

why support the ACCRF?

- The ACCRF has an aggressive and nimble research plan driven by distinguished scientific researchers.
- ACCRF’s Research Agenda actively prioritizes and logically sequences the most important research projects for developing new therapies.
- We award research contracts with clear timelines and deliverables; we don’t just review research proposals passively.
- 100% of your donation goes to research programs (all non-research expenses are covered by ACCRF’s Circle of Sustenance donors)
- Due to ACC’s deliberate course, many current patients may benefit from research launched today.
- Without private funding and patient advocacy, there will simply be no ACC research. And no cure.

please support our angel of hope

Name _____

Address _____

City _____ State ____ Zip _____

Email _____

This donation is in honor of/in memory of (circle one)

ACCRF is a 501(c)(3) public charity.
Please send your tax-deductible donation to:

ACCRF
P.O. Box 442
Needham, MA 02494
 or visit www.accrf.org to make
 an on-line donation

quick facts about ACC

- Afflicting about 5,000 Americans, ACC is diagnosed in about 1,200 new cases each year in the United States.
- ACC’s progression is typically gradual and relentless. Its high propensity to recur has led to 15-year survival rates of around 40%.
- ACC is an equal-opportunity disease that might strike anyone. It is not inherited and is not associated with smoking, drinking, infection or ethnicity. Women comprise nearly two-thirds of ACC cases.
- ACC often afflicts young and middle-aged patients. The median age at diagnosis for ACC patients is a decade younger than for all cancer patients.
- No chemotherapies or targeted drugs have been approved for ACC. Research is needed to find effective therapies for ACC patients.



Adenoid Cystic Carcinoma
 Research Foundation

Adenoid Cystic Carcinoma
 Research Foundation (ACCRF)

P.O. Box 442
 Needham, MA 02494

info@accrf.org
 781.248.9699

www.accrf.org

hope is a powerful
ally.
 and **research** is the
angel of hope.



Adenoid Cystic Carcinoma
 Research Foundation



Adenoid Cystic Carcinoma (ACC) is a rare cancer, typically originating in the head and neck region. This malignancy has a slow – and sometimes relentless – progression with a tendency to grow along nerves. Particularly high rates of recurrence and metastasis to the lungs lead to a poor prognosis beyond 10 years. ACC is not inherited and is not associated with smoking, drinking, infection or ethnicity. ACC is an equal-opportunity disease that might strike anyone.

The Adenoid Cystic Carcinoma Research Foundation (ACCRF) is a tax-exempt public charity based in Needham, Massachusetts. The Board of Directors oversees the operations of ACCRF and its research projects, with the guidance of the Scientific Advisory Board.

founder's story

Marnie Kaufman was 38 years old, with four sons under the age of 10, when she received her devastating diagnosis. Frustrated at the lack of ongoing ACC research, she and her husband, Jeff, formed ACCRF in 2005. A dedicated core of family, friends and researchers jumpstarted a global, cutting-edge research effort. Since then, the generosity of ACCRF supporters has permitted a network of brilliant ACC researchers to flourish. Marnie intends to watch her four young sons grow up to have families of their own and, like thousands of other ACC survivors, to "sit on a rocker in my old age and enjoy watching the sun come up."

our mission

The Adenoid Cystic Carcinoma Research Foundation (ACCRF) supports research into ACC that will accelerate the development of improved therapies and a cure for the disease.

our research strategy

ACC researchers face a complex array of problems: unavailable basic research infrastructure, minimal researcher focus, and very limited funding. Expert and coordinated action is necessary to overcome these challenges while taking advantage of the newer and lower-cost technologies that are driving successes in biomedical research. In order to accomplish its mission, ACCRF implements a strategy focused on three goals:

Building a community of interested researchers

- Sponsoring conferences
- Involving multiple institutions in the foundation's activities
- Establishing a clearinghouse of information and contacts

Creating an innovative plan of action

- Following the guidance of an exceptional Scientific Advisory Board
- Proactively initiating projects within a logically-sequenced Research Agenda
- Accelerating research by contracting for deliverables within clear timeframes as well as ensuring rapid and broad sharing of resources and research findings

Mobilizing patients in support of research

- Providing quality information on ACC to patients
- Informing patients of research developments and clinical trials

research progress

ACCRF-affiliated researchers in the United States, the United Kingdom, China and Sweden are making rapid progress:

- Tumor specimens and models are being banked, developed and shared
- Genomic and proteomic studies are identifying ACC's molecular vulnerabilities
- Drugs are being tested for efficacy
- New projects are being evaluated by the best minds in cancer research

scientific advisory board



Dr. David Sidransky (Chair)
Director, Head and Neck Cancer Research
Johns Hopkins University



Dr. Bruce Chabner
Clinical Director
Massachusetts General Hospital Cancer Center



Dr. Robert Haddad
Clinical Director, Center for Head & Neck Oncology
Dana-Farber Cancer Institute



Dr. Norman Sharpless
Cancer Geneticist
UNC Lineberger Cancer Center

board of directors



Jeffrey Kaufman
Executive Director and Co-Founder



Marnie Kaufman
Director, Co-Founder and ACC Survivor



Thomas DiLenge
Director
General Counsel, Biotechnology Industry Organization



Kara Gelb
Director and ACC Survivor
GM Maternity Services, University College Hospitals London



A. Ralph Mollis
Director
Secretary of State, Rhode Island