

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 75 Summer 2013



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

CMTAA FUNDS MAJOR RESEARCH

The Charcot-Marie-Tooth Association of Australia (CMTAA) has donated \$75,000 to the University of Sydney's Faculty of Health Sciences to fund research on Charcot-Marie-Tooth disease (CMT). The research will establish the cost of CMT to the community and recommend strategies to reduce the health burden of this little known genetic disorder.

Opening and closing lids on bottles, hand writing, walking and hair brushing are tasks most people take for granted. However, even the simplest tasks require a great deal of concentration for those with CMT, according to Postdoctoral Research Associate Dr Scott Denton, who has CMT.

Dr Denton will work on the research under the supervision of Associate Professor Joshua Burns.

"My sense of touch is greatly reduced and my balance is dependent almost wholly on eyesight," Dr Denton says. "If the lights go out, I will immediately fall down. Physical challenges aside, the biggest challenge I have is how it affects those around me. Living with CMT is always frustrating, at times humiliating, but it won't kill me." (Continued Page 5)



CMTAA President Darryl Beitsch (L) with Assoc Prof. Joshua Burns



Dr Scott Denton

INSIDE THIS EDITION

President's Report	Page 2	CMT Aussie Kids Weekend	Page 8
News from the States	Page 3-4	Qantas Foundation Grant	Page 9
Sydney Seminar	Page 6	Letters to the Editor	Page 10
Talk, Share, Learn, Listen	Page 7	Contact your Coordinator	Page 14

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

PRESIDENTS REPORT with Darryl Beitsch



The older I get the quicker the years go by – can you relate to this? Or should I say a little older and hopefully a little wiser (if I can remember)! There has been a huge amount of effort put in by your CMTAA Committee this year. New innovations such as the inaugural “Mix and Mingle” session. This culminated with a very informative and interactive “Group Therapy” time together on the Saturday afternoon preceding the Sydney Awareness Day Seminar.

Website

Our website has had a major upgrade and is very close to being commissioned. The upgrade included the development of a new CMTAA logo that reflects the “neuro” element that is the core of our CMT disease. Our members will be able to access newsletters, Awareness Day seminar video clips as well as current developments with CMT research.

Facebook

In addition to our Aussie Kids Facebook page, it has been evident for some time that we needed to have a Facebook presence for our over 18 members, as this is the current way many people communicate with one another in this day of technology. We now have our active Facebook page and it has generated very positive feedback.

Support Groups

We have seen an increase in the number of our face to face meetings with other members of our “CMT family” through local Support groups.

Seminars

Perth, Tasmania, Sydney and on November 24, Melbourne. This is a time to meet together to hear interesting presenters and most importantly, meet and network with other members of our CMT family.

Youth Weekend

Our second Youth Weekend was a raging success – the comments from the attendees are inspiring.

List of Medical and Allied Health Professionals Who Understand CMT

Our dedicated office volunteers have just about completed this list.

Unprecedented CMT Research Support

This includes volunteering for clinical trials – helping our researchers to help us and future generations. Additionally, we are in the position to offer unprecedented financial support for CMT related research projects.

The reality is that your CMTAA has grown to a level we have never been to before. What really amazes me is that we are all volunteers! To ensure that we continue to consolidate and move forward I am encouraging you, our CMT family to be actively involved through a Support Group or assisting in our National Office. We all have our story to tell that will help and encourage others with CMT.

Take care and keep moving.

Darryl Beitsch

President

CMTAA

NEWS FROM THE STATES

GOLD COAST

Hi! Judy here with greetings from the Gold Coast. Firstly, I would like to thank everyone involved with the Seminar in Sydney, Congratulations on a job well done, I really enjoyed the whole weekend. I had a O.T Student, who also has C.M.T, come to see me to do an interview about C.M.T, for a paper that she has to submit, for her course. I think these sort of things can only help to spread the C.M.T support. I also addressed the Post Polio Support Group, as they have had a few enquiries from people, as they are both so similar, but after a few well placed enquiries at the Seminar, I was informed that anyone who was told that they had Polio as a child, then later were tested positive to C.M.T, were more likely to have early onset of C.M.T, rather than Polio. I also have a few people who can't make the meetings come to my place for a chat. I would like to take this opportunity to wish you all a very Merry Christmas, and a Happy and Healthy New Year. So until next time, take care, and remember to Keep Smiling, because as the saying goes, a day without a smile is a day lost. Judy.

TASMANIA

David and I have just returned from a magical 3 months in West Australia exploring the Pilbara region and the Ningaloo Reef area – what an amazing country we live in! We are just so blessed and so lucky to be Australian and we should count our blessings every day. I even got to swim with the Manta Rays and snorkel on the Ningaloo Reef– the staff were brilliant in helping me in and out of the water. My only difficulty was “unfolding” out of the car after covering long distances especially the long drive across the Nullabor – I'm sure all you CMT folk can relate to that!

Our prayers and thoughts go to all the folk of NSW who have suffered from the devastating bushfires – we are thinking of you. I aim to have a Christmas get-together and catch up with all the folk who registered for our Tasmanian Awareness Day.

Best Wishes go to all the hardworking staff at Concord for the brilliant work they do – may you all have a safe and Happy Christmas. Marilyn Kremmer

SOUTH AUSTRALIA

Hi from South Australia. Dear CMT Community readers it has been an amazing year for CMTAA. I am so glad and feel privileged to have been a part of the CMTAA committee in 2013. In October I was fortunate to attend the CMTAA Inc., awareness day. Wow! On behalf of SA, I wish to congratulate the CMTAA committee (and helpers) for their support and participation for what was a very successful and invigorating weekend! I urge you to diarise this event for next year. From my attendances, over the past 5 years, I have found that the CMT awareness days are not just beneficial, because of their informative value, but incredibly valuable because the gatherings allow for the sharing of experiences. Awareness days are great opportunities for CMT sufferers, their families and friends to pick up a practical life hints and skills as well as get the latest on CMT. After the NSW awareness weekend, I came home so enthused, to have a SA Awareness Day. However, we must walk before we run. Previously, I expressed that I would like to hold an informal get together. So far, I have had some interest. Before the year ends, I would like to propose a gathering and would like to offer my home and family hospitality for an informal gathering. A chance for us to meet and have a chat, where we may gather our thoughts together for future regular meetings and consider the possibility of staging an Awareness Day.

CMT – Pre - Xmas Meet and Chat at Lockleys

When: Sunday 1 December 2013 **Time:** from 2pm to 4pm **Where:** 28 Mellor Avenue Lockleys
CONTACT: Antonia on 0416 051 438

RSVP BY: 23 November 2013 (Light refreshments will be offered. So please advise of your attendance for catering purposes as well as any dietary or allergy issues.)

My family and I look forward to catching up with you for a pre-xmas meet and chat. But if you cannot make it, please feel free to call or email me to offer any suggestions about future dates, times and topics that you may wish for me as SA co-ordinator, to arrange as either as a formal or informal gathering. From my family to yours we wish all our readers and CMTA family a very Merry and safe Xmas and a great start to the New Year.

From my family to yours we wish all our readers and CMTA family a very Merry and safe Xmas and a great start to the New Year. Best wishes Antonia and Family. (81520801 antoniakcmt@gmail.com)

NEWS FROM THE STATES

VICTORIA

Melbourne has been very busy on the CMT side of things the last couple of months! Lots has been happening and it's so exciting to see so many people offering their time and coming together. In preparation for the November seminar which will be held on Sunday the 24th, I have been busy promoting the event on my facebook group page CMT Unites Us and the response has been fantastic. I was also extremely delighted when the Muscular Dystrophy Association put their resources into play and sent out the seminar details to all of their members! Fantastic team work to help us reach out to as many as possible!

I'm also very excited by the new technology for feet scanning that will be on Display. Senior Pedorthist David Sutton from Bilby shoes will be attending and speaking at the seminar and he will also bring along this state of the art scanning machine. This technology has made headlines in the media and is revolutionary in the way casts are made for accurate orthotics, AFOS and custom shoes! Bilby Shoes is located in Thomastown and this technology is available to all. We really look forward to seeing a demonstration at the seminar and hearing this very knowledgeable Pedorthist speak.

I was also thrilled to be contacted by Darren Pierra from Neuromuscular Orthotics in Mount Waverley who asked if he could present a new AFO called a GRAFO! This Ground Reaction Ankle Foot Orthosis (GRAFO) has so far changed the lives of those fitted with them. Yet another exciting new product that I look forward to seeing at the seminar and learn more about how this can potentially change lives.

On the 24th of November Melbourne will shine! It will shine because so many strong, courageous, determined and beautiful people will come together and Unite for a day to learn more about CMT! It will be a day where we will all embrace being unique and different because..... DIFFERENT IS BEAUTIFUL!

Nelly

WESTERN AUSTRALIA

Our last meeting for 2013 is scheduled for 9 November 2013 and our presenter is Andrea King, Senior Physiotherapist, Vestibular Service & Late Effects of Disability Clinic, Royal Perth Hospital. Andrea will be providing physiotherapy advice to people with CMT (eg stretching exercise, hydro etc) to help manage the condition together with information about her work at the Late Effects of Disability Clinic.

We hope you can join us for our last meeting of 2013. As usual tea, coffee and refreshments will be provided but if you'd like to bring a plate, please do – it's always welcome.

When: Saturday 9 November 2013 (2.00-5.00pm)

Where: Genetic Support Council Centre, 1/37 Hampden Rd, Nedlands

Angela Corfe

NEWCASTLE

Hi all, hope everyone is keeping well. I have organised a get together for our Newcastle members for Saturday, the 30th November at Valentine Pool. This is a good opportunity to meet with others with CMT and have some fellowship. If anyone would like to attend they can contact me on my mobile 0412 891 647.

Kind regards,

Gabby Cosgrove
NEWCASTLE CO-ORDINATOR



CONTINUED FROM PAGE 1

CMT is usually hereditary, though Dr Denton's family has no history of it. DNA testing has cleared his three sisters.

"As I have no children, the disease in my family started with and will end with me," he says. "In medical terms I am a 'new mutation'."



While there is data on the cost of neurological disorders such as Muscular Dystrophy and Parkinson disease, there is none for CMT at present. Now, thanks to the generous gift from CMTAA, the Faculty of Health Sciences is able to begin research towards a report on 'Reducing the health burden of Charcot-Marie-Tooth disease in Australia'.

Associate Professor Burns, who in addition to his role as Co-director of the Arthritis and Musculoskeletal Research Group at the University of Sydney, is also a NHMRC Career Development Fellow at the Children's Hospital at Westmead, says the report will establish the cost of CMT and recommend strategies to reduce the burden.

"Some of the possibilities we are looking at to reduce the financial burden include the establishment of a 'CMT Specialty Centre', improvements in the way the education sector accommodates those with CMT, and Pre-implantation Genetic Diagnosis (PGD) supported by Genetic Counselling," says Dr Burns.

The latter allows for those carrying the CMT gene to conceive without the 50% risk of passing CMT on to their offspring. In 2011, only 11 Australian couples carrying CMT utilised PGD treatment, largely due to a lack of awareness.

Throughout the years, Dr Burns and the Faculty of Health Sciences have developed a strong association with CMTAA's President Darryl Beitsch.

Mr Beitsch, who also has CMT, has spoken to students at the faculty about the disease, participated as a 'patient' so the students can see the impact of CMT, and is currently involved in a clinical trial.

"I have been most encouraged by the professionalism of the faculty and their willingness to think outside the square," says Mr Beitsch. "I believe people with the disease will draw significant encouragement from the fact that there will be credible and up-to-date information regarding its actual financial and physical cost. Additionally, this could result in more targeted research, which will both directly and indirectly benefit those with this disease."

Providing this hope and relief for fellow-CMT carriers was a big part of Dr Denton's decision to switch the focus of his academic career to the social societal aspects of CMT after completing his PhD in political science.

"Medical science in the last decade has made significant advances and we are on the cusp of some major breakthroughs, so it is important that CMT research be funded at the levels it deserves."

This gift is also helping us to reach our fundraising goals by supporting INSPIRED – the Campaign to support the University of Sydney.

This article was originally written by Heather Jacobs, Division of Alumni and Development, University of Sydney for the University of Sydney's INSPIRED Campaign website and is reprinted with permission

SYDNEY SEMINAR SUCCESS

More than 70 people attended the new Concord Medical Education Centre at Concord Hospital over the weekend of 12-13 October 2013 to share and learn about all things CMT. Leading presenters covered CMT Research; Management of CMT; General Principles Regarding Medication and CMT; Useful Aids for Improved Quality of Life; plus inspiring interviews with sufferers.

The weekend kicked off with the AGM on the Saturday afternoon, but it was not your normal AGM. All who were there shared in the spontaneous discussion regarding how CMT affects them, and some heartfelt as well as humorous stories came out of this afternoon.

Another new innovation on the Sunday afternoon were the Break out Sessions for participants to be able to contribute and share ideas and stories regarding their CMT experiences. These sessions covered 'Hints for Parenting Children with CMT from Pre-School Through to Transition to Tertiary Education and into the Work Force' and 'Strategies to Face the Challenges of CMT as We Get Older' and were very well received.

Much of the feedback from last years seminar centred on everyone's wish to share and hear how other's live with the challenges that CMT brings everyday and the committee made a conscious decision to provide opportunities to do just that. The new facilities ensured attendees had space to enjoy the catering provided in a comfortable and homely environment.

Some of the positive comments from the Feedback Forms returned include:

- * 'The entire seminar was well planned with a balance of presenters'
- * 'I like the half hour timeslots and fast pace of the sessions'
- * 'The attendees and their camaraderie and inspirational stories were great'
- * 'The vibrancy and hopefulness that characterised all the sessions was inspiring'

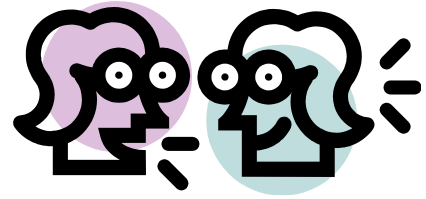
Thanks to all who contributed to the success of the weekend. See you next year!

Check this newsletter for other events coming up in your state.



TALK, SHARE, LEARN, LISTEN

One of the highlights from the Sydney Seminar was a new experiment called the 'Breakout Session'. The committee learnt from feedback from previous years seminars that many people felt supported with their day to day challenges just by being able to talk to other like minded people. Where else can one find a room full of people with CMT, keen and eager to share their experiences with others. In our view, backed up by the feedback from our participants on the day, the breakout sessions were an experiment that was a resounding success.



To sessions covered the topics 'Hints for Parenting Children With CMT from Pre-School through Transition to Tertiary Education/Work Force' and 'Strategies to Face the Challenges of CMT as we get Older' and attendees chose which session they wanted to attend. Each ran concurrently for 45 minutes although could have run for a lot longer judging by the discussions that ensued.

Below are some brief notes from each of the sessions:

'Strategies to Face the Challenges of CMT as we get Older'

1. The CMT diagnosis process – what medical profession can lead you through to establish you have CMT and what type of CMT.
2. The CMT management challenges – Drivers Licence renewal and advising the road and traffic authority in your respective state, virtually impossible to get salary continuance insurance, shop around to get Life Insurance as some companies will not permit it due to having CMT.
3. Toe supports for pain relief with clawing toes.
4. Seek more than 1 surgeon's advice when considering surgery - people shared their experiences about their dealings with good and not so good surgeons
5. Importance of support groups.

Darryl Beitsch presided over this discussion with plenty of food for thought.

'Hints for Parenting Children With CMT from Pre-School through Transition to Tertiary Education/Work Force'

1. Diagnosis of your child—Geneticists, Costs, Feelings
2. Services after diagnosis—Availability of Health services, Early Intervention, Gov't
3. The types of professionals who can help
4. Preparation for education, assessment of additional needs, meeting with and liaising with allied health professionals
5. School challenges—Bullying, Strategies for PE (etc), time out of school for appointments, physically keeping up with peers
6. Tertiary assistance.

Jillian Critchley (mother of 2 children with CMT) presented the above information to get the 'ball rolling' Janeene Payne (also a mother with CMT and 2 children with CMT) spoke of the need for effective record keeping and the issue of advocacy. Dr Scott Denton followed up with an enthralling discussion on the challenges he faces in his quest for further education and equality.

AUSSIE KIDS WEEKEND 2013

On Friday 6th of September 11 kids and 5 adults arrived at Berry Sport and Recreation Centre in NSW. This was the 2nd Annual CMT Aussie Kids Weekend. They were ready for a fun packed weekend doing activities such as Flying Fox, Canoeing, Rock Climbing, Initiative Course and Archery, but of course there had to be food first! After dinner we all caught up with what had happened the



previous year since our last camp and welcomed a new Aussie Kids, Trent, from Melbourne.



Saturday morning arrived and our first activity was Cable Glide. A large flying fox from the top of the hill, we all trekked up the hill to the top, where we were hooked onto a cable, jumped off a tower and went flying. This activity was enjoyed by most of the group, with some of us having 5 and 6 goes.

After lunch it was time for Canoeing. We all got dressed into our water clothes, ready for an adventurous afternoon. We all hopped into canoes with our partners and paddled down under the bridge, through the reeds and fallen trees on the

Broughton Creek. After 2 km of paddling we were all tired, but then we realised we had to paddle all the way back. Some of the boys got stuck in the fallen trees and as we reached the end, had a massive water fight. After a warm shower and some afternoon tea, we got a chance to catch up with Dr Manoj Menedes from The Children's Hospital at Westmead and we thank him for his support of this event.



After more food, - just what we needed—we had a well-earned rest, sitting around a campfire, talking about our day and how much fun we were having.

Sunday morning, and guess what? There was MORE food to eat. We had decided earlier in the weekend we'd split the morning in half, doing Rock Climbing first and then one of the favourites Archery.



Rock Climbing consisted of a team of 4-5 members, 1 climber and 3-4 belay. We all supported each other, and were all encouraged to reach the red line on the climbing wall. There was also a hanging initiative course that we could try to complete.

After about an hour of climbing, or hanging, we all walked down to do some archery. Most of us had done this last year and were pretty much experts. Matt, one of our volunteers placed his video camera in the bullseye of the target and we shot at it. Claire only missing by millimetres. The video is great to watch!

Unfortunately it was then time to go home (after lunch with some of our parents and friends). We all had a fun weekend and can't wait til next year!

SEE YOU IN 2014!

By Matilda and Eleanor, CMT Aussie Kids

CMT AUSSIE KIDS AWARDED QANTAS GRANT



Member, Public Officer and CMT Aussie Kids Organiser Peter Critchley recently applied for a grant from the Qantas Foundation 'Side by Side' program to help CMT Aussie Kids Weekends continue to develop and grow. The 'Side by Side' Program provides Qantas employees with the opportunity to apply for a one-off grant that will be awarded to their nominated eligible community organisation. The Program was established to support and recognise Qantas' amazing employees who have a high-level of passion and involvement in their local community from volunteering their own time to providing pro-bono assistance. The initiative provided an opportunity for the Qantas Foundation to broaden its support base in the local community by coming alongside those organisations that are near and dear to the hearts of Qantas employees.

Peter, who works in Procurement with Qantas saw an opportunity to support the CMT Aussie Kids Weekend applied. To determine the grant recipients, all applications went through a review process conducted by a cross section of Qantas employees, Senior Leaders and ultimately the Qantas Foundation Board.

In 2013, the Qantas Foundation awarded 37 community grants to employees and their eligible community organisations including CMTAA. The \$2,500 grant will be used to help fly CMT Kids from around Australia to the camp in Berry NSW next year – flying Qantas of course. So pack your bags kids and stay tuned.

With thanks to Jonathan Srikanthan, Manager Qantas Foundation



LETTERS TO THE EDITOR



Dear Sir/Madam,

Greetings! My name is Michelle, I'm from Brisbane and I am a fellow CMT sufferer. I would like to share my good fortune at finding a pair of running shoes that I tried on in the store and literally wore home! I don't know about you but this was a first for me!

Since having had successful surgery on both my feet in 2003 (thank-you Dr Terry McGuire!), I have been wearing Ankle Foot Orthotics (AFO's) on both feet and have always had the problem of 'running in' my running shoes (being the only shoes that can accommodate the orthotics) i.e. stretching them as they were too tight, wearing them in, and taking less than 10 minutes to put them on each foot! I had to wear them around the house for months before feeling confident enough to leave my home and catch the bus, or walk for any distance. About one month ago, I bought my first pair of black leather New Balance Extra Wide runners from the Athletes Foot at the local shopping centre. The runners cost \$119.95 and I've been wearing them almost non-stop ever since. I'm thrilled with the depth of ankle support they give, the comfort and the strong and solid feel of them, and the ease of getting in and out of them reasonably quickly (especially when my Podiatrist is waiting for me to put on my socks, my afo's, and then my shoes so he can escort me out to the front desk and usher the next client in! The runners are available in black leather, white leather, and brown suede. I've since bought a pair in brown suede which I'm wearing now! They are tremendous! Not only that, I'm assured by the friendly staff at the Athletes Foot that they will continue to stock these shoes - not like most running shoes where you buy them one season and go back the next season only to find that they've stopped making them!

Cheers and I hope this information is of some use to all the AFO wearers out there!

Yours sincerely,
Michelle Ehrich

Foot and Ankle Strength Training for Charcot-Marie-Tooth Disease (CMT)

A major problem for children with CMT is foot weakness. Currently there are no effective treatments for this problem. Strength training might be beneficial, but is untested in CMT.

We are performing a study at The Children's Hospital at Westmead (Sydney) looking at the effect of foot and ankle strength training in children with CMT aged 6 - 17 years.

If you have a child with CMT or know of any children with CMT who might be interested in this clinical trial, please contact the investigators:

Associate Professor Joshua Burns and Dr Amy Sman
Institute for Neuromuscular Research,
The Children's Hospital at Westmead, Sydney
Phone: (02) 9845 3004 or Email: amy.sman@health.nsw.gov.au



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Has your organisation considered becoming a Sustaining Partner of CMTAA?

Through its Sustaining Partnership Program CMTAA provides opportunities for organisations which support its objectives to partner CMTAA through an annual financial contribution. In return CMTAA will help your organisation promote its objectives and receive acknowledgement for its support of CMTAA.

There are two levels of Sustaining Partnership to suit the varying needs of organisations.

As a **Silver Sustaining Partner** your organisation will receive recognition through a framed certificate; acknowledgement in the CMTAA Annual Report; your logo with a link to your web site on the CMTAA web site; recognition of your organisation's support at CMTAA events held around Australia and in the newsletter; permission to use the CMTAA logo to advertise your partnership; promotion of your events through the CMTAA network; and a complimentary membership of CMTAA.

As a **Gold Sustaining Partner** (only 5 available) your organisation will receive all of the above plus complimentary advertising in the CMTAA newsletter and acknowledgement on the front page of the CMTAA Newsletter and CMTAA home page.

The potential exists to negotiate variations to these packages through part in-kind support.

If your organisation would like to participate in this program then please contact either Darryl Beitsch (President) or Robert Twin (Treasurer) through the CMTAA Office.

THANK YOU for donations from 26th July—31st October 2013

\$500 and over

Qantas Foundation
Mr. L. Wagner

Mr. Karl-Heinz Schott

Mr. Richard Kuras

\$200 - \$499

Mr. Bruce Legge
Mr and Mrs. E and J. Kuras

Mrs. Colleen Bower

Mrs. Rachel Killen

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Mrs. Jean Purvis
Mr. and Mrs. E and J. Reynolds
Ms. Melanie Hammond
Mr. David Sherley

Please follow the steps below to donate to the CMTAA:

Step 1: Electronic Funds Transfer payment : Our bank details are: BSB: 032-069 Account number: 158486

Please indicate the code/s below that your payment has been allocated to, along with your surname for the transaction information.

R—Donation to research

A— Donation to administration

Y—Donation to CMT Aussie Kids Youth Activities

Step 2: Email us at cmtaa@email.cs.nsw.gov.au letting us know of your donation.

Step 3: Smile! Feel good about yourself! Your donation will go to help people with CMT.

KEEP AN EYE OUT FOR DONATION OPPORTUNITIES ON OUR NEW WEBSITE

CMTAA Committee (2013/2014)

Congratulations to the incoming committee elected at the recent AGM

Executive Members

President:	Darryl Beitsch (NSW)
Vice President:	Katherine Matthews (VIC)
Treasurer:	Robert Twin (ACT)
Secretary:	Anycie Berkmann (NSW)

Ordinary Committee Members

Editor:	Jillian Critchley (NSW)
Legal Advisor:	Antonia Karydis (SA)
Joanne Liso (NSW)	
Ann McLaughlin (NSW)	

SEMINAR DVD's & VIDEOTAPES

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 Podiatrist—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

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 Aveue, Engadine 2233 N.S.W. or email: cmtaa@email.cs.nsw.gov.au

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This newsletter is printed by Vision Printing, Engadine, NSW



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).

CONTACT YOUR COORDINATORS

NATIONAL OFFICE—SYDNEY

Phone: (02) 9767 5105 Fax: (02) 9767 5167

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

Website: www.cmt.org.au

REGION SUPPORT CO-ORDINATORS

N.S.W.

Newcastle : Gabby Cosgrove 0412 891 647

Wagga Wagga: Jean Purvis 0402 535 692 or Home (02) 6931 4635 Email: neilandjeanpurvis@gmail.com

A.C.T

Canberra and Region: (Support Group only) Gabrielle Evans (02) 6288 7235

Email: gabriellecmt@gmail.com

QUEENSLAND

Brisbane: Steven Bonner (07) 3324 2972 Mobile: 0404 688 824 Email: stephencmt@iinet.net.au

Ipswich: Lenore McLean-Jones 0411 862 329 or Home (07) 3201 6654 Email: lencmt@gmail.com

Gold Coast: Judy Pinchin (07) 5563 8421 Email: judithpinchin@bigpond.com

Sunshine Coast: Aileen Harrison (07) 5309 6362 Email: aileen_advice@optusnet.com.au

South West: Joy Gath (07) 46 68 9009 Email: joygath67@gmail.com

VICTORIA

Melbourne: Nelly Sutjipto Email: nellycmt@gmail.com

TASMANIA

Hobart: Marilyn Kremmer (03) 6239 1142 Email: mmkremmer1@bigpond.com

SOUTH AUSTRALIA

Adelaide: Antonia Karydis (08) 8152 0801 / 0416 051 438 Email: antoniakfcmt@gmail.com

WESTERN AUSTRALIA

Perth: Angela Corfe 0414 905 013 Email: angelacorfe@hotmail.com

Chris Murphy 0407 214 250 Email: chris_murphy@iinet.net.au

NORTHERN TERRITORY

Darwin: Kaye Bartlett 8 Sunset Drive, Coconut Grove 0810 (08) 89854201 Email: kayeCMT@iinet.net.au

NEW ZEALAND

Gaile Fornusek: 07 8686375 Email: fornuskova10@gmail.com

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.

Deadline for next newsletter: 31st March 2014

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

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

THE CMTAA COMMITTEE WISH TO ADVISE THAT AFTER MUCH DISCUSSION WE HAVE DECIDED TO DISCONTINUE LISTING IN THIS NEWSLETTER THOSE DRUGS THAT MAY AGGRAVATE OR EXACERBATE CHARCOT MARIE TOOTH. WE SUGGEST YOU SPEAK TO YOUR MEDICAL PHYSICIAN FOR ANY FURTHER ADVICE ON THIS MATTER, CONSIDERING YOUR INDIVIDUAL CIRCUMSTANCES.

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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