



PREVENTION | SCREENING | RESEARCH

ADVOCATE TOOLKIT

“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*)



INDIANA UNIVERSITY

**MELVIN AND BREN SIMON
COMPREHENSIVE CANCER CENTER**

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OVERVIEW

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End Lung Cancer Now (ELCN) is an initiative of the IU Melvin and Bren Simon Comprehensive Cancer Center that was founded in 2020 by a bold group of lung cancer advocates. We are an advocate-centric, volunteer-driven, and community-focused initiative fully committed to achieving our vision.

OUR VISION

End the suffering and death from lung cancer in Indiana.

OUR MISSION

Educate and empower community advocates to:



Eliminate tobacco use in Indiana.



Screen all eligible Hoosiers with low-dose CT scans.



Increase participation in lung cancer research.



Support lung cancer survivors and caregivers.

OUR VALUES

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

Lung cancer is the leading cause of cancer-related death – **BY FAR.** Each year, lung cancer kills more people than colorectal, breast, and prostate cancer combined. That wasn't always the case, and it doesn't have to stay that way.



BEING AN ADVOCATE

advocate (ad-vo-cate)

noun / one who defends or maintains a cause or proposal

verb / to support or argue for (a cause, policy, etc.)

The core of ELCN's mission is to educate and empower community members to become lung cancer advocates and help us achieve our vision. Since its inception in 2020, the initiative has connected with hundreds of community members to provide information, opportunities, and resources to join us in making a positive impact in the lives of those impacted by lung cancer.

We understand that this work is personal, and we hope that this Advocate Toolkit serves as a resource to generate ideas as you consider what advocacy looks like and means to you. As you think about your story and your why, also consider your natural gifts, talents, interests, and experiences. What friends, family members, and social circles would benefit from this information? What would you like to contribute and what would you like to gain from your advocacy work?

As you consider the invitation to become a lung cancer advocate, think about what components of our work interest you. Opportunities exist to align your interests with our mission.

Prevention

Tobacco products cause 80-90% of lung cancer, and more than 1 million Hoosiers still smoke daily. Help us accelerate the efforts to eliminate tobacco use in Indiana.

Screening

We know that early detection saves lives, yet only 5.1% of eligible Hoosiers participate in lung cancer screening. Help us educate and empower the community to significantly improve this rate.

Research

Advances in treatment come only from clinical trials, but less than 5% of eligible patients currently participate. We need your help in sharing the message that Research Cures Cancer.

Advocacy

A lack of awareness and undeserved stigma contribute to ongoing challenges for survivors (i.e., a person from the time of a cancer diagnosis until the end of life). While support services exist, coordination of these services is often lacking. Join us in changing the perception.

We hope that this toolkit will inspire and empower you to **start right now, where you are, with just what you have, to make a difference.**

To become an ELCN advocate, simply visit: <https://go.iu.edu/6TqC> or scan the QR code to fill out the online form. An ELCN team member will follow-up with you once your form has been submitted.



If you are interested in connecting with a member of the ELCN team one-on-one to talk further, please contact Leo Rafail, ELCN Community Engagement Coordinator, for more information via email lrafail@iu.edu or by phone 317-274-0301.

SUCCESS STORY – THE WHITE RIBBON PROJECT



ELCN works closely with other passionate and impactful organizations, like The White Ribbon Project, to raise community awareness and crush the stigma around the disease. The origin of The White Ribbon Project demonstrates how one simple idea can turn into a worldwide movement.

When diagnosed with Stage IIIA (Stage 3-A) inoperable lung cancer five years ago, Heidi Onda was given a grim prognosis and only one treatment option. She became so frustrated with feeling rejected and unsupported due to the stigma against lung cancer and decided to take matters into her own hands. She asked her husband, Pierre, to make a white ribbon out of plywood to hang on their front door.

Within six months of Heidi posting a photo with her white ribbon on social media, more than 1,000 ribbons were made and shipped all around the world. The creation of the first white ribbon spurred a global movement to improve all aspects of lung cancer from prevention and early detection, better treatments, research, and survivorship.

The Power of the Ribbon

The White Ribbon Project is about taking power back. Those directly impacted by lung cancer have to be comfortable talking about it before other people will be open to it. This movement is tackling the misperceptions about lung cancer and recruiting advocates around the globe to start conversations within their communities, in cancer centers, and with other lung cancer advocates about how we can support each other and create a sense of community.

It's time to ensure that everyone knows that ANYONE with lungs can get lung cancer, and no one deserves lung cancer.

To learn more about The White Ribbon Project, how you can get involved, and the steps involved in hosting your own white ribbon build, visit www.thewhiteribbonproject.org.



Heidi and Pierre Onda,
Co-Founders



SHARE YOUR STORY

When it comes to advocacy, your story is your **most powerful tool**. Whether you feel comfortable sharing your story with large groups or just one person, your unique and personal experiences can have a major impact. Practice a one-minute and a three-minute version so that you can feel confident sharing in different settings. Be authentic. Keep it simple. Own it. **Your voice has value and your journey matters.**

Consider sharing your story in artistic and creative ways. Write a song about your experience. Create a painting depicting your journey. Create a photo collage humanizing lung cancer. If you are interested in sharing your story with ELCN and being featured in a future video, please email us at elcn@iu.edu.

To listen to stories shared by other ELCN advocate, visit endlungcancernow.iu.edu.

CONNECT

Across the state of Indiana, in every community, small town, big city, places of gathering and worship, we share the same hope to live joyful and meaningful lives free from cancer. We rely on each other. We are in this together. We are truly connected. It is through these connections where we can truly make a difference.

Connecting ELCN with the people in your communities can be done in many ways. It can be as simple as sharing the link to ELCN's website, writing a personalized email or letter to share with family and friends, or inviting ELCN to speak to your school, place of worship, book club, nail salon, barber shop, or place of employment. No idea is too big nor too small.

EMAIL / LETTER SAMPLE

Subject line ideas:

Check this out! / This group is really making a difference! / This organization is doing great work!

Message Body:

Dear friend,

I wanted to share some information with you about an organization that is important to me. End Lung Cancer Now (ELCN) is an initiative of the IU Simon Comprehensive Cancer Center (IUSCCC) and was founded in 2020 by Dr. Nasser Hanna. ELCN's vision is to end the suffering and death from lung cancer in Indiana and their mission is to educate and empower community advocates to improve prevention, screening, research, and advocacy efforts in Indiana. ELCN strives to crush the stigma and ensure that everyone knows that ANYONE with lungs can get lung cancer and NO ONE deserves lung cancer.

{Insert personal story or personal connection to the initiative}

To learn more about their work and gain a better appreciation for their impact, visit their website at www endlungcancernow.iu.edu.

SOCIAL MEDIA TIPS

About 10 years ago, the [ALS Ice Bucket Challenge](#) captivated the world on social media. One person's passion and "small" idea brought ALS to the attention of millions. As the ALS Ice Bucket Challenge demonstrated, intentional use of social media can make a huge impact.






Are you active on Facebook, Twitter, Instagram, or other social media? Get social to help us raise awareness, crush the stigma, and recruit your team to become advocates alongside you. Visit the Advocacy page on our website to find downloadable graphics you can share!

Here are some tips on how to use social media effectively as a lung cancer advocate:

- **Know your team.** Whether they are friends, family, co-workers, or fellow community members, understanding your audience helps your message resonate with your followers.
- **Make it personal.** From the latest buzz on lung cancer screenings to groundbreaking research, educational resources, moving stories of strength, and practical tips for lung cancer prevention and care, share information that is interesting to you that you think others might benefit from.
- **Show, don't just tell.** Visuals like photos, videos and infographics will help grab attention and stick in people's minds to convey your message effectively. You can download shareable graphics from our website on the "Advocate" page.
- **Let's rally together.** Encourage your team to jump in and take action. Whether it's leaving a comment, hitting that share button, or exploring our website for more information, let's spark some action and create change together.
- **Tag it up.** When spreading the word on social media, don't forget those hashtags. Use **#EndLungCancerNow**, **#ResearchCuresCancer**, **#ScreeningSavesLives**, **#AnyoneWithLungsCanGetLungCancer** to ensure your message is heard far and wide.

CONNECT WITH US ON SOCIAL MEDIA



-  @iusimoncancercenter
-  @iusimoncancercenter
-  @iucancercenter
-  linkedin.com/company/iucancercenter
-  @iusimoncancercenter

SUBSCRIBE TO OUR NEWSLETTER



Sign up to receive ELCN's monthly newsletter, CONNECTED, to stay in the know about the latest updates in lung health, lung cancer research, and supportive resources for patients and caregivers. You will also find inspiring stories and learn more about upcoming events and volunteer opportunities for ELCN. This is also a great resource to share with your networks who might benefit from the information.

Visit <https://go.iu.edu/6TqM> or scan the QR code to subscribe today!

VOLUNTEER

The gift of your time and talents is priceless. There are plenty of opportunities to serve as a volunteer for ELCN on an ongoing basis. Help us harness the power and passion to accelerate winning the war against lung cancer.

- **Community events:** ELCN participates in a variety of community events (health fairs, festivals, etc.), throughout the year to promote lung cancer awareness. We are always looking for volunteers to help staff our booths.
- **ELCN-hosted events:** ELCN hosts three signature events each year (Lung Cancer Advocate Rally, World Lung Cancer Day, and the ELCN Gathering). We are always looking for passionate advocates to join our planning committees or serve as an event-day volunteer.
- **Care kits:** ELCN strives to provide all patients diagnosed with lung cancer an ELCN Care Kit, a gift that has been thoughtfully curated to provide a sense of comfort. Opportunities exist to help us pack and distribute these care kits to patients.
- **Focus groups:** As ELCN creates community- or patient-facing materials, we are always looking for feedback. Focus group opportunities are available to review and provide feedback on these materials.
- **Host your own event:** Would you like to host your own event to raise awareness about or fundraise for lung cancer? ELCN can help you refine your idea and provide information and SWAG.

If you are interested in any of the volunteer opportunities available, please contact Leo Rafail, ELCN Community Engagement Coordinator, for more information. He can be reached via email lrafail@iu.edu and or by phone 317-274-0301.

FUNDRAISE

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 or to organize a fundraising opportunity for ELCN, see below for a few ideas.

- **Give online:** Visit endlungcancernow.iu.edu and click “**Give Now**” at the top of the page.
- **Mail a check:** You can mail a check made payable to “IU Foundation/End Lung Cancer Now” to:
End Lung Cancer Now
c/o IU Foundation
PO Box 7072
Indianapolis, IN 46207
- **Host a house party and/or ask your loved ones to consider donating.** Bring together family and friends in an intimate setting to learn more about ELCN.
- **Ask your employer about company matching.** Some employers provide a matching gift for individual donations.
- **Create a Facebook Fundraiser.** Facebook provides an opportunity to fundraise on your profile. If you are interested in this, please contact us for instructions on how to do so.

If you would like more information on fundraising for ELCN, please contact Amber Kleopfer Senseny via email akleopfe@iu.edu or by phone 317-278-4510.

LEGISLATIVE ADVOCACY

You have the power to influence legislation and shape public policy initiatives that could impact the lives of those impacted by lung cancer. When considering how to use your voice for change, consider the following questions:

- WHAT do you want?
- WHY do you want it?
- What person or institution has the POWER to give it to you?
- How will you build credibility with and get access to those in power to influence their decision-making?

Tell Your Story

Simply sharing your story with elected officials can have a significant impact by humanizing the issue at hand. By sharing your story, you can:

- Put a face on facts and figures.
- Connect lawmakers to constituents and what's happening in their district.
- Provide the human-interest side of an issue.
- Help gain media coverage of an issue.
- Inspire new advocates to join the effort.

Contacting Elected Officials

There are various ways to contact your elected officials. Personal telephone calls and sending a personal letter are two of the most popular ways. See below for a few tips:

Identify yourself as a constituent, mention where you live (City, State), and share why you feel so strongly about the issue. Encourage the decision-maker to respond and let you know their position on the issue.

You can use this link to find your local, elected officials: <https://iga.in.gov/information/find-legislators>

If you're interested in staying up to date on current advocacy opportunities and priorities, be sure to connect with some of our partner organizations:

Our partner organizations who have advocacy opportunities and up-to-date information on priorities:



American Cancer Society
Cancer Action Network
<https://www.fightcancer.org/>



American Lung Association
Policy & Advocacy
<https://www.lung.org/policy-advocacy>



LUNGevity Action Network
<https://action.lungevity.org/>

ADVOCATE TESTIMONIES

“
“ The lack of awareness and education about lung cancer has hurt research funding, treatment options, and screening rates. This is not acceptable for the #1 cancer-killer in the U.S. All of this can change for the better with hard work and encouraging others to tell their real stories. As a team, we have the power to change this old narrative.

– **Heidi & Pierre Onda, Co-Founders of The White Ribbon Project**

“
“ I have never seen a vision gather so much energy in such a short period of time. I am honored to be a small part of the fight and stand ready to do anything to support this movement.

– **Victoria Champion, PhD, RN, FAAN**

“
“ My biggest win has been finding my voice and its value – having my journey reach people and motivate them to action. I have come to realize that saying yes to everything is the most important strategy and can lead to some pretty extraordinary opportunities.

– **Terri Ann DiJulio, three-time lung cancer survivor**

“
“ End Lung Cancer Now is a group of people that care. They're raising funds, they're raising awareness, and they're raising friends in this battle against lung cancer.

– **Andre Arnold, lung cancer advocate**

“
“ We need to end lung cancer now and we can do it. We've got the tools. Whatever it takes to get there, I'm all in.

– **Elyse Turula, lung cancer advocate**

“
“ Bearing witness to the suffering and death from lung cancer motivates me every day to do anything and everything I can to help others. It is a promise I've made to patients, and I intend to always keep that promise.

– **Nasser Hanna, MD, Founder of End Lung Cancer Now**

CALL TO ACTION

We need YOU to join us in our efforts to end lung cancer now. We hope that this toolkit has inspired and empowered you to **start right now, where you are, with just what you have, to make a difference.**



Signing up to become an ELCN advocate is simple. Visit <https://go.iu.edu/6TqC> or scan the QR code to fill out the online form. Opportunities exist to align your interests with our mission.

As you are filling out the form, remember these three things:

What is YOUR **story**?

What is YOUR **motivation**?

- Eliminate tobacco use in Indiana.
- Screen all eligible Hoosiers with low-dose CT scans.
- Increase participation in lung cancer research.
- Support lung cancer survivors and their loved ones,

How will YOU **get involved**?

- **Interested** - I am willing to learn more about signs, symptoms, risk factors, protective factors, screenings, treatments, and survivorship related to lung cancer.
- **Informed** - I am willing to share the information I learn from programs and/or training provided by ELCN to encourage others to take action about preventing lung cancer and improving outcomes. This may also include engaging policymakers and decision-makers on cancer-related issues of interest.
- **Involved** - I am willing to meet in-person or virtually to give feedback on programs, concepts, and/or communications being developed by ELCN and/or I am willing to volunteer at future programs and community events hosted by ELCN.
- **Invested** - I am willing to join a planning committee to help plan, execute, and implement programs or activities led by ELCN and/or I am willing to join the fundraising sub-committee to help raise money to support the initiative.



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