

Scottish Parliament Cross Party Group on Psoriasis and Psoriatic Arthritis

Wednesday 16th January 2013

Minutes of AGM

Present: Dave Thompson MSP (convener), Fiona McLeod MSP, James Dornan MSP

Liz McIvor (Rheumatology nurse, Glasgow), Phillip Atkinson (Writer on health matters), Iain Campbell (GP & NHS Education Scotland), Janice Johnson (PSALV), Hilary Wilson (Consultant Rheumatologist, Glasgow), Lorna McHattie (Lecturer, School of Life Sciences, Robert Gordon University), Jim Walker (individual member), Polly Buchanan (NHS Service and Practice Development Manager, Galderma), Denis Johnston (Researcher to Fiona McLeod MSP), Mary Blackford (CPG Secretary)

Apologies: Stewart Douglas, David Bilsland, Stewart Campbell, Duncan Bowers, Daniel Kemmett, Maureen O'Reilly, Lesley Diack, Linda Fabiani

Election of Officers: Dave Thompson re-elected as Convener (proposed by Fiona McLeod, seconded by Janice Johnson), James Dornan elected as Vice-Convener (proposed by Fiona McLeod, seconded by Dave Thompson), Mary Blackford re-elected as Secretary (proposed by Dave Thompson, seconded by Lorna McHattie)

Ken Macintosh is currently a Vice Convener but was not able to attend the meeting. If he wishes to remain a VC, he can be re-elected at a later date.

Minutes of last meeting: The minutes of the last AGM were approved.

Revision of the group's purpose statement: Existing: *To raise awareness, improve public understanding and knowledge and work towards improving services for the needs of people in Scotland suffering from Psoriasis and Psoriatic Arthritis. These are chronic, disabling, systemic, stigmatising and misunderstood conditions which maintain a low profile in Scotland and yet impact greatly on quality of life for many thousands.*

It was agreed to amend the purpose to: *To raise awareness, improve public knowledge and understanding through the Parliamentary process and improve services for the needs of people in Scotland suffering from Psoriasis and Psoriatic Arthritis*

Fiona McLeod stressed that the group should, for example, seek to have issues raised in debates and focus its work in influencing Parliamentarians.

There will be a mental health debate next week (24th) – Fiona suggested she might be able to feed in to any speech she might make, info on Psoriasis and PSA in

speeches if given a briefing. **Action: MB to find relevant research** (Dr Andy Affleck of Ninewells was recommended)

There was agreement on the need for goals and targets re the needs of patients and ways in which clinicians can be supported and instructed on changes in attitudes to what patients need and how those needs can be notified from the patient's point of view. Lorna mentioned the need for psychological help, which very few patients receive

Janice Johnson spoke of the desirability of **linking with other CPGs** on issues of mutual interest (mentioned were Chronic Pain, Dementia and Arthritis & Musculoskeletal Conditions).

Concern continues over **implementation of SIGN Guidelines** generally and 121 in particular – another issue to be discussed with other groups. Despite guidelines being very expensive to produce, there is an issue with motivation to implement and no strategies to ensure implementation. Fiona McLeod suggested that rather than guidelines, there should be guidance. Iain Campbell suggested that instead of multiple recommendations, guidelines should have a small number of points or 'top-line requirements' as Fiona put it.

Lorna McHattie spoke of the immense cost of formulating the SIGN Guideline and says there is NHS advice against recommendations which would cost £5m or more over a 12 month period.

There was agreement that if we link in with other groups regarding implementation issues the group would have more influence. Mary Scanlon has submitted Parliamentary Questions on the subject and might be asked to chair an inter-group meeting.

Hilary Wilson spoke of an IT system called Cellma which would be a Greater Glasgow and Clyde wide for adult and paediatric rheumatology. It would streamline the collection of data on all patients and would be an opportunity to implement the SIGN guidelines for psoriatic arthritis and rheumatoid arthritis. A decision on funding is pending

Discussion took place of the **lack of audit of guidelines** once they are published – issues of time etc.

Action; MB to progress links/meetings with other CPGs on guideline implementation

Use of video clips Lorna spoke about use of this device to reach young people, for example, who use social media and who no longer read emails. ABPI has very strict guidelines on what the industry can support which would prevent companies from funding. Polly Buchanan said that there had been successful partnerships with the industry.

Management of conditions Jim Walker suggested looking at the DALLAS (Delivering Assisted Living Lifestyles at Scale) system as a model for management of conditions. Phil Atkinson suggested there may be a possibility of linking such a system with implementation of SIGN guidelines. **Action: MB to contact Dr Jamie Hogg, NHS Grampian, for further information/a request to speak to the group**

Correspondence with the RCGP on the GP curriculum. In response to Dave Thompson's letter highlighting the need for improved GP training in dermatology, Dr Ben Riley (Medical Director of Curriculum, RCGP) indicated that a proposal to extend GP training from three to four years will be considered by the medical programme boards of all four home nations.

Polly Buchanan made the point that there is a lot of pressure to "ship" treatment to Primary Care with, for example, nurse/pharmacy prescribing. She asked if the group could become involved in quality innovation for this move.

Date of next ordinary meeting: Wednesday 17th April, 2013.

