ALK POSITIVE

A patient-founded nonprofit accelerating research and improving the lives of people living with ALK-positive cancer worldwide.

Building Momentum Together

2025 Year in Review

In 2025, ALK Positive continued to move with urgency and intention toward a future where ALK-positive cancer is curable.

This report reflects not only what we accomplished this year, but how those efforts came together to advance science, expand access to clinical trials, and strengthen connection across our global community.







2025

www.alkpositive.org

Who are ALK-positive NSCLC Patients?

Diagnosed

40-50%
Male

50-**60%**
Female

Avg. age at diagnosis:
52

# of people living with ALK+ in the US
50,000+

No known cause or cure.

ALK Positive Incorporated- Who We Are
ALK Positive Inc. is a patient-founded, patient-driven nonprofit organization dedicated to improving quality of life and accelerating curative research for people living with ALK-positive cancer, worldwide.

Governed by a Board of Directors composed entirely of patients and care partners, ALK Positive is uniquely positioned to ensure that research priorities, advocacy efforts, and programs remain grounded in lived experience.

Our work is guided by a simple belief: patients belong at the center of research, strategy, and decision-making.



Targeted ALK therapies have significantly improved survival, allowing many patients to live for years with stable disease.

Despite this progress, nearly **50 percent of patients experience disease progression within five years,** underscoring the urgent need for continued research and more clinical trials..

Strategic Pillars

A patient-driven roadmap towards cures, care and sustainability.

Vision: A world in which ALK+ cancer is a curable disease

Mission: To seek a cure for ALK+ cancer while improving quality of life and life expectancy worldwide



Drive Research Toward a Cure

- Fund discovery, translational, and clinical research
- Accelerate next-generation therapies and clinical trials
- Leverage a world-class Scientific Advisory Board

Empower and Support Patients & Care Partners

- Education through expert online forums *ALKtALK*, Healing Arts, and the ALK+ Summit
- Access to Second Opinions, clinical trials, and supportive care
- Provide tools that improve quality of life at every stage





Sustain & Expand Impact Through Philanthropy

- Build diversified, predictable funding streams
- Partner with foundations, industry, and individuals.

Strengthen the Organization for Long-Term Impact

- Invest in leadership, governance, and operations
- Strengthen board structure and accountability
- Build brand, communications, and volunteer infrastructure



A Letter from Our President

To our extraordinary ALK Positive community —

Every day, I am inspired by the courage and resilience of the patients, care partners, family members, and allies who make this organization not just possible, but powerful.

This past year has been one of remarkable momentum, and I am honored to share it with you.



Kirk Smith **LIVE!**

Kirk Smith
Patient & President

We know that people living with ALK-positive cancer — and their loved ones — are counting on us. With stakes this high, we made a commitment: be bold with our capital, move quickly, and say yes to the best science. . . . and that is what we are doing.

We launched the ALK Positive Scientific Advisory Board, bringing world-class researchers and oncologists together to guide our most critical investments. And we are thrilled that Dr. Ken Culver has stepped into a dual role as Executive Director and Medical Director — a physician-scientist with deep expertise in oncology, drug development, and nonprofit leadership whose empathy, integrity, and dedication to patient-centered research make him the ideal person to lead us forward.

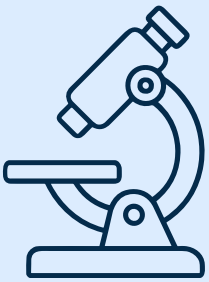
Our aggressive research agenda is shaped by the people who know ALK-positive best: all of you — the patients, care partners, and families whose urgency sharpens our priorities. Goal #1 of our Strategic Plan is clear: drive research to a cure for ALK+ cancer. That means funding discovery research, identifying and prioritizing new therapies, expanding clinical trial access, and leveraging our Scientific Advisory Board to make the smartest possible bets.

Since our founding in 2017, ALK Positive has grown into one of the most impactful patient-led research organizations in oncology — funding more than $10 million in scientific grants and clinical trials and partnering with leading investigators worldwide. Today, we are visible at ASCO, ESMO, TTLC and every major scientific meeting related to lung cancer.

The science is advancing. The community is growing. And our commitment to a cure has never been stronger. **LIVE!**

Highlights at a Glance

Research & Science



$10.8 M

Invested in Research

Funding studies that expand treatment options and accelerate new therapies since 2017

24 **Research Grants Awarded**

Supporting high-impact discoveries with real-world patient benefit

Second Opinions

29

Patients

Connected with world-renowned ALK specialists across 7 countries

24

ALK-Experienced Second Opinion Providers

Giving patients clarity, confidence, and options

Rolling Collaborative Relationships

33 **biotech & pharma**
advancing research, education, and access

26 **academic & research institutions**
driving ALK-specific research

19 **foundations and networks**
working together to advance clinical trials

Community Engagement

200+

Patient Education Programs

Empowering patients to make informed treatment decisions

450

2025 ALK+ Summit Attendees joining in San Diego, CA

55+

Countries Represented

18

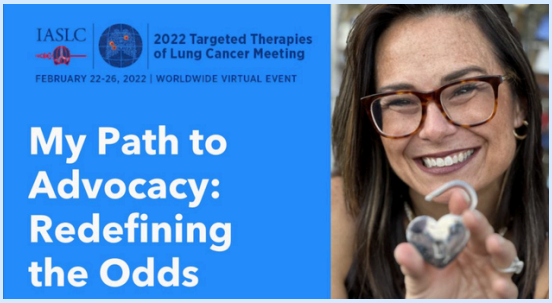
Peer Support Programs

Improving quality of life through connection, guidance, and support

Advancing Research through Collaboration & Advocacy around the World

In 2025, ALK Positive leadership engaged at leading oncology meetings across the United States and internationally, ensuring ALK-positive cancer remained part of high-level scientific dialogue. Through these engagements, we strengthened collaboration with researchers, advocates, and industry partners. Each moment reflects our commitment to moving progress from discovery research to patient impact.

- **IASLC Targeted Therapies of Lung Cancer (TTLC)**: At TTLC, ALK Positive was represented not only through attendance, but through leadership. Summer Farmen delivered a world-class presentation, bringing the patient perspective into a scientific forum focused on targeted therapy in lung cancer research.





- **ASCO Annual Meeting:** ALK Positive leaders attended the American Society of Clinical Oncology Annual Meeting, engaging with researchers, advocates, and industry partners. The team also hosted the organization's annual Scientific Advisory Board meeting during ASCO, bringing leading physician-scientists together in person to review research priorities, discuss emerging science, and guide future investment decisions.

- **World Conference on Lung Cancer (WCLC)**: ALK Positive joined the global lung cancer community at the IASLC World Conference on Lung Cancer in Barcelona. This international presence strengthened relationships with investigators, advocates, and industry partners from around the world and ensured that ALK-positive research priorities were represented on a global stage.



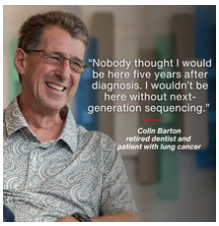
Stronger Together

Patient voice shaped our work in 2025. ALK Positive intentionally connected patients, care partners, researchers, and supporters through community events and industry engagement alike. By creating space for those affected to share their stories and advocate on behalf of ALK Positive, lived experience remained central in every conversation — strengthening collaboration and accelerating research progress.

Partner Engagement and Advocacy



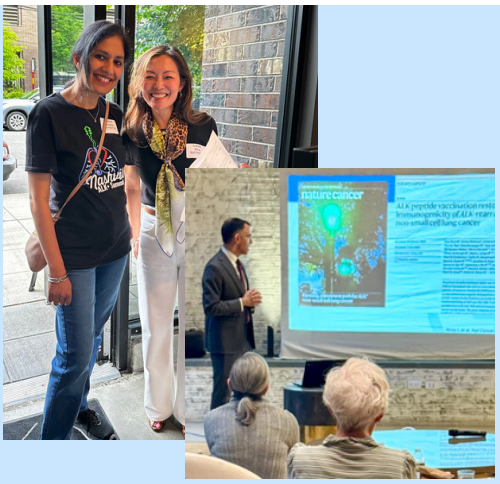
- **Nuvalent Community Event, Boston:** Kirk Smith joined other volunteers and patient advocates in Boston for a Nuvalent-hosted event, strengthening relationships and ensuring patient perspectives remained central to ongoing collaboration.



- **Thermo Fisher Scientific Feature:** Colin Barton shared his experience with next-generation sequencing in an exclusive Thermo Fisher interview, demonstrating how precision medicine transformed his care. His advocacy continues to amplify the patient voice and advance ALK Positive's mission.



- **Lung Cancer Diagnostic Webinar:** Michael Hu shared his personal journey and practical guidance during a national lung cancer webinar, helping patients navigate the uncertainty of diagnosis and next steps. Through education and advocacy, he continues to elevate the patient voice and support informed decision-making within the broader lung cancer community.



In 2025, ALK Positive piloted two in-person Community Builder events in New York and Seattle, welcoming more than 30 patients and care partners at each gathering. The events also brought together local thoracic oncologists, including Dr. Christina Baik of Fred Hutchinson Cancer Center and Dr. Mark Awad of Memorial Sloan Kettering Cancer Center, who shared the latest research and connected directly with the community.

These gatherings created space for education, dialogue, and meaningful connection—**demonstrating how patients, support networks, and clinical leaders together advance research and accelerate progress.**



Building the Infrastructure for Advancing Science

ALK Positive's research strategy is grounded in structure, accountability, and patient-driven leadership. Our Medical Committees exist to motivate, facilitate, and enable the development of novel therapeutics and diagnostics that benefit ALK-positive cancer patients.

Composed of patients and care partners, many with extensive scientific and professional expertise, these committees meet regularly to identify collaboration opportunities, engage priority partners, maximize the value of patient data, and share learnings across the scientific community. Working alongside leading physician-scientists, they ensure that the research we support is strategic, rigorous, and aligned with patient need.

Medical Committees

RAC — Identifies promising therapies for ALK+ and advocates to biotech, pharma, and academia to invest in our future.

CTC — Ensures ALK+ patients aren't left behind—identifying trial options and pushing for inclusion of ALK patients in cutting edge trials.

TIG — Maps the genes driving ALK+ cancer—and matches them to therapies in development—so we can identify partner companies to bring new treatments to life.

Scientific Advisory Board

In 2025, ALK Positive established its Scientific Advisory Board (SAB), a major milestone in the organization's evolution.

The SAB is composed of internationally recognized physician-scientists from leading cancer centers who guide research priorities, evaluate opportunities, and help shape long-term strategy.

The formation of the SAB strengthened scientific rigor, reinforced accountability, and ensured that research investments are informed by expertise and patient need.



Dr. Mark Awad
Memorial Sloan Kettering Cancer Ctr, New York, NY

Dr. Ross Camidge
University of Colorado Anschutz Medical Campus, Denver, CO

Dr. David Carbone
Ohio State University Comprehensive Cancer Ctr, Columbus, OH

Dr. Shirish Gadgeel
Henry Ford Medical Center, Detroit, MI

Dr. John Heymach
MD Anderson Cancer Ctr, Houston, TX

Dr. Vincent Lam
Johns Hopkins Kimmel Cancer Center, Baltimore, MD

Dr. Jessica Lin
Massachusetts General Hospital, Boston, MA

Dr. Christine Lovly
City of Hope

Dr. Ignatius Ou
UC Irvine Cancer Center, Irvine, CA

Dr. Angel Qin
University of Michigan - Rogel Cancer Ctr, Ann Arbor, MI

Dr. Alice Shaw
Dana Farber Cancer Institute, Boston, MA

Dr. Alex Spira
Virginia Cancer Specialists, Fairfax, VA

Together, these committees move discoveries from the lab to patients more quickly.

Better Treatment Pipelines

What we're targeting:

Targeting Resistance and Disease Progression
Several ongoing projects focus on understanding why resistance develops and how it can be prevented or delayed. By studying tumor biology, signaling pathways, and treatment escape mechanisms, these efforts aim to inform next-generation therapies and improved sequencing of existing treatments.

Resistance remains one of the biggest challenges in long-term disease control. These projects will help translate today's progress into tomorrow's durability.

Minimal Residual Disease (MRD) and Earlier Intervention
ALK Positive continues to support research exploring the basis of MRD with Break *Through* Cancer. These initiatives seek to move treatment decisions earlier in the disease course, before clinical progression occurs.

Therapeutic intervention in MRD has the potential to destroy drug-tolerant persister cells, a critical step along the path to a cure.

Translational Research: From Lab to Clinic
Our funded portfolio includes translational studies designed to bridge laboratory discovery with real-world clinical application. These projects emphasize:

- Defining target genes expressed in cancers that are TKI resistant
- Advocating with companies for ALK+ patient trials, based on target genes expressed in ALK+ tumors.
- Improving Clinical Trials by enrolling patients based on specific driver genes, instead of lumping multiple oncogenic driver cancers together.

ALK Positive is working to shorten the time between scientific insight and patient impact—so that discoveries don't stall before reaching those who need them.

11 **Completed ALK-funded Labratory Research Projects**

7 **Ongoing ALK-funded Labratory Research Projects**

8 **Companies starting ALK-inclusive clinical trials, influenced by the work of our Medical Committees**

Patient Advocacy Success Story

How a shared insight became an international clinical trial

This clinical trial did not begin in a laboratory or a boardroom. **It began with patients.**

A published research paper showed that gilteritinib could be active against ALK TKI–resistant cancer cells. Members of the ALK Positive community recognized its potential and shared it with our Medical Committee.

From there, ALK Positive stepped in to do what patients and clinicians cannot do alone.

We collaborated with scientific leaders, facilitated dialogue between investigators and industry, and helped move the concept from promising data to a viable clinical research study at the University of Michigan.

Through persistent advocacy and the data at University of Michigan, these early insights evolved into an Astellas-sponsored multi-site, international clinical trial.

This is what happens when patients are not only participants in research, but catalysts for it.



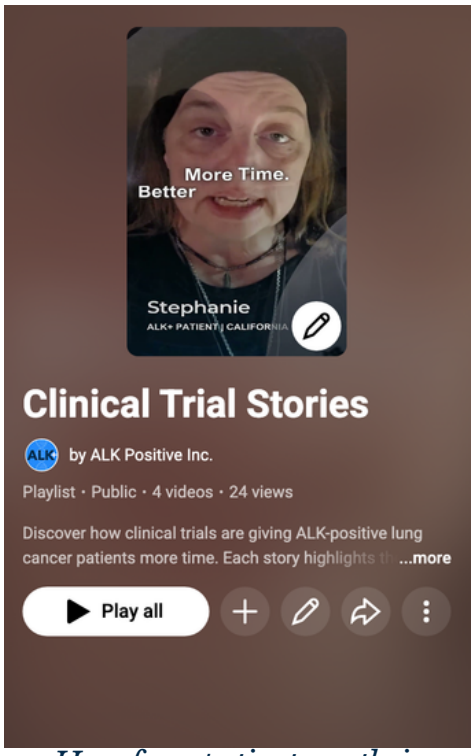
Clinical Trial Advocacy

Advancing Access Through Clinical Trials

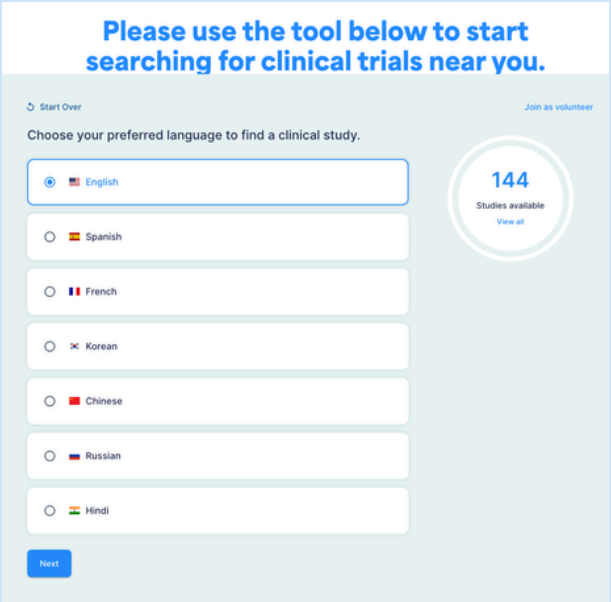
Clinical trials are a critical part of improving outcomes for people living with ALK-positive cancer.

In 2025, ALK Positive Inc. continued to advance ALK-inclusive trials by advocating for trial development, supporting pre-clinical research, and helping patients identify opportunities that may be right for them.

These efforts ensure that promising science does not stop at discovery—but reaches patients who need new options.



Hear from patients on their clinical trial story on our YouTube channel.



In 2025, we launched the ***ALK Positive Clinical Trial Finder***, a new clinical trial matching tool on our website designed to help patients and care partners:

- Search for ALK-inclusive clinical trials
- Filter by treatment history, location, and eligibility
- Identify potential options more efficiently

By reducing barriers to access, the ALK Positive Clinical Trial Finder empowers patients to explore clinical trials with greater confidence and clarity.

Investing in a Better Future for ALK-positive Patients



AACR–ALK Positive Lung Cancer Research Fellowship

In partnership with the American Association for Cancer Research, ALK Positive funded the first AACR–ALK Positive Lung Cancer Research Fellowship, a two-year award supporting early-career investigators focused on ALK-positive lung cancer.

The inaugural fellowship was awarded to Dr. Alice Tzeng, whose research examines epigenetic drivers of resistance to targeted therapy.



Expanding Education for People Living With Advanced ALK+ Lung Cancer

In partnership with Pfizer, ALK Positive helped prepare a global Request for Proposals (RFP) to support independent medical education projects for people living with advanced ALK-positive non-small cell lung cancer (NSCLC).

This grant will fund multiple innovative, patient-focused educational initiatives that help individuals and care partners prepare for ALK inhibitor therapy, recognize side effects early, and access clear, inclusive resources that support informed decision-making and quality of life. Together, ALK Positive and Pfizer are investing in education as a critical tool for empowerment—ensuring patients have the knowledge and confidence they need as treatment options continue to evolve.

Patient Education & Connection

ALKtALK: Where Science Meets Community

In response to a need for deeper dialogue and real-time learning, patient advocate Marc Rosenzweig created ALKtALK — a live Zoom forum designed to bring patients and leading experts together in meaningful conversation.

Before ALKtALKs began (expert Zoom seminars), connection in the ALK-positive community primarily lived in chat threads and Facebook groups.

What began as a grassroots effort to connect has grown into the flagship education program of ALK Positive Inc.

2025 ALKtALK Speakers & Topics

Alice Shaw, MD, PhD
Chief of Strategic Partnerships | Dana-Farber Cancer Institute
Session Topic: All things ALK+

Ryohei Katayama, PhD
Chief, Experimental Chemotherapy | Cancer Chemotherapy Center, Japanese Foundation for Cancer Research
Session Topic: Targeted Therapy Resistance

Catherine J. Wu, MD
Chief, Division of Stem Cell Transplantation and Cellular Therapies; Professor of Medicine, Harvard Medical School | Dana-Farber Cancer Institute
Session Topic: Role of Cellular Therapy & Vaccines in ALK-positive cancer

Laura A. Petrillo, MD
Palliative Care Physician-Investigator | Massachusetts General Hospital
Session Topic: Palliative Care for ALK-positive cancer patients

Shirish Gadgeel, MD
Division Chief, Hematology and Oncology; Associate Director, Henry Ford Cancer| Henry Ford Health
Session Topic: Role of Chemotherapy for ALK-positive patients

Sophia Gilardone, PharmD, BCOP & Corrine Stahura, PharmD, BCOP
Clinical Oncology Pharmacy Specialist | University of Pennsylvania
Session Topic: Managing Meds & More: The Pharmacist's Role in ALK+ Cancer

Jesse Boehm, PhD
Chief Science Officer | Break *Through* Cancer
Session Topic: Break *Through* Cancer Update live from ASCO

Stephen V. Liu, MD
Director of Thoracic Oncology; Head of Developmental Therapeutics; Associate Professor of Medicine | Georgetown University Lombardi Comprehensive Cancer Center
Session Topic: Managing Metastasis

Christine Lovly, MD, Ph.D., F.A.S.C.O.
Associate Professor of Medicine, Division of Hematology and Oncology; Ingram Associate Professor of Cancer Research | Vanderbilt University Medical Center / Vanderbilt-Ingram Cancer Center
Session Topic: Cancer Updates, Advice & Hope

Marc Muskavitch, PhD
Patient & Board Member | ALK Positive Inc.
Session Topic: Medical Committee Update

Angel Qin, MD
Medical Oncologist / Clinical Associate Professor of Internal Medicine | University of Michigan / Rogel Cancer Center
Session Topic: Role of Gilteritinib for ALK-positive Patients

D. Ross Camidge, MD, PhD
Professor of Medicine; Joyce Zeff Chair in Lung Cancer Research; Director, Thoracic Oncology Clinical and Clinical Research Programs | University of Colorado Anschutz Medical Campus / University of Colorado Cancer Center
Session Topic: Living on Both Sides of Lung Cancer

Karen Schurgin,
Palliative Care Physician-Investigator | University of Pennsylvania
Session Topic: Your Holiday ToolKit: Managing Balance, Boundaries and Expectations.

Jesse Boehm, PhD
Chief Science Officer | Break *Through* Cancer
Session Topic: What's next for the PoweRD 2 Cure ALK+ Lung Cancer TeamLab

2025 ALKtALK Participation & Reach

Average attendance: ~100 participants per session
Total participation in 2025: 1,000+ live attendees
Global reach: Patients and care partners across multiple countries
Format: Live, moderated educational forums with interactive Q&A
Enduring materials on website, thousands of views

The Healing Arts

Our Healing Arts programs continue to expand—creating space for connection, creativity, and learning across the entire ALK-positive community. This year, The Healing Arts introduced multilingual chats welcoming those from around the world.

2025 Highlights

150+ Avg. Attendees throughout 2025 & over 143,000 ALKtALK views

16 Healing Arts Programs with a variety of times to encourage participation across time zones

Healing Arts Programs

ALK Chat
A welcoming virtual space for patients and care partners to connect, share, and feel heard.
Art Therapy
Creative expression to manage stress, build coping skills, and foster community.
Book Club
Connection through reading, conversation, and shared understanding beyond cancer.
Care Partner Check-In
Support, resources, and breathing room for those caring for someone with ALK-positive cancer.
Chair Yoga
Gentle movement to improve strength and mobility.
Coffee Talk
An informal, come-as-you-are conversation about life with ALK-positive cancer.
Death Café
Open, meaningful conversations about death, dying, and living fully.
Explore with Writing
Guided writing to process emotions and navigate challenging experiences.
Guided Imagery
Relaxation and visualization to support emotional and physical well-being.
Men's Group
A supportive space for men with ALK-positive cancer to connect and share openly.
Mindset Reset
Reframing life with cancer from surviving to thriving through guided mindset work.
New ALKies
Connection and support for newly diagnosed patients and their care partners.
Single ALKies
Community and friendship for single ALKies navigating life and relationships.
Yoga
Breath-centered movement to support presence, balance, and overall well-being.
Young ALKies
Peer connection and support for ALK-positive individuals age 50 and under.
Multilingual Chat
A welcoming, multilingual support space to share experiences, ask questions, and connect in Spanish, English, or both without language barriers.

> Healing Arts gave me friends, support, and a place to make really big decisions. Invaluable.
>
> -Suzanne Remington, Patient



Check out our calendar and join us today!

Second Opinion Program

Expert guidance. Reduced burden. Confident decisions.

Removing financial and geographic barriers so ALK-positive patients can access expert care when it matters most.

Second Opinions Given since launch	ALK-Expert Oncologists Participating	Participating States in US
175	26	13

What Is the Second Opinion Program?

The ALK Positive Second Opinion Program (SOP) helps cover the cost of expert second opinion consultations for ALK-positive patients who may otherwise be unable to afford them.

By supporting access to oncologists with expertise in ALK-positive cancer, the program empowers patients and care partners to make informed decisions during pivotal moments in their care.

Approved consultations are paid directly to the treatment center, easing financial stress while preserving patient choice.



Why This Program Matters

- Expert ALK-specific insight can change treatment direction
- Second opinions provide clarity during moments of uncertainty
- Financial barriers should never limit access to specialized care
- Virtual consults reduce travel burden
- Patients gain confidence, reassurance, and agency

> Getting a second opinion gave me a new lease on life and reasons to start looking forward to tomorrow's adventures!

ALK+ SUMMIT

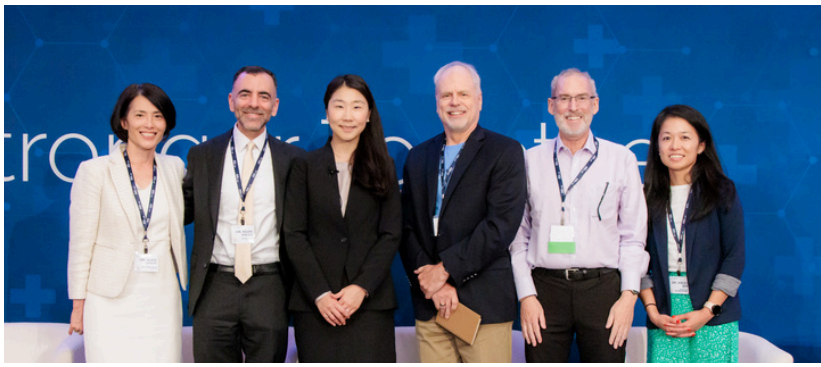
2025 | San Diego JULY 18-20TH

ALK+ Summit: Where Science, Community & Hope Come Together

The 2025 ALK+ Summit in San Diego was more than a conference. The Summit created space for patients, care partners, researchers, clinicians, and advocates to come together to learn, connect, and move research forward. Beyond the science, this weekend fostered connection in ways that are difficult to replicate elsewhere. Early morning walks, mindfulness sessions, science and medical presentations, and informal moments shared over meals, music, and laughter reminded attendees that they are not alone. For many participants, this was the first time they met another person living with ALK-positive cancer, building confidence, reducing isolation, and reinforcing a shared commitment to moving forward together.







★ ★ ★ ★ ★ Rating from post-Summit survey

14 ALK+ Experts

1,222 450 In-Person Participants
772 Virtual Participants
Total Attendees

This year's event featured a keynote presentation, expert-led panels, breakout sessions, and opportunities for direct dialogue between patients and the leaders shaping ALK-positive research.

Highlights included:

- A keynote address by Dr. Jessica Lin of Massachusetts General Hospital, a member of the ALK Positive Scientific Advisory Board, who opened the Summit with a clear and compassionate overview of current ALK-positive treatment options and emerging research
- Multiple Key Opinion Leader panels led by Dr. Ken Culver, translating complex science into accessible, actionable insight
- Medical Committee panels offering transparency into how research priorities are evaluated and advanced
- Patient and care partner panels that created space for honest conversations, including discussions on navigating difficult topics and living fully with uncertainty

Research in Action: Blood Draw Initiative

A cornerstone of the 2025 Summit was the continued partnership with the **University of Michigan Judith Tam ALK Lung Cancer Research Initiative**. Through the generosity and commitment of the community, 152 blood samples were collected from patients and care partners during the Summit.

These samples are already contributing to research focused on understanding how ALK-positive cancer develops, why resistance to treatment occurs, and how earlier detection and more effective interventions may be possible in the future. By participating, Summit attendees directly accelerated discovery and helped shape the future of care.

Funding is Fueling Progress

In 2025, ALK Positive fundraising reflected the strength, creativity, and determination of the community. **Together, patients, families, partners, and supporters raised $3.5 million**, fueling research, patient programs, scientific leadership, and long-term sustainability.

#POWEREDBYPATIENTS

ALK-positive Awareness Month- June

Powered by Patients highlighted the strength of the ALK-positive community coming together to learn, educate, and lead.

During ALK Positive Awareness Month, patients and care partners shared their stories, raised awareness, and mobilized their networks to support research and patient programs.
The campaign demonstrated a core truth of the community: **progress doesn't happen to us. It happens because of us.**



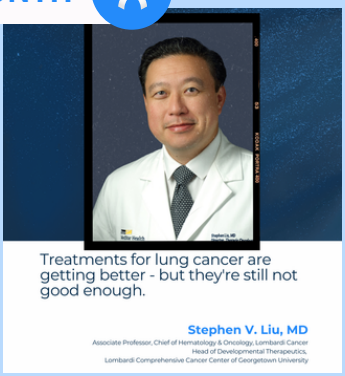
LUNG CANCER AWARENESS MONTH

Lung Cancer Awareness Month
More Research = More Time
In November, in honor of Lung Cancer Awareness Month, we launched More Research = More Time, a patient-centered Lung Cancer Awareness Month campaign that delivered unprecedented results.

In just one month, the community raised over $1.3 million, the largest amount we have ever raised in a single month. The campaign highlighted how research translates into more options, more time, and more hope for families facing ALK-positive cancer.

- $1.3M+ raised in one month
- 47 peer-to-peer fundraisers participated
- Record-breaking engagement across patient and collaborator networks

The success of this campaign underscored what is possible when urgency, storytelling, and community come together.



26 ALK Experts in ALK-positive research and care also participated, sharing what research means to them.





Dave Jasso Foundation

Hosts BBQ Fundraiser raising over $8,500!



Erin Harris- *One Positive ALKie*

Hosted their 3rd annual golf tournament and raised **$50,000** for ALK Positive!

HISTORY

2015 | A Patient Community Begins

Merita Carroll, a stage IV ALK-positive patient and oncology nurse, launches a private online support group to connect ALK-positive patients and care partners worldwide.

2017 | ALK Positive Is Founded

ALK Positive Inc. is established as a patient-led organization dedicated to improving life expectancy and quality of life for people living with ALK-positive cancer.

2018 | First Patient-Funded Research Awards

$600,000 awarded in ALK-positive research grants in partnership with LUNGevity—marking the first time patients directly funded research targeting their own disease.

2019 | Research & Community Expansion

- $500,000 grant awarded in partnership with GO2 Foundation
- Second Annual ALK Summit held in Atlanta, welcoming 200+ patients and advocates

2020 | From Research to Clinical Trials

- $1.6 million in grants awarded in collaboration with LUNGevity Foundation
- First ALK Positive–funded clinical trials launched at the University of Michigan
- Total research funding surpasses $2 million

2021 | Formal Nonprofit & Global Access

- ALK Positive receives 501(c)(3) status (EIN- 85-2221062)
- “Stronger Together” Virtual Summit reaches patients worldwide

2022 | Scale & Scientific Momentum

- Largest ALK Summit to date (Denver: 250 in-person, 850 virtual)
- $500,000 for research grants in partnership with LCRF
- $2 million awarded through ALK Positive–LUNGevity Research Program

2023 | Awareness & Global Strategy

- Launch of ALK-positive Awareness Month

2024 | Cure-Focused MRD Research Partnership

- ALK Positive commits $2 million to Break Through Cancer, becoming its first funding partner for their TeamLab focused on minimal residual disease and curative strategies.
- $600,000 invested in research grants

2025 | Scientific Leadership & Pipeline Growth

- Scientific Advisory Board established
- $1.6 million invested in research grants
- Global Pfizer education RFP announced to improve patient support

Today

Patient-Driven. Globally Connected. Future-Focused.

ALK Positive supports a worldwide community across 55+ countries and continues to accelerate research, education, and advocacy toward cures.

We couldn't have done it without your generous support.

Thank you

to all our donors and volunteers.

We could not do this work without you. To our patients, care partners, volunteers, donors, researchers, and partners, thank you for fueling progress, connection, and hope.

Together, we are building what comes next.

Executive Director and Medical Director
Ken Culver, MD

Philanthropy Operations Manager
Katie Delaney

Medical Team Project Manager
Sadia Yaakov

Board of Directors
Kirk Smith, President
Summer Farmen, Vice President
Christina Weber, Secretary
John O'Sullivan, Treasurer
Teresa Wiant, Legal Chair
Nancee Pronsati, Patient
Amanda Bialack-Stewart, Patient
Duncan Preece, Patient
Greg Wehn, Patient
Jeff Sturm, Patient
Marc Muskavitch, Patient
Yvonne Diaz, Patient

Medical Committees
Colin Barton, Patient & Co-Founder
Duncan Preece, Patient
Ellee Urban, Patient
Emily Venanzi, Patient
Eric Neils, Care Partner
Eva Gefroh, Care Partner
Hannah Le, Volunteer
Irfan Gilani, Patient
Jeff Sturm, Patient
JP Noonan, Patient
Julie Silberger, Patient
Karla Castro-Frenzel, Patient
Karthik Bala, Patient
Kirk Smith, President
Marc Muskavitch, Patient
Michael Hu, Patient
Michelle Hendrick, Patient
Nancee Pronsati, Patient
Ray Hall, Care Partner
Stian Andre Agnes, Patient
Summer Farmen, Vice President
Yvonne Diaz, Patient

Second Opinion Program
Colin Barton, Patient
Debbi Martinez, Patient
Nancee Pronsati, Patient

Finance
John O'Sullivan, Treasurer
Nancee Pronsati, Patient
Debbi Martinez, Patient
Ken Schlosser, Patient
Ed Wortzman, Accountant
Dave Arenberg, Bookkeeper

ALKtALK & The Healing Arts
Marc Rosenzweig, Founder & Host
Summer Farmen, Co-Host
Dana Querido, Healing Arts Coordinator
Dan Wilson, Mens Group
David Cornbrooks, Exploring with Writing Host
Eva La Mar, New ALKies & Coffee Talk
Hanka Mosher, Yoga
Heather Meyer, Mindset Reset
Leslie Blaut, LMD Support Chat
Meghan Prose, Care Partner Check-In
Nikki Hirsch, Single ALKies
Pam Brazas, Explore with Writing
Ruby Blow, Roundtable
Sara C. Jacome, Multilingual Chat
Sonia Khan, Roundtable
Suzanne Remington, Book Club
Tina Adler, Explore with Writing
Jessica Little, Death Cafe
Trish Mullen, Non-Metastatic ALKies
Lia Ridout, Non-Metastatic ALKies
Stephanie Williams, Non-Metastatic ALKies
Jeff Sturm, Clinical Trials Connect
Amanda Bialack-Stewart, Young ALKies
Pam Hardy, New ALKies

Marketing
Yvonne Diaz, Patient
Summer Farmen, Patient
Ronni Reich, Volunteer
Heather Meyer, Patient
Colin Barton, Patient
Kim Schlosser, Volunteer
Christina Weber, Newsletter
Kirk Smith, Newsletter
Juli Chocheles, Newsletter
Jeff Sturm, Newsletter
Ellee Urban, Newsletter

Fundraising
Kirk Smith, President
Summer Farmen, Vice President
Nancee Pronsati, Patient
Colin Barton, Patient
Amanda Bialack-Stewart, Patient
Debbi Martinez, Patient
Noah Weber, Care Partner
Ronni Reich, Volunteer
Stephanie Kenney, Patient

Summit
All About Events, Coordination
Amanda Bialack-Stewart, Patient
Juli Chocheles, Patient
Kirk Smith, President
Marc Muskavitch, Patient
Nancee Pronsati, Patient
Summer Farmen, Vice President
Yvonne Diaz, Patient

2025 Financial Overview

In 2025, 92% of our expenses directly supported programs advancing research, support, and progress for the ALK-positive community.

$3.87M	$2.69M	$1.57M
Total Revenue	Program Services	Research Grants

How funds were used



Program services $2,687,933		92%
Management & general $183,244		6.3%
Fundraising $49,973		1.7%

Where revenue came from

Contributions & grants	$3,665,541
Investment income, net	$169,153
Program & other revenue	$34,843

Year-end financial position

Total assets	Total liabilities	Net assets
$6,855,964	$383,012	$6,472,952

Our full 2025 audited financial statements are available online. Scan the QR code to review them.

Financial figures shown are based on ALK Positive Inc.'s 2025 Audited Financial Statements.

alkpositive.org