An information report prepared for the Colorectal Cancer Association of Canada

Colorectal Cancer Awareness

The most effective method of avoiding colorectal cancer is believed to be a healthy diet that is high in fibre, calcium, fruits and vegetables.

Coming to terms with colorectal cancer

For as long as he can remember, Alain Gourd has been undergoing an annual physical, without much noteworthy to report. But that all changed last year when one routine procedure, the fecal occult blood test, revealed blood in the stool.

Soon after, the Toronto-based executive had a colonoscopy, which revealed a cancerous tumour in the colon. While he felt fine, further tests revealed that the cancer had spread to his liver.

"It sounds funny to say, but I was in excellent health, except for the cancer," Mr. Gourd said in an interview. "And I'm in excellent health today."

The last year has been a whirlwind of surgery, chemotherapy, recovery and change in lifestyle, but his experience demonstrates just how dramatically things have changed in the field of colorectal cancer.

"There's a lot going on," said Barry Stein, president of the Colorectal Cancer Association of Canada. "It's a really hopeful time."

In recent years, there have been significant advances in prevention, screening and treatment, and a new willingness to talk about colorectal cancer, a disease too long kept in the shadows by the embarrassment factor.

It is estimated that 18,000 new cases will be diagnosed this year, and 8,300 Canadians will die of colorectal cancer, making it the second leading cancer killer.

It is recommended that both men and women between the age of 50-74 be screened annually for colorectal cancer. But the biggest impediment in the battle against the disease has been the reluctance of people to undergo that screening.

"We really aren't making a dent," said Linda Rabeneck, head of gastroenterology at Sunnybrook and Women's College Health Sciences Centre in Toronto, who recently published a study looking at screening rates in Ontario. "Any way you look at the numbers, 20 per cent is the upper limit of people being screened."

She said that is tragic because colorectal cancer is one of the easiest cancers to detect, and one of the easiest to treat. "A lot of people are dying of embarrassment — they don't get tested because they're embarrassed to talk about that part of the body."

Mr. Gourd, 57, said that was never a problem for him. Besides, as executive vice-president of Bell Globemedia, a large communications company, he was expected to get a thorough physical annually, and that included a stool sample.

That stool sample, it turns out, showed traces of blood. A blood-sample test showed elevated levels of carcinoembryonic antigen and low iron levels. CEA is present in the blood of some people with colon cancer.

When the next step came, having a colonoscopy and computerized tomography scan to check for cancer, there was no hesitation either.

Mr. Gourd was scheduled to have surgery last April but it was delayed by the SARS scare that buffeted Toronto at the time. When he finally went under the knife, it was for a rare double surgery — the cancer was excised from both his colon and liver in a marathon operation.

After two months of recovery — punctuated by being quarantined because he was in a SARS hospital, and a wound infection that necessitated more surgery (not uncommon because of the bacteria in the colon) — he was ready for chemotherapy.

Again, Mr. Gourd benefited from advances from treatment through a course of intravenous chemotherapy and a regimen of pills, a combined therapy to reduce the recurrence of the cancer,

The chemo for colorectal cancer required a visit to the hospital every three weeks for an intravenous drug. There were few side effects; the patient didn't even lose his hair.

Mr. Gourd said the biggest change in dealing with colorectal cancer today, however, is the support.

He embraced a program pioneered by Alastair Cunningham, a cancer doctor at Princess Margaret Hospital in Toronto called The Healing Journey.

"It was really, really useful. It literally changed my life," Mr. Gourd said.

He joined a support group for cancer survivors, and became a volunteer with the Colorectal Cancer Association of Canada, serving on the board of directors and acting as a phone buddy for newly-diagnosed patients.

"So many people have helped me out during my journey that I want to give back to others," Mr. Gourd said.

He also dramatically changed his lifestyle. Within days of his diagnosis, Mr. Gourd made plans to leave his high-stress executive lifestyle and dedicate himself full-time to fighting cancer. (He now works as a consultant.)

He stopped drinking, abandoned his cigar smoking and adopted a healthy, high-fibre diet. And the man who prided himself on getting by on five hours sleep nightly began sleeping.

"I thought a lot about why I ended up with colorectal cancer," Mr. Gourd said. "There is no doubt it was an accumulation of many things, so I set about to control all the factors I could."

Mr. Gourd was raised in Rouyn-Noranda, in the shadow of the northern Quebec's enormous smokestack. He thinks early exposure to high levels of pollution played a role in his cancer. (A notion bolstered by the fact that his three older siblings also ended up with various forms of cancer, as did his mother.)

But colorectal cancer has been strongly associated with diet and lifestyle, and stress, regular cocktail parties, lack of exercise and the less-than-ideal diet that befalls many frequent flyers all played a part.

Rather than dwell on the past, however, Mr. Gourd has decided to be proactive and focus on the future. Just a few days ago, he got the results of a latest battery of tests and "everything is clean."

Like many modern patients, he has also become a dedicated student of all new developments, one who is just as plugged in to new research as physicians.

"It makes me feel more in control to know all my options," Mr. Gourd said. He has plans for a series of outcomes, from long-term remission to a return of aggressive cancer.

The only thing he has no time for is pessimism.

"For me, cancer isn't a terminal disease, it's a chronic disease, and I plan to live with it for many, many more years."

Colorectal cancer at a glance

THE NUMBERS
This year it is estimated that almost 18,000 Canadians will be diagnosed with colorectal cancer and about 8,300 will die of it.

Colorectal cancer is the second most frequent cause of cancer deaths in Canada and it affects men and women almost equally — only lung cancer takes more lives.

Colorectal cancer is the third most common cancer for both men and women.

Both incidence and death rates (the number of people per 100,000 of a standard age distribution) for colorectal cancer have declined steadily but the total number of people affected have continued to increase.

Since 1972, colorectal cancer death rates for Canadian women have dropped almost 50 per cent and incidence rates have dropped by 19 per cent.

Since 1972, colorectal cancer death rates for Canadian men have dropped by 25 per cent and incidence rates by eight per cent.

RISK FACTORS
Risk factors for colorectal cancer include

Being 50 years of age or older

Having a previous history of colorectal polyps

Having an inflammatory bowel disease such as ulcerative colitis or Crohn's disease.

Having a poor diet, notably one high in red meat consumption and low in fibre, fruits and vegetables.

Having a family history of colorectal cancer.

Having a personal history of ovarian, endometrial or breast cancer.

Little or no exercise.

SYMPTOMS
Almost all cases of colorectal cancer begin with the development of benign or non-cancerous polyps. Polyps develop when cells lining the colon reproduce too quickly. These polyps can become cancerous, invading the colon wall and surrounding blood vessels and spreading to other parts of the body. There are virtually no symptoms in its early stages, when the disease is most treatable, which is why regular screening is important.
Symptoms of colorectal cancer may include:

Change in bowel habits

Alternating diarrhea and constipation

Blood in the stool

Narrower than normal stools consistently

Feeling that the bowel does not empty completely

Rectal bleeding

Persistent abdominal bloating, feelings of fullness, and cramps

Unexplained weight loss

Constant tiredness and unexplained anemia

PREVENTION
The most effective method of avoiding colorectal cancer is believed to be a healthy diet that is high in fibre, calcium, fruits and vegetables.
There is some evidence that other dietary and lifestyle choices can reduce risk including:

Regular exercise

A healthy body weight

There is some evidence that taking micronutrients, like calcium, vitamin D, and folate (folic acid) may reduce the risk of colon cancer; however, the evidence is not strong enough that these should be routinely recommended for this purpose.

There also evidence that daily aspirin or non-steroidal anti-inflammatory agents will reduce the development of polyps or cancers.

For women, hormone treatments such as birth control pills or hormone replacement therapy are associated with lower risk.

However, there are adverse effects of taking each of these medicines, and it is not clear that their benefit in reducing colorectal cancer outweigh their potential harms.

The Colorectal Cancer Association of Canada

The Colorectal Cancer Association of Canada (CCAC) is Canada's best known and largest non-profit organization dedicated to supporting people with colorectal cancer, their families and caregivers.

Its mission is to improve the quality of life of patients, increase awareness and educate the public about prevention and treatment of the disease.

The CCAC provides patient information packages free of charge as well as information both online and through its telephone hotline.

Support and networking groups are established for patients and their families to address the psycho-social and informational needs of patients. Monthly meetings are held in Ottawa, Montreal, Toronto, Oshawa and now in Kingston where patients are frequently "buddied" up with other cancer survivors to best address their needs. Establishing new groups is a priority. Free patient information evenings with expert panels are also held free of charge across Canada.

Currently, the CCAC vigorously advocates on behalf of colorectal cancer patients and their families promoting the need for a national colorectal cancer screening program and timely access to the best medicines and treatments.

A new on line e-advocacy campaign has been created at www.advocacyonline.net/ccac/email.htm kicking off a grass roots movement to motivate politicians on the need to quickly address colorectal cancer screening as they would for other cancers such as breast cancer.

The association supports itself through Corporate and private foundations as well as through the general public, the annual Bernie Faloney golf tournament, a gala event called "Colonoscoparty", their Montreal young adult fundraiser "Cure-osity", and through its popular trademarked Lifesaver Bracelet campaign.

To contact the Colorectal Cancer Association of Canada visit
www.ccac-accc.ca
or call 1-888-318-9442

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Colorectal Cancer Awareness

Researchers are making advances to beat cancer

Earlier this month, Heidi Watts did something seemingly mundane, swallowing a pill that looked a lot like a Contact C capsule. But inside that pill was a miniature camera, one that allowed doctors to probe, with amazing precision, her small bowel, to try and find the source of pesky, seemingly undetectable bleeding.

The pill, called a capsule endoscope, is one of the more spectacular examples of new technologies used to evaluate mostly the small bowel in cases like Heidi's cancer.

The capsule endoscope is not for everyone. In fact, it's used only on rare patient population who may have continued problems that cannot be detected with more common screening techniques or, like Ms. Watts, have a rare genetic form of colorectal cancer and a hard-to-solve problem.

But it is an example of how a disease that, not that long ago was considered all-but-untreatable, is under attack on a number of fronts.

In recent years, there have been a number of important developments in surgery, in drug treatments and work is even fairly advanced on a vaccine.

"Colorectal cancer is really a surgical disease. It has surgical treatments and surgical cures," said Dr. Barry L. Stein, director of the Centre for Colon and Rectal Surgery at the McGill University Health Centre in Montreal.

Not so long ago, colorectal surgery was a way of buying time for gravely ill patients. Often, the treatment was worse than the disease.

"We now have a lot of new surgical techniques and equipment and they have really benefited the patient and in addition new radiation techniques for the treatment of rectal cancer help reduce the possible return of the cancer," Dr. Stein said. Earlier detection also allows less disabling surgery.

If cancer spreads into the rectal wall, both the anus and rectum may have to be removed, and that requires colostomy — where a surgical opening is created between the large intestine and abdominal wall, and feces empties into a bag.

Today, only a tiny percentage of patients require a colostomy.

Ms. Watts, for example, who has had her entire colon removed, did not require a colostomy. Her small bowel is connected directly to the rectum.

"I don't really have any side effects of living without a colon," she said. "I eat what I want and live like everyone else, despite what I've been through."

While she has had two major surgeries for colon cancer (in addition to a prophylactic hysterectomy due to increased risk of endometrial cancer), Ms. Watts never had to undergo chemotherapy or radiation.

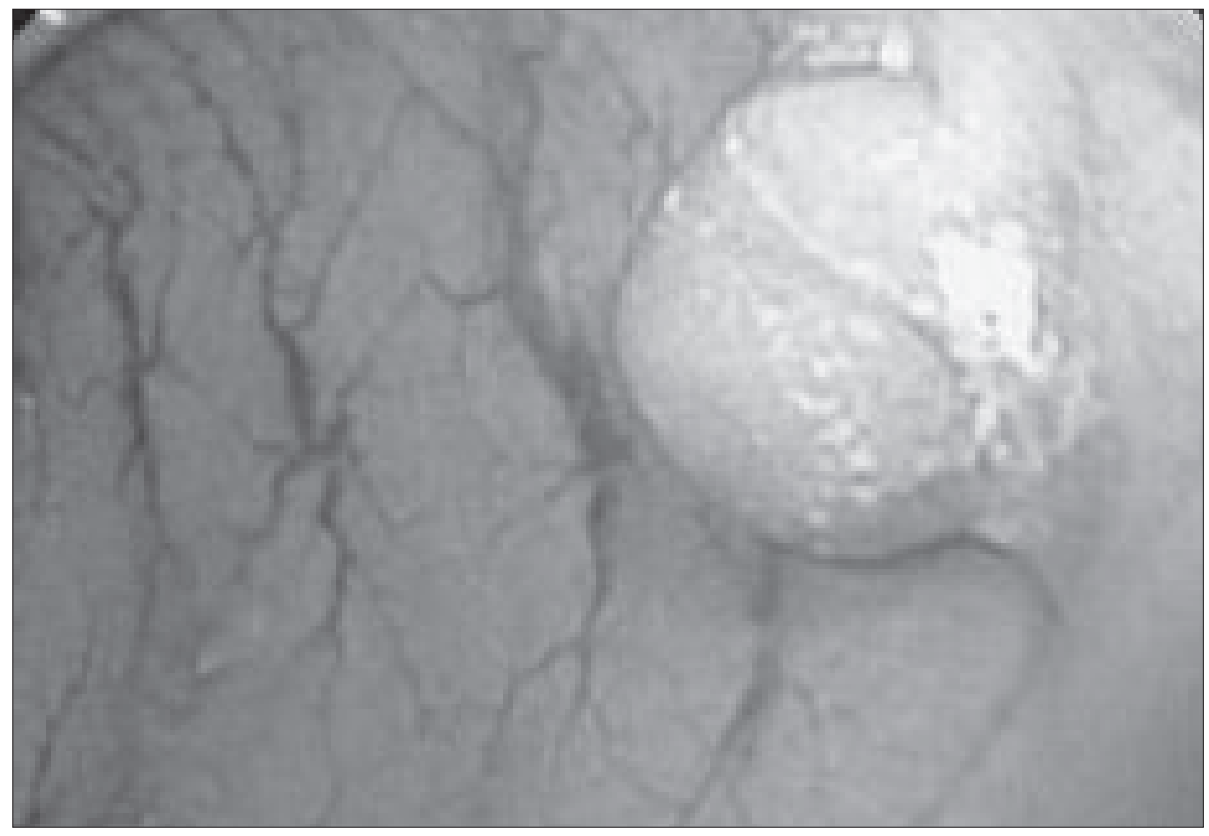
Dr. Stein said when these follow-up treatments are required, they are much better co-ordinated and far more patient friendly.

"We have seen remarkable changes in chemotherapy for colorectal cancer in the past ten years," said Dr. Tony Fields,Chair oif the Medical Advisory Board of the CCAC. "The new drugs irinotecan and oxaliplatin have helped patients whose cancer has spread through their bodies live longer and better. Capecitabine, which is taken in pill form, can for some patients provide a more convenient treatment than the intravenous drugs it replaces. Also, there have been tremendous advances in medicines to support patients taking chemotherapy, for example by preventing nausea."

Anaemia, a side effect causing fatigue for some patients taking chemotherapy, can often be managed with erythropoietin (Eprex®).

Developments on the drug front are equally exciting. cetuximab (Erbitux®), a treatment for people with advanced colon cancer, is one of a new class of cancer medicines designed to specifically target and disrupt certain molecules that spur tumour growth. The promise of the drug, however, has been overshadowed by the fact that a delay in its approval in the U.S. triggered the events that led to the conviction of Martha Stewart.

Another drug that is creating a buzz is bevacizumab (Avastin®), an anti-angiogenesis agent. The drug prevents tumours from developing the blood supply they need for growth. Other promising anti-angiogenesis drugs, such as



The view in a colonscope of irregularies in a colon.

Novartis PTK787, and drugs that target specific growth signals in cancer cells are being tested in clinical trials.

One of the boldest approaches, is creating a colorectal cancer vaccine. Like a traditional vaccine, a cancer vaccine would trigger the patient's immune system to fight the invader. In the case of colorectal cancer, the plan is to target carcinoembryonic antigen (CEA), which is expressed by most colorectal cancer cells. But, unlike a traditional vaccine, the cancer vaccine would be administered to people already suffering from the disease, in addition to, or instead of chemotherapy.

"We believe a vaccine will have many advantages over chemotherapy because it will target only cancerous cells and leave normal cells unharmed," said Dr. Neil Berenstein, assistant vice-president of clinical oncology at Aventis Pasteur.

The vaccine, called ALVAC-CEA/B7.1 is currently being tested in Canada. The hope is that, in the not-too-distant future, a vaccine will become part of the cancer armamentarium.

"It's important to appreciate that this is a cutting edge approach but even impartial cancer observers think that cancer vaccines will be a routine part of treatment within the next 10 years," Dr. Berenstein said.

In addition the study of proteins in a patient's tumor may well tell us what is important about the nature of their cancer and how it should be treated, and gene and protein screens may be used to help direct therapy as well. Levels of the enzymes thymidylate synthase (TS) and dihydropyrimidine dehydrogenase (DPD) and the presence of microsatellite-instability (MSI) in cancer cells may predict the benefit of chemotherapy, helping to determine the course of treatment. The feeling is that one day soon these new approaches , together with better treatments, will make it far easier to control advanced colorectal cancer, transforming it into a chronic condition rather than a short-term killer.

The vast majority of cases of colorectal cancer — probably 75-85 per cent — are preventable but the key is detecting them early.

"Many of us have been given a pre-cancerous lesion that grows slowly. It sits there in the colon and taunts us: 'Come and get me'," Dr. Stein said.

"If we do that, if we take up the challenge with good screening, the vast majority of cases of colorectal cancer are preventable," he said.

But there is hope even for those with more aggressive, genetic forms of colorectal cancer, like Ms. Watts.

She has undergone genetic testing to determine her specific form of cancer. It's known as HNPCC for Hereditary Non-Colyposis Colorectal Cancer.

When Ms. Watts children, aged 13 and 14, get a little older, they will undergo generic testing to determine if they are carriers, and hence at high risk of developing cancer.

In the meantime, she hopes that scientists will continue genetic research to hopefully cure the disease entirely or, at the very least, continue to make progress on many fronts so that colorectal cancer is a manageable disease for the next generation.

Screening for Colorectal cancer

Digital rectal examination (DRE) A doctor inserts a gloved finger into the rectum to feel for abnormalities.
Preparation: No special preparation required.
Pros and cons: For men, DRE is already used to screen for prostate cancer. Very limited ability to detect polyps.

Fecal Occult Blood Test (FOBT) is a test to see if there is blood in the stool (an indication of pre-cancerous polyps) that is not visible to the naked eye. Three separate stool samples are collected by a person in their own home and then sent to a laboratory for analysis.
Preparation: You need to modify your diet and avoid certain drugs (including aspirin) for a few days prior to stool sampling.
Pros and cons: The test is easy and cheap, but it's imperfect. Not all polyps bleed so some cancers can be missed, and blood in the stool does not necessarily mean a person has cancer. If blood is found, a colonoscopy is required.

Genomics-based testing is a stool test that detects the presence of polyps by looking for the altered DNA that is shed by pre-cancerous cells.
Preparation: No special preparation.
Pros and cons: This is new and expensive technology but early indication is that it could be more accurate than FOBT. Because the test is non-invasive, there is a lot of interest from consumers. Still an experimental approach.

Flexible sigmoidoscopy (flex sig) is a test in which a soft, flexible lighted tube is used to look at the lining of the rectum and lower colon to help detect or rule out the presence of polyps or tumours.
Preparation: You need to take a mild laxative or an enema to empty your lower colon.
Pros and cons: Rarely requires sedation. Test can be performed by a medical professional other than a physician. It is a good test but cannot detect polyps higher up the colon.

Barium enema is a test that consists of introducing a liquid containing barium into the colon and then taking X-rays.
Preparation: The colon needs to be cleaned out so you will be put on a liquid diet for a couple of days, and need to take laxatives and an enema.
Pros and cons: Combined with flex sig, it offers a good view of the colon. However, it can miss smaller polyps and cancers and biopsy and polyp removal cannot be done during the procedure.

Colonoscopy: A thin, flexible tube with a camera at its tip, it is like the flex sig but longer. It allows a physician to view the entire colon — a journey of about 100 centimetres — and remove any polyps that are found.
Preparation: Involves drinking a large quantity of foul-tasting chalky liquid, and a lot of visits to the toilet, but the entire colon is scrubbed clean. Most people take a sedative for the test, but remain awake. It is not painful, but the drug helps you relax.
Pros and cons: It's the most thorough test, allowing the best detection and for polyps to be removed immediately. But there is a risk — about 3 in 1,000 cases — of perforating the wall of the colon.

Computerized tomography scan: "Virtual colonoscopy" allows a good look at the entire colon without an invasive procedure.
Preparation: Same as colonoscopy.
Pros and cons: Still an experimental approach as far as screening goes but not for diagnostics. If a polyp is discovered, a colonoscopy would still be required to remove it. Very limited availability in Canada.

Psotiron Emission Tomography. (PET). This is an important new approach for follow-up and diagnostics but not used for screening as yet.

Overcoming the taboos of colon examinations

"Of course the idea of someone steering a telescope up your rear end seems horrific," says Richard Hunt. "But the reality is that it's quite tolerable and provides immensely useful information."

Dr. Hunt, a professor of medicine at McMaster University, is describing, in his own blunt way, the pros and cons of colonoscopy.

There are few people more qualified to express the opinion. Dr. Hunt was one of the first physicians to perform the procedure — which consists of guiding a flexible, camera equipped tube into the colon — more than 30 years ago.

And, in case you're wondering — as people often do when their doctors suggest the test — he has undergone the procedure himself a number of times.

"Personally, I have my colonoscopy done without sedation. There is a lot of fear about this procedure but it's just a little uncomfortable. It's not a big deal."

In fact, many patients will tell you that the worst part of the ordeal is the preparation for the test — which consists of drinking a vile-tasting chalky liquid and taking laxatives to clear the colon — as far more onerous than the colonoscopy itself.

The reality, however, is that very few Canadians have undergone a colonoscopy, or any other type of screening for colorectal cancer.

In 2002, the National Committee on Colorectal Cancer Screening recommended that everyone age 50-74 should be screened for the common cancer using a fecal occult blood test — a laboratory test done on a stool sample. The committee recommended that everyone be tested once every two years and that positive tests be followed up with a colonoscopy.

However, the provinces have not implemented these recommendations, meaning there are, in effect, no national guidelines, and no organized efforts to systematically get people tested, as there is with breast cancer and cervical cancer.

"Mammography and Pap smears are incorporated into practice. Doctors order these tests routinely," said Linda Rabeneck, head of gastroenterology at Sunnybrook and Women's College Health Sciences Centre in Toronto. "But that just isn't happening with colorectal cancer screening."

Her research shows that no more than 20 per cent of Ontarians in the 50-74 age group get a fecal occult blood test. Fewer still, probably no more than six per cent, have undergone a colonoscopy. (The data is imprecise because only the number of tests processed is measured, not the precise number of people taking the tests.)

Numbers like those frustrate and anger Dr. Hunt because they point to a lost opportunity.

"We're dealing with a very common cancer that is easily detectable, easily preventable and imminently treatable in the early and advanced stages," Dr. Hunt said. "If we were able to broadly implement screening we would save a meaningful number of lives."

Barry Stein, president of the Colorectal Cancer Association of Canada, agrees, saying there is no excuse for the provinces not having implemented population-based screening the way they have with other, less frequent cancers.

"The need for a national colorectal cancer screening policy in Canada is urgent," he said. "Our suffering and burden from colorectal cancer in Canada is among the highest in the world. We cannot justify a further delay."

Mr. Stein said such a policy also needs to be flexible so it can be updated regularly as new scientific evidence becomes available.

He also believes that it would be wise to do a lot more first-line screening using colonoscopy rather than a fecal occult blood test because up to 40 per cent of cancers may be missed using a stool sample. (That is because some polyps don't bleed and, if samples are not taken properly, information will not be garnered from large parts of the colon.) However, high costs, lack of equipment and personnel together with low compliance make it a difficult goal to achieve.

The principal argument against colonoscopy screening is cost, but cost-effectiveness studies are highly dependent on uptake; in other words, if far more people were screened, the option would be much more cost-effective.

Dr. Hunt, also a proponent of screening with colonoscopy, concedes that resources are sorely lacking.

"The reality is that we don't have enough colonoscopes or enough qualified personnel," he said. "But that doesn't mean we shouldn't. It behooves government to act on this important public health measure and to provide the necessary resources."

In the meantime, he believes it is incumbent to talk more openly about colorectal cancer, to overcome the taboos and the discomfort.

"Maybe bowel function will never become parlour talk, but we need to find a way to make it easier to discuss issues like screening," Dr. Hunt said. "We need to popularize procedures like colonoscopy, and make it part of a healthy lifestyle, not something that we fear and avoid."