

CROSS-PARTY GROUP ON ARTHRITIS AND MUSCULOSKELETAL CONDITIONS

MINUTES OF THE MEETING ON WEDNESDAY 8 OCTOBER AT 5.30pm

1. Margaret McCulloch welcomed everyone most warmly and apologised that the June meeting had had to be cancelled on the day due to important Parliamentary business.

Minutes and Matters Arising

2. Minutes of the March meeting were formally adopted.

Dates of Future Meetings and Forward Programme

3. Dates of meetings to the end of 2015 had been circulated with details of business arranged up to June; further suggestions for inclusion in the programme would be most welcome

Juvenile Idiopathic Arthritis (JIA)

4. Jamie Hewitt presented the findings of the recent NRAS report, *A Focus on Juvenile Idiopathic Arthritis*, its aims, methodology, key findings and conclusions as well as background on the disease itself and its Scottish policy context. The main conclusions for Scotland were -

1. The Scottish Paediatric and Adolescent Rheumatology Network had adopted the ARMA/BSPAR standards of care.
2. Common protocols and guidelines were in place across the country to drive quality standards.
3. There was evidence of good collaboration with each region managing its own service, alongside regular networking clinics when visiting paediatric rheumatologists attended from Glasgow or Edinburgh.
4. Scotland was in fact performing better than other parts of the UK, with room for improvement particularly in support for transition.

5. Sharon Douglas briefed the Group on the Scottish Network for Arthritis in Children (SNAC), its history, aims, activities, national and local, future plans and an evaluation of its impact on young

members and their families. SNAC was warmly congratulated by members for their approach and achievements.

6. The following points were made in answer to questions and in discussion of the two presentations –

1. JIA is a condition distinct from adult RA but, once diagnosed, treated in a similar way, typically with Methotrexate, Biologics and, intermittently, with steroids. Access to drugs is not a major issue in Scotland, unlike England.
2. Services had moved away from the wheel and spoke model based on Glasgow and Edinburgh in favour of expert local delivery with lead professionals in all Health Board areas bar Western Isles and Orkney.
3. Capacity issues remained, however.
4. Transition into adult services was a critical matter; Arthritis Care Joint Potential Programme had much to offer teenagers at this stage.

The True Cost of Ankylosing Spondylitis to the NHS and Society

7. Dr Stefan Siebert presented the results of a health economics study conducted in Wales, the first of its kind in the UK, seeking to explore and quantify the true cost, in the fullest sense, of Ankylosing Spondylitis, as opposed to the narrower calculation of direct NHS costs. The report, with an extremely high participant response rate, was currently being submitted for publication.

8. The report demonstrated clearly that indirect costs made up a very high proportion of the total per person/per year figure - £16,263 of £19,016 – and that the whole figure was vastly more than previously reckoned and much in excess of treatment costs. Of particular significance was the finding that the entire burden in terms of loss of economic productivity related to those in whom the disease was most severe. In effect, therefore, even marginal progress in reducing disease activity and improving function would deliver huge savings.

9. Margaret McCulloch made the point that proper recognition of these costs would be very much in line with policies of early intervention and proactive spend. **She offered to write on behalf**

of the Cross-Party Group to the National Institute for Health and Care Excellence (NICE) on this matter.

10. The following points were made in answer to questions and in discussion –

1. The National Ankylosing Spondylitis Society (NASS) welcomed the research information in their drive to improve care for people with AS, including access to physiotherapy, to work towards earlier diagnosis and treatment and to help more people remain economically active.
2. Members indicated their personal experience of the condition bore out all that the research highlighted in terms of late diagnosis, fatigue causing difficulty in remaining in work and the likelihood of early retirement.
3. Delay in diagnosis was contributed to by the prevalence among those affected of young men, who tend to delay seeking help, by the huge burden of general back pain which GPs see, by the invisibility of the condition and by the inadequacy of X-rays as a diagnostic tool. (MRI is replacing this and is much more effective.)
4. The issue of benefits affected ability to stay in work potentially making possible shortened hours rather than early retirement.
5. Publication of the research would be a first step in sustaining pressure on Government on the issue of recognising indirect costs of disease.

Any Other Business

11. Members' attention was drawn to the next meeting of the Cross-Party Group on Psoriasis and Psoriatic Arthritis on 4th December 2014 at which Professor Iain McInnes would speak.

12. The next meeting of *this* Group would take place on Wednesday 26th November 2014 at 5.30pm.

13. Margaret McCulloch closed by thanking all concerned and in particular the speakers for their stimulating presentations.