Protecting America's Cancer Intelligence Network: Understanding Cancer Surveillance and the Power of Advocacy

Lori Swain MS, Executive Director - NCRA

- A LITTLE ABOUT NCRA
- OVERVIEW OF CANCER SURVEILLANCE
- NCRA’S WORK IN PROTECTING CANCER SURVEILLANCE

National Cancer Registrars Association

Who we are

Vision Statement

Making Oncology Data Matter.

National Cancer Registrars Association

Mission Statement

Engage and advance our community through innovation, education, credentialing, advocacy, and alliances.

National Cancer Registrars Association

Seven Strategic Goals

1. Membership
2. Innovation
3. Education
4. Credentialing
5. Professional Development
6. *Alliances and Advocacy*
7. Organizational Sustainability and Governance

National Cancer Registrars Association

National Cancer Registrars Association

What is the Cancer Surveillance System?

What Cancer Registries Do

The foundation of the nation's cancer intelligence network

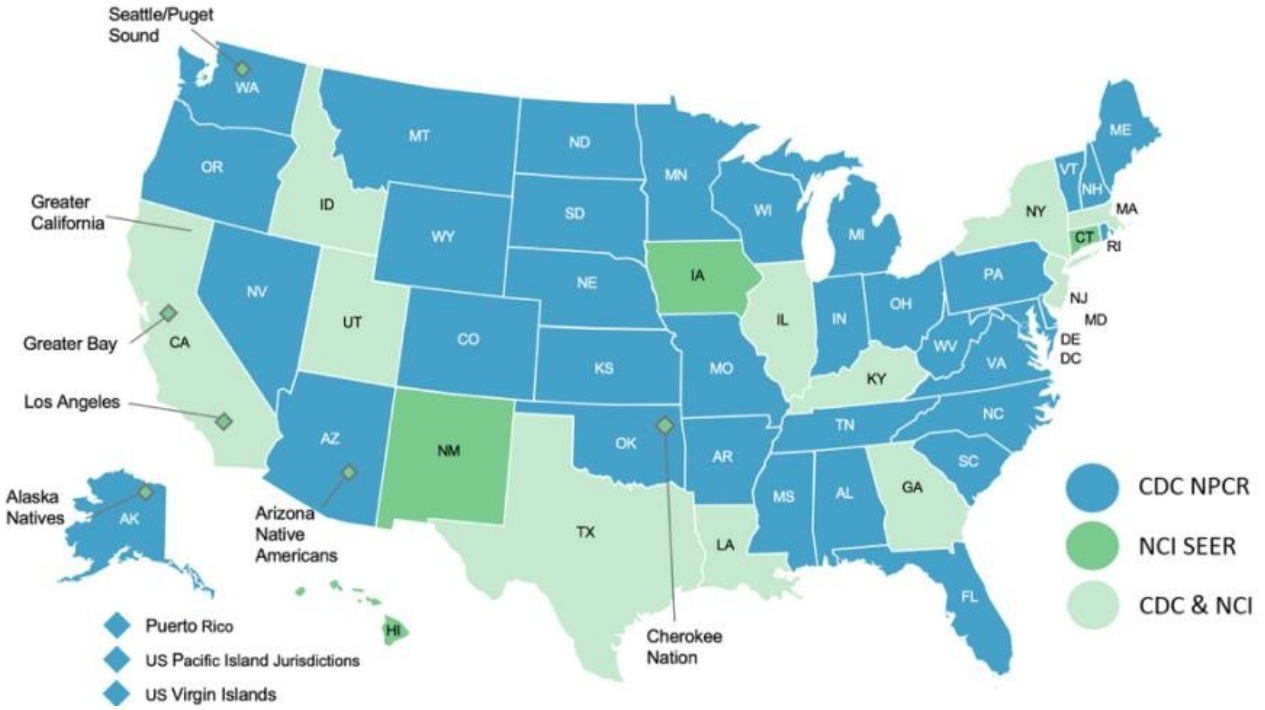
- Collect and analyze information on every newly diagnosed cancer.
- Help answer: who develops cancer, where it occurs, how it is treated, and whether outcomes are improving.
- Provide the only source of information on all Americans for measuring incidence, survival, disparities, treatment patterns, and long-term cancer trends.
- Create standardized, research-ready information used across clinical care, research, public health, and policy.

How the National Cancer Surveillance System Works

Hospitals & providers → State cancer registries → NPCR + SEER support → National cancer intelligence

Workforce

Cancer registrars interpret complex clinical information, abstract and code diagnosis, staging, treatment and outcomes, and support quality assurance and data management.



Why Cancer Registries Matter

From surveillance data to prevention, research, and better care

Measure the burden

Track cancer incidence, disparities, outcomes, and emerging trends.

Guide action

Inform prevention and control priorities, public health policy, and interventions.

Advance research

Support studies of prevention, causes, treatment outcomes, survivorship, access, quality, and environmental exposures.

Build knowledge

Registry data have contributed to advances in cancer genetics, screening, new treatments, survivorship, and population health.

Patient & Community Benefits

- Represent populations that can otherwise be missed, including rural, frontier, Tribal, and other communities with limited healthcare access.
- Provide longitudinal, disease-specific outcomes that can help physicians and patients understand prognosis at diagnosis or when cancer progresses.
- Reveal geographic and healthcare-system gaps in incidence, screening, treatment, and outcomes.
- Support local planning and investment in prevention, screening, treatment, and survivorship programs.
- Guide screening recommendations, resource allocation, and quality-improvement efforts.

Specialty Registries & Federal Investigations

- Population-based cancer registry infrastructure supports specialty registries and investigations involving children, firefighters, veterans, military personnel, mesothelioma patients, first responders, and other populations with unique health risks.
- These data help researchers identify cancer risks, evaluate outcomes, and generate evidence for prevention strategies and healthcare planning.
- Registry infrastructure can support compensation programs and public health interventions.
- Registry records are being used to support the Radiation Exposure Compensation Act (RECA), including disease verification and claim evaluation by the Department of Justice.
- Long-term registry surveillance is also needed to evaluate health consequences of radiation exposure.

Why Federal Support Matters

NPCR and SEER provide complementary national infrastructure

NPCR

Supports nationwide population-based cancer surveillance infrastructure and enables every state to participate in a high-quality, standardized national reporting system.

SEER

Enhances the value of registry data through scientific discovery, data linkages, technology infrastructure, health disparities research, and population-based studies.

State registries

States provide supportive funding in many cases, but the source states that central registries could not solely deliver the multi-faceted national surveillance approach without federal NPCR and SEER support.

The Capacity Challenge

Growing responsibilities, constrained resour

More cancer cases

The source cites an expectation of more than 2.1 million new U.S. cancer cases in 2026.

More demands

Registries are expected to deliver more timely and comprehensive data, support more research, adopt technology, improve interoperability, and address emerging public health challenges.

Funding pressure

The source states NPCR funding has remained essentially flat for five years, while SEER funding has been reduced over the past two years.

Capacity effects

The document warns that some effects may not become evident for years as workforce expertise, technology capabilities, and quality-assurance capacity decline over time.

The Core Message

Cancer registries are not merely databases.

They are the nation’s cancer intelligence network—providing evidence to understand cancer risk,

improve care, advance research, guide policy, support RECA and other exposure-related programs,

and improve outcomes.

Sustained and increased investment protects the surveillance infrastructure needed for emerging

threats, scientific research, and future generations.

NCRA Advocacy

National Cancer Registrars Association

Background– Built Rationale for Action

January 2025 Change in Administration

- Moratorium on Federal Agency Communication (Feb)
- RIF and CDC (Feb)
- SEER Contract Cuts (Feb/March)
- Remote Work Order Rescinded (Feb/ March)
- May 2, 2026 Proposed FY 26 Budget

Protect U.S. Cancer Surveillance

Urge your members of Congress to Take Action

ADVOCACY now

NCRA and our partners are working to protect federal public health employees at the Centers for Disease Control and Prevention, the National Institutes of Health/National Cancer Institute, and the Department of Veterans Affairs to see that US cancer surveillance remains strong.

Be an advocate and support our cancer registry colleagues and the entire cancer surveillance community by sending our messages to your Senators and Representative through our easy online *Advocacy Now* Campaign. Follow the QR Code below to join in.

Join NCRA to advocate:

- Lifting the moratorium on external communications by federal employees.
- Adequately fund cancer surveillance functions of the federal government.
- Restore and retain our critical federal employees at the Centers for Disease Control and Prevention, wthe National Institutes of Health/National Cancer Institute and the Department of Veterans Affairs.
- Repeal the administration's executive orders mandating a return to in-office work for federal employees.

Scan this QR Code to send your message to Congr

The Budget eliminates duplicative, DEI, or simply unnecessary programs, including: the National Center for Chronic Diseases Prevention and Health Promotion; National Center for Environmental Health; National Center for Injury Prevention and Control;

2026 (Released May 2, 2025)

NCI cut 40%

2025 Efforts – Shifting Approach

- Hill Meetings
  - Recruiting Volunteers
  - Collateral Development
- Update Letter Writing Effort

U.S. CONGRESS

Labor, Health & Human Services Appropriations

HOUSE APPROPRIATIONS SUBCOMMITTEE

Labor, Health and Human Services, Education, and Related Agencies

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- Chuck Fleischmann (TN)
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- Stephanie Bice (OK)
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SENATE APPROPRIATIONS SUBCOMMITTEE

Labor, Health and Human Services, Education, and Related Agencies

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- John Kennedy (LA)
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- Patty Murray (WA)
- Richard Durbin (IL)
- Jack Reed (RI)
- Jeanne Shaheen (NH)
- Jeff Merkley (OR)
- Brian Schatz (HI)
- Chris Murphy (CT)

KEY ROLE: These subcommittees fund critical programs at the Department of Health and Human Services, the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), cancer registries (SEER & NPCR), education programs, and more.

BIPARTISAN WORK. BETTER OUTCOMES.

Investing in Health. Strengthening Communities.

Cancer Registries:
An Essential Tool in America's War on Cancer

What is a Cancer Registry?

Cancer registries are information systems that manage and analyze data on cancer patients and survivors. Cancer registries can be classified into three types:

- **Hospital Registries:** one of the main starting points for cancer surveillance; registrars document diagnosis and treatment on all patients, cases are reported to the central or state cancer registry by hospital registries, and includes case reporting by VA medical facilities.
- **Central or State Registries:** combine and maintain data on all cancers occurring in the state's population, collecting data from all hospitals, pathology laboratories, physicians, and other sources.
- **Special Purpose Registries:** maintain data on a specific type of cancer, such as brain tumors, or a special population, such as Native Americans or firefighters.

Together, the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR) and the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) Program collect cancer data for nearly 100% of the U.S. population. These agencies offer financial support and technical assistance to central registries reporting data into our national cancer surveillance programs.

Cancer registrars are data information specialists who are employed by hospital, central, and special purpose registries to capture the complete history, diagnosis, treatment, and health status for every cancer patient in the U.S.

It is estimated that over 2 million cases of cancer will be diagnosed in the U.S. in 2025. Population-based cancer registries in individual states, in partnership with the Surveillance, Epidemiology and End Results (SEER) Program and the National Program of Cancer Registries (NPCR),[1] will collect information on all of these diagnoses. Because of this information, we can answer:

- **WHO** is getting cancer?
- **WHAT** types of cancers are being diagnosed?
- **WHERE** are larger burdens of cancer found?
- **WHEN** are screening and other prevention strategies working?
- **HOW** uniformly are novel therapies being adopted, and how well are they working?

Data collected by cancer registries are the only way that Americans can measure progress in the fight against cancer. Because of the U.S. cancer surveillance system, we know:

- 1 in 3 Americans will be diagnosed with cancer in their lifetime.
- 1 in 5 deaths in men and women are due to cancer each year.
- Childhood cancer survival has improved over the last half century, to over 90% for some cancers.
- Rates of colorectal cancer have increased over 30% among young adults in the past 20 years.
- Death rates from uterine cancer have increased by 30% in the past 20 years.

[1] The National Cancer Act of 1971 led to the creation of the SEER Program; the Cancer Registries Amendment Act of 1992 led to creating and enhancing state cancer registries to achieve true nation-wide cancer registry coverage. In 1998, the Veterans Affairs Cancer Registry System (VACRS) was established but did not consistently report to central registries. With the 2024 reporting requirement as part of the FY '24 Military Construction, Veterans Affairs, and Related Agencies Appropriations Act, VA Medical Facilities are now required to report into the U.S. national cancer surveillance system.

Reductions in Funding and Reductions in Staff Risk...

- Weakening America's ability to fight cancer effectively—we can't manage what we can't measure!
- Interruptions in data collection and reporting, causing delays in recognizing emerging cancer trends and treatment gaps.
- Stalling research breakthroughs, including for cancers occurring in children and young adults.
- Loss of cancer burden data to guide efficient allocation of healthcare resources at cancer treatment centers.
- Inability to develop national and tailored state-specific cancer prevention and control strategies.
- Inability to respond to constituent concerns about cancer risk in their community.
- Undermining Congressional initiatives including counting veterans' cancer, Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act; and the National Firefighter Registry. These efforts rely on cancer registry data to track progress and target investments for maximum impact.
- Disabling the VA cancer registries from reporting accurate and timely data to be meaningful to US cancer surveillance and, in turn, impact veterans' cancer needs.

Benefits Provided by Robust Data Collection at Central Cancer Registries

- Critical data for evidence-based policymaking and efficient allocation of health resources.
- Advances and innovation in cancer prevention, detection, and treatment.
- Ability to identify cost effective prevention and screening efforts, saving billions of healthcare dollars.
- Quantifying advancements in survival among all Americans, including pediatric cancer patients.
- Prolonging lives and improving quality of life through earlier detection and better care.

AT STAKE

- **Central cancer registries within the National Program of Cancer Registries (NPCR) gather, manage, and analyze data about incidence, stage at diagnosis, and treatment. This information guides cancer control programs and helps to ensure health resources are allocated where needed most.**
- **As a research resource, the Surveillance, Epidemiology and End Results (SEER) Program serves as a platform for studies that address emerging issues in the field of cancer and cancer-related care. SEER also plays a critical role in increasing the breadth of scientific research to include various factors such as health disparities, access to and quality of health care, geographic determinants, and other attributes.**
- **Poorer survival rates for all Americans because of less effective screening interventions, and more advanced cancers at diagnosis.**
- **The U.S. will lose ground and decades of progress on cancer control. America cannot surrender in the War on Cancer!**

The Ask

- Reinstate funding to continue support of CDC's National Program of Cancer Registries (NPCR) - FY'26=$63.4 million.
- Remove the 40% reduction proposed in FY'26 for NIH, and fully support the Surveillance, Epidemiology, and End Results (SEER) Program at NCI.

National Cancer Registrars Association

NCRA is a non-profit organization that represents over 7,000 cancer registry professionals and administers the ODS credential. The mission of NCRA is to empower and advance registry professionals through innovations in education, advocacy, credentialing, and strategic partnerships.

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A MAJOR VICTORY FOR CANCER SURVEILLANCE

PASSED BY CONGRESS. SIGNED BY THE PRESIDENT.

Congress passed and the **President signed** the Fiscal Year (FY) 2026 appropriations package, finalizing funding for critical health programs including cancer surveillance.

CDC NATIONAL PROGRAM OF CANCER REGISTRIES (NPCR)

$53.4 MILLION

Provides $53.4 million for the CDC's National Program of Cancer Registries (NPCR) – flat funded from FY 2025.

NATIONAL CANCER INSTITUTE (NCI)

+$150 MILLION

Increases funding for the NCI by $150 million over FY 2025 levels. This increase will support the SEER Program and other critical cancer research initiatives.

> *"This is a tremendous victory for cancer surveillance and the patients who depend on accurate, comprehensive cancer data."*
>
> — *Lori Swain, Executive Director*
> *National Cancer Registrars Association (NCRA)*

> *"Cancer registrars across the country can continue their essential work collecting the data that drives cancer research, guides treatment decisions, and helps save lives."*
>
> — *Lori Swain, Executive Director*
> *National Cancer Registrars Association (NCRA)*

THE CHALLENGE

When the Administration's FY 2026 budget proposal called for eliminating funding for the NPCR and cutting NIH cancer programs by 40%, NCRA mobilized hundreds of volunteers to educate members of Congress about the vital importance of cancer registries to patient care, research, and public health.

OUR RESPONSE

NCRA and its partners led a powerful, coordinated advocacy campaign—reaching out to lawmakers, sharing patiient stories, and highlighting the life-saving impact of cancer surveillance data.

THE OUTCOME

Thanks to the advocacy of NCRA, our partners, and supporters nationwide, Congress rejected deep cuts and instead provided $53.4 million for NPCR and increased funding for the NCI by $150 million over FY 2025 levels.

CANCER SURVEILLANCE PREVAILS. PATIENTS BENEFIT.

Accurate data. Better decisions. Stronger public health.

This funding ensures that cancer surveillance continues to drive research, inform policy, and improve outcomes for all communities.

Efforts for FY27

- Not losing touch with the facts -
- 2025 SEER $ Cut/2026 SEER $ Cut
- CDC-NPCR eliminated in the FY26 Proposed Budget
- We had a winning strategy

- What would the White House do for FY 27?
- How do we prepare?

Pre-White House FY 27 Proposed Budget

- Closed on a strategy to better support SEER
- Aligned with the OVAC increase for CDC-NPCR
- Updated collateral
- Recruited constituent volunteers/ meetings

Waited for White House budget

FY 2026–FY 2027 Proposed Federal Cancer Budget Overview

CDC CANCER SURVEILLANCE

$0

FY 2026 Proposed Budget

$53.4M

FY 2027 Proposed Budget

NIH
NATIONAL CANCER INSTITUTE

NATIONAL CANCER INSTITUTE

40% CUT

FY 2026 Proposed Budget Reduction

FY 27 Proposed Budget: Increase of $8.9M (0.1%) over FY 2026 enacted level

Work Still Needed - House

- Convince the House to buy into our SEER Strategy
- Convince the House to do more than the White House on CDC-NPCR

Partial Success – House!

- Convince the House to buy into our SEER Strategy
- Convince the House to do more than the White House on CDC-NPCR
- SEER Strategy - The Committee recognizes the importance of the NCI Surveillance, Epidemiology, and End Results (SEER) program for building and maintaining a comprehensive, population-based database on cancer incidence, prevalence, and patient survival. The program provides valuable information used by researchers, clinicians, and others on trends in cancer rates, including for different population groups such as children, as well as information on the stage of disease individuals have at diagnosis and how that has changed over time. The Committee urges continued funding for SEER at levels necessary to continue nationwide cancer surveillance activities. The Committee particularly encourages continued assessment of the need for ongoing research in this area, especially in areas with high prevalence of cancer, including pediatric cancers

Work Still Needed - Senate

- Convince the Senate to buy into our SEER Strategy (that the House already did)
- Convince the Senate to do more than the White House or the House on CDC-NPCR

Work Still Needed – FY28

- Influence the White House
- Sign on letter
- Wait and see!

Alliance for Women's Health and Prevention
American Indian Cancer Foundation
Association for Clinical Oncology (ASCO)
Association of North Carolina Cancer Registrars
California Cancer Registrars Association
Cancer Registrars Association of New England (CRANE)
Cancer Registrars Association of the Dakotas (CRAD)
Cancer Support Community
College of American Pathologists
Fight Colorectal Cancer
Florida Cancer Registrars Association
FORCE: Facing Our Risk of Cancer Empowered
HealthyWomen
Hematology/Oncology Pharmacy Association (HOPA)
Hope for Stomach Cancer
Louisiana Cancer Registrar's Association
Livestrong
Male Breast Cancer Global Alliance
Men's Health Network
METAvivor
National Black Nurses Association, Inc.
National Comprehensive Cancer Network
OCRA Ohio Cancer Registrars Association
Oncology Nursing Society
Oncology Registrars Association of NJ
Ovarian Cancer Research Alliance
PACR - Pennsylvania Association of Cancer Registrars
Patient Empowerment Network
Pennsylvania Prostate Cancer Coalition (PPCC)
Prevent Cancer Foundation
Society of Breast Imaging
South Carolina Cancer Registrars Association
St. Baldrick's Foundation
Susan G. Komen
The Latino Cancer Institute
The Tumor Registrar's Association of Connecticut
Triage Cancer
Unite for HER
Wisconsin Cancer Registrars Association (WCRA)
WSTRA
ZERO Prostate Cancer

In Closing

- We have demonstrated our ability to be successful
- Need to keep on getting “wins”
- Our membership being willing to participate is key
- Our work is not done

Our work is recognized

National Cancer Registrars Association

NCRA Video

https://tinyurl.com/What-is-NCRA

"A small group of thoughtful people could change the world."
~ Margaret Mead

National Cancer Registrars Association

Questions

National Cancer Registrars Association