

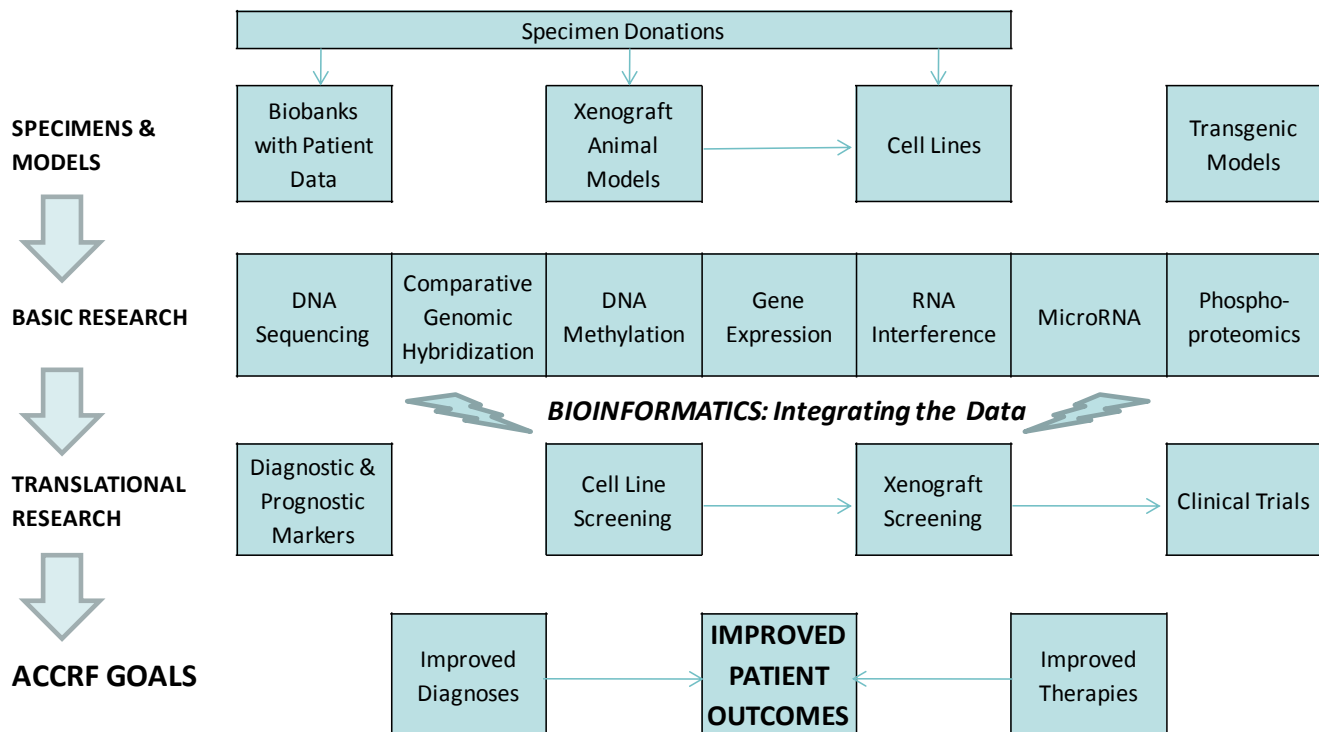


ACCRF ACCOMPLISHMENTS (August 2009 Update)

Since its formation in December 2005, The Adenoid Cystic Carcinoma Research Foundation (ACCRF) has worked relentlessly to achieve its mission to accelerate the development of improved treatments and a cure for ACC. The highlights of the Foundation’s activities in the past three and a half years are:

1. **Scientific Advisory Board** - ACCRF formed an exemplary group of advisors that includes **Dr. David Sidransky** (Director of Head & Neck Cancer Research at Johns Hopkins), **Dr. Bruce Chabner** (Clinical Director of the Massachusetts General Hospital Cancer Center; Member of the National Cancer Advisory Board), **Dr. Robert Haddad** (Medical Oncologist at Dana-Farber Cancer Institute) and **Dr. Norman Sharpless** (Cancer Geneticist at the UNC Lineberger Comprehensive Cancer Center). They have been generous with their time and responsive to all requests – a remarkably capable, committed and compassionate group.
2. **Scientific Meetings** – ACCRF sponsored and/or presented at the following gatherings to build researchers’ focus on ACC: ACC “State-of-the-Science” Meeting (4/06), Project Review Meeting (7/06), NIH Workshop on Malignant Salivary Gland Tumors (10/06), NCI Conference on Rare Cancers (5/07), ACC Scientific Forum at the Salk Institute (4/08), Cancer Drug Discovery and Development Conference (5/08), ACCRF Research Call on Cell Lines (10/08), 2nd NIH Workshop on Malignant Salivary Gland Tumors (11/08), BIO CEO Conference (2/09), 2nd ACCRF Research Call on Sequencing (2/09), and Scientific Advisory Board Meeting (2/09).
3. **Research Agenda** – ACCRF announced its initial Research Agenda in June 2006, drawing on the input and guidance of the Scientific Advisory Board and other interested researchers. The multi-institutional, multi-year plan maps out a logically-sequenced road to progress in biobanking, model system development, molecular targets, bioinformatics and translational research. The latest update is available at <http://www.accrf.org/html/agenda.php>.

ACCRF Research Agenda Framework





4. **Biobanking Projects** – ACCRF directly supports efforts at MD Anderson and the University of Virginia to make ACC specimens available to interested researchers and thereby stimulates new studies. In addition, ACCRF has collaborated with the National Institute of Dental and Craniofacial Research (NIDCR) to create the Salivary Gland Tumor Biorepository that also includes contributors from UCSF, Pittsburgh, Brown and Johns Hopkins.
5. **Model Systems** – ACCRF funds several academic investigators to develop cell lines (human tumor cells grown in vials) and xenograft models (human tumors grown in mice) that are necessary to perform many leading-edge scientific studies. ACCRF has convened expert investigators to generate, validate and distribute cell lines, and has established the first 5 ACC xenograft models. **Research into many rare diseases suffers from the unavailability of model systems, but ACCRF is remedying the situation.**
6. **Molecular Targets** – ACCRF funds, manages and coordinates several leading-edge research projects into the genomic and proteomic drivers of ACC. By identifying the altered molecular pathways that cause ACC, investigators will be able to personalize treatments that will be more effective and will have fewer side effects than current treatment options (mainly surgery and radiation). Scientific collaborators are located in the U.S., England, Sweden and China, and include the Sanger Institute, Mass General, MD Anderson, Johns Hopkins, the Sahlgrenska Institute, Dana-Farber, Virginia, Harvard, and Cell Signaling Technology. **ACCRF has pioneered a patient-driven approach to target discovery that has delivered rapid, broad and high-quality findings – a novelty in cancer research for any tumor type.**
7. **Bioinformatics** – ACCRF-affiliated researchers are generating enormous and complex datasets, each of which provides clues to the potential vulnerabilities of ACC. However, there is even greater power in combining datasets to hone in on the crucial molecular pathways. ACCRF funds bioinformaticians to gather, warehouse, curate, analyze and distribute the various datasets – all with the goal of generating sufficient evidence to move forward with drug screening studies and clinical trials.
8. **Translational Research** – ACCRF contracts with South Texas Accelerated Research Therapeutics (START) to fully establish, propagate and screen ACC xenograft models. Approved anticancer agents are being screened in the models to determine their baseline efficacy and toxicity. In addition, ACCRF has negotiated with pharmaceutical and biotechnology firms to assess promising novel compounds that inhibit molecular targets identified by ACCRF's genomic and proteomic studies. Cell lines screens are planned at Mass General and the NIH Chemical Genomics Center. **The primary goal is to provide scientific rationales and compelling evidence to support clinical trials that hold the promise of curing ACC. To that end, ACCRF is actively engaged with the National Institutes of Health (NIH) as well as pharmaceutical and biotechnology firms to propose, evaluate and carry out clinical trials.** ACCRF representatives are members of the National Cancer Institute's Head and Neck Steering Committee, the NIDCR Salivary Gland Tumor Biorepository and the NIH Rare Disease Clinical Research Network.
9. **Mobilizing Patients** – ACCRF's mission is to accelerate the development of improved treatments and a cure for ACC patients. A pivotal component of pursuing that mission involves building relationships with patients and their supportive families and friends. ACCRF has developed FAQ materials to guide patients through their treatment courses, has responded to countless individual inquiries, and has kept ACC patients informed about the latest research developments. **The entire ACCRF research enterprise is predicated on mobilizing patients – through tumor donations, their willingness to participate in promising clinical trials, and the community's financial support. With over \$3 million raised from the ACC patient community, ACCRF has been able to accelerate research into a rare disease in an unprecedented manner.**

Hope is a powerful ally. And research is the Angel of Hope.