

**Parkinson's NSW
Ultimo Support Group (USG)
Notes from Meeting – Thursday 6th November 2008**

Attendance:

Noel Bishop
Pam and Brian England
Brendan Hartnett
Laurin McKinnon
Jack Kahabka,
Gerald Ganglbauer

Apologies:

Tony Moon
Vern Cork
Deborah Corbett
Stuart Rosewarne
Lynn Chenoweth
Trish Morgan
Chris Davis

The Ultimo Parkinson's Support Group held its 6th meeting at the Ultimo Community Centre.

Laurin spoke about the National Parkinson's Conference.

These are personal notes only; check any details with a second source.

Day 1, Thursday 16 October 2008

Keynote address was by John Ball who's a marathon runner, has run many races and raised money for research, highly motivated on physical strategies.

Prof Lyn Rochester (Glasgow Uni) followed with a review of cueing mechanisms, ie using lines spaced on the floor help PWP who have turning, moving issues. They've found that a metronome can be useful too.

Dr Bryce Vissel (Garvan) did a research summary. This list is not comprehensive.

Most of what he talked about was not of immediate use, ie was long-term discovery.

- 1 Some thinking now that Parkinson's is probably a range of diseases, not a single one.
- 2 This would explain varying responses of drugs etc.
- 3 Q10 formulations are not regular, this might explain inconsistent results.
- 4 Boston Unit has done some work with statins (anti cholesterol drugs?) suggesting risk of Alzheimer's and Parkinson's may be lowered (by 50%!) using them.
- 5 Gene therapy, Ceregene(?) has completed a phase 2 trial, reporting early 2009, thought to have affects with protection, even stop further degeneration.
- 6 GAD (Cornell Uni), in animals, prevents Parkinson's and gives strong protection

Dr Carolyn Sue RNS hospital, reported on nose stem cell work. They are doing animal testing, seem very positive. Now growing human stem cells.

Several workshops on Community Nurses for Parkinson's; WA, Victoria and UK models explained, In Sydney U Notre Dame is offering a course shortly.

Several workshops on depression.

Day 2, Friday 17 October 2008

Keynote address by Dr Abraham Lieberman (USA). With his patients, some 30+ years, he concentrates on erect posture and exercise. (Use it or lose it.) Suggests put your elbows on the table (straightens spine), stand with your hands on your hips like Gen Patton (ditto), keep your chin up to help swallowing, blow up balloons several times a day, go dancing, do specific work on getting your slow bits up to speed (legs hands etc). Do in private if you don't want to be thought of as strange!

Dr Colleen Channing (USyd) reported on their work with exercise. Results say it offers improvements providing you keep it up, there's no adverse affects, used home treadmills with safety extras, but walking is good too. Expanding scope of project.

Dr Kay Double (RPH) reported on brain cell death investigations. They now think that lewy bodies may be a normal reaction of the brain to bad activity, and the brain cells are 'fencing' the bad stuff off, since it can't get rid of it properly. There seems to be a clue in copper levels in 'bad' cells. They've been questioning why the dopamine issues don't affect other parts of the brain that have similar chemistry.

Dr Raymond Cook did a show and tell, before and after, on DBS, it works, we've seen it all before. Had safety figures, apart from a couple in the first 10(?) they've had almost no complications, infections. Now done 150(?) Was convincing about procedure. Still only recommended for some people, not all.

Dr Jasmine Henderson talked about animal experiments with BZAD 01, which looks promising.

Dr Michael Hayes (Concord) did a wide summary of lots of research, uric acid etc. Too much too quick to note down.

Note some sessions were video recorded; there may be a DVD available at some stage.

Summary thoughts, I was too tired to keep going all day so we left about 3/4pm on both days hence I didn't go to all workshops [obviously] nor to the social occasions, but what I saw was professionally done and in most cases quite interesting. The organization was solid and worked well; venue needs better sound proofing between rooms and silent closing doors. I hope there's a DVD available, or full notes especially from those doing summaries. Food was ok, coffee was terrible. I'm on a pension, so it's too expensive at \$200 per head, my call would be that there should be a cheap or free option (and especially make food an optional extra, not inclusive charge.)

This summary concluded Laurin's notes from the conference and was followed by a short discussion on a number of topics, like posture and having regular benchmark tests done to monitor slowly progressing symptoms.

Pam spoke about walking sticks. She also suggested a talk by a specialist for speech therapy and wondered about a possible connection between PD and cramps.

Noel was welcomed and introduced himself as a new member to the group.

Towards the end of the meeting I presented our website and the new links page live on my laptop to members who had not logged on to the site yet. [Note: There is WiFi in the Ultimo Community Centre for free Internet access]

Thanks to Pam and Brian for coffee and bikkies.

Gerald Ganglbauer