

**Parkinson's NSW
Ultimo Support Group (USG)
Notes from Inaugural Meeting – Wednesday 4 June 2008**

The Ultimo Support Group was launched on Wednesday 4 June, at the Ultimo Community Centre, where a room was kindly provided by the City of Sydney. USG is the 55th in NSW, so joins a large family of active Parkinson's stakeholders.

Eight people attended: Mike and Sue Willard, Prof Tony Moon, Jyoti Sachavirawong, Laurin McKinnon, Chris Davis, Dr Teri Merlyn, and Trish Morgan (Parkinson's NSW's Support Group coordinator). Of the eight, four were PWP: Tony, Mike, Chris and Laurin.

After a round of introductions, the group discussed its operating plans. Trish and Chris explained how most groups operate and the range of formalities that may or may not be adopted. The members quickly agreed on the following points:

- Co-convenors for USG will be Gerald Ganglbauer and Chris Davis, to get the ball rolling
- USG will meet on the 1st Thursday of each month, from 10 till noon [say 10:15 – the Centre only opens at 10]
- Members will rotate catering – Sue Willard offered to look after the July meeting
- There will be no formal minute taking or motions, but notes will be kept and distributed
- The Ultimo Community Centre will be the permanent venue for USG
- Members were happy to have their contact details made available for other USG members
- Recruitment channels could include: neurologists; UTS; TAFE; local newspapers like The Glebe, CENtRAL Sydney; CITY NEWS; the Centre notice board.

Dr Teri Delwyn told members about a trial that she was involved with, together with Prof Lynn Chenoweth: KWICI – Keeping Well in Chronic Illness. This study examines the benefits of having carers trained to improve the self-efficacy of PWP. This involves taking part in weekly training sessions for eight weeks, so the carer can adopt strategies to help the PWP to be positively in control of their situation: taking drugs, etc.

For the July meeting, members expressed a desire to hear about drug options for PD, especially the range on offer in Australia, cf overseas.