



## NOgIN Annual Report 2009

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Emma Everingham  
Clinical Nurse Consultant  
Westmead Private Hospital

Diane Lear  
Clinical Nurse Consultant  
Westmead Hospital

Dear Drs. Dexter, Dandie, Kam, McMaster and Owler

Please find attached the 2009 NOgIN annual summary reviewing the current service provided and future initiatives for patient's and their families living in western Sydney diagnosed with a brain tumour.

NOgIN, is a joint nursing initiative between Westmead Private Hospital and Westmead Hospital to support adults and their families affected by brain tumours. The group is registered as a resource with the Cancer Council of NSW. The NOgIN support group continues to evolve and is continually evaluated by the convenors.

### MEETINGS

The meetings/information sessions are held 2<sup>nd</sup> monthly at Westmead Private Hospital. Both the venue and access to the hospital are appropriate to the needs of our patient's and their carers. Westmead Private Hospital generously continues to provide supper and free parking for the meetings. Patient's are invited to the meetings and verbal consent is sought to be added to the database during their admission to hospital by the respective Clinical Nurse Consultant. On confirmation of formal pathology and prior to discharge patient's are provided with a "Cancer Pack" which includes information on tumour diagnosis, radiotherapy, chemotherapy and seizure management. Appropriate follow up is also clarified prior to discharge. There are currently over 200 patients on each hospital database. This year saw our largest attendance at a meeting with 75 participants. The inclusion of nametags at the meetings has improved communication and participation between the attendees. The 2010 program has been developed following a comprehensive review of the evaluation forms collated after each meeting.

### FUNDRAISING

During International Brain Tumour Awareness week we held our primary annual fundraiser. Staff across the Westmead Hospitals purchased bright purple "NOgIN" polo shirts to wear throughout the week whilst assisting with our raffle and BBQ. This is the second year we have held this event, with our raffle prizes growing each year. The first prize was a \$1500 glass splashback donated by DecoGlaze. Our thanks go to Mr. Bill Lockett, an associate of our support group, who rallied his business contacts to donate to our raffle. Many other local businesses also donated goods to support the raffle and food for the BBQ. With the amazing efforts of all these people and the local businesses that supported us, we were able to reach our goal of \$4000. All funds raised are maintained in the NOgIN trust fund account at the Westmead Medical Research Foundation, with a current balance of \$12,000.

## **AIMS**

The aim of NOgIN is for both hospitals to continue to work together to improve services for patient's and their families living in western Sydney with a brain tumour. We continue to strive to provide an empathetic and supportive environment, increase the patient's knowledge and educate patients on communication and coping strategies.

## **ACHIEVEMENTS**

- Our largest meeting with over 75 attendees
- 2<sup>nd</sup> annual fundraiser "Brain Tumour Awareness Week" – raising over \$4000
- Development of website – includes annual programs, newsletters and events  
[www.westmeadprivate.com.au/news](http://www.westmeadprivate.com.au/news)
- 3<sup>rd</sup> edition of "NOgIN News" distributed
- Donation brochure reviewed and amended
- Paper submitted for publication in the Australasian Journal of Neuroscience Nursing

## **FUTURE GOALS**

- Inaugural "carers only" evening with expert panel
- Inclusion in SWAHS and Westmead Hospital Department of Neurosurgery websites
- Development of NOgIN fact sheets
- Multi centred research project – A Disease Specific Measure of Quality of Life for Patient's Diagnosed with a Glioblastoma Multiforme

We would like to take this opportunity to thank the Neurosurgeons for their ongoing and invaluable support of NOgIN.

Yours Sincerely

Emma and Diane