SarcoidosisUK Patient Advisory Panel - Role & Terms of Reference

About us

SarcoidosisUK is committed to improving the lives of all those affected by sarcoidosis by providing the best information and patient support, raising awareness of the disease, advocating for access to the best treatment and care and funding novel research.

The needs of sarcoidosis patients and their family networks are at the heart of everything we do. Ongoing engagement with the sarcoidosis patient community is essential to ensure that we understand the current challenges and that all SarcoidosisUK's activities are relevant and driven by patient need.

The SarcoidosisUK Patient Advisory Panel (PAP)

SarcoidosisUK listens to the patient voice via many channels including our Patient Support Groups, Facebook Groups, and other social media. We now wish to offer a more formal opportunity to engage with the charity by setting up a Patient Advisory Panel (PAP). The role of the PAP will be:

- To provide a platform for panel members to represent anyone affected by sarcoidosis.
- To offer a direct communication channel to the charity's management to share their experience and influence SarcoidosisUK's activities.
- To give an insight into the challenges faced by sarcoidosis patients to enable the charity to advocate for the best possible treatments and care.
- To help guide SarcoidosisUK's activities and strategies.
- To provide feedback, when requested, which may include taking part the selection process for research funding.

Membership of the SarcoidosisUK PAP

The SarcoidosisUK PAP will comprise a maximum fifteen volunteer members (adults over 18 years of age). All members should have either lived experience and/or have/are supporting someone with sarcoidosis.

SarcoidosisUK will endeavour to ensure the panel comprises a broad and diverse range of people from across the UK. We seek members that are representative of the varied types of sarcoidosis and diversity of the patient population to ensure that the experiences of all sarcoidosis patients are considered.

Members will be volunteers and serve on the panel for an initial term of two years, extendable by a further period. Members will have an option to opt out of the panel at any time, take a break or a less active role in the panel. SarcoidosisUK also reserves the right to ask a member to resign from the Panel, but only after a full discussion.

The PAP will be chaired by a member of SarcoidosisUK staff or a charity Trustee.

SarcoidosisUK's Commitment to the PAP

SarcoidosisUK will ensure that participation in the PAP will be meaningful and help guide the activities of the charity. The wellbeing of the members will always come first, and we understand that members may wish to leave or take a break from the panel at any time.

Terms of Reference

All members of SarcoidosisUK's PAP must agree to the Terms of Reference in writing (by email). The Panel will have the following responsibilities and commitments, outlined below.

- Agree to take part in four online PAP meetings per year.
- Provide insight, thoughts and advice based upon the experience of those affected by sarcoidosis.
- Be prepared to share their own experiences and views.
- Ensure a fostering and enabling environment, where every PAP member feels valued, listened to, and respected by other members.
- Listen supportively to other PAP members.
- Provide views, advice and feedback throughout the year if requested.
- Have an appetite to share their thoughts and feedback on SarcoidosisUK's activities, including research funding.
- Provide input into the development and testing of new information, marketing and communications materials, messages and/or campaigns run by SarcoidosisUK.
- Be willing to read paperwork before PAP meetings.
- Represent SarcoidosisUK at external meetings or events.

Expenses

Sarcoidosis may request a PAP member to attend external events. All members may claim reasonable out of pocket expenses and will be reimbursed on receipt of an expenses claim and relevant receipts.

Privacy Policy

By signing up to our Patient Advisory Panel members accept the SarcoidosisUK Privacy Policy. Any information shared with us will be anonymised (unless consent is explicitly refused) e.g. to share a member's story as a patient story.

Updating

SarcoidosisUK Board of Trustees will review these Terms of Reference every two years.

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SarcoidosisUK

214 China Works
100 Black Prince Road
LONDON
SE1 7SJ

www.sarcoidosisuk.org
info@ sarcoidosisuk.org
020 3389 7221

Registered charity number 1204750