



# Kentucky Cancer Consortium Survivorship Committee Meeting Minutes *DRAFT*

**Tuesday, December 15<sup>th</sup>, 2010**

1:00 pm – 4:00 pm

Kentucky Broadcasters Association; Frankfort, KY

## **Next Meeting:**

- **Tuesday, March 15<sup>th</sup>, from 1:00pm-4:00pm- Frankfort Regional Medical Center, Frankfort, KY**

## **Decisions Made/Discussion Items:**

- **Welcome and Introductions**
  - Chris Stockmyer (MPH, RD), the Centers for Disease Control and Prevention (CDC)- Program Consultant for the Kentucky Cancer Consortium, was introduced as well as all attending committee members.
- **CDC Cancer Prevention and Control Priority: Public Health Needs of Cancer Survivors- Discussion led by Chris Stockmyer**
  - CDC Priority list was reviewed for cancer survivorship
    - “Address the Public Health Needs of Cancer Survivors”
  - Emphasis was placed on “Impact and Outcomes”
  - Definition of “Survivorship”
    - CDC is discussing what their definition of cancer survivorship is...their focus is public health. Currently, they define a ‘survivor’ as someone who has completed cancer treatment and is 5-years cancer-free from time of diagnosis.
  - National Cancer Action Plan
    - In 2004, the CDC had a 5 year agreement with the Lance Armstrong Foundation to develop a Plan for survivors.
    - In June 2010, the American Cancer Society was awarded the grant based on merit. The purpose of the National Cancer Action Plan is to identify gaps and help focus efforts in certain survivorship areas.
  - Agreement with the YMCA (Sr. Rita also contributed to the discussion)
    - This program allows for 8 weeks of personal training and exercise for cancer survivors. If they wish to join the YMCA after 8 weeks, they can do so at a reduced rate. The University of Louisville also has a “Living Well” program for cancer survivors as well as other chronic diseases.
  - CDC Survivorship Link: <http://www.cdc.gov/cancer/survivorship/>
- **Norton Cancer Institute’s Survivorship Program - Kay Heady**
  - The Louisville Oncology Group, a Norton physician group, realized years ago the need for a specialized ‘survivorship’ program. Dr. Williams was hired to start a survivorship program for patients no longer in active treatment.
  - Their survivorship program recognized a ‘survivor’ as anyone who is 18 years old and out of active treatment for two years.
  - It was noted that there is a gap in services for survivors of childhood cancer. Dr. Williams is writing a business plan to meet this need in conjunction with Dr. Bertolone in Louisville.

- To gather information, a focus group with childhood cancer survivors was held on Dec. 2, 2010 to gather formative information. Many significant issues were elicited as well as their ideas of a 'perfect' medical clinic:
  - Finding a PCP who wasn't scared to treat an adult survivor of childhood cancer
  - Financial risks- often regarding insurance and being in a 'high risk' pool
  - They want more emphasis on emotional needs
    - Behavioral staff dedicated to help with emotional needs
  - Social support was important
    - Focus group participants meet at Gilda's Club twice a month
    - They want an online chat room, Facebook Friends page, people who understand them, etc.
  - They suggested having a clinic at a mall- shopping makes them feel better and they want the clinic to be bright and cheerful. It was noted by some committee members that cancer survivors do not like going back to the same clinic where they had treatment due to seeing other sick patients, returning to the place where there is a negative connotation, etc.
  - Fertility issues were a concern.
- Norton is working on addressing some of the areas presented by cancer survivors as well as streamlining treatment summaries; Evaluating the structure of their survivorship clinic.
  
- **Cancer Survivorship and Health Reform, to have been led by Jennifer Redmond**
  - This topic will be tabled until the March meeting due to time constraints.
  - The American Cancer Society's handout, "The Affordable Care Act: How it Helps People with Cancer and Their Families", was provided.
  
- **What are the "Big Three" things you and our organization are currently working on?**
  - American Cancer Society, Sister Rita Jarrell
    - Lobby Day will be held on February 8, 2011 in Frankfort. The American Cancer Society's James Sharp will facilitate. This event will last all day beginning at 9:00am. The focus will be on a state-wide, comprehensive, smoke-free ordinance.
    - The American Cancer Society is going through a Transformation! There will be renewed emphasis on volunteers and ACS' working programs. There are also some changes coming to the Patient Service Center... There will be volunteer survivors in every treatment center. There already is one in Louisville and next, Paducah will have one!
    - Planning is beginning for the American Cancer Society's Relay for Life. Sister Rita is a "Hero for Hope" and will be talking about her journey as a cancer survivor. The Relay for Life event is an event celebrating survivors.
  - Kentucky Cancer Program-West, Carol Hurst
    - There will be a continuation of programs and activities. For newly diagnosed cancer survivors and families needing information, they provide Pathfinders and resource kits.
    - For Louisville survivors, there will continue to be quarterly retreats for breast cancer survivors as well as an annual Spring luncheon. The survivors lunch in May coincides with the Kentucky Derby and there is a fall survivors lunch as well.
    - An exciting project being planned again for the summer (August) is an informational booth at the Kentucky State Fair. KCP-West offered a brief survey to survivors to gather some information.
  - Friends for Life, Nicole Guffey Wiseman
    - In the spring, Friends for Life will hold a volunteer training for cancer survivors as well as their caregivers. Once the date is finalized, the event will be advertised.
    - There will be an increased focus effort on reaching the underserved population, specifically the Hispanic, African-American, and homeless populations.

- There will a continuation of the email marketing campaign.
- It was noted that the Friends for Life Facebook page has been dropped from the Facebook website (*update: 12/22 = it's back up!*) The address is... <http://www.facebook.com/FriendForLifeCancerSupportNetwork>
- Markey Cancer Center, Screening and Outreach Program, Carmen Combs:
  - Focus is on continuation of cancer screenings for oral, breast, prostate, and skin cancers
  - Survivorship Day will be April 13: Horses and Hope will be for breast cancer survivors
  - REACH (Racial and Ethnic Approaches to Community Health): focus is on cervical cancer screenings, HPV vaccinations, and minority health issues; There is a Cervical Cancer Coalition; Increased training for Community Health Outreach Workers (CHOWs)
  - University of Kentucky- Markey Cancer Center: A patient navigator, Melanie Wilson, has been approved and is funded by the American Cancer Society. She will handle all cancer types and will supplement the outreach social worker.
  - It was noted that focus groups at UK for Markey cancer survivors were not very diverse.
- Survivor, and Kentucky Public Health Association (KPHA): Garland VanZant
  - KPHA is working with the Legislature for funding of the Kentucky Colon Cancer Screening Program.
  - KPHA is also actively promoting the smoke-free resolution.
- Kentucky Women's Cancer Screening Program, Roanya Rice:
  - Planning is occurring regarding the KY Breast Cancer Coalition Training event which will be held in June. This is a collaborative event with the Breast Cancer Coalition (Vicki Blevins) and the Kentucky Cancer Program-East (Debra Armstrong).
  - They are working on their CDC grant continuation which is due in January.
  - They are also working on completing a "Promising Practices" story to CDC. This will include a snippet of information on Horses and Hope for recognition. This will tell of the field work with the Breast and Cervical Cancer Coalition including screening and recruitment activities. If chosen, CDC consultants will be available to provide technical assistance and help address issues in the future.
- Patient Advocate Foundation (PAF), Luke Barlowe:
  - The new cancer center opened in Bardstown, KY. It is located in the Catholic hospital and offers digital mammography services.
  - Also an American Cancer Society volunteer, Luke is a hospital liaison who visits newly diagnosed cancer patients in the hospital and has offered support and information to numerous patients.
  - Also a volunteer with the Lincoln Trail Aging Advisory Center, Luke has been visiting residents of nursing homes.
  - As a volunteer with the Patient Advocate Foundation, Luke will be speaking at Norton Hospital in Louisville on March 23 to provide information of how the PAF can help cancer survivors.
- Norton Cancer Institute Survivorship Program, Kay Heady:
  - Focus is on wellness activities and screenings. Ongoing efforts are focused on: mobile mammography, helping patients with high PSAs find a treating physician, connecting people for follow-up services, etc. There is greater emphasis in rolling all prevention activities into one "Wellness" arena. There is also increased attention on minority recruitment.
- Kentucky Department for Public Health, Susan Reffett:
  - Outreach and education is the goal #1. The focus is on all cancer, not just colon cancer, although a big effort is focused here.
  - Discussed collaboration with Norton Cancer Institute.
  - Susan attended the Dr. Harold Freeman patient navigation training.

- **Additional Resources were discussed and handouts provided by Katie Bathje**
  - CDC priorities, specifically “Priority 3: Address Public Health Needs of Cancer Survivors”
  - Healthy People 2020: Survivor objectives
  - One-pager with several links to online Cancer Patient Navigation resources
- **Cancer Action Plan Review -See Cancer Action Plan on the website: <http://www.kycancerc.org/cancer-action-plan.htm>**
  - Discussion regarding implementing a cancer survivor survey about the cancer resource centers throughout the state
  - Category: Hospice and Palliative Care
    - There was discussion as to why these services were placed under one category.
    - It was decided to keep the categories together for now as they are frequently lumped together due to funding. There are separate objectives for each- palliative care and hospice.
    - It was noted that data is readily available for Objectives 12.7 and 12.8- KCC staff will provide results.
  - Katie Bathje led a discussion regarding a \$3000-\$5000 funding opportunity and how it might be used to provide survivorship data. Cancer Action Plan goals and objectives were discussed. Committee members were encouraged to ‘think it over’ as to how it might be used in a way that is helpful, useful, and informative for all organizations on the committee.
    - It was noted that some stakeholders were not at the meeting and efforts will be made to engage committee members via the listserv.
    - It was noted that stakeholders comprise multi-regional organizations.

#### **Action Items and Other Business:**

- Survivorship Committee’s Partner Satisfaction Survey link will be sent out in February 2011. Results of the survey will be shared with the membership during the March meeting. The purpose of the survey is to evaluate the functioning of the committee and its processes as well as identify areas for improvement to further meet the needs of committee organizations.
- **To Do:**
  - **Chris Stockmeyer, CDC:** can find out more and let Katie know about OSU adapting LAF tx summaries to make them more youth friendly; Article on Survivorship survey; updates on cooperative agreement for National Cancer Action Plan
  - **Katie:**
    1. Ask Jeanie Phillips about LAF
    2. Add Lobby Day info to website
    3. Send out smoke-free resolution to committee
    4. Email Nicole about email marketing
    5. Put link of CDC survivorship on website and in minutes
    6. find out more about accountable care organizations
    7. Ask for feedback via email from committee members not at meeting regarding how to use the extra funding for data
    8. Consider reaching out to the KY Rural Health Association (says Luke- I think they are on other committees, could they have a Survivorship rep/)
    9. Send out the list of org who we need to contact to take the 12.5 survey: email template for survey, know more orgs?, small conference grant, panel of orgs, survey
  - **Carol:** provide brief report on surveys from the State Fair- template for next year?,
  - **Nicole:** new FB page name, date of spring training for volunteers and caregivers
  - **Kay:** update on Norton (will be done at next meeting so we may not need to include)
  - **Carmen:** Who was doing the focus groups at UK with Markey survivors & how were they obtaining their sample?

- **Jessica:** Data from Objective 12.7 and 12.8

**Meeting Attendees:**

Luke Barlowe  
Susan Reffett  
Carmen Combs  
Jessica Jones  
Jennifer Redmond  
Katie Bathje

Chris Stockmyer (Guest from CDC)  
Sr. Rita Jarrell  
Kay Heady  
Nicole Guffey Wiseman  
Roanya Rice  
Garland VanZant