



CHARITY COMMISSION
FOR ENGLAND AND WALES

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

From: Period start date 01/01/2021 **To:** Period end date 31/12/2021

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> <p>a. 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.</p> <p>b. 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.</p> <p>c. 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.</p>

		<p>d. Supporting and encouraging individuals in their pursuit of diagnosis and treatment, via signposting to appropriate services where necessary.</p> <p>e. 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.</p> <p>f. Maintaining the Information Standard, as was accredited by NHS England, so as to ensure the high standard of all HMSA publications in whichever format deemed suitable.</p> <p>g. 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.</p> <p>h. Collaborating with other organisations on policies, strategies and projects, which are synergistic with the CIO's own strategy and values.</p>
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.

		<ul style="list-style-type: none"> Running thriving social media feeds to raise awareness of hypermobility and the HMSA and to provide timely information and support. For example, our Facebook page had a reach of around 100,000 in the latter months of 2021. Working closely with our group of Medical 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. Liaising with, working in partnership or alongside other relevant partners such as ARMA, 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 stated 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). 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

		<p>editing our journal, to supporting and leading our work with professionals. Almost all our volunteers have personal experience of hypermobility and 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.</p> <p>“Volunteering with the HMSA has meant working with people where I am completely understood and accepted – where I don’t have to explain my limits or why I need to do something differently. Where I can be who I am, how I am...</p> <p>But the best part is that through the work of the charity I am providing that same sense of safety and belonging for the hypermobile community the charity supports.”</p> <p>We are also extremely lucky to have a voluntary group of Medical 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. 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>In a year where the effects of COVID-19 continued to be felt, especially by many in the hypermobile community who were especially vulnerable, the HMSA continued to be responsive and adapt rapidly to changing circumstances.</p> <p>The HMSA maintained - and even expanded - service provision while many other services pulled back and the NHS was under extreme pressure. For a charity staffed mainly by volunteers, many with their own health needs, this continuity of service, at a time when people needed it most, was a major achievement.</p> <p>As a small charity led by people with lived experience, we were 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 needed.</p> <ul style="list-style-type: none">• “You help me to understand things I’ve been going through for 20 years...”• “Thank you. That was the most informative, helpful support session I’ve ever attended.” <p>For example, weekly online relaxation classes introduced during COVID-19 continued to support wellbeing and reduce isolation as did the monthly online ‘ask the Occupational Therapist’ sessions. The #HypnOT (‘Living Well with Hypermobility’) 5 week course was also a great success again and was well attended with excellent feedback.</p>
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		<p>Feedback after 'Ask the OT' session: "I am always so impressed and grateful for the amount of useful information and tips that are in these sessions. It's so nice to have ideas for making day to day living that bit better."</p> <p>Additionally, our local regional groups successfully continued their transition to online delivery providing much needed support, connection and information for our members with 7 groups regularly running with 2 more in the pipeline.</p> <p>Feedback to local group leaders:</p> <p>"I couldn't be more grateful for your emails. Your first was so kind and thoughtful, thank you. And to receive another with more considered responses and detail. I am deeply touched by your kindness and efforts. Thank you so much. I really appreciate all the time you have taken to help me. I am truly blown away!"</p> <p>"Would just like to say thank you for all you've done running the group over the last few months. You always seem to have a smile on your face. I have learnt some useful stuff and it is nice to realise we are not alone."</p> <p>Our professional education team ran a successful well attended Masterclass for the professionals in September. Sessions were led by 5 guest speakers, all of whom, volunteered their time live to answer any questions from the audience in addition to their presentations. A range of topics were covered including - the link between Neurodiversity and Hypermobility; the latest diagnostic and management guidelines for PoTs and its relationship with dysautonomia; and the SPIDER – a multi system diagnostic tool.</p> <p>Our social media team continued to be very active providing information not only about hypermobility but also information on COVID-19, vaccines and shielding – as well as self-management through these difficult times. Over 100 individuals were directly supported with confidential 1:1 advice via Facebook, in addition to the high levels of</p>
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		<p>public engagement with our posts. For a small charity, our reach on social media (c.42k on Facebook, c. 11k 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 200 more people via email and phone.</p> <p>We worked jointly with EDS UK to co-produce an online toolkit for schools with EDS UK which was launched in Summer 2021. The schools hub will improve the support given to children with hypermobility in schools. The toolkit provides clear, practical information for schools on how best to enable and support hypermobile pupils. The HMSA supplied several sections for the toolkit and helped to guide the use of language and overall approach to ensure it was both accurate and inclusive. By the end of November 2021, the online toolkit had reached 11,187 unique visitors and usage levels continue to grow.</p> <p>Many of the key achievements in 2021 were around maintaining stability and ensuring that the HMSA was building the foundations for future growth and development. A key element of this work was the creation of a new HMSA website which was completed in December 2021 and officially launched at the start of January 2022.</p> <p>Website feedback: “I do love your site. I will continue to use it. You have the most information [on hypermobility] I've been able to find. I really appreciate that.”</p> <p>The HMSA was also pleased to welcome four new trustees during the course of 2021 – Mark Austin, Nichola Gardner, Zoe Lomax and Gil Hilleard – who had previously provided pro bono organisational support and advice to the charity. The varied skills and very extensive experience that they jointly bring mean that the HMSA’s board will be even stronger and fully able to meet any challenges ahead while continuing to shape and helping to develop the HMSA’s future strategy.</p>
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		<p>The HMSA was sad to lose Executive Manager, Jane van Velsen, during 2021 but would like to thank her for all the fantastic work that she did and the invaluable changes and developments she instituted while she was in post. The Board was also like to thank Hannah Turner* (then Chair) for her tireless work and her amazing contribution covering Jane's position on a voluntary basis while a replacement CEO was successfully recruited. The post was filled in the autumn of 2021 and the new CEO started in January 2022 and will be able to build on the excellent work achieved in 2021.</p> <p>(Note: *Hannah Turner is also known professionally, under her pen name, as Hannah Ensor.)</p>
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Financial review

Review of the charity's financial position at the end of the period	Para 1.21	<p>See financial information attached:</p> <p>Income for period: £35,125</p> <p>Expenditure for period: £34,752</p> <p>Unrestricted funds at year end: £20, 630</p> <p>Restricted funds at year end: £6217.</p> <p>Total funds at year end: £26,847</p>
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	<p>The HMSA's Reserves Policy takes in account potential risks and liabilities. The HMSA aims to hold a minimum of 3 months running costs in reserves. In 2021 the charity aimed to keep £5000 for essential expenditure and emergency or closure costs, plus a £5000 buffer that can be used to cover temporary income reduction or to provide initial funds for setting up new projects.</p>
Amount of reserves held	Para 1.22	£10,000
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 2021, including the Albert Hunt Trust and the National Lottery Community Fund. n/a
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	The trustees review a detailed and regularly updated risk register at each quarterly trustee meeting. 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 and policies and can offer additional support for new trustees, as required.
		n/a

The charity's organisational structure and any wider network with which the charity works	Para 1.51	
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	
2	Hannah Turner	Chair	Until December 2021	
3	Gil Hilleard	Trustee	June 2021	
4	Nichola Gardner	Trustee	May 2021	
5	Zoe Lomax	Trustee	May 2021	
6	Mark Austin	Trustee (Acting Chair from March 2022)	December 2021	
7	Keith Diaper	Trustee	Until July 2021	
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
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)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

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Other optional information

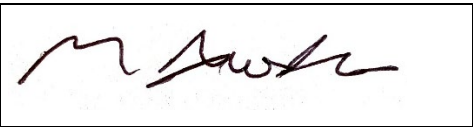
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Declarations

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 Haddon Austin	
Position (for example Secretary, Chair, etc)	Chair	
Date	16/8/22	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Hypermobility Syndromes Association

1186735

Receipts and payments accounts

CC16a

For the period
from

01/01/2021

To

31/12/2021

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	11,686	-	-	11,686	4,913
Charitable Activities	19,712	-	-	19,712	5,322
Trading	2,911	-	-	2,911	2,628
Other Income	816	-	-	816	34,619
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	35,125	-	-	35,125	47,482
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	35,125	-	-	35,125	47,482
A3 Payments					
Charitable Activities	29,833	3,143	-	32,976	21,008
Governance Costs	1,776	-	-	1,776	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	31,609	3,143	-	34,752	21,008
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	31,609	3,143	-	34,752	21,008
Net of receipts/(payments)	3,516	- 3,143	-	373	26,474
A5 Transfers between funds	1,166	- 1,166	-	-	-
A6 Cash funds last year end	15,948	10,526	-	26,474	-
Cash funds this year end	20,630	6,217	-	26,847	26,474

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	20,313	6,217	-
	Stripe	317	-	-
		-	-	-
	Total cash funds	20,630	6,217	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
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)
			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	



Section A

Independent Examiner's Report

Report to the trustees/
members of

Hypermobility Syndromes Association

On accounts for the year
ended

31 December 2021

Charity no
(if any)

CIO19863

Set out on pages

1-2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 December 2021

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 (other than that disclosed below *) 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.

** Please delete the words in the brackets if they do not apply.*

Signed:

V Santer

Date:

19th August 2022

Name:

Virginia Santer

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

FCCA

Address:

Sovereign House, 22 Shelley Road, Worthing, West Sussex, BN11 1TU

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.