

Special Update: COVID-19 and IBC Research Program and Clinic Operations

The COVID-19 pandemic has significantly impacted operations for all institutions, including our program and clinic. Starting in mid-March 2020, research and administrative staff began working 100% remotely to limit the on-site footprint to ensure the wellbeing of employees and patients. In June, our labs gradually re-opened with shift-work schedules to minimize on-campus staff volume. Currently, the lab staff that requires working on-site has access to the laboratory area and the rest of our team continue to support operations remotely. We are grateful to be able to restart and ramp back up on the critical clinical and research work for our patients. No employee clusters of infection have been observed across the institution, indicating the safety measures in place are working well.

Clinical research required substantial changes to normal practices. We have now begun screening and enrolling new patients on all active IBC clinical trials, mindful of the need to push forward with providing the best treatment choices for patients diagnosed with this aggressive subtype of breast cancer. Throughout the pandemic, new IBC patients were accepted in the IBC Multi-Team clinic on Wednesdays, as well as by the IBC-specialized medical oncologists. Second-opinion (previously treated) patients from out of state were unable to be seen during the early part of the pandemic. As of today, the **breast service line has been approved**, and **we are accepting all IBC patients regardless of their home addresses**. Operations are not back to the status quo, however. The **no-visitors policy** has been put back in place with limited compassionate exceptions. The MD Anderson website has a webpage about Coronavirus and how the hospital is altering procedures to enhance the safety of the environment – click [here](#) for more information.

Telemedicine for existing patients is here to stay. Initially, patients who could not travel for care, had telephone follow up appointments. In early April, the institution rapidly rolled out a new Zoom-based video-application that utilized MyChart to allow patients to have scheduled video-conferenced appointments with their doctors. While some states do not yet allow video visits across state lines, many have embraced this new way of maintaining connections with specialists such as the oncology teams at MD Anderson.

COVID-19 is not over, and we are all aware that Houston is a current hotspot for infection. The institutional **leadership has been consistently monitoring and reporting the situation**; we are confident that **MD Anderson is taking all necessary precautions** to keep our patients safe while providing the caring, science-based care we are known for, to our patients.

What is IBC Connect?

IBC Connect is our program's latest endeavor to actively collaborate with like-minded institutional partners and create a network-based approach to enhance the reach of standardized, science-based IBC clinical care into communities, both domestic and international. We recognize the reality that many IBC patients in the US and abroad can't travel to Houston to access the treatments offered at the Morgan Welch IBC Research Program and Clinic, either due to insurance or family constraints. Therefore, we established a **professional network** among interested physicians at multiple geographic locations that would create an excellent opportunity to support IBC patients with high-quality standardized IBC care. Further, by this network, we will enhance IBC research, community education, and outreach opportunities.

Currently, the IBC Connect community consists of **9 institutions, including our program at MD Anderson** and our suburban **Houston-Area Locations (HALs)** network that serves the greater-Houston area. The Morgan Welch Program at the MD Anderson-TMC serves as the administrative leader for all these sites, and program members Drs. Sadia Saleem, Valerie Reed, and Elizabeth Fitz Sullivan serve as the HAL liaison specialty leaders to streamline IBC patient management. These sites are listed and described in future sections of this newsletter.

What are our current activities?

Morgan Welch Inflammatory Breast Cancer (MWIBC) Research Program and Clinic have the pleasure to be actively involved in collaborating with interested institutional partners to pioneer a network-based approach for high-quality patient care and support standardization of IBC clinical practice. Our multi-disciplinary team engages with partners via virtual sessions for:

- IBC Clinical Case Discussion (Quarterly)
- IBC Clinical Practice Consensus (Bi-Annual)
- IBC Physician Webinar (Monthly)

The clinical case discussions are intended to enable members to review and present challenging IBC cases, complications, advanced management care, and research options towards our common goal of enhancing IBC patient care. The webinars, planned for physician and patient audiences, focus on sharing updated IBC care standards, research findings with IBC Connect teams and patients to support consistent IBC practice.

Our **case discussion and consensus sessions** were **launched in early 2019**, and the **webinar series** began in April 2020. The first session was presented by Dr. H. Carissa Le-Petross and Dr. Wendy Woodward, discussing on how to diagnose inflammatory breast cancer from the diagnostic and clinical radiology perspective, respectively. In May 2020, Dr. Savitri Krishnamurthy presented pathology perspectives of IBC. Dr. Michael Stauder reviewed radiation principles regarding IBC, including nodal contouring during our June webinar. Dr. Vicente Valero discussed the management of patients with HER2+ IBC for the July 2020 webinar.

A new initiative, **IBC Patient Webinar Series** is planned to be launched during **Breast Cancer Awareness month in October 2020**, to expand outreach to patients and communities across all the IBC Connect sites. The webinars will be presented by IBC-focused oncologists/supportive team members sharing information with patients, survivors, advocates, and IBC support groups on IBC treatment and survivorship.

An **online platform, IBC Connect dashboard**, has been developed and will be rolled out in September. It will provide a central location to access resources and ongoing discussions in a forum-like site that will be accessible across all the IBC Connect institutions.



How can IBC Connect benefit patients?

Patients who cannot come to Houston may access the MD Anderson standard of care at our IBC Connect institutions and have input from the high-volume Houston program if their disease does not respond well to initial treatments. Also, the collaborations have successfully **built new relationships** that may help patients to be **referred for clinical trials** if that would be the best for them. Clinical research efforts are underway. With select protocols being planned to be rolled out across interested IBC Connect Network institutions, starting with the IBC Registry and moving onto select treatment trials in the coming year.

Within the Houston locations (MDA-TMC, HAL, and LBJ) locations, we have recently initiated a **weekly Quality Assurance virtual meeting**. We will discuss all new IBC cases that are not seen in the IBC multi-team clinic (IBC-MTC). This process ensures that diagnosis is agreed upon by the multi-disciplinary team, and that treatment approaches, including clinical trials offered, are consistent among the sites. This way, if a local patient chooses to receive their care in one of our satellite locations such as Sugar Land or League City, they can be confident regarding receiving IBC care available at our IBC-MTC at the downtown TMC site.

Future directions

Future expansion opportunities are limitless; we plan to continue to rigorously select partner institutions with a commitment to treating IBC as a distinct type of breast cancer following the IBC algorithm and consensus-based discussions acceptable to our faculty teams. Institutions that express a desire to join the community and pledge to participate in learning opportunities may be added upon review by the leadership of the program. If you become aware of another hospital that wishes to join, they may contact our program at ibcp@mdanderson.org for more information.

One of our short-term future areas of focus is to review and update the IBC Registry Redcap database to enable research data entry directly from all institutional sites and enhance opportunities for cross-collaboration with institutional websites. This would also enable IBC data availability with collaborators to partner and advance research. We are also actively working to establish a separate protocol that will allow IBC patients treated outside MD Anderson. This initiative will contribute to IBC research advancement through the completion of an online epidemiology questionnaire. Also, it will enable us to request their tissue from their respective institutions for inclusion in the IBC Tissue Bank. Furthermore, we intend to expand our protocols by working with MD Anderson Cancer Network to create an opportunity to expand research trial protocols to interested collaborating institutions. Clinical research trials are currently being explored as potential trials to expand IBC research once approval is complete.

Another critical area of emphasis shortly is expanding our collaborations within the University of Texas (UT) System. As a state-funded program, engagement across the UT system has been identified as a critical program priority to support IBC patient populations across the State of Texas. Through an analysis of IBC cases reported to the Texas Cancer Registry, we noted a larger IBC population near larger cities in Texas. We are extremely happy and excited to share that we are starting our collaboration with **Mays Cancer Center-UT Health-MD Anderson, San Antonio, and UT Southwestern Cancer Center (Dallas)** as our first steps to collaborate with UT System institutions and support IBC care standardization, research acceleration and community outreach within the UT system. We are also excited to share that we are initiating an IBC collaboration with our local county hospital, **Lyndon B Johnson (LBJ) hospital, to support care for low income and medically underserved residents of Harris County (Houston)**, with the primary goal being IBC cancer care and research opportunity, as an extension of MD Anderson's existing



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relationship with LBJ hospital. By including LBJ physician and fellow teams in IBC Connect, we hope to unify the care provided and quickly refer patients that may benefit from clinical trial participation for this rare, aggressive disease. The September newsletter will highlight our new collaborations further.

We have recently become aware of a funding opportunity through the Department of Defense, which has established a \$7.5M fund focused on Rare Cancers, and we believe IBC would fit under the mission. We are excited to apply once the application window is open. Three types of awards are offered, including the largest of which is a “resource and community development award”. Our current IBC Connect activities, and near-term plan may be the basis for our proposal to create a collaborative infrastructure for enhanced patient-oriented research into IBC.

The University of Texas MD Anderson Cancer Center: Texas Medical Center (TMC) and Houston Area Location (HAL) sites

Location: Houston and suburbs



Photos L-R: 1) West Houston/Katy 2) The Woodlands. 3) League City 4) Sugar Land 5) Texas Medical Center

Like many hospital centers in the Houston market, MD Anderson has satellite locations in the suburbs that allow us to deliver the same standard of care to patients closer to home. These locations include outpatient clinics for medical, surgical and radiation oncology, radiology/diagnostic imaging, surgical suites, laboratory services, and infusion centers. Support services include clinical nutrition, social work, and on-site nurse navigators to make the overall patient experience as straightforward as possible.

The Texas Medical Center location, where the Morgan Welch Inflammatory Breast Cancer (MWIBC) Research Program and Clinic is located, serves as the administrative lead for IBC Connect, under the leadership of Drs. Naoto Ueno, Wendy Woodward, and Swetha Bopparaju.


 Facebook: www.facebook.com/InflammatoryBreastCancer  Twitter: www.twitter.com/InflammatoryBCa

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Location: **Banner MD Anderson Cancer Center
(Gilbert, AZ)**

 Facebook: www.facebook.com/bannermdanderson/

 Twitter: @banner_health

Med Onc – Dr. Lida Mina
Surgeon – Dr. Julie Billar
Rad Onc – Dr. Emily Grade



Arizona. Banner MD Anderson was the first out-of-state clinical enterprise that MD Anderson established, firstly as a site for outstanding clinical care, but more recently expanding in focus to include translational research.

The IBC team at Banner state that “the case discussions and consensus meetings have provided a wonderful opportunity for our breast team to collaborate more frequently and reinforce consistent standards of care”. Part of the uniqueness of this opportunity is that Banner MD Anderson’s breast team is spread across 7 campuses and 2 states, so these types of meetings which can be conducted remotely have provided a springboard for further team discussions, even after the larger virtual meetings end.

At Banner MD Anderson, “patients receive expedited and streamlined care, including **rapid access to consultations with surgery, medical and radiation oncology**, genetic counseling, and **multi-disciplinary tumor board review**” and that they are excited to expand research efforts through future collaborations with IBC Connect. Banner MDA also has a robust Integrative Oncology program that supports their patients from diagnosis, through treatment and onto survivorship with services such as acupuncture, massage, nutrition counseling, smoking cessation, and more. The presentation of IBC patients can be so variable, which was highlighted in one of the IBC Connect webinars. This topic continues to be discussed during our Multi-disciplinary Breast Tumor Boards, as we continue our efforts to ensure appropriate capturing of these patients for optimal treatment. We are delighted to be a part of IBC Connect, and Dr. Ueno has been very encouraging about building this program and collaboration. **“This is a program that truly celebrates the fact that a network of providers can help more IBC patients than a single campus alone. At Banner MDA, we are proud to be a part of that mission”.**

Banner MD Anderson has 4 regions (3 in AZ, and 1 in Northern Colorado). The best way for IBC patients wishing to access MD Anderson standard of care at this center is to call and request an appointment using the numbers below:

BMDA East	480-256-6444 (option 1)
BMDA Northwest	623-876-3880
BMDA Central	602-521-3700
BMDA Northern Colorado	970-810-3034 (Tiffany Scott RN, patient access coordinator)

Location: Baptist MD Anderson Cancer Center (Jacksonville, FL)

Med Onc – Dr. Ed Gorak
Surgeon – Dr. Beth Lesnikoski
Rad Onc – Dr. Cynthia Anderson and Dr. Michael Olson



Baptist Health and MD Anderson decided to join forces for a northeast Florida expansion of the MD Anderson experience. This location, which opened in Jacksonville in 2018 is one of the newer sites in the Cancer Network, designed as a one-stop site for all aspects of cancer care. Since opening, the Baptist MD Anderson location has opened many clinical trials to allow patients to receive these lifesaving treatments closer to home. You might note the DNA-like sculpture in the picture at the front of the building – this was explicitly chosen to project an energetic vibe and portray a culture of high ambition for this center.

When asked about ongoing IBC-specific research activities, the IBC team shared, “we have begun collaboration on an undertaking for evaluating the role of PET/CT in the management of IBC and its impact on radiation field design. We plan this as a retrospective chart review of cases from several of the Connect sites”. Stay tuned for more on this very practical area of research.

Patients interested in obtaining an appointment may request one online at <https://www.baptistmdanderson.com/patients-and-families/request-appointment>.



Location: Georgia Cancer Center (Augusta, GA)

 Facebook: www.facebook.com/GeorgiaCancerCenter

Med Onc – Dr. Priyanka Raval and Dr. Allan Krutchik
Surgeon – Dr. Alicia Vinyard
Rad Onc – Dr. Catherine Ferguson

The collaboration with Georgia Cancer Center at Augusta University began as a result of an invitation extended to Dr. Ueno to participate in the annual Savannah Cancer Symposium in October 2019, where he presented about IBC. Georgia Cancer Center, a state-funded academic institution, sees a significant number of IBC patients, and are seeking collaborative research opportunities, due to their institutional

mission to foster innovation and improve the lives of patients with cancer. Although to date, a separate IBC clinic has not been established, the multi-disciplinary team that have committed to joining IBC connect activities are very much engaged and finding the ability to discuss difficult cases with the IBC experts a major value proposition.

Patients wishing to be seen by the IBC team can self refer to them, and nurse navigator Andrea Anderson (aanderson1@augusta.edu) is ready to assist any potential patient as needed. The phone number to request an appointment is 800-736-2273.

Location: **Hebei Medical University, China**



Med Onc – Dr. Yalei Lyu
Surgeon – Dr. Chao Yang
Rad Onc – Dr. Chao Gao

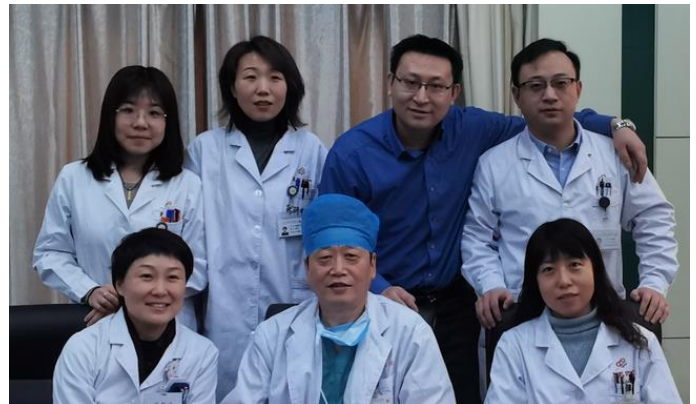
Hebei Cancer Hospital (also known as The Fourth Hospital of Hebei Medical University) is a large comprehensive hospital focused on the diagnosis and treatment of cancer through

integration of medical treatment, education, scientific research and prevention. Patients who receive care at this hospital, have all the needed services onsite including imaging, radiation therapy, chemotherapy infusion suites.


Hebei Cancer Hospital joined IBC Connect serendipitously. Dr. Chao Gao, a radiation oncologist from Hebei was doing a short research postdoctoral fellowship at MD Anderson during the 2018-2019 academic year in our department and was informally discussing the program with Research Nurse Manager, Jie Willey. Discussions led to Dr. Gao contacting Dr. Yunjiang Liu, a breast surgeon at Hebei and introducing him to the MW-IBC team. Interestingly Dr. Liu has reviewed IBC cases in China in the past and found that there were no standards for IBC diagnosis and treatment in China. Seeing an opportunity for improvement, Dr. Liu invited Jie to speak at the hospital on a trip to China in October 2019, and after this meeting, the program met with the Hebei leadership at the SABCS conference in December 2019 which led to them joining IBC Connect in January.

In the future, the IBC team at Hebei Cancer Hospital would like to share their new knowledge with other colleagues in smaller cities, and also target the public using communities where young people gather. In addition, they are excited to bring IBC-focused clinical trials to China.

For patients who wish to obtain an appointment at Hebei Cancer Hospital, self-referral online is the best method. If assistance is needed, Dr. Xiangmei Zhang (xiangmeizhang2001@hotmail.com) is the point of contact.



Location: **Japanese Foundation for Cancer Research ("JFCR") Japan**

 Facebook: <pending revision>

 Twitter: www.twitter.com/Yoko_T

Med Onc – Dr. Fumikata Hara
Surgeon – Dr. Yoko Takahashi
Rad Onc – Dr. Mari Kikuchi and Dr. Arisa Harada

JFCR hospital was the first international site among IBC Connect, and sees the most cases of IBC in

Japan, due to being a large academic center. JFCR's IBC Clinic is the only Japanese IBC specialty center, however the team members hope to expand their knowledge and share this information with colleagues at other hospitals in Japan so that more patients can receive the correct life-saving care for their IBC. The IBC team have been very engaged in IBC consensus and case discussions, and have noted that these virtual meetings have been valuable for

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them especially regarding more controversial topics. “We are excited to join worldwide IBC teams. We can share information and can select the best treatment for IBC patients in Japan. We hope we can help many more people”.

Patients wishing to access MD Anderson standard of care at our location, may contact Dr. Yoko Takahashi, Associate Surgeon via email (yo.takahashi@jfcr.or.jp) for assistance. She notes that during COVID-19 access may be difficult, but she will help as much as possible electronically.

Location: **MD Anderson at Cooper, NJ
(Camden, NJ)**

 Facebook: MD Anderson Cancer Center at Cooper
 Twitter: @CooperHospital

Med Onc – Dr. Robert Somer
Surgeon – Dr. Catherine Loveland-Jones
Rad Onc – Dr. Stuti Ahlawat



MD Anderson at Cooper was one of the earlier IBC Connect sites that began collaborating with us due to one of our former breast surgical fellows, Dr. Vivian Bea, moving there to begin her academic career. While in fellowship here in Houston, Dr. Bea worked closely with our surgical oncology leader, Dr. Lucci, and developed an academic interest in IBC, prompting her to pull together an IBC team at Cooper.

Cooper University joined the MD Anderson Cancer Network back in 2013 and consists of a main campus 600+ bed hospital (Cooper University Hospital), as well as satellite locations in southern New Jersey and Pennsylvania. Since joining IBC Connect and attending the first IBC Connect symposium in February 2019, the IBC team has benefited from the case discussions and consensus meetings focused on the latest practice standards which have been applied in real-time to their patients. **They are looking forward to actively participating in future clinical research collaborations as a member of IBC Connect.**

Patients wishing to access the care in the IBC clinic at Cooper, do not have to wait long for appointments. They are able to provide 24-hour turnaround for appointments, and appointments for imaging within 72-hours. To obtain an appointment, please call the triage line at 856-735-6100, and the nurse navigator will return your call promptly. The nurse navigator, Mary Rooney, plays a key role in facilitating the timely care at this IBC clinic.



Location: **Medical College of Wisconsin
(Milwaukee, WI)**

Med Onc – Dr. Yee Chung Cheng
Surgeon – Dr. Amanda Kong
Rad Onc – Dr. Adam Currey

Medical College of Wisconsin Cancer Center (MCWCC) is one of our newer members of IBC Connect. Dr. Yee Chung Cheng, the director of the Breast Center at MCWCC did his fellowship at MD Anderson in the department of Blood and Marrow Transplantation, which was where Dr. Ueno was a faculty at the time. Dr. Ueno continues to mentor him

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to this day, and a shared interest in IBC led to the formal development of this partnership.

MCWCC is the only academic cancer research center in Eastern Wisconsin, which is a distinct region encompassing a large underserved population of patients experiencing disparities in cancer incidence and outcomes. MCWCC seeks to address these challenges through mobilizing nationally recognized scientists and physicians, the latest research-driven treatments and over 200 clinical trials and community-driven interventions. Through these efforts, they are committed to “reducing the cancer burden for all patients and in every community; in Milwaukee, eastern Wisconsin and beyond”.

Patients wishing to obtain an appointment at MCWCC can either request an appointment online at <https://www.froedtert.com/appointment/request> or call 1-800-DOCTORS.

Location: Scripps MD Anderson Cancer Center (San Diego, CA)

Med Onc – Dr. Sonia Ali

Surgeon – Dr. Ayemoethu Ma

Rad Onc – Dr. Thomas Buchholz



Scripps MD Anderson was the other inaugural member of IBC Connect starting in 2019, when they launched their IBC clinic, under the leadership of Dr. Thomas Buchholz, a former MD Anderson radiation oncologist who was integral in the co-founding the Morgan Welch IBC Clinic as well. Scripps team members

attended the first IBC Connect Symposium and have been engaged ever since. The team appreciate the learning opportunities to validate their practice is in line with the leading experts and incorporates the latest data. Moving forward, the IBC clinic is excited to expand clinical trial options to include their IBC patients.

Patients who wish to obtain an appointment in the IBC clinic can call the general intake line (1-800-Scripps) who will link you to the program navigator. IBC Patient, Ms. Andrea Dean who transitioned her care from Houston to Scripps writes IBC is aggressive and you have to stay on top of it, with a team of doctors who really understand the unique ways it needs to be treated. “It’s a huge step forward for people on the West Coast now that Scripps MD Anderson has its IBC clinic available” (according to Scripps [article](#)). During the COVID-19 pandemic, it has been difficult for some patients in California to travel to Houston, and the IBC team at Scripps report that patients already are aware of the collaboration and are relieved to continue their current therapy closer to home seamlessly.

Last but not the least, we wholeheartedly thank all our IBC Connect team members for their cooperation and promptly sharing exciting information regarding their institutions and allowing us to share with the IBC community.

Newsletter Committee

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