

## DONATION OF FRESH AND/OR FROZEN TISSUE SPECIMENS

**If you are a person diagnosed with adenoid cystic carcinoma who will be undergoing a surgical resection of your tumor and wish to consider donating frozen and/or fresh tissue at the time of surgery, please do the following:**

*Important: Tissue donations usually require a minimum of 10 days notice before your surgery in order to coordinate with your doctors and ensure the tissue can be prepared and shipped properly.*

Step 1) Obtain a consent form for joining the ACC Registry at:

<https://med.virginia.edu/pathology/research/research-opportunities/adenoid-cystic-carcinoma/research-registry-for-adenoid-cystic-carcinoma/>

Fill out the consent form and send it by mail to the ACC Registry. It must be sent in to the Registry before your surgery. Do not give the consent form to your doctor! The Registry will keep all of your information confidential, including the results of all research studies

Step 2) Please notify the Registry that you would like to donate a specimen by calling or e-mailing a Registry Coordinator or the Registry Principal Investigator so we may obtain the details of your surgery and ensure you have completed the correct paperwork.

Step 3) Fill out the Frozen/Fresh Tissue Specimen Donation Information form on the next page, and give it to your surgeon. Ask your surgeon if he or she can arrange a potential donation of fresh or frozen tissue through the Department of Pathology at your hospital.

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### **Reasons why obtaining fresh and frozen ACC tissue is important for furthering research into this cancer:**

- This cancer is relatively rare, and no single institution can collect a large number of samples. Each tissue donation is precious and extremely valuable in the search for answers for why ACC appears and how it behaves.
- Although tissue samples are kept by many hospitals, these are usually fixed in formaldehyde and covered with wax in order to store them at room temperature. This process destroys or damages many of the molecules scientists think are involved in cancer. In order to study these molecules, fresh or frozen tumor samples are required.
- Fresh tumor samples are difficult to obtain and are important to studies of living tumor cells. Since hospitals do not routinely keep frozen tissue samples, it takes a special effort to get such samples for research purposes, too. You have an opportunity to make a unique and important contribution to research studies of ACC.

**Please be aware that clinical circumstances may prevent any tissue from being obtained for research purposes.** Tissue obtained for research purposes should only come from tissue that has been obtained from procedures required for your medical care. No “extra” tissue will be taken from your body for research purposes, and the clinical examination of your tissue should not be compromised for research purposes.

**Frozen/Fresh Tissue Specimen Donation Information**

Patient's name: \_\_\_\_\_

Hospital Identification Number: \_\_\_\_\_

The person named above has given written consent to participate in research studies being performed at The University of Virginia (UVA) which are aimed at understanding the molecular basis of adenoid cystic carcinoma (ACC).

To facilitate these studies, if there is any fresh (non-fixed) ACC tumor tissue available from the patient's resection specimen that is not required for clinical assessment, we would greatly appreciate obtaining it in either fresh in media or in frozen form, not fixed in formaldehyde or other preservatives. Frozen specimens are currently our highest priority. Fresh tissue should only be provided after consulting with registry staff and if they determine it is needed and the logistics are feasible.

It is important that the decision to release a specimen be made by the Pathology staff at your institution, so that the only tissue obtained for research purposes is that determined to be unnecessary for histopathologic assessment and would otherwise be discarded. Specimens as small as 200 mg (0.5 cm<sup>3</sup>) are useful! **Under no circumstances should tissue be removed from the patient solely for the purposes of this research.**

*First Priority: Frozen Specimens:*

- A. **Ideally the tissue should be flash frozen in liquid nitrogen within 30 minutes of resection or arrival in the pathology accession area.** If liquid nitrogen is not available, the tissue may be frozen by placing the specimen container in a -70°C freezer or on dry ice. Acceptable specimen containers include cryovial tubes or tissue cassettes tightly wrapped in aluminum foil. We will accept tissue embedded in OCT compound.
- B. **The frozen specimen should be stored on dry ice, in liquid nitrogen or in a -70° C freezer until it can be shipped.** The specimen should be placed in a leakproof specimen bag and shipped in an insulated container packed in dry ice. If a fresh specimen is also obtained, do not ship them together in the same package.
- C. If such facilities are not available, short term storage in a standard -20° C freezer (or cryostat cabinet) is acceptable, but arrangements for tissue shipment should be made as soon as possible.

*Alternate/Secondary: Fresh Specimens:*

Note: We would like a fresh specimen **only** if you have media available and you are able to arrange to ship to us the same day for arrival the next day. Please consult with a Registry Coordinator before obtaining or sending fresh tissue. We cannot accept Saturday shipments.

- A. Place a single piece of tissue no larger than 0.5 cm or several 2 mm pieces in a sterile conical centrifuge tube containing 5-10 mL of standard tissue culture media without serum such as RPMI or D-MEM and with standard "1x" antibiotics—penicillin (100 U/mL); streptomycin (100 µg/mL). Place the tube in a 4°C refrigerator until ready to ship.
- B. Package the specimen into a leakproof specimen bag and place in an insulated container with either wet ice or gel ice packs. Double-bag wet ice in ziploc type bags to prevent leakage. If using

## Adenoid Cystic Carcinoma Registry at The University of Virginia

gel packs, put a piece of cardboard between the specimen and the gel pack to prevent freezing of the tissue. Fresh specimens should ship as soon as possible by priority overnight.

Specimen Shipping Address: University of Virginia  
Atten: Dr. Christopher Moskaluk  
PATHOLOGY (MOSKALUK LAB)  
RM B705 Carter-Harrison Res. Bldg.  
345 Crispell Drive  
Charlottesville, VA 22908

- The ACC Registry is able to pay for courier shipment by either providing you with our FedEx account number or arranging to have you bill us.
- At your request, the ACC Registry can provide you with a specimen shipping container and labels, packaging materials, sample tubes with media, and dry ice if needed to help facilitate the shipment.
- If there is a tissue procurement fee at your institution, we can make arrangements for payment from the ACC Registry.

Please contact an ACC Registry Coordinator or the ACC Registry Principal Investigator at The University of Virginia Department of Pathology for any additional information or instructions.

### Registry Coordinators:

Craig Rumpel (434)982-6453 voice; (434)924-9438 fax; e-mail [crumpel@virginia.edu](mailto:crumpel@virginia.edu)

Rebecca Blackwell (434) 982-6678 voice; (434)924-9438 fax; e-mail [rb5x@virginia.edu](mailto:rb5x@virginia.edu)

### Registry Principal Investigator:

Christopher Moskaluk, M.D., Ph.D. (434)982-4408 voice; e-mail [cam5p@virginia.edu](mailto:cam5p@virginia.edu)