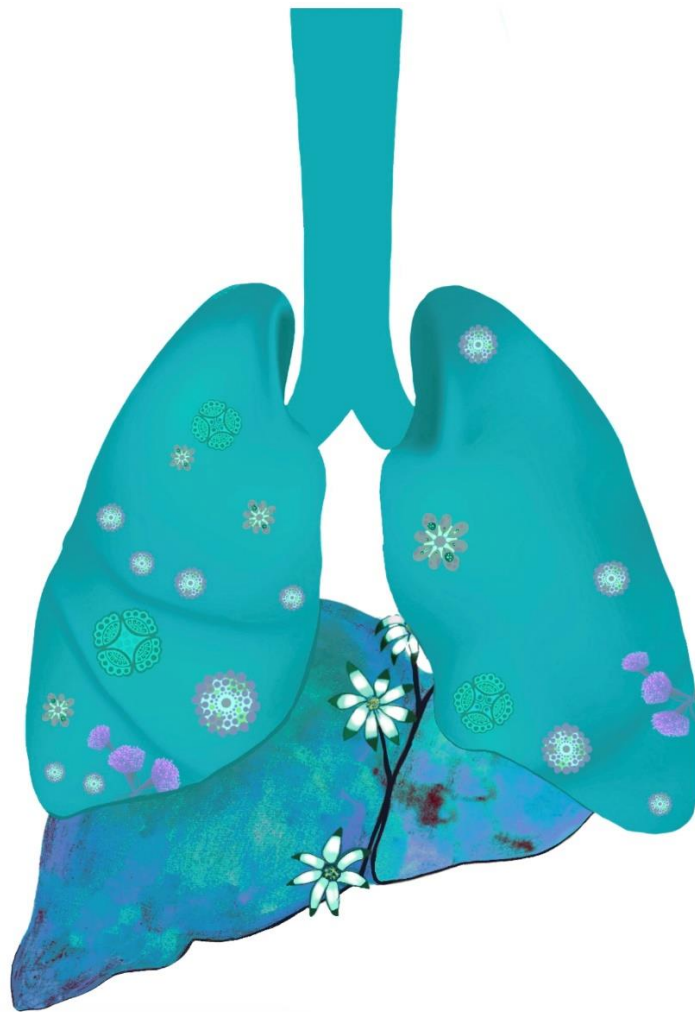


Annual Report 2024



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Message from the President



On behalf of the Board, I am delighted to present our 2023-24 Annual Report

Alpha-1 Organisation Australia inc (A1OA) is well-served by a small group of dedicated volunteers who guide and manage our organisation and help to achieve our charity mission.

Volunteers remain pivotal to our success as we receive no government funding.

Volunteers help in many ways including provision of national support to people with Alpha-1 Antitrypsin Deficiency (Alpha-1 / AATD). Our charity is typically the first point of contact after an Alpha-1 diagnosis, and it is wonderful that we can provide access to the latest evidence and research information. This information builds knowledge about the genetic disorder, keeps everyone abreast of emerging treatments and a possible cure and ways to support health.

A huge thank you to our volunteer board for their support and strong

leadership. I am conscious that some of our volunteers struggle with their own Alpha-1 journey and their dedication is evident.

We have made further strides in tackling and promoting Alpha-1 e.g. providing input into curative clinical trial design and patient information and producing further resources. Our *Alpha-1 Unwrapped* series continues to grow with planning underway for even more episodes.

During 2023-24 we continued our work to help reduce the devastating impact of Alpha-1 on individuals and their families. This work took many shapes including advice to government and academics on the need for cleaner air as Chronic Obstructive Pulmonary Disease remains a leading cause of death in Australia; providing our mental health support service; advocacy for affordable Alpha-1 augmentation therapy, the

only current treatment registered with the Australian Therapeutic Goods Administration. We also raised the need for a review of the latest evidence to support affordable treatment access. We connected with more international Alpha-1 patients and experts and welcomed international members into our monthly Zoom peer support meetings.

I would like to give a huge thankyou to everyone who donated to and supported our charity this year, including members of the public and charity members. Everyone's support provides the energy and means to keep up the fight to save Alpha-1 lives. Our mission remains unchanged as we move into next year – advocating for affordable treatment and a cure, supporting everyone affected by this devastating genetic disorder, raising community and professional awareness, and education about Alpha-1.

Regards

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

Gaynor Heading PhD (Med)
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 an initiative-taking, accountable Australian charity for people diagnosed with Alpha-1. The 2023-24 Board membership includes people with Alpha-1, health professionals and others in public health.

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
Director Communications	Leonie Robison	June 2020
Director Education & Knowledge	Deborah Macfie	Oct 2021 – Nov 2023
Director Grants & Research / Secretary	Sandra Baxendell	June 2020
Director Marketing & Fundraising	Mark Lloyd	Oct 2021
Director	Jov Moratalla	Dec 2023

Our charity is the primary point-of-call for all Australian patients with Alpha-1, their families, carers, health professionals, government, and other interested parties. We foster collaborations and partnerships to expedite our charity objectives. As a collective force we work towards awareness about the genetic disorder and associated diseases, better patient management, patient support and fostering research efforts associated with finding a cure for this devastating genetic disorder.

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

Patient Peer Support

We held monthly peer support meetings via Zoom, providing a safe place for support and information sharing. Meetings were attended by national and international Alpha-1 patients.



Individual Support

An important support mechanism for people affected by Alpha-1 is one-on-one support. We provided information and support to individuals via telephone and email including questions to ask your doctor and information on Alpha-1 clinical trials.

Fundraising

We registered the charity as a fundraising entity across Australian states / territories. Donations support the charity to implement the four objectives in its strategic plan which includes solving the Alpha-1 puzzle.

Website Resources

During the year we added new resources to our website - visit [a1oa – www.a1oa.org.au](http://a1oa.org.au). Questions raised by those seeking support often lead to the development of new resources as was the case this year. Each year we aim to bring further information to our community, hence new publications will be available next year.



Mental Health Support

We provided mental health support to people affected by Alpha-1. This was possible due to our certification in mental health first aid. To access this service email: mentalhealth.a1oa@gmail.com to arrange a time to chat via email or phone.



Aim 2: Education and Knowledge

Journal Manuscript

We drafted and submitted a manuscript on Alpha-1 Antitrypsin deficiency and the need for affordable treatment and submitted it for publication in a health journal (awaiting the outcome).

New Videos in the Alpha-1 Unwrapped – Doctor Series

As part of our video series available on our Alpha-1 YouTube channel we commenced the new Alpha-1 Unwrapped Doctor Series. We produced and published two interviews, one with a respiratory specialist with expertise in Alpha-1 and one with a General Practitioner. The videos explore issues that patients need to consider or will encounter as part of their journey with Alpha-1. The new videos were shared via social media on X, Facebook, Instagram and LinkedIn.



Interview with Dr. Jonathan Burdon | ALPHA-1 UNWRAPPED DOCTOR SERIES



Interview with Dr. Weng Tak Poon | ALPHA-1 UNWRAPPED DOCTOR SERIES

Australian Research Partnership

We supported the *Centenary Institute (the Institute)* in various ways including:

- consulting with COPD and Alpha-1 patients about important research topics from a patient perspective and providing key research questions to the Institute
- partnering and supporting Commonwealth research grant submissions

Presentation to The Rotary Club of Hornsby District

Our Director of Communications presented to The Rotary Club of Hornsby District, providing an update on our latest awareness raising activities and how donations were used to support our strategic plan. The presentation was very well received.

Alpha-1 Newsletters

We published three editions of *Alpha Times*, bringing useful information to the Alpha-1 community. The newsletter provides information on the latest Alpha-1 clinical trials on offer in Australia, trials coming to Australia and international studies, as well as other useful Alpha-1 related information. <https://www.a1oa.org.au/resources/newsletters/>

Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

Issue 14 Spring 2023

Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

Issue 15 Summer 2023/24

Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

Issue 16/17 Autumn/Winter 2024

Conference Participation

We were invited and attended the Centenary Institute's NAME Meeting, held 17 – 18 November 2023 in Sydney and raised awareness about Alpha-1 over the two days.

RARE Portal

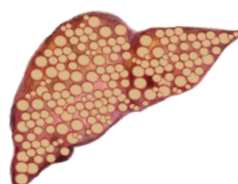
We supported the Rare Disease Awareness, Education, Support and Training (RAREST), a collaborative project between Rare Voices Australia (RVA), the University of New South Wales, the University of Western Australia and Macquarie University to deliver rare disease awareness resources, education, support and training.

Aim 3: Advocate

Advocating for Subsidised Treatment

The only treatment to slow lung decline in Alpha-1 patients is augmentation therapy, a product registered with the Therapeutic Goods Administration but not subsidised nor affordable to most patients, costing typically over \$100,000 per year for life. After writing to the Medical Services Advisory Committee (MSAC) and the Therapeutic Goods Administration (TGA), providing the latest evidence on the benefits of augmentation, advice was received that a new submission to MSAC would be required if there is new evidence. We advised CSL and Grifols about new evidence and advised them about MSAC's requirement - showing survival is linked to augmentation therapy.

We promoted the Grifols Private Purchase Pathway - an option to those who can afford privately purchased augmentation therapy. Few patients take up this option due to the annual cost.



Economics

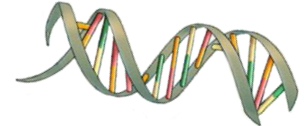
We consulted with a UK based health economist, exploring the economic approach associated with the 2018 MSAC submission and explored a range of economic issues related to subsidised treatment.

Clinical Trials

We liaised with BEAM Therapeutics and KORRO (both in the United States of America). We supported the development of new Alpha-1 clinical trials and advocated for an Australian presence.

BEAM: We provided patient feedback to BEAM and shared information on the BEAM genetic study to potential clinical trial sites in Australia.

KORRO: We provided information to KORRO Bio regarding their Alpha-1 trial design and raised a number of patients' needs and supported KORRO's focus on an Alpha-1 RNA clinical trial being offered in Australia in 2025.



TSANZ Position Paper

We advocated for an update on the TSANZ position paper *Diagnosis and treatment of lung disease associated with alpha one-antitrypsin deficiency: A position statement from the Thoracic Society of Australia and New Zealand* to acknowledge new evidence of survival linked to augmentation therapy.

Genetic Testing

We wrote to the Federal Government indicating the need to support a ban on genetic testing associated with life insurance policies.

Advocating for Clean Air to Support Lung Health

We wrote a Position Paper on *Clean Air to Support Health and Wellbeing in Built-Up Environments* and submitted it as part of the Australian Government's *National Urban Policy for Australia* consultation, led by the Department of Infrastructure, Transport, Regional Development, Communications and the Arts. The paper focuses on liveable, equitable, productive, sustainable and resilient living areas, supported by clean air.



Aim 4: Awareness

Media – Radio Interview

We raised awareness about Alpha-1 via a live-chat radio interview on 13 June 2024 with Eliot Rifkin from 4ZZZ, community radio Brisbane.

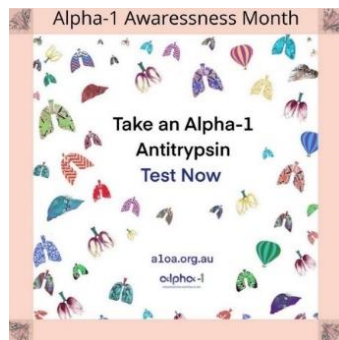
Alpha-1 Awareness Animations

During the year we produced two short animations on Alpha-1 and published them on social media. The animations use artwork produced by Alpha-1 patients and highlight the need to be tested for Alpha-1, along with an offer of hope related to new and emerging treatments and a potential cure.



Social Media - Rare Disease Month and Day

We participated in February's Rare Disease Day (29 February) and in Rare Disease Month (November), dates and months when all rare disease groups unite to raise awareness about rare diseases.



Consumer Representative

Our President became a member of the Lung Foundation Australia's *Consumer Representative Community* and participated in external stakeholder events raising awareness of Alpha-1, including the *Your Air, Your Health* consultation by University of Tasmania which provided an opportunity to discuss Alpha-1, lung irritants and the need for clean air.

Website Access

We reviewed our charity website against Accessibility Standards to support consumer access and continue to review it to support optimal access.

Formal Partnership with Alpha Trail Events

We entered a formal partnership with a business known as *Alpha Trail Events* which promotes Alpha-1 at trail running events in Australia. This partnership supports awareness raising and includes a donation option to A1OA via a registration with *Just Giving*.



Support Gratefully Received

We would like to thank the following groups and individuals:

- Angelo Diano from Alpha-1 Canada for patient advocacy advice
- Dan Grimm (USA) for patient advocacy advice
- Donation from the Rotary Club of Hornsby District
- Donation from John Laing Group Limited via Lara Patterson
- Patient donations
- Patient support



Treasurer's Report

Financial Results

In the period ending 30th June 2024 the charity recorded a surplus of \$5,298 (2023: deficit of \$779). 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 2024 the charity held assets of \$27,235 [2023: \$21,927]. 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 in accordance with a resolution of the members of the board of the Alpha-1 Organisation Australia Inc.



Ian Saunders
Treasurer 9th July 2024

Financial Statements

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

Income Statement

	Note	2024 \$	2023 \$
Revenue from operating activities			
Donations		5,524	4,453
Membership subscriptions		660	820
Merchandise sales		-	15
		\$ 6,184	\$ 5,288
Other revenue			
Interest income		138	-
		\$ 138	\$ -
Total revenue		\$ 6,322	\$ 5,288
 Expenses relating to operating activities			
Advertising, printing & stationery		-	1,082
Bank fees	2	81	235
Gifts	3	124	-
Insurance premiums	4	-	767
IT costs	5	364	356
Membership & association fees		55	55
Professional Services		400	2,496
Travel & Accommodation		-	51
Venue Hire		-	1,045
Total expenses		\$ 1,024	\$ 6,087
Net surplus / (deficiency) for the year		\$ 5,298	\$ (799)

Balance Sheet

	Note	2024 \$	2023 \$
Current Assets			
Cash assets		27,235	21,937
		<u>\$ 27,235</u>	<u>\$ 21,937</u>
Total Assets		<u>\$ 27,235</u>	<u>\$ 21,937</u>
Current Liabilities			
Payables		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Liabilities		<u>\$ -</u>	<u>\$ -</u>
Net Assets		<u>\$ 27,235</u>	<u>\$ 21,937</u>
Members' Funds			
Balance at the beginning of the year		21,937	22,736
Current year earnings		5,298	(799)
Total Members' funds		<u>\$ 27,235</u>	<u>\$ 21,937</u>

Cash Flow Statement

	Note	2024 \$	2023 \$
Cash flow from operating activities			
Receipts from donations		5,524	4,453
Receipts from members		660	820
Receipts from merchandise sales		-	15
Interest received		138	-
Payments to suppliers		(1,024)	(6,087)
Net Cash flow from (used in) operating activities		<u>\$ 5,298</u>	<u>\$ (799)</u>
Cash flows from investing activities			
		-	-
Net cash flows from investing activities		<u>\$ -</u>	<u>\$ -</u>
Cash flows from financing activities			
		-	-
Net cash flows from financing activities		<u>\$ -</u>	<u>\$ -</u>
Net Increase / (decrease) in cash held		5,298	-799
Cash balance at the beginning of the year		21,937	22,736
Cash at the end of the financial year		<u>\$ 27,235</u>	<u>\$ 21,937</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, PayPal*).

3. Gifts

In lieu of payment flowers were given to a UK based health economist who provided advice and guidance regarding the potential cost justification of augmentation therapy.

4. Insurance Premiums

The charity prepares its accounts on a cash basis; the insurance premium for the period ending 30th June 2024 was paid in the 2023 financial year.

5. IT Costs

During the year, the charity continued commercial agreements for the provision of video conferencing facilities and for website hosting. Neither of these agreements has a term exceeding 12 months.

The Year Ahead

Support

We will continue to support Alpha-1 patients and their loved ones, and researchers, and use social media and other mechanisms to share information, and to 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.

Education and Knowledge

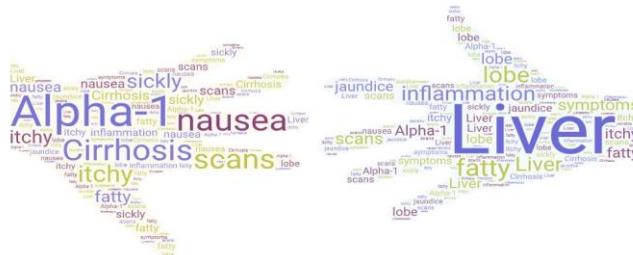
We are exploring Alpha-1 education options and hope to partner with relevant organisations to help with health professional and patient education.

Advocate

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

Awareness

We will continue to have a strong focus on community, health professional and stakeholder awareness and aim to provide Alpha-1 information to more health professional groups. We will promote the Alpha-1 test and spread the word about Alpha-1 prevalence in Australia and management options.



Contact Us

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