The newsletter of the Charcot-Marie-Tooth Association of Australia Incorporated, providing information and support for people with Charcot-Marie-Tooth disease and their carers, health professionals and friends.

VOLUME 85 Autumn 2017

CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

FIRST CMTAA STRATEGIC PLAN RELEASED

In the last newsletter your Committee provided details of a highly successful strategic planning day held in October 2016. This is new ground for CMTAA and we are now pleased to advise that **a plan has been prepared and was approved by the Committee at its March meeting**. Copies will be distributed to those who receive their newsletter by post (look in your envelope) and for all members this is available for download from our CMTAA website. See the link from the announcement on our home page.

The plan encapsulates all the great ideas that were raised in October and distils these down to what are now **7 goals for our Association**. We have also adopted a simpler and more appropriate brand name **'CMT Australia'** for use in our marketing and public interface activities. Officially we remain the Charcot-Marie-Tooth Association of Australia Incorporated, but we feel that this is a bit of a mouthful and impedes our message. 'CMT Australia' is direct in that it uses the simple globally recognised 3 letter acronym 'CMT' and identifies our sphere of influence through the word 'Australia'. We will progressively use this brand name, but rest assured it is still your trusted CMTAA Inc. *(Read more about our Strategic plan on Page 4)*

INSIDE THIS EDITION

Our greatest glory is not in never falling but getting up every time we do—Confucius

PRESIDENTS REPORT

Dear CMTAA Family,

Welcome to 2017. All of us here at the CMTAA hope that everyone enjoyed the Christmas and New Year season and that you have all had a wonderful start to the year.

2017 has certainly started off very eventful for myself and my family; we have hit the ground running. My little boy started kindergarten and my little girl year 1. They certainly keep me busy :) Just to make things even a little more interesting, I will be having surgery on my knee (possibly hip and whole leg, still waiting on second opinion) some time this year. Just before Christmas we decided to take our boat out for a fun family day of fishing and I injured my leg, causing a lot of damage. I am very lucky and very blessed to have so much amazing support around me, which has made things so much easier.

Although mobility is somewhat ok, getting around on a leg that is badly injured has certainly made things interesting :)

I have however had to make the very difficult decision to step down from my role as President for the time being. I don't believe that I would be able to fulfil my responsibilities of the role to the best of my ability, given my current health situation. Not only will I be in and out hospital, rehabilitation and recovery will take up much of my time also.

You are all in the very capable and wonderful hands of the CMTAA committee, and all of your wonderful Coodinators and Support contacts. 2017 is set to be an exciting year, Rebecca Poyner your vice president and the committee are dedicated and passionate about the journey ahead. I would like to thank each and every member for their continued support. I look forward to returning in whatever capacity is needed at the time of my return once I am all recovered :)

May this year be fantastic for you all and I look forward to the day I join the CMTAA Family once again :)

Nelly Sutjipto

A MESSAGE FROM THE VICE PRESIDENT

Dear CMTAA members,

I am writing this letter in correspondence to Nelly's formal application for resignation. The CMTAA committee members thoroughly, albeit with heavy hearts support Nelly's decision to step down from the Association. Nelly has been an extremely passionate and proactive President for the association and will be greatly missed in the day to day running of the CMTAA. Life with CMT can certainly be a difficult path and nothing is ever certain, but we are sure if anyone can triumph these challenges, it will be Nelly. Nelly, we wish you all the very best in your road to recovery. We are confident this will not be the last we see of you within the CMTAA.

While Nelly has been at the forefront of the CMTAA's recent activities and plans to bring the CMTAA into the next chapter, we must express that our work will continue on without her. The CMTAA is composed of a team of individuals who are highly committed to improving the lives of those with CMT and those supporting these individuals.

The CMTAA is currently striving to achieve these objectives along with many other goals and have developed a variety of strategic planning programs to ensure we stay focussed on the tasks at hand.

As expected, our committee members and State Coordinators have banded together and picked up extra tasks and responsibilities in Nelly's unfortunate absence. I am extremely confident this will continue as our adverse team only gains strength each and every day regardless of the challenges we are faced with.

Just like many of our members, we are strong and will continue with our fight to one day live in a world without CMT.

Signing off with this very appropriate quote and hoping all our members are well and giving CMT the boot! We are so much stronger than we give ourselves credit for, but nothing is ever assured, which is why we should strive to make every day count!

"Hardships often prepare ordinary people for an extraordinary destiny." - C S Lewis

Rebecca Poyner

CMTAA Vice President

NEWS FROM THE REGIONS AND STATES

TASMANIA

Unfortunately we didn't have a Christmas meeting of our Support Group last year due to illness so we had a belated get-together on Sunday 22nd January at our home. We had a good group of over 20 folk attending despite the fact that there were a lot of folk away on holidays. We welcomed 3 new members as well as the new and old President of the Muscular Dystrophy Association who have offered assistance to our members.
We spent the afternoon viewing the DVD of last year's Awareness Day in Brisbane as well as bringing them up-to-date with what's happening on the CMT front, followed by a sumptuous afternoon tea. If numbers continue to grow we will have to look at a new venue – our lounge room was a little crowded! I really see the benefit of these support group meetings – folk get so much out of meeting others with CMT and discussing their problems. One person's solution is often of benefit to someone else.

I feel privileged to be on the Committee of the CMTAA . Some of you may feel that nothing much is happening but believe me there is a lot of work going on behind the scenes – remembering that we are all volunteers. I encourage everyone to renew their subscriptions, make a donation or become a new member – your contributions are extremely valuable enabling ongoing research work to be done. Best Wishes to you all.
Marilyn Kremmer, Tasmanian Support Group Co-ordinator

GOLD COAST

Hi All, Judy here with greetings from the Gold Coast. I don't know about any of you, but the humidity has been knocking me and members of the Gold Coast Gang about a bit, but being C.M.T Warriors we cope the best we can. The support group is going well, with a couple of new members attending the last meeting. I am thinking of arranging a Barefoot Bowls Day to see if we can raise some funds for the Kids going to the U.K next year. More on that later. Until next time take care and keep smiling. Judy.

WESTERN AUSTRALIA

Hi, We've had a quiet start to the year over here in Western Australia but are now busy planning our first meeting for 2017 which will be held at The Genetic & Rare Disease Network (GaRDN) Office, 37 Hampden Road, Nedlands towards the end of April / early May from 2.00-5.00pm. As usual, it will be great to touch base with our regular members together with anyone new who's interested in coming along to meet us. Please don't hesitate to contact us via the details provided on the website for further information regarding the meeting, should you wish to attend.
Regards, WA Committee

SOUTH AUSTRALIA

Hello from SA. A lovely end to 2016 after a very busy and sometimes frantic 2016! Finishing the year on a high in late November we shared a beautiful afternoon relaxing, eating and cruising down the Port River. Even though we didn't see the iconic Port River dolphins a great time, was had by all. Managing to get up and close to the visiting Ovation, an international cruise liner was amazing. Maybe if we get enough interest we might arrange a CMTAA event on a cruise liner someday! In February the CMTAA SA Support Group were off for our first 2017 Coffee & Chat. Held at the Blacksmith Cafe in Handorf, located in the beautiful Adelaide Hills. Though a little windy and fresh the great company and food made all the difference. Our next Coffee & Chat will be on Sunday 29th May 2017, at Kibbis Café, 39A Beach Rd Christies Beach between 12-2pm. We would love to meet many more of the SA CMT Community, their families, carers and friends. So why not mark your diaries and join us. We encourage bookings

so we can cater for all needs. September will again be a big focus month in SA with the CMTAA SA Support Group rolling out the CMT awareness campaign across the SA Community. Some of the events will include entering a team in the Fun Run, a stand in the Disability and Lifestyle Expo, a radio interview and an information session already planned for the month. The CMTAA SA Support Group Facebook continues to grow with 43 members, 10 joining us since last year. Through word of mouth, contact at our many events, radio, stands at expos we continue to reach out into the SA community. Take care all and KEEP MOVING! Warm regards
Antonia, Lisa, Simone, Isabella and Andrea - Your CMTAA SA Support Group.

CMTAA STRATEGIC PLAN

(continued from page 1)

Our Vision has been adopted from our sister organisation in North America (CMTA), 'A World without CMT'. Only a year or so ago this would not have been considered feasible; however as we heard from our lead researchers during our October planning day, this is now a real prospect. Whilst it is some way off, we also decided that it was visionary and therefore sets a challenge for us all. Our researchers also noted the blurring of the terms 'CMT' and 'inherited neuropathy' and therefore we have incorporated this latter term into our mission statement which is '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 CMTAA in its goals.'

Our first 5 goals remain much the same, albeit with some ungraded wording; however we have added 2 more goals following our October planning day. These are 'to establish alliances with organisations and groups with similar or complementary objectives'; and 'to assist in the establishment of similar Associations in our region'. An important background to our plan was a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis completed by Darryl Beitsch. This is included on the last page of our plan. Our quest then is to adopt strategies that will help us achieve our vision, mission and goals; whilst also building on our strengths and opportunities, and where possible reducing our weaknesses and threats.

The balance of our plan details our summary of the discussions during our planning day in the context of our goals. Some of these strategies are work in progress, but many are new. We don't expect to achieve them all in the first year, and it will take more than our small Committee to action these. This is where you our members can step up. If you are inspired by what you read in our plan, and believe that you can contribute is some way, then please let us know. By working together we can achieve much of what is set out in this plan over the next 3 years. Keep an eye on communication tools such as this newsletter, our website and Facebook presence to follow the action.

Robert Twin CMTAA Treasurer

NEWS AND VIEWS

CMT Aussie Kids Weekend

It's on again. Are you a young school kid with Charcot Marie Tooth Disease and feel like a fun, challenging time away from home? This year we are changing the location to Cockatoo Island in Sydney Harbour. Camping under the stars! Experience heaps of fun activities like a surf lesson at Manly Beach, Initiative Course around Circular Quay, Scavenge around Cockatoo Island and more.

To be eligible to attend you only have to be a student at school aged from about 8-10 years; be a member of the CMTAA (if you're not already a member, contact us) and have some form of CMT, oh... and want to have fun with other kids just like you. Email Jillian at cmtaussiekids@gmail.com or call mobile 0428 221 264 for more details.

Disabled Parking Australia Mobile App

The "Mobility Parking Scheme" (MPS) provides parking concessions to people with mobility disabilities in NSW. The "Australian Disability Parking Scheme" is an Australia-wide scheme that aims to harmonise all state and territory disability parking programs.
When you apply for a Mobility Parking Scheme permit in NSW, you'll also be issued an Australian Disability Parking Permit and you will need to display both when you park.
There are different parking rules allowed for parking in each state CBD.
A new app called "Disabled Parking Australia" app has been developed to help you:

- Check the rules for each state and territory
- Check parking spots on the map
- Prepare before you park (i.e. cost)

The app is available through iTunes.
For more info on the MPS, go to:
h p://www.rms.nsw.gov.au/roads/using- roads/mobility-parking/

Thanks to Mandy Hanna and The School Therapy Team at St George Hospital for this information.

Can you assist CMT research by helping with Fund Raising?

Researchers and scientists around Australia frequently contact the Charcot-Marie-Tooth Association (CMTAA) for desperately needed funds to assist them in finding a cure for Charcot-Marie-Tooth disease or what it is more commonly known as CMT.

We have excellent scientists in Australia working hard to find a cure but funding is a constant problem. CMTAA assists by funding through donations received for what it carefully considers to be important research. Unfortunately, there have never been enough funds available to assist in the Grant Applications we receive. We frequently have to turn back requests due to lack of research funds we have available.

This is why the Association is now appealing for our members (and non- members) to take on the role of fund raising for CMT research. If you have spare time, you could organise a fund raising event such as an Afternoon Tea, hold raffles or contact companies who may be willing to donate to CMT research. We also have a Sustaining Partnership Scheme where a company can advertise on our website and in our newsletter for a specific fee. We need someone to coordinate and manage this specific work. The National Office can assist of course so you would not be alone in this role.

If you feel you can help in this project please contact our National Office on (02) 9767 5105 or email: cmtaa2@cmt.org.au.

If the office is unattended, please leave your name and contact number and we will get back to you.

Disability Rights BY Shaana Dekker

Disability rights are about more than being allowed to miss PE, getting an ergonomic keyboard at work, or handrails and ramp access to buildings. It is about your right to access and enjoy all that life has to offer, irrespective of your disability. While media stories often focus on court victories and losses, we can all play an important role in achieving day to day equality for people with disabilities. It begins with educating ourselves and continues with the conversations we have with employers, schools, institutions and businesses.

Federal and State laws prohibit disability discrimination in the areas of employment, education, access to premises, provision of goods and services, accommodation, club activities, sport and the administration of government programs. If someone treats you less favourably because of your disability or has a policy or process which disadvantages people with a disability more than others, that conduct is not allowed. It is also discrimination if a person or organization does not make reasonable adjustments to enable you to access what is offered on an equal basis.

So what does all that mean for you on a daily basis? You have the right to insist that schools or employers provide you with the reasonable adjustments you need to work or study comfortably, safely and on an equal basis. For example, you might need to take frequent breaks, work from home, start or finish at different times, complete assessments orally or use specific assistive technology. Reasonable adjustments are also about changing activities and policies so that you can participate equally. For example, instead of allowing you to miss an excursion or meeting, the activity should change so that everyone can participate.

Unless the adjustment would cause unjustifiable hardship, failure to provide you with what you need is unlawful discrimination. Inconvenience is no excuse. People will often point out how 'understanding' they have been, or that something you ask for is problematic or 'unfeasible'. This is often to discourage you from asserting your rights, because accommodating your needs is inconvenient for them. While no one wants to be the 'difficult' person who creates tension at school, at work or in the community, you do not have to put up with a situation that is 'good enough'.

If you feel that you are not being treated fairly because of your disability the first step is to talk to the person or organization involved, make them aware of your concerns and discuss the adjustments you require. Ask them to explain their reasons and remind them about the law. If you don't feel comfortable doing that, you can ask a friend or other representative to advocate on your behalf. If things are not resolved informally, you can call the Australian Human Rights Commission for advice and discuss the benefits of making a complaint.

The Commission investigates and conciliates complaints of discrimination. Calling them, making a complaint and attending conciliation is free. It is a useful path to consider because you may be able to receive an apology, financial compensation or better working or study conditions. You might also contribute to systemic policy change.

For more information, the Australian Human Rights Commission has a wealth of information for people with disabilities. Visit https://www.humanrights.gov.au/

*This information should not be substituted for professional legal advice

Australian Human Rights Commission

How to access the N.D.I.S. BY Matthew McKeon

I am 38 years old and have CMT type 2 with my symptoms appearing at a very early age. I would like to let other CMT persons know about my experience with entering the NDIS program.

In early October of 2016, I received a phone call from the NDIS office in Canberra asking me basic questions about my disability as I am a registered disabled person receiving disability support. Questions as to what condition makes me disabled, my limitations, my strengths etc. were asked and I gave them examples.

Very soon afterwards, I then received an Access Request Form to fill out. The questions on the form included my Primary disability, other disabilities, my current treatment, was my disability due to an injury, was I seeking compensation for my disability and if I had undertaken one or more of a list of assessments or reports in relation to my disability. If any were applicable to my condition then I had to provide a copy of the relevant Report with my returned Access Request Form. To give some examples; Hearing Loss Report, Gross Motor Functional Classification Scale (GMFCS) and the Care and Needs Scale (CANS).

There was a requirement for supporting information about my disability and the impact it has had on my mobility, communication, social interaction, learning, self-care and/or ability to self-manage my condition. To do this I had to provide copies of reports, letters or assessments from my health or education professional detailing my (or if a child's) impairment and the impact it has had on my daily life. Alternatively, I could ask a professional to complete a section of this form. My GP doctor filled out this section. This form was done on October 25th and I sent it back to the National Access Team in Canberra or I could have taken it to an NDIA office.

Strangely, after sending in the form I received a letter from the National Access Team, NDIS, Head office, Canberra on November 9, 2016 requesting to meet me. NDIS advised that a representative would be calling me shortly to ask me questions about meeting the requirements to become an NDIS participant.

On November 15th, I meet their representative at my local library. They did not want to come to my house. The interview lasted about 1 ½ hours and I was asked about where I live, who supports me, my daily life – what I do during the day and what my goals are. They also asked about my supports such as community groups, sporting or hobby clubs or other government services.

On November 24th, I was notified by phone that my plan for NDIS was approved and then I received a confirmation letter which listed my budgets for each support. For example if I needed an AFO or repairs to an AFO, my Assistant technology amount was budgeted at $750 for a year. As well, I was requested to supply my bank account number and BSB number so they could transfer a yearly amount to cover my transport expenses. This is extra even if you are on a pension which I am.

I was then sent a Provider and Services Guide which listed the home care services that were available to me. I was told to contact the providers that I wanted and that I thought would best suit my needs and if I had any problems I was to contact my NDIS community manager listed on the Guide form. Any costs involved are being directly paid to the provider by NDIS. If you find that a Service Provider is not satisfactory, you can change to another provider.

Northcott, a service provider sent out an OT to see what equipment I needed in my house which will be paid for out of the NDIS allowance. The OT did a full report of how I do things and what can be done to makes things easier for me like hand grips for opening things, a high adjustable shower chair, and any other aides to be able to help me. But with that being said, the OT has to put in the request to the NDIS for the equipment to be approved or not, and even though I may say, need hand grips, the NDIS can deny it. So the OT has to fight the NDIS for what i really need.

The plan lasts for one year and will be reviewed at the end of each year.

If you would like more information, you can email me on E: mrwdu1@live.com and I would be happy to answer any questions or concerns you may have.

Patients, Scientists and Doctors advance the frontiers of CMT research

They say it takes a village to raise a child. The same can be said for medical research discoveries – not just scientists and clinicians are involved, but also the patients and their families play important roles in medical research. One of our most recent discoveries clearly demonstrates this.

In July 2016, the Northcott Neuroscience Laboratory, ANZAC Research Institute and their collaborators published an article in PLoS Genetics describing the genetic mutation that causes X-linked CMT subtype CMTX31. Dr Megan Brewer who reported the discovery is a postdoctoral fellow with the research team led by Associate Professor Marina Kennerson and Director Professor Garth Nicholson.

Patients with CMTX3 carry a large DNA re-arrangement, also known as a structural variation, where a portion of chromosome 8 has been duplicated and then inserted into chromosome X. If we consider the human genome to be the blueprint of an individual, this would be the equivalent to finding a second kitchen sink located in the spare bedroom on an architect's plan.

This discovery has been a long time coming. It has been 25 years since the search region for the CMTX3 gene was first mapped to 26 million base pairs on chromosome X2. And ten years since our laboratory confirmed and refined the disease region to a more manageable search of 5.7 million base pairs3. The advances in genome technology and being able to sequence the 3 billion base pairs in the human genome for approximately ~$2000AUD made this finding possible. Our discovery of the large CMTX3 DNA rearrangement most likely causing gene dysregulation was ground breaking for the international CMT research community – as this represented a new disease mechanism for CMT that is highly treatable.

We now offer families with CMTX3 genetic counselling and our laboratory has developed a diagnostic test that can confirm whether a family member will inherit the disease. This is particularly important for family members wanting to have children as the new genetic testing gives options (such as IVF pre-implantation screening) for family planning.

Coming back to the research village, our CMT research has always involved the triad of clinicians, scientists and patients. The extensive author list of our publications include doctors, senior scientists, postdoctoral fellows, research assistants, and students; providing a glimpse into the numerous individuals who have been dedicated to this project over the past decade. A key to our successful discovery has been the ongoing participation and support from the patients' and their families. At the time of our CMTX3 publication we had 105 family members participating in this study. This enabled us to determine the odds of this DNA rearrangement causing CMTX3, to be 10 billion to one in favour of being correct. Without the patients' participation the power of this study would have been lacking, and it would have been impossible to prove the mutation we identified causes CMTX3.

To acknowledge the importance of our patients, one hot summer day in January 2017, the Northcott Neuroscience Laboratory hosted over 30 family members for a lunch at the ANZAC Research Institute. This lunch served as both a family reunion, with several family members meeting for the first time, as well an information session on the recent discovery of their CMTX3 DNA mutation. The day was a great success and showed that our CMT village was nurtured by strong bonds between the family members and the researchers which has been the key to sustaining our research progress.

By Associate Professor Marina Kennerson PhD

Our discovery highlights a new type of DNA mutation causing CMT. Most CMT mutations are single base pair changes that directly affect the amino acid building blocks of a protein. Making an extra copy or removing a gene from a patients' DNA as seen in CMT1A and the PMP22 gene has long been known to cause CMT disease. However, the copying and pasting of one region of DNA (1000 to millions of base pairs) into another region of DNA has not yet been seen in patients with CMT disease. We have now begun to look for large DNA rearrangements in other genetically unexplained families and have solved a large family that has a form of distal hereditary motor neuropathy4.

We are now working to understand how these structural variation mutations are causing disease. We suspect that the extra piece of DNA pasted into the wrong place in CMTX3 patients is disrupting the correct amount of a protein (either too much or too little) in the patient's nerves. If we can identify the culprit protein with abnormal levels then treatments could be developed to restore the correct amount through drug therapies.

Finding the DNA mutation causing CMT in a family is the first step to understanding how it causes disease and looking into treatments. By continuing to work collaboratively with patients, clinicians and scientists we hope to identify the genetic mutation for all CMT patients and develop effective therapies for CMT disease.

Publications from the laboratory:

1. Brewer MH, Chaudhry R, Qi J, Kidambi A, Drew AP, Menezes MP, Ryan MM, Farrar MA, Mowat D, Subramanian GM, Young HK, Zuchner S, Reddel SW, Nicholson GA and Kennerson ML (2016) "Whole genome sequencing identifies a 78 kb insertion from chromosome 8 as the cause of charcot-marie-tooth neuropathy cmtx3." PLoS Genetics 12:e1006177 (This article is publically available at http://journals.plos.org/plosgenetics/article?id=10.1371/journal.pgen.1006177)

3. Huttner IG, Kennerson ML, Reddel SW, Radovanovic D and Nicholson GA (2006) "Proof of genetic heterogeneity in x-linked charcot-marie-tooth disease." Neurology 67:2016-21

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It is with much pleasure that we welcome Mrs. Margaret Burke back into our Association as the Support Group Contact for the North Brisbane area. Margaret has had a long-standing association with CMTAA being the Qld State Coordinator some years ago for over eleven years. She organised very successful CMT Awareness Day Seminars in Brisbane and northern Queensland so that informative medical and allied health professionals could pass on their expertise and valuable information to our CMT members and their families. Margaret will be organising Support Group Meetings in the future and our members will be informed of the venue and dates. Margaret will be available on Tuesdays and Thursdays from 8.00 am to 5.00pm. (Anycie Berkmann, CMTAA Secretary)

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NEW ZEALAND *Vacant*

THANK YOU for donations from 31st October 2016—30th March 2017

$500 and over

Job's Daughters Qld
Mr Karl-Heinz Schott
Busybird Publishing

$200—$499

Grill'd Benowa—Application made by the Magnus family
Grill'd Kotara—Application made by Adams family
Grill'd Yarraville—Application made by Houghton family

Mr David Sutton	Mr Paul Simpson	Fix N Set Pty Ltd
Mrs. Allison Flood	Mr Graham King	Mrs Margaret Hodges
Mrs Kay Boreham	Mrs Thea Ferguson	Zenith Interiors on behalf of Lisa Boreham
Mr Geoff Docker		

$100—$199

Grill'd Coolangatta—Application made by Magnus family

Mr Frank Bancroft	Mrs Barbara Higgins	Mrs Diana Chick
Mrs. Florence Hydon	Mrs. Lisa Hill	Mrs Kay Vaughan
Mrs. Elizabeth McKinlay	Mrs & Mrs Matthew & Jodie Andrews (JMA Creative Concepts)	

$50—$99

Mrs Ann McLaughlin	Mr Paul Finnimore	Ms Beverley Smith
Mrs Lavina Haddad	Mrs Patricia Ingham	Mr. L. Hoffmann
Mr. Peter Lott	Mr Michael O'Dwyer	Mrs Julie Thomas
Ms Marilyn Sciberras	Mrs Marilyn Rowlands	Mrs Margaret Burke

$20—$49

Mr Cosimo Camporeale	Mrs. Barbara McKay	Mrs Eva Setton
Mr Julian Ferenc	Mrs. Beverly Jurd	

$1—$19

Mr John and Margaret Yarnton	Miss Moragh Shield	Mrs Margaret Adams
Mrs Esma Mennie	Ms Michelle Ehrich	Mrs Margaret Psaltis
Ms Beverley Dawn Jurd		

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Please follow the steps below to donate to the CMTAA:

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R—Donation to research
A– Donation to administration
Y—Donation to CMT Aussie Kids Youth Activities

Please email us at cmtaa2@cmt.org.au letting us know of your donation.

CMT Aussie Kids is a youth program run by the CMT Australia. It supports kids with CMT and gives them opportunities to 'play' as equals with peers with the same condition, learning to manage and **respond positively** to the difficulties and challenges they confront every day.

In July 2018, **ten CMT Aussie Kids** are heading over to the UK to attend a 4 day CMT Kids Camp in Keswick, Cumbria, getting to know their British CMT counterparts and touring the country for 2 weeks.

We have created a **GiveNow donation page** where family, friends and supporters can donate to help make our trip a reality.

Go to

https://www.givenow.com.au/cmt

NOW AVAILABLE

CMTAA SEMINAR 2015 DVD

Prof. Garth Nicholson – CMT Research and Achievements

Mr. Michael Carroll: My Life with CMT

Dr. Manoj Menezes – CMT in Childhood: Trials and Interventions

Dr. Scott Denton: Reducing the Health Burden – project update.

Workshop: Prof. Garth Nicholson, Prof. Joshua Burns and Mr. Darryl Beitsch

CMTAA SEMINAR 2016 DVD

Prof. Garth Nicholson – CMT Research and Achievements

Dr. Desmond Soares, Surgical procedures to benefit hand, foot and ankle problems.

Mr. Darren Pereira, Orthotist: The use of Orthotics in Managing CMT

Mr. Ernie Tye, Pedorthist: Custom Appliance Application Based Footwear

Question and Answer Session: Professor Garth Nicholson

These newly released DVDs are available from the National Office for $25 each (including postage and handling). Order your copy now by phoning (02) 0767 5105 or email: cmtaa2@cmt.org.au

CMTAA COMMITTEE (2016/2017)

Executive Members

President:	Vacant
Vice President:	Bec Poynter (VIC)
Treasurer:	Robert Twin (ACT)
Secretary:	Anycie Berkmann (NSW)

Ordinary Committee Members

Newsletter Editor/ CMT Aussie Kids Co-Organiser: Jillian Critchley (NSW)

Legal Advisor: Antonia Karydis (SA)

Marilyn Kremmer (Tas)

SEMINAR DVD's & VIDEOTAPES

October 2014

Prof Garth Nicholson—CMT Research and Achievements
Prof Joshua Burns—Developments in the Management of CMT
Dr Andrew Wines—The surgical management of the foot and ankle in CMT patients
Lyndal Douglas—Genetic Counselling
Lois Tonkin—Principles of Pain Management
Judy Gates, Gavin Fernandes, Leanne Huxley—Posture and Balance Workshop
Young CMTers—CMT Aussie Kids Weekend

October 2013

Prof Garth Nicholson—CMT Research Achievements.
Assoc Prof Joshua Burns—Developments in the management of CMT
Dr Alison Shield—General Principles Regarding Medication and CMT
Rebecca Howard, Senior Occupational Therapist, Independent Living Centre—Technology to Improve CMT Quality of Life

September 2012

CMT Research Achievements—Prof Garth Nicholson
Dev'ts in the Management of CMT—Assoc Prof Joshua Burns
Clinical Psychologist— Helga Hemberger
Physiotherapy in prep for appropriate exercise—Dr Kristy Rose
CMT and Sport—Dr Che Fornusek
Presentation from Inaugural CMT Aussie Kids Weekend
Interviews with the CMT Community
CMTAA research recipient presentation

September 2011

CMT Research Achievements –Prof Garth Nicholson
Dev'ts in the Management of CMT—Assoc Prof Joshua Burns
PGD in IVF— Dr Don Leigh
The role of the Pedorthist—Karl—Heinz Schott
Personal Trainers and CMT—Gerry Fenyo
Interviews with the CMT Community

September 2010—Seminar, Sydney

CMT Research Achievements —Professor Garth Nicholson
An International Research Perspective—Dr Joshua Burns
Successful Podiatry for people with CMT—Ms. Anita Hood
Appropriate footwear for CMT sufferers—Mr Casper Ozinga
Success stories from children and adults with CMT

The **CMT CoMmuniTy newsletter** is produced approximately every four months for the information of CMTAA members. The Editor is Jillian Critchley.

All contributions, letters, and enquiries should be directed to the Editor, CMT CoMmuniTy newsletter, 15 Naranga Avenue, Engadine 2233 N.S.W. or email: cmtaa2@cmt.org.au

ARTICLES AND IDEAS

Your letters and articles are very welcome. This is your newsletter. Let me know what you want. Ideas, letters, articles, photos, anecdotes...anything is welcome that is CMT related.

Deadline for next newsletter: 15th July 2017

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

15 Naranga Avenue, Engadine 2233 N.S.W.

Email: cmtaa@email.cs.nsw.gov.au

Charcot-Marie-Tooth Association of Australia Inc.

The Association is incorporated in NSW and a registered charity (No.CC28099)

ARB No. 076 189 912

ABN No. 63076 189 912

Donations $2.00 and over are tax deductible (DRG No. 018352).

PLEASE NOTE: WHEN PAYING YOUR MEMBERSHIP RENEWALS BY ELECTRONIC FUNDS TRANSFER (EFT) REMEMBER TO MAIL YOUR MEMBERSHIP RENEWAL FORM TO CMTAA SO WE CAN ENSURE YOUR DETAILS ARE CORRECT AND UP TO DATE AND WE KNOW FROM WHOM THE PAYMENT HAS COME. IT WILL ALSO HELP US TO ACCURATELY ALLOCATE DONATIONS AND ANY EXTRA PAYMENTS MADE. IF YOU INCLUDE YOUR MEMBERSHIP NUMBER IN THE EFT TRANSFER DETAILS WE WILL FIND IT EASIER TO RECORD YOUR PAYMENT. IF PAYING BY CHEQUE, PLEASE ENSURE YOUR NAME & MEMBERSHIP NUMBER IS WRITTEN ON THE BACK OF THE CHEQUE .

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OR By Cheque made payable to :Charcot-Marie-Tooth Association of Australia Inc. and post to: CMTAA Bldg 22, Concord Hospital, Concord NSW 2139

International Awareness for Charcot-Marie-Tooth disease

Find out more at
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