

# 2021 ANNUAL REPORT

## Cure Alpha-1 Antitrypsin Deficiency



## Contents

History	1
Did You Know?	1
Governance	3
Structure and Management	3
Support	4
Volunteers	4
Individual Support	4
Organisational Support	4
Financial Support	4
President's Report	5
Alignment, Leadership and Relationships	6
Goal 1: Support	7
Patient Peer Support	7
Individual Support	7
NDIS Access	7
Web Development and Expansion	7
Alpha-1 Newsletters	7
Goal 2: Education and Knowledge	8
Grant Applications to Support Strategic Plan Implementation	8
Goal 3: Advocacy	8
Treatment Access and Health Vulnerability	8
Testing for Alpha-1	8
Addressing Misdiagnosis	8
Clean Air	9
Clinical Trial Access	9
Better Research Outcome Indicators	9
Goal 4: Awareness	9
Lung Health Awareness Month	9
Alpha-1 Awareness Month	9
Awareness Raising Using Social Media	10
Rare Disease Day 28 February	11
Treasurer's Report	12
Financial Results	12
Review of Operations	12

Organisation Assets	12
Committee Member Benefits	12
Significant Changes in the State of Affairs	12
Significant Events After Balance Date	12
Likely Developments and Expected Results	12
Financial Statements	13
Income Statement	13
Balance Sheet	14
Cash Flow Statement	15
Notes to and Forming Part of the Financial Statements	16
Auditor's Report Not Required	16
How You Can Be Involved	18
The Year Ahead	19
Medical and Scientific Advisory Group	19
Advocacy	19
Support	19
Awareness	20
Health Professional Education and Knowledge	20
Contact Us	21

## Mission

*To compassionately provide support and advocacy for Australians with Alpha-1 and to promote education and research which will lead to a cure.*

We advocate for the entire Australian Alpha-1 antitrypsin deficient community, support those affected by this genetic condition and seek to raise awareness about Alpha-1, as most people with Alpha-1 remain undiagnosed.

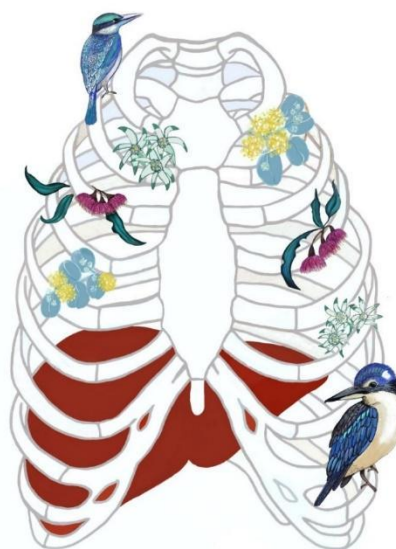
We strive to improve health professional knowledge about Alpha-1, to assist with timely and accurate diagnosis and optimal patient management. We advocate for access to subsidised treatment and a genetic cure.

## Vision

*Cure Alpha-1 antitrypsin deficiency (Alpha-1)*

## Our Values

- A**     Adaptable
- L**     Leadership
- P**     Proactive
- H**     Hope
- A**     Accountable



We model and promote behaviours that demonstrate our values. Our values guide our actions, interactions and decisions, and ensure that Alpha-1 sufferers remain at the centre of our work.

## History

The Alpha-1 Organisation Australia (Alpha-1 Organisation) was established by patients for patients, based on their experience that much was needed to support sufferers.

After officially registering our charity and developing our website in mid-2020, we went to work to produce our volunteer manual, policies, information fact sheets and brochures. We published a position paper on treatment access and infant screening, and built our social media presence. We quickly commenced our advocacy work and made submissions to the Australian Government about Alpha-1 genetic testing and the need for timely access to affordable treatment and a cure. We also raised the need for secure vaccine production in Australia and the vulnerability of people with Alpha-1.

## Did You Know?

Despite Alpha-1 being a serious chronic disorder there is no Government subsidised treatment

Alpha-1 mostly affects the lungs and liver but it can affect other organs including the skin, blood vessels and gall bladder

1 in 9 Australians have a faulty Alpha-1 gene, putting them at risk of liver and lung disease but most are unaware

Most people diagnosed with Alpha-1 are not alive at age 60, with most dying from genetic emphysema

A small percentage of infants will be born with serious Alpha-1 liver damage and will require an urgent liver transplant

Alpha-1 is a systemic disorder, leaving individuals vulnerable to infections, inflammation and viruses

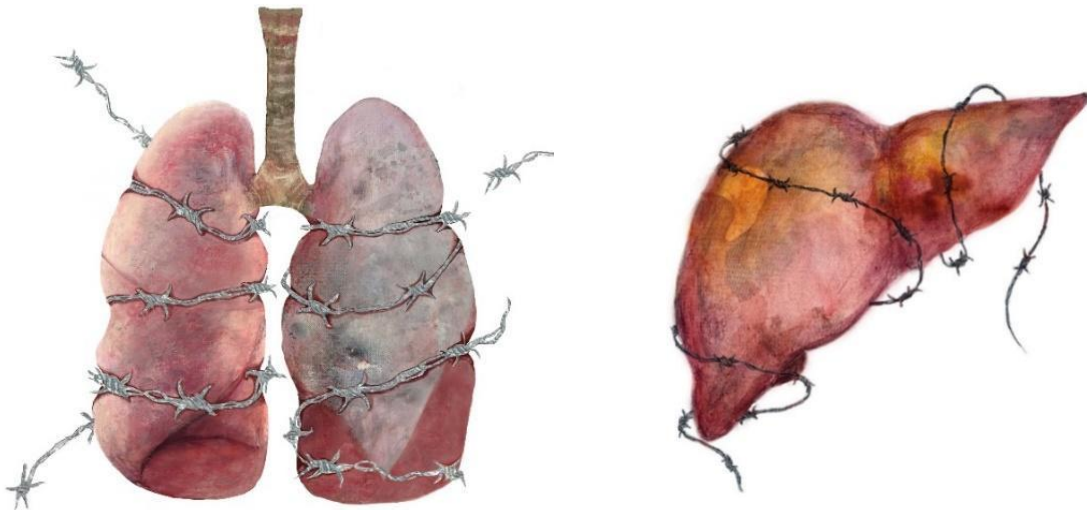
Australia does not do Alpha-1 infant screening, resulting in a late diagnosis after organ damage has occurred

Parents with one faulty Alpha-1 gene can pass it onto their children who may be at risk of liver and lung transplant

Alpha-1 is a rare genetic disease but it is rarely diagnosed or is misdiagnosed as asthma or COPD

## Overview

Alpha-1 antitrypsin deficiency is a devastating genetic disorder caused by a fault in a protective protein called Alpha-1 antitrypsin, which is primarily made in the liver. Alpha-1 antitrypsin is a protein that balances the body's response to infection and injury (e.g. environmental lung irritants, inflammation). If antitrypsin is trapped in the liver through a genetic "misfolding" or if it is destroyed before it reaches organs via the bloodstream, liver injury (i.e. cirrhosis) and lung emphysema can occur. The only treatment to protect lungs from genetic emphysema is infusions with Alpha-1 Antitrypsin but treatment is not subsidised by the Australian Government and is largely unaffordable for private purchase. No liver treatment is available. Without treatment or a cure, patients experience poor quality of life and poor survival with most severely deficient sufferers not making it to 60 years of age. Our charity was established to address these issues.



*Original artwork by Leonie Robison*

## Governance

Our goal is to not only comply with the requirements of our regulators but to uphold the spirit of good governance. The governance committee meets on the first Monday of each month. Members of the Alpha-1 Organisation are welcome to attend as observers. Committee minutes and agendas are available to members upon request. We know the importance of sound leadership and apply strong governance reflected in our ways of working:

We have policies and transparency supporting all aspects of our business

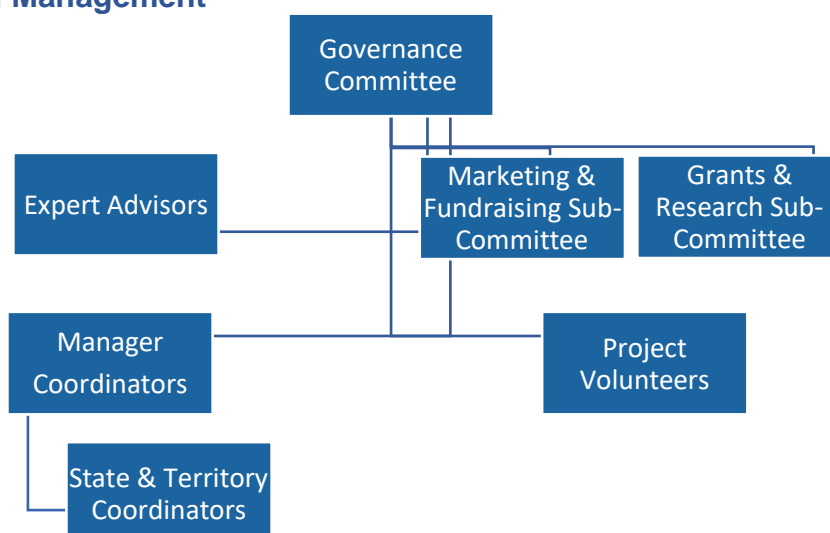
Our governance committee focuses on strategy to ensure impact

We report against our strategic plan's aims and objectives and report achievements

The following people have served on our governance committee:

Position	Holder	Start	End
President	Gaynor Heading PhD	4 <sup>th</sup> Jun 2020	30 <sup>th</sup> Jun 2021
Vice-President	Russell Stedman	4 <sup>th</sup> Jun 2020	23 <sup>rd</sup> Nov 2020
Secretary	Karen Akers	4 <sup>th</sup> Jun 2020	7 <sup>th</sup> Aug 2020
Secretary	Paola Torres	18 <sup>th</sup> Mar 2021	30 <sup>th</sup> Jun 2021
Treasurer	Ian Saunders	4 <sup>th</sup> Jun 2020	30 <sup>th</sup> Jun 2021
Director Communications	Leonie Robison	4 <sup>th</sup> Jun 2020	30 <sup>th</sup> Jun 2021
Director Grants & Research	Sandra Baxendell PhD	4 <sup>th</sup> Jun 2020	30 <sup>th</sup> Jun 2021
Director Support	Jean Gray	4 <sup>th</sup> Jun 2020	3 <sup>rd</sup> May 2021
Director Marketing & Fundraising	Ann Wald	1 <sup>st</sup> Mar 2021	30 <sup>th</sup> Jun 2021
Director Advocacy	Leonie Robison	4 <sup>th</sup> Jun 2021	31 <sup>st</sup> Mar 2021
Director Advocacy	Denise Morden	1 <sup>st</sup> Apr 2021	30 <sup>th</sup> Jun 2021

## Structure and Management



## Support

### Volunteers

Our organisation is made possible by the generous support of volunteers. We are fully volunteer led and run. We wish to acknowledge the support of the following volunteers during this report period:

#### State Coordinators

- Ian Saunders                      State Coordinator Australian Capital Territory
- Leonie Robison                      State Coordinator New South Wales
- Raeleen Whitely                      State Coordinator Northern Territory
- John Hammond                      State Coordinator Queensland
- Ann Wald                      State Coordinator South Australia
- Jean Gray                      State Coordinator Tasmania
- Vacant                      State Coordinator Victoria
- Hayley Argiropolous                      State Coordinator Western Australia

#### Sub-Committees

- Alan Morden                      Marketing and Fundraising Sub-Committee
- Denise Morden                      Marketing and Fundraising Sub-Committee
- Russell Stedman                      Marketing and Fundraising Sub-Committee
- Ann Wald                      Marketing and Fundraising Sub-Committee
- Sandra Baxendell                      Grants and Research Sub-Committee
- Gaynor Heading                      Grants and Research Sub-Committee
- Hariklia Nguyen                      Grants and Research Sub-Committee

### Individual Support

We wish to acknowledge the following people for their advice, advocacy, support and volunteering contributions offered during this period:

- Prof Ashley Buckle
- Prof Philip Hansbro
- Dr Jonathan Burdon
- Fiona Raffan
- Lisa Singleton

### Organisational Support

We value the support from the following organisations offered during this period:

- Lung Foundation Australia
- Milkshake Co
- Rare Voices Australia
- Rotary Club of Hornsby District
- Alpha-1 Foundation (United States)

### Financial Support

We are extremely grateful to our donors and fundraisers. Donations have assisted us to implement our strategic plan and improve the lives of Alpha-1 sufferers. You are helping to change the status of Alpha-1, taking it from a rarely considered, rarely discussed genetic disorder, to one which becomes well-understood and a household name.



## President's Report



In 2020 a group of committed volunteers established and registered a new not-for-profit national charity dedicated to Alpha-1 antitrypsin deficiency. The support from our volunteers is undeniable. It is testament to the commitment and compassion they have about bringing change to the lives of people who suffer from Alpha-1. I would particularly like to thank our governance committee and sub-committee members for their incredible support and contributions, and our state / territory coordinators who have been prepared to volunteer in a state-wide capacity.

We have had a very productive first year raising awareness about Alpha-1, producing publications for members and the public and supporting sufferers. I am proud of all of the work including our submissions to the Australian Government, advocating for access to treatment that can save lives and reduce suffering.

Now that we are established, where do we go from here? Our governance committee spent part of 2020 laying out a strategic plan to assist sufferers in various ways. We have implemented several parts of the plan and aim to implement further components next year with a special focus on health professional knowledge and awareness about Alpha-1 and building further strategic alliances, while we advocate for treatment and a cure.

Our governance committee thanks you for your support, time, expertise and donations which have made this year's achievements possible. It is an honour to present this Annual Report for the period ending 30 June 2021.

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

Gaynor Heading PhD (Med)  
President

## Alignment, Leadership and Relationships

- The *Alpha-1 Lung Peer Support Group* was established with formal support from the *Lung Foundation Australia*.
- We entered a formal partnership with *Rare Voices Australia*.
- We mapped the *National Strategic Action Plan for Rare Diseases* against our strategic plan, to identify strategic opportunities.
- We participated in three *Rare Voices Australia* events during this period which provided valuable information about issues related to rare diseases and gave us an opportunity to raise Alpha-1 issues with members of parliament.
- We are part of the *Connect Groups* community, a Western Australia accredited group dedicated to supporting community groups.
- We liaised with the *Alpha-1 Foundation* in the United States.
- *St Vincent's Hospital* has included a link on their website to our website.
- We were invited to present on Alpha-1 via Zoom to the *Rotary Club of Hornsby District*. Our presentation resulted in the club choosing Alpha-1 as one of their national focus areas. This has led to Alpha-1 being showcased on their website with a link to our website. The presentation is available on the YouTube channel for the Rotary Club of Hornsby District at <https://youtu.be/cVcOVBhl764>.
- We met with *Aegros* to explore their fractionation technology and potential relevance to Alpha-1.
- We wrote to Australian Alpha-1 researchers offering support, resulting in new collaborative arrangements.
- Our meeting with the *National Asthma Council* explored ways to minimise Alpha-1 sufferers being misdiagnosed with asthma, resulting in support from their medical advisors that Alpha-1 will be included in the *Asthma Handbook*.
- We established a *Shopnate* presence, providing an easy mechanism for supporters to donate to Alpha-1 Organisation.
- Our insurance package is with AON.

# Goal 1: Support

## Patient Peer Support

We established the national Alpha-1 Lung Peer Support Group, auspiced by the Lung Foundation Australia. The group follows the Lung Foundation's Online Network Guidelines to ensure a safe and supportive community. This group meets monthly via video and provides support to patients with Alpha-1. Items discussed vary monthly, driven by Alpha-1 members.

## Individual Support

In addition to group support, we provided information and support to individuals. Requests for support come via email, the Messenger app, the telephone, our state and territory coordinators, our peer support group, from members, social media and stakeholder referral.

## NDIS Access

We provided severely affected sufferers with information about accessing support from NDIS as patients are currently denied support. We provided information on both the application and appeals process.

## Web Development and Expansion

With the assistance of Milkshake Co, we developed a website which provides vital information about Alpha-1. Our website provides members with access to additional Alpha-1 resources including research summaries.

## Alpha-1 Newsletters

We published four newsletters *Alpha Times* in this period bringing varied but useful information to the Alpha-1 community. Requests for a copy of our newsletter continue to grow. All issues are available via our website [www.a1oa.org.au](http://www.a1oa.org.au).



## Goal 2: Education and Knowledge

### Grant Applications to Support Strategic Plan Implementation

We applied for two grants during this period to support the development of learning materials, one was unsuccessful while one remains open.

- 1) Pierce Armstrong Grant (unsuccessful)
- 2) Department of Health – Rare Diseases – Support, Education and Training Grant (open).

In anticipation of developing learning objectives and materials for general practitioners, we commenced mapping the Royal Australian College of General Practitioners (RACGP) curriculum against Alpha-1 evidence.

## Goal 3: Advocacy

### Treatment Access and Health Vulnerability

Our main advocacy agenda is focused on gaining access to services, subsidised treatment, and a cure. On behalf of sufferers, we raised a number of important issues with the Australian Government including: the need for subsidised Alpha-1 augmentation treatment; how Alpha-1 vulnerability is worsened during pandemics; the need for early access to safe, highly efficacious COVID-19 immunisations; and, the need for a secure supply of home-grown treatments and immunisations. We encouraged sufferers to raise treatment needs with members of parliament and with government officials, and provided two template letters for patients to use when writing to the Government and members of parliament.

We successfully made a submission to the House of Representative Standing Committee on Health, Aged Care and Sport into the *Approval processes for new drugs and novel medical technologies in Australia*. The inquiry has a focus on accessing new drugs and novel medical technologies with a particular focus on those for the treatment of rare diseases and conditions where there is high and unmet clinical need. In March 2021 we were invited to make a presentation (as a witness) to the Inquiry's panel. The Panel was provided with a copy of our submission.

### Testing for Alpha-1

We made a submission to the Medical Services Advisory Board (MSAC) supporting the inclusion of Alpha-1 genotyping in the publicly funded Medicare Benefits Schedule (MBS). The MSAC enquiry is still open. The outcome will be published elsewhere.

### Addressing Misdiagnosis

Due to the common misdiagnosis of Alpha-1 as asthma and due to the cross over between Alpha-1 and asthma, we advocated for Alpha-1 to be included in the Australia Asthma Handbook. Advice has been received that Alpha-1 will be included in the next version (by the end of 2021).

## Clean Air

We advocated for clean air and wrote to the NSW Health Minister and NSW Environmental Protection Authority, raising the need for tighter regulations and stronger policies to protect residents from smoke caused by residential wood burners. We advised peak lung groups that we are advocating for cleaner air. We provided data on vulnerable health groups, including people with faulty Alpha-1 antitrypsin genes, to national “clean air” advocacy groups, to support state and national advocacy campaigns.

The data we compiled, comparing vulnerable groups and the number of people affected from wood smoke was provided to the parliamentary *Inquiry into the Health Impact of Air Pollution in Victoria*.

## Clinical Trial Access

We advocated for Alpha-1 Clinical Trials to come to Australia.

We entered into discussions with Vertex Pharmaceuticals, exploring the possibility of bringing their Alpha-1 clinical trials to Australia. Unfortunately, their two international Alpha-1 trials were stopped early due to unanticipated outcomes.

## Better Research Outcome Indicators

We discussed the need for better research outcome indicators with international Alpha-1 research groups, as FEV<sub>1</sub> is a poor surrogate for emphysema and FEV<sub>1</sub> is less sensitive to change than other measures.

## Goal 4: Awareness

We applied for funding from the Australian Community Foundation and are yet to be chosen. This application focuses on funding to develop animated Alpha-1 awareness raising materials suitable for use on various media.

### Lung Health Awareness Month

We participated in May’s Lung Health Awareness Month and provided information on how to protect vulnerable lungs from indoor and outdoor pollution and cigarette smoke, and the importance of treating lung exacerbations quickly to preserve lung tissue.

### Alpha-1 Awareness Month

Our members designed 12 colourful posters mostly featuring livers and lungs which were used across our social media platforms to raise Alpha-1 awareness during November – a month internationally dedicated to Alpha-1 Awareness Month each year. The full set of posters is available for free download via our website - [www.a1oa.org.au](http://www.a1oa.org.au).

## Alpha-1 Awareness Month Posters

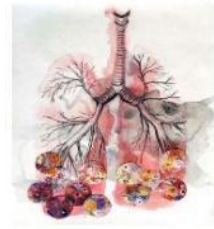
Does your child lack energy and you don't know why?

Information and support  
<https://www.a1oa.org.au>  
[contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)



Have emphysema or COPD but never smoked?

Information and support  
<https://www.a1oa.org.au>  
[contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)



Alpha-1 Antitrypsin Deficiency Awareness Month

**alpha-1**  
ORGANISATION AUSTRALIA INC

Alpha-1 Antitrypsin Deficiency Awareness Month

**alpha-1**  
ORGANISATION AUSTRALIA INC

Chronic fatigue, unexplained bruises and loss of appetite?

Information and support  
<https://www.a1oa.org.au>  
[contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)



Unexplained liver disease? Perhaps we can help

Information and support  
<https://www.a1oa.org.au>  
[contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)



Alpha-1 Antitrypsin Deficiency Awareness Month

**alpha-1**  
ORGANISATION AUSTRALIA INC

Alpha-1 Antitrypsin Deficiency Awareness Month

**alpha-1**  
ORGANISATION AUSTRALIA INC

Childhood jaundice, poor weight gain, raised liver enzymes?

Information and support  
<https://www.a1oa.org.au>  
[contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)



Given up smoking but still short of breath?

If this sounds like you visit our website for information  
<https://www.a1oa.org.au>  
[contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)



Alpha-1 Antitrypsin Deficiency Awareness Month

**alpha-1**  
ORGANISATION AUSTRALIA INC

Alpha-1 Antitrypsin Deficiency Awareness Month

**alpha-1**  
ORGANISATION AUSTRALIA INC

### Awareness Raising Using Social Media

We flew the Alpha-1 flag on social media (i.e. Twitter, Instagram, Facebook) and shared valuable information for Alpha-1 sufferers on how to minimise risk and how to live our healthiest lives while we wait for treatment and a cure. Social media platforms have been valuable to connect with the Alpha-1 community and to provide support. Our followers and members grow on Instagram, Facebook and Twitter.

**Rare Disease Day 28 February**

We participated in Rare Disease day, a dedicated day where all rare diseases unite to raise awareness about rare disease.

# Alpha-1 Antitrypsin Deficiency A genetic condition passed from parent to child through genes



*Rare Disease Day Poster*

## Treasurer's Report

### Financial Results

The period ending 30<sup>th</sup> June 2021 represents the first financial reporting period (from date of incorporation – 4<sup>th</sup> June 2020 – to 30<sup>th</sup> June 2021) of the organisation, and there are thus no prior period accounts available for comparison. The net operating surplus of \$6,529 for the period [2020: N/A] is presented in the Income Statement.

### Review of Operations

To cover operating and capital expenditure during the year the organisation drew its income primarily from memberships and donations.

### Organisation Assets

At 30<sup>th</sup> June 2021 the organisation held assets of \$6,529 [2020: \$0]. All assets at the end of period were held in cash.

### Committee Member Benefits

During the period no committee member of the organisation has received, or become entitled to receive, a benefit, because of a contract that the committee member, a firm of which the committee member is a member, or an entity in which the committee member has a substantial financial interest, has made with the organisation.

### Significant Changes in the State of Affairs

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

### Significant Events After Balance Date

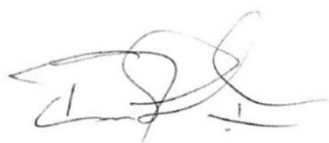
There have been no matters or circumstances that have arisen since the end of the financial year that have significantly affected, or may affect, the organisation's operations in future financial years, the results of those operations or the state of affairs in future financial years.

### Likely Developments and Expected Results

The organisation 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 organisation together with the amount of any donations and or/grants made to the organisation, and the revenue generated by any fundraising activities and/or merchandise sales.

Signed in accordance with a resolution of the members of the committee of the Alpha-1 Organisation Australia Inc.



Ian Saunders  
Treasurer  
5<sup>th</sup> July, 2021



## Financial Statements

### Income Statement

	Note	2021 \$	2020 \$
<b>Revenue from operating activities</b>			
Donations		7369	
Grants		-	
Membership subscriptions		840	
Merchandise sales		81	
		<u>\$ 8,290</u>	<u>\$ -</u>
<b>Other revenue</b>			
Interest income		1	
		<u>\$ 1</u>	<u>\$ -</u>
<b>Total revenue</b>		<u><b>\$ 8,291</b></u>	<u><b>\$ -</b></u>
<b>Expenses relating to operating activities</b>			
Accounting and audit fees		-	
Advertising, printing & stationery		-	
Bank fees	2	53	
Compliance costs		-	
Depreciation		-	
Function expenses		-	
Insurance premiums	3	1,430	
IT costs		92	
Membership & association fees		55	
Merchandise costs		54	
Sundry expenses		78	
<b>Total expenses</b>		<u><b>\$ 1,762</b></u>	<u><b>\$ -</b></u>
Net surplus / (deficiency) for the year		<u><b>\$ 6,529</b></u>	<u><b>\$ -</b></u>

*This statement should be read in conjunction with the accompanying notes*

## Balance Sheet

	Note	2021 \$	2020 \$
<b>Current Assets</b>			
Cash assets		6,529	
Receivables		-	
Inventories		-	
		<u>\$ 6,529</u>	<u>\$ -</u>
<b>Non Current Assets</b>			
Property plant & equipment		-	
		<u>\$ -</u>	<u>\$ -</u>
<b>Total Assets</b>		<u><b>\$ 6,529</b></u>	<u><b>\$ -</b></u>
<b>Current Liabilities</b>			
Payables		-	
		<u>\$ -</u>	<u>\$ -</u>
<b>Total Liabilities</b>		<u><b>\$ -</b></u>	<u><b>\$ -</b></u>
<b>Net Assets</b>		<u><b>\$ 6,529</b></u>	<u><b>\$ -</b></u>
<b>Members' Funds</b>			
Balance at the beginning of the year		-	
Current year earnings		6,529	
<b>Total Members' funds</b>		<u><b>\$ 6,529</b></u>	<u><b>\$ -</b></u>

*This statement should be read in conjunction with the accompanying notes*

## Cash Flow Statement

	Note	2021 \$	2020 \$
<b>Cash flow from operating activities</b>			
Receipts from donations		7,369	
Receipts from grants		-	
Receipts from members		840	
Receipts from merchandise sales		81	
Interest received		1	
Payments to suppliers		-1,762	
<b>Net Cash flow used in operating activities</b>		<u>\$ 6,529</u>	<u>\$ -</u>
<b>Cash flows from investing activities</b>			
<b>Net cash flows from investing activities</b>		<u>\$ -</u>	<u>\$ -</u>
<b>Cash flows from financing activities</b>			
<b>Net cash flows from financing activities</b>		<u>\$ -</u>	<u>\$ -</u>
Net Increase / (decrease) in cash held		6,529	
Cash balance at the beginning of the year		-	
<b>Cash at the end of the financial year</b>		<u>\$ 6,529</u>	<u>\$ -</u>

*This statement should be read in conjunction with the accompanying notes*

## 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 organisation to date.

#### (c) Taxes

##### *Income Tax*

The organisation is exempt from income tax.

##### *Goods and Services Tax (GST)*

The organisation 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 organisation (e.g. *TryBooking*).

### 3. Insurance premiums

The organisation prepares its accounts on a cash basis, and the insurance premiums paid includes a sum prepaid for the 2021/2022 financial year.

## Auditor's Report Not Required

Alpha-1 Organisation Australia Inc is classified as a small charity by the ACNC and is not required to submit an auditor's report.

Further details of income and expenditure are available to members upon request.



*Original woodblock print by Gaynor Heading*

*Reflecting on the Alpha-1 PiZZ genotype and its links to the Vikings.*

## How You Can Be Involved

Become a member

Volunteer on the Committee

Write a short article for the newsletter

Volunteer on an advisory group

Volunteer on a sub-committee

Assist with a project

Organise an event

Donate

## The Year Ahead

### Medical and Scientific Advisory Group

The past year has been exciting, establishing a new proactive charity and commencing the implementation of our strategic plan. In the coming year we aim to move to a more formal advisory structure by forming the following key advisory groups:

- Medical and Scientific Advisory Group
- Establishing a Medical Education Advisory Group

### Advocacy

We will continue to advocate for subsidised treatment to support the quality and length of Alpha-1 lives and to reduce emotional and physical suffering.

We will advocate for Alpha-1 Antitrypsin Deficiency to be included in the NDIS so our most vulnerable patients are provided with the support services and devices that they require to live their best lives and so that they don't have to use precious energy in appealing outcomes.

We will use a variety of mechanisms to raise the need for clean air and the importance of good air quality, to protect vulnerable Alpha-1 lungs.

We will have meetings with the Government and other key stakeholders to discuss the need for Alpha-1 research, affordable treatments and a cure. We will use social media including Twitter and Facebook to advocate for change.

Advocating for  
affordable treatment

Advocating for NDIS  
recognition of Alpha-1

Meetings with  
government

### Support

We will continue to support sufferers, carers and Alpha-1 researchers, and administer a public Facebook page and an Instagram page. Members will experience additional benefits including access to updated summaries on Alpha-1 research.

Alpha-1 Lung  
Peer Support  
monthly  
meetings via  
video

Alpha-1  
coordinators  
to meet and  
greet new  
members

## Awareness

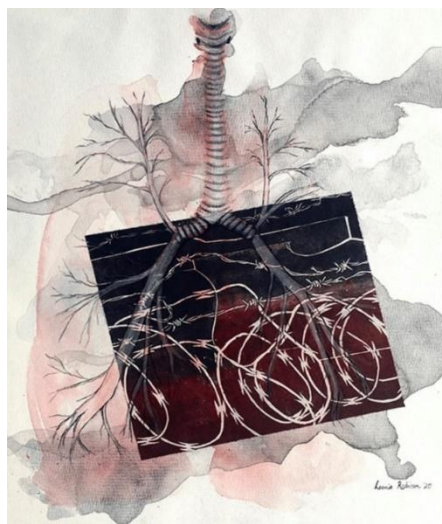
We will have a stronger focus on community, health professional and stakeholder awareness.

Providing Alpha-1 flyers to doctors and patients

Awareness campaigns encouraging people to have a simple Alpha-1 blood test

Providing print on demand flyers and posters for community awareness

Our awareness raising campaigns will continue to use members' art which is memorable. We aim to add animation to our suite of campaigning products.



*Original artwork, mixed media by Leonie Robison*

## Health Professional Education and Knowledge

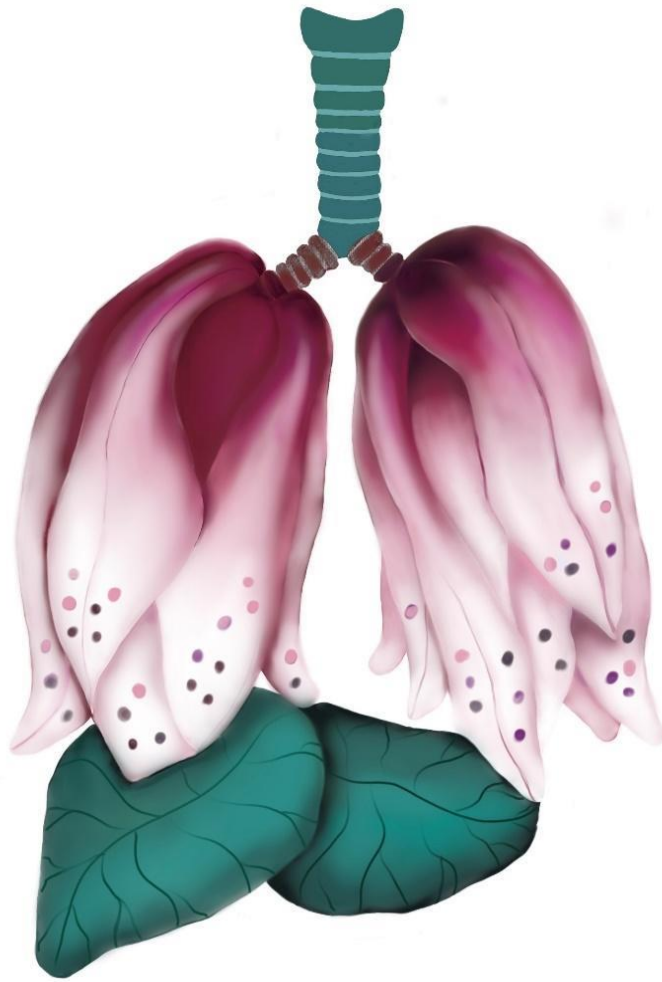
We will continue to submit grants to enable us to develop interactive online learning materials for medical practitioners. We will collaborate, share resources and consider learners' needs.

Collaborations to support Alpha-1 health professional learning

Mapping Alpha-1 evidence to medical college curricula

Providing Alpha-1 evidence for inclusion in external resources





*Original artwork by Gaynor Heading*

## **Contact Us**

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