



GUT CHECK:

YOUNG-ONSET COLORECTAL CANCER IN YOUR STATE



Colorectal cancer has quickly and quietly become a concern for young Americans.

Though it's still thought of as "an older person's disease," cases of colorectal cancer in those under 50 have increased by 51% since 1994. This has led to a drop in the median age of diagnosis from 72 to 66. While overall colorectal cancer death rates are dropping in the U.S., deaths among people younger than 55 increased 2% per year from 2007 to 2016.

"My colonoscopy was set for the beginning of May 2016, just a few weeks after my 50th birthday," said Tim Kavanagh, a colorectal cancer survivor. "I thought I was doing the right thing by having the procedure on time, but it was already too late. I was diagnosed with stage 2 rectal cancer."

The good news: there are several highly effective screening options to detect colorectal cancer early—when successful treatment is more likely—or prevent it completely, saving thousands of lives each year. But even with effective screening tests available, regulatory and policy barriers impede insurance coverage for screening.

Had Tim been able to get screened before turning 50, he likely would have been able to avoid extensive treatment.

"I endured chemo, radiation and surgery that removed 90% of my rectum. Eighteen months later, when I thought life was getting back to normal, I had a rediagnosis of the disease that put me through more rounds of chemo and radiation, a 15-hour surgery and a colostomy bag for the rest of my life," he said.

IN 2020 IN THE U.S.

- ▶ **147,950 people**
will be diagnosed with
colorectal cancer
- ▶ **53,200**
will die from the disease
- ▶ **17,930 new cases**
of those diagnosed and
3,640 deaths
are expected among people
under 50—or approximately 49
new cases and 10 deaths per day

"I thought I was doing the right thing by having the procedure on time, but it was already too late. I was diagnosed with stage 2 rectal cancer."

—TIM KAVANAGH

Until recently, the recommendation was to begin routine screening at age 50 for those at average risk. But in response to the alarming increase of cases in younger adults, the American Cancer Society (ACS) changed its guidelines to recommend screening begin at age 45. However, the U.S. Preventive Services Taskforce (USPSTF) continues to recommend screenings begin at age 50. This discrepancy creates barriers to access, since the Affordable Care Act requires health insurance plans only to cover services with an “A” or “B” rating (screening for adults ages 50-75 has an “A” rating).

Anyone under the age of 50 may have to pay out of pocket for a routine colonoscopy or other colorectal cancer screening, or miss out altogether. Without increased access to screening, thousands are at risk of their colorectal cancer or precancerous polyps being missed.

“We MUST urge the USPSTF to lower the screening age to 45 so no one else has a story like mine.”

— TIM KAVANAGH

HOW DOES YOUR STATE CHECK OUT?

Below are insights from an analysis of state coverage:

- Between 1995 and 2015, 240,915 adults ages 20-49 were diagnosed with colorectal cancer. Many of those cases could have been avoided, but access to screenings for anyone under 50 varies widely from state to state.
- 34 states have a coverage mandate for colorectal screening (Figure 1), but that does not guarantee coverage for people ages 45-49, who are recommended for routine screening by the American Cancer Society (ACS).
- Coverage mandates do not apply to Medicaid in some states.
- Some states have limited provisions for people under 50 who are deemed at-risk or symptomatic. Waiting until a person displays symptoms can lead to a late-stage diagnosis.
- Some states use ACS guidelines to determine coverage, while others use USPSTF—so your access to colorectal cancer prevention or early detection may depend on where you live.
- 37 states and the District of Columbia have adopted Medicaid expansion, while 14 have not. Expanding Medicaid will provide states with additional resources to increase screening access.

Together, these factors provide insight into the growing rate of young-onset colorectal cancer across the country. Figure 2 shows how the incidence rates in your state have grown from 1994 to 2015*.

Evidence shows a growing number of colorectal cancer cases in adults under the age of 50. Tim Kavanaugh said, “When I was first diagnosed, my medical team said this was probably in my system for a while. We MUST urge the USPSTF to lower the screening age to 45 so no one else has a story like mine.”

YOU have the power to save thousands of lives. One simple fix can expand access to at-risk individuals across the country. Together, we can *Stop Cancer Before It Stops!*®

* Based on most recent data available from the North American Association of Central Cancer Registries

What can you do to help your state?

There are steps you can take to curb the rise of colorectal cancer in your state and your community:

- 1 Join us in urging the USPSTF to lower the screening age to 45 by signing our “Dear Colleague” letter to inform fellow members of Congress about the importance of increasing screening rates to prevent or detect young-onset colorectal cancer.
- 2 Invest in education and training for health care providers in addressing young-onset colorectal cancer.

States with mandates use guidelines from the following:

- USPSTF
- ACS
- A combination of USPSTF, ACS or other medical or professional societies
- Not specified

States without mandates

The map shows the following distribution of guidelines:

- USPSTF (Green):** CA, OR, WA, HI, ME, VT, NH, MA, CT, RI, NJ, DE, VA, WV, KY, TN, AR, LA, TX, NM, CO, WY, NE, MN, ND, SD, KS, OK, TX.
- ACS (Blue):** AK, NV, UT, AZ, NM, CO, WY, NE, MN, ND, SD, KS, OK, TX, IL, IN, OH, PA, NC, SC, GA, FL.
- Combination of USPSTF, ACS or other medical or professional societies (Orange):** WA, WI, MI, IA, MO, KY, TN, AR, LA, MS, AL, GA, FL.
- Not specified (Light Green):** VT, NH, MA, CT, RI, NJ, DE, VA, WV, KY, TN, AR, LA, TX, NM, CO, WY, NE, MN, ND, SD, KS, OK, TX.
- States without mandates (Grey):** MT, ID, UT, AZ, NM, CO, WY, NE, MN, ND, SD, KS, OK, TX, MI, IA, MO, KY, TN, AR, LA, MS, AL, GA, FL.

Incidence rate per 100,000

- 8.2 - 9.6
- 9.7 - 11.1
- 11.2 - 12.6
- 12.7 - 14.3
- No data

The map shows that states like Alaska (AK) and Wyoming (WY) have the lowest incidence rates (green), while states like North Dakota (ND) and West Virginia (WV) have the highest (blue). Most states fall into the 11.2 - 12.6 range (orange). Several states, including Minnesota (MN), Kansas (KS), Maryland (MD), and Delaware (DE), are marked as having no data (grey).

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WHAT PATIENTS ARE SAYING



- ▶ **THEIR CASES ARE BEING MISSED.**
 - + Most patients meet with at least 2 physicians before receiving a diagnosis. Some see as many as 4.
 - + 40% of cases in people under 50 are caught at a late stage.
- ▶ **THEY ARE OFTEN UNAWARE OF THEIR RISK.**
 - + Many patients wait at least 6 months to seek help because they don't realize their symptoms are linked to colorectal cancer.
 - + Most patients do not know their family health history. On average, one third of young-onset cases are linked to family history, with higher rates among Alaska Natives and African Americans.
- ▶ **THEY ARE STRUGGLING.**
 - + Patients experience anxiety and/or depression through the screening and treatment process, which can delay or prevent them from seeking appropriate care.

WHAT CAREGIVERS ARE SAYING



- ▶ **PROVIDERS DO NOT ALWAYS PRESENT A CLEAR PICTURE.**
 - + Many did not discuss or ask about elevated risk based on family history.
- ▶ **THERE ARE UNEXPECTED FINANCIAL BURDENS.**
 - + Many caregivers were unaware of potential costs associated with testing, such as follow-up colonoscopies after positive non-invasive screening tests.

WHO'S LEFT BEHIND



- ▶ **SOME POPULATIONS HAVE HIGHER RISK.**
 - + Despite decreases in incidence and mortality, overall, Alaska Natives and African Americans still have higher incidence and mortality rates than their white counterparts.
- ▶ **RATES ARE CLIMBING IN HISPANIC POPULATIONS.**
 - + Colorectal cancer is now the second-most diagnosed cancer in Hispanics—and incidence rates are climbing faster than in whites.

About the Prevent Cancer Foundation

The Prevent Cancer Foundation® is the *only* U.S.-based nonprofit organization solely dedicated to cancer prevention and early detection. Our mission is saving lives across all populations through cancer prevention and early detection. Our vision is to *Stop Cancer Before It Starts!*®

Since 1985, the Foundation's work in research, education, outreach and advocacy has elevated prevention and created innovative programs to fund important research grants and fellowships, provide evidence-based information about how to prevent cancer, empower communities to implement lifesaving programs and engage policymakers and advocates to enact laws and regulations to support the needs of cancer patients and their families.