

# Patient Advocacy Why Does It Matter?

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Oishi Symposium  
SWOG Spring Meeting

# My Story

- Breast Cancer – Before and After
- Career Transition
- Patient Advocacy
- Living in the Moment!

# Why Advocate?

- ⦿ Help others
- ⦿ Work with great people
- ⦿ Exercise your brain
- ⦿ Stay active and healthy

# Patient Advocacy

- Patient Community
- Research Collaboration
- Clinical Trials



# Patient Community

- ⦿ Yourself
- ⦿ Family
- ⦿ Friends
- ⦿ Community

# Research Collaboration

- Cancer researchers
- Peer review
- Funded project implementation

# What is a Research Advocate?

National Cancer Institute Advocate in Research Working Group, 2010:

- A research advocate is an individual who brings and can convey a **nonscientific** viewpoint to the research process and can communicate a **collective** patient perspective.
- A collective patient perspective is created when a person has knowledge of multiple disease experiences and conveys this perspective rather than his or her own exclusive perspective.

## **Involving Advocates in Cancer Research:**

Jane Perlmutter, Nancy Roach, and Mary Lou Smith  
Seminars in Oncology, Vol 42, No 5, October 2015, pp 681-685

# **SWOG Patient Advocate Collaboration in Clinical Trials...**

## **What does that look like?**

# Collaborative Design and Development of Clinical Trials



Collaboration between the Researcher and Patient Advocate should begin when the Committee authorizes development of the Study Concept.

Formal documentation is generated for: *Triage Review; Protocol; Consent Forms* and related patient collateral.

# Collaborative Delivery of Clinical Trials



**Collaboration between the Researcher and Patient Advocate on a specific trial ends when results are disseminated, though portfolio analysis continues.**



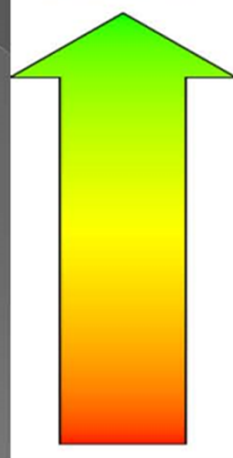
# Researcher-Advocate Engagement Maturity

*I embed my Patient Advocate throughout my research process as a Trusted Partner.*



*I include my Patient Advocate where required.*

*I do not engage my Patient Advocate.*



*I am embedded into the research process and proactively provide significant insight to my Committee. I feel safe in offering my opinion, my opinions are valued, and I take accountability for my disease.*



*I do not reach across the aisle to my research partners – I merely wait and take orders.*

# Accomplishments

- SWOG Lung Cancer Committee
  - > Concept review & patient advocate perspective – including Triage slide presentation
- Collaboration with researchers
  - > Application development, implementation, and researcher mentoring
- Research funding decision support
  - > Peer review (Free to Breathe, DoD, Komen For the Cure)



# Education and Development

- SWOG Patient Advocate & Lung Committee monthly calls; Facebook page
- SWOG Semi-Annual Meetings
- National Cancer Conferences
- Free to Breathe Lung Cancer Leadership Conference
- ListServes and other subscriber online resources
- CURE Magazine
- ASCO Post



# ***Thank you!!!***

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