


MAST CELL
ACTION

MCAS Voices Handbook

www.mastcellaction.org

Registered charity number: 1164917



PHOTOGRAPHY



About Mast Cell Action

Mast Cell Action was founded in 2016 to make a meaningful difference in the lives of those affected by MCAS.

Mast Cell Action is more than a charity; it's a movement, a community, and a collective voice that echoes the needs and concerns of those we serve.

We provide support to the MCAS Community and work to raise awareness and understanding of MCAS amongst relevant professionals and organisations.

We provide support in multiple ways and are led by the voice of the MCAS community. Through virtual sessions, supportive resources, and awareness-raising activities, we are here for everyone in the UK living with MCAS.

Our vision is bold and unwavering: a world where every person affected by Mast Cell Disease is not only heard but truly understood. We envision a world where their symptoms are acknowledged, leading to accurate diagnoses and, most importantly, the compassionate care and support they need and deserve.

Our Mission

Mast Cell Action's vision is of a world where everyone affected by Mast Cell Disease has their symptoms acknowledged and experiences listened to, to achieve a correct diagnosis, and to receive the care and support that they need.

Our charitable objective is to improve the lives of people affected by Mast Cell Activation Syndrome.

About MCAS Voices

MCAS Voices exists to ensure that people living with MCAS or suspected MCAS and those caring for someone with MCAS or suspected MCAS are at the heart of Mast Cell Action and the work we do.

MCAS voices helps us to ensure that we are a community-led charity, with members helping to steer our work, supporting the development of projects and planning, and reviewing and piloting them before they are shared with the wider community.

Members will volunteer a small amount of time to help us focus our plans, ensure projects are on track and make sure that we are focused on the things that matter to those living with MCAS or those caring for someone with MCAS.

Members are offered the opportunity to be involved with various projects, reviews and focus groups and can choose which areas they would like to engage in and support. There is no obligation to participate in any project.

Membership

The main function of members is to be part of an advisory group that helps Mast Cell Action to make directional decisions in regards to projects and planning at Mast Cell Action.

MCAS Voices will support the strategic direction of the work we do at Mast Cell Action whilst supporting our community's voices to be heard and amplified.

We aim to encourage a diverse group of people with a variety of experiences and skills to participate in order to help steer the work of Mast Cell Action effectively and meet the needs of as many people in our community as possible.

Code of Conduct

- Participate in projects and consultations at your discretion.
 - Feel free to give open, honest feedback.
- We are committed to providing equal opportunities and all members should treat fellow members, employees and volunteers with respect, consideration and appreciation.
- Do not do anything that might bring Mast Cell Action into disrepute.
 - Maintain the confidentiality of Mast Cell Action's information.

Key duties:

- Act as a sounding board for initiatives and projects across the organisation •
- Support the strategic direction of projects and other work •
- Give feedback on project plans •
- Participate in the projects you wish to be involved in, and where you feel you could bring some expertise or experience •
- Support decision-making to help steer our work •