

Meeting Notes
Cross-Party Group: Arthritis and Musculoskeletal Conditions
Wednesday 12 September 2018
5.30pm-8pm

Convenor: Brian Whittle MSP

Also attending –new Group member Finlay Carson MSP

1. Convenor Brian Whittle MSP welcomed everyone including invited guests this evening-from the Edinburgh branch of the National Ankylosing Spondylitis Society and the NHS Lothian Rheumatology Team

Apologies – from MSP members -Alex Cole Hamilton MSP and Pauline McNeil MSP .

Rhoda Grant MSP – Deputy convenor-sent late apologies due to other parliamentary business arising

2. Annual General Meeting 2018

a) Election of office bearers. Our present Convenor, Brian Whittle, Deputy Convenor, Rhoda Grant MSP and Voluntary Secretary Anne Simpson have all offered to stand again-all approved

b) Convenor's Report

The 2017/2018 meetings programme has drawn attention to a wide range of conditions and current service provision .

- ***Osteoporosis, fragility fractures and continuing development of fracture liaison services in Scotland***
- ***National Musculoskeletal (MSK) Programme***
- ***Psoriatic Arthritis update and recent research***
- ***Giant Cell Arteritis- the Fife Service – a fast track to diagnosis and treatment***
- ***Psoriatic Arthritis update and recent research***
- ***Scottish Metrics for the Assessment of Rheumatoid Arthritis Treatment (SMART)***
- ***Transitions in Paediatric and Adolescent Rheumatology***
- ***Quality, Efficiency and the Elephant- a presentation on orthopaedic waiting times and targets***
- ***Quality Prescribing for Chronic Pain-a guide to improvement –A Scottish Government publication***

CONVENOR's additional remarks

- **As a member of the Health and Sport Committee, there have been opportunities to feed the issues raised at Group meetings into the Committee work programme as well as via letters and parliamentary questions**
- **Convenor thanked**

the speakers who have contributed their time and expertise to support this year's meetings programme and also the organisations who have covered cost of refreshments

3. Meeting Minutes for approval

Both sets of minutes approved but as the meetings were not quorate, minutes cannot be added to the Cross Party Groups section of the Scottish Parliament website. Minutes have already been circulated to all members but are also available from secretary.

4. Matters arising/Secretary's update

- **Applications to join Group**
 Lauren Bennie Devolved Nations Liaison Officer British Society for Rheumatology
 Ian Forbes Healthcare Network Lead – Scotland & North England UCB Pharma LTD
 -both approved
- **Data Protection Act and Cross Party Groups**
 Prior to completion of 2018 Annual Report ,Secretary will be sending all non msp members a request to confirm if they /their organisations wish to remain as members and also to give permission for their preferred contact details to be retained by the Group Secretary and Office of Convenor for Group business
- **From 16 May Meeting Notes**

Jo Walsh , Consultant Paediatric & Adolescent Rheumatologist, Royal Hospital for Children, Glasgow described the challenges facing the delivery of Paediatric Rheumatology services to children in Scotland

Patient numbers are increasing, there is a shortfall of both medical and nursing staff and there is the question of how to maintain skilled multidisciplinary teams- including physiotherapists and occupational therapists –all vital to support the children and their families

Questions for Convenor's consideration

a) Could the Scottish Government ensure Paediatrics are engaged with whilst

making Policy regarding medicines use?

b) Nationally accessible and standard, highly integrated low user input databases can improve patient care outcomes

Is the Scottish Government supporting initiatives to progress these?

c) What can the Scottish Government do to assist re distributing cost savings benefits to those departments making savings ?Currently money saved within drug budgets remain there?

- **From 6 June Meeting Notes**

a) As reported at last meeting, Convenor's letter to Cabinet Secretary re Giant Cell Arteritis and need for improved care pathways throughout Scotland-response received from Minister for Public Health, Sport and Wellbeing on 6/2/18 felt to be unsatisfactory by Lorna Neill-Chair of Polymyalgia Rheumatica/ Giant Cell Arteritis Scotland – lack of understanding /dismissive and also figures quoted in response are not reflective.

Convenor had therefore written again to Minister for Public Health, Sport and Wellbeing, airing concerns around the response .

Convenor subsequently received further correspondence in August with apologies from the Minister for any confusion ,highlighting that the Scottish Government is committed to improving the lives of all people in Scotland with rare diseases and referred to Scotland's implementation plan " Its not Rare to have a Rare Disease" -circulated to members as attached document

b) General group comments and discussion around quality of responses from Scottish Government:

Convenor to raise with Presiding Officer

c) Letter to Convenor from DOH re effects of Brexit -Joan Kerr felt the response was poor

Convenor continues to seek more information and will report back

d) Motion S5M-12619: Brian Whittle, South Scotland, Scottish Conservative and Unionist Party, Date Lodged: 06/06/2018 Support for Children and Young People with Arthritis (Has achieved Cross Party Support)

Question from Group members –do we have a date for debate?

Convenor will raise with Party Whip

5. Fibromyalgia : Management for the Future

- Dr Gillian Roberts

Consultant Rheumatologist and Rheumatology Managed Clinical Network Clinical Lead, NHS Greater Glasgow and Clyde

- Colin Friel
Specialist Rheumatology Physiotherapists

- Dr Colin Rae,

Consultant Anaesthetist and Pain MCN Clinical Lead

- Dr Martin Dunbar

Consultant Clinical Psychologist, Pain Management Programme

- Lindsay McLean Patient Experience – Pain Management Programme

The presentations from members of the NHS Greater Glasgow and Clyde Team described Fibromyalgia as a long term condition(chronic)condition that can cause widespread pain and tenderness over much of the body and is quite common-1 in every 25 may be affected- and that a multidisciplinary approach including support for people to manage/cope with their condition is essential-presentations were circulated to all members after the meeting

6. Self -managing my condition - keeping active to work

Murray Brown, a member of the Edinburgh Branch of the National Ankylosing Spondylitis Society –and also a long standing member of our CPG delivered an inspiring presentation—described how long it took to have a diagnosis, how he has managed his condition and also supported others over a great many years.

7. Any other business

- Update on charity merger-Arthritis Care /Arthritis Research UK
Angela -Donaldson Bruce, announced that after a very busy year of meetings and planning, the merged Charities would now be known as Versus Arthritis

8. 2019 Meetings Programme and Close

Proposed items so far include

- NRAS report on mental health, for publication November 2018
- Switching from biologics to biosimilars
- Short report-back on EULAR 'Don't Delay Connect Today' campaign sponsored cycle ride in Western Isles
- Out of Area Referrals –the personal cost
- Parliamentary event and exhibition
- Chartered Society of Physiotherapist Scotland

Programme to be discussed as an agenda item at November meeting

Dates for the Diary

Wednesday 13th March 6-8pm

Wednesday 15th May 6-8pm

Wednesday 11th September 2019 6-8pm to include AGM

Wednesday 6th November 2019 6-8pm

Last meeting in 2018 is on Wednesday 7 November at 5.30pm and will include presentations on

- *Effective Prescribing Perspective and National Procurement of Biosimilars/Biologics*
- *The Swedish Rheumatoid Arthritis(RA) Registry and progress in Scotland towards this forward-looking system of disease management*

Convenor thanked all for attending and meeting closed at 8pm

Members

Lauren Bennie	British Society of Rheumatology
Hazel Borland	Fibromyalgia Association UK
Alan Borland	Fibromyalgia Association UK
Murray Brown	National Ankylosing Spondylitis Society
Fay Campbell	NHS Greater Glasgow and Clyde
Jill Carnevale	OT/Rheumatology NHS Lothian
Angela Donaldson -Bruce	Arthritis Care Scotland/Arthritis Research UK
Sharon Douglas	Scottish Network for Arthritis in Children
Alison Elder	National Rheumatoid Arthritis Society
Dr Rosemary Hollick	University of Aberdeen/NHS Grampian
Professor Colin Howie	University of Edinburgh
Joan Kerr	Individual Member
Iain Macdonald	National Ankylosing Spondylitis Society
Sheila Macleod	National Rheumatoid Arthritis Society
Alan McGinley	Arthritis Care Scotland /Arthritis Research UK
Marie Morrison	Individual member
Eddie McGill	National Ankylosing Spondylitis Society
Jean Morton	National Ankylosing Spondylitis Society
Lorna Neill	Polymyalgia Rheumatica/Giant Cell Arteritis Scotland
John Paton	National Rheumatoid Arthritis Society /NRAS
Dr Ruth Richmond	Rheumatology NHS Borders
Amanda Simmonds	Non Celgene
Anne Simpson	CPG secretariat
Dr Margaret Smith	Queen Margaret University
Genevieve Zapate	Rheumatology, NHS Lothian

Invited speakers

Dr Gillian Roberts, Consultant Rheumatologist and Rheumatology MCN Clinical Lead, NHS GGC
 Fiona Collins, Specialist Rheumatology Physiotherapists, NHS GGC
 Robert Friel, Specialist Rheumatology Physiotherapists, NHS GGC
 Dr Colin Rae, Consultant Anaesthetist and Pain MCN Clinical Lead, NHS GGC
 Dr Martin Dunbar, Consultant Clinical Psychologist, Pain Management Programme, NHS GGC
 Lindsay McLean, Patient Experience – Pain Management Programme

Invited guests

Kirsty Barrett	Rheumatology NHS Lothian
Brian Bell	Rheumatology, NHS Lothian
Sandra Lamb	Rheumatology, NHS Lothian
Christina Macdougall	Rheumatology. NHS Lothian
Bill Tough	National Ankylosing Spondylitis Society
Jeanne Mason	National Ankylosing Spondylitis Society