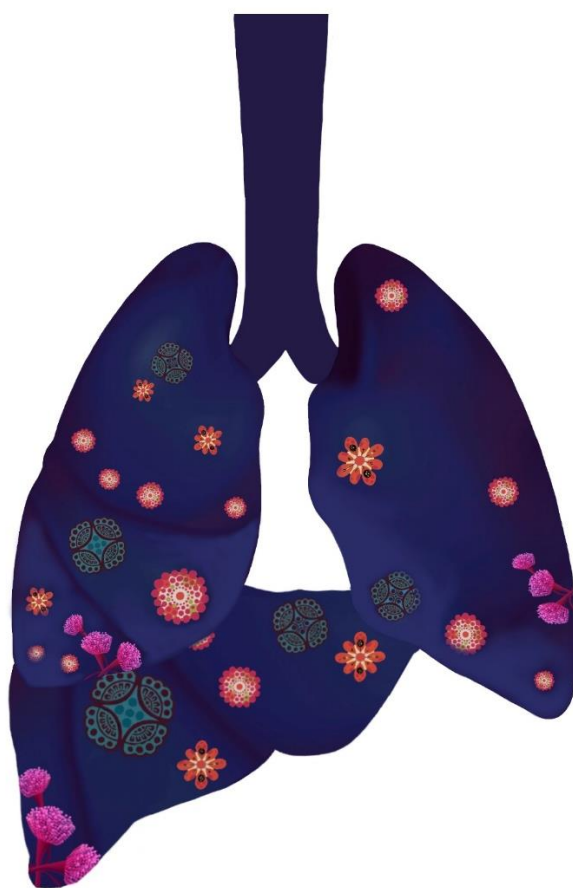


Annual Report 2022

Finding the Cure Starts with Awareness



alpha-1
ORGANISATION AUSTRALIA INC

Alpha-1 Organisation Australia inc

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MISSION

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

Alpha-1 Organisation Australia (Alpha-1 Organisation) advocates on behalf of people and families affected by the genetic condition known as Alpha-1 Antitrypsin Deficiency (Alpha-1).

Alpha-1 Organisation seeks to raise awareness about Alpha-1. One in nine Australians has at least one faulty Alpha-1 gene but most people remain undiagnosed as Alpha-1 is typically considered a rare disease. Alpha-1 is associated with serious lung and liver disease so an accurate and timely diagnosis is important to support individuals to make modifiable risk factor changes. Alpha-1 Organisation supports individuals affected by Alpha-1 and strives to improve health professional knowledge, to assist with better diagnosis and optimal patient management. We also advocate for access to clinical trials, subsidised treatments and a genetic cure.

VISION

Cure Alpha-1 antitrypsin deficiency (Alpha-1)

OUR VALUES

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

HISTORY

Alpha-1 Organisation Australia (Alpha-1 Organisation) was established in June 2020. The charity was formed in recognition of the fact that patients did not have access to treatment and that a lack of Alpha-1 awareness in the medical and general community was associated with poor outcomes, diagnostic delays, misdiagnosis and poor management, placing patients at higher risk of lung and liver decline and poorer survival odds.

Following a strategic review in 2021, Alpha-1 Organisation has continued with its four aims:

1. advocacy for affordable treatments and a cure
2. improved community and health professional knowledge and awareness about Alpha-1
3. timely and accurate diagnosis and management
4. support for patients and carers

ALPHA-1 FACTS

11% percent of the Australian population has a faulty Alpha-1 gene but most people are unaware of their risk of lung or liver disease from antitrypsin deficiency

The natural history of Alpha-1 is poorly understood, leading to the development of patient registries around the world, with one planned for Australia

Antitrypsin protects lungs from neutrophil destruction but the Government refuses to subsidise the only therapy in the world proven to reduce further lung damage

Lung and liver damage are the organs usually associated with Alpha-1 but systemic inflammation is now reported to be a symptom

Australia requires a mechanism (such as new-born screening) to detect people with Alpha-1 BEFORE lung and liver damage occurs

Alpha-1 has been recognised as a disorder of innate immunity which leaves Alphas vulnerable to viruses and bacteria

Infants can be born with serious Alpha-1 liver damage and may require an urgent liver transplant during childhood

In adults, Alpha-1 often presents as early-onset emphysema which occurs due to the loss of protective antitrypsin in the lungs

Lung irritants should be avoided as they cause rapid lung destruction in people with Alpha-1. In particular people with Alpha-1 should avoid smoking

OVERVIEW

Alpha-1 antitrypsin deficiency is a devastating genetic disorder caused by a fault in the body's production of the protective protein known as Alpha-1 antitrypsin, which is primarily made in the liver. Alpha-1 antitrypsin balances the body's response to infection and injury (e.g., environmental lung irritants, inflammation) and it is now recognised that the loss of Alpha-1 antitrypsin impacts immune function (Russell DW, 2016). If antitrypsin is trapped in the liver through a genetic protein "misfolding" or if the protein is destroyed before it reaches organs via the bloodstream, to protect them from injury, then serious organ damage can occur including liver cirrhosis and lung emphysema. The only treatment to protect lungs from genetic emphysema is infusions with Alpha-1 antitrypsin – made from plasma donations, but augmentation therapy (antitrypsin infusions) is not subsidised by the Australian Government and is largely unaffordable for private purchase. No liver treatment is available in the world but a few early-phase clinical trials are underway, including one in Australia – the Estrella study. Without treatment or a cure, patients experience poor quality of life and poor survival. Alpha-1 Organisation was established to support patients and advocate for treatment and a cure and to improve patient survival.



"Infusion Day". Artwork courtesy of Gaynor Heading

About Alpha-1 Organisation Australia inc

Alpha-1 Organisation was founded on 4 June 2020. The organisation is a public health not-for-profit registered charity, endorsed for the following charity tax concessions: Income Tax, Goods and Services Tax (GST) and Fringe Benefit Tax. Alpha-1 Organisation is registered with the Australian Charities and Not-for-Profits Commission and with NSW Fair Trading. We held our first AGM via Zoom in August 2021. We will continue to hold our annual AGMs via Zoom, to enable national participation.

Governance

Alpha-1 Organisation has a Board and a constitution and is an incorporated body. The charity is registered with NSW Fair Trading and the Australian Charities and Not for Profits Commission.

Commitment to Good Governance

Alpha-1 Organisation is committed to sound and effective corporate governance. Our goal is to not only comply with the requirements of our regulators but to uphold the spirit of good governance. The Board meets monthly, typically on a Monday evening. Members of the organisation are welcome to attend board meetings as observers. Board minutes and agendas are available to members upon request.

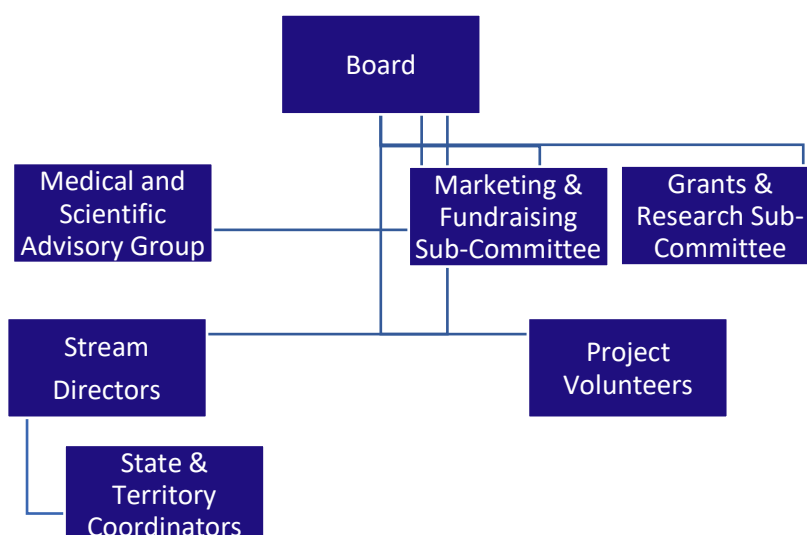
The Board

The Board consists of seven directors who volunteer their expertise and time to oversee the implementation of the strategic plan, support the Alpha-1 community and to drive improvements in treatment and management.

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

Structure & Management

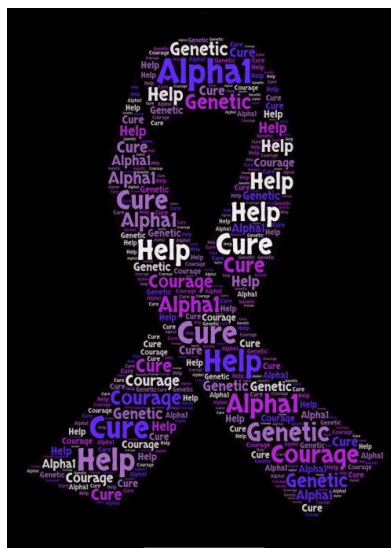
During this financial period, we developed a Medical and Scientific Advisory Group comprised of Australian medical specialists and Alpha-1 scientists.



Support

Alpha-1 Organisation is based on a volunteer model and activities are made possible by the generous support of volunteers. We wish to acknowledge the support of the following individuals and groups during this period:

- Hayley Argiropolous
- Sue Brenton
- Dr Jonathan Burdon
- Jean Gray
- John Hammond
- Dr Sam Kim
- Hariklia Nguyen
- Lisa Singleton
- Paula Torres
- Raeleen Whitely
- Jay Young FEWD
- Lung Foundation Australia
- Rare Voices Australia
- The Rotary Club of Hornsby District



Awareness Raising and Fund- Raising

We are extremely grateful to our donors and fundraisers. Donations have assisted us to implement our strategic plan. Donations are helping to change the status of Alpha-1 from a rarely considered, rarely discussed genetic disorder, to one which is becoming better-understood and known.

In particular the Board would like to acknowledge the epic cycling adventure by Mark Lloyd and Matt Nichols who rode from Sydney to Melbourne to raise awareness about Alpha-1 and funds for Alpha-1 Organisation.



Mark and Matt leaving Sydney on their heroic cycle

President's Report



Casting an eye over the last 12 months reveals the impact of the pandemic on our organisation, Alpha-1 patients, members and stakeholders. Our volunteers rose to the challenge and worked in difficult circumstances to achieve the results presented in this report.

During the year we welcomed new members, implemented strategic activities and made further links with the international scientific community – including important links enabling us to explore Alpha-1 vulnerability and potentially poor outcomes in a COVID-19 environment. We spent weeks examining the emerging COVID-19 literature and contacting biobank researchers to determine if Alpha-1 was included in their COVID-19 risk analysis. We examined theoretical risk, studies correlating poor outcomes with Alpha-1 country prevalence, searched for conference presentations, examined bio-bank and genome-wide study results, considered clinical modelling studies and lab studies, and studies that included Alpha-1 patients and those that used Alpha-1 antitrypsin as an acute intervention in COVID positive hospital patients. We kept stakeholders informed of the emerging data and risk interpretation, and wrote to all relevant Australian Government stakeholders highlighting the increased risk and likelihood of worse outcomes for Alpha-1 patients. Following the May 2022 Federal election, we wrote to the new Government. Unfortunately, concerns raised did not lead to any specific government considerations or access to subsidised augmentation therapy.

Our 2022 strategic planning event reassured the Board that the organisational strategic plan was highly relevant and will serve the organisation well as volunteers work to improve the lives of people affected by Alpha-1. We remain focused on building community and patient awareness, building health professionals' knowledge, supporting patients and advocating for access to subsidised treatments and a cure.

I would like to thank our Board, volunteers, and fund-raisers for their valuable support and contributions. To all our volunteers who generously give support, time and expertise, I am forever thankful. I am delighted to present our Annual Report which contains detailed information linked to our strategic intent and activities, and financial results.

Best regards

Gaynor Heading

A handwritten signature in black ink, appearing to read 'G Heading', written over a light blue horizontal line.

Gaynor Heading PhD (Med)

President

Goal 1: 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. Meetings ranged from one to two hours duration. This year we invited two guest speakers to speak - a respiratory care nurse from *Lung Foundation Australia* and a respiratory physician from Queensland (Dr Sam Kim). We are thankful for their time and the wealth of information shared. Peer support meetings were promoted via social media.



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 and stakeholder referral.

International Community Support

While Alpha-1 Organisation primarily supports Australians, our international community links enabled broader support and awareness raising. We developed an Alpha-1 word forest and shared the results internationally with other Alpha-1 support groups and helped a few patients link with support in their countries.

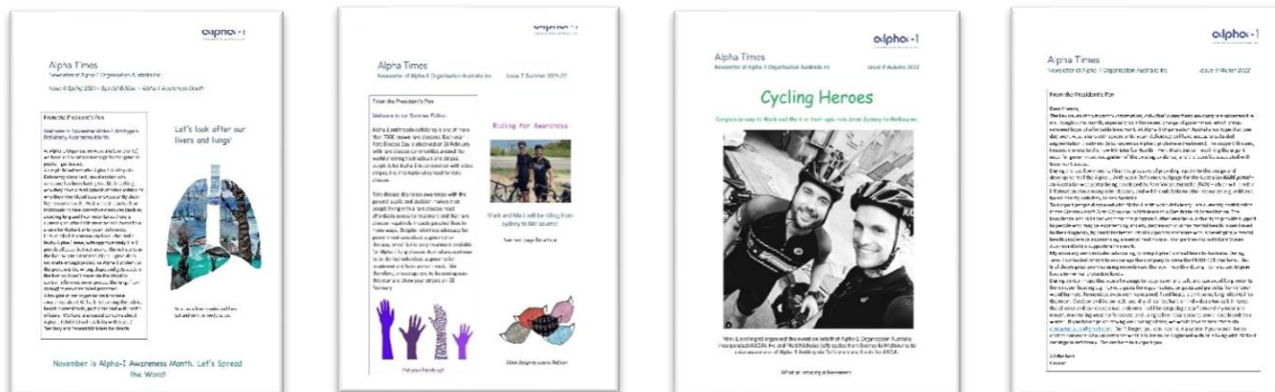


Website Expansion

During the year we moved to a new website host which allowed us to expand the website. We added *Useful Links* to the Resources page including: Alpha-1 Videos, Clinical Trials, State Government Bodies, National Health Organisations, Research, Treatment, Federal Government Bodies, International Alpha-1 Associations and Pharmaceutical Companies (with an Alpha-1 presence in Australia). More information and guidelines can now be easily accessed.

Alpha-1 Newsletter

We published four *Alpha Times* newsletters this year, bringing varied and useful information to the Alpha-1 community. Requests for a copy of our newsletter continue to grow. All back issues are available via our website www.a1oa.org.au.



Goal 2: Education and Knowledge

Grant Applications to Support Strategic Plan Implementation

We applied for financial support from a few pharmaceutical companies to support awareness raising material development and dissemination but, unfortunately, we were not unsuccessful.

Developed Facts Sheets for GPs

We developed evidence-based fact sheets on Alpha-1 for GPs and commenced distribution.

New YouTube Channel

We established an Alpha-1 Organisation YouTube channel and are delighted to have a short video on Alpha-1 disease available – courtesy of Dicerna.

Goal 3: Advocacy

The Pandemic

During the COVID-19 pandemic our advocacy work increased due to emerging literature that indicated that people with Alpha-1 antitrypsin deficiency were at higher risk of poor outcomes if they contracted COVID. The benefits of antitrypsin infusions in COVID-19 patients were reported in peer-reviewed literature and our concerns were raised in letters to the Federal Minister for Health, the TGA, all state and territory Premiers and Chief Ministers, and Ministers for Health. We supplied the literature and requested urgent consideration of access to subsidised augmentation therapy for lung-affected people with Alpha-1.

Treatment Access

We met with Grifols and CSL Behring to discuss their potential resubmission to the Medical Services Advisory Committee (MSAC). They await new evidence before submissions are likely.

We explored Patient Reported Outcomes Measures (PROM), their potential to support an MSAC submission and liaised with Federal Government staff to understand submission

opportunities. We discussed PROM development with the UK peer organisation taking the lead on this project, to support the development of an Alpha-1 specific PROM tool.

Private Purchase of Augmentation Therapy

During the pandemic supply of augmentation therapy from CSL Behring became a challenge for private purchase for qualifying patients under the Government's Special Access Scheme. This situation led to our discussions with Grifols, a company which has not historically sold augmentation therapy to patients, and the development of a new Grifols *private pay access pathway program* in 2022. Arrangements were put in place with a number of specialist centres in Australia allowing clinical oversight of privately purchased Grifols antitrypsin for infusion.

Australian Research on Alpha-1

We promoted the work being done by the Children's Medical Research Institute, Sydney and raised awareness of the need for Alpha-1 donor livers to support genetic research.



Clinical Trials

We advocated to bring the Kamada (inhaled antitrypsin) clinical trial to Australia. The pandemic led to Kamada changing their approach but hope remains that the trial will come to Australia in the next phase.

We actively promoted the Estrella Alpha-1 liver trial and held a webinar with the St Vincent's Melbourne clinical trial nurse, to enable patients' easy access to trial information.

We advocated to have 'gas exchange' as an outcome indicator included in the Kamada trial as FEV1 has been described as a poor indicator. The suggestion couldn't be supported due to the desire to use the same outcomes as used in the RAPID study.

We updated the website and included clinical trial information and on social media, advocating that Alpha-1 patients' consider eligibility for trial inclusion, to support new treatment options.

We advocated to bring the phase 3 ASTRAEUS Mereo BioPharma clinical trial to Australia.

We provided information on the Australian Alpha-1 environment to international stakeholders who are in a position to promote and bring clinical trials to Australia.

Air Quality

We advocated for clean air in a number of ways including:

- We developed and provided a data table on *Vulnerable Populations and Wood Smoke Risk*, to the Victorian Parliamentary Inquiry on air quality
- We researched government roles and responsibilities related to air quality
- We raised the need for good air quality with the Lung Foundation to determine their activity in this area
- We wrote to the NSW Minister for the Environment on the negative impact of wood heaters and asked to meet to discuss the impact on vulnerable populations
- We corresponded with NSW EPA on the negative impact of wood heaters
- We attempted to get media coverage on smoke risk and contacted ABC journalists



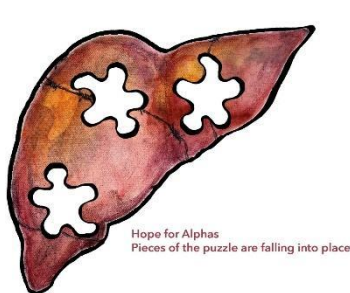
Goal 4 Awareness

Alpha-1 Awareness Month

During November we used our new set-of-four Alpha-1 “**solving the puzzle**” posters to raise awareness about Alpha-1. The posters, depicting livers and lungs, were featured during November 2021 across Alpha-1 Organisation’s social media platforms.

The full set of posters is available for free download via the Alpha-1 Organisation website - www.a1oa.org.au.

ALPHA-1 AWARENESS MONTH
Unexplained nausea, itchiness, bloating?



Hope for Alphas
Pieces of the puzzle are falling into place

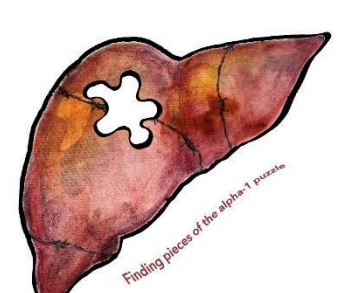
Do you or someone in your family have unexplained liver disease?
Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, which can lead to liver damage. This is a common genetic disorder but very few are diagnosed.
If this sounds like you or someone you know, visit our website, www.a1oa.org.au, or our Facebook page or follow us on Instagram or Twitter, or contact the Alpha-1 Organisation Australia at contactus.a1oa@gmail.com.

Alpha-1 Antitrypsin Deficiency Awareness Month

alpha-1 Alpha-1 Organisation Australia Inc
ABN: 89131526593

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ALPHA-1 AWARENESS MONTH
Is your liver okay?



Finding pieces of the alpha-1 puzzle

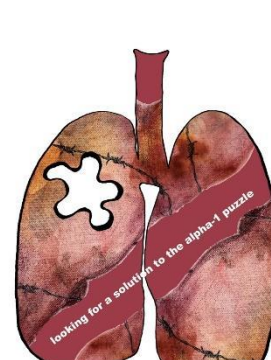
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Alpha-1 Antitrypsin Deficiency Awareness Month

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ALPHA-1 AWARENESS MONTH
How do your lungs feel?



looking for a solution to the alpha-1 puzzle

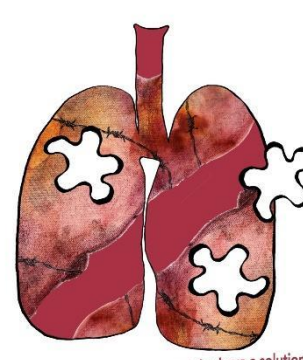
Feeling breathless? Have asthma, emphysema, lung problems?
Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, leading to lung damage. This is a common genetic disorder but very few are diagnosed.
If this sounds like you or someone you know, visit our website, www.a1oa.org.au, or our Facebook page or follow us on Instagram or Twitter, or contact the Alpha-1 Organisation Australia at contactus.a1oa@gmail.com.

Alpha-1 Antitrypsin Deficiency Awareness Month

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ALPHA-1 AWARENESS MONTH
Chest tight? Trouble breathing?



Even the hardest puzzles have a solution

Feeling breathless? Have asthma, emphysema, lung problems?
Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, leading to lung damage. This is a common genetic disorder but very few are diagnosed.
If this sounds like you or someone you know, visit our website, www.a1oa.org.au, or our Facebook page or follow us on Instagram or Twitter, or contact the Alpha-1 Organisation Australia at contactus.a1oa@gmail.com.

Alpha-1 Antitrypsin Deficiency Awareness Month

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Lung Health Awareness Month

We participated in May's *Lung Health Awareness Month* and produced a new **Question and Answer** awareness campaign.

Alpha-1 Antitrypsin Deficiency

Q: What is needed?

A: Targeted detection of Alpha-1

Why: Patients adopt a healthy lifestyle and avoid risks to lungs (e.g. stop smoking) when they know they have Alpha-1 Antitrypsin Deficiency (Franciosi 2021)

Journal reference: Franciosi A.N., et al. (2021) Alpha-1 Antitrypsin Deficiency and Tobacco Smoking: Exploring Risk Factors and Smoking Cessation in a Registry Population. COPD: Journal of Chronic Obstructive Pulmonary Disease. doi.org/10.1080/15412555.2020.1864725.



Alpha-1 antitrypsin deficiency

Q: What is needed?

A: Awareness that Alpha-1 is associated with **bronchiectasis** and lung infection with **NTM / MAC**

*Why: Armed with knowledge about the risks and susceptibility, individuals can adopt **daily airway clearance** and risk avoidance activities.*

Journal reference: Luna Diaz LV, Guerrero AM, Iupe I et al. Prevalence of NTM Infection in Subjects with and Without Normal Alpha-1 Antitrypsin Genotypes. American Journal of Respiratory and Critical Care Medicine. 2018;197:A2600.



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Alpha-1 Antitrypsin Deficiency

Q: What is needed?

A: Rapid treatment with antibiotics when a person with Alpha-1 has a bacterial lung infection.

Why: To control lung neutrophils and inflammation and to reduce the risk of more neutrophil-driven lung damage as an over-exuberant inflammatory response (due to low antitrypsin), damages both cellular and extracellular components of the lung.

Journal reference: Deficiency Russell DW, Gaggar A, & Solomon GM. Neutrophil Fates in Bronchiectasis and Alpha-1 Antitrypsin Deficiency. Ann Am Thorac Soc. 2016 Apr; 13(Suppl 2): S123-S129. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5015725/#>



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World Lung Day

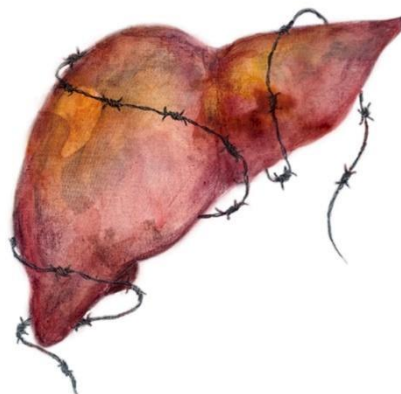
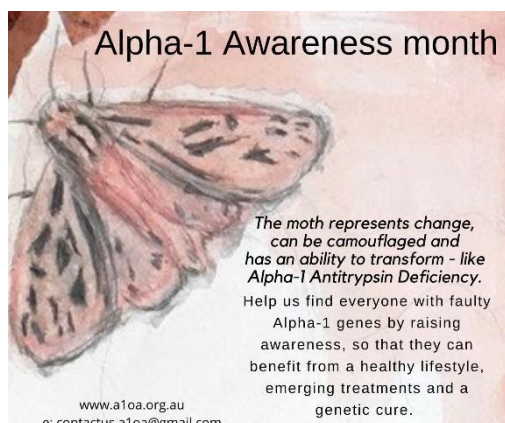
Alpha-1 Organisation participated in World Lung Day, raising awareness about lung health and the need for subsidised augmentation therapy to preserve Alpha-1 lungs.



Awareness Raising Using Social Media and LinkedIn

Our membership grew on all social media platforms and on LinkedIn.

We promoted Alpha-1 on our website, Twitter, Instagram, Facebook, Pinterest and LinkedIn and shared valuable information to raise awareness about Alpha-1.



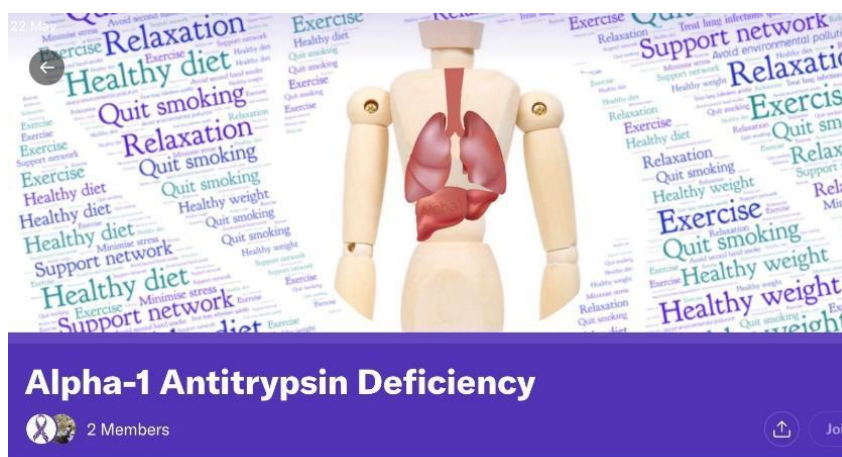
Rare Disease Month and Day

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.

We collaborated with Dicerna Pharmaceuticals inc to release a new Alpha-1 video on our new YouTube channel during Rare Disease Month.

Raising Awareness via an Alpha-1 Twitter Community

We established a new Alpha-1 *Twitter Community* to raise awareness, using evidence-based Alpha-1 related information, management, research developments and emerging treatments.



Participation in Events

Participation in key events allowed Alpha-1 Organisation to raise awareness about the charity and Alpha-1.

During this financial period, we participated in:

- July 2021: Rare Voices' Webinar - *Research for Health Technology Assessment on Consumer Led Research / Consumer Data Collection* and established new links with the Federal Department of Health
- December 2021: Alpha-1 Global survey
- November 2021: *Estrella Liver Clinical Trial Webinar 2021* (presenter)
- March 2022: *Breathing with Confidence Webinar 2022*, Asthma (free registration)
- March 2022: European Lung Foundation *Bronchiectasis Patient Conference 2022* (free registration)
- November 21: *Rare Voices' Virtual Summit* - A person centred approach to implementing the national strategic action plan for rare disease
- April 2022: Rare Voices' consultation on the development of their Rare Disease Portal providing advice about what information and links should be included on Alpha-1
- April 2022: *Improving Care for Alpha-1 Patients 2022* (free registration)
- May 2022: Alpha-1 Global Webinar on Advocacy 2022 (free registration)
- May 2022: Australia European Lung Foundation *Chronic Cough Patient Conference 2022* (free registration)
- June 2022: Alpha-1 National Conference, Alpha-1 Foundation 2022 (free registration)
- June 2022: Mental Health First Aid training and accreditation (sponsored by Rare Voices)

Activities that raise awareness about Alpha-1 and treatment access:

- Provided letters of support to Australian Alpha-1 researchers applying for Alpha-1 research grants.
- Mentioned in the Government's Standing Committee on Health, Aged Care and Sport's Report on the approval processes for new drugs and novel medical technologies: *The New Frontier: Delivering better health to all Australians*
 - "Dr Gaynor Heading, President of Alpha-1 Organisation Australia supports adding more diseases to the newborn screening...newborn screening for alpha-1" ([The New Frontier - Delivering better health for all Australians](#) (aph.gov.au) p217)
- Submitted diet questions to the 26 May 2022 Lung Foundation Chronic Lung Disease: Lived Experience Panel.

Raising Awareness - Stakeholder Engagement

We contacted a variety of stakeholder groups to discuss Alpha-1 needs and opportunities including:

- Letters sent to the Federal Minister for Health, TGA, all state/territory Premiers/ Chief Ministers and Ministers for Health.
- Advised the Thoracic Society Australia and New Zealand (TSANZ) about the need to include all health-related issues in an Alpha-1 patient registry (beyond lungs) – to be developed in partnership with European Alpha-1 Research Collaboration (EARCO)
- Requested that the Liver Foundation included Alpha-1 on their website
- Met with Grifols (German and Australian representations) to discuss evidence and timeframes related a MSAC submission for subsidised augmentation therapy
- Met with head of Cystic Fibrosis Australia to discuss treatment access tactics

Treasurer's Report

Financial Results

The period ending 30th June 2022 saw the charity return a surplus of \$16,207 (2021: \$6,529). While operating costs increased marginally (\$2,038 vs. 2021: \$1,762), a significant increase in donations was received, largely as a result of the Sydney to Melbourne cycle ride undertaken by Mark Lloyd and Matt Nichols. This has put the charity on a sound financial footing, and will allow us to undertake new awareness activities, including a planned series of videos under the banner 'Alpha-1 Unwrapped'.

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 2022 the charity held assets of \$22,736 [2021: \$6,529]. 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, because 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.

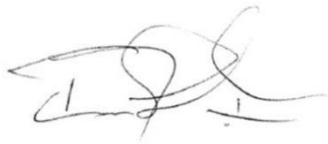
In keeping with a commitment to openness and accountability the charity welcomes the opportunity to provide members with further detail regarding its income and expenditure on request.

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 3rd July, 2022

Financial Statements

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

Income Statement

	Note	2022 \$	2021 \$
Revenue from operating activities			
Donations		17,144	7,369
Membership subscriptions		840	840
Merchandise sales		-	81
		<u>\$ 17,984</u>	<u>\$ 8,290</u>
Other revenue			
Goodwill payment	2	250	-
Interest income		-	1
Loyalty program rebates		11	-
		<u>\$ 261</u>	<u>\$ 1</u>
Total revenue		<u>\$ 18,245</u>	<u>\$ 8,291</u>
Expenses relating to operating activities			
Advertising, printing & stationery		109	-
Bank fees	3	363	53
Compliance costs		53	-
Gifts		106	-
Insurance premiums	4	743	1,430
IT costs	5	357	92
Membership & association fees		-	55
Merchandise costs	6	298	54
Sundry expenses		9	78
Total expenses		<u>\$ 2,038</u>	<u>\$ 1,762</u>
Net surplus / (deficiency) for the year		<u>\$ 16,207</u>	<u>\$ 6,529</u>

Balance Sheet

	Note	2022 \$	2021 \$
Current Assets			
Cash assets		22,736	6,529
		<u>\$ 22,736</u>	<u>\$ 6,529</u>
Non Current Assets			
Property plant & equipment		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Assets		<u>\$ 22,736</u>	<u>\$ 6,529</u>
Current Liabilities			
Payables		-	-
		<u>\$ -</u>	<u>\$ -</u>
Total Liabilities		<u>\$ -</u>	<u>\$ -</u>
Net Assets		<u>\$ 22,736</u>	<u>\$ 6,529</u>
Members' Funds			
Balance at the beginning of the year		6,529	-
Current year earnings		16,207	6,529
Total Members' funds		<u>\$ 22,736</u>	<u>\$ 6,529</u>

Cash Flow Statement

	Note	2022 \$	2021 \$
Cash flow from operating activities			
Receipts from donations		17,144	7,369
Receipts from members		840	840
Receipts from merchandise sales		-	81
Goodwill payment received		250	-
Interest received		-	1
Loyalty program rebates		11	-
Payments to suppliers		(2,038)	(1,762)
Net Cash flow used in operating activities		\$ 16,207	\$ 6,529
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		16,207	6,529
Cash balance at the beginning of the year		6,529	-
Cash at the end of the financial year		\$ 22,736	\$ 6,529

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. Goodwill Payment

The charity's bank agreed to a one-off goodwill payment following some issues which affected its account and necessitated significant time/effort from the treasurer to resolve.

3. Bank Fees

Bank fees include commission fees made to payment/collection platforms used by the charity (e.g. *TryBooking, Paypal etc*).

4. Insurance Premiums

The charity prepares its accounts on a cash basis, and the insurance premiums paid includes a sum prepaid for the 2022/2023 financial year.

5. IT Costs

During the year the charity entered into commercial agreements for the provision of video conferencing facilities and for website hosting (formerly provided on a 'pro-bono' basis). Neither of these agreements has a term exceeding 12 months.

6. Merchandise Costs

The charity contributed to the cost of A1OA branded cycling shirts for the fundraising Sydney to Melbourne cycle ride.

How You Can Be Involved

Become a
charity
member

Help with
fundraising

Raise
awareness
about
Alpha-1

Tell us your
Alpha-1 story
on video or
in writing

Present to
your local
club on
Alpha-1

Volunteer
on the
Board

The Year Ahead

The future of Alpha-1 lies in clinical trials, emerging knowledge and treatments and improved patient management. In the meanwhile, Alpha-1 patients need access to treatment that is currently available in other countries but is not subsidised by the Australian Government.

Advocacy

We will continue to advocate for clinical trials to come to Australia and for affordable treatment.

Support

We will continue to support Alpha-1 patients and researchers, and administer social media pages and have a LinkedIn presence, sharing valuable information. Our monthly peer support meetings will continue via Zoom.

Awareness

We will 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 get the word out about Alpha-1 prevalence in Australia and healthy lifestyles.



Education and Knowledge

New patient videos will be produced in the second half of 2022. This series called "Alpha-1 Unwrapped", will contain videos that will be used in the education of health professionals.

We will continue to submit grant applications to support information and awareness raising.

References

Russell DW, G. A. (2016). Neutrophil fates in bronchiectasis and alpha-1 antitrypsin deficiency. *Annals of the American Thoracic Society*, 13, S123-S129.

Contact Us

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Website and Social Media

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Instagram: [alpha1organisationaustralia](#)

Twitter: [@1_organisation](#)

Twitter community: Alpha-1 Antitrypsin Deficiency

Facebook: Alpha-1 Organisation Australia Inc

LinkedIn: Alpha-1 Organisation Australia Inc

Pinterest: Lungs