

## MND NEUROLOGY CLINIC

Dr Lauren Giles, Neurologist at the Launceston General Hospital has contacted us with the following wonderful information.

2020 has been a year like no other, with COVID-19 causing much disruption and hardship for many. In my work, it's forced us to think creatively about how we deliver healthcare during a pandemic. It's not all been negative; we've seen advances in the use of technology and improved flexibility in getting things done. It's opened our eyes to gaps in our service that we could get around until suddenly we couldn't access the mainland.

For people living with MND, involvement with specialist MND services and participation in clinical trials of new therapies can be a source of optimism and hope. Until now, these co-ordinated services have not been available locally. Under the mentorship of Calvary Bethlehem Hospital in Melbourne, we are setting up a multidisciplinary MND clinic at the LGH to commence in November 2020. The clinic will provide access to medical, allied health and nursing services and will liaise with community services and care-givers. It will also provide access to multi-centre clinical drug trials currently only available on the mainland with recruitment for trials aiming to start in 2021.

The establishment of this clinic will give Tasmanians access to a comprehensive MND clinic closer to home. It will allow us to build the capacity and understanding about MND within our own health workforce to help support Tasmanians living with MND.

## NORTH WEST MND SUPPORT GROUP

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its meetings.

**WHEN:** At 11am on the first Wednesday in the month except January.

**WHERE:** Ulverstone Returned Serviceman's Club, 21 King Edward St., Ulverstone.

**CONTACT:** Junene Stephens is the secretary and can be contacted at 1800 806 632 (message) or email: info@mndatas.asn.au

It has been a tough year for everyone, no more so than Tasmanians who have MND, their families and carers. We had a spell from our meetings for a few months but are now back in full swing. We have a new President, Sandra Stanton and Treasurer, Shirley Batton. Our current Treasurer Denise is moving to warmer climes but will continue to support Shirley until then. We have had an amazing response from our collection boxes placed in various business outlets along the coast and have raised \$831.00. Thanks to those businesses. We have also received \$470.00 donated from a fashion parade event in Ulverstone. We have made the following donations:

- \$250.00 each to members of the group with MND paid twice a year in August and March.
- \$3000.00 to the Menzies Centre for research.
- \$1500.00 each to two families to assist with renovations.

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Two guest speakers have attended our meetings: Miranda Stephens spoke of mindfulness and self care and Chris Symonds, Public Officer, MND Tasmania, who has Kennedy's Disease, shared photos of his home renovations to create a more user-friendly home.

**Someone we love has MND, please help us find a cure.**

### SAVE THE DATE

**Sunday March 21 2021:**  
MND Tasmania AGM in Hobart – information on our website and Facebook (both at [www.mndatas.asn.au](http://www.mndatas.asn.au)) and members will be sent an invitation.

### BOARD

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

President: Michelle Macpherson

Vice-President and Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Chris Symonds

Ordinary Directors: Libby Cohen, Prof. Tracey Dickson, Joyce Schuringa

Ex-officio: Pam Steele-Wareham

### MND ADVISORS & NDIS SUPPORT COORDINATORS

Northern Tasmania: Emma Forsyth (Mon, Wed, Thurs): p: 0456 182 551 e: eforsthy@mnd.asn.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri): p: 0412 599 365 e: jfuller@mnd.asn.au

Team leader: Eric Kelly (Mon-Fri.): p: 0421 323 850 e: ekelly@mnd.asn.au



## NORTHERN MND SUPPORT GROUP

This is an informal coffee and catch-up style group where members come together to talk all things MND and Kennedy's Disease as well as share experiences and helpful tips.

**WHEN:** First Wednesday of every month at 11am.

**WHERE:** Selah Cafe at the Door of Hope, 50 Glen Dhu St, South Launceston.

**CONTACT:** Deb Beyer is the coordinator and can be contacted at 1800 806 632 (message) or email: info@mndatas.asn.au



## MND TASMANIA NEWS | November-December 2020

### FROM THE PRESIDENT, MICHELLE MACPHERSON

This is the final newsletter of a very different year! The social isolation has hit people who have MND extra hard in 2020 and we are thankful that our members here didn't have to suffer it for as long as many people in other states. We have been in sympathy with our fellow-travellers affected by MND, particularly in Victoria.

Fortunately, this is the first year that we have had two (instead of one) MND Advisors with increased hours of support. Little did we know how timely and significant this change would be when we planned it last year. The increased MND Advisor service is possible due to the excellent support we receive from MND Victoria with whom we have had a Memorandum of Understanding (MOU) since 2007. The MND Advisor service is part of this agreement.

The **MND Advisor service** has two parts – one is the role of MND Support Coordinator for people who are eligible to receive NDIS funding. The other is the MND Advisor for people who do not receive this funding.

Our State government also provides funding for **Neurological Nurses** who assist people who have progressive neurological conditions, including MND. There are four such nurses employed within the Tasmanian Health Service (THS) and people with

MND are eligible to receive their support. However, we believe that people with MND need more specialised support which is why each of the State MND organisations in Australia has an MND Advisor service. People with MND who live in the NT and the ACT are supported by MND NSW.

Our MND Advisor service is funded by philanthropy from MND Victoria and MND Tasmania. Last year our Board committed to increase our donation to the MND Advisor service from \$35,000 to \$60,000 per year for the next three years. Little did we know that our income from fundraising and donors would soon plummet due to a pandemic!

However, we are able to adhere to this commitment due to the **MND Tasmania Care Foundation**. This Foundation was established in 2015 following a donation of \$350,000 from the estate of the late Isyabel A. Weir of Westbury. (The meetings which led to the founding of MND Tasmania were held in Westbury in 1985 and 1986.) Additional donations have since been added to the Care Foundation with the primary objective being the sustainability of the vital MND Advisor service which we believe is the most important service our Association can currently offer our members.

We are a volunteer organisation with no funding from government. We depend on donations and fundraising. Funds raised between 1 January and



30 September 2020 amounted to \$39,744 which will not cover our 2020 expenses. Therefore we are very thankful for all those people who have donated generously in the past and for the foresight of previous board members who established the MND Care Foundation. It will enable us to continue to partially fund MND Advisor support for our members with MND into the future.

We are no doubt all planning for a different Christmas this year! Our board is also planning for an AGM with a difference on 21 March 2021. AGMs have been held in March since our Association was instituted in 1986. The Constitution has been changed a number of times since then, the most recent being 2014. This year we have utilised our time of being stuck at home to review it again and bring it up to the current standard set by the



The MND research team at the Menzies Institute for Medical Research, Hobart

## RESEARCH

After the AGM in March this year we had one unfilled vacancy on the Board which can have up to 7 members. I'm pleased to report that **Professor Tracey Dickson** has been appointed to fill this casual position.

After a successful career studying neurodegenerative diseases both in Hobart and New York, Tracey started leading her own lab at the Menzies Institute for Medical Research, a part of the University of Tasmania. This lab has become a leader in the field of investigating the cellular changes that occur in MND. Tracey has been involved in the MND community through her research and her role on the MND Australia Research Committee since 2010.

The lab is now jointly run by Tracey and Dr Catherine Blizzard with 12 people primarily focusing on understanding changes to the activity of neurones in MND. Though each person in the lab has their own project, the work they do comes together to form a body of work targeted at helping understand how MND begins and disease progression, as well as developing and trialing new interventions. It is the goal of everyone that their work contributes to finding a cure for MND.

PhD students, who are supervised in their work by

Tasmanian government and the ACNC (Australian Charities & Not-for-profits Commission). The **revised Constitution** will be presented to the members for approval at the AGM. The venue of the AGM has usually alternated between Launceston and Hobart although this year it was held in lovely Devonport. We hope to meet in **Hobart on 21 March 2021** but as we have now learned to Zoom, we plan to make it more accessible through such technology. Our members will receive notification in the mail but also keep an eye on our website or Facebook page for more information.

Thank you all for your support this year. Best wishes for a happy Christmas and please continue to stay in touch with us in the new year.

**Michelle Macpherson**, President

Tracey and Dr. Blizzard, are a vital and integral part of the lab setup, implementing the ideas at the work bench that the group conceptualises. The lab currently has three PhD students working on MND. MND Tasmania supported these students to present their work at the International ALS/MND Symposium in Perth in December 2019. This was a fantastic opportunity for them to not only share their results and get feedback from leading MND researchers, but it was also a great opportunity for them to establish their own connections in the MND community.

All three PhD students have been awarded competitive top-up scholarships from Motor Neurone Disease Research Australia (MNDRA). Any PhD student studying motor neurone disease in Australia can apply for funding from MNDRA.

Tracey is very pleased to be joining the MND Tasmania Board. *"It is a pleasure to be on the Board for MND Tasmania. I hope that my experience researching MND and being a part of the MND community in Tasmania for the past ten years can contribute to the ongoing success of MND Tasmania and improve the care for everyone in Tasmania living with MND now and in the future."*

## FUND-RAISING AND AWARENESS-BUILDING

The main fundraising activities this year were the **Walk to D'Feet MND** held in Ulverstone and the on-line **Australia-wide AM4MND** (Australia Moves for MND). Thank you to all those who organised, networked and participated in these events and also to those who have continued to donate regularly through other means such as the Longford Primary School community.

At the start of Term 3 staff and students at **Longford Primary School** learned that a long-term staff member had been diagnosed with MND. Other staff and community members also had close connections to MND and decided to fundraise for this worthy cause. In 2019 a successful Ice Bucket Challenge was held but this year there was a goal to raise over \$1,500 in two terms. It seemed like a huge task for a school of 250 students, but they had faith they could do it. The first event was a Crazy Colour Day for the first day of Spring. This was followed up with a Footy Colours Day and a "teachers cut off her long hair" with a raffle for students to make the cut. In one term the school raised over \$1000. The local Rotary Club gave a donation and one student donated the \$20 she received for making a

representative sports team. There will also be a Fun Run where students can make a gold-coin donation. Students are also going to raise funds by sponsoring teachers to complete a crazy challenge. **Longford Primary School** is confident they will exceed their target of \$1500 by the end of this year.



Crazy Colour Day Fundraising Event by Longford Primary School community

## MEMBER STORY – FLINDERS ISLAND TRIP: DALLAS AND SUSAN

**Dallas has MND. His partner Susan wrote about their experience of swimming at Kingston Beach in the July/August MND Tas Newsletter. Since then they have been able to visit Flinders Island. As they have benefitted from, and appreciate the support of the MND Advisor Service, they wanted to share the story of their visit.**

Flinders Island is a unique destination with great beaches. The trip was truly memorable. Luckily the trip happened while Dallas' son Jamie, partner Gabrielle and their six month old son Wolf were visiting Flinders and they picked up Jenny, Dallas and Susan from the airport and drove them around for the two days on Flinders.

The day after arrival was a delightful day. Jamie and Gabrielle took us to Killiecrankie Bay and being swimmers we all had a swim in this spectacular beach. The water was clear with easy visibility to the white sand beneath surrounded by rocky outcrops. The sea water was warmer than we experienced recently at Kingston Beach. (See article in MND Tasmania Newsletter July – August 2020 at [www.mndtas.asn.au](http://www.mndtas.asn.au))

The next day was a bit overcast however two of Flinders Island cafes were tested out and then we drove to Wybalenna and Lillies Beach (via a beautiful small road through a tea tree formed tunnel). The drive continued up to Walkers Lookout but unfortunately it was an overcast day so we'll have to wait until the next trip to experience the 360 degree view over Flinders Island on a clear day. A visit to a shop in Whitemark selling Flinders Island

Art saw Dallas buying a Killiecrankie diamond for his mementos from favourite beaches he has swum which made him very happy.

Flinders and Lady Baron Islands total population is around 1,000 and most people work on the land or fish, and they were wonderful. Always polite and helpful. Gabrielle got into conversation at the airport on arrival and was lent a fancy baby carrying device by a local so they could carry Wolfe while walking up to Mt. Strzelecki and around Mt. Killiecrankie National Park.

Thanks again for making the trip possible and a special thanks to Jenny Fuller (MND Advisor) who made it happen.

**Susan and Dallas**

## MND ADVISOR & SUPPORT COORDINATION SERVICES

### CLIENT NUMBERS

Currently supporting 44 registered members

- ✳ NORTH REGION TASMANIA: 16
- ✳ NORTH-WEST TASMANIA: 9
- ✳ SOUTHERN TASMANIA: 19

### 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 MND Advisors for Tasmania who are also our NDIS Coordinators of Supports. Board members may also be contacted. The contact details are on the back page. The MND Advisor service is managed on our behalf by MND Victoria with MND Advisors who travel Statewide as required to support our members on a needs-basis.

### VALE

We extend our heartfelt condolences to the family and friends of Helen Wharton, Gerald Dare, Wesley James, Stephen Newstead, Dianne Rule, Karl Schwesinger and of any other members who have recently passed away. Donations have been gratefully received in memory of Edmund Ballantyne, David Greenwood and Dianne Rule.



Jenny Fuller

Emma Forsyth

## CLIENT SURVEY REPORT

As highlighted in the September October 2020 MND Tasmania Newsletter, the Annual Quality Survey was carried out in May and was sent to all current Tasmanian clients. The Survey seeks feedback from MND Advisor and Support Co-Ordination clients to help further develop and improve services. A total of 36 surveys were sent and 19 completed which is a 53% response rate which is excellent. A summary of the results are detailed below demonstrating an overwhelmingly positive result.

**Satisfaction with Services (Advisors, Website, Information, News)** was rated between 80 – 100% as good, very good or excellent for all four service types.

**Most Valuable Aspect of Contact** received 17 positive comments.

**Least Valuable Aspect of Contact** received only 1 negative comment.

**Support Co-Ordination** 91% were happy with service and frequency of contact.

**Financial Contribution for Equipment and Home Modifications** 95% know of service and 39% have utilized service.

**Satisfaction with Vic and Tas Associations** 95% either satisfied or very satisfied.

**Complaints** 95% of respondents had not made a complaint.

**Would you Recommend MND Tas?** 72% of respondents mentioned if the need should arise they would be extremely likely to recommend MND Tasmania services.

**Areas for Improvement** include a low number of people who did not have or know if they had a Support Plan. While 78% knew of the Communication Library service, only 31% had utilized this service. There also is a variable level of use of Technology and indicates a need for increased support.

*Many thanks to everyone who completed the Survey.*