

# **Meeting of the Parliament**

**Tuesday 26 February 2019** 



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#### **Scottish Parliament**

Tuesday 26 February 2019

[The Presiding Officer opened the meeting at 14:00]

#### **Time for Reflection**

The Presiding Officer (Ken Macintosh): Good afternoon. Our first item of business this afternoon is time for reflection. Our time for reflection leader today is the Moderator of the General Assembly of the Church of Scotland, Susan Brown.

The Right Rev Susan Brown (Moderator of the General Assembly of the Church of Scotland): Thank you to the Presiding Officer and to members of the Scottish Parliament for the invitation. I think that I did one of the earliest times for reflection, way back at the start of the Scottish Parliament's life. I even remember a wee snippet of what I talked about. We had a brown cross spaniel-Labrador pup at the time. I had taken her to Embo beach—which, if you have not been to, you need to get to-and we had had a walk along the pier. The poor dog, however, had not quite twigged that on the other side of the pier wall was the most enormous drop into the sea, and she took a flying leap over the wall. You could see the "Oh-oh" on her face before she went for her unexpected swim. I said at the time that, for brand new MSPs in a brand new Parliament, the feeling must have been very similar. The members were stepping out into the unknown to face the unexpected.

Twenty years down the line and much the same thing appears to be happening again. Both here and at Westminster, as our elected representatives you face, once more, a step into the unknown as you follow through on the implications of the United Kingdom leaving the European Union. Whatever side of the fence you sit personally and politically, over the next few months and years you will be responsible for shaping a new look UK. At times, that will be exciting, while at other times it will be daunting, if not—thinking of the look on our dog's face at Embo—terrifying.

Be assured of the prayers of many people of all faiths as you plan and make decisions, but please put at the forefront of all your thinking the most vulnerable among us.

In the past few months when, as moderator, I have covered a fair bit of our country, I have seen far too many food banks and have met far too many children needing fed during school holidays. I have heard far too many stories of families and individuals left to live on thin air while their benefits

are sorted out. I have talked to too many people who are homeless and who, because of that, have no access to the help that they need, whether that be mental health services or other support networks. Then there are those who are trying to help but who have to cope with uncertain funding and uncertain futures.

I appeal to you: let us make sure that, in 21st century Scotland, we truly care for all.

#### **Topical Question Time**

14:03

#### **Child Death Review Process**

1. **Kenneth Gibson (Cunninghame North)** (SNP): To ask the Scottish Government, in light of recent Office for National Statistics figures showing that 218 avoidable child deaths occurred in Scotland in 2017, what progress has been made in implementing a child death review process, and when it will report. (S5T-01516)

The Cabinet Secretary for Health and Sport (Jeane Freeman): We are establishing a national hub for the prevention of child deaths, which will launch in March this year. Its focus will be to oversee the child death review process to drive a reduction in child deaths, and it will start in full in early 2020. We are currently piloting that process in three health board areas, with a further two pilots commencing later this year. We will be investing £1 million from April in that important work.

Kenneth Gibson: As the cabinet secretary will be aware, the number of avoidable deaths among infants and children is proportionately higher in Scotland than elsewhere in the United Kingdom. The 2017 figures include victims of violence and accidents, and birth defects, sometimes linked to smoking and alcohol. Does she agree that, for the parents and those closest to the children who have died, it can be particularly traumatic to consider a death to have been avoidable, and therefore that minimising such fatalities must be an absolute priority?

Jeane Freeman: Mr Gibson is right that the number of avoidable deaths among infants and children is proportionately higher in Scotland than elsewhere in the UK. However, it is important to note that, since 2008, there has been a 32 per cent reduction in the number of child deaths under the age of 18 in Scotland.

I agree that minimising avoidable child deaths should be a priority for the Government, and it is. We are committed to driving down the rate of child deaths in Scotland by learning from the child death review process and working with the Royal College of Paediatrics and Child Health to ensure that we get the process right and, most important, that we apply the learning across the whole of our health service.

**Kenneth Gibson:** Professor Russell Viner, the president of the Royal College of Paediatrics and Child Health, said that the Scottish Government is

"certainly moving in the right direction"

"tackling child poverty and obesity. However, despite recommending a Scotland-wide child death review process to be implemented over four years ago, this is yet to ... be established."

I welcome the 32 per cent reduction in deaths that the cabinet secretary has just mentioned and the new hub. Does she agree that the delay over the past four years implies that avoidable child deaths are not getting the priority that they deserve? How will she convince parents and others that the Scottish Government is urgently addressing this matter?

Jeane Freeman: I am grateful to Mr Gibson for that important supplementary question, and I understand why people are frustrated at what they feel has been too long a time before the process is fully in place. It is a priority for me and for the Government. We will launch in full in a month's time. We will continue to update the Parliament on that process. It really does matter.

Over the past 10 years, we have seen a 32 per cent reduction in the number of child deaths under 18, a 28 per cent reduction in neonatal mortality and a 25 per cent reduction in the number of stillbirths. Nonetheless, there is more that we need to do. We are working to establish the hub and to run the pilot processes in a staged way so that learning can be replicated across our boards. We will keep a close eye on the process and, as we make progress in the course of this calendar year, we will update the Parliament in order to reassure people that it really is a priority for the Government.

Miles Briggs (Lothian) (Con): It should concern every member of the Scottish Parliament that avoidable deaths among children, babies and teenagers are higher in Scotland than anywhere else in the UK. Figures that were released in November 2018 showed that 600 babies have been born addicted to drugs in Scotland since 2015. What is the Scottish Government doing to take forward the pre-birth approach, as recommended by Sir Harry Burns?

Jeane Freeman: Much of the work in the best start programme, which I know Mr Briggs will be familiar with, as well as an innovative and improved approach to maternity care and the work that has been undertaken by Mr FitzPatrick on the healthy weight and diet programme, looking at preparation for pregnancy, all feeds into working with mums and those who are about to be mums on what they need to do to be as healthy as they can be so that their child can be as healthy as it can be when it is born.

That work is also picked up by our communitybased midwives and our increased number of health visitors. It all comes together to begin to tackle issues such as smoking in pregnancy. We know that women want to address those issues, but sometimes they can feel that it is all too much and they are not quite sure where to start. Using those healthcare supports through the midwife and the health visitor, who can develop important relationships with pregnant women and new mothers, is important in helping people—in a nonjudgmental way—to make some of the changes that are critical for the healthiest possible birth of their new babies.

Mary Fee (West Scotland) (Lab): There remains a significant link between material deprivation and life expectancy. Figures that were released in December 2018 revealed that a boy who is born in one of the most affluent areas of the country can expect to live more than 10 years longer than one who is born in one of the poorest. What specific steps will the cabinet secretary and the Government take to end the scandal of health inequalities that persists in Scotland?

Jeane Freeman: A number of areas of work to tackle health inequalities are under way. As I am sure Mary Fee appreciates, not all of those sit in the health portfolio, and we need to tackle such inequalities much more widely. Work is being done on measures, such as the baby box and the new best start grant that is being administered by our new social security agency, that attempt to get practical support into the hands of mums, babies and small children. With our deep-end practices, community-based healthcare workers, community mental health workers, link workers and others, we are also looking at how we can reach all the people we need to reach on the preventative and improved lifestyle approaches that we need them to take

However, we need to do that in a way that reflects where people are, rather than appearing to be judgmental and lecturing or being open to the accusation that it is easy for someone like me to say how they should stop smoking, eat more healthily or exercise more. When people are struggling to make ends meet and have families to bring up, such advice can seem too much and too impractical. By using connections with trusted healthcare workers and others to help people to identify practical ways within their means to make changes and improvements to their lifestyles, we will begin to tackle health inequalities. Such work can be done not only in this portfolio but more widely across the Government; work that is going on in education and elsewhere also plays a part.

It would be beneficial if, at some point—perhaps Mary Fee and I could co-operate on this—the Parliament could have a wider debate about how we might tackle health inequalities in the round, across our portfolios in the Government. I would be very happy to meet her to see whether we could make progress on that.

#### **Fatal Accident Inquiries (Legal Aid)**

2. **Daniel Johnson (Edinburgh Southern)** (Lab): To ask the Scottish Government what its position is on providing legal aid to victims' families for fatal accident inquiries. (S5T-01518)

The Minister for Community Safety (Ash Denham): We acknowledge that the families of the deceased may find attendance at a fatal accident inquiry distressing. The purpose of an FAI is to investigate, in the public interest, the circumstances of a death. At an inquiry, the procurator fiscal leads evidence to address the matters upon which the sheriff must make findings, including the cause of death. Where family members seek their own representation to participate in FAIs, applications for legal aid towards the costs of such representation are subject to the statutory tests of probable cause, reasonableness and financial eligibility, which are consistent with the tests for other forms of civil legal aid.

Those arrangements were considered during the passage of the Inquiries into Fatal Accidents and Sudden Deaths etc (Scotland) Act 2016. However, the independent strategic review of legal aid in Scotland, together with recent high-profile cases, including the FAI into the Clutha bar tragedy, have highlighted the need to review the current legislation with regard to the eligibility of families who are involved in inquiries.

I assure Parliament that the Scottish Government will consider the issue in planning a new bill on legal aid in Scotland. The Legal Aid (Scotland) Act 1986 provided for the regulations that are still in force today, which is why we have now set up an independent strategic review of legal aid in Scotland. We will consult on a new bill on legal aid before the summer recess.

**Daniel Johnson:** Many members will have been shocked—as I was, last week—to learn that, following a decision of the Scottish Legal Aid Board, the families of victims of the Clutha tragedy are being asked to contribute as much as £8,000 each for legal representation. I hear what the minister has said about a review, but will the Government intervene immediately to reverse that specific decision?

On the review, does the Government think that the normal means of assessment for legal aid are appropriate in the case of fatal accident inquiries into disasters such as the Clutha tragedy, given the wider public interest?

Ash Denham: Under the statutory regulations that are in place, the Scottish ministers cannot intervene to change the Scottish Legal Aid Board's decision and the legislation, which was passed by the Scottish Parliament, requires contributions to be paid depending on an individual's financial

circumstances. Contributions reduce the cost of legal aid to the public purse and so help to fund vital services.

The figure that I have seen in the media of £8,000 for a family is not correct—that is actually the cumulative amount of money across all the families. The Scottish Legal Aid Board has exercised the full discretion available to it in making its decision in that case.

**Daniel Johnson:** I thank the minister for that clarification.

The question raises broader issues with fatal accident inquiries. In recent weeks, we have heard from families whose loved ones have died abroad and who still cannot get post-mortem examinations; and the family of Craig McClelland are frustrated because the person who committed his murder was on one side of the prison fence rather than the other. Thanks to the work of the Lib Dems, we have learned of the shocking total cumulative backlog of FAIs.

Does the minister accept that there is something seriously wrong with the way in which FAIs work in Scotland, despite the fact that legislative reform took place in 2016?

Ash Denham: As I am sure the member accepts, the decision to hold any fatal accident inquiry and the timing for initiating it are entirely matters for the Lord Advocate, operating independent of Government.

Depending on the circumstances, death investigations can sometimes be very complicated and technical and can involve a number of agencies working together. The Crown Office is committed to the prompt investigation of deaths, but it accepts that, in some cases, the time taken to complete a thorough investigation has been too long.

The Scottish Government has made available additional funding to the Crown Office, and it has used some of that to allow the Scottish fatalities investigation unit to try to reduce the time required to complete death investigations.

Liam Kerr (North East Scotland) (Con): On the delays that Daniel Johnson referred to, will the minister tell us what the cumulative delays in ongoing FAIs are? What conclusions does she draw from those delays about whether staffing levels at the Crown Office and Procurator Fiscal Service are adequate?

The Presiding Officer (Ken Macintosh): That is slightly broader than the original question, but I will allow it.

Ash Denham: I can answer the member's question. The average length of time to complete an inquiry has been gradually decreasing, which is

obviously going in the direction that we would like. We are pleased that the figure is decreasing, although we would like further progress to be made. That is why the Government has made available to the Crown Office additional funding to address the issue and to reduce the amount of time required to complete death investigations.

Liam McArthur (Orkney Islands) (LD): Does the minister agree that a system that makes families wait years to find out the circumstances surrounding their loved ones' death, and then asks them to make a financial contribution towards the process, is broken? Is she aware of recent reports that the family of a victim of an M9 crash were sent a bill by the highway authority to replace the shrubs that were damaged at the side of the motorway? Does she agree that it is time for an independent review of FAIs?

**Ash Denham:** I thank the member for raising that point, which is important. I agree that a review is required.

To reiterate, it is the role of the Scottish Legal Aid Board to make determinations on whether legal aid funding is to be awarded. The Scottish ministers cannot overturn the board's decision and there is no flexibility for the board to decide to disapply or disregard the statutory requirement to assess an applicant's finances. Any changes to the system can be made only through changes to primary legislation, which is why we plan to consult on a new legal aid bill. That will be a full consultation and it will happen this year, before the summer recess. I will consider carefully the issue of FAIs as part of the wider planning for the new legal aid bill. I am happy to meet any member who wants to discuss the issue further and contribute to that bill.

## National Health Service (Patient Safety)

The Presiding Officer (Ken Macintosh): The next item of business is a statement by Jeane Freeman on patient safety in the NHS in Scotland. The cabinet secretary will take questions at the end of her statement, so I encourage all members who wish to ask a question to press their request-to-speak buttons as soon as possible.

14:20

The Cabinet Secretary for Health and Sport (Jeane Freeman): The recent loss of life in which a healthcare associated infection was a contributory factor is a stark reminder of how vital infection prevention and control measures are. I am sure that I speak for everyone in the chamber when I offer my sincere sympathies and condolences to the families and friends who have lost loved ones.

I know from speaking with NHS staff that they, too, are profoundly affected by the loss of their patients. Every day, our front-line NHS staff work to prevent and control, as much as is possible, healthcare associated infections. They have my thanks—and the thanks, I am sure, of everyone in the chamber—for the vital role that they play and the responsibility that they take.

The step change in the approach to managing infections in Scotland stems from the Clostridium difficile outbreak in 2007-08 at the Vale of Leven hospital. At that time, C diff and MRSA were the biggest infection threats to patients. Identification of the outbreak did not happen quickly enough to stop the spread of infection, and many of the cases were only identified as being part of a major outbreak through retrospective analysis. The subsequent inquiry and efforts of the Scottish Government and the NHS led to the introduction of a national inspection and scrutiny programme of healthcare facilities, and the development of a national infection prevention and control manual, with clear and wide-ranging procedures for healthcare professionals to follow. We also set up patient world-leading Scottish programme, which has contributed to significant and sustained improvement in a range of areas, including healthcare associated infection.

Those approaches have delivered real results. In people who are the most at risk—those who are over the age of 65—C diff infections have reduced by 85 per cent, from 6,325 cases in 2008 to 917 cases in 2017. However, although infection incidents on the scale of the Vale of Leven are now markedly rarer, it remains vital that we continue to learn from them and take whatever

further steps are necessary to make sure that our NHS is as safe as possible.

Last year, there was a water contamination incident in the Royal hospital for children in Glasgow. The previous cabinet secretary asked Health Protection Scotland to examine the issues and I published its report, "Summary of Incident and Findings of the NHS Greater Glasgow and Clyde: Queen Elizabeth University Hospital/Royal Hospital for Children water contamination incident and recommendations for NHS Scotland" on Friday. The report makes a number of recommendations, and today I give members my commitment that the recommendations will be addressed.

The report will be passed to the independent review group for it to consider as part of its work to review the design, commissioning, construction, handover and maintenance of the Queen Elizabeth university hospital and how such matters contribute to effective infection prevention and control. My officials are in the concluding stage of appointing two co-chairs of the review. The potential co-chairs have asked for time to consider what would be required of them, in order to ensure that they can fulfil their responsibilities.

I fully appreciate that members will be keen to see the work begin as a matter of urgency—I am, too. However, I am also adamant that we take the time that we need to appoint the right clinical experts to lead this critically important work. The focus is on the Queen Elizabeth university hospital, but the lessons are for NHS Scotland. We need to ensure that our physical infrastructure is designed, built and maintained to maximise infection prevention and control. I expect to be able to advise Parliament shortly on the review's co-chairs, and then its remit and membership, in line with Professor Britton's recommendations.

Since the water contamination incident, NHS Greater Glasgow and Clyde has given notification of a number of other infection outbreaks. Such notifications happen as a result of the clear procedures that were agreed after the Vale of Leven tragedy and set out in the "National Infection Control and Prevention Manual", which is evidence of a monitoring and control system that acts much earlier to identify and control infection and protect patient safety.

Some infections, such as the Staphylococcus aureus bloodstream infections at the Princess Royal maternity unit, are common in the general population but can impact acutely on patients who are very unwell and likely to have a lower immunity. Other infections, such as the Stenotrophomonas maltophilia infection at the Royal Alexandra hospital, are rare. However, no matter whether the infection is rare or not, it is crucial that staff identify it early, deal with it and

prevent it from spreading. In all infection outbreaks, immediate additional measures are put in place to ensure that hygiene and infection prevention is absolutely as good as we need it to be.

Given the serious nature of these incidents, my officials have daily phone calls with Health Protection Scotland so that I can be updated, and the healthcare incident infection assessment tool—HIIAT—reports are delivered following multidisciplinary incident management team updates.

As members know, following the Cryptococcus infection at the Queen Elizabeth university hospital, I asked the healthcare environment inspectorate to undertake an unannounced inspection of the hospital. The report on that inspection will be published by Healthcare Improvement Scotland on 8 March. We will publish our response to it at that time, and it, too, will feed into the work of the expert review.

All those steps are important and it matters that, while the independent review undertakes its work, we make any immediate improvements that are necessary and identified by the reports. I want to make sure that the clinical voice is heard with regard to clinicians' work environment, so that they can continue to deliver safe, effective and personcentred care to their patients.

The Health and Care (Staffing) (Scotland) Bill, which will reach stage 3 in the chamber in the coming months, follows Lord MacLean's recommendation from the Vale of Leven inquiry that we should act to ensure that the staffing and skills mix is appropriate for each ward and that, where that is not the case, an escalation process is in place to respond. The bill provides an opportunity to enable a rigorous evidence-based approach to decision making on staffing, taking account of service users' health needs, including in infection prevention and control.

It is important, too, that we recognise the role and voice of all our front-line staff in NHS Scotland. Porters, domestic and housekeeping staff, catering staff, receptionists and maintenance staff all have a critical role to play in effective patient safety. I will be giving further thought to how we can ensure that, across all our health boards, the voices and expertise of those staff members are integral to the work on infection prevention and control.

Scotland's response to healthcare associated infections is wide ranging, and a number of expert agencies are involved. Health protection Scotland is responsible for undertaking surveillance and horizon scanning for emerging threats and seeking advice from United Kingdom and international organisations where required. When HPS is made

aware of threats, it produces guidance for NHS Scotland to prevent on-going transmission of infections. The Healthcare environment inspectorate leads on independent inspections of every NHS acute and community hospital in Scotland. Since 2009, HEI has published 261 hospital inspections as well as thematic inspections of theatres and invasive devices.

The Scottish Government has underpinned those efforts by launching the mandatory national infection prevention and control manual in 2012, using a once-for-Scotland approach. The manual provides a framework for staff to apply effective infection prevention and control practice and it sets out the process that health boards must follow to manage incidents and outbreaks. We have led the world with the national infection prevention and control approach. It has been adopted by NHS Wales and there are calls for it to be adopted across the UK.

In the past decade, Scotland has made significant progress on infection prevention and control. Spurred by the tragedy of the loss of 34 lives in the Vale of Leven, where C diff was a contributory factor, NHS Scotland is now in a position to identify incidents and outbreaks much earlier and take immediate action.

Infections are present in everyday life. We cannot avoid all infections, but we must ensure that our systems include horizon scanning for emerging infection threats and ensuring preparedness and resilience. I assure Parliament and, through members, the public that a culture of improvement and safety is woven through our national health service and that I am committed to ensuring that our hospitals remain some of the safest healthcare facilities in the world.

Miles Briggs (Lothian) (Con): I thank the cabinet secretary for advance sight of her statement. We pass on the thoughts of members on the Conservative benches to the families involved.

Public confidence has been shaken in the light of recent events in Glasgow. It is now critical that we see leadership and action to ensure that our hospital estate is safe and that all measures are put in place to meet the best infection control standards. I agree that the review will suggest lessons and recommendations for other hospitals—including the new Edinburgh sick kids hospital—on infection control measures and building standards that go above and beyond those that are currently in place.

How will ministers make sure that health boards take forward any and all recommendations, and will the cabinet secretary commit to the publication of any interim findings and recommendations?

Jeane Freeman: I understand that public confidence has been shaken, which, in part, is why I made the statement. I wanted to remind us all of the significant improvements that have been made in infection prevention and control across Scotland, and the steps that have already been taken to ensure that we do not repeat what happened at the Vale of Leven hospital, so that we do not have any outbreak that is not identified until it has progressed quite considerably.

That said, I am not suggesting, by any stretch of the imagination, that therefore everything is fine. When there are infection outbreaks, that suggests to me that there is more that we need to do. I completely commit making public the interim recommendations—if there are any—and our response to them. We will also publish not only the HEI report but my response to it and the actions that I will take on Cryptococcus. I cannot give the details of the overarching review until we appoint the co-chairs, because it will be for them to determine how long they think that it might take. However, I hope that they will agree a remit, a timeframe and an approach that we can publish, within which we will be able to see where there might be milestones and where recommendations will come forward that we can act on. I will certainly share that information with the Health and Sport Committee, but I am also happy to share it more widely with members when we get to that point.

Monica Lennon (Central Scotland) (Lab): I thank the cabinet secretary for advance sight of her statement. The thoughts of Scottish Labour remain with the families of the patients who have died.

What has occurred is no reflection on the hardworking staff in the hospitals affected by these infections. However, it is clear that NHS Greater Glasgow and Clyde has suffered reputational damage. A culture of secrecy has clouded the health board's communications and I think that we all agree that that has had an impact on public confidence. Staff and patients who raised concerns about cleanliness, infection control, building maintenance, workforce pressures and more felt that their concerns were not acted on, which is bitterly disappointing.

In the interests of transparency, will the cabinet secretary update Parliament on how many patients have been affected by the infections referred to in her statement or any other rare infections, how many patients have died, how many have received treatment, and how many cases relating to hospital-acquired infections have been referred to the procurator fiscal in the past 12 months?

Jeane Freeman: In order to be absolutely certain that I provide Monica Lennon with the

accurate detail, if she and other members are content, I will write to her later today with the answers to all those specific questions, including the PF question—as far as we know that information. I will make sure that that detail is shared with the other party spokespersons on health, so that they have that information too.

Ms Lennon knows that, in previous statements in the Parliament, I have recognised that our health board communications across NHS Scotland are at times not as good as I want them to be. I take the view that if we have information we should give it to people and that there is nothing worse than a vacuum that people fill with their understandable worries and anxieties. That is not an approach that I want our health boards to adopt.

We are working with our health boards to ensure that communications are as transparent and detailed as they can make them, bearing in mind that they have an absolute duty under their Caldicott guardian and other responsibilities not to release any information that could lead to the identification of individual patients. That duty curtails the boards to some extent, but it might not always curtail them to the extent to which they believe themselves to be curtailed.

I am also aware of concerns that have been raised in the past in NHS Greater Glasgow and Clyde. I now have information on some of those concerns, which I will ensure is passed on to the independent review. I know that the individuals who have raised such matters with me will make sure of that, too. I have given a commitment that I will make sure that that information is passed on so that the review has the benefit of historical information as well as the evidence that it may choose to take.

Alison Johnstone (Lothian) (Green): In her statement, the cabinet secretary recognised that all NHS staff, from clinicians to those who are involved in catering and maintenance, have a critical role to play in effective patient safety. I appreciate that she said that she will give thought to how we can make sure that all those voices are heard, but given the pressure on staff who work in the NHS, what assurances can she provide that staff will be given sufficient time for the expert training and mentoring that they need, so that we can ensure patient safety?

Jeane Freeman: That issue will be dealt with partly through the Health and Care (Staffing) (Scotland) Bill, which is working its way through the Parliament. We are very keen to ensure that that bill is also applicable in our social care settings, where safety and infection prevention and control are as important as they are in our acute settings.

I want to make sure that, as part of the standard work that a board should undertake on infection prevention and control, which includes all the processes that I outlined, we are assured that important voices such as those of maintenance, housekeeping and catering staff are integral to the overall approach that a board takes in a hospital setting and elsewhere to infection prevention and control. Rather than being seen as additional, their involvement should be considered to be as central as the involvement of nursing and medical staff. That is a case of making sure that the individuals who would be part of those discussions have the time to bring to bear the expertise that they bring from the roles that they play. When additional training or support is needed, I will expect boards to make that available.

As Ms Johnstone knows, I regularly meet the chairs of our health boards to seek their assurance on the areas that I consider to be of the utmost importance, and there can be nothing of higher importance than patient safety. In addition, the chief executive of NHS Scotland regularly meets the board chief executives. All those discussions are aligned with the Government's key priorities. We regularly have the opportunity to get such assurances and to act when we believe that what needs to be done is not being done.

Alex Cole-Hamilton (Edinburgh Western) The investigation into the contamination incident at the Royal hospital for children in Glasgow was instructed by the cabinet secretary's predecessor on 20 March last year in response to a question from Anas Sarwar. The report on the investigation was concluded and given to the Government in December, but the Government released it only this weekend. What was the reason for the delay? Why did the investigation take so long? Why did the Government choose not to release information to the Parliament and the general public until two months after it received it? If there are learning points for all of us and we are to work together to combat and control infection, surely time is of the essence.

Jeane Freeman: I am grateful to Mr Cole-Hamilton for that question. If he has read the report, I am sure that he will understand that it took time for HPS to identify the exact source of the water contamination and to take the necessary steps to address that in what was an everchanging situation in the hospital. HPS had to do that before it could produce conclusions and recommendations that it was confident about and could be assured that it had looked widely for expert advice and support on to allow it to get to that point.

There were two parts to my decision to publish the report last week although I had been made aware of it on 21 December. I took the view that publishing the report in the week before Christmas was not necessarily the most helpful thing to do and would be considered in a critical light. I then took the view that I had to be sure that HPS could see how the report fitted into the work of the wider independent review. There was no intention not to publish it; it was about making sure that the report could be aligned with the independent review. I am sure that members understand that I had hoped to be able to say today who would lead the expert independent review into Queen Elizabeth university hospital. However, for the reasons that I outlined, I am not able to do that.

All those reasons contributed to the reasons why we took longer than we would otherwise have wanted to take to publish the report. There was no intention to conceal anything, as is evidenced by the fact that we have published the report and the fact that I have committed to implement its recommendations, notwithstanding the independent review. It is important that the information is available, understood and acted on.

The Presiding Officer: I am conscious that the minister is giving detailed answers. I welcome that, but we have 10 more questions to get through.

Emma Harper (South Scotland) (SNP): Will the cabinet secretary confirm how the Scottish Government's approach to safe staffing will ensure patient safety as well as the delivery of high-quality, safe care across our hospitals and emergency services?

Jeane Freeman: The legislation on safe staffing is designed to ensure that there is a consistent approach across Scotland to understanding the workload demands of meeting the healthcare needs of any patient cohort at any time and the skills mix that is required to address those demands. Inside that is infection prevention and control, which, as Ms Harper knows from her own experience, varies between different patient cohorts depending on the presenting healthcare need.

Notwithstanding the fact that colleagues will have identified ways in which the legislation could be improved, we all agree that it will provide consistency of assurance and methodology, so that workload is understood in the context of the presenting healthcare needs of patients and the skills mix is understood so that we have the right staff in the right place and a way of escalating if staff feel that they require additional support that is not being delivered to them.

Brian Whittle (South Scotland) (Con): Health Improvement Scotland has no regulatory powers to enforce the implementation of recommendations. For the confidence of staff and patients, and given the seriousness of the situation, will the cabinet secretary commit the Scottish Government to implementing all the HIS recommendations when it publishes the HIS report?

Jeane Freeman: Yes, I will. The question of regulatory powers and the various bodies involved—health facilities Scotland, HPS and HEI—will be part of the review. As I said, the focus is on the Queen Elizabeth university hospital, but the lessons are for NHS Scotland on what more we might do to ensure that there is a more joined-up approach to what needs to happen. It will be for the review to determine whether more regulatory powers are needed. If they are, the review will produce recommendations.

Sandra White (Glasgow Kelvin) (SNP): The cabinet secretary mentioned the Scottish patient safety programme, which is helping to reduce hospital mortality and reduce avoidable harm at every stage of care. Will the cabinet secretary provide an update on hospital standardised mortality ratio figures for Scotland?

Jeane Freeman: The hospital standardised mortality ratio has shown a significant decline, decreasing by 13.2 per cent in the four years from January to March 2014 to July to September 2018. That is all helped by the Scottish patient safety programme, which is one of the key drivers of that reduction. We need to continue the improvement in the ratio, which has been in a steady decline since the introduction of the measures that I outlined.

David Stewart (Highlands and Islands) (Lab): What lessons have been learned about patient safety with regard to new-build hospitals, specifically concerning the handover and maintenance of buildings?

Freeman: Some lessons Jeane immediate-some, in the HPS report that was published last week, have already been picked up by NHS Lothian for the new children's hospital for Lothian—and others are being worked through by our directors of estates with the chief executive of NHS Scotland, together with health protection Scotland and health facilities Scotland, to see what more can be drawn at this point from the HPS report and whether there is anything further to draw from the HEI report. That is what I meant when I said that, although the independent review is very important and its work will be of significance, there are recommendations that we can take forward at this point. Once the HEI report has been published, I will be happy to set out those recommendations that are specifically for buildings, so that members can see what we are doing to act on them.

Rona Mackay (Strathkelvin and Bearsden) (SNP): The Scottish patient safety programme has

contributed to a significant reduction in harm and mortality in our NHS. Will the cabinet secretary outline how that internationally renowned programme can continue to provide public assurance about the quality and safety of care that the public expects?

Jeane Freeman: Healthcare Improvement Scotland is the primary driver of the Scottish patient safety programme. It provides assurance with regard to its inspections and reviews, which are reported and published, and can be used and seen by others. Some of the data that we produce about overall general infection rates are also reassuring about the continuing decline of Clostridium difficile, MRSA and so on. Members can see, for their individual health boards, other work that we discuss with Health Improvement Scotland, including on surgical site infections and other aspects of the Scottish patient safety programme, but there might be merit in pulling that together for the health service across Scotland. Again, I will be happy to look at whether that is worth doing.

Annie Wells (Glasgow) (Con): As the cabinet secretary has pointed out, front-line staff have a critical role to play in patient safety. Despite that, figures show that there was an 11.5 per cent cut in maintenance and estate workers across Scotland in the two years to September 2018. In NHS Greater Glasgow and Clyde, the numbers have reduced by nearly 19 per cent since 2009. What action will be taken to address that drastic reduction?

Jeane Freeman: Ms Wells is correct about the level of vacancies that are being carried in maintenance and, in some instances, in domestic staff. I am very alert to that and have already asked for explanations from boards about what exactly they are doing.

Annie Wells will know that boards are required, in addition, to produce an annual operating plan that shows how they will use their resource. This year, that will be within an overall three-year financial planning cycle, but there will be more detail in the first year. We have been really clear about how we will sign off that annual operating plan, and I will be looking to ensure that capacity—by which I mean staffing—is not being reduced in areas that are critical to infection prevention and control, in which I include all the areas that I have mentioned. Once the plans signed off, they will be published, so the member will be able to see what specific action we are taking.

Ruth Maguire (Cunninghame South) (SNP): I am sure that, across the chamber, we agree that all staff are essential to ensuring patient safety. What impact could a no-deal Brexit have on NHS staffing levels and patient safety?

Jeane Freeman: Ruth Maguire will know that our current estimate is that just under 6 per cent of the current health and social care workforce are non-United Kingdom European Union nationals, and that we have a significant number of non-UK EU nationals in our health service. The figures are greater than that in some parts of the country and in some job roles. Our planning for our workforce needs in areas that Ms Wells identified and other areas has to take account of the fact that we might not, in the current climate of uncertainty, be able to retain all of that workforce.

There are practical steps that we can take, which we hope to be able to set out soon for members in order that we can make good on our words, the intentions of which are genuine. We value all those staff very much and we want them to stay.

An additional issue is how we can attract into our health service people from EU countries from which people have traditionally come here to work. Ruth Maguire will be aware of the 80 per cent reduction this year from last year in the number of nurses from the European Union coming to work in the UK: non-UK EU nationals are not registering.

There are serious issues relating to Brexit, and serious uncertainty and anxiety are being experienced by people who work in our health and social care services. We are doing what we can to reassure them that they continue to be welcomed and valued in our service.

Mary Fee (West Scotland) (Lab): Last week, the cabinet secretary responded to a question from my colleague Neil Bibby on infection control at the Royal Alexandra hospital in Paisley. She said that she shared his concerns about gaps in the domestic cleaning rotas. In light of that case and other tragic cases in NHS Greater Glasgow and Clyde, does the cabinet secretary have any plans to review and update the "National Infection Prevention and Control Manual", which was published in 2012? If so, when?

Jeane Freeman: That matter will be part of what the independent review will consider. The review will consider our existing measures, including that mandatory manual. In addition, I have asked our national clinical director and HIS to review our current measures to see whether we can make other improvements to particular steps, in the light of current knowledge.

I do not yet know the answer to the question. I am mindful of the point that Mary Fee has made about domestic staff, which Mr Bibby has made and which Ms Wells made again. I do not think that I need anything to be reviewed before I can act to make it clear to boards that I do not think that it is acceptable to carry such levels of

vacancies in maintenance, domestic and housekeeping staff. Those staff are central—as central as any other bit of the workforce—to infection prevention and control. We can act on that now, while we consider whether our current procedures require updating and review as a consequence of our recent experience.

**David Torrance (Kirkcaldy) (SNP):** Can the cabinet secretary confirm whether measures are in place to ensure that health boards promptly and effectively implement recommendations that are made by independent reviews?

Jeane Freeman: When a review is undertaken by Healthcare Improvement Scotland, it has in place a process for going back and checking that its recommendations and associated actions are completed. HIS also takes a view on whether actions that a board suggests it should take are adequate to meet the recommendations that HIS has made.

If a review is external and the recommendations are to the Scottish Government, obviously members have a means by which they can check the Government's responses to those recommendations and how we are taking them forward. In addition, we have, as I said earlier, regular meetings with board chief executives, directors of estates, directors of human resources and directors of finance. I also meet chairs of health boards in order to pursue specific recommendations board by board or across the whole health service.

Anas Sarwar (Glasgow) (Lab): I welcome the cabinet secretary's comments. However, clinicians and patients have expressed concerns about NHS Greater Glasgow and Clyde's statement that was issued on Friday, in which it seemed to imply that the cabinet secretary's independent review had limited scope and in which it announced three reviews of its own.

Will the cabinet secretary please confirm that the review that she announced has a broad scope that will include the Queen Elizabeth university hospital's maintenance and upkeep since it opened? Will she outline what the three reviews that NHS Greater Glasgow and Clyde proposes to undertake will cover? Will she guarantee that they will not undercut the work of her independent review?

Jeane Freeman: I am grateful to Mr Sarwar for raising the issue. It is disappointing that the board does not appear to have understood what I have—exceptionally clearly—said. I repeat and absolutely confirm that the scope of the independent review that I have commissioned is exactly as was described in the answer to a written question that was lodged. The review will go back to the design and take us right through.

To comply with the Britton report's recommendations, it will be for the review's independent chairs to work the scope that I have commissioned into a remit, and to decide where they will bring in expert advice, whom they will seek evidence from, how they will seek evidence, how long that will take and whether—on the basis of their work plan—there is an opportunity to make interim recommendations. I will ask the chairs to give permission for all that to be made public. I have no doubt that they will be happy to do that. I take that responsibility.

My understanding—I will make a point of double checking, so that I can confirm it to Mr Sarwar and others who are interested—is that one of NHS Greater Glasgow and Clyde's immediate reviews is of whether it should take additional maintenance and infection prevention and control measures now, at its estate at the Queen Elizabeth university hospital. Another review is about ensuring that infection prevention and control steps are being taken in the right places as people flow through the hospital. As I said, I will ensure that we have the clear detail on that, which I will pass to Mr Sarwar and Opposition spokespeople so that they are clear on the subject.

NHS Greater Glasgow and Clyde's reviews absolutely should not undercut the independent review: they should feed into it. The independent review can take a view on the board's reviews and their conclusions.

## Human Tissue (Authorisation) (Scotland) Bill: Stage 1

The Deputy Presiding Officer (Christine Grahame): The next item of business is a debate on motion S5M-16001, in the name of Joe FitzPatrick, on the Human Tissue (Authorisation) (Scotland) Bill at stage 1.

14:58

The Minister for Public Health, Sport and Wellbeing (Joe FitzPatrick): I am pleased to open the debate on the Human Tissue (Authorisation) (Scotland) Bill. Before discussing specific elements of the bill, I will talk about the bigger picture, which it is always important to remind ourselves of when talking about organ and tissue donation and transplantation.

The transplantation of donated organs and tissue is one of the most incredible developments in modern healthcare. It reflects the best of humanity, as people respond to acute need with incredible generosity, and it is a testament to the wonders of the national health service, to the skills of our nurses, clinicians and surgeons and to the organised efforts of everyone who works to make these life-changing gifts possible.

Scotland has seen tremendous progress over the past decade. Following our work to build and strengthen the system, and as a result of the incredible generosity of donors and families, the number of donors has significantly increased, as has the number of organ and tissue transplants. Those transplants have saved and improved lives. They have allowed people to live fuller lives, to be less dependent on hospital visits and healthcare, to get back to work and to contribute to society.

For the transplant recipient, the gift that they receive represents an opportunity to start life anew. However, not everyone receives the organs or tissue that they need. Although many lives have been saved and improved over the past decade as a result of the hard work that has been done to build the necessary infrastructure, too many people are still waiting for the organ transplant that could save their lives. More than 500 people in Scotland are waiting for an organ transplant at any one time. Those people want to live their lives to the full; they want to work, contribute and support their families. It is my job—it is our job—to make sure that we are doing all that we can to get as many of those people as possible the transplant that they need.

There will always be an absolute limit on the number of people who can become donors. Only about 1 per cent of people die in circumstances in which donation is possible, but if there are steps that we can take to allow more of that 1 per cent to donate, I hope that members will agree that it is important that we do so.

The primary purpose of the Human Tissue (Authorisation) (Scotland) Bill is to introduce a soft opt-out system of organ and tissue donation for deceased donors. The bill would amend the existing Scottish legislation that supports donation—the Human Tissue (Scotland) Act 2006—by introducing a new additional form of authorisation called "deemed authorisation". In practice that means that, if a person was not known to have any objection to donation, donation may proceed.

Deemed authorisation would apply to most adults from the age of 16 who have not otherwise explicitly opted in or opted out of donation. However, the bill contains safeguards to ensure that donation will not proceed if that is not what the person would have wanted. The bill also provides safeguards for those adults who lack the capacity to understand deemed authorisation and for adults who are resident in Scotland for fewer than 12 months—neither will be subject to deemed authorisation.

Evidence suggests that there is no one answer to increasing organ and tissue donation; there is no magic bullet. However, there is evidence that opt-out systems can make a difference as part of a package of measures. Scotland has already made many improvements. With our partners in the national health service, work has progressed over the past 10 years to improve the infrastructure and systems that support donation. That includes learning from other countries such as Spain, and responding to major reviews such as "Organs for Transplants: A report from the Organ Donation Taskforce" from 2008.

David Stewart (Highlands and Islands) (Lab): The minister rightly identifies Spain—it is top of the league table for organ donation. He will know that its success has been because of the high level of intensive care beds rather than to do with issues of consent. Will the minister respond to that point?

Joe FitzPatrick: We should learn lessons from across the world about how we can adapt our system, but we have to recognise that there are differences in systems and we need to be mindful of differences in culture and approaches. I am pleased that the Health and Sport Committee in its review of evidence agrees and specifically makes that point regarding the differences between the Spanish and United Kingdom systems.

Improvements have also been realised through "A donation and transplantation plan for Scotland 2013-2020: More donors, more transplants, more lives saved". That includes the appointment of a Scottish regional manager for specialist nurses for

organ donation and the publication of an education pack for secondary schools, which has contributed to the highest awareness among young people.

Work continues. For example, we have recently confirmed to NHS Blood and Transplant that we will provide funding to support new technology to improve the outcomes for patients receiving liver transplants and increase the proportion of livers that are suitable for transplantation.

A duty on ministers in the Human Tissue (Scotland) Act 2006 to promote donation through regular publicity and awareness raising has resulted in Scotland having 52 per cent of its population on the NHS organ donor register, which is the highest proportion of any of the UK countries.

As support for and awareness of organ donation have grown in recent years, so has interest in a move to opt out. Anne McTaggart's member's (Authorisation Transplantation bill—the Removal of Organs etc) (Scotland) Bill—which was introduced in the previous session, was significant in that regard. Although the approach in that bill was not supported by the Parliament or Government, both recognised the appetite to move towards a different form of authorisation. The Human Tissue (Authorisation) (Scotland) Bill is the product of that appetite, and of the great deal of work that we have undertaken over the past few years following those discussions.

We have worked with a lot of people, including NHS professionals and people affected by donation and transplantation, to consider how best to introduce a system of opt-out in a way that will contain appropriate safeguards and in a way that will not compromise the already complex and lengthy donation pathway.

We place particular importance on making these changes in a way that is transparent and open to the public. Organ and tissue donation enjoys and depends on a high degree of public support, and we do not want to do anything that puts that support at risk.

The bill sets out a framework for pre-death procedures—that is, medical procedures that may be carried out for the purposes of transplantation. The medical procedures that we are talking about here include, for example, blood tests or the collection of urine samples to help ensure that donated organs are more likely to be transplanted successfully, and that a donor's wishes can be fulfilled.

The bill also sets out that the authorisation for some procedures can be deemed in certain circumstances. I am pleased that the committee accepts the proposals in the bill, but I recognise that this is a complex area. I want to reassure members that that sort of clinical practice is not

new, and it is already an important part of the donation and transplantation pathway. We recognise that clinical procedures will continue to change. We want to ensure that there is in place a clear framework that will set out how and when pre-death procedures can be used, and what safeguards must be in place to ensure that future developments in clinical practice can be introduced where appropriate. We agree with the committee that the use of such procedures should be kept under review.

The bill provides that the procedures and proposed changes to them will require consultation to be carried out with the appropriate clinical bodies and will also require scrutiny on the part of the Parliament. As with provisions around opt-out, our approach is to be transparent and to maintain a high degree of trust in donation.

The bill includes a new duty to inquire. In practice, that will ensure that the NHS understands the wishes of the donor before further steps are taken. The aim of the bill is to ensure that the interests and the views of the donor are safeguarded at all times, but also that there is a clear and effective mechanism in place for relatives and other entitled people to provide information to exercise their rights.

To meet those aims while reflecting current good practice, the bill includes a duty to make inquiries in respect of authorisation given by the donor or whether an opt-out decision is in place. For example, the specialist nurse for organ donation or the tissue donor co-ordinator will undertake a check of the information that is held on the organ donor register. Inquiries will also be made of the nearest relative or other person to find out the most recent views of the donor, or whether the donor falls within an excepted category.

To be clear, as with the law as it currently stands, families do not have a right to overrule the wishes of a loved one. However, they have an important role to play in relation to providing information on whether the donor had expressed any wish, or whether they had changed their mind.

Mike Rumbles (North East Scotland) (LD): The bill would change the law as it stands. At the moment, the legislation says that the relative can provide knowledge of the intended wishes of the donor, but the bill says that the relative has to provide evidence to a health worker that would convince a reasonable person. That is quite a different level of bar that the relative has to jump over

Joe FitzPatrick: The standard of evidence in respect of the donor's view was given a great deal of consideration during the development of the bill. The view of those working in the system was that requiring written evidence was impractical, as it is

almost never provided. That is why, although the consultation referred to written evidence, the bill does not. The discussions take place with families and things are rarely written down. I think that we have got the appropriate level of evidence that is required.

Maurice Corry (West Scotland) (Con): We talk about families being consulted, but has consideration been given to powers of attorney and deputies of the court of protection?

Joe FitzPatrick: The aim is to ensure that we are identifying the views of the potential donor. In many cases, that will require consultation with the family, but in other cases, it will require consultation with someone else. That is part of the process as it stands just now. The specialist nurses ensure that they are speaking to the most appropriate person to identify the wishes of the donor. That is our aim, and it is a crucial part of the legislation.

Good public awareness will be crucial to achieving the aim of increasing support for donation. The bill builds on the provisions in the 2006 act for ministers to support and raise awareness of donation by introducing a requirement to raise awareness of the new authorisation processes that it introduces. We need to ensure that members of the public are aware of the opt-out system, are able to exercise their choice to opt out of donation, and are encouraged to tell their families.

In addition to the duties in the 2006 act and those in the bill, the Scottish Government is committed to a high-profile awareness-raising campaign during the 12-month lead-up to the introduction of the opt-out system. Awareness activity will be designed to reach a wide range of people, including hard-to-reach groups, minority groups and people with specific needs. We recognise the importance of raising awareness among young people as they approach the age of 16, so that they are aware of the implications for them. We are exploring ways of achieving that.

A great deal of work has gone into developing the bill over the past 18 months. I am grateful for the expertise, dedication and experience of the NHS clinicians, professional organisations and individuals who helped to shape the bill. I particularly acknowledge the Scottish donation and transplant group, which advises Government on these matters.

Our long-term aim is to increase donation and transplantation rates. I hope that this bill will contribute to that. I welcome the committee's support for the general principles of the bill and I thank committee members for their thorough and constructive consideration at stage 1.

I move,

That the Parliament agrees to the general principles of the Human Tissue (Authorisation) (Scotland) Bill.

**The Deputy Presiding Officer:** I call Lewis Macdonald, convener of the Health and Sport Committee.

#### 15:11

Lewis Macdonald (North East Scotland) (Lab): Lung transplant recipient Gillian Hollis gave the Health and Sport Committee a neat summary of the general principles of the Human Tissue (Authorisation) (Scotland) Bill:

"Tell us if you want to donate, tell us if you don't want to donate, and if you don't tell us anything we'll presume you have authorised donation."

She was one of several people with direct personal experience from whom we heard, formally or informally, and who helped to shape the committee's report at stage 1 of the bill. I thank everyone who assisted with our scrutiny by responding to our call for views or our survey or by giving oral evidence, and I particularly thank those who, like Gillian Hollis, gave evidence from their own experience, including people who have benefited from donated organs, patients who are still waiting for a transplant and relatives who have authorised the donation of an organ from a deceased family member.

I also thank the clerks to the committee and the Parliament's external engagement and media teams.

As is the case with the current law on organ donation, the Human Tissue (Scotland) Act 2006, the bill's fundamental purpose is to enable an increase in rates of organ donation to save lives.

The evidence that we heard at stage 1 was that donation rates have benefited from the changes to law and practice that followed the 2006 act, but have not yet ended the tragedy of people dying while on the waiting list for an organ transplant. Despite all the good work that has been done since 2006, more than 500 people are waiting for a transplant at any one time and there are not enough organ donations to enable them all to survive.

The 2006 act boosted donor rates in Scotland to the highest in the UK, as the minister said, although we are now being challenged by Wales, since the passing of the Human Transplantation (Wales) Act 2013.

In Scotland, about half the population has opted in. However, that is not enough. We know from survey work that 90 per cent of Scots say that they would like their organs to be available for transplantation after death. That means that up to 2 million people in Scotland would like to be organ donors but have not registered their wishes.

The bill deems those who have expressed no view on the matter to be potential donors, thereby bringing the share of the population who can donate closer to the proportion of the population who want to do so. Of course, as Joe FitzPatrick said in his speech, in practice, transplantation is appropriate in only 1 per cent of deaths.

People need to be able to make an informed choice about opting in or out, and they must understand the implications of deemed authorisation. The language around organ donation can be confusing, so we also need a robust and continual engagement strategy, to explain what it all means.

The committee was keen to learn from the experience of other countries. The legislation passed in Wales in 2013 introduced a system of deemed authorisation similar to that proposed here. Evaluation of the impact of the Welsh act confirmed that the new law did not at first lead to a major increase in donor rates but that that has begun to happen in the past year or so. The evidence is that increasing donation follows increasing awareness, not simply a change in the law alone.

Likewise, as we have heard, the evidence from Spain did not prove a direct link between an optout system of deemed authorisation and an increase in transplantation rates. As David Stewart pointed out, high numbers of intensive care beds have been at least as important to the high organ donation rates in Spain, as has the high number of hospitals able to retrieve organs.

When we asked the minister to review the issue of intensive care beds, he indicated that the 2020 strategic forecast did not anticipate an increase in donation rates above existing capacity as a result of the bill. We therefore recommended a review of infrastructure across the country for organ donation, and I very much welcome the minister's commitment today to discuss with stakeholders whether further improvements can be made.

The committee's online survey on the bill attracted 747 responses. The most widely-held concerns related to the rights of the individual who has not expressed a view but whose body could, some felt, be treated as if in some way it belonged to the state. While recognising the ethical and legal issues raised, the committee accepted the minister's view that, in the final analysis,

"the right to authorisation rests with the ... donor"—[Official Report, Health and Sport Committee, 27 November 2018; c 24.]

and, by the same token, so does the right to withhold consent.

The idea that deemed authorisation could undermine the sense of a gift from donor to recipient was also highlighted in our survey.

Patients awaiting transplant, on the other hand, were insistent that any organ would be welcome as a gift, whether it was enabled by registration as a donor or by deemed authorisation. It would be useful for the Scottish Government to revisit that after a period to see whether there is any change in public attitudes and any impact on donor rates. Mr FitzPatrick has indicated that that is his intention. We also want a review after a similar period—perhaps five years—of medical procedures prior to death to help successful transplantation. The minister mentioned that, too. It is critical to ensure that such procedures are being conducted with the necessary sensitivity.

The committee had a valuable session with specialist nurses in organ donation—SNODswho showed us how they work with the families of potential donors. It became clear that families have a dual role in providing the essential medical and social history of the prospective donor, and in enabling donation to go ahead. We were struck by the many and sometimes difficult questions that SNODs have to ask at what is already a distressing time. Those questions standardised across the UK in order to maximise the opportunities for donations and transplants between jurisdictions. We suggested that this would be a good time to review those questions, to ensure that every question continues to be of clinical importance. We welcome the minister's commitment to take that forward.

The law already says that the wishes of the donor are paramount, not the views of family members, but, as we heard from Dr Stephen Cole, consultant in intensive care medicine at Ninewells hospital, doctors

"would find it difficult ... to override the wishes ... expressed by ... patients' relatives."—[Official Report, Health and Sport Committee, 13 November 2018; c 27.]

We accept that, in practical terms, it would not be possible for the medical profession to proceed with donation against the wishes of the family. The role of SNODs in working with families is therefore critical.

We heard from patients on the transplant waiting list who told us about the emotional and financial distress caused by waiting for an organ to become available. Even when an organ is found, 40 per cent of transplants do not proceed for a variety of reasons, which is tough for those on waiting lists, whose hopes can be dashed time and again.

Specialist post-transplant support is provided to recipients of blood stem cell or bone marrow donations, and we see no reason for any difference in approach. We welcome the Government's assurance that psychological support across all those services is under review, including for people affected by organ donation.

Having had that assurance from the minister, we look forward to the findings of that review later this year.

For the bill to achieve its aim of increasing donation rates, a high-profile public information campaign is required, running for at least 12 months before commencement of the new rules. We are pleased that the Government has accepted our recommendation that it reviews the engagement strategy in Wales and undertakes outreach sessions with ethnic minority groups. We also welcome its commitment to build on the existing collaboration between the Scottish Fire and Rescue Service and the Anthony Nolan charity, which work together to promote awareness of stem cell donation in secondary schools and colleges.

The committee supports the general principles of the bill, but we stress that the bill alone will not achieve the desired effect. Scotland, like Wales, must use the change in the law as a vehicle for promoting greater awareness of the benefits and requirements of organ donation. Ministers must therefore ensure that the necessary infrastructure is in place in good time to support the increased number of transplants that we all want to see in Scotland in the 2020s.

15:20

Miles Briggs (Lothian) (Con): When I attended university in Aberdeen, all the students in the granite city became aware of and concerned about our fellow student Millie Forbes. Millie needed a vital bone marrow or stem cell transplant, and significant work to find a donor had led to no suitable match.

As I was a young man who had just escaped rural Perthshire for the city life of Aberdeen, registering for any donation list was the last thing on my mind. However, it was the need to do something and wanting to help that made so many of the student population in Aberdeen sign up en masse to the Anthony Nolan register and donate blood stem cells in the hope of providing the match that Millie needed.

Millie sadly lost her fight aged just 21, surrounded by members of her family at the ANCHOR unit at Aberdeen royal infirmary in 2004, eight months after she had successfully undergone a stem cell transplant operation—her only real hope of survival against acute myeloid leukaemia. Millie was a real inspiration, and it is remarkable to see, 15 years after she lost her life to leukaemia, how Millie's campaign has brought fresh hope and has saved the lives of others with leukaemia across Britain since then.

That experience made me think about these issues and decide, during my time at university, to

sign up to the Anthony Nolan register and the organ donation register. Sadly, for many of our fellow Scots, taking that step or even having a conversation about it with loved ones is just not happening, which is why so many people's wishes on organ donation are simply not registered or not known by family members. The situation clearly needs to be improved. In Wales, the most recent figures since it changed its organ donation legislation show that, from November 2018, the rate of family consent is now at its highest-ever level of 80 per cent compared with 63 per cent in Scotland, 66 per cent in England and 66.7 per cent in Northern Ireland.

I thank all the organisations and groups that have provided briefings ahead of the debate, and I thank them for their contribution to the work of the Health and Sport Committee. I also put on record my thanks to the committee team for their work during the inquiry, and I recognise the work that was done by Mark Griffin in introducing his member's bill on the issue.

In the time that I have, I will touch on some of the important aspects of the bill that we need to get right as it progresses through Parliament. The wishes of the donor's family have already been mentioned, and we need to make sure that those are at the heart of the bill. Throughout our inquiry, it was clear that the role of the donor's family is fundamental to the success of any donation and will be central to the success of the bill.

Keith Brown (Clackmannanshire and Dunblane) (SNP): Is it the member's view that the wishes of the donor's family should supersede those of the donor?

Miles Briggs: The committee found that issue difficult, specifically in the context of what happens if someone is not known to have expressed a wish. The family already have the opportunity not to go ahead with the questionnaire, and the questionnaire is staying as part of the bill. So, in theory, that will still be the case if they are not willing to go ahead with the donation questionnaire. I know that the SNOD team has always found that issue difficult.

During our inquiry, when Keith Brown was still a member of the Health and Sport Committee, the work that we did with the specialist nurse in organ donation team was very important. Listening to examples of the conversations that the team facilitates with families at the most distressing time any of us can imagine showed how incredibly professional they are and demonstrated our national health service at its best. The professionalism of the SNOD team is critical as they provide sensitive assistance and support to the families of potential donors, and the openness and transparency of those conversations is vital to the process. I pay tribute to their work in supporting families at times of unimaginable distress while highlighting the benefits of organ donation and keeping them informed after the process.

It was clear that organ donors' families have always been and will always be at the heart of facilitating donor selection through the questionnaire process and in implementing donors' wishes. As Lewis Macdonald has highlighted, that was demonstrated by the conversations that the committee had with families, and I thank those who generously gave their time to the work of the committee. I am sure that I speak for all members when I say that we learned much from them.

The decisions of families who had decided not to go ahead with donation were understandable, though. I hope that we have been able to make improvements for the future regarding the factors that they outlined as having influenced their decision making at the time and in the organ donation system and such families' experience of it. Refusal by families accounts for 50 per cent of non-donations. In countries that have adopted optout systems, that figure has reduced to an average of around 25 per cent. Clearly, much work remains to be done to improve family consent rates, but I believe that the work that the committee has done on the bill can help to do that.

I do not have time to highlight the amazing work of the Family Donor Network and other organisations such as Transplant Sport, which runs the British transplant games, but I thank them. As has been mentioned, infrastructure is another issue that has been raised with the committee, and I believe that we need to see a significant commitment from ministers on it. As David Stewart outlined, intensive care beds are a key area that the committee highlighted. It is clear that, if the bill is to achieve the outcome of increasing organ donation, we will need to see progress on improving the infrastructure for transplantation. I welcome the minister's response to the committee, but it is important that we have further clarity on what will be done to address capacity issues in order to support the aims of the bill in the future, especially on staffing and intensive care beds.

The useful briefing that the Royal College of Physicians of Edinburgh provided ahead of the debate makes some key recommendations and points that will be important for us to examine as we progress to stage 2.

I hope that the bill will help us to achieve a celebration of organ donation. We need to change the culture in Scotland to recognise organ donation publicly and to celebrate it more. We must see the life-saving and life-changing difference that donors and their families make—in

the majority of cases for total strangers. Giving the gift of life is incredible. The committee's report recommends that a communication programme be established. If the bill passes stage 1, we must ensure that such a public information campaign is one of the best and most innovative that the Scottish Government has undertaken.

Scottish Conservatives welcome the introduction of the Human Tissue (Authorisation) (Scotland) Bill and today's debate as the Parliament moves forward on this important issue. We believe that all options should be considered in order to increase organ donation. Therefore, if the bill passes stage 1, we will engage in the legislative process before the final vote at stage 3.

The SNP Government must ensure that comprehensive information and the infrastructure that we will need are in place so that, in the future, donors and families will be fully informed and it will be possible for organs that are donated to be transplanted successfully.

Every day, someone in the UK dies while waiting for an organ transplant. I believe that, here, we have the opportunity to change that.

**The Deputy Presiding Officer:** I call Monica Lennon to open the debate on behalf of Labour.

15:28

Monica Lennon (Central Scotland) (Lab): I am pleased to speak in the debate on the Human Tissue (Authorisation) (Scotland) Bill at stage 1. Like other members, I thank the Health and Sport Committee for its diligent work and its report, which was ably summarised by the committee's convener, Lewis Macdonald, a few minutes ago. I am also grateful to the British Heart Foundation, the Royal College of Physicians of Edinburgh, the Royal College of Nursing Scotland, Anthony Nolan and Kidney Care UK for the briefings that they provided ahead of the debate.

Scottish Labour supports the general principles of the bill, including its overarching aim of increasing the organ and tissue donation rate and, consequently, the number of transplants that can be carried out. We have long supported a soft optout system. I thank my colleague Mark Griffin for influencing the agenda on the subject through his member's bill of 2016 and Anne McTaggart for her work prior to that on her member's bill of 2015. I look forward to hearing from Mr Griffin and other colleagues this afternoon.

At any one time, 500 people are on the organ transplant list in Scotland, and, each year, up to 60 people die while they are on that list, so there is certainly a need to increase the number of donated organs. That is why I am pleased that there is public support for a soft opt-out system, as

was demonstrated in the Scottish Government's consultation and the committee's survey.

That said, we are all alive to some of the concerns that have been raised about the move to a soft opt-out system. Some people expressed a worry that people will have organs removed against their wishes, so it is important to highlight that people will still be able to opt in and opt out of the system, as we have always been able to do. For people who have not declared, consent will be presumed, but there will be safeguards in place. For example, the next of kin will be able to provide information if donation was against their family member's wishes.

**Mike Rumbles:** As I said to the minister, that is the law as it stands, under the Human Tissue (Scotland) Act 2006, which refers to "knowledge" of the deceased person's intent. However, section 7 of the bill says that the family must provide

"evidence to a health worker that would convince a reasonable person".

That requirement to provide evidence is quite different and is a step change in legal terms.

**Monica Lennon:** I have been reassured by the committee's scrutiny and by the Government that there are appropriate and robust safeguards. I will come on to talk about the public education aspect, which is important.

Fundamentally, it is crucial that we get these things right, because people who are on the transplant waiting list urgently need help. Organ transplants save lives and can make a transformational change to people's quality of life. For example, Kidney Care UK describes dialysis as distressing, extremely painful and hugely disruptive to daily life, with five-hour dialysis sessions three times a week, which is challenging for people in rural areas, as I am sure Mike Rumbles knows. A kidney transplant can give a person their life back.

The committee heard that the wait for a transplant can be a lonely experience and can take a huge toll on people's mental health. There can be an anxious wait for a suitable organ to be found and disappointment when delays and complications arise, which can happen even on the day of surgery. A return to the transplant waiting list can be a source of disappointment and recognise anxiety. the committee's recommendation that, where possible, we need to improve the experience of people on the waiting list by, for example, having specialists provide support.

It is crucial that the bill be backed by clear and consistent messaging throughout Scotland so that people understand the system, and in order to spark conversations about organ donation. The British Medical Association has said that, although half of the population have opted in to organ donation, its experience is that, when asked, nine out of 10 people say that they would donate their organs. Deemed consent will help to close that gap.

I hope that we can all agree that a person who is desperately waiting for an organ transplant, which could be the difference between life and death, should not miss out simply because many of us never got round to opting in to be an organ donor. The committee's convener touched briefly on the work of Anthony Nolan with the Scottish Fire and Rescue Service, which is an excellent partnership that works with young people in our schools. Since 2009, 13,000 people in Scotland have registered on the stem cell donor register, which has potentially saved 42 lives. That is fantastic work, and I hope that the Government can help those organisations to build on it.

The importance of public awareness and frank conversations is brought into sharp focus when we consider that family refusal results in the loss of around 100 donors in Scotland per year. Changing that situation could make a huge difference to people on the transplant waiting list. It might not be an easy conversation, and it might feel morbid to discuss it, but it is important that we overcome the stigma and make our wishes known to our loved ones. I was moved by the stories from families for whom organ donation has been a positive experience, even helping them to come to terms with their loss.

Just recently, I was walking our dog in Chatelherault country park, in Hamilton, where there is a bench that is a tribute to Lanarkshire organ donors. I have passed it a number of times, but I knew that the debate was coming up, so I looked more closely. It is very poignant. As we would expect, there are flowers and little plaques, and it simply says that it is

"to remember those who gave the gift of a life time".

I was pleased to hear about the measures that are currently in place for the families of the deceased through which they get a certificate. That must be hugely important and meaningful, as it is an extraordinary gift.

Evidence suggests that an additional benefit of good public awareness is that it will help to drive up donation rates. Although the soft opt-out system is important, the BMA and others have highlighted that a change in legislation is not a panacea and must be accompanied by investment in the infrastructure to support delivery, which other members have touched on in respect of intensive care capacity.

Scottish Labour supports the general principles of the bill and looks forward to working with others

on amendments. Organ donation is one of the greatest gifts that a person can give, and it is life-changing to receive. It is important that the bill maintains the special way in which organ donation is viewed and that surrounding measures are implemented to ensure its success.

The Deputy Presiding Officer: Thank you. I remind members that, if you intervene, your request-to-speak button will be switched off, so you must check that you have switched it back on again. It is how the wonderful technology in the Parliament works.

15:35

Alison Johnstone (Lothian) (Green): I, too, would like to thank the Health and Sport Committee and all those who were involved in getting the bill to stage 1, including the expert groups and witnesses who gave their time. I also note the contributions of Anne McTaggart and Mark Griffin to the on-going debate.

Right now, about 4,300 people in Scotland are living with a donated organ. Thousands of people have a second chance at life because someone made the active choice to register as a potential donor. We are all aware of the heartfelt letters that organ recipients have sent to the families of donors to give them a sense of what the donation meant to them.

When it comes to getting people to register to be a donor, Scotland is doing well. As we have heard, around 50 per cent of Scots are registered, compared to 38 per cent of people across the UK. As a result, the number of successful donations has increased significantly over the past decade, with waiting lists having reduced by more than 100 in that period.

However, as we know, that is still not enough. In Scotland, 500 or so people are on the waiting list for an organ transplant and, sadly, 40 to 60 people will pass away while they are waiting. Despite having that high proportion of people who are registered, Scotland's level of donations is the lowest in the UK. That is why, among other measures, it is vital to increase the total number of potential donors. Clearly, there is scope to do that, as there is a persistent gap between the number of people who state in surveys that they would wish to donate organs and the number who go on to join the organ donation register.

The question before us is whether an opt-out system, such as that which is proposed in the bill, is likely to increase the number of organs that are available for donation. As we have heard, and as the policy memorandum to the bill rightly notes, the evidence is mixed. Therefore, we need to be clear—and it seems that, across the chamber, we

are clear—that an opt-out system is not an instant solution on its own.

Some countries have experienced increased donation rates after adoption of such systems, and in some there have been decreases. However, the evidence that was presented to the Health and Sport Committee and which is in many of the briefings that members have received suggests that an opt-out deemed authorisation system, as part of a broader strategy to increase donations, may well have a positive impact. Figures that were released by the Welsh Government show that there was a significant increase in the number of families consenting to donation after the new system was established. The figure in Wales stands at 80 per cent, compared with 63 per cent in Scotland.

NHS Blood and Transplant's audit of potential donors in 2016-17 showed that 177 families across the UK said no to donation because they were not sure whether their relative would have agreed to it. Based on last year's average number of 2.6 transplants per deceased donor, those decisions could instead have led to around 460 life-saving or life-transforming transplants. If, as the bill intends, the Scottish Government is able to reduce the high number of refusals by families in Scotland, it will have a very positive impact. However, the ideal is clearly still to have as many people actively opting in as possible. The rate of family consent is always highest when the person who has died opted in, and that is when the intent of the person is the clearest. That is one of the many reasons why section 2 of the bill is particularly important. It places a duty on the Scottish ministers to

"promote ... awareness about how transplantation may be authorised".

It would therefore be useful if, in his closing speech, the minister could give some more detail on how that awareness will be raised.

Deemed authorisation depends significantly on people being well informed about their options, so awareness raising must continue over time. As we have heard, anyone who is resident in Scotland for more than 12 months will be subject to deemed authorisation. The logical conclusion of that is that we must have a continual, year-on-year campaign of awareness raising. NHS Blood and Transplant surveys show that more than 80 per cent of people support organ donation but only around 49 per cent have ever talked about it. We need to have a wider and more effective national conversation about organ donation. I would be interested to hear from the minister how he thinks that can best be achieved.

Before closing, I want to focus on the role of specialist nurses for organ donation. The whole

system really hinges on the incredible work that the specialist nurses do. They lead the discussion about the patient's decision on donation with the family. Where a decision to donate is established, they ensure that the relevant medical tests are carried out and they discuss the patient's medical history with the family. However, the new system will potentially change their role significantly. For example, it is likely that the new duty to inquire that the bill establishes will, in practice, lie with the specialist nurses. There will be retraining needs related to that.

The evaluation of the Welsh system has drawn attention to the pressure to make the policy work that some specialist nurses feel. Some nurses were concerned that they might be blamed if consent and donation rates did not improve. We can learn from that, and I am sure that that is something that we will seek to avoid. It is also important that the guidance for specialist nurses and other professionals is clear, particularly in relation to some of the challenging situations that they might face, such as when the family objects, even though relatives have no formal entitlement to refuse a donation.

As part of a broader strategy to increase donation rates, the bill is welcome. Clearly, this is a sensitive issue, and the bill's provisions will need to be implemented with care, with appropriate safeguards and with respect being paid to the difficult situations faced by families who have lost a loved one. However, if there is a chance that it will lead to more people getting the gift of life, it should be welcomed. Greens support the general principles of the bill and will vote accordingly at decision time.

#### 15:41

Alex Cole-Hamilton (Edinburgh Western) (LD): I am delighted to stand here today and offer my full-throated support for the Human Tissue (Authorisation) (Scotland) Bill. When I was out losing elections as an aspirant Liberal Democrat candidate, I was often asked at hustings and party meetings, as I am sure other members were, "If you make it to Parliament, what will be your member's bill?" It was a hypothetical question, but I always gave the same answer, and it was the bill that we are discussing today. I always supported legislation to introduce a soft opt-out system and presumed consent for organ donation, and I will tell members why.

When I was 14 years old, I met a guy called Anders Gibson. He was 12 at the time. He and I soon became friends, and I was told by adults around Anders that I had to be prepared for the fact that he might not see 20, because he had cystic fibrosis. However, happily enough, he rode the wave of medical advancement and benefited

from new treatments that emerged in his late teens. He went on to become a fierce campaigner on cystic fibrosis issues, an ardent footballer and a brilliant stand-up comic. Very sadly, we lost Anders in 2014, when he was in his mid-30s. I speak in his memory today and I am grateful for his impact on my life and the lives of everybody with cystic fibrosis in this country.

It is for that reason that I entirely understand the personal motivation that led to Anne McTaggart and Mark Griffin introducing members' bills on the subject, and I thank them for their work. They have paved the way for change in this country that might not have happened were it not for their efforts, and rightly so, because we are pushing at an open door here.

As we have heard, we have a high rate of registration with the organ donation register and some 70 per cent of our fellow countrypeople support change in this regard, but there is always a disconnect—it has been alluded to by several speakers in the debate—between those who do not mind the idea of having their organs give life to others in the event of their passing and those who actually sign up to the register. The human cost of that disconnect is that, in Scotland, on any given day, 500 people are waiting for an organ, some of whom may wait in vain and pay the ultimate price.

The bill might not create a huge uplift in the number of organs that are made available, but it is a vital step and one that we need to take. It is important to recognise that, if we introduce a soft opt-out system, it will not mean that everybody's organs will automatically be donated in the event of their death. People will need to die in specific conditions for that to happen. Nevertheless, it will give hope to those 500 people where none existed previously.

We do not need to wait for people to die in order for others to benefit from organ donation. In mid-March, I will be hosting a photo call after First Minister's question time for Give a Kidney, which is a UK organisation of philanthropic organ donors that does not get enough publicity. I urge all members to learn about it because it is truly heaven sent.

The process around the bill has been enjoyable, touching and inspiring. I want to pay tribute to the outstanding work of the specialist transplant nurses: they are a credit to their profession. I had no idea about the pre-death procedures that take place in advance of a transplant. They are onerous; hundreds of questions have to be asked of families at the most vulnerable point in their journey through grief. Often prior to somebody's actual death, families have to take time away from the patient's bedside to answer those questions. The transplant nurses ask them in a way that makes it a cathartic experience. The families get

to unpack their relative's life: their likes and their dislikes, and who they were as a person. It was really touching to see how the nurses make a bureaucratic exercise intensely cathartic for the families around them.

However, it is vital that that process should not become a barrier. Although I understand the duty to inquire, I support the suggestion from my friend and colleague Mike Rumbles that we need an amendment regarding the requirement for families to provide evidence that would "convince a reasonable person" about the deceased's views. Nevertheless, retaining opt-in is important—we need to engender those conversations, to continue to make organ donation feel like giving a gift and to provide an element of the process through which people can proactively make that statement. People who receive organs absolutely regard it as a gift.

One of the most touching moments in the consideration of the bill was a breakfast session with half a dozen recipients of organ donations, who were inspiring people who talked of their gratitude and exhibited such good will towards their donors. They particularly felt the impact of that gift on their lives.

It is so important to recognise that each of those people have been through a roller-coaster of emotions on that journey, and we need to do more for them in the periphery around the bill. Anders, whom I mentioned at the start of my speech, had four abortive attempts at going to Newcastle to get a lung transplant. Waiting by the phone, being turned around to start the whole process again and feeling guilt about waiting for somebody to die had a profound effect on his mental health. At the moment, we do nothing to help people who are on the transplant register, and I hope that the minister will address that in his remarks and agree to meet me to discuss how we can do more.

To get down to brass tacks, I absolutely support the principles of the bill. It will give hope to those 500 people and do more to make sure that people like Anders will have a fighting chance at survival.

The Deputy Presiding Officer: We move to the open debate.

#### 15:48

Emma Harper (South Scotland) (SNP): I am pleased to speak in today's stage 1 debate on the Human Tissue (Authorisation) (Scotland) Bill as deputy convener of the Health and Sport Committee. The committee took a large volume of evidence, and I thank the clerks for their hard work and diligence. I also thank all those who provided evidence to the committee, including healthcare professionals—among them Lesley Logan and her team—who provided us with insight and medical

expertise so that we could be better informed about the process of organ and tissue retrieval and donation, as well as the transplant process.

Like Monica Lennon, I also thank the organisations who provided briefings ahead of this stage 1 debate, including Anthony Nolan, which supports education with the Scottish Fire and Rescue Service and which has previously worked with my colleague Bill Kidd MSP.

As a former member of trauma and liver transplant teams in Los Angeles, I was especially grateful to hear from people who were waiting for an organ. The personal voices of recipients and people waiting for organs and tissues are vital in informing the debate, because around 500 people in Scotland are waiting for a transplant at any given time.

The primary aim of the Human Tissue (Authorisation) (Scotland) Bill is to increase the tissue and donation rate. Organ transplantation is a complicated process. It normally requires two teams of healthcare professionals-and two surgeries-to engage in and co-ordinate the process of obtaining the organ and transplanting it into the recipient. I have participated in the retrieval of organs, as well as the transplantation of solid organs into a recipient patient. On one occasion, I even went up three floors in the elevator carrying a heart in a sterile, ice-filled bowl from one surgical team to the waiting transplant team. It was an awesome—in the true sense of the word—experience to see the gift of an organ being transplanted into a recipient.

The biggest challenge that I have faced while working on the bill has been in relation to deemed authorisation or presumed consent. One of the key arguments in favour of deemed authorisation is the fact that many people in Scotland support donation but have not yet recorded their wishes on the organ donor register. In evidence, Dr Sue Robertson, who is the deputy chair of the British Medical Association Scotland, told the committee that about 50 per cent of the Scottish population have already opted in, so they are already registered to be donors. The committee also heard that 68 per cent of people in Scotland support being organ and tissue donors, but that not all of them have got round to registering.

It is worth highlighting that, when we talk about organ donation, we are referring to the heart, lungs, liver, pancreas, kidneys and even the small bowel; that is before we even start on tissue availability. I believe that we must encourage people to make an informed choice on donation. We need to encourage families, friends and colleagues to have conversations about donation. It is easier to have a conversation about donation when family members meet to engage in a chat than it is at the stressful and traumatic time when

a family member is in the intensive care unit. When the patient has registered their wish to donate, it puts the specialist organ transplantation nurses, who have to have those difficult conversations with the relatives of the patient, in a better position. Therefore, I encourage people to register their wishes.

For me, having such conversations, along with education, is key. During the stage 1 process, I discovered from surveying my family and my staff team that all my family and my staff are on the organ donor register. I was quite chuffed to hear that, because no coercion was needed. My dad, who is 77, proudly pulled out his organ donor card to show me his evidence. He would be absolutely happy to give the gift of his heart, liver, lungs, kidneys, pancreas or even his eyes if they could save the life of someone or support their vision. If, in some terrible, tragic or traumatic circumstances, someone's life depended on the gift of any of those organs, he would be grateful to have the opportunity to make that gift.

Donors could be called superheroes because they have the power to save many lives with the use of their heart, their liver, their lungs, their two kidneys or their pancreas. We can all be superheroes. I am on the donor register, and I would be interested to know how many other superheroes we have in the chamber today.

I was a bit disconcerted by the conversation that I had with my nephews, one of whom is 14 and one of whom is 16. Neither of them has had a conversation about organ donation with any educator. The briefing from the Royal College of Physicians of Edinburgh says that it is particularly important that we provide education in tandem with the measures in the bill. One of my big asks is we engage with education on donation that is provided by schools and with ethnic minority communities. That engagement must be sustained as the bill progresses so that we can save lives in Scotland. We must make sure that people are able to opt in and to opt out, and that there is deemed authorisation. In that way, we will save lives.

15:54

Maurice Corry (West Scotland) (Con): It is my pleasure to speak in the debate on the bill today. The subject is certainly a challenging one for all of us. In the midst of grief over the loss of a loved one, organ donation is one of the most positive and life-changing actions that we can take. Playing a part in giving someone a second chance at life is a privilege. With that in mind, any legislation that alters how the process works needs to be carefully considered, and it must fully inform those whom it affects.

We have seen a rise in the number of organ donations in Scotland over the past 10 years. We can only imagine what organ donations mean for those living with kidney failure or a congenital heart defect and their families. It gives them a renewed outlook on what is possible. However, we have heard that although the number of organ donations in Scotland may be increasing, there are still many living in need of a transplant. The necessity of having more organ donors on the register is clear: over the past year, 27 people in the UK died while awaiting a heart transplant.

That is the area where the proposed legislation seeks to bring about change. By creating three options—opt in, opt out or deemed authorisation—the bill aims to encourage an all-important increase in organ donations in Scotland. I thank John Mason for his email, with his Christian angle on the matter. I found it very helpful and thought provoking as I spent a little time in church today before I came to the debate.

Deemed authorisation—in essence, presumed consent—has been successfully adopted in a number of countries. Indeed, of the top 10 countries in the world for organ donation rates, nine have adopted a similar presumed consent model. In the right circumstances, it can work.

Many people support organ donation but never get round to signing themselves up actively as donors, despite the best of intentions. Often, public support does not translate into actual donations. Deemed authorisation would help to tackle that problem. For many people, it produces the outcome that they may have intended and supported, but which they have not acted on.

The option of deemed authorisation or presumed consent also means that there is a higher chance of medical suitability. With a larger pool of potential donors, the likelihood of identifying a match is greater. We all want to see a rise in organ donations, and in principle the objective of the bill is right and well meant. It has the potential to be effective in leading to more successful donations.

I am pleased to see that there will be safeguards surrounding the change. For example, it is perfectly right that those under 16 or who are incapable of understanding the implications of deemed authorisation will not be automatically opted into organ donation upon their death. Those who have been a resident in Scotland for under a year will also be excluded from that pathway. The measures go some way towards ensuring that the bill is not a blanket change in legislation with no thought for potentially sensitive cases. Having a soft opt-in system solves the issues in cases in which the wishes of a deceased person were not made known before their death. In such situations, it maximises the use of potential donors.

However, although having three options—opt in, opt out and deemed authorisation—might be the right way forward, changing the law alone will not work. The bill should not be implemented without proper investment in organ donation awareness. There must be active engagement alongside the change in legislation.

First and foremost, I hope that there will be engagement with the families of the deceased, including—as I said to the minister—the executors of the deceased's estate, those with power of attorney and the Office of the Public Guardian.

The way in which families are approached and handled by organ donor professionals in the hours after the death of a loved one is important. A sensitive donor liaison team can make all the difference to a family's experience. With generally exemplary training, those teams can help to guide families' decisions—yet Scotland has the lowest family authorisation rate in the whole of the UK. For that reason, the proposed changes will not work unless families are consulted as part of the process. If loved ones are fully informed about what the changes mean, the transition to deemed authorisation will be much smoother. I hope that the bill will be considerate about and mindful of upholding the rights of the deceased as well as the rights of families. The Scottish Government needs to take into proper consideration the ethical concerns that can spring up from that balance.

Secondly, there must be engagement with the wider public, which can surely be done only if there is a strong emphasis on communication and awareness. We cannot take for granted the importance of having a public discussion on changes with such a subject. Without such discussion, how can we expect to see a noticeable rise in organ donations?

We have seen the benefits of the partnered visits conducted by the Scottish Fire and Rescue Service and Anthony Nolan to Scottish secondary schools. Through such visits, teenagers have been equipped to understand what organ donation really means and how they can sign up. Awareness campaigns can be the spark that encourages families to talk about their wishes. Like Emma Harper, I discussed the subject last night with my daughters and son and asked them for their views—they clearly supported the opt-in, opt-out approach. I am glad to say that half of them had donor cards—which I had not realised—and one of them was on the Anthony Nolan register, which I commend.

Organ donation awareness and communication need to be embedded at the root of our communities. In that way, people can understand how they can choose to express their wishes and the implications that their choice could have for their family. The reason why my children had

made their choice was because they had been told about the process at their secondary school, so the approach is working in the Argyll and Bute Council area.

Co-ordinating those efforts to make the handling of the process as efficient as possible but with the utmost consideration is in everyone's interests. Even so, I agree with Mike Rumbles, as I also have concerns about the written proof of the deceased's wishes being necessary to support the family's wishes at such a difficult time. However, I am advised that the required questionnaire is the safety mechanism that will be in place.

I welcome today's debate. We all want to see a rise in donation rates in Scotland, but for that to be possible, all sides must be listened to and taken into consideration. If legislating for a soft opt-out option is the way forward, the Scottish Government must ensure that that is done sensitively and with an effective and supportive infrastructure.

The Deputy Presiding Officer (Linda Fabiani): You must close, Mr Corry.

Maurice Corry: The proposed legislation cannot stand alone; it needs to be connected to increased awareness, communication and coordination.

16:01

Sandra White (Glasgow Kelvin) (SNP): I thank all the organisations, individuals and professionals who took part in the evidence sessions, the meetings and surveys that have proved to be so invaluable to our report. I also thank Mark Griffin and former MSP Anne McTaggart, who introduced a member's bill in the previous parliamentary session. Although the Health and Sport Committee at that time could not support the general principles of the bill, I believe that it has led to the much more comprehensive bill that we are looking at today at stage 1.

I will be perfectly honest: having supported the previous bill, I thought that I had learned a great deal about transplantation and organ donation, but I was very wrong. Having heard the evidence on the bill, I realise that the Human Tissue (Authorisation) (Scotland) Bill is much more complicated and comprehensive than I had thought. The subjects of the evidence included mandated choice, the rights of the individual, the gift element, the authorisation process, the rights of the family and their consent, post-transplant care and mental health. It is a huge and very comprehensive list.

I felt while hearing evidence to the committee that I was learning all the time. An area that I had known nothing about, and to which I paid special

attention, was pre-death procedures. I had never heard of them, so I will concentrate on them. During evidence taking, I was intrigued by the procedures, so I asked questions about them. The committee convener, Lewis Macdonald, mentioned the 2006 act and highlighted many points.

I think that I will take my glasses off, as I do not seem to need them today.

The bill creates two procedures—type A and type B—

"with further details ... contained in regulations. It is anticipated that type A procedures would be more routine".

The minister mentioned in his opening remarks that those are blood and urine tests. Those tests

"would be allowed to proceed under deemed authorisation or when the person has opted-in."

It is anticipated that type B procedures will be

"less routine including the administration of medication or more invasive tests. Regulations could also specify what requirements would apply to type B procedures and how they could be authorised. Deemed authorisation would not automatically apply to type B procedures."

The bill's policy memorandum states:

"In all cases where pre-death procedures may be undertaken, a decision will have been taken that the person is likely to die imminently and that, if the person is receiving life sustaining treatment, this will be withdrawn."

That is very complicated but very necessary. I found it intriguing that those things were going forward.

The stage 1 report says:

"During our informal meeting with families who have authorised donation, we asked their opinion on pre-death procedures. They expressed their discomfort of any invasive tests on relatives but accepted the notion of blood tests and other routine tests."

The subject is very sensitive and very important.

We questioned various experts, including Dr Empson, who confirmed that, although health professionals would not go through specifics with families for every blood test that was taken, families would be involved in respect of tests that help to certify death by neurological criteria—for example, to observe the brain-stem-death test taking place. As Dr Empson explained:

"When a potential donor is going down the route of donation, appropriate information is shared sensitively and compassionately with families."—[Official Report, Health and Sport Committee, 20 November 2018; c 18.]

That might answer some questions that have already been asked.

A lady who gave evidence had gained understanding through seeing the process. That was very brave of her, but she felt that her relative

had not suffered and so agreed to donation of organs. As I said, the issue is very complicated.

There are other pre-death procedures issues to do with the law and doctors. The Law Society of Scotland highlighted such issues.

"Doctors should be concerned with prolonging the life of the patient, rather than viewing them as a source of organs",

although that quotation is not from the Law Society's evidence. The Law Society also mentioned the Hippocratic oath, in which the first consideration is the health and wellbeing of the patient.

I thank the minister, as well. When he gave evidence to the committee, he reiterated the need for transparency to maintain a high degree of trust in donation. I know that the minister has accepted the committee's recommendation on the steps to inform families on pre-death procedures and the proposal to review procedures in five years. That is really important, because medical science moves on, so the approach might not be appropriate by then.

I am very supportive of the bill, and I thank everyone who gave evidence. It is a comprehensive bill, and I certainly learned a lot during its passage.

#### 16:07

Mark Griffin (Central Scotland) (Lab): The Human Tissue (Authorisation) (Scotland) Bill is an important piece of legislation, and the Government has my support for introducing it. I lodged a proposal for a member's bill to introduce the same system that the Government intends to introduce, and was grateful to the Health and Sport Committee for giving me permission to take that forward without consultation because of the extensive work that had already been done. I said at my appearance at committee that I would take forward my proposal only in the event of the Government's deciding not to. Therefore, I very much welcome the bill.

In the committee and in previous debates, I have spoken about my personal experience of the current organ donation system. I want now to talk about the huge impact that increasing the number of organs that are available for transplant could have on the lives of people who are on the transplant waiting list and their families.

Almost 12 years ago, a man received the phone call that he had been waiting for for more than 10 years. He was told that a transplant heart was available and that he should come into hospital to prepare for his operation. He had taken ill 10 years previously, and had struggled with the diagnosed heart condition ever since. His health gradually deteriorated all the time, there were regular

hospital admissions, and he lost the ability to work in his job as a welder or to take part in any physical activity at all.

That man and his family made the trip to the hospital and said their goodbyes that day, full of hope that the operation would lead to a much better quality of life. Unfortunately, that was not the case. After the operation, he was placed in intensive care as expected, but the hoped-for recovery just did not happen. That was not as a result of failure in the care that he received from the NHS consultants who carried out the operation, or from the intensive care nurses who sat vigilantly by his bedside 24/7 during the recovery period. The reason why he did not recover was that his liver, kidneys and other organs failed as a result of having had to work harder in the previous 10 years to compensate for the heart condition, and they just were not strong enough to cope with the operation.

A matter of days after the surgery, the man died at the age of just 47—he was a young man, given life expectancy in this country. He left behind a wife and a family of four children—two boys and two girls. His oldest child was 22 and the youngest was 13 when they lost their dad. Today, he would have been 59. He has missed the university graduations and weddings of his children, significant birthdays, anniversaries and the births of all his grandchildren. So many family milestones have been missed and are still to be missed.

It would be naive to expect everyone to survive a major operation such as a heart transplant, but it is common sense that, for the person to be given the best chance of survival, they have the operation as soon as possible after they have been placed on the transplant waiting list. That is where the bill becomes significant. If we can follow the lead of other countries around the world and implement a system of presumed consent, alongside a high-profile publicity campaign, we can boost the number of organs that are available for transplant, so that people will get access to operations sooner, and we can help to save lives. Even just one more organ donor from one tragic incident means many more saved lives.

I pay tribute to the *Evening Times*, the British Heart Foundation and Anne McTaggart for the fantastic work that they have all done in working towards an opt-out system. I also acknowledge the early adopters and drivers of the policy among Government party members, including Kenny Gibson, whose hard work in pushing for the change has been notable.

During the various campaigns, research has repeatedly shown—as others have said today—that although 90 per cent of people are in favour of organ donation, only just over half the population are on the organ donor register. If people are

willing to receive a donated organ, they should be similarly willing to donate.

The only thing that prevented me from registering as a donor years ago was my unwillingness, as a young man, to confront my mortality. That is a silly reason when we think about it, and we could overcome such things by having a system of presumed consent.

Some members will know whom I was speaking about earlier, and most others will probably have guessed that the reason why I have spoken so personally about organ donation is that the man whom I described was my dad, who was lost to me, my mum and my brother and sisters at such a young age. That is why I feel so strongly about the subject, why I support the bill, why I am speaking today and why I whole-heartedly support the Government in its ambition to introduce a system of presumed consent.

#### 16:12

Mike Rumbles (North East Scotland) (LD): I have been on the organ donor register for the past 20 years. When we passed the Human Tissue (Scotland) Act 2006, I was on the then Health Committee. In the stage 3 debate on the Human Tissue (Scotland) Bill, I said:

"The bill ... is perhaps one of the best bills that the Scottish Parliament will ever pass. It is good news for the families who are waiting for a transplant for their loved ones. I hope that, at decision time, the bill will be passed unanimously."—[Official Report, 2 February 2006; c 22985.]

The bill was passed almost unanimously, with the exception of the votes of four Scottish Socialist Party members. I noted in that debate that we had achieved more than 25 per cent of people in Scotland on the organ donor register. Now, 13 years later, we have more than 50 per cent of Scotland's population on the register.

The 2006 act has been a success. I understand that the Scottish Government now wishes to go further, so we have a bill before us that will change the system from opt in to opt out in order to achieve even more successful organ donations.

The Health and Sport Committee's report says:

"The overarching aim of the Bill is to increase the organ and tissue donation rate".

I could not agree more with that aim, and I will concentrate on that, because I do not believe that section 7 of the bill will achieve it.

The Minister for Public Health, Sport and Wellbeing said at the Health and Sport Committee:

"The current legislation and the proposed legislation are clear that the right to authorisation rests with the potential donor."—[Official Report, Health and Sport Committee, 27 November 2018; c 24.]

Unfortunately, that is not what section 7 says. It says that the deemed authorisation in section 7 does not apply if a person provides evidence to a health worker

"that would convince a reasonable person that"

the adult was unwilling for the transplant to take place. Why have those words been used instead of the wording in the current legislation, which states that

"the nearest relative may not give authorisation ... if the relative has actual knowledge that the adult was unwilling for any part of the adult's body ... to be used for transplantation"?

There is a real difference between those two approaches. In the bill, the evidential bar for the family of the deceased to confirm the wishes of the deceased is being raised unnecessarily. The family of the deceased will have to provide "evidence ... that would convince" about the wishes of the deceased. What sort of evidence does the new wording in the bill require in that regard? The bill is silent on that.

I acknowledge that the public health minister has said that the bill does not change the fact that the right to donation rests with the potential donor. However, that right has to be a real right. Again, I focus on the problems that the family would have in meeting the new evidential test about the wishes of the deceased, particularly if those wishes had been expressed to them only orally.

In summing up the stage 3 debate on the Human Tissue (Scotland) Bill, the then Deputy Minister for Health and Community Care, Lewis Macdonald, said:

"Our new system of authorisation, which is founded on honouring people's wishes, will mean that the person's own wishes are paramount."—[Official Report, 2 February 2006; c 22989.]

I could not agree more. I continue to believe—as, I hope, does Lewis Macdonald—that, if we are to get the uptake in organ donations that we need, we have to get the wording in section 7 of the Human Tissue (Authorisation) (Scotland) Bill right.

**Keith Brown:** Is the member saying that the rights of the donor—someone who is in full possession of their faculties, who has decided to donate—should be superseded, whatever evidential bar is set, by the family? I think that that is what he said.

**Mike Rumbles:** They certainly should not be superseded by the family—absolutely not. With the 2006 act, we said that we had to have a system in which the rights of the individual donor are paramount. That is the important thing.

The reason why I am so exercised about the words in section 7 is that, if those words remain in the bill, I am fearful that the legislation could end

up being counterproductive to achieving an increase in organ donations, which is what all of us in the chamber want.

In 2006, all the members of the Health Committee were concerned about the issues that had arisen at Alder Hey children's hospital, the Bristol royal infirmary and other hospitals, which had resulted in a loss of public trust; I know that the then Deputy Minister for Health and Community Care would acknowledge that. Indeed, we need only look at more recent incidents, such as the baby ashes scandal, to see that public trust is precious and that we must not put it at risk.

I make it clear that I want to vote for the bill at decision time. I am pleased to see that, in paragraph 35 of its report, the Health and Sport Committee agrees with me that,

"if the nearest relative, next of kin, or a longstanding friend is in possession of information regarding the deceased wishes on donation, this information could be taken into account".

That is marvellous. However, the problem is that that is not what section 7 of the bill says. It replaces the wording about "knowledge" of the wishes of the deceased with a requirement to provide "evidence ... that would convince" a health worker of those wishes. Why has that unnecessary change been made?

If the minister confirms in summing up a willingness to return at stage 2 to the language that is used in section 7 of the Human Tissue (Scotland) Act 2006, I will happily vote for the Human Tissue (Authorisation) (Scotland) Bill. If the new words about "evidence ... that would convince" remain in the bill, rather than the current words in the 2006 act about "knowledge", that would strike out one of the fundamental principles of the bill

I am with the Health and Sport Committee on this. In paragraph 10 of its report, the committee says:

"Deemed authorisation would apply when someone dies without making their decision on donation known, with their consent to donation being presumed unless their next of kin provided information to confirm this was against their wishes."

That is what the committee has said, and that is what I support.

**The Deputy Presiding Officer:** You must close, please.

Mike Rumbles: Knowledge is knowledge and evidence is evidence—there is a clear difference. I urge the minister to commit to using the word "knowledge" and not "evidence" in the bill. I want to vote for the bill, but before I can do that at decision time I need to hear a commitment from

the minister that he will look at changing the wording in section 7.

16:19

Kenneth Gibson (Cunninghame North) (SNP): Although this is a stage 1 debate, it is actually the culmination of decades of concerted campaigning by patients, medical professionals, third sector organisations, newspapers such as the Glasgow Evening Times, and, of course, many of my colleagues in the chamber today. Indeed, on 1 November 2012, I led a members' business debate on this issue. I am, therefore, delighted to contribute to this afternoon's debate and to support unequivocally the principles of the bill.

I recognise the excellent work that has been done by the Health and Sport Committee, and I thank the British Heart Foundation in particular for the excellent briefing that it circulated to members ahead of this afternoon's debate, which provided illuminating data on organ donation in Scotland. More important, I acknowledge the organisation's dogged and proactive support for soft opt-out over many years.

We should also, of course, acknowledge the sterling work of Anne McTaggart in the previous session of Parliament and, in this session of Parliament, the work that has been done by Mark Griffin, who gave a moving speech a few minutes ago.

As we know, there has been a significant shift in attitudes towards organ donation in Scotland over the years, and it is incredibly heartening that more than half—50.4 per cent—of the Scottish population are already registered to donate their organs or tissue after death, which is far higher than the UK average of 38 per cent. That shift has yielded positive results, with a 22 per cent drop in people waiting for transplants between 2008 and 2018. However, sadly, I am sure that many of us know someone who waited too long for an organ, or who is still waiting today. Indeed, we heard about such cases in the chamber earlier this afternoon.

At the end of 2018, 577 people in Scotland were waiting. Any reduction in that number, no matter how small, will be life saving. Having campaigned on this issue for many years, I was delighted when the commitment to introduce a soft opt-out system was included in the SNP Government's 2017-18 programme for government. Indeed, we could have passed a member's bill to legislate on the issue in the previous session of Parliament. I voted for it, but the majority of colleagues deemed that it was not robust enough to prevent unintended negative consequences.

The Scottish Government has fully consulted people working in donation and transplantation to

ensure that the proposed system will work not only on paper but in practice. The consultation shows that there is not only expert clinical backing for the bill, but that there is widespread public support for the principle of organ donation; that support needs to be translated into donor numbers, as there is a gap between the number of people who state that they would wish to donate organs and the number who join the organ donation register.

By creating a soft opt-out system, we can more easily capture the estimated 80 to 90 per cent of Scots who support organ donation. Unfortunately, family authorisation for organ donation in Scotland, at only 57 per cent, is the lowest in the UK. As Dr Sue Robertson, the deputy chair of the British Medical Association Scotland, said:

"if you ask people, nine in 10 will say that they would wish their organs to be donated. We are looking for that 40 per cent who have not opted in but who actually want their organs to be donated. Those are the people who we want to have that conversation with their families, because we know that they actually want their organs to be donated."—[Official Report, Health and Sport Committee, 13 November 2018; c 14.]

On that point, I heard what Alison Johnstone said earlier about specialist nurses, and I think that what she said was important.

Of course, the bill would introduce a soft opt-out system, meaning that it incorporates safeguards and conditions that might include seeking authorisation from a person's nearest relative in cases involving certain groups of people or certain circumstances. This is not about the wishes of family overriding the wishes of donors and, as the Minister for Public Health, Sport and Wellbeing, Joe FitzPatrick, has clarified, when the family are asked about donation,

"they will not be asked for their views; they will be asked about what they believe were the views of their deceased relative who is the potential donor."—[Official Report, Health and Sport Committee, 27 November 2018; c 24.]

There is strong evidence to suggest that a soft opt-out system can improve levels of family authorisation, with those who live in countries with opt-out legislation being between 27 and 56 per cent more likely to authorise donation of their relatives' organs. Indeed, that has been the case in Wales, where consent rates have risen by almost half, from 49 per cent in 2014-15 to the current level of 72 per cent.

Of course, medical suitability is key, because only 1 per cent of people die in circumstances that leave their organs suitable for medical use. Unfortunately, we cannot legislate for medical suitability of organs, so we must concentrate our efforts on areas in which we can make real change, such as increasing the number of potential donors and maximising family consent. In doing so, we will increase the pool from which

medically suitable donors can be found and increase the likelihood of patients being matched with suitable donors and getting off waiting lists.

**David Stewart:** The member is correct about the 1 per cent figure. However, does he share my view that, if we increased the number of medical care beds, that would allow the medical circumstance in which more organs would be available for transplantation?

**Kenneth Gibson:** Yes, I agree. I listened with care to what Mr Stewart said earlier. The bill is not a magic bullet, and other issues must be taken into account. As has been shown in Spain, for example, increasing intensive care beds makes a big difference.

As many members said, it is vital that the bill is accompanied by a co-ordinated campaign to raise public awareness and a concerted effort to make all sections of our diverse Scottish society aware of their rights. That is a key feature of the Health and Sport Committee's report on the bill. The committee recommends a high-profile public information campaign, including outreach sessions with minority groups and awareness raising with children, through appropriate methods. Lewis Macdonald covered that in detail. I agree wholeheartedly with that recommendation encourage the Scottish Government to take it forward.

The bill is simply the latest step towards driving a long-term change in attitudes towards organ and tissue donation in Scotland. It is an important step, which I wish that we could have taken many years ago.

#### The Deputy Presiding Officer: Please close.

**Kenneth Gibson:** In supporting the bill, we will be voting to increase the pool of viable organ donations and to improve and indeed save the lives of people in Scotland who are waiting on an organ. We are not stripping away individual choice; we are empowering the majority of people who support organ donation but might not have had the time or knowledge to formally register.

#### The Deputy Presiding Officer: Please close.

**Kenneth Gibson:** In death, our bodies would normally give the world little, but in donation, our bodies can give life and happiness to others for many years.

The Deputy Presiding Officer: Okay. I will have to cut the final two speeches in the open debate to five and a half minutes.

16:26

Tom Mason (North East Scotland) (Con): The issue before us is of unmistakeable importance.

Organ donation is a life-saving procedure for thousands of people every year.

More than 500 people in Scotland are waiting for a transplant, so we need to find ways to increase the pool of available donors and speed up the process of donation for more people.

With that in mind, I support the general principles of the bill and the incorporation of deemed authorisation into the current system. I think that the majority of people in Scotland will welcome proposals to create a soft opt-out system, as is confirmed by consultations by the Scotlish Government, the Royal College of Nursing and the British Heart Foundation.

A fundamental reason for introducing the bill is to put in place a system that will increase the pool of donors and thus the chances of someone on the transplant list getting a suitable organ in a shorter period. In the Health and Sport Committee's discussions on the matter, concerns were raised about the bill's ability to deliver on that aim. However, people were by no means unanimous in taking that view. The bill should be given the chance to progress, with such concerns addressed by the introduction of measures to ensure that it achieves its stated goal.

I also hope that, at the bill's subsequent stages, issues to do with the information that is available to the wider public about the organ donation programme will be addressed.

The Royal College of Nursing has asked for a public awareness campaign for at least a year before any change comes into effect, and the Royal College of Physicians asks for a parallel process of public education about organ donation and the infrastructure that is available to support families.

That is particularly important, given that 80 per cent of Scots support organ donation but only 52 per cent have signed up to the organ donor register. Getting people to support donation is an important first step, but it is vital to capitalise on their support and ensure that they put themselves forward and expand the number of potential donors.

The Law Society of Scotland noted that it would be extremely difficult if donations were to proceed against the wishes of the family. However, allowing families an effective veto over the previously expressed wishes of the potential donor would be contrary to the fundamental aim of the bill. At stage 2, the committee will have to consider how to balance those competing issues, to ensure that the legislation has legitimacy in the eyes of families and the wider public.

We must never lose sight of the human side of this issue and why it is so important. In 2014, one

of my constituents was taken into hospital with an extreme nosebleed. He was diagnosed with high blood pressure. By the end of the year, he had been diagnosed with total renal failure. Fortunately, he was suitable for peritoneal dialysis, which involved liquid transfer treatment up to four times a day and the requirement to have about two litres of chemical fluid attached to his stomach all the time.

That is not easy to say, and that relentless regime was not easy to cope with, day after day, with no end in sight. The only escape was a kidney transplant. In October 2015, my constituent learned that a prospective organ was available, only to find out that it was not suitable.

In 2016, there was the prospect of another kidney, but that was not a successful match either. Deep clinical depression threatened, mitigated only by the dedication of my constituent's family members. At last, at the end of 2016, a successful match was obtained, which allowed his life to get back to normal. So far, this kidney transplant has been successful, but there are signs that a viral infection is slowly destroying the kidney. Once again, donors will need to be found. For my constituent and the countless others in a similar situation, we are obliged to do all that we can to maintain a good supply of organ donors.

In 2017-18, more than 400 people across the UK died while waiting for a transplant. We have the clinical skills and expertise that are necessary; we just need to expand the pool of potential donors so that organs can be made available sooner. The public would, I think, support such a move, so let us move forward. Urgency is important, but so is getting the legislation right. It is with that in mind that I look forward to the bill receiving further consideration in committee and returning to the chamber for stage 3 in due course.

The Deputy Presiding Officer: Thank you for giving me some time back, Mr Mason. As the last of the open debate speeches, Mr Brown, you can have six minutes.

16:31

Keith Brown (Clackmannanshire and Dunblane) (SNP): I was about to ask whether I was allowed to donate half a minute of my time to other members, but I am grateful for getting it back.

The debate has been very good and almost entirely consensual. I am grateful to the members of the Health and Sport Committee. I was on the committee for a short time and I know that they went about their business extremely diligently, through quite a number of lengthy evidence sessions. Like other members, I was very impressed by the specialist nurses, particularly

when they did a role play of family members going through the medical and social history questionnaire. Obviously, that is at a very difficult time for families, but the questions were asked professionally, thoughtfully and with kindness.

I thank donors' families, whose evidence was about what were obviously very difficult circumstances. Even in that evidence session, there was some concern. One family member talked about the questionnaire and said that she would rather not have been part of that process. I cannot remember whether she said that she would rather that there was an opt-out, so that she would not be put in that situation, or whether the rights of the donors were evident and accepted, but she would have liked to have the process taken out of her hands.

The process is exhausting and extremely intrusive, and happens at a very difficult time. As one member said, relatives are sometimes questioned while the donor is still alive. I wonder whether there could be further scrutiny of the process. Would it be possible, for example, to ask the potential donor some of the questions, at an earlier stage? It is difficult for a son, daughter or mother to be asked about the sexual history of their relative. Could more medical tests be done on the person concerned, at that point or earlier? If we can find a way to reduce the intrusiveness of the questionnaire, that would help to increase donor figures.

There were other concerns. Some witnesses who were registered donors told the committee that if there was to be a soft opt-out, they would come off the register. They felt strongly about what they saw as a diminution of their rights if the state could go in and take organs from their body without them having taken any action to prevent it. That concern is out there and it worries me somewhat.

However, my main concern is the relatives' discounting of the wishes of the donor, who is the central person in all this. We heard that that happens time and again. We heard of instances in which people did not want to donate and did donate. We heard of many instances in which people wanted to donate, but the family vetoed it. The family veto exists, whatever some members have said. We heard time and again about family refusals—I think that another member said that there have been about 100 cases in which somebody in full possession of their senses and who knew what they were doing took a legally competent decision to donate, but their wishes were frustrated by someone, for their own reasons, which might be understandable. That person might not even have been a close family member. That should be a real concern to us all. We can imagine somebody who might benefit from, say, the donation of a heart, and somebody who has, in all conscience, taken the decision to donate their heart, and possibly other organs, and then that wish is frustrated by family members, and the person waiting on the heart does not get it. Kenny Gibson said that every one of these cases is crucial, and if we can increase donation by one it would be a tremendous achievement.

It is also true to say that we heard a lot of evidence about the feelings and wishes of the medical staff. The convener is quite right that it was said that medical staff cannot be expected to proceed with a donation when the families are expressly against it, or words to that effect—I do not want to put words in the convener's mouth.

I do not agree with that position. There are jurisdictions where the right of the donor to donate is what is respected. If the family members understand that well in advance—and I support all the work that has been suggested to make sure that there is a campaign so that people are much more aware of this-there should not be a family veto. The donor's right should be respected. Of course relatives, especially in that horrible set of circumstances, will have strong feelings, but it is my view that the person who is at least at that stage in possession of the organs should have the ultimate right over them. I would be grateful if the committee could look at a number of things—I have highlighted some of them-including evidence from some of the jurisdictions where they follow that path.

There is also an issue about the age at which people can decide about donation. I think that the bill proposes that people can decide from the age of 16. That would include 16 and 17-year-olds, a situation that has no counterpart in England and Wales. That might throw up some issues in terms of donation. Organs can go across boundaries within the UK and we have not heard much about that.

Those are some of my concerns. The Health and Sport Committee has done a tremendous job and I hope that the committee and the Government will listen to those concerns as the bill progresses. At this stage, I agree that the intentions of the bill are good: it tries to achieve what we all want, which is more viable organs going to more people who need them. For that reason, as things stand and at this stage, I am willing to support the general principles of the bill.

16:36

David Stewart (Highlands and Islands) (Lab): This has been an excellent debate, with well-informed and thoughtful contributions from across the chamber.

As we have heard from, I think, all members, this is crucial legislation. How do we raise the level of organ donations in Scotland to match the needs of those desperately awaiting transplantation? As we have heard, tragically, 426 patients died in the UK last year while on the transplant list or within one year of removal from it.

We have heard that Scotland has the highest percentage of people on the organ donor register in the UK but the lowest actual rate of organ donation per million people. The key issue is the gap between those who wish to donate organs and the number who go on to join the organ donor register. Around 80 per cent of people support donation but only 52 per cent have signed up to the register. In simplistic terms, the purpose of the bill is to bridge the divide—to encourage those who support organ donation but have not registered to have their wishes respected.

My friend Gary is in his mid-50s and lives in Glenrothes in Fife. Nearly two years ago, he was given the gift of life by a crucially needed heart transplant. Prior to that, he was on the transplant list for 12 months and had a pacemaker. He had been slowly deteriorating, and without the transplant he would have died. When I spoke to Gary at the weekend, he said that he could not praise enough the dedicated support of the medical and nursing staff at the Golden Jubilee national hospital. He said to me, "It was a matter of life or death."

We know that international evidence and best practice are crucial elements of the principles underpinning the bill. We know from background research by the British Heart Foundation that people living in countries with a soft opt-out are 17 to 29 per cent more willing to donate their organs.

In general terms, a soft opt-out means that unless the deceased expressed a wish in life not to be an organ donor, consent will be assumed. As we heard from a number of speakers, of the top 10 countries in terms of donors per million, nine have an opt-out system. That brings us to Spain, on which I made a couple of interventions earlier. Spain leads the world league table for organ donations, and we took evidence at the Health and Sport Committee on why Spain is successful. three main reasons: comprehensive networks of transplant ordinators, a donor detection programme and greater provision of intensive care beds. Even if the UK family refusal rate was reduced to a level that was similar to that in Spain—from 40 per cent to 15 per cent—the UK donation rate would still be only half of that which Spain enjoys. Could the minister comment on that in his closing speech?

We should bear it in mind that, as this is not a zero-sum game, we must also concentrate on increasing the number of intensive care beds to allow for the increased numbers of organ donation patients who will require such care.

Although Labour will support the bill, it considers that some issues will be worth further discussion, such as the position of adults with incapacity, on which we heard from Keith Brown, and the variable age of children's capacity to consent—it is 16 in Scotland and 18 in Wales—which was referred to by many members.

There are issues regarding the rights and obligations that affect decision making on organ donation. As we have heard—this is putting matters in simple terms—the three routes to a decision are opt-in, opt-out and deemed authorisation, which is a passive form of decision. However, as the minister will know, the Law Society of Scotland and others have raised legal questions about those routes, which he might wish to consider.

First, is deemed authorisation consistent with the Supreme Court's ruling on informed consent in the case of Montgomery v Lanarkshire Health Board? Secondly—this issue is perhaps more important and I am sure that the minister will already have information from his advisers on itis the bill consistent with the European convention on human rights, and specifically the case of Elberte v Latvia of 2015? For members who are not familiar with that case, tragically, Mrs Elberte's husband died in a car crash, leaving no record of his wishes on organ donation. However, his tissues were used, and the court later ruled that that was a violation of article 8 of the ECHR. As the minister will know, the bill will have to be deemed consistent with the ECHR before it can gain the Presiding Officer's approval. What assessment has there been of whether, in practice, medical professionals will take into account the wishes of a donor's family, irrespective of the provisions of the bill? Should the law cover that? Will transplant units have the capacity to cope with the increase in donations that I mentioned earlier?

I am conscious of the time, so I will conclude by saying that Labour supports the general principles of the bill. However, we have also highlighted areas in which its provisions could be strengthened. I agree with Andrew Tickell of Glasgow Caledonian University, who said, in response to the Scottish Government's consultation, that

"failure to put the rights of family members and duties of doctors on a statutory footing appears even more problematic".

Therefore, I strongly suggest that the Scottish Government looks again at the question marks around the bill's compliance with article 8 of the European convention on human rights.

Notwithstanding that, the bill is a vital piece of legislation that will improve Scotland's position in the international league table of organ donation and might mean the difference between life and death for the many Scots who are—like my friend Gary once was—desperately in need of life-saving organ donations. As Kahlil Gibran once said:

"You give but little when you give of your possessions. It is when you give of yourself that you truly give."

#### 16:42

**Brian Whittle (South Scotland) (Con):** I am pleased to have the opportunity to close the debate on behalf of the Conservatives.

As has been mentioned, the debate has been very consensual, which is hardly surprising. It has shown that we all want to increase organ and tissue donation rates. However, a number of questions have been raised.

As has been ably demonstrated by the contributions of members from across the chamber, the bill has instigated much thought and deliberation. Given its aim, which I have just mentioned, members might imagine that it will be commended by most of us, and that its passage will be straightforward and smooth. Consequently, Scottish Conservatives will support it at stage 1. However, in doing so, we must recognise the level of investigation and evidence taking that the Health and Sport Committee has undertaken and the discussion that that initiated among its members. Some issues were revealed then and have been revealed again in today's debate.

I think that my fellow committee members would agree that in some cases, the evidence that was taken was as comprehensive as it was uncomfortable to hear. Many members, including Miles Briggs, Alison Johnstone and Alex Cole-Hamilton, have mentioned the specialist nurses and their demonstration of how they do their incredible work, in which they acted out an intervention by means of role play. None of us failed to be moved by what we heard in that session. We learned that up to 300 questions can be asked of family members in those incredibly difficult circumstances when they have just lost a loved one.

The minister highlighted that one reason why it is so important to increase organ donation is that only about 1 per cent of people meet their end in a way that means that donation is possible. Maurice Corry reminded us that people who are on an organ waiting list die while waiting for donation, so the bill is incredibly important.

Throughout the Health and Sport Committee's consideration of the bill, Keith Brown was exercised by the rights of organ donors. He consistently raised that issue and he has done so

again today. On the face of it, I agree with Mr Brown that if someone decides to donate their organs, their wishes should be paramount. However, as Miles Briggs highlighted, the wishes of the family will be taken into account and healthcare professionals will not go against those wishes. Because the family has to fill in a questionnaire before organs can be donated, if they do not want to take part in the questionnaire, that will in essence supersede the wishes of the individual. That is a conundrum. I recognise Keith Brown's campaign to highlight the rights of the deceased, and we will continue to discuss how to get round that issue. One thing that we can do is to encourage discussion among family members long before we get to the stage of donation, so that the donor's wishes are understood completely by the family.

Dave Stewart raised the situation in Spain and the comparison between it and Scotland. We have to be careful with that, because we are not comparing apples with apples. As he rightly said, Spain has a different system from ours, with intensive care beds in every hospital and therefore a capacity that we currently do not have. In conjunction with the bill, it is important that we consider the capacity in Scotland and how many more donors we can take. There is an idea that presumed consent is a magic bullet, but it will not necessarily increase organ donation in the way that we would like.

I have been exercised quite a lot by the fact that there is a significant difference between actual consent—a stated opt-in—and deemed consent. My view is that we should ensure that the opportunities for people to take the stated position are made widely available. Ensuring awareness of the bill is crucial. It was not until I became a member of the Health and Sport Committee that I was made aware that I was one of the 40 per cent who would donate organs but who have not consented, and it was only because I happened to move house and had to change my driving licence that I got the opportunity to sign up. It is a very simple process that takes seconds. We need to be cognisant of that and ensure that the opportunity is as available as possible.

I want to mention Mark Griffin's and Anne McTaggart's personal contribution to the cause. They have both been influential in bringing the debate to the stage that we are now at.

I believe that the bill in itself will not necessarily lead to an increase in organ donation. However, the scrutiny of the bill by the Health and Sport Committee and the subsequent awareness raising will create an environment in which individuals can speak about the issue and consider their situation. It is the Scottish Conservatives' view that, along with the bill, it is essential that we have a

continuing awareness-raising campaign that encourages a clear decision by the 40 per cent of the population who are yet to make their views clear.

It is said that 50 per cent of marketing works, but we are just not sure which 50 per cent. If we raise awareness and encourage people to have such conversations and take a position, and if that ultimately leads to an increase in organ donation, which could save many lives, the bill will have been worth it.

**The Deputy Presiding Officer:** I call Joe FitzPatrick. Nine minutes or so, minister, will take us up to decision time.

#### 16:49

Joe FitzPatrick: I thank members for an interesting debate on a complex and sensitive subject. There are differing views on how we get there, but I think that everyone in the chamber is of the view that we want to increase donations. The evidence suggests that there is no one solution to increasing organ and tissue donation, but I am sure that we all agree that it is important that we do what we can—and that we take the initiative to do so.

It is hoped that, over the long term, deemed authorisation will continue to change the culture around support for organ and tissue donation. I thank the Delegated Powers and Law Reform Committee, the Finance and Constitution Committee and, in particular, the Health and Sport Committee for their work in informing the Parliament's consideration of the bill. I also add my thanks to those of other members to the many organisations that have provided briefings, which we have all found helpful.

I will use my time to pick up on as many of the issues that members raised during the debate as time permits, and I will follow up on others in writing if I do not quite get there. I thank members who raised personal experiences today, which I think is always particularly helpful. Miles Briggs talked about Millie, Mark Griffin made a very moving speech about his father and Emma Harper talked about her experience as a nurse. All those experiences are important in understanding what the bill means to so many people.

Lewis Macdonald talked about the on-going process of culture change and awareness raising around organ and tissue donation, which is important in encouraging more people to support donation. Many members have said that an optout system alone is not the answer to making the change; it has to be part of a package of measures—measures that we already have—in order to make a real impact.

Maurice Corry, Emma Harper and Brian Whittle talked about an important point that I think will make a big difference, which is about people making a decision but also discussing that decision with their family. I know that the progress of the bill has taken longer than some members would have liked, but I hope that the process has got more people talking about donation, and talking about it to their families, which will make the donation process easier.

Before I touch on some of the points that I need to respond to, I recognise the important point that Alex Cole-Hamilton made about living donors. I echo the praise that he and Keith Brown, and possibly others, gave to our specialist nurses, who, along with others in the donation and transplantation community, do a fantastic job.

A number of members—Miles Briggs, Alison Johnstone and Keith Brown in particular—talked about the role of families. Families will remain critical to the process in communicating the views of the potential donor and in providing information about them to ensure the safety of organs and tissue for transplantation. Families will also continue to perform an authorisation role in certain circumstances. Any potential donor's family members would be fully involved in the process.

**David Stewart:** I reinforce that I support the bill, as the minister knows, but I think that there are issues around article 8 of the European convention on human rights and, in case he has forgotten, I stress again the relevance of the case of Elberte v Latvia in the European Court of Human Rights. I am sure that the minister has his lawyers working on that test case.

Joe FitzPatrick: I need to make progress, but the member raises one of the points that I was going to cover. We are content that the bill is compliant with article 8. There was a specific issue in the Elberte v Latvia case, the outcome of which turned on its own particular facts and circumstances. The issue was the quality of the Latvian organ donation legislation, which gave family members a right to object to donation but provided no mechanism for that right to be given effect to. The case involved a very different set of processes. If we have learned anything from the case, it is that we need to make it clear that the bill is about the rights and the views of the person who would be making the donation. It is an important point and we should learn lessons from other countries, but I am confident that the bill team has learned those lessons.

Keith Brown spent some time talking about his concern that there is, in effect, a family veto in some cases. I make it clear again that authorisation is for the person who makes the donation, but we need to remember that losing a loved one is always a very difficult time for

families. The current system deals with the issues sensitively, and that will continue under the new system. The principle behind the proposed system, as with the current system, is to give effect to the donation decision that the person made in life, but we also need to be mindful that donation happens at a distressing time for the family, so it is right that clinicians are able to respond to that.

Sandra White talked about pre-death procedures, and we discussed with the committee whether there is a better term. However, it is important that our transplant system be transparent, and the term "pre-death procedures" describes what those procedures are about. The inclusion of those provisions in the bill means that it not only sets out a framework for carrying out the procedures that will be able to respond to change but brings transparency to the donation process by letting people know what they are agreeing to. We have made it clear that, if there are changes to the process, we will come back to the Parliament for them to be approved under the affirmative procedure.

A large number of members, including Lewis Macdonald, Alison Johnstone, Emma Harper, Kenneth Gibson and, I am sure, others, talked about the need for awareness raising, as did the committee. The Government is clear that that is an important part of taking the matter forward. Indeed, it is essential if a soft opt-out system is to work. As was set out in the consultation, the intention is to have a high-profile awarenessraising campaign over at least 12 months before the introduction of the new system and regular campaigns after implementation in order to maintain awareness. That is a crucial part of the safeguards that will underpin the system, which are aimed at ensuring that people will not become donors if that is not what they want, and that they will become donors if that is what they want. We will work with a range of groups, including disability groups and faith groups, to research, develop and test clear and accessible information, which will always be available in a range of languages.

Alex Cole-Hamilton talked about support for families, which is a very important subject. NHS National Services Scotland is reviewing the provision of psychological support across all our nationally commissioned specialist services, including organ transplantation, to ensure that appropriate provision is in place, and the Scottish Government understands that the review will be completed later this year.

**Alex Cole-Hamilton:** Will the minister take an intervention?

**Joe FitzPatrick:** I apologise, but I have to make progress in order to respect other members who took part in the debate.

Miles Briggs and David Stewart talked about infrastructure. The 2008 UK organ donation task force report considered the introduction of an optout system but prioritised improvements in infrastructure as it was considered that they would have the greatest impact on donation at that time. Throughout the task force's work and the subsequent Scottish plan, we have seen significant developments around donation and transplantation infrastructure over the decade. However, I recognise—as I recognised in my response to the committee—that there is an ongoing commitment to supporting measures, including infrastructure, to increase donation.

I move on to a point that was raised by Mr Rumbles in particular, and I think by Maurice Corry, too. We are satisfied that the wording in the bill is not overly burdensome, but I am happy to discuss that further with Mr Rumbles to make sure that I fully understand his point. I hope that, with officials, I will be able to allay his concerns. I offer a serious discussion to make sure that we all understand what the bill is trying to do. The approach in the bill is broadly similar to that in the legislation in Wales, and we are not aware of the issues that Mr Rumbles is concerned about arising there. As we have heard, our specialist nurses are highly skilled in having conversations with families and the provisions largely mirror the current practice around conversations exploring a loved one's views with family members. As that is taken forward, guidance will be produced by NHSBT and the Scottish National Blood Transfusion Service, but I am keen to have that discussion with Mr Rumbles.

I acknowledge and thank the Scottish donation and transplant group, which advises the Scottish Government on donation transplantation matters, for its assistance in the development of the bill. I again pay tribute to everyone who has contributed to the debate today, everyone who has donated in the past and every family that has supported those donations. Through such selfless acts, lives are saved and improved. I hope that the bill will lead to further increases in donation to save more lives, and I offer any such progress as a tribute to all those who have donated in the past.

Members have raised several issues during the debate. I will respond in writing to members whose issues I have not managed to cover. If members want to discuss particular issues to ensure that the most robust bill goes through stage 2 and into stage 3, I will be happy to have those discussions. I thank all colleagues for taking part in what I think is a very important debate.

# Human Tissue (Authorisation) (Scotland) Bill: Financial Resolution

### 17:01

**The Presiding Officer:** The next item of business is consideration of S5M-15594, on the financial resolution for the Human Tissue (Authorisation) (Scotland) Bill.

### Motion moved,

That the Parliament, for the purposes of any Act of the Scottish Parliament resulting from the Human Tissue (Authorisation) (Scotland) Bill, agrees to any expenditure of a kind referred to in Rule 9.12.3(b) of the Parliament's Standing Orders arising in consequence of the Act.—[Derek Mackay]

# **Decision Time**

#### 17:01

**The Presiding Officer:** The first question is, that motion S5M-16001, in the name of Joe FitzPatrick, on the Human Tissue (Authorisation) (Scotland) Bill, be agreed to. Are we agreed?

Members: No.

The Presiding Officer: There will be a division.

#### For

Adam, George (Paisley) (SNP)

Adamson, Clare (Motherwell and Wishaw) (SNP)

Allan, Alasdair (Na h-Eileanan an Iar) (SNP)

Arthur, Tom (Renfrewshire South) (SNP)

Baillie, Jackie (Dumbarton) (Lab)

Baker, Claire (Mid Scotland and Fife) (Lab)

Ballantyne, Michelle (South Scotland) (Con)

Bowman, Bill (North East Scotland) (Con)

Briggs, Miles (Lothian) (Con)

Brown, Keith (Clackmannanshire and Dunblane) (SNP)

Burnett, Alexander (Aberdeenshire West) (Con)

Cameron, Donald (Highlands and Islands) (Con)

Campbell, Aileen (Clydesdale) (SNP)

Carlaw, Jackson (Eastwood) (Con)

Carson, Finlay (Galloway and West Dumfries) (Con)

Chapman, Peter (North East Scotland) (Con)

Coffey, Willie (Kilmarnock and Irvine Valley) (SNP)

Cole-Hamilton, Alex (Edinburgh Western) (LD)

Constance, Angela (Almond Valley) (SNP)

Corry, Maurice (West Scotland) (Con)

Crawford, Bruce (Stirling) (SNP)

Cunningham, Roseanna (Perthshire South and Kinrossshire) (SNP)

Denham, Ash (Edinburgh Eastern) (SNP)

Dey, Graeme (Angus South) (SNP)

Doris, Bob (Glasgow Maryhill and Springburn) (SNP)

Dugdale, Kezia (Lothian) (Lab)

Ewing, Annabelle (Cowdenbeath) (SNP)

Ewing, Fergus (Inverness and Nairn) (SNP)

Fabiani, Linda (East Kilbride) (SNP)

Fee, Mary (West Scotland) (Lab)

Findlay, Neil (Lothian) (Lab)

Finnie, John (Highlands and Islands) (Green)

FitzPatrick, Joe (Dundee City West) (SNP)

Fraser, Murdo (Mid Scotland and Fife) (Con)

Freeman, Jeane (Carrick, Cumnock and Doon Valley) (SNP)

Gibson, Kenneth (Cunninghame North) (SNP)

Gilruth, Jenny (Mid Fife and Glenrothes) (SNP)

Golden, Maurice (West Scotland) (Con)

Gougeon, Mairi (Angus North and Mearns) (SNP)

Grant, Rhoda (Highlands and Islands) (Lab)

Gray, Iain (East Lothian) (Lab)

Greer, Ross (West Scotland) (Green)

Griffin, Mark (Central Scotland) (Lab)

Halcro Johnston, Jamie (Highlands and Islands) (Con)

Hamilton, Rachael (Ettrick, Roxburgh and Berwickshire) (Con)

Harper, Emma (South Scotland) (SNP)

Harris, Alison (Central Scotland) (Con)

Harvie, Patrick (Glasgow) (Green)

Hepburn, Jamie (Cumbernauld and Kilsyth) (SNP)

Johnson, Daniel (Edinburgh Southern) (Lab)

Johnstone, Alison (Lothian) (Green)

Kelly, James (Glasgow) (Lab)

Kerr, Liam (North East Scotland) (Con)

Kidd, Bill (Glasgow Anniesland) (SNP) Lamont, Johann (Glasgow) (Lab) Lennon, Monica (Central Scotland) (Lab)

Leonard, Richard (Central Scotland) (Lab) Lochhead, Richard (Moray) (SNP)

Lockhart, Dean (Mid Scotland and Fife) (Con)

Lyle, Richard (Uddingston and Bellshill) (SNP)

MacDonald, Angus (Falkirk East) (SNP)

MacDonald, Gordon (Edinburgh Pentlands) (SNP)

Macdonald, Lewis (North East Scotland) (Lab)

MacGregor, Fulton (Coatbridge and Chryston) (SNP)

Mackay, Derek (Renfrewshire North and West) (SNP) Mackay, Rona (Strathkelvin and Bearsden) (SNP)

Macpherson, Ben (Edinburgh Northern and Leith) (SNP)

Martin, Gillian (Aberdeenshire East) (SNP)

Mason, John (Glasgow Shettleston) (SNP)

Mason, Tom (North East Scotland) (Con)

Matheson, Michael (Falkirk West) (SNP)

McAlpine, Joan (South Scotland) (SNP)

McArthur, Liam (Orkney Islands) (LD)

McDonald, Mark (Aberdeen Donside) (Ind)

McKee, Ivan (Glasgow Provan) (SNP)

McKelvie, Christina (Hamilton, Larkhall and Stonehouse)

McMillan, Stuart (Greenock and Inverclyde) (SNP)

Mitchell, Margaret (Central Scotland) (Con)

Mountain, Edward (Highlands and Islands) (Con)

Neil, Alex (Airdrie and Shotts) (SNP)

Paterson, Gil (Clydebank and Milngavie) (SNP)

Rennie, Willie (North East Fife) (LD)

Robison, Shona (Dundee City East) (SNP)

Ross, Gail (Caithness, Sutherland and Ross) (SNP)

Ruskell, Mark (Mid Scotland and Fife) (Green)

Russell, Michael (Argyll and Bute) (SNP)

Sarwar, Anas (Glasgow) (Lab)

Scott, John (Ayr) (Con)

Simpson, Graham (Central Scotland) (Con)

Smith, Liz (Mid Scotland and Fife) (Con)

Smyth, Colin (South Scotland) (Lab)

Somerville, Shirley-Anne (Dunfermline) (SNP)

Stevenson, Stewart (Banffshire and Buchan Coast) (SNP)

Stewart, Alexander (Mid Scotland and Fife) (Con)

Stewart, David (Highlands and Islands) (Lab)

Stewart, Kevin (Aberdeen Central) (SNP)

Sturgeon, Nicola (Glasgow Southside) (SNP)

Todd, Maree (Highlands and Islands) (SNP)

Tomkins, Adam (Glasgow) (Con)

Torrance, David (Kirkcaldy) (SNP)

Watt, Maureen (Aberdeen South and North Kincardine)

(SNP)

Wells, Annie (Glasgow) (Con)

Wheelhouse, Paul (South Scotland) (SNP)

White, Sandra (Glasgow Kelvin) (SNP)

Whittle, Brian (South Scotland) (Con)

Wightman, Andy (Lothian) (Green)

Yousaf, Humza (Glasgow Pollok) (SNP)

Rumbles, Mike (North East Scotland) (LD)

#### **Abstentions**

Beattie, Colin (Midlothian North and Musselburgh) (SNP) Grahame, Christine (Midlothian South, Tweeddale and Lauderdale) (SNP)

The Presiding Officer: The result of the division is: For 107, Against 1, Abstentions 2.

Motion agreed to,

That the Parliament agrees to the general principles of the Human Tissue (Authorisation) (Scotland) Bill.

The Presiding Officer: The final question is, that motion S5M-15594, in the name of Derek Mackay, on the financial resolution for the Human Tissue (Authorisation) (Scotland) Bill, be agreed

#### Motion agreed to,

That the Parliament, for the purposes of any Act of the Scottish Parliament resulting from the Human Tissue (Authorisation) (Scotland) Bill, agrees to any expenditure of a kind referred to in Rule 9.12.3(b) of the Parliament's Standing Orders arising in consequence of the Act.

The Presiding Officer: That concludes decision time. We will take a few moments before the next item of business to allow members and ministers to change seats.

# **LGBT History Month**

The Deputy Presiding Officer (Christine Grahame): The final item of business is a members' business debate on motion S5M-15694, in the name of Jenny Gilruth, on LGBT history month. The debate will be concluded without any questions being put.

#### Motion debated,

That the Parliament welcomes the 13th LGBT History Month; notes that this is marked every February across Scotland with events that celebrate LGBT culture and history and that consider the future of activism; acknowledges that the theme for 2019, Catalyst: 50 Years of Activism, recognises the 50th anniversary of the Stonewall uprising in New York City; understands that the events at Stonewall spread to several other cities in the United States and sparked the modern equal rights movement for LGBT people around the world; welcomes the efforts and achievements by the Fife-based LGBT charity, Pink Saltire, and wishes all of the groups celebrating and marking the month every success with their events and ongoing endeavours.

### 17:04

Jenny Gilruth (Mid Fife and Glenrothes) (SNP): I am grateful for the opportunity to lead this members' business debate on LGBT history month. It is also a privilege to do so in a Parliament that Professor Andrew Reynolds of the University of North Carolina has described as

"the gayest Parliament in the world."

I am delighted to see that the Minister for Older People and Equalities, Christina McKelvie, will respond to the debate, as she has always been a true ally of the LGBT community.

"Who controls the past controls the future: who controls the present controls the past."

That was George Orwell, writing in the novel "Nineteen Eighty-Four". In the year of the title of that book, Chris Smith, the Labour member of Parliament for Islington South and Finsbury, became the first openly gay MP, 10 years after Maureen Colquhoun, the MP for Northampton North, came out as the first lesbian MP. The year before I started school, in 1989, the then Prime Minister, Margaret Thatcher, introduced section 28 of the Local Government Act 1988, which stated:

"A local authority shall not ... intentionally promote homosexuality or publish material with the intention of promoting homosexuality"

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"promote the teaching in any maintained school of the acceptability of homosexuality as a pretended family relationship."

That was to remain the case until the year 2000, when I turned 16. For all but my final year at school, my teachers were told not to teach about

being gay. They were not to promote it as being acceptable. Being gay was wrong, and the system enshrined it in law.

Thankfully, we now live in more enlightened times. Back in 2000, who would have thought that the Scottish Parliament would back laws to create equal marriage, to support inclusive education in our schools—which is the absolute antithesis of section 28—or to pardon gay men and, importantly, apologise to them for their ever being criminalised just because of whom they loved? It is undoubtedly the case that we live in better times.

However, I wonder whether, as the Prime Minister braced herself for an impromptu game of pool with the Italian Prime Minister on Sunday night, she paused to consider Mohamed al-Gheiti, a television presenter who was charged with promoting homosexuality, fined 3,000 Egyptian pounds and sent to prison for a year last month? Perhaps she had a glass of prosecco with the Italian Prime Minister after the TV cameras had left. I wonder whether Giuseppe Conte mentioned his minister for families, Lorenzo Fontana, who was against civil unions, the law on which Italy passed in 2016, because—he said—

"next they will ask to marry dogs."

I am not convinced about our Prime Minister's commitment to the LGBT community, because she already leads a Government that is propped up by the Democratic Unionist Party.

If the history of the LGBT community from the time of Margaret Thatcher to the time of Theresa May has taught us anything, it has taught us that our activism must continue. That is why the theme of this year's LGBT history month—"Catalyst: 50 years of activism"—is so important. In my constituency, Glenrothes high school is the living embodiment of that activism. Staff in the school have been trained to raise awareness of lesbian, gay, bisexual, transgender and intersex issues and their impact on pupils. The school is celebrating LGBT history month through displays and presentations around the school, and, within departments, subject-specific LGBT content is being taught. Added to that, pupils have been delivering assemblies on homophobic, biphobic and transphobic bullying. Things have definitely changed for the better in our schools.

I remember, 10 years ago, attending an inservice day in this city that was focused on discrimination in the classroom. It was around the time of the Stonewall campaign "Some people are gay. Get over it!" It was also not that long after the BBC Radio 1 presenter Chris Moyles had attracted controversy by describing a mobile phone ringtone as "gay". He said,

"I don't want that ringtone. That's gay"

live on air. I remain unsure about how a ringtone can have a sexuality, but what Moyles's intervention did was spark a debate about the use of the word "gay" pejoratively, which was acceptable practice when I was at school and in the early days of my teaching. Indeed, I was working in a profession whose members had been instructed-in law-not to discuss sexuality with pupils in any way, shape or form. They were not used to calling it out, and many did not know that they could. That is why the work of the time for inclusive education campaign transformational in Scotland's schools over the current parliamentary session alone.

The TIE campaign achieved its campaign goal last November, when the Scottish Government fully accepted the recommendations of the LGBTI inclusive education working group. Throughout February—LGBT history month—the TIE campaign has been championing LGBT icons every day. One of those icons is fellow Fifer and former paraswimmer, swimming coach and triathlete Stefan Hoggan. Ahead of today's debate, he told me:

"LGBT History month means so much to me because it is a way for me to celebrate the hard work and sacrifice our community has gone through in the past—so that I can marry the man I love in the present. As a community we need to celebrate this month to make sure that young people today know what our community had to go through only a short 25 years ago."

Stefan is right—we should celebrate. Almost exactly a month ago, I was delighted to host Fife's Pink Saltire in the Scottish Parliament at a reception to mark LGBT history month. It was a particularly powerful event, at which people shared their personal stories of what LGBT history month meant to them. They included a couple from Fife, a student from Dundee and a transgender woman. They had all fought battles, but they were all activists.

# George Orwell told us that

"who controls the present controls the past."

The same writer also used the words "nancy" and "pansy" in his disdain for what he called "the pansy Left" and "Nancy poets". I hope that the *Daily Record* would not today print the headline

"Gay sex lessons for Scots schools"

as it did in 2000. The *Daily Mail* was happy to run with the warning

"Gay rights lessons in all schools"

in November last year. Time has moved on, but ingrained prejudice remains. It may be 2019, but I still cannot marry my girlfriend in the church I was brought up in. If I had a boyfriend, that love would be welcomed.

LGBT history month is about celebrating our history, but we should never seek to shy away from the darkness that history also tells us about. From section 28 and criminalising men just for whom they loved to a seemingly harmless round of pool, the need to challenge homophobia, biphobia and transphobia has never been greater.

We should celebrate the lives of the LGBT icons who lived and fought battles before our time, but we should also commit to that enduring legacy of activism and work to be the catalysts for LGBT equality every month of the year, remembering that we control the present.

17:10

Gillian Martin (Aberdeenshire East) (SNP): I thank my friend and colleague Jenny Gilruth for securing this debate on an issue that I feel pretty strongly about. The reason for that is that I want to express my solidarity with people who feel erased from history, because history as written does not give voice to all the influencers and agents of change.

No group is more erased than gay women. I certainly would not claim any right to speak on their behalf; rather, I want to express my long-felt solidarity with gay women in particular, who are woefully underrepresented in culture and history.

I feel this about women in history in general. It is difficult to find key women who changed their world, but it is doubly difficult to find gay women who did so, because history has just not been written by women or gay women. Stories of those catalysts need to be told and brought into the main stream.

When talking about women in elected positions, I often use the phrase, "If you can't see it, you can't be it". In the case of young women realising their sexuality, if they do not see it, they may think that they have to hide it. The mainstreaming of LGBT characters and specific films, television series and literature recognising the sexuality of historic figures, and the unearthing of the stories of LGBT figures in history, are epically important ways of ensuring a society that does not discriminate and are a platform for ensuring that our telling of history reaches a truth that includes every agent of change. If the catalysts who fought for LGBT rights are not agents of change, who is?

I will use the rest of my time to talk about the importance of cinema in rebalancing gay women's erasure from history and reflecting history from the perspective of gay women. I am a former film student, so forgive me for indulging myself.

Sadly, many of the films that people have heard of detailing gay female relationships were directed by men—"Blue is the Warmest Colour" springs to

mind, as does "Carol", which, although based on the work of the lesbian Patricia Highsmith, was directed by Todd Haynes. I cannot think of many English language films in which the protagonist is a gay female of significance. There is one in the Swedish language about Queen Christina of Sweden, but surely there are great films to be made about Gladys Bentley, Tallulah Bankhead or any of the many women in the suffragette movement who were gay.

There are many great gay female directors out there, including Lisa Cholodenko, Kimberley Peirce, Lisa Gornick, Kanchi Wichmann and Cheryl Dunye, and we must not forget the work of the Scottish queer international film festival, which showcases work by LGBT artists.

We have watched television change from that momentous appointment viewing of the kiss between two women on "Brookside" in the 1980s to gay female characters being present in drama almost as the norm. Films about LGBT relationships are multiple and, in many cases, mainstream. Casting our attention backwards into history and retelling history with the airbrushing of female gay sexuality removed is vital if we are to get closer to the truth of what really happened. It needs to be in our cinemas, in our living rooms and—as Jenny Gilruth eloquently said—in our classrooms.

There needs to be a recognition that stories about gay women in history are as relevant as stories about white upper-class men in history. They are not of niche appeal. Just as "Hidden Figures" righted a wrong over the part that African American women played in the space race, I want to hear stories in which gay women changed the face of the earth. I want the gay women in my family to see something of themselves on screen—something of themselves that is not just, in its core, about struggle for acceptance, important as that is, or the nature of sexual relationships but that is also about how women led the change and were protagonists of their own time.

I thank Jenny Gilruth again for the opportunity to make my points on the importance of mainstreaming LGBT film and to stick my oar in as a sister and an ally.

#### 17:15

Annie Wells (Glasgow) (Con): I thank Jenny Gilruth for bringing the debate to the chamber. It is always a huge privilege to speak in the debates that celebrate LGBT history month. Each year, I am reminded of how far we have come from when I grew up in the 70s and 80s, and of how drastically the lives of LGBT people have changed. LGBT history month provides the perfect

opportunity to celebrate that and to reflect on what comes next for activism.

As Jenny Gilruth said, this is a significant year. The theme for 2019—"Catalyst: 50 years of activism"—marks 50 years since the Stonewall uprising in New York City, which kickstarted the equal rights movement for LGBTI people across the globe. Fifty years of hard work and personal sacrifice by dedicated activists have resulted in a sea change. We have equal marriage, the right to adopt, LGBTI inclusive education and, last year, the passing of the landmark Historical Sexual Offences (Pardons and Disregards) (Scotland) Act 2018. The lives of LGBTI people have changed immeasurably and, with them, society's views.

I know how proud I am to be in the LGBTI community, about which I have spoken before. It was a real journey to get to this point. That is why I feel so strongly about the need to celebrate LGBT history month and why I am encouraged by the level of activity in Scotland, from Stornoway to Dumfries.

As LGBT Youth Scotland has highlighted, the popularity and awareness of the history month is increasing quickly. This year, 125 events are listed, which is up 25 per cent from 2018, and the dedicated Twitter account—@LGBTHistoryScot—has 10,000 followers.

In Glasgow, many events have marked the month. It is not just individuals who are getting involved: communities, third sector organisations and businesses are, too. Last week, the Scottish national gallery of modern art held a round-table event to discuss future strategies for documenting and collecting objects that would increase the visibility of LGBTI history. Earlier this month was the annual rainbow run. Unfortunately, I was unable to take part, but I will do so in 2020. Glasgow also hosted LEAP Sports Scotland's corporate tenpin bowling tournament, which gave businesses the opportunity to mark the month and to show their support. Those are just a few examples of the many events that were hosted. I thank everyone who was involved in organising them.

As well as celebration, LGBT history month provides an opportunity to address where our priorities should lie. LGBTI people are still affected by discrimination, prejudice, hate crime and social isolation, and in rural areas in particular there is still much more to be done by way of making progress. In 2015, 18 per cent of the Scottish population still believed that sexual relations between two adults of the same sex is always wrong. Prejudice about trans rights is even more prevalent, with little public awareness of what it is like to be a trans person. In 2015, 32 per cent of people said that they would be unhappy if a close relative married or formed a long-term relationship

with someone who had undergone gender reassignment. It is clear that there is still some way to go.

Using politics as a marker, we see that although inroads have been made with the representation of gay people in the Scottish Parliament, we are yet to see an openly trans or intersex politician in Scotland. The Gender Recognition Act 2004 still needs discussion in Parliament in terms of reforming the process by which a person can change their legal gender without intrusive medical assessment.

I praise and wish every success to the LGBTI groups across Scotland that are organising events up and down the country. It is so important that LGBTI rights remain firmly on the agenda, and in the Scottish Parliament. I believe that we can continue to work together to achieve positive and life-altering change.

#### 17:19

David Torrance (Kirkcaldy) (SNP): I thank Jenny Gilruth for lodging her motion to raise awareness of LGBT history month in Scotland. I also thank LGBT Youth Scotland for co-ordinating that incredible nationwide event. Now in its 13th year, LGBT history month is a fantastic opportunity to celebrate LGBT culture, to look back at LGBT history and to look forward to the future of LGBT activism.

As we have heard, this year's theme—"Catalyst: 50 years of activism"—marks the 50th anniversary of the Stonewall uprisings in New York in 1969 and the birth of the modern pride movement. The Stonewall riots were a decisive and era-defining moment in the struggle for LGBT equality and were the catalyst for the modern fight against LGBT oppression across the world.

In the early hours of 28 June 1969, a gay bar in the West Village in Manhattan became the epicentre of an event that changed the course of LGBT history. One year later, in June 1970, on the first anniversary of the Stonewall rebellion, the first gay pride march was held in Manhattan. Since then, millions have attended the LGBT pride marches, parades and festivals that have taken place all over the world.

Fast forward 50 years, and many great strides have undoubtedly been made in LGBT equality. We all know that Scotland has become a leader when it comes to LGBTI equality. We are considered to be among the most progressive countries in Europe, and Scotland has regularly been ranked as among the best countries in Europe in relation to legal protections for LGBTI people. Last year, in an historic move, Scotland became the first country in the world to embed the teaching of lesbian, gay, bisexual, transgender

and intersex rights in the school curriculum. By teaching our children about sexual diversity, we can help to tackle discrimination and promote acceptance of different lifestyles.

In Fife, we are extremely lucky to have many fantastic ambassadors for LGBT equality. I want to highlight the positive contributions of just a couple of those groups. They are Pink Saltire and the LGBT+ group at Kirkcaldy high school.

Since its formation in 2014, Pink Saltire has been an inspiration to the LGBT+ community in Fife and wider Scotland. The team's commitment and dedication to breaking barriers and promoting equality and diversity is amazing. A couple of weeks ago, I visited its pop-up heritage hub at the Mercat shopping centre in Kirkcaldy and met some of the team. The exhibition featured the most detailed LGBT history timeline ever produced in Scotland, showing key facts and major highlights in the fight for equality, including same-sex marriage and the abolition of discriminatory laws against gay and bisexual men. The event provided a real insight into the struggles that the LGBT community has faced through the years, and the bravery of activists throughout those years.

Figures from the "Pink Saltire Annual Report 2017-18" show an astonishing 1,350 hours of voluntary work and 13,626 miles travelled in delivering community work. Fife has a lot to thank Pink Saltire for, from the inaugural Fife pride event to its positive engagements with community consultations across Scotland, and the continued development of its LGBT awareness training and support. I, for one, look forward to seeing what the future holds for it.

The Kirkcaldy high school LGBT+ group was established tackle negative attitudes. discrimination and bullying across the school, and to improve the mental health and life chances of LGBT+ young people. The group meets weekly and comprises people who identify as LGBT+ or as "allies" who have an interest in equality and promoting human rights. In the relatively short time since its formation, the group has very quickly become a leading group in the fight against discrimination and in the promotion of equality, and it is a proud recipient of the Convention of Scottish Local Authorities' tackling inequalities and improving health award. One of its members-Cameron Bowie-was named young volunteer of the year at Fife Voluntary Action's 2018 awards. Collectively, the group has shown that it is a force to be reckoned with, and it shows no signs of slowing down.

It was great to see purple Friday feature so heavily across social media last week, and it was wonderful to see the level of engagement from all across Fife. From Kirkcaldy high school staff and pupils to our fellow councillors, individuals pledged

their support for LGBTI equality and to tackling homophobia, biphobia and transphobia.

In conclusion, I welcome LGBT history month and offer many thanks to LGBT Youth Scotland and its partners that have been involved in the organisation of this year's events. Although there have undoubtedly been many great strides in equality, the LGBT+ community still faces significant challenges and discrimination, so we must not allow ourselves to become complacent. We must continue to fight against discrimination and prejudice wherever and whenever we encounter them, and we must continue to stand up for equal rights.

**The Deputy Presiding Officer:** I call Kezia Dugdale, to be followed by Patrick Harvie.

#### 17:24

**Kezia Dugdale (Lothian) (Lab):** Thank you for calling me to speak, Presiding Officer, knowing that I have to leave the chamber immediately after my contribution. I advised you of that 24 hours ago, and am grateful to you for giving me the opportunity to speak.

To Jenny Gilruth, I want to say congratulations on securing the debate and on all the work that you have done as a constituency MSP since your election. I know that your first event in the Parliament was for Pink Saltire and that you have consistently hosted events and created opportunities for LGBT people to tell their stories and to talk about forthcoming campaigns. I know that you will always continue to do that.

LGBT history month is a celebration of the journey that we as a community have made. I reflect that, when Jenny Gilruth and I were outed as a couple about 18 months ago, people were far more interested in the difference in our politics than in the fact that we are of the same gender. In many ways, that demonstrates how far we have come as a country.

However, the reality is that there is still a lot of work to do. I was reminded of that when Jenny and I travelled to New York about a year ago to see at first hand the Stonewall inn-as she mentioned, this year marks the 50th anniversary of the Stonewall riots. The Stonewall inn sits on Christopher Street in downtown Manhattan. The first thing that people pass at the doorway into the bar is a big old red sign from the New York police department that says, "Raided Premises"—that is the original sign from when the police invaded the bar all those years ago. Inside the bar, as Jenny will remember well, there are posters on the wall for the Gay Teachers Association, which are sprayed with painted blood. They represent the gay teachers who marched for equality in 1975— 25 years before we even considered section 2A

and section 28 in this Parliament. Those teachers demonstrated bravery in marching for equality then, long before many countries had faced up to the problems that the teachers sought to address.

It is worth reflecting on what is happening in our schools, as Jenny Gilruth did. When I was young, people were lucky if LGBT young people were tolerated. Ten years ago, they were accepted. Now, we actively talk about including them. The journey from tolerance to acceptance to inclusion is one that we hope that our trans friends will now be able to take; they should expect exactly the same tolerance, acceptance and inclusion as the LGB community had before them.

Jenny Gilruth touched on something else that is happening in our schools. Whenever I have been in schools recently, I have seen posters for the school's LGBT group. I have thought about what the 15-year-old version of me would have thought of that. In the 1990s, the idea of having a group in my school where LGBT kids could come together to talk about life did not exist.

Last week, I heard kids from Madras college talk openly and casually about what it is like to be out at school. I could not have dreamt of being out at school. I did not really know who I was as a teenager, but I knew that I was different and I knew to keep my mouth shut. There was one gay kid in my secondary school; everybody knew who he was, and he was tormented—his life during his school years was a living hell. I wonder where he is and how he is, and I am so sorry that I did not do more to stand up for him then. However, I know that, collectively, we in the Parliament are doing much more to stand up for him and people like him now.

Keeping quiet is not something that happened only 20 years ago; some people are still doing it today. A recent Stonewall Scotland report told us that one third of people in Scotland still will not come out at work. For a long time, I was one of them in the Parliament. I was outed by a national newspaper—many people knew that I was gay, but I did not openly talk about it. I was not in command of my coming-out story, which was taken away from me.

Harvey Milk told us that the most political thing that someone can do is come out, but people need to be in a supportive environment to do that. I was not able to be in charge of telling my story, but people being able to do that is immensely important, and we must continue to create an environment in which everyone can do that.

Another problem that I have frequently talked about in the chamber is the homelessness that LGBT young people experience. Of the young people who present as homeless in this city, 40 per cent do so because they have had a negative

experience of coming out at home. That transcends all class barriers—it affects working-class kids, middle-class kids and kids who turn up in private school uniforms. We can do much more to help all young people to realise their potential.

Finally—I appreciate that I have gone over my time, Presiding Officer—I will say something quickly to the cabinet secretary about the forthcoming gender recognition bill. I understand why the Government has postponed the bill—the Government wants to get the legislation right, because it is incredibly sensitive—but the Government needs to understand that the delay has created a vacuum. In that vacuum, fear and ignorance are growing. People's understanding of what the proposals are and what they will mean is festering in an unhelpful way. I know that the cabinet secretary probably agrees with that.

There is nothing contradictory between my feminism and my LGBT activism—neither is a threat to the other. I know that and I am comfortable with that, but I am not the one who needs to be convinced. Collectively in the Parliament, we need to do much more.

I am sorry that I cannot stay to hear the final speakers or the summing-up, but I will try to read all the contributions tomorrow. I am grateful for the time, Presiding Officer.

The Deputy Presiding Officer: I do not know whether the minister will thank you for promoting her so publicly several times, but there we have it.

17:29

Patrick Harvie (Glasgow) (Green): I, too, thank Jenny Gilruth for securing the debate and the organisations that are taking part in LGBT history month.

Kez Dugdale's excellent speech touched on the anniversary of the Stonewall riots, which the motion mentions. I want to go back a little bit before then. In 1957, the "Report of the Departmental Committee Homosexual on and Prostitution"—the Wolfenden report—recommended the beginnings of the decriminalisation of gay male sex in the United Kingdom. It was at that point that Scotland diverged. James Adair, one of the most notable Scottish voices on that committee, vociferously said that he would not support the report recommendations. As a voice of the socially conservative religious establishment in Scotland, he was taken seriously. That is probably one reason why the beginning of and partial decriminalisation did not happen in Scotland until much later-the Criminal Justice (Scotland) Act 1980 did not come into force until 1981. That legislation was due, in no small part, to the efforts of Robin Cook, whose role is sometimes not

recognised this long after those events. He played a significant role in ensuring that Scotland eventually had decriminalisation legislation.

Why did it take that much longer in Scotland? Why was there that delay in Scotland's story? In part, it was due to social conservativism; more often, it was due to the perception of social conservatism. Scotland had a story of itself as a more religious, socially conservative society—not just more than we are now, but more than the rest of the UK. In the run-up to devolution, that perception was still there. Our community genuinely had anxieties. What would a Scottish Parliament do with our human rights and our equality? We did not know.

As it happens, things have turned out better than some feared. The Parliament has sometimes been ahead of the curve; sometimes it has taken longer to do things. However, in its 20 years of existence, it has never voted against our equality and human rights on any issue. That is a record to be proud of, and a record to cherish. As I said, that anxiety was there beforehand; we did not know what the Parliament would do.

In the Scottish Parliament's first session, we had the section 2A—or section 28, as it was commonly called—campaign. As members know, I was an LGBT youth worker in Glasgow at the time. I had to walk to work past billboards that said, "Protect our children". That meant that they should be protected from people like me.

There were echoes of that nasty homophobic campaign in Margaret Thatcher's 1987 party conference speech, when she complained:

"Children who need to be taught to respect traditional moral values are being taught that they have an inalienable right to be gay."

In the same speech, the Prime Minister complained that children were being taught such things as anti-racism. Those were the traditional moral values that she was trying to defend, and that attitude echoed through the rhetoric of the keep the clause campaign in the early years of this devolved Government.

Those values, and the bigotry of Brian Souter and Thomas Winning, were faced down at the time and defeated, but they did not disappear. Have we moved on? How much have we moved on? Others have mentioned the *Daily Record* headline, "Gay sex lessons for Scots schools". That would probably not be printed in the *Daily Record* now, but it is little different from *The Sunday Times* headline that was printed this weekend, "Gay and trans lessons for primary schools". *The Sunday Times* is one of the newspapers that have so cynically driven the vicious anti-trans backlash that is taking place at the moment.

Those issues resonate and echo through time. Telling the stories of our history is so important, because it grounds us in who we are and where we come from, but learning the lessons of history matters even more. The lessons from those few examples tell me that we must stand together—that is the only way that we will make progress.

Those who are trying to separate the T from LGBT will fail. We must stand up to them, just as we stood up to those who sought to oppose our equality and human rights before, because, if they succeed in that, they will not stop there. We must ensure that we continue to stand together across the LGBT community, across women's organisations and feminist organisations that support us, across the whole of our society, and, I hope, across the whole of our Parliament.

The Deputy Presiding Officer: Because several members still wish to speak, I am minded to accept a motion without notice, under rule 8.14.3, to extend the debate by up to 30 minutes. I ask Jenny Gilruth to move the motion.

Motion moved,

That, under Rule 8.14.3, the debate be extended by up to 30 minutes.—[Jenny Gilruth]

Motion agreed to.

### 17:35

Emma Harper (South Scotland) (SNP): I am pleased to be able to speak in this important debate to welcome the 13th LGBT history month, which has the theme "Catalyst: 50 years of activism". I congratulate my friend and colleague Jenny Gilruth on securing the debate.

From the outset, I note that Scotland is a world leader in promoting equality, inclusivity, fairness and respect. Jenny Gilruth mentioned that, and noted that this is "the gayest Parliament". I am pleased that the Scottish Government has those values at the heart of all decision making—something that, I am sure, all of us in the chamber are proud of.

In preparing for the debate, I reflected on some of the history of tackling LGBT discrimination in Scotland. It is worth highlighting. In 2005, discrimination on the basis of sexual orientation and gender was made illegal. Then, in 2009, equal rights were given to same-sex couples who were applying for adoption. Just last year, the Parliament unanimously passed the Historical Sexual Offences (Pardons and Disregards) (Scotland) Act 2018, which allows for gay people to be pardoned from historical convictions that were based on outdated legislation that targeted them just because of their sexual orientation. More recently, Scotland has been regarded as the best country in Europe for LGBTI equality. Further, the

Scottish Government's review of hate crime legislation was also welcome, and I am pleased that the Government is currently working to implement some of its key recommendations.

I also reflected on the time that I spent living and working in West Hollywood, Los Angeles, during the 1990s, a time when LGBT issues were contentious across America. Members might recall that, when I led a debate in the chamber to mark last year's world AIDS day, I spoke about some of the stigma that I witnessed while living and working there. Challenging stigma and discrimination is important, and I note in that regard the success of the TIE campaign, which Jenny Gilruth mentioned. It is fantastic to see that work going forward.

In my region of South Scotland, the LGBT community can sometimes struggle to access support because of the rurality of the region. I welcome Annie Wells's comments on rurality, which were great to hear from a Weegie. We have several outstanding people working in the LGBT community and I would like to give a shout out to Johnathon Gallagher, Iain Campbell and Alice Polley from Dumfries & Galloway Lesbian, Gay, Bisexual and Transgender Plus. They know the struggles that people in our rural communities face, and they keep me up to date with their vital work to support people and tackle homophobia and transphobia, with support from other agencies.

For my part, I have contacted the Scottish Horticultural Society, with support from a local couple, to have a discussion about LGBT issues. The society has agreed to take part in an LGBT event and photo opportunity at the Royal Highland Show this year to show support for LGBT issues in the horticultural sector.

Again, I would like to congratulate Jenny Gilruth on bringing this important debate to the chamber and reaffirm my support for the progress that the Parliament has made in bringing about equality for all across the LGBT community, while also stressing the need for further action to be taken, particularly in our rural areas, to continue to make Scotland the fairest and most progressive country that it can be.

I love Kezia Dugdale's words, "tolerance, acceptance and inclusion". Those are perfect words to take this work forward.

17:39

Finlay Carson (Galloway and West Dumfries) (Con): I thank Jenny Gilruth for bringing this important debate to the Parliament. It is important that we continue to mark LGBT history month.

I will focus on the contribution of organisations and groups that are based in Dumfries and Galloway—a hugely rural area, where delivering support can be much less straightforward than it is in more populated areas.

The debate also gives us an opportunity to consider what more can be done to support the LGBT community, as we strive for equality in all quarters of society. However, as members such as Kezia Dugdale noted, there have been great strides across the globe on LGBT matters.

In rural constituencies such as mine, Galloway and West Dumfries, ensuring equity and equality is more difficult, whatever the issue, whether we are talking about health, education or social inclusion—and that is to put aside the historical barriers and prejudices that face our LGBT communities. There are issues to do with delivering equity and equality, not just in relation to resources and support for organisations but in the context of reaching individuals who might live at the end of a farm road or in a rural village.

That is why I was extremely pleased to see positive things happen this month in Dumfries and Galloway. Dumfries & Galloway LGBT Plus received £120,000 from the national lottery community fund. The group will use that six-figure sum over the next three years to offer support and ease isolation in rural communities, through a range of social activities.

The importance of the funding to the group is tangible. Service manager lain Campbell said that when the funding was announced, quite a few of the group's members burst into tears. He said:

"We don't want people to travel to us, we want to travel to them".

The provision of resources to enable that to happen in a rural area such as Galloway and West Dumfries can only send a positive message to the LGBT community.

Dumfries & Galloway LGBT Plus recognises that issues relating to LGBT identity affect not just individuals but their friends, families and colleagues. The group therefore offers different types of support across the region, such as one-to-one support, advocacy, befriending, transgender support, regional drop-ins and a range of other services. During the summer the group gets out into the field—quite literally—at agricultural shows, where it is warmly welcomed by the farming community.

As members such as my colleague Annie Wells noted, this month there has been a welcome rise in the number of events that are taking place in local areas. In Dumfries, I was pleased that renowned group, lavender menace, and local artists group, we agree on eggs, ran a queer pop-

up library in the heart of the High Street over the past weekend.

A host of other free events were on offer this weekend, from tea and chats to workshops and a human library that gave LGBT people a chance to talk about their experiences of living in the area. I hope that more such events can take place, not just this month but all year round.

On Sunday, there was speculation regarding potential LGBT use of one of Dumfries's iconic buildings. The church in the High Street has stood for more than 150 years, but the number of attendees has unfortunately continued to dwindle. People are trying to put together a funding package for LGBT-friendly housing at the site, which would be for older people, in particular. The aim is to create more town-centre housing.

Such an idea would have been unthinkable a few decades ago—or even a few years ago—never mind in the 1860s, when the church was constructed. If we are linking a major issue such as the need for good-quality housing in our town centres with LGBT support, there can be no doubt that we have made significant progress.

A few months after my election in 2016, I was delighted to visit, alongside other politicians, Relationships Scotland's premises in Dumfries, after the charity had been awarded a silver charter by LGBT Youth Scotland. The charity had carried out extensive engagement with the LGBT community and had commemorated a number of LGBT events throughout the year—those are just a couple of reasons why it was awarded the charter.

A lot of great work is being done across Dumfries and Galloway and Scotland, which is why it is so pleasing to hear so many members highlight successes in their areas. We have many disagreements in this chamber, but on this subject we can all play our part to support the LGBT community. If we do, the future will no doubt be very positive.

### 17:44

Gail Ross (Caithness, Sutherland and Ross) (SNP): I thank my good friend and colleague Jenny Gilruth for bringing this timely and important members' business debate to the chamber of the Scottish Parliament, and I congratulate her on a truly brilliant speech. I also thank everyone who got in touch to send material and briefings for the debate, in particular LGBT Youth Scotland. I thoroughly recommend looking at its Twitter account and website to see some of the fantastic work that it is doing.

Many members have mentioned the great work that we have done and are doing in this

Parliament. I am a member of the Equalities and Human Rights Committee, and we pride ourselves on furthering equality and human rights for everyone. Our former convener, Christina McKelvie, is sitting in front of me and, as the minister, will reply to the debate. A lot of the work that we are doing and have done is down to her and her commitment to the cause.

Through the committee's work, we have heard some worrying examples of discrimination and stereotyping, but we have also heard about lots of fantastic work that going on. One of the core values of LGBT history month is to

"Focus national attention on the LGBTI community, and enhance LGBTI equality at a local and national level".

Being from a huge rural constituency, I am acutely aware that in some areas, a lot of the attitudes towards the LGBT community have not really changed over the years. We still have a lot of work to do to make sure that people, especially our young people, are supported. LGBT Youth Scotland has done a lot of research on that. Its parliamentary briefing tells us:

"Increasing numbers of LGBT young people in Scotland think it's a good place to live—81% of respondents to the 'Life in Scotland' survey said this in 2017, compared to just 57% in 2007.

However, there is noticeable difference from respondents in rural and urban areas across a number of relevant policy areas such as transport, education and isolation.

LGBT young people are at risk of social isolation when there are limited socialisation opportunities available to them and/or when discrimination stops them from seeking or accessing opportunities.

There is also some evidence to suggest that young people who experience social isolation are more likely to experience poor mental health. Expendable income can also play a role in an individual's ability to access certain socialisation opportunities, particularly when the only available socialisation takes place in commercial venues or when a significant amount of travel is required.

It is also clear that LGBT young people can have reduced social networks if family or friends reacted negatively to them 'coming out'. LGBT young people may face homelessness as a result of 'coming out' to a parent or carer, or feel as though they need to leave home in order to avoid discrimination.

For example, 22% of transgender young people who responded to our survey left home under negative circumstances, and often commented that this was typically due to how their family reacted to their LGBT status."

# The briefing goes on to say:

"As a result of a lack of access to safe spaces locally, young people will often need to use public transport to access services such as LGBT youth work.

However, 2017 research shows that whilst 67% of Lesbian, Gay and Bisexual young people said they felt safe on public transport, this is not the case for transgender young people, for whom only 51% felt safe.

Frequency, reliability, cost and having to rely on a singular mode of public transport are all well documented concerns of rural young people, which are arguably more likely to impact on rural LGBT young people. In addition, young people are often reliant on their parents or carers for transport to LGBT services so if they are not 'out' or their families are not supportive of their gender identity or sexual orientation this can be a significant barrier."

LGBT history month celebrates, raises awareness and calls out inequality, but inequality exists not only within society but geographically. LGBT Youth Scotland captures it perfectly when it says:

"It is important that young people across Scotland have access to the same support and resources in order to ensure they are adequately supported; this will help build resilient and welcoming rural communities which are open and welcoming to LGBTI people."

#### 17:49

The Minister for Older People and Equalities (Christina McKelvie): I thank Jenny Gilruth for securing the debate, and I thank all the members who have spoken for their amazing contributions. Jenny is a true champion. Gillian Martin said, "If you can't see it, you can't be it". Many young women and men who saw Jenny Gilruth leading the debate were able to see what they can be, which is great and something to be proud of. Well done, Jenny.

I, too, had the privilege of attending Pink Saltire's parliamentary reception, which was a fantastic event celebrating LGBT history month. We heard many personal stories from individuals, many of whom were highlighted by us for their incredibly hard work on progressing equality in the LGBT community. We heard from the couple from Fife who spoke about their personal experiences and the young purple dragon from Dundee who talked about her experience as a young person, and we heard a very deep, emotional and honest speech from a trans woman called Stevie Maybanks. We heard absolutely speeches from all of them. Those people had different perspectives but were all saying the same thing: we have made progress but we have much more to do.

It is hugely important that we celebrate LGBT history month, in order to acknowledge the challenges that people have faced and understand the impact of each person's contribution. I cannot overstate how moving every speech at that event was. It took us another step towards eradicating discrimination and prejudice and creating the equal world that we want to see for LGBT people.

To see so many social media posts from people in schools, workplaces and communities, and even from politicians, all of whom were sporting purple on purple Friday and celebrating, commemorating and, most importantly,

educating—being the catalysts for change that we all want to see—was an absolute joy.

To see my friends on the TIE campaign's daily icon has been an enlightening education for me. We have had one of those every day of LGBT history month and they have demonstrated clearly how many people came before us—the people who fought those battles. We have to take up those battles and continue to fight, but let us hope that the battles that we fight are not big battles anymore but are only small, and that we can push away all that discrimination.

This Government recognises the discrimination that gay, lesbian, bisexual and trans people face every day of their lives for no reason other than their being who they are. They are just trying to be true to themselves. That, for me, epitomises why we need to celebrate LGBT history month with a series of events to recognise the struggles that people before us have faced and are still facing today. We need to mark the progress that has been made and proudly state who we are—regardless of our sexual orientation or gender identity—and that no one will change that. That is very important.

As has been mentioned by others, this year's theme is "Catalyst: 50 years of activism". It marks the 50th anniversary of the Stonewall uprising in New York city in 1969, which was a pivotal moment in the pride movement. However, LGBT history month is not only about LGBT people standing up for their rights; the power of allies and role models should not be underestimated and we have heard from many of them today.

There is no greater ally for LGBT equality than this Parliament and, I would like to say, this Government. Patrick Harvie reminded us that we should be rightly proud of that. We still have work to do, but this Parliament voted overwhelmingly in favour of legalising same-sex marriage. It was a great day when we did that—I was here and it was wonderful. This Parliament legislated to allow pardons and disregards for gay men who were convicted of same-sex activity which would now not be considered illegal. Importantly, there was an apology from this Government to those men who did nothing but love who they loved.

This Government is absolutely committed to reviewing and reforming gender recognition legislation to improve the lives and experience of trans people in Scotland. I hear the calls from many that we have to ensure that we get that right and we are working closely with everyone we can to get it absolutely right.

This Government is committed to reforming hate crime legislation, which we heard some comments about earlier. Emma Harper reminded us that we have to get on with that work and that we have to

get it right as well. Emma also told us, very interestingly—these debates are always very diverse; we hear about a range of wonderful things—about a horticultural project in the Royal Highland Show. I am sure that all the rural members will be interested in hearing about that.

Jenny Gilruth reminded us how far we have come since the time of section 28. She reminded us about Glenrothes high school and the all-school approach. I was a wee bit worried when Jenny was making her remarks about not being able to marry her girlfriend in the church that she wants to marry her in—I thought that we were hearing a proposal. By the time I had picked my hat out, Kezia Dugdale was off. [Laughter.] Jenny reminded us about the wee things that make someone the person they are and how important they are.

Gillian Martin reminded us about intersectionality and the issue of gay women who are in politics, who are influencers or who are agents of change telling us, in our cinemas, our living rooms and our schools, about their history and their truth. For people to be able to see what they can be is incredibly important.

Annie Wells talked about the community approach to LGBT history month. If she runs in the rainbow run I will sponsor her—I might even go and run behind her for a bit of a laugh. It is great when people commit themselves to doing things. Are all the members who are here going to watch Annie Wells in the rainbow run? Yes, we are. [Laughter.]

David Torrance reminded us of the vibrancy of the pride movement. Education changes cultures, as he knows from the activities of Kirkcaldy high school—as do I, because we have heard from the school's representatives in the Parliament. Mr Torrance also warned us against complacency.

That leads me to Kezia Dugdale's remarks. She reminded us about the sign in the Stonewall Inn that said "Raided Premises" and the blood-daubed posters for the Gay Teachers Association, and about how we should take the route from tolerance to acceptance and inclusion. She also reminded us that people were tormented—as we know people are being tormented now—and about how we must create an environment in which people can tell their own stories.

Patrick Harvie said that we should learn the lessons of history, which is why LGBT history month is so important. Emma Harper, Finlay Carson and Gail Ross reminded us of the challenges of being in rural communities and how areas are working closely together to make a difference. It looks as though there is loads going on in Dumfries and Galloway, so I might have to go there for a visit. With my Minister for Older

People and Equalities hat on, I would be especially interested in seeing the LGBT housing. Gail Ross also recalled the fantastic work of LGBT Youth Scotland and everything that it does.

Our achievements have meant that Scotland is recognised as one of the most progressive countries in Europe on LGBTI equality and human rights issues. However, the truth is that such progress would not have been made had it not been for the tireless work of the organisations and activists—some of whom I expect will be watching the debate—who, day and night, have sought to advance equality for LGBTI people in Scotland. We thank them deeply for their activism and their work.

The Scottish Government's open dialogue with LGBTI organisations has been vital in informing our approach to policy, on which we will continue to work. Our engagement with those organisations will continue as we work on eliminating the inequalities that continue to exist in our society, so that anyone who is L, G, B, T or I is empowered to fulfil their potential in our Scotland.

Meeting closed at 17:57.

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