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# Community and Collaborations – From Hope to Change

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September 26, 2025

✓ Precise Definition (General Use):

A **community** is a group of people who share a common geographic location, identity, interest, or set of circumstances, and who interact with each other in ways that create a sense of belonging or shared purpose.

✓ Precise Definition (General Use):

**Collaboration** is a structured process in which two or more individuals, groups, or organizations actively work together toward a shared goal by contributing resources, knowledge, or effort, while maintaining mutual respect, accountability, and shared decision-making.



Community = HOPE

Community is a powerful source of hope!



**First LCI Summit (2014)**

# Community is a powerful source of hope!



**First LCI Summit (2014)**



**Second LCI Summit (2018)**

And our community has been increasing



**This is the power of community – LCI Summit (2024)**

# There is science backing this



## **The Importance of Social Support, Optimism and Resilience on the Quality of Life of Cancer Patients**

*Iván Ruiz-Rodríguez\*, Isabel Hombrados-Mendieta, Anabel Melguizo-Garin and  
María José Martos-Méndez*

### Study included:

- 142 people with cancer
- Tested whether social support, optimism, and resilience impacted quality of life

From: PMID:35356348

# There is science backing this



## The Importance of Social Support, Optimism and Resilience on the Quality of Life of Cancer Patients

Iván Ruiz-Rodríguez\*, Isabel Hombrados-Mendieta, Anabel Melguizo-Garin and María José Martos-Méndez

functioning scales). The regression equation for global health shows  $R^2=0.166$ ,  $F=13,841$ ,  $p<0.001$ . Resilience ( $\beta =0.330$ ,  $p<0.001$ ) and satisfaction with informational support from friends ( $\beta =0.161$ ,  $p=0.049$ ) relate to an increase in cancer patients' global health. Regarding functioning scales, the

### Study included:

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- Tested whether social support, optimism, and resilience impacted quality of life

People who are more satisfied with the information and support they get from friends tend to have better overall health

From: PMID:35356348



“Online”  
Community = ?

# It started with a meeting of like-minded people



**From left to right:** Stuart Grief, Lisa Goldman, Tori Tomalia, Janet Freeman-Daily, Lysa Buonanno

Picture courtesy: Janet Freeman-Daily's personal blog, Gray Connections

# It started with a meeting of like-minded people



They had a lot in common:

1. They were seeking out community
2. Their lung cancers shared an oncogenic fusion – ROS1
3. Their lung cancers were relatively rare

Picture courtesy: Janet Freeman-Daily's personal blog, Gray Connections

# They founded a patient & caregiver group

The **ROS1**ders

## Our Mission

**The ROS1ders is a global group of patients and caregivers living with ROS1+ cancer. We seek to improve outcomes for all ROS1+ cancers through community, education, and research.**

From: <https://www.theros1ders.org/about-the-ros1ders>

# What about the proof?

Supportive Care in Cancer (2021) 29:4493–4500  
<https://doi.org/10.1007/s00520-021-05989-1>

ORIGINAL ARTICLE



## A qualitative study of online support communities for lung cancer survivors on targeted therapies

Casey A. Walsh <sup>1,2</sup> • Morhaf Al Achkar <sup>3</sup>

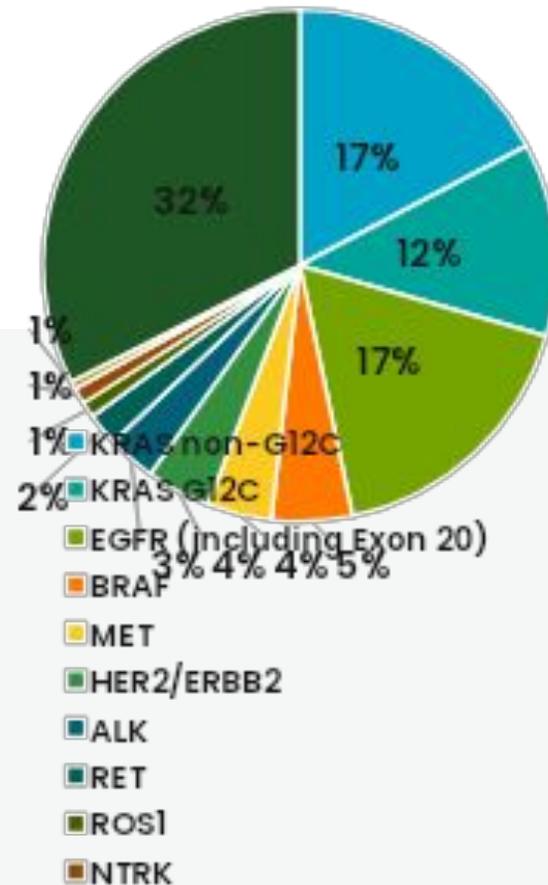
### Psychological

Positive impacts included feelings of hope and support, such as being reassured after learning about their disease from peers and hearing what they considered inspirational stories in survivors' journeys, e.g., "It was late, and I was in my bed terrified and so alone. I put something on there. This woman in Australia, within five minutes, posted back, 'Hey, my husband's been alive for four years and going strong.' Nothing in the world could have felt better than a real human being saying to me, 'There's hope. I'm with you right now in this moment'" (1004). Receiving support from survivors who listened and understood reduced the emotional burden on family and friends.

From: PMID:33458808

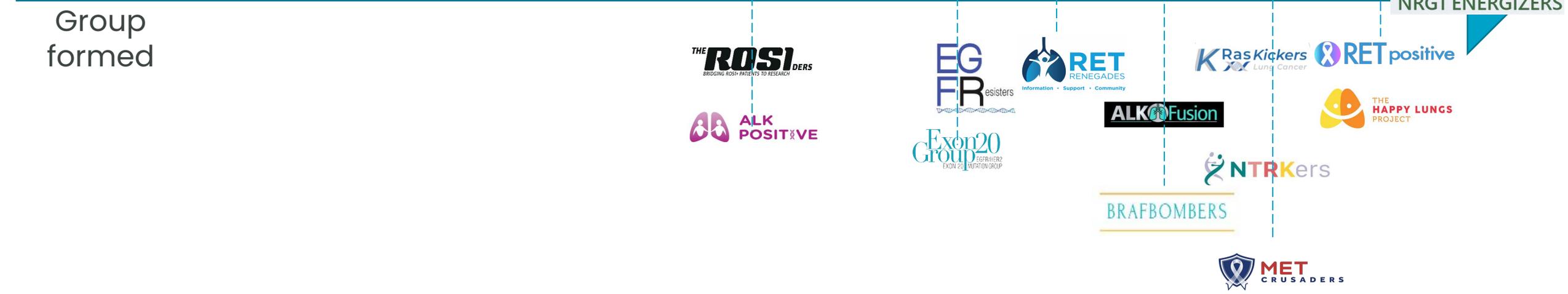
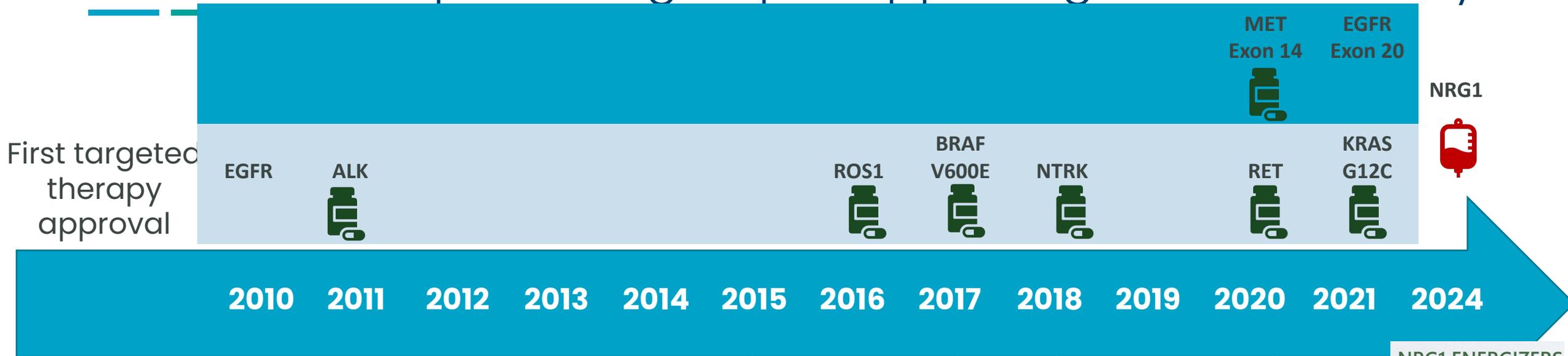
# Some lung cancers have targetable biomarkers

Targetable biomarkers in nonsquamous NSCLC



From: PMID: 34273294

# And there are patients groups supporting the community



 THE ROSI DERS BRIDGING ROS1 PATIENTS TO RESEARCH	ROS1+ cancer	info@theros1ders.org	ros1cancer.com	@ros1cancer
 ALK POSITIVE	ALK+ NSCLC	info@alkpositive.org	www.alkpositive.org	@ALKLungCancer
 Exon20 Group EGFR & HER2 EXON 20 INSERTIONS	EGFR & HER2 Exon 20 insertions	exon20@exon20group.org	exon20group.org	@Exon20Group
 EGFR Resisters	EGFR+ NSCLC plus resistance to EGFR TKIs	egfresisters@gmail.com	www.egfrcancer.org	@EGFRResisters
 RET RENEGADES Information - Support - Community	RET+ NSCLC	retrenegades@gmail.com	N/A	@RETRenegades
 ALK Fusion	ALK+ NSCLC	info@alkfusion.org	www.alkfusion.org	@alk_fusion
 K Ras Kickers Lung Cancer	KRAS+ NSCLC	terri@kraskickers.org	kraskickers.org	@kRasKickers
 NTRKers	NTRK+ cancer	info@ntrkers.org	ntrkers.org	@NTRKers
 MET CRUSADERS	MET+ NSCLC	info@metcrusaders.org	www.metcrusaders.org	@METCrusaders
 BRAFBOMBERS	BRAF+ NSCLC	brafbombers@gmail.com	--	@BRAFBombers
 RET positive	RET+ cancer	info@retpositive.org	https://www.retpositive.org	@RETpositive
 THE HAPPY LUNGS PROJECT	RET+ NSCLC	info@happylungsproject.org	https://happylungsproject.org/	
 NRG1 ENERGIZERS	NRG1+ cancers	connect@nrg1energizers.org	https://www.nrg1energizers.org/	





**Community =  
Driver of AWARENESS**

# The White Ribbon Project – Driving change



## Origin of the Ribbon

By October, Heidi Onda became so frustrated with being rejected by hospital administrators and marketing departments that she asked her husband, Pierre, to make a white ribbon out of plywood to hang on their front door. “No one can stop me from putting a white ribbon up on my own house!” she said. Pierre made the ribbon with a sticker reading “Lung Cancer Awareness,” and Heidi shared pictures of it on a private Facebook page for lung cancer survivors in Colorado. Everyone loved the images of the Ondas’ ribbon and began asking for their own.

Heidi and Pierre turned their garage into a ribbon-making warehouse and began personally creating and shipping white ribbons all over the country, each one signed by its maker. Heidi even handwrites a personal note to accompany each ribbon she and Pierre send. Fighting the lung cancer battle is very personal and unique to every person affected by lung cancer; these signed ribbons and notes remain a very important part of the effort, both to Heidi and to those receiving a ribbon.

## A Symbol of a Movement

Pierre and Heidi’s creation of the first ribbon has spurred a movement to build community, reframe education, increase awareness, and remove the stigma against the lung cancer community. Some ribbon recipients use their own ribbon to make more ribbons for friends, caregivers, and medical personnel in their local community.

From: <https://www.thewhiteribbonproject.org/origin-story>

# The White Ribbon Project – Driving change



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# The White Ribbon Project aims to connect the lung cancer community.

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From: <https://www.thewhiteribbonproject.org/origin-story>

# TWRP is increasing awareness

ASSOCIATION NEWS



## White ribbons around CHEST HQ raise awareness for lung cancer screening and early detection

December 1, 2024 | Estimated time to read: 2 minutes



CHEST, or the American College of Chest Physicians, is a professional organization focused on advancing the prevention, diagnosis, and treatment of lung and chest diseases through education, research, philanthropy, and advocacy for chest medicine and patient care

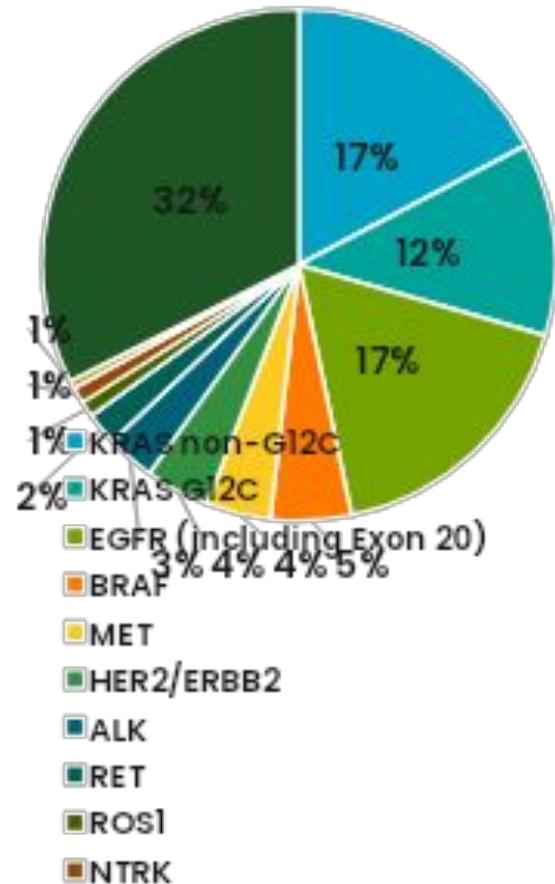


**Community =  
Agent of CHANGE**

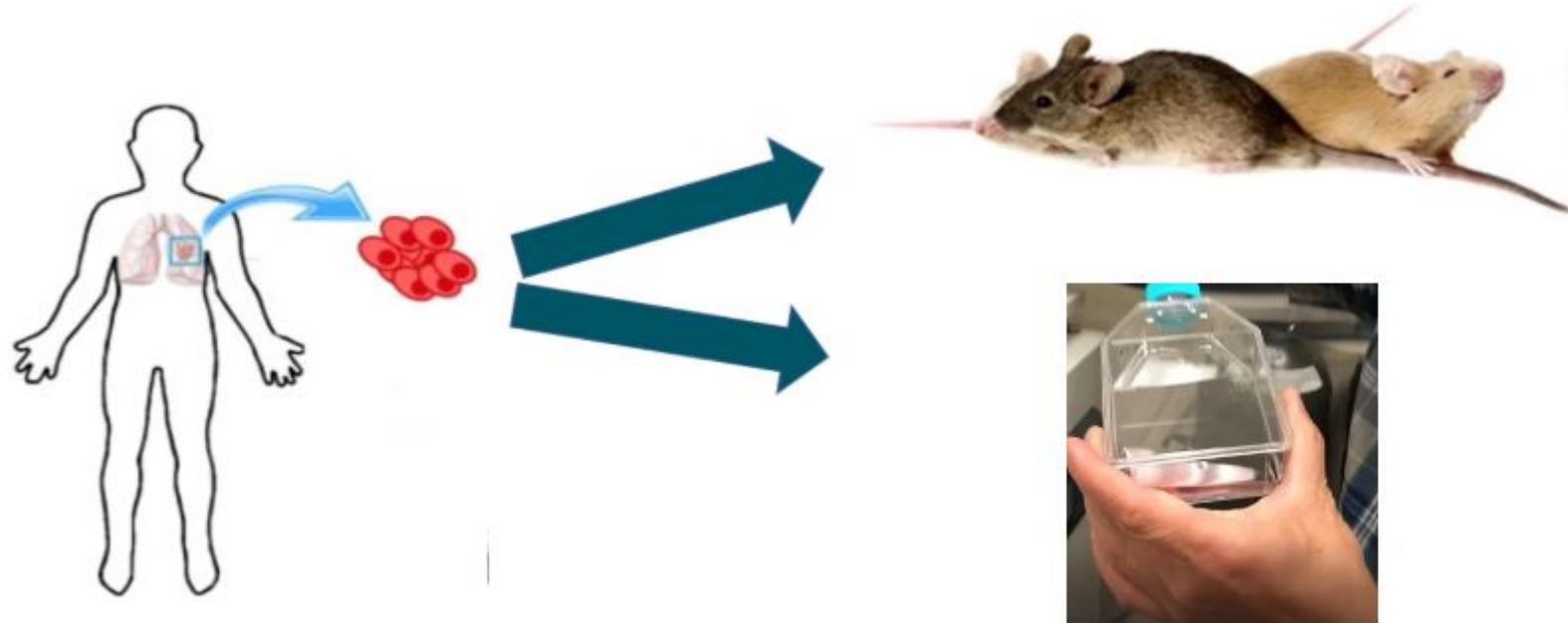
# An example of ROS1+ cancers

Targetable biomarkers in nonsquamous NSCLC

ROS1+ non-small cell lung cancer - 1%-2% of the pie (rare) Studying it can get difficult



# What is a cancer model?



- Cancer models allow us to study cancer outside the human body.
- To make these types of models, researchers need live cancer cells donated by patients.

# ROS1ders Cancer Model Project

Patients



Families



Doctors



Nurses



Laboratory  
Scientists



Advocacy  
groups



# ROS1ders Cancer Model Project

Patients



Nurses

PRECISION MEDICINE AND IMAGING | JULY 15 2018

## Resistance Mechanisms to Targeted Therapies in *ROS1*<sup>+</sup> and *ALK*<sup>+</sup> Non-small Cell Lung Cancer **FREE**

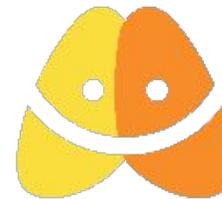
Caroline E. McCoach ; Anh T. Le; Katherine Gowan; Kenneth Jones; Laura Schubert; Andrea Doak; Adriana Estrada-Bernal; Kurtis D. Davies; Daniel T. Merrick; Paul A. Bunn, Jr; W. Tom Purcell; Rafal Dziadziuszko; Marileila Varella-Garcia; Dara L. Aisner; D. Ross Camidge; Robert C. Doebele 

We would like to thank the ROS1ders patient

advocacy group ([ros1cancer.com](http://ros1cancer.com)) for their support of ROS1 research and their donation of tissue samples for the creation of novel ROS1 cell lines.



**ALK  
POSITIVE**



THE  
**HAPPY LUNGS**  
PROJECT



✓ Precise Definition (General Use):

**Collaboration** is a structured process in which two or more individuals, groups, or organizations actively work together toward a shared goal by contributing resources, knowledge, or effort, while maintaining mutual respect, accountability, and shared decision-making.



Collaboration =  
One Voice

# Lung Cancer Action Network



**All lung cancer advocacy groups in the United States**



# U.S. Advocacy Strategy Nets a 25 Percent Increase in Lung Cancer Research Funding

PRESS RELEASE | SEP 11, 2023

In January 2022, the Lung Cancer Action Network (LungCAN) took action by forming a dedicated Steering Committee of passionate advocates led by Jill Morningstar, a strong advocate with Capitol Hill experience, along with her husband Al Fitzpayne, a lung cancer survivor. The committee developed a strategic plan to increase the LCRP budget, aiming to allocate funding based on the amount needed to support top-rated research proposals from the previous year.

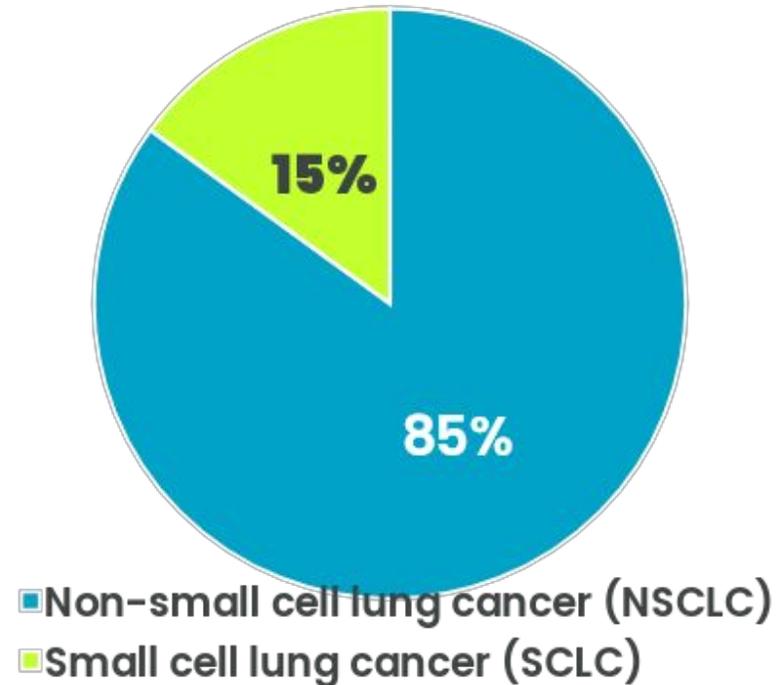
A unified and concentrated lung cancer advocacy program in the United States resulted in a 25 percent increase in funding to a U.S.-based lung cancer research program, according to a presentation given today at the International Association for the Study of Lung Cancer 2023 World Conference on Lung Cancer in Singapore.



# Collaboration = Foundation of HOPE

# The story of Small Cell Lung Cancer (SCLC)

Types of lung cancer

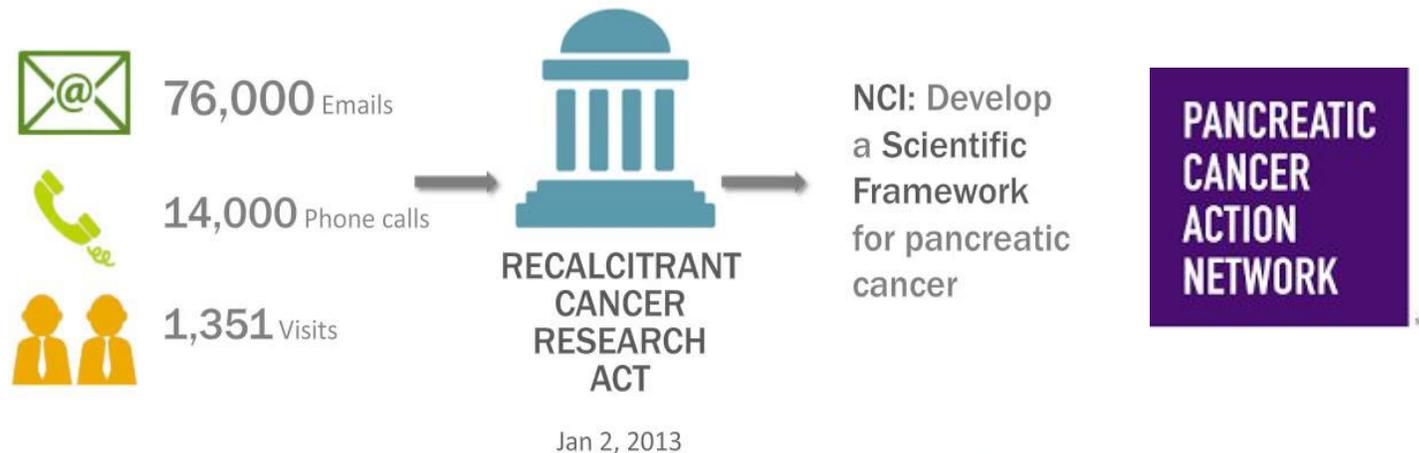


# How collaboration changed SCLC research

## Lessons from the Recalcitrant Cancer Research Act

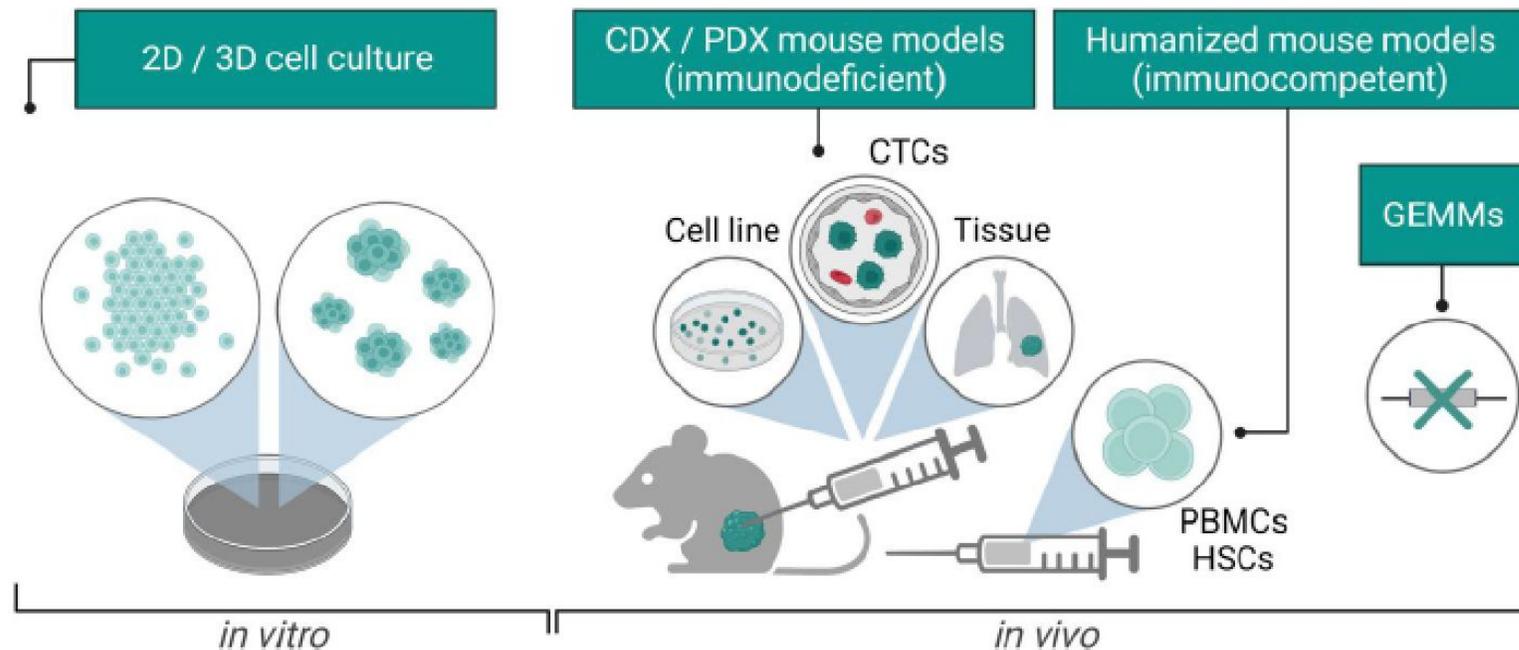
- The Recalcitrant Cancer Research Congressional Act of 2012 (H.R.733) directs National Cancer Institute (NCI) to utilize resources for research and treatment of **recalcitrant cancers** having five-year relative survival rates of less than 20%
- Initial focus on pancreatic carcinoma and SCLC – – > **Because SCLC has five-year survival rate of less than 7%**

### Power of Policy Advocacy



# National Cancer Institute SCLC research consortium

- \$20 million in funding for SCLC research and more than 600 collaborative publications between US and international researchers
- Consortium has allowed for the development of publicly shareable tools to study SCLC



2D/3D indicates 2-dimensional/3-dimensional; CDX, cell line-derived xenograft; GEMMs, genetically engineered mouse models; HSCs, hematopoietic stem cells; PBMCs, peripheral blood mononuclear cells; PDX, patient-derived xenograft;

From: PMID: 37551311

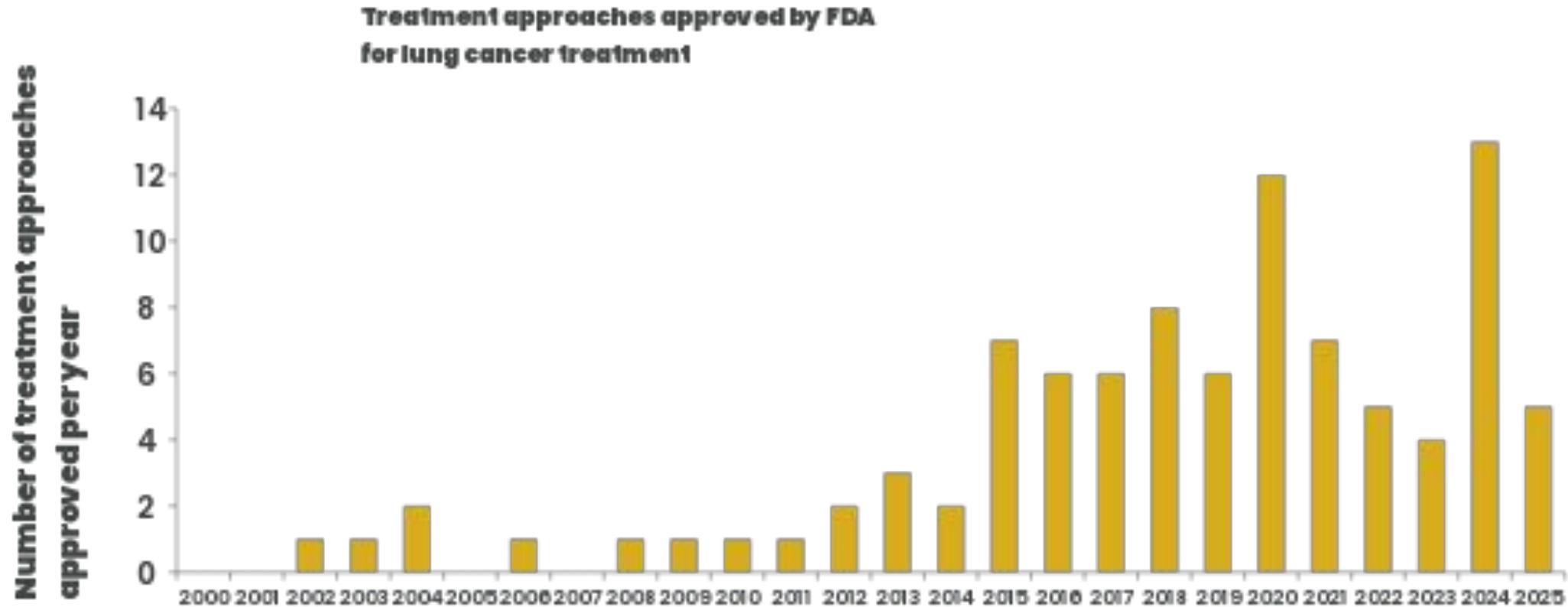


# Collaboration = HOPEFUL Present

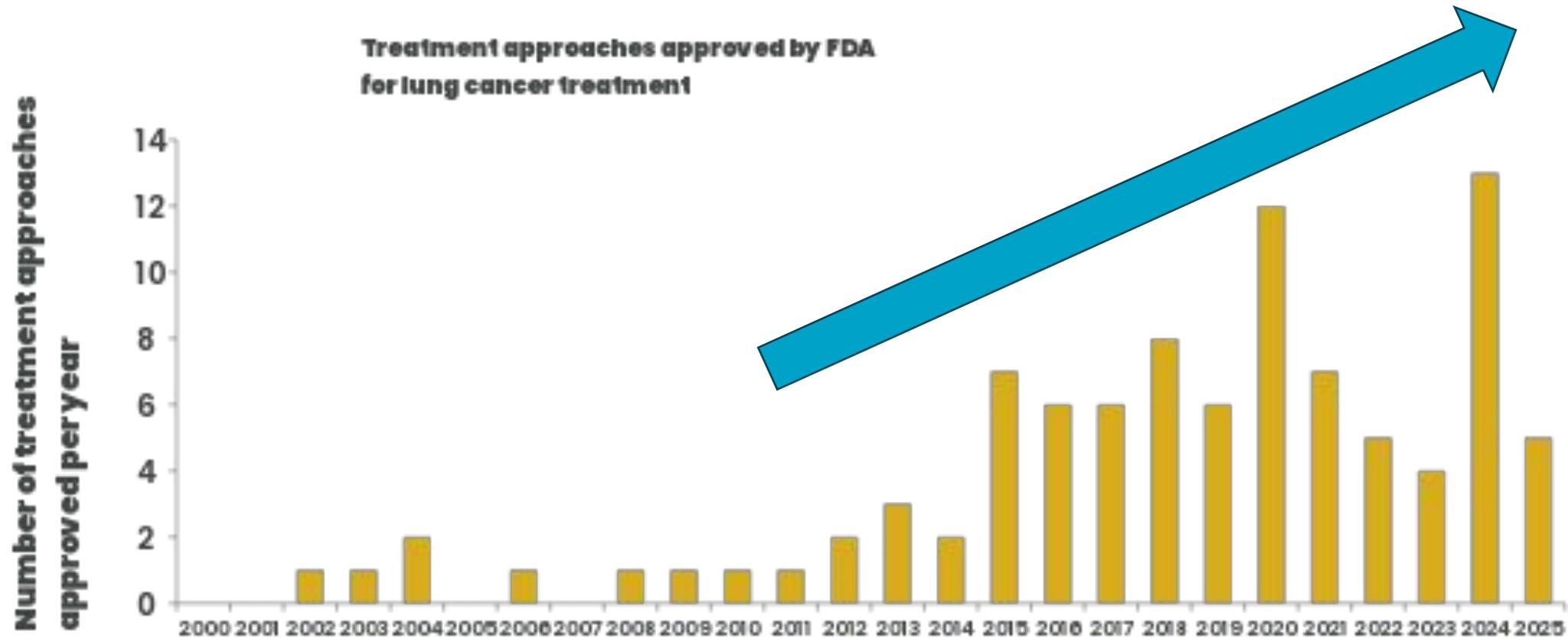
# How collaboration has made new treatments possible



# 2025 lung cancer treatment landscape



# 2025 lung cancer treatment landscape





Collaboration =  
HOPEFUL future

# Lung Cancer Initiative – LUNGEvity collaboration



LUNG CANCER INITIATIVE  
A NETWORK OF HOPE AND ACTION



LUNGEVITY  
Transforming Lung Cancer



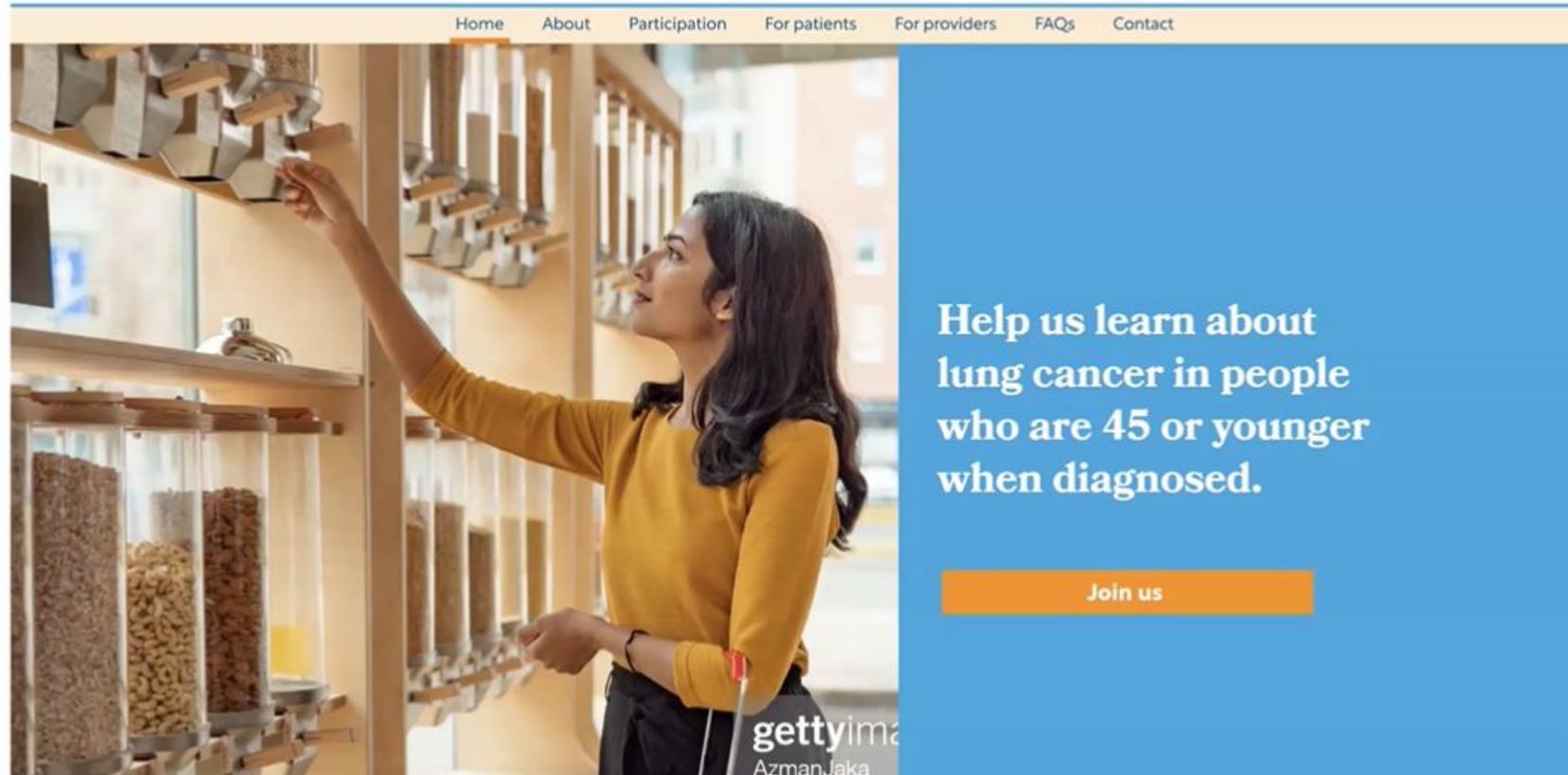
Dr. Jaclyn LoPiccolo  
DFCI

**Problem:** The median age of diagnosis of lung cancer is 70 years. However, lung cancer is increasing in people younger than 45 years. Is there a genetic cause?



**Impact:** Increase our understanding of the contribution of genetics in young lung cancer development and help develop potential early detection strategies

Study website: [younglungstudy.org](https://younglungstudy.org)



# Much more than just research

FACEBOOK LIVE

Wednesday, Feb. 14 • 12 p.m. ET

## Is Lung Cancer in Young Adults **Hereditary?**

an LCI-LUNGEvity research partnership investigates



2024 event --- 2.5K views

500 participants enrolled

LUNGEVITY

MEET THE PANELISTS

**GWEN ORILIO**  
Patient Advocate

**JACLYN LOPICCOLO, MD, PHD**  
Dana-Farber Cancer Institute

**Jenni Danai**  
Lung Cancer Initiative

**Upal Basu Roy, PhD, MPH**  
LUNGEvity Foundation

FRIDAY, AUGUST 1 • 12 PM ET

2025 event --- 1.4K views



Community = HOPE

Community = CHANGE

Collaboration = HOPEFUL Present and Future



**Advocacy** is the deliberate act of supporting, promoting, or defending the rights, needs, interests, or well-being of individuals or groups—often to influence decisions, improve outcomes, or effect systemic change.



Community = HOPE

Community = CHANGE

Collaboration = HOPEFUL Present and Future

Community + Collaboration + Advocacy =

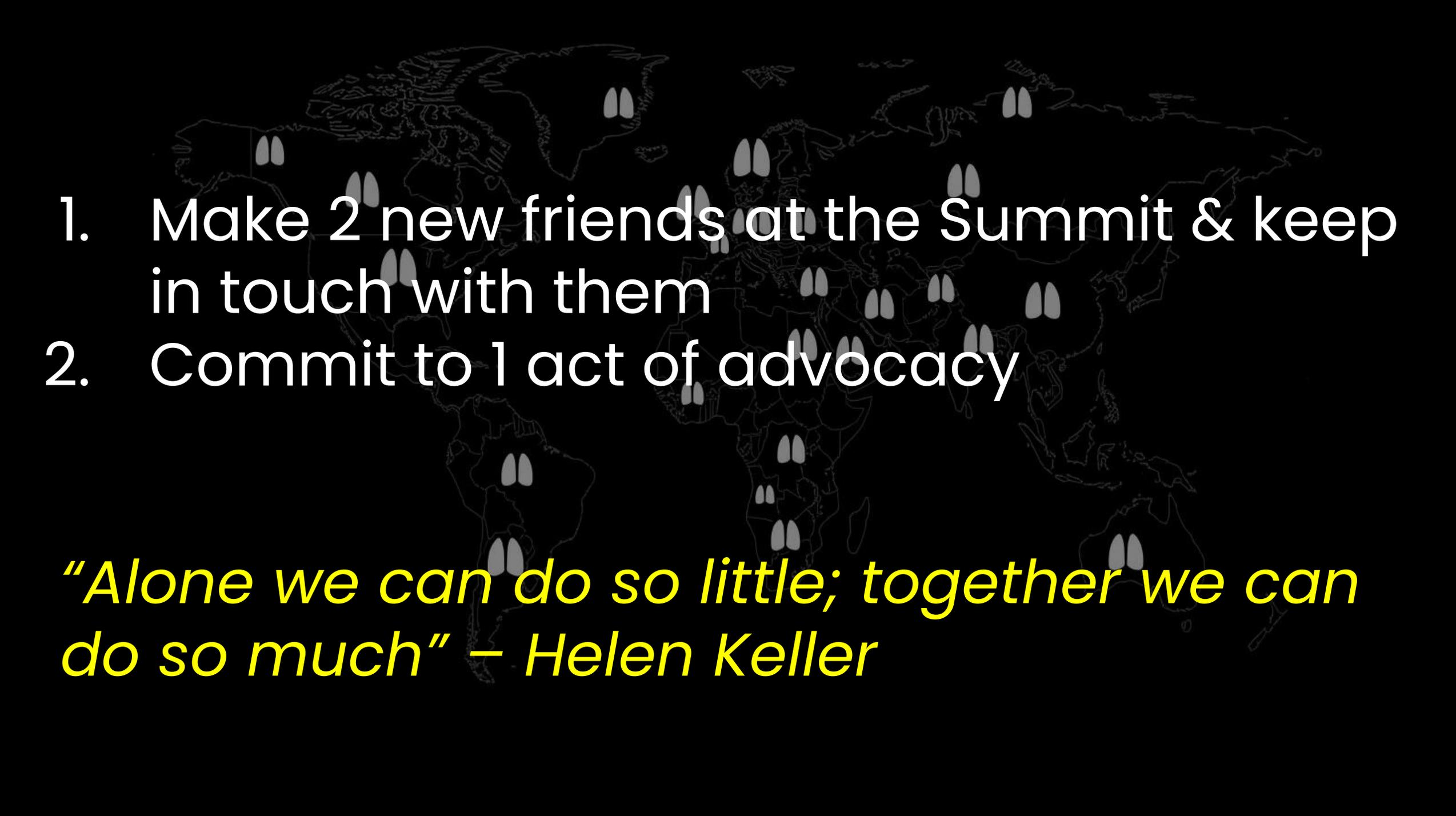


Community = HOPE

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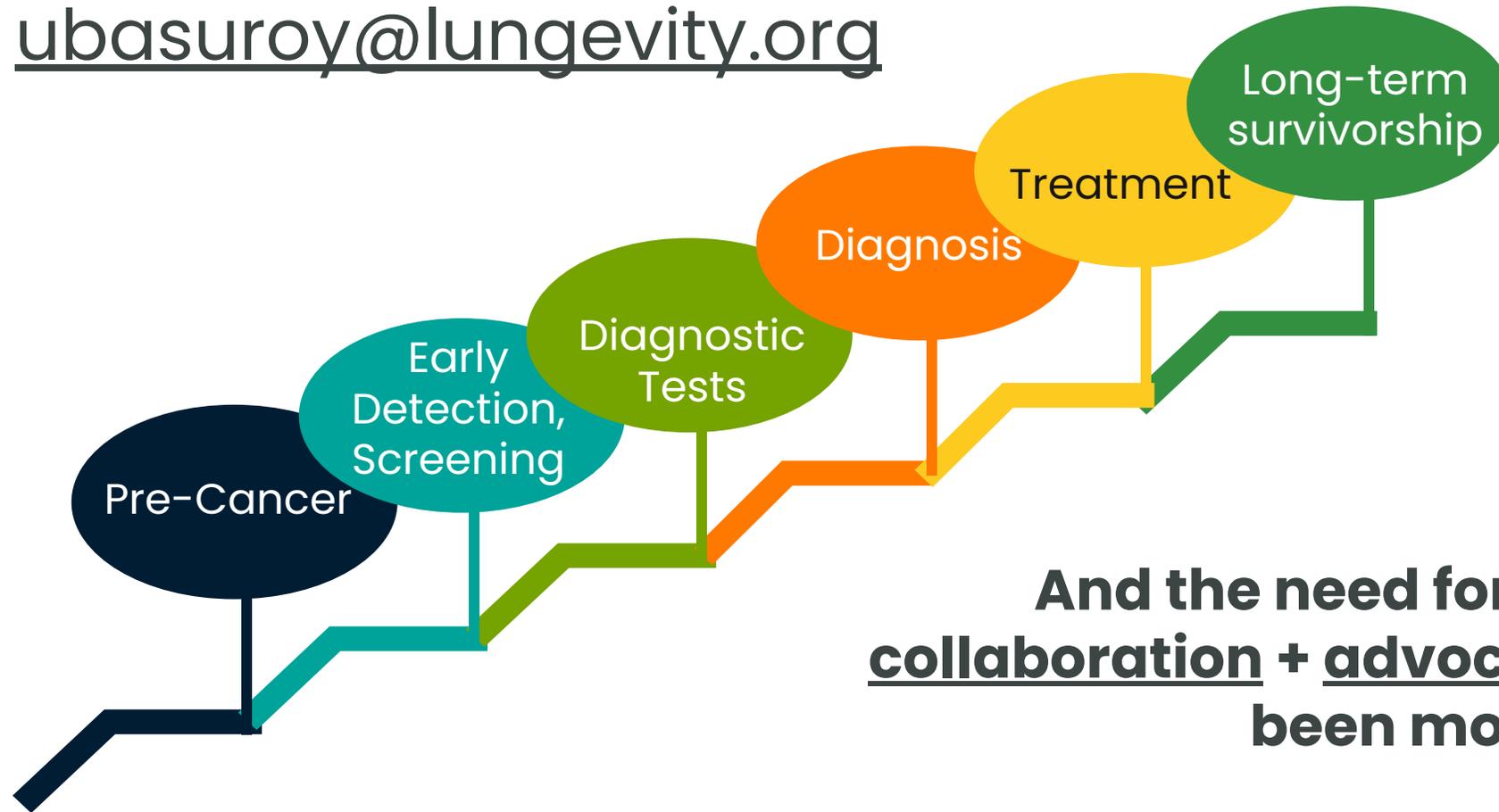
Community + Collaboration + Advocacy =  
HOPE + CHANGE

- 
1. Make 2 new friends at the Summit & keep in touch with them
  2. Commit to 1 act of advocacy

*“Alone we can do so little; together we can do so much” – Helen Keller*

# Lung cancer detection and treatment is progressing...

Email: [ubasuroy@lungevity.org](mailto:ubasuroy@lungevity.org)



**And the need for community + collaboration + advocacy has never been more than before**