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Making Your Voice Heard: Advocacy for the Lung Cancer Community

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Overview

- My “Why”
- About LUNgevity
- Policy Priorities
- LUNgevity Action Network
- Advocacy Tips
- Call to Action

My "Why"

Cancer advocacy is a passion and a profession for me



LUNgevity: A Patient-Driven Organization

LUNgevity is...



About people diagnosed with lung cancer and **For** people diagnosed with lung cancer

***Our vision is a world where no one
dies of lung cancer***

We are focused on two goals:

Improve outcomes
for people diagnosed with
lung cancer



Improve how people live
with lung cancer



Survivor and Caregiver Connections

Online communities – Biomarker specific and cancer type specific social media communities. Blogs and forums to connect with others on the same journey.

Lung Cancer HELP line – Offer toll free connection to social workers fluent in English and Spanish. They can provide help with emotional, financial and other challenges faced by lung cancer patients and caregivers. **844-360-5864**

Lifeline Support Partners – Peer-to-peer support from survivors and caregivers. No one should take this journey alone.

Survivor and Caregiver Connections (cont.)

Clinical Trial Ambassadors – Peer-to-peer connection with survivors who will share their clinical trial experience with someone contemplating or just starting a clinical trial.

Virtual Meetups – Our online support groups moderated by LUNGeVity navigators. There is a community for everyone whether it be by biomarker, caregiver or general. Lively conversations, support and celebrations via Zoom.

Survivorship Conferences – Opportunities to meet in person or virtually and learn about the latest research, connect with other survivors and caregivers and have fun. (**HOPE Summit, ILCSC**)

Educational Opportunities

LUNG CANCER 101 – a comprehensive guide to understanding lung cancer basics

Gateways – dynamic information on specific lung cancer issues

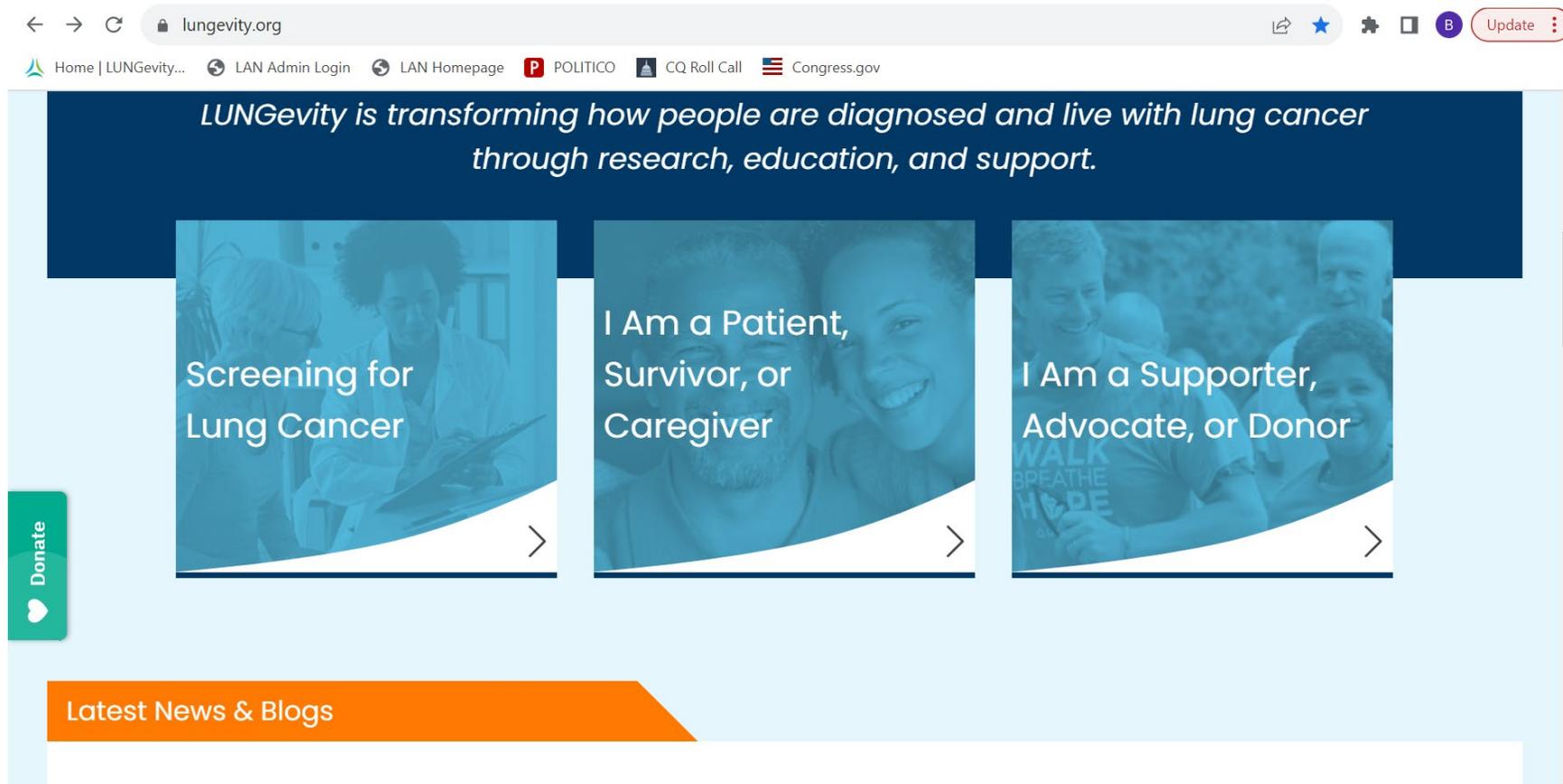
Survivor Resource Center – practical information on the everyday issues of lung cancer

Caregiver Resource Center – practical information for caregivers to help them care for themselves while caring for a loved one.

Learn With LUNgevity – regional mini conferences that are held virtually or online in partnership with providers

More information at www.lungevity.org

LUNGevity Website



LUNGeivity Public Policy

Focus on public policy issues that promote and remove barriers to:

- Advancement in innovation in diagnostics and therapeutics
- Access to quality care across the lung cancer continuum for **ALL** people diagnosed with lung cancer

Policy and Advocacy Partnerships

Collaborations

- Monthly Policy Check-in Calls with partners (American Lung Association, GO2 for Lung Cancer, American Cancer Society Cancer Action Network)

Coalitions

- LungCAN
- One Voice Against Cancer
- Cancer Leadership Council
- Personalized Medicine Coalition
- Defense Health Research Consortium
- Alliance for a Stronger FDA
- Cancer Early Detection Alliance
- ...and many more

Policy Priorities

Coverage across the continuum of lung cancer care

- Screening, diagnosis, biomarker testing, treatment, survivorship

Reducing barriers to optimal care

- Such as prior authorization, step therapy, copay accumulators

Clinical trial access and process improvements

- Support for out-of-pocket, non-medical expenses
- Making clinical trials more patient-friendly

Policy Priorities (cont.)

Research Funding

- National Institutes of Health/National Cancer Institute
- Lung Cancer Research Program, part of the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense

LUNGevity Action Network



Advocacy Updates

| Take Action

| Join Now!

| Resources ▾

| LUNGevity's Public Policy Work



Welcome Advocates

The LUNGevity Action Network gives lung cancer advocates information, training, and tools to create positive change. Advocates take important actions like signing petitions, sending messages to policymakers and regulators, and sharing impactful stories. This group helps advance LUNGevity's mission to improve how people are diagnosed, navigate, and live with lung cancer.

LUNGeivity Action Network

Advocacy Updates

- LAN newsletters, LUNGeivity statements, and other news

Take Action

- Make your voice heard by sending messages to policymakers

Join Now!

- Sign up to receive email updates on upcoming events, action alerts, and news

Resources

- Previous webinars, advocacy terms, and FAQs

LUNGeivity's Public Policy Work

- More information on our policy approach and issues we engage on

Current Action Campaigns

Federal Funding for Lung Cancer Research

- Asking Congress to provide the highest possible funding for the NIH, the NCI, and the Lung Cancer Research Program at the Department of Defense in Fiscal Year (FY) 2024.

Lung Cancer Screening

- Support the Increasing Access to Lung Cancer Screening Act, which would reduce barriers such as cost sharing and prior authorization; broaden eligibility for smoking cessation therapies; improve screening awareness; and study additional populations that should be considered for screening.

Current Action Campaigns (cont.)

Step Therapy

- Support the Safe Step Act, which would establish important guardrails on insurers' use of step therapy.

Cancer Drug Parity

- Support the Cancer Drug Parity Act, which would prevent insurers from requiring higher copays for oral cancer drugs compared to IV therapies.

Cancer Survivorship

- Support the Comprehensive Cancer Survivorship Act, which would improve the quality and coordination of care for cancer survivors.

More opportunities to learn and engage

Advocacy Events and Hill Days

- Rally for Medical Research (September)
- OVAC Grassroots Lobby Day (March)

Legislative Briefings

- Priorities for the lung cancer community
- Virtual and in-person
- Stay tuned to the LUNgevity Action Network for upcoming events!

Panels and Advisory Boards

- Lung Cancer Research Program Consumer Reviewers
- FDA Advisory Committees

Advocacy Tips

Your story is a powerful tool

- What is most important for the policymaker to understand this issue from your perspective?
- Have a short (2-minute) and longer (5-minute) version of your story ready to share.

Data can also be helpful

- Statistics can help illustrate the impact of lung cancer and the urgency to act.
- The more local the information, the better.

Advocacy Tips (cont.)

Lung cancer is a nonpartisan issue

- Approach each meeting or communication as an opportunity to connect on this topic, even if you don't agree on other issues.
- You may be surprised who ends up becoming a champion because of their personal connection or because of your own story.

Staff are key to policy decisions

- Many staffers are subject matter experts in the topics you want to discuss. Others may be learning but you can help shape their views.
- Building and maintaining relationships is invaluable.

Advocacy Tips (cont.)

Be persistent

- Don't be discouraged if it takes multiple tries, or if you need to find another way forward.
- Advocacy “wins” build off each other to get us closer to our ultimate goals.

Work together

- No one has all the answers, but we all have something to contribute.
- Find partnerships with other advocates and organizations to complement and strengthen your advocacy.

Call to Action!

Visit action.lungevity.org

Three actions you can take today:

- Join the LUNGevity Action Network to get the latest information and updates
- Send a message to your members of Congress using one or more of our action campaigns
- Share your story

Thank You!

Questions?

Reach out to Brandon:
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or contact the LUNGevity Action Network:
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