

KCC Survivorship Meeting November 16, 2022



Action Items:

- Incorporate participants' ideas into new KY CAP
- Follow up on recommended organizations not already engaged

Upcoming KCC Meetings

- **KCC Meeting** December 8, 2022 | 12:00 pm – 2:00 pm EST | [Register here](#)
- **Wellness Through Cancer Digital Storytelling** – December 15, 2022 | 9:00 am – 11:00 am EST

Meeting Notes

- **Welcome – tell us why you are here**
 - Partners attended meeting for connection, support, updates on what is going on around the state to help survivors, resources, solutions, advocacy, looking for ways to expand survivorship in my region
- **KCC Cancer Survivorship Series [Link](#)**

Ways to use KCC Cancer Survivorship Series

 - Training for my staff, volunteers
 - Start discussion with staff about survivorship needs and programming.
 - Developing programs
 - Give this info to new patients, because at first, we are like a deer in the headlights!
- **Comprehensive Connected Cancer Care (C4)**
 - Contact Pam Hull, UK Community Impact Office pam.hull@uky.edu
- **Digital stories – Possible Next Steps**
 - Integrate the stories into educational materials used in training physicians, patient navigators, oncology social workers, and other public health providers – possibly even in educating administrators or other policy makers on the needs of cancer survivors. This can help providers to better understand what to say and what not to say – and better understand the issues at play. They could also be part of a broader public health campaign to make a case for increasing access to therapy and other types of needed supports.
 - Integrate the stories into educational programming, communications, and conversations with cancer survivors and their families (through Extension programming or possibly KCP programming or through non-traditional outlets such as at the point of diagnosis/treatment when survivors are already receiving treatment and have time to read/watch relevant material or talk with a nurse/occupational therapist; other important non-traditional places where we volunteer, such as church).
 - Use the digital stories to help recruit and expand the network of peer supports and have them at community health clinics and cancer centers ready to talk

- Build out a public website that explains the project and outlines best practices for how to share and use these digital videos in a respectful and appropriate way. As I mentioned, a really good model for how to do that with minimal work is this instructional handbook which was developed to accompany the videos that feature breast cancer survivors. Note that this handbook includes discussion questions around each video as well as careful advice on how to create space to support people as they watch and respond to such powerful stories.
- See Story Center <https://www.storycenter.org/public-health-human-services>
- **Kentucky Cancer Action Plan – Survivorship Section Discussion**
 - Include diagnosis, treatment, late effects and long-term management, end of life
 - Quality of Life – define further, too much jargon. QOL is a medical term that many patients may not understand. Define terms when needed.
 - Need community coalitions and networks to identify and coordinate quality of life services.
 - Resource for disseminating information to navigators should be thorough and promoted consistently.
 - Support Groups - Have support meetings in libraries or other public place that feels more neutral than a clinical care setting
 - Genetic testing – include in diagnosis phase
 - Biomarkers – does it belong in diagnosis or prevention/risk reduction? Or both?
 - Develop strategies around QoL services such as financial, mental health, physical, etc.
 - Palliative Care – training/education for volunteers, include across all phases of survivorship as needed, not just end of life
 - Clinical trials – promote clinical trials more generally – not just for people in treatment and need to promote outside of healthcare settings in more generalized public places. Not just for cancer but things like screening, tobacco, nutrition, resources, etc.
 - Partners Mentioned
 - Volunteers – retired nurses or retired physicians
 - Community Health Workers – need more in the state and need them outside of the clinical/health system side, as well.
 - Local Health Departments
 - Commission on Cancer

Other Resources /Links shared in chat:

- **KY Cancer Needs Assessment** <https://www.kycancerc.org/2022/02/>
- **National Comprehensive Cancer Network (NCCN)** <https://www.nccn.org/>
- **Cancer Survivor Provider Network** <https://thecspn.org/about/>
- **Friend for Life** - Facing cancer, with someone who's been there www.friend4life.org
- **American Cancer Society Survivorship: During and After Treatment** <https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html>
- **GO2 For Lung Cancer** <https://go2.org/>
patient support services, online and through help line. buddy program, online community
- **Lung Cancer Support Community - Stages** | Facebook Scott Kindred (Stages):

Attendees:

Name	Organization
Julie Waters	American Cancer Society
Ruth Hoffman	American Childhood Cancer Organization
Tami Cappelletti	American Lung Association
Jennifer Hutchinson	Baptist Health
Crystal Labbato	Baptist Health
Eugenia Smither	Bluegrass Care Navigators
Lori Beth Miller	Friend for Life
Judy Kasey-Houlette	Friend for Life
Robin Mohon	GO2 Foundation
Rudy Bess	Hope Light
Amanda Beckett	KCC
Elaine Russell	KCC
Jennifer Knight	KCC
Kristian Wagner	KCC
Rita Jarrell	KCP
Tonya Pauley	KCP East
Amy Oliver-Steinkuhl	KCP East
Khadijah Wallace	KCP East
Mindy Rogers	KCP East
Mary Schneider	KCP East
Wynona Padgett	KCP East Lake Cumberland RCCS
Jeff Russell	KCP East Cumberland Valley
Melissa Karrer	KY Cancer Link
Melanie Hunter	KY CancerLink
Nancy Alvey	KY LEADS, Cancer Survivor
Lindsey Fannin	Lifepoint Health
Lisa Stump	Lifepoint Health
Maggie Motley	Norton Healthcare
Nicole Leach	Owensboro Health
Priscilla Schwartz	Passport Health Plan
Michele Heuglin	Passport Health Plan
Jessica Oldham	St. Claire Hospital
Brenda Burns	St. Elizabeth Cancer Center
Michael Gieske	St. Elizabeth Cancer Center
Shayna Hamilton	St. Elizabeth Cancer Center
Scott Kindred	Stages Community, Cancer Survivor
Meghan Kissell	Tobacco Free Kids

John Villano	UK
Natalie Riney	UK CIO
Pamela Hull	UK CIO
Christine Stroebel	UK CIO
Todd Burus	UK CIO
Jane Morgan	UK CIO
John Kim	UK MCCAN
Melissa Darsey	UK MCCAN
Deborah Carey	UK MCCAN
Kristal Vaughan	UK MCCAN
Ming-Yuan Chih	UK MCCRN