

PLAYBOOK



4th Annual

END LUNG CANCER NOW GATHERING

Friday, November 8, 2024

NCAA Hall of Champions | Indianapolis, IN

END
LUNG
CANCER
NOW

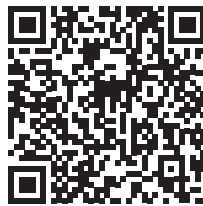


INDIANA UNIVERSITY

MELVIN AND BREN SIMON
COMPREHENSIVE CANCER CENTER

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Scan QR code or visit www.endlungcancer.iu.edu to access a digital copy of this playbook, copies of the slides from today's presentations, and other advocacy resources.



WELCOME TO THE GATHERING

On behalf of End Lung Cancer Now (ELCN), an initiative of the IU Simon Comprehensive Cancer Center, we welcome you to the 4th Annual End Lung Cancer Now Gathering. ELCN's vision is to end the suffering and death from lung cancer in the state of Indiana. Our mission is to educate and empower community advocates to help us eliminate tobacco use in Indiana, screen all eligible Hoosiers with low-dose CT scans, increase participation in clinical trials, and support lung cancer survivors and their loved ones.

It's a **bold** vision that requires a **TEAM** and **LEADERSHIP** to achieve it. ELCN has built a team of experts by identifying, coordinating, and accelerating the ongoing efforts of many groups, organizations, and community advocates already engaged in this work. We must not work in silos; **we must work together.**

The Gathering serves as a meeting place for those who are passionate about helping us realize our vision. Last year's Gathering brought together more than 120 advocates to discuss the importance of advocacy and what we each can do to drive meaningful change. Today's Gathering is all about the critical importance of research to advance treatments and improve outcomes for those impacted by lung cancer. We have planned a thought-provoking and engaging morning that includes a unique opportunity for you to contribute to the development of a research toolkit that will be published in early 2025. We have a powerful lineup of keynote speakers and hope that you enjoy the learning and networking opportunities ahead.

Many thanks to those who have helped create this year's Gathering: the ELCN Advisory Board, the Gathering planning committee, IU Simon Comprehensive Cancer Center, our generous supporters, and most importantly - our ELCN advocates.

We know that advocates are responsible for saving more lives from lung cancer than medical science and we know that, together, we can End Lung Cancer Now.



Nasser Hanna, MD
Chair



MacKenzie Church
Executive Director



Elyse Turula
Advocate Committee Chair

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only thing that ever has.” — Margaret Mead, (Anthropologist, 1901-1978)



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GIVE NOW



**SCAN
ME!**

<https://go.iu.edu/4B13>

GAME PLAN

1ST QUARTER - THE LINE OF SCRIMMAGE

Room: Christine Grant Ballroom

- 8 a.m. Opening Remarks
MacKenzie Church
- 8:05 a.m. End Lung Cancer Now - A Year in Review
MacKenzie Church
- 8:20 a.m. Current State of Lung Cancer
Nasser Hanna, MD

2ND QUARTER - GAME FILM ANALYSIS

Room: Christine Grant Ballroom

- 8:30 a.m. Navigating the Research Playbook: Strategies for Patient-Clinician Communication in Clinical Trials
Eric K. Singhi, MD
- 8:50 a.m. Barriers to Participation in Clinical Research
Brian Stemme
- 9:10 a.m. The Heart of Research: The Impact of Patient Perspectives on Lung Cancer Research
Jill Feldman
- 9:30 a.m. Special Teams Overview
- 9:40 a.m. Break

3RD QUARTER - SPECIAL TEAMS

Room: Various

- 10 a.m. Refining the Research Toolkit **See schedule below.*
- Session 1 - 10-10:30 a.m.
 - Session 2 - 10:35-11:05 a.m.
 - Session 3 - 11:10-11:40 a.m.
- 11:40 a.m. Break

4TH QUARTER - GAME PURPOSE

Room: Christine Grant Ballroom

- 12 p.m. Lunch
- 12:30 p.m. Lung Cancer Survivor Story & Call to Action
- 1 p.m. Adjourn

SPECIAL TEAMS SCHEDULE

	Red Team	Blue Team	Green Team
Session 1	Patients (TR)	Clinicians (CG)	Research Operations (PP)
Session 2	Research Operations (PP)	Patients (TR)	Clinicians (CG)
Session 3	Clinicians (CG)	Research Operations (PP)	Patients (TR)

Room Key: CG - Christine Grant, PP - Palmer Pierce, TR - Theodore Roosevelt

STARTING LINEUP

MacKenzie Church



MacKenzie Church serves as Executive Director of End Lung Cancer Now at the IU Simon Comprehensive Cancer Center. With a strong background in non-profit leadership and public health, MacKenzie leads the strategic implementation of the initiative's mission and works across multi-institutional boundaries to champion lung cancer prevention, early detection, and advocacy efforts. Under her leadership, the initiative has expanded its outreach efforts, formed key partnerships, and significantly grown its philanthropic portfolio.

MacKenzie developed her passion for healthcare education and awareness initiatives during her time as program manager at the IU School of Medicine, Division of Continuing Medical Education. She received her bachelor's degree from IUPUI and is currently working towards her master's degree in public health, with a concentration in Health Policy and Management. She is inspired daily by her family and all of those who have been impacted by lung cancer.

Nasser Hanna, MD



Dr. Nasser Hanna received his MD from the University of Missouri School of Medicine in Columbia. He followed an internship and residency in internal medicine at the University of Iowa in Iowa City with a fellowship in hematology-oncology at the Indiana University School of Medicine. Dr. Hanna is a professor of medicine at Indiana University School of Medicine, the Tom and Julie Wood Family Foundation Professor of Lung Cancer Clinical Research at IU Melvin and Bren Simon Comprehensive Cancer Center, and serves as the Chair of the End Lung Cancer Now initiative.

Dr. Hanna's research has focused on thoracic oncology, specifically the study and management of all forms of lung cancer. Dr. Hanna's work has been published in book chapters and in journals such as the New England Journal of Medicine, the Journal of Clinical Oncology, and the Journal of Thoracic Oncology.

Eric K. Singhi, MD



Dr. Eric K. Singhi is an assistant professor and thoracic medical oncologist at the University of Texas MD Anderson Cancer Center. He completed his internal medicine residency at Vanderbilt University and served as chief hematology/oncology fellow at MD Anderson during his training.

Dr. Singhi specializes in patient education research, and the care and research of young patients with lung cancer. Additionally, within MD Anderson Cancer Center, he serves as the patient safety and quality officer for the Thoracic/Head and Neck Medical Oncology Department, and as co-director of the thoracic medical oncology rotation for the medical oncology fellowship program.

Brian Stemme



Brian Stemme is the CEO of Hoosier Cancer Research Network Inc., (HCRN), a nonprofit organization that advances clinical research by collaborating with academic institutions, community hospitals, pharmaceutical companies, and cancer-focused nonprofits to bring new treatments to patients. HCRN manages 90 clinical trials and supports multiple research collaborations, including the Big Ten Cancer Research Consortium. He oversees a team of 60 professionals.

Prior to HCRN, Stemme was a senior vice president at BioCrossroads and manager at Eli Lilly and Company. He is a member of the Butler University Board of Trustees, his undergraduate alma mater.

STARTING LINEUP

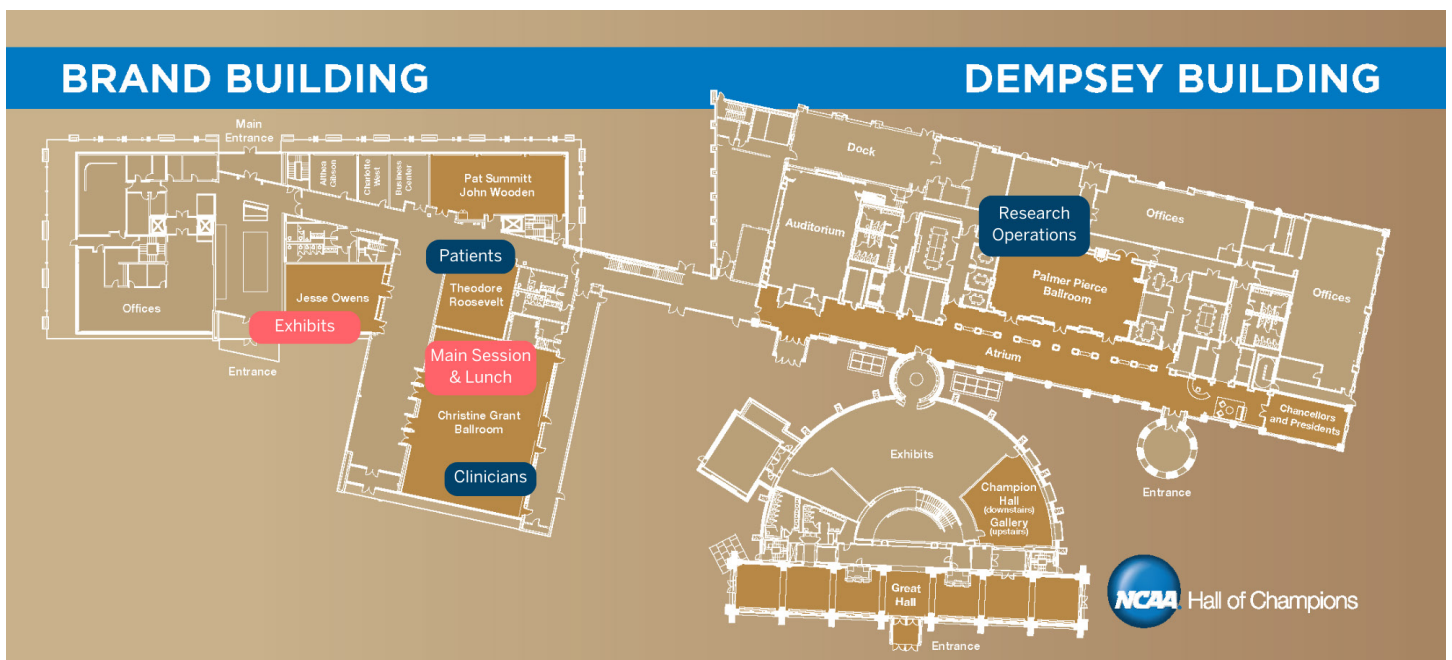
Jill Feldman



Jill Feldman is a lung cancer patient and advocate. With an extensive family history of lung cancer, Jill got involved in lung cancer advocacy in 2001, when it was in its infancy. In 2009, at 39 years old with four small children, Jill herself was diagnosed with EGFR-positive lung cancer.

Jill is committed to understanding and promoting patient-centered research as past chair of the International Association for the Study of Lung Cancer's patient advisory board, a member of the programmatic panel for the Department of Defense Lung Cancer Research Program, a member of the ECOG-ACRIN Research Group's patient advocate committee and thoracic committee, and as the patient advocate on the National Lung Cancer Round Table steering committee. In addition, she is a co-founder of the EGFR Resisters, a grassroots, patient-driven community committed to accelerating research that will pro-long and better the lives of people diagnosed with EGFRm-positive lung cancer.

Jill serves in various other leadership roles to improve the speed and quality of research and use her voice and privilege to embed a health equity lens in all aspects of research and care. She is passionate about advocating for the critical aspects of the lived experience, including the physical, psychosocial, logistical, and financial effects of cancer and treatment on patients and families.



1ST QUARTER: THE LINE OF SCRIMMAGE

End Lung Cancer Now - A Year in Review

MacKenzie Church

The Vision

End the suffering and death from lung cancer in Indiana.

The Mission

Educate and empower patient advocates to:

- **Eliminate tobacco use in Indiana.**
Tobacco causes 80-90% of lung cancer, and more than 1 million Hoosiers still smoke daily.
- **Screen all eligible Hoosiers with low-dose CT scans.**
We know that lung cancer screening scans significantly reduce mortality, but less than 10% of all eligible Hoosiers participate in a screening program.
- **Increase participation in lung cancer research.**
Advances in treatment only come from clinical trials but less than 5% of eligible patients currently participate.
- **Support lung cancer survivors and their caregivers.**
Awareness of lung cancer and its associated stigma contribute to ongoing challenges for patients. While support services exist, coordination of these services is often lacking.

Values

Accountability | Inclusivity | Integrity | Partnership | Passion | Promise to Patients

The Accomplishments

In addition to continuing to build and strengthen community partnerships, ELCN has accomplished the following since last year's Gathering:

- Secured nearly **\$2.5 million** in philanthropic dollars to support the initiative's work.
- Secured nearly **\$250,000** in sponsorship dollars to support the initiative's events and marketing campaigns.
- Launched a digital lung cancer awareness campaign that has received more than **1.5 million impressions** across the state of Indiana.
- Published ***The Blueprint to Transform Lung Cancer Screenings in Indiana***, a report developed by the End Lung Cancer Now Lung Screening Taskforce to significantly scale lung cancer screenings.
- Helped support a nearly **3 fold increase in lung cancer screenings** conducted at IU Health in the Adult Academic Health Center through the recommendations outlined in ***The Blueprint***.
- Commissioned and premiered End Lung Cancer Now's anthem, ***"Blue Again."***
- Published the ***End Lung Cancer Now Advocate Toolkit***, a guide to lung cancer advocacy developed as a result from what we learned at the 3rd Annual Gathering.
- Hosted the inaugural **Lung Cancer Advocate Rally and World Lung Cancer Day** celebration.
- Facilitated the **End Lung Cancer Now Mobile CT Taskforce** to develop the implementation plan for Indiana's first-ever mobile screening program, scheduled to launch in early 2025.
- Partnered with the thoracic oncology team at IU Simon Comprehensive Cancer Center to provide ELCN Survivor Care Kits and educational resources to nearly **400 patients**.

Contact information: Email: MacKenzie Church | Email- mjchurch@iu.edu | Phone – 317-278-4742

Call to Action

BECOME AN ADVOCATE

We need YOU to join us in the fight to end the suffering and death from lung cancer in Indiana.



Advocacy looks different for everyone. We want you to feel inspired and empowered to start right now, where you are, with just what you have, to make a difference. Opportunities exist to align your interests with our vision.

If you are interested, we would like to hear about your story, journey, and passion. You can visit our website to learn more about our advocacy program and find various advocacy resources.

GIVE NOW

ELCN is funded through philanthropy. It is only through the generous support of our donors and sponsors that we are able to continue our work towards achieving our mission. If you feel inspired to give to the organization, please scan the QR code or contact Amber Senseny at 317-278-4510.



BECOME A PARTNER

Community partnerships and collaborations provide the foundation for the work that we do. If you or your organization is interested in becoming an engaged partner, let us know! Together, we can End Lung Cancer Now.

Notes

1ST QUARTER: THE LINE OF SCRIMMAGE

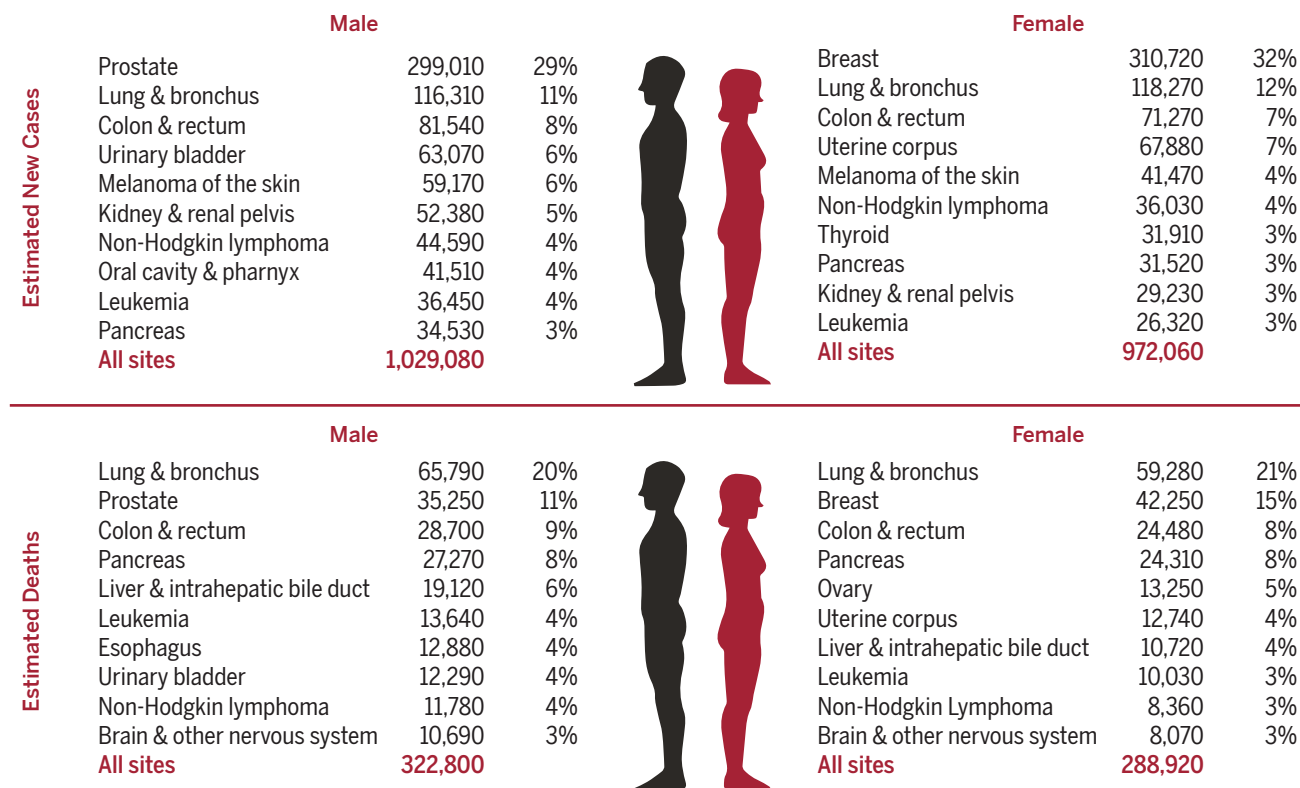
Current State of Lung Cancer

Nasser Hanna, MD

LUNG CANCER FACTS AND FIGURES 2024

- In 2024, the number of new cases of lung cancer diagnosed in the U.S. is estimated to be 234,580 (116,310 in men and 118,270 in women). This means that for the first time more women than men will be diagnosed with lung cancer in the U.S.
- Lung cancer remains the leading cause of cancer-related death in the U.S., with colon cancer and breast cancer being second and third.
- There are estimated to be 125,070 deaths due to lung cancer in 2024. This includes 65,790 deaths in men and 59,280 deaths in women. That is more than colon (53,010), breast (42,250), and prostate cancer (35,250) combined.
- In the U.S., the incidence of lung cancer is steadily falling 2.5% each year in men and by 1% in women since 2006.
- In Indiana, there will be 5,930 Hoosiers diagnosed with lung cancer. This will make lung cancer the 3rd most common cancer in Hoosiers behind prostate cancer (6,470) and breast cancer (6,270).
- While lung cancer is the 3rd most common cancer in Hoosiers, it is still the number one cause of cancer-related death, by far. There will be an estimated 3,390 Hoosiers who die from lung cancer in 2024, compared with 1,220 from pancreatic cancer, 1,190 from colon cancer, 910 from breast cancer, and 760 from prostate cancer. This means that lung cancer will kill more Hoosiers in 2024 than pancreatic, colon, and breast cancer (numbers 2, 3, and 4) COMBINED.

Figure 3. Leading Sites of New Cancer Cases and Deaths - 2024 Estimates



Estimates are rounded to the nearest 10, and cases exclude basal cell and squamous cell skin cancers and in situ carcinoma except urinary bladder. Estimates do not include Puerto Rico or other US territories. Ranking is based on modeled projects and may differ from the most recent observed data.

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IMPORTANCE OF RESEARCH

Research is important to me because it offers the best hope to expand our knowledge and make the therapeutic advances needed to reduce the suffering and death from cancer.

KEY TAKEAWAYS FOR ATTENDEES

My hope from today’s Gathering is that attendees will be empowered and inspired to advocate for research and to help End Lung Cancer Now develop the research toolkit that can help other people, communities, and cancer programs scale and transform their research efforts.

PASSION FOR LUNG CANCER RESEARCH

Bearing witness to the suffering and death due to cancer motivates me every day to do everything I can to make a difference. Over the 24 years I’ve been a practicing oncologist, I’ve witnessed remarkable scientific discoveries that have translated into saving so many lives.

CHALLENGES TO INCREASING RESEARCH PARTICIPATION

I think the biggest challenge is a combination of availability of high-quality research trials at every center, the complexities of care required of those trials, and the lack of urgency that is felt by key stakeholders to make the necessary changes to scale and transform lung cancer research participation.

Notes

Contact information: Nasser Hanna, MD | Email: nhanna@iu.edu

Navigating the Research Playbook: Strategies for Patient-Clinician Communication in Clinical Trials

Eric K. Singhi, MD

IMPORTANCE OF RESEARCH

Research is vital because it propels advancements in both treatment and patient care, allowing us to turn groundbreaking discoveries into tangible benefits for patients with lung cancer. It's not just about developing new therapies but also about improving our understanding of the disease and its impact on patients' lives. For me, research is a pathway to translating complex scientific findings into practical solutions, enhancing how we diagnose, treat, and support our patients.

KEY TAKEAWAYS FOR ATTENDEES

I hope attendees will gain a comprehensive understanding of how patient education intersects with the latest research in lung cancer. I'm excited to share insights on how we can effectively bridge the gap between emerging research findings and patient understanding. By focusing on tailored education strategies, we can empower patients to make informed decisions about their treatment options and actively participate in their care. This approach not only enhances patient engagement but also contributes to better health outcomes and a more informed patient community.

PASSION FOR LUNG CANCER RESEARCH

My passion for lung cancer research stems from the opportunity to make a meaningful impact on a disease that remains one of the most challenging and prevalent cancers. Research offers us the opportunity to address and overcome the unique difficulties faced by patients, particularly those with young-onset lung cancer.

CHALLENGES TO INCREASING RESEARCH PARTICIPATION

One of the primary challenges in increasing participation in lung cancer research is overcoming the stigma and misconceptions that surround the disease. Many people still only associate lung cancer with smoking, which can obscure the need for broader awareness and support. Additionally, there's often a lack of understanding about the potential benefits of participating in clinical trials and the role of research in advancing treatment. To address these challenges, it's crucial to collaborate with all stakeholders—patients, caregivers, healthcare providers, and advocacy groups—to enhance education, raise awareness, and dispel myths. By doing so, we can improve trial participation and ultimately drive progress in lung cancer research.

Contact information: Eric K. Singhi | Email: eksinghi@mdanderson.org

Barriers to Participation in Clinical Research

Brian Stemme

IMPORTANCE OF RESEARCH

Research is important to me because it represents a collective commitment from society – patients, caregivers, doctors, nurses, life sciences companies, government, and others – to refuse to accept current treatments and to make a conscious decision to seek new knowledge that might help patients suffering from cancer. More importantly, research represents hope for patients and their families. The time and effort of those individuals performing research (and those funding it) shows patients that they matter and that they are not alone in their desire for a cure.

KEY TAKEAWAYS FOR ATTENDEES

I hope that the attendees will leave the meeting with information about current barriers to clinical trial participation, the causes of these challenges and ideas on how those barriers can be overcome. I want audience members to walk away with ideas on how they can support patients and contribute to more clinical research for lung cancer.

PASSION FOR LUNG CANCER RESEARCH

Like many others involved in cancer research, I have family and friends that have been touched by cancer. Lung cancer is worthy of additional research time and funding because it is the deadliest cancer in the United States. In addition, lung cancer patients face the perception that they have caused their illness. In medicine, healthcare providers do not blame their patients. They try to extend – and save – their lives. We need to provide extra support to those diagnosed with lung cancer, not less.

CHALLENGES TO INCREASING RESEARCH PARTICIPATION

Barriers to participation include trial coordination, lack of understanding of medical research, increased procedures, and lack of trust in the healthcare system. I believe we can overcome these challenges over time to help more patients.

Contact information: Brian Stemme | Email: bstemme@hoosiercancer.org

Notes

Lined area for notes.

2ND QUARTER: GAME FILM ANALYSIS

The Heart of Research: The Impact of Patient Perspectives on Lung Cancer Research

Jill Feldman

IMPORTANCE OF RESEARCH

The true value of research for patients and families is Hope. Hope to live longer AND better so we can celebrate moments and milestones with our families. My family history illustrates hope and progress in lung cancer. My dad died 3 months after he was diagnosed with lung cancer and my mom died just 6 months after she was diagnosed. Because of advancements in research and treatment, over the past 15 years, I have celebrated moments and milestones with my family, ones that were stolen from my parents because they didn't have the options I have. For some patients, clinical trials are often the best treatment and for some it's the only treatment. But for all patients, clinical trials offer the fundamental human need of Hope - Hope represents a chance... EVERY patient deserves a chance!

KEY TAKEAWAYS FOR ATTENDEES

I hope attendees learn and understand what patient centered research looks like from a patient perspective because after all only the patient can tell you if something is 'patient centered', right? Advocates must be a true partner/part of the team from the start, and patient experience data can NOT replace patient engagement. You can have the best intentions and a great strategy, but if a trial doesn't meet the needs, preferences and realities of patients' lives the consequences can be significant. I have witnessed the impossible become possible in lung cancer over the past decade and all that can be accomplished when we work together, across disciplines and institutions, and recognize the value and utilize the patient perspective. The lived experience should absolutely shape research questions and study designs.

PASSION FOR LUNG RESEARCH

Research is our most powerful tool! Awareness & funding is critical to advances in research and treatments that help patients live longer and better. But just as important are the people who participate. Oncology is a discipline driven by evidence and data, but in the era of precision medicine and personalized medicine, knowing the data is rarely enough. Yes, we celebrate longer survival, but time is not an abstract concept; it's the currency of being able to live a life of value in the context of having lung cancer. OS isn't the only important endpoint. The science is exciting and promising, but behind every data point is a person whose life, and family, have been profoundly impacted beyond statistics and survival. There are many very important stakeholders in the drug development/clinical trial life cycle. But patients and families are the only ones impacted by every single decision made. So, I implore all researchers to change their mindset: Instead of asking why patients are hesitant to participate in trials, ask why aren't we changing the way we develop trials that would allow more patients to participate - if they do that then they will think to include patient advocates from the start!

CHALLENGES TO INCREASING RESEARCH PARTICIPATION

Barriers to participation whether it's logistical, financial, or eligibility. As the field of genomics rapidly progresses, clinical trials have become increasingly complex and complicated, involving more procedures, eligibility criteria, travel and increased costs. Communication is another huge barrier. Communication isn't something doctors learn in school, and their degree doesn't depend on it, BUT....It is at the heart of patient-centered care! Just as research and treatments advance, the way we talk about it needs to as well. Using patient friendly language to communicate science empowers patients & families to participate in SDM. We must work together!

3RD QUARTER: SPECIAL TEAMS

The Research Toolkit - The Patient's Perspective

Head Coach: Jill Feldman

Special Teams Players: Paula Pettis-Garrett, Dave Bjork, Leslie Sherman

Team Objectives

Brainstorm content to include in the **ELCN Research Toolkit** that...

- Describes the **life cycle of research** and **humanizes** the process.
- Illustrates the **bidirectional relationship** between patients and research.
- Addresses the **need for research** through the lens of lessons learned and advances in treatment.

Team Huddle Questions & Points of Discussion

1. What is the **most** important information to highlight? (*Are we missing anything?*)
2. When is the **best/most appropriate** time to share this information with patients? (*How can we share this information most effectively?*)

In addition to the live discussion, you may also submit your responses virtually by scanning this QR code:



Scan here to join an ongoing working group to review and finalize the development of the ELCN Research Toolkit:



The Research Toolkit - The Patient's Perspective

Objective 1: Humanize the Life Cycle of Research

All research begins with an idea or a question. The research process thereafter is **extensive** and **complicated**, involving several crucial steps from idea to protocol to clinical trial, which are carried out by a team of research physicians and pharmacists, nurses, study coordinators, the principal investigator (PI)*, and most importantly, the study participants.

*A **principal investigator** is the lead researcher responsible for the study design, execution, and oversight.

Content ideas to consider:

1. Explain the **entire research process** and **different phases** and/or **types** of research.
2. Highlight the **people involved** in each step of the process and **their WHY**.
3. Emphasize the **exhaustive pre-work** before a trial even begins.

Notes

3RD QUARTER: SPECIAL TEAMS

The Research Toolkit - The Patient's Perspective

Objective 2: Illustrate the bidirectional relationship between patients and research.

Patients are an integral part of the research process and team. Indeed, there has been a shift towards a more patient-centric approach to clinical research, in which patients are becoming more involved in decision-making, trial design, and result interpretation. This approach **recognizes patients as active contributors to the research process**, going beyond mere participation.

Furthermore, participation in clinical research allows everyone to help everyone – **clinical research is the key to discovering new methods of treatment**, keeping physicians up to date on the latest approaches and, in turn, helping them be strong advocates for patients. By participating in clinical research, patients gain access to new methods of treatment while receiving careful medical attention from a research team.

Content ideas to consider:

1. Describe the **critical role of the patient** as active contributors to the entire research process.
2. Highlight the goal of helping others – **research is a collective effort**.
3. Develop resources that are **patient-centric** and **easily accessible** to ALL.

Notes

The Research Toolkit - The Patient's Perspective

Objective 3: Address the need for research through the lens of lessons learned and advances in treatment.

Improved methods of treatment and patient care **only exist** because of clinical research. In fact, today's most effective standard treatments are a result of clinical research. **Because of progress made through clinical research, many people treated for cancer are now living longer!**

With that said, there is a mistrust of research stemming from historical events that has been reinforced by systemic issues and other discriminatory events. Past exclusion of participants most affected by certain conditions being studied has led to gaps in knowledge about diseases and treatment options. However, **the lessons learned through these historical low points account for the high ethical, scientific, and regulatory standards represented in today's practice.**

Content ideas to consider:

1. Describe the **lessons learned** through historical lows and **standards** in place today as a result.
2. Highlight the **importance of diversity** in clinical trial participation to further advance treatment for all.
3. Identify the **advances in treatment** that are a direct result of research.

Notes

3RD QUARTER: SPECIAL TEAMS

The Research Toolkit - The Clinician's Perspective

Head Coach: Eric K, Singhi, MD

Special Teams Players: Ryan Nguyen, MD, Bharathi Muthusamy, MD, Misty D. Shields, MD, PhD

Team Objectives

Brainstorm content to include in the **ELCN Research Toolkit** that...

- **Enhances clinician-patient communication** through education and patient-centric resources.
- **Educates and empowers patients** to participate in research through the development of patient-friendly resources.
- Emphasizes the **importance of research and the role of the patient** in advancing lung cancer care and treatment.

Team Huddle Questions & Points of Discussion

1. (As a clinician) What are the **gaps in knowledge/experience** when talking to patients about clinical research? (*If you aren't a clinician, do you have any experience/observations you'd like to share?*)
2. (As a patient) What would you **want/need to hear** from your provider regarding clinical research that would make you consider participating? (*As a caregiver, what would you need to hear to feel comfortable when it comes to your loved one participating in research?*)

In addition to the live discussion, you may also submit your responses virtually by scanning this QR code:



Scan here to join an ongoing working group to review and finalize the development of the ELCN Research Toolkit:



The Research Toolkit - The Clinician's Perspective

Objective 1: Enhance clinician-patient communication through education and patient-centric resources.

Recent survey results show that not only do most Americans believe that participation in clinical research should be a part of regular healthcare, but an even greater number believe that discussion of clinical research should at least be part of standard care¹. Therefore, **all clinicians should be prepared to discuss research with patients**. However, **there is a lack of formal training on this topic**, leading to potential misunderstandings and/or missed opportunities for patient participation in research.

1. Research!America survey of U.S. adults conducted in partnership with the ACRO and Zogby Analytics, October 2023.

Content ideas to consider:

1. Develop a **research discussion guide** that highlights best practices and communication strategies in a patient-centric way.
2. Emphasize the **importance of timing** and use of **patient-friendly language**.
3. Incorporate the **patient experience** to humanize the process.

Notes

The Research Toolkit - The Clinician's Perspective

Objective 2: Educate and empower patients to participate in research.

Fear, lack of understanding, and **language** all present **barriers** to patient participation in research. For example, a patient may be afraid of experiencing negative side effects during treatment, or they may not have received a clear explanation of the risks and benefits of participating in clinical research, which may deter them from enrolling in a study. Patients may also worry about the **time, effort,** and/or **research participation costs** – all of which may present additional barriers to participation in clinical research.

Therefore, **it is important to “level” with patients when discussing participation in clinical research.** First, it is important to be transparent with patients – address any concerns, questions, confusion, and/or fears the patient may have up front. Second, opt for clear, **patient-friendly language** when explaining clinical research and how it works. Third, consider sharing **your “why”** (i.e., passion for clinical research, personal anecdotes, commitment to meeting patient’s needs) with patients, which can build trust and foster a deeper understanding about the care being recommended.

Content ideas to consider:

1. Develop a **language guide** that translates clinical language into lay terms for patients.
2. Create **patient-friendly resources** that are **easily accessible** to all patients covering various topics.
3. Incorporate clinician and patient **stories and experiences** to break down barriers and mitigate fears.

Notes

3RD QUARTER: SPECIAL TEAMS

The Research Toolkit - The Research Operation's Perspective

Head Coach: Brian Stemme

Special Teams Players: Christy Yoder, Lisa Wood, Gabrielle Tiggs

Team Objectives

Brainstorm content to include in the **ELCN Research Toolkit** that...

- Humanizes the **technical aspects** of the clinical research enterprise.
- Emphasizes **patient safety and protections** throughout research.
- Highlights the importance of **research funding**, how it is acquired, and how it is used.

Team Huddle Questions & Points of Discussion

1. Based on the more technical aspects discussed (i.e., research process, patient safety, research funding), do you **agree** or **disagree** that this information is the most important to share? (*Is there anything you would add, remove, revise, etc.?*)
2. How can we **share** this information in a creative, effective, and interesting way? (*What would entice you to read and learn about it?*)

In addition to the live discussion, you may also submit your responses virtually by scanning this QR code:



Scan here to join an ongoing working group to review and finalize the development of the ELCN Research Toolkit:



The Research Toolkit - The Research Operation's Perspective

Objective 1: Humanize the technical aspects of the clinical research enterprise.

The clinical research enterprise can be complicated and confusing, so it must be broken down into digestible steps.

Idea to Protocol

All research begins with an **idea** – also known as the **discovery phase** – to solve a problem. The researcher will propose their idea to potential sponsors to obtain **funding** for their research. Next, the researcher develops a study plan, or **protocol**, based on their idea. During this stage, the researcher conducts **preclinical research** to test the safety and efficacy of their idea. The protocol is reviewed by multiple **scientific and ethics boards** and must comply with the FDA's good laboratory practice (GLP) regulations before advancing to the next stage.

Protocol to Publication

Once the protocol is approved, **clinical trials** begin. During this stage, other physicians agree to participate in the study and participants enroll in the study to begin receiving treatment. There are four clinical trial phases:

- **Phase 1 (Safety & dosage):** 20-100 volunteers or people with the condition (Several months)
- **Phase 2 (Efficacy & side effects):** Several hundred people with the condition (Up to 2 years)
- **Phase 3 (Monitoring of adverse reactions):** 300-3,000 people with the condition (1-4 years)
- **Phase 4 (Safety & efficacy):** Several thousand people with the condition (1-4 years+)

While clinical trials are underway, **data** is collected and analyzed by the study team. Finally, the **findings** of the study are summarized in a report and released to the public through scientific journals and/or presentations. **An average of 10 years will pass between initial discovery to full approval, with clinical trials taking up to seven years of that time.**

Content ideas to consider:

1. The **entire research process** from idea, to protocol, to clinical trial, to publication, to standard of care.
2. The **different phases and types** of research.
3. Personal **stories of people** involved – highlight the WHO behind the WHAT.

Notes

3RD QUARTER: SPECIAL TEAMS

The Research Toolkit - The Research Operation's Perspective

Objective 2: Emphasize patient safety and protections throughout the entire research process.

Participating in research can be **scary** and there is **mistrust** that exists, so it is important to emphasize **patient safety** and the **protections** in place. There are multiple layers of patient protection woven throughout the clinical research process, beginning with an **approved, established process**. In addition to the **principal investigator (PI)** in charge of study design and execution, an **institutional review board (IRB)**, the **Data Safety Monitoring Committee (DSMC)**, and the **federal Food and Drug Administration (FDA)** serve as added layers of oversight throughout the study.

Informed consent is the first, and arguably most important, layer of patient protection. This is an **ongoing process** where potential participants are given **detailed information about the study** – purpose, procedures, risks/benefits, cost(s), contact information, and confidentiality – allowing them to make a voluntary and informed decision about whether to participate. In short, informed consent addresses the **who, what, when, and why** details of the study, and it **must be signed prior to participating in any research activities**. Many people are part of the informed consent process and questions are encouraged!

Content ideas to consider:

1. The four W's of the **informed consent process** – who, what, when, and why.
2. The **multiple layers** of patient protection woven throughout the entire process.
3. The **people involved** in ensuring safety throughout the research process.

Notes

The Research Toolkit - The Research Operation's Perspective

Objective 3: Highlight the importance of research funding, how it's acquired, and how it is used.

Despite accounting for 25% of total cancer deaths in the U.S., lung cancer research only receives **9% of federal cancer research funding**. In comparison to breast cancer, which has a 91% five-year survival rate, **lung cancer patients have a five-year survival rate of only 23%**, underscoring the need for greater research funding. Although lung cancer research has made exciting progress in the last 10 years, greater funding could speed up progress against lung cancer – **the deadliest cancer** – drastically by building on recent gains and substantially reducing mortality.

Content ideas to consider:

1. The **different types** of research funding (federal vs. foundation vs. industry).
2. The **rules and regulations** to obtain different types of funding.
3. Strategies to **advocate** for more research funding.

Notes

4TH QUARTER: GAME PURPOSE



Dr. David Heilbronner was unexpectedly diagnosed with late-stage lung cancer nearly 10 years ago and was the first patient in the world to receive consolidation immunotherapy after chemoradiation for stage III non-small cell lung cancer. This happened because he was the first person to enroll in the clinical trial that was the first study to ever employ this strategy. Dr. Heilbronner is alive nearly 10 years later and the strategy used in this study is now the world-wide standard.

To watch Dr. Heilbronner's full story and learn how you can get involved with End Lung Cancer Now, visit

www.endlungcancer.iu.edu



Katie Smith was born and raised in Mishawaka, Indiana. She went on to attend Ball State University, where she studied early childhood and elementary education. After graduating, she returned to her hometown and has been teaching kindergarten for the last 24 years. Katie has two sons, Mason and Kaden. Mason is currently studying physical education and health education in college and Kaden is a senior in high school. At the age of 46, Katie was diagnosed with ALK positive Lung Cancer in January 2023.

To hear more stories like Katie's and learn how you can get involved with End Lung Cancer Now, visit

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BLUE AGAIN

Through the dark unknown, took
a gravel road and it led you
Into the booming thunder
Given nothing but a hand to take

So you close your eyes, knowing
nothing but the hand you
hold onto
And a day on the horizon
Where the clouds are
gonna dissipate

And you just have to hold on,
hold on
You just have to hold on, hold on

And we're not letting go
Not until it's all over
'Til the storm is behind us
and the skies are blue again

When you start to feel lighter
just look over your shoulder
At the thunder behind us
Now the skies are blue again
Blue again

From the city gates to the fields
upstate there's a fabric
That ties us all together
Through the weather like a
battle cry

And the darkest skies are no
match for our eyes on each other
We're marching to the same beat
Of the same drum to the
other side

And we just have to hold on,
hold on
We just have to hold on, hold on

And we're not letting go
Not until it's all over
'Til the storm is behind us
and the skies are blue again

When you start to feel lighter
just look over your shoulder
At the thunder behind us
Now the skies are blue again

Blue again

No we're not letting go,
Not until it's all over

If the storm is a year long
Or a hundred, or a thousand
We will fight to feel lighter
And fight to get older

When the thunder's behind us
The skies will be blue again
Blue again



END LUNG CANCER NOW

PREVENTION | SCREENING | RESEARCH

endlungcancer.now.iu.edu

“Blue Again” was created for the thousands of Hoosiers whose lives have been impacted by lung cancer. As those who have borne witness to the needless and preventable suffering and death from lung cancer, End Lung Cancer Now is committed to navigating the unknown and storm-filled journey alongside those who need it.

We will continue to tirelessly advocate for change, promote messages of hope and love, and build a strong network of support until the skies are blue again.

Anyone with lungs can get lung cancer. You are not alone.

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https://cancer.iu.edu/community/elcn/events/20241108-annual_gathering.html

You can access a digital copy of this playbook, copies of the slides from today's presentations, and other advocacy resources by scanning the QR code above or visiting

www.endlungcancer.iu.edu.

