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## MND Tasmania

PO Box 379, SANDY BAY, 7006  
Inc. No. 01323C; ABN: 21 877 144 292  
MND Tasmania is a member of MND Australia. The MND Research Institute of Australia is part of MND Australia. MND Tasmania is a member of the Neuro-muscular Alliance of Tasmania (NMAT).

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### Patron

Lady Sallie Ferrall

### Support

Website: Shane Chugg

### Regional Advisor

Leanne Conway: [lconway@mnd.asn.au](mailto:lconway@mnd.asn.au)  
Telephone 1800 806 632

## November - December 2014

### Freecall 1800 806 632

This number is at the MND Victoria office. To assist the volunteer receptionist, please say that you are from Tasmania.

If you wish to speak to a Committee member or to Leanne Conway, you will be asked for your contact details. Your call will be returned by that person as soon as possible.

### Board

President: Tim Hynes  
Vice-President: Joyce Schuringa  
Treasurer: Helen Fleming  
Secretary: Michele Newton  
Public Officer: John Hughes OAM  
Northern Support Group: Mary Erickson  
Fundraising Coordinator: Mary Erickson  
Libby Cohen

## Paul's Pinnacle Pilgrims

In August 2014 our beautiful dad Paul was diagnosed with MND. We were stunned, devastated, and heartbroken. Dad is the most amazing, loving, caring, and generous father anyone could have the good fortune to meet. We are two extremely lucky sisters. But in true Dad style, he doesn't give in to any illness or hardship, so as a family we kicked into gear and devised a fundraising and MND awareness raising campaign in Dad's honour.



So Paul's Pinnacle Pilgrims was formed, and our team of five (the two of us plus three gorgeous friends, Alf, Denise and Melita) raced up Mt Wellington in Hobart, in the Point to Pinnacle half



marathon on Sunday 16 November. The race is called 'The world's toughest half marathon' and for good reason! With 21km straight up a mountain, it is a gruelling race of endurance that pushes both physical and mental boundaries. But the thought of Dad helped propel us up that mighty mountain, and we all finished in good time and in one piece!

And thanks to our fellow Pilgrims and wonderful friends and family supporting us every step of the way, Paul's Pinnacle Pilgrims has raised about \$8,000 for the MND Association Tasmania (and the tally is still growing). We are so appreciative to everyone getting behind our cause, and supporting not only our Dad but also the broader MND community.

*Melissa Yard-Smith and Anna Yard-Cumming*

## Awareness-building

The **Ice Bucket Challenge** came as a bolt out of the blue in August! Shortly after hearing of Neal Daniher's diagnosis of MND on 18 August, we received invitations for interviews about MND, were requested to attend functions to receive donations for MND care and research and we were challenged to participate in Ice Bucket Challenges.

What a delightful windfall of attention and gifts for all of the families who are living and have lived with MND in Tasmania and beyond!

The wonderful publicity was accompanied by some associated challenges such as donors who expected an immediate response from our volunteer Treasurer, people who collected funds which purported to be for MND Tasmania but were not transferred to the Association and criticism and myths circulating on social media.

However, these drawbacks were vastly outweighed by the outpouring of encouragement and support received by the Association at multiple levels.

Indeed, the increased scrutiny was welcome as we have a Board whose members know what it is to live with MND, and they take their governance responsibility seriously.



## Member support

### What then were the outcomes of all of those cold wet Ice Bucket Challenges?

The short-term benefits have included more people knowing that MND exists and what it is.

The long-term benefits will be the outcomes of effective utilisation of the funds we received to fulfil our objectives, which are listed in our Constitution and on our website.

Donations to MND Tasmania which were specified to be from Ice Bucket Challenges were \$17,489.15. In addition, \$20,700 received by our national body MND Australia will be reallocated to MND Tasmania.

Funds marked by donors for research will be forwarded to the MND Research Institute of Australia.

### Regional Advisor

The most tangible benefit of being a member of MND Tasmania is the support offered by the Regional Advisor. Leanne Conway has just passed her first anniversary in this vital role and we are thankful that she has been willing to travel to and around our state regularly to support people living with MND and their families and to provide education and training to health and support service providers.

This position is a result of an initiative in 2007 to form a cooperative partnership between MND Tasmania and MND Victoria. Due to the small size of MND Tasmania, the Regional Advisor is a part-time position and is employed by MND Victoria. Leanne also works in the MND Victoria office.

Leanne has learned how the health, disability and care support systems in Tasmania operate and has

successfully built up linkages and networks to assist members with MND, their families and their service providers.

All of the costs associated with the role have been funded by donations. The first government grant to supplement this role is from Tasmania Medicare Local and was described by Leanne in the previous edition of MND Tasmania News.

## Equipment

Many people who are newly diagnosed with MND receive advice and equipment from well-meaning friends and relatives. Time and money can be wasted on unnecessary, inappropriate or unsafe items of equipment.

Via the Regional Advisor, MND Tasmania may contribute funds towards specific equipment or home modifications for a member if prescribed by a health professional and if there is no other source of funding. Over \$18,617 has been donated to members for this purpose during 2014.

## New members

We welcome new members living with MND and their families to the MND Tasmania community and network

Please feel free to contact our staff member Leanne Conway, who is the MND Regional Advisor for Tasmania or any member of the MND Tasmania Board via the email address, website or telephone (message).

## Vale

We extend our sympathy to the family and friends of the late S. Mansfield.

## Northern Support Group

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

Meetings are held on Mondays at 11am – 1pm at the **Kings Meadows Community Health Centre, McHugh St., Kings Meadows** (Launceston).

**First meetings in 2015:** 23 February, 30 March.

Mary Erickson  
Northern Support Group Coordinator



## Donations

Donations have been received in the memory of S.Mansfield.

Thank you to all those who sent in Ice Bucket Challenge donations.

Donations have been gratefully received from people and organizations including the LEO Club of Penguin, IGA Ravenswood, M.Viney, St Helens Tucker Newsagency, Queechey High School, Fox and Hounds staff of Port Arthur, Tongs Sheet Metal, Risdon Vale School, Leighland Christian School, Huon Pony Club, Tasmania Police recruits, Glenview Home and Huon Valley Council.

## A Family's Story

*On 9 November 2013, the Lions 34th District 201T1 Convention was held in Wynyard. The invited guest speakers were Kerry and Sharon Upchurch who presented their story of living with MND. They received a standing ovation.*

*They have agreed to their story being released on the MND Tasmania website and we have published an excerpt for our newsletter readers below.*

During our early years of our marriage, Kerry and I enjoyed attending concerts and bush walking, often with family and friends. Kerry loved playing sport with my family, especially cricket and football. Often I would come after a few hours to collect him, much to my brothers' disgust!

We enjoyed travelling, often around Tasmania, but also Victoria, New South Wales and Queensland. During our holiday in Queensland in 1995 we decided it was time to start our family.

Early during 1996, Kerry started having difficulties with his fine motor skills, dropping dishes, having difficulty climbing stairs and putting on his gloves at work. We had noticed some muscle wasting in his left hand between his thumb and finger. We saw a specialist on the North West coast who did some tests on Kerry as well as his family. He had no real idea what was wrong.

By May, Simplot (his employer) referred Kerry to the Royal Melbourne Hospital's Neurological Department. Before leaving Tasmania, Kerry said to me "I probably have some muscle eating disease." I thought he was being ridiculous and it would be nothing serious. I had no idea what was to come.

Kerry spent roughly a week in hospital being poked and prodded with several tests being done. Towards the end of this stay the neurologist took us aside and gave us the life changing news, that Kerry had motor neurone disease and had only three years to live. He was only 26. One of the questions I asked was regarding children. The doctor informed us that in some cases MND is hereditary but not in Kerry's case, and to be prepared for our children to grow up without a father.

All of this news was extremely hard to process and I spent nights crying myself to sleep while Kerry was still in hospital. I had many heart-wrenching phone calls to family and friends back home.

When Kerry returned to work, Simplot decided to stop him from working there due to slippery floors, and his condition. We did fight to get him back but sadly we and his Union were not successful. This was another major blow for us. Kerry loved his job and may have been capable of working there for a few more years.

We decided to get a second opinion, so we went to see Dr Siejka in Launceston who also did several tests including CT scans, MRI, EMG and a very painful lumber puncture. Testing for MND requires a process of elimination. Dr Siejka was saddened to break the news that he also thought it was MND.

In recent years Kerry again saw a Neurologist who was visiting Launceston, Dr Simon Bower and was tested for Kennedy's Disease which is a disease that presents with similar symptoms to MND but with a more normal lifespan. The tests came back negative.

In May 1998 we were blessed with the birth of our first child Benjamin. Less than three years later we were blessed with twins Jacob and Samuel.

2001 was the beginning of many hospital trips for Kerry with numerous falls and pneumonia. I would often joke that Kerry would try to renovate our home by putting holes in walls during his falls! Some of his falls could have been so much worse such as when he fell through our glass top table. His head has been cracked open many times; calling an ambulance was becoming a regular occurrence.

A lot of pride has also had to be dealt with. For a long time Kerry did not want a disability card as he thought even though walking independently was becoming difficult, there was always someone worse off than him. So it makes me extremely angry when I see so many people who park in disabled spots in cars that do not have an actual disability card.

Having a support worker to come in for me to go out was also hard to accept. Not only for him but also for me as you are having strangers coming into your home. In time, these support workers become friends.

For a few years during times of clear deterioration, every Christmas or birthday I would think, "Is this the last one?"

In 2005 we added to our home loan a loan to go on our Australian trip to many of Kerry's dream places. This dream holiday quickly became a nightmare. From start to finish, things went bad. The worst being while at Kakadu on the eve of our wedding anniversary, Kerry took ill and had to be airlifted to Darwin Hospital with pneumonia, dehydration and malnourishment.

He was very frail and it did not look good at all. This was the closest he came to death. After a nine day stay in hospital, we continued on our holiday.

A few months later he was back in Burnie Hospital with deep vein thrombosis which he has had twice. Fortunately he has only been back to hospital once in the last eight years.

Some of the other things we have had to deal with are broken friendships. People who do not know how to speak to Kerry have avoided him. While Kerry was still driving during his early stages of speech problems, during breathalyse testing, police would often ask a lot of questions due to his slurred speech. So we had to get the Doctor to write a letter to explain.

When out in public, some people just stop and stare. Most times people are good and will offer their assistance. A lot of the public's reactions have been due to the lack of knowledge about the disease and I am often surprised when out fundraising each year for MND how many people have not heard of it.

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Often the ones that have heard of it are only because they know of someone who has it or has died from it. Due to the lack of information, people will generally speak to Kerry as if he is deaf and yell at him or speak really slow like he does not understand.

In the past the boys have asked questions about the disease and I have not answered as well as I could have. The boys are good now that they are older at helping in the house and with Kerry.

Our house has had to have many modifications done over the years. Starting with a ramp at the back entrance of our home, a disabled shower in our bathroom, and most recently an extension of a large bedroom with a lift bed, as well as a fully disabled bathroom. The new area has been brilliant with plenty of room and great access. These have mainly been done by the Lions, Apex and Rotary Service Clubs, MND, Tasmania and the Ulverstone Baptist Church. We would like to say thank you for all of your help. You have made things much more manageable.

Often we took little things for granted. MND changed that. I miss walking along, holding hands with Kerry and him being able to join the boys and I bushwalking. Saying this though, I feel very blessed. We are Christians and draw on the Lord's strength daily. Philippians 4:13 says, 'I can do all things through Christ who gives me strength.'

We often joke about things. Kerry's nickname is "Mr Bump". Each family member has a Mr Men name. I bought a shirt for Kerry with "I can do all my own stunts" on it. It's a way of coping. Kerry has been reasonably stable over the last few years and has remained fairly free from too many flus and colds. He still walks with his walking frame assisted. Kerry has now had motor neurone disease for 17 years.

We praise God that he is still here.  
November 2013

## Regional Advisor's Report

Hello everyone.

This year seems to have passed so quickly, so for the last newsletter for 2014, I would like to wish you all the very best for the festive season.

I would also like to take the opportunity to thank everyone in Tasmania who has helped and supported me during my first year as Regional Advisor.



In September, I was once again kept busy meeting with clients and health professionals in the North West, North and South regions as well as providing a presentation to hospice volunteers in Burnie. I was also fortunate to attend a workshop presented by the Tasmanian Association for Hospice and Palliative Care (TAHPC) on Advance Care Planning which was very informative.

In October I flew back down for the day to attend a forum presented by TasMedicare Local. This was another informative day and gave me a better understanding of some of the systems.

November was also a busy time spent in the North catching up with clients and health professionals.

Until next year,  
Leanne Conway  
Regional Advisor Tasmania  
Apologies - Leanne Conway

## Margaret's Aqua Group

Margaret Eldridge has raised thousands of dollars for research into MND since losing a friend to MND seven years ago. She also hosts morning teas for her Aqua Group friends who donated \$126 in exchange for an individual copy of her jingle!

As we head for Christmas 2014, we have published an extract of her Aqua Ausmas 2014 ditty for us all to enjoy!

"Christmas comes but once a year"  
And Ausmas is the same;  
But as we recreate the day,  
It's only done in name.



Oh yes, we'll eat and drink a lot,  
We'll laugh and join the chatter,  
But carols bright, I haven't heard,  
I s'pose it doesn't matter!  
This aqua group is quite unique,  
It's more than just a class;  
It has become a way of life,  
We hope will never pass.

I haven't lost a bit of weight,  
I'm still what some call chubby,  
And though I've tried I haven't found  
A tall, dark, handsome hubby!



However, this I surely know,  
I am a whole lot fitter,  
And thanks to you, my aqua friends,  
I never will be bitter!

You light my life, you cheer me up,  
You make my life worth living.  
I think I say it for us all,  
You're generous and giving!

We're here today to celebrate  
Our friendship and good feeling,  
So raise your glasses, "Here's to us"  
Please do not go home reeling!



### Correction

In the previous newsletter, I wrote that in 2015, visits to Tasmania will be every six weeks. I have since been advised that information was incorrect and visits will remain every eight weeks.

Leanne Conway, Regional Advisor