PUBLIC PETITIONS COMMITTEE CONSIDERATION OF PE1398, PE1399 AND PE1401

QUESTIONS / ISSUE ARISING FROM COMMITTEE MEETINGS

TUESDAY 13 DECEMBER 2011

The Scottish Government—

- In the response of 8 November 2011, the Scottish Government states that it will "give consideration to the extant arrangements for appraisal of medicines to treat rare diseases". What form will this consideration take, who will be involved and what is the intended timeframe?
- What is the timeframe for the review being carried out by the Chief Medical Officer and Chief Pharmaceutical Officer of the IPTR arrangements?
- It is noted that the National Planning Forum is currently reviewing national commissioning for highly specialised services. What is the timeframe for this work?
- In the earlier response, the Scottish Government states "Within the context of PPRS and procurement legislation the NHS in Scotland can improve the procurement of orphan drugs…" What improvements can be made and what legislation is being referred to?
- Will the reviews give consideration to the specific issues raised in recent submissions by Rare Diseases UK (PE1398/N), the British Pharmaceutical Industry (PE1398/K), The Association of Glycogen Storage Disorders (UK) (PE1399/M) and PNH Alliance / PNH Scotland (PE1401/N)?

NHS Borders, NHS Dumfries and Galloway, NHS Highland, NHS Shetland, NHS Western Isles—

- Please would you respond to the Committee's earlier request for information as follows:

  Annex D of CEL 17 (2010) sets out a specific guidance framework for NHS Boards to apply when developing a written policy for Individual Patient Treatment Requests. As part of the process NHS Boards were to have written policies in place for dealing with such Requests by 1 April 2011. Does your Board have such a policy in place, if not when do you expect to have a policy in place?

NHS National Services Scotland—

- Please would you provide some background information on the Patient Access Scheme Assessment Group. What is its role? How is its membership made up? What is its relationship with the SMC?
- How does the Patient Access Scheme Assessment Group support efforts to improve the procurement of orphan drugs in order to mitigate the high cost of these medicines and improve availability?

TUESDAY 4 OCTOBER 2011

The Scottish Government—

- What are your views on the issues raised in the petitions?
- Will you undertake a review as requested by the petitioners?
- Will you ask the Chief Medical Officer to undertake a review of the criteria for accessing the individual patient treatment requests?
- What is your response to the suggestion by Alastair Kent that "the Scottish system is more likely to say no than yes to access to therapies for rare diseases"?
- The Committee was told that The Advisory Group for National Specialist Services (AGNSS) has two observers from the Scottish Government's Health Department. What consideration has the Scottish Government given to adopting a similar approach for Scotland, please give reasons?
- Within the context of the Pharmaceutical Price Regulation Scheme and procurement legislation what opportunities are there for the NHS in Scotland to improve the procurement of orphan drugs in order to mitigate the high cost of these medicines and improve availability?
- Is National Procurement managing any pharmacy contracts which include orphan medicines, and if not does it have any plans to do so. In addition, does National Procurement, from its experience, believe that there could be more cost effective ways for procuring orphan medicines?"

The Scottish Medicines Consortium

- What are your views on the issues raised in the petitions?

The Association of the British Pharmaceutical Industry (ABPI)

- What actions has the industry taken in order to make orphan medicines more economical, and what discussions has it had with the Scottish and UK Governments concerning the availability of orphan medicines?

NHS Boards

- Annex D of CEL 17 (2010) sets out a specific guidance framework for NHS Boards to apply when developing a written policy for Individual Patient Treatment Requests. As part of the process NHS Boards were to have written policies in place for dealing with such Requests by 1 April 2011. Does your Board have such a policy in place, if not when do you expect to have a policy in place?