ANNUAL REPORT 2024

The Angelman Network

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CONTENTS

ABOUT US 3

WHAT WE DO 4

CHAIR REPORT

Strategic Highlights 5
Financial Highlights 6
Operating Highlights 7
Looking Ahead 8

FINANCIAL SUMMARY 9
FINANCIAL STATEMENTS 10
NOTES TO FINANCIAL STATEMENTS 11

Accounts 11
Debt 11
Going Concern 11
Contingent Liabilities 11
Takeaways 11

INDEPENDENT AUDITOR’S REPORT 12

ABOUT US

The Angelman Network
Connecting and supporting those impacted by Angelman Syndrome (AS)

Te Hononga Angelman
kia whai hononga me te tautoko hoki i a rátou e pá kii ana ki te mate Angelman Syndrome

The Angelman Network is a volunteer-driven charitable trust in New Zealand that supports families affected by Angelman syndrome. Trustees from across the country meet regularly online and in person to fulfill governance duties. As a Registered Charitable Trust (CC46746), we actively collaborate with various organizations, MPs, families, professionals, and research teams both in NZ and globally to achieve our objectives.

1. MĀTĀPONO / PRINCIPLES

1.1 The Trust is committed, in attaining its purposes, to:
(a) respecting and implementing the dual heritage of the partners of Te Tiriti o Waitangi (the Treaty of Waitangi);
(b) respecting the cultural diversity of people and encourage people from all nationalities to utilize the Trust’s facilities and services.

1.2 Our principles:
(a) The Angelman Network is a NZ support network with a global web presence, which aims to enhance the lives of people with Angelman Syndrome in New Zealand. We aim to be an inclusive, collaborative, and transparent organisation that operates with integrity and respect for all cultures.

WHAT WE DO

The Angelman Network is New Zealand's only organization focused on providing current information about Angelman Syndrome, a rare neurogenetic disorder affecting chromosome 15, impacting about 1 in 15,000 people. We share resources through our website, social media, and newsletters, keeping families connected and supported through advocacy, public awareness, gatherings, and fundraising activities.

1. Network

We provide evidence-based information on Angelman Syndrome and network with NZ organizations, local councillors, politicians, researchers, and specialists. We also connect with AS organizations globally.

2. Support and Advocacy

We support families in New Zealand affected by Angelman Syndrome through our website, Facebook page, support groups, and newsletters. We collaborate with organizations advocating for rare disorders, communication support, access to treatment, inclusivity in schools, and caregiver wellbeing.

3. Resources and Publications

The TAN website is our main resource, regularly updated with information on Angelman syndrome. NZ families can reach out for support and access publications, resources, media articles, and relevant links on our Resource page.

4. Grants

We offer small grants ($2K - $5K) for research on Angelman syndrome and related social policy issues benefiting NZ families. We also provide Family Grants ($300 annually) to help families attend conferences and workshops about Angelman syndrome.

CHAIR REPORT

This annual report covers the performance of The Angelman Network, 1 April 2023 to 30 March 2024. It provides an overview of our mahi over the past year, contributing to our objectives, as set out in our strategic plan. The Board consists of four trustees: Ursula Christel (Chair), Nicola Eley (Treasurer), Tareen Ellis (Secretary) and Alison Barta.

STRATEGIC PLAN 2022/2023:

The Angelman Network has followed the activities as outlined in our Strategic Plan set at the 2023 AGM:

Recommended Strategic plan for 2023/24. To focus on:

1. **NZ Angelman Clinic and Registry – proactively plan to set up an Angelman clinic in Auckland and work with FAST AU to create our own NZ database within the Global Angelman Registry.**
2. **NZ Advocacy: Continue to actively contribute to current campaigns of our 3 key NZ advocacy orgs: Rare Disorders NZ, Carers NZ, Access Alliance**
3. **Finances: Continue to promote small Givealittle fundraising campaigns when possible**

Strategic Highlights

1. IAD Feb 2024

The Angelman Network co-founded and managed the global IAD Collective for the past decade, involving national AS organizations worldwide. At the end of 2023, we passed on this responsibility to the Angelman Syndrome Foundation (ASF) in the USA, which has launched a new website for the annual event.

We promoted the IAD 2024 campaign on social media, with many NZ families and friends raising awareness in their local communities. Our online campaign also served as a fundraiser by promoting our Givealittle page, and a platform to promote our plans for setting up an Angelman registry and clinics in NZ. More details on those initiatives to follow.

We created a short *Thank You* video (on YouTube here) featuring photos from families across the country, wearing blue and celebrating IAD in their own communities.

Financial Highlights

The Angelman Network launched its annual IAD awareness and fundraising campaign in February 2024. We encouraged families to actively promote our Givealittle page, leveraging their local networks to maximize contributions. Additionally, fundraising efforts by kindergartens and schools have resulted in larger donations, significantly boosting our overall fundraising capacity.

These collective efforts not only enhance awareness of Angelman syndrome across the country, but also strengthen our financial foundation, allowing us to better support our initiatives and families. We are grateful for the ongoing support from our AS community, and look forward to building on this momentum in the coming year.

Operating Highlights

New Zealand is a small country and Angelman syndrome is a rare condition, so collaboration is key to all our operations. We actively seek out allies and partnerships, because together we are more efficient in achieving our collective goals.

1. **NZ Advocacy:** We have continued to collaborate with the following groups:

    1) **Rare Disorders NZ** is the umbrella group for rare disorders in New Zealand, advocating for an equitable healthcare system for the 300,000 Kiwis with a rare condition. As a member of the RDNZ alliance, we work with government, clinicians, researchers, and industry to promote diagnosis, treatment, services, and research. Now that we have a national Rare Disorder Strategy (July 2024), we will be working to ensure that it is implemented effectively in the new Health System. TAN will also continue to support RDNZ to establish a Centre of Expertise, which we believe is the quickest path to launching AS clinics and potential trial sites in NZ.

    2) **Carers NZ** is the national peak body providing information, advice, learning and support for carers. TAN continues to support and add our voice to the **Carers Alliance** of 50+ national not for profits (TAN is a member of this alliance). The current campaign is a petition that calls for a home in government for family carers, and for action to protect their mental, physical, and financial wellbeing.

    3) **Access Matters Aotearoa Trust** leads a social change campaign in Aotearoa New Zealand, advocating for all areas of public life to be accessible to everyone, regardless of access needs. The **Access Alliance** is New Zealand's largest alliance of Disabled Persons Organisations, disability advocacy groups, and service providers. We are campaigning for the introduction of an Accessibility for New Zealanders Act.

2. **Research in NZ:** I have been in contact with Rich Easton (Neurological Alliance and Neurological Foundation) and Dr Peter Bergin (ADHB) who is involved with 2 studies of Sudden Unexpected Death in Epilepsy (SUDEP). I sent Dr Bergin the study on

Community-Sourced Reporting of Mortalities in Angelman Syndrome (1979-2022) Compared to Prospective Natural History and Registry Data, that shows SUDEP to be one of the top 4 causes of death in AS. We have signed up to receive regular newsletters, and will closely monitor their research interests.

3. **Newsletters**: Four newsletters were sent out from July 2023 – July 2024, via the email database on our WIX website. Angel Chat - Issue 15, July 2023; Issue 16, Nov 2023; Issue 17, Jan 2025; Issue 18, June 2024

> *Ehara taku toa i te toa takitahi engari he toa takitini.*
> *It is not my strength alone, but the strength of many that contributes to my success.*

Looking Ahead

Overall, the Board is satisfied with the progress we have made over the 2023/4 period. Of great concern to us, is the detrimental impacts of the funding cutbacks that began on March 18th 2024. Not only have these changes traumatized the disability sector, they have also taken up a lot of time to fully understand, in order to be able to formulate new action plans. Considering that our Parent Poll last year rated a *very high need for more respite*, we will be actively protesting with several like-minded organizations who are pushing back on these changes.

THE ANGELMAN NETWORK

New Zealand / Aotearoa

Angelman syndrome occurs in approx 1:15000

Based on our current population we COULD have approx. **350 people** living with Angelman syndrome

CONTACT LIST UPDATE!

Do we have your latest details?
Can you help us find the others?

Whangarei → 7 ?
Auckland → 98 ?
Wellington → 28 ?
Christchurch → 27 ?
Dunedin → 7 ?

PLUS 185 others ? - scattered across the regions

WHY DO WE NEED THIS INFO?

We need accurate numbers and good data so we can advocate for AS clinics in NZ, better care services and family support
angelmannetwork@gmail.com

We are planning a series of **Zoom meetings** for AS families in NZ to explain the Centre of Expertise, our vision for an AS Clinic, and options for a national AS registry. The focus for 2024/25 will be to:

1. Update our current contact list
2. Seek out people with AS who may not be on our current database
3. Encourage all families to sign up on the Global Angelman Registry*.*

Ursula Christel
Chairperson, The Angelman Network

FINANCIAL SUMMARY

Statement of Financial Performance and Position for the Year Ended March 2024

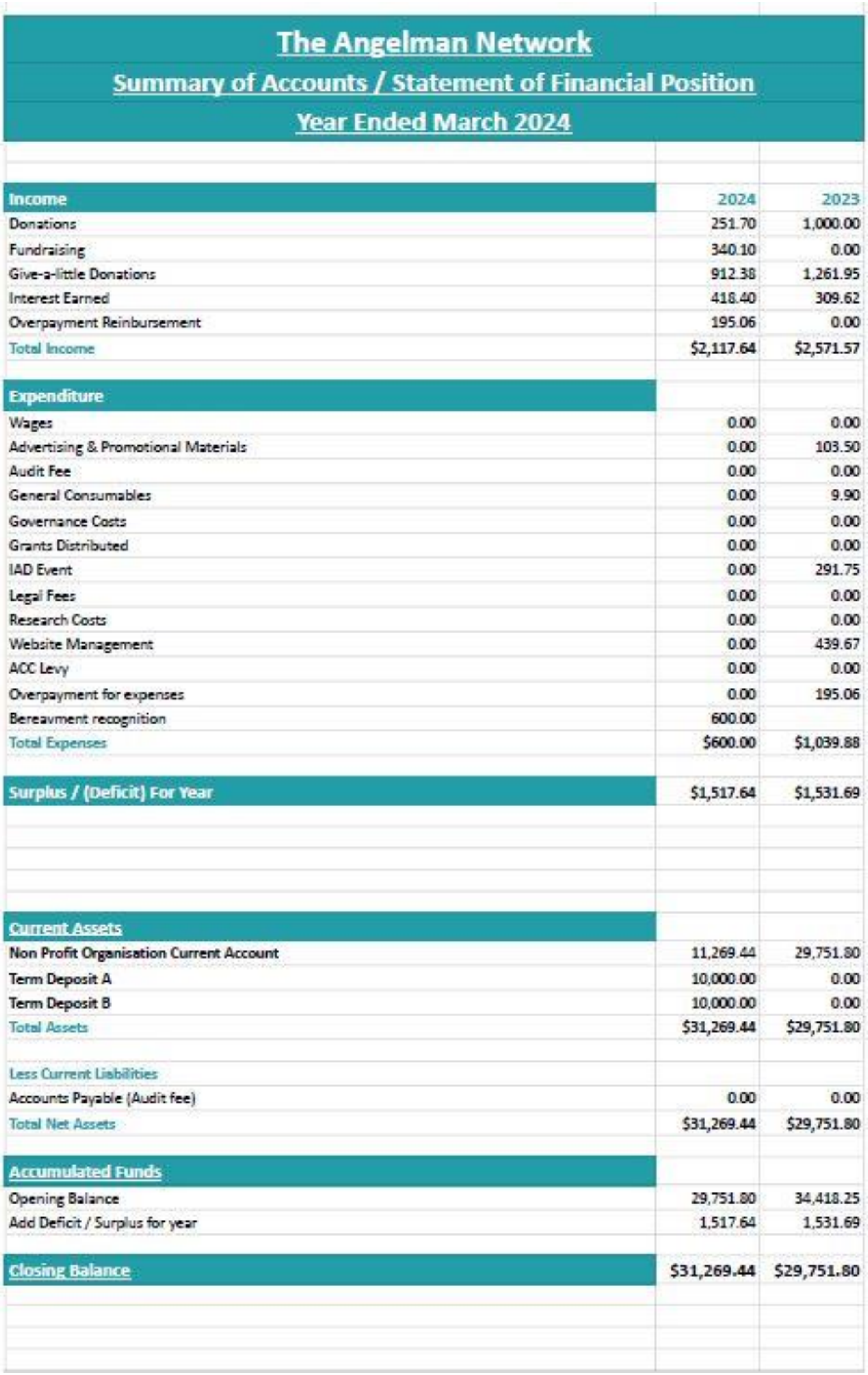
The Angelman Network Trust has continued to operate through the 2023-2024 period primarily as a support network for New Zealand families with Angels. The financial operation has been limited with very little account activity.

We had a surplus of operation for the year of $1517.64. Due to this the Trusts overall financial position has remained stable with equity of $31,269.44 at the end of March 2024.
Income for the year was generated through Givealittle Donations, fundraising and interest received on accounts. The only expenditure recorded was bereavement recognition made to two families who unfortunately lost their child who had Angelman syndrome.

At the time of finalising this report it is to be noted that no website management fee has been incurred for this period and this will need to be investigated further. A decision was made by the Trustees to open 2 Term Deposits and invest $10,000 in each. This happened in August 2023, with the period of investment being 180 days. At the maturity date of these term deposits the funds were reinvested for another quarter.

Nicola Eley
2023/2024 Treasurer

FINANCIAL STATEMENTS



The Angelman Network

Summary of Accounts / Statement of Financial Position

Year Ended March 2024

Income	2024	2023
Donations	251.70	1,000.00
Fundraising	340.10	0.00
Give-a-little Donations	912.38	1,261.95
Interest Earned	418.40	309.62
Overpayment Reimbursement	195.06	0.00
Total Income	$2,117.64	$2,571.57
Expenditure		
Wages	0.00	0.00
Advertising & Promotional Materials	0.00	103.50
Audit Fee	0.00	0.00
General Consumables	0.00	9.90
Governance Costs	0.00	0.00
Grants Distributed	0.00	0.00
IAD Event	0.00	291.75
Legal Fees	0.00	0.00
Research Costs	0.00	0.00
Website Management	0.00	439.67
ACC Levy	0.00	0.00
Overpayment for expenses	0.00	195.06
Bereavment recognition	600.00	
Total Expenses	$600.00	$1,039.88
Surplus / (Deficit) For Year	$1,517.64	$1,531.69
Current Assets		
Non Profit Organisation Current Account	11,269.44	29,751.80
Term Deposit A	10,000.00	0.00
Term Deposit B	10,000.00	0.00
Total Assets	$31,269.44	$29,751.80
Less Current Liabilities		
Accounts Payable (Audit fee)	0.00	0.00
Total Net Assets	$31,269.44	$29,751.80
Accumulated Funds		
Opening Balance	29,751.80	34,418.25
Add Deficit / Surplus for year	1,517.64	1,531.69
Closing Balance	$31,269.44	$29,751.80

NOTES TO FINANCIAL STATEMENTS

Accounts

The Angelman Network has a Business Premium Current Account with ANZ. At the 2022 AGM, Trustees agreed to reinvest funds into Term Deposits in order to benefit from the interest. This was actioned in August 2023 and is noted in the 2023/24 financial statement.

Debt

none

Going Concern

Fundraising activities and sourcing income streams is an ongoing concern, particularly as the cost-of-living continues to rise. We will set up another fundraising campaign for IAD 2025

“He waka eke noa
A canoe which we are all in
with no exception”

Contingent Liabilities

none

Takeaways

The Angelman Network has always self-funded activities and resources. The Board has not yet deemed it necessary to seek outside grants for small projects. However, should we decide to undertake any larger project over this next term, e.g. an information-sharing event for families, or a collaborative event with other rare disorder groups, it will be prudent for the Board to seek the expertise of a consultant to assist TAN with large grant applications.

INDEPENDENT AUDITOR'S REPORT

The Angelman Network is a small, Tier 4 charity.

It is not a legal requirement or noted in our Trust Deed, that our annual accounts must be audited. Due to the minimal activity of the Trust's finances in this post-pandemic period, the Board did not deem it necessary to have the accounts audited.

TAN Trust Deed, item 10.4:
"If deemed necessary, the Board may arrange for the Accounts of the Trust for that financial year to be audited by an accountant appointed for that purpose."

As we move forwards with our proposed plan to find and encourage all families to register on the global registry and then set up AS clinics, we may need to apply for external funding and grants. Audited accounts are a required criteria for most funding applications. It will therefore become necessary at that point, for the Board to seek the services of an independent auditor.

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