Post Summit Report:

May 2009 Rural Health Summit
National Colorectal Cancer Roundtable
Rural Health Summit May 6 and 7th, 2009
Columbia, South Carolina

MEETING GOALS:

- Shed light on the unique challenges that shape our rural communities from health disparities to the geography of our states.
- Identify barriers and exchange solutions to strengthen existing and developing CRC screening & navigation & awareness programs.
- Identify policy needs and legislative initiatives related to CRC issues, particularly those that are unique to the rural setting.
- Ensure the continuity and quality of CRC screening and awareness initiatives for our rural communities

STATISTICS ON RURAL COMMUNTIES:

- Nearly one in five of the uninsured – 8.5 million people – live in rural areas.
- Rural residents pay on average for 40% of their health care costs out of their own pocket, compared with the urban share of one-third.
- One in five insured farmers had medical debt.
- Rural residents:
    - are more likely to report fair to poor health status than urban residents
    - are more likely to have experienced a limitation of activity caused by chronic conditions than urban residents
    - over age 50 are less likely ever to have had a colorectal cancer screening than were urban residents

WELCOMING REMARKS:

The Summit was chaired by Dr. Thomas Weber, chair of the National Colorectal Cancer Roundtable and Dr. Frank Berger, director of the Center for Colon Cancer Research at USC. Dr. Weber and Berger expressed a warm welcome to all participants and the importance of addressing unique challenge sin rural states to increased colon cancer screening.

DAY 1:

The first day involved a multi- state conversation tackling the unique regional issues and challenges for the underserved and uninsured in rural states. Each conversation was set up as a plenary session. The areas of discussion were:

- CRC awareness campaigns locally and nationally
- Existing state and community screening programs
- Importance of navigation
- Role of the physician community
- Overview of specific CRC screening programs in:
    - Kentucky
    - Colorado
    - North Carolina
- Role of the scientific and academic communities

Emergent issues and questions:

Common Issues in Rural Communities:

Rural communities in KY, CO, NC, and SC shared similar financial issues and patient barriers with regard to their CRC programs:

- Transportation challenges to local endoscopy sites, which could be 40 or more miles away.
- Lack of medical providers/facilities in rural communities.
- Low literacy rates.
- Poverty issues.
- Co-morbid medical conditions.
- Growing Hispanic population.
- Increasing numbers of migrant/seasonal workers.
- Lack of insurance, along with inadequate coverage.
- Loss of jobs/insurance due to economic downturns
- Need for a medical home or regular source of medical care
- Unexpected increases in co-pays when a polyp is found or removed during a screening colonoscopy, making it a diagnostic procedure.
- Needs of symptomatic individuals.

- Medical follow up for individuals in which cancer is detected.

Key Points Regarding Messaging in Rural Communities:

- A variety of well-managed messaging and awareness campaigns exist for CRC; however, they are not reaching communities as effectively as they could. Is a lack of cohesiveness an underlying reason for low impact?
- People still don't identify "blue" or the "blue star" with CRC.
- CRC screening programs and awareness efforts are greatly enhanced by keeping academic researchers involved and "in the loop".
  - They can write grants and proposals to obtain funding.
  - They can provide rigorous evaluation of community-led programs.

Key Points Regarding Disparities in Rural Communities

- CRC incidence and mortality rates are significantly higher for African Americans compared to European Americans in rural states, as well as in urban regions.
- In terms of addressing disparities, CO has a larger focus on their Hispanic/Latino community than KY, SC, and NC.
- Though CO and SC do have ongoing navigation programs, there is a clear need for medical and community-based outreach navigators, the funding for which is scarce. Challenges will be in developing a navigation infrastructure in clinics as well as in the community to help with recruitment. The "*If you build it they will come*" mantra does not hold.

Role of Policy Change in Rural Communities:

- Having a legislative agenda at the state level can have impact:
  - SC received one-time funding of $1 million to support four pilot screening projects, termed SCOPE SC. Several organizations joined in this effort, which is implemented through the state's Department of Health and Environmental Control. Also, the BlueCross BlueShield Foundation of SC has funded a program to provide CRC screening services in four rural counties. In January 2007, the state health insurance plan agreed to provide CRC screening to state employees.
  - CO's screening program is funded by revenues from Amendment 35 (Tobacco tax) via a grant award from CCPD program at CDPHE
  - KY passed HB 415, the COLON CANCER SCREENING ACT, but the legislation has not been funded. Currently, KY is developing a statewide program for implementation when the legislation is funded.
- It was emphasized that support from state and local groups to push policy changes at the national level is of utmost importance.

DAY 2:

MORNING SESSION:

The morning session was a plenary session with three CRC survivors: David Wright, Ros Squirewell, and Wanda Addy. All poignantly described their experiences with CRC, and how it impacted them and their families. They emphasized how early screening and detection could have changed the course of their lives. Each survivor had some instance in which the "system" broke down and their cancer was not detected as early as it could have been. David Wright also share the important role his wife played in ensuring that he was screened, encapsulated by a t-shirt he held that read, "Nagging saved my life." Each survivor also discussed the impact their diagnosis had on their family, and the importance each of them place on ensuring their family members, including children, are screened. This was followed by a presentation from Mr. Roderick Samuels, one of South Carolina's barbers in the Shop Talk Movement. Some of the key points Mr. Samuels made were the importance of taking the time to understand what's important to the businesses involved in the intervention (in this case, allowing the businesses to become certified as "cancer friendly," thus making them more marketable from participating in the intervention) and understanding that each field has its own culture and values (salons are in the business of selling beauty).

Key Discussion Points:

- Risk Stratification – Family History
- Role of stool testing programs vs. colonoscopy
- Comparison to State(s) with Insurance access, e.g. Massachusetts
- The need for more CRC stories from survivors and family members
- The need to involve survivors and families in awareness and screening efforts
- Quality Assurance including 30 DAY (all) complication documentation and follow-up

AFTERNOON SESSION:

The afternoon session was facilitated by Cliff Springs and Will Bryan with Genesis Creative. Genesis was contracted to develop messaging materials for a multi-state campaign promoting awareness of CRC and the importance of early detection. The end- product would be a CRC "toolkit". Genesis Creative is sponsored by the Center for Colon Cancer Research, the CRC Workgroup of the South Carolina Cancer Alliance, the American Cancer Society-South Atlantic Division, and the Colon Cancer Alliance.

Each year, South Carolina, North Carolina, Colorado and Kentucky has implemented various statewide colorectal awareness campaigns. In March 2010, CO, KY, SC, NC in partnership with C3, CCA, and NCCRT are making an effort and raise public awareness about CRC screening and prevention through a cohesive and broad-based fashion. The

group agreed to support a collaborative campaign allowing each state and it's extended networks to leverage 1.) a series of coordinated actions efficiently 2.) use of a single, potent, culturally sensitive messaging effort that resonates with target rural populations in all the participating states. Such a collaborative endeavor could increase the effectiveness, the impact, and the derived benefit of each state's campaign. To make the creative design of a campaign work in each state it was critical the tools developed by Genesis were: 1) flexible resources that can be adapted 2.) the look and feel of the materials as well s the text would resonate with the unique needs of the various communities.

Upon final approval, the participating states will receive a disc containing:

1. Campaign logo in a variety of the most common graphic file formats for both the full-color version and a one-color version as well as versions with the slogan included as part of the graphic.
2. A "brand identity" instruction document will be included to clarify proper usage of the logo imagery, slogan, and preferred fonts so as to maintain consistent branding across multiple states and media.
3. Template layouts for a flyer, a print ad, and a billboard in a variety of file formats that can be edited and customized for each individual state/organization.

The group agreed on two campaign designs, "factual" and "what's up your butt?" And key messages identified reaching the majority populations in each state. Representatives from each state agreed to test the identified materials (See attachment A) in their home communities. Once feedback from the communities were collected and provided to Genesis a final draft would be provided and disseminated.

Key Messages:

It's Beatable:
A. "9 out of 10 colon cancer cases are beatable if caught early."
B. "If colon cancer is caught early, it's beatable 9 out of 10 times."

It's Very Common:
A. "1 in 19 people will develop colon cancer."
B. "1 in every 19 people will get colon cancer."

You Can't See it Coming #1: No Family History
A. "8 out of 10 colon cancer cases have no family history."
B. "8 in 10 people with colon cancer did not have it in their family."

You Can't See it Coming #2: No Symptoms
A. "7 out of 10 colon cancer cases have no symptoms."
B. "7 in 10 people with colon cancer had no signs to warn them."

Call to Action:
"Get checked starting at age 50." (General)
"Get tested starting at age 50." (Hispanic)

Slogan/Logo:
A. "Get checked. Live."
B. "Get checked. Live on."

<u>What the Participants Thought About the Summit?</u>
Thirty-six attendees (<90% percent response rate) submitted evaluation forms at the close of the summit day 1. On day 2 and evaluation was not conducted. Attendees represented a variety of public and private employers, health related associations, government agencies, and educational institutions. Attendees were asked to use a five-point scale, from 1-Poor to 5-Excellent, to rate a number of statements. Attendees rated the following meeting effectiveness categories:

1. CLARITY OF GOALS FOR MEETING:
Rating: Between Good and Excellent (Score 4.5/5)
Comments:
- Too many presentations (2)
- Should have collapsed speakers
- Some redundancy in presentations (3)

2. GENERAL LEVEL OF PARTICIPATION IN THE MEETING:
Rating: Excellent (Score 5/5)

Comments:
- Presentation fatigue
- Needed more time for interaction
- Too many speakers
- Good interaction

3. LEADERSHIP DURING THE MEETING:
Rating: Excellent (Score = 3/5)
Comment:
Did not stay on time

4. QUALITY OF DECISION-MAKING:
Rating: Satisfactory (Score 4.5/5)
Comment:
- No real decision making took place

5. COHESIVENESS AMONG MEETING PARTICIPANTS:
Rating: Excellent (Score 4.5/5)
No comments

6. & 7. PROBLEM SOLVING/CONFLICT/ RESOLUTION
Rating: Score 2 = no conflict
Comments:
- Conflict avoided not discussed (2)
- No real antagonists present though they do exist
- Healthy resolution (FOBT vs colo)

8. ORGANIZATION OF MEETING:
Rating: Good Between Good and Excellent (Score = 4.4/5)

Comments:
- Duplication of information presented (3)
- Some speakers rambled
- Needed a break in the afternoon (2)

9. PRODUCTIVITY OF THE MEETING:
Rating: Between Good and Excellent (Score = 4.3/5)
Comments:

- Tom did a great job tying it all together
- Content good but mixed outcome (2)
- Great

***Evaluation Tool adapted from FD Butterfoss, 1995 (4.0).*