

HOW WE CAN HELP

In our first year we:

- Provided support, advice and information to people seeking help.
- Launched our website and produced publicity material.
- Developed a vibrant support community for parents of children with suspected MCAS.
- Attended conferences and events to raise awareness and engage with doctors.
- Responded to consultation documents and started to engage with MPs.

Going forward we will:

- Grow our support capabilities for sufferers.
- Enhance our website and communications.
- Continue to raise awareness through attendance at medical conferences.
- Develop our relationships with MPs.
- Pursue initiatives with doctors.

While we are achieving these goals we will support MCAS patients seeking advice, diagnosis, doctors or treatment. We will support doctors with an interest in MCAS or those that suspect they may have a patient with MCAS. We will also be happy to discuss any ideas or initiatives that require support or funding.

HOW CAN YOU HELP?

None of our aims can be achieved without the support of both patients and doctors.

Amongst patients, their friends or family we are looking for additional trustees or team members with specific skills. We also need financial support. If you feel you can contribute towards making a better life for MCAS patients or have any ideas or feedback, we would like to hear from you.

Mast Cell Action are looking for Doctors and Researcher who are interested in supporting our aims and might be able to help us build on the progress we have already made.

We would welcome Doctors ideas on how we might be able to help them, for instance we could help put you in touch with other doctors, paediatricians and immunologists with an interest in MCAS.


MAST CELL
ACTION

Contact: info@mastcellaction.org

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MAST CELL
ACTION

**AWARENESS,
DIAGNOSIS
& TREATMENT**

**FOR SUFFERERS OF MAST
CELL ACTIVATION SYNDROME**

WHAT IS MAST CELL ACTIVATION SYNDROME?

Mast Cell Activation Syndrome (MCAS), is a newly recognised disease (2007).

The mast cell plays an important role in the body's immune system. The cells reside in the body's tissue and when they detect an intruder (e.g. bacteria) or respond to injury, they release specific chemicals (mediators) depending on the nature of the problem. An allergic reaction is an example of mast cell driven symptoms where allergens such as pollen trigger the mast cells.

For someone with MCAS, the mast cells inappropriately and excessively release these chemical mediators in response to a normal "trigger". These unwanted chemicals then cause major problems in their own right resulting in reactions, pain and illness including anaphylaxis. The triggers are many and individual. Heat, cold, smells, chemicals, exercise, stress and specific foods are typical. Some people have an extremely limited diet with only a few foods that they can tolerate without adverse reactions.

Given the range of mediators and their different release locations there are wide range of MCAS symptoms covering all

the systems of the body. Many patients suffer increasingly severe symptoms, have an extremely poor quality of life and are unable to work or attend school. Patients commonly spend decades going in circles visiting different specialists and achieving no proper diagnosis or treatment.

MCAS forms part of a spectrum of mast cell disorders involving a proliferation and/or excessive sensitivity of mast cells. We will aim to concentrate initially on MCAS as we feel there is an urgent need for a wider understanding and acceptance of this form of Mast Cell Activation Disorder. We will, however, welcome input from all those with another form of the disorder or their doctors.

There is at present no cure and it is difficult to diagnose with great confidence. A detailed symptom history, exclusion of possible alternatives, evidence of a chemical mediator and response to treatment form the basis of the diagnostic criteria. There is gradual acceptance and recognition of MCAS in the NHS and recently better tests have been introduced, but it is still extremely challenging to obtain a diagnosis in the UK. Many patients have a range of suspected mast cell related symptoms but no formal diagnosis which results in them receiving limited treatment.

Following diagnosis, personalised treatment can be cheap and effective and can greatly improve the patients quality of life.

HOPE FOR MAST CELL ACTIVATION SYNDROME SUFFERERS

THE NEEDS



Mast Cell Action are responding to an urgent need to support the growing numbers of Mast Cell Activation Syndrome Patients.

MCAS patients have no natural “home” in the NHS.

There are very few medical specialists with an in depth knowledge of MCAS. There are no centres that focus on this condition and it is not recognised by the formal health institutions (DOH etc.). The American Centre for Disease Control (CDC) has issued a revised edition (2017) of ICD 10, the International Classification of Diseases, which for the first time includes a diagnostic classification of Mast Cell Activation Syndrome.

As with any newly recognised condition, there is limited knowledge of it within the broader medical community, and differing views regarding its causes, symptoms and treatment. Consequently MCAS patients have a mountain to climb to achieve recognition, meaningful diagnostic tests and knowledgeable treatment.

Solutions:

- To raise awareness and improve education in respect of Mast Cell Activation Syndrome and act as a resource hub, hosting seminars and workshops.
- Publish information to educate medical professionals in order to increase diagnosis and to educate patients and families and the general public.
- Engage with the various government bodies and the medical community to promote the needs of MCAS patients.
- Provide a supportive community through the provision of practical advice, support and information for everyone affected by mast cell disorders.
- To relieve sickness through the advancement of research into the causes of mast cell disorders.
- Engage with the research community and raise funds to enable them to develop better diagnostic tools and treatments for mast cell disorders.

More specifically:

- Create a high profile online presence to define and bring together the Mast Cell Activation Syndrome population. Focusing on MCAS but inclusive of other variants.
- Provide a supportive community through the provision of practical advice, support and information for everyone affected by MCAS.
- Provide information for affected adults and their families and the parents of many severely affected children.
- Network with specialists to provide guidance and support for patients seeking diagnosis and treatment.
- Work with doctors with an interest in MCAS to identify their needs and implement fundraising campaigns.
- Develop training and publicity material.
- Create a patient data base to gather more detailed patient data and link patients and providers.
- Develop a regular income from registered members while targeting large donors, trusts etc.
- Support and commission MCAS research.
- Forge alliances between international experts and UK doctors and researchers.
- Engage with rare disease lobby groups to ensure MCAS and its variants are included in the Department of Health and NHS initiatives.



THE SOLUTIONS

**RAISE
AWARENESS
INCREASE
EDUCATION
PROGRESS
DIAGNOSTIC
TESTS
IMPROVE
TREATMENT**

WHO ARE WE?

We are a small group
of people making
significant progress
towards our goal:



Chris Wood
Communications and
Marketing Executive currently
Chairman of Purpose
(purpose.co.uk). He is
committed to helping the
MCAS patient community.



Gawain Paling
Senior manager in
energy industry until 2012 –
probable MCAS rendered
unable to continue work.



Helen Bowes
Veterinary physician – Helen's
young daughter suffers
from suspected MCAS, also
hypermobility and autonomic
symptoms, as does Helen.
Helen is dedicated to helping
families in our support group.



Prof. John Fox
Professor at Oxford University.
John develops decision
support tools for medical
professionals using IT
and artificial intelligence
(openclinical.net).



Jennie Shellard
Retired advertising
industry executive with
a special interest in charity
fundraising. MCAS.



Ruth Slater
A healthcare communicator
with a passion for making
the patient voice heard.
Ruth has a young daughter
with severe food allergies
and allergic sensitivities.