The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

MEETING OF THE PARLIAMENT

Thursday 1 May 2014

Session 4

Thursday 1 May 2014

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Scottish Parliament

Thursday 1 May 2014

[The Presiding Officer *opened the meeting at 11:40*]

Business Motion

The Presiding Officer (Tricia Marwick): Good morning. The first item of business is consideration of business motion S4M-09883, in the name of Joe FitzPatrick, on behalf of the Parliamentary Bureau, setting out a revision to the business programme for today. I call Joe FitzPatrick to move the motion.

The Minister for Parliamentary Business (Joe FitzPatrick): The revision will allow for a statement this afternoon on the Mortonhall investigation report.

I move,

That the Parliament agrees to the following revision to the programme of business for Thursday 1 May 2014—

delete

2.30 pm	Public Petitions Committee Debate: Petition 1453, Organ Donation in Scotland

and insert

2.30 pm	Ministerial Statement: Mortonhall Investigation Report
followed by	Public Petitions Committee Debate: Petition 1453, Organ Donation in Scotland.

Motion agreed to.

General Question Time

11:41

Funfairs (Licensing)

1. Richard Lyle (Central Scotland) (SNP): I refer members to my entry in the register of members' interests; I am the convener of the cross-party group on the Scottish Showmen's Guild.

To ask the Scottish Government whether it will consider proposals to amend the Civic Government (Scotland) Act 1982 in relation to the licensing of funfairs in light of the reported economic impact on showpeople. (S4O-03166)

The Cabinet Secretary for Justice (Kenny MacAskill): We have no current plans to amend the licensing arrangements for funfairs.

The provisions of the Civic Government (Scotland) Act 1982 enable local authorities to make decisions that are informed by local priorities and circumstances to ensure that funfairs are operated safely and to minimise any nuisance that may be caused—for example, by noise or litter.

Richard Lyle: Does the Scottish Government share my concern that councils are now using planning legislation and requesting the erection of fencing to prevent funfairs from being held?

Kenny MacAskill: It is appropriate that regulation is proportionate and balanced. It is right that local licensing authorities protect their communities by ensuring that funfairs are operated safely, and that they cause minimal nuisance to those who live around them. It is also appropriate that there is an adequate balance to ensure that the fun that fairs provide for many people who live locally can happen. We believe that it is best left to the judgment of the local authority in the particular circumstances at the time, but we encourage authorities to be balanced and proportionate.

John Mason (Glasgow Shettleston) (SNP): Does the cabinet secretary agree that some councils are verging on being discriminatory against a minority group? Glasgow City Council, for example, charges £597 for a licence.

Kenny MacAskill: I am not aware of the circumstances in Glasgow, but I am aware of the events that take place in my constituency in the city of Edinburgh. I know that they are welcomed by the local authority and the local community, and by the police, who play their part.

As I said to Mr Lyle, it is a matter of proportionality and balance. Fairs provide a great deal of fun and enjoyment as well as economic benefits for those who work in them. It is appropriate that local authorities take on board the need for balance and remember that the regulations are meant to be proportionate.

Bareboat Tax

2. Mike MacKenzie (Highlands and Islands) (SNP): To ask the Scottish Government what its position is on the impact of the so-called bareboat tax on the North Sea oil and gas industry. (S4O-03167)

The Minister for Energy, Enterprise and Tourism (Fergus Ewing): I am concerned about the changes to the bareboat charter tax regime for two reasons.

First, I am concerned about the impact that it will have on the industry, and especially exploration drilling, at a time when Oil & Gas UK and, in the new report that it published this morning, Deloitte have warned about a downturn in exploration drilling and have raised concerns about the effect of the bareboat charter changes in that regard.

Secondly, I am very concerned about the impact on the taxpayer. Colin Pearson of Ernst & Young has warned:

> "As rig owners increase the price of hiring their assets, exploration could decrease, leaving us with a scenario that sees a drop-off in the number of new developments. The loss of just one field would certainly outweigh the extra tax raised from this measure."

Mike MacKenzie: Does the minister agree that the change is just another example in a long list of significant fiscal changes—16 in the past decade, by the last count—that have been applied to the oil and gas sector, and that the cumulative risk and uncertainty may have the effect of depressing investment and thereby reducing the economic benefit and revenues that accrue from North Sea oil and gas?

Fergus Ewing: Yes, I do. The bareboat charter tax is bad for both the taxpayer and the industry. Malcolm Webb, the Oil & Gas UK spokesman, said of the tax:

> "This can only increase costs on the UKCS where operating costs have increased sharply in recent years ... In addition, we fear that this move will drive drilling rigs, already in short supply, out of the UKCS. Exploration over the last three years has been at its lowest in the entire history of the industry in the UK".

The industry has said very clearly that the bareboat tax is a very damaging measure that will damage both the industry and the tax return.

Murdo Fraser (Mid Scotland and Fife) (Con): I am surprised at the gloom and doom on the issue from Mr MacKenzie, because he was with other members of the Economy, Energy and Tourism Committee at the committee's meeting in Aberdeen on Monday, at which he raised this very issue. We were told by Oil & Gas UK how much it welcomed the engagement with the United Kingdom Treasury that there has been on the issue; it did not paint the dismal picture that has been painted thus far today in relation to what is an anti-avoidance measure. Why cannot the minister be more positive?

Fergus Ewing: We are being more positive, because we know that, rather than build up an oil fund of zero, Norway, for example, has used the powers of independence to build up an oil fund of £500,000 million. We are being positive, because our message is that the regime in the North Sea and west of Shetland should enjoy fiscal stability and predictability, which it has never had. We are being positive, because we entirely endorse Sir Ian Wood's report and his conclusion that fiscal stability has not been a feature of the UK's sad stewardship of the oil and gas industry. I am happy to reassure Mr Fraser that I am entirely positive, and I hope that he will join the yes campaign with us to deliver Scotland's potential from the oil and gas industry for the next 40 years, as opposed to continuing the misfortune and neglected opportunity of the past four decades.

The Presiding Officer (Tricia Marwick): Question 3 is in the name of Maureen Watt. She is not in the chamber to ask her question. I will expect an explanation from her by the end of the day.

Local Authorities (Support for Former Police Scotland Duties)

4. John Pentland (Motherwell and Wishaw) (Lab): To ask the Scottish Government what support it gives to local authorities that take on the duties being given up by Police Scotland. (S4O-03169)

The Cabinet Secretary for Justice (Kenny MacAskill): This Government continues to support local authorities in the delivery of their responsibilities in the best interests of the people of Scotland. Police Scotland's top priority is keeping people safe, which it is successfully delivering. I am confident that it will continue to do so, working in partnership with local councils, to ensure that the needs of all members of the community are supported.

John Pentland: Does the minister believe that it is fair that the budgets of cash-strapped councils should be spent on sorting out parking problems and traffic duties that have been dumped on them by Police Scotland? Will he find the funds to cover the costs to local authorities of dealing with police cuts?

Kenny MacAskill: A variety of issues are involved. First, we should remember that the budget available to local authorities has been maintained by the Scottish Government. Secondly, we should remember that local authorities are the statutory agencies or organisations responsible for traffic enforcement. Police Scotland has confirmed that it will continue to address parking that is considered to be dangerous or obstructive or parking issues that relate to disabled parking bays or blue badges. Police officers regularly undertake such duties. Twelve local authorities have already introduced decriminalised parking enforcement and another two—Argyll and Bute Council and Inverclyde Council—are going through the legislative process. The other 18 are either considering whether to do that, too, or considering what other process they are prepared to undertake. However, the legislation puts the responsibility for traffic enforcement on local authorities.

With regard to police cuts, let us remember that this Administration has delivered a record number of police officers, a 39-year low in recorded crime and significant drops in crime rates across the board, especially for violent crime and the handling of offensive weapons. That is a record that we are proud of.

Police Scotland (Meetings)

5. Margaret Mitchell (Central Scotland) (Con): To ask the Scottish Government when it last met representatives of Police Scotland and what issues were discussed. (S4O-03170)

The Cabinet Secretary for Justice (Kenny MacAskill): I was with the chief constable and representatives of Police Scotland at the equality and diversity event hosted by the Gay Police Association, SEMPERscotland, the Scottish Police Muslim Association and the Scottish women’s development forum at Tulliallan earlier today. It was a pleasure to be there and to pay tribute to all those involved, at whatever rank and in whatever capacity.

I continue to meet the chief constable regularly to discuss important issues around keeping people safe. It is now 13 months since Police Scotland was formed, and policing in Scotland continues to perform excellently. Crime is at a 39-year low, violent crime is down by almost half since 2006-07 and homicides are at their lowest level since records began. The risk of being a victim of crime is falling and confidence in the police is high and rising.

In stark contrast to England and Wales, we are protecting police numbers, and we have 1,000 extra officers compared with 2007.

Margaret Mitchell: I thank the cabinet secretary for that comprehensive reply. I am sure that he will join me in welcoming the recent nomination of the Scottish crime campus in Gartcosh for a Royal Incorporation of Architects in Scotland award. Is he aware, however, of the problems associated with inadequate parking provision at the campus, resulting in staff members parking their cars on the verges in surrounding roads? That affects the drainage systems, potentially leading to flooding, and causes traffic problems.

Will the cabinet secretary investigate the issue and, if necessary, intervene in an effort to ensure that Police Scotland replies to the various parties, ranging from Gartcosh community council to Scottish Enterprise, which for some time have sought unsuccessfully to engage with it to resolve the problem?

Kenny MacAskill: I concur with Margaret Mitchell about Gartcosh. The building is outstanding and has been admired by people from a variety of organisations, not just within but outwith Scotland. I know that having met the director general of MI5 and the permanent secretary to the Home Office, both of whom cast envious glances at what we possess here.

There are and have been issues regarding parking that have been raised with me by union representatives and constituents. There is a limitation on parking for good reason, given that it is a secure site. Covert vehicles and other things require to be protected and security needs to be provided.

There is a travel-to-work plan. Discussions are taking place between me and Unison; indeed, I will meet Unison in the next fortnight to ensure that access is available. Parking is available off site, and the rail station is adjacent to the Gartcosh campus.

I give the member an assurance that Police Scotland and the Scottish Police Authority, together with other agencies, including Her Majesty’s inspectorate of constabulary for Scotland and the Crown Office and Procurator Fiscal Service, are doing everything that they can to ensure that workforce access issues are eased.

The issue is not all about people going to the campus by car, which is why we have to consider public transport issues, but those issues are being taken on board and are being addressed by the authorities.

Alex Rowley (Cowdenbeath) (Lab): I have already welcomed the additional police officers, but can the minister assure us that that measure is not now at risk, given the number of back-office staff who have been paid off and the number of police officers who now find themselves in offices doing office work, rather than being on the streets?

Kenny MacAskill: Yes, I can give the member that assurance. Mr Rowley is not on the Justice

Committee but, as members of the Justice Committee and the Justice Sub-Committee on Policing know, the chief constable, who is clearly the man in operational charge, has made quite clear his intention to ensure that police officers are utilised and are not routinely back-filling.

Sports Clubs (Commonwealth Games Tickets)

6. Duncan McNeil (Greenock and Inverclyde) (Lab): To ask the Scottish Government how many tickets for the 2014 Commonwealth games sportscotland will allocate to people involved in sports clubs across the country. (S4O-03171)

The Cabinet Secretary for Health and Wellbeing (Alex Neil): I am standing in for my Cabinet colleague, Shona Robison, in answering this question.

Sportscotland has been allocated 1,000 tickets from the Scottish Government legacy ticket initiative. They are being distributed to people who have made a significant contribution to sports clubs, which are key to the development of community sport hubs.

Duncan McNeil: I thank the cabinet secretary for his response. Does he believe that 1,000 tickets will be sufficient to ensure a fair distribution across Scotland among those in sports clubs who deliver sport in their communities every day, every night and every weekend? Will he describe to me how we will have a fair distribution of those tickets through sportscotland?

Alex Neil: Although those are the only tickets that have been allocated in that way, there are other allocations of a similar nature. Sportscotland has been identified as one of the legacy 2014 partners. Other partners include Education Scotland, Young Scot, NHS Health Scotland and the Big Lottery Fund. Allocations will be made to groups, individuals and networks whose partners currently work with and are part of the legacy 2014 national programme.

Agricultural Methods and Yields (Improvements)

7. Nigel Don (Angus North and Mearns) (SNP): To ask the Scottish Government what it is doing to improve agricultural methods and yields. (S4O-03172)

The Cabinet Secretary for Rural Affairs and the Environment (Richard Lochhead): Through our strategic research programme, which is delivered in partnership with our world-leading institutions, we are investing £57 million per annum in agricultural scientific research to support the industry's long-term sustainability.

We are also providing around £8 million per annum to the SRUC to ensure that Scotland's farmers have direct access to free or subsidised expert advice on a host of issues designed to improve their productivity and farm efficiencies.

Nigel Don: I note that if we were an independent country, Scotland would be €1 billion better off under the common agricultural policy rules as they stand—never mind the better negotiation of the pillar 2 fund, which I am sure that the cabinet secretary would have managed.

Will the cabinet secretary give me some clues as to what he might have been able to do if he had that extra money?

Richard Lochhead: Had Scotland been an independent country for the recent negotiations on the European formula for farm funding and rural development funding, we would have achieved a much better deal. Indeed, under the funding formula that is applied to all member states, big or small, we would have achieved an extra €1 billion between 2015 and 2020. The cost to Scotland's farmers of our constitutional arrangements at the moment is €1 billion from that fund alone between 2015 and 2020. We can fix that by being a member state in our own right.

Farming and Fishing (Impact of United Kingdom Government Ministers' Actions)

8. Dennis Robertson (Aberdeenshire West) (SNP): To ask the Scottish Government what impact it considers the actions of United Kingdom Government ministers at European level are having on Scotland's farming and fishing industries. (S4O-03173)

The Cabinet Secretary for Rural Affairs and the Environment (Richard Lochhead): It gives me no pleasure to repeat the point that, as the chamber will be aware, the UK Government has, in effect, negotiated Scotland to the bottom of the European league table for agriculture funding under the common agricultural policy in both pillar 1, which is direct payments, and pillar 2, which is the rural development fund, leaving us with the lowest allocation per hectare in the whole of Europe.

To compound that, the UK Government also completely ignored cross-party support in this chamber for Scotland to be given the full external convergence uplift of €223 million that the UK qualifies for only because of Scotland's low payment rate. The UK Government has decided to withhold that from Scotland and instead spread the uplift over the whole of these islands.

Dennis Robertson: Does the cabinet secretary agree that we can assure a better deal for our farmers and fishing fleets only by having a voice at the top table in Europe, through an independent Scotland?

Richard Lochhead: Well, indeed. Our fishermen benefited from only 1.1 per cent of the European fisheries fund, despite having 7 per cent of the European Union catch and 13 per cent of EU aquaculture production. There is no way whatsoever that any independent Scottish Government, no matter who was in charge of it, would have negotiated such poor deals for Scotland’s farmers, crofters and fishermen, which shows why we would all be better off with a yes vote in September.

MV Loch Seaforth (Stornoway and Ullapool Linkspan Contingency Plans)

9. Rhoda Grant (Highlands and Islands) (Lab): To ask the Scottish Government what contingency plans are in place to allow the MV Loch Seaforth to berth should any problems arise with the newly fitted linkspans at the ports of Stornoway and UIlapool. (S4O-03174)

The Minister for Transport and Veterans (Keith Brown): The Scottish Government is investing in more than £60 million-worth of new assets for the Stornoway to Ullapool ferry service, which includes a new vessel, the MV Loch Seaforth, and significant harbour works at both ports. However, neither of those harbour projects includes the newly fitted linkspans that are referred to in Rhoda Grant’s question. We do not anticipate any problems with the existing linkspans, which have been performing reliably over a number of years and are regularly inspected and maintained by the harbour authorities.

Rhoda Grant: Given that there are no contingencies in place should anything happen to the linkspans, would it have been wiser to commission two smaller vessels and use the existing infrastructure? That would have been more responsive to seasonal demands. Will the minister now consider how CalMac will meet unmet demand for additional capacity on all routes to the islands? Will he take steps to tackle the record level of service cancellations that have occurred recently on many island routes?

Keith Brown: I am not sure whether Rhoda Grant took into account the answer that I gave to her substantive question, in which I said that neither of the harbour projects includes the newly fitted linkspans to which she referred in both her substantive and supplementary questions. We do not anticipate any problems with the existing linkspans and there has been no criticism of or countervailing view to the idea of having one very large ferry to cater for both freight and passenger services. Discussion is on-going and consultation will happen on the timetable for that service. We will have contingencies in place for some time after it is introduced, through the retention of one of the existing vessels.

Of course we have contingencies should there be a problem, but, as I said, given regular inspection and maintenance by the harbour authorities and the fact that the two linkspans to which Rhoda Grant referred are not included in projects that we are undertaking, we anticipate a successful launch of the new vessel and a successful service, which will enhance the experience of freight users and passengers to and from the Western Isles.

First Minister's Question Time

12:00

Engagements

1. Johann Lamont (Glasgow Pollok) (Lab): To ask the First Minister what engagements he has planned for the rest of the day. (S4F-02047)

The First Minister (Alex Salmond): With your permission, Presiding Officer, I say that I think that members will be interested to know that figures released today reveal that, as of 10 March, more than 98,000 16 and 17-year-olds have registered to vote in the independence referendum. That is some 80 per cent of all 16 and 17-year-olds, and there is still four months to go before the registration deadline.

Johann Lamont: I thank the First Minister very much for that information. Of course, we should all reflect on all those young people who not only have a vote but are currently sitting examinations. We wish them well.

According to Amnesty International, Vladimir Putin has effectively criminalised homosexuality, has cracked down on democratic dissent, carries out arbitrary arrests and has corrupted the judicial process. Also, many journalists have disappeared after criticising the Kremlin. However, the First Minister has expressed his admiration for Putin. Will the First Minister now withdraw his ill-judged comments and apologise to the people of Scotland and the people of Ukraine?

The First Minister: No—but I will explain my comments.

The first thing that I said was that I do not approve of a range of Russian actions, by which I meant the attitude not just to Ukraine but to human rights, and in particular to homosexuals. I said that I believe that Vladimir Putin has been underestimated by the western press—I think that that is now pretty obvious—and I also expressed my admiration for "Certain aspects." I had in mind the restoration of Russian pride, given that I was speaking in the aftermath of the Sochi Olympics. [*Interruption*.]

The Presiding Officer (Tricia Marwick): Order.

The First Minister: Indeed, I was speaking during the Paralympics.

I believe that our attitude to the issue is reasonable and consistent. On 9 January the Cabinet Secretary for Culture and External Affairs met the Russian consul general to express our opposition to Russian policies on homosexuality; on 13 March we expressed, again to the consul general, our concern about the Russian attitude to Ukraine; and on 26 March we withdrew the invitation to the consular corps dinner—an action that was widely reported—and said:

> "We have taken this step following the Russian Federation's illegal and illegitimate referendum in the Crimea and the steps subsequently taken to annex the territory".

The Scottish Government's—and my—position on those matters has been totally consistent.

Strangely enough, I was searching today to find what Johann Lamont has said about the situation in Ukraine. I could not find a single comment—not just by Johann Lamont, but by any of the Opposition leaders this year. I think that my explanation of the serious attitude that we have taken to this serious subject sets out a reasonable perspective that reflects the views of the people of Scotland.

Johann Lamont: No matter how hard the First Minister Googles it, he will not find me expressing any admiration for Vladimir Putin.

On the Sochi Olympics, I think that the protesters who were beaten with horsewhips there might have a different view of the success of those Olympics. The First Minister says that his position is reasonable and consistent, but to Amnesty International and others it is something different. Michael Ostapko, who leads Scotland's Ukrainian population, has expressed that community's

"hurt, disgust, betrayal and astonishment"

at the First Minister's comments. In a letter to the First Minister, he said:

> "We cannot see any good in Putin's actions and we fail to see how you can be so effusive in admiration towards this despotic and criminally run nation whose own citizens are cowed into submission (not admiration) by arrests, assassination and rabid nationalism."

Will the First Minister now withdraw his support of Vladimir Putin and apologise?

The First Minister: I make it absolutely clear that when I expressed my view about the restoration of Russian pride, I was referring to the Olympics and the Paralympics. We expressed our opposition to the attitude to homosexuality prior to the Olympics, but based on a range of indications in terms of their organisation, the Olympics were widely regarded as a substantial success. I have a range of quotations before me that indicate that.

When I said that I did not approve of a range of Russian actions, I was reflecting a serious view that has been put forward by the Scottish Government consistently, before I gave that interview and since I gave it. That view has also consistently been put to the Ukrainian authorities in several meetings. We have done that, and I have expressed my opposition to a range of Russian actions and have explained that we have held that position consistently. Is not that a reasonable position to adopt?

Why is it only now that Johann Lamont has anything whatever to say about human rights in Russia or the situation in Ukraine, and why is it only now that the Labour Party in Scotland decides that it is something that is worth raising?

The position that we have put forward has been consistent and balanced. It shows that we do not approve of Russian actions and consists of comments that are reasonable in the circumstances, and we back that up by the action that we have taken. None of the Opposition parties in this Parliament have expressed any concern in public, that I can find—[*Interruption*.]

If Johann Lamont can point to a quotation that shows that she was interested in this topic before today, I will be delighted to acknowledge that she expressed such a view. [*Interruption*.]

The Presiding Officer: Order.

The First Minister: I have pointed to the Scottish Government's consistent actions over a period of time. I think that it is reasonable to find out whether the Labour Party in this Parliament has any similar record of action or concern.

Johann Lamont: I am a proud member of Amnesty International and I support what it has said on this question, and I recognise all the human rights abuses that it has identified across the world.

The First Minister does not seem to understand that all the things that his Scottish Government has said on the question are completely undermined by the assertion that the Sochi Olympics and what Putin did there are worthy of any admiration whatsoever.

Putin has annexed Crimea. Putin says that acts such as annexing Crimea have restored Russian pride. Alex Salmond has praised Putin for restoring Russian pride. Does the First Minister, even at this stage, not see that his comments were, at best, ill judged and must be withdrawn? What on earth does he admire so much about Putin? If the First Minister bullies and threatens Scottish newspapers because he does not like their cartoons, perhaps we can see what he admires about Putin.

Even at this stage, will Alex Salmond now apologise for praising Vladimir Putin?

The First Minister: No. I state again the first thing that I said in the interview, which was that I do not approve of a range of Russian actions. I have told how we have communicated that to the consul general and publicised it. I have also, on many occasions, drawn a contrast between the legitimate democratic referendum process in Scotland and the lack of constitutionality and process in the referendums that were arranged in the Crimea. That is a reasonable thing to do, backed up by action.

I think that there are reasons to doubt the bona fides of Johann Lamont and the other parties on this issue; it is not just about the absence of comment. I have seen the letter to the Association of Ukrainians in Great Britain, Scotland that was signed by the three leaders of the better together campaign. Nowhere in that letter is there reference to better together's leading donor, Ian Taylor, the boss of Vitol, who made a £500,000 donation to the campaign. Is Johann Lamont aware that Vitol is engaged in a business relationship, including a loan of $10 billion, with Rosneft, whose boss Igor Sechin is on the banned list of the American Government? [*Interruption*.]

The Presiding Officer: Order.

The First Minister: Will Johann Lamont think about apologising to the people of Ukraine for that association? Furthermore, will any consideration be given to returning to Mr Taylor the better together donation of £500,000?

Johann Lamont: Only in the SNP could that be regarded as an appropriate answer to a serious question when the reputation of the people of Scotland has been damaged by the performance of the First Minister.

The First Minister would not meet the Dalai Lama, but he praises Rupert Murdoch, Nigel Farage and an ex-KGB officer who is accused of abusing his own citizens' human rights—all in the one interview—and then slags off Barack Obama.

The Cabinet Secretary for Education and Lifelong Learning (Michael Russell): Eh?

Johann Lamont: You should read the interview.

Alex Salmond criticised Obama for not doing enough, but then said that Vladimir Putin is "more effective" than most

> "and you can see why he carries support in Russia."

He said that he admires "Certain aspects" of Putin's character. He also said:

> "He's restored a substantial part of Russian pride and that must be a good thing"

regardless of the price that people in Russia have paid for that restoration. If, as is evidently the case, the First Minister will not withdraw those remarks and apologise, will he tell us—the people of Scotland and people around the world—precisely what aspects of Vladimir Putin he so admires?

The First Minister: I did that in my answer to the first two questions. I point out, for the record, that Johann Lamont has engaged in a series of misquotations. To take one example, I said:

> "Putin's more effective than the press he gets".

That has been confirmed by the magazine. I had in mind the fact that the western press have consistently underestimated President Putin. I think that that is pretty obvious from the events of the past few weeks.

I have said—let me say it again—that I do not approve of Russian actions across a range of issues. Consistently, the Government has set out what those issues are, despite silence from all the Opposition parties on those issues.

On the issue of Lord George Robertson's call last month for Russia to be admitted to NATO, the president of the Association of Ukrainians in Great Britain, Zenko Lastowiecki, has said:

> "We can't comment on his reasoning but it is extremely bizarre whilst insulting to the Ukrainian nation".

I am sure that, when Johann Lamont explains why better together's biggest donor has business links with people on the American Government's banned list, she will also apologise for the insult that has been caused by her party colleague, Lord George Robertson.

We have deprecated Russian actions and attitudes to Ukraine and we have spelled out that we do not support Russia's attitude to human rights and to homosexuality. We have done those things consistently throughout this year. We did not want to alight on the issue as part of a combined better together political opportunity. We said those things before, during and after the interview with *GQ*, which is why we have substantially more credibility than the Opposition parties in this chamber, and we will continue to say them without fear or favour.

Secretary of State for Scotland (Meetings)

2. Ruth Davidson (Glasgow) (Con): To ask the First Minister when he will next meet the Secretary of State for Scotland. (S4F-02044)

The First Minister (Alex Salmond): No plans in the near future.

Ruth Davidson: The First Minister has said that he wants us to put his comments into context, so let us do that.

On the same day that the First Minister sat down with Alastair Campbell, 10,000 Russian troops were massing on the Ukrainian border. Ukraine's Prime Minister said that Russia was demonstrating

> "military aggression"

that had

> "no reason and no grounds".

Two days earlier, President Obama pledged to "stand with Ukraine". Twenty-four hours later, Angela Merkel, the German Chancellor, attacked Russian actions, warning that

> "The territorial integrity of Ukraine cannot be called into question."

On 14 March, the United Kingdom's Foreign Secretary, William Hague, called on the international community

> "to take a united stand together"

to defend the

> "territorial integrity of another nation."

That was the day that Alex Salmond used to praise Vladimir Putin, an act that he is still defending in the chamber.

Kenneth Gibson (Cunninghame North) (SNP): Your party supported the Khmer Rouge and Pinochet.

The Presiding Officer: Order.

Ruth Davidson: The First Minister says that he was not wrong, but can he see why so many other people think that he was?

The First Minister: I will be writing to the Association of Ukrainians in Great Britain and its Scottish branch explaining the full range of the Scottish Government's action on the matter and making it clear how, all through the meetings with the Russian consul general and the Ukrainian representatives, and the public statements that I and others have made, which have been substantially reported, we have made our attitude towards the Russian attitude to Ukraine absolutely clear, as well as expressing our concern with human rights in Russia, as indeed I did when I deprecated a range of Russian actions in the interview that Ruth Davidson cites.

I have been unable to find any comment on the issue not only from Johann Lamont but from Ruth Davidson. Ruth Davidson should also have some understanding that, when the Scottish Government has a substantial record of consistent comment on exactly these matters over the past few months, that stands in stark comparison with Opposition parties that had nothing to say on the issue until they sensed a political opportunity.

I repeat for the record that we deprecate Russian actions in Ukraine. We are concerned for human rights not just in Russia but all over the planet. We have consistently said that and we will continue to do so.

Ruth Davidson: A substantial number of the people of Scotland would have preferred an absence of comment from the First Minister in admiration of Vladimir Putin.

This is a question of judgment. The First Minister says that he backs our key British alliances around the world. He has shifted his tack to support NATO. He says that he wants to show our closest allies in Europe and the United States that he will stand alongside them. At the same time, however, we see a leader who continues to make poorly timed and badly judged interventions on foreign affairs. The First Minister was wrong about Kosovo and he is wrong about Putin. We know what Amnesty International thinks, we know what the Ukrainian people in Scotland think and we know what other world leaders think. How can we trust the First Minister to represent Scotland on the global stage when he so consistently gets it wrong?

The First Minister: That question really was on the nub of the issue facing the people of Ukraine. Let me express again our concern about Russian actions in Ukraine, our concern for the Ukrainian people and our concern for human rights in Russia, which are the substantial issues. However, I am interested in when Vladimir Putin suddenly became persona non grata with the Conservative Administration.

“Cameron’s plea to Putin: help me stop Salmond” was the headline from earlier this year, repeated in this Parliament last month at committee, when a Scottish official from the Scotland Office confirmed that he had discussed that report in a meeting in which he was briefing the Russian Government. Perhaps he was just asking for information and he was doing things in a totally balanced way. However, Ruth Davidson will understand why, if in January her party was appealing for Vladimir Putin’s support, it is ill judged to come to the chamber and tell us that the Conservatives have condemned him throughout.

Cabinet (Meetings)

3. Willie Rennie (Mid Scotland and Fife) (LD): To ask the First Minister what issues will be discussed at the next meeting of the Cabinet. (S4F-02046)

The First Minister (Alex Salmond): The next meeting of the Cabinet will discuss issues of great importance to the people of Scotland.

Willie Rennie: The First Minister is not a homophobe nor does he support the Syrian regime, but he must realise that if he praises people who do, he diminishes himself. He mentioned Sochi. The Prime Minister and leaders of the western world spoke for us all when they boycotted Sochi because of Putin, but the First Minister praises Putin because of Sochi. Considering the international storm, is he still adamant that he did the right thing?

The First Minister: There is an acceptance from a range of people internationally, including the American ambassador and the Canadian Olympic president, that the Sochi Olympics were well organised and helped to restore pride to the people of Russia. The International Olympic Committee praised the excellent Sochi 2014 games. Across a range of international opinion, that was accepted.

Why does the Liberal Democrat leader not accept that there is concern across this Parliament for the issue of human rights, that the Scottish Government’s record on human rights internationally has been described as exemplary and that we have worked with the Scottish Human Rights Commission and a wide range of civil society organisations to produce the first ever national action plan for human rights in Scotland as well as recognising our responsibilities internationally? It would be wonderful if, just occasionally, Willie Rennie would accept that other people, apart from the Liberal Democrats, have expressed a consistent concern for human rights in our country and across the planet.

Willie Rennie: The First Minister said that his remarks were balanced. Moscow did not think so. President Putin lapped up the praise. I do not get why the First Minister’s spokesman thought earlier this week that it was okay to praise President Putin back in March. Putin has not just started persecuting gay people, restricting free speech, threatening to cut off Europe’s gas supplies, backing the Syrian regime and invading his neighbours. He has been doing it for years. And it is not the first time for the First Minister, either—kowtowing to the Chinese over the Dalai Lama, on Kosovo, and now on Russia. The First Minister wants us to stand tall in the world, but does he not just look small?

The First Minister: Well, where will I start with Willie Rennie?

Duncan McNeil (Greenock and Inverclyde) (Lab): Here we go.

The Presiding Officer: Order.

The First Minister: Willie Rennie, like his two colleagues in Better Together, did not mention the £500,000 donation from the man who has business links with people on the American banned list.

Apart from that, Willie Rennie has never acknowledged—he actually claimed the opposite, I think—that I raised human rights with the Chinese leadership. Can he please explain the BBC report that shows me and the Chinese leadership with the headline “Salmond raises China’s human rights”? I think that I have a track record of raising human rights with countries around the world without fear or favour. In contrast, Willie Rennie, rather like his two colleagues, has said nothing about this issue that I can find on the record until today.

It was, of course, Willie Rennie's party colleague the Secretary of State for Scotland who, when the Scotland Office official was about to divulge to this Parliament's committee exactly what the briefing at the Russian embassy was about earlier this year, interrupted him and said that that information could not be disclosed. No doubt there are limits to the Liberal Democrats' wish for freedom of expression and freedom of information, but when it comes to denying this Parliament's committees information about what exactly was going to be briefed to the Russian embassy, I think that at some point Willie Rennie might accept that he and his party have associations of which they should not be proud, and that he and his party, who were calling in aid Vladimir Putin earlier this year, look a bit ridiculous condemning him now when they have said nothing up until this moment.

Independence (European Union Membership)

4. Christina McKelvie (Hamilton, Larkhall and Stonehouse) (SNP): To ask the First Minister what recent contact he has had with the UK Government regarding an independent Scotland's membership of the EU. (S4F-02065)

The First Minister (Alex Salmond): As is well known, the United Kingdom Government has repeatedly refused to jointly approach the European Commission with the precise legal scenario on Scottish independence—a point that I made in correspondence with the Foreign Secretary on Sunday. He wrote me a letter and I replied that day. I hope that new, intimate communication between ourselves and the UK Government will result in the UK Government changing its mind and our jointly going to the European Commission with the precise legal scenario so that we can take these matters forward.

Christina McKelvie: I thank the First Minister for that answer and note how well attended the speech that he made this week at the College of Europe was. That demonstrates the huge interest that there is across Europe—which I have seen on the European and External Relations Committee—in the debate over Scotland's constitutional future. [*Interruption*.]

The Presiding Officer: Order.

Christina McKelvie: What consideration has been given to the consequences of Scotland not being in the European Union, particularly for our friends and neighbours elsewhere in the EU?

The First Minister: In contrast to the position of the better together parties in the Parliament, there is a wide appreciation across Europe of Scotland's contribution to the European Union. We may make up 1 per cent of the population of the EU, but we have 60 per cent of the oil resource, 25 per cent of the renewable energy potential and 20 per cent of the fishing stocks of the EU. Therefore, although this country has 1 per cent of the EU's population, it has a substantial role to play in Europe. That is appreciated by our friends and colleagues across the continent but, sadly, it is not appreciated by the better together alliance.

Patricia Ferguson (Glasgow Maryhill and Springburn) (Lab): The First Minister's trip to Bruges, to which Ms McKelvie has just referred, has borne fruit somewhat earlier than he might have expected, in that he now has advice that his Government is perfectly entitled to implement a living wage through public sector contracts. Therefore, will he now instruct his members to back Scottish Labour's amendments to the Procurement Reform (Scotland) Bill and acknowledge that the way is now clear to allow him finally to do the right thing for Scotland's workers?

The Presiding Officer: That is a bit wide of the mark, but the First Minister may respond.

The First Minister: Let us just remember that it was this Government that introduced the living wage across the public sector in Scotland.

I presume that the legal opinion that Patricia Ferguson cites is the view of the spokesperson who was quoted in *The Scotsman* as saying that European law was

> "not preventing it, but it was possible it could be challenged by companies at a later stage".

That is exactly the issue. The European Commission has suggested in correspondence with the Scottish Government that it would be incompatible with the posting of workers directive for us to set a living wage that was higher than the minimum wage. [*Interruption*.] Well, I cite the correspondence from the European Commission that does that and I will put it in SPICe. I contrast what it said with the quote in *The Scotsman*, which said that making a living wage a requirement of public sector contracts

> "could be challenged by companies at a later stage".

This Government has introduced the living wage across the Scottish public sector; that is something the Labour Party omitted or forgot to do. We are proud of that. This Government is introducing procurement legislation to encourage the adoption of the living wage across Scottish society. This Government is pressing the European Commission to make it unambiguous that the living wage can be part of public sector contracts, so that councils such as Glasgow City Council do not have to answer freedom of information requests and admit that they share the same opinion as the Scottish Government as regards the European Commission.

Can we not join together and say that, if the European Union is to be meaningful to workers across the continent, it should have a social purpose? The living wage is a grand example of such progress.

Mortonhall Investigation (Support for Parents and Families)

5. Kezia Dugdale (Lothian) (Lab): To ask the First Minister, following the publication of the Mortonhall investigation, how the Scottish Government plans to support parents and families affected. (S4F-02053)

The First Minister (Alex Salmond): I know that the thoughts of all of us are with the families affected, who have suffered not only the loss of a child, but the additional trauma that the Mortonhall report highlights. That experience has been going on for decades.

No one should ever have to experience that pain, and we are determined that no one will ever have to do so again. That is why the outcome of the work of Lord Bonomy's infant cremation commission, along with the findings of Dame Elish Angiolini, will lead to new burials and cremation legislation.

Stopping such terrible events happening again is a priority of the Parliament, but we must care for those who are affected in the here and now. Last year, we provided additional funding to assist the two counselling organisations that have done such sterling work through their close involvement with the parents affected by the issue. Today, I can announce that we are making available an additional £100,000 for counselling services for the families affected. Scottish Government officials have already begun discussions with the two counselling organisations to take that forward.

I assure Kezia Dugdale that the Scottish Government will implement the recommendations of Elish Angiolini's report as regards the Government; the City of Edinburgh Council has made a similar commitment. We will put into legislation the recommendations of Lord Bonomy's infant cremation commission at the earliest possible moment, so that such events never befall any family in Scotland again.

Kezia Dugdale: I welcome the additional funds. I know that the services that the Stillbirth and Neonatal Death Society and the Simpson's Memory Box Appeal offer parents are very important and make a difference.

Presiding Officer, when you or I lose someone who is close to us, we have countless memories to call on, as well as photographs and possessions. Parents who lose a baby have only those brief moments. That is why the ashes matter so much.

Parents affected by Mortonhall wanted the truth. Thanks to Elish Angiolini's report, many now know with certainty that they will never know where their baby's ashes are. Will the First Minister promise parents beyond Mortonhall—those in Aberdeen, Falkirk, Glasgow and elsewhere—that his Government will do everything in its power to access the truth for them, no matter how hard it is to accept?

The First Minister: I give that commitment. Kezia Dugdale is right. There are a number of key priorities in the issue. The first is to find out exactly why, over many decades, the processes at Mortonhall—and perhaps elsewhere—were allowed to exist and to continue in the way that they did.

Secondly, I should tell the Parliament that the Lord Advocate has referred Elish Angiolini's report to the police for further investigation. We must first allow that investigation of any possible criminality to take its proper course.

The third aspect is perhaps the most important of all; Kezia Dugdale referred to it. I have met a number of the parents, as ministers and Opposition members have. A key priority is to ensure as far as possible—although Elish Angiolini's report indicates that it will never be possible in some cases—that every possible investigation has been made into every individual case. I assure Kezia Dugdale that that is predominant in the Scottish Government's consideration of how we proceed from here.

The Presiding Officer: I am aware that a number of members wish to ask questions on this very important issue, but there is to be a statement later this afternoon, when members will have ample opportunity to ask whatever questions they wish. I will ensure that sufficient time is available for all the issues in the report to get a fair hearing.

Curriculum for Excellence (Funding)

6. Liz Smith (Mid Scotland and Fife) (Con): To ask the First Minister what discussions the Scottish Government is having with the Scottish Qualifications Authority regarding the future funding of the curriculum for excellence. (S4F-02050)

The First Minister (Alex Salmond): As we heard earlier, I am sure that the whole Parliament wishes luck to all the young people who are taking exams this year—not least those who are sitting the higher English exam as I speak and those who will sit advanced higher English this afternoon. We have seen excellent exam results in recent years and I am sure that the dedication and hard work of pupils and their teachers will once again pay off.

The Scottish Government is in regular discussion with all partners, including the SQA, on implementing the curriculum for excellence.

Liz Smith: I add my good wishes to the pupils.

The Herald reported earlier this week that, at a recent SQA board meeting, warnings were issued that the current position of financial deficit is likely to continue for the foreseeable future, because of the increasing costs of implementing the curriculum for excellence and the related support for teachers. Teachers' representatives told the Parliament recently that some of the preparations for the new higher and the new advanced higher have barely begun. What is the revised estimate for the full cost of implementing the curriculum for excellence, including the new higher and the new advanced higher?

The First Minister: I have a range of calculations, following that report, which show the Scottish Qualifications Authority's income and expenditure balance, and I am prepared to make them available to the member. Each year, the Scottish Government works closely with the SQA to ensure that the SQA reaches a balanced budget position. The obligations of implementing the curriculum for excellence are obviously part of that budget consideration. I assure the member that that is being and will be done. I will provide the range of figures that give the detailed answer to her question.

Multiple Sclerosis Week 2014

The Deputy Presiding Officer (Elaine Smith): The next item of business is a members' business debate on motion S4M-09251, in the name of George Adam, on multiple sclerosis week 2014—treat me right. The debate will be concluded without any question being put.

Motion debated,

That the Parliament welcomes MS Week 2014, which takes place from 28 April to 2 May; understands that Scotland has one of the highest incidences of MS in the world and that over the last decade the availability of treatments for MS has been instrumental in supporting many people to manage their condition and its symptoms; supports the notion that everyone with MS should be able to access the right treatment at the right time; notes recent research by the MS Society that highlights current barriers to accessing MS treatments in Scotland and considers that, with new treatments on the near horizon, this situation will hopefully be urgently addressed; welcomes the MS Society's Treat Me Right campaign, which aims to ensure that licensed treatments for MS are freely available to everyone who needs them and that people with MS are active, informed and equal partners in their care, and notes debate on what steps must be taken in Scotland to achieve this goal with the partnership of the Scottish Government, the NHS, the voluntary sector, industry and people affected by MS.

The Deputy Presiding Officer: I call George Adam to open the debate. [*Interruption*.] Could we please have silence in the public gallery?

12:35

George Adam (Paisley) (SNP): Thank you, Presiding Officer. The noise in the public gallery is probably just my family getting overexcited at the thought of me debating here today.

Most members will know that my connection with multiple sclerosis is through my wife Stacey, who, as members can see, is up in the public gallery. It is almost like "Romeo and Juliet", with her up there on the balcony—and, yes, we are that romantic with each other. When Stacey was diagnosed at 16, that was a life-changing experience for her. Nobody knew about MS and she had to see general practitioners and consultants, so everything was difficult. Her family instantly went into a panic and did not understand what MS was. Her father, Tom, just thought, "Oh, now we know it's MS." It was only when her mother explained to him the life-changing aspect of MS that he understood and just broke down.

However, Stacey went on to university and, obviously, she eventually met the love of her life, so things got a lot better. Stacey is very positive about her MS, as is just about everybody I know who has it. I do not think that I have met one individual with MS who complains or moans about their situation. They want to be part of everything and to get on with stuff.

I apologise to my MSP colleagues for Stacey being the MS Society badge police for the past week. She has made sure that just about everyone has worn the badge. In fact, Rebecca Duff from the MS Society Scotland said, “I’m just glad she’s on our side, because I wouldn’t like to be on the other side.” That is how passionate Stacey is about making sure that we get the message out there. Sometimes, MS is not as high up the agenda as it should be.

Here we are in year 3 of Stacey’s annual MS awareness week debate. At the MS Society event in the Parliament last night, I talked to many families who are dealing with MS. My family has come here, too—they almost treat it as a busman’s holiday when they come over to see the debate.

My mother-in-law does this thing where she says, “You know, if someone stopped me in Paisley High Street about”—insert whatever subject—“I would say this.” That normally means that I have to listen, as she is trying to influence my opinion on various things that are happening in the world. She has said that a few times. When we discussed MS, we said that some of the problems for families who deal with MS are the shock, feeling alone and the ignorance of not knowing what MS is. Things have changed quite a bit and are moving forward, but those are still issues for many families.

Since last year, things have moved on quite a bit, with the creation of the cross-party group in the Scottish Parliament on MS. I see that my deputy convener on the group, Lewis Macdonald, is in the chamber. In creating an agenda, we ensured that we focused on what we can achieve, so that we have a work programme that can deliver something. We want to ensure that we do not just sit every quarter talking—in effect, moaning—about things not happening. That has been because the MS Society, partner organisations and other people who are involved with MS and who want to make a difference have got involved with the Government and the Parliament. That is the big difference for us.

Yesterday, Neil Findlay made the important point to me that many MSPs have a family member who has MS. That is an example or representation of what we are dealing with in Scotland.

At the first meeting of the cross-party group we started talking about access to medicines, which is currently a big, big issue. We need the pharmaceutical companies, the Scottish Government, partner organisations and the national health service to work together to deliver access. The MS Society said in its report, “A lottery of treatment and care: MS services across Scotland and the UK”, which was published last year:

> “Only 36 per cent of people living with MS in Scotland who are eligible take medicines that alter the course of MS.”

It went on to say:

> “29 per cent of people in Scotland told us they do not have enough information about medicines.”

That brings me to the people and families who deal with MS on a daily basis. The MS Society in Scotland decided to gather evidence on what its membership and people in Scotland are doing. It went to Inverness, Airdrie, Edinburgh, Hamilton, Aberdeenshire and Dunfermline to speak to people, and it found that the big issue is access to the drugs that people need. One woman said that she had been on—excuse my pronunciation—Tysabri for five years and it had made a huge difference to her. She said, “Although the treatment clinic I go to is quite a distance away, I see my MS specialist regularly, but this is partly because of the treatment I’m on—there might be side effects.”

Another woman said, “When planning my life and business, I don’t need to worry about fridges for my syringes because now I’m on Gilenya, which is a tablet.” She said that she could just keep the drug in her handbag. She has access to dedicated staff, but she said that she worried about whether other individuals had similar access.

I will mention a wee wifie from Paisley who I speak to on the High Street, Rosemary Thompson—she is Stacey’s mum, incidentally. She says that it is important that people with MS get more support and more access to MS professionals from an early stage. She also thinks that GPs should be better informed. We constantly hear from people with MS that their GPs do not have the full information.

Therapy centres such as the Revive MS Support centre, in Glasgow, offer the best support. Often, what is needed is someone to listen and talk to people and the opportunity to get further information.

We have been lucky. Stacey had a problem with her mobility but got physiotherapy only after she had a fall—at that point, after having had MS for 20 years, she was taught how to walk with crutches. That kind of support should be happening at an earlier stage.

Elizabeth Quigley talked last night about how she wants progress on access to drugs. There is a two-way street: the drugs companies must make applications to the Scottish Medicines Consortium if we are to be able to get the drugs. Fampyra has been licensed since 2012 and Sativex since 2010, but nothing has been done with those drugs yet.

We have to ensure that those drugs are available, because they can make a difference in people’s lives. At last week’s meeting of the cross-party group, Stacey said, “It’s like someone showing you a new designer house but not giving you the keys—you just look at it for five years.” She also said that not giving access to the drugs is “evil”.

That is an important point, because in Scotland we have more MS sufferers per head of population than anywhere else does. It is a very Scottish disease. We say that 11,000 people in Scotland are dealing with MS, but we do not know for sure. I ask the cabinet secretary to look at extending reporting for the Scottish MS register, which was launched in 2010. Currently, only people who are newly diagnosed with multiple sclerosis are registered. We need to expand the register so that everyone in Scotland who has MS is on it. Only when we know exactly how many people there are and where they are can we plan for prescribing and treatment.

Only when we start to do the things that I have talked about will we start to treat people with MS right.

The Deputy Presiding Officer: Thank you. We will have speeches of four minutes, and I will be grateful if members stick to their times, because the debate is heavily subscribed.

12:44

Neil Findlay (Lothian) (Lab): Thank you, Presiding Officer, and I apologise, because I will have to leave after making my speech.

I thank George Adam for lodging the motion and for his work on getting the cross-party group on MS established. I also thank the MS Society for its proactive work programme for the group.

I do not want to go over the grim statistics on MS in Scotland, because they have been covered time and again in our annual debates on the issue. I want to focus on the impact of the illness and the reality for sufferers. One of the things that concerns me most about the treatment of MS in Scotland is unequal access. Only 36 per cent of sufferers have access to drugs that alter the course of MS, 25 per cent are unable to see a neurologist when they need to, and six out of 10 eligible people are not taking disease-modifying drugs.

Many sufferers are struggling financially with care costs; only a quarter of sufferers are in work. Many, like my brother, have had to stop working because they cannot physically continue with it. There is unequal access to specialist nurses, emotional support, physiotherapy, continence advisers and so on. Last night, I spoke to the only MS social worker in Scotland—Duane Patterson, who works in Dundee—and surprise, surprise, it is the poorest and most disadvantaged who suffer most and who are denied access to services.

Recently, I had to watch a friend of mine who experienced excruciating nerve pain for several months. It attacked his face, mouth and tongue, and impacted on his ability to speak. It destroyed his quality of life by causing him to become housebound and to lose weight, and it affected his social life. He found himself left to his own devices for all that time and got very little support, and he did not want to ask for any. I also had to deal with a constituent who has severe mobility problems and required a home visit from his dentist to carry out a denture repair, but no appointment could be made for a whole month. We should think about how that made him feel.

However, I hear about other areas in which people have direct access to specialist nurses, phone numbers so that they can contact someone directly for advice and support at any time, and access to other services to help them to manage their condition.

This week, the MS Society is highlighting the further inequality in access to medicines and licensed drugs. The Scottish Government often compares Scotland with other countries, but we would not be so keen to make that comparison in this area. Scotland is 25th out of 27 in Europe, with almost half the rate of access compared with that in Northern Ireland.

People who have been diagnosed are supposed to see a specialist once every 12 months as a minimum, but for many that is still a significant issue. When they see a specialist, the information on treatment and new developments becomes a big secret. Elizabeth Quigley spoke very eloquently about that last night.

In my area, we have an ability centre in Livingston that has the West Lothian community rehabilitation and brain injury service. It provides community-based specialist assessment and rehabilitation for people who are over the age of 16 and who have either a physical disability or an acquired brain injury, and it includes MS in its work. It provides help with daily living, mobility, communication, emotional support, social activity and so on. However, despite that service being available locally in my community, GPs still do not refer people to it. Why is that? Why is something as simple as a referral to a support service not being made? My brother has never been referred to that service. The person whom I spoke about earlier who had the excruciating nerve pain has never been referred to that service.

Last night, the minister made some very positive statements, which are very welcome. I hope that those words result in action. I am sure that all in the cross-party group on MS will be saying to the minister that we are watching.

12:48

Bob Doris (Glasgow) (SNP): I thank George Adam for bringing this members' debate to the chamber.

I will make a brief contribution. I am lucky, in that my connection with MS is not through a family member. Many people whom I have met over the years have had a family member who has had to suffer MS and find a way of living positively with it. That is really important.

George Adam referred to an organisation in my constituency called Revive MS Support. It was based down the road from my house and lots of my constituents worked there, so I went along—as MSPs do—and I was absolutely blown away by what people were doing there. The first thing they told me was that the organisation is not just for talking about what is wrong with people. It exists to provide people who have MS, and their family members, with a place to hang out. It is there to help if someone wants aromatherapy, a massage, access to an MS specialist or whatever. It takes a holistic approach to those who live with, and those who have relatives who live with, MS.

What that organisation does is quite spectacular. It provides a series of outreach services across the west of Scotland. I wrote to the Cabinet Secretary for Health and Wellbeing recently about Revive MS Support, because such is its success that it has outgrown its Maryhill base. It is looking to colocate beside the Southern general hospital; it hopes to buy a property there. I was at its fundraising launch dinner, so I know that it hopes to raise £850,000 to enable it to do that.

My colleague George Adam has written to John Swinney about how we can sustain such excellent third sector organisations. I have written to Mr Neil about that, too. Revive MS Support tells me that it is confident that it can get many trusts and charitable organisations to donate to its campaign to raise £850,000 to develop an excellent new centre. It also tells me that any Scottish Government money—even a small amount—would be hugely powerful in leveraging in additional moneys from elsewhere.

I will leave my comments about Revive MS Support there. I would have done the organisation and my constituents a disservice if I had not mentioned it during the debate. I hope that the cabinet secretary will agree to meet George Adam and me to work out how we can take things forward.

The other thing that I want to talk about is access to medicines and treatments. As deputy convener of the Health and Sport Committee, I am incredibly proud of the cross-party approach that we took to the issue of access to new medicines in Scotland. Our committee got our teeth into that issue and it ceased to be a case of tabloid newspapers reporting which part of the UK could get one medicine and which part of the UK could not. We just looked at improving the system to make it work for the people of Scotland. That is kicking in now; it will work for the people of Scotland.

However, I am concerned that there could be pharmaceutical companies out there that, although they have life-enhancing drugs for those who are living with MS, are not for whatever reason making applications to the Scottish Medicines Consortium. I know that the SMC is world class at carrying out scoping exercises to identify drugs that could be of benefit to the people of Scotland and encouraging companies to deliver the evidence required to have those drugs approved by the SMC. However, I understand that two companies have not done that. I would welcome anything that the cabinet secretary can do in relation to those companies and the SMC in order to encourage submissions to be brought forward. I believe that we now have a first-class system in Scotland, but it can work only if the pharmaceutical companies bring forward their medicines for consideration.

I said that I would be brief, but I have gone over my time. I apologise for that, Presiding Officer. I hope that the cabinet secretary will take those points on board for his summing-up speech.

12:53

Jackson Carlaw (West Scotland) (Con): I, too, congratulate George Adam on securing the debate. In fact, more than that, I congratulate him on becoming a champion for this issue in the Scottish Parliament. Having a champion for such issues brings an added dimension and impetus, which I hope will lead to the very progress that the debate is designed to achieve.

George Adam began by saying that this was a Romeo and Juliet occasion, with his wife Stacey perched on the balcony, so we will check the wall afterwards for messages of endearment having been posted, as is the custom and habit.

The problem that we have is that multiple sclerosis is a condition about which everyone is really aware. Most people on the street when asked would say, “MS—oh yes, that is multiple sclerosis”; it is one of those conditions. However, what I and others have perhaps totally underestimated or made unfounded assumptions about is the quality of the treatment that is available for people who suffer from multiple sclerosis. What is becoming apparent is that, in a number of ways, that treatment is deficient. It is certainly deficient given the standard that some lesser-known conditions have achieved through focused promotion of that particular agenda.

The reality is depressingly and unacceptably different. It might be matched—as I was pleased to hear—by the positivity of sufferers who are determined to make the very most of and achieve the potential of the life that they have, but none of us can be happy that Scotland languishes nearly next to the bottom in a league of international countries in terms of the availability and success of treatment.

There are a number of issues at hand. First, there is the poor dissemination of information about the disease and, secondly, the restricted quality of the service. A number of members have cited access to medicines—especially the symptomatic medicines—as an issue, and George Adam went through the list of drugs in question. A number of medicines that are licensed are not being prescribed, and a number of medicines exist for which licences are not being sought.

It is slightly unfortunate and ironic that, by focusing so much on cancer drugs in discussing access to new medicines in the past three or four years, we have to some extent undermined, undervalued and overlooked many other conditions. Access to and prescribing of medicines for MS can make a qualitative improvement in treatment now for a disease for which people have been seeking qualitative improvements in treatment for generations. The services are there but—to return to the “designer house” comment that we heard earlier—those who need them are not being given access to them.

Another issue is the provision of access on a proactive basis to regular consultant services. That should not be something that people do not realise they are entitled to, but a service to which they are routinely offered access, and I hope that we will get that improvement.

I welcome the Government’s announcement last night of further enhancement of the services on offer. However, we should also do more to advertise to all those who are sufferers—a group that we believe numbers approximately 11,000 in Scotland—the various treatments that are available. The national register would be a prerequisite in that regard.

I was at the Standards, Procedures and Public Appointments Committee when it approved the establishment of the cross-party group on multiple sclerosis. Like many members, I sometimes wonder whether we do not have just that few too many cross-party groups in the Parliament. However, what impressed those of us who were present at that committee meeting was George Adam’s underlying commitment to ensuring that the cross-party group would have a direct focus. That focus is producing an agenda that will, we hope, translate into results.

I am sorry that I was unable to be at the function last night—no slight was intended at all. I, like other members, know people who have suffered or suffer from the condition, and the campaign has my support. The focus on the treat me right campaign will enjoy the support of my party, and I wish George Adam and the cross-party group every success in working with the cabinet secretary and the Government to make the progress that we all wish to see.

12:57

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): I congratulate George Adam on bringing the debate to the chamber and for being, as Jackson Carlaw said, a champion of MS issues in the Parliament. I certainly do not have any great experience or expertise in the area, although I am, like Bob Doris, pleased that there is a great voluntary organisation, in the form of the MS therapy centre, based in my constituency. I thank all the members who supported my recent motion on the centre, in which I praised its support services and the innovative therapies that it offers to people with MS in Edinburgh and the Lothians and the dedicated and diligent care of the centre’s staff and volunteers.

The voluntary sector is important in dealing with MS, and we have been privileged to have representatives of the MS Society in the Parliament this week. We have been able to talk to them and to read the various materials that they have presented. They told us in particular about the society’s treat me right campaign, and I was interested to read the research that lay behind the campaign and the recommendations—or perhaps I should say the demands—that the campaign makes.

Two pieces of information from the research were particularly interesting. One, which was UK wide, was that

> “Six out of 10 ... people”

with relapsing MS

> “are not taking medicines which can alter the course of the condition.”

That probably corresponds with the 36 per cent of people in Scotland who are, according to the research, getting the drugs that would benefit them.

The other very interesting piece of information from the research is that people who feel informed about the medicines and who say, crucially, that they have regular access to an MS specialist are far more likely to be in treatment. The contrast is astonishing: 69 per cent of those people and only 7 per cent of other people, which highlights the importance of the issue.

The research led to the treat me right campaign's four recommendations. The first is that all licensed treatment should be approved and available. On this occasion, it is not the SMC that is being criticised, which is great to know; in some cases, it is the pharmaceutical companies that have not put forward their drugs for approval by the SMC. The SMC should in fact be praised, because it has recently approved two new drugs.

Crucially, the report goes on to say that people with relapsing MS should be informed about the options and should discuss them with a specialist. That is recommendation 3, which is related to recommendation 2: that everyone should be invited to a regular review by an MS specialist. That is a key issue. Again, I give credit to the Government for having the neurological standards, one of which is to invite patients to a review with a specialist every 12 months. However, we know that that is not happening in every case. The 2012 report "Neurological health service in Scotland" said that a quarter of people were not able to see a neurologist when they required to do so. That is clearly an area that needs some attention.

There is a related recommendation about having access to a multidisciplinary team. Nurse specialists for MS are particularly important in that regard. Again, only about half of affected people have such access, so there is clearly more to do, but I give credit to the Government for having the standards and the group that is overseeing their implementation.

I thought that the last recommendation in the report was equally important, because it states that all people with MS should be supported to be equal partners in decision making about their treatment. That is obviously an important general principle for the health service and is linked to patient participation and the patient groups that support them.

When talking to the MS Society today, I was interested to note that it emphasised the importance of not just the society but the Neurological Alliance, of which the society is a member. The MS Society said that many of the issues affect a range of neurological services, so it is clearly important that the Neurological Alliance and the neurological voices project that it has spawned receive support from the Scottish Government.

The Deputy Presiding Officer: Before I call Jim Hume, I advise Parliament that due to the number of members who still wish to speak in the debate, I am minded to accept from George Adam a motion without notice under rule 8.14.3 to extend the debate by up to 30 minutes.

Motion moved,

That, under Rule 8.14.3, the debate be extended by up to 30 minutes.—[*George Adam*.]

Motion agreed to.

13:01

Jim Hume (South Scotland) (LD): I, too, start by congratulating George Adam on securing this debate in MS week. I also congratulate him on taking as long as two minutes into his speech to mention Paisley, which I think is a record. He did manage to get Paisley into his speech twice, however, so well done on that.

It is true that Scotland has one of the highest incidences of MS in the world. Sadly, it remains unclear why that should be the case. Diet, genetics, environment or a combination of those might be the reason. I speak in this debate from a heartfelt perspective. At the end of the previous parliamentary session, there were concerns that the Leuchie house MS respite centre in my region might close because of lack of funding. The users and their families, who need the vital respite care that it provides, come from across Scotland, north England and even from the continent, and they faced losing an invaluable service. Iain Gray, Jackie Baillie and I all supported the campaign for Leuchie house—Jackie Baillie hosted a members' business debate on the issue. I am glad that the cross-party campaigning in support of the work of Mairi O'Keefe and her team at Leuchie house ended with the centre being saved, which is to the benefit of people with MS and other conditions.

MS sufferers need not just respite but treatment, however. Concerns have been raised about the treatment of sufferers by different health boards. I share the view that health boards need to keep data about treatments given by their various health professionals and the time taken for people to get treatment. From that data we can see where we might need to target improvements so that no MS sufferer in Scotland is at a disadvantage just because of where they live. Once we have that data, we can share best practice across health board regions and look to improve care for people with MS. If that does not work, then perhaps we should look at health improvement, efficiency, access to services and treatment—HEAT—targets for the treatments offered and waiting times to treatment.

Those ideas were discussed at the recently formed CPG on MS, of which I am glad to be a member. At the CPG, we also shared concerns about follow-up doctor appointments after a patient is diagnosed with MS. We heard that often when a doctor diagnoses someone with MS, no recommendation is made for initial treatment because the patient is in the early stages. The patient can then go home and, because MS can get worse slowly, realise several years down the line that they have missed out on new treatments or early intervention. Therefore, it is vital that GP practices have in place a best-practice system that ensures that, at a set time, MS patients are invited back in for a review to see whether the condition has progressed.

At the CPG, there was frustration that many innovative new drugs are not available to sufferers, although we heard from the industry that due process and testing of the drugs was finished. It is, I suppose, a chicken-and-egg situation: we cannot freely license drugs without some due process. There are horror stories from the past, when due process was not enough.

I would like it if people with MS, wherever they are in Scotland, were informed of all the options available to them, whether through drugs or therapy centres such as the excellent example just a mile from here that Malcolm Chisholm mentioned, the MS therapy centre Lothian. At the therapy centre, Nancy Campbell and her team help not just people from the Lothians; people from Fife and the Borders also use that great centre.

We must ensure that there is not a postcode lottery. Diagnosis and treatment must be carried out timeously, with regular reviews of patient progress. I look forward to working with the CPG on MS and the MS Society on those matters in future. Given the prevalence of MS in Scotland, I look for assurances today from the cabinet secretary that the disease will be treated with urgency, as its sufferers deserve.

13:05

Clare Adamson (Central Scotland) (SNP): I, too, congratulate George Adam, and I echo members who have complimented him on the work that he does. I also compliment the cross-party group on its work, and acknowledge the excellent information that has been made available to us during MS week. Last night's successful reception had excellent attendance.

I do not often speak in health debates and I am not on the Health and Sport Committee. I am by no means an expert in this area. I am lucky, though, in that, throughout my working life, I have been able to seek expert advice from my big sister. Whether as an information technology professional dealing with GP fundholding systems or on health-related issues, I have always sought my big sister's support.

My older sister Eileen has been a GP in England for more than 30 years and is a fellow of the Royal College of General Practitioners. As well as her GP duties, she trains and examines GPs on behalf of the college. However, in seeking her help for this debate, I was also asking for her experience as an MS sufferer of more than 30 years.

Despite being part of the medical profession, and an English patient, my sister's experience echoes much of the testimony from the MS Society about a lack of coherence and there being no golden pathway through diagnosis and support for MS sufferers. Because of the nature of the disease, sufferers see different consultants as the disease progresses, which makes it difficult to build the rapport that would enable someone to talk through the options and possibilities as they move forward with the disease.

I was delighted to learn so much at last night's event. In the debate this afternoon, many members have talked about the symptoms of MS, and Neil Findlay made a powerful speech about that. We should highlight to people who might not understand the disease as much as those who live with it, and their families, friends and carers, that MS drugs are extremely powerful. When we talk about disease-modifying drugs, we perhaps do not talk about the effects that the treatment itself can have on MS sufferers. It was not until my sister described her treatment as being like chemotherapy that it struck me how powerful the drugs can be. The word "chemotherapy" brings that home to us because chemotherapy is normally associated with cancer treatment. My sister and many other sufferers have to make a choice every day to take a treatment that they know will make them feel awful in the short term for what might not be a guaranteed long-term gain.

I was particularly interested to learn last night about the tablet forms of DMDs, because my sister's experience is of injections, with all the associated problems that have been mentioned to do with travel and the need for fridges—things that we might not associate with the disease.

My sister is very lucky: she is still working and the other day she attended a Pilates class for people with various types of disease that benefit from that sort of therapy. She asked people at the class what they would want me to say today about their experience of being sufferers. She told me that it is all about getting everything right, not just the medicine; it is about all the support services that members have discussed today and people with MS having the confidence to know that they are making the right decisions about their options, in conjunction with their medical practitioners.

The treat me right campaign is fantastic and will take the debate forward. I thank everyone who has been involved in the process leading to this week and I look forward to the cabinet secretary's response.

13:10

John Finnie (Highlands and Islands) (Ind): I, too, congratulate George Adam and thank him for his work throughout the year. Likewise, I thank the MS Society and the various MS therapy and treatment centres around the country.

I want to give the example of a constituent. I hope that I will not say anything that could remotely identify the individual, but her case graphically illustrates some of the issues.

In May last year, I was approached by a young woman who was the mother of a pre-school child. She had been prescribed Fampridine by her neurologist, as she suffers a lack of mobility and the drug would help with walking speed. The pharmacy refused to supply the medication, but she was told that she could self-fund at a cost of £250 per month.

She was aware that Fampridine did not have SMC approval and, like many MS sufferers, she was very well informed, so she appealed the decision. The notes that Linda, who works in my office, took said:

> "Upset—knows the drug may not make her quality of life better but feels she could be given chance."

At that point, the treat me right approach would have been highly appropriate.

At the end of June, the appeal had still not gone through, but the young woman got in touch to tell me that she was in the third week of a four-week trial that she had started. The cabinet secretary alluded to that in a letter to me and quite rightly said that it was a "private arrangement". The young woman said:

> "I have had really positive results. This is great but I am preparing myself for having to not take it as I can't afford it and until pharmacy approves funding I will not be able to stay on it."

She was offered face-to-face meetings with various people, but she declined them because she did not have the necessary mobility to get to them and asked for information in writing. I wrote a letter in support of the appeal, in which I suggested that wider aspects should be considered—I will come to them later. On 16 August, the appeal failed.

Further representations were made. I wrote to the individual patient treatment request co-ordinator about procedural issues and I wrote to the cabinet secretary with some general questions about drugs and treatment, to which I got a comprehensive response. I wrote to the company Biogen, which told me that it hoped to have data available at some point in the future. I would be very keen to get its paperwork for Fampridine.

Moving on—and missing out a lot of trauma in between—on 19 December I got a lovely email that said:

> "Last night is the first good night of sleep I have had in months! Great news to get before Xmas and the New Year".

Those months were months of anguish.

The private arrangement is called a responder identification scheme, but I do not think that people are interested in what it is called. It might be considered a prescription. We use a lot of phrases and buzzwords in the chamber, such as GIRFEC—for getting it right for every child—and we talk about integration of health and social care and holistic approaches. I am not suggesting for one minute that the young woman's child was not brilliantly looked after by two loving parents—quite the opposite—but prescribing such drugs can have a positive impact on not only the child but the rest of the family. We also talk about preventative spend, which, considered in the broadest sense, is terribly important.

Prescriptions have been referred to and I agree with the term "a tax on the sick". As I have said, there are the finer points of debate, but people are not really bothered about procedures; they want to be treated properly.

Like many others, I took a lot of reassurance from what the Minister for Public Health said last night. At the reception was Dr Michael Foxley, a former council colleague who is very involved. He echoed what a lot of people have said, which is that MS sufferers have a lot of positive attitude.

We heard a positive attitude from the minister last night. There is progress, and I can tell you that the woman continues to do very well. I hope that that example can be followed elsewhere.

Thanks again to George Adam for bringing the debate.

13:14

Lewis Macdonald (North East Scotland) (Lab): I, too, congratulate George Adam on securing this debate and thank him for his proactive role in setting up our cross-party group.

Multiple sclerosis impacts on thousands of people across Scotland, but nowhere more so than in the north-east and the northern isles. The proportion of people with MS in Aberdeen is 20 per cent higher than the Scottish average, while the proportion in Orkney is more than double. Given that Grampian shares certain health services with Orkney and Shetland, NHS Grampian has a particular responsibility to give a lead in supporting people with MS, and in many ways it does that job well. Indeed, Marsali Craig, a trustee of the MS Society who attended yesterday evening's reception, often says, "If you're going to have MS, Aberdeen is not a bad place to have it." That not only says quite a lot about Marsali's positive outlook and, as others have pointed out, the positive outlook of many other people with MS, but reflects the good access to services and excellent support from staff that many people in Grampian experience.

Critical to that is the continuing provision of good-quality neurological services at Aberdeen royal infirmary, which must not be compromised by any temptation to centralise services in the central belt. Also critical is the outstanding service provided by MS nurses in Grampian. Any temptation to cut costs there would be self-defeating, as support from those nurses is not only clinical good practice but cost effective in reducing the need for hospital admissions.

Although the Horizons rehabilitation centre in Aberdeen provides a very valuable service for people with a range of neurological conditions, it is only for people recovering from relapses, and increasing access to that service would again be cost effective, as good physiotherapy support can help people to maintain mobility and manage their symptoms. Of course, the Stuart resource centre, which is funded by the MS Society in Aberdeen, also provides invaluable support that deserves to continue.

Aberdeen is not a bad place to have MS in some respects—but not in all. Although it is true that NHS Grampian was ahead of the game in prescribing beta interferon for MS patients from an early stage, access to treatments has more recently become less readily available.

Anne Ferguson from Tough in Aberdeenshire can vouch for that. Five years ago, her consultant at ARI recommended that she have access to the drug Sativex to deal with the involuntary spasms that, for her, are the most significant symptom of her MS. In the absence of approval by the Scottish Medicines Consortium, an individual patient treatment request was made to NHS Grampian on her behalf. When it was refused, an appeal was lodged, but that, too, was unsuccessful. Three years ago, Anne's GP wrote her a private prescription for Sativex, but, again, NHS Grampian instructed him that the drug was not suitable for prescribing in its area. Yesterday, a constituent told me about similar difficulties in obtaining a prescription for Fampridine, either in Aberdeen or in Glasgow, even though he is a health service professional and was willing to pay for the drug himself.

Such access to treatment issues are national, not local. Indeed, as we have heard, people with MS have better access in all but two European Union member states. Ultimately, these issues are for ministers to resolve, which is why it was good to hear the Minister for Public Health, Michael Matheson, pledge on the record yesterday evening that people with MS should receive the right treatment at the right time. That will require early and positive actions by the manufacturers as well as early and positive decisions by the SMC, for which, of course, ministers are responsible.

My constituents and thousands of others, including members across the chamber, will look to all concerned for rapid progress on these issues, and I look forward to hearing from the Cabinet Secretary for Health and Wellbeing how his Government intends to carry out the promise that was made last night.

13:18

James Dornan (Glasgow Cathcart) (SNP): As everyone else has done, I thank George Adam—and, indeed, Stacey Adam—for bringing the debate to the chamber.

It has been a very informative week. The stall and last night's event taught me a lot of things that I did not know about MS. For that, I thank everyone involved. My colleague Bob Doris has already described in great detail Revive MS Support's work, so I will not dwell too much on that. All I will say is that I have been fortunate to see some of the work that is carried out by the branch in my constituency, which meets every Friday in Cathcart Trinity church.

A few months ago, I was reminded of how much of a lifeline local Revive MS Support groups are for many people with MS across the south of Glasgow when I met an old friend of mine whom I had not seen in ages. The guy looked great; as I had expected, he was still fit and healthy. He was a great footballer—and I mean "great". He was classy and energetic, and he played into his 30s and, I believe, his 40s. Members can imagine my surprise when he told me that he had heard of my visit to the organisation because he suffers from MS and is a member. That brought home to me just how little I knew about MS, who it affects, why it affects them and what we can do to make life easier for those who suffer from it.

Access to drugs and so on has been dealt with by others; time is getting on, so I will not deal with that further.

Colleagues might remember that, last September, I secured a members' business debate on a report by the independent living in Scotland project on widening access to politics. During that debate, I spoke of my desire for Parliament to implement some kind of programme for people with disabilities. I wrote to the Presiding

Officer and, due to the support and guidance that I received from her, we have managed to bring about a parliamentary internship programme for people with disabilities. It is funded by the Scottish Government through the Scottish Council for Voluntary Organisations and Inclusion Scotland, ably supported in Parliament by our fantastic equalities team. That is important because, when I suggested the idea of an internship, it was because I firmly believe that we make better decisions as a Parliament if we have many voices and experiences articulated in the chamber and by the people we meet in our role as MSPs.

Inclusion Scotland has secured funding from the Scottish Government for another six interns over the course of the next 10 to 12 months, and we are having an event in Parliament at the end of this month to discuss the internship and how members can get involved. I will discuss the matter in greater detail then, but I am sure that there will be plenty of interest from my colleagues across the chamber in participating in the programme.

I have brought up the issue because the programme's first intern, Catriona Johnson, has recently been appointed and will begin work in my office in the next couple of weeks. Catriona had to go through a rigorous selection process against some formidable candidates, and she won through because she deserved to. Catriona has MS. Many of you will have met her, as she has been one of the people on the MS stall in the garden lobby this week and was at the event last night. I have now had the good fortune to meet her on a few occasions and it is clear that Catriona, like many others suffering from MS, will not be defined by her condition or let it curtail her ambitions. I have no doubt that she will bring a great deal to my office and will be a great role model for interns who follow in her footsteps. We are both looking forward to this internship starting. It will help Catriona to get a sense of what Parliament is like and it will help me to try to grasp some of the everyday problems that someone with MS might have to deal with.

One of the important roles in the programme is for interns to undertake a project, and I will discuss with Catriona the idea of examining in greater detail the reasons why manufacturers are reluctant to put the drugs out to review by the SMC, and what impact decisions like that have on those who suffer from the condition. We will pass the information on to the cabinet secretary when the project is finished.

I fully support the aims of the treat me right campaign, and it is clear that there is broad support across the chamber to move forward with it to try to get the answers that will ensure that folk with MS across the country are afforded the quality of care that they deserve, and that they can access it.

13:22

The Cabinet Secretary for Health and Wellbeing (Alex Neil): James Dornan thanked George and Stacey. I, too, would like to thank them, because Stacey's influence in this matter is well known. I think that this debate is very appropriate. Unfortunately I could not make the reception last night because I was travelling back from Brussels, but I believe that it was successful.

I would also like to congratulate the MS Society. It deserves enormous credit for the contribution that it makes to improving the lives of people with MS, and it continues to play vital roles in promoting new research and in raising awareness of the condition.

I will try in my speech to answer some of the specifics points that have been made. First, I say to Jim Hume that we have now provided three-year funding for Leuchie house, which I am sure he will welcome. To Bob Doris—although he is no longer here—I confirm that either Michael or I would be happy to meet the Revive MS group. I met it last year, and we have supported it with just over £21,000 of funding. I am more than happy to meet the group again.

I will try to answer the points that were made about medicines and the register as I go through my notes.

Access to treatment has been highlighted as a major issue. The MS Society's treat me right campaign for appropriate treatments is especially important. It emphasises the need for disease-modifying drugs for people with relapsing and remitting MS, which can help them to manage relapses and their impacts; and for symptom-management treatments for people with either relapsing or progressive MS, which can help them to manage some of the symptoms of MS, including spasticity, walking speed and incontinence. We want the pharmaceutical industry to engage with the SMC in that regard.

Let me make two points. First, I am happy to take the initiative and to contact the companies that have yet to apply to the SMC for acceptability of licensed products. I accept the general principle that our objective should be to have all licensed products available to MS sufferers through the SMC process. Secondly, I make the point to Lewis that, as a result of the reforms that were recently introduced in the SMC process, including the replacement of the individual patient treatment request process with the peer approved clinical system, I hope that we will see significant improvements in the reduction and elimination of any postcode lottery in the availability of the drugs.

Although, as Jackson said, many of the changes were motivated by problems with cancer-related drugs, we are conscious that they also relate to drugs for MS and a host of other ailments, including cystic fibrosis. I underline our commitment to dealing with that situation.

The Deputy Presiding Officer: I am sorry to interrupt you, cabinet secretary, but you have referred to several members by just their first names. Although members will be aware that "Michael" is Michael Matheson MSP, I ask you to clarify for the record and for those who are watching the proceedings who you mean, by referring to members by their full names.

Alex Neil: "Lewis" is Lewis Macdonald and "Jackson" is Jackson Carlaw.

With regard to access to specialists, the Government recognises the vital importance of seeing the right person at the right time in the right place. Michael Matheson recently had pleasure of speaking at the national neurological advisory group's learning and sharing event. The group was formed to take forward work to ensure continued improvements in neurological care, including for those who are living with MS. Access to specialists has been recognised by the group as a continuing priority and it is taking forward work in that area.

I am keen, as part of what Michael Matheson announced last night, for us to tackle variation between health board areas in access to treatment and in necessary resources. Last week, we published an audit of chronic pain services throughout Scotland, which looked at the variation between different board areas. I am keen to do the same for MS, with a view to eliminating those variations so that everybody gets first-class treatment, irrespective of where they live. That is extremely important.

It is also important that we have the right skills mix and the right number of staff in the right place at the right time. We are keen to ensure that that is the case particularly in relation to neurological resources. Six trainee neurologist posts will be advertised in the 2014 recruitment round, and will be filled via the national recruitment process. That will be a further enhancement of the neurological resource that is available to patients.

The treat me right campaign rightly highlights the need for people with MS to receive the necessary advice and information to make informed decisions about their care and treatment. The national advisory group is well placed to identify and address gaps in provision of the information that supports people to make decisions. We must also ensure that clinicians across Scotland consistently provide high-quality information that not only supports decisions about treatment, but supports people to self-manage their condition. That will be taken forward through the work on care pathways and patient experience. I am pleased to hear that the MS Society is an integral member of the advisory group and is, through the group, well positioned to help to shape delivery of neurological services.

I turn to the MS register. As a Government, we recognise that data is an important element in the delivery of improvement. We have provided funding of £70,000 to support the establishment of the Scottish MS register, which commenced work at the beginning of 2010. The register was set up to gather reliable data on which to establish the incidence of MS in Scotland. The MS Society has also provided funding to support the register and has been involved in the register since its inception to ensure that it has people with MS as its focus. The register is hosted by NHS National Services Scotland's Information Services Division, and in 2013 it published its first national report. It has provided assurance that the MS clinical community is engaged fully in the register. Scottish morbidity report SMR01 data are being used to measure data completeness and, potentially, to identify patients who have not been reported to the register.

The data that are collected are used to produce quality feedback reports, which are provided to MS teams. Those include all known patients who have been given a confirmed diagnosis of MS in the past 12 months. However, I agree with George Adam's point that we should look to expand the register, so that it will eventually include every MS sufferer in Scotland. I undertake to progress that specific action point, as well as the others that I have mentioned, because I am very conscious of the benefits of comprehensive registers in taking forward treatment and research for finding cures for conditions such as MS.

The register also monitors the referral process from the time of diagnosis to contact with an MS nurse. Boards can use the report to assess which stage in the referral process needs to be improved.

We are making substantial progress on all those areas, but further substantial progress needs to be made. I underline that—I think that all the parties in the chamber are at one on this—Scotland is the world capital for MS incidence. Therefore, a particular onus falls on us all to do whatever we can to make life as comfortable, easy and high quality as possible for sufferers, although the ultimate goal must be to find a cure.

The Deputy Presiding Officer: Many thanks, cabinet secretary. I inform Parliament that Bob Doris has apologised to me and members in the chamber for having to leave the debate early.

13:31

Meeting suspended until 14:30.

14:30

On resuming—

"Mortonhall Investigation Report"

The Presiding Officer (Tricia Marwick): Good afternoon. The first item of business this afternoon is a statement by Michael Matheson on the "Mortonhall Investigation Report". The minister will take questions at the end of his statement, so there should be no interventions or interruptions.

The Minister for Public Health (Michael Matheson): I am grateful for the opportunity to make this statement to Parliament.

Yesterday, Dame Elish Angiolini's substantial report on her investigation into the events at Mortonhall was published. There is no doubt in my mind that Dame Elish Angiolini's investigation was robust, detailed and comprehensive. I am incredibly grateful to her for the work that she and her team have put into the investigation, and for the sympathy that she has shown to those who have been affected by events at Mortonhall. The families who are affected had already endured the pain and grief of losing a child. For that to be revisited on them due to the actions at Mortonhall was particularly cruel.

It will take some time for all of us to digest the report in full, but already it is clear that Dame Elish Angiolini has identified what she believes are serious failings in the operational management of the Mortonhall crematorium and in the oversight of Mortonhall by the City of Edinburgh Council.

Dame Elish Angiolini talks about

> "an inward-looking and isolated managerial approach"

and

> "an absence of meaningful supervision or leadership".

She describes

> "a comprehensive and long-term failure to provide an acceptable service to some of society's most vulnerable next of kin."

Those comments go to the roots of the problems at Mortonhall.

I also note that Dame Elish Angiolini concluded that there is

> "overwhelming evidence that foetal bones do survive cremation, at least from 17 weeks gestation",

which should put to rest once and for all the received wisdom that that is not the case.

Members will be aware that the Infant Cremation Commission is currently completing its work and plans to report in the near future. In that context, I would like to set out next steps in relation to Mortonhall and the rest of the country. On Mortonhall, Dame Elish Angiolini's report makes many recommendations for the council. The council in Edinburgh did the right thing in commissioning the independent investigation, and it has indicated that it will take forward the recommendations. We stand ready to provide any assistance that we can to ensure that that is done swiftly.

It is important that the council ensures that the voice of parents is heard in that work. The response to the report should be transparent and open and should involve affected parents. It is important that those who have been so badly affected by past events can have a stake in ensuring that it cannot happen again.

There is of course much for the Scottish Government to reflect on in Dame Elish Angiolini's report. In particular, I note that she concludes that

> "The legal framework governing the cremation of foetuses and infants in Scotland is peppered with gaps, ambiguity and uncertainty."

Work had already commenced on that, and plans were in place to bring forward new primary legislation to update the law in the area. Indeed, there is already a legislative slot for that in the parliamentary programme. However, it is important that we ensure that our work now captures the findings from Dame Elish Angiolini's report.

As members will be aware, last year, the Government asked Lord Bonomy to lead an independent Infant Cremation Commission to look at these matters. Over the past 12 months, Lord Bonomy and his commission have worked hard to review the policies and procedures in crematoria, the funeral industry and the national health service right across Scotland. Lord Bonomy has met affected parents and has spoken to people who work in the industry, both in Scotland and elsewhere in the UK. I also know that Lord Bonomy and Dame Elish Angiolini worked together closely while taking forward their respective investigations in order to learn from each other.

The commission will consider many, if not all, of the issues raised by Dame Elish Angiolini and, once Lord Bonomy has reported, we will move swiftly to set out clearly how we will respond. It would be premature for us to respond in detail to Dame Elish Angiolini's recommendations today, before we know what Lord Bonomy will say, but I am happy to reassure members that, in broad terms, we very much support the recommendations that have been made.

Lord Bonomy has advised us that he hopes to provide his report by the end of May. Before he does that, he has committed to sharing his draft report with affected parents to give them an opportunity to comment on his findings and conclusions. We want our next steps to be owned by those they most affect. We want affected parents to have a voice in the future.

Clearly, updating and improving the law is only part of the solution. We know that many parents across Scotland will continue to be affected by these events. Last year, the Scottish Government provided additional funding to two different charities that are supporting parents who are affected by these issues. As the First Minister announced earlier today, we have set aside an additional £100,000 this year to enable those organisations to continue to provide the support that is needed by those parents. We are already in discussion with the organisations to understand how much funding they need.

I am sure that many parents feel that they still do not have the answers that they need. In the case of Mortonhall, as Dame Elish Angiolini has concluded, the tragedy is that we may never know, and parents will be left with a lifetime of uncertainty. No amount of investigation will provide the answers that the parents want.

I know that some parents in other parts of Scotland feel that their circumstances have not been investigated in the same thorough way as has been done at Mortonhall. As the First Minister said today, we want parents to have the best answer that is possible for their own child. We will consider how best that can be ensured when any potential criminal investigations are concluded and when we have the Infant Cremation Commission's report. All affected parents must receive the same level of investigation as happened for the 253 families affected at Mortonhall.

I know that some parents have reiterated their call for a public inquiry. I reassure those parents that I hear that call. We have never ruled out a public inquiry. We always said that we would reflect on that once we received the reports from Dame Elish Angiolini and Lord Bonomy. That is what we will do.

I reassure members that we will continue to give these issues absolute priority. When these issues emerged last year, we did not hesitate to launch a robust, independent process to learn lessons and make recommendations for the future. We will not hesitate to bring forward the necessary legislation and take the necessary steps once the commission has reported, and we will do all that we can to support affected parents through these difficult times.

The Presiding Officer: The minister will now take questions on the issues raised in his statement. I intend to allow around 20 minutes for questions; I also intend to be flexible, if that is required. After that, we will move to the next item of business.

Johann Lamont (Glasgow Pollok) (Lab): I thank the minister for today's statement on this very sad and distressing issue. No one could have escaped seeing yesterday's harrowing pictures of the families who are still trying to make sense of these tragedies and come to terms with the failures of a system that was supposed to ensure that their loss was met with the dignity and respect that it deserved.

I put on record my thanks for the thoroughness of the report into what happened in Edinburgh, which has done an important job, and I recognise the campaigners who, through their grief, got us to this place at which the investigations have taken place. I know that many colleagues in the chamber will have been dealing with similar cases all over the country, and the minister will know about my involvement at the Scottish level, and with my constituents and families in Glasgow. I have found their stories to be difficult and disturbing, and I fear that their hurt will never be properly resolved, but we have a responsibility to try.

I welcome the undertakings that the Scottish Government and other organisations have made. Scottish Labour stands ready to work with them to help the process in any way that we can. There is a clear consensus that we should do all that we can to find answers for the families all over Scotland who have been tormented by this experience.

Does the minister accept that too many families have lost confidence and trust because they have been misled throughout about what has happened to their child, often on more than one occasion? Does he accept that this is a matter for all Scotland? Does he accept that, should he agree to hold a public inquiry now, he would be able to draw together the past and the future? It would allow us to respond to need right across Scotland. Although it might produce information that is hard for the families to bear, it would give them certainty that the truth is being established, and it would give confidence to those families who were not given the truth. Does the minister accept that establishing a public inquiry would respond to the scepticism of so many families that has been born out of the terrible reality of what has happened to them?

I ask the minister to reflect on that point and to accept that we will do all that we can to support the Scottish Government in proceeding with this matter.

Michael Matheson: I am grateful for the Labour Party's response and offer to assist with any legislation that we can make in Parliament to address the issue. I share Johann Lamont's views about the distress and pain that the findings of the Angiolini report will cause many families. If there was something that I could do to ease that pain for them, I would be more than willing to do it.

The member's principal point was about a public inquiry. As I said in my statement, we have not ruled that out. We will consider it once we have Lord Bonomy's report and have considered it alongside Dame Elish Angiolini's report.

With the publication of Dame Elish Angiolini's report, I have been struck by the widespread acceptance of the thoroughness and detail that she has gone into. Sadly, as she has said in the report, some parents will never get the answers that they are looking for because of the nature of the practices that were undertaken at Mortonhall. No further or subsequent investigation will be able to provide those families with the answers that they are looking for.

I recognise that there are parents who feel that there is a need for further investigation into their personal circumstances. I am sympathetic to that and will consider it as part of the work that we will do after Lord Bonomy reports. However, it is right that we give Lord Bonomy and his commission their place so that they can complete their detailed investigation. Once that report has been submitted to the Scottish Government, we will consider the most appropriate approach to take to give those parents who feel that there are still unanswered questions the answers that they are looking for where they can be provided.

Jackson Carlaw (West Scotland) (Con): Like others, Conservatives have met many of the parents, and we offer our support in the face of the distress, dismay and frustration that they have endured, particularly during the past year.

I, too, welcome the minister's statement and thank him for advance sight of it. I acknowledge the Government's obvious desire to meet the scale and scope of the recommendations that are already emerging. Of course, we also offer our support for any legislation that the Government feels is necessary.

Ruth Davidson called for a public inquiry a year ago, but the First Minister felt that the investigations that were being led by Dame Elish Angiolini and Lord Bonomy were the best approach to give earlier certainty. We disagreed with that approach but we understood what the First Minister was seeking to achieve. I think that Dame Elish Angiolini's report is deeper and more disturbing than any of us could have imagined—she herself uses the word "grim."

I echo Johann Lamont's comments: given that the experience of parents at Mortonhall was shared by others across Scotland—that is the characteristic that we have yet to understand fully—I urge the minister to reconsider our request, which has been repeated today, for a full public inquiry. That is not something that Conservatives seek often or lightly. I understand that the decision might be reached in the wake of Lord Bonomy's report this month, but I ask the minister to appreciate that the sheer scale of the issue across Scotland underlines and justifies the need for a full public inquiry, to give the certainty that I think all of Scotland needs.

Michael Matheson: I welcome the constructive response from the Conservatives to work with us to take forward any necessary legislation.

I recognise the call that was made by the Conservatives previously—and by Ruth Davidson in particular—to have a public inquiry. When we were considering the matter, one of the most important issues was to find the best way to give answers to parents who had questions and uncertainty. In her report, Dame Elish Angiolini has been able to investigate 253 individual cases in great detail—something that I am sure that the member would appreciate would not happen with a public inquiry, because a public inquiry would look at only a sample of cases and use them for general purposes and reference. The approach that the City of Edinburgh Council has taken has allowed a much greater level of detail to be gone into in those individual cases, which I think has been helpful in looking at the issue in context.

The member is right that we will consider the possibility of a public inquiry once we have Lord Bonomy's report. The member referred to the issue of scale. Lord Bonomy will consider the process in every crematorium in Scotland. He has looked at every policy and practice, including the paperwork, that operates in our crematoria in Scotland. Once we have his report, we will have a clearer understanding of the scale of the matter in Scotland. At that point, we will be in a better position to make an informed decision about whether a public inquiry will add any extra value to the work that has already been carried out by Lord Bonomy and Dame Elish Angiolini.

Jim Eadie (Edinburgh Southern) (SNP): I ask the minister to join me in paying tribute to the work of Sands Lothians and, in particular, that of Dorothy Maitland, who has done so much to support other families through what has been an unbelievably difficult process. Does he agree that the pain of the 253 families is deepened by the shocking findings of the report and the news that in many cases the families will never know what happened to their babies' ashes? Given that, and given the finding at page 548 of the report that

> "the precise extent to which remains of babies have been mixed in with an adult cremation ... is also unknown but appears likely to be extensive",

will he provide further details on the potential for a lasting and dignified memorial, if that is something that the parents wish to see, so that they can have a focal point for their grief?

Michael Matheson: Like Jim Eadie, I acknowledge the tremendous amount of work that Sands Lothians has done, and, in particular, the way in which Dorothy Maitland is taking that work forward, given that she is also an affected parent in this tragedy. There is no doubt that the report from Dame Elish Angiolini will reopen many difficult memories for many families.

With regard to the memorial, I know that there are some recommendations in Dame Elish Angiolini's report around the existing ground at Mortonhall. I have no doubt that the council will wish to take forward those recommendations, and I would encourage it to do so with affected parents.

Once we have Lord Bonomy's report, I will be more than happy to discuss with respective organisations the possibility of a national memorial, if that was felt appropriate. My guiding light in relation to any type of memorial will be the affected parents and whether they feel that one would be appropriate in the first place.

Neil Findlay (Lothian) (Lab): The findings of the report are multiple and very complex in nature, and I think that they will reverberate across the United Kingdom, around Europe and possibly even beyond. We know that more than 200 families have been affected by practices at Mortonhall, but we do not know how many have been affected in other areas of Scotland. What action has the Government taken in respect of other Scottish local authorities, and what advice has it offered them about how they can establish what has gone on in their area? What should other bereaved parents who may have suffered in a similar way now do to find out if indeed they have been affected?

Michael Matheson: When Lord Bonomy's commission was established, one of its early acts was to write to all crematoria in Scotland setting out the process that should be put in place and adhered to if any concerns were raised by parents regarding the cremation of infants.

Alongside that, the commission is examining the procedures and practices that are in place in every crematorium in Scotland in order to evaluate whether any aspects of their practices are not acceptable. When we have Lord Bonomy's report, we will be in a position to consider whether we need to take further measures with regard to specific crematoria in any part of the country.

The advice that was given when the commission was set up was that any parents who had concerns should initially, under the current legislation, raise those concerns with the crematorium in question, which should then follow Lord Bonomy's advice on investigating the matter.

Once we have Lord Bonomy's report, we will be able to consider specific crematoria in Scotland that have been operating in a manner that is not acceptable. We will then consider what measures need to be taken in order to investigate those matters further, if appropriate.

Marco Biagi (Edinburgh Central) (SNP): In several of his answers, the minister has referred to the plight of parents in other parts of Scotland. A constituent of mine had an experience in Edinburgh with a different crematorium, but as it was run independently rather than by the local authority, it fell outwith the scope of the Mortonhall investigation.

Can the minister provide a guarantee that the review of what has been going on, and any changes that are made, will apply to all crematoria, no matter how they are operated? Will there be a review not just of current practices but of historical cases from 10 or 20 years ago that are continuing to bubble up?

Michael Matheson: Lord Bonomy's commission is looking at all 27 crematoria in Scotland, of which 14 are local authority run, 12 are privately run and one is run jointly by the local authority and the private sector. All the crematoria have been contacted by the Bonomy commission so that it can examine their policies and practices and the procedures under which they operate.

I assure the member that the commission's approach applies to all establishments, public or private. If there is a view that there may have been some form of criminal activity in individual cases that come up, the advice is for individuals to report the matter to Police Scotland, which has a team that will investigate any individual circumstances that parents bring to it.

Jim Hume (South Scotland) (LD): My thoughts today are with all 253 families who are affected by the Mortonhall tragedy.

The minister said that he wants to wait for Lord Bonomy's findings. Does he agree with me and other members on all sides of the chamber that regardless of what is contained in those findings, which will be of a technical nature concerning practices and legalities and will not deliver all the answers that families across the country need and deserve, only a full public inquiry can ascertain whether other crematoria were involved? It would help to avoid any further delay in giving families the answers that they were promised. We need to know about the mistakes of the past so that we can be sure that they never happen again. I, like members of other parties, will be happy to help the Government in that regard.

Michael Matheson: I am grateful for Jim Hume's support for any legislative changes that may need to be introduced. As I mentioned in some of my answers, we have not ruled out the possibility of a public inquiry. However, it is right that we allow due process to take place and the Bonomy commission to complete its work. We can then come to a final decision on the matter.

It is worth emphasising that the approach by Dame Elish Angiolini resulted in the investigation of 253 individual cases. If we had instigated a public inquiry at national level and not had the Angiolini inquiry, which was set up by the City of Edinburgh Council, those 253 cases would not have been subject to the level of investigation that has now occurred.

If the objective is to ensure that concerned parents get their case thoroughly investigated to try to get the answers that they are looking for, we must recognise that a public inquiry might not be the best route for achieving that. If it is the best route, then the Government will consider it once we have received Lord Bonomy's report. We need to be sure, though, what the objective of any further investigation would be. If its purpose is to try to give parents the answers that they need about their baby's circumstances, a more detailed investigation of their case might be the best way of achieving that, as was the case with Dame Elish Angiolini's report.

I hope that the member will be reassured that our commitment is to try to get the answers for parents as best we can and to try to find the best mechanism to achieve that. If that can be served only by a public inquiry, we will consider that, but if it can be achieved in a better and quicker way, we will consider that as well.

Kezia Dugdale (Lothian) (Lab): Can the minister clarify the role of Lord Bonomy's work in relation to the NHS? The minister will be aware that the report looks at practices within hospitals, particularly those involving midwives and nurses who deal most immediately with families who have just lost a baby. If it is not the case that the NHS will be part of Lord Bonomy's review, can the minister look to revise with immediate effect the guidance that midwives use to advise parents immediately after the death of a baby and ensure that practices that happen today, tomorrow and next week do not need to be reviewed three months down the line, when they could be reviewed today?

Michael Matheson: I can give the member the reassurance that she requires: Lord Bonomy's commission is looking at the funeral industry, local authority and private crematoriums, and the NHS. He is looking at the full process of dealing with families who have lost a baby. Dame Elish Angiolini's report highlights a number of failings within the NHS that are unacceptable and will need to be addressed. The Government is ready to ensure, once we have Lord Bonomy's detailed report, that we can take the necessary action to ensure that staff within the NHS have the right skills, knowledge and support to advise parents in such tragic circumstances of the information needed to make an informed decision.

Gordon MacDonald (Edinburgh Pentlands) (SNP): Given the number of recommendations in the report, can the minister tell us what communication the Scottish Government has had with the City of Edinburgh Council since the report was published, as there are recommendations for both the Government and the council to consider?

Michael Matheson: Our officials have been in regular contact with the City of Edinburgh Council since the publication of the report. The member may be aware that the council has announced that it intends to establish a working group to consider the recommendations set out in the report. We have made it very clear to the City of Edinburgh Council that we stand ready to offer it what assistance and advice we can provide in order to support and implement the recommendations as swiftly as possible. We will also implement the recommendations that are set out for the Government. Once we have the full report from Lord Bonomy we will consider whether we need to take any further measures that might have an impact on the way in which all local authority and private crematoriums in Scotland operate.

Sarah Boyack (Lothian) (Lab): I will pick up on the answers that the minister has given to colleagues about what happens for parents living in other parts of Scotland. What will the timetable be for the introduction of legislation following both the Mortonhall report and the Bonomy commission report? We must also think about what impact the reports will have on parents in other parts of Scotland and what routes there will be for them to get answers to questions that they might have. The minister has acknowledged that the questions are about not just the operation of different crematoria, but very personal family experiences.

It would be helpful to get some sense of how the minister thinks that that will be addressed. Although he has said that he does not think that a public inquiry is appropriate, he has not ruled it out. Nor has he said what alternative mechanisms there might be and who might commission them. The City of Edinburgh Council commissioned the Mortonhall report. What would be the alternative for other parts of Scotland?

Michael Matheson: I acknowledge the member's desire to set out a clear path for going forward. I am cautious about setting out too much detail however, because whether we choose a public inquiry or a different approach will be determined on the basis of Lord Bonomy's report. There are options that go in different directions.

I reassure the member that, once we have received Lord Bonomy's report, we will come to an informed decision about whether to have a public inquiry. If we decide not to, we will consider what measures could be taken to help those parents in other parts of Scotland who feel that their circumstances have not been thoroughly investigated. If we are to provide something to achieve that for them, we will consider what form that should take in order to reassure parents and give them confidence that the measure will do the right thing for them and that they can trust the nature of the investigation.

I do not want to set out what an alternative option would be because it would appear that I was completely ruling out a public inquiry. I assure members that an inquiry has not been completely ruled out. Once we have Lord Bonomy's report, we can make an informed decision about the best way forward.

The Presiding Officer: A further seven members have indicated that they wish to ask a question of the minister. I intend to let this session run on for as long as it takes to allow those seven questions to be asked and answered. That will impact on the debate that follows, but we will give you guidance from the chair when we come to the next debate. Given the importance of this issue, that is the right thing to do.

Colin Keir (Edinburgh Western) (SNP): I thank the minister for his statement and pay tribute to the parents in Sands Lothians.

Will the minister expand on how much consideration has been given to the report from Dr Clive Chamberlain, which appears in an annex to the main report?

Michael Matheson: I am aware that Dr Chamberlain was a specialist who gave expert advice to Dame Elish Angiolini's team. As I outlined in my statement, Dame Elish and Lord Bonomy have worked closely and the full report has been submitted to Lord Bonomy's commission, including the annex to which the member refers. I have no doubt that Lord Bonomy's commission will want to consider that particular piece of evidence that was submitted by the expert who supported Dame Elish Angiolini's team.

Drew Smith (Glasgow) (Lab): I reiterate Johann Lamont's comments that there are parents in Glasgow who believe that they have been affected by this tragic scandal. Those that I have spoken to believe that a full public inquiry is needed in order to have a chance of getting at the answers. Critical to that is their loss of trust; they believe that they have been misled before.

I understand that Lord Bonomy will report very soon, but does the minister understand that every day and sleepless night that such an inquiry is delayed adds to the prolonged anguish for those families? Further to Sarah Boyack's question, I ask the minister whether Lord Bonomy has been asked to make any recommendation about an alternative to a public inquiry, and whether he expects Lord Bonomy to say more about potential routes for getting the answers that these families need?

Michael Matheson: I recognise that there are parents in Glasgow and other parts of the country who may feel that they have not had the same level of investigation into their case as the parents affected at Mortonhall. However, as I have said on a number of occasions, it is right that we allow the Bonomy commission time to do its work. It will report in the coming weeks and I assure the member that soon after we have received the report, we will come to a position on the best way forward. There is no intention on our part to try to delay matters. Once we have Lord Bonomy's report, we will try to respond as quickly as possible.

For example, the Bonomy commission has committed to sharing its report with affected parents before it is published, so we will ask whether parents would wish the Bonomy report to be published alongside the Scottish Government's response to its recommendations. That may take a little bit longer to do, to allow us to consider the recommendations, but it would mean that one report is published and that parents will not have to wait for the Bonomy report and then for our response to it. If parents feel that that would be helpful, I am more than happy to work with the commission to achieve that, in order to try to give parents as quickly as possible the Scottish Government's perspective on what we will do to move forward.

Mark McDonald (Aberdeen Donside) (SNP): The minister referred to other parts of Scotland, and there have been concerns in Aberdeen. I note today that the housing and environment convener at Aberdeen City Council has announced that there will be a review of its process. Given that the minister has announced that legislation will be introduced during this parliamentary session, what guarantees can he give that there will be discussions with those councils that are reviewing their practices, to ensure that any reviews and actions that are taken are complementary to the legislative process, not contradictory to it, to ensure a joined-up approach?

Michael Matheson: The review to which Mark McDonald refers is a process that Lord Bonomy set out and I encourage Aberdeen City Council to follow the Bonomy commission's guidance on it.

The process is set out in such a way as to ensure that affected parents can have confidence in it, and so that it is independent of the council's process.

When taking forward any legislation we will have to engage with stakeholders and consider the matters in detail. I am sure that all members will recognise that although we want to move swiftly on this matter, we also need to take considered time to ensure that we get it right, so that there is no repeat of this situation.

Mark McDonald can be assured that we will work with all stakeholders so that any legislative changes will ensure that such issues can never occur again. I encourage Aberdeen City Council to follow the process that Lord Bonomy outlined when it carries out any review of its own process.

Alison McInnes (North East Scotland) (LD): Bereaved parents in my region suffer the same heartache and raised concerns about Aberdeen crematorium last year. In response, the council carried out an extremely limited sample audit of records; I am grateful that it is looking at that again.

Dame Elish Angiolini recommends that crematoria should not be allowed to continue cremating infants unless they can demonstrate confidence in retrieving remains. Can the minister assure me that every support will be given to Aberdeen City Council and, indeed, councils around the country to ensure that they can act promptly to develop the necessary competence and thereby ensure that the utmost respect and dignity are accorded to the handling of infant remains?

Michael Matheson: Alison McInnes may be aware that a couple of professional bodies are responsible for standards in the cremation and burial industry. As Dame Elish Angiolini outlined in her report, they have been found wanting to some degree, in relation to some of the practices on which they have issued guidance.

Once we have Lord Bonomy's report, it will be important to ensure that those different regulatory bodies operate on the same standards and that those standards are being implemented effectively. We have to look at how the action that we take forward in any future legislation can ensure that those standards are being properly adhered to and what sanctions there could be if they are not.

Alison Johnstone (Lothian) (Green): I am grateful that this thorough investigation has occurred at Mortonhall and I recognise the part played by those brave parents, who campaigned through grief that we can barely contemplate. It is difficult to understand why the procedures were ever deemed acceptable and it is hard to think of a situation that requires more sympathetic and compassionate attention and care than the cremation of a much-loved baby.

Will the Government work with local authorities to ensure that those who work in crematoria possess all the necessary attributes—not solely paper qualifications—to carry out all aspects of this incredibly important work with the greatest sensitivity?

Michael Matheson: I am more than happy to give Alison Johnstone that reassurance. One of the important lessons that needs to be learned is making sure that staff have the right type of empathy and attitude for their role. Clearly, local authorities have an important role in ensuring that they have the right staff to perform this work.

Equally, I want to ensure that private sector crematoria have the right staff and can offer bereaved parents the right type of support and assistance in their time of need. I say to Alison Johnstone yes, but let us ensure that private crematoria do the same thing, in offering a good-quality service.

Bob Doris (Glasgow) (SNP): When I meet affected parents in Glasgow once again on Monday, can I reassure them that the Scottish Government will use any mechanism it takes to maximise the opportunity for them to get the detailed answers that they desperately need?

Moreover, although I welcome the additional resources that the First Minister announced earlier today, I should point out that concerns had been raised with me that resources for bespoke counselling services were under great pressure. Will that matter be kept under constant review? After all, the more publicity this issue gets, the more people will be retraumatised by their losses, whether they have been affected by the baby ashes scandal or otherwise.

Michael Matheson: I am aware of concerns that have been expressed by some parents in the Glasgow area about the support and counselling services that are available to affected parents. Last year, we were able to provide some start-up funding to Forget-me-not Care and Counselling, which was established by an affected parent, and it is one of the organisations that we are in contact with to find out whether they require any more financial resource so that they can continue to provide support to affected parents in the west of Scotland.

The Presiding Officer: That ends the minister's statement.

Organ Donation

The Presiding Officer (Tricia Marwick): The next item of business is a debate on motion S4M-09847, in the name of David Stewart, on petition 1453, on organ donation in Scotland. At this stage, I must indicate to speakers in the open debate that I intend to reduce the time for their speeches from six to five minutes, so you should start working on them now. That will get us back on track for decision time at 5 o'clock.

I call David Stewart to speak to and move the motion on behalf of the Public Petitions Committee. Mr Stewart, you may have your full 13 minutes.

15:11

David Stewart (Highlands and Islands) (Lab): Thank you very much, Presiding Officer.

The petitions system is the window to our Parliament. It is etched in our history and has been echoed in Parliaments across the globe. Today's debate is an example of how to petition effectively, and I praise the *Evening Times* and Kidney Research UK in Scotland for their first-class work. Caroline Wilson from the *Evening Times* is in the gallery, and I congratulate her on her work.

I welcome the opportunity that has been given to the Parliament this afternoon to highlight the issues in the petition and the evidence that the committee has received to date in the course of its work. The *Evening Times* petition, which was lodged in November 2012, has attracted more than 20,000 supporters. It calls on the Scottish Government to introduce an opt-out system of organ donation in Scotland in order to help save more lives.

On 11 December 2012, Tony Carlin, the editor of the *Evening Times*, told my committee:

> "I could speak for hours about some of the stories that we have been told or have come across in the course of our campaign: the anguish of parents who have watched their children needlessly die of genetic conditions that could have been resolved with a transplant; the desperation of a man who flew to India in the hope of buying a kidney; and the deep satisfaction that is felt by grieving relatives who have, following the death of loved ones, consoled themselves with the knowledge that others have been given the gift of life. However, there is little point in detailing those stories, because each of you knows or has read of people in the same position—waiting for the phone call that may never come while living a life of increasing misery, fear and despair."—[*Official Report*, *Public Petitions Committee*, 11 December 2012; c 939.]

The UK currently has an opt-in system, although next year opt-out legislation will come into force in Wales. However, for now, I or any other person can actively decide to donate organs or tissue by joining the organ donor register; in other words, we are required to actively opt in. An opt-out system requires an individual to explicitly make it known, while they are alive, that they are not in favour of their organs being used for transplant when they die. The key difference is that an opt-in system involves people expressly stating a wish that their organs and tissue can be used for transplant on their death, while an opt-out system assumes that organs and tissue are available for transplant unless there is a specific instruction to the contrary. The petitioner and others argue that moving to an opt-out system will increase the availability of organs for transplant.

The decisions that we in Scotland and indeed any other country need to make involve ethical, legal, medical, organisational and societal components, and the important balance to be struck is between respecting the views and rights of a potential donor and obtaining organs in an efficient manner. In the United Kingdom, at present, the fundamental principle is that organs are donated actively, freely, voluntarily and unconditionally, using a soft opt-in system.

Organ donation is not a new topic for the Scottish Parliament or, indeed, for the *Evening Times*, which has campaigned on the matter for a number of years. The Parliament's health committees have done work on this area, and my friend George Foulkes held a members' business debate on presumed consent in the previous session. In early 2008, the Parliament mandated the report of the UK organ donation task force. The task force had been asked to identify barriers to organ donation and the factors that might have a bearing on donation rates across the UK. It spent two years considering the issues in detail before reaching its conclusions and recommendations. It did not recommend making any change in 2008 to the UK's existing system, but recommended that action be taken within the existing frameworks to increase levels of organ donation by 50 per cent within five years.

The priority is to promote organ donation more widely and to raise levels of consent, improve public awareness and ensure best practice at all stages of the donation process. The task force noted that countries with an opt-out system tended to have higher organ donation rates but said:

> "presumed consent alone does not explain the variation in organ donation rates between … different countries .... Many other factors affect donation rates."

The legal and ethical implications of introducing an opt-out system were considered in detail by the task force, and it did not identify any barriers to the introduction of a soft opt-out system, as long as sufficient safeguards were built in. In 2008, the position of the task force, which was accepted by the Scottish Government, was that, although a move to an opt-out system would bring real benefits, there were risks.

The task force made 14 recommendations for increasing organ donation throughout the UK without moving to an opt-out system. It recommended that, after a period of five years, progress could be reviewed, at which point the option of an opt-out system could be considered again.

I recall that, when we debated that report and its conclusions, the then Cabinet Secretary for Health and Wellbeing said that, although the Scottish Government was not considering an opt-out system for Scotland, she had increasing sympathy with presumed consent and that the Scottish Government planned to review its position in five years' time.

It is now six years on. Public support for change is growing, and I pay tribute to the contribution that has been made by the *Evening Times* with regard to keeping the issue in the spotlight and engaging and influencing the public on what can be an emotive subject.

Scotland has not been standing still on this issue since 2008. The Scottish Government has been running annual organ donation campaigns, the Scottish campaign has a website and, last year, the Scottish Government published its donation and transplantation plan covering the period from 2013 to 2020. Further, NHS Greater Glasgow and Clyde has run the respect my dying wish campaign to reduce the frequency with which relatives refuse to allow the use of organs, even when the deceased person has signed up to the donor register.

It is very welcome to see that sign-ups to the donor register are high in Scotland. As of the end of March 2014, more than 2 million people living in Scotland had made their organ donation wishes known by joining the UK organ donor register—that is around 40 per cent of the Scottish population, against a UK average of 32 per cent. However, as of March this year, there were still more than 600 people in Scotland waiting for an organ to become available.

I have already mentioned that the Welsh Assembly recently legislated on the matter. In acknowledgement of that, in February, the Public Petitions Committee held a useful and thought-provoking evidence session with Mark Drakeford, the Welsh Minister for Health and Social Services. After hearing about what has been done in Wales and what was achieved with cross-party agreement, the view of the Public Petitions Committee was that it would be good to take stock of where we are in Scotland on organ donation and levels of consent and see whether there is more that we should be doing to maintain progress. Mark Drakeford told us that, last year, 35 people on the Welsh organ waiting list died. Those deaths were the main motivation for making the changes and for increasing the efforts to improve consent rates in Wales.

The debate in the Welsh Assembly began in 2008. The minister was keen to stress that deemed consent was not something that Wales moved towards quickly, but over the course of a number of years. By the time of the Welsh Assembly elections in 2011, three of the four political parties that are represented in the Assembly had included a commitment in their manifestos to legislate to create a system of deemed consent. After the elections, the discussion process continued, leading up to the legislation being passed. The legislation is due to come into force in December 2015 and there will have been a two-year lead-in to the legislation going live.

Christine Grahame (Midlothian South, Tweeddale and Lauderdale) (SNP): I was in the 2008 debate with Lord Foulkes. Can you please clear up for me the difference between deemed consent and presumed consent?

David Stewart: I will go on to cover that, if the member can be patient.

When the Human Transplantation (Wales) Act 2013 comes into force, three choices will be available in Wales—I hope that this will help with the member's point. First, people can continue to opt in, with their names being placed on the register. Secondly, they can opt out and have that decision recorded in the existing UK-wide register, which will be revised to take account of the legislative change. Thirdly, they can choose to do nothing, in which case consent to organ donation will be deemed—that choice is known as a soft opt-out.

We were told that the process for opting out would be very straightforward, with people being able to opt out at general practitioner surgeries, online or by phone. During the two years between passing the act and it coming into force, the Welsh Government and the health authorities have been engaging in a process of awareness raising and education to ensure that people in Wales are aware of the changes to the law and the new choices that they will have.

Christine Grahame: Will the member take an intervention?

David Stewart: I am very short of time—I apologise to the member but I am keen to get this on the record.

We were told that the act has been a popular success in Wales and has gained substantial and growing public support. Information campaigns have been targeted at groups of people for whom it was judged that more needed to done to ensure that they were informed. For example, additional steps were taken to improve levels of understanding among faith groups, especially given that faith groups had made it clear that they were in favour of increasing rates of organ donation.

Young people are another group at which campaigns have been targeted—particularly 16 and 17-year-olds. People will not be capable of having their consent deemed until the age of 18, but as young people approach that age, it is important for them to be aware of their options and the choices that are available.

The use of real-life case studies in Wales has been extremely powerful in swaying public opinion and we were told that a good bank of case studies has been established.

The Welsh minister told us that 45 more organs are expected to become available as a result of the legislation, or 15 new donors a year—on average, three organs come from each donor. A feature of the Welsh legislation—and another aspect that the minister was keen to stress—is the continuing involvement of the family at the point of donation.

In any situation of deemed consent, in which a person has not indicated their wishes either way on the register, the family will always be asked whether they have any better information about the potential donor’s views and wishes. The minister stressed that the family members are not being asked for their own views. Rather, they are being asked to indicate what they know of the potential donor’s views. We must not underestimate how difficult it must be for families to find themselves having to deal with the death of a loved one and at the same time being asked about organ donation. It is understandable that some families, when faced with such a situation, might feel unable to take such a decision. There might be a variety of reasons but we know from research that sometimes families feel unable to agree to organ donation. On occasion, they can override the wishes of the deceased.

Being able to guarantee that the donor’s instructions are carried out and are not overridden by the family was discussed at length in Wales during the passage of the legislation. The Welsh minister told us that they had decided on two safeguards. The first safeguard is that people will still be able to opt in or opt out. A person who is a strong supporter of organ donation or, on the other side, a person who has strong views that they do not wish to donate, can record their wishes on the register.

Further, a person who is anxious that their views might be contested by a family member who has a different view will be able to appoint a representative who will exercise consent on their behalf to the clinical team. Where a representative has been appointed, that person will take priority over the family. The thinking behind that is that if an individual has taken the trouble to appoint a representative, that person’s view will be the one that prevails. If someone has no family and has appointed a representative, the donation will go ahead; if somebody dies and no family or representative can be found, donation will not be progressed.

All that said, no Parliament can legislate for every contingency. The minister told us that that was one of the conclusions that was reached as the Welsh bill made its way through the Welsh Assembly.

We know that there are costs involved with the introduction of this new system in Wales. We were advised that £7.5 million had been set aside to support a range of activities around the change in the law. However, the minister advised that all the evidence available suggested that if Wales was able to secure just two more donations, the system would pay for itself, given the cost of kidney dialysis. If two people could be taken off dialysis, the cost savings would cover the cost of the law change. It seems almost incredible that such a small change in the number of donations can cover the cost of the legislation and that point certainly grabbed the committee’s attention.

I welcome the opportunity to debate the issues raised in the petition and I look forward to hearing the views of my colleagues in the chamber.

I move,

That the Parliament notes Petition PE1453 by Caroline Wilson on behalf of the *Evening Times* and Kidney Research UK (Scotland), which calls for an opt-out system of organ donation in Scotland; congratulates the petitioner on her efforts to raise awareness of organ donation, and commends the issues raised in the petition and the evidence received by the committee to the Scottish Government for further consideration.

15:24

The Minister for Public Health (Michael Matheson): I welcome the debate, as any interest in organ donation is a good thing. I am also very grateful for the committee’s work on the issue.

The Scottish Government remains committed to increasing organ donation. No other country in the United Kingdom can say that it has done more on this agenda over the last five years than we have, but we remain unconvinced that we should make any move to introduce an opt-out system. I will ensure that we keep the issue under review and learn from what happens in Wales, but we are making great progress in Scotland with the programme of activity that we have under way.

People believe that opt out would mean that more organs will become available, but our experts tell us that that would not necessarily be the case. Opt out means increasing the proportion of the population on the organ donor register, but one does not need to be on the register to be a donor. Over the last five years, 62 per cent of all donors in Scotland were not on the register.

David Stewart: Will the minister give way?

Michael Matheson: I will just finish my point before doing so.

The number of donors is limited by the number of people who die in circumstances in which donation is possible. Unfortunately, to become an organ donor, one must die in intensive care and only about 1 per cent of deaths in Scotland occur in those circumstances. Sadly, that is not something that opt out can change.

David Stewart: The petition says:

> "When Belgium switched to an opt-out system of organ donation in 1986, there was an 86% rise in the number of kidneys retrieved for life-saving transplants."

Will the minister comment on that?

Michael Matheson: That is very welcome, but I will move on to the issue of international comparison, because one must take the figures with a significant level of caution.

As the member has just done, the argument is often made that countries with opt-out systems have higher donation rates than Scotland and that is indeed the case for some countries. Spain is often cited, but its opt out was in place for 10 years before its donation rates started to increase. Furthermore, there are areas where Scotland does better than Spain. For example, we have a much higher rate of living organ donation than Spain. As I say, we must be cautious when making such international comparisons.

There are many differences in how organ donation works, and not just the opt-out system. Countries such as the United States of America do not have opt out, yet have higher donation rates than Scotland, while countries such as Sweden, which has an opt-out system, has lower donation rates than we do. No single thing will bring about a revolution in donation rates; we need to look at the whole system in order to increase donation rates.

As I said, Scotland is doing very well. In the past six years, we have almost doubled the number of donors in Scotland. We have delivered a 62 per cent increase in the number of transplants that are carried out, which is the highest number in any part of the UK, and there has been a 25 per cent reduction in the transplant waiting list since 2006-07.

I reassure members that the fact that we are not yet convinced by opt out does not mean that we are doing nothing. We are delivering a significant work programme. Last year, we published a seven-year plan containing 21 separate actions that we will progress. I encourage members to read the document in full, so that they see the many things that we are working on. The key point is that the plan was written in partnership with the Scottish donation and transplant community—the people working with donors and delivering transplants day in, day out. The priorities set out in our plan are what they told us that we need to do in order to increase donation rates even further. The success that we have seen over the past five years is down to those very people. Given that we have achieved the success that we have on the basis of the advice that we have been given by the donor and transplant community in Scotland, it is important that we listen to their advice in going forward.

We are making the best progress in the UK, working with our donation and transplant community. We are seeing more donors and delivering more transplants, and we are saving more lives as a result. I welcome members' interest in the issue and I offer my reassurance that we will continue to look at and review how the opt-out process progresses in Wales, but while we are making the sort of progress that we have been delivering in recent years, I believe that it is prudent and appropriate to wait to see what happens in Wales before we start to introduce significant legislative change here in Scotland.

Although we are not convinced about opt out at present, I want to reassure members about the range of actions that we have been taking forward over the past five years. I hope that members are reassured by the significant improvements in the donor and transplant system that we have achieved here in Scotland—they are better than those in any other part of the UK.

15:31

Rhoda Grant (Highlands and Islands) (Lab): This is an extremely important debate and I am grateful to the Public Petitions Committee for bringing it to the chamber. I am also grateful to the petitioners, the *Evening Times* and Kidney Research UK for bringing their petition on a soft opt-out organ donation system to the Parliament.

As we heard, about 600 people in Scotland are waiting for an organ transplant. Sadly, some of them will die before being offered a transplant, yet we could come closer to meeting that need if everyone who could donate did so. Donating is like giving somebody the gift of life. However, in Scotland, we ask families to make the decision at the most harrowing time of their lives. Corneas can be donated as late as 24 hours after death, but the other organs need a body to be kept on life support to allow donation to happen, and decisions therefore need to be made very quickly. The petition calls for a soft opt-out system similar to that which has been adopted in Wales.

The Welsh system presumes consent but allows people to opt out. They can also confirm their wish to opt in. If no preference is registered, the assumption is that they wish to donate. At the time of death, the family is asked whether they know whether the person wished to opt out. They are not asked to make a choice but simply to confirm, if they can, their loved one's wishes. If they do not know their loved one's wishes, donation is presumed. If donation appears to add to the family's distress, it is up to the trained staff in the donation unit to decide whether to take the donation. However, if a potential donor knows that their family's wishes will be not to donate, they can nominate a representative to make their views clear, and that representative can overrule the family's wishes.

That system has the ability to increase donation. Some 90 per cent of people agree with donation, yet only 41 per cent of Scots have registered on the organ donation register. We know that, when the next of kin are asked, 43 per cent refuse donation if they do not know their loved one's wishes, and that is even if they are informed that their loved one was indeed on the organ donation register. If they have had a prior discussion, only just over 11 per cent refuse donation.

I am concerned that people are often asked to make this decision at times of great distress, when it is almost impossible for them to think straight. I wonder how many come to regret the decision to refuse donation when they have time to reflect and perhaps reconsider. Given that only 10 per cent object to donation, it is surely best to ask those people to register that objection. In that way, every potential donor can have their wishes prevail. Our system puts the onus on the next of kin; a soft opt-out system puts the onus on the donor.

Previously, the Scottish Government indicated support for a soft opt-out system, but today it appears to be pulling back from that. That is really disappointing. I urge it to reconsider, because if it waits for an evaluation of the changes in Wales, we will be well into the next decade before we see changes happening in Scotland, and that will be too late for pretty much everyone who is already waiting for a donation. We need to make a step change now, and I urge the minister to reconsider.

Whichever system of donor registration we have in place, we must underline the need for people to discuss their wishes with their family so that they know what their wishes are. I have made my wishes clear to my family and I urge everyone else to do the same.

However, we cannot just depend on registration. We must take other steps to increase donation, and there is a lot more that we can and should do. Donation and registration are markedly lower among black and ethnic minority groups, while the need for donation is higher. There are also issues to do with religious belief. In Jewish and Muslim communities there is a requirement for quick burial but, with some thought and planning, it is possible to allow for that and to facilitate donations. More work needs to be done with those communities to ensure that we have a sufficient number of donors to meet needs.

There is also the issue of suboptimal organs. Because of the shortage of organs that are available, clinicians have to consider the use of suboptimal organs, which are organs from older people or people who have died from illness rather than as a result of an accident. When I was first told about the practice, I expressed surprise, but I was told that, when a person's organs are not working at all, frankly, any old replacement organ will do. Suboptimal organs can buy the recipients time and it is important that we pursue the issue of how they should be used.

The donation process requires access to life support to keep organs functioning while preparations are made for harvesting. There is also a requirement for theatre facilities to allow retrieval to take place. Retrieval teams can take the donor back to specialist centres to harvest their organs, but that can be distressing for the family, especially in cultures in which a loved one's body is normally kept close until burial.

Such issues are especially important in rural areas, where many potential donors are not given the opportunity to donate. We need to review facilities so that we can put together local action plans for donation that identify pathways that can be used. That would require an audit of facilities and skills, as well as consideration of how we facilitate retrieval teams coming into such areas.

Many other options are available, but I am conscious that time is running out. I urge the Scottish Government to draft the legislation that we need to introduce a soft opt out. Wales has put that in place, along with the systems that are required. We could act now, and we should.

15:37

Jackson Carlaw (West Scotland) (Con): I congratulate the petitioners whose petition led to the debate that we are having, which is a significant one, in that it is the first time since I entered the Parliament that there will be a vote at the end of a discussion on the subject of organ donation, as the previous debates on the issue in which I have participated have been members' business debates.

Somewhat to my surprise, I found that I agreed with every word that the minister said. For Conservatives, this has always been a vote of conscience. I do not know whether that is the position of other parties, but we have said that, when it comes to any legislative change, individual members will be able to come to their own view. However, all Conservative members will support the motion at decision time, because we are of the view that, although some people remain to be persuaded—I am not someone who has any issue with the principle that we are discussing—a fully worked through legislative solution is to be implemented in Wales from December 2015, but we do not yet know whether that fully worked through legislative solution will prove to be wholly robust or wholly effective. It seems to me that the minister's assessment is correct that the best course of action is to remain sympathetic to what is being done in Wales, to wait and see and watch carefully what happens there, and to use the Welsh system, if it is successful, as a template for legislation in the Scottish Parliament.

One aspect of what we have heard so far that I slightly regret is the hint that a politicisation of organ donation could suddenly emerge in the Parliament. One of the things that the Welsh minister said in the evidence that he gave to the Public Petitions Committee was that the broadest possible coalition of political support was fundamental to the success of any legislation.

Christine Grahame: I have not spoken to my whips, but that does not matter. Does the member agree that this is one of the issues on which we hope that the parties will have a free vote?

Jackson Carlaw: Personally, I agree, but it is not for me to dictate the approach beyond the position that the Conservatives will take.

If I have not had a concern about the principle, I have had a concern about robustness. As the minister pointed out, Scotland has the highest level of voluntary donor registration of any nation in the UK. Of the people who become donors, 62 per cent are not on the register. That has been achieved because of a broad appreciation in Scottish public opinion of the desirability of people offering organs on death and the need for that. However, some make a distinction between the voluntary nature of such donation or its being achieved on a voluntary basis in concert with the remaining family, and the presumption that the state owns somebody's body at the point of death, which is a completely different proposition.

My concern about robustness goes slightly further. The voluntary support in Scotland for organ donation has been hard won. I am afraid that there is a history of failure in the NHS—particularly in systems—to ensure that there is public confidence that an individual's wishes will be observed.

Drew Smith (Glasgow) (Lab) *rose*—

Jackson Carlaw: I will finish this point. Nothing would be more detrimental to voluntary organ donation in Scotland than moving to a system under which it was demonstrated thereafter that an individual's wishes were not respected either way. I am afraid that we live in an environment in which we know that the media would make the most possible hay of such an event, which could have a fundamentally detrimental effect on public opinion.

Rhoda Grant: Will the member give way?

Jackson Carlaw: I will give way to Drew Smith, who sought to intervene first, and then to Rhoda Grant.

Drew Smith: Does Jackson Carlaw accept that people's wishes are not being respected under the system at the moment? If, when somebody dies, they are able—I do not know whether to say fortunately or unfortunately—to make a donation, there is no guarantee that their decision to carry a card will be respected.

Jackson Carlaw: That is why I am sympathetic to the system that is being progressed in Wales. However, there is a distinction between that and a legislative change under which an individual's wishes are not respected. To be frank, the non-observance of wishes could have a far more detrimental effect on public opinion. If it were proven that somebody's organs were used when they had asked for them not to be used, that could prejudice public opinion significantly.

Rhoda Grant: Drew Smith made a point that I was going to make. I make it clear that there is an opt-out and a register on which people can make their wishes known. The fallback system for people is to tell their family that they do not want to be a donor. The soft opt-out system takes a belt-and-braces approach.

Jackson Carlaw: I accept both the points that have been made, which is why I would like the system that has been constructed for Wales—we took considerable and persuasive evidence on it from Mark Drakeford—to be tested, so that I am assured that the points that Rhoda Grant makes have been substantiated in practice. If that were the case, there would be scope in the next parliamentary session for the Government, having considered the practice in Wales, to consider whether to introduce a legislative solution. At this stage, we remain unpersuaded but sympathetic.

15:43

Angus MacDonald (Falkirk East) (SNP): I extend my thanks to Caroline Wilson, who brought the petition to the Public Petitions Committee on behalf of the *Evening Times* and Kidney Research UK (Scotland). As we heard from the convener, the petition calls on the Scottish Parliament to urge the Scottish Government to introduce an opt-out system of organ donation to help to save more lives. Saving lives is the crux of the matter. Organ donation saves lives, so increasing the rate of donation will allow us to save more lives.

NHS Blood and Transplant reports that, as of 8 April, 595 patients in Scotland were waiting for a transplant. Last year, unfortunately, 34 people died in Scotland while waiting for a transplant. More are taken off the waiting list as they become too ill to receive an organ.

A conservative estimate from the British Medical Association is that around 70 per cent of people are willing to donate their organs after death, but only 40 per cent of the population in Scotland are registered as organ donors. I am both proud and ashamed of that figure. I am proud because, for the past five years, as the minister said, the number of transplants has gone up and the waiting list has got smaller. The proportion of registered donors in Scotland is now about 8 percentage points higher than in the UK as a whole.

Those improvements are a result of the efforts of the Scottish Government and the regional health boards in implementing the recommendations in the organ donation task force’s 2008 report. However, I am concerned that lives are still being lost unnecessarily because people who are willing to donate organs after their death simply never get round to making their views known. That results in relatives making a decision without knowing that the deceased was willing to donate. For that reason, I believe that it is essential that we consider ways in which the organ donation system can be improved further to reduce the number of avoidable deaths.

Since 2008 and the implementation of the organ donation task force’s recommendations, significant improvements in the infrastructure have been made and donor rates have increased. Now that that has reached fruition and the new systems and arrangements have become settled, we need to decide as a society and as a Parliament what the next steps should be. We have a well-organised, well-funded and comprehensive infrastructure in place to facilitate organ donation, but there is clearly still a great deal of scope for improvement.

The organ donation task force commissioned the University of York to undertake a systematic review of all relevant published data on an opt-out system of organ donation. In the countries that were looked at, the review found that opt-out law or practice was associated with an increase of 21 to 30 per cent in the rate of donation following the introduction of an opt-out system. However, it would be misleading of me not to inform Parliament that the study found that a number of other factors appear to be associated with improved organ donation rates, such as transplant capacity, health expenditure per capita and public awareness. I believe, though, that those areas have already been improved on. Indeed, the 2013 publication “Taking Organ Transplantation to 2020” follows up on the previous organ donation task force 2008 report and shifts focus to donor apathy. The new strategy builds on the achievement of an increase in donor registration and focuses on reducing the high family refusal rate, which at 43 per cent is one of the highest in the western world.

If Scotland was to move to an opt-out system of organ donation, we would not be starting from scratch. As well as having examples to draw on from the well-established opt-out systems in Spain, Austria, Portugal and Belgium, some of which have been referred to, the Scottish Government can follow the precedent that has been set by the National Assembly for Wales. The Welsh legislation, which received royal assent on 10 September last year, introduces a soft opt-out system. The Public Petitions Committee was pleased to take evidence from Mark Drakeford AM, the Minister for Health and Social Services, during a useful videolink session. I had hoped to cover the points that were raised during that session, but my time is limited.

I welcome Michael Matheson’s assurance that he will follow progress in Wales with interest, although I believe that it will be at least two years before we can judge whether it has been successful. I take on board the minister’s view that the Scottish Government is not yet convinced of the benefits, but I believe that it is clear that an opt-out system is an effective mechanism to increase availability of organs for transplant and ultimately save the lives of people with end-stage organ failure who have no other treatment options available to them.

An opt-out system of organ donation should be considered as part of the Scottish Government’s broader strategy to improve donation rates. Under the system, individuals would have exactly the same choice as in an opt-in system—to donate or not to donate. I therefore look forward to the issue being debated further in Parliament, with a view to progress being made on the issue, which I hope will be at some time in the not-too-distant future.

15:49

Drew Smith (Glasgow) (Lab): I am grateful for the opportunity to speak in the debate. I thank David Stewart and his colleagues on the Public Petitions Committee and their clerks for providing Parliament with a welcome opportunity to consider the issues again, as Jackson Carlaw said.

I have previously said that I fully support a move to a soft opt-out organ donor register, and I support legislation on that being introduced as soon as possible. I have put that view to the Parliament previously and I made it known to the Public Petitions Committee during its consideration of the *Evening Times* petition, which was supported by more than 10,000 *Evening Times* readers. I have had the privilege of having a degree of involvement in the campaign that the *Evening Times* has run. I thank Anne McTaggart for taking up the issue and I look forward to her speech.

Under the current system, there is no guarantee that our judgment in life will be respected in death. Ninety per cent of Scots support organ donation, but fewer than half of us carry a donor card, as Rhoda Grant said. The minister was right to say that only a tiny percentage of us will die in circumstances in which organ donation might be possible, but the ultimate decision is taken by family members, in the most difficult circumstances, and there is no requirement whatever to respect the views of the potential donor.

A change from an opt-in register to an opt-out register would help to support families who are unsure about what to do. I know families who have said no but gone on to regret the choice that they made for their loved one. A change to an opt-out system would give people who want to donate a greater degree of confidence that their wishes will be respected.

Notwithstanding what the minister said about the evidence, that position is held by the British Heart Foundation, Kidney Research UK and the British Medical Association. It was the view of the Cabinet Secretary for Health and Wellbeing, when he was in opposition, that an opt-out system could lead to a rise in donations. That is the crux of the issue: a simple change would save lives. The approach is supported by almost half the MSPs in the Parliament, across the parties, who have given public backing to the *Evening Times* campaign—and that is before we have had any detailed debate that might allay people's initial concerns.

I came to my view over time, as other members, particularly my friend Richard Simpson, helped to bust the myths around so-called presumed consent. Whether we have an opt-in register or an opt-out register, the fundamental choice remains the same: it is a choice for individuals. The choice to give remains something to celebrate rather than take for granted. I see nothing in a change to an opt-out register that would diminish that. Hundreds of people are on organ waiting lists. We have the opportunity, not to remove the choice but to make the choice as easy as possible.

The Parliament is capable of being bold from time to time. My party's front bench has committed its support, but this does not need to be a political issue if the Government is prepared to bring forward a consultation or allow time for a member's bill on the matter. A free vote can go either way, and I hope that the Government would be open to its back benchers supporting a bill, given that the breadth of support for an opt-out system is a matter of public record.

I acknowledge that people would need reassurance and that we would need complex safeguards. We would need new procedures, and a significant public information campaign would be essential before we could use a new register.

When I spoke in the debate on this issue in November 2012, I said that if we agreed to go ahead with an opt-out register, change would still be years off and, in the meantime, more people would die. That is the reality. People have died while the petition has been being considered. I absolutely recognise the progress that has been made but, unless there is a clear timetable for reform, more families will lose a loved one after months of waiting and dashed hopes, knowing that a donor who could and would help might be out there somewhere, but knowing, too, that the current system makes it harder for a match to happen.

The Welsh Government has gone ahead with the approach. I asked the Public Petitions Committee to take evidence from the Welsh Government because I thought that the Welsh experience of winning the public debate would be of great value in assisting Scotland in doing the same. I see no need to await a review of the legislation in Wales before we act. Before this debate, I thought that the Government no longer objected in principle and that it was just the timing that would cause delays, so I am disappointed by the minister's comments this afternoon, which I think represent a departure from what we have heard in the past from Alex Neil and Nicola Sturgeon.

15:54

Bob Doris (Glasgow) (SNP): I said in the past that I was undecided on whether there should be an opt-out system of organ donation in Scotland. I expected the matter to come before the Health and Sport Committee, of which I am deputy convener, so I knew that I would have to scrutinise any proposed legislation on the matter, and I thought that being undecided would be a distinct advantage in that regard.

In recent weeks, I have come to the growing realisation that that might just have been a way of avoiding coming to a personal position on opting out and then advocating that in the Scottish Parliament. In the meantime, I have looked on in admiration at Caroline Wilson’s petition on behalf of the *Evening Times* and Kidney Research UK on an opt-out system.

I also had an unnerving feeling that I might not have been doing all that I can to help the constituents who I represent. What really impacted on me was a meeting that I had with the Cystic Fibrosis Trust, which supports an opt-out system for organ donation. However, that was not my reason for meeting the trust. The meeting was about the organisation’s calls for changes to the lung allocation scheme for transplants. It is seeking a new national system as opposed to a regional system of lung allocation for transplants. Indeed, I have corresponded with various public bodies on that matter, and there is clinical evidence on both sides of the debate. I understand that the evidence is being reviewed, which is important, because there is strong evidence on both sides and there is no clear way forward. As MSPs, we have to balance what is best for our constituents.

The Cystic Fibrosis Trust raised some other matters that relate to organ donation as part of a wider campaign. In particular, the trust talked about the invidious choices that those who are living with cystic fibrosis have to make when they are desperately waiting for a transplant. For accuracy, I will quote directly from the briefing. It uses the terminology “extended criteria lungs”. What are extended criteria lungs? They are

> “lungs which fall outside the traditional donor criteria set by the International Society for Heart and Lung Transplantation. They may come from a donor who is over 55, smoked, or has some mild lung abrasions.”

I should point out that those lungs are tested and cleaned before they are used.

However, the science is not perfect. There are a small number of recipients of lungs from former smokers who have gone on to develop lung cancer and died relatively shortly afterwards. What a tragedy. Imagine a CF sufferer having to choose between no organ or such lungs. I could not imagine what I would choose if I was in that situation. Would I wait for the perfect lungs to become available or would I take a punt on what have been described as suboptimal organs. That was the story that Yvonne Hughes of the Cystic Fibrosis Trust brought home to me as the reality for many who are waiting for organs.

Where does that leave me in relation to the opt-out system? Do I still have concerns about it? Yes, I absolutely do, and the contradictions in my head only get greater as the debate goes on. To quote again some of the figures, 93 per cent of people in Scotland say that they want their organs to be used but 43 per cent of families refuse, and 62 per cent of organs that are used come from people who did not carry an organ donor card. In the past five or six years, without an opt-out system, we have doubled the amount of organs that have been made available for transplants.

No one in the chamber should say that this issue is easy, simple or straightforward. It is most definitely not a partly-political issue with me. In her intervention, Christine Grahame said that she had not spoken to whips about this, but why would she? We say what we like about this matter in Parliament and that is what I am doing. There is no need to speak to anyone. We just need to look at the facts and the evidence ourselves.

Today’s debate has enabled me to look seriously at the issue. Should I come to a position now on an opt-out system? I am not quite there yet, but I would have to find some strongly compelling reasons not to have an opt-out system in the years ahead, and hopefully in the not too distant future. It is very important that the Parliament proceeds on the basis of consensus.

I have not yet decided, and I have a number of concerns that I do not have time to put on the record this afternoon. I am left with the lasting impression that it is almost certainly the right thing to do, whether it makes a difference or not, because if one life can be saved, surely it is worth moving to an opt-out system to do that.

The Deputy Presiding Officer (John Scott): Given the slightly changed and, indeed, changing circumstances, I can now allow speeches of between five and six minutes. I call Mary Scanlon, to be followed by Christine Grahame.

15:59

Mary Scanlon (Highlands and Islands) (Con): I am very pleased to speak in the debate in the absence of my colleague Dr Nanette Milne.

In the debate secured by George Foulkes in January 2008, I stated:

> “I do not support the concept of presumed consent. It is a contradiction in terms. Presumed consent is not consent. Consenting means agreeing or giving assent. Consent ... can only be given freely by an individual.”

I said that I felt strongly that donating organs is willingly giving, not willingly taking, and that

> “Organ donation is a matter of individual conscience and individual freedom—it is not a matter for the state.”—[*Official Report*, 24 January 2008; c 5548-9.]

In that debate, I also quoted a consultant at Addenbrooke's hospital, who stated:

> "If as a doctor you have turned your thoughts to your patient being a donor when they are still living, that is a real conflict."—[*Official Report*, 24 January 2008; c 5549.]

That debate was six years ago, and I still hold those views, although I carefully read the evidence to the Public Petitions Committee from Mark Drakeford, Minister for Health and Social Services in the Welsh Government. I commend the members of the Public Petitions Committee; I also commend members across the political divide in the Welsh Assembly for the excellent consultation that they carried out and the excellent work that they have done in moving to a soft opt-out system for organ donation. Like others, I am not saying that I will vote for a soft opt-out system if we are presented with the opportunity, but I certainly find many aspects of the soft opt-out system much more acceptable than the previous proposal for presumed consent.

I put on record that I have no problem agreeing with the motion that is before us today. I like the idea that people can continue to opt in by putting their name on the organ donor register but that they can also opt out or, indeed, choose to do nothing. As others have said, it is commendable that we in Scotland have the highest percentage of the population registered on the organ donor register—currently, it is 10 per cent above the UK average.

We should commend the 50 per cent increase between 2007-08—which coincides with our previous debate in Parliament on the issue—and 2012-13 in the number of people whose organs were donated after their death and the significant increase in transplants. However, there is no doubt that more needs to be done, given the UK transplant waiting list of more than 7,000. It is also a concern that 43 per cent of families refuse to allow donation to go ahead, sometimes even overturning the recorded wishes of their loved ones. For all those reasons, although I am not signed up to the soft opt-out system, I think that it is worthy of consideration.

There are further issues to be worked through in the evidence to the Public Petitions Committee. One that really struck me, which was raised in the questions from Chic Brodie and Jackson Carlaw, was the changing structure of many families. If someone has not opted out, there might not have been any discussion within the family about their commitment to donate organs. Members of the family could also disagree about their understanding of the person's wishes. I appreciate that a person can be appointed to represent the views of the individual, which is very helpful, but many people might not exercise that option. I have to admit that the issue is not one that I have ever discussed within my family.

At the Public Petitions Committee, Jackson Carlaw rightly asked who would arbitrate at the point of donation in the event of a person doing nothing. Who makes the ultimate decision for the transplant to proceed? He sought confirmation that the family's view would prevail. The primacy of the appointed representative is very helpful, but there is no doubt that considerable awareness raising and publicity would be needed prior to a move to any new system that is under consideration.

I found the BMA briefing helpful. I do not agree totally with it, but I acknowledge the point that

> "Statutory guidance surrounding new legislation must provide clear guidance to professionals on how to deal with relatives' refusals."

Dealing with relatives in that situation must be very difficult, even if the assessment of what would be likely to "cause 'distress'" to bereaved relatives

> "would ... be carried out on an individual basis by trained professionals".

The soft opt-out system sounds good, but it is not without some unintended consequences and challenges.

To sum up, I find presumed consent wholly unacceptable. The soft opt-out system addresses some of the concerns relating to presumed consent, and I would certainly welcome input from a named representative and from families.

The Deputy Presiding Officer (Elaine Smith): I am afraid that the member must close now.

Mary Scanlon: I am delighted that much progress has been made. Like Jackson Carlaw, I am keen to follow the outcomes of the soft opt-out system, and I acknowledge my party's free vote on the issue.

16:06

Christine Grahame (Midlothian South, Tweeddale and Lauderdale) (SNP): To respond to my colleague Bob Doris, the point that I was trying to make when I intervened on Jackson Carlaw is that it was inevitable that there would—as indeed there must—be a free vote among all the parties in the Parliament.

I congratulate the petitioner on raising the issue, which I have spoken on in previous debates. I fully support obtaining an increase in organ donation through the opt-in system. I have opted in myself—it is easy to do so simply by going online and clicking a button to put yourself on the opt-in register. I also support an opt-out register, which I will come to later.

I want to tackle some of the definitions that have been used in the debate. We are talking about donation. If someone is donating something, it is willingly given: a blood donor willingly gives blood. If there is silence—I will come to whether that equates to deemed or presumed consent—there cannot be donation. There cannot be refusal or willingness to donate—we do not know—but there is certainly not donation.

I intervened on David Stewart to challenge him on the difference between "deemed consent" and "presumed consent". It is sophistry to say that there is a difference between the two terms. Deemed or presumed consent is a contradiction in terms, because consent must be clearly and freely given and must be informed, and the individual must have the capacity to decide. Silence cannot contain any of those elements whatsoever, and mistakes could be made, as has been mentioned.

I have a problem with the terms "donation" and "deemed consent", but I do not have a problem with having two registers. However, the registers should not place mandatory requirements on any family members—they should be persuasive regarding the wishes of the person when they had the capacity to decide and gave or withheld consent, depending on which register they are on. Registration would express their views clearly.

I will pray in aid a quotation that I used in 2008.

Rhoda Grant: Will the member give way?

Christine Grahame: I will continue, if I may. I will let the member in if I have a little bit of time.

The quotation is important, as it comes from a senior consultant surgeon at the Western infirmary who was present when trauma patients came in and brain-stem death was imminent. He said:

> "It is ... unthinkable that a dead patient's organs would be taken without family agreement, and hence discussion with the deceased's family after brain-stem death will need to continue as before",

whether or not we have the two registers. He went on to say:

> "It is vital that this discussion is informed by accurate knowledge of the patient's wishes expressed before death. This can only be guaranteed by ... registration of patients' wishes, whether for or against donation."

Chic Brodie (South Scotland) (SNP): Will the member take an intervention?

Christine Grahame: In fairness to Rhoda, I will just finish my point.

The surgeon went on to say:

> "Anything less than this form of balanced registration would be invalid as an indicator of the deceased's wishes, and could not reasonably be used to inform the discussion with the deceased's family which will ... need to take place, even with a change in the law to presumed consent."

My problem is not with the two registers but with that bit in the middle: the deemed or presumed consent. We have to tread very carefully with that. It is right to have both an opt-out register and an opt-in register: that makes the surgeon's job so much easier when they discuss the issue with the family, even as they do now. However, with deemed or presumed consent, a surgeon might have to say to a parent that, although their dead or dying son or daughter is not on either the opt-in register or the opt-out register, the law tells the surgeon that they can deem consent. I think that that makes the surgeon's job, and the conversation, tougher. The matter should be left to the discretion that surgeons exercise just now.

Clearly, having two registers gives a better chance of persuading the family and of their having some guidance, which is much needed in the circumstances.

The Deputy Presiding Officer: You are in your final minute.

Christine Grahame: I am happy to take the intervention from Rhoda Grant now if I have a minute.

The Deputy Presiding Officer: You have to finish after five and a half minutes.

Christine Grahame: Does Rhoda want to come in now?

The Deputy Presiding Officer: Please use full names.

Rhoda Grant: Thank you for allowing the intervention, Presiding Officer.

The current system allows families to make a decision on behalf of a person although they might have no knowledge of whether the person consents to donation. A soft opt-out system would allow people to register either their consent or their wish not to donate, and would remove the onus from families. Is Christine Grahame saying that the donations that are made when people are not on the register—the figure is 63 per cent—should not be made?

The Deputy Presiding Officer: You must draw to a close, Ms Grahame.

Christine Grahame: I am saying that if we change the law such that silence becomes deemed or presumed consent, we make the situation more difficult for the surgeon who has to inform the dying person's parents that that is the position in law. Having two registers is a good idea, but having a presumption about silence is not.

The Deputy Presiding Officer: Thank you very much. I now call Jim Hume, to be followed by Anne McTaggart. Speeches should be a maximum five and a half minutes, please.

16:12

Jim Hume (South Scotland) (LD): This is a debate of the utmost importance because it concerns, literally, matters of life and death. It is appropriate that we are debating the issue today, as a national conversation on organ donation has not been held since the debate on the Human Tissue (Scotland) Act 2006. I believe that Scotland needs to have an open and robust debate on the tricky issue of death, because as a society we too often postpone dealing with the difficult topics of palliative care and, as in this case, organ donation until it is too late.

I would like to begin by praising the work of the Public Petitions Committee in considering Caroline Wilson's petition, and for taking evidence from key stakeholders. Praise should also, of course, be given to Caroline and the rest of the *Evening Times* team for leading an effective campaign and garnering more than 18,000 signatures in support of the petition, thereby ensuring that organ donation continues to occupy our thoughts.

In its evidence submission to the Public Petitions Committee, the BMA said:

> "A culture in which donation is discussed more openly and perceived as the norm would fit better with what most people claim to support."

The key question is this: how do we arrive at the point at which donation is the norm? Currently, there are 7,500 people waiting for organ transplants in the UK, about 600 of whom are in Scotland. Three people on the transplant list die each day while waiting for an organ. However, the reality is that many people whose lives would benefit from, and be enhanced by, a new organ will die each year before making it on to the waiting list, so the demand for organs in Scotland is greater than the statistics tell us.

We should acknowledge that progress has been made by the Scottish Government. The organ donation task force report of six years ago has helped to oversee a 74 per cent increase in donations, with 40 per cent of Scots now on the organ donor register. I believe that transitioning towards a soft opt-out system will help to close the gap between the 40 per cent of Scots who are registered as donors and the 90 per cent of Scots who support organ donation. I believe that that system would be the means to include the lost 50 per cent of people who support organ donation but who, for various reasons, fail to become registered donors. Surveys have consistently shown that support for the soft opt-out system is in excess of 70 per cent of the population. Countries that operate that model have roughly 25 per cent higher donation rates than informed consent countries.

There are national health service boards that are reluctant to endorse the soft opt-out system. NHS Tayside is one, but it is not alone. It highlights its concern that

> "any assumption or presumption of patient's wishes would be detrimental to the doctor patient relationship. This could actually result in a reduction in levels of consent and authorisation."

We all wish to avoid any measure that would lead to erosion of patients' trust in doctors, but I doubt that that would be the case. BMA Scotland—the voice of Scotland's doctors—is one of the most vocal advocates of the soft opt-out system and seems satisfied that it will not be a problem; therefore, so am I.

In preparation for the debate, I reviewed some of the evidence that has been received by the committee from stakeholders. The contribution from NHS Fife concerned me. In it, Dr Brian Montgomery explained that fear of failure in transplanting units throughout the UK is leading to too many healthy organs not being transplanted, with several instances in which such organs

> "are subsequently transplanted successfully into European recipients."

I wonder whether the minister would address Dr Montgomery's point, investigate whether that is common in Scotland and, if it is, try to ensure that we are not failing to utilise healthy organs.

Similarly, we must tackle the practice of registered donors not having their organs utilised following relatives' refusal to give consent. I understand that in NHS Greater Glasgow and Clyde, that represents as much as 15 per cent of donors. That relates to our society's reluctance to have the difficult conversations that need to take place, so we must encourage people to have those conversations. I would like the Scottish Government to take the lead in ensuring that that happens.

The Government's recent donation and transplantation plan recommended a full public consultation on approaches to increasing organ donation in Scotland. I welcome that. What I do not welcome is the failure of the plan's talking points to mention soft opt-out as a potential measure; instead, it referred to paying for the funerals of donors or giving priority to people on waiting lists who are registered donors. Soft opt-out must be included in any consultation to allow the public to have their say.

With the proper safeguards and procedures in place, the vast majority of people would be satisfied with the soft opt-out model in Scotland. It is an effective means to drive up the number of donated organs that are available to help to save lives and prevent people from dying before they receive an organ or even a place on the waiting list. Soft opt-out has been demonstrated to work overseas. I am confident that it could work here, too.

16:17

Anne McTaggart (Glasgow) (Lab): As a member of the Public Petitions Committee, I, too, thank Kidney Research UK and Caroline Wilson of the *Evening Times*, who is in the gallery, for their tireless work in bringing this vitally important issue to the attention of the Scottish Parliament. As a result of the evidence that was presented to the committee by a wide range of individuals and organisations, I have become convinced that the introduction of a soft opt-out system of organ donation would be in the best interest of patients and would ultimately save lives.

We know that most people in Scotland support the opt-out system of organ donation, yet the majority of the population have not yet chosen to register as an organ donor. A survey that was undertaken in early 2012 by the Scottish Government demonstrated that only 5 per cent of the population oppose organ donation in principle, yet the United Kingdom continues to have one of the lowest organ donation rates in Europe.

Enabling and encouraging those who support the transplantation of their organs after death to sign up to the register is a key priority. However, that is no longer enough when it comes to saving precious lives. In order truly to tackle the crippling shortage of organs in Scotland, we must adopt the Welsh model of a soft opt-out system of organ donation, which will dramatically increase the number of organs that are available to terminally ill people while allowing those who do not wish to donate the opportunity to remove their name from the register.

Evidence that was presented to the committee by the Welsh Government highlighted some of the key reasons why the Welsh Assembly chose to pass the Human Transplantation (Wales) Act 2013. That legislation will come into force in December 2015 and it is expected that the move to an opt-out system will result in donations from 15 more donors a year in Wales, each of whom will donate an average of three organs. As many as 45 lives could be saved every 12 months as a direct result of changing the way in which people can become donors.

Under an opt-out system individuals have exactly the same choice as in an opt-in system: to donate or not to donate. The proposal does not compromise the freedoms of an individual who objects to organ donation and wants to make known their views. In reality, the proposal would make it easier for those who object to becoming organ donors to make their wishes clear. In an opt-out system, those who do not wish to be organ donors have the opportunity to make a positive declaration that they are opposed to transplantation of their organs, and that decision cannot be overturned by medical professionals after death.

Christine Grahame: As Anne McTaggart is aware, I agree with an opt-in and an opt-out register, but what should be done with the silent people in the middle?

Anne McTaggart: We do not propose to remove anybody’s rights. In the soft opt-out system there is the right to opt in or opt out. There is no silence. The family will still be consulted and there will be guidance and support throughout.

If we can achieve reform, it is my ambition that organ donation will become the default position which, with public support, will change cultural expectations. That will result in a more positive view of becoming an organ donor, which should be encouraged in order to increase the number of people in Scotland who owe their lives to the incredible gift of organ donation.

Following the evidence that has been presented to me by a wide range of organisations and individuals, I am delighted to announce my intention to introduce a member’s bill on this important subject. Building on the excellent work of my colleague Drew Smith MSP, I intend to launch a consultation in the coming weeks to gather responses from interested parties on reform of the organ donation system in Scotland.

I am hopeful that a member’s bill on this subject will provide Parliament with another opportunity to look at the compelling evidence in support of change, and to scrutinise the powerful submissions that have been made by medical professionals, third sector organisations and transplant patients in support of this important reform.

I welcome further debate on this important issue and I look forward to introducing my member’s bill over the next few weeks—I hope that it is weeks and not months—on the introduction of an opt-out system, and I aim to convince the minister and my colleagues in the chamber that an opt-out system is the way forward to changing lives in Scotland.

The Deputy Presiding Officer: Many thanks. I am afraid that we have to return to just over five minutes each for the next two speeches.

16:23

John Wilson (Central Scotland) (SNP): I rise to speak in this debate as a member of the Public Petitions Committee. I will remind members what the motion before us says, because there seems to be a debate about opt in, opt out, soft options and all the rest of it. The motion actually says:

> "That the Parliament notes Petition PE1453 by Caroline Wilson on behalf of the *Evening Times* and Kidney Research UK (Scotland), which calls for an opt-out system of organ donation in Scotland; congratulates the petitioner on her efforts to raise awareness of organ donation, and commends the issues raised in the petition and the evidence received by the committee to the Scottish Government for further consideration."

It mentions an opt-out system and it asks the Scottish Government to consider the issues further. Based on the minister's response today, quite clearly the Government is looking at the various options that are before us. The minister outlined some concerns regarding the Spanish and Welsh systems. In such debates, we must consider all the issues, especially what happens in other countries. After all, what we should be aiming for—indeed, what we be striving for is the best possible system to progress the issue.

This is a very emotive issue for many people. I am going completely off my speech now. I recall a constituent asking me at my surgery to sign off her consent form to allow her to donate her body to medical science. She had to sit down with her children and other family members when they were all together at Christmas to discuss the matter and to make clear her express wish. It has already been pointed out in the debate that many people find it difficult to talk to their parents, their children or other members of their family circle about what will happen to their organs when they die.

The difficulty is that when many people lose a loved one and are asked whether the person's organs can be donated to help save someone else's life they are not in the right frame of mind to make a clear thought-out decision or informed choice. When we lose a loved one, it is a very emotive time.

We have heard evidence about what happens in Wales and it is clear that, although relatives are consulted, it is the medical professionals who make the final decision on whether organs are used for transplant. The problem with that approach is that the trust between families and the medical professionals who are trying to do their job in hospitals and elsewhere could be lost. We have to be very careful—[*Interruption*.] Richard, if you want to intervene, go ahead.

The Deputy Presiding Officer: Full names, please.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I have wrestled with this issue since my original report to the Health and Community Care Committee back in the first session of the Parliament. John Wilson is absolutely right to say that at the time of a death it is incredibly difficult for a person to make a positive decision about their deceased relative. However, changing the system to have a firm opt-out that allows people to register their right not to donate would make things much easier for the silent portion in the middle, to which Christine Grahame referred, because the situation changes from their having to make a positive decision to their being asked, "Do you know what the deceased's wishes are and do you know of any reason why they might not want their organs to be donated?"

The Deputy Presiding Officer: Mr Wilson, you must draw to a conclusion, because your time is up.

John Wilson: Not everyone has the capacity to opt out, and we have to think very carefully about what opt-out system we would put in place in order that we ensure that everyone has the opportunity to make a clear, distinct and informed choice.

The Deputy Presiding Officer: I call Margaret McCulloch. Ms McCulloch, I am afraid that I can give you only five minutes.

16:28

Margaret McCulloch (Central Scotland) (Lab): It has been six years since the organ donation task force reported on ways to improve organ donation, and the progress that has been made in that time has quite rightly been welcomed across Parliament and the medical profession. The task force's findings have shaped policy, have informed the work of the Government and the Scottish transplant group and have contributed to an increase in donation rates that has exceeded expectations. As we have heard, many of the task force's recommendations continue to be reflected in the new strategy in "Taking Organ Transplantation to 2020".

However, for all the progress that has been made in recent years, more than 600 patients in Scotland are still waiting for transplants. As too many families out there know from their own tragic experiences, the sad truth of the matter is that many of those people will die waiting. We have to ask ourselves—as a Parliament and as a society—whether we are doing all that we possibly can.

As the BMA put it in its submission to the Public Petitions Committee on the topic last year:

> "Now that we have a well-organised, well-funded, comprehensive infrastructure in place, is that enough? Can we say we have done all we can? Or, should we now look to go further and build on this progress by shifting our attention to new ways of increasing the number of donors and the number of lives saved?"

I believe that there is scope to do more and I believe that there is merit in a soft opt-out system of organ donor registration, like the system that is now used in Wales. I will explain why.

We know that there is widespread support across Scotland and across the UK for organ donation. Figures that were quoted in evidence to the committee put the figure at 90 per cent. However, we still face a huge challenge in translating majority support for organ donation into better levels of donor registration.

If organ donation is such a widely supported concept, what is wrong with normalising the practice—a practice that can save lives? For Scotland—a country that has already improved its infrastructure and its capacity to transplant organs—surely the next step is to consider new ways of increasing donation rates through legislative and cultural change and by giving serious consideration to the soft opt-out. It is not just a matter of changing the law and moving towards a position of presumed consent; it is also about changing attitudes and creating a culture of openness and understanding in which we can more readily talk about what we want to happen to our bodies if the unthinkable should occur.

Of course, there should be rigorous safeguards to make sure that liberty and choice are protected. Presumed consent does not mean doing away with choice, and I do not accept that it curtails liberty. Choice must remain, and safeguards would have to be put in place. Families should be consulted—even when their loved ones have failed to opt—to establish whether they are aware of any objections and whether proceeding with organ donation would cause them distress. Further, we would have to step up on-going campaigns to educate people about organ donation and encourage people to talk to their families about their wishes.

The University of York was commissioned by the organ donation task force to consider the experience of countries that applied the principle of presumed consent to donor registration. It found that, although there were various factors that could be affecting donation rates, the opt-out system was associated with an increase.

The task force decided in 2008 not to recommend a soft opt out, but it suggested revisiting the issue at a later date. That time has now come, so let us take this opportunity today to put a soft opt out back on the agenda. Let us take the next step to improve donation rates and, ultimately, to save lives. Let us opt for something better by giving this petition our time, our consideration and our support.

16:33

Jackson Carlaw: I want to begin by singling out Bob Doris—who is, sadly, not in his place at the moment—for the attention that he gave to the issues around cystic fibrosis, and his summation of those issues. Ten days ago, I crystallised those issues in a motion to which I hope that he will lend his support.

In my opening speech, I concentrated very much on the potential reputational damage issues. In my closing speech, I would like to give voice to Mark Drakeford, the Welsh Minister for Health and Social Services, who responded to the concerns that I raised. He said:

> “Those are really important points. The issue of reputational damage to the system, were organ donation to go ahead in circumstances where the donor clearly did not wish it to happen—or vice versa—has preoccupied us during the process of the bill. I say to people who ask me in Wales that opting out will be absolutely as easy as opting in; it will not be made more difficult. We will make sure that anybody who wants to opt out can do it as easily as anybody who wants to opt in can do it. People will be able to opt out at general practitioner surgeries, by visiting the internet site and so on; it will be very straightforward.
>
> The safeguard in our system comes through the role of the family. Donation cannot go ahead without the involvement of the family. As you suggested, someone might have opted in on the register many years previously but might subsequently have changed their mind and come to a different view. If the family knows and is able to tell the clinical team that, even though the individual is on the register as being in favour of organ donation, their views had changed and they would not wish to be a donor, the family’s view would prevail. The safeguard comes through having the discussion at the point where a decision has to be made. We will not rely simply and solely on the register, even though we are confident that the register itself will be as friendly to users and accurate as it can be. … Where people have no family, if they have appointed a representative, the donation will go ahead, but if somebody dies and no family member or representative can be found, the donation will not go ahead. We have had debate about that, because somebody with no family members might have opted in and put their name on the register, but there are issues other than consent. For example, the clinical team will have to pursue with the family issues of medical history and whether the person is in a proper clinical condition to be a donor. From the clinical evidence, we know that those circumstances will be rare but, to protect the integrity of the system, our decision has been that if a person has no family and no representative, the donation will not proceed.”—[*Official Report, Public Petitions Committee*, 18 February 2014; c 2033-34.]

I hold Drew Smith in high regard and I thought he looked rather crushed—I was slightly affected by the sense of disappointment emanating from him about the position that the minister and I articulated. I say to him that I believe that there is the prospect of achieving the widest possible political consensus around this issue in the chamber. However, it would not be wise to push ahead when we have evolved what I think the Welsh have got right in their legislation without—I do not think that it is such a huge window—giving it the opportunity to prove itself, as it will do in very early course. Any difficulties in it will materialise quite quickly, which will give the opportunity for any legislation that is subsequently produced here in Scotland to reflect that.

Nigel Don (Angus North and Mearns) (SNP): I hope that he will forgive the interruption, but I want to address the issue that Jackson Carlaw addressed previously. I recognise that there are other aspects to the debate, but surely if a member of the public has the card in their pocket and is run over by a bus there will be no dispute about their having signed up. If we can encourage people to sign up and to carry the card, much of that debate would go away.

Jackson Carlaw: We have been pursuing that course, and Scotland has been more successful in that than any of the other nations in the United Kingdom. It is a remarkable tribute that we are at that point.

I accept that, out of this, there may be the opportunity for far more lives to be saved, but the debate this afternoon has left me deeply troubled. Any progression of the issue should enjoy the widest possible political consensus in Parliament. I think that that political consensus can be achieved, but Mary Scanlon and other members are not quite there yet. It would be wrong to push us there on such an important issue when we could all get there without political confrontation over something that is so terribly important. Confrontation would fundamentally undermine public confidence.

Drew Smith: I had hoped that one thing that would have come out of the debate would be a commitment from the Scottish Government to a level of consideration and consultation on the issue that goes beyond saying that we will wait to see what another country does before we put the case for change.

Jackson Carlaw: I think that that is a slightly ungenerous characterisation of what the minister was suggesting. I find myself very much in agreement with him in all this. In all practical senses, from 1 December 2015 we will have an opportunity early in the next Parliament to assess the implications of the legislation in Wales. If it is proved to have made a significant advance, similar legislation could come to this Parliament, and Conservatives would have a free vote on it whenever it came before Parliament. I would be moved to support it, but I would want to know that we carried public confidence with us. I would also want to be confident that the public would see the Parliament united in that move; if it were not, that could have a profound effect on the reputation of organ donation in Scotland. That is the last thing that any of us wishes to see.

16:39

Neil Findlay (Lothian) (Lab): It has been a welcome and important debate and petition. The Parliament has a duty to discuss, consider and recommend improvements or changes in relation to this type of issue, as it gets right to the heart of one of the most important issues of all—the ability of politicians to make decisions not only to change lives but, as Jim Hume said, to sustain and extend life. That is what is at stake; the matter could not be more important.

Rhoda Grant and Angus MacDonald mentioned that around 600 people are waiting for organ donation. Those people are affected by debilitating conditions and their families are on hold waiting for the phone to ring. Unfortunately, for too many of them, the phone never rings. We have the power to do something about that if only we have the political will to act.

Organ and other forms of transplantation have always been at the cutting edge of medical innovation and development. We have witnessed the most astonishing advances in medical science, from the very first skin grafts of the 19th century through to recent years when, remarkably, we see whole-face transplantation. For a non-scientist and non-medic, those are medical miracles, which have changed and sustained the lives of heart, kidney and liver patients and lung disease sufferers around the world. How many more people could we help if we had a better system that allows more organs to be donated and transplanted? By allowing people to opt out not opt in, we could provide many more donors and donations.

I listened carefully to the Conservative representatives, in particular Jackson Carlaw and his appeal for the issue not to be politicised. Although his was not a party-political speech, given that he raised as one of his great concerns the spectre of the state against the freedom of the individual, he was very ideological in his objections. We can dispel that concern as we debate the issue further.

I, for one, would never say that the issue is simple, but other countries successfully operate an opt-out system. We could and should do that too. It would have to be done with the general public’s buy-in because they are the future donors. We need them to support the move; we need them to be full and active partners in any new system. That can be done. A major public education programme could change things and be highly effective. As Dave Stewart and Margaret McCulloch mentioned, we can put in place safeguards and options for people who have concerns.

The current system sees a third of people register. Some people have their own particular and often very personal reason for not registering; but for many people it is simply something they have just not got round to doing. I suspect that a number of members fall into that category. An opt-out system could change things dramatically not only by providing many more life-saving and life-changing organs for donation, but by raising the debate and breaking down some of the taboos about death and end-of-life care.

Bob Doris: I agree that some people do not get around to registering but, in a sense, the same principle would apply to an opt-out system. For example, certain communities are less likely to register to vote or to vote; they might also be the least likely to opt out. That would change the nature of campaigns. A public information campaign would have to take place to encourage people to opt out should they wish to do so. Therefore, a very different dynamic would have to be grappled with.

Neil Findlay: Absolutely. Those are the challenges that we face and, if we are serious, we must face up to those challenges.

The opt-out system would also be good for our NHS in raising awareness of health issues, improving the training of staff and, in the long run, saving much-needed resources. Most of all, it would provide extra years of quality life for those affected.

In countries that have adopted the soft opt-out system, the number of organs available has increased. In Norway, the system provides a high level of donation, whereas in neighbouring Sweden, which has a mandated system, the figures are significantly lower. I accept though that, as the British Heart Foundation says, other issues are at play, including the level and quality of infrastructure supporting any system, social norms and practices and some religious interpretations.

I absolutely respect the concerns of Jackson Carlaw, the minister and others but, like Drew Smith, I believe that many of the concerns can be overcome.

The Deputy Presiding Officer: You have 30 seconds left.

Neil Findlay: Several members mentioned the Welsh system and said that the Welsh Assembly has been leading on the matter. It has had an informed public debate and secured public support.

For people who are in need of transplantation, life is very tough, but the thought of healthy, life-changing organs not being available can only exacerbate their feelings of desperation. This Parliament has a chance to change and extend lives and it is my judgment that there would be a majority for such change. I look forward to Anne McTaggart introducing her member’s bill on the matter. It is a difficult and emotive issue, but such issues are what we were elected to this Parliament to debate and to take decisions on. We should do the job that we were elected to do.

16:45

Michael Matheson: I listened to the views of members from across the chamber with real interest this afternoon. I recognise that the issue is emotive and that there are a wide range of differing views. However, I want to strike a note of caution. There is a danger that the matter could start to become politically polarised, given the way in which some of the issues are being presented. We must recognise that although there are views across the Parliament for and against opt out, soft opt out and opt in—whichever mechanism people might wish to bring forward—it is important that we all stick together on the shared agenda of looking to increase organ donations in Scotland and finding the best way in which to achieve that.

The approach that we have taken over the past five years has reaped significant improvements—better than in any other part of the UK—and that should not be forgotten. We have taken the approach that we have taken to date in order to build on that progress yet further. On that point, I say to both Rhoda Grant and Drew Smith that there has been no change in the Scottish Government’s position on the matter. Nicola Sturgeon has previously given her personal view on the matter and her view remains the same, as does that of the Cabinet Secretary for Health and Wellbeing—his personal view remains the same. However, the Scottish Government has previously said that it was not persuaded, and the position that we have taken now is that we are not persuaded as yet and want to see how things progress in Wales before we come to a decision on the matter.

However, it is not a question of waiting to see what happens in Wales and doing nothing. It is about doing all the work that we set out in our strategy to continue to build on the excellent progress that has been made over the past five years. I hope that all members will get behind that work in order to ensure that we build on the progress that has been made.

The approach that we have taken in the Scottish Government is based on the expert opinion that has been put to us on what we should do to increase organ donation. I was struck by some of the expert opinion that was given to the committee on the issue. In particular, Dr Stephen Cole from Tayside—Jim Hume mentioned the situation there—is an intensive care consultant and a doctor with a great deal of experience in supporting organ donors and their families. Until recently, he was the regional clinical lead for organ donation for Scotland and he has also been a long-standing member of the Scottish transplant group and the Scottish donation ethics committee, so he is an individual with a lot of experience in the field. He stated:

> "The view of most professionals who are closely involved with the organ donation and transplantation process is that an 'opt out' system would not convey any additional advantages over and above those which are already seen with the current initiatives. In particular the view of most professionals involved in intensive care where the vast majority of potential organ donors are located is that any assumption or presumption of patient's wishes would be detrimental to the doctor patient relationship. This could actually result in a reduction in levels of consent and authorisation."

That is his view on the matter, and it is his view from the professional group that he is involved in. We cannot ignore such a view, and it is important that we recognise it.

I also want to quote the submission from the British Transplant Society, which represents those who work in the transplant field. It stated:

> "The Society has previously voted on the issue of opt-out legislation and no clear consensus was reached. Concern was expressed by some who voted regarding the effects such legislation would have".

Neil Findlay: Will the minister give way?

Michael Matheson: I want to finish the point that I am making. The society went on to state:

> "Opt-out legislation has been laid before the Welsh government. It would seem unnecessarily hasty to follow the same route elsewhere in the UK until the result of the Welsh experiment is known, both in terms of changes in organ donor numbers and also the cost involved."

I think that we should take the reasonable approach of seeing how things progress in Wales, so that we can identify what further measures should be taken here in Scotland.

Neil Findlay: Will the minister give way?

Michael Matheson: No; I have too much to say.

I want to reiterate a number of points. Over the past six years, there has been a 96 per cent increase in donations, a 63 per cent increase in transplants and a 25 per cent decrease in the number of people on the transplant waiting list. That is due in large part to the work that we have done, particularly the infrastructure work, which has made a significant difference in increasing the number of donors in Scotland. It is important that we build on that and maximise its benefit.

That is why, as a Government, we have said that, at the moment, we are not persuaded of the case for adopting the Welsh system, but we will monitor, review and watch with close interest what happens in Wales. Once we can evaluate the progress that has been made there, we will be able to come to a considered view on whether an opt-out system would add to the significant improvements that we have already made in Scotland.

The Deputy Presiding Officer: Chic Brodie will respond to the debate on behalf of the Public Petitions Committee.

16:51

Chic Brodie (South Scotland) (SNP): As the deputy convener of the Public Petitions Committee, I am delighted to support the motion in our convener's name. The tone of the debate and the manner in which it has been conducted have mirrored the emotional nature of the issue that we have discussed.

Like John Wilson, I draw members' attention to the fact that we are not discussing whether to implement an opt-out system of donation; we are simply recognising that petition PE1453 took us a bit further forward. I recognise that Drew Smith, Mary Scanlon and Bob Doris, in particular, made telling speeches.

On my appointment to the committee, it was suggested to me that progress on the committee's agenda might be painstaking, difficult and slow, but nothing could be further from the truth. It is a tribute to the convener, my fellow committee members and the clerks that, in my experience, it has proved to be anything but painstaking, difficult and slow. It is also a tribute to all our petitioners, who have sought action from their Parliament on issues such as flooding, the registration of interests by the judiciary and speed cameras, as well as a number of key medical issues, including chronic pain and hypothyroidism. In addition, we have carried out a critical inquiry on child sexual exploitation.

However, none of our work has touched our psyche to as great an extent as the petition that we are debating, although I am sure that the Assisted Suicide (Scotland) Bill will do so when it comes before us for our consideration. Petition PE1453 calls on the Parliament to consider the introduction of an opt-out system for organ donation in Scotland. I pay particular tribute to Caroline Wilson who lodged the petition on behalf of the *Evening Times* and Kidney Research UK (Scotland). It is a brave petition because it confronts the demands of donation and challenges the emotional approach that is taken by individuals and families alike to an issue that most people would prefer not to encounter. We will have to confront that approach in any subsequent debate that we have on what is an extremely important issue.

The petition also brings our society and the Parliament to a crossroads, without detracting from the progress that has been made on the road that has already been, and is still being, travelled on organ donation. It asks the Parliament to consider a new or alternative route, albeit one with hurdles that have yet to be overcome, such as those of presumed consent and its definition, to which I will come later.

The choice before the committee was to consider proceeding with the petition, which called for a change from the existing opt-in system for organ donation, in which an individual expressly states their wish that their organs and tissues should be donated by joining the organ donor register, to an opt-out system, in which it is assumed that organs and tissues are available for transplant unless there are specific instructions to the contrary. The issues of emotion and distress enter the debate regardless of whether we are talking about a soft opt-in system, in which the family of the deceased can object, or a soft opt-out system, in which they can determine whether to proceed after consulting the appropriate authority. The hard options are clearer.

It cannot be denied that, whichever route is chosen, organ donation saves lives, as Mark Drakeford succinctly pointed out. In his powerful speech, Jackson Carlaw stressed the evidence that we took from Mark Drakeford. We all know that Wales is moving to a soft opt-out system, which the BMA is promoting. As David Stewart said, 35 people in Wales died last year while they were on the transplant waiting list. That was but one reasonable argument for considering the petition and its progress seriously.

Organ donation saves lives. The committee's recommendation to the Scottish Government and the Government's further proposals will await the evaluation of the impact of the Welsh legislation. While we wait for that, I applaud the *Evening Times* and NHS Greater Glasgow and Clyde for bringing organ donation to the forefront of our minds, through their respect my dying wish campaign, and keeping it there.

We cannot deny that the proposals by the organ donation task force in the recent past and the recommendations in "A Donation and Transplantation Plan for Scotland 2013-2020" seem to be having an effect. Since January 2008, when the task force published its first report, with 14 recommendations on overcoming barriers to organ donation and achieving an outcome of increasing the organ donation level by 50 per cent over five years, Scotland has achieved a 74 per cent increase. In its second phase, the task force considered the measures that might be required to move to an opt-out system. It referred to caveats on risk, but it did not rule out such a system.

In the transplantation plan for 2013 to 2020, the Scottish Government set an expectation for Scotland to be among the best-performing countries in the world on organ donation. If the high-level outcomes and priorities for action—21 in total—are implemented in full and achieved, they will secure the objective of the plan and of the Scottish transplant group.

Over the past six years, donations have increased by 96 per cent, transplants have increased by 62 per cent and registrations have increased by 25 per cent. That suggests that the plan is working, but the trend will depend on achieving priorities such as funding and delivering high-profile organ donation awareness campaigns, so that the public are informed about and engaged in the organ donation and transplantation issues. The petition and today's debate will certainly add to that.

Above all, it is incumbent on the existing framework or the proposed soft opt-out system to ensure that all parts of the NHS in Scotland and the public support donation and transplantation. The Scottish Government should publish an annual report card on the four or five key national measures for organ donation, whether we have a soft opt-in or a soft opt-out system.

When the Government reviews progress, we must consider all aspects of progress. If we go down the opt-out route, we must measure the success or otherwise that the Welsh programme has brought.

I mentioned at the beginning of my speech the emotional impact that is associated with the soft opt-out option. I have no doubt that that will be a consideration in the debate.

In this sensitive area, consultation, education and engagement are essential if the Scottish Government is to be persuaded to follow the Welsh route. There is no doubt that the Government remains committed to organ donation, whatever process we follow.

On this sensitive subject, on which members will have their personal views, we must of course take advice not just from experts but from the families who might be or have been affected.

I like to think of the Public Petitions Committee as the prodding committee. Today, I and, I am sure, the other committee members, applaud the petitioner, Caroline Wilson, and the *Evening Times* and Kidney Research UK, for prodding us on this very important issue.

Point of Order

17:00

Mary Fee (West Scotland) (Lab): On a point of order, Presiding Officer. At First Minister's questions today, the First Minister, in answer to questions from Johann Lamont, said:

> "None of the Opposition parties in this Parliament have expressed any concern in public, that I can find".

He added:

> "I think that it is reasonable to find out whether the Labour Party in this Parliament has any similar record of action or concern."

That is wrong. Those statements are incorrect, and the First Minister needs to correct the *Official Report* this afternoon. On 30 July 2013, I lodged motion S4M-07362, which condemned the anti-gay legislation that was passed under Vladimir Putin. The motion talked about putting

> "pressure on President Putin and Russia's leaders to overturn the country's anti-gay laws".

That motion received support from Scottish National Party members of the Scottish Parliament. On 6 February, I lodged motion S4M-08982, which condemned the openly homophobic attacks against gay men in Russia, as revealed in the Channel 4 "Hunted" programme. That motion received cross-party support.

On 13 February, my colleague Drew Smith wrote to the Minister for External Affairs and International Development regarding the Sochi Olympics and raised concerns regarding the rights of lesbian, gay, bisexual and transgender people in Russia.

The First Minister said that Labour members have not raised human rights violations in Russia and have expressed no concerns about the Putin regime. He was wrong. As laid out in the guidance on the correction of inaccuracies of information provided in parliamentary proceedings,

> "Members (including ministers) have a personal responsibility to be accurate and truthful in their contributions during Parliamentary proceedings."

Under paragraph 5 of that guidance, the First Minister is under an obligation to correct the record. The First Minister needs to take this opportunity to apologise for giving the very wrong impression that my party has not spoken out in the Parliament about Vladimir Putin and his regime, which the First Minister is so keen to praise.

The Presiding Officer (Tricia Marwick): I thank the member for providing advance notice of the point that she has just made. These are matters of debate. I have said repeatedly that the Presiding Officers are not responsible for the veracity of the contributions that are made by any member in the chamber.

Decision Time

17:03

The Presiding Officer (Tricia Marwick): There is one question to be put as a result of today’s business. The question is, that motion S4M-09847, in the name of David Stewart, on petition PE1453, on organ donation in Scotland, be agreed to.

Motion agreed to,

That the Parliament notes Petition PE1453 by Caroline Wilson on behalf of the *Evening Times* and Kidney Research UK (Scotland), which calls for an opt-out system of organ donation in Scotland; congratulates the petitioner on her efforts to raise awareness of organ donation, and commends the issues raised in the petition and the evidence received by the committee to the Scottish Government for further consideration.

Meeting closed at 17:03.

Members who would like a printed copy of the *Official Report* to be forwarded to them should give notice to SPICe.

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