



MULTIPLE SCLEROSIS & PARKINSON'S CANTERBURY (INC)

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PATRON Hon. Ruth Dyson

MP Port Hills

PRESIDENT Malcolm Rickerby

president@ms-pd.org.nz

VICE PRESIDENT Dawn Baker

TREASURER **Ann Morrison**

COMMITTEE

Lindsay Daniel, Glenn Sparrow, Ingrid Robertson, Danielle Kennedy, Tessa Kain, Eamon Reyn, Sharon Blair and David Rowe

OUR TEAM

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PRESIDENT'S MESSAGE

The year started with a great bit of weather and now we are into autumn.

Last year was busy, kicking off with the shift to Sir William Pickering Drive. I think we are all feeling at home now, and it is great to see the gym so busy as the number of members using our facilities continues to increase.

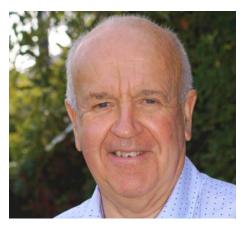
During 2018 the committee worked extremely hard to put in place updated rules and new guides which enhance our governance process. I would like to thank the team for all the time and energy they devoted to these projects. especially Lindsay Daniel for his work in this area.

Our financial year has changed to start from 1 April and close on 31 March. This has meant that, in shifting to that new timeframe, we have had a 15-month financial year. We made this move to bring us into line with the financial year parameters used by both Dementia Canterbury and the Canterbury Brain Collective Ltd. This also means our AGM will be held later in the year. This year it will be held on Monday 17 June at 5.30pm (details below) and I urge members to attend if possible.

I will be stepping down as President in June. I was elected President in 2003

and feel privileged to have remained in that position, providing governance support for the high calibre of staff and volunteers who are a pleasure to work with. Over the last 16 years, our membership has grown considerably, and the services we deliver have grown accordingly to support the needs of our members. I believe that the programmes we offer now are well ahead of any other MS or Parkinson's society in the country.

Best wishes for the future and I hope to see you at my final AGM.



Malcolm Rickerby president@ms-pd.org.nz

ANNUAL GENERAL MEETING

The Multiple Sclerosis & Parkinson's Society of Canterbury Inc

Monday, 17 June 2019

TIME:

5.30pm **VENUE:**

MS & Parkinson's Society

ADDRESS:

49 Sir William Pickering Drive, Burnside

Drinks and nibbles will be provided

We are currently awaiting confirmation of our Guest Speaker. We can assure you that he/she will cover a very interesting topic.

For catering purposes RSVP by 12 June 2019



MANAGER'S MESSAGE



Warmest greetings to everyone. Later this month it will be our first anniversary in our new spot.

As I'm writing this I'm reflecting back to the end of last year. We enjoyed seeing familiar friends and meeting new folks at our rolling afternoon tea in December. The Papanui Club provided a wonderful lunch for our organisation together with Dementia Canterbury, and we had several other end of year events with a Christmas flavour. Many were supported by the generosity of Good Bitches Baking, a group of volunteers who provide delicious baked treats for our members.

Most of that month was cool and cloudy, but we're having a real summer now to make up for it. Everyone enjoyed a well earned holiday to regenerate for 2019.

PHYSIOTHERAPY

We are delighted to announce that On The Go Physio is now providing our professional physiotherapy service. It is great to reconnect with Jessie and her team and know that they are all experienced in working alongside people with Parkinson's and Multiple Sclerosis. Jill is covering Open Gym times on Mondays and Wednesdays 1–3pm. Tara has been providing assessments and from late this month, Rachel will take over assessments and Tara will start working Fridays with Open Gym cover, programme reviews, and service development.

Many thanks to Rocio Guerra and Carmyn Barnes, volunteers who helped with the gym and groups.

GROUP CHANGES

From the beginning of this year Gaynor Morris has volunteered to facilitate the Parkinson's Spouses Morning Tea group each month, and the Men's Social Group (MS and Parkinson's) has some new life and ideas brought by John Keenan. Younger people with MS (18 – 40), now have their own peer support group run by Karen Gentle. We now have two venues for Yoga – Tuesdays 1.30–2.30pm at St Martins Community Centre, Wilsons Rd; Thursdays 2.15–3.15pm in our gym.

If any of these groups sound interesting to you, just give us a call and we can tell you more.

COMMUNICATION MAINTENANCE WITH SPEECH LANGUAGE THERAPIST

Kirstie Koller's monthly Communication Maintenance group for people with Parkinson's runs on the last Thursday morning of each month in our small seminar room. This is a really practical group which includes voice exercises and encourages 'think loud'.

AMPLITUDE EXERCISE CLASS

Tim Webster has designed his Amplitude exercise class with Parkinson's-specific work around amplitude, balance and agility. Tim has gradually introduced boxing into the content of the class. Amplitude is held on Wednesday mornings 10–11am in the gym.

NORDIC WALKING IN RANGIORA

Thanks to Frances Young our Christchurch instructor, we are expanding this great form of exercise to include Rangiora. A trial period is underway finishing 17 May. If people are keen, we will aim to continue this. Nordic walking is a low-impact exercise that provides the highest benefits for health, wellness and fitness for people of all ages and fitness levels.

Robin Furley

manager@ms-pd.org.nz

STAFF CHANGES

As most of you will know, **Annette MacFadyen** resigned after almost 17 years with the society. Along with members, staff farewelled Annette at a lovely afternoon tea, and presented her with a framed photo collage and a jewellery voucher. Annette was the friendly first point of contact for most members, and over the years became familiar with many. We wish her all the very best for her future. (photos on back cover)



HOW WOULD YOU LIKE TO RECEIVE YOUR NEWSLETTER?

Due to increased postage costs we thought it timely to check out with members their preferred method of receiving the newsletter. Currently we post around 50% of newsletters and email the rest. If you want to change the way you receive your newsletter please let us know. Either phone 366 2857 ext 6 or email support@ms-pd.org.nz

SNAPSHOT OF NEW MEMBERS OF OUR TEAM

SHARON BLAIR



Sharon joined the Society in 2014 after being diagnosed with MS in 2012. Born in Oamaru, Sharon spent three years in the NZ Navy in communications before leaving the military and taking up a variety of full-time roles until the progression of her MS meant a need to cut back. She now works "a bit more than part-time," depending on work requirements at Maxwell Logistics. She is very supportive of the work of the Society, uses the physio and MS nurse services and the peer support groups.

Sharon says she has joined the committee because she likes to keep informed and, as a member, believes it is important for clients to have a voice. "It's good to keep in touch with what's going on and to be part of what I think is a committee of forward thinkers."

EAMON REYN



Christchurch born and bred Eamon joined the society when he was diagnosed with Relapsing Remitting MS in 2017.

Eamon's background is in information technology. He has a Certificate in Computing and a Diploma in Information Communication Technology from CPIT (now ARA). He started his working life as a computer programmer, which he says he did not particularly enjoy, and moved into the more peoplefocused IT support, first at St Thomas of Canterbury College and then with Christchurch IT company CodeBlue.

Since diagnosis Eamon has become a regular user of the MS and Parkinson's gym, joined the yoga group and attended courses such as Minimise Fatigue Maximise Life and Living Well with MS.

He believes the Society's services are very beneficial for people with MS, and decided to join the committee to become more a part of the organisation.

DAVID ROWE



Retired academic David initially joined the research sub-committee of the MS and Parkinson's Canterbury governing body, and has moved on to the committee since the research group was disbanded recently.

A former Head of Department and Associate Dean of the University of Canterbury's Law Faculty, David completed a five-year phased retirement in 2010. Following his Parkinson's diagnosis in 2015, he has embraced a fitness regime which includes regular use of the MS and Parkinson's gym, yoga, Dance for Life, and PD Warrior which, as well as a weekly class, involves an exercise programme at home. He says with the Society's services and other fitness programmes he's "much fitter and more agile" than he was before diagnosis, and is a strong supporter of MS and Parkinson's Canterbury.

DANIELLE KENNEDY



Danielle originally hails from the United States, where she was born and raised in Chicago. She moved to New Zealand just under four years ago, and was living in Auckland prior to moving to Christchurch.

Danielle is the Financial Accountant at Ara Institute of Canterbury. Prior to joining Ara, Danielle was a Manager at PwC, working on audits throughout New Zealand. It was during her time at PwC that Danielle started and completed her CPA with CPA Australia. In addition to her role at Ara, she is the Treasurer for the YWCA Christchurch. She is looking forward to contributing to the committee.

Danielle has fully embraced the kiwi lifestyle and in her spare time she loves travelling and enjoying "all that this beautiful country has to offer".



FROM THE FUNDRAISING OFFICE

ARCHIBALD MOTORS - DRIVE FOR GOOD INITIATIVE

In December, 2018, to celebrate 100 years, Archibald Motors announced it was donating \$100,000 to nominated charities. We were one of 10 shortlisted. The money was allocated according to public voting, with the charity getting the most votes receiving \$50,000 and the two runners up getting \$25,000 each. In February, John Fairhall of Archibald's announced an additional \$50,000 boost to the Drive for Good initiative, increasing the total gifted amount to \$150,000, ensuring all ten charities

would receive acknowledgement of their invaluable services.

Although MS and Parkinson's Canterbury didn't make it into the top three in Drive for Good, the Society finished a creditable fifth out of 10 and received a \$7,200 share of the Drive for Good fund.

In total over 20,000 votes were cast. Champion Centre took first place followed in descending order by Canterbury West Coast Air Rescue Trust, Ronald McDonald House South Island, MHAPS, MS &



Parkinson's Canterbury, Cholmondeley Children's Centre, Dementia Canterbury, The Mental Health Foundation and The Cancer Society Canterbury.

MS and Parkinson's president Malcolm Rickerby said he was very pleased with how the MS and Parkinson's community got behind the project and gave of their best to get people voting.

"Although we didn't get one of the big three, we've still come away with \$7,200. It was also a great opportunity to get our name out there and to connect with all our amazing supporters," he said.



A LASTING GIFT

A NOTE FROM LYNNE

"Recently MS and Parkinson's received a wonderful surprise in the form of a bequest of over \$94,000.

Normally we are notified prior to receiving a gift such as this. However, this time a cheque just arrived in the mail. I have to say it caused great excitement in the office. The bequest was from a woman who had used our services about 12 years ago. Receipt of this bequest started me thinking about the immense value bequests have for an organisation such as ours, whether it be for a small or a large amount. A bequest tells us that the person who has remembered us in their

Will respects our organisation and sees value in the work we do.

A bequest can either be open and we can choose how to use the money where it is most needed, for example the day to day costs of running the Society, or for a specific item or project. This flexibility is greatly appreciated by us. At times a bequest will state a special purpose that the money must be used for. We respect this and ensure that the wishes of the bequestor are followed out.

For the most part we are not aware until after somebody's death that they have remembered us in their Will and we respect that for many people this is their preference. If you have decided to support us through a bequest and feel comfortable sharing this information with us, please do so. We would really value the opportunity to thank you for your thoughtfulness."

If you are considering a bequest to Multiple Sclerosis & Parkinson's Canterbury and would like to discuss options with us, please contact Lynne Trowbridge on 366 2857 ext 8 (all enquiries will be treated confidentially).

NURSE'S CORNER

MS GUFST SPEAKER "INSPIRING"

An "incredibly inspiring" address from British MS Consultant Nurse Bernie Porter MBE was a highlight for MS Nurse Judy McKeown at the annual MS Nurses Meeting in Auckland earlier this year.

The meeting involved about 12 MS nurses from around the country and included key addresses, workshops and case studies.

Bernie Porter received her Queen's Birthday honour for her trailblazing work for people with MS. At the meeting her address focused on looking at initiatives that can help people with MS stay out of hospital.

Judy said Bernie Porter's emphasis was on keeping care in the community and removing the need for out-patient or hospital-based care, plus saving money.

"As an example, she talked about the high number of people with MS admitted to hospital with Urinary Tract Infections, sometimes resulting in a week-long stay. This can lead to other issues such as reduced motivation as well a big cost to the health system. If people used urine testing kits in their own home and downloaded an app on their phone, they could monitor their urine themselves."

"It's about getting better services for people in their own homes, looking for new initiatives, liaising with other health professionals such as district nurses, so they are aware of what's available."

"It was incredibly inspiring, and I came away with lots of ideas," Judy said.

KYOTO CONGRESS AN EXCITING PROSPECT

Parkinson's Nurse Anna Fraser is excited to be attending the 5th World Parkinson's Congress in Japan in June thanks to the support of MS and Parkinson's Canterbury and the Lottery Minister's Discretionary Fund.

More than 3,000 delegates from 60 countries are expected to attend the three-day event in Kyoto and they include people involved in understanding, researching, treating, and curing Parkinson's including those who are living with it.

Anna says delegates will include representatives of professional medical and scientific organisations, nurses and rehabilitation professionals, voluntary, lay, and patient services organisations, the pharmaceutical industry, and the research and health services ministries of national governments, "and of course people living with Parkinson's and their care partners".

"It also goes without saying that a number of delegates from New Zealand are attending.

"When I return I will be holding a seminar for my colleagues and members highlighting what I experienced and learnt from the conference and I look forward to sharing this with you all."

SOME OF THE SERVICES WE

Exercise

MS and Parkinson's Society offers a gym facility that is overseen by two specialist physiotherapists. People with MS or Parkinson's are assessed by a physiotherapist and given an exercise programme specific to their needs.

We have open gym (where members follow their own individual programmes) Monday and Wednesday 1–3pm, and Friday 10.30am–12 noon, which members can attend providing they have been assessed by one of our physiotherapists. Each session costs \$5.00 or a 10 session card can be purchased from our office for \$45.

There are eight gym classes a week with specially designed programmes for those with MS or Parkinson's. Assessment by a physio is required first. Cost is \$5.00 per session.



Tim Webster runs an Amplitude Class for people with Parkinson's on Wednesdays 10-11am. Assessment by a physio is required first. Cost is \$8 per session.

Power of Dance: There are high and low-level sessions which are facilitated by professional dance instructor Adriaan Beddie at Impact Dance. Cost is \$7.00 per session.

Yoga class: Yoga classes take place each Tuesday 1.30pm and Thursday 2.15pm and are suited to most levels. These are run by a professional yoga instructor. Cost \$5.00 per session.

Nordic Walking: Each Friday morning with a trained Nordic instructor. Cost is \$5.00 per session.



Self-Management and Education

The Living Well with MS programme runs for six weeks once a week on a Saturday morning.

The programme includes but is not limited to: What is Multiple Sclerosis, What is a relapse and how to tell the difference between a relapse and pseudo relapse, Symptom check list, Employment, Fatigue, Diet and Exercise, The Mental Battle, and Planning for the Future. Each week is different with time for group interaction and discussion. If interested, it's important to let the MS Community Nurse Judy McKeown know so you can be registered for the next intake, as numbers are always limited to keep groups small. We recommend that you bring your partner or significant person, as they also live with your diagnosis and it will give them a better understanding of how it affects you.

The Living Well with Parkinson's

programme runs for six weeks twice a year. The first for the year is currently under way. The second is planned for September. Register your interest with Parkinson's Nurse Anna Fraser. The programme features a guest speaker each week talking on an area of expertise, with a range of different topics.

Fatigue Management

Minimize Fatigue Maximize Life is a sixweek programme aimed at people with MS. MS fatigue can't be cured and can't be pushed through, but you can learn to manage and create balance in your life. This programme usually runs two weeks after LWMS. Places are limited. Please ensure you register by contacting Judy McKeown. This programme is only for people with Multiple Sclerosis. Partners are not included.

We also runs workshops and educational sessions throughout the year.

Health Support

Health professional support includes home visits from the MS or Parkinson's nurses, assessment by a physiotherapist, referrals to GPs, education to rest home staff, GPS and other health professionals.



Social Groups

MS Peer Support Groups: We have peer support groups in Christchurch, Ashburton, Rangiora and an under 40 group in Christchurch. Most of the groups meet six-weekly and often there is a speaker for 20 minutes. Topics may be related to MS, natural therapies, diet and exercise or whatever people are keen to know about.

MS Morning Teas: This is a new group established this year and replaces the MS Lunch. However, needs change and we have been responsive to this. The group is mainly for people who have had MS for some time and enjoy getting together each month at the Society for a friendly chat over morning tea.

Suburban coffee groups: Held regularly in Christchurch, Rangiora and Ashburton for people with MS or Parkinson's and carers. Check with Social Activities Coordinator Lesley Williams Ph 323 6228 for dates.

Men's Social Group: Has been held at Armadillo's, 155 Colombo Street, Christchurch, 4.30–6pm. Dates for the year are 16 April, 18 June, 20 August, 15 October, 17 December. Venues and dates may change.

OTHER RESOURCES

We produce a newsletter three times a year. Paper copies are posted out, or digital copies are emailed, to those who wish to receive it, and it is published on our website **www.ms-pd.org.nz** Notifications of events are sent out via email and are available on our website and Facebook page **www.facebook.com/MSPDCHCH/**. We have a small library of useful resources. We also handle Total Mobility cards.



JILLY VERINA – MENTALLY RECALIBRATING

Overwhelmed by the aftermath of the earthquakes, evicted from her home and then diagnosed with Multiple Sclerosis, this self-confessed "sensitive soul who worries about the state of the world" was feeling near rock bottom.

Jilleen Verina, artist, said that by 2012 her body, mind and spirit were broken. "My tank was empty."

After dabbling in art in the 90s, work commitments mounted and art took a backseat.

But after her world began to crumble and following an attempted suicide, she rediscovered her art and began a therapeutic journey back to herself.

Her pen-and-ink abstract geometrical works are mainly about feelings and emotions that are universal. "They are not about just me but about everybody." And there is usually a humorous twist.

"One day I felt so frustrated with what was happening in the world I felt like pushing the big red button... but in my drawing I made my button a shirt button. So, no nuclear Armageddon today."

She starts with a ruler and a pen and creates shapes then fills them in, sometimes by hand, or sometimes using a computer program. They create themselves as the feelings flow.

When Jilly was diagnosed with Primary Progressive MS and symptoms worsened, she felt she was no longer contributing. "Becoming disabled was

really hard to accept. I just felt I was sitting round wasting time."

"My sister said 'no, you're a time billionaire ... you're lucky you've got lots of time when so many people are time poor ... don't feel guilty about it '. So, I realised I don't have to race around anymore, I can do things in my own time. I consider my free time a gift now."

This inspired her work *Time Billionaire* which portrays – in abstract – past, present and future in a space continuum with nano-time bubbles waiting to exist.

Port Hills June 13 2011 shows the Southern Alps with a dust cloud in front and a shattered glass window. "In the big earthquake on June 13 2011, we were in a house on the Port Hills holding hands to stabilise each other, the house rocking like an agitator washing machine, when we saw out of the window a dust cloud caused by the quake in the CBD. And this is my picture."

Jilly doesn't leave the house other than for appointments. She fills her days with her art. She is a member of a couple of chat rooms focusing on MS and mental health issues, and accesses other internet- based forums. She is also a fan of Netflix and is susceptible to a bit of binge-watching.

She says she's still processing having MS.

"When I was at my most unwell, I couldn't talk, couldn't eat, lost 10 kilograms. I'd tear up. I'd freak out

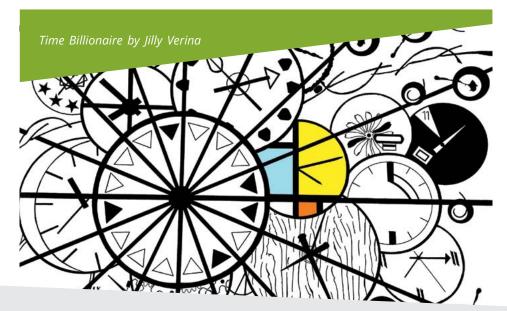


when the phone rang. It was very real." Advances in neuroimaging show drawing improves visual fluency. "It's expression without vocalisation, when trauma silences its victims by closing down the Broca's speech area of the brain."

Now, she is working on her repairing her "broken Broca". "My art is therapeutic and helps with my mental health by way of recalibrating."

And something new has happened. "I have started using colour and going back and using it in some of my original art and that's been fun."

Jilly's art features on the art website Redbubble. Go to https://www.redbubble.com/people/starbursting/portfolio?asc=u







LOVE AND SUPPORT INSPIRES RETURN TO PASSION

Professional wood turner Soren Berger, who left his craft after being diagnosed with Parkinson's four years ago, has returned to his passion following inspiration from his son.

Born in Sweden, Soren came to New Zealand as a seven-and-a-half year-old with his family. He started working with wood with his father, making toys and the beads, blocks and rods that were used in maths classes in New Zealand schools.

"This was not woodturning. It was working with wood to precise measurements within 1000th of an inch."

About 40 years ago he moved into wood turning, a more free-form style of working

Soren Berger at work

with wood, after being inspired by seeing what could be achieved with wood during a visit to an uncle in Sweden.

Initially Soren started with a stall at the New Brighton market, and from there developed a successful business producing everything from the typical bread boards, candle sticks and salad bowls to extremely finely turned vases, translucent lampshades and beautifully bold urns.

He also became an international instructor, travelling regularly to America to hold workshops.

Problems with getting medication adjusted satisfactorily and losing the physical strength to deal with a chainsaw and large blocks of wood saw Soren abandon his passion.

However, recently son Rikki has taken up the craft and is helping with the heavy side of the work and now the two are collaborating on projects.

It has given Soren the inspiration to get back into what he enjoys most, even though it has required relearning all the skills and techniques. He now has sympathy with his students. "I have had to relearn everything... none of my responses is automatic any more... now I know what my students had to cope with while they were learning what was second nature to me." He sees it in his grandchildren also, as they learn to walk, struggling along until they master the skill and it no longer requires concentration.

He believes that finding a passion or an interest is essential for people dealing with disorders like Parkinson's.

"It is important to find something that you love, that gets you involved and gets you moving, whether that's dance or Nordic walking, whatever it might be. I enjoy walking and the stationary bike. But I love working with wood, and I've been able to come back to it through the love and support of my partner, Raewyn, and Rikki."



DO YOU HAVE A STORY TO TELL?

We are continually hearing about a wide range of skills/ talents that you, the members possess. We would love to share your story in the newsletter.

Please give Lynne or Deb a call on **366 2857 ext 8 or 9** or email **frassistant@ms-pd.org.nz**

FIRST NEW ZEALAND VOYAGE "BRILLIANT"

In a first for down-under, a group of people with Multiple Sclerosis took to the water on 8 November 2018 for a coastal voyage under sail around the upper half of the North Island.

On board were MS and Parkinson's Canterbury members Ingrid Robertson, who co-ordinated the adventure on behalf of the international organisation Oceans of Hope Challenge, Eamon Reyn and Glenn Sparrow.

Diagnosed with MS in 1999, Ingrid, briefly joined an Oceans of Hope circumnavigation challenge when it called in at Auckland in 2015.

"Only two hours on the boat but it was so amazing. I immediately loved the feeling of being on the water."

Hooked, she kept an eye out for the next challenge, which came in 2017 with a seven-day voyage around the Croatian coast.

After a marvellous experience, Ingrid decided it was time for a down under sailing challenge for people with MS.

So, last November, on the Spirit of New Zealand, 40 people did a five-day voyage along the Coromandel coast from Auckland to Tauranga. There was a mix of nationalities, from Australia, New Zealand, the Netherlands, Denmark and

Jane

the US. There were men and women of a variety of ages. What they all had in common was MS.

Ingrid said the voyage was "brilliant".

"It was a dream after Croatia to bring the experience to New Zealand ... and that dream came true."

Ingrid said she could see there was some trepidation as the passengers came aboard, but everyone worked as a team "from day one".



"Everyone helped each other, sharing what they had to overcome. I looked at the faces again at the end of the voyage and there were big smiles and new friendships made."

Ingrid, who worked in the security industry for 24 years before changing tack and studying business administration, certainly likes a challenge, having bungy-jumped and sky-dived in the last five years. She cites gym sessions at Multiple Sclerosis and Parkinson's Canterbury and support from the society's physios and nurses for helping her maintain fitness.

"I think you can get used to things and just accept what you think you can't do. I found that the group on board the Croatia trip were really inspirational. You can prove something to yourself which gives you confidence about what you can do. You might be surprised with the result."

The same thing happened with the New Zealand trip. "One of the participants got up and went to the toilet and then realised 'Where's my stick?' He hadn't noticed he wasn't using it."



The Oceans of Hope Challenge is part of the Sailing Sclerosis Foundation, founded by Danish doctor and sailor Mikkel Anthonisen. Visit **www.oceansofhope.co.uk** for more information.









/2020 FNTFRTAINMENT BU

We are happy to announce that we will once again be a place where Entertainment Books and Apps can be purchased through for 2019. The new 2019/2020 Books and Apps will be released earlier this year, in early April, meaning you will have more time to use the offers. If your family

or someone you know does or might want to purchase an Entertainment Book or App, please make sure they purchase through us as 20% from each purchase goes back to us for our fundraising. With hundreds of up to 50% off and two for one offers for restaurants, takeaways and activities,

your Entertainment Book or App pays for itself within a few uses!

We are now able to take pre-orders via our unique ordering website address

- https://www.entertainmentbook. co.nz/orderbooks/13x4351

With your help we can make this another successful fundraiser.



Chapman Tripp, E B Milton Trust, William Toomey Charitable Trust, Jones Foundation, PAC Fund and MU Welfare Trust Board





























MAINLAND

FOUNDATION



Four Winds





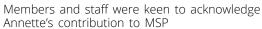




ANNETTE MACFADYEN'S FAREWELL













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