MAST CELL
ACTION

MCAS Voices Handbook

Registered Charity Number 1164917

WELCOME

Thank you for your interest in joining our MCAS Voices Group. Mast Cell Action exists to support people living with MCAS, or suspected MCAS, and their carers or loved ones.

Our MCAS Voices group helps 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. MCAS Voices members help to steer our work and ensure that everything we do is community-led. You will help us to keep focused on the things that matter to you most.

The main function of MCAS Voices members is to be part of an advisory group that helps Mast Cell Action make informed decisions about projects and priorities. MCAS Voices supports the strategic direction of Mast Cell Action's work while ensuring that the voices of the MCAS community are heard and amplified. We aim to build a diverse group of members with a variety of experiences and perspectives to reflect the needs of the wider MCAS community.

As a member of MCAS Voices, you may:

- Provide feedback on ideas for resources and projects.
- Sense-check the work of Mast Cell Action – we'll ask – for your honest views about how we're doing and how we could improve.
- Review draft resources before they are published.
- Complete the yearly community survey to help us continue to understand the needs of people living with MCAS and prioritise the right work.
- Share ideas for news initiatives that would benefit the MCAS Community.
- Contribute to projects using your own experiences, helping us create resources that support others living with MCAS.

Your Commitment as an MCAS Voices Member

We will contact you by email around once a month with updates and opportunities to contribute to MCAS Voices activities.

As a member of our MCAS Voices group, we ask that you respond to at least two requests for feedback each year.

We estimate that the total time involved will be around 1-2 hours per year, with more opportunities to get involved if you would like to. We understand that living with MCAS can be unpredictable, and we appreciate any contribution you are able to make.

Code of Conduct

- Participate in projects and consultations at your own discretion when you have capacity
- Give open, honest feedback to help improve Mast Cell Action's work.
- Always treat fellow members, staff and volunteers with respect, consideration and appreciation.
- Support Mast Cell Action's commitment to equality, diversity and inclusion, ensuring everyone feels welcome and valued.
- Avoid any actions or behaviour that could bring Mast Cell Action into disrepute
- Maintain the confidentiality of Mast Cell Action's information, including any draft resources, internal discussions or project details shared with the group.

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 with professionals and organisations. We are led by the voice of the MCAS community.

We provide virtual movement and wellbeing sessions, tailored to the MCAS Community, MCAS information resources, online support groups, peer-to-peer support service, information webinars, resources for healthcare professionals, an MCAS Voices group and Young MCAS Voices group and signposting to UK Doctors that can help with MCAS. We also raise awareness of MCAS with the public and work in partnership with the Overlapping Illness Alliance to campaign for better recognition of MCAS and other associated conditions. 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

Vision 2030: A world where everyone with MCAS get the diagnosis, treatment and care they need.

Mission: To transform the lives of people affected by Mast Cell Activation Syndrome through better healthcare, medical breakthroughs, and a stronger, supported community.

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