

PERTH CHILDREN'S HOSPITAL — VIDEO ELECTROENCEPHALOGRAPH MONITORING

Grievance

MS L. METTAM (Vasse — Leader of the Liberal Party) [9.27 am]: My grievance is to the Minister for Health. I thank the minister for taking this grievance about the lack of capacity at Perth Children's Hospital to provide critical video monitoring for children who require this support. I raise this issue on behalf of the Kovacevic family and their daughter Katalina, who is five years old. The Kovacevic family is a great advocate for other families in Western Australia who are experiencing the same distress in accessing this monitoring service for their children.

Katalina Kovacevic was diagnosed at birth with a rare genetic condition called tuberous sclerosis complex. The condition affects the heart, skin, brain, kidneys, lungs and eyes, but the largest challenge with this condition is generally the brain. Katalina has a number of tumours on her brain that cause seizures. The consequences of continuous seizure activity are nerve cell injury and brain damage. An electroencephalogram monitors brain activity and seizures, and seizure control is imperative for a child's overall long-term development. Katalina's seizures are often not noticeable. They are not convulsive, so it can be hard to pick when she is having a seizure. In February last year, Katalina's father, Boris, emailed the minister's office. Katalina required critical epilepsy brain surgery to remove the tumours causing her epilepsy, and, despite having to wait several months for this surgery, the scheduled January date was then cancelled. The reason the family was given was the lack of specialist equipment required for surgery. No rescheduled date was provided for this surgery until later in the year. The Perth neurology team suggested the family go to Brisbane to have a video electroencephalogram, as there was no availability to do an overnight EEG in Perth.

Katalina has developed infantile spasms on top of her refractory epilepsy and the many other issues she has had to endure. Infantile spasms are considered a medical emergency, and the family were deeply distressed that there had been no sense of urgency provided to assist her. Katalina was experiencing up to five spasms daily, in addition to seizures, that, left untreated, were detrimental to her development.

Perth Children's Hospital eventually offered a surgery date, but the family decided to travel interstate to obtain the vital surgery for their daughter given the uncertainty that they had experienced previously. The family were losing hope for their daughter being able to live a normal life and felt utterly let down. Katalina had epilepsy surgery in May 2023 at the Royal Children's Hospital in Melbourne. Once again, the Kovacevic family feel that they have been let down by the WA health system, which failed to obtain critical treatment for their daughter.

In November last year, Katalina's mother, Kirsten, wrote to the then leader of Perth Children's Hospital regarding the inability of Perth Children's Hospital to perform a 24-hour EEG for neurology patients. To be clear, appointments for 30-minute EEGs have been offered, but this time span is not sufficient for neurologists to adequately monitor Katalina's debilitating seizures. At the time, the family were living in Karratha and in order to have this critical service for Katalina's ongoing health monitoring, Katalina and Kirsten had to travel to Brisbane. This was not the first time they had travelled interstate to get answers via 24-hour EEGs.

In 2018, Kirsten voiced her deep concern to the then Minister for Health, Roger Cook, highlighting this very concerning and exasperating issue. Kirsten asked that Perth Children's Hospital investigate this critical issue and address the shortfall for not only their family but also other families in WA. In December, Kirsten was advised by Perth Children's Hospital that initial inquiries had resulted in advice that several complex factors were impacting accessibility, including a specialist workforce, technology and facilities, and that more time was needed to explore these factors. The Kovacevic family have again had to wait on tenterhooks whilst a failure to provide this critical video monitoring service was investigated. They struggled to understand why this was not common practice at Perth Children's Hospital in Western Australia, and with no alternative and at their own expense they again travelled to Melbourne for Katalina to have an overnight EEG and to receive surgery.

Perth Children's Hospital advised in May that services had resumed and that the clinical team at PCH would liaise with the clinical team in Melbourne to facilitate the smooth transfer of Katalina's care back to PCH. However, no transition eventuated, and the family have to return to Melbourne in October for another 24-hour EEG and magnetic resonance imaging. PCH is unable to offer a 24-hour EEG for Katalina post her surgery.

The Kovacevic and other families were advised through a letter that PCH has regressed to the simply unacceptable position of a suspension of all video EEG services. The advice from PCH was that this was due to a shortage of highly skilled staff. This is a frustrating situation that causes a huge upheaval to the lives of both patients and their families. How can this critical 24-hour video EEG service be available at one time and then be withdrawn from the state-of-the-art Perth Children's Hospital when in other states, including Victoria, Queensland and New South Wales, it is a matter of course? If the WA health system is not able to provide an ongoing, regular 24-hour video EEG service, would it not be reasonable to provide reimbursements to families who have no option but to travel interstate to access this critical service for their children?

Again, I thank the minister for taking my grievance.

MS A. SANDERSON (Morley — Minister for Health) [9.33 am]: Long-term video electroencephalogram monitoring is a specialised form of EEG test, in which in addition to measuring electrical activity in the brain, the patient is monitored over video. It is most commonly used at PCH to investigate children with complex epilepsy to determine whether they are suitable for epilepsy surgery and to review patients post epilepsy surgery. Although a routine EEG lasts up to only one hour, a VEEG is a longer and more complex test that requires a patient to be admitted for anywhere between one to five days.

The inpatient elective VEEG monitoring service at PCH has been temporarily suspended from 6 June for a period of approximately six to 12 months due to a critical shortage of trained neurophysiology scientists to safely undertake the VEEG monitoring. However, in the event of a child having complex epilepsy and a need for urgent consideration of epilepsy surgery, a VEEG can still be provided at PCH. There is a shortage of neurophysiology scientists across Australia, particularly paediatric neurophysiology scientists. Neurophysiology scientists have been recognised as a critical niche workforce. PCH has commenced new initiatives to increase staff retention and succession planning such as offering support to complete a postgraduate qualification for current staff. PCH is also actively recruiting, both in Australia and internationally, to ensure VEEG services can be re-established.

There are currently 35 children on the Perth Children's Hospital waitlist for VEEG monitoring. I acknowledge and understand that this is and will be a stressful time for families awaiting VEEG. Timely access to the service for children remains the priority for Perth Children's Hospital. Options for prolonged video monitoring are discussed at the patient's scheduled PCH neurology outpatient appointment with the treating neurologist. The team at Perth Children's Hospital are doing everything they can to assist patients and families impacted by this change. Each child on the waitlist is assessed, and where clinically indicated, alternative arrangements are made to access safe and appropriate VEEG. Alternative solutions include inpatient VEEG monitoring services at other paediatric hospitals, such as Royal Children's Hospital in Melbourne, Westmead Hospital in Sydney and Queensland Children's Hospital. This is clinically prioritised for high-risk patients.

For these patients, applications are made to the department's interstate patient travel scheme to support application for eligible travel costs to access these services interstate. For some other children, adult neurophysiology services at WA tertiary hospitals may be suitable. Privately provided in-home VEEGs are not clinically suitable for all patients. Options for contract are currently being established with Child and Adolescent Health Service procurement for clinically urgent patients. Safely remaining on the PCH waitlist until the service resumes may be the most appropriate option for some patients.

I acknowledge that this is incredibly challenging. I am not authorised to talk about individual cases for the purposes of privacy. I do not have permission from the family to talk about their particular circumstances, so I will not be talking about them in Parliament. I will say that I understand that this is incredibly challenging. It is a very highly specialised niche workforce, and PCH is working very hard to fill recruitment targets. I am aware of the circumstances and I understand that my office has been working with the family over a number of months and, in some instances, provided support for travel. I know that Perth Children's Hospital and its staff work very closely with all those families with very debilitating circumstances. If they are not able to access treatment in WA, they are supported to access treatment elsewhere.