

Cross Party Group on Muscular Dystrophy meeting: 22.04.15

Present:

Jackie Baillie MSP, Chair of the Cross Party Group on Muscular Dystrophy
Nanette Milne MSP, Vice-Chair of the Cross Party Group on Muscular Dystrophy
Jim Eadie MSP
Jonathan Kingsley, Muscular Dystrophy UK, Secretariat for the Cross Party Group
Michael Adams
Mark Chapman with PA
Kay Hepworth
Martin Hepworth
John Miller, Action Duchenne
Mariana Pierotti, Muscular Dystrophy UK
Claire Turnball, Children's Hospice Association Scotland
Dean Widd, Muscular Dystrophy UK

Jackie Baillie MSP welcomed MSPs and guests and outlined the agenda of access to Translarna, care advisor support in the North of Scotland and access to hospice and respite facilities.

1. Translarna

Jonathan Kingsley updated everyone on the latest situation and highlighted Muscular Dystrophy UK's aim to help families who can benefit from Translarna in Scotland to access the drug as soon as possible and that time is of the essence.

Discussion points:

- Scotland has its own separate method of assessing new treatments, with the Scottish Medicines Consortium (SMC) and NHS Scotland taking decisions on which new drugs to fund. While the SMC will be observing NICE and NHS England's assessment, the SMC can reach its own decision.
- PTC Therapeutics is in discussions with the SMC and NHS Scotland about submitting an application for Translarna but a formal submission is yet to be made.
- Before this goes ahead, PTC Therapeutics must agree with the SMC on what evidence the drug company will need to submit.
- There is also a potential for NHS Scotland to take a decision directly through Health Boards, without Translarna having to go through the SMC
- PTC Therapeutics representative will attend the next Cross Party Group meeting.
- Jackie Baillie tabling Parliamentary Questions as a follow-up to these discussions.

2. Care Advisor support

The meeting was also an opportunity to discuss the need for Care Advisor support in the North East of Scotland.

Jackie Baillie briefly covered the history of securing commitment to three care advisors in Scotland and the CPG meetings putting pressure on NHS Scotland to fulfil these commitments.

Reference was made to then Health Minister Michael Matheson in a muscular dystrophy debate in the Scottish Parliament saying:

The north of Scotland has confirmed that it intends to re-advertise the post. We will monitor the situation closely, because we want the care adviser post in the north of Scotland to be filled as soon as possible. (20th November 2012)

Mariana Pierotti shared anecdotal evidence received by Muscular Dystrophy UK on the need for specific neuromuscular care advisor support in the north of Scotland.

Jackie Baillie will be raising these issues in a letter to Health Improvement Minister Jamie Hepburn MSP, and tabling Parliamentary Questions to investigate the lack of support provided. Work with the Scottish Muscle Network can move the discussion forward on gathering further evidence, next steps and possible solutions.

3. *Hospice and respite provision in Scotland*

Claire Turnball, Transition Manager at Children's Hospice Association Scotland, spoke about the work CHAS is doing to combat the lack of hospice and respite provision in Scotland. CHAS is working in collaboration with the likes of Leuchie House and to provide short respite breaks for young adults. CHAS is working closely with the 87 young adults who are being effected by the changes in the CHAS age limits so that by 2017 all 87 will have fully developed transition plans based on first hand information about the individuals and their future.

Claire Turnball talked about having individualised plans with each young person, looking at their aspiration and goals and their options. She is in close contact with Julie Robb from the Scottish Government who is closely following their work.

The team are looking at setting up short respite breaks and working with hospice providers for future options, as well as covering the emotional and psychological aspect. She emphasised the aspect of choice for the young adults and that they are doing what they can to influence care providers. The CPG will be inviting Claire Turnball later in the year to update the CPG on the progress of the team's work.

Muscular Dystrophy UK provides all the organisational support for the Cross Party Group on Muscular Dystrophy in the Scottish Parliament. For more information about the meeting and the group's activity, please get in touch on 020 7803 4839 or by email to j.kingsley@musculardystrophyuk.org