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MND Tasmania Annual General Meeting—Sunday 6 March 2016

Fourteen members and supporters including Harry and Pat Stafford attended the AGM which was held at the Ravenswood Community Health Centre. Harry and Pat have been stalwarts of the Association since Pat was diagnosed with MND 20 years ago and they announced that they will be celebrating their 70th wedding anniversary on March 21. Congratulations Pat and Harry! Every 2015 Director was re-elected to the same positions for 2016 and the President's Report and Financial Statements for 2015 were accepted. The Association currently has 40 members who are living with MND or Kennedy's Disease.

Following the meeting, Speech Pathologists Jacqui Bannon and Dennis Lee from the

Independent Living Centre (ILC) demonstrated the variety of communication assistive technology that is available to people who live with MND. MND Tasmania assists members to obtain such equipment when it is prescribed by a Speech Pathologist. Hayley Tristram is our Regional Advisor who supports our members and she liaises with Health Professionals so that our members living with MND can have access to the assistive technology that they need. As the symptoms of MND can change from week to week or month to month, it is important that our members have timely access to the best expertise available to assist them with the changes in equipment that they may need.



President's Annual Report - 2015

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We've had a busy, productive, exciting and sad year for MND Tasmania in 2015.

We farewelled our previous Tasmanian Regional Advisor from MND Victoria, Leanne Conway and welcomed our new Regional Advisor Hayley Tristram. Leanne was an excellent resource for people living in Tasmania and packed in the most activity she could during her fly-in and fly-out visits. With Leanne vacating the Regional Advisor role, it prompted MND Victoria and MND

Tasmania to consider the best model of delivery services in the future. As such it was decided the time was right to locate the position in Tasmania to be closer to the people and services impacted including greater flexibility with face-to-face visits around the state. We welcome Hayley (based in Launceston) into the role and look forward to working with her closely.

In March I attended the MND Health Professional Forum in Launceston organised by MND Victoria.

It was another successful attendance by many in the health professional community from across the state as well as service providers in the palliative care, disability, aged care, health and community sectors. The title of the forum was “*Partnerships, supporting people living with MND*” and it was clear from the day that there is still much work to improve the coordination and response of service providers to people with MND, especially with major reforms in disability and aged care currently underway.

It was with great pleasure and relief to Mary Erickson and the Northern Support Group that their spiritual home of Ravenswood Community Centre was ready for return. After a significant renovation and refurbishment the Northern Support Group was able to host their meetings with improved parking, access and facilities.

In the south of the state, MND Tasmania Secretary Michele Newton initiated the inaugural Southern Support group based in Lindisfarne. We warmly welcome members of MND Tasmania and their carers, family and friends to attend the Southern Support Group for an opportunity to meet and chat with other people fighting this disease. Look out for the dates on our website and newsletters in 2016.

We have planned and nearly completed the work to create our MND Tasmania Care Foundation announced in 2015. Three trustees have been appointed from the MND Tasmania Board to oversee and administer the Foundation funds.

Similar to 2014, we have monitored and kept abreast of the changes and rollout of the National Disability Insurance Scheme (NDIS) during 2015 and in particular the rollout schedule for Tasmania. You may have noticed that the rollout in Tasmania is by age cohort over the next few years with all eligible disability participants (under 65) coming into the scheme by 1st July 2019. In partnership with MND Victoria we are keeping close tabs on their experiences and learning's from members currently in the Barwon trial region for NDIS.

It was with great sadness that we learnt of our patron's (Lady Sallie Ferrall) death in September. Her proactive support for people living with MND in Tasmania started over 30 years ago when her first husband, John Barnett, was diagnosed with MND. She initiated informal meetings and networks which resulted in the first public meeting at her home at Quamby on October 15 1985 to consider the formation of a society

for people with MND in Tasmania. From then on Lady Ferrall provided support and advocacy to those people suffering from the disease and she will be dearly missed in the MND Tasmania community.

The Committee is continually grateful for those MND Tasmania members who faithfully support MND Awareness Week and donate to our cause. MND Awareness Week in May 2015 was again led by our volunteer Fundraising Coordinator Mary Erickson and the dedicated volunteers in the North, North-West and South of the state. Thanks must also go to our volunteer Facebook and website managers Shane and Jackie Chugg. Both these mediums continue to provide a great source of information sharing.

Finally, I'd liked to once again extend my thanks to my colleagues on the Board of MND Tasmania who all share the commitment and personal sacrifice to serve the Board and members of MND Tasmania. I look forward to the next year of again striving to improve services to those living with MND.

Vale

We extend our sympathy to the family and friends of Scott Newton and of our other members who have recently passed away.

Support Groups



Northern Support Group

All are invited to join us at 11am – 1pm on Monday April 18 and May 30 at the Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood.

The contact person for this group is Mary Erickson on 1800 806 632 (message).

Southern Support Group

All are invited to join us at 12.30pm – 2pm on Friday April 29 and May 27 at the Lindisfarne Community Activities Centre, 37A Lincoln St., Lindisfarne.

The contact person for this group is Michele Newton on 1800 806 632 (message).



MND Week: 1–7 May 2016



This annual event provides a window of opportunity to raise the profile of MND and to raise funds to support people living with MND in Tasmania. We are indebted to the committed people who faithfully work hard to contribute to this cause every year.

During 2015, \$8,784 was raised during MND Week. Thank you! In addition, donations of \$11,455 were received during the year for research which will be sent to the MND Research Institute of Australia.

Donations not allocated to research are used to support people living with MND in Tasmania and their families. For example, during 2015, \$17,426 was spent on equipment and home modifications for members in accordance with the MND Tasmania Equipment Policy and \$30,000 was donated to MND Victoria as a contribution towards the Regional Advisor service.

Collection Day

MND Week is early this year with the first full week of May being right at the start of May! The Charitable Collection Day is WEDNESDAY MAY 4.

A copy of the Police Authorisation and Insurance documents and the MND Tasmania authorisation form for the collection of funds on public footpaths are available from Mary Erickson (see below).

We are looking for volunteers to participate in collections and raising awareness on as many

streets around the State as possible. We have merchandise boxes with pens, cornflowers and wristbands for placement in sympathetic businesses and workplaces.

If you would like to help or to know who will be fundraising in your area, please contact Mary on 0438 523 382.

Bunnings BBQ

The annual BBQ is planned for Bunnings Warehouse North Launceston at 78 Lindsay St., Invermay on SATURDAY MAY 7.

Roll up between 8 a.m. & 4.30 p.m. to support MND Tasmania and to buy a snag or two and encourage the volunteers!

Bring and Buy

Margaret invites you to the Annual BRING and BUY fun fundraiser at her home!

WHAT? Soup & bread; a bring and buy trade table; \$5 entry donation

WHERE? 43 Maning Ave, Sandy Bay (Parking may involve a bit of a walk which varies from day to day. The driveway has room for a car and another across the driveway for those who are unable to walk the distance.)

WHEN? Saturday 7 May at 11am - 1.30pm

Regional Advisor's Report

Hi everyone, I hope this edition finds you well.

I've just returned from a visit to the lovely North West. Along with visiting a bunch of our members in far flung places, I was also able to meet up with and share ideas and information with a large number of health professionals who work with MND in this region.

A number of people I met this trip, both people living with MND and their family members talked with me about the value for them in connecting up with others who's lives were affected by MND, and how tricky it was to locate them at first.

If you are a person living with MND, a carer, family member or friend interested in having contact with others in similar circumstances, I'd be happy to help.

This can be done through existing support groups, facilitating contact either in person, by phone or by email or giving you information about external/online support groups.

If you would like to be in contact with others, but are uncertain of how to go about it, then contact me and we can talk through the options.

Just some advance notice that my next planned regional trips around the state are: South: 11-12th April, North West : 9th-11th May

Meantime, as always, I'm a phone call/text or email away so don't hesitate to get in touch if I can be of assistance-1800 806 632/ 0412599365 and email htristram@mnd.asn.au

Best wishes, Hayley

Fundraising & Awareness

Kirk Dicker is one of our members living in the North-West who has been prominent in the media due to his innovations in raising awareness of the practical lifestyle implications of MND. For example, he assembled and drove an MND float in the Wynyard 2015 Christmas Parade, was featured on 936 ABC Radio on January 12 2016 and in The Advocate on February 22. As a founding member of the Boat Harbour Beach Surf Life Saving Club who has continued with his rostered Club duties, Kirk has adapted equipment and brought new assistive technology to Australia so that he can continue to have an active and participating lifestyle. He has also initiated the annual Kirk Dicker Challenge at Boat Harbour in March to raise funds for MND support and research.

The photos illustrate some of his activities. After being diagnosed with MND, Kirk expected that he would not be able to continue his loved activities of going bush or patrolling the beach. After he found out about the Austrian Zeisel chair which was designed for alpine conditions, he imported the first one into Australia and has driven it on sand, rocks and other off-road terrain. He has also discovered a roll up mat used in South Australia and made by Envirex, an Australian company, that will allow access for wheel chairs, prams and anyone wanting a steady surface to get across soft sand to enjoy a walk along the beach. He has been raising funds to purchase such mats for local beaches.

For more stories about Kirk, visit our Facebook pages www.mndatas.asn.au



MND Tasmania

PO Box 379, SANDY BAY, 7006

Inc.No.01323C

Telephone: 1800 806 632 (MND Victoria office)

Email: info@mndatas.asn.au

Website: www.mndatas.asn.au

MND Tasmania has a volunteer Board and no paid staff.

It is a member of MND Australia and of the Neuromuscular Alliance of Tasmania.

Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: Mary Erickson

Equipment: Libby Cohen

Ex-officio wisdom: John Hughes

Support

Website: Shane Chugg

Facebook: Jackie Chugg

Regional Advisor

Hayley Tristram

Email: htristram@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the Regional Advisor service which is based in Launceston and provides State-wide support for members.

Services include:

- needs-based support and assessment, home visits and referrals to appropriate care and support services as required;
- information and member support by telephone on 1800 806 632, Monday-Friday, 9am – 5pm;
- information, support and training for service providers for people with MND in Tasmania;
- free membership and bi-monthly newsletters from MND Tasmania and MND Victoria for people living with MND in Tasmania.

Freecall 1800 806 632

This number is at the MND Victoria office. To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or the Regional Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.