



## **Just Diagnosed with ACC?**

Patients who are struggling with a new diagnosis have so many issues to face. Here is a brief list of action items worth considering:

- 1. Focus first on your diagnosis and treatment plan.** Get as comfortable as possible with the medical choices you are making with the assistance of a trusted physician and your support network. Consider seeking a second opinion from a physician with experience in treating ACC patients; the [ACC Physicians List](#) may help you find an expert close to home. Look through the [Frequently Asked Questions](#) (FAQ) page of ACCRF's website to learn about treatment options as well as suggestions on how to manage living with ACC.
- 2. Join the free Yahoo Email Information Group** for ACC patients, families and caregivers at [http://health.groups.yahoo.com/group/Adenoid\\_Cystic\\_Carcinoma\\_Organization/](http://health.groups.yahoo.com/group/Adenoid_Cystic_Carcinoma_Organization/). The group is moderated by [ACCOI](#) and is an excellent resource for ACC patients who would like more information on their individual situation. A community of more than 800 people offers tips on treatment plans, treatment side effects and much more. Patients can search through prior postings for information or start a discussion on a topic of interest. The information should not substitute for the advice of an experienced physician, but may provide additional perspectives.
- 3. Consider donating part of your tumor for research** in order to speed the discovery of improved therapies. It is free, won't interfere with your treatment, maintains your privacy and is reversible if you should change your mind. The tissue is most valuable if cooled or frozen immediately after surgery, so ask your surgeon about tumor donation and complete the appropriate forms prior to surgery. Otherwise, your tumor is likely to be fixed in paraffin, limiting the types of analyses that may be performed on it. There are two established alternatives for getting your tumor from the operating room to researchers working on ACC.

(A) The following institutions are part of a collaborative Salivary Gland Tumor Biorepository supported by the National Institute of Dental and Craniofacial Research (NIDCR) and ACCRF:

MD Anderson  
Johns Hopkins University  
University of Virginia (UVA)  
University of Pittsburgh Medical Center  
University of California San Francisco (UCSF)  
Rhode Island Hospital

If you are having your surgery at one of these academic medical centers, they will automatically ensure that your tumor and relevant clinical information become "banked" in the proper form and available later for researchers. Simply confirm with your surgeon that the appropriate paperwork is in place prior to surgery.

(B) If your surgery will occur at an institution other than those listed above, please consider having the tumor sent (at no cost to you) to the University of Virginia's [ACC Registry](#). Fill out the [donation form](#) and provide it to your surgeon. You may call (434) 982-4408 for assistance.

Your tumor donation will bring closer the day when new therapies will benefit ACC patients.