



THE IBC NETWORK FILES

A newsletter for our donors, friends, and patient advocates

Letter from our founder, Terry Arnold ***Traction***

The word that comes to mind as a theme for this message I want to convey to our supporters. Definitions of traction: the contact of two objects, for example a tire to the road, and other definitions is: to drag something across a surface. Both apply here. In the beginning I felt like we were dragging IBC into the “pink” conversation and honestly it was not always welcomed. Identified as “too rare” and “too scary to discuss”, the conversations often just trailed off. However, our determination has paid off and we have traction this year and it is only growing.



October of 2017 has contained more publicity regarding IBC than I have seen in the past years added together. I must admit I'm quite proud of this. Almost all of the IBC patients I have seen in the news have some type of relationship with the IBC Network. We are mentoring them, giving them talking points, and coaching them to be comfortable sharing their stories in an effective way. Reporters are more comfortable listing us as a resource as our respectability is growing, due to our commitment to funding research and our transparency. Our relationships at IBC focused centers are growing past a cursory relationship, and now have a depth that is holding great promise for improvements on all fronts. Our app is being recommended by all the major IBC clinics and is being downloaded worldwide.

Measurability of our success is always on my mind. I see this component as three-tiered, Patient Impact, Research and Education, which can be hard to track. We know women are getting better care due to our informative website. We hear from them often, so we know we are impacting the current patients. The impact of the research we are funding is significant and in November of 2017 we will have crossed over the 1-million-dollar mark of research funded! This December we will once again have a booth at SABCS to reach oncologists attending the largest breast cancer conference in the world.

Donor support-wise we are growing and now have just over 5000 households in our database, many of whom have donated more than once. We are also growing in our international outreach so please see future newsletters with updates on these projects.

The takeaway message here is we are a force to be reckoned with and that you can be very proud of your association with the IBC Network. We are pleased to have you on board with us. Hope always, Terry

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UPCOMING EVENTS

December

5th-9th, San Antonio Breast Cancer Symposium (SABCS) (We will have an educational booth manned by several volunteers. Follow the news on twitter - search #SABCS, official hashtag is #SABCS17)

April

Yellow Rose Boot Scoot, Houston, Texas, Date/Time: TBD

External Collaborations

Our mission to fund research means that we are delighted to support university fundraising efforts directed at IBC research. Last year MD Anderson Cancer Center began the Boot Walk to End Cancer, a walk for employees, patients and supporters. The IBC clinic formed a team which raised close to \$90,000. This year, the IBC Wranglers are back with a goal of \$100,000 which has been surpassed. The IBC Network has completed a matching pledge for \$5,000 this year towards this goal.

No doubt inspired by MD Anderson's success, the IBC program at Dana Farber joined the Boston Marathon Jimmy Fund walk. Dr Beth Overmoyer led a team of IBC staff and patients, and were able to raise over \$24,000 for their program. The IBC Network contributed \$2,500 as a match towards this total to support the team's efforts.

* * *

A leading breast reconstruction surgeon in Texas has developed a mobile app to help women understand their options for breast cancer surgery: lumpectomy, mastectomy, oncoplastic and breast reconstruction. We are delighted to have partnered with them on the section regarding reconstruction for IBC patients. This shared decision app will be available for beta testing in January. For more info and to sign up for the free beta release, please go to <https://breastadvocateapp.com>.

National RFA for Grants

To date, we have approached known IBC researchers and solicited applications from them in order to present a funding goal to our donors. This was necessary while we were building our name and reputation as a reliable funder of IBC focused research. However, now that we are growing rapidly the time is right to begin an open call for applications (RFA = Request For Applications, in academic speak). We are working on writing up this information for dissemination widely in the new year. Please watch the website for this information by early December.

Why is this exciting? We are looking forward to seeing more research into IBC and other aggressive breast cancer subtypes such as TNBC which may also apply to TN-IBC due to the overlap in biology. By opening up a call nation-wide, we hope to fund the most exciting research, regardless of whether we already know about their work or not, and perhaps even encourage new researchers to study IBC.

As a brief overview of the process, we will solicit a one page overview letters, Letters of Interest, (LOI) in February. If the topics submitted fit the scope/goals of our charity, we will encourage full applications by April.

The applications will be peer-reviewed by a panel of both scientists and advocates to ensure the science is meaningful and the approach will provide answers to the stated questions. We will announce the top 2 winning grants by June 1 2018, and anticipate the start date being July 1 if all regulatory approvals have been obtained.

How can you help?

- 1) Please keep the donations coming. We would love to have the funds ready prior to the funding date.
- 2) We could use some help in spreading the word. Please share any contacts at universities/institutes that we have not previously funded so we include them in the mailing. A research infrastructure must already be in place. Email: grants@theibcnetwork.org

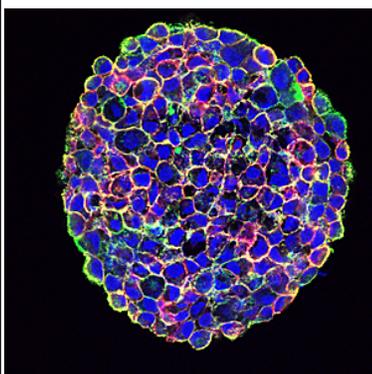
IBC Researcher Spotlight: Dr Kenneth van Golen, University of Delaware

In a previous newsletter, we profiled a young, up-and-coming investigator who's just beginning his independent research career, and in whom we have invested a couple of grants so far. This time, we thought we'd profile a more senior investigator who has been in the inflammatory breast cancer research arena for a while. We're delighted to share some of Dr Kenneth van Golen's story, both leading up to our funding and updating you with what his laboratory has been learning about the interaction of radiation with IBC cells.

Dr van Golen began working on IBC over 20 years ago during his scientific training. After completing his PhD in cell and cancer biology, he took a postdoctoral fellowship in Dr Sofia Merajver's lab at the University of Michigan. Back then, IBC was not thought to be a distinct type of breast cancer, and the research ongoing was very rudimentary compared to the state of knowledge today. He was intrigued by the observation of how differently IBC behaved compared to conventional breast cancer and was struck by the stories of the women with IBC. At this point he decided to dedicate his career to understanding inflammatory breast cancer.

Dr van Golen and his mentor realized that there must be some underlying differences in the biology of IBC that drive the distinct aggressive clinical behavior. His early gene-discovery work identified a protein called RhoC that is overexpressed in IBC, and he discovered the functions that RhoC plays in IBC metastasis.

In 2006, Dr van Golen became a faculty member in the Department of Biological Sciences at the University of Delaware, where he currently is an Associate Professor, and he is also a Senior Research Scientist at the Helen F Graham Cancer Center in Newark, DE. His lab focuses on IBC and dabbles in prostate and pancreatic cancer biology as well. He actively mentors students and postdocs who work in his lab.



Immunofluorescent image of emboli of cells. Emboli (or clusters of cells) are particularly characteristic of IBC and frequently found in the skin.

More recently, his research has focused on cell signaling pathways that are important in IBC and that may be therapeutic targets. These include the PDGFR pathway and the TGF beta signaling pathway as a driver of IBC skin metastasis. This work on TGF beta was the focus of his seed funding from the IBC Network. Along with his graduate student, Sangjunta Barkataki, he has generated some provoking preliminary results from our first grant to his laboratory. TGF beta is frequently suppressed in IBC patients and this property may be what keeps IBC cells stuck together as clumps. Upon stimulation by TGF beta from surrounding non-cancer cells (for example as a response to radiation), the IBC cells change to a single-cell type of invasion, which may promote skin metastasis. The current work is aimed at understanding whether blocking this signal could decrease the skin metastatic behavior of IBC. We are looking forward to hearing more about the results of these studies, which we have just funded an additional \$26,000 towards.

FUNDING UPDATES

Recent Funding Awarded

We have awarded a 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 \$26,000 for a total of \$52,000

The IBC Network Foundation supported an upcoming MD Anderson's 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). We have committed to award \$150,000 a year for three years. We will release \$75,000 in November for year two of the three year commitment.

With these 2 grant commitments fulfilled, we will have crossed the **\$1M** mark of research into IBC and late stage breast cancers. Kudos to all our fabulous volunteers and donors who have made this possible.

Future Funding

RFA - 2 grants worth \$100,000 will be selected from this competitive request for applications cycle.

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

#BecauseResearchMatters T-shirts - Now available!

After brainstorming with IBC sisters, Christen Boisse and Tess Skaggs, a simple but powerful phrase came to us and we felt we must proclaim it. We feel very strongly that without good quality research focused on late stage breast cancer, like IBC, we can't have the impact we want to have to save lives. Christen and Tess created the art and this is how #BecauseResearchMatters was born. We had shirts printed and the message shared. Our goal is to get 5,000 of these shirts in circulation, bringing focus to the importance of research.



Why 5,000? It turns out there are approximately 5,000 new cases of IBC diagnosed each year in the US. The first test run of the shirts was so popular we actually got behind in mailing them out, as we had over 200 requests in just a few hours. We are so grateful we have mailing support now, as our friends at Forever Stainless Steel, a company in Nebraska, have not only offered to handle all our mailing for us but have even offered to underwrite all the mailing costs. This is a huge gift to us of time as well as offsetting overhead cost.

Recently we heard from an ob-gyn's office that would like to have #BecauseResearchMatters shirts for all of their staff to encourage conversation with patients in a non threatening manner. This meant a great deal to us because this team has not dealt with an IBC patient directly, but have been following our work. This is the largest OB GYN practice in Texas and to have their patients informed will lend a ripple effect that can be powerful. This as an incredible measure of our success because of the potential to secure a diagnosis earlier than later, is a greater probability if we can get our frontline doctors on board.

How can you get one?

You can fill out the form at <https://www.theibcnetwork.org/order-t-shirts/>. The suggested donation is \$25 per shirt, although we will send a shirt for a donation of \$10 or more. We hope you will get one, wear it often, and please snap a picture and share on social media telling the world #BecauseResearchMatters

Insider secrets about running successful fundraisers: Tips from the Ohio Hunt for Hope



The Hunt for Hope is our signature fundraiser held in several cities around the US each year. We started out hosting the Hunts in the fall. However, there have been events run in the spring as well, such as the Alligator's Hunt for Hope (run by Ms Carter Lee and her family) in Houston Texas. The first Ohio hunt raised just over \$30,000, but since then the events have grown considerably both in terms of funds raised, encouraging education in the lay community and allowing for bonding moments as the event connects us to others who have shared our experiences. We credit the success of the Hunt held in Ohio each year to the unwavering faithfulness to research and the passion of its organizers, Lori Grennan's family and friends. This year they raised \$76,701.00, for which we are tremendously grateful.

We shared in a previous newsletter the story of how Lori inspired the formation of the IBC Network, and her legacy lives on in a large exciting Hunt for Hope each year in Lewisville, Ohio. We would like to share some observations of what they do to make the event run smoothly and be so successful.

Tips

- Start working on the event well in advance - they start making initial arrangements soon after the close of the current Hunt, and give out a Save the Date Announcement for next year at the current Hunt.
- They have made a science of not only how to process "Hunters" but also how to track them the day of the event. for example seen next bullet
- A command station is set up, with about 8 volunteers with cell phones and laptops on the ready.
- Team Leaders are given a cell phone number to the command station. The team leader will text progress in real time to their contact person, allowing realtime updates of success on a master board for all to see.

We hope as our events grow, more will learn from the impressive Hunt held yearly in Ohio. Questions about organizing your own event such as the Hunt for Hope? Please contact Terry at terry@theibcnetwork.org.

Welcome new board member, Ms Kiwana Gayden

We wish to announce the addition of Ms Kiwana Gayden, from Jackson Mississippi to our board of directors. Kiwana was diagnosed with stage 3 triple negative IBC in January 2016. Since completing treatment in October 2016, she has remained NED (no evidence of disease). Kiwana has become passionate about IBC awareness and education since her diagnosis, and so is a natural fit for our board.

Kiwana's professional experience is in STEM. She graduated from Jackson State University with bachelors and masters degrees in chemistry, and she currently works as an asphalt binder technician. Prior to this, she worked in the Mississippi Department of Health also in a chemistry capacity and overseeing regulatory aspects related to public health.

Kiwana's role in the IBC Network as Director of Community Outreach will focus on networking more education in the lay community. She was a tireless advocate prior to joining us so now we are very fortunate to have her on on our board.



New Annual Golf Outing Fundraiser in memory of Lindsay Thul

The first annual Lindsay Thul Memorial Golf Outing was held on Friday, September 29th 2017. Lindsay's family decided to establish this annual event to memorialize Lindsay, educate about Inflammatory Breast Cancer, and raise funds to support IBC education, research and patient support. We are incredibly grateful for the efforts of the organizers, Lindsay's mom, her brother, Nick Thul and one of Lindsay's good friends, Deanna Jensen Valliere. Their leadership for this event resulted in raising **\$13,500** for our charity. The family feels that The IBC Network Foundation is focused in all the desired areas and trust that we will put the funds raised to good use.



Who was Lindsay?

Lindsay Marie Thul died at the young age of 29 on February 1, 2017, less than 10 months following her official IBC diagnosis. When she was diagnosed, there was no family history of any type of cancer and Lindsay was a healthy, active 28 year old young professional in the prime of her life. Additionally, her diagnosis was triple negative and her cancer was resistant to all of the traditional therapies used.

Lindsay's mom, Diane Koster, the primary organizer of the event gave us a brief overview of the event.

"We were fortunate to have close family friends that offered the use of their golf course, Glynn's Creek, which is where the event was held. We had room for 144 golfers (36 teams – 2 flights), with a shotgun start. We limited each team to one mulligan to keep play moving. Shotgun at 1:00 and last golfers in at 6:15 pm. The event filled up with 144 golfers participating in total. We kept the outing simple with no food or meal offered, although they could purchase food and beverages in the clubhouse.

At the awards party on Oct. 1st, all golfers received a free meal (burgers, chips) and a free beverage of their choice, compliments of the bar owners. Prizes were awarded to the 2 top teams, which was donated back to the cause. The top team also received a small trophy commemorating the outing. All hole sponsor signage, welcome banner and golf ball printing was donated and the overhead expenses were kept to a minimum."

Lindsay was very committed to funding research, so we are honored to be partnering with her family to fulfill this desire.



Lindsay Thul

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