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**Guidelines March 2018**

**Epilepsy Consortium Scotland (ECS)**

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**Epilepsy Consortium Scotland (ECS)**

1. **Aim**

To act as a collective voice for epilepsy-related organisations and individuals in Scotland in order to inform the Scottish Government and other policy makers in matters of health, social care and public policy relating to epilepsy.

1. **Objectives**

The objectives of the Consortium are:

* 1. To identify and work collaboratively on relevant Scottish-based issues.
  2. To maximise the efficiency and impact of epilepsy-related campaigning and

lobbying work at the Scottish Parliament and Government.

* 1. To provide information and comment to the Scottish Government and other

statutory bodies on proposed policy changes for health and social care.

* 1. To ensure that people with epilepsy benefit from policy changes.
  2. To share existing best practice and identify new models which will improve

services and care available to people with epilepsy.

* 1. To communicate and exchange information with other Scottish, UK and

international epilepsy organisations.

1. **Activities**
   1. On a cycle submit topics for consideration by the Consortium.
   2. Prioritise topics and agree responsibilities of member organisations to

achieve required outcomes.

1. **Membership**
   1. Membership is subject to agreement to the Aims and Objectives of the Consortium, to its way of working and the payment of the appropriate membership fee. A Consortium sub group will designate appropriate membership rates to cover the Aims and Objectives which will be approved by a majority of members. The categories of membership are:
      1. Organisational - has one vote
      2. Professional – has one vote
      3. Individual – (for those who have epilepsy or who are a carer or parent of a person with epilepsy who are in agreement with the Aims and Objectives of the Consortium. There will be a maximum of five members in this category, no membership fee will apply). Each individual has one vote
      4. Associate membership for individuals nominated by organisations (see 4.3 and 4.4).
   2. Application for membership will consist of a written request to the Chair stating agreement with the Aims and Objectives of the Consortium and an agreement to abide by the Consortium’s way of working.
   3. Associate Membership is open to individuals who are in agreement with the Aims and Objectives of the Consortium and agree to abide by its way of working. Associates must be nominated by an organisation which is currently a member of the Consortium on the basis that the Associate will contribute towards the Aims and Objectives. Associate Members will not be required to pay a membership fee and will not have the right to vote at a meeting.
   4. Nomination for Associate Membership will be made by the nominating organisational member in writing to the Chair and will state the contribution the Associate will make towards the Aims and Objectives.
   5. Applications for membership will be circulated to all current members and a decision to accept membership will be reached at the next full meeting of the Consortium.
   6. Membership may be refused if a majority of existing members object on the grounds that the individual or body seeking to join will damage the interests of the Consortium. Reasons to refuse membership should be passed to the Chair at or before the full meeting at which a decision on the application will be reached.
   7. A list of current members is available. For organisations this will also include the person authorised to vote on their behalf if the organisation is not represented at a full meeting.
   8. Membership fees will be set and reviewed annually based on actual and projected expenditure. Annual membership runs in line with the financial year April-March.
   9. Membership fees:

Organisational Member

Income > £250k £250

Income > £50k £125

Income < £50k £55

Professional member £25

Associate Organisational Member (member can attend meetings however have no voting rights, will receive meeting minutes, and can participate in research and data collection. £40

Associate member Membership through Organisation

Individual member (max of 5) No Fee

* 1. Membership fees will cover the cost of the general running of the Consortium and its aims, including the Cross Party Group meetings (hospitality, administration, speaker’s expenses and secretariat) venue hire for full meetings and administration costs. Fees may also be used for agreed specific campaigns / promotional events and materials.
  2. Reasonable expenses for Consortium members attending exhibitions / party conferences will be reimbursed where the member is representing the Consortium. Reasonable expenses may include reimbursement of public transport costs to and from the venue and/or the cost of lunch up to the value of £5 per claimant per day. Claims should be made after the event to the treasurer and be accompanied by appropriate receipts. For Organisational Members one claimant per organisation per day is permitted.
  3. Any other use of membership fees can be raised for discussion and sanctioned at full Consortium meetings.
  4. Membership fees will be collected annually. ECS will contact each member when their fees are due to be renewed. Payment of fees should be made within 28 days. If fees are not paid a further reminder will be sent. Following this, if fees remain unpaid they will be given written notification that their membership has lapsed.

1. **Structures**
   1. Elected office bearers are a Chair (and Vice Chair if deemed appropriate), Treasurer and Secretary. Elected office bearers will determine how often they meet. Tenure for elected office bearers will initially be for 2 years with the option to stand again for a further year. All current members will be eligible to stand, including Associate Members. Only members with voting rights may elect office bearers.
   2. Office bearers will be elected by way of an e-ballot election. Role descriptions of each position will be made available prior to the election. Members can put themselves forward for election and will submit a brief biography to support their application. Following this an e-ballot will be held. Results will be collated and circulated.
   3. The Chair will chair full meetings of the Consortium. Full meetings will usually be held 4-6 times a year. A meeting will be quorate where a minimum of 4 member organisations are represented. No-cost available venues will be sought to suit the travelling needs of current members and IT options such as Skype and teleconferences will be investigated to insure the inclusion of member organisations outwith the central belt. Travel expenses for attending meetings and working groups will not be reimbursed.
   4. The Treasurer will be a current member organisation or an agency nominated by the membership which holds funds on the Consortium’s behalf. Annual accounts will be presented for inspection each year to a full meeting.
   5. The Secretary will issue papers and record minutes.
   6. The primary mechanism for achieving the Consortium’s Aims and Objectives will be short term working groups consisting of members with an interest and contribution to make to an area of work agreed by the Consortium. Working groups will autonomously manage their work and report to full meetings of the Consortium.
2. **Way of Working**
   1. As mentioned above, full meetings of the Consortium will take place 4-6 times per year. In order for the Consortium to move forward, members are expected to attend these meetings or to nominate someone to attend in their stead. To aid this, provisional meetings dates will be scheduled for the year ahead.
   2. The membership of the Consortium consists of organisations and individuals from different sectors (private, public and third sectors). There will also be members with a personal association with epilepsy. Different working backgrounds will also be represented (amongst which will be health, social care, policy, research, academic, and others). It is recognised that this will be strength of the Consortium because the full spectrum of professional and personal backgrounds, areas of expertise and spheres of influence will be represented.
   3. The spectrum of membership will also create a challenge for the Consortium to achieve joint working towards its Aims and Objectives. The Consortium brings together organisations and individuals who come from different backgrounds with different priorities, timescales, resources and routes to solutions. Organisational members will have Aims and Objectives unique to their organisation which may be different from the Consortium’s.
   4. It is expected that there will be differences of opinion within the Consortium and that there will be disagreements on emphasis, interpretations of facts and evidence, and the best approach towards achieving a shared goal. In order to achieve efficient decision-making, and cohesion, the following guidelines will apply in conducting the business of the Consortium:
      1. Areas of work for the Consortium are agreed by majority at full meetings.
      2. Once an area of work is agreed, membership of a working group is dependent on self-selection based on areas of interest and/or expertise.
      3. Where an item of work is completed by a working group or endorsed by the Consortium, a Member of the Consortium who disagrees with the conclusion of the work or the endorsement may request their dissent be formally recorded in the minutes of a full meeting. The item of work or endorsement will however stand as the settled view of the majority of Members and the public view of the Consortium.
      4. Members are free to express their opinions concerning an area of work of the Consortium. Specifically they are free to express an opinion contrary to the settled view of the majority of the Members that has become the view of the Consortium as a whole; however they should not express this opinion in a way that brings the Consortium into disrepute.
      5. It is expected that certain agreed areas of work of the Consortium will have a focus of interest and/or expertise for a only a minority of Members and it will therefore be they who form a working group, allocate most time and carry most of the work for that area. However, if following a full meeting a majority of members are not in favour of the conclusion of the work it will not be adopted as the view of the Consortium.
      6. The Consortium will not object to the group of Members continuing their work independently of the Consortium but reserves the right to state its disagreement if the work is made public. It will do so, however, in a way that does not bring the Consortium into disrepute nor the individual members.
3. **Voting**
   1. When a vote takes place at a full meeting each organisation will have only one vote regardless of how many individuals present are representatives of that organisation.
   2. Members not present at a full meeting may register their vote by doing so in writing/fax/email before the start of the meeting. Members can also nominate someone who is attending the meeting to vote for them by proxy.
   3. The Chair does not have a casting vote. If a vote is tied the vote is not carried.