

#### Fundraising story collection questionnaire

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

I'm doing a sponsored tai chi practice.

#### How is the challenge going so far?

I haven't started yet.

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

I was hoping to raise £200 but have exceeded that!

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

I have MCAS. I was diagnosed about 18 months ago but had my first anaphylactic reaction aged 13. I'd always assumed that I just had allergies and a bunch of minor ailments, but when I ended up in A&E in early 2020 and a stroke was suspected (but all the tests showed I hadn't had a stroke) I knew that something more must be going on. That started me reading and researching, and with the help of my lovely GP practice I saw a consultant privately, who made the diagnosis, but then got referred to an NHS clinic where I receive treatment. At my worst point it was hard work to get up and down the stairs at home without a rest and I was on a very, very limited diet. Currently I'm able to exercise several times a week and I work full-time (from home), so a lot can change with diagnosis and treatment.

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

It helped me to get my diagnosis by providing useful information.

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

I'm enjoying raising awareness of MCAS. Some of the people who have sponsored me have been in touch to say they'd learned about the condition through this fundraising.

# Is there anything you would do differently next time?

No.

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

Go for it!

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

Yes, you're not mad, it isn't in your head, and with access to the right treatment you can lead a good life with MCAS.

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

I'd like to share with the medical community that taking the time to listen to your patients is incredibly valuable.