



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' annual report (including Directors' report) for the period

From: Period start date 01/01/2024 **To:** Period end date 31/12/2024

Charity name: Hypermobility Syndromes Association (working name: HMSA)

Charity registration number: 1186735

Company number: n/a

Objectives and activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	<p>We support all hypermobile people and the professionals who work with them.</p> <p>The object of the Hypermobility Syndromes Association, as set out in our governing document, is to preserve and protect good health, and support the needs of people affected by Hypermobility Syndromes, by:</p> <ul style="list-style-type: none">• Providing validation, education, rehabilitation and positive self-management advice for people with hypermobility related disorders and their entire support network, including their families, teachers, friends and colleagues. Encouraging a culture of support while raising awareness, knowledge and self-determination.• Improving the quality of life, and enabling effective self-management for affected individuals through a variety of resources, including (but not limited to): self-management programs, support groups, social media, publications, helpline and support from our expert patient volunteers.• Working with and educating the relevant medical, social and health professionals in developing awareness and understanding of the biopsychosocial impact of hypermobility related disorders for individuals and their entire support network.• Supporting and encouraging individuals in their pursuit of diagnosis and treatment, via

		<p>signposting to appropriate services where necessary.</p> <ul style="list-style-type: none"> • Providing an environment which enables people affected by a hypermobility syndrome to volunteer, furthering the charity's aims whilst developing their own workplace skills and confidence. • Working with other organisations to undertake and promote research into hypermobility related disorders, the useful results of which will be published for the public benefit. To seek to be the patient partner and to disseminate research, surveys and investigations whilst maintaining our high standard of information. • Collaborating with other organisations on policies, strategies and projects, which are synergistic with the CIO's own strategy and values.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	<p>The HMSA's main activities include:</p> <ul style="list-style-type: none"> • Provision of evidence-based resources, information and support to anyone affected by hypermobility and the professionals and that support them to promote self-management, informed care, and improved quality of life. • Free support given via helpline, email and social media offering signposting, validation, and guidance to individuals seeking diagnosis, treatment, or day-to-day management strategies. • Running our membership scheme to provide extra, tailored support for the hypermobile community promoting self-management, peer connection, and access to exclusive educational resources. • Regional groups providing additional peer to peer support for members fostering community, shared experience, and practical advice for living with hypermobility-related disorders. • Bi-annual production of journal for members featuring expert articles, lived experience stories, and research updates to educate, empower, and inform the hypermobile community. • Organising and leading regular events for both professionals and those affected by hypermobility to share knowledge and promote best practices in care and self-management.

		<ul style="list-style-type: none"> • Running thriving social media feeds to raise awareness of hypermobility and the HMSA and to provide timely, accessible information and support. • Working closely with our group of Clinical Advisors to ensure our resources and guidance reflect current best practice and support both individuals and professionals. • Delivering the HMSA Professional Educational Model and wider professional education, including tools like the HMSA Clinicians Guide Quick Reference Poster, to improve recognition, diagnosis, and management of hypermobility-related disorders and support individuals in accessing appropriate care • Contributing to and keeping abreast of the latest research, supporting multiple research projects, assisting researchers in finding participants and disseminating results to benefit the wider community. • Liaising with, working in partnership or alongside other relevant partners such as ARMA, Mast Cell Action, EDS Support UK or PoTS UK, to strengthen advocacy, research and service development aligned with our values. • Enabling volunteers to contribute their own skills and lived experience in support of the charity's aims, while also offering opportunities to learn from peers and develop new capabilities.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The Hypermobility Syndromes Association's board takes seriously the Charity Commission's guidance on public benefit. All our activities are relevant to improving health outcomes, wellbeing, and support for people with hypermobility in line with our charitable purposes stated above.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	n/a
Policy on social investment including program related investment	Para 1.38	n/a
Contribution made by volunteers	Para 1.38	Our team of around 40 volunteers make a vital contribution to the work of the Hypermobility Syndromes Association (HMSA). Almost all our volunteers live with hypermobility, and we see it as

		<p>essential that the charity is truly led by people from within our community of need. Our volunteers genuinely understand hypermobility syndromes and have daily lived experience and are empowered to shape the support, advice and solutions we provide. Their lived experience and insight, combined with an ethos of practical self-management, enables the HMSA to provide validation, support, and practical advice that cannot come from theoretical understanding alone. The composition of our trustee board, staff and wider volunteer team all demonstrate the value we place on being led by lived experience.</p> <p>We do a huge amount with very limited resources thanks to our amazing volunteers who cover a wide range of roles from social media, to fundraising, to running local groups providing peer-led support, to editing our journal, to supporting and leading our work with professionals. Through these roles, many volunteers gain valuable experience, build confidence, and develop transferable skills.</p> <p><i>"It makes me feel I belong. After years being supported by the HMSA, I can now give something back."</i></p> <p><i>"I absolutely adore volunteering for them, and I hope to continue to do so for many more years to come... I am passionate about empowering the audience with knowledge to self-manage better"</i></p> <p><i>"I believe it's vital for the voices of people who have hypermobility to be heard and valued - in everything the HMSA does and in its own board and organisation. I've met people with a wide range of backgrounds and experiences since becoming a Trustee. Hearing their stories and seeing how these stories can support and improve other people's lives is one of the best parts about being a Trustee"</i></p> <p>We are also extremely lucky to have a voluntary group of Clinical Advisors, led by Dr Philip Bull, who bring expertise, skills and knowledge across a range of specialist fields relevant to hypermobility ensuring that the information we provide is up to date, rigorously checked and comprehensive.</p>
Other		<p>The HMSA is run by 2 paid, part-time staff whose total hours do not equate to 1 full-time role. Both paid members of staff also live with hypermobility. All other work is carried out by volunteers.</p>

Achievements and performance

<p>Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.</p>	<p>Para 1.20</p>	<p>The HMSA is here to support <i>everyone</i> with symptomatic hypermobility, whatever the cause, and however mildly or severely they may be affected.</p> <p>We promote a holistic, solution-focussed approach to living well, providing self-management tools and support including:</p> <ul style="list-style-type: none">• Patient Support Groups• Education Programmes• Information and Advice for hypermobile people• Evidence-based information and advice for healthcare professionals <p><u>Our mission:</u></p> <p>Improving the quality of life for everyone affected by symptomatic hypermobility by:</p> <ul style="list-style-type: none">• accelerating access to timely and accurate diagnosis;• promoting awareness and understanding amongst professionals to support better care;• providing validation, support and practical self-management tools from a community who truly understands <p><u>Our vision:</u> everyone affected by symptomatic hypermobility is able to access the care, support and advice they need – from both peers and professionals.</p> <p><u>Our Values:</u> Empowering, inclusive, collaborative, community-led, trustworthy.</p> <p><i>"The Hypermobility Syndromes Association ... has done more for me than any other organisation or appointment to help me manage my symptoms, feel heard and to improve the quality of my everyday life" (member)</i></p> <p>With the NHS continuing to be under extreme pressure, with waiting lists still growing, we help to reduce the burden on statutory services by delivering support when it was not available elsewhere. This is especially important as on average it takes 10 years for hypermobility syndromes to be diagnosed.</p> <p>As a small charity led by people with lived experience, we are able to be very agile and quickly pivot our services to provide the expert, specialist services our members, the professionals who support them and the wider hypermobile community need.</p> <p>We have continued to build on the patient events we offer on a wide range of topics from nutrition to exercise to pain management to help people with hypermobility self-manage their condition better, so</p>
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		<p>they are able to live well. Session content was shaped by feedback from members and volunteers. This series of events has been extremely well attended and received with over 2200 people registering for live events – with many more watching them on playback. A threefold increase on attendance from last year, shows the growing need and demand for these sessions.</p> <p><i>"It's good to know we are not alone. I'm learning all the time and since I joined the organization I feel more confident helping my Granddaughter..."</i></p> <p><i>"Absolutely amazing. I look forward to more sessions in the future to help me develop my own resilience within my hypermobility."</i></p> <p><i>"Very good information provided in an understandable format."</i></p> <p><i>(Post event feedback)</i></p> <p>For a charity staffed mainly by volunteers, many with their own health needs, this level of service provision when services are so stretched is vital and is a major achievement.</p> <p><i>"The information given was very useful and personalised to my questions. Jo's delivery is fantastic and her communication skills are brilliant. I felt very much at ease. (Feedback about our support.)"</i></p> <p>The 'Living Well with Hypermobility' 5 week course for members at the start of the year was also a great success again and was extremely well attended with excellent feedback. The sessions included: Anxiety and mental health; Pain management; Sleep management; Weight management and an open Q&A session. Feedback given from participants post sessions told us:</p> <ul style="list-style-type: none"> <i>• "They're really good at getting trusted information to the public / patients, who would struggle to find it elsewhere."</i> <i>• "Just vital for us. Please continue forever!!! (with pacing of course) . Thanks"</i> <i>• "Excellent session wish I had had this years ago. I will go pass on what I have learnt to my 3 adult daughters all of whom have these issues too as well as myself. Cannot thank you enough."</i>
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		<p>We also run a helpline and deliver online support, offering validation, signposting and practical advice.</p> <ul style="list-style-type: none"> • <i>"Thank you. No one else has understood or listened or helped me like you have." (Helpline feedback)</i> • <i>"Thank you so much. No one else understood and not only have I been heard, I've been helped with practical advice." (Helpline feedback)</i> <p>As well as offering support via a wide range of sessions and events including weekly online relaxation classes to support wellbeing, we also run monthly online 'ask the Occupational Therapist' sessions which are free and open to all.</p> <p>Feedback after 'Ask the OT' session: <i>"I love ALL of these sessions .please continue. They are vital for my health."</i></p> <p><i>"I cannot wait to attend more sessions. ""Calm, friendly, constructive approach "</i></p> <p>Additionally, our local regional groups successfully continued their transition to hybrid delivery providing much needed support, connection and information for our members with regional groups regularly running. In response to feedback, we have also started to offer national online support groups that focus on specific issues. Feedback stresses the importance of sharing and support within a community of peers that understand.</p> <p>Feedback: <i>"...The feeling of community and being with people who understand is so important."</i></p> <p><i>"Community - a group of people who understand and not being preached too by a healthcare professional who doesn't get it"</i></p> <p>Our social media team continued to be very active in raising awareness and providing information not only about hypermobility but also a wide range of related conditions. Over 500 individuals were supported with 1:1 advice and support via Facebook or online enquiries, in addition to the very high levels of public engagement with our posts. For a small charity, our reach on social media which continues to grow (c.50k on Facebook, c. 12k on twitter and 3k on Instagram) continues to be impressive. Additional help was provided by our trained helpline team led by volunteers helping to support over 800 more people via email, online and phone.</p>
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		<p>During 2024, we continued to work closely in partnership with relevant charities in the field. Together we worked hard behind the scenes to ensure that key hypermobility services remain open and that more healthcare professionals are better informed about hypermobility. This important work is necessary so that patients can access earlier diagnosis as well as better support in their local area in the future.</p> <p>We liaised with a wide range of clinicians and attended some key events such as the British Society of Rheumatologists' Annual Conference in Liverpool attended by over 2000 professionals. Supported by volunteers and our Lead Clinical Advisor, Dr Philip Bull, we spoke directly to hundreds of professionals, delivered a very well-attended presentation and shared new resources.</p> <p>Many of the key achievements in 2024 were ensuring that the HMSA was continuing to build the foundations for future growth and development. Significant progress was made in reviewing and stabilising the financial position, helping to sustain and develop the charity's work. The board and CEO reviewed the charity's strategy and future plans. The key priority for the short-term remains on raising vital funds so that the charity can extend and further develop its work.</p> <p>We were pleased to receive an Awards for All grant from The National Lottery Community Fund. This will help us to run a national awareness event with a range of sessions to reach more people, and offer advice, support and resources in June 2025 – sessions will be led by both clinical experts and those with lived experience on how to manage symptoms and will be an opportunity for the whole community to come together to learn and share. We would like to thank The National Lottery Community Fund for making this possible.</p> <p>Key changes: After years of fantastic service and contributions – particularly with strategy development – Gil Hilleard retired from the board. The HMSA is indebted to the support and expertise Gil provided and we extend our thanks to him for all that he has done to strengthen and develop the charity.</p> <p>We are lucky to have a strong trustee board and the varied skills and very extensive experience that they jointly bring means that the charity is fully able to meet any challenges ahead while continuing to shape and develop the HMSA's future strategy.</p>
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		<p>We are also pleased to confirm the reappointment of Rachel King, Nichola Gardner, Zoe Lomax, and Mark Austin (Chair) for a further three-year term. We are deeply grateful to them and to the entire board for their continued commitment, insight, and leadership.</p>
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Financial review

Review of the charity's financial position at the end of the period	Para 1.21	See financial information attached. Income for period: £44,301, split between £34,551 of unrestricted funds and £9,750 of restricted funds. Expenditure for period: £35,943, split between £35,675 of unrestricted funds and £268 of restricted funds. Unrestricted funds at year end: £11,998; Restricted funds at year end: £9,482. Total funds at year end: £21,480.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The charity aims to keep around 3 months in reserves up to a maximum of 6 months. This allows us to manage smoothly any month-on-month income/expenditure and cash flow variations as these can have a greater impact on a small charity. In determining appropriate reserves levels, our reserves policy takes into account the size of the charity and its sources of funding and also follows the Charity Commission Guidance that recommends we consider the following when determining reserves levels: <ul style="list-style-type: none"> • “plans for the maintenance of essential services for beneficiaries” • “the risks of unplanned closure associated with the charity’s business model, spending commitments, potential liabilities and financial forecasts” • “addresses the risks of unplanned closure on their beneficiaries (in particular, vulnerable beneficiaries), staff and volunteers” Reserves are actively considered as part of our financial planning and cash flow monitoring, ensuring we maintain a sustainable and responsive approach to managing our resources. In this way, trustees can ensure that we prevent the build-up of excess reserves or of reserves being unexpectedly or rapidly depleted.
Amount of reserves held	Para 1.22	£11,998. This amounts to just over 4 months of unrestricted expenditure, based on the 2024 expenditure.
Reasons for holding zero reserves	Para 1.22	n/a
Details of fund materially in deficit	Para 1.24	n/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	n/a

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The HMSA's principal sources of income are fundraising, membership, and grant income. We would like to thank everyone who supported the HMSA in 2024.
Investment policy and objectives including any social investment policy adopted	Para 1.46	n/a
A description of the principal risks facing the charity	Para 1.46	There are no immediate risks causing undue concern. However, the trustees take risk management seriously and the trustees maintain a risk register, which is reviewed periodically at trustee meetings. The risk register outlines key risks (e.g. financial, IT, operational, safeguarding) and ensures that any action needed to ameliorate risks is taken promptly and on the basis of full information. The Finance Committee regularly reviews the charity's financial position. Internal control risks are minimised by the implementation of procedures for the authorisation of all financial transactions.
Other		

Structure, governance and management

Description of charity's trusts:		n/a
Type of governing document: for example, trust deed , memorandum and articles of association etc	Para 1.25	Constitution
How is the charity constituted? for example limited company , unincorporated association , CIO	Para 1.25	CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Trustees are appointed in accordance with the charity's governing document. All trustee vacancies are advertised. New trustees are nominated and approved by the existing board, subject to a majority vote.

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	<p>References, and detailed checks are provided before trustees start. As a small charity, the HMSA takes a practical approach to trustee induction. New trustees are given key documents such as the governing document, recent minutes and financial information, a trustee Handbook, code of conduct and relevant policies to help them understand the charities work and their responsibilities.</p> <p>Induction is supported by existing trustees and the CEO who share knowledge and provide guidance as needed.</p> <p>As members of the National Council for Voluntary Organisations (NCVO), we encourage trustees to access NCVO's resources and training opportunities. Trustees are also signposted to the Charity Commission's guidance for trustees to support their understanding of governance and legal duties.</p>
The charity's organisational structure and any wider network with which the charity works	Para 1.51	n/a
Relationship with any related parties	Para 1.51	n/a
Other		n/a

Reference and administrative details

Charity name	The Hypermobility Syndromes Association
Other name the charity uses	HMSA
Registered charity number	CIO 19863
Charity's principal address	49 Greek Street, London W1D 4EG

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Rachel King	Trustee	From December 2020 - present	
2	Gil Hilleard	Trustee	From June 2021 – December 2024	
3	Nichola Gardner	Trustee	From May 2021 - present	
4	Zoe Lomax	Trustee	From May 2021 - present	

5	Mark Austin	Trustee (Chair)	From December 2021 - present	
6	Zoe Walker	Trustee	From March 2022 – March 2025	
7	Tia Cheang	Trustee	From August 2023 - present	
8				
9				
10				
11				
12				
13				
14				
15				
16				

Corporate trustees – names of the directors at the date the report was approved

Director name	
n/a	

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year
n/a	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	n/a
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	n/a
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	n/a

Additional information (optional)

Names and addresses of advisers (optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (optional information)

Lisa Bone, CEO

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

Other optional information

None

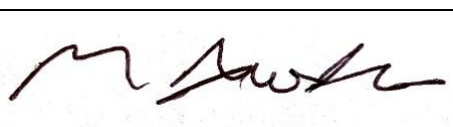
Declarations

The company has taken advantage of the small companies' exemption in preparing the report above.

The trustees declare that they have approved the trustees' report (including directors' report) above.

Signed on behalf of the charity's trustees/directors

Signature(s)



Full name(s)

Mark Austin

Position (for example
Secretary, Chair, etc)

Chair

Date

5-8-25



Section A

Independent Examiner's Report

Report to the trustees/
members of

Hypermobility Syndromes Association

On accounts for the year
ended

31 December 2024

Charity no
(if any)

1186735

Set out on pages

16-17

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/12/2024**.

Responsibilities and
basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

11/8/25

Name:

Virginia Santer

Relevant professional
qualification(s) or body
(if any):

ACCA

Address:

Monetaire Accountants Limited, Sovereign House

22 Shelley Road, Worthing, BN11 1TU

Section B

Disclosure

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

**Give here brief details
of any items that the
examiner wishes to
disclose.**



CHARITY COMMISSION
FOR ENGLAND AND WALES

Hypermobility Syndromes Association

1186735

Receipts and payments accounts

CC16a

For the period
from

1/1/2024

To

12/31/2024

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 and Legacies	7,458	-	-	7,458	9,265
Grants	1,000	9,750	-	10,750	1,000
Charitable Activities	22,598	-	-	22,598	19,760
Sales and Trading	3,195	-	-	3,195	4,243
Bank Interest	300	-	-	300	227
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	34,551	9,750	-	44,301	34,495
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	34,551	9,750	-	44,301	34,495
A3 Payments					
Charitable Activities	34,691	268	-	34,959	37,392
Governance Costs	984	-	-	984	515
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	35,675	268	-	35,943	37,907
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	35,675	268	-	35,943	37,907
Net of receipts/(payments)	- 1,124	9,482	-	8,358	- 3,412
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	13,122	-	-	13,122	16,534
Cash funds this year end	11,998	9,482	-	21,480	13,122

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Bank	10,314	9,482	-

Paypal	1,643	-	-
Go Cardless	41	-	-
Total cash funds	11,998	9,482	-
(agree balances with receipts and payments account(s))	OK	OK	OK

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

Details			
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

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)
Accountancy	Unrestricted	-	
		-	
		-	
		-	
		-	

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

Signature	Print Name	Date of approval