigmentation of back of neck. Case 39, age 15, F.

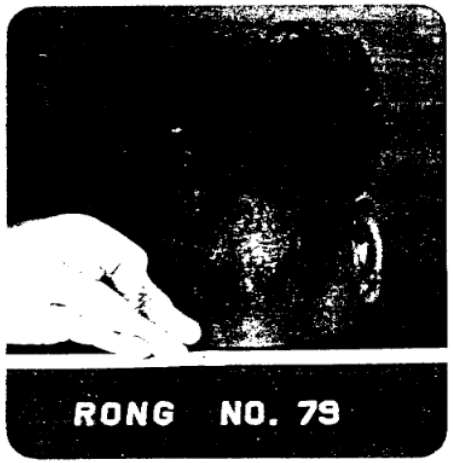


Plate 3.14 Epilation in man at 18 days. Case 79, age 41. Scalp lesions present in areas of epilation. (Same case as in Plates 3.12 and 3.13.)

Plate 3.15 Spotty epilation in boy, age 13, at 28 days. Case 26. Note scalp lesions in areas of epilation. (Same case as in Plates 3.8–3.11.)

Plate 3.16 Epilation in 7 yr old girl at 28 days Case 72.

Plate 3.17 Pigmented bands in semilunar area of fingernails at 77 days.

https://www.dtra.mil/Portals/125/Documents/NTPR/newDocs/NTREReport/WT-923-Proj%204.1%20Response%20of%20Humans%20Accidentally%20Exposed%20to%20Significant%20Fallout%20Radiation%20Op%20CA.pdf

Projected proportion (in%) of total cancer risk attributable to radioactive fallout by population and cancer site

Population group and cancer type	Lifetime Attributable Risk (%)		
	Mean	5%	95%
Rongelap Island community (cohort exposed on Rongelap Island in 1954)			
Leukemia	78	39	91
Thyroid	95	87	97
Stomach	48	11	73
Colon	64	36	78
Other solid	43	20	54
Total	55	28	69

- Until 2010, there had "*not been a broad epidemiologic study of the Marshallese to determine the total numbers of cancers and other serious illnesses resulting from exposure to radioactive fallout*"

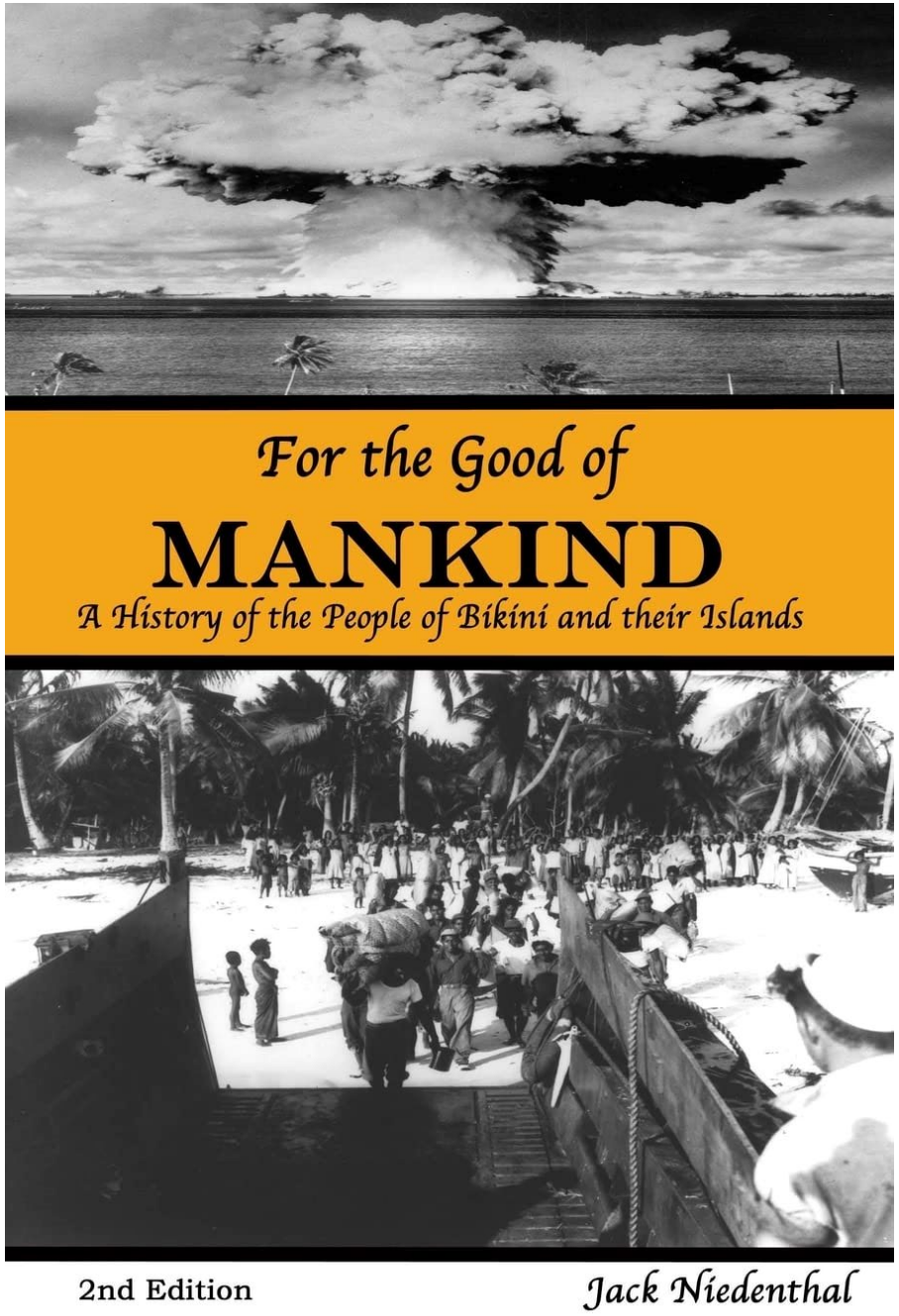
- In 2010 it was calculated that by sub-population, the projected proportion of cancers attributable to radiation from fallout between 43% and 95% on Rongelap Island (1.6% across all islands)

Health Phys. 2010 August ; 99(2): 105–123. doi:10.1097/HP.0b013e3181dc523c.

Daigo Fukuryu Maru

- 23 men on Japanese fishing vessel exposed to fallout from Castle Bravo
- Radiation illness developed within days
- Fishermen received annual checkups starting in 1957 at the National Institute of Radiological Science in Chiba

By carpkazu - 投稿者が撮影, Public Domain, https://commons.wikimedia.org/w/index.php?curid=3381752
Aikichi Kuboyama on deathbed



Photograph: World Bank

Cultural and Historical Context

- Essential to providing patient-centered medical care

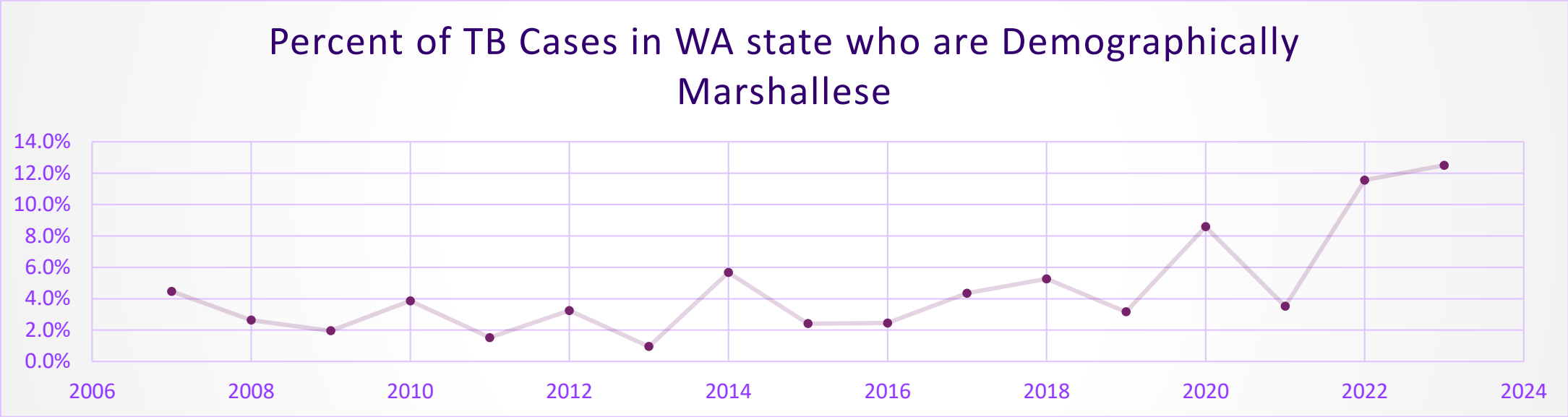
- Can inform the provider/researcher:
  - What diseases should be considered based on geography and history
  - Potential sources of distrust
  - How best to approach diagnosis and care

TB and Cancer

- **Stigma**: Both carry stigma across communities regarding testing, treatment
- **TB previously untreatable:** in Amharic, the term literally translates to "cancer of the lung"
- **Incomplete understanding:** Limitations of understanding of both diseases across communities regarding treatment, prognosis
- **Barriers to access:** Both diseases require prolonged treatment course, navigation of a complex medical system
- **Potential for misunderstanding:** Side effects of treatment, poor outcomes, adverse effects can lead to mistrust from the community

TB in the Marshallese Community in WA State

Community members identified as Marshallese demographically accounted for **12.5% of cases in WA state in 2023**



2010 census: 22,434 Marshallese in the U.S. (2207 in WA State)

2020: estimated 47,000 Marshallese in the U.S.

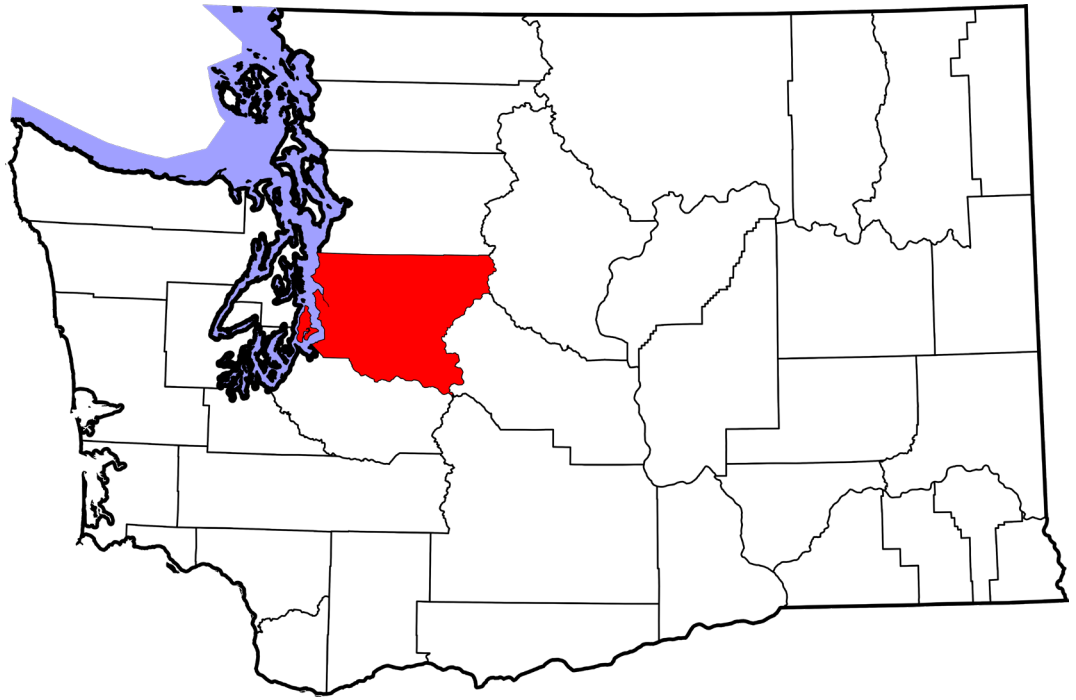
Tuberculosis in King County, Washington

In 2023 in King County:

- 109 cases of active TB
- Incidence of 4.6 cases per 100,000
- 92% of cases occurred in people who were born outside the U.S.

Public health encountered :

- resistance to screening and treatment
- different levels of understanding across different communities



Wikimedia commons, Public domain

KENT REPORTER

About 135 people at Kentridge High to be evaluated for tuberculosis

Steps taken after one person at school diagnosed with active TB; exposure was March to September 2023

THE NEWS TRIBUNE

Tacoma warned of active TB case; TPCHD could seek court order after patient declines meds

BY DEBBIE COCKRELL

UPDATED JUNE 02, 2023 10:47 PM

CDC Centers for Disease Control and Prevention

CDC 24/7: Saving Lives, Protecting People™

Morbidity and Mortality Weekly Report (*MMWR*)

Tuberculosis Outbreak in a State Prison System — Washington, 2021–2022

Weekly / March 24, 2023 / 72(12);309–312

Randy M. Stalter, PhD[1,2]; Monica Pecha, MPH[2]; Lana Dov, MSN[2]; David Miller[2]; Zainab Ghazal, MBChB[3]; Jonathan Wortham, MD[4]; Sandy Althomsons, MHS[4]; Molly Deutsch-Feldman, PhD[1,4]; Rebekah Stewart, MSN, MPH[4]; Derrick Felix[4]; Sophia Hsu, MSN, MPH[4]; Lara B. Strick, MD[3,5] (VIEW AUTHOR AFFILIATIONS)

The Seattle Times

Tuberculosis case in Auburn School District prompts evaluations

One Auburn School District community member has been diagnosed with active tuberculosis, according to Public Health – Seattle & King County.

Dec 13, 2022

Primary Care Screening Rates are Low

Open Forum Infectious Diseases

BRIEF REPORT

Latent Tuberculosis Screening Cascade for Non–US-Born Persons in a Large Health System

Adrienne E. Shapiro,[1,2] Ayushi Gupta,[2] Kristine Lan,[2] and H. Nina Kim[1,2]

[1]Department of Global Health, University of Washington, Seattle, Washington, USA, and [2]Department of Medicine, Division of Allergy and Infectious Diseases, University of Washington, Seattle, Washington, USA

Review of electronic health records revealed substantial drop-off at each stage of the latent tuberculosis infection (LTBI) care cascade among non–US-born persons in an academic primary care system. Of 5148 persons eligible for LTBI

Only 20% of those eligible for TB screening based on country of birth were screened in the **UW primary care system**

Cultural and Historical Context

- Essential to providing patient-centered medical care

- Can inform the provider:
  - What diseases should be considered based on geography and history
  - Potential sources of distrust
  - How best to approach diagnosis and care

TB Cultural Profile Project

This project represents a collaboration among:

King County Public Health, TB Program

EthnoMed

Community House Calls, HMC

TB Cultural Profile Project

This project represents a collaboration among:

King County Public Health, TB Program

- Community Navigator Program representing over a dozen communities in King County

EthnoMed

- A web resource based at Harborview Medical Center focused on cross-cultural medicine

Community House Calls, HMC

- Cultural Mediator Program in the Interpreter Services Department

King County Public Health, TB Program

Performs community outreach, education, contact tracing, treatment

Issues with screening and treatment in the community:

- Low rates of clinic screening
- Stigma
- Poor understanding of disease (latent vs active TB), treatment options
- Barriers to health care access

King County Public Health, TB Program

Community Navigator program established in 2020 as a response to COVID

Includes 25 Community Navigators and two Project Managers

- Expanded to include community outreach on a variety of topics, including tuberculosis

Franky Erra
Manager
Community Navigator Program

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EthnoMed.org

EthnoMed is intended to be a community voice in the clinic.

We have relationships with local ethnic communities and the providers who care for them.

Content is developed in partnership with healthcare providers, community members, and UW students.

Duncan Reid
Medical Director

Celine Barthelemy
Manager

James Sherrell
Program Coordinator

Nityia Przelockii
Website Specialist

Chelsea Ng
Congolese TB Profile

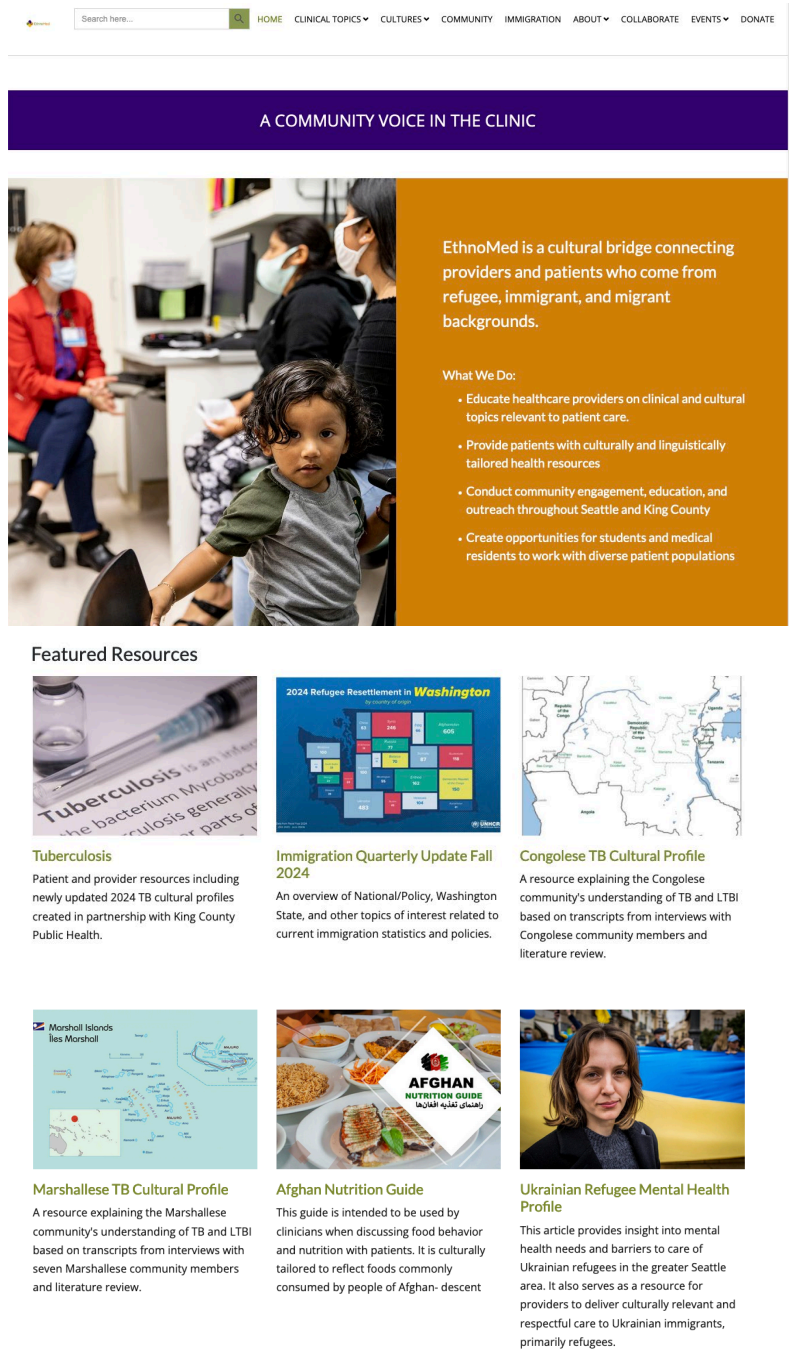
Angshita Dutta
Marshallese TB Profile

EthnoMed.org

Founded in 1993

We facilitate:

1. Provider Education and Support
2. Community Outreach
3. Collaboration across the UW system



EthnoMed

Community-Centered Approach

- **Nothing about us, without us, is for us**
- Slogan developed by South African disability rights and youth activists
- Aligned with the goal of EthnoMed to involve communities in the development of resources

©Ricardo Levins Morales

EthnoMed

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Ethnomed

- A web resource based at Harborview Medical Center focused on cross-cultural medicine

Community House Calls, HMC

- Caseworker Cultural Mediator Program in the Interpreter Services Department at Harborview

Interpreter Services Department

Yvonne Simpson
Senior Director
Language Access and
Cultural Advocacy
UWMC

Jean Jacques Kayembe
Director,
HMC Interpreter Services

Asmeret Tesfalem
Manager,
CCM Program

Caseworker Cultural Mediator Team

TB Awareness Interview with Lupe, King County Public Health Samoan Navigator

Dr. Duncan Reid

Harborview Medical Center

EthnoMed.org

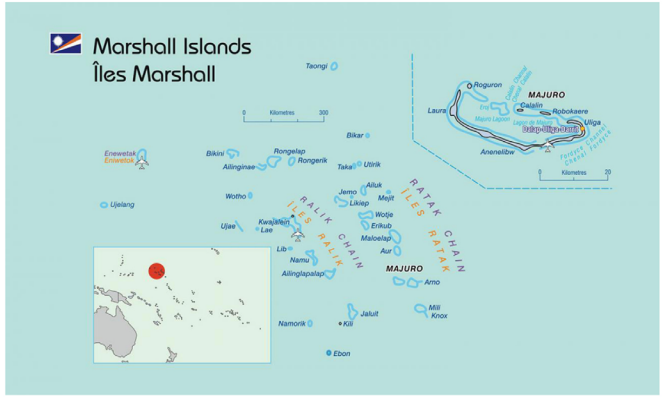
Health Education with the Cambodian Community- Learning About TB

TB Cultural Profiles

- Summary
- Recommendations
- Methods
- Burden of disease
- Languages spoken
- BCG vaccination (rates and understanding)
- Diagnosis and clinical features (recognized by community)
- Testing of TB disease and LTBI
- TB treatment (in home country)
- Social factors and care delivery (in home country)
- Experience with TB and barriers to care (in U.S.)
- Other relevant historical factors
- Comorbidities

Marshallese TB Cultural Profile

Author(s): Dr. Duncan Reid, Angshita Dutta
Contributor(s): Katie Budd and Franky Erra, Public Health - Seattle & King County; Esther Debrum, Public Health Community Navigator
Date Authored: March 20, 2024



Summary

The Marshall Islands have an extremely high incidence of tuberculosis (TB) disease, at least 100 times higher than in the U.S. as a whole. Individuals who identify as Marshallese accounted for approximately 12% of all TB disease cases in Washington State in 2023. The prevalence of latent tuberculosis infection (LTBI) is estimated to be much higher (approximately 30% based on recent WHO testing). The history of nuclear testing by the U.S., lack of trust in the U.S. medical system, barriers to healthcare access, and stigma regarding TB can make individuals hesitant to undergo screening. There is confusion in the community regarding diagnosis of latent TB compared to active TB disease. There is also less awareness of blood testing (e.g. interferon gamma release assay, Quantiferon) as skin testing has been more prevalent in the Marshall Islands. Many recent immigrants will be familiar with the recent World Health Organization (WHO) TB campaign in the Marshall Islands which aimed for universal screening.

▶ 0:00 / 0:22

Recommendations

- Recommend TB screening for all individuals from the Marshall Islands, consider screening for U.S. born members of the Marshallese Community.
- Recommend screening with blood test (e.g. interferon gamma release assay, Quantiferon) rather than skin testing (e.g. tuberculin skin testing, Mantoux).
- Recommend addressing other common health issues such as diabetes, obesity, and renal disease.

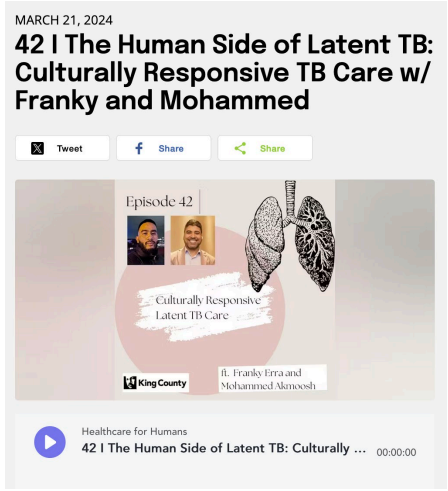
CONTENTS

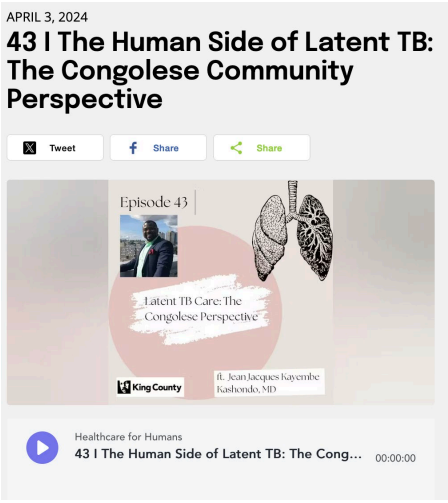
RELATED MATERIALS

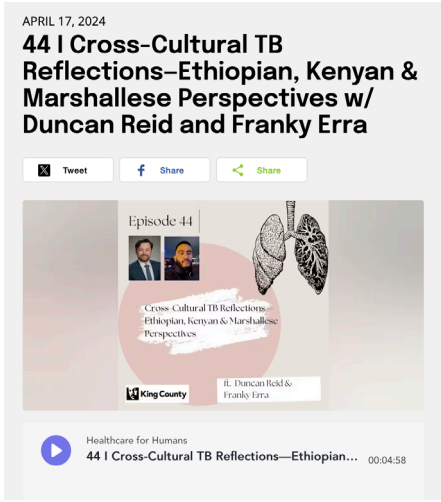
Community Interviews

Recordings / Podcast

- Professional quality audio recordings of all interviews
- Collaboration with podcast Healthcare for Humans
- Upcoming EthnoMed podcast based on these and other interviews
- Transcripts for thematic analyses







TB education materials

- Webmaster Nityia Przewlocki has been taking photos and video to be used in community-level TB information campaigns

- Social media posts
- YouTube videos

- Catherine Evangelista with public health developing social media videos

TB Cultural Profiles

We have completed 63 interviews with **88 participants** spanning 15 communities

- **Marshallese**
- Congolese
- Kenyan
- Ukrainian
- Ethiopian
- Afghan
- Samoan
- Cambodian
- Mexican
- Cameroonian
- Vietnamese
- Chinese
- Filipino
- Iraqi
- Somali

Take-home points from Marshallese Community

Awareness of coughing and weight loss as symptoms; less awareness of extrapulmonary TB

Confusion regarding:

- TB disease vs LTBI (diagnosis, treatment)

Take-home points from Marshallese Community

Social Factors in the Marshall Islands

- Little privacy in the Marshall Islands
- Social culture: not acceptable to isolate from close family
- Stigma surrounding diagnosis of both TB disease and LTBI

Testing and Treatment in the Marshall Islands

- Recent WHO campaign to screen and treat all individuals for TB disease and LTBI: DOT for both caused confusion about who had TB disease vs LTBI

Take-home points from Marshallese Community

Barriers to care in the U.S.

- Reluctance of patients to discuss TB with new providers
- Travel a common barrier
- Difficulty accessing translators

Cultural barriers

- Increased privacy in the U.S. decreased social pressures of getting tested and treated
- Reluctance to participate in screening events due to stigma, concern that results could jeopardize employment
- TB not a priority
- Common complaints of side effects from LTBI treatment

Take-home points from Marshallese Community

Other relevant history

- Nuclear history: respondents were open about this history and wanted it more widely-shared, legacy of distrust; this is your history too

Other health concerns

- Diabetes, renal disease: barriers to care, often present late
- Poor diet established in the islands: prohibitively expensive produce
- Cancer screening and treatment

Approaches

- Collaboration with community church leaders who can build trust
- Help coordinate clinic travel

Some additional take-home points

Kenyan Community:

- Two severe reactions to INH in the community, many community members unwilling to be treated for LTBI out of concern for side effects

Afghan Community:

- Those with TB disease would be given designated dishes to use at home, could affect marriage prospects

Ukrainian Community:

- Legacy of distrust from Soviet era medicine, including vaccination hesitancy; history of religious persecution

Chinese Community:

- Concern that TB could be hereditary

Next steps

Explore opportunities and partnerships with cancer providers and researchers, including the Fred Hutch

- Maintain longitudinal relationships
- Build out existing community partnerships:
  - Public Health Community Navigators
  - Harborview Caseworker Community Mediators

Our team at EthnoMed.org can collaborate to develop community profiles

Acknowledgements

- Tuberculosis Elimination Alliance
- Firland Foundation
- Public Health Seattle King County
- HealthPoint clinic system
- Interpreter Services Department at Harborview Medical Center

- Community Volunteers
- Mohammed Akmoosh
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- Jasmine Alik
- Katie Budd
- Bayle Conrad
- Esther Debrum
- Marie Rose Embage
- Franky Erra
- Almaz Eshetie
- Catherine Evangelista
- Katelynne Gardner-Toren
- Srirama Josylua
- Svitlana Kryshtanovska
- Disney Langilur
- Susie Salem

Students

Angshita Dutta
Betelihem Gabreselassie
Zacharia Ismaio
Sahra Jama
Ria Mohan
Chelsea Ng
Hannah Perez

CCMs/Interpreters

Anab Abdullahi
Omar Abow
Bich Bui
Jeniffer Huong
Kim Lundgren
Yodit Wongelemengist

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EthnoMed

Integrating cultural information into clinical practice

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- Students/Researchers: Check out our "Collaborations" page at EthnoMed.org
- Email: ethnomed@uw.edu

We want to hear from you!

EthnoMed.org

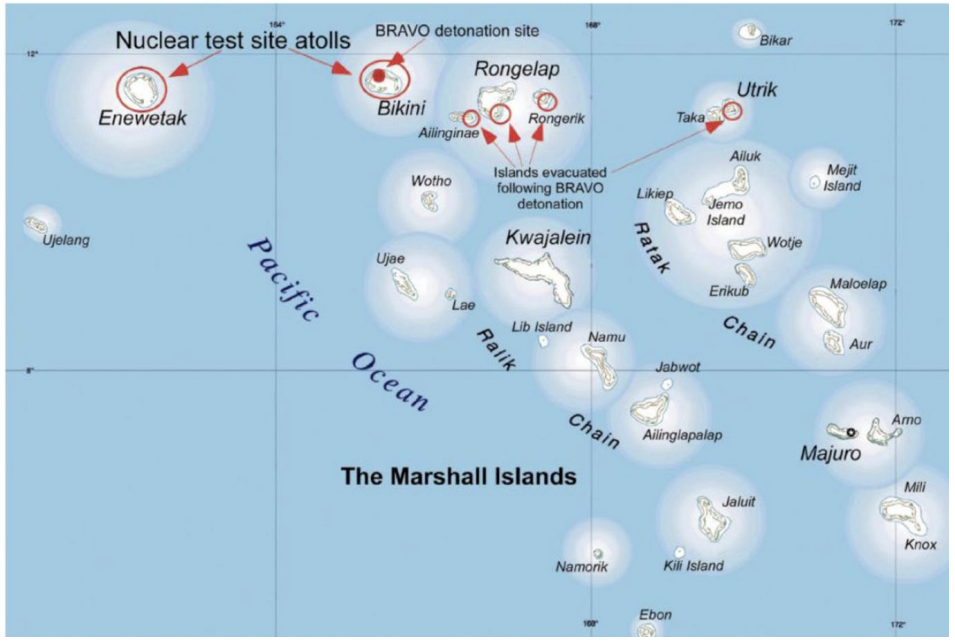
social: @EthnoMedUW

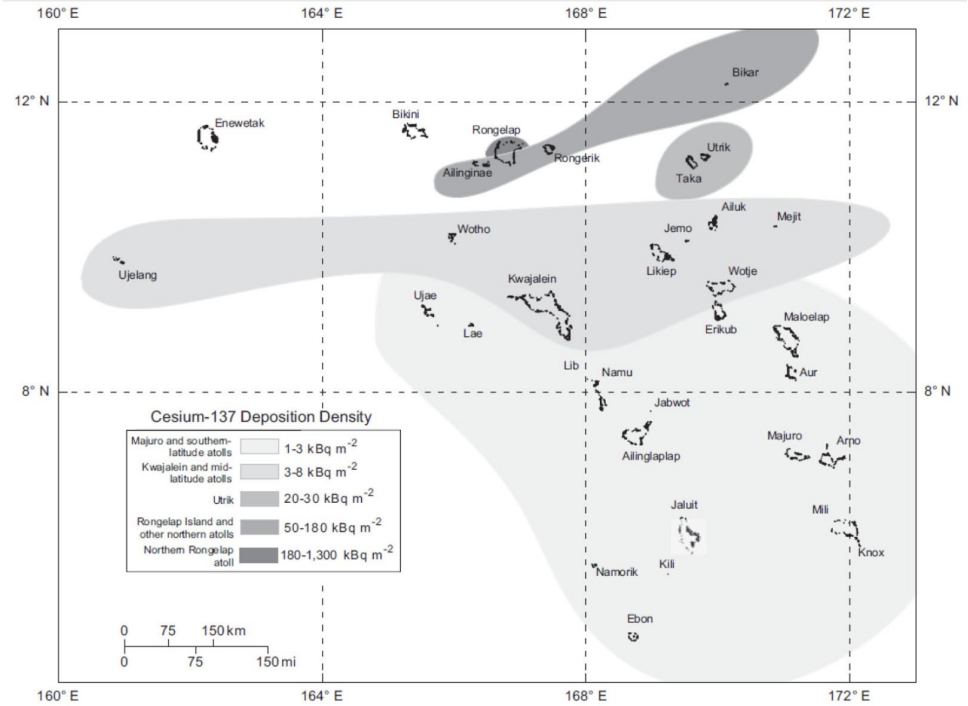
Duncan Reid
reidd@uw.edu

Franky Erra
ferra@kingcounty.gov

EthnoMed.org
social: @EthnoMedUW

Additional Slides





- 20 of these nuclear tests deposited measurable fallout on the Marshall Islands

- Three sources of radiation
  - **External radiation** from fallout deposited on the ground
  - **Internal irradiation** from **acute** radionuclide intake soon after deposition of fallout
  - **Internal irradiation** from **chronic** intakes of long-lived radionuclides

Health Phys. 2010 August ; 99(2): 105–123. doi:10.1097/HP.0b013e3181dc523c.

Projected proportion (in %) of total cancer risk attributable to radioactive fallout, by population, cancer site, and time period. Uncertainty distributions represented by their means and 90% uncertainty bounds.

Population group and cancer type	Lifetime Attributable Risk (%)			Attributable Risk (%) 1948–2008			Attributable Risk (%) from 2009		
	Mean	5%	95%	Mean	5%	95%	Mean	5%	95%
Rongelap Island community (cohort exposed on Rongelap Island in 1954)									
Leukemia	78	39	91	83	43	93	63	29	77
Thyroid	95	87	97	95	85	97	95	91	97
Stomach	48	11	73	44	9.2	71	52	13	77
Colon	64	36	78	60	32	75	68	40	81
Other solid	43	20	54	48	23	61	32	17	43
Total	55	28	69	59	30	73	47	26	62
Utrik community									
Leukemia	19	4.3	45	26	5.4	57	9.0	2.5	17
Thyroid	71	32	86	69	29	86	74	35	87
Stomach	4.8	0.64	14	4.5	0.63	12	5.0	0.67	17
Colon	9.4	3.2	19	8.4	2.8	17	10	3.1	21
Other solid	6.7	1.5	14	6.8	1.8	15	6.5	1.1	14
Total	10	2.4	22	11	2.7	25	9.0	1.8	19
Kwajalein and other mid-latitude atolls									
Leukemia	8.4	1.7	20	15	2.9	36	2.9	0.75	5.5
Thyroid	25	6.1	45	28	7.0	49	21	5.1	39
Stomach	1.9	0.26	5.7	2.8	0.37	8.5	1.5	0.20	4.3
Colon	2.3	0.73	4.8	3.3	1.1	6.6	1.8	0.57	3.8
Other solid	1.4	0.34	2.9	2.3	0.60	4.6	0.96	0.20	2.0
Total	2.2	0.50	4.8	3.5	0.86	7.9	1.4	0.30	3.0
Majuro and other southern-latitude atolls, including Rongelap control population									
Leukemia	2.2	0.41	6.0	4.2	0.67	12	0.76	0.22	1.4
Thyroid	12	2.5	27	13	2.7	29	11	2.2	25
Stomach	0.47	0.069	1.3	0.63	0.089	1.8	0.39	0.058	1.2
Colon	0.69	0.23	1.4	0.90	0.31	2.0	0.59	0.20	1.2
Other solid	0.48	0.11	1.0	0.65	0.18	1.4	0.37	0.071	0.81

- Until 2010, there had "*not been a broad epidemiologic study of the Marshallese to determine the total numbers of cancers and other serious illnesses resulting from exposure to radioactive fallout*"

- In 2010 it was calculated that by sub-population, the projected proportion of cancers attributable to radiation from fallout between 43 and 95 percent on Rongelap Island

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