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

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

Advocate Goals

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