

e-collaborating

collaborating (and communicating) to conquer cancer

issue #2 spring 04

June Semi-Annual Meeting "from Dialogue into Action"



Les Silverman, Director, McKinsey & Company and Leader of their Global Nonprofit Practice

At the last Semi-Annual Meeting in December, our membership celebrated a name change from the "National Dialogue on Cancer" to "C-Change," the conclusion of a successful fundraising campaign, and many other tangible milestones in terms of corporate structure and hiring of staff. By now we have self-corrected enough times that we no longer say, "ND...I mean C-Change." We also heard a message repeated, "from dialogue into action." The months that have passed since our last meeting have been filled with actions by the Board of Directors, the Teams, and the staff to build on the foundation created by the NDC, further engaging our members and leveraging the efforts of our Teams.

The agenda for the June Semi-Annual meeting has been constructed with these thoughts in mind. The Program Work Group is responsible for conceptualizing the agenda for the Semi-Annual Meetings and has worked diligently over the past four months to create an environment that uses our valuable time together with the end goal of action. The meeting will focus on opportunities to advance new and existing initiatives by collaborating within C-Change and by leveraging the power of our individual organizations.

The June Semi-Annual Meeting is designed to advance initiatives and leverage the power of organizations

Friday, June 18

The introductory address will be delivered by Les Silverman, Director, McKinsey & Company and Leader of their Global Nonprofit Practice. His presentation will be based upon his research and experience in working with entities that span the public and private sectors and focus on proven strategies to drive organizational performance. A reaction panel will discuss major themes of his keynote address from the perspective of C-Change as well as their own organizations and experiences. Willis Goldbeck will moderate a panel comprised of Marguerite Baxter, RN, MN, Zora Brown, Patricia Nolan, MD, and Robert C. Young, MD.

Since the Teams of C-Change are the vehicles for effecting change, the meeting agenda for Friday has been designed to afford teams ample time together. Two sequential sessions will allow the teams to conduct their typical agenda as well as the opportunity to achieve a project milestone or completion. All C-Change Members and guests are welcome to participate in the Team Meetings as well as the Team-based Working Sessions.

Saturday, June 19

As C-Change continues to turn its "dialogues into action", one way it can bring action to bear is through the network within each member's organization and beyond. Collectively, our network of expertise and channels for effecting change is enormous. The agenda for Saturday will focus on opportunities for C-Change Members and their organizations to collectively access thousands of employees, dependents, and volunteers as well as their even more expansive network of contacts through recipients of care, services, and publications.

Collectively, our network of expertise and channels for effecting change is enormous.

The Town Hall meeting will explore strategies to leverage the power of this network and bring measurable change to the world of cancer. As outlined in the March article in *Fortune Magazine*, cancer research is extremely fragmented, with many redundancies, and with many gaps evident in cancer detection, prevention, treatment, follow-up, and policy. With the *Fortune* article in mind, our movement from "dialogue into action" and our commitment to unleash the power of the organization, our discussion will explore opportunities for C-Change to overcome this fragmentation.

Following the general discussion in the Town Hall Meeting, several Teams will present their work-in-progress. The Prevention Team and the Access Team are planning to review the findings and to identify priorities from their recent Summit meetings. They will identify priorities best suited for their Teams to pursue as well as other priorities best suited for other entities or groups.

After the morning break, Members will hear from Bob Ingram about *The CEO Roundtable on Cancer*, an example of what organizations can do together. The *CEO Cancer Gold Standard* is a focused and powerful initiative with the potential to impact the lives of millions of people through better access to prevention, detection, and cancer therapeutic options. The CEO Roundtable has collaboratively defined a standard of excellence and begun to leverage the power of its corporate membership. Bob Ingram, who is the founding chairman of the CEO Roundtable, will describe their progress and C-Change will issue a "Call to Action" to all of its members to implement the *CEO Cancer Gold Standard* in an effort to leverage the power of our organizations and impact the lives of thousands more.

Mark McClellan, M.D. PhD., Administrator for the Center for Medicare and Medicaid Services, will deliver Saturday's closing keynote address. Dr. McClellan has addressed C-Change before in his former role at the Food and Drug Administration. We look forward to his return and invite the opportunity to engage a payer in discussion related to access to cancer care and treatment.


Collaborating to Conquer Cancer

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Former First Lady Barbara Bush, Co-Chair
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LaSalle Leffall, Jr., President and Board Chair
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Collaborating to Conquer Cancer



from the executive director connie curran

Time flies...So many things are happening at C-Change and with our members. Just in the past few weeks **the Board decided that we will be a co-sponsor of this year's Tour of Hope**. The tour is designed to increase awareness and participation in clinical trials. C-Change's teams on clinical trials and on research will most directly benefit from our participation. I am sure that the tour also **will increase awareness of cancer in the general population and promote action on their part**. An important aspect of the Tour is asking individuals to **"take the pledge."** The goal is to have 1.5 million Americans (a number about equal to those that will die from cancer this year) to pledge to be proactive regarding the disease and support research efforts focused on cancer. More information about the tour and how you can participate will be presented at our June Member meeting.

Many hospitals celebrated "Hospital Week" and "Nurses' Week" during May. Hospitals are plagued with so many problems. Many of them have full beds and empty pocket books. They are experiencing significant shortages of nurses, pharmacists, and radiology techs. Their emergency rooms are overflowing with 52 million uninsured Americans. These and other issues confront the **Cancer Workforce Team**. Recently, Maureen Lichtveld, MD, MPH, has agreed to serve as vice-chair of that team with Don Coffey, MD and Co-Chair George Vande Woude, PhD.

Our teams are implementing their strategic plans. This includes the **Access to Quality Cancer Care Team** that convened a two-day meeting in to focus on strategic plan implementation. Also, **the Prevention and Early Detection Team** developed an action plan to move the priority recommendations forward that were generated through our September 2003 Prevention Summit. The team will look to tap the resources and expertise of our Members and their organizations to champion one or more of the recommended actions.

One of the delightful experiences I had this month was attending a celebration by the **National Center for Tobacco-Free Kids** with **Matt Meyers**. Awards were presented to high school students for their work against tobacco use. The student's enthusiasm, creativity and commitment are essential to win this battle. I cannot help but believe that involving young people in all our efforts will make us more successful in our battles.

I recently spent some time in **California** with one of our newest board members, **Dileep Bal**, and his team. What an experience! Their 18 years of work for the state's Department of Health Services, Cancer Control Branch, is yielding the most fabulous results in preventing cancer. The breath and depth of their efforts is incredible. From research, to screening, to their very provocative use of the media, their multivariate approach to prevention is laudable. They have offered to share their processes and products with all of us. Tenacity, creativity and generosity are yielding great results in the war against cancer in California.

The **June meeting** is planned to offer a fabulous blend of new information, networking opportunities, and time for teams to meet and work. **Les Silverman**, one of our featured speakers, leads **McKinsey's Global Not-for-Profit practice**. I found his December 2003 article in the HBR so helpful that I distributed it to the board. His insights and experience will help all of us in optimizing C-Change, as well as your own organizations. **Bob Ingram**, the founder of the **CEO Roundtable on Cancer** will be sharing the work of the Roundtable on defining their **CEO Cancer Gold Standard**. I am hopeful that this work will enable many of you to insure that your employees have benefit plans that provide services to prevent and diagnose cancer and to support clinical trial participation. We are very fortunate to hear from the **administrator of CMS, Mark B. McClellan, MD, PhD**. We all have an enormous stake in the policies and plans of CMS in its role as the principal payor of cancer care.

In our **recent Member survey**, many of you expressed your interests in **"dealing with cutting edge issues"** and **"working on areas of cancer that are broader** than those of your particular organization". The June meeting has been designed with both of those priorities in mind, while emphasizing action. We are no longer limited to dialogue...we are now empowered to act! I am looking forward to seeing you at the meeting!



C-Change meet the members

Zora Brown

C-Change Member since 2001.
Member, Access Team and Communication subcommittee
Founder and President, Breast Cancer Resource Committee, Inc.

Q: What brought you to the cancer fight?

Zora Brown: It was a personal experience with the disease and a heartfelt need to promote cancer awareness in the African- American community.

Q: How did you come to join C-Change?

Zora Brown: I was nominated based on my more than 15 years in generating breast cancer awareness and advocacy. I, in turn, felt C-Change could bring the resources to be effective in the fight and to develop a comprehensive plan to really attack this set of diseases by simultaneously addressing the funding, policy, educational, research, and advocacy support components so essential.

Q: What do you think will be most critical in the fight against cancer in the near future?

Zora Brown: It is critical that we approach the fight in a comprehensive way. We need to increase research dollars and resources to discover and create new and novel treatments, and then educate people about their availability. There has been significant improvement since I was treated for breast cancer 24 years ago and even more since my mother was treated for the same disease 40 years ago. Until we find a true cure for all the types of cancer, we depend on research to improve the quality of life for those affected or in jeopardy.

Q: What is your vision long-term, an ideal development in the fight?

Zora Brown: My ideal would have a cure, a vaccination, or a pill to make everyone immune. Not only that, but everyone susceptible would have access to it. I work hard to assist with making it possible for African American men and women to have access to service; but service must be inclusive and comprehensive. We cannot just provide screening. We must also provide state-of-the-art treatment.

Q: How do you see C-Change's impact in the fight?

Zora Brown: C-Change has brought together some of the best minds, including researchers, policymakers, corporate leaders, and ardent advocates. I see an unselfish respect among the members. I am in awe at their level of commitment, from a former United States President, to a sitting U.S. Senator, to corporate CEOs, to top scientists, and so many others. I am not a major "player," but I feel that I am someone who can bring another perspective. That is my job. My mother, who just turned 90, told me that "if you see a problem and do not seek a solution, you have no right to complain." And I will not change my mantra until each and every person in need of service has it.

Q: What does C-Change need to do to achieve its mission?

Zora Brown: We need committed minds and souls who recognize there is a great divide between the haves and the have nots. We all need to do just a little bit more...if the scientist puts in just one more hour in the lab late at night, the caregiver sees one more patient, the advocates speak out one more time.

Q: Tell us a little about your personal background.

Zora Brown: I have had a rich career in the public and private sectors. I have had the opportunity to work in The White House, in Congress for the Majority Leader at the time, for federal agencies, and the Ford Motor Company, in the venture capital industry, among others. As a result, I understand how government works as well as private industry. A strong background in public relations and communications has enabled me to craft my own advocacy organization.

Q: What would you tell a young person just about to join the fight against cancer?

Zora Brown: Follow your passion. That enables each of us to get up and do the unthinkable every day. Your passion is that burning desire that makes you think all the time about that thing you want to do, and gives you great satisfaction while you are doing it, no matter what aspect of the fight you have chosen.

Q: What would you say to a veteran already engaged in the fight if they told you their spirit was flagging a bit?

Zora Brown: One, in this work, you will not be rewarded externally. You have to create your own internal rewards. You have to know, without any reinforcement, that you are making progress, making a difference. It is like the water that drips onto the rock, ever so slowly eroding the stone until a beautiful sculpture emerges.

Two, it is good to stop and take a step back and see where you can have the greatest impact. I was recharged by cancer in 1997. I had to take personal stock. I had to reorder, reorganize my approach. It was good for me because I ended up with more creativity and balance in my life, along with a wonderful husband...would you believe a seventh-grade classmate!

Q: Is there anything else you would like to add?

Zora Brown: C-Change is an absolutely astounding group of people from all sectors of the cancer community who in turn represent their constituencies. I speak for the African-American women and men from all across the United States who cannot be there, and for so many other women. I hope I bring the honesty they would want me to just as I see other Members doing for those they represent. I recently gave a speech where I told the audience that I felt if we can illuminate the landscape of Mars, we can provide healthcare for every citizen in this country and ultimately find a cure for this disease. Compared to 20 to 30 years ago, I do not know anyone who smokes and so many of my friends and family now are very conscious of diet and nutrition. We are making progress. It takes doing a little bit at a time, just like that water dripping on the rock.

C-Change news notes

Health and Human Services Issues Cancer Health Disparities Report

The U.S. Department of Health and Human Services recently issued a report of the Trans-HHS Cancer Health Disparities Progress Review Group, "Making Cancer Health Disparities History." The report details 14 call to action-priority recommendations, which HHS plans to spearhead to eliminate cancer health disparities. The report includes a call to action to "Collaborate with the private and voluntary health sectors to ensure that all Americans receive the full range of lifesaving information, services and quality care from cancer prevention to screening to diagnosis and treatment."

A number of C-Change members and partners participated in the development of this important report through their work on the Progress Review Group. They included Moon Chen, Ph.D., Mark Clanton, M.D., MPH, Donald Coffey, Ph.D., Harold Freeman, M.D., Robert Hiatt, M.D., Ph.D., Judith Knauer, M.D., Jon Kerner, Ph.D. and Armin Weinberg, Ph.D.. To learn more about the HHS report, go to the National Cancer Institute's website at www.cancer.gov.

U.S. Hispanic/Latino cancer incidence data

A panel of experts of the North American Association of Central Cancer Registries (NAACCR) has published a monograph describing the burden of cancer in the U.S. Hispanic/Latino population. Statistics in the monograph reflect the cancer experience of more than 86% of the U.S. Hispanic/Latino population.

The report was designed, prepared, and released by a NAACCR expert panel that had worked for several years to enhance identification of Latinos among the newly diagnosed cancer cases reported to central cancer registries. The report is available on the NAACCR web site at <http://www.naacr.org>.





C-Change meet the members

William J. Mayer, MD, MPH

Member since 1999

Teams: Resource Acquisition Subcommittee (Chair); State Cancer Plans Team Partner, Stryker Center at Kalamazoo College

Q: What brought you to the fight against cancer?

Bill Mayer: My passion is prevention. The fact that so much of cancer is preventable has led me to be committed in this fight.

Q: What led you to join C-Change?

Bill Mayer: I have known quite a few of the people in the cancer community, having worked at the National Cancer Institute. In fact, Tom Kean, who has been quite active in C-Change, is perhaps most responsible for my nomination. I was an officer of the Kellogg Company at the time.

Q: What do you think will be most critical in the fight against cancer in the near future?

Bill Mayer: There is a tremendous power in engaging the public through social marketing. We have only scratched the surface. Just think of the gains we can make in prevention, in helping patients and families navigate the system, encouraging increased enrollments in clinical trials, and more. With all the Members in C-Change and the organizations they represent, we have a great opportunity to engage the public and get action.

Q: What do you see as the most critical development long term in the fight?

Bill Mayer: We are dealing with a set of diseases that will take a long time to conquer. But there is an enormous opportunity in research to identify prevention and treatment strategies to eradicate the disease. Just look at what has happened already in proteomics and genomics research to personalize treatment and prevention. Just imagine what is to come. Also, we need a national cancer plan and a visionary strategy on how we can best work together.

Q: What would you tell a young person just about to join the fight against cancer?

Bill Mayer: Match your passion to the need. With all the obvious need in cancer, there are tremendous opportunities to make a meaningful contribution.

Q: What would you say to veterans of the fight if they told you their spirit was failing?

Bill Mayer: Get closer to the people who are struggling daily with the risk factors or the disease. It is easy to lose touch if you are involved in a programmatic, research, or administrative role. My contact with patients is what maintains my enthusiasm to work for cures.

Q: How do you see C-Change's impact in the fight and what does it need to do to achieve that result?

Bill Mayer: If C-Change can create advances in three key areas, we will have made a tremendous impact. One, we need to communicate cancer control to the public. Look at the fantastic work by The American Legacy Foundation in their "Truth" campaign and the dramatic impact the State of California has had on smoking rates with its tobacco counter-advertising campaigns.

Two, we need to improve the availability of cancer control services. We need better access to programs such as smoking cessation, screening, and clinical trials.

Three, we need to create an environment that reinforces people taking action. That means cultivating role models in popular culture and promoting a public policy agenda in such areas as environmental tobacco smoke, food labeling, and health care coverage of cancer screening and clinical trials.

If C-Change can produce advances in these three areas, we will have had a significant impact. The CEO Cancer Gold Standard is an excellent example of what C-Change can accomplish. We can extend and expand this program to more workplaces and to society more generally. It is a model effort.

Q: Tell us a little about your personal background.

Bill Mayer: I live in the Kalamazoo, Michigan, area with Annie, my wife, and our two sons, ages 9 and 12. The boys always ask me why I have to go away to be with C-Change. They keep me accountable for doing what I can to help C-Change make a difference.

I work at the Stryker Center at Kalamazoo College. It is a regional economic and leadership development program of the college. The Stryker Center is the home of the region's U.S. Small Business Administration Small Business and Technology Development Center. We serve as consultants to business and non-profit executives on issues related to strategy and leadership development.

My interests include my role as Chief Medical Officer at a federally qualified community health center in nearby Battle Creek. More than 70 percent of our patients live in poverty and are uninsured or on Medicaid. They have tremendous social and medical needs. When I speak of staying passionate in the fight against cancer, it is our patients that inspire me and keep me grounded. Being on the frontlines and trying to create an environment conducive to cancer prevention and control is challenging and rewarding.

Q: Is there anything you would like to add?

Bill Mayer: We have an awesome responsibility and opportunity in C-Change. There are millions who are counting on us to get it right and to make it happen. I am personally committed to making the most of the opportunity on their behalf.

C-Change news notes

Foti, Kim, and Young Honored by ASCO

Congratulations to C-Change Members Margaret Foti, Paula Kim, and Robert Young for receiving Special Awards from the American Society of Clinical Oncologists' (ASCO) at its annual meeting this month.

Margaret Foti, PhD, who is the Chief Executive Officer of the American Association for Cancer Research (AACR), will receive ASCO's Special Recognition Award for her instrumental role in the development of the ASCO/AACR Joint Workshop, "Methods in Clinical Cancer Research." The workshop has served as the prototype for subsequent workshops designed to introduce beginning oncologists in Europe and Australia to the essentials of effective clinical trials design. Dr. Foti has served as AACR CEO for the last 22 years. At AACR, she has worked to provide vital links between translational scientists and clinicians, and has fostered important connections between these two research groups. She is a Distinguished Member of the European Association for Cancer and has served as President of the National Coalition for Cancer Research and the Society for Scholarly Publishing.

Paula Kim, is a C-Change Board Member and the cofounder and President of the Pancreatic Cancer Action Network (PanCAN). She receives the American Society of Clinical Oncologists' (ASCO) Partners in Progress Award in recognition of her commitment to improving the quality of care for patients with pancreatic cancer.

Established in 2003, the award honors "extraordinary patient advocates whose dedication and work have had a measurable effect on public awareness about cancer and have led to advancements in cancer treatment, research, prevention, and education."

After her father was diagnosed with the disease in 1997, she has dedicated her time to raising public awareness about the need for more research, effective treatments, prevention programs, and early detection methods for pancreatic cancer. Paula has also lobbied to increase funding for pancreatic cancer research. Beyond C-Change, her participation in the advocacy and research community includes service on the National Cancer Institute (NCI) Pancreatic Cancer Progress Review Group, the NCI Director's Consumer Liaison Group, and the National Cancer Legislative Advisory Committee.

Robert C. Young, MD, is President of Fox Chase Cancer Center and will receive ASCO's Distinguished Service Award for Scientific Leadership. This award was established to recognize the achievements of individuals who, through a blend of outstanding leadership skills and groundbreaking scientific vision, have transformed the practice and profession of medicine. Dr. Young is being recognized for his nearly 40 years of service in the field of oncology and his contributions to advancing the understanding of ovarian cancer. His groundbreaking studies determined the optimal procedures for staging early and advanced ovarian cancers as well as the optimum treatment regimens for these diseases. He was instrumental in advancing clinical trials on the chemotherapy regimen which is now the standard of care for patients with early and advanced ovarian cancer. Dr. Young has also served as a past president of both ASCO (1989-1990) and the American Cancer Society.

"from Dialogue into Action"

June Semi-Annual Meeting

June 18-19, 2004 Grand Hyatt Washington at Washington Center Washington, D.C.

Friday, June 18

8:00 – 9:00

Breakfast

9:00 - 9:15

Welcome & Introduction

9:15-10:30

Introductory Address

- Les Silverman
Director, McKinsey & Company
Leader, Global Nonprofit Practice

Reaction Panel Discussion

Facilitator:

- Willis Goldbeck, President & CEO, The Health Project

Panelists:

- Marguerite Baxter, RN, MN, Vice President, Government Affairs, Chiron Corporation
- Zora Brown, Founder & President, Breast Cancer Resource Committee, Inc
- Patricia Nolan, MD, Director, Rhode Island Department of Health
- Robert C. Young, MD, President, Fox Chase Cancer Center

10:30-10:45

BREAK

10:45-1:30

Team Meetings

1:30–1:45

Lunch Buffet

1:45-3:45

Team Based Working Sessions

Working Session Topics

Surveillance and Information Summit Priorities and Action Plan
National Biospecimen Network Pilot Site Promotion & Economic Impact of Cancer Study Approach
Model State Clinical Trials System Concept Paper
Prevention and Early Detection Summit Priorities and Action Plan
State Cancer Plans Call to Action

Team

Access
Research

Clinical Trials

Primary Prevention
State Cancer Plans

3:45-4:00

BREAK

4:00 – 5:30

Business Meeting of C-Change

Executive Briefing
Tobacco Knowledge and Attitudes Survey
Tour of Hope

5:45 – 7:30

Reception

Saturday, June 19

8:30-9:00

Opening remarks

9:00-9:45

Town Hall Meeting

"Setting the Stage: Leveraging the Power of Organization"

9:45-10:30

Dialogue with the Teams

"Work in Progress: Leveraging the Efforts of the Teams"
Access Team – Surveillance & Information Summit Action Plan
Prevention Team – Prevention and Early Detection Summit Action Plan

10:30-10:45

BREAK

10:45-11:45

Presentation of CEO Cancer Gold Standard

- Robert Ingram
Chair, CEO Roundtable
Vice Chairman Pharmaceuticals, GlaxoSmithKline

- Call to Action

11:45-12:45

Keynote Address & Discussion

- Mark B. McClellan, M.D., Ph.D
Administrator
Centers for Medicare & Medicaid Services

12:45-1:00

Closing Remarks – Adjourn

"from Dialogue into Action"

June Semi-Annual Meeting

June 18-19, 2004 Grand Hyatt Washington at Washington Center Washington, D.C.

Meeting Registration Checklist/Resources

Members have received the email invitation welcoming you to attend the C-Change Semi-Annual Meeting, June 18-19 in Washington, D.C. If you have not already done so, please:

- RSVP on-line at the C-Change Web site**
www.c-changetogether.org. See Calendar of Events.
- Contact the Grand Hyatt Washington to make your hotel reservations**

Hyatt Reservation Center directly at **800-233-1234**. <http://grandwashington.hyatt.com/groupbooking/ndoc>.

- Arrange for your air travel needs**

EWA Travel 800-368-4055
bettyanne@ewatravel.com or **marife@ewatravel.com**

If you have not sent an RSVP, please do so as soon as possible.
More information about the meeting agenda, logistics, and financial assistance can be found on the Web site.

- For any questions regarding the program aspects of the meeting, please feel free to contact Alison Smith of C-Change at alisonpaigesmith@aol.com or (847) 432-6301.
- For any questions regarding meeting logistics please contact Zoe Santiago-Font at zsantiago-font@air.org or (301) 592-2196.

Thank You to The Program Work Group

The Program Work Group has done an outstanding job preparing for our June Semi-Annual Meeting. We appreciate their thoughtful efforts to plan an agenda designed to advance the thinking and action of the organization.

Program Work Group Members

Armin Weinberg, PhD, Chair
Dileep Bal, MD, MS, MPH
Anne Barker, PhD
Helene Brown
Connie Curran, EdD, RN
Willis Goldbeck
Paula Kim
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Marty Murphy, MD
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