

The UK Mastocytosis Support Group
Report to March 31, 2025
Charity Number 1201970

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1. Chair's Annual Report

Overview

I am pleased to share that The UK Mastocytosis Support Group has had a successful year in carrying out its mission, its second in the present form as a CIO, but building on the many years as an unincorporated charity and informal voluntary organisation before that.

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

We are enormously grateful to the many people who make small and larger donations to the charity and who participate in fund raising challenges that allow us to do our work! Thank you SO much to Jennifer Hodd, Heather Kilsby, Chris Gray, The Rogers Family, Mark Williams and Richie Stephens for raising funds for the charity.

Social Media

During this year we have continued to benefit from having Becky Williams (now also a trustee) leading our social media leading to regular posts and a continued 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. We are pleased that we gained many new followers on Facebook in FY 24/25. Regular platforms included Facebook (via The UK Mastocytosis Support Group Information Page), 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 Face book group.

Health Unlocked has 685 members, up from 613 in January 2024. 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 2,240 members, an addition of 200 people since 2024, and more than 1,000 were “active” (according to Facebook) in the seven days before this report was written.

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. We are wary of information provided by AI, which when shared in our group has occasionally included wrong information (not consistent with the research literature) and are carefully moderating that content now that it is so readily available.

We reflected on our experience with our in-person even in March 2024 which was lovely but had a lot of drop-off of attendees as the day neared and decided to hold off on more in-person events given the financial constraints people are under, the difficulties of traveling with a mast cell disease, and the increased costs of renting space and staff travel. This isn't a forever decision, as we did host a hybrid event in September 2025 at the ECRM in London (where the hosting costs were covered by the ECRM), but it is a decision to revisit.

Advocacy and Public Policy

We are delighted to report that during this fiscal year the new medicine avapritinib was approved for people with advanced forms of systemic mastocytosis by the Medicines and Healthcare product Regulatory Agency (MHRA) and by the National Institute for Health and Care Excellence (NICE) for use in England, Northern Ireland and Wales. As stakeholders in the NICE assessment of avapritinib, our job was to communicate about the experience of people with advanced SM and to ensure that the information that was being used to do the economic assessment reflected the patient experience as well as possible. In June of 2024 we were asked by NICE for additional inputs on particular areas they felt were still unclear and we consulted with doctors and other patient group leaders about how best to meet these requests and consulted again with patients to ensure we understood their experience. I want to recognise Andrew Dugdale for his efforts at that time. I want to thank the other patients who were willing to

participate in the July 2024 committee meeting and in particular to thank the one who ultimately did participate alongside me. Committee meetings can be daunting experiences, but the patient voice is so important. We are very pleased that avapritinib was approved by NICE (which led to approval for Wales and Northern Ireland) in November 2024 for advanced SM and by early in 2025 was being used by patients. Approval in Scotland is pending though the process has been initiated, and patients are receiving approval for individual use in the interim.

We also continued to engage with NHS England on implementation of the Rare Diseases Framework and Action Plans through membership in the England Rare Disease Action Plan Patient Advisory Group. 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 from patient groups on these issues.

With the goal of improving access to regular medicines such as ketotifen and sodium cromoglicate, 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. This involvement continued in FY 24/25, though supplies have been more stable. Of concern has been the increase in cost of sodium cromoglicate. 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 continued their role on the Clinical Reference Group for Specialised Services in Allergy and Immunology (as a Patient and Public Voice member) with new specifications for allergy practice now being implemented that explicitly address what care mastocytosis and MCAS patients should expect in adult allergy specialised services. 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. Recently we have joined two of their committees (access to medicines and data working group) in order to learn from other charities about their experiences with NICE and interact with NICE about the experience of small rare disease charities, and to learn from others to inform our registry development. In January, 2025 we also joined the National Allergy Strategy Group, with the goal of nudging the strategy for future for allergy policy in the UK to include mast cell diseases.

Trainings

Our team attended training on the research funding landscape, and on running peer support programs, run by Beacon for Rare Diseases. We were also glad to be part of Beacon's mentoring program in FY 24/25, receiving support from an experienced leader of a patient registry.

Registry

During FY24/25 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 identify and choose registry platforms to be used in parallel in the UK and US to develop this vital tool for moving research forward. Those registry contracts are now in place (FY25/26) and we are moving forward with the concentrated work that will lead to the launch.

Collaboration with Biosciences

We have maintained contact with a number of pharmaceutical companies including three 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 inform patients about trials where appropriate. We also work to ensure that companies understand the experience of our patients and take that into account when developing clinical trials and consent materials, and that they understand what kind of data needs to be collected to make approval by MHRA and NICE more likely.

International Collaboration

Two trustees attended a gathering of patient group leaders from around Europe in February 2025 to strengthen ties, share experiences, and consider developing collaborative projects to improve the lives of patients with mast cell diseases. This event was funded by Blueprint Medicines, but the content of the event was not related to drug development or any particular medicine. We are members of the International Mastocytosis and Mast Cell Disease Awareness Day Committee and provide regular input about our communal work. We are members of EURODIS, the European rare diseases organisation, and of Global Skin, an international dermatology group. In the winter of 2025 we also became members of the Patient Organisation Committee of the European Academy of Allergy & Clinical Immunology, the first time a mast cell disease group has been represented there.

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 was sponsored by Blueprint Medicines. During FY24/25 the main paper reporting the data was drafted and submitted for publication, with a number of scientific posters written up and submitted to medical congresses in allergy and haematology. 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 papers.

Outreach

We attended the annual meeting of the British Society for Haematology, a first for the charity. It was a great opportunity to connect with new haematologists, meet patient group leaders and share information to improve the speed of diagnosis and quality of care of mast cell disease patients. We had the satisfying experience of sharing photos of the typical skin lesions of systemic mastocytosis and having a haematologist realise he'd seen a patient recently and hadn't recognised it. The haematologist said hadn't though he needed to know about mastocytosis because of his area of specialty, which was unrelated.

For the first time in many years, we were unable to attend the British Association of Dermatology (BAD) annual congress due to ill health. We provided a QR code that our friends from another charity put at our stand at the event that led to a webpage with key materials we would have shared in person. Jess Hobart attended the annual conference of the European Competence Network on Mastocytosis in Berlin, where she helped patients share their questions with a panel of experts during a panel shared on Zoom in addition to learning about the latest research.

New Logo and Brand

We engaged a company to help us with developing our new brand and logo and another to help us launch a new website. We have begun a slow rollout of the new logo and look forward to sharing the new website in 2026.

Patient Materials

We received a BAD grant this year to support development of new materials on indolent SM and paediatric mastocytosis. That project has been delayed by volunteer ill-health, but is in process.

We also helped conceptualise and identify interviewees for the issue of Rare Revolution Magazine about systemic mastocytosis (released in June 2025) that included conversations with UK patients, patient leaders from around the world, and two of our UK physicians.

In Remembrance

We want to acknowledge the valuable role Andrew Dugdale played in the charity and in particular in explaining life with advanced systemic mastocytosis to NICE without pulling any punches. Andrew died in October 2025. His spirit of speaking truth to those who need to hear it will continue in his absence.

Looking Forward

As we look forward from January 2026, we have already made good progress in some areas since the end of FY 24/25. Here are some additional areas we will be focusing on.

Patient Support–Community Corner

In addition to the support we continue to provide 1:1 by phone or videoconference and via our Facebook and Health Unlocked platforms, we are looking forward to launching our first Community Corner Zoom event in February 2026 at which patients and families will have the opportunity to share their experiences and feel more connected to a community. We recognise that mast cell diseases can be isolating and look forward to seeing how our community responds to this new series of events.

New Patient Materials and Website

We are continuing work on developing new patient materials with a grant received from the BAD in FY24/25 to support those publications and look forward to completing the development of our new website and launching it. Both of these projects were delayed due to ill health of a key volunteer in FY24/25 but will be completed in 2026.

Advocacy, Access to Medicines, Care Pathways

During the summer and autumn of 2025, we engaged in the first stages of the NICE assessment of avapritinib for moderate to severe indolent systemic mastocytosis. Many thanks to everyone who participated in the survey we put out to support our submission. That participation allows us to paint a vivid picture with your words of what it's like to live with ISM. The process continues with the next key step (the committee meeting) in May 2026. We don't have control over many things in this process—and can't make maths work if it doesn't, but we will do our best to ensure that the committee decisionmakers understand how much

new medicines are needed for moderate to severe ISM. We are also awaiting (likely spring 2026) for the assessment of avapritinib for advanced SM in Scotland and will play our role in that process when invited. We are also continuing to develop our skills related to NICE processes and to understand patient experience.

We are commenting on the NICE's proposed Quality Standards for Rare Diseases (January 2026 consultation) in hopes that the standards are useful and implementable and ultimately improve the quality of care received by MCD patients.

We look forward to participating in the development of the care pathway for systemic mastocytosis in 2026 under the auspices of the British Society of Haematology. We will continue to work toward improved access to and quality of care for all people with mast cell diseases through the Clinical Reference Group.

Job Centre letter—Collecting info from patients about their experiences in the workplace to develop a set of examples of how employers might be able to accommodate people with mast cell diseases. Developing resource. Ca

Registry

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. We are at the key stage where we are making decisions about exactly what data to collect for both patient-entered data and clinician-entered data. We are also beginning to put in place the legal/ethics/data protection infrastructure and taking other practical steps towards launching the registry this year.

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

2. Trustees' Annual Report

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

Charity Number: 1201970

Period: 01 April 2024 to 31 March 2025

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 £126,164 held at year end FY 24/25. 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 FY24/25 we spent funds to help develop a new logo and branding for the charity, which were an investment into the new charity. A new website is being developed using that and will be launched in 2026. That is reflected in the increased spending in the “marketing and fundraising” category.

The charity’s 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. We are grateful to our community for their fundraising efforts and expect that our community will continue to engage in such events.

The charity holds £40,000 that is intended to be directed to the registry project, a contract for which was signed in late 2025 and it is expected that some of that £40,000 will be used to support that project in FY 26/27.

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 accounting period runs from April 1 to March 31.

Trustees during FY 2024/2025:

Jessica Hobart (Chair)

Becky Williams (Secretary)

Lewis Williams (Treasurer)

Charlotte Lane (Secretary- retired January 2025)

Randolph Perkins-Smart (Treasurer-retired Feb 2025)

3. Financial Report (following)



CHARITY COMMISSION
FOR ENGLAND AND WALES

UK Mastocytosis Support Group

No (if any)

Receipts and payments accounts

CC16a

For the period
from

April 1 2024

To

March 31 2025

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	8,905	-	-	8,905	565
Charitable Activities	-	-	-	-	3,181
Subscriptions	357	-	-	357	-
Honorariums	255	-	-	255	-
Interest Income	230	-	-	230	-
Grants Received	2,465	-	-	2,465	-
	-	-	-	-	-
	-	-	-	-	-
AR)	12,212	-	-	12,212	3,746
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	12,212	-	-	12,212	3,746
A3 Payments					
Conferences	595	-	-	595	5,227
Marketing and Fundraising	9,135	-	-	9,135	2,320
Postage	30	-	-	30	9
Computer & Software	2,437	-	-	2,437	1,502
Insurance	171	-	-	171	486
Other Direct Expenditures	340	-	-	340	135
Subscriptions & Memberships	76	-	-	76	148
Accountancy Fees & Compliance	125	-	-	125	-
Publications	330	-	-	330	-
Training	155	-	-	155	-
Sub total	13,394	-	-	13,394	9,827
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	13,394	-	-	13,394	9,827
Net of receipts/(payments)	- 1,182	-	-	- 1,182	- 6,081
A5 Transfers between funds	- 40,000	40,000	-	-	-
A6 Cash funds last year end	127,346	-	-	127,346	-
Cash funds this year end	86,164	40,000	-	126,164	- 6,081

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

B1 Cash funds

	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
Cash in bank	85,739		-
PayPal cash balance from old charity awaiting transfer	425		-
Registry Funds	-	40,000	-
Total cash funds	86,164	40,000	-

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

B2 Other monetary assets

Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

B3 Investment assets

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

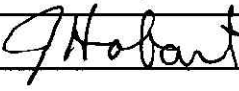
B4 Assets retained for the charity's own use

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

B5 Liabilities

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

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

Signature	Print Name	Date of approval
	JESSICA HOBART	31/1/26

Declarations

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

Signed on behalf of the charity's trustees

Signature: 

Full Name: Jessica Hobart

Position: CHAIR

Date: 31/01/26