

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 78 Summer 2014



CMTAA
Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

INAUGURAL SERVICE RECOGNITION AWARDS

The Charcot Marie Tooth Association (CMTAA) is the leading body supporting people living with CMT in Australia. The Association was founded in 1988 and incorporated in 1990.

Over the nearly 25 years of the Association, there has been no formal recognition of the significant efforts of volunteers and medical/allied health professionals to the 'cause' whether that be the development of the Association, the search for a cure or better management of the condition. The association recently put into place such a scheme to recognise service to CMTAA.

The Award Scheme comprises 5 levels and recognises: Medical and Allied Health Professionals; Volunteer members of the Association or non-members (non-medical) who have made a significant contribution to the Association or to research into CMT and the search for improved management or a cure. Award criteria is closely allied to the aims and objectives of the Association.

Further details regarding nominations and criteria will be available on our website shortly.

This years inaugural recipients were presented with their awards at the recent CMTAA Sydney Awareness Day Seminar. They are (l-r) Mrs Stella Weir, Mrs Kaye Boreham, Mrs Phyllis Critchley, Prof. Garth Nicholson and Prof. Joshua Burns. A sixth recipient, Mrs Margaret Dawes was unable to attend the presentation due to ill health.

Congratulations to our hard working advocates for CMTAA.



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

PRESIDENTS REPORT with Darryl Beitsch



It is indeed a pleasure to be re-elected as your President for another term. I would like to congratulate all our 2013 team who were re-elected and especially our 2 new team members Lisa Moore (SA) and Louise Battaglione (QLD). I am most encouraged by the drive and passion the team has to serve you, our “CMT family”.

The National Office

Throughout the year we receive numerous phone calls and emails from people with CMT who just want direction and someone to talk to who understands their situation. There is nothing more satisfying when we receive the words “Thank You” as people realize that they are not alone and that there are many options available to successfully manage their CMT with the aim of enhancing their quality of life. To hear the voice on the other end of the phone turn from despondency to hope confirms the vital role your CMTAA plays in supporting our “CMT Family”.

Aussie CMT Kids Youth Weekend

Record numbers, unprecedented fun and lasting friendships summarized by an outstanding presentation at our Awareness Day that captured the wonderful time enjoyed by all attendees.

Sydney CMT Awareness Weekend October 11 and 12

Saturday was our AGM and “Mix ‘n Mingle” afternoon. Once again, this was very well attended with people having the opportunity to share their “CMT” stories in a relaxed environment. We were all the better for hearing people’s stories as they continued to be told over a sumptuous afternoon tea.

The very well attended Awareness Day Seminar on Sunday was action packed with enlightening presentations from Professor Garth Nicholson – CMT Research, Professor Joshua Burns – reporting on the developments of CMT clinical trials, Lyndal Douglas - Genetic Counselling and a very thorough presentation on the pros and cons of PGD, Dr Andrew Wines - The Surgical Management of the Foot and Ankle in CMT (including some very interesting pictures to illustrate what happens to the feet and ankles), Lois Tonkin – Principles of Pain Management including the “BIG PICTURE” of chronic pain management. The afternoon included a challenging and informative Posture and Balance Workshop followed by an interesting Q & A session with our panel of speakers. My thanks to our presenters who gave up their Sunday to share their expertise, our attendees, Brent our video guru and especially to the people who worked tirelessly behind the scenes to ensure everything went smoothly.

CMTAA Website

As a Financial member of the CMTAA, you can access special content including newsletters and seminar videos on our website. If you have not already registered on the CMTAA website, we invite you to initially register your details on our site. These are similar details to those provided with your membership; however if you are already a financial member you do not need to complete the payment section. You will also only need to complete this once. Simply go to www.cmt.org.au and click on “Become a Member” on the right of the Home page. This takes you to the “Apply for Membership” page where you can enter your details. The email address you provide will be your Username and will be used for future correspondence. Record your Password and we will advise you by email when your login is activated.

CMTAA Research Grants

Having done some recent homework, it gives me great pleasure to report that your CMTAA, since 2010, has given \$117,513 to research. This figure excludes the Federal Government, Department of Health and Aging, research grant that is being used to fund the research project “Reducing the Health Burden of Charcot-Marie-Tooth Disease in Australia”. This is being carried out through the University of Sydney by Professor Joshua Burns and Associate Fellow Doctor Scott Denton. Regarding this project, stay tuned for your invitation to participate in a survey and possible involvement in focus groups.

As this will be our final newsletter for 2014, on behalf of your CMTAA Management Committee, have a wonderful and safe Christmas celebration and holiday season.

Take care and keep moving. Darryl Beitsch. President CMTAA

NEWS FROM THE REGIONS

AND STATES

GOLD COAST

Hi ! Judy from the Gold Coast. Hope you are all well and happy ! Firstly, I would like to thank everyone involved with the Awareness Day weekend in Sydney, what a great weekend. I personally found it very enlightening , and gained some valuable information. I must congratulate all the kids, what an inspiration to everyone, well done kids! I would like to say how well the web site is working, I have had six new enquiries in the last few months, all found contact details on the web, so it can only lead to bigger and better awareness ! my group is slowly growing, and we always end up having a good laugh, so if you are not a member of a support group, please consider it ! I would like to take this opportunity to wish everyone a very Merry Christmas and a safe, healthy and happy New Year ! Until next year, stay happy, take care and keep smiling ! Judy.

TASMANIA

We've had a quiet winter with our group, but we did have a meeting on 26th October where I reported back to members of our Support Group on the Sydney Awareness Day. What a great time I had in Sydney and recommend to everyone that they make a concerted effort to attend these informative sessions. It was good to catch up with our support Sydney staff and other State Co-ordinators. I especially enjoyed the stories of attendees to the AGM on Saturday afternoon where each person told of their CMT journey. So many wonderful stories of disappointment and hope with such positive attitudes. Thanks to the CMTAA organisation in getting such a wide variety of speakers.

During our afternoon tea with our Hobart folk, I got some of the folk to practice the balance and alignment exercises taught by Gavin and Judy (guest speakers) which created a few laughs as folk tried to balance on their "CMT legs". Hopefully they will continue practicing and reap the reward of perseverance. Every time I stand now I concentrate on where my feet are and keep my "soft" knees.

We're looking forward to warmer weather (no bushfires please!!!!) and send best wishes to all our CMT folk for a safe and Happy Christmas. Kind Regards, Marilyn

WESTERN AUSTRALIA

Hi everyone, Just a quick note from WA with apologies that we didn't get to include a note in the last newsletter.

Our July meeting at the 'Independent Living Centre' was a great success and we hope that everyone managed to take away some useful information and/or piece of equipment that will help to make their lives easier.

One of our committee members attended a 'Connect Groups' networking day recently and brought away a lot of useful information/ideas which may assist the WA group. The day enabled members from many different WA volunteer groups to exchange information on how they ran the groups, problems encountered along the way and information to assist with these issues. Such events remind us of how useful our own meetings can be in exchanging and providing information and support to members.

Our next meeting is scheduled for Saturday 22 November from 2.00-5.00pm at the Genetic & Rare Disease Network (GaRDN), 1/37 Hampden Road, Nedlands. Final details will be circulated to members, but please come and join us and if you wish to bring a plate for the afternoon tea - please do!!

We wish everyone a very happy Christmas, safe and prosperous New Year - and look forward to continuing to offer support to our members in WA in the future. Kind regards, WA Committee

HANDY TIPS FROM A CMT SUFFERER

Looking around my home, I was surprised at the everyday equipment that we have to make life a little easier for our CMT sufferer; I would like to share some with you.

Ribbons and Shower chair

Where possible I put ribbon through top of zippers on pencil cases, make up bags, wallets it gives you extra to hang on too. Shower chair is very handy on bad days.



Tap Turners

Living in a rented home we are unable to change taps, these are a fantastic.



Apple corer, big handle knife, Multi Jar opener

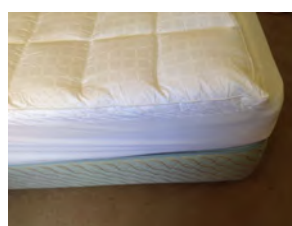
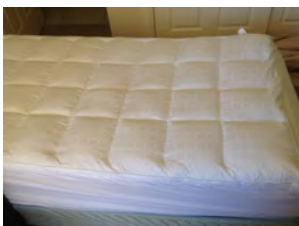


Medicine bottle opener, can opener and bottle opener



Mattress Topper

This is fitted, goes on top of mattress, so comfortable like sleeping on a big cushion.



BY SUZANNE DAY

Elastic hand, ankle, knee and finger splints

Sometimes you need a little extra support



Crutches Cover Cushions & Big universal remote control

They go over the top of the crutches, and provide some comfort under the arms. When your hands seem to be getting worse here is the answer a big remote



Play doh or modelling clay and foot spa

This is great to just roll in your hands and knead, hours of entertainment. Treat those tired and painful feet a bit of rejuvenation.



Button and Zipper helper and Long handle grabber

One end does up the button's other end hooks zippers. Too tired to be over the grabber reaches things for you.



Wheat pack and Plaster Boots

Heat packs go in the microwave and warm up to take away muscle pain. The plaster boots keep plaster in tact and save you from slipping

Games and Puzzles

This is a great way to keep your mind busy when you are feeling sore and tired.

NEWS FROM THE REGIONS AND STATES continued

AUSTRALIAN CAPITAL TERRITORY

Greetings from Canberra, the best place to live in the world. Well, the OECD may think so, but those of us with an uncommon medical condition may not necessarily agree!

Last year I responded to an appeal for more Support Group coordinators. There was no group meeting in Canberra, so I put up my hand. I would have to admit that my motivation was primarily selfish – at that stage, I hadn't met anyone else with CMT (apart from my brother). I hadn't been able to drive for more than 10 years, so I decided that it would be easiest for me if meetings were held in my home. The first surprise came when I received a list of CMTAA members in the Canberra region – I was far from alone. Then I saw that one of the members lives just a few streets away in my suburb!

Our first meeting gathered 5 enthusiastic members. It was hard to get a word in over the buzz of conversation, as we all had so many questions to ask of one another. We all agreed that it was just wonderful to talk to people who understood what we were experiencing. That first meeting went on much longer than I'd expected, but no one seemed to want to go home!

Since then, we've tried to meet every second month, if my health allows. We've grown to 9 regulars and are still hoping for more to join us. We cover a wide spectrum of ages and abilities; not all of us have CMT, but we all deal with it in some way – if not personally, then as a parent or a spouse. We never seem to be short of things to talk about, from our stories of misdiagnoses to the latest in footwear, orthoses and walking aids. When one of the group is facing a particular challenge, the others are usually able to offer suggestions for a solution. For some input to each meeting, I have been showing presentations from previous years' Awareness Days, or similar conferences overseas.

For me, the experience of being a Support Group coordinator has brought with it unexpected benefits. I now have a new set of friends whose company I enjoy and who share one aspect of my life in a way that others can't. I would really encourage anyone who doesn't have a Support Group available to think seriously about starting one. Regards Gabrielle Evans

SOUTH AUSTRALIA

A warm hello from Antonia, Lisa and Francesca, it has been an interesting and productive year for the SA team. We have met on three occasions and a lot has evolved from our many discussions. Whilst we appreciate and acknowledge that some CMT sufferers cope successfully on their own with the support of family and friends, others find it beneficial and recognise the many benefits in participating in a support group. Our aim therefore for 2015 is to continue to raise awareness in SA and offer support group opportunities for CMT sufferers, their families, carers and friends. As a small group, we have achieved many milestones this year. Firstly, I (Antonia) wish to sincerely thank Lisa for her support, and enthusiasm this year and particularly for her efforts in establishing the CMTAA SA regional website page and spreading the word on a number of Bulletin Boards. We invite the SA CMT community to seek out and use this communication resource. Big congratulations to Lisa for her election as committee member to the CMTAA committee 2014/2015. I would also like to sincerely thank Francesca for her enthusiasm and support throughout the year and particularly for her attendance as one of the mentors at the August CMT Aussie Kids weekend. Lisa, four-year old James and I were fortunate to attend the CMT awareness day in NSW. What an amazing experience for all of us to meet, greet and share our CMT stories and issues with like minded individuals in an extremely supportive environment. An informative and invaluable October awareness weekend that included an AGM and a Mix and Mingle Open Forum that was superbly organised and attended. Enthused by the CMT awareness momentum the SA team aim to present a September 2015 SA CMT awareness day. We ask you to mark September as a special month that is also National CMT Awareness month and watch this space! I take this opportunity to earnestly thank my CMTAA committee colleagues who have tirelessly worked on many fronts this year to continue to raise the CMT awareness for Australian CMT sufferers as well as undertaking the tedious administrative tasks that help strengthen CMTAA Inc. I encourage the CMT Community out there to seek out the priceless experience of working with the CMTAA committee that I have immensely enjoyed over the years.

As a final event this year we would like to invite you to CMT SA region's Xmas BBQ/Picnic break up. Sunday 7 December 2014 from 11am to 3pm at Freemont Park, Yorktown Road Elizabeth. BYO picnic gear and drinks. Please RSVP (for catering) and for further details by contacting any of the team. A very Merry Xmas and a safe and Happy New Year to all. Antonia 0416051438 Lisa Moore: mobile: 0459 084 437, Isabella Frisan and Francesca Herdahl-Thorsing mobile 0420 870 263

VICTORIA

Dear fellow CMT'ers

Kia Ora from Melbourne. As our cool winter subsides and our spring is now here with warmer months we will start setting more regular catch up "MEET and GREETs" all around Melbourne to make it fair for a long distance travellers.

We have started to keep an email log of members and the suburbs they live in to make informed decisions on when and where the next meetings can be held.

For those that attended our last meet, Mal is doing marvellous and hasn't lost his sense of humour, he informs me that he is on the road to recovery - so we look forward to reading more of his poems.

Earlier in the year we had a sad farewell to our Nelly Sutjipto as her family have headed up to the warmer climate of Queensland.

We have been extremely busy organising the Melbourne Seminar, to be held 29th November 2014 at the John Madden Hall, Dundas Street, Frankston from 1-4pm. We hope to you there, it would be good to meet many new members. Guest Speakers at the seminar include Eppie Yiu – Paediatric Neurologist, Rachel Kennedy – Physiotherapist, David Sutton – Bilby Shoes and Darren Pereira – Neuromuscular Orthotics. We have a lot of items to auction off at our silent auction on the day so bring all your spare money - all the proceeds will of course be going back to the CMTA association. For pre bookings – please contact Paula Gailey 0429 050 004 or email: paulacmt@hotmail.com

A quote I found today which fits for us today -

"Every time you understand and affirm someone's feelings, you build fellowship".

Other than the excitement of the Seminar, we are anticipating the excitement of Christmas, such a lovely time to share with friends and family.

Once again hope to see you all at our seminar....Arohanui. Paula.

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.

CMT AUSSIE KIDS WEEKEND 29—31 AUGUST 2014

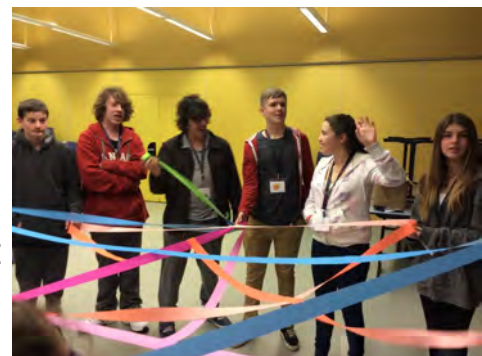
This year, instead of a formal article about the camp we're going to let the kids speak. After all it is *their* weekend. The following are quotes from each of the 19 youth participants from all states and territories across Australia (except Tasmania and the Northern Territory) who enjoyed a weekend of indoor rock climbing, cable glide, initiatives and 'The Great Race' but most of all friendship and understanding. Many of these quotes were 'selected' from a wonderful card Peter and I received at the recent Sydney seminar. We find many of their thoughts quite moving and are clearly our motivation. Thanks so much to the CMTAA, and our volunteers Matt, Meaghan, Tim & Francesca + visitors Amy and Kayla from the Children's Hospital at Westmead for your support.

Zeb—Amazingly good at finding friends

Eliza— So great to meet people that aren't going to treat you differently because of your disability. I've met some amazing people through this camp and I know we're always there for each other

Matilda— I loved the CMT Aussie Kid Camp 2014. I met so many great people how I feel and the struggles I face. Cant wait for next year.

Brittany— 'Understanding is so much deeper than knowledge. Many people know you but only a few understand you'. The CMT Aussie Kids weekend 2014 gave me the opportunity to meet the few people that truly understand.



Alex—It was amazing. I loved every bit of it!

Jaycob—The camp has shown me that I can do things that I never thought I could do

Ewin—I love all the stuff we do

Steph—All the work everyone puts in doesn't go unnoticed

Scarlett –I really enjoyed the camp and it was really good to meet other kids my age with CMT

Tim—Fellowship Understanding Respect



Eleanor—The CMT Kids weekend lets us connect with people our age who have CMT

Ashleigh—Its because of the camp that I have met many people I now call friends

Sarah—I had the best fun

Sebastian—I had lots of fun. Can't wait until next year

Maddy—I t was lots of fun and I liked meeting people my age with CMT

Llana—The camp has really helped me with my confidence

Claire—It's always awesome to meet people that go though the same challenges.

Kellie—The camp pushes me to achieve things I never thought I could



Scott—I had heaps of fun

Trent—I get heaps of support from everyone on the camp

Looking forward to next years camp
tentatively 28-30 August 2015
Contact: Jillian and Peter Critchley
(cmtaussiekids@gmail.com)



STATE COORDINATORS

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VICTORIA

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Bendigo and District

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Adelaide North

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NORTHERN TERRITORY

Darwin

Mrs. Kaye Bartlett (See above)

NEW ZEALAND

Thames and District

Mrs. Gaile Fornusek (See above)

THANK YOU for donations from 16th July 2014—31st October 2014

\$500 and over

City of Hobart Preceptory and Priory

Mrs. Shirley Kerr

\$200 - \$499

Mrs. Rona Pape
Mr. Mason Allamby

Mrs. Rachell Killen
Mr. Dutnin Seeto

Ms. Rosemary Crossthwaite
Mrs. Hilda Newstead

Mr. John Twin
Mr. Robert Pearce

\$100 - \$199

Mr. Peter Evans
Mr. David Cavenagh

Mr. Gavin Aker
Mr. Paul Simpson

Mrs. Barbara Higgins
Mr. Alan Moore

Mrs. Margaret Miller
Alex Battaglione

\$50 - \$99

Mr. Elmo Caust
Mrs. Carolyn Buchan
Mr. Frank Henning
Mrs. Lisa Hill
Ms Marilyn Bentley
Mrs. Joan Lyon

Mrs. Colleen Bower
Mrs. Florence Hydon
Mrs. Alison Greenslade
Mr. Dennis Simpson
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Mrs. Denise Thomas

Mrs. Kelly Horgan
Mrs. Patricia Ingham
Mr. Chris Murphy
Mrs. Eva Setton
Mrs. Margaret Hodges
Ms. Judy Osborn

Mrs. Sandra Stephens
Mrs. Christine Kien
Mr. Victor Christou
Prof. Joshua Burns
Mrs. Pam Strange

\$20 - \$49

Mr. Patrick Thomas
Mr. Lance Fennell
Mr. Matthew Green
Mrs. Barbara McKay

Mr. Raymond Willis
Mrs. Theresa Woolley
Mrs. Jean Boal
Mrs. Ann Mc Laughlin

Mr. John Gold
Mrs. Julianne Cross
Mrs. Elizabeth Lumsden
Mr. Larry Trippitt

M. Walker
Mr. Edward Burrows .
Mrs. Felicity Andrews
Dr. Susan Dickinson

\$1 - \$19

Mrs. Carmen Frendo
Mr. Stephen Pritchard
Ms. Elizabeth Cox

Mr. Darryl Beitsch
Mrs. June Heffernan
Miss Melanie Hammond

Mrs. Dorothy Tait
Ms. Kayla Cornett
Mrs. Margaret Anderson

Mr. David Sherley
Mrs. Yvette Black
Mrs. Carol Newman

CMT FAST FACTS

CMT was discovered in 1886 by three physicians for whom it was named; Jean-Martin Charcot, Pierre Marie, and Howard Henry Tooth.

Patients may lose feeling in their hands and feet putting them at risk for blisters, burns, and sores.

CMT has no known cure, although physical therapy, occupational therapy and moderate physical activity are beneficial.

It usually does not affect life expectancy, but can, in rare instances, cause severe disability. CMT can be detected at any age. Typically, the first signs may include leg weakness, frequent tripping and falling.

Unlike some neurological disorders, CMT isn't life-threatening, and it almost never affects the brain. It causes damage to the peripheral nerves — tracts of nerve cell fibres that connect the brain and spinal cord to muscles and sensory organs

At least 3 sportsmen with CMT competed in the 2012 Paralympics in London. They competed in swimming, cycling and shooting

CMT is not contagious

Charcot Marie Tooth was mentioned in Federal Parliament. Federal Member for Throsby Mr Stephen Jones moving a motion that the Australian Parliament recognises that CMT is an issue. This occurred on Monday, 26th November 2013 and this prompted discussions on the national airwaves with CMT being mentioned on radio throughout the country.

CMT NEWS

You're the expert!

What's it like living with CMT in regional areas? How much does CMT 'cost' you in your daily life? These are the types of questions the Australian Government is seeking to answer in an upcoming survey on CMT. University of Sydney Postdoctoral Research Associate Dr Scott Denton will soon be in an area looking for volunteers to participate in focus group discussions.

The information gathered from these groups will assist Dr Denton, who has CMT and Prof Joshua Burns in their research to establish the cost of CMT to the community and recommend strategies to better streamline resources.

Focus groups will be conducted in early 2015 in each state of Australia as well as the ACT . These groups will consist of people with CMT, those caring for people with CMT and family members of those with CMT. Each focus group will run for about an hour.

Participants will be given the opportunity to share their experiences of living with CMT.

Stay tuned for further details on how you can help in this important research.

Walk With Me Book Launch

Walk With Me is a beautiful full-colour photographic journey detailing the trek by Kev Howlett, up to Mount Everest Base Camp and back, to raise awareness of Charcot-Marie-Tooth (CMT) disease and funds for the CMT Association Australia.

Kev Howlett is a photographer and illustrator with thirty years experience in the commercial photographic industry. He's photographed everything from babies to prestige cars and architecture. *Walk With Me* combines his love of travel, adventure and imagery.

Kev's son Dylan suffers from CMT. A champion footballer as a teenager, Dylan has had both feet reconstructed surgically as a stopgap measure to counter the clawing caused by CMT. Now, he struggles with things many of us take for granted.

Walk With Me is the journey Kev would've liked to take with Dylan. Kev details his expedition so that you, too, can walk with him to Everest Base Camp and back and not only enjoy the beauty of Nepal, but also contribute to a good cause.

A portion of proceeds from the sale of *Walk With Me* will go to Charcot-Marie-Tooth Association Australia. If you'd like to learn a little more about how this project came about, as well as CMT, check our About CMT page on the publishers website www.bushbird.com.au

Enquiries re purchasing the book can be made with Media Contact, Blaise van Hecke, Bushbird Publishing Ph: 03 9434 6365/0416 157 281 or email bushbird@bigpond.net.au



CMTAA COMMITTEE (2013/2014)

Executive Members

President:	Darryl Beitsch (NSW)
Vice President:	Katherine Matthews (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)

Joanne Liso (NSW)

Lisa Moore (SA)

Louise Battaglione (Qld)

SEMINAR DVD's & VIDEOTAPES

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

Breakout Sessions

Interviews with people with CMT.

A panel of speakers with CMT Q & A

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

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ABN No. 63076 189 912

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

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: 31st March 2015

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

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

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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.

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