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MND News

Winter 2024

Magazine of the Motor Neurone Disease New Zealand Charitable Trust



Living well with MND

**“Returning to painting and photography
has given me a voice”**



Message from our Chief Executive

Kia ora koutou,

I am very pleased to let you know that I have been appointed to the permanent position of Chief Executive for MND NZ. I count this as a real leadership privilege, given the passion and quality of our MND NZ team, and I very much want to be a part of building our support for the MND community.

We are a small organisation, supporting a small community with big challenges. We do this through the support of our donors and sponsors, and we are privileged to be connected to people right across the continuum of the MND community through service, advocacy, and research.

This edition of the MND NZ magazine looks at a range of activities in the portfolio of work that we either deliver or support. There is always a lot going on, and a lot to do in keeping connected at individual, local, national and international levels.

We have been thinking a lot about the idea of living well with MND, and of having a sense of **whakahou tumanako** – a renewal of belief. Anthony Coulter, and his story of a return to art and finding his voice, is the perfect embodiment of this.

We've recently published a position statement on the trial of an **investigational drug** called tofersen (brand name Qalsody) for people with SOD1 type motor neurone disease, and here we extend that discussion and include a personal account of being involved with the trial. Organisational statements are one thing, but the view from experience is that much more informative. Our thanks to Brooke King and her husband Jimmy, who participated in the trial, for their insights.

Our Regional Support Advisor from the lower North Island, Moira, talks about her work and in doing so provides a bit of a **wider view of the impact MND has** on her clients, their families and whānau.

I also want to highlight our annual **Action Month**, taking place in June. We can only do what we do through the involvement and generosity of New Zealanders across the country, whether as individuals, groups or organisations and companies. We are all truly stronger and more effective together, and when we pool our resources. Our Action Month focuses on why we do what we do as we continue to seek your support to not only continue the 'doing', but to enhance and improve our work with and on behalf of the MND community.

Finally, we acknowledge that over the past few months there have been some staff and service gaps that have caused concern to us and to the MND community. Our core reason for being is to provide service and support to the MND community, and we would like to assure you that we are working to rectify these and **build our capacity and capabilities**.

Thank you for being with us.

Ngā mihi nui

Mark Leggett

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Cover: Anthony Coulter, who in this issue shares how he's returned to painting and photography as he navigates through the challenges of MND.

A special thank you

Our heartfelt appreciation goes out to the below for their kind support in making the MND News Winter 2024 issue a reality.

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Charitable Trust

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If you're moving, please let us know your new address so that you don't miss the next issue of MND News.

Disclaimer

This magazine provides information only. Content should not be taken as a recommendation for any individual, or as an endorsement by MND NZ. We strongly advise you discuss options with those who know you best before making any changes to your routines.

This winter, we are inspired by:

Kiwi cyclists **Craig Luxton, James Wilkins, and Gerald Patterson** (pictured) who are taking part in the 5150km Ride USA and fundraising for MND research and support.



Sam Stuchbury, who shared with us his story of finding laughter and joy in the darkest places after his dad's diagnosis of MND: "he faced this brutal disease with such kindness, strength and humour that it's a story worth telling". If you haven't read it yet, head on over to our Instagram @mnd_nz



Jonny Beardmore, who has thrown in his day job and became the Galapagos Postman for 2024. His challenge is to hand deliver 50 letters to strangers around the world to raise awareness and funds for MND. Follow Jonny's adventures on Instagram @bigoadventures



Moira's stories from the frontline

MND NZ Support Advisor Moira Young on expecting the unexpected and finding hope and humour among the challenges

If I were to write a Support Advisor job description, it would start by stating "Expect the unexpected". I've worked part-time for MND NZ for 12 years and cover the lower North Island from Whanganui/South, to Wellington. I have a home office like all other MND NZ Support Advisors, so I don't have traffic to navigate, public transport woes and/or I don't get wet on my way to work... bliss!

My part-time week usually has a structure of home and work-site visits, health meetings, delivering presentations, and office time to work on tasks such as phone calls, referrals, and advocacy. This sounds very orderly, doesn't it? But regularly the reality is to expect the unexpected. In my time, the "unexpected" has and continues to challenge me, expand my knowledge and experiences with those who I support and provide some humour and touching moments to all involved.

Here are a few of the unexpected highlights of recent times.



Neurons that really can motor

A client and his wife emailed me on their return from a holiday in Melbourne. The subject line read "An interesting discovery on our Melbourne trip." I was expecting a couple of lovely wildlife holiday photos...but not so! I read, that they had discovered by chance, that if one was to part with a relatively small amount of money, it was possible to obtain the use of neurons that really could motor! Alas, I thought, what was this incredible break-through in science as I opened the email attachment picture. Not quite what I was expecting to see but in tongue and cheek fashion, these battery powered street scooters for hire made a good story and like most breakthroughs come when we least expect them to, this one delivered hope and humour to us! Thank you, R & M.

A client asked for my thoughts on nominating her Hospice volunteer for "The Good Sorts" award (TV One with Hayden Jones). We decided we would work together and see where it led to. Well...it led to numerous Zoom calls with my client to compose her application followed by months of secrecy and at times, having to tell "fibs" to others while we waited to hear if she had been successful. My phone rang one morning, and it was Hayden to deliver the good news that my client had pulled-it-off and her application had been successful. After my client gained permission for filming to be done at her rest home, weeks of more secrecy and

"fibs" were needed as we waited for the film date to arrive... we were ready to burst by then. The film event went without a hitch and captured my client and her Hospice volunteer using the partner-assist controlled Power Chair on another great escape/outing and time off from the challenges of MND. Thank you, J & A.

While visiting a client who resides in hospital level care, his sister was having difficulty with administering eye drops and wasn't confident to recline her brother's power chair to get good access to his eyes. With much humour as the eyes drops dribbled down his cheeks, she asked me to "have a go". I got permission from my client to recline his power chair and within a minute, the drops were in his eyes and relief was felt. The sister and I righted the chair. All was good so we thought, until the chair wouldn't move forward and no amount of fiddling with the hand control worked. Worried that his sister and I had broken his chair, we got down on hands and knees like wheelchair technicians and desperately looked to find a solution. Meanwhile this brought great delight to my client who was laughing at us. Finally, the discovery of a loose plug gave us hope that we'd found the issue...with bated breath, it was plugged in and voilã, to our relief the chair's controls for movement were restored. I was wondering how I would have explained this to the local Occupational Therapist had we not got it working. Thank you, R & G.



Moira, her client, and the power chair

A few years ago, I gave a ride to my client so he could attend a small gathering of clients over a cuppa. He needed help with transferring in and out of the car and he used a small manual wheelchair for energy conservation. On our return to his rest home, I got his wheelchair out of the car, placed it by his passenger door and helped him transfer. I was thinking, we've almost "nailed it" with a successful and fun trip out. So, with him and I standing in an embrace while doing the transfer, he tells me he's "stuck" and his legs won't move. We moved closer together for support and safety, like a dance couple entwined together as one, waiting for the music to begin. He began to sway to try and activate his legs, and as his dance partner I swayed with him, and we both began a nervous laugh which hid the internal scream of "help- someone...please". I don't know how long we were dancing but finally a staff member came to our rescue and gave us a telling-off. My client waved me off with smiles as he was hurriedly wheeled inside. Later I received a wonderful text from the client, thanking me for a great time out and the best dance he's had in a very long time. Thank you, B.



The Gorgeous Gang at Gorge Café, Otaki

A few of us met for a chat over a cuppa, scones and pies. As we know, things are never as straight forward as we would like them to be with MND. But with determination, excellent navigation skills and coping with an unexpected event, we managed to get together. From care delays and getting ready, being discharged from hospital that morning after an unexpected overnight stay and no sleep, taking time out from preparing to travel overseas and driving the easier route rather than the winding road route, were no deterrents for this group! A big thanks to Maria for her excellent navigation skills to me to take the correct off ramp along the new Otaki expressway road. Had we missed this, we joked that we'd just travel on for a further three hours to Taupo for lunch like in the movie *Thelma and Louise* and message the group to join us there. Thank you, M, B, N&H, M&A, T&P and R&M.

While these stories are fun to share, there are many more people and experiences which I hold dear to my heart. No words can ever express fully my admiration to you, my clients, and your partners and whānau for your courage, determination, dedication, problem-solving approach, resilience, humour, and you're your unlimited source of love for your loved ones! Thank you everyone, both past and present! You are remembered and continue to make a difference.

I would like to acknowledge and say thank you to the various health teams and Neurology departments in my area for your responsive care and tailored

health care, not only to my clients and their whanau but to also me. It has been/is a privilege to work with you as a bigger team, experience your patience and action focused approach when I've needed you, and by the way...I'm very happy to continue to provide feedback for your work appraisals, so keep them coming.

So, if you've used my service a lot, that's awesome! If you're reading this piece and it encourages you to get in touch, right now, that's awesome too! We can see what's going on for you and just take it from there, because often the unexpected, can be very rewarding, when we do it together.

Here for you



Our charity was built on the ethos of helping people affected by MND – it's the cornerstone of all that we do.

If you or a loved one has MND, we're here for you. Our team of compassionate regional support advisors provide free, personalised support and advocacy to people with MND and their loved ones.

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MND ACTION MONTH

In June 2024, as part of international awareness month, MND NZ will again launch its annual fundraising campaign to encourage more people to help making time count for people living with motor neurone disease (MND) and their loved ones.

When raising awareness about tough diseases, there's no denying that conversation and connection go a long way.

This June, we are delighted to have partnered with Bunnings, who will be taking part in a nationwide sausage sizzle across all 40 stores as part of MND Action Month.

Saturday, 15 June 2024
9am – 3pm
Your local Bunnings store

Bunnings team members will be behind the BBQs, but we are also on the lookout for volunteers to help take donations and be the point of information about the realities of MND and why raising funds is so important.

If you can help, please contact Rob Bloch at rob.bloch@mnd.org.nz

Recognising the power of kōrero, Motor Neurone Disease NZ is highlighting the disease, and again launching our fundraising initiatives: **Cuppa Tea for MND** and the iconic **MND Ice Bucket Challenge** to encourage Kiwis to shine a light on MND by fundraising and raising awareness of the disease and all its challenges.

We caught up with two of last year's organisers and put some questions to them about what's involved.



Great fun for a great cause: Tira and the Ice Bucket Challenge

The team at Tira (formerly known as NDA) lost a great friend and colleague to MND in 2022. "He worked alongside of us for as long as he possibly could, even though he was non-verbal and physically deteriorating. We were with him right to the end and witnessed the devastating effect this disease had on him, his family and friends. A truly bright and witty mind whose body was failing around it, his strength of character was in finding humour in the bad bits and to laugh and cry with us at the worst. The frustration, especially for him on losing ways to communicate with family and friends, and the helplessness on our part when we could not understand what he was trying to communicate. Our friend truly brought this disease to the forefront for all of us at Tira, and it is something we will never forget" recalls Jason Aitken, from the Health and Safety team.

The Ice Bucket challenge was identified as a way for Tira to reflect its company value of 'Caring' and raise funds to help support others going through this horrible disease, raise awareness of MND, and for future medical insights into this disease.



The Challenge was run by the Health and Safety team, and the planning process ran smoothly – a group page was set up for donations and everyone across the six Tira sites across the country were keen to be involved. Dates were selected, and staff were encouraged to nominate colleagues to have a bucket of ice water dumped over their head for a \$10 donation. The nominees were encouraged to dress as their favourite childhood sports person or superhero.

“We could not believe the number of staff who wanted to be involved and the fun we had while raising money for this cause. Timaru workshop had the most innovative iced water emptying system, where their workshop made ‘throw a ball at the metal plate’, and when it hit – you got wet” says Jason.

The Tira team will continue to support the Ice Bucket Challenge every 2nd year (they have other charities they like to support) in memory of their colleague, and in support of others affected with MND. “This has affected all of us that worked closely with our friend. Enjoy life and have fun, treat people and family with love, respect and kindness, as you never know what is around the corner in the future”.

The team does have one piece of advice: “we have learnt to specify the rules beforehand on the tipping time and the sizes of the buckets used – for the preservation of the volunteers!! Hopefully if the workshops get inventive with new tipping devices, then it will no longer be a problem!” laughs Jason.



MND ACTION MONTH Cuppa Tea For MND

Laura's Cuppa Tea for Richard

Laura Berry's father-in-law Richard lost his life to MND in 2010 at the age of 55. "I feel lucky that I got to know him, but I'm sad that he didn't get a chance to meet any of his grandchildren who have since been born" says Laura. Originally from a small South Westland community, she is no stranger to MND and knows several people who are either living with or have passed away from this brutal disease.

Laura was inspired to host Cuppa Tea for MND as a way of getting Richard's family and friends together for a catch up, and an opportunity to reminisce. "I was just hoping to provide a relaxed and loving place for families to get together to remember Richard. We had a lovely event with our family and friends. It was so nice to see everyone come together. I also asked family to bring photos of Richard, which was really nice to see and talk about him with happy memories".

She kept the event low key, and fundraising through the MND website. "I would love to make this an

annual thing, to continue to raise awareness and to make time to get together and remember Richard and others affected by this horrible disease" says Laura.

Her advice to anyone considering hosting Cuppa Tea for MND is to just do it! "Loved ones will step up, especially if they know it is important to you. And don't forget to take photos!"

Ways to get involved this June

Cuppa Tea for MND

Host a morning or afternoon tea for your family, friends, workplace, club, or school and ask for a donation to support MND research and support. If you're a business, offer a tea and cake bundle with proceeds supporting the cause.

MND Ice Bucket Challenge

Nominate a willing chief executive, principal, or other group leader to have a bucket of ice water tipped over once you've reached a fundraising target. Another way is to recruit a selection of willing staff or group members and ask for a donation per vote. The person with most votes receives the soaking!

To sign up or find out more visit www.mndactionmonth.org.nz.





Living well with MND

Returning to painting and photography has given me a voice

Anthony Coulter has been drawing and painting for as long as he can remember. "Through my school years I excelled in art and managed to receive a Scholarship to attend art school in Christchurch. However, it is very difficult to make a living as a painter, so I extended my skills to photography and worked as a photojournalist. This led to some travel overseas. On returning to New Zealand in the early 1980s I worked as a graphic designer and photographer in the commercial world. This provided an income, but I was never completely satisfied with the commercial fields. In the 1990s I started my own design and photo business with my wife until about 2008" he recalls.

After a major departure from the art field and a career in the addiction and mental health sector, he has returned to painting and photography as he

navigates his way through the challenges of MND. "I find that returning to painting and photography has given me a voice and perhaps a way to say something about who I am. It is more about me finding a way to express positivity and relevancy into my day" says Anthony.

"I have a strong Christian faith which helps me in those dark times. I believe that through overcoming

It is more about me finding a way to express positivity and relevancy into my day.

struggles that we find the strength to carry on and try to give others hope despite any handicaps we have. To look at what we can do rather than what we cannot".



Leading up to his diagnosis, Anthony had experienced some weakening in his legs and arms but nothing significant. "I was able to do most things that I enjoyed, like gardening and walking. I had been a club runner and was very competitive, and enjoyed tramping and climbing, although I had stopped any competitive activities preferring to just enjoy the walk with a camera. When I retired, I was looking forward to keeping active with tramping and combining my photography and painting. I thought, after all I am reasonably fit, don't smoke, don't drink, and have no illness. The time is mine to enjoy" says Anthony.

After a trip to Wellington in September 2022, he developed

foot drop. What followed was a long road of specialist referrals and tests before a diagnosis of MND almost a year later in August 2023. The next few months were almost overwhelming, as Anthony learned about the disease and connected with various support services and organisations. "One of the best things I did was to attend the Christchurch support group which my wife and I both attend. This helps with others talking about their lived experiences and how they have overcome adversities. This also serves as positive feedback and celebration of enduring strength and hope by people who have this condition and their supporting families and loved ones" says Anthony.

Anthony and his wife live in a Tiny House, and so were confronted with many obstacles to make their home MND friendly. "I am grateful that I can still paint and take photos as it helps me to appreciate the beautiful world around and express myself through my art. I keep an interest in the world around and try to bring help to others where I can even if it is just a positive attitude. There are some black days where the reality hits and I am not able to take the top off a tube of paint or I need to rely on someone else to do a task that I use to do without thinking. These days I try to accept my limitations and let go. I also talk to people and let them know where I am at. I am fortunate that I have a team of understanding people around me and I try to lower my expectations" reflects Anthony.

"I decided not to waste my time trying to figure it all out and accepted my condition and looked for the things I can have some control of. In

There are some black days where the reality hits and I am not able to take the top off a tube of paint or I need to rely on someone else to do a task that I use to do without thinking. These days I try to accept my limitations and let go.

reality it is like a mourning period, and I needed time to reset my life. Sharing with close friends was helpful and prevented me from isolating. I wake up with this condition and go to bed with it and [there are] little reminders every day that things will never be the same again. In a way I am learning to make friends with my failing body knowing that my mind is as sharp and agile as it ever was. It's like you have got me physically but not mentally".



Spotlight on: SOD1 type MND

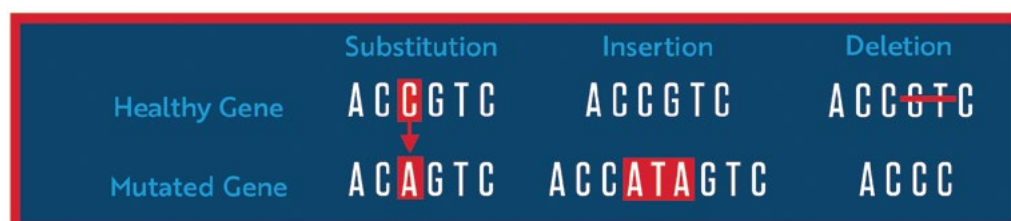
When describing motor neurone disease (MND), a distinction is usually made on whether it is sporadic (appears to occur without a family link) or inherited/familial (where there is a family history of MND or frontotemporal dementia). Research suggests that about one in ten people with sporadic MND, and about two out of three with inherited MND have a mutation in at least one of the more than 40 genes linked to the disease. Some of these genes include *SOD1*, *C9orf72*, *TARDBP*, *FUS* and *ATXN2*.

The *SOD1* gene mutations were discovered in 1993, and account for about 15–30% of familial and 2% of sporadic MND cases in people of European descent. In people of Asian descent, *SOD1* gene mutations are the most common genetic cause of Amyotrophic Lateral Sclerosis (ALS) – the most common form of MND. Overall *SOD1* mutations happen in about 2% of ALS cases.

Genes and Gene Mutations

Genes are found in every single cell in the human body. Each cell contains a nucleus, which houses chromosomes that are made of DNA – the molecules that contain genetic information called genes.

Genes contain instructions for making proteins that cells need to function and remain healthy. A mutation changes the instructions for making a specific protein, so that when a cell needs to make this protein, genetic errors are copied from the DNA into RNA during a process called transcription.



Genetics: Illustration courtesy of the ALS Association.

The RNA then works as a messenger, taking the instructions from the nucleus to the protein making cell structures called ribosomes. As the instructions have now been changed by the mutation, it changes the protein that is produced.

The *SOD1* gene contains instructions for creating a protein called superoxide dismutase type 1 (*SOD1*), which helps to clear out toxins that are normally produced in the brain. When this gene is mutated, a toxic *SOD1* protein is created instead. This abnormal protein not only fails to do its normal job of clearing toxins, but also clumps together. It is these clumps, known as aggregates, that damage the neurons, leading to the development of ALS.

Gene Therapy for MND

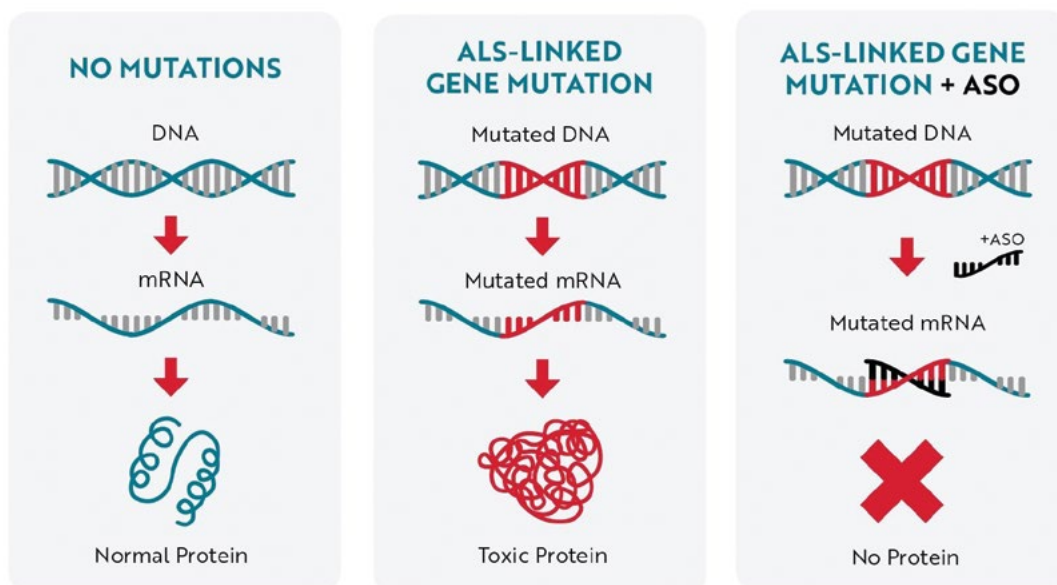
The discovery of MND-linked genetic mutations has paved the way for the development of gene therapies, which are designed to eliminate, block or reduce the toxic proteins and their aggregates. They do this by targeting the genes themselves (DNA), the messenger RNA (mRNA), or the toxic proteins.

The majority of therapies being tested to treat MND caused by genetic mutations target the mutated mRNA, instructing the cells to destroy the mRNA before it can be turned into toxic proteins.

One treatment targeting this goal is antisense therapy, which uses short DNA-like molecules, antisense oligonucleotides, to bind to RNA produced from mutated *SOD1* genes and stop the production of toxic proteins.

Tofersen and *SOD1* MND

Tofersen (brand name Qalsody), is a drug developed by the company Biogen to treat MND caused by a mutation in the *SOD1* gene. It works by targeting the *SOD1* RNA to reduce the amount of *SOD1* protein being made. It is only effective in *SOD1*-type ALS and cannot be used in



Tofersen: Illustration courtesy of the ALS Association.

other types of MND. The medication is given once a month via injection into the spinal fluid.

The VALOR trial included 108 adults with SOD1 ALS who were treated with either tofersen or a sham drug (placebo) for ~6 months. The trial showed that tofersen reduced SOD1 protein levels in the spinal fluid and a marker of neurone damage (neurofilament light) in the bloodstream. However, the primary goal of the trial was to test if tofersen slowed the rate of disease progression, and while some benefit was seen, it was not enough to be certain.

After the first 6 months, everyone in this study could choose to have tofersen, with people who had been on placebo now starting tofersen. At the 12 month point, people treated with tofersen since the start (for 12 months) had better function than those who had been on placebo first then changed to tofersen for six months. This time it was significant. It has been suggested that earlier treatment, even before symptoms begin, may provide more benefit and there is another trial, called the ATLAS trial, underway to test that. This trial is predicted to be completed in 2027.

Tofersen was granted accelerated conditional approval by the Food & Drug Administration (FDA) in the United States in April 2023, and Biogen has announced an early access program that eligible patients (diagnosed with MND caused by a SOD1 gene mutation) can apply to. In late February 2024, the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) has recommended approval be granted for marketing under exceptional circumstances.

What does this mean for New Zealanders with MND?

- Most people with MND **do not have** SOD1 ALS. These people will get no benefit from tofersen and will not be able to access it.
- Some people in New Zealand with SOD1 ALS are receiving tofersen – through the trial or compassionate use.
- We understand that people with SOD1 mutation causing ALS in New Zealand could be eligible for compassionate use of tofersen.

We do not know exactly how many New Zealanders with the ALS form of MND have the SOD1 gene mutation, but it might be up to 2% of ALS cases. Some of these may not know they have the SOD1 mutation because there has not been a known family link and they have not had genetic testing. There are pros and cons for doing genetic testing, and this can be discussed with your neurologist or GP.

Testing for this gene may be requested by neurologists or patients may pay to be tested in private. However, tofersen can only be used in known SOD1 ALS, and may not be suitable for everyone so should be discussed with your neurologist or another medical professional.

‘Proving to be working’ – tofersen a game-changer

Jimmy King was just 30 years old when he first noticed that walking felt uneasy. Putting it down to a rugby injury, he had a physio check it out. A barrage of tests and specialist appointments followed, and Jimmy was diagnosed with SOD1 type MND in January 2018.

Jimmy’s wife Brooke threw herself into learning everything she could about the disease, and searched everywhere for a drug trial that Jimmy might join. “Being a stay-at-home mum at the time I was able to research more into this disease. I found a Facebook group where I was able to ask if there were any drug trials for MND. A lady

from Australia reached out to me as her husband had a slower version of MND and he was travelling to Japan to receive other remedies. She then told me about tofersen, which back then had no name, just a number, and that it was proving to be working” recalls Brooke.





She started reaching out to research centres, and eventually Jimmy was offered a place on the tofersen trial based in Canada. In June 2019, with two young children in tow, Brooke and Jimmy relocated to Montreal for six months.

Initially Jim had three doses of tofersen administered via lumbar puncture two weeks apart, followed by one dose every four weeks. The first few doses were difficult, with spinal leaks and headaches that left him in bed for a week but with a different lumbar puncture technique, he soon only needed a day's rest afterwards.



The family flew back to New Zealand in December, just before Christmas 2019. Jim continued travelling to Canada every four weeks, until the start of the COVID 19 pandemic. A year into the pandemic, Biogen arranged a location here in New Zealand for Jimmy to continue to participate in the trial.

"Since getting back on this drug trial, Jim is still walking and has started his own contracting businesses with heavy machinery as well as some diesel mechanic work on the side. He still has very minimal muscle in his legs and is aided with splints that he wears everywhere. While life isn't where we were before tofersen it really has given Jim a

more promising outlook on life as he also refuses to sit down. Not to mention he can still have his independence and hang out with his kids and family. While he cannot race and ride a two-wheeler motorbike anymore, he still gets out most weekend with his friends on his four-wheeler" says Brooke.

"I am in awe of Jim every day, he is a great father and friend to many and his determination to not sit down blows my mind. Some nights he has more energy than I do. Considering over four years ago he thought he would be in a wheelchair, I believe whole heartedly that without tofersen he would not be here today".

Thank you

Motor Neurone Disease NZ is the only charity focused on improving quality of life, funding research and campaigning for people affected by motor neurone disease (MND) in New Zealand but relies on donations to do so.

Your donation, big or small, will help grow the support, information, and advocacy for those affected by MND today, as well as funding research for a brighter future.

Ways to support

Online

You can donate via our website at www.mnd.org.nz/donate

Or simply scan this QR code with your phone to go directly to the donation page.



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