

Fundraising story collection questionnaire

What have you done/are you doing to raise funds for Mast Cell Action?

Hiking the Green Chain Walk in South East London.

How is the challenge going so far?

I've done 3 consecutive days of hiking, and though I'm really enjoying it, it's taking a toll and I'm starting to wonder if I bit off more than I could chew!

How much are you hoping to raise/did you raise?

My initial target was £500, but seeing as I've already raised £340 and I've had promises of more coming in, I've bumped my goal up to £750.

What is your link to Mast Cell Activation Syndrome? Can you share a brief history of your story with us?

I've been living with MCAS for the past 5 years or so. It was initially very frightening, as I had absolutely no idea what was wrong with me. Doctors would shrug their shoulders when blood test results came back fine, and it was left to me to figure out what was wrong. I seemed to be having adverse reactions to food, but over time I realised there were many other triggers, like toiletries, temperature changes, and even fluctuations in mood.

Once I had figured out it was something to do with mast cells, it was just a matter of time before I encountered histamine intolerance and MCAS during research. Online resources have been so crucial for me in not just getting to the bottom of all of my weird symptoms, but in helping me to figure out how to manage the condition. This is why I feel so passionately about supporting MCA, and the work that they do. Their online resources are invaluable for those trying to educate themselves on what might be going on with their health.

Now that some time has passed, I've learned to avoid my triggers as much as possible, and have found a way to live with MCAS. I still don't have a diagnosis, but thanks to MCA I know that that's a very common story for people in our position. It is a struggle, to live a life of restrictions, but it can be a life worth living if you practice gratitude and focus on all of the wonderful things you can still do, and all of the amazing connections in your life!

Why did you choose Mast Cell Action? What impact has Mast Cell Action had for you?

Mast Cell Action have done an awful lot for me on my journey with MCAS. For a time a few years back I organised in person meet ups through the charity. It was extremely helpful for me to meet people in a similar position, to get practical advice and pointers, and to have my experience of chronic illness validated. If ever I have an MCAS related question, I post it on Mast Cell Action's Facebook group, which as well as having many lovely members who are quick to respond, also has a wealth of handy resources.

What did you enjoy most/are you enjoying about your fundraising experience?

I love being out in nature, so I knew I'd love the greenery and the time outdoors, but I hadn't bargained on all of the other sights I've come across so far- street art, wildlife, tree carvings, there's been all sorts of weirdness!

Is there anything you would do differently next time?

I would definitely factor in pacing, rest days, and perhaps picking a more manageable physical activity! My health has seen a dip in recent months, and I'm still adjusting to that change and learning what my capabilities currently are.

What would you say to other people considering doing a fundraiser for Mast Cell Action?

It feels good to have meaningful activities to focus on, particularly if your health means you aren't able to gain that sense of purposefulness through employment. When I first set up a fundraiser for MCA I thought it would be complicated and require a lot of organisation, but it's actually a doddle to set up a JustGiving page. Then it's just a case of sending the link to everyone you know, and doing whatever it is you've promised to do!

What message would you like to share with the MCAS community?

Thank you for being there whenever I have needed advice and support through MCA's Facebook group.

And also, a big hug to all of you. Sometimes, chronic illness just sucks. You're all remarkably brave for bearing it so well x

What message would you like to share with the wider community?

I used to think of MCAS as a rare condition, but that's just because it goes widely undiagnosed- it's actually pretty common. If you know someone having unusual, allergic type responses to food or other triggers, but all their test results come back negative, point them to Mast Cell Action's website!