

### Category III

#### An Integrative Approach to Improving Outcomes for Inflammatory Breast Cancer (IBC) Patients: Creating a Diagnostic Tool, Advocating for ICD-10-CM Codes, and Establishing a Task Force to Address Critical Research Gaps

Lindsey J. Anstine<sup>1</sup>, Alexandra A. Erwin<sup>1</sup>, Molly L. Guthrie<sup>1</sup>, Hosea D. Baker<sup>1</sup>, Sunil S. Badve<sup>2</sup>, Mary L. Alpaugh<sup>3</sup>, Kimberly A. Sabelko<sup>1</sup>, Glendon M. Zinser<sup>1</sup>

<sup>1</sup>*Susan G. Komen*

<sup>2</sup>*Department of Pathology and Laboratory Medicine, Emory University School of Medicine, Georgia, USA*

<sup>3</sup>*Department of Biological and Biomedical Sciences, Rowan University, New Jersey, USA*

**Objective:** Inflammatory breast cancer (IBC) is a rare, highly aggressive form of advanced breast cancer that is challenging to diagnose due to its ambiguous clinical nature. Gaps in awareness in clinical and patient communities further contribute to diagnostic delays. Together these issues hinder research, leaving patients with few treatment options and poor prognoses.

**Materials and Methods:** To address these challenges, Susan G. Komen partnered with IBCRF and the Milburn Foundation to form the IBC Collaborative, launching a multidimensional initiative to overcome systemic barriers to IBC research and care.

**Results:** Early efforts focused on developing the IBC Scoring System, a quantitative diagnostic scoring rubric for IBC. Available as an online tool ([komen.org/ibc-calc](http://komen.org/ibc-calc)), the IBC scoring system is gaining global adoption, with over 7,800 users in more than 115 countries to date. Additionally, IBC-dedicated clinics, multi-institutional IBC networks and community oncology centers have reported using the tool to support clinical decision making in ambiguous patient cases. Validation studies have shown that the system can distinguish IBC from non-IBC cases (AUC-ROC 0.84; 95% confidence interval: 0.82–0.87). Additional efforts to enhance its clinical utility are underway and funded by Komen. With a diagnostic system in hand, Komen pursued formal disease recognition by engaging with the U.S Centers for Disease Control and Prevention to establish three ICD-10-CM codes (C50.A0, C50.A1, C50.A2) for IBC. Effective October 2025, use of these codes is expected to enhance tracking of IBC incidence, facilitate IBC inclusion in national health datasets and improve coordination of multidisciplinary care. In parallel, a task force was convened to identify key knowledge gaps limiting progress in IBC research and to propose actionable solutions. Through structured discussions, three priority areas in IBC biology emerged: (1) IBC onset and development, (2) detection and monitoring and (3) metastatic dissemination. The group also identified limited shared resources, data silos and the lack of open-access datasets as major obstacles and prioritized areas with high potential to improve the understanding and management of IBC.

**Conclusion:** Together, this integrative approach has advanced IBC research, diagnosis and care through development of a validated diagnostic tool, formal disease coding and identification of critical research gaps. Continued momentum in these areas is expected to improve IBC outcomes.

**Keywords:** IBC; codes; research gaps