



Alliance for  
Continuing Education  
in the Health Professions

FEBRUARY 5-8

NEW ORLEANS, LOUISIANA  
SHERATON NEW ORLEANS HOTEL



ALLIANCE 2024

*Unlocking Your Potential*  
ANNUAL CONFERENCE

# Lending Patient Experiences to Medical Education: More Than the Journey



Pam Mason, CHCP  
Sr Director of Medical Education  
Grants Office at AZ

Supporter's Call to Action



Rebecca Weaver, CHCP  
Sr Account Director  
Creative Educational Concepts

The Origin Story



Jill Feldman, MA  
Co-Founder EGFR Resisters

My Many Roads Traveled in IME



Lily Zurkovsky, PhD  
Director of Business Development and  
Supporter Relations  
Creative Educational Concepts

Impact of Patient Advocates



# Supporter's Call to Action

Pam Mason, CHCP



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# The Origin Story

Rebecca Weaver, CHCP

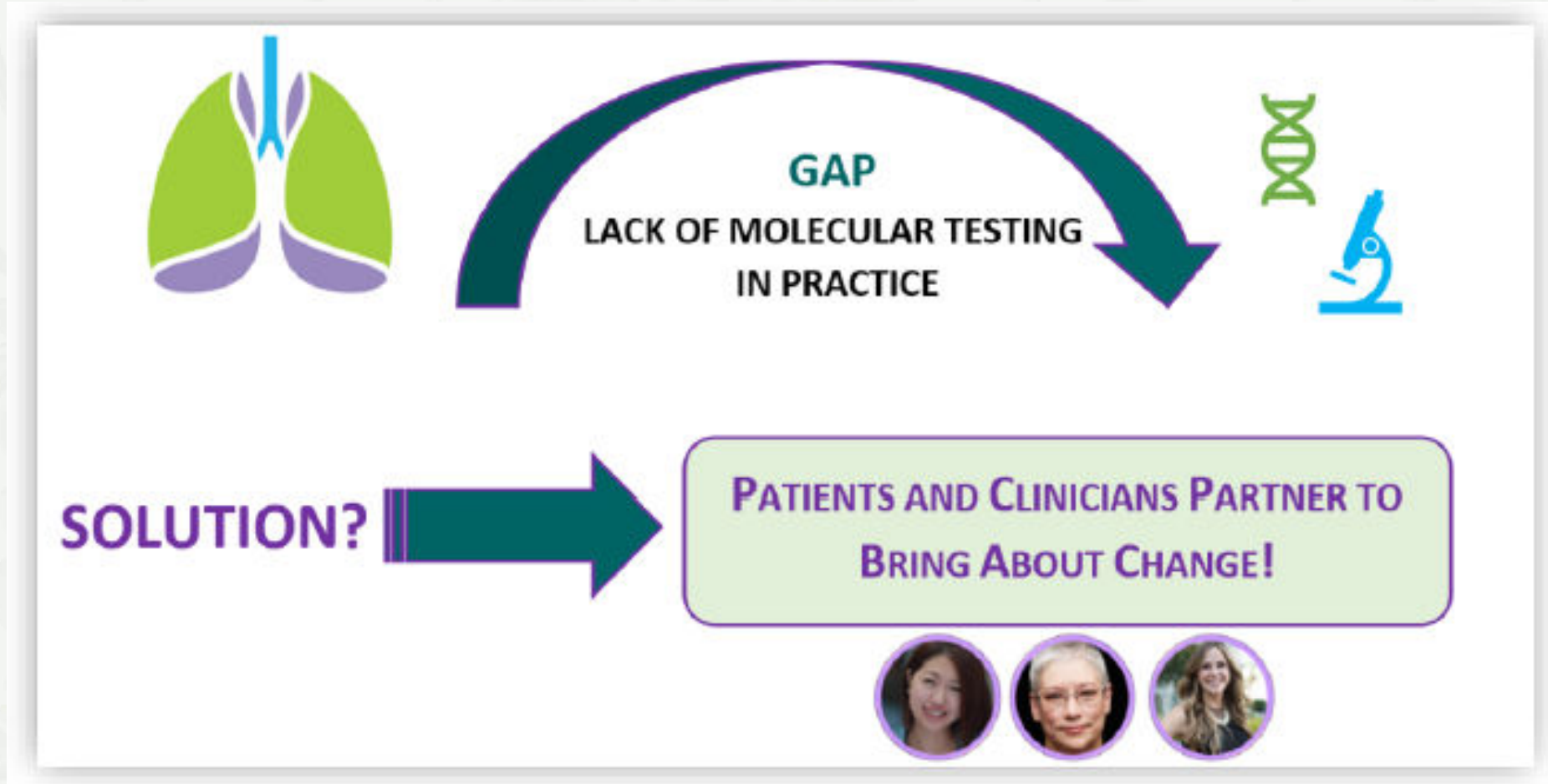


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# Identified Gaps



# Partnership Outreach: EGFR Resisters

Founding members are serving as:

- Poster and platform **presenters** at national oncology meetings;
- **Panelists** for medical & media events related to NSCLC;
- **Advocates** to link researchers with patients for clinical trials;
- **Consultants** with newly diagnosed patients who are seeking more information about biopsies, providers, and treatments;
- **Board members** for lung cancer-related non-profits; and
- **Liaisons** with scientists and clinicians to disseminate information about NSCLC into the community.





# CEC & EGFR Resisters Collaborative Activities



2019



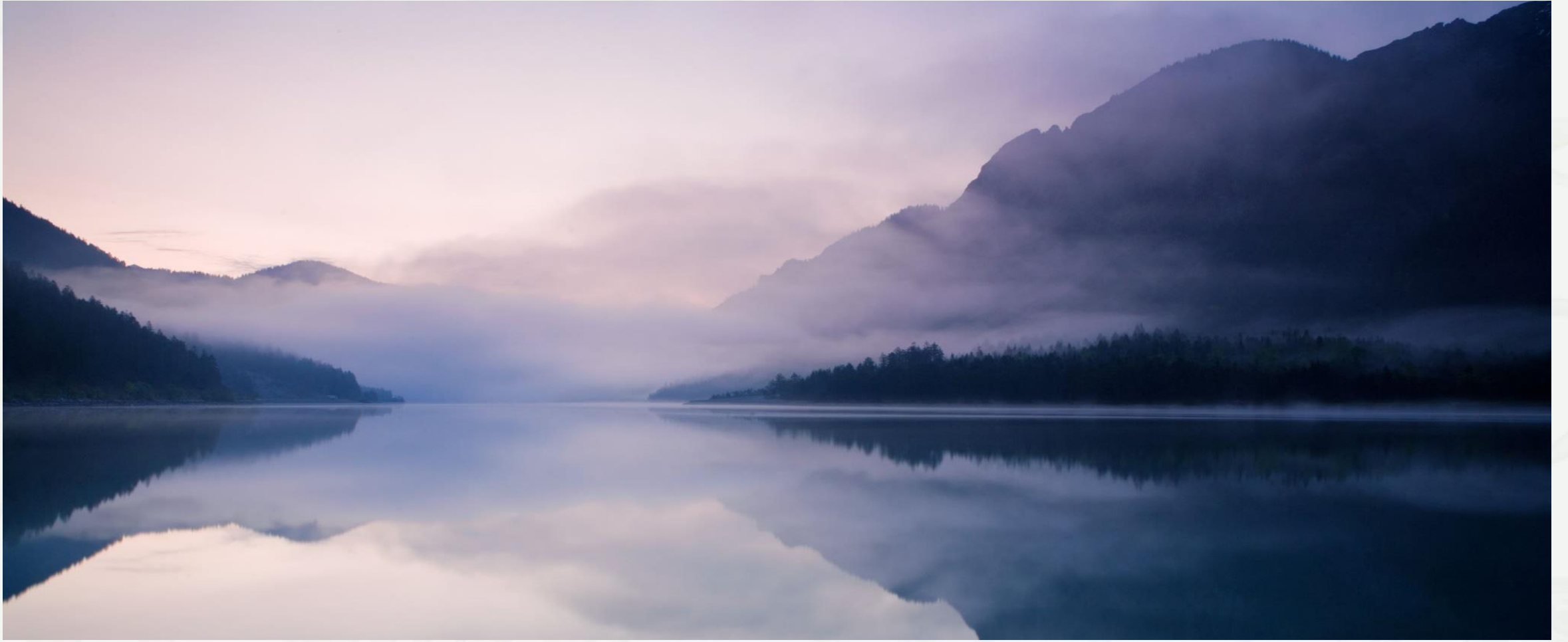
2023 EGFR Resisters Research Summit



2018

EGFR Resisters Inaugural Think Tank Proceedings & Call to Action





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# My Many Roads Traveled in IME

Jill Feldman, MA

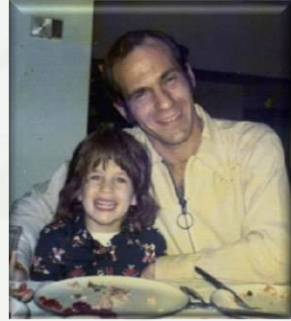


# My Credentials

## Family Lost to Lung Cancer



Mom



Dad



Aunt



Grandmother



Grandfather













## My diagnosis in 2009





# Disrupting the Paradigm: Patient and Caregiver Groups Partner to Propel Research

## Biomarker Groups

GROUP	FOCUS	CONTACT EMAIL	WEBSITE	TWITTER
 The <b>ROS1</b> ders	ROS1+ cancer	info@theros1ders.org	theros1ders.org	@ros1cancer
 <b>ALK POSITIVE</b>	ALK+ NSCLC	info@alkpositive.org	www.alkpositive.org	@ALKLungCancer
 <b>Exon20 Group</b> EGFR/HER2 EXON 20 MUTATION GROUP	EGFR & HER2 Exon 20	exon20@exon20group.org	exon20group.org	@Exon20Group
 <b>EGFR Resisters</b>	EGFR+ NSCLC plus resistance to EGFR TKIs	egfrresisters@gmail.com	www.egfrcancer.org	@EGFRResisters
 <b>RET RENEGADES</b>	RET+ NSCLC	retrenegades@gmail.com	N/A	@RetRenegades
 <b>ALK Fusion</b>	ALK+ NSCLC	info@alkfusion.org	www.alkfusion.org	@alk_fusion
 <b>KRAS Kickers Lung Cancer</b>	KRAS+ NSCLC	teri@kraskickers.org	kraskickers.org	@KRASKickers
 <b>NTRKers</b>	NTRK+ cancer	info@ntrkers.org	ntrkers.org	@NTRKers
 <b>MET CRUSADERS</b>	MET+ NSCLC	info@metcrusaders.org	metcrusaders.org	@metcrusaders
 <b>BRAF Bombers</b>	BRAF+ NSCLC	brafbombers@gmail.com	brafbombers.org	@BrafBombers
 <b>RET positive</b>	RET+ cancer	info@retpositive.org	retpositive.org	@RETpositive
 <b>THE HAPPY LUNGS PROJECT</b>	RET+ NSCLC	Info@happylungsproject.org	happylungsproject.org	--

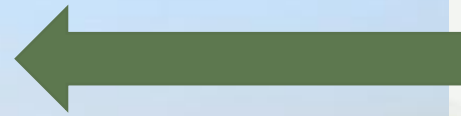
## Who are the EGFR Resisters

- Founded in 2017, we have over 5,000 members from 90 plus countries
- Our purpose is to build a community of survivors & caregivers to share knowledge, provide support and collect patient data
- Our goal is to improve outcomes for people with EGFR+ lung cancer by accelerating research
- We have a closed Facebook group for our members and communicate with the broader EGFR+ community through our website (egfrcancer.org) Twitter (@EGFRResisters) and Instagram @EGFRResisters\_lungcancer





# She looks GREAT!



How my care team and others perceive I feel



How I actually feel

Trouble with word retrieval/Focusing

Foggy Brain

Severe dry eye

Anxiety/Depression

Mouth Sores/change in taste

Dental problems

Dry mouth

paronychia

Chest wall pain

Rash

SOB – loss of lung function

Numbness/pain surgical sites

Fatigue

Diarrhea/nausea

Joint pain/muscle aches

Acid Reflux

Dry Cracked Skin

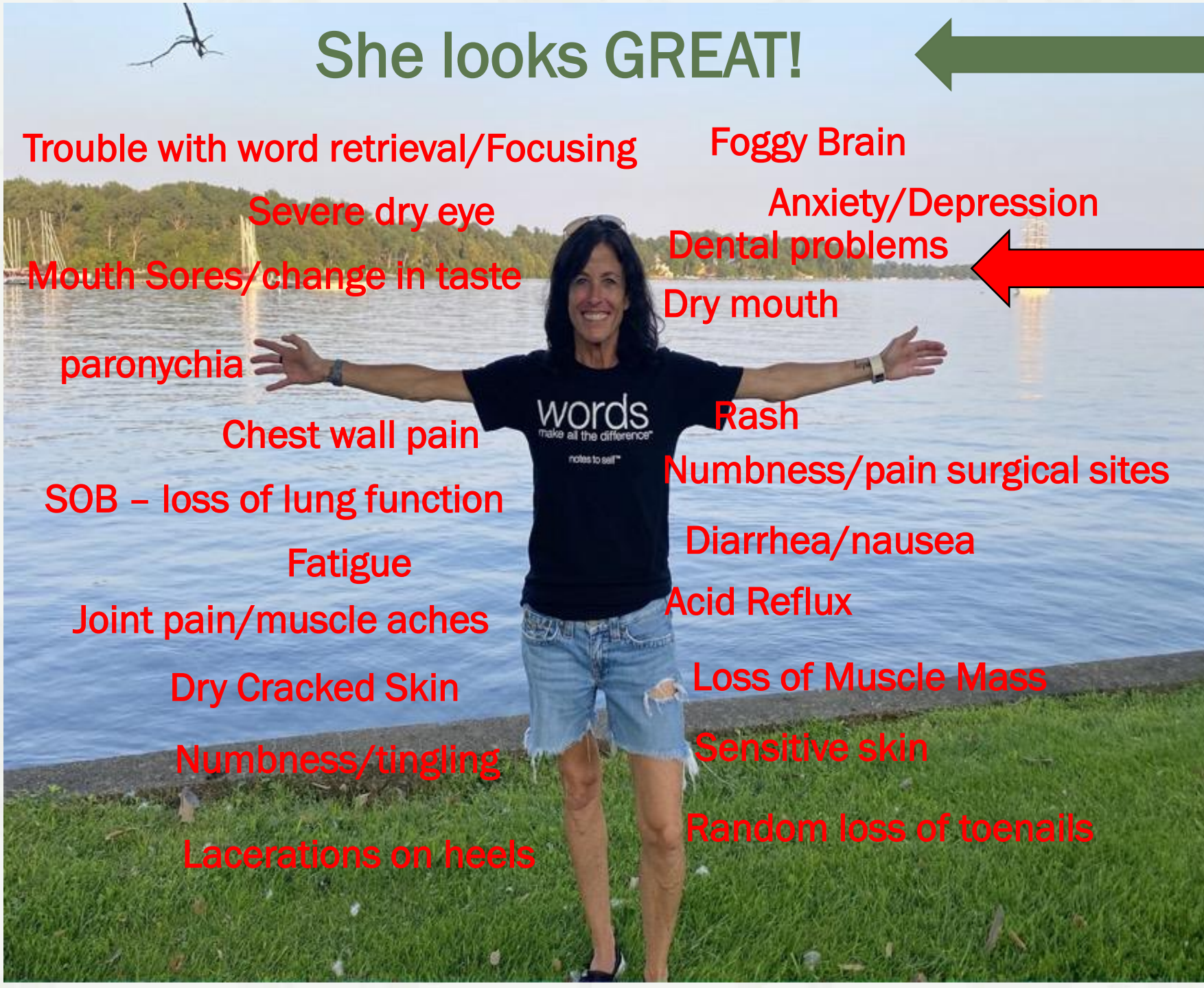
Loss of Muscle Mass

Numbness/tingling

Sensitive skin

Lacerations on heels

Random loss of toenails



# Challenges

- Finding patients who are **educated** about disease state & are comfortable working with scientific content
- Selling “**value**” of **patient voice** to learners
- Patient ability to speak on behalf of **group vs self**
- **Functional Barriers:** Time, health, provider bandwidth
- **Aligning** philosophies/factions
- Ability of provider to **close the loop**

# Resources



AACR American Association  
for Cancer Research

SCIENTIST↔SURVIVOR PROGRAM®:

<https://www.aacr.org/patients-caregivers/patient-advocacy/scientist-survivor-program/>



<https://researchadvocacy.org/advocate-institute>

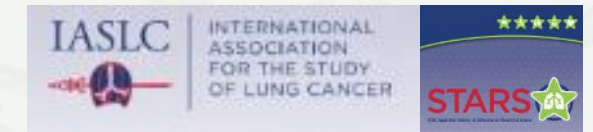


Advocates for Collaborative Education

<https://advocatecollaborative.org/>



<https://learn.colontown.org/>



<https://www.iaslc.org/patient-advocacy/stars>



<https://www.pcori.org/engagement/research-fundamentals>



<https://www.stopbreastcancer.org/what-we-do/education/project-lead/>



# Impact of Patient Advocates

Lily Zurkovsky, PhD





# Do patient advocates make a lasting impact?

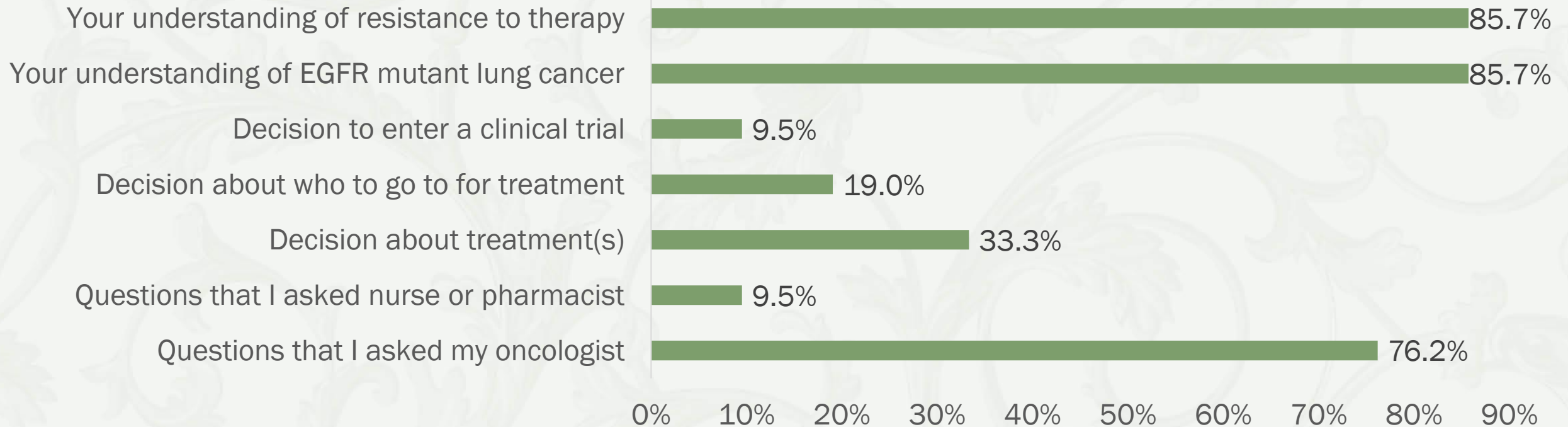


- “I've made new connections professionally and I plan on staying in contact with LCRF, IASLC and the EGFR Resister community as I transition to an independent position.”  
–Young investigator
- “I have met many close friends and colleagues through the EGFR Resisters. They have helped me find a strong research community as well as support throughout many struggles of being a junior faculty member. I have also been fortunate enough to find several strong research advocates willing to work with me on meaningful collaborations! I am very thankful for this group!”—Christine Bestvina, MD

# Survey of the EGFR Resisters Members

Which of the items below did the education impact?

21 respondents



# Survey of the EGFR Resisters Members (cont.)

Why is it important to you, to get education from the EGFR Resisters and other patient groups?

- The information provides *hope* as well as understanding. Helpful to know that doctors/scientists are passionate about this need area.
- Helps me be *proactive* and to at least know *I am doing everything* to keep myself alive. I also will have no regrets knowing I am doing the best to advocate for myself. I also have ruffled a few oncologist, but I know I must say what I think and be a part of my health treatment plan.
- Staying educated gives me a *feeling of control* that I didn't have before. It helps me know I can direct donations to organizations that could really help the community. It makes me an advocate.



# Survey of the EGFR Resisters Members (cont.)

Why is it important to you, to get education from the EGFR Resisters and other patient groups?

- I love getting info from this site so I can discuss with my oncologist. I like seeing some of these posts so *I feel like I'm not alone* on this scary journey
- Because it is *trustworthy and relevant* info I need to stay alive and presented in a way that I can understand
- I'm *continually learning about my disease*. The more I can educate myself the better prepared I am to advocate for treatment. It's a roadmap with many turns and being prepared as I approach them is in my best interest. I trust my medical team but they really only educate if I'm prepared to discuss results etc. Also helps me explain my disease to family and friends who are clueless like I was about lung cancer!

*We request many questions*

**THANK YOU** FOR ATTENDING OUR SESSION

