



2004
M i l e s t o n e s &

 **C-Change**
Collaborating to Conquer Cancer

A c c o m p l i s h m e n t s
2005

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Front cover

(top to bottom): Peter Dolan, Member, C-Change Board of Directors;
John Seffrin, Treasurer, Board of Directors; and Zora Brown, Member.

Above (left to right):

C-Change's first class of Summer Interns; Matt Myers, Co-Chair, Tobacco Control Team;
President George H.W. Bush, C-Change Co-Chair ; and the 2004 Tour of Hope National Team.



1776 I Street, NW, Suite 900
Washington, D.C. 20006
800.830.1827 202.756.1600
202.756.1512 FAX
www.c-changetogether.org

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& A c c o m p l i s h m e n t s



Organization-Wide Development

- "Calls to Action"
- Key Relationships & Collaborations
- Planning & Operations Infrastructure

Team-Specific Developments

- Access To Quality Cancer Care
- Cancer Prevention and Early Detection
- Cancer Research
- Clinical Trials
- State Cancer Plans
- Tobacco Control
- Cancer Workforce



“Calls to Action” Leveraging the Power of the Organization

In the spirit of the C-Change™ mission, “To leverage the expertise and resources of our membership to eliminate cancer as a public health problem at the earliest possible time,” C-Change issues “Calls to Action” to tap into the collective and synchronous power of its networks among patients, health professionals, industry leaders, and public officials. Several “Calls to Action” have been issued to date.

June 2004

- **Tour of Hope Promises**

The membership was challenged to collect “Promises” from clients, employees, friends, and family in support of the 2004 Tour of Hope. The “Promise” pledges a commitment to adopting a healthy lifestyle, seeking routine cancer screening, and considering clinical trials if faced with the diagnosis of cancer. C-Change contributed numerous promises to the nationwide initiative.

November 2004

- **Summer Internship Program**

The Cancer Workforce Team asked the membership to host summer interns to promote careers in cancer and nominate them to participate in a supplemental program through C-Change. This program provides a unique multi-disciplinary and multi-sector experience among peer interns and the Members of the organization. The pilot program included 14 interns from across the country. As students in undergraduate, graduate, and doctoral programs, the interns are pursuing careers in research, medicine, nursing, health communications, health law, public policy, and public health. Three of the 14 internship positions were sponsored by C-Change to support specific Team initiatives.

- **State Cancer Plan Assistance**

The State Cancer Plans Team urged the membership to assist individual states with their efforts to develop and implement their comprehensive state cancer plans. Members were specifically asked to provide assistance ranging from strategic plan and budget development to forging partnerships with the business community.

May 2005

- **Careers in Cancer Speakers’ Kit**

The Cancer Workforce Team asked the membership to disseminate the speakers’ kit messages, personally, or through their employees, or by posting the materials on their respective Web sites.

- **Smoke-Free Jurisdiction Resolution**

The Tobacco Control and Cancer Prevention and Early Detection Teams challenged the membership to adopt a smoking resolution mirroring the policy adopted by the Board of Directors which directs organizations to host major meetings in smoke-free jurisdictions only.

- **Tobacco Action**

The Tobacco Team urged the membership to take action within their states to increase smoke-free air laws, increase tobacco taxes, protect and increase State funding for tobacco prevention programs, and other actions to help enhance this nation’s tobacco control efforts..

Key Relationships & Collaborations

In addition to fostering collaboration within the C-Change community, the C-Change staff has represented the organization in a number of formal and informal ways to continue to build relationships and to promote credibility and presence in the cancer community.

Formal Partnerships/Membership

- **Institute of Medicine – National Cancer Policy Forum**

C-Change was invited to become a formal member of the IOM's new National Cancer Policy Forum. IOM forums are designed to allow government, industry, academic, and other representatives to meet, confer, and plan privately on subject areas of mutual interest.



U.S. Senator Dianne Feinstein, C-Change Vice Chair.

This Forum will be the successor to the IOM Board in providing a focus within the National Academies for the consideration of issues in science, clinical medicine, public health, and public policy relevant to the goals of preventing, palliating, and curing cancer.

- **Tour of Hope**

Since 2003, Bristol-Myers Squibb has sponsored the Tour of Hope, a national awareness campaign regarding cancer clinical trial participation and cancer research. The Tour involves Lance Armstrong and 24 cyclists riding across the country in 9 days, making stops in small towns and large cities to share their messages of hope. As a partner of the Tour in 2004, C-Change involved the support of the C-Change membership, soliciting "Promises," and helping organize rally events in Chicago, Illinois, and Washington, D.C. C-Change will again be a partner in the 2005 Tour of Hope.

- **2006 CDC Cancer Partners Summit Work Group Guidance**

C-Change was invited to become a member of the work group to help identify and plan program content for the 2006 Summit. This Summit is designed to meet the needs of the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Division of Cancer Prevention and Control (DCPC)'s public health partners and constituents.

Sponsorship/Grant Contributions

C-Change has demonstrated its support of various organizations and issues by endorsing specific initiatives and providing funding to projects believed to impact the fight against cancer.

- **Omnibus Survey of 1,000 Americans (February 2004)**

C-Change sponsored a study of American's attitudes and actions toward cancer. The survey revealed the degree to which American's fear cancer in contrast to their true knowledge of its risks, and actions to prevent cancer.

- **"Cancer: Caring and Conquering" Column in MEDSURG Nursing**

Beginning in February 2005, C-Change sponsored a column enlisting medical-surgical nurses in the battle against cancer. The column highlights basic and emerging issues in cancer related to screening, prevention, smoking cessation, clinical trials, and treatments as well as resources for nurses and patients. *MEDSURG Nursing* is the official journal of the Academy of Medical-Surgical Nurses and is a leader in adult-health nursing education.

- **Summit Series on Cancer Clinical Trials**

In 2002, 2003, and 2004, C-Change contributed grant funding to the Cancer Research and Prevention Foundation for this conference focused on improving the clinical trial system.



Speaking Engagements

Several organizations have requested the Executive Director to speak at key meetings and events:

- **Comprehensive Cancer Control Leadership Institutes**
In partnership with the CDC, NCI, ACS, ACoS, ICC, and other member organizations, C-Change delivered an introductory address, facilitated focus groups, and participated in five regional workshops (Austin, Washington DC, San Diego, Chicago, and Hawaii).
- **Comprehensive Approach to Cancer Strategy Marketing Workshop**
In collaboration with the CDC, C-Change presented and participated in two workshops.
- **CDC's National Program of Cancer Registries (NPCR) Program Directors Annual Meeting**
C-Change delivered keynote address focused on C-Change and collaboration.
- **Association of Cancer Executives Annual Meeting**
C-Change presented a breakout session.
- **National Tobacco Cessation Collaborative**
Active members of this collaborative include the CDC, ACS, American Legacy Foundation, the Campaign for Tobacco Free Kids, Robert Wood Johnson Foundation, American Heart Association, American Lung Association and other stakeholder organizations.

Event Participation

C-Change has also played a role as an organizer and/or participant in a variety of events in the cancer community:

- **T.J. Martell Foundation 29th Annual Awards Gala**
In May 2004, the Foundation honored President George H.W. and Mrs. Barbara Bush as Humanitarians of the Year due to their support of C-Change and the M.D. Anderson Cancer Center. C-Change was named a recipient charity of the Foundation that year.
- **U.S. Senate Cancer Coalition Hearing**
In March 2005, C-Change attended the hearing at the request of Senator Dianne Feinstein, leader of the Senate Cancer Coalition.
- **Other Awards & Briefings**
American Cancer Society Awards, American Legacy Foundation Honors, Campaign for Tobacco Free Kids Awards, Friends of Cancer Research Briefings.

Relationship Building

C-Change continues to foster new relationships that will enhance its leadership, membership, and donor base

Recruitment of three new governors as C-Change members

- Honorable Jon Huntsman, Jr., Governor of Utah
- Honorable Ruth Ann Minner, Governor of Delaware
- Honorable Janet Napolitano, Governor of Arizona

Development of C-Change relationships with the private sector

- Fred Frank – Lehman Brothers
- Bruce Pyenson – Milliman

Planning and Operations Infrastructure

• Strategic Planning

In July 2004, the Board of Directors approved a set of 14 Strategic Priorities designed to focus 80 percent of the organization's efforts and resources on program initiatives. In December 2004, the Board of Directors engaged in a more comprehensive strategic planning process, examining aspects of C-Change's uniqueness and sustainability.

Planning & Communications Infrastructure, continued

- **Media Launch**

In March 2004, C-Change hosted a news conference at the National Press Club to announce itself as a formal 501(c)(3) organization with specific goals to conquer cancer.

- **Communication Tools**

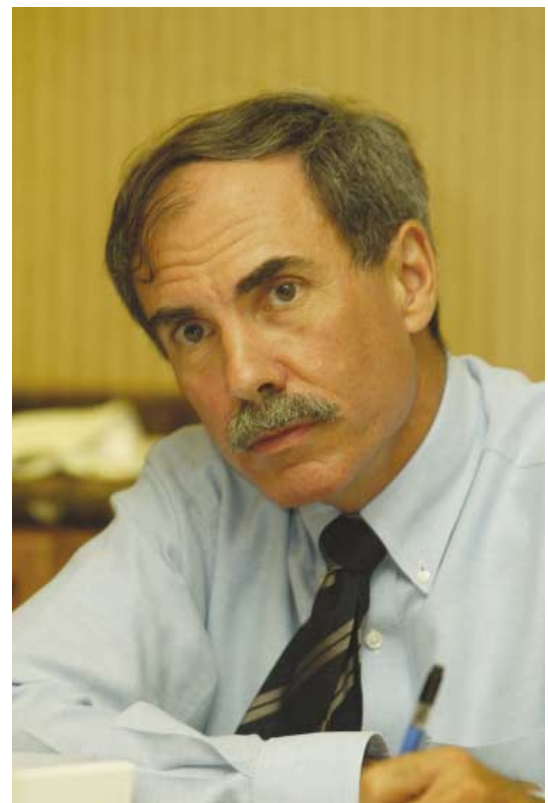
The staff of C-Change has created several communication tools with the assistance of creative and technical experts, including quarterly newsletters, an image brochure, and an intranet. These multi-purpose tools assist with communication among the staff, within and among Teams, and with current or potential members or donors.

- **Financial Management & Accounting**

Since being awarded a temporary 501(c)(3) designation, C-Change has implemented a system of financial management, including accounting, payroll, and audit procedures. C-Change is compliant with the charitable Gold Standard for all expenditures.

- **Human Resources**

In addition to naming the first full time Executive Director, six staff members have been hired to manage finance, team activities, development, information systems, marketing, and administrative support. Several consultant agreements exist to support special functions such as meeting management, communications, and graphic design.



Governor Bob Wise, West Virginia, 2004 Team Chair, State Cancer Plans.

TEAM-SPECIFIC MILESTONES & ACCOMPLISHMENTS

Access To Quality Cancer Care Team

Foreword

Within the U.S. population, patients across localities and among certain ethnic and minority groups receive significantly disparate cancer care. Research has shown that those who receive substandard primary and cancer-related care have greater incidences of cancer and more cancer deaths.

The Team's objectives are to decrease the national gap between those who receive quality care and those who do not. It will formulate a national strategy linking cancer data (including prevention, screening, treatment, and rehabilitation) into useful national and local measures that ensure access to quality cancer care. The Access to Quality Cancer Care Team efforts are focused on assuring timely access to quality care across the continuum of cancer care services.

To date, the team has accomplished the following milestones and projects:

- **National Summit on Cancer Information and Surveillance**

In 2004, the Team mobilized C-Change Members, including the American College of Surgeons, National Cancer Institute, U.S. Oncology, and the Centers for Disease and Prevention to convene and sponsor the Summit. Experts from all sectors made recommendations for securing more precise knowledge on the national cancer experience, which have been distilled into priority recommendations for data collection and management. With improved data quality and quantity regarding the diagnosis, treatment, and outcomes of patients with cancer, researchers will be better able to focus their efforts while clinicians will be able to make better treatment decisions. The recommendations have been approved with the highest level of endorsement by the Board of Directors and are currently being pursued.

- **Patient Navigation Guide**

The Team spearheaded efforts to enhance the nation's capacity to provide patient navigation services. As a first step, in 2004 the Team facilitated a partnership with the National Patient Advocate Foundation to publish and distribute a state-by-state guide of financial resources for patients. This guide was distributed to providers of services to underserved populations.





LaSalle Leffall, C-Change Chairman of the Board.

Access To Quality Cancer Care Team, continued

- **HRSA Cancer Collaborative-Open House Project**

In 2004, C-Change provided funding through the Access to Quality Cancer Care Team to support an initiative designed to raise awareness regarding disparities in cancer care within specific communities.

Clinical Trials Team

Foreword

The present clinical trials system cannot keep pace with the growing number of agents that merit testing. By efficiently translating recent scientific discoveries into practice, eliminating the backlog of agents for testing, and increasing access for patients and individuals at risk, the capacity of the national clinical trials infrastructure will be enhanced.

The objectives of the C-Change Clinical Trials Team are

to double the current accrual for participation in clinical trials and make the majority of cancer patients aware that participation in clinical trials provides an important opportunity to receive quality cancer care.

Fewer than 5% of eligible American adult cancer patients participate in Phase II and Phase III clinical trials. Because the rapid development of new drugs and treatments is primarily dependent upon a significant increase in the number of American adults participating in trials, it is essential to remove barriers and increase access to clinical trials.

There are a number of barriers to increasing patient access and participation in clinical trials. These range from limited patient understanding of the benefits of trial participation to complex management, regulatory and cost reimbursement issues. C-Change's Clinical Trials Team is engaging its multi-sector Members to help systematically address these access and accrual barriers.

To date, the team has accomplished the following milestones and projects:

- **Clinical Trials Guidance Document**

With the assistance of The Lewin Group, the Team created a definitive guidance document that detailed the functional or operational requirements and associated costs of conducting cancer clinical trials. The guidance document will be disseminated to public and private sector policymakers and clinical trial sites. The guidance document was approved with the highest level of endorsement by the C-Change Board.

- **"Reducing the Regulatory Barriers" Paper**

The Clinical Trials Team described a series of regulatory reforms that will help to expedite the clinical trials process. The recommendations were consistent with the NCI's Clinical Trials Working Group's plan to enhance the efficiency of the system. These recommendations were approved by the National Cancer Advisory Board on February 17, 2005. The recommendations were also approved with the highest level of endorsement by the Board of Directors.

- **State Clinical Trials Network Model Design Grant**

The Team created a grant opportunity for an organization to develop a model state-wide clinical trials network with links to state's comprehensive cancer control plan. The goal of this network is to increase access and accrual for Phase II and Phase III adult cancer clinical trials. Currently, awareness about clinical trial opportunities among physicians and patients is fragmented leading to slow and/or low levels of trial accrual. Nineteen applications were received and the contract was awarded to the Pennsylvania Cancer Control Consortium (PAC³). Additional funding is being sought to sponsor other promising proposals.

Clinical Trials Team, continued

- **Public and Patient-Focused Survey on Clinical Trial Participation**

Under the auspices of the Coalition of Cancer Cooperative Groups, the Northwestern University Center for Biomedical Communications conducted a survey on the attitudes, beliefs and behaviors associated with clinical trial participation among the general public and cancer patients. This survey data will be useful in understanding what educational or communication strategies could be employed to increase trial participation.

Primary Prevention & Early Detection Team

Foreword

Primary prevention and early detection are the most significant defenses against cancer. The objectives of this Team are to increase awareness of primary prevention and early detection methods and to encourage all Americans to adopt them.

Over 60 percent of cancer deaths are linked to the modifiable risk factors of tobacco use, unhealthy dietary practices and lack of regular physical exercise. As the science of prevention has become more sophisticated, so have the tools and tests available for early detection.

To date, the team has accomplished the following milestones and projects:

- **National Cancer Prevention and Early Detection Summit**

In the fall of 2003, C-Change sponsored a Cancer Prevention and Early Detection National Summit and invited stakeholders from the private, public and not-for-profit sectors. More than 100 recommendations were generated and distilled into fourteen priority items. The Prevention and Early Detection Team is currently engaged in addressing items related to communication, promotion of best practices, policy development, and research.

- **C-Change/Agency for Healthcare Research Quality (AHRQ) and Symposium**

In May 2005, C-Change hosted a symposium with AHRQ. The objectives of the symposium were to provide a venue in which knowledge transfer occurs among the business, insurance and healthcare delivery sectors, identify each sector's role in improving the delivery of services, and provide an opportunity for collaboration. At the conclusion of this symposium, attendees had a template for improving the delivery of cancer prevention and early detection services, providing a better understanding of the challenges, opportunities, and business case as identified by each sector.

- **“Application of High Resolution CT Imaging Data to Lung Cancer Drug Development” Workshop**

C-Change and the Cancer Research and Prevention Foundation co-sponsored a workshop to consider the current and emerging technologies for lung cancer screening and develop a consensus statement for public and professional dissemination. The workshop brought together a multidisciplinary group, including medical oncologists, radiologists, academic oncologists from the NCI SPORE program, nurses, patients and patient advocates, along with representatives of the FDA, AHRQ, CDC and NCI and the pharmaceutical and diagnostic imaging industries. During the course of the two days, the state of the science in imaging, as well as the application of high-resolution spiral CT technology were discussed, with the goal of improving outcomes for all patients diagnosed at every stage of lung cancer.





Sam Donaldson, C-Change Member.

Cancer Research Team

Foreword

In the post-genomic era, cancer research has never been more promising. With this promise comes a need to address ongoing barriers to research and for increased funding and attention for all levels of research— from basic research to clinical trials investigating specific therapeutic agents. The objectives of the Cancer Research Team are to address barriers to progress in cancer research and promote investment in research across all sectors.

To date, the Cancer Research Team has been successful in defining new approaches and resources to accelerate research:

- **“National Biospecimen Network Blueprint” Publication**

In 2003, the Team published the “National Biospecimen Network Blueprint,” (Constella, 2003) as a strategy to address tissue access as a barrier to research. This model defines standards for specimen collection and data management with consideration for related legal, ethical, and economic issues. The Blueprint is based upon a prior publication, “Case Studies of Existing Human Tissue Repositories: “Best Practices” for a Biospecimen Resource for the Genomic and Proteomic Era.” The Research Team commissioned the RAND Corporation to survey and publish a summary of varying practices across institutions (RAND, 2003).

- **“Surrogate Endpoint” Papers**

In June 2004, the Team published a series of six articles on biomarkers and surrogate endpoints, an emerging research strategy that has provided earlier and more sensitive

measures of efficacy, response to treatment, and cancer recurrence (Clinical Cancer Research 10: 3881-3933, June 1, 2004). Using examples in prostate, ovarian, and colorectal cancer, this body of work provides a survey of new and current thinking and identifies promising opportunities for the research and regulatory communities to explore further with the aim of accelerating drug development. Each paper involved the collaboration of at least a dozen scientists from multi-sector organizations across the country.

- **“Accelerating Cancer Drug Discovery And Development: Leveraging the Nation’s Academic Cancer Centers” Paper**

In 2005, the Team completed and obtained the highest endorsement by the Board of Directors to seek publication of the paper in a nationally recognized peer-reviewed journal. The paper emphasizes the need for “applying scientific advances to the development of new cancer diagnostics, therapeutics, and preventive strategies,” while “rethink(ing) the entire drug discovery and development pipeline.” Removing the barriers imposed by time, cost, and economic return depend upon more collaboration among academic cancer centers to further advance basic science as well as more partnerships with the biotech and pharmaceutical industries to bring innovations to patients.

- **Hill Briefings**

One strategy that the Research Team has employed to address issues related to funding has been to host educational briefings with members and staff of the U.S. Senate and House of Representatives. These programs typically involve physician scientists illustrating the promise of a particular area of cancer research and patients sharing their experience with clinical trials. By educating Senators, U.S. Representatives, and their staff members, the Research Team hopes to enable more informed decisions regarding research appropriations.

- **March 14, 2005**

“Funding Cancer Research: Progress, Opportunities, and the Role of Government”

- Tom Curran, MD, a neurobiologist at St. Jude Children’s Research Hospital
- Harold Moses, MD, Director Emeritus of the Vanderbilt-Ingram Cancer Center
- Sam Donaldson of ABC News

- **October 18, 2004**

“Advances in Imaging Technology and Image-guided Cancer Therapy”

- C. Norman Coleman, M.D., Director, Radiation Oncology Sciences Program, Center for Cancer Research, National Cancer Institute
- Mauro Ferrari, Ph.D., Professor of Internal Medicine, Division of Hematology and Oncology, The Ohio State University
- Peter Choyke, MD, FACR, Research in the Molecular Imaging Program, The National Cancer Institute

State Cancer Plans Team

Foreword

C-Change Members in each state are working together to generate political and public support for a more coordinated and synergistic approach to cancer control across the country. The objectives of the C-Change State Cancer Plans Team are to engage all states and territories in a data- and stakeholder-driven planning process that will result in each state and territory implementing a collaborative cancer plan.

Through the work of the State Cancer Plans Team, its first Chairman, Pennsylvania Governor Tom Ridge, 2004 Chairman, West Virginia Governor Bob Wise, and current Governors Jon Huntsman, Ruth Ann Minner, and Janet Napolitano, that goal is in sight. Nearly every state has created a plan and the remaining states are in the process of developing their plans.

To date, the team has accomplished the following:

- **Comprehensive Cancer Control Leadership Institutes (CCCLI)**

Co-sponsored by C-Change, the American Cancer Society, American College of Surgeons, Centers for Disease Control and Prevention, Intercultural Cancer Council and the National Cancer Institute, the CCCLI brings teams of officials from each state to learn from experts, and one another to develop and implement their respective comprehensive cancer control plans. Phase I focused on cancer planning fundamentals. In 2004, a thousand attendees from all states and territories participated in these Institutes. In 2005, the CCCLI programs were adapted for an institute involving tribal nations and U.S. Pacific Territories. Phase III Institutes will provide specialized modules on tobacco control, palliative care, clinical trials, workforce development, survivorship and colorectal cancer screening.

- **State Planning Assistance Team Visits**

Onsite follow up support has been given through expert Planning Assistance Teams, who travel to states that have requested specialized guidance with their planning process. In a related November 2004 effort, the State Cancer Plans Team issued a "Call to Action" that linked C-Change Members and Partners with states seeking planning assistance.

Tobacco Control Team

Foreword

Tobacco use is the greatest single cause of cancer incidence and mortality. To address the threat posed by tobacco, C-Change established a team that is charged with fostering a targeted multi-sector approach to tobacco control.

The 1998 Master Settlement Agreement (MSA) between the tobacco industry and 46 states and five territories, estimated to total more than \$246 billion over 25 years, and recent increases in state tobacco excise taxes have created an unprecedented opportunity to fund vital public health-related programs and initiatives. Unfortunately, the states are spending less than 3.5% of their tobacco-generated revenue on tobacco control efforts.

The objectives of C-Change's Tobacco Control Team are to ensure that states spend a major portion of their tobacco settlement funds on tobacco-related public health activities; that states increase their tobacco excise taxes; and that states enact and implement tobacco control programs meeting or exceeding CDC's 1999 Best Practices for Comprehensive Tobacco Control Programs.

To date, the team has accomplished the following:

- **Smoke-Free Resolution**

In 2005, the Tobacco Team, in conjunction with the Prevention and Early Detection Team, proposed a policy to the Board of Directors requiring that future meetings be held in smoke-free jurisdictions. Since the Board's approval, the Team has challenged Members and Partners through a "Call to Action" to facilitate adoption of a similar meeting policy by their respective organizations.



Tobacco Control Team, continued

- **State Tobacco Control**

The Team issued a “Call to Action” to the C-Change membership to participate in state tobacco control efforts. These efforts include promoting smoke-free jurisdictions, assuring access to appropriate cessation services and products, raising tobacco excise taxes, and assuring that both state tobacco and cancer control programs have adequate funding. In addition, the Team is identifying five states for more targeted intervention.

- **State Tobacco Control and Cancer Control Plans Integration**

In addition, the team has identified five states to focus on the integration of their respective tobacco control and cancer control program efforts. This includes an effort to help adequately fund these two complementary programs.



Cheryl Heaton, Member, C-Change Board of Directors

Cancer Workforce Team

Foreword

Optimizing and accelerating C-Change's mission to control cancer will require the development and training of professionals in modern techniques of care delivery and research. However, workforce shortages currently exist or are predicted for professionals, including physicians, nurses, researchers, pharmacists, social workers, laboratory, and allied health professionals. Despite progress in lowering both incidence and mortality on an age-adjusted basis, the aging of the “baby boomers” and continued increases in life expectancy will result in many more people requiring cancer care. C-Change is committed to building the requisite “surge capacity” in the workforce to care for these new cancer patients while advancing the skills of the existing workforce to keep pace with developments in science and technology.

The Cancer Workforce Team is currently engaged in efforts to strengthen both the quantity and quality of the cancer workforce with the knowledge and skills necessary to meet the needs of an aging and increasingly diverse population.

To date, the team has accomplished the following:

- **Summer Internship Program**

Through an initial “Call to Action,” the Cancer Workforce Team invited Members to support summer interns within their own organizations and have their interns to participate in a supplemental program during the C-Change Semi-Annual Meetings. This program provides a unique multi-disciplinary and multi-sector experience for interns and members of C-Change. The pilot program included 14 interns from across the country. Students in undergraduate, graduate, and doctoral programs, the interns are pursuing careers in research, medicine, nursing, health communications, health law, public policy, and public health. Three of the 14 internship positions were sponsored by C-Change to support specific Team initiatives.

- **“Careers in Cancer” Speakers’ Kit**

The Cancer Workforce Team created a set of presentation materials emphasizing the wide variety of career opportunities in cancer. The message targets high school and college students, to “be part of the generation that cures cancer.” Careers in nursing, medicine, social work, pharmacy, public health, and health information management/cancer registration are highlighted with information about educational training, licensing, work settings, and funding. A “Call to Action” was issued to members to promote careers in cancer by posting the materials on their web sites and delivering the presentation through their respective networks.

