Letter from our founder, Terry Arnold

Thank you for your support of the IBC Network Foundation. In this, our inaugural issue of the IBC Network Files, I wanted to share a little history of our organization.

Little did I know where a simple facebook message would lead. It was “hey, I hear you live in Houston, can we meet?”

After my diagnosis in the summer of 2007, I scoured the internet looking for anything on Inflammatory Breast Cancer. The lack of information on a 200 year old disease was shocking. In time, I started meeting women with this disease. Realizing IBC was not as rare as one might think, I felt more called into action daily. Even though many doors were opened to me, more often than not, my requests were met with blank stares: “You want to talk about what?” Since I had been pushing for IBC education, my name was being circulated as someone who wanted to champion this orphaned cause. That is how Lori Grennan came into my life.

We agreed to meet at MD Anderson, as I had done with many others battling this disease. She was in her early 30’s, bald, thin, with two young kids in tow, seeking treatment for a disease that was ripping her body apart. We talked at length. Not only was she a patient, she was also a family practice doctor. She knew firsthand the lack of IBC education in the medical community. Since IBC had been labeled rare, education and funding was limited as well. I shared my frustration as to how to make the best impact. That day was a tipping-point for me. Lori was a cut-to-the-chase person, I can still hear her voice in my mind. She looked at me with those clear blue eyes and said, “Tell them about me.” I filed for a 501(c)3 so we could request donations to fund research to stop the thief that is IBC from destroying lives around the world. We met with a researcher we both had great respect for, Dr. Wendy Woodward and a project was selected, and the IBC Network Foundation was launched!

In this issue:
* Recent events including attending the International IBC conference
* IBC mobile app for patients and doctors
* Funding updates
* IBC Research updates
* Upcoming fall events and how you can help
UPCOMING EVENTS

August
26th - Invited presentation at MD Anderson “Tools for Patient Empowerment and Research Collaboration” (Houston, TX)

September
20th - Educational dinner for physicians (NC)
25th - Hunt for Hope, Alabama (Tuscaloosa, AL)

October
1st - Hunt for Hope, Florida (Sebastian, FL)
2nd - Hunt for Hope, Texas (Friendswood-Houston, TX)
2nd - Hunt for Hope, Ohio (Lewis Center, OH)
23rd - Concert in memory of Maria Tilly Meyers (Memphis, TN)

December
6-10th - San Antonio Breast Cancer Symposium (San Antonio, TX)

5TH BI-ANNUAL INTERNATIONAL INFLAMMATORY BREAST CANCER CONFERENCE

In July we had the pleasure to attend the 5th International Inflammatory Breast Cancer Conference. This 2-day conference was a continuation of an annual CME event at Dana Farber, allowing some great IBC education for general oncologists attending that program as well as promoting an exchange of new and recently published data among IBC experts from the US and Europe.

One of the highlights of our attendance was presenting an idea to the board of the International IBC Consortium regarding an initiative to accelerate research and information sharing. This idea was well-received, and we intend on sharing more details in the future as the idea is brought to fruition.

Also in attendance, were about 20 patient advocates from around the US, who attended not only to learn more about IBC scientific progress but find ways to contribute to furthering research. At the beginning of the conference, much discussion was held in an advocate-focused session about productive ways advocates can become involved. We will share such opportunities as they become available.

Group photo taken at the end of the IBC conference in Boston, July 2016. Not all attendees were still in attendance due to travel logistics on a Sunday afternoon.
HOW YOU CAN HELP

There are many ways to help beyond financial contributions. How? We are all volunteer-run and can use help in many areas. Do you like to write? Perhaps you’d like to write a guest article for the website about a topic related to IBC. Are you artsy and enjoy design? Do you like to plan events? Great - we could use your help to plan something for our 31 days of October campaign or a future Hunt for Hope event in your community.

Contact us and we will find ways to utilize your talents and keep you in the loop about future needs.

FUNDING UPDATES

Recent Funding Awarded
Our most recent funding was in July 2016 to Dr Beth Overmoyer at Dana Farber Cancer Institute for a project on optimizing HER2 pre-operative therapy. A clinical trial is already underway involving HER2-positive IBC patients who are receiving Trastuzumab, Pertuzumab and Paclitaxel for their initial IBC treatment. Our funding will permit correlative studies to analyze the biopsies that have been collected in this study. The goal is to understand the molecular features that predict pathological complete response as well as lack of efficacy of this regimen.

In June 2016, we funded a second project under the direction of Dr Justin Balko at Vanderbilt University. The goal of the project is to investigate the responses of IBC tumor models to treatments with proteins called cytokines to mimic the effects of non-cancer cells within the breast that contribute to the aggressive biology.

In February 2016, we gave our first small grant to the University of Delaware for research in Dr Kenneth Van Golen's laboratory on the biology of skin metastasis and the interplay between IBC and radiation. This preliminary work which is very promising was presented as a poster by graduate student, Sangjucta Barataki at the International IBC conference in July.

Future Funding
We have committed to a further $50,000 to fund the above-described Dana Farber project by the end of 2016, and the second half of the Vanderbilt University project by June 2017 which will total $50,000 as well.

Several other investigators have contacted us with requests for further grants, so we will keep working intensely on meeting these needs!

NEW: IBC MOBILE APP

A recent project we are most proud of is the launch of our IBC mobile app, which is available on both iOS and Android platforms. This app was developed when we consistently heard that online information about IBC is out of date and misleading. The app contains accurate scientific information, and stories of hope from survivors. Additionally we aimed to help women find clinical trials that are recruiting IBC patients and present the scientific rationale behind them in an accessible way. We include detailed summaries of all IBC-focused clinical trials, and we are adding more general trials that are reasonable choices for women with IBC. This app is not meant to replace patient’s own oncologists, but provide a starting point for conversations, particularly for women receiving care in the community in settings where clinical trials aren’t available.

We would love to hear your feedback on the app and how we can make it even more useful to you.

Recent research articles from our funded research projects

Our research funding is making a difference in the area of inflammatory and triple negative breast cancer. We consistently receive letters from our grant recipients who are incredibly grateful for our support in these times of ever-competitive federal grants. Did you know less than 10% of NIH grant applications that are submitted are awarded, and each grant requires hundreds of hours of effort from the scientist and administrators in their departments.

Here’s some of the articles that have been published in peer-reviewed journals describing the high-quality work we have supported. These have also been added to our website as updates, but in case you missed them, please read below.

The role of statins in IBC
The goal of this MD Anderson led project was to obtain preclinical evidence about the effectiveness of statins in IBC models to determine whether a randomized clinical trial is warranted. This followed from an epidemiological finding that in IBC patients, those taking a hydrophilic statin had better outcomes than non-statin users. This paper was original published in July 2013 in the British Journal of Cancer online at [http://www.nature.com/bjc/journal/v109/n2/full/bjc2013342a.html](http://www.nature.com/bjc/journal/v109/n2/full/bjc2013342a.html).

Follow up research directly from our research funding includes 2 publications described below, which collectively provide strong rationale for a clinical trial, which is the subject of our more recent funding (February 2016).

The first paper looked at the role of simvastatin to enhance the effects of radiation, which is a critical component of IBC treatment and especially important when chemotherapy has done a sub-optimal job at eradicating IBC throughout the breast. This research found that simvastatin could potentiate radiation including targeting the radiation-resistant stem cells. The paper may be read at [http:// stemcellstm.alphamedpress.org/content/3/7/849.abstract](http://stemcellstm.alphamedpress.org/content/3/7/849.abstract) - free account needed or [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4073823/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4073823/).

A follow up study was also published in Breast Cancer Research and Treatment. The research used metastatic models of triple negative breast cancer (including 1 IBC cell line), and demonstrated that simvastatin significantly reduced metastatic potential and stem-cell features. The mechanism underlying this phenomenon is also described in the abstract which can be read at [http://www.ncbi.nlm.nih.gov/pubmed/26590814](http://www.ncbi.nlm.nih.gov/pubmed/26590814), and the full text PDF is available by request due to publisher paywall.

IBC Brain Metastasis
This project, which aimed to generate novel brain metastasis models and identify targets involved in the underlying biology of brain metastasis in IBC, was successfully completed recently. The manuscript was published in the Journal of the National Cancer Institute in April 2016 ([http://jnci.oxfordjournals.org/content/108/8/djw026.abstract](http://jnci.oxfordjournals.org/content/108/8/djw026.abstract)). In this paper, Dr Debeb and colleagues from MD Anderson generated models of human IBC cells capable of brain metastasis in mice. They also discovered that a specific micro-RNA (miR-141) promotes brain metastasis via genetic manipulation of the tumor cells prior to inoculation into mice. Ongoing work continues to explore how this may be translated into new treatments to prevent or treat IBC brain metastasis in patients. In addition this work has led to additional funding including a $174,000 R21 National Cancer Institute grant to continue this work ([http://grantome.com/grant/NIH/R21-CA188672-02](http://grantome.com/grant/NIH/R21-CA188672-02)). We are excited our small grant has led to further funding in this area and hope to see other projects lead to successful federal grant applications.
Recent research articles from our funded research projects (continued)

JAK2 as a target in aggressive breast cancers
Dr Justin Balko and colleagues from Vanderbilt University published the results from this research in April 2016 in the prestigious journal Science Translational Medicine. The article can be read at http://stm.sciencemag.org/content/8/334/334ra53. The major discovery in this paper is that a subset of TNBC (10%) have extra copies of the JAK2 gene, and this genetic abnormality in tumors results in increased aggressiveness and poor survival. The implication of this research is that JAK2-specific inhibitors in combination with chemotherapy may be useful in this patient population based on the preclinical data we funded.

IBC and “blood biopsies” for diagnosis and treatment of IBC
Dr Massimo Cristofanilli (funded while at Thomas Jefferson University, now at Northwestern University) has been pioneering work into non-invasive methods to monitor IBC patients disease burden and treatment responses through what are colloquially called “liquid biopsies”. Liquid biopsies are tests that either characterize circulating tumor cells (CTCs), or circulating DNA (ctDNA) that is shed from tumors into the blood. By sequencing these DNA fragments, doctors can identify what mutations are found in the patients tumors, and therefore select targeted treatments that may work more effectively and minimize unnecessary side effects. Some of this research was presented at the AACR annual meeting in 2015. AACR is the world's largest comprehensive cancer meeting encompassing basic, preclinical, clinical and epidemiological research. The abstract may be read at http://cancerres.aacrjournals.org/content/75/15_Supplement/2788. Although the number of patients sequenced so far is not the full cohort intended, so far the project has been successful in identifying mutations from these samples (10 pairs of IBC-non IBC samples) and following these mutations serially over time to monitor response to therapy. The funds have not been completely used, so this project is still ongoing and further work needs to be completed prior to a publication.

FAST FACTS ABOUT THE IBC NETWORK
To date we have funded 2 clinical trials plus laboratory research. We have awarded $630,500 in total research grants as of August 2016 at 5 institutions - University of Texas MD Anderson Cancer Center, Dana Farber Cancer Institute, Thomas Jefferson University, Vanderbilt University and the University of Delaware.

Keep up with us on social media

www.facebook.com/TalkIBC
www.twitter.com/TalkIBC
www.instagram.com/TalkIBC

Contact information
Website: http://www.theibcnetwork.org
PO Box 908, Friendswood, TX 77546

2 plaques newly displayed in the Morgan Welch IBC clinic at MD Anderson to acknowledge our considerable funding track record ($250,000 pledge completed).