

Cross Party Group on Muscular Dystrophy

15/06/2016, 5.30pm to 7pm, TG20/TG21

Attendees:

Jackie Baillie MSP
Brian Whittle MSP
Graeme Dey MSP
Anas Sarwar MSP
Sheonad MacFarlane, Chair of Muscular Dystrophy UK's Scottish Council
Robbie Martin
Tess Martin
Barbara Martin
James Martin
Judith MacMillan
Alan MacMillan
Michelle Young
Claire Turnbull, CHAS
Martin Hepworth
Ian Robinson, Advocacy Ambassador, Muscular Dystrophy UK
Mariana Pierotti, Muscular Dystrophy UK
John Miller, Action Duchenne
Jonathan Kingsley, Muscular Dystrophy UK
Mark Chapman

Meeting summary:

AGM

Jackie Baillie MSP re-elected at Cross Party Group's Convener
Brian Whittle MSP elected as Deputy Convener
Muscular Dystrophy UK to continue as the Secretariat

Muscular Dystrophy UK update

Manifesto for Muscle during the Scottish Parliament campaign saw 17 MSPs who were elected pledge their support for faster access to treatments, better access to specialist healthcare and welfare support.

Care Advisor in north east of Scotland – paediatric care advisor / physio starting at end of June
More work to be done for improving provision for adults but paediatric role a sign of progress.

Translarna

- Michael Young met Nicola Sturgeon earlier today handing over a petition of almost 140,000 signatures calling for Translarna to be available for boys with Duchenne who would be eligible for the treatment.
- Raised concerns about the Scottish Medicines Consortium assessment and way in which Patient and Clinician Engagement process is conducted
- Asked the First Minister to write to the SMC to review its processes to incorporate a managed access agreement option like NICE have done in England

- Fundamental flaws with the process – not able to challenge evidence which is presented at an SMC meeting
- Need to tackle inconsistency between Health Boards and the postcode lottery of Individual Patient Treatment Request process
- Dr Brian Montgomery review of Access to New Medicines – findings due next month
- SMC reassessed last year to help with access to new drugs for rare conditions – changes don't seem to have improved process
- Need to highlight examples of SMC failings
- Managed Access Agreement would allow for more information and evidence gathering, gives an opportunity to negotiate on price, but would need to be a Scotland-wide agreement
- 6 monthly repeated IPTR through Health Board doesn't give any stability
- Question raised of whether denying Translarna is a human rights issue and the emotional and ethical side
- PTC – made commitment to Youngs to continue access to Translarna on compassionate grounds after clinical trial – question of how long this will continue under a duty of care
- Families asking whether moving to England is an option – but shouldn't have to relocate to access the treatment
- Scottish Government has pledged £100million for cancer research – why are rare and ultra-rare conditions worth less?
- Need to establish evidence for ambulant boys before moving to an extension trial of non-ambulant boys

Actions:

- Letter from CPG to Nicola Sturgeon on her actions following meeting with Michael
- Letter from CPG to PTC on commitment to Translarna provision for Michael
- Try to add MSP names to Translarna motion from 13th May and look to table new motion in September
- PQs over the summer to maintain awareness
- When Scottish Parliament returns on 7th September, seek to raise Translarna in Government debate

CHAS transition update

- Update from Claire Turnball at CHAS Transition Team
 - Halfway through the transition process – 20 transitioned to new arrangements so far, tailored to each individual's needs
 - Nearly 50% of those being transitioned have muscular dystrophy – most Duchenne, but also Becker and congenital
 - Looking at existing provision and linking in with adult hospices across Scotland – e.g. utilising existing space and units but avoiding unsuitable placements in care home for the elderly
 - Supporting and facilitating respite breaks where that need is identified
- Robert Watson's petition was closed by Scottish Parliament but he could re-submit

Priorities for the forthcoming year

- Translarna
- Hydrotherapy
- Hospice and respite
- Blue Badge
- Improving specialist respiratory support – lost ventilation services
- Delayed hospital discharge – costly stays in hospital and delays in setting up care packages
- Accessible housing – long waiting lists and shortage of accessible housing

PQs for Jackie Baillie to table:

“To ask the Scottish Government what assessment it has made of the provision of hydrotherapy pools for people with muscular dystrophy and neuromuscular conditions in Scotland.”

“To ask the Scottish Government what steps it is taking to improve specialist respiratory support for people with muscular dystrophy and neuromuscular conditions.”

“To ask the Scottish Government what steps it is taking to reduce delays in setting up a care package after a hospital admission.”

“To ask the Scottish Government when the next meeting of its stakeholder review group on appropriate hospice and respite facilities for young disabled adults is taking place.”