

**THE IBC
NETWORK
FOUNDATION**

**Inflammatory
Breast Cancer
Quick Facts**

2023

TheIBCNetwork.org

Inflammatory Breast Cancer (IBC)

Quick Facts

1. **Inflammatory Breast Cancer (IBC) represents only 2-5% of total breast cancers, but 10% of breast cancer deaths.**
2. What is IBC? IBC is an aggressive breast cancer that has outward physical signs. Look for: swelling, rash, shooting pain, or itching. Commonly misdiagnosed as mastitis.
3. No tumor-specific molecular definition exists for IBC. Many studies have been done which find different mutations and patterns of gene overexpression, however nothing so far that is 100% specific for IBC.
4. Current research to differentiate IBC focuses on defining non-tumor cells in the breast that may cause IBC to behave differently.
5. Who can get IBC? IBC doesn't discriminate. IBC tends to strike younger women, but all ages are at risk. Men too. The average age at diagnosis is 5 years younger than other breast cancers.
6. IBC can arise during or shortly after pregnancy which can be a reason for delayed diagnosis. Pregnancy frequently causes breast changes, making differences difficult to attribute to the cancer.
7. IBC doesn't care what race you are either. Caucasian, African-American, Asian, Middle Eastern...all races are susceptible. Also, IBC skin changes can look different from Caucasian women. The redness/rash might be hidden on darker skin.
8. **Diagnosing IBC is difficult. It is not easy to see on a mammogram. Mammograms of patients with IBC can have a classic appearance including skin thickening and distortions. There may or may not be a mass.**
9. Mammograms are not effective typically on younger women due to breast density (which shows up as white on the mammogram) and therefore it becomes difficult to find underlying masses or distortions.
10. IBC skin thickening and diffused tumor areas are more easily visualized by MRI and ultrasound, but often a mammogram is the first test ordered.
11. **Only 10% of women with IBC have palpable lumps. IBC can spread very quickly throughout the breast undetected. #NoLumpStillCancer**
12. Have signs of IBC? Make a doctor appointment promptly! **IBC progresses quickly and earliest detection is by definition stage 3 due to skin involvement.**

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13. **At diagnosis, 30% of IBC patients have stage 4 (metastatic) disease.** The remaining 70% are viewed as stage 3. **There is no earlier diagnosis than stage 3.**
14. IBC cells on the move can block lymphatics around the breast. The result is the IBC affected breast may swell to 2-3 times the size of the other breast. Some patients have nipple retraction during progression of the cancer.
15. There are several more differences from other breast cancers to be aware of: can have shooting pains, or other physical signs such as skin redness, nodules and itching from initial presentation. Take-home message: if something looks or feels different about one breast or armpit, seek medical care for assessment.
16. Common IBC misdiagnoses are mastitis, abscesses, or reactions to bug bite. Antibiotics are often prescribed if the caregiver is unaware of IBC.
17. "Peau d'orange" (the skin literally looks like orange peel) is a classic appearance, but not required for diagnosis of IBC.
18. **IBC treatment is different from regular breast cancer.** If you are concerned, get an IBC specialist's attention - you're worth it.
19. There are only a few IBC specialist clinics in the world. MD Anderson opened the first clinic in 2006 and is still the largest clinic for IBC care.
20. **A lumpectomy is not recommended for IBC. The disease is webbie and diffused throughout the breast, so a modified radical mastectomy is the standard of care to remove all the cancer and involved skin.**
21. Radiation is not optional. Its job is to mop-up any remaining microscopic tumor cells scattered throughout the breast tissue.
22. **IBC treatment is called a tri-modal approach because all three types of treatment are important: Chemotherapy, Surgery and Radiation**
23. Stage 4 IBC treatment is personalized. Some might receive surgery and radiation and stay on maintenance systemic drugs forever.
24. For patients with metastatic IBC, when one treatment fails, another treatment is initiated until treatment options run out. **Stage 4 IBC is considered incurable, but treatable.**
25. IBC is not taught in depth during medical school. Textbooks on medical oncology or breast cancer often only have a few paragraphs on IBC.
26. Future IBC specialists learn IBC care specifics during residency/fellowship if they train at a high-volume center with enough IBC patients. Others may only see one or only a few cases their entire career.

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27. **Some pathological differences between IBC and other breast cancers: IBC is less often ER/PR+; 40% of IBCs are HER2+; 30% of IBCs are triple negative (ER, PR, HER2 negative).**
28. IBC metastatic patterns are similar to other breast cancers. Bone is the most common distant site. Lung and liver are also very common organs that are affected.
29. **Brain metastasis and skin metastasis are more common in IBC than other breast cancers.** These are particularly difficult sites of disease for treatment, so expertise at a specialty center is important, where focused research is conducted.
30. Triple negative IBC recurrences, when they occur, are often early events. On the other hand, making it past 5 years without a recurrence doesn't mean you're home free in IBC.
31. Accurate stats on IBC stages and recurrence are difficult to find. **One reason is that IBC lacks an ICD code, even in the ICD10 system.**
32. We don't know of any IBC specific genetic predisposition genes. Regular breast cancer risk genes (BRCA1 and BRCA2) are relevant in IBC and treatment options based on these gene mutations apply to IBC patients.
33. **Family history of IBC is rare** - but not impossible. Many women with IBC do not have a strong family history of cancer.
34. Healthy diets may reduce your risk of developing breast cancer for multiple reasons. Obesity is a risk factor for IBC, however not all patients are overweight.
35. Intriguing epidemiological data exist about exposure to certain viruses leading to IBC. For example, viral DNA may be found in tumors. Viral etiology is difficult to prove.
36. A few more facts of IBC risk factors summary: IBC like most cancers is multifactorial. Genes, environment, lifestyle, luck all play a role in the etiology of IBC.
37. While IBC is still a significant disease, there is hope. We know some 20-30 year IBC survivors! IBC is NOT a death sentence. #HopeAlways
38. Now that you're educated about IBC, we request you to share these facts and/or become a donor to improve the landscape of IBC forever.
39. The IBC Network Foundation is a charity; funding research as fast as we can. Please donate at TheIBCNetwork.org/donate.