

The UK Mastocytosis Support Group

Report to March 31, 2024

Charity Number 1201970

1. Chair's Annual Report
2. Trustees' Annual Report
3. Financial Report

1. Chair's Report

Overview

I am pleased to share that The UK Mastocytosis Support Group has had both a very successful first year in carrying out its mission as a CIO, and another year in a long string of many in which we as a team have been moving the mission forward in the unincorporated charity that preceded the CIO.

We are hugely grateful to our volunteers who carry out our work, to our community who support and help each other in our support forms, and to the physicians and researchers who collaborate with us and help us do our part to improve the lives of people suffering with mast cell diseases.

We are also grateful to the many people who make small and larger donations to the charity and who participate in fundraising challenges that allow us to do our work. Because of the overlap of the old unincorporated charity and the new CIO, some of those fundraising events are not evident in the accounts (appearing instead in the accounts of the unincorporated charity whose assets then transferred to the CIO), but they are greatly appreciated!

Social Media

During this year we had the benefit of having Becky Williams take over our social media, leading to regular weekly posts and a significant increase in our engagement. We participated in the annual awareness campaign for International Mastocytosis and Mast Cell Diseases Awareness Day (www.mastocytosis-mcas.org) via our international partnership as well. Regular platforms included Facebook (via The UK Mastocytosis Support Group Information Page), Twitter, Instagram and LinkedIn, with content aimed at educating patients about their disease and raising awareness about the conditions and patient experiences among clinicians.

Support

We continue to provide 1:1 support by telephone and text to several patients per week, with the bulk of our support being provided through Health Unlocked and our associated private Facebook group.

Health Unlocked has 613 members, up from 275 in January 2023. It remains less active by far than Facebook, but we are glad to provide this alternative to people who prefer not to share information on Facebook. The Facebook group now has more than 2,042 members, an addition of 400 people since 2023, with 1250 considered by Facebook to be "active" members.

We pride ourselves on ensuring that the information we share in our support forums is either based patient experience or draws from the increasing peer-reviewed evidence base about our conditions.

Advocacy and Public Policy

In this fiscal year we began our engagement with NICE for the appraisal new medicine, avapritinib, for advanced systemic mastocytosis. In July and August 2023, we submitted extensive comments on the Draft Scope after consultation with a group of UK haematologists and in January and February surveyed people with AdvSM and their carers and prepared our Technical Engagement submission. We again submitted together with the charity Leukaemia Care, as we did for midostaurin, with us taking the lead in drafting because of our knowledge of the diseases and patient and physician contacts. We appreciate their expertise around the NICE STA process and clarifying what is expected. The final steps of this process (which led to approval for all types of advanced systemic mastocytosis) occurred in the following fiscal year.

We also engaged in the development of the Rare Diseases Framework and Action Plans for NHS England through membership England Rare Disease Action Plan Patient Advisory Group. Our messages for the Action Plan were around access to old medicines (supply issues) and new medicines (NICE/NHSE routing for technology assessment), ensuring that adult-onset and non-genetic conditions are considered, ensuring that services that are not highly specialised are also improved, and that concerns of people with non-life shortening but difficult chronic conditions were also included in the plan. We had ongoing participation in meetings of the Genetic Alliance UK's Patient Empowerment Group, which highlights key policy issues and acts as a conduit for input on key policy issues. We participated in a working group meeting with NICE about how they can engage more effectively and support very small charities engaging in their technology appraisals.

With the goal of improving access to regular medicines such as ketotifen and sodium cromoglycate, which frequently go out of stock, a trustee sits on the British Association of Dermatology's Medicines Working Group, allowing the BAD to help in outreach around these issues. We also participate in the BAD's Patient Advocacy Group Board, which allows us to engage with the BAD senior leadership and make connections to other patient groups in the field for collaboration and co-learning.

A member of our team has also joined the Clinical Reference Group for Specialised Services in Allergy and Immunology (as a Patient and Public Voice member), an NHS England body that includes several patients/patient advocates to include the voice of patients in discussions related to services for adults in allergy and immunology. We also are members of Cancer52, an umbrella charity that advocates for people with rare cancers (such as the advanced forms of systemic mastocytosis) and take opportunities to learn from them and from the other rare cancer charities.

We also attended several All-Party Parliamentary Group meetings to raise issues important to our community. These included one on access to medicines (and delays at the MHRA) and one about developing national alert cards for people with rare diseases that could be used in A&E.

Training

Three of our team participated in a two-part training program on how to support calls/messages from people who may be feeling suicidal. We also attended training in the use of AI for patient charities, run by Beacon for Rare Diseases.

Registry

During FY23/24 we very actively engaged with stakeholders in the UK and the US regarding the co-development of a mast cell diseases registry. We helped convene and lead meetings with leading clinicians and researchers, pharmaceutical companies, and patient advocates to help understand the needs of these key stakeholders and to understand what resources may be available. We had a number of possible platform vendors pitch to us about their products and worked toward narrowing down those platforms. The transition to a CIO lays the foundation for being able to create the structures needed for a registry.

Patient Conference

We held our first in-person event post-COVID, with a day-long conference for people with mast cell diseases and their carers in Manchester. The event attracted 47 attendees. Speakers were Dr Deepti Radia, Dr Priya Sriskandarajah, Dr Andrew Whyte and Dr Peter Arkwright. Sessions focused on paediatric and adult forms of mast cell diseases, including mastocytosis, MCAS, and hereditary alpha tryptasaemia, along with special sessions on managing anaphylaxis. The day ended with the opportunity to share experiences with others about living with or caring for someone with a mast cell disease. Attendee feedback was very positive. "I've attended many conferences over the years, and they have all been very well organised and amazing information. I have learnt something different and new at this latest one and hope that we have these amazing doctors and conferences to look forward to in the future." "Thank you so much for a great day! I got so much from the doctors on the day! Great to see everyone too! Been at this 8 years now and still learning!" But also, members noted that they would have liked to have recordings for those who could not travel for the event.

Collaboration with Pharma

We have maintained contact with several pharmaceutical companies including two who are running trials in the UK to understand how the trials are unfolding, whether there are regulatory hold-ups that we could try to help to clear, and to help direct patients to the trials where appropriate.

PRISM study

The PRISM study is a collaborative project involving patient group leaders, clinicians, and researchers with the aim of gathering information about the quality of life and patient experience in systemic mastocytosis. The study has been sponsored by Blueprint Medicines. During FY23/24 the surveys closed for new responses and analysis began, with a number of scientific posters written up and submitted to medical congresses in allergy, haematology, and in health economics and outcomes research. Our team helped to develop the survey, our members and UK clinicians completed the survey, and members of our team helped to analyse the data and develop the scientific posters.

Outreach

Charlotte Lane and Jess Hobart attended the British Association of Dermatology (BAD) annual congress in Liverpool, sharing materials with dermatologists and helping them understand the needs of mast cell disease patients. We also attended, for the first time, the annual congress of the British Society of Allergy and Clinical Immunology in Harrogate, and met new allergists who are seeing people with mast cell diseases. Jess also attended the annual conference of the European Competence Network on Mastocytosis in Antwerp, where she gave an update from European patient groups on developments in their countries, and gave a presentation about patients' top concerns and about engaging in health technology assessment, with the aim of helping to shape future research agendas.

We attended an online meeting with mast cell disease patient group leaders from around Europe and shared experiences and challenges. We expanded our network of doctors we collaborate closely with, particularly around the NICE process for avapritinib, and via the congresses.

New Logo and Brand

With the transition from unincorporated charity to CIO occurring during this fiscal year we began thinking about developing a new logo and brand and identified companies to help with that work in FY24/25.

Looking Forward

We are beginning work on developing new patient materials with a grant received from the BAD in FY24/25 to support those publications and our engagement with the Patient Information Forum, who provide a quality standard mark for patient information. Those standards will also be applied to a new website, which will include more video materials as well revised written materials, and will feature our new logo and branding. A theme of our work for FY 25/26 will be around the development of self-advocacy skills.

In the autumn of 2024, our role in the NICE assessment of avapritinib for advanced forms of mastocytosis was completed with their positive decision. It is now available in England, Wales and Northern Ireland on the NHS as a standard medicine available. In Scotland it remains a medication for which there would need to be an Individual Patient Treatment Request. We stand by, ready to play our role should Scotland agree to assess avapritinib for advanced systemic mastocytosis. We are also continuing to develop our skills related to NICE processes and to understand patient experience. Recognising that a targeted therapy for the indolent form of systemic mastocytosis (ISM) has been approved in the US and in Europe and more are in trials, we are hopeful to have the chance to tell NICE about the experience of people with ISM should those therapies be approved by the MHRA and assessed.

The work to develop a registry will also continue, with key decisions being made about platform, data to be collected, and the underlying infrastructure for the project. A well-created and run registry creates a rich environment of data that will allow researchers to begin to develop new insights about the nature of mast cell diseases, what is similar

and different across populations, what treatments have which effects, and which people do well over time and which ones face additional challenges. Such a registry can transform the research landscape but is also an expensive endeavour and ensuring that it is financially viable and sustainable will be the work of the next few years.

I thank everyone for their support of our work in the past and look forward to working together to make life better for all people with mast cell diseases.

Jess Hobart, MPP, MPH
Chair of Trustees

2. Trustees' Annual Report

Charity Name: The UK Mastocytosis Support Group, also known as UK Masto

Charity Number: 1201970

Period: 16 February 2023 to 31 March 2024

Principal address:

As the charity has no premises, it can be reached through its postal address:

86-90 Paul Street

London EC2A 4NE

Summary of purposes:

The UK Mastocytosis Support Group (CIO) was established for the preservation and protection of health and the relief of need in particular by:

1. Providing advice, support and information to improve quality of life for mast cell disease patients and their carers
2. Providing or assisting in the provision of information to the public about mast cell diseases
3. Supporting medical professionals in their understanding of mast cell diseases, their diagnosis, prognosis and treatment
4. Supporting research into mast cell diseases, their causes and the means to improve the health and quality of life outcomes for those suffering with the condition and promoting the dissemination of the useful results of such research.

While this CIO was established only in 2023, it was created to take over the work of the unincorporated charity of the same name that had been established in 2014 (and closed in 2024), and that unincorporated charity built on the work of the less formal support group that was first formed in 2004 by Irene Wilson.

The newly formed CIO was approved by the Charity Commission on February 16, 2023, and the old unincorporated charity was formally closed by the Charity Commission on January 30, 2024.

Statement of Main Activities and of Achievements: See appended Chair's Report

Governance:

The UK Mastocytosis Support Group is registered charity number 1201970, governed by the Charities Act 2006. The charity is a Charitable Incorporated Organisation registered on 16 February 2023 (Foundation model). Its only voting members are its Trustees. The UK Mastocytosis Support Group's governance is described in its constitution. The policy and operating decisions of the charity lie with its Trustees, who are listed below. New trustees are appointed by the serving trustees, considering the skills required by the board.

Financial Review:

The UK Mastocytosis Support Group is in a reasonable financial position in that it has substantial assets that have been transferred from the unincorporated charity, with £127,346 held at year end FY 23/24. The usual expenditures for the unincorporated charity ranged from approximately £5,000 to £10,000 per year, with no fixed staff costs and costs associated only with carrying out the activities that move the mission forward such as outreach, patient events, and software and services for e.g. communications, data storage and maintenance of the charity and its website. In the past the unincorporated charity has made several small grants to researchers and money has also been raised in support of a registry. It is with those activities in mind that the charity maintains such a large balance relative to typical annual expenditures, given the size of the potential outlay for such larger projects.

Its primary sources of income are subscriptions from the community of people with mast cell diseases, fundraising events taken on by members of our community, occasional large or small donations, and occasionally, honoraria for services provided that relate directly to and further the mission of the charity.

Some fundraising events held in FY23/24 were held under the auspices of the old unincorporated charity with those funds transferred to this CIO under an s105 order approved by the Charity Commission and completed on January 29, 2024. It is for that reason that they do not appear separately in this financial report. But we are grateful to our community for their fundraising efforts and expect that our community will continue to engage in such events.

Reserves Policy:

1 Operating & Office Expenses:

This fund is used to finance the total operating expenses of the charity (excluding gifts and allocations). Income to this fund is from direct gifts, legacy income and any investment income received.

Level to be held: one year's equivalent of expenses.

2 Strategic Projects:

The main contents of this fund are strategic initiatives and training and support of volunteers and any future employees. The main source of income is from designated gifts and funds allocated by the Trustees.

Level to be held: two years equivalent allocation is retained as a reserve.

3 Capital Requirements:

This fund will be used to plan and execute capital projects. The reserve will also be used to allow for unexpected costs, i.e. items which are not detailed in the financial plan but are mandatory. An example of this would be legal and regulatory changes. Funding will come from internal transfers from the general fund and planning process.

Level to be held: £10,000

Accounting Period: The first accounting period (this one) runs from the date of registration of 16 February, 2023 to March 31, 2024 (approximately 13.5 months) but in future will run from April 1 to March 31.

Trustees during FY 2023/2024:

Jessica Hobart (Chair)
Randolph Perkins-Smart (Treasurer)
Charlotte Lane (Secretary)

The trustees declare that they have approved the trustees' report above.

Signature



JESSICA HOBART 31/01/2025



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name

The UK Mastocytosis Support Group

No (if any)

Receipts and payments accounts

CC16a

For the period
from

Period start date
16/02/2023

To

Period end date
31/03/2024

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
donations)	565	-	-	565	-
Charitable Activities (conference income and honoraria)	3,181	-	-	-	-
		-	-	3,181	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
AR)	3,746	-	-	3,746	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	3,746	-	-	3,746	-
A3 Payments					
Conferences (outreach and patient support)	5,227	-	-	5,227	-
Marketing and Fundraising	2,320	-	-	2,320	-
Postage	9	-	-	9	-
Computer & Software	1,502	-	-	1,502	-
Insurance	486	-	-	486	-
Other direct expenditure	135	-	-	135	-
Subscriptions & Memberships	148	-	-	148	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	9,828	-	-	9,828	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	9,828	-	-	9,828	-
Net of receipts/(payments)	6,082	-	-	6,082	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	6,082	-	-	6,082	-

Section B Statement of assets and liabilities at the end of the period

		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		127,346	-	-
		-	-	-
		-	-	-
	Total cash funds	127,346	-	-

(agree balances with receipts and payments account(s))

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature

Print Name

Date of approval

J Hobart

JESSICA HOBART

30/01/25