

MS+PD



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

May 2010



In this Issue:

Changes to Gym Times

School Holiday Programme

Welcoming New Staff

www.ms-pd.org.nz



We're Not for Profit!

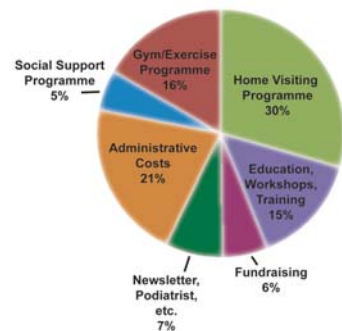
Did you know that the Society is not for profit? Those of us working every day to support people with MS and Parkinson's sometimes forget that our members are most likely quite unaware how the Society is run.

We are a non-profit body, which relies on many different income streams to bring you the services you rely on, such as: Home Visiting Programme, Gym & Exercise Programme, Social Support Programme, Newsletter, Website and Workshops. The various ways the Society raises funds are not guaranteed and vary from year to year. This is why, from time to time, the Society must rely on its members to help raise money.

What we're up to this year

This graph represents where the Society's money will be spent in 2010. You'll notice that our largest expenses are the services we provide our members.

2010 Expected Expenses



How we'll fund these programmes

Since we are a non-profit organisation we search far and wide for our funding. A few of these sources are:

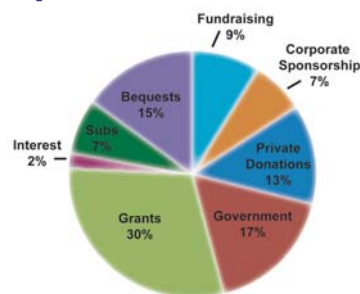
- Fundraising – this includes events such as a fun walk, quiz or theatre night and the Carnation Day Street Appeal
- Private donations from our members and the wider community
- Government contracts
- Grants – this includes both private trusts/foundations and gaming trusts
- Bequests – these are legacies left to the Society in a person's Will
- Subscriptions/Annual Donations – by focusing on

other funding streams we aim to keep this figure as small as possible

- Interest earned on money invested by the Society

This graph represents where the Society expects its income to come from in 2010. This is just an estimate because none of these income streams are guaranteed and the Society must be prepared to find new ways to raise money if one of these avenues fails.

2010 Expected Income



I hope this gives you a better understanding about how the Society works, where the money comes from and how it is spent. It is important that our members get involved in our fundraising efforts so we can grow the Fundraising portion of the graph and rely less on grants and the government, whose funding can vary greatly from year to year.

If you, as our member, are unable to get involved, please ask friends or family to take part on your behalf and help the Society raise the funds needed to provide support information and education for people with Multiple Sclerosis and Parkinson's throughout Canterbury.

Yours Kindly,

Malcolm Rickerby
President
03 338 1770
malcolm.jeanie@slingshot.co.nz



Will You Participate...Fun Walk 2010?



A group participating in the 2009 Auckland Fun Walk

The Multiple Sclerosis and Parkinson's Society of Canterbury is looking to team-up with other MS Societies around the country to hold a National Fun Walk. Wouldn't it be great if all throughout New Zealand there are hundreds of people raising thousands of dollars with just one goal: **To Support people with MS and Parkinson's.**

This event could be a reality in November 2010, but only if our members say, 'YES, WE WILL PARTICIPATE!'

Running for a Reason

Although she completed three triathlons over a three month period, it was during the third and final one that Melissa Cameron (partner of Board Member Mike Cameron) decided to raise money for the Society.

'This was because I started this challenge to do something for myself. As a mother of two who has never been particularly sporty, I wanted to set a positive outlook towards sports and healthy living for my girls.'

Once Melissa completed the first two triathlons, she felt that not only could she reach her fitness goals, but perhaps she could now raise money for the Society to help them reach their goals.

Before the dreaded date in December to do the last triathlon, she started asking her friends and family to sponsor/donate money for her to complete this event. Some people even offered to double the amount they pledged if she did it in less than 1hr 30mins, which was her goal. The final triathlon consisted of a 250m swim,

We need you to take action today. Phone **Annette on 366 2857 ext. 6** and tell her that you, your family, friends, neighbours and/or co-workers will mark it in your diary to be a part of this national event. If we do not have at least 50 people saying they will take part, we will not be able to organise this event and Canterbury will not be represented in this inaugural walk.

Fun Walks are a major fundraiser throughout the world:

- In America 'Walk MS' has been hugely successful. Their slogan is: Because every movement you make and every dollar you raise supports the mission to create a world free of MS. In 2009 they raised over \$3 million!
- In Australia 'Unity Walk for Parkinson's' drew over 1,500 people in 2009. This event began in America and has since become a worldwide phenomenon. It is the largest grassroots event raising Parkinson's awareness and funds to find a cure.

Let's work together to create a nation-wide event like the examples above. If all the Societies work together, it will be amazing the awareness we can create for MS, Parkinson's and Societies providing necessary services throughout New Zealand. Register your interest **TODAY**, so our Society can be a part of this event.

20km bike ride and a 5km run and Melissa was pleasantly surprised when she finished in 1hr 16mins.

'I managed to raise \$700 for the Society' says Melissa. 'Providing you don't mind asking people to put their hands in their pockets, it is relatively easy to raise funds in this way. If only 10 people per year managed to do what I did, we would have amassed \$7,000!'



'It was the best feeling ever to complete my own personal goal, but I was also very grateful to all my friends and family who continue to support Mike and myself and our girls living with MS in the family.'





Shirley, Jan, Raewyn, Annette, Donna, Jenny, Lindsey, Sandy, Janet, Jessie

Meet The Staff

For your reference, listed below are the staff, their role at the Society, extension numbers and their hours of work.

**Jenny Boyer
Manager** **Ext. 2**
Monday – Thursday 8.30am – 4.30pm
Friday 8.30am – 1.30pm

**Annette MacFadyen
Office Manager** **Ext. 6**
Monday – Friday 8.30am – 4.30pm

**Sandy Connolly
MS Resource Nurse** **Ext. 3**
Monday – Thursday 8.30am – 4.30pm
Friday 8.30am – 2.00pm

**Janet Wills
PD Resource Nurse** **Ext. 4**
Monday – Wednesday 8.00am – 2.30pm
Thursday 8.00am – 12.00pm

**Donna McLelland
MS & PD Outreach Nurse** **Ext. 5**
Monday – Wednesday 8.30am – 2.30pm
Friday 8.30am – 12.00pm

**Rachel Bladon (Jessie Maternity Leave Cover)
Physiotherapist** **Ext. 1**
Wednesday 8.30pm – 5.00pm

**Jan Rait
Exercise Supervisor** **Ext. 1**
Monday 9.30am – 4.00pm
Wednesday 1.00pm – 4.30pm

**Raewyn Turner
Administration Assistant** **Ext. 7**
Monday & Tuesday 9.30am – 3.00pm
Thursday 9.30am – 3.00pm

**Shirley Noonan
Social Activities Coordinator** **Ext. 8**
Tuesday 9.30am – 1.00pm
Wednesday 9.30am – 1.00pm
Thursday 9.30am – 2.00pm

**Lindsey Kerr
Project Coordinator** **Ext. 9**
Monday – Wednesday 8.30am – 4.30pm

**The Society's phone number
is: (03) 366 2857**

Hello and Good-bye for Society Staff

Sandy Connolly – MS Nurse

Sandy started working with us several weeks ago and has already met some members. She will be contacting you and offering you the opportunity to meet her either in your home or here at the Society. Sandy is a Registered Nurse with experience in chronic conditions.



Thank you for coming to work with us Sandy, we do hope you enjoy being part of our team. If you would like to talk to Sandy she can be contacted on 366 2857 ext. 3.

Shirley Noonan – Social Activities Coordinator

We extend a very warm welcome to Shirley who is organising and attending the various Morning Teas and is responsible for the Total Mobility Voucher Scheme. We hope you will enjoy your involvement with the Society, Shirley.



Farewell to Margaret Chapman

Many of you will be aware that Margaret 'retired' from her position as MS Nurse in March after 14 years to the day since she started working for the Society.

We thank you Margaret for all your hard work, dedication and loyalty to the Society over this time. Your sensitivity, kindness and respectful, non-judgemental approach will be greatly missed by us all. You have been a big part of our member's lives for many years, so on their behalf and from all your friends here, we wish you long and happy lazy days of retirement.

World MS Day

Did you know that 2 million people in the World have MS? The second international World MS Day will be held on 26 May 2010 and aims to raise awareness and mobilise the global MS movement.



For more information or to become a supporter of World MS Day, visit www.worldmsday.org.

World Parkinson's Day



World Parkinson's Day this year was held on 11 April 2010 and was an important opportunity to boost awareness about Parkinson's Disease and to show support for those diagnosed. People throughout the world rallied together for this significant event. Currently, there is still no cure for Parkinson's and it is hoped that by taking a unified approach, new research and treatment innovations will result.

How you can help a person with MS or Parkinson's in your Community

By remembering the members of the MS and Parkinson's Society in your Will, you can secure the future programmes the Society provides. The sample request below may be useful, but we always recommend that you seek legal advice from your Solicitor when adding a request to your Will.

SAMPLE BEQUEST

I give \$ _____ or _____% of my estate to The Multiple Sclerosis and Parkinson's Society of Canterbury (Inc), to be applied for its general purposes. A receipt taken by my trustees as being given on behalf of that beneficiary will be a complete discharge to my trustees for this legacy.



Resources on Complementary Therapies

Donna McLelland, MS & PD Outreach Nurse

The following is an article written by our staff member, Donna McLelland. This information is for your interest only and is not to be seen as a recommendation by the Society as a mainline treatment or medical advice.

Complementary therapies are sometimes used alongside traditional medication for the management of Parkinson's and Multiple Sclerosis. A range of different therapies are available which claim to alleviate a variety of symptoms. While there is little evidence based information on the effectiveness of these therapies, some people find that they are beneficial especially for a sense of well-being.

Before trying any alternative method, please discuss these options with your Doctor or Neurologist. Remember that 'complementary' means: That which fills out or makes whole. Complementary medicine does not replace orthodox medicine.

Parkinson's New Zealand has a fact sheet available which gives a brief explanation of several complementary therapies that are commonly used. The fact sheet is available online at www.parkinsons.org.nz or the Society has copies available at the office. You can ask one of the Nurses to get a copy for you.

Taranaki Multiple Sclerosis Society Inc have a publication titled 'The Multiple Sclerosis Guide to Complementary & Alternative Medicine' – researched

and written by Lorraine Knightbridge 2004. Copies of this are available at the Society. Included in our library, is 'Overcoming Multiple Sclerosis' by Professor George Jelinek, which is his latest publication. Dr Jelinek is a Clinician and Medical Researcher diagnosed with Multiple Sclerosis, who has developed a programme based on a diet with no animal products, exercise, meditation and a daily dose of sunlight. A decade later, he remains fit and well and many people with MS in Australia, New Zealand and other countries have reported benefits from his programme.

We also have available copies of 'I've Got Nothing To Lose By Trying It' – prepared and published by Sense About Science UK 2008. This publication weighs up claims about cures and treatments for long term conditions.



Also the Multiple Sclerosis International Federation has just produced an issue titled 'Complementary & Alternative Therapies in MS' – this can be downloaded from www.msif.org or is available from one of our Nurses. As some of these issues are rather large, there may be a small cost for printing/copying.

Please remember there is always a cost involved in the purchase/use of these treatments. If you wish to discuss any of these publications, you are welcome to contact one of the Nurses at the Society.

Tai Chi - Change of Time

As of 21 April, Tai Chi classes are now being held on Wednesday afternoons, from **1.15pm to 2.00 pm**. These classes are open for members with MS, Parkinson's and their spouses

Benefits of Tai Chi include improved flexibility, increased muscle strength and improved balance and overall fitness. It also helps correct posture and promotes relaxation.

If you are interested in joining our class, please contact Donna on 366 2857 ext. 5 or email d.mclelland@ms-pd.org.nz.

Thank you!

Thank you to all those members who responded to the invitation to participate in our Blue Prescription study. We had an overwhelming response (58 responses). As it is a pilot study, only 15 people have been included in the study. These 15 people are currently working on increasing their levels of physical activity via Blue Prescription, where physiotherapists work to support individuals to participate in recreational exercise of their own choice. The activities that have been chosen are as diverse as yoga at home, aqua-jogging in the local pool, and a progressive walking programme. We expect to report the findings of this study towards the end of 2010.

Dr Leigh Hale and Hilda Mulligan, School of Physiotherapy, Otago University

Carnation Day Volunteers Needed – 3 September 2010

Lindsey Kerr, Project Coordinator

I have been working for the Society for 18 months now and one thing I know for certain, without volunteers we would not be able to offer the members even a portion of the services we currently put forward. It is these volunteers who enable us to do our jobs by helping with those 'extra' tasks.

'If you think you are too small to be effective, you have never been in bed with a mosquito.'

Carnation Day is where we need the most volunteers and in 2009 it was a success because of them. Last year we had over 300 volunteers, including 50 members, approximately 110 community volunteers and 140 students.

School Holiday Programme

We have been fortunate enough to receive funding from the Christchurch City Council for this year's School Holiday Programme, which took place in April. This funding enabled us to organise and offer two events:

- A movie at Reading Cinemas – The children watched 'How to Train Your Dragon' with popcorn, ice-cream and a drink.
- A trip to Science Alive – The children explored the 'Interactive Area' and enjoyed pizza and lemonade for lunch.

Over these two events a total of 30 adults and 43 children attended. This is a great opportunity for both members and their children to meet and share a fun time. If you would like more information about this programme, please contact Annette on 366 2857 ext. 6.



More Member Involvement Needed

In 2010 we hope that more of our members will volunteer, or if you are unable that you will ask your friends or family to volunteer on your behalf, so please talk to those around you about how they can help the Society. A volunteer form will be included in the August Newsletter, so be sure to look out for it.

If you, or a family members or friend, would be able to donate your time to the Society for Carnation Day or any other events we organise, please contact Annette on 366 2857 ext. 6 or email support@ms-pd.org.nz.

Podiatrist

The Podiatrist is at the Society, 314 Worcester Street, on the first Tuesday of the month. This service is available in Room 6 from 9.00am – noon and bookings are essential. The fee for this service is \$15.00 and is significantly subsidised by the Society.

If you cannot make your appointment you must ring to cancel. **If you do not cancel at least one day in advance you will be charged for the missed appointment.** To book or cancel an appointment, please contact Annette on 366 2857 ext. 6.

Annual Donations

A huge thank you to those of you who have already paid your Annual Donation, as this helps the Society's cash flow position at this time of the year. A form was included in the last newsletter with a payment due date of **21 April**, so **if you haven't paid, your Annual Donations are now overdue.** If you have misplaced your form, you can contact Annette on 366 2857 ext.6 if you wish to receive another form.



Exercise Classes

As you are aware Jessie our Physiotherapist is taking six months maternity leave – her last day of work at the Society is Friday 14 May and she will return on Monday 15 November. Because of this we have had to make the following changes to our Gym timetable. **Please note:** The Friday MS Group will move to a Wednesday 1pm time from **Wednesday 12 May**. We have yet to finalise the arrangement for the Yoga group – those who participate will be contacted soon.

We welcome Rachel Bladon, Physiotherapist who has agreed to come and work at the Society. She will be responsible for the individual physiotherapy assessments and will work on a Wednesday 8.30am – 5pm. Rachel can be contacted on 366 2857 ext. 1. We are also very grateful to Jan Rait who has agreed to be available and take responsibility for the open gym and the MS exercise group, thank you Jan.

| Monday | |
|-----------|--|
| 10am | Parkinson's Exercise Class – This is a high level class offering strengthening and stretching exercises with Jan. |
| 11am | Parkinson's Exercise Class – This is a high level class offering strengthening and stretching exercises with Jan. |
| 1pm | Parkinson's General Exercise Class – This is a more gentle class for people who may use a walking stick or frame with Jan. |
| 2pm | Open Gym – The gym is open for general use with Jan. |
| 3pm | Gym Circuit – This is a strength circuit class for people with MS or Parkinson's with Jan. |
| Wednesday | |
| 1pm | MS General Exercise Class – This is a class for people with decreased mobility with Jan. |
| 1:15pm | Tai Chi – For those with MS or Parkinson's and their spouses/partners with Donna. |
| 2pm | Open Gym – The gym is open for general use with Jan. |
| 3pm | Gym Circuit – This is a strength circuit class for people with MS or Parkinson's with Jan. |
| Friday | |
| 10am | Nordic Walking – This is for people with Parkinson's and their spouses and takes place in Hagley Park with Donna. |

Outward Bound®

Congratulations to Outward Bound Participants

Congratulations to our two members who participated in the Parkinson's UPBEAT Outward Bound Course, which took place from 28 March to 2 April. Murray Stewart and Nicky Jenkins joined the Societies MS+PD Resource Nurse Donna McLelland for a week at New Zealand's leading organisation for showing people their full potential through outdoor challenge and adventure.

Here are their experiences...



Murray's Experience

After being back home for two weeks Murray says he hasn't felt so good in a really long time and he enjoyed his entire experience, even the challenging parts. He was amazed at his ability to get up at 5.30am for a morning walk/run, but with the group support it was easy.

'Since I got back I haven't missed a morning walk and swim on the beach in Waikuku' says Murray. 'Before Outward Bound I wasn't doing that.' Murray felt it was a challenge mentally, physically and emotionally, but overall it was absolutely brilliant.



Nicky's Experience

– by Nicky Jenkins

What are those long stick things? What, oars? What, row? We were from all over the country, and all walks of life, but the thing we had in common was Parkinson's, and they wanted us to row a boat.

Every day our instructors pushed us beyond our individual comfort zones, and every day we met the challenge through personal willpower, group camaraderie, encouragement, and lashings of humour. And every night we fell into bed exhausted, and listened to the snorers get a good night's sleep.

The highlight for me was our time sailing. Usually a 'gin and tonic' sailor, I was a little perturbed to find our Clipper completely devoid of mod cons. And then there were the oars. We wouldn't make the NZ rowing team, but once under sail we looked pretty damn good, and there's nothing better than sailing the Queen Charlotte Sound on a sunny day.

The founder of Outward Bound, Kurt Hahn is right – there is more in us than we think. My sincere gratitude to Hayden and Jess for always making us feel safe, to Outward Bound for providing such an incredible experience, to Douglas Pharmaceuticals for their sponsorship, and thereby making it possible. A big thank you to our caregivers Donna and Sue, for their (almost) endless patience, and last (but not least) to my personal sponsor, family and friends for all their support and encouragement.

I did it. We did it. Would I do it again? In a flash, but next time I'm taking industrial strength earplugs.



City 2 Surf Success



A huge thank you to the dozen people who joined the MS+PD City 2 Surf team. We had a fantastic time while accomplishing a great goal. As our Physiotherapist Jessie Snowden has explained many times, the benefits of exercise not only impact strength and fitness but quality of life and fatigue as well. The members of our team pushed themselves to complete their own personal goals and felt a great sense of accomplishment afterwards.

The Society had the added bonus of having new branded bibs, which proudly displayed for whom we were raising money and awareness. The money raised by our members and their families paid for the postage of this edition of the Newsletter!

Educational Workshops

Event: MS Presentation on Fatigue/Motivation/ Moods/Emotions
– By Dr Debbie Mason

Date: Tuesday 1st June

Time: 5.30pm Refreshments, 6pm Presentation

Venue: Holiday Inn of Avon – Bealey 1 Room

RSVP: For more information or to RSVP please contact Annette on 03 366 2857 ext. 6 or email support@ms-pd.org.nz

Event: Short Term Memory Issues & Keeping the Brain Stimulated

– By Joyce Alberts

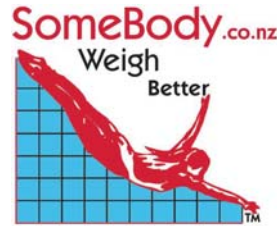
Date: Tuesday 17th August

Time: 5.30pm

Venue: Holiday Inn on Avon – Rolleston Room

Note: Please see the next issue of the Newsletter for more details

We'd also like to thank Personal Trainer Cher Hunter, from Somebody Weigh Better (who leads our Friday Nordic Walking group) for her generous donation to the Society and providing great food for us to eat after the City 2 Surf.



The member participation in the City 2 Surf was a bit disappointing and we hope that next year there will be more of you who chose to challenge yourselves to participate. The activities and events planned at the Society can only be a success if our members take the time to become involved in them.

Let's all make a mid-year resolution to become more involved in our Community and keep these programmes and activities going!

Research Participants Needed – Study on Family Life

Parents with MS or Parkinson's are invited to participate in a research project about family strengths. A team from the University of Canterbury is conducting a study exploring the experiences of families when a parent has a disability. We would like to learn about what helps or hinders family life, what contributes to families' resilience, and what organisations can do to improve their support for families.

To gain a broad view of family life, we are seeking the perspectives of parents, children and family friends. This study is limited to families where at least one child is 16 years old or younger. If you would like to learn more about the study please contact Marilyn Raffensperger on 364 2987 ext. 3540 or marilyn.raffensperger@canterbury.ac.nz or you can contact Jenny at the Society on 366 2857 ext. 2.

Important Dates

Morning Tea

Morning Teas are organised regularly and are held in a different suburbs of Christchurch. Please ring Shirley Noonan, Social Activities Coordinator, on 366 2857 ext. 8 or visit the Society website (<http://www.ms-pd.org.nz/social-activities.html>) to see when and where the next Morning Tea is being held.

MS Lunch

The MS Lunch Group is held in the hall at the Society (Worcester Centre), 314 Worcester Street, on the first Thursday of each month.

Upcoming dates are: 6 May, 3 June, 1 July, 5 August

2010 UPBEAT Weekend

Please write in your diary that this year the UPBEAT Weekend will be held in Palmerston North, 5-7 November. This weekend is for people with early-onset Parkinson's (60 years old and younger). More details will be available closer to the time.



Parkinson's Spouses Support Group

Event: Coping with Stress

– presented by Cher Hunter, Personal Trainer

Date: Monday 14th June **Time:** 1.30pm

Venue: Worcester Centre Hall

Cost: Gold coin donation to cover costs please.

Note: Cher will be known to some of you as the leader of our Nordic Walking group. She has been recently studying the effects of stress and coping strategies for stress. This is sure to be an informative and lively session.

Event: Morning Tea – Our morning teas are a good way to meet up and chat with other spouses.

Date: Tuesday 13th July **Time:** 10.30am

Venue: Café del Mar, 2 Waterman Place, off Ferry Rd

Note: Coffee and cake available to purchase

Please RSVP to confirm your attendance to Donna on 366 2857 ext. 5 or email d.mclelland@ms-pd.org.nz

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Ask your specialist if Copaxone is right for you. Copaxone is Fully Funded with Special Authority Criteria for Multiple Sclerosis. Your specialist can advise on funding criteria. Normal doctors fees apply. Additional information can be obtained from My Support Team. Freephone: 0800 502 802



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

PO Box 32-135
314 Worcester St
Linwood
Christchurch 8147
Phone: 03 366 2857
Fax: 03 379 5939
Email: support@ms-pd.org.nz

A special thanks to the following organisations for their continued support.

| | | | |
|---|---|---|--|
|  |  |  | Burrows Brothers Charitable Trust |
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|  |  |  | Thank you for your continued support. |

Officers of the Society

Patron: Mr Cyril L.L. Smith M.B.E
President: Malcolm Rickerby
Treasurer: Graeme Ell CA, PP
Committee: Eunice Bengier
Ann Morrison CA
Noel Noonan
Lew Airey
Bryan Beechey
Mike Cameron
John George
Life Members: Keith McArtney
Noeline McLlroy Q.S.O

Staff

Manager: Jenny Boyer
Office Manager: Annette MacFadyen
Resource Nurses: Sandy Connolly RGON, ADN
Janet Wills EN
MS & PD
Outreach Nurse: Donna McLelland EN
Administration
Assistant: Raewyn Turner
Project Coordinator: Lindsey Kerr
Physiotherapist: Jessie Snowdon
Exercise Supervisor: Jan Rait
Social Activities
Coordinator: Shirley Noonan

The views and opinions expressed in this newsletter may not necessarily be the views of the Multiple Sclerosis and Parkinson's Society of Canterbury (Inc) or its members.

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