Case No: MK16C00127

IN THE FAMILY COURT SITTING AT MILTON KEYNES

Milton Keynes Family Court MK9

Date: 26/04/2017

Before :

HER HONOUR JUDGE VENABLES

- -

Between :

In the matter of the Children Act 1989	
And in the matter of F(A minor)	
Buckinghamshire County Council	**Applicant**
- and -	
Carla Andrew	**1st Respondent**
And	
Craig Stillwell	**2nd Respondent**
And Effie Stillwell	**3rd Respondent**
(A minor by her Guardian)	

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Mr Giles Bain appeared on behalf of the Applicant
Mr Cyrus Larizadeh QC and Michael Bailey (instructed by **GT Stewart**) for Mother
Mr Paul Storey QC and Mrs Alexa Storey-Rea (instructed by Wollen Michelmore**) for Father**
Ms Victoria Teggin (instructed by Reeds) on behalf of Guardian
Hearing dates:3rd,5th,6th,7th,10th,12th,13th,19th,20th,21st,26th April 2017

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APPROVED JUDGMENT

Her Honour Judge Venables :

1. The court has been concerned with a fact-finding hearing relating to a little girl named Effie Stillwell born in late spring 2016. Her mother is Carla Andrews and her father Craig Stillwell. She was made the subject of an emergency protection order made on 18th August 2016. She has remained in foster care under interim care orders. Effie is the only child of her young parents. The father shares parental responsibility through registration. The parents remain in a committed relationship.

2. Mother is represented by Mr Cyrus Larizadeh QC and Mr Michael Bailey. Father is represented by Mr Paul Storey QC and Mrs Alexa Storey-Rea. Buckinghamshire County Council is represented by Giles Bain. The child appears by her Children's Guardian Debbie House through Ms Victoria Teggin.

3. At the outset of these proceedings the local Authority sought findings that Effie had suffered an inflicted injury at the hands of one of her parents, most likely through shaking, which caused brain injury and her subsequent collapse and admission to hospital in August 2016. The local authority's application for a care order was founded on this single issue.

4. Within these proceedings Effie was diagnosed with EDS IV, formerly known as vascular EDS. The court gave permission for a range of experts to assist in determining what significance, if any, this syndrome might have had in Effie's clinical presentation. At the conclusion of the medical evidence (and before the court heard the parents evidence) the local authority asked for time to consider the medical evidence now before the court. After a period of reflection the local authority applied for permission to withdraw their application for a care order. The application was unopposed by the parents and the guardian.

5. This judgment sets out my reasons for granting the local authority's application for permission to withdraw.

6. The parents have asked that I give my reasons in an open judgment to enable them to openly engage in the debate and development of knowledge around the syndrome known as EDS IV. I give this open judgment with the agreement of all parties.

Events leading to proceedings

7. Effie was admitted to the Accident and Emergency unit at her local hospital at 3:50 am on 15th August 2016 after a reported collapse. On admission to hospital she was unresponsive and had difficulty breathing. She had two seizures lasting 30 seconds. The anterior fontanelle was tense and full. Her head circumference was 39 cm. No external injuries were documented. The working diagnosis was sepsis or intracranial bleed/ infection.

8. A CT head scan was carried out which show that Effie had bilateral chronic subdural hygromas. There also appeared to be a bilateral mild acute subdural haemorrhage. The treating consultant paediatrician Dr Shrestha was of the view that non-accidental injury could not be excluded.

9. A skeletal survey was undertaken. No fractures were seen although an abnormality was observed in respect of the irregularity and splaying of the anterior end of the right six rib. The initial clotting screen of Effie's PT was above the usual limit of 13 at 16.5. The haematologist did not think that this would cause the level of bleeding noted on Effie's brain. An examination was carried out which noted bilateral retinal haemorrhages and no disc swelling. No external injuries were noted on admission.

10. Effie was made the subject of police protection on 15th August. An EPO followed on 18th August. The police commenced a criminal investigation

which is ongoing. Both parents have cooperated with all channels of enquiry.

11. On 16th August 2016 Dr Shrestha the consultant paediatrician summarised the relevant documented injuries and noted two bruises and a small mark to the lip. On 17th August 2016 Effie's condition deteriorated. She suffered two seizures. Concerns were raised regarding further bleeding to her brain. She was transferred to the John Radcliffe hospital. A shunt was subsequently inserted to release pressure on the brain with the release of fluid. Retinal haemorrhages were identified on 16th August 2016.

12. On 22nd August 2016 Effie was discharged from the high dependency unit and referred back to the children's ward at her local hospital. On 15th September she was discharged into foster care. She has remained in the same placement throughout these proceedings. Effie was readmitted to hospital from foster care on the 15th/16th of November 2016 due to concerns about a swelling to the right side base of her skull. She was discharged without treatment. She was further admitted on 10th March 2017 as there were concerns she might have had a seizure. She was discharged without treatment.

13. Effie is now reported to be thriving. It would appear she has suffered no long term consequences from these medical events.

14. During the currency of these proceedings Effie's Mother was diagnosed as suffering from Ehlers Danlos syndrome. Effie was subsequently assessed. Genetic testing identified a definite pathological mutation (deletion) in a gene called COL 3 A1. This gene deletion, in combination with Effie's clinical presentation confirmed a diagnosis of Ehlers-Danlos syndrome (EDS) type IV, formerly known as vascular EDS. Effie thus has a collagen deficit which impacts on the formation of all tissue particularly noted in the formation of the arterial and venous system. It is characterised by thin and

translucent skin, easy bruising, vascular and arterial rupture which may occur spontaneously. Vascular dissection or rupture, gastro intestinal perforation, or organ rupture are the presenting signs seen in the majority of adults with vascular EDS.

15. I am informed that this is the first child with a known diagnosis of EDS IV to be the subject of forensic enquiry in a fact finding hearing before the family courts. In consequence of this diagnosis it has been necessary for all of the medical experts, the other professionals and the court to consider its significance in Effie's presentation at hospital on 15th August. I am most grateful to all of those experts and indeed to the lawyers involved in preparation of this case for the measured, sensitive and child focused manner in which the competing issues have been canvassed before the court. I would also like to commend these 2 young parents for the extraordinarily dignified way in which they have conducted themselves over the course of this hearing. They have been required to listen to a mountain of medical evidence relating to their young and vulnerable daughter all of which served to confirm that she has a life changing diagnosis which will significantly impact on her health, lifestyle and likely longevity.

16. The working hypothesis of the local authority at the outset of these proceedings was that this child had been subject to an inflicted injury, most likely consistent shaking with a force that falls outside the range of normal handling. In consequence of which Effie suffered subdural and retinal haemorrhages and encephalopathy.

17. There has been a lengthy forensic process taken over 10 days with much conflicting medical evidence and research material. At the outset the court was asked to consider whether the child's presentation was

    1) Consistent with unknown aetiology

2) Related in some ways to the complex Ehlers-Danlos IV

3) Consistent with an inflicted injury such as shaking.

However as the hearing progressed the weight of the medical evidence shifted away from the hypothesis of inflicted injury to a direct or indirect causal link to the complex syndrome EDS IV.

The background summary

18. The parents are both in their early 20's. The couple of been together for a little over 5 years. Mother sadly had a miscarriage 2 years into the relationship. They became engaged during the course of that pregnancy. They were both pleased to discover that mother was pregnant with Effie. The couple plan to marry. In common with many families the parents have struggled to obtain accommodation of their own. Mother had been known to social care as a child partly in consequence of her easy bruising, now recognised feature of EDS. Effie and her parents were otherwise unknown to social care before the events of 15th August 2016.

19. Effie was born one month prematurely. She had a natural birth. The labour was prolonged albeit the mother did not experience contractions. There were concerns for the unborn child and mother's health as a result of the mother's blood loss. Effie was born jaundiced. She was discharged home from hospital within 10 days of birth. The baby had a problem with reflux which was the subject of a telephone diagnosis when she was but one month old.

20. The parents were regularly in contact with medical services during the early weeks and months of Effie's life. She was a little girl who was often slow to settle, who vomited and had difficulty in digesting her milk. It took her some weeks to recover her birth weight. The on-call GP service was consulted by the parents on a number of occasions as a result of these issues. During the

course of an on-call GP consultation on 5th June a soft fontanelle was noted. On 4th August 2016 she was seen by the GP during a health check. Her head circumference was measured at 37cm. The physical examination was satisfactory. The parents took her back to the GP on the afternoon of 14th August 2016 because they were concerned about orange markings on the nappy. The parents were reassured. No bruises were noted. The doctor recorded that the head circumference should be monitored by the health visitor. Father was concerned Effie had a hard head. No head measurement is recorded.

21. Approximately 12 hours later (reported to be between 2 am - 3 am or 3 - 3:20 am) the parents woke to Effie's crying. The couple were housesitting for the paternal grandfather. They slept on the floor with Effie in a Moses basket beside them. Mother checked on Effie who appeared normal leaving her in the care of father while she went to prepare a feed. While in father's care she is said to have stopped crying and become stiff. She then became floppy, pale, with a fixed gaze and gasping for air. At 3.23am the emergency services were called by father. The transcript of the father's telephone call to the ambulance service reveals a very distressed and concerned father. His anxiety and obvious panic is in direct contrast with the measured tones recorded in his earlier telephone calls to the 111 service seeking advice on Effie's care.

22. The paramedics arrived to attend to Effie at 3:29 am. She appeared pale floppy and unresponsive (appearing dead). She arrived at hospital at 3:50am and was treated in the emergency department where she was initially noted to be unresponsive and having difficulty breathing.

23. She was seen by Dr Mazumder (a specialty doctor in paediatrics) who observed 2 seizures lasting 30 seconds. The anterior fontanelle was noted as tense and full. Effie's head circumference is recorded as 39 cm. No external

injuries were documented. The working diagnosis of the receiving doctors was sepsis or intracranial bleed/infection.

24. Dr Michelle Russell-Taylor Consultant Paediatrician arrived as the on-call consultant paediatrician for that night at approximately 4:30am. She spoke to both parents to obtain a history and advise on the medical observations. Her recordings of that meeting with the parents were made retrospectively at 6:20 am. On examination she noted a small scratch at the top left of arm (3 cm long) a small area of pink on the top of the lip (noting mother's account that this had only occurred since her admission to hospital). No other marks or injuries are noted.

25. In her oral evidence Dr Russell-Taylor described how very upset both mother and father were on learning that the baby appeared to have had more than one bleed to the brain. She observed that they were so traumatised that they were not really listening. She was not concerned by their response to her enquiries. The parents endeavoured to provide explanations for what might have happened to Effie. Dr Russell-Taylor considered them entirely cooperative recording in her notes "no obvious safeguarding concerns but need to be in (sic) differential".

26. Dr Russell-Taylor noted that the parents made a phone call to the ambulance service. She did not make a record of which parent had made the call. Dr Shrestha's subsequent assumption that it was mother who had made the call was accepted by Dr Russell-Taylor as nothing more than a misunderstanding at the time of case transfer.

27. A non-contrast CT scan was considered by Dr S Banavali on 15th August Consultant Radiologist of Medica. Dr Russell-Taylor has no personal knowledge of Dr Banavali and assumes him/her to be an emergency out of hours resource. Dr Banavali (G72) notes

"*widening of the subdural spaces bilaterally with maximum depth of 10 mm on each side suggestive of chronic subdural hygromas. In addition to this, there appears to be acute subdural haemorrhage which is shallow along the right cerebral convexity and this appears to extend posteriorly towards the inter-hemispheric fissure. Minor degree of left cerebral convexity acute subdural haemorrhage also noted. The appearances suggest possibility of acute on chronic subdural haemorrhage. No midline shift or ventricular compression. Bulging anterior fontanelle is noted. No focal collection. No hydrocephalus. No skull fracture is seen. No evidence of retinal haemorrhage."*

28. On the 16th August 2016 retinal haemorrhages were noted which resolved by 20th of August 2016. On the right there were multiple retinal haemorrhages and in the left eye only one haemorrhage. There were no pre-retinal haemorrhages, retinal folds or swollen optic discs in either eye.

29. On 17th of August a further CT scan was taken verified by Dr Dinuke Warakaulle, Consultant Radiologist. Notes record "*comparison is made with previous CT scan from 15th August. Essentially stable appearances, with evidence of acute on chronic subdural haemorrhage. No other significant you findings."*

30. Effie was thereafter referred to the John Radcliffe Hospital where a further CT scan was performed on 19th August. The scan was conducted by Dr Pretorius Consultant Neuroradiologist who found "*no significant spinal abnormality demonstrated*". He concluded that the subdural collections in the intracranial compartment are most likely to represent chronic subdural haematoma's but there are also more acute small volume haemorrhages within the subdural collections as well as subtle evidence of previous subarachnoid and intra-ventricular haemorrhage.

31. In view of the nature of Effie's presentation at the time of her admission on 15th August a strategy meeting was called. DS Wheeler a Child Protection officer joined that meeting at 2 o'clock and then went on to meet the parents. The police and social care were understandably concerned to understand Effie's presentation and to identify whether her injuries were of a medical, genetic or inflicted, root. In his oral evidence DS Wheeler acknowledged that mother and father were very distressed during the course of his meeting with them. He accepted that this was a very difficult time for them. He described how within 15 minutes of his meeting with the parents he decided to arrest the father on suspicion of actual bodily harm. His reason for doing so being father's agitation and his concern that the father might seek access to the child on the ward. DS Wheeler said he was concerned that the father would not work with him or the other agencies on a voluntary basis. He concluded that arrest was necessary in order to protect the child. The father was restrained in an arm lock.

32. The father subsequently apologised and cried as he explained that he was scared. The father was subsequently re-arrested on suspicion of GBH later that day. The father was interviewed under caution at the police station and kept apart from his partner throughout the day until he was released from detention in the early hours of 16th of August. The father has no criminal history and had never been the subject of arrest. The criminal investigation is ongoing and has been transferred to another officer.

33. This was clearly a very difficult episode for all concerned. It is noteworthy that the parents make no criticism of the doctors, social care nor the police for the manner or fact of the investigation. The child's presentation on admission to hospital required a full and robust investigation but it should never be assumed that the outcome of the investigation is predictable nor that

emotional responses of parents under investigation are easily anticipated. Parents respond to intervention and inquiry in very different ways and whilst those responses might inform the manner of an investigation they should not dictate it.

34. The mother and father have remained consistent in their own account as to the child's presentation on the date of her admission to hospital and in the period leading up thereto. Their accounts to the police given in interview corroborate the accounts of the other parent. Neither parent has been able to provide any specific event that might explain the child's presentation save to describe Effie as a child with a very weak neck and wobbly head who had once banged her head on her mother's teeth and her father's chest as she had been unable to control her own movements even at 4 months old. The only other explanation proffered is an account of Effie banging her head in a car seat whilst in the care of the paternal grandparents two weeks before admission on 15th August. It is noteworthy that Effie's current foster carer observed that Effie was unable to properly manage her own head weight until she was 8 months old presenting with the neck development of a new born.

The findings of fact originally sought

35. On or around 15 August 2016, Effie, then aged almost 3 months was found to have the following:

a. Sudden-onset of a cessation of crying, going stiff and then floppy, going incredibly pale, having a fixed stare and gasping (acute encephalopathy). (Dr C, 18)

b. Acute subdural blood over the cerebral hemispheres and in the posterior fossa (Dr C,18)

c. Large and bilateral subdural fluid collections (seen on 15

August 2016)

d. A tense and full anterior fontanelle about one hour after admission to hospital

e. Widening of the cranial sutures (on CT scan dated 15 August 2016)

f. Subarachnoid blood found on the MRI scan dated 19 August 2016

g. Intraventricular blood found on the MRI scan dated 19 August 2016

h. Mild hypoxic-ischaemic brain injury on the MRI scan dated 19 August 2016

i. Acute subdural bleeds at several different sites (including in the spinal canal), probable acute traumatic effusions, acute subarachnoid haemorrhage and a mild degree of hypoxic-ischaemic brain injury.

j. Multiple right-sided retinal haemorrhages and a single left-sided retinal haemorrhage on 16 August 2016, which had gone by 20 August 2016.

k. Subdural blood in the thoracic and lumbar spine on 19 August 2016.

Causation

The injuries are likely to be due to an episode of abusive head trauma involving a shaking mechanism, with or without an impact against a semi-unyielding object.

In the alternative, the injuries are likely to be due to more than one episode of abusive head trauma.

Timing

The causal event occurred immediately before the onset of the markedly adverse symptoms.

It is likely Effie was harmed just prior to the attendance of the emergency services on 15 August 2016.

Presentation of Effie at time of the injuries:

There was likely to be a change in the behaviour of Effie at the time she sustained the injuries.

Whoever inflicted the injuries is likely to have been aware of a change in behaviour of Effie.

Perpetrator

Effie has suffered inflicted head trauma as a result of either her mother or father handling her in an inappropriate manner, probably by shaking.

Degree of force

If witnessed by another it would be obvious to that person that the handling was inappropriate. The degree of force required to cause the injuries to Effie were greater than that encountered in day to day handling of a 3 month old child.

There is currently no history of accidental head trauma of sufficient severity to account for the totality of the injuries

suffered by Effie.

Pre-existing medical condition

There is currently no evidence of any naturally occurring medical condition that would reasonably explain Effie's clinical presentation or the constellation of injuries.

Evidence

36. I have read the documents contained in the bundles before me and the preliminary documents of all parties. I have also had the benefit of receiving the joint written submissions prepared on behalf of the parents by Mr Storey QC and Mr Larizadeh QC. All parties agree with those submissions as to the law and the evidence and I shall unashamedly rely on them throughout the course of this judgment. I have considered the video recordings produced of Effie which are described as the "wobbly head videos". I have heard the audio recordings of the father from the 111 and 999 calls. I have also seen a selection of images from the parents' phones produced under police disclosure and a bundle of texts/WhatsApp messages similarly produced.

37. In addition to the expert witnesses I have also heard from DS Wheeler, child protection officer, involved in the original strategy meeting at the hospital on 15th August and the subsequent arrest the father. I've also heard from Effie's foster carer and from Dr Russell-Taylor Consultant Paediatrician on-call on 15 August.

The medical evidence

38. Effie presented with no external injuries save two minor bruises to the arm and a mark to her lip which it is accepted was probably caused by the oxygen

mask. There were no other external markings, a feature which, of itself, attracted comment in light of the child's vascular fragility.

39. There has been much debate between the medical practitioners and an evolving jurisprudence in relation to the identification of non-accidental head injury. The presence of the oft described "triad" of intracranial injuries made up of subdural and retinal haemorrhage and encephalopathy whilst being an indicator of non-accidental head injury cannot and should not be treated as a certain diagnosis. I accordingly keep in mind the judgment of Gage LJ in R v Harris [2005] EWCA Crim. 1980. in relation to the triad ...

    (a) *"... at the heart of these appeals, as they were advanced in the Notices of Appeal on the appellant's skeleton arguments, is a challenge to the accepted hypothesis concerning "shaken baby syndrome" SDS; or, as we believe it should be more properly called, non-accidental head injury (NAHI). The accepted hypothesis depends on findings of a triad intracranial injuries consisting of encephalopathy (defined as disease of the brain affecting the brain's function); subdural haemorrhages (SDH); and retinal haemorrhages (RH). For many years the coincidence of these injuries in infants (babies aged between 1 month and 2 years) has been considered to be the hallmark of NAHI. Not all three of the triad of injuries are necessary for NAHI to be diagnosed, but most doctors who gave evidence to us in support of the triad stated that no diagnosis of pure S v S (as contrasted with impact injuries or impact and shaking) could be made without both encephalopathy and subdural haemorrhages. Professor Carole Jenny (a paediatrician and consultant neuro-trauma specialist called by the Crown) went further and said that she would be very cautious about diagnosing*

SDS in the absence of retinal haemorrhaging. In addition the Crown points to two further factors of circumstantial evidence, namely that the injuries are invariably inflicted by a sole carer in the absence of any witness; and they are followed by an inadequate history, incompatible with the severity of the injuries."

40. This case concerns a child with a unique medical profile in the medico-legal context. It is a case that has caused all of the medical professionals and the experts who have assisted the court much pause for thought. The words of Dame Elizabeth Butler-Sloss P in Re U, Re B [2004] EWCA Civ. 567 at Para 23 in which she emphasized the following considerations are, thus, in part relevant to the current case:

    i) *The cause of an injury or an episode that cannot be explained scientifically remains equivocal.*

    ii) *Recurrence is not in itself probative.*

    iii) *Particular caution is necessary in any case where the medical experts disagree, one opinion declining to exclude a reasonable possibility of natural cause.*

    iv) *The Court must always be on guard against the over-dogmatic expert, the expert whose reputation or amour propre is at stake, or the expert who has developed a scientific prejudice.*

    v) *The judge in care proceedings must never forget that today's medical certainty may be discarded by the next generation of experts or that scientific research will throw light into corners that are at present dark.*

These comments are particularly apposite where, as here, there are at least two experts who supports a likelihood that the presentation is due to natural causes

and where only one does not accept that the child's clinical presentation is affected by the diagnosis of EDS IV.

Expert evidence

41. I am extremely grateful to all of the experts who have given evidence to this court. All six of the experts appointed are well known in their field and have international reputations. The early diagnosis of Mother as a sufferer of EDS quite properly led to an application by Mrs Story-Rea on Father's behalf for genetic testing of the baby. That testing and the consequent diagnosis of EDS IV has in many ways shaped the course of the litigation and informed its ultimate conclusion. Whilst there is not consensus between all doctors it has been the courts privilege to observe and consider the healthy and robust debate of some of the world's leading medical practitioners. There is no doubt that in cases such as this, it is essential that the court is enabled to hear from appropriately qualified relevant experts who can assist the court in delivering a fair and just outcome.

42. I have received written and oral evidence from:-

a. Dr Keenan, Consultant Haematologist (report dated 13 November 2016)

b. Dr Neil Stoodley, Consultant Neuroradiologist (report dated 8 December 2016)

c. Mr Peter Richards, Consultant Paediatric Neurosurgeon (report dated 12 December 2016 with addendum dated 23rd February 2017).

d. Mr William Newman, Consultant Paediatric Ophthalmologist (report dated 13 December 2016 and addendum 22nd February 2017)

e. Dr P Cartlidge, Consultant Paediatrician (report dated 23 December 2016 and addendum 15th February 2017).

f. Dr AK Saggar, Consultant Physician and Clinical Geneticist (report dated 11 February 2017).

43. I have also heard from Dr Michelle Russell-Taylor Consultant Paediatrician, the senior doctor on call on 15th August 2016, whose evidence has also been of enormous assistance to this court.

44. An experts meeting took place by telephone on 3rd of March 2017 in order to reduce the areas of dispute and to clarify the points agreed. All 6 experts attended that meeting.

45. In view of the diagnosis of EDS IV I shall begin with evidence of Dr Saggar.

Dr Saggar

46. In his report Dr Saggar confirmed the diagnosis of EDS IV saying (G951): –

"this gene deletion, in combination with the clinical presentation and findings, in my opinion confirms the diagnosis of Ehlers-Danlos syndrome (EDS) type IV, formerly known as vascular EDS. This diagnosis would adequately explain a history of easy bruising, which can occur with normal handling and the cerebral haemorrhage/retinal haemorrhage, after an injury that might be considered by other experts to be minor, i.e. that would not cause bleeding in a normal child. There are significant risks of further easy bruising and bleeding after any trivial or minor injury. This diagnosis has significant implications for the future management and follow-up of this child. Quality of life is affected with this condition and the parents need to be informed in more detail of the implications, risks and complications of this diagnosis".

47. Dr Saggar is a consultant geneticist of international standing. He made the original diagnosis of Effie as a child with EDS IV. Effie has a gene deletion

giving rise to a milder form of the syndrome.

48. Dr Saggar has extensive clinical experience of patients with connective tissue disorder. He has seen children with internal haemorrhages in organs other than the brain as well as the brain. He has treated children with ruptured organs and older people with stretching of their blood vessels. Some patients present with just hypermobility and some with more serious vascular problems. He made clear however, that connective tissue disorder was unpredictable. Dr Saggar was not prepared to be drawn on the degree of collagen deficit and consequent injury. Furthermore Dr Saggar was clear that collagen disorders are not persistent or progressive in nature.

49. He said it is not possible to determine which range of tissues or organs might be affected or at what time or in what circumstances. Spontaneous bleeding or bleeding through normal handling is possible. There is a small ledger by way of database about the impact of EDS. EDS is unpredictable and unique and the symptoms may present differently at different times. He gave evidence that in a young girl aged 13 there was a spontaneous rupture of her uterus following her first menstrual cycle. Until that point her only overt symptom was hypermobility. According to Dr Saggar Effie may never have a further serious episode but then again she might. In this case in August 2016 a perfect storm may have brought it all together.

50. Dr Saggar has over 34 years' experience as a medical doctor and 20 years' experience specifically in clinical genetics and is regularly consulted in medico-legal work. He holds approximately six genetics clinics a month with approximately 60% of his patients being children and small babies.

51. He was asked the written question 'Whether Effie may be suffering from Ehlers-Danlos syndrome or any condition within the scope of your expertise to diagnose which may explain any of the clinical findings thought to point

to abuse?' to which he replied: –

"*the gene test result has unequivocally identified a deletion (mutation) in the gene associated with Ehlers-Danlos syndrome type IV, formerly called vascular EDS. This confirms the diagnosis of EDS type IV in Effie. This in my opinion would adequately explain the presenting clinical findings that might otherwise point to abuse*"

In his oral evidence he expanded on this answer adding that Effie has a susceptibility to easy bruising, vascular fragility which in other patients has given rise to bruising from handling that would otherwise be regarded as normal. He was entirely comfortable accepting the parent's assertion that the mark to Effie's lip, as noted in hospital, arose from the use of the oxygen mask.

52. When asked about the retinal haemorrhages he made clear the limits of his expertise in identifying cause. He posited that something must have occurred to precipitate the haemorrhages because of the number. However, whilst acknowledging the limitations of his expertise, he reiterated the child's susceptibility to bleed and the unpredictable nature of the syndrome. He was unwilling to be drawn further in considering whether there was an external event or something that had happened spontaneously to precipitate the retinal haemorrhages. He made clear that he didn't routinely examine eyes in patients with EDS IV and further accepted that retinal haemorrhages may be more prevalent than we know. He further accepted that there was a risk of haemorrhage from any vessel and thus retinal haemorrhages. Importantly he could not exclude EDS as a real possibility of the cause of Effie's presentation in this case.

53. He advised against any form of head injury which could give rise to retinal haemorrhage or subdural haemorrhage for example through contact sport. He

accepted that in clinic he conducted more external examinations with some limited internal examination of organs.

54. Dr Saggar was clear that the parents would need comprehensive advice as to how to manage Effie's care going forward. He was shown a collection of short videos of Effie including one where her father was acting like a puppeteer. Having seen the videos produced of father and child he saw nothing of concern albeit he repeated his advice as to the need for the parents to be careful with her. He said that generally his advice to parents tends to be 'expect the worst but hope for the best'. He would not advocate contact sport but opined that children have to live and that common sense has to prevail. He emphasised the need for Effie to avoid activity with acceleration / deceleration forces at work.

55. Dr Saggar accepted Mr Storey QC's contention that EDS is a developing area and that there are many unknowns. He confirmed that collagen is known to be associated with the vascular system, the arterial system including the small capillaries, the formation of membranes, including the 3 membranes over the surface of the brain. The collagen deficit is not easily observed in the blood vessels or tissue. He advised that collagen is involved in not just the formation but also in the healing process. This means that the healing process in Effie is therefore not as robust and strong as it might otherwise be and thus is intrinsically weaker.

56. In this case no membranes are noted in Effie's scan taken on 5th September 2016 some 3 weeks after her admission. Thus it appears she is not developing scar tissue within the subarachnoid space as would more usually be observed.

57. Dr Saggar made clear that there is currently no real protocol for dealing with children with EDS and that it tends to be done rather badly within the health

service. There are 2 national treatment centres to which he refers patients. There is no treatment beyond a single drug (Celiprolol) which is now being used and which is believed to help. Dr Saggar said it was really a question of applying common sense advice and ensuring a patient is able to wear a bracelet which can alert doctors to the presence of the disorder. He accepted the professionals needed guidance as to hand how to handle a child with EDS IV. He repeated that it is a rare condition and that the categories within it are not closed and are constantly under review. He opined that clinical classification is based upon clinical presenting features but that as the range of clinical findings change and evolve it becomes necessary to accept that the clinical classification is only really suitable for severe cases. Patients can present with features in one particular subgroup only to develop other features over time. The science and understanding of Ehlers-Danlos is thus evolving.

Mr Newman Consultant Paediatric Ophthalmologist

58. The identification and aetiology of retinal haemorrhages is an important element of the clinical assessment. As Mr Newman advised in his report the mere presence of retinal haemorrhages does not give rise to diagnosis but the need to investigate searching for diagnosis. The presence of multiple retinal haemorrhages is however, in the absence of underlying medical cause or disclosed appropriate trauma, commonly found either as a result of birth or inflicted head injury.

59. He advised that the appearance of retinal haemorrhages in one eye only or gross asymmetry is reported in about 20% of cases. In respect of birth related retinal haemorrhages Mr Newman reported that this is the most common known cause of extensive retinal haemorrhages which may be bilateral, asymmetrical or unilateral. He referred to a recent study where haemorrhages

were most frequently found (77%) following assisted delivery reducing to 30% in normal natural delivery.

60. Mr Newman made clear that retinal haemorrhages cannot be accurately dated. Relying on published data he opined that most superficial retinal haemorrhages would likely resolve within a few days and intraretinal haemorrhages within about 17 days. He was content to accept however that there are some reported outliers with unresolved haemorrhages noted 50 days after identification. In his report Mr Newman advised that retinal haemorrhages do not "mature" or change in a way that allows accurate timing by clinical observation alone or further to determine if there has been more than one period of haemorrhage prior to the first examination

61. Mr Newman accepted that in asserting (G613) "*the retinal haemorrhages have likely occurred within about a 17 day period prior to their identification on 16th of August 2016 and are consistent with having occurred at around the time that Effie became acutely unwell*" that the 17 day period was likely to be the maximum period. This period was identified from birth cohort data and research of birth haemorrhages. He was clear that this was not an absolute period. He considered it unlikely that the retinal haemorrhages noted in Effie occurred at birth.

62. He accepted that the retinal haemorrhages were superficial and resolved swiftly between the 16th and 20th of August 2016. He was only able to assess those that were seen. It was not possible to tell whether there were others at the time of any index event. He accepted that it was not possible to say when the haemorrhages actually occurred just because of when they resolved. The superficial retinal haemorrhages resolved within a short period of time. He did not consider that there was anything particularly abnormal with that. He acknowledged that the mere presence of retinal haemorrhages

doesn't identify the cause and repeated that it was essential that the clinicians looked at the wider picture including history context and examination.

63. Mr Newman accepted that there was a respected body of belief that raised intracranial pressure may give rise to retinal haemorrhages. This is addressed in the joint publication of the Royal College of ophthalmologists and Royal College of paediatrics of 2013 "abusive head trauma and the eye in infancy" which concludes: –

> " *conclusion: experimental and clinical data demonstrate that an acute dramatic rise in intracranial pressure (ICP) may produce unilateral or bilateral retinal haemorrhages in infants that resemble those reportedly caused by abusive head trauma*."

Whilst Mr Newman said he would agree with the conclusions of this document it was still necessary to interpret the statements and conclusions in the context of the clinical findings of any one particular case. Insofar as Effie's case is concerned he observed that the retinal haemorrhages identified are not those usually seen in acute or chronic raised intracranial pressure in children and observed that there were no intracranial vascular or abnormalities identified on the neuroradiology.

64. Mr Newman referred the court to an error in his contribution to the expert's telephone meeting (E 29 line 14). He accepted that Mr Patel had not seen Effie. She had been seen by the Head of Paediatric Ophthalmology Mr Hildebrand previously and on at least 2 other occasions by other consultants.

65. In his main report Mr Newman opined that it was unlikely that EDS IV was responsible for the retinal haemorrhages noted. In his addendum however he made clear that he could not exclude EDS IV as a cause or contributor. He accepted his view had changed in light of the diagnosis setting out his

opinion as follows;

"Effie has a genetic abnormality in COL 3 A1 which I previously referred to as Ehlers-Danlos type 4. She was identified as having one retinal haemorrhage in the left I and in the right eye 10/20 retinal (multiple) retinal haemorrhages. There is no one pattern of haemorrhaging that clearly identifies the cause of that haemorrhaging.

In this very complex case from the information provided and in the knowledge that not everything in medicine has a clear explanation there are in my opinion 3 possible scenarios: –

that the ocular findings are;

1) cause unknown/undetermined

2) related in some way to the complex Ehlers-Danlos 4, which has not been previously reported to my knowledge

3) consistent with an inflicted injury such as shaking.

I would say that Effie has been extensively investigated, and setting aside "unknowns" that the clinical finding in Effie's eyes are most commonly associated with a traumatic head injury, however she clearly has a complex underlying genetic condition which is a wide field of potential abnormalities and I cannot exclude the Ehlers-Danlos from being a realistic possibility as a cause or contributor in some way. I am therefore not able to conclude from the eye findings alone which of scenario 2 or 3 is the more likely.

It remains for the court to determine the facts of the case"

66. Mr Newman accepted that no cases of retinal haemorrhage had been reported in children with EDS IV. It is a particularly rare syndrome and the cohort

necessarily small. It is possible that retinal haemorrhages are associated with this type of EDS IV. It cannot be excluded. In evidence he restated that the type of harm seen in the absence of other abnormalities might be due to head injury. He accepted however that the doctors do not know enough about EDS IV for him to exclude it as a realistic possibility underpinning the haemorrhages. The doctors must look at the wider picture including the history the context and the medical examination.

67. When cross-examined by the local authority Mr Newman accepted that his use of the term “realistic possibility” in his addendum report at (G964) did not necessarily equate to the legal construction of such phrase.

68. In the view of Mr Newman the retinal haemorrhages were consistent with evidence of inflicted injury most likely shaking. Having considered the video clips he saw nothing to suggest that the handling of Effie would likely result in retinal haemorrhages. He went on to say that it was still his view that if the retinal haemorrhages were caused by trauma it is likely the force required, and taking into account the fact that Effie has been diagnosed with vascular EDS, would still be significant. He would however defer to Dr Cartlidge. He thought it unlikely that spontaneous bleeding would lead to the retinal haemorrhages identified. There are no reports of such retinal haemorrhages.

69. When cross-examined by Mr Larizadeh QC on behalf of mother Mr Newman accepted that he had not examined a child of 3 months with the presentation of Effie nor examined a child with EDS IV who has been shaken. He accepted that it was necessary for the experts reporting in the case to be very cautious, as the effects of EDS IV had not been studied in detail.

70. Mr Newman acknowledged in his report that EDS is a complex group of conditions. There have not been specific studies looking at retinal haemorrhages in these conditions. He accepted that spontaneous retinal

haemorrhages were a possibility and further acknowledged that there were large cavities in the medical knowledge.

71. Mr Newman accepted that it was necessary to put the ophthalmic findings into perspective in considering a) causation b) contribution / degree of force c) unknown cause and readily conceded that the ophthalmological findings did not trump all and were but part of the picture.

72. Mr Newman accepted that by the time that Effie was seen for her first ophthalmological examination she had been in hospital for more than 24 hours. There was evidence of raised intracranial pressure and a bulging fontanelle. He was then asked to consider 1) trauma – accidental and non-accidental and 2) the degree of force/trauma dependent upon susceptibility. Mr Newman accepted that Effie has an abnormality in the superstructure of her blood vessels as a result of the missing collagen gene. Mr Newman further accepted that retinal haemorrhages were most common in birth and that the level of incidence varied according to the type of birth. He accepted that doctors did not know the cause of the largest group of retinal haemorrhages and acknowledged that the evolving medicine surrounding connective tissue disorders sits in parallel with the understanding and care management of haemophiliacs from 20 years ago.

73. Mr Newman concluded that he remains of the view that he could not exclude Ehlers-Danlos as being a realistic possibility as cause or contributor to the retinal haemorrhages identified in Effie. He described ESDIV as a very complex condition giving rise to much thought.

Dr Keenan Consultant Paediatric Haematologist

74. Dr Keenan is a consultant paediatric haematologist at the Alder Hey

Children's Hospital. He qualified in 1990 and is a fellow of the Royal College of Pathologists and member of the Royal College of Physicians. He has been a Consultant Paediatric Haematologist since 2002 and involved in the preparation of medico-legal reports for the past 7 years.

75. The blood tests on Effie were extensive and thorough and no disorder of blood clotting cells or blood clotting proteins were noted. It was however Dr Keenan who observed that Effie's Mother had been identified by Dr Trench rheumatologist, to have Ehlers-Danlos syndrome and who accordingly recommended that Effie should be subject to genetic testing.

76. In his report he observed that Ehlers-Danlos syndrome is a disorder that affects collagen which is a structural protein in many parts of the body including blood vessel walls. He recorded that there are different subtypes of Ehlers-Danlos syndrome and some are a cause of spontaneous bleeding. He expressed the view that if Ehlers-Danlos syndrome is present in Effie this would not have any effect on the haematological blood tests but would still lead to a risk of bleeding.

77. In evidence he confirmed that he does not have expertise in EDS IV and would defer to Dr Saggar in relation to Ehlers-Danlos syndrome. He advised that he had seen two or three children with Ehlers-Danlos syndrome in his clinical practice and was aware EDS IV can give rise to spontaneous major vessel bleeding. Dr Keenan reminded the court that he was the expert responsible for raising the issue of EDS IV in his report. As a Consultant Paediatric Haematologist the possibility of EDS IV would always be considered. As a haematologist he would not make such a diagnosis and would refer any child (where this was a live issue) to an appropriate expert such as Dr Saggar for diagnosis and care management. He made clear that he would not take responsibility for the clinical management of patients with

EDS IV in the long term.

78. He advised that haematological blood tests undertaken were conducted outside the body. As a haematologist he would not be responsible for testing blood vessel walls or function in any way. He described how the stop code in the EDS IV condition affects blood vessel walls. This type of mutation where a child inherits the gene deletion from one parent but is able to produce collagen from another, means that there is a small amount of natural collagen present. EDS IV predisposes the individual to major blood vessel and life-threatening bleeding. There doesn't need to be additional trauma or additional cause for spontaneous bleeding to occur.

79. Under cross examination by Mr Larizadeh QC on behalf of the mother Dr Keenan advised that his role was to consider whether there was an underlying bleeding problem or not. Whilst acknowledging that he was not an expert in the field of EDS IV he confirmed that it was his understanding that a child with EDS IV will be at risk of potential bleeding problems.

80. Dr Keenan asserted that there was unanimity between the professionals during the experts meeting that the level of force required to cause a bleed in a child with EDS IV may be appropriate or inappropriate. He opined that with EDS IV spontaneous bleeding can occur with no trauma whatsoever. He went on to say that in his view bleeding can occur when handling has been appropriate.

81. Whilst Dr Keenan has come across EDS IV in the context of his clinical work he acknowledged that EDS IV was rare. He accepted that there was a reasonable amount of information in literature as to the condition. He has attended international lecture talks where the issue has been addressed. He

accepted under cross-examination from Mr Storey QC that this was an evolving area of medicine particularly from the genetic perspective. He opined that vascular fragility was a consequence of EDS IV whether venous or arterial.

82. Dr Keenan confirmed that he had personal experience of one case with severe EDS IV where there was severe spontaneous bleeding with no obvious trauma. He described that the blood vessel wall as lacking the usual strength and will not heal as well.

83. He accepted that the cautious and careful advice given by Dr Saggar to patients with children who have EDS IV was in keeping with the advice given by haematologists to haemophiliacs some 20 years ago. At that stage the medicine and treatment of haemophilia was undeveloped and risk management more difficult. He acknowledged that in today's medical world those treating children with EDS IV would necessarily take a cautious approach to their care and management.

84. Ms Teggin, for the child, asked if there was a root cause for the spontaneous bleeds experienced by patients with EDS IV. Dr Keenan opined that it was likely the "normal" population would regularly have small bleeds which resolve because of the effective collagen within the individuals. Such collagen enabled the blood clotting system to work effectively and seal off rupture. Patients with EDS IV do not heal as effectively. He accepted that once there has been a bleed there was a heightened risk of further bleeding in that area of vulnerability.

<u>Dr Cartlidge consultant paediatrician</u>.

85. Dr Cartlidge has been a consultant paediatrician since 1990. He is also Senior Lecturer in Child Health and has extensive teaching and research experience.

He is a fellow of the Royal College of physicians and Deputy Editor of Archives of Disease in childhood. He is regularly consulted as a forensic expert.

86. In his main report he considered the presentation of encephalopathy and intracranial injury in conjunction with the retinal haemorrhages in the wider clinical context. Encephalopathy is defined as disturbance of the brain's function. A range of clinical presentations may be noted. Dr Cartlidge notes acute encephalopathy in the period leading to Effie's admission with sudden onset of a cessation of crying, going stiff and then floppy, going pale having a fixed stare and gasping. She had seizures about one hour later. Other salient clinical features are recorded as acute subdural blood over the cerebral hemispheres and in the posterior fossa (which Dr Stoodley advised was up to 10 days old on 15th August 2016 and about 3 to 7 days old on 19thAugust 2016). There were large and bilateral subdural fluid collections on the CT scan on 15thAugust 2016 which grew larger during subsequent 4 days. A tense and full anterior fontanelle about one hour after admission, a widening of the cranial sutures. An absence of subdural membranes (including the CT scan of 5th September 2016). Subarachnoid blood and intraventricular blood is noted on 19th August 2016 with mild hypoxic ischaemic brain injury. No focal brain injury, multiple right-sided retinal haemorrhages and a single left-sided retinal haemorrhage on 16th August 2016 resolved by 20 August 2016. Subdural blood in the thoracic and lumbar spine on 19th August 2016.

87. In his original report Dr Cartlidge expressed the provisional view that Effie's presentation was most consistent with non-accidental head injury. Dr Cartlidge made clear that his provisional view was subject to the results of the genetic testing for EDS IV. In evidence he made clear that even without the confirmation that Effie suffered from EDS4 there were aspects of Effie's

presentation that were difficult relating to the subdural fluid collection, the hypoxic ischaemic collapse, the number and speed of resolution of the retinal haemorrhages and the fact that no membranes were noted as developing. In light of the diagnosis of EDS IV Dr Cartlidge revised his opinion. In evidence he made clear that he had now reached the conclusion that Effie's presentation was most likely caused by the evolution of a natural disease. He said that he did not have the level of confidence he normally had in assessing causation because of the unusual features in the case. He said he found it very difficult to accept that the EDS IV had nothing to do with this.

88. Dr Cartlidge was a careful and considered witness. He made clear that Effie's presentation coupled with the diagnosis of EDS IV was extremely rare and opined that it was unlikely that any medical expert would have come across such a combination before. As a consequence he was very cautious about the way in which he treated the medical evidence and made clear that he could not be certain what had caused Effie's injuries. In his view it was difficult to accept that EDS IV had nothing to do with the child's presentation. There was a question as to whether or not there was spontaneous bleeding or whether there was some event to prompt it including the possibility of haemorrhage at birth. He didn't consider that the child's admissions to hospital from foster care in November 2016 or March 2017 helped his understanding what it happened to Effie in August 2016.

89. He made clear that although he would be advising that features of the injuries were consistent with non-accidental head injury if EDS IV was not present, he was nonetheless anxious about that conclusion because of the unusual features of Effie's presentation. He explained that if the retinal haemorrhages and the injury to the head occurred at the same time as the deterioration happened, the resolution of the retinal haemorrhages as noted on 16th August

by 20th August was unusually rapid in his experience. Whilst he deferred to Dr Newman as the expert he still considered the resolution to have happened very quickly in his clinical experience. Furthermore, in his view, logic dictated that the speedy resolution must mean that there was not a lot of blood which was surprising and indeed counter intuitive in a child who has a propensity to bleed.

90. Dr Cartlidge said he hadn't thought this through at the time of the experts meeting but had since reflected on this part of the history. He opined that now we know that Effie has EDS IV it would seem likely, on balance, that she has a fragility and a propensity to bleed. This would suggest that there would be more bleeding in the retina rather than lesser bleeding: another unusual feature. He went on to say that if the retinal haemorrhages occurred with shaking we must assume that the small amount of blood seen in the retina is unusual for a child with this vulnerability. He posited that the only way there could not be a significant amount of blood was if the retinal haemorrhages were not sustained on 15 August. Mr Newman had suggested they may be up to 17 days old. That takes us to the beginning of August. However as Dr Cartlidge observed, no adverse symptoms were noted at the beginning of August to underpin the theoretical possibility of two causal events.

91. The possibility of two causal events was addressed in the experts meeting and reviewed in evidence. Dr Cartlidge said that he was seeking a better understanding of the disappearance of the retinal haemorrhages. If, deferring to Mr Newman, the retinal haemorrhages were a consequence of shaking, he posited such an event would have to occur at the beginning of August followed by an acute subdural event which was found by Dr Stoodley to be between 3 and 7 days old on 19th August 2016. This would give 2 episodes of

bleeding whether this was spontaneous or shaking. Dr Cartlidge said that he didn't think it was appropriate to exclude a birth bleed as a cause of the event giving rise to the subdural fluid collection.

92. In the experts meeting Dr Cartlidge was keen to consider the child's presentation before the collapse. She was seen by an out of hours GP on 14th August 2016 and note was made that her head size should be monitored. It was further recorded that the father was concerned that her head was hard. Furthermore the head was large very shortly after the collapse with a full fontanelle which increased in size very rapidly. Furthermore 3 neuroradiologists who considered the neuro-radiological images considered the images of 15th, 16th and 19thAugust 2016 to reveal chronic subdural collections with the smaller acute collections noted.

93. During the experts meeting it was suggested that retinal haemorrhages could not have resulted from the birth. Dr Cartlidge accepted that the retinal haemorrhages, found on 16th August 2016, were unlikely to have been directly caused during birth. He stressed however that the fluid collection in the subdural space of this child, now known to have a vascular fragility, could increase the risk of retinal bleeding. He stressed how important it was for the doctors to acknowledge the uncertainties in an unusual case such as this.

94. In the experts meeting he expressed the view that the clinical evidence was suggestive of chronic subdural effusions examining the possibility that chronic lesions give rise to the risk of consequent rebleeds saying

"I have to discuss the fluid in the brain because Neil feels that this is acute traumatic effusions. I feel that when you look at the clinical evidence within that that they're most likely chronic subdural effusions and that actually is quite an important issue because if there are chronic lesions here, then you

have got the chronic lesion which might rebleed. Also, you've got a child with Ehlers Danlos Syndrome who has a greater propensity to bleed, so this causes a child to have by the time August comes along a pre-existing situation where there may be multifocal bleeding within the head, so I don't think things are anything like as clear cut as Neil was just saying. I feel that this child's got a chronic subdural, which is the reason why the GP highlighted some problem with the head. He was not specific but he asked the health visitor to monitor the size of the head, which you wouldn't do unless there was an anxiety about it. So I've got---- I've got unease about suggesting that this is an acute traumatic effusion when I think we've got evidence that somebody was already worried about the head beforehand and the head size was---- had increased sharply by2cm in an eleven-day period and about one hour after the child collapsed somebody noticed that the fontanel was full and tense. This is not what normally happens with an acute traumatic effusion. It doesn't normally happen as rapid as that and I think that this is more in keeping with there being a chronic subdural effusion and that makes a big change to the situation because if you've got a pre-existing lesion, then you've got a reason for the child having multifocal fresh bleeding. So whilst I answered to question---- one of the questions earlier on, 7, whether the subdural bleeding that was shown on the scan could have been from birth and I agree that it wasn't, that doesn't mean to say that the root cause of the more recent subdural bleeding can't be from---- either from birth or from an earlier episode of inappropriate handling or a knock that would otherwise be considered to be trivial but isn't in the presence of Ehlers Danlos Syndrome sparking off something that led to a chronic subdural effusion. Also, if that's the case, I think that if you've got a chronic subdural effusion, I've seen several cases, and Bill will know about these cases, where it seems to have increased the likelihood to later retinal haemorrhages. I can't

prove that but that's my emerging observation on quite a few cases now"

95. Dr Cartlidge accepted that if the chronic subdural bleed was not birth related then it was likely linked to a memorable event. However he considered that logically the total energy/trauma required to cause subsequent bleeding would be less because Effie has fragile vessels. Dr Cartlidge did not feel able to say what type of handling might cause her to bleed. He considered the video clips from the parents' phones, described by the lawyers as the 'wobbly head videos', which included a recording of father holding Effie around her tummy and acting as a puppeteer with her before the camera. So far as the earlier videos are concerned he did not see anything inappropriate in the handling and considered the content to be entirely innocent. He did not accept the local authority suggestion that the father's actions might be seen as abusive saying only that he would advise caution where father was acting as puppeteer because of the risk of dropping her rather than anything that appeared inherently dangerous.

96. Dr Cartlidge opined that if there was no birth related injury where the incidence of intracranial bleeding was now accepted to be relatively common occurring in approximately 20% cases (Looney) and 46% (Rooks) then you would still be looking for an incident involving a sharp acceleration/deceleration of the head which includes a shake adding that the energy likely to be required being less than would normally be necessary.

97. Dr Cartlidge was uncomfortable in limiting considerations to an incident of shaking and instead preferred to consider the possibility of a sudden change of movement. He considered the car seat incident described by the paternal grandparents at Gulliver's land which reportedly involved a movement of about 1 cm but thought it unlikely that this would generate sufficient energy because of the limited rebound reported. In any event there were no other

symptoms at that time. However he suggested that if there was a bleed with less force it would likely be relatively asymptomatic with no obvious signs of her being unwell. He said he would defer to Dr Saggar to the amount of force necessary to create the bleed.

98. Dr Cartlidge accepted that Mr Newman had not considered the number of retinal haemorrhages or the fact of their early resolution to be unusual. Dr Cartlidge was surprised that for this child with EDS IV there was not greater bleeding. That there was not more in terms of volume he didn't feel had been explained. He thought it was logical that if this child had fragile blood vessels there were more likely to be haemorrhages. He acknowledged that whilst he deferred to Mr Newman he had a different clinical experience. He said that multifocal bleeding would be significant if not for the presence of EDS IV. He added that he understood the fragile vessels continued throughout the subdural space. An important feature in this case is the child's propensity to bleed.

99. As a consultant paediatrician it is Dr Cartlidge's role to put together the pieces of the clinical jigsaw. He acknowledged that it was possible that Dr Stoodley was correct in identifying the subdural collections as acute. However Dr Cartlidge remained of the view that this child's clinical presentation, when considered in light of the EDS IV, was more consistent with a child who had an experienced acute on chronic collection.

100. It was put to Dr Cartlidge that Dr Stoodley had been unequivocal in his view that this child had experienced an acute subdural haematoma immediately preceding her collapse. He preferred to take a more cautious approach. He was aware that Dr Stoodley was of the view that the blood in the spinal canal could not have tracked from the posterior fossa and yet, Dr Cartlidge explained, he has a number of cases in clinic at any one time and at

the moment has 2 cases in clinic where two very experienced neuro radiologists are firmly of the view that such tracking is possible. He did not consider the presence of blood in the spinal canal as probative of a shaking event.

101. Dr Cartlidge also sought to distinguish another of the features that Doctor Stoodley relied upon namely that there was no loculation of fluid. The absence of loculation is treated by Dr Stoodley as indirect evidence that there are no membranes present in mid-August and therefore no evidence of healing. However Dr Cartlidge noted that the scan undertaken in September some 3 weeks after Effie's first admission did not reveal any membranes. So far as Dr Cartlidge is concerned the medical picture is thus further complicated by the presence of EDS IV which means that the patient doesn't heal well, tending to produce wafer thin scar tissue meaning subdural membranes can have difficulty in forming. The presence or absence of membrane is therefore an unreliable marker for distinguishing between acute and chronic haematomas.

102. Dr Cartlidge accepted that the change in the volume of the fluid collections in the first few days after Effie's collapse is more in keeping with a dynamic process than an acute traumatic effusion - adding that of course it can be both. Dr Cartlidge's reading of the situation was that something had destabilised the system. He posited that if there is a chronic subdural, a minor bleed might destabilise situation. It's that instability in the subdura that may give rise to the sudden change in size. He said '*I can't exclude a major incident in August but if there is a chronic subdural bleed in a patient with a propensity to rebleed that may be sufficient to destabilise. Moreover in Effie's case in a child with EDS 4, that rebleeding is likely to be more. That does have to have some relevance logically'*

103. Dr Cartlidge was asked if he accepted that Effie's presentation could be explained by natural causes. The two things that concerned him were the hypoxic ischaemic damage and the possibility of acute bleed. He accepted irritation to the surface of the brain caused by the build-up of fluid causing a restriction in respiratory and cardiac output. Dr Cartlidge agreed that Effie was at an increased risk of subdural bleed at birth because of the presence of EDS IV and accepted there was no reason why a birth related subdural bleed should behave any differently to any other form of subdural haematoma.

104. Thus Dr Cartlidge remained clear in his view that this was a little girl whose clinical presentation revealed a number of unusual features. These considered alongside her diagnosis of EDS IV led him to conclude that her injuries were the consequence of a naturally evolving disease rather than the consequence of an inflicted injury.

Mr Richards consultant paediatric neurosurgeon

105. Mr Richards was a Consultant Paediatric Neurosurgeon from 1987 to January 2017 when he retired from the NHS. He has extensive experience as a medico legal expert and an international reputation. He had some limited involvement in Effie's care on admission to the John Radcliffe hospital in August 2016. Mr Richards was on-call when Effie was transferred on 19th August 2016. He was consulted by one of his senior junior doctors (who was in fact a Swiss consultant working at the John Radcliffe during a period of training). Mr Richards did not perform any of the subsequent operations on Effie albeit that she was his last patient before retirement seen in his outpatient clinic.

106. Having seen the updating material Mr Richards confirmed that nothing had changed his view since his brief letter written by way of addendum in an email of 23rd every 2017 where he said "*if Effie has Ehlers-Danlos type 4, as*

Dr Saggar indicates, it changes my opinion. Ehlers-Danlos type 4 syndrome is associated with intracranial haemorrhage, so may account for the findings identified'.

107. Mr Richards accepted that the features noted in Effie were in common with shaking cases but there was nothing suggestive of repeat abuse. Mr Richards acknowledged that this was the first case in which he had been asked to report with a child who had a diagnosis of EDS IV. He stressed this was therefore a very unusual case. EDS IV is a genetic disorder of a type known to be associated with easy damage to tissue and easy bleeding. He took particular note of the advice Dr Saggar gave as to the management of this child's care. Advising that she should not participate in contact sports or other forms of robust activity. For Mr Richards this served to underline how serious the problem is for Effie.

108. He observed that there were a number of troubling and worrying features about this child's presentation even before she was identified as suffering from EDS IV. He considered it unusual that the retinal haemorrhages disappeared so quickly. Like Dr Cartlidge he deferred to Mr Newman but reiterated that in his clinical experience this was unusual. He said it was necessary to question if her healing was as it should be even before the diagnosis. Then she was diagnosed with EDS IV.

109. In his written opinion he noted her to be in a state of moderate encephalopathy (disturbance of brain function) on admission. Neuro - radiological investigation identified a subdural collection with some separation of sutures and subarachnoid blood. Retinal haemorrhages were observed and resolved 4 days later. She continued to suffer neurological dysfunction over subsequent days with intermittent episodes of seizure and notwithstanding aspiration her subdural collections did not settle and needed

an overflow pipe, a subduro peritoneal shunt inserting to drain the fluid.

110. She is thus described as a child who suddenly becomes unwell with subdural haemorrhagic collections, subarachnoid blood identified radiologically in retinal haemorrhages seen. Features consistent with a child who has been forcibly shaken at the point of collapse. However Mr Richards notes that there were no features of a severe violent assault with no extracranial injuries and no features of repeated abuse. Whilst examining the possibility of a single forceful shake perhaps consistent with a momentary loss of control Mr Richards noted a number of features in the case which raised concern as to whether that was not the explanation for Effie's illness. He observed that Effie had been unwell in the days leading up to her admission. She was noted to be vomiting and this is said to have been worsening. It was unclear as to whether this was indeed due to the oesophageal reflux previously diagnosed. He also noted that there had been concern about the size of the child's head even before her collapse.

111. Effie had a large volume of fluid in her subdural space which was seen by Mr Richards and which was bloodstained. In the view of Mr Richards this could be either chronic subdural haematoma breaking down and becoming watery or fresh blood mixed with cerebrospinal (CSF) fluid, an acute traumatic effusion. He observed that there were features pointing to both possibilities although radiologically they may look similar. He noted that the head circumference had moved from the 9th to the 50th centile over a 6 week period.

112. When pressed, Mr Richards said it was his conviction that his original conclusion that this child's features were typical of shaking was shaky. He said it was clear that in Effie's case the injury threshold had been exceeded but he questioned whether in a normal child the handling would have

exceeded the injury threshold. He opined that the weakened collagen simply dropped the injury threshold. Thus if the child is vulnerable it is possible less handling can cause the same damage. Everything is weaker. In a child such as this normal handling causes an abnormal response.

113. Under cross examination by Mr Bain for the local authority Mr Richards was asked about his observations at paragraph 1.16 of his report which suggested the possibility of membranes being visible within the fluid on 15th August. He advised that the CT scan was not clear and he could not be confident that he observed membrane. At paragraph 1.37 he commented on the ultrasound of 30th August. He stressed that ultrasound are generally considered to be a poor diagnostic tool. In his view ultrasound are really only useful for telling you about the size of the collections. He went on that if membranes are observed those can be possible indicators of chronic subdural haemorrhage. If they are not there however that is not necessarily probative of anything. He said there was no clear evidence of membranes. He said that he had to consider the possibility of an acute traumatic effusion, a chronic traumatic effusion or a mixture of the two. He expressed caution however in applying generally accepted medical observations in this particular instance since Effie is not a 'normal' child. He opined that since she has been diagnosed with EDS IV, it follows that normal handling may give rise to injury.

114. Mr Richards accepted that acute blood was noted in the subarachnoid space which was fresh as was seen when she was aspirated. However it was necessary to consider whether or not she had had a little rebleed onto a chronic subdural haematoma. He added that the existence of a chronic subdural haematoma would give rise to another source of fragility in the child. Looking at the wider clinical picture he expressed the view that there is

radiological evidence, coupled with the slight increase in head size before admission which points to chronic subdural haematoma. The lack of membranes points to an acute traumatic effusion but is not conclusive. The blood in the spinal canal could suggest acute traumatic effusions but there is nothing certain in this case.

115. Mr Richards posited that if there was a chronic subdural haemorrhage then something caused the rebleed but not necessarily a “nasty” event. An aggravating event was not necessarily a “nasty event” and indeed may have been caused by the EDS. As he explained by way of metaphor the collagen deficit means the bricks are weak but their weakness might not show itself until something knocks into them.

116. So far as the November and March admissions to hospital were concerned Mr Richards didn’t consider them connected. He accepted that there had been problems following the insertion of the shunt. He acknowledged that she’d had surgery and that had gone well. However in his view the fact that the surgery had gone well and the fact the shunt didn’t give rise to any ongoing problems didn’t invalidate the other argument or concerns around EDS IV.

117. Mr Richards accepted that Effie’s presentation was consistent with the possibility of a shake but he returned once again to the diagnosis of EDS IV and the vulnerability of Effie in consequence. Such a vulnerability could give rise to injury when normal people would not suffer such injury. He described Effie as having a generalised fragility. He said that he liked to describe the brain as a three-storey building with the top story occupied by the upper hemispheres, the middle storey by the posterior fossa and the ground floor by the spinal canal. The presence of EDS IV can cause problems with all 3 stories. He went on to say that the subdural haemorrhages are markers of an event around the brain but it’s what happens to the brain itself that is of

primary concern. In Effie's case there is no indication of brain damage at all.

118. Mr Richards was content to acknowledge that he could not be sure what had happened to Effie but felt that that was an entirely respectable response in the circumstances. He considered that Effie's case was unique amongst the clinical cases he had dealt with and indeed with the medico legal cases on which he had given expert advice. He said that EDS presented an ever-changing picture. It now appears that the categories of EDS are not closed.

119. Mr Storey QC on behalf the father asked Mr Richards a series of questions about the issue of patterning. Mr Richards accepted that a significant number of children are born with subdural haemorrhages from birth. It is not clear as to whether or not those haemorrhages are caused pre-birth or during birth. Mr Richards said it was hard to talk about patterning and the differential markers between the abuse and non abuse. He spoke of a recent study conducted by a colleague who had gone to conclude that patterning was not necessarily a satisfactory indicator of abuse.

120. Mr Richards accepted that when a collection of fluid or haemorrhages are identified with a part of the brain this is merely a means of describing where the collection sits over the brain beneath it. This does not however mean that the fluid sits in defined pockets. He said he had experience of fluids moving in the subarachnoid space and described how he had aspirated a child's fontanelle and observed fluid moving beneath the surface of the skin. He said in his view the fluids can communicate or move but thought it more likely when the fluid becomes watery, as when blood mixes with the CSF.

121. Mr Richards accepted that all 3 of the hospital radiologists who had considered the scans of Effie were of the view that they were seeing acute on chronic collections. He accepted that if it was a chronic haemorrhage it could

be birth related. He opined that EDS alters the healing responses and where there is vulnerability he would be surprised if you didn't see subdural bleeding from birth. Indeed he went on to say that he would agree that there was a substantial possibility that she was born with subdural bleeding.

122. Mr Richards posited that where, as appeared to be the case here, the head circumference was growing before the child's collapse it may be part of the picture of chronic subdural bleed. He acknowledged that the most likely source of a cerebral bleed was the bridging veins. He described how the bridging veins (which he likened to guy ropes) become stretched. In normal circumstances this opens a patient up to rebleeds which would or could occur spontaneously in a normal child. In this child, he considered there was even more proneness to bleeding. Thus he concluded there would not necessarily be a "memorable" event. He was content to accept the proposition that spontaneous rebleeding does occur. He acknowledged the theory accepted by some ophthalmologists that intracranial pressure can cause retinal haemorrhages. He said he would not be surprised if the presence of EDS IV affects vessels in the eye. He was advised that Dr Cartlidge had shared his concern about the rapid clear up rate of the retinal haemorrhages and shared the view of Dr Cartlidge that this was an extraordinary feature in a child where her vulnerability to bleeding would, logic suggests, be prone to losing more blood.

123. He noted that the use of a drain to reduce the fluid collection on the brain did not work for Effie even over a number of days and that it was in consequence of that continued fluid collection that a shunt was required. He considered that to be yet another slightly abnormal feature in the case.

124. Finally Mr Richards sought to assist the court by distinguishing between the textures of the dura and arachnoid, describing the dura as the toughest

rather like gristle and the arachnoid like cling film. He was content to accept that this child might have a compromised arachnoid as anything has the potential to be weakened if there is collagen deficit. He stressed that collagen is the building block and is in deficit in this child.

Dr Stoodley consultant Neuroradiologist

125. Dr Stoodley has been a Consultant Neuroradiologist since 1998 and based at the Southmead Hospital Bristol since 2002. He is Honorary Consultant Paediatric Neuroradiologist at the Bristol Royal Hospital. He has extensive clinical and medico legal experience. Dr Stoodley's expertise is in the interpretation of imaging investigations. He considered the abnormalities seen on Effie's scan as likely to be due to an abusive head trauma involving a shaking mechanism.

126. In his written report Dr Stoodley provided an explanation of terms. He described how the brain is surrounded by a series of membranes with the whole surface of the brain covered by a very fine membrane called the pia mater. The brain, within its pia covering, lies within a bag - like covering of another fine membrane, the arachnoid mater. A much tougher, thicker membrane lies between the arachnoid and the inner aspect the skull itself and this is known as the dura. Fluid in the subarachnoid space that's between the pia and the arachnoid membrane is normal and entirely innocent. Fluid in the subdural space i.e. between the arachnoid and the inner layer of the dura is always due to a pathological cause such as infection or trauma.

127. Describing how images are interpreted he advised that relatively fresh blood on CT scan is of high attenuation (i.e. is brighter than the underlying brain) but as the blood becomes older it becomes progressively less bright and over a variable period of 1 to 3 weeks becomes of the same attenuation as the underlying brain before becoming of a low attenuation (i.e. darker) than

the underlying brain. He acknowledged that the appearance of blood on MR scans is more complex, depending on the passage of time between scanning and bleed, scan sequences as well as other factors such as the depletion of blood into pre-existing fluid collections or cerebral spinal fluid (CSF), making it difficult to give accurate estimates as to the time that blood has been present on a head scan.

128. Dr Stoodley noted in the CT scan of 15th August 2016 small amounts of high attenuation on both sides of the posterior interhemispheric fissure and in the posterior fossa. Dr Stoodley acknowledged that it was not possible to accurately age the blood since the high attenuation on the CT scan can be seen from soon after an episode of bleeding for up to 7 to 10 days. He also noted evidence of a large low attenuation (dark) subdural fluid collection over both convexities with uniform attenuation throughout with no evidence of membrane formation or loculation. He poses 2 main possible explanations. The dark fluid could either represent acute traumatic effusion (believed to occur when the arachnoid is damaged at the time of the head injury allowing dark cerebral spinal fluid (CSF) to leak from the subarachnoid space into the subdural space), or chronic (older) subdural bleeds. Dr Stoodley preferred the first hypothesis to the second suggesting that if the collections were due to chronic subdural haematomas then as the blood is darker than the underlying brain it would be at least 2 to 3 weeks old at the time of examination whereas if the dark fluid is due to acute traumatic effusion then all of the subdural abnormalities could be explained by single event.

129. He noted no membrane formation in any of the subsequent scans taken on 15th,17th19th, 26th August 2016 and 5th September 2016. He told the court that the only absolute way for him to distinguish between chronic and acute collections would be if he saw the presence of membranes or the laying down

of scar tissue. Such membranes or scar tissue would normally develop over a minimum period of 2 to 3 weeks for healing to show. He acknowledged that the absence of membrane doesn't prove an acute bleed as membranes do not always form or indeed may be too fine to be visible on the scans. Another differential feature referred to by Dr Stoodley was his observation that the fluid collections were getting bigger in sequential scans. This increased the probability of acute traumatic effusions in his view.

130. Dr Stoodley confirmed that he had no clinical experience of a child or children with EDS IV. He was aware of its principal features and accepted that the collagen deficit would give rise to a predisposition to vascular fragility. However he considered that this predisposition would not fundamentally alter the child's presentation following trauma of different types. Whilst he would expect more bleeding on one site he did not consider that the pattern of bleeding would be changed.

131. Dr Stoodley considered it unlikely that recent blood noted on the scan was from a birth related subdural haemorrhage as subdural blood usually resolves by 4 weeks. Whilst he accepted that there had been very few follow up scans in children known to have been born with subdural haemorrhage he posited that it was likely a well recognised group of children would have become identifiable if bleeds at birth gave rise to subsequent birth abnormalities.

132. MRI imaging of the spine on 19th August 2016 was noted by Dr Stoodley to show subdural blood posteriorly from the upper thoracic to the lower lumbar region. This was not noted by the hospital neuroradiologists. Dr Stoodley considered this to be potentially very significant citing unpublished data from his hospital unit in Bristol which records spinal subdural haemorrhage in about 50% of cases of abusive head trauma whilst being unusual in cases of accidental head trauma. Dr Stoodley did not consider it

possible for blood to track from the posterior fossa to the spinal canal as posited by both Dr Cartlidge and Mr Richards describing it as anatomically unlikely. It was put to Dr Stoodley that the tracking of fluids through the subdural cavity was now accepted. Dr Stoodley remained firm in his opinion that fluids could not track.

133. In the view of Dr Stoodley the scan abnormalities in Effie can be explained on the basis of abusive head trauma with the most likely mechanism being shaking. It being the majority medical opinion that the shaking of an unsupported infant head backwards and forwards leads to an acceleration / deceleration and rotational forces. The consequential differential rotation of the brain stretches the bridging veins, leading to bleeding in the subdural space which is created during the assault. In Dr Stoodley's view, the nature of the associated brain injury where abusive head trauma leads to admission would likely result in

a) a change in the child's behaviour at the time of the causative event;

b) a magnitude of change in behaviour which will to some extent reflect the severity of the brain injury;

c) the child not behaving normally after the causative event;

d) the rate of progression of symptoms and signs, to some extent, being reflected in the severity of the brain injury.

134. Turning then to the issue of force; (E 51 line 9 – 19) he opined that nobody knows the absolute degree of force required to produce the constellation of injuries. Multifocal bleeding and acute traumatic effusions indicate obvious inappropriate handling to the objective view. Dr Stoodley has been instructed in approximately 850 cases as an expert. Of those he would say that approximately 10% involved accidental head injury a further

10% persistent abuse. The remaining 80% have resulted in judgments where the court has found momentary loss of control. In the experts meeting there was general consensus that Effie's predisposition could affect the level of external force used to produce the injuries. So far as Effie is concerned and whilst acknowledging that there is only a mild degree of brain injury and she is unlikely to have long-term consequences, Dr Stoodley was emphatic that he could not see how EDS IV would give rise to presentation such as Effie's on 15th August 2016.

135. Under cross examination by Mr Larizadeh QC on behalf mother he acknowledged that EDS IV was a complex syndrome with a wide field of abnormality. Dr Stoodley accepted that his contribution to the investigation provided but part of the jigsaw. He accepted that his findings did not trump those of the other experts. All the pieces of the jigsaw needed to be seen both individually and together. Dr Stoodley was referred to the fact that Effie's head had enlarged between 4th August when it was recorded at 37cm and 15th August when it was recorded as 39cm. He felt that such enlargement was a paediatric issue. He accepted that there were no physical signs of external abuse. This was a matter of fact. He added however that with improvements in cross-section imaging the medics knew rather more than they had done previously about a child's presentation. In the old days he would only get to see children and scan those who presented with obvious injury. In more recent times he's been asked to investigate children who have no external injuries.

136. Dr Stoodley was asked to consider the child's history in parental care. The history suggested that there were no concerns about the care offered; no evidence of neglect; the parents had sought appropriate medical advice throughout her young life. The father's account of the child's presentation (H

OCP) is yet another part of the jigsaw. Dr Stoodley accepted that he did not know the impact of EDS IV on the development of membrane. He opined however that if the presence of an underlying collagen or bleeding disorder gave rise to this presentation he would have expected it to be the subject of research and well-recognised. When asked about the possibility of spontaneous bleeding he was resistant. He said "I have problems with spontaneous bleeding". There may appear to be no apparent cause for a spontaneous bleed but something would have to happen for it to occur such as in a valve rupture where there is pressure elsewhere in the system. He was of the view that connective tissue disorder would more likely give rise to the presence of more blood on sites of injury rather than the pattern as presented on the images relating to Effie. He opined that if the child was more vulnerable to rebleeding it would follow that this would be into the same site.

Evidence from the foster carer

137. It is unusual for the court to have the benefit of hearing from a foster carer but all parties agreed that it would assist the court to have some understanding of how Effie presented on her reception into care and the occasions of her admissions to hospital from foster care in November 2016 and March 2017 and her vaccinations. I found her evidence most helpful in completing the picture of this child's presentation and development.

138. The foster carer has cared for Effie since September 2016. She described how on her reception into foster care Effie appeared very behind in her development, particularly with regard to her muscle development and her ability to control her head. She told the court that she would ordinarily expect a child of 3 to 4 months to have more control over their head. She advised that it wasn't until January 2017 (by which time Effie was 8 months old) that the child was able to hold her own head. Effie is now doing very well. She

has had a recent appointment with the physiotherapist. She is reaching her milestones albeit that she is at the bottom end of each progression marker. She is now trying to weight bear.

139. The foster carer described in her statement the 2 occasions on which Effie was admitted to hospital from foster care. The 1st occurred over the 15th/16th of November 2016 and the 2nd occurred on Friday, 10th March 2017. The foster carers took Effie to hospital in November after they noted some swelling on the base of her head on the right-hand side. The swelling was in the area in which Effie had had a shunt fitted a couple of months before. That section of her head been shaved and appeared swollen and puffy but there was no reddening. The foster carers were reassured by the doctors that all appeared well, suggesting that the swelling could have been there previously. It is however noteworthy that neither of the carers (both experienced foster carers) noted the swelling in the 2 months before this admission.

140. The second admission in March 2017 was prompted by Effie's unusual presentation. She was reluctant to take a bottle and vomited a little (not an unusual event for Effie). She is then described by the foster carer as making a funny noise (like she was hiccuping at regular intervals). Her eyes are then reported to have glazed over. The foster carer described Effie as being unable to focus and appeared to be looking through the foster carer. She did not go limp or stiff. She coughed and projectile vomited before she reportedly started to "come round". An ambulance was called and she was taken to Stoke Mandeville hospital where she was observed but discharged home before midnight. The foster carer noted a couple of red spots under Effie's eyes. The doctor advised that these were likely burst blood vessels after Effie had been coughing.

141. The foster carer was also able to describe Effie's reaction to one of her

vaccinations. She had her first set of vaccinations with the foster carer without event. On the second occasion that she received her booster vaccinations in December 2016 she had a marked reaction. Her leg immediately went very red with the colour emanating from the vaccination site. Effie's reaction was monitored for a brief period thereafter. The redness subsided and Effie returned home.

142. In the medical notes the foster carer is recorded as describing how Effie will roll her eyes up into the back of her head. Obviously a matter of note for the foster carer but nothing which caused concern for the medical teams.

143. I'm aware that the parents have established a very good relationship with the foster carers. The parents have expressed their profound gratitude for the care that Effie has received and the foster carers have spoken positively of the care and devotion that these 2 young parents have shown towards their young daughter.

The parents

144. I have not had the benefit of hearing from the parents as the local authority decided to apply for permission to withdraw at the conclusion of the forensic medical evidence. I have however had the opportunity of observing them throughout the course of this trial and indeed during earlier case management hearings. They have always conducted themselves with extraordinary dignity at every hearing before this court.

145. I understand that they have developed a good working relationship with social care as well as a good relationship with the foster carer. I am of course aware that in the hours after Effie's admission to hospital on 15th August 2016 Mr Stillwell became very distressed and agitated. His distress and agitation led to his subsequent arrest. DS Wheeler who has given evidence to

this court of course acknowledged that this was an extremely difficult and distressing time for this young couple. The circumstances of DS Wheeler's interview with the parents at the hospital were inevitably strained. It is perhaps unfortunate that the meeting at the hospital was allowed to escalate so quickly to the point where DS Wheeler felt it was necessary to make an arrest.

146. As Ms Teggin for the Guardian said in her submissions, this young couple have lived through unimaginable horror over the last few months beginning with their daughters collapse in August, her subsequent removal and then her life changing diagnosis. It is the view of all professionals that this young couple have matured throughout these proceedings. Particular comment has been made about Mr Stillwell and how he has become more measured and reflective. They are a couple and are determined to remain so. The Guardian has been very impressed by the way in which these young parents have conducted themselves and the growing maturity they have demonstrated. They have done much research into Effie's condition and wish to continue in their journey of self-education to protect Effie in the future.

147. Both parents have made clear through counsel that they have no criticism of any the professionals in the case and respect and understand the role of all of the protective agencies. It is perhaps worth adding that both Mr Storey QC and Mr Larizadeh QC make particular point of commending their clients not just for their presentation in court but more generally. They have understood the challenges for the child protection agencies and shown a determination to work with them in circumstances that all accept have been distressing and stressful.

148. The court has seen a number of texts and WhatsApp messages produced under police disclosure. The local authority place no reliance on them: an

entirely appropriate position to take. They reveal nothing of assistance to the court save to suggest that the parents occasionally conducted disagreements through texts and messaging. What they do reveal however is there were no concerning text messages shortly before Effie's admission into hospital. They also appear to demonstrate among other things that:

1. Effie is a much loved and much wanted baby;
2. The parents were proud of the pregnancy;
3. They enjoyed preparing for the birth with great care and thoughtfulness;
4. They were delighted with the birth;
5. They had bonded well with Effie;
6. There have been many happy times for the parents and Effie in the lead up to the pregnancy and after the birth;

149. I have also heard the NHS111 and 999 calls. The transcripts fail to convey how very differently Mr Stillwell presented in those calls. In the calls to 111 seeking advice Mr Stillwell was calm, measured and polite. In the 999 call Mr Stillwell was distressed, tearful, anguished, and bewildered. He followed all instructions given to him but he was clearly so concerned for Effie who was on the point of collapse that the operator had to help him recover his composure. His responses to the operators during both calls were entirely consistent with a father concerned for the welfare of his child and reflected the significance and seriousness of his daughter's presentation.

150. This is echoed in the evidence of Dr Russell-Taylor who described the parents appearing shocked and struggling to absorb what was happening at the hospital. They were bewildered and desperate to understand what could have caused Effie's collapse. She spoke of how the parents tried to help with possible causes and there was no hesitation in their trying to help. The

parents' behaviour in the hospital with the medics was caring, child - centred and appropriate.

151. The child focused approach of the parents has gone on to inform the way in which they have worked with the foster carers. The parents are clear that the foster parents have offered wonderful care for Effie. They now wish for the foster carers to feature in Effie's life story work so that as Effie gets older she is able to understand the extraordinary care she received in their hands.

152. I have also seen a small album of photographs prepared by Miss Andrews and Mr Stillwell. It is a beautiful collection of photos and has written into the back page a message that they can never have anticipated that the court would see. It was written by Miss Andrews and says this:-

153. "*It's December 24th 10:15pm Xmas eve. I'm ready for bed, but as I write this I am dreading Christmas tomorrow because our baby won't be here. I am missing you Effie…we all are. Me + daddy promise to have you home soon. We love you, always have. Always will xxx*"

The application for permission to withdraw

154. The local authority seeks permission to withdraw their application for a care order. They do so on the basis that the evolving medical evidence would no longer enable them to make out the threshold. Such application is made pursuant to FPR 2010 r29.4. In determining the application to withdraw the paramountcy principle applies. The paramount consideration for the court is whether the withdrawal of proceedings would promote or conflict with Effie's welfare. The court must consider each case on its own facts to see whether there is some 'solid advantage to the child to be derived from continuing the proceedings'. *Re N (Leave to withdraw Care Proceedings [2000]1FLR134).*

155. It is of course for the local authority to discharge the burden of proof in establishing threshold on the balance of probabilities. No more and no less. The standard now authoritatively established is the balance of probabilities: ***Re B*** [2008) UKHR 35. As confirmed in the direction of Mr Justice Mostyn in ***Lancashire v R*** [2013] EWHC 3064 (Fam) there is no pseudo-burden upon a parent to come up with explanations for things (paragraph 8(vi)).

156. The local authority's review of the medical evidence in this case accords with that of the court and leads me to conclude that the local authority would be unable to make out the threshold. I can see no solid advantage to Effie in requiring the proceedings to continue.

The law and my analysis of the evidence.

157. So far as the medical experts are concerned this case is unique. None save for Dr Saggar had ever come across a child with EDS IV in the medico-legal context. Dr Cartlidge and Mr Richards changed their minds about the likely cause of Effie's injuries as a direct consequence of the diagnosis of EDS IV. Both came to the view that her injuries were the likely consequence of a naturally evolving disease. Doctor Saggar considered that the EDS IV would adequately explain the presenting clinical findings. Mr Newman could not exclude EDS IV as a possible cause or contributor and nor indeed could Dr Keenan. I remind myself once again of the words of Dame Elizabeth Butler Sloss P in Re U, Re B [2004] that the court must show particular caution where one of the medical experts disagree and where one opinion declines to exclude a reasonable possibility of natural cause.

158. In cases of non-accidental head injury there is always, as here, expert medical evidence from a variety of different disciplines. There is a significant body of case law which deals with the fact that whilst proper attention should be given to the opinion of medical experts it is essential that those opinions

are considered against a background of all of the other evidence. In ***A County Council v K, D & L*** [2005] EWHC 144 (Fam) at paras 13 and 44, Charles J stated:

> *7. "It is important to remember (1) that the roles of the court and the expert are distinct and (2) it is the court that is in the position to weigh up the expert evidence and give its findings on the other evidence. The judge must always remember that he or she is the person who makes the final decision."*

159. The medical findings in this case are acute subdural bleeding, superficial retinal haemorrhaging, encephalopathy and mild hypoxic ischemic damage coupled with the diagnosis of EDS4.

160. I consider it important that none of the injuries frequently found on children who have been shaken or subjected to some form of abusive head trauma are present. This is of particular significance where, as here, Effie has a diagnosed predisposition to bruising and bleeding by virtue of her vascular fragility. Whilst the absence of such external features does not exclude non-accidental head trauma, their presence can give the court greater confidence in making a positive finding. In Effie's case there is a mixture of unusual features and absences in the child's presentation which I shall set out as follows:

a) An absence of any bruising on the body. In particular the absence of any bruising that the Dr Cartlidge and Mr Richards consider would have been likely in a child with vascular EDS around the rib cage trunk area associated with holding a child tightly whilst shaking her.

b) An absence of methaphyseal fractures which may be associated with the flailing of the limbs when a child is shaken.

c) The absence of posterior rib fractures which are associated with shaking on the expert evidence in this case, again due to gripping and the leverage of the posterior ribs against the spine.

d) An absence of any damage at the cranio-cervical junction.

e) An absence of any focal contusions on the outside or inside of the skull. Thus, there is no evidence whatsoever of impact.

161. The best evidence of soft surface impact would be some form of focal internal contusion. Similarly, the best evidence of impact against a hard surface would be external / internal contusion at the site of impact. There is no evidence of impact and therefore I consider that the only other likely mechanism of inflicted injury would be shaking. That proposition is challenged by the lack of any bruising on a child with vascular EDS IV and is relevant to my consideration of the evidence.

162. Dr Keenan confirmed that EDS IV affects the superstructure of the vascular system in both the arterial and venous system. He likened the effects of EDS IV to haemophilia sufferers prior to treatment where there would be spontaneous bleeding to the vessels without the need for a trigger**.** He was able to give first hand evidence of a patient with a severe spontaneous bleed with no obvious trauma. He was content to accept that spontaneous bleeding might have no obvious cause and indeed posited that normal people probably had spontaneous bleeds all the time: the difference being that such bleeds resolve in ‘normal’ people because of their ability to heal: an ability which is compromised in Effie as a sufferer of EDS IV.

163. The court also heard from Dr Saggar that vascular EDS also affects smaller capillaries. Mr Richards wondered in the expert meeting whether and to what extent Ehlers Danlos as a connective tissue disorder affected the strength of membranes. He talked about this in his oral evidence, but in fact it was laid to rest by Dr Saggar in his oral evidence that the membranes over the brain are composed of and associated with collagen along with every other organ in the body, including bone. Indeed, the court heard that collagen

is the biggest protein in bone.

164. Dr Saggar's evidence on the unpredictable course of EDS IV was as alarming as it was persuasive. He said in oral evidence that it would be a foolish person who predicted how severe EDS IV and its impact might be and which range of organs might be affected. In his view symptoms do not manifest the same way all the time. He could not exclude inflicted injury but he wouldn't want to speculate about any previous event. Importantly he could not exclude EDS as a real possibility of the cause of Effie's presentation in this case.

165. Mr Richards and Mr Cartlidge are experienced clinicians and experts. They were both evidently troubled by the nature of the advice that Dr Saggar felt it necessary to give to the parents of their young EDS patients. A safeguarding plan needs to be put in place asap to help the parents and Effie and others in terms of her handling. Lack of collagen can affect the membranes and healing process. There is not enough knowledge about EDS and impact on the brain and on retinal haemorrhaging. However having heard the evidence of Dr Cartlidge and Mr Richards and that of Dr Saggar, I am persuaded that spontaneous bleeding or bleeding through normal handling is possible. There is a small ledger by way of database about the impact of EDS. EDS is unpredictable and unique and the symptoms may present differently at different times. The example of the young girl aged 13 who died as a consequence of an unforeseen and unforeseeable spontaneous rupture of her uterus following her first menstrual cycle was tragically vivid. According to Dr Saggar Effie may never have a further serious episode but then again she might.

166. It is apparent from the medical records that Effie was a little girl who was difficult to feed, who regularly vomited, had a diagnosis of oesophageal reflux and who did not easily settle. She was born prematurely and was

delayed in her development. The foster carer confirms that she presented like a new born on placement and could not bear her own head weight until 8 months. There is no evidence to suggest that her muscle development was delayed as a consequence of the brain injury. It is clear that Miss Andrews and Mr Stillwell regularly sought medical advice about their young baby. All such advice would appear consistent with a premature, sickly baby in the care of young and inexperienced parents. I heard nothing to cause me concern in Mr Stillwell's consultations with the 111 service. His evident distress in the subsequent 999 call, in my view, was genuine and entirely appropriate in the circumstances.

167. Dr Cartlidge and Mr Richards observed a number of unusual features in Effie's case even before the diagnosis of EDS IV. In my view the clinical findings point towards a chronic subdural effusion with a small acute bleed or rebleed. It is significant that there is an absence of any external bruising or markings in this child with her predisposition to bruising and bleeding. Furthermore Effie was unwell in the days leading up to her admission. She was noted to be vomiting and this was said to be worsening. The child's presentation to the GP on 14th August prompted the GP to note that her head circumference should be monitored. This was not the intended focus of the consultation and thus leads me to conclude that the GP was concerned about her head size. Furthermore Mr Stillwell thought the child's head was hard when seen on 14th August 2016 which again suggests that there was already some activity. Dr Cartlidge also noted that Effie's head circumference increased with greater rapidity than usual in the hours immediately following her collapse again suggesting that the fluid collection began before her collapse. I am also mindful of the radiological findings of Dr Banavali on 15th August 2016, Dr Warakaulle on 17th August 2016, Consultant Radiologists and Dr Pretorius Consultant Neuro-radiologist on 19th August 2016 who all

identified small acute on chronic collections.

168. I am conscious that the considered views of Dr Stoodley do not accord with this analysis. Dr Stoodley is very clear that there is both a spinal bleed and acute traumatic effusion, namely cerebral spinal fluid from the subarachnoid space rather than chronic subdural haemorrhaging. However Dr Stoodley accepted that it is frankly impossible to make the distinction between CSF and chronic bleeding by scanning alone as the signal on the scan is identical. Furthermore both Dr Cartlidge and Mr Richards confirmed that they had clinical experience of blood tracking from the posterior fossa to the spinal canal, challenging Dr Stoodley's view that tracking was not possible and was a clear marker of abuse. Dr Cartlidge as consultant paediatrician is required to take an overview. He shares the view that the empirical evidence supports a conclusion of chronic subdural. Moreover Mr Richard who was on hand as Consultant when Effie was received at the John Radcliffe observed blood stained fluid in the subdural space. He considered that this could be either chronic subdural haematoma breaking down and becoming watery or fresh blood mixed with CSF, an acute traumatic effusion. Looking at the wider canvas I consider there is empirical support for my conclusion that there is chronic subdural.

169. The unique feature in this case is that Effie is now known to have EDS IV with a consequent fragility. Bleeding in the subdural space is common at birth and on the Rooks paper affects around 46% of the population and on the Looney 20%. Dr Keenan observed that it was likely that the general population had little bleeds all the time. Mr Richards posited that it is likely there subdural bleeding in everyone at birth. In a child with a vascular fragility I consider there to be a high probability supported by the evidence that Effie almost certainly had subdural bleeding at birth. She was a normal vertex delivery which is associated with birth bleeding to a significant

statistical degree. Her likelihood of bleeding would have been enhanced by the existence of her EDS IV susceptibility. This on the evidence of Dr Cartlidge would have made, or could have made the bleeding more significant and longer lasting. Dr Cartlidge was not persuaded by the absence of membrane formation as argued by Dr Stoodley in respect of whether the images seen were chronic blood or acute traumatic effusion. Dr Cartlidge did stress that the absence of membrane formation within the accepted period of formation for acute bleeds i.e. after 21 days was unusual and proposed its absence as a likely feature of EDS 4 and not be relied upon as support for Dr Stoodley's hypothesis for acute traumatic effusion.

170. The expert evidence is that if Effie had bled at birth and there were chronic subdural bleeds, then the bridging veins crossing between the arachnoid and the dura would have had further to travel and would have been more likely to bleed either spontaneously or on normal handling. I am satisfied on the evidence that this child's vulnerability significantly and directly impacted on the risk of further bleeds post birth. Furthermore I accept, as, Mr Richards opined, any event likely to cause a rebleed did not necessarily need to be a 'nasty' event because the threshold for injury had been lowered by the presence of the EDS IV and thus in a child such as this normal handling can give rise to an abnormal response: a view shared by both Dr Saggar, Dr Keenan and Dr Cartlidge. It therefore follows that the parents cannot necessarily identify a trigger or indeed the clinical response to a spontaneous bleed or rebleed in a child with EDS IV. Effie is acknowledged to be a child who was hard to settle, a poor eater, and prone to vomiting. Her parents were young and inexperienced. There was nothing in her behaviours that would have caused any reasonable parent to be alarmed or concerned about her medical response to an event prior to her eventual collapse.

171. The presence, pattern and speedy resolution of retinal haemorrhages add

to the complex picture. Mr Richards and Dr Cartlidge, who have considerable experience in this area were surprised at the rapid clear-up rate of the retinal haemorrhages but were simultaneously troubled by how little blood was present. Two apparently contradictory features in the child's clinical presentation most likely linked to EDS IV. The rapid resolution of the haemorrhages did not surprise Mr Newman but he accepted that he has little experience of EDS IV. There were no observed abnormalities in the vascular system of the eye but as Dr Saggar opined EDS affects all tissue. Moreover I note that the unpredictable course of EDS IV is not easily observed in clinical assessment. I find myself returning to the example given by Dr Saggar of the 13 year old girl with EDS with clinical features limited to hypermobility who subsequently haemorrhaged and died.

172. Mr Newman accept that there is a respected body of ophthalmologists who support raised intracranial pressure as a cause of retinal haemorrhages rather than traction physical injury and that it is likely that this child was experiencing increased intracranial pressure at the point of collapse. At the experts' meeting Dr Cartlidge spoke of the coincidence he had observed in a number cases where there are retinal haemorrhages in circumstances where there is also chronic bleeding.

173. Mr Newman was appropriately cautious in his evidence accepting that even when EDS IV or any other contributory cause is absent, cases such as this are the most difficult. His revised position in the addendum report reflects the complexity of this child's clinical presentation. Thus considering the expert evidence as a whole, including the fact that vascular fragility affects the eyes as much as anywhere else, I consider on balance, that EDS IV is involved in the retinal findings. Whether it is the cause, or whether normal handling would have been sufficient, or indeed whether the cause is unknown does not really matter. The retinal haemorrhages could not found a finding of

abuse in respect of eyes on the evidence as a whole in this case.

174. The other thing that concerned Dr Cartlidge potentially was the existence of hypoxic ischemic damage. In cross examination, he accepted, as do I, that this could well have been accounted for by cerebral irritation caused by the build-up of fluid causing a restriction in respiratory and cardiac output. Thus, in the end he was where he was in the experts' meeting by the time he had concluded his evidence. In other words, he was of the view that Effie's case was one of evolving natural disease.

175. Thankfully Effie has made a full recovery and there is no reported concern about her brain function.

176. It is of course necessary for the court to consider the forensic evidence against the wider canvas. It is clear from the parent's engagement with the medical services before her collapse that she was a precious baby, adored by both parents. In my view they acted entirely appropriately at the time of her collapse seeking medical assistance in timely fashion. They worked openly with the doctors on admission to hospital. The unfortunate exchange between Mr Stillwell and DS Wheeler occurred at a time of high emotion. Neither parent has a criminal history. Both parents have worked well with all professionals since she was received into care. Their accounts to the police in interview are consistent with the other and internally robust. They had no opportunity to consult after the point of fathers arrest and little time alone after she was admitted to the hospital. Finally there is unanimous acknowledgement by all professionals that this young couple have shown maturity and restraint in their dealings with all professionals and remain committed to the long term care of their young and vulnerable daughter. For these reasons, which must be considered alongside my analysis of the medical evidence, I consider that Effie's collapse was most likely the consequence of a naturally evolving disease either in the form of a

spontaneous rebleed after haemorrhage at birth or in consequence of the lower injury threshold and an event consistent with normal handling.

177. I thus concur with the local authority's analysis of the evidence and have no hesitation in concluding that there is no solid advantage to this little girl in the proceedings continuing. I therefore give the local authority permission to withdraw their application.

Acknowledgments.

178. I am grateful to the experts for their time, thoughtfulness and robust consideration of the issues. I am aware that the pool of experts who are prepared to report in these difficult matters continues to reduce. It is imperative that the courts are enabled to hear from those who are leaders in their medical field when matters of such import are before the court. Robust and meaningful debate of medical issues is an essential prerequisite of fair and proper judicial investigation.

179. I am most grateful to Mr Bain and the rest of the local authority team, both social work and legal, for the sensitive, pragmatic and professional way in which they have managed this case. It has been known for some time that this case involved a number of unique issues. The local authority quite properly brought the matter to trial and have remained alive to the need to keep the evidence and their position under review. I would also like to say a special thank you to the other legal teams. To Mr Storey QC and Mr Larizadeh QC, leading counsel for the father and mother, for their clarity, focus, brevity and invaluable assistance on the law: to the extraordinary work of Mr Bailey and Mrs Storey Rea, junior counsel for the parents, who, behind the scenes, have done so much to ensure that the court had all relevant material to reach a proper and fair decision. I know how much the parents have valued their help. I should also like to say a special thank you to Mr

Bache and Miss Carter, the parents' solicitors for the skill and expertise shown in their case preparation. I would also like to say thank you to the Guardian and her team. Miss House and Miss Teggin have worked tirelessly to ensure that the child's needs have remained in focus at all time. Finally I would like to say thank you to Mr Wainman solicitor for the child who has been responsible for coordinating the evidence of the experts and without whom this hearing might not have taken place.
