C3 COLORECTAL® CANCER COALITION

2009 ANNUAL REPORT



C3's Mission

To win the fight against colorectal cancer through research, empowerment and access.

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Dear Friends,



Four years ago, the idea of a national screening program for the un- and under-insured was just a dream.

The Food and Drug Administration (FDA) and Medicare frequently made decisions about colorectal cancer coverage and drugs without input from patients. And Congress was largely unaware of how many butts were uncovered.

Not anymore. In 2005, C3: Colorectal Cancer Coalition (C3) was formed, stepping up to give a voice to the individuals and families struggling with colorectal cancer. We help them tell their stories and put human faces to impersonal statistics, affecting dramatic change along the way.

Today, C3 remains dedicated to providing focus, infrastructure and support for the growing colorectal cancer advocacy movement. Through its efforts, C3 has quickly become recognized as a leading national patient advocacy organization.

C3's growth and success have been possible only because of the generosity and passion of each and every one of our donors, advocates and, of course, the frontline fighters – the individuals and families who are directly affected by colorectal cancer.

We see that passion every day at C3 in ...

- ... the researchers whose work we support
- ... the families who unite to keep a loved one alive and fighting
- ... the individuals who raise funds to fuel our fight
- ... the faces of the advocates many of them actively fighting cancer who bring their personal passion to C3's efforts.

C3 brings the voice of patients to the highest levels—to the President, the halls of Congress, and leading medical research centers—as well as to offices of local physicians and the kitchen tables of patients and families across the United States.

We make that voice heard by recruiting, training and empowering grassroots and research advocates who work hand-in-hand with C3 to share their personal experiences and focus their passion to change the future.

C3 knows that a national commitment to better prevention, screening and treatment of colorectal cancer will one day make colorectal cancer no more deadly than the common cold.

We know that you share our vision, as do our dedicated advocates, and the more than one million people in the U.S. with a history of colorectal cancer. We share this vision with the 150,000 Americans who will be diagnosed in 2010, and the 50,000 who will not survive next year. Our promise to all of them: We will work in your honor and in your memory, to rid the world of colorectal cancer.

Noted anthropologist Margaret Mead said it best: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has." Thank you for your past support. We look forward to working with you in the future to continue changing the world of colorectal cancer.

Sincerely,

Carlea Bauman, President C3: Colorectal Cancer Coalition

Carlea Bauman



Renowned Expert Blogs For C3 Website

It isn't every day that an internationally recognized cancer expert is available to answer questions and respond to comments on a public website, but C3 has arranged for exactly that with the addition of a blog by Dr. Heinz-Josef Lenz. Along with being a member of the C3 Medical Review Network, Dr. Lenz is a Professor of Medicine in the University of Southern California (USC) Departments of Medicine and Preventive Medicine. the Scientific Director of the Cancer Genetics Unit, the Director of the Gastrointestinal Oncology Program, and the Co-Director of the Colorectal Center at the USC/Norris Comprehensive Cancer Center.



Education & Awareness

C3 is dedicated to bringing the message, loud and clear, to the public and to people living with colon or rectal cancer that colorectal cancer can be prevented, detected early enough to be cured, and treated successfully even in later stages.

C3 serves people coping with colorectal cancer—patients, family members, and loved ones. They need access to timely, pertinent and medically reviewed information about colorectal cancer so they can work with their doctors to make the best possible health care decisions.

C3 also serves the people working to change the future of colorectal cancer—advocates, health care providers, researchers, and policy makers. They need to know what's happening in the world of colorectal cancer advocacy, and what they can do to make a difference.

To accomplish these goals, C3 provides information tiered to all levels of complexity—from basic, clear facts for those just learning about the disease, to detailed descriptions of state-of-the-art treatment protocols, to research findings just emerging at scientific meetings, to policy issues of the day.

To make this information easily accessible 24/7, we use a variety of media:

- Frequent news posts, plus monthly email updates
- Our continuously updated website
- Printed newsletters mailed three times a year
- A Toll-free Answer Line, so patients can talk with experienced C3 associates to get answers to their colorectal cancer questions

The Centers for Disease
Control reports that as
many as 60% of deaths from
colorectal cancer could
be prevented if everyone
age 50 and older were
screened regularly.

Research Empowerment Access









Answer Line

Since March 2008, C3's Answer Line (877-4CRC-111) has personally helped more than 1,000 callers—patients, caregivers and family members. Kim Ryan, C3's Director of Patient Information Services, talks with more than 50 callers a month, fielding questions ranging from general inquiries about colorectal cancer to specific queries about diagnosis and treatment options. Callers can also get reliable and practical information about possible clinical trials—for patients with early as well as later stages of colorectal cancer.

Website

C3's website (www.FightColorectalCancer.org) receives more than 20,000 unique visitors each month. It is continually expanding, and at this time provides more than 1,000 pages of the latest patient-focused and medically reviewed information for patients, survivors and healthcare professionals.

Kate Murphy, C3's Director of Research Communication and a 25-year survivor of Lynch Syndrome colorectal cancer, brings her personal interest and wide clinical knowledge in both research and basic patient care and comfort to the C3 website. In addition to frequent updates of breaking colorectal cancer news, Kate produces a weekly roundup of pertinent colorectal cancer news. She and other C3 staff also report from major cancer conferences. All reports are filed and searchable by topic on C3's website. Readers can also subscribe and have the C3 medical and/or policy news delivered directly via email or news reader application.

In 2009, C3 added a blog by Dr. Heinz-Josef Lenz, a member of C3's Medical Review Network. Dr. Lenz is a nationally recognized expert in both clinical care and basic research. His blog exchanges with patients show both his excitement about emerging research discoveries and his warm, practical suggestions for day-to-day concerns of colorectal cancer patients.

C3's newsletter: *Momentum*

C3 publishes *Momentum*, a free newsletter sent to the entire C3 constituency three times a year. The newsletter features stories about people: the researchers testing new treatment options, the people with cancer who continue to exercise and stay healthy, and the C3 advocates who raise their voices to influence the laws and regulations affecting colorectal cancer patients. In addition, C3 produces a minimum of 12 e-newsletters throughout the year. These online newsletters provide a roundup of breaking news that affect colorectal cancer patients, as well as valuable news and information about C3's activities.

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2009 Lisa Fund Grant Recipient

In 2009, the second Lisa Fund research grant was awarded to Dr. Jeffrey Chou of the Fred Hutchinson Cancer Research Center in Seattle. Dr. Chou will study ways to make colorectal cancer stem cells more vulnerable to the body's own immune system.

The Lisa Fund is named for its founder, Lisa Dubow, who passed away in 2007 after a nine-year battle against colorectal cancer. Lisa's dream was to support young researchers looking for new ways to treat advanced colorectal cancer. Lisa's dream lives on, thanks to the generosity of our donors.

Photo: Dr. Jeffrey Chou received his award with Former C3 Board Member Andy Giusti, Ph.D; Lisa Dubow's son, Sean Twersky; and Dr. Raymond Dubois of the American Association of Cancer Research (AACR).



Research

TEN YEARS AGO, colorectal cancer was very much the cancer that no one spoke about. Too often, people at risk didn't even know they were at risk because family members were reluctant to use the words colon or rectal.

Ten years ago, Medicare didn't cover screening colonoscopies, and screening wasn't routinely offered as part of preventive care. Thus, too many patients were diagnosed late, when treatment is less effective. And back then, there were only two chemotherapy drugs available for treatment.

Today, research has proven that routine screening after age 50 saves lives and dollars by detecting precancerous polyps. Colorectal cancer can be prevented.

Today, when patients are screened and diagnosed at the earliest stage, about 90% can be cured with surgery alone. Colorectal cancer can be cured.

Today, patients with more advanced cancers have numerous treatment choices, including targeted biologic therapies, advanced surgical techniques and interventional radiology. Some people diagnosed with stage IV colorectal cancer can be cured, and those who cannot are living longer than ever before.

Research will bring us a low-cost accurate screening test, personalized treatment, curative treatment for stage IV disease, and better ways to cope with treatment side effects and improve quality of life during treatment.

Today, research is finding biomarkers to predict which medicines will help which patients, new molecular targets to attack and treatments to do it with, and tests to help personalize treatment. Our challenge is to translate this research into safe and effective treatments for patients.

C3's staff and research advocates are a well-known, respected voice at the National Cancer Institute (NCI), FDA, and major colorectal cancer research centers across the United States — always speaking on behalf of colorectal cancer patients.

Research Empowerment Access



Advocate
Pamela McAllister
Serves on
American Cancer
Society Screening
Panel

Long-time C3 research advocate Pamela McAllister, Ph.D, served on a national panel of the American Cancer Society (ACS) that, after reviewing the latest research, updated ACS screening recommendations for colorectal cancer.

2009 Research Activities Research Regulation

In the world of research, there are many vital behind-the-scenes regulatory and policy issues that are invisible, but directly affect colorectal cancer patients. In 2009, C3 staff and research advocates:

- Continued efforts to improve the clinical research enterprise through the NCI Clinical Trials and Translational Research Advisory Committee; the FDA-Duke Clinical Trials Transformation Initiative; NCI's Gastrointestinal Steering Committee and associated task forces; and Brookings Institute Conference on Clinical Cancer Research
- Supported National Institute of Health (NIH) and FDA efforts to improve the transparency and quality of data reported in clinical trials
- Provided comment to FDA Advisory Committee meetings about the use of diagnostics for personalized cancer treatment and sedation during colonoscopies
- Worked with the Centers for Medicare and Medicaid Services and key research organizations to quickly integrate KRAS research findings into clinical practice
- Continued to work with the NIH and NCI to ensure its data system accurately tracks colorectal cancer research spending—a key to future public research funding

Research Advocates

C3 works with and trains research advocates who sit on key academic and government committees that regulate, fund or oversee research, to improve their ability to effectively participate in the research process and best provide the patient's perspective during the design of clinical trials. In 2009, research advocates brought the patient's perspective to:

- The Food and Drug Administration
- National Cancer Institute and research groups funded by NCI
- Institutional Review and Data Safety Monitoring Boards overseeing clinical trials

In addition, C3 advocates are working with NCI to define the role of research advocates across the spectrum of NCI activities, and develop appropriate training and support mechanisms for the advocates.

The Lisa Fund

Lisa Dubow, a C3 founder, credited cutting-edge research and clinical trials for her nine-year survival with stage IV colorectal cancer. Prior to her death in 2007, the C3 Lisa Fund was established specifically to support research on late-stage colorectal cancer treatments. Fully 100% of every donation to the Lisa Fund goes directly towards research. C3 works in conjunction with the American Association for Cancer Research (AACR) to administer the grant to a promising young researcher.



Former C3 Director of Policy Receives National Honor

Former C3 Director of Policy Joe Arite was honored for his work during his tenure at C3, receiving the Cancer Prevention Laurel for Advocacy during a ceremony in April of 2009 at the National Dialogue for Action in Baltimore, MD. The Prevent Cancer Foundation created the **Cancer Prevention Laurel** to recognize and celebrate innovators and leaders in the fight against colorectal cancer.

The Prevent Cancer
Foundation recognized
Joe for his "dedication and
work as Director of Policy
at the Colorectal Cancer
Coalition and manager
of its grassroots action
committee," also noting
his role in C3's Call-On
Congress, Congressional
Butt-In and the Cover Your
Butt campaign.



Policy & Advocacy

WHAT INSPIRES PEOPLE TO DEDICATE THEIR TIME AND TALENTS in the fight against colorectal cancer? In C3's experience, the stimulus is twofold:

- Passion: When a personal connection makes the statistics suddenly all too real
- Empowerment: When a person receives the skills, tools, knowledge and peer support to transform their actions from well-intentioned to powerful

C3's goal is to provide our grassroots advocates with the tools they need to constantly, loudly and effectively advocate for both funding and policies—the laws, regulations, and priorities in both the public and private sectors—that drive the nation's prevention, detection, research and treatment of colorectal cancer.

In the four years since its founding, C3 has emerged as one of the most respected colorectal cancer advocacy organizations in the U.S. by:

- Empowering our national network of grassroots advocates so they can mobilize at a moment's notice
- Collaborating with like-minded coalitions
- Strategically engaging C3 advocates and staff in all 50 states and with the federal government to lobby for increased funding, research, screening and treatment
- "... There's no reason we shouldn't be catching diseases like breast cancer and colon cancer before they get worse. It saves money, and it saves lives."
- President Barack Obamabefore a joint session ofCongress on September 9, 2009



Grassroots Advocacy

Over the past three years, C3 has trained nearly 150 grassroots advocates. C3 teaches how to effectively bring personal stories and passion to key legislators and policy-makers at the national, state, and community levels. C3 regularly supplies the C3 advocate network with new tools and up-to-the-minute information to make their actions more effective.

Call-On Congress

C3 trained 65 colorectal cancer advocates—patients, survivors, families, and caregivers—at the 2009 Call-on Congress. Many had never been to Washington, D.C., let alone lobbied Congress. At the training, C3 staff, advocacy experts and a Member of Congress reviewed the ins and outs of effective lobbying. Physicians also spoke on issues related to treatment and research funding. On the last day, the advocates flooded the halls of Congress in their Cover Your Butt t-shirts, holding more than 80 face-to-face meetings with Members of Congress and their staff.

According to the Centers for Disease Control, when colorectal cancer is found early and treated, the five-year relative survival rate is about 90%. Unfortunately, because screening rates are low, less than 40% of colorectal cancers are found early.



Congressional Butt-In

After traveling to our nation's capitol, C3's friends from across the nation continued to make their voices heard within Congress. C3's annual Congressional Butt-in phone blitz generated 3,000 calls on one day (an increase of 33% over 2008) to Congressional offices, urging support of colorectal cancer screening coverage.

The advocates' personal visits and phone calls played a vital role in advancing legislation that will create a national screening and treatment program for colorectal cancer. In the weeks following C3's Call-on Congress and Congressional Butt-In, more than 40 Representatives signed on to sponsor H.R. 1189, The Colorectal Cancer Prevention, Early Detection and Treatment Act.

Collaboration

C3 collaborates with multiple coalitions to bring the patient's voice to every table that matters. C3 works with groups such as the National Colorectal Cancer Roundtable, Cancer Leadership Council, One Voice Against Cancer, Alliance for a Stronger FDA, and the Partnership to Improve Patient Care.

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Action Alerts: Rallying the Troops

Grassroots action is the key to attracting widespread attention and creating the momentum necessary to move colorectal cancer prevention and treatment forward. To this end. C3 notifies advocates and supporters of key Congressional actions with simple instructions on what individuals can do and when they should do it to increase effectiveness.

Several times during the fight to gain support for H.R. 1189, C3 used action alerts to rally the troops and add dozens of cosponsors to the bill.

Policy Actions in 2009

- C3 worked with Congressional leaders to draft and introduce legislation creating a National Colorectal Cancer Screening Program for low-income, under- and uninsured people aged 50 to 64. With bipartisan sponsorship, the Colorectal Cancer Prevention, Early Detection, and Treatment Act (H.R. 1189) would create a program modeled after the national breast and cervical cancer screening programs
- C3 supported the House "Coverage Act," which would require private insurers to cover colorectal cancer screening
- C3 advocated for, and saw passage of a resolution in the U.S. House of Representatives urging the federal government to make fighting colorectal cancer a priority and recognizing the tenth anniversary of Colorectal Cancer Awareness Month

According to a Lewin Group study, if H.R. 1189 passed, increased screening of pre-Medicare citizens (age 50 to 64) could save Medicare at least \$13 billion. The earlier the screenings start, the greater the savings to Medicare.

- To reinvigorate the war on cancer, C3 worked with sponsors Sen. Edward Kennedy (D-MA) and Kay Bailey Hutchinson (R-TX) on the 21st Century Cancer ALERT Act (Access to Life-Saving Early Detection, Research, and
- C3 endorsed The National Cancer Fund Act to increase NCI funding which has decreased 16% since 2003 (adjusted for inflation)
- C3 worked with Defense Appropriations Committee leadership in both the House and Senate to establish a new Peer Reviewed Cancer Research program within the Department of Defense that will focus on colorectal cancer research
- During the health care reform debate, C3 staff and advocates worked with both Congress and the Administration on provisions that impact colorectal cancer patients, such as elimination of pre-existing condition exclusions; protections from annual and lifetime insurance limits; and increased screening coverage

Fueling the Fight Against Colorectal Cancer

www.FightColorectalCancer.org/donate

IN 2009, AN ESTIMATED 150,000 MEN AND WOMEN IN THE U.S. WILL BE DIAGNOSED WITH COLORECTAL CANCER.

Prevention, early diagnosis, and personalized treatments will save lives and dollars. C3 staff and advocates work every day of the year to make that happen—and the generous support of our donors provides the fuel that make our fight possible. C3 runs a lean, efficient operation so that every dollar invested by our donors results in action and impact.

C3 offers a variety of ways for people to contribute financially.

Individual Gifts

Individual donations ensure C3's ongoing financial strength and ability to expand efforts in research, policy and education & awareness. Donations can be designated for a specific program.

Memorial and Tribute Gifts

Memorial gifts, in honor of individuals who lost their personal battle, are a powerful way to keep their spirit alive. Tribute gifts celebrate and support individuals currently fighting and surviving this deadly disease. Many gifts honor a birthday or anniversary. C3 recognizes those honored and memorialized in each issue of its newsletter. *Momentum*.

Lisa Fund Donations

The C3 Lisa Fund provides an annual grant to a researcher working on treatments for late-stage colorectal cancer. 100% of every donation to the Lisa Fund goes directly to the research grant, which is administered by C3 and the American Association for Cancer Research. More information about the Lisa Fund grants can be found at www.FightColorectalCancer.org/LisaFund.

Workplace Giving

Many employees, in both the public and private sectors, can give to chosen charities through convenient payroll deduction. Employees of the federal government and members of the military can designate C3 through the Combined Federal Campaign (CFC #78265) and nongovernment employees can designate C3 through their charitable employee giving program. C3 is a proud member of Community Health Charities - National Capital Area. Many companies also match their employees' charitable gifts, effectively doubling or tripling your contribution. Individuals should ask their human resources office about its matching program.

Corporate Sponsors

Corporations and foundations generously fund C3's work through program grants and event sponsorship. These grants and sponsorships play a major role in C3's ability to continue our efforts in the fight against colorectal cancer.

Individual Sponsorship Efforts

Our supporters are creative. One 13 year-old girl honored her neighbor by asking for C3 donations in lieu of birthday presents. A town held a walkathon to show support for a beloved neighbor. C3's website makes it easy for supporters to share individual stories, honor loved ones, and give friends and family an easy and effective online way to express their support. Personal Fundraising Pages can be viewed or created at http://advocacy.fightcrc.org/personal

Planned Giving

Planned gifts provide possible tax benefits for you, and predictable long-term funding for C3. Donors can either bequeath money or assets to C3 at their death, or set up an investment fund so the donor receives benefits during his/ her life and then bequeaths remaining funds to C3. Planned giving is future funding, ensuring C3's long life.

Questions? Contact Ben Basloe at (703) 548-1225 x17 or Ben.Basloe@FightColorectalCancer.org.

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Joy Zigo

omission.

C3 tried very hard to include the name of every donor but unfortunately we know that mistakes do occur. Therefore, if we left out your name we are

truly sorry and ask that

you make us aware of the

Michael Zoosman



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C3 ANNUAL REPORT 2009

2008/2009 Financial Highlights

Audited Statement of Activities for year ending June 30, 2009

	UNRESTRICTED	TEMPORARILY RESTRICTED	TOTAL
REVENUES			
Contributions	\$545,895	\$400,000	\$945,895
Product Sales	36,659		36,659
Events	7,800		7,800
Interest Income	2,840		2,840
Net assets released from restriction: Satisfaction of program accomplishment	362,543	(362,543)	
TOTAL REVENUES	\$955,737	\$37,457	\$993,194

EXPENSES			
Program Services			
Awareness & Education	372,038		372,038
Policy & Advocacy	230,213		230,213
Research	111,834		111,834
Total Program Expenses	\$714,085		\$714,085
Supporting Services			
Fundraising	70,385		70,385
Management & General	80,444		80,444
Total Supporting Expenses	\$150,829		\$150,829
TOTAL EXPENSES	\$864,914		\$864,914
CHANGE IN NET ASSETS	\$90,823	\$37,457	\$128,280
NET ASSETS, BEGINNING OF THE YEAR	385,782	10,291	396,073
NET ASSETS, END OF YEAR	\$476,605	\$47,748	\$524,353



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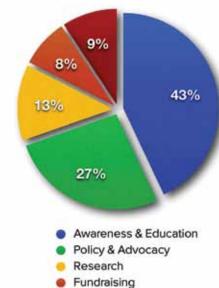
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