

# An Unexpected Turn: My Life as a Cancer Advocate

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“April is the cruelest month,” T.S. Eliot wrote in “The Waste Land,” and in 1997 it certainly was for my family. That’s when my husband Jay and I discovered he had stage IV colon cancer that had spread to his liver. He was 41, and by all appearances, perfectly healthy. Never smoked, drank only moderately, exercised, and was at a normal weight. But he’d become increasingly thin and seemed fatigued. He had been practicing law while traveling and working as a legal commentator for MSNBC. At the time, he was attending the trial of Oklahoma City bomber Terry Nichols. Our daughters were just 1 and 5, and given my demanding job on the “Today” show, we surmised that we were just overworked and a bit stressed out. But life was good. Healthy children, fulfilling careers, and the perks of a network job, including a sun-filled Park Avenue apartment, were daily proof of our good fortune.

One day, after the “Today” show was over, I got a call from our nanny, a young Irish woman named Nuala, who told me Jay was doubled over in pain and needed to see a doctor immediately. Because Jay had recently relocated from Washington, D.C., he didn’t have a doctor in New York. Come to think of it, I realized he didn’t have a doctor in Washington either. Like most healthy men his age, he hadn’t needed one...or so we thought. I arranged for him to see my doctor, a wonderful internist named Tom Nash, and met Jay at his office. Dr Nash sent us immediately to New York Hospital. That was the proverbial first day of the rest of Jay’s life—and the beginning of a 9-month nightmare.

Parts of that time are a blur: the hepatic artery pump, the initial response to the first few rounds of chemo (your CEA has dropped significantly!), the lung and brain mets, the desperate calls to an Israeli research institute, Jay’s toupee on the styrofoam wig stand, his courage, my unfounded confidence that “we would figure it out,” my efforts to protect him from the truth (there are “just some shadows” on your liver, when there were actually tumors all over it). The Saturday morning when I heard a glass shatter on the floor of our powder room and ran in to see Jay lying on the floor. The 911 call. The doctor who walked in to tell me sadly that my brave, handsome 42-year-old husband had died. The funeral, the sympathy cards, and the return to work.

I received an extraordinary education during those 9 months. Terms like “monoclonal antibody” and “anti-angiogenesis” tripped off my tongue. It had become depressingly clear that there were no real therapies for metastatic colon cancer. At that time, the only thing that could stop this disease was early detection. I decided I needed to help educate the public about the importance of screening, to try to spare other families the loss and devastation mine had suffered. And thus began my new, unexpected life as a cancer advocate.

In March 2000, with cancer activist Lilly Tartikoff and the Entertainment Industry Foundation, one of Hollywood’s leading charities, I co-founded the National Colorectal Cancer Research Alliance (NCCRA) to raise both badly-needed research dollars and awareness.

For the latter, I had the built-in bully pulpit of the “Today” show, so we decided to televise my colonoscopy. Millions of people watched the segment—from my downing the prep to Dr Ken Forde inspecting every nook and cranny of what I called (blame the drugs) my “pretty little colon.”

We forged alliances with people, organizations, and companies that could help champion our cause. “Judge Judy” Sheindlin, whose mother died of colon cancer, was one of the celebrities who lent their star power, speaking about the importance of colonoscopy. Millions of free educational brochures were placed at 25,000 pharmacy counters nationwide, thanks to a partnership with the National Association of Chain Drug Stores. We started collaborating with the Centers for Disease Control and Prevention on public service announcements urging people to get screened. In March 2004, we joined NewYork-Presbyterian Hospital/Weill Cornell Medical Center and Dr Mark Pochapin to launch The Jay Monahan Center for Gastrointestinal Health.

I heard from many people who told me they had gotten screened because they’d watched my procedure. It felt like our efforts were making an impact. But then we got the data: the University of Michigan found that my televised colonoscopy and educational outreach contributed to a sustained 19% increase in the number of colonoscopies performed nationwide. They called it “The Couric Effect” (1). That was incredibly gratifying to me, my “Today” show colleagues, and everyone who helped with our awareness efforts.

I decided to branch out beyond colorectal cancer, join with other activists, and attack cancer across the board. In 2008, eight other women and I created Stand Up To Cancer (SU2C), with the entertainment community encouraging the public to support a new collaborative model of research. “Dream Teams” of scientists from different disciplines and institutions work together to speed up the pace at which new treatments and therapies get to the patients who so desperately need them.

Stand Up’s emphasis on collaboration proved to be a smart approach. Our scientists are developing new approaches to nipping cancer in the bud, or at least managing it like a chronic disease. We now have 19 Dream Teams, and I’ve never met a smarter, more committed group of people. An international Dream Team is working on a more effective stool test for colorectal cancer. Another SU2C team has developed a tiny chip that can detect circulating tumor cells in a blood sample. This kind of progress gives me real hope that we’ll figure out even better ways to screen for this disease and that more lives will be saved.

Although colorectal cancer is still the second-leading cause of cancer death in the United States (2,3), there has been some very good news. We’ve seen the incidence drop by ~30% from 2001 to 2010 in those age 50 and older (4). The American Cancer Society credits this decline to more colonoscopy screenings, which increased from 19% in 2000 to 55% in 2010 in people age 50 to 75 (4).

To help keep this momentum going, in 2014, the National Colorectal Cancer Roundtable launched the “80% by 2018” campaign, with the goal of screening 80% of adults age 50 and older for colorectal cancer by 2018. The 80% by 2018 effort calls for an all-hands-on-deck approach to achieve this national goal, by moving individuals to action; removing policy barriers that make screening less accessible; and asking physicians, hospitals, health plans, and others to make evidence-based, systematic changes that support screening. The 80% by 2018 campaign also includes making sure people are aware that there are screening test options (5). Although I am a great believer in colonoscopy, I have to agree with Dr Sidney Winawer, who said, “The best test is the one that gets done” (6).

As positive as the trends in colorectal cancer screening, incidence, and mortality rates have been for those over 50, recent reports show (4,7–10) more people under 50 are being diagnosed with this malignancy. This news reminds me that, like Jay, many individuals never have the chance to reach the screening age of 50. They are struck by this disease in their 40s, 30s, and even 20s. Although the overall number of people under 50 with colorectal cancer is small (10), the uptick in new diagnoses in this group is troubling.

This is why, I believe, we need to focus significant attention and energy on addressing the increasing colorectal cancer incidence among younger adults. We must work together to tackle this growing threat—and to support research to answer critical questions such as:

1. Why are colorectal cancer incidence rates increasing in younger adults?
2. What can be done to stop this trend?
3. Are there risk factors we have not yet identified?
4. Do we need to focus more on screening in those with a family history?
5. Do we need to re-examine the potential risks and benefits of screening in the younger-adult population?
6. What do clinicians need to know to ensure prompt and effective diagnosis of this disease in younger people?
7. What do people under 50 need to know to protect themselves?

With a vast and diverse collaboration of advocacy organizations, professional societies, government agencies, health professionals, survivors, and family members, we have made real progress in the fight to increase colorectal cancer screening in those over 50. I hope we can all double down on our efforts. Let’s reach that 80% by 2018 goal. And together, let’s also roll up our sleeves and figure this out for our younger adults—and bring an end to what we know should be a highly preventable, treatable cancer, for everyone.

#### CONFLICT OF INTEREST

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#### REFERENCES

1. Cram P, Fendrick AM, Inadomi J *et al*. The impact of a celebrity promotional campaign on the use of colon cancer screening: the Katie Couric effect. *Arch Intern Med* 2003;163:1601–5.
2. Cancer Facts & Figures, 2016. American Cancer Society: Atlanta, GA, 2016.
3. Siegel R, Miller KD, Jemal A. Cancer statistics, 2016. *CA Cancer J Clin* 2016;66:7–30.
4. Siegel R, Desantis C, Jemal A. Colorectal cancer statistics, 2014. *CA Cancer J Clin* 2014;64:104–17.
5. National Colorectal Cancer Roundtable. 80% by 2018 campaign. <http://nccr.org/tools/80-percent-by-2018/>.
6. Winawer SJ. Screening of colorectal cancer. *Surg Oncol Clin N Am* 2005;14:699–722.
7. Siegel RL, Jemal A, Ward EM. Increase in incidence of colorectal cancer among young men and women in the United States. *Cancer Epidemiol Biomarkers Prev* 2009;18:1695–8.
8. Meyer JE, Narang T, Schnoll-Sussman FH *et al*. Increasing incidence of rectal cancer in patients aged younger than 40 years: an analysis of the surveillance, epidemiology, and end results database. *Cancer* 2010;116:4354–9.
9. Bailey CE, Hu CY, You YN *et al*. Increasing disparities in the age-related incidences of colon and rectal cancers in the United States, 1975–2010. *JAMA Surg* 2015;150:17–22.
10. Hubbard JM, Grothey A. Adolescent and young adult colorectal cancer. *J Natl Compr Canc Netw* 2013;11:1219–25.