

2025 IMPACT REPORT



Adenoid Cystic Carcinoma
Research Foundation

20 Years of Groundbreaking Research



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A LETTER FROM ACCRF'S CO-FOUNDERS

Dear Friends,

December of 2025 marked 20 years since we founded ACCRF. It is a milestone that is difficult to fathom when we think back to those earliest days. ACCRF was begun shortly after Marnie's diagnosis, at a time of great uncertainty and fear that is all too familiar to many of you reading this. We were searching for answers and connection when there seemed to be little available. In that moment, our sole focus was finding any information we could about this rare disease that had suddenly become an all-consuming part of our lives.

It seems auspicious, then, that this year has brought more progress, more hope, and more connection than we could have ever imagined those many years ago. Our decades-long work of understanding the biology of ACC and targeting its vulnerabilities has resulted in the first MYB inhibitor drugs and multiple new antibody drug conjugates (ADCs) showing the best-ever response rates in ACC patients. At the close of our 20th year, we are standing at the threshold of new treatments we could have only dreamed of in 2005.

But when we consider the many achievements, highlights, and breakthroughs ACCRF has brought into our lives, it is ultimately the people who make up our community that we hold most precious. These 20 years have connected us to the most remarkably passionate, caring, joyful individuals who have shaped not only our lives, but the lives of patients around the world. The dedication we have witnessed from patients, families, friends, researchers, physicians, and advocates reminds us exactly why we do this work. We have lost too many friends along the way, and as we mourn them every day, their memories remain the fire that continues to fuel our work. We are forever grateful to them and to you for all you have given ACCRF.

You have believed in us for two decades. You have shown us support, faith, and encouragement to continue through the many challenges that this endeavor has brought. As you read this report, we trust you will find the progress of the past year provides renewed hope and encouragement that our collective efforts are making a real difference. The future of ACC research is brighter than ever because of you. Let's finish the work we started 20 years ago.



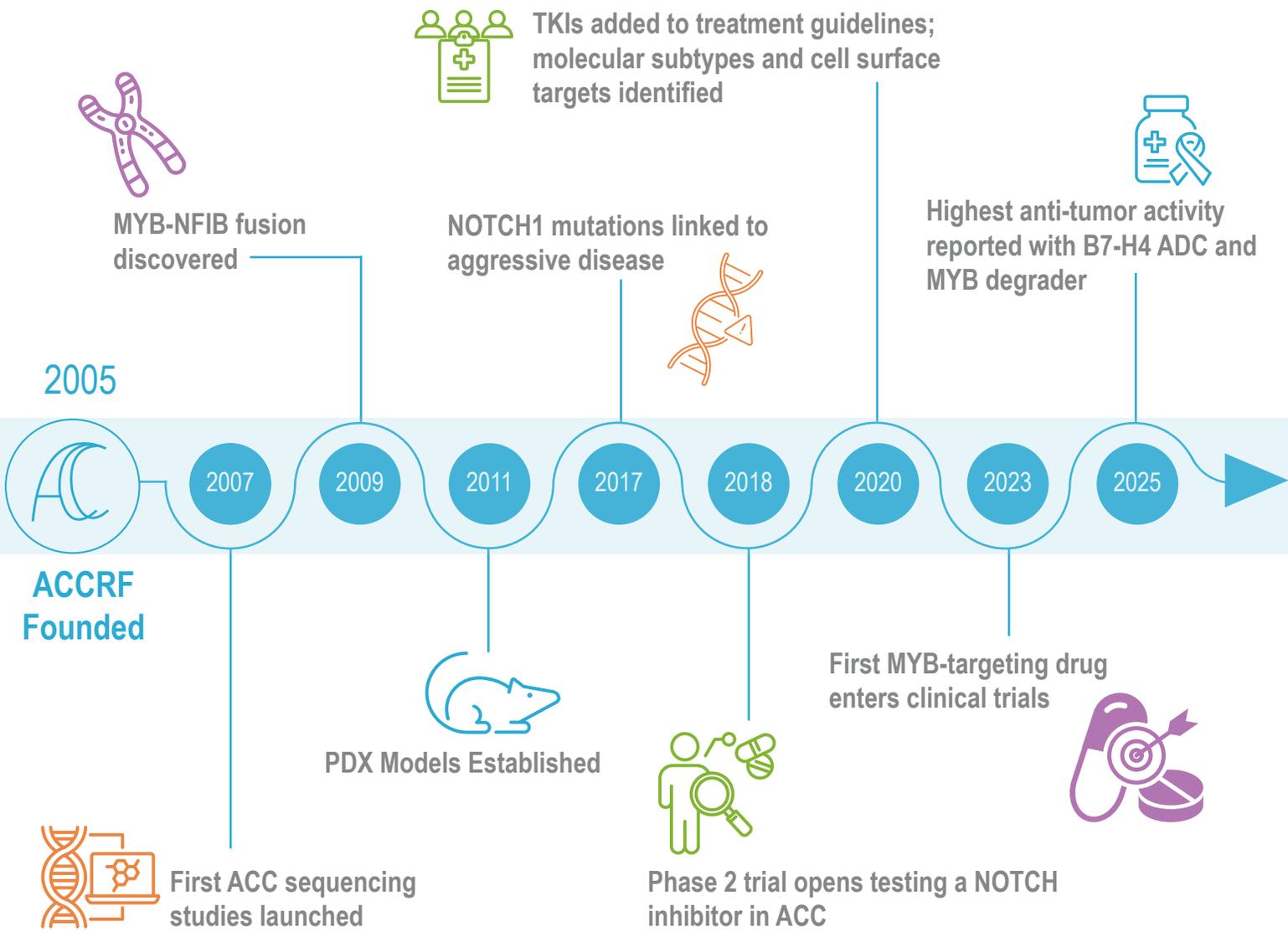
Marnie and Jeff Kaufman, ACCRF Co-Founders

20TH ANNIVERSARY RETROSPECTIVE

HISTORIC SCIENTIFIC ACHIEVEMENTS

The 2025 ACCRF Impact Report provides an opportunity not only to highlight the accomplishments of the past year, but to take a holistic view of our achievements of the last 20 years and the ways in which we have reshaped the landscape of ACC research. For two decades, ACCRF's bench-to-bedside ethos has driven every step of progress in ACC, from understanding its biology and identifying key drivers to developing targeted therapies and advancing new treatments through clinical trials.

We are seeing better responses in clinical trials available to ACC patients, and our relationships with researchers and biopharma companies have affirmed ACC as an important and worthy subject for study. Our collective efforts have made ACCRF the essential hub of ACC research, powering collaboration across academia, clinics, and industry to deliver better treatments and, ultimately, a cure. Below are some of the strides we have made toward that goal.



RESEARCH EFFORTS

2025 OVERVIEW AND HIGHLIGHTS



As we celebrate 20 years of advancements in the field of ACC research, it is with great pride and gratitude that I share the clinical and scientific milestones achieved by the ACCRF network in 2025. This past year brought some of our most encouraging advances to date, with early Phase 1 clinical trials reporting unprecedented response rates in patients treated with the B7-H4 antibody drug conjugate Emi-Le and MYB degrader REM-422.

These achievements reflect ACCRF's two-decade strategy of supporting every stage of research from basic biology through clinical trials to ensure that new therapies for ACC are built on the strongest scientific rationale possible. By focusing on identifying druggable targets in ACC, we have helped enable ACCRF's academic grantees and biopharmaceutical partners to more effectively attack the underlying vulnerabilities of this disease. Together with our preclinical drug screening platform, these efforts provide the scientific basis for today's most promising new treatments. Highlighted below are some of the most encouraging developments from the past year.



Nicole Spardy Burr, PhD, Director of Research

DRIVING PROGRESS

Phase 1 clinical trials for two separate drugs - [B7-H4 antibody drug conjugate Emi-Le](#) and [MYB degrader REM-422](#) - showed some of the highest response rates ever in ACC patients. Both drugs were built off of [ACCRF-supported research](#) demonstrating that B7-H4 and MYB are highly prevalent in ACC tumors and are viable targets for treatment.



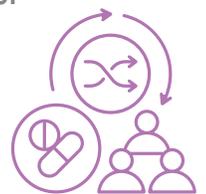
GROWING COLLABORATION

ACCRF began a [new collaboration](#) with bio-pharma company **Pin Therapeutics**, building on the preclinical success of their **Ck1a degrader, PIN-5018 in ACCRF models** and supporting their Phase 1 trial to test the drug in ACC patients.



EXPANDING THE PIPELINE

Sixteen clinical trials of anticancer drugs were [open to recurrent/metastatic ACC patients](#) in 2025. These trials included ADCs targeting TROP2, NECTIN-4, c-KIT and FAP cell surface proteins, highlighting the **growing diversity of drug targets** that are being clinically explored in ACC.



ACCELERATING RESEARCH

In 2025, [twenty eight research articles](#) were published by the ACCRF grantee network, advancing our understanding of ACC from many angles. Publications included studies revealing how [ACC tumor cells can hide from the immune system](#), as well as studies [evaluating whether local treatment of lung metastases](#) or [combined chemotherapy and radiation](#) can influence patient outcomes.



FUELING INNOVATION

[Seven new grants](#) were awarded by ACCRF to support cutting-edge ACC research. These included follow-up studies aimed at understanding how immune evasion mechanisms can be therapeutically reversed in ACC tumors, as well as a global collaboration investigating the prognostic value of the p63 biomarker across 700+ ACC samples collected from twelve international research centers.

RESEARCH EFFORTS

CLINICAL TRIALS

Over the past 20 years, the number of clinical trials available to ACC patients has grown dramatically. This progress reflects our deeper understanding of ACC biology, a strong and engaged network of medical oncologists, and a well-informed, motivated patient community willing to participate in clinical research. You can learn more about past clinical trials on our [website](#).

In 2025, **two Phase 1 clinical trials (Emi-Le and REM-422)** shared encouraging early results in subsets of ACC patients. In the Emi-Le study, 5 out of 9 ACC-I patients (55.6%) treated with Emi-Le, a B7-H4 antibody drug conjugate (ADC) saw partial responses (tumors shrinkage by 30% or more), representing **the highest response rate ever reported for a drug tested in ACC patients**. REM-422's early Phase 1 clinical trial results showed that 43% of biomarker-positive patients treated with REM-422 for at least 6 months also experienced partial responses.

The main goal of Phase 1 trials is to ensure a new drug is safe and to find a dose that people can tolerate. Phase 1 trials may also provide an early indication of whether the drug is able to shrink or stabilize the growth of tumors. If successful, these drugs may move on to later Phase studies (2 and 3) where the safety signal is cemented and the level of activity further refined.

For 20 years, there has been a steady growth in the number of targeted therapies—treatments designed to attack specific features in cancer cells—being tested in clinical trials for ACC patients. Because ACC tumors can differ from one patient to another, some treatments may work better for certain tumors than others. Continued research is essential to better understand these differences, and ACCRF remains committed to funding studies that clarify the different molecular subtypes of ACC and how drug targets may vary across patients. We are deeply grateful to the patients who have donated tumor tissue from surgeries or clinical trial biopsies and to those who have participated in clinical trials. Their generous contributions make this critical research possible.

PIONEERS OF CLINICAL RESEARCH

ACCRF's impact is driven by a longstanding and productive partnership with a global network of clinical leaders in ACC research. Physicians across the United States, Europe, and Asia have played a pivotal role in advancing clinical trial design and outcomes for ACC patients. Their work has significantly expanded our understanding of actionable targets, therapeutic potential, and the natural history of the disease. We thank them for their contributions and look forward to continuing these collaborations—alongside our broader research network—as we enter our third decade.



RESEARCH EFFORTS

RESEARCH PUBLICATIONS

In 2025, ACCRF grantees were among the authors of [28 articles](#) about ACC. These findings help to advance the overall understanding and increase the visibility of ACC in the medical and research communities. Below are important advances published in the past year by ACCRF grantees.



ACCRF grantees **Drs. John Iafrate, Annie Li, Lori Wirth, William Faquin, and Julia Thierauf** discovered that [ACC tumors can evade the immune system](#) by lowering the amount of a helpful protein called B2M. Because of this work, one ACC patient was treated with two drugs (a STING agonist and Pembrolizumab) that may help to raise B2M levels and activate the immune system and their tumor shrank by 70%. Dr. Iafrate was awarded a new grant in 2025 to perform follow-up studies to identify druggable pathways that regulate B2M and activate the immune system in ACC.

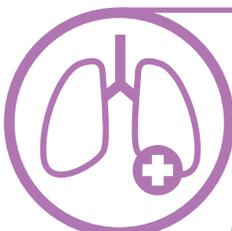
ACCRF grantees **Drs. Bitá Esmaeli and Renata Ferrarotto** undertook [a retrospective study](#) (looking at clinical outcomes across patients previously treated) of 52 ACC patients with lacrimal tumors. The 5-year and 10-year disease-specific and overall survival rates for patients who had eye-sparing surgery were better than for patients who had orbital exenteration. Patients that had lacrimal tumors with non-solid histology tended to have better outcomes compared to those with solid histology.



ACCRF grantees **Drs. Renata Ferrarotto, Adel El-Naggar, Yoshitsugu Mitani, Camila Oliveira Hoff, and Luana Guimaraes de Sousa** studied 165 ACC tumors and found that 97% were [positive for a protein called TROP2](#), which is the target of an antibody drug conjugate called sacituzumab govitecan (FDA approved for other non-ACC cancers). They also found that ACC-II tumors, which typically contain cribriform and tubular histology and do not have NOTCH mutations, had the highest levels of TROP2. These findings helped support the launch of a clinical trial testing sacituzumab govitecan in ACC patients (NCT05884320). Another trial testing a different TROP2 ADC, LCB84, alone or in combination with Pembrolizumab (NCT05941507) was also open to recurrent/metastatic ACC patients in 2025.



Using data from 215 ACC patients, ACCRF grantee **Dr. Guopei Zhu** found that [addition of chemotherapy to intensity-modulated radiation therapy](#) (IMRT) in the postoperative setting did not lead to a survival advantage in high-risk head and neck ACC patients.



ACCRF grantee **Dr. Xiaohong Chen** [published a study](#) comparing ACC patients who had surgery to remove their lung tumors with those who received other treatments, such as radiation or chemotherapy. The study found that after 5 years, 95.75% of patients who had lung surgery were still alive, compared with 82.9% of patients who received non-surgical treatment. The 5-year progression-free survival (the time before the cancer grows or spreads again) was 86.93% for the surgery group and 73.86% for the non-surgery group. The authors noted that the patients who may benefit the most from lung surgery are those who: 1) had a long time between their first ACC diagnosis and the development of distant metastases (e.g. more than 36 months), 2) have fewer lung metastases—especially if there is only one, and 3) do not have pleural effusion (a buildup of fluid around the lungs).

RESEARCH EFFORTS

AWARDED GRANTS

ACCRF has funded **more than \$12 million in research grants** to individuals working towards new treatments and a cure, rapidly expanding the field of ACC research in the process. **In 2025 ACCRF awarded 7 grants totaling \$689,920 to field-leading scientists** to pursue the frontiers of ACC research and treatment.



Amanda Swain, PhD

The Institute of Cancer Research

“Generating and Using Genetic Preclinical Models to Identify Novel Therapeutic Options for Patients with Adenoid Cystic Carcinoma”

A.John Iafrate, MD, PhD, and Lori Wirth, MD

Massachusetts General Hospital

“Investigating the Immune Microenvironment of Adenoid Cystic Carcinomas: A Novel Therapeutic Approach by Reversing HLA/B2M Downregulation”

Alan Ho, MD, PhD

Memorial Sloan Kettering Cancer Center

“Multicenter Validation of P63 Immunohistochemistry (IHC) as a Prognostic Marker for Adenoid Cystic Carcinoma (MSK)”

Laura Spurgeon, MD, MPhil; Guy Betts, MD;

and Robert Metcalf, MD, PhD

The Christie NHS Foundational Trust

“Multicenter Validation of P63 Immunohistochemistry (IHC) as a Prognostic Marker for Adenoid Cystic Carcinoma (Christie NHS)”

Renata Ferrarotto, MD*

MD Anderson Cancer Center

“Multicenter Validation of P63 Immunohistochemistry (IHC) as a Prognostic Marker for Adenoid Cystic Carcinoma (MDA)”

J.Jack Lee, PhD, MS, DDS

MD Anderson Cancer Center

“Multicenter Validation of P63 Immunohistochemistry (IHC) as a Prognostic Marker for Adenoid Cystic Carcinoma (MDA)”

John Ngo, PhD

Boston University

“Protease-activated Antibodies for Tumor-selective NOTCH-1 Inhibition”

*Grantees pictured in listed order from top left
Recipient of the 2025 ACCRF Kara Gelb Memorial Grant

RESEARCH EFFORTS

RESEARCH CONFERENCES

In September 2025, ACCRF hosted our biennial ACC Research Conference in Boston, bringing together nearly 70 members of the global ACC research community for two days of presentations, discussions, and collaboration, all focused on advancing new treatments and a cure. These dedicated individuals shared their latest work in basic, translational, and clinical ACC research, including biomarker discovery for diagnosis and treatment and early results from projects focused on developing new drugs for patients. We are incredibly grateful to all those who shared the latest in ACC research and to everyone who joined virtually making this an internationally-attended event. Select topics from the [conference agenda](#) included: ACC Models, ACC Target Discovery, ACC Immune Landscape, Systemic Therapies for ACC, Understanding and Targeting MYB, and Emerging Clinical Tools and Data for ACC.



ACCRF also remained deeply engaged with the global research community, participating in the annual [American Society of Clinical Oncology \(ASCO\) meeting](#), and presenting science updates at several conferences including:

- NRG Oncology's Head and Neck Cancer working group
- Salivary Gland Cancer UK's 2025 working group
- University of Cincinnati working group
- Beijing Tongren Hospital, Rare Diseases of the Head and Neck Conference
- Shanghai 9th People's Hospital, ACC Symposium
- Mersana Therapeutics MIND Series

PATIENT COMMUNITY

EDUCATION & RESOURCES

ACCRF Webinar Series

ACCRF remains dedicated to providing educational resources for patients to better understand ACC and advocate for their care. Patient Webinars are a key part of this programming, providing patients with access to the latest in research and treatments presented by leading oncologists, researchers, and scientists. In 2025 the foundation hosted two webinars discussing the current research and clinical trial landscape. All webinars can be found in the [Patient Webinar Archive](#) and the [ACCRF YouTube channel](#).

Liquid Biopsies in ACC

ACCRF grantee **Dr. Daniel Pelaez** (University of Miami) discussed his work on a less invasive test that can detect levels of MYB found in the blood of ACC patients that may correlate with overall tumor burden. This test is still in development and not yet widely available to patients.

[Watch the webinar](#)



Antibody Drug Conjugates (ADCs) and Current Open Clinical Trials

ACCRF leadership discussed the latest developments in ADCs and reviewed clinical trials for novel ACC treatments that are currently open to patients.

[Watch the webinar](#)



Patient Resources

Social Media

In 2025, ACCRF expanded our social media presence to include [Instagram](#), [LinkedIn](#), and a [YouTube channel](#) alongside our existing [Facebook](#) community page. These new channels help us to extend our community, reach new members, and expand our ability to share high-quality educational materials for patients and researchers alike. We encourage you to follow these new pages below and sign up for our [research update emails](#) to stay up-to-date on the latest in ACC research and news.



Facebook



Instagram



YouTube



LinkedIn



Research Updates

PATIENT COMMUNITY

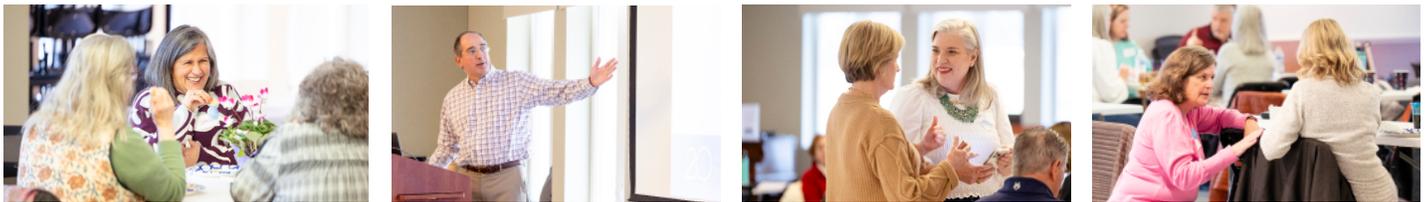
EVENTS

Patient Meetings

Patient gatherings build community among ACC patients and their loved ones, offering opportunities for individuals to connect, share experiences, and support one another. These gatherings also provide a chance for patients to hear from guest speakers (doctors and researchers) to better understand the ACC research landscape and available treatment options.

Needham, MA, USA - April 12, 2025

Our annual patient meeting brought together over 30 individuals from 3 countries for round-table discussions on treatment experiences, and presentations on the overall landscape of ACC research and ACCRF's efforts in the field. The day's keynote address was given by **Dr. Daniel Pelaez of the University of Miami** discussing his work on liquid biopsies in ACC. This address also served as our first Patient Webinar of 2025.



Patient Meeting Restrospective

Patient Meetings were also featured as part of our 20th Anniversary retrospective, highlighting and honoring the courageous individuals who have built the ACC community through their strength, candor, and hope. You can read the [full article](#) to learn more about the history of ACCRF's patient meetings and the people who made them possible.

PATIENT COMMUNITY

FUNDRAISING

ACCRF is proud and grateful to be supported by a dedicated community of donors whose generosity directly funds the foundation's ongoing research efforts. From individual donors to fundraising events, our community is the engine that drives ACC research forward. Below are some fundraising highlights from 2025.



Move For Munira 2025

This year saw the First Annual Move for Munira Walk & Run on April 19 in Houston, TX, USA. Held in memory of **Munira Wirani**, the event raised over \$11,000 in support of ACCRF's research efforts. ACCRF Co-Founder and Director **Marnie Kaufman** and ACCRF grantee **Dr. Renata Ferrarotto** of MD Anderson Cancer Center were both in attendance, along with many friends and family members for a wonderful day of community, movement, and hope.

Kristen Windscheffel Memorial Run

For the second year in a row, the community gathered together to pay tribute to Kristen and run to raise money for ACC research as part of the 2025 Boulevard 10k in Kansas City, MO, USA.

Head Strong Voices for Healing

Head Strong Voices for Healing hosted their first-ever walk-a-thon in support of ACCRF on Saturday, September 20th. Walkers and runners gathered in Chicago, IL, USA to raise over \$3,000 for ACC research while increasing awareness and supporting patients of head and neck cancers.



Gamers Against ACC

Charlie Andelman hosted their annual live gaming stream in memory of their dad, Bob Andelman. The 12 hour live stream in support of ACCRF raised over \$1,000 for ACC research and continues Charlie's impressive tradition of this marathon fundraiser!

Social Media Fundraisers

Thank you to the many people who hosted fundraisers for ACCRF on social media, including on our brand new [Instagram](#). Their combined efforts and generosity raised over \$8,000 in support of ACCRF's programming.

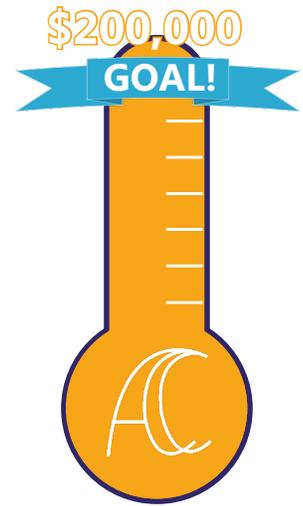
PATIENT COMMUNITY

20TH ANNIVERSARY FUNDRAISING MATCHING CHALLENGE

In celebration of ACCRF's 20th Anniversary, **Diana and Ogie Yanakiev** partnered with the current and former members of the **ACCRF Board of Directors** to create a **\$200,000 matching fund**. This remarkable gift matched all donations made to our year-end fundraiser dollar-for-dollar up to \$200,000.

Not only did we meet our goal, but we are proud to say that **this was the most successful year-end fundraiser in ACCRF's 20 year history**. This was in no small part due to an incredibly generous donation of \$100,000 from the **Adenoid Cystic Carcinoma Organization International (ACCOI)** in support of our efforts.

Thank you to everyone who donated to ACCRF in 2025. Your belief in our mission propels our efforts to find better treatment and a cure for ACC.



Interested in hosting your own event in 2026? Contact us at info@accrf.org to learn how you can get involved.



FINANCIALS

OVERVIEW

ACCRF derives funding from three main sources:



Direct Public Support

ACCRF is supported by generous donations from the public, all of which go directly to supporting our research efforts. Public donations have comprised **80% of all ACCRF's funding** since the foundation's inception.



Preclinical Screening

ACCRF manages and makes available preclinical ACC models for studying disease biology and screening drugs. Fees paid to ACCRF to access these models directly support the foundation's research efforts and programming.



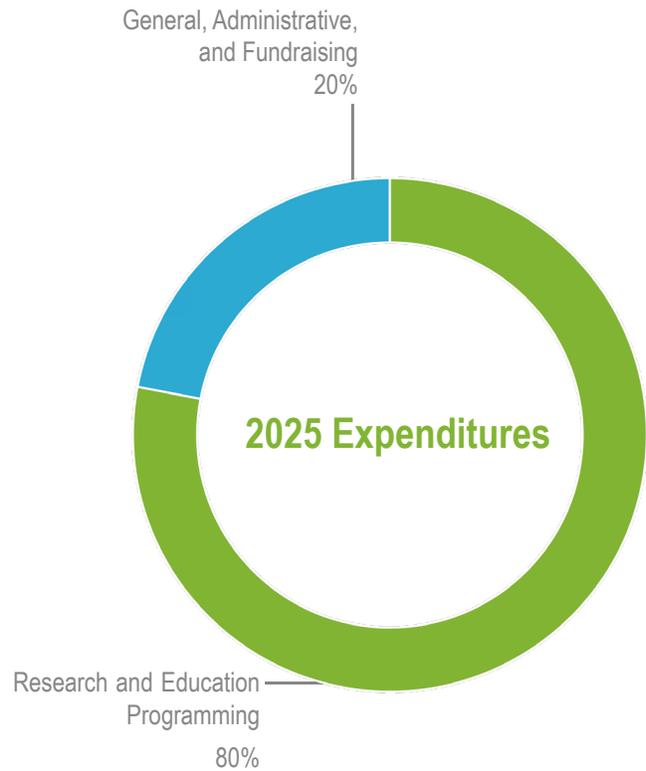
Investment Income

Any funds not immediately directed to research are invested and the income is applied to future research programs.

2025 Revenue and Expenditures*

Funds Raised	\$ 1,107,000
Direct Public Support	\$908,000
Preclinical Screening	\$118,000
Investment Income	\$81,000
Total Expenditures	\$1,157,000
Research and Education Programs	\$923,000
General, Administrative, and Fundraising	\$234,000

* preliminary cash basis financial results



ACCRF is proud to hold a four-star "Give With Confidence" rating from Charity Navigator

LEADERSHIP

ACCRF is an organization founded and led by patients and guided by world-leading scientists. Below is the foundation's full leadership and staff for 2025.

BOARD OF DIRECTORS



Jeffrey Kaufman
Co-Founder and
Board Chair



Marnie Kaufman
Co-Founder and
Director



Tom DiLenge
Director, Vice Chair
Senior Partner,
Flagship Pioneering



Shalil Giannone
Director
Certified Public Accountant



Emma Kinloch
Director
Founder,
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Ralph Mollis
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Town Manager,
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David Morse
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Investment Management,
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MD, PhD**
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Ophthalmologist and
Retinal Surgeon



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Cancer Research,
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Harvard Cancer Center



Dr. Bruce Chabner
Clinical Director,
Massachusetts General
Hospital Cancer Center



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



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MD Anderson Cancer Center



Dr. Gregory Verdine
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Dr. Robert Vonderheide
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University of Pennsylvania
Abramson Cancer Center

Emeritus Members



Dr. Ned Sharpless
Former Director,
National Cancer Institute



Dr. Lillian Siu
Director,
Phase I Program,
Princess Margaret
Cancer Centre

LEADERSHIP

STAFF



Jeffrey Kaufman
Co-Founder,
Board Chair,
Executive Director
(through 2025)



Marnie Kaufman
Co-Founder,
Director



Nicole Spardy Burr, PhD
Director of Research,
Executive Director
(beginning 2026)



Reed Motz
Development and
Communications Manager



Katelyn Hache
Development and
Operations Coordinator

GROWING THE ACCRF TEAM

ACCRF continues to expand our patient community and research network as we work towards new, effective treatments. And, as our efforts and initiatives grow, we are committed to likewise growing our leadership to better serve our mission. In 2025, ACCRF proudly welcomed two new members to our team:



Shalil Giannone

In July of 2025, the ACCRF Board of Directors unanimously elected Shalil Giannone as the newest member of the Board. An active and prominent member of the ACC patient community for 15 years, Shalil has been a consummate partner in the work of ACCRF and an ally and champion to her fellow patients.

You can learn more about Shalil in her [Patient Champions feature](#) from 2024.



Katelyn (Katie) Hache

Katie joined ACCRF as Development and Operations Coordinator in 2025, helping to institutionalize much of the foundation's daily operations and support strong, productive communications with our donor and patient communities. She first began working with ACCRF in 2017 as a bookkeeper, assisting with development operations.



Adenoid Cystic Carcinoma Research Foundation

20 Years of Groundbreaking Research

Adenoid Cystic Carcinoma Research Foundation

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