MS+PD

Multiple Sclerosis and Parkinson's Society of Canterbury (Inc)

May 2015

YOUR STORIES:

INGRID: OCEANS OF HOPE

FAY: GATEWAY ANTARCTICA

ROD: UPBEAT OUTWARD BOUND

'IT REALLY MAKES MY LEGS FEEL ALIVE'

www.ms-pd.org.nz

PRESIDENT'S MESSAGE

ANNUAL GENERAL MEETING

It was very heartening to have a good turnout of our members at our AGM held in March. It is encouraging to see your interest in the Board of MS and Parkinson's Canterbury, who represent you as members of the Society. Feel free to make contact with any of us Board members with your ideas or feedback.

Welcome to the 4 new board members Marion Savill, Ingrid Robertson, Stacey Rod, and Peter Scott. We appreciate your commitment to contribute in this important volunteer role. Copies of the Annual Report are available at the office.

STRATEGIC PLANNING

This is the process where we consider and decide on our long term objectives and goals for MSP Canterbury and is the next task on the agenda for the Board. We will create a vision of where we want to be in five years time. The Board and staff will have 2 planning sessions with Garth Nowland Foreman in June and July. In the next newsletter I will share with you some of our ideas and long term plans.

ANNUAL SUBS

So far 45.5% of members have paid – many thanks for responding to our February mail out. And thanks also to those who were able to make an extra donation on top of your sub – this really helps contribute to the running of our services.

WORLD MS DAY - MAY 27

We were delighted to listen to Professor Miller, who spoke at the Transitional Cathedral. Originally from Christchurch, David Miller works internationally and his update on MS research and treatments was appreciated by all of us who came along. The Oceans of Hope video was a bonus, too.

It was a very emotional morning on the Auckland water front in early May when a group of us welcomed the Oceans of Hope 67-foot yacht with its crew of 10, of whom 6 have Multiple Sclerosis. The yacht is on a 17 month round the world trip, and was in Sydney for World MS Day 27 May. Two New Zealanders with MS, Russell Watts from Rotorua and Neil Barnett from Akaroa are part of the crew of 10 for the Darwin to Singapore leg of the trip. The Oceans of Hope yacht was founded by Dane Dr Mikkel Anthonisen who found that sailing could be a very positive and empowering experience for people with MS. A large Danish team shares crew duties and changes over at the various stop overs in different countries. Biogen Idec is the Official Partner of Oceans of Hope – Sailing Sclerosis round the world venture, a wonderful story.

Best regards

Malcolm Rickerby
president@ms-pd.org.nz

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OUR TEAM

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MANAGER'S MESSAGE

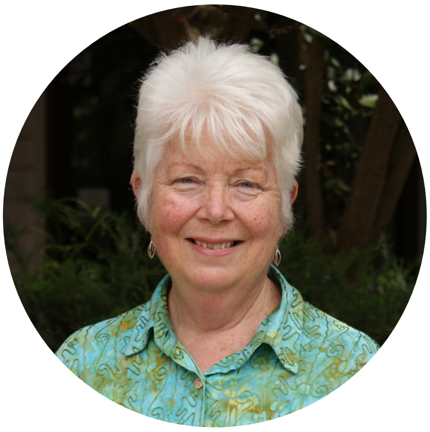
Greetings everyone.

Many thanks for your warm welcome to me in the manager's role. I am very much enjoying the opportunity to meet members on a variety of different occasions, such as at gym sessions, the movie and quiz nights, the Ashburton morning tea and MS support group, Parkinson's spouses' group, Upbeat group, MS lunches, home visits, and Living well with Parkinson's sessions.

I want to acknowledge all our wonderful staff whose commitment and professionalism really enhance our services for members. Here's an introduction to some newer staff and farewells to two who have left this year.

Nicola Morrison Admin Assistant. Nicola who grew up in Christchurch and later spent several years living in Japan, has been with us since November last year. Nicola's previous admin experience, her attention to detail and the calm warm approach she brings to her work mean that she is a welcome addition to our team here. Nicola enjoys ballet classes and her two cats.

Frances Young Nordic Walking Instructor. Frances lives her belief in the importance of a healthy balance between body and mind. She is a professional counsellor and specialist in pain management and also teaches Nordic walking at WEA. Frances is committed to helping our organisation make a beneficial difference in our community, and we are utilising her counselling and group facilitation skills as well as Nordic walking.



Lynne Trowbridge Funds Development Manager. Lynne is an experienced senior fundraiser who has worked in the not for profit area for 15 years. Lynne's previous successes at the Royal Foundation for the Blind, Home and Family, and Council of Social Services mean that we are fortunate to have her on board with us. Lynne starts her role at the end of May and is excited about getting to know members through our different activities and events.

Cate Walton Volunteer Resource Nurse. Cate works as a volunteer alongside Bronnie our Parkinson's Community Nurse Educator. Read Cate's introduction on page 4.

We farewell and thank two staff members who have resigned this year –

Sharron Emslie, former Nordic Walking Leader. For four years the Nordic walking group with Sharron as leader was so committed that they met each week to walk, no matter the weather, even in snow. Sharron leaves to devote more time to her work in specialised areas of child care.

Jan Saville, previously Admin Assistant and most recently Social Activities Coordinator brought liveliness and warmth to her roles with us. Jan will be focusing more on her catering business in 'Dorothy', her purpose built caravan.

Our services are always developing to meet the needs of members For example in June we will launch a new Christchurch MS support group, and we have added 2 new Parkinson's Spouses morning teas for North Canterbury.

Robin Furley
robin.furley@ms-pd.org.nz

4 & 5 SEPTEMBER 2015

ANNUAL STREET APPEAL

You can make a big difference by donating a couple of hours of your time to raise funds for our services.

If you have strong networks please consider forming a collection team. Or maybe your children or grandchildren can organise a team or a mufti day in their school?

We will ensure that everyone will have a sign, bucket and stickers to give away to those who donate. We will also take care of banking the money, so you do not have to worry about having too much money at any time.

If you would like more information or have questions contact **Denitsa** or register as a volunteer/team leader on http://www.ms-pd.org.nz/volunteers-needed/

MEET CATE - OUR VOLUNTEER NURSE

Hello everyone.

My name is Cate Walton and I am a Registered Nurse (RN) who works alongside Bronnie at the MS & Parkinson's Canterbury for 6 hours a week, usually Tuesdays.

I grew up and lived all my life in Wellington until 2012 when my husband Chris and I moved to Christchurch so he could join the team at SCIRT. We are enjoying living in Christchurch very much, love the city and the people and have settled into our new home with our two dogs.

I worked as a RN at Porirua Psychiatric Hospital and later after completing my Plunket Certificate, I have worked as a Plunket Nurse, both in the community and as a PlunketLine TeleNurse. I have also worked as a Practice Nurse, a Research Nurse and after completing my training to be an Early Childhood teacher, in education as well.

I completed a Master's in Nursing in 2006 through Massey University and a Graduate Diploma in Social Science Research in 2011. Currently I am studying towards a Master's in Counselling at Canterbury University.

I am also the mother of four adult children, three boys and a daughter. The boys live and work in Wellington and my daughter is working at the University of Minnesota in Minneapolis. We are hoping that we may get to visit her there before she moves on to other places.

I like knitting and reading and spending time on Skype and Facebook keeping up with my children's lives. I also love to learn new things and meet new people.

I have a special interest in how people support each other through such activities as volunteering and other forms of social support.

I am looking forward to meeting and making connections with members and hope we get to meet soon!

Many thanks

Cate Walton, NZRN, MN

YOU ARE INVITED: NEW GROUP FOR PEOPLE WITH MS AND THEIR SUPPORT PERSON

WHY MIGHT YOU BE INTERESTED IN COMING ALONG?

- **Support** – listening and learning about commonalities and differences, to feel you are not alone, and link with others who understand what you are going through
- **Sharing experiences, thoughts, ideas** – to learn how other people adjust to situations related to MS; learning to reframe experiences as a resource rather than a problem
- **Information** – to learn more about MS, including current research
- **Encouragement and optimism** – inspiration, improved quality of life and ideas about how to achieve the best outcome, exploring new ways of learning or acquiring new skills
- **Change, grief and loss** – support can help acknowledge a loss or adapt to changes of a longterm condition

Guest speakers can be invited to talk about topics of interest to the group. We welcome your thoughts and ideas.

Judy will work alongside the MS group, while Robin works alongside the group of partners or friends/carers. We'll conclude the evening with time for all to mix and mingle over a hot drink.

First meeting - Wednesday 24th June, 6pm – 7.30pm. RSVP to Judy by Friday June 12th.

Location - Board room at South Library Service Centre, entry through the side door. Parking just outside or on Colombo St – please note library car park is closed after hours.

NOTICEBOARD

MS LUNCH CLUB

This group is for members with MS, who have been living with the condition for many years. If you would like to join, please contact Judy on 03 366-2857 ext. 3. The Lunch Club meets on the first Wednesday of the month at noon.

3 June – Antiques and collectables

1 July – Yummy winter soups and exchanging recipes

5 August – Sing-along

PARKINSON'S UPBEAT GROUP

MID-WINTER CHRISTMAS DINNER & DANCE

@ the Papanui Club, 310 Sawyers Arms Rd, Bishopdale, Christchurch

Friday 12 June from 6:45 pm

PARKINSON'S SPOUSES GROUP

NORTH CANTERBURY members – please note two extra locations to meet up on June 16 and October 15.

16 June @ Café Euro, Avonhead Mall, Merrin St, phone 358 8490 **&** @ Coffee Culture Kaiapoi, 121 Raven Quay, phone 03 3277255

23 July @ Spouses Info Day at the Oxford Terrace Baptist Church, 288 Oxford Tce

20 August @ Terra Viva, Cnr. Roydvale Ave/ Wairakei Rd, phone 358 7978

15 September @ Arancio Café, Eastgate Mall, phone 381 0461

15 October @ Station One Café, 509 Papanui Road, phone 982 1118 **&** @ Artisan Café & Bakery, 18 High Street Rangiora, phone 03 3118837

PODIATRIST

Our excellent value podiatrist service is available on the first Tuesday of the month. MS & Parkinson's Canterbury subsidises these visits from donated grant funding. Bookings are essential due to the popularity of the service.

2 June ◆ **30 June** ◆ **4 August** ◆ **1 Sept**

Cost is $25.

If you have booked and cannot attend you **must** phone Annette to cancel or you will be charged for the missed appointment.

MEN'S SOCIAL GROUP

(MS & Parkinson's)

16 June & 18 August @ Becks Alehouse Sydenham, 4:30-6 pm

Look for … the pukeko on the table.

QUIZ NIGHT

Book your table now!

Sunday 26 July, from 6 till 9 pm

@ the Papanui Club, 310 Sawyers Arms Rd, Bishopdale

$15 per person; up to 8 people per team

ANNUAL STREET APPEAL

We need a couple of hours of your time - you can make a difference!

Friday 4 September & Saturday 5 September 2015

Register as a volunteer at http://ms-pd.org.nz/volunteers-needed

FUN WALK

Save the date and start training/moving!

Sunday 2 November 2015, 10 am
North Hagley Park, Christchurch
More details will follow soon.

worldMSday
www.worldmsday.org

2015: IT IS ALL ABOUT ACCESS

Since its inception in 2009, World MS Day has grown to include people from more than 78 countries. World MS Day brings the global MS community together to share stories and provide the public with information about MS and to raise awareness of how it affects the lives of more than 2.3 million people around the world.

This year's campaign theme is access to diagnosis, treatment and support; to buildings, travel and leisure facilities; to education, training and employment - access to the same tools, services and facilities that people who do not have MS enjoy.

The barriers to access faced by people with MS vary depending on where they are and what their symptoms are. By sharing people's experiences, World MS Day hopes to improve the understanding of the complex nature of MS in the community.

Read our members' stories on page 8 - 9.

HELP US LEARN MORE ABOUT HOW PARKINSON'S AFFECTS YOU

Over the past 8 years, we've been following nearly 200 people with Parkinson's, in what has grown to be an internationally significant study. Our clinical direction comes from movement disorders specialist neurologist, Professor Tim Anderson, while Professor John Dalrymple-Alford drives the neuropsychological aspects of the research.

The findings have been at the forefront of efforts to define and understand the impact of the cognitive impairment Parkinson's can cause.

The New Zealand Brain Research Institute is looking for 300 Cantabrians with Parkinson's to take part in a brief screening test. This involves a session of appoximately 30 minutes, assessing your memory, reasoning and thinking abilities.

Depending on the results of that screening session, you may be invited to take part in one of the more in-depth projects, involving more extensive memory testing and MRI brain scans.

For more information contact **Leslie Livingston**, 378 6257, leslie.livingston@nzbri.org or **Marie Goulden** , 378 6348, marie.goulden@nzbri.org.

A SPECIAL THANKS TO THE FOLLOWING ORGANISATIONS FOR THEIR SUPPORT!

Air Rescue and Community Services
COGS Community Organisation Grants Scheme
thetrust ASHBURTON
TRILLIAN Trust Inc. SERIOUS ABOUT YOUR COMMUNITY
TRUST AORAKI
Christchurch City Council
Lane Neave LAWYERS
the Southern trust
THE LION FOUNDATION
Bayer
PAPANUI CLUB
The Dublin Street Foundation
First Sovereign
Pub Charity
Jones Foundation
Community TRUST Mid & South Canterbury
THE TRUSTS Community FOUNDATION
MAINLAND FOUNDATION Proud to Support Our Community
NZCT NZ COMMUNITY TRUST
William Toomey Charitable Trust
Four Winds FOUNDATION
NIGEL THOMPSON MOTOR COMPANY
Lottery Grants Board Te Puna Tahua LOTTO FUNDS FOR YOUR COMMUNITY

THE MOTOMED IS IN THE GYM!

The Motomed is here and is up and running in the gym. Thanks to all the donations and fundraising, we were also able to purchase the arm attachment which was a great bonus and extends the use of the machine to lots of our members.

Those lucky enough to use it so far have loved the opportunity to bike again after not being able to access our other bikes. They are benefiting from the assist function of the Motomed as it is helping them bike even if they don't have sufficient muscle strength.

A number of members have commented how alive their legs feel after using the Motomed and have been surprised at how much they can assist the biking motion despite having muscle weakness. One member fed back that 'It really makes my legs feel alive'. The Motomed has certainly brought many smiles to the faces of those who use it.

Once again thanks to everyone who made a donation for this machine.

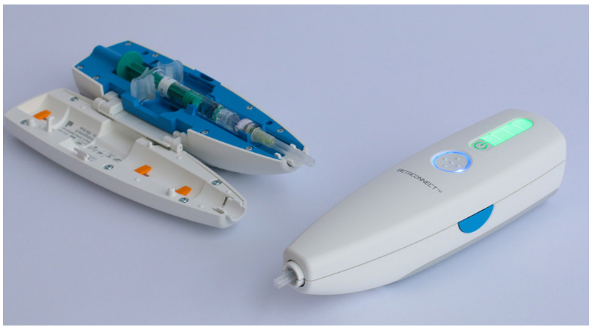
If anyone thinks they would like to use the Motomed, then please contact Rachel or Maree to discuss further.

NEW AUTO INJECTOR PEOPLE USING BETAFERON

The BETACONNECT auto injector will help people optimize their treatment as the system provides notifications based on client preferences, such as audio or visual reminders, and feedback on injection depth and speed. People can opt to share the information with their healthcare providers to further improve treatment.

Bayer marketed the product first in Germany and it is now available in New Zealand. The MS & Parkinson's Canterbury has several and is replacing the older injectors as required. The New BETACONNECT Auto-injector has a "softer touch" and doesn't require priming although it does need to be charged via a computer or electrical outlet.

Bayer indicate there is less bruising at the site of injecting. If people using the older injector wish to change or would like a demonstration please contact Judy and book a time.



INGRID ROBERTSON: MY OCEANS OF HOPE EXPERIENCE

When I applied to go on Oceans of Hope, I didn't honestly think I would get on - I knew there would be lots wanting to experience this.

I don't have any sailing experience. My Dad had a Sunburst yacht when we were little, but I am not really sure if that counts. I have been on friends' boats but I have never had to do any work!

So when I got accepted I was so excited!

On the day itself, first we got the run down on what we needed to do. We were all sitting in the boat and it was spitting. But then we went out in the harbour and it was beautiful - the sun was on our side!

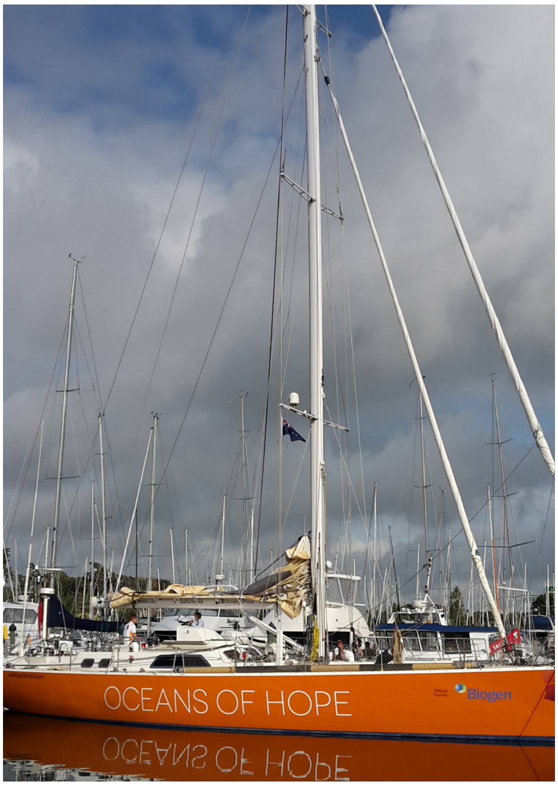
We all had the opportunity to steer and you could help put the sails up and down if you wanted to. Gen, Kristian and Louise were great, they made us all feel like nothing was a problem. I talked with Kristian about what happens when they finish this journey and he said they may be based in Europe and do trips from there. I asked how I could qualify as my balance wasn't 100% and he said -

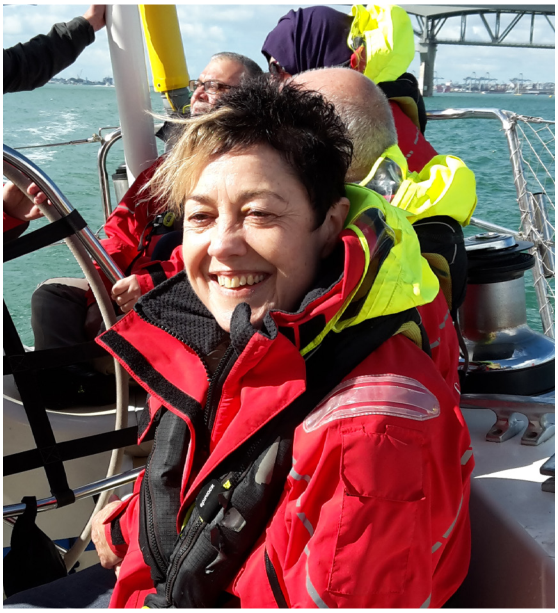
"When we are on a boat we are all the same as everyone needs to hang on to things..."

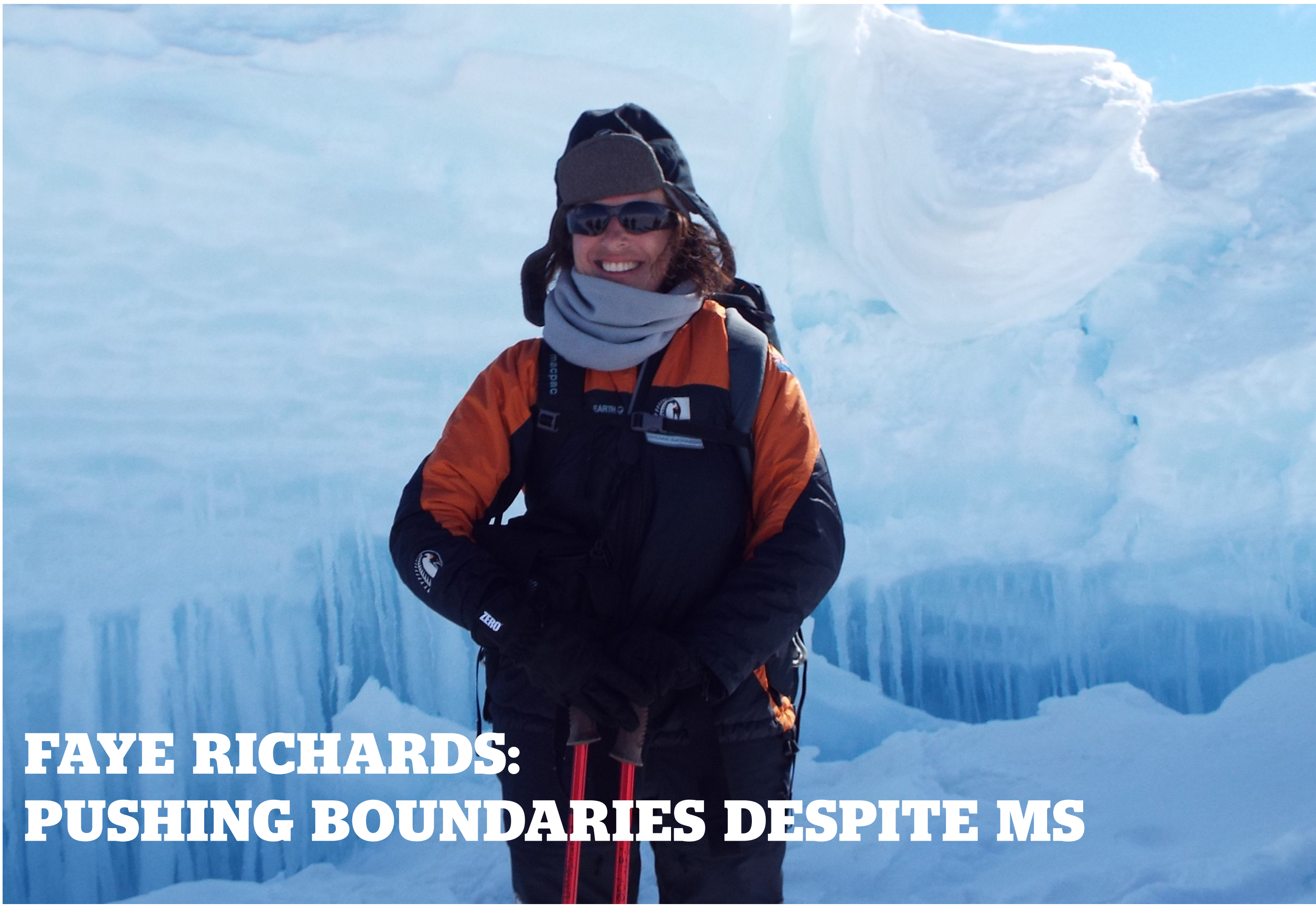
And that is so true. They had a gentleman on one legs of the trip and he said that for two weeks he didn't have to use his stick and felt great!

I met some great people and had a brilliant time. Everyone had smiles on their faces! It is nice to do some things with others who are in the same boat (excuse the pun...)

My little goal now is to follow their blogs and go to Europe if they end up still doing the trips - I would love to sail round the Caribbean for a couple of weeks. ◆







FAYE RICHARDS: PUSHING BOUNDARIES DESPITE MS

In 2003 I was diagnosed with the potential of having Multiple Sclerosis after losing colour to the left eye for a few weeks. Life continued on without incident until 2008 when I experienced vertical double vision, where the question mark over Multiple Sclerosis was taken away and it became a certainty; You have Multiple Sclerosis. In 2009 my ability to walk was impaired and much physiotherapy was needed to retrain me to walk.

Multiple Sclerosis has not deterred me from living to the best of my ability; in fact it has spurred me on to gain my Bachelor in Applied Sciences, Environment Major. This allowed me to realise a dream of getting down to Antarctica. I have been carrying that dream for quarter of a century stemming back to my NIWA days.

My degree was the minimum requirement to do the Post-Graduate Certificate in Antarctic Studies. I completed my degree in June 2014 and applied for the Antarctica course soon after, starting with the University of Canterbury and Gateway Antarctica in November 2014 which saw me on an ice-shelf at Windless Bight Christmas Day in Antarctica surrounded by my fellow classmates and tutors. In 2014 I also achieved getting my Tracks license and my Level 1 Basic Traffic Controller.

Aside from the studying I have been busy with my music, enjoying most of all making music videos; I currently have six music videos on You-Tube under Faye Richards, with “The Box” depicting life as a disabled person.

Currently I am working on three music videos; one song was written about my spray painting of an old Mark 2 Cortina (Donkey) in 2003 and was used to complete my National Certificate in Performing Arts Technology, another one is the song “Short-tailed Bat”, where the lyrics not only pertain to the plight of the short-tailed bat, but also deal with disabilities, and the last one “Bell Ringer”, which will see me falling from a trapeze.

How has Multiple Sclerosis affected me? I move more slowly, I get tired but it is definitely not enough to stop me from having mad ideas of where to go next.

I hope this article inspires you to be the best you can be. ◆

I HAVE PARKINSON'S DISEASE.

Author: Unknown

It is not catching or hereditary.

No one knows what causes it, but some of the Dopamine cells in the brain begin to die at a faster rate. Everyone slowly loses some Dopamine cells as they grow older. If the cells suddenly begin to die at an accelerated rate, Parkinson's disease develops. It is slowly progressive and usually occurs as people get older. Medicine can help. I will take newer, stronger kinds over the years. Some will make me sick and have lots of side effects. Stick with me. I have good days and bad days.

TREMORS. You are expecting me to shake. Maybe I will, maybe I won't. Medicine takes care of some of the tremors. If my hands, feet or head are shaky, ignore it. I'll sit on my hand or put it in my pocket. Treat me as you always have. What's a little shakiness between friends?

MY FACE. You think you don't entertain me anymore because I'm not grinning or laughing. If I appear to stare at you or have a wooden expression, that's the Parkinson's. I hear you. I have the same intelligence. It just isn't as easy to show facial expression. Swallowing is a problem so I may dribble. This bothers me, I try not to.

STIFFNESS. We are ready to go somewhere and as I get up, I can hardly move. Maybe my medication is wearing off. This stiffness or rigidity is a part of Parkinson's. Let me take my time. Keep talking, I'll get there eventually. Trying to hurry me will not help. I can't hurry. I must take my time. If I seem jerky when I start out, that's normal. It will lessen as I get moving.

EXERCISE. I need to walk and work every day. I will do as much as I can. It may be a slow walk but I will get there. Remind me if I slump or stoop. I don't always know I am doing this. I try to do as much work as I can but some tasks are now beyond me. Encourage me to keep trying. Better to walk behind the grass mower slowly if I can, than to ride on one.

MY VOICE. As my deeper tones disappear, you will notice my voice is getting higher and wispy. That's Parkinson's. It has nothing to do with what I ate or how early I went to bed. I may nap during the day. Let me sleep when I can. I can't always control when I am tired or feel like sleeping.

EMOTIONS. I must try to avoid stress and confrontation. I know Parkinson's can make me difficult to live with but I do try my best. However my moods can be good and bad. Pain is a constant companion and is usually caused by muscles cramping up anywhere in the body so this can make me a bit more than uptight.

PATIENCE. My friend, I am the same person, I've just slowed down. It is not easy to talk about Parkinson's, but I'll try if you want me to. I need my friends. I want to continue to be part of life.

THANK YOU for reading this.

◆

Share your stories with us

If you have tried something new, if you found a way to deal with limitations or even if you had a great day - write it down, add a photo or two and send it to the Society at events@ms-pd.org.nz

SPOUSES INFORMATION DAY

Thursday
23 July 2015
10am

BODY, MIND & SPIRIT

10:15
"Getting up from the floor"
Rachel Bladon, Physiotherapist

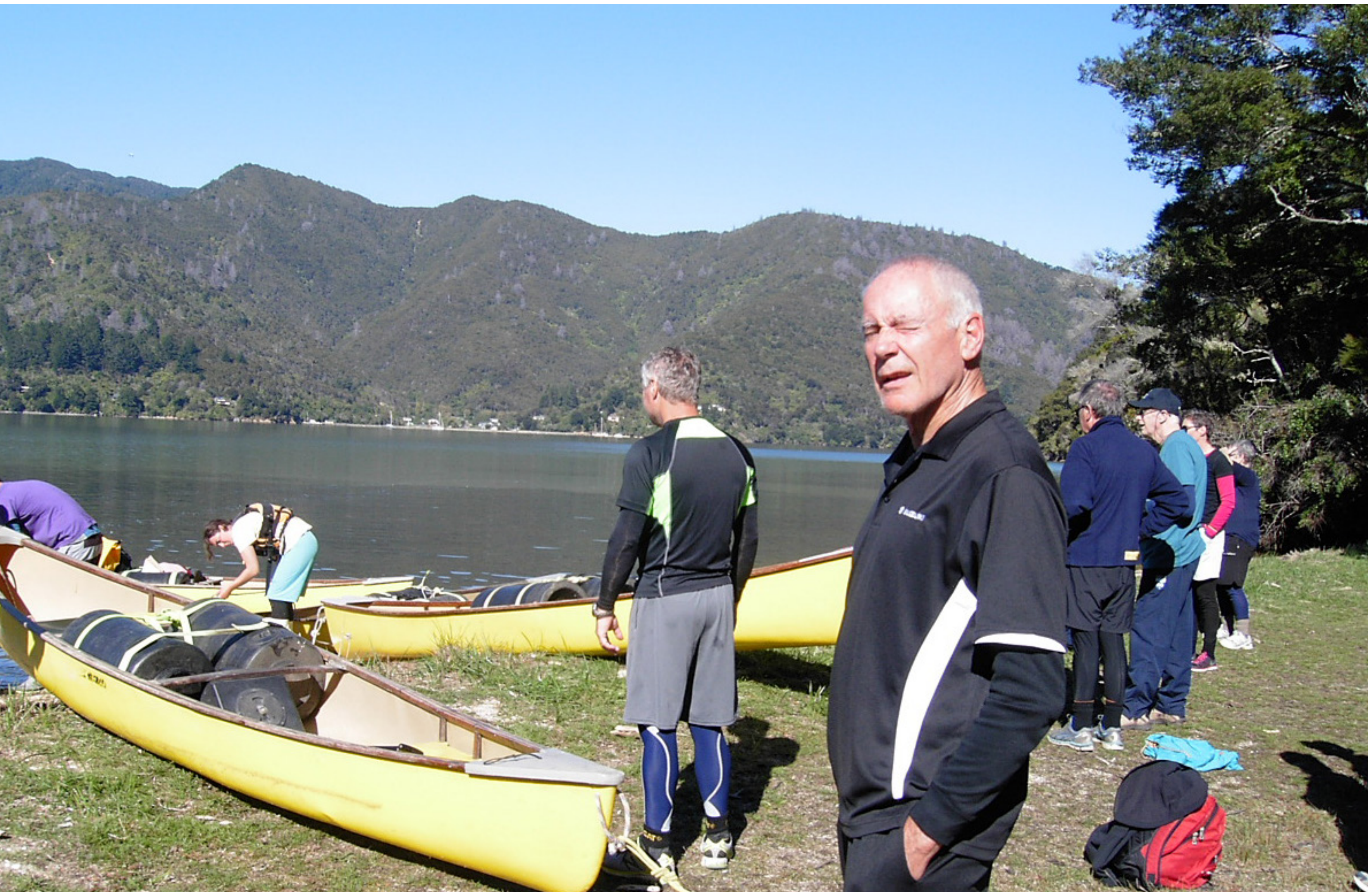
11:15
"Living with a chronic condition"
Elizabeth Hamilton, Social Worker

12:00
"Looking after your brain"
Philippa Cosgrove, Alzheimer's Educator

Oxford Terrace Baptist Church
288 Oxford Terrace (corner Madras Street)

Charge: $5.00 per person to help cover the costs.

As seats are limited, please RSVP to Bronnie by Thursday 16th July
b.alexander@ms-pd.org.nz



I DID THE UPBEAT OUTWARD BOUND COURSE

I recently joined nine other very anxious Parkinson people and four carers and supporters at Picton to head for Anakiwa, for what was to prove to be a life changing six days for all of us. It was an incredible experience which words cannot really describe, but I'll do my best.

Up early every morning for exercise and a run, or fast walk for those of us who couldn't run. A dip in the sea and a cold shower near the beach. Breakfast and then the start of the day's activities. An Outward Bound day finishes around 8 pm.

I never considered I could keep up with such a routine but like the other participants I realised with the ' I CAN ' attitude, instilled in us by the instructors, more is always possible. This aspect of the course really made it Life Changing for me.

Exercise stretched us, but we all did remarkably well for a group that had strengths in different areas. Teamwork brought us all together, from the dining room preparation to lots of verbal support for the tricky bits like the high wire walking 10 metres up in the trees!

Every day had an element of surprise, as the instructors had an uncanny knack of delaying telling us what was in store next. However these instructors had a remarkable ability to push us to our limits. At the same time they showed compassion when they saw things were getting a bit tough for some. They more than once told us how impressed they were by our tenacity in coping with our disabilities. There were a few tears of sadness and happiness along the way.

This was a first for me, spending six days with Parkinson's people. Eight women and 6 men all with a Parkinson's connection living and laughing in close quarters, sleeping in 14 bunks in the one dorm.

Only two of us were from the South island sadly, but the North Islanders were great and I now have a group of friends around NZ, who are committed to stay in touch with each other.

Yes, I can highly recommend the Upbeat Outward Bound course.

By Rod Logan

◆

HOW OUR RESOURCE NURSE CAN HELP YOU

Both MS & Parkinson's are long term conditions, so over time your symptoms may change and it could be helpful to talk to the nurse for information or if you require specialist assistance. Management focuses on individualised plans to assist in living well with your symptoms, which may involve referral to the wider health team in the community.

Your GP is your first contact person, but if you have a question or concern relating to MS or Parkinson's, our specialist nurse may be able to help. One of the most important services we provide is the nurses' home visits, made at a time and place to suit you.

Our nurses do not have direct access to your discharge letters or hospital appointments. Should you have significant changes that require a hospital admission we rely on you to let us know, if you wish to. Or you may ask your GP to send us a copy of your discharge letter.

We do appreciate you keeping us up to date and staying in contact with staff.

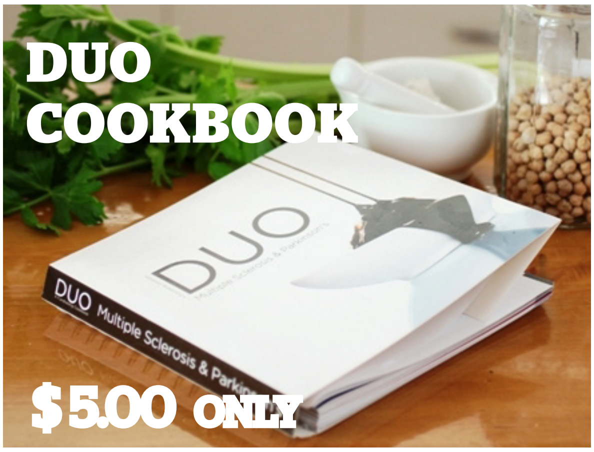
As we work outside the centre at times, and your call is important to us, please leave a message and we will contact you as soon as possible. If you have no response please ring again, as sometimes messages can be difficult to hear. If your call is urgent, please call Robin or Annette for assistance.

Judy McKeown 366 2857 ext 3
j.mckeown@ms-pd.org.nz

Bronnie Alexander 366 2857 ext 4
b.alexander@ms-pd.org.nz

CONTACT JUDY (MS) OR BRONNIE (PARKINSON'S) IF:

- you want a review or just a chat
- you are unwell
- you are unsure if you're having an MS relapse
- you have an issue or concern.
- you wish to discuss symptom management
- you or your partner is in hospital, or to update us
- you have any questions before or after clinic appointments



A GREAT GIFT FOR ANYONE INTERESTED IN FOOD! BUY NOW AND STOCK UP FOR CHRISTMAS!

TO FUNDRAISE FOR THE SOCIETY ORDER ONLINE NOW OR SHARE THE LINK

www.entertainmentbook.co.nz/orderbooks/13x4351