

SCOTTISH PARLIAMENT

CROSS PARTY GROUP ON ARTHRITIS AND MUSCULOSKELETAL CONDITIONS

MINUTES OF MEETING ON 24 OCTOBER 2012

Introduction

1. Helen Eadie welcomed those present, in particular the speakers, Dr Joyce Davidson, Consultant Paediatric Rheumatologist, RHSC Glasgow and Edinburgh, and Professor Faisal Ahmed, Samson Gemmell Chair of Child Health, University of Glasgow.

Meeting on 27 June

2. The minutes were approved.

3. Following World Arthritis Day on 12th and World Osteoporosis Day on 20th October, the meeting would focus on arthritis and complex bone disorders in children.

Arthritis in Children

4. Dr Joyce Davidson reported that, against a background of musculoskeletal conditions being the biggest cause of disability in children, with all their educational, social and physical implications, expectations were now high for children and young people with Junior Idiopathic Arthritis (JIA): that they should enter adult life without significant disability or irreparable joint damage.

5. JIA was a common childhood condition affecting around 900 in Scotland. Where previously it had been thought children 'grew out of it', it was now clear up to 50% had some active disease in adult life. The risk of poor outcomes in cases of inadequate treatment could be markedly reduced by prompt diagnosis, early disease control, access to appropriate drug therapy and good, multi-disciplinary input.

6. Specialist paediatric rheumatology services were essential: JIA was a different disease from adult arthritis and the patients had quite distinct needs. The Scottish Paediatric and Adolescent Rheumatology Network, a managed clinical network (MCN) established in 2009, had as its aims to ensure that all children with rheumatoid disease in Scotland achieved their optimum outcome regardless of where they lived and to develop high-quality, accessible and sustainable specialist services Scotland-wide through support for local multi-disciplinary teams (MDTs) delivering care that met the highest professional standards. Support took the form of service development and guidelines, quality assurance, education and training, working with families (Scottish Network for Arthritis in Children [SNAC] was the key in this) and focusing on a smooth transition into adult services.

7. Much had been achieved: service delivery in all areas of Scotland was now linked to the MCN and with an identified, dedicated MDT; local teams were enthusiastic and knowledgeable; many more children had access to specialist care; the MDT education programme was a success; links with parents/carers were excellent. The main challenges for the future were numbers, complexity of delivery, staff turnover, the need to improve data collection and audit and the scope for a bigger Scottish contribution to research.

Osteoporosis and Complex Bone Disorders in Children

8. Professor Faisal Ahmed outlined the range of conditions for which the Bone Health Service at Yorkhill was responsible, with their origins, genetic and acquired. Osteogenesis Imperfecta (OI), a genetic disorder of reduced bone mass, might present in severe, moderate or mild forms at the rate of about 12 per annum: Yorkhill would be involved in the care of all these, to a greater extent in severe cases, as well as in the education of local centres. Though the condition endured into adulthood, all patients might expect to grow up to a good quality of life. Another concern was secondary Osteoporosis, acquired as a result of treatment for Leukaemia: fracture risk during therapy was significant and improved survival rates of these children created for the future a significant number of people with uncertain bone health. In making treatment decisions it was important to consider the whole child.

9. Rickets, a disorder of bone mineral resulting from Vitamin D deficiency, once prevalent in the indigenous white population, was now a problem more typically in people of south Asian, African and Middle Eastern origin and could present at the level of forty cases a year. Nutrition was in fact an issue in most childhood bone disorders.

10. The Glasgow Bone Health Service at Yorkhill could be seen as a hub connecting to local services, related specialists and allied health professionals (AHPs), voluntary bodies and bone services for adults: it provided education and support for patients, parents and professionals. Challenges for the future included the need to raise awareness among the public and professionals both of rare bone diseases and of Osteoporosis, the need to improve self-help strategies and pathways for long-term care into adulthood and the need to reduce variations in care across Scotland.

11. Gillian Smith, a volunteer for Arthritis Care working with the twelve to twenty-five age group, spoke of her experience of the transition process from childhood to young adult care: this period could be highly stressful, moving from the children's service which was holistic, personal and educative to the adult which, of its nature, was much less so and involved joining a patient group largely much older. Self-management was important, assertiveness training could be helpful and peer support a useful way of combating a sense of isolation, fear of the future, low self image.

12. Questions and discussion raised a number of important issues:

- At present the inherited element of JIA was not clearly understood: studies in progress would improve understanding of genetic factors.
- The CPG could help children with JIA and benefit the services which support them by raising awareness and by defending the need for specialist services which were critical to success.
- SNAC made an invaluable contribution by promoting consistent, best treatment throughout the country.
- Services which covered the key stage of transition from children/young people to adults had scope for significant improvement. A common approach should apply to and benefit all MSK conditions. **The CPG would focus on this issue at a future meeting.**
- Transition from hospital to community was another important issue: the planned integration of Health and Social Care and changes in Community Health Partnerships might stand to weaken the position and role of AHPs, so vital in supporting this transition. **The CPG might consider setting up a sub-group to discuss issues relating to AHPs.**
- **The public health message of the importance of vitamin D supplements should be promoted by MSPs using all available means.**

- The collection and analysis of sound data was vital in underpinning good practice. The Scottish Government Life Sciences Strategy favoured the development of Scotland as a centre of excellence on data: there was already significant data capture potential in the system. Experience in practice, however, varied in the consistency and quality of material currently available for use. Examples of areas in which progress would be helpful were data on the destination of adults who had passed through paediatric care and on the incidence of fractures in patients receiving therapy for other conditions. **Clinicians were asked to set out in writing precisely where there were gaps in data needed for effective service planning and provision: the CPG could then write with accuracy to the Cabinet Secretary and table a motion in Parliament.**
- Setting up the Scottish Paediatric and Adolescent Rheumatology Network had involved funding available from the National Delivery Plan: this had been allocated chiefly to specialist nurse posts and some physiotherapists. Data had proved difficult to collect – time and resources being the limiting factor – but having better information would be beneficial for assessing the quality of outcomes. The broad data which was available had been encouraging.
- The key role played by the nurse specialist was emphasised, the risk of undervaluing the post, the need for improved numbers to avoid having to treat patients, both adults and children, in oncology wards – a situation both inappropriate and tending to cause delays in treatment. **A particular problem in the Borders should be brought to the notice of Borders MSPs.**
- Raising awareness in primary care of arthritis and bone disorders in children was a priority as a means of increasing prompt diagnosis and promoting improved outcomes.
- The failure of the present system to diagnose one quarter to one half of cases of Hip Dysplasia in infants – leading to premature Osteoarthritis – was an issue which needed addressed. While Scotland's performance was in line with the rest of the UK outcomes elsewhere pointed to scope for improvement. **The CPG would discuss this at a future meeting.** [Mr Alastair Murray will make a presentation at the meeting on 12th June 2013.]

Any Other Business

13. Dr John Hunter had undertaken at the last meeting to look into whether patients were facing delays in receiving biologic treatments even after their need for these had been clinically established. He had information on this which would be sent out to members.
14. The meeting closed with warm thanks to the speakers for their excellent presentations.
15. The next meeting would be held at 5.30pm on Wednesday 5 December 2012.

Attending:

Forename	Surname	Organisation
Margaret	McDougall	MSP
Anne	McTaggart	MSP
Nanette	Milne	MSP
Faisal	Ahmed	Royal Hospital for Sick Children
Guy	Armstrong	UCB Pharma Ltd
Philip	Atkinson	
Derek	Baxter	Greater Glasgow and Clyde
Sharon	Campbell	RGN
Diane	Crake	NHS Tayside
Joyce	Davidson	RHSC, Glasgow and Edinburgh
Sharon	Douglas	Scottish Network for Arthritis in Children
Tom	Downie	NASS
Liz	Foster	National Osteoporosis Society
Jamie	Hewitt	National Rheumatoid Arthritis Society
John	Hunter	The Scottish Society for Rheumatology
Kenryck	Lloyd-Jones	Chartered Society of Physiotherapy Scotland
John	Macgill	GlaxoSmithKline
Iain	Macdonald	NASS Edinburgh
Julia	MacKinnon	National Rheumatoid Arthritis Society
Sheila	MacLeod	National Rheumatoid Arthritis Society
Sophie	Matthew	NASS
Steve	McBride	Arthritis Care/ ARMA Scotland
Alastair	Murray	NHS Lothian
Paulo	Quadros	Intlife
David	Reid	University of Aberdeen
Tracy	Rendall	Scottish Network for Arthritis in Children
Anne	Simpson	National Osteoporosis Society
Gillian	Smith	Arthritis Care
Diane	Thomson	Pfizer
Kate	Wright	NHS Forth Valley
Sandy	Young	

Apologies

Forename	Surname	Organisation
Catherine	Stihler	MEP
Duncan	McNeil	MSP
Bill	Walker	MSP

Carole	Callachan	Edinburgh Western General Hospital
Alison	Culpan	Government Relations for Devolved Nations
Ian	Dingwall	
Margaret-Mary	Gordon	Greater Glasgow and Clyde
Amy	Hefford	Abbott
Catherine	Lees	Scottish Paediatric and Adolescent Rheumatology Network
Irene	Logan	Fibromyalgia Friends Scotland
Elizabeth	Longsdale	Edinburgh Petitions Team
Alan	MacDonald	NHS Grampian
Katie	McAlarey	Greater Glasgow and Clyde
Ann	Murray	NHS Ayrshire and Arran
Michael	New	
Bea	Nicholson	Polymyalgia Rheumatica and Giant Cell Arteritis Scotland
Patricia	Osborne	Brittle Bone Society
Stuart	Ralston	Edinburgh Western General Hospital
David	Reid	University of Aberdeen
Margaret	Revie	Chartered Society of Physiotherapy Scotland
Joanne	Sheddon	GlaxoSmithKline
Roger	Sturrock	Glasgow Royal Infirmary