

Tuberous Sclerosis Complex New Zealand

Performance Report For the Year Ended 31 March 2024

Non Financial Information	Page
Entity Information	2
Statement of Service Performance	3
Financial Information	
Statement of Receipts and Payments	4
Statement of Resources and Commitments	5
Statements of Accounting Policies	6 & 7
Review Report	8

Tuberous Sclerosis Complex New Zealand

Entity Information

Who we are, and why do we exist?

For the Year Ended 31 March 2024

Legal name of the entity:	Tuberous Sclerosis Complex New Zealand	
Type of entity and Legal Basis	An unincorporated society registered as a charity with the Charities Commission	
Charities Commission Number:	CC50554	
Purpose of Entity	To provide a community network which informs, connects and supports the NZ Tuberous Sclerosis Complex, (TSC) community (individuals with TSC, their families and health professionals).	
Entity Structure:	The entity is governed by a management committee comprising of a President, Secretary, Treasurer and committee members decided by the society.	
Main Source of entity's Cash	The entity's activities are funded by subscriptions from members , donations from individuals and philanthropic organisations.	
Main Method used by entity to raise funds:	The network established by the entity is the main source of donations and membership subscriptions.	
Entity's reliance on volunteers:	The entity relies on gifts of volunteers time and expertise in essential roles such as governance, administration, accounting and fundraising.	
Additional Information:	Physical Address	11 Riverlea Drive, Katikati, 3129
	Mailing Address	11 Riverlea Drive, Katikati, 3129
	President	Mrs Helen Willacy
	Email	info@tsc.org.nz
	Website	www.tsc.org.nz
	Give a little	https://givealittle.co.nz/org/tscnz
	Facebook	https://www.facebook.com/TSCNZ

Tuberous Sclerosis Complex New Zealand

Statement of Service Performance

What did we do, When did we do it?

For the Year Ended 31 March 2024

Purpose

To provide a community and network which informs, connects and supports the NZ Tuberous Sclerosis Complex (TSC) community (individuals with, TSC, their families and health professionals).

Inform

- a. Organising and hosting a very successful National TSC Conference on 13th May 2023 at Parkside Hotel in Auckland, which was attended by 49 individuals with TSC and family members alongside representatives from Tuberous Sclerosis Australia, Epilepsy NZ, Neurological Alliance, Rare Disorders NZ. 100% of attendees who completed the feedback form rated the conference 4 or 5 stars.

Medical professionals generously donated their time to present on a range of topics, related to TSC including neurology, kidneys, transition, genetics, skin, the surveillance and management guidelines, multi-disciplinary care, Tuberous Sclerosis Associated Neurological Disorders (TAND), and LAM. Huge thanks to Drs Claire Spooner, Melinda Nolan, Murray Likes, Juliet Taylor, Laura Boddington, Jacque Gambrell, Lisa Underwood, and Prof Petrus de Vries for their knowledgeable, sensitive and helpful presentations. We also had the privilege of hearing the Gempton family's journey of living with TSC and had opportunities to socialise and net work with New Zealanders from both Islands and even a visitor from the USA. It was a pleasure to recognise paediatric neurologist's Dr Claire Spooner's long time commitment and care of NZ TSC patients with the presentation of the Dr Tonya Kara Memorial Award for her services to the TSC Community by Dr Chanel Prestidge. Most sessions were videoed and uploaded to our You Tube Channel.

The conference also marked and celebrated Global Awareness Day on the 15th of May.

Funds were raised in the previous financial year to subsidise the conference costs and provide travel and accommodation grants. Thanks to Industrial Tube Limited, Christchurch Casino, AFT Pharmaceutical and COGS community grant scheme for their support.

- b. Contracting Helen Willacy to be TSCNZ Community Organiser for up to 16 hours a month to co-ordinate the activities of the society.
- c. Maintaining a mailing list of 64 individuals, families, and supporters in the TSCNZ community, 9 health professionals and 2 organisations.

Connect

- d. Three email newsletters were sent to members and supporters in the TSCNZ network and published on our website. The website was maintained and updated with links to the conference videos.
- e. TSCNZ attended meetings of Rare Disorders NZ Support Group Leads and supported Rare Disorder NZ's advocacy efforts to achieve a commitment from the government to create a Rare Disorders Strategy for Aotearoa New Zealand.
- f. Leah Bos, committee member, who lives with TSC, attended Rare Disorders NZ in Wellington in February 2023 to mark Rare Disorders Day and the launch of their white paper Impact of Living with a Rare Disorder in Aotearoa New Zealand. based on survey results which we promoted and our community participated in.
- g. TSCNZ attended meetings of the Neurological Alliance.
- h. TSCNZ maintained our international relationships with TSCi and TS Australia.
- i. The management committee met 6 times via teleconferencing to exchange information views and ideas. and administer the society.
- j. The AGM was held on Zoom, on 7th August. Frances Morton stepped down as secretary after five years of service. Tom Mailing is the new secretary.

Support

- k. Support and updates on the society activities were provided on the Facebook pages <https://www.facebook.com/TSCNZ>

and <https://facebook.com/groups/AuTSC>. Instagram, X and Linked in accounts were updated regularly.

As of April 2024, followers were: Facebook - 532, LinkedIn-36, up from 16, Instagram 199 up from 164, X 66 up from 61.

- l. The society was successful in attracting financial support through donations, grants, fundraising and conference ticket sales totalling \$11,737. Special thanks to Silver Linings Charitable Trust, The Geary Family, Christchurch Casino and COGS for their support.
- m. Phone and online support was given to 7 individuals and families and 1 medical professional.
- n. TSCNZ Supported families affected by Vigabatrin supply issues and advocated to Pharmac and the pharmaceutical company for a quick resolution to the problem. We also requested ongoing funding of vigabatrin sachets.

The committee has put many volunteer hours into making these achievements happen and I would like to thank them very much for their dedication. We always welcome new volunteers. Please contact us if you have some time to offer TSCNZ!

Nga mihi nui
Helen Willacy
President

Jul-24

Tuberous Sclerosis Complex New Zealand

Statement of Receipts and Payments

"How was it funded?" and What did it cost"

For the Year Ended 31 March 2024

	2024	2023
OPERATING RECEIPTS	\$	\$
Conference Ticket Sales	1924	1258
Donations and Fundraising	6485	15547
Interest Received	328	250
COGS Grant	3000	4500
Total Operating Receipts	11737	21556
CONFERENCE EXPNESES		
Catering	4898	
Conference Printing	539	
Conference Video	4481	
Gifts for Doctors/ Speakers	97	
Speakers Costs	1029	
Merchandise/ Giveaways	0	854
Travel & Accommodation Grants	5210	
Venue Hire	1380	
	17634	854
OPERATING PAYMENTS		
Advertising	19	0
Badges	0	118
Committe Travel	778	200
Community Organizer - Contract	3881	6762
Consulting & Accounting	1411	1012
Donations made	575	0
Fundraising Expenses	0	0
General Expenses	0	35
Gifts	0	106
Graphic Design	300	126
Insurance	1512	1340
Meeting Costs	244	628
Postage	0	20
Printing	0	545
Printing Newsletters	0	180
Reasearch Grant	0	0
Subscriptions Charities Commission	51	51
TS Australia Magazines	0	150
Website Hosting	63	57
Wellington support/ Travel	0	356
Xero Accounting Fees	217	363
Total Operating Payments	9051	12050
Total Payments	26685	12904
Operating Surplus/ (Deficit)	(14949)	8652
Capital Receipts	0	0
Capital Payments	0	0
Money owing but not yet paid	0	0
Increase / Decrease in Bank account	(14949)	8652
Bank Accounts at Start of Financial Year	28673	20021
Bank Accounts at End of Financial Year	13724	28673
Represented by:-		
Savings Account	10464	20276
Cheque Account	3260	8397
	13724	28673

Tuberous Sclerosis Complex New Zealand

Schedule of Resources and Commitments

"What the entity owns?" and What the entity owes?"

For the Year Ended 31 March 2024

	2024	2023
<u>RESOURCES</u>	\$	\$
Bank Accounts (from Statement of Receipts and Payments)	13724	28673
Money owed to Society	0	0
Other Resources		
Website Development	0	0
Total Assets	<u>13724</u>	<u>28673</u>
<u>COMMITMENTS</u>		
Money Payable by the Society	0	0

For and on behalf of the Committee:

Mr Willacy President

James Treasurer

Tuberous Sclerosis Complex New Zealand

Notes to the Performance Reports

"How did we do our accounting?"

For the Year Ended 31 March 2024

STATEMENT OF ACCOUNTING POLICIES

These financial statements are for Tuberous Sclerosis Complex New Zealand.

Tuberous Sclerosis Complex New Zealand (the Society) is an unincorporated society registered as a charitable entity with the Charities Commission under the Charities Act 2006.

The financial statements of Tuberous Sclerosis Complex New Zealand have been prepared in accordance with the Not-for-Profit framework, Tier 4, issued by the New Zealand Accounting Standards Board of the External Reporting Board.

The accounting principles recognised as appropriate for the measurement and reporting of earnings financial position on cash basis have been used, with the exception of certain items for which specific accounting principles have been identified.

Changes in Accounting Policies

There have been no changes in accounting policies. All policies have been applied on bases consistent with those used in previous years.

Specific Accounting Policies

In the preparation of these financial statements, the specific accounting policies are as follows;

(a) Goods and Services Tax

These financial statements have been prepared inclusive of GST as Tuberous Sclerosis Complex New Zealand is not registered for GST.

(b) Taxation

The society has charitable status and is exempt from income tax.

Contingent Liabilities

The society did not have any capital commitments for the year ending 31st March 2024. contingent liabilities, (2023, \$15,709).

Related Parties

The Community Organiser Contractor was approved and minuted by the committee.

The contract was awarded to Helen Willacy who is the president of TSC.

The contract has been invoiced and to paid Tamihai Limited. 31/03/2024, \$3,881.00 (2023, \$6,762.00)

The contract is expected to be developed into a sustainable role, where another person can be awarded this in the future.

A clause in the contract states 'that being a contractor doesn't preclude you from being on the committee as well – with the proviso that the contractor doesn't make any decisions with regards to the terms and conditions of the contract while a member of the committee'.

The treasurer Julianne Managh invoices TSCNZ for Accounting services provided through Assist Accounts.

The accounting engagement contract was signed and approved in December 2016.

The committee has yearly re-nominated the engagement to be continued.

Accounting & Xero fees 31/03/2024 \$1,628.00, 31/03/2023 \$1,375.40

Further related Party Transactions

Tom Maling (committee member) was reimbursed for the Conference dinner for \$1,298.00.

Mac Willacy (son of Helen who has TSC) received a travel grant to attend the conference towards flights and transfers from Wellington. \$400.00.

Helen Willacy (president) has been reimbursed expenses paid on behalf of TSC for \$2,826.00.

Leah Bos (committee member) received a travel grant to the conference and Rare disorders meeting reimbursement \$277.50.

Donations and receipts have been made into the TSC account which are related party transactions.

Helen Willacy Donation \$100.00 & conference ticket sales \$360.00, Ruth Morton donation \$100.00,

Tom Maling donation \$150.00.

Reviewers Report for the period to 31 March 2024

To the members of Tuberous Sclerosis Complex NZ

I have reviewed the financial statements of the Organisations annual accounts. These show the Statement of Receipts and Payments and a Schedule of Resources and Commitments as at 31 March 2024.

The management committee are responsible for the preparation of the financial statements which comply with generally accepted accounting principles and give a true and fair view of the financial position of the Association as at 31 March 2024 showing accumulated funds of \$13,724 and a deficit from operating for the period ending on that date of \$14,949.

It is my responsibility to express an independent opinion on the financial statements presented to the Association and report my opinion to you.

My review includes examining on a test basis, evidence relevant to the amounts and disclosures in the financial statements. I have obtained all the information and explanations I considered necessary in order to provide me with sufficient evidence to give a reasonable assurance that the financial statements are free from material misstatements whether caused by fraud or error. In forming my opinion, I have also evaluated the overall adequacy of the presentation of information in the financial statements.

In my opinion,

1. Proper accounting records have been kept by the Organisation as far as appears by my examination of those records; and
2. The financial statements comply with generally accepted accounting principles and give a true and fair view of the financial position of the Association as at 31 March 2024 and the results of the operations for the period to that date.

My review was completed on 1st of October 2024.



Clive Lock

Bachelor of Commerce

Retired Accountant