



Breast Cancer Tissue Donation Frequently Asked Questions (FAQ)

Introduction

There are many ways for breast cancer patients, survivors, and advocates to contribute to breast cancer research. One way is for a person to donate their own tissue or blood to be used in scientific research. LBCA frequently gets questions about how someone can go about donating tissue from their breast surgery to contribute to breast cancer research. This frequently asked questions (FAQ) document offers information on tissue donation and how to donate tissue and/or blood samples to breast cancer research, including a few programs focused on invasive lobular carcinoma (ILC) research.

What is tissue donation?

Tissue donation is when a person donates a tissue or blood sample to an established entity to be used specifically for medical research. Some programs are general and support research for many types of cancer, and some are specific to breast cancer, even subtypes of breast cancer.

What are the types of tissue donation?

There are three types of tissue donations used in the context of cancer research.

- *Tissue and blood donations* are given by living people for use in cancer research. Often the organizations using the tissue and blood samples are academic research programs or a nonprofit in conjunction with medical institutions. Most often the tissue is from a tumor or site of metastatic disease taken at the time of a biopsy. However, there is one program to which people can donate healthy breast tissue to be used in comparative studies.
- *Rapid Autopsy* programs harvest specific organs or tissue samples from solid tumors from the body of a deceased person who, before death, consented to the donation. The donated tissues are used for medical research including cancer research.
- *Whole body* donations are usually made to a medical school for medical and dental education programs.

How does one go about making a tissue donation?

Someone interested in making a tissue donation should first consider which type of donation they want to make. Often, tissue donations are only accepted from donors who are within a specific proximity to the institution, so location is another consideration to make. Since each institute and location have their own requirements, it's best to reach out directly to the institution of interest well in advance of when a person



wants to make a tissue donation to find out the specifics of that institute's program requirements and process before deciding to consent to the donation. Typically, donations are on a voluntary basis with no payment required to be given or received to participate.

If there is a Tumor Banking program at a particular institution, then there is usually a system in place to take a small piece of the tumor and freeze it for future potential studies. However, some Tumor Banking programs cannot bank breast tumor specimens if the tumor is small because if a piece of the tumor is frozen for banking, the pathologist does not get to look at it. If the tumor is large this may not be the case, but for a smaller tumor, generally the entire specimen needs to be evaluated by the pathologist, which means that the best option is to embed the whole tumor in paraffin.

If there is no Tumor Banking program, then the tissue all gets embedded in paraffin and the tissue can be used for future research with essentially no time restriction (other than the fact that some hospitals discard the tissue after a few years). Some research requires frozen tissue, and some research can be conducted with paraffin embedded tissue. If there is not a Tumor Banking program, it is almost impossible to have the tissue processed and frozen immediately after surgery because of the resources required to do so. However, occasionally a university will have a specific researcher who has an active protocol to collect and freeze that tissue.

Depending on the type of tissue donation you wish to offer, programs may need several weeks of lead time to enroll you, get your informed consent, and give you instructions for tissue donation. Find the program of interest to you, talk to your clinician, and talk with your family to make your wishes known if you are considering a rapid autopsy donation.

What questions should I ask my provider?

Here are a number of questions that may be helpful when talking to your provider about tissue donation:

1. Does this institution have a Tumor Banking program?
2. Does your institution conduct breast cancer research? If so, does this include invasive lobular carcinoma?
3. Does your institution accept donated tissue from breast cancer mastectomy or other procedures?
4. What is the process for making the donation?
5. If there is no Tumor Banking program, can I request that my pathology be saved now so that it may be able to be sent to a lab or a central clearing house later? How long will it be saved?



The table below offers some examples of institutions that have tissue donation programs.

Facility or Program	Types of cancer studies tissue can be used for	When is tissue collected?	Location	Notes	URL and Contact Information
TISSUE DONATION PROGRAMS					
Leigh Pate Living Biorepository of Invasive Lobular Breast Cancer (Tissue Donation)	Invasive Lobular Carcinoma specimens (surgery or biopsy)	Surgery or biopsy	USA - University of Pittsburgh Medical Center Hillman Cancer Center, Pittsburgh, PA, USA		https://www.bcrf.org/blog/leigh-pate-living-biorepository-invasive-lobular-breast-cancer-2022/ Contact: Jagmohan Hooda, Ph.D., MBA email: hoodaj@upmc.edu
Susan G. Komen Tissue Bank and the IU Simon Cancer Center. (Tissue Donation)	All types of breast cancer	At one of three annual tissue collection events per year.	USA - Indianapolis and two other locations TBD.	Normal breast tissue or blood samples from living people without breast cancer.	https://komentissuebank.iu.edu/donate-tissue/about-tissue-donation.php
Count Me In (Tissue Donation and medical records)	All types of cancer, early-stage breast cancer and metastatic ILC	Anytime	USA and Canada. Specimens made available to researchers worldwide.	Medical records, saliva, blood tumor samples and tissue samples are collected.	https://joincountmein.org/ https://www.cbioportal.org/study/summary?id=brca_mbcproject_wagle_2017
UCSF Helen Diller Family Comprehensive Cancer Center – UCSF Breast Program Tissue Core (Tissue Donation)	All types of breast cancer	Tissue collected at time of surgery	USA - San Francisco, CA		https://cancer.ucsf.edu/research/programs/breast/breast-tissue-core
UC San Diego Moores Cancer Center (Tissue Donation)	Different types of cancer including Invasive Lobular Carcinoma		USA – San Diego	Blood and tissue samples are collected	https://moorecancercenter.ucsd.edu/research/shared-resources/biorepository/index.html

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					Contact: Sharmeela Kaushal, Ph.D. email: skaushal@health.ucsd.edu phone: (858) 543-7302
Stefani Speilman Breast Cancer Cohort & Tissue Bank (Tissue Donation)	All types of breast cancer		USA - Ohio State University, Columbus, OH	Early stage and metastatic breast cancer samples – tissue, blood	https://cancer.osu.edu/about/publications-and-reports/magazines-and-publications/legacy/2020/25-million-reflects-spielman-fund-growth-and-impact/spielman-tissue-bank
George Washington University Biorepository (Tissue Donation)	Different types of cancer		USA - Washington, DC		https://gwbiorepository.smhs.gwu.edu/faq Contact Medea Tsulukidze at (202) 994-0993 when you are scheduled to have surgery at the GW University Hospital
Breast Cancer Now Tissue Bank (Tissue Donation)	All types of breast cancer		UK – London, Aberdeen, Norwich, and Sheffield.	Breast tissue and blood samples	https://breastcancer.org/breast-cancer-research/breast-cancer-now-tissue-bank/about-tissue-bank
Australian Breast Cancer Tissue Bank (Tissue Donation)	All types of breast cancer		Seven locations in NSW, Australia	Breast cancer tissue, healthy breast tissue, blood samples. Men and women diagnosed w/ Breast cancer can participate. Women undergoing breast reduction surgery can participate.	https://www.abctb.org.au/abctbNew2/default.aspx
RAPID AUTOPSY PROGRAMS					
University of North Carolina Breast Tumor Donation Program	All types of breast cancer	Tissue collected within six hours of death from breast cancer.	USA - Death within a three hour drive of UNC for rapid autopsy.	Healthy and diseased tissues from people who died from	https://unclineberger.org/octr/our-research/tumor-donation-program/



(Rapid Autopsy)				metastatic breast cancer.	Contact: Paige Stem (919) 966-7817 email: paige_stem@med.unc.edu
HOPE for OTHERS Breast Disease Research Repository in collaboration with UPMC Hillman Cancer Center (Rapid Autopsy)	Collects metastatic breast cancer specimens.	Shortly after death	USA - Pittsburgh, PA, USA	Clinical Coordinator - Lori Miller email: millerl15@upmc.edu (412) 439-1489	https://leeoesterreich.org/hope-for-others-tissue-donation (See YouTube Interview with Steffi Oesterreich, Ph.D. here on this program: https://youtu.be/1ih6qAdJRd4?si=mHRgnNNPJS289t3G) Clinical Coordinator - Lori Miller email: millerl15@upmc.edu (412) 439-1489
MD Anderson Cancer Center "Final Gift Program" (Rapid Autopsy)	Breast cancer tissue	Within six hours of death	USA - Houston, TX		Website under development as of 9/6/23. Contact: pmtc@mdanderson.org
Memorial Sloan Kettering Memorial Hospital (Rapid Autopsy)	All types of cancer	First business day after death.	USA - Patients pass away within three hours of MSK Hospital in NY, NJ, CT or PA	Patients may opt to donate blood samples before death.	https://www.mskcc.org/sites/default/files/node/146506/document/appendix-d-program-brochure_new.pdf
John's Hopkins Medicine (Rapid Autopsy)	All types of cancer	Shortly after death	USA - Baltimore, MD		https://pathology.jhu.edu/autopsy/rapid/
Brigham and Women's Hospital (Rapid Autopsy)	Different types of cancer	Shortly after death	USA - Boston, MA		https://www.brighamandwomens.org/pathology/anatomic-pathology/autopsy
University of Michigan Legacy Tissue Program (Rapid Autopsy)	All types of cancer	Within three hours of death	USA - Ann Arbor, MI		https://www.pathology.med.umich.edu/mltp/for-patients#:~:text=What%20is%20a%20rapid%20autopsy,that%20particular%20type%20of%20cancer.



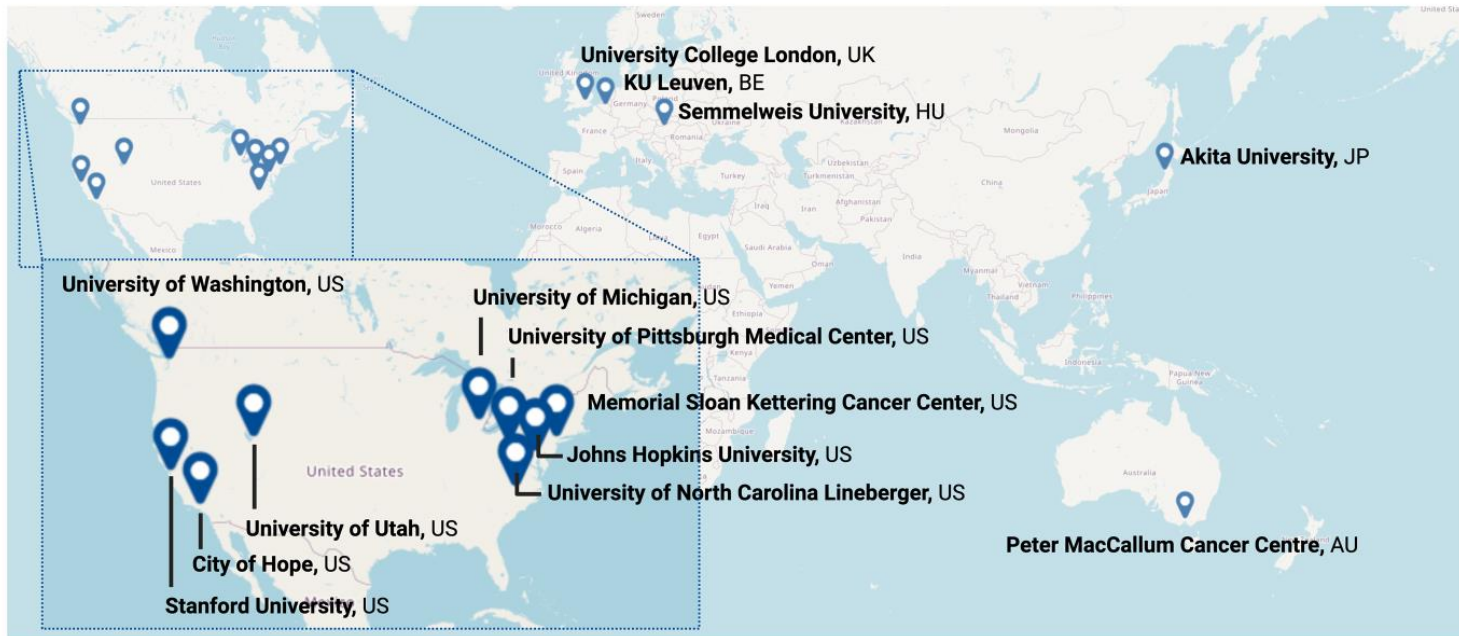
University of Utah Huntsman Cancer Institute (Rapid Autopsy)	Cancer tissue that is authorized by the donor	Within six hours of death	USA - Salt Lake City, UT	(801) 587-7000	https://healthcare.utah.edu/huntsmancancerinstitute/treatment/legacy-to-life
Leuven University UPTIDER (Rapid Autopsy)	Metastatic breast cancer tissue		Belgium		https://gbiomed.kuleuven.be/english/research/50488876/54887282/ltbcr_uptiderproject Contact: Christine Desmedt Ph.D., email: christine.desmedt@kuleuven.be

NOTE: This resource has been developed to assist individuals who are interested in tissue donation to begin to learn about the process and locations where these programs may exist. LBCA acknowledges that this is not an all-inclusive list and recommends that you reach out to your own medical center if it is not listed above. LBCA does not endorse any specific program or institution and provides this list as a resource only. If you know of another program you believe should be listed on this document, please contact info@lobularbreastcancer.org.

Additional Resources:

1. To learn more about tissue donation in general, please visit: <https://www.cancer.gov/about-nci/overview/contributing/tissue-donation-video>
2. LBCA Lobular Breast Cancer Chat with Dr. Karen Van Baelen on how lobular breast cancer research is being enhanced with post-mortem tissue donation. A link to the recording can be found here: https://youtu.be/BNN_8H_dcoQ
3. Dr. Karen Van Baelen has given LBCA permission to include the following map from her presentation to this resource document:

Post-mortem tissue donation programs worldwide



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Geukens T, Maetens M, Hooper J, ... Desmedt C. Under review at *Journal of Pathology*.

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