



The Freya Foundation

Trustee Report and Accounts

For the year ended 18 May 2025

Trustee's Annual Report & Accounts
For the year ending 18 May 2025

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Charity details

Charity Number	1157764
Operational Address	12 Lewis Road Bedminster Down Bristol BS13 7JB
Trustees	Kelly Gilbert Steven Watson David Hayward Michelle Perry Richard Nicholls Lisa Saundry
Charity Manager & Founder	Kelly Gilbert
Bankers	Lloyds Bank PLC 25 Gresham Street London EC2V 7HN

Charity Manager's foreword

The Freya Foundation was formed in 2014 by myself and my husband, Dave Gilbert, after our daughter Freya was diagnosed with Pyruvate Dehydrogenase deficiency (PDH Deficiency).

This means that those born with this disorder are unable to convert some of their food into energy. Unfortunately, those born with this condition have severe medical issues often resulting in death in childhood. There is no known cure currently.

We had little knowledge of PDH Deficiency, what it meant and how to look after Freya. We were offered very little support, and we felt completely lost and scared. We wondered how many other parents with children who were diagnosed with PDH Deficiency managed. After much research and communications, we fast realised there was no support and little reliable information, so we decided to create a charity with the main aims being:

- Raise awareness of the condition throughout the UK
- Build a support network of families
- Support research into the condition

This is our 10th year as a charity, and we now support 33 families across the UK. Each year brings new families, and we have been working closely with hospitals across the U.K not only with the research project but also continue providing support and guidance throughout their diagnosis.

We continue to have several strands of activity as we continue to grow and support our many families: -

1. Family support group
2. Counselling support
3. Family meet up
4. Research
5. Bereavement and sibling support

This year was a massive achievement for us as we celebrated our 10-year anniversary as a charity, something I am massively proud of.

As my challenge this year I decided to run the distance of 10 marathons in 10 months (ish), one for each of the years we've been running. I was very fortunate in having many Freya supporters join me on this crazy mission. It was a huge success although very tiring.

The last run was a marathon distance, and I was joined 10 others who braved the elements to complete the 26.2 miles. Due to various injuries, we had to slow the pace a little, but we were determined to complete it even if we did get rather wet. The marathon finished with us arriving at our local community centre where we were met by nearly 150 people and rapturous applause. This was a great evening of celebration and acknowledgement of our achievements over the last 10 years, we were even joined by many of the Freya Families we support.

We had a wonderful time and managed to raise just over £1,200 on the night and more in sponsorship.

We continue to work tirelessly and dedicate our time in improving information available to families with our latest project being the first patient information leaflet which will be released later on this year. This leaflet is the first of its kind and will be available to anyone affected by PDH Deficiency this is due to our important collaboration with Great Ormond Street Hospital (GOSH)

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Finally, I would like to express my thanks on behalf of the trustees for all the support received on our journey so far and look forward to your continued support as we continue to grow and support more families in the future.

Trustee's Annual Report

Objectives and Activities

The primary objective of the charity is to promote physical and mental health, and provide relief for children suffering from Pyruvate Dehydrogenase Deficiency (PDH) and their immediate families by:

- Providing support families through funding and advice
- Research into the cure and management of PDH.
- Raising public awareness of PDH and educating the public about the condition.

The charity also works and networks with medical professionals primarily from Bristol Children's Hospital and Great Ormond Street Hospital, to streamline and improve diagnosis, treatment and research efforts into PDH, and provide a support network for families living with PDH and bereaved families. In the year for which this report covers the main activities undertaken by the charity are as follows:

- Large family meet ups to share experiences, have chance to discuss and learn of new developments from the medical experts.
- Increased counselling services.
- Online support.
- Family support group.
- Fundraising activities including our 10-year celebration and Marathon.

Achievements and Performance

Since the announcement of the breakthrough last year in the research on PDH Deficiency progress is continuing to be made.

Patient journey documents were produced in association with The Freya Foundation and published via Great Ormond Street Hospital (GOSH) this year. The patient journey is an important step and one we are very proud of as it offers information for patients, families and medical professionals once a diagnosis has been received, as well as signposting families to the Freya Foundation for further support.

In September of 2024 the Freya Foundation celebrated its 10th birthday. Going into the 10th year Kelly, the charity Founder and Manager, set herself the task of running 10 marathons in 10 months which was completed, crossing the finish line into a fundraiser and 10th birthday party for the charity.

During the year we were awarded £19,435 from The National Lottery Community Fund to cover the costs of our family meet up.

Future – in the year ahead we will be:

1. Holding our family meet up at Chessington World of Adventure in October 2025, where there will be presentations from the medical team at Great Ormond Street Hospital and Research progress update from the team at University College London.
2. Continue to offer support and counselling to those in need, as well as grants to families that are struggling.
3. Continue to offer Freya Foundation merchandise at the Charity events.

Financial Review

All reserves left over at the end of the financial year are carried over into the following year entirely for the use of the charity in the fulfilment of its objectives as set out above.

Over the past year the charity has mostly raised funds through donations made by individuals from sponsored events and activities, leading to a surplus of £30,423 (2024: £2,592).

Our unrestricted reserves have increased this year to £62,612 (2024: £34,219). These reserves are being built up in preparation for further funding of research in the next couple of years.

In each year our expenditure has enabled the formation of an informal support network of families giving the opportunity for them to meet and support one another as well as with experts to ask questions and gain information on the latest treatments and research from medical experts and dieticians.

Signed:



Name: David Hayward

Position: Trustee

Independent examiner's report to the Trustees of The Freya Foundation

I report to the Trustees on my examination of the accounts of The Freya Foundation (the Charity). As set out on page 8 for the period ended 18 May 2025.

Responsibilities and basis of report

As the Trustees of the Charity 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 Charity'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 giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by section 130 of the Act; or
2. the accounts do not accord with those records.

I have no concerns and have come across no other 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: 

Name: ANDREW WEBB

Address: 36 PRIORY COURT ROAD, BRISTOL . BS9 4DE

Date: 15 JANUARY 2026

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**Receipts and payments accounts
for the year ending 18 May 2025**

	2025 Unrestricted Funds £	2025 Restricted Funds £	2025 Total Funds £	2024 Total Funds £
Receipts				
Donations & Grants	15,008	19,435	34,443	29,699
Fundraising events				-
Fundraiser	36,700		36,700	24,400
Hunters	510		510	1,586
Other	3,973		3,973	1,042
Total Receipts	56,191	19,435	75,626	56,727
Payments				
Cost of fundraising and events	11,307		11,307	5,431
Research Grants				13,000
Family Gatherings/Support	1,944	13,744	15,688	17,171
Wages/Salaries	171	3,661	3,832	5,439
Printing, Postage, Stationery	1,373		1,373	1,522
Telephone	609		609	579
Sundry	1,645		1,645	147
Office Running Costs	4,800		4,800	4,800
Merchandise	5,949		5,949	6,046
Total Payments	27,798	17,405	45,203	54,135
Net of receipts/(payments)	28,393	2,030	30,423	
Cash Funds B/fwd from 2024	34,219	3,661	37,880	
Cash Funds at year-end	62,612	5,691	68,303	-

