

NOgIN News



Issue 3 - March 10

Co-ordinators Comment

Since our last edition of NOgIN News there have been some great developments, as our group continues to expand. For our third year running we have held 6 meetings annually.

To summarize the highlights of 2009 we had our biggest ever meeting in April with over 75 people attending. The presentation by Professor Owler discussed the causes and current research on treatment of brain tumours. This was also very topical in the media at the time. Due to this overwhelming response RSVP for all of our meetings is now essential, in order to provide you with the best venue and catering. We are very fortunate to have all of our catering sponsored by Westmead Private Hospital and catered by Sodexho.

2010 Meeting Dates:

2nd February

6th April

1st June

Carers Only - 24th June

3rd August

5th October

7th December

7pm - 9pm Conference Room
Westmead Private Hospital

For the first time in July we promoted a "Carers Only Night", with a panel of experts. This format was prepared in response to the evaluations we receive. Unfortunately, we had to cancel due to insufficient numbers. It was during a peak influenza time for Sydney and we are keen to hold this event again this year. So please keep Thursday 24th June free and reply ASAP, as numbers will be limited.

We also held our second annual fundraising and awareness event for NOgIN, during International Brain Tumour Awareness Week 1-7th November 2009. Staff across the Westmead Hospitals purchased bright purple NOgIN polo shirts to wear throughout the week, whilst assisting with our raffle and BBQ.

Nursing staff from both the neurosurgical units volunteered their time to help out at the BBQ and sell raffle tickets. A lot of staff came in on their days off to help, along with some of our regulars from NOgIN meetings. It was an amazing team effort.

With the incredible efforts of all these people and the local businesses who supported us, we were able to reach our goal of \$4000!

A huge thank-you to everyone who helped out. Please refer to our list of sponsors.

The third exciting development is information on NOgIN is now available on 2 websites (the Westmead Private Hospital website and the neurosurgeons website).

Visit: www.westmeadprivate.com.au/news and www.westmeadneurosurgery.com.au for programs, newsletters and events.

As we are continuing to develop this type of media, we are open to any suggestions for additional information you would like to see on the webpages.

Finally, once again we acknowledge the support of our neurosurgeons who provide ongoing support for the development of NOgIN: Dr Mark Dexter, A/Prof Brian Owler, Dr Gordon Dandie and Dr Jacqueline McMaster.



NOgIN BBQ fundraising and awareness event at the entrance to Westmead Private Hospital - What a team!

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NOgIN Information Nights

April 2009 - Session 1

Current research in the treatment of brain tumours

Presented by: Assoc Prof Brian Owler, (Consultant Neurosurgeon)

Hallmarks of tumours

- Self sufficiency in growth signals
- Tissue invasion and metastasis
- Sustained angiogenesis
- Evading apoptosis (programmed cell death) – cell destroys itself

Genetic basis of cancer

- Proto-oncogenes
- Tumour suppressor genes
- Neurofibromatosis Type 1 – optic neuroma, ependymoma, acoustic neuroma, meningioma, neurofibroma
- Neurofibromatosis Type 2 – acoustic neuroma, meningioma
- Tuberous sclerosis
- Von Hippel Lindau Syndrome – haemangioblastoma

Genetics of Gliomas

- Low grade gliomas (astrocytes) – less tumour suppression gene P53 (17p), PDGF (growth factor) over expression
- Oligodendrogliomas – 1p/19q loss heterozygosity, different chemo response
- Progression – anaplastic astrocytoma grade 3 TP53 mutation
- Progression – GBM PTEN gene

Areas of Research

- Prevention Surveillance/ epidemiology
- Treatment and Management
- Clinical Trials Website – www.cancer.gov.au

Potential Benefits

- Health care provided by leading physicians
- Access to new drugs and interventions
- Close monitoring of health care
- Active role in own health care
- Opportunity to make a valuable contribution to cancer research
- Side effects or unknown risks
- Even if a treatment has benefits it may not work for you

April 2009 - Session 2

Possible causes of brain tumours

Presented by: Assoc Prof Brian Owler, (Consultant Neurosurgeon)

Risk factors/causes

- Unknown
- More common in males (glioma)
- Meningiomas more common in females
- Family history – slight increase in risk
- More prevalent in Caucasians
- Radiation causes and certain chemicals
- Leukemia as a child
- Radiotherapy increases risk of developing meningiomas
- CT scans as a child
- Working with vinyl, textiles, plastics
- Mobile phones – (journal article) Lemart Hardell, International Journal of Oncology 32:1097-1103 2008.

Q. If the tumour has shrunk on the MRI scan how good is this?

A. It is unusual for complete removal of the tumour following radiotherapy. Radiation necrosis often mimics tumour progression on a CT scan.

Q. What is the percentage of tumour recurrence.

A. In a high grade glioma the incidence is high.

June 2009 - Session 1

Overcoming communication changes

Presented by: Colleen Kerr (Speech Pathologist)

Colleen presented an overview of the primary communication changes that can occur in Brain Tumours. These included:

- Speech muscle changes resulting in slurred or imprecise speech quality (Dysarthria) These changes are often accompanied by changes in swallowing function.
- Voice changes resulting in hoarseness, weak voice quality or lack of expression in the voice
- Language changes (Aphasia) which can range from severe difficulty understanding even simple everyday words, to an occasional failure to recall someone's name. These changes can impact on both spoken and written language.
- Cognitive Communication Changes which can alter the 'social' use of language eg talking too much, interrupting.

Colleen provided case studies, examples of therapy and details of communication aids for different problems. Participants were encouraged to work in pairs to simulate communication problems in order to understand how best to overcome daily communication breakdown. Colleen was assisted in her presentation by a person who has experienced Aphasia, Mr Stephen Arkins, whose recovery story and therapy experiences were deeply inspirational to all who attended.

For more information on Communication Changes following Brain Injury call Colleen on 0403903822 or email colleenkerr@optusnet.com.au

June 2009 - Session 2

Dietary advice during treatment and recovery

Presented by: **Maureen Lynden**
(Dietician)

August 2009 - Session 1

Seizure management and driving

Presented by: **Dr Jacqueline McMaster** (Consultant Neurosurgeon)

What is a seizure - An abnormal electrical activity in the brain. There are various types – generalised, partial, focal.

Who has seizures - Approximately ¼ of patient's with a brain tumour will present with a seizure. It depends on the location of the tumour. Some seizures occur after the surgery.

What predisposes to seizures.

- Sleep deprivation
- Hyperventilation
- Flashing lights in some patient's
- Infection in any part of the body
- Head injury
- Electrolyte imbalances such as the salt level in the blood

How do we treat seizures - Anti epileptic drugs

- Preventative - prior to or after neurosurgery for 3 months
- Therapeutic – if a seizure occurs before surgery, medication usually continues for up to 12 months

Common medications used

- Phenytoin (dilantin) – ensure you have regular blood tests by your local doctor to avoid toxicity (too much medication)
- Tegretol (carbamazepine) - ensure you have regular blood tests by your local doctor, monitor salt (Na) levels
- Valporate (epilum)

- Levetiracetam (keppra)
- Clonazepam (rivotril)

Q Why do seizures occur?

A. Having an operation on the brain can irritate the brain causing seizures.

Q. Why do I have to stay on seizure medication?

A. This is individual depending on the type and location of the brain tumour and any previous history of seizures.

Q. Can I have a seizure and not know?

A. Yes, seizures may occur during sleep.

Q. Can you have a seizure up to 8-9 months after surgery?

A. The majority of seizures occur in the first 3 months after surgery, there is no evidence to support putting a patient on long term therapy if they have not had a seizure.

Q. Would I be classified as an epileptic?

A. Epilepsy is more than two seizures.

Q. Is the abnormal electrical activity caused from scarring or pressure?

A. In a brain tumour, it is usually due to the effects of pressure. In a head injury, it is usually from scarring.

Q. How often should blood levels be taken?

A. Every week at least on commencement, when the medication has established or a "steady state" has been reached, generally monthly.

Q. Can you still have seizures on anti epileptic drugs?

A. Yes, you may need to change the medication or add another one. Most seizures are controlled with one medication.

Q. Does the risk of seizures decrease over time?

A. Yes, usually after 3 months.

First Aid for seizures.

- Don't panic
- Remove ties and tight clothing
- Put the patient in a place where they can't be injured or move harmful objects
- Place the patient on their side
- If concerned, call an ambulance on 000

Q. Can you swallow your tongue?

A. You can bite your tongue causing swelling. Place the person on their side so tongue falls to the side.

Q. Can I drive?

A. The guidelines for driving are on the RTA website, some patient's may require a driving assessment by the RTA. Following a brain operation you are not allowed to drive for 3 months. For patient's who have had a single seizure you are not allowed to drive for 6 months. You are not allowed to drive when you are weaning anti epileptic drugs.

Q. Can I ride my bike?

A. The same restrictions apply as driving a car.

Q. Can I exercise?

A. There are limitations when you are alone, such as swimming and extreme sports.

Q. Can I travel?

A. Yes, if you are considering flying you may have to wait until healing occurs and there is no air in the head after surgery.

Q. Can I work?

A. There may be limitations where the risk of a seizure may be life threatening.

Q. Can I drink alcohol?

A. Alcohol can interact with anti epileptic drugs.

Q. Do seizures cause brain damage?

A. Partial seizures do not cause brain damage, generalised seizures mostly only last 2-3 minutes, but it depends on the length of the seizure.

visit www.rta.nsw.gov.au or www.epilepsy.org.au for more details

August 2009 - Session 2

Management of headaches and pain

Presented by: Dr Jacqueline McMaster (Consultant Neurosurgeon)

Q. Can acupuncture help?

A. It is very individual, some people find this helps.

Q. The sensation near my wound feels strange after surgery, is this normal?

A. Yes, the nerves have been cut, causing numbness, tenderness or the wound to be hypersensitive.

Q. Does a similar headache indicate tumour recurrence?

A. Not necessarily. See your doctor and you may need to have a repeat scan.

Q. Can you massage your head with oils?

A. Yes, once the wound has healed. The bone has been replaced and fixed into place.

Q. Is there any reason a CT scan will not pick up a tumour?

A. Some low grade tumours may look like normal brain tissue, a MRI scan is more sensitive

October 2009 - Session 1

Managing changes to cognition/ returning to work

Presented by: Matthew Sproats (Occupational Therapist)

Cognition – defined as a persons capacity to acquire and use information in order to adapt to

environmental demands and carry out desired actions.

Environment:

- Reduce clutter
- Choose the best time (when you are at your best) in the day to do your task
- Reduce sensory stimulus e.g.; the television

Memory

- Write down a list of tasks
- Keep objects in the correct place e.g.; toothbrush in the bathroom
- Keep a note pad beside the telephone
- Keep to routine e.g.; shower at the same time each day
- Break down the tasks into smaller goals
- Modify the way you complete the task e.g.; use a shower chair, replace buttons with velcro

Q. As a carer, when your family member is re learning e.g.: cooking, what is the best thing to do?

A. Least to most prompting. Breakdown the tasks into manageable goals. Observe at first, then help the patient to work through each step e.g.; let's peel the vegetables, now turn the oven on, put the meat in the oven. Talk through each task, prior to commencing the task. Make tasks easier to perform e.g.; use of frozen vegetables.

October 2009 - Session 2

Where does palliative care belong?

Presented by: Dr Philip Lee (Palliative Care Consultant)

Palliative Care – an approach that improves the quality of life of patient's and their families facing the problems associated with life threatening illness.

Role

- Relief of suffering
- Quality of life
- Comfort
- Holistic care
- Dying with dignity

Goals

- Patient goals
- Family/carer goals
- Health professional goals

Q. Does hypnotherapy help?

A. Relaxation therapy with a psychologist is very useful.

Q. Is marijuana being used?

A. Marijuana is still illegal in Australia so it has not been trailed here. There are reported benefits in the literature in social users, however there are too many side effects on previous non users. There is a discrepancy in the potency dependent on the plant.

Q. Is there a place for the family to work with palliative care specialists?

A. Yes, it is important to understand the patient's wishes (advanced care directives) early in the illness.

Summary

- Dying is normal
- Palliative care may prolong life but not at the expense of prolonging suffering
- Focus on quality of life and "living well"
- Palliative care does not actively shorten life
- Patient choice, family support

A quote from a family member:

"All the care received before meant nothing because she died the way she died".



Dr Philip Lee

December 2009 - Session 1

The wonders of the brain : basic neuroanatomy

Presented by: **Dr Gordon Dandie**
(Consultant Neurosurgeon)

The brain is a complex organ so can compensate when things go wrong for a long time. The outside of the brain is the main part of the nerve cells or grey matter. The inside is the white matter or nerve fibres (wiring). The brain is divided into four main lobes in each hemisphere. 85% of tumours develop in the cerebrum or main part of the brain. Movement and sensation is controlled by the opposite side of the brain.

Frontal lobe

- motor function/power
- speech
- sense of smell
- personality
- regulation of behavior/social skills
- bladder function

Temporal lobe

- memory
- hearing
- comprehension of language
- visual pathways

Parietal lobe

- appreciation of music
- ability to play a musical instrument
- geographical sense
- ability to dress/spacial orientation
- visual pathways

Occipital lobe

- vision

Q. Do deficits occur because of the tumour or because of the surgery?

A. Deficits often occur because of the tumour and associated swelling in the normal brain. The deficit should resolve if just the tumour cells have been removed and the swelling has reduced.

Speech areas

98% of people are left sided dominant or right handed. However in left handed people approximately 50% are still left sided brain dominant.

December 2009 - Session 2

Grading of cerebral tumours

Presented by: **Dr Gordon Dandie**
(Consultant Neurosurgeon)

Definition - Lump or mass, benign or malignant.

- Benign – compresses surrounding tissue but does not invade or spread.
- Malignant – tendency to invade surrounding tissues or spread to distant sites in the body.

Classification

Location – aids in differential diagnosis

Grade – WHO (World Health Organisation) 1 - 1V

Histological – based on tissue of origin

Location

Frontal lobes – astrocytomas, oligodendrogliomas, metastasis

Cerebellar – medulloblastoma, ependymoma, pilocytic astrocytoma, metastasis

Grading

WHO – used to standardise the description and aggressiveness of tumours. Grading is important for clinical research.

GRADE I – tumours are slow growing and benign

GRADE II – relatively slow growing but sometimes recur as higher grade tumours. Can be malignant or non malignant.

GRADE III – tumours are malignant and often recur as higher grade tumours

Grade IV – reproduce rapidly, very aggressive and malignant

Epidemiology

- Gliomas 40%
- Meningioma 25%
- Pituitary adenoma 10%
- Nerve sheath tumours 8%
- Lymphoma 3%
- Medulloblastoma 2%
- Craniopharyngioma 1%
- Others 10%

Q. Are tumours genetic?

A. Some cancers are genetic although not primary brain tumours. There is a lot of research being undertaken. There are environmental factors associated with brain tumours.



NOGIN members win lucky door prize donated by The Flower Factory

International Brain Tumour Awareness Week

1 - 7th November 2009

Recognition of our sponsors:

- DecoGlaze, Seven Hills
- Westmead Private Physiotherapy Services
- Sodexo
- Bungaree Butchery, Toongabbie
- Bing Lee, Merrylands
- Stationary World, Castle Hill
- Kuringai Cycles, Hornsby
- Bars N Racks, Hornsby
- Nads Laser Clinic, Baulkham Hills
- Vitality Health Fitness Management
- Karin Murton Hair Design, Northmead
- The Flower Factory, Westmead
- Merrylands Bowling Club
- Peters Meats, Merrylands
- Best N Less, Merrylands
- Fresh Scent, Castle Hill
- Food Choice Family Restaurant, Merrylands
- Bharsi, Merrylands
- Global Patisserie, Merrylands

"Carers Only Night"

Book your seat for dinner with a panel
of experts!

When: Thursday 24th June, 2010

Where: Conference Room
Westmead Private Hospital

Time: 7.00pm

Bookings are essential as numbers are limited
RSVP to Emma on 8837 8926 by 1st June

Save the date!

Wednesday 5th May 2010
The Menzies Hotel

A free information day for brain cancer patients and their families presented by the Cancer Institute NSW Oncology Group Neuro Oncology.

The day features educational sessions presented by brain cancer clinicians and professionals involved in all spectrums of care throughout the patient journey. There will be both adult and paediatric programs.

For further information contact Julie MacDonald on 8374 5683 or julie.macdonald@cancerinstitute.org.au

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