Terry Lynn Arnold is the founder and president of the IBC Network Foundation.

Almost 10 years ago, Arnold was told by her doctors, “We are so sorry, but it is most likely too late.” This came after four months of hearing, “There is nothing seriously wrong with you.” What a jump, a mind-stretching leap from “not to worry” to “oh my, you have Inflammatory Breast Cancer, an out-of-control cancer that most physicians have never heard of, and treatment knowledge is limited.”

When Arnold was first told she had Triple Negative Inflammatory Breast Cancer (IBC) she went through a range of emotions, reactions and coping skills.

Flashing back to the late 1970s, when her grandfather was diagnosed with lung cancer, she remembered her family whispering the “C” word. They were afraid if the word cancer came out of their mouths, it would somehow boomerang back and get them all. Knowing how barbaric cancer staging was at that time, one can understand the fear. Exploratory surgery was common in order to determine the spread of the disease.

Arnold says, “In my cancer experience, I felt like I was walking on quicksand. Nothing was as I would have expected it.”

In a world so filled with “pink” and “awareness,” it seemed — to Arnold — that this form of cancer, over 200 years old, was orphaned. Arnold was determined to change that.

She used her skills — honed in past efforts of bringing injustices to a place of conversation. A founding member of the first rape crisis program in Fort Bend County (as part of a program of the Houston Area Women’s Center) in 1986, and later, in 1997, to help establish the Laura Recovery Center for Missing Children. She was used to rolling up her shirt sleeves and committing to the work needed to effect change. She started by forming support groups internationally, for this disease — IBC — was being found on multiple continents.

In a few years, as it became clear more was needed, she founded the IBC Network Foundation to fund research. This volunteer-led organization has now funded just over a $1 million for research and now has a sister charity in the United Kingdom, funding research, as well.

The charity has developed an app to help educate others about IBC, and Arnold is quick to say, with pride, that the app has been downloaded worldwide.

Arnold and the IBC Network Foundation work closely with the MD Anderson Cancer Center, Dana Farber, Duke and Vanderbilt (and others); they are leading the way in funding research for inflammatory breast cancer.

Arnold looks forward to the day doctors have the answers needed to stop breast cancer. Out of the 40,000-plus women who die each year of breast cancer in the United States alone, the largest percentage of those deaths were due to Inflammatory Breast Cancer.