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COLON CANCER: GREATER USE OF SCREENINGS WOULD SAVE LIVES

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BEFORE THE

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COLON CANCER: GREATER USE OF SCREENINGS WOULD SAVE LIVES

MONDAY, MARCH 6, 2000

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 1:05 p.m., in room SH–216, Hart Senate Office Building, Hon. Charles E. Grassley, (Chairman of the Committee) presiding.

Present: Senators Grassley, Craig, Collins, Reid, Bayh, and Lincoln.

Also present: Senators Specter and Hutchinson.

OPENING STATEMENT OF SENATOR CHARLES GRASSLEY, CHAIRMAN

The CHAIRMAN. I welcome everybody who has come to this very important hearing, and I want to extend a warm welcome to our very special guest, Katie Couric. Thanks to so many of my colleagues for showing up when we normally might either be out of town on a Monday or be very busy on a Monday. I would like to ask our colleagues to give their opening statements after we are done with the first panel. But we will have an opportunity for everybody to have a 5-minute round of asking questions of Ms. Couric.

So I want to welcome everybody today to our hearing, which is in honor of the First Annual National Colorectal Cancer Awareness Month. We have many honored guests today, including someone who is the Nation's visible advocate for colon cancer screening. Katie Couric is here as the co-founder of the National Colorectal Cancer Research Alliance.

The Senate unanimously declared March 2000 as the first National Awareness Month. Colorectal cancer is the second leading cause of cancer-related deaths in the United States. This year 129,400 Americans will be diagnosed with this type of cancer; 56,000 Americans will die from it. Colorectal cancer affects men and women equally. In fact, more women over age 75 die of colorectal cancer as opposed to breast cancer.

One of the hallmarks of colorectal cancer is that in its early stages symptoms are difficult to detect. That is why many people fail to learn about their cancer until it has progressed to an advanced stage.

Family history, diet, and age are indicative of significant risk factors. Individuals whose families have a history of cancer are at a higher risk. Diets high in fat and cholesterol have been linked to

an increased risk of colorectal cancer. Although colorectal cancer can develop in individuals under age 50, anyone over the age of 50 is considered at average risk, with the incidence of colorectal cancer approximately doubling with each decade of a person's life.

Many of these deaths are avoidable. Several screening methods can be used to detect the cancerous growth and removal can prevent the onset of colorectal cancer. If detected and treated early, this cancer is curable in up to 90 percent of the diagnosed cases.

In an effort to increase detection and treatment of colorectal cancer with the Medicare beneficiary population, Congress enacted as part of the Balanced Budget Act of 1997 a preventive benefit package, which included Medicare coverage for colorectal cancer screening starting January 1, 1998. Unfortunately, now, many primary care doctors and Medicare beneficiaries are not educated about the tremendous benefits of this screening. Therefore, the Health Care Financing Administration established a partnership with the Centers for Disease Control and Prevention and the National Cancer Institute to increase awareness of colorectal cancer screening through the Screen for Life campaign.

In spite of this partnership, recent studies indicate that colorectal cancer screening is not well utilized by the Medicare population. One study from Dartmouth Atlas of Health Care 1999 stated that one out of eight elderly people get recommended tests for colon cancer. In an effort to educate the public and learn more about how we can improve upon existing outreach efforts, we have two panels of witnesses today.

I have already referred to our first witness. Katie Couric will tell us how this type of cancer has affected her life, and we compliment her on leading a national education campaign to bring attention to the importance of screening.

Our second panel will focus on Federal interagency efforts to educate Medicare providers and beneficiary populations. And I would also like to announce today that Senator Breaux and I are circulating a letter to the Appropriations Committee that we would like other Senators on this committee to sign. I will pass this around if my staff haven't given you one, but we would like to have you consider signing this letter. The letter asks the Appropriations Committee to fully fund the authorized amount of the National Medicare Beneficiary Education program, which provides comprehensive information and counseling to seniors on their Medicare health plan choices, covered benefits, including preventive screenings, rights and protections under the program.

The Balanced Budget Refinement Act of 1999 drastically cut the amount of authorized funds that were to be collected from user fees which had been funding the program. Therefore, the program will become virtually obsolete unless money is appropriated to make up the difference. So I urge my colleagues on the committee to sign this letter in support of the Health Care Financing Administration's educational efforts.

Also, Senator Breaux and I have put together a colon cancer scorecard. It will be available at our office and on the committee's website, and we hope that everyone will take a few minutes to use this document and gauge their knowledge of this illness.

I want to thank the witnesses for taking time out of their busy schedule to testify before the committee, and I also want to make known why Senator Breaux can't be with us today because he is always so loyal to the work of this committee. His mother-in-law is having surgery for breast cancer, and he wanted to be with her and with his wife during this difficult time. We certainly understand that, and we thank Senator Breaux for his interest in this hearing even though he can't be here today.

I now call on Senator Reid to speak for the Democrats.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR GRASSLEY

Good morning.

I would like to welcome everyone to this Senate hearing in honor of the first annual National Colorectal Cancer Awareness Month.

The U.S. Senate unanimously declared March 2000 as the first National Colorectal Cancer Awareness Month.

Colorectal cancer is the second leading cause of cancer-related death in the United States. This year 129,400 Americans will be diagnosed with this type of cancer and 56,000 Americans will die from it.

Colorectal cancer affects men and women equally. In fact, more women over the age of 75 die of colorectal cancer than breast cancer.

One of the hallmarks of colorectal cancer is that in its early stages, symptoms are difficult to detect. This is why many people fail to learn about their cancer until it has progressed to an advanced stage.

Family history, diet, and age are indicative of significant risk factors. Individuals whose families have a history of cancer are at higher risk. Diets high in fat and cholesterol have been linked to an increased risk of colorectal cancer.

Although colorectal cancer can develop in individuals under age 50, anyone over the age of 50 is considered at average risk, with the incidence of colorectal cancer approximately doubling with each decade of a person's life.

Many of these deaths are avoidable. Several screening methods can be used to detect the cancerous growth and removal can prevent the onset of colorectal cancer. If detected and treated early, colorectal cancer is curable in up to 90 percent of diagnosed cases.

In an effort to increase detection and treatment of colorectal cancer within the Medicare beneficiary population, Congress enacted, as part of the Balanced Budget Act of 1997, a preventive benefits package which included Medicare coverage of colorectal cancer screening as of January 1, 1998.

Unfortunately, many primary-care doctors and Medicare beneficiaries are not educated about the tremendous benefits of screening. Therefore, the Health Care Financing Administration (HCFA) established a partnership with the Centers for Disease Control and Prevention, and the National Cancer Institute to increase awareness of colorectal cancer screening through the Screen for Life Campaign.

In spite of this partnership, recent studies indicate that colorectal cancer screening is not well-utilized by the Medicare population. One study, from the Dartmouth Atlas of Health Care 1999, stated that one out of eight elderly people get recommended testing for colon cancer. In an effort to educate the public and to learn more about how we can improve upon existing outreach efforts, we have two panel of witnesses today.

For our first panel, Katie Couric will tell us how colorectal cancer affected her life.

STATEMENT OF SENATOR HARRY REID

Senator REID. Thank you very much for being here. It is not often we have a celebrity that we feel so close to that we can call them by their first name, but I think most of America feels that we know you, Katie, and can talk to you in that manner.

Your being here says a lot. Tomorrow, as we know from watching your program this morning, you are going to allow the American public to watch your colonoscopy. I think it is important that you are really extending yourself to alert the American public to the insidious nature of dealing with colon cancer.

I have had some experience with colons. My wife has a disease called ulcerative colitis, and when she had her colon removed, the doctor told here that the good news was that she would have probably gotten cancer anyway. Because she had her colon removed, of course, she doesn't have to worry about the colon cancer.

My message to you today is one of thanks. By focusing attention on this disease, we will be able to get more money for research. We applaud you for doing that.

This is a disease that isn't very fashionable. It is not easy to talk about colons and what needs to be done to identify the diseases. It isn't something that has attracted a lot of media attention. Thanks to your status as a media personality there is media attention here today. I think it says it all to have this room full of people on a Monday and to have the room full of Senators. Senator Grassley has staffed many of these meetings by himself. It is not often we get the attention that we have here today.

I recognize that we have made some progress. As Senator Grassley mentioned, the Balanced Budget Act of 1997, created a new Medicare preventive benefits package, which included Medicare coverage of colorectal cancer screening. In spite of this, colon cancer lags far behind screening for other cancers, even though it is the second leading cause of cancer-related death in the United States.

This year approximately 130,000 Americans will be diagnosed with colon cancer, and 56,000 of those people will die. In Nevada, a State of very sparse population, about 1,000 new cases of colorectal cancer will be diagnosed, and about half those people will die. Many of these individuals friends and loved ones will be left wondering if early detection could have made a difference .

So I think it is time to break the silence surrounding colon cancer and encourage all Americans to overcome their fear and embarrassment and talk to their doctors about screening opportunities. Again, I guess we are here to be a little bit personal, but I am at an age now where I have had three or four of these. Now we only need them every 4 or 5 years. And I can say to everyone within the sound of my voice, it is a lot easier now than it was the first one that occurred. The techniques are so much better and easier, and it is something that we shouldn't be afraid of.

So, again, thank you very much from the committee, from the Senate generally, and from the American people. Thank you for being here.

The CHAIRMAN. Now, just a short introduction for somebody who needs no introduction. Katie Couric is co-host for the NBC Today Show. She is here because of the tragic death of her husband from colon cancer in 1998 when he was only 42 years of age. Since his death, Ms. Couric has become an outspoken advocate on behalf of families afflicted with this terrible disease and has encouraged others about the importance of screening. Ms. Couric has co-founded and serves as national spokesperson for the National Colorectal Cancer Research Alliance, which recently launched a 5-year public education campaign on this type of cancer. She has volunteered to talk today about her experience in dealing with a spouse who had colon cancer. We greatly appreciate her coming. I am pleased to welcome you. Thank you very much. Take as much time as you need.

STATEMENT OF KATIE COURIC, HOST, NBC TODAY SHOW, AND CO-FOUNDER, NATIONAL COLORECTAL CANCER RESEARCH ALLIANCE, NEW YORK, NY

Ms. COURIC. OK. Thank you, Senator Grassley, Senator Breaux—who I know wanted to be here but unfortunately couldn't; we wish his mother-in-law well—and members of the committee.

This is a very different experience for me. I have never testified on Capitol Hill before, but I am very pleased to be here—not so pleased for the reason, of course, that brought me here. As many of you know, my husband Jay Monahan was diagnosed with colon cancer in 1997. He had no family history of the disease. After an unbelievably courageous battle, he died 9 months later, just 2 weeks after his 42nd birthday.

During this terrible 9-month struggle, motivated by fear and desperation, I got a quick and painful education about this devastating disease. Some of the statistics I think bear repeating. I learned that colon cancer is the second leading cancer killer in this country: 130,000 people are diagnosed every year, 56,000 of them die. It kills more people than any other cancer, with the exception of lung cancer. And if we were lucky enough to convince people to stop smoking, colon cancer would have the unfortunate distinction of being at the top of the list. Women get it. In fact, they are diagnosed at a slightly higher rate than men. Minorities get it. African Americans are at increased risk. And young people get it; 13,000 people under the age of 50 are diagnosed every year.

But I also learned that it has a 90 percent cure rate, or better, if it is detected early. That means that colon cancer screening is a critical weapon in the fight against a disease no one needs to die from.

Unfortunately, people are woefully unaware and uneducated about this killer. A lot of people simply don't want to talk about it. Colons, rectums, bowels—it is not exactly the stuff of cocktail party conversation. It is hard to believe when you see some of the dresses at the Grammys and hear some of the language on television that anyone is embarrassed about anything these days. But they are. And in this case it could cost them their lives.

But if you recall, not that long ago people were hesitant and uncomfortable talking about breast cancer, and men rarely discussed their prostates. Now those cancers are routinely discussed with family members and friends, and, most importantly, doctors. We have to do the same for colon cancer.

So removing the stigma of this disease is my first dream. But people need to not only talk the talk, they need to walk the walk. And in this case, walking the walk, of course, means getting tested.

According to the CDC, a whopping 60 percent of people who should be screened never have been. Some people find the procedures like stool tests, flexible sigmoidoscopies, and colonoscopies unappealing. I can tell you firsthand they are all much more appealing than dying of this disease.

I also have a dream that sometime in the near future everyone could have their colonoscopies—considered, by the way, the gold standard for screening—covered by insurance. That should be the case even when there is no family history since 80 to 85 percent of colon cancer cases fall in that category. They should also be cov-

ered before people become symptomatic, because when symptoms start to present themselves, that often means the disease has already progressed.

I am very gratified that Medicare now covers colon cancer screening for people 65 and over. It is incumbent that we convince seniors to take advantage of this fact. Had Charles Schulz, for example, been screened, he and we would still be enjoying his beloved "Peanuts" gang.

The need for greater awareness and more widespread screening is the reason that last week I, along with Lilly Tartikoff and the Entertainment Industry Foundation, founded the National Colorectal Cancer Research Alliance. Together I know we can make a difference, and I know we can save lives.

The NCCRA has placed five million educational brochures in more than 25,000 chain drug stores around the country to educate people about colon cancer. We have put together public service announcements from Dennis Franz of NYPD Blue, whose father had this disease and died from it; Judge Judy, whose mother died of colon cancer; professional baseball player Eric Davis, who was diagnosed when he was just 35 years old; and Sean Ferrer, Audrey Hepburn's son. Most people, in fact, don't even realize that Audrey Hepburn, someone so delicate and glamorous who epitomized femininity, died from a disease like colon cancer, but she did. Those ads have already begun airing on TV stations nationwide.

Our medical advisory board consists of scientists from all across the country conducting cutting-edge research on prevention strategies, new diagnostic tools, and treatment options. Incidentally, those scientists say that awareness alone could cut the mortality rate from this disease in half. We are talking about saving the lives of 28,000 fathers, mothers, sisters, brothers, sons, and daughters.

To that end, this week, as part of the National Colorectal Cancer Awareness Month, deemed by Congress last November, I am anchoring a five-part series on the Today Show. And to prove to people just how easy and important it is to be screened, tomorrow on the program, as I believe Senator Grassley mentioned, I will give them the true inside story, sharing exclusive video of my own colon shot during my first colonoscopy.

The bottom line, so to speak, is this: I know all too well, as perhaps many of you do, about the lives shattered and families devastated by these three words: You have cancer. Of course, there are many happy endings, but, still, too many sad ones. We have a unique opportunity to change that. Please help us make sure this disease is no longer ignored or whispered about. No one needs to die of embarrassment. Every person screened is a potential life saved. Knowledge is power.

Thank you for providing the people of this country—truly our greatest natural resource—with this important information, motivating them to get screened and helping them all lead longer, healthier lives.

Thank you very much.

[The prepared statement of Ms. Couric follows:]

Colon Cancer Congressional Hearings
Topic: Greater Use of Screenings Would Save Lives
Katie Couric Remarks

SENATORS, GUESTS, MEMBERS OF THE PUBLIC, THANK YOU SO MUCH FOR INVITING ME HERE TODAY. AS MANY OF YOU KNOW, I HAVE A VERY PERSONAL REASON FOR BEING HERE. MY WORLD FELL APART WHEN MY HUSBAND JAY MONAHAN WAS DIAGNOSED WITH COLON CANCER IN 1997. HE HAD NO FAMILY HISTORY OF THE DISEASE. AFTER AN UNBELIEVABLY COURAGEOUS BATTLE, HE DIED NINE MONTHS LATER, JUST TWO WEEKS AFTER HIS FORTY-SECOND BIRTHDAY. DURING THIS TERRIBLE STRUGGLE, MOTIVATED BY FEAR AND DESPERATION, I GOT A QUICK AND PAINFUL EDUCATION ABOUT THIS DEVASTATING DISEASE. I LEARNED THAT COLON CANCER IS THE SECOND LEADING CANCER KILLER.

130,OOO PEOPLE ARE DIAGNOSED WITH IT EVERY YEAR. 56,000 OF THEM DIE. IT KILLS MORE PEOPLE THAN ANY OTHER CANCER, WITH THE EXCEPTION OF LUNG CANCER. AND IF WE WERE LUCKY ENOUGH TO GET PEOPLE TO STOP SMOKING, COLON CANCER WOULD SOON HAVE THE UNFORTUNATE DISTINCTION OF BEING AT THE TOP OF THE LIST. WOMEN GET IT – THEY ARE DIAGNOSED AT A RATE SLIGHTLY HIGHER THAN MEN. MINOROITIES GET IT - AFRICAN AMERICANS ARE AT A SLIGHTLY HIGHER RISK. YOUNG PEOPLE GET IT – 13,000 PEOPLE UNDER THE AGE OF 50 ARE DIAGNOSED EVERY YEAR. BUT I ALSO LEARNED THAT IT HAS A 90 PERCENT OR BETTER CURE RATE IF IT IS DETECTED EARLY. THAT MEANS THAT COLON CANCER SCREENING IS A CRITICAL WEAPON IN THE FIGHT AGAINST A DISEASE NO ONE NEEDS TO DIE FROM.

UNFORTUNATELY, PEOPLE ARE WOEFULLY UNAWARE AND UNEDUCATED ABOUT THIS KILLER. A LOT OF PEOPLE DON'T WANT TO TALK ABOUT IT. COLONS. RECTUMS. BOWELS. NOT EXACTLY THE STUFF OF COCKTAIL PARTY CONVERSATION. IT'S HARD TO BELIEVE WHEN YOU SEE SOME OF THE DRESSES AT THE GRAMMIES AND HEAR SOME OF THE LANGUAGE ON TELEVISION THAT ANYONE IS EMBARRASSED ABOUT ANYTHING THESE DAYS...BUT THEY ARE...AND IN THIS CASE, IT COULD COST THEM THEIR LIVES. BUT IF YOU RECALL, NOT THAT LONG AGO, PEOPLE FELT UNCOMFORTABLE TALKING ABOUT BREAST CANCER...AND MEN RARELY DISCUSSED THEIR PROSTATES. NOW THOSE CANCERS ARE ROUTINELY DISCUSSED WITH FAMILY, FRIENDS...AND MOST IMPORTANTLY, DOCTORS. WE HAVE TO DO THE SAME FOR COLON CANCER. SO REMOVING THE STIGMA IS MY

FIRST DREAM. BUT PEOPLE NEED TO NOT ONLY TALK THE TALK, THEY NEED TO WALK THE WALK. AND WALKING THE WALK MEANS GETTING TESTED. ACCORDING TO THE CDC, A WHOPPING 60 PERCENT OF PEOPLE WHO SHOULD BE SCREENED NEVER HAVE BEEN. SOME PEOPLE FIND THE PROCEDURES LIKE STOOL TESTS, FLEXIBLE SIGMOIDOSCOPIES AND COLONOSCOPIES UNAPPEALING. I CAN TELL YOU THEY ARE ALL MUCH MORE APPEALING THAN DYING OF THIS DISEASE. I ALSO HAVE A DREAM THAT SOMETIME IN THE NEAR FUTURE EVERYONE COULD HAVE THEIR COLONOSCOPIES, CONSIDERED THE GOLD STANDARD FOR SCREENING, COVERED BY INSURANCE. THAT SHOULD BE THE CASE EVEN WHEN THERE IS NO FAMILY HISTORY, SINCE 80 TO 85 PERCENT OF COLON CANCER CASES FALL IN THIS CATEGORY. AND THAT THEY DO IT BEFORE THEY BECOME SYMPTOMATIC -- BECAUSE WHEN SYMPTOMS START TO PRESENT

THEMSELVES, OFTEN TIMES THE DISEASE HAS ALREADY PROGRESSED. I AM GRATIFIED THAT MEDICARE NOW COVERS COLON CANCER SCREENING FOR THOSE 65 AND OVER. IT IS INCUMBENT THAT WE CONVINCE SENIORS TO TAKE ADAVANTAGE OF THIS. HAD CHARLES SHULTZ BEEN SCREENED, HE AND WE WOULD STILL BE ENJOYING HIS BELOVED PEANUTS GANG.

THE NEED FOR GREATER AWARENESS AND MORE WIDESPREAD SCREENING IS THE REASON LAST WEEK I, ALONG WITH LILLY TARTIKOFF AND THE ENTERTAINEMENT INDUSTRY FOUNDATION, LAUNCHED THE NATIONAL COLORECTAL CANCER RESEARCH ALLIANCE. TOGETHER, I KNOW WE CAN MAKE A DIFFERENCE AND I BELIEVE WE CAN SAVE LIVES. THE NCCRA HAS PLACED 5 MILLION EDUCATIONAL BROCHURES IN MORE THAN 25,000

CHAIN DRUGSTORES AROUND THE COUNTRY TO TELL PEOPLE ABOUT COLON CANCER. WE HAVE PUT TOGETHER PUBLIC SERVICE ANOUNCEMENTS FROM DENNIS FRANZ OF NYPD BLUE, JUDGE JUDY, BASEBALL PLAYER ERIC DAVIS AND SEAN FERRER, AUDREY HEPBURN'S SON...MOST PEOPLE DON'T EVEN KNOW SHE DIED FROM COLON CANCER. THOSE ADS HAVE ALREADY BEGUN AIRING ON TELEVISION STATIONS NATIONWIDE.

OUR MEDICAL ADVISORY BOARD CONSISTS OF SCIENTISTS FROM ALL OVER THE COUNTRY CONDUCTING CUTTING-EDGE RESEARCH ON PREVENTION STRATEGIES, NEW DIAGNOSTIC TOOLS, AND TREATMENT OPTIONS. INCIDENTALLY, THOSE SCIENTISTS SAY AWARENESS ALONE COULD CUT THE MORTALITY RATE FROM THIS DISEASE IN HALF. WE'RE TALKING ABOUT SAVING THE LIVES OF 28 THOUSAND

FATHERS, MOTHERS, SISTERS, BROTHERS, SONS AND DAUGHTERS. TO THAT END, THIS WEEK AS PART OF NATIONAL COLORECTAL CANCER AWARENESS MONTH DEEMED BY CONGRESS LAST NOVEMBER, I AM ANCHORING A FIVE PART SERIES ON THE TODAY SHOW. AND TO PROVE TO PEOPLE JUST HOW EASY AND IMPORTANT IT IS TO GET SCREENED, TOMORROW ON THE PROGRAM I WILL GIVE THEM THE TRUE "INSIDE STORY" – SHARING EXCLUSIVE VIDEO OF MY VERY OWN COLON, SHOT DURING MY FIRST COLONOSCOPY. THIS IS JUST THE BEGINNING.

THE BOTTOM LINE -- SO TO SPEAK -- IS THIS: I KNOW ALL TOO WELL, AS PERHAPS MANY OF YOU DO, ABOUT THE LIVES SHATTERED AND FAMILIES DEVASTATED BY THESE THREE WORDS -- YOU HAVE CANCER. OF COURSE, THERE ARE MANY HAPPY ENDINGS, BUT STILL TOO MANY SAD ONES. WE HAVE A

UNIQUE OPPORTUNITY TO CHANGE THAT. PLEASE MAKE SURE THIS DISEASE IS NO LONGER IGNORED OR WHISPERED ABOUT. NOBODY NEEDS TO DIE OF EMBARRASSMENT. EVERY PERSON SCREENED IS A POTENTIAL LIFE SAVED. KNOWLEDGE IS POWER.

THANK YOU SO MUCH FOR PROVIDING THE PEOPLE OF THIS COUNTRY, TRULY OUR GREATEST NATURAL RESOURCE, WITH THIS IMPORTANT INFORMATION, MOTIVATING THEM TO GET SCREENED, AND HELPING THEM LEAD LONGER, HEALTHIER LIVES.

THANK YOU SO MUCH FOR HAVING ME HERE TODAY.

The CHAIRMAN. Obviously, we thank you for your testimony, and we will take 5 minutes each on a round of questioning for Ms. Couric.

I think I feel like Senator Reid does. I think instead of calling you Ms. Couric, I am just going to call you Katie as well.

Ms. COURIC. No problem, Chuck. [Laughter.]

The CHAIRMAN. First I want to congratulate you and your network. This committee wants to raise awareness and knowledge of this type of cancer, but how can we help break the stigma of this disease, for educating people about colon cancer. Could you give this committee and Congress some advice on what we can do as a public body to break the stigma?

Ms. COURIC. I think proclaiming March as National Colorectal Cancer Month is a wonderful start because it will focus a lot of attention during the month, and hopefully other committees can talk about this issue if it is within their area of expertise.

I would be glad to include an emphasis in our literature the fact that Medicare does cover this, and I know that very few people, as you mentioned, Senator, take advantage of this. And I think that perhaps they just don't know. So I think part of the way we can do this is also focus on doctors, because I think sometimes doctors need to make sure their patients are aware of this. Oftentimes, doctors don't bring up colon cancer with their patients, and one doctor I know said, "Don't wait for an invitation."

But we should really educate doctors so the burden won't be entirely on the patient to say, "Let's talk about colon cancer screening. I am getting to be of a certain age or I am 65, does Medicare cover this?" I mean, I think this should be given to patients on a voluntary basis.

I read somewhere that only 5 percent of doctors take a complete family history, and that is so important when it comes to this disease. So, obviously, I think if we can target and do an education program for the physicians themselves, that would be extremely helpful.

And as I said, if I could be of any assistance in helping inform older Americans, in fact, I will make sure that I include that in my series because we haven't spent enough time focusing on them. But I will certainly be more than happy to do that and, again, to include it in the literature for the NCCRA.

I guess anything that you can do to raise awareness, if you can allocate more money for public service announcements specifically targeting people 65 and over, if you could hit publications like the AARP's publication or Modern Maturity or magazines like that that will hit or target that segment of the population, I think that would be advisable as well.

The CHAIRMAN. It is my understanding that your Research Alliance has launched a 5-year public education campaign, and you are doing this in collaboration with 25,000 chain pharmacies. It would be nice if we could see other organizations taking on a similar campaign.

I don't know whether you have had enough experience with this educational campaign yet, but what type of educational activities have proven to be effective or do you think will be effective?

Ms. COURIC. I haven't studied this exhaustively, to be honest with you. The National Association of Chain Drug Stores stepped forward as one of our partners in this, and they have allocated a million dollars to the education campaign. And one reason we wanted to use chain drug stores across the country is in this current era of managed care, many people get a lot of their medical information from their pharmacists. So we wanted to go somewhere and be present in a place where we thought would get a lot of traffic, where people would go and ask questions.

Many chain drug stores across the country are offering fecal occult blood tests at a reduced price to try to encourage people to at least take that step in terms of getting screened. So we are hoping that will be extremely effective.

Obviously, we are hoping public service announcements will be effective, the ones that I mentioned by Dennis Franz and some of the others who have participated. But all the PSAs in the world don't really mean anything if they are not placed during time slots when a lot of viewers are watching. If they are buried at 3 a.m., they don't do a heck of a lot.

So we have put some pressure, needless to say, on some of the broadcast networks, particularly NBC, to place my PSA in some prominent spots. It ran during "Providence," which is a very popular show. It ran during a golf tournament this weekend and will apparently run during the daytime as well. And I think ABC has made a similarly strong commitment to make sure that Dennis Franz's PSA is aired.

You know, we are open to suggestions. I am very new at this whole thing, and I am by no means an expert. Paul Stewart, who is a referee with the National Hockey League who saw my series in 1998 and was tested a day after his son was born and had, I believe, Stage IV colon cancer, is another great spokesperson who has volunteered his services and offered time at NHL games to run perhaps a PSA that he can put together.

This is really just the beginning of what we hope will be a long, sustained campaign. We don't want it to end at the end of March. We want it to be an ongoing process because it is one of those things where you have to nudge people and nudge people and nudge people until they finally acquiesce and talk to their doctors and get screened.

The CHAIRMAN. Thank you.

Senator Reid.

Senator REID. Once you made the decision that you were going to come public on this tragedy of your own life, what obstacles have you found in getting to the point where you are today?

Ms. COURIC. In terms of public awareness or——

Senator REID. Yes, just moving forward in your program, did you run into any problems with anyone or any organization, or has it been pretty easy to get here once you decided to come forward?

Ms. COURIC. Well, I think that we have had an incredibly unique opportunity in that we really have started on the ground floor. There are a number of very strong and passionate colorectal cancer groups, but we are all really neophytes and just embarking on this journey. So with a lot of other advocacy movements that are already established and people have already been fairly firmly

entrenched, we have this opportunity to start it, as I said, from the ground floor. And we have had a lot of cooperation from all the groups. We don't want to be dueling diseases, first of all, and we don't want to have dueling organizations working at cross-purposes. You know, we all want to join forces and work for the common good, as corny as that might sound. But we don't want to compete against each other.

But so far, we haven't really found many obstacles at all. People, I think after they get over the initial sort of discomfort or squeamishness about the disease itself and sort of turn their nose up at the notion of colorectal cancer—people can't even say it. But after they get over that, I think people are very, very enthusiastic because they see that we have this unbelievable opportunity to actually affect public policy and save lives, because there is such a disconnect between what people know about the disease and the number of deaths—as I said, it is the second leading cancer killer. We really feel that we have the opportunity to close the gap through screening.

And so it has been relatively easy to get people excited and involved.

Senator REID. In addition to the compassionate needs for coming forward, there will be testimony later today that will show prevention actually saves money. In the long run, the money we put forward for screening in the Medicare program will save the country money in Medicare dollars. So in addition to being the right thing to do from an emotional perspective, it is also the right thing to do from a financial perspective.

Ms. COURIC. Well, unfortunately, really widespread studies haven't been done comparing—doing a cost/benefit analysis, if you will, about widespread screening versus caring for people who have Stage III or Stage IV colon cancer. Some of those studies are being conducted right now. There was one at the Veterans Administration in Portland, OR, talking about screening colonoscopies which seemed to indicate they were quite an efficacious and quite life-saving and cost-saving procedure. Sid Winower, who is at Memorial Sloan-Kettering in New York, is now doing widespread studies about colon cancer screening and how beneficial they were—or they are or possibly might be. But I can't help but believe that it would be much more cost-effective to get people screened than to treat people, 130,000, or at least the 56,000 people who have advanced colon cancer, that it would be much less expensive to be screened.

I think one of the problems is that colon cancer hasn't gotten a lot of attention. So without a lot of attention, it hasn't gotten a lot of money. And without a lot of money, they haven't been able to do much research or conduct many studies.

In fact, the first-line chemotherapy treatment for advanced colon cancer, 5–FU, has been used since the 1950's. Only in the last couple of years have they come up with a second chemotherapy called CPT–11, which is now being used sometimes in conjunction with 5–FU.

So, you see, this cancer has really never gotten the attention it deserves, and as a result, it has never gotten the money it deserves or the research it deserves.

Senator REID. In past interviews, you have mentioned that the competition between pharmaceutical and biotech companies makes finding comprehensive information about the disease and treatment options difficult. Do you recall those interviews?

Ms. COURIC. Yes. I think I think that is probably a much bigger issue in terms of what biotech companies and pharmaceutical companies are doing in terms of their research, because obviously there is a lot of money in cancer research and in the formation and development of cancer drugs.

I think actually it has gotten much better since my husband was diagnosed in terms of finding helpful research about clinical trials. I know that the National Cancer Institute has beefed up its program, and there are all sorts of things on the Internet that are much more helpful. But at the time my husband was diagnosed, I found it very frustrating because it was very, very difficult for me to find good, available, understandable information about what was going on in the field of colon cancer research. And, sadly, I think the case really was there was not much going on in colon cancer research at that time my husband was diagnosed.

Senator REID. Thank you.

The CHAIRMAN. Thank you, Senator Reid.

Senator Collins.

Senator Collins. Thank you very much, Mr. Chairman.

Katie, I first want to express my admiration for your leadership in promoting public awareness of this disease. Through your courage and your candor, you have done more than anyone to encourage people to get the screenings that they need, and I really commend you and appreciate your efforts.

As I listened to your testimony, I was reminded of how far we have come in this country in encouraging women to get mammograms. Ten years ago, a lot of women were very reluctant. It was unpleasant, it was uncomfortable, it was too personal to discuss. And yet today, as we know from the testimony of Dr. Levin, who will testify next, four out of five women get the recommended screenings for cervical and breast cancer.

Does this suggest that, in addition to promoting awareness among us, the consumers, we need to do more to educate doctors to get them to recommend these screenings and to get people to talk about the issue?

Ms. COURIC. Yes, I think those are all issues and all areas that we need a lot of work on. We need to obviously get people feeling comfortable.

As I mentioned in my testimony, women didn't like to say "breast" and men didn't like to say "breast" in the context of breast cancer for a long, long time. And it has become part of the lexicon, as it should be. People are so concerned about their health, almost obsessed with their health these days, that to be squeamish or embarrassed or ashamed to talk about any part of your body I think is really a shame. And so, obviously, I think the more we discuss it openly and candidly and the more we say the words "colon" and "rectum" and "colonoscopy"—I know it is not easy; it took me a while to be able to say it as well—the better off we will be. I think that really is the first step, just getting it out there and starting a dialog.

You know, I hope in the future that doctors will be much more proactive, as I said, and much more aggressive with their patients and that policymakers will really be leaders in this area and get out there and be out front in terms of saying at what age you should get screened, what you really need to do, and that we will really focus on the research, because I sometimes feel that people under the age of 50, the 13,000 people who are diagnosed with colon cancer every year—like my husband, our executive producer Jeff Zucker, who was diagnosed when he was just 31—that they have no options, that they are basically a completely neglected segment of the population.

Dr. Ken Ford, the doctor who did my colonoscopy for me that I am airing tomorrow on the Today Show at 7 a.m. [Laughter.]

Not that we care about ratings. He was very forthright and honest about seeing more and more young people coming in with this disease, to the point where he said he would like people to really consider getting screened at 40. Many of the doctors I know themselves get screened starting at age 40, and that always tells me a lot.

So I think that we need to look very carefully at the guidelines, and if the research doesn't warrant changing the guidelines, maybe we need more research. And that is one of the main goals, as I mentioned, of alliance, to perhaps come up with some new diagnostic tools, perhaps a simple blood test or perhaps a test that will check for DNA in the stools to see if there is any genetic mutation going on and colon cancer might be developing. And virtual colonoscopies are being developed, which are obviously much less invasive. They are like MRIs.

Senator Collins. That is much more appealing.

Ms. COURIC. Yes, but they are really far away. And my one concern about talking about the future is that we will discourage people from getting tested today.

Senator Collins. One of the recommendations that we consistently hear is to increase our fiber intake and that that may help prevent this kind of cancer. As host of the Today Show you have interviewed—I have seen interviews of a lot of fad diets that are high protein and high fat but very low on fiber. Do you have any concern that these diet doctors are putting their followers at increased risks of colon cancer?

Ms. COURIC. Gee, I saw the hearing with all those diet doctors. I don't know if I want to step into this can of worms. But I can tell you, that what you all probably know to be true, that a sensible diet high in fruits and vegetables—and there is some evidence that folate or folic acid is very, very helpful. There is research being done on calcium, research being done on aspirin and so-called NSAIDs, non-steroidal anti-inflammatory drugs, which are some of those osteoarthritis medications, that holds a lot of promise as well.

The 15-year nurses' study done at Harvard by Harvard epidemiologists apparently showed that fiber wasn't that beneficial, but I am not sure it is conclusive, and fiber is certainly helpful in staving off a number of different diseases. I am going to continue to eat a lot of fiber as well.

In terms of those other fad diets, I think that people know going in they are not very healthy. They have got to. They are not idiots.

But we just need to keep reminding people through more, I guess, just sensible advice of the importance of eating a well-balanced diet, and, of course, a lot of red meat isn't considered all that good and high fat isn't considered all that good for overall health, not just for colon cancer.

Senator Collins. Thank you.

[The prepared statement of Senator Collins follows along with prepared statement of Senator Burns:]

PREPARED STATEMENT OF SENATOR COLLINS

Thank you, Mr. Chairman, for holding this hearing this afternoon to raise awareness about the risks and prevalence of colon cancer and the critical importance of colorectal cancer screening. I also want to commend the Ranking Member of our Committee, Senator Breaux, for his leadership in raising public awareness about these issues by introducing the resolution declaring March 2000, as the first National Colorectal Cancer Awareness Month.

Colorectal cancer is the second leading cause of cancer-related deaths in the United States for both men and women: more than 56,000 Americans will die from this disease this year. The sad irony is that cancer of the colon is probably the most treatable and survivable of all cancers, but only if it is detected and treated early.

Despite the fact that we have extremely effective screening tests for colon cancer and despite the fact that Medicare now covers these procedures, our screening rates for colon cancer—even among those Americans who are most at risk—are woefully inadequate. In 1997, only 41 percent of adults aged 50 or older had ever had a sigmoidoscopy for screening purposes, and only 39 percent of adults aged 50 and older reported having a fecal occult blood test. Moreover, even the addition in 1998 of a new Medicare benefit covering these services has not improved the situation. As the GAO will tell us later, in 1999, only 14.1 percent of Medicare patients had one or more of the newly covered tests for screening or diagnostic purposes. This is roughly equivalent to the rates in 1995, when only 13.6 percent of Medicare patients were tested.

Clearly, we must find ways to heighten public awareness about colon cancer and the importance of colorectal cancer screening services. As we will hear from our witnesses, this can literally be an issue of life or death for thousands of Americans and their families and, in the vast majority of cases, those deaths are avoidable. For far too long, Americans have been embarrassed or reluctant to talk about these issues, even with their physicians. This afternoon's hearing gives us the opportunity to set a new standard of objectivity, candor and public discussion about colon cancer.

Finally, Mr. Chairman, I want to express my admiration for the leadership of Katie Couric in raising public awareness of this disease. She has done more to encourage people to undergo screenings than anyone I know. I appreciate her courage and her candor.

PREPARED STATEMENT OF SENATOR CONRAD BURNS

Mr. Chairman, Thank you. I would like to first thank those who are presenting testimony before the Committee today. We all appreciate you for taking the time to be here today.

It is my hope that through this hearing we can begin to develop a better understanding of colorectal cancer and its diagnosis, treatment, and prevention. I am encouraged by the fact the colorectal cancer, if detected early enough, is almost 90 percent curable. However, we can see by the alarming death rates connected with this disease that the major problem is early diagnosis. We must encourage more utilization of the Medicare screening program, increase awareness of the importance of screening for the general population, and stress the importance of a healthy diet in an effort to prevent contracting the disease.

The rural conditions which exist in Montana exacerbate the problem. With nine counties without even one single doctor, Montanans must offer travel 100 miles or more to get access to a doctor. Often this must be accomplished during adverse weather conditions. I believe that in addressing the problems associated with rural health care we may also be able to increase the rates of early diagnosis and therefore effective treatment of colorectal cancer.

The fact that just over 40 percent of Americans who are at higher risk of developing colorectal cancer receive appropriate screening is a sobering one. Such low screening rates doom us as a society to continue to suffer the pain and loss that

this cancer brings. Let us commit today to bring down the occurrence of this disease and raise public awareness of its occurrence, impact, and treatment.

Again, thank you all for coming today. Hopefully by erasing the misunderstanding surrounding colorectal cancer and increasing awareness and screening we will reign in this killer.

The CHAIRMAN. Thank you, Senator Collins.

Senator Bayh.

STATEMENT OF SENATOR EVAN BAYH

Senator BAYH. Thank you, Katie, for being here. I would like to echo the words of my colleagues in expressing my appreciation for your presence. We have too much that divides this institution today, but we are gathered here as Democrats and Republicans across the ideological spectrum to help shine the light on an issue that has gone neglected for much too long.

You mentioned that there has really been no good cost/benefit analysis to date about early detection versus the cost of treatment. But I couldn't help but wonder, if 55,000 Americans were dying in combat, wouldn't the Nation be mobilized to do something about the cause of that? About the number of Americans who died in Vietnam pass away every year because of colorectal cancer, and it is about time we did something about this. And so I salute you.

I feel some personal connection to this, not because my family has been touched by this particular form of cancer, but my mother was diagnosed with breast cancer and spent the last several years of her life as a spokesperson for the American Cancer Society trying to do for women in the area of early detection for breast cancer what you are trying to do for the colorectal form of cancer. So I admire your work here today.

There are many unavoidable reasons why our loved ones are taken from us. Ignorance should not be one of them. In my State—Senator Reid mentioned the figures from Nevada—3,100 citizens were diagnosed last year with this form of cancer; 1,300 passed away. You mentioned that with early detection and treatment, 90 percent could be saved. And yet in Indiana, only 10.5 percent of people in the at-risk category, 10.5 percent were tested last year. We need to do better.

I would suggest to my colleagues your presence here today is going to do a lot. Our NBC affiliate from Indianapolis met me outside my office, at their initiative, I might say. There is an opportunity for all of us to follow—they were there because of you. They were there because of you, but it gave me an opportunity to talk about this issue and thereby give it more attention. And I would perhaps suggest that to my colleagues. We have NBC affiliates and others in all of our States.

Let me ask you just a few very brief questions. It is a tough thing when people are getting a disease with no family history and no symptoms. Is one of your messages to us today and to the public at large that really there is no substitute here for regular screening because, for many people, there will just be no advance warning?

Ms. COURIC. Yes. I think that one of the most shocking things about colorectal cancer, is oftentimes you are completely asymptomatic. And the time to get tested or screened is when you are feeling perfectly healthy, and that seems to be counterintuitive for

many people. They don't necessarily go to their doctors to practice preventive medicine or when they are feeling really well.

Clearly, if people have symptoms, such as blood in the stools, a change in stool shape—not to be gross or anything—a change in bowel habits, abdominal discomfort, a sudden loss of weight, fatigue that might be caused by anemia, certainly they should never kiss off those symptoms. They need to see their physicians immediately. Many people see blood in the toilet bowl and say, oh, I just must have hemorrhoids. Well, chances are they do. But there is also a chance that they don't.

So we want to make sure that those people go right away and get over any fear. But you are right, Senator Bayh. We want to tell people the time to be tested, the time to be screened, is when you are feeling well, because it is very insidious, it is very silent. As you all know, it starts with a polyp that becomes cancerous. And it is a very slow-growing cancer. Sometimes tumors take 10 years to develop. That is why you need to go get screened, get the potential cancerous tumor removed as soon as possible, and then continue to be monitored.

If you have no polyps, you only need to be screened every 5 to 10 years. But if you do have polyps, you have to be screened much more frequently. And I often say that no family history is no guarantee.

You know, I think sometimes we are lulled into a false sense of security when we think, oh, I have no family history of breast cancer, whew, I dodged that bullet, or there is no colon cancer in my family. Oftentimes, people don't even know their family histories because relatives can have colon cancer, but by the time it was diagnosed, it could have metastasized to a different organ, and the doctor perhaps didn't even know the primary source of the cancer.

So I would urge everyone to find out their family history, to talk with their relatives, but that, as I said, no family history is no guarantee. Even if you don't have a family history, you don't want to be the beginning of a family history as my husband was, because now, obviously, I will have to be extremely careful about our daughters.

But you are exactly right. The time to be screened is when you are feeling just great.

Senator BAYH. Mr. Chairman, could I ask one more question? And then a brief comment, Katie. You mentioned in your testimony that one of your long-term dreams is that insurance would routinely cover these screens. In our State, we have done that for breast examinations for women, and now health insurance sold in our State is required routinely to cover that for women. Do you feel this would be a significant step forward in preventing this disease from occurring to so many?

Ms. COURIC. Well, I think there are so many obstacles that keep people from being tested. The psychological one is something we have to deal with, and hopefully the more we talk about it and the more other people are screened and can spread the word about how easy it is, the better off we will be in that arena. But I think that insurance companies not reimbursing colonoscopies can be yet another obstacle.

Again, I am not sure what comes first, the chicken or the egg, if we are going to need these cost/benefit analyses. I think many insurers will pay for the procedure, for example, a colonoscopy, if the primary care physician or internist feels it is necessary, or if you have any kind of symptoms at all, or if you are over 50 and you are just concerned. I think, this is a very complicated area that I am not completely knowledgeable about. But certainly, yes, if insurance companies would pay for this, I think it would be a huge step and a huge motivator in terms of getting people to actually get screened.

I think sometimes now doctors say to their patients who are 50 or over, for example, have you ever had any abdominal pain? Have you ever in the last 20 years seen blood in your stool? And they will get around insurance companies that way? But I think doctors need to fight harder and public policymakers such as yourself could do great things by convincing insurance companies that in the long run this is a very, very cost-effective and humanitarian thing to do.

Senator BAYH. I think it is an excellent suggestion, and my final comment, Mr. Chairman, 4 years ago I had just turned 40 and had a significant unexplained weight loss, and they had eliminated about everything else and finally said, well, you are not really in the age category but you ought to have a colonoscopy done. So I did. And it was no big deal. I mean, certainly the temporary inconvenience was far outweighed by the peace of mind.

I admire you for what you are going to do tomorrow. I was able to, while the procedure was taking place, actually follow it on the monitor.

Ms. COURIC. Yes, I did, too. I talked the whole time.

Senator BAYH. I am not going to share it with the country, like you are, but——

Ms. COURIC. You didn't have a camera crew with you.

Senator BAYH. I did not. I did not. But I admire you for doing that and, again, would like to be helpful in this cause. So thank you for being here.

Ms. COURIC. Well, what happened? Why did you have unexplained weight loss?

Senator BAYH. Well, that is a good question. I am not sure we know to this day. Mostly stress coming——

Ms. COURIC. Oh, there you go.

Senator BAYH. I was Governor at the time. That is a stressful job, too, but——

Ms. COURIC. But your colonoscopy was fine?

Senator BAYH. It was great. As a matter of fact, they told me at that time—I heard Senator Reid mention every 4 or 5 years. They took off a couple benign polyps and said 6 or 7 years you should be good, we don't need to see you until then. So I thought really for the temporary inconvenience to have that peace of mind was well worth it.

Ms. COURIC. Well, that is good news.

The CHAIRMAN. Senator Hutchinson, and then Senator Lincoln.

Senator HUTCHINSON. Senator Bayh, if you could explain that unexplained weight loss, you might want to write one of those books, too. [Laughter.]

Katie, let me join my colleagues in commending you and expressing our appreciation. I can only imagine how painful it has got to be to have experienced the personal tragedy that you have experienced, but to turn that personal tragedy into something that is good and productive and positive and saving lives, I commend you very highly. And thank you for being before us today.

I have been struck by a lot of the grim statistics. I think as you have said that Congress did a very good thing in providing Medicare coverage for colorectal cancer screening, but the challenge is getting people to do it. And the 1998 figures I think were out of 38 million Medicare beneficiaries that would have been eligible, there were only 1 million who had the screening. And 1 million, that is a lot of lives potentially saved, but there are so many more who are not yet taking advantage of that.

Senator Bayh mentioned his State and said 10.5 percent. In Arkansas it is 11.4 percent, still well below the national average, which is pitiful, too, at 14 percent. So we have a lot of work to do, and I think what your organization is doing and what the CDC with its Screen for Life initiative and perhaps making March National Colorectal Cancer Awareness Month, these things I hope will help.

I was also struck, I think, if I heard you correctly, that only 15 percent is related to family history. Did I hear that correctly?

Ms. COURIC. Yes, 15 to 20 percent of cases involve family history.

Senator HUTCHINSON. This underscores the importance of getting that family history, but also that is a huge amount that has no such relationship. Are there predictors that—a lot of what we have talked about today is early detection, which is clearly the best thing that we could possibly do in saving lives. But research and prevention and other things that are being done in that area, how much?

Ms. COURIC. A lot. In fact, probably the more appropriate person to go into all this medical information will be Bernard Levin from M.D. Anderson, who is part of our Colon Cancer Alliance, part of the NCCRA. He is doing a tremendous amount of research on prevention and things that you can do from a lifestyle perspective to try to stave off this disease, the importance of things we discussed, like proper diet, exercise. Joggers have a very low rate of colon cancer, which you might have seen in the Time Magazine article. As I mentioned, some of the other minerals that they are talking about, like selenium, is something that has been discussed, calcium, folate acid, according to the Harvard epidemiology study——

Senator HUTCHINSON. I am smiling because I am taking all of those so far. [Laughter.]

Ms. COURIC. They are supposedly very helpful. Much of this research is in its early stages, so you can't really go out and tell the public do this, this, and this. Some things you can say, obviously, eating a balanced diet and exercising, and, of course, that is helpful no matter what kind of disease or malady you are talking about. But there is certainly a lot of research going on. There is research—hopefully I know that anecdotally some doctors have said if you have a family history of glandular cancers, like ovarian, prostate, breast, uterine, that sometimes you are at increased risk. My husband's mother passed away of ovarian cancer in the fall.

His grandmother had breast cancer. So I am not sure if that could have been some indicator. But many people say you need to be particularly vigilant if you have a family history of those cancers.

Again, I am not sure if there is clear-cut evidence. It might be largely anecdotal, but it is something certainly that I think researchers need to look into. People who have ulcerative colitis, like Senator Reid's wife, and other things like Crohn's disease, they need to be scoped I think earlier and more frequently than the average American.

So there are some indicators, but more research is needed to even figure out who may be at risk. There are certain genetic mutations that I think are present in some colon cancer cases. Dr. Levin is probably laughing at me struggling with all this medical stuff because I feel like I went to medical school, but I am certainly not a doctor. But one of the doctors on our alliance, Bert Vogelstein, who is a total brainiac from Johns Hopkins, discovered one of the genes involved in colon cancer, and there are certain family cases where there is a genetic mutation that is inherited.

I think the bottom line is that much more research needs to be done. We can sort of target those people because it would be great if we didn't have to screen the general population. But we could look at people who may be predisposed. But that is certainly way down the road.

Senator HUTCHINSON. This may be a question for the second panel, too, but how does colon cancer research stack up? I know there is a lot of competition sometimes for the scarce research dollars that we have tried to increase on NIH. But how are we doing in that regard?

Ms. COURIC. I don't think you are doing very well, to be perfectly honest.

Senator HUTCHINSON. It is the second leading cause of cancer death.

Ms. COURIC. Yes, I don't think that the amount of funding is proportionate to the number of lives that colon cancer claims, and I would love you all to try to do something about that.

Senator HUTCHINSON. I will sign the letter, Mr. Chairman. Thank you for calling the hearing, and thank you for your testimony.

Ms. COURIC. Thank you.

The CHAIRMAN. Senator Lincoln.

Senator Lincoln. Thank you, Mr. Chairman. And, again, I certainly appreciate you holding hearings bring about an awareness of issues. And certainly for you, Ms. Couric, this is fabulous. For you, as a public figure, to be able to really focus in on an issue like this, it can go far beyond what we can do in a regular hearing setting like this, and I think we all are here to compliment you and to tell you how much we appreciate the way that you have elevated the issue and allow us to begin to go back to the table and work toward additional funds, and certainly bringing about better awareness and being able to work with insurance companies and others to do more. We are very appreciative of that.

As my colleague from Arkansas mentioned, we still have 1,300 new cases of colorectal cancer diagnosed in a year among men and women. I think sometimes there is a little bit of a misnomer that

colorectal cancer effects more men than women, and certainly that it is something that affects older people rather than younger. But we will have 600 men and women in the State of Arkansas who will die this year of colorectal cancer, and it certainly makes sense that we should be here trying to do all that we can to improve that.

In terms of the National Colorectal Cancer Research Alliance that you have mentioned that you have played an enormous part in starting, I would be interested to know more about the mission and the goals of that alliance as well as if there are any resources there, resources provided through the alliance to assist families who are dealing with colon cancer at the time.

Ms. COURIC. We have under the auspices of the NCCRA, the CCA—everything is initials—the Colon Cancer Alliance, which I think is specifically made up of loved ones, survivors, and family members to help form a support group for other people.

Our main mission really is awareness and research, making people aware and then prompting them to get screened, and then providing the scientists with badly needed research dollars, unrestricted money, if you will, so they don't have to go through a cumbersome grant process that is often very bureaucratic and time-consuming and really often stops research in its track. We are hoping that if we can give these so-called unrestricted funds to prominent, exceptional scientists doing, as I said, cutting-edge research, they will be able to speed up what they are doing and we won't have to wait 5 or 10 or 15 or 20 years until we see the fruits of their labor.

So those are really our primary goals in terms of what the alliance is designed to do. The paradigm was really what Lilly Tartikoff did with raising money with Ronald Perlman of Revlon, which helped develop Herceptin, which is one of the newest drugs to be used in breast cancer treatment. And basically Lilly just raised gobs of money, gave it directly to scientists so they could proceed and work with different drugs and put them into clinical trials in different parts of the country and really put these therapies on the fast track.

So we are the kind of people we want things done yesterday, and we are hoping that the money we raise will enable the scientists to do what they do best.

Senator LINCOLN. Well, I think that is great, and certainly the push, as you said, wanting things done yesterday, is a critical part of it, and the stories that you collect of families from those who have suffered. If there is anything I have found in my short time on Capitol Hill, it is that when dealing with colleagues and others on issues, a real-life story has a lot more punch than numbers or something you might get out of an almanac.

Ms. COURIC. That is why we wanted to focus on Mickey Litteri this morning on the Today Show. The nicest, sweetest, in his own admission, average guy, 58 years old, was a gym teacher in New York, never got sick, was always healthy. His wife pushed him into getting a colonoscopy. He had seen my series or read an article about what had happened to Jay. He went and got tested. There was a cancerous polyp, and as he said this morning on the Today Show, if he hadn't been screened, 2 years from now there would be no Mickey Litteri.

So it is those kinds of personal stories, and I think that people who have been touched by this disease are so desperate to have an advocate, they feel like nobody has really spoken out for them or the people they love, that people haven't felt comfortable even talking about the disease in memory of someone. So the response we have gotten has been absolutely incredible, people so thrilled that finally this disease is being brought out of the closet, if you will, and put on the front burner and getting the attention it deserves.

Senator LINCOLN. That is great, and the only thing that I would add is I went to school down the road from you. I was at Randolph-Macon when you were at UVA.

Ms. COURIC. Oh.

Senator LINCOLN. So I know a lot of your classmates. But one of the things that I hope that the alliance will do is to target men and women in their 30's and 40's, because if we don't begin to instill those habits at a good time when they are 30 and 40, it is going to be even more difficult as they get older. We may miss the opportunity to save their lives.

Seeing how we can target that age group is going to be critical.

Ms. COURIC. Well, hopefully you all can allocate more money so that the necessary research on what is really happening in the population at large can be done and then public policy can be formulated as a result. And in terms of Senator Grassley hitting the people who are 65 and over, perhaps you all can have task forces in your own States to talk about the best way to direct this information, whether it is through the Committee on Aging or various aging organizations within your States to talk about having nursing homes be part of a public awareness campaign. I am sure there are a lot of volunteers in your State who have been affected by this disease who would be more than willing to even travel to nursing homes or to senior citizens' community centers to talk about this and to talk to doctors as well.

So I think the potential to do something is great. You just have to take it from the discussion stage and actually put your money where your mouth is and make sure that action is taken and that the right people are targeted in the right way and that this is followed through.

Senator LINCOLN. Thank you, Mr. Chairman.

The CHAIRMAN. I have no further questions. Do any of my colleagues have maybe one short question they want to ask? [No response.]

Do you have any last thing you want to say to the committee?

Ms. COURIC. No. I just really appreciate your time. I appreciate your compliments. But I want you all to know that I think I am doing what anyone in my position would be doing in a similar situation. Because I have this forum, hopefully people feel comfortable watching me and know a little more about my life than sometimes I wish they did, but I feel like this is a really incredible opportunity and a gift, that I have been given to get the word out, and I am so pleased to be able to be a part of that.

The CHAIRMAN. We thank you very much. Now we will turn to the second panel.

Ms. COURIC. OK. Thank you.

The CHAIRMAN. I would ask the second panel to come while I am introducing you. And if I pronounce any of your names wrong, please correct me.

Our first witness is Shirley Heiligman, who is 72 years of age, and a Medicare beneficiary. She discovered that she had colon cancer after receiving a Medicare-covered colorectal cancer screening. She will testify today about why she decided to have the test performed, how the Medicare benefit helped her, and about ways to inform other seniors how important it is to be tested for this disease.

Then we have Dr. William Scanlon, Director of Health Financing and Public Health Division at the General Accounting Office. Earlier this year, I asked Dr. Scanlon to look into the utilization of the Medicare colon cancer screening benefit. Dr. Scanlon will testify on the results of his findings and the reasons why we seem to have low utilization of this benefit.

The third witness, Michael McMullan, is Deputy Director, Health Care Financing Administration, Center for Beneficiary Services. Ms. McMullan will provide a description of the Health Care Financing Administration's Medicare beneficiary preventive screening program and the educational efforts connected with it. And she will also discuss how HCFA is trying to reach minority populations to educate them on the importance of screening.

And our final witness today is Dr. Bernard Levin, who will provide expert testimony as a practicing physician and researcher. He is vice president for cancer prevention, at the University of Texas, at the Anderson Cancer Center, and a member of the American Gastroenterological Association. He engages in beneficiary and provider colorectal cancer screening education and will identify the segments of the Medicare beneficiary population at greater risk for developing colorectal cancer and efforts needed to educate those beneficiaries and their primary care providers.

We will start with you just the way we introduced you. Would you go ahead, Shirley?

STATEMENT OF SHIRLEY HEILIGMAN, NEW YORK, NY

Ms. HEILIGMAN. Well, unaccustomed as I am to public speaking, following Katie Couric is a real hardship.

I just wanted to say that this is a most unusual Monday for me because ordinarily I would be getting my chemotherapy treatment. But my doctor was so delighted that I was coming down that he was flexible about changing that.

Only about 2 weeks ago, I had asked my oncologist if there wasn't some advocacy group that was working to make the public more aware of colorectal cancer, and I immediately got in touch with the Colon Cancer Alliance. And at their request I am here today to discuss my personal history.

In 1993, at my doctor's suggestion, I went for a routine sigmoidoscopy because my sister had had colon cancer about 5 years earlier. Fortunately, she is just fine today, and that screening showed no evidence of the disease for me. Then in October 1998, 5 years later, I went for a routine colonoscopy on the advice of my internist, although I was in excellent health and had absolutely no symptoms.

Unfortunately, this screening was blocked by a malignant tumor. Further scans and biopsy revealed metastases. Coincidentally, and luckily, Medicare coverage had just recently become available for these procedures. Surgery was performed in November 1998 followed by chemotherapy. As Katie Couric mentioned, there are only two drugs available for my cancer, and both were ineffective. I am currently on an experimental protocol at Memorial Sloan-Kettering, and so far it seems encouraging.

The doctors feel that I have had minimal side effects because of my general good health and my very positive spirit, which has allowed me and my family to maintain a very fair quality of life. How secure it is to have Medicare enlisted in this fight.

A more intense screening the first time around, specifically at my age, might have kept the disease localized, but that is hindsight. It is time now to educate both medical providers and patients to the importance of proper testing early on, and this must be free from concern about financial coverage. The cost of screenings are a drop in the bucket compared to the thousands of dollars for what can be many years of treatment.

Hopefully, your designated National Colorectal Cancer Awareness Month, going on right now, will be a very meaningful start. Friends have advised me that they receive solicitations and information about just about every disease in the book, but they have never, ever received anything specifically on colon cancer. I think we need more funds for research, legislation requiring insurance providers to cover appropriate testing, and more help to organize a more efficient campaign for reaching out to the medical profession and to the public. We need to accept the whispered word "colon" as we learned to accept the private word "breast." I am delighted to be here to speak out. I thank the Colon Cancer Alliance for their progress, for Katie Couric's group, and for this committee showing their interest. Thank you.

[The prepared statement of Ms. Heiligman follows:]

February 29, 2000

United States Senate
Special Committee on Aging
Washington, DC 20610-6400

Dear Senator Breaux, Senator Grassley and others on the committee,

Thank you for my opportunity to speak before you on March 6.

My name is Shirley Heiligman. I am married with two sons and two grandsons, and am a life-long resident of New York City. I worked as a travel consultant for thirty years. After retiring, I became a volunteer advocate for foster children in the Manhattan Family Court. Today, I am here as a member of the Colon Cancer Alliance, a national organization dedicated to support and advocacy for those touched by colorectal cancer.

My journey with colorectal cancer began in the late 1980's. My sister was diagnosed with colorectal cancer in 1988. After surgery and a short treatment course, she recovered and is doing well today.

In 1993, my doctor recommended that I be screened for colorectal cancer. He performed a sigmoidoscopy, in which a slender flexible lighted tube was used to inspect the lower third of my colon. The test was negative, and my doctor pronounced me to be in excellent health. In hindsight, a test which examines the entire colon, such as a colonoscopy or double-contrast barium enema, might have found my cancer earlier.

In October 1998, my doctor recommended that I have a routine screening colonoscopy which was luckily covered by Medicare. A colonoscopy uses a flexible lighted probe which can examine the entire colon and remove small polyps. I felt great and had no symptoms of illness, but the colonoscopy detected a tumor. Further diagnostic tests and surgery in November 1998 showed that the tumor had metasticized and spread to my lymph system.

There are two approved chemotherapy drugs for treatment of colorectal cancer – 5-fluorouracil and Camptosar. My cancer was non-responsive to both drugs so I began to look for other treatment options. Fortunately I live near Memorial Sloan-Kettering Cancer Center, an institution known for its excellent research. I have enrolled in an experimental protocol at Sloan-Kettering; the protocol is presently showing good results. I have minimal side effects from the treatment; this has allowed me to maintain an adequate quality of life.

I have also begun to work with the Colon Cancer Alliance, a national patient advocacy and patient support organization. I am committed to raising awareness about this very preventable disease.

I was fortunate that my colonoscopy occurred in 1998. Prior to 1998, screening for colorectal cancer was not covered by Medicare. I find it very alarming that insurance companies are not routinely required to cover screening for colorectal cancer. It is my understanding that the risk of colorectal cancer increases after age 50 and for those with a family history of the disease. It seems to me that insurance coverage of colorectal cancer screening should be required for everyone at higher risk.

I believe that the best way to increase screening rates for senior citizens is to educate their doctors. Colorectal cancer screening should be a routine annual procedure, recommended uniformly by all physicians.

I also believe that general awareness and education efforts are very important. Senior citizens need to learn that these tests will detect colorectal cancer before their lives are threatened. Senior citizens need to feel comfortable asking their doctors about screening and talking about some of the common symptoms of colorectal cancer such as blood in stools, or a change in bowel habits.

The Senate has helped with awareness efforts. On behalf of the Colon Cancer Alliance, I applaud the Senate for passing Colorectal Cancer Awareness Month legislation in November 1999. The Colon Cancer Alliance is happy to be working with 34 other organizations in the country to make March 2000 -- the first National Colorectal Cancer Awareness Month -- a success across the country. Our members are working hard to get the word out about awareness and screening.

I would also like to thank Miss Couric for her efforts in raising awareness and increasing the research dollars available for colorectal cancer, two critically important goals. I have no doubt that her efforts and commitment will save many lives.

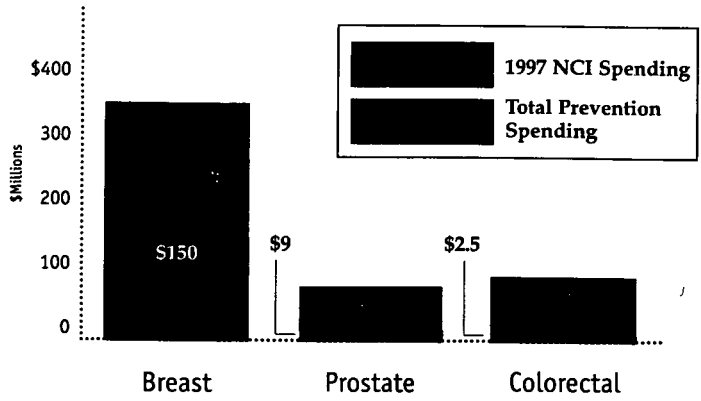
In closing, as a life-long New Yorker, I would like to tell you about my personal favorite awareness effort. You may have noticed my blue ribbon. Blue symbolizes colorectal cancer survivorship, in the same way that Miss Couric's organization has made a silver star the symbol of colorectal cancer awareness. On March 15 and 16, the Empire State Building will be bathed in blue light, on behalf of colorectal cancer survivors and in memory of those who have lost their battle.

Thank you again for inviting me to speak.

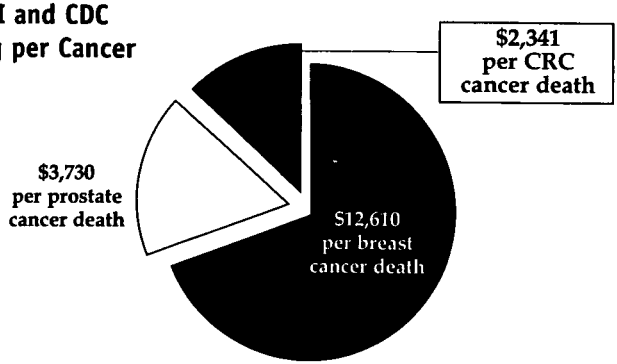
Shirley Heiligman
116 East 66th Street
New York, NY 10021
Email contact via Nroach@CCAlliance.org

The Colorectal Cancer Gap

COLON CANCER ALLIANCE



1999 NCI and CDC Spending per Cancer Death



Source: ACS, CDC, NCI

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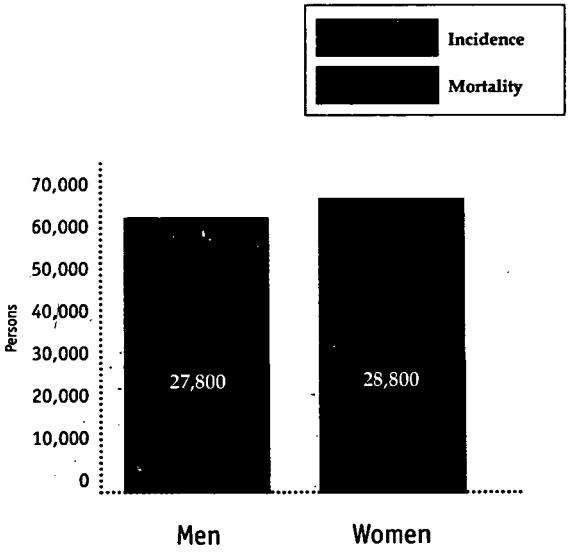
CRC Incidence and Mortality Rates

COLON CANCER ALLIANCE



Source: ACS cancer facts and figures 1999

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The CHAIRMAN. Thank you, Shirley.

We are going to have everybody testify, and then we will ask questions. So just wait, please.

Dr. Scanlon.

STATEMENT OF WILLIAM J. SCANLON, DIRECTOR, HEALTH FINANCING AND PUBLIC HEALTH ISSUES, UNITED STATES GENERAL ACCOUNTING OFFICE, WASHINGTON, DC

Mr. SCANLON. Thank you very much, Mr. Chairman and Members of the Committee. I am very pleased to be here today as you discuss efforts to reduce the incidence and mortality related to colorectal cancer through greater use of screening and diagnostic services.

Screening, as we have heard, can detect the disease early and in many cases prevent colorectal cancer, yet only about a third of all colorectal cancers are diagnosed at an early stage when survival rates can reach 90 percent.

You have asked us to examine the extent to which Medicare beneficiaries are using colorectal cancer screening and diagnostic services and potential efforts to address barriers that might limit their use. Regrettably, despite the fact that the medical community agreed upon a unified set of clinical practice guidelines for colorectal cancer screening in 1997 and Congress expanded the Medicare coverage to include colorectal cancer screening services that same year, Medicare beneficiaries' use of screening and diagnostic services falls far short of the recommended guidelines.

In 1999, only 14.1 percent of beneficiaries used any of the covered services, either a fecal occult blood test, a flexible sigmoidoscopy, colonoscopy, or barium enema. Although the guidelines recommend annual fecal occult blood testing for all people age 50 and older, only 9 percent of Medicare fee-for-service beneficiaries had that test. Flexible sigmoidoscopy exams were significantly rarer, with only about 2 percent of beneficiaries receiving one. The use of these services has remained virtually constant since 1995. Making them—Medicare-covered services has not led to a perceptible increase in their use.

While we are accustomed to widespread variation in the use of medical services, even the States doing the best in terms of these services are not doing very well. Hawaii, Massachusetts, and Maryland lead the country with only about 20 percent of their beneficiaries using any of these services.

These data apply to Medicare beneficiaries in the fee-for-service program. Comparable data are not available for Medicare beneficiaries in Medicare+Choice plans. However, research suggests that enrollees in managed care plans are at least as likely to have colorectal cancer screening as those in fee-for-service Medicare. But two-thirds of the studies indicate that the health plans are doing no better than the fee-for-service sector.

Enrollees in group and staff model HMOs who account for about a quarter of Medicare beneficiaries in managed care were significantly more likely than those in fee-for-service Medicare or in other types of HMOs to obtain all types of preventive services. Nevertheless, even their rates for colorectal cancer screening are likely falling well below the recommended levels.

There are a number of possible reasons why rates have remained so low. Patients may not be aware of the benefits of screening, in particular that screening can make an important difference in survival rates. Many persons may find the screening procedures overly invasive, unpleasant, or embarrassing, as we have heard today. This is seen as a significant barrier even in the case of fecal occult blood test screening. Finally, patients may not realize that Medicare coverage has expanded.

Physicians' practices may also affect screening rates. Some doctors may lack the time to inform patients about the need for screening and explain the procedures. They may also lack the skills and appropriately trained staff to perform flexible sigmoidoscopy. Physicians may also be unfamiliar with the guidelines which only relatively recently have achieved broad-based support.

As you have indicated, and as we will likely hear more from Ms. McMullan, HCFA and the CDC are working together along with other agencies in the Department of Health and Human Services to promote screening. Publicity and education are very powerful tools in this endeavor. I would draw a parallel between this situation and our efforts to combat breast cancer. In the past decade, a wide array of activities—public sector, private sector, non-profit—have dramatically increased awareness regarding the benefits of mammography and its use.

In 1999, 80 percent of women over 65 reported having a mammogram within the past 2 years. That is the recommended frequency. In 1992, the year after Medicare added mammography screening as a covered service, the percentage was 55 percent. Patient awareness did make a difference.

Encouraging physicians and health plans might also be beneficial. Use might increase if colorectal screening were part of the HEDIS measures, which are used to assess HMO performance. Scorecards that compare plans' provisions of preventive care services can motivate HMOs to devote increased attention to such procedures. Work is underway, fortunately, to try to develop a colorectal cancer screening measure that could be included as part of HEDIS.

In conclusion, I would note that our data indicate that the use of screening and diagnostic services is very low among Medicare beneficiaries and is very disappointing. The consensus on recommendations regarding appropriate clinical practice and the expansion of coverage to ensure reimbursement need to be viewed only as first steps. Broad-based and continuing efforts to enhance public awareness of the risk of colorectal cancer and the benefits of screening are critical to improve the use of these services over time.

Mr. Chairman, that concludes my statement, and I would be happy to answer any questions you or other members of the committee may have.

[The prepared statement of Mr. Scanlon follows:]

United States General Accounting Office

GAO

Testimony

Before the Special Committee on Aging,
U.S. Senate

For Release on Delivery
Expected at 1:00 p.m.
Monday, Mar. 6, 2000

MEDICARE

Few Beneficiaries Use Colorectal Cancer Screening and Diagnostic Services

Statement of William J. Scanlon, Director
Health Financing and Public Health Issues
Health, Education, and Human Services Division

GAO/T-HEHS-00-68

Mr. Chairman and Members of the Committee:

We are pleased to be here today to discuss the use of Medicare-covered screening and diagnostic services to prevent colorectal cancer and minimize its effect on beneficiaries' health status through early detection and treatment. Colorectal cancer is the second leading cause of cancer death in the United States. Currently, only about a third of all colorectal cancers are diagnosed at an early stage. Widespread screening aims to detect the disease early, and in many cases, the detection and removal of precancerous growths may actually prevent colorectal cancer. The Balanced Budget Act of 1997 expanded Medicare coverage to include colorectal cancer screening services. The Congress' decision to include colorectal cancer screening as a Medicare benefit reflected an awareness that early screening and detection are important to maintaining beneficiaries' health.

At your request, we examined the extent to which this new preventive health service has been used since its addition to the Medicare benefit package. Accordingly, my remarks will focus on (1) the extent to which Medicare beneficiaries (both aged and disabled) are using colorectal cancer screening and diagnostic services and (2) efforts to address barriers identified as limiting use. To do this analysis, we determined patient use rates from Medicare claims data from 1995 through June 1999.[1] We could not measure use rates for screening services alone because of coding and other technical issues.[2] In addition, we reviewed recent literature and obtained information from medical specialty organizations, patient advocacy groups, agencies in the Department of Health and Human Services (HHS), and several health maintenance organizations (HMO) with Medicare contracts.

In brief, we found that the use of colorectal cancer screening and diagnostic services by Medicare beneficiaries is very low relative to recommended use rates and has remained almost unchanged over the past 5 years. Although guidelines recommend annual fecal occult blood testing for all people aged 50 and older, only 9 percent of fee-for-service beneficiaries received that test each year. Use rates for flexible sigmoidoscopy are significantly lower and have also remained constant at about 2 percent of beneficiaries. Women's use of some colorectal cancer screening and diagnostic services was slightly

[1]We used physician claims from Medicare's 5 percent Standard Analytic File, which contains all claims for a 5 percent sample of Medicare Part B beneficiaries.

[2]We included diagnostic and treatment codes in developing our use rates because it is likely that at least some services coded as diagnostic are for screening. In fact, one study has estimated that approximately 44 percent of beneficiaries who had a diagnostic fecal occult blood test in 1995 could be identified as lacking clinical evidence of a digestive system disease or general symptoms and therefore represented a screening population. In addition, physicians might not have used the new screening codes consistently on their 1998 and 1999 claims for colorectal cancer screening since the amount reimbursed for the new screening services was the same as that for diagnostic services. Furthermore, colonoscopies begun as a screening procedure are coded as treatment procedures under certain circumstances, such as if a polyp is removed.

higher than men's, and white beneficiaries received the services at somewhat higher rates than African Americans, Asians, and Hispanics. Although use data are not available for Medicare beneficiaries in HMOs, research suggests that enrollees in managed care plans are at least as likely to have colorectal cancer screening as those in fee-for-service Medicare. Various factors contribute to the low use of screening and diagnostic services, some of which are beginning to be addressed by public health agencies and private organizations. Key among these is poor patient awareness of recommendations and coverage for screening, physician reluctance to perform the procedures because of the time and complexity involved, and lack of monitoring systems to encourage greater use.

BACKGROUND

Colorectal cancer is the third most commonly diagnosed cancer for both men and women in the United States. An estimated 129,400 new cases and 56,600 deaths from colorectal cancer were expected in 1999. Among the general population, the colorectal cancer mortality rate in 1997 was 21.6 per 100,000 individuals. Broken down into demographic groups, the mortality rate for African Americans was twice that for Hispanic, Asian, or Native Americans, and for men it was more than 40 percent greater than that for women.[3] According to medical experts, the risk factors for colorectal cancer include older age, family history, certain hereditary conditions, a diet high in saturated fat and low in fiber, excessive alcohol, and sedentary life style.

Research shows that the number of people developing and dying of colorectal cancer could be reduced through screening (identifying people with precursors to or early signs of the disease) and surveillance (monitoring people with previously diagnosed colorectal disease). Studies have shown that in the majority of colorectal cancers, noncancerous polyps grow slowly for 10 years or longer in the colon in a benign state before becoming cancerous. Identification and removal of the polyps during that time can prevent colorectal cancer from developing. In 1997, a consortium led by the American Gastroenterological Association produced clinical practice guidelines to address uncertainty about the choice and frequency of screening tests for different groups of patients.[4] For people at average risk of developing colorectal cancer, the practice guidelines recommend that people aged 50 and older have a fecal occult blood test annually, a flexible sigmoidoscopy every 5 years, an optional double-

[3]Mortality rates per 100,000 in 1997 were 28.8 for blacks, 21.1 for whites, 14.5 for Native Americans, 13.5 for Asians, 12.8 for Hispanics, 26.0 for men, and 18.4 for women. See HHS, Healthy People 2010 (Washington, D.C.: 2000).

[4]These guidelines were based on work initially funded by the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality, or AHRQ). After the agency discontinued its guideline program in May 1996, the project was completed with funding from several professional associations in fields related to gastroenterology. The American Cancer Society, the Crohn's and Colitis Foundation of America, and a number of other organizations have endorsed the guidelines.

contrast barium enema every 5 to10 years, and a colonoscopy every 10 years. For groups at high risk, experts recommend more frequent screening through colonoscopy.

The Medicare benefit for colorectal cancer screening addresses several of the clinical practice recommendations. Before January 1, 1998, Medicare covered the fecal occult blood test, sigmoidoscopy, colonoscopy, and barium enema only for diagnosis and treatment, such as for evaluating a specific complaint or monitoring an existing medical condition. The Balanced Budget Act of 1997 extended coverage of these services for screening purposes, with no coinsurance and deductible for the fecal occult blood test. For all other tests, the cost sharing is the same as for treatment services, which is payment of 20 percent of the Medicare approved amount after the yearly deductible.[5] For people at average risk for colorectal cancer (those with no predisposing factors), Medicare now pays for a screening fecal occult blood test every year and a screening sigmoidoscopy every 4 years for beneficiaries aged 50 and older. In addition, for individuals at high risk, Medicare covers a screening colonoscopy every 2 years.[6] For both risk groups, a double-contrast barium enema may be substituted at the same frequency as the sigmoidoscopy or the colonoscopy, if the physician believes that it is appropriate.

FEW BENEFICIARIES HAVE COLORECTAL CANCER SCREENING OR USE DIAGNOSTIC SERVICES

Overall use of colorectal cancer screening and diagnostic services among Medicare beneficiaries is generally low. Despite the issuance of the clinical practice guidelines in 1997 and the expanded Medicare benefit that became effective in 1998, use has not changed significantly since 1995. Use rates for these services varied slightly among demographic groups and across states. Studies show that the use of colorectal cancer screening services in managed care health plans is the same as or higher than in fee-for-service arrangements.

Overall Use of Colorectal Cancer Screening and Diagnostic Services Remains Low

Despite the fact that nearly all older Americans report having a regular source of health care and a large majority report receiving routine checkups, Medicare beneficiaries' use of colorectal cancer services falls far short of recommended levels. In 1999, 14.1 percent of beneficiaries had one or more of the covered services (fecal occult blood test, flexible sigmoidoscopy, colonoscopy, or double-contrast barium enema) for screening or diagnostic

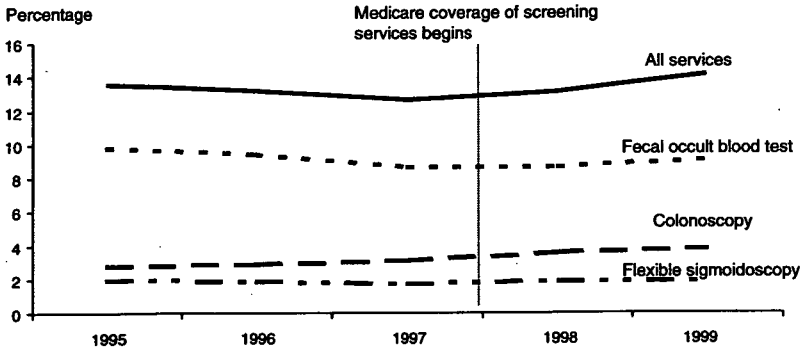
[5]The President's proposed budget for fiscal year 2001 calls for eliminating copayments and deductibles for these services to further facilitate patient's access to care.

[6]There is no minimum age for a screening colonoscopy for high-risk beneficiaries.

purposes.[7] Overall use is roughly equivalent to rates in 1995, when 13.6 percent of beneficiaries used any of these services.

Among the colorectal cancer screening and diagnostic services, the most common and least invasive is the fecal occult blood test. In 1999, the use rate for this service was 9.1 percent of beneficiaries, well below the recommended rate of once a year.[8] In the same year, the use rate for flexible sigmoidoscopy, which is covered every 4 years, was 1.9 percent, while 3.8 percent of beneficiaries received a colonoscopy.[9] Figure 1 shows use rates for these services over the past 5 years.

Figure 1: Little Change in Medicare Beneficiaries' Use Rates for Colorectal Cancer Screening and Diagnostic Services, 1995-99



Note: The rate for all services includes beneficiaries who received a barium enema (not shown separately). Data for 1999 were based on claims paid from January to June 1999.

Source: GAO analysis of Health Care Financing Administration claims data.

[7]We estimated 1999 use rates from claims paid between January and June 1999. The overall use rates include treatment colonoscopies because such procedures may have been initiated for screening purposes. Although screening colonoscopy is covered only for beneficiaries at high risk for colorectal cancer, diagnostic and treatment colonoscopy is covered for all beneficiaries.

[8]This may be an undercount of actual use. Because fecal occult blood testing is inexpensive (payments average less than $4.00 per service), it may be performed more often than it is billed to Medicare.

[9]We did not separately identify rates for double-contrast barium enema because use was extremely low.

Similar data are not available on the use of colorectal cancer services by enrollees in the Medicare managed care program, called Medicare+Choice, because the Health Care Financing Administration (HCFA) does not require Medicare+Choice plans to report patient-specific data. However, evidence suggests that colorectal cancer screening rates among Medicare HMO beneficiaries may be similar to or higher than use rates among fee-for-service beneficiaries. In a recent synthesis of studies on the use of preventive care, researchers found that enrollees in managed care plans were at least as likely as those in other plans to obtain colorectal cancer screening services.[10] One-third of comparisons of colorectal cancer screening use found that managed care enrollees were more likely to use the services and two-thirds of comparisons found no difference in use between enrollees in managed care plans and nonmanaged care plans. Enrollees in group and staff model HMOs—which accounted for 4.4 percent of Medicare beneficiaries in 1998—were significantly more likely than those in fee-for-service Medicare or other types of HMOs to obtain preventive services in general.

The Use of Screening and Diagnostic Services Varied Slightly Among Demographic Groups and States

Analyzing use rates by patients' demographic characteristics, we found that use varied only slightly by age, race, gender, and geography. These rates also remained relatively constant over the 5-year study period. (See appendix for a breakout of demographic and geographic differences in use rates.) Specifically,

- Women had higher use rates in 1999 for fecal occult blood test (about 10 percent, compared with 8 percent for men) and similar rates for flexible sigmoidoscopy and colonoscopy.

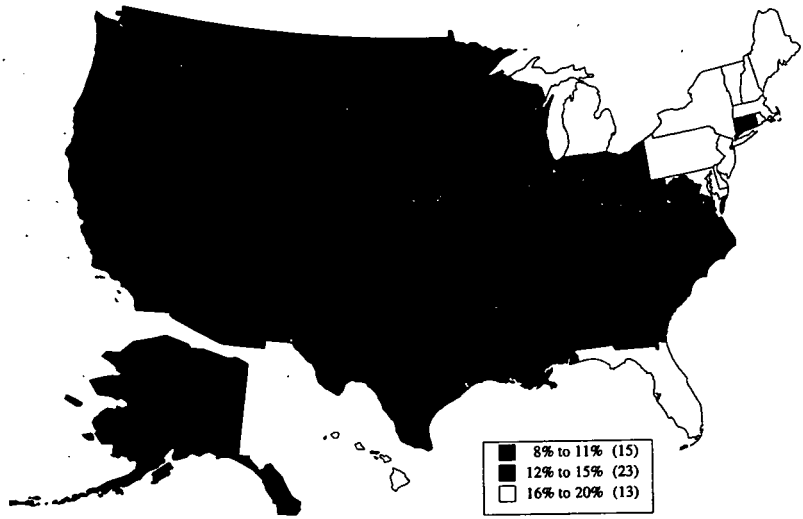
- Beneficiaries aged 70 to 79 were most likely to use screening and diagnostic services, but their use rates were only about 13 percent higher than for those aged 65 to 69 or 80 to 84.

- White beneficiaries received the screening and diagnostic services at consistently higher rates (about 15 percent in 1999) than Asians (about 13 percent), African Americans (approximately 9 percent), or Hispanics (approximately 8 percent).

- In general, a higher percentage of beneficiaries in Massachusetts and Rhode Island (18 to 20 percent) received screening and diagnostic services consistently over the 5-year period than beneficiaries in other states. (See figure 2 for more information about use rates across states.)

[10]Kathryn A. Phillips and others, "Use of Preventive Services by Managed Care Enrollees: An Updated Perspective," Health Affairs, vol. 19, no. 1 (Jan.-Feb. 2000), pp. 102-16.

Figure 2: States Varied in Use Rates for Colorectal Cancer Services, 1999



Source: GAO analysis of Health Care Financing Administration claims data.

EFFORTS TO OVERCOME BARRIERS TO COLORECTAL CANCER SCREENING

Many factors affect the use of colorectal cancer screening services, including patient, physician, and delivery system issues. Some patients find the procedures overly invasive, and others, including some physicians, may be unaware that an effective preventive opportunity exists and that Medicare provides coverage. In addition, the lack of attention to colorectal cancer screening compared with other preventive services may also be a reason for its low use. Federal agencies, medical societies, and patient groups are undertaking a variety of initiatives to improve the use of colorectal cancer screening.

Patient Barriers

Researchers have identified a lack of patient awareness, understanding, and inclination as the most significant factor inhibiting the use of colorectal cancer screening services. In a

1997 report, the Agency for Healthcare Research and Quality (AHRQ) found a very low level of awareness about the risks of colorectal cancer and its symptoms among adults. It also found that people are more likely to participate in screening when they understand the nature of the disease and feel they are at risk for it. Good communication between health care providers and patients and the effective use of educational materials could enhance patient participation in screening, AHRQ researchers concluded.

Although information for patients is essential, it may not be enough.[11] In 1998, the Centers for Disease Control and Prevention (CDC), in partnership with HCFA, conducted 14 focus groups with adults aged 50 and older to examine the factors that inhibit appropriate use of colorectal cancer screening. Consistent with AHRQ's 1997 study, CDC found that the participants were not aware that colorectal cancer is the third most prevalent cancer, nor were they aware of the benefits of screening and early detection. However, the focus groups also revealed that older adults, particularly those older than 65, are unwilling to discuss issues of colorectal cancer screening, even with their physicians.[12] Representatives of several physician and patient groups echoed these results, telling us that many people find colorectal cancer screening tests inconvenient or embarrassing or that they may be concerned about potential discomfort during the screening.

Because Medicare now covers colorectal cancer screening services, HCFA is taking steps to promote beneficiary awareness of the new benefit, as are other agencies within HHS. For example,

- HCFA's Medicare and You handbook, which was mailed last year to all beneficiaries, describes the colorectal cancer screening benefit along with other covered preventive services. In addition, HCFA has distributed pamphlets regarding colorectal cancer screening to beneficiary groups, posters for senior citizen centers, and television and radio public service announcements, some of which target women and African Americans.

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[11]A recent study of elderly patients visiting their primary care providers for routine office visits examined the effect of information on preferences for colorectal cancer screening. It found that a large proportion preferred not to be screened and concluded that factors other than information determine screening decisions. See A. M. Wolf and J. B. Schorling, "Does Informed Consent Alter Elderly Patients' Preferences for Colorectal Cancer Screening? Results of a Randomized Trial," Journal of General Internal Medicine, vol. 15, no. 1 (Jan. 2000), pp. 24-30.

[12]CDC expected to find a certain level of reluctance regarding sigmoidoscopy, colonoscopy, and barium enema, which are involved screening tests that require significant preparation and, in some cases, a hospital (usually outpatient) visit. They were surprised to find resistance to the fecal occult blood test, which patients reported as unpleasant, confusing, and frustrating.

- Along with the American Cancer Society, CDC has established the National Colorectal Cancer Roundtable to bring together state health departments, professional medical societies, and other public and private organizations to promote colorectal cancer screening among medical providers and the public. The roundtable seeks to determine clinical and consumer barriers to screening, assess current public awareness of and interest in screening, and develop and disseminate promotional messages.

- In collaboration with HCFA and the National Cancer Institute (NCI), CDC has launched a public awareness campaign, "Screen for Life," to promote colorectal cancer screening that includes public service announcements and brochures in both English and Spanish, press kits, and a Web site on colorectal cancer (www.cdc.gov/cancer/screenforlife). CDC has also supported studies regarding participation in screening.

In addition, some health plans that participate in Medicare+Choice have set up programs to encourage the appropriate use of screening services. While these activities do not represent those of the managed care industry overall, they illustrate a variety of approaches to improving patients' use of colorectal cancer screening tools. For example:

- Kaiser Permanente in Northern California has screened more than 300,000 members older than 50 with sigmoidoscopy and has reported a one-third reduction in advanced colorectal cancer cases among the targeted population.

- Group Health Cooperative in Puget Sound has used mailings to members to provide information about the importance of regular screening and to improve familiarity with the screening procedures.

- Aetna U.S. Healthcare mails a fecal occult blood test kit to members aged 50 and older, along with instructions for completing the test, and educational materials about colorectal cancer. The plan's Prudential Center for Health Care Research is conducting a study to determine the rate of colorectal cancer screening among plan members older than 50, assess barriers to screening, and improve screening rates.

Physician Barriers

Physicians practices, too, can affect rates of colorectal cancer screening. In a 1999 report, CDC stated that physicians may lack skills (such as training in prevention) or time to counsel patients, or they may be unfamiliar with updated colorectal cancer screening

guidelines (which now have broad-based support).[13] A study of primary care physicians in a large health care system found that half of those trained in flexible sigmoidoscopy chose not to perform this procedure. The reasons most often given were the time required for the procedure, the availability of adequately trained staff, and the availability of flexible sigmoidoscopy services from other clinicians.[14] One study has also attributed the reluctance of primary care physicians to provide this screening to their impression that reimbursement rates are inadequate to cover their costs.[15]

Federal agencies, physicians' groups, and others have special programs to address the lack of widespread physician use of these services. For example,

- To obtain nationally representative data on barriers to colorectal cancer screening and early intervention, NCI is supporting a survey of primary and specialty care physicians and health plan medical directors that will assess physicians' knowledge, attitudes, and practice patterns.

- Both the American Association of Family Physicians (AAFP) and the American College of Physicians have guidelines for their members. In addition, AAFP distributed information to its members about the new Medicare coverage for these services and the importance of screening patients.

- A program developed by a large academic medical center in Louisiana has an arrangement with local primary care physicians that allows patients to be referred to the clinic one morning every week, without appointments, for screening flexible sigmoidoscopies.

Health System Barriers

Colorectal cancer screening may also be limited by insufficient attention to prevention, in general, and a lack of systems to track and monitor the provision of screening services. The Healthy People 2010 report noted that measuring and reporting how well preventive care is provided are essential to greater compliance with recommendations. It recognized that significant progress in the delivery of clinical preventive services is unlikely without appropriate data systems. Physicians' practices often lack service tracking systems that could automatically notify patients of the need for routine preventive services.

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[13]CDC, Morbidity and Mortality Weekly Report, vol. 48, no. 6 (Feb. 19, 1999), pp. 116-21.

[14]J. D. Lewis and others, "Primary Care Physicians' Decisions to Perform Flexible Sigmoidoscopy," Journal of General Internal Medicine, vol. 14, no. 5 (May 1999), pp. 297-302.

[15]See J. D. Lewis and D. A. Asch, "Barriers to Office-Based Screening Sigmoidoscopy: Does Reimbursement Cover Costs?" Annals of Internal Medicine, vol. 130, no. 6 (Mar. 1999), pp. 525-30.

Unlike other preventive care services, such as cholesterol screening, breast cancer screening, and cervical cancer screening, colorectal cancer screening is not a component of the Health Plan Employer Data and Information Set (HEDIS), a standardized, voluntary HMO performance reporting system developed by the National Committee on Quality Assurance (NCQA).[16] NCQA plays an influential role in prevention by including HEDIS reporting in its accreditation standards. That is, plans seeking accreditation encourage their network physicians to improve the delivery and reporting of measured services.[17] AHRQ, with support from CDC, is working with NCQA and researchers at RAND and the Harvard University School of Public Health to develop measures of colorectal cancer screening that could possibly be included in HEDIS. Developing effective measures to determine whether enrollees are screened appropriately is more challenging because only one of the screening services is recommended annually.

CONCLUDING OBSERVATIONS

Our data suggest that the use of colorectal cancer screening and diagnostic services is quite low among Medicare beneficiaries. There is substantial room for better outreach and education. Consensus on appropriate clinical practice and expansion of coverage to ensure reimbursement are only first steps. In addition to these developments, efforts under way to enhance public awareness of the risks of colorectal cancer and the benefits of screening may result in the greater use of these services over time.

Mr. Chairman, this concludes my statement. I would be happy to answer any questions from you and other members of the Committee.

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[16]HEDIS data are the most commonly used HMO performance measures for the under-65, employer-insured, HMO population.

[17]NCQA accreditation is important to public and private purchasers, who view it as an indicator of HMO quality.

GAO CONTACT AND ACKNOWLEDGMENTS

For future contacts regarding this testimony, please call Jan Heinrich, Associate Director, Health Financing and Public Health at (202) 512-7250. Other individuals who made key contributions include Jenny Grover, Rosamond Katz, and Debbie Spielberg.

MEDICARE BENEFICIARIES' USE RATES FOR COLORECTAL CANCER SCREENING AND DIAGNOSTIC SERVICES, 1995–99

The table shows demographic and geographic differences in use rates. The rates represent the percentage of Medicare beneficiaries having a fecal occult blood test, flexible sigmoidoscopy, colonoscopy, or barium enema. The rates include use of these services for screening, diagnostic, and, in the case of colonoscopy, treatment purposes.

	1995	1996	1997	1998	1999
Total	13.6%	13.2%	12.6%	13.1%	14.1%
Gender					
Male	12.8	12.4	11.9	12.1	13.2
Female	14.2	13.8	13.2	13.8	14.8
Race					
White	14.2	13.8	13.3	13.9	14.9
Black	9.0	8.9	8.5	8.4	9.1
Asian	11.8	11.2	8.9	11.2	12.6
Hispanic	8.0	8.2	5.9	7.7	8.1
Other and unknown	10.5	10.5	11.9	9.0	10.6
Age					
Younger than 65	4.6	4.6	4.5	4.5	4.9
65-69	15.0	14.6	13.7	14.7	15.6
70-74	16.6	16.2	15.6	16.3	17.6
75-79	16.8	16.4	15.7	16.4	17.9
80-84	15.2	14.8	14.4	14.8	15.9
85 and older	10.9	10.5	10.3	10.0	11.0
State					
Alabama	15.1	15.1	9.5	10.5	12.4
Alaska	11.1	10.9	8.3	9.9	10.7
Arizona	14.8	11.6	11.4	12.8	14.6
Arkansas	13.3	11.7	9.6	11.1	11.4
California	15.5	15.6	15.4	13.2	14.9
Colorado	6.3	5.9	5.9	9.9	9.6
Connecticut	9.8	9.2	8.7	12.9	15.3
Delaware	15.5	15.5	15.0	15.0	17.1
District of Columbia	16.5	16.0	14.6	13.1	13.8
Florida	15.6	15.6	15.2	16.9	18.6
Georgia	13.6	11.4	10.7	12.1	13.5
Hawaii	15.6	12.9	13.8	16.7	20.3
Idaho	7.4	7.4	7.0	10.2	9.8
Illinois	12.4	12.3	12.0	11.5	11.8
Indiana	6.8	6.5	6.2	10.0	10.5
Iowa	15.5	11.0	7.7	12.1	12.3
Kansas	13.1	9.4	10.7	11.9	12.9
Kentucky	12.1	11.6	11.8	12.5	13.5

APPENDIX

	1995	1996	1997	1998	1999
Louisiana	7.3	6.7	7.1	8.2	8.8
Maine	17.8	16.9	15.7	16.5	16.9
Maryland	18.2	17.2	17.2	17.0	19.5
Massachusetts	19.4	19.9	19.1	18.3	19.9
Michigan	16.2	16.2	16.3	15.8	15.6
Minnesota	10.6	12.0	12.7	13.7	14.9
Mississippi	10.9	11.1	10.5	10.9	11.9
Missouri	11.4	10.2	10.6	11.9	12.5
Montana	7.8	7.7	7.5	9.1	10.9
Nebraska	10.6	7.0	8.2	9.6	10.7
Nevada	9.7	7.5	8.2	9.0	10.4
New Hampshire	16.6	16.8	15.7	16.9	16.6
New Jersey	15.8	16.0	15.5	14.9	16.1
New Mexico	8.3	8.5	9.1	10.1	8.2
New York	17.2	17.4	15.2	14.4	15.7
North Carolina	13.6	12.9	12.8	12.7	14.2
North Dakota	12.3	8.4	8.0	12.4	11.9
Ohio	14.4	13.5	13.1	12.1	11.4
Oklahoma	10.3	10.6	10.9	12.1	11.9
Oregon	11.8	13.6	11.8	12.0	14.5
Pennsylvania	14.4	14.1	13.7	14.0	15.5
Rhode Island	18.1	19.1	20.2	17.5	17.8
South Carolina	16.2	16.7	15.6	15.4	14.5
South Dakota	12.8	7.1	7.2	10.7	12.8
Tennessee	12.4	12.4	11.8	10.2	10.9
Texas	13.1	13.2	13.1	13.0	14.1
Utah	7.3	6.8	6.6	8.1	10.2
Vermont	17.8	17.0	16.0	16.4	15.6
Virginia	9.7	10.4	10.5	12.8	14.9
Washington	10.5	10.9	11.0	13.5	15.0
West Virginia	11.3	11.2	10.4	10.2	10.4
Wisconsin	7.6	7.7	7.5	11.8	12.9
Wyoming	10.6	8.1	6.7	9.6	10.0

Note: Rates for 1999 are estimated from claims paid January through June 1999.

Source: GAO analysis of Health Care Financing Administration claims data.

(201026)

The CHAIRMAN. Thank you.

Ms. McMullan, would you move the microphone over, almost directly in front of you, and pull it down maybe just a little bit? Thank you.

STATEMENT OF MS. MICHAEL McMULLAN, DEPUTY DIRECTOR, CENTER FOR BENEFICIARY SERVICES, HEALTH CARE FINANCING ADMINISTRATION, BALTIMORE, MD

Ms. MCMULLAN. Chairman Grassley and distinguished committee members, thank you for inviting us here today. Increasing colon cancer screening rates is a high priority for HCFA. We want all Medicare beneficiaries to know that we now pay for these tests that can detect cancer early and even detect polyps before they become cancer.

It isn't the easiest topic for people to talk about, though, so we have been working not only to raise awareness but to help people discuss the issue with their doctors. For example, we have produced a poster—and there is a copy over at the side—that we have distributed, and it has cards at the bottom of it that people can take with them when they visit their doctor and can help get the conversation started. We are also distributing public service announcements and participating in efforts such as Colon Cancer Awareness Month. All these efforts are critically important, and we are eager to explore new ways to educate the public and providers.

Right now far too few people are being screened. Only a fraction of Medicare's 38 million beneficiaries had claims submitted for these life-saving tests in 1998, the first year they were covered.

While we have made some progress, much work remains to be done. One thing that would help is eliminating the cost-sharing for these tests. The President has proposed doing that for all preventive services that Medicare covers, and we look forward to working with this committee to enact legislation that would do so.

With continued support from this committee and our other partners, we believe we can make a difference. We can greatly increase the number of people who are screened, and we can thereby reduce suffering from this disease.

We look forward to working with you in these efforts. Thank you again for inviting us, and I will be happy to answer any questions.

[The prepared statement of Ms. McMullan follows:]

Statement of

MICHAEL McMULLAN

DEPUTY DIRECTOR

HCFA CENTER FOR BENEFICIARY SERVICES

HEALTH CARE FINANCING ADMINISTRATION
on

MEDICARE COLON CANCER PREVENTION EFFORTS

before the

SENATE SPECIAL COMMITTEE ON AGING

March 6, 2000

Testimony of
MICHAEL MCMULLAN, DEPUTY DIRECTOR
HCFA CENTER FOR BENEFICIARY SERVICES
on
MEDICARE COLON CANCER PREVENTION EFFORTS
before the
SENATE SPECIAL COMMITTEE ON AGING
March 6, 2000

Chairman Grassley, Senator Breaux, distinguished committee members, thank you for inviting us to discuss Medicare's efforts to increase awareness and screening for colon cancer. We are especially proud to be here as partners in National Colorectal Cancer Awareness Month.

Colon cancer kills more than 55,000 Americans each year. But many of these deaths can be prevented by screening tests that Medicare now covers. These tests can detect polyps that can be removed before they become cancerous, and find early stage cancers for which treatments are highly effective. This is one of several important new preventive health benefits enacted as a part of the Balanced Budget Act of 1997 (BBA).

We have several outreach efforts underway to help Medicare beneficiaries and their physicians understand and take advantage of Medicare's colon cancer screening benefit. Our colleagues at the Centers for Disease Control and Prevention and the Agency for Healthcare Research and Quality are also working to promote screening.

However, far too few people are being screened. Only about 1 million of our 38 million beneficiaries had claims submitted for these life-saving tests in 1998, the first year they were

covered by Medicare. We are eager to explore new ways to educate beneficiaries and providers about these important tests, and to address special challenges among groups such as women and minorities.

That makes this hearing very valuable and timely. We greatly appreciate the support of this Committee in helping us to raise awareness of the benefit of early detection and Medicare's coverage for screening tests. With your help and the assistance of our many partners in this effort, we believe we can meet the challenges before us, increase the number of beneficiaries who are screened, and save lives as a result.

BACKGROUND

Colon cancer is the second leading cause of cancer-related deaths in the United States for both men and women. When caught early, the five-year survival rate is 91 percent. However, if not caught before spreading locally, the five year survival rate drops to 60 percent. And if not caught before further spreading, the five-year survival rate plummets to only 6 percent.

The U. S. Preventive Services Task Force recommends colorectal cancer screening for all persons aged 50 or over. However, the National Colorectal Cancer Roundtable found that half of all Americans over age 50 are not getting these tests. Women and members of minority groups have particularly low screening rates. And most not screened say physicians never recommended screening to them.

Prior to the Balanced Budget Act (BBA) of 1997, the Medicare statute prohibited coverage for colorectal cancer screening and most other preventive care services. Medicare could cover tests for colon cancer only when conducted to investigate related symptoms or to monitor an individual with a history of colon cancer or inflammatory bowel disease.[1]

Congress and the Clinton Administration changed this policy in the BBA. It authorized coverage for colon cancer screening, along with several other important preventive services, most of which took effect January 1, 1998. Regulations implementing the colon cancer screening benefit, published in the *Federal Register* on October 31, 1997, are based on recommendations by the American Gastroenterological Association, the Agency for Healthcare Research and Quality, and other appropriate agencies, associations, and medical groups.

- **Fecal occult blood tests** are covered annually for all beneficiaries age 50 and over. This is the least expensive and least invasive colorectal cancer screening test. It detects blood in the stool that is an indication of the need for further investigation.
- **Flexible sigmoidoscopy** is covered every four years for beneficiaries not at high risk. It is more expensive and invasive and can require local anesthesia. But it gives a view of one-third to one-half of the colon, there are fewer false positive results than with fecal occult blood tests, and lesions can be removed for biopsy.

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[1]This is consistent with other preventive screening services. Section 1862 of the Social Security Act prohibits Medicare coverage for services which "are not reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the funcitoning of a malformed body member." Unless Congress specificallyh authorizes coverage of specific screening services (e.g., colorectal cancer or prostate screening as authorized in the BBA), screening services are not covered by Medicare.

- **Colonoscopy** is covered every two years for beneficiaries at high risk. This is the most expensive and invasive colorectal screening option and can require anesthesia. But it gives the best view of entire colon and lesions can be removed for testing.
- **Barium enemas** are covered as an alternative if a physician determines that its screening value is equal to or greater than sigmoidoscopy or colonoscopy.

Other Preventive Services

The BBA authorized or expanded coverage of preventive services for several other diseases, as well, and in some cases reduced beneficiary cost sharing in order to further encourage use.

- ***Breast Cancer:*** Annual mammography screening is covered for all female beneficiaries age 40 and over, and a one-time baseline mammogram for beneficiaries ages 35-39. Patients pay 20 percent of the Medicare approved amount, but there is no deductible.
- ***Cervical Cancer:*** Screening pelvic exams, screening pap tests and clinical breast exams are covered every three years for most women, and every year for women at high risk. Patients do not have to pay either a copayment or deductible for pap tests. For pelvic and breast exams, they must pay the standard 20 percent coinsurance but not the deductible.
- ***Prostate Cancer:*** Annual digital rectal exams and prostate specific antigen (PSA) tests are covered for all males age 50 and over, with no coinsurance or deductible for the PSA test.
- ***Diabetes:*** Glucose monitors, lancets, and test strips which help patients control blood sugar are covered, as are programs to teach diabetics how to care for their condition.
- ***Osteoporosis:*** Bone density measurement is covered for all beneficiaries at risk.
- ***Vaccinations:*** Annual vaccinations for influenza, as well as vaccinations for

pneumococcal pneumonia, are covered with no coinsurance or deductible. Hepatitis B shots are also covered for patients at medium to high risk.

The Presidents fiscal 2001 budget would further encourage beneficiaries to take advantage of life-saving preventive benefits. It would:

- eliminate existing cost-sharing for all Medicare-covered preventive benefits, including colorectal screening (**NOTE:** As indicated earlier in my testimony, there are a variety of different beneficiary cost-sharing requirements for the individual preventive services authorized for coverage under Medicare. The President's Budget would waive all existing cost-sharing for these services to simplify the process for beneficiaries and to encourage their utilization.);
- initiate a three-year demonstration to evaluate the most successful and cost-effective smoking cessation services; and
- launch a two-year, nationwide education campaign to promote the use of preventive health services by older Americans and people with disabilities.

We believe these provisions are important and prudent steps that will help increase use of preventive services, reduce illness and costs related to preventable conditions, and save lives. We look forward to working with this Committee to secure their passage.

Beneficiary and Provider Education

Helping beneficiaries and providers understand and take advantage of the colorectal cancer screening benefit is a high priority for us. We are working to raise consciousness and encourage

use of these tests among both beneficiaries and their physicians. We have several educational efforts already underway.

- **"Screen-for-life" posters and tear-off sheets.** We have produced and distributed more than 23,000 of these posters with tear-off sheets that beneficiaries can take with them to their physician as a reminder to discuss their screening options. The tear-off sheets are particularly helpful, since screening can involve unfamiliar words, sensitive issues, and unpleasant options that may be difficult for patients to bring up on their own.
- **Public Service Announcements.** We distributed to 873 television and radio stations public service announcements (PSAs) that address the misconception that colorectal cancer is a man's disease and promote discussion with physicians.
- **CDC Partnership.** We are partners with the Centers for Disease Control and Prevention (CDC) in its national colorectal cancer screening campaign, *Screen for Life*. This campaign, which began in March 1999, encourages Medicare beneficiaries and others to take advantage of screening and promotes the new Medicare coverage of colorectal cancer screening procedures. We are also working with the CDC in conducting formative research and developing targeted messages for this national effort.
- **AHRQ Consumer Guide.** Our colleagues at the Agency for Healthcare Research and Quality have produced a consumer guide with information on colorectal cancer screening.
- **National Colorectal Cancer Roundtable.** We participate with several other public and private organizations on this Roundtable, which was established by CDC and the American Cancer Society. Through this effort we are strengthening the network of public

and private organizations promoting colorectal cancer screening among all people for whom screening is appropriate.

- **Medicare.gov.** We provide information on colorectal cancer on our beneficiary web site, including information on Medicare coverage of colorectal screening tests; questions and answers on the colon and colorectal cancer; causes of the disease; symptoms; who is at risk; screening techniques, risk and treatment; and where to find additional information.
- **Medicare & You Handbook.** Information on colorectal cancer screening and other preventive benefits is featured in this guide sent to all Medicare beneficiaries each year.

We are sharing these materials through senior centers, hospitals, health plans and insurers, state and local health departments, medical colleges and foundations, Aging Councils, Medicare Peer Review Organizations, advocacy groups including those focused in minorities, and others. And materials can be ordered through our website and our 1-800-MEDICARE hotline.

We face important challenges in our efforts to encourage colorectal screening. One of these challenges is the need to address the misperception that colorectal cancer is a man's disease. We therefore have campaign materials that target women. For example, we and our CDC partners aired a live, interactive satellite broadcast on women's health to more than 5000 physicians last August that focused on colon cancer screening. A booklet explaining Medicare coverage for colorectal screening tests was distributed to all attendees.

Another challenge is reaching African Americans, who are at higher risk of colon cancer than other population groups. We therefore, have materials targeted directly at them, as well as other ethnic groups who have low screening rates. For example, four versions of our *Screen for Life* poster were printed, targeting African-American, Caucasian, Hispanic and Asian populations. We are sharing materials with organizations such as The National Black Leadership Initiative on Cancer and disseminating them through our Medicare claims processing contractors, who have specific contract requirements to outreach to minority populations on health care issues.

We are also now working with partners to expand efforts to specifically educate physicians and provide them with materials and support to help them educate their patients. These include:

- a fact sheet for physicians on the importance of screening;
- a decision aid tool that physicians can use to help patients understand and choose among the various screening options;
- a brochure to share with patients on how removing polyps can prevent cancer;
- a teaching aid poster illustrating the colon and explaining screening options;
- a "Get Screened" poster that physicians can put up in their office waiting rooms; and
- public service announcements discussing screening and prevention through polyp removal.

We share these materials through our *hcfa.gov* website and through items included in newsletters sent to physicians by Medicare claims processing contractors.

To further these efforts, Medicare's physician-lead Peer Review Organizations are beginning a special study to better understand the use of colorectal cancer screening and determine effective

ways to promote testing through such things as physician office reminder systems. We will also calculate national and state screening rates among Medicare beneficiaries to help us target our outreach efforts.

These steps are in addition to steps already taken to distribute articles on colon cancer prevention in newsletters that our claims processing contractors send to physicians, and to make Continuing Medical Education credits available for physicians who take the time to learn about colon cancer screening and prevention by studying the video of our satellite broadcast or taking computer-based courses on that are available through our Internet site.

Colorectal Cancer Awareness Month

As mentioned above, we are proud participants with the Cancer Research Foundation of America, the National Colorectal Cancer Roundtable, and the American Digestive Health Foundation, the CDC, National Cancer Institute, and others, in National Colorectal Cancer Awareness month. This collaborative effort can help to generate widespread awareness of how to prevent the disease through a healthy lifestyle and regular screening.

During the month, participants will:

- distribute a video news release that we have prepared on colorectal cancer screening;
- air a colorectal cancer television segment on CNBC and the Bravo Network;
- develop radio and print PSAs and articles for distribution in medical journals; and
- conduct an advertising campaign.

Conclusion

While we have made some progress, much work remains to be done to increase use of Medicare's colorectal cancer prevention benefit. With support from this Committee and our many other partners, we believe we can meet this challenge. Enactment of the President's fiscal year 2001 budget proposals would provide further incentive to Medicare beneficiaries to use their preventive benefits and further resources for Medicare to publicize their availability and importance. We look forward to working with you further in all these efforts. Thank you again for inviting me to be here today, and I would be happy to answer any of your questions.

# # #

The CHAIRMAN. Thank you.
Now, Dr. Levin.

STATEMENT OF DR. BERNARD LEVIN, M.D., OFFICE OF THE VICE PRESIDENT FOR CANCER PREVENTION, UNIVERSITY OF TEXAS M.D. ANDERSON CANCER CENTER, HOUSTON, TX, ON BEHALF OF THE AMERICAN GASTROENTEROLOGICAL ASSOCIATION

Dr. LEVIN. Good afternoon, Mr. Chairman and distinguished Members of the Committee. My name is Bernard Levin. I am pleased to represent the American Gastroenterological Association at this important hearing. The AGA is an organization of more than 10,000 physician clinicians, researchers, and educators who specialize in the prevention and treatment of digestive disorders.

On a personal note, in addition to my involvement with the AGA, I am a physician and vice president for cancer prevention at the University of Texas M.D. Anderson Cancer Center in Houston and serve as co-chair of the Colorectal Campaign of the American Digestive Health Foundation.

I also serve as Chair of the National Colorectal Cancer Roundtable and have been very proud to serve under Katie Couric's leadership on the National Colorectal Cancer Alliance. Founded approximately 2 years ago by the American Cancer Society and the Centers for Disease Control and Prevention, the roundtable is a coalition of over 34 medical professional, consumer advocacy, and voluntary organizations. Our mission is to reduce the suffering and death rate from this disease by achieving screening rates that are equivalent or better than those of other cancers.

Currently, about 4 out of 5 women who are eligible are screened for breast and cervical cancer. Colorectal cancer screening rates in men and women are nowhere near this level, as we have already heard, and need to be increased if we are to be successful in reducing the suffering and death for colorectal cancer.

Many times I have sat by the bedside of a patient with advanced colorectal cancer and wished that we had detected this insidious disease earlier and treated it appropriately, thereby saving that patient's life and the misery of many of the family members.

Mr. Chairman, I would like to thank you and your colleagues for the passage of landmark legislation in 1997 which provides a colorectal cancer screening benefit to Medicare recipients. This legislation was based on medical research and the considered opinions of multidisciplinary groups of experts. This brought us a significant step forward toward our mutual goal of preventing the tragedies related to colorectal cancer. However, our task is far from over, as you have already heard.

The sad irony is that cancer of the colon is probably the most treatable and survivable of all cancers if it is detected early through proper screenings. Removal of adenomatous polyps before they can transform into cancers is a most powerful preventive measure.

The CDC has found that in 1997, only 41 percent of adults age 50 and older had ever had a sigmoidoscopy for screening purposes, and only 29 percent of adults reported having had one in the past 5 years. In addition, the CDC survey found that only 39 percent

of adults age 50 and older reported having had a fecal occult blood test. These screening rates are woefully inadequate.

As my first visual indicates, the incidence of and mortality from cancers of the colon or rectum increases significantly for men and women over 50 years of age. In order to enhance treatment and reduce mortality rates, proper screening procedures must be followed. As Dr. Scanlon has already mentioned, these include annual fecal occult blood testing, a flexible sigmoidoscopy every 5 years beginning at age 50, or total colon examination by colonoscopy every 10 years, or by double-contrast barium enema every 5 to 10 years.

As the other visual I brought along today indicates, adults in the United States age 50 and over, as we have already also heard, are simply not availing themselves of the protection that proper screenings clearly provide. We must find ways to heighten public awareness about this disease and to remove any barriers that may exist for access to regular screening procedures.

Cost-effectiveness studies of colorectal cancer screening show it to be cost-effective, but we simply can't put a price on the opportunity to save the lives of our loved one.

Today, I have also been asked to evaluate the Screen for Life campaign that has been jointly initiated by the Health Care Financing Administration, the Centers for Disease Control and Prevention, and the National Cancer Institute. I would like to commend each of these agencies for their commitment and dedication to informing the American public about the dangers of colorectal cancer and the Medicare screening benefits.

In the remainder of my time, Mr. Chairman, I would like to briefly offer several recommendations on how the Screen for Life campaign could be more targeted and other suggestions to help reduce the incidence of colorectal cancer.

Specifically, on behalf of the American Gastroenterological Association, I would like to recommend the following: that Congress consider appropriating funding to the CDC for public service announcements during prime time on television and radio on the need for screening for colorectal cancer; the Screen for Life campaign focus on messages to abate the embarrassment factor associated with colorectal cancer; the Screen for Life campaign take into account the literacy levels, cultural sensitivity, and access to effective educational materials for all groups; the Screen for Life campaign continue to reach out to advocacy groups such as the American Gastroenterological Association, the American Cancer Society, the Colon Cancer Alliance, to take advantage of the expertise available in colorectal cancer; in addition to effective patient education materials, messages targeted to physicians, nurses, and other health professionals on effective communications to patients would be extremely valuable; that Congress address the issue of access to colorectal cancer screenings for the non-Medicare population by enacting S. 1044, the Eliminate Colorectal Cancer Act of 1999, put forward by Senators Kennedy and Helms, which would extend the same Medicare screening benefit to those covered by private insurance; and, finally, Congress sufficiently fund research efforts currently being identified by the National Cancer Institute through its Progress Review Group on colorectal cancer to further reduce the incidence and mortality from colorectal cancer.

Mr. Chairman, thank you again for the opportunity to appear before your committee. My colleagues and I look forward to working with you and other Members of Congress on this issue, which is truly a matter of life and death.

[The prepared statement of Dr. Levin follows:]

Statement of the
American Gastroenterological Association

Presented by
Bernard Levin, MD

Before the
Special Committee on Aging
United States Senate

Concerning
Colorectal Cancer Screening

March 6, 2000

AMERICAN GASTROENTEROLOGICAL ASSOCIATION
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Good afternoon, Mr. Chairman and members of the Committee. My name is Bernard Levin and I am pleased to represent the American Gastroenterological Association (AGA) at this important hearing. The AGA is an organization of more than 10,000 physician clinicians, researchers and educators who specialize in the treatment of digestive disorders. In addition to my involvement with the AGA, I am a physician and Vice President for Cancer Prevention at the University of Texas M. D. Anderson Cancer Center in Houston and co-chair of the Colorectal Campaign of the American Digestive Health Foundation. I also serve as chair of the National Colorectal Cancer Roundtable.

Founded approximately two years ago by the American Cancer Society and the Centers for Disease Control and Prevention (CDC), the Roundtable is a coalition of over 30 medical professional, consumer advocacy and voluntary organizations. Our mission is to reduce the suffering and mortality from this disease by achieving screening rates that are equivalent or better to those of other cancers. Currently, about four in five women who are eligible are screened for breast and cervical cancer. Colorectal cancer screening rates in men and women are nowhere near this level and need to be increased if we are to be successful at reducing the incidence of colorectal cancer morbidity and mortality. Many a time I have sat by the bedside of a patient with advanced

colorectal cancer and wished that we had detected this insidious disease earlier and treated it, and given the patient the cure.

Mr. Chairman, I would like to thank you and your colleagues for passage of landmark legislation in 1997 which provides a colorectal cancer screening benefit to Medicare recipients. This represents a tremendous step toward our mutual goal of preventing the sad tragedies related to colorectal cancer which we hear so much of. However, our task is far from over. According to the CDC, cancer of the colon and rectum is the second leading cause of cancer-related deaths in the United States. The American Cancer Society estimates that 56,000 Americans will die of colorectal cancer in 2000. Of the 140,000 new colon and rectal cancer cases in the United States every year, 60,000 occur in women. For men, colorectal cancer follows prostate and lung cancer in frequency. African Americans are more likely than Caucasians to be diagnosed with this disease and are more likely to die from it.

The sad irony is that cancer of the colon is probably the most treatable and survivable of all cancers—IF it is detected early through proper screenings. The CDC has found that in 1997, only 41% of adults aged 50 and older had ever had a sigmoidoscopy for screening purposes, and only 29% of adults reported having had one in the past five years. In addition, the CDC survey found that only 39% of adults aged 50 and older reported having had a fecal occult blood test (FOBT). The AGA finds these screening rates woefully inadequate.

As the visual I have brought along clearly indicates, the incidence of and mortality from cancers of the colon and rectum increases significantly for men and women 50 years of age and older. In order to enhance treatment and reduce mortality rates, proper screening procedures must be followed. The guidelines for such procedures are clear; for all average risk adults age 50 and older, the following procedures are essential:

- Annual FOBT and flexible sigmoidoscopy every 5 years, or
- Total colon examination by colonoscopy every 10 years or by Double Contrast Barium Enema (DCBE) every 5-10 years

Those at higher risk (i.e., incidence of inflammatory bowel disease, a family history of colorectal cancer, incidence of colorectal polyps and certain hereditary syndromes) should be offered more intensive surveillance. The recommended screening for Medicare beneficiaries and other high-risk individuals is appropriate: flexible sigmoidoscopy every 18 months and colonoscopy every 24 months. But, as the other visual I have brought along today indicates, adults in the United States aged 50 and older are simply not availing themselves of the protection that proper screenings clearly provide. We must find ways to heighten public awareness about this disease and to remove any barriers that may exist for the access to regular screening procedures.

Studies clearly show the cost effectiveness of screening for this disease. Analyses performed by the Congressional Office of Technology Assessment (OTA) and other agencies reflect that the cost per year of life saved by colorectal cancer screening is approximately $15,000-$20,000, well within the benchmark figure of $40,000 considered by the federal government to be cost- effective.

Beyond the arguments for cost effectiveness, we simply cannot put a price on the opportunity to save the lives of our loved ones and prevent this unnecessary suffering. I have also been asked to evaluate the Screen for Life campaign that has been jointly initiated by the Health Care Financing Administration (HCFA), the CDC and the National Cancer Institute (NCI). I would like to commend each of these agencies for their dedication to informing the American public about the dangers of colorectal cancer and the availability of the

Medicare screening benefit. In the remainder of my time, Mr. Chairman, I would like to offer several recommendations on how the Screen for Life campaign could be more targeted and other suggestions to help reduce the incidence of colorectal cancer.

Specifically, and on behalf of the AGA I would like to recommend the following:

- Congress appropriate funding to the CDC for public service announcements, during prime time, on television and radio on the need for screening for colorectal cancer;
- The Screen for Life campaign focus on messages to abate the embarrassment factor associated with colorectal cancer and appropriate screening;
- The Screen for Life campaign take into account the literacy levels, cultural sensitivity and access to effective educational materials;
- The Screen for Life campaign continue to reach out to advocacy groups, such as the AGA and the American Cancer Society, to take advantage of the expertise on colorectal cancer which we and other similar organizations can provide;
- In addition to effective patient education materials, messages targeted to physicians on effective communications to patients would be extremely valuable;
- Congress address the issue of access to colorectal cancer screenings for the non-Medicare population by enacting S. 1044, the "Eliminate Colorectal Cancer Act of 1999" which would extend the same Medicare screening benefit to those covered by private insurance; and
- Congress sufficiently fund research efforts, currently being identified by the NCI through its Progress Review Group on Colorectal Cancer, to further reduce the incidence and mortality of colon cancer.

Mr. Chairman, thank you again for the opportunity to appear before your Committee. My colleagues and I look forward to working with you and the Congress on this issue which is truly a matter of life and death.

The CHAIRMAN. Thank you very much. Again, we will have 5 minutes for each member to ask questions. Or now that we have fewer members here, if you want some more time, I will be glad to keep the time open.

I will start with you, Ms. Heiligman, and my question is about what prompted you to get screened. I know, for instance, from your history that you had a sister that was diagnosed in 1988. At that time did you know that the history of colon cancer in your family increased your chances of your having it? And did this prompt you to get screened, or did your physician recommend screening?

Ms. HEILIGMAN. Well, at the time I had absolutely no knowledge of family history or even that there were such things as screenings. Basically, it was 5 years later, and my internist recommended the sigmoidoscopy at that time.

The CHAIRMAN. Did you find the Medicare Handbook, which you should have received in the mail, or any other material that you may have received from Medicare helpful in determining what preventive screenings are covered?

Ms. HEILIGMAN. No. I don't ever remember receiving them.

The CHAIRMAN. OK. Dr. Scanlon, there appears to be a need for more sources from which to collect data on screenings. You stated that screening data is not available on the use of colorectal cancer services by enrollees in the Medicare managed care program because HCFA does not require Medicare+Choice plans to report patient-specific data. Do you believe it would be helpful for future screening studies for Medicare managed care programs to collect such information?

Mr. SCANLON. Mr. Chairman, we believe that it would be helpful for both examining the utilization of screening services for colorectal cancer, and also for examining the performance of managed care organizations in terms of preventive services more generally. As we have indicated, including colorectal screening as one of the HEDIS measures would not only give us the information as to how well the plans are doing, but simultaneously give the plans an incentive to put into place efforts to encourage the use of services.

We know for other kinds of services that plans will send out reminders to individuals saying this is a recommended service and you haven't gotten it, and if you don't respond, they may send out another reminder. Those are the kinds of steps that can be effective in terms of changing people's behavior.

The CHAIRMAN. Dr. Levin, as chair of this roundtable, the National Colorectal Cancer Roundtable, can you tell us about the efforts of the roundtable to increase utilization of Medicare-covered screening?

Dr. LEVIN. We have a three-pronged policy, a three-pronged attempt now to do just that. We are working on public education. We believe that is very important that the Medicare population understand both the benefits as well as the risks that they negotiate each day if they don't have screening. We are interested in providing education to providers so that the health professions understand the importance of colorectal cancer screening. And we are interested in changes in public policy, in health policy of insurers

who are providing the benefits to people both over the age of 65 as well as under 65.

We believe that a three-pronged attack is necessary to fully realize the benefits that can be obtained by screening on a regular basis.

The CHAIRMAN. Through the Research Alliance Medical Advisory Board that you are a member of—and I already made reference to the fact that the alliance announced a 5-year educational campaign in conjunction with 25,000 chain pharmacies, it is my understanding that as part of this campaign, participating pharmacies are going to make colon cancer home screening test kits available at a reduced cost. How do these test kits work? And how effective are they?

Dr. LEVIN. The test kits that are available currently rely on the detection of traces, hidden traces of blood in the stool. The blood is not visible, and these tests are not designed for people who have symptoms of colorectal cancer, which Ms. Couric already described. They are for people who are asymptomatic, and they are taken at home. Each time there is a bowel movement on three successive occasions, a tiny sample is placed on a test kit card, and that is then folded over. And at the end of the 3 days, this is delivered to a laboratory or to the doctor's office and a chemical test is done for traces of hidden blood.

This requires a certain amount of compliance with avoidance of certain medications that can irritate the lining of the gastrointestinal tract, as well as the avoidance of some foods that can give a false positive. These tests are done annually beginning at age 50.

Now, there are improvements in these tests being developed, and other tests that detect other products that are shed by cancer cells are also being developed under research protocols.

The CHAIRMAN. One last question before I turn to Senator Collins.

The extent to which a person's diet can effect his or her health how important is it in the occurrence of colorectal cancer?

Dr. LEVIN. The quantification of diet depends actually on the kind of risk factor that one inherits. For example, there are people who have a hereditary disorder, and it is rare, relatively rare, where diet probably plays a relatively small part. But for the majority of people where the risk is not related to inheritance, diet, physical activity, and other lifestyle factors—the avoidance completely of tobacco, limitation of alcohol—perhaps the supplementation of the diet with folic acid-containing multivitamins, but a diet that is healthful in respect of being replete with fruits and vegetables, low in fat, low in red meat, those components of the diet we believe to be valuable in reducing the risk.

How much it reduces the risk for an individual is hard to quantify, but in general, we believe that diet and lifestyle does play a very significant role.

The CHAIRMAN. Senator Collins and then Senator Lincoln.

Senator COLLINS. Thank you, Mr. Chairman.

Mrs. Heiligman, I first want to thank you for your testimony this morning—this afternoon, I should say. It is really important that we have a human face to put on this disease, and I really appre-

ciate your courage and your candor in coming forward. We wish you well with your treatment.

Ms. HEILIGMAN. Thank you.

Senator COLLINS. Ms. McMullan, we have heard testimony from Mrs. Heiligman today, as well as from the GAO, that raises a lot of concerns in my mind about whether HCFA's efforts have been effective in raising the awareness of beneficiaries and providers of the new coverage under Medicare for this screening.

In your testimony, you list all of the initiatives that the administration is undertaking, and yet if we look at the GAO's testimony, colon cancer screening rates are really virtually the same now as they were before Medicare was expanded to cover these tests. That raises real questions in my mind about the effectiveness of the efforts of the Health Care Financing Administration.

Could you address that, please?

Ms. MCMULLAN. It takes a long time to change the behavior of any portion of the public, and when you are talking about reaching 39 million people with many messages—we reach them with messages about preventive services, we reach them with messages about health plan choice, we reach them with messages about protections—it is very difficult for people to sort all of that out. And that is one of the reasons for health promotion that we ally with our colleagues in the Public Health Service organizations—the National Institutes of Health, the Centers for Disease Control—so that we can leverage their initiatives.

But even in doing that, it takes a long time to gain the attention of the public, and I think you heard in Ms. Couric's testimony that we need to do more to de-stigmatize this disease. We need to heighten people's awareness and give them language to talk about this disease so that it is more familiar and it is more part of the ongoing dialog in the community.

Senator COLLINS. Well, the Balanced Budget Act of 1997 not only extended coverage for screening for this disease, but also for others, such as prostate cancer, breast and cervical cancers.

Have we seen an increase in the use of those screening tests by Medicare beneficiaries?

Ms. MCMULLAN. I think that the use of mammography and prostate cancer screening are at a higher rate than of colon cancer screenings. That I think has been advantaged by a lot more information in the media and a longer commitment to health promotion.

We have a variety of other preventive services that we cover, including flu shots and pneumococcal vaccinations, and we have seen the greatest increase in those rates, and some of that is related to the amount of effort that is put into it through the partnership that we work with and the simpler message.

Senator COLLINS. Dr. Scanlon, I want to thank you for your usual excellent work in this area. I can understand why Medicare patients might underestimate their risk of colon cancer or might be uncomfortable about talking with their doctors and asking for screenings. But I have a more difficult time understanding why their physicians are not taking the initiative in recommending these tests, particularly now that they are covered by Medicare so there shouldn't be a financial issue here anymore.

Can you give us any advice on why physicians are not recommending screening, particularly for high-risk patients?

Mr. SCANLON. One would hope that the primary reason is that the guidelines and the agreement upon the guidelines is relatively new and that over time we will overcome any resistance to discussing these tests and providing these tests to patients.

At the same time, though, there are concerns raised that physicians may be as uncomfortable as patients sometimes in discussing colorectal cancer testing, and also there are concerns about the delivery of the services being more complicated and more time-consuming than they feel they have available to serve their patients.

We need to look into each of those issues and to address them if they are appropriate, either through education efforts or through making sure that these services can be delivered as effectively and as easily as possible.

Senator COLLINS. Dr. Levin, the Dartmouth Atlas of Health Care notes that there is a tremendous variation in colorectal cancer screening rates among beneficiaries of Medicare depending on where you live, and we found that no area of country did very well. But the report notes that compliance with the screening guidelines varied by a factor of almost 10, from a very low rate in one location in Indiana to more than a 22 percent rate in Takoma Park, MD.

How do you account for that tremendous regional variation?

Dr. LEVIN. I think there are several complex reasons for that. First, I think the public in these different areas understands the health risks differently, a matter of public education or public perception. I think physicians vary considerably, as Dr. Scanlon has already alluded to, in their ability to communicate the need for screening and their ability to deliver it effectively.

Colorectal cancer screening is more complicated than ordering a mammogram or obtaining a prostate-specific antigen, which is a simple blood test, and communicating how screening needs to be done actually takes time and has to be done very well. And in the modern rushed environment of most primary care physicians' offices, it is actually hard to do this.

So there are probably a number of reasons accounting for the geographic variation, but my guess is that it is due to a combination of both public lack of awareness and perception as well as physician lack of ability to communicate the importance of screening.

Senator COLLINS. If I could just make one final comment?

The CHAIRMAN. Take as long as you want.

Senator COLLINS. Thank you, Mr. Chairman.

The tremendous variation reminds me of studies that were done in my home State of Maine on the rate of cesarean sections in one area of Maine versus another, and there was this tremendous variation that the Maine Medical Assessment Foundation discovered in doing research. And what they did to identify the outliers is they had essentially peer counseling and had physicians whose rates were more the norm talk to those who were the outliers. And, sure enough, it brought the rates down.

I wonder if we should be looking at something similar to bring the rates of screening for colorectal cancers up. It seems to me that physicians are much more receptive to information presented by their peers. It just seems to me we have a tremendous problem not

only with the low rate in general, but the fact that we have this huge variation.

Could you comment on that?

Dr. LEVIN. Through the National Colorectal Cancer Roundtable, we are trying to bring together in the form of a dialog just the very issues you have mentioned. Having physicians communicate with others and other organizations, not only with physicians but with nurses, with lay organizations, I think this is very much an issue for the primary care physician. That is where a lot of screening has to begin, and we are working with organizations such as the American Academy of Family Practice to address these very significant issues.

We also think that we need to involve others in the health professions. Nurses have a role to play. They work with doctors. They can influence patients very positively, and I think that they, too, could act tremendously to increase the rate of screening as they talk to the patients who are sitting in the offices.

Senator COLLINS. Thank you, Doctor, and thank you, Mr. Chairman, for this excellent hearing.

The CHAIRMAN. If you wondered what the fun was here, I keep calling her "Senator Snowe," our colleague from Maine. I do know the difference, so forgive me.

Senator Lincoln.

Senator LINCOLN. Thank you, Mr. Chairman. And I would like to also join my colleague from Maine, Senator Collins, in thanking you, Mrs. Heiligman. I think it is so important in these discussions that we hear personal stories that you and Ms. Couric are willing to share with us. We wish you well in your treatment and do thank you, as we thank all of our panelists for being here.

I would also like to comment on my colleague Senator Collins' astuteness. I am married to a physician, and they definitely pay better attention to their colleagues and to their peers, without a doubt.

Mrs. Heiligman, after you were diagnosed with colon cancer in 1998, how did you really learn about the cutting-edge treatments for colon cancer? How did you find out about that?

Ms. HEILIGMAN. Well, actually, I never knew anyone with the disease, and it was step by step. I was very fortunate to have been put into the care of an oncologist whom I could speak to very readily, and that was extremely helpful. And I guess all doctors aren't as caring as we might like them to be. So it was very nice to be able to discuss each step along the way, and without that, I really would not have known where to begin. And we have had to take it step by step, and the Colon Cancer Alliance, which is new to me now, but what their efforts are involved with certainly is wonderful, wonderful progress in actually reaching out to patients and their caretakers because they are setting up things like the buddy system and getting down to the basics of how we should understand our own diseases and what is going on.

Senator LINCOLN. Well, now, I understand that you are enrolled in an experimental treatment program at Sloan-Kettering, and as a participant, are you able to talk with others in the program? And do you have any access to support groups through that or other means?

Ms. HEILIGMAN. Well, I have been very, very lucky in that I have a very supportive family and wonderful, wonderful friends, and I just never felt the need for going out to a support group.

As far as the experimental program, I was the first one at Sloan-Kettering to go on this, and in recent weeks, they have had—there is a very technical receptor that you have to have. Dr. Levin, you probably would know how to answer that better than I technically. But there is a certain receptor that one has to have in order to be able to use this particular protocol. I was fortunate enough to be a candidate. And since I started, there now are several, but there is not enough to even make a comparison.

I just asked the doctor last week, Have we got any results? You know, and he said, Not yet, not yet. But if my results are good, I can be very happy about that.

Senator LINCOLN. Yes. That is great.

Dr. Levin, what do you really think is the greatest challenge that is facing the alliance right now as we talk here about of what you want to achieve there? What are the biggest challenges?

Dr. LEVIN. Ignorance on the part of people about colorectal cancer, a reluctance to undergo screening, perhaps sometimes engendered by physicians who are uncomfortable or don't know the information, and I think embarrassment. We have a saying: Don't let your patients die of embarrassment. And I think that is terribly important.

I think this has to be aired. What Ms. Couric and others are doing is incredibly important. And the American public have to recognize that something that is the second leading cause of cancer deaths can't be swept under the rug anymore, and we have to become very active.

There is no question that better tests are needed, and better tests are being developed, more convenient, less cumbersome for screening. But even if we use the tests that are available right now, we could save perhaps 28,000 lives every year.

So there are advances that need to be made, and research is vitally needed. But we already have the tools that could do a lot of good.

Senator LINCOLN. Being able to overcome some of that pride and ignorance to really use the tools that we have, that makes sense.

Dr. LEVIN. Absolutely.

Senator LINCOLN. Dr. Scanlon, thank you again for being here. You have been a wonderful resource for us here at the Aging Committee, and in your written testimony you said that the CDC and HCFA had conducted 14 focus groups, I believe, in 1998 to look at the factors that really inhibit the use of colon cancer screening by adults age 50 and older. Of course, I addressed with Ms. Couric how important it is to really bring about an awareness with 30- and 40-year-olds, but I think the focus groups are an excellent idea and I hope that they have brought forth some very valuable information. I think they would.

But will you continue to conduct the focus groups in the future as a way to really assess the success of the Screen for Life campaign?

Mr. SCANLON. We only reported on the focus groups. Ms. McMullan might be able to tell you if CDC is planning them in the

future. And hopefully, I think that we would be looking to see how effective efforts to overcome the ignorance that Dr. Levin has talked about have been. These focus groups, identified important information about people not being aware of the benefits of screening, their concerns about the discomfort, and the embarrassment of screening. These are the kinds of things that we need to be able to address through the various education efforts that are going to be undertaken.

Senator LINCOLN. Well, hopefully, as Senator Collins mentioned, in terms of what HCFA is doing in terms of better educating those individuals of what is available to them, I would think the focus group information should play certainly a great deal to your advantage. And I would hope that HCFA is using that information.

Ms. MCMULLAN. We do. Part of using focus groups and other consumer testing is having evidence in order to move forward. And so we use those techniques to identify what people want to know, what they do know, what is the source of information they use. And you have heard from all of the different panelists that there is an ignorance of what the screening tests are. The beneficiaries say that physicians don't always give them advice to take the test, and so they don't understand the importance of it.

And so for us to be able to change people's behavior, we have to understand it first, and so we are very reliant on using consumer testing to understand who and how to convey information, and which channels. And in this case, physicians are an incredibly important part of the equation.

Senator LINCOLN. But just in reference to what Senator Collins mentioned, the fact that there is not really—there hasn't been an increase since the program—what, it has been 2 years at HCFA?

Ms. MCMULLAN. 1998.

Senator LINCOLN. Yes. So the program was implemented at the same time that you started the focus groups. I guess the other question would be, Do you feel the focus groups have been productive?

Ms. MCMULLAN. Well, the cancer screening tests were approved in the Balanced Budget Act, and so you have to develop a program, and as I mentioned earlier, it takes a very long commitment. In order to change behavior, you have to be in it for the long haul. We have learned that in the message about smoking, the messages about teen pregnancy. There are all sorts of landmark programs that demonstrate that in order to change the behavior of individuals, they have to understand it. And it takes a long commitment to provide the information.

So the fact that we haven't seen a remarkable change in just one year of experience is not surprising. We will see increases. It will take a long time to see a remarkable change.

I think that one thing that will make a significant impact is the visibility, and Ms. Couric and her colleagues are raising visibility in a way that is almost priceless.

Senator LINCOLN. Sure.

Ms. MCMULLAN. The Government would never be able to make that kind of an effect without that kind of visibility. So I admire what she is doing, and it is very important to this population.

Senator LINCOLN. I don't know why, but it just doesn't seem to be very comforting when you say it is going to take a long, long time to achieve just the minimum of what we are talking about here when we know that the technology is there.

Ms. MCMULLAN. Education is a long commitment.

Senator LINCOLN. I definitely realize that. So we hope that we will continue on it. Thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much.

I have two questions for you, Dr. Levin, and then a couple questions for Ms. McMullan. Getting back to this Dartmouth Atlas of Health Care study—and I won't go through a lot of figures, but basically it found that even with insurance coverage of screening and with research documenting their effectiveness, there are not very many people seeking for such tests. You gave us some suggestions in your testimony, but based on the Screen for Life campaign and based upon your experiences as a provider, do you have any other suggestions to improve utilization of Medicare-covered screening?

Dr. LEVIN. I have a couple of observations and then a suggestion. I have just come back from Australia where I was involved in an evaluation of their national program, and they are facing somewhat similar problems. So I would say that this is probably a fairly universal finding that people throughout the world don't like talking about colons and rectums and colonoscopy. So overcoming the barrier that particularly the aging population feel by virtue of culture and habit, these are not subjects that have in the past been the subject of discussion, and it is going to be more difficult, I think, for the aging population. So there is a special educational effort to overcome the barriers that that creates, and I think paying attention to literacy and culture in the messages is going to be very important for the aging population. And as the population is aging and is continuing to age, that is a particular challenge.

I also think that physicians are going to become more comfortable with the results of research done on colorectal cancer screening. There is data now from a number of places in the world that are forming a consortium of information that strengthens the data that colorectal cancer screening is effective. And as that is communicated to physicians, their level of security in communicating this to patients will increase. I think as Ms. McMullan has mentioned, this educational process of physicians and the public takes a longer time than perhaps we have given it credit for.

The CHAIRMAN. This wasn't really one of my questions, but it was prompted by your saying that several societies have this problem. Is this a cultural problem with white European cultures? Or is this also a problem with Asian cultures and African cultures? Is it common throughout the world, or is this just a problem in American society, or other caucasian cultures?

Dr. LEVIN. I think it is very common throughout the world. In the United States, African Americans have a higher mortality rate from colorectal cancer, and we think that is due to a number of factors. It may be due to less screening. It also may be due to a slightly different biology, the fact it seems to occur more on the right side of the colon than the left side of the colon.

But all segments of the society seem to share this problem that——

The CHAIRMAN. That is in the United States, but what about China, or India, or the African continent.

Dr. LEVIN. Colorectal cancer is actually rare in Sub-Saharan Africa. It is rare in India. In China, we think due to westernization of the lifestyle, diet in particular, it is on the increase.

The CHAIRMAN. So, in other words, we are eating ourselves to death.

Dr. LEVIN. They are. And in Japan, colorectal cancer, which was formerly not common, is very much on the increase, and even more dramatically, the highest incidence right now of colorectal cancer in the world are Japanese who migrate to Hawaii. When they were living in Japan, they were somehow protected by the diet or their lifestyle. The same people within one generation moving to Hawaii have the highest rate of colorectal cancer in the world. They are exposed to something, perhaps diet—that would be a reasonable assumption—that completely makes their risk escalate enormously.

The CHAIRMAN. My last question to you is related to the effectiveness of barium enema and the fact that it doesn't explore the entire intestinal tract. Is that still a viable option for screening?

Dr. LEVIN. May I respectfully correct you on one statement? The double-contrast barium enema actually examines the entire colon and the rectum in most situations. It is a test that is relatively cheap, that is relatively safe. It is an indirect test. If you see an abnormality, it may have to be confirmed by endoscopic means, such as colonoscopy.

The problem with barium enema is that the art of doing the barium enema is, in fact, being lost because modern young radiologists like to do CAT scans and MRIs and ultrasounds and PET scans. Not as many radiologists actually practice this. And unless it is done exquisitely well, it is not a useful test.

The American College of Radiology is trying to set standards as it did for mammography, but I must say that the pendulum, unfortunately, has swung away from barium enema because of the fact I have already mentioned. But if done well, it can be a useful screening test because of its relatively low cost.

The CHAIRMAN. OK. Ms. McMullan, based upon the participation of your agency in the Screen for Life campaign—and let me congratulate you on your doing that—does the agency collect feedback from networked public and private organizations through its work as part of the roundtable?

Ms. MCMULLAN. Yes. I mean, part of the design of what we do in all of our educational efforts, including the health promotion efforts is to assess whether or not what we intended to accomplish was accomplished and what are the issues around the actual dissemination of the information. Was it used the way we thought it would be used? Did it have the effect that we thought it would have? And it is a little early in that process for us to have findings, but we do incorporate feedback to improve the manner in which we convey information.

The CHAIRMAN. Aetna U.S. Healthcare offers at-home testing kits and other educational initiatives for its managed care members. Since early detection is so useful in this particular disease, does

HCFA have any educational programs targeted at Medicare+Choice plans to encourage these plans to do outreach to their members for the same reasons we have been talking about all day?

Ms. MCMULLAN. As part of the contract with Medicare managed care plans, we encourage them to use preventive services, and part of their techniques in doing that is to convey educational messages. I am not aware that we have an explicit requirement in the contract, however, that they do at-home education. But preventive services are, I think, across the board more routinely used in managed care settings.

The CHAIRMAN. Can HCFA encourage Medicare+Choice plan—members to be screened? In other words, can HCFA do it or do the plans have to do it?

Ms. MCMULLAN. We can do both.

The CHAIRMAN. And do you do both?

Ms. MCMULLAN. We do not do any direct mailings on health promotion information other than the Medicare Handbook, and as part of the Medicare Handbook, there are charts that explain the preventive benefits.

How we do disseminate the information is through our partners and community-based organizations, but up to this point, we have not done any direct mailing to beneficiaries about preventive services.

The CHAIRMAN. OK. My last question goes back to something that Dr. Levin said about African Americans being more likely to be diagnosed with colon cancer and even more likely to die from it than causasians. What types of outreach activities is HCFA doing to reach these beneficiaries on the importance of regular screening? Do you have anything targeted just to African Americans?

Ms. MCMULLAN. We don't have anything targeted to just African Americans at this point other than we have created the poster in culturally competent manner so that they are targeted to different culture groups, so that in using the poster, they can be put up in different settings.

We are investing research in understanding the different cultural needs of the different cultural groups. There are different mechanisms to reach individuals in different cultural groups. African Americans have different people whom they trust. They may rely more on family, as an example, than other cultural groups. So we are trying to understand what people need and how to convey information to them and what channels of information that they most trust. And one of the groups that we are targeting is the African American population.

The CHAIRMAN. That is all the questions I have. I ought not forget to congratulate Dr. Scanlon because you have been very helpful to this committee on so many health care issues. My colleagues congratulated you for me but as Chairman I should have done it as well.

Mr. SCANLON. Thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you.

I have no further questions, so I thank you very much for your participation. The hearing is completed. Thank you.

[Whereupon, at 2:58 p.m., the committee was adjourned.]

APPENDIX

P.O. Box 182 Kensington, Maryland 20895 (301) 879-1500 semicolonclub@yahoo.com colorectal-cancer.net

Saving Lives Through Patient Support and Advocacy

COLORECTAL CANCER NETWORK

My name is Laurette Savary. I am the co-director of the Colorectal Cancer Network. I am also a four year survivor of Stage II colon cancer. I am one of the lucky ones. Every day people are dying from this disease. Each year more than 130, 000 people are newly diagnosed and of those more than 50,000 will die. Colorectal cancer is the second leading cause of cancer deaths in men and women in the United States. It is also one of the most curable, the most treatable of cancers. Estimates from most sources indicate that there is a 90% survival rate if the tumor is found early enough.

Routine screening would find most of these cancers. Sadly those who should be screened are not. Why? Why, when we have the tools available to be saving lives, and money I might add, are so many people dying? Part of the reason is embarrassment. People do not talk easily about their bodily functions, especially when it involves the colon, the rectum and the anus. People are also afraid. Afraid of the diagnosis, afraid that it is a sure death sentence, afraid of having a colostomy, even though very few people with colorectal cancer end up with colostomies. And those who do say it is better than the alternative. But I would say that the major reason that people are dying is ignorance. Most people do not know how prevalent colorectal cancer is. Most do not know that it affects men and women in equal numbers. Most people are completely unaware of their own risk.

Physicians and insurance companies play an enormous role in this ignorance. The vast majority of those at risk are not being adequately screened by their doctors. Even when they have symptoms, they often are not sent for follow-up diagnostic tests. Part of this is lack of awareness on the physicians part. But it is also due to the fact that very few insurance companies cover screening. For the working lower middle class and poor who often have no insurance coverage, the chance that they will receive proper screening is unlikely.

The Colorectal Cancer Network, a community of survivors helping survivors, is a non-profit organization which sponsors support groups called the SemiColonClubs and The SemiColon Friends. We are also advocating for our members for better legislation, and better health coverage across the nation.

We must stop the needless thousands of deaths each year from this disease. We must insure that screening is available for all those who should be screened. You can help reduce the death toll by your actions here in Washington, DC. There is no better honor, no higher deed than saving a life.

Testimony submitted to the Senate Subcommittee on Aging
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