

Meeting Notes Cross-Party Group: Arthritis and Musculoskeletal Conditions

Wednesday 8 November 2017

Committee Room 5

5.30pm-7.30pm

Deputy /Acting Convenor : Rhoda Grant MSP

Secretariat: Anne Simpson

1. Rhoda Grant welcomed everyone to this last meeting for 2017 -with the focus on rheumatology-research and services in Scotland.

There were apologies from MSP members-Brian Whittle MSP(Group Convenor), Pauline McNeil MSP, David Stewart MSP, Alex- Cole Hamilton MSP.

Rhoda Grant welcomed new Group member- Alexander Stewart MSP .

2. Minutes of 13 September 2017 Annual General Meeting had been circulated to all Group members and were approved.

Approved : Lorna Neill Polymyalgia Rheumatica Scotland.

Seconded : Jane McNeil Medac Pharma.

3. Matters arising/Secretary's update.

a)2018 meetings programme-meetings topics now drafted for all 4 dates –and waiting for speakers to confirm availability

b)2018 CPG Reception /Garden Lobby-some members have responded but funding not secure enough yet to proceed to application -can Group members please consider and communicate with AS as soon as possible.

c)Question from Joan Kerr/individual member(June Meeting) re effects of Brexit and access to services- Convenor Brian Whittle MSP has written to David Davis MP /Westminster and waiting on response.

d) Following on from presentation by Dr Stephan Gallacher, Consultant Physician and Lead Clinician for osteoporosis services in NHS Greater Glasgow and Clyde -Mayrine Fraser, National Osteoporosis Society, has very recently written to Brian Whittle MSP/Group Convenor re possible parliamentary question or motion to be submitted or debate to be tabled re Fracture Liaison Services in Scotland.

4. Rhoda Grant welcomed Dr Stefan Siebert , Clinical Senior Lecturer in the Institute of Infection, Immunity and Inflammation in the University of Glasgow and Honorary Consultant, in Rheumatology, NHS Greater Glasgow and Clyde.

Psoriatic Arthritis update and recent research (presentation sent to all Group members)

Dr Siebert emphasised that psoriatic arthritis is a complex conditions and can affect any age and will vary from person to person. The main points from presentation were:

The accompanying fatigue and depression not so well treated.

A psychologist in a clinic setting would be very beneficial but hard to prove cost effective.

Biologics have transformed treatment but come at a cost both to patient and to NHS.

GP knowledge not as good as it could be.

There is always the question of how aggressively to treat.

Huge advances but significant unmet need.

PsA treatment needs a stratified medicine approach

Moving towards pathogenesis-led therapeutics.

How to get the right patient the right treatment at the right time.

The Scottish Psoriatic Arthritis Observational Study (SOPHOS) and Immune-Metabolic Associations Study in PsA (IMAPA) study are indications of how Scotland will be at the forefront of improving outcomes for people with PsA.

Janice Johnson/individual Group Member (former Cross Party Group :Psoriatic Arthritis-now closed) asked if a new SIGN Guideline(Scottish Intercollegiate Guideline Network) is needed ?

Dr Siebert indicated that the upcoming NICE quality standards for spondyloarthritis should be of benefit .

(This quality standard is expected to publish in June 2018 and will cover diagnosis and management of spondyloarthritis . Spondyloarthritis is a group of inflammatory conditions that have a range of manifestations)

Maureen McAllister/ Arthritis Care Scotland commented that although medicines can be expensive, they can keep people in work. Employers do not have a good understanding of the various MSK conditions and what might be required to support people to keep working.

5. Rhoda Grant welcomed Dr Jane Gibson, Consultant Rheumatologist NHs Fife for the past 20 years and Head of the Rheumatic Diseases Unit.

The Fife Quick Pathway for Giant Cell Arteritis-fast track to diagnosis and treatment (presentation sent to all Group members).

Dr Gibson described how GCA is the most common inflammation of the blood vessels in adults in Europe.

It is disease of the elderly affecting large vessels especially temporal arteries and other extracranial branches of the carotid arteries.

The conditions presents with a variety of symptoms

New onset Headache

Visual loss

Scalp tenderness

Jaw claudication

Weight loss

Fever/sweats

Polymyalgia rheumatica (PMR)

Audit in NHS Fife had revealed weakness in the care pathway- with the impact on individuals - losing their sight – and resulting in loss of independence-but also with the implications for NHS and Social care services .

The new fast track pathway has improved outcomes – is cost effective and for the patient – preventing blindness--but GCA is a consultant diagnosis and there is a shortage of rheumatologists . Specialist training was needed prior to implementation and awareness of the new service has had to be widely disseminated throughout primary and secondary care.

Re Scotland-This fast track pathway is currently only available in NHS Fife.

Dr Gibson proposed questions to the Cabinet Secretary for Health as follows:

- Does the Cabinet Secretary know how many individuals lose sight in one or both eyes, due to GCA, each year in Scotland?
- Will the Cabinet Secretary provide both encouragement and financial support to Rheumatology departments in Scotland for the provision of staff training and ultrasound machines which would allow a Fast Track pathway to be made available for all those presenting with symptoms suggestive of GCA?

Lorna Neill ((PMR-GCA Scotland)was particularly concerned about the lack of awareness of the condition by GPs - also considering the shortage of rheumatologists throughout Scotland.

Rhoda suggested letter to be drafted to Cabinet Secretary for Health and Sport-Group members agreed.

Meeting Break - 5 minutes

6. Rhoda welcomed Dr Ruth Richmond ,(RR) Consultant Rheumatologist, NHS Borders and current President of The Scottish Society of Rheumatology .

Dr Richmond described how a project is now underway aiming to improve the quality of care provided to rheumatology patients in Scotland. A quality registry is now being introduced that will facilitate symptom tracking, self-management, shared decision-making during clinical interventions and recording of outcome measures.

(An estimated 60,000 people in Scotland have a rheumatology diagnosis, placing substantial burden on the health care system and reducing patients' quality of life. Many of these patients have difficulty accessing the information and resources they need to maintain their health.)

This project, led by Healthcare Improvement Scotland, in partnership with the Scottish Society for Rheumatology, the Health Information Centre and The Dartmouth Institute, will build on the learning from countries such as Sweden, where quality registries have been shown to lead to improvements in outcomes.

The quality registry will be piloted in two health board clinics in Scotland-NHS Lanarkshire and NHS Greater Glasgow and Clyde.

Group secretary indicated that Dr Elizabeth Murphy is already confirmed to update the Group on the project at the November 2018 meeting.

Iain Macdonald (NASS) felt that this would also be useful for other conditions

Dr Siebert reminded of the need to manage expectations. For example, his unit sees very complex cases so therefore those results may be poor-and necessary therefore not just to compare numbers.

Sheila Macleod (NRAS) welcomed this development-feeling one aspect of the project would be to act as a driver to make the patient/doctor relationship better long term.

Sheila Macleod CPG Group Member on behalf of the National (UK) Rheumatoid Arthritis Society then contributed to the session providing some update on:

Scottish Metrics for the Assessment of Rheumatoid Arthritis Treatment (SMART)

In September 2016 an initiative called SMART (Scottish Metrics for the Assessment of RA Treatment) was launched. It had been designed by a partnership working group which included clinicians (Scottish Society of Rheumatology), patient organisations (NRAS and Arthritis Care) and the pharmaceutical industry (Roche Products Ltd). The aim of SMART was to improve the quality of RA management in Scotland by means of collecting, recording and examining information gathered in routine clinic appointments. This system has been in place for a year and, in light of experience, is being relaunched.

So far, only newly diagnosed patients have been included. The second initiative – launched in October - will focus on people with established disease (diagnosed one year or more ago). Where SMART measures patient outcomes, this is looking for information and views on people's experience of the treatment and care they receive; these will be used as a basis for developing the best possible rheumatology service in line with the wishes, needs and priorities of people with the condition.

For further information, Sheila commended members to look at the 2 videos available on NRAS website- one with Dr Neil McKay from the Scottish Society for Rheumatology and the second with Sheila, John Paton and colleagues/ NRAS Scottish Ambassadors. www.nras.org.uk

7. Any other business /secretary's update

a)Iain Macdonald, National Ankylosing Spondylitis Society(NASS) announced that Debbie Cook, Chief Executive of NASS is leaving the Charity after a number of years.

Anne offered to send a letter on behalf of the Group wishing her well for the future-all approved.

b)Cross Party Group :Chronic Pain- Cross Communication continues with Group Secretary, Dorothy - Grace Elder.

Anne thanked Group members who have responded to the consultation on the DRAFT document- *Quality Prescribing for Chronic Pain – A guide for Improvement* -by the closing date of 3 November.

Background to draft document as forwarded by Dorothy-Grace Elder:

The Effective Prescribing and Therapeutics Branch of Scottish Government has been developing a document on Quality Prescribing for Chronic Pain – A guide for Improvement. This is aimed at Prescribers, Boards and Clusters in NHS Scotland. The document has been developed by a working group with representatives from pain consultants, GPs, physiotherapists, prescribing advisors and patients (through Pain Concern)and aims to promote high quality prescribing of analgesic medicines and, equally importantly, to promote non-pharmaceutical therapeutic approaches to management of chronic pain.

8. Summary of 2017 meetings and close

Rhoda Grant gave a brief overview of the wide scope of topics presented during 2017- for example how an increasingly ageing population is increasing the burden on NHS and Social Care- orthopaedic initiatives in progress to improve efficiency, save money but also improve the patient experience- but concerns remaining around resources and timely access to services- how the increasing obesity epidemic in the Scottish population and unhealthy lifestyle choices may influence the development and management of arthritis and MSK conditions -various reports from Arthritis Care re Scotland, the National Ankylosing Society and National Rheumatoid Arthritis Society have been presented reflecting the difficulties facing people with Arthritis and MSK conditions to manage their conditions and sustain and remain in employment.

Rhoda Grant reminded members that the first meeting of 2018 is on Wednesday 21 March at 5.30pm when we will hear from Andrew Fell , Paediatric Nurse Specialist and Dr Elaine Morrison , Consultant Physician/Rheumatologist . The meeting will focus on children and young people with juvenile arthritis /musculoskeletal conditions , the transition from paediatric to adult services and the work of the Scottish Paediatric and Adolescent Rheumatology Network.

Rhoda thanked this evening's speakers for their contributions and also the various organisations and charities who have covered the cost of refreshments at meetings in during 2017.

Meeting closed at 7.30pm

Attending

- MSP Members

Rhoda Grant MSP

Alexander Stewart MSP

- Speakers

Dr Ruth Richmond NHS Borders

Dr Stefan Siebert NHS Greater Glasgow and Clyde

Dr Jane Gibson NHS Fife

- Non MSP Members

Jackie Berg NHS Lothian
Alison Bacigalupo Queen Margaret University
Marion Butchart Novartis
Jill Carnevale NHS Lothian
Mayrine Fraser National Osteoporosis Society
Gail Grant ABVIE
Professor Colin Howie University of Edinburgh
Andrea Hynes- Whalley NHS Lothian
Janice Johnson individual member
Katrina Lowndes Novartis
Iain Macdonald NASS
Sheila Macleod NRAS
Jane MacNeil Medac-Pharma
Maureen McAllister Arthritis Care Scotland
Lorna Neill PMR-GCA Scotland
John Paton NRAS
Sheila Terry NRAS
Anne Simpson CPG secretariat

- Invited guests

Michael Benniworth
David Brockett
David Carrott
Jenny Carrott
Mary Mansi

Apologies

- MSP members
Brian Whittle MSP, Pauline McNeil MSP, Alex Cole Hamilton MSP, David Stewart MSP
- Non MSP members
Murray Brown NASS
Alison Culpan ABPI Scotland
Dr Joyce Davidson SPARN
Angela Donaldson Bruce Arthritis Care Scotland
Nicky Gray NHS Borders
Joan Kerr/individual member
Angie Lloyd Jones NHS Borders
Dr Elizabeth Murphy NHS Lanarkshire
Bea Nicolson PMR-GCA-Scotland
Marion Read PMR-GCA Scotland
Tracy Rendall SNAC
Dr Margaret Smith Queen Margaret University
Paulo Quadros Intlife