



January - February 2017

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## MND Tasmania 1986-2016: supporting people living with MND in Tasmania for 30 years

### Thirtieth Anniversary Celebration – 27 November 2016

The 30th birthday of MND Tasmania was celebrated by over 30 people in Launceston on Sunday 27 November 2016.

leadership of the Northern Support Group and in fundraising.



Welcome by Tim Hynes, President

Thank you to all who travelled from Sydney, Melbourne and around the State to make this a memorable occasion by mixing freely and chatting with and encouraging each other. Also, thank you to those who sent us their apologies and donations.

Some of us had communicated by phone and email for many years and it was a delight to finally meet in person. It was wonderful to meet longtime stalwarts of the Association including Life and Founding Association members Anne Steer and John Hughes AM with his wife Nancy as well as Founding member Rosemary Stobart. Longstanding member with MND Kerry Upchurch was there with his wife Sharon, their three sons and his mother Yvonne. Past Committee members Denis Lyne and Dora Hugo joined us as did Rod Harris, Julie McConnell and Leanne and Andrew Conway from MND Victoria. Mary Erickson was there with her signature raffle and prizes and she was presented with a gift in appreciation of her years of faithful



Tim Hynes and Mary Erickson



Mary's signature raffle

We were also joined by Dave Brelsford who has been running for MND in Tasmania since 2011.

Photos scrolling on the wall showed past events and current and former members including Bill Braithwaite and Kevin Anderson, each of whom almost single handedly kept the Association going at times.

The focus of the speeches were the relationships which have been formative in the birth, growth and development of MND Tasmania during the 30 years.



Tim Haynes, President, presented the priorities and objectives of those who initially drove the Association and how that compares with the results of the 2016 annual member survey.

John Hughes AM described the relationships between the enterprising and motivated individuals which resulted in the birth of the Association in 1986.

Rod Harris, CEO, MND Victoria, spoke about the relationship between MND Victoria and Tasmania and the relationship between members in Tasmania and three MND Advisors.

Joyce Schuringa explained the relationship with Palliative Care services.

Dr Catherine Blizzard from the Menzies Centre was scheduled to provide an account of the story of MND and research in Tasmania but unfortunately was unable to attend at the last minute.

Denis Lyne and Chris Symonds spoke about the relationship between MND Tasmania and people living with Kennedy's Disease.



*Kennedy's speeches*

Selected excerpts of speeches will be published in future newsletters.

We invite contributions from other past and present members who would like to add to their story to this historical account. (See MND Tasmania postal and email addresses on page 4.)

## New Members

We welcome new members living with MND and their families to the MND Tasmania community, network and services. Please feel free to contact our staff member Hayley Tristram who is the MND Advisor for Tasmania or any member of the MND Tasmania Board. The contact details are on page 4 of this Newsletter. The MND Advisor service is managed on our behalf by MND Victoria and Hayley is based in Launceston. She travels Statewide as required to support our members on a needs-basis.

## Vale

We extend our heartfelt condolences to the families and friends of Audrey (Fran) Howe, George Huizing, Leonard Oates, Jacobus (Jack) Sonneveld and of any other members who have recently passed away.

## Tasmanian Health Professionals' Forum

MND Tasmania has a Memorandum of Understanding with MND Victoria in order to support people and their families who live with MND in Tasmania. A vital objective of the service is to provide information, support and training for service providers for people with MND in Tasmania. One feature of this is an annual Forum held alternately in Launceston and Hobart. The 2016 Forum was held in Hobart on Thursday November 24 with over 50 community and palliative care health professionals, volunteers and other service providers.

Tim Hynes, President, closed the Forum with the following summary -

We started with Neurologist Dr Helen Castley this morning giving us a rundown of MND in Tasmania. There are 5 Neurologists in the South and one in North and the Southern ones allocate Statewide workload evenly. On average 7-15 people are diagnosed with MND every year in the State. The only proven risk factors for MND are age and genetics so far. There are other possible causes that are theorised yet unproven. One of the things that stood out for me was a clinical diagnostic red flag for Neurologists - a person who presents with wasted muscle but maintains a reflex. She also mentioned the importance of communication in social inclusion.



*Dr Helen Castley*

We were honoured to have Michele Newton talk about her very touching, raw and real experience as a carer for her husband Scott who had MND and died earlier in the year. We heard about Scott and that for him his computer was a bit of a window into staying connected to the world. Michele spoke honestly about the social isolation that occurred as friends and family began to visit less as Scott's condition worsened. It was made clear to us that there are little options for respite (age appropriate) in Tasmania and that the continuity of services needs to be improved, especially in the community setting.



*Michele Newton*

Unfortunately, I made a get-away during the sessions of the Occupational Therapy, Speech Pathology and Nutrition Health Professional speakers and took the opportunity to meet and progress some MND Tasmania

business with the Board while we were together. However, the sessions were highly practical and based on real life and recent examples across the disciplines.

Dr Christine Edwards, Palliative Care Physician, started with a Q&A session that I thought we all did very well at! No question went unanswered. The first striking statistic was that on average a GP will only see one patient with MND in their career. We were reminded that Palliative Care starts at the beginning but... that is not often what patients and families want to hear so Health Professionals need to be alert to that resistance. I feel lucky looking back now at the early conversations our family had with my Dad (who had MND) to determine what medical interventions he wanted or not. The frequency of visits and interventions can be overwhelming to a family that feels like it is a revolving door of people in and out of the home. My Mum often commented to me that when the weekend came around she had a "day off" and loved it. Christine also shared a great line: 'MND is a disease of continual losses and there is grief associated with each stage of loss'. I immediately thought of one of those stages where we had to take the car keys off Dad as he was no longer safe to drive. He grieved hard over that loss of independence and that was a clear stage in the overall losses he inevitably suffered.

Julie McConnell finished us up by outlining the partnership that MND Tasmania and Victoria have forged over the last 8 or so years and the key development of the MND Advisor service in Tasmania. Initially the Advisor service was enabled by a philanthropic grant creating a fly-in and fly-out position that serviced the members of Tasmania. In 2014 PHT funded the Care Coordination Program in Tasmania and MND Victoria was awarded a contract to deliver this service through a Launceston-based position. Julie also outlined the MND Tasmania Equipment Donation service that assists members with a financial contribution in the event that other government or private sources of equipment funding cannot be found.

## Regional Advisor's Report

Hi everyone,

Just a short note from me this time around. What a great start to the year to see Craig Machen launch his solo paddle around Tasmania raising funds for MND Tas. Craig and his support team have done a great job of raising both awareness and funds.

It's been great to be on the road again and able to get around the state in the past few months. I've made several trips to the North West and to the South since the last newsletter.

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—0412 599 365 or email [htristram@mnd.asn.au](mailto:htristram@mnd.asn.au)

I look forward to working with you all in 2017.

Best wishes, Hayley

## Christmas Lights for MND

Every year the Lowe family decorates their house with Christmas lights which attract the attention of passersby. Last Christmas an elderly lady pulled over to enjoy the scene and slipped Kallum \$5. In the excitement, his mother

suggested that he donate the money to MND Tasmania rather than keeping it for himself. He happily agreed to this and asked Mary Erickson for several MND donation tins. When cars were lined up in the street to look at the lights, every night for the next 3 weeks, Kallum asked the drivers for donations. He collected \$390.85 before the lights were taken down for the new year. We are really very thankful for people like Kallum and his family who are thoughtful and proactive in their support of people affected by MND.



## MND Tasmania – Annual General Meeting, 5 March 2017

All members, family and friends who are supportive of people with MND in Tasmania are warmly invited to attend



**2pm, Sunday 5 March 2017**  
**Clarence Senior & Citizens Centre**  
**17 Alma St, Bellerive 7018**



(The Centre has accessible facilities and parking.)

Tim Hynes and Mary Erickson will be retiring from the Board this year. Please join us as we celebrate and express our appreciation for the years they have worked in their various roles in MND Tasmania to improve the lives of people and their families who live with MND in Tasmania.

After the AGM, our Guest Speaker will be Michele Newton who is the current Secretary of the Association. Michele will share her experiences and thoughts about living with MND with her husband Scott. There will be an opportunity for questions and discussion. Michele wrote this presentation for the MND Tasmania/Victoria Health Professionals Annual Forum in November 2016 where it was very well received.

### Nominations for the Board

The term of office for Directors of MND Tasmania is one year. The election of nominated members of MND Tasmania to the positions of Directors is conducted by the members at the AGM.

If you are a member who is unable to attend the AGM and would like to be nominated for a place on the Board and/or would like a proxy voting form, please contact Secretary Michele Newton on 1800 806 632 (leave message for Michele to contact you) or via email at [info@mndatas.asn.au](mailto:info@mndatas.asn.au)



## Fund-Raising and Awareness-Building

Donations have been gratefully received in the memory of Mrs Jackie Chugg, Mrs Ruth Little, Mr George Huizing and Mr Jack Sonneveld.

Thank you to our generous fund-raisers and awareness-builders including -

- Craig Machen paddling around Tasmania (at Cockle Creek at the time of writing)
- Think Pink for MND team
- Citywide Fitness Hobart
- Riverside Lions Club
- Hands on Craft Classes (Clarence Baptist Fellowship)
- Eric Jarrett Bike Ride
- Murray & co. in Burnie Run
- Marquis Hotel Motel.

## Northern Support Group



The Northern Support Group invites all members and supporters of MND Tasmania to its meetings. The Ravenswood facility is comfortable and suitable to use as a stopover venue for a day trip.

**WHEN:** Meetings are held from 11a.m. to 1p.m. on the fourth Monday of every second month.

**Meeting dates 2017:** March 27, May 29, July 24, September 25, November TBA.

**WHERE:** Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood with excellent, accessible and comfortable facilities and parking.

The contact person for this group is Libby Cohen who may be contacted at 1800 806 632 (message) or email [info@mndatas.asn.au](mailto:info@mndatas.asn.au).



## MND News Tasmania

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 3 March 2017.

## MND Tasmania

PO Box 379, SANDY BAY, 7006

Inc.No.01323C

Telephone: 1800 806 632 (MND Victoria office)

Email: [info@mndatas.asn.au](mailto:info@mndatas.asn.au)

Website: [www.mndatas.asn.au](http://www.mndatas.asn.au)

MND Tasmania has a volunteer Board and no paid staff. It is a member of MND Australia and of the Neurological Alliance of Tasmania.

## Board

President: Tim Hynes

Vice-President: Joyce Schuringa

Secretary: Michele Newton

Treasurer: Helen Fleming

Fundraising: vacant

Equipment: Libby Cohen

Ex-officio wisdom: John Hughes

## Support

Website: Shane Chugg

## MND Advisor

Hayley Tristram, email: [htristram@mnd.asn.au](mailto:htristram@mnd.asn.au)

## Support Service

MND Tasmania and MND Victoria work together to provide the MND 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 MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.