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INQUIRY INTO THE CONVICTIONS OF KATHLEEN MEGAN FOLBIGG

MONDAY, 18 MARCH 2019 at 10.00am

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PRESENT:

Legal representatives

15 **Gail Furness SC**, Senior Counsel assisting the Inquiry

Ann Bonnor, counsel assisting the Inquiry

Sian McGee, counsel assisting the Inquiry

Jeremy Morris SC, Senior Counsel for Ms Folbigg

Robert Cavanagh, counsel for Ms Folbigg

Isabel Reed, counsel for Ms Folbigg

20 **Kate Richardson SC**, Senior Counsel for Dr Allan Cala

Ian Fraser, counsel for NSW Health

Ragni Mathur, counsel for Professor John Hilton

Witnesses

25 **Professor Rosemary Horne**, Deputy Director of the Hudson Institute's
Ritchie Centre at Monash University

Professor Dawn Elder, Head of the Department of Paediatrics at the
University of Otago (by AVL)

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SPECIAL INQUIRY

THE HONOURABLE REGINALD BLANCH AM QC

5 MONDAY 18 MARCH 2019

INQUIRY INTO THE CONVICTIONS OF KATHLEEN MEGAN FOLBIGG

10 Ms G Furness SC with Ms A Bonnor and Ms S McGee counsel assisting the Inquiry

Mr J Morris SC with Mr R Cavanagh and Ms I Reed for Ms Folbigg

Mr I Fraser for NSW Health

Ms R Mathur for Professor John Hilton

Ms K Richardson SC for Dr Allan Cala

15

JUDICIAL OFFICER: Yes, can we take appearances?

20 FURNESS SC: Thank, your Honour, my name is Furness. I appear with my learned juniors, Ms Bonnor and Ms McGee, instructed by Ms Richards of the Crown Solicitor's Office, to assist your Honour.

JUDICIAL OFFICER: Thank you, Ms Furness.

25

MORRIS SC: May it please, your Honour, my name is Morris and I appear with my learned juniors Mr Cavanagh and Ms Reed in the interests of Ms Folbigg.

30 JUDICIAL OFFICER: Thank you, Mr Morris. Any other appearances?

RICHARDSON SC: May it please, your Honour, Richardson, I appear in the interests of Dr Cala.

35 JUDICIAL OFFICER: Yes, Ms Richardson, thank you.

FRASER: May it please your Honour, Fraser, and I appear in the interests of New South Wales Health.

40 MATHUR: Your Honour, Mathur, I appear in the interests of Professor Hilton, instructed by Mr Mineo of Avant.

JUDICIAL OFFICER: Thank you, Ms Mathur. No one else? Thank you. Yes, Ms Furness.

45

FURNESS SC: Thank you, your Honour, there was one matter I wished to raise with your Honour before the opening, and that's in relation to the service and receipt of expert reports. As your Honour will recall, a timetable was set for the receipt of expert reports instructed and engaged to prepare a report in respect of this tranche of the hearings, that is, the forensic pathologists and

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SIDS part of the hearings. They were to be received by the Inquiry by Monday 18 February.

5 The Inquiry has received the following reports from those representing
Ms Folbigg on the following dates: Professor Duflou's report was provided on
13 February 2019, within the timeframe; various statements from those
engaged or employed by the Victorian Institute of Forensic Medicine were
received on 18 February; a report from Professor Blackwell was received on
10 7 March; a second report from Professor Blackwell was received on 12 March;
a third report from Professor Blackwell was received on 14 March; a first report
of Professor Clancy was received on 14 March; a second report of
Professor Clancy was received on 17 March; and a report from
Professor Ryan, a neurologist, was received on 15 March.

15 In addition, a 71 page index to literature was received by the Inquiry on
15 March. In addition, three affidavits were received, two on 11 March and
one on 14 March 2019. I raise those matters for your Honour's attention.

JUDICIAL OFFICER: Mr Morris.

20 MORRIS SC: Yes.

JUDICIAL OFFICER: I appreciate the difficulties in organising a lot of this
25 material, but those reports, many of them are basically a month beyond the
time, and some of them, of course, have only been received over this
weekend.

MORRIS SC: Yes your Honour.

30 JUDICIAL OFFICER: And that puts the Inquiry in a very difficult position.

MORRIS SC: I understand that your Honour, the delay is regrettable but as
your Honour would well be aware, during the course of preparation, things
35 come to our attention and those who instruct me, as soon as those matters
have come to their attention have taken steps to procure reports within a very
very short time of that information coming to their attention. We note your
Honour's concern, we accept the validity of your Honour's concern about the
impact it has on the orderly conduct of the Inquiry but regrettably your Honour,
40 when this information has come to our attention, we've raised it as soon as
we've been able.

One of the issues which your Honour would appreciate is that the sudden
unexpected death of an infant is a multi-factorial inquiry and the evidence I
45 think will come out that issues like infection, cardiac function, neurological
function, are areas which have become increasing areas of focus by those
people with that experience. And your Honour that was not immediately
apparent to us when the material was first being served by the Crown at the
end of last year. There's a massive amount of material, there's a huge
50 scientific complexity and your Honour we're trying to deal with it.

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JUDICIAL OFFICER: I appreciate that but we do have to have some order in relation to the Inquiry, in theory the Inquiry could go on for years, as more and more material came forward. That can't be allowed to happen and one reason of course is that your client is in custody serving a sentence and--

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MORRIS SC: Absolutely.

JUDICIAL OFFICER: --if her application was successful, she would be released from custody. So, it is important that the matter be dealt with expeditiously, from everybody's point of view.

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MORRIS SC: Yes.

JUDICIAL OFFICER: Are we to expect any further material being served in relation to any of this?

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MORRIS SC: Your Honour I'm not aware of any at the time being, other than that arising out of the genetics investigations.

20

JUDICIAL OFFICER: Yes, genetics is yet to come, and I think the time given for that material was 29 March, so you're still in time for that.

MORRIS SC: We're working towards that your Honour.

25

JUDICIAL OFFICER: I appreciate the difficulties but as I said, there are a number of considerations to be taken into account.

MORRIS SC: I understand that your Honour.

30

JUDICIAL OFFICER: Is there any other matter to be raised in a preliminary way. Yes, Ms Furness.

FURNESS SC: Your Honour before I open, I may tender some additional documents. Given that there had been a number of directions hearings and documents have been tendered at each of them, it may be of some assistance to those at the Bar Table and otherwise listening, to indicate which documents have been so far tendered.

35

Firstly, the direction was tendered, which is exhibit A. Secondly the various judgments, exhibit B. Expert reports of Professor Cordner and Professor Pollanen, exhibit C. Professor Byard and Professor Duncan's SIDS book was tendered as exhibit D. Various exhibits were tendered from the trial as exhibit E. A complete set of trial transcripts, including voir dire and matters heard in the absence of the jury were tendered as exhibit F.

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Documents I wish to tender this morning your Honour as one exhibit are various judgments, firstly on the defence application for adjournment, application for vacation of hearing date on 21 February 2003, judgment on Crown application to open on the late served statement of Dr Cala 1 April 2003, judgment on admissibility of video of 28 February 1999 (3 April),

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5 judgment on application to cross-examine Professor Hilton (14 April), judgment on admissibility of medical evidence of the probable state of health of Laura Folbigg (14 April), judgment on admissibility of evidence of Dr Cala (16 April), judgment on admissibility of evidence of Professors Berry and Herdson (24 April), judgment on Crown application for exception to earlier ruling regarding Professor Byard (7 May) and two exhibits from the voir dire in relation to Dr Beal and an unedited diary entry dated 14 October 1996.

10 EXHIBIT #G BUNDLE OF DOCUMENTS TENDERED, ADMITTED WITHOUT OBJECTION

EXHIBIT #H FORENSIC PATHOLOGY TENDER BUNDLE TENDERED, ADMITTED WITHOUT OBJECTION

15 In relation to exhibit E, I seek leave to amend a document within that exhibit. That's the exhibits of the tender at the 2003 trial, for various reasons the document needs to be taken back and replaced with another, if anyone is interested in the details, I can happily provide them.

20 On 10 June 2015, pursuant to s 76 of the *Crimes (Appeal and Review) Act 2001*, Kathleen Folbigg presented a petition to the Governor of New South Wales, seeking an inquiry into her convictions. On 22 August 2018 the Governor of New South Wales directed that an inquiry be conducted into her convictions in respect of her children, for the manslaughter of Caleb, the malicious infliction of grievous bodily harm upon Patrick and the murder of Patrick, Sarah and Laura. The direction records:

25
30 "It appears that there is a doubt or question as to part of the evidence in the proceedings leading to the conviction of Kathleen Megan Folbigg, which concerns evidence as to the incidence of reported deaths of three or more infants in the same family attributed to unidentified natural causes."

35 On completing the inquiry, the Judicial Officer is to cause a report on the results of the inquiry to be sent to the Governor. In addition, if the judicial inquiry is of the opinion that there is a reasonable doubt as to the guilt of Ms Folbigg, the Judicial Officer may refer the matter, with a copy of the report, to the Court of Criminal Appeal for consideration of whether the conviction to be quashed.

40 It is for the Judicial Officer to form his own concluded opinion as to whether there is a reasonable doubt. The Act does not require that the Judicial Officer be bound by the rules of evidence when conducting an inquiry or in preparing the report. As such, in forming an opinion as to the existence of a reasonable doubt, the Judicial Officer may have regard to all of the information and evidence received by the inquiry. If there is a reference to the Court of Criminal Appeal, that court is also not bound by the rules as to admissibility of evidence.

50 Your Honour has determined the scope of the Inquiry as follows; any new

5 research or advances in medical science relevant to the causes of death of each child and the cause of the apparent or acute life threatening event in respect of Patrick, referred to as an ALTE; expert medical opinion as to the causes of death of each child and the cause of the ALTE in respect to Patrick, in light of any relevant new research or advances in medical science; any new research or literature concerning the incidence of reported deaths of three or more infants in the same family attributed to unidentified natural causes; any other related expert medical evidence. Ms Folbigg is allowed to give evidence if she wishes to do so about the diary entries, possession of the diaries and her disposal of the diaries. The evidence from her will be restricted and cross-examination of her will be restricted to those particular issues.

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15 At the fourth directions hearing on 11 February 2019, your Honour made the following additional order in respect of the scope of the Inquiry; and that is that the scope will not include the evidence of Ms Folbigg unless the Inquiry is notified in writing by 17 March 2019 that she does intend to give evidence. Your Honour, the Inquiry has been notified in writing that Ms Folbigg intends to give evidence.

20 Turning now to the legal proceedings, on 19 April 2001, Kathleen Folbigg was arrested and charged with four counts of murder for the deaths of her four children, Caleb on 20 February 1989, Patrick on 13 February 1991, Sarah on 30 August 1993 and Laura on 1 March 1999. On 25 October 2002, the Crown presented an ex officio indictment laying an additional charge of one count of maliciously inflicting grievous bodily harm, with intent to do grievous bodily harm, in respect of Patrick's ALTE on 18 October 1990. Ms Folbigg was rearraigned and entered pleas of not guilty to each count.

25
30 The Crown case relied wholly on circumstantial evidence. It consisted of three categories of circumstantial evidence. Evidence of the circumstances of each child's death and Patrick's ALTE, medical evidence from doctors and medical experts and Ms Folbigg's diaries. In his judgment as to the pre-trial application for separate trials, brought by Ms Folbigg, and in the context of assessing the probative value of the medical evidence, Wood CJ at Common Law summarised the circumstantial evidence:

- 35
- "(a) The infrequent incidence of SIDS;
 - 40 (b) The rarity of repeat incidence of SIDS and of unexplained infant deaths or ALTEs within the one family;
 - (c) The absence of any metabolic abnormality in any of the children, let alone a common abnormality;
 - 45 (d) The fact that each was a healthy child and that such physical or medical conditions as were observed at post mortem were unlikely causes of death;
 - 50 (e) The absence of any sleeping abnormality in the three children who were tested and/or monitored;

- 5 (f) The fact that monitoring was provided but then ceased in relation to Sarah and Laura, a matter of some importance in view of the diary entry of 25 August 1997;
- (g) The fact that two of her children were found by the mother within the very brief window between a child being found moribund and dead;
- 10 (h) The fact that all children were found by the mother while they were still warm, even though in four of the five relevant instances, this occurred at night;
- 15 (i) The unexplained absence of Sarah and the mother at about 1am, shortly before she was found dead:
- (j) The unusual behaviour of the accused in getting up from the bed, leaving the room, returning and then getting up again, only to discover in the case of some of the children, that they were moribund or lifeless;
- 20 (k) The fact that she claimed to have observed in the dark and from some distance away, that some of them were not breathing;
- 25 (l) The stress and anger which the mother had expressed toward the children;
- (m) The fact that the mother would not nurse or endeavour to resuscitate the children when they were found."
- 30

35 The Crown case also comprised a fourth category of evidence described as coincidence evidence. This referred to similarities in the evidence of the circumstances of each child's death and Patrick's ALTE relied on by the Crown to disprove by way of coincidence reasoning permitted under s 98 of the *Evidence Act*, that the five events were merely coincidental.

40 In this regard the Crown case relied on ten particular features which were common across the five events to disprove coincidence. Those features as described during the closing address were firstly, all five events occurred suddenly, the events were over in a matter of minutes. Second, all five events occurred unexpectedly, no child had any health problem that preceded the sudden deaths or ALTE, or gave any sort of warning sign or previous symptom. All five events occurred at home, in circumstances where the children spent a proportion of their time away from the home.

45 All five events occurred during the child's sleep period rather than while playing at home, watching television, in the bath or in the garden, for example. All five events occurred when the child was in bed, cot or bassinet rather than while asleep on the floor or sitting, standing, running, jumping, skipping, eating or watching television. All five events occurred when the only person effectively

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5 at home or awake was Ms Folbigg, noting that Mr Folbigg was a deep sleeper which gave her the opportunity to have done the children harm. Each child was discovered dead or moribund by Ms Folbigg. Each child was discovered by Ms Folbigg during what she claimed was a normal check on their wellbeing during the course of their sleep period including on three occasions when she said she was on her way to the toilet.

10 Each child was discovered dead or moribund at around or shortly after death when they were still warm to touch and two of them still had a heartbeat so they were found literally minutes after the cessation of breathing. In relation to four of the five events, Ms Folbigg failed to render any assistance at all to the children after discovering them dead or moribund to the extent that she did not even lift them up out of their beds.

15 It was the Crown case that these features were incapable of being explained except by the common feature of Ms Folbigg because she was responsible for all the events. The Crown case relied in this regard on evidence from doctors that there had never been recorded a family such as this where four children died of natural causes either from the same natural cause or from different
20 natural causes and there had never been three or more deaths in one family recorded from SIDS. The Crown also relied on tendency evidence. The tendency particularised by the Crown was that Ms Folbigg had a tendency to become stressed and lose her temper and control with each of her four children and then to asphyxiate them.

25 On 29 November 2002 Wood J had ruled evidence on each count in the Crown case admissible as coincidence evidence in relation to the other counts and dismissed Ms Folbigg's application for separate trials on that basis. Ms Folbigg applied for leave to appeal against that decision. On 13 February
30 the Court dismissed the application for leave. Hodgson J considered that he would find a deficiency of proof of guilt in relation to each count without the evidence concerning the other children but that the additional evidence concerning the others would leave no rational view consistent with innocence. His Honour cited the same reasons as Wood J for this view, that is, the
35 extreme improbability of four such deaths and one ALTE occurring to children in the immediate care of their mother without the mother having contributed and asphyxiation being a substantial possibility. His Honour noted these matters were significant, particularly in light of the diary entries.

40 Ms Folbigg filed an unsuccessful application in the High Court for a stay of the trial pending hearing of an application for special leave to appeal against the decision of the Court of Criminal Appeal. The trial commenced before Barr J and a jury of 12 on 1 April 2003. The transcript of proceedings during both the
45 pre-trial and trial stages reflects efforts at cooperation between the Crown and the defence to attempt to narrow the issues in dispute which required rulings from the trial judge. A number of evidentiary and procedural matters were dealt with during the course of the trial in the absence of the jury. In particular, and of most relevance, the parties sought a series of rulings about the evidence of individual medical expert witnesses concerning the admissibility of
50 opinions expressed about the cause of death and ALTE in the individual

cases, including opinions based on the facts and circumstances of the death and ALTE of the other children.

5 The effect of the rulings was that the experts could give evidence about the possible or probable cause of death of each child and of the ALTE based on circumstances directly relevant to the event in question, that is, the medical history of the child; the circumstances in which the child was found; the results of the post-mortem examination; and the results of subsequent tests, but could not give evidence about the possible or probable cause of death based on
10 additionally the fact that each of the other children had died unexpectedly or that one had unexpectedly suffered an ALTE. The rulings also determined that medical experts with relevant practical and research experience could give evidence of their knowledge of there not having been any case of three or more deaths attributed to SIDS within the same family reported in the literature
15 or encountered in the course of their own experience.

In one ruling concerning one expert's proposed evidence, his Honour observed that a statement that an unexplained death is more likely to be called a SIDS death if there is no prior unexplained death in the family but is less likely to be properly called a SIDS death if there is such a prior unexplained death as not
20 being a statement of medical opinion. Although his Honour disallowed the Crown from adducing that evidence from the expert, his Honour noted "It may nevertheless be a statement of common sense and it may be right." In summing up to the jury, the trial judge noted the general medical opinion,
25 about which there seemed no dispute, was that, except where there are obvious physical signs of deliberate or accidental suffocation, "it is virtually impossible to distinguish between a death resulting from asphyxiation and a death resulting from natural but unidentified causes."

30 On 21 May 2003 Ms Folbigg was found guilty of three counts of murder in respect of Patrick, Sarah and Laura, one count of manslaughter in respect of Caleb, and one count of maliciously inflicting grievous bodily harm in respect of Patrick. After the trial Ms Folbigg appealed against the convictions and sentence to the Court of Criminal Appeal. Ms Folbigg's initial sentence was
35 reduced on appeal to an effective sentence of 30 years' imprisonment with a non-parole period of 25 years. Ms Folbigg will be eligible for parole on 21 April 2028 and the balance will expire on 21 April 2033.

40 The grounds of the conviction appeal were, the first ground, the trial miscarried as a result of the five charges being heard jointly; therefore, this involved consideration of the admissibility of coincidence evidence. The second ground was that the verdicts of guilty were unreasonable and could not be supported having regard to the evidence. The third ground was that the trial miscarried as a result of evidence being led from prosecution experts, to the effect that
45 they were unaware of any previous case in medical history where three or more infants in one family died suddenly as a result of a disease process; and finally, the fourth ground, the trial judge erred in his directions as to the use the jury could make of the coincidence and tendency evidence.

50 The Court of Criminal Appeal rejected each ground of Ms Folbigg's appeal.

Ms Folbigg then filed an application for special leave in the High Court. That application was heard and refused on 2 September 2003. Ms Folbigg raised two grounds: whether the tendency and coincidence reasoning was permissible, and whether it was available to the prosecutor to lead evidence that three or more infant deaths in the one family from natural causes is without precedent. That latter ground was on the basis that such evidence reverses the onus of proof. As I said, that application was heard and refused.

On 27 November 2007 the Court of Criminal Appeal heard a further appeal against conviction. The grounds of that appeal were that the trial miscarried because a juror or jurors obtained information from the internet which revealed that Ms Folbigg's father had killed her mother and secondly, a juror or jurors informed themselves away from the trial as to the length of time an infant's body is likely to remain warm to the touch after death. The appeal was dismissed. McClellan J was satisfied that the irregularities were not material and did not give rise to a miscarriage of justice. His Honour observed:

"I have reviewed the whole of the evidence. I am satisfied this was an overwhelming Crown case. I am entirely satisfied that notwithstanding the irregularities, no substantial miscarriage of justice has occurred."

Turning now to the forensic pathology and SIDS evidence at the trial, over 20 medical practitioners and experts gave evidence at the trial or produced reports concerning the matters the subject of the trial. Those witnesses of particular relevance to this inquiry were: Dr Allan Cala, a senior staff specialist, forensic pathologist, at Newcastle Department of Forensic Medicine, who conducted the autopsy on Laura in March 1999. In 2003 he was a forensic pathologist at the NSW Institute of Forensic Medicine. Professor John Hilton is a retired consultant in forensic medicine. He conducted Sarah's autopsy in August 1993. Professor Hilton was director of the NSW Institute of Forensic Medicine at Glebe from 1991 until 2001.

Experts who had not been clinically involved with the Folbigg children also gave evidence. Professor Roger Byard was a specialist forensic pathologist at the Forensic Science Centre, Adelaide and clinical professor of pathology and paediatrics at the University of Adelaide. Professor Berry was a consultant paediatric pathologist at the Bristol Royal Hospital for Sick Children since 1983 and was professor of paediatric pathology at the University of Bristol. Professor Herdson was a consultant forensic pathologist with around 40 years' experience in pathology. He was emeritus professor of pathology at the University of Auckland in New Zealand, honorary professor of pathology at the University of Sydney and formerly director of pathology at Canberra Hospital.

Dr Susan Beal was a paediatrician at the Children's Hospital in Adelaide with 35 years' experience. She had a particular expertise in epidemiology and SIDS research. A key issue at the trial was whether the cause of death of each of the children should be attributed to SIDS, sudden infant death syndrome, or should be classified as undetermined. At the time of the trial SIDS was defined as:

5 "the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history."

10 While slightly differing definitions were given by experts, the trial judge referred to death from SIDS being from some unknown natural cause whereas death from undetermined causes implies a death from some unknown natural or unnatural cause.

15 It was generally accepted by the witnesses that SIDS usually occurs during sleep and 90% of deaths occur in the first six months, peaking at two to four months. There was evidence as to the environmental risk factors thought to give rise to a SIDS death. The main risk factors were: prematurity; low birth weight; exposure to maternal smoke; sleeping on one's stomach; shared sleeping platforms; being overbundled or overheated; soft bedding; covered faces; the age of the mother; socioeconomic circumstances; and evidence of neglect. It was accepted by those who gave evidence as to the environmental factors that none of the children possessed the most common risk factors.

20 Turning now to the deaths of each of the children, Caleb died on 20 February 1989 when he was 19 days old. The autopsy report and death certificate gave the direct cause of death as SIDS. He had a diagnosis of floppy larynx at the time of his death meaning that the cartilage in the larynx was soft and could collapse on inspiration. The experts gave evidence that it was most unlikely that Caleb had died from a floppy larynx. Most witnesses gave evidence that his death was consistent with deliberate suffocation while acknowledging that the findings were the same as or indistinguishable from SIDS, a matter that was referred to earlier.

25 Dr Beal opined that she would have diagnosed his death as SIDS with the proviso that he was under three weeks of age and found on his back. Professors Herdson and Byard would have said the cause of death was undetermined, while not excluding SIDS. For Professor Byard that was based on Caleb having had a floppy larynx and there being no death scene investigation and that his brain was not examined. Professor Berry gave evidence that the presence of haemosiderin, which is iron present in the lungs and signifies the presence of bleeding from the lungs, usually 24 to 48 hours before death, was very unusual in infant deaths, and therefore he would call the death unascertained.

30 Professor Byard referred to literature that said that that iron stain was found in 20% of SIDS babies. In relation to the question from the Crown whether Caleb had died from a catastrophic asphyxiating event, Professor Berry said we all do, because we all stop breathing. Patrick had an acute life-threatening event on 18 October 1990, when he was four months old and 15 days. It resulted in him having epileptic seizures and he became blind. The evidence was that the event was unlikely to have been a result of an epileptic seizure. It was described by one expert as some catastrophic event that caused the lack of

oxygen to the child's brain, and another as being most likely caused by an asphyxiating event of unknown causes.

5 Patrick died on 13 February 1991 at the age of eight months and ten days. His death certificate recorded the cause of death as asphyxia due to airway obstruction, one hour, and epileptic fits, four months. The autopsy report recorded a diagnosis of encephalopathic disorder leading to intractable seizures, the underlying cause of which was not determined, and cardiac arrest at home. Encephalitis is an inflammation of the brain. There was 10 evidence at the trial about the role encephalitis played in his death, however by the time of the trial the key experts discounted that as a reason.

15 Most experts would have said his death was from undetermined causes because of the history of the ALTE and the fact that epilepsy or a seizure could not be excluded as a cause. No witness in evidence before the jury suggested that his cause of death should be attributed to SIDS. Again there was evidence as to his death being consistent with suffocation and being a catastrophic asphyxiating event. Sarah died on 30 August 1993 aged ten 20 months and 16 days. The autopsy report completed by Professor Hilton and the death certificate gave the direct cause of death as SIDS.

25 On autopsy two tiny punctate abrasions were present near the lips. No photos were taken. Sarah was also found to have a reddened uvula. Professors Byard and Berry gave evidence that they would have classified her death as SIDS, however there were some misgivings voiced because she was older than usual for that diagnosis and there was some evidence of a narrowing of the upper airway. Dr Cala and Dr Beal would have found her death to be undetermined because of her age, and additionally for Dr Cala because of the abrasions. 30

35 Laura was 18 months and 22 days old when she died on 1 March 1999. The autopsy report completed by Dr Cala gave the cause of death as undetermined. Dr Cala said that she had myocarditis, an inflammation of the muscular walls of the heart, however this represented an incidental finding. He opined that Laura was too old for SIDS. Professor Herdson had a similar view about the myocarditis, believing it to be incidental, while Professor Byard could not exclude myocarditis and gave the cause of death as undetermined. Others gave evidence that myocarditis could have led to or been the cause of her death, and others were less certain. 40

45 Again, there was evidence as to the consistency with suffocation and a catastrophic asphyxiating event. A number of experts had prepared reports or statements in which they gave their opinion, considering the deaths of all four children and Patrick's ALTE together. None of those who were asked at trial said they had come across a family where there had been three or more children who had died from natural causes. The doubt or question that gave rise to this Inquiry was in relation to that evidence as to the incidence of reported deaths of three or more infants in the same family attributed to unidentified natural causes. 50

5 That evidence gave rise to the submission to the jury by the Crown Prosecutor that, and I quote, "It has never been recorded that the same person has been hit by lightning four times," and again I quote, "I can't disprove that one day some piglets might be born with wings and that they might fly. Is that a reasonable doubt?" The trial judge dealt with those submissions by directing the jury, "SIDS deaths are rare in the community. There is no authenticated record of three or more such deaths in a single family. This does not mean, of course, that such events are impossible. It is an illustration of the rarity of deaths diagnosed as SIDS."

10 It is clear from the work of this Inquiry that before 2003 there had been reported cases involving the deaths of three or four infants in the same family attributed to unidentified natural causes, or at least not established as attributable to unnatural causes. There is also evidence which has been
15 tendered as to the current state of knowledge concerning this issue. In 2018, as I referred to earlier, the publication which Professor Byard edited with Dr Duncan was published. The editors made the following observation:

20 "The association of SIDS deaths among siblings is still debated. There have been reports of an increase in the incidence of SIDS of between two and ten times in infants who have had a sibling or twin death, including an increase in risk based on the presence of SIDS in second and third degree relatives. However, some of these
25 outcomes have been explained once environmental and maternal factors have been controlled for and these families may only represent a small subgroup of individuals with increased vulnerability."

30 There have also been reports of simultaneous sudden death in siblings, supporting a genetic basis, although the importance of environmental factors should be taken into account in consideration under these circumstances. In addition, a report by Diamond et al indicated five consecutive sibling deaths in the same family. That was a 1986
35 publication.

However, the authors feel - that is, Professor Byard and Dr Duncan - that:

40 "multiple deaths within the same family should raise concerns about other possible inherited conditions such as prolonged QT interval or metabolic disorders, homicide, or potentially misclassified deaths of unknown cause. Thus, while multiple SIDS deaths in the one family may represent a genetic component in the aetiology of SIDS, for
45 92% of families the risk of recurrence is considered small."

Turning then to the diary entries, entries in various diaries recorded by Ms Folbigg between 1989 and 1998 were one of the three categories of circumstantial evidence in the Crown case. The diaries had been
50 obtained by police during the course of their investigations. The diaries obtained by police did not span the entire period between Caleb's birth

day in February 1989 and Laura's death in March 1999. The diaries which were relied on in the trial covered February to March 1989, 1990, and June 1996 to April 1998.

5 Bearing in mind that Caleb was born and died in February 1989, Patrick's
ALTE was in October 1990, and he died in February 91, Sarah died in
August 1993 and Laura was born on 7 August 97 and died on 1 March
99, the following are some of the diary entries referred to by various
judges during the separate trials application and the appeals. I quote
10 from each diary entry:

"3 June 1990. This was the day that Patrick Allan David Folbigg
was born. I had mixed feelings this day, whether or not I was going
to cope as a mother or whether I was going to get stressed out like I
15 did last time. I often regret Caleb and Patrick, only because your life
changes so much, and maybe I'm not a person that likes change,
but we will see.

16 May 1997. Craig says he will stress and worry, but he still
20 seems to sleep okay every night, and did with Sarah. I really
needed him to wake that morning and take over from me. This time
I've already decided if I ever feel that way again I'm going to wake
him up.

25 25 October 1997. I cherish Laura more. I miss her, Sarah, yes, but
am not sad that Laura is here and she isn't. Is that a bad way to
think? Don't know. I think I am more patient with Laura. I take the
time to figure what is wrong now instead of just snapping my cog.
30 Wouldn't have handled another like Sarah. She saved her life by
being different.

3 November 1997. Lost it with her earlier. Left her crying in our
bedroom. Had to walk out, that feeling was happening, and I think it
was because I had to clear my head and prioritise, as I have done in
35 here now. I love her, I really do, I don't want anything to happen.

9 November 1997. He" - that is, Craig - "has a morbid fear about
Laura. Well, I know there's nothing wrong with her, nothing out of
the ordinary anyway, because it was me, not them. With Sarah all I
40 wanted was her to shut up, and one day she did.

31 December 1997. Laura's a fairly good-natured baby, thank
goodness. It has saved her from the fate of her siblings. I think she
was warned.

45 28 January 1998. I've done it. I've lost it with her. I yelled at her so
angrily that it scared her and she hasn't stopped crying. Got so bad
I nearly purposely dropped her on the floor and left her. I restrained
enough to put her on the floor and walk away. I feel like the worst
50 mother on this earth, scared that she'll leave me now like Sarah did.

5 I know I was short-tempered and cruel sometimes to her, and she left, with a bit of help. I don't want that to ever happen again. I actually seem to have a bond with Laura. It can't happen again. I'm ashamed of myself. I can't tell Craig about it because he'll worry about leaving her with me. Only seems to happen if I'm tired of her moaning, bored, whingey sound. Drives me up the wall."

10 As Sully J acknowledged when setting out these and other entries in his reasons for judgment on appeal, and I quote: "There was a deal of this material and it cannot be fairly compressed into a brief paraphrase." We note that Sully J went on to observe that the diary entries made, and I quote:

15 "Chilling reading, and had damning probative value, giving terrible credibility and persuasion to the inference suggested by the overwhelming weight of the medical evidence that the five incidents had been anything but extraordinary coincidences unrelated to acts done by the appellant."

20 During the course of the special leave hearing in the High Court McHugh J observed, "The diary entries lend very cogent weight to what inferences can be drawn from the unexplained deaths," and queried why, when the coincidence evidence is read in the light of those diary entries, was it not open to a Court to think that the evidence was of significant
25 probative value?

30 There was also genetics-related evidence available at the trial. Professor Bridget Wilcken, a clinical geneticist at the time of the trial, conducted particular genetic testing in respect of the four children, and gave evidence at the trial in her capacity as the director of New South Wales Newborn Screening Program and the New South Wales Biochemical Genetics Service. She said the results from this testing, which concerned inheritable metabolic disorders, in respect of each child, were entirely normal.

35 Dr Jones was a consultant paediatric cardiologist engaged by the defence to opine in relation to Laura's death. He said there was no credible evidence for an inherited disorder of cardiac rhythm such as long QT syndrome in the Folbigg family. There was no evidence at the trial for an intrinsic, congenital or
40 acquired cardiac abnormality causing or contributing to the deaths of Caleb, Patrick and Sarah.

45 The Inquiry has considered advances in genomics and genetic testing. The inquiry obtained a report from Dr Alison Colley, a clinical geneticist at the Newcastle and Northern New South Wales Genetics Service, to whom Mr and Mrs Folbigg were referred in 1991. Dr Colley is now the director of South West Sydney Local Health District Clinical Genetic Services. Dr Colley identified there had been significant changes in genetic testing since the time of the trial. She explained that the changes particularly in the development of technology
50 which enables sequencing of the whole genome and the whole exome of a

person, have enabled hypothesis-free study of DNA. Now a known or presumed diagnosis as a starting point is not needed, rather the DNA sequences are studied and variants interrogated against the known human genome and the clinical features of a patient.

5

Genomic sequencing technology has emerged in 2009, since 2013 two major genomics sequencing technologies have become mainstream. Whole exome sequencing, WES, sequences the whole exome which is that small part of the genome, about one to two per cent of the whole, that is involved in coding for proteins. Proteins are the key components of cells and damage to them causes serious if not catastrophic problems. This part of the genome is the location of the majority of mutations that cause developmental or cognitive disabilities and disorders. Whole genome sequencing, WGS, sequences all of the genome that is accessible. In addition to the exome, this comprises non-coding elements in the genome and mitochondrial DNA.

10

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Since the introduction of genomic sequencing, the pace at which the genes underlying genetic disorders are discovered per year has increased. The proportion of discoveries made by the genomic approaches as compared with conventional approaches has steadily increased. Together WES and WGS have discovered nearly three times as many genes as conventional sequencing approaches that were available in the 1990s.

20

In light of the significant advances relevant to the scope for the Inquiry, further investigations into genetic testing of the four deceased children, and Kathleen Folbigg, have been pursued by the Inquiry. For this purpose the Inquiry has engaged genetic pathologist, Dr Michael Buckley. Dr Buckley is the clinical director of the New South Wales Health South Eastern Area Laboratory Services and current president of the Human Genetics Society of Australasia. In addition to engaging Dr Buckley, the Inquiry has also engaged a multi-disciplinary panel of experts to interpret any sequencing data produced by the testing and provide additional comment on the testing process.

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Ms Folbigg, through her legal representatives, has been afforded the opportunity for experts engaged on her behalf to be involved in that interpretational process.

35

Material produced to the Inquiry by the New South Wales Department of Health in compliance with summonses issued by your Honour, included samples of material containing DNA from each of the four children. These samples were taken either at birth as part of the newborn screening program or following death as part of the autopsy procedures. In December 2018 the Inquiry was informed that Ms Folbigg had provided to her legal representatives, a swab sample for the purposes of genetic testing. Ms Folbigg consented to that sample being made available to the Inquiry for genetic testing. Samples from each of the children and Ms Folbigg were submitted to laboratories for genetic sequencing in January this year. Sequencing data was delivered to the Inquiry in February and is being analysed by the multi-disciplinary expert interpretation panel. I will open further on these matters when evidence relating to genetics is given in April.

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5 This week, Dr Cala and Professor Hilton will be giving evidence. As indicated earlier, Dr Cala performed the autopsy on Laura, observed by Professor Hilton and Professor Hilton performed the autopsy on Sarah. Each gave evidence at the trial. Professor Stephen Cordner, who authored the forensic pathology report which accompanied Ms Folbigg's petition for this Inquiry, will give evidence. He is professor of forensic medicine at Monash University and has been the Director of Victorian Institute of Forensic Medicine since 1987.

10 Professor Johan Duflou is a consultant forensic pathologist in private practice, part-time specialist forensic pathologist at the Forensic Medicine Centre in Canberra and he holds various other positions. He is giving evidence at the request of Ms Folbigg's legal team. Professor Dawn Elder is Deputy Dean, consultant paediatrician and head of the Department of Paediatrics at the
15 University of Otago in Wellington. Professor Rosemary Horne is a senior research fellow at the Richie Centre at the Monash Institute of Medical Research at Monash University, her PhD is from that university and it is on arousal responses from sleep as an underlying mechanism for SIDS.

20 Each of these professors has been engaged by the Inquiry and Professor Elder will be giving evidence via audio visual link from New Zealand. Each will give evidence about the developments in SIDS and SUDI, environmental risks and protective factors. They will be giving evidence today. It is expected that there will be further witnesses towards the end of the week but they have not
25 been finalised as yet your Honour.

There is general agreement between the experts that the current definition of SIDS has changed little although there's been various subcategories added and other matters that the professors will speak to this morning. There is a
30 better understanding of protective factors as well as more certainty as to the importance of particular risk factors, mainly maternal smoking and sleeping arrangements.

35 In his 2015, I assume, they've given us undated statements, Professor Cordner has concluded that there is nothing from a forensic pathology viewpoint to suggest that any of the children had been killed, let alone smothered. He opined that there are identifiable natural causes of death for two of the children, Patrick and Laura. And natural causes are a plausible explanation for the other two deaths, Caleb and Sarah. And the acute or
40 apparent life threatening event concerning Patrick. Professor Duflou is expected to generally agree with the conclusions reached by Professor Cordner. At a general level Professor Hilton has expressed that he is in substantial agreement with the comments, views and opinions of Professor Cordner, however in essence and given the trial process limitations, his views
45 expressed in his evidence at the trial remain the same. It is expected that Dr Cala's evidence will be the same as his evidence at trial.

50 At the trial an issue which remained in some dispute was whether Laura died from myocarditis or that her death was best classified as undetermined because of the presence of myocarditis and that she was the fourth child to

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5 have died. In their statements to this Inquiry, Professor Cordner and Professor Duflou have referred to Dr Cala's finding as undetermined for Laura's death and stated that this finding is acceptable and not unreasonable. Professor Hilton is expected to express the opinion that Laura died with and highly probably because of florid myocarditis. His evidence at the trial was that myocarditis could possibly have led to her death. It is expected that this issue will be of some evidence this week. Your Honour, that is the opening.

10 JUDICIAL OFFICER: Thank you. Ms Furness, we'll adjourn at this stage.

FURNESS: Your Honour, just before you adjourn, it might be worth mentioning that, as I understand it, Ms Folbigg is able to hear and see us, and is listening.

15 JUDICIAL OFFICER: Yes, I have checked that previously, and I am assured that that is correct.

SHORT ADJOURNMENT

20 JUDICIAL OFFICER: Yes, Ms Furness.

FURNESS SC: Thank you, your Honour. I call Professor Dawn Elder and Professor Rosemary Horne. Professor Horne is with us and Professor Elder is in New Zealand.

25 AUDIO VISUAL LINK TO NEW ZEALAND COMMENCED AT 11.41AM

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<ROSEMARY HORNE AND DAWN ELDER, SWORN(11.42AM)

HONOURABLE BLANCH QC: You can hear us okay?

5 WITNESS ELDER: I, I can. I didn't hear quite all at the beginning, but I can hear you now.

HONOURABLE BLANCH QC: Okay, thank you. Yes, Ms Furness.

10 FURNESS SC: Thank you, your Honour. Can I start with you, Professor Horne? What's your current position?

15 WITNESS HORNE: I am a senior principal research fellow in the Department of Paediatrics at Monash University and the Hudson Institute of Medical Research.

FURNESS SC: Your PhD was in what area?

20 WITNESS HORNE: So my PhD was in understanding the mechanisms involved in SIDS. I will acknowledge in a lamb model, in a sheep model, but we were looking at arousal responses.

FURNESS SC: And you were awarded a Doctorate of Science recently?

25 WITNESS HORNE: Yes, yes, so for my work both in SIDS research and also in sleep disorders in children.

30 FURNESS SC: More recently last year you were awarded a Distinguished Researcher Award by the International Society for the Study and Prevention of Infant Death?

WITNESS HORNE: Yes, I was.

35 FURNESS SC: What did you receive that for?

WITNESS HORNE: For, for my research into understanding the mechanisms involved in SIDS.

40 FURNESS SC: You have also been involved with the National Scientific Advisory Group of the Red Nose organisation?

WITNESS HORNE: Yes, I have.

45 FURNESS SC: I think as chair, is that right?

WITNESS HORNE: Yes, I was chair for four years.

FURNESS SC: Red Nose, is it still called Red Nose?

50 WITNESS HORNE: Yes.

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FURNESS SC: And that's concerned with SIDS and the like?

5 WITNESS HORNE: Yes, so it was previously SIDS and Kids.

FURNESS SC: Thank you. You are a member of the Australasian Sleep Association Research Committee?

10 WITNESS HORNE: Yes.

FURNESS SC: And on editorial boards of the Journal of Sleep Research, Sleep Medicine, and Sleep?

15 WITNESS HORNE: Yes.

FURNESS SC: And you are a reviewer for multiple paediatric and medical journals?

20 WITNESS HORNE: Yes.

FURNESS SC: You have provided a statement for the Inquiry. Do you have a copy of that with you?

25 WITNESS HORNE: Yes, I do.

FURNESS SC: I think that's dated 10 February. That's right?

WITNESS HORNE: Yes.

30 FURNESS SC: And the contents of that are true and correct, Professor?

WITNESS HORNE: Yes, they are.

FURNESS SC: I tender that, your Honour.

35 EXHIBIT #J STATEMENT OF ROSEMARY HORNE DATED 10/02/19
TENDERED, ADMITTED WITHOUT OBJECTION

40 FURNESS SC: Can I turn to you, Professor Elder? Would you tell the Inquiry your full name, address, and occupation?

45 WITNESS ELDER: I'm Dawn Elizabeth Elder. I reside in Wellington, New Zealand, and I'm currently Professor of Paediatrics and the head of the Department of Paediatrics and Child Health in the University of Otago, Wellington.

FURNESS SC: And you have a Doctor of Philosophy I understand?

50 WITNESS ELDER: I do.

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FURNESS SC: What area did you study for that award?

WITNESS ELDER: My research was in the area of respiratory variability in infants and children.

5

FURNESS SC: And you're trained I think in both neonatal medicine as well as paediatric sleep medicine?

WITNESS ELDER: That's right, I initially worked as a neonatologist for a number of years and then changed to becoming a paediatric sleep physician, my research has always been focused more on baby breathing, but I now see patients of all ages with regards to sleep problems.

10

FURNESS SC: And you have an active research interest in the study of sudden unexpected death in infancy, that's correct?

15

WITNESS ELDER: I do, I have, did some early work when I was training in this area and in more recent years, I've been a co-investigator in the New Zealand case control SIDS study.

20

FURNESS SC: Can you explain what the national case control study is?

WITNESS ELDER: Yes well some years ago there was an original, it was called the New Zealand Cot Death Study, there was a decision made a few years ago to repeat that study because of the new demographics of sudden infant death and so that data collection has finished now and the first papers from the second study have come out starting from last year, so this was looking at babies who died suddenly and unexpectedly and matching with controls to look at the risk factors again.

30

FURNESS SC: Professor Elder you've also provided a statement to us dated 15 February 2019?

WITNESS ELDER: That's correct.

35

FURNESS SC: Are the contents of that true and correct?

WITNESS ELDER: They are.

EXHIBIT #K STATEMENT OF PROFESSOR ELDER DATED 15/01/19 TENDERED, ADMITTED WITHOUT OBJECTION

40

FURNESS SC: Can I come back to you Professor Horne and can I ask you to provide the Inquiry with a potted history of the development of research into sudden infant death syndrome?

45

WITNESS HORNE: Yes. So sudden infant death syndrome or SIDS, is also called cot death and this is the name generally in the United Kingdom or crib death as it's called in the United States. So we've heard the definition earlier, it has the original definition did not include occurring during sleep and in 2004

50

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5 this was changed to occurring during sleep, but it's the death of an infant less than one year of age, where no cause can be found, so it's a diagnosis of exclusion. There have since been changes to try and further subdivide the deaths of infants and this has mainly been for a research - for research because a lot of deaths, depending on the coroner or the person deciding on the cause of death, called unascertained and this makes it quite difficult to decide for research purposes if this really is a SIDS death or not. These days it's generally called sudden unexpected death in infancy or SUDI and this encompasses both SIDS and sleeping accidents that have been diagnosed.

10 FURNESS SC: Just going back to pre-2003, there was a lot of work done in relation to the back to sleep campaign?

15 WITNESS HORNE: Yes.

FURNESS SC: Can you tell us about that?

20 WITNESS HORNE: Yes. So, in the early 80s, it was found in both large studies in Tasmania, in the United Kingdom and in New Zealand, that a disproportionate number of babies were found to have died when they were sleeping on their stomachs, so in the prone position, and so recommendations were made to not sleep the babies prone. Initially it was to put babies on their side, so my eldest daughter was born in 1986 and she slept on her side, it was later found that the side position was unstable and that many babies were rolling from the side on to their tummies and so by 1989 babies were recommended to sleep on their backs and this has been consistently shown to reduce the risk of SIDS and death and the back to sleep campaign has been attributed to saving in Australia, nearly 10,000 baby lives and reducing the incidence by over 85%, simply by not sleeping babies on their tummies.

25 FURNESS SC: I'm not sure we have Professor Elder with us.

30 HONOURABLE BLANCH QC: Professor Elder, can you hear us? I think we must have lost the link.

35 FURNESS SC: Perhaps we'll continue hoping she rejoins us. Can I have up on the screen the definitions of SIDS and perhaps if that could be expanded somewhat.

40 Do you see there that's the 1991 definition?

WITNESS HORNE: Yes.

45 FURNESS SC: That's the definition which was in place effectively in 2003?

WITNESS HORNE: Yes.

FURNESS SC: And then there's the 2004 definition?

50 WITNESS HORNE: Yes.

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FURNESS SC: And as you said, one of the major differences between the two was the reference to occurring during sleep?

5 WITNESS HORNE: Yes.

FURNESS SC: And also the addition of various subcategories?

10 WITNESS HORNE: Yes.

FURNESS SC: Can I just take you through some of those subcategories. The first one is 1(a), classic features with complete investigation, is that what you would call now as the current SIDS definition?

15 WITNESS HORNE: Yes, so this is the death of a baby that's older than 21 days and under nine months, a term baby, normally growing and developing and there have been no other deaths in the family, so the SIDS definition requires a history of the baby and also a death scene investigation so to rule out any of the major risk factors for SIDS, such as being slept prone or being exposed to maternal smoking and it also requires an autopsy which rules out any known cause of death.

FURNESS SC: Why is the older than 21 days prescribed in that definition?

25 WITNESS HORNE: It's because a lot of post - just immediately post neonatal deaths occur and these are generally within the first months of life, so it was to exclude those deaths which occurred in a very young infant which could have been attributed to by things that happened in utero and following birth.

30 FURNESS SC: Why is it limited to nine months?

35 WITNESS HORNE: The definition is under 12 months but as you stated in your overview, 90% of babies die in the first six months of life and there's this unique peak in incidence between two and four months of age and so in this definition the majority of babies would be dying under nine months of age.

FURNESS SC: So that reflects what was currently known at the time?

40 WITNESS HORNE: Yes.

FURNESS SC: There's reference to no similar deaths in siblings, what's the relevance of that to that definition?

45 WITNESS HORNE: So although as we've said, the incidence of SIDS is very low, and the risk of recurrent SIDS is also thought to be very low but you can't discount that there will be similar genetics if there was an underlying genetic abnormality or similar environmental factors in the same family, so the 1(a) definition which is the classic case rules out any deaths within the same family.

50 FURNESS SC: For primarily genetic and environmental reasons?

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WITNESS HORNE: Yes, because I think - because they can co-occur, I mean you'd have the same genetics in the same family and sometimes the - usually the same environmental factors as well.

5

FURNESS SC: If you had the same environmental factors, could they still not be SIDS deaths if they met the other criteria of set out in 1(a)?

10 WITNESS HORNE: Not in this definition which excludes having a sibling or close relative die.

FURNESS SC: If you go down to the circumstances it refers to not providing an explanation for death found in a safe sleeping environment?

15 WITNESS HORNE: Yes.

FURNESS SC: So that if it isn't a safe sleeping environment, you know the child is prone or covered in some way, that takes it out of the definition of SIDS?

20

WITNESS HORNE: Then it would usually be defined as accidental suffocation or unascertained.

25 FURNESS SC: Turning over to category 1(b) SIDS, that's the classic features with an incomplete investigation?

WITNESS HORNE: Yes.

30 FURNESS SC: Why to your knowledge is there a category to that effect?

WITNESS HORNE: Because we know that having a complete death scene investigation and a complete autopsy including all of the toxicology, microbiology, radiology, vitreous chemistry and metabolic screening is quite commonly not performed.

35

FURNESS SC: Would a death that fits ordinarily category 1(b) SIDS, also be able to be described as undetermined given that in fact various one or other of those matters weren't satisfied?

40 WITNESS HORNE: Yes, so undetermined or unascertained.

FURNESS SC: What do those two terms mean in the context of SIDS Professor?

45 WITNESS HORNE: I'm not a pathologist so I do not make these diagnoses, but as SIDS is a diagnosis of exclusion it has to exclude all of the possible causes whether they are environmental so there's an unsafe sleeping situation or whether there could be some intrinsic factor.

50 FURNESS SC: Can I turn to the other definitions, if we go further down that

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page, there's reference to SUDI?

WITNESS HORNE: Yes.

5 FURNESS SC: I might just mention that these definitions are taken from Professor Byard's 2018 book and so there's various commentaries from him and Dr Duncan?

WITNESS HORNE: Yes.

10

FURNESS SC: Tell us about SUDI?

15 WITNESS HORNE: So SUDI is now the term most commonly used and it is - it can describe the death of an infant that was due to an unsafe sleeping environment, so for instance if the face was covered with bedding. It sort of covers these so called diagnostic shifts where people have been reluctant, pathologists have been reluctant to diagnose SIDS and there have been lots of diagnoses of unascertained, so it includes these sleeping accidents.

20 FURNESS SC: So given your background as a researcher, is it the case that these subcategories provide particular assistance for you in being able to more closely categorise deaths?

25 WITNESS HORNE: Yes, so even if we went right back to the definition in the 1990s there would quite often be cases that should have been probably diagnosed as unascertained and this has made trying to investigate how the risk factors that lead to SIDS quite difficult if babies - some babies in the same situation are called SIDS and others are called unascertained, so it's tried to broaden the definition so that research can look at the risk factors.

30

FURNESS SC: You're back with us Professor Elder.

WITNESS ELDER: Yes, sorry about that.

35 FURNESS SC: I'm sure it's not your fault. Can I bring you into the discussion about the current definition and subcategories of SIDS. I'm not sure what you're able to see. Can you see anything on the screen here?

40 WITNESS ELDER: I do have the summary that Professor Horne wrote and sent to me yesterday.

FURNESS SC: Right.

45 WITNESS ELDER: So I have that available and I can see the screen.

FURNESS SC: Thank you. What's your understanding of the purpose of the subcategories in the current definition?

50 WITNESS ELDER: I think it's just to account for the fact particularly that you don't always have all the information you would like to make a firm diagnosis.

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FURNESS SC: So do you use them in the work that you do?

5 WITNESS ELDER: There has been a process in the research work. In the clinical work that I do it's really - the final diagnosis really rests with the pathologist.

FURNESS SC: So do you use it in any research work that you do?

10 WITNESS ELDER: We would think about it in that way definitely.

FURNESS SC: While you were offline, I was asking Professor Horne about the reference in category 1(a) SIDS to no similar deaths in siblings. Can I ask you the same question: how does that factor in to that definition?

15 WITNESS ELDER: I think if you have more than one death in a family you have to consider either whether the risk factors and the circumstances are the same or whether there is some other influence and particularly you've got to think about undiagnosed congenital disorders or inborn errors of metabolism that might present in this way.

20 FURNESS SC: If you were satisfied that one or more of those things did present, you wouldn't classify it as a SIDS death. Is that right?

25 WITNESS ELDER: That's correct.

FURNESS SC: In terms of environmental factors, how do they play on your thinking as to whether a death fits within category 1(a) when there is a similar sibling death?

30 WITNESS ELDER: Well, I have seen a circumstance where babies have been in the same risk situation and a second baby has died in the context of a mother being a smoker, baby being found in an unsafe sleeping situation. Sometimes those situations can occur again. Mostly parents will do all they can to ensure that the same situation doesn't happen again.

35 FURNESS SC: Thank you. Can I just have on the screen the triple risk model? Can you see that, Professor Elder?

40 WITNESS ELDER: Yes, I can.

FURNESS SC: Coming back to you, Professor Horne, this model was developed in about 1994-ish. Is that right?

45 WITNESS HORNE: Yes.

FURNESS SC: And it's still relevant today?

50 WITNESS HORNE: Yes.

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FURNESS SC: Perhaps you could take us through that model. There's three intersecting circles with SIDS in the middle.

WITNESS HORNE: Yes.

5

FURNESS SC: How does that work?

WITNESS HORNE: It's believed that SIDS is multifactorial and so an infant will only die if there's concurrent three factors. You have a vulnerable infant so this may be one who has been born preterm so preterm babies have about four times the risk of dying from SIDS as a baby born at term or if the baby has been exposed to maternal smoking which is another large risk factor for SIDS. So you have a vulnerable infant who's then exposed to an exogenous stressor. This may be being placed prone to sleep or sleeping in bed with a parent. Now about half of the babies are found in a co-sleeping situation or have their face covered or buried in soft bedding.

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Then you have this critical developmental period. In the first year of life cardiorespiratory control is developing very rapidly and it's quite unstable and also sleep is developing very rapidly and so particularly at two to four months of age when the risk of SIDS is greatest this is an extremely vulnerable period. It's then thought that the baby has some cardiorespiratory abnormality or a prolonged pause in breathing or a sudden drop in heart rate and to extract themselves from that the baby should awake from sleep. They should arouse from sleep. Simply by arousing from sleep you increase your breathing, you increase your heart rate and your blood pressure and most importantly, if you have your head covered with bedding, which occurs a lot of the time, you can move your head away to get fresh air. So it's thought that arousal is the critical response.

FURNESS SC: Thank you. Professor Elder, looking at the factors associated with SIDS, can you explain to the Inquiry how they fit in?

WITNESS ELDER: Do you mean how they fit into the model?

35

FURNESS SC: Yes, yes, in the circle towards the bottom, can you see that?

WITNESS ELDER: Sure.

40

FURNESS SC: How are they relevant?

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WITNESS ELDER: Well, again, they're risk factors. They're not in themselves causes. As Professor Horne has said, a fatal outcome can occur when everything runs together and perhaps a good way to explain this would be a situation where a baby might - there have been babies who have died when they have slept prone for the first time. That might be a baby where the mother was a smoker but previously at home they were slept on their back and other risk factors were modified and then they have perhaps been - some of these cases have happened in day care - they have been put prone by somebody else and that's been the step that's been the fatal factor. So a risk

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isn't a cause but it's a factor that can contribute.

5 Geographical location: in the past when I was first aware of SIDS early on in
my training I was based in Dunedin and the southern part of New Zealand and
indeed the southern part of Australia had a higher risk of SIDS than the
northern parts of the country. This appeared to be because people were
overwrapping children. They were managing them in bed with too many
clothes thinking of the outside temperature instead of the temperature inside
10 the house. Some of these factors we understand now and so we've been able
to modify - the outcomes have been modified.

FURNESS SC: What's the reference to ethnicity?

15 WITNESS ELDER: There have been studies that have shown in various
countries that indigenous people have higher rates. Often, I think this is really
- when you control for other factors - relates to co-risks, comorbidities like
maternal smoking and things like that.

20 FURNESS SC: And the reference to parental characteristics, example young
age?

25 WITNESS ELDER: Yes, well, young age has been a factor in the past. Again,
I think that is often a reflection of other characteristics - socioeconomic
characteristics and demographic characteristics of people who have infants at
an early age. Obviously, a lot of young parents don't have babies that die but
it has been one of the risk factors described.

30 FURNESS SC: Professor Horne, I think there has been research in the UK
which has looked at what might be termed young age in relation to that. Can
you help us with that?

35 WITNESS HORNE: Yes. There have been a number of studies - large
studies in the United Kingdom and we do need to be aware that the
socioeconomic status is quite different in the UK but the study by Peter Blair
which I'm just trying to find exactly what he said in his paper, sorry. He found
that mothers who were less than 26 years of age had an increased incidence
of having babies die from SIDS and this was actually confirmed in the
meta-analysis by Professor Carpenter that he published in 2013 that did
40 attribute an increased risk for younger mothers and that was a risk of between
1.9 and 3 in these younger mothers.

FURNESS SC: By younger he also meant under 26?

45 WITNESS HORNE: Under 26, yes.

FURNESS SC: I think he ascribed risk factors to other risks, didn't he, in that
paper?

50 WITNESS HORNE: He did, he did, yes. In his meta-analysis he's attributed
an odds ratio of increased risk to a number of factors. We've been talking

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5 about sleeping babies on their tummies in the prone position. That increases the risk tenfold so sleeping on the tummy is 10.1. Having your head covered was 12.5. He doesn't define premature babies but low birth weight so having a birth weight under 2000 grams which means you've been born pre-term increases the risk by nearly ten times. But if you look at maternal age it's quite small, between 1.9 and 3.

FURNESS SC: What about exposure to maternal smoking?

10 WITNESS HORNE: Exposure to maternal smoking is an increased risk and it has been suggested that if mothers didn't smoke you would significantly reduce the rate of SIDS even further so that now babies are being slept supine it is the biggest risk factor, maternal smoking is the biggest risk factor.

15 FURNESS SC: What about exposure to cigarette smoke more generally?

WITNESS HORNE: Environmental cigarette smoke and paternal smoking just increases the risk slightly to about 1.1 according to Professor Carpenter.

20 FURNESS SC: Thank you. Professor Elder, you were involved in a study, I think you referred to it earlier, in New Zealand. The combination of bed-sharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study?

25 WITNESS ELDER: Yes.

FURNESS SC: That was published in June 2017?

30 WITNESS ELDER: That's correct.

FURNESS SC: What were the major findings of that study?

35 WITNESS ELDER: Well, again, they confirmed the risk of prone but as Professor Horne has said, maternal smoking was now a greater risk, 6.01 times the risk. But the interaction between smoking and bed-sharing conferred a 32.8 times increased risk of death so bed-sharing looked at alone, it's nearly five times the risk so those were the factors that are prominent today in recent times.

40 FURNESS SC: Thank you. Your Honour, I'll get together a bundle of these articles and tender them and provide them later if I may.

45 HONOURABLE BLANCH QC: Yes, thank you.

FURNESS SC: Just finally in the Triple Risk Model, there's reference in the intrinsic risk factors to male gender. What is that risk factor, Professor Horne?

50 WITNESS HORNE: Male babies are at increased risk of a number of things. They are just generally more vulnerable. If you're born pre-term it's worse if

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you're male. There's only a slight increase in the incidence in males now.

FURNESS SC: Did you want to add anything to that, Professor Elder?

5 WITNESS ELDER: No, no, it, it, it's not just - as has been indicated, it's not just in relation to SIDS that this can be a risk factor.

10 FURNESS SC: Perhaps if we could have up the Institute of Health and Welfare figures and the Triple Risk Model can be removed. Now, Professors, what's about to come up on the screen is from the Australian Institute of Health and Welfare website, and you can see that this is the latest data, and there's a reference in 2017, there were 87 deaths, a rate of 0.3 deaths per 1,000, classified as sudden unexpected death in infancy, which includes SIDS, and fatal sleeping accidents. Now, it's not possible from that figure to understand what might be called SIDS death within that because it is a subset. That's right?

15 WITNESS HORNE: That's right.

20 FURNESS SC: Is there anything we can gain from the current incidence of SIDS that helps us understand any more about risk factors or its incidence today?

25 WITNESS HORNE: So, so as I alluded to before, the, the incidence has decreased dramatically since the Back to Sleep campaign, and this has been found not only in Australia but in most Western countries where these health messages have been promoted, so it is concerning, though, that from about 2006 the numbers seem to have plateaued, so there are various--

30 FURNESS SC: Sorry, 2006?

35 WITNESS HORNE: Yes, so, so the - so there was a dramatic drop in the early 90s and then a further drop when babies were placed on their backs rather than on their sides, but since then across multiple countries the, the, the fall has plateaued, and so there's a lot of concern about that internationally, whether it's smoking or whether there are other factors which have not altered that have maintained this rate, so I think also on the Red Nose website there used to be a graph of the - since the Reducing the Risks campaign which shows this dramatic drop occurring in the early 90s.

40 FURNESS SC: Thank you. Professor Elder, did you want to add to that?

45 WITNESS ELDER: Well, I, I think a similar experience has been in New Zealand. The Child Youth Mortality Review Committee release our data and they are looking at deaths above a month of age and in 1985 the national rate was four per thousand live births, and it - there was that sharp decrease. In the year 2000 it was 1 to 1. - 1 to 1.5, and in 2015 it has gone down further to 0.7 per thousand live births. I think what's generally being felt over here is there has been an excess of Maori babies dying and there has been some persistence of smoking with Maori mothers and so that's where the prevention

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efforts have gone into more latterly.

5 It's relatively easy to change to sleeping your baby on your back. It can be a harder thing to give up smoking, and so I think, as Professor Horne has indicated, it's the persistence of smoking that has left some of this tail behind.

10 FURNESS SC: There are various protective measures also that impact on the rate of SIDS, Professor Elder. Can you talk us through some of those protective measures?

15 WITNESS ELDER: Well, breastfeeding is thought to be protective. It's obviously a good thing for many reasons, and there is evidence that having the baby in the room with you, at least for the first six months, is also protective. I think it may have already been mentioned there's some protective effect of dummies, dummy use. Those would be - I mean obviously the avoiding smoking during and after pregnancy and sleeping the baby in a safe sleep position or recommended sleep position are, are two most important.

20 FURNESS SC: What about vaccination?

25 WITNESS ELDER: Well, vaccination is recommended again for many reasons. There was concern that vaccination would be contributory. That has not been shown to be the case, vaccination is safe and does not put you at risk of SIDS or sudden infant death.

FURNESS SC: Thank you, Professor Horne, did you want to add to that?

30 WITNESS HORNE: Yes, so there have, there have been recent studies that have shown that about - if the babies are fully immunised the risk of SUDI is actually halved, so it is - it certainly is protective.

35 FURNESS SC: Are there any other ways in which SIDS is considered today, other than those that you have mentioned, that differ significantly from the thinking about SIDS back in the early 2000s and the 1990s?

40 WITNESS HORNE: So I, I went back and found the original SIDS brochure, which was around, I think, in the time, in the late 80s, and so there were three main things, put your baby on the back to sleep, make sure the baby's head remains uncovered during sleep, and keep your baby smoke free before and after birth. The recommendation to breastfeed babies was originally - it was always recommended, and then it actually came as one of the recommendations in 2011.

45 FURNESS SC: Are there any other advances or changes that you wish to tell us about, Professor Elder?

50 WITNESS ELDER: No, I don't think so. I mean, we - in my statement I did mention the study we did on babies in the first month of life. I think it's been increasingly recognised that infants have been dying in the first month of life, some even in hospital, before discharge home, and in that study we showed

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that the majority of those babies were in a - found in a bed sharing situation.

FURNESS SC: You referred earlier to protective factors. If those protective factors are not in place, that doesn't equal a risk factor, does it?

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WITNESS ELDER: I'm not quite sure what you mean by that.

FURNESS SC: Well, they're separately considered. There are risk factors and if a risk factor is present it is what it is, a risk, but if a protective factor is not present it's neutral as opposed to negative in terms of a risk of SIDS. Is that right or not?

10

WITNESS ELDER: I think that's - well, I, I suppose I don't quite look at that that way. I, I think there, there - I mean, I have had some babies die without apparent - you know, unexpectedly and we haven't found a cause. Usually these days there is some - one of those risk factors that we, we see, we don't know how it's directly contributed to the death, but usually there's something that - one of those significant risk factors involved in the death.

15

FURNESS SC: Thank you. Professor Horne?

20

WITNESS HORNE: So I suppose, you know, if you took breastfeeding as an example, so breastfed babies - breastfeeding is protective, but if the baby is - conversely is formula fed, they do have an increased risk. It's a slight risk, the paper by Professor Carpenter says it's 1.5.

25

FURNESS SC: What about the risk of not sleeping in your parents' room? Is that something that Dr--

WITNESS HORNE: So - that's right, so he, he quotes a, a, a, an adjusted odds ratio of 2.4 if the baby is not sleeping in the parental bedroom.

30

FURNESS SC: And in relation to using a pacifier?

WITNESS HORNE: I will have to look at the actual paper for that. Is that okay? I don't have that summarised.

35

FURNESS SC: That's all right, we can perhaps come back to that.

WITNESS HORNE: So I will - in terms of - in terms of dummy use or pacifier use, the American Academy of Paediatrics recommends that dummies be given to babies after breastfeeding has been established and the data shows that routine use of a dummy is protective, so if it was - the parents had been asked if it was used in the last sleep. The Australians and the New Zealanders and in the UK, dummies are not recommended, but they are not actively discouraged, so the Americans actually recommend them, but the other countries don't.

40

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FURNESS SC: Thank you. Professor Elder, does that cause you to wish to tell us anything further?

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5 WITNESS ELDER: No, I think, I think the way we talk about things being protective is tricky because I think definitely you could say avoiding dangerous sleep position is definitely protective, I think - I would think of breastfeeding as decreasing risk rather than, you know, it's a semantics with words, but some, some changes are more important, I think, to decreasing the risk of death than others. Does that - do you see what I'm getting at?

10 FURNESS SC: Yes, thank you for that. Professor Horne, can I come back to you and your report? Do you have that in front of you?

WITNESS HORNE: Yes, I do.

15 FURNESS SC: It's page 6 of your report.

WITNESS HORNE: Yes.

20 FURNESS SC: You refer there to, "More Than One SIDS in a Family," as your heading?

WITNESS HORNE: Yes.

25 FURNESS SC: You refer in those couple of paragraphs, going over the page, to the research you are familiar with. Would you take us through your views in relation to that topic?

30 WITNESS HORNE: So the general consensus seems to be that SIDS - more than one SIDS in the family is very rare, so SIDS itself is rare, but having more than one in a family is also very rare. The - I have asked my colleagues on the International Society for the Study and Prevention of Infant Death, so in the UK and in the USA, and they - none of them could recall having three or more deaths in the family.

35 FURNESS SC: When you say none of them could recall it, within their practice, are you referring to?

40 WITNESS HORNE: Within their practice, but these, these are people - so, for instance, Betty McEntire is from the American SIDS Institute, and Carrie Shapiro-Mendoza also runs the SIDS database in the USA, so it, it's more than their practice, it's, it's maintaining these databases. In terms of the 1986 publication which is mentioned in Professor Byard's book--

FURNESS SC: That's the Diamond report?

45 WITNESS HORNE: That's the Diamond paper, where they report five deaths in one family. Now, I will say from a scientific point of view that this is not really a scientific paper. It's more just a case report. He's just reporting one family that he's been aware of, and the unusual thing in this is that there were three different fathers involved. It was published in 1986, so it probably, you know, 50 may not have been accepted for publication today, but it - I think it raises a lot

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of questions about the family, more than it answers the question of multiple deaths in one family.

5 FURNESS SC: Now, you have read that section of Dr Byard, Professor Byard and Dr Duncan's--

WITNESS HORNE: Yes.

10 FURNESS SC: --2018 publication--

WITNESS HORNE: Yes.

15 FURNESS SC: --in which he sets out a summary as at that time, 2018, as to the literature, and their thoughts on it, and concludes ultimately that the risk is small.

20 WITNESS HORNE: Yes, he does, and it is also - excuse me. That conclusion is also supported by a number of other papers by Peter Blair and Peter Fleming from the UK who also say that it is you know, it is a very small risk and also the paper by Bacon and Campbell.

FURNESS SC: So you used the language very rare before, rare in relation to SIDS and very rare in relation to recurrence?

25 WITNESS HORNE: Yes.

FURNESS SC: Language can be important in terms of degrees?

30 WITNESS HORNE: Yes.

FURNESS SC: Professor Byard's referred to small, what would you, based on your research knowledge and experience, and based on the literature that you have read, call the risk of recurrence?

35 WITNESS HORNE: So if we go back to the data that we've just been presented, saying that in 2017 there were 87 SUDI deaths in Australia, so I would say that the risk is low and we know that that's .3 per thousand births and if you take Professor Byard's section in the book where he says that in 40 92% of the families, you know, there would be no increased risk, so I think you know, as you say, semantics, rare and very rare maybe.

FURNESS SC: Thank you. Professor Elder?

45 WITNESS ELDER: I think this is a difficult thing to give an opinion on because the past literature has lumped all these deaths together and looked at risk with all these deaths together, I feel that we see some classic situations, which is the baby in an unsafe sleep position, of a mother who smokes and that is still - that is currently the classic of what we see for a baby dying and if the next child in that family is in the same situation, there's going to be an increased risk of 50 that baby dying, if the mother still smokes and the baby is still in an unsafe

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5 sleep position. Then we do have the group where we look for genetic events, and if you find a genetic reason for sudden infant death, then the risk of another death of the same sort is going to be based on the risk for that genetic event and then certainly if you find that there - you know we have - clinically when there is repeated death that we can't explain in any way, either by risk factors or genetics, then we do have to consider whether there's been an unnatural cause in my opinion and that would be a clinical process.

10 FURNESS SC: In terms of then looking at the recurrence, you would have to control that for both genetic and environmental factors, is that what you're saying?

15 WITNESS ELDER: That's correct, so I think it's a difficult thing to give a single number to. I have seen twins die simultaneously in a same unsafe situation, that's been apparent to me clinically, I haven't in my clinical experience seen another baby die where it wasn't in a similar risk factor issue.

FURNESS SC: Mainly lying on its stomach as opposed to on its back?

20 WITNESS ELDER: Yeah or in a bed sharing.

25 FURNESS SC: Can I just turn now to the four children who were the subject of the convictions and if I can take you through reasonably briefly what is known about the children, not in terms of medical matters post death but more what was known about them when they were alive and ask each of you to give your opinion as to the risks for them in respect of SIDS, based on the evidence you've just given.

30 Can I turn first to Caleb, he was born on 1 February 1989 and died on 20 February, aged 19 days old, he was a full-term baby, he was not underweight, his mother did not smoke, he was found on his back with his face uncovered in his own bed, his bed was in his own room, not in the parents' room, there were no signs of neglect and the family was not socio economically disadvantaged. Kathleen Folbigg was 21 years old at Caleb's birth and whilst she didn't smoke, Caleb's father smoked, but the evidence is he smoked outside. Taking into account those matters, can you - one additional matter, he was not breastfed, he was formula fed and it's not known in relation to the use of a pacifier or whether he was vaccinated. Professor Horne can I ask you first, applying what you know about risk factors to what we know about Caleb?

45 WITNESS HORNE: Well he doesn't have the major risk factors, as you've said he is not - he's sleeping on his back, his face wasn't covered, he was a full-term baby and from my reading of the documents he appeared well and healthy at the time, I would've said that he would've been a low risk baby.

FURNESS SC: He certainly wouldn't have fitted within the intersecting three circles of the triple risk model?

50 WITNESS HORNE: No but we must also remember that he was under one

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month of age.

FURNESS SC: Why is that relevant?

5 WITNESS HORNE: Whether you put the complete definition of SIDS as we looked at, less than a month.

FURNESS SC: Professor Elder.

10 WITNESS ELDER: Sorry I missed some of that but I'm back, I--

FURNESS SC: I can go through again what we know about Caleb, would you like me to do that?

15 WITNESS ELDER: I got that and I got the beginning of Professor Horne's comments, I mean I would agree that there are no clear classic SIDS risk factors, he didn't have a completely pristine medical history however and that - so that does raise some questions. Against that he was apparently thriving at the time of death and if there had been a significant influence from his medical
20 problems, he possibly wouldn't have been thriving because when you are very little, the main thing you do is eating and growing and if you have significant health issues that can affect eating, feeding and growing. He did have this respiratory distress noted at birth and there was snoring I think noted or some noisy breathing and the clinical diagnosis laryngomalacia, so I think that's just
25 a little question mark around how that might have affected him, even though he appeared to be thriving.

FURNESS SC: When you say a question mark, are you speaking in terms of whether or not the death would have fitted the current SIDS definition?

30 WITNESS ELDER: Well it wouldn't have fit the absolutely pristine history definition which we would use for SIDS, however on the other hand, we see quite a few babies with laryngomalacia who thrive and do well, so I don't you know, when I was talking to parents about their infant's laryngomalacia, I
35 wouldn't consider I needed to tell them that the baby was at risk of death.

FURNESS SC: Can I then turn to Patrick and as we know, Patrick was born on 3 June 1990 and he had an acute or apparent life threatening episode on
40 18 October 1990 when he was four months and 15 days and I'll come back to his death, he was in a similar position to Caleb, in that he was full-term, he wasn't underweight, his mother didn't smoke and he was found on his back with his face uncovered in his own bed and the other environmental factors were the same, the probably only difference is that there's some evidence that he used a dummy, although it's certainly not clear for how long and his mother
45 was 22 years old, one year older than Caleb.

In addition to those features in relation to Patrick, he had had a sleep study carried out when he was one and a half weeks old, the results of which were the evidence is entirely normal, that was by Dr Cooper, and Dr Marley, who
50 was his GP also gave evidence at the trial that he - this is up until the time of

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his ALTE was no different from any other children and he was seen for minor respiratory infections. Now with that background in mind Professor Horne, what do you say about Patrick's risk?

5 WITNESS HORNE: Well so we're talking for the ALTE.

FURNESS SC: For the ALTE, I'm just talking about the ALTE?

10 WITNESS HORNE: Okay so we're talking about the ALTE. So I would've said that he was low risk for having an ALTE, ALTEs are episodes which are really frightening to the parents, the baby can change colour dramatically, be quite pale and appear not to be breathing, but generally as soon as they're picked up or stimulated in some way they start to breathe again. So these events are not linked to SIDS, there is no relationship between having an apparent life threatening event and dying of SIDS, earlier in the - you know, it was thought that they were precursors and they were called near miss SIDS, but we now know that the aetiology of both conditions are very different.

20 So ALTEs are more common in pre-term babies and they are more common in younger babies, between one and three months of age and as said, the episode is generally resolved, parents often take them to hospital but by the time they get to hospital they're fine. It can be that the babies are in quiet sleep, babies have two different sleep states, as we do, quiet sleep where their breathing can be quite regular and shallow, they can be quite pale, appear quite pale and so it's generally thought that you know, a lot of the ALTEs are the baby is just sleeping very deeply.

25 FURNESS SC: Is that recent research you're referring to about the lack of connection between an ALTE and SIDS?

30 WITNESS HORNE: It's been around for quite a while, so people have - I mean a number of studies have been done to compare the features of ALTEs and the features of SIDS and as I've said they are quite distinct, there was a very large study done in the USA, where they put cardiorespiratory monitors on over 1000 babies, and they only had one - they had one baby that had an ALTE I think - if I can just check what I said, that went on to die. So they really didn't find a link at all. I just can't find--

35 FURNESS SC: What's the year of that study?

40 WITNESS HORNE: That was Carl Hunt, the CHIME Study and I'd have to--

FURNESS SC: That's all right Professor, we'll get the details off you--

45 WITNESS HORNE: Yeah. So it's in - it's in the report. So as I said, it was a very large study and most of the ALTEs as other people have found were in preterm babies.

50 FURNESS SC: Thank you. Professor Elder?

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WITNESS ELDER: Well, there are no significant factors for sudden infant death. Babies can have reflux as a presentation of an apparent life-threatening event. I gather Patrick had had a barium swallow specifically to look at reflux.

5

FURNESS SC: The results of that were normal?

WITNESS ELDER: That's correct, so no apparent risks. I suppose you could consider the death of a previous child a risk which is why those other investigations were done which were shown to be normal.

10

FURNESS SC: In terms of the risk from the death of Caleb, how would you take that into account in considering Patrick's risk?

WITNESS ELDER: Well, at the time a clinician would have been concerned about it. I think it's hard to judge that risk in retrospect but at the time if I had been the clinician looking after him, I would have been concerned to do those studies and make sure that the breathing was okay and there were no other factors that could put him at risk.

20

FURNESS SC: Thank you. Can I turn to Patrick's death. Is there anything in relation to his death, Professor Elder, that given your background and experience in terms of risk factors that you could opine on?

WITNESS ELDER: I think at the time of his death he was a quite different boy from the time of his ALTE. I have not been able to read his original medical records in their entirety but I understand that after the apparent life-threatening event he had significant developmental issues. He had recurrent seizures and he was in and out of hospital more than you would expect a healthy boy to be and so I don't think it's really possible to apply SIDS risk factors to him in that context.

30

FURNESS SC: Thank you. You have the same view, I take it, Professor Horne?

35

WITNESS HORNE: Yes.

FURNESS SC: Yes, thank you. Can I then turn to Sarah. Sarah was born on 14 October 1992 and died on 30 August 1993 aged ten months and 16 days. She was in a similar position to Patrick in terms of the factors that you've given evidence about this morning. The differences were that her mother was 25 when she was born. We know she was vaccinated and used a dummy, query the extent of that use. But also she slept in her cot in her parents' room which was different from the two previous children. Taking that into account together with the fact that she left hospital with an apnoea alarm and slept with an apnoea blanket - although that wasn't used at the time of her death, she nevertheless went home with both of those. She also had a sleep study carried out when she was three weeks of age and showed a very small handful of apnoeas which were, according to the doctor who carried out the study, "normal for infants of that age."

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5 Other tests and the like were done and ultimately the sleep physician gave evidence that the last sleep study was normal for her age. She also had a metabolic screen which ultimately needed no follow-up. Her GP gave evidence that he had seen her for routine vaccinations and she seemed to be a normal healthy infant, there had been a viral infection of mild severity, and then finally on 18 August she had had prescribed for her an antibiotic for a flu or cold-type virus and that was last taken a few days before her death. That's the evidence in relation to Sarah up until that time. Is there anything, Professor Horne, you can tell us about Sarah's risk or protective factors at the time of or just before her death?

15 WITNESS HORNE: Sarah is older than the usual SIDS. At ten months she's older. It is common that babies have had a mild respiratory infection. About half of babies have had a mild respiratory infection so half of babies who die but the respiratory infection itself has not been severe enough to be attributed to the cause of death. As you've said, she was vaccinated. She was sleeping in the parents' bedroom and so the only thing would be that she was not breastfed, so I would also have said given the position that she was found in, on her back, without her head being covered she was well, healthy apart from the cold, I would have also said that she was at low risk.

FURNESS SC: Thank you. Professor Elder?

25 WITNESS ELDER: I agree with those comments. There is some commentary about snoring at times. I'm not sure if that was just something that happened with the more recent infection or if it had been a longer term thing but otherwise there is an absence of the usual risk factors and there is a slightly older age as Professor Horne mentions.

30 FURNESS SC: Thank you. Your Honour, I'm just about to turn to Laura. Is this a convenient time for a luncheon break?

35 JUDICIAL OFFICER: Yes. I'm only concerned about Professor Elder and our connection and how that's going to work out over a lunch break of an hour.

FURNESS SC: Yes, your Honour.

40 JUDICIAL OFFICER: Is that convenient for you, Dr Elder?

WITNESS ELDER: That's fine. I was expecting to be needed.

45 JUDICIAL OFFICER: Okay. All right, thank you, if you're okay with it then we'll adjourn for one hour until 5 to 2.

LUNCHEON ADJOURNMENT

JUDICIAL OFFICER: Yes, Ms Furness.

50 FURNESS SC: Thank you. Your Honour, it's just been brought to my

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5 attention that the ABC has - on its website has written a lengthy article and it's
clear from the article that they have had access to Professor Clancy's reports,
which I indicated this morning were received by the Inquiry over the last few
days, Professor Blackwell's and Professor Ryan's reports. They are reports
that were prepared for the purpose of the Inquiry and have been provided to
that Inquiry. Also Professor Duflou's report. None of them have been
10 tendered, and certainly I wasn't proposing to tender at least one of them in
their fullness, and I don't know whether anyone else had any objections to any
part of those reports, but they have clearly been made available to the media
before your Honour has had an opportunity to consider what the Inquiry may
make of them.

15 JUDICIAL OFFICER: Mr Morris, are you appearing in this Court or are you
running your case in the media?

MORRIS SC: Your Honour, I'm sorry, I'll make enquiries. I am running the
case in this Court, but I'll--

20 JUDICIAL OFFICER: What about those instructing you?

MORRIS SC: Well, I'll make some enquiries, your Honour, and find out--

JUDICIAL OFFICER: Because it appears that there are parts of material that
were to be tendered which will not be admitted into evidence.

25 MORRIS SC: Your Honour, I will make some enquiries.

JUDICIAL OFFICER: It is an appalling situation. In the ordinary course of
events, if this were a Court, it would be a contempt of the Court to be putting
30 forward material such as that through the media before it even has had an
opportunity of being considered here.

MORRIS SC: Your Honour, I'll make--

35 JUDICIAL OFFICER: I know I can leave it to you, Mr Morris.

MORRIS SC: Yes.

40 JUDICIAL OFFICER: I will leave it to you, but do you understand what I'm
saying?

MORRIS SC: Absolutely, your Honour, absolutely. Thank you, your Honour.

45 JUDICIAL OFFICER: Yes.

FURNESS SC: Thank you, your Honour. Professor Elder, you can see and
hear us?

50 WITNESS ELDER: I can.

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5 FURNESS SC: Thank you, and Professor Horne is still with us. Can I turn now to Laura, the fourth child, and indicate that Laura was born on 7 August 1997 and died on 1 March 1999 aged 18 months and 22 days? As with the other three children, she was full term, not underweight, her mother didn't smoke, and she was found on her back with her face uncovered and in her own bed. Now, her mother was 30 at the time of her birth, and Laura was vaccinated and used a dummy and was breastfed, but only for two weeks, so similar factors.

10 She also underwent significant testing, including biochemical, blood, and metabolic investigations, as well as sleep studies and the like, and she also was monitored on a Corometrics home cardiorespiratory monitoring device, and according to the doctor who organised those tests she had that monitor at home for 12 months, but there is some evidence that it wasn't used all the time, and according to her general practitioner she was seen about 13 times, normal, healthy child with no chronic illness, and same with the visiting medical officer at the hospital who saw her, she had slight upper respiratory infection for a few days and a croupy cough and the like, however in the last 24 hours before she died she had been administered Demazin and had the last dose on 20 27 February.

25 So that's in broad terms her background and the circumstances before she died. She was 18 months and 22 days, so it's clear that she was well out of the timeframe for SIDS, however, with that background, is there anything, Professor Elder, you wish to say about Laura in terms of risk factors or protective factors?

30 WITNESS ELDER: Well, again, those common risk factors that we've discussed are not present. The, the death is - occurred at an age range that's not usual for SIDS, but I have - by the original definition, but when we speak about sudden unexpected death in infancy we do broaden that age a little, and I certainly have seen children of an older age die in circumstances where we haven't been able to understand exactly why, so really a SIDS-like death. Again there is this history of recent infection which has been seen in children 35 who have died suddenly and unexpectedly. Those are the main things, I think.

FURNESS SC: Thank you, Professor. Is there anything you wish to add, Professor Horne?

40 WITNESS HORNE: So I would only add that sudden unexpected death in childhood is actually more rare than SIDS, and that's also quoted in Professor Byard's book, that, you know, there's one to 1.4 deaths per hundred thousand, so it's certainly very uncommon.

45 FURNESS SC: Thank you. Thank you, your Honour, I have nothing further.

JUDICIAL OFFICER: Thank you. What order do you want to do this in? Mr Morris, do you want to go first?

50 MORRIS SC: Your Honour, I'm happy to go first, but I'm happy to go last. It

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really depends on what you think--

JUDICIAL OFFICER: Let me ask the others if - there may not be any questions.

5

MORRIS SC: Yes, thank you, your Honour.

JUDICIAL OFFICER: Ms Richardson, any questions?

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RICHARDSON SC: No, your Honour.

JUDICIAL OFFICER: Mr Fraser?

FRASER: No, your Honour.

15

JUDICIAL OFFICER: Ms Mathur?

MATHUR: No, likewise, your Honour, no questions.

20

JUDICIAL OFFICER: There you are, you are first and last, then, Mr Morris.

MORRIS SC: Solved that problem. Thank you, your Honour. Firstly, I'll direct this question to you, Professor Horne. As I understand it you're a clinician.

25

WITNESS HORNE: No.

MORRIS SC: Sorry, you're not a clinician?

WITNESS HORNE: No.

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MORRIS SC: No. You're more in the research field, is that right? And you would have to defer in giving any opinion to any opinion by a forensic pathologist?

35

WITNESS HORNE: Absolutely, yes.

MORRIS SC: And similarly I take it you haven't really extensively looked at the clinical records relating to these children, have you?

40

WITNESS HORNE: I've read the documents that I was sent, yes.

MORRIS SC: I see. Just in relation to that, were you sent Patrick Folbigg's complete hospital file, do you know?

45

WITNESS HORNE: No.

MORRIS SC: I think the answer was, "No," to that, your Honour.

JUDICIAL OFFICER: You were not sent?

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WITNESS HORNE: Not, not - I don't think so, not the whole--

FURNESS SC: She certainly wasn't from--

5 WITNESS HORNE: No.

FURNESS SC: --those assisting the Inquiry.

10 MORRIS SC: No, thank you, and just on that question, you have only received information from those assisting the Inquiry. Is that correct?

WITNESS HORNE: Yes.

15 MORRIS SC: You've had no other communication with anybody else--

WITNESS HORNE: No.

20 MORRIS SC: --in relation to this? Just in relation to the epidemiology, the epidemiology, can I suggest, is prepared in large part in order to guide clinical decisions and giving advice. Do you agree with that general proposition?

WITNESS HORNE: I'm not sure that I understand your question.

25 MORRIS SC: Well, in - sorry, you're not a clinician, it's fine, I'll move on. In relation to the definition of SIDS, one of the features is that the death occurs during sleep?

WITNESS HORNE: Yes.

30 MORRIS SC: Another feature is that the death remains unexplained after a thorough investigation?

WITNESS HORNE: Yes.

35 MORRIS SC: And so to that extent if the death is explained after a thorough investigation it falls outside the SIDS definition. Is that correct?

WITNESS HORNE: That's correct.

40 MORRIS SC: And we've got to understand the - sorry, to the extent that there is epidemiology relating to the frequency and risk factors with SIDS, is it correct to assume that those people who are preparing those epidemiological studies are using this definition of SIDS?

45 WITNESS HORNE: That would depend on when the studies were done, so the majority of studies which have come from the United Kingdom have been done quite a while ago, as I mention in my report. The confidential inquiry into stillbirths and deaths was conducted between 1993 and 1996, and as we alluded to originally about the definitions for SIDS, mainly the new definition
50 with the category 1(a), 1(b), and 2 is for research purposes, so when looking at

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the epidemiology it makes it difficult to interpret whether the actual definition of SIDS has been made or whether some of these who were described as SIDS would, if you reviewed the case subsequently, have been called unascertained or an accidental sleep - a sleep accident.

5

MORRIS SC: In other words, we've got to be careful to distinguish between sudden infant death syndrome as defined by this definition and simply sudden infant death. Is that--

10

WITNESS HORNE: Well, that's what we explain, that sudden unexpected death in infancy, SUDI, describes both SIDS and accidental deaths that have occurred during sleep.

15

MORRIS SC: But we would need to look at the specific paper and try and determine which definition they're using. Is that correct?

20

WITNESS HORNE: Yeah, so, so that, that, that is true, but what is consistent with the epidemiology are the risk factors that we have alluded to, as in sleeping prone, being exposed to material smoking, being born prematurely, these, these are very consistent across countries--

MORRIS SC: Professor Elder--

25

WITNESS HORNE: --and times.

MORRIS SC: I'm sorry.

WITNESS HORNE: Yeah.

30

MORRIS SC: Professor Elder, do you agree with those comments?

35

WITNESS ELDER: Yes, I think, you know, in the early days the studies were done on a, a mixed bag of cases because they were all the cases that people didn't understand, and as time has gone on the cases that we see clinically, most - the majority of them do fall into the unsafe sleep position which we now recognise to be a risk, but we understand those risks when we started. Does that make sense?

40

MORRIS SC: Yes, and just in relation to the unsafe sleep position, is the risk there a risk of accidental suffocation?

45

WITNESS ELDER: Well, I think there, there - if, if the infant is in bed it's thought that that is an important risk, if, if the infant is in bed with an adult or on an unsafe surface where they can slide into a, a position, I mean, babies have been described in a number of positions down - sliding off a bed, being caught between a wall, those sorts of things. That, that's clear, as to what's going on. If you've got a baby in bed, but in prone or with the head covered, then there may also be a component of heat as well as possible obstruction to the airway, overheating might be part of it as well.

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MORRIS SC: In that regard it seems from the evidence you gave this morning, that the heat of the child, the degree of swaddling, the degree of clothing or external heat sources, may be a contributor, is that correct?

5 WITNESS ELDER: It certainly has been felt to be a contributor to children who
have died in the past suddenly and unexpectedly, there was research done
looking at weight of bedding and the effect of bedding and doing calculations
of what temperature the infant might have got to with that degree of bedding
and looking at the temperature of the room. Mostly the advice now is clearer
10 to parents about how to dress babies and how to monitor their temperature.

MORRIS SC: Professor Horne, on page 3 of your report, you make note that
the potential, one of the potential risk factors were that all infants were formula
15 fed, and you said that it was thought that breastfeeding was protective and we
had that discussion, were you aware of any studies which indicated that infants
fed with a cow's milk preparation could suffer from an ALTE type response
because of the Casomorphin enzyme in cow's milk?

20 WITNESS HORNE: No I'm not aware of that.

MORRIS SC: And so you're not aware of those studies, is that right?

WITNESS HORNE: No.

25 MORRIS SC: Professor Elder, were you aware of those studies?

30 WITNESS ELDER: I'm not aware of the studies directly, I'm aware that infants
can have allergy to cow's milk and can present with symptoms of a rash
around the mouth sometimes and irritability, I don't personally particularly think
of ALTE in relation to that but that doesn't mean it hasn't been reported.

MORRIS SC: And just to finish off that topic, that after the introduction of
genetically modified A2 milk, that pattern may have abated, that is the pattern
of difficulties with young children, I take it if you're not aware of the studies you
35 can't really comment on that, is that correct?

WITNESS ELDER: That's correct, I'd be happy to look at that if the papers
were provided.

40 WITNESS HORNE: Are you asking this for being fed cow's milk or formula.

MORRIS SC: Cow's milk based formulas?

45 WITNESS HORNE: Right.

MORRIS SC: The next thing is the - I think it's accepted by both of you that
paternal smoking is a risk factor for SIDS?

50 WITNESS HORNE: A small risk factor yes.

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MORRIS SC: Does that depend on the nature of the exposure, has that been measured at all or is it--

5 WITNESS HORNE: Yes it does, so it depends on the number of cigarettes smoked and whether or not the child is actively exposed to second-hand smoke, we from our information that we had that Mr Folbigg smoked outside, so the children were not you know, may not have been directly exposed but just from his clothing.

10 MORRIS SC: Clothing and breath, is that correct?

WITNESS HORNE: Possibly yes, but it's a very small risk compared to maternal smoking.

15 MORRIS SC: I understand. But the extent of smoking and the nature of the exposure may be important?

WITNESS HORNE: Yes it is, there's been studies which have shown that it's dose dependent.

20 MORRIS SC: Professor Elder, do you have anything to add to that?

WITNESS ELDER: I think the most profound effect in my opinion is exposure to smoking in utero, because there is evidence that the brain is different in the babies who've died who were exposed to cigarette smoke in utero and I can't quite personally see how that same mechanism works with exposure to paternal smoking only. So there must be perhaps some other mechanism by which paternal smoking contributes to risk, because certainly the risk of smoking exposure in the womb seems more related to alteration of the infant's arousal responses and of course you need the two-pronged affect exposure to smoking and therefore a change in your arousal responses, plus something that happens to you where you need to arouse, like getting your face obstructed, you need to be able to get your head out of the obstruction and have an appropriate arousal response, as Professor Horne was discussing this morning, so I would certainly think of maternal smoking exposure in utero is the most significant risk.

25 MORRIS SC: Professor Horne, in relation to your comments on page 5 of your report in relation to the relationship between ALTE and SIDS, is the - one of the problems in determining the relationship between ALTE and SIDS, one of the difficulties that there's a complication by the existence of natural conditions that might present in a similar manner to SIDS?

45 WITNESS HORNE: I'm--

MORRIS SC: Does that make sense?

WITNESS HORNE: No I'm sorry I don't quite understand that.

50 MORRIS SC: The fact is that there are a number of natural conditions that can

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give rise to a sudden death in a child correct, in an infant?

5 WITNESS HORNE: So as I said this morning in the terms of SIDS, it's believed that there's an abnormally long respiratory pause or a fall in heart rate to which the infant does not arouse from and doesn't respond, but that seems to be a different scenario to an ALTE, which I also talked about this morning, because ALTEs can actually happen when the child is awake and they generally happen during the day, rather than when the child is asleep at night.

10 MORRIS SC: In relation to SIDS, let's put this ALTE to one side. Sorry - let's not call it SIDS, let's call it sudden infant death?

WITNESS HORNE: Right.

15 MORRIS SC: Sudden infant death can be caused by an epileptic seizure?

WITNESS HORNE: I'm not a clinician, you'll - sorry.

20 MORRIS SC: So you wouldn't--

WITNESS HORNE: No.

25 MORRIS SC: So you wouldn't want to comment upon the alternative causes of sudden infant death?

WITNESS HORNE: No I'm sorry I don't have that expertise.

MORRIS SC: Professor Elder?

30 WITNESS ELDER: Yes. I could comment.

MORRIS SC: Would you kindly just give us your views on alternative causes for the sudden death of an infant?

35 WITNESS ELDER: Sure, so a sudden unexpected infant death is a death that has not been expected within the previous 24 hours before death. And we did a review of cases locally in Wellington some years back now that we referred to the Coroner, so all those deaths would be referred to the Coroner and these were all deaths over a month of age and there was 64 deaths in our group and
40 there were ten where it was felt that the diagnosis was explained, the reason was explained after the post mortem.

45 And so in one of those cases it was thought to be an inflicted injury, a child abuse death, four there was infection found that was thought to explain the death, three there was a congenital anomaly that hadn't been noted before, one had acquired heart disease and the other had an acute gastrointestinal illness and those were thought to have clearly explained the death. Then when we look at, if we have a good death scene and history exam, there may be another group where you can tell by the history particularly, that there was
50 definite accidental asphyxia, so that would be pretty hard evidence such as

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somebody has actually found an adult lying on the baby or you know, that sort of situation.

5 And then you get into the cases where you know, you're concerned about the
circumstances, the sleep circumstances, the baby was in a non-recommended
sleep position or a non-recommended sleep environment, but sometimes you
can't be exactly sure what the final mode of death was for those infants and
that's why you know, there are concerning circumstances but yeah it's hard to
10 know exactly what happened at the point of death, and then relatively rarely
now, you find infants where you really can't find anything and as we said
before, that's - those are the infants that we would now use the term SIDS for
because sudden infant death syndrome now is really a diagnosis of exclusion,
you've excluded everything else, you've had your autopsy, you've had a good
15 clinical history taken, somebody has reviewed the scene where the baby died
and taken information from that.

MORRIS SC: And in relation to the, Professor Elder, in relation to the extent of
the autopsy, is it one of those things, I'm not sure whether you can comment
on it, the extent of the autopsy and the sufficiency of the autopsy is an
20 important consideration?

WITNESS ELDER: Yes it is and you know, that will vary.

MORRIS SC: And it's fair to say that as at 2003, the tools available to be able
25 to identify for instance, congenital syndromes, has increased enormously
hasn't it?

WITNESS ELDER: Yes.

MORRIS SC: And also since the 80s we've had the advent of the MRI scan,
30 which is more sensitive than CT, is that correct?

WITNESS ELDER: Well if you're talking about it as a post mortem tool, I'm not
35 a pathologist, but I believe very strongly in the value of post mortem rather
than MRI, for an examination after death, it's important to look at tissues
histologically to be sure about the diagnostic pathway.

MORRIS SC: I'm not suggesting that MRI would replace a close macroscopic
40 and microscopic examination of various organs, but it is a tool that has become
available since the 80s, hasn't it?

WITNESS ELDER: Yes, yes it has.

MORRIS SC: One also needs to take into account I suggest, the resources,
45 both the practical and financial resources available to the forensic pathologist,
in examining whether there has been a complete investigation and the quality,
to be able to assess the quality of that investigation, would you agree with
that?

50 WITNESS ELDER: Well I wouldn't be able to comment on that, I think you'd

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need the forensic pathologists to comment on the resources they have available.

5 MORRIS SC: But certainly, the technical developments, particular in genetic testing, have had a considerable impact on the capacity to investigate the death of an infant?

10 WITNESS ELDER: I think that's true but there are so many things that you could test for now. I think still the basic diagnoses we're looking at are very similar. It's the tests we have to confirm those diagnoses that are different. So we've always worried about some inborn errors of metabolism being the cause of death. It hasn't been so easy to test for that. It's now easier to test for that. We've been worried about the long QT type syndromes and whether that could be implicated and we have some better techniques for looking at that. But I think basically we're using the new techniques to look for things that we were thinking about before.

15 MORRIS SC: One of the other areas where there have been considerable advances, can I suggest, is the recognition of infection and an activated immune system involved in the sudden unexpected death of an infant. Is that correct, Professor Elder?

20 WITNESS ELDER: Well, there have been theories about the role of infection for a long time. As Professor Horne indicated, it has been documented for some time, the association between a recent not apparently very severe infection and infant death. I haven't had time to read all the documentation that's been offered in relation to infection in the last day or two. There will be some new things there that I'm not aware of. To me the issue still is that even with new possibly genetic reasons for death, you still have to explain how that can - in this context can cause the death of four children in a row in the absence of their parents seemingly having similar genetic issues. That might be possible but that's the question in my mind that needs to be answered.

25 MORRIS SC: Do you agree with the statement in Professor Horne's paper, her report, that almost half of SIDS infants had a mild respiratory infection in the last days prior to death?

30 WITNESS ELDER: It's a commonly found thing, yes.

35 MORRIS SC: Sorry, page number 4.

40 WITNESS ELDER: I couldn't tell you the number off the top of my head but I trust that she has looked it up. It is certainly often described and I have heard parents describe that when I've met with them also.

45 MORRIS SC: It's thought that genetic variation in cytokine genes are most likely involved?

50 WITNESS ELDER: I am not familiar with that literature. It's not specifically in my area of expertise. I guess one of the reasons that I have not kept up in

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detail with that literature is that in this day and age, the day and age I'm clinically working in currently, it's not applicable to most of the deaths that I see. They're usually children that have been in unsafe sleep circumstances.

5 MORRIS SC: In relation to infection and the cytokine response, Professor Horne, it's thought, is it not, that this infection can give rise in the child with genetic variations in the cytokine genes, it can give rise to toxicity which can trigger an arrhythmia. Is that correct?

10 WITNESS HORNE: Again, I'm not an expert in this area. I think you have reports from Professor Blackwell who is an expert and I believe she's speaking later in the week and she is in Australia the infection in SIDS expert. For Professor Elder the reference to the genetic variations in cytokine genes is actually from 2018 in the Roger Byard book so she may not have actually read that chapter as yet.
15

MORRIS SC: We were talking about the risk of subsequent death in SIDS and in this regard, Professor Horne, I'm referring you to page 6 of your report at the bottom. In providing that opinion in those bottom two paragraphs you are
20 using the SIDS definition at the beginning of your report. Is that correct?

WITNESS HORNE: In the bottom paragraph where I spoke to my colleagues as I mentioned this morning from the ISPID working groups. They are using the current definition and they also had said to me that having a baby with minimal risk factors, so SIDS 1(a), is very rare as Professor Elder has alluded to and is not very common at all.
25

MORRIS SC: One of the articles which you cite is an article by Oyen, Professor Horne.
30

WITNESS HORNE: Mm-hmm.

MORRIS SC: Are you aware that in that paper it was suggested that there was a threefold increased risk of a baby dying from a cause other than SIDS when there's been a prior death?
35

WITNESS HORNE: A cause other than SIDS?

MORRIS SC: Yes.
40

WITNESS HORNE: No, because I was actually talking about subsequent SIDS deaths in a family.

MORRIS SC: So this analysis here on page 6 is limited only to SIDS and is not related to any study of children who have died suddenly for which there has been an explanation. Is that correct?
45

WITNESS HORNE: No. I was asked to comment on more than one SIDS death in a family and particularly more than three SIDS deaths in a family.
50

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MORRIS SC: You made a comment in relation to the Diamond article from 1986.

WITNESS HORNE: Yes.

5

MORRIS SC: And you said, well, really you've got to understand that that's a case report and it probably wouldn't be published these days.

10 WITNESS HORNE: Well, it is just a simple case report. It's one and a half, not even one and a half pages and it just lists the circumstances of the five deaths within the family. It says this is a case report. It involves a kinship in which five consecutive siblings died from SIDS and no child survived.

15 MORRIS SC: Yes. To that extent we are somewhat constrained - do you consider that there's the possibility of a constraint on the promotion or the notification of multiple deaths in individual circumstances because case reports may not get published?

20 WITNESS HORNE: That is likely. If the children are not seen by the same practitioners, they may be in different areas, then having them followed up and realising that there were five in the one family may be difficult but there have been studies which - I am going to be very vague about this but there was one where they looked at all of the deaths and matched them and I'm sorry, I can't remember the absolute details of this study, but I'm pretty sure I cited it and so
25 they actually did match the children from a large database.

MORRIS SC: Professor Horne, at page 6 of your report in the middle of the page you say that it is likely that the ALTE experienced by Patrick which preceded his death led to his epilepsy and this may have contributed to his
30 death. To the extent that you seek to express an opinion as to the development of epilepsy referable to the ALTE experience or the ALTE experience, would you defer to a neurologist on that question?

35 WITNESS HORNE: Absolutely. As we discussed this morning, Patrick after his ALTE was not the same child.

MORRIS SC: As to the extent to which there may have been some potential underlying condition which triggered his ALTE, you would not wish to venture
40 an opinion?

WITNESS HORNE: No, other than what we discussed this morning which was, you know, reflux or a pause in breathing in quiet sleep to which he was not immediately aroused from.

45 MORRIS SC: This morning you were taken to a number of risk factors and asked to identify whether they were present or not?

50 WITNESS HORNE: That is correct. As I said, the major risk factor is sleeping babies on their tummies followed very closely now by maternal smoking and being born prematurely. These factors did not appear to be playing a role in

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5 the deaths of these four children. I just wanted to come back to what you said about the definitions and how things have changed over time. I think Professor Elder can probably address that because the most recent study that's been conducted is the New Zealand cot death study which has just finished and the papers are just coming out. This is providing contemporaneous evidence with the modern definition of SIDS and I think we still find that maternal smoking and particularly bed-sharing are the biggest risks, but Professor Elder can probably elaborate on that.

10 MORRIS SC: Professor Elder?

WITNESS ELDER: I agree. As I said earlier in the day, the combination of maternal smoking and bed-sharing is the highest risk.

15 MORRIS SC: But in expressing the opinions that each of you expressed this morning, you each assumed that each of the children was otherwise in good health other than to the extent that you were specifically directed to the presence or infection in both Laura and Sarah?

20 WITNESS HORNE: From the--

WITNESS ELDER: Well, as--

25 WITNESS HORNE: Yeah.

WITNESS ELDER: As I pointed out, there was - I pointed out that Caleb had had some issues as a baby, and I didn't think his medical history was completely pristine.

30 MORRIS SC: No, and to that extent each of you would defer to any further findings on autopsy or any further specialist opinion that this commission of inquiry may receive. Is that correct?

35 FURNESS SC: Your Honour, I object to that question. The two witnesses are giving evidence about risk factors in relation to the children, they're not giving evidence about the broader matter my friend just raised.

40 MORRIS SC: I'm sorry, your Honour, I might - I don't wish to waste time or be obtuse, but might I rephrase it, withdraw the question and rephrase it? It may well be that in each of these cases, each of these deaths, there are elements about the child's prior medical history which may give rise to indicators as to what might have triggered their deaths. Do you accept that?

45 WITNESS HORNE: Well, I think I actually conclude with that, that now we have genome-wide testing and we have the ability that - to be able to now - if there was some subtle abnormality that was missed in 2003 then we have that ability to now pick that up, and so yes, if the - you know, the, the data, the tests that are going to be presented later on, next, next month, show this, then it may be completely different, and the risk factors that were absent may not be
50 important.

5 MORRIS SC: Is it possible to get the Triple Risk Model? You see the Triple Risk Model that was shown to you this morning, and it's up on the screen now, in relation - and this follows on from the earlier question. In relation to the Triple Risk Model, there's no reference made in the various factors of presence of prior infection, is there?

10 WITNESS HORNE: In, in this version - this is the - this is the version that Roger Byard has put together, yes.

15 MORRIS SC: Is the Inquiry to understand, looking at this in its simplest form, that each of the three intersecting circles, and the risks identified - are we to take away from this that each of the intersecting circles cover young children who have died suddenly, from this model?

20 WITNESS ELDER: Can I just perhaps answer this? That we have to always remember that risk factors are risk factors, they're not - they won't always cause death, so some - many babies have slept prone and not died, many babies have been bottle fed, such as myself, and not died. It's - the model is about things that might work together, and for all risk factors, as a clinician, faced with a baby who's died, I still need to be able to process some mechanism by which that risk factor might have resulted in the death of a child. Now, there is some of these factors when they work together - I certainly feel that there is a plausible evidence base, as I discussed earlier, the in utero exposure to smoking affects serotonin supply in the brainstem, so that when you are faced with an asphyxial insult you can't respond and gasp and self-resuscitate. That's reasonable well-documented.

25 For all the other risks, such as exposure to infection, there are some theories about how that might cause death, as has been discussed, through a toxin effect on the heart rate, but all, all these things you have, you have to kind of go to the end point to truly understand how the infants died.

30 MORRIS SC: And so in relation to the end point, Professor, what are we talking about? When you use that term, what are you - what are we dealing with? Just explain that to me.

35 WITNESS ELDER: Well, you know, to die you have to - either your heart stops and then everything stops or you stop breathing and eventually your heart stops, so something has to be the trigger for that final event, so, so there are infants will - who will tolerate what seem to be unsafe sleep positions and there, there are infants who don't seem to be able to tolerate, so the, the information that we have gained from the epidemiological studies tells us how we can reduce the risks, but we still don't completely understand some of the final mechanisms of death for some of these factors.

40 MORRIS SC: In relation to this Triple Risk Model which we have here on the screen, where each of these circles intersect and it says, "SIDS," we are talking, are we not, in relation to the current definition, which is on the first page of Professor Horne's report. Is that correct?

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5 WITNESS ELDER: I think this becomes difficult because mostly clinically now we don't use the term "SIDS" for managing the babies as they come into our clinical care. It's again a diagnosis of exclusion and, you know, a lot of those early papers, as I said before, they were a mixed group of, of causes of death, probably including some accidental asphyxia and possibly including some unnatural deaths that were not recognised.

10 MORRIS SC: Okay.

15 WITNESS HORNE: And can I, can I just say that if you were talking about SIDS 1(a), if the baby is prone or has their head covered then it would not be called SIDS because there would be that evidence that the baby was in an unsafe sleeping arrangement.

MORRIS SC: Right, so that would take it--

20 WITNESS HORNE: And it would - it - I mean, the baby may still have died, but they're - in this - today it would probably have been called accidental suffocation.

25 MORRIS SC: Okay, and just finally, in relation to the opinion - and I'm directing this to you, Professor Horne - in relation to the relationship between ALTE and SIDS, this opinion here again applies the definition that you have got on the first page of your report. Is that correct?

30 WITNESS HORNE: So - yeah, so the, the relationship has been - you know, in a number of studies have shown that the, the features that are risks for ALTE, so being born prematurely, being one to three months of age, are not the same as the risks for dying from SIDS, and the fact that not very many babies who have an apparent life threatening event have any significant adverse effects.

35 MORRIS SC: But in that paragraph you are using the definition of SIDS set out on the first page of your report. Is that correct?

40 WITNESS HORNE: Again, it would depend when the paper was written, and as we've said, the definition of SIDS is for, for research purposes, and because, because there has been this diagnostic shift that - I mean, you could argue if a baby was prone with its head covered, why didn't it arouse? You know, why didn't it arouse and wake up? So it could have died from SIDS in that position, but now we're trying to sort out which ones have absolutely no risk factors and which babies do have risk factors.

45 MORRIS SC: But when you use the term SIDS in that paragraph you're talking about an unexplained death--

WITNESS HORNE: Yes.

50 MORRIS SC: --after a complete and thorough autopsy and investigation?

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WITNESS HORNE: Yes, so after, after a death scene investigation - so yes, the babies must have a history, a death scene investigation, but the categories that we've discussed of 1(a), 1(b), and 2 are research definitions.

5

MORRIS SC: Yes. Excuse me a moment, your Honour.

JUDICIAL OFFICER: Yes, certainly.

10 MORRIS SC: I have no further questions. I'd like to thank the witnesses for their evidence.

JUDICIAL OFFICER: Anything arising?

15 FURNESS SC: Just one, your Honour. Professor Horne, you were referring to a paper in your oral evidence which you had referenced in your report. Now, there were two that might fit the bill. One is on page 2, the CHIME study, Collaborative Home--

20 WITNESS HORNE: Yes.

FURNESS SC: --Infant Monitoring Evaluation. Was that the study you were talking about?

25 WITNESS HORNE: That's the, the study where they had over 1,000 babies monitored, yes.

FURNESS SC: And the other is the Utah paper, which you refer to on page 6.

30 WITNESS HORNE: On page 6?

FURNESS SC: That's the study of the Utah population database for the death certificate diagnosis--

35 WITNESS HORNE: Yes, yes.

FURNESS SC: --of SIDS?

WITNESS HORNE: Yes, that's right, sorry, yeah.

40

FURNESS SC: Thank you. Nothing further, your Honour.

JUDICIAL OFFICER: Yes, thank you. Well, Professor Horne and Professor Elder, thank you very much for coming--

45

WITNESS HORNE: Thank you.

JUDICIAL OFFICER: --and giving us your time and assisting the Inquiry, and you can go now.

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WITNESS HORNE: Thank you.

<THE WITNESS WITHDREW

5 AUDIO VISUAL LINK CONCLUDED AT 2.57PM

JUDICIAL OFFICER: Yes?

10 FURNESS SC: Your Honour, they are the witnesses for today. Tomorrow we have Professor Cordner, Professor Hilton, Professor Duflou, and Dr Cala, to give evidence concurrently. There will be an interesting shift of chairs. I was proposing to leave it up to the witnesses to decide which single witness wanted to sit here and which three wanted to sit over there, so it's over to those representing the witnesses to choose where they sit.

15

JUDICIAL OFFICER: You can speak to Mr Morris about that.

FURNESS SC: Yes.

20 JUDICIAL OFFICER: Mr Morris, I would be grateful if you would speak to those instructing you to make sure that they understand that I will be deciding the case and it would be very unfortunate if material that maligns people that is not going to be admitted into evidence is given out. I will leave it to you to deal with.

25

MORRIS SC: Your Honour, I'll deal with it, thank you.

JUDICIAL OFFICER: I will adjourn.

30 ADJOURNED PART HEARD TO TUESDAY 19 MARCH 2019