

Cross Party Group 27/01/2016

Attendees:

Jackie Baillie MSP
Roderick Campbell MSP
Jim Eadie MSP
Iain Gray MSP
Jenny Marra MSP representative

Mark Chapman
Gary Fegan
Kathryn Fergusson, Scottish Government
Natalie Frankish, Genetic Alliance
Yvonne Grant
Jonathan Kingsley, Muscular Dystrophy UK
John Miller
Kenny Munro
Mariana Pierotti, Muscular Dystrophy UK
Aaron Revel, Action Duchenne
Alex Smith, Harrison's Fund
Peter Sutton, Muscular Dystrophy UK
Lesley Swan
Michelle Young

Minutes:

Jackie Baillie welcomes guests and introduces discussion on access to Translarna.

Translarna

Jonathan Kingsley update on timeline of Translarna assessment by SMC.

9th Feb PACE meeting – as part of highlighting importance of access, necessary to show development of condition and impact of Duchenne; quotes very important.

1ST March SMC Committee meeting – PACE evidence and PTC information considered before a decision is made

11th April - Translarna decision released publicly

Michael Young to meet Nicola Sturgeon to deliver his letter on Thursday 28th January – extensive media coverage.

Jonathan Fox (SMC Chair) – write letter to increase awareness, show politicians backing campaign

ACTION: Jonathan Kingsley to write letter on behalf of CPG.

Cormac Fegan – access may run out and vital not to have a break in access. Iain Gray MSP writing to NHS Lothian to ask for update.

Jackie Baillie suggests tabling a motion for members debate before end of March (parliament dissolves) – no need to go through petitions committee. Need signatures from 3 parties.

ACTION: Jonathan Kingsley to draft motion.

PQ – data on number lost to DMD

Kathryn Fergusson – PTC has opportunity to put forward a second patient access scheme; patient/family quotes read out at SMC meeting; confidentiality around any data and information which is submitted by the company.

Hospice and Respite Facilities

CHAS transition team to release interim report end of Feb and prepared to update CPG

Independent evaluation end of year 3 (Dec 2017)

No news from Julie Robb re next meeting date

ACTION: JK to draft PQs for Jim Eadie re next meeting date and info on suitable alternatives