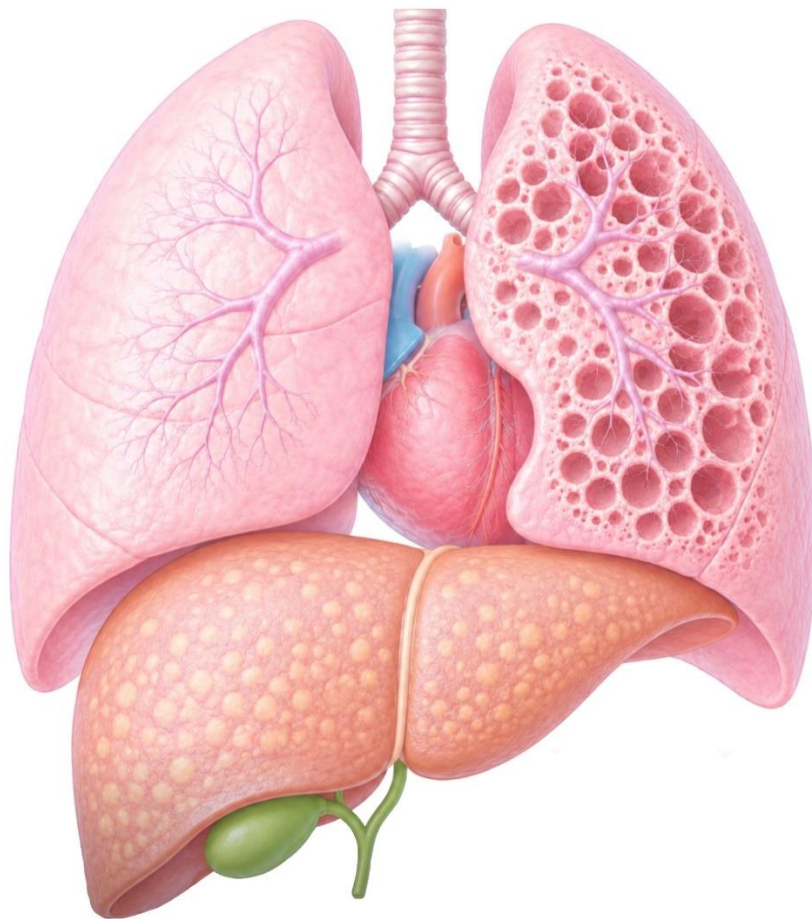


Annual Report 2026



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Together Making a Difference

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Message From the President



On behalf of the Board of Alpha-1 Organisation Australia inc, I am pleased to present our 2025-26 Annual Report

This annual report presents activities and achievements against our strategic plan during 2025-26. As the President of Alpha-1 Organisation Australia inc (A1OA) I am pleased to report that our mission and purpose remain strong. Our commitment to patients and the future health of everyone in Australia diagnosed with Alpha-1 Antitrypsin Deficiency (Alpha-1) remains unwavering. This commitment was reflected in various activities throughout the year including stakeholder collaborations, monthly patient peer support meetings, one-on-one patient support and advocating for and promoting Alpha-1 clinical trials, which will potentially lead to new treatments to improve quality and length of life.

A handwritten signature in black ink, appearing to read 'Gaynor'.

Gaynor Heading

President, Alpha-1 Organisation Australia Inc

We remain a national point of contact for new clinical trials for Alpha-1 in Australia and proactively promote such opportunities. Our commitment to new therapeutic opportunities has led to additional international consultations and contacts with new research groups wishing to bring their clinical trials to Australia.

Working with our volunteer Board members, who wear a number of hats, has allowed our small not-for-profit charity to remain focused on its strategic plan and to keep a national and international presence.

As detailed in this report we creatively used various means to promote Alpha-1 awareness within Australia and elsewhere, including Europe. I am forever thankful for the Board's support and commitment.

This year's member survey allowed us to remain focused and respond to patient's ideas. Our new

"Tips" series posted across our Alpha-1 social media channels is a direct reflection of highly-valued patient input.

We developed a Knowledge Hub on our website which goes hand in hand with our quarterly newsletter *Alpha Times* to provide timely information related to Alpha-1 including information on Alpha-1 clinical trials in Australia.

Thank you to everyone who contributed financially to our charity. This generosity has allowed us to remain on target producing and disseminating information and awareness about Alpha-1.

Raising awareness about Alpha-1 and treatment inequity still remains important, as does educating health professionals about Alpha-1.

We remain optimistic that a cure will be on offer soon following successful clinical trials which should lead to a brighter future.

About Alpha-1 Organisation Australia inc

Vision	Mission
To find a cure for Alpha-1 Antitrypsin Deficiency	To compassionately provide support and advocacy for Alpha-1 Australians and to promote education and research which will lead to a cure

A1OA is a not-for-profit charity registered with the *Australian Charities and Not-for-profits Commission* (ACNC). A1OA was registered in June 2020 to provide a supportive, proactive, accountable Australian charity for people diagnosed with Alpha-1 Antitrypsin Deficiency. The 2025-26 Board membership is presented below.

Governance – Our Board

Position	Holder	Board Member From
President / Public Officer	Gaynor Heading	June 2020
Vice-President	Gerri Simmons	August 2025
Treasurer	Jane Gordon	August 2025
Director Communications	Leonie Robison	June 2020
Director Grants Research / Secretary	Sandra Baxendell	June 2020
Director Marketing & Fundraising	Mark Lloyd	October 2021

A1OA is the first point-of-call for Australian patients with Alpha-1, their families, carers, health professionals, government, and interested parties. During 2025-26 we raised awareness about Alpha-1, promoted better patient identification and management, provided group and one-on-one patient support, shared important information on relevant clinical trials in Australia and advocated for affordable treatment and finding a cure for Alpha-1.

Strategic Plan - Aims and Objectives

	Aims	Objectives
1	Support	Support people and their families affected by Alpha-1
2	Education & Knowledge	Education to support early identification and management of Alpha-1 patients by health professionals Easy access to reliable information for everyone
3	Advocate	Accurate information Available treatment and a cure
4	Awareness	Increase testing Increase community awareness Increase health professional awareness of Alpha-1

Strategic Plan Implementation during 2025-26

Aim 1: Support

Individual Support

When people are first diagnosed with a rare genetic disorder like Alpha-1, they typically seek out individual support, allowing them to ask questions and connect with others with a similar diagnosis. During this year we offered individual support and group support, spending numerous hours supporting newly diagnosed adults and parents of children who had been diagnosed with Alpha-1 and are navigating the health system trying to comprehend the severity of the disorder. Feedback from Alpha-1 patients indicates that individual and group support is highly valued.

Patient Peer Support

During 2025-26 we held monthly peer support meetings, on the third Wednesday of the month via video. The video meetings are supported by the Lung Foundation via their use of the Mighty Networks platform and the provision of peer support facilitator training and support. The peer support meetings offered an opportunity for Australians with Alpha-1 to connect with others, share lived experience, gain information and support, and have questions answered. Our meetings provided authentic engagement and support and helped to build connections, rapport and inspired hope through knowledge exchange about the latest Alpha-1 clinical trials offered and coming to Australia.

Member Consultation and Member Drive

A1OA undertook an online member survey and promoted charity membership. The survey produced useful information on various topics including clinical trial interest, desire for practical tips for daily living and communication preferences. As part of this campaign, we offered free bucket hats to survey respondents. Recipients were invited to share a photo of themselves on social media wearing their hat which resulted in several posts. Sharing such images and personal stories remains incredibly powerful in helping raise awareness about Alpha-1.



Fundraising

We remained a registered fundraising entity across Australian states / territories. Our main source of income came from membership fees and donations from members and non-members, for which we are extremely thankful. The support of members and strangers allowed us to continue to implement our strategic plan including raising awareness about Alpha-1.

International Support

Following enquiries from international travelers to Australia asking for information about: a) how to access infusion lounges when traveling within Australia with their own supply of augmentation medicine; and, b) how to bring augmentation therapy equipment and medicine into Australia, we provided information to the Alpha-1 Europe Alliance. The Alliance shared the information with European Alpha-1 colleagues to assist future travelers.

Aim 2: Education and Knowledge

Manuscript

A1OA published a manuscript titled *Inequity of testing and treatment for patients with Alpha 1-Antitrypsin Deficiency - Time to Reconsider*. This paper provided general education and increased knowledge related to the plight of Australians with Alpha-1 and the international inequity stemming from no government subsidy for augmentation therapy for people living in Australia with Alpha-1.

Social Media

We remained active on various social media platforms including Facebook, Instagram, Pinterest, X and the A1OA YouTube channel. Using various platforms allowed us to rapidly bring information to members and followers. A1OA took advantage of social media platforms to raise awareness during specific health-related months and days for example, those related to liver disease, fatty liver, Alpha-1 lung disease and Alpha-1 clinical trials. Stemming from member feedback, we trialled a new information format on social media with an emphasis on health tips.

Alpha-1 Newsletters

We published four editions of *Alpha Times* (Issue 22 Spring; Issue 23 Summer; Issue 24 Autumn; Issue 25 Winter). The newsletter shared information on various aspects related to Alpha-1 including clinical trials.

Website

We commenced an important digital review of our website to determine whether it was effectively achieving the charity's mission online and to strengthen search engine optimisation (SEO) to make it easier for people to find the website through online searches.

Aim 3: Advocacy

Access to and Affordability of Medical Specialists in Australia

In response to the Australian parliament's inquiry into *Access to and Affordability of Medical Specialist in Australia* we undertook consultation with our rare disease community on issues related to specialist access and affordability. We then participated in *Rare Voices'* partner consultation with rare communities to support their submission to this parliament inquiry. We raised important issues including the long wait-times to gain an appointment, rural travel and accommodation requirements and costs, benefits of having Alpha-1 included in national medical coding schemes, high out-of-pocket costs related to having to see many different types of specialists due to the systemic nature of Alpha-1, opportunities related to receiving standing referrals and longer referral duration, lost opportunities related to telehealth, the need to have easy access to specialist, which can support timely referral to Alpha-1 clinical trials, and gaps in workforce skills and essential equipment (e.g. no CT machines or limited staff, leading to long delays in seeing specialists).

Rare Disease Disability Network

As a partner organisation, we were invited and participated in Rare Voices Australia's "Rare Disease Disability Network", linked to the development of a Rare Disease Advocacy Toolkit enabling families easy access to advocacy resources. A1OA participated in planning meetings and helped to shape the national disability reform. A1OA raised several challenges related to having disability from COPD and liver disease associated with Alpha-1, and the challenges charity members have experienced when trying to access the National Disability Insurance Scheme (NDIS).

Grant Support for Rare Disease Centres of Excellence

The *National Health and Medical Research Council (NHMRC) Community Research Priorities Portal* allows groups and consumers to submit research topics that warrant dedicated funding. A1OA supported *Rare Voices Australia's* grant submission for nationally networked rare disease centres of excellence in response to this NHMRC opportunity.

Consultation on Life Support Devices at Home and Power Outages

We participated in the Victorian Essential Services consultation on life support equipment used at home. This led to A1OA sharing information on social media including the importance of having a power outage plan, a back-up power source, and registration of life support equipment with one's energy supplier.

Clinical Trials

We participated in several video conferences and email communication with key representatives from research and medical companies actively involved in clinical trials in Australia or planning on bringing new Alpha-1 clinical trials to Australia. Such groups included Tessera Therapeutics, AIRNA, KorroBio about KKRO-110 and their potential new trial using a different delivery method, and another international group that is in the planning confidential stage.



Aim 4: Awareness

Global Fatty Liver Day Partnership

We partnered with the *Global Liver Institute* to raise awareness via social media about the risk of liver disease including fatty liver and its association with Alpha-1. This led to information about fatty liver being shared via A1OA's social media networks.

Alpha-1 Awareness Month

We raised awareness about Alpha-1 during Alpha-1 awareness month (November each year) using various A1OA social media and information platforms.

Social Media - Rare Disease Month and Day

We participated in February's Rare Disease Day (28 February) and in Rare Disease Month (November), when all rare disease groups unite to raise awareness about rare diseases.

Wallet Cards depicting Alpha-1

We printed additional wallet cards about Alpha-1 to enable members to hand them to friends, family or interested contacts. The two-sided cards provide a rapid insight into Alpha-1 giving high level details about Alpha-1's genetic background, symptoms, information on testing and charity contact details.



Other Awareness Raising Activities

During 2025-26 we:

- actively engaged with charity members and encouraged them to share their story related to their Alpha-1 journey. Story telling remains an important and powerful way to promote awareness of Alpha-1.
- partnered with *Rare Voices Australia* and participated in their consultation meetings on NDIS and the *Rare Disease Disability Network*
- partnered with the *Global Liver Institute* and promoted Global Fatty Liver Day - 11 June 2026.
- provided input to *Safe Work Australia* on their draft model *Code of Practice: Managing the risks of biological hazards at work*, raising awareness about Alpha-1 and respiratory risks
- provided information on Alpha-1 via video to the *European Lung Society* about Alpha-1 as part of the *European Lung Foundation Global Voices Project*
- registered for the *European Lung Foundation* webinar on Aspergillus lung
- provided feedback to *KorroBio* about clinical trial publicity in Australia and distributed trial information across all A1OA social media platforms
- gave feedback to Australia's *Centre for Disease Control (CDC)* about their website
- wrote to the *Medical Services Advisory Board (MSAC)* to explore if the simplified application process related to a previous application on Alpha-1 subsidised augmentation therapy
- participated in a media interview and raised awareness about Alpha-1
- applied to be considered by and approved by to the *Australian Communities Foundation* for potential funding

- participated in the US 2026 *Alpha-1 Education Day*
- participated in the *Social Media Summit* for non-profits
- provided advice to *St Vincents Hospital Sydney* about Alpha-1 clinical trials

Formal Partnership with Alpha Trail Events

Our formal partnership with *Alpha Trail Events* remained in place during 2025-26. This partnership raises awareness about Alpha-1 while offering an opportunity for event participants to donate to A1OA.

Support Received

As a not-for-profit charity that receives no government or grant funding the A1OA Board greatly appreciated the time and effort provided by all volunteers. Donations and membership fees supported our work and we would like to acknowledge generous donations from the Rotary Club of Hornsby, Lachlan Robison and Philip Bell.

Treasurer's Report

Financial Results

For the reporting period 1 July 2025 to 30 June 2026, the charity recorded a surplus of \$1,716 (2025: \$4,816). Basic operational costs were maintained at a similar level to previous years.

Review of Operations

To cover operating and capital expenditure during the year the charity drew its income primarily from membership fees and donations.

Organisation Assets

At 30 June 2026 the charity held assets of \$33,766 (2025: \$32,051). All assets held at the end of the reporting period were in cash, including funds invested in term deposits.

Board Member Benefits

During the reporting period, no board member of the charity received, or became entitled to receive, any benefit arising from a contract between the charity and the board member, a firm of which the board member is a member, or an entity in which the board member has a substantial financial interest.

Significant Changes in the State of Affairs

There were no changes to the state of affairs of the charity during the year, other than those identified in this financial report.

Significant Events After Balance Date

There have been no matters or circumstances that have arisen since the end of the financial year that have significantly affected, or may affect, the charity's operations in future financial years, the results of those operations or the state of affairs in future financial years.

Audit and Accountability

A1OA is classified as a small charity by the Australian Charities and Not-for-profits Commission and as such there is no requirement to have its financial report reviewed or audited.

In keeping with a commitment to openness and accountability the charity welcomes the opportunity to provide members with further detail regarding its income and expenditure on request.

Likely Developments and Expected Results

The charity will continue to seek funding through memberships and donations to support patients, raise awareness, provide health professional education and advocate for treatment and research.

The expected financial results for future years depend on the number of charity members (who currently pay an annual membership fee of \$20), the amount of donations received, and revenue generated from any fundraising activities and merchandise sales.

Signed on behalf of the members of the A1OA Board.



Jane Gordon
Treasurer, Alpha-1 Organisation Australia Inc
4 July 2026

Financial Statements

These statements should be read in conjunction with the accompanying notes.

Income Statement

	Note	2026 \$	2025 \$
Revenue from operating activities			
Donations		916	8,388
Membership subscriptions		2,080	700
		<u>\$ 2,996</u>	<u>\$ 9,088</u>
Other revenue			
Interest income		589	627
		<u>\$ 589</u>	<u>\$ 627</u>
Total revenue		<u>\$ 3,585</u>	<u>\$ 9,715</u>
 Expenses relating to operating activities			
Advertising, printing & stationery		943	325
Bank fees	2	36	136
Insurance premiums	3	510	1,320
IT costs		324	214
Membership & association fees		56	55
Professional Services	4	-	2,849
Sundry expenses		-	-
Travel & Accommodation		-	-
Venue Hire		-	-
Total expenses		<u>\$ 1,869</u>	<u>\$ 4,899</u>
Net surplus/(deficit) for the year		<u>\$ 1,716</u>	<u>\$ 4,816</u>

Balance Sheet

	Note	2026 \$	2025 \$
Current Assets			
Cash assets		33,766	32,051
		<u>\$ 33,766</u>	<u>\$ 32,051</u>
Total Assets		<u>\$ 33,766</u>	<u>\$ 32,051</u>
Current Liabilities			
Payables		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Liabilities		<u>\$ -</u>	<u>\$ -</u>
Net Assets		<u>\$ 33,766</u>	<u>\$ 32,051</u>
Members' Funds			
Balance at the beginning of the year		32,051	27,235
Current year earnings		1,716	4,816
Total Members' funds		<u>\$ 33,766</u>	<u>\$ 32,051</u>

Cash Flow Statement

	Note	2026 \$	2025 \$
Cash flow from operating activities			
Receipts from donations		916	8,388
Receipts from members		2,080	700
Interest received		589	627
Payments to suppliers		<u>(1,869)</u>	<u>(4,899)</u>
Net Cash flow from (used in) operating activities		<u>\$ 1,716</u>	<u>\$ 4,816</u>
Cash flows from investing activities			
		<u>-</u>	<u>-</u>
Net cash flows from investing activities		<u>\$ -</u>	<u>\$ -</u>
Cash flows from financing activities			
		<u>-</u>	<u>-</u>
Net cash flows from financing activities		<u>\$ -</u>	<u>\$ -</u>
Net Increase/(decrease) in cash held		1,716	4,816
Cash balance at the beginning of the year		<u>32,051</u>	<u>27,235</u>
Cash at the end of the financial year		<u><u>\$ 33,766</u></u>	<u><u>\$ 32,051</u></u>

Notes to and Forming Part of the Financial Statements

1. Summary of Significant Accounting Policies

(a) Basis of Preparation of the Accounts

The financial report is a special purpose financial report prepared for distribution to members.

The financial report has been prepared using generally accepted accounting principles and is in accordance with the historical cost convention. The accounting policies adopted are consistent with the previous year unless otherwise stated.

(b) Depreciation

No depreciation has been incurred by the charity to date.

(c) Taxes

Income Tax

The charity is exempt from income tax.

Goods and Services Tax (GST)

The charity is not required to be registered for GST. Where GST is incurred on a purchase of a goods and services item, the GST is recognised as part of the expense item or part of the cost of acquisition of the asset.

2. Bank Fees

Bank fees include commission fees made to payment collection platforms used by the charity (e.g. TryBooking).

3. Insurance Premiums

The charity prepares its accounts on a cash basis; insurance premiums for the 2024-25 and 2025-26 financial years were both paid in 2024-25. The insurance premium for 2026-27 was paid in June 2026.

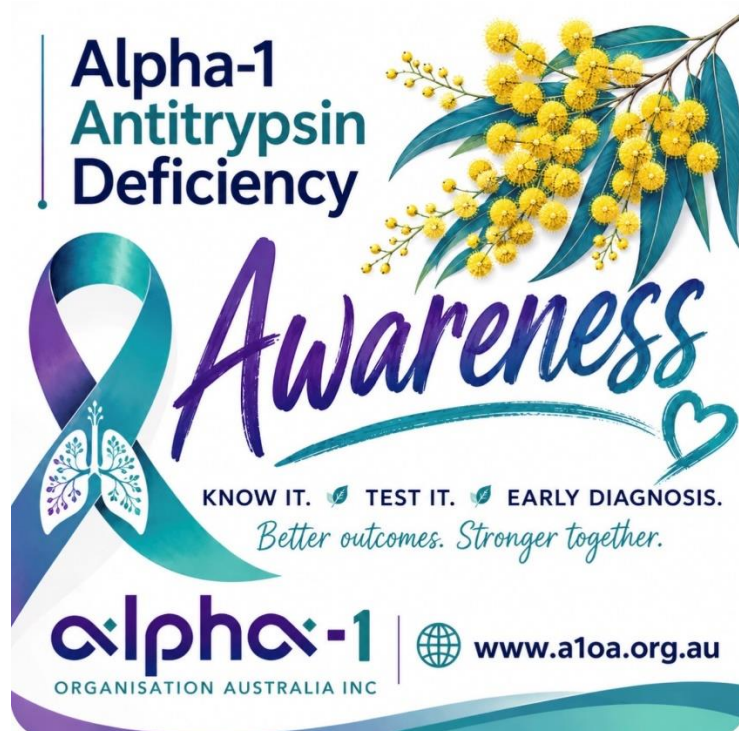
4. Professional Services

In 2024-25 the charity recorded and published additional awareness videos which incurred preparation service fees.

The Year Ahead

A new Board will lead A1OA in 2026-27. As the founding President and after six years leading A1OA Gaynor Heading is stepping aside to allow a new Board to lead the organisation. The new Board will build on strong foundations and bring energy and optimism. Gaynor played a pivotal role in establishing the charity and shaping its vision, governance and strategic direction. Through commitment, leadership and generosity, Gaynor helped build a strong foundation from which the organisation can continue to grow and support the community it serves. On behalf of the Board, our members and the wider community, we thank Gaynor for her outstanding contribution.

Building on strong foundations, bringing energy and optimism, the Board's focus will remain on building Alpha-1 awareness, information provision supporting education and knowledge, patient support and advocacy. Awareness comes in many guises and is vital in many ways including: identifying patients with Alpha-1; the importance of an early diagnosis; understanding genetic risk and environmental risks; symptoms that could actually be related to Alpha-1; how to test for Alpha-1; living beyond a diagnosis and tips for daily living; and explaining why Alpha-1 clinical trials bring hope and a potential cure. 2026-27 will have an exciting focus on awareness raising, which will support individuals, families and health professionals.



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