



NIH Workshop Update – October 2006

During October 23rd and 24th, the National Institutes of Health (NIH) held their first-ever “Workshop on the Biology and Treatment of Malignant Salivary Gland Cancers” in Bethesda, MD. The sponsoring organizations were the Office of Rare Diseases (ORD), The National Institute of Dental and Craniofacial Research (NIDCR) and the Cancer Therapy Evaluation Program (CTEP) of the National Cancer Institute (NCI). ACCRF Trustees Marnie and Jeff Kaufman helped develop the list of speakers and attended the conference as the only Patient Advocates. In addition, ACCRF sponsored a dinner for all participants. The researchers who participated were:

Robert Angerer, PhD (NIDCR)	Paul Meltzer, MD, PhD (NCI)
George Blumenschein, MD (MD Anderson)	Alfredo Molinolo, MD (NIDCR)
Barbara Burtness, MD (Fox Chase)	Christopher Moskaluk, MD, PhD (Virginia)
Dimitrios Colevas, MD (NCI CTEP)	Jeffrey Myers, MD, PhD (MD Anderson)
Adel El-Naggar, MD, PhD (MD Anderson)	Martin Pruschy, PhD (USZ)
Isabel Fonseca, MD, PhD (IPOFG)	Ana Raimondi, PhD (NIDCR)
Arlene Forastiere, MD (Johns Hopkins)	Mary Reyland, PhD (Colorado)
Henry Frierson, MD (Virginia)	John Ridge, MD, PhD (Fox Chase)
Adam Garden, MD (MD Anderson)	Yasaman Shirazi, PhD (NIDCR)
Stephen Gruber, MD, PhD (Michigan)	Lillian Shum, PhD (NIDCR)
Silvio Gutkind, PhD (NIDCR)	Lillian Siu, MD (Toronto)
Patrick Ha, MD (Johns Hopkins)	Sharon Spencer, MD (UAB)
Robert Haddad, MD (Dana Farber)	Goran Stenman, DMD, PhD (Sahlgrenska)
Tina Jaskoll, PhD (USC)	Randal Weber, MD (MD Anderson)
Frederic Kaye, MD (NCI)	Gregory Wolf, MD (Michigan)
Maria Carmo Martins, PhD (IPOFG)	Stuart Wong, MD (Wisconsin)
Michael Melnick, DDS, PhD (USC)	

The agenda topics ranged from pathology to molecular biology to surgical management to radiation treatment to clinical trials. Following the ACCRF meetings in Washington (April) and Baltimore (July), these meetings made further progress in expanding the universe of interested researchers and building a collaborative spirit. Many of the researchers who focused on salivary glands had never met each other and there were many offers to exchange materials and data. The meeting ended with a concrete list of action items:

- Steering Committee on Salivary Glands – The overlapping and confusing jurisdictions of SPORES, cooperative groups, professional societies, etc. need to be rationalized into one task force that will guide and coordinate research efforts and clinical trials. These steering committees are being set up across most disease sites and are most crucial for rare diseases.



- Biobanking – Tumors, tissues, saliva and serum need to be catalogued across all academic institutions and made available for worthy projects. (Note: ACCRF is helping coordinate a virtual biobank with some of the workshop participants).
- Better education on initial treatment – Reflecting the principle that the first chance is the best chance to treat salivary gland malignancies, patients need to be pointed in the direction of specialized centers as early as possible, ideally before their initial surgery.
- Better website communication – NCI, NIDCR, CTEP and patient groups need to coordinate better to make crucial information easily available to newly-diagnosed patients with salivary gland malignancies.

In addition, there were some interesting observations that are particularly relevant to the ACC patient community:

- Some NIH participants expressed to the ACCRF trustees the importance of patient presence at conferences and activism in Congress to demonstrate grassroots support for research. The number of salivary gland cancer diagnoses are about 3% of the level of lung cancer diagnoses, yet the relative research budget for salivary gland cancers is much lower than that percentage.
- NIDCR was very well represented at the workshop, indicating its high level of interest, both historically and prospectively (perhaps due to the Director's background in salivary gland research).
- ACC is the second most common salivary gland cancer after muco-epidermoid carcinoma (MEC). However, MEC's prognosis is much less dire, making ACC of greater interest to most researchers.
- The medical oncologists generally felt that ACC patients should be separated from non-ACC patients in clinical trials when assessing the data; many rarer salivary gland cancers get lumped together. There was widespread agreement that clinical trial participants with ACC ought to be coordinated better among the cooperative groups, hopefully leading to similarly-structured, sequential trials that would cycle through many classes of drugs.
- The Eastern Cooperative Oncology Group (ECOG) had planned a clinical trial for ACC to test Sorafenib. However, funding cuts from the NIH resulted in reduced ability to fund trials, and the ACC-Sorafenib trial was not approved.
- Dr. Martin Pruschy's work was instigated by a European ACC patient, and his findings may be validated further by ACCRF-instigated projects. Clearly, communication within the ACC patient community is important and must parallel collaboration within the research community.

ACCRF will continue to attend conferences and workshops to raise the profile of ACC in the minds of researchers and funding organizations.