MNDNews

The newsletter of the Motor Neurone Disease Association of Tasmania



MESSAGE FROM THE PRESIDENT

Another year, another Annual General Meeting. The AGM is a great chance to reflect on our achievements and look at the opportunities to focus on in the coming year, and to provide a forum for in-depth reporting to our members. This was our first year holding the meeting online and it worked quite well. We were able to include members who otherwise would not have been able to travel, and we could easily record the presentation. This will be available on our website if you are interested – it's great, so make sure you have a look!

We were fortunate to have Anna King and Sharn Perry present to us on their areas of research and we had a fantastic Q&A afterwards. Their work is so important and it's great to have such dedicated researchers working on understanding this disease. I would like to extend a heartfelt thank you to Anna and Sharn for taking the time to spend with us on their weekend.

Our Board Member, Tracey Dickson, attended the Symposium in QLD last month which brought together researchers from across the country and people living with MND in the region. It's a great approach to bring together the academics and people with lived experience to facilitate knowledge sharing from both sides. You can read more about it in the article written by Fariha Kabir, further in this newsletter.



We have started planning the 2022 Walk to D'Feet MND, so please mark Sunday 16th October in your diaries. It is always a great event where we can connect and support each other while having a bit of fun. Keep an eye on our website around July/August to start setting up your team pages for fundraising. We are now able to do this directly on our website rather than using MyCause.

We love to hear from our members, so please don't hesitate to get in touch. Please write and share your stories, opinions, questions, or any thoughts about this newsletter. Write to me at info@mndatas.asn.au and see our contact details on the back page.

Kate Todd President

MND TASMANIA SAYS THANK YOU



Swim for Bryn

In 2020, Dr Brynley Parry was diagnosed with MND and faced a challenge that changed his career and his family's life forever. In 2021, he joined the Devonport Devils Masters Swimming Club which is helping him to continue exercising for as long as he can.

Bryn has shown himself to be a determined club swimmer and the Devils honoured their swimming buddy by creating an endurance swimming event to raise awareness and funds for MND research.

For this MND event, members of the Masters Swimming Club swam from 6:00 am to 6:00 pm in a mega-swim endurance relay on Sunday 13th March 2022. The event went live on the MND Tasmania website on 7th February and, in just 5 short weeks, \$17,817 was raised for research at the Menzies Centre in Tasmania. This was certainly more than the \$12,000 goal that was originally set.

The swimming goal was to have a swimmer in the water for the entire 12 hours, forming a continuous relay. Nineteen club members received donations to swim in this event. They had differing swims throughout the day, ranging from distances of 400m up to 5km in all the recognised swimming strokes. Most people swam freestyle, and some even swam 2.5km of breaststroke and 1.25km of butterfly. Bryn himself swam freestyle and backstroke for around 2 hours of that 12-hour relay. During the 12 hours of the relay, 70.85km were completed by the 19 participating club members.

Organiser for the event and club member, Marilyn Brack, had emailed businesses requesting donations for prizes at the event. Printed 'Swim for Bryn' t-shirts were worn when businesses were approached personally and as a means to advertise the event around the pool. Volunteers on the day were also able to wear these t-shirts.

On the day, each swimmer was able to select a reward from the prize table that displayed recognition (thanks and advertising) for the donor. There was also a BIG prize for the swimmer who raised the most funds through individual sponsorships. This went to Bryn who, besides being first into the pool at sparrow fart and last out of the pool, raised over \$6,000. He had this to say about the event:

"Thanks very much to all the swimmers and the supporters who participated. It was a very encouraging and uplifting experience. I reached my swim goal, achieving 5.3km on the day. Myf (daughter) swam alongside me the whole way and ended up swimming a total of 7km! Dave (son) swam 3km and Clare (wife) also kept us company but didn't count!"

Acknowledging Peter MacFie

Peter MacFie, a singer, songwriter and social historian, sadly passed away on 28th April 2022, succumbing to MND.

The History Societies and the Folk Music Federation wish to thank him for all his contributions to the folk scene in Tasmania and historic research over many years.

One of Peter's many projects was the research and publication of a book about the former convict fiddler Alexander Laing, based on a hand-written manuscript of tunes presented by Laing in 1863, with most of his tunes dedicated to Tasmanian people and places. Groups such as the Tasmanian Heritage Fiddle Ensemble and Van Diemen's Angels now regularly play many of these tunes.

Rob, Peter's brother, writes: "The Laing tunes are listed with notation in Peter's 'On The Fiddle' book, which is available on Pete's website (petermacfiehistorian.net.au/publications) as are other books written by Peter. Peter's social history of



Maydena forestry, 'The Newsprint', has sold very well through most Tasmanian book stores. We have also published music on Peter H MacFie Historian YouTube. It is staggering the amount of research and influence Pete has had over the years. When we packed up Dulcot Cottage in January 2020, his friend, archivist Margie Bryant, labelled 120 boxes of research papers, which Peter donated to the Tasmanian State Archives. His song 'Lean Too' is a beauty with sublime fiddle solo by Hamish Pike. You can listen to it here: www.youtube.com/watch?v=KblhseqON_0."

Jan Horton, Peter's dedicated editor, and brother Rob MacFie, will continue to publish Peter's works substantially completed prior to the onset of MND, including a wonderful childhood memoir of growing up on the Glebe, Hobart 1946-1953.

MND TASMANIA SAYS THANK YOU



The Symposium that connected MND Researchers with People living with MND!

By Fariha Kabir, PhD Candidate at the UTAS Wicking Dementia Research and Education Centre

For the first time, Australia and New Zealand MND Research Symposium 2022 took place in Brisbane, supported by Fight MND and MND Research Australia. I am very honoured to have received Research Travel Grants from MND Tasmania which gave me this golden opportunity to attend the 3-day Symposium.

The first two days were filled with scientific talks, where presenters shared their research in the MND field along with information about organisations that are devoted to improving the quality of living for people with MND. Mel Syron, whose father was diagnosed with MND, shared her personal experience and struggle throughout the journey. Furthermore, we heard about SALSA, which is working to aid in the discovery of new genes and the pathogenesis of sporadic ALS by collecting biological and clinical samples and patient information. At the end of day 1, I presented my poster titled "HDAC6 Inhibition in the TDP-43 Q331K mouse model of ALS" at the poster presentation session, which also provided opportunities to meet new people working in MND. I was honoured to receive an award from UQ Queensland

Brain Institute preclinical/discovery focussed presentation at the end of day 2 for my poster.

We received an update from not only the Australia-wide research community but also from New Zealand MND researchers. Particularly promising in the research talks was the interest in working with post-mortem tissue to understand the disease pathology more deeply, despite the challenge of working with these samples. Additionally, there were highlighted presentations on ALS pathophysiology, polytherapy, drug delivery system, clinical trials on non-invasive ventilation systems, and identifying biomarkers for MND diagnosis.

Day 3 was the most heart-touching and insightful moment of this symposium where we got to hear from Sean Dorney who has been living with MND for 5 years. He talked about how difficult his journey had been so far and how much he appreciates the work the researchers are doing. The talk from Colin Mahoney was really valuable where he gave a full overview of the MND drugs which are currently in the clinical trials pipeline worldwide. Also, there were presentations on two phone apps - MiNDAUS and Prism - which are being used to connect MND patients with their carers and health providers, managing their day-to-day appointments, health conditions, and medications.

Overall, through this symposium, I was able to hear and feel the voice of people with MND, connect with them and researchers around Australia and New Zealand, and learn about current research work in the MND field. Truly speaking, I have a new perspective now on doing my research, as someone who is eagerly seeking a cure.

Fast Launceston Bowls Club

Thank you, Jason and Drew!



Each year the East Launceston Bowls Club holds an MND fundraiser in honour of our life member Alain DeSousa, who fought MND for over 10 years.

The disease unfortunately brought an end to him playing the game he loved so much. Jason Barker and Drew Berwick organise this yearly fundraiser to cherish and remember their dear friend, while generously donating all the funds raised to MND Tas.

We are all very grateful for their efforts and the support we received from the Club over the years, and we thank them very much!

Thank you for your support!

We are grateful for the support we received from Penny Cromarty, Wendy Burbury, St John All Saints and the continued support we receive from Salters Hire and Kevin Burgess.

We have also received donations in memory of Yvonne Crane and Peter MacFie.

MND RESEARCH

New research highlights the importance of nonneuronal cells in MND

By Dr Samantha Barton

In motor neuron disease (MND), it is the nerves that send messages from the brain to muscles that die. These nerves are called motor neurons. The death of these motor neurons is what leads to symptoms like muscle weakness.

Extensive research has gone into understanding what specifically is going wrong in these motor neurons that causes them to get sick and die. Whilst many pathways of disease have been identified, research has also uncovered that other cell types in the brain and spinal cord contribute to motor neuron death; these cell types are called glia.

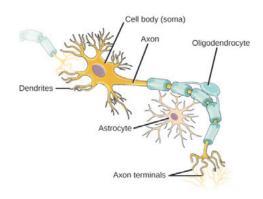
This was first discovered through research in mice. Researchers typically use mice that carry a genetic mutation known to cause MND in humans. When this genetic mutation was removed from motor neurons (meaning all cells in the mice carried the MND gene but the motor neurons were otherwise healthy), the onset of disease and the rate of its progression were improved, but the mice were not cured. This suggested that cells other than the motor neurons must be involved in the disease processes that underpin MND. Thus, our research focuses on unravelling precisely how glia contribute to dysfunction and death of motor neurons in MND.

Within our lab, the main type of glia we are interested in are called oligodendrocytes. Oligodendrocytes produce myelin, which is the insulating sheath that all motor neurons are wrapped in. If you consider a power cord for an electrical appliance – myelin is like the rubber coating around the wires, except that myelin not only insulates and conserves the electrical signal, but it can also supply the motor neuron with essential energy sources. In MND, we know the motor neurons that die are covered in myelin and we (and others) have shown that oligodendrocytes themselves are sick and harbour some of the known MND pathologies such as build-up of a protein called TDP-43. So our lab hypothesises that oligodendrocytes, and their myelin, could be dysfunctional in MND and therefore contribute to dysfunction and death of motor neurons.



Dr Samantha Barton is a senior post-doctoral researcher leading a team of scientists at the Florey Institute of Neuroscience and Mental Health which is aiming to understand the causes of MND. Dr Barton's research has received funding support from MND-RA, FightMND, CASS Foundation, BGRF, the Hayes

Foundation and NHMRC.



By CNX OpenStax [CC BY 4.0 (https://creativecommons.org/licenses/by/4.0)], via Wikimedia Commons

To find out about the role of oligodendrocytes in MND, we use a combination of model systems including mouse models, human post-mortem tissue samples and induced pluripotent stem cell (iPSC) models. We have a particular interest in using iPSC - this technique relies on us accessing a small skin biopsy from people living with MND. In the lab, we can then convert these skin cells to iPSC, which means that they are master stem cells capable of becoming any cell type. We then convert these iPSC into oligodendrocytes, motor neurons and also into three-dimensional 'mini-brain' and 'mini-spinal cord' like structures. The beauty of this technique is these cells are genetically identical to the person who donated the original skin sample so we can compare oligodendrocytes from a person living with MND to a person who does not have MND, and identify how they are different, why they are different, and how we can fix them. Indeed, through the use of iPSC, as well as using human post-mortem tissue, we have shown that myelin structure and its composition differs in people with MND, which could have a negative effect on motor neuron health and function. We hope that, through our research, we will continue to identify pathways that could be contributing to MND onset and progression, because we believe that MND treatments will be far more effective if they are able to treat the whole cellular network, including glia, as well as the motor neuron.



Sexuality and Intimacy in MND

About intimacy and sexuality

Intimacy and sexuality are important to quality of life and emotional well-being and remain important to people living with motor neurone disease (MND) and their partners, regardless of age and level of disability. For some people, sex becomes more important following diagnosis, for others it becomes less important. Close physical contact, touch and time together becomes more important as a person's condition deteriorates.

What you should know

- MND can affect intimacy and relationships but the condition itself has no direct impact on sexual function, arousal or needs.
- Having a partner who is also acting as a carer may impact relationships.
- Intimacy and sexuality may be experienced through sexual and non-sexual touch.
- Talking with a GP, MND Association Advisor, neurologist, nurse or allied health professional regarding intimacy and sexuality may be beneficial.

Impact of MND on intimacy and sexuality

Understanding how living with MND affects expression of sexuality and intimacy is an important first step in addressing problems that may arise. It may be reassuring to know that MND itself does not directly impact sensation, sexual function, arousal, fertility, or the ability to have an erection or orgasm. However, people living with MND and their partners report experiencing barriers to physical expressions of intimacy in their sexual and non-sexual relationships. Physical, emotional, psychosocial, and cognitive-behavioural features of MND, lack of social support, and use of assistive technology, may indirectly affect intimacy and sexuality. The need for partners to take on a caring role can also create barriers.

Talking about intimacy and sexuality – it's not just about sex

As MND progresses, things will continue to change, and it is important to try maintaining open communication with your partner and/or loved ones about the impact of these changes, and to seek help as required.

Research highlights the need for healthcare professionals working at MND clinics to give people living with MND and their partners the opportunity to talk about intimacy and sexuality, if they wish to, as part of the assessment process. Some professionals, however, will find it difficult to raise and talk about this subject and may instead invite the person with MND and/or their partner to telephone or email with any concerns they may have. Either approach opens the door for people with MND and/or their partner to talk about the impact of MND on their sexuality and relationships. If the subject is not raised at clinic visits, ask for help if you and/or your partner are struggling with the impact MND is having on intimacy and sexuality. Your GP, MND Association Advisor, nurse, palliative or allied health care professional will be able to talk through your concerns and refer you to the right person. Not all barriers can be overcome but it is possible, with support, to adapt and make changes to maintain intimacy.

What can help?

Depending on the stage of the disease, you may need to change how you do things to maintain intimacy and sex. It may take some time to adjust and feel comfortable with these changes, and it is therefore important to try to:

- Be open with your partner: talk about how you are both feeling and communicate what you can and can't do as the disease progresses, and what does and doesn't work for each of you.
- Be flexible: make changes to consider the physical impact of MND such as tiredness and fatigue, by having sex at a time when you are least tired or by trying massage and relaxation techniques.
- Be creative: try different sexual positions, ask your partner to take on a different or more active role, or consider using sexual aids (available online or from specialist shops).



MND may affect speech, however sex is often a time when people can express themselves without having to talk. You may already have a special way of communicating with your partner using signs and signals such as blowing a kiss, but you may need to try new ways of communicating and signalling how you feel. Whatever you try, a willingness to laugh together while you experiment can help to maintain intimacy.

Who can help?

Not everyone requires help or advice when they experience barriers to physical and sexual intimacy. It is important to be aware that some of the features of MND can be managed to minimise impact on intimacy and sexuality. Talk about any worries you may have with someone from your healthcare team who you trust and feel comfortable talking to. You can do this as a couple or separately if needed. They will be able to talk through your concerns and, if needed, refer you to the appropriate health professional.

How to bring it up with healthcare professionals?

Conversations about sex and intimacy are not always easy to initiate and can feel awkward. If your healthcare team does not start the conversation, you might like to ask:

- Can we talk about something personal?
- Do other people with MND find that...?
- Can we talk about how MND affects...?

This article has been adapted from the MND Australia factsheet 'Sexuality and Intimacy in MND'.

For more information, visit www.mndaustralia.org.au/mnd-connect/information-resources/ sexuality-and-intimacy-in-mnd (or scan the QR code on the right), contact your local MND State Association or call the MND Info Line on 1800 777 175.





Seas-ing the Day

Chris Symonds' Incredible Para Sailing Career

Chris Symonds truly epitomises the phrase "Never Give Up". An avid sailor from a young age, Chris has not let his diagnosis of Kennedy's Disease* stand in the way of his dreams. Chris is a decorated para sailor and continues to travel all over the world to compete in para sailing competitions. He is also very involved in the MND Community, having been a volunteer on the MND Tasmania Board for a number of years. Below is an interview with Chris about his career and recent success at the Para World Sailing Championships in Italy.

How long have you been sailing for?

"I started sailing when I was nine years of age when my family moved from a farm behind Wynyard to a home 200 meters from the Wynyard Yacht Club."

What inspired you to start sailing?

"I guess the river was my backyard. My parents were farmers. When the farm didn't work out, they came to town and Mum took on a teaching role while Dad worked in a grain store in town. Their friendships with other sailors inspired the whole thing to happen. There was a community project where 12 families got together and built all these boats. In the end, they drew names out of a hat to decide who would get which boat. So that was the start of the journey and the program at Wynyard, and I was part of that some 50-odd years ago, and it's continued on ever since. Sailing has been a big part of my life. I've had some pretty high-flying jobs with roles in management of big companies, international companies, but I've always viewed sailing as a place to just take you away from the world and focus on other things."

Tell me about competing in (and winning) the World Championship in Italy. What was the experience like?

"Wow! To travel in COVID lockdown, compete and win against 70 other yachts from 25 nations was very special. Although it was my third World Championship (I have previously won gold in the Netherlands and in Wisconsin, USA and have been runner up in Kiel, Germany and in Spain), this was special, as I did it with Ela, not alone. Ela is my NDIS support person, coach and respected friend. She's been supporting me for three years now and had never been involved in sailing before she met me. Her planning and preparation are second to none. She helps me with my sailing, making sure I'm all organised and planned, and together, we're a great team."

You've been named Para Sailor of the Year a few times. How does it feel to be recognised on this level?

"I have won the award in three consecutive years now. Awards and wins are nice, not only for me but my team, partners, club, local community, Tasmania, and Australia. For me, ensuring our values are of the highest standard is more important. Values are things we can control, results are not."

What has living with Kennedy's Disease taught you?

"Plan ahead for condition changes, patience, not to get frustrated, use supports and equipment to keep you safe, and a huge respect for others living with MND who have the same symptoms as KD but faster progressing."

Have you learned anything new or gained a new perspective on life?

"'Never give up' is an MND motto that is so true. Don't be afraid to ask for help when needed. Be positive, and ensure that you have positive people around you. Life is short, if you can't make a difference, move on to something else where you can make a difference."

Is there anything else you would like to say?

"I want to thank my wife, Fayellen, who is so supportive of my busy life over 40 years of marriage and raising four very special children. I also want to thank my NDIS support team who assist me to achieve amazing outcomes, not only with my sailing but giving to the community."

* Kennedy's Disease (KD) refers to Spinal and Bulbar Muscular Atrophy (SBMA) and is a rare kind of inherited disease that affects the nerve cells in the human brain. KD and MND share a lot of similar symptoms as they both cause the weakening and wasting of muscles. MND Victoria and MND Tasmania also provide support for people living with KD.

For more information on KD, visit www.mndaustralia.org.au/mnd-connect/information-resources/kennedy-s-disease or scan the QR code on the right.



UPCOMING **EVENTS**



MND Tasmania's Annual General Meeting (AGM)

The MND Tasmania AGM was successfully held online on Sunday 27th March 2022 at 10:30 am. All MND Tasmania Board members were present, as well as the Advisors and some members.

It was great to hear Kate Todd, our President, outline her views and achievements of this past year, as well as the outlook for the coming year.

Jules Driessen, our Treasurer, presented the Association's financial performance for the past year and we are happy to report that MND Tasmania continue to maintain a stable and healthy financial position.

We have not received any new nominations for Office Bearers, and therefore all of our current Office Bearers will continue in their current positions for another year.

We were honoured to have Associate Professor Anna King present at our AGM, and she kindly agreed to share with us her most recent data on 'Investigating the neurodegenerative diseases of aging', as well as the progress on Biomarker development for neurodegenerative diseases, particularly MND.

Professor Anna King is an NHMRC Boosting Dementia Research Leadership Fellow and Associate Director (Research) at the Wicking Dementia Research and Education Centre in the College of Health and Medicine. She leads an active research team in the field of neurodegenerative disease and ageing, including Alzheimer's disease, frontotemporal dementia and amyotrophic lateral sclerosis.

You can find the recording of her presentation on our website – www.mndatas.asn.au.





MND Tas Website

We hope that you have visited our new website and that you are loving it as much as we are! It not only has a fresher look and feel but it also makes your experience while using it much easier. It is an information hub for members as well as a supporter hub with specific information and resources for Health Professionals.

You can find us at www.mndatas.asn.au

Please let us know your feedback and suggestions by sending us an email at info@mndatas.asn.au

UPCOMING EVENTS



MND Support Groups

The MND Support Groups in Tasmania are independently run by community members for community members. We appreciate their willingness to devote their time and volunteer for such a worthy cause.

North West MND Support Group

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

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

WHERE: Ulverstone Returned Servicemen's Club Back Room, 21 King Edward Street, Ulverstone

CONTACT: Junene Stephens is the secretary and can be contacted on 0428 252 763 or email: istephens@berendsen.net.au

Northern MND Support Group

This is an informal 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. The group have currently ceased in-person meetings, and are instead communicating via a private Facebook group. You can request to join at www.facebook.com/

QR code on the right.

groups/337315731509176 or scan the



Drink Tea for MND

Calling upon our TEA-riffic community!
"Drink Tea for MND" is a fun (and delicious!)
way to raise awareness and funds to support
MND Tasmania.

Your DT4MND event can be held ANYTIME, ANYWHERE that suits you! You can host your tea your way, on the date of your choice. It could be a morning tea at work, a virtual afternoon tea, a luncheon - the ideas are endless!

Please register online at www.drinkteaformnd.org or scan the QR code on the right.



GIVING

Bucket List Wish Campaign Appeal

This year, our Tax Appeal is a bit different... All proceeds raised through this Appeal will fund a wish for someone living with MND through our new BUCKET LIST WISH PROGRAM.

Living with motor neurone disease is incredibly hard for those diagnosed, and for their loved ones. This new initiative and pool of funds will be able to provide experiences, gifts or services to help make a wish come true, and give families a chance to create memories they can cherish together during an incredibly difficult time.

This is where we need YOUR help. The more we raise through our 2022 Tax Appeal, the more wishes we can grant.

About the Bucket List Wish Program

The Bucket List Wish Program provides the opportunity for those diagnosed with motor neurone disease to have a wish granted. Every wish is unique – it could range from sky diving to a family weekend away, to trying a new hobby or watching your favourite football team play. There are some wishes that may not cost anything, such as meeting your favourite celebrity.

MND Bucket List Wish Program MND Tasmania has focused on care and support programs

to improve the lives of thousands of Tasmanian families impacted by MND for the last 36 years.

But there is one thing we are yet to tick off our list...

We kindly ask you to consider a donation to MND Tasmania this end-of-financial-year. Your gift will help to make a wish come true, and give families a chance to create memories which they can cherish during an incredibly difficult time.

Help us to add another layer of support to the services we have been providing since 1986.

Visit www.mndatas.asn.au/ bucketlistwish or scan the QR code on the right.





MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 47 registered members:

North West Region Tasmania	8
North Region Tasmania	20
Southern Tasmania	19
TOTAI	47





MND Tasmanian Board Members:

MND Tasmania has a volunteer Board and no paid staff.

President: Kate Todd

Senior Vice President and Fundraising: Michelle

Macpherson

Vice President & Public Officer: Chris Symonds

Secretary: Lucy Polizzi **Treasurer:** Julie Driessen

Member Support: Elisa Howlett

Ordinary Directors: Tracey Dickson, Steve Issac

Ex-officio Support: Libby Cohen

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon-Thur):

p: 0456 182 551 or e: eforsyth@mnd.org.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri):

p: 0412 599 365 or e: jfuller@mnd.org.au

Team leader: Kim Hamilton (Tue - Fri):

p: 0422 149 445 or e: khamilton@mnd.org.au

FREECALL 1800 777 175

This number is at the MND Victoria office (Monday - Friday, 9 am - 5 pm). To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or an MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.





We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands in which we live, work, and learn. We recognise and respect the enduring relationship they have with their lands and waters, and we pay our respects to Elders past, present, and emerging.

MND TASMANIA

PO Box 379, Sandy Bay, TAS 7006 Australia

Freecall: 1800 777 175

Charity ABN: 21877144292

