



The Parkinsonian

The Quarterly Magazine of Parkinsons New Zealand

Peter Snell Honoured



Photo: Peter Krall

Dr Peter Snell, Parkinsons NZ Patron, Judy Buchanan, PSNZ CEO, and Mary Baker, President, European Parkinsons Disease Association, at the Auckland Division 2001 seminar

Congratulations to Peter Snell from all in the New Zealand Parkinsons community.

The Patron of Parkinsons New Zealand, Peter Snell has been awarded the highest honour bestowed in New Zealand. In the 2002 New Year's Honours, he was made a Distinguished Companion of the NZ Order of Merit (DCNZM). This is equal to a knighthood in the former honours system.

Peter was delighted to accept the honour. "A knighthood would have been a little uncomfortable for me,"

he said, "so I'm happy with the way it is now."

Peter is a modest person whom we are privileged to have supporting our organisation. He has received many public acknowledgments over the years.

These included an OBE in 1964. In 1999, Peter was one of the first inductees into the International Scholar-Athlete Hall of Fame at the University of Rhode Island. In 2000, he was named New Zealand's sportsman of the century in recognition of his achievements in athletics at national

and international level. His impressive achievements include winning three Olympic gold medals and two Commonwealth gold medals, and eight world and two Olympic records.

Peter has a doctorate in sports medicine and is now an associate professor in the Department of Internal Medicine at the University of Texas, Dallas. His research topics include his special interest in exercise and the aging process.

Peter regularly visits New Zealand and says he hopes to enjoy a talk with many members when he is attending our functions.

Peter was initially involved with the Parkinsonism Society Auckland Division as their Patron, and Parkinsons NZ is most appreciative that he was willing to extend this support to all people in New Zealand with Parkinsons.

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From the President

During 2001, 'The Year of the Volunteer', we celebrated the contribution of many long-serving, dedicated committee members in our Divisions, some of whom have served since the first days of Parkinsons New Zealand. The efforts of all our Division committees are of vital importance to the Society's work in the community and it was an honour for me to meet many of these people last year and thank them for their magnificent work.

Over time committee members' circumstances change and some committees struggle to find new members to replace those leaving. New energy and ideas are always greatly appreciated – every person has skills they can offer and the rewards of such involvement are priceless.

Therefore I would like to take this chance to encourage younger members and their families to become involved as volunteers. I can personally vouch for the great sense of satisfaction and achievement I feel from my many years of voluntary work, including eight on the Parkinsons National Committee.

Finally, a reminder that October 2002 is the date of our Parkinsons International Conference in Wellington. This is fast approaching and now is the time to make your own preparations. Organisation is well underway and a stimulating programme is emerging with international experts agreeing to be speakers, as well as members of New Zealand's own medical community. (See p8.)

I remember Mary Baker telling us, "The best educators are people with Parkinsons." So please consider volunteering to join the programme.

Eleanor Marra

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Deep Brain Stimulation

You may have noticed reports in the newspapers and television about a 'miracle new treatment' for Parkinsons that involves putting electrodes in the brain and sending a current through them.

This is not a new treatment. It has been available for several years in many countries around the world, and a number of New Zealanders have had the operation in Australia.

The publicity is because this procedure, deep brain stimulation, was recently approved by the United States Food and Drug Administration (the FDA). This means that the procedure is now more affordable to more people in the US, as it is covered by their Medicare and medical insurance.

Our media has picked up on the reports relating to the FDA approval saying it is a new development. Unfortunately this has raised some people's hopes. The deep brain stimulation procedure is suitable for only a small proportion of people with Parkinsons.

For further information about deep brain stimulation talk with your field officer or doctor.

National Office Library

National Office has bought some recently published books for its library. We purchase these for members and staff to read and decide if they want to purchase a copy for themselves.

If you would like to borrow any books or tapes from the PSNZ library please contact Tricia Hastings, on 0800 473 4636.

New Books

- Caring for the Parkinsons Patient, A Practical Guide
- Parkinsons Disease, A Self Help Guide
- When Parkinsons Strikes Early
- Parkinsons Disease, The Way Forward, An Integrated Approach
- Parkinsons Disease, A Guide for Patients and Family
- Parkinsons Disease and the Art of Moving
- My Spirit Still Sings, Younger People Living Alone (+video)
- Loss and Grief for Older People

Also available for you to borrow from the library are books on general Parkinsons topics, nutrition, movement, personal stories, etc.

If you have a question about anything in this issue of The Parkinsonian or you would like an audio cassette of the content, contact Eva Petro, Information Officer, on 0800 473 4636.

Politics and Parkinsons

One of the roles of the national society, Parkinsons New Zealand, is to advocate to the Government on appropriate matters, on behalf of people affected by Parkinsons.

Topics

The Society is currently involved in advocacy on several topics. For example:

- Increasing the availability of effective medications (i.e. subsidised by Pharmac).
- Encouraging the Ministry of Health to consult more frequently and more fully with community not-for-profit groups on its strategies, policies and planning, e.g. for disability services, services for older people.
- Negotiating for increased funding for our services to more accurately reflect its value to the state and society.
- Commenting on government proposals that would affect the Society and its members, e.g. the proposed charity tax reform, the impact of the amendments to the Human Rights Act, the proposal for volunteers to be treated as workers under health and safety legislation, terms of reference for the community advisory committee for Pharmac, strengthening the relationship between government and the community, etc.

Methods

This advocacy involves national staff and committee members:

- Meeting with staff from government departments to discuss policy proposals and the impact of current policies.
- Taking part in events and forums that government and its agencies arrange.
- Contributing when departments are consulting and seeking public input.
- Making submissions to select committees on Bills before the House.
- Writing to and meeting members of parliament and ministers.
- Working cooperatively with other agencies to advance our common issues.
- Raising our concerns about rationing decisions and promoting transparency and fairness.
- Presenting papers at conferences.
- Maintaining a profile in the media.

We are also part of the Alzheimers Coalition that is undertaking a campaign to ensure the

human rights of older people and their access to effective medication are not ignored.

Raising awareness of MPs

The Society's members can also play an effective part in this work.

This year is election year and all the current members of parliament who want to be re-elected, and all the new candidates, value hearing from you. They want you to vote for them and they want you to be happy with their party's health policies. They need to hear from you about your problems with the health system.

To tell political candidates what you need: visit members of parliament at their local offices; write to MPs (no stamp required); invite candidates from all parties to your meetings; attend public meetings and ask questions; write letters to the papers; talk to lots of people about what people with Parkinsons need for a better quality of life.

Tell your story

PSNZ wants all prospective members of parliament to be aware of how people are affected by Parkinsons and what will help.

Telling your own story is the most powerful form of advocacy there is. Do not worry that what you say has to be 'terribly clever' because if you speak from the heart people will know it is real.

Your local management committee receives information about PSNZ advocacy activities. If you are interested in getting involved in this work at a national or local level, please contact Judy Buchanan, Chief Executive Officer, PSNZ, 0800 473 4636.

Help lobby for a better drugs deal

New Zealand lags behind other developed countries in subsidising the cost of newer Parkinsons drugs.

Parkinsons New Zealand is working to improve this situation by being proactive. We have asked Pharmac why some drugs that have been submitted to it are not yet subsidised, and some drug companies to submit their newer drugs for subsidisation.

You can help. If you are willing to contact a member of parliament to give them our message or contribute in other ways ring 0800 473 4636 for an information sheet.

Using your medication safely

Courtesy of Age Concern NZ Inc

Take care of yourself by taking care with your medication

It is important that you use your medication properly. You will manage this better if you understand what each medication is for and get as much information about it as you can.

Medication affects different people in different ways, so do not be influenced by what other people are doing with their medication. We know that as your Parkinsons progresses and as people age the way their medication or its dosage affects them can change. Incorrect dosage or mixing of medication can cause problems such as confusion and disorientation.

It is important to regularly visit your doctor to review your medication.

Get the right information

Before a doctor's visit

Make a list of all the medications you are currently taking, the dosages and when you take them. Your list should cover:

- prescribed medication
- non-prescription medications, e.g. aspirin, cough mixture, laxatives, creams or lotions used on the skin
- vitamins, supplements and 'natural' remedies.

Write a list of all the questions you want to ask about your current medication, as well as any other health issues you want to discuss. Remember to record all your symptoms and

any other information you think might be important or helpful.

Consider taking a relative or friend with you to the doctor. They can remind you of questions you want to ask and take notes of what the doctor says.

During your visit

Show the doctor your list of current medications. Ask all the questions on your list and take notes as they are answered. If you find writing difficult ask the doctor or your relative/friend to make notes for you.

If you find it embarrassing or difficult to ask about some matters, give a copy of your questions to the doctor.

Questions to ask

Ask the following questions about any medication the doctor prescribes:

- What diagnosis or ailment is the medication for?
- What is this medication called?
- Is there any alternative to medication or to this particular medication?
- When should I take it and how often?
- How long will I need to take it and when should I have my use reviewed?
- How long is this problem likely to last?
- Are there any special instructions or restrictions?
- What are the common side effects?
- What should I do if I experience these or any other side effects?

- What should I do if I miss a dose?
- Is there anything else I should be doing to help myself?

At the chemist

Your local pharmacist (chemist) is also a trained health professional and can give you a lot of information regarding your medication.

If you forget to ask your doctor something or can't remember his/her instructions ask your pharmacist. You can talk to them any time, not just when you get your prescriptions filled.

When buying non prescription medication remember:

- Tell the pharmacist what other medications you are taking, including prescription medication, and check if it is safe to take these together.
- Ask about any side effects from the non prescription medication.
- Ask how long you should take the non prescription medication before checking with a doctor.

When getting a prescription filled or buying non prescription medication ask if any of the medications will deteriorate if taken out of the container or if left exposed to the air, damp or sun, and if any special care, e.g. refrigeration, is needed.

If your eyesight is poor ask to have the name of the medication and instructions printed out in large type.

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Organising your medication

Most people with Parkinsons are taking many pills each day, and making sure they are doing it right is often very stressful for them and their spouse/partner.

However, there are lots of different ways people organise their medication to reduce the chance of taking it wrongly. You may need to experiment to find out what works best for you.

Some ideas and options

1. Draw up a chart that describes the details for each medicine. Stick it on the fridge door or somewhere you can find it easily.

Drug Name	What it's for	Colour & shape	Times to take it	How to take it
XYZ	Heart	Small pink pill	3x per day	Before meals

2. Make a 'Weekly Check Off' chart:

Drug	Sun	Mon	Tue	Wed	Thur	Fri	Sat
ABC	8am	8am	8am	8am	8am	8am	8am

3. There are several models of medication holders with divided sections that you can buy from various places, e.g. chemists, \$2 shop, disability resource centres. For example, a container with a section for each day of the week, and others that have divisions for different times during each day. These help you to know you have taken all your medication for that period.
4. Your chemist can put your medication into pre-sorted groups in a bubble pack, so each bubble contains the right mix of tablets for each day. The cost for this can sometimes be met from the Disability Allowance from the Department of Work and Income.
5. Buy a medication holder with a timer that beeps at pre-set times to remind you to take your medication. Some people use their wrist watch alarm for this.
6. Fill a film roll tube, or similar, with your daily medication. Keep it in your shirt pocket or somewhere you can feel it and so are aware of it. If you fill seven tubes you have a week's supply and do not have the daily worry of sorting out your pills.
7. Some people become aware of how their body feels when the medication is running low, and use this as a trigger to check if it is time for more.

Warnings

- Take all your prescribed medicine and take it at the same time each day.
- Keep your medication out of the reach of children.
- Dispose of any expired medication. Your pharmacist can do this for you.
- Never throw away the labelled container your current medication came in.
- Do not use other people's medication or allow other people to use yours.

Herbal medicines

There has been an enormous increase in the number of people taking herbal medicines while also taking prescription medicine. Herbal medicines have the potential to interact with other drugs, prescribed or bought from the supermarket. Even herbal medicine can produce adverse reactions or an adverse event related to an interaction between two drugs.

When considering adding any new medicine, always tell your doctor and pharmacist about all the medication you are currently taking. Be aware of the need to check for possible adverse reactions.

Your field officer can give you the PSNZ booklet which describes the most common adverse reactions between Parkinsons drugs and other commonly used drugs. Remember to have a doctor's check up from time to time, as having appropriate medication is vital to achieving the best possible quality of life.

Drivers - have you told your insurer you have Parkinsons?

Your safety and the safety of others using the roads is important

The Insurance Council of New Zealand advises drivers to tell their insurers of any changes in their health circumstances straightaway so the company can then evaluate the risk. Failure to do this can breach an insurance contract which means that should there be an accident a claim could be turned down.

The Council suggests it may be prudent to seek medical advice to clarify whether or not you should be driving, as your insurer is likely to ask for a medical certificate. Your doctor and field officer can tell you about the Land Transport Safety Authority requirements regarding your licence. Please talk to them about your driving ability.

Secrets of the Brain

Based on an article in the Daily News, New Plymouth

Many of our members have been enthralled by Professor Richard Faull talking about his work involving the Auckland brain bank. His enthusiasm for his topic is infectious.

Professor Faull is Professor of Anatomy at the University of Auckland's school of medicine and a fellow of the Academy of the Royal Society of NZ. He has an international reputation for his research into diseases of the human brain and has published more than 100 major papers.

Professor Faull established New Zealand's Human Brain Bank a decade ago. It has tissue relating to nine different neurological diseases, as well as over 70 normal brains and is the only brain bank in the country.

New brain cells

"We now know everyone is making new brain cells. I would have been taken out at dawn and shot if I had said that two years ago – absolute heresy. Every other organ in the body can repair itself and we are finding the brain actually does do that too.

"There are going to be major advances in understanding how stem cells repair the human brain, certainly over the next five to 10 years. (Stem cells are immature cells that

have the potential to develop and grow into any type of cell.)

"That is not going to solve all diseases but it opens up a completely new avenue for treating brain diseases where there was previously no possibility.

"If we can unlock the mechanism and the key to tell these cells to divide we can help people," Professor Faull says.

And here New Zealand research is leading the world.

Brain bank research

Most research worldwide is with stem cells from embryos. This is a controversial issue which causes much moral and ethical debate. But there are adult stem cells in the brains bequeathed to the brain bank. There is no controversy in these being used in research.

"Our research is leading the world in terms of looking at the potential of adult stem cells.

"We are looking for the magic chemical or gene that makes them divide and grow faster.

"There is also evidence that stem cell growth may be related to a person's environmental conditions. Patients in a supportive environment, who are positive and outgoing, always do better," says Professor Faull.

Ethics

The Auckland Neurological Foundation Human Brain Bank is one of the most extensive collections of human tissue in the Southern Hemisphere. It operates from the highest possible ethical standards.

Precise records are kept and tissue from each brain is identified by a code number to ensure confidentiality.

The brain bank has provided opportunities for productive international collaborative studies with leading research scientists in a variety of countries. With consent of next of kin, tissue is sent overseas for research that cannot be done in New Zealand.

The staff at the brain bank acknowledge they would not be able to function without the cooperation of the families of those who suffered from the disease, as well as the support of the community neurological groups.

"The bequest of human tissue is a very special gift which we treasure and respect and we view our research as a special partnership with the community," said Jocelyn Bullock, Division of Anatomy Radiology, Auckland University.

Webguide

- **Do you know you can get the news online?** The Dominion, Evening Post and Christchurch Press are all available on www.stuff.co.nz, the NZ Herald is at www.nzherald.co.nz and the Otago Daily Times is at www.odt.co.nz
- The Northwest Parkinson's Foundation (Canada) website at www.nwpcf.org has interesting media articles on Parkinsons on its 'In the News' page.
- The website of the Parkinsons Disease Foundation of India has an informative newsletter on www.parkinsonsdiseaseindia.com

Parkinsons People



Dorothy Neal and Jean Rodger cutting the Christmas cake at the Blenheim Parkinsons group Christmas gathering. Both these ladies attended the inaugural meeting of the group on 13th October 1985 and have been involved ever since.

Bert and Betty Lowen of New Plymouth were recently honoured by the Taranaki Division with life memberships to acknowledge their many years of outstanding contribution to the Society.



'Past, Present and Future' Auckland field officers gathered in Cornwall Park during the first meeting of the Central Auckland Care & Share Group. Lt. to Rt. Back: Sue Petty, Deirdre Rogers (now a volunteer supporter) and Annette McNevin. Front: Toni Hodgkinson (now full time mum, with daughter Camryn), Cilla Barkhuizen, Kay McGarry and Sally Anderson.

Nick Dangerfield, Chairman and Treasurer Parkinsons New Zealand, Tan Geok Tian, Singapore Parkinsons Disease Society and Professor John Nutt, USA, at the Asia Pacific Parkinson's Disease Association Conference in Hong Kong, December 2001.



New Zealand International Parkinsons Conference



Programme Update

The conference will provide a rare opportunity to hear from and meet some leading Parkinsons experts from around the world. Parkinsons New Zealand is delighted three excellent keynote speakers are confirmed for the conference. They are:

- Professor Y Mizuno from Japan, who was involved in the research that identified the Parkin gene.
- Dr A Lieberman from America, who has written several excellent books on Parkinsons and provides an internet question and answer service.
- Dr J Brotchie from the UK, a leading pharmacological scientist whose current work includes research on the drug Ecstasy.

The international input to the conference will be further extended by a number of Australian and other overseas health professionals who have indicated their interest in attending.

Date changed

To accommodate some of our guests, the conference dates have been slightly changed. It will now take place on the 23rd to 25th October, with a workshop focussing on younger people and the cocktail party on 22nd October.

Getting involved

This conference is for people affected by Parkinsons wherever they live in New Zealand. The organising committee would like to have your ideas and suggestions.

We welcome offers from people with Parkinsons, health professionals and others to share their experiences – for example, models of care, making a diagnosis, telling your family, the challenge of driving, stress on a spouse, etc. These could be in short 5-10 minute sessions or longer 30 minute sessions.

Members' assistance with some tasks would be appreciated. Could you assist by:

- making or painting tulips
- sewing or stitching banners
- filling envelopes

or maybe organising some other contribution?

Please contact Michelle Perry with your ideas and offers on 0800 473 4636.

Keynote Speaker

Dr Jonathon Brotchie is a researcher in a neuroscience biotechnology company developing new treatments for Parkinsons. He will be a guest speaker at our International Conference later this year. The following is a short extract relating to some of his work.

The Future is Bright

It appears there is a real possibility of finding a cure or effective medication which can control Parkinsons symptoms. The future is bright because of the promise of non-dopaminergic drugs and drugs that can control dyskinesia.

It's known that the brain makes other chemicals besides dopamine and these have not been studied as intensively as dopamine. The following could be important: serotonin, cannabis, opioids and adrenaline.

When dopamine production in the brain is reduced the rate of production of these other chemicals may change. By controlling the quantity and action of the chemicals at points along the signal pathways of the brain it's possible to greatly reduce Parkinsons symptoms or side effects.

There will be two new waves of drugs: the first will aim to control the side effects of dopamine-based drugs, such as dyskinesia, and the second to control Parkinsons without using dopamine-based drugs. The availability of drugs to control dyskinesia will mean that use of levodopa can continue successfully.

**Thank you for your support
Parkinsons New Zealand relies on grants and donations to continue its work on behalf of people affected by Parkinsons.**

**To make a \$20 donation please call
0900 FOR PD (0900 367 73)**

When you call this number, \$20 is automatically added to your telephone bill. Telecom forwards these donations to PSNZ each month. The donations are used to fund our general services for members.