



The Scottish Parliament  
Pàrlamaid na h-Alba

## Official Report

# **PUBLIC PETITIONS COMMITTEE**

Tuesday 1 March 2011

Session 3

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**Tuesday 1 March 2011**

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**PUBLIC PETITIONS COMMITTEE**

**5<sup>th</sup> Meeting 2011, Session 3**

**CONVENER**

\*Rhona Brankin (Midlothian) (Lab)

**DEPUTY CONVENER**

\*John Farquhar Munro (Ross, Skye and Inverness West) (LD)

**COMMITTEE MEMBERS**

\*Bill Butler (Glasgow Anniesland) (Lab)  
 \*Cathie Craigie (Cumbernauld and Kilsyth) (Lab)  
 \*Nigel Don (North East Scotland) (SNP)  
 \*Robin Harper (Lothians) (Green)  
 \*Anne McLaughlin (Glasgow) (SNP)  
 \*Nanette Milne (North East Scotland) (Con)  
 \*John Wilson (Central Scotland) (SNP)

**COMMITTEE SUBSTITUTES**

Jamie Hepburn (Central Scotland) (SNP)  
 Jamie McGrigor (Highlands and Islands) (Con)  
 Dr Richard Simpson (Mid Scotland and Fife) (Lab)  
 Nicol Stephen (Aberdeen South) (LD)

\*attended

**THE FOLLOWING ALSO ATTENDED:**

Christine Grahame (South of Scotland) (SNP)  
 Alex Johnstone (North East Scotland) (Con)  
 Des McNulty (Clydebank and Milngavie) (Lab)

**THE FOLLOWING GAVE EVIDENCE:**

Anne Carpenter (Time to be Heard)  
 Dr Peter Craig (Scottish Government Directorate for Chief Medical Officer, Public Health and Sport)  
 Dr Alan McNair (Scottish Government Directorate for Chief Medical Officer, Public Health and Sport)  
 Professor Bill Scott (Chief Pharmaceutical Officer)  
 Tom Shaw (Time to be Heard)

**CLERK TO THE COMMITTEE**

Fergus Cochrane

**LOCATION**

Committee Room 1

## Scottish Parliament

### Public Petitions Committee

*Tuesday 1 March 2011*

[The Convener *opened the meeting at 14:02*]

### Current Petitions

#### Institutional Child Abuse (Victims' Forum and Compensation) (PE1351)

**The Convener (Rhona Brankin):** Good afternoon and welcome to the fifth meeting in 2011 of the Public Petitions Committee. We have received no apologies for today's meeting. As usual, I ask everyone to turn off all mobile phones and various electronic devices.

Under agenda item 1, we have 11 current petitions for consideration. We will take oral evidence on the first two petitions only: with the committee's agreement, I intend that we should spend approximately half an hour in dealing with them.

The first petition is PE1351, by Chris Daly and Helen Holland, on time for all to be heard. I welcome Tom Shaw, chair of the time to be heard forum, and Anne Carpenter, a commissioner from the forum. I also welcome Des McNulty to the committee for this petition.

Last week members received Mr Shaw's report, "Time to be Heard: A Pilot Forum Report". I ask Mr Shaw to begin by making some remarks to the committee.

**Tom Shaw (Time to be Heard):** Thank you. I want to reiterate briefly the purpose of the pilot forum—or, as it became known, time to be heard. It was set up to test the effectiveness of a confidential independent forum as a means of achieving two things: acknowledging for those who wanted to come forward the wrongs of the past that they had experienced, and providing them with an opportunity, if it worked for them, to gain some sense of progress towards closure—in a sense, some sort of therapeutic benefit—from it. Its subsidiary function was to provide information for those who needed and wanted it about what and how many other avenues they might be able to pursue other than being heard purely through the time to be heard forum.

It is fair to say that when the forum was first established, we faced three issues that caused some difficulty. One was the framework for human rights for former residents and survivors of abuse that the Scottish Government commissioned, which indicated that for a forum of our kind to be

effective, it had to be independent. Initially, we were to be part of the SurvivorScotland structure and supported from within that system. The forum then had to be developed as a separate free-standing entity. We took our own legal advice to ensure that we understood the implications of acting in that way, and we had our own staff, whom we appointed.

One of the difficulties that that threw up for us was the fact that we did not have legal protection for confidentiality. In order to protect the confidentiality of those who came to speak to us, we had to put in place arrangements to minimise the amount of identifiable information that we held, and anonymise any information that we held and ensure that we held it for as short a time as possible.

Another issue was the fact that our forum was an acknowledgement forum, not an acknowledgement and accountability forum. For some survivors, the lack of accountability was a significant issue: some saw it as the Government renegeing on what had been consulted on prior to the establishment of the pilot forum.

The third issue was concern among some former residents that time to be heard was restricted to those who had been former residents of Quarriers. They particularly wanted it to be open to all. The rationale for that restriction was set out at two stakeholder events this time last year, and it is given in part in the report. The full rationale will be on the website of SurvivorScotland alongside the report.

Because the forum was a pilot, we wanted to test as many dimensions of the process as we could. There were advantages in having an institution that had a large number of former residents about whom there were records, that drew children from all over Scotland—they were not exclusively from one geographical area—and in which there had been convictions. Those are not the only reasons, but they are some of the reasons.

In due course, we heard from 98 people. One hundred and sixty-eight people asked for information and 116 made an application. I subsequently had to refuse two of them: one had not been a resident in Quarriers and the other had worked in Quarriers at some stage but had not been a resident. In the end, of the remaining 114 people, 98 were heard. A few changed their minds after having been offered a place and a few were ill and could not come. A few others read through carefully again what it was that they would be involved in and, perhaps in the light of that, decided not to go forward.

Of the 98 from whom we heard, we had people from a range of ages and backgrounds who were

living in a very wide distribution. About two thirds were still living in Scotland, around 20 per cent were living in England and Wales and the others were scattered in Australia, the USA, Canada, Italy, France and Germany. As members may know, the other commissioner, Kathleen Marshall, and I went to Canada and heard five people there, with a view to testing the effectiveness of that as a context.

Anne Carpenter will say something about the response of the participants and some other matters such as why they chose to be heard.

**Anne Carpenter (Time to be Heard):** As the committee knows, a piece of work was commissioned separately from our work to examine how survivors felt the experience had been for them. We have had some preliminary feedback that they found the forum very helpful. There was a level of seriousness in having the Government commission Tom Shaw, Kathleen Marshall and I to run the forum independently: it had a level of seniority that gave it some credibility for the survivors. The way in which the work was carried out—people assisted the participants, both before they came in to us and again afterwards, in a supportive and non-judgmental way—was useful for people.

We asked people why they had come forward. The overriding reasons were because they wanted to have their accounts heard with some level of respect and dignity and because they wanted lessons to be learned for future generations of children who are in care. Interestingly, only three out of the 98 participants asked for financial compensation. For the rest of them, the issue of accountability seemed to be about an acknowledgement of what had happened to them. We feel that the restorative justice aspect may offer some accountability—not necessarily financial, but some acknowledgement from representatives of the organisations that inflicted the lack of care that the care that was delivered was not adequate.

**Tom Shaw:** May I add something? We were also asked to try to distil from what we heard any messages or lessons relevant to the provision of residential care today. I can summarise what we heard by saying that three themes came through.

One theme was lack of communication with children and between adults. Another was the centrality of respect in the care of a child: children were not only disrespected and denigrated but differentially respected. Some were favoured and some were not, and those experiences bear heavily in the memories and pain that individuals spoke about. The third theme was preparation for leaving care. Many felt that they were ill prepared—some would say not prepared at all—

and that, as some put it, they were abandoned after they moved out of full-time residential care.

We appreciate that standards, provision and expectations have changed dramatically since then, but we believe that those issues remain significant in 2011. We urge those who make provision to keep focusing on them—judging, evaluating and, whenever they can, improving through training and practice what is being done in those areas today.

**Bill Butler (Glasgow Anniesland) (Lab):** Good afternoon, colleagues. I have a couple of questions. They arise from the written submission from Former Boys and Girls Abused of Quarriers Homes, which was submitted at the end of November last year. In the opinion of that group of survivors,

“TTBH does not have a sufficient mandate or remit to address the issues in line with the recommendations of the Scottish Human Rights Commission ... There are no effective remedies, redress, reparation, nor effective inquiries nor access to justice remedies in the TTBH process.”

What is your reaction to that?

**Tom Shaw:** Time to be heard tests one element of what would be part of the Scottish Human Rights Commission framework, which is that of a confidential hearing committee. Recognising that, the Scottish Human Rights Commission set out five key recommendations that we should adopt in piloting this aspect of what it saw as part of a future framework, and we sought to follow those recommendations. That is one thing, for example, that led to us being established as an independent forum. In my opinion, the element of our being a confidential, non-judgmental hearing committee is critical, and such a facility has to be available to those who want it.

If you wanted me to comment on a combination of acknowledgement and accountability in one, I would say that that is impossible if we want to have the beneficial outcomes of the confidential hearing committee. If we introduce an investigative or accountability dimension, we instantly introduce an adversarial element into the forum, which would prevent a number of the people from whom we heard from coming forward to be heard.

Those people do not want to be challenged and disbelieved again; it is sufficiently traumatic for them to come back, remember the experience and recount it to people such as us. It would change the whole dimension, operation and experience of that. That is not to say that there should not be such an opportunity; however, in my opinion, there is a need for a confidential forum that does not involve that. We provided people, if they wished, with guidance on what other action they could take. That was one way of helping them. However,

we do not see accountability forming a practical combination with acknowledgement.

14:15

**Anne Carpenter:** The need for acknowledgement was the overriding reason that our participants gave for coming along to see us. They wanted an opportunity to talk. Some people had not even told their closest family members what had happened to them. There is, rightly, a strong body of people who are involved in survivor groups, but we saw a substantial number of people who had not been members of such groups. Acknowledgement, rather than accountability, was what they were looking for.

**Bill Butler:** I have one more question. What is your reaction to the strong suggestion in the document to which I have referred that the way ahead on Quarriers homes is, in the view of FBGA, that the Scottish Human Rights Commission recommendations be

“fully implemented in line with the framework document”?

You say that the framework is separate from this issue, and you have talked about the need for an investigative opportunity. What is your response to that suggestion as a way of proceeding?

**Tom Shaw:** As I understand it, the framework largely advocates a series of opportunities akin to those that were available in the Republic of Ireland. As you may know, those operated and were available through an investigative committee and a redress board. I am hesitant about saying whether that is the right way forward in the context of needs here in Scotland, as my attention has been focused specifically on the acknowledgement dimension. Some people are certainly looking for more than the time to be heard forum was able to provide. It is reasonable that their expectations are addressed and a way forward found. Whether the framework is the only way of doing that remains to be seen. I understand that the Scottish Government is yet to respond to the framework. For all that I know, it may indicate other ways in which some of those expectations could be met.

This ties back into your other question. At an event for survivors and service providers that we had this morning—we will have two further events tomorrow in Glasgow and one on Thursday in Aberdeen—the facilitator was the person who worked with the investigative committee. She was adamant that the people who came to the acknowledgement or confidential committee would not have come to the other committee. In Ireland, they did not have the option to attend both—they could go to one or the other. It was the experience of the accountability or investigative committee that in the region of half the people dropped out

before the experience was carried right through. They found the process too difficult to take as they went through it. I am not saying that that is an argument for not proceeding with it, but it is an issue that would have to be addressed in whatever came forward in another development for the needs and rights of survivors.

**Anne Carpenter:** I endorse those comments.

**Nigel Don (North East Scotland) (SNP):** It occurs to me, as I am sure it has to others, that one way forward might be to put the acknowledgement phase ahead of any other phase—unless, of course, a survivor insists that they do not want to go through the acknowledgement phase and that they are concerned about other matters.

**Tom Shaw:** I would be very reluctant to take things consecutively. Whatever happens needs to happen concurrently. After all, we are dealing with a body of people, many of whom are in their 70s, 80s and 90s, who simply cannot wait any longer. Anything that is done has to be front loaded and priority given to those who are older and ill. We sought to do that in the time to be heard hearings, but it was quite difficult because the illness that led us to prioritise those people was the very thing that kept pushing back the hearings. However, any other avenues that might be proposed need to come on stream sooner rather than later. If I am allowed to say this, I think that if confidential hearings are to form part of all this they need to be undertaken very soon and supportive legislation needs to be in place to protect those who come forward in such hearings and those, like us, who carry them out. Nevertheless, I would be cautious about saying that we should do this first, that next and the other after that.

**John Wilson (Central Scotland) (SNP):** I thank Mr Shaw and Ms Carpenter for their attendance and welcome their report, which I think is a step in the right direction in trying to identify and acknowledge some of the issues that have arisen for children in care. Following Mr Shaw's opening comments and Nigel Don's previous question, I note that the report indicates that the forum had no statutory protections or powers in undertaking its work. Was that a failure on the part of Government? After all, it is clear from the report that the lack of such statutory protections might have led to restrictions or limitations on certain issues that arose, details of what was happening to individuals and the information that those individuals were able to impart.

**Tom Shaw:** In line with the guidance that was provided to us, which set out the five conditions from the Scottish Human Rights Commission report that we had to meet, we sought to put in place ways and means of facilitating those who wanted to report what had been done to them and

who had not previously done so. Forgive me if I am repeating myself but I point out that, despite the fact that they had already secured convictions, some people still came to be heard. Others who came to be heard—a very small number now—are in the course of taking action, and we had to make a very straightforward arrangement with them: before they spoke to us, they should look at their legal advice and think about what they could say to us. In practice, however, they were commonly told that as long as they did not discuss the case they could talk about their experiences, which they did. Others asked us how they might take further action, and we were able to refer to guidance from In Care Survivors Service Scotland and to set out our own knowledge of these matters. Moreover, if they wanted, we were prepared to help them make contact with the police, and some of them chose to do so. Without any doubt, however, any future confidential forum's effectiveness and smooth running would be assured if the appropriate legal framework were to be in place.

**Anne Carpenter:** The legal framework could have made it quite difficult for the independent chair and commissioners and we individually sought quite a lot of independent legal advice to ensure that our obligations were made clear.

**John Wilson:** I thank Mr Shaw and Ms Carpenter for those responses. It is important that people understand the legal protections that are available not only to witnesses but to the commissioners themselves with regard to what they could ask, what they could do and how they could take forward any issues that were identified.

Returning to your report, I wish to examine an issue that is covered on page 6. There, you indicate the number of people who were contacted and how they were contacted. You indicate that you advertised the work of the time to be heard forum. That was done through the national press and one or two other publications, including *The Big Issue*.

You go on to indicate that Quarriers sent out letters to individuals who had been in touch with it over the previous five years. In addressing some of the problems that existed or which have been identified, was it sufficient for Quarriers to contact former residents and others who had been in touch with the organisation over those five years? Would it have been more appropriate for the forum to get in touch with former residents and others from Quarriers, rather than for the communication to come from Quarriers itself?

If we take forward the report, should it be up to the individual organisations with which children were in care to write to the people who should be participating in any future investigations? Should it instead be the investigatory body—given access to the resident records and possibly employee

records—to make the contacts, rather than having them come through the very organisation that some people are making complaints against?

**Tom Shaw:** That is an absolutely fair question. We operated as we did because we had to address practicalities and realities. We were concerned that advertising in the national papers and *The Big Issue* and putting information on websites might well not be enough. To be honest, we were delighted with the way in which Quarriers was willing to add a further channel. Quarriers had contact details for the 500 or so people who had been in touch with it, but it could not release them to us under data protection legislation. Quarriers took my letter and acted as a postal service. The people who came to our hearings commonly turned up with my letter, which had come through that channel.

Mindful of all the sensitivities around that, and of the position that Quarriers was in when it sent out those letters, people were thankful that that had been done. Some of them said that they did not see anything about the forum in the press—they did not know anything about it.

I did not give you one piece of information. This is a detail about the 98 people we heard from and the 114 applicants who were accepted. Four of them were accepted after the closing date. I felt that I should not refuse anyone as we were within the limit of 100 that had been set. However, some people had not heard about what was happening. One of those people was someone living in Hong Kong, whose previous address had been in Germany, and whose letter had gone from Quarriers to Germany to Hong Kong. Obviously, they did not receive the letter for quite some time.

If there was more direct responsibility on the part of a future forum in determining the distribution of such things, that would be better. We have said in our report that, were the time to be heard pilot forum to be rolled out, it would be better for the commissioners, the chair and the staff to be in place much farther in advance of the commencement of the exercise. I firmly believe that none of the information that comes from someone who wants to be heard should go to a third party. There should be privacy in all dimensions. We eventually got that, but some applications initially had to go to a postbox at SurvivorScotland. That is the way that things were intended to be, but it did not happen with the majority of applications. In future, it would be better if there was no contact of that kind.

14:30

**John Wilson:** I accept Mr Shaw's comments about how data protection could have been used to prevent the forum from directly contacting

former residents and other people associated with the homes. That is an issue.

A concern of some former residents of children's homes is that the organisations with which they were placed continue to deny any wrongdoing and to deny that anything happened in homes when those people were residents. We need to ensure that no adult who wants to raise an issue is sifted through the organisation with which they were placed. We must reach people directly, so that they can come forward without feeling that the process involves a gatekeeper that is the organisation against which they have a grievance. That needs to be on the record.

**Des McNulty (Clydebank and Milngavie)**  
**(Lab):** I have read the report and listened to what you have said, Mr Shaw. You focused strongly on acknowledgement rather than on accountability—it is obvious that the time to be heard forum focused its attention on that. As you acknowledged, you reached only the tip of the iceberg, because you focused on one institution. Historically, we know that child abuse took place in a series of institutions, so we have put one toe into a pool and not gone deeply into the matter.

You emphasised that the system is closed and confidential, which you argued has positive aspects, as it gives people who want such a system confidence in the process. However, I have two problems with the system. A confidential and acknowledgement-focused approach will not uncover the true extent of child abuse that happened in Scotland. One consequence of the route that is being taken is that, almost by definition, it will not open out the reality of what happened.

We can compare Ireland and Scotland. The consequence of the Irish process has been that historical child abuse and its extent have had a high profile in Ireland, caused all kinds of political debates and been controversial in the political system. Many people who have been subject to such abuse in Scotland feel that we have drawn the matter only slowly and grudgingly out of the closet. I do not criticise what the time to be heard forum has done—it is valid for the people who welcome the methodology—but the methodology, piloting and confidentiality have in some ways not allowed or encouraged the stories of what happened to individuals to emerge into the public domain.

Of course, there are examples of cases—I have an article from *The Sun* last week in which an individual set out what had happened to her—but I am sure that many people's stories will not be uncovered by the process that you have laid out. Even if we accept that your process is good for the people who choose to use it, does it do what we

as a society need to do to acknowledge the true extent and nature of what went on in the past?

Some people want to follow a process that involves simply acknowledgement, but other people want a process that encompasses accountability. To an extent, we have not provided that yet. The more we emphasise the track that you are here to talk about, the less likely it is that we will go down the route that some people want to see us go down, which is that there should be a formal process of accountability for what has happened.

Ultimately, people who are victims should have the right to choose between an acknowledgement route, if that is what they prefer, and an accountability route. Our problem in Scotland is that there is no accountability route. In a newspaper report on what Shona Robison had to say, it is stated that

"The forum would also help provide people seeking compensation with information on how to do so."

I do not understand how you will be able to do that. My understanding is that it is almost impossible for people to get their cases into court. There is no mechanism through which people can get legal aid for this kind of case. As long as we deny people the ability to go down the accountability route, we are not properly acknowledging what went on and it will stay in the cupboard. Some people who do not want acknowledgment will not take their cases down a route that they do not think will give them satisfaction. By the way in which it has been constructed, the acknowledgement route is designed to maintain confidentiality and thereby avoid exposure. If we carry on down that route, we will not uncover what happened or face up to it as a society.

Although I can understand what you say about needing to offer individuals who want an acknowledgement route the best thing for them, if we are also denying people an alternative and not getting the facts as they are beginning to be uncovered out into the public domain, we are not facing up to the issue.

Can I make one final point, convener?

**The Convener:** Briefly please. We set aside half an hour for the item and we have already gone over that.

**Des McNulty:** I think that the point that I have heard you make before, Mr Shaw, which is that we will learn lessons through the process, is very strange. I do not need a lengthy process that costs hundreds of thousands of pounds to tell me that the kinds of things that happened in what we describe as historical child abuse are wrong. That is not what this is about. It does not really tell us

much about good practice, which is, I hope, miles removed from the kind of things that we are talking about today.

We need to talk about systems of protection and how we prevent this kind of thing from ever being allowed to happen again. We need to find a way of getting the truth out, to give people a different route to the justice or accountability that they seek, and to stop pretending that what we are doing here is a way of delivering good practice, because I do not think that it is.

**Tom Shaw:** It is certainly not a pretence about how to deliver good practice. It is a test to see whether a particular model is effective in allowing those who want this kind of opportunity to be heard. It is not a statement that being heard is the be-all and end-all. We were asked to pilot one dimension of one aspect of responding to the needs of former residents, and we are convinced that that has value in its own right.

The lessons to be learned are about how experiences in the past can inform practice today. We focused heavily on reports of people who have left care during the past nine years and we saw the same issues being referred to in those reports as we identified from people who were there 30 years ago. There is therefore something wrong with the adjustment of practice, provision and priority that means that we are not succeeding in delivering the improvement and the guarantee.

As Anne Carpenter said, the motivation of everyone who came to be heard was to see what they could do to make the situation better for people today. That is an extraordinarily generous and responsible view from people who were there in the past.

The pilot did not attempt in any sense to say, "This is typical or representative of the whole population of former residents." That is why I keep emphasising that it was a test of a model and just one way of doing it. We will not know the extent of the problem until other opportunities are in place—whether a confidential forum or a combination of that and other things. It will take a while. It took nine years in Ireland for the process to work its way through. It is not something that will happen instantly. As I see it, one of the great frustrations for those who are former residents is about how quickly it can happen. However, you cannot let it just happen instantly; it must work its way out.

The outcome of the process is to say that here is one part of what could be an effective range of opportunities for former residents. It is vital that those who want to have that opportunity have it. More important than what Anne Carpenter and I can say is that that is what the independent evaluation of the process said. Eighty-seven per cent of those who were heard and were then

separately and independently consulted about it said that it was a worthwhile process for them. I feel that that is a very powerful affirmation of its appropriateness for them.

**Des McNulty:** For them, but that is a self-selecting group.

**Anne Carpenter:** Mr McNulty referred to lessons being learned. There is absolutely no doubt that we know that child abuse is wrong in any context. What we got from the pilot as well was that many participants said that all they ever wanted was to feel loved and cared for. My concern is that a lot of the practice in child care settings now is so much about avoiding abuse that it is not necessarily about providing a loving and caring background in which abuse is not possible. One of the lessons that can be learned, therefore, is how we can make children feel safe and cared for in a context that also balances against abuse happening. That is probably a very good lesson to get.

**Bill Butler:** I am sure that colleagues will concur with me in thanking Ms Carpenter and Mr Shaw for coming along today and talking to the committee. At the meeting in late December at which we decided to invite them to discuss the forum's report with us, it was also suggested that there might be time to invite Government ministers to give oral evidence on what happens next. That will not be possible, given that dissolution is on 22 March. However, given what we have heard today, I think that the time to be heard forum is a step in the right direction, as John Wilson said, but it is not the only thing that needs to be done along the way. It has opened up the acknowledgement dimension, to which both witnesses alluded. However, what happens next has still to be considered in terms of creating good practice and a dimension of accountability, all with the objective of creating environments in which the safety of children is paramount.

Having said all that, we cannot possibly close the petition—that would be absurd. We need to suggest to our successor committee in the legacy paper, which I think we will consider next week, that it seriously consider inviting Scottish ministers to come to the committee to talk about what happens next in light of the forum's report, and that it consider what can be taken from the report as progress as well as the other things that the report does not deal with, so that both the acknowledgement dimension and the accountability dimension are progressed and we get to a stage where survivors—victims—can, according to their own lights and wishes, progress their case as far as they wish. I suggest that we put all that in our legacy paper.

**The Convener:** Does the committee agree with that?



**Members indicated agreement.**

**The Convener:** The petition will be continued and will be put forward for the legacy paper. I thank Tom Shaw and Anne Carpenter very much for coming, as well as Des McNulty, who I am sure will follow the petition's progress with interest.

**Low-dose Naltrexone (PE1296)**

**The Convener:** The next petition is PE1296, by Robert Thomson, on behalf of LDN Now Scotland, on national health service availability of low-dose naltrexone. As the committee agreed on 8 February, we will take evidence on the petition to clarify issues around the process for considering research bids of the nature highlighted in the petition. I welcome from the Scottish Government Professor Bill Scott, chief pharmaceutical officer; Dr Alan McNair, research manager; and Peter Craig, research manager. I invite the committee to ask questions.

14:45

**Anne McLaughlin (Glasgow) (SNP):** Good afternoon. When we had an evidence session with the petitioners, we were all struck by their personal testimonies. I think that we took evidence over a year ago—certainly the petition came to us 15 months ago. Since then, I have been contacted by a number of people who have benefited from the use of LDN. As you know—this is the point of the petition—the difficulty is that it is not widely prescribed by general practitioners, which means that people often have to get it by private prescription.

There are two issues. One relates to LDN itself, which I will come on to, but there is also a broader question. If, as the petitioners and others have suggested, the pharmaceutical companies are not interested in research, primarily because it is not that profitable, does that mean that it is low cost to the NHS? What other routes to getting that research done could the petitioners go down? They are not medical experts or researchers and they do not have the contact lists. They want LDN because they are suffering from illness. They do not have the money that you would normally need to do this research without the aid of one of the pharmaceutical companies.

**Professor Bill Scott (Chief Pharmaceutical Officer):** Where there are large patient populations with unsolved need, the pharmaceutical industry would generally be interested. The profitability then becomes about whether the patient population is large enough for the industry to invest.

We met LDN Now at the committee's request. I think that we had a good meeting. The outcome was probably unsatisfactory for the petitioners in

that they did not go away with many solutions. However, all of us in the room agreed that, in order for clinicians to have some sort of faith in LDN as a potential treatment, they need to gather evidence. In order for any product to make its way through to full licensing, there needs to be robust evidence of its effect. It can then proceed through by manufacturers picking it up and applying for a licence. When it has a licence, it can be prescribed within the NHS, provided that the Scottish Medicines Consortium approves or recommends it.

What we have at present is a product for which there is no product licence, which has to be prescribed as a special medicine. That means that the prescriber takes greater responsibility for that drug than they would do were it a licensed medicine. As I understand it, the petitioners' frustration is how you get the evidence if you cannot get the research.

Today, my colleagues from the chief scientist office will, I hope, take you through some of that process to see whether we can find some accommodation or even help the petitioners to take things forward. We made it clear to them that, in our opinion, because there is a plethora of diseases in the treatment of which LDN could be used, the best way forward would be to start by focusing on one disease—probably, in common parlance, the low-hanging fruit—on which effect can be demonstrated. Making such a breakthrough would give other researchers confidence to pick up other areas.

**Anne McLaughlin:** Did you say that your colleagues were going to take us through how they might help? Although the petition is on the provision of LDN, I would like to know how people who feel that other medicines help can go down the same route.

I want to come back on what you said about special medicines and medicines that are not licensed but which can be prescribed. We were given the example of mitoxantrone, which is prescribed as an anti-cancer drug. It is not licensed to be used to treat multiple sclerosis, but it is routinely used for people with MS. The petitioners asked why, given that that is the case with that drug, it cannot be the case with this one. Moreover, naltrexone, which is 10 times the strength of low-dose naltrexone and is toxic, is routinely prescribed and is licensed. For me, that is quite confusing. I am interested to find out about those seeming contradictions.

**Professor Scott:** If a clinician prescribes a medicine off licence, they take responsibility for that. That responsibility is wider than it would be if they were prescribing a licensed medicine, so there is an additional risk.