

# e-collaborating

collaborating (and communicating) to conquer cancer issue #3 summer 05

## Three Governors Join C-Change

Members and Partners learned at the Semi-Annual Meeting that three Governors have joined C-Change. Jon Huntsman of Utah, Ruth Ann Minner of Delaware, and Janet Napolitano of Arizona are now C-Change Members. Governors Huntsman and Minner will co-chair the State Cancer Plans Team.

"We are very pleased that these three outstanding leaders have chosen to join with us in our mission to eliminate cancer as a public health threat as early as possible," said LaSalle Leffall, Jr., C-Change Board chair. "Their participation will be a tremendous resource to our State Cancer Plans Team and all other aspects of our efforts. My thanks to President Bush, Jean Becker, and the National Governors Association for helping us arrange for their involvement."

All three governors have a strong interest in reducing cancer morbidity and mortality for their citizens.

### Governor Jon Huntsman, Jr, Utah

Jon Huntsman, Jr., a Republican, took office in 2004. A native of California, he attended the University of Utah and graduated with a bachelor's degree from the University of Pennsylvania.

As a business executive, he has held several leadership positions with Huntsman Corporation, a multi-national petrochemical corporation based in Salt Lake City. He most recently served as Chairman and CEO of its holding company.

His public service career includes serving as the first president and CEO of the Huntsman Cancer Foundation at the University of Utah.

*cont. on page 4, Three Governors...*



*Collaborating to Conquer Cancer*

## C-Change Meets, Moves Forward



**Co-chair Mrs. Barbara Bush visits with Tisha Fowler and the other C-Change Summer Interns during a break at the May Semi-Annual Meeting.**

The movement forward was palpable. In two days of dynamic, action-oriented, thought-provoking meetings, C-Change™ Members, Partners, guests, and staff came together on May 20-21 at the Renaissance Hotel in Washington, D.C., for the Semi-Annual Meeting. In the true spirit of C-Change collaboration, the attendees took visible, measurable strides forward in their attack on cancer.

President George H.W. Bush, C-Change Co-Chair, set the tone at the opening of Saturday's Plenary session. He called upon Members and Partners to keep moving "from attendance to

true involvement." After quipping that the job of sitting and listening had been taken by himself and co-chair, Mrs. Barbara Bush, President Bush dared the Members and Partners to take action and move C-Change closer to its goal.

Soon after, there was plenty of evidence on stage that C-Change was moving forward when Maureen Lichtveld, chair of the Workforce Team, introduced 14 Summer Interns, the first ever such group for C-Change. Ranging in education levels from college undergraduates to medical resident, eleven of the interns are being sponsored by Members

*cont. on page 5, C-Change Meets...*

## C-Change Planning Bold Strategic Initiatives

In early 2005, the Board of Directors began to define a strategic plan for C-Change. The architecture of the plan aims to leverage the unique capabilities of the organization with an eye toward sustainability. Early in the process, the Board determined the need to focus the attention and resources of the organization on finite, but ambitious initiatives to accelerate progress and strengthen C-Change's impact on cancer. The Board chose three areas of focus—prevention, research, and access—as targets for bold initiatives.

Board Chair LaSalle D. Leffall, Jr. commented, "The Board has asked each Team of C-Change to propose bold initiatives in the these areas. We want to identify a few opportunities that would truly capitalize on our unique capabilities and draw upon the resources of all Teams and the entire membership."

Cancer Research Team Chair Ron Herberman commented on the pending discussion of the prevention and early detection initiative. "Research has the potential to play an

# C-Change directors & staff

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*Collaborating to Conquer Cancer*



## from the executive director connie curran

If I had a dollar for every time I heard “best meeting ever” after the May Semi-Annual Meeting, I could begin funding the un- and under-insured. I believe these sentiments stemmed from several sources.

On Friday, the Teams conducted intense and productive meetings and are seeing many of their complex initiatives come to fruition. Then, Saturday’s Plenary Session started with mission-testing “Calls to Action,” moved into riveting remarks by John Kitzhaber and others, and culminated in a discussion of major fundamental health policy issues. The day ended with standing ovation-winning remarks by cancer survivor Joel Siegel—a reminder of why we are here, how quickly we need to work, and who is depending upon our progress.

In essence, a thoughtfully planned meeting played out in a community of truly invested leaders. My thanks to all who organized and participated in, as you said, the “best meeting ever.”

While it is hard to visualize the ‘snowball’ effect in the height of the summer, the efforts and accomplishments of C-Change have grown exponentially in the past 18 months. The Board, Team Leaders, Members and Partners, and staff have successfully worked to accelerate projects and answer “Calls to Action” while building the infrastructure and resources to sustain and focus our future. The contents of this newsletter are proof of our progress.

Moving forward, our organizational growth is taking on a more mature shape in the form of a guiding strategic plan that will be supported by an engine of impact-oriented strategic initiatives and team projects—all fueled by a performance-dependent fundraising plan. The strategic plan will serve as the architecture to ensure that we are focused on truly bold opportunities and maximizing our unique position.

Within this framework, the Board has asked the Teams to propose bold initiatives that would tap our true potential as an organization. Paraphrasing Bob Comis, we have the opportunity “to make gold coins or gold bars.” I believe we were created to make gold bars. Since we are past the stage of initial faith-based giving, our efforts to fund our mission going forward will hinge on our ability to communicate our purpose and demonstrate our results.

Yet another critically important effort to building infrastructure and stability in the organization hinges on the work of the Nominating Committee. Under the leadership of Charles Balch, the Committee has focused on ensuring the ongoing balance and caliber of our membership. They are making recommendations to the Board of Directors to address issues of sector balance and inactive members. The committee is also considering the inclusion of leaders critical to our impact, such as those from other public agencies, pharmaceutical and biotech companies, and insurance firms.

As C-Change continues to evolve and mature, I want to encourage you to become more involved in activities that help shape the organization, and more importantly strengthen our impact on cancer. As President Bush noted during his remarks at our May Semi-Annual Meeting, “In the past, we have described our efforts as moving ‘from dialogue to action.’ Now, I ask that even more of you move from ‘attendance to involvement,’ true involvement.”

Regards,

Connie

## AHRQ, C-Change Discuss Case for Cancer Prevention with Business and Insurance Leaders

On Wednesday, May 19, 60 representatives of business and industry, major health plans, healthcare providers, and the public and not-for-profit sectors attended an invitational meeting at the Renaissance Hotel in Washington, DC, to begin a discussion of the business case for delivery of cancer prevention and early detection services.

Sponsored by the Department of Health and Human Services' Agency for Healthcare Research and Quality (AHRQ) and C-Change, this milestone meeting tackled the issue of how business, industry, health insurers, government, and healthcare delivery providers can foster greater availability and use of programs to prevent, detect, and minimize cancer's devastating effects on employees, health plan members, their families and the general population.

While the day-long meeting sparked a vigorous review and discussion of issues and ideas,

many agreed that the most significant accomplishment was bringing this notable group of leaders together in collaboration to explore their roles, individually and collectively, in creating a healthier, more cancer-free population.

C-Change's executive director, Connie Curran, and Phil Huang, Prevention and Early Detection Team chair, and Carolyn Clancy, AHRQ Director, see the meeting igniting an ongoing planning process to develop programs and policies that will enable all the organizations to create more extensive prevention services. Symposium participants and other partners will be invited to develop an action plan and implement the steps necessary to impact improved delivery of cancer prevention and screening services.

A report of the meeting will be available at: [www.c-hangetogether.org](http://www.c-hangetogether.org).

*cont. from page 1, ...Bold Strategies...*



**The bold strategic initiatives will be designed to leverage the collaborative resources of C-Change Members and Partners.**

enormous role in prevention, ranging from efforts to further our understanding of genetic predisposition to cancer and the interplay with environmental factors, to developing more chemo-preventative agents and preventative cancer vaccines, to discovering methods for earlier detection that we know increase chances of long-term survival. All Teams have an important role to play in prevention," Herberman concluded.

Phil Huang, Chair of the Cancer Prevention and Early Detection Team, underscored the

Board's approach. "Focused strategic planning gives us the opportunity to capitalize on the strength and potential of C-Change. Aligning and coordinating the efforts of all of the Teams and the organization around prevention creates the opportunity for us to have an impact on cancer incidence now and into the future," said Huang.

While these bold initiatives will become a primary focus of the Board, Teams, and the membership, other Team-specific projects will continue.

### Fall Semi-Annual Meeting

October 14-15, 2005

Renaissance Hotel

Washington, D.C.

## C-Change Annual Member and Partner Directory

C-Change is assembling the 2005 Annual Member and Partner Directory. Watch for the directory update form that will be sent via email to each Member and Partner. Please complete the update form and return it as quickly as possible to ensure that your information is accurate and complete.

## 2005 Tour of Hope Team Announced

Even as Lance Armstrong competed for an unprecedented seventh Tour de France title, the Tour of Hope™ national team of 24 cancer survivors, caregivers, researchers, nurses, and physicians is preparing to ride from San Diego to Washington, DC, September 29 to October 8. Armstrong will lead the Team at the kick-off in San Diego and into Washington, DC for the finale, and will join the Team at points along the route.

C-Change is a partner for a second consecutive year of the Tour of Hope, which is primarily sponsored by Bristol-Myers Squibb. Six other C-Change member organizations are also Tour partners.

The team of cyclists will cover 3,300 miles in nine days to share their experiences and inspire those they meet along the way to learn more about cancer prevention and research. The Team will stop at events hosted by cancer centers and cancer organizations to encourage communities to support research and invite them to be a part of the fight against this disease, and especially to participate in clinical trials.

Selected by members of the cancer and cycling communities from a pool of nearly 1,100 applicants, the 2005 Tour of Hope Team is comprised of people from all walks of life. The diverse group includes healthcare professionals, an Army reservist, a biologist, educators, a realtor, a sports attorney, in addition to individuals from the restaurant, software, business and investment industries.

Kinga Bartoszek, a C-Change Director, was on the selection committee.

Visit <http://www.tourofhope.org> to learn more about the Tour of Hope™ and how to get involved.



## C-Change & UICC To Create U.S. National Cancer Calendar

C-Change and the International Union Against Cancer (UICC) are teaming up to create a web-based "U.S. National Cancer Calendar." The UICC first developed its international calendar as a website tool for use by its members and for all in the cancer field. C-Change's partnership with the UICC spurred the idea for development of a similar calendar for the United States to promote awareness of cancer events.

The "U.S. National Cancer Calendar" will be accessible via the C-Change website. Visitors to the Calendar will be able to add specific events using a basic online form and to conduct detailed searches for information on upcoming U.S. cancer-related events and meetings.

Connie Curran, C-Change's executive director, points out, "UICC's international calendar has been a very successful tool. We foresee the "U.S. National Cancer Calendar" to be a similarly valuable asset to our Members and Partners and to everyone concerned about cancer."

The "U.S. Cancer Calendar" is in Phase II of a three phase development process with an estimated release of late September 2005.

*cont. from page 1, Three Governors...*

### Governor Jon Huntsman, Jr, Utah



Gov. Huntsman also has served as a White House staff assistant to President Ronald Reagan. Under President George H. W. Bush, he

was deputy assistant to the secretary of commerce for trade development, deputy assistant secretary of commerce for East Asian and Pacific Affairs, as well as U.S. ambassador to Singapore, the youngest U.S. ambassador in a century. He is fluent in Mandarin. He also served as a deputy U.S. trade representative and U.S. trade ambassador under President George W. Bush.

Gov. Huntsman, a seventh generation Utahn, and his wife Mary Kaye have six children, one of whom is adopted from China.

### Gov. Ruth Ann Minner, Delaware



Gov. Ruth Ann Minner, a Democrat, was born in Delaware and left school at age 16 to help on her family's farm, later marrying Frank Ingram. Widowed suddenly at 32 with three sons to raise, she worked two jobs while going to school to earn

her General Education Development diploma. She built a family towing business with her second husband, Roger Minner, who died of lung cancer in 1991. Minner began in politics by stuffing envelopes, then worked as an aide in the state legislature and as receptionist to then-Governor Sherman Tribbitt. She was elected to four terms in the state House of Representatives beginning in 1974, to three terms in the state Senate beginning in 1982, and to two terms as lieutenant governor in 1992 and 1996.

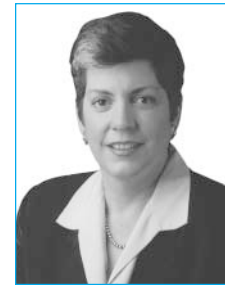
Minner was elected governor of Delaware in November 2000. Since taking office, she has worked to reduce cancer and improve healthcare, improve schools, preserve and protect the environment, as well as create and keep jobs. Her initiatives to reduce industrial pollution include the Environmental Right-To-Know Act, repeat offender law, and the first-ever regulation of above-ground storage tanks.

Gov. Minner has championed a comprehensive fight against high cancer rates with \$15 million to date for increased education and screening and treatment; the creation of a cancer registry to identify cancer case "hot spots" or environmental causes; a first-in-the-nation program to pay for cancer treatment for those who cannot afford it; and the Clean Indoor Air Act, which has reduced cancerous pollutants in Delaware's restaurants, bars and casinos by more than 90 percent.

Gov. Minner, elected to a second term in 2004, is working to reduce levels of mercury in Delaware's air and water and prevent developers from rolling back her Livable Delaware rules. She wants to keep reducing the number of uninsured in Delaware and ensure that the state's fight against cancer continues.

She lives on a farm in Milford and enjoys spending time with her three sons and their wives, her seven grandchildren, her great-granddaughter, and two step-great-grandsons.

### Gov. Janet Napolitano, Arizona



Governor Janet Napolitano, a Democrat, was sworn into office in January 2003 as Arizona's twenty-first governor and America's first woman to succeed a woman as governor.

In her first year in office, she won approval of a budget that erased a billion-dollar state budget deficit without raising taxes or cutting funding for public schools or other vital services.

In healthcare, Gov. Napolitano launched what is now the CoppeRx CardSM, a discount program designed to save Medicare-eligible Arizonans more than an aggregate \$100,000 a week on prescription drug prices.

One of Gov. Napolitano's administration's goals is to ensure that all Arizona children will report to the first grade safe, healthy and ready to succeed academically. She is working to establish full-day kindergarten and a quality childcare rating system as options available to parents throughout Arizona. She is also working to redirect Arizona's economy toward high tech, knowledge-based industry to ensure quality job opportunities in the state.

Prior to being elected Governor, she served one term as Arizona Attorney General and four years as U.S. Attorney for the District of Arizona. Born in New York City and raised in Albuquerque, New Mexico, she is a distinguished alumna of Santa Clara University and the University of Virginia Law School. She has lived in Arizona since 1983, when she moved to Phoenix to practice law.

Gov. Napolitano, a breast cancer survivor, is on the Board of the American Legacy Foundation. She is a frequent hiker, an avid reader, a regular patron of the arts, and a diehard fan of the Arizona Diamondbacks.

Former governors Bob Wise (W. Va.) and Tom Ridge (PA) have also been actively involved with C-Change and served as chairs of the State Cancer Plan Team.



**Board Chair LaSalle Leffall and Co-Chair Pres. George Bush opened the Plenary Session.**

while C-Change is sponsoring three itself. (See p. 10 for complete list of interns.) The Summer Internship Program is an initiative of the Workforce Team and was introduced as a "Call to Action" at the November 2004 Semi-Annual Meeting where candidates were first solicited. The interns will present results and reports of their projects at the October 14-15 Semi-Annual Meeting.



**Maureen Lichtveld introduced Workforce's "Careers in Cancer Speaker's Kit."**

### **Calls to Action Issued**

Lichtveld also presented another Workforce project, the "Consider a Career in Cancer Speaker's Kit." The kit includes a speaker guide, reference and handout materials, and a CD with a slide presentation designed for 15 to 25 year olds.

Lichtveld told the audience, "I accept President Bush's dare to become more involved and hope the Members and Partners will accept my double-dare to respond to Workforce's Call to Action and schedule 'Careers in Cancer' presentations." She also asked the audience to further disseminate the Speaker's Kit through their organizations. The kit is available online at the C-Change website or by contacting Alison Smith at [alisonpaigesmith@aol.com](mailto:alisonpaigesmith@aol.com).

The momentum of the meeting was continued by the chairs of the Tobacco Control and the Prevention and Early Detection Teams who issued two joint "Calls to Action." Phil Huang, Prevention and Early Detection Team chair, issued the first Call on behalf of the Teams. He asked the audience to "commit your organizations to adopt C-Change's smoke-free city meeting's resolution or to adopt a similar policy." The C-Change Board earlier in the year adopted a new policy declaring that, as of January 2006, C-Change will hold its major

meetings only in smoke-free jurisdictions. C-Change's Smoke-Free Meeting policy can be downloaded from [www.c-changetogether.org](http://www.c-changetogether.org) or contacting the C-Change office at 800.830.1827.

In a related "Call to Action," Tobacco Control Team co-chairs Jerry Mande and Matt Myers called upon Members and Partners to become involved in promoting or supporting evidence-based tobacco use reduction initiatives. The Teams are asking Members to work with state or regional bodies to boost smoke-free air laws, increase tobacco taxes, protect or increase



**Phil Huang asked Members and Partners to adopt C-Change's Smoke-Free Meeting policy.**



**Matt Myers urged Members and Partners to help states to increase tobacco reduction measures.**

state funding of tobacco prevention programs, work on FDA tobacco regulations, adopt or promote the CEO Cancer Gold Standard™, and more. (The "Call to Action" Response Form can be downloaded from [www.cchangetogether.org](http://www.cchangetogether.org).)

In other business matters, Executive Director Connie Curran reported that the meeting had

the highest attendance ever—190 Members, Partners, and guests, with two-thirds of Members attending. Financially, she reported that program spending is up and operational expenses are coming in under budget.

### **McClellan, Kitzhaber and Panel Talk Change and Funding**

Following the business portion of the program, several speakers took the stage who prepared the audience for new approaches to a key governmental health program that could advance cancer care; challenged everyone to lead a revolution in healthcare; flooded listeners with suggestions to protect and enhance



**Jerry Mande asked Members and Partners to help governments maintain a strong commitment to evidence-based tobacco reduction efforts.**

resources for cancer care and research; and reminded everyone how all the grand policies and practices play out in the life of one cancer patient and survivor.

Keynote speaker Mark McClellan, Administrator of the Centers for Medicare and Medicaid Services, used his address to detail how the pending and most significant changes in Medicare since its implementation 40 years ago will impact on efforts to lighten the "burden of cancer."

McClellan pointed out that the Medicare reforms will place an "emphasis on better results, not just paying more." The reforms will play a role in expanding scientific evidence and in implementing new steps in prevention. McClellan pointed out that when he took office, "over 90 percent of payments went to treating complications of health problems after they occurred." He pointed out that Medicare is closing the gap in preventive care, "now covering a broad array of screening services in breast, cervical, colorectal, and prostate cancers."

Medicare policies are also changed to improve the quality of care, based on standards set by the field. McClellan commented that his agency is seeing impressive results in control of nausea, as one example, due to expanded coverage of nausea medications. His agency is looking to achieve similar progress in fatigue and pain as markers of patient comfort and quality of life.

McClellan is looking to create a "Cancer Quality Improvement Alliance" to facilitate more



**Mark McClellan discussed the impact of new Medicare rules and benefits on cancer care and advances.**

advances and to realize the “great potential for quickening the science against cancer,” McClellan concluded.

to a publicly financed education through high school, while allowing private services as an option. Unlike education, which is all-inclusive and offers universal coverage for a basic benefit, Kitzhaber said that current healthcare policy tries to allocate public dollars one individual at a time and manipulates categories of eligibility to ration resources.

Kitzhaber pointed out that Medicare was designed to fix the problems of its day. “Whereas 40 years ago the elderly represented one of the poorest segments of our society, today those over 65 constitute the single wealthiest segment . . . followed only by those between 55 and 65.”

Kitzhaber applied his plea for a new approach to healthcare directly to C-Change. “. . .As your struggle with the question of funding cancer research – as well as early diagnosis and treatment – you need to be aware of the fact that both the growing cost of healthcare as a percent of our GDP and our lack of explicit policy on universal coverage are frustrating those very efforts. . . .In order to fulfill the primary mission of C-Change, we must also approach our overall healthcare system with the same eye to equity and sustainability with which we approach public education.”



**Gov. John Kitzhaber passionately argued for a health system patterned after the education model.**

Governor John Kitzhaber, MD, then took the stage to offer the prologue to a distinguished panel and audience discussion on paying for cancer care and research progress. An emergency room physician and two-term governor of Oregon until 2003, Kitzhaber challenged the audience to take the leadership role in changing a healthcare system that leaves 45 to 80 million persons medically uninsured for at least part of the year and that drains public resources away from other needs such as cancer research and care.

Kitzhaber charged the audience to lead a “revolution, not of violence, but of vision; not of arms, but ideas,” to make healthcare available to all.

Kitzhaber suggested that the U.S. move to an approach to healthcare similar to its policy regarding education, which entitles all children



**Panelist Fred Frank**

The panel then picked up the discussion, mediated by Gretchen Helfrich, host of “Odyssey” on WBEZ Chicago Public Radio. Fred Frank, vice chair, Global Healthcare Group at



**Panelist Les Silverman**

Lehman Brothers, focused on the successful role the biotech field has had in creating both progress and challenges in the attack on cancer.

Jim Greenwood, President of the Biotechnology Industry Organization (BIO), predicted that biotechnology will be the most transformational experience in human history and that biotech will



**Panelist James Greenwood**

win the war on cancer in a convergence of wet and digital biology. Greenwood says a key to achieving biotech advances is meeting the significant requirement for capital investments, which totaled \$21 billion last year.

Les Silverman, Director Emeritus of McKinsey & Company, and advisor to the C-Change Board, emphasized fundamental organizational and management strategies that could enable



**Andy von Eschenbach responded to the panel discussion.**

progress. In addition to opportunities present in cross-sector partnerships, he noted the importance of balancing mission focus and financial realities. He illustrated the success of organizations that have consolidated functions to achieve more efficiency so they can direct more dollars toward mission instead of overhead.



## NewsNotes

### Hillmans to Give UPMC \$20 Million for Cancer Research

Henry and Elsie Hillman have announced a \$20 million donation, the single largest gift ever for the University of Pittsburgh Medical Center (UPMC) and the University of Pittsburgh Cancer Institute, to establish The Hillman Fellows Program for Innovative Cancer Research.

Previous gifts by the Hillmans provided seed money to 14 researchers which proved successful in securing millions more in other private and federal research support.

The donation from the Hillman Foundation and the Henry L. Hillman Foundation will launch a new initiative at UPMC to raise \$200 million to hire 50 to 100 more researchers.

Dr. Ronald Herberman, director of the the UPMC cancer institute, and chair of the C-Change Cancer Research Team, said that Mr. Hillman came to understand how important seed money was to the research process yet how difficult it is obtain initial funding.

### California Bans Tobacco in Prison

All California prisons are now tobacco free. Previously, about a third of the state's 33 prisons had outlawed inmate tobacco use in whole or part.

Although many other state prison agencies around the country have full or partial bans on inmate tobacco use, a variety of experts say that California is one of only a few to pass a near prohibition into law. California's law also covers all tobacco products, while some states permit chewing tobacco and snuff. California's ban extends to employees when they are inside prison walls.

Department of Corrections officials say they offered smoking-cessation programs and literature to inmates and staff.

Officials at prisons where the ban has been in effect have reported a drop in respiratory ailments and asthma-related complaints.

*(From Associated Press report)*



**ABC-TV Film Critic Joel Siegel recounted his personal battle against colon cancer and underscored the importance of prevention and early detection.**

### Joel Siegel: A Cancer Survivor's Journey in Review

Joel Siegel, film critic on ABC-TV's "Good Morning America" since 1981, shared his struggle with cancer for C-Change Members, Partners, and guests to close Saturday's Plenary session. His intimate account brought into human perspective all of the Semi-Annual Meeting's previous discussions, planning, and progress.

In 1997, 54 years old and expecting a child, Siegel, following a colonoscopy, heard his doctor tell him, "I don't have good news." A week later, surgery revealed an advanced disease requiring simultaneous radiation and chemotherapies. Siegel struggled to find hope and strength to witness the birth of his child. After recounting the emotional and physically draining journey through his courses of treatment, Siegel told the audience how he got to bring his newborn son Dylan home on the last day of chemotherapy treatments.

It was not until just before Dylan's second birthday that Siegel got the word that his CT scans were finally clear. "I was standing on 5<sup>th</sup> Avenue when I received the call. I walked into a shop and bought Dylan a cashmere sweater for his birthday. Not the wisest present for a two-year old boy. If I'd been on Park Avenue in front of the Mercedes dealer, I would have bought him a car."

Siegel's joy did not last long. "The next day I got the 'oops' call. They found a lesion on the left lung."

In all, Siegel reported that, after six years, three surgeries, chemotherapy, radiation, and a temporary colostomy, he still faces future battles with the aftermath of his colon cancer. In September, a CT scan revealed "small volume, bilateral, stage 4, metastatic colo-rectal cancer in the lung." Although his prognosis is very good for when treatment will be needed in a year or two, "it is like waking up in the middle of the night, and the room is dark, and all you hear is a ticking clock," Siegel said.

One of Siegel's main reminders to the audience was the critical importance of early diagnosis. "...If I had done one simple thing, all of this – the pain, the surgery, the time, the anxiety, the fear – could all have been avoided." As Siegel pointed out, if he had a colonoscopy at age 50, his oncologist said Siegel would have had at most a polyp or two, most likely precancerous. Siegel said, "the oncologist estimated a 75 to 80 percent chance my cancer would have been literally nipped in the bud and I would be cancer-free." In referring to the impact of the disease on his now seven-year old son Dylan, Siegel said, "I would have given anything to have spared him that."

Besides his ABC-TV roles, Siegel is president of Gilda's Club and is a co-founder with actor Gene Wilder of the non-profit, emotional and social support facility for cancer patients, their families, and friends. Gilda's Club honors Wilder's late wife and comedian Gilda Radner.

# "Meeting Seen"

# May 2005 Semi-Annual Meeting



Elmer Huerta and Mike Richards



Jon Kerner and Robert Hiatt



Joel Siegel, Peggy Conlon, and John Seffrin



Anna Barker



Bo Aldige and Kevin Brady



Jim Marks



Gary Gordon, Betty Duke, and Connie Curran



Armin Weinberg and Tom Kean



## "Meeting Seen"



Pamela Bennett and Alan Must of Purdue Pharma present a donation to Connie Curran to fund a palliative care module for the Comprehensive Cancer Control Leadership Institutes.



President Bush, Bill Winkenwerder, Fred Frank, and Mark McClellan



Georgia Decker



Talbot Smith and Paul Nusbaum



Paula Kim and John Potter



President Bush and Connie Curran welcome three guests from England to the May meeting: (l to r) Mike Richards of St. Thomas Hospital, and Maxine Taylor and Alex Markham, both of Cancer Research UK.



Co-Chairs Mrs. Barbara Bush and President Bush enjoy the Cancer Art Exhibition during the May meeting. Art was provided by Guests at the NIH's The Children's Inn and Diana Nevarro; Members of Gilda's Club-Chicago and Laura Jane Hyde; and Annette Meyer and Kimberly Thomas, also shown on the right with Brian Alexander and Michaelann Cooke of C-Change



# NewsNotes

## Web-book Chapter Features President and Mrs. Bush

ConversationsInCare.com has announced a new chapter in its Web-book. The chapter features President George H. W. Bush and Mrs. Barbara Bush and how they have taken their personal, family experience with cancer to form their voluntarism in the fight against the disease, including their work as co-chairs of C-Change.

In "The Key to Cancer Care: Access and Support," President and Mrs. Bush address two of the key issues on which they have helped C-Change to focus since its founding in 1998: The need for all cancer patients to have access to care, including support services for patients and their loved ones. Good communication between cancer patients and their healthcare professionals is one of the cornerstones for meeting these needs.

In addition to discussing access to care and support, the chapter also includes a call to action for all oncology professionals to become involved with public advocacy. The chapter emphasizes the impact that a physician or other healthcare professional who is willing to speak out about an issue such as cancer can have on policy-makers.

Log onto [www.ConversationsInCare.com](http://www.ConversationsInCare.com) to visit this chapter as well as previous chapters.

EMD Pharmaceuticals, Inc. is the sponsor of the "Conversations In Care" program.

### REMINDER

"Calls to Action" materials and speaker remarks from the May Semi-Annual Meeting can be found on the C-Change website at [www.c-changetogether.org](http://www.c-changetogether.org).



## 2005 C-Change Summer Interns

### Ahmed Tahsian Al-Kalla

University of Houston/Senior  
Intercultural Cancer Council  
Houston, Texas  
Create fact sheet on "Fatigue in Cancer" and a manual for implementing collegiate career councils nationwide.

### Hien Dang

Michigan Tech University/Senior  
Van Andel Research Institute  
Grand Rapids, Michigan  
Conduct image and tissue analysis.

### Kayla Effertz

University of North Dakota/BA, BBA  
C-Change  
Bismarck, North Dakota  
Assist with implementation of ND state cancer plan.

### Tisha Fowler

University of Michigan/MSW  
Presidential Management Fellow  
National Cancer Institute  
Bethesda, Maryland  
Work on health disparity initiatives.

### Benjamin Hamlin

Columbia University/MPH  
Nat'l Assn of County and City Health Officials  
Poughkeepsie, New York  
Conduct research re: cervical cancer vaccine.

### Samara Lorenz

New York University/MPA  
Health Resources and Services Administration  
Rockville, Maryland  
Create a HRSA cancer prevention awareness campaign for HRSA/Parklawn employees.

### Laura Meehan

Georgetown University/Senior  
C-Change  
Washington, District of Columbia  
Website resource development.

### Tricia Moo-Young

Washington University/PGY-4  
St. Louis, Missouri  
Program for Eliminating Cancer Disparities (PECaD)  
Compile speaker's kit re: racial prejudice in research.

### Robert Nedved

University of Chicago/Senior  
Abbott Labs  
Abbott Park, Illinois  
Lab research.

### Grace Peng

University of Southern California  
2nd year medical school  
Children's Hospital-LA  
Los Angeles, California  
Pediatric oncology research.

### Makeva Rhoden

George Washington University/MPH  
Health Resources and Services Administration  
Rockville, Maryland  
Create a HRSA cancer prevention awareness campaign for HRSA/Parklawn employees.

### Dyana Rumpf

Columbia University  
Oncology Nurse Practitioner student  
C-Change  
New York, New York  
Core competency development.

### Anthony Santella

Tulane University School of Public Health and Tropical Medicine/Yr 2 of DrPH  
Centers for Disease Control and Prevention  
Atlanta, Georgia  
Develop cancer survivor resources related to disparities, blood diseases, and women's health issues.

### Felicia W. Seton-Larry

Rice University/Junior  
Intercultural Cancer Council  
Houston, Texas  
Create fact sheet on "Fatigue in Cancer."

# Team News

## TEAM

	Priorities	Recent Actions Taken / Accomplishments
<b>Access to Quality Cancer Care</b>	<p>Publish proceedings and recommendations from the Surveillance &amp; Information Summit</p> <p>Finalize and pursue the achievement of the priority recommendations generated through the Surveillance &amp; Information Summit</p> <p>Plan the next Summit to be focused on one of the priority recommendation generated through the Surveillance &amp; Information Summit</p> <p>Distribute Patient Advocate Foundation's National Financial Resource Directory Guide (hard copy and CD Rom versions)</p> <p>Develop patient navigation promotion educational training programs</p> <p>Develop a palliative care module for use in the Phase III Comprehensive Cancer Control Leadership Institute</p>	<p>Information and Surveillance Summit Report approved by the Board.</p> <p>Developing a strategy to achieve the Summit priority recommendation through C-Change Member/Partner organizations and other selected stakeholders</p> <p>Developing the plan and goals/objectives for the next Summit to be focused on Standardization of Information; Summit II planning committee formed.</p> <p>Successfully distributed 5,000 CD Rom copies of the PAF's National Financial Resources Directory Guide as well as 771 hard copies.</p> <p>Convened a meeting of Member/Partner organizations with an active interest in patient navigation programs to plan this initiative; developed a policy statement on patient navigation and a document defining patient navigation (both documents to be submitted to the Board for review)</p> <p>Module draft under development by stakeholder workgroup convened in mid-June.</p>
<b>Cancer Research</b>	<p>Convene forums for independent pilot sites implementing the National Biospecimen Network Blueprint</p> <p>Publish additional papers on the use of surrogate endpoints in removing barriers to drug discovery</p> <p>Publish a paper on the role of academic medical centers in drug development</p> <p>Conduct Congressional educational briefings related to cancer research</p> <p>Plan an approach to an economic impact study of cancer</p> <p>Plan &amp; conduct Forum III to explore diagnostic approaches driving therapeutic developments</p>	<p>Continuing to network with interested research centers</p> <p>Convening work group to develop a paper on lung cancer surrogate endpoints.</p> <p>Completed paper and received highest level of approval and endorsement from the Board of Directors. Journal submission and acceptance pending.</p> <p>Conducted a briefing on 3/14/05 on "Funding Cancer Research: Progress, Opportunities, and the Role of Government." Considering future topics.</p> <p>Evaluating conceptual approaches and possible study partners</p> <p>Defining conference scope</p>
<b>Cancer Workforce</b>	<p>Develop plan to build a national "Cancer Corps" from the health work force with the necessary surge capacity and competency to deliver cancer care to an aging population</p> <p>Conduct initial phase of Summer Internship Program, including 3 C-Change-sponsored interns and 9 Member sponsored interns</p> <p>Develop a Summer Internship web portal to help students find cancer-related summer jobs</p> <p>Develop a "Careers in Cancer" speakers kit and issue a "call to action" to Members to help recruit students and healthcare professionals into cancer careers.</p> <p>Develop a module and guidance documents on workforce issues to support state cancer planning efforts and future CCCL workshops</p>	<p>Awarded contract to define core competencies in cancer to Kristine Gebbie, DrPH, RN, Columbia University. Currently identifying expert panel from academic, scientific, and clinical arenas. Completion targeted for early 2006.</p> <p>Admitted 14 Summer Interns and conducted a program orientation on May 19, 2005. Summer Interns attended the May Semi-Annual meeting. The October Semi-Annual meeting will include a poster presentation by the interns. Program expansion being considered for 2006.</p> <p>Developing specifications for web site content and functionality.</p> <p>Developed initial phase of speaker's kit materials and issued a "Call to Action" at the May Semi-Annual meeting, challenging Members to promote careers in cancer by posting materials on their web sites and delivering the presentation through their respective networks.</p> <p>Drafting module content, including workforce assessment tools and an inventory of best practices. Module planning session held in June 2005 in conjunction with the State Cancer Plans Team .</p>
<b>Clinical Trials</b>	<p>Develop a guidance document on the cost of conducting clinical trials for use by public and private sector policymakers, and by oncology practices nationwide.</p> <p>Publish a paper on series of regulatory reforms to expedite the clinical trials process and pursue the paper's recommendations through a Member organization.</p>	<p>Completed "The Clinical Trials Guidance Document" through contract with The Lewin Group. Pending Board approval.</p> <p>Completed "Reducing the Regulatory Barriers" recommendations. Board approved the paper and dissemination plan on June 16, 2005.</p>



# Team News

## TEAM

	Priorities	Recent Actions Taken / Accomplishments
<p><b>Clinical Trials, cont.</b></p>	<p>Develop a model State Clinical Trials Network designed to increase access and accrual to clinical trials.</p> <p>Conduct and disseminate the findings of a public and patient focused survey on the attitudes, beliefs, and behaviors associated with clinical trial participation.</p> <p>Develop a clinical trials module for the Phase III Comprehensive Cancer Control Leadership Institute.</p>	<p>Reviewed the 19 responses to a RFP for development and implementation of a state clinical trials network. Pennsylvania's Comprehensive Cancer Coalition (PAC3) was awarded the grant through a competitive review.</p> <p>Survey conducted Spring 2005 by the University of Chicago under the auspices of the Coalition of Cancer Cooperative Groups. Analysis is underway with report expected by mid-summer 2005.</p> <p>Developing the module, in conjunction with the State Cancer Plans Team. Workgroup met in June to develop the module.</p>
<p><b>Primary Prevention &amp; Early Detection</b></p>	<p>Achieve at least two of the priority recommendations generated from the Prevention and Early Detection Summit</p> <ul style="list-style-type: none"> <li>Enhance access to and the delivery of cancer prevention and early detection services</li> <li>Gain evidence-based consensus on lung cancer screening and early treatment</li> <li>Work to achieve the remaining communication, promotion best practices, policy development, and other research-related priority recommendations generated from the Prevention and Early Detection Summit</li> </ul>	<p>Held a multi-sector symposium, "The Business Case for Delivery of Cancer Prevention and Early Detection Services" with the Agency for Health Care Research and Quality on May 19, 2005. Follow-up plans are underway.</p> <p>Co-sponsored a consensus conference, "Application of High Resolution CT Imaging Data to Lung Cancer Drug Development," with the Cancer Prevention and Research Foundation on April 28-29, 2005, in Annapolis, MD.</p> <p>Five C-Change Members have agreed to work on a communication piece related to three major risk factors (tobacco, nutrition, and physical activity) with the C-Change Communications subcommittee.</p>
<p><b>State Cancer Plans</b></p>	<p>Conduct Planning Assistance Team [PAT] visits in 5 targeted states to enhance comprehensive cancer control program planning and implementation efforts</p> <p>Conduct Comprehensive Cancer Control Leadership Institutes (CCCLI) for tribal nations and U.S Territories</p> <p>Develop Phase III CCCLI modules on the topics of tobacco control, clinical trials, workforce development, palliative care, survivorship, and colorectal cancer screening</p> <p>Develop the State Cancer Plans Awards initiative</p> <p>Assist states with comprehensive cancer control program efforts through the expertise and resources of C-Change Member organizations</p>	<p>Team decided at its May 20, 2005 meeting, to reallocate funding to tribal nation CCCLI, scheduled for September 2005.</p> <p>Developed and delivered the CCCLI for the United States Associated Pacific Island Nations (USAPIN). Planning final stages of the 2005 CCCLIs tailored to the needs of tribal nations in conjunction with a network of national partners.</p> <p>Developing modules in conjunction with other C-Change Teams and Member organizations to be piloted in the Phase III CCCLI in the Fall of 2005.</p> <p>Planned State Cancer Plans Award initiative program. Board review and approval pending.</p> <p>Issued a "Call to Action" at the November 2004 Semi-Annual Meeting linking Member/Partner respondents with associated state cancer control program officials through a partnership with the CDC.</p>
<p><b>Tobacco Control</b></p>	<p>Develop a tobacco control module for use at a series of Phase III Comprehensive Cancer Control Leadership Institute (CCCLI).</p> <p>In conjunction with the Prevention and Early Detection Team, issue a "Call to Action" challenging members to convene their major organizational meetings in smoke-free cites or jurisdictions</p> <p>Develop a multi-sector action plan to address nagging tobacco control issues at the federal and state levels in conjunction with ASCO</p> <p>Actively engage C-Change Member organizations and other stakeholders in addressing tobacco control issues in targeted states and other jurisdictions.</p> <p>Provide assistance to five targeted states to help them address a specific tobacco control issue [e.g., clean indoor air legislation].</p> <p>Provide assistance to five targeted states designed to enhance the integration of state tobacco control and cancer control programs and facilitate the funding of cancer control plans with state tobacco tax revenues.</p>	<p>Workgroup, in conjunction with State Cancer Plans Team, met in mid-June 2005 to develop module.</p> <p>Issued smoke-free meeting "Call-to-Action" at the May Semi-Annual meeting.</p> <p>Convened a series of stakeholder meetings and have begun the process of developing the multi-sector action plan</p> <p>Issued a "Call to Action" with Prevention and Early Detection Team at May Semi-Annual Meeting to have Members/Partners become effectively involved in geographic areas of interest and/or public policy activity.</p> <p>Developing and implementing the state specific issue intervention.</p> <p>Developing and implementing an integrated initiative.</p>