



Symposium Report

Comprehensive Cancer Control Policy and Practice Summit

Hyatt Regency O'Hare, Rosemont, IL

May 19–21, 2008

Table of Contents

Executive Summary.....	<i>i–v</i>
Summit Proceedings.....	6
Welcome and Overview of the CCC National Partnership.....	6
Meeting Purpose and Outcomes.....	6
Keynote Speaker: Delaware Governor Ruth Ann Minner.....	7
Access to Care Discussion.....	8
Practice Panel Discussion 1: C-Change.....	14
Colorectal Cancer Screening Discussion.....	14
Wrap Up of Day 1.....	19
Welcome and Agenda for Day 2.....	19
Practice Panel Discussion 2: National Cancer Institute, American Legacy Foundation, Intercultural Cancer Council.....	19
Funding for CCC Plan Implementation Discussion.....	19
Practice Panel Discussion 3: National Association of Chronic Disease Directors, American College of Surgeons Commission on Cancer, Centers for Disease Control and Prevention, American Cancer Society.....	24
Group Discussion: Assisting CCC Coalitions in Building Their Capacity to Affect Policy Change and Providing National-Level Support for Coalitions.....	24
Call to Action: Former West Virginia Governor Bob Wise.....	28

Executive Summary

The purpose of the Comprehensive Cancer Control (CCC) Policy and Practice Summit, held May 2008 in Chicago, was to: (1) engage leaders from CCC Coalitions in a dialogue about identified priority CCC areas and potential policy approaches to address those areas; (2) share and discuss CCC experiences, successful strategies, challenges encountered, and new approaches to affect policy change on identified CCC priority areas; (3) identify the policy approaches that Coalition leaders can consider for their own CCC efforts; (4) identify a set of policy-related actions for CCC National Partners to support and assist Coalitions to build their capacity affecting policy change; (5) identify a set of policy-related actions for the National Partners to address at a national level that support Coalitions in their priority policy-related efforts; and (6) provide information and materials on CCC implementation materials that Coalitions can use in their implementation efforts of their CCC plans.

In addition to hearing a keynote speech from Delaware Governor Ruth Ann Minner and a call to action by former West Virginia Governor Bob Wise, participants learned about tools, products, and resources that the National Partners have available to assist state Coalitions with implementation of CCC plan priorities and objectives. Summit attendees also engaged in dynamic discussions about access to care, colorectal cancer screening, and funding for CCC plan implementation.

Access to Care Discussion. Nebraska's efforts to increase access to colorectal cancer screening by building on an existing breast and cervical cancer program were highlighted during the discussion on access to care. This project is a statewide effort that utilizes an established network of approved cancer centers in Nebraska to ensure that all patients within the demonstration project who are diagnosed with colorectal cancer receive treatment despite any inability to pay for care.

States and organizations discussed a variety of experiences regarding access to care. A CDC colorectal cancer screening demonstration project has been implemented to determine the feasibility of community-based screening. The State of Maryland's initiation of a statewide colorectal cancer program that did not include a treatment component, thereby causing a breakdown of the state-sponsored health insurance program, highlighted the need to consider the unintended consequences of policy decisions. In response to a recently added section on CCC and community outreach in the core grant renewal application, M.D. Anderson Cancer Center has developed a process to promote a cancer strategic plan—which will be linked to the state plan—that includes information about how cancer centers can be involved in CCC and community outreach. As a result of a failed 1985 plan, California's new cancer control plan focuses on community-level implementation of access to quality care. Colorado has implemented mobile colonoscopy unit that will travel anywhere in the state on the condition that at least 12 patients will be screened at the location. Colorado, Maryland, and Kentucky have implemented income tax checkoffs for cancer funding; West Virginia implemented a diagnostic and treatment fund, which is designated each year by the state legislature. The American Cancer Society has formed a Cancer Action Network specifically to be involved in electoral and policy issues related to cancer. The Policy Workgroup of the Kansas Cancer Partnership developed relevant questions to ask candidates for the state legislature. Delaware's approach to access to care was to narrow its

focus and build on smaller successes. A recent survey in Utah indicates that there is a dramatic inability to access appropriate care for gynecological cancers; CDC is developing a nationwide gynecological campaign with recent funding from Johanna's Law. Because of access to care issues in Montana, pediatric cancer patients consult out-of-state pediatric oncologists. Recent findings in Connecticut highlight the fact that free screening, previously seen as important only for the uninsured population, is becoming an important issue for the insured population as well.

The term "access to care" includes multiple issues, such as affordability, availability, and utilization; the new federal mantra is access to *quality* care. There is a rift between policymakers and cancer centers/health departments as well as a rift between CCC Coalitions and cancer centers. The lack of access to care for Native Americans is a significant problem. As a result of the Deficit Reduction Act proof-of-citizenship requirements, tens of thousands of Native Americans have been removed from the Medicaid Program. Developing culturally appropriate health communications for Native Americans also is a challenge. A national plan that recognizes a standard level of care must be developed and implemented because the lack of such a plan creates funding hardships that make it difficult to fund programs to help meet the basic needs of communities.

Lessons learned:

- Engaging the governor and state legislature in planning and implementing state CCC action plans is the key to success; success breeds success.
- Unintended and downstream consequences must be considered during planning.
- Implementation must be built into any cancer plan. Additionally, the plan must be powered by action, and the operational level is the community level.
- Examining many different methods to ensure access to screening and care can provide successful, visionary solutions.
- It is important to engage political candidates and understand what their programs encompass as well as ensure that elected officials recognize that cancer must be a top priority.
- Focusing on small pieces and building a series of successes that ultimately address the larger problem has been a successful approach.

Colorectal Cancer Screening Discussion. Washington State's and Colorado's experiences with colorectal cancer screening were highlighted during the discussion. Washington State demonstrated that existing breast and cervical health program infrastructure could be used as a model for colorectal cancer screening for uninsured individuals. The 2-year effort resulted in funding via a line item in the state budget. The goal of the Colorado Cancer Coalition's Colorectal Task Force is to ensure that 75 percent of Colorado's over-55 population are compliant with American Cancer Society colorectal cancer screening guidelines by 2010; improving public and provider awareness were two important components of achieving this goal. The program provides colorectal cancer screening and treatment to qualified individuals within the medically underserved population; also included is an effort to educate the insured population about the need for screening.

Other states and organizations shared their anecdotal experiences. The Pennsylvania Cancer Control Consortium is working on achieving a line item in the legislature for colorectal cancer screening, delivered a testimony to the legislature to support a mandate for insurance coverage for colorectal cancer screening, and, to generate funding in this area, identified organizations with a vested interest in increasing colorectal cancer screening. Maryland's colorectal cancer screening program is funded by tobacco settlement money, and the Coalition has been able to add additional program initiatives to state budget line items each year. Nevada's recent colonoscopy screening crisis as a result of a hepatitis C outbreak has prompted surveys to assess the damage this crisis has caused. Colorado and Ohio have had problems reimbursing Medicare co-pays for those who cannot afford to pay the co-pay because of federal statutes. The Texas Comprehensive Cancer Control Coalition worked with the state legislature to mandate that insurance companies cover colorectal cancer screening. A tool-kit that provides evidence-based tools to increase colorectal cancer screening rates in practice is available at the American Cancer Society Web Site; Montana will be implementing this tool-kit, and Massachusetts already has successfully implemented it. Nebraska CARES (Cancer Awareness, Research, Education, and Service) has been approached about a 1-year media campaign that would be incorporated into Husker sports broadcasts. The Hawaii Coalition has attempted to lobby the state legislature to require insurance coverage for colonoscopy screening; the lack of a national guideline for colonoscopy recommendations has hindered this effort. Colorado faced a similar challenge; the state Coalition increased public demand for colonoscopies and worked with insurance companies to successfully solve this problem. Additionally, the American Cancer Society has developed talking points to respond to insurance company and policymaker barriers.

Other topics of discussion included examples of improvements in medical technology that make screening more readily accessible, implementation of electronic medical records, and standardization and transparency of colonoscopy costs.

Lessons learned:

- Key factors in Colorado's success were embedding the colorectal cancer screening program within the health care system, patient navigation, and providing treatment.
- Vendors that exhibit at meetings can be important resources.
- Funding for treatment is as important as funding for screening.
- Evaluation programs are important components of CCC plans.

Funding for CCC Plan Implementation Discussion. Iowa's and Maryland's fundraising efforts were highlighted during this discussion. The Iowa Consortium for Comprehensive Cancer Control advocated for tobacco control and increasing the state's tobacco tax, resulting in increased funding for tobacco control, a line item in the state budget dedicated to cancer control, and an increase in Iowa's tobacco tax. Additionally, the Consortium's efforts have resulted in strong collaborations that have allowed the construction of accommodations for cancer patients and their caregivers. An Iowa Department of Public Health Request for Proposals, however, did not include a provision to keep funds within the state, and state funds from the state tobacco tax dedicated to tobacco control are being used outside of Iowa. The significant component of implementing a voluntary income tax checkoff in Maryland was writing the regulations. The funds raised are distributed via grants, which include grants for treatment in qualified cases.

Other states and organizations shared their fundraising experiences. Utah, Georgia, Texas, and Kentucky have proposed and/or implemented special purpose license plates as a fundraising source. Several states, including Michigan, Georgia, and Kentucky, have implemented income tax checkoffs. The Kentucky Cancer Program is funded by the general assembly each year to provide regional outreach and education across the state, whereas Delaware's cancer control money is derived primarily from the state's tobacco fund. The Texas Cancer Council is supported by a line item in the state budget. Arizona negotiated with the Colon Cancer Alliance to receive a share of event profits from the inaugural "Undy 500" for colorectal cancer treatment. A Michigan women business owner association funds breast cancer screening in a large, underfunded county. The National Comprehensive Cancer Control Program will continue to fund programs. Finally, state-level data regarding the monetary amounts and types of mechanisms was identified as beneficial.

Lessons learned:

- Provisions should be included in state plans to keep state funding within the state.
- Being creative and focusing on the mission allows for innovative fundraising solutions.
- Good policy cannot happen by accident, but bad policy can.
- Even if a policy is not passed, it can be impacted in the regulations process.
- Money makes the opposition go away.
- There are methods to accomplish cancer control goals without using grants.
- Cancer advocacy group expertise and business owners passionate about cancer control are excellent resources.

During the Summit, participants identified opportunities for the National Partners to: (1) assist Coalitions in building their capacity to affect policy change, and (2) play a role in national agendas and approaches to assist Coalitions' priority policy-related efforts.

Building Coalitions' Capacity. Dissemination of various types of information was identified as a key action for the National Partners to undertake to build capacity. Of particular benefit would be the quick dissemination of information and results from various CCC efforts, such as evaluations, successful CCC plan implementation funding endeavors (e.g., solicitation of state funds, marketing income tax checkoff initiatives, private foundation philanthropy efforts), community-level implementation of CCC plans, the transition from an informal coalition to a 501(c)(3) organization, and policy initiative actions (i.e., information regarding unintended consequences and management of unusual/adverse circumstances). The National Partners also could disseminate information about: successful arguments in response to policy roadblocks; individual National Partner efforts on policy; practice patterns and gaps in practice patterns that could be addressed through Coalitions; sources of learning (e.g., books) that focus on health care reform issues and discussions; and costs and outcomes associated with cancer treatment mechanisms that can be used to make the case for various policy initiatives (e.g., colorectal cancer screening as a cost saving investment).

In addition to dissemination, Coalitions identified other activities for building capacity. The National Partners also can: provide examples and lessons learned regarding how to involve elected leaders and other public officials in CCC efforts; help position colorectal cancer screening policy decisions; continue to develop budgeting guidance and tools around CCC interventions, including the ability to project the cost and cost savings of interventions; develop a list that details how much each state receives in federal, state, private, and other funding and for what purpose; ensure that all terms being used in the cancer dialogue are understood to mean the same thing to all groups across the national landscape; and provide training to facilitate the development of Coalitions.

Roles Involving National Agendas and Approaches. Two major efforts that the National Partners could undertake include creating a national CCC plan or strategy and developing a national cancer policy agenda that includes prioritization. A related action is to determine a common approach for Coalitions and National Partners to adopt (i.e., a strategy to speak with one voice) during the forthcoming national discussion on health care reform, including encouraging a paradigm shift from “health care reform” to “health reform.” Another approach is to work with the national media to reframe the discussion about the War on Cancer.

The relationship between Coalitions and cancer centers also was discussed. The National Partners can advocate for stronger relationships between CCC Coalitions and National Cancer Institute-designated cancer centers and other academic organizations as well as advocate for clearer guidelines about cancer center interactions with CCC Coalitions. The National Partners can address the value and rewards system as related to CCC engagement (e.g., cancer center involvement) and urge scientific institutions to consider how critical the community voice is to cancer control and realize that ancillary community outcomes also are meaningful. A related action is to address any potential or actual rifts between groups that have an advocacy focus and those that cannot advocate.

Also identified as important to consider are the disparities in Native American access to care. The National Partners can address this issue by seeking the help and advice of tribes and tribal organizations, engaging the Indian Health Service (IHS), examining the capacity and relationships of IHS, reviewing tribal compacts in terms of cancer control, examining federal legal barriers to access that have negative impacts, engaging the National Indian Health Board and Area Health Boards, and promoting state and tribal opportunities to address access collaboratively.

Other activities that the National Partners can engage in on a national level include more broadly examining common workforce issues (e.g., primary care provider capacity); addressing access policies that potentially violate federal laws; advocating for continued Centers for Disease Control and Prevention support for state Coalitions and the CCC movement, with the understanding that not all National Partners can participate in this effort; approaching the Department of Defense about ceasing tobacco sales on military bases; addressing access-to-care policies so that every individual diagnosed with cancer must see an oncologist for some part of their evaluation and/or treatment recommendations; addressing policy issues about health literacy; and encouraging a shift in paradigm so that cancer treatment follows the infectious disease model instead of the chronic disease model.

Summit Proceedings

The following is a summary of the information presented at the Summit, including participant discussion and shared ideas.

Welcome and Overview of the CCC National Partnership

Dr. Armin Weinberg, Co-Founder of the Intercultural Cancer Council (ICC), welcomed participants to the Comprehensive Cancer Control (CCC) Policy and Practice Summit. Making CCC efforts relevant can be challenging, but this diverse and unique gathering, which represents 45 states, four tribes and tribal organizations, and a Pacific island jurisdiction, is a tremendous accomplishment and a step in the right direction. Summit participants should share their stories with each other, because collaborative efforts will be increasingly beneficial as each participant learns about the factors that reinforce each other's cancer control efforts.

The National Partner Organizations came together many years ago and laid the foundation for these efforts. The National Partners include representatives from the American Cancer Society (ACS), the American College of Surgeons (ACoS) Commission on Cancer (CoC), the Association of State and Territorial Health Officials, C-Change, the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration, ICC, the Lance Armstrong Foundation (LAF), the National Association of Chronic Disease Directors (NACDD), the National Association of County and City Health Officials, the National Cancer Institute (NCI), and the North American Association of Central Cancer Registries. The group has worked tirelessly to advance cancer control efforts and establish a foundation to help states, tribes, territories, Pacific Island jurisdictions, and other local entities fight cancer. This Summit will focus on policy, with the goal of advancing efforts to remove the burden and suffering of cancer. Dr. Weinberg encouraged participants to relax, be comfortable, and learn from each other.

Meeting Purpose and Outcomes

Mr. Tom Kean, Executive Director of C-Change, explained that in addition to representatives from the National Partners, the planning committee for the Summit included Dr. Michael Bukstein, President and CEO, Missouri Cancer Consortium; Dr. Lynn Butterly, Director of Colorectal Cancer Screening, Dartmouth-Hitchcock Medical Center; Dr. Al Einstein, Steering Committee Chairman, Washington Comprehensive Cancer Control Partnership; Carter Steger, ACS Cancer Action Network (CAN); and Dr. George Weiner, Chair, Iowa Consortium for Comprehensive Cancer Control.

This is the first-ever convocation of chairs from CCC Coalitions from across the country. During the past decade, individual Coalitions, working on behalf of the citizens within their jurisdictions, have created a larger national movement that has a significant opportunity to effect change. The state and tribal Coalitions are the engines of change, and this change moves to the national scene. The National Partners want to enable state and tribal CCC Coalitions to achieve the best results possible. The goal of the Summit is to: (1) engage in a dialogue with CCC Coalition leaders on identified priority areas and potential policy approaches to address those areas; (2) share and discuss CCC experiences, successful strategies, challenges encountered, and new approaches on how to affect policy change on identified priority areas; (3) identify the

policy approaches that Coalition leaders can consider for their own efforts; (4) provide information on materials that CCC Coalitions can use for their plan implementation efforts; (5) identify a set of policy-related actions for the National Partners to support and assist CCC Coalitions to build their capacity to affect policy change; and (6) identify a set of policy-related actions for the National Partners to address at a national level that support CCC Coalitions in their priority policy-related efforts.

Three priority policy issues were identified and will be addressed at the Summit: (1) access to cancer care, (2) colorectal cancer screening, and (3) funding issues related to the implementation of CCC plans. The National Partners intend to finalize the 5-year strategic plan this summer so that all CCC Coalitions will understand the support available to them at the national level; feedback from this Summit will inform this process.

Keynote Speaker: Delaware Governor Ruth Ann Minner

Governor Ruth Ann Minner stated that since she took office in 2001, increasing cancer prevention and treatment options for all Delaware citizens has been at the forefront of her administration, especially for those who previously could not afford cancer treatment. At the time she took office, Delaware's cancer incidence and mortality rates were the highest in the nation. Cancer incidence and mortality are important issues for the governor, who lost her husband to lung cancer. Within 21 days of taking office, she introduced a state senate joint resolution to establish the Delaware Advisory Council on Cancer Incidence and Mortality; her original plan was to issue an executive order, but the state house and senate expressed interest about being involved in the effort. The legislation was passed quickly and signed in March 2001; an action plan to increase cancer prevention efforts and create treatment programs for Delaware residents was in place by April 2002. Governor Minner stressed the importance of keeping current about cancer issues—as they frequently change—and working collaboratively. Delaware's action plan has been a success as a result of the diversity represented within the Council, which started with 15 members. The Council now has more than 200 members and an additional 150 volunteers and has evolved into the Delaware Cancer Consortium.

The Consortium meets monthly to assess what can be accomplished in terms of policy and care. In creating the action plan, it re-evaluated standard procedures, got creative with possible treatment options, analyzed existing state prevention programs, and changed the state's response to public health problems. The resulting action plan was all encompassing and took into consideration social, environmental, and biological causes of cancer; it offered actionable measures to treat existing cases of cancer and prevent others from occurring. The action plan also considered available funding and resources.

The State of Delaware created a landmark “Screening for Life” program that offers free screening for breast, cervical, and colorectal cancer to un- and underinsured citizens. The state also was the first to provide funding for treatment and care for un- and underinsured citizens. The Delaware Cancer Treatment Program is the only program in the United States paid for by a state; enrollees are covered for 2 years. A Nurse Navigator program also was implemented to help patients understand and navigate the health care system; feedback has indicated that cancer patients and their families and caregivers find this to be a very important component. Another goal of the Consortium was to reduce the number of smokers in the state; Delaware's stringent

Clean Air Act, banning most indoor smoking in all public places, including prisons and casinos, went into effect in November 2002. Programs were funded with tobacco settlement money and state funds. As a result of these efforts and initiatives, Delaware's cancer incidence rate has decreased at a rate of four times the national average, and the death rate has decreased at a rate of twice the national average. The percent of Delawareans who smoke has decreased from 37 to 19 percent.

Governor Minner attributes the state's successes to the collective effort of the many people who worked on this endeavor and exerted the power of their voices to speak out about what was needed. The described actions have made a difference in the lives of her citizens, including those that cannot afford health care. These examples illustrate the great amounts that can be accomplished with collaboration and determination.

In response to a question, Governor Minner related the story of a restaurant owner who was initially angry at the smoking ban but eventually realized the benefits and embraced the legislation. In response to another question, Governor Minner described her experiences sharing her expertise with other governors. She speaks to as many of her colleagues as possible at the National Governors Conference, but the feedback that she receives is that most states use tobacco settlement money to balance budgets. She encourages state leaders to consider the fact that investing resources for prevention and early treatment costs less in the long term, as evidenced by the impact that screening and early treatment has made in Delaware.

In response to a question about how to effect change in a state such as South Carolina that resists legislation restricting tobacco use, Governor Minner described a cigarette tax increase that she proposed, linking it to three programs that were of significant interest to the state legislature; if the tax increase was not passed, the programs would not be funded. Although the legislature was initially resistant to any cigarette tax increase, after 6 months of debate, the body ultimately increased the tax above the governor's proposed increase so that additional programs could be funded. Delaware has increased its cigarette tax twice, and each time the tax increases, more people ask for help to quit smoking. Mr. Kean pointed out that this type of discussion is important, as there are more than 55 jurisdictions represented at the Summit. Delaware is an example of how a coalition of people with leadership from the political sector can effect change. For those jurisdictions that do not have this type of leadership, the focus should be on how to inspire the next generation of leaders. Governor Minner agreed that inspiring the next generation is important. To ensure that future administrations continue Delaware's cancer efforts, the Executive Committee of the Delaware Cancer Consortium includes the lieutenant governor, the insurance commissioner, and four members from the state house and senate.

Access to Care Discussion

Dr. Alan Thorson, Chair of Nebraska CARES (Cancer Awareness, Research, Education, and Service), started the discussion by presenting information about Nebraska's approach to improve access to care to colorectal cancer patients diagnosed through a CDC demonstration project. Five projects were selected by CDC, and the Nebraska project is the only statewide effort. One initial concern about the demonstration project was that there was funding available for diagnosis but not treatment, so one goal was to ensure that patients diagnosed through the project would be able to receive treatment. The project was built on an existing breast and cervical cancer program

and followed a successful 2-year colorectal pilot project. Through CARES, ACS, and ACoS, a network already had been established with all of the approved cancer centers in Nebraska, and this network was utilized for the project. Each cancer center was contacted and informed of the demonstration project, as was the Director of the Nebraska Hospital Association. Discussions occurred at the Nebraska Annual Cancer Center Meeting about how to ensure access to care for these patients; physician liaisons were included in the discussion. The cancer centers agreed to provide care to patients diagnosed through the demonstration project who did not have the ability to pay for care. In terms of policy, project leadership reminded cancer centers that it was policy to provide free or reduced-cost care, particularly in cases in which centers were receiving federal funding. As this was a statewide initiative, all cancer centers were on equal footing. A collaborative plan was put in place to ensure that one cancer center did not bear the burden of cost more than the others. Leaders ensured that there was broad support for the project by approaching many organizations outside of cancer centers. The names of cancer centers that agreed to participate in the program were provided to peer organizations, which prompted these centers to join. All cancer centers agreed to participate within 1 year of being contacted. In response to a question about exploring a colorectal option similar to the Breast and Cervical Cancer Prevention and Treatment Act, Dr. Thorson explained that because there was no funding available for treatment, alternative options had to be pursued.

A CDC colorectal cancer screening demonstration project was implemented to determine the feasibility of community-based screening. In addition to the Nebraska project, projects were established in St. Louis, Seattle, Baltimore, and New York (Stony Brook). One idea was to use the breast and cervical cancer infrastructure to assist with the colorectal cancer screening. The project sites currently are being evaluated, and CDC will be determining next steps following the evaluation. There is no federal legislation for colorectal cancer screening as there is for breast and cervical cancer screening.

Washington Governor Chris Gregoire, a breast cancer survivor, promotes screening for breast cancer, but cancer groups in Washington State have not engaged the governor or state legislature in terms of their action plan as was done in Delaware. Policy issues and lobbying have been challenges, and Delaware's example has been an inspiration to engage the governor and legislature more formally in the process.

Unintended consequences of policy decisions must be considered. The State of Maryland used its tobacco settlement money to initiate a statewide colorectal cancer program that did not include a treatment component; screening began in 2001, and treatment coverage was provided by the Maryland Health Insurance Plan (MHIP), a state-sponsored health insurance program for residents that do not have access to health insurance. This decision is causing the collapse of the MHIP system, which was set up as an insurer of last resort and not as a repository for state program treatment patients. The program is being used for a purpose for which it was not intended, and as a result, costs are increasing significantly and forcing citizens out of the program. The lesson is that downstream consequences must be considered when planning; thinking ahead is crucial.

One major issue is the large rift between policymakers and those individuals that examine evidence (e.g., comprehensive cancer centers) and those that provide services in the community (e.g., health departments). In Arizona, the state health department staffs the CCC Coalition. One approach is to promote advocacy and education with elected officials. To make meaningful,

sustained change, there is a need for processes that get CCC Coalition personnel into decision-making chambers and a need for dialogue with policymakers to bridge the divide. Although the State of Delaware has had success with this, much of it has been a result of the governor and the relationships that she cultivated; this is rare. The inevitable rift that occurs within Coalitions as a result of the differences between the government sector and private and nonprofit sectors (e.g., advocacy) brings up two questions: (1) How can future leadership that is not present today be cultivated? (2) Can this rift be eliminated? For example, within C-Change, government members often must recuse themselves from advocacy discussions. These rifts must be considered immediately so that they can be eliminated, if possible.

There also is a large rift between CCC Coalitions and academic cancer centers, which in addition to basic research and clinical trials, have significant expertise in the areas of cancer control, cancer prevention, access to care, and so forth. Many Coalitions struggle with bringing expertise within cancer centers together with implementation of CCC activities, and some of the issues relate to research versus evaluation. There is great potential with even a limited amount of seed funding from NCI and CDC to encourage academic experts in cancer centers to work with CCC Coalitions.

One possible approach is to add criteria to NCI's review of cancer centers that require relationships with CCC Coalitions regarding access to care issues; this could have an immediate impact on the interest and enthusiasm of NCI-designated cancer centers to play an active role in CCC. NCI also could make available supplemental funding that supports the establishment of a dialogue between NCI-designated cancer centers and CCC Coalitions. These two efforts could allow NCI-designated cancer centers to quickly play an active role in CCC. C-Change could play a role in facilitating the dialogue.

Recently, the M.D. Anderson Cancer Center applied for its core grant renewal, and the grant application contains a recently added section on CCC and community outreach. As a result, M.D. Anderson has developed a process to promote a cancer strategic plan that includes what actions cancer centers can and should execute to be involved in CCC and community outreach. The institutional plan will be linked to the state plan; the process will be to assess current involvement, compare this with the state plan, assess gaps, and determine how M.D. Anderson can fill the gaps. Also, cancer centers could be engaged as National Partners, either as individual cancer centers or as a group.

California developed a cancer plan in 1985 that included the right components, goals, and objectives; however, the plan failed. The lesson learned was that implementation must be built into any plan. As a result, implementation became the watchword for cancer control planning when California developed its new cancer plan 5–6 years ago. The focus of the plan was access to quality cancer care with implementation at the community level. A pilot project was carried out in the City of Oakland to provide community access to cancer care. The resources in the community were assembled in a manner similar to those at the state level during plan development. The goal was not to develop a specific plan for this community but to determine how the state plan can relate to communities in general. The pilot project was successful, so the California Dialogue on Cancer implemented the plan in other communities. Currently, 11 counties representing 72 percent of the state population are involved in access to cancer care quality

program planning. This plan is in place and successful because of the previous lessons learned: (1) The plan must be powered by action. (2) The operational level is the community level.

When access to care is discussed, many people speak of affordability, but availability also is an issue. Another concern is the availability of trust relationships. Montana has seven federally recognized reservations, and there is a trust with Indian Health Service (IHS) clinics and the IHS contract in terms of screening, colorectal cancer, and some treatments. The state is working on improving relations, but much begins at the national level. It would be helpful if more discussions of this nature occurred at the national level and filtered down to the state level. The term “access to care” includes multiple issues, such as affordability, availability, and utilization; additionally, the new federal mantra is access to *quality* care.

Colorado has implemented a mobile colonoscopy unit, which relates to policy because a state-funded screening program inspired people with vision to examine many different methods to ensure access to screening and care. Colorado is a large state defined by two areas, its metropolitan strip and the mountains and plains regions that comprise the rest of the state. The mobile screening program makes use of a Fifth Wheel recreational vehicle that an endoscopist established to perform colonoscopy for clinics in areas that otherwise have no access to screening. This has been successful for a number of communities. If there is a guarantee that 12 patients will be screened, an endoscopist has committed to drive anywhere in the state; this endoscopist is more than willing to speak about the expenses and logistics of the program.

Colorado also has instituted a voluntary income tax checkoff for breast and women’s reproductive cancers. The state’s access to care issues revolve around the limitations of the breast and cervical cancer treatment program, because the state implemented the narrowest option available under the Medicaid Breast and Cervical Cancer Treatment Act. The program currently is being designed and most likely will be funded by grants because the income tax checkoff probably will not provide enough funding to support the gaps that exist. The fund also is designed to support education that will help with the issue of access to care; the Advocacy Committee of the Colorado Breast Cancer Task Force is performing the educational outreach, which is aimed at primary care providers that triage women. Women must be accurately triaged to the proper screener to receive treatment. Providing access to care includes educating people so that they know where to go to receive appropriate screening and treatment. Access to care also includes educating health care providers and the general public about symptoms of ovarian cancer.

The Maryland Cancer Fund, supported by an income tax checkoff and direct donations, includes a treatment component, a small fund to which residents can apply to pay for treatment. There are no data available because the program was put into action very recently. Kentucky also implemented an income tax checkoff 2–3 years ago for breast cancer, which provides community grants to increase educational outreach. Thus far, it has raised approximately \$45,000 and provides a continued revenue-generating source. Similar programs that focus on additional cancers are desirable. West Virginia implemented a diagnostic and treatment fund for breast and cervical cancer in 1996. The funds are used to subsidize treatment for patients that do not qualify for the Medicaid Breast and Cervical Cancer Treatment Act. Although the funding is designated each year by the legislature, the West Virginia Mountains of Hope Cancer Coalition must monitor the funds and is required to provide additional fundraising to receive the funds. This

fundraising increases awareness and education through activities such as walks and quilt making. The model is being examined for colorectal cancer screening.

There is a current opportunity to work with presidential candidates as they strive to develop health care reform plans. LAF was active in engaging candidates in an initial round of dialogue and is planning a subsequent dialogue with the current remaining candidates. Additionally, stakeholders are communicating with candidates' health staff. It is important to engage candidates and understand what their programs encompass. The challenge for health care reform will continue for many years beyond the election.

ACS has formed a 501(c)(4) organization, ACS CAN, specifically to be involved in electoral and policy issues related to cancer. This group has developed and released a voter's guide for the presidential election. Those interested in getting involved with these efforts can visit the organization's Web site at <http://www.acscan.org>; also available at the Web site are regular updates regarding advocacy and policy efforts. ACS CAN is very active in access to care issues, and the voting guide encompasses many issues relate to access to care.

There are a number of national organizations that are challenging the candidates. Kansas had an especially challenging legislative session this year. Health care reform was expected to be a topic of focus, and it was not. During this current election year, in which all of Kansas' legislators are up for re-election, legislators were invited to forums across the state to discuss health care. The Policy Workgroup of the Kansas Cancer Partnership developed four to five questions for its members to ask legislators at these forums. Legislators were asked whether they support a quality clean indoor air bill and whether they would increase the tobacco tax to pay for health care reform. State Coalitions, because they are dependent on state funding to implement their CCC plans, must become extremely active in the election and re-election of state legislators so that elected officials understand that cancer must be a top priority.

The power of momentum should never be underestimated, and momentum can be gained by narrowing objectives. Access to care is a substantial national problem, and states should focus on small pieces to build a series of successes that ultimately address the larger problem. Delaware's approach was to narrow the focus and build on smaller successes; the state focused first on building short-term success around colorectal cancer screening. As a result, real change has occurred, and there are many testimonials to this. Involving the governor and/or the head of the legislature is the key to success, and success breeds success. Many hospitals within the state want to join the Delaware Cancer Consortium as a result of its achievements. The Delaware approach brings together its NCI-designated cancer center, public health departments, and politicians as well as ACS and keeps the four groups moving in the same direction in areas in which they can collaborate. State Coalitions should gradually build momentum and not "bite off more than they can chew."

Louisiana has become a smoke-free state and, in 2005, passed a colorectal cancer screening bill for insured citizens. Currently, a similar bill for uninsured citizens is in progress and hopefully will be passed this year. ACS CAN launched the "Fight Back Express" in Cleveland, which will be traveling throughout the United States to encourage the presidential candidates to make cancer a priority issue in their administration.

One significant problem is that many Native Americans do not have access to care via federally funded programs as a result of Deficit Reduction Act proof-of-citizenship requirements and how these requirements translate to the state level. For example, the Centers for Medicare and Medicaid Services require proof of U.S. citizenship to obtain benefits; it is very difficult for tribal members, especially elderly ones, to obtain birth certificates that satisfy this requirement. As a result, more than 30,000 Native Americans have been removed from the Medicaid Program. Although there are no proposed solutions at this point, supplying proof of citizenship could be made easier at the state level. Individuals born in rural areas outside of a hospital have the same problem, and Washington State has struggled with this issue for a many years. One approach to address this may be to meet with IHS and review tribal compacts and determine whether they need to be revitalized or modified to cover access to care. Additionally, every tribe and tribal organization is represented on the National Indian Health Board via Area Health Boards, and the problem of access to care needs to be addressed by the Area Health Boards and then elevated to the national level for action. This is an issue that is difficult for tribes to address individually. Each tribe appoints, by resolution, a delegate to the appropriate Area Health Board; the delegate represents the tribe to address its various health issues.

One critical concern in South Dakota is developing culturally appropriate health communications for Native Americans. The South Dakota Comprehensive Cancer Control Program organized a seminar/workshop to address this issue, and Coalition members from across the state attended. The seminar was well received within South Dakota's CCC spring programs and resulted in funding to work with people who do not understand what they need in terms of their health.

Arizona's CCC program and state Breast and Cervical Cancer Early Detection Program (BCCEDP) have committed to work with tribes within the state, as well as New Mexico, Utah, and Nevada. A critical factor in these efforts is to understand that there are tribal and other organizations willing to be partners in health care delivery and access to health care with whom Coalitions and other stakeholders must develop solid communication practices.

Access to quality care is particularly important for ovarian cancer; there is a disparity in access to quality of care for gynecological cancers. Studies in Utah and other major metropolitan areas have shown that less than one-half of ovarian cancer patients see an ovarian cancer specialist; this is a dramatic inability to access appropriate care. In Utah, 46 percent of these patients within counties contiguous to Salt Lake City see an appropriate specialist; this rate drops to 27 percent outside of the metropolitan area. These same rates are seen across the country, even though: (1) national organizations such as the Society of Gynecological Oncologists and the American College of Obstetricians and Gynecologists have a very structured referral system regarding which patients should see a gynecological oncologists, and (2) ovarian cancer patients who see gynecological oncologists have an increased survival rate of 25 percent. The reason for this disparity is not known. The State of Utah is attempting to address this issue by initiating a dialogue for action in ovarian cancer; stakeholders across the state are examining why this disparity occurs. When discussing access to care, ovarian cancer issues must be considered, and gynecological oncologists should be involved. It is difficult for gynecological oncologists to insist that they see these patients, as this appears to be self-serving; therefore, efforts are being made to educate health care providers about this need via Podcasts, Webcasts, and other media that provide continuing medical education (CME) credits. In addition to the increased survival

rates, ovarian cancer patients who are treated by gynecological oncologists have less unnecessary surgeries and chemotherapy treatments and a decreased financial burden.

Through Johanna's Law, CDC received approximately \$6.5 million this fiscal year and, with partners, is developing a nationwide gynecological campaign. CCC Coalitions will be included in an effort to educate providers and women about the importance of gynecologic cancers and what specialists should be consulted following a diagnosis. The campaign is in the early stages, and organizers want to ensure that it has the greatest impact possible; input from CCC Coalitions and other stakeholders is very valuable.

In Montana, pediatric cancer patients consult out-of-state pediatric oncologists. These oncologists then work with local oncologists via telehealth technologies to provide appropriate treatment so that the patients can return home. The ability of these technologies to be utilized for gynecological or other cancers is cancer specific. Experts in each specific cancer field must define the quality of care standard for all patients. For example, ovarian cancer patients should receive thorough staging and adequate debulking, which requires the presence of an ovarian cancer specialized surgeon. It will take a paradigm shift in the planning and communication to find the specialized manpower to meet the needs of these patients.

Connecticut has low provider reimbursement for Medicaid, but the cancer care providers participate in Medicaid, so cancer treatment issues for Medicaid patients in the state is not a problem. A survey of Medicaid recipients in Connecticut, however, found that 70 percent were unable to find a primary care provider because these physicians limit the number of Medicaid recipients that they will see. As a result, these patients have no access to screening despite being insured. Free screening, previously seen as important only for the uninsured population, is becoming an important issue for the insured population as well.

It is necessary to broadly examine disparities across the ethnic and genetics spectrums. Another issue is that many of the cancer plans being discussed are local plans; this lack of a universal, national plan creates funding hardships that make it difficult to fund programs to help meet the basic needs of communities. A national plan that recognizes a standard level of care must be developed and implemented. A national agenda on cancer that addresses the entire spectrum is a similar concept; education, training, and workforce factors are an important component of this.

It is critical for Coalitions and stakeholders to educate themselves by reading about and examining diverse opinions. Strong leadership that can bridge the gaps between all of the varying ideas is necessary, and this leadership only can be identified if all of the various concepts and ideas are known. Broadening the perspectives of stakeholders is critical.

Finally, the National Partners could help with billing issues between IHS and state BCCEDP programs.

Practice Panel Discussion 1: C-Change

The first practice panel focused on introducing tools and products available from C-Change that can help state Coalitions implement CCC plan priorities and objectives. This panel is composed of C-Change members who are engaged in facilitating various initiatives, including a cancer patient navigation emotional toolkit, a cancer core competency project, an access to care guid-

ance document developed for CCC Coalitions, a cancer prevention and early detection messaging campaign and products for public education activities, an initiative that makes the business case for prevention and early detection, and a CEO Cancer Gold Standard employer-focused initiative to get employers engaged in cancer prevention and early detection.

Colorectal Cancer Screening Discussion

Dr. Einstein started the discussion by presenting information about Washington State's role in the CDC demonstration project that investigated whether the existing breast and cervical health program infrastructure could be used as a model for colorectal cancer screening for uninsured individuals; the project has been successful in demonstrating that this mechanism can be used for colorectal cancer screening. The study occurred in three counties near Seattle, but leadership, which included members of the Washington State Colorectal Cancer Task Force, understood early on that if the project was successful, state-level funding would be needed beyond the 3-year grant period. Public Health–Seattle & King County staff worked with the ACS directors responsible for government affairs and grass roots networking to strategize a plan to obtain state funding. The plan did not include a state legislative act, instead focusing on adding a line item in the state budget. The team focused on involving legislators in key counties, and ACS used its lobbying day at the state legislature to call attention to colorectal cancer screening issues. The effort took 2 years and resulted in \$956,000 line item that was approved unchanged during the 2008 legislative session. The program can expand to nine counties and ensure continuity beyond the expiration of the initial CDC grant.

Dr. Holly Wolf, Director of the Colorado Colorectal Screening Program, presented information about the program. The goal of the Colorado Cancer Coalition's Colorectal Task Force is to ensure that 75 percent of Colorado's over-55 population are compliant with ACS colorectal cancer screening guidelines by 2010. Improving public and provider awareness were two important components of achieving this goal. Additionally, the system had to be transformed to provide screening for the medically underserved. In 2004, the state increased its tobacco tax by \$0.64 per cigarette pack with the guarantee that the funds would be used to improve health care. In 2006, a grant was awarded to provide colorectal cancer screening to the medically underserved population who met certain requirements. The University of Colorado Cancer Center became the coordinating center for the effort. The program provides payment for: (1) endoscopic screening, (2) followup and treatment for adverse events, (3) treatment for patients diagnosed with colorectal cancer (payment of last resort), and (4) patient navigators to triage patients into screening and provide followup as needed. There also is an evaluation component to the program that assesses quality of care and justification for the program. During the 2 years of the program, more than 4,100 patients have been screened; 23 percent had adenomas, and 1 percent were diagnosed with colorectal cancer. Approximately 150 cases of colorectal cancer have been prevented via removal of the adenomas, which represents a savings of approximately \$15 million in treatment costs; the program cost \$10 million during the same time frame. The second portion of the effort seeks to educate the insured population about the need for screening. This endeavor includes the collaboration of a variety of state organizations, and the screening rate is increasing by approximately 5 percent each year as a result. State legislation to mandate colorectal cancer screening coverage for small business owners has been passed and is waiting the governor's signature. Key factors in the program's success were: (1) embedding the colorectal cancer

screening program within the health care system, (2) patient navigation, and (3) providing treatment, which encourages patients to get screened and providers to recommend screening.

Vendors that exhibit at meetings can be important resources. Via an informal conversation at a meeting, one vendor donated 1,000 screening kits that were about to expire and would have been thrown away otherwise. This initiated a screening program in South Dakota.

The Pennsylvania Cancer Control Consortium is working on achieving a line item in the legislature for colorectal cancer screening and delivered a testimony to the legislature to support a mandate for insurance coverage for colorectal cancer screening. The Consortium revised its mission to focus on providing a forum for collaborative action and identifying and disseminating best practices to reduce cancer-related disparities. There are many best practices: screening tests, treatments, and methods to encourage behavior change. To increase colorectal cancer screening, best practices for screening need to be identified in primary care practice settings. Funding for translating research findings into routine care is lacking, and this is an important issue to address. The Pennsylvania Cancer Control Consortium sought such funding by identifying Organizations Aligned for Strategic Initiatives and Support (OASIS) in colorectal cancer screening. Organizations with a vested interest in increasing colorectal cancer screening include manufacturers of colonoscopes and stool blood tests, insurers, and employers. The Consortium instituted an OASIS roundtable with these stakeholders to generate funding for an initiative to implement, evaluate, and disseminate best practices for increasing colorectal cancer screening.

Improvements in new medical devices for performing colorectal cancer screening may enable many more people to receive screening. Some improvements include a pill camera that is swallowed and produces and sends results, a virtual colonoscopy tool, stool DNA tests, and immunochemical stool blood tests that do not require a dietary regimen; a survey has indicated, however, that primary care physicians consider colonoscopies and stool blood tests to be the procedures of choice. The stool DNA test has not yet been approved by the Food and Drug Administration. Additionally, there is a distinction between those tests that detect early cancer and those designed to prevent cancer. The recently updated screening guidelines for colorectal cancer include some of these modalities. Newer endoscopic devices that are used in Europe (e.g., Aeroscope and other computer-directed endoscopic devices) may address improvements in the technology that make screening more readily accessible. Dr. Ronald Summers, NCI's point of contact for emerging technologies in colon cancer screening, recently spoke to the Maryland Comprehensive Cancer Control Plan on 10–12 modalities that are being investigated.

Maryland's 8-year-old colorectal cancer screening program uses colonoscopy as its primary screening modality and has screened approximately 30,000 individuals since its inception. It is based out of the local health departments, and faces a challenge in that the screening costs are higher as compared to the rest of the nation as a result of state-regulated hospitals. Interestingly, the screening program enrolls 80 percent women and only 20 percent men. The program is funded by tobacco settlement money, and the Coalition has been able to add additional program initiatives to state budget line items each year.

Funding for screening is an important issue, but funding for treatment also must be considered in these types of discussions.

Nevada is having a significant colonoscopy screening crisis as a result of a hepatitis C outbreak in endoscopy clinics in southern Nevada. The Nevada Cancer Council and its Colon Cancer Task Force are surveying the population to determine the impact that the negative publicity has had on people's willingness to undergo screening and donate blood. Another survey will examine the differences between primary care provider screening recommendations during the past 2 months compared to 1 year ago.

The Colorado Cancer Screening Program investigated the possibility of reimbursing Medicare co-pays for those individuals who had insurance but could not afford to pay the co-pay; however, the group was advised that this would violate two federal statutes. In terms of national policy, this is an area that may be beneficial to investigate and change. The reasoning behind the statutes is that because the screening program provides funding for treatment, it is encouraging people to take advantage of Medicare, which is an abuse of federal funds. Ohio has had a similar problem.

The Texas Comprehensive Cancer Control Coalition worked with the state legislature to mandate that insurance companies cover colorectal cancer screening; the legislation passed, and insurance companies readily pay for colonoscopies. The Coalition is working along the Texas Cancer Plan goals. Each goal has a dedicated subcommittee to find priorities and develop plans to accomplish the goal. The subcommittee investigating Goal 2, which seeks to increase early detection and treatment, has determined that increasing colorectal cancer screening is a priority. The Texas Cancer Council, part of the Texas Comprehensive Cancer Control Coalition, has funded five different pilot projects to determine the cost of implementing the Texas Cancer Plan in populations that are unfunded or uninsured; the estimated cost for this screening is \$22 million per year. Currently, it is estimated that the cost of cancer in Texas is \$30 billion annually. Proposition 15 passed in Texas, giving the state the authority to borrow \$300 million each year for 10 years to fund cancer research; up to 10 percent of the funds will be dedicated to cancer prevention.

Montana determined, via survey, that the state has the capacity to increase the number of colonoscopies performed. Additionally, regional contractors work on local-level CCC. The state does not have the funds to provide screening for un- or underinsured individuals, but a significant number of citizens do not use their insurance for colorectal cancer screening. A tool-kit is available at the ACS Web Site for primary care providers that was developed by ACS, the National Colorectal Cancer Roundtable, and Thomas Jefferson University. The tool-kit provides evidence-based tools to increase colorectal cancer screening rates in practice. Regions within Montana will implement this tool-kit in one clinic per region and evaluate its impact on screening rates. The Montana Comprehensive Cancer Control Program is very interested in learning about other states' experiences in implementing this tool-kit. The developers of the tool-kit are in the process of evaluating it through focus groups to ensure that implementation occurs, and an interactive version of the tool-kit linked to CME credits will be released this summer. The National Colorectal Cancer Roundtable is willing to help state Coalitions implement this tool. The Massachusetts Comprehensive Cancer Control Coalition implemented the tool-kit in more than 300 practices; risk management and quality improvement CMEs have been incorporated with the tool-kit in Massachusetts.

Nebraska CARES has performed community education through print media but recognizes that many individuals who read print media already have some connection to the subject matter. The Coalition has been approached by broadcast media about a 1-year media campaign that would be

incorporated into Husker sports broadcasts, which reach a large audience within and outside of the state. The potential to reach audiences that have not been reached previously is great. There also will be opportunities for messaging within sports venues. A tailgating event at a football game and a second event at a basketball game will draw additional attention. Each message will be tailored geographically to reach specific populations (e.g., the mayor of a specific city providing a closing message following the main message). Nebraska cancer centers also may be involved.

The Connecticut Cancer Partnership was awarded \$7 million 2 years ago by the state legislature, and the Early Detection Committee recently received \$750,000 via a Request for Proposals (RFP) mechanism for colorectal cancer screening. The Early Detection Committee is working with 12 federally qualified health centers in the state to screen 600 high-risk individuals.

Evaluation programs are important components of CCC plans. Feedback from states that have data from their evaluation programs should be shared with other states, so that more governors and legislators can be educated about the savings in lives and financial burden that occur as a result of screening and early detection. This could result in increased line item funding for CCC initiatives.

Hawaii is just beginning to embark on a campaign for colorectal cancer screening. This is an employer-based health insurance state in which employers must provide health insurance for full-time employees. Colonoscopy as a screening tool, however, is not currently on the list for insurance benefits. Each time the issue has been brought before the state legislature, insurance organizations assert that there are not enough providers to provide the screening and that there are too many different guidelines to follow, and the bill is tabled. To address this, a national standard must be implemented; a further refinement of such a standard that clearly indicates those individuals that are at greater risk for developing colon cancer would allow areas with decreased capacity to provide screening for the highest priority individuals.

When the screening guidelines for colorectal cancer were recently reviewed, baseline quality criteria for acceptable tests for colorectal cancer screening were included. The current ACS guidelines were developed by many different expert groups and emphasize that prevention is the key; prevention means having a structural exam such as a colonoscopy. Cultural and ethnic practices and beliefs, however, can limit the modalities available to certain individuals; this is the reasoning behind the issuance of a broader set of guidelines, which provide practical alternatives that can still significantly reduce morbidity and mortality from colorectal cancer. From a policy standpoint, legislators may need to be educated about the distinction between prevention and early detection and the financial impact each can have. Primary care providers also should be included in the discussion.

Colorado experienced the same objections from insurance companies, so the Colorado Cancer Coalition took two approaches: (1) pushing public demand so that the public chose insurance companies that offered coverage for colonoscopies over those that did not, and (2) working directly with insurance companies to develop a comprehensive cancer screening package that included colorectal cancer screening and emphasized the prevention mode. The resulting increase in demand for colonoscopies has not surpassed capacity, and insurance companies now are proactively encouraging individuals to schedule a colonoscopy when they turn 50.

ACS has been working on colorectal insurance requirements for several years and has collected a great deal of information and messaging about responses to insurance company and policymaker statements. These helpful responses have been compiled as talking points and are available from the ACS National Government Relations Department and may be requested from ACS advocacy or government relations staff in each state.

Another issue that must be considered is the implementation of electronic medical records, and national guidelines regarding this implementation should be instituted. Anecdotal evidence indicates that some providers disable the screening alerts out of convenience. In February, C-Change sponsored the Cancer Information and Surveillance Summit II, at which the issue of electronic medical records and their connection to existing sources of surveillance and research was discussed at length; the proceedings will be available soon.

Colonoscopy is a special situation because of its cost and risk; the issue of transparency must be addressed. The cost of colonoscopies can vary greatly in the same geographic region, and these costs are not known until they are incurred. Efforts should focus on standardization and transparency of costs. Some countries require clinics to post their prices for procedures within the clinic.

Wrap Up of Day 1

Dr. Weinberg recognized Mr. Kean's efforts in moderating the day's discussions. As this is a policy summit, the participants and discussions should focus on policy. Many of the programs and projects mentioned during the discussions have underlying policies that can be evaluated and utilized, but policy requires deliberate thought and action. The National Partners are interested in specific actions that can be taken to affect policy change.

Although it was not mentioned during the discussions, the issue of illegal immigrants will need to be addressed at some point.

Borders and boundaries typically in place dissolved during the day's discussions, resulting in very effective dialogue. The group identified common opportunities and challenges that can be addressed by policy and programs that result from such policy. The message illuminated by the discussions is that, "We are in this together." The discussions also included geographic and Coalition-size diversity.

Dr. Weinberg thanked participants for their contributions and recessed the meeting for the day.

Welcome and Agenda for Day 2

Ms. Lori Belle-Isle, Director of Planning for ACS, welcomed participants to the second day of the Summit. This Summit has facilitated robust discussions that have occurred across disciplines and state lines. The amount of expertise at the Summit is impressive, and the discussions have illuminated for the National Partners what can be accomplished when a set of dedicated leaders stay the course; the Partners are impressed with the best practices that are being carried out. Ms. Belle-Isle thanked the participants for their work, passion, and commitment to reducing the burden of cancer in the United States.

Practice Panel Discussion 2: NCI, American Legacy Foundation (ALF), ICC

The second practice panel session focused on products and tools available from NCI, ALF, and ICC, including the PRIME (*Program Resources for Implementation, Management, and Evaluation*) Web-based tool, the Cancer Control PLANET (*Plan, Link, Act, Network with Evidence-based Tools*) Web portal, and the *Using What Works: Adapting Evidence-Based Programs to Fit Your Needs* trainer materials (NCI); a unique public education media campaign targeted to smokers called the “Be an Ex” cessation initiative (ALF); and EDICT (*Eliminating Disparities In Clinical Trials*) policy recommendations (ICC).

Funding for CCC Plan Implementation Discussion

Dr. Weiner started the discussion by presenting information about the Iowa Consortium for Comprehensive Cancer Control’s funding accomplishments. The Consortium was organized too late to be involved in directing tobacco settlement funds in the state. Instead, the Consortium advocated tobacco control and increasing the state’s tobacco tax; as a result, the state tobacco tax was increased by \$1. Increased funding for tobacco control was granted, and a \$500,000 line item dedicated to cancer control was added to the state budget. Part of Iowa’s tobacco control initiative is the Quitline, a toll-free, statewide smoking cessation telephone counseling hotline. The Iowa Department of Public Health decided to institute an RFP mechanism for use of Quitline funds for tobacco control. The RFP did not provide credit for collaborations within the statewide consortium or for keeping the funds within the state. Because of the increased funds available for the Quitline made available through the tobacco tax, groups from outside the state became interested. As a result, an external group competed and won the RFP, and much of the state funds from the state tobacco tax dedicated to tobacco control are being used outside of Iowa. Previously, the state cancer center managed the Quitline and collaborated with the Consortium. The Consortium’s efforts have resulted in very strong collaborations with ACS and other organizations. These collaborations have led to construction of a Hope Lodge in Iowa City, which will provide a home away from home for cancer patients and their caregivers. The Consortium is in the process of developing a 501(c)(3) provision and also is discussing fundraising with ACS and the Holden Comprehensive Cancer Center to identify a scientific director for the Consortium who can bridge the gap between research and implementation and also ensure rigorous evaluation. A lesson learned from the fundraising efforts is that it is possible to find ways to move forward by being creative and focusing on the mission.

Mr. Robert Villanueva, Program Director of the Maryland Comprehensive Cancer Control Plan, presented information about the Maryland Cancer Fund, which is an income tax checkoff that passed the state legislature in 2004. This came about as a result of a state legislator who wanted to provide funding for smaller community organizations; the original income tax checkoff proposal was widened from being breast cancer specific to a general income tax checkoff and then transformed into a nonlapsing, nonreturning fund. Taxpayers wishing to contribute can donate any amount, which is then subtracted from their refund or added to their tax payment. Writing the regulations was a significant part of this effort and took nearly 2 years. In early 2008, an RFP for secondary prevention and screening was released. The Maryland Cancer Fund includes prevention; primary, secondary, and tertiary cancer control; research; and treatment. The intent of the fund is to be a resource for smaller groups and organizations and not allow the academic and medical institutions to dominate use of funds. Funds are distributed via grants, and

a number of projects have been funded, including one-time \$10,000 treatment grants for individuals enrolled in projects funded by the Maryland Cancer Fund. Lessons learned include: (1) Good policy cannot happen by accident, but bad policy can. (2) Even if the policy is not passed, it can be impacted in the regulations process. (3) Money makes the opposition go away. More information can be found at <http://www.fha.state.md.us/cancer/cancerfund>. In response to a question, Mr. Villanueva explained that the income tax form indicates that taxpayers are donating to the “Maryland Cancer Fund.”

An informal survey of Summit participants indicated that approximately seven to eight states have a line item in the state budget dedicated to cancer control efforts.

A list of the amounts of money and mechanisms that states have gained through the Coalitions would be helpful for those Coalitions in their infancy. Dr. Phyllis Rochester, CDC, explained that her agency has a performance measure for the 65 CDC-funded programs that asks specifically about money, in-kind resources, and number of people involved. The aggregated data are available, but the ability of CDC to share data on specific states will need to be investigated. Dr. Rochester promised to investigate whether and how these data could be shared, possibly through a national partner mechanism. If individual state amounts cannot be shared, it would be helpful to include the sources of funding with the aggregate data. In Kentucky, many resources are leveraged, so it is difficult to determine exact numbers. The Kentucky Cancer Program is funded by the general assembly each year to provide regional outreach and education across the state. Much of what is accomplished is via seed money from organizations such as CDC. The idea of examining funding sources is helpful; employers and companies can be involved via the CEO Cancer Gold Standard and then encouraged to provide additional funding.

Delaware’s cancer control money is derived primarily from the state’s tobacco fund. The lieutenant governor chairs the Delaware Health Care Commission, which distributes funding for cancer control efforts. There is additional funding dedicated to cancer control within the budget of the Delaware Secretary of Health and Social Services. Initially, Delaware sought a grant for their proposed plan and was told that the plan was too ambitious. The state found alternative methods to fund the plan, has not applied for a grant since that time, and has accomplished everything that it set out to do. There are methods to accomplish cancer control goals without using grants.

Utah has line items in the state budget for cancer control efforts, but more creative methods of fundraising are needed to supplement this. As a result, special purpose license plates with the phrase “Cancer Awareness Saves Lives” have been proposed that will provide funding to the Utah Department of Public Health specifically for cancer awareness programs. The effort is expected to be successful during the current state legislative session. The license plate will serve as an ongoing fundraiser and also promote awareness.

Initially, the Colorado Cancer Coalition was substantially funded by CDC, but the Coalition recognized the need to be an independent organization and moved toward this goal. This independence has allowed the Coalition to compete for grants, which has in turn allowed infrastructure establishment and increased involvement in policy and advocacy development that was not possible previously.

There may be opportunities for collaboration related to marketing income tax checkoff initiatives; C-change, which performs excellent marketing, could be a resource. A new income tax checkoff initiative in Michigan, which will begin in 2009, will raise money specifically to screen more women for breast and cervical cancer in cases in which there is a limit on federal funds; some money is available for prostate cancer. The Michigan Cancer Consortium is interested in input regarding marketing strategies to highlight the new income tax checkoff.

Georgia has an income tax checkoff focused on breast, ovarian, and prostate cancer research that was initiated by an advocacy group. To market the income tax checkoff, information is sent to tax preparation businesses, survivorship groups, and Georgia citizens. The state also passed legislation for a license plate that raises funds to provide grants for women to receive screenings and treatment; \$21 of the \$25 cost of the license plate is given to the fund.

A parallel income tax checkoff to those being discussed is the Michigan Children's Trust Fund. As this income tax checkoff asks taxpayers to donate \$10 to the fund, the initial marketing campaign focused on what could be done with \$10. The daily cost of supporting a child in foster care is less than the cost of a medium pizza with two toppings; this comparison helped people grasp the concept. Communities are generous when it comes to cancer, but they need analogies—such as the pizza analogy—to “bring it home”; finding methods by which people can donate in honor or memory of someone is a great way to accomplish this. Utilizing the expertise of cancer advocacy groups and their leaders and finding business owners that are passionate about cancer control are other methods to tap into resources.

There are two major issues to consider in regard to marketing income tax checkoffs. First, asking ACS or other nonprofit cancer organizations for funding for marketing is difficult because income tax checkoffs can potentially reduce donations to these organizations, and therefore there is some competition. Second, large groups willing to fund marketing efforts cannot receive any funding from the income tax checkoff money and would have to sign acknowledgment of this with the state ethics board; this limits the organizations that can be utilized for fundraising. The Maryland Cancer Fund is trying to utilize as many free marketing opportunities as possible.

The CDC Behavioral Risk Factor Surveillance System (BRFSS), the largest health survey in the world, will include questions on survivorship in its 2009 survey. This will provide states with survivorship data at the county and, in some cases, the subcounty level. State BRFSS coordinators approved an optional module that will supply information about cancer type, palliation, and other issues. State CCC Coalitions should meet with their state BRFSS coordinators to encourage their state to adopt this module if this information will help address a need in the survivorship section of the state CCC plan. These modules will provide data about the burden of cancer that are meaningful to communities.

The Colorado cancer income tax checkoff was implemented recently for the 2007 tax year, and marketing efforts were at the grassroots level. Informational fliers were sent to e-mail lists and certified public accountants. The Colorado Cancer Coalition is investigating the possibility of using a firm for the 2008 tax year. A nonprofit organization in Colorado coordinates marketing for the 15 income tax checkoff organizations in Colorado. Colorado has implemented a breast cancer awareness license plate, but all proceeds go to the Colorado Department of Transportation.

The Texas state budget includes a line item of \$3.3 million to administer the Texas Cancer Council and primarily targets underserved minorities in rural populations. Money from the Texas license plate program funds patient services support in areas in which it is most needed. Proposition 15 will increase Texas cancer research, providing up to \$30 million year, but there is concern that there will be undesirable consequences in that the federal government will deny additional funding. It is estimated that 15 million Americans will be diagnosed with cancer within the next 10 years, and 6 million will die without aggressive prevention efforts. These estimates indicate that 1 in every 15 people will be from Texas, so every community, county, and region in Texas must be involved in cancer prevention efforts, and state legislators must continue to be involved in these efforts.

Kentucky has an income tax checkoff specific to breast cancer, and there is virtually no marketing other than to survivor groups. Kentucky also has implemented a license plate for breast cancer. It is challenging to raise funds for holistic cancer prevention and detection or lesser known cancers when there is a push to specify a specific cancer site. Addressing this issue in a comprehensive manner would be helpful. One value of state Coalitions is their ability to facilitate discussion between the various groups that focus on one cancer site.

There are many small foundations that are created in memory of loved ones; these foundations want to donate money, but they do not have staff or the ability to create a grants program. A broker to connect these foundations (i.e., the money) with state Coalitions (i.e., the ideas) would be helpful; perhaps C-Change could help in this capacity.

The Kansas Cancer Partnership has had limited experience seeking state funding for its plan. It would be helpful to know which state Coalitions were successful in obtaining state funding for their plans (including treatment, prevention, and screening funds) and which were successful in obtaining line item funding through state health departments for expanding cancer screenings and/or cessation programs. No state cancer plan is fully funded by its state.

As a result of the aggressive colorectal cancer screening efforts in the Arizona, the state was able to convince the Colon Cancer Alliance to select Arizona as one of three inaugural states for an “Undy 5000” 5,000 meter walk/run event in 2008; the understanding is that this will be annual event. The state negotiated with the organization to receive a share of event profits to use for colorectal cancer treatment. Obtaining funding for treatment versus screening is a significant accomplishment.

CDC is confident that it can continue to fund programs through the National Comprehensive Cancer Control Program (NCCCCP). In 1998, CDC funded pilot projects in five states (Colorado, North Carolina, Michigan, Texas, Massachusetts) and for one tribal organization (Northwest Portland Area Indian Health Board). Since this time, funding has increased, and the NCCCCP funds 65 projects, encompassing 50 states, the District of Columbia, seven tribes and tribal organizations, six U.S. Pacific Island jurisdictions, and Puerto Rico. The CDC’s Division of Cancer Prevention and Control, however, faced budget cuts for the first time this year, and tough decisions had to be made to ensure that all national programs (i.e., NCCCCP, NBCCEDP, and the National Program of Cancer Registries) were funded; as a result, CDC itself took the cuts. CDC is aware of the impact that its funding has on state programs and is doing everything that it can to sustain these programs. Just as there must be cancer advocates at the state and local levels, there

must be advocacy at the federal level; it is the responsibility of those that have the ability to advocate at this level to do so. In terms of a national agenda to increase funding for state CCC plans, it is important that the nongovernmental members of the National Partnership have this conversation.

It is easier to get body parts and diseases funded by legislators than it is to receive funding for holistic plans. If state Coalitions can get the specific body parts and diseases funded, then further work can be done to eventually receive funding for the general, holistic plans.

A recent national network news story proclaimed that the “War on Cancer” could be finished. The national perception is that the War on Cancer is about research, and the news story asserted that cancer research funding is declining and that cancer researchers are leaving the field because they are paid less than their counterparts in industry. Stakeholders need to educate the public and media on the true nature of the War on Cancer and redefine the term as necessary.

Johns Hopkins University reviewed Maryland’s CCC plan and determined that it would cost approximately \$7 billion to implement the plan as a whole. Proponents for the plan therefore focused on obtaining funding for smaller pieces of the plan. Legislators and decisionmakers must be told that cancer funding needs to be increased and why; it cannot be assumed that they will come to this conclusion on their own.

Although the subject of tobacco as a carcinogen and the tobacco industry’s objectionable practice of promoting this carcinogen has not been discussed at this Summit, these issues are at the forefront of many organizations.

Women should be remembered as a powerful resource for supporting local and state BCCEDP programs. A women business owner association in the Upper Peninsula of Michigan funds breast cancer screening in a large county in which breast cancer screening is underfunded and women residents do not have the means to obtain breast cancer screening.

There are many reasons that the American Indian/Alaska Native population does not participate in randomized, controlled trials, and it may be beneficial if the National Partners work with these communities via focus groups to better understand why they are not participating if they are asked. If they are not being asked, then this is an issue on which local Coalitions can work. Culturally and linguistically appropriate health care documents are excellent to help with these cultural communities.

How to be truly comprehensive is an issue, especially given that most funding received is for specific cancer sites. Unless stakeholders aggressively promote the issue of comprehensiveness, CCC goals may never be met. Perhaps the National Partners and state Coalitions can discuss what it truly means to be comprehensive and move forward from there. Some of this can be accomplished via creative efforts. As it is impossible to be all things to all people, however, being focused becomes critical. As the health care system changes, it is necessary to ensure that factors and resources that represent comprehensiveness are a part of the new health care system. It is the responsibility of state Coalitions and the National Partners to determine what these items are; C-Change is actively engaged in this effort. These items should be underlying attributes of the new system so that they are provided for without requiring additional fundraising efforts.

Practice Panel Discussion 3: NACDD, ACoS CoC, CDC, ACS

The third practice panel focused on initiatives and tools to use in CCC plan implementation efforts from NACDD, ACoS CoC, CDC, and ACS, including a collaborative CCC evaluation project (NACDD); the role of ACoS CoC in CCC (ACoS CoC); colorectal cancer control activities (CDC); and an access to care and CCC initiative (ACS).

Group Discussion: Assisting CCC Coalitions in Building Their Capacity to Affect Policy Change and Providing National-Level Support for Coalitions

Mr. Kean explained that the National Partners comprise an informal organization; the Partners work well together because they share a common vision about CCC, but each organization conducts business differently. Some of the suggestions put forth in this Summit will be taken up collectively by some or all of the National Partners, whereas others will be advanced by a single partner organization in terms of its own organizational approach (i.e., not as a National Partner). Mr. Kean reminded participants that some National Partners are not in a position to advocate.

The suggestions for action that have been discussed during the Summit can be divided into two themes: (1) The potential capacity building roles in which the National Partners can engage. (2) The potential roles for the National Partners in terms of national agendas and approaches.

Capacity Building Roles. The National Partners can:

- Provide examples and lessons learned regarding how to involve elected leaders and other public officials in CCC efforts.
- Quickly disseminate information and results from various CCC efforts including:
 - Evaluations.
 - Unintended consequences of policy initiatives and managing unusual/adverse circumstances.
 - Successful CCC plan implementation funding efforts including:
 - Solicitation of state funds.
 - Marketing income tax checkoff initiatives.
 - Private foundation philanthropy efforts.
 - Community-level implementation of CCC plans.
 - Implementation of general versus specific plans.
 - Advantages and disadvantages of transitioning from an informal coalition to a 501(c)(3) organization.
- Disseminate information about successful arguments in response to policy roadblocks.
- Inform Coalitions about individual National Partner efforts on policy.
- Collect and disseminate information related to practice patterns and gaps in practice patterns that could be addressed through Coalitions.

- Provide information on sources of learning (e.g., books) that focus on health care reform issues and discussions.
- Disseminate information about costs and outcomes associated with cancer treatment mechanisms that can be used to make the case for various policy initiatives (e.g., colorectal cancer screening as a cost saving investment).
- Help position colorectal cancer screening policy decisions.
- Continue to develop budgeting guidance and tools around CCC interventions, including the ability to project the cost and cost savings of interventions.
- Develop a list that details how much each state receives in federal, state, private, and other funding and for what purpose.
- Ensure that all terms being used in the cancer dialogue are understood to mean the same thing to all groups across the national landscape.
- Provide training to facilitate the development of Coalitions.

Roles Involving National Agendas and Approaches. The National Partners can:

- Address disparities in Native American access to care by:
 - Seeking the help and advice of tribes and tribal organizations.
 - Engaging IHS.
 - Examining the capacity and relationships of IHS.
 - Reviewing tribal compacts in terms of cancer control.
 - Examining federal legal barriers to access that have negative impacts.
 - Engaging the National Indian Health Board and Area Health Boards.
 - Promoting state and tribal opportunities to address access collaboratively.
- Advocate for stronger relationships between CCC Coalitions and NCI-designated cancer centers and other academic organizations.
- More broadly examine common workforce issues (e.g., primary care provider capacity).
- Create a national CCC plan or strategy.
- Address access policies that potentially violate federal laws.
- Address the value and rewards system as related to CCC engagement (e.g., cancer center involvement).
- Advocate for continued CDC support for state Coalitions and the CCC movement, with the understanding that not all National Partners can participate in this effort.
- Work with the national media to reframe the discussion about the War on Cancer.

- Determine a common approach for state Coalitions and National Partners to adopt (i.e., a strategy to speak with one voice) during the forthcoming national discussion on health care reform.
- Address potential and actual rifts between groups that have an advocacy focus and those that cannot advocate.
- Approach the Department of Defense about ceasing tobacco sales on military bases.
- Encourage a paradigm shift from “health care reform” to “health reform.”
- Address access-to-care policies so that every individual diagnosed with cancer must see an oncologist for some part of their evaluation and/or treatment recommendations.
- Address policy issues about health literacy.
- Encourage a shift in paradigm so that cancer treatment follows the infectious disease model instead of the chronic disease model.
- Urge scientific institutions to consider how critical the community voice is to cancer control and that ancillary community outcomes are also meaningful.
- Advocate for clearer guidelines about cancer center interactions with CCC Coalitions.
- Develop a national cancer policy agenda that includes prioritization.

Following this recap of previous discussions, Mr. Kean opened the floor for additional discussion.

Because citizens can purchase cigarettes and other tobacco items on military bases and avoid state tobacco taxes, it would be helpful for the National Partners to approach the Department of Defense about ceasing tobacco sales on military bases. The Veteran’s Health Administration has transitioned to a smoke-free environment in its facilities.

One component of the CDC colorectal cancer screening evaluation is to determine whether fecal occult blood testing is more cost effective than colonoscopy, but currently there are not enough data. Although policy can focus broadly on prevention or screening, it should not focus on specific tests that will eventually evolve and/or be replaced.

One manner in which state Coalitions and the National Partners can come together regarding health care reform is to change the term to health reform. Health care implies treatment only, whereas health reform can promote a healthy nation.

One tool that the National Partners could develop to help states pass policies is a list that details how much each state receives in federal, state, private, and other funding and for what purpose. Policy directors need this information easily accessible in one place because they often are asked this question. Stories and examples of best practices help, but such a list would create healthy competition that could drive increased funding. CDC provides a list of every state, territory, and

tribe funded by CDC for colorectal cancer screening, detailing federal, state, and other colorectal cancer screening funding as well as legislation that has been passed. This information is shared among CCC program directors. The information is publicly available because it is not sensitive; it is, however, fluid, and therefore needs to be presented in a manner that takes into account the constant changes. Additionally, a list of all CDC programmatic awards sorted by state is available on the CDC Web Site. This information is restricted to total award amounts and does not specify the specific pieces being funded.

A clinical issue that needs to be addressed in access to care policies is that every individual diagnosed with cancer must see an oncologist for some part of their evaluation and/or treatment recommendations; this currently is not happening. Policy issues about health literacy also need to be addressed. Approaches to treating cancer should transition from a chronic disease approach to the very different infectious disease model.

It would be beneficial for the National Partners to urge scientific institutions to consider how critical the community voice is to cancer control. Basing cancer education programs in community core values (e.g., Native American core values) will provide the motivation for the community to act; making this connection is critical. Funding agencies need to realize that ancillary community outcomes are also useful, important, and meaningful. For example, teachings must integrate Native American core values and concepts of health with Western health paradigms.

For a cancer center to become an NCI-designated comprehensive cancer center, the guidelines require interaction with the community but do not specifically state that the center needs to interact with local and/or state CCC Coalitions. To receive the designation, the cancer center must: (1) demonstrate excellence in basic, clinical, and population research; (2) show that these components work together; and (3) prove that the center has had a positive impact on cancer burden in the community. The manner in which the cancer center meets these criteria is its decision. It would be helpful for cancer centers to receive clearer guidelines about interactions with CCC Coalitions as well as the resources to pursue these interactions.

Coalitions and the National Partners should ensure that all terms being used in the cancer dialogue (e.g., alliance, coalition, consortium) are understood to mean the same thing to all groups across the national landscape.

Most cancer plans contain goals that span the entire cancer spectrum from primary prevention to early detection to treatment to quality of life to survivorship to end of life. Tools are available for most of these stages from the National Partners and other organizations. For example, CDC and LAF collaborated on a book describing survivorship issues, and the National Hospice and Palliative Care Organization has tools that deal with end-of-life issues. CDC provides funding for planning and implementation of CCC plans, and during the planning phase, the state health department or tribe is responsible for designing a CCC plan that covers the cancer control spectrum from prevention to survivorship. CDC is on the verge of launching a search engine that will search all CCC plans available at the Cancer Control PLANET Web Site so that states can learn what is being done in other areas.

Although it is not a policy issue, it would be helpful for the National Partners to provide training. The Nevada Cancer Council is in its infancy and has difficulty accessing some of the materials

that more organized Coalitions possess. The National Partners should examine standardization to facilitate the development of Coalitions. The National Partners recently discussed continuing technical assistance, training, and leadership institutes when considering the next 5-year strategic plan.

The term “policy” is broad in terms of the various policies that can be implemented at a number of levels. For example, at the hospital-level, one policy could be to institute a smoke-free hospital campus; at the state-level, an example is state health departments helping local communities establish policies that help with cancer control. It would be beneficial for the National Partners to develop a national cancer policy agenda that includes prioritization. National Partners and CCC Coalitions could work together to identify key policy areas to ensure support and information is available that benefits states and local communities. Although public health professionals are not trained to develop policy, events stemming from tobacco control have indicated that policy change is where the public health field needs to focus and improve its efforts.

After the strategic plan is complete, the National Partnerships have an obligation to the Coalitions to report back regarding in which of the suggested activities the Partners will engage.

Call to Action: Former West Virginia Governor Bob Wise

Governor Bob Wise explained that policies are in politics, and politics is what will get policies adopted. The governor shared several political maxims he has learned as president of a nonprofit organization.

1. *Whenever possible, have a governor like Governor Minner.* During Governor Wise’s tenure in West Virginia, the tobacco tax was raised in a state vehemently opposed to tobacco tax increases, the state insurance plan and Medicaid began to cover tobacco cessation, and the state insurance plan funded two clinical trials. These were significant accomplishments. Governor Minner, however, took on casinos and won. She made it easier for other governors and legislators to pass clean air acts and other tobacco control legislation.
2. *Ultimately, every important decision regarding cancer made by a patient, physician, or family member is going to be influenced by an elected official.* Examples include county health officials making budget decisions regarding prevention efforts, state legislature actions, and the President of the United States submitting budget allocations for CDC and NCI. Decisions ultimately are made by elected officials.
3. *If you can’t get the message to the folks in the little white houses, you’re not going to get it done.* Until the public is engaged, the importance of the message will not be communicated. Americans are demanding change, and this will affect the political landscape following the 2008 elections.
4. *No matter how hard everybody works, 10 PhDs, MDs, and MPHs are always trumped by one state legislator.* This is not meant to be discouraging. Important research and established practice must be translated into appropriate policy that is enacted in the political world. Research to practice to policy to politics is the key, but all four components

must be integrated pieces of the whole. To make this happen, researchers must communicate research in a manner that compels legislators to respond.

5. *Like it or not, almost every piece of major legislation is directly affected by anecdote.* Solid research must contain anecdote, and researchers must provide a human face to research—research combined with anecdote is an unbeatable combination. By accomplishing this, Coalitions are reaching out and giving people a voice. Bounceback is an important related concept—nothing happens in a state or national capitol that does not bounce back from events and occurrences in the legislative district.
6. *The power of one is important.* Each accomplishment is built one step at a time. Although tobacco companies have more money, cancer control has more “ones”—passionate and committed individuals that are doing what needs to be done. Tobacco companies can no longer claim that the research is unavailable or that the best practices are unknown; cancer control has the research and the best practices on its side. Tobacco companies now must rely on marketing and false arguments. Even in adverse times opportunities exist because committed individuals recognize that the work that they are doing has great power and can be further magnified. These individuals recognize the need to combine research, practice, policy, and politics to help those in need.

Governor Wise concluded his remarks by thanking the Coalitions and National Partners for the opportunity to speak; the committed individuals gathered at the Summit are the ones making a difference.

Produced by:



Collaborating to Conquer Cancer

1777 Eye Street, NW
9th Floor
Washington, DC 20006
202-756-1600

www.c-changetogether.org