



Fred Hutchinson Cancer Research Center
CORE Family Studies
1100 Fairview Ave. N
M4-B402
P.O. Box 19024
Seattle, WA 98109-1024

Address Service Requested

Participant name
Participant address
City, State ZIP

fredhutch.org

CURES START HERE



Colorectal Research in Epidemiology
Colon Cancer Family Registry Cohort
1100 Fairview Avenue North, M4-B402, Seattle, WA 98019-1024
1-800-276-0127 • corestudies@fhcc.org • FredHutch.org/corestudies

Happy holidays to all our CORE Studies participants! It's the perfect time of year to update you with the latest edition of CORE News. This year brings fascinating stories about longevity: studies about surviving and thriving after a cancer diagnosis, as well as a personal story from a (very) long life.

In going back through our records, we found an active participant who's more than a hundred years old! Meet Gwendellyn Roberts, who's been contributing information to the CORE Studies for nearly two decades.

We also bring you summaries about two recent studies based on information you've shared over the years. Wine lovers might be cheered by learning about our research on the links between wine consumption and long-term colorectal cancer survival. And CORE Studies researchers have made an unexpected discovery about how body weight affects long-term survival. (Here's a hint: it's NOT a "lose-weight-now" finding.) You'll also get an update about returning genetic results generated in the research context.

We just can't say it enough: your continued, personal contributions to colorectal cancer research are priceless! It's quite rare for a study project to last more than two to five years. Thanks to you and your fellow participants, we've been going strong for more than twenty years. We recently submitted an application to get another 5 years of funding and are hopeful that this will not be the last time you hear from us. Again, we offer our deepest gratitude for your ongoing generosity, and wish you the best for the coming year!

Sincerely,

*Polly A. Newcomb, PhD, MPH
Principal Investigator*



Photo Credit:
Robert Hood/Fred Hutch News Service

fredhutch.org
CURES START HERE



CORE Studies Participant Gwendellyn Roberts



Photo credit: Debbie Gallagher

Last summer, CORE Studies participant Gwendellyn (Gwen) Roberts celebrated her second birthday -- of her second century of life, that is. Today, **she's 102 years old**, and we're thrilled that Ms. Roberts is still willing and able to contribute information to colorectal cancer research. Being one of the most senior people around comes with a few privileges, we've learned, during a recent phone interview with Ms. Roberts. "I tell everybody I'm one of those 'terrible twos,'" she quips, "because if I want to act like a terrible two, I can."

We first contacted Ms. Roberts back in the year 2000. Back then, we learned she was the oldest of ten children; three of her siblings have also completed the comprehensive initial interview for the CORE Studies project. In the following seventeen years, the centenarian has completed three follow-up interviews as well.

She attributes her long life to "clean living and lots of hard work," starting on the dairy farm where she lived as a child. In recent years, age has compelled Ms. Roberts to give up eating salads because raw vegetables are too hard on her digestive system, "and that breaks my heart because I've had salads all my life."

Unfortunately, cancer has also been a part of Ms. Roberts' life for quite some time. She remembers her paternal grandfather died of stomach cancer, when she was eleven years old. Cancer diagnoses and treatment were radically different in the early 20th century, because scientists knew very little about the disease. "They couldn't do anything for him," Ms. Roberts recalls. "They sent him to Chicago for radiation. What I heard when I was a little girl was that 'they burned him up inside.' People didn't talk about cancer much or say the word 'cancer'; they were just 'ill.'"

Ms. Roberts herself has been diagnosed -- and treated successfully -- for skin cancer three times. But because many others before her participated in cancer research decades ago, scientists have learned a great deal about the disease. When people affected by cancer share their family histories and personal experiences in a research study, their contributions update the current scientific understanding of the disease. With every follow-up interview, we see how cancer behaves over time, and most importantly, how the condition might be prevented.

The generosity of Gwendellyn Roberts, and people like you, is why we at the CORE Studies are immensely grateful to talk to you every few years. "Almost everyone says I'm an inspiration," Ms. Roberts notes. "They say I look like I'm in my 70s or 80s." All of you inspire us to continue our work, no matter what your age. Wishing you all long and healthy lives.

Body Weight & Life After Colorectal Cancer

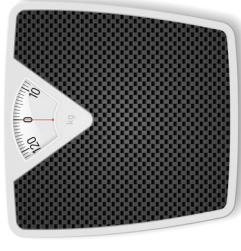
It's common for people with colorectal cancer to lose weight after being diagnosed with the disease. And health care providers often encourage cancer survivors to work hard at maintaining a healthy body weight later on. But is it possible dropping the pounds might not be such a good idea after all? A recent Fred Hutch study comes up with a surprising conclusion about the relationship between body weight and life after a colorectal cancer diagnosis.

Dr. Jonathan Kocarnik analyzed CORE Studies project data on survivors who lived for longer than five years after being diagnosed. Other studies have measured body weight changes after a colorectal cancer diagnosis, but generally checked the survivors' body mass index (BMI) only one time: either just before diagnosis or around the time of treatment. Dr. Kocarnik's team looked at participants' self-reported body weight and height at the first interview, and then five years later.

It turns out people who lost weight within five years of diagnosis were more likely to pass away, regardless of the cause of death. There was no association between weight gain and long-term survival. This seems at odds with the usual health guidelines, which recommend overweight or obese people diagnosed with cancer should lose some weight and try to keep it off after treatment. "Increasing evidence suggests that the story is not so simple once cancer has developed," says Dr. Kocarnik. "In fact, some increased adiposity [higher weight] may actually be associated with increased survival within this context."

In future studies, Dr. Kocarnik hopes his team's findings can be confirmed or expanded upon in various areas. For example, people may lose weight for a variety of reasons. Researchers still don't know if an intentional change in weight (versus weight loss due to cancer side-effects) makes a difference for long-term colorectal cancer survival. Dr. Kocarnik also would like to see if diet, exercise, or the ratio of muscle to fat affects the likelihood of survival.

To complete these in-depth studies, researchers all rely on one element: people, like the CORE Studies participants, who are willing to update researchers over long periods of time. A resource like the CORE Studies project, Dr. Kocarnik says, "is vital for 'helping cancer survivors live longer, healthier lives'."



Wine & Colorectal Cancer Survival

Photo credit: Fred Hutch File



You've probably heard reports that a glass of wine with dinner generally doesn't hurt – and it might actually help improve your health. But did you know [your contributions](#) to the CORE Studies provide some proof for that idea? An article in the medical journal **Cancer** concludes wine drinkers – not beer or liquor drinkers – appear to be more likely to survive colorectal cancer.

Drs. Amanda Phipps and Polly Newcomb examined CORE Studies data about the alcohol participants had consumed in the years before their cancer diagnoses. They traced the vital status of these CORE Studies participants between 1997 and 2007, including those who passed away between 2007 and 2013.

Alcohol consumption in general didn't seem to affect overall survival, or disease-specific survival. But consuming wine appeared to make a beneficial difference. Dr. Phipps and Dr. Newcomb found that people who drank a little more than one serving of wine per day had a 30% higher likelihood of surviving the disease, as compared to those who drank less than one drink per week. The effect of wine consumption was strongest in men and in former smokers. (Of course, any wine consumption should be done in moderation.)

As in many research projects, Dr. Phipps notes that answers from this study also bring up new questions. "[I]t also begs the question as to the possible benefits of wine consumption after colorectal cancer diagnosis," she said. "That's a question we haven't been able to address with our studies thus far, but we know the answer to that question is likely to be of great interest to colorectal cancer patients."

Findings from studies like these could influence future investigations. The conclusions from this research may direct scientists to the biological pathways that may provide more in-depth understanding of this relationship. Such future findings eventually may lead to more effective recommendations for survival after a cancer diagnosis, and reducing the risk of developing cancer in the first place.

Confirming Genetic Testing Results Done in a Research Study

Sometimes, in the course of research, a study will discover that someone carries a cancer gene mutation that increases their risk of developing cancer. With that information, the participant could be screened for the disease sooner – maybe even prevent the cancer from developing. For this reason, these results are often being returned to participants.

But there is a catch. This kind of testing for genetic mutations can be informative, but genetic testing in a research setting is not held to the same set of laboratory quality standards as testing for clinical purposes. Current guidelines strongly recommend that people who get research results have them verified in a clinical laboratory. But how often does getting a second



Some important notes: If you didn't hear from us, please know that *only some CORE Studies participants were tested*, primarily due to federal research funding constraints. Also, other CORE Studies participants chose not to donate a biospecimen sample for testing at all. Finally, some testing results were too inconclusive to meet the regulatory criteria for being returned.

opinion to confirm the research study's findings actually occur? Our staff genetic counselor Dr. Mercy Laurino posed that question in a recent study that used data from a small group of CORE Studies participants. As some of you may know, we performed some genetic testing as part of the CORE studies.

When genetic testing revealed results that might affect a person's future healthcare, we offered participants the opportunity to speak with Dr. Laurino about what those results might mean for them. Later, she recontacted participants to find out if they'd had the CORE Studies results verified by a clinical laboratory.

For the most part, only about 15% of participants followed up with a doctor or genetic counselor to verify the research project findings within 12 months of receiving results. However, the majority of participants did not, for two reasons. Some said they didn't have health insurance that would cover testing costs. Others didn't see much personal benefit, given their knowledge of their own disease and their family, in having the CORE Studies testing results verified. Laurino concludes future research will need to consider ways to help participants get past barriers that keep them from fully understanding their genetic testing results.

If you're curious about whether this type of cancer gene mutation occurs in your family, please start the process with your doctor or primary care provider. You can also find a genetic counselor in your area by visiting the National Society of Genetic Counselors' website (www.nsgc.org). Laurino's original study article appears in the 2017 Journal of Molecular Genetics & Genomic Medicine.