

Kentucky Cancer Consortium Survivorship Committee Mtg.
September 22, 2009
Council on Postsecondary Education offices, Frankfort, KY

Save the Date! Next Meeting: Tuesday, January 12, 2010
1pm - 4pm
Gilda's Club, Louisville, KY
Directions: <http://gilda.metromoj.com/8/Contact>

Progress on Action Items from June 2009 meeting:

- Regarding: *What other orgs should be invited to the Committee table?*
 - Kentucky Council of Churches is interested in identifying a volunteer from their Board to attend future meetings. The Director, Dr. Marian McClure Taylor, is in touch with Katie.
 - Lance Armstrong Foundation has two active volunteers (based out of Louisville) who hope to attend the meeting in January.
 - American Association for Cancer Education has a business meeting in October, where Paula Brown, AACE representative, will share our interest in having state representation on the Committee. Specifically, we are targeting a rep who could speak to KY cancer resource centers.
 - The National Association of Hospital Hospitality Houses does not have a Kentucky chapter. There are 5 member organizations in KY however, and Hope Lodge (represented by Sheldon Koze on our Committee) is one of them. NAHHH holds a conference once a year.
 - FYI: The American Lung Association now runs all its Kentucky operations out of the Louisville office. The Lexington office is closed.
 - Susan G. Komen for the Cure/Louisville Affiliate: To our knowledge they have not yet appointed a new executive director.

- Regarding: *Online survey of Kentucky Cancer Survivorship Organizations*
 - The purpose of the survey is to provide a resource for staff (of organizations that work with cancer survivors) as to what kinds of education, services, and outreach their fellow organizations provide. Organizations who take the survey should have a multi-regional or statewide impact. We hope the information collected will enhance coordination and collaboration of survivorship efforts.
 - Suggested changes and revisions to the survey were made by KCC staff research assistant, Keisha Houston (Doctoral student in the UK College of Public Health).
 - Keisha created an Excel Data Workbook with the results from the online survey taken by 14 KCC Survivorship Committee organizations. The document can be updated on an ongoing basis, as new organizations take the survey, and as responding organizations change the services they offer. The survey results can be viewed on the KCC Survivorship Committee webpage at: <http://www.kycancerc.org/SurvivorshipCommittee.htm>
 - Katie shared briefly as to the online cancer survivorship resource directories that other state comprehensive cancer control coalitions have been a part of maintaining (specifically: Colorado, Iowa, Minnesota, South Carolina). These were for public use, and required considerable staff time and financial investment (averaging \$25,000).

- All agreed at the September meeting that the Committee continue to focus its efforts on providing a resource for cancer survivorship organizations staff use; not gathering information on all cancer survivorship resources available, for public use.
- Regarding: *Creation of Mission/Vision Statement for KCC Survivorship Committee*
 - Katie provided the mission/vision statement from the KCC Colon Cancer Prevention Committee for use in drafting the KCC Survivorship Committee's mission/vision.
 - Also provided were various definitions of 'cancer survivor' from ACS, CDC, LAF, NCI, NCCS. We knew that defining 'cancer survivor' would be critical to the development of a mission/vision statement.
 - All agreed to adopt the CDC/LAF definition of 'cancer survivor', as used in the 'National Action Plan for Cancer Survivorship'. "People who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends, and caregivers.
 - All agreed to adopt the following as our Mission/Vision statement: "To bring stakeholders together to collaborate, share resources, generate synergy, and further our specific missions to reach our common goal: To increase the proportion of cancer survivors who receive services that improve the quality of life from diagnosis onward."
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Action Items created at September 2009 meeting:

- *Re: What other orgs should be invited to the Committee table?*
 - Veterans Medical Center(s): Carol Hurst, via her connection with the Adult Oncology Nursing Society, will explore potential representation from VA.
 - American Association for Cancer Education, Kentucky Council of Churches, Lance Armstrong Foundation: Katie will follow-up with each contact in October.
 - Association of Oncology Social Work: Katie will get in touch with Tara Schapmire, Oncology Social Worker at Baptist Hospital East.
 - Susan G. Komen for the Cure/Louisville Affiliate: Carl will let us know when the Louisville Affiliate has appointed a new Director.
 - NOAAH (Navigating Obstacles in African American Health) and/or Kentucky African Americans Against Cancer: Katie will talk with KCP East and West to discuss which organization might best represent cancer survivorship efforts on the Committee.
 - Association of Pediatric Oncology Nurses: Katie is working with Amy Steinkuhl to identify a KY representative.
- Regarding: *Online survey of Kentucky Cancer Survivorship Organizations*
 - Two or three orgs in attendance confirmed their intention to fill out the survey soon.
 - It was recommended to recruit more organizations to fill out survey, to make it even more representative of organizations (with a multi-regional or statewide reach) that offer services to cancer survivors. Katie will email a list of organizations (suggested by the Committee) to ask to take the online survey. Committee members will respond as to their personal contacts within those organizations. Katie will provide text for an email that can then be sent from the Committee member to the personal contact, asking them to take the survey.

- If a Committee member has changes to the services offered by their organizations, they should contact Katie at kbathje@kycancerc.org who will make revisions to the master document.
- Regarding: *Creation of Mission/Vision Statement for KCC Survivorship Committee*
 - Katie will ask Suzanne Froelich, KCC webmaster, to add the mission/vision statement, definition of cancer survivor, and September meeting minutes to the KCC Survivorship Committee webpage.

Other discussion items:

- Luke believes there is a real need around the state for a centralized cancer support group directory. Carol shared that KCP's Pathfinders list support groups by Area Development Districts. Pathfinders can be found on KCP's website in PDF form, or in paper form in hospitals, doctors' offices, etc. It was suggested by some members of the Committee that Pathfinders may be more utilized online if they were able to be accessed by county rather than only by ADD, as some people are not aware of what ADD they live in; i.e. by clicking on your county, the corresponding Pathfinder ADD would pop-up.
- Sue shared that this week was final call for requests to add questions to the BRFS. The Committee agreed to re-visit the possibility of adding two cancer survivorship questions to the BRFS next year. The first would likely be: "Have you ever received a diagnosis of cancer?" Questions can cost \$3,000.
- Jennifer shared that Daniel's Care (Children's Hospice) has had to make financial cutbacks. If a child is receiving palliative care ONLY, they are not eligible for in-home visits and must come to the clinic. But they have expanded their available clinic times from two to three days a week. Questions can be directed to Donna Armstrong, (859) 276-5344, Ext. 510, or 1-800-756-6005.

Upcoming committee organization events:

- KCP announced several upcoming 'Horses and Hope' events, to include screenings as well as celebrations: 9/29 at Turfway Park; 10/29 at Keeneland; 11/15 at Churchill Downs. Get the details at <http://www.horsesandhope.org/>
- Indian Summer Camp, ECU and Madison County Breast Cancer Coalition are partnering to host cancer survivorship events for pediatric cancer survivors and their families the evenings of Nov. 13th and Nov. 20th, and during the day on Dec. 5th. Contact Amy Steinkuhl for more information: 859-219-0772, ext. 265.
- Luke will be speaking on Oct. 15th, from 6-8pm at Central Baptist Hospital in Lexington, about how to manage cancer care costs. Contact Victoria Meyer for more info: (859) 260-6413. Luke will also be speaking at events in Lincoln County, Paducah, and Somerset. Contact Luke at kynpaf@kymail.com
- Health Literacy Summit is going to be held in November 20th (Location TBA), with nationally known speakers to present. Hosted by UK, Humana, and other community partners. They would like to develop a health literacy coalition. For more information, contact Debbie Murray dmurray@email.uky.edu
- KCP West's 'Faces of Cancer' exhibit is still on tour. Contact Suzanne Gude for info: s0gude01@gwise.louisville.edu

- Survivor resource bags are available from KCP West, which includes resources for newly diagnosed cancer patients and their caregivers.
- Also, KCP West is hosting 2 weekend retreats for survivors, as well as an event at Buckhead's in Louisville to promote the Race for the Cure, and 'Pretty in Pink' parties throughout the western part of the state. Contact Carol Hurst for information: churst@louisville.edu
- There will be a press conference in the Capitol Rotunda for Colon Cancer Screening Awareness in October, most likely the week of October 12th, exact date TBA. Contact Bill Beam for more info: wfbeam@insightbb.com
- The Colon Cancer Prevention Project and Gilda's Club are collaborating to host a colon cancer networking group for colon cancer survivors and their families and caregivers. The group meets the 4th Thursday of every month at Gilda's Club at 6:30. Dinner is available for participants at 6pm. See CAPP's website for more info: <http://www.coloncancerpreventionproject.org/>

September 22, 2009 meeting attendees:

Organizations In Attendance	Representative
Colon Cancer Prevention Project	Bill Beam
Hospice of the Bluegrass	Jennifer Johnson
Kentucky Cancer Program UK / Indian Summer Camp	Amy Steinkuhl
Kentucky Cancer Program – U of L	Suzanne Gude
Kentucky Cancer Program – U of L	Carol Hurst
Kentucky Dept. for Public Health	Sue Thomas-Cox
Kentucky Dept. for Public Health	Susan Reffett
National Patient Advocate Foundation	Luke Barlowe
University of Kentucky HEEL	Debbie Murray

Notes from those unable to attend:

- American Cancer Society: Sister Rita Jarrell was participating in the ACS CAN Leadership Summit and Lobby Day in Washington, D.C. Find out what federal campaign issues are currently on the table for ACS CAN and how your partners might get involved at <http://action.acscan.org/site/PageServer?pagename=Campaigns>
- Friend for Life Network: Nicole Guffey was working with UK staff in anticipation of FFL Network receiving the 2009 Fifth Third Bank Innovative Nonprofit Award. Congratulations FFL! Read the press release [here](#). Consider attending the [7th Annual Kentucky Nonprofit Leadership Forum](#), the only statewide conference for Kentucky nonprofits, to be held on Thursday, October 15, 2009 at the Lexington Convention Center. FFL will receive their award during the Forum.

See you at our next meeting: January 12th!