From: Alison Strath < [redacted S.38(1)(b)] >
Sent: 23 April 2025 14:20
To: Cabinet Secretary for Health & Social Care 2024 <CabSecHSC@gov.scot>
Cc: [redacted S.38(1)(b)]; First Minister <FirstMinister@gov.scot>; DG Health & Social Care <DGHSC@gov.scot>; [redacted S.38(1)(b)]; [redacted S.38(1)(b)]; [redacted S.38(1)(b)]; Chief Medical Officer <CMO@gov.scot>; [redacted S.38(1)(b)]; [redacted S.38(1)(b)]; [redacted S.38(1)(b)]; [redacted S.38(1)(b)]; Communications Health and Social Care <CommunicationsHealthandSocialCare@gov.scot>; Alison Strath <[redacted S.38(1)(b)]>
Subject: RE: DMD - access to givinostat - Board meeting tomorrow

Dear PO colleagues

Here are some key points that the Cabinet Secretary may wish to cover in the meeting with Health Boards

1. Family perspectives
2. Perceived or actual barriers to implementing the Early Access Programme for givinostat
3. Board/regional progress to date
4. Options to collaborate nationally
5. Actual timeline for commencement
6. Communications from Health Boards to families
7. AOB

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Cabinet Secretary for Health and Social Care – virtual meeting with NHS Boards (Grampian, Lothian, Tayside and Greater Glasgow and Clyde) on access to givinostat on 23 April 2025.

Attendees

NHS Boards
Nicky Connor – NHS Tayside (NC)
Caroline Hiscox – NHS Lothian (CH)
William Edwards – NHS Greater Glasgow and Clyde (WE)
Hugh Bishop – NHS Grampian (HB)

Scottish Government
Cabinet Secretary for Health and Social Care
Alison Strath – Chief Pharmaceutical Officer (AS)
John Burns – Chief Operating Officer (JB)
[redacted S.38(1)(b)] – Professional Lead Health Planning/Sustainability, for NHS Scotland ([redacted S.38(1)(b)])
[redacted S.38(1)(b)] – Special Adviser
[redacted S.38(1)(b)] – Team Lead Access to New Medicines
[redacted S.38(1)(b)] – Unit Head Ministerial Private Offices

The Cabinet Secretary welcomed colleagues to the meeting and provided an overview of the meeting he and AS attended yesterday (22/04) with Aamer Anwar and some of the families whose children have a diagnosis of Duchenne muscular dystrophy (DMD). He highlighted the difficulties the families face in bringing up a child with DMD and the hope they have for givinostat – a new medicine for DMD currently being offered by the company through an early access programme (EAP).

The Cabinet Secretary was keen to hear from Health Boards on what progress has been made to facilitate access to givinostat through the EAP, what if any barriers are in place to delivery, how Scottish Government can support removal of these barriers and how this can be moved forward at pace to provide hope, dignity and a standard of living that these children deserve.

NHS Tayside
NC advised that numbers in NHS Tayside are low and eligible individuals are in the process of being assessed for treatment. NC advised that there are no known barriers but highlighted the need to know whether this will be eligible for the financial risk share scheme once it has been assessed through the Scottish Medicines Consortium – however this is not a barrier to access.

NHS Lothian
CH advised the situation in Lothian is similar to Tayside. There is support for use of givinostat and this is currently going through NHS Lothian's governance processes. NHS Lothian also provide care for NHS Fife and NHS Borders. There are a total of ten eligible individuals for the EAP with a further eight non-ambulatory individuals who will require more stringent monitoring – two additional staff are required for the additional monitoring associated with the medicine. The lead clinician has reportedly written to and had personal dialogue with the families about the EAP and has also been in contact with pharmaceutical company – no specific barriers have been

identified, and a timeline is being worked through with the families and the clinical team.

NHS Greater Glasgow and Clyde
WE advised that NHS GGC is coordinating across the West, there are ten eligible individuals in GGC, with a total of 23 in the West region. Dialogue is ongoing across the West to scale up the required infrastructure with a likely start date for the first cohort of eligible individuals starting treatment at the end of May which will be accelerated where possible.

NHS Grampian
HB advised that there are six eligible individuals in Grampian and one of the island Boards. The clinical and management teams are scheduled to meet shortly and don't anticipate any barriers to access. It is likely that a prioritisation exercise will take place as the clinician has reported some concern about starting all patients at once.

The Cabinet Secretary thanked colleagues for their helpful updates and was clear that it is not his role to interfere in clinical matters but stressed his preference for treatment to be rolled out on an equitable basis across the whole of Scotland and would encourage where possible timelines to be expedited. If there is a need for a phased approach to implementation rather than all eligible individuals starting treatment at once, he would take clinical advice on that but would expect each cohort to be started as closely as possible to one another – noting that families will find it difficult to understand why one individual is prioritised over another.

The Cabinet Secretary requested that Health Boards provide clear timescales and further information on plans for starting treatment over the next few days to inform a collective response back to the families on progress. JB advised that he and [redacted S.38(1)(b)] will work with Health Boards to coordinate this.

The Cabinet Secretary concluded the meeting by thanking colleagues for their time and the work being done to facilitate access to givinostat.

Medicine Policy Unit
Pharmacy and Medicines Division
23 April 2025