ANNUAL REPORT 2025

The Angelman Network

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CHAIR REPORT

ABOUT US

The Angelman Network - Connecting and supporting those impacted by Angelman Syndrome
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 registered charitable trust (CC46746) in Aotearoa New Zealand.

- The Trust remains the sole support organisation and information source for Angelman syndrome in Aotearoa New Zealand.
- We actively pursue opportunities to improve national health care and education systems, supply relevant resources, and to achieve better coordinated support and health outcomes for individuals living with Angelman syndrome.
- The Trust also supports families, advocates on their behalf, promotes research, and gives a voice to those individuals living with Angelman syndrome.

Trustees volunteer from across the motu, meeting online (in person when possible), to fulfill governance duties. We are community-driven and work collaboratively - both nationally and internationally - with research teams, key organisations, and professionals, to achieve our objectives.

WHAT WE DO

The Angelman Network is Aotearoa New Zealand’s only organization dedicated to Angelman Syndrome (AS), a rare neurogenetic disorder affecting about 1 in 15,000 people. We provide up-to-date information, connect families, and promote awareness through our website, social media, newsletters, events, and fundraising.

1. **Network -** We collaborate with global AS networks and share evidence-based information. We engage with national organizations in Aotearoa New Zealand, MPs, clinicians, and researchers, to raise more awareness and advance shared goals.
2. **Support & Advocacy -** We support individuals and families via digital platforms, and partner with national groups to advocate for rare disorders, AAC access, inclusive education, best current treatments, and caregiver wellbeing.

3. **Resources & Publications -** Our website is a key hub for AS resources, including info packs, media articles, and relevant links. We update it regularly. We also fund and publish new resources to support families in Aotearoa NZ.
4. **Grants -** We offer small research grants ($2K-$5K) and annual Family Grants ($300) to support conference attendance. We also provide bereavement donations to families who have lost a loved one with AS.

CHAIR REPORT

This annual report covers the performance of The Angelman Network, 1 April 2024 to 30 March 2025. 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 & Secretary), Nicola Eley (Treasurer), Tareen Ellis, and Alison Barta.

STRATEGIC PLAN 2024/25

The Angelman Network focused on our annual Strategic Plan, as set at the 2024 AGM:

1. **NZ Angelman Registry -** In collaboration with FAST AU, we initiated a strong campaign during February/March (IAD and Rare Disorders month) to promote the Global AS Registry to all NZ families. This is an ongoing campaign.
2. **Promote a Rare Disorders 'Centre of Expertise' / Leadership & Coordination Mechanism** TAN participates in the NZ Rare Disorders Collective 'Leads' team, working to fast-track a national approach to rare disorders within Te Whatu Ora / Health NZ. Our urgent focus is establishing a Leadership & Coordination Mechanism to improve care delivery across the health system. For the Angelman community, this outcome is a priority as it would:
   1. Support more coordinated and consistent healthcare
   2. Lay the groundwork for dedicated multidisciplinary Angelman syndrome (AS) clinics
3. **Research**
   - A promising list of AS global Research news for 2025 has been updated on our website. There has been great progress this year with TWO treatments in Phase 3 in the US (Ionis and Ultragenyx) being granted FDA Breakthrough Therapy Designation.
   - In March, a small global group of parent leads (me included) and scientists published the first-ever 'Report on Mortalities in Angelman Syndrome,' along with a family-friendly

summary. This citizen science study offers key insights into causes of death and how they might be prevented.

- In April, I reconnected with Dr Jessie Jakobsen from the Centre for Brain Research to discuss their new Autism Clinic in Auckland. We explored how Angelman syndrome could be included and the potential to collaborate on a NZ Standards of Care document.
- In May, I met via Zoom with Anna Mackey (ADHB/NZ Cerebral Palsy Register) to discuss TAN funding a student or clinician to create an Angelman syndrome resource for newly diagnosed families, based on the *CP Early Years Kete* template.
- In June, I met with Meagan Cross (FAST AU) to discuss expanding the Global AS Registry for NZ research and data use, and the potential for a collaborative Pacific AS entity.
- RDNZ is considering a collaborative Rare Disorders Research Conference to be held in Auckland in May/June 2026, and I have offered to be part of this planning group.

4. **NZ Advocacy -** We continue to work with our advocacy alliances.
   - **RDNZ Collective:** The has been a priority as we focus on how to implement the Rare Disorder Strategy in the new Health system.
   - **Carers Alliance:** We are working to ensure family caregivers and the voices of our family members with AS are heard in the new Disability Strategy and continue to advocate for their formal recognition in government.
   - **Access Alliance***:* campaigned to withdraw the current Accessibility Bill as it stood, due to it not being fit for purpose. The bill was discharged on 14 August 2024. There has been no further news on this.

   We will submit our own response to the draft **Disability Strategy,** covering issues related to Angelman syndrome as a rare disorder, and advocating for more inclusion of the non-verbal community, and more support and acknowledgment of family/whanau caregivers.
5. **Family Support**
   - **Info Packs**: Sent to families and professionals on request. A Waitakere Hospital paediatrician recently contacted us about a newly diagnosed family – he mentioned it was one of three new AS diagnoses in Auckland this year.
   - **Family contact:** I regularly respond to parent queries via email, website, and Facebook. However, we lack capacity for a full family support programme as this would require a paid role. Regional support needs vary greatly across the country. The Complex Care Group is best placed to provide national support.
   - **In the News:** A Mount Maunganui family lost their home in a fire. They weren't in our database and hadn't heard of us so we passed on our details via a parent contact. We

shared their fundraiser online, but haven't heard from them yet. The Winther Family featured in a TV1 News segment sharing the stress of caring for a child with complex needs. I visited them and shared Transition resources, after the airing.

- **Welfare Guardianship**: I assisted a local mother with her Family Court application and accompanied her to lodge it. Their only cost was the GP medical form.
- **Christmas Parties**: I coordinate tickets each year. Last year, only one family requested them but later cancelled. It is limited to under-12s with no siblings allowed, which also may impact general interest.
- **Bereavement**: We are deeply saddened by the passing of a young child with AS in September. His grandmother had previously volunteered to support South Island families. We have reached out to the family.

6. **Finances**
    - We continue to circulate our **Givealittle fundraising campaigns** when opportunities arise, especially during February (IAD) and March (Rare Disorders month in NZ).
    - In February, Woodlands Park School (Auckland) held an IAD Mufti Day fundraiser for TAN. This is an annual event in acknowledgement of a student who has AS. We print and post a Thank You card and Certificate of Appreciation to display in their classroom.
    - In May, inspired by his siblings abroad, a family set up a Givealittle fundraiser for TAN to honour a grandfather of a child with AS who recently passed. They raised a substantial amount that will be reflected in next year's financial records. We are incredibly grateful for their generous gesture, at such a sad time.
    - Expenses went to new postcards, brochures, signage, and event items for IAD 2025; and to parent fees for those who attended Erin Sheldon's AAC seminars (AssistiveWare) run by ATANZ in Auckland and Christchurch, Feb 2025.

Strategic Highlights

1. **IAD Feb 2025:** For IAD NZ, we ran our own campaign on social media using the month of February as an opportunity to fundraise, to promote the vision for a Centre of Expertise & AS clinics, and to encourage everyone to sign up to the Global Angelman Registry.
    - We coordinated a NZ Family Zoom meeting with Meagan Cross (CEO of FAST AU) to share info about the Global Angelman Registry
    - We promoted the IAD 2025 campaign on social media and our newsletters. Many NZ families, whanau and friends got behind the campaign, raising awareness in different ways, in their own local communities.

- We held a big family gathering in Warkworth that was very successful, and brought together many old as well as new families, from the wider Auckland region. This also generated an article in the local news media.
- We created a short *Thank You* video (on our YouTube channel, here) acknowledging all the families across the motu, who helped raise funds and awareness in their own communities.
- The global IAD 2025 event was managed by the Angelman Syndrome Foundation in the USA and they set up a new, bigger website with new resources. They now wish to pass on the stewardship or share it, for IAD 2026.

INTERNATIONAL ANGELMAN DAY, New Zealand, 15 FEB 2025

Financial Highlights

We launched our 2025 IAD fundraising campaign in February, encouraging families to promote our Givealittle page. Support from families and schools led to larger donations, boosting both awareness and funding. We're grateful for the community's support and look forward to building on this momentum.

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. Advocacy: We continue to collaborate with TWO key national advocacy groups:

   Rare Disorders NZ: As part of this national alliance, we work with government, clinicians, and researchers to improve diagnosis, treatment, and services for the 300,000 Kiwis with rare conditions. We are focusing on the implementation of the Rare Disorder Strategy (launched in

July 2024) and the need for a Centre of Expertise. This is key to more coordinated health care for rare disorders and establishing AS clinics / trial sites in NZ.

Carers NZ: TAN is a member of the Carers Alliance (50+ organisations), backing its petition for formal government recognition of family carers and measures to support their wellbeing.

2. **Research in NZ/Internationally:** We continue to network and seek out ways to progress our objectives – to improve health care and generate AS research / resources in Aotearoa NZ. We are an associate member of the Angelman syndrome Alliance (ASA), who are planning a global conference in Japan in September 2026.
3. **Newsletters**: Three newsletters were sent out from July 2024 – July 2025, via the email database on our WIX website. Angel Chat - Issue 20, Aug 2024; Issue 21, Dec 2024; Issue 22, Jan 2025; Issue 23 March 2025

Looking Ahead

Overall, the Board is satisfied with the progress made over the 2024/5 period. However, this has been a particularly challenging year for me personally as a parent of an older individual with Angelman syndrome, emphasizing the urgent need for the Board to prioritize succession planning. We need active trustees with defined roles, stronger teamwork, and a more balanced distribution of responsibilities. It’s not sustainable for me to continue to cover the multiple roles of Chair/Secretary, website & social media manager, newsletter editor, campaign organiser, family liaison, resource distributor, and national/international networker.

I volunteer to do this work because those with Angelman syndrome cannot advocate for themselves, and because we have made so much positive progress since the founding of this organisation. But as I approach retirement next year (August 2026) and the digital landscape continues to evolve beyond my capabilities or my interest, it is essential to bring in new voices and younger families to carry this work forward. I therefore highly recommend recruiting two additional trustees, to ensure continuity and progress for the Trust in the future.

Ursula Christel
Chairperson, The Angelman Network

FINANCIAL SUMMARY

Statement of Financial Performance and Position for the Year Ended March 2025

The Angelman Network Trust has continued to operate through the 2024/2025 period, serving as a source of information on Angelman syndrome in Aotearoa New Zealand, supporting families, advocating on their behalf, and giving a voice to those living with the condition.

The financial operation has been limited with very little account activity. We had a deficit operation for the year of $407.35 however due to interest of $1221.11 received from Term Deposits, overall funds increased by $813.76. Due to this the Trusts overall financial position has remained stable with equity of $32,083.20 at the end of March 2025.

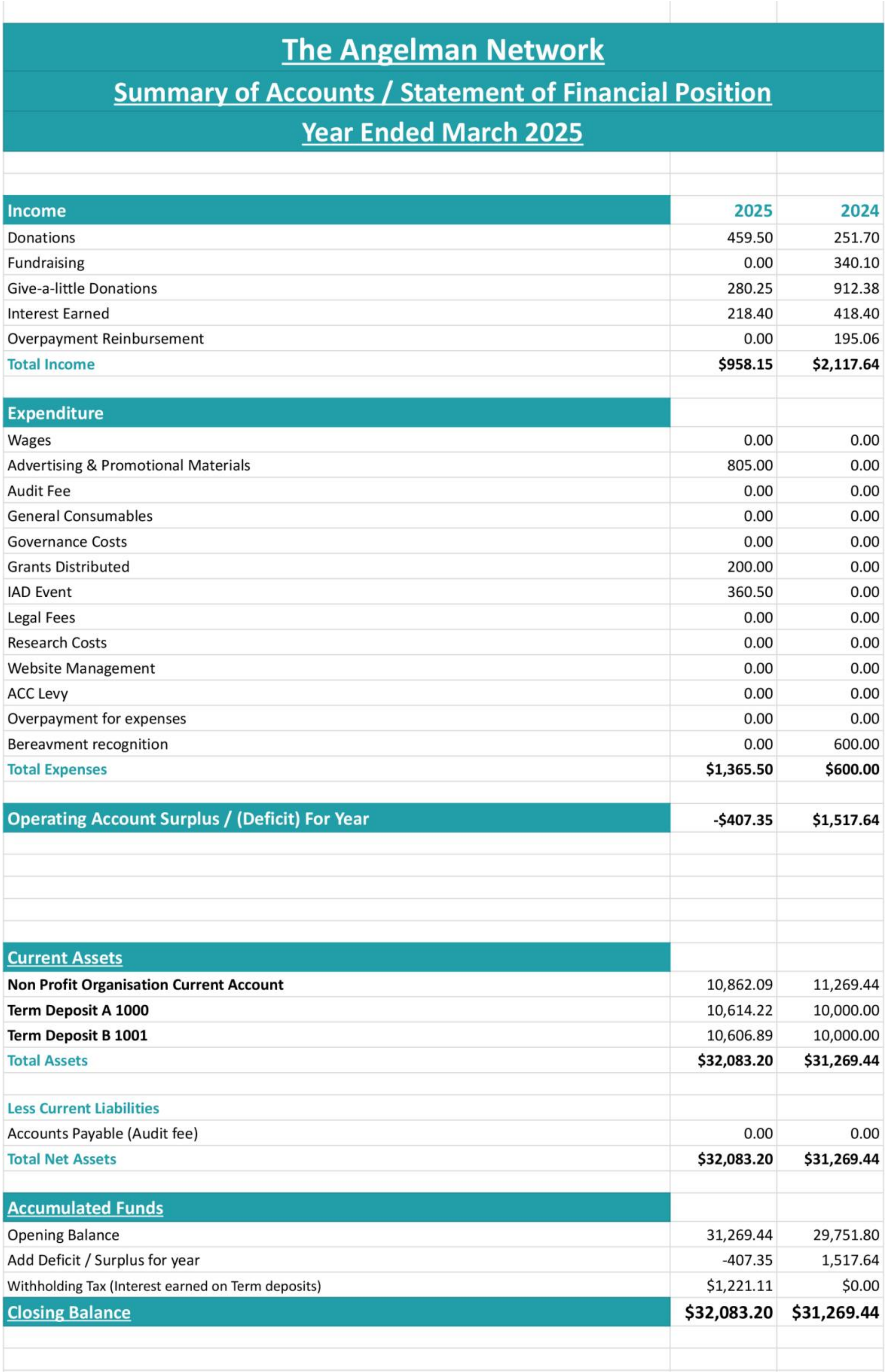
Income for the year was generated through GiveAlittle Donations, general donations and interest received on accounts. A significant donation of $359.50 was raised by Woodlands Park School, which we are very grateful for.

Expenditure for 2024/2025 related to IAD events, promotional material, and 4 x $50 grants. Both term deposits continue to generate interest at 5.6% and 5.9%, both being reinvested quarterly.

Please find attached to this report the EOY Summary for the accounts to March 2025.
I request this AGM to approve them.

Nicola Eley
2024/25 Treasurer

FINANCIAL STATEMENTS



The Angelman Network

Summary of Accounts / Statement of Financial Position

Year Ended March 2025

Income	2025	2024
Donations	459.50	251.70
Fundraising	0.00	340.10
Give-a-little Donations	280.25	912.38
Interest Earned	218.40	418.40
Overpayment Reinbursement	0.00	195.06
Total Income	**$958.15**	**$2,117.64**
Expenditure		
Wages	0.00	0.00
Advertising & Promotional Materials	805.00	0.00
Audit Fee	0.00	0.00
General Consumables	0.00	0.00
Governance Costs	0.00	0.00
Grants Distributed	200.00	0.00
IAD Event	360.50	0.00
Legal Fees	0.00	0.00
Research Costs	0.00	0.00
Website Management	0.00	0.00
ACC Levy	0.00	0.00
Overpayment for expenses	0.00	0.00
Bereavment recognition	0.00	600.00
Total Expenses	**$1,365.50**	**$600.00**
Operating Account Surplus / (Deficit) For Year	**-$407.35**	**$1,517.64**
Current Assets		
Non Profit Organisation Current Account	10,862.09	11,269.44
Term Deposit A 1000	10,614.22	10,000.00
Term Deposit B 1001	10,606.89	10,000.00
Total Assets	**$32,083.20**	**$31,269.44**
Less Current Liabilities		
Accounts Payable (Audit fee)	0.00	0.00
Total Net Assets	**$32,083.20**	**$31,269.44**
Accumulated Funds		
Opening Balance	31,269.44	29,751.80
Add Deficit / Surplus for year	-407.35	1,517.64
Withholding Tax (Interest earned on Term deposits)	$1,221.11	$0.00
Closing Balance	**$32,083.20**	**$31,269.44**

NOTES TO FINANCIAL STATEMENTS

Accounts

The Angelman Network has a Business Premium Current Account with ANZ. Funds are also invested into two Term Deposits to gain maximum benefit from the higher interest rates.

Debt

none

Going Concern

The Angelman Network's overall financial position has remained stable with equity of $32,083.20 at the end of March 2025.

If we embark on our own national AS resource project during 2025/26 or a collaborative research conference, we will consider applying for grants for to additional cover costs.

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. a collaborative event with other rare disorder groups, or a new AS resource project, it will be prudent for the Board to seek the expertise of a consultant to assist TAN with large grant applications.

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

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 plans to work on new Aotearoa-specific AS resources, find and encourage all families to register on the global registry, and establish 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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