

BARTH SYNDROME UK



2024 Annual Report



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BARTH SYNDROME UK

TRUSTEES' REPORT

The trustees present their report for the year ended 31 December 2024.

General Information

REGISTERED CHARITY NUMBER: 1181830

TRUSTEES:

Mr Ralph Easterbrook – Chairperson

Mr Geoffrey Parish – Treasurer
Mrs Kelsey Doran – Trustee
Mrs Isabel Easterbrook – Trustee
Mr Stephen Cotterill – Trustee (resigned 17th July 2024)
Mrs Cheryl Parish - Trustee
Mrs Suzanne Green – Trustee
Mr Paul Ford – Trustee (added 17th January 2024)
Ms Joanna Kozminska (added 18th September 2024)

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

Another year flown by - or perhaps that's just my advancing years catching up with me at long, long last.

We've seen changes to the board, welcoming Paul (Ford) and Joanna (Kozminska), whilst Steve (Cotterill) and Isabel (Easterbrook) have, sadly, decided to step down. Our heartfelt thanks go to both Steve and Issi for their dedication, hard work and input over the years, and we appreciate their continued support in essential, non-trustee roles.

Further changes will take place in January 2026, when both Geoff and Cheryl Parish step down. Geoff has been our Treasurer, financial wizard and skilled strategist, whilst Cheryl – a former Chair of the Board - has proved invaluable in supporting and mentoring other board members, including myself, for which I will be eternally grateful. As sad their retirement will be - and like Steve and Issi they will be sorely missed - this does provide an opportunity for other individuals to put themselves forward and bring fresh thinking and insight. If you (or someone you know) would like to find out more, please contact me, another board member or Michaela Damin to discuss further.

In a similar vein, our young adults have continued to interact on both a social and charitable level, and have now formed an Advisory Committee, AdComm, reporting to the BS UK Board. Some will be attending the monthly BS UK board meetings over the coming months as invited guests, hopefully sparking some interesting new ideas and directions for consideration. Perhaps some future potential board members?

Have you had the chance to explore the updated [BS UK website](#) yet? Many thanks to the Chelmsford Round Table whose generous donation helped make this update possible. Sincere thanks also to the Foyle Foundation for their grant of £7,500, and Barratt Redrow, who have continued to support the charity (more details are available later in this report).

We know that we will inevitably face some difficult challenges during the coming year, but I believe that with your help and support, we will overcome any challenges that come our way and 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:

Thank you to every person who supported us in 2024 as we continued to provide our vital services.



We are incredibly fortunate to have the support of a dedicated NHS Barth Syndrome Service, a passionate and committed Board of Trustees and a hardworking band of volunteers, families and friends, all keeping us strong and positive.

All of us at Barth Syndrome UK pledge to keep working hard in 2025 to serve our affected families and make a positive difference in their lives.

Michaela Damin

REVIEW OF ACTIVITIES

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.

Group Support and Information

National Info and Support Day: October 2024

The Barth Syndrome Community had the opportunity to meet in person in Bristol, along with key representatives from the NHS Bristol Specialised Service. This was a chance for individuals and families to provide vital feedback regarding their needs as well as learn about new developments regarding Barth syndrome. Families' travel and food expenses were paid for by BSUK and the Bristol Service respectively, to allow for equal access by everyone. The day was an enjoyable and informative one for all.

Oct 2024 Family Day Feedback



94% found the Family Day useful
(with 88% rating it in the Good or Excellent category)

Suggestions for future sessions:

Genetics

Mental health sessions for affected adults

More group sessions for affected individuals only

Disability employment rights

More fun social activity time

More opportunities to move around physically



No-one found any of the sessions unhelpful

Location, venue and the food were all rated at the very highest level

Most highly rated sessions: neutropenia research & new medications (cardiology and elamipretide)

Suggestions for improvements:

- Many people asked for a shorter day or split over 2 days with more creative/interactive sessions : this would help with fatigue (mental and physical) but also create more time for families to bond
- Presentations could have more engaging visuals to make learning easier and written handouts could have been used for large chunks of information Children and affected individuals struggled with lecture/school atmosphere



Barth Syndrome Family Day Saturday October 5th, 2024

9.30-10.00	Registration and photo/playroom consent Tea/ coffee on arrival		
10:00-10:15	Welcome to the day -Dr Germaine Pierre		
	MORNING SESSION (Chair Dr Effie Chronopoulou)		
10.15 – 10.45	Updates from BSF Florida Conference 2024 Michaela Damin, Kelsey Doran, Victoria Wilkins, Gillian Alexander, Germaine Pierre		Under 10's room open -play specialist led (Emma Clarke) Play activities available- games/ books/ toys
10:45-11:00	Group photos		
11:00-11:15	Coffee Break		
11:15- 11:50	Cardiology Updates- Dr Catherine Armstrong		Under 10's room open -play specialist led Play activities available- games/ books/ toys
11:50 -12:00	Allied Health Professional Bits and Bobs Sam Whiting (Metabolic Pharmacist), Gillian Alexander, Catherine Oliver		
12:00-12:20	BSF UK engagement discussion – Michaela Damin		
12:20-13:10	Lunch and BSF cake sale		
	AFTERNOON SESSION (Chair Dr Maria Pelidis)		
13:10-13:40	Projects, Past present and future: Dr Katy Flemming (Haematologist), Maria Pelidis, Natasha Taylor, Victoria Wilkins		Under 10's room open -play specialist led Play activities available- games/ books/ toys
13:40-14:05	Fun activity for all ages Laura Crowther		
	Parallel session 1	Parallel session 2	
14:05 – 14:35	CPR training- Gillian Alexander In Room 4	Mindfulness techniques– Catherine Oliver In Lecture Theatre	Under 10's room open Signs and symptoms of becoming unwell game -Natash Taylor, Laura Crowther
14:35-14:40	Introduction to next sessions		
14.40 – 15:10	Parents and carers resilience tree- Catherine Oliver In Lecture Theatre	Individuals with Barth Syndrome brainstorming session -Oliver Baxter-Smith, Nicholas Damin In Room 1	Under 10's room open Lunch box activity fruit and veg and shopping trolley games- Victoria Wilkins
15:10-15:25	Feedback from sessions		
15:25- 16.00	Q and A session with Barth Syndrome Multidisciplinary Team – With Coffee and tea		Under 10's room open -play specialist led Play activities available- games/ books/ toys
16:00	Close of day Evaluation forms		

Young Adults and Men Project funded by Jeans for Genes



Thanks to a generous grant from Jeans for Genes, we have been able to create weekly online meet ups for our adults with Barth syndrome and in March 2024, some of the guys made plans to meet up in person for a meal and a catch up.

Later on in the year, this group of young adults and adults with Barth syndrome formed a new Advisory Committee (AdComm) and they now 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.

Counselling, Coaching & Cognitive Hypnotherapy

Having Barth syndrome unsurprisingly results in many additional mental health issues for affected individuals and their families. BS UK has partnered with [Longcroft Therapy](#) to offer 1:1 cognitive hypnotherapy and coaching sessions to affected individuals, siblings and parents.

This project has been a huge success, enabling family members to deal more effectively with the challenges that are faced on a day-to-day basis and to consider alternative mindsets to manage the long-term anxieties and quality of life issues that so often accompany lifelong medical interventions in a genetic condition.

In 2025, we were pleased to welcome a new psychologist to the NHS Bristol Service, Dr Martha Kenyon who was hired to provide support over a short, medium or longer term as needed. Dr Kenyon was available for one day per week.



International Barth Syndrome Family, Medical and Scientific Conference

CONFERENCE UPDATE

Barth Syndrome Foundation Conference 2024: Impact on Research, Connection, and Progress

The 2024 Barth Syndrome Foundation (BSF) International Conference was a resounding success, bringing together 350 attendees, including 56 affected individuals, to advance research, medical care, and connections within the community.

Thanks to your fundraising support, BSUK was proud to sponsor two key medical professionals from the Bristol Barth Syndrome Service to attend, to learn and share best practice.

Research and Poster Presentations

Eight groundbreaking research projects were conducted onsite, covering a wide range of topics including cardiac data collection, strength testing, arrhythmia, cardiolipin testing, quality of life studies, pill swallowing techniques, and the Barth Syndrome Registry.

There were **38 different poster presentations**, covering a wide range of topics. UK dietician Victoria Wilkins won the Favourite Poster Award with her depiction of weaning – a project featuring none other than the famous Mackenzie!

Along with a packed agenda of **Scientific & Medical Talks**, BSF launched a significant new initiative this year—**Online Medical Training Modules**—designed to train the next generation of doctors about Barth syndrome. The Bristol team played a key role in developing these four hours of recorded sessions, which will be invaluable for future medical training and awareness.



Workshops were held on quality of life, feeding, occupational therapy, physiotherapy, and sleep issues. These small group sessions, tailored to different age groups, provided valuable insights for both medical professionals and families.

Building Connections and Collaboration

A major takeaway from the conference was the **power of connection**. In a single week, face-to-face interactions between researchers, doctors, and families led to collaborations that would take months or years to achieve remotely. These connections are critical in pushing forward research and medical care for Barth syndrome.



Looking Forward

This conference was all about connection—between families, medical professionals, researchers, and affected individuals. From restorative sessions like yoga and meditation to emotional discussions around grief and resilience, there was something for everyone. The laughter, tears, and hugs shared throughout the week underscored the power of this community to support one another and drive progress.

As we look to the future, the bonds formed at the conference will continue to fuel our shared mission: to improve the lives of those affected by Barth syndrome through research, care, and above all, connection.

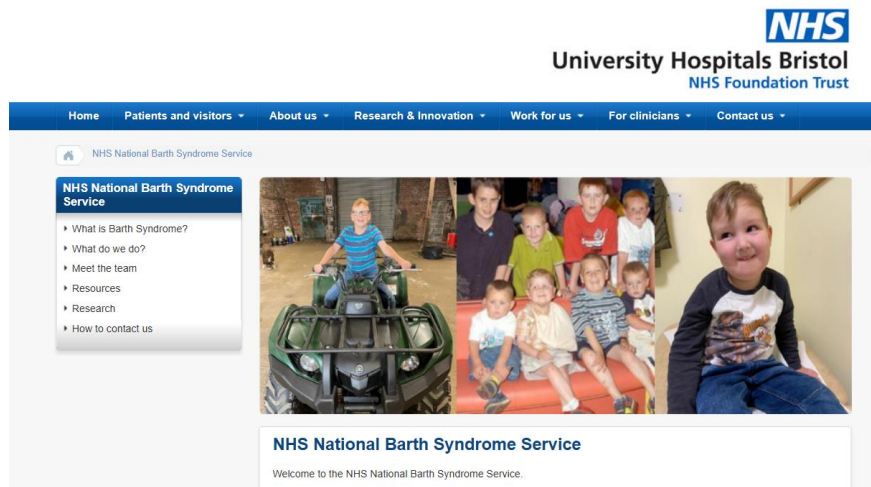


A Community United

One of the most poignant moments was the Luminary ceremony below, with 331 glowing bags symbolising each living person with Barth syndrome, and 240 dragonfly cutout bags representing those we've lost. This moving tribute reminded everyone of our shared mission.



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 as far as Scotland to attend specialist clinics.

RAISING AWARENESS

Website Redesign

Our previous website was an excellent source of quality information. However, since it was designed over twelve years ago, the Board voted to redesign it to modernise it and to make it mobile friendly. Thanks to Tom at Viscreo, the new [website](#) was launched in Jan 2025.



Improved Communications

Our social media presence continues to grow steadily, and we also provide communications via shorter news blasts to our community. With a dedicated volunteer running this project, we're seeing a growth in our online presence, and we have plans to continue this growth in 2025.

RESEARCH AND MEDICAL PROGRAMS

Research

Unfortunately, in 2024 we were not in a financial position to fund research projects, due to a lack of income and the soaring costs of research. However, the charity has been saving towards future research costs by ringfencing a conservative amount of income and once enough has been accumulated, there is a plan in place to once again fund approved research projects.

International Registry

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

NHS England Generational Study

Barth syndrome has been chosen to be included in the upcoming [Generation Study](#)

The Generation Study is an NHS-embedded research study which will explore the benefits, challenges and practicalities of sequencing and analysing newborns' genomes. The study will sequence and analyse the genomes of 100,000 newborn babies in the UK. 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 provide our community access to this potentially life changing drug.

STRATEGIC PLANNING

The Board of Trustees and the Chief Executive met for an in-person weekend planning session in August 2024 with a view to creating an updated Fundraising Strategy and to grow the Board. This resulted in an effective blueprint for activities for the second half of the year and beyond. In addition, the board meets virtually on a monthly basis to ensure effective running of the charity.

We are pleased to welcome two new trustees this year: Mr Paul Ford (who is focusing on grant applications and corporate fundraising) and Ms Joanna Kozminska who is a legal expert. We also had to bid a sad farewell to Mr Stephen Cotterill and Mrs Isabel Easterbrook who both provided years of support, advice and service.

FUNDRAISING

We are hugely grateful to all our supporters in 2024. Without your donations and fundraising, we would not exist. We don't publish names of individual donors for privacy reasons, but we know who you are and we are immensely grateful for your support, thank you!

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



[The Foyle Foundation](#) who provided a grant of £7 500 towards core costs. This type of grant is essential for building financial resilience and providing a base upon which we can deliver our planned outcomes for our community.



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



A generous donation of £500 from Chelmsford Round Table was put towards the relaunch of our new website.

Rotary Club of Brentwood £750



Club of Billericay

Billericay Rotary Club £100

Fordham Football Club



Benevity

BARTH SYNDROME UK

Receipts and Payments Account for the period 1 January 2024 to 31 December 2024 with 2023 comparative

	2024 Total £	2023 Total £
RECEIPTS		
Standing order donations	3,700	2190
Payroll Donations	0	185
JustGiving Donations	1,586	6,467
Other Donations including Cash	18,183 ^(A)	68,079
Gift Aid claims	986	1,838
Interest received	612	615
Total receipts	25,067	79,374
PAYMENTS		
Fundraising Expenses	328	256
Science and Medicine	0	20,417
Family Support and Education	8,518 ^(B)	17,336
Accountant Fees	704	487
Bank Service Charges	60	60
Awareness	0	133
Computer and Internet Expenses	782 ^(C)	106
Dues and Subscriptions	50	50
Insurance Expenses	96	201
Office Expenses	98	182
Salary	22,570	21,340
Total payments	33,206	60,572
Surplus/Deficit of receipts over payments	(8,139)	18,802
Bank balances brought forward	60,488	41,871
Total bank balances at year end	52,349 ^(D)	60,488

NOTES

- (A) Includes £7,500 Grant from Foyle Foundation
 (B) Includes £1,453 for Board Development event
 (C) Includes £655 for new website
 (D) Includes £1,999 restricted assets

BARTH SYNDROME UK

Restricted Funds Report

Jeans for Genes Grant

Opening Balance 1 Jan 2024: **£1045.01**

Annual Spend: (£546.01)

Closing Balance 31 Dec 2024: **£ 499.00**

Foyle Foundation

Opening Balance 3 Oct 2024: **£7500.00**

Annual Spend: (£6000.00)

Closing Balance 31 Dec 2024: **£ 1500.00**

Statement of Assets and Liabilities as at 31 December 2024 with 2023 comparative

Assets

The charity has the following bank and cash balances:

	2024	2023
	£	£
Current account (CAF)	8,232	1,945
Savings account (CAF)	14,059	28,543
Designated account (for reserves)	30,057	30,000
	<hr/>	<hr/>
	52,349	60,488
	<hr/>	<hr/>

Liabilities

None

Approved by the trustees on 12.03.2025 and signed on their behalf by Ralph Easterbrook



Mr Ralph Easterbrook
Chairperson

BARTH SYNDROME UK

Independent Examiners Report

I report on the accounts of Barth Syndrome UK for the year ended 31 December 2024 which are set out on pages eleven to twelve.

Respective responsibilities of trustees and examiner

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act;
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act); and
- To state whether particular matters have come to my attention.

Basis of independent examiner's Statement

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or

I 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.

David Courtier FMAAT AATQB for and on behalf of:



Community360, Winsley's House
High Street, Colchester, Essex

Date 31/10/2025