

# **Cross-Party Group on Epilepsy**

4 December 2025, 1300–1400

Minute

## **Present**

### **MSPs**

Jeremy Balfour MSP

Alasdair Allan MSP

## **Non-MSP Group Members**

Epilepsy Scotland – Secretary

PAMIS

Epilepsy Connections

Ann Greenall

Pat Graham

Pamala Martis

## **Invited Guests**

Lesslie Young

Medeia Cohan

Michael Sturrock

Scott Coyne

Martin Elliott

Julia Shillitto

Lindsey Greer

Nikolaos Arakis

James McGrouther

Gemma Clark

Graham Loan

Jamie Martin

Richard Roberts

Colleen Wilson

Lucas Martin

Rodi Kiourktzoglou

Ann Greenall  
Gemma Clark

## **Apologies**

None recorded.

## **Agenda item 1**

Jeremy Balfour MSP opened the meeting, noting the strong attendance and thanking members and guests for their continued engagement over the parliamentary term. He confirmed that this was the final meeting before the Scottish Parliament elections in May and expressed appreciation for the work undertaken by the group. Members were reassured that steps would be taken to re-establish the CPG in the new session. The agenda was introduced, and attendees were invited to participate fully in the discussions. Jeremy also acknowledged the support provided by Epilepsy Scotland in coordinating the group's activities throughout the year.

## **Agenda item 2**

Professor Martin Elliott delivered an extended reflection on SUDEP, combining insights from clinical evidence with personal experience. He outlined the continued lack of awareness among clinicians and the public despite SUDEP being a significant cause of premature mortality, particularly among young adults. He highlighted that existing data systems and post-mortem processes often fail to record epilepsy-related deaths consistently, which hinders research and policy development. He emphasised the disparity in research funding between epilepsy and cardiac conditions, despite broadly comparable mortality rates. The absence of standardised post-mortem investigation, national biobanking, and coordinated data-gathering limits progress in understanding SUDEP's mechanisms. Contributions from MSPs and attendees reinforced concerns about limited communication of SUDEP risks, variability in access to specialist neurology services, and the implications of nocturnal seizures. Members reflected on the need for stronger political commitment to early intervention, specialist pathways, and robust national data infrastructure.

## **Agenda item 3**

Epilepsy Scotland provided an update on concerns about national proposals to restructure managed clinical networks. Members heard that Scotland's paediatric epilepsy network is regarded as a model of excellence due to consistent

specialist-led care, shared expertise, and coherent pathways. Proposed structural changes risk reducing access to specialist paediatric neurology input, increasing pressure on generalist services, and fragmenting the consistency of care. The group discussed risks to children with complex epilepsy who rely on regular specialist review. A consultant paediatric neurologist will brief the next parliamentary session. Members were encouraged to attend due to the significant long-term implications.

## **Agenda item 4**

Epilepsy Scotland outlined its forthcoming partnership with the Commonwealth Games during National Epilepsy Week. Activities include the Breaking Barriers event with elite athletes living with epilepsy, a citywide scavenger hunt promoting awareness, and a themed quiz night aimed at public engagement and fundraising. The partnership offers national reach and visibility that would be difficult for the charity to achieve alone. Attendees were encouraged to support the initiative by promoting events, sharing communications, and participating where possible. The update was welcomed as a strong example of leveraging national platforms for epilepsy awareness.

## **Next meeting**

To be confirmed in the next parliamentary session.