

## SUMMARY OF THE FIRST TRANSATLANTIC SYMPOSIUM ON STRATEGIES TO INCREASE COLORECTAL CANCER SCREENING AND SAVE MORE LIVES

Cancer survivors, leaders of non-profit organizations, research investigators, physicians, and journalists met at the Consulate General of the Federal Republic of Germany in New York in April 2009 for the **First Transatlantic Symposium on Strategies to Increase Colorectal Cancer Screening and Save More Lives**.

Even though colon cancer, a leading cause of death from cancer worldwide, is preventable, over one million new cases of colorectal cancer (CRC) will be reported this year and over 500,000 people will die.

The Transatlantic Symposium was convened to examine colorectal cancer screening (CRCS) strategies utilized in North America and Europe with the ultimate goal to prevent more people from developing CRC. Western Europe and North America have the highest reported incidence of CRC; in Europe approximately 400,000 new cases will be reported this year, over 140,000 cases will be reported in the U.S. In Europe and North America alone, an estimated 250,000 deaths will occur this year from CRC. Screening can lead to prevention or early detection resulting in fewer deaths from CRC.

This report is a brief summary of the Symposium; video recordings and complete presentations are found on the Internet: [www.ts-colon-cancer-prevention.com](http://www.ts-colon-cancer-prevention.com) Presentations and discussions were organized around four topics: (1) current screening guidelines and quality assurance, (2) barriers to screening including gender, psychological barriers, and costs, (3) successful strategies utilized to overcome barriers, and (4) public education programs.

The keynote address titled, *The Lifesaving Potential of Colon Cancer Screening*, was delivered by **Katie Couric**. Ms. Couric is anchor of the U.S. television program, *CBS Evening News with Katie Couric*. In 2000, Ms. Couric's colonoscopy was broadcast on national

*Special thanks are extended by the Symposium organizer, the Felix Burda Foundation, to the Steering Committee and to Dr. Stephan Grabherr, Deputy Consul General, German Consulate, for a warm welcome and hosting the Symposium at the German Haus.*

### *Steering Committee:*

*Carolyn Aldigé, Prevent Cancer Foundation, Alexandria, VA  
Berndt Birkner, German Network Against Colorectal Cancer, Munich  
Meinhard Classen, University of Munich  
Steven Itzkowitz, Mount Sinai Hospital, NY  
David Lieberman, Oregon Health Sciences University  
Christa Maar, Felix Burda Foundation, Munich  
Mark Pochapin, The Jay Monahan Center for Gastrointestinal Health, NY  
Moshe Shike, Memorial Sloan-Kettering Cancer Center, NY  
Felice Schnoll-Sussman, The Jay Monahan Center for Gastrointestinal Health, NY  
Sidney J. Winawer, Memorial Sloan-Kettering Cancer Center, NY*

television to demystify the procedure and promote colorectal cancer screening. This effort led to *The Couric Effect*, an unprecedented, 20% increase in colonoscopies in the U.S. A video of Ms. Couric's presentation, including a touching, first-hand account of the death of her husband, Jay, from colon cancer can be viewed in its entirety: [www.ts-colon-cancer-prevention.com](http://www.ts-colon-cancer-prevention.com)

*"Do everything you can to prevent other people from having the tragedy that I have."*

Felix Burda

The work reported by Symposium presenters points directly to the need for people to hear first hand from *trusted advisors*, e.g., a friend, family physician, or staff at a community health center, about the way in which screening can detect or prevent cancer. Symposium participants drafted a Declaration to be used to increase support for colon cancer screening worldwide: [www.ts-colon-cancer-prevention.com](http://www.ts-colon-cancer-prevention.com)

## THE POWER OF SCREENING

**Christa Maar, Chief Executive Officer of the Felix Burda Foundation and President of the German Network Against Colorectal Cancer**, opened the Symposium and established the framework for participants, *"the time to change the rate of colorectal cancer screening is now...there are powerful tools at our disposal but they have not been fully implemented."*

## FELIX BURDA – A MESSENGER OF HUMANISM AND HOPE

**Moshe Shike, Director of Clinical Nutrition and Attending Physician, Memorial Sloan Kettering Cancer Center**, described the courage in the face of great suffering exhibited by Felix Burda who fought a two year battle with colorectal cancer. Mr. Burda was an art scholar, teacher, and the father of two young children. Before his death at the age of 33, Mr. Burda asked his family to, *"engage in efforts to save others from having my fate, from having the tragedy that I have."*

*"Quest for new knowledge must always be tempered in medicine by the recognition that our means are limited and that part of the means has to be dedicated to applying the knowledge... medicine is ultimately about suffering, death, and helping people..."*

Moshe Shike, M.D.,  
Memorial Sloan  
Kettering Cancer  
Center, NY

In 2001, the Felix Burda Foundation was established by his parents, Dr. Christa Maar and Professor Dr. Hubert Burda in Munich, Germany. The Foundation impacts

thousands of lives, having increased the level of awareness in Germany about the need for colorectal cancer screening. Because of the determination of the leaders of the Felix Burda Foundation, preventative colonoscopy became a compulsory benefit of the German Health Insurance in 2002; it is estimated that this preventative measure and resulting early detection of colorectal cancer (CRC) will decrease the incidence rate of CRC by 15,000 people by 2010 and decrease the mortality rate from CRC by 1,000 people annually.

## TOPIC I: GUIDELINES, SCREENING AND QUALITY MEASURES

CRC is the 2<sup>nd</sup> leading cause of cancer deaths in North America and Europe and the 4<sup>th</sup> most common cause of cancer death worldwide. There is strong evidence that colorectal cancer screening (CRCS) reduces mortality and the incidence of colon cancer. In the first session, Symposium participants examined three main questions:

- What is the best test to use for screening the general population?
- What has and can lead to a positive outcome for patients going forward?
- What are the current challenges?

**Sidney J. Winawer, M.D., Memorial Sloan Kettering Cancer Center**, said, *“The best screening test is the one that gets done...and done well. Do what you can with what you have.”* A leader of the International Digestive Cancer Alliance, Dr. Winawer reviewed main elements of the international cascade based guidelines for colon cancer screening of the World Gastroenterology Organisation (WGO). Screening recommendations for a country are based on the resources in the country to perform the tests, i.e., financial, and medical facilities. Recommendations are ranked from 1 (highest resources available) to 6 (minimal resources). For complete details: [http://www.guideline.gov/summary/summary.aspx?ss=15&doc\\_id=12143&nbr=6244&string](http://www.guideline.gov/summary/summary.aspx?ss=15&doc_id=12143&nbr=6244&string) In countries with limited resources, the option is the fecal occult blood

## TOPIC I ORGANIZERS AND MODERATORS:

*Leaders of the International Digestive Cancer Alliance, Meinhard Classen, M.D., Professor of Gastroenterology, University of Munich, Sidney J. Winawer, M.D. Paul Sherlock Chair, Memorial Sloan Kettering Cancer Center, NY and Jean Faivre, M.D., Ph.D., Registre des Tumeurs Digestives, Dijon Cédex-France.*

*“The best screening test is the one that gets done...and done well. Do what you can with what you have.”*

*\_ Sidney J. Winawer, M.D., Memorial Sloan Kettering Cancer Center, NY*

test (FOBT) every 1-2 years for people 50 years old or older. By contrast, colonoscopy is advised in countries with a high level of resources and where CRC is a high public health priority. Average risk people are advised to undergo a colonoscopy every 10 years beginning at 50 years old. People with a greater risk from inherited or life-style factors are advised according to their level of risk, e.g., advised to screen at a younger age.

**David Lieberman, M.D., Oregon Health Sciences University**, reviewed two sets of guidelines released in 2008 for screening the U.S. population for CRC: (1) U. S. Preventative Services Task Force of the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality, and (2) American Cancer Society, Multi-Society Task Force on CRC, and the American College of Radiology. For entire guidelines see: [http://www.cancer.org/docroot/MED/content/MED\\_2\\_1x\\_Health\\_Groups\\_Issue\\_Updated\\_Colorectal\\_Cancer\\_Screening\\_Guidelines.asp](http://www.cancer.org/docroot/MED/content/MED_2_1x_Health_Groups_Issue_Updated_Colorectal_Cancer_Screening_Guidelines.asp)

If the goal is to detect CRC early, both U.S. guidelines recommend **multiple** sample stool tests, Guaiac Fecal-Occult Blood Test (gFOBT) or fecal immunochemical test (FIT); more than 50% of serious polyps are undetected with one test. The tests are non-invasive, can be done at home without special equipment, and are relatively inexpensive. But, the potential for cancer prevention is poor for FOBT and variable among the FIT tests marketed.

The guidelines of the American Cancer Society differentiate between tests for early detection of cancer and cancer prevention, i.e. tests that find both cancer and pre-cancerous polyps. If the objective is cancer prevention and a person is willing to undertake a more invasive test, the American Cancer Society recommends structural tests designed to detect both polyps and early cancer, e.g., colonoscopy or CT colonography. CT colonography is less invasive and more accepted by some people while others are concerned about the radiation exposure. If the goal of screening is to prevent cancer, a colonoscopy and polypectomy is the ultimate endpoint. Compared to stool based tests, structural tests have more risk of complications, e.g., bleeding and perforations can occur. Quality assurance programs can reduce these risks.

*“New evidence from 2.5 million people in Germany who received colonoscopies as a result of a national screening program championed by the Felix Burda Foundation will be useful for more fully assessing the use of colonoscopy for screening the general population of the U.S.”*

*— David Lieberman, M.D.  
Chief, Division of  
Gastroenterology,  
Oregon Health Sciences  
University*

Fifty percent of adults over 50 years of age in the U.S. now participate in CRCS, and the incidence of CRC is declining. A decline in the death rate in the U.S. from CRC coincides with the increased use of all methods for CRCS with the most recent increase in CRCS due to the increase in colonoscopies.

**Lawrence von Karsa, M.D., International Agency for Research on Cancer, Lyon, France**, traced the development of new CRCS guidelines to be released in 2009 for the European Union (EU) to the Recommendations of the Council of the EU on the design and implementation of national cancer screening programs and reporting systems in 27 EU countries. In formulating guidelines for the general populace, the EU Commission viewed it important to:

- personally invite all persons of eligible age, so that each person in the target population has an equal chance to benefit from screening.
- include quality control measures
- recommend cost-effective screening measures to ensure that resources needed for other health priorities are available

In the EU, with approximately 100 million people 55 years of age or older, the fecal occult blood test is recommended for CRCS.

The session presenters were reminded of the tragic experience of Felix Burda and asked by a member of the audience what in their work has or could lead to a positive outcome for patients who like Mr. Burda, unknowingly inherit a greater risk for CRC and need to be screened at a younger age.

Each presenter pointed out that *“deficiencies exist on both sides of the Atlantic”* in identifying and monitoring high risk people. **Jean Faivre, M.D., Ph.D., Registre des Tumeurs Digestives, Dijon Cédex-France**, noted that less than 10% of the people in the European CRC screening registry are younger than 50 years old. **Hans F.A. Vasen, M.D., Medical Director of the Netherlands Foundation for the Detection of Hereditary Tumors, Leiden University**, and a group of

*“The goal of the European Guidelines is to provide comprehensive recommendations to assure an appropriate balance between the benefit and harm of screening. This includes efforts to assure that all people who may benefit have an equal opportunity to be screened.”*

*Lawrence von Karsa, M.D., International Agency for Research on Cancer, Lyon, France*

collaborators from across Europe called the *Mallorca Group*, are identifying people in Europe who are at higher risk for CRC. About 2% or about 5 million people in Europe aged 45-70 years have a familial risk for CRC, having a first degree relative with colorectal cancer and a higher than normal risk to develop colonic tumors and adenomas. Another one million people in Europe are carriers of a mismatch repair mutation, responsible for the so called Lynch Syndrome (HNPCC). In Europe as well as in the U.S., Lynch Syndrome causes 3-5% of all CRC cases. People, who are carriers of this mutation, are at an increased risk for CRC and other cancers and often develop CRC at a younger age than the average population. A survey of 12 European countries indicates that family-physicians, who are the first point of contact for many patients, need to be better educated about how to collect family histories and identify high-risk individuals. Because these high-risk individuals need earlier and more frequent monitoring, they should be referred to a genetics center and any tumors that arise are tested for the specific gene mutation. At present, patients who are suspected to be among these high-risk individuals are only provided this level of genetic monitoring in 12 European countries. Led by Dr. Vasen, the *Mallorca Group* has set a goal to identify all Lynch Syndrome families in Europe in the next five years.

More work is needed to develop and standardize quality indicators for use internationally according to **Berndt Birkner, M.D., German Network Against Colorectal Cancer, Munich**. With the introduction of the preventive colonoscopy for the German population over the age of 55 in the year 2002, a quality assurance program was implemented to examine all the critical elements of screening colonoscopies, e.g., the quality of the technique and equipment, and cancer detection rates. As a result, colonoscopies performed in Germany are reported online by physicians. In Bavaria, the data are used to provide feedback to the physicians who receive indicators of how their procedures rank compared to other physicians, e.g., the percentage of lesions detected and the completeness of colonoscopies. **Lawrence von Karsa, M.D., International Agency for Research on Cancer, Lyon, France**, cautioned that population screening appears “logical and easy” but requires time and financial resources to develop a comprehensive program; efforts are ongoing in Europe

*“An estimated five million people in Europe are at risk for familial colorectal cancer and need to be screened for colorectal cancer at an earlier age.”*

***Hans F. A. Vasen, M.D., Netherlands Foundation for the Detection of Hereditary Tumours, Leiden University***

*“Quality assurance [of colonoscopy] results in highly efficient performance, with increasing confidence, increasing acceptance, increasing completeness, increasing effectiveness, decreasing mortality and increasing safety”*

***Berndt Birkner, M.D. German Network Against Colorectal Cancer, Munich***

to help establish and improve programs, e.g., through an independent Foundation.

Several discussants noted that at present, a non-invasive, low cost test with high sensitivity and specificity to detect precancerous polyps is not available. While a colonoscopy is widely considered the *gold standard* for prevention of cancer, the exact number of lives saved is not available for colonoscopy, a dilemma that could be addressed by a large, randomized clinical trial. Because of the added cost, expertise, and invasiveness associated with colonoscopy, most of the screening done worldwide is with a fecal occult blood test and, thus, emphasizes early detection of cancer not prevention.

A Symposium participant asked, “If a relatively simple blood test is developed to detect CRC, what level of sensitivity and specificity is required to make it practical for population screening?” The moderator of the session, **Sidney J. Winawer, M.D., Memorial Sloan Kettering Cancer Center**, explained that in high resource countries, a test with increased sensitivity that may result in an increase in the number of false positives because of a lower specificity is tolerable but countries with more limited resources would choose an increase in specificity over sensitivity. In the latter case, some cancers would be overlooked but limited resources would not be used on patients who do not have cancer. An acceptable balance of sensitivity and specificity must be decided by the people in each country in the context of resources and other public health priorities, e.g., high rate of HIV. Dr. Winawer noted that guidelines for evaluating new tests are currently being addressed by the Colorectal Cancer Screening Committee of the World Organisation of Digestive Endoscopy (OMED) chaired by Dr. Graeme Young. The guidelines will be released this year. **David Lieberman, M.D., Oregon Health Sciences University**, reiterated the current guidelines that new tests should be able to detect at least 50% of cancers.

## **TOPIC 2: BARRIERS TO SCREENING**

CRCS is underutilized in the U.S. and Europe even though it has a high priority for the investment of health resources, e.g., CRCS is among the five top

*The presenters' remarks regarding limited resources and the need to take family histories at a younger age prompted some of the audience to suggest that all cancer groups should work together to screen and develop educational materials and outcome measures, i.e., breast, cervical and CRC screening can be done at the same time.*

## **TOPIC 2 ORGANIZERS AND MODERATORS:**

*David Lieberman, M.D., Chief, Division of Gastroenterology, Oregon Health Sciences University, and Steven Itzkowitz, M.D., Mount Sinai School of Medicine, NY*

recommended prevention services of the U.S. Preventative Services Task Force, making it on level with an influenza vaccine in its importance and effectiveness in preventing a life-threatening disease. Colon cancer can be prevented by screening when lesions are detected at a pre-cancerous stage or at an early enough stage to be successfully treated. Presenters and audience members discussed possible barriers to CRCS that were attributed to patients, organizations, or systems, for example:

- fear of learning that one might have cancer
- male gender
- perceived cost
- message used to inform people about CRCS
- failure to be advised by a physician or other *trusted advisor* about screening

By comparison, circumstances that prompted patients to screen were a recommendation from their physician, a family history of cancer, and knowing someone who has screened.

In a research project done with colleagues at the University of California at Los Angeles, **Melissa Farmer, Ph.D.**, currently with the **Veterans Affairs, Greater Los Angeles Health Services Research, and Development Center of Excellence for the Study of Healthcare Provider Behavior**, used telephone surveys of members of a health plan who were at least 50 years old to understand patient views on CRCS independent of barriers related to healthcare access. No matter the type of CRCS test, i.e., take home stool test or endoscopy, two variables were consistently found to be significantly related to a person's decision to participate or not in CRCS. The greatest predictor of a person's decision to screen was having discussed CRC with their physician and reasons for not screening included worries about paying for the test, fear of results showing they had cancer, thinking they only need to be screened when they have symptoms, and not believing CRC is important to them.

**Johannes Blom, M.D.** Karolinska Institute, Karolinska University Hospital, Stockholm, Sweden, described a study in which 2,000 people, from the general population in Sweden, ages 59-61 years, were asked to participate in a CRCS program, 39% or about 800

*"Having discussed colorectal screening with their doctor was the most powerful predictor of whether or not a patient was screened and it didn't matter what test was used."*

*- Melissa Farmer, Ph.D.,  
Veterans Affairs,  
Greater Los Angeles  
Health Services  
Research, and  
Development Center of  
Excellence for the Study  
of Healthcare Provider  
Behavior*

people accepted. The participants group had a higher percent of people living in a small town, and people with a family history of cancer. A follow-up study nine years later revealed a larger percent of the non-participants developed colon cancer or died, either from colon cancer or other diseases, when compared to those that participated. The group of non-participants included a higher percent of unmarried, low income males leading Dr. Blom to conclude that those who did not participate have less healthy lifestyles and a more rigorous program is needed for CRCS of low-income men in Sweden.

*“Single, lower income males were self-selected, non-participants in the colorectal cancer screening program in Sweden.”*

*Johannes Blom, M.D.  
Karolinska Institute,  
Karolinska University  
Hospital, Stockholm,  
Sweden*

**Monika Sieverding, Ph.D., Department of Differential Psychology and Gender Research at the University of Heidelberg,** described studies undertaken to understand why cancer screening, provided at no-cost, is underutilized by men in Germany. Surveys of more than 20,000 people indicated that the people most apt to participate in CRCS have a family history of cancer, undertake regular medical exams, and/or their physicians recommended it to them. Fewer men than women have annual medical exams, 24% of men said they have never had an exam. Among men who have medical exams, 56% said a physician never suggested they undergo CRCS. Also, men reported fewer incidences of cancer in their family than women, this phenomenon, i.e., men failing to report cancer in their family, is found in other studies in Europe and the U.S. There is a higher probability that a man will screen, if friends and family members encourage screening and men are even more motivated to screen if they perceive that other men routinely undergo CRCS. Also, CRCS in Germany is offered in tandem with prostate cancer screening; the digital rectal exam for prostate cancer is objectionable to some and prostate cancer screening becomes a barrier to CRCS. Because everyone in Germany has medical insurance, psychological barriers to CRCS are more important than socio-economic ones. Dr. Sieverding suggests that to increase CRCS among German men, the media message should be re-crafted and prostate cancer screening separated from CRCS. Instead of reminding men how few men are screening, the media message should be that *two thirds of men already participated in cancer screening.*

*“Gender studies indicate that the media message in Germany must not be how many men do not participate in screening but how many men have participated.”*

*\_Monika Sieverding,  
Ph.D. Department of  
Differential Psychology  
and Gender Research,  
University of  
Heidelberg*

Session organizer, **David Lieberman, M.D., Oregon Health Sciences University**, noted that the presentations by Drs. Sieverding and Blom indicate that German men and lower income, unmarried Swedish men, respectively, are less likely to participate in CRCS, while Dr. Farmer reported a higher than average screening rate, over 60%, for patients treated by the U. S. Veteran's Administration (VA), a largely male population. Dr. Farmer said some suggest the higher screening rate for the VA is due to the computerized reminder system that indicates when screening is needed. Cost is not a barrier for men in Germany and for VA patients in the U.S., the service is free-of-charge.

Several participants suggested other barriers to CRCS. E.g., age of the targeted group, i.e., people at average risk for CRC are asked to begin screening at the age of 50 years. The screening rate for cancers for which younger people are screened, e.g., mammography, declines with the age of the patients. Another barrier may be the way in which screening is initially presented, i.e., people are assured of the availability of pain medication. One member of the audience said that many people are uncomfortable talking about *that part of the body* and a key element to increasing CRCS may be educating physicians and others about how to educate their patients.

**Melissa Farmer, Ph.D., Veterans Affairs, GLA, HSR&D Center for Excellence for the Study of Healthcare Provider Behavior**, said that efforts to increase CRCS must address not only patient barriers but barriers of the providers and their organization. The University of California Los Angeles study surveyed physicians serving adults at least 50 years old and four categories of barriers to recommendation of CRC screening emerged: (1) Health system, e.g., inadequate reimbursement, lack of time, (2) Issues with test used to screen, e.g., too many false positives or actual positives too rare in their practice, (3) Patients, e.g., lack of follow through and knowledge about screening, and (4) Providers, e.g., other health concerns take priority and didn't remember to screen.

A physician in the audience said that having more than one recommended screening method can be a barrier at the organizational level. If there is more than

*"There is a need for quality, educational materials targeted to specific demographics for patients and physicians to not only inform about the importance of CRCS, but to explain the details of colonoscopy, e.g., the preparation needed."*

*—Moshe Shike, M.D.  
Memorial  
Sloan-Kettering Cancer  
Center, NY*

one recommended test for CRCS, the added cost of colonoscopy can prevent some physicians from recommending it because full reimbursement may not be provided by insurers. It is believed that one of the reasons the CRCS rate for New York City exceeds the national average is that City leaders mandated that colonoscopy would be **the** method for CRCS.

To address barriers to CRCS from an organizational perspective, **Melissa Farmer, Ph.D., Veterans Affairs**, reported on a national survey of VA primary care clinics linked to performance measures on CRCS. In 2001, the CRCS rate for the VA was 62%, which was higher than the national average but ranged among clinics from 29-89%. Higher screening rates were found at clinics reporting a high level of authority over clinical protocols, e.g. guidelines, and those reporting sufficient clinical support arrangements, e.g., space and computers. Larger clinics had lower rates, possibly because of more problems with coordination across all units.

**Michael Pignone, University of North Carolina Hospital, Chapel Hill, NC, U.S.**, addressed the cost and cost-effectiveness of CRCS which is perceived by some to be a large barrier to CRCS of the general population. Studies undertaken in the past provide ample data to create good cost models. Dr. Pignone reviewed a number of specific techniques and variables used in modelling costs as well as the results of benchmark studies. For full presentation see [www.ts-colon-cancer-prevention.com](http://www.ts-colon-cancer-prevention.com) While data is not presently available to determine which of the current CRCS tests is best, all the recommended methods for CSRC are effective and cost-effective when compared to no screening.

### **TOPIC 3. OVERCOMING BARRIERS ON THE LOCAL AND NATIONAL LEVEL**

Identifying barriers to colorectal cancer screening (CRCS) was the topic of the previous session. Overcoming barriers and customizing programs for different local and national populations in order to increase the rate of CRCS is taken up in the next

*“The health impact and cost-effectiveness places CRC screening in the top 5 of the most highly recommended prevention services by the U.S. Prevention Priorities Project”*

*\_Michael Pignone, M.D, MPH., University of North Carolina Hospital, Chapel Hill, NC, U.S.*

### **TOPIC 3 ORGANIZERS AND MODERATORS:**

*Mark Pochapin, M.D.  
The Jay Monahan  
Center, New York, and  
Carolyn R. Aldigé,  
Prevent Cancer  
Foundation, Alexandria,  
VA*

session. **Jean Faivre, M.D., Ph.D., Registre des Cancers, Université de Bourgogne, Dijon, France**, says efforts to initiate a national colon cancer screening were enhanced when in 2003, the Advisory Committee on Cancer Prevention of the European Commission, recommended that EU countries set up CRCS programs. Immediately, the French Society of Gastroenterology launched a press campaign to underscore for public officials the importance of CRCS for asymptomatic people 50-74 years of age. Nationwide CRCS was conducted in France in 2008; the program provides a Guaiac Fecal-Occult Blood Test every two years to about 4 million persons 50 years or older, who are registered with the national health insurance (only 0.4% of the people in France do not have health insurance). Early evaluation of the program shows a 42% screening rate for 19 districts; the rate varied by district from 31%-54%. The rate of positive tests was 2.7%. Although health policy is made at the national level in France, CRCS is carried out by the staff of 19 regional centers overseen by non-profit organizations. The active participation of local General Practitioners (GPs) was found to be essential to the French program. To insure the GPs participated, they were provided regular feedback about the program in small group meetings.

**Christa Maar, Ph.D., Felix Burda Foundation, Munich Germany**, described the development and outcomes of the national colon cancer awareness campaigns undertaken by the Burda Foundation in Germany. Although screening was available in Germany since 1971, the rate of screening was low and the mortality rate from CRC was among the highest in Europe, 58%. The first step taken by the Burda Foundation in 2001 was to saturate the media, e.g., creating and running ads for eleven months in 45 Burda Media magazines and placing promotions on all television stations. The ads were positive and informative, with eye catching photos to heighten awareness about CRCS. Also in 2001, the Burda Foundation convened a conference of stakeholders, i.e., physicians, public health insurers, health ministries and advocates. The *Munich Declaration* was spawned from a spirited exchange of ideas, the *Declaration* identified colonoscopy as the preferred screening test and set forth the goal of a 50% decrease in CRC mortality in Germany in 5 years. Equally

*In response to the misconception of many that abdominal pain will alert them when they have colon cancer, the Felix Burda Foundation launched the "I feel good campaign," a parody of the James Brown lyric. The message is you can feel good and not know you have colon cancer unless you are screened.*

important was the increased networking among practitioners and people who could make a difference.

In 2002, to broadcast the information more widely, the Foundation partnered with other organizations and all large media companies to initiate the first nationwide Colon Cancer Awareness Month. BILD, the largest German tabloid, reaching 12 million readers daily, supported the Cancer Awareness Month with numerous reports and interviews. During the month, 18 million TV viewers and an estimated 350 million readers of periodicals learned about colon cancer prevention. The colonoscopy of a celebrity was broadcast on television. As a result, the German version of the *Couric Effect* was realized; the rate of colonoscopies increased by 25% and the rate of awareness increased from 20% to 50%. Public health insurers began to offer colonoscopies free-of-charge to all people over the age of 55 years. Additional milestones include:

- About half of all the large German companies include CRC screening in their health programs, benefiting over 2 million employees.
- The annual Felix Burda Awards recognize those who have contributed significantly to the fight against colon cancer.
- A comparison of 2002 and 2008 surveys, indicates more people feel well informed about CRC, the number rose from 21% to 44%; the number who know there are good methods for the early detection of CRC rose from 24% to 72%, and the number of people 50 years old or older who have spoken with a physician about CRCs rose from 35% to 72%.

Unfortunately, awareness does not always translate into complete understanding and action. Seventy-five percent of people recently surveyed think they only need to go for screening if they feel pain and 66% believe modern medicine can cure CRC. Annually only 3% of the people who are eligible to receive a colonoscopy free-of-charge do so. Nevertheless, since the work of the Felix Burda Foundation began in 2001, the incidence of mortality from CRC has decreased from 58% to 38%, due in part, to the detection and removal of 200,000 advanced adenomas from the 3.5 million people who had screening colonoscopies by the end of 2008. Seventy

percent of the carcinomas now diagnosed in Germany are in the early stage.

**Carrie Klabunde, Ph.D., Division of Cancer Control and Population Sciences, National Cancer Institute**

**(NCI), U.S.**, says that NCI, the U.S. Government lead agency on cancer and a component of the National Institutes of Health (NIH), supports research on colon cancer screening. In 2010, NCI will convene the *NIH State of the Science Conference on Enhancing Use and Quality of Colorectal Cancer Screening* to evaluate the current science and delineate research needs. A supplement to the journal, *Medical Care*, titled *"Improving Delivery of Colorectal Cancer Screening in Primary Care Practice"* summarizes results of NCI-funded studies and is available free-of-charge by sending an e-mail request to: [HRQPubs@ahrq.hhs.gov](mailto:HRQPubs@ahrq.hhs.gov) NCI also supports the International Cancer Screening Network of over 20 countries with population-based cancer screening programs focused on evaluation of those programs. For the most part, CRCS is decentralized in the U.S., i.e., dependent upon primary care practices. Through time people who do not screen have reported a lack of awareness about CRCS and/or their physician did not advise it. The main reason primary care physicians give for low CRCS rates is non-compliance, i.e., patients do not follow through on screening. Previously, FOBT was the most recommended test, but a 2007 survey shows that colonoscopy is now the most often recommended test in the U.S.

**Moshe Shike, M.D., Memorial Sloan-Kettering Cancer Center, NY**, conducted a study that shows the *trusted advisor* role when assumed by staff of a well-respected community mammography center can result in individuals who do not have primary care physicians choosing to participate in CRCS. In the U.S., inadequate screening for CRC is highest in minority communities such as Harlem, NY, where the 5-year survival rate of CRC patients is reported to be as low as 20% compared with the national average of 47-62%. This low survival rate is attributed to late diagnosis related to a low screening rate. While women are more likely to participate in preventive healthcare, the rate of CRCS is low among women when compared to the number who screen for cervical and breast cancer.

*"People [in U.S.] who do not participate in screening report a lack of awareness about CRCS and/or their physician has not recommended it to them...We know that reminder systems work [for physicians and patients] but most primary care practices do not have such systems."*

*\_Carrie Klabunde, Ph.D., Division of Cancer Control and Population Sciences, National Cancer Institute (NCI), U.S.*

*A supplement to the journal, Medical Care, titled "Improving Delivery of Colorectal Cancer Screening in Primary Care Practice" summarizes results of the U.S. NCI-funded studies and is available free-of-charge by sending an e-mail request to: [HRQPubs@ahrq.hhs.gov](mailto:HRQPubs@ahrq.hhs.gov)*

A random survey of New York's Harlem households from 1992-1994 showed that 80% of women age 50 to 65 years have mammograms. Women do not have to have a regular physician or financial means to receive mammograms at the Breast Examination Center of Harlem (BECH). BECH, a program of Memorial Sloan-Kettering Cancer Center since 1979, is known in Harlem for free, quality care, having screened more than 118,000 women for breast cancer. In a visit to BECH, women were offered CRCS, thus, eliminating the need for a physician referral. Of the 611 women who accepted, 92% were black or Hispanic, and 337 women (55%) chose to screen. Most of the women lacked insurance, yet, 29% of those who completed colonoscopy offered to pay the reduced fee of \$300, indicating a desire to screen. Donations covered the cost for patients who lacked insurance. Introducing women to CRCS through a community mammography center without a physician's referral was effective as was the process of arranging medical appointments. The most common barrier to CRCS was lack of medical insurance. Alternatives to traditional medical insurance are needed for the uninsured.

Similarly, **Laura Seeff, M.D., Centers for Disease Control and Prevention (CDC), Atlanta, GA, U.S.**, described a partnership with five existing state cancer screening programs to provide CRCS for the 60% of lower income people in the U.S. who are not covered by health insurance. The CDC found that many screening models are effective. The programs reached people who were previously unscreened; 67% of over 3,600 people screened by year two had no previous history of screening. As reported by others, CDC finds lower income men more difficult to reach and someone to help low income people to *navigate* through screening is crucial. A U.S. Government agency, the CDC contributed to the *2009 Annual Report to the Nation on the Status of Cancer* focussed on colon cancer.

**Steven Itzkowitz, M.D., Mount Sinai School of Medicine, N.Y.**, says that once an individual decides to screen, a *navigator*, can help low income individuals complete screening colonoscopies. Barriers to CRCS for patients at Mount Sinai Hospital were analyzed and three types of barriers became evident: (1) physician, e.g., failure of primary care physicians to recommend

*“Since some people do not go to the doctor, alternative ways must be found besides physician referral to stimulate people to participate in colon cancer screening.”*

*Moshe Shike, M.D.,  
Memorial Sloan  
Kettering Cancer  
Center, NY*

*Additional information about CDC's colon cancer prevention and control programs can be found on the Internet as follows:*

*Cancer Prevention and Control Programs:*  
[www.cdc.gov/cancer](http://www.cdc.gov/cancer)

*State Cancer Plans:*  
[www.cancerplan.org](http://www.cancerplan.org)

*U.S. Preventive Services Task Force:*  
[www.ahrq.gov/clinic/uspstf/uspscolo.htm](http://www.ahrq.gov/clinic/uspstf/uspscolo.htm)

*National Colorectal Cancer Roundtable:*  
[www.nccrt.org](http://www.nccrt.org)

colonoscopy, (2) organizational, e.g., scheduling and insurance problems, and (3) patient barriers, e.g., inconvenience, language difficulties, and fatalism about outcome, i.e., *if God meant for me to have colon cancer there is nothing I can do about it*. An *Open Access Endoscopy* program was initiated and a patient *navigator* employed to address these barriers. Patients were able to go from their primary care physician directly to the colonoscopy appointment without an interim visit to a Gastroenterologist and patients were guided through the process of completing a colonoscopy by a patient *navigator* who answered the patient's questions about the procedure and the preparation needed, reminded patients of their appointments, and assisted with transportation, when needed. In 2004, 77% of the 688 people successfully recruited to participate in a test program for *Open Access Endoscopy* were navigated. Sixty seven percent of those navigated, i.e., 532 people, completed their colonoscopies. In this completion group, two cases of cancer were diagnosed and 16% of the patients were found to have adenomas. Women were more likely to complete the procedure than men, and a higher percent of Hispanic people completed the colonoscopy than those of African American heritage. Because most of those who completed the procedure were Hispanic women, it is postulated that perhaps this was due to the fact that the *navigator* was a thirty year old Hispanic woman. Studies are underway to test the effectiveness of *peer navigators*, e.g., an African American male *navigator* for African American men. Sixty-four percent of the people who had the colonoscopies said they would not have completed the procedure without the help of the *navigator*. With regards to their understanding of the procedures, 84% said they understood their physician's explanation, 92% said the *navigator* increased their understanding. Similarly, 35% understood from their physician the preparation needed, but, 59% said the *navigator* increased their understanding.

#### TOPIC 4. PUBLIC EDUCATION PROGRAMS

The variety and creativity of the public education programs described during this session led the attendees to lively discussions of programs that

*In focus groups at Mount Sinai Hospital, Harlem residents of African American descent were asked why they had not participated in the CRCS. Responses included:*

- *No cancer in family, so not important*
- *Doctor does not say a colonoscopy is mandatory*
- *Preparation for colonoscopy too difficult*
- *Colonoscopy too invasive*
- *Some women expressed concern about what happened when they were asleep; they wanted someone they knew in the room.*
- *I had a prostate exam, i.e., some men thought digital rectal prostate exam also screened for CRC.*
- *My friends haven't had colonoscopy, why should I?*

#### TOPIC 4 ORGANIZERS AND MODERATORS:

*Moshe Shike, M.D., Memorial Sloan-Kettering Cancer Center, NY, and Felice Schnoll-Sussman, M.D., The Jay Monahan Center for Gastrointestinal Health, NY*

might translate into global initiatives and those that were more applicable locally.

**Laura A. Linnan, Sc.D., University of North Carolina School of Public Health, Chapel Hill, NC**, said, *“Grass roots efforts that involve local people in discussions about cancer prevention will help move people along on the path to change, so that when a large, global campaign ‘hits,’ they are ready to receive and act upon the message.”* The North Carolina BEAUTY and Health Project began with the formation of an advisory board composed of beauty salon owners, cosmetologists, customers and research investigators from the University of North Carolina at Chapel Hill School of Public Health and the Lineberger Comprehensive Cancer Center. The Board was uniquely qualified to explore how to promote health and cancer prevention in beauty salons and to assist with implementation. Beauty salons are located in all communities and are places where customers feel safe and have a bond with their stylist. Seven health campaigns were conducted over 18 months. Salon owners, stylists and customers were highly enthusiastic about promoting health, but, there was not a significant difference for most of the targeted health behaviours between customers who were a part of an intervention program and those who were not. Future plans are to more fully engage stylists in the programs, vary the type of intervention, and offer continuing education credits to stylists who attend training. A new health promotion program for African American men who frequent barbershops is initially more effective than the program for beauty shops and a program is planned to reach new immigrants through Latina salons.

**Berndt Birkner, M.D., German Network Against Colorectal Cancer, Munich**, said, *“In Germany, many men are more interested in the care of their cars than in the care of their intestinal health.”* A colorectal cancer screening campaign undertaken in the states of Bavaria and Baden-Württemberg focused on men who brought their cars in for a mandatory, biennial, safety inspection. The campaign was held in March 2008 as part of the Felix Burda Foundation initiated Colon Cancer Awareness Month in Germany and the public was informed about the campaign in advance by newspaper articles and pamphlets. For two days, men who brought their cars in for inspection were met at

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**Laura A. Linnan, Sc.D.,  
UNC School of Public  
Health, Chapel Hill, NC,  
U.S.**

*“In Germany, many men are more interested in the care of their cars than in the care of their intestinal health.”*

**\_Berndt Birkner,  
German Network  
Against Colorectal  
Cancer, Munich,  
German.**

the checking station by a Gastroenterologist and by Hans Joachim Stuk, a famous German race car driver of the 1970s, who is well known among the target group. To increase the confidence of the general public, a company that owns 180 checking stations, DEKRA, established a rigorous audit process and granted certificates of quality to Gastroenterology practices, as a guarantee to the public that the screening colonoscopy of these practices was safe, clean and painless.

**Daniel Mauss, European Aeronautic Defence and Space Company (EADS), Munich, Germany,** noted, *“Company disease prevention programs are an important way to increase participation in the presently underutilized German CRC screening program.”* With the support of Mannheim Institute for Public Health at the University of Heidelberg, the European Aeronautic Defence and Space Company offered employees a complete medical exam for chronic diseases such as diabetes, coronary heart diseases and high blood pressure. The medical package included the immunological stool test (iFOBT) for CRC. The health check was well accepted. By integrating the iFOBT into this program an unprecedented 62% participation rate was realized. Before, only about 20% of employees participated in the company screening.

**Lynn Faulds Wood, European Cancer Patient Coalition, London,** a TV personality in the UK who fought a successful battle with advanced colon cancer and who routinely hosts television programs on colon cancer, says, *“It is logical to ask politicians to set the example for the general population by undergoing CRCS. Some of the politicians may have early, treatable cancers and they will learn first hand why CRCS is so important, thus, creating strong advocates for funding CRCS programs.”* Efforts to motivate members of European parliaments to undergo CRC screening and to fund national screening programs are ongoing because CRCS programs are not well developed in most European countries with less than half initiating national population-based programs. In Central and Eastern Europe there are strong cultural attitudes to be overcome, i.e., *cancer equals despair and certain death.* Nevertheless, through the efforts of Lynn Faulds Wood and the European Cancer Patient Coalition, most of the members of parliament in Slovenia have

*“It is logical to ask politicians to set the example for the general population by undergoing CRCS.”*

***Lynn Faulds Wood,  
European Cancer  
Patient Coalition,  
London***

been screened and early cancers detected. In the UK, an ambitious plan to park a mobile endoscopy truck at the Parliament and offer flexible sigmoidoscopy for members of the House of Commons and Lords who are 55 years old or older is endorsed by the Royal College of Nursing. Meanwhile, some members of parliament in the UK have been screened and the Coalition is already thinking about expanding the plan to include the members of the European Parliament in Brussels.

**Carolyn R. Aldigé, Prevent Cancer Foundation, Alexandria, VA,** described community programs in the U.S. to increase the awareness of early detection and prevention of colorectal cancer supported by the Prevent Cancer Foundation. The message of the Foundation of prevention and early detection reaches the general public through its Super Colon Exhibit, Buddy Bracelet Campaign, public service announcements, Internet site, and media initiatives. It reaches out to health care providers and community leaders through the *National Dialogue for Action to Increase Colorectal Cancer Screening* and State and Tribal *Dialogue for Action* Programs. The Foundation enhances its impact by collaborating with local organizations, see [www.preventcancer.org](http://www.preventcancer.org)

**Mark Pochapin, M.D. The Jay Monahan Center for Gastrointestinal Health, New York, NY,** described the collaborative efforts of Katie Couric, anchor and managing editor of the *CBS Evening News*, the Entertainment Industry Foundation's National Colorectal Cancer Research Alliance (EIF Alliance), The Jay Monahan Center, and the Centers for Disease Control and Prevention (CDC). Because screening remains significantly underutilized for this cancer that is highly treatable and highly preventable with screening and early detection, Katie Couric co-founded the EIF Alliance in 2000 and helped to launch The Jay Monahan Center for Gastrointestinal Health at New York-Presbyterian Hospital/Weill Cornell Medical Center in 2004. The Center is named in memory of her husband, Jay, who died of colon cancer. Collaborative campaigns to promote CRCs include the CDC's *Screen for Life* public service announcements featuring celebrities such as Morgan Freeman, Diane Keaton, Jimmy Smits

*The Prevent Cancer Foundation sponsors the creation and placement of public service announcements about colorectal cancer screening. One such announcement suggests that if you are old enough to remember Elvis, you should be screened for colorectal cancer. See [www.preventcancer.org](http://www.preventcancer.org)*

and Terrence Howard. In 2007-2008, the collaboration also partnered with the New York City Department of Health and Mental Hygiene, and NYC Taxi and Limousine Commission to place videos of the announcements in New York City taxicabs. Also, in 2007-2008, the collaboration partnered with the American Society for Gastrointestinal Endoscopy, American College of Gastroenterology, and American College of Obstetricians and Gynecologists to provide information to obstetricians and gynecologists about colonoscopy as the recommended screening for CRC, and the importance of screening women for CRC along with breast and cervical cancers. To date, Ms. Couric and the EIF Alliance have raised more than \$30 million to support CRC research and awareness campaigns.

*“With this Symposium, the Felix Burda Foundation crosses the Atlantic with the life-saving strategies it employs in Europe.”*

*\_ Symposium Participant*

### **CALL TO ACTION**

Symposium participants discussed next steps and began the work of drafting a Transatlantic Declaration. The words used by **Christa Maar, Ph.D., Felix Burda Foundation, Munich Germany**, to open the Symposium were heralded at the close, *“the time to change the rate of colorectal cancer screening is now...there are powerful tools at our disposal but they have not been fully implemented.”* See Transatlantic Declaration at [www.ts-colon-cancer-prevention.com](http://www.ts-colon-cancer-prevention.com)

*\_Summary Report  
Compiler, Lynne Jordan  
Bowers, Ph.D.*