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The Beginnings of



As noted in our previous Newsletter, the Patron of MND Tasmania, Lady Sallie Ferrall, passed away on September 10. Sallie's 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 including discussions with John Hughes who was the Tasmanian District Governor of Lions in 1983-1984.

At that time, MND was a National Lions project which had been initiated by Lions in Victoria. As many Tasmanians who had MND needed to travel to Melbourne for specialist diagnostic and other health services, the National Lions challenged their Tasmanian District to support the formation of an association in Tasmania to provide advocacy and support for people who were living with MND.



Nina Buscombe and Mavis Gallienne of the Motor Neurone Disease Society of Victoria (as it was known at the time) were very supportive and gave practical advice and assistance to the volunteers who were working to establish an association to support people living with MND in Tasmania.

The first public meeting to consider the formation of a society for people with MND in Tasmania was

held on October 15 1985 at Sallie's home at Quamby. The Motor Neurone Disease Association of Tasmania was subsequently incorporated on December 9 1986. His Excellency Sir Guy Green, the Governor of Tasmania, often attended meetings and his wife Lady Rosslyn Green became the Association's first Patron.

Lion John Hughes was the inaugural Chairman and Lion John Piggitt the Vice-Chairman. Geoffrey Wall who had lost his wife to MND was the Secretary and Rosemary Stobart who had attended early informal meetings at Quamby was the Treasurer. Dr MacLaine Cross was the Medical Liaison Officer. Sallie Barnett was the Fundraising and Publicity Officer and the other Committee members were Margaret Robinson, Beryl Howie, Mary Peypers, Carl Bullock and Helen Minchin.

Helen Minchin had MND and later her husband Bob Minchin became the second President of the Association, followed by Guy Barnett in 1996.

In 1985, Sallie sent the donations from John Barnett's funeral to the Motor Neurone Disease Society of Victoria and requested that they be earmarked to support people living with MND in Tasmania. Thirty years later, our small Association with its Board of volunteers, still offers services to our members, their families and their health workers due to the ongoing close and cooperative relationship with the Board of MND Victoria and their staff.



Fundraising and Building Awareness



#EveryAugustUntilACure

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.

In August 2014, the ice Bucket Challenge inspired our member Jackie Chugg to initiate and manage the MND Tasmania Facebook page.

Visit our Facebook page at <http://www.mndatas.asn.au> to keep up with Tasmanian, Australian and International news about MND and the people who are linked though MND.

Memorial Cricket Match

The ACL Cricket Club held their annual Memorial Match and Fundraiser at the Mowbray Cricket Club grounds on Saturday October 10. This event has now been held annually for over five years. The game started at midday and many supporters came along to support the teams and their fundraising by buying a BBQ lunch and MND merchandise!

The two teams were Skeggs in memory of Leon Skeggs (road trauma), and Crash in memory of Brendan Barry (MND).

Team Skeggs won the toss and batted first. The final score was Skeggs 118 with Crash at 128 winning the match.

The Examiner promoted the match and supporters included Alderman Rob Soward, Guy Barnett MHA and Debbie Crick from Road Trauma Support Tasmania.

Thank you yet again, ACL Cricket Club, for your wonderful support.



Member support

Vital statistics

During the year July 1 2014 – June 30 2015 -

- 23 people contacted MND Tasmania with a new diagnosis of MND.
- 47 members living with MND were supported by our Regional Advisor.
- Notifications were received of the death of 11 of our members who had MND.

- Leanne Conway delivered 250 hours of service in her capacity as MND Regional Advisor for Tasmania during that time.
- Leanne made 51 visits to members living with MND.
- She conducted 4 information sessions about MND for 124 health workers and volunteers in the North, South and North-west.
- 10 members received financial assistance from MND Tasmania to purchase or hire 20 items of equipment.

Equipment

Members of MND Tasmania who are living with MND are supported by the Association with donations of funds if required to assist with the purchase or loan of aids and equipment. Such items are also known as Assistive Technology and are designed to help people regain, retain and extend their independence in many ways.

The Association fills this role when items cannot be provided from other sources such as the State Government's equipment scheme in an acceptable time frame.

On many occasions MND Tasmania has been able to assist with the full purchase cost of an item. In other situations, funding may be available from a variety of sources and the Association assists with part of the cost.

In all cases, the Regional Advisor works together with the member and their health professional to ensure that the most appropriate Assistive Technology is made available as soon as it is required.

We suggest that members contact their local health professional and/or Haley Tristram our MND Regional Advisor about any equipment needs as it is not unusual for people to feel pressured into buying or hiring items which are inappropriate or only of very short-term use.

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 back page of the Newsletter.

The Regional Advisor service is part of MND Victoria and Hayley is based in Launceston. She travels State-wide 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.

Regional Advisor's Report

In the past couple of months I have had the privilege of visiting some people in their homes to talk about MND and how they are managing, and what assistance they might need, and others I have spoken to by phone. I've travelled to the far flung valleys south of Hobart, and next week head to the farther reaches of the North West. I'm really enjoying getting to know our clients and their families, and the health professionals who support them.

In thinking about my time with MND Tas so far, a couple of things stand out for me. I am struck mostly by the high levels of skills, knowledge and dedication in Tasmania's health professionals. I'm also struck by community support around MND in Tasmania and the amount of generous fundraising events and activities that are dedicated to support people living with MND. We are fortunate to have such an active Association in Tasmania to help raise awareness and build community around MND.

Just a reminder that providing information to interested groups is part of my role, so next week I will be discussing MND within a workplace, and also participating on a panel of health professionals around working with MND. This latter event in Launceston has around 125 health professionals registered to attend. So feel free to discuss group education needs with me.

As this may be the last newsletter for this year, I'd like to take the opportunity to wish you and your loved ones all the best for the upcoming holiday season.

Please do not hesitate to contact me should you need anything. I know many of you have already started to do so. My telephone number is 1800 806 632 and email is htristram@mnd.asn.au.

Northern Support Group

All long-standing and newer members and supporters are very welcome to join these monthly get-togethers.

The Ravenswood Community Health Centre has excellent accessible and modern facilities and parking.

WHEN: Meetings are held on the last Monday of each month at 11am – 1pm.

Meetings planned for 2016 – February 29, March 28.

WHERE: The Ravenswood Community Health Centre, 39 – 41 Lambert St., Ravenswood (Launceston).

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

Southern Support Group



The Southern Support Group kicked off in Lindisfarne on September 25 with nine members and supporters enjoying each others' company and a light luncheon. Donations were received in the form of the Lucky Door Prize from the Beltana Hotel and jewellery from Margaret Eldridge.

Members and supporters are welcome to join the gatherings planned for 2016.

WHEN: Last Friday of each month at 12.30pm – 2.00pm

Meetings planned for 2016 – January 29, February 26.

WHERE: Lindisfarne Community Activities Centre, 37A Lincoln St., Lindisfarne. Enter at the upper car park and park in the lower car park. Access to the building is via the door at ramp entrance at the top of the lower car park.

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

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 January 6, 2016.