# **A blue and orange logo Description automatically generated…..Welcome**

## **Please read this page before completing the questionnaire**

**Thank you for agreeing to complete this questionnaire. The results of this survey will be used to help build a summary of the similarities often experienced in the journey to an MCAS diagnosis and help to demonstrate the need for better care for those living with MCAS.**

**This questionnaire has been developed by Mast Cell Action in conjunction with medical professionals.**

**The results will be published and made available on our website (mastcellaction.org) once completed.**

**Below are some tips which you may find helpful when completing this questionnaire.**

* All personal details will not be used beyond this single questionnaire, please see [Data Protection | Mast Cell Action](https://www.mastcellaction.org/data-protection) for further information on how Mast Cell Action handles personal data.
* You may find it helpful to have access to your medical notes, medication lists and hospital letters to support your responses.
* Please answer to the best of your ability, thoughtfully and truthfully to ensure the results are as effective as possible in supporting our community going forward.
* We expect this questionnaire to take around 30-60 minutes to complete. It is divided into 5 sections for ease of completion, please take breaks if needed.
  + Demographic and General
  + Diagnosis
  + Treatment & Medication
  + Satisfaction
  + Symptoms
* The questions about demographics are an essential part of the data we are gathering. This information will help us to understand how MCAS affects different cohorts of people. It will also help us to understand any discrepancies between income and access to medications and treatment.
* This questionnaire can be completed by those with a diagnosis and those who suspect they have MCAS. We are hoping to highlight the differences and similarities between those with an official MCAS diagnosis and those without. Please note that **official diagnoses are those which have been made by a healthcare professional.**
* While it is important to be as accurate as possible with your answers, we appreciate that the history of many people living with MCAS is complex and it may be difficult to recall exact dates or information. For these questions, please give the closest approximation.

**If you have any questions or need help at any point, please contact** [**Lauren@mastcellaction.org**](mailto:Lauren@mastcellaction.org) **for further support.**

**If you are completing this form on behalf of someone else, please ensure that you include their information in this survey, rather than your own.**

**Name:**

**Date of Birth:**

**County:**

**Demographic Questions: Please delete as appropriate**

|  |  |  |  |
| --- | --- | --- | --- |
| **1** | **What gender were you at birth?**  **Male**  **Female** | | |
| **2** | **Which age bracket are you currently in?**  **0-17**  **18+** | | |
| **3** | **What is your ethnic background?**  **White - British/English/Scottish/Northern Irish**  **White - Irish**  **White - Other**  **Multiple Ethnic Groups - White/Black Caribbean**  **Multiple Ethnic Groups = White/African**  **Multiple Ethnic Groups - White/Asian**  **Multiple Ethnic Groups - Other**  **Asian/Asian British - Indian**  **Asian/Asian British - Pakistani**  **Asian/Asian British - Bangladeshi**  **Asian/Asian British - Chinese**  **Asian/Asian British - Other**  **Black/African/Caribbean/Black British - African**  **Black/African/Caribbean/Black British - Caribbean**  **Black/African/Caribbean/Black British - Other**  **Arab - Arab**  **Arab - Other**  **Other** |  |  |
| **4** | **What is your average annual household income?**  **Up to £15,000**  **£15,001 - £30,000**  **£30,001 - £45,000**  **£45,001 - £60,000**  **​Above £60,001** | | |
| **5** | **Do you reside in the UK?**  **Yes**  **No** | | |
| **6** | **How Long have you had symptoms of MCAS?**  **(*Please think carefully and include all early symptoms which may be attributed to MCAS)***  **Less than 1 year**  **2 to 4 years**  **5 to 7 years**  **8 to 10 years**  **More than 11 years** | | |
| **7** | **What triggered your first episode/symptom of MCAS?**  **Infection (bacterial/viral/parasite)**  **Physical trauma (injury)**  **Allergic reaction (sting/venom/food)**  **Hormones (puberty/pregnancy/menopause)**  **Unknown**  **Other… please specify** | | |
| **8** | **Do you have any other diagnoses of a long-term or chronic condition or other medical condition?**  ***(EG: EDS, POTS or Fibromyalgia)***  **Please specify…** | | |
| **9** | **Do you have an immediate relative (parent, sibling, child) with an official diagnosis of a Mast Cell Disorder or co-morbidity such as EDS, POTS or Fibromyalgia?**  **Please specify…** | | |
| **10** | **Do you have an immediate relative (parent, sibling, child) with a suspected or diagnosed Mast Cell Disorder or co-morbidity such as EDS, POTS or Fibromyalgia?**  **Please specify…** | | |

**Questions relating to Diagnosis:**

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| **11** | **How long have you had an official diagnosis of MCAS?**  **Please note that diagnosis must have been made by a healthcare professional.**  **Less than 2 years**  **2 to 4 years**  **5 to 7 years**  **8 to 10 years**  **More than 11 years**  **Undiagnosed (go to Q15)** |
| **12** | **At what age were you diagnosed with MCAS?** |
| **13** | **Who diagnosed you with MCAS?**  **NHS GP**  **Private GP**  **NHS Specialist**  **Private Specialist**  **Other… Please specify** |
| **14** | **If a Specialist diagnosed you with MCAS, which specialist diagnosed you?**  **Allergist**  **Immunologist**  **Dermatologist**  **Gastroenterologist**  **Haematologist**  **Rheumatologist**  **Other… Please specify** |

**Questions relating to Treatment.**

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| **15** | **Are you being treated for MCAS? (with or without a diagnosis)** | **Yes  ​** | **No** |
| **16** | **Are you on a restricted diet?**  **Dietician-guided**  **Nutritionist-guided**  **Self-guided**  **No restrictions**  **Other… please specify**  **​** | | |
| **17** | **If so, what restrictions are you currently following? (Please state)** | | |
| **18** | **Are you, or have you ever, been prescribed an Adrenaline Auto Injector?** | **Yes** | **No** |
| **19** | **How is your MCAS currently managed? For example, you may be seen as and when symptoms arise, regularly seen under the pain management team or you may email/speak with your medical team as needed.** | | |

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| **20. Please tell us about the medications you have been prescribed and over-the-counter medications. (Add any prescribed medications that are not listed)** | | | | | | | | |
| **Medication  (delete where appropriate)** | **Currently taking**  **Y/N** | **Previously taken**  **Y/N** | **Dose and frequency** | **Type of specialist / centre prescribing or over the counter (OTC)** | **If known, which order were you prescribed the medications (1st, 2nd, 3rd etc)** | **Did this treatment work?? (Y/N)** | **Reason for stopping if you no longer take** | **Additional comments** |
| **Chlorphenamine** |  |  |  |  |  |  |  |  |
| **Cetirizine** |  |  |  |  |  |  |  |  |
| **Loratadine** |  |  |  |  |  |  |  |  |
| **Desloratadine** |  |  |  |  |  |  |  |  |
| **Ketotifen tablets** |  |  |  |  |  |  |  |  |
| **Ketotifen eye drops** |  |  |  |  |  |  |  |  |
| **Fexofenadine** |  |  |  |  |  |  |  |  |
| **Solifenacin** |  |  |  |  |  |  |  |  |
| **Tolteradine** |  |  |  |  |  |  |  |  |
| **Famotidine** |  |  |  |  |  |  |  |  |
| **Nizatidine** |  |  |  |  |  |  |  |  |
| **Cimetidine** |  |  |  |  |  |  |  |  |
| **Montelukast** |  |  |  |  |  |  |  |  |
| **PGE2 Inhibitors (E.G. Seratrodast)** |  |  |  |  |  |  |  |  |
| **Aspirin** |  |  |  |  |  |  |  |  |
| **Ibuprofen** |  |  |  |  |  |  |  |  |
| **Naproxen** |  |  |  |  |  |  |  |  |
| **Diclofenac** |  |  |  |  |  |  |  |  |
| **Sodium Cromoglicate capsules** |  |  |  |  |  |  |  |  |
| **Sodium Cromoglicate eye drops** |  |  |  |  |  |  |  |  |
| **Imantinib** |  |  |  |  |  |  |  |  |
| **Nilotinib** |  |  |  |  |  |  |  |  |
| **Dasatinib** |  |  |  |  |  |  |  |  |
| **Midostaurin** |  |  |  |  |  |  |  |  |
| **Masitinib** |  |  |  |  |  |  |  |  |
| **Omalizumab** |  |  |  |  |  |  |  |  |
| **Steroids – EG: Prednisolone,**  **Dexamethasone** |  |  |  |  |  |  |  |  |
| **Ipratropium bromide nasal spray** |  |  |  |  |  |  |  |  |
| **Mometasone nasal spray** |  |  |  |  |  |  |  |  |
| **Low Dose Naltrexone (LDN)** |  |  |  |  |  |  |  |  |
| **Vitamin C** |  |  |  |  |  |  |  |  |
| **Vitamin D** |  |  |  |  |  |  |  |  |
| **Magnesium (orally or topically)** |  |  |  |  |  |  |  |  |
| **Probiotics** |  |  |  |  |  |  |  |  |
| **Quercetin** |  |  |  |  |  |  |  |  |
| **Luteolin** |  |  |  |  |  |  |  |  |
| **Adrenaline Autoinjectors – E.G. Emerade, Epipen, Jext** |  |  |  |  |  |  |  |  |
| **Other…please specify…** |  |  |  |  |  |  |  |  |

**Questions relating to Investigations: You may find it helpful to access to your medical records where possible to help you to answer these questions, if you are unsure, please give the closest approximation.**

**21.**

|  |  |  |  |  |  |
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| **Specialist** | **Order of visits (e.g. 1st, 2nd, 3rd)** | **Location of specialist** | **Total number of appointments with all specialists** | **Was this a Private or NHS appointment?** | **Do you still see this specialist?** |
| **Allergist** |  |  |  |  |  |
| **Immunologist** |  |  |  |  |  |
| **Rheumatologist** |  |  |  |  |  |
| **Gastroenterologist** |  |  |  |  |  |
| **Haematologist** |  |  |  |  |  |
| **Dermatologist** |  |  |  |  |  |
| **Cardiologist** |  |  |  |  |  |
| **Neurologist** |  |  |  |  |  |
| **Psychologist** |  |  |  |  |  |
| **Other…please specify.** |  |  |  |  |  |

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| **22** | **How many times have you attended planned hospital appointments in relation to your MCAS symptoms?**  **0 to 10**  **11 to 30**  **31 to 50**  **More than 51** |
| **23** | **How many times have you attended hospital due to an emergency in relation to your MCAS symptoms?**  **0 to 10**  **11 to 30**  **31 to 50**  **More than 51** |

|  |  |  |  |
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| **24. Which tests, that you are aware of, have you had to investigate an MCAS diagnosis and in which order? If you have had other tests but are not certain what these were for, please note additional tests – for example: unknown blood tests** | | | |
| **Test** | **Order of tests (e.g. 1st, 2nd, 3rd)** | **Results** | **Type of specialist/centre conducting the test** |
| **Serum tryptase** |  |  |  |
| **Urinary N-methyl histamine** |  |  |  |
| **Urinary Prostaglandins (PGD2/PGDM/PGF2a)** |  |  |  |
| **Leukotriene E4** |  |  |  |
| **Carboxypeptidase** |  |  |  |
| **Methylimidazole acetic acid** |  |  |  |
| **Other – please specify where possible (e.g. bone marrow biopsy, genetic and physiological tests)** |  |  |  |

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| **25. Please use the table below to indicate any tests or investigations that you underwent prior to testing for MCAS.** | | | | |
| **Test** | **Order of tests (e.g. 1st, 2nd, 3rd)** | **Were any diagnoses made for any condition? (e.g. a blood test found anaemia)** | **Type of specialist/centre conducting the test** |
| **Blood tests** |  |  |  |
| **Endoscopy +/- biopsies** |  |  |  |
| **Colonoscopy +/- biopsies** |  |  |  |
| **Stool samples** |  |  |  |
| **Breath tests** |  |  |  |
| **Manometry** |  |  |  |
| **Impedance** |  |  |  |
| **Other** |  |  |  |

**Questions relating to satisfaction.**

|  |  |  |  |
| --- | --- | --- | --- |
| **26** | **How satisfied are you overall with the diagnostic process?**  **Very satisfied**  **Satisfied**  **Neither satisfied nor dissatisfied**  **Dissatisfied**  **Very dissatisfied** | | |
| **27** | **How satisfied are you overall with the support received during the diagnostic process?**  **Very satisfied**  **Satisfied**  **Neither satisfied nor dissatisfied**  **Dissatisfied**  **Very dissatisfied** | | |
| **28** | **How satisfied are you overall with the treatments you have received?**  **Very satisfied**  **Satisfied**  **Neither satisfied nor dissatisfied**  **Dissatisfied**  **Very dissatisfied** | | |
| **29** | **How satisfied are you overall with your current MCAS treatment and management plan?**  **Very satisfied**  **Satisfied**  **Neither satisfied nor dissatisfied**  **Dissatisfied**  **Very dissatisfied** | | |
| **30** | **How would you describe your MCAS journey from start to finish?**  **Very bad**  **Bad**  **Neither good nor bad**  **Good**  **Very good** | | |
| **31** | **If you could improve anything during your diagnostic process, what would it be?** | | |
| **32** | **How would you describe the impact of MCAS on your everyday life?** | | |
| **33** | **Is there anything else that you would like to tell us?** |  |  |

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| **34. Please use the table below to indicate the symptoms you have experienced in the past 3 months, along with their severity.**  **(Please use the notes column for additional details such as the frequency and onset of symptoms, how these have changed over time and which symptoms affect you the most):** | | | |
| **Symptom type** | **Symptoms** | **How bothersome are these symptoms? *(where 0=least and 5=most)*** | **Notes**  *Please specify frequency, for example:*  *Infrequent flares of insomnia every 4 weeks or so...* |
| **Nose and eyes** | **Nose congestion** |  |  |
| **Eye watering and itching** |  |
| **Runny nose** |  |
|  | **Other, please specify** |  |  |
| **Lungs and breathing** | **Sore throat** |  |  |
| **Hoarseness** |  |
| **Wheezing** |  |
| **Shortness of breath** |  |
| **Throat swelling** |  |
|  | **Other, please specify** |  |  |
| **Muscles and bones** | **Joint and muscle pain** |  |  |
| **Brittle bones** |  |
| **Loss of bone mass** |  |
|  | **Other, please specify** |  |  |
| **Genital and urinary** | **Genital pain or swelling** |  |  |
| **Pain when urinating** |  |
| **Vaginal pain, discharge or itching** |  |
| **Bladder urgency or loss of control** |  |
|  | **Other, please specify** |  |  |
| **General** | **Extreme tiredness** |  |  |
| **Anaphylaxis** |  |
| **Chills** |  |
| **Weight loss** |  |
| **Fever** |  |
|  | **Other, please specify** |  |  |
| **Skin** | **Flushing/redness** |  |  |
| **Hives or wheals** |  |
| **Itching with or without a rash** |  |
| **Swelling** |  |
| **Flushing with sweating** |  |
|  | **Other, please specify** |  |  |
| **Brain and nerves** | **Headache** |  |  |
| **Brain fog (memory and concentration difficulties)** |  |
| **Numbness, pain or tingling skin** |  |
| **Anxiety** |  |
| **Behavioural issues, rages** |  |
| **Sleep problems** |  |
| **Dizziness (head spinning)** |  |
| **Panic attacks** |  |
| **Depression** |  |
| **Tinnitus** |  |
|  | **Other, please specify** |  |  |
| **Heart and blood vessels** | **Chest pain** |  |  |
| **Low blood pressure** |  |
| **Fast heart rate** |  |
| **Fainting or light-headedness** |  |
|  | **Other, please specify** |  |  |
| **Digestive system** | **Bloating** |  |  |
| **Stomach cramps or pain** |  |
| **Reflux** |  |
| **Feeling or being sick** |  |
| **Diarrhoea** |  |
| **Constipation** |  |
| **Dumping syndrome** |  |
| **Food allergies or intolerance** |  |
|  | **Other, please specify** |  |  |
| **Other (please specify)** |  |  |  |
| **Other (please specify)** |  |  |  |
| **Other (please specify)** |  |  |  |

**Thank you for taking the time to complete this survey. Without you, we could not begin to compile information which can be used as evidence to support the development of better care pathways, treatment and diagnosis for people with MCAS.**