

Keeping epilepsy in mind

Representatives from Olympic, sporting, medical and public arenas uniting to launch landmark research into chronic brain disorder

Olympians, sporting legends, doctors and everyday heroes will join forces today (Tuesday, September 20) to release landmark research into the country's most common, chronic brain disorder affecting 1-in-100 (55,856) Victorians*.

The Australian-first longitudinal study paints a candid picture of the psychological, social and physical challenges and barriers encountered by people living with epilepsy.¹

Visiting Franco-American Olympic medallist and six-time World Champion cyclist, Marion Clignet, is leading today's announcement and sharing her remarkable story about living and winning with epilepsy, ahead of this weekend's **Ride4Epilepsy** at Sandown Raceway, Melbourne. Supporting her is Commonwealth cycling medallist and media commentator, John Trevorrow, Australian Water Polo Olympic team goal keeper, Luke Quinlivan, Collingwood cheer-squad leader who has a daughter with epilepsy, "Joffa" Corfe and everyday Victorians living with the stigmatised disorder.

According to Professor Mark Cook, Chair of Medicine and Director of Neurosciences, St Vincent's Hospital, Melbourne, the new research reveals the significant burden of uncontrolled epilepsy on people's lives.

"Current literature suggests that 10 per cent of Australians will have a seizure during their lifetime, one-third of whom will be diagnosed with epilepsy.²

"New data from the Epilepsy Australia and Epilepsy Foundation of Victoria national epilepsy longitudinal study – *Needs, perceptions and experiences of people with epilepsy* – show more than one-in-two participants have been hospitalised or injured due to epileptic seizures,"¹ said Prof Cook.

"The number of seizures a person experiences is strongly related to their Quality of Life (QoL).³ Disturbingly, one-in-five research respondents had experienced more than 20 seizures in just 12 months.¹

"More than half (52 per cent) of the research respondents living with epilepsy had experienced depression,¹ highlighting the psychological toll of the disorder," Prof Cook said.

"Furthermore, a remarkable one-in-two study participants reported unfair treatment in the workplace, school, community organisation, public place or at home due to their epilepsy."¹

Marion Clignet says the stigma faced by people living with epilepsy is often worse than the disorder itself⁴ – a barrier she understands well, after living with epilepsy for more than 25 years.

Despite being dropped from the United States Cycling Federation due to her epilepsy, Marion continued her quest for gold, becoming a dual Olympian, winning silver medals for France in the Atlanta 1996 and Sydney 2000 Games. She has also won more than 180 cycling races world-wide.

"Epilepsy doesn't need to define you. I discovered I was living with epilepsy at 22 years of age. Since then, I made a promise to myself that nothing would get in the way of achieving my dreams," said Marion.

"If I can learn to live with epilepsy, the community should learn to live with it too by shaking the stigma. As the social consequences or stigma faced by people with epilepsy are often worse than the disorder itself.

"The first annual *Ride4Epilepsy* this Sunday, September 25 at Sandown Park Raceway, Melbourne, represents a great opportunity to help shake the stigma associated with epilepsy. By registering for the ride, participants are not only supporting those living with the disorder, but helping to raise community awareness and understanding of the brain disorder," Marion said. **To register for the *Ride4Epilepsy* head to www.ride4epilepsy.com.au.**

According to Dr Christine Walker, President of Epilepsy Australia, CEO of the Chronic Illness Alliance and lead author of the national epilepsy longitudinal study, Melbourne, epilepsy ranks in the top five causes of avoidable deaths among 5-to-29 year olds.⁵

“Australians across all age groups living with epilepsy have a mortality rate two-to-three times greater than the general population,⁶ causing approximately 250 deaths per year.⁷ Yet despite these grave statistics, the disorder continues to be neglected by Australian public policy.³

“A third (32 per cent) of the epilepsy research participants revealed they earn less than \$249 per week,¹ while the average government funding per year for an Australian living with epilepsy is only \$8,”³ Dr Walker said.

Moreover, Dr Walker warns epilepsy does not occur in isolation. “The social burden and stigma of this common neurological disorder has a ripple effect on family members, carers and the wider community. Up to 3.5 million Australians are directly and indirectly affected by epilepsy over their lifetime.”⁸

Mrs Christine Walker, of Mernda, Victoria, is familiar with the obstacles and challenges of epilepsy, as her husband, Darrell and their three children, Cassandra, 17, Daniel, 15, and Ronan, 11, all have different stages and levels of the disorder.

“Cassandra experienced a seizure at eight-and-a-half months and, after three more seizures, she was referred to a neurologist who eventually diagnosed her with epilepsy. Today, Cassandra is a bright, independent young woman who hopes to forge a career in hospitality.

“Our second-born, Daniel, was 18-months-old when he had what appeared to be a fall from a couch. It never occurred to us or the ambulance staff that it may have been due to an epileptic seizure. At nine years of age, tests showed that Daniel had frontal lobe activity that was causing epilepsy,” said Christine.

“Daniel’s epilepsy is managed well,” said Christine, “and other than when he’s stressed or over-tired, he’s reasonably okay.

“My message to other families living with epilepsy is that they don’t have to cope alone. The greatest support is from people in your own situation. It’s okay to tell people what you’re going through,” Christine said.

About epilepsy

Epilepsy is a diverse group of complex brain disorders resulting in recurrent seizures.^{9,10,11} Seizures occur when there is sudden, excessive electrical activity in a group of brain cells,¹² and range from brief attention lapses, muscle jerks and repetitive movements, to severe and prolonged convulsions and loss of consciousness.^{9,11} A person with epilepsy has two or more unprovoked seizures.^{10,11} There are number of different types and classifications of seizures.⁹

The exact cause of epilepsy is unknown in approximately 6-out-of-10 people living with the disorder.¹¹ Some of the known causes of epilepsy are head trauma, central nervous system (CNS) infections, tumours and inherited, developmental or genetic conditions.¹² Epilepsy can occur at any age, but is more common among infants and children and those over 65 years of age.¹³ Research suggests between 660,000 and 880,000 Australians will have epilepsy in their lifetime.³

About the research

The *Socio-economic longitudinal study of epilepsy* is a national survey investigating the psycho-social impact of epilepsy on Australians over a decade, initiated and conducted by Epilepsy Australia and the Epilepsy Foundation of Victoria. The latest wave of the study – *Needs, perceptions and experiences of people with epilepsy* – involved 343 participants living with epilepsy and their carers, who reflect a representative sample of the Australian population.¹

About the Ride4Epilepsy

The inaugural *Ride4Epilepsy*, to be held on September 25, 2011 from 8am to 2pm at Sandown Park Raceway, Melbourne is a car free cycling event for riders of all age groups and abilities, aiming to raise awareness and funds for the Epilepsy Foundation of Victoria. For more information and to register, head to www.ride4epilepsy.com.au.

About the Epilepsy Foundation of Victoria

The Epilepsy Foundation of Victoria is a state-based organisation that aims to help people living with epilepsy and their families to manage epilepsy while enhancing their quality of life. Their services include information, support, epilepsy counselling and practical assistance, as well as education and training, and research and advocacy on behalf of people with epilepsy. **To learn more or to register for the longitudinal study, call the Foundation on (03) 9805 9111 or visit www.epinet.org.au**

* Calculation based on 1% (point prevalence of epilepsy world-wide) of Australian and Victorian populations as at December, 2010.

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For more information, or to coordinate an interview with Prof Mark Cook, Dr Christine Walker, Mr Graeme Shears (CEO, Epilepsy Foundation Victoria), Prof Sam Berkovic, Associate Professor Wendyl D’Souza, Marion Clignet, Jeff “Joffa” Corfe or Mrs Christine Walker, please contact Kirsten Bruce or Denise Vrontas from VIVA! Communications on 02 9884 9011 or 0401 717 566 / 0414 524 383.

See References overleaf

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