Scottish Parliament

Cross Party Group on Psoriasis and Psoriatic Arthritis

24th September 2014

Minutes

1) Present: Dave Thompson MSP, Fiona McLeod MSP, Barbara Page (Skin Conditions Campaign Scotland SCCS)), Elizabeth McIvor (Rheumatology Nurse Specialist GG Health Board), Jim Walker (individual member), Stewart Campbell (individual member), Stewart Douglas (SCCS), Jennifer Stewart (Psoriasis Scotland Arthritis Link Volunteers PSALV), Pat Evans (PSALV), Andrew Dempsey (Scottish Inflammatory Diseases and Rheumatology Industry Group of the Association of the British Pharmaceutical Industry SIDRIG/UCB), Steve Fenwick (Novartis), Catherine O'Hara (SCCS), Carol Hallesy (PSALV), Hoda El-Mahrouki (Rheumatologist), Ewen MacLean, researcher from Robert Gordon University, Iain Campbell (NHS Education for Scotland), Mary Blackford, Group Secretary

2) Apologies: John Hunter, Lesley Diack, Lorna McHattie, Janice Johnson, Girish Gupta, Lesley Ferguson, John Macgill, Joyce Leman, Colin Morton, Amanda Simonds, Daniel Kemmett, Margaret Mitchell MSP, Linda Fabiani MSP, Claire McMahon, Malcolm Chisholm MSP, Sheila Hannay, Polly Buchanan, Marion Butchart

3) Minutes of the meeting dated 11th June 2014. Liz McIvor and Stewart Campbell had been omitted from the minutes, although all attended. On page 2 of the minutes Margaret Mitchell is noted as saying it would not be realistic to hold meetings every three months. This should read 'every month'.

   Matters Arising: Jim Walker suggested the group should register an interest in NICE Guideline development, feeling that the SIGN process in Scotland could learn from that process.

4) The future of the group

   Options: a) to retain the group as currently constituted, b) to dissolve the group and set up a completely new CPG covering a wider scope of skin and allied rheumatic conditions, or c) Submit a proposal to change the name and purpose for consideration by the Standards Committee.

   Stewart D favoured option C as did Catherine O and Hoda. Stewart C felt that to a change of name including, 'associated rheumatic conditions' would be too general. Further discussion however saw the group settle on Option C.

   Suggested name : *Cross Party Group on Skin and Associated Rheumatic Conditions*

Suggested purpose: *To provide a forum to raise awareness of skin and associated rheumatic conditions in the Parliament; including general policy, diagnosis, treatment, self-management, medical training, options for care, and to liaise with health boards and clinicians in the improvement care.*

Discussion regarding the group name. It was felt by some members that the name must include 'rheumatic' rather than mentioning PSA and but not other conditions. Hoda felt that this would be appropriate as some allied rheumatic conditions affect parts of the body other than joints.
Jim W stressed the need not to take attention from the original purpose of the group.

Stewart C was concerned about unresolved discussion concerning comorbidities and associated diseases, feeling it is very important that patients feel they are not forgotten. The title should be general, rather than one of great length trying to include a list of conditions. Suggested adding 'comorbidities', although some members felt that 'related conditions' would be more readily understood.

Jim W, however, felt that 'comorbidities' should be included in the title – they are mentioned thus in SIGN.

Steve F suggested use of 'impact of disease' in the title. Fiona suggested 'comorbidity and quality of life'. Another suggestion was the addition of 'empowerment' after 'patient care'

Early diagnosis was thought to be very important. Fiona, as a member of the Standards Committee, suggested the group would not need to indicate every issue it might consider in its title – that would be too restrictive.

Finally, the following wording was set out as the one to be put to the Standards Committee;

To provide a forum to raise awareness of skin and associated rheumatic conditions in the Parliament; including general policy,early diagnosis and treatment, self-management, medical training, options for care, comorbidities and quality of life, and to liaise with health boards and clinicians in the improvement of patient care and empowerment.

The group agreed that once any change was sanctioned by the committee, it would write to as many patient organisations as possible to publicise its work.

5) Communication from the British Association of Dermatologists (concerning reasons for not supporting the WHO resolution on psoriasis i.e. that it stigmatised psoriasis sufferers for overconsumption of alcohol and obesity. Stewart D felt the WHO could possibly be misinterpreted – in fact, the psychological effect of psoriasis could result in over-consumption of alcohol and /or food.

Clearly BAD is now well aware of the CPG. Stewart Douglas made the group aware that the new BAD President, Dr David Eedy (from Belfast) ran and was elected on a 'whole UK' ticket.

6) AOB

a) Ewen Maclean spoke about his research. Focus groups are to be set up in Edinburgh, Glasgow and Aberdeen to discuss apps for the self-monitoring of patients with skin psoriasis. Group members were asked to mention the groups to patients who might like to participate. Time required would be one session of approximately two hours. Jim Walker to inform Dr Jamie Hogg of Grampian

b) Stewart Douglas notified the group of concerns over proposed changes at the new Southern General hospital in Glasgow. The current specialist dermatology ward has 14 beds and patients are cared for by specialist nursing staff. The majority of patients occupying those beds have psoriasis. Such specialist wards have great psychological benefits over mixed wards in the treatment of skin disorders – in the latter there can be considerable stigmatisation of patients. It is proposed that dermatology patients should in future be nursed in 8 designated beds situated in general wards.

SCCS has written to the Chair of the G Glasgow Health Board, with no helpful result. Aside from the ward in Glasgow there are now only two other specialist dermatology wards in Scotland, at Monklands in Airdrie (in the constituency of Alex Neil, Cabinet Secretary for Health) and Ninewells in Dundee. Should the proposed changes be carried out in Glasgow, those other wards could also be at threat.

Since the changes at Crosshouse in Ayrshire which the group campaigned against and which saw dermatology patients nursed in general wards, difficulties with non-specialist staff have been reported. The health board has been persuaded to put in more specialist nurses than had originally been proposed.

Stewart D will keep the group informed. Jim W said that patient feedback is needed. Barbara Page said there are many moves in NHS Scotland to provide avenues for patient opinion and feedback to encourage health literacy and the empowerment of patients.

Thus far, specialist dermatology wards in Paisley, Inverclyde, Fife and Aberdeen have also been lost.

Stewart D said that Dr Robert Dawe of Ninewells wrote a paper on specialist dermatology wards which quoted some figures about, for e.g. length of stay in hospital.

Barbara Page will be attending a specialist nursing meeting as part of the European Academy of Dermatology and Venereology conference in October. She will report back to the next meeting.

7) The next meeting on Wednesday 3rd December at 6pm will include a talk by Professor Iain McInnes, Director of the Institute of Infection, Immunity and Inflammation in the College of Medicine, Veterinary Medicine and Life Sciences, University of Glasgow and Consultant Rheumatologist based in Glasgow Royal Infirmary.