

## Cross-Party Group Annual Return

### Name of Cross-Party Group

Cross-Party Group on Epilepsy

**Date Group Established** (the date of establishment is the date in this parliamentary session that the Group held its initial meeting, where the office bearers were elected and not the date that the Group was accorded recognition. All Groups should hold their AGMs on, or before, the anniversary of this date.)

30/09/2021

### Date of Most Recent Annual General Meeting (AGM)

29/09/2022

### Date Annual Return Submitted

26/10/2022

**Date of Preceding AGM** [this date is required to aid clerks in verifying that the most recent AGM has taken place within 11 to 13 months of the previous AGM]

30/09/2021

### Group Meetings and Activities

Please provide details of each meeting of the Group including the date of the meeting, a brief description of the main subjects discussed and the MSP and non-MSP attendance figures.

Details of any other activities, such as visits undertaken by the Group or papers/report published by the Group should also be provided.

29 September 2022

Present: *Minutes yet to be published*

Business:

- AGM Election of Office Bearers
- Dr Ailsa McLellan and Sara Whittaker presentation on PAVES (Psychology Adding Value: Epilepsy Screening) followed by Q&A

9 June 2022

Present:

Carol Mochan MSP

David Torrance MSP

Donald Cameron MSP

Maree Todd MSP

Alice Struthers, Neurological Alliance of Scotland

Alistair Haw, Scottish Huntington's Association

Anissa Tonberg, Scottish Government

Anna Telfer, Epilepsy Scotland

Avril McLean, Action for ME

Cassie Patterson

Christine Jeans, SUDEP Action

Claire Mellor, Scottish Government

George Allan, SPPN

Gerard Gahagan, Scottish Government

Gill Wilson, Epilepsy Connections

Helen McDade, #MEAction

Hilary Mounfield

Jack Norquoy, office of Liam McArthur MSP

Jacqui Downs, NHS Ayrshire & Arran

Jan Campbell, UCB

Jay Shetty, NHS Lothian

Jenny Preston, NHS Ayrshire & Arran

Julie Dock

Katie Russell

Keith Park, MS Society

Kitty Miller, MS & MND Clinical Nurse Specialist for Argyll and Bute

Kristin McPhee, Scottish Government Mental Health

Laura Ingram, MS Society Scotland Chair

Lorraine MacKenzie

Lynn Young, Salvesen Mindroom Centre  
Mary Ramsay, Scottish Tremor Society  
Mhairi Coutts, NHS Ayrshire & Arran  
Morna Simpkins, MS Society Scotland  
Paul Gillon, Veriton Pharma  
Philip Robinson, Lanarkshire Epilepsy  
Rachel Lloyd, NHS Lothian  
Rebekah Canning  
Richard Brewster, Scottish Government  
Rona Johnson, Epilepsy Scotland  
Stephen O'Keane, MS Society Scotland  
Steve Brown  
Tanith Muller, Neurological Alliance of Scotland  
Thomas Mulvey, MS Society Scotland  
Vicki Burns, Epilepsy Scotland  
Victoria Wareham, Dystonia UK  
Zoe Hisbent, office of David Torrance MSP

#### Business:

- This was a joint meeting with the CPG on MS. the purpose of the meeting which is the launch of the Neurological Alliance of Scotland report from the findings of the UK wide “#MyNeuroSurvey”.
- Alice Struthers, the Programme Director of the Neurological Alliance of Scotland, gave a presentation on the report and its findings. A Q&A followed.
- The Minister for Public Health, Women's Health & Sport delivered the Government's response to the report. A Q&A followed.

10 February 2022

#### Present:

Alasdair Allan MSP  
David Torrance MSP  
Jeremy Balfour MSP  
Johanna McQuarrie, the Scottish Centre for Employment Research  
Patricia Findlay, the Scottish Centre for Employment Research  
Richard Lochhead MSP  
Andrea McKenna, Salvesen Mindroom Centre

Andrena Hughes  
Anna Telfer, Epilepsy Scotland  
Audrey Noble, Angelini Pharma  
Colleen Wilson, Epilepsy Connections  
Derek Robertson  
Jacqueline Dempsey  
Jan Campbell, UCB  
Jeanette Hagerstrom, Scottish Government  
Jen Irvine, NHS Lanarkshire  
John Thomson  
Kieran Lumsden, Scottish Government  
Kirsten Sinclair  
Lesslie Young, Epilepsy Scotland  
Michael McCulloch  
Michael Sturrock  
Norma Crawford, Quarriers  
Rona Johnson, Epilepsy Scotland  
Stephen Bolan, Angelini Pharma  
Vicki Burns, Epilepsy Scotland

Business:

- Presentation from Professor Patricia Findlay, Director of Scotland's Centre for Employment Research, who presented new research, commissioned by Epilepsy Scotland, on epilepsy and employment. A Q&A followed this.
- There was also an update from the Minister for Just Transition, Employment and Fair Work, Richard Lochhead MSP followed by a Q&A. CPG members had the opportunity to ask questions to the Minister about disability employment.

25 November 2021

Present:

Alasdair Allan MSP  
David Torrance MSP  
Anissa Tonberg, Scottish Government  
Frauke Hunter, Scottish Government  
Pauline Bennett, Scottish Government  
Alex Wilson  
Andrea McKenna, Salvesen Mindroom Centre  
Ann Greenall, NHS Lothian

Anna Telfer, Epilepsy Scotland  
Audrey Nobel, Angelini Pharma  
Charlie Bethune, Valporate Scotland  
Christine Jeans, SUDEP Action  
Collen Wilson, Epilepsy Connections  
Derek Robertson, NHS Lothian  
Elaine Collard, NHS Highland  
Elanora Saturno, NHS Fife  
Fiona Burton  
Graeme Aitken  
Helen MacDonald, Lanarkshire Epilepsy  
Hillary Mounfield, Scottish Epilepsy Centre  
Jan Campbell, UCB Pharma  
Jen Irvine, NHS Lanarkshire  
Jenny Hunt  
John Campbell, Neuraxpharm UK  
John Thomson, Eisai Ltd  
Jude Kilbee, Bial Pharma  
Katie Russell  
Lesley Perkin, UBC Pharma  
Norma Crawford, Quarriers  
Pat Graham, PAMIS  
Paul Gillon, Veriton Pharma  
Philip Robinson, Lanarkshire Epilepsy  
Rona Johnson, Epilepsy Scotland  
Shirley Maxwell, Epilepsy Connections  
Dr Susan Duncan  
Victoria Burns, Epilepsy Scotland  
Will Wood

Business:

- The Scottish Government provided an update on the Patient Safety Commissioner in Scotland and an update on the implementations of the Cumberlege recommendations in Scotland. A Q&A followed.

**MSP Members of The Group**

Please provide names and party designation of all MSP members of the Group.

Alasdair Allan – Convener (SNP)

David Torrance – Deputy Co-Convener (SNP)

Jeremy Balfour – Deputy Co-Convener (Conservative)

Collette Stevenson (SNP)

Carol Mochan (Labour)

Kenneth Gibson (SNP)

### **Non-MSP Members of The Group**

For organisational members please provide only the name of the organisation, it is not necessary to provide the name(s) of individuals who may represent the organisation at meetings of the Group.

#### **Individuals**

Ann Greenall

Patricia Graham

Michael McCulloch

Elaine Collard

Ailsa McLennan

Derek Robertson

Pamela Martis

Karen Gray

Jennifer Irvine

Lorraine MacKenzie

Celia Brand

Jay Shetty

John Toland

Susan Duncan

Jo Campbell

Jean Barclay

Sylvia Lawrie

Yvonne Leavy

	Richard Chin Rachel Lloyd
<b>Organisations</b>	<p>Epilepsy Scotland – Secretary</p> <p>Blue Sky Autism</p> <p>Bial Pharma</p> <p>Carita Neurological Solutions</p> <p>Citizen’s Advice Scotland</p> <p>Community Pharmacy Scotland</p> <p>Division of Clinical Psychology Scotland</p> <p>Eisai ltd</p> <p>Enable</p> <p>Epilepsy Connections</p> <p>Epilepsy Consortium Scotland</p> <p>Epilepsy Nurses Association (ESNA)</p> <p>Glasgow Children’s Hospital Charity</p> <p>Headway</p> <p>Lanarkshire Epilepsy</p> <p>LivaNova</p> <p>Mindroom</p> <p>PAMIS</p> <p>Positive and Active Behaviour Support Scotland (PABSS)</p> <p>Quarriers/ Scottish Epilepsy Centre</p> <p>Royal Pharmaceutical Society Scotland</p> <p>SUDEP Action Scotland</p> <p>UCB Pharma</p> <p>Veriton</p> <p>West Dunbartonshire Epilepsy Support Group</p>
<b>Group Office Bearers</b>	
Please provide names for all office bearers. The minimum requirement is that two of the office bearers are MSPs and one of	

these is Convener – beyond this it is a matter for the Group to decide upon the office bearers it wishes to have. It is permissible to have more than one individual elected to each office, for example, co-conveners or multiple deputy conveners.

<b>Convener</b>	Alasdair Allan MSP
<b>Deputy Convener</b>	David Torrance MSP Jeremy Balfour MSP
<b>Secretary</b>	Ross Cunningham, on behalf of Epilepsy Consortium Scotland
<b>Treasurer</b>	N/A

#### **Financial Benefits or Other Benefits**

**Please provide details of any financial or material benefit(s) the Group anticipates receiving from a single source in a calendar year which has a value, either singly or cumulatively, of more than £500. This includes donations, gifts, hospitality or visits and material assistance such as secretariat support.**

The Epilepsy Consortium Scotland donates in kind assistance to cater for the CPG on Epilepsy when the group meets in person.

#### **Convener Contact Details**

<b>Name</b>	Alasdair Allan MSP
<b>Parliamentary address</b>	M4.14
<b>Telephone number</b>	01851 700357