

# Adenoid Cystic Carcinoma Research Foundation



P.O. Box 442  
Needham, MA 02494  
(781) 248-9699  
[www.accrf.org](http://www.accrf.org)



## Mission

The Adenoid Cystic Carcinoma Research Foundation (ACCRF) supports research into adenoid cystic carcinoma that will accelerate the development of improved therapies and a cure for the disease. ACCRF was founded by Marnie and Jeff Kaufman after Marnie's diagnosis in 2004.

## Strategy/Approach

In order to accomplish its stated mission, ACCRF implements a strategy focused on three goals:

- **Building a community of interested researchers** – Sponsoring conferences focused on ACC, involving multiple institutions in the foundation's activities, and establishing a clearinghouse of information and contacts for ACC-focused researchers and clinicians
- **Creating and implementing an innovative plan of action** – Following the guidance of an exceptional Scientific Advisory Board, proactively initiating projects that conform to a coherent and logically sequenced research agenda, accelerating research progress by contracting for deliverables within clear timeframes, and ensuring rapid and broad sharing of research findings
- **Mobilizing patients in support of research** – Providing quality information on ACC to patients and informing patients of research developments and clinical trials

Projects start at the basic research level through drug screening of combined therapies, with the ultimate goal of supporting clinical trials. Funded researchers are located in the United Kingdom, Australia, Sweden, and the United States.

## Research Portfolio

ACCRF has committed more than \$7 million to targeted research projects as of 2014. This funding has gone to 37 different laboratories over the past eight years.

ACCRF sees its role as a provider of seed capital to advance pre-clinical drug discovery and development to the point where clinical trials are supported by the National Institutes of Health (NIH) and private sponsors. It seeks to build a diversified portfolio of promising research projects, foster multi-institutional collaboration, identify high-impact projects and researchers with the capacity and interest to carry them out, carefully manage and monitor deliverables and timeframes, and widely disseminate research findings.

The projects supported by ACCRF fall into three broad categories:

1. **Specimens & Models** – Includes specimen donations, biobanks and patient databases, and cell line and animal model development
2. **Basic Research** – Includes DNA sequencing, comparative genomic hybridization, DNA methylation, gene expression, RNAi, phosphoproteomics, MicroRNA, and bioinformatics
3. **Translational Research** – Includes biomarker identification, drug screening, and clinical trials

## Partnership Practices

ACCRF works to foster multi-institutional collaboration within its research agenda. Currently, approximately 25 projects are underway with investigators, representing 20 institutions.

**ACCRF partners with biotech and pharmaceutical companies.** While the majority of its partners are research institutes and academic organizations, ACCRF does work with some private organizations, for example South Texas Accelerated Research Therapeutics.

Some partnership highlights include:

- ACCRF coordinates the efforts of researchers at several institutions to grow new ACC cell lines from fresh tumor donations and animal models. The foundation facilitated the development of minimum validation criteria for cell lines.
- ACCRF has convened an ACC Bioinformatics Collaboration to combine, analyze, and disseminate the data sets of its grantees at the M.D. Anderson Cancer Center, Memorial Sloan-Kettering Cancer Center and Johns Hopkins University.
- ACCRF provides an open platform for industry and academic partners to screen novel drugs in animal models.

## Financials

ACCRF is a nonexempt charitable trust. The most recent financial information available is from 2012.<sup>1</sup>

Year ending 12/31/12:

- Revenue: \$1,692,225
- Assets: \$2,848,746
- Grants paid: \$864,887
- Gifts received: \$1,677,911
- Expenditures: \$1,377,751

<sup>1</sup> Information obtained from GuideStar. <http://www.guidestar.org>, February 2014.

## Key Accomplishments

- Development of biorepository resources with hundreds of high-quality specimens
- Discovery of ACC cell line misidentifications
- Creation of substantial patient derived xenograft resources
- Generation of genomic datasets across multiple platforms from the same specimens
- Discovery of a highly recurrent translocation that drives most ACCs
- Preclinical drug screening of 30 approved and 40 novel agents in xenografts
- Coordination with the National Institute of Dental and Craniofacial Research to increase NIH focus on and funding (now over \$20 million) for salivary gland cancer research
- Initiation of the first-ever clinical trial in ACC with a clear scientific rationale and supportive preclinical drug screening data
- International MYB Conference hosted over 40 researchers to discuss therapeutics targeting MYB proteins. ACCRF received research proposals from conference discussions.

## Leadership

The Adenoid Cystic Carcinoma Research Foundation is governed by a **Board of Directors** and counseled by a **Scientific Advisory Board**.

- **Executive Director:** Jeff Kaufman, [jeffreykaufman@comcast.net](mailto:jeffreykaufman@comcast.net)
- **Co-Founder and Director:** Marnie Kaufman
- **Scientific Advisory Board Chair:** Dr. David Sidransky