

Annual Report 2025



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Together Making a Difference

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Message from the President



On behalf of the Board, I am pleased to present our 2024-25 Annual Report

Our not-for-profit charity - Alpha-1 Organisation Australia inc (A1OA) is recognised internationally and nationally as a key player in supporting clinical trials for Alpha-1 Antitrypsin Deficiency (AATD) in Australia. We continued in this role this year and supported new trials being offered in Australia and met via Zoom and in person with international senior clinical trial staff. These opportunities supported the provision of key input from a patient perspective on trial design and ensured that patient resources would reflect the Australian landscape and culture.

My gratitude goes to the members of our volunteer Board who continue to bring strategic ideas to the table as well as holding key volunteer positions that keep the organisation functioning. As an unfunded organisation, volunteering is our backbone and strength. Volunteers drew upon their lived experience to ensure that activities and resources developed in light of patient needs and evidence. Patient input ensures that the

organisation remains relevant and focused. Non-patient Board members also made valuable contributions and brought a range of expertise and knowledge to the table.

Our monthly video patient support meetings remained a vital support to Alpha-1 patients, including those newly diagnosed and those with a longer diagnosis. Other activities continue to be valued by patients including the provision of new electronically available resources such as our fact sheet, *Questions that You Could Ask your Respiratory Specialist*. Our website provided a rich range of information and resources which were readily available thanks to our team with advanced IT skills.

We expanded our *Alpha-1 Unwrapped* video series. We released an in-depth interview with one of our Alpha-1 patients. This story revealed the suffering endured by Alpha-1 patients and the importance of our work advocating for affordable treatment.

Our quarterly newsletter *Alpha Times*, remained an important

source of information and included evidence-based information about issues and diseases linked to AATD. I remain extremely thankful to everyone who contributed content to the newsletters and to our Editor who worked tirelessly to bring important information to our readers. A special thanks also to our Founding Treasurer who is standing down at the AGM in August 2025. His ability to juggle multiple activities and his strategic input will be missed.

Our work was supported financially by everyone who donated to our charity, including members and strangers who supported fundraising events. Their generosity allowed us to professionally produce our latest video resources.

Our vision continues as we move into next year. We will continue to advocate for affordable treatment and a cure, support everyone affected by this devastating genetic disorder, raise community and professional awareness, support clinical trials in Australia and provide education and information about AATD.

Regards

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

Gaynor Heading,
President

About Us

Vision

To find a cure for Alpha-1
Antitrypsin Deficiency

Mission

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). The charity formed in 2020 to provide a supportive, initiative-taking, accountable Australian charity for people diagnosed with Alpha-1. The 2024-25 Board membership includes people with Alpha-1 and health professionals.

Governance – Our Board

Position	Holder	Board Member From
President / Public Officer	Gaynor Heading	June 2020
Vice-President	Dr Laxmi Iyengar	Oct 2021
Treasurer	Ian Saunders	June 2020 – June 2025
Director Communications	Leonie Robison	June 2020
Director	Gerri Simmons	Aug 2024
Director Grants & Research / Secretary	Sandra Baxendell	June 2020
Director Marketing & Fundraising	Mark Lloyd	Oct 2021

A1OA is the first point-of-call for Australian patients with AATD, their families, carers, health professionals, government, and interested parties. During 2024-25 we collaborated with key organisations to expedite our objectives. We raised disease awareness (including diseases recently linked to AATD), promoted better patient identification and management, provided patient support, and advocate for affordable treatment and finding a cure for AATD.

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 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

Aim 1: Support

Individual Support

When receiving a diagnosis of AATD having easy access to someone with good knowledge about AATD and the health system proved important again. Our Board members provided patient support in various ways. This year support requests came via our website, via our contact email address - contactus.a1oa@gmail.com, via social media and texts. Having Board members located in various states and prepared to wear several hats supported individual support. They answered general and specific questions e.g. about clinical trials locations, and specialists.

Patient Peer Support

We held 11 monthly peer support meetings during the last financial year, held on the third Wednesday of the month at 3pm – accessible at no cost for everyone affected by AATD. The Zoom meetings provided a safe place to chat about the impact of the disorder and an opportunity to share information and to ask questions. We welcomed newly diagnosed patients, as well as those well into the AATD journey, including those facing or who have undergone organ transplant. Special guest Kate, Respiratory Nurse Lung Foundation spoke at our November 2024 meeting about lung health which was well received.

We applied for a peer support grant to support Alpha-1 patients in Western Australia. Unfortunately, the application was unsuccessful. We organised a special video meeting for the *Institute for Respiratory Health*, to allow AATD patients to ask questions about clinical trials on offer in Western Australia. This meeting led to an invitation to one AATD patient to be a consumer representative for the Institute.

Website Resources – Doctor Questions

During the year we added new resources to our website - visit [a1oa – www.a1oa.org.au](http://a1oa.org.au). As a complex disorder we require resources on many different organs affected by AATD. This year we published *Questions That You Could Ask Your Respiratory Specialist* and *Liver Questions to Ask Your Doctor*.

Fundraising

We remained a registered fundraising entity across Australian states / territories. Our main source of income came from donations organised by members, for which we are extremely thankful. The support of members and strangers allowed us to produce new resources to support patients in various ways including via video conference.

Mental Health Support

We provided mental health support to Australians affected by Alpha-1. This was possible due to our certification in mental health first aid. Following a request, we provided information on mental health support to the Alpha-1 European Alliance.



Aim 2: Education and Knowledge

Journal Manuscript

Our draft manuscript on Alpha-1 Antitrypsin deficiency and the need for affordable treatment remained unpublished as we were not in a position to pay thousands of dollars for open access journal publishing. We are planning on publishing the paper on our website to support the spread of information about the impact of AATD and the impact of unaffordable augmentation therapy.

New Video - My life with Alpha-1 and the Cost of Hope

As part of our Alpha-1 Unwrapped video series, we produced a video featuring Lou – a patient with Pi*SZ phenotype. As at the end of June 2025 this video has been viewed over 300 times in the 3 months it has been available. This video explores the impact of AATD on the patient's life and the need for affordable augmentation therapy to improve quality of life and slow down lung disease. The video was shared via social media on X, Facebook, Instagram, Pinterest and LinkedIn.

Social Media

Facebook: The Board maintains an active Facebook page which has 383 members. Board members post regularly and the newly diagnosed often post with specific questions for others to answer. There were 177 posts from 31 Jul 2024 - 22 Jun 2025.

Pinterest: There are only 6 followers on Pinterest but it is useful for saving interesting websites and articles.

A1OA YouTube Channel: There are 43 subscribers to our YouTube channel.

X (previously Twitter): Our X page has 103 followers and 383 people following.

Instagram: We have made 112 Instagram posts since establishing the charity. We have 243 followers and 110 following.

Alpha-1 Newsletters

We published four editions of *Alpha Times* (Issue 18 Spring; Issue 19 Summer; Issue 20 Autumn; Issue 21 Winter). The newsletter shared important information on various issues including diseases and issues linked to AATD and clinical trials.

Conference Participation

We were invited and attended the Alpha-1 Global conference held in Lisbon, Portugal in April 2025. This sponsored participation allowed a Board member to hear from Alpha-1 experts, trends and potential treatment breakthroughs and to report to the broader Australian Alpha-1 community, sharing new knowledge and emerging treatments.

Aim 3: Advocacy

Rare Disease Disability Network

As a partner organisation, we were invited and participated in Rare Voices Australia's "Rare Disease Disability Network", linked to their work on developing a Rare Disease Advocacy Toolkit enabling families easy access to advocacy resources. We participated in planning meetings, and helped to shape the national disability reform. We raised several challenges related to having disability from

COPD and liver disease associated with AATD, and the challenges charity members have experienced when trying to access the National Disability Insurance Scheme (NDIS).

Advocating for Subsidised Treatment

Our Alpha-1 Unwrapped series highlights the need for affordable treatment such as augmentation therapy to slow lung decline in Alpha-1 patients, a product registered with the Therapeutic Goods Administration (TGA) but not subsidised nor affordable to most patients, typically costing over \$100,000 per year for life. We provided CSL with updated evidence on life-shortening diseases associated with AATD, and advocated for them to review the evidence and to make a new funding application to the Medical Services Advisory Committee (MSAC) for subsidised augmentation therapy.

Clinical Trials

On several occasions we met key representatives from BEAM Therapeutics (via videoconference) and Korro Bio (in person and via videoconference) and provided patient input to ensure that clinical trials coming to Australia are well-designed and that patient materials are relevant to the Australian patient context. We provided advice about potential clinical trial sites and met with the Korro Bio's communication team in Australia, to support the release of clinical trial information via social media as it becomes available. We also provided information about Alpha-1 trials in the Australian context to the Tiger Med Group and explored ways to promote Fazirisan with Takeda.



Augmentation Therapy

We submitted a Freedom of Information request to the Federal Government to better understand their 2018 consideration and rejection of the MSAC application for government subsidised augmentation therapy. Government feedback remained the same – that current evidence does not support subsidised therapy, that new evidence is required and a new full MSAC submission would be required if/when new AATD clinical trial evidence emerges.

Aim 4: Awareness

Stakeholder Information Provision

We provided patient reviews to the Australian Liver Foundation in regard to information about AATD on their website and had our website link included on their AATD Liver Disease webpage. We agreed to cobrand joint resources.

Alpha-1 Awareness Month

During Alpha-1 awareness month we raised awareness about AATD using various social media platforms. We continued to place relevant Lung and Liver information on Pinterest as well.

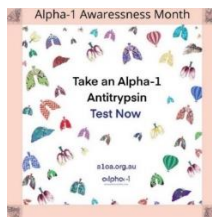
Social Media - Rare Disease Month and Day

We participated in February's Rare Disease Day (28 February) and in Rare Disease Month (November), dates and months when all rare disease groups unite to raise awareness about rare diseases. These actions led to members sharing the provided information about AATD.



Consultation

We participated in the Lung Foundation's strategic plan consultation, provided input to the strategic plan and raised awareness about the needs of patients diagnosed with AATD.

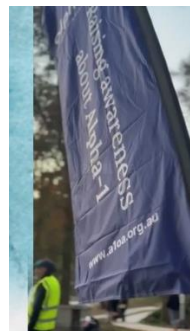


Support from the Lung Foundation Australia

The Lung Foundation Australia supported A1OA in several ways including a letter of support for a grant application which highlighted the valuable peer support provided by our charity members; provided helpful information about lungs and healthy lifestyle to A1OA members via our peer group, hosted by their Mighty Networks platform.

Formal Partnership with Alpha Trail Events

Our formal partnership with *Alpha Trail Events* supported Alpha-1 awareness raising. The flag sponsored by A1OA (shown here) was used at events. Use of the flag has increased awareness about A1OA and the partnership is enhanced by donations from event participants.



Support Gratefully Received

We would like to thank the following groups and individuals:

- Penleigh and Essendon Grammar School (certificate of appreciation issued)
- Mr and Mrs McIldowie
- Members, donors and volunteers

Treasurer's Report

Financial Results

In the period ending 30th June 2025, the charity recorded a surplus of \$4,816 (2024: \$5,298). 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 memberships and donations.

Organisation Assets

At 30th June 2025 the charity held assets of \$32,051 [2024: \$27,235]. All assets at the end of period were held in cash.

Board Member Benefits

During the period no board member of the charity has received, or become entitled to receive, a benefit as a result of a contract that 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, has made with the charity.

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

Alpha-1 Organisation 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 from membership, donations and grants to support patients, raise awareness, provide health professional education and advocate for treatment and research. The expected financial result of future years is dependent on the number of members who join the charity together with the amount of any donations and or/grants made to the charity, and the revenue generated by any fundraising activities and/or merchandise sales.

Signed on behalf of the members of the board of the Alpha-1 Organisation Australia Inc.



Ian Saunders
Treasurer 1st July, 2025

Financial Statements

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

Income Statement

	Note	2025 \$	2024 \$
Revenue from operating activities			
Donations		8,388	5,524
Membership subscriptions		700	660
Merchandise sales		-	-
		<u>\$ 9,088</u>	<u>\$ 6,184</u>
Other revenue			
Interest income		627	138
		<u>\$ 627</u>	<u>\$ 138</u>
Total revenue		<u>\$ 9,715</u>	<u>\$ 6,322</u>
Expenses relating to operating activities			
Advertising, printing & stationery		325	-
Bank fees	2	136	81
Gifts		-	124
Insurance premiums	3	1,320	-
IT costs		214	364
Membership & association fees		55	55
Professional Services	4	2,849	400
Travel & Accommodation		-	-
Venue Hire		-	-
Total expenses		<u>\$ 4,899</u>	<u>\$ 1,024</u>
Net surplus / (deficiency) for the year		<u>\$ 4,816</u>	<u>\$ 5,298</u>

Balance Sheet

	Note	2025 \$	2024 \$
Current Assets			
Cash assets		32,051	27,235
		<u>\$ 32,051</u>	<u>\$ 27,235</u>
Total Assets		<u>\$ 32,051</u>	<u>\$ 27,235</u>
Current Liabilities			
Payables		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Liabilities		<u>\$ -</u>	<u>\$ -</u>
Net Assets		<u>\$ 32,051</u>	<u>\$ 27,235</u>
Members' Funds			
Balance at the beginning of the year		27,235	21,937
Current year earnings		4,816	5,298
Total Members' funds		<u>\$ 32,051</u>	<u>\$ 27,235</u>

Cash Flow Statement

	Note	2025 \$	2024 \$
Cash flow from operating activities			
Receipts from donations		8,388	5,524
Receipts from members		700	660
Receipts from merchandise sales		-	-
Interest received		627	138
Payments to suppliers		(4,899)	(1,024)
Net Cash flow from (used in) operating activities		\$ 4,816	\$ 5,298
Cash flows from investing activities			
		-	-
Net cash flows from investing activities		\$ -	\$ -
Cash flows from financing activities			
		-	-
Net cash flows from financing activities		\$ -	\$ -
Net Increase / (decrease) in cash held		4,816	5,298
Cash balance at the beginning of the year		27,235	21,937
Cash at the end of the financial year		\$ 32,051	\$ 27,235

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, Paypal etc*).

3. Insurance Premiums

The charity prepares its accounts on a cash basis; insurance premiums for the periods ending 30th June 2025 and 30th June 2026 were both paid in the 2024-25 financial year.

4. Professional Services

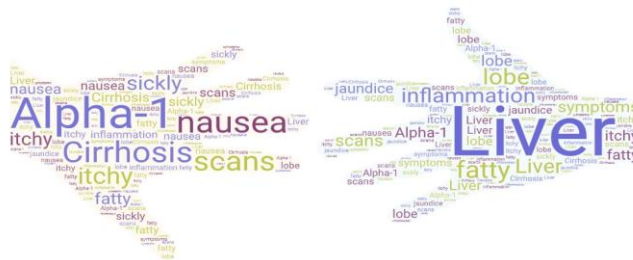
During the year the charity recorded and published additional awareness videos which incurred preparation service fees.

We will continue to support Alpha-1 patients and researchers interested in AATD. We will use a range of social media platforms to share important information about AATD, and raise the profile of Alpha-1. Our monthly peer support meetings will continue via Zoom. To request Zoom log-in details, email contactus.a1oa@gmail.com.

We welcome education partnerships to raise the profile, understanding, timely diagnosis and discussion of treatment and clinical trial options related to AATD.

As treatment access is crucial to support patient longevity and quality of life, we will continue to advocate for Alpha-1 clinical trials and affordable treatment across Australia. Advocating for access to existing treatment, new treatments and a cure are all important as patients need access to affordable treatments and emerging therapies. We hope to expand our set of Alpha-1 Unwrapped videos which support treatment advocacy.

We will continue to have a strong focus on AATD awareness raising and aim to provide further videos in our Alpha-1 Unwrapped video series, available for viewing on our YouTube channel - [Alpha-1 Organisation Australia inc - YouTube](#) - and further patient resources via our resource page on our website - [Resources – a1oa](#).



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