

PROJECT: KCP

GROUP/TOPIC TITLE: Full Membership Meeting

ATTENDING: In-Person with virtual option

DATE: 4.5.2023

TOPIC	DISCUSSION/NOTES			
Welcome and introductions	Details on Continuing Education for today provided by KDHE staff.			
Jennifer Bacani	Introduction from Jennifer (Jen) Bacani McKenney, KCP Chair.			
McKenney, MD, Chair	Shared story about growing up as child of doctor practicing in Fredonia, Kansas. Recalled "things showing up" from patients including a			
 Daniel Craig, MS, TTS, 	goat, "Peaches". Sometimes as payment for services. The work we do in Cancer Prevention is collaborative. Thanks for all you do!			
Vice-Chair	Jen introduced Daniel Craig, Vice-Chair. Daniel growing weary of following the Chair who is great storyteller			
	optimistic/excited about today's agenda/presentations that includes good, practical information. Challenge for the day: What is 1 thing you can take back and use in practice in the next 30 days.			
	Daniel noted the importance of clinical trials in Kansas and recognized Masonic Cancer Alliance that allows for fantastic clinical trials in			
	the state.			
	Daniel introduced Hope and Laurie.			
Why Care About Clinical	Hope Krebill presentation on PIVOT - The University of Kansas Cancer Center's Patient & Investigator Voices Organizing Together			
Trials?	Patients, families, caregivers and researcher accelerating innovative approaches to re-define cancer research together!			
 Hope Krebill, MSW, 	Identify a survivor or co-survivor and encourage them to join pivot.			
BSN, RN - Masonic	Only rural NCORP			
Cancer Alliance, KU	Cancer research doesn't just happen in the cancer center – it happens through all providers and practices			
Cancer Center	How many people participate in cancer clinical trials? 6% participate in treatment in clinical trials.			
	Why do so few participate in clinical trials? No trial is available at their center. Or a trial available for the current treatment			
Laurie Mitchell, Patient	Clinical trials save lives by leading to new and improved treatments			
Research Partner - The University of Kansas Cancer Center's Patient & Investigator Voices Organizing Together	Clinical trials are not only end of life. There are prevention trials, early detection trials, quality of life, etc.			
	Are clinical trials safe? Multiple phases. People of different backgrounds.			
	The old paradigm would take up to 10 years in clinical trials. That's too long.			
	New paradigm Phase 1/II combined. Some new trials are now taking 3.7-5.4 years.			
	Clinical trial myths – It's not a last resort.			
	What Can KCP Do? – talk to payor related to preauthorization,			
	What Can you Do? – learn more online, talk to your friends, family, co-workers, volunteer to drive a friend to clinical trials			

• Video about clinical trial was shown to group. Faces were not shown during video – just voices. Patient voices are incredibly important. Their voices are heard.

Lauri Mitchell – Personal story about experience with clinical trail

- Lauri and her husband went through clinical cancer trial. (prostate cancer)
- Husband treated each cancer appointment like a business appointment
- Husband diagnosed in 2011 (lived on east coast). Did lots of research and reading on treatment. He wanted to know what he was getting int
- Determined treatment plan and did radiation and chemo
- Moved to back to KC and was offered a phase 3 clinical trial. Learned there is a whole lot of people involved, paperwork, and scheduling of appointments.
- Doctor left during mid treatment. So they got a second opinion from another doctor.
- Found a new doctor that was a distance away and changed treatment plan with a new clinical trial in phase 1.
- Communication is key between provider, patient and clinics.
- Living in the grey area is hard. Clinical trials have lots of grey area.
- They were not afraid of the trial process.
- You are helping those in the future if not for me now but for others.

Q&A

• Why haven't we standardized care for patients in clinical trials? They stop going to primary care and work with oncologists. They start managing the patient fully. But the challenge is with that not all doctors speak together (i.e. oncologist, primary care, heart doc, emergency room, etc.). You are counting on them to connect.

Partners in Providing Care: Panel Discussion of Resources Available

- Katy Horst Angel Flight
- Allison Probert Wichita Cancer Foundation
- Debbie Cruz and Lianna
 Fry Livestrong Program

Wichita Cancer Foundation (Allison Probert)

- Provide financial assistance to KS cancer patients Ensure patients receive care needed while minimizing financial stress
- Cancer diagnosis has detrimental effect on patient's finances No one should have to choose between caring for themselves or providing for their family
- Process for those looking for help: Connect with foundation visit website (wichitacancerfoundtation.org) to see if qualify (criteria on website); apply online and send in insurance information; application reviewed and decision provided to patient; if approved, medical premiums paid for 6 months
- 2022 stats:
 - 84 Kansans assisted (in 29 counties)
 - \$252,562 in assistance provided
 - Funding care. Funding hope. (100% of recipients stated that due to assistance, experienced decrease in financial and emotional stress)
- Quote from Alex Teeters (former recipient) shared on slide

 WCF relies heavily on community partnerships – contact Allison (<u>allison@wichitacancerfoundation.org</u>) for more information or to discuss partnership opportunity

LiveStrong at the YMCA program - Lianna Fry

- KC and Wichita YMCA programs still going on (Dodge City YMCA has been on hold since COVID started)
- Project demonstrates the impact of exercise on cancer survivorship
- Certified PT's given specialized training to helping cancer survivors
- Free 12 week exercise program for any cancer survivor
- LiveStrong Foundation defines survivor as from the point of diagnosis
- Program meets twice/week for 12 weeks to provide exercise, fitness assessments Have seen improvements in strength and balance, decreased obesity and metabolic conditions that are common for after cancer diagnosis
- In addition to the exercise, there is a component called community time not just exercise, but support as well (in a community of other survivors) this is the heart of the program
- Well-being assessment done at end of 12 weeks in addition to the fitness assessment strong outcomes reported from program
- Limited to 1 time participation for survivors; but there is an allowance for repeat participation if there is another diagnosis
- Also have other opportunities for alumni or other survivors in the community; Wichita has Cancer Survivor Retreat coming up for example
- Funding comes from different avenues depending on community doing the program
- Digital documents have been provided that will be shared with participants

Angel Flight – Natalie

- Free flights since 1995; covers 10 North Central states
- Flights provided from volunteer pilots who use their own small planes and pay for fuel on their own
- Examples of types of flights provided:
 - o Fly people to clinical trials, for 2nd opinions, other treatments they can't receive at home
 - Humanitarian and compassion flights sometimes as well (ex: flying a puppy to training as a support dog)
 - Transport breast milk to serve babies in NICU's
 - o Transport kids to specialized summer camps kids affected by cancer, burns, HIV/AIDS, etc
 - A few domestic violence situations after research to make sure not putting volunteer pilots at risk
 - Really, anything that involves a plane and a pilot to help provide health services
- 330 volunteer pilots currently
- Angel Flights Central is "one of the best kept secrets in the Midwest" want to increase partnerships to get word out
- Referrals can come from anyone (friends, family, healthcare providers, social workers, etc) call or put in referral on website/through
 email
- To determine if they can help, some of the components to look at include:
 - o Is the person comfortable flying on small plane, mobile enough to get in and out of this plane?

- Timeframe no emergency flights taken and resources aren't available if there is something with a short timeframe (like transplant patient that needs to get somewhere within a few hours with no notice). Typically need 5-7 days to get something set up, but prefer to have a 10 day window when sharing with sister agency (Angel Flight South Central)
- Weight is a factor (usually about 500# weight limit), so sometimes companionship is limited try to accommodate both caregivers when a child, but usually only 1 other person can come with patient.
- Limit on luggage that can come along due to space and weight constraints
- O Distance typically 300 nautical miles per leg, so limit is usually about 900 nautical miles. Do have a grant that can help out if someone needs to go further
- Angel Flight staff:
 - Katy and Jenna outreach
 - Natalie Flight coordinator

Q&A:

- For Wichita Cancer Foundation: Do you have brochures that can be handed out?
 - Like to send over virtual versions that an organization can print out on their own. Email or call, also a place on website to request communication. allison@wichitacancerfoundation.org; 316-928-2273; wichitacancerfoundation.org.
- For LiveStrong Program: What does 12 week program look like?
 - Conducted in a group setting with trainers who are equipped to provide variety that meets everyone's needs. Class size is limited to a max of 8 participants (to be able to better adjust and provide modifications). 1 hour exercise and 30 minutes Community Time. Don't need to be coordinated or athletic to participate not uncommon that someone will start the program with a walker or cane.
- Shout out was given to Angel Flight Central from one of the participants.
- For all panelists: With end of PHE, people may be falling off of Medicaid. Is anyone doing anything to proactively reach out and encourage people to reenroll?
 - Wichita Cancer Foundation A lot of communication is done with social workers in cancer centers. The social workers are the ones that help with that, but the foundation does maintain communication to help coordinate care.
 - Opened to others in the room Stat provided from Jared (section director in BHP at KDHE): About 150,000 people will be dropping off in Kansas. Early detection works program a lot of their demographic population will fit within this challenge, so will be putting the information out to their clients.
 - o Additional information: May 10th is when the Public Health Emergency is supposed to end. Not everyone will lose benefits at once (will come in "waves")
 - Medicaid is doing a lot to reach out and make sure patients know presumptive eligibility will be ending soon let them know they'll need to reapply and requalify. Kansas is doing a good job of reaching out, but there is a concern for people that have moved and/or kids in the foster care system vulnerable people that we should be worried about.
 - o Is there an opportunity as a coalition to reach out and make sure people are aware. A video will be shared with meeting participants that can be pushed out on social media.
 - Toolkit on KanCare Advocates website
 - https://www.communitycareks.org/medicaid-renewals-social-media-toolkit/

	Advocacy organizations working to get work out – challenge to advocates and providers in the room to let legislators
	know how this unwinding is affecting patients as more and more people fall off; legislature needs to be kept aware!
Workgroup Meetings	Early Detection
(Group chairs will report out for each group. Gather key ideas.)	 Just finished going through the cancer plan and what our objectives were. Lots of new faces HPV Vaccine and early detection was identified Working with Greek life and university health centers to provide presentations on HPV Vaccine – One presentation has been provided to Emporia State
	 Working on getting into nursing schools to talk about EDW. Need to get Kansas Cancer Alliance to present at the nursing board At GPHC conference – provided materials to universities about EDW.
	 Need to educate our nurses on more than just direct care. Need to pivot the mindset to think more than just direct care. Need to provide more education on all the resources that are available. But where do we start. Correctol Cancer
	 What's May going to look like with Medicaid ending? Hope people are renewed Connect patients with Wichita Cancer Foundation
	 Need to update resources and keep updating resources. But how and how to get the word out. Unite Us – social referral program
	 Group learned about new resources today – how can they get the word out to other nurses and medical professionals Double entry on EHR and catatlyst – complaint from providers. Technology is there. But need to get it set up and working. Coding is an issue
	• Lots of side bar conversations © All trying to figure out to make all the technology to talk to each other. Will there is a way.
	Need to put the right parties together to move this idea forward
_	Health Equity Steven Black (Olathe Health Cancer Center) leading workgroup
	Minutes from last meeting reviewed • Workgroup will select specific strategies from the Kansas Cancer Prevention and Control Plan
	 Determine how the group will know progress is being made. Kansas Cancer Survivorship ECHO program working with Community Health Workers to send information.
	Additional discussion: Next meeting will be Monday, May 1 from 1-2 – based on survey to participants – meeting invite will be sent out to get it on calendars.

- Telemedicine what's going to happen to Medicaid and insurance post-pandemic? Will telemedicine go away? Work with ACS CAN to promote policies. Dr. Holzbeierline Lobbying with Insurance Commissioner (representing KU Cancer Center) with state of KS to talk about how important telemedicine is for care especially those that have to travel for access to care.
- Medicaid expansion
- Plan to invite Cristina Cowert to join workgroup
- Megha is leaving the Cancer Equity Workforce, so can't be part of this workgroup
- Kansas Broadband Roadshow Dept of Commerce April 11 (Kansas City) and 13 (Olathe and Paola) listening tour shape state digital equity plan; digital connectivity plays a role in thriving and growing communities
- Digital privacy need to work on in terms of health equity; when we tell people there's an app for something, making sure they know there isn't a free app need a digital bill of rights to make people aware of who is getting their information and that their diagnoses could be commoditized (hidden in terms and conditions, but often not explicitly explained); relates back to the digital connectivity issues (i.e., for someone without internet access at home, they're told to go to the library, but should they be having a health appointment in a public place?)
- Cancer Transitions (Cancer Support Community) 4 weeks targeting counties outside of Kansas City healthy lifestyles, exercise, journaling patients coming to the end of active treatment

Action plan:

- Steven F/U with Survivorship group and find out what's happening with CHWs prior to meeting on May 1
- Steven invite Cristina Cowert (American Cancer Society) and Mike Mitchell (Unite Us) to present on May 1 meeting

Key ideas for Report-Out

- Next meeting May 1 from 1-2 will ask Cristina Cowert and Mike Mitchell to present
- Discussions on telemedicine, upcoming Kansas Broadband Roadshow, and digital privacy (and how it relates to health equity)

Survivorship

- Participants: Lianna Fry, Karin Denes-Collar, Jennifer Bacani McKenny, Ty Kane (notes)
- Recent focus lately has been on updating website resources and promoting available resources.
- Promotion
 - Steven Henson has been promoting idea of a roadshow to share info about the group and resources with oncology offices and primary care offices.
 - Engaging oncologists:
 - What's do oncology offices want? What are they doing now?
 - Workgroup interested in identifying ways KCP can support oncologists in a way that is best for them. E.g. resources that fit into workflows?

- There's some interest in promoting the idea of survivorship to oncologists.
- In primary care setting, sometimes patients don't tell you they are cancer survivors.
- Oncologists want to engage in this type of care. Some better than others. Jen's experience has been oncologists could improve the information provided to patients upon discharge. Getting good info to patients quickly is important.
- Nurse navigators are a key player in this work too.
- Important to include a success story including clinical and survivor experience.
- QR code on business card and/or social media link and/or business cards in oncology offices that link to resources. For online, could promote to KDHE communications and other KCP partner organizations.

Website updates

- Nebraska Cancer Coalition website "resource tab" is categorized in a way Survivorship Workgroup folks have used as a model.
- Kansas a BIG state. How to promote the variety of services across the state that don't serve the whole state? E.g., offerings in Ellsworth.
- o Plan to include a site feature for users to "submit" resources or information.
- Stacy (KDHE) KCP to support ongoing updates, monitoring to site.
- Want to be thoughtful about the best formats for sharing resources/info: PDF, video, etc.
- o Sexual health and/or psychotherapy (including telehealth) resources for cancer survivorship resources.

Key ideas for Report-Out

- Website updates including survivorship resources.
 - KDHE team supporting website review/updates.
 - Nebraska Cancer Coalition website an example the KCP Survivorship team using as a model.
- Promotion of survivorship resources.
 - Strong resources exist. A focus is on engaging providers (especially oncologists) to equip them to effectively promote resources.
 - This is technical (what is best way to present resources, print vs. electronic, etc.) and adaptive (what factors will energize partners (oncologists), who can energize this work, how to measure progress).
- What's needed to move these ideas forward (updating site & promoting resources)?
 - Pace of web update has improved with support from Stacy and now that website development vendor has been identified.
 - Stacy and Olivia have provided excellent administrative and other support!
 - It was hard times after Holly left, when Ann E. stepped in. Things are great w/ Olivia/Stacy. Feeling very supported and KDHE team very responsive.
 - Having a note-taker is very nice!
 - o Initially Karin contacted those on workgroup roster and has been in communication. Work group now meets monthly, where in the past, it met every other month.
 - o As volunteer workgroup chair, there has been good support from KDHE to update the Cancer Plan and Action Plan.

KU Cancer Center NCI	CI Governor Kelly Video			
designation	 Connection between Ad Astera per Aspera and KU NCI designation as comprehensive cancer institute. Noted what the designation means for Kansas (e.g., superior care, cancer research, reduced cancer rates in KS). Cancer center impacts all of us. Appreciation for KU team who led the coordinating effort. 			
	Karin Denes-Collar			
	This is a win for Kansas, a win for KCP and a win for cancer centers throughout the state.			
	Steve Black –			
	 Cancer Center Director, Olathe Health. January 5, Olathe Health became part of KU Health System. Only 53 comprehensive cancer centers in the country. 20 years, effort, funds to make this happen. Dr. Jensen should be recognized for his role in spearheading the effort. 			
Kansas Palliative Care State	Donna Yadrich, 1st Family Caregiver appointed to Palliative Care Council. Began work w/ the Council 2 years ago.			
Plan • Donna Yadrich,	History of the Council – A 2018 bill initiated the Palliative Council and Plan. Council role is to advise KDHE related to palliative care efforts cross the state and to advice the Palliative Care Program at KDHE.			
MPA	Make-up of the Palliative Care Council. Note: Details of Council included in presentation slides.			
 KU Center for Telemedicine and Telehealth 	• 5-year (2022-2027) Palliative Care Plan approved in January 2023. The plan is available for download on the KDHE website. Doug Neal is the KDHE health promotion team member staffing the Palliative Care Program at KDHE. Doug on hand at today's meeting and has copies of the 5-year plan.			
	 Link to KDHE PC Program: https://www.kdhe.ks.gov/834/Palliative-Care-Program 			
	Definition of Palliative Care. Note: Details in presentation slides.			
	 Donna provided a vignette from the 5-year Plan from Theresa Meyer, Council's Founding Patient Representative. Key message: KS needs more palliative care providers to support those in need. 			
	 Access to Palliative Care in Kansas – KS ranks 41 of all states for access to palliative care. 			
	 Value of Palliative Care – Improves quality of life, caregiver burden and depression, symptom distress, documentation of resuscitation preferences, patient satisfaction, and survival. 			
	• 5-year Plan includes 4 Priority Areas, : Access, Education and Health Care Workforce Training, Public and Community Awareness, Emergency Preparedness and Disaster Planning. Details, including action items, in the 5-year plan.			
	 KU Center for Telemedicine and Telehealth is working to become a center for excellence for Palliative Care education and support. The Council needs your support and input. Current opportunity to provide input. Link available in slides. 			
	 Question/input from Karin – What efforts are taking shape to define/clarify palliative care and hospice? Donna noted Project ECHO evaluation identified opportunities to educate providers about this topic. Also important to support the community of practice for individuals involved with palliative care. 			
	 Question from zoom participant representing American Cancer Society in Kansas: Curious about any specific public policy recommendations in the report? Donna, yes, the plan includes key public policy areas. Doug added the plan and policy details are included on the KDHE PC website. More information in the Plan. 			
Kansas Cancer Plan	Olivia Burzoni presented on Kansas Cancer Plan.			

Olivia Burzoni, MPA -	Favorite animal is an elephant.		
Cancer Program	Kansas Cancer Prevention and Control Plan 2022-2027 is published		
Manager, KDHE	Governor Laura Kelly wrote a letter for the plan		
	Kansas Governor announces <u>largest</u> , <u>most comprehensive plan</u>		
	Next 5 years is going to be amazing!		
	Printed copies are available upon request.		
Workgroup updates to	Survivorship		
entire group	Workgroup new meeting monthly, had been meeting every other month.		
	 Workgroup currently focused on updates to KPC website, specifically survivorship resources: 		
	 Engaged workgroup around what resources are most beneficial and what is best way for providers to access those? 		
	——Workgorup Vetting/recommending resources to the website		
	 KDHE staff updating the website with new resources 		
	Health Equity		
	Look at different strategies and objectives – health equity related race, income – use CHWs		
	 Advocate for continuation of coverage for telehealth – ACS CAN is advocating for these benefits within the state and federal lev 		
	 Financial burden – CHW to work with patients on resources for treatments and other finances related to getting care (rent, food 		
	May 1 at 1:00 is next meeting for HE/Financial Burden group		
	ividy I de I loo is next meeting for the firmational burden group		
	Early Detection		
	 A lot of moving pieces – using the Cancer plan as their "playbook" 		
	 How to continue to work with new nurses and educational programs. Make sure they have the tools and knowledge when they 		
	graduate. Resources available in our state.		
	HPV education with Greek life at university		
	 Incorporation of patient navigators and CHWs in EDW. 		
	Colorectal Cancer screenings – start the discussion/roundtable		
	Prevention		
	Sun safety/UV protection/Radiation		
	Breastfeeding – breastfeeding-friendly designations – focusing on LHDs		
	Partner with Safe Kids (sun protection, HPV, etc)		
	Tarana marana (can procession, m. 1, etc)		
	Policy		
	 Policy solution on radon at the local level – new homes to be built with radon systems. 		
	HB2058 – Smoke free at state owned casinos. Started with an employee at casino.		
	Tobacco bill – age of sale from 18 to 21. On Governor's desk for signature		
	Medicaid Expansion – leadership against it – not happening this year		

- Tobacco budget Jull (tobacco company) lost their lawsuit and have 6-10 years to pay. Currently be paid in General Fund. But FY 24 should go to the tobacco use prevention program. 9.8 million dollars.
- Next session create momentum on bio metric screening
- Question what can we be doing for Medicaid extension? It's a party issue. Vote Democrats And get people registered to vote. Support candidates who support KanCare Expansion

Updates from Regional Coalitions

North Central Regional Coalition Update

- Activities on colorectal cancer during the month of March
- Increase testing

South Central Regional Coalition

• In February team presented HPV info to Greek life. Great turnout. Very interactive. Found most of the college students received the vaccine but didn't know what/why. Next step: continue to provide the training to other college students in Kansas.

What About You?

 Karin Denes-Collars, LSCSW, LCSW - Masonic Cancer Alliance, KU Cancer Center

Self-care

- From this segment:
 - Will have an idea or 2 about what participants can do for themselves
 - Think about how to take care of yourself
 - Learn skills for how we take care of ourselves
- Most of us are in the field where we are taking care of people at work, or taking care of others at home or for someone else's benefit
- Turning Point kansashealthsystem.com/health-resources/turning-point/programs organization part of University of Kansas Health System
 - Provide trainings for people with serious or chronic illnesses all online trainings
 - Also teach resilience skills for healthcare staff
- Resilience ability to bounce back and recover from life's challenges
- 10 facets of resilience today, will talk about exercise and self-care; self replenishment; self compassion
- Karin led participants through a "pursed lip breathing" exercise together normal breath through nose and exhale through pursed lips longer than inhalation. Repeat 3-4 times this exercise is a way to take care of brain and feel less anxiety
- What gets in the way of self-care?
 - Time, obligations, no plan for self-care, feels selfish (ask yourself, am I really doing self-care for myself without regard for others if we're taking care of ourselves, we have better ability to give out care for others)
- Exercise and Self-Care
 - Self-care is about having a firm foundation better able to handle things that come up when we have a firm foundation (exercising, eating in a balanced way, and getting adequate sleep)

- What is one small something I can do to start to set that firm foundation
- Self-Replenishment filling up our bucket anything that helps restore your energy
 - Everyone has an invisible bucket that is being filled and drained all day. Stay mindful about "water level" of your bucket;
 by the time you're thirsty, you are already dehydrated
 - What kinds of things "fill you up" and what kinds of things drain you?
 - What is one thing you can do in less than 30 minutes to make a difference in how you feel each day?
 - O How would improving self-care help you do your work or take care of the people and things that are important to you?
- Self-Compassion what happens when people are kind to themselves?
 - o 3 components to self-compassion:
 - Mindfulness (recognize and name what's happening to us internally)
 - Self-kindness (kind and supportive to ourselves instead of harsh and critical)
 - Connectedness (common humanity remembering everyone makes mistakes and experiences difficulties at times)
 - Think about a time when a friend called with something not going well. What would you say to that person in the moment? Now imagine if it was you that had something not go well. What would you say to yourself? Most of the time, we find that people are much harsher on themselves than on someone else.
 - o Did practice using the Self Compassion Rake worksheet available from Dr. Kristin Neff
 - O When we are kinder to ourselves, we are more likely to change
 - Compassion with equanimity: Inhale "one for me", exhale "one for you"
 - As you go through the day, pay attention to the soles of your feet; soothe yourself with touch (hands over heart, holding your hands)
- Spend some time today or this week asking self:
 - O What did I learn or relearn today that I want to make time for in my life?
 - o If I do that, how do I hope it will help me?
 - O What are some small steps I can take to get there?
- Sign up for the Resilience Tip of the Day (https://bit.ly/MCATips)
- Check out resilience videos on YouTube page: https://www.youtube.com/watch?v=OzGBJ5WlfPk (Masonic Cancer Alliance YouTube)
- Apps:
 - Healthy Minds
 - o Calm
 - Headspace
 - Mindfulness Coach
 - o Insight Time
- Websites with more info:
 - UCLAhealth.edu/marc
 - Mindfulnessforteens.com

0	Self-compassion.org
0	www.rickhanson.net/find-your-north-star