In this issue of Epilepsy Matters, we highlight initiatives on the global epilepsy stage and activities taking place closer to home.

In June, I was fortunate to travel to Bangkok for the 33rd International Epilepsy Congress, where I attended symposiums covering topics such as the social impact of epilepsy and the importance of taking medication as prescribed.

As a Board member of the International Bureau of Epilepsy, and Chair of the Capacity Building project, it was an opportunity to network with other epilepsy service providers from around the world and hear about their achievements and the challenges they face in helping to improve the lives of people with epilepsy.

The congress was also the forum for the release of the World Health Organization’s new report Epilepsy: A public health imperative. The report highlights the burden of epilepsy throughout the world and the fact that, even in Australia, a developed nation with a sophisticated health system, people with epilepsy still often experience discrimination and stigma. This affects their education, employment and quality of life.

We have a way to go to reduce this discrimination and much of our work, in addition to providing important services to people experiencing the day-to-day effects of epilepsy is about increasing understanding to overcome the discrimination and make a difference.

Our annual Walk for Epilepsy is on again this year. We hope you can join us at Princes Park, Carlton, on Sunday 20 October for a fun, healthy and worthwhile activity that will help to raise much-needed funds for people living with epilepsy.

I’m pleased to say we have recently launched our new website, after listening to those who use the site about their needs for information and access, and much hard work at the Foundation to get the job done. It is a vast improvement on our previous site and contains the latest information about understanding, managing and living with epilepsy. I hope you find it useful.

As always, thank you for your support of the Epilepsy Foundation and if you require any further information about our organisation you can either visit our website or telephone our Epilepsy Infoline 1300 761 487.

Graeme Shears
Chief Executive Officer
Discrimination and stigma still adversely affect Australians living with epilepsy, according to a new World Health Organization report, Epilepsy: A public health imperative released on 24 June at the 33rd International Epilepsy Congress in Bangkok.

The report reinforces our mission that ‘no one with epilepsy should go it alone’. It stresses the importance of ‘engaging governments and civil society in taking concrete action to promote access to care and to protect the rights of people with epilepsy.’

Currently 250,000 people in Australia are living with epilepsy. The report showed that in an Australian study, 47 percent of people living with epilepsy who were currently employed reported unfair treatment while in the workplace. This is despite Australia being a high income, developed nation.

The report highlighted people with epilepsy are the target of discrimination and human rights violations.

This can discourage people from seeking treatment adversely affecting quality of life, employment, finances and social inclusion.

In summary, the key messages in this report are:

**Burden** – The burden of epilepsy is high and often neglected in public health agendas. Epilepsy is one of the most common neurological diseases, affecting nearly 50 million people of all ages around the world. The risk of premature death in people with epilepsy is up to three times that of the general population. Roughly half of adults with epilepsy have at least one other health condition. Psychiatric conditions, such as depression and anxiety, make seizures worse and reduce quality of life. Epilepsy has significant economic implications in terms of health care needs and lost productivity at work.

**Discrimination and stigma** – In all parts of the world, including Australia, people with epilepsy are the target of discrimination and human rights violations.

The stigma of epilepsy can discourage people from seeking treatment and has consequences for quality of life and social inclusion.

Improving knowledge and raising awareness of epilepsy in schools, workplaces and communities is needed to reduce stigma. Legislation based on internationally accepted human rights standards can prevent discrimination and rights violations, improve access to health care services and raise the quality of life for people with epilepsy.

**Prevention** – An estimated 25 percent of epilepsy cases are preventable. The major modifiable risk factors for epilepsy are: perinatal insults, central nervous system infections, traumatic brain injury and stroke. Preventing epilepsy is an urgent unmet need. Effective interventions for prevention are available and delivered as part of broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health.

Read the full report here: World Health Organization (WHO)

Research Roundup

Here are some highlights of the research being done looking at epilepsy and its impacts, both by the Epilepsy Foundation and by other organisations:

A recent survey by UCB studied the associations between anti-epileptic drugs (AEDs), and quality of life.

The study found that depression/anxiety issues and memory problems were very commonly reported among people living with epilepsy and both were particularly reported as having a negative impact on quality of life. More information can be found here.

The Australian Epilepsy Research Fund (AERF) is an initiative of the Epilepsy Foundation that was announced in March 2018.

The aim of the AERF is to support high quality research into finding a cure for epilepsy and supporting people currently living with epilepsy. For more information about the AERF, visit our website.

The Epilepsy Foundation has been collaborating on a project with The University of Melbourne looking at the relationship between epilepsy and body image. More information can be found here.
2019 Walk for Epilepsy

Our second Annual Walk for Epilepsy is on again in October and it promises to be a huge event on our fundraising calendar.

Please come along and walk with us to ensure that no one living with epilepsy ever has to go it alone. Bring your friends and family, and your dog! and enjoy a beautiful walk around Princes Park, Carlton.

Ask your friends, family, colleagues and social networks to help you achieve a fundraising goal. All funds raised will help provide support for people living with epilepsy and funding for research with the aim of finding a cure for epilepsy.

The walk will be held on Sunday 20 October 2019. Registrations start at 9.00am and the walk will commence at 11.00am. You can walk one lap (3.2k) or two laps (6.4km).

You won’t go hungry or thirsty as there will be a coffee van, sausage sizzle and water available on the day.

The Walk for Epilepsy is fully accessible to mobility scooters, wheelchairs and prams.

To register visit: Walk for Epilepsy

For further information:
Phone: 03 8809 0655 or 1300 437 453
Email: events@epilepsyfoundation.org.au

33rd International Epilepsy Congress

Golden Light Awards

The congress is an important meeting of the global epilepsy community, including researchers, clinicians, service providers and advocates.

It was a great opportunity to congratulate the winners of the Golden Light Awards, which recognise the achievements of young people with epilepsy and their contributions to the epilepsy community. Ten Golden Light winners from around the world attended.

Young Epilepsy Foundation volunteer, Scarlett Paige, was awarded the Golden Light for Australia after being nominated by the Foundation for her community service and commitment to volunteering to support people with epilepsy in Tasmania and Victoria. Scarlett initially worked tirelessly to run the Hobart epilepsy support group for two years, which brought people from all over southern Tasmania together, before moving to Melbourne for work. In Melbourne she continued her commitment to supporting people living with epilepsy by facilitating peer support groups, helping run the Epilepsy Foundation’s adult camp and women’s weekends away.

"Being a volunteer has been one of the most enjoyable things I have done," Scarlett says. "It has seen many highs and some very sad lows. But knowing when you hear the diagnosis of 'epilepsy' that you are not alone, and there are those to support you every step of the way, makes the road less rough."

Since winning her award, Scarlett has been given a number of opportunities to advocate for people with epilepsy including: presenting on her personal experiences at events, being featured in epilepsy newsletters in Victoria and Tasmania, taking part in epilepsy promotional videos and workshops, conducting a radio interview on the ABC Radio National program Life Matters, and work with the Australian Government Department of Social Services, reviewing ads the government will use during the Disability Royal Commission. The Epilepsy Foundation has also approached Scarlett for her assistance in the development of our new Epilepsy Smart Workplace program as her ideas and experiences are important to develop a relevant and effective workplace program.

We congratulate Scarlett and the other award winners from around the world who received Golden Light Awards.
Epilepsy Specialist Series

Each person with epilepsy experiences the condition in different ways, depending on the type, frequency, severity and predictability of their seizures. Our Epilepsy Specialist Series is an opportunity for people living with epilepsy, and parents and carers of people with epilepsy to ask any questions they may have of two epilepsy specialists.

Prof. Ingrid Scheffer, a Paediatric Neurologist at Austin Health and Royal Children’s Hospital and Dr Silvana Micallef, Senior Clinical Neuropsychologist, Department of Clinical Neuropsychology at Austin Health, will present on the diagnosis, treatment and challenges relating to the management of epilepsy.

The next Specialist Series event will be held on Saturday 26 October 2019 at 587 Canterbury Road, Surrey Hills, from 1.30pm – 3.30pm. Lunch will be provided.

Please register to attend here. For further information email here or phone 8809 0600.

World Kindness Day High Tea

Be kind to yourself by joining us for an afternoon of fun, games and socialising with a ‘kindness and tea party’ theme to celebrate World Kindness Day.

This is one of our Adult Social Events for people living with epilepsy who are over 18 years old.

The event will be held at:

The Angliss Conference Centre, 5th Floor, 555 Latrobe Street, Melbourne CBD, on Wednesday 13 November 2019 from 1.30pm – 4.00pm.

Places are limited, so please email us to secure your place. RSVP by 7 October 2019 or phone 1300 761 487.
Our Epilepsy Smart Schools program is gaining traction across Australia as more and more school principals, teachers and nurses are seeing the benefits of being trained in managing epilepsy in their school through our evidence-based program.

Currently, more than 200 schools across Australia have teachers that have received epilepsy-specific training in coping with and understanding the needs of students with epilepsy. These schools have participated in our three-step program to become ‘epilepsy smart’ including ensuring all students have a current Epilepsy Management Plan in place, that all teachers, nurses and other staff with a duty of care are properly trained in understanding and managing epilepsy and, if required, in the administration of emergency medication, and the school has engaged in awareness-raising to reduce stigma in their communities.

Research shows 1 in 200 students has epilepsy, meaning it is likely that every teacher in Victoria will teach a student who has epilepsy at some stage. Epilepsy is more than just seizures and first aid training is not enough.

Graeme Shears, CEO of the Epilepsy Foundation, says, “The Epilepsy Smart Schools program aims to inform and educate teachers, students and the wider school community on how best to support a student with epilepsy. The program is designed to help all schools to meet their duty of care obligations to provide an inclusive and supportive environment for all students, in order for them to achieve the best possible education outcomes.”

“Teachers need epilepsy-specific training to understand the symptoms and effects of epilepsy, which is different for everyone, and how to manage a student’s epilepsy. With more than 40 types of epilepsy it is important every student with epilepsy has an Epilepsy Management Plan and that teachers with a duty of care have been trained in how to cope with the needs of each individual student who may have epilepsy.”

Beyond the immediate health and safety impact of seizures, epilepsy can have a significant effect on a student’s ability to concentrate, remember and focus, which in turn will have an impact on their learning.

For more information on how to become an Epilepsy Smart School, visit https://www.epilepsysmartschools.org.au/

Congratulations to Ringwood North Primary School and Clonard College Geelong which have both recently become Epilepsy Smart Schools.
In this issue of Epilepsy Matters we profile one of our Epilepsy Nurse Educators, Marg Jarvis.

Can you explain what an Epilepsy Educator is?

"I am a nurse educator/trainer. This involves providing epilepsy education programs to a variety of audiences in a formal setting – childcare and early learning, schools (primary, secondary and special schools), disability organisations and, most recently, into aged care settings. Sometimes people living with epilepsy require a rescue medication because their seizures go on too long and in those cases I would also be training staff to give that emergency medication. We also provide education training for families who need to be able to give the medication."

Before you came to the Epilepsy Foundation, where did you work?

"I was a school nurse in a large secondary school for 19 years and was also involved in first aid training as a sideline. I found that I loved the involvement in education and after a long stint at the school was ready for a change. The role at the Epilepsy Foundation combined the opportunity to be an educator with the nursing side of things and turned out to be a very happy fit for me!"

Day to day, what does your role entail?

Depending on what training is required, where it is and by what method the session will be delivered, I might be traveling in the metropolitan area of Melbourne, sometimes regionally in Victoria, or I might be presenting via webinar from our Surrey Hills office. So, there will be preparation for those training sessions. If emergency medication (usually Midazolam) is involved, I would be checking over plans to make sure they are current, clear and accurate to train with and I would contact families to update on how the person living with epilepsy was doing. There can actually be a few hours of work just in the preparation for the session. I may have more than one session in the day also. Hours wise, I might not even start a session until 6.30pm at night and it might take 2-3 hours to present and I would then travel back to home. No day is the same!"

What do you think the general community needs to know about epilepsy?

"Similar to my previous answer but also understanding that everyone’s epilepsy is different, in that they might have more than one seizure presentation with each requiring different assistance, a first aid response to convulsive seizures and also to seizures without convulsive activity where the awareness may have been affected. They should know that epilepsy is not something to be afraid of and that a person shouldn’t be regarded differently just because they have seizures."

What’s your favourite part of your work day?

"I love working with my colleagues so I enjoy being in the office but I also love the education times and seeing people’s knowledge and confidence shift once they have a better understanding of what is happening with the person in their care. That is very satisfying!"

Why is educating people about epilepsy important?

"One of the most important things I’ve learned is that people can have quite a narrow view of what epilepsy looks like. Being able to educate them to have a better understanding of the many different seizure types, the support they require and the impacts that epilepsy can have, quite aside from seizure activity, will enable them to better understand and support people living with epilepsy."

What do people around the office know you for?

"My calmness, my freely given advice on spelling and grammar (whether it’s wanted or not) and my sense of humour!"

Thanks Marg!
Matt Dick has experienced epileptic seizures since he was 15 years old and, while they were disruptive when he was a boy, his seizures are now well under control and pose no barrier to a fulfilling working life. In a twist of fate, Matt’s partner, Natasha Radovanovic, has also had experience with the condition as her younger brother, Milutin, has epilepsy.

Matt explains his early life with seizures. “My first seizure, a tonic-clonic one, was in 2006 when I was 14. I was playing cricket in the backyard with my family when I began to feel dizzy. Shortly after, I fell unconscious into a rose bush. I remember waking up with a few scratches on my face but, luckily, my family was there to look after me,” he says.

‘Three months later, I had my second seizure while we were all on a family holiday on Lindeman Island. I was asleep at the time, but had to be air-lifted to Mackay Hospital. After seeing a specialist, it was noted that due to my going through puberty, the increase in hormones in my body led to my first seizure.”

Matt says he had had surgery when he was one year old for a cyst on his brain, which developed into hydrocephalus. “Doctors said the seizures were originating from the same location as the brain surgery.”

‘I then had a lot of medical appointments and was diagnosed with epilepsy that year. My seizures are always the tonic-clonic type where I am rendered unconscious.’

Matt says it was at this point that his seizures were having a serious, negative impact on his life. “They really affected my life when I was younger, especially my early adulthood when I wanted to go out at night with friends and when I was getting my licence,” he says.

‘After getting my learner’s permit, my licence was suspended every time I had a seizure. This was especially frustrating in Year 12, when most of my friends were driving themselves to school.”

Matt says he continued having seizures in his late teens, but they were sporadic. “I tended to have them when I grew out of the medication or if I was overtired or, say, if I got up too early in the morning.”

Now 27 years of age, Matt manages his seizures well with medication and has been seizure-free for almost six years. “They are much more under control now and are not really affecting my life at all. Epilepsy is just a part of who I am.”

Matt is now working as one of the ground crew at Melbourne Airport, a job that entails shift-work, something he acknowledges is not the best circumstance for someone with epilepsy. He says his mum, Sue, who has since passed away, was very concerned when he first went into full time work. “She would say, ‘make sure you get enough rest, don’t go out too late’.”

“I’ve now been in this job for six months, waking up at three in the morning and sometimes working till 9.30 at night. So far so good; I’ve had no issues.”

Matt’s partner Natasha Radovanovic also has first-hand knowledge of epilepsy as her younger brother, Milutin (Luti), now 21, has the condition.

“Luti had seizures in primary school and while, for the last five years, he hasn’t had one, they have flared up again recently. He is on medication and it is now under control, but he does have to manage his sleep and travelling as time zone changes causes problems too.”

Natasha says while it’s coincidental and unfortunate that both her younger brother and her partner have epilepsy, Matt has been a big help to her and her own mother since her brother’s diagnosis. “Matt has been able to explain how medication helps, about the importance of sleep and managing the condition, so that we’re now much more confident in letting Luti be independent.”

Matt’s mum was also right onto understanding as much as she could about epilepsy, to help her son. “She contacted the Epilepsy Foundation and got up-to-date information about epilepsy and medication options. I think she may have reached out for herself as well, to learn as much as she could about my condition.”

To demonstrate to their family that life with epilepsy can be satisfying, Matt and Natasha participated in the Foundation’s inaugural Walk for Epilepsy in 2018. “Our motivation was to show support while raising money for the Foundation. We raised $1,570, while also raising awareness among our families as well.”

This year, Matt and Natasha are planning to participate again in the Walk for Epilepsy and expect that a big turnout of family members will participate in support of the Foundation.
The event was hosted by Michael Motta, who harmoniously combined fundraising for a cause that is close to his heart with the season opening of a vegetable that has built his family business over the last 50 years. With family members directly affected by epilepsy, an often-hidden condition, the support of programs to help those dealing with the condition is a priority for Michael. He even put in the time to handcraft the box the asparagus was presented in, and emblazoned it with the Motta Produce logo, showing his personal commitment to even the smallest details of the event.

Our CEO Graeme Shears, says, “For the support and generosity of Motta Produce, Michael, staff and all at the Melbourne Market who make this event and the associated fundraising activities such a success, I say a very big thank you. It is wonderful to see the market community get behind Michael and his team. Michael and all of Motta Produce must be proud of what this event has become.”

White asparagus is unique in that it is grown in the dark, inside igloos that are made up of dark plastic to keep out the light. The have a distinct nutty flavour with a smooth texture. White asparagus has grown in popularity and can now be found in many restaurants.

Motta Produce is a second-generation family run business specialising in the growing and packing of fresh asparagus. Motta Produce exports to over a dozen countries worldwide and is Australia’s largest asparagus producer. The company supplies Woolworths, Coles, Aldi and all leading domestic retailers. Motta Produce is 100% Australian owned and has been growing asparagus for nearly 50 years.

Epilepsy Foundation offers evidence-based general and person-centred epilepsy education and training programs designed for families, schools, communities and the workplace. Our training programs increase awareness and understanding of epilepsy in the community.

Past participants have told us that they feel more confident in recognising seizure activity and providing person-specific support after completing our training programs.

The Epilepsy Foundation is a registered NDIS provider. We provide services relating to the development of epilepsy management plans and epilepsy training. We do not provide support coordination services.

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