



CHARITY COMMISSION
FOR ENGLAND AND WALES

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

From: Period start date 01/01/2023 **To:** Period end date 31/12/2023

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 among, and relieve the needs of, people affected by Hypermobility Syndromes, in particular 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. • h. 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. • Free support given via helpline, email and social media feeds to anyone that needs it. • Running our membership scheme to provide extra, tailored support for the hypermobile community. • Local groups providing additional peer to peer support for members. • Bi-annual production of journal for members. • Organising and leading regular events for both professionals and those affected by hypermobility. • Running thriving social media feeds to raise awareness of hypermobility and the HMSA and to provide timely information and support. • Working closely with our group of Clinical Advisors. • Delivering the HMSA Professional Educational Model and wider professional education. • Contributing to and keeping abreast of the latest research and supporting multiple research projects - assisting researchers in finding participants and disseminating results.

		<ul style="list-style-type: none"> • Liaising with, working in partnership or alongside other relevant partners such as ARMA, Mast Cell Action, EDS UK or PoTS UK.
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	<p>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 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.</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</i></p>

		<p><i>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> To improve the support and access to treatment for anyone affected by hypermobility so they can live well.</p> <p><u>Our Values:</u> Empowering, inclusive, collaborative, community-led, trustworthy.</p> <p><i>"The Hypermobility Syndromes Association ... works so hard to support individuals and families struggling to cope with the various related syndromes that can be profoundly life-impacting but are still not widely understood." (member)</i></p> <p>While 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</p>
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		<p>members, the professionals who support them and the wider hypermobile community need.</p> <p>We have continued to build on the wide range of 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 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 1000 people attending live events – and many more watching them on playback. A threefold increase on attendance from last year, showing the growing need and demand for these sessions.</p> <p><i>"I would also like to say a very big thank you to HMSA. I became a member last Autumn and as a consequence I have learnt a huge amount about Hypermobility. I was diagnosed in 2015, however at the time of diagnosis I did not fully understand the significance of the diagnosis. No guidance or advice was given to me on how to live well with hypermobility. HMSA has helped me to do that so thank you very much.." (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>"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." (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"> • 100% of were more now confident managing their condition • 92% would now make changes to how their manage their condition. <p><i>"Nuggets of information of everywhere."</i></p> <p>We also run a helpline and deliver online support.</p> <ul style="list-style-type: none"> • <i>"Thank you. That's the best help I've ever had." (Helpline feedback)</i>
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		<ul style="list-style-type: none"> • <i>"Thank you so much. It's so helpful to talk to someone who actually understands." (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><i>Feedback after 'Ask the OT' session: "I have learned so much. Just a little message to say how reassuring it is to be in a room with such well-informed, understanding and compassionate hosts. So much gratitude for you and all HMSA does, thank you.""</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 regionally groups regularly running. In response to feedback, we have also started to offer national online support groups that focus on specific issues.</p> <p><i>Feedback: "It's so lovely to pop into any of the local groups and meet people all over the country and hear their stories and share support hints and tips."</i></p> <p><i>"The group was so nice tonight. Thank you for being so welcoming! I'm quite isolated so it's really nice to join a group with similar people."</i></p> <p>Our social media team continued to be very active providing information not only about hypermobility but also a wide range of related conditions. Over 500 individuals were directly supported with 1:1 advice via Facebook, 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.46k 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> <p>During 2023, 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>
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		<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 2023 were ensuring that the HMSA was continuing to build the foundations for future growth and development. The board and CEO reviewed the charity's strategy and future plans. The key priority for the short-term remains focussing on strengthening and stabilising the organisation and raising vital funds so that the charity can extend and further develop its work.</p> <p>Key changes: The HMSA was delighted to welcome a new trustee during the course of 2023 – Tia Cheang. Tia brings a wealth of experience and a deep personal connection to her role at the HMSA. As someone who has lived with Ehlers-Danlos Syndrome, she joined to bring her own experience and understanding to help guide our mission.</p> <p>Tia has had a long career in IT, mainly in the NHS, where her involvement in Genomics UK and the 100k Genome Programme aimed to unravel the complexities of genetic conditions, much like EDS, offering hope and potential pathways for better treatments.</p> <p>Tia draws upon her own experience of living with EDS to advocate for Hypermobile individuals and improve inclusivity, disability rights, and greater awareness through her lobbying work at Parliament. Tia is passionate about supporting disabled individuals in the workplace. She coaches and mentors disabled individuals to overcome barriers and achieve their professional goals, demonstrating her commitment to improving employment opportunities for those with long-term conditions.</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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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: £34,495 Expenditure for period: £35,265 Unrestricted funds at year end: £13,122. Total funds at year end: £13,122
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	<p>The charity aims to keep at least 3 months in reserves up to a maximum of 6 months. In 2023 we held £13,122 which falls within this range and 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:</p> <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” <p>We review reserve levels annually as part of our planning, budgetary and financial control processes and also monitor levels monthly. In this way, trustees can ensure that we prevent the build-up of excess reserves or of reserves being unexpectedly or rapidly depleted.</p>
Amount of reserves held	Para 1.22	£13,122
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, sponsorship and grant income. We would like to thank everyone who supported the HMSA in 2023.
	Para 1.46	n/a

Investment policy and objectives including any social investment policy adopted		
A description of the principal risks facing the charity	Para 1.46	The trustees review a detailed, and regularly updated, risk register regularly at trustee meetings. The risk register outlines key risks and ensures that any action needed to ameliorate risks is taken quickly and on the basis of full information.
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	Elected by other trustees

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	References, and detailed checks are provided before trustees start. The HMSA has an induction procedure including provision of all relevant documents, a trustee Handbook, code of conduct and relevant policies and can offer additional support for new trustees, as required.
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 - present	
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 - present	
7	Tia Cheang	Trustee	From August 2023 - present	
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

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
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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

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	30/7/24	



Section A

Independent Examiner's Report

Report to the trustees/
members of

Hypermobility Syndromes Association

On accounts for the year
ended

31 December 2023

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 **31/12/2023**.

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:

V Santer

Date:

12/8/24

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

01/01/2023


To

31/12/2023

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations and Legacies	9,265	-	-	9,265	10,021
Grants	1,000	-	-	1,000	-
Charitable Activities	19,760	-	-	19,760	16,092
Sales and Trading	4,243	-	-	4,243	3,053
Bank Interest	227	-	-	227	62
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	34,495	-	-	34,495	29,228
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	34,495	-	-	34,495	29,228
A3 Payments					
Charitable Activities	34,750	2,642	-	37,392	38,265
Governance Costs	515	-	-	515	1,276
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	35,265	2,642	-	37,907	39,541
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	35,265	2,642	-	37,907	39,541
Net of receipts/(payments)	- 770	- 2,642	-	- 3,412	- 10,313
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	13,892	2,642	-	16,534	26,847
Cash funds this year end	13,122	-	-	13,122	16,534

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	11,844	-	-
	Paypal	1,237	-	-
	Go Cardless	41	-	-
	Total cash funds	13,122	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	to nearest £	to nearest £	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)
	Accountancy	Unrestricted	-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Rachel King	30/07/2024	
			14/08/2024	