

BEYOND BLUE

A Quarterly Update For Those In The Fight Against Colorectal Cancer

SHERYL CROW JOINS THE FIGHT!

- ☆ *A Million Miles for Colorectal Cancer*
- ☆ *Top Ten Gifts for Survivors*
- ☆ *The Affordable Care Act: What you need to know*
- ☆ *What's the Deal with Aspirin?*



Fight Colorectal Cancer demands a cure for colon and rectal cancer. We educate and support patients and caregivers, push for changes in policy that will increase and improve research and empower survivors and those touched by cancer to raise their voices against the status quo.



SHERYL CROW

Joins the Fight against Colorectal Cancer

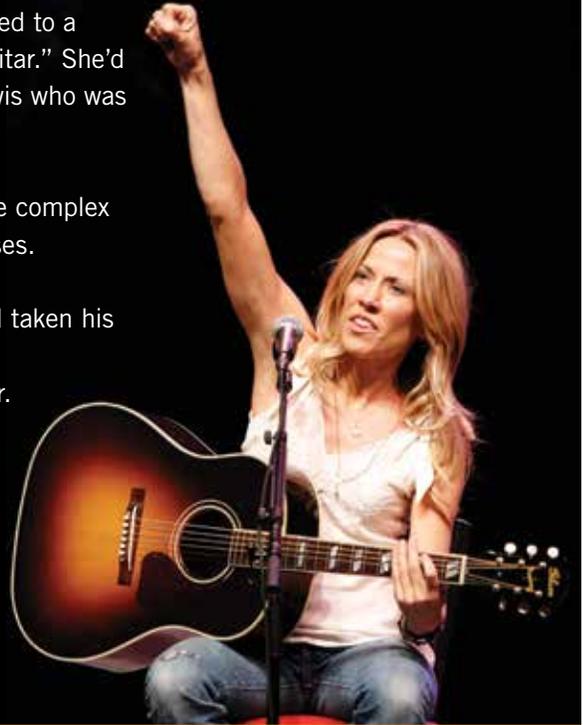
The guitar strings slowly strummed as singer-songwriter Sheryl Crow explained to a packed stadium in Springfield, Mo., "Some bring a casserole. I bring my guitar." She'd returned to her home state to play a benefit concert for her friend Drew Lewis who was battling stage IV colorectal cancer.

Sheryl, a cancer survivor herself, helped Drew and his wife Amy navigate the complex journey of cancer treatment and raised money to cover their medical expenses.

Fight Colorectal Cancer met Drew on April 1, 2013. We met a man that had taken his personal battle and turned it into an opportunity to advocate for others who would come after him. He had thousands show up for a concert in his honor.

Sadly, Drew's colorectal cancer story is not unique. Diagnosed too young, neither doctors (nor Drew) anticipated that his symptoms pointed directly to the cause - colorectal cancer. To make sure his situation didn't happen to someone else, Drew talked and blogged openly about his diagnosis, his journey and his passion for raising awareness about colon cancer.

(continued on pg. 7)



Medical Advisory Board:

Al B. Benson III, MD, FACP, Northwestern University
Nancy Baxter, MD, FRCSC, St. Michael's Hospital, University of Toronto
Richard M. Goldberg, MD, The Ohio State University Medical Center
Carolyn Grande, CRNP, AOCNP, University of Pennsylvania
Axel Grothey, MD, Mayo Clinic College of Medicine
Heather Hampel, MS, CGC, The Ohio State University Medical Center
Heinz-Joseph Lenz, MD, FACP, University of Southern California
John Marshall, MD, Georgetown University Medical Center
Howard McLeod, PharmD, Medical Director, Moffitt Cancer Center
Neal J. Meropol, MD, Case Western Reserve University
Edith Mitchell, MD, Thomas Jefferson University
Nicholas Petrelli, MD, Christiana Care Health System
Daniel J. Sargent, Ph.D., Mayo Clinic College of Medicine
Joel E. Tepper, MD, University of North Carolina School of Medicine

Board Members:

Nancy Roach, *Chair*
Alan Balch, Ph.D.
Gordon Cole
Hélène Byrnes
Andrea Kramer, *Secretary*
Indran Krishnan, MD
Dana Rye, *Treasurer*
David Wicks, Vice Chair

To receive the latest edition of **Beyond Blue** via email, please visit FightColorectalCancer.org/SignUp

The quarterly newsletter by Fight Colorectal Cancer is made possible through the generous donations of the following sponsors:



Genentech
A Member of the Roche Group

Disclaimer: The information and services provided by Fight Colorectal Cancer are for general informational purposes only. The information and services are not intended to be substitutes for professional medical advice, diagnoses, or treatment. If you are ill, or suspect that you are ill, see a doctor immediately. In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products or treatments for any condition.



A MILLION MILES FOR COLORECTAL CANCER

She walked the narrow row and found her seat. Sitting comfortably near the aisle on the United Airlines plane, she stretched out her legs and scanned the passengers to see if any congressional staff members were on the direct flight from Washington, D.C. to Portland, Oregon with her.

“I like to hassle them about our legislative agenda.” But on this flight, representatives did not join her. So she sat back, tried to make herself comfortable despite the lymphedema in her legs from past cancer treatments and waited for the flight crew to deliver the all-too-familiar flight safety instructions before takeoff.

Once the “ding” sounded, indicating portable devices were permitted for in-flight use, she read through messages from others within the research advocacy community needing her advice, review and support. It helped pass the time. This was nothing new for Fight Colorectal Cancer founder Nancy Roach. She’d traveled the familiar six-hour path from Virginia to Oregon for many years. Except this trip had one special caveat to it: *Nancy was about to fly her millionth mile.*

“I spent a lot of time in D.C. understanding how policy and advocacy made a difference and how research made a difference. I met amazing people at the Food & Drug Administration (FDA), National Cancer Institute (NCI) and other groups who showed me what could be done through policy and government action.”

- Nancy Roach, Founder of Fight Colorectal Cancer

CHANGING THE LANDSCAPE OF COLORECTAL CANCER

It was 1996 and Nancy Roach’s mother-in-law had just been diagnosed with stage II rectal cancer. Like all patients and their family members, Nancy and her mother-in-law flocked to the Internet for information and resources. It was there she met a group of survivors also looking for colon and rectal

cancer answers on an ACOR ListServ. Connections began forming and soon, members from the group realized a change needed to happen.

Empowered by their experience and discontent with colorectal cancer resources, funding and information, the group took steps to change the landscape of colorectal cancer in the United States. They founded the first nonprofit colorectal cancer group, The Colon Cancer Alliance.

While working on building the CCA, Nancy began getting involved in advocacy. Through meetings and conversations, she realized the critical need for research advocates within the political landscape.

As her understanding of the research progress grew, advocacy became her sole focus. Nancy became a loud

cont'

voice for colorectal cancer and began accepting invitations to participate in the research process.

Fueled by the need (and gap) of colorectal cancer advocates, Nancy shifted her focus to work exclusively on research advocacy. With the financial backing of three supporters, Genentech, Sanofi and Bristol Myers Squibb, she formed the Colorectal Cancer Coalition in 2005, a nonprofit focused on colorectal cancer advocacy.

OPENING THE ADVOCACY DOOR

Since its inception, the group has made a name for colorectal cancer within the medical research community, the halls of Congress and the homes of men and women across America suffering from the disease.

Renamed to Fight Colorectal Cancer in 2011, the nonprofit continues to build on the original vision of Nancy who serves as Chair of the Board: advocates creating real change in the realm of advocacy and screening. And if you ask anyone at Fight Colorectal Cancer... this is only the beginning.

WILLING TO FLY A MILLION MORE

Switching from the computer to a book of Sudoku puzzles, Nancy takes a break from the glow of her screen. It's not easy

“I've always been drawn to engaging and making a difference. And in colorectal cancer, I believe I can make a difference.”

emotion of those she advocates for.

“I got involved with regulatory advocacy, which was fascinating. It taught me how companies and research work. They invited me to their training and asked for my input. I learned that there are so many squeaky wheels in politics, if you don't have a squeaky wheel there all of the time, nothing will change.”

to relax when it comes to research advocacy. She shuffles her legs once more, trying to get comfortable for the remainder of the fight. A survivor of advanced cervical cancer, she can relate to the pain and



The strength of her mother-in-law and other friends who make up the one million colorectal cancer survivors, and the memory of close friends who've passed away, propels her to do more. She's determined to create change and make a difference. A woman who's flown a million miles for research advocacy is willing to fly a million more.

CALL-ON CONGRESS
MAKING COLORECTAL CANCER A NATIONAL PRIORITY
at Home

You can be an advocate from home!
 Join us in two ways:

BLUE STAR STATES
 We've teamed up with The Colon Cancer Alliance to make EVERY state a "Blue Star State" in March 2014. Simply get your governor to sign a state proclamation. For tools and to get started, visit FightColorectalCancer.org/BlueStarState.

BECOME AN E-ADVOCATE
 Make your voice heard from home! Learn how to become an eAdvocate at FightColorectalCancer.org/eadvocacy

LEARN MORE:
FightColorectalCancer.org/Advocacy



How the Affordable Care Act impacts Colorectal Cancer

As a colorectal cancer survivor, advocate, caregiver or family member, it is important that you understand how the Affordable Care Act (ACA) will affect access to screening. The ACA extends not only to the health insurance industry, but also to prevention and wellness programs throughout the country. Both the expansion of health coverage and the funding of prevention programs have the potential to significantly affect the screening and treatment of colorectal cancer.

COLORECTAL CANCER SCREENING

Coverage of colorectal cancer screening tests is mandated by the ACA, but you may experience some costs. Despite the federal government's attempt to provide clarifications, it is still confusing. The ACA requires that most health plans cover a range of preventive health services without any cost sharing by patients if they're recommended by the U.S. Preventive Services Task Force, this includes colorectal cancer screening & colonoscopies. But this doesn't apply to health plans that were in place before it was passed. Screening colonoscopies are fully covered by Medicare and by many private insurers, but if a polyp(s) is found and the procedure is considered diagnostic, patients may receive bills for co-insurance and some out-of-pocket costs related to anesthesia. In light of this, Fight Colorectal Cancer is pushing for better policies for screening and diagnostic procedures. In the mean time, it is important to review your health plan or speak to your benefits administrator about potential out-of-pocket costs you may incur.

PRE-EXISTING CONDITIONS

Under the ACA, no one can be denied coverage for any reason, including an existing medical condition. Insurance companies can no longer impose lifetime limits on benefits. That's a big deal for those with serious illnesses, such as colorectal cancer, or other chronic conditions requiring ongoing and/or very expensive care. As you shop for a new plan be sure to read the fine print and check for "annual" limits.

KEY DATES

The Marketplace (new health plans created by the ACA) opened on Oct. 1 and health coverage will begin Jan. 1, 2014. Open enrollment ends March 31, 2014, you must have some form of health coverage by this date. If you are uninsured and do not enroll, you will face penalties. Enrolling is not an immediate process; it may take several weeks to process and coverage may not begin until the first day of the month. For up-to-date information, follow our blog posts at FightColorectalCancer.org and call our Answer Line for help navigating the system at 1-877-427-2111.

CANCER INSURANCE CHECKLIST

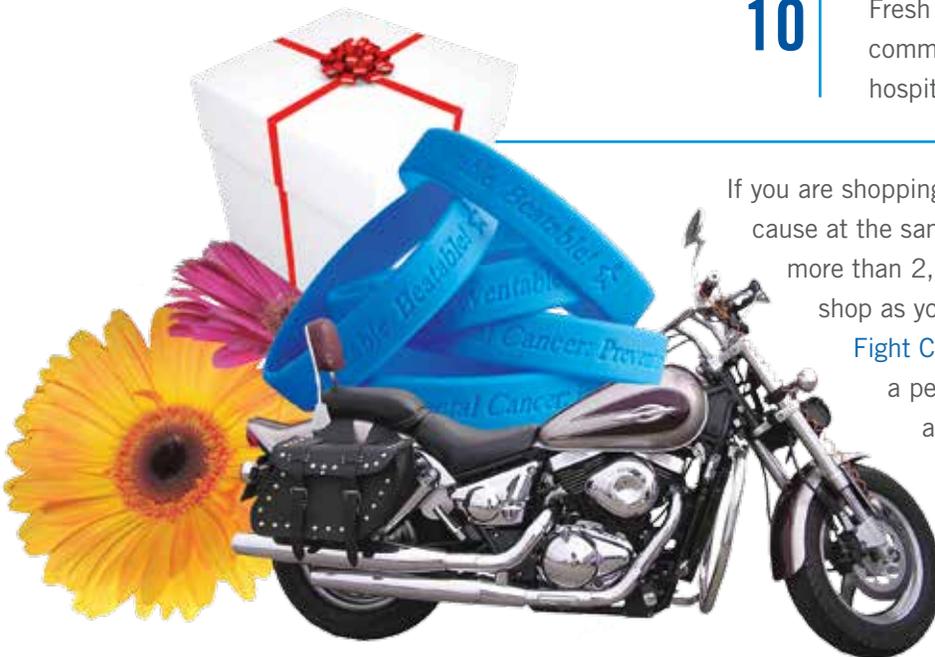
Navigating the Marketplace as a Cancer Survivor? Need help understanding how the new healthcare plans impact you?

Visit www.cancerinsurancechecklist.org to download a helpful guide today!

TOP 10 LIST

TOP TEN GIFTS FOR A CANCER SURVIVOR

- 1 | During treatments – good, healthy meals or even gift cards to restaurants. After treatments - movie gift certificates - always a good escape for me!
~Liz Dennis
- 2 | For over a year my friend has come over every week and changed the sheets on my bed, run the vacuum, cleaned up the bathrooms, washed a load of laundry and went shopping if I needed it.
~Nancy Kohr
- 3 | Gas gift cards for those who have to travel for treatments. ~Linda Meisel
- 4 | A portrait day for family pictures.
~Wendy Jane Taubinger Stanton
- 5 | My favorite gift - a ride on my buddy's Harley on a beautiful day.
~Elesa Brandenburg Dillon
- 6 | My ideal gift as a survivor would be a donation, in my name, to The Lisa Fund through Fight Colorectal Cancer! That would make my heart sing!
~Kristin Keesen
- 7 | A five-year subscription to something since that is such an important milestone to reach.
~Erica Lindsay Lee
- 8 | My favorite gift has been learning that friends and family are talking to their doctors about colorectal cancer. They are listening to my plea to get checked so we can save more lives.
~Christina Pucillo Thompson
- 9 | The best gift I got was a mentor. She's been through this and is going through it again. She listens, answers any question I may have, and gives me words of comfort and encouragement.
~Wanda Brenot Charles
- 10 | Fresh beautiful flowers with encouraging comments. A personal visit to the house (not hospital) is good too. ~Indran Krishnan



If you are shopping for a survivor and want to donate back to the cause at the same time, We-Care.com lets you do that. With more than 2,500 merchants, you can visit the online mall to shop as you normally would. The bonus? You can select [Fight Colorectal Cancer](http://FightColorectalCancer.org) as your cause of choice and a percentage of the transaction amount will be automatically donated to us.

Don't forget to check out Store.FightCRC.org. We have lots of fun colorectal cancer items to help you raise awareness and encourage the survivor in your life.

WHAT'S THE DEAL WITH ASPIRIN?



There's often a lot of discussion surrounding aspirin and the colorectal cancer patient. Certain studies have shown that taking a daily, low-dose of aspirin MAY reduce the risk of colorectal cancer. A study reported in the July 2013 *Annals of Internal Medicine*

discovered "the incidence of colorectal cancer was 20 percent lower in the aspirin group than in the placebo group" among women ages 45 years or older who took 100 mg of aspirin each day for up to 18 years.

While the study is one among many that indicate aspirin MAY reduce the risk of colorectal cancer, it's important to also remember that aspirin increases risks for other conditions like GI bleeds and peptic ulcers. Patients considering taking daily aspirin need to weigh the risks and benefits with a healthcare professional before use.

Disclosure: Fight Colorectal Cancer has accepted funding for projects and educational programs from Bayer, a producer of aspirin, in the form of unrestricted educational grants. Fight Colorectal Cancer has ultimate authority over content.

Source: N.R. Cook, I.M. Lee, S.M. Zhang, M.V. Moorthy, and J.E. Buring. Alternate-Day, Low-Dose Aspirin and Cancer Risk: Long-Term Observational

Follow-up of a Randomized Trial. Annals of Internal Medicine 2013 July 16;159(2):77-85.



(continued from pg. 2)

Drew passed just a little over a month after the concert but his legacy lives on and the power of a supportive community rallied around one man's journey continues to grow. Thousands across the country still draw encouragement from Drew's Facebook page where he openly shared journal entries and photos. Since his passing, his wife Amy continues to write about being a caregiver and a widow.

To honor Drew and those lost to this dreadful cancer, Fight Colorectal Cancer continues to keep pushing for change and ultimately, for a cure. We want others to encourage the people they love to be screened. Drew showed us the power of engaging in a dialogue wherever we can.

If you are in the fight, we need you to join us! We believe that together, we can make a difference. Let's continue what Drew and Amy started. Let's make today matter. Join the movement. Fight with us today. FightColorectalCancer.org/OneMillionStrong

Watch *Sheryl Crow* become part of One Million Strong
www.FightColorectalCancer.org/drew-lewis-story

Drew Lewis and wife Amy Blansit Lewis



Living Legacy

Fight Colorectal Cancer received donations in honor or memory of the individuals listed below from May 1 through July 31, 2013. Their living legacy, through these generous donations, keeps the fight alive - for all of us. Thank you.

In Honor Of:

Rick Billman
Jim Chesnutt
John Fuehrer
Mikey Mifflin's Grandpa
Rose Hausmann
Andrea Kramer
Robert Kramer
Rob and Dureen Kraybill

Brianna Christine Mitchell
Christopher James Palmatier
Nancy Roach
Dana Rye
Doug Squire
Lauren Squire

In Memory Of:

Gene Campbell
Sandy Connolly
Rebecca Dague
Lisa Dubow
Eli Pick
Judith Franz
Curt Hohn
Michael Krulikowski
Cliff Merritt
Kate Murphy

Christine Niemi
Jessica Lynn Nixon
Karen J. Poth
Barbara Schifter
Carole Siepielski
Pat Steer
Richard L. Tade
Becky Thompson
Ken Weiner
Douglas Wilson

Upcoming Patient Webinars:

- Surgery for colon and rectal cancer
- Where to begin after a colorectal cancer diagnosis
- Research & treatment news from the Gastrointestinal Cancer Symposium
- Healthy lifestyle choices that may reduce your risk of a cancer recurrence

Register online today:

FightColorectalCancer.org/webinars

Make a donation to honor or memorialize your loved one. Any amount will help.

Visit FightColorectalCancer.org/Donate or call (703) 548-1225.

HAVE QUESTIONS? WE HAVE ANSWERS.

Our toll-free Answer Line is a way patients, caregivers and others curious about colorectal cancer can find answers.

1-877-427-2111

FightColorectalCancer.org/AnswerLine



INTRODUCING:

BEYOND BLUE

Beyond Blue is our new and improved quarterly patient newsletter. To read past editions, receive more copies or view electronically, please visit: FightColorectalCancer.org/BeyondBlue