

Tuberous Sclerosis Complex New Zealand

Performance Report For the Year Ended 31 March 2023

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Tuberous Sclerosis Complex New Zealand

Entity Information

Who we are, and why do we exist?

For the Year Ended 31 March 2023

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 2023

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. Contracting a Community Organiser for 16 hours a month to co-ordinate the activities of the society.
- b. Maintaining a mailing list of 67 individuals, families, and supporters in the TSC Community, 8 health professionals & 2 Organisations.
- c. TSCNZ marked global awareness day campaign on 15 May 2022 by publishing 15 facts about TSC on social media and encouraging donations to support our work.
- d. Updating and printing our 3-fold brochure and sending it to relevant organisations.
This can be viewed at <https://www.tsc.org.nz/>
- e. Planning undertaken for National Conference which was held in May 2023 in Auckland including organizing venue, speakers, advertising and raising funds for conference costs and travel & accommodation grants.
- f. TSCNZ attended some online sessions of the World TSC Conference which was held in Dallas in July, 2022.
Questions were asked of the experts there that were relevant to New Zealanders.
Videos promoted on our social media and through our newsletter.

Connect

- g. Three email newsletters were sent to members and supporters in the TSCNZ network and published on our website.
The Website was maintained.
- h. 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.
- i. Attended Rare Disorders NZ Hui in Wellington in November 2022 which was a valuable networking and training opportunity.
- j. TSCNZ attended meetings of the Neurological Alliance and made a commitment to support the advocacy and advisory work of Anne Kelly.
- k. We maintained our international relationships with TSCi and TS Australia.
- l. The management committee met 6 times via teleconferencing and twice in person to exchange information views and ideas and administer the society. We welcomed back Leah Bos to the committee and regretfully accepted the resignation Kaitlin Pearson.
- m. A workshop was held in October 2022 to review and revise the Strategic Plan.
- n. The AGM was held at Auckland Botanical Gardens in Auckland and on Zoom on the 7th August.

Support

- o. Support and updates on the society activities were provided on the facebook pages <https://www.facebook.com/TSCNZ> (472 likes - up from 414) and <https://www.facebook.com/groups/AuTSC>. Instagram, Twitter and LinkedIn accounts were activated. As of June 2023 followers were: LinkedIn – 16 up from 3, Instagram 164 up.
- p. A community meet up was held in Wellington at Te Papa following the Rare Disorders Hui in November.
Information on TSC and TSCNZ was shared.
- q. An online "TSC Chat" Coffee Group was held on 30 November 2022 with parents caring for children with TSC.
- r. An online survey of the TSC community was conducted in May and June to gain feedback to help focus our efforts and further improve our service.
- s. The society was successful in attracting financial support through donations, grants, fundraising and conference ticket sales totalling \$21,555.95. Special thanks to Industrial Tube Limited, Christchurch Casino, AFT Pharmaceuticals and COGS community grant scheme for their generous support.
- t. Information packs including brochures on TSC, surveillance and management guidelines, and checklist were sent to newly newly diagnosed families. 9 Individuals needing support were given information and/or connected with others with relevant experience by phone or online.

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-23

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 2023

	2023	2022
OPERATING RECEIPTS	\$	\$
Conference Ticket Sales	1258	0
Subscriptions	0	177
Donations and Fundraising	15547	13452
Interest Received	250	12
Other Revenue	4500	0
Total Operating Receipts	<u>21556</u>	<u>13641</u>
Conference Expenses		
Merchandise/ Giveaways	854	0
	<u>854</u>	<u>0</u>
OPERATING PAYMENTS		
Badges	118	0
Bank fees	0	11
Committee Travel	200	734
Conference Grants	0	427
Community Organizer - Contract	6762	0
Consulting & Accounting	1012	929
Donations made	0	0
Fundraising Expenses	0	258
General Expenses	35	67
Gifts	106	110
Graphic Design	126	500
Insurance	1340	1351
Meeting Costs	628	395
Postage	20	83
Printing Brouchurers	545	3787
Printing Newsletters	180	197
Research Grant	0	0
Review Fee	0	0
Stationery	0	47
Subscriptions	51	0
TS Australia Magazines	150	517
Website Hosting	57	57
Wellington support/ Travel	356	0
Xero Accounting Fees	363	150
Total Operating Payments	<u>12050</u>	<u>9620</u>
Total Payments	<u>12904</u>	<u>9620</u>
Operating Surplus	<u>8652</u>	<u>4021</u>
Capital Receipts	0	0
Capital Payments	0	0
Money owing but not yet paid	0	0
Increase / Decrease in Bank account	<u>8652</u>	<u>4021</u>
Bank Accounts at Start of Financial Year	20021	16000
Bank Accounts at End of Financial Year	28673	20021
Represented by:-		
Savings Account	20276	4935
Cheque Account	8397	15086
	<u>28673</u>	<u>20021</u>

Tuberous Sclerosis Complex New Zealand

Schedule of Resources and Commitments

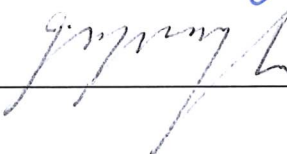
"What the entity owns?" and What the entity owes?"

For the Year Ended 31 March 2023

	2023	2022
<u>RESOURCES</u>	\$	\$
Bank Accounts (from Statement of Receipts and Payments)	28673	20021
Money owed to Society	0	0
Other Resources		
Website Development	<u>0</u>	<u>1164</u>
Total Assets	28673	21185
<u>COMMITMENTS</u>		
Money Payable by the Society	0	0

For and on behalf of the Committee:

 _____ President

 _____ Treasurer

Tuberous Sclerosis Complex New Zealand

Notes to the Performance Reports

"How did we do our accounting?"

For the Year Ended 31 March 2023

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 2023.

contingent liabilities for conference expenses in May 2023 \$15,709 at year end, (2022 nil);/.

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. 31/03/2023, \$6762.00

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 fees 31/03/2023 \$1,012.00, 31/03/2022 \$929.00.

Website Development

The Website development cost has been written off in these accounts of \$1164 as there is no future expected income from this asset.

Events after Balance Date

The TSCNZ Conference is to be held in May 2023.

The conference was budgeted for in the 31st March 2023 year.

The conference expenses which will be incurred in the next financial year \$15,709.00.

The next TSCNZ Conference is expected to be held in approximatley 3 years.

Reviewers Report for the period to 31 March 2023

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 2023.

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 2023 showing accumulated funds of \$28,673, and a surplus from operating for the period ending on that date of \$8,652.

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 2023 and the results of the operations for the period to that date.

My review was completed on 22nd of August 2023.

Clive Lock

Bachelor of Commerce

Retired Accountant