



THE IBC NETWORK FILES

A newsletter for our donors, friends, and patient advocates

Letter from our founder, Terry Arnold

In our first newsletter, which was issued in the Fall of 2016, I gave an overview of our history to date. I felt it was very meaty newsletter, as we had a great deal of information to share. This issue will be more forward looking. I believe we have established ourselves as a major contributor in the world of IBC. Researchers and patients look to us for support. Our mobile app is being recommended by major cancer centers, and we are the “go to place” for advocate assistance by patients as well as researchers. We hosted our first booth at the recent San Antonio Breast Cancer conference and spoke to thousands of physicians and researchers. We listened and understand the struggles of the researchers, especially the lack of funding, but also discussed what resources are needed to make their work more effective. We have been in conversation with major medical institutions about how we can impact current patient care. There is the need to increase education in the medical community so doctors can diagnose properly and quickly, the need of an encoding number for proper tracking, or even ways to have multi institutional trials. There are so many issues, and we want to help facilitate clearing these hurdles.

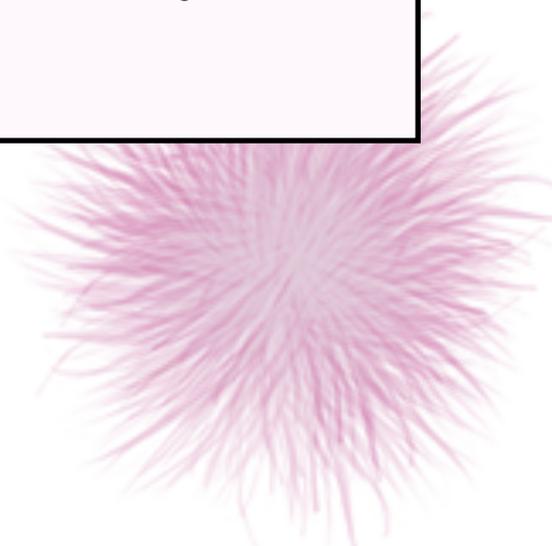


Now that we have crossed the five-year mark in our charity, I look forward to the future. I feel we have enough history behind us to show we are not just a flash in the pan and we have earned our place at the table to help make decisions and give input that can matter long term. Not only are we a niche charity focused on a somewhat rare disease, we are a unique charity. We are all volunteer ran, and we are focused on helping the researchers. We strongly feel that will best help the patients in the long run. However, because we run the most active support group for women diagnosed with IBC - in addition to being founded by an IBC survivor - we have a strong understanding of patient’s needs, short and long term. Sometimes it can be tempting to look more impressive to hold our funds back and release a huge grant. However, when a researcher calls you and explains that a small grant of \$5,000 can kick off a project that they think will really matter matter and because it is regarding IBC they know they will not be able to get those funds anywhere else, your heart just pounds a little faster. We are in the trenches with this, as deep as it gets. I hope you enjoy the articles you will read in this issue, so you can see some of the growth we are spearheading. Thank you for believing in us.

Hope always. Terry

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- * Researcher profile: Dr. Justin Balko
- * Recap of our first information table at SABCS
- * IBC research updates
- * Upcoming spring events and looking forward to October (31 days in October campaign)



UPCOMING EVENTS

February

11th-12th - 10th Anniversary Morgan Welch Inflammatory Breast Cancer Conference (Houston, TX)

14th - Oklahoma Capital Day lobbying (Oklahoma City, OK)

26th- Alligator's Hunt for Hope (Houston, TX)

31 Days of October

We must be creative to get IBC information into the general breast cancer conversation. Last year we brainstormed and came up with the "31 Days in October" campaign. It was effective and we want to make it an annual event. The idea was to find ways for everyone to bring IBC awareness into their community via, well, their community, and it worked!

Each October, pink events abound but few focus on IBC and we wanted to change that! The point was to have some type of event every single day of the month of October focused on IBC. People joined us all over the country to get involved. Some had dinners at restaurants that doubled as fundraisers, others used their workplace newsletters to get articles published. The ideas were great, effective and were of little to no cost. It was a very edifying campaign, as it was customizable to each person. Some could not do a physical event but used social media for virtual events or education. We listed the events on our website calendar and people were encouraged and got creative along with us. We loved this because it reflected our grassroots movement, with a single branded focus but allowed some individual ownership, community personality and resources to be utilized. We hope you will consider joining our campaign this coming October by hosting an event or by checking the calendar and joining a planned event.

The 10th Anniversary Conference: The Future of Inflammatory Breast Cancer

We are so pleased to support MD Anderson's 10th Anniversary Conference entitled The Future of Inflammatory Breast Cancer. The conference which celebrates the 10 years since the dedication to Morgan Welch, is open to all interested parties - researchers, clinicians, trainees, patients, and patient caregivers.

The conference will span both basic and clinical research - covering current issues related to standard of care, and recent laboratory discoveries and robust discussion of where future research should be focused. There will be platform talks, panel sessions, poster sessions and ample time for questions and discussions by all. This will be a who's who event of leaders in the IBC community and a great opportunity for networking and learning. There will be a special advocacy session co-chaired by Terry Arnold and Angela Alexander for patient advocates and their supporters to attend on Saturday afternoon.

This first version of the program does not mention that the registration fee for non-physicians/non-healthcare providers is only **\$15** (i.e. patients, patient advocates, family/friends). Please see all program details at bit.ly/IBC-Conference

Registration is still open - and if you are having trouble with the online site, the form can be emailed or printed and faxed into the MD Anderson Conference Department as indicated in the PDF. Contact us if you need assistance registering or need advice about travel arrangements.

The IBC Network is serving as a major sponsor of this meeting - we have pledged \$10,000 towards the costs as a "gold level" sponsor to indicate our serious commitment to facilitating networking of IBC researchers and clinicians. We truly hope our supporters will attend the conference and find it beneficial!

IBC Researcher Spotlight: Dr. Justin Balko, Vanderbilt University

The IBC Network has a growing history of supporting the research of young investigators, those already involved in IBC research and those that are new to the field. We believe it is critical to bring in young, enthusiastic scientists to help solve the challenge of curing IBC. In today's highly competitive grant funding environment, young investigators who don't have decades of scientific accomplishments and resources are most vulnerable to being unable to do the exciting research they spent years training to do. In this series, we will profile some of these amazing people we have met and some of their accomplishments related to our funding. Dr. Justin Balko, Assistant Professor of Medicine and Cancer Biology at Vanderbilt University couldn't be a better person to begin with.



We were initially introduced to Dr. Balko through a chance encounter with his postdoctoral mentor Dr. Carlos Arteaga at the San Antonio Breast Cancer Symposium. A relationship grew through the University Development Office and before we knew it, we had received a proposal for some interesting research Dr. Balko was doing on triple negative breast cancer (TNBC) that needed some funding....and the rest is history! We wrote about this project and a subsequent IBC-focused grant we provided in our Fall 2016 newsletter.

Dr. Balko began his independent research career in January 2015 when he received his Assistant Professorship (which means he was given his own lab space and start-up funds to hire staff and students to work with him). In these mere 2 years he has developed a robust research program merging his background in clinical pharmacy with the cancer biology training he received as a postdoctoral fellow in Dr. Arteaga's lab, to develop a program to identify and exploit new therapeutic targets in TNBC and now IBC to deal with therapy resistance. One of his post-doctoral projects involved interrogating the residual disease that remains in some TNBC patients who did not completely respond to neoadjuvant chemotherapy - which is also a frequent problem in IBC. This residual disease which is termed "chemo-resistant" is the likely cause of recurrent disease, so Dr. Balko asked whether there are genetic changes (such as mutations or amplified genes) that can be found in these samples that could be potential targets for developing better TNBC-focused clinical trials. Amplification of JAK2 (i.e. extra copies of the JAK2 gene) was one discovery from this analysis.

Dr. Balko's current IBC seed funding (June 2016-June 2017) builds on new research in IBC that suggests that one of the reasons IBC behaves differently from non-IBC is that the non-cancer cells ("tumor microenvironment") surrounding the tumor cells play a complicit role in increasing the aggressiveness of the IBC tumor cells that, as best we know, are genetically similar to regular breast cancer cells. We currently do not fully understand how all these bad-actors work together to promote classic IBC biology, and don't have great models established to perform these controlled experiments. Therefore, the goal of Dr. Balko's current grant is to develop better models to test some new hypotheses regarding potential secreted factors and how they influence IBC biology. Stay tuned for what we learn from these studies over the next few years!

FUNDING UPDATES

Recent Funding Awarded

Our most recent funding was in December of 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. If you have been following our work, you would have seen we originally funded this in July 2016 and some additional funds were requested to help complete this project. We funded \$50,000 in December 2016

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, Sangjuncta Barataki at the International IBC conference in July 2016. Since this research looks so promising, we have funded an additional \$14,000 for the next step with plans for more support in the spring of 2017.

Future Funding

The IBC Network Foundation supported an upcoming MD Anderson's Morgan Welch Clinic clinical trial under the direction of Dr. Naoto Ueno. The project is to determine if the addition of a statin to standard therapy will be effective in reducing the chance of IBC/TNBC recurrence. This trial is based on considerable rationale from the Morgan Welch clinic that in preclinical models, statins reduce inflammation and target treatment-resistant cells (called cancer stem cells). This is a randomized phase II study that will be held at MD Anderson Cancer Center under the direction of Dr. Ueno. We have committed to award \$150,000 a year for three years. We will release \$75,000 in February for year two of the three year commitment.

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

Our first informational table at the San Antonio Breast Cancer Symposium (SABCS)

Last month (December 6-10th) we were excited to be able to attend the 39th annual SABCS conference, now held the first full week of December, which brings together the world's best and brightest breast cancer researchers and clinicians, to share advances in biological research and clinical care. It is an information-packed week of talks, poster sessions, meetings and, for the first time in our history, a table in the exhibitors area. We were delighted that 2 of our volunteers, Liz Tobin and Leslie Sullivan (pictured below) were able to staff the table for much of the time. Our goals for the table were to share information on IBC diagnosis, treatment and survivorship as well as highlight our solid resources they would find useful (including the app), since IBC gets little coverage in the main sessions.



We were lucky to meet researchers from around the world, both young and well-established who we might be able to help with research funding or other needs. Volunteer feedback included the following quotes: "I found it amazing, just by talking and asking questions of them we were able to start making some connections, connections not just for The IBC Network, but for a cure for IBC...Being able to be a part of this effort gives me a new fuel to know that these people do what they do because they care". "Hopefully I was also able to represent all of us that have been through the nightmare of Inflammatory Breast Cancer and help raise awareness of the disease"

The Birth of the Hunt for Hope

From the family of Lori;

Our beloved Lori (Gill Grennan) was diagnosed with IBC at age 32 in August 2009. Faced with a 9-12 month survival prognosis, she promptly “pulled up her big girl pants,” as she liked to say and got busy. She made a bucket list and was determined to do everything possible to buy herself more time and help others. She teamed up with the IBC Network Foundations’ founder, Terry Arnold to educate others, including medical personnel, and get funding for critically needed research aimed at this little understood, aggressive killer. She first met Terry at the MD Anderson Morgan Welch IBC Center in Houston, TX while undergoing treatment. Lori knew funding was critical so she came up with a great idea to raise money to support the research at the IBC Network- “Races and walks are great. I want a fun, memorable, family oriented event that people talk about and anticipate. Let’s do a task oriented scavenger hunt and call it something catchy.” Her sister, Kara suggested the name Hunt For Hope and the rest, as they say, is history. Lori organized the first two hunts in 2011 and 2012. Sadly, Lori passed away in January of 2013, 41 months after her diagnosis. Lori’s family and friends continued the Hunt for Hope to keep Lori’s dream alive. The 2016 Hunt For Hope Ohio raised over \$67,000.

Fundraising for research is a huge focus, but seeing friends, strangers and people all across the country join together with a common focus is beyond inspiring. While the subject of cancer is such serious business, it is the sense of fun, the competitive spirit, the good natured challenges, the kid’s lemonade stands, the restaurant fundraisers, and the silent auction contributions that all make this so event so special and unique. It has become exactly what Lori envisioned. Lori would be so proud and excited to see how many people now know about and care about the women and families impacted by IBC and what a difference her brainstorm has made in lives all around.



Above Picture: "Team Ohio Hunt for Hope" - Lori Gill Grennan's family continuing her legacy by leading Hunt for Hope events yearly in Lewisville, OH
Kara Kent (holding daughter), and behind her is her husband and his parents. Center, Jerry and Sheila Gill, right, Matthew and Rebecca Gill.

Left Picture: Lori Grennan and her children, Oct 2012

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