Meet the SA CMT Team  

The Team’s work so far has enabled dialogue that has resulted in many networks created for persons living with CMT, their families, their carers and their treatment specialists. We estimate that more than 500 South Australian persons have become more aware of CMT. We are particularly encouraged by the approaches made to the SA CMT Team and the attendances at scheduled events. As in 2015 we intend to move around the state with our planned events and look forward to a big year in 2016 with September in focus as International CMT Awareness month. We encourage the SA community to contact us with their feedback and any ideas for future events.

Coffee & Chat Gatherings

The SA Team, decided in May 2015 to increase its reach to contact and support persons with CMT. We travelled to Murray Bridge for our first Coffee & Chat session. We had a great turnout on the day, and it was great to be a part of the sharing that included triumphs and difficulties.

The second meeting on the road this year, was held in July, in the beautiful town of Victor Harbor. A great turnout, with some familiar faces, but also many new ones. Another great session of sharing and feedback on planning the upcoming September Awareness Day.

Our final Coffee & Chat for 2015 was held in the western suburbs at the Love On Cafe at Mile End. Many new faces attended, most of whom attended the Awareness day, and it was great to hear their stories and feedback.

The final gathering for 2015 was held November 28 at the Findon Hotel. We enjoyed the festive spirit and celebrated a great end to the year.

The SA CMT Team thank all who have attended the various gatherings in 2015. Your sharing and feedback will be used for planning purposes.

Survey Focus Groups With Dr Scott Denton

Over the Anzac Weekend 3 focus groups were held in the City, Blakeview and Murray Bridge with Dr Scott Denton and his assistant Jill Poynton. Dr Denton is the author of the Australian CMT survey entitled Cost-utility, Wellbeing and Management with CMTAA managing the process.

Dr Denton took away with him a wealth of information to include in his report. He has expressed his thanks to the SA community for the welcome and enthusiastic participation. We eagerly await the final report of Dr Denton’s findings and can make it available as soon as it has been received.

SA CMT Support Group Questionnaire

During May, the SA CMT Team prepared and sent out a questionnaire to all known members. We kindly thank MDASA, for their assistance in forwarding our questionnaire to their CMT clients. The purpose of the questionnaire was to seek feedback from the community about what they wanted from the SA CMT Team. We received some great feedback and would like to thank all who responded. We will forward a 2016 questionnaire in January so that we can tailor our events to the needs and wants of the South Australian CMT community.
Attendance exceeded all expectations with 40 preregistrations and 5 on the day. It was great to see a great mixture of persons with CMT, carers and professionals and podiatry students shared with us what was an action packed day.

Featuring 9 speakers, including key speaker Professor Joshua Burns from Sydney, who gave 2 sessions on the latest and greatest in CMT relating to the management and measurement of CMT. Local Podiatrist Rebecca Healey spoke on the importance of foot care and orthotics/AFO and gave a demonstration of foot mobilization in the afternoon session. Neurophysiotherapist Ann Buchan presented on physiotherapy and CMT management. Sam Paior gave an informative overview on the NDIS. Representatives from TADSA, Independent Living Centre and Muscular Dystrophy Association of SA also presented on their organisations and CMT management.

We were also fortunate to have informative displays from the Julia Farr Foundation, Carers SA, Disability SA, DACSSA and 2 modified vehicles on display in the car park. A full program and list of displays and sponsors is attached to this newsletter for your interest.

More than 60 people shared the day.

The SA Team sincerely thank our members and the SA community for their support in attending the day. We thank all our sponsors the Adelaide Pavilion, who provided the venue and the catering, the Julia Farr MS McLeod Benevolent Fund for their grant, MDASA and their staff Amber Pyle, Aisling O'Toole and Hoda Teimorzedah of the client services team for their assistance in planning the Awareness Day, also for their participation and assistance on the day.

Feedback from Speakers and Professionals:

“I want to congratulate you all for such an informative, well planned seminar on Saturday, we were impressed and grateful to be part of the day.”
- Annon

“I really enjoyed your awareness day, and can say after just presenting at the Stanford CMT family awareness day that you all put on a world class event - well done.”
- Annon

“Thanks for a great day on Saturday, I learned so much and hope the day will develop an opportunity for new relationships.”
- Annon