



UPBEAT

The Newsletter for People with Early Onset Parkinson's
 Understanding Parkinson's by Belief in Education, Attitude and Treatment



The UPBEAT National Weekend 2012

The UPBEAT National Weekend was held 23-25 March at the Waipuna Hotel in Auckland. Forty four people with early onset Parkinson's and 26 carers attended.

The conference began on Friday afternoon with a presentation by Christchurch physiotherapist Tara Martin on the new LSVT-BIG physical therapy programme for Parkinson's. This has been attracting good reviews overseas. (See the March edition of *The Parkinsonian*.)

Saturday and Sunday morning sessions began with a group Tai Chi session led by UPBEAT member and Tai Chi instructor Oscar Getreuer. Oscar's sessions provided an opportunity for us all to start the day with some exercise.

Other sessions covered new therapeutic approaches to Parkinson's; cognitive issues; financial planning and insurance; and gadgets, technology, and the Internet.

The weekend ended with a presentation by Helen Spence from the Mobility Assistance Dogs Trust and her dog Chance.

Highlights? One of the recognised highlights of the weekend was an impromptu performance by Brian and Gailene Hewlett from Kerikeri describing their experience of Brian's Deep Brain Stimulation operation. When he managed to get a word in edgewise, Brian said the therapy had been "simply amazing" and had turned him back into a golfer.

For many though, the highlight of the weekend was Dr Barry Snow's address. (See over)

Highlights aside, many people said what they really appreciated about the weekend was the opportunity to spend time in relaxing surroundings amongst people who "understood".

"It was such a pleasure to be here, just to be able to sit, eat, and talk and not have to do anything else."

Good breaks between sessions allowed members to eat, drink, and converse in a leisurely fashion or simply rest. In these intervals, members made good use of the Wii games consoles to try their hand at golf, skiing or one of the other sports available.



Tara Martin talks BIG



Nikki & AJ talk insurance



Keynote speaker Dr Barry Snow

Thank you to Oxford Sports Trust who kindly sponsored the UPBEAT weekend

Keynote address: Dr Barry Snow

Neurologist Dr Barry Snow's keynote address covered the Parkinson's therapies available today and the therapeutic approaches under development for the future.

Dr Snow said because the supply of new medicines is drying up, more invasive therapies for Parkinson's are being examined, including the implantation of cells directly into the brain.

A lot of effort is going into finding ways of limiting the neurodegeneration using growth factors, which somehow induce the dying networks of dopamine-producing neurons to grow back. One approach, under development by an Auckland team, involves transplanting choroid plexus cells from the brain of a healthy disease-free pig into a human with neurological degeneration. The choroid plexus regulates the production and blending of growth factors in the brain.

The technique involves encapsulating pig choroid plexus cells in a membrane that renders them invisible to the human host's immune system yet is permeable enough to let nutrients in and growth factors out.

Injecting these capsules into rats and monkeys has brought results in a matter of weeks in some cases, Dr Snow said.



Dr Barry Snow

(This observation prompted him to add: "If you have to get Parkinson's make sure you're a rat. We've got plenty of things that work on rats.") The time was fast approaching when human subjects will be required to trial the technique, he said.

"The question we have to ask ourselves is should we do this research here in New Zealand or wait for somebody else to do it?"

Goal Setting: It's the journey not the destination

Dr John Parsons, senior lecturer at the School of Nursing, University of Auckland presented on setting personal goals.

Personal goal setting involves three steps. The first involves a person taking a stocktake and figuring out where they are right now. The third step involves defining the goal itself. The step in the middle involves establishing the specific tasks that must be achieved in order to keep moving forward.

A goal must be challenging, something that a person may or may not actually achieve. "There is very very seldom a goal that you can't strive toward and try to achieve. Having

that goal really drives you to do things that are too hard for you. Whether or not you get there is beside the point."

Even if the ultimate success doesn't come, benefits will still flow, Dr Parsons said. "If you identify what you want to achieve, do the middle bit and address the issues, by the time you've come to the conclusion that it's too hard for you, you will have achieved a lot of the intermediate steps along the way."

Support and motivation are critical. "Involving family and carers in working toward goals is absolutely vital. Getting everybody on board is most important."

Carers and Cognitive Decline Workshops

On Saturday UPBEAT members and their partners/carers separated and attended different workshops. Laurie Hilsen chief executive of Carers New Zealand led a workshop for carers, while Lea-Anne Morgan, Parkinson's New Zealand clinical lead, led a workshop on cognitive decline in Parkinson's for people with Parkinson's. The separation was intended to allow for free and frank discussion. In the session following, the sessions were reversed - the carers attended Lea-Anne's workshop while the people with Parkinson's attended Laurie's.

All sessions were an opportunity for attendees to vent a little and discover many of their challenges and frustrations were common to others. From the carer's session:

"I wish that once, just once, somebody would ask how I'm doing, how I'm feeling."

"I don't like the word carer. It means we aren't equal anymore."

From the cognitive decline workshop for people with Parkinson's:

"Understand there are things I can't do, even though I want to, and understand there are still many things I can do, so let me do them."

"I am not doing things on purpose, please try and remember this, even when you are stressed."

"Don't make me feel guilty, I already feel guilty."

Both workshops were valuable opportunities for people to be able to share their doubts and fears and anger...and have a few laughs.

The cognitive decline workshops provided what one attendee described as a sobering glimpse into the future; however, Lea-Anne said that overall, studies indicate at any given time, of all the people with Parkinson's, only about one quarter to a third have cognitive impairment.

Insurance: It can be a nightmare-be prepared

UPBEAT members Andrew Johnson (AJ) and Nikki Matthews discussed the importance of different types of insurance for people with Parkinson's and their partners and shared some tips on dealing with insurance companies.

Both are well placed to speak on the subject as both have been through the process of claiming insurance benefits under policies purchased before their diagnosis. And both found the process a long, fraught, and exacting one.

AJ, an insurance lawyer, said the guiding principle of insurance is one of utmost good faith on the part of the buyer. The prospective insuree must accurately disclose what he or she knows is material to the insurer.

Non-disclosure is grounds for an insurer to void a policy, and refuse to pay any claims. "What you tell the insurance company and how you fill out the proposal form will have a dramatic

affect on whether you get a claim paid." Nikki had her claim disallowed following her Parkinson's diagnosis at age 44 because she had forgotten to mention when she applied for cover ten years previously that she'd had glandular fever when she was 22.

What followed was a "very stressful and scary process" but eventually, after consulting the ombudsman, Nikki achieved a good result.

Nikki urged the audience to learn from her mistakes. "Overcomplete the application form; make sure you understand your policy; think about what you say and how you say it to any medical person. Demand to know, preferably in advance, the qualifications of any so-called specialist assessing you."

"And remember that you didn't ask to get Parkinson's; and that it's not your fault. Don't be bullied. Stand up for yourself, stay strong."

Gadgets, Technology, and the Internet

Andrew Johnson (AJ) and Nikki Matthews presented on Internet security and useful gadgets for the digitally-inclined.

Security

AJ kicked off the session with a warning: “Like the real world, the Internet is full of bad people who want to do you harm.” Internet privacy is a real concern, and unless a person took steps to protect their privacy they were leaving themselves wide open to theft, computer infection, loss of data, or at the very least intrusive advertising.

AJ urges people to:

- Use an open source browser such as Firefox. These are constantly being tweaked to make them more secure
- Adjust browser settings to prevent web-browsing being tracked
- Look at downloadable add-ons (often free) to stop information leaking out of a computer
- Consider using free antivirus software (AVAST) and free firewall software (Design Alarm)
- Beware of using the free WiFi on offer at airports and cafes
- Remember that smartphones suffer from exactly the same sort of security issues as laptops and desktop computers.

eReaders

Nikki introduced eReaders, which are small(ish) handheld devices used to read digital books. Nikki is a great fan of her Kindle because it is small, lightweight—an important point for a person with Parkinson’s whose hands may be tired and painful—and can hold 1000 books in digital form. (Some readers can hold more than twice as many.)

Many eReaders are easier to read in sunlight than conventional devices like laptops, and can easily be tweaked to suit user’s needs. Nikki said she found this particularly useful when slight cognitive issues meant she was unable to keep her place on a full page of text; simply changing font size resolved the issue. Some models have a text-to-speech function that lets the device read the text aloud—a handy feature when tiredness sets in.

A range of eReaders is available—Kindles, Kobos, Nooks, each have their plusses and minuses. Nikki’s Kindle cost around \$200 and the books she downloads from the online bookstore Amazon cost between \$2 and \$6. Many electronic books are available free.

Apps

At the end of the session, downloadable applications (apps) were discussed, including:

Where’s My Phone? Where’s My Droid?

Where’s My Phone and Where’s My Droid are two apps that locate and help to recover lost (or stolen) smartphones. The apps allow an alarm on the phone to be triggered remotely or the phone to report its GPS position when the owner logs onto a website.

Thick Fingers

Most Android phones, at least compared to the iPhone, don’t have big enough screens to text without making clumsy mistakes. Download and install Thick Buttons and start typing-- and the size of the letters on the keyboard changes, predicting what you are about to type. Letters commonly used after other letters will get bigger so your oversized thumbs hit the right key.

More extensive coverage of the UPBEAT Weekend has been posted on the UPBEAT section of the Parkinson’s New Zealand website, including a lightly edited transcript of Dr Barry Snow’s keynote address.