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Lady Sallie Ferrall



People who have a long association with MND in Tasmania were saddened to hear of the death of the Patron of MND Tasmania, Lady Sallie Ferrall, on September 10. Lady Ferrall was an active Patron of the Association, hosting the memorable annual Christmas Parties in her gardens at Quamby and Elphin House until recent years.

Her proactive support for people living with MND in Tasmania started over 30 years ago when her first husband, John Barnett, had 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.

After the incorporation of The MND Association of Tasmania on December 9 1986, Sallie was the Fundraising and Publicity Officer on the 11 member Committee. Another memorable milestone occurred on March 17 1996 when one of Sallie and John's four sons, Guy, was elected President of The MND Association of Tasmania.

We are very thankful for Lady Ferrall and her vibrant personality, passion and drive which resulted in the birth, growth and development of an organisation to support people and their families living with MND in Tasmania. Our sympathy is with her sons and their families at this time.

#EveryAugustUntilACure

This time last year we were caught up in the frenzy of the inaugural ALS/MND Ice Bucket Challenge.

We were amazed at the outpouring of support from footballers and all the other Ice Bucket Challenge participants which resulted in a boost of funds into MND Tasmania and a huge injection of capital into MNDRIA, Australia's dedicated MND research body.

The Ice Bucket Challenge was initiated by Pete Frates and Pat Quinn who were living with ALS/MND in the USA. When accepting a Webby Award, Pat used his five-word speech to

make a special announcement:

"Every August until a cure" before launching the Ice Bucket Challenge in 2015.

Tasmanians were on the ball, kicking off with an Ice Bucket Challenge on July 29. Jackie Chugg wrote about it on the MND Tasmania Facebook page as follows -

It was a bitterly cold winter's night in Tasmania's Derwent valley. A large group of people stood bare



foot on concrete, outside the church hall. Skimpily clad bodies jiggled around desperately trying to fight the chill that filled the air. Nervous voices mumbled to one another, what on earth had they gotten themselves into? It was too late to back out now and besides, I was there, waiting, watching and they wouldn't let me down.

The icy water spilled out over their bodies, making them shriek and jump around, the ice water pooled on the ground, saturating every part of them and coming to rest around their bare feet. I watched on, feelings of excitement, awe, pride, jealousy and hope washed over me. It had been a whirlwind of a week. The Ice Bucket Challenge had sent the media into a spin. It seemed that Motor Neurone Disease was in the forefront of everyone's mind.

I helped create the MND Tasmania Facebook page to keep up with the new found enthusiasm for Ice Bucket Challenge videos and information. Suddenly the fact that I use my eyes to control the computer was insignificant.

I'm a part of a silent group of MND sufferers, each one of us doing whatever we can, whenever we can for as long as we are able.

How has the Ice Bucket Challenge affected me? It's changed my world. I used to feel forgotten, living on a small island at the bottom of the world can make you feel isolated. I wished I had a voice so I could say "hey listen up, this disease is so unbelievably cruel, why is nothing being done, why are they just letting us die?" The National Health and Medical Research Council allocated only \$2 million of a \$420 million pool into Motor Neurone Disease this year.

I am slowly becoming weaker, my prognosis hasn't changed, and there is still no cure for what is described as "the most incapacitating disease of our species." So I will never give up, please don't give up on MND. Without continued community support we won't find a cure.

I nominate those who have read this, who have not taken the challenge before to do so. [#EveryAugustUntilACure](#)

Memorial Cricket Match

The ACL Cricket Club will be holding their annual Memorial Match and Fundraiser on Saturday October 10 at the Mowbray Cricket Club off Brooks Road, Mowbray University Campus, Mowbray. The game starts at 12 noon.

Come along, support the teams and their fundraising by buying a BBQ lunch and MND merchandise! The two teams will be Skeggs in memory of Leon Skeggs (road trauma) and Crash in memory of Brendan Barry (MND).

It is an honour to be invited yet again by this Club to who have held this event for over five years.



Bach & Vivaldi in New Norfolk



Did you know that the oldest church in Tasmania is St Matthew's Church in New Norfolk? The address provides a clue to its era – it is in Bathurst St. opposite Arthur Square – and it was built in 1823. However, it is not the same church which was built on the site in 1823. All that is left of the original church are the walls and flagged floor of the nave and part of the western transept. The most striking feature of the interior are the beautiful stained glass windows.

This setting was just perfect for a concert to raise funds for MND Tasmania on Sunday August 16.

Over 100 people enjoyed an hour of listening to music from the great Baroque composers, J.S.Bach and

A.Vivaldi. The St Matthew's Singers with the visiting Jubilate Singers from Sydney were accompanied by an eight-piece orchestra from the TSO. The musicians donated their time to enable this concert to take place. Just wonderful!

Northern Support Group

All long-standing and newer members and supporters are very welcome to join these monthly meetings which have been running for over 30 years.

Following its refurbishment, the Ravenswood Community Health Centre has excellent accessible and modern facilities and parking.

Meetings are held on the **last Monday of each month** at 11am – 1pm at the Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood (Launceston).

Meetings in 2015 – Monday, October 26.

The annual Christmas Party is planned for Sunday November 22.

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

Southern Support Group

Although there has been an MND Support Group meeting regularly in Launceston for 30 years, there have not been regular support meetings in the South since 2001.

We have therefore decided to commence a schedule of meetings on the last Friday of the month with more to follow if members and supporters are interested. The first one was held on September 25.

WHEN: Friday October 30 : 12.30pm – 2pm.

WHERE: Lindisfarne Community Activities Centre

37A Lincoln St., Lindisfarne (bottom side ramp entrance). We would love to see you there!

Regional Advisor's Report

Hello everyone, I started in my role as Regional Advisor for MND Tasmania in late July, with a whirlwind tour around the state with Leanne Conway, outgoing Regional Advisor, as an introduction to the association and its work. We even copped some considerable snow as we drove to the North West so it was a great send off for Leanne! Leanne has done an exemplary job as a "fly in fly out worker", covering lots of ground in her regular visits to the state. It will be a little easier for me to get around, with my home base being Launceston, and having worked in all regions of the state in other positions.

By way of introduction, I started as a nurse at the Launceston General Hospital in 1984, and since that time have worked in a range of roles as a counsellor, trainer and community educator in non government and

government organisations. I have two children aged 9 and 11, and we recently returned from two years volunteering in Viet Nam. In addition to my work with MND Tasmania, I'm also currently a Health Promotion Consultant with the Department of Health and Human Services.

I am really enjoying my work with MND Tasmania so far, albeit I'm on a steep learning curve! By now, I have either spoken with many of you by phone or met you in person, and look forward to meeting those that I haven't. For those of you I haven't yet met, the same contact details apply and are listed below, so please get in touch if there's anything I can assist you with. As I work a maximum of two days per week, please be aware it may be some days until I am able to get back to you.

On the news front, I was fortunate recently to attend a national professional development event with people working with MND from around Australia and from New Zealand. This was a great way for me to get up to speed with some of the great work being done nationwide by an experienced and committed team of health professionals. More locally, a Health Professional Day with a focus on complex care for MND and Huntingtons Disease is planned for November at the Tailrace Centre in Launceston, I will be participating on a panel, and speakers include Dr Jim Howe, Neurologist and Dr Luke Smith, Clinical Neuropsychologist, both from Calvary Health Care Bethlehem in Victoria.

Hayley Tristram, Regional Advisor Tasmania

Telephone: 1800 806 632 or

Email: htristram@mnd.asn.au

East Ulverstone Football Club Charity Game

The Upchurch family were invited to the well-publicised East Ulverstone Football Club Charity Game and they sent us their report on the highlights as follows -

On the 4th of July we were honoured to be invited to the Motor Neurone Disease Charity Football Match between East Ulverstone and Rosebery-Tullah starring Brownlow medalist Tony Liberatore. Brian Dixon (former Melbourne premiership player) also took part in the fundraiser as he had lost his son 10 years ago to this terrible disease and the emotions were still very raw.

Kerry was given a guernsey to wear with Upchurch printed on it. The East Ulverstone Football Club had sold out of the special guernseys before the match began. There was a great crowd there, with a raffle in which Kerry helped to draw the winners.

Later that evening we also attended the Sports Forum where they had another raffle and an auction with interview with both Tony Liberatore and Brian Dixon. We



also got to have a chat to both of them. Other highlights were meeting a couple from Sisters Beach affected by MND and being donated a couple of nights away at Sisters Beach in the auction.

It was a big day but a fantastic effort from the East Ulverstone Football Club, raising over \$10,000 for MND Tasmania.

Statewide Christmas Party

Invitation

The Northern Support Group invites all members of MND Tasmania, friends, families and supporters to the Annual Christmas Party to be held at Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood (Launceston)

on Sunday 22 November at 11am – 2pm.

Drinks will be supplied and please bring a small plate of food to share.

Also please bring a small gift to share marked M (male), F (female) or C (child).

Best of all, SANTA will be coming along with his supply of presents!!



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 Regional Advisor for Tasmania or any member of the MND Tasmania Board via the MND Tasmania email address, website or telephone (message). The details are on the right hand column of this page of the Newsletter.

The Regional Advisor service is part of MND Victoria and Hayley is based in Launceston. She travels Statewide as required to support our members on a needs-basis. For more information, refer to the organisational summary on the back page.

Vale

We extend our sympathy to the family and friends of members who have passed away recently including Dianne Williams, Sarah Davis, Warner Waite and Terence Ashlin.

Donations

Donations have gratefully been received in memory of Dianne Williams including from the Scamander River Golf Club Inc. We have also received donations in our PO Box including from the East Ulverstone Football Club Inc. and the Kings Meadows IGA. The IGA in Ravenswood is also a regular donor.

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.

MND Tasmania News

Contributions and information for this publication may be sent to the Editor at our postal or email address. The deadline for the next issue is October 19.