

Constitution for PEM Friends Patient Support Group

NAME

The name of the group is PEM Friends.

PURPOSE

- We help people and their loved ones who have been diagnosed with the autoimmune blistering diseases pemphigus and pemphigoid (PEM) and who live in the UK to find mutual support and information about their disease;
- We create connections to others who can alleviate the condition and would benefit from the connection to this network.

AIMS

- Facilitate access to a network of PEM Friends who have been diagnosed with PEM who live in the UK;
- To raise the profile of PEM Friends and awareness of autoimmune blistering disease;
- Build awareness of the disease amongst the medical community in order to reduce the wait for a diagnosis;
- To secure funds to enable the group to pay for necessary expenses;
- To campaign for improving the diagnostic process;
- Involve more medical specialists and experts in PEM Friends;
- Involve some volunteers not affected by the disease;
- Help medical professionals develop new ways of treating PEM, for example, by participating in or supporting research into the diseases and trials for new treatments;
- Collaborate with other organisations who can help us achieve our aims (and we can help too).

PRINCIPLES

- Every PEM Friend is equal;
- We manage the network with a minimal overhead in an organic way with minimal formal roles;
- We don't ask for payment from patients/carers, but welcome their donations;
- We occasionally intervene on behalf of patients (with their permission);
- We assume people want to know as much as they can about our diseases;
- We are approachable and helpful to all members;
- We share learnings where applicable and possible;
- We respect all our PEM Friends and promote their growth;

- We comply with all legal requirements including privacy laws;
- We value our partners, stakeholders, and funders;
- We are not medically trained but offer help based on our experience;
- We respect everyone regardless of disability, ethnicity, sexual orientation, age, or any other protected characteristic;
- Any member found to be harassing or discriminating against another member or the group's associates will be removed from the membership.

POWERS

To further these aims, the group may exercise the following powers:

- To raise funds and receive grants, contributions, donations and otherwise, provided that the group shall not undertake any permanent trading activity;
- To bring together representatives of voluntary and statutory organisations, medical professionals and individuals;
- To produce leaflets, posters, internet resources and promotional merchandise to publicise the group;
- To hold meetings;
- To pay the necessary expenses involved in running the group;
- To support students, when necessary, to carry out work on behalf of the group;
- To attend conferences and events specifically aimed at raising awareness;
- To undertake any other lawful activity to further the group's aims.

MEMBERSHIP

Membership of the group shall be open to anyone who resides in the UK and who either:

1. Has pemphigoid or pemphigus or
2. Cares for someone with pemphigoid or pemphigus

MANAGEMENT COMMITTEE (KNOWN AS THE PEM COUNCIL)

The group is run by a small group of volunteers. Volunteers are individuals who care about the development of PEM Friends and who are willing to take on tasks that further the aims of the group.

The PEM Friends members will elect a committee of between 8 and 10 members who will direct the policy and management of the group. They shall be elected to serve for two years after which time they may stand for re-election. The chair will have a casting vote in the event of a tie. The management committee will have the power to co-opt members if it wishes to use this power. The PEM Council will meet a minimum of six times a year. The quorum level will be set at 4 members.

From amongst the PEM Council, a chairperson and a treasurer will be elected by the Council members. Other members may be appointed to undertake particular responsibilities within the group, eg fundraising.

Everyone in the core team is an unpaid volunteer (although we pay for expenses and may pay for specific tasks)

- We work as a team of equals;
- We may own an area or participate in a team working on a specific area;
- We may also have a student assigned and supervise them in accomplishing specific tasks.

ACTIVITIES OF THE PEM COUNCIL

- Manage the member networks (Facebook, Zoom, e-mails) and encourage sharing;
- Build awareness amongst patients or carers;
- Build awareness amongst medical experts in the UK;
- Build and maintain relationships with strategic partners;
- Keep up to date and relevant information (via our website);
- Generate necessary funding.

MEETINGS

An annual general meeting (AGM) of the group shall be held every year in February (to allow preparation of a statement of accounts following the group's financial year end on 31st December). All members shall be notified not less than fourteen days before the meeting. An agenda will be circulated. Business of the AGM will include electing the committee, reporting on the activities during the year, amendments to the constitution and approval of the group's accounts.

An extraordinary general meeting (EGM) can be held at the chair's discretion or by a written request to the chair of not less than 4 (four) members. The meeting shall be called within 21 (twenty-one) days of such a request and appropriate measures taken to inform all members. An EGM should only consider the business specified in the request.

MEETING PROCEDURES

All questions that arise at any meeting will be discussed openly and the meeting will seek to find general agreement that everyone present can agree to. If a consensus cannot be reached a vote will be taken, and a decision will be made by a simple majority of members present. If the number of votes cast on each side is equal, the chair of the meeting shall have an additional casting vote.

FINANCES

- Any money raised shall be used to further the aims of the group and for no other purpose;
- A bank account will be opened in the name of the group. The account will have 3 (three) signatories;
- Expenditure on the account will require the approval of two members. There will be two signatories available to the treasurer for signing cheques. The group shall decide the signatories to any account set up in the name of the group;
- A simple written note of the group's financial position will be produced and available at committee meetings;
- A statement of accounts verified by a competent person who is independent of the group shall be tabled at the AGM;
- The group's financial year shall be 1st January to 31st December;
- No member shall derive any financial benefit from the group, except for payment of 'reasonable' expenses;
- No money will be paid out in the name of the group without appropriate proof (eg a receipt) being presented;
- Expenses are approved by at least two members of the PEM Council.

AMENDMENTS TO THE CONSTITUTION

If amendment(s) to the constitution are necessary, members will be informed in writing and given the opportunity to consider and vote on the amendments. The amendment(s) will be made if there is a two-thirds majority vote of members.

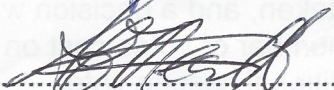
DISSOLUTION

If the Council, by a simple majority, deem it advisable to dissolve the group, it shall call a meeting of all PEM Friends, giving not less than 14 days notice. If such a decision is confirmed by a majority of those present, then all the assets of the group shall be transferred to another voluntary group or community group with similar aims.

adopted on the 29th day of June 2022

Signed  (Chair) ISOBEL DAVIES

Signed  (Treasurer) KALPESH PATEL

Signed  (PEM Council Member) ANDREW HEATH