

Annual Report 2023

Waiting for Treatment and a Cure



alpha-1
ORGANISATION AUSTRALIA INC

Alpha-1 Organisation Australia inc

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Welcome from the President



On behalf of the Board, I am delighted to present our 2022-23 Annual Report

When I commenced this journey, I was aware of the challenges associated with obtaining treatment access for people with Alpha-1 Antitrypsin Deficiency (Alpha-1) and medical gaps in knowledge. While remaining dedicated to our vision to have affordable treatments, it seems clear that we need ongoing education and new evidence to support subsidised treatment and improved outcomes for those affected by Alpha-1.

On a positive note, our volunteers' optimism has led to new awareness raising resources, suitable for health professionals, the community and government. This year we produced three patient videos in our *Alpha-1 Unwrapped* series. Having released these videos we have now turned to expanding the series and we have begun production of interviews with health

professionals which explore being diagnosed and the management of Alpha-1.

The response to the first set has been epic and we can't wait to release the next set. I am in awe of what a small group of volunteers can achieve.

Our small volunteer team has made new strides in supporting people affected by Alpha-1. We gained accreditation for mental health support, were able to offer support to people struggling with a new diagnosis and grew the membership of our support group, which has members from across Australia.

The effort to obtain government subsidised treatments and more Alpha-1 related clinical trials across Australia continues. We wrote to government officials raising the urgent need, but the standard response remains (high cost and better

evidence required) was disappointing.

On a happier note, support came in many ways this year, including those who donated to our cause. A heartfelt thanks to volunteer Directors, charity members, and everyone who supported me and our team this year. A huge thankyou to everyone who made a financial donation too. The support, passion, resilience, and relentless dedication are the power that keeps us going and will help save lives. The support also enables us to continue and expand.

We will continue to advocate for treatment and a cure, and support people affected by this devastating disorder. I look forward to watching Alpha-1 Organisation Australia grow, and the dedication of people living with the disorder and others with an interest in improving the health of those affected.

Kind regards

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

Gaynor Heading PhD (Med)

President

About Us

Vision

To find a cure for Alpha-1
Antitrypsin

Mission

To compassionately provide support and advocacy for
alpha-1 Australians and to promote education and
research which will lead to a cure

We were registered as a charity on 4 June 2020. Our inaugural governance committee identified the need to have a new Australian charity for Alpha-1 that is accountable to its members and advocates for treatment and a cure for Alpha-1. The current Board membership includes people with Alpha-1 and health professionals.

Governance – Our Board

Position	Holder	Board Member Since
President	Dr Gaynor Heading	June 2020
Vice-President	Dr Laxmi Iyengar	October 2021
Secretary / Public Officer	Dr Gaynor Heading	June 2020
Treasurer	Ian Saunders	June 2020
Director Communications	Leonie Robison	June 2020
Director Education & Knowledge	Deborah Macfie	October 2021
Director Grants & Research	Dr Sandra Baxendell	June 2020
Director Marketing & Fundraising	Mark Lloyd	October 2021

Our charity intends to be the primary point-of-call for all Australian patients with Alpha-1, their families, carers, health professionals, government, and other interested parties, and to foster collaborations and partnerships to expedite our charity objectives.

Strategic Plan - Aims and Objectives

	Aims	Objectives
1	Support	Support people and their families affected by Alpha-1
2	Education and 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: Awareness

Alpha-1 Awareness Month

During November we used our new of Alpha-1 Unwrapped videos in social media to raise awareness about Alpha-1 and to have the simple Alpha-1 blood test.

Aim 2: Education and Knowledge

New Video series - *Alpha-1 Unwrapped*

As part of this new video series we developed and released three patient videos where Alpha-1 patients described their experience living with Alpha-1 (phase 1). As part of phase 2, we commenced working on interviews with health professionals, where we explore each part of the patient journey with Alpha-1 and the role of health professionals along the journey. All videos are available via the Alpha-1 Organisation YouTube channel and the website and promoted using social media.



Facts Sheets

We are expanding our set of facts sheet and drafted a fact sheet on Supplementary Oxygen which will be available on our website along with other evidence-based resources.

Australian Research Partnership

The President accepted an invitation to join the *Centenary Institute* as an Associate Investigator of the MRFF Chronic Respiratory Diseases grant submission and on future grant submissions. Collaborations such as this are valued and ensure that a patient / consumer perspective is considered in Alpha-1 research.

RARE Portal

We contributed to the Rare Portal for Rare Disease hosted by Rare Voices Australia. A presence in the portal not only provides information about Alpha-1 but helps consumers find our charity via our website link.

Conference Attendance

Alpha-1 Global sponsored a Board member to participate in the 5th International Research Conference in April 2023 in Dublin. Participation is essential to learn about the latest research and developments in Alpha-1 which were reported to the Board. Conference attendance enabled additional links to be made with international Alpha-1 researchers, the broader Alpha-1 community, and new international collaborations.

Aim 3: Support

Patient Peer Support

Alpha-1 Organisation's monthly online peer support meetings continued this year, providing a safe place for people affected by Alpha-1 to support each other and share information.



Individual Support

In addition to group support, we provided information and support to individuals. Requests for support came via the website, email, Messenger, telephone, the peer support group, from members, social media, stakeholder referral and from the mental health support email.

Mental Health Support

As a charity with a first aid certified mental health volunteer we were able to provide one-on-one support to newly diagnosed patients and their loved ones who often struggle with a new diagnosis of Alpha-1 Antitrypsin Deficiency. To access this service email: mentalhealth.a1oa@gmail.com to arrange a time to chat via email or by phone.



Website Redesign and Rebuild

During this year we rebuilt our website to add functionality which will improve the user experience. The redesign provides opportunity to share information and keep everyone updated more rapidly – visit [a1oa – www.a1oa.org.au](http://a1oa-www.a1oa.org.au).

Aim 4: Advocacy

Advocating for Subsidised Treatment

Our advocacy work continues with the aim to raise awareness of the need for subsidised augmentation treatment in Australia for lung-affected individuals who have the severe forms of Alpha-1 and are severely deficient in the essential protein 'antitrypsin'. We wrote to government representatives raising flaws with the Medical Services Advisory Committee (MSAC) recommendation from the November 2018 and the benefits of antitrypsin infusions. Sadly, the government has not changed its position, citing level of evidence and treatment cost. We, therefore, promote the Grifols Private Purchase Pathway as an option to access privately purchased augmentation therapy.



Artwork by Leonie Robison 2023

Advocating and Promoting Clinical Trials in Australia

We contacted Australian clinical trial sites and pharmaceutical companies involved in Alpha-1 clinical trials, encouraging them to offer new Alpha-1 studies across Australia.

We promoted the Estrella Liver trial.

Rare Disease Month and Day

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



Artwork by Leonie Robison 2023

Alpha-1 Newsletters

We published several editions of *Alpha Times*, bringing varied and useful information to the Alpha-1 community. Requests for a copy of our newsletter continue to grow.



Treasurer's Report

Financial Results

The period ending 30th June 2023 saw the charity return a deficit of \$799 (2022: surplus of \$16,207). Basic operational costs were maintained at a similar level to previous years, while the decision to invest in the series of 'Alpha-1 Unwrapped' videos to raise awareness added one-off costs of approximately \$4,700.

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 2023 the charity held assets of \$21,937 [2021: \$22,736]. 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

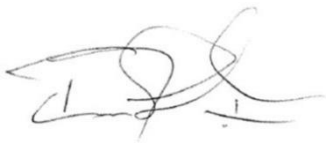
Alpha-1 Organisation is classified as a small charity by the Australian Charities and Not-for-profits Commission and as such there is no requirement to have its financial report reviewed or audited. In keeping with a commitment to openness and accountability the charity welcomes the opportunity to provide 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.

A handwritten signature in black ink, appearing to read 'Ian Saunders', with a stylized flourish at the end.

Ian Saunders
Treasurer 10th July, 2023

Financial Statements

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

Income Statement

	Note	2023 \$	2022 \$
Revenue from operating activities			
Donations		4,453	17,144
Membership subscriptions		820	840
Merchandise sales		15	-
		<u>\$ 5,288</u>	<u>\$ 17,984</u>
Other revenue			
Goodwill payment		-	250
Interest income		-	-
Loyalty program rebates		-	11
		<u>\$ -</u>	<u>\$ 261</u>
Total revenue		<u>\$ 5,288</u>	<u>\$ 18,245</u>
Expenses relating to operating activities			
Advertising, printing & stationery	5	1,082	109
Bank fees	2	235	363
Compliance costs		-	53
Gifts		-	106
Insurance premiums	3	767	743
IT costs	4	356	357
Membership & association fees		55	-
Merchandise costs		-	298
Professional Services	5	2,496	-
Sundry expenses		-	9
Travel & Accommodation	5	51	-
Venue Hire	5	1,045	-
Total expenses		<u>\$ 6,087</u>	<u>\$ 2,038</u>
Net surplus / (deficiency) for the year		<u>(799)</u>	<u>\$ 16,207</u>

Balance Sheet

	Note	2023 \$	2022 \$
Current Assets			
Cash assets		21,937	22,736
		<u>\$ 21,937</u>	<u>\$ 22,736</u>
Non Current Assets			
Property plant & equipment		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Assets		<u>\$ 21,937</u>	<u>\$ 22,736</u>
Current Liabilities			
Payables		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Liabilities		<u>\$ -</u>	<u>\$ -</u>
Net Assets		<u>\$ 21,937</u>	<u>\$ 22,736</u>
Members' Funds			
Balance at the beginning of the year		22,736	\$ 6,529
Current year earnings		-799	16,207
Total Members' funds		<u>\$ 21,937</u>	<u>\$ 22,736</u>

Cash Flow Statement

	Note	2023 \$	2022 \$
Cash flow from operating activities			
Receipts from donations		4,453	17,144
Receipts from members		820	840
Receipts from merchandise sales		15	-
Goodwill payment received		-	250
Interest received		-	-
Loyalty program rebates		-	11
Payments to suppliers		(6,087)	(2,038)
Net Cash flow from (used in) operating activities		(799)	\$ 16,207
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		(799)	16,207
Cash balance at the beginning of the year		22,736	6,529
Cash at the end of the financial year		\$ 21,937	\$ 22,736

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, and the insurance premiums paid includes a sum prepaid for the 2023/2024 financial year.

4. 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. A month-by-month agreement was also entered into for video-editing software which will support the production of future videos and podcasts.

5. One-off Video Preparation Costs

During the year the charity recorded and produced a series of patient interviews under the banner 'Alpha-1 Unwrapped' to be used in raising awareness and general publicity.

The Year Ahead

Advocacy

We will continue to advocate for affordable treatment, clinical trials in all states and territories, and for a cure. We believe that the future of Alpha-1 lies in research and clinical trials. We will collaborate with the Centenary Institute which specialises in COPD research, including Alpha-1, on research grants and exploring patient perspectives on priority areas for research. We will assist Alpha-1 researchers identify patient priority research questions.



Artwork by Gaynor Heading 2023

Support

We will continue to support Alpha-1 patients and their loved ones, and researchers, and use social media to share information and to raise the profile of Alpha-1. Our monthly peer support meetings will continue via Zoom. To request Zoom details, email contactus.a1oa@gmail.com.

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 aim to have a key awareness campaign reminding people to take an Alpha-1 test and to spread the word about Alpha-1 prevalence in Australia, management and healthy lifestyles.

We receive no government funding and are grateful to our donors, fundraisers and supporters including the *Rotary Club of Hornsby District* who promoted Alpha-1 and Rare Disease Day. This year funds supported the development of our new video series *Alpha-1 Unwrapped*.

Education and Knowledge

During phase 2 of the *Alpha-1 Unwrapped* video series, new videos featuring health professionals will be released. The videos will be useful for health professional education and Alpha-1 patients. Videos are available via our YouTube Channel [Alpha-1 Organisation Australia inc - YouTube](https://www.youtube.com/channel/UCa1oa).

Contact Us

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