



ACCRF Update – March 2009

Summary

In its first three years of existence, the Adenoid Cystic Carcinoma Research Foundation (ACCRF) has made great strides in achieving its mission of accelerating the development of improved therapies and a cure for ACC. A community of interested researchers has blossomed, driving forward an ambitious Research Agenda. And patients are stepping forward in support of each other as well as the scientists' amazing efforts.

Looking back over ACCRF's accomplishments in 2008, the ACC patient community may be encouraged from several important developments:

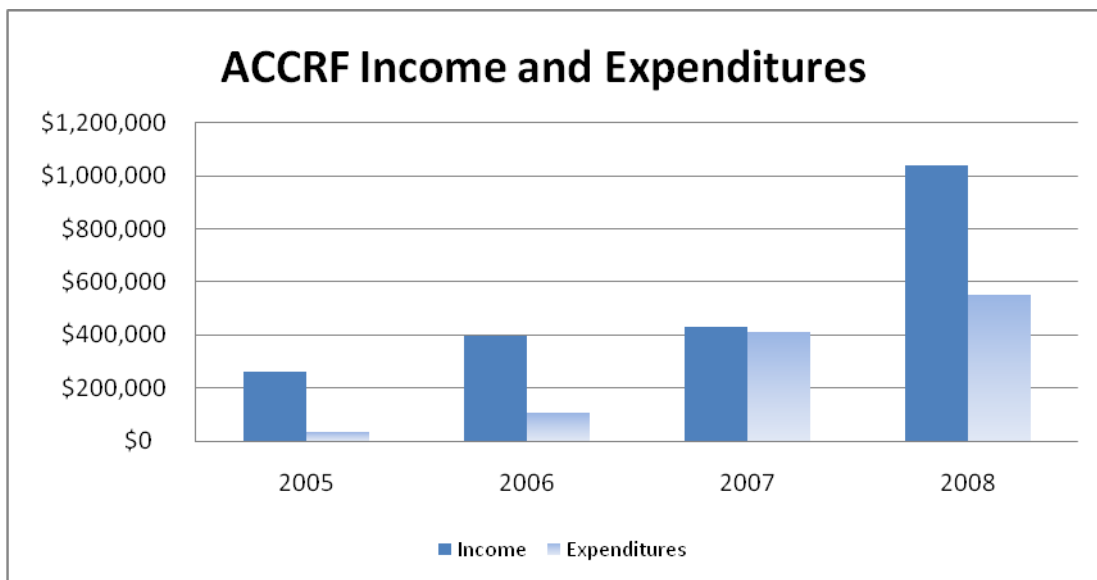
- The Salivary Gland Tumor Biorepository (SGTB) began collecting ACC specimens across 6 medical centers nationwide
- Researchers at MD Anderson, Johns Hopkins, INCELL, Dana-Farber, MGH, Brigham & Women's and Virginia are developing new ACC cell lines for researchers to study the nature of the disease and identify promising drugs
- Six new xenograft mouse models have been created and two baseline drugs screens were completed on them
- The two largest gatherings of ACC patients ever were convened, building grassroots support for research
- The first large-scale DNA resequencing study of ACC tumors identified the prevalence of genetic mutations
- The first large-scale phosphoproteomic study of ACC tumors was initiated to determine which genes are particularly active or inactive
- Genomic studies searched for methylation status and chromosomal imbalances in ACC that might explain the cancer's growth
- Two studies of nerve invasion in ACC were begun
- The first agreement was signed with a pharmaceutical company to screen a novel compound in ACCRF's models
- A network of medical oncologists was formed to propose and conduct clinical trials

Yet there is still so much to do. ACCRF's Scientific Advisory Board and affiliated researchers were convened in person and on conference calls throughout the year to discuss adjustments to existing projects and to explore potential new projects. The Research Agenda is being evaluated and revised constantly, with full knowledge that ACC patients are relying on researchers for rapid, significant progress. Beyond the expansion of ACCRF's current projects, plans for 2009 include:



- The initiation of a bioinformatics project to merge and analyze the many data sets generated by our investigators
- The development of epidemiological studies to understand the population characteristics of ACC patients
- A concerted approach to public institutions to raise awareness of, and funding for, rare cancers like ACC
- An integrated program to help ACC patients support research with their specimen donations and benefit from cutting-edge genomic and proteomic analyses that might customize their treatment.

The remarkable progress witnessed in ACCRF's research efforts would not have been possible without the generous support of the ACC patient community, including families and friends. ACCRF recently passed the \$2 million mark in total donations, a truly impressive feat in the realm of rare diseases. Conservative investment policies avoided market losses during the financial crisis and contributed modestly to total income. However, as expenditures rise with our expanding research programs, it is imperative that we maintain and expand our funding base.



Fully 96.6% of expenditures since ACCRF's 2005 inception have been on research-related programs; the remaining 3.4% of expenditures represent legal, accounting, website and postage costs that have been more than covered by donations from ACCRF's founders. Accordingly, all donations from the general public are spent directly on research.

Looking forward, ACCRF will continue to be a stable and pivotal source of support for ACC researchers and patients. That is only fitting as it is the efforts and support of researchers and patients that have driven all of the research progress.