

Kentucky Cancer Consortium Survivorship Committee Meeting Minutes

January 12, 2010

Gilda's Club Louisville, Louisville, KY

Save the Date! NEXT Meeting:

- Tuesday, September 14th, 2010; 1pm - 4pm
- American Cancer Society offices, next to the Hope Lodge. [Directions.](#)

Progress on Action Items from September 2009 meeting:

- Regarding: *What other orgs should be invited to the Committee table?*
 - Kentucky Council of Churches will now have a representative on the KCC Steering Committee. They will stay apprised of Survivorship Committee news through this new role.
 - We are still looking for representatives for: **Veterans** Medical Center(s); American Association for **Cancer Education** (local chapter); Association of **Oncology Social Work** (local chapter); Susan G. Komen for the Cure/Louisville Affiliate; Association of **Pediatric Oncology Nurses** (local chapter).
 - If you are aware of a potential representative, please let Katie know. kbathje@kycancerc.org
- Regarding: *Online survey of services offered by cancer survivorship organizations on the Committee*
 - To date, 16 organizations who work with Kentucky cancer survivors have filled out the survey on our Committee webpage outlining the services they offer. This is to be a resource to all Committee member organizations, to keep abreast of what other organizations do. If you have changes to the services offered by your organization, contact Katie who will make revisions to the master document available on the webpage <http://www.kycancerc.org/SurvivorshipCommittee.htm>
- Regarding: *Creation of Mission/Vision Statement for KCC Survivorship Committee*
 - The mission/vision statement, definition of cancer survivor, and September meeting minutes were added to the KCC Survivorship Committee webpage.

Discussion Items at January 2010 meeting:

"What are your organization's "Big 3" this winter/spring?"

- KDPH Colon Cancer Screening Program conducting two pilot projects (Pike and Fleming Counties). Thursday, January 14th, there will be a Cabinet Health and Welfare Committee meeting to vote on whether proposed funding of a statewide program should proceed to the Appropriations and Revenue Committee. Also working with Colon Cancer Prevention Project on building a Super-Colon exhibit for touring around Kentucky.
- UK College of Medicine, Dept. of Behavioral Science: Jamie continues to study behavioral aspects of cancer prevention and control. Tobacco focused grant from NIH regarding participation in clinical trials. Discussed evidence-based practices and the disconnect

between data/literature and translating it all into practice. NIH is investing in this translation.

- American Cancer Society: Lobby days in Frankfort (Louisville area volunteers to go on the 24th). Relay for Lifes to be held in each county. For first time, they will be combining all Louisville races into one - Cardinal Stadium May 21. Living Well Workshop - - currently training educators. All people with chronic illness, not just cancer. Strong in Louisville, slower in rest of the state. Pilot from Stanford. Contact Rita for more information.
ritajosephosu@juno.com
 - Health Reform legislation – biggest issues affecting cancer survivors: age of entering Medicare; and pre-existing conditions clauses. Hospice benefits would be 7% ↓ now in reform bill.
- Leukemia and Lymphoma Society covers all of Kentucky and 16 counties in Southern Indiana. Note they have a new mailing address. http://www.leukemia-lymphoma.org/all_page?item_id=5015 Working with Dr. Hayslip (University of Kentucky) in eastern Kentucky via a CDC grant, series of clinical trials on educating healthcare providers.
- Indian Summer Camp will be July 11-17^m with eligible campers being children age 6-18 who have cancer or are survivors of cancer. Applications on website.
<http://www.iscamp.org/home.html> Counselor applications (aged 21+) also available.
- Kentucky Cancer Program East - Horses & Hope events for breast cancer survivors at race track venues. Screenings and education and celebration. Fundraising too – 3 race days.
<http://www.horsesandhope.org> Celebration of Hope will be Monday after Derby.
- Markey Cancer Center – Carmen working on screenings and outreach. They piggy back on Horses & Hope events. Social worker onsite at Markey is Ethel Nikolakopoulos.
nikolakopoulos@uky.edu . Support group 1x a month. Also working with athletic dept. at UK on awareness activities.
- UK HEEL – their volunteer groups that sew/knit hats and blankets for cancer patients. Big project right now is health literacy. Humana/UK Healthcare are partnering on a Health Literacy Summit in Louisville Feb 26th. Goal is to develop a state coalition on health literacy.
<http://healthliteracyky.org/about-us.htm> HEEL also worked with Hospice on palliative care fact sheets.
- Gilda's Club Louisville - Sponsoring 'Rhythm on the River', a giant drum circle, April 11 on water front. Will invite other organizations who are resources for survivors. Encourage survivors to bring picnic spend the day, attend workshops. Feb-March – program for kids: Cancer 101 - - 6-12 years old who are affected by cancer – anyone welcome.
<http://www.gildasclublouisville.org/calendar/> Talking with ITT re: development of 'Gilda to Go', a virtual Gilda community, which would take the Gilda concept to underserved communities.
- Colon Cancer Prevention Project – partners with Gilda's Club to host a colon cancer support group the 4th Wednesday of every month. Marsha Risen facilitates. Guest speakers welcome. Getting the word out about group is biggest hurdle. 4th annual walk will be held in September. Survivors lead walk. They are adding a five-K run – moving it to Belvedere. Will

also be hosting the Catch a Killer show on KET in March.

<http://www.coloncancerpreventionproject.org/index.html>

- Friend for Life Network – will be hosting volunteer trainings in March and April. Cancer survivor forms are on website. <http://www.friend4life.org/index.php> Nicole is working on social networking and Twitter. Also partnering with a medical school project, where first year med students are spoken to by group of cancer survivors. Would like to expand this to nursing school as well.
- Patient Advocate Foundation. Has spoken at KCP events, re: what PAF does, etc. They now do intake for ACS and LAF. Last year 180,000 called PAF from Kentucky. Break away from cancer bike ride also coming up. <http://www.breakawayfromcancer.com/>
- Division of Women’s Health - Just hired B&C recruiter (to recruit rarely and never screened) - - Roanya Rice. She will attend Survivorship Committee mtgs in the future. Asking for more \$ to screen more people (CDC), some is put towards coalitions (59 of them) across the state. Web page/blog – Roanya will set up so coalitions can see what all is going on and utilize eachothers’ resources/ideas. Breast cancer trust fund. \$250,000 in up to \$20,000 grants. Anyone can apply <http://chfs.ky.gov/dph/info/wpmh/>
- Kentucky Cancer Program West - Breast cancer survivors retreat in February. Legal clinic for survivors also coming up. Spring – annual survivor event Thursday before Derby April 29th. 2 fly fishing events also taking place. Other events: Horses & Hope! Pink Day at Churchill Downs. http://www.kycancerprogram.org/kcp_west_homepage
- Briefly discussed results of SurveyMonkey survey “Priority Needs of Kentucky’s Cancer Survivors”, sent to Committee members in late December 2009.

Action Items for next meeting:

- Compile and prioritize results from survivors’ needs survey (Katie). Utilize results to plan next steps of Committee, firstly, the agenda for Fall meeting.

January 12, 2010 meeting attendees:

Organizations	Representative
American Cancer Society	Sister Rita Jarrell
Colon Cancer Prevention Project	Bill Beam
Friend for Life Cancer Support Network	Nicole Guffey
Gilda’s Club Louisville	Joe Ferry
Kentucky Cancer Program UK / Indian Summer Camp	Amy Steinkuhl
Kentucky Cancer Program – U of L	Carol Hurst
KY Dept. for Public Health – Div. of Women’s Health	Connie White
KY Dept. for Public Health – Comp Cancer/Colon Cancer Program	Susan Reffett
Leukemia/Lymphoma Society	Debbie Phillips
Markey Cancer Center	Carmen Combs
National Patient Advocate Foundation	Luke Barlowe
UK College of Medicine, Dept. of Behavioral Science	Jamie Studts
University of Kentucky HEEL	Debbie Murray