

A YEAR IN
REVIEW

ANNUAL REPORT



Our Mission:

We are dedicated to improving the lives of patients, caregivers, and families affected by ALK-positive cancer, while working towards a future where this disease is curable. We are committed to providing accurate information, fostering a supportive and inclusive community, and advocating for progress in research and treatment through education, awareness and collaboration.

Our Vision:

A future where ALK-positive cancer no longer exists.



A MESSAGE FROM THE PRESIDENT

As this is the very first annual report from ALK Positive Canada, welcome—and thank you for being here. I'd like to take a moment to share how our organization came to be, and why we exist to support Canadian ALK patients and caregivers who so generously volunteer their time.

The idea for this organization began in early 2024. At the time—and continuing today, since 2020—I was serving on the Board of Directors of ALK Positive Inc. in the United States, and as an active member of its medical committee. Over time, I found myself asking a simple question: why were so few Canadians involved in what is arguably the most significant ALK-focused organization outside of China?

That question led to a deeper realization—Canada lacked a national organization dedicated to ALK-positive patients, one that reflects the unique realities of our healthcare system, including provincial differences in access to care, and the absence of a unified voice connecting patients, caregivers, and healthcare professionals, particularly thoracic oncologists. As a former healthcare professional myself, this gap was difficult to reconcile.

In May 2024, after reaching out to ALK patients across the country, I brought together approximately 30 patients and caregivers for an initial video call. The response was strong, and from that group, eight individuals stepped forward to help build what would become this organization.

From the outset, a key priority was ensuring the long-term sustainability of this effort. We made the decision to pursue federal incorporation as a non-profit. Following extensive discussions and coordination with Corporations Canada, ALK Positive Canada was formally incorporated in February 2025.

Today, our Board consists of 10 directors, which I have the honour to chair and contribute in meaningful ways across a range of initiatives, forming a committed and collaborative team.

We look forward to continuing to grow our network of patients and caregivers across Canada in the months and years ahead.

Duncan Preece



GREETINGS FROM THE BOARD

2025 was a pivotal year for ALK Positive Canada (APC). We strengthened our governance as a newly established Canadian non-profit organization, expanded our national advocacy efforts, and deepened our partnerships with patients, clinicians, researchers, and industry partners across the country.

What continues to drive our work is the community behind it. APC was built by and for people affected by ALK-positive cancer, and every initiative we undertake is grounded in the shared goal of improving outcomes and quality of life for Canadians



living with this disease. Through education, advocacy, and peer support, we are working to ensure that no one faces an ALK-positive diagnosis alone.

This report highlights key achievements from 2025 and early 2026—milestones made possible through the dedication of volunteers, supporters, and partners who believe in this mission.

Thank you for being part of this community. APC exists because of you, and together we will continue to move this work forward.

Warm regards,

ALK Positive Canada

WHO ARE WE

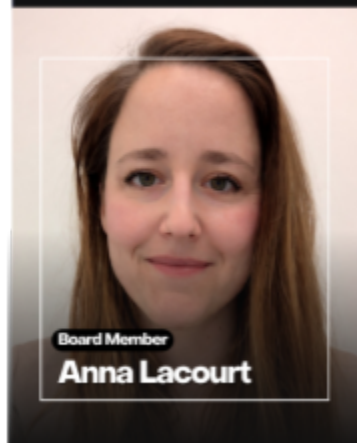
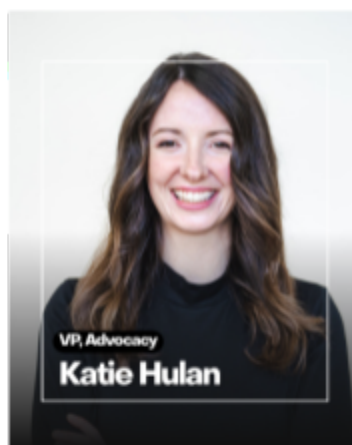
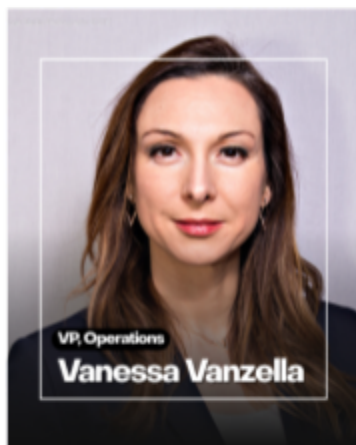
ALK Positive Canada Inc. (APC) is a registered not-for-profit organization. We are a Canadian-based, Canadian-focused, patient-led, volunteer-driven organization dedicated to helping find a cure for ALK-positive cancer and improving the life expectancy and quality of life of ALK-positive patients nationwide.

Our work is grounded in the four pillars of CARE:

- **Community**
Connecting Canadians facing ALK-positive cancer, so everyone is supported.
- **Advocacy**
Promoting better access to treatments and improved patient experiences.
- **Research**
Supporting research efforts to improve treatment outcomes and move toward a cure.
- **Education**
Offering trusted resources, expert-led webinars, and up-to-date information.

Our Board and Committees include people with lived experience of ALK-positive lung cancer, caregivers, and allies from across Canada who contribute expertise in advocacy, clinical care, research, communications, and operations.

BOARD OF DIRECTORS



2025 HIGHLIGHTS



WEBINAR WITH DR. LIU

APC delivered its first grant-funded webinar, "Understanding and Managing Side Effects with Dr. Geoffrey Liu".

- 44 total registrants and 29 live attendees
- 100% of survey respondents rated the session excellent
- The webinar continues to be available as an on-demand educational resource.

PFIZER CANADA MEETING

APC met at Pfizer's National Meeting to share patient perspectives on lorlatinib access, TKI side effects, and the realities of navigating care.



COMMUNITY MEET-UPS

APC launched community meetups, creating a dedicated space for people living with ALK-positive lung cancer and their caregivers to connect, share experiences, and ask questions. From Montreal, Toronto, Ottawa and Calgary, these meetups brought together our community in a meaningful way.

Advocacy for Drug Access: Lorlatinib Campaign

In 2025, advocacy for equitable access to lorlatinib remained a central priority.

Lorlatinib Campaign:

1. APC led a sustained campaign urging the Ontario government to fund lorlatinib. Key activities included:
 - Outreach to Premier Doug Ford, Health Minister Sylvia Jones and Members of Provincial Parliament
 - Coordinated phone-call campaigns targeting government offices
 - Engagement with opposition health critics and parliamentary assistants

Board members and volunteers helped mobilize the community to raise awareness about access barriers facing Canadians living with ALK-positive lung cancer.

Canada House of Commons Petition:

APC worked with Members of Parliament to advance both physical and electronic petitions calling for improved access to lorlatinib. By year-end:

- Petition was developed in collaboration with MPs Adam Chambers and Peter Schiefke.
- Community members helped gather signatures across Canada.

These efforts laid the groundwork for a broader, pan-Canadian advocacy campaign that carried into 2026.

Patient Voice in National Policy: CDA Feedback

APC played an active role in national discussions about how patient input is integrated into drug reimbursement decisions.

In 2025, APC submitted feedback to Canada's Drug Agency (CDA) on its patient engagement processes in drug reimbursement reviews.

The agency presented feedback including:

- Better information and resources for patient groups.
- Support to help patients contribute effectively.
- Simpler language and more diverse methods for gathering input.

APC's contribution ensured that the ALK-positive community was represented in this national conversation and helped influence more patient-centred approaches to reimbursement reviews.

Education & Support for Patients and Families

Education and patient storytelling were core strategies in 2025 as APC worked to empower patients and their families.

Blogs and Written Resources

APC invested in building a library of patient-focused resources:

- Blogs and side-effect management content were drafted, edited, and prepared for translation to ensure accessibility in both English and French.
- Planning began for a tyrosine kinase inhibitors (TKIs) overview page to help patients better understand their role, and therapy sequencing considerations.

APC also began developing a national patient education brochure designed for distribution through oncology clinics across Canada.

Storytelling & Media

Sharing the experiences of people living with ALK-positive lung cancer helps raise awareness and reduce isolation. In 2025:

- Patient stories featuring Craig Smith, Alexandra Chassé and Katie Hulan, appeared in Maclean's and L'Actualité magazine publications.
- APC collaborated with Lung Cancer Canada on a podcast featuring oncologist Dr. Cheryl Ho.

Building Visibility & Partnerships

In 2025, APC strengthened its presence and forged new partnerships across the cancer community.

ELIXR

Duncan Preece represented ALK Positive Canada at the 2025 Early-stage Lung cancer International eXpert Retreat in Montréal—an invitation-only forum convening leading global experts. Duncan's participation ensured the patient perspective was present in high-level discussions aimed at improving outcomes, strengthening international collaboration, and advancing more timely, effective care for those diagnosed earlier in their disease journey.

▶ Duncan Preece – A patient's perspective on what matters

Grant-Funded Education Initiative (RFP)

APC was awarded a [grant by Pfizer](#) to power a multi-year education initiative for people living with ALK-positive lung cancer in Canada.

- Deliverables included a website, webinars, blogs, brochures for oncology offices and translated resources.
- APC delivered its first RFP progress report on January 1, 2026, reflecting strong early execution on commitments.

Collaborations with Lung Cancer Canada (LCC)

APC worked closely with LCC on multiple fronts, including a podcast episode, connections to policy advocates, and joint reflections on treatment access and patient needs.

University Health Network (UHN) Collaboration

Through the Pride in Patient Engagement in Research (PiPER) partnership APC presented to a multidisciplinary research group on the importance of including people who have never smoked in lung cancer research and screening strategies.

Communications & Digital Infrastructure

Strengthening APC's communications infrastructure was a key enabler of impact in 2025.

Website and Events Page

APC designed and developed its first website in 2025, and continued to expand its website and online resources including the launch of a dedicated events page for webinars and community programming.

First Newsletter

In November, APC launched its first newsletter as part of Lung Cancer Awareness Month (LCAM).

- Distributed to 503 people in English and French.
- Achieved a 67% open rate.

Global Platform Visibility

APC expanded its reach across multiple platforms, sharing advocacy updates, patient stories, and educational content.

- Collaborative video posts with organizations such as Oncogene Cancer Research and Young Lung Cancer reached thousands of viewers internationally.
- Contributed a guest feature blog, "Introducing ALK Positive Canada," on the ALK Positive Inc. website, highlighting our founding story, pillars of CARE, and future vision.



Operational Capacity & Infrastructure

Governance

Governance work included updates to APC bylaws and board governance structures in preparation for formal filing in 2026, along with onboarding of new board members and expanded committee participation.

Charitable Status

APC continued advancing its application for Canada Revenue Agency (CRA) charitable status, with supporting documentation and governance materials prepared during 2025.

Systems & Infrastructure

Internal systems were strengthened through the implementation of collaborative digital tools to support project management, grant deliverables, and volunteer coordination.

Communications Infrastructure

The organization also continued developing communications infrastructure, including improvements to email outreach, social media planning, and content workflows to support growing engagement with the community.

These operational improvements help ensure APC can sustainably expand its advocacy, education, and patient support programs across Canada.

2026 HIGHLIGHTS



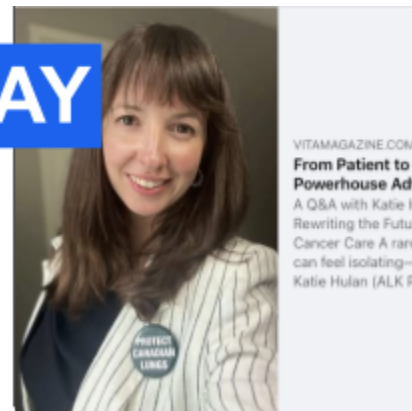
BETTER BREATHING WEEK

APC participated in BBW 2026, contributing lung cancer patient perspectives and advocacy priorities:

- A conference recap and a deep dive on lung cancer screening were developed to share learnings with our community.
- These materials highlight the importance of screening, especially for people who never smoked or have rare driver mutations like ALK.

WORLD CANCER DAY

- APC was highlighted in Pfizer's national awareness campaign.
- Katie Hulan participated in media interviews including **CP24** and **CityNews**.
- An in-depth article profiling APC's work also launched that day, helping raise awareness about ALK-positive lung cancer and patient advocacy.



TTLC EVENT

At the 2026 Targeted Therapies of Lung Cancer Meeting, researchers and clinicians shared the latest advances in precision treatments for lung cancer, including updated results showing strong long-term outcomes with first-line lorlatinib. Discussions also highlighted emerging research on resistance mechanisms, co-mutations, and new approaches such as targeted protein degradation. A key message from the meeting was the importance of balancing scientific progress with patient quality of life and lived experience.

Policy & Systems Change

APC co-led a major joint submission to the CDA on proposed reforms to the drug reimbursement review process, alongside partners including:

- Canadian Cancer Survivor Network (CCSN)
- Bladder Cancer Canada
- Canadian Chronic Myeloid Leukemia (CML) Network.

The submission supported modernization of the process while raising concerns about reduced transparency and the removal of public comment opportunities.

Coalition-Building & Campaigns

CanCertainty Coalition

APC joined the CanCertainty coalition, a national alliance of more than 30 organizations across Canada to advocate for fair and equitable access to cancer drugs.

Lorlatinib Campaign – Continued Momentum

Early 2026 saw continued momentum on both federal and provincial fronts:

- A Canada House of Commons petition in support of lorlatinib access surpassed 1,500 signatures in under three weeks, with more than two months remaining in the campaign.
- Partner organizations, including Right2Survive (R2S) and CCSN, committed to promoting the petition through their channels.
- APC pursued targeted strategies, including outreach to MPPs and coordination with local advocates and patient connections.

FINANCES

ALK Positive Canada

Income & Expenses

February 10, 2025 to December 31, 2025

(Unaudited)

	<u>2025</u>
INCOME	
Grant Income (note 2)	100,000.00
Donations (note 3)	1,650.00
Interest Income	0.04
Total Income	\$101,650.04
EXPENSES	
Subscriptions	103.48
Bank charges	16.00
Conference Fees	182.85
Travel Expenses (airfare, hotel, meals)	3,511.47
Total Expenses	\$3,813.80
Excess / Deficiency	\$97,836.24

ALK Positive Canada
Statement of Financial Position

As at December 31, 2025

(Unaudited)

	<u>2025</u>
ASSETS	
Current Assets	
Cash	\$101,530.56
Total Assets	\$101,530.56
LIABILITIES AND FUND BALANCES	
Current Liabilities	
Accounts payable and accrued liabilities	3,694.32
NET ASSETS	\$97,836.24
Total Liabilities and Fund Balances	\$101,530.56

ALK Positive Canada

Notes to Financial Statements

February 10, 2025 to December 31, 2025

(Unaudited)

- 1** ALK Positive Canada was incorporated on February 10, 2025 under the Canada Not-for-profit Corporations Act. The mission of the organization is to be dedicated to improving the lives of patients, caregivers and families affected by ALK-positive cancer, while working towards a future where the disease is curable. The Corporation is committed to providing accurate information, fostering a supportive and inclusive community, and advocating for progress in research and treatment through education, awareness and collaboration.
- 2** ALK Positive Canada was awarded a grant from Pfizer Canada on September 16, 2025 to build a national patient education initiative for Canadians diagnosed with ALK-positive metastatic non-small cell lung cancer (ALK+ mNSCLC). The program addresses gaps in patient understanding of treatment sequencing, side effect management, and communication with oncology teams—key contributors to early treatment discontinuation and poorer outcomes. This initiative empowers patients with evidence-based, Canadian-focused education and peer support mechanisms to improve treatment adherence and quality of life. Funding will be used exclusively for non-promotional, independent education activities in alignment with Pfizer's Independent Medical Education Grant guidelines. The project timeline is 18 months.
- 3** ALK Positive Canada has applied to the CRA to become a Registered Charity under the Income Tax Act and expects to be approved in April 2026 at which time the organization can begin raising funds for further activities to carry out its mission and issue charitable donation receipts to donors.

LOOKING AHEAD

Building on the foundation laid in 2025 and the strong start to 2026, APC is focused on:

- Advancing equitable access to lorlatinib, biomarker testing, and clinical trials across all provinces and territories.
- Expanding our library of bilingual, patient-centred educational resources, including TKI overviews, symptom management tools, and clinical navigation guides.
- Influencing national policy and reimbursement processes to ensure the ALK-positive community is meaningfully represented in decisions affecting access.
- Strengthening partnerships with research teams, advocacy coalitions, and industry, while maintaining our independence and patient-centered focus.
- Investing in organizational capacity, committee structures, and governance to sustain and grow APC's impact.
- Fostering opportunities for connection, peer support, and shared learning across the ALK-positive community.

We are deeply grateful to our volunteers, Board members, partners, clinicians, researchers, funders, and—most importantly—the people living with ALK-positive lung cancer and their families who trust APC with their stories, time, and energy. Your courage and collaboration drive everything we do.

Together, we will continue to push for earlier testing, better treatments, and fair access to life-extending therapies for all Canadians living with ALK-positive lung cancer.

CONTACT US

General Information: info@alkpositivecanada.org

Media Inquiries: media@alkpositivecanada.org

Governance and Ethics: compliance@alkpositivecanada.org

Donations can be made directly to ALK Positive Canada via e-transfers at: donations@alkpositivecanada.org. We are unable to offer tax receipts at the moment.

ALK POSITIVE CANADA

www.alkpositivecanada.org

Facebook: @alkpositivecanada Instagram: @alkpositivecanada

610 East River Road Suite 260 New Glasgow NS B2H 3S2