



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period 29th September 2024 to 31st May 2025

Charity name: The MVA Society Charity registration number: 1210996

Objectives and Activities

Summary of the purposes of the charity as set out in its governing document	<p>To find a treatment for Mosaic Variegated Aneuploidy (MVA) Syndrome.</p> <p>To support this, we are building an MVA community – patients, families, clinicians, researchers. This is enabling us to grow an international network of MVA champions across the globe.</p> <p>In turn, this helps advance the education and awareness of MVA in the wider public too.</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.	<p>The charity aims to benefit the public by providing a source of information and support for families effected by MVA syndrome.</p> <p>Due to the rare nature of the medical condition (1:10,000,000), dedicated, aligned, medical support is not readily available via the NHS or private health care. We are bringing together experts from around the globe to help piece together a more bespoke surveillance regime and begin (through research) to find a treatment for this ultra rare condition.</p> <p>The charity's aim is to fund research to create treatment options for patients with MVA.</p>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	<p>The trustees are aware the guidance issued by the Charity Commission on public benefit.</p>
Contribution made by volunteers	<p>The MVA volunteers are in fact the Board of Trustees. There are 8 Trustees in total. Their contribution consists of attending the monthly Trustee meetings plus ad-hoc projects that come up that fall under their area of expertise.</p>

Achievements and Performance

<p>Achievements against objectives set</p>	<p>The MVA Society was started in Nov 2024. The main achievements have been:</p> <ul style="list-style-type: none">- Recruited a highly experienced Board of Trustees – this is from the medical world (geneticists and clinicians) and from the commercial pharma world.- Ran an ‘expert’ MDT workshop (multi-disciplined team) representing the main specialisms relating to MVA. This gave us a clear pathway for a feasible research strategy.- Held monthly Trustee meetings. This has given momentum to getting plans in place and up and running to progress the aims of the Charity.- Produced a highly professional 15 minute documentary film on MVA. The first ever on MVA.- Established the first ever dedicated MVA website in the world. This acts as a focal point for the MVA community (patients, families, clinicians, researchers).- Established MVA specific patient information (on the website). These are the only MVA specific patient leaflets, videos, fact sheets available anywhere in the world.- Had a team of 3 run the London Marathon for the MVA Society, raising £10k in the process.- Started 3 ‘mini’ research programs in Spain, USA and UK – all of which should produce preliminary data to link into our main research program (2026).- Commissioned an in-depth report on MVA by the Cambridge Consultancy Network (CCN).
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Performance of fundraising activities against objectives set

During the short period to 31st May 2025, the trustees have been busy working on the 4 goals of the Charity:

- 1. Developing patient information and ensuring its accessible via the website (www.mvasociety.org).**

This is the first website in the world dedicated to MVA. Its aim is to be the focal point for patients, families and clinicians/researchers for all MVA related matters & information.

We have already developed specific MVA patient / family information – fact sheets, video's and on-line chat/advice forum.

- 2. Growing awareness of the condition and beginning to build a community of patients/families, clinicians, researchers.**

We have ensured MVA is now represented with all major rare disease 'umbrella' organisations eg NORD. Additionally, we have established an MVA point of contact in 12 countries around the globe (in 5 continents). This global reach is both very necessary (due to the rareness of the condition) and is also growing as we find more centres/physicians with experience of it.

This allows all/any MVA patients, families, clinicians or researchers to get direct access to first hand insights and information relating to MVA.

We are also finalising a ~15 minute documentary film on MVA. This will be posted on the website as well as being sent across our global MVA network and to the rare disease umbrella organisations.

- 3. Developing and operationalising a research plan!**

We have already held an 'expert' MDT (multi-disciplined team) workshop on MVA. This allowed experts across the different specialisms that relate to MVA, to put their viewpoints forward on 'the art of the possible' from a research perspective. This resulted in clear-cut plan to begin our research – which is dependent upon several factors, namely taking skin biopsy's and growing fibroblasts in a lab, raising £250k to fund a researcher, and identifying and recruiting a post-doc researcher to carry out the work. This should all be in place by the end of 2025 – meaning the research can start in 2026.

Concurrently, we have been fortunate enough to start 3 other mini-research projects (one in London, one in Spain and one in the USA).

These should produce preliminary data to support the main research project in due course.

In addition to that, we have had an independent report from the University of Alabama on MVA and treatment options. And by the end of July we will have the results of a global hackathon to look at likely medication options that will have a positive effect on MVA.

4. Fundraising

Our year 1 goal is to raise £250k to support the hiring and recruitment of a post-doc PhD student to start our research project. So far, we have achieved ~£90k, but have a clear plan to reach to the £250k mark by the end of the year.

The main activities linked to fundraising so far have been running the London Marathon – raising ~£10k, attracting philanthropic donations from companies and individuals (~£75k)

Further fundraising event are planned for 2025, including a Kayleigh in Scotland, a golf tournament and a 1st Anniversary Gala Dinner in London.

With these planned events and the philanthropic promises/assurances we have, we are on track to hit our Year 1 target of £250k.

Fundraising activities have progressed well. Our activities have been – and are planned to be – in 3 broad areas:

- Philanthropic donations from individuals. We have raised £35k via this channel
- Corporate donations from pharma / related companies. We have raised £40k via this channel. However, this is a channel that we are aiming to raise a lot more money from in the months to come.
 - Fundraising events. We have completed 1 main fundraising event, namely the London Marathon. 3 of us ran for the MVA Society and we raised £10k in the process. We have 3 more fundraisers planned for 2025, namely
 - A golf tournament in September
 - A Kayleigh in September (in Scotland)
 - A 1st Year Anniversary Gala dinner in November.

We are currently on track to hit our 1st year target of £250k

Financial Review

Review of the charity's financial position at the end of the period	During the period, £89,402 was raised from donations and events. Net inflow for the period was £87,642. The amount of cash funds as at 31st May 2025 were £87,642
Statement explaining the policy for holding reserves stating why they are held	The cash reserves are held to initially fund fundraising activities. It is estimated that a minimum of £250,000 will need to be held before funding of meaning full research into MVA Syndrome can commence.
Amount of reserves held	£87,642 of cash reserves were held as at 31st May 2025

The charity's principal sources of funds (including any fundraising)	The MVA Society's principal sources of funds so far have been: <ul style="list-style-type: none"> - Donations from companies - Donations from individuals - Fund raising events eg the London Marathon
A description of the principal risks facing the charity	The MVA Society has completed a risk assessment and risk register. The top 6 risks identified are: <ol style="list-style-type: none"> 1. Funding (as low patient numbers) 2. Lack of interest, attention and exposure due to lack of awareness of this condition 3. GDPR (handling patient data) 4. Sufficient resource to achieve our aims 5. Relying on goodwill (Trustees and wider community) 6. Finding patients

Structure, Governance and Management

Type of governing document	The Charities governing instrument is a constitution document dated 29th September 2024
How is the charity constituted?	The Charity is a Charitable Incorporated Organisation (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	There must always be a minimum of three trustees. The number of trustees can not exceed twelve. The period of appointment of the initial trustees is set out in the constitution document. Any further appoints must be for a term of three years by a resolution properly convened. In selecting individuals for appointment, the trustees must have regard for the skills, knowledge and experience needed for the effective administration of the CIO.
Policies and procedures adopted for the induction and training of trustees	All Trustees have been introduced to the on-line training resources available on the Charities Commission website. Governance policies have been written and shared to protect against the current identified areas of concern.
The charity's organisational structure and any wider network with which the charity works	The organisational structure is very simple. We have 8 x Trustees, which includes 1 x Chairman (& Founder). The list is below <ul style="list-style-type: none"> - Chairman & Founder – Jonathan Bracey - Trustees – Prof Anil Dhawan, Dr Sharon Jheeta, Prof Harry Leitch, Dr Ellie Seaby, Rob Keel, Scott Healy, Kate Diston-Hunter.

Administrative Details

Charity name	The MVA Society
Registered charity number	1210966
Charity's principal address	50 Cumberland Terrace London NW1 4HJ

Board of Trustees

Mr Jonathan Edward Bracey (Chairman)
Mrs Kathryn Louise Diston-Hunter
Mr Robert Philip Keel
Professor Anil Dhavan
Mrs Sharon Kaur Jheeta
Mr Scott William Healy
Professor Harry Leitch
Dr Eleanor Seaby

Declarations

Signature	
Full name	Mr Jonathan Edward Bracey
Position	Chairman
Date	1 st July 2025



Receipts and payments accounts

For the period from	29/09/2024	To	31/05/2025
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	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	79,855	-	-	79,855	-
Events	9,547	-	-	9,547	-
Sub total (Gross income for AR)	89,402	-	-	89,402	-
Total receipts	89,402	-	-	89,402	-
A3 Payments					
Fundraising expenses	1,760	-	-	1,760	-
Sub total	1,760	-	-	1,760	-
Total payments	1,760	-	-	1,760	-
Net of receipts/(payments)	87,642	-	-	87,642	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	87,642	-	-	87,642	-



Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		87,642	-	-
	Total cash funds	87,642	-	-
	Signature	Print Name	Date of approval	
		Mr Jonathan Bracey	01/07/2025	



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
The MVA Society

On accounts for the
period ended

31st May 2025

Charity no

1210996

Responsibilities and
basis of report

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended **31/05/2025**.

As the charity's trustees, 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 all 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:

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

Signed:

nileshpatel

Date:

01-07-2025

Name:

Nilesh Patel FCCA Reg No: 1197617

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

ACCA

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