

Issue 68 - February 2021

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

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A night with Guy Carter



Covid-19 changed many things but it didn't slow down Karyn Jones enthusiasm for fundraising.

Karyn set about organising a hypnotist fundraiser at the Whangamata RSA club, originally planned for awareness week; this was able to go ahead in November.

Securing Guy Carter for the night was an amazing coup and as a result the tickets sold like hot cakes!

For those of you who are not familiar with Guy, he is a New Zealand born comedian and hypnotist.

For over 25 years, Guy has entertained audiences around the world using hypnosis in his comedy act.

Karyn shared with us, "Guy provided a wonderful night of entertainment.

We were entertained with his comedy and magic show followed by the hypnotising of some of our audience, all in aid of fundraising for MS Waikato.

Due to Covid-19, the show had been postponed twice. Most people who bought tickets were able to make it on the night, with a few who unfortunately couldn't, but very generously donated their ticket money.

All in all, it was a fantastic night and provided an opportunity for a lot of laughter! Something I think we all needed after such a tough year.



Continued on page 2

ManuScript is brought to you by:



A night with Guy Carter

Continued from page 1

We would like to thank Guy Carter; he discounted his show to support our fundraising. Guy shared with us on the night that he has personal experience of Multiple Sclerosis so he truly understands the importance of the support that is needed.

The biggest thanks goes out to our wonderful community who got right behind this event and purchased tickets. I know it was about supporting the cause as much as the great night out as many people have a family member or friend who is affected by MS.

We were able to bank \$4,200 into MS Waikato's bank account. This money will ensure continued support for those affected by MS in Whangamata.

Due to the great response and support from the RSA committee I have asked Guy to come back next year so we can have another great night to go in line with our Awareness week fundraising.

Thank you all for your continuing support."

Karyn Jones

Other fundraising in Whangamata raised an additional \$840. This started in September with an awareness stall at New World Whangamata and donation boxes placed in our local businesses around town. Dave Cordery organised the stall and spent the day busking with his guitar, ukulele and lovely voice. When asked by the management at New World if he would come along and play his guitar again during the Beach Hop Dave readily agreed, on the condition that it could be another fundraiser for MS Waikato.

We would like to express our sincere thanks and appreciation to Karyn Jones and Dave Cordery and all that assisted and supported the events in Whangamata. In particular, we would like to thank the RSA club and the Black Court Motel who unexpectedly offered free accommodation for Guy on the night of the show and New World Whangamata for support of our stalls.



Kawhia Cruise

Here in Hamilton, the Muir family put together another fantastic Kawhia Cruise for us in November.

On what started out as a wet day it certainly didn't deter our enthusiastic cruisers. Attendees came from Auckland, Taupo and Tauranga to join our local enthusiasts on what was the 7th Kawhia Cruise.

With 48 cars participating the event raised \$4,031.

A huge thank you to Ash and Adam for organising the cruise, and to Jas and Kim for running the day, much passion and many hours are put in to make it the fun day out that it is. Thank you to the supporters who come along on the day, without which we wouldn't have a cruise. A huge thank you too to the sponsors without which it would not be a fundraiser.

The sponsors were:

- Shot Gun Band
- Waikato Aviation
- On Guard security
- Jason Scrivener
- Frank Café
- Front Paddock Café
- The Rocks
- Ara Studios
- Auto Trail
- Deep Dive NZ
- Erika Watson Jewellery
- Alex Haskell Design
- Fox Kennedy
- Thrift Hunter
- Senora Mariposa Print
- Lila Boutique
- Bee Pressure



Adam and Ash





Upcoming Events - The Michael Ford Memorial Charity Golf Tournament

Do you enjoy a game of golf or have family/friends who may? Do you know of any organisations who may be interested in sponsoring the tournament?

Michael Ford, a client affected by MS, originally established our tournament over 20 years ago. This is usually an annual event and one of our major fundraisers, unfortunately last year's event was cancelled due to Covid.

The tournament is taking place again at Ngahinepouru Golf course on Friday 9th April and we are seeking both sponsors and players.

It will be a stableford tournament, entry is \$30 pp for registrations received by the 31st March, (\$40 for late entry after this date). This includes morning tea and a sausage sizzle.

For sponsors, we offer a wide range of sponsorship to suit different organisations.

For more information on participating or sponsoring the event please contact Janet on 07 834 4740 or email janet@mswaikato.org.nz

All funds raised are used to directly assist with the provision of support services for you, our clients.

Work in Progress – Now Complete!

For those of you who have been members for a few years you may recall an article in Manuscript back in 2014 featuring Aaron Beere who was renovating a 1956 2-door Buick sedan. The Buick had originally been purchased by his Dad in 1989 in a million pieces, with Aaron taking on the job in 1998. It's fair to say that Aaron is a car fanatic, spending hundreds of hours, as time and money permitted on a renovation that has been a labour of love for him. Aaron's renovation is now complete and the car looks amazing, brought back to its former glory it is a beautiful aubergine colour. He proudly brought it along to the Kawhia Cruise.



Aaron's Buick (2014)



Aaron's Buick (2020)

Do you have any great ideas for fundraising? Perhaps you have some friends or family members who would like to be involved with an activity too. Please get in touch if you do, we would love to hear from you. As a charity we are dependent on fundraising to be able to continue to provide our services to you and your families.

Telling people you have MS

If people understand MS, they are more likely to accept any adjustments or support you may need.

Telling people that you have MS can be difficult. Accepting the diagnosis yourself is hard, let alone sharing the news with others. Being able to talk about being diagnosed with MS can take courage, but it can be helpful too. If people understand MS, they are more likely to accept any adjustments or support you may need.

When you are considering talking to others about your MS, remember that everyone is different. Everyone you talk to has a different relationship with you, may want or need different information about MS, and may react in different ways to your news.

For each person, it is a good idea to consider if the person needs to know about your MS, and if so, what you want them to understand about MS and what is the best way to tell them. This way, you can tailor the way you talk to them about it. Some people find it good to practice what they want to say first.

Many MS organisations have printed information about MS which you can give to people to read and digest later.

Who to tell?

Partners or potential partners

If you are dating, or have recently met someone, you may not want to disclose your MS initially. Usually, it is not a good start to a relationship to keep secrets, but you also need to feel close enough to them to want to share important information. There is no one ideal time – you will know when you feel that the relationship is ready for this next stage. If the person is right for you, they are likely to be supportive. If they aren't, then perhaps they weren't ready or right for you anyway.

If you already have a partner, then your MS will change their life too. This can be worrying for both of you and you may need to support each other. Make sure you give your partner time to absorb the information, and remember to keep communicating about it over time.

Remember you cannot predict the future. All relationships have their ups and downs, and any number of things can bring them to an end or make them stronger. As with all issues that affect couples during their relationship, communication and understanding are really important.

Parents and other family members

Disclosing your MS to your family, who may have known something was wrong anyway, can help to begin the coping process. Grief and worry are normal emotions for family members to feel when someone they love has news about their health. Parents in particular worry about their children, even after they have grown up. Other common emotions can include guilt if parents feel that they have somehow 'given' their children the condition.

Your children

How to explain MS to your children can be worrying, but you are the best judge of how, when and what to tell your child about your MS. Children are naturally likely to have questions, feelings and worries about the impact of MS on you and your family, and it is a good idea to encourage them to share these with you. It may be important to explain, for example, that MS is not contagious.

Friends

It may be a good idea to start with your closest friends and with those that you feel most comfortable with. With time and practice, you'll be able to decide how much you want

to share and with which friends. A change in someone's health can be a challenge to friendships, especially if symptoms such as fatigue affect a person's ability to take part in social activities, and many people with MS say that telling them helped them to identify their true friends.

Employers and colleagues

Disclosure at work can have a significant impact on your job security, employment options and career path. Before disclosing your MS in the workplace, learn about your rights (these vary from country to country – your national MS society should be able to help) and think carefully through the pros and cons of sharing this personal information. Many people say they have supportive employers and colleagues, but this is not always the case. Read more in our Global MS Employment Report [[PDF, 1MB](#)].

How will they react?

Each person will react differently to what you tell them, so be prepared for a range of reactions. People may be shocked, fearful, calm, distressed or quiet. Some may not really understand and will need time to digest what you are telling them. Others may go out of their way to help and sometimes this can be frustrating if it is not wanted. Some people may avoid you because they don't know what to say. They don't know how to deal with you having MS, so they choose not to discuss it, which can be difficult.

Whatever a person's reaction, talking about it with them can be really helpful. This may be easier once you have come to terms with the diagnosis yourself, so talk to people when you really feel ready.

Source: *MS International Federation (msif.org)*

MS Exercise Class

The exercise class at Anytime Fitness is still going strong, but does have space for new members. Run for us by our instructor Margaret Thomson the class caters for all clients and is supported by 2 wonderful volunteers, Sue and Richard. Remember, the right kind of exercise can significantly help with your health and wellbeing. The classes are also social, enabling members to meet with others affected with the same condition, share challenges and experiences. Classes are held twice weekly, on a Monday and a Wednesday morning at 10.30 and last an hour at each session.

The classes are subsidised by MS Waikato through grants. The only thing we ask from you to attend is that you become a financial member (if you are not already) and make a contribution of \$2 for each class that you attend.

If you have not been before and would like to give it a try please call Liz, Karen or Tracey and they will arrange an introductory visit.

Making a Bequest to MS Waikato

What is a bequest?

A bequest is a gift made through your will, giving you the opportunity to acknowledge the worthwhile and ongoing work of MS Waikato.

A bequest enables the gifting of cash, property, an insurance policy or other assets from your estate to a specified recipient such as MS Waikato.

Such instructions in your will enable you to gift to those closest to you as well as helping people in need. Leaving a bequest to MS Waikato guarantees you will continue to help improve the lives of those who need your help.

Why are gifts so important to charities?

It's a common myth that only the rich and famous leave money to charity when they die. This couldn't be any further from the truth. The reality is without the gifts left in wills by people like you, many of the charities in New Zealand wouldn't even exist.

Bequests are the foundation for many of the charities in the NZ and are vital in making sure that all the good work they do can continue. For some people, giving through their estate is the only time they will be able to give a significant gift to an organisation that they support.

Making a bequest to MS Waikato is simple

Of course, your loved ones come first, but even just a small gift in your will helps us continue to improve the lives of people living with MS, HD and allied neurological conditions. A gift to M S Waikato is very easy to leave in your will and is a gift that makes a difference and lives on in memory. Your gift will help future generations living with the effects of MS and HD. Ways you can help M S Waikato in your bequest include:

- Provide a percentage of your estate to M S Waikato
- Residual Bequests, gifting the amount left over from your estate once you have provided for loved ones
- Leave a fixed amount of money to M S Waikato
- Leave specified items or property to M S Waikato
- Gift a life insurance policy to M S Waikato

Whatever choices you make having a will is important as it allows you to say how you want your property to be dealt with when you die. If you don't have a will the law will determine how your estate is divided, and may cause your loved ones more heart ache if they are not able to sort things in accordance with your wishes.

If you would like any further information or to discuss bequests please contact Janet - janet@mswaikato.org.nz or phone 07 834 4740.

Mental Preparedness Is Crucial Ahead of Genetic Testing

As I mentioned in my debut column of “Negative to Positives” a couple weeks ago, I have a genuine passion for helping those undergoing genetic testing for Huntington’s disease, which is an incredibly challenging life hurdle.

Many members of this community watch their parents slowly and progressively decline, and then must look in the mirror and wonder if their own future holds the same unfortunate fate.

People outside the Huntington’s community might think that getting tested is a no-brainer. Why wouldn’t someone want to know whether they will get Huntington’s? This question may seem simple, but actually it is quite complex.

With many other rare genetic disorders, people may seek a diagnosis because treatments can halt disease progression. But with Huntington’s, as one observational study noted, about 90% of those who are at-risk choose not to take a genetic test. Essentially, participants were saying, “Why learn about a possible life sentence when there isn’t much one can do about it right now?”

Getting tested is an incredibly personal decision, but I do think it can be simplified a bit. And regardless of available treatments, I believe a positive outcome is possible, regardless of genetic inheritance.

From my experiences, including my own testing process and the testing of others close to me, I think the chance of a positive outcome after testing depends on having a prepared mind.

What do I mean by that? A prepared mind has thoroughly thought through the many angles and avenues that both a positive and a negative test can take you down as an individual.

This isn’t like a high school test or a big work presentation you can expect short-term success from by cramming for it in a short period. I see this cramming strategy a lot in online Huntington’s chat groups. Many learn of their at-risk status after they are adults, so they’ll immediately seek out Google MD and Facebook chat groups, and then speak to their general practitioner. Often, they’ll feel prepared within a few weeks to face the Huntington’s coin toss.

On the surface, this person may know much more about Huntington’s than they did a few weeks ago, and they may feel like they are ready for whatever result comes at them. But I don’t believe this is an example of a prepared mind.

I was only 23 when I went through with my genetic testing, and I can say with certainty that I wasn’t the smartest, wisest, or most mature mind in the room. However, I feel confident in saying I was 100% prepared to receive my results.

Since the ripe age of 10, I attended local and national Huntington’s fundraisers, support groups, and education days where I was able to absorb information, connect with others, and build an army-like support system. I had the opportunity to digest information and think carefully and strategically about my future – with or without Huntington’s disease.

Ultimately, I was able to prepare my mind to visualize a future down one of two paths. Path A was life with Huntington’s, and Path B was life without it. Clearly, these two paths were different. They involved different education, career, and life choices. But my mentality for the future remained the same. Regardless of the path that my genetic makeup had in store for me, I would live happily because I had prepared my mind for both paths. I was OK walking down either one.

I understand that my situation is unique to me. However, I have seen many young people who are at risk get tested, and it’s easy to tell who has a prepared mind and who quickly crammed in the knowledge. Those who are prepared take their time. They connect with others from all angles. They are engaged in the Huntington’s community well before they decide to test. Nobody wants to receive a positive test result, but I believe that those who are prepared will have a much more positive outcome, regardless of the result.

If you’re still at-risk for Huntington’s, take your time to prepare your mind for what’s ahead. There are many easily accessible resources available (such as HDYO, HDSA, and NSGC). Speak with a genetic counsellor. Speak with others in the Huntington’s community. Connect with the proper resources. Talk to those around you who also will be affected. Talk to yourself. Take your time to absorb all the details.

Think through your two paths. They won’t be the same, but you can prepare your mind to accept both of them and live a full life, whatever is in front of you!

Author B J Viau

*Information sourced from
<https://huntingtonsdiseasenews.com>*

NOTICE BOARD

HD Education Evening

A neurologist led HD Education Evening is being organised for

Date: Monday 22nd March at 6.30pm

Venue: Fellowship lounge, The Link, Te Aroha St, Hamilton

For more information or to book a place contact Tracey – 8344745 or email tracey@mswaikato.org.nz

MS Education Evening

A neurologist led MS Education Evening is being organised for Thursday 27 May at the Link, Te Aroha St, Hamilton. Keep the evening free, more information will be sent out soon.

Cooling Vests

If you are feeling the heat and need a cooling vest Liz has had a chat with our friends at Hydro cool and they have again offered a 15% discount on all vests and a complimentary towel with all orders.

If you enter the link below it will take you to their website, you need to enter MSWAIKATO into the Promo/Discount area to be able to receive the discount.

Feedback from last year is that it is a really good product.

<https://www.hydrocool.nz/discount/MSWAIKATO?redirect=%2Fproducts%2Fhydro-cool-sport-vest>

If you would like us to email the above link to you please let us know.

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.

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

AGM

The AGM will be taking place on Thursday 25 March, 5.15pm in the Life Unlimited Board Room. Financial members will be entitled to vote. To reserve a seat or receive the zoom link please email janet@mswaikato.org.nz by Tuesday 23rd March.

DOGS IN HOMES

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

Payments

If you wish to make any payments directly to MS Waikato please pay into account number 02 0316 0488196 000 Please remember to include your name and what the payment is for eg Subs.

Donations

Donations to MS Waikato can be made at anytime through our website www.mswaikato.org.nz, please click the link 'Donate now' and it will take you to the Spark Foundations give a little website. Alternatively a direct link to this site is through www.givealittle.co.nz/org/MSWT

Subscriptions

Please note 2021 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. *Thank you for your support.*

Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

Alinkers

MS Waikato has 2 Alinkers which are for client use. If you are interested in trialling an Alinker for about 6 weeks please contact Liz for further information. This is open to all MS clients within our region.

Thanks to our Sponsors and Supporters



Sir John Logan Campbell Residuary Estate



WDFW Karamu Trust • Waipa District Council • COGS- Hamilton City, South Waikato & Waikato West Rehabilitation Welfare Trust • Anytime Fitness - Hamilton Central • Gallagher Charitable Trust Stockbridge Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Waipa District Council Glenice and John Gallagher Foundation

MSWT EVENTS CALENDAR



March 2021

SUN	MON	TUE	WED	THU	FRI	SAT
	1 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	2 MS Support Group Churchill Cafe Te Awamutu 10.30am	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4 MS Support Group Hamilton The Café - Summerset Down the Lane, 206 Dixon Rd Hamilton, 10.30am	5	6 MS Walking Group 9am The Veranda Cafe Hamilton Lake
7	8 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	9	10 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	11 ME/CFS Support Group Melville Methodist Church Bader St Hamilton, 10.30am	12	13 MS Walking Group 9am The Veranda Cafe Hamilton Lake
14	15 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	16	17 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	18 MS Support Group Mometewa Morrisville 10.30am	19	20 MS Walking Group 9am The Veranda Cafe Hamilton Lake
21	22 MS Exercise Class 10.30am - 11.30am HD Education Evening The Link, Te Aroha St Hamilton, 6.30pm	23 ME/CFS Support Group Social Group, Jukebox Diner, Railside Terrace, Hamilton, 2 - 3pm	24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25 AGM 5.15pm	26	27 MS Walking Group 9am The Veranda Cafe Hamilton Lake
28	29 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	30	31 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton			

April 2021

SUN	MON	TUE	WED	THU	FRI	SAT
				1 MS Support Group Hamilton Venue to be advised, 10.30am	2 Good Friday	3 MS Walking Group 9am The Veranda Cafe Hamilton Lake
4	5 Easter Monday	6	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8 ME/CFS Support Group Melville Methodist Church Bader St Hamilton, 10.30am	9 Michael Ford / MS Waikato Charity Golf Tournament Ngahinepouri Golf Club	10 MS Walking Group 9am The Veranda Cafe Hamilton Lake
11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15 MS Support Group Mometewa Matamata 10.30am	16	17 MS Walking Group 9am The Veranda Cafe Hamilton Lake
18	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23	24 MS Walking Group 9am The Veranda Cafe Hamilton Lake
25 ANZAC Day	26 ANZAC Day Holiday	27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	30	

May 2021

SUN	MON	TUE	WED	THU	FRI	SAT
30	31 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton					1 MS Walking Group 9am The Veranda Cafe Hamilton Lake
2	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4 MS Support Group Churchill Cafe Te Awamutu 10.30am	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 MS Support Group Hamilton The Café - Summerset Down the Lane, 206 Dixon Rd Hamilton, 10.30am	7	8 MS Walking Group 9am The Veranda Cafe Hamilton Lake
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Please cut here