

## Kentucky Cancer Consortium Survivorship Committee Mtg.

June 23, 2009

ACS Offices, Louisville, KY

Organizations In Attendance	Representative
American Cancer Society – Reach to Recovery	Rita Jarrell
Colon Cancer Prevention Project	Bill Beam
Consultants in Blood Disorders and Cancers	Kim Arrington
Friend for Life Cancer Support Network	Nicole Guffey
Gilda's Club	Karen Morrison
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
Markey Cancer Center	Carmen Combs
National Patient Advocate Foundation	Luke Barlowe
Susan G. Komen for the Cure – Lexington Affiliate	Carl Gilford
University of Kentucky HEEL	Debbie Murray

### Notes:

#### What other orgs should be invited to the table?

- Discussed what organizations (with a statewide or multi-regional presence) still need to be invited to the Committee. *(Committee member in charge of contacting the org follows org name):*
  - Association of Oncology Social Work – Kentucky Chapter. Tara Schapmire was recommended as contact. *(Katie)*
  - Kentucky African Americans Against Cancer *(Katie)*
  - Hospital Hospitality Houses. There are several in KY, including Ronald McDonald Houses. *(Katie will inquire with national office as to a state representative.)*
  - Association of Oncology Nursing – Kentucky Chapter. *(Amy Steinkuhl will contact Stacey Peach)*
  - There was interest in including cancer resource centers found in hospitals and clinics. *(Katie is looking into potential Kentucky representatives from CPEN or AACE.)*
  - Lance Armstrong Foundation. Committee members only knew of a Louisville presence for this organization. LAF will be contacted to see if there is a rep for entire state. *(Luke)*
  - Kentucky Council of Churches *(Katie will contact new Director)*
  - Susan G. Komen for the Cure – Louisville Affiliate (Carl will notify Katie once a new director is appointed)
- Discussed importance of keeping membership on the Committee to those organizations that have a multi-regional or statewide presence. If we were to invite one hospital's cancer resource center, for example, we would have to extend an invitation to them all.
  - Local/Regional organizations should be directed to regional cancer control efforts.
  - Note: Friend for Life Support Network has nationwide reach.
  - Lung Cancer Alliance may begin a chapter in Louisville. Kim Arrington will keep us updated.

### **Online survey of committee organizations**

- Initial results of the organization survey were discussed. 14 respondent orgs. Two or three orgs in attendance confirmed their intention to fill it out soon.
  - Suggested changes/revisions to the survey will be made by KCC staff in the next week.
  - It was recommended to recruit more organizations to fill out survey, to make it even more comprehensive.
  - Katie will find out how to change or update information already submitted by orgs, as some in attendance needed to change certain information.
  - And a reminder about the initial survey results handed out – these formats (bar graphs and percentages) will be best used as we look to identify gaps in services, i.e. ‘get a lay of the land.’
  - It was agreed that committee members would like to see the results in a grid format, with orgs listed down the lefthand side; services offered across the top, with an ‘X’ for each service they offered. This would allow orgs an at-a-glance table of who they could easily partner with.
- Agreed to create a Vision/Mission Statement for Committee. (Bill and Katie)
  - This may include agreeable definitions of cancer survivorship and patient navigation

### **Potential for online KY Cancer Resources Directory?**

- Long discussion of the potential venues for compiling cancer resources for the public. Is there a need for a one-stop-shop for Kentuckians to access cancer resources?
  - Many committee orgs have such compilations in different iterations (handouts, online, etc.)
  - Questions asked: could these existing resources be compiled in one place in a user-friendly format? How could it be done? From a survivor’s perspective, what is already ‘out there’ in KY as far as cancer resource directories?
  - Amy mentioned ‘3-click’ health marketing theory – no information should be more than 3-clicks away if it is to be best utilized.
  - Luke met with Anthony Coggiola, of the South Carolina Cancer Alliance, who spearheaded the creation of software and information collection for an online cancer resource directory. Anthony was willing to make all this information available at no cost.
    - For our next meeting, Katie will compile the process SC into a 2-page summary for distribution to the Committee, and also include links to Minnesota and South Carolina webpages. Katie will also compile a list of existing Kentucky cancer resource webpages.
  - Committee agreed to focus on current organization survey, and postpone discussion of cancer resource directory until future meetings.

### **Upcoming committee organization events:**

- Kentucky Cancer Program West (and partners) Hope Soars – Celebrating Life, Cancer survivor celebration, June 28<sup>th</sup> 2-4 p.m., My Old Kentucky Home State Park, Great Hall, Bardstown. Cancer

patients, survivors, families, friends and health care professionals will gather to demonstrate that vibrant life after a cancer diagnosis can be reality. Special photo exhibit.

- ACS Lexington Relay for Life – June 26<sup>th</sup>

- Mayors Parade – July 4<sup>th</sup> – Komen Lexington

- Indian Summer Camp – July 11-18<sup>th</sup>. 90 kids expected at Cedarmore Camp and Conference Center this year.

- Colon Cancer Prevention Project – Walk Away from XColon Cancer at E.P. Tom Sawyer Park. August 29<sup>th</sup>.

- Colon Cancer Prevention Project - SuperColon at the Louisville Bats game. August.

- Colon Cancer Prevention Project is partnering with Gilda's Club to start a colon cancer support group in August.

- Race for the Cure – Komen Lexington – Sept. 26<sup>th</sup>

- ACS Making Strides, Louisville – Waterfront Park, Oct. 25<sup>th</sup>

- ACS Making Strides, Kentucky Horse Park, Oct. 25<sup>th</sup>

- Horses and Hope - KCP and Office of the First Lady – Oct. 29th

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