

To whom it may concern,

I am the founder of the IBC Network Foundation. We are a 501c3 that focuses on education and research funding for inflammatory breast cancer (IBC).

Daily we have the privilege of interacting with IBC patients from all over the country. On average we interact with over 150 new IBC patients per year in the United States alone. IBC was first written about in the 1800's but due to the rare status of this disease (SEER reflects under 5,000 dx a year in the US) standard of care is not commonly taught in medical school or even included in breast cancer medical conferences. As a matter of fact, the first CME written for IBC was only offered this year for the first time in September of 2018. I am citing the Reuth et al National cancer database article <https://goo.gl/oQVfjb> to reflect the need of a specialty tri-mode clinic for this less common and highly fatal form of breast cancer. Recognizing the significant struggle for a healthcare team to treat an IBC patient, I am writing to request permission to allow a patient to seek and have care coverage outside of the normal network.

We are not soliciting a response. We only hope this letter will prompt productive dialogue between the policy makers at your insurance company to have an "allowed" or "recognized amount" for a rare diagnosis. This would give support to patients who need to seek multi-disciplinary IBC care under the IBC guidelines. There are only three IBC specialty centers in the United States so that information alone can reflect the necessity to seek care out of network.

We have solid information about resources on our website that may be useful to your decision makers including our educational app and a free CME focused on IBC treatment. Please do not hesitate to reach out to us at any time if we can be a help to your policy management team. If you can think of anything more we can do to help improve the landscape in IBC care and insurance support, we would love to discuss this more fully in the future.

With greatest respect and appreciation,

Hope always,

Terry Arnold