

Cross-Party Group on Medicinal Cannabis

Date and Time

7 May 2025, 6pm

Minute

NHS prescriptions for Bedrolite on a named patient basis

Present

Scott Davidson (Medical Director Greater Glasgow and Clyde)

Rob Forbes

Jenny Forbes

Christelle Kelley

Laura Wilson

David Braidwood

Tess Whitei

Ben Mcpherson

Marc Landers

David Johnson

Kate Spence

Christelle Kelley

Anna Ross

Derek Stewart

Lisa Quarell

Les Angus

Jim Mills

Milica Prokic

MSPs

Tess Whitei

Ben Mcpherson

Invited guests

Scott Davidson (Medical Director Greater Glasgow and Clyde)

Rob Forbes

Jenny Forbes

Christelle Kelley

Laura Wilson

David Braidwood

Non-MSP Group Members

Marc Landers
David Johnson
Kate Spence
Christelle Kelley
Anna Ross
Derek Stewart
Lisa Quarell
Les Angus
Jim Mills
Milica Prokic

Apologies

None

Agenda item 1

Minutes and news.

A minute of silence was observed for Hannah Deacon, mother of Alfie the first child to get medicinal cannabis prescribed in the UK via NHS, who passed away after a brief battle with cancer.

Minutes of the previous meeting were accepted.

Members are invited to reflect on recent Parliamentary actions, and to report relevant news to the group.

Dr Milica Prokic, a research associate to Prof Jim Mills, who joined to bolster the CPG research capacity, was introduced to the group.

The CPG Secretary Jim Mills opened with the discussion by returning to the recent news from Northern Ireland, discussed at the previous meeting, that the NHS would now licence Bedrolite on a named patient bases, complemented by the tender for this medicine now published and available at the UK Government Website, showing that in Northern Ireland administering Bedrolite is now approached as an administrative matter.

Mother of Cole Thomson, child with intractable epilepsy Lisa Quarrell discussed major concerns about Bedrolite and Bedrocan products in terms of production and supply in the UK after Brexit. She also discussed the Northern Ireland case Sophia Gibson, a child with intractable epilepsy whose prescription was signed by all the paediatric neurologists at

Belfast children's hospital as a solution to avoid an individual stigma that is still attached to prescribing cannabinoids.

The discussion next turned to MSPs Pauline McNeill and Monica Lennon's questions about legal can medicines in the Parliament back in February 2025. They got a non-

committal answer from the First Minister who implied that the administration of cannabinoid medicines, including Bedrolite, to children with intractable epilepsy is a Westminster issue. However, as the Northern Ireland case shows, children in the rest of the country can get their medicine prescribed via NHS, leaving Scotland as an outlier in the issue where prescribing medicine such as Bedrolite on compassionate basis to children with intractable epilepsy through the NHS is still impossible. The group discussed resolving this as an issue within the Scottish parliament's power. The discussion then moved to the jurisdiction for providing guidelines of prescribing and licencing, as well as the approaches to the questions of supply, licencing and prescribing through the NHS in Scotland

Agenda item 2

Presentations and Discussion.

Dr Scott Davidson discussed challenges prescribing the yet unlicensed cannabinoid medicines for conditions including intractable epilepsy in children through the NHS in Scotland. He recognised the clear benefit in a small number of conditions. However, he flagged the legislative and policy challenges that stand in the way. These include the conditions for consideration of evidence of benefit on existing UK guidelines, and the to UK legislation which leaves the prescription of unlicensed medicines as problematic, and a sole responsibility of a prescribing clinician. Another challenge flagged by Dr Davidson was the no policy for shared care between private and NHS providers, and clear separation in legal status, liability, and accountability between the NHS and private health care providers. Dr Davidson flagged the challenge of research being funding dependent (among many variables) subject to private companies' confidence on return on investment, which is often an issue.

Dr Rob Forbes commented on the new of Bedrolite prescriptions through the NHS in Northern Ireland as encouraging and discussed Scotland being far behind every other part of the home nations on this issue. As pain specialist since 2004, Dr Forbes shared that patients reporting benefit from medicinal cannabis more than any other medication he has come across in the chronic pain field. He reminded that when the medicinal cannabis was legalised in 2018, the driving force of it were the parents of children with intractable epilepsy. As one of the very few prescribers of medicinal cannabis in the country, he reiterated that the unlicensed medication as the prescriber will take full responsibility and said that getting Bedrolite licensed would make a massive difference in closing this gap.

Dr Forbes further reminded that for the handful of children with intractable epilepsy, medicinal cannabis is 'truly life changing', allowing these children to go from having multiple seizures daily, and potentially being in intensive care for prolonged periods of time, to living essentially a seizure free life. This, Dr Forbes emphasized, would make the NHS prescription of medicinal cannabis in Scotland not only truly life changing for the individual, but for their whole existence and life, for the close family, and in avoiding the cost associated with managing these patients, such as for example an intensive care setting

where the parents are often forced to seek treatment for their children with intractable epilepsy if left without medicine.

The discussion following the presentations covered the questions of lack of infrastructure between guidelines, scheduling and licencing the medicine as well as the gap left the physicians and means to treat their patients due to the unlicensed status of these legal medicines. The discussion wrapped up with immense challenges put before the parents of children with intractable epilepsy who live in Scotland who, who act as 'middlemen' between the NHS and private clinics which places a significant burden on parent's finances and causes both them and their children a great amount of emotional financial, and health related distress.