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MS Waikato Trust supports people affected with Multiple Sclerosis and Huntington's Disease; MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

MS Waikato

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ManuScript is brought to you by:



NZ Surf Champion Philip Burbage



In 2022 I was diagnosed with MS at the age of 58.

The diagnosis took some time as initially I was diagnosed with a stroke.

My neurologist checked my MRI and said I've had it for quite a while. We talked about possible previous attacks and issues with surfing came up. I'm a keen surfer, however balance and fatigue impacted on my surfing, and I am now riding a longer board because it is more stable and easier to balance.

Around the time of my diagnosis, I had been booked on a lifelong dream surf trip with my closest friends. I had to cancel it due to the hot climate affecting my MS, this was a great disappointment as I loved surfing.



I connected with MS Waikato and was provided support and information, and life resumed as I settled into the new diagnosis and got used to living with MS.

Understanding good lifestyle changes and beginning on medication meant that I have continued to work full time, travelled overseas and enjoyed surfing again.

I noticed that the New Zealand Surfing Association had an adaptive surfing division and asked if I met the criteria, to my great excitement I did! With support from Ben Kennings of the NZ Surfing Association, I was able to enter. This meant that I was going to go to the National Surfing Competition in Taranaki this summer. Surfing regularly with my mates over summer, I didn't miss an opportunity to remind them I would be taking part in the competition, and that they had to let me get every better wave! On the 13th of January I became the New Zealand Adaptive Surf Champion.

To others with MS I would say, if you have a favourite pastime, just keep doing it as it will put a smile on your face. Good luck 😊

Philip Burbage

Client Survey and Future of MS Waikato

In September we sent out a client survey, this was completed by 40% of recipients. The information we received back is essential in ensuring we are providing the services and support that is important to you all.

For both client groups, phone calls from the Client Services Staff were valued most highly, this was closely followed by Face to Face contact, emails and the newsletter. We appreciate you taking the time to complete the survey and the comments we received with it.

A number of people indicated in the survey that they would be interested in receiving more information on the sustainability of services. We wanted to share with you all options in which you or your loved ones may be able to help support MS Waikato too.

Fundraising

Without fundraising, we wouldn't be able to maintain our level of services to you. Each year we organize a golf tournament and stalls during awareness week. Over the past few years, we have been fortunate to have had support from some amazing individuals organizing fundraisers to support us too. This included the Kawhia Cruise, a garage sale, a donation in lieu of birthday presents, sale of marmalade, quiz night, hypnotist show, bike ride and Kakepuku 10 challenge.

The need to fundraise is ongoing each year, perhaps you or your family/friends may consider doing something this year or have a great suggestion for us. We would love to hear from you if you do, even small fundraisers help, please contact janet@mswaikato.org.nz.

The Michael Ford Golf Tournament is taking place this year on Friday 14th March at Ngahinepouri golf club. It is a Stableford tournament, playing 18 holes. We are currently seeking individuals or businesses who may be interested in sponsoring the event, there are a variety of sponsorship options. Again, please contact Janet – janet@mswaikato.org.nz for further information.

Making a donation

Donating is a wonderful way to consider supporting MS Waikato. As a registered charity MS Waikato doesn't pay tax on any donations received.

A donation can be any amount that you would like to donate and paid at a time that works for you.

You may wish to consider setting up a regular donation, perhaps \$5 or \$10 when you receive each salary payment. A \$5 donation is less than the cost of a cup of coffee in most café's, yet if 50 people each made a \$5 fortnightly payment, this would add up to \$6,500 each year for MS Waikato.

Every dollar makes a difference and assists with the provision of support services.

Donations can be made directly to the MS Waikato bank account – 02 0316 0488196 000, remember to include your name and donation with the payment. Receipts are provided for all donations, any supporters who are not

currently clients, please contact janet@mswaikato.org.nz with contact details.

You can claim 33.33 cents for every dollar you donate to MS Waikato for monetary donations of \$5 or more. To claim your tax credit you need to submit your donation receipt within four years of making the donation.

Leaving a Gift in your Will

We will be setting up a Gift in Wills programme and would love to hear your thoughts and receive any feedback you may have.

Leaving a gift in your will helps ensure we are here for future generations, to continue to provide support to families throughout the Waikato and Coromandel regions. It is a way to support MS Waikato that does not affect your finances now while you are needing them to live your life.

After taking care of family and loved ones would you consider leaving a gift in your will to MS Waikato to help ensure we are here to help others in the future? Any donation large or small is gratefully accepted as it all contributes to allowing us to continue to provide our services well into the future.

It's important that we are able to honour and acknowledge people with a recognition programme. Do you have any suggestions what the recognition programme could be called?

If you are considering leaving a gift in your will, perhaps you have a story relating to support from MS Waikato you may like to share for the gift in wills programme.

Whatever your wishes may be, having a will is important as it ensures that you are able to provide for your family and loved ones in the way you want to, and that your final wishes are carried out accordingly. Without a will, if your assets are over \$15,000, the Probate process would be processed through the high court, with high court costs and processes. The court will decide how your assets will be distributed. This can make a difficult time even more difficult for the loved ones you leave behind.

If you would like to talk about leaving a gift in your will, have already set up a gift in your will or have any suggestions or stories for our programme, we would love to hear from you. Please email Janet – janet@mswaikato.org.nz or phone 07 8344740.

Volunteering

Volunteers are essential and assist in a variety of different ways. In particular volunteers assist with our stalls and raise public awareness of MS during awareness week. Awareness week will be taking place 15 – 21 September, if you are interested assisting or receiving further information nearer the time please contact janet@mswaikato.org.nz. Volunteers also assist with the mailout of our newsletter and occasionally with office support. Our Trustees and minute taker also all serve in a voluntary capacity.

Client Survey and Future of MS Waikato

Payroll Giving

Payroll giving is a scheme that enables employees to make regular donations directly from their wages to a registered charity of their choice. You choose the amount you want to donate, and your employer will take the appropriate payment out of your wages before you receive it. There is no cost to the employer, and if you choose to donate more than \$5 you will receive an immediate tax credit of 33% towards your PAYE.

For example:



For more information or to advise if you are setting this up with your employer, please email Janet – janet@mswaikato.org.nz.

Research shows genetically engineered human cells can repair myelin in mice

Scientists at our Edinburgh Centre for MS Research have used a gene-editing technique to boost myelin repair.

Myelin is the protective coating around nerves. In MS myelin is damaged, making it harder for messages from the brain to get through. Our bodies can repair myelin. But in MS, and as we age, this becomes less effective. And there are currently no treatments that can boost this process.

What did the researchers do in this study?

In this study, researchers grew human oligodendrocyte precursor cells (OPCs) in the lab. These are a type of cell found in the brain that normally transform into myelin-making cells called oligodendrocytes. But signals in the environment of MS lesions stop this from happening.

Professor Anna Williams and her team used a technique called CRISPR to edit a small section of the DNA of these OPCs to make them ignore anti-repair signals. And found that when these cells were transplanted into mouse brains, they were able to improve myelin repair.

Professor Williams told us:

"Many studies in the past have tried to transplant oligodendrocytes or similar cells into the brain to repair myelin. However, the hostile environment of MS lesions stops these transplanted cells from working.

"The difference in our study – which was six years in the making – is that we were able to genetically modify the transplanted cells so that they would ignore these negative signals and repair myelin.

This is exciting as now we have shown that we can scientifically tweak cells in a dish and transplant them into models to improve repair - Professor Anna Williams, co-lead of the MS Society Edinburgh Centre for MS Research

What does this mean for people with MS?

Dr Laura Wagstaff, a postdoctoral researcher at the University of Edinburgh who worked on the study, says: "Our work is a proof of concept. The next step is to see if we can remove the need for transplants and edit the cells directly in humans. This is an approach similar to gene therapy which may be an effective method of promoting remyelination in the future."

Caitlin Astbury, Research Communications Manager, says: "Current treatments for MS work by targeting the immune system, making it less likely to attack the protective myelin coating around nerves. But we desperately need to find ways to repair the damage to myelin that has already been done.

"We're really proud to have funded this innovative study and the results are invaluable in helping us understand how myelin repair could work."

"More than 150,000 people live with MS in the UK and research like this brings us one step closer to finding treatments that can stop disability progression for everyone."

<https://www.mssociety.org.uk/research/news/research-shows-genetically-engineered-human-cells-can-repair-myelin-mice>

HD Family Day

A HD Family Day was held in November at Hamilton Gardens, with a wonderful group of speakers, their presentations are summarised below:

HD Research Update

– Dr Malvinder Singh-Bains

Malvinder provided an overview of the Human Brain Bank and brain tissue bequest programme at the University of Auckland Centre for Brain Research. She discussed what type of techniques the donated brain tissue is used for and conveyed her gratitude to the HD community for their support of the programme with over 150 brain bequests coming from HD families nationwide. She delved into some of the projects her laboratory are undertaking which cover the following areas:

1. Developing better tools to study Huntington's disease human brain tissue
2. Understanding huntingtin protein in the human brain
3. Understanding other "disease causing" proteins in the Huntington's disease human brain
4. Understanding the role of other brain cell-types (apart from neurons) in Huntington's disease

Malvinder highlighted that these studies are critical for understanding the cause of HD and will ultimately provide valuable information for its treatment, particularly for the development of therapeutics targeting the huntingtin protein. Malvinder looks forward to updating the Waikato community with her progress as these critical studies unfold.

HD International Clinical Trials and HDYO Update - Dr Stephanie Carr

This year, Stephanie conducted a project at the Centre for Brain Research (CBR) at the University of Auckland. Despite Huntington's classically being considered a disease affecting neurons (the "main" brain cells) in the basal ganglia, the laboratory group Stephanie worked with has previously reported a loss of Purkinje neurons from the post-mortem cerebellum (a brain region involved with balance and coordination) of HD cases that were predominantly affected by movement symptoms (look up the article "*Cerebellar degeneration correlates with motor symptoms in Huntington disease*" by Singh-Bains et al., 2019, for more information). Her research builds on this work by looking at the involvement of microglia in the HD cerebellum. Microglia are the brain's resident immune cells which help maintain a healthy environment for other brain cells but can also contribute to inflammation and disease. Stephanie's study's findings are yet to be published, but the results suggest that these cells are displaying changes in the HD cerebellum. The hope is that by studying cells like microglia, we may understand how the interaction between brain cells are affected by Huntington's disease, and uncover ways of restoring the



function of other cell types to support the health of neurons in HD.

Next, Stephanie provided an update on key international trials for HD being run by Prilenia, Sage Therapeutics, Roche, uniQure, PTC and Wave Life Sciences. Despite the unfortunate track record of failed clinical trials to date, it is encouraging to see the ongoing international interest in developing a treatment to slow down or halt the progression of HD, and many of these companies believe they are getting closer to achieving this goal. If you would like to learn more about each trial, please contact Liz Hogan, email liz@mswaikato.org.nz for a copy of the presentation, or visit HD Buzz (<https://en.hdbuzz.net/>).

"To finish off, Stephanie spoke about the work being done by the Huntington's Disease Youth Organisation New Zealand (HDYO-NZ), a charity which aims to support, educate and advocate for youth impacted by HD in New Zealand. Their main projects at present are the HD youth camps inaugurated last May which we hope to run biennially, and a Counselling Support Fund to enable youth impacted by HD to access mental health services. If you would like to learn more about these initiatives, please visit the website (<https://www.hdyo.co.nz/>) or email hdyonz1@gmail.com."

HD Family Day

Service and support available in the community – Barbara Walters

Disability Support Services [DSS] have gone under some significant changes over the past few months. DSS have moved from Whaikaha Ministry for Disabled People to the Ministry of Social Development [MSD] Whaikaha now have an advisory role for government agencies.

All Needs Assessment and Service Coordination [NASC] around the country continue to accept referrals for those eligible for funded services. They are however unable to refer clients into residential care as there is a 'freeze' at government level for these services. Hopefully this will loosen up in time.

People can self-refer to DSL, and if eligible they will contact the client/whanau and introduce the coordinator assigned and explain the process of assessment and coordination. For any queries, Barbara Walters can be contacted on 021 243 5345 or barbara.walters@waikato-hb.health.nz

Service and support available in hospital and HD House – John Young

DSS or disability support services assist people with physical, sensory or intellectual disabilities. Huntington's disease is covered by DSS. There are no set entitlements, rather it is based on the person's needs.

DSS assists with physical needs like assistance with showering, home help, carer support and in cases of extreme need, residential care with either a community provider or aged care facility depending on need and where we can access supports. DSS sadly, does not assist with psychological needs.

They have 2 disability equity nurses based at Waikato hospital (John Young and Shirley Murdoch), who can assist by supporting people in hospital, being part of discharge planning, advocating, attending family meetings, or just explaining what the doctors have said. If you are with DSS and you are in Waikato Hospital you are very likely to see them. If you do not need their assistance, that is OK too.

They also spoke at the Huntington's day about the possibility of having a residential service through Aspire that would have specialty knowledge of assisting people with Huntington's disease. While there are many positives to having a facility with an expertise, the down side is that you may be confronted by some harsh realities, as you may be with people whose disease is more progressed than yours. It also needs to be noted that you may not get along with others in the facility due to who they are, rather than the disease they have, and have to choose to move to a different facility that doesn't have the same knowledge set.

In reality, a facility that caters for neurodegenerative disorders is unlikely to only cater for one disease, so the facility would be a mix of other disorders as well, such as Multiple Sclerosis, Parkinson's and possibly people with other disabilities that are at the end of their life journey.

A family's experience including supporting a HD family member in Hospital – Barbara Dunn

Barbara Dunn very kindly shared her personal experience of Huntington's Disease. Barbara's daughter Joanne is remembered for her infectious laugh, wonderful sense of humour and for usually finding the funny side of most things. Over time Barbara gained insight and ideas for supporting Joanne when she was hospitalized.

Barbara said her first call when Joanne was admitted was to phone Ruth Mylchreest, HD Clinical Nurse Specialist. "Ruth does an amazing job of supporting families and individuals during their stay in hospital". Barbara's next call was to MS Waikato so Liz and Karen could be involved as much as possible.

Barbara has printed sheets she put on the wall with blue tack in the hospital room, one explaining HD, a couple of sheets with some photos and information about Joanne's interests and one suggesting ways to communicate with Joanne:

'When working with Joanne please gain her attention, explain what you are doing, and she will help as much as possible. She fully understands all that is being said and when she tries to speak, please try to take time to understand. If you can't understand say so, sometimes asking her to say the first letter helps.'

She always carried Enduring Power of Attorney (EPOA) paperwork, contact numbers, a pen and note book to write EVERYTHING down and a medication list.

If you would like a copy of the sheets Barbara wrote as an example, please contact Liz – liz@mswaikato.org.nz ."



Barbara Dunn

HD Family Day

Ketogenic Metabolic Therapy in Huntington's – Dr Matt Phillips

Modern medicine is strongly attuned to a “germ-theory” approach to medicine, which emphasizes the targeting and elimination of disease symptoms. However, a “terrain-theory” approach, which emphasizes restoring the actual health of the body, may be helpful in Huntington's (HD). There is ample evidence that HD is associated with damaged mitochondria (the little “processors” inside virtually all our cells), which can explain why HD leads to degenerative changes not only in certain parts of the brain, but also many regions throughout the body, such as the skeletal muscles and heart. Although the mutant huntingtin gene and its protein are dominant triggers of this degeneration, evidence from animal and human studies (including identical twin studies) shows that environmental factors, such as diet and exercise, can play a strong role as well in the timing of the onset of HD, as well as how it manifests. Given this background, a ketogenic metabolic therapy (KMT) program, which could incorporate a fasting protocol, a ketogenic diet, or both, might lead to non-genetic changes in the body's terrain (metabolism and mitochondria) that could be helpful for the symptoms of HD.

To date, there is only one human study investigating KMT in HD, which showed improvements in many symptoms for this person. However, in order to investigate this more thoroughly, a clinical trial is needed. If we can find enough people who are interested in such a trial, we may be able to commence such a trial in late 2025 or early 2026. If you are potentially interested in staying apprised about the possibility of a clinical trial of KMT in HD, please email Dr Phillips at Matthew.Phillips@waikatohdhb.health.nz.

Role of the genetic service, IVF, pre-conception, prenatal options – Harry Fraser

Harry spoke about the Genetic Health Service NZ (GHSNZ), a national service that offers input for families known to be at risk of Huntington's disease, and predictive testing for those at risk and keen to know their own genetic status. We make a distinction between diagnostic genetic testing, which is usually carried out by a Neurologist or similar specialist in somebody who is suspected to have symptoms of HD, and predictive testing, which is carried out by the GHSNZ in people known to be at risk of HD but who are currently asymptomatic. We can meet with individuals who wish to consider predictive testing several times before they make a decision that is right to them. As our guidelines are based on international protocol, we will always meet with people at least two times before going ahead with testing, and in most cases, only offer testing over the age of 18. Understandably, there are a number of reasons somebody may decide to have a predictive HD test. For some, the not knowing their gene status is a difficult position to be in. Others may wish to aid future practical decision making and provide information to younger relatives. For some, predictive testing opens up the options of prenatal genetic testing or preconceptual procedures such as Preimplantation Genetic Testing (PGT). Everybody's HD predictive testing journey is different and influenced by their own personal experience – we are here to support this person on their own journey. There is never a ‘right’ or ‘wrong’ approach. If you are at risk of HD, and would like to discuss your options, you can either ask your GP for a referral to your local Genetics Service, or self-refer if your family is also known to our service.

HD Research in the Waikato – Kate Ives

The Waikato Hospital Neurology Department is currently running the Generation HD2 Clinical Trial: **A Phase II, Randomised, Double-Blind, Placebo-Controlled, Dose-Finding Study to Evaluate the Safety, Biomarkers, and Efficacy of Tominersen Patients with Prodromal and Early Manifest Huntington's disease.**

Generation HD2 is an international study, sponsored by the Roche Pharmaceutical company. Tominersen is a drug designed to lower levels of the mutant huntingtin protein in the brain. The drug is injected, via lumbar puncture, into the spinal canal every four months.



Harry Fraser, Ruth Mylchreest, Dr Matt Phillips, Dr Stephanie Carr, Kate Ives

HD Family Day

The study has been open to participants aged 25-50 years with prodromal or early manifest HD who have a CAP score of 400-500. CAP score is calculated as: Age x (CAG repeat length minus 33.66). Recruitment to the study is now closed, with 300 participants recruited worldwide. Participants will continue on study for the next 16 months. At the end of the 16 month period, the study data analysed. If Tominersen is demonstrated to have been effective, study participants will be offered the opportunity to continue receiving Tominersen.

In New Zealand, two participants have been recruited into this study, one in Canterbury and one in the Waikato.

Future research opportunities:

- The Waikato Hospital Neurology Department hopes to become a site for the ENROLL-HD registry: A Prospective Registry Study in a Global Huntington's Disease Cohort
- We are in contact with research organisations and Pharmaceutical Companies around the world and hope to be offered opportunities to participate in future HD clinical trials and research.

HD Clinical Nurse Specialist

– Ruth Mylchreest

Ruth spoke about her role as Clinical Nurse Specialist for people living with Huntington's Disease. This included her working with and making referrals to the Interdisciplinary team (IDT).

The IDT are the health professionals available to support people's progressive needs. For example; Neurology, MS Waikato, GP, Occupational Therapy, Physiotherapy, Speech and Language therapist, Dietitian, Social worker, Orthotics, Hospice and Neuropsychology make up our team here at Waikato Hospital.

Ruth discussed a few community based organisations;

- Carers Zealand <https://carers.net.nz/> is a community resource that can be helpful for families to navigate changing home situations.
- Time out charity <https://timeoutnz.org/> is an organisation that offers people free holiday accommodation when they are living with a life limiting condition.

Ruth talked about how Psychological support can be helpful for people and their families living with HD.

In particular Acceptance and Commitment therapy (ACT), recent evidence suggests this therapeutic approach can reduce depression and anxiety in those living with HD. Focussing on the 'here and now', not the 'what if and when'. The Huntington's association have a useful webinar on the benefits of ACT for HD. <https://www.youtube.com/watch?v=S8-81f7Cx3M>.

Funding from the Kakepuku challenge is available for psychological support for people living with HD and their families via MS Waikato, contact Liz or Karen at MS Waikato for more information.

Support Groups

Support groups are about people coming together to connect, they are people who understand what you are going through with the opportunity to build friendships.

The discussions are not always about MS or HD, the groups talk about all sorts. But they are also a space to discuss challenges and help others do the same. Talking to people who understand can be hugely beneficial.

It's more than a support group—it's a place to connect, grow, and even have fun along the way! Talk with Liz or Karen about finding a group that is right for you.

HD Carers Group – Bi-monthly meeting 2nd Tuesday in the month (11th March, 13th May) – Turtle Lake Café, Hamilton Gardens – 10.30am

Exercise Class – Every Monday and Wednesday - Anytime Fitness, Cnr Anglesea and Clarence St – 10.30 – 11.30am, \$2 for financial members or \$5 for non-financial members. Contact Liz or Karen to organize an initial assessment.

MS Walking Group – Every Saturday - The Veranda Café, Hamilton Lake – 9.00am

Hamilton

MS Support Group – 1st Thursday in the month, (6th March, 3rd April & 1st May) - location varies, contact Liz or Karen for details – 10.30am

Raglan

MS Support Group – 3rd Tuesday in the month, (18th March, 15th April & 20th May) - Orca Café - 10.30am

Te Awamutu

MS Support Group – Quarterly group meeting Wednesday 12th March, Churchill Café – 10.30am

NOTICE BOARD

The Michael Ford Golf Tournament

Friday 14th March,
Ngahinepouri golf club
We are currently seeking businesses or individuals who may be interested in sponsoring the event. We have a wide range of sponsorship options. For more information, please contact Janet -
janet@mswaikato.org.nz

AGM

Thursday 27th March,
Your Way - Kia Roha
Board Room, 20
Palmerston St,
Hamilton, 5.15pm.
Financial members will be enlisted to vote, to register your attendance or receive the zoom link please email
janet@mswaikato.org.nz by Tuesday 25th March

Subscriptions & Payments

Please note 2025 subscriptions are now due. The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received. Any payments or donations can be made directly to the MS Waikato bank account - 02 0316 0488196 000.
An Eftpos machine is also available, please let staff know if you would like them to bring this with them when they visit.
Thank you for your support.

World MS DAY

Friday 30th May
- A global awareness day to raise awareness of Multiple Sclerosis

Cooling Vests

Hydro cool are again supporting us with a great promotion on cooling vests, which may help on hot summer days. They are offering a 25% discount on all orders for cooling vests, and will include a complimentary towel.

Please visit <https://www.hydrocool.nz/>. After selecting products, go to the checkout, you will need to enter MSWAIKATO into the promotion code area to receive the discount.

Feedback from previous years is that it is a really good product.

Entertainment App

MS Waikato are selling the Entertainment apps again, these also make a great gift. The apps contain thousands of dollars worth of vouchers. They can be purchased as a single city, multi city or multi year. MS Waikato will receive 20% from each app sold. For more information and to view any current offers visit <https://nz.entdigital.net/orderbooks/1b54128> or contact janet@mswaikato.org.nz to receive this link.

TravelScoot

We have a TravelScoot available for short term loan, for a donation. For more information contact Liz or Karen.

Scooter Batteries

If you need to replace the batteries in your mobility scooter we may be able to help with the cost. A generous gift in a will, is assisting with this, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

Dogs in Homes

For the safety of our staff please ensure all dogs are secured when staff visit.

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok. The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

Thanks to our Sponsors and Supporters

WDFW Karamu Trust • COGS- Hamilton City, South Waikato, Waikato West and Hauraki Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central • Gallagher Charitable Trust
The Norah Howell Charitable Trust • Ruth Mylchreest • Glenice and John Gallagher Foundation



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