# Counties Manukau District Health Board

## A Report by the
## Health and Disability Commissioner

## (Case 18HDC01075)

Health and Disability Commissioner
*Te Toihau Hauora, Hauātanga*

## Contents

## Executive summary

1. This report considers CMDHB's management of a child and her complex but numerous presentations to a public hospital from February 2017 onwards. The case highlights the importance of critically assessing and responding to a consumer's repeated presentations to hospital with a greater level of concern and investigation.

### Findings

2. Initially, the child was investigated for persistent abdominal pain, but new and concerning neurological symptoms arose from May. On 5 May, she was seen by a number of staff, but was not reviewed in person by a senior medical officer (SMO). There were missed opportunities for CMDHB staff to think critically about the child's presentation with reference to her history, and to carry out further investigations into her symptoms with greater urgency, both on 5 May, and certainly by 10 July. These failures involved numerous individuals across multiple presentations, and the Commissioner considered that this indicated a pattern of poor care, for which, ultimately, CMDHB was responsible.

3. Accordingly, the Commissioner found that CMDHB did not deliver services to the child with reasonable care and skill and breached Right 4(1) of the Code.

### Recommendations

4. The Commissioner recommended that CMDHB consider the HQSC resource on *Patient, family and whānau escalation: Kōrero mai projects — what we know so far* and advise whether any continuous improvement projects could flow from the learnings in this investigation; use this investigation as an anonymous case study for emergency medicine and paediatric teams; review resident medical officer (RMO) to SMO escalation practices in the Paediatric Department, including RMO knowledge of when to ask for SMO review, whether SMOs regularly confirm with RMOs whether a review of a person is being requested, and what situations SMOs will attend without a request to do so; advise on the outcome of the morbidity and mortality meeting in which the child's case was reviewed, in particular on whether a guideline outlining an approach to children who present with focal findings has been produced; and provide a written letter of apology to the child and her parents for the failures identified in this report.

## Complaint and investigation

5. The Health and Disability Commissioner (HDC) received a complaint from Mrs A about the services provided to her daughter, Miss A, by Counties Manukau District Health Board (CMDHB). The following issue was identified for investigation:

- *Whether Counties Manukau District Health Board provided Miss A with an appropriate standard of care in 2017.*

6. The parties directly involved in the investigation were:

| | |
|---|---|
| Miss A | Consumer |
| Mrs A | Complainant |
| CMDHB | Provider |

7. Also mentioned in this report:

| | |
|---|---|
| Dr B | Consultant paediatrician |
| Dr C | Paediatric house officer |
| Dr D | Consultant paediatrician |
| Dr E | Emergency medicine registrar |
| Dr F | Paediatric medical officer of specialist scale |

8. Independent clinical advice was obtained from a paediatrician, Dr Thorsten Stanley, and is included as Appendix A.

## Information gathered during investigation

### Introduction

9. In 2017, Miss A (aged 5–6 years at the time of the events) was under the care of CMDHB's paediatric service. She also presented to a public hospital on four occasions with symptoms of abdominal pain, vomiting, and headache. On the fourth presentation, a CT scan was carried out and led to a diagnosis of a rare brain tumour. This report considers CMDHB's management of Miss A and her complex presentations from February 2017 onwards.

### Care provided in 2017

10. At the end of 2016, Miss A was referred to Outpatient Care by her general practitioner (GP) owing to persistent abdominal pain. The referral from the GP, dated 7 December 2016, stated:

> "[P]ain abdomen and vomiting off and on, no diarrhea father stating cannot tolerate fried food as a child has reflux problem, previously on Gaviscon[1] and ranitidine[2] some 2 years back, currently taking Gaviscon … Father keen to see specialist and hence referred, thanks."

*17 February — outpatient clinic*

11. On 17 February 2017, Miss A and her parents were seen by a consultant paediatrician, Dr B, for chronic recurrent abdominal pain, mild constipation, and low iron stores. Dr B's clinic letter noted:

> "[Miss A's parents] report that she seems to have had these similar symptoms since she was around three months of age … She has brief periods of central to epigastric pain[3] which can last from 30 seconds to a minute. During a bad period it will happen 3–4 times over a day and it usually occurs around three times a week. On the days when she is having a lot of pain she will have decreased appetite and won't eat that much. She may have a vomit towards the end of the day. She will be quite windy. She may look a little pale and sometimes has some shivering attacks. About once a week the pain will wake her from sleep but again she will only be awake for a brief period of time. She usually feels tired, has a sleep and then the pain goes away. Occasional[ly] she has small vomits into her mouth or reflux like symptoms … [Miss A] also very occasionally will complain of a headache."

12. On examination, Miss A was noted to be looking well. She was "quite skinny" with minimal fat stores but normal muscle bulk. Dr B documented that Miss A had difficulty following commands to complete a neurological examination, but did have normal tone and reflexes in her upper and lower limbs and appeared to have normal strength. She had a normal gait but did have difficulty walking heel to toe. Dr B told HDC that she felt that this was because of understanding and age.

13. CMDHB noted that this assessment was completed in the context of a child presenting with non-neurological symptoms, and a tandem gait is not always performed with accuracy in a child of this age.

14. Although not documented, Dr B told HDC: "I remember inspecting her face for asymmetry, her pupils for light reactivity and attempting (but not successfully obtaining) visual fields and fundi."

15. Dr B's clinic letter noted her impression of Miss A's presentation as:

[1] A medication used to treat heartburn (acid reflux) and indigestion.
[2] A medication used to decrease stomach acid production.
[3] Pain or discomfort in the upper abdominal area directly below the ribs.

> "[Miss A] is a 5 year 8 month old child with recurrent chronic abdominal pain. There may be a component of abdominal migraine[4] although there is also an indication that there may be a food related cause. I will trial Omeprazole[5] and see how this goes."

16. Dr B arranged for a stool test, a pain diary, and a therapeutic trial of omeprazole and lactulose, and a review in two months' time.

17. Dr B told HDC: "My overall assessment was of an atypical cause of abdominal pain that required investigation." She stated: "[I]n retrospect, I feel that I would not have changed my management at this stage, for example arranging a CT scan of the head, as there was no indication to do so."

*21 April — follow-up outpatient clinic*

18. On 21 April 2017, Miss A and her father were seen by Dr B for a follow-up outpatient appointment.

19. Dr B's clinic letter noted:

> "It is pleasing to hear that since starting Omeprazole [Miss A's] symptoms have improved ... Since starting Omeprazole the pain has decreased in the number of days with pain and the frequency of the pain during those days."

20. Miss A's family had noticed through using the food diary that Miss A experienced symptoms after eating fried food, and that mostly her symptoms related to the development of pain during eating, which then resulted in a vomit. Over the previous two months, Miss A had had five vomits, one of which was in the middle of the night.

21. Dr B's clinic letter concluded:

> "[T]he fact that her symptoms have improved with the Omeprazole does make me suspicious that there may be something going on with her stomach and for this reason I will discuss her with the Gastro Team for consideration of a scope."

22. Dr B referred Miss A for an ultrasound scan (USS) and to the Gastroenterology Department for further investigations and advice. Dr B told HDC that she requested a follow-up appointment in 2–4 months' time (the time within which she estimated Miss A would have had the USS and been reviewed by Gastroenterology).

23. Dr B stated:

> "I was a little reassured that the trial of omeprazole had improved things somewhat and the history and pain diary seemed to be indicating an abdominal process such as coeliac disease, oesophagitis or an irritable bowel type disorder."

[4] A condition characterised by stomach pain, nausea, and vomiting.
[5] A medication used in the treatment of gastroesophageal reflux disease.

*25 April — first presentation*

24. On 25 April 2017, Miss A was referred to the Emergency Department (ED) by a GP. The GP's letter to ED stated the reason for the referral as "Vomiting — unwell" and noted that Miss A was "under specialist — last seen on [21]/04/2017".

25. Miss A and her family presented to ED at approximately 7.30pm. Miss A's presenting complaint was documented as abdominal pain and vomiting, and she was given a triage score of 4.[6] Her weight was noted to be 23kg.[7] A nursing assessment carried out at 8.20pm noted:

> "1130hrs started vomiting [with] abdo pain. Seen GP, started on ondansetron,[8] had 1x vomit post ondansetron on way home, came to ED. Tolerated 1x cup [of] water [with] Paedialyte.[9] Some pain."

26. On examination, Miss A was noted to be "pink and warm to touch, moist mucosa, not distressed, nil respiratory distress, well perfused. Nil abdo[minal] pain on palpation or movement." Miss A was given a further 2mg of ondansetron at this time.

27. At 10.43pm, a clinical nurse specialist (CNS) assessed Miss A and noted her history of "ongoing abdominal pain, ?abdominal migraine". The CNS recorded that Miss A's vomiting had settled while she was waiting to be seen, and that Miss A had had one episode of pain while being assessed, and had drunk 600ml of fluid while in ED. The CNS noted that Miss A was "to be discussed with [the senior medical officer (SMO)]". A decision was made that Miss A was "for discharge home with GP review in two days if there was ongoing vomiting and pain".

28. Dr B told HDC: "I did not receive notification of a presentation to ED on 25 April 2017, 4 days after my appointment with [Miss A]." CMDHB told HDC that it has an expectation that the primary paediatricians are informed if a patient attends ED, either by a telephone call, an email, or a copy of the discharge summary.

*Outpatient referral to paediatric gastroenterology*

29. On 4 May 2017, as per Dr B's plan at her outpatient clinic with Miss A on 21 April, Dr B sent a referral to the paediatric gastroenterology service at another hospital [DHB2]. In the referral letter, Dr B wrote:

> "Thank you for providing advice and possibly a consultation +/- a gastroscopy for the 5 year 10 month old girl … I would appreciate any advice regarding management from here."

[6] A triage code of 4 means that the presentation is potentially serious, or potentially could have adverse outcomes from a delay of greater than 60 minutes.
[7] Miss A's weight was recorded as 23.7kg by her GP on the same date.
[8] A medication used to prevent nausea and vomiting.
[9] A therapeutic oral hydration solution that replenishes minerals and nutrients lost during diarrhoea and vomiting.

*5 May — second presentation*

30. On 5 May 2017, Miss A was referred again to the ED by her GP. In the letter addressed to "Paed reg, [CMDHB]", the GP noted:

> "With parents, concerned hiccoughs and burping for 3 days, tired and wants to sleep often, sleeps through the day … nausea feeling, vomited once yesterday, no vomiting today … [History of] recurrent abdominal pain, under care of [Dr B] … Discussed [with] paed[iatric] reg[istrar] who kindly agreed to see her, sent to [CMDHB] with letter."

31. Miss A and her family arrived at the ED at approximately 10am. The clinical record noted that Miss A presented with lethargy, nausea, and abdominal pain, and she was given a triage score of 4. Her weight was noted as 22.9kg.

32. A nursing assessment carried out at 10.40am noted:

> "Wed — sleeping, not eating, Thursday — breakfast — nausea — sleep, needs to be woken for food. Vomiting when eats. Unable to keep awake. Generalised abdo[minal] pain. [Miss A] was observed to be alert, responsive with no respiratory distress. She was warm, well perfused but did have a pale face."

33. At 11.36am, Miss A was reviewed by a paediatric house officer, Dr C. Dr D was the supervising consultant paediatrician.

34. Dr C noted a two-day history of lethargy, nausea, and vomiting, and documented:

> "Felt achey throughout whole body. Mobilised well when awake, no limp. Complained of neck pain bilaterally when mum gave her a massage. Today symptoms have resolved …
>
> No fevers, rashes, coryza,[10] coughing, [shortness of breath], chest pain, ear pain, sore throat …
>
> Complaining of headaches most days for past couple of weeks. No change to vision. Gets better when reads or watches TV. Unsure if associated with abdominal pain …
>
> 2 x episodes of slurred speech in past couple of weeks. 1 recorded by Dad on his mobile. [Listened] approx. 30 seconds and followed by approx. 2 hours of not talking just nodding or shaking head. No collapse or seizure activity, no focal neurology, no absence like episodes associated with it."

35. Dr D told HDC that the above episodes were thought to be possible focal seizure[11] episodes, and atypical migraine was also considered in the differential diagnosis.

[10] A contagious disease involving the upper respiratory tract.
[11] When a seizure occurs in only one area.

36. In response to the provisional decision, Miss A's mother, Mrs A, told HDC that the possibility of focal seizures was never disclosed to her. She stated that each time she presented, she was told that it was acid reflux or side effects of omeprazole.

37. On examination, Miss A was alert and afebrile, and her observations were stable. Dr C's provisional diagnosis was "?viral illness ?underlying omeprazole side effects". Blood and midstream urine tests were carried out and returned normal results. Dr C documented: "[Discussed with] [Dr B] — will kindly organise an outpatient EEG[12] given speech episodes and I have requested an outpatient abdominal ultrasound."

38. Dr D told HDC that Miss A was discussed with her, and she advised on a management plan but did not review Miss A herself or meet with her family.

39. Dr B told HDC that she received a telephone call from Dr D informing her that Miss A was in ED, and that Miss A had been having some unusual episodes of non-specific weakness that had been attributed to the increased dose of omeprazole, and an episode of slurred speech and aphasia.[13] Dr D told HDC that "these episodes were thought to possibly be focal seizureepisodes (atypical migraine was also considered in the differential diagnosis)" and, therefore, an outpatient EEG was requested in discussion with Dr B.

40. Dr B told HDC: "I queried whether a CT head was indicated, but [Dr D's] opinion was that this was not necessary. As she was currently reviewing [Miss A], I deferred to her decision."

41. Dr D explained to HDC that there did not appear to be any focal neurological[14] findings on examination or concerns of rapidly evolving symptoms to suggest a need for urgent imaging, and that "the need for non-urgent imaging ... was to be reviewed in outpatients".

42. At approximately 1pm, Miss A was discharged back to her GP. Her discharge summary stated her plan as:

> "Discharge
> Reduce omeprazole to [once daily]
> Return advice
> [Outpatient] abdominal USS
> [Outpatient] EEG"

*EEG, paediatric gastroenterology referral, and abdominal USS*

43. On 16 May 2017, Dr B made a referral for an EEG, which was scheduled for 4 September 2017. Dr B told HDC that she also checked on Miss A's outpatient appointment status (planned at the previous outpatient clinic on 21 April) and noted that an appointment had yet to be booked. Dr B sent an email to the booking team requesting an appointment booking.

[12] Electrical tracing of the brain to look for seizure activity.
[13] An inability to comprehend or formulate language.
[14] A problem with nerve, spinal cord, or brain function that affects a specific location.

44. On 23 May 2017, in response to Dr B's gastroenterology referral dated 4 May 2017, a letter from DHB2's paediatric gastroenterology service noted the referral for possible endoscopy,[15] but commented that "the yield of endoscopy for recurrent abdominal pain is extremely low and therefore we request other tests prior to considering this". The service suggested that Miss A have a *Helicobacter pylori*[16] stool antigen[17] and a faecal calprotectin.[18] The letter concluded: "I would suggest that she have the stool tests performed and then a re-referral made if her symptoms persist."

45. The abdominal USS was performed in June 2017 and returned a normal result.

*10 July — third presentation*

46. Miss A presented to ED at approximately 6pm on 10 July. The emergency care assessment form documented her presenting complaint as "vomiting x3, episode of unable to verbalise, ?confusion". Miss A was given a triage code of 3.

47. At 6.15pm, a nurse reviewed Miss A and documented that she was closing her eyes intermittently, lying still with a decreased respiratory rate, and complaining of headache and elbow pain. She was also noted to be talking about people not in the room. Miss A's weight was recorded as 22.4kg.

48. At 7.15pm, Miss A was assessed by an emergency medicine registrar, Dr E. Dr E noted that Miss A had last been admitted to ED a few months ago with similar problems and was being seen by paediatrics as an outpatient for "?migraine ?seizures". He also noted that an EEG had been booked but had yet to be undertaken.

49. On examination, Dr E noted that Miss A was distressed after a large vomit on her bed, and was hyperventilating intermittently with shivers. Dr E documented his impression as "cyclic episodes of vomiting + abdo/head pains + strange behaviour, ?type of seizure, migraine ?cause". Dr E planned to discuss Miss A's presentation with a paediatrician for further management and investigation.

50. At 8.22pm, Miss A was reviewed by a paediatric medical officer of specialist scale (MOSS), Dr F.[19] Dr F told HDC that she took a full history and reviewed the clinical letters about Miss A's medical history, including her outpatient assessments. Dr F noted that Miss A presented to ED because of concerns about her vomiting, disorientation, and impaired ability to speak or vocalise.

51. Dr F told HDC that on further enquiry she elicited that Miss A had a known three-year history of episodic upper gastrointestinal (GIT) discomfort and pain. During these episodes, Miss A had burping, flatulence, and epigastric pain, followed by vomiting and headache. She would feel better after the vomit and a lie-down in a quiet dark room. During the

[15] An examination of the upper digestive tract using an endoscope.
[16] A type of bacteria usually found in the stomach.
[17] Any substance that causes the immune system to produce antibodies against it.
[18] A biochemical measurement of the protein calprotectin in the stool. Elevated faecal calprotectin can indicate intestinal inflammation.
[19] CMDHB advised that Dr F is a highly experienced MOSS.

burping and dry-retching, she could not speak. Dr F documented that Miss A's headaches, apparent disorientation, apparent inability to speak, increased frequency of vomiting, and apparent car motion sickness were new symptoms in the past two months. Dr F observed Miss A to be pale and restless, but her vital sign recordings were all within normal ranges.

52. In terms of investigations, Dr F noted Miss A's outpatient referral to DHB2's paediatric gastroenterology service and the advice received to re-refer if symptoms persisted. Dr F also noted that Miss A's primary paediatrician was Dr B, and that Miss A was awaiting a clinic follow-up.

53. Dr F's impression was "upper GIT symptoms", with a differential diagnosis of "inflammatory e.g. gastritis vs structural abnormality". She documented:

> "Observed in ED with no further vomits. Woke up, appropriate but quiet. After discussion with parents who were happy for discharge. I will inform [Dr B] of this presentation. Discussed with [paediatrician]."

54. Dr F told HDC that prior to discharge, she discussed Miss A's history and symptoms with the paediatrician on duty. She also advised Miss A's parents that Miss A should continue with her regular medications, and to return to the ED should Miss A have further vomiting or become acutely unwell.

55. Dr F told HDC that her clinical impression of Miss A's presentation was similar to the chronic GIT symptoms noted in the past. Dr F understood that Miss A had been referred for a gastroenterology opinion at DHB2 and was awaiting investigations to determine the cause of the symptoms. Dr F considered that at this time, there was no clinical indication to perform a CT brain scan.

*6 August — fourth presentation*

56. At approximately 2.45am on 6 August 2017, Miss A presented to ED with her mother and father. The emergency care assessment form documented her presenting complaint as "vomiting since 1700hrs, abdo[minal] pain, drowsy". She was given a triage code of 3. Her weight was recorded as approximately 22kg.

57. At 3.20am, a nursing assessment noted:

> "[Patient] presented [with] headache from 1400hrs, abdo[minal] pain + vomiting [at] 1700hrs (x5 since), knee aches, limping (— has presented [with] same symptoms on previous occasions, under investigations). Intermittent confusion (x3 episode this year) that coincide [with] above symptoms."

58. At 6.30am, Miss A was seen by an emergency medicine registrar. He noted Miss A's complex past medical history and her previous presentations to hospital. The registrar's impression was an "unusual constellation of symptoms on [a] background of [a] complex history of chronic abdominal pain". It was noted that Miss A's symptoms were worsening, with more frequent disorientation. The registrar considered the possibility of atypical

seizures or a neurological disorder. The registrar planned to refer Miss A for paediatric review, given her highly complex situation and non-specific presentation.

59. At 12.15pm, Miss A was reviewed by a paediatric registrar, who noted the recurrent episodes of disorientation, headache, shivering, confused and slurred speech followed by vomit — each episode lasting a few minutes. In between episodes, Miss A was noted to be asleep or restless with slurred speech and a right facial droop. It was noted that her symptoms were similar to her previous presentations, but that "usually the confusion doesn't last this long". The registrar also noted an up-going plantar reflex[20] with involuntary muscle contractions (beats of clonus).[21]

60. The paediatric registrar's impression was "?complex partial seizures [with] incomplete recovery ?status epilepticus[22] ?encephalitis[23]", and her plan, among other things, was to discuss Miss A's case with a consultant paediatrician, carry out a CT scan of Miss A's head, and admit her to the ward. CMDHB told HDC that by this presentation, "there were clearly abnormal neurological signs which led to organising an acute CT scan".

61. At 12.28pm, a CT scan identified significant bleeding on the right side of Miss A's brain. There was also evidence of movement of the brain and other damage from old bleeding. Left-sided lesions were also identified, and the radiology report recommended an urgent neurosurgical opinion and further MRI imaging with contrast. This was discussed with Neurosurgery, PICU, and ICU, and at approximately 1.30pm Miss A was transferred to [DHB2] for further management.

*Subsequent events*

62. Miss A was later diagnosed with a very rare aplastic[24] brain tumour.

**Further information**

63. Miss A's mother, Mrs A, told HDC:

> "[W]e have made countless visits to [CMDHB] from April or May 2017, all the doctors who observed her were unable to relate her symptoms to what she was diagnosed with.
>
> …

[20] An abnormal reflex that can occur when the sole of the foot has been stroked firmly. The big toe moves upwards or towards the top surface of the foot.
[21] A neurological condition in which involuntary muscle contractions result in uncontrollable, rhythmic, shaking movements.
[22] When a seizure lasts longer than five minutes or when seizures occur close together and the person does not recover between seizures.
[23] Inflammation of the brain.
[24] Characteristic of cells or tissues that have lost their mature or specialised features, as in malignant tumours.

> I don't want any other child to go through what our daughter had been through ... If a patient keeps on coming back to you, it means something is wrong, perform all the required tests, and think out of the box."

64. CMDHB commented that historically (including at the time Miss A was presenting), the primary paediatric team was not always advised when a patient of theirs was seen in ED. However, over the last two years, a lot has been done to improve communication between the ED team and the patient's primary team, in recognition that good communication is very important for patient safety. CMDHB advised that there has been considerable improvement in this area.

65. CMDHB told HDC that Miss A's case was presented at the internal combined emergency medicine and paediatric mortality and morbidity meeting on 28 November 2018, and even with the benefit of hindsight, there was an overwhelming sense from the senior clinical team that the difficult presentation, coupled with the very rare nature of both the tumour type and final diagnosis, would have been challenging to all who faced it.

66. CMDHB wishes to apologise to Miss A's family for the distress that the delayed diagnosis of her brain tumour has caused. The DHB would like to reassure the family that at each presentation, both in clinic or in ED, a fresh review of Miss A's symptoms was made, together with a considered plan based on her history and clinical findings. Unfortunately, the rare nature of Miss A's presentation made it a challenge to come to the final diagnosis. CMDHB acknowledges that there was an evolving red flag for weight loss, and that there was a missed opportunity to perform neuroimaging when the history of slurred speech was given.

**Responses to provisional decision**

*Mrs A*

67. Miss A's mother was given an opportunity to comment on the "information gathered" section of my provisional decision. In her response, Mrs A highlighted the number of missed chances to investigate Miss A's symptoms further with a CT scan.

68. Mrs A stated to HDC: "[T]he distress caused by CMDHB to our entire family, especially my daughter, we are still struggling to recover from it. We have been emotionally and mentally destroyed."

*CMDHB*

69. CMDHB was given an opportunity to comment on my provisional decision. It stated again that this case involved an extremely rare diagnosis associated with atypical, complex presentations. It is the DHB's view that the care provided was in accordance with standard care based on what was presented clinically at the time. However, it accepted the Commissioner's recommendations, as well as the follow-up actions.

70. CMDHB acknowledged the overwhelming pain and sadness felt by Miss A's parents, and their disappointment in the care provided to Miss A. CMDHB stated that there are no words that will provide appropriate comfort or change the outcome for Miss A and her

family, but the DHB would like the family to be assured that the team is acutely mindful of the devastation that Miss A's condition caused.

71. CMDHB emphasised that there was a change in diagnostic thinking when new symptoms occurred. The clinicians involved, and the team as a whole, aim to detect malignant conditions early. However, for any shortcomings in the high standards it sets for itself, CMDHB "without reservation apologise[s] sincerely".

## Opinion: Counties Manukau District Health Board — breach

### Introduction

72. At the outset, I acknowledge the complexity of Miss A's presentations to CMDHB and her ultimate diagnosis of a very rare brain tumour. However, on two key dates (5 May and 10 July 2017), Miss A presented with new and deteriorating neurological symptoms that should have prompted a greater level of concern and investigation. This was in the context of Miss A and her parents having presented to hospital on several occasions within a relatively short period of time.

73. I sought expert advice from paediatrician Dr Thorsten Stanley to assist my assessment of Miss A's care.

### Presentations on 5 May and 10 July

*5 May 2017*

74. On 5 May 2017, the family reported to the hospital Miss A's new symptoms of slurred speech followed by a period during which Miss A would not talk, and would just nod or shake her head. Despite these symptoms, Dr C, the paediatric house officer who reviewed Miss A, considered there to be no focal neurology (no problems with nerve, spinal cord, or brain function affecting a specific location), and made a provisional diagnosis of "?viral illness ?underlying omeprazole side effects". Although Dr C discussed Miss A's presentation with Dr D, the on-call consultant paediatrician, Dr D did not review Miss A in person. Dr D told HDC that focal seizures and atypical migraines were considered a part of the differential diagnosis.

75. Dr D then discussed Miss A's presentation with Miss A's responsible paediatrician, Dr B. It was determined that Miss A would have an outpatient EEG. In Dr B's response to HDC, she stated that she did query whether a CT scan should be carried out. However, she mistakenly understood that Dr D had reviewed Miss A in person, and was guided by Dr D's opinion that Miss A did not require a CT scan.

76. My expert advisor, paediatrician Dr Thorsten Stanley, is of the view that given that focal seizures were considered a possibility at this presentation, Miss A should have been seen by a consultant in person and had a full neurological evaluation at this time — that is, there should have been a senior review.

77. I agree with Dr Stanley, noting that the junior doctor (house officer) who reviewed Miss A was not able to reach a conclusive diagnosis, and, at this time, it was Miss A's third presentation to hospital since February. Miss A also presented with new symptoms of slurred speech and an inability to speak. In this context, in my view it would have been prudent for a senior medical officer to review Miss A personally before initiating Miss A's management plan (an outpatient EEG).

*10 July 2017*

78. On 10 July 2017, Miss A presented with worsening symptoms of confusion and inability to speak. She was noted to be talking to people who were not in the room, and she continued to have headaches. Miss A's weight had declined from 23kg in April 2017 to 22.4kg in July 2017 — a significant weight loss given her small size. The emergency medicine registrar, Dr E, queried seizure activity and noted that an EEG had been booked for Miss A but had yet to be performed.

79. When Miss A was reviewed by paediatric MOSS Dr F, it was felt that Miss A's presenting history and symptoms were similar to the chronic gastrointestinal symptoms noted in the past. As such, Miss A was discharged from hospital with no investigation of her neurological symptoms.

80. Dr Stanley considers that the episodes of slurred speech, followed by an inability to talk, represents a "potentially serious complaint". He said that this was a "red flag", and that a brain tumour was an important potential cause of such a presentation. Dr Stanley stated: "[The] decision to not take urgent action but simply wait for another episode of slurred speech was … erroneous."

81. Dr Stanley advised that Miss A's symptoms should have led to earlier imaging (a CT or MRI scan). He regards the failure to undertake that imaging as a "severe departure from the standard of care".

82. Dr Stanley further noted that Miss A had lost weight since the beginning of the year. He advised: "The lack of normal weight gain in the last few months was another red flag that there was significant underlying pathology." This, coupled with the apparent disorientation and acquired inability to speak, should have led to a fresh attempt to find an underlying pathological process with some urgency.

83. I accept Dr Stanley's advice. The family reported new symptoms that did not appear in keeping with previous working diagnoses of a gastric cause. By 10 July, Miss A was displaying concerning neurological symptoms (which had begun to emerge on or before 5 May). I note that a CT scan was queried by Dr B in May, and that seizure activity was queried in July, yet on both occasions, Miss A was discharged from hospital to await outpatient care. Additionally, in my view, Miss A's new symptoms in the context of repeated presentations to hospital ought to have triggered a reconsideration of the working gastric-related diagnosis, and broader investigations into the cause of the neurological symptoms, with greater urgency.

**Conclusion**

84. As set out above, Miss A and her family presented to hospital on multiple occasions. New and concerning neurological symptoms arose from May, and Miss A was seen by a number of staff. In response to my provisional opinion, CMDHB submitted that the care it provided Miss A was in accordance with standard care, based on what was presented clinically at the time. CMDHB also referred to the fact that hindsight can greatly influence how the care provided is viewed.

85. It is of course important to be mindful of hindsight bias. In my assessment of this complaint I have carefully considered what symptoms Miss A presented with at the time of each of her assessments, and expert advice regarding those symptoms. I am satisfied (as outlined) that on 5 May and 10 July Miss A presented with new and concerning symptoms (in the context of other red flags, including weight loss) which warranted consideration of a different approach to her diagnosis and management. This is not a case of clinicians failing to diagnose a rare brain tumour, but rather, is focussed on the failure to think more critically and respond with greater urgency to those emerging and concerning symptoms. As identified, it is my view that on 5 May it would have been prudent for a senior medical officer to have reviewed Miss A in person.

86. The above failures involved numerous individuals across multiple presentations, and, in my view, indicate a pattern of poor care across Miss A's patient journey. I consider this to be a service delivery failure for which, ultimately, CMDHB is responsible. Accordingly, I find that CMDHB did not deliver services to Miss A with reasonable care and skill and breached Right 4(1) of the Code of Health and Disability Services Consumers' Rights.[25]

**Other issues**

87. My expert advisor, Dr Stanley, commented on a number of other aspects of Miss A's care, which I discuss briefly below.

*Abdominal pain and vomiting*

88. Dr Stanley commented that there is little information about whether Miss A's abdominal pain awoke her in her sleep, and noted that the presence of such symptoms "might have led clinicians to seek another explanation (although there is no guarantee they would have discovered the cause of her pain)".

89. Dr Stanley also advised:

> "Abdominal pain or vomiting that wakes a child from sleep should be regarded as symptoms of a more severe process and should encourage the clinician to question the previous diagnosis; such severity would be highly unusual in abdominal migraine, which virtually never wakes the child. Paediatric surgical referral would have been wise."

90. I note that Dr B's notes at the outpatient clinic on 17 February 2017 do indicate that pain would wake Miss A from her sleep about once a week. At the outpatient clinic on 21 April,

[25] Right 4(1) states: "Every consumer has the right to have services provided with reasonable care and skill."

Dr B also noted that on one occasion Miss A had vomited in the middle of the night. CMDHB may wish to consider Dr Stanley's comment about a paediatric surgical referral in future similar cases.

*Assessment of gait*

91. Dr Stanley advised:

> "The inability to perform a tandem gait at nearly 6 years of age in a child who to all intents and purposes was of normal intelligence was in my opinion a red flag. I would regard this as a moderately severe departure from the standard of care."

92. CMDHB considered that this assessment was completed in the context of a child presenting with non-neurological symptoms (on 17 February 2017), and that a tandem gait in a child of this age is not always performed with accuracy. Dr Stanley disagrees with this, and advised that this would be an expected milestone for a normal three-year-old child. He further noted that he could not find any subsequent description of Miss A's gait at this time, and considers that it would have been helpful for clinicians to have documented that her gait was normal. He noted that there were no reports from Miss A's parents or GP about any issues with her gait.

93. Acknowledging that Miss A's presentations in February 2017 were being considered as gastrointestinal in nature, I accept that it may be with the benefit of knowing Miss A's ultimate diagnosis that issues about her gait may now be scrutinised more closely. I could find no reference to concerns about Miss A's gait having been raised in any other clinical records. As my report focuses on the 5 May and 10 July presentations, I do not consider it necessary to comment further on this issue.

## Recommendations

94. I recommend that CMDHB:

a) Consider the HQSC resource on *Patient, family and whānau escalation: Kōrero mai projects — what we know so far* and advise whether any continuous improvement projects could flow from the learnings in this investigation, within three months of the date of this report.

b) Use this investigation as an anonymous case study for emergency medicine and paediatric teams, and confirm with HDC that this has occurred within six months of the date of this report.

c) Review RMO to SMO escalation practices in the Paediatric Department and report back to HDC on the following within four months of the date of this report:

- RMO knowledge of when to ask for SMO review;
- Whether SMOs regularly confirm with RMOs whether a review of a person is being requested; and

- What situations SMOs will attend without a request to do so.

Where any areas for improvement are identified, CMDHB is to report back to HDC, within six months of the date of this report, on the remedial actions that will occur.

d) Advise on the outcome of the morbidity and mortality meeting in which Miss A's case was reviewed, in particular on whether a guideline outlining an approach to children who present with focal findings has been produced, within three months of the date of this report.[26]

e) Provide a written letter of apology to Miss A and her parents for the failures identified in this report. The apology is to be sent to HDC within three weeks of the date of this report.

## Follow-up actions

95. A copy of this report with details identifying the parties removed, except CMDHB and the expert who advised on this case, will be sent to the Health Quality & Safety Commission, the Australasian College of Emergency Medicine, and the Royal Australasian College of Physicians, and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

[26] As per Dr B's letter dated 5 July 2018 — paragraph 25.

## Appendix A: Independent advice to the Commissioner

The following expert advice was obtained from paediatrician Dr Thorsten Stanley:

"Thank you for asking me to provide an expert opinion on the management of [Miss A]. I apologise for the delay in this report, related to initially incomplete records and the complexity of the case. Thank you for providing the complaint from the family. I hope to be able to answer their queries as well as I possibly can.

I am a general paediatrician with an interest in, amongst other things, paediatric neurology. I qualified MB ChB 1973 Edinburgh, completed MRCP (Paeds) specialist training in 1977 (Edinburgh, Glasgow, UK), was elected FRCP London 2000, and have been in practice as a consultant paediatrician in New Zealand since 1980. I therefore review this case as it would present to a general paediatrician.

Thank you for providing me with correspondence from both [DHB2] and also Counties Manukau DHB. I have been provided with a very complete record of the [DHB2] medical records (although body measurements were not originally provided) and primarily outpatients records from Counties Manukau.

I believe [Miss A's] parents primarily wish an opinion on her care PRIOR to her presentation with her stroke, at which time imaging showed her brain tumour. It would be inappropriate for me to comment on her care from that time on, as it relates primarily to neurosurgical and oncological management which is well outside my area of expertise.

I note [Miss A] first presented to Counties Manukau with a history of recurrent episodes of abdominal pain on 10 November 2014. The history was of eight or nine months of recurrent abdominal pain. The episodes lasted from seconds to minutes and were often associated with a need to go to sleep afterwards.

The episodes occurred two or three times a day. Unfortunately, correspondence does not delineate whether the pain occurred at night time, or in particular, whether it woke her.

In retrospect, it may have been helpful to have asked that question, as stress-related abdominal pain and abdominal migraine of course do not occur in sleep.

From the correspondence I think her early investigations and management were appropriate. Abdominal pain is very common in children. In many cases no underlying pathology is found and the management at that early stage I think was appropriate.

I note she had recurrent presentations with abdominal pain. Management included the use of antacids and hydration fluids. Careful examination failed to find a serious cause of her abdominal pain, and there were no real clues originally to suggest clinicians should look outside the gastrointestinal system.

Because of a history of possible involuntary movements of upper limbs lasting 10 or 20 seconds, she was referred to [a paediatric neurologist] on July 2014. [The paediatric neurologist] did not find any history to suggest these actually were seizures. She viewed a video that her father brought. The episodes seen in the video were not suggestive of a seizure.

[The paediatric neurologist] was happy that these episodes were not seizures and wondered if they might in some way have been related to abdominal discomfort or gastro-oesophageal reflux. She did *not* mention abdominal migraine, which I agree would have been an unusual diagnosis in a child of four.

Subsequently she was seen on a repeated basis by her GP and then by paediatricians at Counties Manukau in May 2015, her episodes of abdominal pain remained essentially undiagnosed. I note the paediatricians at Counties Manukau wondered if these were stomach migraine. The letter including this potential diagnosis was copied to [the paediatric neurologist], but I believe it is not common practice for tertiary consultant staff from other hospitals to read through letters sent to them when they are only being copied in without a request for further review. As a result, [the paediatric neurologist] did not advise Manukau that in her opinion a diagnosis of abdominal migraine was highly unlikely.

It is in fact uncertain whether the episodes [abdominal pain and unusual movements] described in 2015 had the same cause as the episodes when she was subsequently seen in 2017. It can sometimes be very challenging to be sure what is the cause of a symptom like abdominal pain in a small child and if it is serious or not, and a paediatrician will use other clues such as rate of growth, appetite, sleep, energy etc to reach a decision whether further investigations are required. None of these red flags were present in [Miss A] at this time.

She was subsequently seen again in February 2017, having been referred in December 2016 by her GP because of persistent abdominal pain, now accompanied by vomiting. It is not clear to me whether her pain had continued since 2015 or whether this was a new problem. She was again seen by [Dr B] on this occasion.

A thorough examination was done including neurological examination of upper and lower limbs, and [Dr B] remembers examining her cranial nerves as far as is possible in a child of nearly 6 years of age. She was said to have normal gait at this time *but had difficulty walking heel–toe* and a Fogg gait test was not mentioned.

- **I believe heel–toe gait examination (tandem walk) should be easily achieved by a 6-year-old (normally this is achieved by 5 years of age) and a) difficulty understanding what to do and b) inability to do this, even when shown, should have rung some alarm bells, at least to repeat the test after a short period.**

(For comparison, riding a bike without trainer wheels is also achieved on average by age 5.)

It was felt that perhaps her abdominal pain and vomiting was in some way associated with a tendency to be constipated. There was an apparent partial response to probiotics. There was a possible partial response to omeprazole and to laxatives.

NB. Vomiting would be an unusual presentation for constipation or indigestion and was essentially unexplained.

There was a suggestion that some of her abdominal pain might have been related to her diet. Again, there is little information in the notes about whether she woke with these symptoms (vomiting or abdominal pain) which I would have regarded as more significant. There was a suggestion she might be seen by the gastroenterology team at [DHB2] and a referral letter was sent in May 2017. The paediatric gastroenterologists evaluated her symptoms as described in the referring letter and felt that she did not require more invasive investigations, simply symptomatic treatment and later referral if this did not resolve the symptoms. For a while, she did appear to get better.

I note subsequently she had multiple attendances with a history of persistent abdominal pain and/or vomiting in April, May and July 2017.

I could not find any subsequent description of her gait at this time; it would have been helpful for clinicians to have documented that her gait was normal, but I presume it must have been, or her parents or GP would surely have mentioned this? Brain tumours in children may often present with unsteady gait or frequent falling [and of course an inability to perform a tandem walk] and such a symptom might have directed clinicians to look at her neurological system in detail, instead of concentrating on her abdominal system.

On 5 May 2017 she was referred to the Emergency Department with what was suspected to possibly be some sort of seizure, with episodes of slurred speech followed by no speech, and a plan was made for her to have an EEG and abdominal ultrasound scan. I believe a neurological examination was carried out and was felt to be normal ('no focal neurological neurology'). More detail of what was actually looked at would have been useful (again including gait), and I was not provided with any hand-written record of this attendance (if it exists) where more details may have been included as to what was actually examined. There is a note 'mobilising well' but I'm not sure what that means in a 6-year-old: perhaps it refers to gait?

She was not seen by a consultant on this occasion, but by a trainee paediatrician ([Dr C]) who discussed this presentation with the duty consultant, [Dr D].

[Dr D] wondered if [Miss A] was having focal seizures (see HDC report from [Dr D], Page 2 paragraph 2).

- **In my opinion a child presenting for the first time with focal seizures should have been seen by a consultant *in person* and had a full neurological evaluation. Two episodes of slurred speech, followed by inability to talk for 2 hours represents a potentially serious complaint, and a brain tumour was an important cause of such**

**a presentation. This was another RED FLAG and a decision to not take urgent action but simply wait for another episode of slurred speech was in my opinion, erroneous.**

Two months later, on 10 July 2017, she re-presented with recurrent episodes of vomiting and now appeared disoriented and had some interference with her normal ability to speak and vocalise. She continued to suffer from abdominal pain. She had non-specific headaches and she showed evidence of wishing to be in a dark room. She was making comments that were out of normal context. At this point it was noted that she had not gained weight and indeed she had lost weight from 24 kilograms at the beginning of the year to 22.4 kilograms in July 2017.

**This was clearly another RED FLAG**. The doctor on this occasion was a junior doctor who completed a very detailed assessment and thorough list of problems, could not reach a unifying diagnosis and apparently discussed [Miss A] with her consultant; a decision was however made in consultation that she could be discharged home.

- **I believe this was an error of judgement and a consultant review *in person* should have taken place, which should almost certainly have led to admission and consideration of imaging.**

A month later on 6 August 2017 she presented to the Emergency Department with confusion and an unusually slow pulse and some weakness of her face, lack of orientation to place and neurological signs consistent with a stroke. There was suggestion of status epilepticus. At this point a CT scan was done which demonstrated the presence of a stroke as a complication of a brain tumour.

In retrospect (and it is always more straightforward to make a diagnosis in retrospect) her previous episodes of abdominal pain were probably a type of seizure. This is exceptionally rare. I have discussed abdominal pain as a presenting symptom of seizures with a number of colleagues including specialised paediatric epilepsy colleagues and none remembered experiencing this, at least in the recent past. I have seen one case in forty years in practice. The modern classification of epilepsy in childhood no longer talks about 'abdominal epilepsy' but does recognise that epilepsy arising from occipital, frontal or temporal lobes may occasionally present with apparent abdominal pain. The widely-used medical database, 'Up to Date', barely mentions this in the adult epilepsy section, and does not discuss it at all in the 'abdominal pain in a child' section.

Abdominal pain as a type of seizure is therefore exceptionally rare and one would not expect this diagnosis to be made without a strong indication of it being seizure-like. The symptoms in a small child such as [Miss A] would make such a diagnosis extremely difficult. Most cases of 'abdominal epilepsy' have been described in older children who are able to express their experiences much more readily.

I was not provided with the result of the EEG when it was eventually done. However, even in the presence of epilepsy, EEGs in small children can often be completely normal and the diagnosis is essentially made on a history suggestive of seizures. This makes a diagnosis in somebody with abdominal pain even more challenging.

I note that Counties Manukau have used [Miss A's] case as a learning experience for themselves. I would find her presentation with abdominal pain, very challenging myself.

The progression from abdominal pain to recurrent vomiting could have alerted paediatricians that there might be a progressive process occurring.

As to whether a CT scan earlier, before her stroke, would have altered the prognosis, I would suggest this question be asked of the neurosurgeon involved. However, there would still need to be a justification to do a CT scan.

Sometimes the presence of an underlying brain tumour can be recognised because a child is clearly unwell. However, [Miss A] did not show signs of significant unwellness until the last few months prior to her final presentation.

[Miss A] unfortunately has an underlying diagnosis of an extremely rare brain tumour. In fact, the tumour she has was only first classified in detail in 2012. None of the consultant paediatricians involved in her care would have been aware of this particular tumour, which was first delineated to any great extent after they had all completed their training. They are certainly highly unlikely to have ever seen a child with one, and in view of its rarity, it would not be included in specialist paediatric training anyway.

I have looked at published cases of diffuse leptomeningeal glioneuronal tumour (DLGNT) presenting in children. The presentation is commonly challenging, with very atypical presenting symptoms and signs. Many of the cases described have had long delays between the onset of the first symptoms and the final diagnosis. The average age of diagnosis is actually eight years of age. Most patients with DLGNTs have non-specific symptoms. Some patients may initially be thought to have meningitis because this tumour leads to abnormal cells in the cerebrospinal fluid and there may be abnormalities of the fluid biochemistry also. As a result, some cases are managed as if they had an infection to start with. The tumour is very slow growing. It is not clear to me at which point the tumour first appeared clinically, and indeed I suspect this would only be guess-work.

There is a good review of this tumour in Child Neurology Open (Megan R Lyle et al) entitled 'Newly Identified Characteristics and Suggestions for Diagnosis and Treatment of Diffuse Leptomeningeal Glioneuronal Neuroepithelial Tumours: A Case Report and Review of the Literature' (Child Neurology Open 2015 January to March; pages 1–7). They mentioned this tumour was described in its entirety for the first time only in

2010. In the case described, the symptoms were present for a year before a final diagnosis was made.

This was a 14 year old child. The paper also describes an eight-year-old child with elevated protein level in the cerebrospinal fluid but no malignant cells. In many cases cerebrospinal fluid analysis fail to demonstrate a primary tumour, with simply signs of inflammation in the spinal cord.

There was another review article in Acta Neuropathologica (Nov 2012, first author Rodriguez FJ), which delineated 36 patients with DLGNT and after some searching, I was able to find the clinical descriptions of those cases. Again, the children presented in all sorts of ways, often not obviously related to the central nervous system. Some patients presented with headaches (hard for a small child to describe) often for months or years, sometimes complicated by sudden paralysis, apparent meningitis, etc. and one child had a history of intermittent vomiting for 2 years.

Sometimes brain tumours can be associated with rapidly increasing head size. However, I have been through [Miss A's] case notes from when she was a baby until recently and although measurements were few and far between, there was no such evidence; in her case, her head circumference has remained on the 50$^{th}$ percentile. This would make a diagnosis of a brain tumour even harder. She did not develop classical symptoms of raised pressure inside her head until towards the end of her presentation.

[Miss A] therefore has two extremely rare problems:

a) abdominal pain presumably explained on the basis of seizure disorder, rarely seen in childhood and;
b) An extremely rare brain tumour which is characterised by very subtle presentation often with symptoms that are not typical of brain tumours and with a very slow rate of growth.

I do not believe a CT scan was indicated early on, as she did not have enough symptoms to justify this. CT scans are associated with their own very real risk, especially when done in small children.

However, I think a CT scan might have been considered in May 2017. An MRI scan is an alternative without radiation but would have required a general anaesthetic, also not totally risk-free.

It is very likely an EEG would not have led to a diagnosis, as commonly in small children with epilepsy it is normal. Allowing one to look at EEG changes at the time when a child experiences symptoms, using *continuous video EEG* monitoring over several days, *might* have led to an earlier diagnosis of epilepsy. However, this is a very time-consuming and resource-hungry form of investigation and is reserved for children where there is a strong suspicion of epilepsy, which I don't believe was present in this case until a month or two before admission.

In summary, I believe [Miss A] had a very rare clinical presentation of a very rare tumour, known for its challenging, subtle presentation, making it very hard to diagnose. Having looked through the information made available to me regarding her management at Counties Manukau Hospital and subsequently at [DHB2], I believe the following areas of management might have been a bit more optimal:

…

2) A fresh review of her recurring and persistent abdominal pain when she repeatedly presented might have led her clinicians to completely re-examine her differential diagnosis, given that her symptoms were persistent, that the suggested diagnosis of abdominal migraine was not in keeping with her age at first presentation nor her clinical progress, and in particular when vomiting became a persistent feature.

   - I would regard this as a moderate departure from the standard of care.

3) Functional abdominal pain in this age group is usually fleeting — easily distractible — and usually an underlying social or emotional stress is readily demonstrated. Indeed, I believe such a positive history of stress needs to be present for this diagnosis to be entertained.

   - I would regard this as a mild departure from the standard of care.

4) The presence of symptoms waking her from sleep, if present (and I suspect in retrospect they were), *might* have led clinicians to seek another explanation (although there is no guarantee they would have discovered the cause of her pain).

   - I would regard this as a mild departure from the standard of care.

5) The inability to perform a tandem gait at nearly 6 years of age in a child who to all intents and purposes was of normal intelligence was in my opinion a red flag.

   - I would regard this as a moderately severe departure from the standard of care.

6) Two episodes of slurred speech, followed by inability to talk for 2 hours represents a serious presentation and a brain tumour was an important cause of such a presentation. Clinicians raised the suspicion of focal seizures (I suspect correctly). This should have led to early imaging (CT or MRI) in a child where no cause for focal seizures was known.

   - I would regard this as a severe departure from the standard of care.

7) The lack of normal weight gain in the last few months was another red flag that there was significant underlying pathology, as were symptoms of apparent disorientation and acquired inability to speak. They should have led to a fresh attempt to find an underlying pathological process, and treated with some urgency.

- I would regard this as a moderately severe departure from the standard of care.

I am uncertain if at that late stage, (May 2017), even if imaging had confirmed her intracranial tumour, her prognosis would have been altered. I would suggest you seek advice on this point from her neurosurgeon.

**CONCLUSION**
I do not believe there was evidence of recurrent *major* suboptimal management in her care, but feel the issues raised above are worthy of review by the team at Counties Manukau.

However, I also believe her outcome was largely the result of the very difficult to diagnose and treat tumour she had, with very difficult presenting features. This was a very challenging case.

My sympathies go to [Miss A] and her family for this tragic outcome.

Yours sincerely

Dr T V Stanley
MBChB (Edin) DCH (Glas) D Obst RCOG (Lond) MRCP (UK) FRCP(Lond)
**Consultant Paediatrician, Capital and Coast DHB Wellington and**
**Senior Lecturer in Paediatrics University of Otago, Wellington"**

The following further expert advice was obtained from Dr Stanley:

"[**MISS A]**
**[DHB2] and Counties Manukau DHB**
**Your Reference: C18HDC01075**

Thank you for asking me to comment on the responses from [DHB2] and Counties Manukau services.

I will reply to your correspondence (included for review) point by point:

…

**Issue 2**
I agree abdominal migraine may be diagnosed even in a child as young as 2 but this is very unusual, and when a symptom begins at an age that is unusual, I believe a clinician should particularly keep an open mind to other possibilities. Abdominal pain in abdominal migraine is nearly always periumbilical, not epigastric as experienced by [Miss A]. One would expect other typical features of migraine such as marked pallor during the episode, associated headache or photophobia, infrequent episodes

perhaps occurring in runs as is also seen in classical migraine, and one would normally expect a strong family history of migraine, which I don't believe was present.

I did not have the impression from reading through the notes on each consultation that a fresh review had occurred, which I believe should include taking a full history again (from the pregnancy, right up until presentation), in case salient features had been missed, as well as a complete reexamination of [Miss A], as her progress was not as had been predicted from her earlier diagnosis. It appears several clinicians were content to accept a diagnosis of abdominal migraine, although I note there was an (appropriate) referral to paediatric gastroenterology which did not lead to a gastroscopy but a suggestion for medical treatment of dyspepsia without a confirmed diagnosis. I suspect an endoscopy would have confirmed there was no pathology in the stomach or oesophagus: such a NEGATIVE diagnosis might have led clinicians to look for an alternative explanation for her symptoms. Pancreatic pathology should also have been considered.

**Issue 3**
I have been through the notes forwarded to me by the office of the HDC which are a small extract of the original huge file I reviewed earlier. I agree there is no mention of functional abdominal pain in these files — If I have made this up, I apologise. I do not wish to go through the thousands of pages of the original notes again ...

**Issue 4**
I remain of the opinion abdominal pain or vomiting that wakes a child from sleep should be regarded as symptoms of a more severe process and should encourage the clinician to question the previous diagnosis; such severity would be highly unusual in abdominal migraine, which virtually never wakes the child. Paediatric surgical referral would have been wise.

**Issue 5**
I disagree that an otherwise neurologically normal 5 year 9-month-old child (in my report I say 'nearly six years of age') would not be expected to be able to perform a heel–toe walk. This is an expected milestone for a normal three-year-old.

See for example:

https://depts.washington.edu/dbpeds/Screening%20Tools/Devt%20Milestones%20Table%20(B-6y)%2OPIR%20(Jan201.6).msg.pdf

**Issue 6**
In my opinion episodes of slurred speech in a child who has previously achieved normal age-appropriate speech, are a red flag that there is a neurological process that requires urgent investigation — whether these be seizures, disturbances in consciousness, or temporary paralysis.

Thank you for the opportunity to comment and my apologies again for the delay in my response.

Yours sincerely

**Dr T V Stanley**
**MB ChB DCH (Glas) D Obst RCOG (Lond) MRCP (UK) FRCP (Lond)**
**Consultant Paediatrician CCDHB and Senior Lecturer in Paediatrics University of Otago Wellington**"