

One Person Can Make A Difference

March is Colorectal Cancer Awareness Month. Even though we are making progress in treating this disease, there is much that we, as individuals, can do. Many people still need to know about the importance of being screened. Too little information reaches the people who need it.

In this issue, we are highlighting stories of people who have made a difference: Mary Bakke, has been honored by Blue Cross/Blue Shield of Minnesota as a Champion of Health, members of ACE and health professionals have offered their stories and collaborated in a book written by Carol Larson, *Positive Options For Colorectal Cancer*, and Jeff Smedsrud has inspired other cancer survivors by running a marathon in Antarctica. Behind the scenes, Jane Nielsen has devoted long hours to being president of ACE for more than two years, and Cindy Iverson, Director of Development of the Minnesota Colon and Rectal Foundation has linked ACE to other local and national organizations. In 2004, Cindy received the Cancer Prevention Laurel for Dedication to Advocacy.

Is there a secret to overcoming cancer? So far, we have established these clues:

1. Pay attention to what your body is telling you and heed those warning signs.
2. Do not delay in getting appropriate testing and screening.
3. Find doctors and nurses who will give you excellent care. Seek a second opinion if you are not satisfied.

Take an active part in your recovery. Become informed. Practice self-advocacy. Use your skills to spread the word to others and offer your support. You can make a difference.

Many Thanks... To ACE President Jane Nielsen who along with Anna Leininger, Genetic Counselor from the Minnesota Colorectal Cancer Initiative and Cindy Iverson, Director of Development of the Minnesota Colon and Rectal Foundation, spoke to the staff of Colon and Rectal Surgery Associates, Ltd., on January 12th, about the "Ins and Outs of Colorectal Cancer".

the ADVOCATE

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Volunteer Takes Pay it Forward Idea to Heart

At age 45, Mary Bakke was diagnosed with colorectal cancer. Her ensuing treatment and recovery period was a long and tedious one. During this time, Mary began beading as a therapeutic outlet.

Several years later, Mary became a charter member of ACE. When the ACE'ers came together, they wanted to establish a symbol for colorectal cancer, but wanted to avoid the now seemingly endless array of ribbons attached to causes. Mary suggested they could create a beaded bracelet instead that could be handed out at events to remind others to get their colorectal screening. Mary and the group seized on the idea of a very popular movie of the time. Not only would they encourage others to wear the bracelet until they were screened, they would ask the wearer to pass the bracelet along once they had been screened to another individual they knew who should do the same.

In 2003, the Cancer Research and Prevention Foundation (CRPF), the organization behind the establishment of March being named Colorectal Cancer Awareness Month, was looking to establish a national symbol for the disease. Being in town for the planning of the Colossal

Colon event, the group was introduced to the ACE bracelet. With the wholehearted support of Mary and the ACE group, the CRPF adopted the concept and introduced it in March of 2003. The CRPF contacted only their 50 collaborating partners about the launch of the bracelet, with the hopes of distributing 10,000 during the March Awareness Month campaign.

To their great delight and surprise, the bracelet, now named the Buddy Bracelet, and its accompanying message of support, was an overwhelming winner. The organization distributed 50,000 bracelets in approximately six weeks when it had to suspend its effort due to lack of adequate funding. Groups from all



Mary Bakke, Julie Weaver and Jane Nielsen of ACE, volunteer their time and talents at the Minnesota Colon and Rectal Foundation booth at the Minneapolis Women's Expo, January 14, 15 and 16 at the Minneapolis Convention Center. Thanks to all who came by to visit and pick up some information about colorectal cancer - as well as the new Buddy Bracelet!

over the country ordered the bracelet and news organizations began to report on the campaign. The CRPF is producing 250,000 bracelets for the 2005 March Awareness month effort, and is developing a special outreach effort to members of Congress.

Mary has become a shining example of how a seemingly small idea can greatly impact an effort. She continues to be an active member of ACE, makes presentations on that group's behalf and co-facilitates the monthly colorectal cancer support group at North Memorial Hospital, the only dedicated colorectal cancer support group in the Twin Cities.

For all these efforts, Mary has been chosen as a Blue Cross Blue Shield of Minnesota Champion of Health. Mary, and other outstanding individuals, are being honored for going above and beyond to improve the health of their community. During the January 12th meeting of the support group, Mary was presented a plaque along with a \$500 check to be used to continue ACE's work in Minnesota. On March 5th, Mary and her fellow honorees will be celebrated at a special dinner. We hope you will join us in congratulating and thanking Mary for her hard work, keen insight and very caring support of those going through the colorectal cancer journey.



Our Mission Statement

Advocates for Colorectal Education is a survivor group striving to reduce colorectal disease incidence and mortality by advocating for early education, surveillance and patient support.

Survivor's Story by Carol Ann Larson

Six years ago, on the way to a Christmas party, I asked my husband Dave to drive me to an Urgent Care facility. I was looking out the window thinking how beautiful Minnesota was in the winter. Some ancient wisdom was telling me if I wanted to continue to live in this world of magical seasons, I needed to check out some suspicious physical signs I had been ignoring. I had been tired lately, but I was a high school teacher and it was not unusual to be tired before winter vacation. However, I also noticed minor traces of blood coming from my rectum. I knew this was a warning signal alerting me to the fact I needed help. This knowledge saved my life.

Four days later, three polyps were removed from my rectum during a colonoscopy. When a biopsy revealed they were malignant, I was referred to Dr. Frederick Nemer, from Colon and Rectal Surgeons, Ltd. He conscientiously watched over me for the next two months. In March, Dr. Charles Finne III, from the same firm, found evidence during a rectal ultrasound test that cancer had invaded my lymph nodes. It was invisible to the naked eye. If these doctors had not been so vigilant, my cancer would have gone on undetected.

The rest is history. I was scheduled for radiation and surgery and was referred to Dr. Sborov, an outstanding oncologist, for chemotherapy treatments. For the next nine months I was taught to do everything I could do to become healthy again and to take an active part in my medical treatment. A temporary ileostomy became a permanent one, due to radiation damage—a rare occurrence. Two enterostomal nurses, Vicki Haugen and Julie Powell, guided me through that ordeal.

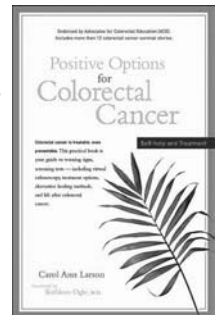
Now I am considered a cancer “survivor” like millions of others before me.

Part of my recovery has been to learn that I could not have done it alone. My family helped me go through this experience each in their own separate ways. My brother let me lean on him



and my husband took me to my medical appointments. My daughters became my caregivers at times and kept my spirits high. My friends became my lifelines with their letters, phone calls, and concern. My faith in God helped to carry me through.

Two years later, when I recovered from this experience, I was contacted by a group of people from ACE, (Advocates for Colorectal Education). They helped me realize the importance of passing on to others what we learn from our experiences. I joined a writers' group and channeled my emotions into writing a book. This February, the book, called *Positive Options for Colorectal Cancer*, will be published by Hunter House. It includes more than 12 cancer survival stories and includes questions asked by patients and answered by doctors.



Every year we are discovering new ways to counteract cancer and some day, hopefully, we can put this disease to rest. Until then, screening, education, information, and the help we can give to one another are the best cancer deterrents we currently have available. I am living proof that the system works.

Reflections From Our President

Healthy Curiosity



From my earliest recollection, I was curious about the human body. How did it work? Why were people different sizes and colors? Why did some die while others lived?

I had lots of questions, and a lifetime to find the answers.

As a curious 7-year-old, I discovered the human anatomy section of the local library. Thankfully, it was along the bottom shelf of adult books in a dark corner where I could look at pictures without embarrassment. Even though I could not read all the words, it satisfied my curiosity, and I thought I had things figured out.

As a curious teenager, I painfully learned that not everything I “knew” was accurate. My peers were amused and I was embarrassed that my assumptions were incorrect. I knew medical terminology, but little application. To put it bluntly, I was not street-smart. I wondered why words my classmates used never appeared in textbooks.

As a curious student nurse in an inner-city hospital, I observed contrasting differences in health care delivery. Celebrities were given their own room and a private-duty nurse. Welfare patients were on 20-bed wards and shared two nurses. The insured had more diagnostic testing, while those economically challenged accepted what others decided without benefit of tests. They simply didn’t know what questions to ask. I learned I had to ask for them.

As a graduate nurse, I overcame my fear of approaching doctors, and used my curiosity to advocate for my patients. Sometimes my patients wanted to know about treatment alternatives. Sometimes I was my patient’s voice when they were on life support. Sometimes I was the catalyst for families and physicians to discuss end-of-life issues.

Throughout the decades, I did not anticipate how I would apply these lessons to my own health care. I could not have guessed that my curiosity would ultimately save my life.

In 1993, after my daughter entered college and my parents celebrated their 50th wedding anniversary, I wondered about very subtle changes in my bowel habits. I could no longer attribute them to diet or stress, so I mentioned it to my doctor during a routine ob/gyn exam. A colon screening was not ordered, but other diagnostic tests came back normal.

By early 1994, not satisfied that we got to the bottom of my problem (or aware of what a pun that would be later), I sought a second opinion. A very wise general practitioner considered my family history and suggested a “baseline” colonoscopy. It was not an easy exam, for I had a sleeping giant growing in my sigmoid. Adenocarcinoma, and eight inches of surrounding tissue, were resected days later.

Now, as a thankful survivor, curiosity about cancer and longevity fuel my passion for advocacy. I’ve pursued genetic counseling and made lifestyle changes. I ask for what I need, confident I know the fine-tuning of my body as a virtuoso knows her Stradivarius. I surround myself with health care professionals who listen to and respect me. And I encourage others to do the same.

Years from today, when my final curious chapter approaches, I expect I will wonder about the ease with which my spirit leaves my body and enters heaven. For sure, I’ll have lots of questions. Until then, I’ll visit the bottom shelf of my humble library, where anatomy books abound, and where I am not embarrassed to seek the answers.

Jane Ellen Nielsen

A handwritten signature in cursive script that reads "Jane Ellen Nielsen".

Minnesota Colorectal Cancer Awareness Efforts

A unique two-day event is taking shape in Minnesota. Cancer Prevention in Clinical Practice will be held on Friday, March 4th, at the Mayo Clinic in Rochester, Minnesota. The meeting, the fourth Summit of the Minnesota Colorectal Cancer Consortium, will offer focused, interactive discussions of topics related to cancer prevention for all screenable cancers: colorectal, breast, prostate, lung, skin and oral. The intended audience is medical professionals from the disciplines of family practice, internal medicine, obstetrics and gynecology, genetics, gastroenterology, and colon and rectal surgery. The hope is to engage participants in candid discussions of optimal screening and treatment recommendations for patients affected by these cancers.

Three parallel sessions will be held in the afternoon. *Session one* is entitled “Genetics in Cancer”, *Session two*, “Overcoming Clinical Barriers to Improve Screening Rates”, and *Session three*, “A Plan of Action: Examples of Success in the Colorectal Cancer Crusade”. Participants will be encouraged to interact with each other, along with faculty and medical vendors during break sessions, lunch and the evening reception.



Carol Larson, left, and Jane Nielsen, right, join keynote speaker Suzanne Metzger at the 4th Annual Speaking of Women's Health Expo hosted by Medica on October 23rd.

On the Saturday immediately following the Summit, March 5th, the Mayo Civic Center will play host to a Cancer Prevention Health Fair, a day-long event filled with creative, hands-on and interactive demonstrations for the whole family to learn about cancer prevention, screening and treatment.

The highlight of the Fair will be the new offering from the Cancer Research and Prevention Foundation, “Check Your Insides Out from Top to Bottom.” We will also be showcasing a new mobile showroom from Olympus America where attendees can learn more about the type of equipment used for colorectal

cancer screening. A variety of health agencies and facilities will be participating in the fair as well. Displays will consist of learning stations as well as games, cooking

and exercise demonstrations, and many interactive activities that encourage learning in a far more unique and less passive way. We are envisioning a “State Fair” kind of feel except indoors and in winter.

For more information, log on to www.mcrfmn.org or contact Cindy Iverson at the Minnesota Colon and Rectal Foundation, 651-312-1556.



Julie Weaver of ACE is joined by Kristin Tabor of the Colon Cancer Coalition at the Minneapolis Women's Expo. They are standing beside a growing ACE project. At each event ACE participates in, they ask those touched by cancer to sign their name or add a message on a square that will be added to others to form a Quilt of Hope. ACE hopes to unveil its quilt by March Colorectal Cancer Awareness Month 2006.

Honoring Caregivers

On November 6, 2004, more than 200 cancer survivors, families and friends gathered in the Great Hall of Metropolitan State University, St. Paul, for the third annual Honoring Caregivers Ceremony. Among them was ACE member Julie Weaver, and her caregiver Rachel, the loyal friend who slept by her bedside during chemotherapy. Weaver was a participant in the ceremonial procession of scarves, a highlight of the event.

Created and directed by Ellen Hufschmidt, who lost a close friend to cancer, the ceremony provides “an intimate structure for people in health crisis to publicly acknowledge their caregivers.” She believes the interactive performance combining dance, music, poetry and ritual, is the first of its kind in the country. ACE and 15 other nonprofit organizations co-sponsored the event.



To The End of the Earth

Jeff Smedsrud is a successful business person in the Twin Cities. While his business endeavors would be interesting to most people, it is his personal quest after wrestling colon cancer that we think you will find particularly interesting. Jeff will be leaving Minneapolis February 21st – destination Antarctica. Why is he going to Antarctica? Well, to run a marathon, of course. But we'll let Jeff tell his story.



“Middle-aged guy in good physical condition finally visits a doctor for first time in 15 years and gets talked into a colonoscopy by his doctor because there was a small inconsistency in red blood cells; discovers he has colon cancer and is told that his Stage II could have been Stage III or IV in a few years. When I turned 45, just after the colon cancer, I set a goal for myself to run a marathon on all seven continents before I turned 50, and to use that experience to benefit others, particularly those who have a mindset like I used to have that nothing physical (or mental) could ever be wrong.”

The trip to the end of the earth is a marathon in itself. Jeff will be routed to Buenos Aires, flying out the next day to Ushuaia, the world's southernmost city.

In Jeff's words, “Surrounded by mountains and sea, this mid-size city on a peninsula is supposed to be one of the prettiest spots in South America, nestled at the base of jagged glacial peaks nearly 5,000 ft. high. Late that afternoon, I will board a 65-passenger scientific/cruise ship for a three-day trip across the Drake Passage considered the roughest bit of ocean in the world with waves 20-30 feet high and monumental winds. From what I've read it can be pretty tough on a queasy

stomach. After crossing into the Antarctic Convergence, we cruise in and around icebergs and coves through a string of islands stretching out from the mainland.

On one of these islands, on a scientific base of the Chilean government, I will become a participant of ‘The Last Marathon.’ The run is scheduled for February 26, 2005 depending on wind and weather conditions. The key factor is the wind. Assuming the winds are calm – less than 20 miles per hour – and temperatures are around 0 degrees or warmer, we will go ashore at least once before the big race. Then we line up... and begin.

The course itself is three loops of about 8 1/2 miles, up at least one steep, icy hill, down to rock-strewn beaches, through muddy and sloppy paths, and on a single dirt path full of potholes. All the while, we might be dodging penguins and ducking our heads while skuas – raven-like birds – dive-bomb us.

Before we depart Antarctica, if the weather doesn't dip much below freezing, I will spend my final night on land, zipped tightly in a sleeping bag, burrowed into a three-foot snow fort of my own digging, staring up at the southern sky. And then, three days back across the worst sea God has made, we will arrive in Ushuaia, fly to Buenos Aires, and take a midnight flight back home.

Why am I doing it? Because once in a while, even if for only ten days every decade or so, the wide-eyed boy inside of me needs to be awakened. And also because maybe – in some way great or small – I can inspire others to live out their dreams. That which we are, we are.

1. I'm thankful to be alive, and want to use that gift to see as much, and do as much, as I'm able. There is a responsibility to set an example for others.
2. Because a neighbor was diagnosed with throat cancer two weeks before I was and he died about a year ago. He'll never get to see his kids grow up, or grow old with his wife, or see whether boyhood dreams would (or would not) come true. So I'm determined not to wait.
3. And as my wife asks me, ‘How far would you go to tell people to have colon screenings?’ I laughingly reply, *‘to the end of Earth’.*”

Upcoming Events

Please Join Us!!!

Feb 24 – **An Evening of Food, Wine and Friends**

The official **kick-off fundraising event** for Colorectal Cancer Awareness Month and the new 5K run/walk, **Get Your Rear in Gear**

Midland Hills County Club, 6:30 p.m. – 9:00 p.m.

Tickets are \$35

Master of Ceremonies: *Governor Wendell Anderson*

Hosted by Minnesota Gastroenterology, PA and St. Paul Radiology Foundation

March 4 – **Cancer Prevention in Clinical Practice – Mayo Clinic**

Fourth Annual Summit of the Minnesota Colorectal Cancer Consortium

An educational opportunity for physicians and other health professionals to receive information on colorectal and other other screenable cancers

Keynote Speaker: *Bernard Levin*, M.D. Anderson Cancer Center

Course Fee: \$75

March 5 – **Check Your Insides Out Family Health Fair**

Mayo Civic Center, 9:00 a.m. to 5:00 p.m., free and open to the public

Multiple family activities including Check Your Insides Out display from the Cancer Research and Prevention Foundation; the new mobile Olympus Showroom; new Circus Minimus Cancer Prevention Puppet Show sponsored by Fleet; lots of games, raffles, food and fun

March 15th – **Presentation to Faculty and Staff of Bethel College**

Presenting: *Dr. Michael Spencer*, Colon and Rectal Surgery Associates, Ltd; *Anna Leininger*, Genetic Counselor, Minnesota Colorectal Cancer Initiative; *Ruth Edstrom* of ACE

March 26th – **Colon Cancer Coalition Get Your Rear in Gear**

5K Run and Walk and 1/2 mile Kids Dash Lake Harriet Bandshell

Kid's Dash at 8:30 a.m., 5K begins at 9:00 a.m.

Cost is \$18 in advance, \$23 day of event, donations accepted

Sponsored by Minnesota Gastroenterology, PA and St. Paul Radiology Foundation

March 30th – **Wright County Retreat, Buffalo, Minnesota**

“Women Surviving Cancer”

Beginning 9:00 a.m. March 30 and continuing to March 31

Julie Weaver of ACE presenting. Call Sally MacNabb 612-670-8045 For more information, log on to the newly launched MCRF Web site at www.mcrfmn.org or at the ACE Web site at www.acemn.org



Upcoming Events Please Join Us!!!

An Interview with Kristin Tabor, Founder of the Colon Cancer Coalition and Chair of the newly created Get Your Rear in Gear Event



"Hope Is Where It's At"

The Colon Cancer Coalition began as a dream for my sister Susie Lindquist Mjelde who wanted nobody to ever undergo what her late stage diagnosis of colon cancer brought her in December of 1999. Upon diagnosis, Susie underwent surgery to remove an 8 inch tumor, 52 weeks of chemotherapy followed by news of cancer spreading to her bones, ultimately requiring 24 hour chemotherapy and heavy radiation. Susie, a mother of three (the youngest being seven) succumbed to the disease in August of 2002 at the age of 46.

The mission of the Coalition

- We will partner with local and national corporations, media and foundations to raise awareness for the second deadliest cancer by establishing a colon cancer run and/or alignment with an existing run in every state by 2010.
- We will identify and donate the funds to the best local organizations that can ensure the best use of funds in each state.

How We Got Started

Doing the one thing that brought a smile to the face of someone who made so many people laugh was reason enough for family and friends to honor the dream for Susie. The first coalition run was sponsored in 2001 in Mercer Island, Washington (Seattle) by Susie, her husband Jeff and her brother and sister-in-law Tom and Juli. Today, the Seattle event has 5000 participants and spectators and is partnered with the state of Washington, Rotary clubs, foundations, corporations, cancer clinics, hospitals and the EIF Foundation of Katie Couric. I am so proud to say that this spring Minneapolis will proudly host the second official Colon Cancer Coalition Run and serve as the model for the Coalition to go nationally to cities in every U.S. state by 2010.

"Get Your Rear in Gear"

was Susie's own slogan. In it is a message telling people to take charge of their lives by getting checked, pursuing medical attention and by living a healthier lifestyle. While early detection saves lives, detection is not occurring and people are not getting screened. Until awareness campaigns can surmount the barriers of cost, insurance, patient acceptance and availability to screening, the statistics won't change nor will colon cancer research receive funding to improve detection options.

Saturday, March 26, 2005
Lake Harriet
5K Run, Walk, Children's Fun Run
www.getyourrearingear.com

I am so gratified for the support

of so many friends and volunteers who are donating their time and talents for this first Minneapolis event, and to our growing list of sponsors:

Minnesota Gastroenterology, P.A.
St. Paul Radiology Foundation
Colon & Rectal Surgery Associates, Ltd
Merchant & Gould Law Firm
Minnesota RED Running Club
North American Banking Company
TransAmerica Life Insurance Company
Boston Scientific
Abdo, Eick & Meyers LLP
Fleet Pharmaceuticals
Milio's
Cub Foods
Abdo Publishing
Yusett Thepace
Zeno Caf 
Calhoun Beach Club
Patrick Gibbs Art Great White North, Inc.
Kineysis
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