



Petitions and Health Committees

Oral evidence: [Petition on the meningitis B vaccine](#),
HC 900

Tuesday 15 March 2016

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Members present: Helen Jones (Chair), Ian Blackford, Paul Flynn, Catherine McKinnell, Andrew Percy, Emma Reynolds, Paul Scully, Paula Sherriff, Maggie Throup, Helen Whately, Dr Philippa Whitford, Dr Sarah Wollaston.

Questions 1-54

Witnesses: **Lee Booth**, petition creator, **Jenny and Neil Burdett**, parents of Faye Burdett, **Matt Dawson**, father of Sami Dawson, **Claire Timmins and Linda Parkes**, mum and grandma of Mason Timmins, gave evidence.

Q1 Chair: May I first of all welcome our witnesses this afternoon? Mr Booth, Ms Timmins, Ms Parkes and Mr and Mrs Burdett—and Mr Dawson. Sorry, you're hidden away. We are very grateful to you for coming along this afternoon and for agreeing to share your experiences with the Committee. Perhaps I could start by asking Mr Booth: what led you to start the petition? Would you like to tell the Committee what led up to that?

Lee Booth: I have two daughters, one of whom was eight months old at the time we took her for a regular set of inoculations, to be told that she was too old to qualify for the meningitis B vaccine, which we had found out had just become available on the NHS. Obviously, as a parent that did not sit very well with me. She was still susceptible and in a high-risk category for contracting meningitis, so I thought I would do something about it.

Q2 Chair: You say that you think all children should be given the vaccine. You might not have a view on this, but do you have an idea of which age group you would want to start with? Or would you want to start with all children at once, and if so, up to what age group?

Lee Booth: Obviously children born after 1 May last year are getting the inoculation anyway as part of the normal routine. Children under the age of five are considered the next highest risk, so it makes sense logistically to vaccinate them next. Teenagers going to university are considered high risk as well, as they also carry the meningitis infection. Obviously, logistically it is not feasible to do everyone all at once, so to answer your question, we would start with the under-fives.

Q3 Chair: Linda, can you tell us what happened to your family and why you have been led to support this petition?

Linda Parkes: We're supporting the petition so that no other family has to go through what we have gone through. Claire, my daughter, had meningitis C when she was little, so I was aware of some of the signs and symptoms of meningitis. Mason was a little ball of fire—energetic and confident. I saw him in the morning at about 8.30. He had been sick. I waved him bye and took his sister to nursery. By four o'clock that afternoon, Claire was taking him to the GP. She called me, so I met her at the GP and saw him going in an ambulance. He was then at hospital, and by midnight I was trying to support my daughter and son-in-law with the fact that Mason wasn't going to survive.

Q4 Chair: That is a horrible story, a horrible thing to happen to anyone, and we are very grateful to you for letting us hear it. Any of our witnesses want to respond to this: we are told that it is often quite difficult to get a diagnosis when a child has meningitis. Does anyone have anything to say about the difficulties that they encountered in getting a diagnosis?

Neil Burdett: Faye became ill at midday. My wife was with her, and Faye became very irrational and was screaming and crying, which was very unlike her. My wife rang 111 and spoke to a nurse. They sent a paramedic round, and he had a look; he knew something was wrong, so he suggested that we went to our GP. We went straight to the GP, and he also looked over her and decided that something wasn't right—he wasn't happy. He rang a clinic at our local hospital and sent her straight down. We went to the clinic, and she was looked at in the clinic. We were there for probably two hours, and she was discharged with a viral infection. Six hours later, we were back there and she was critically ill, so they obviously have issues with diagnosing it. What doesn't help, as we found out later, is that they tell you to give them Calpol before you go to the hospital, and you're just masking the symptoms by doing that. You should take them in ill; the doctor needs to see them ill, so that is one thing that they could change. We are suggesting that people mask whatever is wrong with their child by giving them Calpol or ibuprofen. There is definitely a difficulty in diagnosing it—either that or they don't want to jump to that. It is one or the other, but I would say there is definitely an issue.

Q5 Chair: We will raise that with our expert witnesses when we have them next week. Thank you for that.

Before your children had meningitis, or in Lee's case before you were refused the vaccination, did you know much about it? Do you feel that there is public awareness?

Claire Timmins: Until my son had it, I didn't even know that there was a meningitis B and that there was a vaccine available privately.

Neil Burdett: We were the same, until we got to hospital.

Q6 Chair: Of course, Claire, you had had meningitis C when you were young.

Claire Timmins: Yes, I actually had meningitis when I was young and we were still not fully aware or informed. In fact, the day after Mason died, only something like 11 children turned up for school purely because parents were frightened that their child was going to catch something—it was pure lack of understanding. I am sure I would have done the same in their position if I hadn't known.

Matt Dawson: It may also have been a lack of awareness of those symptoms from a parent's perspective. I very much put my hand up as being ignorant. I remember holding Sami's hand when he was going through all the things that have been discussed already and it being freezing cold—really, really cold—yet I was seeing him sweat. I just remember thinking that that was really odd. Of course, everywhere I read now there are the symptoms and that is one of them. That would have been four hours' difference, possibly.

Jenny Burdett: We diagnosed the symptoms to every health professional without realising what we were diagnosing.

Q7 Chair: You as parents were not aware what to look out for. That is what I am trying to get at.

Neil Burdett: Again, when we were told that it was meningitis, our instant reaction was, "But she's had a vaccination for that," and they said, "No, we think it's B." We didn't know there was a B.

Lee Booth: As parents, meningitis sends the fear of God into you, and that is certainly what spurred me on to start this campaign.

Neil Burdett: It does. When we were in hospital, as soon as we told other parents in the hospital what was wrong, they literally just—that was the worst thing that could ever go wrong. The look on their faces—their children were critically ill, but we were something else, just because she had meningitis.

Chair: Thank you for that. I am going to open up questioning to members of the Committee. Who wants to go first?

Q8 Andrew Percy: Thank you for coming. It is a really important petition that has caught the attention of many members of the public. For me, it is really important. My nephew had meningitis B and septicaemia, and if it had not been for my sister, who is a nurse, actually rejecting medical advice and making her own decision on where to take him, he might not be with us today. He is now 11, so we have been very lucky.

On the issue of the lack of access to the vaccination, that is a question that we will put to the practitioners and medical professionals next week. Because of my family interest I definitely

understand the passion, but I wonder whether you have a comment on the effectiveness of the vaccine and whether you have been looking at the discussion and debate around that.

A real difficulty for us as policy makers is that the NHS has finite resources, as does every health system in the world. One thing that we keep hearing back from medical professionals and officials is that there may not necessarily be the funding there to provide this, and it may have to be taken from somewhere else. Do you have a comment on that? What would you say to policy makers about that? When we hear next week from the medical professionals, that will probably be the response we hear. We don't like to talk about value for money because that sounds cruel and dispassionate, but that is the challenge that comes back. This is your opportunity, ahead of what we think they will say, to say something back to that.

Chair: Who wants to answer that?

Lee Booth: Meningitis B now accounts for 90% of all meningitis infections. The Bexsero vaccine that is given for meningitis B covers against strains of meningitis C and an up-and-coming strain, meningitis W. The JCVI back in 2014 actually looked at dropping the meningitis C vaccination from the programme altogether for under-12-months. From a cost-effectiveness point of view, you can basically lose one vaccine and have a wider spread by giving that dose. Like I said, 90% of infections now are meningitis B, which kills within hours, as we all know. I do not see how you can afford not to vaccinate people. Survivors have life-changing disabilities. Caring for those children over the course of a lifetime—they may have had amputations and brain damage—the cost to the Government and to the taxpayer runs into millions of pounds.

Claire Timmins: The average is around £3 million in a lifetime for each child. A lot of the time, they are weighing it against the deaths from meningitis, and they say that there is such a small number of—

Neil Burdett: If you look at—

Chair: Can witnesses please speak one at a time? Otherwise our reporters can't keep up.

Lee Booth: You are looking at 450 cases annually of children surviving meningitis but being left severely disabled. Multiply that by £3 million annually and that is an awful lot of money that will pay for an awful lot of vaccines, and then you take away all that stress and worry from parents who are having to look for the symptoms of meningitis. As I said, I don't see how you can look at it realistically and say that we cannot afford to vaccinate. That is really what we need to be doing.

Q9 Helen Whately: Can I reiterate the thanks to the families who have come here today? It is very helpful to hear from you directly. I know how difficult it can be to talk about something very painful in this kind of forum, so thank you.

I want to pick up on the awareness of symptoms. Those of you who have been through this, if you had an instinctive feeling that your child was very sick—it wasn't just the flu, and your

instinct was that it was something much worse—did you feel able to put that across to the health professionals you encountered? Did you feel that you were encouraged to express that instinct? I open that up to anyone who wants to answer.

Chair: Who wants to start us off?

Jenny Burdett: I suppose ours was the most recent.

Neil Burdett: You were there so perhaps you should take that one.

Jenny Burdett: I'll be honest: our GP was amazing. He has been our long-standing GP and knows the family. He knew that she had never been to the doctors in the two years of her life. We are not people who ring up every 30 seconds. When we got there, he looked her over and trusted that I knew something was not right. We believe that the failing was when we got to the hospital. I wouldn't say we were pushed aside, but we were—

Neil Burdett: Not taken seriously, I think. Also, the GP wasn't taken seriously—there was a flippant comment about an over-cautious GP. As it turned out, he wasn't over-cautious.

Jenny Burdett: You put your faith—we are believers in our healthcare system. It is amazing and we have seen the best of it, in one sense.

Neil Burdett: It only takes one person to make a mistake and the whole thing falls apart.

Jenny Burdett: Yes, she was dismissive.

Neil Burdett: Very dismissive. Even if we had kind of had that thought that it was meningitis, which we didn't really because as far as we were concerned Faye was vaccinated, I don't think she would have entertained it, if I'm honest. I think we would have been told we were being a bit over-cautious and a bit neurotic ourselves.

Jenny Burdett: We believed that the doctor is our last stand, so if she told us that Faye had something different and to go home and that she would be fine, we believed her.

Chair: Of course you would.

Neil Burdett: And that's what we did. We had seen three health professionals that day who had sort of moved us along the line. Again, we could only trust what they were telling us, which is what we did.

Q10 Chair: Matt, can you tell us your experience? How did you feel?

Matt Dawson: On the awareness and instinct, I think that when the child is at a point where, as we have just heard, you know something is wrong, everybody in the room who is a parent has that instinct—there is no question about that. Linking it to the



awareness, a little bit earlier, before it got to the stage where we really knew something was wrong, our instincts were not the right ones. That is where I think it links to more of an awareness. I feel that the minimum that needs to come out of this is the awareness for the parents so that that instinct just gets taken back a few hours, which can make all the difference.

I know I am generalising, but based on having met the other witnesses and heard many other stories myself, at the moment it's all been around the rash, which was not applicable. There are so many different ways and means of finding out about the seriousness of meningitis. At the moment, the instinct has been about the rash, and ibuprofen and Calpol have also been mentioned. That seems to be a default system for this type of disease. I put my hand up. I did exactly the same and I wish that I hadn't, but that is what it was.

Sami had had febrile seizures before, and we had been to A&E before and sat there for three, four, five, six hours. It had been diagnosed as a febrile seizure: "He should be absolutely fine. Give him some Calpol," and that was the case, in his first six months. He had another one, and we dealt with it at home—it was fine. His elder brother had had them, I had had them, and yet when he had one in the morning when he was then admitted to hospital—it was directly affected—but because of my ignorance that instinct that we all talk about was not there at the right time. I know, and my wife knows, that we are very lucky to be in a position to still talk about Sami. That is not always the case, and it is a matter of minutes and hours that makes the difference.

Neil Burdett: We found that it is so quick. Within 12 hours you go from the beginning to critically ill. Literally within 12 hours—it is so quick. People look for a rash, and you do get a rash but by the time there is a proper rash it is too late, and you are running out of time. As soon as those symptoms start the clock is running, and the quicker you deal with it the better the outcome. The longer it is left, the less hope you have, basically.

Chair: Thank you. Do you want to follow up on that Helen?

Q11 Helen Whately: I have a different question, unless anyone particularly wants to comment on the instinct question—whether you can trust your instinct.

Lee Booth: I just want to say that this campaign really has highlighted that children are not covered against all strains of meningitis, and that is what has really kicked off the run, if you like, for the meningitis B vaccine. At least it has put it out there in the public domain that you still need to be aware of the symptoms of meningitis and that your children are not currently vaccinated for that strain.

Q12 Helen Whately: You all know that the Government make their decisions about vaccinations on the grounds of whether they are cost-effective, and on that basis they launched the vaccination programme for meningitis B for babies under one. This is the first country in the world to do that, but on that basis it is currently not vaccinating older children.

I would like to know your views on that approach to deciding who should be vaccinated in a vaccination programme. Do you think it is reasonable, at least in principle, that it is looked at on the basis of cost-effectiveness? There is a separate debate as to what is cost-effectiveness, but is that a way of deciding on this allocation of resources? Do you have a view on that approach?

Chair: May I ask Lee to answer that one, as the initiator of the petition?

Lee Booth: The simple answer is: what price do you put on a child's life? At the end of the day, these are children's lives that we are talking about. We are a modern country, not a third-world country. We have a vaccine out there and we should be using it. On the vaccine itself, the Government pay somewhere between £27 and £60 for the three doses. I have already alluded to this: how can we afford not to vaccinate? It looks like it costs us more to not vaccinate than it would to vaccinate in the first place.

Matt Dawson: Regarding the cost-effectiveness, right now, if you are lucky enough to be able to find the vaccine you can buy it, but it costs hundreds of pounds—in some cases, thousands—to get the vaccination privately. Is there an avenue to try to bring that cost down? We are all realistic people. Does it have to be zero straight away? Perhaps not, but I think that the general consensus of where we are coming from is: let's see something, whatever that may be.

Chair: Okay. That is something that we can explore with the expert witnesses next week.

Q13 Paul Scully: Thank you very much. I will just echo the thanks that have been expressed by other members of the Committee, because as a Petitions Committee we have considered a number of petitions that have come up. Frankly, having a go at Donald Trump and considering whether we should ban him is one thing, but this issue is really serious. It affects people's lives and we have seen that, so we are really grateful to you for coming in to inform us, because we want to ensure that when we have a debate on this subject we will come at it from a point of being incredibly informed, so that we can push those points across to other people and to the Government.

Matt, I will just come to you first of all. When was Sami diagnosed? How long ago was that? Was it recently?

Matt Dawson: It was 2 February this year.

Q14 Paul Scully: So you've been directly involved in this campaign just from February?

Matt Dawson: The campaign was brought to my attention because of reading the story about Faye, and that the time period pretty much mirrored where Sami was. So it was really about being inspired by what the Burdett family had done and I thought it was a great opportunity to spread awareness. I wasn't quite expecting—

Jenny Burdett: Nor were we.

Neil Burdett: Neither were we. Not this sort of impact.

Paul Scully: No, exactly, but—

Neil Burdett: We hoped, but we weren't expecting it.

Q15 Paul Scully: It's a remarkable number of signatures on a petition.

Neil Burdett: Again, it was just to raise awareness, if nothing else. We wanted to raise awareness to stop other families and other children going through the two weeks that we had just had, because as Matt said, we mirrored Matt's situation and he mirrored ours, but we lost our fight and Sami survived.

Q16 Paul Scully: This is what I was going to ask, actually, because the two things that came out were early diagnosis and awareness. Obviously, in your campaign you have been speaking to other parents—and thanks very much for the stories that you shared with us, Lee; they were really helpful. I wasn't reading with a view about early diagnosis. I don't know whether you have got any stories of other parents and whether you have got a sense of what these other stories have in regard to other parents' experience of early diagnosis, or not.

Lee Booth: As Neil has said, through seeing the case studies that we have and through the examples from parents whose children have either survived or sadly passed away from meningitis, parents have been sent away with people saying, "It's teething problems," or, "It's a cold"—all sorts of different reasons, apart from the main one, which is meningitis. Obviously, for parents that is the word that you don't really want to hear and, like you say, it kills so quickly.

Neil Burdett: The later the treatment, the worse the outcome; that seems to be the trend. If you can get on it quickly, then the child gets less damage, because that is really what it comes down to. If it's not going to kill instantly, it will maim and damage; you never walk away with nothing. You will never walk away with just a scar left behind. So, you could be talking fingers, toes, and if it's left for a long time legs and arms. It is literally about time—time is what you are losing, and it equates to what you lose in your life later on if you keep your life. Speed is everything. Diagnosis and everything is against the clock. As soon as it shows, you need to be on it.

Q17 Paul Scully: Can I ask you very quickly about awareness? This is something else that you'd have seen. Obviously we've talked a little bit about your campaign, which is bringing it home to a lot of people very quickly, but what do you think the Government can do more of to make parents aware, not only about the existence of the disease or of a vaccine, but also about the diagnosis, the symptoms and what people need to do? Not giving Calpol—the sort of things that you describe. What can Government do?



Matt Dawson: There are plenty of opportunities in the very early stages of a child's life when they are either going back via the GP or the midwife—those stages are probably every two weeks. And part of the education of a mother and a father may well be as simple as, “How do you change a nappy?” I would like to think that the awareness, at its ultimate, should be red flag from day one. This is the top of your list.

Meningitis is a word that, for any parent, is probably their No. 1 concern and worry, but like all these things, it tends to be on the back of some kind of adversity, which is why it gets on the agenda. Why not have it there from day one, so that it is part of the language and it is not necessarily feared, but is understood? Then, all of a sudden, the research and the work that the likes of Meningitis Now and the Meningitis Research Foundation can work on with the Government, with medics, with families, with case studies—we all want to be a part of it. Personally, I believe it should be on the agenda from day one.

Q18 Catherine McKinnell: I would like to follow up on that question. It is very powerful listening to your testimony, so I want to reiterate my thanks to you for coming today; it is incredibly brave.

You talk about the sixth-sense awareness that you ought to have about your children, but I do not think there is any way that you can ever rely on that or hold yourself responsible if that is not as acute as it ideally could be. I think that every parent worries every day about their children in different ways. That is why you need the medical profession to stand in for you when your child is unwell.

I am interested to hear what you say about the GP being very good but that you had difficulty at the hospital. Some people have the opposite experience: they cannot get past the GP and perhaps if they had got to hospital sooner things would have been different. You are raising awareness of this issue, which is really important. It is about the vaccine, which is an important issue to get right, but it is also about the wider issue of raising awareness and ensuring that we have the right care in place when it shows itself. Do you have any further thoughts—we are going to be putting questions to the medical profession, charities and experts—on that and on what could be done to improve that? It almost sounds as though it is not just parents who need to be better aware; medical professionals do as well.

Chair: Can I just bring in Claire on that point? You are nodding away. Did you want to say something about that?

Claire Timmins: I had an example yesterday. I happened to be speaking to a paramedic and mentioned that I was coming here. He was not really aware of meningitis B or the vaccine and what it is for. That is a paramedic. I know that my mum has spoken to professionals in her job and they've been asking us the questions. I spoke to a midwife who did not even know about the meningitis B vaccination, and they are supposed to be the health professionals who are advising us. We were so lucky. I mean, Mason obviously lost his life, but from the second he walked through the GP's door, she was brilliant. She recognised that it was meningitis and gave him the antibiotic but, sadly, from Mason showing his first symptom of being sick at 6.30 in the morning, it was 4.30 at teatime when he lost consciousness. That is how quick it was. I just want to highlight the fact that the rash is very important and it is



important to promote that, but Mason—from the second he became ill until he passed away—never had one spot. So don't always think, "Oh, it's not meningitis because of that."

Chair: Thank you. Did you want to come in on that Neil?

Neil Burdett: For the medical profession, I think it's almost like they are too scared to jump to it. I think that might be a lot of it. They don't want to say, "It's that", but because it is such a fine line, they decide to say, "Oh, it's a viral infection", which is what we were told, because it shows similar symptoms. I read on the internet, which is probably a bad place to read things, that one of the standpoints in America is that if they suspect meningitis B, they start medication and they take a blood sample because you're not going to hurt anyone. If it turns out they haven't got it, they just stop the medication, but their first reaction is to start medicating, take a blood sample and get it diagnosed. If it's not, they stop, and no harm is done. That seems to be a more sensible way of doing it. In our case, three doctors—obviously, our GP was very good, but he is not in a state to do anything. It's almost like they are too scared to diagnose it in case it's wrong, but it is better to diagnose it and be wrong than not to diagnose it and it turns out that that's what it is. That is the worst way round. They need to be more cautious and diagnose it and then investigate; if it's not, let it go. That is the way they need to do it, not, "Let's just wait and see." As we have said, you don't have time to do that; they need to act there and then.

Matt Dawson: As a working example of exactly that, Sami went to Chelsea and Westminster. He had W135, which is a very rare strain indeed. It was obvious that it was meningitis; they could not diagnose that it was meningitis, but they dealt with it there and then as if it was. That could well have been the difference.

Neil Burdett: With meningitis B, you get septicaemia, so you are fighting two different things. Once you've got rid of the meningitis, you've then got septicaemia coming up behind it, which is blood poisoning. You are fighting to save somebody's body. There are two fronts to fight, and speed is the main thing. If they were to be not so cautious in diagnosing it, that would help. It is almost like they don't want to make a mistake, but they're making a mistake by not wanting to make a mistake. It's a Catch-22, in a sense, but if they erred on the side of caution, that would be safer for children.

Q19 Paul Flynn: If your child's condition had been diagnosed when the GP saw her, at a very early stage, would it have made a difference to the outcome, and in what way? Can you describe it?

Neil Burdett: It would probably not have got hold of her so much. The meningitis does the damage, and then because of the damage the septicaemia starts, so the quicker you stop the meningitis, the less damage it does. We probably would have kept her, but she would have possibly had to have limb removal, and she could have been blind. It would have minimised the damage. Once you've got it, you've got it.

Jenny Burdett: We were also told by the hospital that meningitis is exceptionally weak to antibiotics.

Neil Burdett: It is weaker than a common cold. The actual bug itself is weak, so it is very easy to kill. But, as I say, the more damage the bug does, the more septicaemia you get with meningitis B—it is not the same with C and W, I believe. The longer that it is left to run, the more damage it is doing, which means that once you've got rid of the meningitis, you then have to start looking at the septicaemia. It is then limb removal and getting rid of the parts that are sending the poison back. Speed is very, very important.

Chair: Can I bring in Maggie, who has been waiting for a while to ask her question?

Q20 Maggie Throup: Once again, I commend you for being here today and sharing your experiences. Our thoughts are with you. We were talking about awareness and the fact that you had a parental instinct and an awareness that something was not right. You said that you did not think it was meningitis because there was no rush. Matt, you quite rightly said that there are opportunities for health education in the early months of a child's life.

When you take a child to a healthcare professional when they are quite young, you are thinking about why you are going and not everything else that you can be told at the same time. Have you had a chance to reflect on how else you might have learnt about meningitis? Should there be leaflets and posters in GP surgeries, apart from just the verbal communication? Sometimes that can go in one ear and out the other, whereas if you take things home with you, you can sit back and read them a bit more. Do you have any thoughts on that, from what you have been through?

Jenny Burdett: It's in our GP surgery; it is already there, but who sits there and reads every poster in their GP surgery? The leaflets are on the wall. I've been in since and seen them, but I didn't pick one up.

Q21 Maggie Throup: So do you think you should be handed the leaflets?

Neil Burdett: I think if the Government had made a bit more of a fanfare in a sense about the fact that there was a vaccination, that would have made people more aware of it. They would say, "Well, if there's a vaccination, it must be quite bad" and then they would look into it.

I think because that was brought out and no one was aware—everybody just assumes that you get a meningitis C vaccination and that is meningitis covered. They do not realise that there are so many different factions of it. Like you say, there are leaflets out there, but I think people think, "Well, I've had that, so I don't need to read that."

Q22 Maggie Throup: So it is about getting that message out there?

Neil Burdett: Yes, it is making people realise that there is more than one.

Q23 Maggie Throup: So just because you have had the vaccination, you are not safe.

Neil Burdett: That is right; there are still three others that could affect you. Obviously now there is a vaccine for one, which they hope will cover more than just that one. I think the information is out there, but nobody realises how different they are, each strain, with B obviously being the worst. Like you just said, people just do not pick it up. They know their child has had meningitis C, so, as far as they concerned—as we were—they are covered.

Maggie Throup: They have ticked the box.

Neil Burdett: That's it. They think they are safe, but they are not. I think that is what people do not realise. That was our position. When we got to hospital and we were first told that was what it was, our first reaction was, "But she's had her jab." Then they said, "For B? No, that doesn't cover it."

Q24 Maggie Throup: So there is quite a bit of misunderstanding out there.

Neil Burdett: That's right. People hear "meningitis" but they do not realise quite how much of a subject meningitis is.

Lee Booth: I think it is one of those things that you do not realise you need it until it is too late. A lot of the charities—Meningitis Now and Meningitis Research Foundation—provide a lot of good literature as well, but, going back to my earlier point, it is often too late by the time you think, "Maybe I should have read that leaflet".

Neil Burdett: Either that or when the child—obviously for newborns now they know. Again, if it was given to people when their child was born, but that is happening now anyway because they are offered the vaccine. But five or six years after that, those people—we are in this category—had no idea that it was even out there. As I said, it was not until we were four days in that we even found out there was a vaccine—we did not realise there was a B. I think it is about education. I think that part of the problem is that a lot of people do not realise that the disease is bigger than just one strain.

Chair: Thank you. Can I bring in Philippa Whitford and then Sarah Wollaston?

Q25 Dr Whitford: Thank you very much. Like others, I would like to pay tribute to you for going through such a painful testimonial with us. Having worked on the other side in a children's hospital in Glasgow, I absolutely have seen the speed with which these children are lost. That is one of the arguments that will and should be looked at from the point of view of vaccine, because from it being, "They're a bit off-colour" to them fighting for their life is so short.

You were saying that you thought the doctors were thinking about it but anxious about diagnosing it. I have to say that, having been in that position, I am not actually sure that is the case. I think they see thousands of kids who are a wee bit off and picking out this child—these parents have spotted this as something worse—to be honest, normally, if it does go through your mind, you do tend to give it credence, but it is so difficult to diagnose. I think we probably need to do more education, as was said, with medics. They may be waiting for the rash as well, and that is too late.

For Faye, was the unit that you went to in the hospital a paediatric unit?

Neil Burdett: Yes, it was a paediatric clinic.

Dr Whitford: But it was an out-patient clinic, not an emergency—

Neil Burdett: Yes, it was an out-patient clinic that we were sent to.

Dr Whitford: Why were you sent to that rather than—

Jenny Burdett: It is the only one we have. We live in Maidstone and Maidstone hospital does not have a paediatric ward; they have Pembury.

Neil Burdett: It is all sent down to Pembury.

Jenny Burdett: Yes, so we went to Maidstone because that is where our GP sent us, and they only have an out-patient paediatric unit.

Neil Burdett: Again, not to get political, but sometimes you feel like they don't want you—I know it is not bed-blocking, but, if you are there, they want to get rid of you, don't they? It is a rotating door in a sense. So, as you just said, if they are struggling and they don't want to jump to that, they say, "It's a viral infection"—and so many parents have said to us, "That's what they tell you"—and then you go home.

Because Faye had never been ill—we had never seen her with anything worse than a sniffle—when we were told that, we thought, "Well, we've seen three health professionals. We'll go home." We watched her being ill and we just thought, "She's obviously got flu, or she's obviously ill." In time we found out that it wasn't flu.

Q26 Dr Whitford: Obviously, in Faye's case you did actually see health professionals. We had the terrible situation of the little boy, William Mead, with NHS 111 trying to diagnose children over the phone. I've seen children running around in the morning, and then half an hour later they have a burst appendix and are completely out for the count. They go off very, very quickly.

Neil Burdett: Yes, that is very true. As I say, we'd already seen two health professionals. We'd explained that she had cold hands and cold feet, she was floppy, she didn't want to be touched and she was in and out of consciousness. You'd think that that would be more than a viral infection.

Jenny Burdett: I rang 111 to start with, and a nurse came on the phone—they went and got a nurse. I believed at that point that I was diagnosing meningitis, which is why the paramedic—

Neil Burdett: And then the paramedic comes and says, “It could be. I’m not sure. I’ll send her to a GP.” The GP had a look and said, “This doesn’t look right.”

Q27 Dr Whitford: So the paramedic voiced that this could be meningitis?

Jenny Burdett: No, the paramedic said that our GP would know Faye better than him. If it was out of character, he would have a better idea of that.

Neil Burdett: As it turned out—because our GP hadn’t seen her since she was six weeks old because she had never been ill—he didn’t, but he could tell from Jen and just by looking at her face that something wasn’t right. She was seriously ill. She had a very high temperature, cold hands and cold feet. She had a rash and mottling on her skin. He knew that something wasn’t right. As a doctor who’s been doing it for 40 years, he could tell that something wasn’t right. His next step was to send us to that clinic. He thought that that was the best place for us to go.

As I said, the Calpol didn’t help. As we found out later, it masked some of Faye’s symptoms—her temperature came down a little bit, and she became a little bit more alert. But within half an hour to an hour of us leaving, she was back on her bed, sucking her thumb, not very well. They didn’t even take a blood sample from her. They took a urine sample and said that it would take 48 hours to culture and that if she needed antibiotics they’d contact us. We went to Evelina hospital, and the doctors said that even if she’d just given her an amoxicillin—a general antibiotic—it would have slowed it and given her a chance, but she didn’t give her anything. She said, “It’s a viral condition. Go home.”

That’s where it falls apart. As you say, we’d gone back at 1 o’clock in the morning and if she’d already had a dose of antibiotics, it would have given another small chance, but that opportunity was missed. For us—certainly for me—you can never forget that. For those seven hours, we basically just sat with her while she was getting worse. As far as we were concerned, three doctors had looked at her and we’d been sent home. We just sat there watching her getting worse and worse.

Dr Whitford: As I say, I’ve seen that.

Neil Burdett: That’s not right. It should be diagnosed. There should be a way of saying, “I’m not sure. Let’s do a blood test and keep hold of them for a few hours. Then if it’s not, we’ll send them home.” But it’s almost like hospitals are too scared to keep hold of them. It’s like, “No, no. If they don’t have to be here, send them home.” It’s very political, but it’s that attitude. You feel that now. They wanted us to go—“It’s a viral infection, 50:50; go home.”

Q28 Dr Whitford: I think that’s also the argument regarding the virus. Obviously, it’s not actually the Government that make the decision; it’s the Joint Committee on Vaccination and

Immunisation, which looks at evidence. It did consider whether to go to five years or not. Obviously, hopefully one of things to come out of this and our discussions next week will be that they look at that decision.

Neil Burdett: Our standpoint is under five. As my wife said, one of the doctors actually asked Faye, “Where does it hurt?” They can’t communicate; they can’t tell anybody what’s wrong with them. We’re the only ones who can do that for them. If children were vaccinated up to five years old, that will cover the massive vulnerable group and take the pressure off the parents, who are left feeling that they did everything they could, but if they or a doctor had just done something—it takes that away, and it takes the pressure off the doctor. When a child is older, he can communicate. He can say, “My neck hurts. I’ve got a headache.” Up until five years old, you can’t expect a child to do that.

Q29 Dr Whitford: You commented earlier that you are always chasing the clock. I have seen a child brought in, put in intensive care with no rash and no clear indication of what it is, and we still lost her. That is part of the evidence that the JCVI will take into account.

Neil Burdett: As I say, by having a vaccination, it takes it away from doctors as well. They don’t have that decision to make any more, that 50:50 “Do I send them home or do I keep hold of them? They don’t want to be kept hold of while I wait for a blood test.” It eradicates that whole side of it. For us, it could have been the difference between keeping Faye and losing her. During those seven hours, it ran havoc in her body and that is really when we lost her.

Q30 Dr Whitford: But we would still need to educate parents, as was mentioned, to spot strains that might exist, because even if there was a change it would not necessarily eradicate all forms of meningitis.

Neil Burdett: That’s right.

Q31 Dr Wollaston: Thank you for coming today. You have done more through your brave testimony than any Government-led programme or leafleting campaign to save lives and raise awareness.

Hon. Members: Hear, hear!

Dr Wollaston: Could I take up a point about the existing vaccine programme? We face a challenge in persuading parents to take up existing vaccines. Do you have a message for parents who may be following this about the importance of vaccination?

Chair: Who will come in on that?

Claire Timmins: It is important that children are vaccinated. The facts and figures are there, and obviously the vaccination would not be passed if they weren’t. I know children are not 100% safe, but I think Lee said they were about 80% safer in terms of the chances of getting men B. Hopefully increased awareness and reading our stories

and others will make people get their children vaccinated and at least give them a fighting chance against contracting the disease.

Q32 Dr Wollaston: The other very important issues that have been raised by your campaign is that this is not just about meningitis; it is about septicaemia as well. A number of reports have looked at the variation and the importance of early intervention for septicaemia. If we hear from expert witnesses next week that when they weigh up all the risks and benefits, and within a financially limited system, we could save more lives if we put in place much better early intervention programmes for septicaemia, would you feel that was a reasonable approach, given that they are trying to weigh up, within a certain amount of money, how we can save the most children's lives? If their conclusion is that that is where we should prioritise resources—especially because, as we have heard, vaccination won't protect everyone—how would you feel about that?

Neil Burdett: The septicaemia obviously comes after the meningitis. I think it all comes down to the financial side of things. If you can prevent something from happening, as Lee said earlier, you must look at it as more than just the vaccination programme. If you are preventing this from happening, it affects the National Health Service. Faye would have lost both legs and one arm, so for the rest of her life she would have had to have care from the NHS and support during her education; we would have had to become full-time carers. We are talking Department for Work and Pensions and so many other Departments with millions of pounds being taken. Our stance is that if you vaccinate and stop that happening, across the board you will save millions of pounds and prevent families like ours from having to go through life-changing experiences. The child can grow as it would have done and fulfil its potential.

If you can speed up the diagnosis and the damage isn't as bad, the septicaemia isn't as bad. Again, that only comes with B, I believe, not with the other strains. Our viewpoint has always been that if you can stop it happening, when it comes down the financial argument you have to look at the bigger picture of an estimated 450 or 470 children who have to be supported for the rest of their lives. That is a massive cost and to ignore it for a few pounds at the beginning is like a business deal. If you spend £75 now, you can save £500,000 later. A businessman would spend the £75 and save the £500,000 down the line. That's how we see it.

Q33 Dr Wollaston: So would you like the Committee next week to probe the JCVI very carefully on how much account they take of not only the very personal cost to individuals, which is impossible to put a price on, but of the lifetime consequences, especially for the youngest children?

Neil Burdett: They seem to concentrate on the deaths—there are only 30 deaths. We've heard it on television from various doctors so many times: there are only 30 deaths. They are tragic, but there are 470 survivors. That is worse, because their lives are completely changed, and as a society we have to support them for the rest of their life. That's got to be worse. If you spend £75, all that anguish and heartache is gone, and the Government also save millions at the end of the day.

Q34 Dr Wollaston: Having read the documentation from the JCVI, they do take account of lifetime costs, but it is a question of how much weighting they put on it. Is that something you would like us to explore with them in detail next week?

Neil Burdett: Yes, I think so. They need to look into it deeper, as a lifetime, because it's not just until someone gets to 16. They've got to live like that for the rest of their lives, and if they are not able to work—they need constant care for the rest of their lives. That has to come into the equation.

Q35 Paula Sherriff: Like my colleagues, I would like to thank you for the amazing courage that you have shown by coming to talk to us today. I hope you can find some comfort in knowing that you will make a difference. Some of the things I wanted to ask have been covered by colleagues in terms of the awareness agenda, but I also wondered what could be done in terms of working with schools—I appreciate that school nurses go into schools—childminders and nurseries. Obviously, a lot of children at that age will not necessarily be with their parents, and if they are at school for six hours, that time could be critical. Does anyone have any thoughts on raising awareness with teachers, school nurses and first aiders in any of those establishments?

While I think we all acknowledge that it is notoriously difficult to diagnose meningitis and that there is some ambiguity around the symptoms, do we have any statistics—perhaps this is something we can ask the expert witnesses next week—on how many people are diagnosed with meningitis B at the first episode with the first healthcare professional they see? In terms of early intervention, although we have alluded to the fact that it still would be a life-changing episode, it might be that fewer children would die. I was wondering what we can learn from cases where meningitis has been diagnosed at a very early stage.

Chair: Can we take that one first? Does anyone know? I certainly don't. It is something we might need to explore later.

Neil Burdett: The way it was explained to us was: the quicker the treatment, the less damage and the more chance of survival—that was pretty much the way it was put to us at Evelina. The quicker they start administering the antibiotics, the less damage can be done by the disease. If you have B, like ours, that also limits the amount of septicaemia that comes behind it. I would guess that it is the same with C and W. They affect the brain and spinal cord more. Again, it is all to do with speed. In every case we have ever seen, within 12 hours they are critically ill.

Jenny Burdett: I don't know how they would find out whether or not it has been seen at the first person, unless you as the parent say, "We've been here before." I don't think anyone is going to log that someone missed it the day before.

Neil Burdett: They probably haven't logged it, I would say.

Chair: That is something we can ask the experts when they come in.

Neil Burdett: But if you ask the doctor, I'm sure they would agree on the speed.

Q36 Chair: May I ask you about raising awareness among not only parents, as Paula said, but among slightly older children who are in nursery, in school or with a childminder?

Claire Timmins: I speak with Meningitis Now, and that is something we have been discussing over the last few years. I work in a school, and they have tried to put together a programme where a school can become “meningitis aware”, and you have to have their logo on your school letters. They hand out leaflets and can even provide somebody to come in and talk to staff, parents and children—that sort of thing. That is something that they are in the process of rolling out at the moment. Hopefully, that can go into schools and nurseries. That is what I would like to see come from it.

Neil Burdett: That is probably the best way—knowledge. That is all you can do. If everybody is aware, you stand more of a chance. You are at school for six or seven hours a day. If teachers are aware of what to look for, it all goes towards diagnosing it and the speed of getting them to where they need to be.

Q37 Paul Flynn: I share the admiration that we all have for those of you who have come forward. You have already achieved a great deal, as Sarah has said, through public education. I don’t think there is a parent or grandparent in the country who is not far more aware now than previously. It is the biggest petition we have had, at 800,000 signatures, which is why we as a Committee are looking into this.

What we are going to be told next week is about the cost-benefit calculations that have to be made. We have been told that X amount of money can prevent a small number of deaths here, but the same amount could save many times that number in other areas of medicine. I don’t know if you have any information about the cost of the vaccine. In other areas of medicine, we find that the pharmaceutical companies play all sorts of complicated games involving patents and costs, where a vaccine is produced for pennies and is sold for £30 or £40. Is there any case you could make that if there is a wide use of the vaccine, its costs should come tumbling down? That would make it more attractive for Government to use it on a wider scale, at least to relieve the anxiety as well. That is an important point that you made. Do you know anything about the pharmaceutical arrangements?

Chair: I think Lee has something about that.

Lee Booth: I have got some figures. The information I have been given is that GlaxoSmithKline and the Government have managed to negotiate a price of £9 and £20 a dose. It is not an exact figure and I don’t know if it has been released. Those are the figures that we have been given on which we have worked our calculations. Realistically, you are looking at a maximum of three doses, ranging between £27 and £60, to do one child. As I say, when you are talking about 450 children each year who are left disabled and brain damaged—£3 million. It does not take a genius to figure out that it is far simpler to vaccinate people in the first place and save all this heartache and pain in the long term.

Q38 Paul Flynn: The company you mentioned was fined billions of dollars in America a few years ago for a particular offence. I think all those costs should be challenged, if we could find out what the manufacturing costs are of this drug. The amount of things they pile on to it about research, patents and so on and the games that are played are terrible. We have to challenge them because that is the way to make the drugs lower cost and universally available.

Neil Burdett: Now, with the awareness, there has been a scramble to private clinics. When you look at private clinics, their prices have gone up, so the clinics are also cashing in to a point on everybody's worry. Everybody has thought, "We can't get it on the NHS and we want to get it now. We'll go to a private clinic." One week it is £120 per injection; all of a sudden it is £180. They are just as bad. They are making money out of a vaccine and out of, not a panic, but people wanting to protect their children. There are companies and clinics making money, I think.

Lee Booth: The NHS was set up, many years ago obviously, to stop this hierarchy of those who can afford healthcare and those who cannot. I think we have gone back in time where we are at the stage now where you have people who can afford healthcare and to pay for the vaccine privately, and you have those who cannot.

Neil Burdett: We have said that if you are in a low-income family and you have three children, how do you pick which child to vaccinate first? If you have to save up, how do you do that? How do you say, "I will do that one and not those two."? That is unfair as well.

Q39 Paul Flynn: For the first 13 years of my life there was no health service. I remember it being set up; I also remember the terrible choices that my mother and other parents had to make before that time. It was literally a choice between whether it was diphtheria or nothing and—

Neil Burdett: We have come a long way since then and we should not be bringing this down to cost—down to money. We are all part of this country. Our Government should protect us. If they can, they should.

Q40 Dr Whitford: I want to follow up on the idea of putting the information in schools, which I think is a great idea, because you don't know where the child would be. What kind of educational material would it be? We have talked about the fixation with the rash, but there are the other types of meningitis. Everyone is sitting there, twiddling their thumbs, waiting for a rash. So what are the key messages that Meningitis Now is putting out to schools and nurseries? What are you telling them to look for?

Neil Burdett: The leaflet we were given in hospital starts by talking about a headache and children screaming and crying generally without parents being able to control them or calm them down. It talks about children not wanting to be touched, not liking the light, and vomiting. You do get spots. In the early stages, Jenny and her mum wondered whether it was measles, because there was a kind of spot. There is mottling of the skin. That's just on a card that you can put in your wallet.

Q41 Dr Whitford: Did it talk about cold hands?

Neil Burdett: Yes, the cold hands and cold feet. I'm just trying to go through it in my head. Then it comes to a rash.

Q42 Dr Whitford: That is a sign of septicaemia.

Neil Burdett: Yes, then it comes to a rash.

Q43 Andrew Percy: I have to say, Lee, that I slightly disagree when you say we have gone backwards. I think we should be very proud that we are the first country in the world to have introduced this. We should acknowledge that the protection that children have now is better than anything that we have had before. We should be very proud of that.

I want to raise the issue of particular elements in the medical profession. Is there a theme as to where you think education and better training would be of most benefit? We have heard conversations about, obviously, hospital doctors. We have heard conversations about GPs and paramedics as well. In all that you have heard from other patients and parents over the last few months, has there been a theme of one area, not where people have failed—I don't say that—but where you feel the greatest benefit could be gained from training?

Chair: Before that question is answered, I say to whoever in the Public Gallery brought in a drink from the cafeteria, could you kindly take it outside? This isn't a café. Now, who wants to take Andrew's question about parts of the medical profession?

Neil Burdett: I suppose I could try.

Chair: Go on; give it a go.

Neil Burdett: As I said, it could be lots of different things, so there isn't any education you can give them; there can only be caution. So I think the only training you could give to a doctor is: if you suspect meningitis in any way, take a blood test. Keep hold of the patient, take a blood test, get it confirmed. If it is not, let them go home.

Jenny Burdett: Can I also point out that when we went to the hospital, the doctor who saw us was training a junior? She sent us home, teaching a junior that it wasn't meningitis. That worried us afterwards.

Neil Burdett: As I have said, there are a lot of places in America where their stance is: if you suspect it, try to diagnose it there and then. Don't say, "Oh, I think it's a viral infection. Go home." If they suspect it, the only thing they can do is get a blood sample, get it away and keep hold of the patient. Even if they do not start any antibiotics, keep hold of them; keep them in the hospital until you get the results back.

Q44 Andrew Percy: I understand that and I would agree. So there is no theme in terms of whether it is GPs or—I am particularly interested in the paramedic element of it, because obviously if you call 111 or 999, it is very likely that paramedics will be the first one to see them. Was there a theme anywhere that in a particular area somebody is showing more caution and then, in another area of the profession, they are not?

Neil Burdett: I think everybody is just too scared to say, “I think it’s meningitis.”

Q45 Andrew Percy: So that cautiousness is across the whole medical profession.

Neil Burdett: Yes. The nurse didn’t want to say it on the phone, so she sent a paramedic. The paramedic wasn’t sure so he sent us to a GP. The GP knew something wasn’t right so he sent us there and she said, “No,” but it was. When you get to the hospital, they say, “Right, we think it could be. Let’s do a blood test and find out.” If it comes back and it is, the patient is there; they can start medicating straightaway. If they send the patient home, when they get the test back, they have then got to try to find that patient and get that patient back. They should just be kept hold of until you can decide whether it is or isn’t.

When they decided that Faye had meningitis B, the whole family were given antibiotics to stop it spreading. By letting somebody go, they could be spreading it to other people. The only way is to keep hold of people, to diagnose it there and then. If they suspect it, then diagnose it.

Q46 Chair: You are really advocating a precautionary approach, aren’t you?

Neil Burdett: Yes. I think that is the only thing. You can’t train somebody, like the doctor said. It is so hard to spot, how do you train somebody to do that? Unless you can actually take a blood sample and get that back saying, “Yes, it is,” you can’t do any training to find out. Everybody is pre-guessing everybody else. As we saw, it is almost like everybody thinks it could be, but they don’t want to say it, so you just keep getting knocked down the line until someone says, “No, it is not,” and takes that risk.

Matt Dawson: On that topic, that is exactly what happened with Sami, and he has recovered. That is exactly what happened. He was not diagnosed for days afterwards. In fact, while he was in intensive care he was diagnosed with meningitis W, but until then nobody—I was dealt with brilliantly well and managed superbly well. We all understand that medics can’t jump in unless they are 100% sure. It was managed very well and the precaution was taken.

Neil Burdett: Again, that reiterates that if they were to give a vaccine then no one would be in that position again. If the vaccine were there no one would have this umming and aahing. Then you would take away holding people back waiting for emergency blood tests. It is such an up in the air thing, whatever you do.

Lee Booth: There is that much procrastination going on, in such a narrow window of opportunity.

Neil Burdett: That's it. Everybody is umming and aahing.

Lee Booth: If you could take that element out by vaccinating in the first place, you would take all that stress from so many different people. You will have nailed it straightaway.

Neil Burdett: All that has gone just by giving a vaccine. It takes so much pressure off every profession, including parents and families.

Q47 Emma Reynolds: Picking up on what Matt just said, could you flesh out the timescale and the diagnosis? Because, obviously in your case, Sami was diagnosed, but I am interested in the different experience for you and the Burdetts. Could you talk us through again how it happened? Should Sami have been diagnosed earlier?

Matt Dawson: There was no contact with a GP or a paramedic until we got to A&E at Chelsea and Westminster. From the moment he woke up he was very groggy, as if he had a bit of a fever. He had a seizure, cold hands and feet, was a little bit sick and didn't like the light: all those things that we should all know about but I and my wife did not. After he had a little bit of a nap in the afternoon my wife noticed tiny, tiny little spots and wondered whether it was a heat rash. He had been sweating and lying on a bean bag. It could be or couldn't be. We were still not really thinking of meningitis.

Then there was a call to my doctor who couldn't get to me at that time but just said, "Go to A&E." Then we thought, "Do we want to go to A&E and be told he just had a virus and would be fine?" Right, we decided we would all go. We all went in the car and got to A&E. From the moment we got to A&E they were amazing. He did not have any obvious signs other than being really groggy and tiny little spots, which had maybe got a little bit more. They went down this line, "All paths are leading to meningitis here. Let's deal with it." It was then a line in the arm.

Neil Burdett: That's the difference.

Matt Dawson: Just to highlight the time element, from being in a cubicle and having a line put in his arm—with the faintest of spots that you would hardly have seen—to being told that they are putting him into an induced coma, with him being covered in large spots, we are talking an hour, maybe an hour and a half. I was out of the room, but it was to the point where you could see it happening in front of you. I am sure it was the same.

Neil Burdett: It comes down to hours, it really does.

Matt Dawson: It was 5 or 6 o'clock, something like that, but it was fast and furious. The treatment that I got from Chelsea and Westminster—their management of me and my wife—and I know that I wouldn't have been easy in that position with the questioning, was excellent, but they still didn't tell me what type of meningitis it was.

It was hinted towards that way, but they dealt with it there and then. I am convinced that that is the difference as to why he is here.

Neil Burdett: We feel the same. It is the gap that we had. It is the seven hours where she was given no treatment. That is the bit where we lost Faye, because the meningitis was allowed to progress too far. By the time they got on top of the meningitis, the sepsis was so bad, because it was so much of the body, that you can't beat it. You beat one but you can't beat the other. If the timescale had been reduced, the damage wouldn't have been as bad, and I feel quite confident that we would still have her if it wasn't for that gap of time. I say that it all comes down to time.

Q48 Ian Blackford: The point you are making is very clear. You want everyone to have access to the vaccination, which would deal with the situation you all face. Something I am slightly concerned about, particularly given your evidence—Neil, you referred to the speed of getting effective treatment—is that, even in the interim where you saw a paramedic, I am slightly surprised that a paramedic is directing you towards the GP. One would have thought that the common-sense solution under the circumstances, whether it looks like it could be meningitis or a number of other possible conditions, is to go straight to A&E, because that is the place where you would get the appropriate treatment. I am slightly concerned if that is the guidance given to the paramedics.

Jenny Burdett: The paramedic who came out to see us was not the most confident paramedic in the world. He kept giving me bits of paper to read while my daughter was screaming as I was holding her. I think he thought that the way out was to pass it to another person.

Neil Burdett: That is our feeling about the whole thing: no one wants to make that decision. No one wants to say, "Do you know what? I think this could be meningitis." They just say, "Hmm, she's a bit ill. We'll send her to the GP." The GP says, "She's definitely ill. Let's send her to hospital." She looks at her and says, "Viral infection." That is the standard reply to a parent. No one wants to make that jump. You either vaccinate and take the whole thing away or you just say, "Blood tests. Let's find out for sure. Let's make it 100%."

Q49 Ian Blackford: There may be an issue with the kind of guidance that is given to paramedics.

Jenny Burdett: He had all the paperwork. He had a little card from Meningitis Now, which said what meningitis was.

Neil Burdett: And he still doesn't want to make that decision. He still doesn't want to make that leap to, "It could be meningitis." No one wants to say it. They are just, "Well, we'll send you to the GP." The GP is not sure, so they say, "We'll send you to hospital." The hospital is not sure, so they say, "Viral infection." It is like no one wants to actually admit that it could be meningitis: "Let's not even mention that. Let's just ignore it, and if they get a rash, we'll treat it." As we just said, it is then too late a lot of the time.

Jenny Burdett: When we took her back to A&E, the level of care was exactly what Matt got. It was incredible.

Neil Burdett: As soon as we walked through the door, they could see what it was. That is the other side of it. At 1 o'clock in the morning, with that six-hour gap for it to incubate, we walked through the door and they jumped on us. They knew exactly what it was and started treating it straightaway.

Q50 Ian Blackford: That is where you should have been directed in the first place.

Neil Burdett: As I said, if it happened six hours earlier, we probably would still have our little girl. That is the difference. Three people don't want to make that decision, so take it away from them. That is the easiest way, then no one has to make it.

Chair: Very interesting. Thank you.

Q51 Helen Whately: I have two further questions. It is helpful to have this conversation about treatment and the speed of treatment. Since meeting you, I have heard from another constituent who had a paramedic turn up to their child and said, "I think I know what this is." They immediately put antibiotics into the child and the outcome was very different. It strikes me from all we are hearing that there seem to be very different responses to a set of symptoms. That raises questions about what we know is happening in the NHS: great variability in treatment. I think we will be able to explore that when we speak to the experts next week about the variation in treatment.

Something else we know can be a problem in the NHS is learning from mistakes. I would be interested to hear from those whose experience has been a little bit longer whether you feel the NHS is learning from your experience, whether questions were asked about what happened, whether it was done right and whether you heard that things would be done differently in future? Do you sense that the NHS is learning from the experience?

Claire Timmins: I hope it is. In our case, as soon as a medical person at our GP saw my son, she was brilliant and recognised it straightaway. He did not have a rash or anything but she gave me the antibiotics straightaway. Unfortunately, as she gave them, he fell asleep and never regained consciousness. His first symptom had been being sick at 6.30 in the morning and it was then 4 o'clock in the afternoon. It happened that quickly. I would like to think the NHS has learned from it. We have been in contact with our local hospital, which said it had taken on board what we had said and would take that away.

I want to get something else across. The doctors at Stoke, where my son ended up in intensive care, were brilliant and the outcome would have been the same but they did everything they could. But even the aftercare—you said you were all given antibiotics. The doctors were saying, "Do we give them antibiotics?" There was a conversation outside: "Do we have to give them antibiotics and who do we give them to?" They were going to give them just to me and my husband. I said, "I'm not being nasty, but my husband hasn't been with him all day. My mum was there when he was being sick and holding him." They were saying, "No, I don't think we give them to

everyone; it would cost too much.” My mother-in-law was also there. She has leukaemia and I asked whether she should have them. She left the hospital and called her own GP the next day who chased it up. It’s that side of things as well.

Q52 Chair: So you are asking for a clear protocol.

Claire Timmins: Yes, because the medical staff when you get there know about meningitis, but what about after?

Chair: That’s a very good point.

Neil Burdett: Training that many doctors to diagnose something that is relatively rare is, again, not cost effective. You would have to train thousands of doctors to spot it and that doesn’t seem cost effective to me.

Lee Booth: Not if the child is taken in with a runny nose.

Neil Burdett: That doctor may see only two or three cases in his whole time.

Q53 Dr Whitford: I think you would still have to do that.

Neil Burdett: Yes, but you can’t rely on that, because you can’t rely on the doctors diagnosing now, so I think you need to cut out the diagnosing by just looking. That doesn’t work. You may get the rough problems, such as headaches, not liking light, the floppiness, cold hands and cold feet, and straightaway, if you haven’t vaccinated because they won’t do the vaccination, you need to take a blood sample. You need to find out 100% if that is what it is. You can’t just look at someone and make a decision because one day they might say it is, and it is flu. It is so random that I don’t think you can rely on people just looking at someone. I think it has to be 100% diagnosed there and then, as quickly as humanly possible.

Q54 Chair: We have kept our witnesses for quite a long time now. You have all been very good at sharing your experiences with us, and we do not want to overload you too much. We will be speaking to the experts next week and then we will schedule a debate. I am going to ask each of you in turn whether there are particular issues or questions that you would like us to raise with those experts or when we have the debate, which a Government Minister would answer. That is quite a hard question to ask you, but I am trying to get at what your key issues would be if you could pick them.

Lee Booth: My aim is really with the JCVI—the need to look at the whole cost associated with dealing with meningitis, particularly meningitis B. Take into account, from a cost-effectiveness point of view, the fact that the meningitis B vaccine covers different strains such as meningitis C and meningitis W. Also take into account the long-term care of a meningitis sufferer who has been left brain damaged or had amputations, and their entitlement to benefits and things like that for the rest of their life. Also, my aim is for the Government to work with GlaxoSmithKline and get a better cost on the vaccination itself.



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Chair: Thank you. As Sarah said, the weighting the JCVI gives to those costs is very important as well. Claire or Linda?

Claire Timmins: Again, pretty much what Lee said. If we don't get the result we want, at least can they try to get a set agreed price so that parents could have the option to pay. I know, like you said, working people with two or three children—who do you decide to vaccinate? But, at the moment, private clinics are cashing in. Some have been known to charge up to £900 a dose, whereas, like Lee said, it is estimated at what the NHS can get it for—possibly even cheaper if they negotiated more on bulk. Could it not be a better price so that some parents could pay?

Linda Parkes: One thing to take into account is the ripple effects. In Mason's case, he was at school so there is an emotional effect on all his school friends, teachers, and doctors and GPs who were treating him at the hospital. There are costs afterwards such as bereavement counselling. All those costs need to be taken into account, not just the fact of an immunisation and that the child has died.

Matt Dawson: A couple of bits just based around two recommendations going back to 2013 that were put across to the JCVI around the working group to review the cost-effectiveness framework and undertake work on adolescent carriage—*[Interruption.]* Was that the end of my time?

Chair: No, something hit under the table. We're not timing you out.

Matt Dawson: They seem to have stalled. Obviously there is plenty going on at the moment, but this has been ongoing for the past two to three years, so a nudge in that direction would be very handy.

Chair: Jenny and Neil.

Jenny Burdett: I think it would be interesting to ask Meningitis Now how many families they assist financially every year who have been affected by meningitis. If the Government were to realise that this is not solely about vaccination, like we just said, and there are other things they could do if they didn't want to vaccinate, they could try to help with the diagnosis side of things. We are all here to make a change to ensure that children are not killed and maimed by meningitis. As long as they look at it in that respect. We are trying to protect children and families. Whatever they can do—whichever is the best—that is what should happen.

Chair: Thank you very much. Again, may I repeat my thanks to all the witnesses this afternoon? Some of the evidence you have given us has been quite harrowing, even to listen to, so we can only assume how harrowing it is for you to come and give it to us. Those of you who have lost children have our deepest sympathy and our admiration for your determination to try to make something good come out of your personal tragedies. It has been a great privilege for all of us to listen to what you have said to us this afternoon. We are very grateful to you for coming. Thank you very much indeed.