



**CMT AUSTRALIA**  
Charcot-Marie-Tooth Association Australia Inc.



**2022 - 2023  
Annual Report**

**Charcot-Marie-Tooth Association Australia Inc.  
CMT AUSTRALIA**

*‘Enhancing the Quality of Life  
for People with CMT’*

## OUR MISSION

TO UNITE ALL THOSE IN AUSTRALIA WHO ARE IMPACTED BY CMT, THE MOST COMMON INHERITED NEUROPATHY; EMPOWER THOSE WITH CMT TO LIVE THEIR LIVES TO THE FULLEST; AND TO ENCOURAGE OUR COMMUNITY TO SUPPORT CMT AUSTRALIA IN ITS GOALS.

## OUR VISION

A WORLD WITHOUT CMT

## OUR HISTORY

THE CHARCOT MARIE TOOTH ASSOCIATION AUSTRALIA INC. (CMTAA) BEGAN AS A SUPPORT GROUP IN 1988 AND WAS INCORPORATED IN 1990 AS A REGISTERED CHARITY.

THE MOTIVATION TO ESTABLISH CMTAA INC. WAS TO MEET THE NEED FOR PEOPLE WITH CMT TO COMMUNICATE WITH EACH OTHER AND PROVIDE MUTUAL ENCOURAGEMENT.

OVER THE YEARS WE HAVE SLOWLY “EVOLVED” AND ARE NOW MOVING FORWARD AT AN UNPRECEDENTED PACE. IN 2018, THE NATIONAL COMMITTEE PROPOSED THE ASSOCIATION BECOME KNOWN AS CMT AUSTRALIA, THIS CHANGE WAS PROPOSED AND ACCEPTED AT THE 2018 NATIONAL AGM.

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## ABOUT US

### Raising Awareness of CMT

We are:

- Engaging with persons with CMT, their families, carers, and the community. This occurs with contact with the National Office, face to face support gatherings, holding of a National Conference, on social media – Facebook and Twitter, publication of our Newsletter three times a year and this website.
- Engaging with Medical and Allied Health Professionals in every State to raise their awareness of the condition, and to inform them of strategic options they can assist their patients with to enhance their quality of life.
- Using data compiled for the 'Reducing the Health Burden of Charcot-Marie-Tooth in Australia' Report to approach Members of Parliament to raise awareness, and of the need for facilities to assist persons with CMT access services they need in one place to enhance their quality of life.
- Through our Research Grants, attracting applications to fund research into CMT and engaging with the research community.
- Acknowledging and promoting September: International Awareness Month for CMT.



*'Enhancing the Quality of Life  
for People with CMT'*

## OUR PEOPLE

### Governance

Name	Position	Dates acted (if not full year)
Dr Peter Critchley	Public Officer	

### National Committee Members 2022 - 2023

Name	Position	Dates acted (if not full year)
Robert Twin	President/Treasurer	re-elected for 2023 - 2024
Dr Helen Burnie	Vice President	re-elected for 2023 - 2024
Lisa Moore	Secretary	re-elected for 2023 - 2024
Jillian Critchley	Committee Member	re-elected for 2023 - 2024
Darryl Beitsch	Committee Member	re-elected for 2023 - 2024
Ellen Woodbrige	Committee Member	re-elected for 2023 - 2024
Shaana Dekker	Committee Member	Resigned position July 2023
Nickolas Peachey	Committee Member	From July 2023 re-elected for 2023-2024

### Employees 2022 - 2023

Name	Position	Dates acted (if not full year)
Eleanor Critchley	National Office Assistant	to September 2022
Anna Siddell	National Administration Assistant	from November 2022

### Volunteer National State and Regional Area Support Coordinators/Contacts - July 2022 - October 2023

Name	Position	Dates acted (if not full year)
Darryl Beitsch	National Support & NSW State Coordinator	
Roger MacRury	ACT Support Coordinator	
Annie Dawson	QLD State & Brisbane Regional Coordinator	to September 2023
Larissa McKinnon	VIC State Support Coordinator	
Marilyn Kremmer	TAS State Support Coordinator	
Lisa Moore	SA State & Regional Support Coordinator	
Vic Christou	WA State & Regional Support Coordinator	
Kaye Bartlett	NT State & Regional Support Coordinator	
Paula Hodgson	Vic Regional Support Contact	
Meryl Grew	Nambucca Heads Regional Support Contact	
Gabby Cosgrove	Newcastle Regional Support Contact	
Tanya Peachey	Bathurst Regional Support Contact	
Stephen Bonner	Central Brisbane Regional Support Contact	
Judy Pinchin	Gold Coast Regional Support Contact	
Joy Gath	South West QLD Regional Support Contact	
Ann Purcell	Bundaberg Regional Coordinator	
Francesca Herdahl-Thorsing	New Zealand Support Contact	

### National Committee & National Assistants 2022- 2023



**Robert Twin**  
President/Treasurer



**Dr Helen Burnie**  
Vice President



**Lisa Moore**  
Secretary



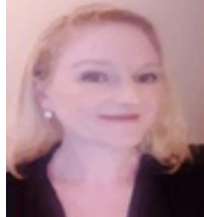
**Darryl Beitsch**  
Committee Member



**Jillian Critchley**  
Committee Member



**Ellen Woodbridge**  
Committee Member



**Shaana Dekker**  
Committee Member  
November 2022 to July 2023



**Nickolas Peachey**  
Committee Member  
July to November 2023

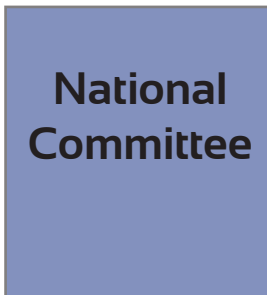


**Eleanor Critchley**  
National Office  
Assistant  
to September 2022



**Anna Siddell**  
National Assistant  
from November

### National Committee & National Assistants 2023- 2024 (elected October 2023)



**Robert Twin**  
President/Treasurer



**Dr Helen Burnie**  
Vice President



**Lisa Moore**  
Secretary



**Darryl Beitsch**  
Committee Member



**Jillian Critchley**  
Committee Member



**Ellen Woodbridge**  
Committee Member



**Nickolas Peachey**  
Committee Member



**Anna Siddell**  
National Assistant

## OUR SUPPORTERS

GOLD		
		
Concord Hospital		
SILVER		
		
<p>Brazier Mobility Vehicle Modifications (SA)</p>	<p>Footpower (Shoetech - NSW) Custom Footwear, Orthotics and AFO providers</p>	<p>TaxBiz Australia Tax, Business, Superannuation and Retirement Planning Specialists (VIC)</p>

## LIFE MEMBERS

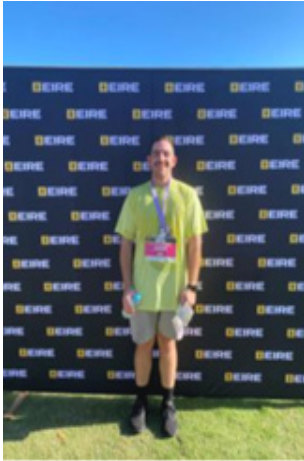
Professor Garth Nicholson





## HIGHLIGHTS OF 2023

### *Fundraising for CMT Australia*



We would love to congratulate the incredible Jimmy Read who raised \$2,437.07 in funds for CMT Australia. Jimmy completed the Port Macquarie half Marathon at the start of March 2023. We are extremely grateful to Jimmy for taking on this endurance challenge. Jimmy said he was sore afterwards, but it was a great and truly rewarding experience.

We are all so proud of you Jimmy.

## CMT AUSSIE KIDS WEEKEND - THREDBO MARCH

*In March 18 KIDS, 2 COOKS, and founders Peter & Jillian Critchley travelled to Thredbo for this years CMT Aussie Kids Camp.*



This year, we welcomed Brooke, all the way from NZ to join us on camp.

*"I thoroughly recommend this camp to any young people out there who have CMT. I was made to feel at ease as soon as I got there, and it felt like I was being welcomed into a big family".*

Brooke's words sum up the spirit of the weekend for all the kids

Activities included Chair lift ride, Bob-sled, stroll up Mt Kosciusko, and many games, laughs and bonding back at the base. The smiles say it all, and many memories were made.

## CMT Australia "Big Kids"

*2023 also saw the CMT Aussie Kids program expand to the Big Kids, for youth 18 - 30.*



The first Big Kids weekend was held in Sydney, during the CMT Awareness Month of September.



## STRUCTURE & MANAGEMENT

Charcot-Marie-Tooth Association Australia Inc. (CMT Australia) is led by a National Committee of 7, comprised of 4 Office Bearers (President, Vice President, Treasurer and Secretary) and 3 General Committee Members. The National Committee are all Volunteers. The Constitution allows for a 4th General committee member, if an Office Bearer holds more than 1 position. This being the case again in 2023 - 2024 with Robert Twin holding office for President and Treasurer.

To assist the committee, CMT Australia have employed a part-time National Administration Assistant, who manages incoming calls to the National number, processing of payments and receipts, mailing out to our postal members, and general assistance to the National Committee in their tasks.

To gain a National Support presence, there is 7 State Support Coordinators, 8 Regional Support Contacts around the Nation. We also have a Support Contact in New Zealand. These roles are all Volunteer.

All who Volunteer in the above roles either have CMT or are Supporting Family with CMT.

Charcot-Marie-Tooth Association Australia Inc. (CMT Australia) is registered in all states to Fundraise.



Charcot-Marie-Tooth Association Australia Inc. (CMT Australia) is registered with the Australian Charities and Not-for-profits Commission (ACNC).

## PRESIDENT'S REPORT - ROBERT TWIN



This is my second annual report as President of CMT Australia. It has been another very busy year during which your committee has advanced a number of our goals. This has again been a real team effort and members can be assured that our Association is working hard to justify your support.

In my previous report I noted our desire to further the progress we had made against our 2017 Strategic Plan. This document included 56 strategies across our 7 goals. My assessment is that we have actively pursued around half of these. Given that this work has been undertaken by our small volunteer committee of 7 plus our State Coordinators and support groups, I believe that this is a good outcome. Particularly given the more restricted meeting options as we recover from COVID19.

The highlights have included the following:

- Our 2023 National Conference held in September returning to a face-to-face format, but integrating the ZOOM option to extend our reach to our members across the Nation;
- Enhancements to our Newsletter format and distribution, particularly the new web-based presentation.
- Our capacity to support our committee and membership through the extended employment of our new Administrative Assistant Anna Siddell;
- Advances in the content of our website and outreach through social media;
- Completion of our conversion of all records across to a professionally supported online system that integrates with a single web-based membership database;
- Adoption of a marketing/communications strategy, and focused implementation of this to first priority stakeholder groups, primarily our members, and Allied Health Professionals;
- Continuation of our youth program and its expansion through staging to mentors and a 'Big Kids' network;
- Raising the awareness of CMT and its personal impacts to key health related Federal Ministers;
- Engagement with our research community and providing financial support of around \$60,000;
- Altering our constitution and awarding our inaugural Life Membership to Professor Garth Nicholson;
- Actively engaging with CMT America (CMTA) and building their recognition of our role in this region;
- Reaching out to parents of children with CMT to share experiences and promote support options;
- Participation in a grant program alongside the Pathways Telehealth Nurse initiative, which whilst unsuccessful, has opened options to participate in the future; and
- An invitation was accepted by Jillian and Peter Critchley to be Associate Investigators at ANZAC Institute.

I would like to thank the members of your committee, our State Coordinators, and our Sustaining Partners for their support. During the year we welcomed our first CMT Aussie Big Kid Nick Peachey to our committee as a replacement for Shaana Dekker who found it necessary to step down. Thanks also to all our loyal members who give us the encouragement and resources to do what we do.

Robert Twin, President.

## OUR OBJECTIVES AND ACTIVITIES

‘To unite all those in Australia who are impacted by CMT, the most common inherited neuropathy; empower those with CMT to live their lives to the fullest; and to encourage our community to support CMT Australia in its goals.’

How did we meet these challenges over the last year?

- **We maximised the capacity of our limited volunteer base** by allocating specific responsibilities across our goals and market segments.
- **We continued to implement our 2017 strategic plan** to steer us towards targeted outcomes based on our goals.
- **We retained and enhanced our strengths**, including activities such as the
  - [CMT Aussie Kids program](#), enhanced now with the addition of the “Big Kids” program, to further develop the bonds and mentorship for the younger kids.



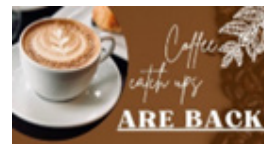
- [our CMT CoMmuniTy newsletter](#), now enhanced online for our members, as a flip book.



- [our website https://www.cmtaustralia.org.au](https://www.cmtaustralia.org.au)



- [our Hybrid conference, National Zoom meetings, In person Coffee Catch Ups](#)



The 2023 September National Conference was held in a Hybrid format, with in person attendance at Concord and online via zoom. Over 100 attended, with the majority joining via zoom. This format opened the opportunity to attend to many more of our members, and we will consider continuing this format into the future. It was good to be able to meet up with others in person after so long just online. We also welcomed our first international attendees, via zoom.

- [our support of our researchers](#) - We granted around \$60,000 in research funding provided by you, our biggest supporters.



- our social media interfaces: National



CMT Australia featured a series of CMT Podcasts through the year, highlighted Key outcomes, and recognised the achievements of our researchers.

- our sustaining partner support, our member communications, our nationally distributed network of supporters, and our sympathetic ear when required.
- We branched out to other groups and programs which offered support to us, as a patient support organisation. Or we could assist to promote their research. We are actively looking at partnering in the Pathways telehealth nurse program to further assist our members navigate the journey. Details will be released to our members, when they become available. Many thanks to Helen Burnie, and Robert Twin for the fine tuning in this process.
  - Helen Burnie, is also keeping up to date with CMT happenings Internationally, and reporting in the magazine, and via updates to the website. We also strengthened our collaboration with CMTA in America.
  - Two of our members, Peter and Jillian Critchley, have accepted an invitation to be Associate Investigators at Anzac Institute.



- We enhanced our capacity to operate nationally and efficiently by taking advantage of government support for digital conversion and marketing.
- We have expanded our administration support by employing Anna as our Part-time Administration Assistant to enable our volunteer committee to focus on our core business.
  - Jillian Critchley is working on a program to assist Parents of children with CMT.
  - Lisa Moore is working on a marketing program which consists of ten segments. The first of these was to engage with our members, through a series of surveys to find CMT Aware professionals nationally. Response was good and came from almost all states.



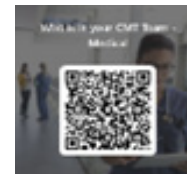
Therapies



Foot Care



Wellbeing



Medical

- Increased Awareness of CMT contacting The Hon. Mark Butler MP, Federal Health Minister, and The Hon. Bill Shorten MP, Federal NDIS Minister, to inform them of the challenges our members face, due to the nature of CMT.

**PLANNED ACTIVITIES FOR 2023 - 2024**

- National funday for the Aussie Kids – 5 Parks, in 5 states in 1 day – Nov 4, 2023

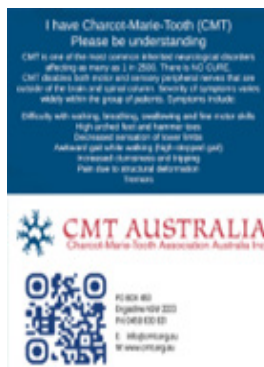


- Sydney – Luna Park
- Melbourne – Luna Park
- Brisbane – Dreamworld
- Adelaide – The Beachouse
- Perth – Adventure World.

- Launch of Moving forward with CMT – Second edition



- New CMT Info card – October 2023 – digital and hard copy



- Aussie Kids Youth Weekend – 2024,
- National Zoom Meetings and Regional Coffee Catchup – throughout the year



- National Conference – Hybrid, city to be determined – Sept 2024
- National Fun Day – CMT Aussie Kids – Venues and Date TBA - 2024
- Trial of Pathways Telehealth Nurse – updates on progress through 2024



## Highlights of 2023

### *CMT Australia welcomes our first Life Member*



**CMT AUSTRALIA**  
Charcot-Marie-Tooth Association Australia Inc.

**Awarded in recognition of 35 years of Service and Support to CMT Australia and the CMT Community, Commitment and Dedication to Research into CMT in Australia and Internationally.**

### *Professor Garth Nicholson*

Professor Nicholson is a physician and neurogenetics researcher. While training as a neurologist he completed a PhD in protein chemistry in neuromuscular diseases at Sydney University. He was awarded postgraduate research fellowships at Duke University and at the Muscular Dystrophy Laboratories, Newcastle upon Tyne. His particular interest was to apply newly discovered DNA techniques to map the genes causing hereditary diseases of the nervous system.

On returning to Sydney as a neurologist at Concord Hospital he obtained funding to establish a research laboratory. By investigating families, he mapped the genetic defects in the most common hereditary peripheral neuropathy (CMT1A) and familial forms of motor neurone disease (MND). Using these new molecular techniques, his research group was involved in finding genetic defects causing other hereditary disorders of muscle, nerve, spinal cord and brain.

This work was the foundation of the Concord Hospital diagnostic and research laboratories as a national referral resource, and stimulated the establishment of CMT patient support groups and international research consortia. The group found the cause of the most common hereditary sensory neuropathy, now leading to treatment trials. The research program continues at the Neurobiology research laboratory at the ANZAC Institute at Concord Hospital, and the Motor Neurone Disease Centre at Macquarie University where Professor Nicholson was recently awarded an Honorary Doctorate.

As can be seen, our CMT Association owes its existence to the pioneering work of Professor Nicholson and his recognition that research into disorders such as CMT was dependent on examination of those presenting with the disease. A fledgling Charcot-Marie-Tooth Association came into being in 1988 through the support of Professor Nicholson who forwarded invitations to become members to those his research team had identified as having CMT.

Professor Nicholson and his team have continued their support of our Association ever since by referring patients, circulating information, and presentations at our Awareness Seminars. Tracking back through our website, every annual seminar between 2012 and 2019 has featured a presentation by Professor Nicholson. Our records show that during the intervening period he also presented at many of the annual seminars conducted by our Association.

In 1991 a breakthrough into the cause of the commonly inherited type of CMT (Type 1A) had been confirmed by Professor Garth Nicholson at the Molecular Genetics and Medical Laboratory at Sydney's Concord Hospital. His article in our Spring 1999 newsletter informed our members that diagnostic testing had now become available for three forms of CMT: CMT Type 1A on chromosome 17p, CMT Type 1B on chromosome 1q and CMTX on the X chromosome. He also stated that, as a result of recent research, CMT neuropathy was now recognized as the most commonly inherited disease of the human peripheral nervous system.

Professor Nicholson was also instrumental in securing our first CMT Association Office in the grounds of Concord Repatriation Hospital. On the 20th March 1999 he cut the ribbon and gave words of encouragement to the Committee to continue its patient support role. His continued support also featured sage advice to our Committee at its first strategic planning day in 2016.

There is no doubt that Professor Garth Nicholson has made a significant impact to research into CMT, and CMT Australia through his support and advocacy. We all owe a debt of gratitude to him and wish him well in his well-deserved retirement.

## TREASURER'S REPORT - ROBERT TWIN



This is my 13th Treasurer's report for CMT Australia, and I'm pleased to report that we continue to be in a sound financial position. The earnings for 2022/23 shows a net profit of \$15,284 which is around \$2,000 down on the previous year; however, this translates to an improved equity of \$119,626. Comparisons between financial years is always problematic, as donations and research grants represent our largest financial transactions, and these vary in timing, and across financial years.

CMT Australia is now exempt from the requirement to have a formal audit due to the scale of our turnover. Your committee agreed last year that we not seek a formal audit, and instead find a suitably qualified financial expert to review the accounts and pass judgment on their veracity. We were fortunate to have TaxBiz as one of our sustaining partners, and Max Newham has again completed such a review at no charge to our association. This is a saving of over \$1,000. Max has again concluded that the accounts for the Association are true and correct and I thank Max for his support in this regard. We will place on our website the 'profit and loss' and 'balance sheet' figures assessed by TaxBiz, along with Max's report to our membership.

We have retained our membership fees at their very modest rate of \$40.00 per household per year to ensure support for CMT Australia is affordable. This brings us around \$11,000 in revenue. To enable us to apply for government grants we have retained our GST reporting status. Whilst this depreciates our membership income, it does enable us to claim back GST on items of expenditure. We currently hold a credit of \$5,038 in this regard and I am experiencing some difficulty in securing these funds back from the ATO.

Our Association provided nearly \$60,000 in research grants over the last 12 months, some of which will be paid from the current financial year. The funds to enable this came from our members, our sustaining partners, and some bequests. All our researchers respond through updates on their projects at our National Conference.

I would like to express our appreciation to our four sustaining partners, Concord Hospital (in kind support), TaxBiz, Brazier Mobility, and Footpower. If you know of a company who would be interested in supporting CMT Australia through this program, please contact me so we can discuss options with them.

I would like to make a special thank you to Lisa Moore and our Admin Assistant Anna Siddell for their support in reporting our various income streams. We understand that some members have had issues in dealing with our payment options and ask for your patience while we finetune these and assist where required.

I propose that the financial statements for the year 2022/23 be approved.



Robert Twin, Treasurer



## INDEPENDENT REVIEW STATEMENT



25 October 2023

**PRIVATE & CONFIDENTIAL**

The Members & Committee  
Charcot-Marie-Tooth Association Australia Inc  
Building 22  
Concord Hospital  
CONCORD NSW 2137

Unit 16  
653 Mountain Highway  
Bayswater VIC 3153

**Mailing Address**  
PO Box 919  
Bayswater VIC 3153

Ph: 9721 0000  
Fax: 9720 6114

everyone@taxbiz.com.au  
www.taxbiz.com.au

Dear Members & Committee

**Re: Review of the Accounts for the year ended 30 June 2023**

I advise that I have reviewed the attached accounts, being the Profit & Loss and Balance Sheet reports for the Charcot-Marie-Tooth Association Australia Inc that covers the period from 1 July 2022 to 30 June 2023.

That review covered verifying large payments made on behalf of the Association, reconciling and verifying material items on the Balance Sheet.

As a result of that review, I believe the accounts for the Association are true and correct.

Yours sincerely,

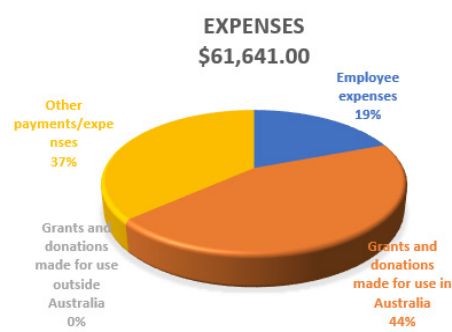
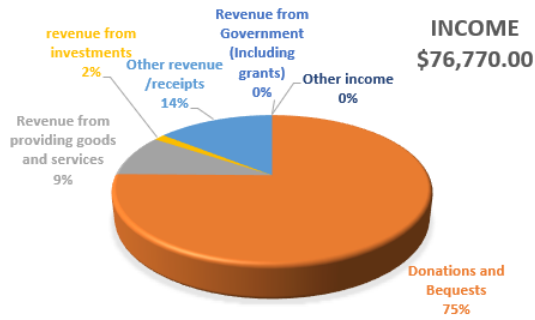
A handwritten signature in black ink, appearing to read 'Max', written over a light blue horizontal line.

Max Newnham  
CA – Financial Planning Specialist

**TAX BUSINESS SUPER AND RETIREMENT PLANNING SPECIALISTS**

Liability limited by a scheme approved under professional standards legislation other than for the acts or omissions of financial services licensee.  
SMSF Survival Centre Pty Ltd ACN 141 145 879 T/A Taxbiz Australia

## Financial Statements



### Profit and loss report

#### Charcot-Marie-Tooth Association of Australia Inc.

Building 22Concord Hospital, Concord, NSW, 2137

0409840042

Accrual mode

01 Jul 2022 - 30 Jun 2023

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	Total	
	Actual	Last Year
<b>Income</b>		
<b>4-0001 CMT Aussie Kids</b>		
4-3100 Camp Fees - National	6,681.81	4,909.08
4-3110 Other Event Fees	0.00	1,609.12
4-3120 Youth Sales	0.00	113.64
<b>Total CMT Aussie Kids</b>	<b>6,681.81</b>	<b>6,631.84</b>
<b>4-0003 Memberships</b>		
4-1200 Membership fees	9,974.07	10,879.39
<b>Total Memberships</b>	<b>9,974.07</b>	<b>10,879.39</b>
<b>4-0004 Miscellaneous Income</b>		
4-8000 Promotional income	909.10	0.00
8-1200 Interest income	1,047.88	17.62
8-1400 Other income	56.03	185.00
<b>Total Miscellaneous Income</b>	<b>2,013.01</b>	<b>202.62</b>
<b>4-0005 Sales</b>		
4-1410 Videos	0.00	9.09
4-1420 Booklets	81.83	159.12
4-1440 National Seminar Reg.	54.54	0.00
4-1450 Stress Ball Postage	181.81	0.00
<b>Total Sales</b>	<b>318.18</b>	<b>168.21</b>
<b>Total Income</b>	<b>18,987.07</b>	<b>17,882.06</b>
<b>Gross Profit</b>	<b>18,987.07</b>	<b>17,882.06</b>
<b>Expense</b>		
<b>6-0001 Finance Expenses</b>		
6-1410 PayPal fees	178.55	265.74
6-1420 Poli Fees	0.90	1.62
6-1700 Dues and Subscriptions	56.00	0.00
6-2600 Insurance	2,847.49	2,124.22
<b>Total Finance Expenses</b>	<b>3,082.94</b>	<b>2,391.58</b>
<b>6-0002 Internet</b>		
6-1900 Domain name	0.00	21.81
6-1910 Web site development	635.00	1,415.77
6-1920 Web site hosting	719.57	109.09
6-1930 Internet access	186.93	312.07
<b>Total Internet</b>	<b>1,541.50</b>	<b>1,858.74</b>
<b>6-0003 National Seminar Expenses</b>		
6-1860 Seminar -Misc costs	279.00	222.00
<b>Total National Seminar Expenses</b>	<b>279.00</b>	<b>222.00</b>

## Financial Statements

<b>6-0004 Office Expenses</b>		
<b>6-0008 Computer Costs</b>		
6-1300 Computer software	1,068.96	611.83
6-1500 Depreciation expense	1,088.00	263.00
<b>Total Computer Costs</b>	<b>2,156.96</b>	<b>874.83</b>
6-3400 Meeting expenses	20.99	20.99
6-3600 Office supplies	235.83	124.37
6-4000 Postage	1,443.95	665.06
6-4100 PO Box rental	0.00	160.00
6-4200 Printing	808.00	920.09
6-5400 Superannuation expense	1,077.48	0.00
6-5600 Telephone	90.90	811.64
6-5800 Teleconference	0.00	167.92
6-5900 Travel expenses	178.20	0.00
6-6200 Wages & salaries	10,783.04	4,759.72
<b>Total Office Expenses</b>	<b>16,795.35</b>	<b>8,504.62</b>
<b>6-0005 Promotion Expense</b>		
6-1210 Promotional material	0.00	2,088.00
6-1230 Conference registration	58.86	225.25
<b>Total Promotion Expense</b>	<b>58.86</b>	<b>2,313.25</b>
<b>6-0006 Region Activities</b>		
6-7000 Activities - NSW	100.00	0.00
<b>Total Region Activities</b>	<b>100.00</b>	<b>0.00</b>
<b>6-0007 Youth Activities</b>		
6-6100 Youth - Camp expenses	9,398.24	3,266.48
6-6110 Youth - travel reimbursement	2,971.25	641.00
6-6120 Youth - other	0.00	4,792.37
<b>Total Youth Activities</b>	<b>12,369.49</b>	<b>8,699.85</b>
<b>Total Expense</b>	<b>34,227.14</b>	<b>23,990.04</b>
<b>Operating Profit</b>	<b>-15,240.07</b>	<b>-6,107.98</b>
<b>Other Income</b>		
<b>8-0001 Donations</b>		
4-1300 Donations - admin	7,543.33	20,878.45
4-1310 Donations - research	27,107.14	45,895.62
4-1320 Donations - youth	23,107.13	8,834.50
<b>8-0003 Special Donations</b>		
4-1610 Re Kaye Boreham	0.00	3,250.00
4-1611 Cause - MORC2	39.88	0.00
<b>Total Special Donations</b>	<b>39.88</b>	<b>3,250.00</b>
<b>Total Donations</b>	<b>57,797.48</b>	<b>78,858.57</b>
<b>Total Other Income</b>	<b>57,797.48</b>	<b>78,858.57</b>
<b>Other Expense</b>		
6-1810 Gifts	0.00	27.27
6-3800 Research Grants	27,272.72	22,855.00
<b>Total Other Expense</b>	<b>27,272.72</b>	<b>22,882.27</b>
<b>Net Profit</b>	<b>15,284.69</b>	<b>49,868.32</b>

## Financial Statements

### Balance sheet report

#### Charcot-Marie-Tooth Association of Australia Inc.

Building 22Concord Hospital, Concord, NSW, 2137

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	Total	
	Actual	Last Year
<b>1-0000 Asset</b>		
<b>1-0001 Banking</b>		
<b>1-0004 Petty Cash</b>		
1-1300 Petty cash NSW	0.00	149.50
<b>Total Petty Cash</b>	<b>0.00</b>	<b>149.50</b>
<b>1-0005 Saving Accounts</b>		
1-1505 Youth account	42,375.83	29,200.47
1-1510 Research account	7,351.44	19,696.27
1-1515 Admin account	42,383.68	35,544.04
1-1520 PayPal transfers	92.53	26.86
<b>Total Saving Accounts</b>	<b>92,203.48</b>	<b>84,467.64</b>
1-1000 Cheque account	12,518.40	12,239.26
1-1100 Debit card	928.73	891.86
1-1200 PayPal	1,106.78	2,047.04
1-1250 Give Now	3,650.51	1,454.08
<b>Total Banking</b>	<b>110,407.90</b>	<b>101,249.38</b>
<b>1-0002 Current Assets</b>		
1-1800 Accounts receivable	1,500.00	0.00
<b>Total Current Assets</b>	<b>1,500.00</b>	<b>0.00</b>
<b>1-0003 Fixed Assets</b>		
1-2400 Office equipment and computers	12,852.97	9,871.89
1-2600 Accumulated depreciation	-10,083.00	-8,995.00
<b>Total Fixed Assets</b>	<b>2,769.97</b>	<b>876.89</b>
<b>Total Asset</b>	<b>114,677.87</b>	<b>102,126.27</b>
<b>2-0000 Liability</b>		
<b>2-0002 Current Liabilities</b>		
2-2200 GST collected	3,815.95	2,039.11
2-2400 GST paid	-8,853.99	-4,254.28
2-3200 Superannuation payable	89.78	0.00
<b>Total Current Liabilities</b>	<b>-4,948.26</b>	<b>-2,215.17</b>
<b>Total Liability</b>	<b>-4,948.26</b>	<b>-2,215.17</b>
<b>Net Assets</b>	<b>119,626.13</b>	<b>104,341.44</b>
<b>3-0000 Equity</b>		
<b>3-0001 Current Earnings</b>		
3-1800 Current year earnings	15,284.69	49,868.32
<b>Total Current Earnings</b>	<b>15,284.69</b>	<b>49,868.32</b>
<b>3-0002 Retained Earnings</b>		
3-1600 Retained earnings	104,341.44	54,473.12
<b>Total Retained Earnings</b>	<b>104,341.44</b>	<b>54,473.12</b>
<b>Total Equity</b>	<b>119,626.13</b>	<b>104,341.44</b>

## Highlights of 2023

### *WEHI LAB VISIT – VICTORIA September*

Our Victorian Coordinator, Larissa McKinnon again joined Dr Winnie Tan and the research Team at the Walter Eliza Hull Institute for research (WEHI), for a guide tour of the Lab, a presentation, and morning tea. This is the second year this visit has been held. It was also streamed online, so could join in From anywhere across the nation.



### *Local Catchups*

Our local coordinators continue to hold local catch ups around the Nation, to enable our CMT community a safe environment to connect with others living with CMT, to share experiences, gain some new insights and perhaps hear from a local professional



### *Congratulation's Professor Joshua Burns.*

CMT Australia are excited to announce that friend, collaborator and all-round nice bloke, Professor Joshua Burns has been selected as one of the 27 newly elected fellows.

Professor Joshua Burns is Paediatric Neuromuscular Rehabilitation Professor and Head of School and Dean of the Sydney School of Health Sciences in the Faculty of Medicine and Health.

He co-leads the Peripheral Neuropathy Management Clinic at The Children's Hospital at Westmead and is Director of the Paediatric Gait Analysis Service of New South Wales at the Sydney Children's Hospitals Network.



Professor Burns is the inventor of ClinicalOutcomeMeasures.org, a web-based scoring system for monitoring response to therapy, housing key clinical trial endpoints such as the Charcot-Marie-Tooth Pediatric Scale (CMTPedS), CMT Functional Outcome Measure (CMT- FOM), CMT Infant Scale (CMTInfS), Rasch-modified CMT Neuropathy Score (CMTNSv2-R) and items from the 1000 Norms Project.

"Fellows are elected by their peers for their significant contributions to health and medical sciences – it is a selective process that recognises the best and brightest in Australia and highlights those who are truly making a difference in health," said the Academy's Interim President Professor Ingrid Scheffer AO FRS FAA FAHMS.

"The Academy recognises individuals who have made outstanding contributions in their respective field. The new fellows have demonstrated international research leadership in the broad areas of health sciences, medical sciences, medicine and public health," said Professor Robyn Ward, Executive Dean and Pro Vice-Chancellor Medicine and Health.

CMT Australia is proud to have such a strong, professional relationship with Prof Burns and congratulate him on this incredible distinction.

## ACKNOWLEDGEMENTS & THANKYOU

CMT Australia recognises without the support and kind donations we receive; we would not be able to provide the support and information we do to our CMT community and the general community or provide funding to our local researchers to further research into CMT.

CMT Australia Sincerely thanks:

### **Donors**

Those who have given generously to our income streams, organised fundraising events through Bun-nings Barbecue Days, Grill'd Local Matters Campaigns, Specific Research Campaigns.

### **Corporate & community partners**

Concord Hospital – Our Gold Sustaining Partner, for their In-Kind support for our National Office Space

Brazier Mobility, Tax Biz Australia and Shoetech – Our Silver partners for their continued financial support this year, to help us keep delivering some of our programs.

Our research partnerships – Whether contacting us for a possibility of funding or part funding a new research project for CMT, or inviting our members into your labs, to bring a greater understanding of the work you are doing, building a connection between the Science and the patient.

Reaching out to CMT Australia to participate as Community Rep in these projects.

### **Volunteers**

Without our Volunteers, we would not exist. To Our National Committee – thank you for your dedication to the Association, and drive to bring new projects and programs to keep us moving forward towards our goals.

To our Support Coordinators and Regional Contacts – You assist to bring CMT Australia to all in Australia, to let us be a truly National Organisation.

### **Members**

Most importantly, thank you to our 300+ paying members. We thank you for your support and loyalty to CMT Australia, helping to guide us in what you want from your Association.



## HOW YOU CAN HELP

For many people, the diagnosis of Charcot Marie Tooth (CMT) comes as a complete shock. CMT is a disease caused by genetic faults. In some cases, they are inherited, in others the fault is a new mutation in the gene.

CMT Australia was established to assist those affected by CMT through a range of programs. Your support can help us in our mission.

There are a number of ways you can support us: Donate direct to CMT Australia or through Workplace Giving, make a Bequest, Fundraise, Volunteer, become a Member, provide Sponsorship, or make a purchase from us.

### Become a member

Membership is \$40/yr. and covers all in one household.

Visit <https://cmtaustralia.org.au/membership/>, download, complete and email application form to [info@cmt.org.au](mailto:info@cmt.org.au), then click Join Now to select and pay for your membership. Payment options include PayPal/Credit Card, EFT/Direct Deposit, and Cheque/Money Order.

### Volunteer your time

There are ways you can volunteer for CMT Australia:

- Organising and/or assisting at fundraising events
- Encouraging donations to CMT Australia through GiveNow for fundraising events
- Assisting at CMT Australia events
- Do you have Marketing or Promotions experience – CMT Australia would love to have you on board to help
- Join the CMT Australia Committee and help the Association meet its goals and grow in the future
- Encourage your workplace to support CMT Australia through Workplace Giving program

If you are interested in becoming a CMT Australia Volunteer in your area, please contact our National office on 0458 630 631 to discuss.

### Make a donation

All donations over \$2 are tax deductible.

CMT Australia has 3 Donation Streams – **Youth** (CMT Aussie Kids Program), **Admin** (applied to Promotional Materials, Salary for Office Assistant, Running the National office) and **Research** (Support for projects that our researchers have put forward and have been approved by the Committee. These can vary in scope and financial commitment, but usually involve thousands of dollars and can extend over more than a year).

Donations can be made through

- **Online direct through PayPal/Credit card** – complete the online blue donation form and click the Donate button to complete your donation. Visit <https://cmtaustralia.org.au/donate/>
- **GiveNow Platform**  
CMT Australia has 3 Ongoing Crowd raising Platforms – Research, Support CMT Australia, CMT Aussie Kids, which fund our 3 streams of Research, Admin and Youth. [Visit https://www.givenow.com.au/organisation/public/236](https://www.givenow.com.au/organisation/public/236).  
We plan to add a 4th platform – Pathways telehealth Nurse, to help fund a telehealth nurse, to assist our members to enhance their lives, by connecting with the professionals needed locally.



- **Workplace Giving** – Many people are familiar with the opportunity to salary sacrifice part of your salary for a range of purposes such as superannuation or leasing a car. Did you know that you can also salary sacrifice through a Workplace Giving Organisation to a charity with ATO Deductible Gift Recipient status (CMT Australia).

We signed up with the Workplace Giving Organisation: Good2Give to facilitate supporters who would prefer this method of donating to our causes.

#### **Leave a bequest**

You would be required to update your Will, make a decision as to the amount of the bequest and how you wish CMT Australia to allocate the funds (Research, Youth or Admin stream), notify your loved ones and notify [CMT Australia](#).

#### **Support an event or fundraising activity**

To help us reach our goals you can use our [GiveNow fundraising page](#) in conjunction with our [Fundraising Policy](#), to raise funds for CMT research. All donations from this page go to fund CMT Research in Australia.

Or come up with your own fundraising idea and setup a fundraising page on Give Now. Online fundraising is the easiest way to start fundraising. You will need an 'Authority to Fundraise' letter if you are fundraising on behalf of CMT Australia. Please contact the national office to get this organised.

You can support an event or activity by helping out at the event, Donating to the event via the donation method nominated.

Promoting the Event in your network.

#### **Become a corporate partner Two Levels Gold or Silver Partnership**

Basic inclusions in sponsorship package include –

- recognition of your support through a framed certificate
- acknowledgement in the CMT Australia Annual Report
- your logo on the CMT Australia website with a link to your site
- recognition of your organisation's support at CMT Australia events and in the newsletter
- permission to use the CMT Australia logo to advertise your partnership promotion of your events through the CMT Australia network
- a complimentary membership.

Please contact Treasurer, Robert Twin on 0409 840 042 or email [treasurer@cmt.org.au](mailto:treasurer@cmt.org.au) to discuss your partnership with CMT Australia.

#### **Other ways you can help our cause**

Make a purchase from CMT Australia

- 2x Stress balls – Member only purchase
- CMT Australia has a couple of Publications for Purchase.
- Non- Member access to Member Events

Visit <https://cmtaustralia.org.au/shop/>

## Highlights of 2023

### *CMT Australia Hybrid Conference - Sydney NSW & Zoom September.*

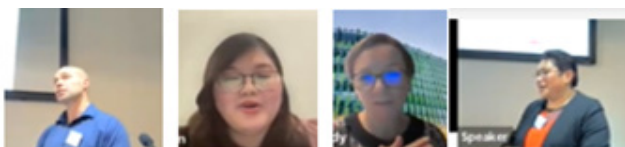


2023 saw the introduction of a hybrid format for the national conference, being in person at the Sydney University Medical Education Centre at Concord Hospital in Sydney, and live streamed via zoom. This concept enabled CMT Australia to connect with all our members, no matter where they were. via Zoom. We had over 100 registered to attend both in person and via zoom.



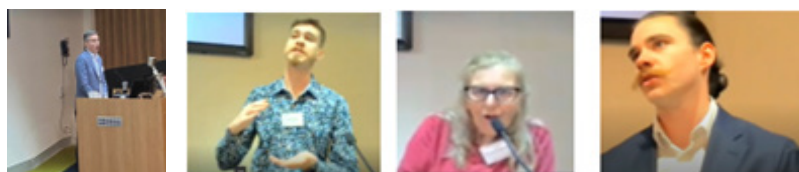
### Research Updates

Presentations from Professors Marina Kennerson and Joshua Burns on Research both Australian and International. Also updates from our 3 2022 grant recipients on their respective projects.



### The program featured:

### Personal Stories



Some personal stories of Living With CMT, and challenges, including overcoming mental health issues.

Presenters Nick Peachey, Dr Helen Burnie and Chris Peachey.

### An Award

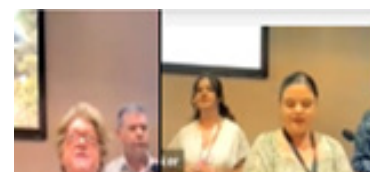


President Robert Twin virtually presented CMT Australia's first Life Membership to Professor Garth Nicholson, who joined the conference via Zoom from Adelaide. We thank Professor Nicholson for his dedication to CMT research over many years.

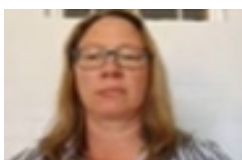


### CMT Aussie Kids & Big Kids

Peter and Jillian Critchley, founders of the CMT Aussie Kids program launched the video of their 2023 Aussie Kids camp at Thredbo. The program is expanding and now has the 'Big Kids' for youth 18 - 30. This was introduced by current mentors Matilda, Eleanor and Nick.



### Allied Health Professionals



Tanya Walsh, Physiotherapist in Bathurst NSW, gave an informative presentation on what is CMT?, how it can affect those living with CMT, how physiotherapy can benefit those living with CMT and what to expect at a physio assessment appointment.

Brittany Hulme, a former Aussie Kid, is an Occupational Therapist, living and working in WA. Brittany's presentation broke down the application process for NDIS, and how an OT can help, types of assistance you may be able to get, specialised assessments which can be done by an OT.



## LOOKING TO THE FUTURE

- Implementation of Full Marketing plan
- Strong Connections with Medical/Allied Health Professionals through greater awareness of CMT, dedicated pages for these professionals on the website
- Strong connections with our researchers, with some progress in management, diagnosis and ultimately a cure
- Support Contacts actively engaging with communities in all areas of Australia
- Growth of our membership base and Supporting Partnership programs
- Information and support dedicated to Parents of children and Parents with CMT
- Adult getaway experience for adults with CMT ( Activities similar to the Kids Program)
- Introduce Pathways Telehealth Nurse to assist our members to navigate their journey with CMT



**CMT AUSTRALIA**  
Charcot-Marie-Tooth Association Australia Inc.

**CMT AUSSIE KIDS**  
www.cmt.org.au  
Phone: 0458 630 631 Email: info@cmt.org.au



# CMT AUSTRALIA

Charcot-Marie-Tooth Association Australia Inc.

## CONTACT US

PO Box 493 Engadine NSW 2233

0458 630 631

[cmtaustralia.org.au](http://cmtaustralia.org.au)

[info@cmt.org.au](mailto:info@cmt.org.au)

[Facebook](#), [Instagram](#), [Twitter](#)