

Tuberous Sclerosis Complex New Zealand

Performance Report For the Year Ended 31 March 2022

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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 2022

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 2022

OUTCOMES

a. 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).

OUTPUTS

a. Maintaining a mailing list of 64 individuals, families, professionals and supports in the TSC community including 9 health professionals and 2 organisations.

b. TSCNZ marked global awareness day campaign on 15 May 2021 with supporting NZers to attend TS Australia's online conference. 5 community members and 2 health professionals were sponsored to attend.

c. TSCNZ sponsored one NZer to attend TS Australia's TAND+ event online on 20th November.

d. TSCNZ published 800 Parachute Packs (information for families and individuals with a new TSC diagnosis) and 200 copies of information on the updated Surveillance and Management Guidelines for TSC. The packs were posted out to the TSC community and 150 medical services working with the TSC community.

e. Sharing advice from TS Alliance on Covid vaccination and management in individuals with TSC.

f. Three email newsletters and two physical newsletters and issues of Reach Out magazine were sent to members and supporters in the TSCNZ network.

g. Information packs including brochures on TSC, surveillance and management guidelines, TAND checklist were sent to 3 newly diagnosed families. 13 Individuals needing support were given information, connected with others with relevant experience by phone or online.

h. TSCNZ supported Rare Disorder NZ's advocacy efforts to increase funding for Pharmac and recognise Rare Disorders in the health restructure. TSCNZ made submissions of the Pae Ora (Healthy Futures) Bill and Pharma's Covid Anti-viral proposal.

i. TSCNZ attended meetings of the Neurological Alliance.

j. We maintained our international relationships with TSCi and TS Australia.

k. The management committee met 5 times via teleconferencing and once in person to exchange information, views and ideas and administer the society. We welcomed Tom Maling and Kaitlin Pearson to the committee and regretfully accepted the resignations of Leah Bos and Ryan Powell.

l. The AGM was held on at Crave Café in Auckland and on Zoom on 1 August. This combined with the launch of our Parachute Packs and a grateful farewell to Leah Bos for her 7 years service as a committee member.

m. Support and updates on the society activities were provided on the facebook pages <https://www.facebook.com/TSCNZ> (414 likes - up from 364) and <https://www.facebook.com/groups/AuTSC>. Instagram, Twitter and LinkedIn accounts were activated. As of April 2022 followers were: LinkedIn - 3 - Instagram - 18 - Twitter – 24.

n. The society was successful in attracting financial support through donations and fundraising totalling \$13,641. Special thanks to the family and friends of Jo Maling and Industrial Tube Limited for their generous donations.

o. TSCNZ supported local TSC research through publicising the NZ topical sirolimus trial and supporting Ryan Powell's application to ClinVar to register a new genetic variant he discovered of TSC.

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! E waka eke noa.

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 2022

	2022	2021
OPERATING RECEIPTS	\$	\$
Conference Ticket Sales	0	0
Subscriptions	177	238
Donations and Fundraising	13452	12029
Interest Received	12	5
Other Revenue	0	0
Total Operating Receipts	<u>13641</u>	<u>12272</u>
 OPERATING PAYMENTS		
Bank fees	11	20
Committe Travel	734	0
Conference Grants	427	0
Consulting & Accounting	929	861
Donations made	0	500
Fundraising Expenses	258	0
General Expenses	67	0
Gifts	110	0
Graphic Design	500	0
Insurance	1351	1294
Meeting Costs	395	0
Postage	83	115
Printing Brouchurers	3787	0
Printing Newsletters	197	196
Reasearch Grant	0	2000
Review Fee	0	200
Stationery	47	0
TS Australia Magazines	517	279
Website Hosting	57	56
Xero Accounting Fees	150	108
Total Operating Payments	<u>9620</u>	<u>5629</u>
 Operating Surplus	<u>4021</u>	<u>6643</u>
 Capital Receipts	0	0
Capital Payments	0	0
Money owing but not yet paid	0	0
Increase / Decrease in Bank account	<u>4021</u>	<u>6643</u>
 Bank Accounts at Start of Financial Year	16000	9357
Bank Accounts at End of Financial Year	20021	16000
Represented by:-		
Savings Account	4935	10922
Cheque Account	15086	5078
	<u>20021</u>	<u>16000</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 2022

	2022	2021
<u>RESOURCES</u>	\$	\$
Bank Accounts (from Statement of Receipts and Payments)	20021	16000
Money owed to Society		
Other Resources		
Website Development	1164	1164
Total Assets	<u>21185</u>	<u>17164</u>

COMMITMENTS

Money Payable by the Society	0	0
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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 2022

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 and 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 or contingent liabilities at year end, (2021 nil);/.

Grant Waring
Chartered Accountant

14 July 2022

Helen Willacy
Tuberous Sclerosis Complex New Zealand
11 Riverlea Drive
Katikati
3129

Dear Helen

RE: REVIEW OF FINANCIAL STATEMENTS

As requested by the committee, I have recently undertaken an independent review of the financial statements and accompanying records for the Tuberous Sclerosis Complex New Zealand for the year ended 31 March 2022.

This review did not identify any issues of concern, and I therefore provide confirmation of this position in the report accompanying this letter.

Should you require clarification on any matters please do not hesitate to contact me on 021 066 0301.

Yours sincerely,



Grant Waring
Chartered Accountant