



the
Freya
foundation

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The Freya Foundation

Trustee Report and Accounts

For the year ended 18 May 2024

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Charity details

Charity Number	1157761
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).

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, 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 managed. After much research and communications, we quickly 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 9th year as a charity, and we now support 27 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 to continue providing support and guidance throughout their diagnosis.

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

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

In August 2023 we held our annual fundraiser – Pullin' for Freya. We had decided to get together a team of friends, family and Freya family members to pull a Boeing 737 a distance of 50 metres. It was a tremendous day and what is more it was successful, not only did the team succeed we also raised £2,000.

An exciting development this year was the inception of the first ever gene therapy project with a team from UCL (University College London). The aim is to develop a model gene therapy for PDH Deficiency. The UCL team are currently undertaking a pre-clinical proof of concept study to determine whether this gene therapy could be used in clinical trials. This project is the first of its kind in the UK and Europe. We are excited to see how the project will progress, and we will report on it regularly.

We have also affiliated with MetabERN (the European Reference Network for Hereditary Metabolic Disorders) and as a result of our collaboration we have produced the first ever patient Journey for PDH Deficiency. When a patient is diagnosed with PDH Deficiency they will receive the same patient journey information whether they are in the UK or Europe. This includes information on symptoms, diagnosis, treatment, monitoring and adult life.

The patient journey is currently published in the following languages: English, Portuguese, Norwegian, Polish, Spanish, Swedish and Georgian and will soon be available in French, Dutch, German, Italian, and Estonian. The goal is to get them translated into many more languages over the coming months.

We continue to work extremely hard behind the scenes, and this patient journey is the first steps towards getting standardised patient guidelines written, which as you can imagine takes a huge amount of time and legal red tape.

Charity Manager's foreword continued

2025 is the 10th year of the charity. To mark this special anniversary, we shall be holding a party in September where I will cross the finish line after completing a full marathon distance which completes my challenge of the distance of 10 marathons in 10 months, which I started in January 2024.

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.

Kelly Gilbert
Founder

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.
- Offer respite services as extra support to families.
- Increased counselling services.
- Online support.
- Family support group.
- Fundraising activities including a plane pull.

Achievements and Performance

We continue to support and fund a research project which has made a major breakthrough in its research into PDH.

This year has seen us become affiliated with MetabERN, the European Reference Network for Hereditary Metabolic Disorders, as a supporting patient partner. With this affiliation, we will be working closely with a wide range of medical professionals who help deliver the best care for those affected by rare metabolic disorders, specifically for us, PDH Deficiency.

This is a massive achievement and milestone for us as the result of this affiliation will mean that there will be clear patient guidelines distributed throughout hospitals ensuring that PDH Deficiency is better understood, and treatments are better recognised.

We held a very successful fundraising event called "Pulling for Freya" this was thought up by our treasurer, seeing 21 'plane pullers' travelling to Dorset to pull a Boeing737. This event was well supported by families of the Freya Foundation and friends that travelled from many areas of the country.

Hunters Estate Agents in Bishopsworth have given us amazing support over the past year and in May 2023 they presented us with a cheque in excess of £8,000, which they had raised over the previous year. They have also continued to support us during 2024, we would like to say a massive 'Thank you' to them.

There have been many individual fund-raising activities and events. In May 2023 Emma and Theo ran the "Great Manchester Run", Rose Winter completed the "100 mile London Bike Ride" and Hannah Murphey completed the London Marathon in April 2024. We would like to say a huge thank you to everyone who has taken on fundraising challenges to support us this year.

During the year we were also awarded a grant of £9,100 from the National Lottery Community Fund towards administrative support within the charity, we are very grateful to them for supporting us.

January '24 saw the start of Kellys challenge to celebrate the 10th Year of The Freya Foundation, by completing the distance of 10 marathons in 10 months. Finishing on 21 September '24 with a full marathon.

Trustee Annual Report Continued

There was a Clay Pigeon shoot supporting Lila and family in February, which raised almost £2,000. A Just Giving page was set up when Lila was newly diagnosed, sharing the proceeds between The Freya Foundation and the hospice that support them.

We would like to thank all our amazing families for the work they all do to support the Foundation. You are all amazing.

During November '23 we had another successful family meet up, at Chessington World of Adventure, with guest speakers from UCL (University College London) who gave details to families of our groundbreaking research project into PDH Deficiency

Future – in the year ahead we will be:

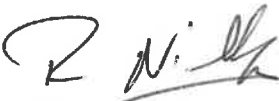
1. Having our family meet up at Ribby Hall.
2. Celebrate The Freya Foundations 10th. year. We shall be doing Kelly's challenge with a celebration event on completion of the final marathon in September.
3. Continue to offer Counselling and Grants to families struggling in the current climate.
4. Offer 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 raised £56.7k (2023 – 30.5k) from donations from Hunters and individuals from sponsored events and activities.

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. In this year the funding of the research project has also enabled a major break through on the road towards the management and possible cure for PDH.

Signed: 
Name: RICHARD NICHOLLS
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 2024.

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 RD, BRISTOL
Date: 12 FEB 2025

**Receipts and payments accounts
for the year ending 18 May 2024**

	2024 Unrestricted Funds £	2024 Restricted Funds £	2024 Total Funds £	2023 Total Funds £
Receipts				
Donations & Grants	20,599	9,100	29,699	5,080
Fundraising events				-
Fundraiser	24,400		24,400	17,900
Hunters	1,586		1,586	5,400
Other	1,042		1,042	2,204
Total Receipts	47,627	9,100	56,727	30,584
Payments				
Cost of fundraising and events	5,431		5,431	8,525
Research Grants	13,000		13,000	
Family Gatherings/Support	17,171		17,171	19,046
Wages/Salaries		5,439	5,439	3,212
Printing, Postage, Stationery	1,522		1,522	1,435
Telephone	579		579	556
Sundry	147		147	816
Office Running Costs	4,800		4,800	8,600
Merchandise	6,046		6,046	-
Total Payments	48,696	5,439	54,135	42,190
Net of receipts/(payments)	(1,069)	3,661	2,592	-11,606
Cash Funds B/fwd from 2023	35,289	0	35,289	
Cash Funds at year-end	34,220	3,661	37,881	-

