

e-collaborating

collaborating (and communicating) to conquer cancer

issue #1 spring 04

Now the world knows...



Former President George H. W. Bush addresses the inaugural C-Change news conference

On Wednesday morning, March 3, C-Change formally introduced itself to the public through a news conference held at the National Press Club in Washington, D.C.

On top of other recent organizational developments such as a new name and logo, non-profit status, establishment of a full-time executive director, a highly successful funding campaign, and a revitalized action-oriented agenda, the news conference was the first significant effort by C-Change or its predecessor, the National Dialogue on Cancer, to take its message public.

C-Change's message was well told by a leadership panel that included former President George H.W. Bush, Senator Dianne Feinstein, Zora Brown, Dr. Andy von Eschenbach, Robert Ingram, and Dr. John Seffrin. Chairman Dr. LaSalle Leffall, Jr. skillfully moderated the panel.



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More than 16 national, local, and trade media outlets attended the conference. News reports ran in newspapers and on TV and radio stations across the country.

In news released at the launch, C-Change announced its goal to prevent one million new cancer cases and 500,000 cancer deaths by 2010.

In addition, the media learned that the CEO Roundtable on Cancer will debut its Gold Standard on Cancer in late May. The Roundtable's 40-plus members will implement the Gold Standard within 18 months, benefitting more than 30 million employees and dependents. More companies and organizations are reported to have expressed interest in joining the Roundtable.

In other news, C-Change released results of a survey it commissioned on public attitudes about cancer. The survey revealed significant gaps between American's attitudes and perceptions of cancer and their behavior around prevention, early detection, and treatment. For details of the survey, see the article, *Fear: The Gap Between America's Attitudes and Actions Toward Cancer*.

The following is a brief summary of key points made to the media by panel members.



Pres. Bush: After recounting C-Change's first "meeting" on November 8, 1998, that brought several cancer leaders together at his Presidential library in Texas, Pres. Bush underscored the important value driving C-Change's functions and achievements—collaboration.

"In all my years of professional life, it is difficult, if not pretty near impossible, to solve conflicts or difficult issues unless first there is some way for the parties most directly involved to begin to talk, get to know one and another, tee up the issues, and to collaboratively address them."

"Barbara and I have been so impressed by the energy of all these busy and over-committed people and by the time they are willing to give to C-Change. They are determined to make a difference, to help save lives."

"This is a day of renewed hope for Americans everywhere in the fight against cancer."



Sen. Feinstein: C-Change's vice chair, Sen. Feinstein told how cancer has dominated her life through family members and friends lost to the disease. She said that led her to vow, when she came to the U.S. Senate, that, if there was anything she could do to help in the fight, she would do it.

Commenting on her involvement in C-Change, Sen. Feinstein said, *"What this group is all about, 150 Members strong, led by a former President of the United States and a former first lady, two great people, is to really concentrate their efforts and move a cancer solution forward for all of the people in the country. I hope everyone is rooting for this."*

Sen. Feinstein also called for an increase in cancer research funding to accomplish what the *"scientific frontiers now offer."*



Zora Brown: With five generations in her family affected by cancer, Zora Brown described how C-Change gives a venue to those in the cancer community *"to hear other perspectives in a way they have never heard before."*

She pointed out that one of the areas that can make a difference is in helping eliminate cancer disparities. She said, *"The poor, the medical underserved, and communities of certain ethnic groups have a higher risk of developing cancer and poorer chances of early diagnosis, optimal treatment, and survival."*

"One of the things that drew me to participate in C-Change was its holistic way of approaching the cancer problem. I firmly believe that it is the only way we can solve complex problems, like growing cancer disparities..."



Dr. Andrew von Eschenbach: Dr. von Eschenbach restated his belief that C-Change will play a critical role in accelerating our nation's fight against cancer.

"One significant area where accelerated change can have an impact is on the 70 percent of cancer that can be eliminated through prevention and early detection. We can work to reduce the use of tobacco and better address lifestyle issues like obesity. We



c-change new staff

Connie Curran, C-Change Executive Director, has announced the appointment of three new staff members. Gary Gurian, Alison Smith, and Kinga Bartoszek are joining C-Change as Directors. Gurian and Smith will work primarily with Teams and Work Groups to facilitate these core groups in achieving their goals and action plans. Bartoszek will oversee operations and finances.



Gary Gurian

Gary Gurian is an experienced and highly regarded member of the cancer community. Most recently, he was Vice President of Public and Governmental Affairs for the Coalition of National Cancer Cooperative Groups (CNCCG). He was responsible

there for establishing and maintaining working relationships with the National Cancer Institute, U.S. Food and Drug Administration, Centers for Disease Control and Prevention, state health departments, cancer patient advocate organizations, and other stakeholders such as the American Cancer Society.

"Gary Gurian brings a wonderfully broad experience working with states and other public bodies," Connie Curran, C-Change Executive Director said. *"He knows how to make things happen in complex organizations as well as within the entire cancer community."* He will be working with State Cancer Plans, Primary Prevention and Early Detection, Clinical Trials, Tobacco, and Access to Quality Cancer Care Teams.

"I look forward to this exciting opportunity to work with Member organizations, the Board, and the specialized action teams to help assure that C-Change fulfills its vitally important mission and achievable mission of eliminating cancer as a major public health problem at the earliest possible time," Gurian said.

In addition to his work with the Coalition, Gary has served in senior level management and leadership positions with the U.S. Department of Health and Human Services, the Pennsylvania and Illinois Departments of Health, as well as with county and municipal health departments. His educational background includes a bachelor's degree from Bradley University and a Masters of Science in Public Administration from the University of Illinois-Springfield.



Alison Smith, RN

Alison Smith brings to C-Change 15 years of experience in healthcare that ranges from the bedside to the boardroom.

As a nurse, she has served as a hospital clinician, manager, and director for

a top 100 hospital. Her leadership responsibilities

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The inaugural C-Change news conference held at the National Press Club

now the world knows... cont. from page 1

can strengthen our efforts to find better methods of detection through functional imaging and through genomics and proteomics." He pointed out that recent progress in proteomics shows that ovarian cancer can be detected at its earliest, most curable stage with one drop of blood. Dr. von Eschenbach concluded by telling the media, *"With C-Change, and the dedication and vision of its members, I am confident that we will reach that day when suffering and premature deaths are eliminated, when cancer is conquered."*



Bob Ingram: Bob Ingram reported that the current priority project of the CEO Roundtable on Cancer is the development of a cancer Gold Standard. It provides through corporate health plans access to cancer education, early detection, and clinical trial availability. Ingram reported that beyond the more than 40 corporate members, state governments are becoming involved with the Roundtable. West Virginia and Arkansas are rapidly moving toward full implementation of the Gold Standard. In addition, all states were invited to join at the National Governors' Meeting in February. Six governors have already accepted an invitation to be at the May meeting of the Roundtable.

Ingram, who was asked by Pres. Bush to be *"bold and adventuresome"* in founding the Roundtable, enthusiastically underscored its success to date. *"I believe the CEO Roundtable on Cancer is a great example of corporate America's desire to do the right thing for the right reasons."*



Dr. John Seffrin: Calling C-Change an unprecedented and an historic partnership, Dr. Seffrin pointed out that C-Change brings all three sectors to a mutually shared commitment to significantly reduce our nation's cancer burden more efficiently and effectively.

Dr. Seffrin also reported on several of the key findings of a C-Change survey on the American public's knowledge, attitude, and behaviors about cancer. Dr. Seffrin reported striking gaps between attitude and behavior, suggesting fertile areas of the cancer community to target for a greater reduction in cases and deaths. (See the article, "Fear: the Gap..." on pg. 5)

After recalling C-Change's success in helping states develop and implement cancer plans, he offered insights into other steps essential to greater success in the fight against cancer. Dr. Seffrin said, *"Three things must happen. One, we must continue to fuel and redouble our discovery efforts. Two, we have to promote prevention in public policy everywhere because we can prevent most cancer. Three, we have to drive delivery of a state of the art standard of cancer care at the community level where people are usually treated for their disease."* He concluded, *"These will not happen without collaboration among stakeholders from all three key sectors."*

In the question and answer session that followed the panel's presentations, reporters questioned the difference between C-Change's incidence and mortality goals for 2010 versus the National Cancer Institute's 2015 goals. Several panel members and Jim Marks responded saying that while both are stretch goals, what is more important than the specific targets are the trajectories of the goals. Both promise and expect significant progress to continue in the years ahead.

C-Change's national media launch was organized and coordinated by Peggy Conlon, Communications subcommittee chair, her committee, Margaret Maruschak, and Edelman public relations.



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included quality improvement, case management, and continuing medical education. Alison also has been a consultant for the largest consulting firm specializing in healthcare and, most recently, was with Virtual Executive where she assisted client hospitals with a variety of clinical management and leadership issues. She also provided clinical and marketing advice to healthcare start-up companies.

Alison continues as assistant editor of "Nursing Economics," a national journal for healthcare leaders and is past president of the Women Health Executives Network in Chicago. She holds a Bachelor of Arts in Human Biology from Stanford University and a Bachelor of Science in Nursing from Johns Hopkins School of Nursing.

"From her healthcare consulting and leadership experiences, Alison brings a perspective on care delivery from a wide range of community and academic settings," Connie Curran said. *"She has dedicated her career to improving the outcomes and experiences of patients through evidence-based practice and operational improvements."*

Alison will be working with the Cancer Research and Cancer Workforce Teams. She also will be responsible for organizing C-Change's semi-annual meetings. *"One of my main roles will be to support the teams in synthesizing their ideas and bringing them to fruition,"* Smith said. *"Gary Gurian and I will strive to find common interests among the teams so an integration of efforts can achieve even more momentum with a greater impact on care delivery and outcomes."*



Kinga Bartoszek

Kinga Bartoszek has been named Director, Finance and Operations, for C-Change. A native and resident of Chicago, Bartoszek brings to her post more than eight years of administrative experience in healthcare provider and consulting organizations.

Connie Curran, commented on Kinga's qualifications. *"I have worked with Kinga for more than four years and am constantly impressed with her intelligence, diligence, and willingness to go the extra distance to get the job done. She has a remarkable level of experience in human resources, finance, and operations that will serve C-Change very well."*

"I look forward to working with the leadership and all the Members in supporting their vital goals and mission," Kinga said. *"My goal is to make our operations as seamless as possible while providing accurate and reliable data and information that will enable Connie and the other leaders to base their critical decisions on a current and accurate understanding of our financial and operational status."*

Kinga holds a Bachelor of Science degree with honors in Business Management from St. Xavier University in Chicago.



from the executive director connie curran

There are so many great things happening that it is not enough to communicate with you only at our two members' meetings. I am hopeful that this newsletter...**"e-laborating"**...will serve as the glue to help hold us together in our collaboration and the grease to help move us ahead more rapidly.

The new year has begun with incredible velocity. As we started our first year as a 501c3, we **moved into a set of wonderful offices** at 14th and F. We were very fortunate to find the fabulous space at a bargain basement rate. We have held several C-Change functions in the offices already. We can easily accommodate a group of 25. The board is now having its meetings in the office. I am hopeful that many of you will have your team meetings and committee meetings there. We even have guest office space if you are in DC and need a place to work.

We have assembled **a great staff**. Each of the key individuals is profiled in this newsletter. Gary and Alison have very complementary skills sets. Several team leaders have commented to me about how helpful the staff has been in assisting the teams to move forward. Kinga's financial skills were apparent when one of our board members commented that "these are the best financial reports I have ever seen." Kinga has been working closely with the auditors preparing our first set of audited financials and designing new forms, policies, etc. to assure compliance with the various regulations for nonprofit entities. We will have a total staff of six. We are currently recruiting for the remaining position, director of major gifts.

The **Access Team**, chaired by Armin Weinberg, **sponsored a Surveillance Summit** at the end of January. The meeting was a great blend of lectures and small group work. Clem Bezold donated his time and talents to facilitate the meeting, which was chaired by Ed Sondik.

The **media launch**, covered extensively in this newsletter, was a great milestone event. It was wonderful to have our fabulous leaders together, sharing our successes and challenges. The excitement was palpable. Several media opportunities have emerged from the launch. If your organizations would like any of our media materials, feel free to contact us.

The **June Members' meeting** promises to be a very exciting event. It will be at the Washington DC Grand Hyatt on **Friday, June 18 and Saturday, June 19**. Friday's program will focus on **"Evidence into Action."** The Program Work Group has designed the agenda to provide two opportunities for team meetings. The first team session will be devoted to team work and strategic planning; the second session will focus on a single topic with the goal of advancing a specific team priority. Les Silverman, the leader of the non-profit division of McKinsey consulting, will address his research on proven strategies to drive organizational performance. A reaction panel will discuss major themes of the keynote address from the perspective of C-Change and the panel member's own organizations.

Saturday's theme is **"Leveraging the Power of the Organization."** The concept of leveraging the power of the organization has become a focus of C-Change. This session will focus on moving from fragmentation to unification. Bob Ingram, founding chairman of the CEO Roundtable, will present the Roundtable's "Gold Standard of Cancer Care." This gold standard represents the opportunity to impact the lives of millions of people and many thousands of cancer patients through better access to prevention, detection, and treatment. Dr. Mark B McClelland, the new director of CMS, will deliver Saturday's keynote address. Please plan to attend. The detailed meeting agenda and **registration materials will be on our website, C-ChangeTogether.org, in early May**. Please see the final page of "e-laborating" for preliminary information.

Finally, I want to share my pride and passion in leading this organization. I am extremely impressed with the generosity, skills, and talent of our members. The potential to conquer cancer is within us. As a nurse and cancer survivor, I am passionate about C-Change, our mission and our membership. I believe we will greatly improve the lives of patients and those who care for them. I am looking forward to meeting more of you and am eager to have you elaborate your ideas on how we can optimize our collaboration to conquer cancer. (Feel free to write me anytime at ccurran@aol.com.)

Connie

c-change directors & staff

Leadership

Former President George H. W. Bush, Co-Chair
Former First Lady Barbara Bush, Co-Chair
Senator Dianne Feinstein, Vice Chair
LaSalle Leffall, Jr., President and Board Chair
Andrew von Eschenbach, Board Vice Chair

Board of Directors

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Andrew von Eschenbach, Vice Chair
John Seffrin, Treasurer
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Donald Coffey
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c-change team news

Cross-fertilizing ideas remains one of the key ways in which C-Change can leverage the power of our membership. Collectively, our network of expertise and channels for effecting change are enormous.

The Team Initiatives for 2004 are described in Table below. If you would like to learn more about a team initiative or are pursuing a similar initiative in your organization, please contact Gary Gurian or Alison Smith to become more involved in the Team efforts. Ideally, all C-Change members contribute to as well as benefit from the collective work of the organization for the good of the greater cancer community.

During the Fall of 2003, each of the C-Change Teams identified project priorities and estimated the funding required to pursue their work in 2004. The Board of

Directors reviewed these priorities and allocated \$2.1M to fund the work of the teams. In an effort to bring more focus on tangible outcomes, the Board has asked each team to develop a strategic work plan for completing their projects during the year and will review progress toward completion on a monthly basis. We will highlight progress toward these project priorities in subsequent Team News articles.

During the course of the this year, each team will be asked to provide input to the Work Force, State Cancer Plans, and Tobacco Control Teams to advance their efforts from the perspective of prevention, detection, research, clinical trials, and access. In addition, each team had been asked to develop a "Call-to-Action" for C-Change members to pursue within their organization and through their network of contacts.

c-change team projects & priorities

Access to Quality Cancer Care

- Develop and distribute a national/community patient navigator resource guide
- Continue support of Open House programs promoting cancer awareness through HRSA-funded community health centers
- Pursue recommendations from the Surveillance & Information Summit
- Develop a White Paper on improving access to quality cancer care

Cancer Research

- Convene forums for independent pilots sites who are implementing the National Biospecimen Network Blueprint
- Publish 6 White Papers on the use of Surrogate Endpoints in removing barriers to drug discovery
- Publish 3 White Papers on means to encourage the private sector to engage in cancer drug development
- Conduct 2 Congressional Educational Briefings
- Plan an approach to an Economic Impact Study of Cancer for 2005

Cancer Work Force

- Define initiatives to recruit students and healthcare professionals into careers in cancer research and care
- Pursue the concept of a "Cancer Core" to develop professional cancer-specific competency

Clinical Trials

- Develop a bluebook on conducting clinical trials for the purpose of policy deliberations and clinical trial funding
- Publish a White Paper on regulatory reforms that will expedite the clinical trials process
- Secure funding for a state clinical trial systems model

Prevention & Early Detection

- Pursue recommendations from the Prevention Summit
- Develop prevention initiatives related to tobacco and obesity

State Cancer Plans

- Conduct Planning Assistance Team visits to the 4 remaining states without comprehensive cancer control programs
- Conduct 4 regional Comprehensive Cancer Control Leadership Institutes to provide guidance for state cancer plan implementation
- Develop State Cancer Plan Awards initiative and secure program funding

Tobacco Control

- Distribute Tobacco Symposium Report and Recommendations for further action
- Conduct an opinion survey of leaders regarding tobacco control issues
- Develop a Tobacco Control Action Plan for C-Change and its members

c-change coming events

May 27

The T.J. Martell Foundation 29th Annual Awards Gala

Honoring
President George H.W. Bush & Mrs. Barbara Bush
Humanitarians of the Year

New York Hilton Hotel

(C-Change is a designated charity of this benefit gala.)

For more information: 212.833.5444, or go to
www.tjmartellfoundation.org/events

June 18-19

12th Meeting of C-Change

Grand Hyatt Hotel
Washington, DC

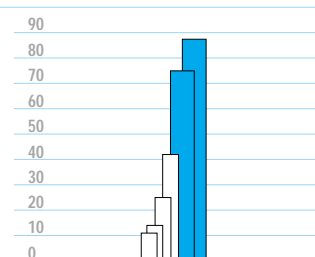


fear: the gap between american actions and attitudes on cancer

As part of its media launch, C-Change reported results of a study it commissioned on Americans' attitudes and actions toward cancer. The survey revealed a dramatic gap between cancer awareness and behaviors, despite Americans fearing cancer more than any other disease. With 70 percent of cancers preventable, the survey suggests fertile ground for efforts that help Americans adopt risk-lowering changes in behaviors.

Fear of diseases

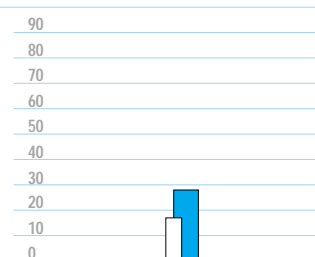
| | |
|---------------|------------|
| Stroke | 11% |
| Diabetes | 14% |
| Heart | 27% |
| Cancer | 42% |



Touched by cancer in family 75%
Know someone with cancer 88%

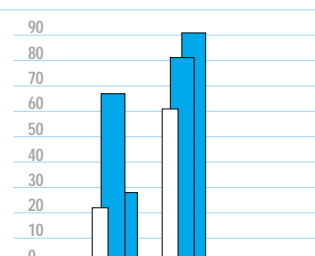
Estimating Cancer Risk

| | |
|--|------------|
| Men who are aware their chance of getting cancer is 1 in 2. | 17% |
| Women who are aware their chance of getting cancer is 1 in 3 | 28% |



Prevention

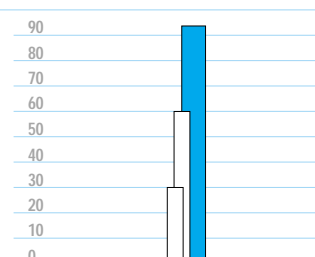
| | |
|---|------------|
| Those who still use tobacco | 22% |
| <small>(From Balanced Risk Surveillance System)</small> | |
| Those who know there is a strong link between tobacco use and cancer | 67% |
| Those who are aware that 70% of cancers are preventable | 28% |



| | |
|--|------------|
| Those who have changed lifestyle to reduce risk | 61% |
| Those who believe they can take steps to decrease cancer risk | 81% |
| Those who would alter lifestyle if they knew it reduces cancer risk | 91% |

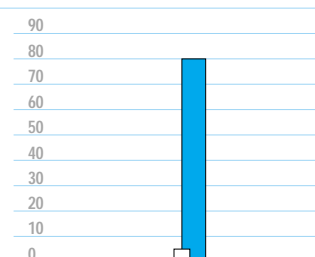
Early Detection

| | |
|--|------------|
| Women 40 and older who get annual mammograms | 30% |
| Men and women age 50 and older NOT screening for colorectal cancer | 60% |
| Those who believe cancer screening is important | 94% |



Clinical Trials

| | |
|---|-------------|
| Those with cancer who do participate in clinical trials | 3-5% |
| <small>(From Coalition of National Cancer Cooperative Groups)</small> | |
| Those willing to participate in clinical research if diagnosed with cancer | 80% |



Primary source: February 2004 Omnibus survey of 1,000 Americans, supported by C-Change.
For more information, go to www.c-changetogether.org.



**Semi-Annual Member Meeting
June 18-19, 2004
Grand Hyatt Washington at Washington Center
Washington, D.C.**

“from Dialogue into Action”

The Program Work Group is pleased to announce an exciting agenda for the June meeting.

| Friday, June 18 9:00 am – 5:30 pm Meeting 5:45 – 7:30 pm Reception | Saturday, June 19 8:30am – 1:00pm |
|---|---|
| <p>Plenary Session & Reaction Panel <i>Les Silverman</i> <i>Director, McKinsey & Company</i> <i>Leader, Global Nonprofit Practice</i></p> <ul style="list-style-type: none">• Proven strategies for driving performance in multi-sector organizations• Approaches to balancing mission and action <p>Team Meetings</p> <ul style="list-style-type: none">• Advancing Strategic Work Plan initiatives• Planning for 2005 project priorities, leadership, and funding <p>Team-Based Working Sessions</p> <ul style="list-style-type: none">• Singular focus on a specific team priority• Emphasis on strategies for moving ideas into action <p>C-Change Business Meeting</p> <ul style="list-style-type: none">• Exciting updates from the Executive Director• Knowledge & Attitudes Survey on Tobacco | <p>Town Hall Meeting Setting the Stage: Leveraging the Power of the Organization</p> <p>Dialogue with the Teams Work in Progress: Leveraging the Efforts of the Teams</p> <p>Call to Action CEO Roundtable Presentation of the Cancer Gold Standard tool kit</p> <p>Keynote Address <i>Mark McClellan, MD, PhD</i> <i>Administrator</i> <i>Centers for Medicare & Medicaid Services</i></p> |

**A meeting invitation and registration information will be distributed in early May.
Please make every effort to participate in this pivotal meeting.**