IN THIS ISSUE:

Make the Most of Specialist Visits

How the Society Nurse Can Help You

Carnation Day Volunteers Needed

Quiz Night - 27th July
PRESIDENT’S MESSAGE

The Multiple Sclerosis and Parkinson’s Society of Canterbury (Inc.) held its Annual General Meeting towards the end of March, providing an opportunity for us to reflect on what we have accomplished over the previous 12 months.

I’m thrilled to report that the Society is in a sound financial position at present. This isn’t, however, a call for complacency; there’s as strong a need as ever to strengthen our relationships with the Canterbury District Health Board, other neurological societies, the business sector, and you, our highly valued Members.

It’s worth noting that the Society has reaped the benefit of sound management and equally strong financial practices, resulting in income growing by almost $20,000 and expenditure dropping by almost $9,000 compared to the previous year.

I’m also pleased to report that the Society continued to provide excellent value to its Members through the strenuous efforts of our dedicated staff. In 2013 the Society:

- Provided over 1,500 visits to members with MS, their families and caregivers plus a similar number to members with Parkinson’s through our Home Visiting Programme.
- Made over 1,800 phone calls to members with MS, their families and caregivers, plus a similar number to members with Parkinson’s and a further 1,800 to health professionals on behalf of our members.
- Held more than 550 Exercise Group Classes, including Nordic Walking, Yoga and Open Gym.
- Hosted over 300 members at 24 Morning Teas.
- Arranged 30 special groups such as MS Lunch, Men’s Happy Hour, Spouses’ Group, School Holiday Programmes and UPBEAT, throughout Canterbury.
- Produced and distributed four editions of the MS+PD Newsletter to over 750 households.
- Attracted the enthusiastic participation of over 400 volunteers through Society activities and fundraising opportunities.

The AGM was also an opportunity to welcome new trustees and to offer grateful thanks to those who had chosen to step down, as well as to our supporters and sponsors.

We said thank you to Fleur Harris and Murray Stewart for their contribution to the Society and welcomed existing trustee Don Parlane as our new Vice President. You’ll find a full list of officers of the Society on the back cover of this Newsletter.

MEMBERSHIP FEES

Annual membership fees were due on 23 April 2014. If you are unsure if you have paid, please contact Annette on 366-2857 ext. 6.

Membership fees are an important part of the Society’s income and essentially enabling us to offer a rich and varied range of services.

If you are finding it difficult to pay your annual membership, please contact Society Manager Jenny Boyer on 366-2857 ext. 2.

STAFF NOTICES

Bronnie Alexander, our PD Resource Nurse, received her Post Graduate Certificate in Nursing Practice at the recent CPIT Graduation Ceremony. Congratulations from all of us, Bronnie; well done, an excellent achievement.

We extend a very warm welcome to Michael Herman who has joined us recently. As our new Project Coordinator, he has responsibility for our funding applications, Street Appeal and other fundraising activities, and our Newsletter. Michael will be in the office Monday to Wednesday 8.30am to 4.30pm and can be contacted on 03 366-2857 ext. 9 or at m.herman@ms-pd.org.nz.

We also welcome Jan Saville as our new Administrative Assistant. We are thrilled Jan was available to snatch the baton from her predecessor Raewyn Turner immediately after she stepped into retirement, providing for easy continuity and the least possible disruption to members. Jan will be in the office Monday to Thursday 9.30am to 3pm and can be contacted on 03 366-2857 ext. 7 or at office@ms-pd.org.nz.

Please be aware of our upcoming events:
- 27 July - Quiz Night at Papanui Club (see page 4)
- 5 & 6 September – Carnival Day Street Appeal (see page 10 for more details)
- TBA in October - Charity Golf Tournament
- 2 November - Footloose Fun Walk in Hagley Park

Yours sincerely,

Malcolm Rickerby, President
03 338 1770, president@ms-pd.org.nz

Laura Wishart, Secretary
03 366-2857 ext. 3

Laura Wishart, Treasurer
03 366-2857 ext. 4

Library books

The Society has a good selection of books available to take out on loan. Please ensure that you take the book back to the Administration Assistant (Room 3A) to book it out so that we can track them.

If you have any recommendations on books about MS, Parkinson’s or caring for people with a chronic condition, please let Jan know on office@ms-pd.org.nz or 03 366-2857 ext. 7.

Podiatrist

Podiatry visits are the first Tuesday of the month with upcoming dates of 3 June, 1 July and 5 August. The cost for this service is $20 a visit and is significantly subsidised by the Society for our members.

As this service is very popular, it is essential to book. If you make an appointment and find you cannot attend, you MUST phone to cancel. Otherwise the Podiatrist will charge you for the missed appointment.

To book or cancel an appointment, please contact Annette at support@ms-pd.org.nz or on 03 366-2857 ext. 6.

Have your contact details changed?

If so, please email Annette at support@ms-pd.org.nz to ensure we have the most up-to-date contact details for you.

Please remember, email addresses are an important and cost effective (FREE) way for the Society to communicate. Please keep us up-to-date on your email address.

2014 UPBEAT WEEKEND

The 2014 UPBEAT weekend for people with early-onset Parkinson’s will be held in Napier at the Kennedy Park Resort Friday 29 to Sunday 31 August.

The event is open to anyone diagnosed before the age of 60 and currently aged under 65 years. The organisers are inviting expressions of interest from UPBEAT members for presentations on anything related to Parkinson’s.

For more information, please email upbeat@parkinsons.org.nz

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If you have any recommendations on books about MS, Parkinson’s or caring for people with a chronic condition, please let Jan know on office@ms-pd.org.nz or 03 366-2857 ext. 7.

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To book or cancel an appointment, please contact Annette at support@ms-pd.org.nz or on 03 366-2857 ext. 6.
One of the most important services offered by the Society is the free home visiting programme. It may be that you have not seen a staff member for a while, or you have something that you need to discuss. The visits can be made at a time and place to suit you: at work, at your home or at the Society.

As staff members work outside of the office at times, and your call is important to them, please leave a message on their answer phone and they will contact you as soon as possible.

If your call is urgent, please call the Manager or Office Manager for assistance.

TO CONTACT
Please dial (03) 366 2857 and then the appropriate extension number listed below:

- Rachel/Maree (Physiotherapists)  1
- Kim (Exercise Supervisor)  1
- Jenny (Manager)  2
- Judy (MS Resource Nurse)  3
- Bronnie (PD Resource Nurse)  4
- Annette (Office Manager)  6
- Jan (Administration Assistant)  7
- Denitsa (Events Co-ordinator)  9
- Michael (Project Co-ordinator)  9

FAREWELL TO RAEWYN
At the beginning of May we said farewell and thank you to Raewyn as she retired from her position of Administration Assistant with the Society.

Raewyn has been working with us for over six years and has been a very important part of the administration team.

Some of our members may have met her when checking in/out library books or more recently at a couple of the coffee mornings.

Raewyn, on behalf of us all we thank you for your hard work and dedication to the work we do. We hope you will keep in touch with us from time to time.

TO CONTACT
Please dial (03) 366 2857 and then the appropriate extension number listed below:

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Preparing for Your Specialist Appointment

Something strange happens when many of us arrive for an appointment with a medical specialist—we seem to forget the symptoms that have appeared since our last visit.

As neurologist Professor Tim Anderson, Clinical Director of the New Zealand Brain Research Institute, pointed out at the MS+PD ‘Keeping Up With Parkinson’s’ Education Day at the Papanui Club in early May, this is a common occurrence for many patients which limits the usefulness of a consultation.

No matter their level of accomplishment, specialists simply aren’t able to guess an individual client’s specific experience of their condition since their previous visit, the symptoms that have appeared—or disappeared—and any favourable or unfavourable response to the medication they’re on.

Given the importance of these visits in the effective management of MS or Parkinson’s, applying simple strategies to be better prepared for visits allows us not only to help our doctors to help us but also to be more strategic about our health care.

So, what are the things you can do before, during, and after you see your specialist to get the greatest benefit from the visit?

A good first step is to approach an appointment with the same strategic intent as you would an important business meeting—be well prepared. Unlike a business meeting, you’re not entering a negotiation to persuade a good deal out of a reluctant supplier or client, but just like a business meeting you are trying to get the most out of the situation and this requires some planning.

Being able to report your symptoms and concerns accurately helps specialists get a better handle on your situation more quickly and will most likely lessen any anxiety you might usually experience as your appointment date approaches.

At the Education Day, Professor Anderson provided a short list of six things to take with you to a meeting with a specialist (see sidebar).

Keeping a written record of any symptoms you’re experiencing, including any that may seem unrelated to your condition, is a good practice. While this is obviously useful for your next meeting, it also provides you with an accurate historical record over time—a handy memory aid as time moves along.

You might want to create a journal for this purpose so that all your notes are in one place.

Add as much context as necessary when you make your notes.

For example:

- Is the symptom you’ve identified present continuously or just occasionally?
- How severe is it?
- Does anything seem to improve it?
- Does anything seem to worsen it, for example, a major stress or life change?

Any good planner needs an ally so, if possible, don’t go it alone; have a family member or friend accompany you along with your notes. A lot of information is shared during consultations and your support person may remember something you missed or forgot. They can also help by taking notes during the meeting to clarify afterwards discussions and advice given to you.

What is helpful when seeing your Specialist?

- Updated medication list
- The things that bother you most
- What things you would most like to be better
- Any other new medical problems
- A “significant other” to accompany you
- Written notes if your memory is a problem

Source: Professor Tim Anderson

Quiz Night

Make a date to join us for another fantastic Quiz Night on Sunday July 27 at the Papanui Club, 6pm to 9pm.

We’ve received terrific feedback from Members who have attended these events in the past and this year is shaping up to be at least as good as its predecessors!

Members who have attended these events in the past and this year is shaping up to be at least as good as its predecessors!

Your teams can comprise six to eight people or to book your team!

Contact Annette on 03 366-2857 ext. 6 or at support@ms-pd.org.nz for more information or to book your team!

What is helpful when seeing your Specialist?

- Updated medication list
- The things that bother you most
- What things you would most like to be better
- Any other new medical problems
- A “significant other” to accompany you
- Written notes if your memory is a problem

Source: Professor Tim Anderson
EXERCISE HELPSREWIRE THE BRAIN

PD WARRIOR NOT ONLY RETRAINS YOUR BRAIN, IT ALSO HELPS YOU TO:

• Get back to doing the things you love
• Become stronger and healthier, so you feel better about yourself
• Grow more comfortable doing several things at one time
• Achieve better balance to prevent dangerous accidents and falls
• Do all the little things that you have recently abandoned.

The PD Warrior programme has been available in Australia at Advance Rehab Centre since 2012 and initial results have been impressive. PD Warrior is now available in Christchurch through Muscle People Physiotherapy clinics at YMCA Hereford Street and Bishopdale.

For more information about PD Warrior visit www.PDWarrior.com or telephone Muscle People at YMCA Hereford Street on 961-0236 or Bishopdale on 360-3606 if you are interested in an initial assessment or to find out about the cost of joining the programme.

There is a charge for both the PD Warrior and LSVT BIG exercise packages and hence they won’t be an option for some of our members.

If you would like to know if either of these exercise packages would be of benefit to you or wish to see one of Physiotherapists, then please contact Rachel on r.bladon@ms-pd.org.nz or Maree on physio@ms-pd.org.nz, or by phone on 366-2857 ext. 1.

There are also a variety of non-PD-specific exercise classes available in the community as well as the classes offered by the Society. We suggest an assessment with one of our Physiotherapists to ensure that the exercise you choose is the most suitable for your needs.

Being sedentary is one of the fastest ways to see your symptoms get worse. To be the best you can be at every stage of your Parkinson’s disease, review your exercise programme and consider a new Parkinson’s programme called PD Warrior.

Purposeful movement can combat the loss of motor control seen in Parkinson’s disease and PD Warrior combines a high effort, intensive workout with a challenging combination of movements and mental strategy. It is targeted at people with early stages of Parkinson’s and aims to slow the progress of the disease.

The programme uses a special combination of physical and cognitive activities to drive your brain’s natural ability to rewire itself.

A MAGIC DAY OUT FOR PARKINSON’S CARERS

Roy Reid (Member)

Wonderful generosity and effort on the part of
members and partners of the Christchurch Altrusa International club saw a group of carers thoroughly spoilt with a day “on the loose”.

And what a fun-filled day it was! We started at 9:30am at St Margaret’s, Bishopdale, for an informal meet and greet while enjoying a magnificent morning tea, and then off for a round of mini golf at Pirate’s Island Adventure Golf which produced much fun and lots of laughter.

Next stop was a leisurely lunch at the Talbot Restaurant in Yaldhurst before motoring off to the nearby Transport Museum for a delightful trip down memory lane.

At 3.15pm we headed back to St Margaret’s Church Hall for afternoon tea. To cap it all off, each member was then presented with a hamper of goodies plus a potted cyclamen to take home. It was such an unexpected surprise and a fantastic gift to take home to wives and partners.

The kindness, friendship and hospitality extended to the group left an indelible impression on us all and on behalf of the group I send a heartfelt thank you to the outstanding people at Altrusa District Fifteen for giving us such a wonderful day out.

SWALLOWING DISORDERS IN PD

The Evaluation and Treatment of Swallowing (EATS) Clinic (www.eatsclinic.co.nz) and the UC Swallowing Rehabilitation Research Laboratory are great resources for people with swallowing disorders, whether months or years after diagnosis.

EATS is looking for participants to investigate chewing and swallowing solid food and need:

• 10 people with advanced Parkinson’s disease (need help from others for personal care or mobility)
• 20 healthy adults (particularly men aged 55 to 80 years old)

Participation involves a brief, one-off assessment with a survey, eating and drinking, and for those with Parkinson’s disease, an assessment of movement.

They are also looking for participants to undergo a specific swallowing study and are looking for people with Parkinson’s referred for a swallowing x-ray (called a videofluoroscopic swallowing study). Participation involves three swallowing x-ray studies over six months.

For more information, contact Dr Maggie-Lee Huckabee or Kristin Lamvik at (03) 378-6348 or go to www.cmds.canterbury.ac.nz/swallow/research.shtml.

DOROTHY L NEWMAN SCHOLARSHIP

MSNZ has opened applications for the Dorothy L Newman Scholarship, which assists people who have been diagnosed as having MS as a result are unable to continue in their present employment, so need to change their employment and undergo a course of retraining in order to do so.

Applications are open solely to people with MS needing to retrain for paid employment.

Applicants will be required to explain in a statement in their application the reasons why they chose their course of study, how they intend to use their qualification on successful completion of their course and the likelihood of employment following the course.

Applications for the Dorothy Newman Scholarship fund are now open. To receive a copy of the guidelines and application form, email info@msnz.org.nz.

Applications close 8th September 2014.

“Through MSNZ it has been feasible for me to return to university and acquire a new qualification that will allow me to return to the workforce, a workforce where I may be able to help myself and others with multiple sclerosis.” - Katarina, 2012/13 Recipient
HOW THE SOCIETY NURSES CAN HELP YOU

Our 2013 Membership Survey revealed that most members were happy with the staff service but some felt they would like more contact with us. In most instances we assume that our members will take an active role in their self care and management, so we encourage you to make contact with the Society if you feel you need assistance or advice.

The Society employs two Registered Nurses; our MS Resource Nurse is Judy and our PD Resource Nurse is Bronnie. They offer a variety of services, including:

- Home visits/Assessments/Pre- and post-clinic reviews. We encourage an initial assessment when you become a Society member and then regular reviews. We rely on you to contact us to request a review.
- Facilitating family/whanau meetings.
- Supporting groups and social activities: PD Spouses Group, Men’s Happy Hour, UPBEAT, Suburban Morning Teas.
- Referrals to other health professionals as appropriate. For example, a referral to a Clinical Assessor can provide home supports like showering or domestic assistance.
- Working alongside GPs, specialists and other health professionals.
- Advice about the monitoring of medication.
- General advice.
- Advocacy.
- Providing training and information for staff at rest homes, hospitals and care facilities.
- Educational seminars.
- Assisting in delivering self-management programmes such as ‘Living Well with Multiple Sclerosis or Parkinson’s’.

Both MS & Parkinson’s are chronic conditions, so over time things change and you may need to talk to someone for advice or require specialist assistance. Some symptoms can be difficult to cope with, so management focuses on individualised plans to help deal with these challenges, which may involve referral to other Health Professionals. Communicating with other Health Professionals has been proven to enhance care and outcomes.

Obviously your GP is your first contact person but if you have a question or concern relating to MS or Parkinson’s, our specialist nurses may be able to help.

WHEN SHOULD YOU CONTACT A SOCIETY NURSE?

- If you want a review or just a chat.
- If you are unwell.
- If you have an issue or concern.
- If you are, or your partner is in hospital, or to update us.
- If you have any questions before or after clinic appointments.
- We are not an emergency service, but sometimes we can help in a crisis. It is always better to avoid crises, so please make contact early if something’s bothering you.

It is important to understand that unless we hear from you we assume that everything is going well. The Society does not have direct access to discharge letters or hospital appointment records which means that unless we hear from you, we are unaware of what is going on in your life. Alternatively, you could instruct your doctor to send us copies of your letters.

Up-to-date contact information has been very changeable for many people since the earthquakes started, so informing us of address changes as they happen is important, and making regular contact with staff so we know how you’re doing is a good idea.

You can email or phone our nurses; please leave a message if the call diverts to voicemail. If you have no response then please ring again as sometimes messages can be difficult to hear or get misinterpreted.

Judy McKeown 366-2857 ext. 3 or j.mckeown@ms-pd.org.nz
Bronnie Alexander 366-2857 ext. 4 or b.alexander@ms-pd.org.nz

PARKINSON’S NZ DONOR MAIL

Most of our members with Parkinson’s will have received from Parkinson’s New Zealand donor appeal letters; to avoid confusion we want to clarify what these are.

Parkinson’s New Zealand supports 20 divisions and branches throughout New Zealand and these donor appeals are sent out from the National Office in Wellington.

Half of the net donations from the donor mails are returned to the area they come from; the remainder of the donations that come from MSPD Canterbury are used by Parkinson’s New Zealand to provide information to people within our area. This includes paying for the quarterly magazine The Parkinsonian, new publications like the recent new editions of Parkinson’s; a guide for the newly diagnosed and The Drug Treatment of Parkinson’s, the UPBEAT programme for people with early-onset Parkinson’s, and other areas of their work that our members benefit from.

The next donor appeal will be mailed with September’s edition of The Parkinsonian.

COST-SAVING ENTERTAINMENT BOOK

Copies of the cost-saving Entertainment Book are still available at $65.00.

Packed with heaps of listings offering up to 50% off and 2 for 1 offers, the Entertainment Book is a fantastic guide to the most popular restaurants, attractions, shopping, travel and more.

A digital version of the book for smart phones is available for the same price when you purchase online.

To pay securely online or to order your Digital Membership please visit www.entertainmentbook.co.nz/orderbooks/13x4351 or you can order copies through the Society by sending your details and a cheque to us at PO Box 32-135, Linwood, Christchurch, 8147.

If you would like more information, please contact Annette on 366-2857 ext. 6.
HELP WITH ANNUAL STREET APPEAL

Friday 5 September & Saturday 6 September

The Society needs over 400 volunteers for our Annual Carnation Day Street Appeal. This is our biggest fundraiser of the year and we need you to volunteer to make it a success.

You can email Michael Herman (Project Co-ordinator) on m.herman@ms-pd.org.nz with your details and when/where you would like to collect.

Once again this year there are a few select locations for a Saturday collection. Hopefully this will allow our members who work to volunteer their time to collect between 10am – 4pm.

WHAT COLLECTING INVOLVES

If you have never collected for Carnation Day before, don’t worry, you are not the only new kid on the block. Being a volunteer collector is easy, just complete the volunteer form and our staff will ring you to confirm the day, time and location. Then all you need to do is show up with a positive attitude and hold the bucket for an hour or two. Chairs are available at some locations, otherwise you can always bring your own.

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

TEAM LEADERS

We are always looking for volunteers to be team leaders. Team Leaders look after a location for the entire day and find the volunteers to man the site throughout the day. If you have 6-8 friends who you think would help, this would an amazing way to support the Society. We will provide you with the signs, buckets, and stickers; either you can bank the money or we can.

If you would like more information about being a team leader or have a question regarding Carnation Day, contact Michael on m.herman@ms-pd.org.nz or 03 366-2857 ext. 9.

COFFEE MORNINGS

With the recent changes to existing staff and the poor attendance at some of the coffee mornings, we have decided to suspend these meetings during the winter time. Once the warmer weather arrives we will contact you about the next series of coffee mornings in various cafes around Christchurch, and will evaluate the response again at that time.

We regret having to do this as some of our members have indicated to us how much they enjoy getting to know others in their areas.

PD COMMUNICATION MAINTENANCE GROUP

The Parkinson’s Communication Maintenance Group has been meeting one morning a month since 2010.

Group membership has increased significantly over the past 18 months and results of an initial survey of participants and support people indicated that the group successfully enabled people to maintain communication skills and enhanced social confidence.

The meetings are facilitated by Kirstie Koller, Speech Language Therapist. They involve group discussions, therapy activities, informal socialising, and education sessions focused on “using and improving” communication and voice skills.

Maintenance of swallowing safety and enjoyment of eating and drinking is also addressed. Social confidence is aided by the supportive group environment. The group meets on the last Tuesday of every month from 10.30am to noon in the Parkinson’s Society Physiotherapy Gym, 314 Worcester Street, and is open to any members of the society who have completed a programme of Speech Language Therapy and/or LSVT*.

Morning tea is provided and partners or support people are welcome to attend.

For further information please contact: Kirstie Koller, Community Speech Language Therapist, CDHB, on 387-1350.

* Lee Silverman Voice Therapy (LSVT) is a 16-session programme completed with a certified clinician.

(RED) CROSS TOWN SHUTTLE

Recovery community transport assists Christchurch residents with limited mobility by providing transport options to respond to an increased need post-Earthquakes and to support measures which will promote recovery.

Limited mobility is defined as those who do not have access to their own form of transport; are financially restricted from accessing other transport options; and not serviced by, or physically unable to utilise, public transport. The service is for transport to medical appointments; earthquake-related appointments; ‘leisure and pleasure’ activities; and socialising opportunities. This is a referral by selected agencies and organisations only, service.

If you are finding it difficult to get to appointments or exercise classes, this could be an option for you. Obviously there are certain criteria that must be checked for you to be eligible for this service.

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TOTAL MOBILITY SCHEME (TAXI VOUCHERS)

By now you will have received a letter from Environment Canterbury (Ecan) informing you about the new Electronic Smart Card. Ecan have informed our Society that they hope to have this system up and running by July 2014. At this stage, please continue to use the paper vouchers that are supplied to you.

ASPIRE CENTRE NOW SMOKEFREE

Shockingly, around 350 new Zealanders die each year because of exposure to second-hand smoke.

The Manager and the Board of Aspire Canterbury decided that the grounds and the building at the Centre would become smokefree from the beginning of May this year.

This means that when you come in to exercise programmes, to see one of the staff or to attend a group session, you will not be able to smoke anywhere on the property.

The Health Promotion Council (HPC) reports that second-hand smoke (where non-smokers breathe in the smoke of others around them) can result in serious health issues, including heart disease, lung cancer, stroke, asthma and the worsening of asthma symptoms, eye and nasal irritation, and nasal sinus cancer.

Exposure of non-smoking women to second-hand smoke during pregnancy can reduce foetal growth and is also associated with Sudden Infant Death Syndrome.

We greatly value your co-operation in helping to improve conditions for other members and for staff.

For more information about the health risks of smoking and for information on how to quit, or World Smokefree Day on 31 May 2014 go to HPC’s Smokefree website at www.smokefree.org.nz.
STAFF
Manager: Jenny Boyer
Office Manager: Annette MacFadyen
Resource Nurse: Bronnie Alexander, RN
Resource Nurse: Judy McKeown, RN
Administration Assistant: Jan Saville
Project Coordinator: Michael Herman
Physiotherapist: Maree Stewart
Exercise Group Leader: Kim Veenings
Administration and Funding Assistant: Denitsa Stoeva

OFFICERS OF THE SOCIETY
Patron: Hon. Ruth Dyson, MP for Port Hills
President: Malcolm Rickerby
Vice President: Don Parlane
Treasurer: Ann Morrison
Committee: Lew Airey, Dawn Baker, John Davies, John George, Mike Johnson

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

MULTIPLE SCLEROSIS AND PARKINSON’S SOCIETY OF CANTERBURY (INC)
314 Worcester Street
(PO Box 32-135)
Linwood, Christchurch
Phone: (03) 366 2857
Fax: (03) 379 5939
Email: support@ms-pd.org.nz

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.