

Patient Education and Information Forum

SUNDAY 8 October 2023

Hilton Sydney 488 George Street

Facilitated by **Marina Kastelan**Neuro Oncology Nurse Practitioner, The Brain Can<u>cer Group</u>

9.30am-10.00am Registrations. Morning tea on arrival

10.00am A/Prof Eng-Siew Koh: Forum Opening

10.10am Prof Martin Taphoorn: Patient Reported Outcomes and Advance Care

Planning in Brain Tumour Patients; the importance for patients, caregivers

and clinicians.

10.30am Dr Ben Kong: Clinical Trials Update.

10.50am Prof Matthew D. Dun: From bedside to bench to bedside & back again,

leukaemia researcher come DIPG dad.

11.10am Dr Sarah Bray: Brain Tumours Online Project.

11.30am Peter Ramstadius. Brain Tumour Alliance Australia Update.

11.40am Q&A Panel Discussion.

12.00pm - 1.00pm Lunch

1.00pm *PATIENTS* - Mindful Meditation - A tool for Patients.

Facilitated by David Hewitt of Mindful Meditation Australia

CARERS - Sharing Session

Facilitated by Philip Steel, Diane Legge and Catherine Hindson

1.45pm Break

2.00pm CARERS - Mindful Meditation - A tool for Carers.

Facilitated by David Hewitt of Mindful Meditation Australia

PATIENTS - Sharing Session

Facilitated by Philip Steel, Diane Legge and Catherine Hindson

2.45pm Altogether - Questions and Conclusion

3.00pm Afternoon tea



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Patient Education and Information Forum Speakers



Prof. Martin Taphoorn MD PhD Leiden University

Martin Taphoorn obtained his MD at Leiden University and subsequently specialized in clinical neurology in Amsterdam VU Medical Center, where he also wrote his PhD thesis "Treatment of Primary and Metastatic Brain Tumours; Beneficial and Adverse Effects". He further specialised in clinical neuro-oncology at University Medical Center, Utrecht and during a sabbatical leave visited MD Anderson Cancer Center, Houston Texas (Dr Levin) and Memorial Sloan-Kettering Cancer Center, New York (Dr DeAngelis).



Dr Ben Kong BSc(Hons), MBBS, PhD, FRACP

Medical Oncologist - Prince of Wales Hospital, NHMRC Clinical Trials Centre, UNSW

Ben Kong is a medical oncologist and cancer researcher with interests in clinical trials, immuno-oncology and translational research. He trained in General Medicine at Concord Hospital and Medical Oncology at Westmead Hospital. In addition to his clinical duties, Ben is currently an Oncology Research Fellow with the Co-Operative Group for Neuro-Oncology at the NHMRC Clinical Trials Centre and a Senior Research Fellow with the SPHERE Cancer Clinical Academic Group at UNSW.



Prof. Matthew D. Dun PhDThe University of Newcastle (UON)

Professor Matt Dun is a National Health and Medical Research Council (NHMRC) Emerging Leadership Fellow (2020–2024) and a Defeat DIPG Chadtough New Investigator (2020–2021). Matt is a medical biochemist and Professor of Paediatric Haematology and Oncology Research the University of Newcastle, Australia, and a Deputy Director of the HMRI Precision Medicine Research Program. His position and research has been supported by state and/or national funding bodies continuously since 2012, as well as supplemented by philanthropic and industry contributors throughout.



Dr Sarah Bray
Project Manager - Brain Tumours Online at University of Melbourne

Dr Sarah Bray is an experienced research project manager and consumer engagement coordinator, passionate about science engagement with the wider community and using her research and communication skills to achieve a better, more equitable, sustainable and healthier world. Sarah has thrived on working in a diverse range of projects over her career, from her PhD project wrangling ancient DNA from extinct bears, to medical research in cancer biology, and more recently, managing a national 'Big Data' project linking the health and aged care sectors in Australia.



Peter Ramstadius

Website Coordinator and Helpline - Brain Tumour Alliance Australia (BTAA)

Peter is a semi-retired civil engineer from Coffs Harbour. He has enjoyed a varied career specialising in construction project management for both government and the private sector, but more recently in a self-employed role working in the mining industry. Peter became involved in the brain tumour community when his wife, Jenelle developed a GBM and passed away in 2017 after a 20-month battle. Jenelle had an unrelated meningioma removed a few years earlier.



David Hewitt

Manager School Relations & Seeking Equanimity - Mindful Meditation Australia

David is a dedicated professional at Mindful Meditation Australia, specialising in building connections with schools and non-education organizations to facilitate the integration of mindfulness practices. With a focus on enhancing workplace culture, relationships, and personal well-being, David plays a pivotal role in inspiring positive transformations.



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