

Exploring Cancer
Examining the Role of Biology, Race, Class, and Socioeconomics

Welcome to the
UNC Lineberger Cancer Network's
live webinar

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Exploring Cancer
Examining the Role of Biology, Race, Class, and Socioeconomics

A collaboration between

NC Central University **UNC** **LINEBERGER COMPREHENSIVE CANCER CENTER** **NORTH CAROLINA AGRICULTURAL AND MECHANICAL STATE UNIVERSITY**

www.exploringcancer.org

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Exploring Cancer
Examining the Role of Biology, Race, Class, and Socioeconomics

Fridays
11:00 - 11:50 AM EST/EDT

August 26 Welcome to Cancer(s) and Health Disparities 101 - The Introduction	September 30 Including the patient voice in cancer research	November 11 Precision Medicine and Immunotherapy
September 9 Genomics/Microbiome and Disparities for Endometrial Cancer	October 14 Breast Cancer Health Disparities	November 18 Cervical Cancer, Basics of Treatment and Disparities in Outcome
September 16 Building the Oncology Careforce in Malawi to Meet the Needs of Individuals Living with Cancer and their Guardians	October 21 Inflammatory Breast Cancer	

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Examining the Role of Biology, Race, Class, and Socioeconomics


September 30, 2022

Including the Patient Voice in Cancer Research



Patty Spears, BS

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Patty Spears, BS

Ms. Spears is an over 20-year breast cancer survivor and a recent liver cancer survivor. She has been a cancer research patient advocate for over 20 years. She is currently working as a scientific research manager and patient advocate at Lineberger Comprehensive Cancer Center (LCCC) where she leads the UNC Lineberger Patient Advocates for Research Council (PARC) and the UNC Breast SPORC Advocates. At UNC she focuses on communicating research to the public and facilitates the engagement of patient advocates with Lineberger researchers and clinical trials. Patty is also a patient advocate for national organizations including the NCI, ASCO, AACR and FDA.

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Including the patient voice in cancer research

Patty Spears
Research Patient Advocate
Exploring Cancer
September 30, 2022
@paspears88

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What you need to know

WHO	WHY	WHAT	WHEN	HOW
Who are patient advocates?	Why are you including patient advocates?	What do you want patient advocates to do?	When do you need to contact an advocate?	How do you engage patient advocates?

EXAMPLES OF PATIENT ENGAGEMENT
 ALLIANCE FOR CLINICAL TRIALS IN ONCOLOGY
 LINEBERGER EXCELLENCE IN ADVOCACY PROGRAM (LEAP)
 PATIENT ADVOCATES FOR RESEARCH COUNCIL (PARC)
 UNC BREAST SPORE

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Who are Cancer Research Patient Advocates?

- People who have had a **diagnosis** of cancer, been a **caregiver** of someone with cancer or **affected** by someone with cancer.
- People who are **motivated** to make a broader impact in cancer and it's treatment.
- People **interested in research** and willing to learn more about the research process.

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Types of patient advocacy

What we advocate for

- Political
- Support
- Fundraising
- Watchdog
- Research

Who we are

- Patients
- Patient Groups or Organizations (PG)
- **Research Patient Advocates (RPA)**




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NCI definition of a research advocate (2011)

Someone who brings a nonscientific viewpoint to the research process and communicates a collective patient perspective.


A collective patient perspective is created when a person has knowledge of multiple disease experiences and conveys this collective perspective rather than his or her own exclusive experience



Collective Patient Perspective




Broad Impact



Interested in Science, NOT a scientist

REF: Advocates in Research Working Group Recommendations (National Cancer Institute, Bethesda, MD, 2011)




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WHY involve patient and community advocates?

The Perception of Value


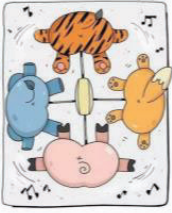
Different stakeholders may have different perspectives about value

Government/non-profit	↔ vs. ↔	Pharmaceutical Industry
Individual	↔ vs. ↔	Population
Researcher	↔ vs. ↔	Society
Patient	↔ vs. ↔	Physician



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Perception Matters ---- Context Matters

Doctors	Patients
	






"Oncologists most valued gains **in survival**, whereas patients assigned a higher monetary value to treatments that enhanced **QoL**." (Dilla 2016)

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WHAT can advocates do?

Advocates are involved in all types of research

	Basic Research	Bench research in laboratories
	Translational Research	Pre-clinical research (e.g. animal models, human tissue)
	Clinical Research	Clinical trials in patients
	Epidemiology/Population	Studies of associations in populations
	Drug Approval	FDA panels and Pharma

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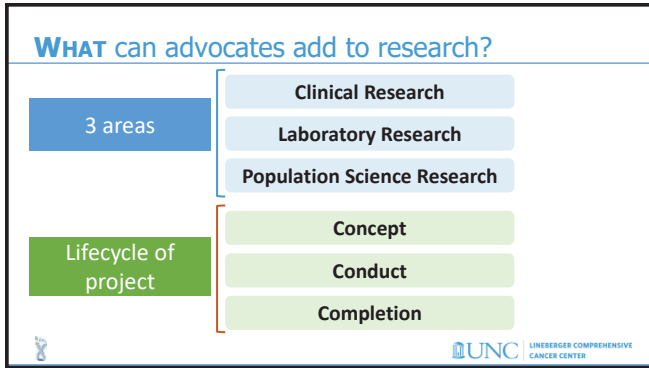
Adding the patient/community voice to cancer research

Putting some effort into specific ways advocates can be involved to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient.

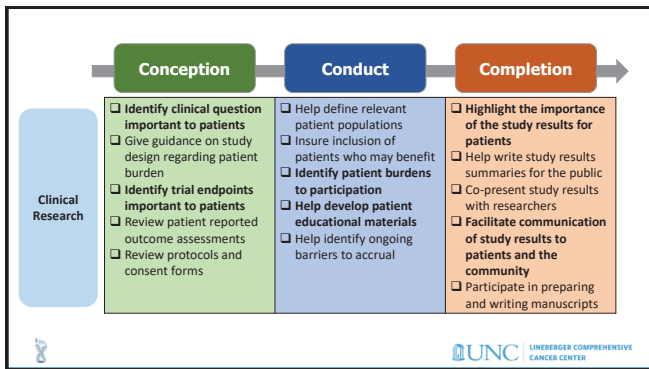
- 1 **Clinical trial development:** ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.
- 2 **Laboratory research:** enhance research to be more patient centered and community focused. Engagement can instill a sense of urgency in all research throughout the course of the research project.
- 3 **Population science research:** provide the patient and community perspective on implementation feasibility and to help communicate the importance of the research to the broader community.

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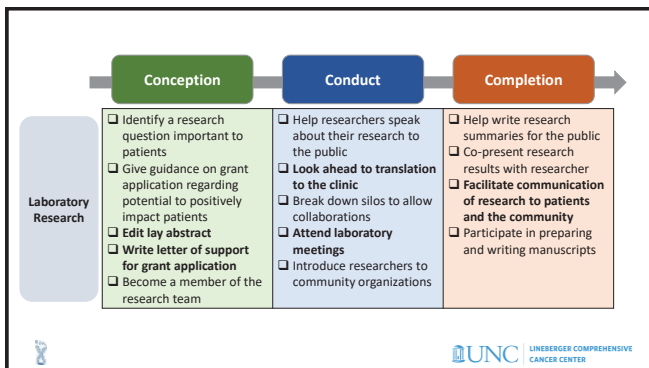
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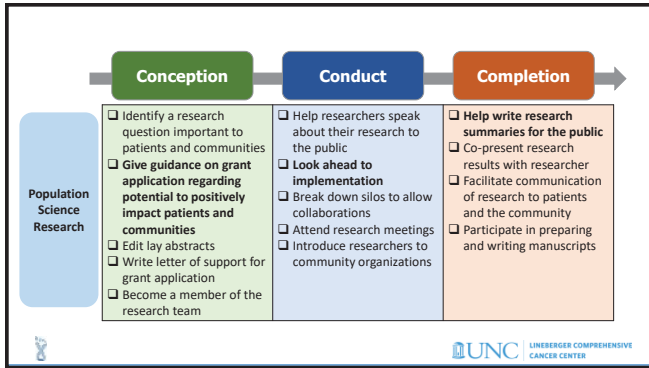
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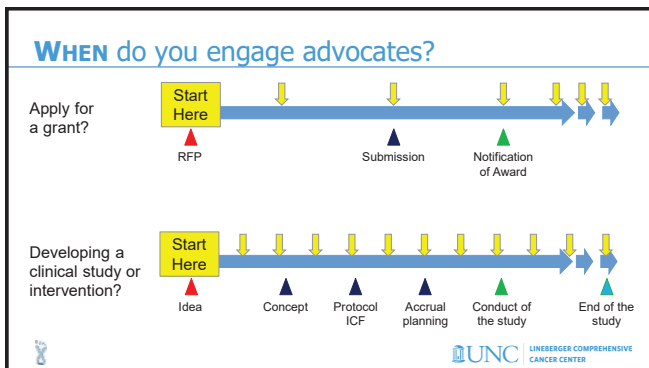


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Engaging patients and advocates adds urgency to cancer research

- **Early and often** – throughout the entire project or process
- Patients understand the **burden** of cancer treatments
- Patients know what is **important** to them – they know what is patient centric and what is not
- Advocates can help design clinical trials that will **accrue and retain** participants
- Advocates can help identify **barriers** and potential accrual problems before trials open, saving time and money and ensuring the completion of trials
- Advocates can help identify how your research will ultimately **improve the lives of cancer patients**

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How do you begin to engage an advocate in your research?

- Each project is different, one size does not fit all projects
- Build a foundation with common goals
- Have a purpose for engagement
- Have an idea about what a successful engagement will be
- Have an environment of respect, equitable power and trust
- Compensate if possible, shows you value the patients time and expertise

Colyar, Nat Rev Can, 2006; Perlmutter, Can Res, 2013, ARVO 2011; Deverka, JNCI, 2018; Harrison Health Exp, 2019; Hamilton, PLoS One, 2018; Ciccarella, Ann Trans Med, 2018

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STEPS to meaningful engagement

- 1** Decide why advocates will be engaged in the research project

 - How will including advocates benefit the research project?
 - How will advocates contribute?
 - What information will be gained from advocate engagement?
- 2** Identify advocates for the research project

 - What type of patients or community members are needed for the project?
 - Do the advocates need to have a specific experience?
 - Should there be more than one advocate included?
 - How will advocates be identified?
- 3** Discuss roles, responsibilities, and expectations

 - What is the role of advocate on the project?
 - What will advocates be required to do?
 - Will advocates be involved at different levels?
 - What is the expectation of the advocate?
- 4** Discuss how researchers and advocates will communicate

 - How often will researchers and advocates communicate?
 - How will researchers and advocates communicate?
 - Who are the contact people on the research project and their roles?

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Including the Patient and Community voice @ the Alliance for Clinical Trials in Oncology

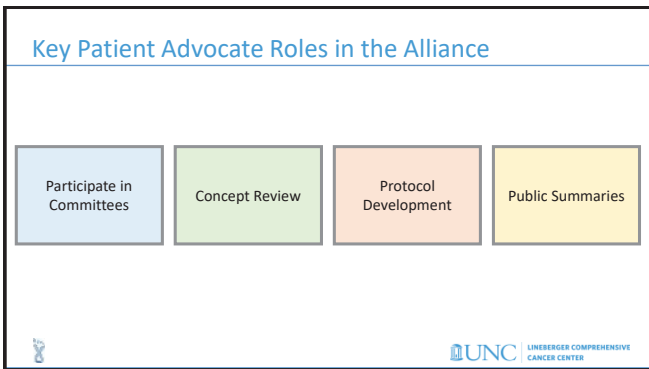
Adding the patient and caregiver voice to Clinical Research

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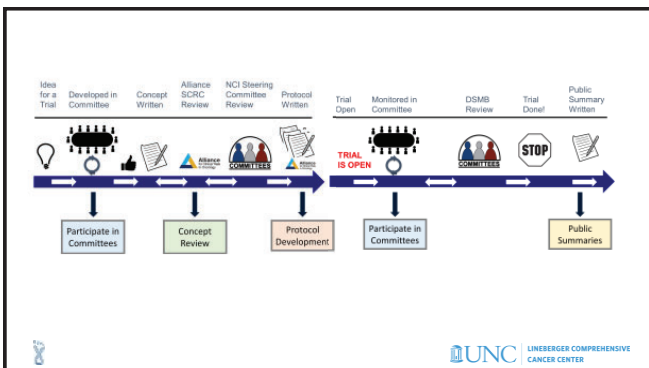
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What do advocates consider? Participate in Committees

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Concept Review	Protocol Development
Advocates evaluate:	Advocates evaluate:
<ul style="list-style-type: none"> <input type="checkbox"/> Study Impact <input type="checkbox"/> Study Feasibility <input type="checkbox"/> Level of Innovation <input type="checkbox"/> NCTN Relevance <input type="checkbox"/> Study Design <input type="checkbox"/> Overall Impression 	<ul style="list-style-type: none"> <input type="checkbox"/> Participate as protocol is written to review: <ul style="list-style-type: none"> • Eligibility criteria • Questionnaires (PROs, QoL) • Schedule for patient burden <input type="checkbox"/> Review the consent form and help ensure a good readability level. <input type="checkbox"/> Other protocol specific patient concerns (<i>accrual, equipoise, patient population, etc...</i>)

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Alliance Public Results Summaries Public Summaries

- Within Alliance operations
- Template (via Deb Collyar)
- Written in plain/regular language
- Written after or at the same time as the publication
- Written by a 'team' including a patient advocate
- On the Alliance web-site.

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Abstract Public Study Report Summary
Study Number A011022

What this study is about

Why this study was done

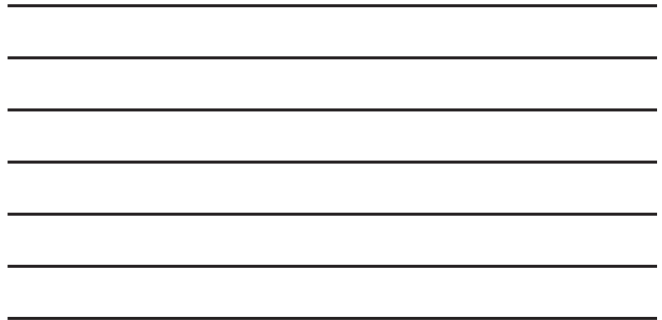
How the study worked

Key findings

What this study means

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Abstract Public Study Report Summary
Study Number A011022

What this study is about

Why this study was done

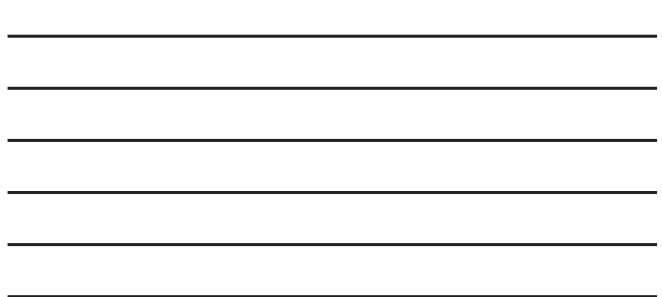
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What this study means

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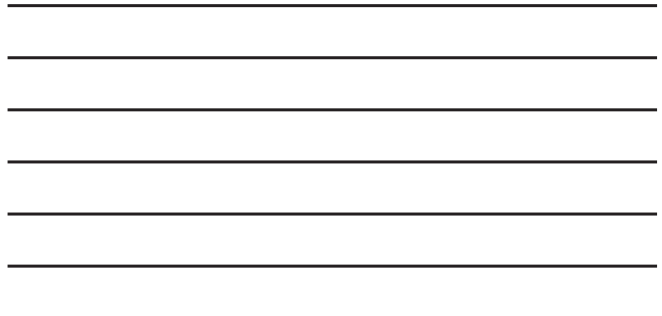


Including the Patient and Community voice @ UNC Lineberger

Adding the patient and community voice to Lineberger Research

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Lineberger Engagement



CAB
Community Advisory Board
Community Voice







PARC
Patient Advocates for Research Council
Patient & Caregiver Voice in Research



PFAC
Patient & Family Advisory Council
Patient & Caregiver Voice in Cancer Care Delivery

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Research Projects	Research Grants	Research Materials	Patient-Centered Programs
			
<p>Large Programs</p> <ul style="list-style-type: none"> UNC Breast SPORE Stand Up 2 Cancer Project Patient and Community Advisory Boards <p>Individual Projects</p> <ul style="list-style-type: none"> Young investigator projects Investigator projects Laboratory visits Feedback 	<p>Applications</p> <ul style="list-style-type: none"> Provide feedback – join the research team Edit lay/public abstract Submit letter of support Submit a bio-sketch <p>Reviews</p> <ul style="list-style-type: none"> Review the LCCC Developmental Funding Award applications Review for national organizations 	<p>Patient Facing</p> <ul style="list-style-type: none"> Review informed consents for clinical trials Review patient educational materials Review concise summaries <p>Public Facing</p> <ul style="list-style-type: none"> Review website content Review public materials not associated with a clinical trial 	<p>PEER</p> <ul style="list-style-type: none"> Patient and Community Engagement to Educate Researchers Bringing the human element to research through engagement <p>PART</p> <ul style="list-style-type: none"> Patients And Researchers Together Patient-centered tissue collection project

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Engaging Patient & Community Advocates in Research

BENEFITS

- ✓ Builds trust and respect in communities
- ✓ Creates a renewed sense of purpose
- ✓ May lead to future sources of funding
- ✓ Enhances the relevance of your research
- ✓ May identify potential concerns and solutions
- ✓ Can increase recruitment to research studies



Lineberger Excellence in Advocacy Program

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Your Voice is Needed

Work With Our Researchers and Staff as an Advocate



Who can be an advocate?

- Cancer patients
- Cancer survivors
- Community members
- Caregivers and family members of a person with cancer

How do advocates help?

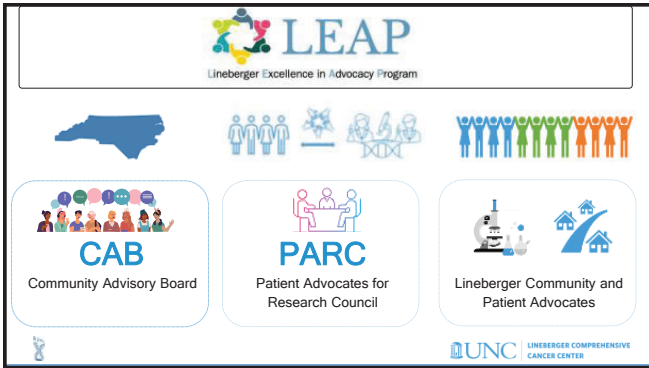
Share thoughts and opinions on programs and research studies

Review patient materials to make sure they are easy to understand

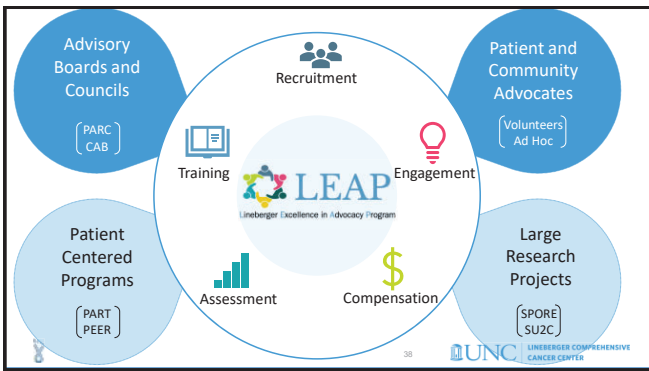
Highlight issues that are most important to patients and their families

Advocates are often paid for their time. To learn more visit gsl.unc.edu/LEAP or email LEAP@unc.edu

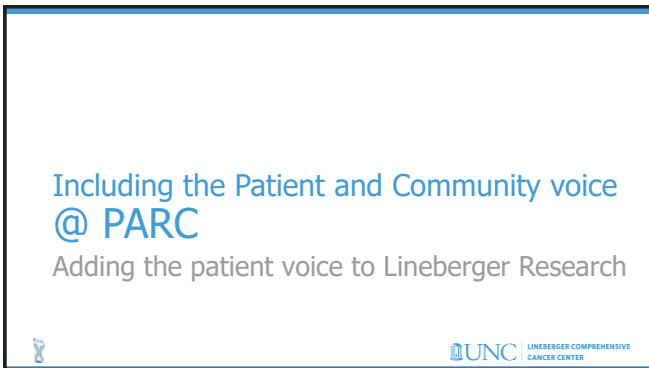
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UNC Patient Advocates for Research Council (PARC)





- Patients, survivors, caregivers and researchers **working together** on research projects and clinical trials to create knowledge that will improve the lives of all cancer patients.



Patient Advocates	Multiple cancers	
Laurie Betts Clay Brumbaugh Barbara Dean Catherine Huffman Laura Jensen Aishia McClellan David McNelis Susan Palmer Patty Spears (Chair)	Breast Colon Ovarian Cervical Esophageal Prostate Liver	
	Survivors Living with metastatic cancer Caregivers	

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PARC/SPORE: Patient Engagement in Research

-  Provide the patient perspective in research to ensure the knowledge created will improve the lives of all cancer patients
-  Participate in clinical trial design and conduct to improve accrual, retention and ensure clinically meaningful benefits to patients
-  Facilitate communication of research to the public
-  Promote the inclusion of patient centered materials to help educate patients volunteering to participate in clinical trials


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PART
Patients And Researchers Together

-  **PART**nership between patients, advocates, community members, researchers, oncologists, surgeons and clinical staff (CPO/OCTR).
-  Motivate patients to donate the biospecimens that researchers need to create new and meaningful treatments for cancer.
-  Ensure biospecimen donations reflect the UNC Lineberger catchment area.

Patient Materials

Public Website

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PEER

Patient and Community **E**ngagement to **E**ducate **R**esearchers

PARTnership between patients, advocates, community members, researchers, trainees, CRTEC and community organizations.

Expand the education of researchers and trainees to include the human element of cancer by engagement with patients and community members.

Instill a sense of responsibility to the public by preparing them for and providing outreach opportunities

PEER Lectures

PEER Engagements

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PEER Outcomes

Connections through engagement

Connect young researchers, patients, and community members for grant submission requiring consumer advocates, lay abstracts and translational potential.

Well-rounded training for researchers

The PEER program will produce well-rounded researchers who are aware of translational potential of their research

Researchers who participate in the PEER program will be able to speak in community settings to enhance the scientific knowledge of society.

Appreciation of research

Patients and community members who participate in the PEER program will appreciate the complexity of the research process.

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Communicating and Engaging with the Community:

A workshop on communicating your cancer research to patients & the public for UNC LCCC T32 trainees and patient-community partners

Hear 'Elevator speeches' from your PEERS

Engage with your PEERS and patient/community members to gain valuable feedback from a diverse audience

Communicate your cancer research to PEERS and patient/community members

Food will be provided

Date: May 19, 2022 Time: 12:00-1:30 pm Location: In-person in Marsico 2004 and online

Register: <https://go.unc.edu/PEER-Comms-Workshop>

Hosted by: **UNC** LINEBERGER COMPREHENSIVE CANCER CENTER

Patient and Community Engagement to Educate Researchers (PEER)

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Including the Patient and Community voice
@ UNC Breast SPORE (Specialized Program of Research Excellence)
 Adding the patient and community voice to Lineberger Research



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2022 UNC Breast SPORE Advocates

 Patty Spears Chair of the UNC Lineberger Patient Advocates for Research Council, and Associate Group Chair for Advocacy of the Alliance for Clinical Trials in Oncology PROJECTS: all	 Eva May Member of the UNC Lineberger Community Advisory Board and Alliance for Clinical Trials in Oncology PROJECT: 2	 Missy Van Lokeren Volunteer with Susan G. Komen and a member of UNC Lineberger Patient And Researchers Together Leadership Team PROJECT: 4
 Coleen Crespo Member of the Sisters Network Triangle/NC and Alliance for Clinical Trials in Oncology PROJECT: 3	 Susan Palmer Member of UNC Lineberger Patient Advocates for Research Council, and Patient and Family Advisory Council PROJECT: 4	 Vernal Branch Member of UNC Lineberger Patient And Researchers Together Leadership Team and The Alliance for Clinical Trials in Oncology PROJECTS: 1, 3
 Barbara Dean Member of UNC Lineberger Patient Advocates for Research Council, and The UNC Board of Visitors PROJECTS: 2, 3	 Marian Johnson-Thompson Member of UNC Lineberger Community Advisory Board, Susan G. Komen Advocates in Science Steering Committee and Komen Scholar PROJECT: 1	 Laura Jensen Member of UNC Lineberger Patient Advocates for Research Council, and The UNC Board of Visitors PROJECTS: 1, 4


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NCI SPORES

- UNC Breast SPORE**
 - Funded since 1992
 - 9 Patient Advocates
 - 4 Projects
 - Each advocate is assigned to 1-2 projects based on their interest



Scientific Meetings <ul style="list-style-type: none"> Entire SPORE group Monthly for 2 hours 2 presentations Advocates are on the speaker rotation 	Advocate Meetings <ul style="list-style-type: none"> Advocate Team Monthly for 1 hour – prior to the scientific meeting Invite speakers that are presenting at the scientific meeting
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Final Thoughts

- Be thoughtful when including the patient or community voice in your research
- Advocates can help you communicate your research to the public and put the human element into your project
- Patient and Community engagement in research adds new perspectives:
 - For researchers in understanding the patient experience and
 - For patients in understanding the research process

Contact us at COE or LEAP@unc.edu if you want to find out more about the Lineberger advocacy program

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Questions?



Patients And Researchers Together
PARTners in Cancer Research

Contact us
paspears@med.unc.edu
LEAP@unc.edu
PARTinfo@med.unc.edu
PEERinfo@med.unc.edu



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UNC Lineberger Cancer Network

Questions/Comments?

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Start the presentation to see live content. For screen share software, share the entire screen. Get help at polls.com/app

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Exploring Cancer
Examining the Role of Biology, Race, Class, and Socioeconomics

Upcoming Live Webinar

Breast Cancer Health Disparities



Checo Rorie, PhD
Chair of the Department of Biology
Associate Professor of Genetics
Department of Biology
College of Science and Technology
North Carolina Agricultural and Technical State University

Live Lecture
October 14
11:00 AM

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Examining the Role of Biology, Race, Class, and Socioeconomics

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Examining the Role of Biology, Race, Class, and Socioeconomics

Exploring Cancer is a webinar series taught by cancer biologists, physicians, public health experts, and other cancer specialists from NCCU, UNC-Chapel Hill, and NC A&T.

We hope to see you next time!

UNC Lineberger Cancer Network



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