Lobular Breast Cancer Alliance Inc. - Strategic Plan for FY24 (July 1, 2023 – June 30, 2024)

The following Goals and Objectives comprise LBCA’s FY24 strategic plan as developed with input from the Scientific Advisory Board (SAB) and the Patient Advocate Advisory Board (PAAB) and approved by the Board of Directors (BOD) on April 7, 2023. The strategic plan is organized into three sections Programmatic Goals, Infrastructure Goals, and Fundraising Goals. Each section contains the overarching strategic goal and the specific objectives and associated activities by which to achieve the objectives for the fiscal year. The programmatic strategic goals correspond to LBCA’s goals related to our vision and mission as shared on our website. Accomplishments related to the objectives under each goal will be reviewed with the SAB, PAAB, and BOD in the Spring of 2024 and updated for FY25 in June 2024.

Programmatic Goals

Goal 1: Raise Awareness and Educate about ILC and Need for ILC Research

**Objectives:**

1. Increase accessibility of LBCA materials and events
   - Translate at least two patient resources into foreign languages in addition to Spanish.
   - Provide real time translation services and/or closed captioning for international summit with patient advocates to be planned.
   - Post/disseminate the slides and recordings from all LBCA-sponsored virtual ILC Symposium wrap-up sessions, LBCA Advocate Chats, and other virtual events. Determine how to and begin to provide written transcripts from virtual events.

2. Expand LBCA’s reach to new audiences and media
   - Identify and make connections with at least two major sports figures, leagues, women driven companies, or other corporations (including sportswear or gear) that support breast cancer charities.
   - Expand social media presence on Facebook, Instagram, LinkedIn, YouTube, and Twitter by increasing the frequency of posting across platforms to at least weekly and more around significant dates.
• Identify at least two additional strategies for disseminating LBCA PR materials (new and existing) more broadly and more frequently and incorporate them into communications plan.

• Create and disseminate a marketing campaign message for breast cancer awareness month (BCAM) 2023.

• Share outreach materials about ILC with at least two organizations with which LBCA seeks to establish a connection (e.g., AMA, ASCO, NCI, CDC, legislative bodies, SBI, Society of Nurse Oncologists, and other professional organizations and licensing boards).

• Assist with the development of ILC specific curriculum for breast cancer nurse practitioners and physician assistants with UT Southwestern and disseminate widely. Consider initiative to modify for other clinical professionals (e.g., PCPs, NPs, MDs, Radiologists, etc.).

3. Raise awareness of ILC and LBCA and need for more ILC research among clinicians/researchers

• Conduct at least one survey a year highlighting critical ILC treatment and detection/monitoring issues/develop abstract from results for submission to be invited to present a poster SABCS.

• Develop and/or sponsor ILC-focused sessions for at least one major cancer conference focusing on/or including breast cancer.

• Complete email outreach campaign to all major breast cancer center identified contacts, including NCI Designated Comprehensive Cancer Centers and others across the US, to introduce LBCA and resources available.

• Encourage and facilitate SAB members’ use LBCA’s logo in their presentations related to ILC research.

• Obtain updated SEER ILC incidence data and work with NCI, Office of Cancer Surveillance, on improvements to access to and production of regular reports on ILC as a subtype of breast cancer, as well as promoting the publication of breast cancer subtype SEER data beyond hormone receptor status.

• Conduct at least one more strategy meeting with partner BC organizations and another meeting with NCI to discuss how to implement data collection related to recurrence data.

4. Provide and keep updated educational materials about ILC for ILC community

• Develop downloadable resource about ILC and imaging for individuals living with early stage and metastatic ILC.

• Develop resource for website on how individuals with ILC can donate tissue and/or body to support ILC research.

• Create at least two PSAs about clinical trial participation and create two PSAs raising awareness about ILC and LBCA.

**Goal 2: Be Go-To Source for ILC Research Findings and New Treatments/Clinical Trials**

**Objectives:**

1. Update publications library with new work and cull to remove old publications at least twice annually.
2. Update website page highlighting SAB member current research (update every six months) and as appropriate provide a lay summary and interview with the SAB researcher and/or post a blog by the SAB member.

3. Maintain current list of clinical trials accepting ILC patient enrollment.

4. Ensure that new ILC findings are publicized via all of LBCA media platforms and shared with the private ILC FB groups. Identify ways to facilitate open access for articles published on ILC, including exploring providing a fund for SAB members with which to fund the open access options for their publications.

Goal 3: Support ILC Patient Research Advocacy and Ultimately, Identification and Implementation of ILC-specific NCCN Guidelines

Objectives:

1. Develop, present, record and share on website at least six new Advocate Chats/year for patient advocates to provide tools and information for ILC awareness raising and research advocacy.

2. Maintain and expand ILC Advocate Registry for the purposes of a) volunteering to be paired with a researcher seeking a research advocate and b) connecting with other advocates in similar geographic locations. Publicize availability of ILC Advocate Registry to both researchers and ILC community at least once each year.

3. Share advocacy learning opportunities, as LBCA becomes aware of them, with the ILC Advocate network via email communication.

4. Assist interested ILC patient advocates to participate on breast cancer research consumer review panels (provide letters of support and promote DoD opportunities, etc.).

5. Provide travel funding scholarships for up to 20 ILC advocates to attend travel to major breast cancer conferences via the LBCA Travel Scholarship Program.

6. Assist SAB members in creating/publishing white papers on ILC-specific treatment and imaging techniques and promote more research on them to facilitate their being turned into ILC-specific treatment protocols.

7. Initiate at least one letter writing campaign to NCCN to promote their adoption of lobular specific guidelines.

Goal 4: Build Alliances Among U.S. and International Breast Cancer Advocacy Orgs to Jointly Promote/Support ILC research

Objectives:

1. Participate in ILC Symposium (September 23) planning and development of wrap up session.

2. Participate in at least one ELBCC project.

3. Conduct at least two initiatives such as webinars or in person panels or awareness raising efforts with a sister breast cancer organization.

4. Implement mechanisms/materials & publicize LBCA’s ability to support ILC patient recruitment into multi-center ILC clinical trials.
5. Assist SAB members to develop at least one multicenter collaboration around research initiatives (e.g., ILC data analysis, collaborative research grant proposals to pharmaceutical companies, standardizing ILC pathology, creating more ILC research models, etc.).

6. LBCA staff and representatives will continue to participate on DFCI patient advocate group, breast protocol group and ER+ group, SNMMI Patient Advocate Advisory Board, ACS Breast Cancer Round Table, ASCO Conquer Cancer Foundation Council, MBC Alliance working groups, Tigerlily Race Alliance Roundtable, NBCC C-4 Board, and other national boards or collaboratives to raise the issue of the need for more ILC research, and will add one new collaboration during the fiscal year.

7. Consider development a collaborative grant application with SAB members and member institutions to support ILC research (e.g., Department of Defense Consortium Grant, or other).

8. Identify and outreach to at least two sister agencies with like missions to forge relationships and plan future collaborations.

9. Plan/convene at least one virtual summit of ILC patient advocates to discuss shared ILC treatment challenges and ID a shared initiative.

10. Investigate LBCA joining BCRF.

**Goal 5: Promote and Fund ILC Research**

**Objectives:**

1. Continue to fund Early Investigator awards in partnership with ASCO and AACR.

2. Pursue additional grant funding partnerships.