

# Advocacy Breakout

- Discussed the advocate role and educational opportunities
- This round table discussion was the initiation of an advocacy effort
- “Where do we go from here?”

# Advocate Demographics

Newly diagnosed through 28 years of survivorship

Cross-section of US plus Canada represented (total of 30!)

Pre-menopausal and post-menopausal

ILC survivors and co-survivors

Early stage through metastatic at diagnosis

# One Over-Arching Priority

**ILC officially recognized as a  
breast cancer subtype !**

## **Advocate Task**

Requests the meeting leadership to write a position paper to  
recognize ILC as a subtype of breast cancer that is  
characterized by its unique molecular and genomic profiles,  
unique imaging and pathology features (diagnostic difficulties  
and lack of targeted therapies  
(npj Breast Cancer)

# Subsequent Directions

## Effective screening for ILC

- o For diagnosis
- o For follow-up
- o Mammogram and Ultrasound are not enough

## Advocate Goals

- o Establish a diagnosis protocol or a best-case approach to diagnosing based on current technologies?
- o Standardization of QUALITY pathology protocols; work towards consensus of staining for diagnosis; identify emerging markers and move quickly into clinical application
- o Establish predictors of recurrence

# Subsequent Directions

## **Education and Awareness**

- Advocates to actively promote, both locally and nationally (internationally), ILC as a subtype and to push for research support and education
- Create awareness of symptoms not only among the general public but among the medical community.

## **Advocate Task**

- Establish long-term national (and international) network
- ILC BC recognition protocol program

# Subsequent Directions

## Clinical Trials

- Identify ILC within current trials and analyze as a separate subgroup
- Collaboration between centers to encourage participation; ensure trial accrument/success

### **Advocate Ask:**

- Collaboration between centers to increase participation and share results!!!
- Establish a global tumor bank for ILC tissues.
- Increased focus on ILC specific trials.

# Advocate Action Items

## **Local action**

- Support groups, local researchers

## **National action**

- Approach national organizations (NCI, NBCC, Komen) to bring a focus on ILC
- Establish recurrent ILC-focused international meetings
- Self-train in advocacy educational opportunities



