The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

PUBLIC PETITIONS COMMITTEE

Tuesday 5 February 2013

Session 4

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PUBLIC PETITIONS COMMITTEE
3rd Meeting 2013, Session 4

CONVENER

*David Stewart (Highlands and Islands) (Lab)

DEPUTY CONVENER

*Chic Brodie (South Scotland) (SNP)

COMMITTEE MEMBERS

*Jackson Carlaw (West Scotland) (Con)
*Adam Ingram (Carrick, Cumnock and Doon Valley) (SNP)
*Angus MacDonald (Falkirk East) (SNP)
*Anne McTaggart (Glasgow) (Lab)
John Wilson (Central Scotland) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Lorraine Cleaver
Sandra Whyte

CLERK TO THE COMMITTEE

Anne Peat

LOCATION

Committee Room 4

Scottish Parliament

Public Petitions Committee

Tuesday 5 February 2013

[The Convener *opened the meeting at 10:03*]

Decision on Taking Business in Private

The Convener (David Stewart): Good morning everyone, and I welcome you all to today's meeting of the Public Petitions Committee. As usual, I ask everyone to switch off any mobile phones or other electronic devices as they interfere with our sound system.

We have apologies from John Wilson.

Agenda item 1 is a decision on taking business in private. I seek the committee's agreement to take item 4 in private. Is that agreed?

Members *indicated agreement.*

New Petitions

Thyroid and Adrenal Testing and Treatment (PE1463)

The Convener: There is one new petition for consideration today. Petition PE1463, by Sandra Whyte, Marian Dyer and Lorraine Cleaver, is on effective thyroid and adrenal testing, diagnosis and treatment. Members have a note from the clerk, the Scottish Parliament information centre briefing and the petition.

I welcome the petitioners. Thank you for coming to the Parliament. It must have been quite difficult for you to travel today; it is not a nice day at all. Thank you so much for coming. I ask Sandra Whyte to make a brief presentation of approximately five minutes, after which I will start with some questions and then pass over to my colleagues. We are grateful to both of you for giving up your time.

Sandra Whyte: Convener and members of the committee, thank you for bringing us here today. We are very proud to be Scottish today and to be showing how it is done. Many thousands of people and agencies are trying to get our point across to Parliament and asking it to do something about it. We are speaking for them.

I have personally had a nightmare trying to get a diagnosis from the national health service. It was 14 years before I got a diagnosis. I was in so much excruciating pain that the NHS investigated me for multiple sclerosis and did a muscle test on me for muscular dystrophy. I was that disabled. I was becoming unconscious three or four times a day. I ended up as an emergency case because I was dying. I did not have a pulse, I was grey and my lips were blue. I went to the hospital and I was brought round, but I was sent out without a diagnosis.

Doctors are seeing this all the time and they are frustrated. What is happening is not fair on our doctors, because they want to help us but they do not have access to the testing and treatment for the condition that we are talking about today: a conversion failure of the inactive T4 thyroid hormone to cross over into the active T3 hormone. That does not happen in the thyroid gland at all. The Royal College of Physicians guidance seems only to cover people who can convert normally, and we agree with it that levothyroxine is the right treatment for those people. We do not convert normally and we are stuck in a no-man's-land of not being able to get a diagnosis. Doctors need to have much more autonomy so that they can do the proper testing.

The tests are out there, but they are not in the NHS. We had to get private testing done, and that showed it up straight away. After 14 years, this miracle doctor said, “This is what’s wrong with you, Sandra.” I got the T3 tablets and, within two weeks, my pain had gone. I went back to the doctor and asked him to do a muscle enzyme test on me. It had been raised for 10 years and my cholesterol had been sky high. Both of those tests were back to normal within two months. Despite that, thousands of people out there are not being given the right treatment.

We are asking for guidelines for the specific non-conversion condition. We also need our adrenals to be working properly for that conversion to take place, so adrenal testing should also be done, even before the patient is given levothyroxine. We need to have enough cortisol from the adrenals to be able to convert. The conversion happens within the peripherals of the body such as the liver and the gut, not in the thyroid. By definition, primary hypothyroidism is a problem within the thyroid gland, but the condition that we are talking about is not within the thyroid gland. It is about the hormone that comes from the thyroid gland that becomes inactive. If there is a failure of deiodinase of any kind, and it could be because of low adrenals, the conversion does not happen.

Doctors see the signs, and we were telling them what was wrong. I was saying that something was wrong with my metabolism and I was not getting any energy from my food. I felt like I could not breathe. We were telling the doctors what was wrong and giving them our symptoms. Doctors need to be trained in this area.

Not being diagnosed has a knock-on effect for so many other conditions and it is costing the NHS billions of pounds. We are talking about fibromyalgia, chronic fatigue and the pain that goes with it. At the beginning of January, we watched a lady with chronic pain talking to the Parliament. What about the amount of money that is spent on that? How many of those people get a metabolic test to see whether that is the problem? The thyroid stimulating hormone T4 test can look normal so another test needs to be done for the peripheral level to see whether the hormone has gone into the cells and is working to give us energy.

Lorraine Cleaver: I am considered a success story. On advice from endocrinologists, I had my thyroid removed, with the assurance that they would replace the hormones that my thyroid could no longer make. That did not happen. I was given the standard T4, but I could not convert it. However, when I said that I had all these symptoms and severe illness, I was told that it was in my mind, that it was anxiety and that I had fibromyalgia. I nearly lost my marriage. Twelve months ago, I was about to commit suicide, but I have a little boy and a husband. If it was not for a charity, I would not be here. Thyroid UK put me in touch with a humane doctor, who saved my life.

I will finish by saying that there are 82 medicines for type 2 diabetes available on the NHS list, 47 for depression, 45 for acne, 16 for athlete’s foot, three for hiccups, three for dandruff and one for thyroid—there is something very wrong.

The Convener: Thank you very much for raising the committee’s awareness of the difficulty that both of you have experienced. I think that Lorraine’s story captured the imagination of the committee, and I am sure that it would do so more widely. I am certainly convinced by the story that both of you have told the committee today. However, is there evidence that there is a wider problem with the way in which general practitioners are behaving on this issue? Clearly, that is the issue that the Government will throw back to us. We would like to do some spadework as we pursue the petition through its next steps.

Sandra Whyte: I think that the problem starts with GPs’ training. However, they are frustrated by the issue as well. We have gone for help after our diagnoses, but they say that their hands are tied. They are frustrated that they cannot help us.

Lorraine Cleaver: There are no guidelines in Scotland for the treatment or diagnosis of hypothyroidism. Everybody refers to the Royal College of Physicians policy document, but that was never requested by the health department—it is just the RCP’s own policy document. Ultimately, the RCP is a charity. So, because of the lack of guidelines, GPs crib from the RCP document and base their guidelines on that. However, those guidelines do not provide for people like us who do not convert T4.

Sandra Whyte: There is no mention of that in the RCP guidance notes on primary hypothyroidism. You will note that the RCP document is called “The diagnosis and management of primary hypothyroidism”. There is nothing in it about conversion failure. If we could get guidelines for that specific area that also took into account the adrenal problem, that would open up the whole area.

The Convener: So part of the issue is about procedures in the wider sense. Normally, there is Scottish intercollegiate guidelines network guidance to direct doctors on how to deal with different diseases.

Sandra Whyte: Doctors feel constrained at the moment because, if they help us—and they want to help us—they get dragged up in front of the Royal College of Physicians, which is a nightmare. The one who helped me and saved my life had that battle a number of years ago. After 14 years of my not knowing what was wrong with me, that doctor knew what was wrong with me within five minutes of seeing me. To me, that man deserves a knighthood, never mind getting struck off—in fact, he was not struck off; he ended up retiring because he wanted to help people.

The Convener: One of the positive things about this committee—although I would say this, wouldn't I?—is the fact that we can focus on issues. Recently, we have focused particularly on medical issues, such as pain relief, as has been mentioned. I will say a bit more about this later, but we have had a number of successes recently. It is thanks to Alex Neil in particular that we have managed to achieve a number of solutions to problems that petitions have raised with us. There have been three or four good examples of the committee working extremely well in that regard.

I will now pass over to my colleagues for questions, starting with Anne McTaggart.

10:15

Anne McTaggart (Glasgow) (Lab): Good morning, Sandra and Lorraine, and thank you very much for your opening comments. To follow on from the convener's question, can you describe to us any evidence that you have collated from United Kingdom sources or even further afield?

Sandra Whyte: We have been in touch with world-renowned people in the field, who are quite willing to come to Scotland with their abundance of proof. Dr Lindner in particular has so much evidence on his website alone to prove the point. It deals with all the different conditions and shows what they go on to if they are not treated. The proof is out there in abundance.

Anne McTaggart: Where is that physician from?

Sandra Whyte: Dr Lindner, who deals with hormone restoration, is in Pennsylvania.

Anne McTaggart: Could you elaborate on what communication you have had with the Scottish Government and the Westminster Government?

Sandra Whyte: Yes. Elaine Smith has been wonderful.

Anne McTaggart: She is that.

Sandra Whyte: We got in touch with Elaine Smith originally because she had debated the issue. She asked Anthony Toft about the issue. We could not believe that we were seeing in print that he was saying that doctors need to take a holistic approach to the issue and look for signs and symptoms, and that there is conversion failure. That inspired us to do what we are doing today. Elaine is brilliant; she is very passionate about the issue.

Anne McTaggart: Thank you for doing what you are doing today. It is great to see you along here.

Chic Brodie (South Scotland) (SNP): Good morning. I add my welcome to Anne McTaggart's. I just want to dwell for a minute on a particular aspect. I acknowledge what you said about the doctors, but my dilemma is about whether doctors in general—I know that you have specific examples—follow through with T4 and T3. At what stage do they decide that they must go further clinically? Are they trained sufficiently on the issue? Do they recognise the symptoms?

Lorraine Cleaver: Before I answer you, I want to say that our petition is not a gripe about the NHS. All my treatment was private. Obviously, I started with a GP, but it was private thereafter. The issue is not the NHS but the training from the RCP that filters down, which results in doctors' hands being tied on the issue.

Sandra Whyte: It is a delicate area, but the whole system needs looking at, to be perfectly honest, right back to the source. Why are we keeping people ill? That is the simple question. It was 14 years before my illness was diagnosed, and I am not the only one: there are so many out there who are getting treatment for conditions that are not the condition that they have, because doctors have not diagnosed it. Such people are given antidepressants—they are going great guns out there—because doctors do not know what else to put people's condition down to.

Lorraine Cleaver: The problems have ramped up since the introduction of the TSH test as the gold standard for diagnosing thyroid disease. That has been the standard since the 1970s but, since then, just a couple of years after the insistence on having the TSH test, two new diseases have been identified—fibromyalgia and chronic fatigue syndrome. Wherever you fall in the parameters that some laboratory has set, which change from city to city—

Sandra Whyte: They are actually denying us all the hormones. I cannot take T4, because I have a—

Chic Brodie: I understand that. The difficulty that I have—it is not a difficulty but, clearly, it is something that has to be resolved—is this. In the document "The diagnosis and management of primary hypothyroidism", the RCP states:

> "Patients with continuing symptoms after appropriate thyroxine treatment should be further investigated to diagnose and treat the cause."

Why is that not happening?

Lorraine Cleaver: We are given antidepressants, except when we get cognitive behavioural therapy, and told that we have a somatoform disorder.

Sandra Whyte: We are told that it is in our heads.

Chic Brodie: So you are saying that the diagnostic process is not being followed.

Lorraine Cleaver: Absolutely. I had fibromyalgia, allegedly. Last year, I weighed 13 stone, had high cholesterol, used a walking stick, wore a wig and was ready to take my life. I do not have any of those problems now. My new problem is that the General Medical Council is intent on deregistering the doctor who saved my life, so where will I source the pig thyroid that keeps me alive?

Chic Brodie: How often are patients referred to endocrinologists? Can endocrinologists prescribe wider treatments?

Sandra Whyte: They can prescribe T3.

Chic Brodie: Why is that not happening?

Sandra Whyte: I do not know. It is probably because GPs are not seeing the signs of thyroid and adrenal disorders in the first place. Some of the symptoms are weird—you would laugh at some of them, but they are not funny.

It is lucky that both my friend Marian Dyer—who cannot be here because she is too ill—and I had a private test, because that gave us diagnostic proof that we have adrenal exhaustion. However, I am on treatment only because I source it. When we took the proof to the doctor, he said that he could not prescribe treatment. Doctors seem to think that the hydrocortisone treatment for adrenal deficiency is a drug. It is not—it is a replacement hormone. They need to realise that the treatment is to replace hormones.

The T4 is denying us T3, T2, T1 and calcitonin. Not having those is causing all sorts of hassle. T3 is active; T2 helps to control moving from T4 on to T3; and T1 sends messages to the brain. Researchers are finding out more all the time—the references are out there.

Chic Brodie: Let us think outside the box. Are there any recommended homoeopathic cures?

Sandra Whyte: No. When we go to holistic practitioners, they basically provide replacement hormones. There are bioidentical treatments that can be sufficient.

Doctors are of the opinion that holistic practitioners are quacks. However, we are being cured, which is proof that it works. I am so grateful to be alive, but Marian Dyer is in a mess, to be honest.

Lorraine Cleaver: I am taking porcine thyroid, which is from a pig. That was in common use up until the late 1950s and into the 1960s. If you cannot tolerate the one and only medication that is available and you have a reaction to every side-effect listed on the patient leaflet, you go and tell the endocrinologist. They said to me that my condition was not thyroid related but was something else. Where do you go when faced with such an attitude? There are none so blind as those who will not see.

The NHS cannot afford the tests that we are asking for—we are aware that that might be thrown at us—but it cannot afford not to do them. I was seen privately, but that should have been done in the system. Sandra Whyte has had muscle biopsies and magnetic resonance imaging scans. The money that we must be costing the NHS is mind-boggling.

Angus MacDonald (Falkirk East) (SNP): Good morning, Sandra and Lorraine. You have raised valid points. Clearly, we will take those on board. It is also clear that you have done considerable research—well done.

According to the briefing that we have received, the Royal College of Physicians

> “does not support the use of thyroid extracts or levothyroxine and T3 combinations without further validated research”.

From what we have heard, it is fair to say that you have a negative view of the Royal College of Physicians.

I note that the background information in your petition states that a

> “Swedish Study says 70% patients are not symptom free on T4 only.”

As a follow-up to Anne McTaggart’s earlier question, given that the issue is being looked at in other countries, have any European countries taken your proposed action or the action that you would like to see in Scotland with regard to accurately diagnosing and treating thyroid and adrenal deficiencies?

Sandra Whyte: Do you mean within the equivalent of NHS-based systems?

Angus MacDonald: Yes.

Sandra Whyte: No. That is why I am proud to be Scottish. In Scotland, they have gone further than anyone else.

Lorraine Cleaver: They are slowly but surely making changes in the States. They have narrowed the reference range in which people are diagnosed, and they are looking again at that.

We are connected by social media. We are finding out that the disorder is endemic across the world. I met Sandra Whyte for the first time last night, but I feel like I have known her all my life. People such as us have to come together. We are speaking to people in the States who are horrified by what they are finding out.

Thyroid awareness month was last month. The comments on the website of the American Association of Clinical Endocrinologists are astonishing. They are beginning to listen, but that will be too late for our lifetimes.

Sandra Whyte: Thyroid Change, which is another agency that we got in touch with, is in contact with people in 125 different countries. That gives you some idea about the disorder—it is an epidemic.

Doctors' preferred treatment is T4 only—if we took only T4, we would eventually become toxic and go into an Addisonian crisis. You can die from that—it is that simple—because you are not converting the thyroid hormone. The natural treatment is perfect for the likes of Lorraine Cleaver, who have had their thyroid taken out. Those people's thyroids are not converting—they are not giving back all the hormones that we need to stay alive.

Addison's disease is when your adrenal glands fail. That condition is getting more awareness but, a few years ago, when members of my family had problems and they were taken into hospital in an Addisonian crisis, they were told that they were having a panic attack. One relative had horrendous treatment. He went years without the proper fludrocortisone treatment for Addison's disease and, after about 20 years, he found out that he was not getting another hormone, which is called dehydroepiandrosterone—DHEA—which is also made in the adrenal glands. It is crucial that that works alongside fludrocortisone. He asked the endocrinologist and the doctor whether he could get a prescription for that. He was told that they did not prescribe it—DHEA is not prescribed when your adrenals have failed.

Lorraine Cleaver: Research emerging from this country is questioning the accuracy of a TSH test. I have papers here from John Midgley in Yorkshire, who is a clinical biochemist. His latest paper, "Is pituitary TSH an adequate measure of thyroid hormone-controlled homoeostasis during thyroxin treatment?", was published two weeks ago.

Basically, thyroxin can make the blood look great, but it does not show what is going on inside your cells.

Sandra Whyte: They come up normal.

Lorraine Cleaver: The bloods look great, but that is all that is great. However, the evidence is coming through.

Angus MacDonald: I want to get back to the original question. As far as you aware, no other country is ahead of us.

Lorraine Cleaver: Not as far as I am aware. They are looking at the disorder with interest in America.

The Convener: To follow on from Angus MacDonald's question, have you had any correspondence with the World Health Organization? Its role is to co-ordinate health initiatives across the globe.

Lorraine Cleaver: No.

I noticed that, in 2008, Scotland's chief medical officer launched a three-year long-term conditions collaborative. I do not know what the outcome was, but I know that not one of the long-term chronic condition alliances in Scotland that I have looked at mentions hypothyroidism or thyroid disease, even though it is up there with diabetes.

The Convener: If the committee is so minded, it might be useful for us to contact them to get a response.

Adam Ingram (Carrick, Cumnock and Doon Valley) (SNP): I am curious about the prevalence of the disorder. You mentioned that there is increasing awareness of the condition across the world, and the committee's briefing suggests that about 103,000 people in Scotland have been diagnosed with hypothyroidism. I take it that the condition varies from individual to individual. Will you flesh that out a little bit?

10:30

Sandra Whyte: That is why we are asking for the medication to be targeted to individuals. Our chemical build-ups are all different, and we all have to adjust differently to our chemistry. That is why there should be the tests that we are asking for. There is a fantastic metabolic analysis test that covers the whole spectrum.

I am sorry—did you mention 103,000 people in Scotland?

Adam Ingram: Yes. Some 103,000 people have been diagnosed with hypothyroidism.

Sandra Whyte: They are lucky. If they are on levothyroxine and are converting the thyroid hormone, that is excellent. They are on the right treatment with levothyroxine. We do not have a problem with that or the guideline on it, but we need to address the problem of the failure of that.

Adam Ingram: I was trying to tease out the numbers. How many people who are diagnosed with hypothyroidism have the problem that you have described?

Lorraine Cleaver: I spoke to my endocrinologist on Friday. He is an NHS endocrinologist, and he said that, obviously, he is just sent the people who still have problems, and everybody else is at home doing great. He said that he sees possibly 20 per cent of the people who have been diagnosed. About 20 per cent have problems and still have symptoms, and he prescribes T3 on occasion. However, he has also told me that he feels hamstrung. He feels that giving those people T3 is still frowned upon, but he is frustrated that he cannot make his patients well.

My response to that was, “You’re seeing the 20 per cent of people who are questioning things in the way that I did. For six years, I believed what I was told, which was, ‘You’ve got high blood pressure. You need to lose weight. You’re depressed. You’ve got fibromyalgia.’” If a person believes those tags, they will never push to see an endocrinologist, get help, and work out that the T4 is not converting. They will not know about that.

Twenty per cent of 103,000 people are sent to endocrinologists. That is not a lot. They are the people who are lucky enough to have been diagnosed in the first place and to have fitted into the little TSH parameter, and the people who have said, “No, I’m sorry. I don’t have fibromyalgia or lazyitis.”

Adam Ingram: The figure of 20,000 is quite a lot. We are talking about 20 per cent of 100,000.

Lorraine Cleaver: Yes, but I asked why it is acceptable that the test misses so many people, and it comes down to money.

Adam Ingram: You both alluded to doctors who have tried to provide a solution for you getting into trouble with their professional bodies. On what basis did they get into trouble with their professional bodies?

Sandra Whyte: It tends not to be the patients who make the complaints; rather, it tends to be other doctors who do so.

Lorraine Cleaver: My doctor is Scottish and he is called Dr Skinner. He is not an endocrinologist. He started out as a virologist, but he restores people to health. He says, “I’m doctoring. I will treat you by your symptoms first and foremost, because the blood test doesn’t always accurately show what’s wrong.”

Sandra Whyte: We are now getting so good that we can spot people with a problem ourselves. I met my sister for the first time—

The Convener: I am sorry to interrupt, but on a technical point, it is probably best if we do not name individual doctors.

Sandra Whyte: Right. Sorry.

My sister has been in New Zealand for 25 years, and I had not seen her until this summer. As soon as I opened the door, I thought, “You have a conversion problem,” and she did. She got the tests done and she went back to New Zealand. She has been ill all her life and on levothyroxine, and she was toxic. She is now on T3 only and is fantastic.

Chic Brodie: Does that suggest that there is a genetic disorder?

Sandra Whyte: Yes, there is. That has been proven. A gene has been found with a default in the deiodinase, which can cause a bit of a problem. There are quite a few references to that in various books; Mark Starr refers to it in his book. There is evidence that the condition can be genetic, as well, so there is quite a wide range of reasons for it.

Chic Brodie: I want to ask about the figure of 20,000 that my colleague Adam Ingram mentioned and the research that you have done. This is probably an unfair question, particularly for Lorraine Cleaver, on the basis that she was seen privately. Is there any health board area in Scotland where diagnosis is not being done effectively? Let me be positive: is there a particular health board where it is being done effectively?

Sandra Whyte: About three months ago, I met the doctor who helped me and said that I was a genuine soul and that the problem was not in my head, and I told him what was wrong with me 14 years ago. He said, “Oh, well. The TSH test wouldn’t have been any good to you.” I said, “I don’t believe you’ve just said that.”

Chic Brodie: I understand that, but is there—

Sandra Whyte: I am saying: please send them to him in the Lochaber area.

Chic Brodie: I am sure that he will be delighted to hear that.

Is there any evidence that some health boards are being more effective than others in addressing the issue? If there is not, please say so.

Lorraine Cleaver: There is no evidence that we could find. We could not believe how little statistical data there is on the illness, considering that for every man that it affects, it affects 10 women. It is an extremely common condition. People often think that it is easily treated and that you just take one little thyroid pill a day. It is unfair that it has garnered that reputation, because the British Thyroid Foundation opens its paper on the condition with the sentence:

> “Hypothyroidism is an insidious condition with significant morbidity and the subtle ... symptoms and signs may be mistakenly attributed to other illnesses”.

It also says that it is

"ten times more common in women than in men."

There is no reason for it to be missed.

Anne McTaggart: My question has been answered; it was about the gender-specific nature of the condition. You have said that it is 10 times more common in women.

Lorraine Cleaver: It is also hormonal. Women tend to bear the hormonal burden, with pregnancy and so on.

Sandra Whyte: Childhood sexual abuse is horrendous. A child who is constantly stressed produces cortisol all the time. Eventually, that knocks the thyroid out and causes the conversion problem. Post-traumatic stress kicks in and it continues throughout their life. The same is true of people who are in war zones. A system that would help such people should be looked at.

The Convener: Thank you for that point. Do members wish to ask anything else?

Members: No.

The Convener: As we have no more questions, I thank both witnesses for coming along. Although, at one level, it is quite a technical issue, you have raised the committee's awareness of the massive problems that the condition causes.

My view is that we certainly need to continue the petition and to do a bit more work on it. We would usually write to the Scottish Government, and it might be useful to ask it for a working group to be set up to do a bit more spadework on the issue. Lorraine Cleaver mentioned that there are hardly any statistics on the condition, which is quite worrying.

The clerks have suggested some other action that we could take, such as writing to the GMC, the Royal College of Physicians and Thyroid UK. We do not usually write to the WHO, but given the number of countries that are involved, it must have done some overall work on the issue.

Angus MacDonald: In addition to writing to the organisations that the convener mentioned, perhaps we should write to the Scottish intercollegiate guidelines network, which is the body that is responsible for publishing clinical guidelines for the NHS in Scotland. I do not know whether the committee feels that that would be appropriate.

The Convener: Certainly.

Chic Brodie: I agree.

Jackson Carlaw (West Scotland) (Con): I am concerned that we frame carefully the question that we put when we write to organisations. Given everything that we have heard, not much would be served by their writing back to us to tell us that they do not recognise the condition or that they do not have systems for it. Part of our questioning should be framed around why their approach, as we understand it, has been as it is and what they intend to do about the condition.

It would be interesting to write to the authors of the Swedish study, if possible, because otherwise we will write only to people who seem not to be very proactive on the matter. Beyond that, I do not know whether the petitioners can point us to anyone with an international awareness or specialisation to whom we could write to seek evidence. I suspect that, from the organisations that we would usually write to, we will get several responses that say, "We're not very enthusiastic," or, "A lot more needs to be understood and done before we do anything." As I said, that will not advance us much.

The Convener: The petitioners mentioned that there is best practice in America. Can you perhaps let us know after the meeting the name of that study?

Sandra Whyte: Yes, we can. The top people are willing to speak to the Parliament.

Lorraine Cleaver: Thyroid UK definitely has a database on that.

Sandra Whyte: Thyroid UK's advisers are wonderful, so please get in touch with them.

The Convener: Yes—we mentioned that earlier.

Lorraine Cleaver: Can I ask the committee something?

The Convener: Sure.

Lorraine Cleaver: It is my belief that the national health service in Scotland has always been separate and devolved and that that is nothing to do with devolution in 1999. We have always had our own health service. I saw a discussion in the committee with a lady who has congenital heart defects, and her problem was that the NHS kept waiting for updated or revised guidance from England. I wonder why that is the status quo. When we have a separate devolved health authority, why do we mimic or wait for English guidelines?

The Convener: There are long and short answers to that. The National Institute for Health and Clinical Excellence is the body that we tend to consider when it comes to the approval of new drugs. In Scotland, we have the Scottish Medicines Consortium, which does that job, too. However, if work has been done on a new pain-relief drug, for example, and NICE has approved it, it is sensible to listen to that UK body. As with education, we had a strong track record of NHS initiatives in Scotland long before devolution, so you are right that there were elements of devolution long before the Parliament was set up. However, that does not mean that we ignore best practice when organisations such as NICE make recommendations.

Sandra Whyte: It says something when NICE does not have any guidelines.

Lorraine Cleaver: I e-mailed NICE and it replied:

> "NICE has not yet been asked to produce guidance on this topic. Topics for the NICE work programme are referred to NICE by the Department of Health in line with the national priorities";

that is to say, "the national priorities" of the Department of Health in England.

The Convener: I hope that we will get some answers for you when we write to the various organisations. We will keep you up to date with progress. The petition is important.

I know that it is difficult to come before a committee, so I thank both of you for giving up your time and coming in today. The discussion has been educational for members. We will certainly pursue the issues in line with the points that my colleagues have made.

10:43

Meeting suspended.

10:44

On resuming—

Current Petitions

NHS 24 (Free Calls from Mobile Phones) (PE1285)

The Convener: Agenda item 3 is consideration of seven current petitions.

The first current petition is PE1285, by Caroline Mockford, on free calls to NHS 24 from mobile phones. Members have a note by the clerk and the submissions. Members might wish to comment, although I am sure that you will all know that the Government has agreed that the 111 number for non-emergencies will be effective from April 2014. In that light, I recommend that we close this very good petition.

On a wider issue, we should draw attention to the positive impact that our petition system in the Scottish Parliament is having on the lives of people across Scotland. I say that because the Scottish Government has announced a series of commitments in response to calls for action in three health-related petitions that we have considered. Action on the 111 number is one response. As members will know, the others are the specialist drug for cystic fibrosis and the residential pain service that it is reported will be established.

Ordinary members of the public put all those initiatives to us and the committee spent a lot of time and effort on them. We have achieved success in all those areas. Of course, we cannot achieve that on every occasion, but I thank the committee and the petitioners for raising awareness of the issues and I thank the health minister for achieving success on the initiatives.

Members: Hear, hear.

The Convener: I formally thank Caroline Mockford for raising the issue in PE1285. I recommend that we close the petition, because its aim has been achieved. Is that agreed?

Members *indicated agreement.*

Lesser-taught Languages and Cultures (University Teaching Funding) (PE1395)

The Convener: The second current petition is PE1395, by Jan Čulík, on targeted funding for lesser-taught languages and cultures at universities. Members have a note by the clerk and the submissions.

Members will know that the petition has been effective. We have raised it on a number of occasions—most recently with the Scottish Further and Higher Education Funding Council.

There is an interesting point in relation to the responses from the Scottish funding council and the petitioner. It is probably a truism that students cannot apply for courses that are not on offer. In general, how can universities assess and tap into demand, when there is no mechanism for doing that? We have considered the petition a number of times, but the Scottish funding council suggests that we write—perhaps finally—to the University of Glasgow to try to get an answer to that interesting question. We all know that there are difficulties with resources, but it is important to get to the bottom of the issue.

Members *indicated agreement.*

The Convener: We will write to the University of Glasgow to try to determine the answer to the question that I asked. The petition is important. As members know, we have had a good turnout from petitioners and students to raise awareness of the issue.

Chic Brodie: An important thing that we must be able to do is sell and export abroad, but we lack the ability to communicate effectively in the technical and commercial marketplace. When we write to the university, it would be right to raise that concern.

The Convener: I do not want to extend the argument too much—

Chic Brodie: No.

The Convener: I will make a personal point. When I was in Taiwan recently, I spoke to university students. Students from Taiwan want to study in the United Kingdom, but Scotland is not getting its fair share of students. There is demand, but how do universities sell their product—their courses—effectively in the UK and abroad?

Adam Ingram has experience of the subject from his involvement in the past.

Adam Ingram: We have a deficiency in our language expertise and we do not appear to be catching up on that.

As well as writing to the University of Glasgow, should we write to Universities Scotland for its perspective?

The Convener: It can cover the wider issue—that is a good point. Do members agree to what has been proposed?

Members *indicated agreement.*

The Convener: We will write to the University of Glasgow and Universities Scotland.

Wild Animals in Circuses (Ban) (PE1400)

The Convener: The third current petition is PE1400, by Libby Anderson, on behalf of OneKind, on a ban on the use of wild animals in circuses. Members have a note by the clerk and submissions. Members will have noted Libby Anderson’s point that regulations in England have been changed to ban the use of wild animals in circuses, and her concern is that circuses could move from England to Scotland as a result—I think that that summarises her point reasonably well.

It would be sensible to consider the petition after the Easter recess, when I hope that we will have an answer from the Scottish Government about its programme. In fairness, I say that the Scottish Government appears to be sympathetic to the point, so I do not think that there will be a huge problem, but I would rather get something in black and white from the Scottish Government. Is that agreed?

Members *indicated agreement.*

Ambulance Services (Remote and Rural Areas) (PE1432)

The Convener: The fourth current petition is PE1432, by Joseph and Anthony Duncalf, on improving emergency ambulance provision in remote and rural areas. Members have a note by the clerk and submissions.

It has been a useful petition. It appears to me that we have satisfied its objective and I suggest that we now close it because of the work that the Scottish Ambulance Service has carried out.

Members *indicated agreement.*

Miscarriage (Causes) (PE1443)

The Convener: The fifth current petition is PE1443, by Maureen Sharkey, on behalf of Scottish Care and Information on Miscarriage, on investigating the causes of miscarriage. Members have a note by the clerk and submissions.

I highlight the fact that there are still two substantial bits of evidence that we do not have: those from the British Medical Association and Tommy’s. Do members agree to wait until we get those before deciding on the petition?

Anne McTaggart: I was saddened to hear that we still await those two replies. Is it possible for us to continue the petition until we hear from those organisations to ensure that we give it a fair hearing?

The Convener: Are members happy with that?

Members *indicated agreement.*

Chic Brodie: When did we write to those organisations? I know that we discussed the petition in November.

The Convener: It was shortly after the meeting in November.

Chic Brodie: Can we encourage some of the organisations to which we write to understand on whose behalf we are asking such questions and that they should be a bit more expeditious in responding?

The Convener: Members will be aware that we raised that matter at the previous meeting and it was agreed that I would raise it at the Conveners Group to find out whether the other committees have the same issue across the board. We have had particular problems with health boards. I will try to raise it and get an answer back to the committee as soon as possible.

Chic Brodie: Thank you.

Congenital Heart Disease Patients (Care) (PE1446)

The Convener: The sixth current petition is PE1446, by Dr Liza Morton on behalf of Scottish adult congenital heart disease patients, on Scottish standards for the care of adult congenital heart disease patients. Members have a note by the clerk and submissions.

This is another very good petition. It is important that we write to the Scottish Government about it in some detail.

Do members want to add anything else about the next steps for the petition?

Jackson Carlaw: As mentioned in connection with the petition on which we took evidence today, it looks as if considerable work is being done in the NHS in England. However, it also looks as if there is no imperative to draw that work to a conclusion or expedite it. Therefore, it might be helpful if, when we write to the Scottish Government—which, to some extent, is plugged into that process and awaiting its outcome—we invite it to seek to clarify the status of that work and when it expects something to come out of it.

Most of the other evidence that we have read is highly supportive of the issues that the petitioner raised and, because I do not think that the evidence that will emerge from England will compel us to move in a different direction, I can see no reason to hesitate before Scotland gets on with doing something a bit more effective.

Adam Ingram: I am interested in the submissions with which we have been presented, particularly the one from the Golden Jubilee national hospital, which takes the lead in the Scottish adult congenital cardiac service—that is quite a mouthful.

It appears that a lot of work has been going on and that a new strategy is being put in place. I see that a new clinical network is to be launched early this year and that the first task for the adult sub-group of the network will be to consider standards appropriate for the Scottish service, which is what the petition calls for.

It would be good to get an update on where we are with all that, convener. I hope that progress has been made without necessarily waiting on what is happening down south.

Jackson Carlaw: I thought that the Scottish Government's response was quite defensive. Its response to the question "What are your views on what the petition seeks?" was rather circular. It said:

> "Scottish Government awaits with interest the outcome of the Public Petitions Committee's consideration of this petition".

I think that our consideration is that something should be being done. Adam Ingram might be correct that standards are being considered, but I am surprised that the Scottish Government was not slightly more alert to those in its response. All of that leaves me lacking confidence that there is a great impetus, despite what I read in various submissions.

The Convener: I am happy to write the Scottish Government's health policy for those standards, but I suspect that it would not want my influence.

Chic Brodie: One of the questions that we raised concerned the fact that, with this particular problem, there are no records, should a patient need to have treatment somewhere other than where they normally have treatment. The network must have some form of meaningful database so that the paperwork follows the patient and people are treated appropriately.

The Convener: Do we agree to continue the petition in terms of the points that have been raised by the committee?

Members *indicated agreement.*

The Convener: For the record—this is not to take anything away from the petition—do members agree to confirm our general position that we do not accept confidential papers, for the reason that we want all the paperwork to be open and transparent and because of potential difficulties with FOI requests?

Members *indicated agreement.*

The Convener: Of course, that general position might not apply in relation to extremely exceptional items. I will raise any such incidents with committee members.

Court Records (Access) (PE1455)

The Convener: The final current petition is PE1455, by James Macfarlane, on public access to court records. Members have a note by the clerk and the submissions.

Again—there appears to be a bit of a theme developing—we have not received the substantial response, which, in this case, is from the Law Society of Scotland. It is clearly an important body in relation to the subject of the petition. All the other evidence that we have received clearly goes in one direction but, for completeness, I would prefer to get the Law Society's view and make a decision at that point. Do members agree to do that?

Members *indicated agreement.*

The Convener: As agreed earlier, the committee will move into private session to deal with the final item of business.

10:57

Meeting continued in private until 11:40.

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