

BARTH SYNDROME UK



2025 Annual Report



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BARTH SYNDROME UK

TRUSTEES' REPORT

The trustees present their report for the year ended 31 December 2025.

General Information

REGISTERED CHARITY NUMBER: 1181830

TRUSTEES:

Mr Geoffrey Parish – Treasurer
Mrs Kelsey Doran – Trustee
Mrs Isabel Easterbrook – Trustee (resigned 30/01/2025)
Mrs Cheryl Parish - Trustee
Mrs Suzanne Green – Trustee
Mr Paul Ford – Trustee
Ms Joanna Kozminska (resigned 13/06/2025)
Mrs Susan Williams (added 02/10/2025)

STAFF:

Mrs Michaela Damin - Chief Executive

REGISTERED OFFICE:

1 The Vikings
Romsey
Hampshire
SO51 5RG

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are required to prepare accounts for each financial year, which reflect the receipts and payments of the charity and of the surplus or deficit of income against payments for the year.

The trustees are responsible for:

- keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity; and
- safeguarding the assets of the charity and hence for taking reasonable steps for prevention and detection of fraud and other irregularities.

LEGAL AND ADMINISTRATIVE

The charity was registered on 31st January 2019 as a Charitable Incorporated Organisation (CIO) with the Charity Commission. The charity is governed by a CIO - Foundation Governing document.

RESERVES POLICY

Barth Syndrome UK (BS UK) requires a level of free reserves to safeguard the organisation, protect options for future development and to achieve the following: -

- The option to develop new services or expand current ones in line with the changing needs of the community.
- To ensure that shortfalls in expected income, or delays in the receipt of expected income, do not interrupt services, or prevent the payment of salaries, or cause financial difficulty for the charity.
- The ability to survive unexpected setbacks and problems arising from internal or external causes.

The **minimum** level of such reserves, taking into account only funds which are not restricted by the donor or ring fenced by the charity for another purpose, should be at least equivalent to the expected core funding requirement for a period of 12 months. Should the level of reserves fall below or be expected to fall below this level, the Board of Trustees will develop a plan to restore the level of reserves.

The **maximum** level of such reserves, defined as above, should be no greater than the expected core funding requirement for a period of 24 months. Should the level of reserves be higher than this level, the Board of Trustees will develop a plan to allocate these funds towards agreed program goals.

For these purposes, the core funding requirement is defined as all known mandatory costs (salary, fees, insurance) and a contingency of £5k for unforeseen essential costs.

What is Barth syndrome?

Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder primarily affecting boys and men. Affected people may suffer from heart failure, muscle weakness, and infection (caused by neutropenia).

Additional characteristics of the syndrome commonly include growth delay, impaired lipid metabolism, debilitating fatigue, and cardiolipin deficiency. For some people with Barth syndrome, symptoms can be very severe, sometimes resulting in heart transplant, potentially lethal infections, and even death.

OUR VISION: A world in which people with Barth syndrome live and live well.

OUR MISSION: Saving lives through education, advances in treatments and finding a cure for Barth syndrome.

OBJECT(S)

The objects[s] of the CIO are:

The relief of individuals with, and carriers of, Barth syndrome and their families, within the United Kingdom and elsewhere in the world in particular but not exclusively by:

- a) providing access to information, advice and support in relation to the condition to the public and, in particular, diagnosed individuals and their extended families and those in the educational, scientific, medical and allied health care professions.
- b) the promotion and funding of research into the causes and effects of the condition and the dissemination of the useful results of the same for the benefit of the public.



INTRODUCTION FROM THE CHAIR

Hello again lovely people.

Another year, and as is usual, we've seen some changes to the board. Isabel (Easterbrook) and Joanna (Kozminska) have stepped down, although both are thankfully still involved in voluntary capacities - Isabel with Family Services, whilst Joanna provides ad hoc, pro-bono legal advice. We are grateful to both for their continued commitment and engagement, appreciating all that they have done and continue to do.

Further changes are taking place even as we prepare this report, with both Geoff and Cheryl Parish stepping down. Both will be hugely missed, not just for their enormous input and positive impact upon the board and the overall functioning of the charity itself, but as much for their warmth, friendship, support and invaluable advice to their fellow trustees and wider Barth community. Thank you both so much.

We are, however, extremely fortunate in that Susan (Sue) Williams has joined the board, not just as a trustee but as a treasurer, succeeding Geoff. I worked with Sue for more years than either of us would care to remember, and cannot state how delighted I was when Sue agreed to join; I know full well her impressive capabilities and dedication. (By the way, I say 'worked with', but in truth Sue was my immediate boss for many years, so I know I have to up my game – again!)

Should anyone wish to put themselves forward as a trustee, to help bring fresh thinking and new insight to the board, or as a volunteer to help the wider community, please don't hesitate to contact either myself, another board member or Michaela (Damin) to discuss further.

2026 will see the bi-annual worldwide Barth conference taking place in Florida, always a highlight for those able to attend, being a perfect place to deepen bonds with other affected individuals and their families. This is also the place to be for the latest news on research and treatments into Barth syndrome. Look out for updates from ourselves or our colleagues at Barth Syndrome Federation (BSF) - more details follow later in this report.

The roll-out of the 'new' drug elamipretide (trademarked and to be marketed under the name 'Forzinity' is particularly exciting, perhaps marking the dawning of an era where treatments are specifically designed to counter-act Barth syndrome at source, rather than the serious effects that arise because of Barth syndrome. Again, look out for more news on this in the very near future.

The AdComm (Advisory Committee, made up of young, affected adults) is now securely established, with members being invited to attend meetings of the full board of BS UK Board (on an ad-hoc basis). AdComm would dearly love for even more affected individuals to join their meetings, so that the views of **ALL** are represented. It's not necessary or required that everybody attends each and every meeting, only that as many as possible join as and when able, to provide their thoughts, concerns, opinions, and most importantly, have fun.

There have been some devastating losses within our Barth community over the past year, and regrettably, we all know and realise that further difficult challenges lie ahead. However, with your help and support, we will together face these challenges head-on, continue to make progress in our mission to find better treatments, and ultimately, a cure, for Barth syndrome.

Ralph Easterbrook, Chair, Barth Syndrome UK

MESSAGE FROM THE CHIEF EXECUTIVE, Michaela Damin:



Just a quick message to say a heartfelt thank you to all our supporters in 2025: our donors, fundraisers, trustees, volunteers, corporate partners, our dedicated NHS Barth Syndrome Service and our friends and family members. All of us at Barth Syndrome UK pledge to keep working hard in 2026 to serve our affected families and make a positive difference in their lives.

With warmest wishes

Michaela Damin

REVIEW OF ACTIVITIES

Board (Strategic Planning)

During the year, the Board of BS UK held a face-to-face meeting, which led to an agreement for a reorganisation, changing our approach to the many tasks faced; the aim was to embed a better structure, thereby improving the chances of delivering a better service, with volunteers and trustees feeling more engaged and better supported (even though in essence each trustee is now doing more). As such, we feel that we trustees are now in a better position to give of our best.

Another aim of the reorganisation was to free up time so that our CEO (Michaela) would be able to engage and interact even more with our community, and delve even more into research and medical updates.

The salary paid to the CEO is fundamental in the delivery of our services, particularly to affected individuals and their families (which in turn leads to increased engagement within our community). It is also intrinsic in keeping the charity appraised of the latest developments in science & medicine (the upcoming elamipretide trial is a perfect example), both of which are hugely important in helping us fulfil our mission and vision.

We are always on the look-out for volunteers and potential trustees. If interested, please tell us where your skills and passions lie, and we'll do our very best to find a suitable role for you!

Supporting Families

One-on-One Support for Families and Individuals

Much of our day-to-day work consists of supporting individuals from pre-diagnosis onwards. This is done in person, by telephone and via private online forums.

BS UK offers affected families financial help via a Transport Costs Scheme which allows families to claim back their travel expenses when attending a specialist Barth syndrome clinic in Bristol. These clinics are held on a monthly basis. We also offer families the ability to claim back the cost of a meal when clinic attendance requires an overnight stay.

AdComm (Advisory Committee)



We previously advised of the formation of an Advisory Committee (AdComm), consisting of young, affected adults, which goes from strength to strength; members regularly attend planning and trustee meetings to ensure that they are at the core of all decisions made by the charity and to help make sure that they continue to be supported as and when they need it. All young, affected adults are welcome to participate, (with there being **no** obligation to attend each and every meeting) so that **ALL** have the opportunity to voice their thoughts and opinions.

Counselling, Coaching & Cognitive Hypnotherapy

BS UK partnered with [Longcroft Therapy](#) to offer 1:1 cognitive hypnotherapy and coaching sessions to affected individuals, siblings and parents.

The project was hugely successful, with measurable positive impacts upon well-being being recorded following such sessions.

Unfortunately, personal circumstances mean that Penny (Longcroft) has stepped down from her role; our sincere thanks go to Penny, together with our best wishes for a bright future.

We hope to develop the program further and offer more coaching and support when funding and resources allow.

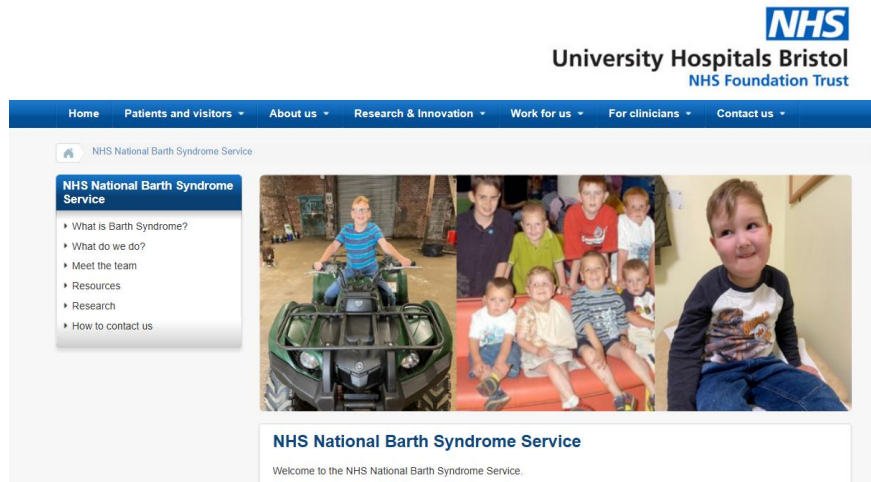
In happier news, in late 2026 we were fortunate to welcome Dr Sarah Downey, who has joined the Bristol NHS Service as a specialist clinical psychologist. She is available to provide support to affected individuals and parent/carers during clinic visits or referrals.

International Barth Syndrome Family, Medical and Scientific Conference

Last year, we brought you news from the 2024 conference; this year we eagerly look forward to the upcoming 2026 conference hosted by our affiliates at BSF.

Please look out for the numerous newsblasts from BSF regarding this opportunity. During the week-long event in July 2026, there will be meaningful opportunities to learn about recent scientific and medical advances, take part in research studies and meet families and professionals from all around the world.

Bristol NHS Specialised Service



We continue to send a representative from the charity to every monthly Barth syndrome clinic in Bristol to ensure that patients' voices are heard and to make sure that we can ask what our families need from us. We also reimburse families' travel costs to make the clinic accessible to all. Families travel from all over the United Kingdom to attend these specialist clinics.

RAISING AWARENESS

Website Redesign

Our [website](#) was revamped and launched in Jan 2025 - we continue to review, update and improve. Please visit and let us know what you think.



Communications

Our social media presence has seen some steady growth, and we also look to provide communications via shorter news blasts to our community. With a dedicated volunteer overseeing our communications, we're steadily increasing our online presence, and we look to continue this growth in 2026.

RESEARCH AND MEDICAL PROGRAMS

Research

During 2025, we were in the fortunate position to partner with affiliates from Canada and Italy to part fund an exciting new research project headed by Dr. Jason Moffat. If successful, this project could pave the way towards new treatment options for our community.

The charity endeavours to contribute towards relevant research costs by ringfencing conservative amounts of income and once enough has been accumulated, to fund (at least partially) approved research projects.

International Registry

We continued to encourage families to sign up to the [International Registry and Biobank](#) in our efforts to promote research.

NHS England Generational Study

Barth syndrome has been chosen as one of the conditions included in the [Generation Study](#).

The Generation Study is an NHS-embedded research study which is exploring the benefits, challenges and practicalities of sequencing and analysing newborns' genomes. It is a hybrid clinic-research study that aims to generate evidence on whether whole genome sequencing can be used to screen newborns for rare genetic conditions, and to assess the feasibility of doing this within the NHS.

Centres Of Expertise

Together with Barth Syndrome US and other licenced affiliates, BSUK continues to support the creation of new Centres of Expertise and new patient groups around the world, all with a shared vision and purpose. Through a spirit of collaboration, we hope to accelerate progress into the care offered to all individuals with Barth syndrome wherever they may live.

Elamipretide And Pharmanovia

Elamipretide is a new drug which has the potential to be the first Barth-specific approved medication. It has been shown to cause improvements in strength, functional exercise performance and cardiac function. In the UK and Europe, Pharmanovia holds the licence to market the drug if it is approved. BSUK is working closely with Pharmanovia to hopefully provide our community access to this potentially life changing drug. We hope to be able to share more news on this exciting development in the very near future!

FUNDRAISING

We are hugely grateful to all our supporters in 2025. Without your donations and fundraising, we would not exist. We don't publish the names of individual donors for privacy reasons, but we know who you are and we are immensely grateful for your support, thank you!

Some go above and beyond, participating in marathons, nuclear races and even boxing events, showing a dedication that borders on insanity.

Some funds were received as a result of the passing of dearly beloved and much missed family members, with the sad and tragic circumstances making the donations even more commendable. We send these families our heartfelt condolences.

Sensory equipment and toys were donated to Bristol Children's Hospital – these were warmly welcomed, especially by our younger affected individuals.

Cosmetic products were donated by GlowForGood and included an amazing Charlotte Tilbury hamper worth over £400, and which was our first prize in the Christmas Raffle.

We sincerely thank each and every donor from the bottom of our hearts.

We would like to make special mention of the following organisations who provided essential grants and donations:



Thank you to Barratt Redrow for another donation of £3 000, as well as their matching program which allows employees to amplify the impact of their support

Rotary Club of Brentwood - £900
following quiz night



Fordham Football Club
£200



£3,048

£2,500



Marsh Charitable Trust - £500

Glow For Good // the charity beauty sale £18,250 GlowForGood

BARTH SYNDROME UK**Receipts and Payments Account for the period 1 January 2025 to 31 December 2025 with 2024 comparative**

	2025		2024 (Re-Styled)	
	Total		Total	
	£		£	
RECEIPTS				
Standing Order Donations	3,988		3,700	
Grants	6,400	(a)&(c)	11,000	(a)
Campaigns (Fundraising)	10,324	(a)	1,586	
Miscellaneous donations	34,035	(a)&(d)	7,183	
Gift Aid Claims	1,823		986	
Interest Received	1,509		612	
Total Receipts	58,080		25,067	
PAYMENTS				
Fundraising Expenses	216		328	
Science and Medicine	7,661		-	
Family Support and Education	1,496		7,065	(b)
Accountant Fees	521		704	
Bank Service Charges	91		60	
Awareness	-		-	
Training and Development	2,439	(b)	1,453	
Dues and Subscriptions	20		50	
Insurance Expenses	215		96	
Office Expenses	647		880	(c)
Salary	23,281		22,570	
Total Payments	36,586		33,206	
Surplus/Deficit of receipts over payments	21,494		-8,139	
Bank Balances brought forward	52,349		60,488	
Total bank balances at year end	73,843		52,349	(d)

NOTES 2025

NOTES 2024 (Re-stated)

- (a) Receipt category revised 2025 (2024 figures restated for comparative)
- (b) Payment category revised 2025 (2024 figures restated for comparative)
- (c) Includes £2,500 Grant (Enterprise Mobility) & £3,000 (Barratt)
- (d) Includes £18,250 donation from GlowForGood

- (a) Includes £7,500 Grant from Foyle Foundation, £3,000 from Barratt & £500 Chelmsford Round Table
- (b) Original accounts included the additional training & development costs for board development
- (c) Includes £655 for new website
- (d) Includes £1,999 restricted assets

**Statement of Assets and Liabilities as at 31 December 2025
with 2024 comparative**

Assets

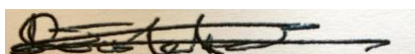
The charity has the following bank and cash balances:

	2025	2024
	£	£
Current account (CAF)	40,918	8,232
Savings account (CAF)	2,287	14,059
Savings account (Dudley)	30,639	30,057
	<u>73,843</u>	<u>52,349</u>

Liabilities

	£
Accountancy	<u>320</u>

Approved by the trustees on 21/01/2026 and signed on their behalf by Ralph Easterbrook.



Mr Ralph Easterbrook
Chairperson

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF BARTH SYNDROME UK

I report to the trustees on my examination of the accounts of Barth Syndrome UK (the Charity) for the year ended 31 December 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 Trust 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.



Mr J P Foxwell FCCA FCIE
independent-examiner.net

12 Hillbourne Road, Poole, BH17 7JB

Date: 7 March 2026