

# 2022 NPCR VERMONT SUCCESS STORY

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## Vermont Cancer Registry – Twenty-Nine Years Later and How it All Began

### National Program of Cancer Registries SUCCESS STORY

#### SUMMARY

Since 1993, the Vermont Cancer Registry (VCR) has collected information about cancer diagnosed in Vermont residents and in Vermont health care settings. The Vermont Cancer Registry's data and collaborations have created an important source of public health information. The registry has a significant impact on the health of Vermonters providing valuable information about the prevention and treatment of cancer. In June of 2022, the Vermont Cancer Registry celebrated its 29<sup>th</sup> year. This Success Story highlights many of Vermont's achievements, challenges, and growth over the past three decades.

#### RESULTS

1988: The Vermont Coalition on Cancer Prevention and Control was formed to address cancer in the State of Vermont as a public health concern. The coalition recommended that a statewide, population-based cancer incidence registry be established for Vermont.



1991: Cancer survivors and advocates Virginia Soffa and Joanne Rathgeb, concerned about the many Vermont women dying from breast cancer, campaigned for a national cancer registry with a petition drive called *Do the Write Thing*. As a result of their efforts, the Vermont Congressional delegation introduced the National Cancer Registry Act (HR 4206).

1992: The United States Congress established the National Program of Cancer Registries (NPCR).



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

Sponsored by senators Bernie Sanders (I-VT) and Patrick Leahy (D-VT), the Cancer Registries Amendment Act of 1992, as part of the National Institutes of Health (NIH) reauthorization bill, won Senate approval. The bill provided funding to establish and improve Vermont's first statewide cancer registry and created a national program of statewide cancer registries. Vermont was one of 19 states without a state registry but had the eighth-highest mortality rate for breast cancer. The bill provided federal grants that would establish and support cancer registries in all 50 states (Hill, 1992).

1993: The Vermont Cancer Registry Act was signed into law by Governor Howard Dean, establishing a population-based, statewide cancer registry within the Vermont Department of Health.

*"Joanne Rathgeb, an actress, director and educator who fought for greater awareness and increased resources to fight breast cancer, died of the disease on Nov. 19 at her home in Essex Junction, Vt. She was 64. In 1992, she started a cancer registry in Vermont, and Congress passed the Cancer Registries Act, which established a national standard for the collection of cancer data."*

The New York Times  
November 29, 1994

2000: The first three years of Vermont's cancer incidence data were compiled by the Vermont Cancer Registry. In 2002 the VCR published *Cancer in Vermont 1994-1996* which included data on cancer incidence, mortality, and leading sites.



2001: In 2001 VCR began work with the National Cancer Institute and others to research the causes of elevated bladder cancer rates in northern New England. Several papers have since been published from the New England Bladder Cancer Study, investigating the effects of smoking, occupation, hair dye use, and analgesic use on bladder cancer risk.

2002: The Vermont Cancer Registry submitted five years of data for its first participation in the NPCR-CSS "Call for Data."



2005: Vermont's statewide cancer coalition, Vermonters Taking Action Against Cancer (VTAAC) was established. VCR works with VTAAC's statewide coalition of cancer survivors, advocates, public health and health care professionals and others, to reduce the impact of cancer among all Vermonters.

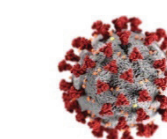
2007: Vermont Cancer Registry achieved NAACCR Gold Certification (with a total of 14 through 2021).

2010: VCR data were used to identify differences in cancer treatment received between rural and urban residents. The Oncology Care in Rural Northern New England Study, published in the March 2010 *Journal of Oncology Practice*, demonstrated that rural residents of Maine, New Hampshire, and Vermont diagnosed with breast or colon cancer were less likely to receive certain standard-of-care treatments than urban residents.

2012: Vermont received the Model Coordination Award at the 2012 CDC Cancer Conference for our commitment to integration and our demonstrated ability to collaborate across programs to achieve outcomes.



2016: The Vermont Cancer Plan: A Framework for Action 2016-2020 was released.



2020: On March 13, 2020, the Vermont Governor enacted an executive order declaring a State of Emergency in Vermont in response to the COVID-19 pandemic. Three of four VCR staff members participated in the Department's response, deployed for 18 months. Registry activities were greatly reduced but the registry continued collect high quality data, submit data to NPCR-CSS and to NAACCR, collaborate with partners and programs, and utilize data to monitor efforts to reduce the burden of cancer among all Vermonters.

2021: Vermont began using survival data in Cancer Control Planning. The *2021-2025 State Cancer Plan*, released in December, was the first plan to have an objective relating to Vermont cancer survival data.



The Cancer Registry Chief, Ali Johnson, having led the Vermont Cancer Registry for 20 years, retired in November 2021.

2022: The Vermont Cancer Registry celebrated 29 years. The registry started the year with a new Registry Chief, welcomed a new data analyst to our team, and transitioned to a new division within the health department as the Division of Health Statistics & Informatics with a focus on health informatics. As we turn the corner towards a total of 30 years as a registry, the Vermont Cancer Registry has new ideas, a fresh perspective and looks forward with renewed energy for the future of the Vermont Cancer Registry!

#### SUSTAINING SUCCESS

Changes in federal data collection requirements occur each year with much more data being collected now compared to when the registry was founded almost thirty years ago. VCR data consistently meets or exceeds national standards for fitness for use by both NPCR and the North American Association of Central Cancer Registries (NAACCR). Vermont's data contribute to cancer prevention and control activities at the local, regional, and national level with the goal of reducing the burden of cancer among all Vermonters.

#### STORY QUOTE

"Let us not forget the reason we labor so hard to collect these data - to prevent and control cancer."

Dr. Daniel Miller, CDC Chief of Cancer Surveillance,  
November 29, 1994

#### REGISTRY CONTACT INFORMATION

(802) 651-1977  
<https://www.healthvermont.gov/health-statistics-vital-records/registries/cancer>

#### REFERENCES

Hill, Toya (1992, January 7) Sanders calls for research on cancer, Bill would pay for statewide registries. Burlington Free Press. <https://www.burlingtonfreepress.com/>.  
Saxon, Wolfgang (1994, November 29) Joanne Rathgeb is Dead at 64; Was Crusader on Cancer Issues. New York Times. <https://www.nytimes.com/1994/11/29/obituaries/joanne-rathgeb-is-dead-at-64-was-crusader-on-cancer-issues.html>.