

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 77 Winter 2014



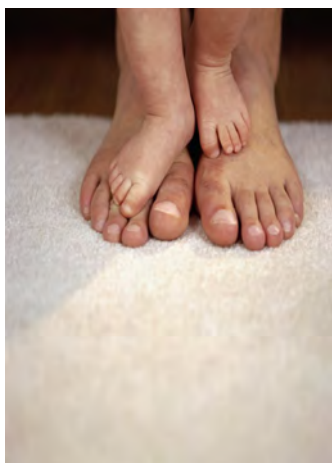
CMTAA

Charcot-Marie-Tooth Association Australia Inc.

The CMT CoMmuniTy

ADVANCE NOTICE OF AN EXTENSIVE CMT SURVEY

Dr. Scott Denton, in collaboration with the University of Sydney and Professor Joshua Burns, is now finalising the CMT specific survey that is a key element in collecting accurate CMT data. This is the first (and probably the only) CMT specific survey commissioned by the Australian Government through the CMTAA, written by a person with CMT, in collaboration with the University of Sydney, for people with CMT to respond to. This is our big opportunity to invest a small amount of our time into answering the survey questions to provide realistic and accurate data that can be compiled, disseminated and presented to the Australian Government. This will provide the Australian Government with solid and credible data to make decisions to improve the quality of life for our generation and future generations of people with CMT and those caring for them.



VERY EXCITING!

Stay tuned for more information as to how you can make a difference through participating in this survey.

Darryl Beitsch, CMTAA President



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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



I trust that you are coping with the winter chills. My electric blanket works well to “thaw out” my cold legs. In recognising this problem, my wife Robin bought me a pair of heat pack “bootees” that can be heated in the microwave. They work well for me but I strongly suggest that you don’t walk in them as they are NOT designed as slippers. I must take them off before any midnight dash to you know where!

CMTAA Development

Your CMTAA is developing and growing at an unprecedented rate with over 35 new members this year alone, primarily through our simple online membership application through our web site. This has resulted in the need to review the way we go about administrative tasks. Very shortly, those with active email addresses will be receiving emailed receipts for membership renewals, donations and other “purchases” you may make. This will provide reduced receipt processing time for our office volunteers and reduced postage. For those without email addresses, receipts will be sent by post. If you have an active email address, can you please advise the office if you want to “opt out” of emailed receipts and other communication.

Volunteers

Our unprecedented growth is placing increased pressure on our National Office team. Please be aware of the fact that we do not have any paid workers – we are all enthusiastic volunteers with a passion to assist others with CMT, those caring for them and our medical and allied health researchers. I invite those living in the Sydney area to consider giving 4 hours per week as a CMTAA volunteer at our National Office located at Concord. Benefits include a complimentary morning tea, free parking, opportunities to assist other members of our “CMT Family”, recognition and appreciation as a valued member of our National Office team. To pursue this further please contact the National Office by email cmtaa@cmt.org.au or phone 9767 5105.

Youth Weekend

In August we will be holding our third Youth Weekend with a record number of 19 attendees! Thank you Jillian and Peter for facilitating this outstanding event.

Sydney Awareness Day Seminar

See page 8 in this newsletter for details.

CMT Survey

Advance notice to advise you that we will be communicating with you in the near future regarding a CMT specific survey. The survey will be an integral part of the “Reducing the Health Burden of Charcot-Marie-Tooth Disease in Australia” report that was commissioned by the Federal Government. Your CMTAA, in collaboration with Sydney University and Dr. Scott Denton has the responsibility of preparing this report to be presented to the Federal Government in September 2015.

This is most likely our one and only opportunity to contribute to a CMT specific survey, compiled by a person with CMT (Dr. Scott Denton) to equip the Federal Government with credible information that will have the potential to benefit people with CMT and those caring for them in current and future generations.

Take care and keep moving.

Darryl Beitsch

President

NEWS FROM THE REGIONS

AND STATES

WESTERN AUSTRALIA

Hi everyone. Even though we had a very low attendance at our first meeting for 2014 those attending enjoyed themselves and once again, a lot of useful information was presented and shared within the group. We very much hope that our July meeting will tempt more of you to attend, with a presentation and tour provided by the staff at the Independent Living Centre (ILC).

It would assist us to have some idea of numbers for the day so we'd appreciate an email reply or call/text to either Angela (0414 905 013) or Chris (0407 214 250). Note: The ILC has very kindly provided their centre and staff at no charge to us. Your support of this meeting would be greatly appreciated.

However, if you don't have a chance to respond and you find you're able to attend – please come as we're sure it won't be a problem!

Details of the meeting are: Saturday 26 July (2:00-4:30pm) at the Independent Living Centre, The Niche, 11 Aberdare Road, Nedlands.

Kind Regards, Angela and Chris

TASMANIA

Our little band of CMT folk in Tasmania continues to grow with more enquiries coming through from Concord. Unfortunately I've been unable to organise a mid-winter get together as all our energies have gone in to supporting our daughter, and granddaughter Josie who has spent the last month in Royal Children's Hospital in Melbourne. Unfortunately during her stay to have a rod removed from her femur following a break when she fell last year on the day of the fires that devastated Dunally, she picked up a superbug as well as Influenza B so she was a very sick girl. She has a rare condition called Kabuki Syndrome and has no immune system which leaves her open to all bugs and viruses. It brings home to us how important it is to stay at home if you have a cold and wash hands to prevent the passing on of viruses and bacteria to these poor children with low or no immune systems. She has had 23 anaesthetics in her short life involving heart surgery, knee surgery, hip surgery, dental and eye surgery. Thankfully she is now home with her family and beloved dogs and receiving ongoing treatment at the Royal Hobart Hospital. I can't speak too highly of the care and treatment she received at Royal Children's Hospital – it's an amazing place.

It's so sad that children from Tasmania have to go the mainland for some treatments and the strain it puts on families, both emotionally and financially is immense. Sometimes in Tassie we feel so isolated from specialist treatment – especially neurologists – waiting lists are so long and I'm not able to help folk who ring me to find out if there is a neurologist in Hobart who knows about CMT. Come on you trainee neurologists – come to Tasmania – it's a beautiful place with a great lifestyle – you will be welcomed with open arms!!!!!!

Apologies to all in our support group for not having a mid-year get-together but I will be going to the Awareness Day in Sydney in October and I will certainly contact you all when I get back and arrange a meeting where I can bring you up-to-date with the latest news on the CMT front.

Keep warm! Marilyn Kremmer, Tasmanian Co-ordinator

CANBERRA

The Canberra and Region Support Group met on 6 July, after an 8 month break. I wasn't well during that time, so I hadn't been up to hosting a get-together. We were only a small group of four, as four of our regulars couldn't be there, but it was great to catch up again. After sharing our news of progress and challenges, we watched Joshua Burns' presentation at the 2012 Awareness Day on current research projects associated with CMT. We all found it extremely informative, particularly his investigations into appropriate footwear and orthotics. We expect to meet again in September and we'd love to have some newcomers join us!

Regards Gabrielle

INSPIRATIONAL STORIES



My name is Nicky Goozee and I have Charcot Marie Tooth disease (CMT) which was first diagnosed in 1976. By 1978 I got my first pair of 'splints', just in time for Year 7 but by the end of Year 12 and the start of University I realized I needed a wheelchair. Once I began using a wheelchair, I loved the freedom and independence it provided me with and I happily never walked again. Thirty years later, I still feel content with not being able to walk, work full time and am very happy with my life.

In 1988 I married and moved from Newport on the northern beaches of Sydney to the South Coast. After having 2 delightful daughters I returned to post graduate studies and then began my career as a teacher. Although I have an obvious 'disability', I have never considered myself to be 'disabled' or less able than anyone else. My attitude has always been positive and I have never really cared that I have CMT, it's just not important to me, nor have I ever let it define who I am.



Even though CMT is rarely spoken about at home, I have always participated in research. So after 30 years of blood donations I have decided to do a little bit more and enter this year's City@Surf fun run with a team of good friends and raise some funds to help with research. We aim to raise \$20,000 to purchase a specialist fluorescent dissecting microscope to assist researchers find a cure for CMT.



Dixie Papast tells her story:

I am a 42 year old, from Sydney. I was diagnosed with CMT approx 5 years ago, after I realised that my feet were behaving "weird". I asked one of my best girlfriends, who is a podiatrist about my feet & together we started on the journey that is CMT.

My family still don't know what type of CMT I have. Professor Nicholson & his team are working together to determine my type and this has been going for 2 years now. This is really important for me, as I have 2 children. My girls are 8 & 10, and show no symptoms, but neither did I at that age!

For my 40th, I decided that I didn't want to receive presents, and so instead I held a party & asked my friends to donate to CMT. Together we raised \$1,500.

This year, I will be walking / limping the City2Surf, and am again asking all my friends to donate to CMT. My aim is to raise \$2,000. I've never participated in the C2S, so it will tick a bucket list item for me & I am so excited to again be fundraising for CMT.

I participated in the Michelle Bridges 12 week body transformation in Feb & I lost just under 10 kgs. I have also started my walking training & am now up to 11km. I couldn't have done it all without my husband's support & my ankle braces. Of course I look funny with my braces on, but you know, I don't notice that I'm wearing them anymore or people staring.

I'd like to thank Darryl for his enthusiasm & for updating the website to make it easier for people to donate. Together we are all making a difference.

People can support Nicky and her team and Dixie by going to the CMTAA website www.cmt.org.au and completing the online donation form. Insert "Nicky Goozee" or "Dixie Papast" in the section referring to "making a donation on behalf of". All donations \$2 and over are tax deductible.

INSPIRATIONAL STORIES

My name is Mike Carroll and I am 54 years of age. My friends at the Surf Club have nicknamed me Calves Carroll, which has stuck for over 30 years. I was first called Calves, by one of the greatest Surf Swimmers and Ironman from Manly in the eighties, Craig Riddington.

I am not offended by the name and quiet enjoy the fact that the guys at the surf club have respect for me. Plus it is the Australian way to give someone a nickname.



I was first diagnosed with CMT when I was 20, which was in 1980. I had just competed in the Australian Surf Life Championships in Queensland in many events including the Ironman when I noticed I had difficulty walking on hard surfaces. I would finish board training on the beach and needed to carry my board to the gear shed, which was a concrete path. The pain would be agonising walking on the concrete. Also after Swim training at the pool, when I got out of the pool to go to the showers I would be in pain.

As I thought I was bullet proof, I was reluctant to see a doctor, and just put the pain down to over training and tiredness. Eventually I went to Newcastle Hospital and after several visits and tests the diagnoses was CMT. I then spent 6 weeks in hospital with both legs in plaster, having had operations on my Achilles Tendons and straightening of my toes as they were curling upwards.

While in hospital all I could think about was getting through the six weeks in plaster and then getting back into training. Not at any stage did I think I could not compete at the highest level again in Surf Life Saving. After the 6 weeks in plaster, I noticed the difference in my lower legs, that they have become very thin. I was determined to get back to full training and competition. It was not easy however the next season I was able to compete again in a Surf Carnival and do fairly well competitively.

Since that time I have never stopped training, whether it be swimming, board and surf ski paddling. I did run for a while, especially on the sand, however I prefer to spend my time training in the pool or surf.

In 1985 I started and Finished the Forster Ironman which was a 3.8km Swim, 180.2km bike ride and 42.2km run. My time was just over 13 hours and as far as sporting achievement's goes was a very proud day in my life. I still compete in Surf Lifesaving events, mainly the Swim and Board races. Surf Life Saving holds Masters Carnivals which are very popular and enjoyable. In the last 5 years Ocean Swimming races have become very popular and I regularly compete in these Swims. The distances can be anywhere from 1km to 10km. I enjoy the longer distances, as I can get into a rhythm and go at the same pace all day. The hardest part of the swim for me is the run up the beach, especially if the tide is low.

In my own Surf Living Club, which is Manly, I was honoured with a Life Membership in 2003, which is the highest award in our Club. And also in 2004 I was awarded with the National Medal from Surf Life Saving Australia for over 30 years of active Patrols as a Surf Life Saver.

I live by the philosophy that Exercise is Medicine, and never give up, no matter how hard it gets. I have people look at me strangely from time to time because of the size of my calves, however I think I am lucky and remember the saying that CMT is not for wimps."

CMT NEWS

The Passing of June Shepherd, Founding Secretary CMTAA

On the 11th February this year, Mrs. June Shepherd, mother of three and wife of John passed away in Perth after a long illness. June and John had left Sydney some years ago with June resigning her long held position of CMTAA Foundation Secretary at the National Office. June's health had steadily declined over the past three years but she still enjoyed receiving the CMT newsletter which kept her up with the news.



June began her association with CMTAA back in early 1997 with a chance meeting at Concord Hospital with then long term volunteer, Phyllis Critchley who over a cup of tea persuaded June that her talents were badly needed. June, her husband, John, her son, Donny and family were instrumental in setting up a permanent CMTAA office in the grounds of Concord Hospital. Together with other CMT members they equipped the office having first to knock down and take out fixtures in the old storeroom that the new office used to be. Donny still assists the association with his advice and knowledge of computers and technical expertise.

June held the position of secretary/office manager for many years and without her commitment and great contribution, the Association could not have continued.

The Charcot-Marie-Tooth Association of Australia gratefully acknowledges June's dedicated work and extend our heartfelt sympathy to John and his family.

Anycie Berkmann, CMTAA Secretary

Independent Living Centre Update



The Independent Living Centre recently wrote to the CMTAA office to let the members know of the services available.

The Independent Living Centres Australia (ILCA) is a collective organisation with members in each Australian state and the ACT.

Each state organisation assists a wide range of people from all walks of life. Clients include older people who wish to remain independent in their homes for as long as possible, as well as children and adults with a disability.

As well as their website (<http://ilcaustralia.org.au>) which is one way to find out information, members can call the Info-line from anywhere in Australia on 1300 452 679 and/or call and make an appointment. For people in regional areas, they are exploring ways they could do a virtual appointment via Skype.

There are various new videos about the service on YouTube, a Facebook page and also on the website, in the advanced section – you can log in/sign up for free to access this. They also have a new Virtual Tour of their one bedroom apartment and various equipment in it, on the website – so members could also take a Virtual Tour at any time.

CMT Motivates Trek to Mt Everest Base Camp

As reported in the last edition of the CMT CoMmuniTy newsletter, Kevin Howlett was departing on a trek to the Mt Everest Base Camp. We are pleased to report that Kev made it up and back in style and is in the process of selecting the most suitable 300 photos for his full colour glossy coffee table book. The book is currently on track for the scheduled launch in November. Stay tuned for more details. Profits raised from the sale of the book will be donated to our CMTAA.

Thank you Kev for increasing the awareness of CMT.

HAVE YOU EVER THOUGHT ABOUT DONATING TO CMTAA???

Remember 'We Need Your Help To Stay On Our Feet'

Step 1: There are a variety of ways to donate to CMTAA.

* Electronic Funds Transfer payment.

Our bank details are: BSB: 032-069 Account number: 158486

* Visit our website www.cmt.org.au and click on 'Make a Donation' on the Home page.

* Cheques made payable to Charcot Marie Tooth Association of Australia and mailed to CMTAA Bldg 22, Concord Hospital, Concord NSW 2139

If paying by EFT 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 (only necessary if paying by EFT)

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

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.



ABN 63 076 189 912

NSW Registered Charity

Building 22, Concord Hospital,
Concord NSW 2139 Australia

Ph: (02) 9767 5105

Fax: (02) 9767 5167

E-Mail: cmtaa@email.cs.nsw.gov.au

Website: <http://www.cmt.org.au>

CMT AWARENESS WEEKEND OCTOBER 11th and 12th, 2014

Venue: Building B26, Concord Medical Education Centre, entrance Gate 3, Hospital Rd., Concord Hospital, CONCORD NSW

Time: Saturday 11th: AGM and Mix and Mingle and Open Forum: 2pm to 5pm

Sunday 12th: Awareness Seminar: 9.00am to 3.30pm.

Speakers:

Topics include:

Professor Garth Nicholson – CMT Research, Professor Joshua Burns – CMT Management, Lyndal Douglas - Genetic Counselling, Dr Andrew Wines - CMT Surgery, Lois Tonkin – Principles of Pain Management, a Posture and Balance Workshop, CMTAA Research Grant presentations, Interviews with people with CMT and our Q and A session.

Cost: Saturday 11th: AGM followed by Mix and Mingle and Open Forum (including light refreshments): FREE

Cost: Sunday 12th: Awareness Day Seminar: \$30 per person, \$10 per child (under 18 years). \$70 families (2 adults and their dependent children under 18 years). This includes an attendee kit, morning tea, lunch and light refreshments.

Parking is conveniently available in the hospital car park opposite the entrance to the Concord Medical Education Centre. Concession parking cards will be available when registering to enable you to park all day for \$5 which is payable when exiting the car park. Disabled parking is available in front of the Concord Medical Education Centre.

Please register your attendance through the Seminar RSVP link at the end of the Sydney Awareness Day Seminar article on the CMTAA website, by filling out the section below and sending back to the office address above or by emailing or phoning the National Office on 02 9767 5105 by October 4th 2014 together with your attendance fee. Alternatively, please call our National Office on 02- 9767 5105 to register your attendance and pay on the day.

A Certificate of Attendance for professional development will be available if required.

Name/s:

Number attending:Email:

Address:

Amount enclosed: \$ Telephone contact number:

I/We will be attending the **AGM and Mix & Mingle on the 11th October:** Yes: No:

I/We will be attending the **Awareness Seminar on 12th October:** Yes:No:.....

SRF8/14V2

THE BENEFITS OF SUPPORT GROUPS

Charcot-Marie-Tooth (CMT) disease can be a very isolating illness and joining a support group can be of huge benefit to you and your family members. It means that you are not alone and that there are other people with the same problems as you. Knowing this can be a huge relief with members of a group supporting each other and sharing new ways of dealing with their illness and problems. Interacting with other people in an enjoyable environment can assist feelings of isolation, improve your coping skills and reduce your stress and anxiety. The sharing of information about possible treatment options and medical professionals can also give you a sense of control of your situation as well as helping other CMT people.

Support groups may vary in the number of participants depending on the number of CMT people in your area. Social 'Coffee Meets' can be great fun where you can talk about anything not just CMT.

The full list of the coordinators per state, town and local areas appear on pages 10 and 11 of this newsletter. These coordinators will from time to time, hold meetings and 'coffee mornings' to allow people and their families to have the opportunity of supporting each other with the problems they may be encountering and dealing with their CMT.

For venue and meeting times, please contact them either by phone or email. As well if you would like the national office to contact the Support Group Coordinators on your behalf please contact us. Your contact details will then be sent to your local CMT Support Group coordinator.

If you feel you would like to become a Support Group coordinator for your town or area please contact the National Office by email: cmtaa@email.cs.nsw.gov.au or phone 02 9767 5105.

CMT AUSSIE KIDS WEEKEND

Plans are in their final stages as the third CMT Aussie Kids Weekend approaches with excitement and anticipation building. This year has seen a dramatic increase in attendees, with 19 'kids' coming to the camp at Berry Sport and Recreation Centre on the South Coast of NSW. This represents an increase of well over 40% from previous years with attendees travelling from all states and territories of Australia with the exception of Tasmania and the Northern Territory (although we're working on them!). We have been able to offer all interstate participants travel assistance with their flights as a result of receiving a grant from The Qantas Foundation in 2013 and have also arranged for the first time a shuttle bus from Sydney Airport to the camp for the 'kids' arriving from interstate. We have continued to seek funding for the camp to assist as many kids with CMT in attending the fun weekend and this is an ongoing passion of us both.

The camp will be held from Friday 29th August—Sunday, 31st August 2014 with activities including canoeing/kayaking, rock climbing and cable glide. Kids aged from 9 to 49 (and a little bit over if you push us) will be joining in this year with a special visit from Dr. Amy Sman and Kayla Cornett from the Children's Hospital at Westmead who will be participating in the activities available to all during the Saturday afternoon—hope they like getting wet! A big thank you to our supporters who have got the word out about the camp and to others for their generous donations specifically for the kids camp. Look out in the next newsletter for a report and photos from the camp.

Jillian and Peter Critchley. Organisers CMT Aussie Kids Weekend



STATE COORDINATORS

NATIONAL OFFICE—SYDNEY

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

Email: cmtaa@email.cs.nsw.gov.au Website: www.cmt.org.au

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Mrs. Gabrielle Evans
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Email: gabriellecmt@gmail.com

QUEENSLAND

Position vacant

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Mrs. Paula Gailey
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SUPPORT GROUP COORDINATORS (continued)

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TASMANIA

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THANK YOU for donations from 1st April 2014—15 July 2014

Total donations received for Nicky Goozee's Research Project \$3,470

Total Donations for research on behalf of Dixie Papast \$240

\$2000

Mr. and Mrs. James and Bev Galloway Mr. Kenneth Schmack
Friends and Relatives of Mrs. Marion Ericson \$1850.00

\$500 and over

Guardian Interlock Systems

\$200 - \$499

Mr. James Christou Mr and Mrs. David Critchley Mrs. Joan Izzard

In Memory of the Late Mrs. Katherine Douglas- From Jo and Nicholas Harley

\$100 - \$199

Mr. Roger MacRury	Mr and Mrs. John Boyle	Ms. Carolyn McKay	Mr. Russell Holmith
Mrs. Benita Robbie	Mr. Darren Cuomo	Mrs. Gabby Cosgrove	Dr. Andrew Wines
Annette Roberts			

In Memory of the Late Mrs. Katherine Douglas—From D.J. and E. M. Bleby

\$50 - \$99

Mrs. Kay Boreham	Mrs. Denise Eastwood	Mr. John Head	Mr. John Etchells
Mrs. Beth Smith	Mr. Paul Finnimore	Mrs. Lesley Polmear	Ms. Janis Floyd
Mr. Peter Lott	Mr. George Germantse	Ms. Anne Leggett	Mrs. Helen Hickey
Mrs. Anne Dawson	Mr and Mrs. Stokes	Mr. Mark Bainbridge	Mr. Greg Baker
Mrs. Barbara Deuis	Mrs. Phyllis Critchley	Mrs. Gabrielle Evans	Beryl Smith
Mrs. Marilyn Kremmer	Mrs. Michelle Pile	Mrs. Gaile Stebbings	

In Memory of the Late Mrs. Katherine Douglas—From Ms Theresa Hayward, Mrs. P. Herriot, M. and C. Herriot, Mrs. Elizabeth Puddy, Ms Christine Munday, The Late Mr. Michael Fitzpatrick, Dr. Elizabeth Thompson, M. Hutchison

\$20 - \$49

Mr. Stephen Stokeld	Mrs. Phyl Logan	Mrs. Marilyn Rowlands	Mrs. Eileen Ranage
Anonymous	Mrs. Julie Rowe	Mr. Robert Hinds	Mande Allen
Mrs. Sarah Jane Mann	Mr. Richard Seymour	Mr and Mrs. Douglas Hardgrave	
Mr. John Collis	Mr. James Koios	Mr. Stephen Patterson	

In Memory of the Late Mrs. Katherine Douglas—From Ms. Diana Osmond, Mrs. Betty Huntley, Ms. Janet Wills

\$1 - \$19

Mrs. Joanne Liso	Mrs. Toni Huckstepp	Mrs. Aileen Harrison	Mrs. Cecily Ravesi
Mr. Edward Ivey	Miss Annette Maie	Ms Vicki Ferrier	Mr. Edward Brown
Mr. Barry Brown	Thyra Oakley	Mr. Malcolm Pugh	E and J Reynolds
Mrs. Gabrielle Evans	Toni Huckstepp	Che Fornusek	Mr and Mrs. Ron and Stella Weir

In Memory of the Late Mrs. Katherine Douglas- From M. Howie

September is International CMT Awareness Month

This year we are preparing to join our “International CMT Family” through our participation in the September CMT Awareness Month.

Background

As the result of the international support group leaders meeting at last year’s Antwerp CMT Consortium (your CMTAA was represented), it was decided to promote the month of September as International CMT Awareness Month.

The 2014 Plan

Unfortunately last year we were not in a position to participate, however, we are in a better position to participate this year here in Australia. Our goal is to direct people to our website where they can access information about CMT, CMT management, latest research, clinical trials and, through our links, visit credible international CMT related sites. Knowledge is the key to enhancing the life of a person with CMT and those who care for them.

To facilitate this we will have our Australian poster ready for distribution to those who can use them to promote CMT Awareness. This may mean placing them in the practices of medical and allied health professionals or other places where people with CMT may visit. In addition to the poster, we will also have our CMTAA bumper stickers available.

The deadline for ordering your posters is Monday, 4th August. Please contact the National Office by phone or email to ensure that we can have them distributed to you prior to 1st September.

Please take a look at our poster below.



International Awareness for Charcot-Marie-Tooth disease

**Find out more at
www.cmt.org.au**



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

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)	
Ann McLaughlin (NSW) (resigned)	

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

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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).



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 October 2014

Jillian Critchley

The Editor, The CMTAA CoMmuniTy

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

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

KEEP IN TOUCH

Name: Mr/Mrs/Miss/Ms (please circle)

Address: _____

State: _____

Postcode: _____ Phone: () _____

Email: _____

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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

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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