Northern Ireland
Assembly

COMMITTEE FOR
HEALTH, SOCIAL SERVICES AND
PUBLIC SAFETY

# OFFICIAL REPORT
(Hansard)

## Group B Streptococcus:
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14 September 2011

**NORTHERN IRELAND ASSEMBLY**

# COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

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**Members present for all or part of the proceedings:**
Ms Michelle Gildernew (Chairperson)
Mr Jim Wells (Deputy Chairperson)
Ms Paula Bradley
Mr Mickey Brady
Mr Gordon Dunne
Mr Mark H Durkan
Mr Sam Gardiner
Mrs Pam Lewis
Mr John McCallister
Mr Kieran McCarthy

**Witnesses:**
Dr Alison Bedford-Russell )
Mr Andrew Boyd )
Mrs Jillian Boyd ) Group B Strep Support
Ms Jane Plumb )
Professor Philip Steer )

**The Chairperson:**

You are all very welcome. Fáilte romhaibh. Jane, Phil, Alison, Jillian and Andy, it is great to see you. We also have with us Sarah, who is in the Public Gallery, and we have not forgotten that she is there. Jane, I will hand over to you for the presentation. We will try to be as succinct as possible.

**Ms Jane Plumb (Group B Strep Support):**

I thank Janice Thompson for her overview of group B strep in the previous session. Given what she said, I can now flick through some of the pages of our handout more quickly than I might have done otherwise. Members should all have the handout.

**The Chairperson:**

Yes we do.

**Ms Plumb:**

First, thank you so much for inviting us. It is wonderful to have this opportunity, and wonderful that the Northern Ireland Health, Social Services and Public Safety Committee is looking so closely at this important issue.

Group B strep is a very normal bacterium. It is carried by about 25% of women; men carry it too but, clearly, as the issue is normally around childbirth, it is important to know about women carrying it. It usually causes no problems whatsoever, but it can cause serious infection in babies. When it does so, those infections can be absolutely devastating.

Early-onset group B strep infections are what we are here to talk about today, because those are the ones that are usually preventable and are much more common than the late-onset group B strep infections that Janice described. At the moment, approximately 75% of all group B strep infections in babies will be early-onset, compared to about 25% that will be late-onset. Most of those show within the first 12 hours and, even with the best medical care, around 11% of those sick babies will die. Most of the rest will recover fully, but, sadly, about 7% will suffer long-term problems as a result.

I will talk about the scale of the problem. As has already been said, it is quite difficult to get a handle on how many cases there are of group B strep infections in babies. We can start from the position of culture-proven cases, which is obviously the most stringent measure, and the UK estimate for that is about 0·6 cases per 1,000 live births. If we add to that the babies who were probably infected with group B strep — babies with all the signs and symptoms of the infection but where we have not been able to grow it from blood or spinal fluid — that can take the number up to about 3·6 cases per 1,000 live births. However, there is no good data on stillbirths. If we were to include stillbirths, that figure would be higher, but how much higher, who knows.

As Janice described, there are known risk factors for babies developing early-onset group B strep infection that can be identified, usually during pregnancy or labour. Research has shown that about only 60% of babies who develop early-onset group B strep infections will have any of those risk factors present. This means that, with the best will in the world and even if a risk factor strategy is perfectly applied, infections are absolutely not preventable for 40% of those babies. We do not know that they are at risk, so there is no chance to prevent infection.

We can identify more babies who are at risk of developing group B strep infection by testing mum late in pregnancy to find out whether she is carrying group B strep. There are fundamentally three types of test. First, there is a standard high vaginal swab. Although not done routinely in the UK, the test is available at all NHS hospitals, which is great. When you get a positive result from that swab, that is also great, because a positive is a positive. However, sadly, it is not a particularly reliable test, and, when the result comes back, up to half of the women who have been swabbed will be told, wrongly, that group B strep is not there. Therefore, you get a completely unacceptably high false negative result, and women are sent away thinking that everything is fine when it may not be.

Secondly, there is an enriched culture medium (ECM) test, which Janice described excellently, so I will move on. Thirdly, polymerase chain reaction testing is in the pipeline, but we are not there yet.

Carriage can be intermittent, so the best time to test is late in pregnancy. The ideal time would be in labour but we do not have that facility because the test needs time to get the result. Therefore, the best time to do the test is late in pregnancy so as to predict whether mum is likely to be carrying the bacteria when she goes into labour. As we have seen, intrapartum antibiotic prophylaxis is highly efficient at reducing the risk of early-onset group B strep infections in babies.

Our handout lists some of the countries that already screen for group B strep as a routine part of their antenatal care. The list may not be comprehensive, but all those countries have seen their early-onset group B strep infections plummet. The USA, Spain, Australia and France have all seen their incidence of early-onset group B strep infections fall by more than 70%. In countries where they do not routinely screen and where they use a risk factor approach, the ECM testing

methodology is available. Therefore, at least the health professionals and the mums can request a sensitive test. Unfortunately, in the UK, that is just not possible.

Janice said that the Royal College of Obstetricians and Gynaecologists (RCOG) issued its risk-based guidelines in 2003. Its audit in 2007 found that very few hospital policies fully complied with those guidelines, which was disappointing. The UK National Screening Committee has said that routine screening is not recommended, and it mentioned clinical and cost-effectiveness issues, which we dispute. There is plenty of evidence that screening reduces the incidence of early-onset group B strep infection in babies and is also at a much lower cost than what is happening at the moment.

Janice also mentioned the randomised controlled trials. The difficulty is that a superb randomised controlled trial comparing the risk-based and screening approaches was proposed a few years ago but was rejected. Therefore, having put forward a proposal for an excellent piece of research, we are hugely disappointed that one of the reasons being given for being unable to introduce screening is that we do not have a good randomised controlled trial.

Our handout contains a lovely graph, which shows a blue line cutting a swathe across the page. It shows the incidence of early-onset group B strep infections in the United States, and it indicates how that has plummeted since prevention measures have been taken. The dotted line at the bottom shows how late-onset group B strep infections have been unaffected by intrapartum antibiotics. Unfortunately, there are no known ways at the moment of preventing late-onset infections. We are waiting for a vaccine.

We then have a similar graph for the UK, but, unfortunately, the line is going the wrong way. The RCOG guidelines were introduced in 2003, and, unfortunately, since that time, the number of early-onset group B strep infections has risen, not fallen.

The next chart shows what Janice said: the blue columns represent the incidence in Northern Ireland and the pink columns — not grey as I said in the text — represent England, Wales and Northern Ireland. The chart shows clearly that the issue is more prevalent here than in the rest of the UK.

Our handout then summarises the opportunity that Northern Ireland has to lead the way, based

on what is happening here. We believe that the first step is to ensure that health professionals are fully informed about group B strep so that they can proactively inform. It is not good enough just to have it in a book that people may or may not read: it is better to proactively inform women as part of their antenatal care about group B strep and about the availability of good tests for it, and to make those sensitive tests available, ideally routinely, in Northern Ireland, both for pregnant women and for their health professionals.

Our handout then summarises Group B Strep Support's preferred approach, which is to offer sensitive testing for group B strep late in pregnancy for all women at low risk, from 35 weeks to 37 weeks, and to make sure that all women at higher risk — including those who deliver babies before that time plus those who get a positive result from that test — are offered antibiotics in labour. It is more clinically effective and cost-effective than what we are doing now.

The next page of our handout is a personal plea. My middle child died in 1996, aged 17 hours, as a result of group B strep infection, though it was potentially preventable. Loads of things happen in this world that are not preventable, but group B strep infections in babies are potentially 80% preventable. They should not happen.

The handout then shows two pictures that demonstrate how much I know that prevention works. The first picture shows Professor Steer holding my daughter within hours of her birth back in 1998. I must say that my daughter has given me permission to share these pictures, because, in the other picture, she is 13 and so she has to agree to everything. It was taken on her thirteenth birthday. She was and remains wonderfully healthy, so we know that prevention works. Sadly, these infections are still happening. Please, make a change.

**The Chairperson:**

Thank you for that, Jane. Does Jillian want to say anything at this point?

**Mrs Jillian Boyd (Group B Strep Support):**

I take it that you all heard about our story. Only six months ago, our much-wanted gorgeous wee baby was making her entrance into the world. Somehow, this bacterium crossed her path and she was not one of the lucky ones. She died in labour. She did not even have the chance to be born so that it could be treated; it got her before anyone could try to do anything for her. As Kieran said earlier, not only would we have benefited from a routine test, we would have benefited had

someone just told us that this bacterium existed. We read all the pregnancy books and did our best for her. We know that if someone had told us about it, we would have researched it. We would have come across Jane's charity and, no doubt, we would have availed ourselves of the test, which at the moment costs £32 to take privately. We feel aggrieved and angry that the system and the policy let us down and that there was information that no one told us about. Although we tried to do as much reading as we could, we did not come across it. Our baby should be here today and she would be nearly six months old, but she is not.

**The Chairperson:**

Thank you, Jillian.

**Mr Wells:**

It is difficult to read the material without feeling emotional about it.

A couple of points were made. First, because the tests are not yet refined, there is a risk that some people will be tested and, as you said, given the all-clear, but there will be recriminations from aggrieved parents if something happens subsequently. Secondly, can we quantify how many children's lives are being saved as a result of the much more stringent regulations that one sees in other countries, such as the States, Slovenia, France, and, interestingly, Kenya? I have been to Kenya many times, and, frankly, if you saw some of the conditions in hospitals in Kenya and compared them with those here, you would find it extraordinary that they are that much further advanced. Can we quantify how many children are alive in Kenya or Slovenia who would not be were it not for these tests?

**Ms Plumb:**

I do not have that data. However, if 10% or 11% of babies who develop early-onset group B strep infections will die as a result, the fact that the incidence has fallen by 86% in the States is a positive indicator. Professor Steer will comment on the test accuracy.

**Professor Philip Steer (Group B Strep Support):**

The test is only a bit more than 90% sensitive, so if you tell somebody that they are negative, there is always a caveat that there could be what we call a false negative. However, the other reasons why women get antibiotics in labour would still apply. If the woman is displaying the other risk factors, such as fever or prolonged ruptured membranes, or if the baby is showing signs

of distress, they would still get the antibiotics. We would give the antibiotics if they had prolonged ruptured membranes, a temperature, etc, but the key factor is whether the mother carries group B strep. That is the one risk factor that is, somehow, being ignored. It seems illogical to me to respond to the other risk factors and then ignore group B strep carriage. We should see this as a positive, not a negative. If you have a positive test, it is a positive, and that is reliable. If it is negative, you always have to bear in mind that there may still be a risk, and then we use the other risk factors.

You asked about the babies who are being saved. The evidence suggests that a risk factor approach may prevent about six in 10 of the potential infections, but a screening approach can prevent nine out of 10. The difference — the babies we are missing — are those three in 10, the mothers of whom are not being given the opportunity to be treated, because no one knows that they are carriers. There is an inequity in that some women find out by accident from tests of a vaginal discharge, for instance, that they are carriers, and they get all the treatment. However, the woman who is a carrier but does not know has no opportunity to have that treatment. That seems inherently unfair to me. If women want the test, the correct test should be available to them.

**Mr Wells:**

If you did all of that, you would automatically have intravenous antibiotic use during labour.

**Professor Steer:**

Nothing is automatic. We would say to the women, "This is what your risk is. If you would like to avail yourself of intravenous penicillin, this is the protective element". They can choose whether or not they will have it. It is exactly the same whether they have a fever in labour, prolonged ruptured membranes or are group B strep carriers. Fundamentally, it is not any different. We offer them the treatment now if they become feverish; why not offer them the treatment if they are a group B strep carrier? It seems to me to be no different.

**Mr Wells:**

Am I right in thinking that that is not entirely risk-free and that there are side effects for some women?

**Professor Steer:**

The side effects of intravenous penicillin are extremely rare. It has very few immediate side

effects. The side effect that everyone talks about is the risk of an anaphylactic reaction. About one in 10,000 women may get such a reaction, and it has been suggested for reasons that are not entirely clear historically that about one in 100,000 women may die from that reaction. However, a surveillance of the first 1·8 million women to be given intravenous prophylaxis in the United States was carried out, and there were no deaths from anaphylaxis or intravenous penicillin. There may be a risk, but I would argue that if there are no deaths in 1·8 million administrations, it is a very low risk.

**The Chairperson:**

Jim, I am conscious that other members wish to speak, but I will bring you back in later if there is time.

**Mr McCallister:**

We spoke about this earlier in the year, so I am delighted to see that we have everybody here at the Committee. I will start off by saying how sorry I am for your loss. As one of the most recent parents in the Committee, I agree with what Janice found in the Bounty research. I had no idea about group B strep. I have a daughter who is 11 months old, so we were going through all of that last year and I never heard it mentioned. In defence of the health service, we thought that the treatment, monitoring and looking after that we got was very good, but I never heard tell of it. It was literally only because of what happened to Sarah, who is in the Public Gallery, that I heard about it. I know her husband and the family very well, and when that happened it became an issue.

Jane, you mentioned that Northern Ireland has a higher incidence rate. Is that a big enough differential to justify having a different approach here than in other parts of the country, if we have a 30% to 40% higher incidence rate here than in England and Wales?

**Ms Plumb:**

I personally believe that we should be screening in the UK as a whole. Given that the rate is higher in Northern Ireland, I do not think it should be different in Northern Ireland; I think there should be screening here.

**Mr McCallister:**

Yes, it should be across the board. Do we know what the absolute gold standard of a test would

cost? Presumably the health argument is that it is not cost-effective at that level. However, given the number of countries that are doing it and the size of the sample that Philip referred to in places such as the United States, surely the response that they are getting — I think the lowest of the four examples you gave was 71% and the highest was 86% — indicates that what you are proposing would be very beneficial.

**Ms Plumb:**

There was some research by Kaambwa published last December that estimated the cost of the ECM test if done through the NHS. As Jillian rightly said, buying that privately costs £32, but the estimate in that research paper was £10·63.

**Mr McCallister:**

Is that a complete test?

**Ms Plumb:**

Yes.

**Mr McCallister:**

As Philip said in answer to Jim's question, the risk factor is also built-in, so if a test comes back negative, the system does not just say all is fine; other risk factors are looked for. That is certainly very cheap. Thank you for that, and thank you for coming.

**Mr Durkan:**

I welcome everyone here today. I have met some of the people here previously, as have other members. John has touched on what I was going to ask, regarding the cost of a gold standard test. We have quite a lot of information and figures in front of us, a lot of which pertains to research done throughout the UK. I am just wondering whether any figures from the Irish Republic are available.

**Ms Plumb:**

I think there were incidence figures from the Republic of Ireland in the Paul Heath study, were there?

**Dr Alison Bedford-Russell (Group B Strep Support):**

No; the figures that we are most familiar with are for Northern Ireland. I am not entirely clear what the figures for Southern Ireland are, but if we stick to the remit here, there is no doubt that recurrent audits have demonstrated that there is a higher incidence.

On the question about whether it should be a particular priority for Northern Ireland, I agree with Jane that, for it to be effective, ultimately it would be good to have it across the UK. Even within London, there are pockets where the incidence is higher and pockets where it is lower. It is a reflection of the situation in the US before universal screening came in, when there were areas of the US that had much higher rates than others, so different states had different approaches to prophylaxing mothers. It was only when the Centers for Disease Control and Prevention brought in universal screening that there was a massive decline, because everyone got treated the same.

It comes back to a very pertinent question that Jim Wells asked. The issue is partly about screening, but education is also important. If there is screening, but no education, healthcare workers do not know what to do with the results and parents do not know about it. That, too, is a problem. The two, in a way, go hand in hand. We must improve on that aspect.

Data collecting is quite difficult. The only reason that we know that culture-negative sepsis is present, which is when babies are colonised with group B strep and have every other feature of sepsis but not a positive blood culture, is from a deep ear swab. Those babies can be very sick, and some of them die. Phil quoted figures from our study, which was published in 'The Lancet' some years ago. Culture-negative sepsis is a reflection of actual disease in a baby. When you look at it properly, it has, prospectively, a much higher burden of disease than what is suggested by the culture-proven results.

We are in a situation. We have heard about Jillian and Andy's experience. They exemplify why screening might have made a difference. If Jillian had been screened, and if she had been one of the vast majority who screened positive, her management might have been quite different, particularly if healthcare workers had been educated and knew how to manage it. They may have had a little six-month-old now, rather than having gone through the trauma of stillbirth. It would have been lovely to have the Health Technology Assessment programme fund the study about which Jane and Phil have been talking, but it did not. Therefore, we do not have accurate UK

data, let alone Northern Ireland data, on cost-effectiveness.

Part of the consideration is the intense psychological trauma of loss to parents and the trauma to surviving babies. I am sorry to say this, but in a cost-effectiveness analysis, a dead baby is cheaper than a baby who survives with neurodevelopmental disability. We wanted to put all of those issues into a cost-benefit analysis. However, that is not being funded or viewed as a particular priority. Yet, although the disease does not sound all that common, when it happens, it is devastating. I am a neonatologist in a large perinatal centre. I get incensed at the number of babies with the disease whom I have to look after. We get some of them through with intensive care, etc, and some have a relatively OK time. However, others die: some during labour. It is all preventable.

**Mr Durkan:**

I am sorry; I did not want to reduce the matter to a question of cost. As far as I am concerned, one infant death is one too many. As legislators, if we have the opportunity to prevent such occurrences without putting others at risk, we should be doing that. Going by the copious amount of material that has been given to us, routine screening certainly seems to be the way to go, combined with increased awareness and public information, as Kieran mentioned earlier.

**The Chairperson:**

I will try to find out the rates in the rest of Ireland. The issue came up at my party's ard fheis at the weekend, but I did not have time to get the figures. I notice on page 4 that a report in 'The Lancet' talks about infants in the UK and Ireland. I will get a copy of that and see what it says, because the issue affects the entire island. Thanks for that, Mark.

**Mr McCarthy:**

I just want to follow on from my earlier question about information and education. I sympathise enormously with Jane, Andy and Jillian on their tremendous loss; I am sure that we all do. Even in the past six months, are you aware of any improvements that have been made, Jillian? Have there been further deaths since you lost your wee one? I know that Jillian and Andrew are raising the profile of this particular disease. We had not heard about it until you came on the scene. Why is that? Is any information given to parents-to-be across the water, to prevent such things happening? We have very senior people in the room with us today who are listening to what is being said. Hopefully, Jillian and Andrew, they will do something, so that this will not happen to

colleagues or friends of anyone else.

**Mrs J Boyd:**

To answer the first part of your question, Sarah is in the Public Gallery today, and she lost baby Harry exactly one month after we lost Erin.

**Mr McCarthy:**

So, this will continue until something dramatic is done to prevent it. There are very senior people in the Public Gallery who are listening to this, and I am sure that they are as compassionate as we are. This situation should stop.

**Mr Brady:**

Thank you for a very informative presentation. I met Jillian and Andy in Stormont recently. My daughter-in-law is expecting in the next 12 or 13 weeks, and, after meeting Jillian and Andy, I asked her whether anyone had mentioned group B strep to her, and she told me that she had heard nothing about it. I suppose that it comes back to the point that was made about the need for education. She has attended a gynaecologist for a number of months and has undergone screening and all sorts, yet no one mentioned that there was a possible risk. My daughter-in-law is now aware of that risk and will pursue the matter.

On the way in from Newry today, I listened to your radio interview, and I thought that one of the points that you made was quite interesting. You can correct me if I am wrong, but I think your point was that you felt that enough research had been done in other countries without needing to undertake expensive research in Britain or in the North to legitimise the need for screening.

**Professor Steer:**

About 10 years ago, there was a discussion in the UK about where the evidence was to show that screening really was effective. At that point, we discussed and designed a trial and put forward proposals, and it would have been very timely if those proposals had been accepted. However, since then, the experience in America, Spain and other countries has shown that the effect of screening on the incidence of group B strep has been so dramatic that we must question whether we need a trial. Those things did not happen in those countries by accident. It was not random; the falls were dramatic and they were consistent in every country where that approach has been

applied. If it works in the States, Belgium, Spain, Germany, Italy and other countries, why would it not work in the UK? We would expect to see the same fall in numbers, and I cannot see a logical, scientific reason why we would not get the same result. It may be that the cheapest thing to do would be to simply implement the screening and monitor what happens, rather than trying to do a very expensive and complicated trial, when it has already been so effectively demonstrated in so many other countries.

**Mr Brady:**

Just to let Michelle know that I do listen to her sometimes, I heard her interview on this issue and in it she said that routine screening is offered if you go private, but not through the NHS. That flies in the face of the principle of care at the point of need, which we are constantly told is the ethos of the National Health Service and the welfare state. That may push vulnerable people towards going private when they can ill afford to do so. If you can afford to go private, you lessen the risk, but if you cannot, you are taking pot luck.

**The Chairperson:**

People may choose not to go private. So it is not even about affordability; it is about choice.

**Dr Bedford-Russell:**

Having a randomised control test (RCT) in the UK would have been helpful. When the National Institute for Clinical Excellence (NICE), the RCOG committee and the National Screening Committee create the guidelines, they do so on the basis of UK evidence. However, the frustrating thing is that, recurrently throughout medicine, we know that absence of evidence is not the same as evidence of absence. There is an absence of UK evidence, but, as Phil said, there is a huge amount of data from other countries.

**Mr Brady:**

And in the meantime babies are dying.

**Dr Bedford-Russell:**

Yes, and as a neonatologist, I recurrently look after babies who should not be as sick as they are.

**Mr Wells:**

Leading on from Mickey's point, a recurring theme that the Committee encounters is that it is

very difficult for us in Northern Ireland to step outside of the guidelines that apply in the rest of the United Kingdom. The obvious reason for that is that Wales and Scotland would be straight in asking why Northern Ireland is being treated more favourably. Is there enough evidence to show that there is a significant enough difference in the rates of group B strep in Northern Ireland to justify us stepping out of line because of the significantly increased risk to mothers in Northern Ireland? The figures that we quoted from research indicate that we have a 35% to 40% difference. Is that the hook to hang this on?

**Professor Steer:**

You can certainly say that it is 30% more cost-effective if the incidence is that much higher. However, the study by Kaambwa that was published in 'BJOG' last December looked at the overall rate in the UK and said that for the whole of the UK it was clearly more cost-effective than the current system, which is a curious mishmash that sees some people get prophylaxis because they have heard of it and others getting it because of risk factors and so on. The confusion about what should be happening is why so many health professionals are confused and do not give a clear message to women about the implications; it is not being applied consistently.

**Dr Bedford-Russell:**

Jim may be right. Northern Ireland would certainly be ideal to spearhead that sort of initiative. In the absence of RCTs, good audit and data collection to plot what is happening with the disease might be an ideal way forward. A couple of things are happening that would help. In neonatal circles in general we are having to tighten up our data collection in newborn networks, etc. The other thing is that, as time goes on, the tests for group B strep are becoming more and more sensitive through molecular techniques; what is called the polymerase chain reaction (PCR). We have just completed a study looking at that; it is a lot more sensitive than conventional culture.

One of the reasons why the Americans have been so successful is that alongside their screening comes an education package. So, in general, people are more aware of it. The incidence there is not 0%, but there is a significantly lower rate of group B strep there than here.

**The Chairperson:**

In response, Jim, if devolution means anything it is that our Minister can make decisions that may not otherwise be made. I certainly made decisions when I was Minister of Agriculture that affected farmers here but that my counterparts in Scotland, Wales or England did not necessarily

feel the need to make. We have to do what is best for our population and we would encourage the Health Minister to listen to this evidence session and to take stock of it.

Jillian and Andy are here today and we heard about Erin. Sarah is here and we heard about Harry. Members' meeting packs also contain information about babies Finn Kevin McClafferty, Grace McGroarty and Aimee Rose Mullan. Each of those stories would draw a tear from a stone. We need to remember that it is not just about the 11 babies affected by group B strep whom we know of; there are babies whom we do not know about and other stillbirths and late miscarriages that are equally tragic. We want to ensure that we speak on behalf of everybody, but it was Jillian and Andy's story that I heard first as well and that brought the issue to my attention. We have become friends and I think that we, as a Committee, have a duty to listen to people who have experienced this, so that we can help to influence the Department and the Minister.

**Ms Lewis:**

I do not really have a question. As a mother of three children aged between 15 and 19, I want to express my thanks, especially to Jane, Jillian, Sarah and anybody else here who has suffered the loss of a child through this disease, which I had not heard of before I received this information. If there were a miracle tomorrow and I became pregnant, I would certainly pay £32 for the test. It is just not a risk that you would humanly take; given any choice, you would not risk it. Awareness is a huge issue and, although not ideal, it would be a start towards creating awareness among people that they have the choice of having a simple test that could save their baby's life. I thank you for coming here today and for your presentation.

**The Chairperson:**

My baby is two-and-a-half, and I had not heard of it either.

**Mr Dunne:**

The delegation is welcome; both those who came from the mainland and, obviously, Jillian and Andrew. We are very impressed with the case that you made, and, as parents, we are most sympathetic to you.

Is it true to say that group B strep risk is not managed in the system? To me, risk is based on historical data. Is action taken only when a woman is pregnant?

**Professor Steer:**

group B strep is identified partly if a mother has already lost a child or has had a child who is severely affected. Of course, that is a terrible way to find out that you are a group B strep carrier. It can also be identified by chance, if a woman happens to have a swab test for some other reason and it comes up. That is the strange lottery of the whole thing in that, in a sense, a woman who has a random test and is identified with it is lucky because she has that extra information. I always say that knowledge is power, and knowing that you are a group B strep carrier enables prompt intervention and treatment if you develop a problem either in pregnancy or with a newborn baby.

**Mr Dunne:**

So, a system is there for those for whom a risk has been identified.

**Professor Steer:**

Yes, and for those who are fortunate enough to have heard about it through a colleague, a professional or from someone who has, sadly, been affected. They will take steps to ensure that they have the information to help safeguard their child. The thing that troubles me most is that inequity; it is about who you know and what happens to you by chance rather than there being a proper agreement to make the information available to anyone who wants it across the board. That is what has driven me to support testing.

**Mr Dunne:**

The standard test gives 50% of carriers a false negative result.

**Professor Steer:**

The test is not designed to pick up group B strep; it is designed to pick up other various infections that can cause infection in the vagina. It just happens to pick up around half of the group B strep carriers.

**Mr Dunne:**

Is that true of high-risk patients?

**Professor Steer:**

That is true of high-risk patients as well. To identify group B strep effectively, a special enriched

culture medium is needed, which is not routinely available in NHS hospitals. If you go privately, of course, it is. That seems to be a source of great inequity. If a mother has read about it or heard these sad stories, she might think that she would like to have the test to protect her child. Her NHS hospital is likely to say that it cannot do the test because it does not have the facilities in its laboratory, even though it is a relatively cheap test to do. In our hospital, the senior pathologist has said that, if people ask for it enough, the hospital can provide it without any problem. It is not a logistical difficulty; it is purely an issue of perception and demand.

**The Chairperson:**

Is it the ECM test that is available on the internet?

**Professor Steer:**

Yes.

**The Chairperson:**

The campaign has been very helpful in creating awareness. If a pregnant woman buys the test on the internet and gets the results at home, can she discuss that with her GP and ask for antibiotics in labour?

**Professor Steer:**

Absolutely.

**The Chairperson:**

To clarify: am I right in thinking that she does not need to go private to get the antibiotics?

**Professor Steer:**

That is absolutely standard. If someone is known to be a group B strep carrier, they will be offered intrapartum antibiotic prophylaxis, because everyone agrees that that is appropriate. It is only if you do not know that you are a carrier that you do not get that offer. That is the fundamental problem of the whole situation.

**Mr Dunne:**

What are the side effects of the antibiotics?

**Professor Steer:**

As you know, penicillin was one of the first antibiotics to be discovered, and, apart from the anaphylaxis side effect, which I have mentioned already, the side effects are remarkably few. That is why it became such an incredible success story around the world. The harmful effects to the mum are negligible, apart from anaphylaxis. Remember, we are giving it only in labour, and it is usually only two or three doses. It is not a long course of the broad-spectrum antibiotic, which can cause all sorts of other disturbances. It is a very specific, narrow-spectrum antibiotic that is given for a short period to an organism that has always remained sensitive. There is no resistance to penicillin in group B strep. Some require a higher dose, but there are no known strains of group B strep that do not respond to an adequate dose.

**The Chairperson:**

For clarification, what is anaphylaxis? Is it a form of shock?

**Professor Steer:**

That is when you become swollen up, cannot breathe and are wheezing. It is really dangerous and is a real allergy. Lots of people describe having a tummy upset, thrush or a bit of a rash, and we call those mild adverse reactions; they are relatively common but essentially harmless. Anaphylaxis is the dangerous thing and it is very rare.

**Mr McCallister:**

I have a question about some of the risks. Do you recommend screening in all pregnancies? In Jillian and Andy's case, it was an awful way to find out. I note that in your case, Jane, it was your middle child; so you obviously had no difficulties before that. Should screening be carried out in every pregnancy even if the first child was healthy?

**Ms Plumb:**

Yes. The only time that you would not do it in a subsequent pregnancy would be in cases such as mine, when I was pregnant with Camilla, and in Andy and Jillian's case, if they have another baby. Treatment would be automatic for us because we have already had a sick baby. You can carry the infection in one pregnancy, not in the next, but in the one after that. It can come and go, so, if you are testing, it is important to test each time.

**Dr Bedford-Russell:**

I will just add to what Phil has said about screening. One element is the enriched culture medium test, but the other is the location of the site from which the swab is taken. Studies show that false negatives are much more likely to take place if tests are carried out on the wrong site. Education is very important. A high vaginal swab has a much lower yield of group B strep on any test than a low vaginal swab or a vagino-rectal swab, which is even better. The reason is that group B strep, like all our other bacteria, live largely in the lower gut. It gets into the vaginal tract, the birth canal, from the gut. That is another point of education for healthcare workers and the general public who might feel a bit squeamish about having a rectal swab. If the yield is negative, it is much more likely to be a proper negative than if the swab were taken from the wrong site. Those two things are crucial.

The other thing to add about the antibiotics, which is confused recurrently, is that giving a narrow spectrum antibiotic, such as penicillin, at the end of labour has a very minimal effect, if any, on maternal faecal flora. The reason that that is important is that we are in the global era of trying to reduce bacterial and antibiotic resistance. Broad spectrums, not narrow spectrums, are more associated with bacterial resistance, abnormal faecal flora and abnormal immune development. Therefore, it is like comparing apples to bananas.

The Oracle study is a very different study and uses a broad spectrum for a long period of time, as Philip alluded to. It is brought up as a reason to not give antibiotics to mothers, but that is a very different scenario. I do not like giving out antibiotics unnecessarily, but I always recommend trying to get rid of group B strep before it is a problem.

**The Chairperson:**

I want to ask about something that has intrigued me for a while. The test can be bought privately for £32. Therefore, someone is making a profit from that, whether it is the lab or whoever is analysing the result. If routine screening were done on the NHS, the costs would be considerably lower, somewhere between £10 and £20. Even if it was £20, that is half the cost of a visit to a GP.

I have no doubt that when we talk to the departmental officials cost will be one of the factors that they mention. I understand the sensitivity. One cannot separate, or put a price on, the human cost. However, if the cost of the swab is so low, is the cost of using intravenous antibiotics

during labour high?

**Professor Steer:**

No.

**The Chairperson:**

I assume that the cost of treating babies who survive labour and then develop septicaemia, pneumonia or meningitis is high. Some of those babies who are — to use Alison's word — "damaged" will require long-term care. Presumably, the cost of managing the consequences of group B strep has not been factored into any of these discussions. The Department is looking at the cost of testing the 20,000 births that we have per year. It is totting up the cost of testing every pregnancy for group B strep. The financial cost of dealing with group B strep is much greater, but the human cost is infinite.

**Dr Bedford-Russell:**

That might have been addressed by the randomised controlled trials that were never funded. We do not have an accurate quantification of that because there was going to be a health economic analysis. Again, there is an absence of evidence of financial benefits; there is no solid data. One understands where the National Institute for Health and Clinical Excellence and the National Screening Committee are coming from, but there are other sources for that kind of data. As you say, the human cost is huge.

**Mrs J Boyd:**

I will add to that, Michelle. Ten members of the families affected met the Health Minister last Tuesday: I sent Mark an updated version of the collection of stories, and I think that I sent you five or six in June. Over the summer, we managed to get about 40-odd stories, so there are a lot more personal experiences that you can hear about. Two of those experiences are from Anthony and Roseanne Duffy from Rathfriland, who met the Health Minister with us. Their firstborn, Katie-Rose, was infected. She made a recovery but has been left with lasting developmental problems and learning difficulties. She is four years old: she just started nursery today, and we all saw a photograph of her this morning. Last Tuesday, Anthony was able to tell the Health Minister about all of the care that Katie-Rose needs. They receive disability living allowance, and she has a social worker, an educational psychologist and a speech therapist. I think that, when she was infected at birth, for the first 10 months of her life she was in and out of the Royal

being treated. There were so many different courses of antibiotics. Anthony was able to tell the Health Minister that personal story last Tuesday. That is just one example.

**The Chairperson:**

If you do not mind me saying, Jillian, Erin would have been six months old by now. You have not been back to work. Presumably, you have been attending your GP and have been receiving help. That is also something that you and Andy have suffered inordinately throughout this, but you have suffered financially as well. That cost has to be factored in, too. You are lost from the workforce for now and, hopefully, you will be back. That is something that we also have to take into consideration.

**Mrs J Boyd:**

Also, we will have consultant-led care for subsequent pregnancies. If this were managed properly and if the infection had been prevented, I should not be high risk, because it would be something that we know about. We were talking about this earlier: I should be treated as low risk again, but I will not; I will have consultant-led care. I will be at the doors of the Royal every day for scans to make sure that the baby is OK.

**The Chairperson:**

When you were having Erin, it was a textbook pregnancy; there was not a problem and everything went completely smoothly. I suppose that it is like having a cold sore; you might have one this year but might not have one next year. The infection comes and goes in all of us. We do not know when we have it a lot of the time, but, when you are pregnant, it can be fatal. Andy, do you want to say anything?

**Mr Andrew Boyd (Group B Strep Support):**

As Janice said earlier, there is a little bit about group B strep in the pregnancy book, but the way in which it is worded leads you to believe that the Health Service actively tests for it. The sentence begins with the words "If this is found". When you think of the number of tests that a woman has during her pregnancy, it leads you to think that they will test for this infection and that there is nothing to worry about.

**Mr Brady:**

You seemed to indicate that the risk of anaphylaxis is negligible. In America, 1·8 million people

were tested and nobody had an anaphylactic reaction. Statistically, there is obviously a much bigger risk to the baby. Presumably, if the mother had an anaphylactic reaction, it would occur in the hospital setting. I know people who carry EpiPens around with them because they have nut allergies. Presumably, that risk would be lessened because they would be in a situation in which adrenaline, or whatever, could be administered very quickly.

**Professor Steer:**

Yes, that is absolutely right. The historical suggestion of one in 100,000 deaths probably related to giving penicillin in the community where there was no immediate availability of resuscitation. Giving antibiotics in hospital when the woman already has a cannula ready is a completely different situation and probably accounts for the fact that, as I said, in 1·8 million administrations, there were no deaths from this cause.

**Mr Brady:**

My father, God rest him, was allergic to penicillin, so I know about it first hand.

**Professor Steer:**

I have personally been involved in one case in 35 years of practice. It is not exactly common.

**The Chairperson:**

Jim, I said that I would let you back in at the end. Do you have anything else to ask?

**Mr Wells:**

No, my questions have been answered. It seems to me to be down to a tenner. I have been on the Health Committee off and on for five years in this Assembly and in previous Assembly sessions, and, until I heard your interview on the radio, I had never heard of group B strep. I have three children, and no one has ever mentioned it. So, if people are at least aware of the condition, it will be an achievement. However, it will be interesting to hear what the Department says during the next evidence session.

**Mrs J Boyd:**

When it happened to us, and when we found out the cause of Erin's death, we could not believe that it was preventable. We have had so many sleepless nights thinking that that can happen. It happened to Sarah. We believe that there is another case, but the post-mortem results have not

come through yet. However, we cannot do this anymore. We have run the awareness campaign, but we are still grieving, and it is not our responsibility. So, we want you to pass that to you if you would, please, take that off our shoulders.

**The Chairperson:**

You are here today, Jillian, so that we can help to raise awareness and try to persuade the Department to do what it needs to do. Wendy Austin on 'Talkback' has been brilliant in profiling and highlighting the issue. There are a number of cases, and I had contact from families in Derry. I am sure that every time it is mentioned, it opens things up again for you. It must be difficult to grieve when you are dealing with all this.

So, I thank Jillian, Andy, Sarah and everybody who has contacted members of the Committee to highlight the issue. Jane, I did not know about Theo until today, so my heart goes out to you. We have deep sympathy for anybody who has ever lost a child under any circumstances, but to find out that you have lost your precious baby and that it was preventable must certainly add to the grief. So, it is fantastic that all of you — Alison, Phil, Jane, Jillian, Andy and Sarah — have come to the Committee today. We will hear from the departmental officials next. I know that some of you have to get flights back to England, but thank you so much for coming over and helping us to highlight the issue. It is an issue that will not settle until we try to make a difference and persuade the Department that this is the way to go. On behalf of the Committee, I wish all of you the best, and I hope to hear good news at some stage.

**Mrs J Boyd:**

Not yet.

**The Chairperson:**

I did not mean to pry, but we are thinking about you. Thanks a million; we will keep in touch and send you a transcript of today's Committee meeting so that you can reflect on it. If there is other information that you think we need, please send it to us. We wish all of you well in your endeavours and work. Please keep up the good work until we get a result. Go raibh míle maith agaibh.