



Esme's Umbrella
Report and Unaudited Accounts
For the period ended
31 December 2024

Registered with the Charity Commission as Esme's Umbrella
Charity No. 1197087

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REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISORS

The Trustees who are also the only members of the charity, being a Charitable Incorporated Organisation present their report and the financial statements of the charity for the period ended 31 December 2024.

Registered office

26 Western Gardens, LONDON, W5 3RU

Board of Trustees

Professor Dominic Hannes ffytche
Professor Mariya Fakhrudin Fidahusen Moosajee
Helen Khan
Judith Anne Potts

Bankers

Lloyds Bank, **OLDHAM BRANCH (309626) 16 Market Place, Oldham
OL1 1JG**

STRUCTURE AND MANAGEMENT

AIMS AND ACTIVITIES FOR THE PUBLIC BENEFIT

Structure

Esme's Umbrella is registered with the Charity Commission as a Charitable Incorporated Organisation (CIO), registration number 1197087. The constitution was created using the Charity Commission's 'Foundation model' designed for CIOs of this nature.

The charitable objects of Esme's Umbrella are:

To preserve and protect good health for the public benefit of all ages in the UK, whose loss of sight has led to the development of Charles Bonnet Syndrome (CBS) by

- a) Raising awareness of CBS to healthcare professionals and the wider community
- b) Creating support for the care and welfare of anyone who develops CBS and their families/caregivers
- c) Sourcing and raising funding for CBS research and to publish all useful results arising from the research.

The board may comprise up to twelve Trustees (who are also the only members of the Charity in accordance with the constitution). They have legal responsibility for the effective use of resources, in accordance with the constitution, and for providing effective leadership and direction.

Trustees have been appointed to the Board in accordance with the trustees' selection policy. A skills audit is conducted periodically to ensure that the Board has the required range of skills to carry out its responsibilities.

All trustees give of their time freely and no trustee remuneration was paid in the year. Trustees are required to disclose all relevant interests and register them with the Founder and, in accordance with the Charity's constitution, withdraw from decisions where a conflict of interest arises.

Each new trustee is given an appropriate induction programme and training relevant to his/her responsibility.

The Board met three times during this year and controls the Charity but delegates responsibility for the day to day management of the charity to the Founder.

Statement of trustees' responsibilities

The Charity's Trustees are responsible for preparing the Annual Report and Accounts in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. In preparing these accounts, the Trustees are required to:

- a) Select suitable accounting policies and apply them consistently;
- b) Make judgements and estimates that are reasonable and prudent;
- c) State whether applicable accounting standards and statements of recommended practice have been followed, subject to any departures disclosed and explained in the financial statements; and
- d) Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable the Trustees to ascertain the financial position of the Charity and ensure that the financial statements comply with relevant legislation. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Management

The Trustees are mindful of the guidance provided by, and requirements of, the Charity Commission and HMRC, and in particular the Commission's guidance "The Essential Trustee: what you need to know (CC3)" and Nolan's seven principles of public life. They believe that where such guidance is not mandatory for the Charity, it should, as a public interest body, adopt these guidelines as best practice.

AIMS AND ACTIVITIES FOR THE PUBLIC BENEFIT

Esme's Umbrella's principal aim is to raise awareness of Charles Bonnet Syndrome; to create support for people who develop the condition; and to source funding for research.

The Trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives and in planning future activities. Our services are open to all blind and partially sighted people regardless of their age, socio economic group, disability, gender reassignment, pregnancy and maternity, marital or civil partnership status, race, religion or belief, gender, and sexual orientation.

We fulfil our purpose by

- Sharing knowledge, information and thought leadership based on lived experience of sight loss
- Creating connections – people, organisations and opportunities
- Encouraging participation and leadership by blind and partially sighted people
- Supporting VI communities and community infrastructure
- Innovating and piloting new approaches
- Influencing change which benefits all
- Starting a new conversation about what it means to live with Charles Bonnet Syndrome in England, Wales and Northern Ireland.

Our vision is to ensure everyone who lives with Charles Bonnet Syndrome is informed and supported; and research is encouraged.

Activities and financial performance for the period ending 31 December 2024

Financial Performance

The charity generated a surplus of £9,013 (2023: £8,246) in the financial year ending 31 Dec 2024 with income of £19,086 (2023:£14,716) and expenditure of £10,073 (2023: £6,470). Reserves are £30,417 (2023: £21,404) of which £21,183 (2023: £15,800) are unrestricted and £9,234 (2023: £5,604) are restricted.

Activity highlights

Raising awareness of Charles Bonnet Syndrome

Event at Manchester Metropolitan University in March was a very successful day.

Speakers included Judith Potts, Dr Lee Jones, Dr Jasleen Jolly and lived experience was described by Miles Northwood.

James Edward Kilpatrick, a member of the team who made the film, *Aspectum*, joined Miles for the Q and A.

The audience feedback was very positive and supportive of the need to keep raising awareness of CBS.

Esme's Children and Young People – which focuses on children and young people who develop CBS after sight loss, has developed further. Nina Chesworth – who joined Esme's Umbrella for one day a week in November 2024 – is leading the campaign.

The Campaign has been supported by every charity in the sight loss sector, plus The Rehabilitation Workers' Professional Network, The Eye Clinic Liaison Officers' Network, The Worshipful Company of Spectacle Makers, The College of Optometrists, BIOS, Habilitation VI UK, VIEW, The CYP Network and the Paediatric Sub-Committee at the Royal College of Ophthalmologists.

Professor Mariya Moosajee (Trustee of this charity) and Dr Lee Jones have published a ground-breaking paper on the subject - ['They're creepy creatures with human-like features': children's experiences of visual hallucinations in Charles Bonnet syndrome—a qualitative study | Archives of Disease in Childhood](#)

Webinar – hosted by Visionary – was received very positively.

Feedback informed us that there are still healthcare professionals who are not aware that CBS is so common, that it can be permanent and that children are as likely to develop it as are adults. A successful outcome.

Booklets specifically for children, parents and teachers

Optelec chose Esme's Umbrella as its charity of 2024 and working with this company has been very beneficial.

With the help of Dr Lee Jones, new booklets, designed for children, for parents/guardians/caregivers and for teachers have been written and distributed widely by *Optelec*.

Animated Film called *Em* was created. This film is aimed at young children who live with, or might develop CBS. It has audio description and is available on Esme's Umbrella's YouTube Channel. The film has been distributed to all the children's sight loss charities and on social media. Work is proceeding to ensure that all paediatric clinics have the link to Em and also the appropriate booklets.

Judith Potts visited Moorfields' Paediatric Clinic on CBS Day – 16 November – and the **Stargardt's Conference** – 23 November – to talk to parents about CBS.

Esme's Umbrella at the Visionary Conference

Luke Spink led the Workshop at the Visionary Conference. He was joined by Dr Lee Jones and James Edward Kilpatrick. Aspectum was shown and Dr Jones talked about the current 'CBS in children and young people' research.

Raising Awareness of CBS to healthcare professionals included: Running another Essay Prize, which was very successful and won by Vanessa Chou from the University of Edinburgh. Privately funded by a supporter of Esme's Umbrella, the Prize ensures that the next generation of doctors is aware of CBS.

Talks, training sessions, Webinars and presentations given by Judith Potts to audiences from across the healthcare spectrum included: The University of Wolverhampton, The Stroke Unit at Southmead Hospital in Bristol, the staff of Blind Veterans, the staff of Guide Dogs, Service Users of Guide Dogs, interviews on RNIB Connect Radio, Visionary, RNIB's on-line information for Care Homes, RNIB's Connecting Families' Group, Vision Ireland, the nurses at Manchester University, Focus Birmingham, Rochdale and area ECLOs (with BAME Vision), South West Yorkshire Partnership Foundation Trust, BASIS South Essex, Northumberland Sensory Services, CYP VI Network, Halifax Society for the Blind, Esme's Friends' online support groups, East Anglia's Sensory Services, Middlesex Society for the Blind, Essex Care's Sensory Team.

Support for people who develop Charles Bonnet Syndrome

Eye Care Support Pathways - Success was achieved and CBS now has its place in both the adult and the children's Eye Care Support Pathways.

The new CVI Form will carry a tick-box which states that CBS has been discussed with the patient. With the change of Government, there has been a delay and the new Government requires a Review of the Explanatory Notes and FAQs before it can go to the Department of Health for approval.

At the moment, if the Ophthalmologist asks the right question, CBS will be recorded in the diagnosis section of the form, but this tick-box would improve awareness and understanding.

Booklets and posters

Optelec re-printed the original booklets and these are sent by *Optelec* – with reprinted posters - to everyone who requests them from Esme's Umbrella. *Optelec's* staff also carry these with them to all their appointments. Requests for these have increased.

Esme's Friends' support groups are still flourishing, with more being created.

Members – The Membership Campaign is free to join and members receive a quarterly Newsletter and a chance to volunteer for the various CBS research projects.

CBS Champions – For areas where the local charity cannot create an Esme's Friends' group, people are encouraged to become CBS Champions. These will have up to date information about CBS and be a 'listening ear' for others.

The website was moved from its original host to Wix, which makes it much easier to use. GoDaddy still has the domain. Information on the website is reviewed often and any new research is added. It is possible to contact Judith Potts via the website, which happens frequently.

Emails and telephone calls – Raised awareness has encouraged people who develop CBS, ECLOs, ROVIs and sensory workers to contact the charity. Judith Potts replies to each email and makes the

necessary calls to people who need reassurance and a better understanding of CBS. Numbers have increased.

Esme's Umbrella features on all social media platforms.

Counsellors – Esme's Umbrella has a list of Counsellors who understand CBS. Referrals can be made but the charity cannot pay for the appointments. Several referrals have already been made.

Charles Bonnet Syndrome Research

Esme's Umbrella's work is inspiring research and 2025 will see the results published. The UK is leading the world, particularly in paediatric studies.

Going forward to 2025

'Pop up CBS days' if events are too complicated and expensive.

New CBS flow chart from Professor ffytche and Professor Moosajee for use by low vision clinics.

Diagnosis pathway created by NHS.

Publication of all CBS research in one journal.

CVI form, with CBS tick-box, accepted.

Trustees – one new one to join the team.

Essay Prize

APPG meeting to be dedicated to CBS.

Fundraising projects will begin.

Esme's Umbrella
Statement of Financial Activities
For the period ended 31 December 2024

STATEMENT OF FINANCIAL ACTIVITIES

	Note	2024			2023		
		Unrestricted Funds £	Restricted Funds £	Total Funds £	Unrestricted Funds £	Restricted Funds £	Total Funds £
Income from:							
Grants and Donations	2	7,730	11,233	18,963	3,416	11,300	14,716
Other		123	-	123	-	-	-
Total Income		7,853	11,233	19,086	3,416	11,300	14,716
Expenditure on:							
Raising Funds		136	-	136			
Charitable Activities	4	2,334	7,603	9,937	774	5,696	6,470
Total Expenditure		2,470	7,603	10,073	774	5,696	6,470
Net income/expenditure for the year		5,383	3,630	9,013	2,642	5,604	8,246
Reconciliation of funds							
Funds brought forward		15,800	5,604	21,404	13,158	-	13,158
Funds carried forward		21,183	9,234	30,417	15,800	5,604	21,404


Esme's Umbrella
Balance Sheet
For the period ended 31 December 2024

BALANCE SHEET

	Note	2024 £	2023 £
Current Assets			
Debtors & prepayments	6	1	40
Cash at bank		31,027	21,365
Total		31,028	21,405
Creditors: Amounts due within one year	7	(611)	(1)
		(611)	(1)
Net Current Assets/ Net Assets		30,417	21,404
Funds of Charity	8		
Restricted income funds		9,234	5,604
Unrestricted funds		21,183	15,800
Total Funds		30,417	21,404

The notes on pages 12 to 18 form part of the financial statements.

Approved by the trustees and signed on their behalf by



Professor Dominic Hannes ffytche (Trustee)

Date: 30/9/2025

Esme's Umbrella
Notes of the Financial Statement
For the period ended 31 December 2024

1. Accounting Policies

Basis of accounting

The accounts are prepared in accordance with the Charities Act 2011 and Accounting and Reporting by Charities: statement of recommended practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102).

The Charity is a public benefit entity as defined by FRS102

Income recognition

Income is recognised once the charity has entitlement, receipt is probable, and the amount can be measured reliably.

Income from donations, gifts and grants, including donated facilities and services, comprises income for core activities and are of a general nature. Such income is only deferred when the donor specifies it must be used in future accounting periods or the donor has imposed conditions, which in themselves are not restrictions, which must be met before the Charity has unconditional entitlement.

Income from charitable activities comprises income received under contract or where entitlement to grant funding is subject to specific performance conditions. This income is recognised as the related services are provided. Income is deferred when the amounts received are in advance of the performance of the service or event to which they relate.

Income from investments comprises bank interest. This income is recognised when credited to the charity's bank account.

Esme's Umbrella
Notes of the Financial Statement (continued)
For the period ended 31 December 2024

1. Accounting policies (continued)

Expenditure recognition

Resources expended are included in the Statement of Financial Activities on an accruals basis, inclusive of non-recoverable VAT.

Allocation of costs

Charitable activities include all costs directly related to the objects of the charity.

Support costs are incurred in support of the above activities. Included in support costs are costs incurred in governance of the charity which are primarily associated with the constitutional and statutory requirements. Support costs are allocated to activities based on an estimate of staff time spent on each activity during the financial period.

Donated facilities and services

Donations received in kind and not in cash are brought into the Statement of Financial Activities at a value which the Trustees consider would represent the cost to the Charity if these items were purchased. The income is accounted for under donations and the expenditure under the appropriate expenditure.

Esme's Umbrella
Notes of the Financial Statement (continued)
For the period ended 31 December 2024

1. Accounting policies (continued)

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the Trustees. Restricted funds can only be used for particular restricted purposes within the objects of the Charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

2. Grants and donations

	2024	2023
	£	£
Thomas Pocklington Trust	10,000	4,800
The Powell Family Foundation	1,233	-
Guide Dogs for the Blind	-	5,500
Fight for Sight	-	1,000
Gift Aid	744	-
Donations	<u>6,986</u>	<u>3,416</u>
Total	18,963	14,716

3. Charitable activities

	2024	2023
	£	£
Activity Income	<u>-</u>	<u>-</u>
Total	-	-

Esme's Umbrella
Notes of the Financial Statement (continued)
For the period ended 31 December 2024

4. Charitable expenditure

	2024	2023
	£	£
Administration costs	5,848	505
Service and Information costs	3,139	963
Trustee costs	221	9
Website costs	729	4,993
Total expenditure	9,937	6,470

5. Staff costs

	2024	2023
	£	£
Staff costs	-	-

No staff were employed by the charity.

Esme's Umbrella
Notes of the Financial Statement (continued)
For the period ended 31 December 2024

6. Debtors

	2024	2023
	£	£
Accrued income	1	40
Total debtors	1	40

7. Creditors: amounts due within one year

	2024	2023
	£	£
Creditors	611	1
Total	611	1

Esme's Umbrella
Notes of the Financial Statement (continued)
For the period ended 31 December 2024

8. Funds of the Charity- 2024

Movement of funds

	2023	Income	Expenditure	2024
	£	£	£	£
Restricted funds	5,604	11,233	7,603	9,234
Total	5,604	11,233	7,603	9,234
Unrestricted funds	15,800	7,853	2,470	21,183
Total	15,800	7,853	2,470	21,183
Total funds	21,404	19,086	10,073	30,417

Allocation of net assets by fund

	Restricted £	Unrestricted £	Total £
Current assets			
Cash at bank	9,715	21,312	31,027
Debtors & prepayments	-	1	1
Total assets	9,715	21,313	31,028
Creditors: Amounts due within one year	(481)	(130)	(611)
Total creditors	(481)	(130)	(611)
Net Assets	9,234	21,183	30,417

Esme's Umbrella
Notes of the Financial Statement (continued)
For the period ended 31 December 2024

8a . Funds of the Charity- Prior Year
Movement of funds

	2022	Income	Expenditure	2023
	£	£	£	£
Restricted funds	-	11,300	5,696	5,604
Total	-	11,300	5,696	5,604
Unrestricted funds	13,158	3,416	774	15,800
Total	13,158	3,416	774	15,800
Total funds	13,158	14,716	6,470	21,404

Allocation of net assets by fund

	Restricted	Unrestricted	Total
	£	£	£
Current assets			
Cash at bank	5,604	15,761	21,365
Debtors & prepayments	-	40	40
Total assets	5,604	15,801	21,405
Creditors: Amounts due within one year	-	(1)	(1)
Total creditors	-	(1)	(1)
Net Assets	5,604	15,800	21,404

10. Related party transactions

There are no related party transactions