The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 1 December 2015

Session 4

Tuesday 1 December 2015

CONTENTS

PUBLIC PETITIONS COMMITTEE
20th Meeting 2015, Session 4

CONVENER

*Michael McMahon (Uddingston and Bellshill) (Lab)

DEPUTY CONVENER

David Torrance (Kirkcaldy) (SNP)

COMMITTEE MEMBERS

Jackson Carlaw (West Scotland) (Con)
*Kenny MacAskill (Edinburgh Eastern) (SNP)
*Angus MacDonald (Falkirk East) (SNP)
*Hanzala Malik (Glasgow) (Lab)
*John Wilson (Central Scotland) (Ind)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Lorraine Cleaver
Jim Eadie (Edinburgh Southern) (SNP) (Committee Substitute)
Gil Paterson (Clydebank and Milngavie) (SNP)
Elaine Smith (Coatbridge and Chryston) (Lab)
Stewart Stevenson (Banffshire and Buchan Coast) (SNP)

CLERK TO THE COMMITTEE

Catherine Fergusson

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Public Petitions Committee

Tuesday 1 December 2015

[The Convener opened the meeting at 10:00]

Decision on Taking Business in Private

The Convener (Michael McMahon): Good morning, everyone, and welcome to the 20th meeting in 2015 of the Public Petitions Committee. I ask everyone present to please turn off mobile phones and any other electronic equipment, as they interfere with the sound system.

Apologies have been received this morning from David Torrance and Jackson Carlaw. We have Jim Eadie in attendance to substitute for David Torrance—welcome to the committee, Jim. Angus MacDonald is moving amendments at the Education and Culture Committee, but he will join us later.

Agenda item 1 is a decision on taking business in private. Does the committee agree to take in private agenda item 3, which relates to witness expenses?

Members *indicated agreement.*

Current Petitions

Thyroid and Adrenal Testing and Treatment (PE1463)

10:00

The Convener: Agenda item 2 is consideration of current petitions. The first is PE1463, by Lorraine Cleaver, on effective thyroid and adrenal testing, diagnosis and treatment. We are going to take evidence from the petitioner, but I am delighted to say that we have been joined by Elaine Smith MSP, who has an interest in the petition.

As I have said, we will hear first from Lorraine Cleaver. Lorraine, I will open the meeting up to you for two or three minutes, after which we will move to questions. Over to you.

Lorraine Cleaver: Thank you, convener, and thanks to the committee for letting me speak today.

As you will know, it has been almost three years since I lodged the petition with two co-petitioners, who have now left the project. I am a bit concerned that the petition has come to a kind of impasse, because at the last meeting at which it was discussed it was agreed that the Scottish intercollegiate guidelines network would look into doing a piece of work on guidelines for the illness.

As I noted in my submission to the committee last week, I had a meeting with SIGN because I have concerns about guidelines. For many illnesses, guidelines are fraught with problems, because they are not about personalised medicine but about putting people in a box. I think that I was right to have those concerns, because it was in the press a few months back that some of the people working on the guidelines committee have financial conflicts of interest—or, certainly, financial interests.

Anyway, we had quite an intensive meeting, the upshot of which was, I think, that SIGN will do a sweep of all the current evidence. Although there is really good evidence backing my petition, the volume of it would be drowned out by the current older evidence, so we could end up with the same old same old at the end of a five-year project.

It was agreed that we would try to work with the Royal College of General Practitioners in Scotland and produce a kind of best practice document. Essentially, though, that would do what should already have been done. It would not actually achieve anything new, which was what I asked for in the petition; it would simply flag up to GPs that if a patient comes to them with continued problems on thyroxine, they should do this, this, this and this. Those guidelines already exist, but they have never been adhered to or noticed.

Although that piece of work would be really useful for 80 per cent of the population with thyroid problems—after all, they go back to their doctors with odd symptoms, and doctors are not aware of the things that they should be doing next, such as checking their B12 levels, iron, cortisol et cetera—it will do absolutely nothing to address the people who have no ability to use levothyroxine, which is the one and only national health service-prescribed medication for the illness and who, according to the Royal College of Physicians, make up 5 to 10 per cent of the population with thyroid problems. I have to say that we think that that figure is a lot higher; in my experience, it is vastly higher than that.

The piece of work that SIGN will conduct will never touch those people, and they were the entire reason why I came to the Public Petitions Committee. Quite apart from that, the work will not address the fact that the medication that I need to stay alive is not available on the NHS and is not licensed in this country. That is a job for the Medicines and Healthcare Products Regulatory Agency.

I do not know whether the committee will recall this, but Alex Neil came to the committee a year and a half or two years ago to give evidence on the situation. Although he acknowledged that it was the MHRA’s job to look into licensing, he said that maybe that situation would change if we got independence—so, of course, it has not changed. I am concerned that, although we have a Scottish NHS, we have no method for looking into the licensing of new drugs for Scottish patients, and I urge the committee to have one more round-table meeting to look again at the fresh evidence that is coming through and which I have discussed on the 10 to 20 per cent of people who do not recover.

The committee could also look at the licensing situation. The European Parliament has closed down my petition there and says that the issue is up to the Medicines and Healthcare products Regulatory Agency. We are just not moving forward in any way. I know why the issue is not being looked at; it is because I am looking for a natural product, and a product from nature cannot be patented, so there is no great will to put a lot of money into research.

However, as the late Dr Skinner said, there is something rather disingenuous in a situation where we have to prove the effectiveness of something that was used for 80 years and was then cast aside and removed from the British national formulary in favour of a new synthetic that did not have to prove its mettle. We are having to prove a negative, which is a ridiculous position to be in. The issue is costing the NHS billions, and the drugs that we are looking for are cheap. There is no reason why Scotland cannot conduct a trial to compare the old natural thyroid with the relatively new levothyroxine, which is giving all the problems.

To sum up, I urge the committee not to close the petition because, in three years, all that we have ultimately achieved is a piece of work by SIGN that has not begun, that might take two years and which will address only patients whom I was never campaigning on behalf of.

Thank you.

The Convener: Thanks very much for bringing us up to speed with how things are.

I will come to Elaine Smith first, because she has had a long-standing interest in the issue. Do you want to add some comments before I open it up to questions from the committee?

Elaine Smith (Coatbridge and Chryston) (Lab): As Lorraine Cleaver says, she has been working on the issue for more than three years. The committee has looked at the issue and the Government has conducted a listening exercise, although I do not think that we have had anything back from that yet.

To me, the bottom line is that a lot of patients in Scotland are not getting the right treatment, and some of them do not even know that. There are even patients—I know many of them—who should be on levothyroxine but who are deemed as being borderline and are not getting the medicine. Frankly, the whole situation with thyroid medication is a bit of a mess, and it needs much more work done on it. More research needs to be done to show what is happening.

I would not even be sitting here talking to the committee if I had not been able to push my case with my general practitioner, even though I was very ill at the time, to get to the right consultant who was willing to try me out on triiodothyronine—T3—and basically bring me back to life. I have said that to the committee before. That is the bottom line.

It is a shame that so many other people out there are not getting that opportunity, perhaps because their GP is not referring them or because they are not getting to the right consultant. A wee while back, I put together in a hurry about 50 stories for the committee. If members read them, they will find that they basically back up what I am saying and show the situation that people find themselves in. Also, the issue is predominantly although not exclusively for women, so it is a gender issue as well.

A lot could be done in NHS Scotland. Personally, I would like natural desiccated thyroid to be available so that people do not have to go to

America to buy their prescriptions. I think that I might do well on that, but I am not willing to go to America. I prefer to work with my consultant and, at the moment, she will not prescribe that because of the situation that she might find herself in.

Obviously, the committee does not have a lot of time left until the end of the session of Parliament. I certainly support Lorraine Cleaver's request to the committee for another round-table meeting, if you have time to do that. A call for evidence could produce a lot more than the nearly 50 stories that I gave you—you would get hundreds. My plea is that, if you cannot fit that in, you do not close the petition but instead put it in your legacy paper and request the Public Petitions Committee in the next session to look into the matter and consider how it can be taken forward.

The Convener: Thanks very much.

Before I go to committee members, I have one question just to absolutely clarify an issue. Would the best practice document that Lorraine Cleaver mentioned be purely for the 5 to 10 per cent who have been identified as the patients for whom the current treatment does not work?

Lorraine Cleaver: No. In essence, it would be for the everyday situation that every GP finds of a patient on levothyroxine coming back and saying, "I don't feel this is working. I don't feel great, and I've still got all these symptoms."

Where does that figure of 5 to 10 per cent come from? It is quoted in the Royal College of Physicians documents, but other people report a level of 16 per cent. Thyroid UK's survey for the Scottish Government says that it is higher, and it is for everybody with continued symptoms who goes back to their GP.

Within that figure for people with symptoms is a percentage of people who just cannot tolerate the one NHS drug, yet there is no other provision for them. It is acknowledged that there is a percentage who cannot convert it in their body, but there is absolutely no provision for what to do with them, so they are all getting stuck on anti-depressants.

The document would be useful. GPs try very hard with us heart-sink patients, but ultimately they do not have a document to refer to. It will still not be far reaching enough in any case, because it will not offer them the medication that many of us use—T3 or natural thyroid, which brought me back from the dead.

I hope that you do not mind, but I would like to say something that I forgot to say earlier. I know that you were notified by a coroner about a thyroid suicide last year. It was not put on the website, but I am sure that it has been lodged among the documents. I have probably received about 40 similar letters from families of people who have committed suicide, because of the appalling way in which this illness is treated. To pick up on Elaine Smith's suggestion, I would say that, if you were to put out a call for evidence, we would have a shocking amount of it to back this claim.

The Convener: Just to clarify, I believe that that related to a specific set of circumstances involving an individual. Although committee members might find it useful to have that evidence circulated, just for fullness of information, it could never be put on our website.

Lorraine Cleaver: No. I am okay if it is not put on the website.

The Convener: I hope that that helps to clarify the situation.

Lorraine Cleaver: Yes.

Hanzala Malik (Glasgow) (Lab): Good morning. Did you say that a listening document is being put together by the Scottish Government?

Lorraine Cleaver: I am sorry—I did not hear what you said.

Hanzala Malik: I asked about the listening—

Lorraine Cleaver: The listening exercise?

Hanzala Malik: Yes. Who is carrying that out?

Lorraine Cleaver: The Scottish Government. That was last March or April. It is probably running late with coming back with the results. It asked a charity, Thyroid UK, to conduct a survey of patients and get their views on how they have been treated. The results of that survey have come in and are now back with the Scottish Government. I do not know what the next move is. The results were quite astonishing with regard to the length of time that people are waiting for a diagnosis and how ill they remain when they are on levothyroxine.

Hanzala Malik: I am happy to continue the petition. It is important to get all the information that we need. If we do not have time ourselves, we could pass it on for another committee to look at.

The Convener: We will have a discussion about what to do with the petition at the end of our questioning.

Jim Eadie (Edinburgh Southern) (SNP): I seek some clarification, so that I know I have understood the issues correctly. There is medication available called T3, which 5 to 10 per cent of patients do not respond to, although they might benefit from the alternative.

Lorraine Cleaver: Five to 10 per cent—allegedly—do not respond to the standard drug levothyroxine, and they request either T3 or natural thyroid.

Jim Eadie: Okay. I am just trying to understand the issues with regard to access to treatment.

Lorraine Cleaver: It is a very valid question.

Jim Eadie: If the manufacturer and the Scottish Government are saying that there are no supply issues, what are the barriers to treatment?

Lorraine Cleaver: I do not know where they have got that information from. We have had three supply issues in the past three years, which have been noted by the MHRA and circulated.

Jim Eadie: If I have understood it correctly, the information that committee members have received states that, in relation to T3, the Scottish Government was

> "not aware of any supply issues having arisen in 2015 ... the manufacturer, AMCo, has advised DH that they are working on an improvement to the manufacturing process ... and are committed to ensuring good supply of this product in the future".

That suggests that issues are still to be overcome. Can you clarify that for us?

Lorraine Cleaver: Yes. That is the only manufacturer of the drug in the UK, which is why it can hold the NHS to ransom and charge more than £100 for 28 tablets. That issue was brought up at a previous meeting here, but nothing has changed. The NHS is paying over the odds for that medication, which is available for €2 in Europe.

Cost is therefore an issue, because GPs do not want to prescribe the drug for cost reasons. In fact, GPs are not actually supposed to prescribe it; they are supposed to refer patients to a consultant endocrinologist. Of course, because of cost cutting, they do not want to do that. They will make the opening gambit to an endocrinologist by email and will be told immediately that the thyroid levels are fine and that it must be something else. As a result, patients are not forwarded to the endocrinologist, and they never really get the T3 that they need. If they get it, they never get enough. There are many problems in all of these areas.

10:15

Jim Eadie: For the sake of completeness, can you tell us whether you have had any discussions with the manufacturer or the MHRA about overcoming those issues?

Lorraine Cleaver: Yes. I have repeatedly contacted the MHRA and Amdipharm Mercury—I think that that company has had three different names in three years—and I have been consistently told that, because one company makes the drug, it has to recalibrate all its machinery when it does a manufacture run. It forecasts what it will need and if that does not meet the need, it will be another several months before it is ready to recalibrate and make another batch. That is a danger of having one manufacturer in the country of one medication.

The medication is used not just for thyroid patients but for cardiac patients and heart failure. It is quite serious medication.

Elaine Smith: On the back of Jim Eadie's questions, I want to ask Lorraine Cleaver to go through the difference between T3 and T4, the conversion issues and the problems with the laboratory testing of the results. Perhaps she can also tell us why other countries have different ranges for their testing results, which might result in different prescriptions in this country.

Lorraine Cleaver: Sitting here speaking to members, I feel that they are looking for the gist of the problem. However, the fact is that there are problems with obtaining medication, referral to a specialist and passing the hypothyroid test to be diagnosed, because in this country we have set a reference range of 10. Unless a person gets to the magic figure of 10, they will not be treated; in America, however, the figure is sometimes three, four or 2.5. Different cities have different reference ranges. There is no parity across the board for people being lucky enough to get diagnosed. While people wait for that diagnosis, they can be diagnosed as depressed or as having fibromyalgia, or there could be some other inaccurate result.

I am sorry, but what was the other question that you asked?

Elaine Smith: I asked you to explain the difference between T3 and T4. Five to 10 per cent do better on T3 or desiccated thyroid.

Lorraine Cleaver: The standard medication level of thyroxine that everyone is offered is T4, which is synthetic and is not an active hormone. A person's body—their liver, gut and peripheral tissue—must convert it into T3 to be active, but there are deiodinase genetic defects and many other reasons why people cannot do that. They might have pituitary, cortisol or iron deficiency issues. There are many reasons that are just never checked when a person repeatedly goes back to a doctor and says that they do not feel well. Although the thyroxine never converts, it will make a blood test look hunky dory and make everything look fine. It will lower a person's thyroid-stimulating hormone and make everything look fine to the untrained eye. As a result, people are never diagnosed and get neither sufficient treatment nor the correct medication that they need.

When a person has complete thyroid failure, their thyroid is no longer able to produce five things: T1, T2, T3, T4 and calcitonin. The NHS gives people one thing, not five; they are given a synthetic hormone that not everybody can convert, which is total medical negligence. We know for a fact what the thyroid produced when it functioned, and people are given one out of five things and told that that is sufficient.

When my thyroid gland was removed, I was told, "We'll replace everything that it used to make." However, they did not. There was a reason why I became obese, bald and suicidal, and there is a reason why people take their lives. We are not talking about depression. This is not in their head, and it is not fibromyalgia; it is simply a lack of thyroid hormone.

John Wilson (Central Scotland) (Ind): Welcome again, Lorraine. The committee has considered the petition for a couple of years now, and we thought that we had resolved some of the issues, but it is clear from what we are hearing that we have not resolved the issue of a regular supply of T3. You have indicated that there is only one manufacturer of T3 in the UK. Can you tell me how many manufacturers of T3 there are in Europe?

Lorraine Cleaver: Not off the top of my head, John, but there are certainly more than five in mainland Europe. I also happen to know that patients are now booking holidays to Turkey or elsewhere just to come across some T3 medication if it is in short supply here or if they have just been refused it for cost reasons.

John Wilson: That is an issue. The drug T3 is available in Europe and manufactured in Europe to European standards, but we seem to have a situation where the MHRA says that we can have only one manufacturer in the UK supplying that drug and that it is not prepared to procure the drug elsewhere.

Lorraine Cleaver: Yes, although when there was quite a lengthy shortage last year, the MHRA was prepared to go to Europe, because it had to supply the drug to patients. The loophole was opened when it had to be. However, it is definitely not best practice for the NHS to be overpaying one manufacturer in the UK.

That situation does not address my need for natural thyroid, though, which was ultimately the reason why I wanted to petition the Parliament all those years ago. I do not want to be worried sick for the next 20 or 30 years of my life about being able to import the only medication that I can take. I have tried the NHS T3—levothyroxine—but my endocrinologist has acknowledged that I am just not able to tolerate it at all. When he asked my GP whether he would consider prescribing natural thyroid because lots of his patients were recovering and because he felt that, with its previous fantastic record, it was high time that Scotland conducted some trials on it, I think that my GP's words were, "It's more than my job's worth to prescribe it."

John Wilson: That is what my next question is about. Who manufactures natural desiccated thyroid? Is it manufactured in the UK and Europe, or is it manufactured only in the United States?

Lorraine Cleaver: It seems that it is manufactured only in the States, although people are sourcing some that is made in Thailand. I source mine in the States, and it is well controlled under the "United States Pharmacopoeia". It is safe, but it is still not safe for me to buy drugs online. I do not care what anyone says—this is a ridiculous situation for a 21st century NHS Scotland.

John Wilson: And there is no manufacturer of natural desiccated thyroid in the UK.

Lorraine Cleaver: Not that I am aware of, no.

John Wilson: Clearly, convener, this is an issue of patient care and treatment. I thought that we had resolved it when the previous health secretary came along to the committee and gave us assurances in relation to guidelines by SIGN, the MHRA and others. I will make a suggestion at the end of our questioning about how we take the issue forward.

The Convener: To be honest with you, John, I think that we have reached that point. There are no other questions. Hanzala Malik has already—

Jim Eadie: Convener, can I ask some final questions?

The Convener: Sure.

Jim Eadie: Ms Cleaver, you touched just now on the issue of safety. I will read from a letter that the committee received from an official in the Scottish Government, which states:

> "In relation to prescribing of desiccated thyroid hormone treatment, it is felt that there is insufficient evidence of benefit and lack of risk, at present, to support the prescribing of thyroid extract and that there are alternatives which have a licence and safety data."

What you seem to be suggesting with regard to the availability of desiccated thyroid hormone treatment in the United States is that there is probably quite a lot of data available to establish whether there is a risk to patient safety.

Lorraine Cleaver: I know what you are saying, but I have just found out—

Jim Eadie: I am just wondering why a Scottish Government official would say that there was a lack of safety data. North America is the biggest market for licensed medicines, so I would have thought that over time quite a lot of data would have built up on whether the medication works, its safety profile and so on.

Lorraine Cleaver: There is plenty of data. There is over 100 years of data that the medication is safe and effective. Whether it is peer-reviewed, medically collated data, I do not know. I actually do not believe that it is even licensed in the States, although it is still manufactured and commonly used there. There used to be a belief that it was a grandfather drug and that because it had existed for so long, it had been granted safe status and its continued use was no problem. I am not sure that it is even licensed in the States, but it is regularly prescribed. The Food and Drug Administration has a safety profile on it, and it has fewer safety recalls than levothyroxine or liothyronine.

I see what the Scottish Government is saying, which is that we lack a body of evidence to back it up. However, when levothyroxine was introduced in the 1960s and 1970s, it was not trialled on females or on a large number of patients; it was simply introduced. In fact, I have made quite a few comments about that over the past three years.

I have continually asked the MHRA, the National Institute for Health and Care Excellence, the European Medicines Agency and whoever else I could think of, "Can I see this safety data for levothyroxine?" It does not exist. The drug was introduced against the only medication, which was natural thyroid, and now we are being asked to prove that the previous 70 years was a safe period. I do not know how we can prove a negative. Nobody is prepared to do the studies now because, as I have said, there is no money in a natural product—but it is a heck of a saving for the NHS.

The Convener: We need to decide what we are going to do with the petition. I take it from what colleagues have said that there is no desire to close it. Indeed, the evidence that we have heard this morning has raised more questions that we need to pursue. Hanzala Malik mentioned an area that we need to go back to the Scottish Government and ask about, and I think that John Wilson has a suggestion.

John Wilson: Yes. I suggest that we invite the new Cabinet Secretary for Health, Wellbeing and Sport along to give evidence, particularly in light of the listening exercise report that is supposed to have been produced. We should ask the cabinet secretary to give us feedback on that exercise, answer some of the questions that have been raised today, particularly on the continuing problem with the supply of T3 in the UK, and comment on the natural alternatives that are available.

Lorraine Cleaver mentioned figures that show that up to 16 per cent of patients could benefit, but the reality for many patients out there in society, particularly women, is that if they are not an Elaine Smith—a determined individual who goes and argues with her GP to get referred to the right consultant—they will continue to struggle to get the best treatment. People need treatment that gives them the quality of life that we would all expect.

It is two years since we had the previous cabinet secretary here to answer questions. It would be useful to ask the current cabinet secretary to come along before we move on to consider the possibility of holding our own inquiry. Of course, that might be time barred because of the upcoming elections.

The Convener: That is a good suggestion. We should certainly invite the cabinet secretary to the committee to find out whether she takes the same position as her predecessor in relation to the comment that was made earlier about where we could be in the future. We are in a different place from where the previous cabinet secretary wanted us to be, but that does not mean that things cannot be taken forward. I do not always buy into the idea that we would have arrived at the land of milk and honey next year, but we will be able to test that theory if we get the cabinet secretary in front of us to answer our questions and say whether she agrees with the previous incumbent of her post on that matter.

Jim Eadie: I thought that Lanarkshire was the land of milk and honey. [*Laughter*.]

The Convener: It is, Jim. We take that for granted in our part of the world.

Elaine Smith: May I add one thing? Some of the committee members have changed since the stories that were put together were submitted to the committee. Could they be recirculated to the committee? They give an overview of what people are going through and suffering. Maybe they could even be submitted to the cabinet secretary before she comes to give evidence. They were put together in a hurry, but they give a good indication of what is happening to people across the country.

The Convener: Yes. I think that the stories are already available to committee members, but we will certainly take up that suggestion for those who might find that useful.

We will take the petition forward on that basis. I thank Lorraine Cleaver for coming in again this morning.

Lorraine Cleaver: Thank you.

The Convener: I suspend the meeting for a couple of minutes.

10:29

Meeting suspended.

10:30

On resuming—

St Margaret of Scotland Hospice (PE1105)

The Convener: Our next petition is PE1105, by Marjorie McCance, on St Margaret of Scotland Hospice. I welcome Gil Paterson to discuss the petition. He has a constituency interest in it and has pursued it for the duration of its consideration by the committee.

Gil, would you like to make some comments before we deliberate on the petition?

Gil Paterson (Clydebank and Milngavie) (SNP): Yes, convener. Thanks for allowing me in.

I thank the committee again for the decision that it took the last time that the petition was before it. The fact that the two parties will sit down to discuss the matter vindicates that decision.

I remind members that the Government had recommended that the petition be closed, but I asked that it should not be and gave some reasons why. The committee had its own views. I wonder and worry what would have happened if the committee had closed the petition, but the fact is that the words that the committee used and the view that it expressed have resulted in the action that is being taken. We do not know what will happen as a result of any discussions that take place, but the fact that people are sitting down and talking about the matter is a very positive step.

I have lost track, but I think that I have attended every meeting of the committee at which the petition has been discussed, apart from one in Dumfries, which I could not get to because I had business in the Parliament. However, I put it on record that people from the hospice have attended every one since 2007, which is a tremendous record. In the public gallery we have Jean Anne Mitchell, who has taken over the petition, Clare Murphy, who is from the hospice, and another great supporter of the hospice: the former provost of West Dunbartonshire Council, Councillor Denis Agnew. They have put in a lot of time and have always been at committee meetings to lend support to the petition and hear what the committee has to say. When I speak to them, they tell me that they are grateful for how the Public Petitions Committee handles petitions, particularly this one.

We all appreciate the fact that the petition has been going for a long time, but, to be frank, it has had to. We are not there yet and I hope that the committee will decide yet again not to close the petition. To do so would be premature. The committee might need to consider closing it at some point, but this would not be the right time to do that.

The Convener: I agree with you. We cannot know whether it is right to close the petition until we know the outcome of the discussions that came about after the last time that we discussed it. We need to wait to see what the discussions bring about. If we can get a report on them, we can consider it at a future committee meeting and decide at that point whether we will need to be party to further discussions. Do colleagues agree with that?

John Wilson: I agree that we must keep the petition open. I think that I have been on the committee for every meeting at which it has been discussed. The Scottish Government’s position is the same as it was when we last considered it, which is to set up a meeting between all parties—the Government, the hospice and the health board. I am concerned about the delay in organising that meeting. As well as keeping the petition open, I would be keen to write to the Scottish Government and impress upon it the urgency of organising a meeting as soon as possible. It should not let the issue drag on. It has dragged on for eight years and we need to try to get some early round-table discussions with all the parties concerned so that we can consider how to take the petition forward.

The Convener: Are we happy to write to the cabinet secretary on that?

Gil Paterson: I understand that there is a suggested date for the meeting, and that it is very early. However, it would not be for me to say that you should not write to the Government.

The Convener: We could write just to confirm that that is the case.

Gil Paterson: I was about to suggest that. It might give you some comfort to know that a date has been scheduled.

The Convener: We can establish whether that is the case.

Gil Paterson: I would be delighted with that.

Hanzala Malik: I recall that we requested that the Government deal with the issue as a matter of urgency. I do not know whether we had a response. Can we check exactly what we asked for and whether we have had a reply?

The Convener: We can check that out. The important thing is that we keep the petition open, ask for confirmation of the date of the meeting and await the outcome before we deliberate any further. Is that agreed?

Members *indicated agreement.*

Gil Paterson: Thank you.

School Bus Safety (PE1223)

The Convener: Our next petition is PE1223, by Ron Beaty, on school bus safety. I welcome to the meeting Stewart Stevenson, who has a constituency interest in the petition. Members have a note on the committee's previous consideration of the petition, a submission from the petitioner and a submission from Transport Scotland. We also have copies of the evaluation report of Glasgow City Council's pilot programme on school bus signage.

I invite Stewart Stevenson to make some comments.

Stewart Stevenson (Banffshire and Buchan Coast) (SNP): I am obliged to the committee for the opportunity to update members who may not have been here for all of the 10 years that the petition, in various forms, has been before the committee. The petition's origins date back to a road traffic accident involving Ron Beaty's granddaughter. Once again, Ron Beaty is here in the public gallery; over the 10 years in which he has been coming to Parliament he has missed only two meetings at which his petitions have been considered. That represents a round-trip drive of approaching 350 miles for each meeting, so members will recognise the level of his commitment to improving safety for all school pupils in the vicinity of school buses, which is the core issue.

We have seen a fair amount of activity, but rather less action. I want to draw out a couple of points from the Glasgow report, which I know that members will have read. Enhanced signage, particularly flashing lights, on school buses appears to have made them more visible, especially in darkness. The question that is posed is: to what extent does enhanced signage improve driver behaviour? The Glasgow study says that most drivers recognised that the signage told them to slow down and to be more aware and cautious. In the on-road tests, a number of drivers said that they were being more cautious. However, it is fair to say that the report is not unambiguous in suggesting that such signage the way forward.

The decision is entirely up to committee members, but I suggest that the committee seeks ways, with Transport Scotland, of extending the work that has been done in the Glasgow pilot and the changes in practice that have been undertaken in Aberdeenshire across all 32 local authorities. Although we have had a number of accidents in Aberdeenshire involving school pupils in the vicinity of buses, it is not just a local problem but a problem for the whole of Scotland. We should not allow the debate around the issue and the fruits of Ron Beaty's relentless campaign to wither without a practical result.

The Convener: Do members have any comments on how we can take the petition forward, if that is possible?

Kenny MacAskill (Edinburgh Eastern) (SNP): I take on board what Stewart Stevenson has said. We want to get a practical result and, to some extent, we have run out of road with the Scottish Government, which has been doing what it can. Given that we, too, are running out of road, we must ensure that intimation is put to the UK Government, where power rests on a variety of road traffic issues.

The issues are not minor, but quite substantial. In many ways, we are not looking for a massive change, but the change could have significant benefits. We should certainly get in touch with the Department for Transport to say that there is an issue and, to some extent, we should put our shoulder to the wheel regarding what I assume Derek Mackay and Transport Scotland have been doing.

The Convener: I would be happy with that.

John Wilson: I suggest that we continue the petition. I note that Transport Scotland, in its response of 16 November, claims to have had sight of the Glasgow report. Glasgow City Council must be commended for taking forward that piece of work, because it shows what can be done when there is determination to highlight an issue.

As well as writing to the Scottish Government and asking it to keep pressure on the Department for Transport, I suggest that we write to that department to ask its views on the Glasgow City Council report, so that we know whether it is prepared to take action. Five years ago, the then UK transport minister promised the committee that the powers to take action on the issue would be transferred to the Scottish Government. Clearly, the Department for Transport and the UK Government have failed to do that. We need to ask the department whether, on the basis of the Glasgow City Council report, it is prepared now to transfer the powers to the Scottish Government or to take the appropriate necessary action to prevent any future road traffic accidents due to the failure of school bus safety signage on British roads.

The Convener: I would be happy to do that.

Hanzala Malik: I am a little hesitant about politicising the issue. We should ask the Department for Transport exactly what it will do in response to Glasgow City Council's report, whether it is happy to adopt the approach across the country, and, if it is, what steps it will take or what programmes it will put in place to do that. Its response would indicate whether it intends to take the matter seriously.

The Convener: I think that asking that question has been suggested. The only difference was that John Wilson wanted to test how far the UK Government is prepared to go with the power. The transfer of that power has not come up in the Scotland Bill discussions, although there has been ample opportunity for that to take place. We can check out the position.

John Wilson: My point was that when the UK transport minister was at this committee in 2010, he assured us that he saw no reason why the powers on road signage could not be transferred to the Scottish Government and that meetings among officials from the Department for Transport, the Scottish Government and Transport Scotland could take place to look at transferring the powers. The issue may not have been included in the Scotland Bill, but there was an assurance at that time that that would happen. We need to remind the Department for Transport that a UK minister gave that commitment. If the UK Government is not prepared to transfer the powers, clearly the Department for Transport must look at the Glasgow City Council report and the petition in the light of road safety in Britain today, and make suggestions on how it intends to improve school bus transport safety. As I said, we should write to find out whether it is prepared to do that.

The Convener: We can ask the question; that is not a problem.

Hanzala Malik: I was suggesting that, rather than muddy the issue by asking for the UK transport minister’s views, I would rather get on with the job, and that job is the safety of children. I would rather that we get the Department for Transport to tell us what it is doing to resolve the issue and ensure the safety of our youngsters on the roads.

The Convener: That is the suggestion, Hanzala. The only difference is that an additional question will be asked.

Hanzala Malik: I did not want the issue to be confused by—

The Convener: I am not sure that it would. I am sure that the clerks will be able to formulate the letter so that it separates and distinguishes between each of the questions.

10:45

Stewart Stevenson: I say for clarity that Mike Penning was the UK minister in question. His contribution was particularly powerful because he was a fireman before he became an elected politician and he had experience of dealing with road traffic accidents as a fireman.

The issue of the power is quite narrow; it relates purely to the ability to mandate what signage there should be on buses. It is perfectly permissible to put signage on buses that goes beyond the minimum that is mandated. Mike Penning made quite a powerful point when he pointed to some examples of accidents in Wales and England, if I recall correctly, so there would be benefits to other jurisdictions if the Department for Transport, as part of the UK Government, were to take action. It could either give us the power or it could respond and act itself. In this forum, I would not want to point in a particular direction. All that matters is that the appropriate measures are taken, and that is all that my constituent Mr Beaty wishes to happen.

The Convener: I think that the committee agrees that it is prepared to ask those questions. We will take the petition forward in that way and see what responses we get. I am sure that Stewart Stevenson will continue to keep an eye on it.

Pernicious Anaemia and Vitamin B12 Deficiency (Understanding and Treatment) (PE1408)

The Convener: Our next petition is PE1408, by Andrea MacArthur, on updating the understanding and treatment of pernicious anaemia and vitamin B12 deficiency. Members have a note on the committee’s previous consideration of the petition, an update from the Scottish Government and the submissions from the petitioner. In her most recent response, the petitioner explains that she has now had sight of the guidelines and has provided comments on the content of those guidelines.

What do colleagues think?

Kenny MacAskill: I understand why the petitioner still has some concerns but, in the main, she seems to be broadly satisfied with the direction of travel. It might be that we require to allow the guidelines to bed down. If further issues follow on from that, it might be more appropriate for a fresh petition to be lodged on how the guidelines are unsatisfactory. It seems to me that some of what the petitioner initially wanted has been provided. I understand that it is too early to say whether the guidelines are working, but, if they are not, I think that that would be a new issue. It would not simply be a case of reviewing the initial petition.

The Convener: Given that the petitioner has provided more evidence, it might be worth while passing that on to the Scottish Government and asking it to comment. That will not change the guidelines, but it will allow us to get an understanding of the Government’s views on the petitioner’s comments. We can bring the petition back to the committee once we have seen those comments.

I entirely accept the point that Kenny MacAskill makes—we must wait and see how the guidelines bed in—but, given that the petitioner has made some comments on them, it would be worth seeking a response from the Government. Do members agree?

Members *indicated agreement.*

Judiciary (Register of Interests) (PE1458)

The Convener: Our next petition is PE1458, by Peter Cherbi, on the creation of a register of interests for members of Scotland's judiciary. Members have a note on the committee's previous consideration of the petition and the submissions from the petitioner.

Do members have any comments?

Kenny MacAskill: We have heard from the previous Lord President and I think that we should hear from the new Lord President, whoever he is likely to be—I do not think that there is a "she" on the shortlist. That appointment is likely to be made in the next week or so, so there is still time for him to appear before us.

The Convener: In that case, we will write to the new Lord President, as we said that we would.

Restraint and Seclusion in Schools (National Guidance) (PE1548)

The Convener: Our next petition is PE1548, by Beth Morrison, on national guidance on restraint and seclusion in schools. Again, members have a note from the clerk and the submissions from the Scottish Government.

Will we just keep the petition open and see what progress is made? We can look at it again in the new year. Is that okay?

Members *indicated agreement.*

American Signal Crayfish (Trapping) (PE1558)

The Convener: The next petition is PE1558, by John Thom, on behalf of the RNBCC Crayfish Committee, Ken-Dee Catchment, on the American signal crayfish. Members have a note on the committee's previous consideration of the petition. We have received submissions on the petition from Scottish Natural Heritage, the Scottish Environment Protection Agency, the petitioner and Abigail Stancliffe-Vaughan.

I think that we might have to get back to SEPA and SNH to ask for an update on where they stand on the proposal. We could also ask the Scottish Parliament information centre to do a bit of work on it. Do members think that that would be useful? It cannot do any harm to ask. We will do that to get as full a picture as we can. Are there any specific questions that members think we need to pursue?

John Wilson: I suggest that we ask SEPA and SNH to respond to Abigail Stancliffe-Vaughan's comments on trapping and the other issues that have been raised in her submission so that they have something tangible to respond to. There seem to be divided opinions about the best way to deal with—or not to deal with—American signal crayfish, so it would be useful for SNH and SEPA to respond to something tangible, and the issues raised by Abigail Stancliffe-Vaughan are something that they could look at.

The Convener: Are members agreed on that?

Members *indicated agreement.*

Scottish Red Ensign (PE1569)

The Convener: Our next petition is PE1569, from George McKenzie, on the reintroduction of the Scottish red ensign. Members have a note on the committee's previous consideration of the petition. Do members have any suggestions?

Angus MacDonald (Falkirk East) (SNP): Given that we are still awaiting a response from the petitioner to the minister's recent letter, I think that we should wait to see what the petitioner's response is. The minister's letter is quite encouraging. He states:

> "I have sought advice on the legal position in relation to the flying of different ensigns within the same shipping register. Our understanding is that this is not currently permitted under international maritime law."

However, he goes on to say that he would be prepared to pursue the issue with the UK Government along with the petitioner, so it is only right that we hear from the petitioner before we make any further decisions.

The Convener: The petitioner did send a letter on 27 November. We might want to send that letter to the minister and get the minister's response to it. We could then consider the petition again in the new year. Is that okay?

Members *indicated agreement.*

John Wilson: I am looking at the letter from the DFT. I might be misreading it, but it seems to conflict with what the minister said about the flying of the red ensign. It states:

> "Any such request for colours other than those that constitute the red ensign should include an example and description".

I am looking for clear guidance on what the DFT is saying in relation to any application. I know that there are a number of ships that sail in Scottish waters and fly under different colours, and it would be useful to get clarification. The committee cannot ask the DFT to grant the power to fly the red ensign with a saltire on it, but it would be useful to find out whether the Scottish Government would be prepared to advise the petitioner on how to make such an application if they were so minded.

The Convener: I am happy to pursue that point.

Hanzala Malik: I am very pleased with the minister's response. It is important to try to assist the process of allowing people to fly the flag. It is important for our shipping to be able to do that. A lot of other nationalities do it, so I do not see why we cannot do it. I would very much welcome the ships being registered in Scotland as well, unlike many shipping companies that are registered all over the world and fly different flags on their ships. I think that we should continue the petition on that basis and allow the minister to go the extra mile for us.

The Convener: There seems to be agreement that we have a few questions to ask, so we will continue the petition and ask those questions.

Child Contact (Parental Rights) (PE1570)

The Convener: Our next petition is PE1570, from Alan Lee, on parental rights to child contact. Members have a note from the clerk and a number of submissions. The submissions include a response from the organisations that we wrote to as well as a submission from Families Need Fathers Scotland in support of the petition.

There are other petitions that relate to this one. It would be useful if we got all the information back on those other petitions so that we could consider them together—not necessarily in one bundle, but certainly around the same time and with the full information available to us. I suggest that we defer consideration of the petition until we have more information in relation to the other petitions.

Hanzala Malik: I am happy to continue the petition.

Members *indicated agreement.*

The Convener: Thank you. We will do that.

Food Banks (Funding) (PE1571)

The Convener: Our final petition is PE1571, from John Beattie, on food bank funding. Members have a note on the committee's previous consideration of the petition and the submissions that we have received from food banks, local authorities and the Scottish Government.

Given that the Scottish Government is establishing the social justice action plan, it might be useful to wait until we see the outcome of that and look at the submissions that we have received in the context of the plan that the Government has set out. The Government will be talking to the same organisations as we would, and I do not think that there is any point in duplicating the work. Are members agreed on that?

Members *indicated agreement.*

The Convener: We will now go into private session to discuss agenda item 3.

10:56

Meeting continued in private until 11:00.

Published in Edinburgh by the Scottish Parliamentary Corporate Body

All documents are available on
the Scottish Parliament website at:

www.scottish.parliament.uk

Information on non-endorsed print suppliers
Is available here:

www.scottish.parliament.uk/documents

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000
Textphone: 0800 092 7100
Email: sp.info@scottish.parliament.uk