

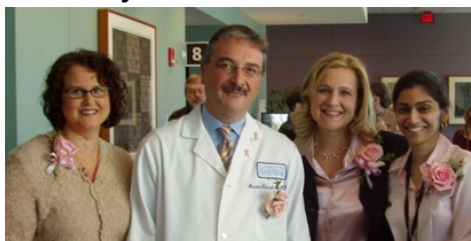
Celebrating Women's History IBC Morgan Welch Program and Clinic's 15th Year Anniversary

Women's History Month is an annual declared month that highlights the ideas and contributions of women who played major roles to events in history and modern society. This year, the Morgan Welch Inflammatory Breast Cancer (IBC) Program and Clinic would like to **commemorate and celebrate the women who helped establish the program.**

The story of the Morgan Welch IBC Program and Clinic is not just a story of Morgan Welch, MD Anderson, or Texas, although significant events and people allowed MD Anderson (MDA) to be the hub of activity. Advocates from across the country abetted in developing an IBC-focused clinical and research center that has had an extensive impact across the world. From the beginning, there were other significant people involved, many of whom are still involved, and others in remembrance.

Recognizing the enormous need to broaden public awareness about IBC, a frequently misdiagnosed and inappropriately treated disease, **we realized the great need to have a specialized facility to focus on treating and researching this rare and aggressive type of breast cancer.**

Advocacy in Action!



In **January 2006**, Dr. Massimo Cristofanilli met with Susan G. Komen fellow Dr. Shaheena Dawood and advocates Dorothy Paterson and Jeannie Frazier to express his concern and care about the rare disease of IBC that was affecting young women like Morgan Welch.

Jenee Bobbora, now a 21-yr IBC survivor, and Dorothy Patterson, a fellow long-term survivor of breast cancer, united in seeking philanthropic donations to help contribute to the opening of the IBC Clinic, which was kicked off in **October 2006**. The outpouring of support was amazing, Jenee Bobbora and her family were instrumental in the success of that special day. Before the clinic was formed, MD Anderson was seeing about 25 IBC patients per year. Now the number of new patients receiving specialized, expert medical care for IBC, including IBC-dedicated clinical trials, has quadrupled – and the numbers of people receiving the right kind of care continue to grow!

Advocates Changed the world of IBC Care

Patricia K. Jennings, a patient of Dr. Cristofanilli, and her husband, Timothy, were largely **responsible for the state funding of the program.** She and her husband were determined that the voiceless women who died with IBC be given a voice. In their efforts to make a difference, **Senator Jennings introduced a bill to the New Mexico legislature for \$3.2 million for IBC research to be used by the New Mexico Cancer Center, specifically in partnership with MDACC** under Dr. Cristofanilli's leadership. In **February 2007**, Senator Tim and Patty Jennings (originally



diagnosed with IBC), Dr. Tom Buchholz, Dr. Cristofanilli; Advocates: Jeannie Frazier, Jenee Bobbora, Angie Elliott, Karen Funk, Dorothy Paterson, and Dr. Melanie Royce University of New Mexico (NM) met before the NM Legislature who approved the first funding for the Inflammatory Breast Cancer Clinic. Angie Elliot and Jenee Bobbora were two of the original team members making the appeal to the New Mexico Legislatures. Later, the Angie and Vincent Elliot Scholarship was established in her memory.



Patricia K.
Jennings
1955-2009

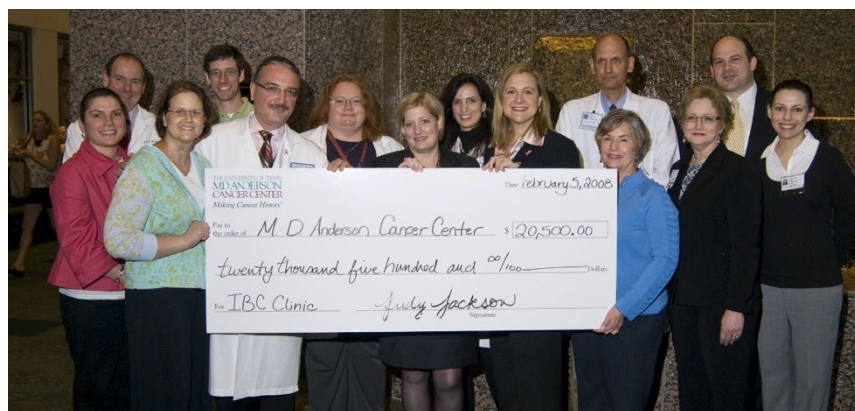


Knowing that the funds coming from NM were not enough, Linda Dewhurst and her brother-in-law, LT. Gov. David Dewhurst (left picture) secured additional funding from the state of Texas legislature. In **April 2007**, IBC advocates in Texas joined Senator Timothy Jennings and Lt. Governor Dewhurst, which resulted in creating the \$4 million **"State of Texas Rare and Aggressive Breast Cancer Research Program"** at M. D. Anderson.

Initiated in **September 2007**, with the funding from the State of Texas, the Inflammatory Breast Cancer (IBC) Research Program morphed into a unique group of investigators and research staff with a shared dedication to improving the outcome of patients with IBC through clinical care, research and education. The matrix organization draws its membership from multiple departments and divisions across the institution. In **October 2007**, the official dedication of the Morgan Welch IBC Program and Clinic occurred, and we were recognized by Dr. Mendelsohn (right picture).



MD Anderson created the first comprehensive IBC Clinical and Research Program in the world, involving **multidisciplinary clinics, IBC case discussions, and seminars to promote team-science. Team collaboration is essential to improve our understanding of this challenging disease.** Crossing administrative hurdles from one division to another was equally as challenging as breaking down barriers administratively, financially, and scientifically. The program counted among its leadership a highly engaged advocate group (Patty Jennings, Jeannie, Dorothy, Jenee, and others) and considered the education of healthcare professionals and the public its primary goal. Expanding the recognition of IBC as a distinct clinical diagnosis was among the very first goals of the program, and we continue this mission today to ensure women who develop IBC are correctly diagnosed and treated.



In **February 2008**, Jenee Bobbora's sorority, **Zeta Tau Alpha Association**, donated \$20,500.00 in her honor and **continues to make yearly donations.** In addition, thanks to Glenda Kane (on the MD Anderson Board of Visitors), the Longhorns Breeders Association also donated to the IBC clinic.

Building on the state funding for the program, in **August 2008**, Susan G. Komen for the Cure® announced their first-ever "Promise Grant"



was being awarded to the MDACC IBC team for laboratory research under the direction of Dr. Fredrika Robertson (right picture), a leading IBC researcher.



We are happy to see that our IBC Team continues to grow and would like to thank our many long-time members, including Dr's Ueno, Valero, Woodward, Reuben, Lucci, Le-Petross, Bartholomeusz, Debeb, Wang, Singh, El-Zein, Jie Willey and advocates, Dorothy, Jeannie, David Baker.

IBC Team 2008
(Photo courtesy of Dorothy Patterson)

In **December 2008**, MDACC hosted the first international IBC technical conference right in Houston at Hotel Derek. Dr's Cristofanilli and Buchholz presented Patty Jennings with an award to honor and thank her for her outstanding efforts and for teaching and empowering each one of us along the way. At the IBC conference, there was a separate break-out session specifically for the advocates led by David Baker (picture of advocates at the session below).



Our special thanks to Mrs. Carter Lee (Hunt for Hope), Mrs. Terry Arnold (IBC Network Foundation), Mr. Forrest Smith, Family Committee, and Alessandra Land, a first advocate who served as co-captain to help raise funds for Boot Walk in 2021. We have had many advocates and donors who have contributed in the past, and we apologize if we have inadvertently missed acknowledging you personally.



Mrs. Carter Lee and Family
Alligator Hunt for Hope



Mr. Forrest Smith and Family
Cathy Rain Smith Immunotherapy Acceleration Award



Terry Arnold (left)

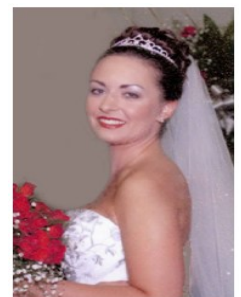


Alessandra Land (right)
IBC Boot Walk Wranglers 2021
Co-Captain



To the **amazing advocates, faculty, and staff**, both past and present, who donated their time, we would like to **thank each of you** for your hard work and dedication to building our world-class program.

What began 15 years ago with a promise by one doctor to a patient has now expanded to a national and international referral source, not only for patients with IBC but for clinicians who are unsure of how to treat and diagnose patients who may have this rare disease.



In Remembrance

We want to remember these wonderful advocates and thank them for their dedication and support.



Eileen M. Campbell



Ileene Robinson



Angie Elliott



Cathy Rain Smith

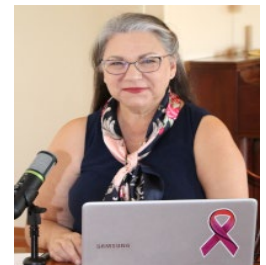
Treatment News: First PARP inhibitor approval in early breast cancer

In early March, the **FDA approved the use of Olaparib in the adjuvant setting** for patients with inherited (germline) mutations in BRCA1/2 genes who also have HER2-negative tumors, based on the OlympiA study. The data leading to this approval was presented at the ASCO meeting last year, and we summarized it in our July 2021 newsletter. Please refer to the archives if you want to read more about this drug or ask your oncologists whether it is appropriate.

With this new approval, one implication now is that **genetic testing has become more important as part of the workup of many cases of IBC** and other breast cancers due to this treatment option that may be relevant in up to 10% of cases. In addition, **Olaparib is now approved for early-stage and metastatic BRCA-related breast cancers**, and many more combination studies are underway to find beneficial combination treatment strategies or patient populations who may benefit from these drugs.

IBC Connect Webinar: Role of Patient Advocacy in IBC Program/Clinic

In March, our topic for the **IBC Connect Webinar series** was focused on the **role of advocates in building programs and research advocacy**. As the largest and most well-established IBC program globally, we aimed to highlight how advocates can assist with clinical and research efforts. Instead of a didactic lecture, a **panel discussion was held with two patient advocates, Mrs. Terry Arnold and Mrs. Trish Vickery**, representing MDA and Dana Farber patient advocates, respectively **as well as Dr. Bisrat Debeb**, a faculty member in our program who has worked extensively with patients to refine research proposals and had success in this submission. **Our advocates shared some experiences of attending research meetings, helping to plan conferences (such as patient forums), one-on-one advocacy for individual patients, and providing feedback about patient education materials.** Dr. Debeb made some remarks about how faculty can demonstrate that advocates are involved in research projects, including advanced planning and enough time to discuss the proposals in the earliest stages. The importance of timeliness in requesting advocate input and letters of support was emphasized since patient advocates who don't do these tasks full-time may need additional time to refine the materials with the PI's (principal investigator's) input. During the final stages of grant submission, the PI may run out of time for this important part of the application. Increasingly, grants require patient advocate involvement. The



required letters take time to develop. Patient advocates can also help with clinical trial protocols, such as communicating with pharma sponsors and revising patient educational materials to be easily understood by the layperson. The advocate panelists also shared about opportunities for research training and how this helps them be effective advocates. **If any of our partner locations need assistance identifying advocate opportunities, we are here to help.**

New Institutional Clinical Funding: Prime Award to Dr. Ueno for a new trial for IBC

We have just opened a **new neoadjuvant study for newly diagnosed triple-negative IBC**, a combination of Panitumumab plus the standard of care, Pembrolizumab, Carboplatin, Paclitaxel followed by Pembrolizumab, Adriamycin, and Cyclophosphamide. For the first cohort of patients, metastatic TN-IBC is required; however, once the safety of the novel combination is established, we will allow both stage 3 and stage 4 patients who are newly diagnosed to be enrolled. Panitumumab, the new agent, is an EGFR targeting antibody studied in Dr. Ueno's lab and 2 prior clinical trials and has **shown exceptional promise in IBC**.

We are also delighted to share that **Dr. Ueno was awarded an institutional PRIME award** to support some of the clinical care costs of this study that would not be covered by the patient's insurance, such as the research biopsies. The **PRIME (Prioritizing Research Innovation and Mentoring Excellence)** covers up to \$100,000 per year for three years for crucial costs for accomplishing **high-impact studies** that have not yet received external funding.

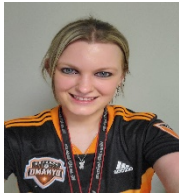
IBC Team Member Spotlight featuring Huiming Sun



Huiming earned her MD and a master's degree from Harbin Medical University in China. As a physician, she practiced pulmonology for ten years. In 2002, she joined her husband, a PhD student at the time, in San Diego in the US and then followed him to Houston a year later. At Baylor College of Medicine, she worked in the field of DNA sequencing in a Molecular Diagnostic Laboratory for 8 years.

In 2012, Huiming joined the Breast Medical Oncology at MD Anderson as an IBC Program research data coordinator. She grew and excelled quickly and was promoted to a position as coordinator of Regulatory Compliance. Her current role is to ensure all our clinical studies comply with FDA/NIH/NCI and institutional guidelines. Huiming finds her job very challenging in many ways - constant changes in policies and protocol management system and urgent deadlines. Even though Huiming is not involved in direct patient care, her knowledge in medicine and research gives her the confidence and assurance to provide the best quality care, behind the scenes, for our patients. She is proud to say that "The IBC program is the best program to learn, serve, and thrive, and I am happy to be part of Making Cancer History." Huiming actively participates in many of the IBC program's academic, outreach, and social activities. In her spare time, Huiming enjoys traveling and handcrafting. The colorful flowers and greeneries in her backyard are evidence of her passion for gardening. **"We sincerely appreciate Huiming for her 10 years of excellent service in the IBC Program".**

Welcome New Program Staff/Trainees



Heather McBride
Research Assistant II



Thuy Lee, M.D.
Rotating Fellow



Fan Zou, Ph.D.
Research Investigator



Van Ngu Trinh, Ph.D.
Postdoctoral Fellow



Young Gin Ji, DACM
Research Investigator



Nakyoung Oh, M.D.
Research Assistant I

Events of Interest to the IBC community

BLACK WALNUT CAFE

5510 Morningside Drive, Suite 150
Houston, TX 77005
(713) 526-5551

Boot Walk 2022 June 14, 5–9 pm Spirit Night

Join us for a night out or pick up dinner for your family. On the first of our Spirit Nights for 2022, Black Walnut will **donate 15% of sales** to kick off the **2022 Boot Walk Fundraising!** The donation is only valid for sales at the Rice Village location (address on the left).

Recent Awards and Grants

Naoto T. Ueno, M.D., Ph.D. and **Toshiaki Iwase, MD., Ph.D.**, received the **Prioritizing Research Innovation & Mentoring Excellence (PRIME) Award** from MD Anderson. Title: Enhancing Immunotherapy by Targeting the EGFR Pathway in Inflammatory Breast Cancer: A phase II study of Panitumumab (PmAb) And Pembrolizumab (Pembro) in Combination with Neoadjuvant Chemotherapy (NAC) In Patients with Newly Diagnosed Triple Negative Inflammatory Breast Cancer (TN-IBC).

Chandra Bartholomeusz, MD, Ph.D, Associate Professor, Department of Breast Medical Oncology– Research. Received the **MD Anderson Cancer Center Bridge/Seed Funding**. Abstract Title: **MELK as a Driver of IBC progression and Metastasis**.

We are pleased to announce the winner of the 'Cathy Rain Smith Immunotherapy Acceleration Award.'



The grant funds have been awarded in honor and memory of former IBC patient Mrs. Cathy Rain Smith, a fearless advocate for IBC research and participant in various program research efforts. This year, the Program awards a \$50,000 seed funding grant recognizing efforts with exceptional quality of IBC research and high impact (or potential impact) on our IBC patients.

Xiaoping "Maggie" Wang, Ph.D., Assistant Professor, Department of BMO - Research

Abstract Title: Targeting EGR1 to enhance the therapeutic efficacy of immune checkpoint inhibitors in inflammatory breast cancer

IBC Advocate: Kelly Gonzalez

Special thanks to Forrest Smith and family members who took the time out of their busy schedules to review each application submitted.

IBC Research Seminar Meetings

IBC Program Update

Naoto T. Ueno MD, Ph.D.

Professor, Breast Medical Oncology

James Reuben, Ph.D.

Professor, Hematopathology - Research

Wendy Woodward, MD

Professor, Breast Radiation Oncology

Swetha Bopparaju, MD, M.B.A.

Program Director, Breast Medical Oncology

Remodeling the inflammatory breast cancer tumor microenvironment to enhance immunotherapy: a novel therapeutic

Xiaoping 'Maggie' Wang, Ph.D.

Assistant Professor

Breast Medical Oncology – Research

Role of a novel second-generation MELK-selective inhibitor in inflammatory breast

Chandra Bartholomeusz, MD, Ph.D.

Associate Professor

Breast Medical Oncology – Research

IBC Research Seminar meetings are held on the 1st and 3rd Friday from 12:00 pm to 1:30 pm CST monthly. If you are interested in participating, please send your name and e-mail address to ibcp@mdanderson.org to be added to the distribution list.

Recent Publications and Abstracts:

Trends in Sentinel Lymph Node Biopsies in Patients with Inflammatory Breast Cancer in the US.

Authors: Alan Sosa, MD; Xiudong Lei, PhD; Wendy A. Woodward, MD, PhD; Mariana Chavez Mac Gregor, MD, MSC; Anthony Lucci, MD; Sharon H. Giordano, MD; Kevin T. Nead, MD, Mphil.

JAMA Netw Open. 2022;5(2):e2148021. [doi:10.1001/jamanetworkopen.2021.48021](https://doi.org/10.1001/jamanetworkopen.2021.48021)



IBC defined: proposed common diagnostic criteria to guide treatment and research.

Authors: Jaggi R, Mason G, Overmoyer BA, Woodward WA, Badve S, Schneider RJ, Lang JE, Alpaugh M, Williams KP, Vaught D, Smith A, Smith K, Miller KD; Susan G. Komen-IBCRF IBC Collaborative in partnership with the Milburn Foundation. *Breast Cancer Res Treat.* 2022 Apr;192(2):235-243. doi: 10.1007/s10549-021-06434-x. Epub 2022 Jan 1. Erratum in: *Breast Cancer Res Treat.* 2022 Feb 8;: PMID: 34973083; PMCID: PMC8926970.

ASO Visual Abstract: Inflammatory Breast Cancer at the Extremes of Age

Authors: Adesoye T, Babyemi O, Postlewait LM, DeSnyder SM, Sun SX, Woodward WA, Ueno NT, Hunt K, Lucci A, Teshome M.

Ann Surg Oncol. 2022 Jan;29(1):389. doi:10.1245/s10434-021-10586-x. PMID:34743277

NDRG1 in Aggressive Breast Cancer Progression and Brain Metastasis.

Authors: Emily S Villodre, PhD, Xiaoding Hu, PhD, Bedrich L Eckhardt, PhD, Richard Larson, MS, Lei Huo, MD, PhD, Ester C Yoon, MD, Yun Gong, MD, Juhee Song, PhD, Shuying Liu, MD, PhD, Naoto T Ueno, MD, PhD, Savitri Krishnamurthy, MD, Stefan Pusch, PhD, Debu Tripathy, MD, Wendy A Woodward, MD, PhD, Bisrat G Debeb, DVM, PhD, *JNCI: Journal of the National Cancer Institute*, 2021 Dec;: djab222, <https://doi.org/10.1093/jnci/djab222>. PMID: 34893874

Comparative transcriptional analyses of preclinical models and patient samples reveal MYC and RELA driven expression patterns that define the molecular landscape of IBC

Authors: Rypens C, Bertucci F, Finetti P, Robertson F, Fernandez SV, Ueno N, Woodward WA, Van Golen K, Vermeulen P, Dirix L, Viens P, Birnbaum D, Devi GR, Cristofanilli M, Van Laere S.

NPJ Breast Cancer 2022 Jan 18; 8(1):12 . doi:10.1038/s41523-021-00379-6. PMID: 35042871

Ultrastructural Analysis of Inflammatory Breast Cancer Cell Clusters in an Ex Vivo Environment Mechanically Mimicking the Lymph Vascular System

Authors: Yuka Fujii, Savitri Krishnamurthy, Randa El-Zein

Breast Cancer (Auckl) 2021 Dec 12;15:11782234211056134. doi:10.1177/11782234211056134. PMID:34924757

“Why and What” for the Optimal Management of inflammatory breast cancer

Authors: Ueno NT, Alexander A

Chin Clin Oncol 2021 Dec;10(6):54. doi:10.21037/cco-21-158. PMID: 34930010

Contemporary surgical management of inflammatory breast cancer: a narrative review

Authors: Adesoye T, Irwin S, Sun SX, Lucci A, Teshome M

Chin Clin Oncol 2021 Dec;10(6):57. doi:10.21037/cco-21-113. PMID: 35016511

Baseline FDG PET-CT Imaging is necessary for newly diagnosed inflammatory breast cancer patients: a narrative review

Authors: Patel M, Le-Petross HT

Chin Clin Oncol 2021 Dec;10(6):56. doi:10.21037/cco-21-82. PMID: 34806397

Why diagnosing inflammatory breast cancer is hard and how to overcome the challenges: a narrative review

Authors: Le-Petross HT, Balema W, Woodward WA.

Chin Clin Oncol 2021 Dec;10(6):58. doi: 10.21037/cco-21-116. PMID: 35016512

What is the best treatment recommendation for HER2+ IBC with residual disease? – a narrative review

Authors: Zakon DB, Valero V

Chin Clin Oncol 2021 Dec;10(6):59. doi:10.21037/cco-21-122. PMID: 35016513



How should radiation be done for inflammatory breast cancer patients? – a narrative review of modern literature

Authors: Corrigan KL, Woodward WA, Stauder MC.

Chin Clin Oncol 2021 Dec;10(6):60. [doi.10.21037/cco-21-153](https://doi.org/10.21037/cco-21-153). PMID: 35016514

Contralateral Axillary Metastasis in Patients with Inflammatory Breast Cancer

Authors: Postlewait LM, Teshome M, Adesoye T, DeSnyder SM, Lim B, Kuerer H, Bedrosian I, Sun SX, Woodward WA, Le-Petross HT, Valero V, Ueno NT, Lucci

Ann Surg Oncol 2021 Dec;28(13):8610-8621. [doi.10.1245/s10434-021-10148-1](https://doi.org/10.1245/s10434-021-10148-1). PMID:34125346

ASO Author Reflections: Metastasis of Inflammatory Breast Cancer to the Contralateral Axilla: A Finding Meriting Further Study

Authors: Postlewait LM, Lucci A

Ann Surg Oncol 2021 Dec;28(13):8622-8623. [doi.10.1245/s10434-021-10208-6](https://doi.org/10.1245/s10434-021-10208-6). PMID: 34076808

A phase II study of talimogene laherparepvec for patients with inoperable locoregional progression of breast cancer

Authors: Kai M, Marx AN, Liu DD, Shen Y, Gao H, Reuben JM, Whitman G, Krishnamurthy S, Ross MI, Litton JK, Lim B, Ibrahim N, Kogawa T, Ueno NT.

Sci Rep 2021 Nov 15;11(1):22242. [doi.10.1038/s41598-021-01473-2](https://doi.org/10.1038/s41598-021-01473-2) PMID:34782633

Current Surgical Management of Inflammatory Breast Cancer

Authors: Adesoye T, Lucci A.

Ann Surg Oncol 2021 Oct;28(10):5461-5467. [doi.10.1245/s10434-021-10522-z](https://doi.org/10.1245/s10434-021-10522-z). PMID: 34346020

Current Clinical IBC Trials Open for New Patient Enrollment

Neoadjuvant (newly diagnosed before surgery):

2020-0715 - Enhancing Immunotherapy by Targeting the EGFR Pathway in Inflammatory Breast Cancer: A phase II study of Panitumumab (PmAb) And Pembrolizumab (Pembro) in Combination with Neoadjuvant Chemotherapy (NAC) In Patients with Newly Diagnosed Triple Negative Inflammatory Breast Cancer (TN-IBC) – **NEW**

Adjuvant (after surgery and radiation):

2016-0096 – A phase II study of anti-PD1 (Pembrolizumab) in combination with hormonal therapy in patients with hormone-receptor (HR)-positive localized inflammatory breast cancer (IBC) who did not achieve a pathological complete response (pCR) to neoadjuvant chemotherapy

2018-0550 - Atorvastatin in triple-negative breast cancer (TNBC) patients who did not achieve a pathologic complete response (pCR) after receiving neoadjuvant chemotherapy, a multicenter pilot study

Radiation:

SWOG1706 – A phase II randomized trial of olaparib administered concurrently with RT vs. RT alone for inflammatory breast cancer



Metastatic IBC:

- 2014-0533 – A phase II study of anti-PD1 (MK-3475) therapy in patients with metastatic inflammatory breast cancer (IBC) or non-IBC triple-negative breast cancer (TNBC) who have achieved clinical response or stable disease to prior chemotherapy.
- 2016-1096 – A Phase I Study of OTS167PO, a MELK inhibitor, to Evaluate Safety, Tolerability, and Pharmacokinetics in Patients with Advanced Breast Cancer and Dose-Expansion Study in Patients with Triple Negative Breast Cancer.
- 2016-0890 – A phase II study of triple combination of Atezolizumab, Cobimetinib, and Eribulin (ACE) or Atezolizumab + Eribulin (AE) in patients with chemotherapy-resistant metastatic inflammatory breast cancer
- 2021-0077 – Phase Ib/II study of grapiprant (IK-007) and eribulin combination treatment for metastatic inflammatory breast cancer (mIBC)
- 2021-0327 – A phase 1, first-in-human study of adenovirally transduced autologous macrophages engineered to contain an anti-HER2 chimeric antigen receptor in subjects with HER2 overexpressing solid tumors

We are currently actively developing additional clinical trials for patients with newly diagnosed IBC and patients with metastatic disease and will share more details once activated.

Current Clinical IBC Lab Studies:

We currently have 6 open clinical IBC laboratory studies that collect blood and tissue to analyze host and tumor biology and clinical correlations.

Newsletter Committee

Marcy Sanchez	Angela Alexander
Swetha Bopparaju	Hope Murphy
Jie Willey	Naoto Ueno

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