

Why are state cancer registries  
critically important  
in the fight against cancer?

**Cancer Registry Impacts**

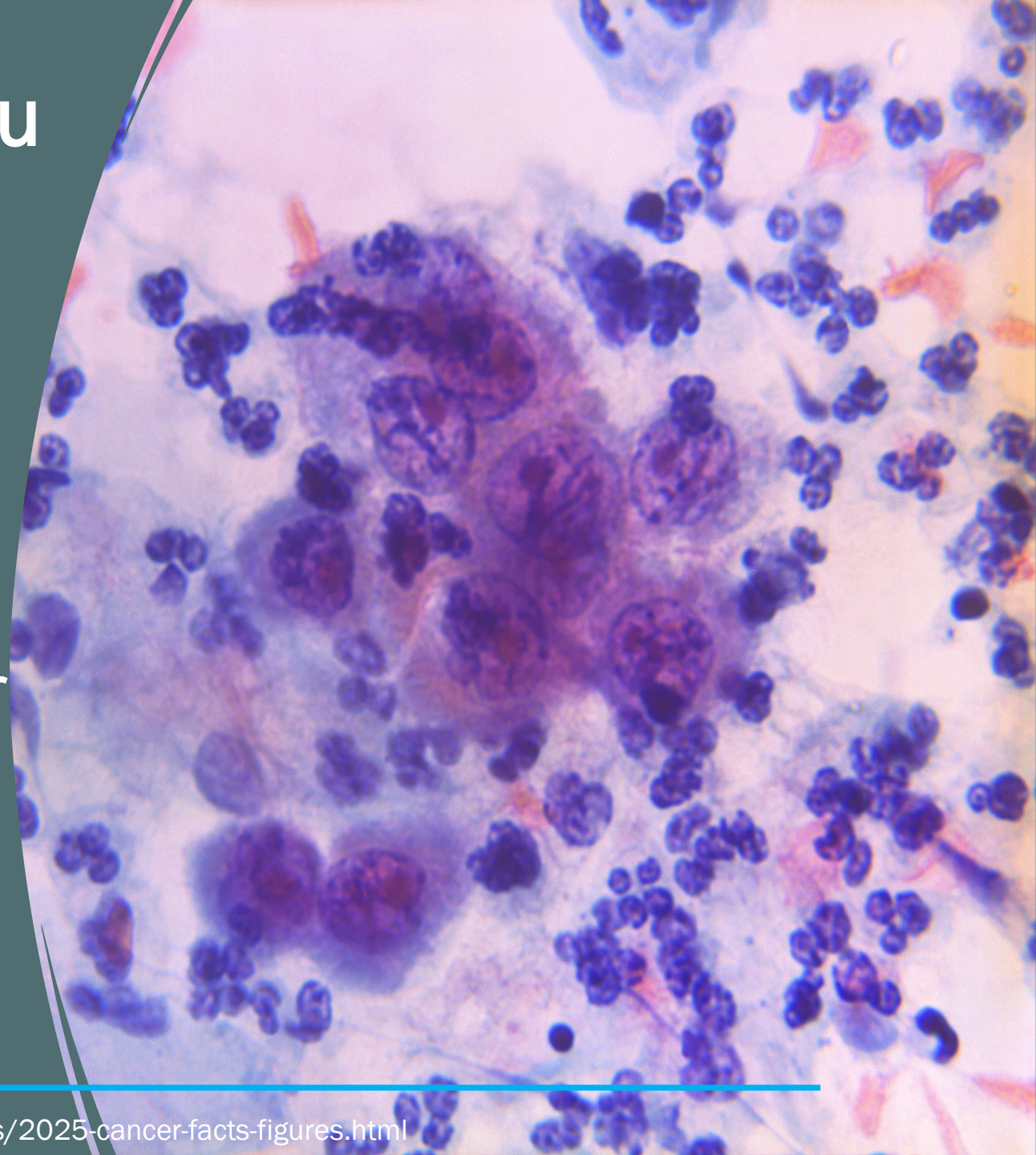
# 1. Cancer registries tell you how important cancer is

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1 in 3 Americans will get cancer

Every day, 5,600 Americans are newly diagnosed with cancer

Every minute, 1 American dies from cancer





## 2. Cancer registries are a cornerstone of cancer research

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PubMed research publications including “cancer registry/ registries”, “SEER”, or “cancer surveillance” → **42,756 research papers**

Even more studies & clinical guidelines cite cancer registry data, covering:

- Trends in incidence and mortality
- Cancer in children, adolescents, young adults
- Early onset cancer (<50)
- How to prevent cancer
- How best to screen for cancer
- What are the causes of cancer?
- Who is at greater risk of cancer?
- Investigating “cancer clusters”
- Is treatment effective?
- Is treatment cost effective?
- Developing new treatments
- Developing standard treatment guidelines
- How long do people live after diagnosis?
- Factors predicting good or bad outcomes
- Who is at risk of a second cancer?
- Whose family is at greater risk of cancer?



## 2. Cancer registries are a cornerstone of cancer research

The most cited publications on aging & cancer are registry-based  
(Top 10 from Web of Science through 2022)

Rank	Article title	Times cited	Published	Citations per year
1	Cancer statistics, 2010	39,141	2010	3262
2	Cancer statistics, 2014	20,730	2014	2591
3	Cancer statistics, 2016	16,789	2016	2798
4	Cancer statistics in China, 2015	12,298	2016	2050
5	Cancer statistics, 2008	9642	2008	689
6	Cancer statistics, 2009	9047	2009	696
7	Cancer statistics, 2018	6774	2018	1693
8	Cancer statistics, 2007	6614	2007	441
9	Effects of chemotherapy and hormonal therapy for early breast cancer on recurrence and 15-year survival: an overview of the randomized trials	5599	2005	329
10	Cancer statistics, 2020	5533	2020	2766.5



### 3. Cancer registries provide data for many important studies

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#### EXAMPLES

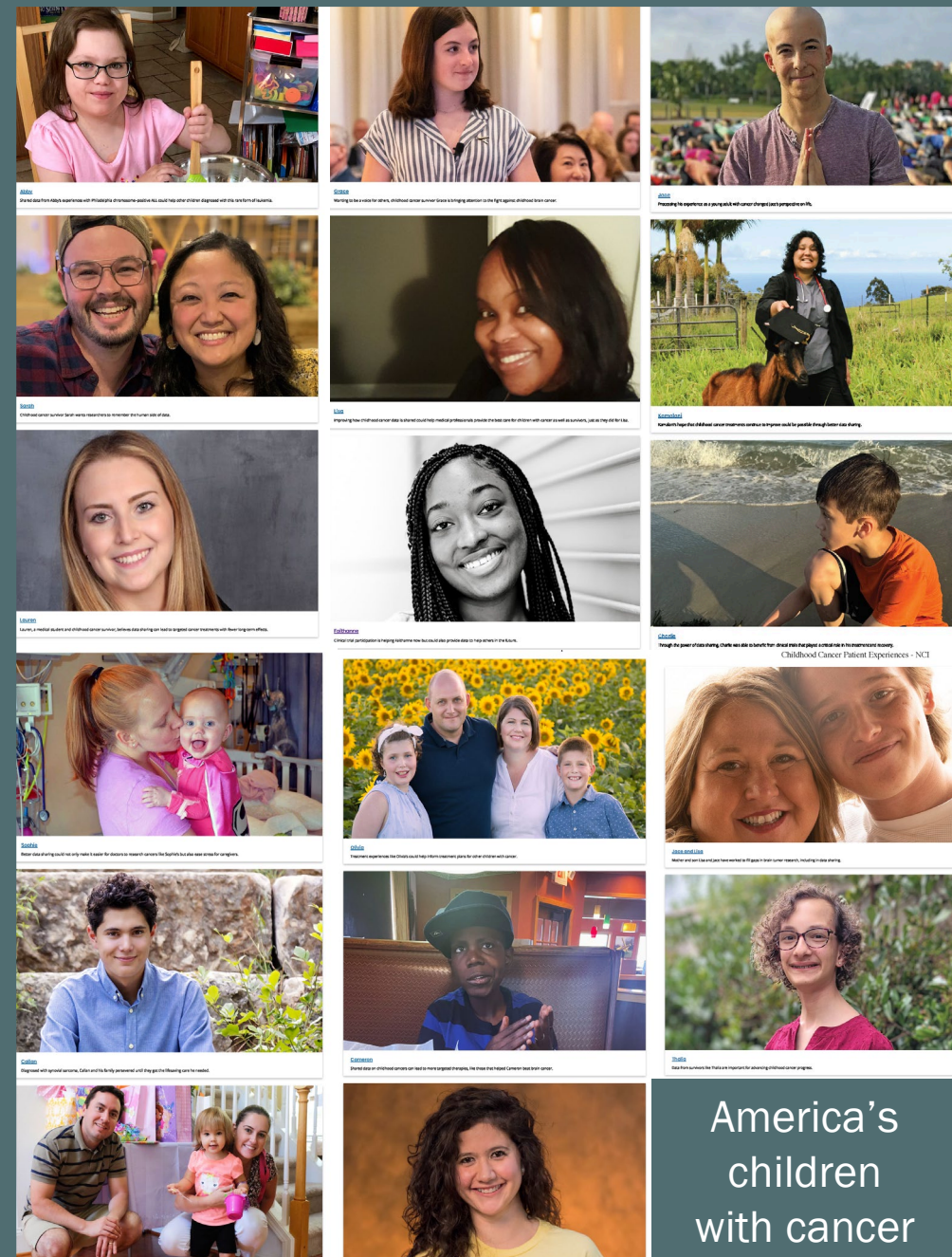
- Breast Cancer Surveillance Consortium
- California Teachers Study
- Cohort Study of Lead-Exposed Workers
- Colon Cancer Family Registry
- Cancer Prevention Study-3
- Childhood Cancer Survivor Study
- Iowa Women's Health Study
- National Childhood Data Initiative
- National Firefighter Registry for Cancer
- New England Bladder Cancer Study
- NIH-AARP Study
- Skin Cancer Prevention Study
- Southern Community Cohort Study
- Transplant Cancer Match Study
- U.S. Radiologic Technologist Study
- Women's Health Initiative



### 3. Cancer registries provide data for many important studies

## National Childhood Cancer Data Initiative

- Aims to pool data for every US child, adolescent & young adult with cancer, using cancer registry data to create the largest, strongest possible dataset for research
- This initiative needs data from every state. Funding for all state cancer registries is critical



America's  
children  
with cancer



# 4. Cancer registries provide data for many important public health interventions

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## EXAMPLES

### Breast & Cervical Cancer Early Detection Program

- Congressionally mandated CDC-funded screening for low-income women

### Comprehensive Cancer Collaboration

- Cancer coalitions in all states to reduce the burden of cancer

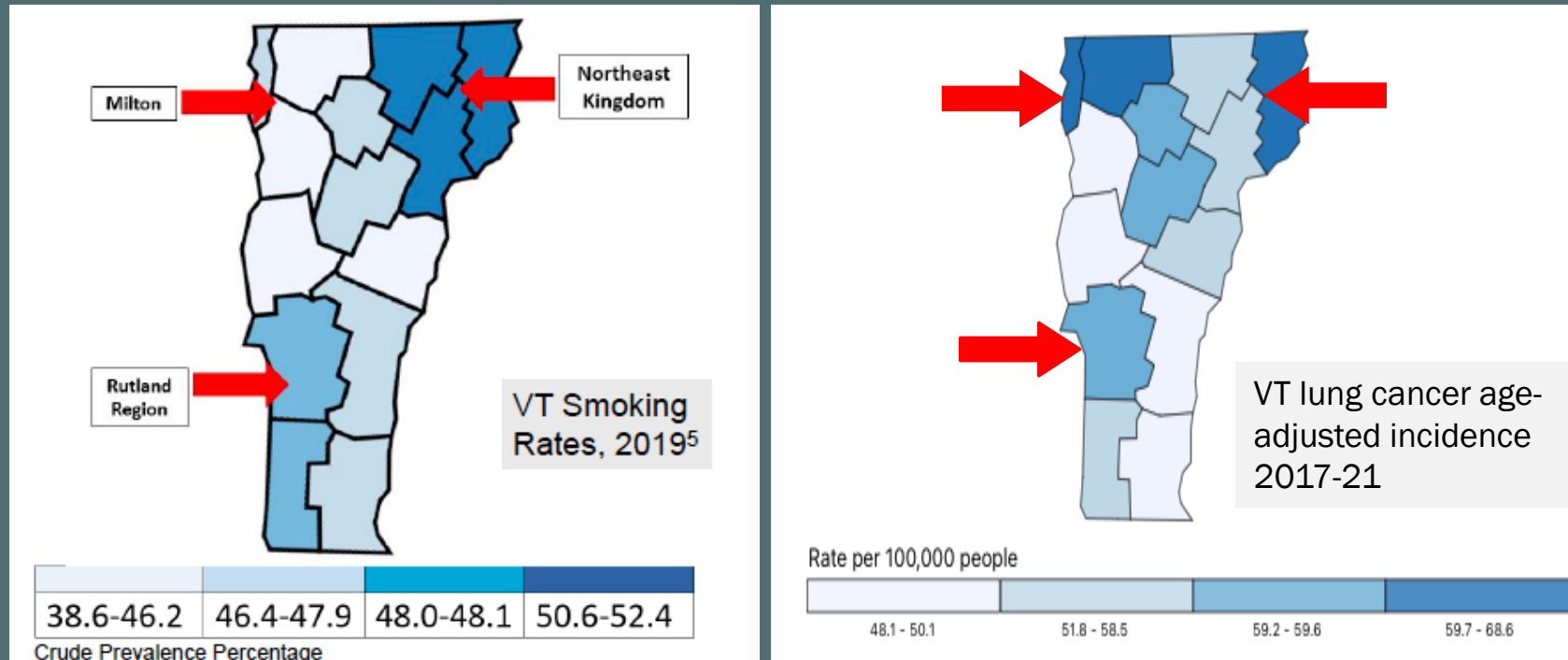
### NCI Cancer Center Support Grants (P30)

- 57 NCI-designated Comprehensive Cancer Centers, whose work includes outreach to reduce cancer burden in catchment areas

### World Trade Center Health Program

- Covers health care for 137,000 responders and survivors

# 4. Cancer registries provide data for many important public health interventions



Lung cancer screening interventions in Vermont targeted resources to areas of greatest need, based on smoking prevalence & lung cancer incidence

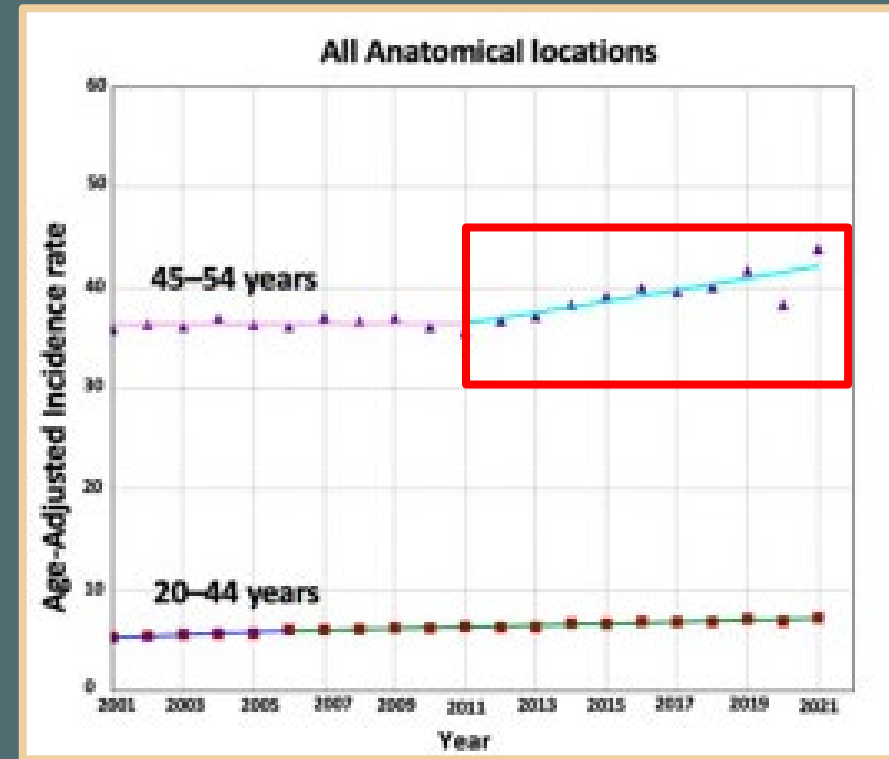


# 5. Cancer registries identify concerning trends over time

Early-onset colorectal cancer is increasing:

- in ages 45-54 by 0.7% per year
- in ages 20-44 by 1.5% per year

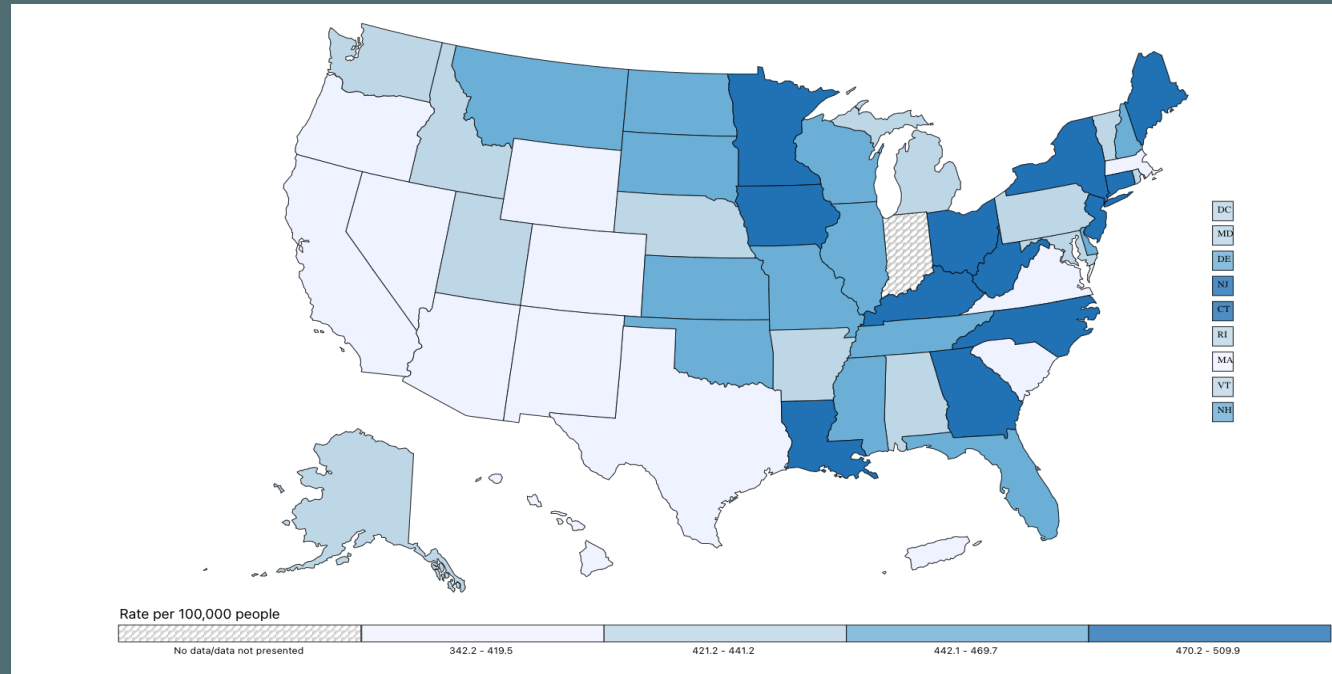
And the Colon Cancer Family Registry, using cancer registry data has taught us a lot about inherited cancer syndromes & early-onset cancer (>700 published research papers)





# 6. Cancer registries identify concerning patterns

Kentucky's cancer rate is 39% higher than New Mexico's

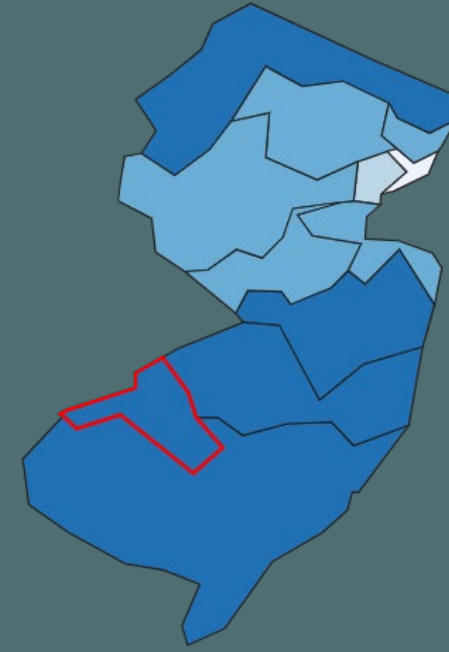




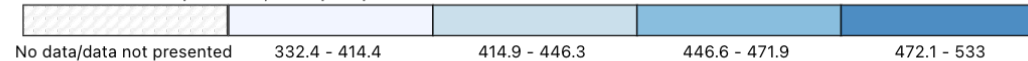
# 7. Cancer registries inform legislators about cancer in their districts

California Congressional District 24 has the highest rate of cancer in CA - 22% higher than District 28

New Jersey Congressional District 1 has the highest rate of cancer in NJ - 14% higher than District 12



Estimated rate per 100,000 people



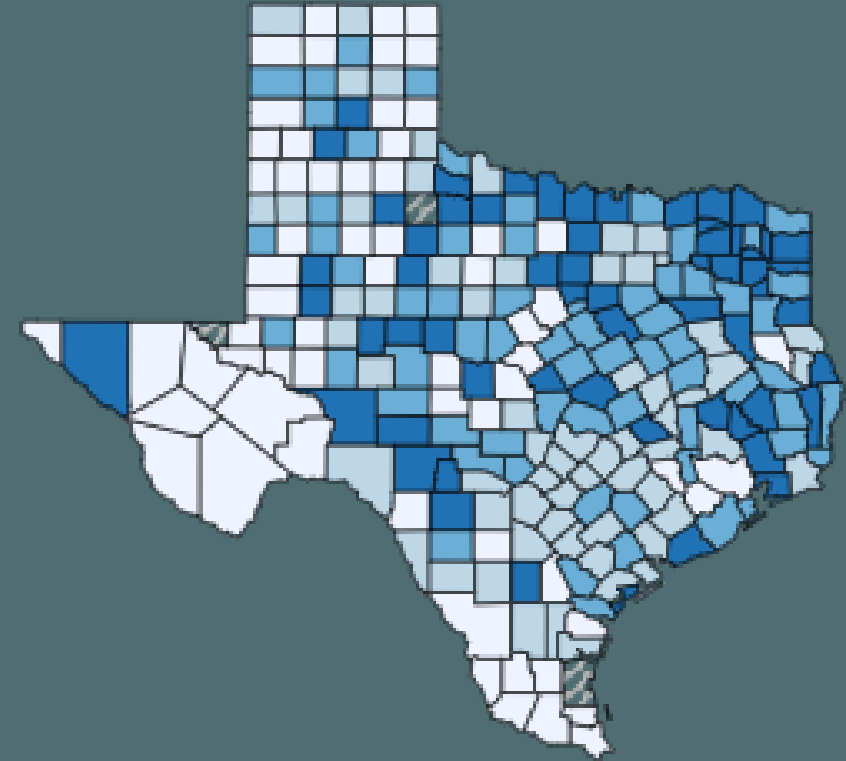


## 8. Cancer registries inform legislators about concerning trends

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Texas Cancer Registry reported to legislators on cancers before age 50, with increases in:

- Early-onset uterine cancer (APC 3.5%)
- Early-onset colorectal cancer (APC 2.3%)
- Early-onset kidney cancer, breast cancer



APC = Annual Percent Change

<https://narrative.naaccr.org/tcr-investigates-early-onset-cancer-trends/> <https://gis.cdc.gov/cancer/USCS/#/StateCountyTerritory/>

# 9. Cancer registries inform public policy



*President Trump cited cancer statistics in Feb 2025 Executive Order:*

*“Across 204 countries and territories, the United States had the highest age-standardized incidence rate of cancer in 2021, nearly double the next-highest rate. Further, from 1990-2021, the United States experienced an 88 percent increase in cancer, the largest percentage increase of any country evaluated.”*



## 10. Cancer registries provide data to investigate community cancer concerns

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### EG Camp LeJeune Study, North Carolina

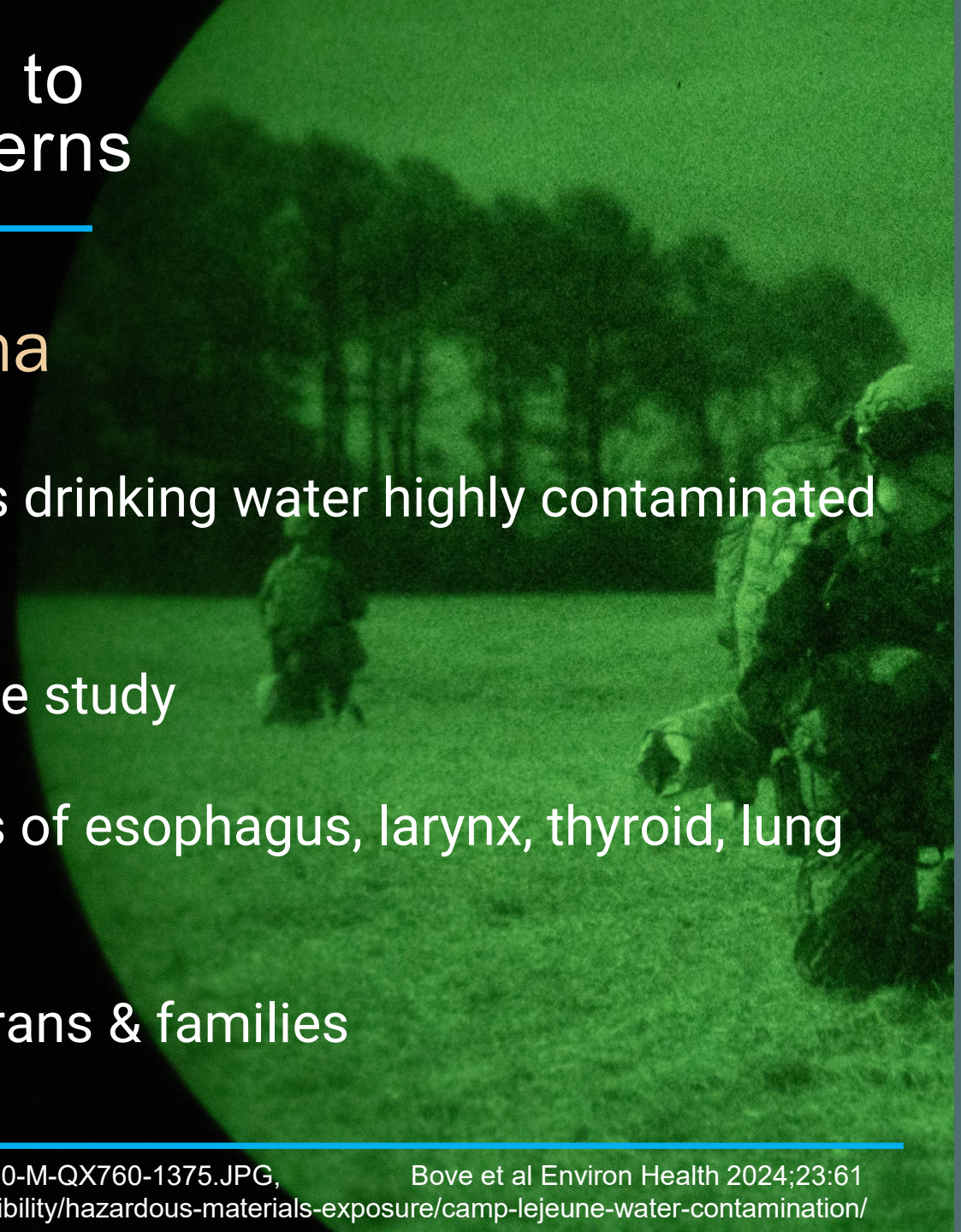
1953-85 - US Marine Corps Base Camp Lejeune's drinking water highly contaminated eg TCE, benzene, vinyl chloride

54 US Cancer Registries identified cancers for the study

↑ hematological cancers, lymphoma, & cancers of esophagus, larynx, thyroid, lung

~ 1 million people exposed over 32 years

Disability & healthcare benefits provided to Veterans & families





# 10. Cancer registries provide data to investigate community cancer concerns

## EG Merrimack, NH Kidney Cancer Study

- PFAS manufactured in Merrimack Town, NH, entered public drinking water via air from the factory
- 2023 Merrimack Town kidney cancer SIR 1.42 (95% CI 1.10-1.81)
- Led to State funding of pilot study to investigate it and the factory is being demolished

State Rep Wendy Thomas has dealt with “cancer that she attributes to 12 PFAS chemicals detected in her blood above the toxic limit for humans”





# 11. Cancer registries identify people at greater risk from cancer

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- Firefighters are at greater risk of cancers
  - Pleura (60% higher risk), testis (34%), thyroid (22%), melanoma (21%), prostate (15%), colon (14%), bladder (12%), rectum (9%)
- Firefighter Cancer Registry Act of 2018
  - Began the National Firefighter Registry for Cancer, run by NIOSH
- This initiative needs data from every state.  
Funding for all state cancer registries is critical



<https://www.cdc.gov/niosh/firefighters/registry/cancer-awareness-month-toolkit.html> Jalilian, Int J Cancer 2019; 145; 10; 2639-2646

<https://nihrecord.nih.gov/2023/08/18/fire-department-celebrates-70th-anniversary> Photo Mat Chibbaro

<https://www.cdc.gov/niosh/firefighters/registry/index.html>

[https://gc.nh.gov/bill\\_status/legacy/bs2016/billText.aspx?id=856&txtFormat=html&sy=2023](https://gc.nh.gov/bill_status/legacy/bs2016/billText.aspx?id=856&txtFormat=html&sy=2023)

# 11. Cancer registries identify people at greater risk from cancer

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## FANS Study (PI Scarlett Gomez)

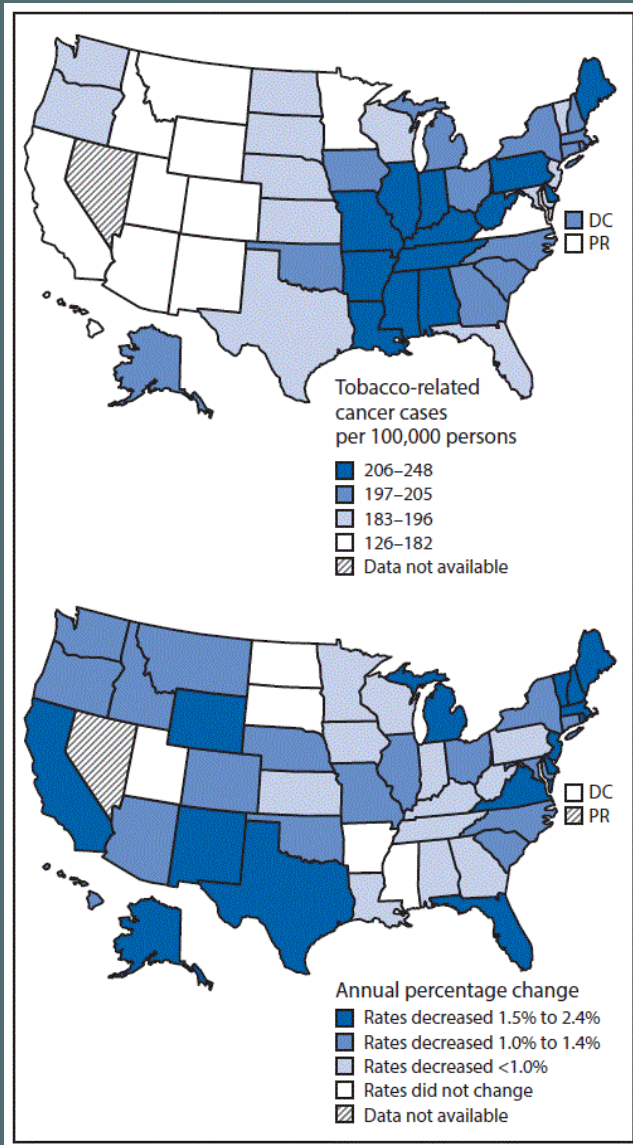


Investigates the unexpectedly high rates of lung cancer in  
Female Aasian Never Smokers

- Usually, 15% of people diagnosed with lung cancer are 'never smokers'
- But 57% of Asian American women diagnosed with lung cancer have never smoked



## 12. Cancer registries show if investments in public health are working



Tobacco causes at least 12 types of cancer

These cancer rates are very different on the east and west sides of the country

Tobacco-related cancer incidence has decreased significantly in 44 states

Age-adjusted rate of tobacco-related cancers (2009–2013) and trends in rates (2004–2013), by state — NPCR and SEER, United States

<https://www.cdc.gov/mmwr/volumes/65/wr/mm6544a3.htm>

# 13. Cancer registries help identify causes of cancer

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Our understanding of cancer risk due to ionizing radiation was based on cancer registries in Hiroshima and Nagasaki, Japan ....



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Thompson, Radiat Res 1994, 137 (2s): S17-S67.

The atomic cloud rising over Nagasaki, Japan. National Archives ID 535795 - <https://www.archives.gov/news/topics/hiroshima-nagasaki-75>



## 13. Cancer registries help identify causes of cancer

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... 80 years on, minimizing radiation exposure from CT scans is being prioritized.

~ 4870 cancers may result from the 4 million CT scans done every year on US children.

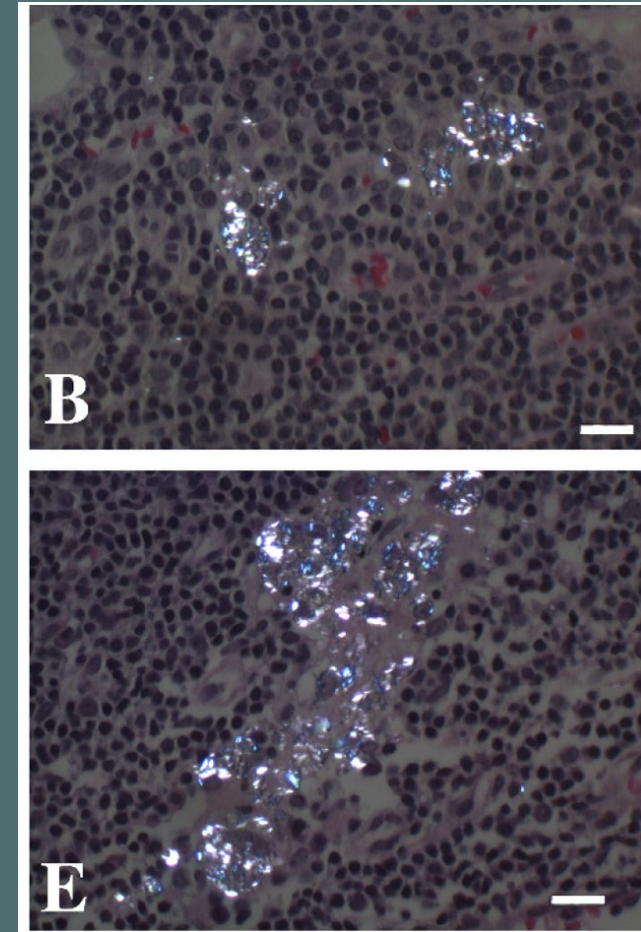


# 13. Cancer registries help identify causes of cancer

## Ovarian cancer studies -

- 1992 - talcum powder linked to ovarian cancer
- Talc contaminated with asbestos is classified as a carcinogen (IARC Group 1)
- Talc alone is classified as a probable carcinogen (IARC Group 2A)

2023 - Johnson & Johnson discontinued talc-based baby powder



Talc in ovarian cancer  
lymph nodes

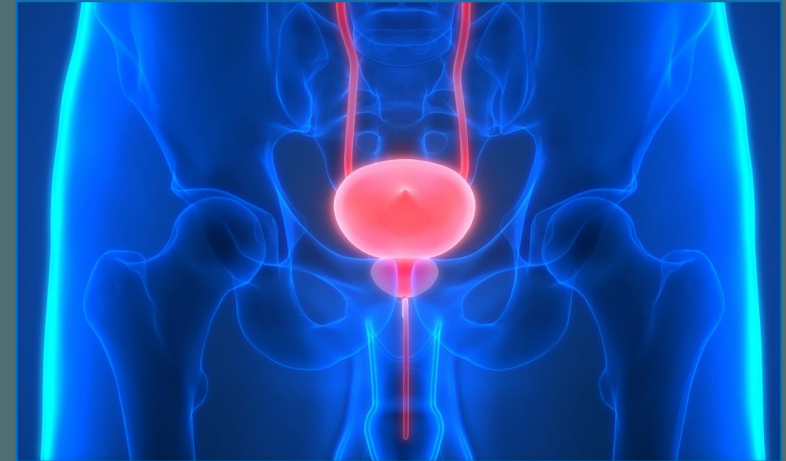


# 13. Cancer registries help identify causes of cancer

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## Bladder cancer studies -

- Exposure to arsenic in drinking water is linked to bladder cancer
  - **even at low concentrations**
- 2021 NH law reduced arsenic MCL in drinking water from 10 to 5 ppb....
- ... and led to a large birth cohort study of early life exposures to arsenic & other environmental health risk factors

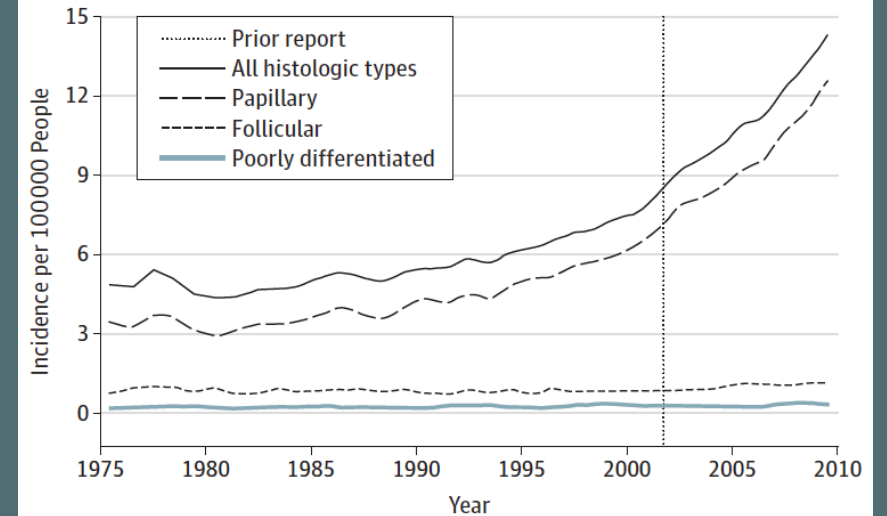


# 13. Cancer registries help identify causes of cancer

## Thyroid cancer studies -

- Increasing thyroid cancer in US first reported through Connecticut Cancer Registry after Chernobyl disaster,<sup>1</sup> driven by small papillary thyroid cancer<sup>2</sup>
- Mortality is stable
- Radiologic imaging is playing a role in diagnosis or causality<sup>3</sup>

Figure 2. Thyroid Cancer Incidence by Histologic Type, 1975 to 2009



Trends are shown for thyroid cancer of all histologic types and for the 3 major histologic groups: papillary, follicular, and poorly differentiated cancers (anaplastic and medullary). Data are from Surveillance, Epidemiology, and End Results (SEER) 9, 1975 to 2009, maintained by the National Cancer Institute, National Institutes of Health, released April 2012, based on the November 2011 submission.

Cramer. Surgery 2010. 148(6):1147-1153



# 14. Cancer registries help understand how complex cancer is

## The RESPOND cohort

- The largest study ever of prostate cancer health in 12,500 African American men
- Participants identified through cancer registries



# 15. Cancer registry data is cited in key clinical guidelines

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- Breast cancer screening 2024
  - All women screen every other year from 40 (vs. start between 40-50)
- Colorectal cancer screening 2021
  - Start to screen from 45 (lowered from 50)
- Lung cancer screening 2021
  - Annual low-dose CT in adults 50-80y with a 20 pack-year smoking history and currently smoke or have quit within past 15 years.





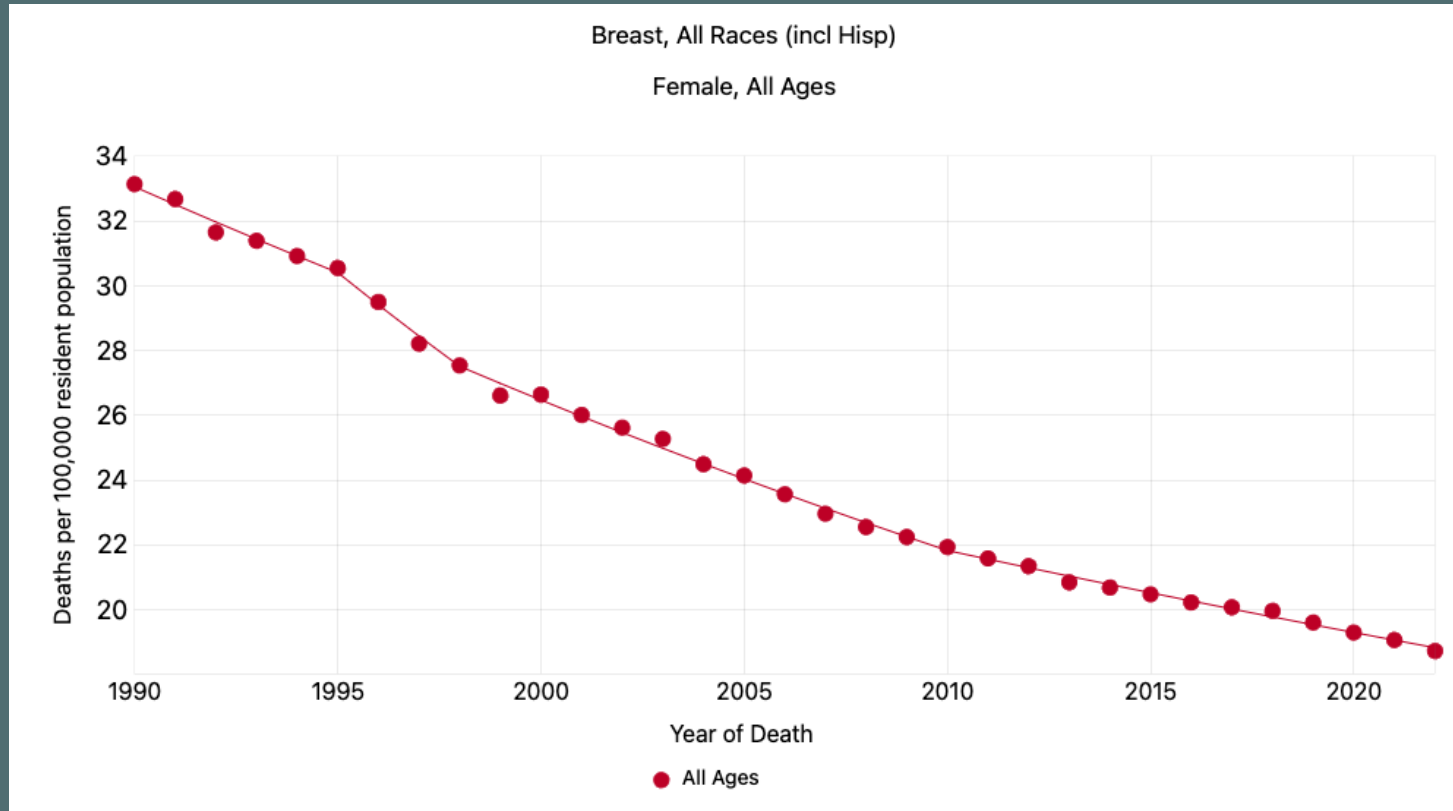
# 15. Cancer registry data is cited in key clinical guidelines

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Skin cancer: screening	2023
Breast Cancer: Medication Use to Reduce Risk	2019
BRCA-Related Cancer: Risk assessment, genetic counselling & testing	2019
Pancreatic Cancer: Screening	2019
Cervical Cancer: Screening	2018
Prostate Cancer: Screening	2018
Skin Cancer Prevention: Behavioral Counseling	2018
Ovarian Cancer: Screening	2018
Thyroid Cancer: Screening	2017
Oral Cancer: Screening	2013



# 16. Cancer registries show you if we are winning the fight against each type of cancer





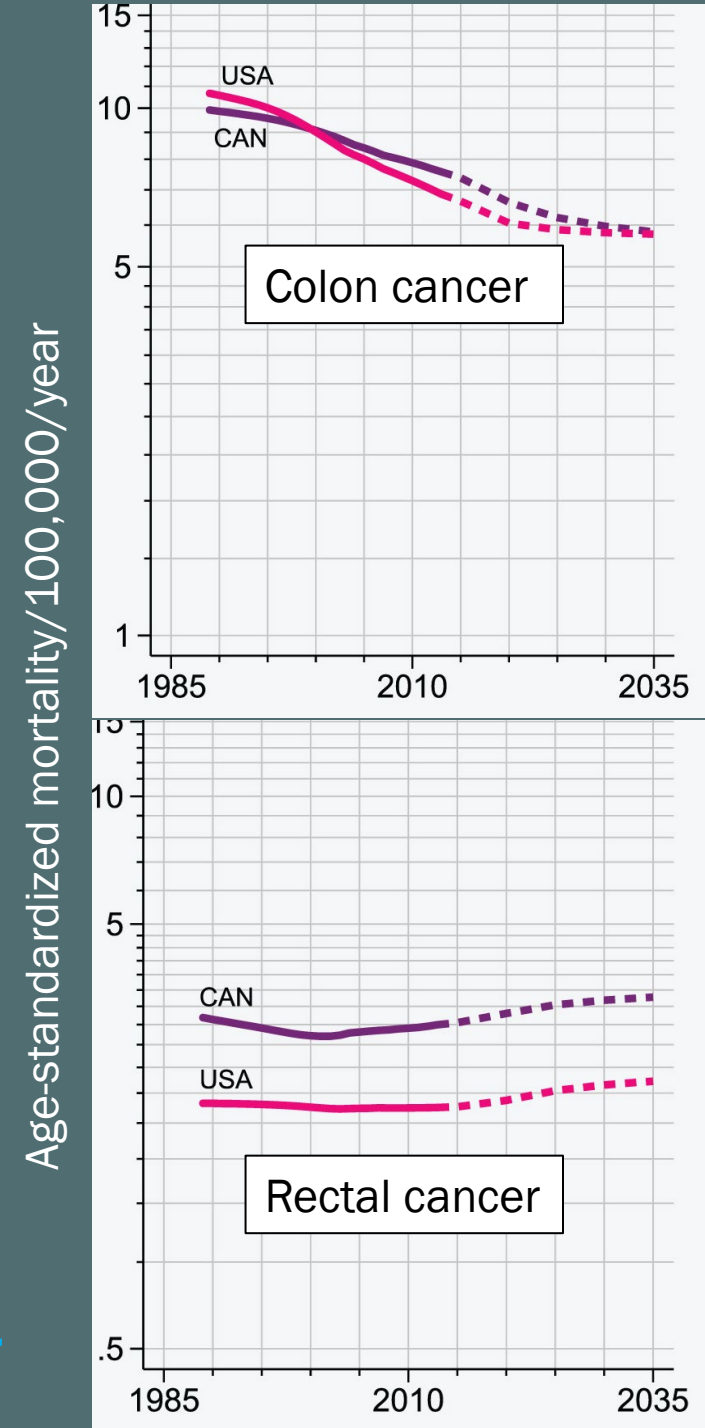
## EXAMPLE

Breast cancer mortality has fallen by 42% since 1990



# 17. Cancer registries help plan for the future

- Despite decline in overall colorectal cancer mortality rate (2013-2035), there are opposite trends for colon  and rectal cancer 
- The number of rectal cancer deaths will double by 2035 in the U.S.



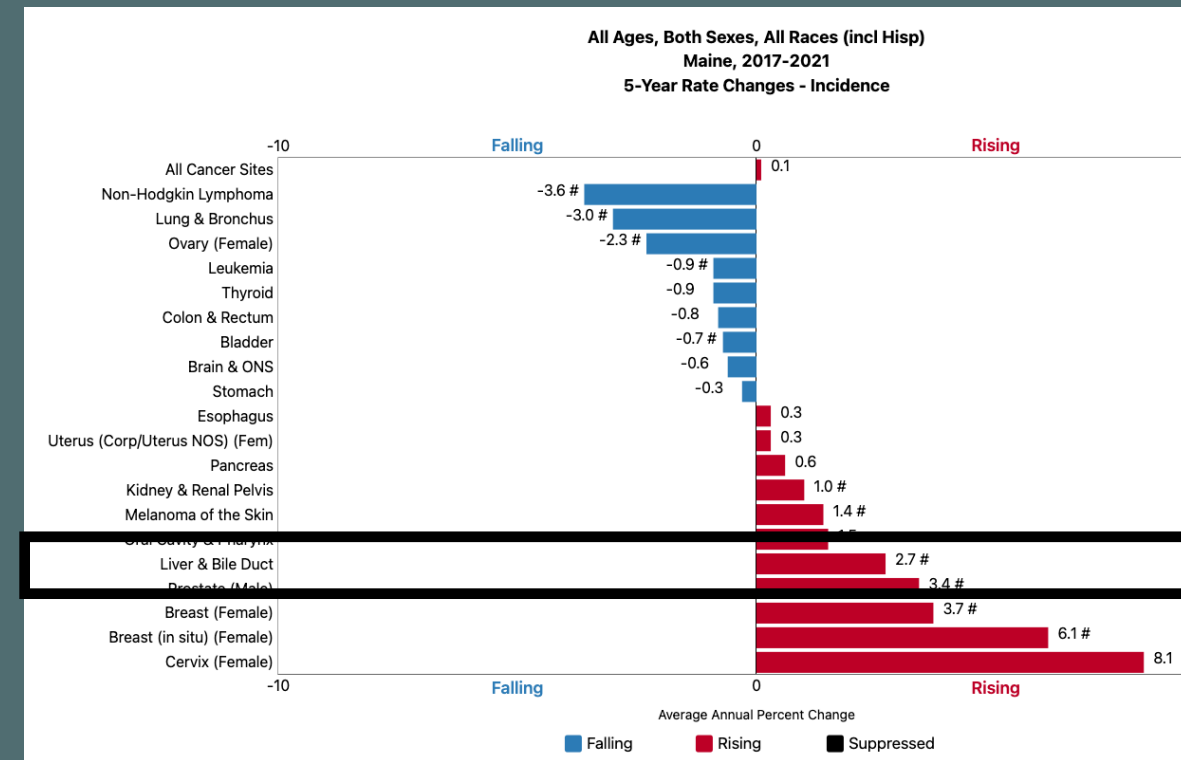
# 17. Cancer registries help plan for the future

But national and state cancer patterns are not necessarily the same

## EXAMPLE

- US liver cancer is decreasing by 1.2% each year
- But in Maine, it's increasing by 2.7%

Every state must have a cancer registry

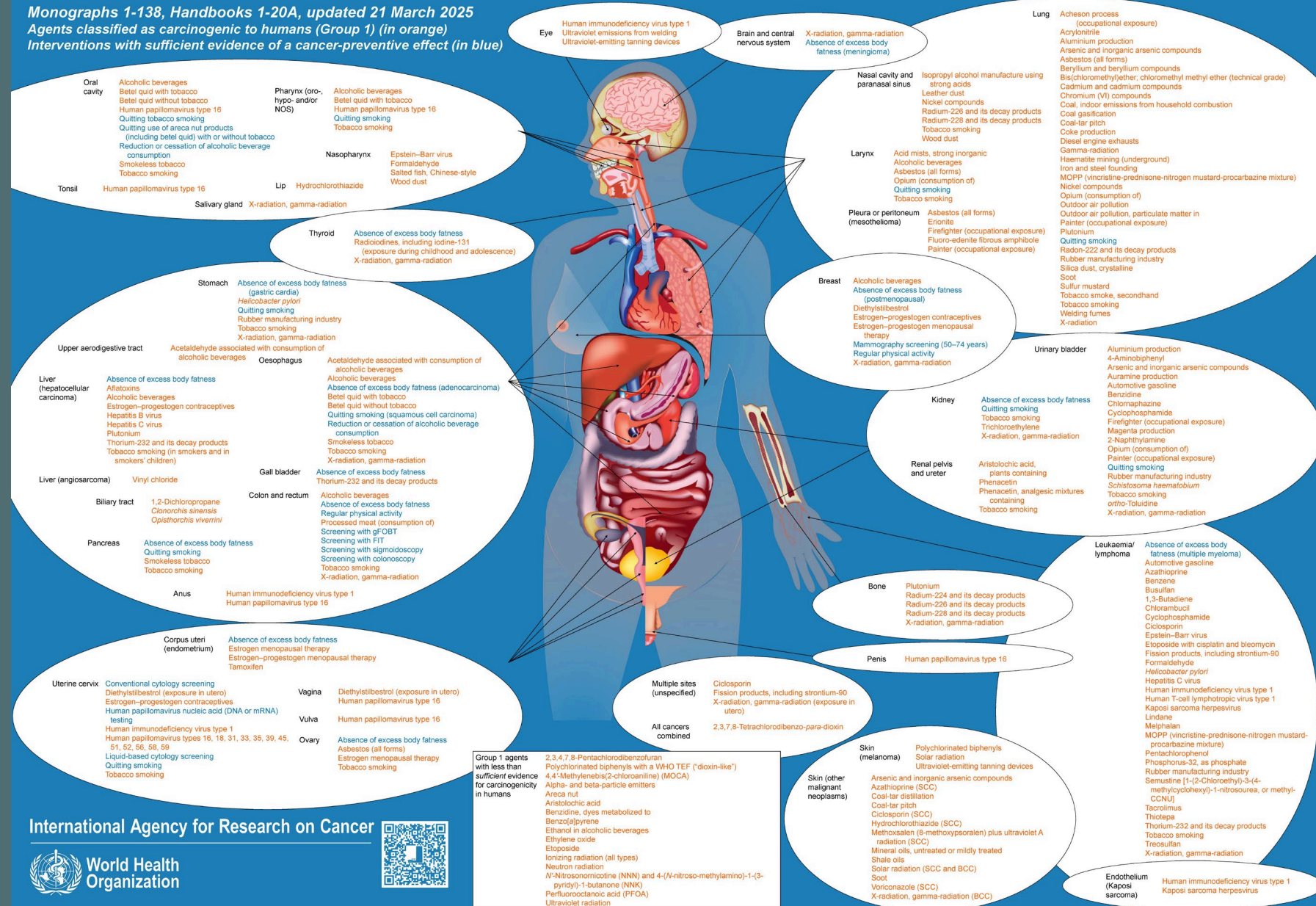




# Human Cancer: Known Causes and Prevention by Organ Site

IARC Monographs on the Identification of Carcinogenic Hazards to Humans and Handbooks of Cancer Prevention

Monographs 1-138, Handbooks 1-20A, updated 21 March 2025  
Agents classified as carcinogenic to humans (Group 1) (in orange)  
Interventions with sufficient evidence of a cancer-preventive effect (in blue)



International Agency for Research on Cancer



Our data are the basis for much of what we know about cancer and how to fight it.

Without properly funded cancer registration in every state to tell us what's going on, we are blindfolded in this fight.