BARTH SYNDROME UK

England & Wales · Charity number 1181830

Details

Status	Registered
Legal form	CIO
Registered	2019-01-31
Register	View on the Charity Commission register

Contact

Address	1 The Vikings Romsey SO51 5RG
Phone	01794518785
Email	info@barthsyndrome.org.uk
Website	www.barthsyndrome.org.uk

Activities

Objects: 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.

Activities: Working throughout the UK, we assist families with Barth syndrome with support, information and access to expert care.We fund research into treatments and a cure.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups

Geography

- **Area of benefit:** WITHIN THE UNITED KINGDOM AND ELSEWHERE IN THE WORLD
- Ireland
- Scotland
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£58,080	£36,586	-	-
2024-12-31	£25,067	£33,206	-	-
2023-12-31	£79,374	£60,567	-	-
2022-12-31	£11,845	£46,135	-	-
2021-12-31	£31,007	£44,840	-	-

Trustees

Name	Role	Appointed
RALPH STEVEN EASTERBROOK	Chair	2022-08-14
Kelsey Leigh Doran		2022-10-19
Paul Laurence Ford		2024-01-17
Susan Williams		2025-10-02
Suzanne Michelle Green		2023-08-10

BARTH SYNDROME UK

England & Wales - Charity number 1181830

Accounts

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.

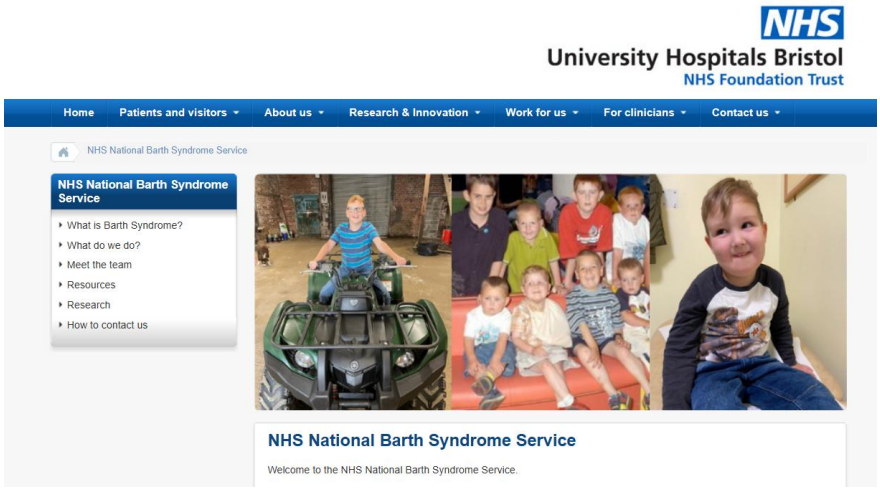
In happier news, in late 2026 we were fortunate to welcome Dr Sarah Downey, who has joined the Bristol NHS Service as a specialist clinical psychologist. She is available to provide support to affected individuals and parent/carers during clinic visits or referrals.

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

Rotary Club of Brentwood

Fordham Football Club £200

benevity £3,048

£2,500 Enterprise Mobility™

MARSH Charitable Trust

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 Total £		2024 (Re-Stated) 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

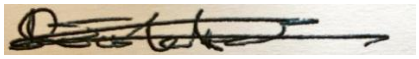
Assets

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
	73,843	52,349

Liabilities	£
Accountancy	320

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

BARTH SYNDROME UK

England & Wales - Charity number 1181830

Accounts

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

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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.

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

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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)

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 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

Suggestions for improvements:

- Many people asked for a shorter day or split over2 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.

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.

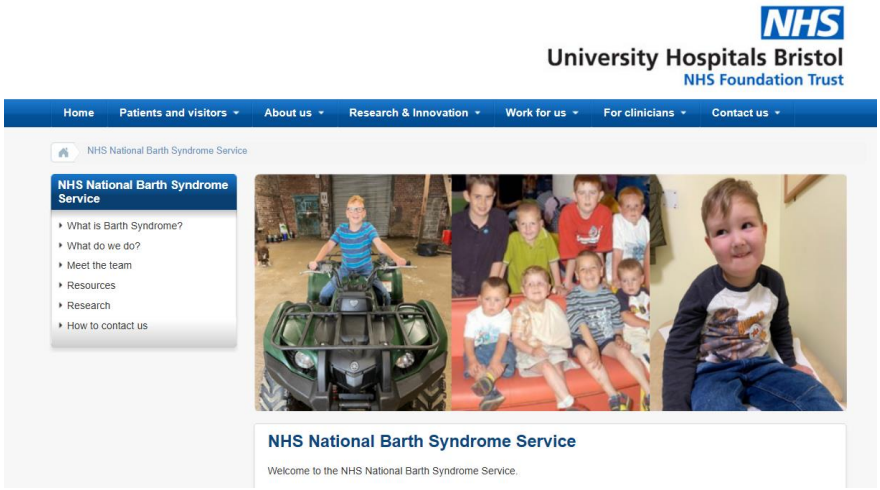
Workshops were held on quality of life, feeding, occupational therapy, physiotherapy, and sleep issues. These small group sessions, tailored to different age groups, provided valuable insights for both medical professionals and families.

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.

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

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
	52,349	60,488

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

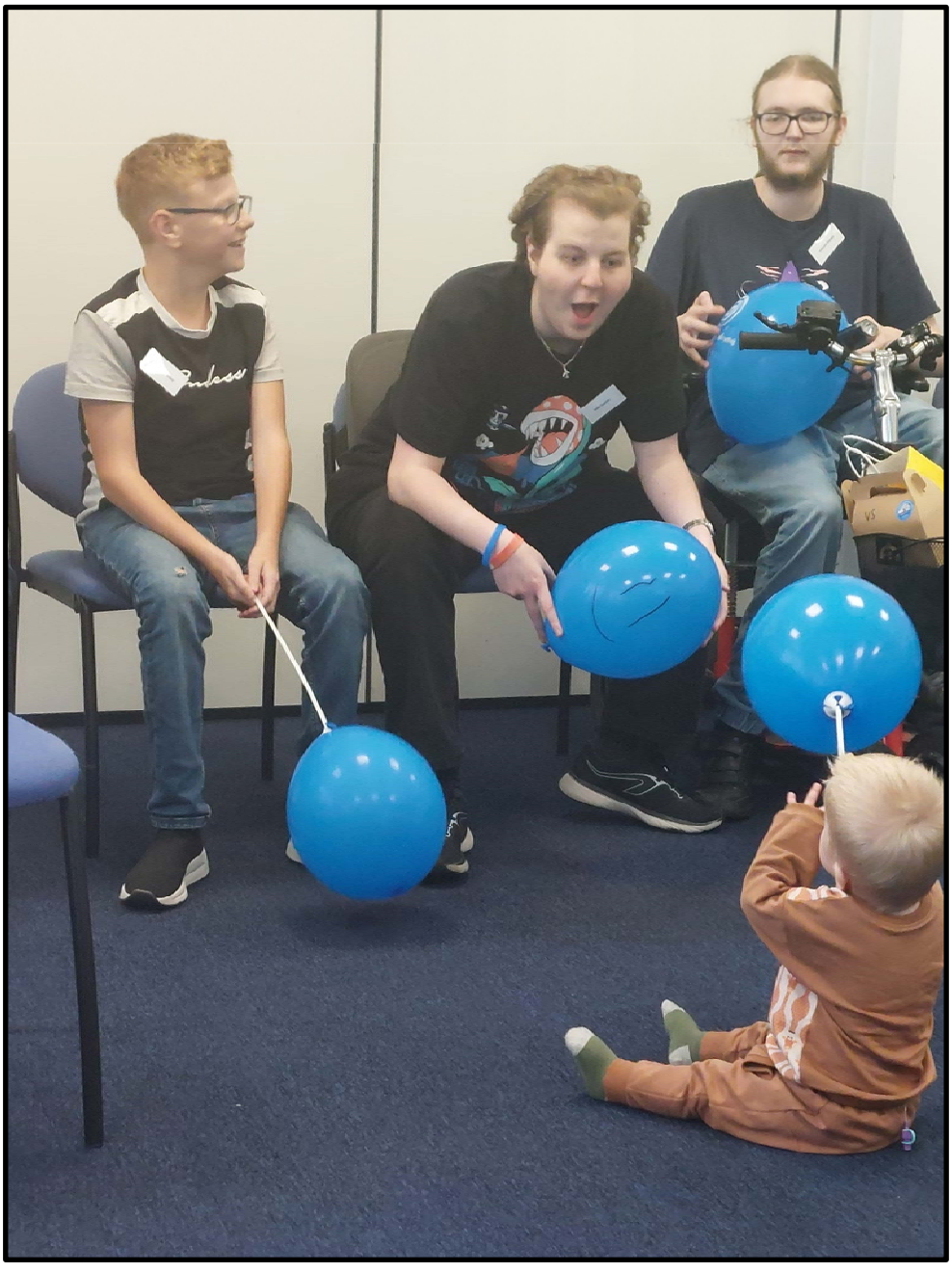
BARTH SYNDROME UK

England & Wales - Charity number 1181830

Accounts

BARTH SYNDROME UK

2023 Annual Report



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BARTH SYNDROME UK

TRUSTEES' REPORT

The trustees present their report for the year ended 31 December 2023.

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 Mrs Cheryl Parish - Trustee Mrs Suzanne Green – Trustee Ms Kate Riseborough-Evans (resigned 26th July 2023)
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 should be at least equivalent to the expected outgoings 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 should be no greater than the expected outgoings 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.

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 treatment 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 challenging year for the charity; as always, the constant need for funds weighed heavy, but the concern was lightened somewhat by being the chosen charity for Barratt's and David Wilson Homes, to whom we are eternally grateful. Many thanks and huge appreciation to Shea and Kelsey Doran, who identified and made the best possible use of this opportunity.

A successful weekend was held at Penny Brohn, Bristol, disseminating the latest medical advances and research opportunities, and perhaps more importantly, enabling families to connect and engage after the Covid-19 crisis. The feedback was almost entirely positive, and hopefully other similar events can be organised and held in the near future.

Our young adult cohort continue to meet and interact via social media, zoom etc. and now also in face-to-face gatherings funded by the charity; we feel it is important that those affected can meet and share their experiences with their peers in a safe and welcoming arena. These young men (almost all affected are males) also act as role models for the families of young infants diagnosed with Barth Syndrome – I know from personal experience that in the dark times it is especially important to have hope and to know that it is possible not just to survive but actually thrive.

However, the charity is also here to care for, support and help those who are going through a medical crisis or suffer the loss of a loved one; we have a wealth of information built up over the years to help families and medical practitioners, as well as a family support section available to any who require assistance.

Ralph Easterbrook
Chair, Barth Syndrome UK

MESSAGE FROM THE CHIEF EXECUTIVE, Michaela Damin:

Thank you to every person who supported us in 2023 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 2024 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.

In 2023 the Board voted to extend this help by also offering families the ability to claim back a meal when clinic attendance requires an overnight stay.

GROUP SUPPORT AND INFORMATION
NATIONAL WEEKEND MEETING: 15TH-16TH APRIL 2023

On Sat 15th April 2023, 19 researchers and health professionals from around the world met with 51 family members at the beautiful Penny Brohn Centre near Bristol.

Thanks to funding from the NIHR, Barth Syndrome UK was able to organise this national gathering to share the results of the CARDIOMAN clinical trial, the first ever trial in Barth syndrome in the UK.

The weekend kicked off on Friday with dinner and an evening of catching up over some fun games such as bingo whilst everyone wound down from travelling.

On Saturday we hosted informative talks and presentations from leading researchers and medical professionals around various topics, followed by an entertaining quiz enjoyed by those of all ages.

Sunday was spent learning new skills like archery and laser clay pigeon shooting and carers were offered massages and facial treatments for some rare pamper time.

After the isolation brought about by Covid, this weekend was a chance for our Barth community to re-connect and to feel inspired by the hope of new research and treatments for this life-limiting condition.

Feedback after the event was collected via a survey and the feedback received was overwhelmingly positive, with 100% of respondents rating the event as Excellent, Very Good or Good.

YOUNG ADULTS AND MEN PROJECT FUNDED BY JEANS FOR GENES GRANT

Our babies are growing up. And that's always a great sign in a rare, life-limiting condition because it means that advances in medicine are resulting in a longer life for many in our community.

Thanks to a grant from Jeans for Genes, BS UK was able to organise specialist training for two of our young men to act as mentors and facilitators. After training was completed, the two young men set up weekly online meetings for affected individuals 16 yrs+ to provide peer-to-peer support and a chance to meet socially. These meetings have proved to be popular and are ongoing. A face-to-face meeting was also organised by the group members towards the end of the year with everyone meeting up in Bristol in November 2023.

COUNSELLING & COGNITIVE HYPNOTHERAPY

Having Barth syndrome unsurprisingly results in many additional mental health issues for affected individuals and their families. In response to a lack of access to counselling and psychological support, BS UK partnered with Longcroft Therapy to start a pilot project, offering 1:1 counselling sessions to those in need.

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.

Plan to grow this pilot scheme are in place for 2024.

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

RARE DISEASE DAY AND BRITISH PAEDIATRIC SURVEILLANCE UNIT (BPSU)

Kelsey Doran (Trustee and mother of an affected child) travelled to London to raise awareness for Rare Disease Day at the BPSU annual meeting, accompanied by Barth Syndrome Service Specialist Nurse, Gillian Alexander. They provided an overview of Barth syndrome, both from a medical and from a family point of view and their presentations resulted in increased requests for testing from medical professionals in the audience.

IMPROVED COMMUNICATIONS

In 2023 we set out to improve our social media presence and to improve 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 2024.

WEBSITE REDESIGN

Our current website continues to be 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. Work will commence in 2024 on this new project.

RESEARCH AND MEDICAL PROGRAMS

Funding Research

Barth Syndrome UK, along with Barth Foundation Canada, co-funded the following research project in 2023:

Investigating the basis of neutropenia in Barth Syndrome
Borko Amulic, Professor, University of Bristol

This research project - led by Profs Borko Amulic and Colin Steward in Bristol, UK - hopes to increase our understanding of neutropenia in Barth syndrome, i.e. **why people with Barth syndrome have neutropenia and why their neutrophil counts fluctuate so much at times**.

INTERNATIONAL REGISTRY

We continued to encourage families to sign up to our International Registry and Biobank in our efforts to promote research.

INTERNATIONAL CONFERENCE

Work started in 2023 as we plan the International Barth Syndrome Conference which will be held in Bonita Springs, Florida in July 2024. This is a joint Family, Scientific and Medical conference and it attracts the largest number of affected families and experts in the world.

ASPIRE BIOSCIENCES LONDON

In December 2023, BS UK was fortunate to attend the Aspire Biosciences Industry Partnering Event at the Royal Society of Medicine in London.

This was a very well organised and productive event, and its aim was to partner patient group charities with biotech and pharma industries, with a view to accelerating advances in therapies for patients.

Michaela Damin, Chief Executive and Dr Germaine Pierre (Co Lead for the NHS Barth Syndrome Service) presented at the event and their attendance has led to some successful and ongoing collaborations.

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.

STRATEGIC PLANNING

The Board of Trustees and the Chief Executive met for an in-person weekend planning session in July 2023 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. In addition, the board meets on a monthly basis to ensure effective running of the charity.

FUNDRAISING

We are hugely grateful to all our supporters in 2023. Without your donations and fundraising, we would not exist.

The charity received £2190 from regular standing orders from families and supporters, gift aid of £1837 and bank interest of £614.

Fundraising activities and events brought in £13685; special mention to Mark Wass, who raised £2415 running the London Marathon, and the Doran family who raised £4226 taking part in a mud racing event. Other events included car boot sales, sales of Christmas merchandise, and a number of funeral collections.

By far the largest amounts received during the year were via grants and/or donations received from Barratt David Wilson Eastern Counties (£41 946), Jeans for Genes (£3 000) & Cardioman Research Project grant (£16 100).

BARTH SYNDROME UK

Receipts and Payments Account for the period 1ST January 2023 to 31 December 2023

	Notes	2023 Total £	2022 Total £
RECEIPTS			
Fundraising events		-	5,291
Gifts and donations		76,921	5,305
Gift Aid claims		1,838	1,093
Interest received		615	156
Total receipts		**79,374**	11,845
PAYMENTS			
Group development		698	784
Fundraising expenses		256	2,080
Science and medicine		20,417	14,991
Family support and education		16,638	2,369
Bank service charges		60	124
Awareness		133	647
Administration		231	94
Insurance		201	96
Accountant and examiner fees		487	180
Computer expenses		106	156
Salary expenses		21,340	24,614
Total payments		**60,567**	46,135
Surplus (deficit) of receipts over payments		**18,807**	(34,290)
Cash and bank balances brought forward		41,681	75,971
Cash and bank balances carried forward		**£60,488**	**£41,681**

BARTH SYNDROME UK

Statement of Assets and Liabilities at 31 December 2023

Assets

The charity has the following bank and cash balances:

	2023	2022
	£	£
Current account (CAF)	1,945	7,050
Savings account (CAF)	28,543	4,631
Restricted account (for reserves)	30,000	30,000
	£60,488	£41,681

Liabilities

None

Approved by the trustees on 07.03.2024 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 2023.

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

39 Enfield Road, Poole, BH15 3LJ

Date: 8 March 2024

BARTH SYNDROME UK

England & Wales - Charity number 1181830

Accounts

Barth Syndrome UK
Annual Report 2022

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BARTH SYNDROME UK

TRUSTEES' REPORT

The trustees present their report for the year ended 31 December 2022.

General Information

REGISTERED CHARITY NUMBER: 1181830

TRUSTEES:

Mr Ralph Easterbrook - Chairperson
Mr Geoffrey Parish – Treasurer
Mr Stephen Cotterill
Mrs Cheryl Parish
Mrs Isabel Easterbrook
Ms Kate Riseborough Evans (newly elected 19th October 2022)
Mrs Kelsey Doran (newly elected 19th October 2022)

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.

What is Barth Syndrome?

Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder primarily affecting males. 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, fatigue, and cardiolipin deficiency. In some people affected by Barth syndrome, the 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 treatment and finding a cure for Barth syndrome.

OBJECT(S)

The objects 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.

REVIEW OF ACTIVITIES

SUPPORTING FAMILIES IN 2022

Private WhatsApp group

This group was set up at the start of the first lockdown and has been a very successful way for families to communicate with and support each other. It is owned by the members, rather than the charity and is open to all UK based individuals with Barth syndrome and immediate family members.

One-to-One Support

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.

Our Chief Executive and our Family Services Support team are available to support new families through the testing process as well as providing ad hoc support to all member families.

Group Support

All UK Barth families were able to meet up at two events organised in 2022.

The first event was an Information Day, organised by the Bristol Barth Syndrome Service which was a great success. The day included a range of informal workshops, presentations and CPR training. Barth Syndrome UK provided breakfast, snacks and cold drinks and families met up for dinner after the event.

The second event was organised and funded by Barth Syndrome UK and was held at the National Space Centre in Leicester. On the Saturday, families explored the centre at their leisure and then met up for dinner. The following day, the charity ran a focus group meeting to touch base with affected families to get their input regarding the future direction of the charity.

Plans are in place to start up a peer led parent online monthly meeting in 2023 to provide ongoing group support.

Bristol Barth Syndrome NHS Service

The Chief Executive worked closely with the Barth Syndrome Service to provide joined up care throughout 2022 in a tailored approach.

The charity provides financial assistance to affected families through a travel Costs Scheme aimed at

making clinic attendance accessible for all throughout the UK.

Transition: Older Boys' and Men Project

The charity is in consultation with various experts and is continuing to identify needs and is planning possible projects to meet these needs. Examples include careers advice and support for independent living.

Plans are in place in 2023 to start a monthly peer led online meeting for young adults with Barth syndrome.

SCIENCE AND MEDICINE

Research Projects

1. Barth Syndrome UK, along with Barth Foundation Canada, co-funded the following research project in 2022:

   Investigation of a new nutraceutical for treatment of Barth Syndrome

   Robin Duncan, PhD, Associate Professor, University of Waterloo, Waterloo, Ontario, Canada - $41,580 over 2-year period

This project is assessing the therapeutic potential and activity of a nutraceutical (a possible supplement therapy that is available without prescription) in preserving the viability of Barth syndrome cells.

2. Barth Syndrome UK also funded the salary costs of a dedicated research associate to ascertain the prevalence of any neurocognitive conditions within our community. This project has led to some very interesting results and will help the charity to support families going forward.

International Registry

We continued to encourage families to sign up to our International Registry and Biobank in our efforts to promote research.

BARTH SYNDROME UK

Receipts and Payments Account for the period 1ST January 2022 to 31 December 2022

RECEIPTS	£
Fundraising events	5, 291
Gifts and donations	5, 305
Restricted fund donation	0
Gift Aid claims	1,093
Interest received	156
Total receipts	**11,845**
PAYMENTS	
Group development	784
Fundraising expenses	2, 080
Science and medicine	14 991
Family support and education	2 369
Bank service charges	124
Awareness	647
Administration	94
Insurance	96
External Examiner fees	180
Computer expenses	156
Salary expenses	24 614
Total payments	**46 135**
Surplus (deficit) of receipts over payments	**(£34 290)**

BARTH SYNDROME UK

Statement of Assets and Liabilities as at 31 December 2022

Assets

The charity has the following bank and cash balances:

	£
Current account (CAF)	7, 050
Savings account (CAF)	4, 631
Hampshire Trust Bank 90-day deposit	30 000
Total	**41 681**

Liabilities

None

Approved by the trustees on 23/02/23 and signed on their behalf by .....

Mr Ralph Easterbrook
Chairperson

BARTH SYNDROME UK

England & Wales - Charity number 1181830

Accounts

Barth Syndrome UK
Annual Report 2021

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BARTH SYNDROME UK

TRUSTEES' REPORT

The trustees present their report for the year ended 31 December 2021.

General Information

REGISTERED CHARITY NUMBER:	1181830
TRUSTEES:	Mrs Cheryl Parish – Chairperson Mr Geoffrey Parish – Treasurer Mr Stephen Cotterill Mr Ralph Easterbrook Mrs Isabel Easterbrook
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

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Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder primarily affecting boys. 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, fatigue, and cardiolipin deficiency. In some people affected by Barth syndrome, the symptoms can be very severe, sometimes resulting in heart transplant, potentially lethal infections, and even death.

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OBJECT(S)

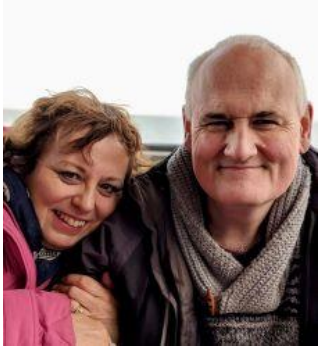
The objects[s] of the CIO are:

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, Cheryl Parish:



2021 has proved to be as challenging for our families as 2020. As our community is highly vulnerable, we have had to maintain a higher degree of social distancing and consider very carefully how to balance safety and mental health and wellbeing. Our communication platforms have continued to provide possibilities for interaction, both for help and support alongside regular socialising opportunities. We did manage to host a small face to face get together, which for those able to attend, was highly rewarding. We fervently hope that 2022 will enable us to offer more occasions to be together in person. We were very pleased to be able to initiate a cognitive function study to assess the prevalence of any learning needs within the community, the results of which we intend to utilise in our future project planning. Money has also been allocated to continue funding a medical research program in partnership with our affiliate Barth Syndrome Foundation of Canada. Our volunteers, CEO and Trustees have worked tirelessly together to offer help and support to our families and to have effective dialogue around the world with our wider communities and scientists to give all Barth families a better future.

MESSAGE FROM THE CHIEF EXECUTIVE, Michaela Damin:

2021 has been a bit of a mixed bag: on the one hand, we were relieved to see the resumption of some sort of normality but for our community, any social interaction has still been quite different compared to what it used to be.

We were excited to learn the results of our first ever clinical trial, but we were disappointed that the drug did not perform as well as we had hoped.

We had to navigate through the worrying decrease in fundraising events, but we were relieved that our families were staying safe and looking after themselves. And we recognised that many of us are exhausted with the ongoing pressures of work, home and health, exacerbated hundredfold during the ongoing pandemic.

We learned again the importance of quality mental health support while dealing with the crisis within our national health service which means that vital services are just not available to most of us.

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.

We are so grateful to each and every one who worked tirelessly, bravely and cheerfully through another challenging year.

All of us at Barth Syndrome UK pledge to keep working hard in 2022 to serve our affected families and make a positive difference in their lives.

Fond wishes
Michaela

Michaela Damin

REVIEW OF ACTIVITIES

SUPPORTING FAMILIES IN 2021

Private WhatsApp group

This group was set up at the start of the first lockdown and has been a very successful way for families to communicate with and support each other. It is owned by the members, rather than the charity and is open to all UK based individuals with Barth syndrome and immediate family members.

One-to-One Support

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.

Our Chief Executive and our Family Services Support team are available to support new families through the testing process as well as provide ad hoc support to all member families.

GDPR and Consents

In 2021 we refreshed all our families' consent forms to ensure that their choices around data sharing and storing are met, in line with GDPR legislation.

Christmas Party

Barth families were finally able to meet up at our small Christmas party, which was held at the Star Inn, Bristol in December 2021. Private hire of a restaurant as well as social distancing and mask wearing meant that it was a COVID safe event for all. Party games, a delicious Christmas dinner and lots of fun was had by all.

Bristol Barth Syndrome NHS Service

The Chief Executive worked closely with the Barth Syndrome Service to provide joined up care throughout 2021 in a tailored approach. This combined a mix of multidisciplinary virtual appointments, as well as the resumption of face-to-face clinics.

The charity provides financial assistance to affected families through a travel Costs Scheme aimed at making clinic attendance accessible for all throughout the UK.

The charity conducted an extensive service user survey towards the end of 2021 to identify areas of strengths and scope for improvement.

Transition: Older Boys' and Men Project

The charity is in consultation with various experts and is continuing to identify needs and is planning possible projects to meet these needs. Examples include careers advice and support for independent living.

International Conference

We, along with volunteers from Canada and the USA, have been planning the International Barth Syndrome Conference which is to be held in Florida in July 2022, Covid permitting.

SCIENCE AND MEDICINE

Research Projects

Barth Syndrome UK, along with Barth Foundation Canada, co-funded the following two research projects in 2021:

1. **Investigation of a new nutraceutical for treatment of Barth Syndrome**

Robin Duncan, PhD, Associate Professor, University of Waterloo, Waterloo, Ontario, Canada - $41,580 over 2-year period

This project will assess the therapeutic potential and activity of a nutraceutical (a possible supplement therapy that is available without prescription) in preserving the viability of Barth syndrome cells.

Although COVID-19 resulted in delays due to the researchers not being able to access their laboratory for many months, this project is ongoing and will continue into 2022 when a second payment of approximately £10 000 will become due.

2. **Surveying TAZ genetic interactions and mutational landscape in human cells**

Jason Moffat, PhD, Professor, University of Toronto, $50,000 over one year

This project enables us to better understand the TAFAZZIN gene and has the potential to expand our understanding about gene variants in our community. Data from this project could help us better understand the differences in severity of symptoms among our affected individuals.

The charity also plans to commit further funds towards new research projects in 2022.

Neurocognitive Service Evaluation Project

Our work with our affected families raised a concern that there may be a higher rate of neurocognitive conditions like ADHD, autism, dyslexia and dyspraxia within our community. For this reason, the charity commissioned a review in 2021 of our UK families to systematically investigate this previously unknown aspect. Full results are expected in the first half of 2022.

With the knowledge that the National Health Service is unable to provide timely intervention for these kinds of issues, the charity expects to commit further funds in 2022/2023 towards helping families who need access to proper diagnosis and support for any neurocognitive condition.

Cardioman Clinical trial

CARDIOMAN was the UK's first ever clinical trial using a repurposed medication called bezafibrate, which is normally used for treating lipid disorders.

This clinical trial was spearheaded by Professor Colin Steward – and later by Dr Guido Pieles – and was sponsored by the National Institute for Health Research (NIHR).

The affected individuals who took part made regular trips to Bristol for intensive cardiac examinations, exercise testing and regular blood tests. To make the clinical trial more enjoyable, patients' visits were grouped so that they could spend some quality time together.

In 2021 we hosted an international online meeting for researchers to share the results of the trial. Although the results were not as positive as we had hoped, we learned many valuable lessons about conducting similar trials within our super rare community, lessons which we are keen to take forward to new clinical trial opportunities as they arise in the future. Our families demonstrated their incredible and ongoing commitment to taking part in innovative new research in an effort to find a treatment for our rare disease.

International Registry

We continued to encourage families to sign up to our International Registry and Biobank in our efforts to promote research.

AWARENESS

Website

Work on our website has been ongoing in 2021, with a recent user commenting that it was ' very helpful! I've shared it with everyone who has questions about my pregnancy. It's very well organized and to the point.'

In 2021 we created a detailed set of resources around transitioning into Secondary School, details of which can be seen on our website.

FUNDRAISING

We saw a devastating 50% reduction in fundraising events in 2021, indicative of the fatigue that COVID has caused, especially to our small group of committed Barth families, many of whom are understandably struggling. However, thanks to our committed volunteers and donors, we have managed to prevail through 2021. Our carefully managed reserves have left us in a stable position, and we are confident of being able to continue our ambitious and vital plans for the years ahead. Thank you to all our incredible fundraisers, donors and volunteers, you have been amazing as always.

BARTH SYNDROME UK

Receipts and Payments Account for the period 1ST January 2021 to 31 December 2021

	Notes	2021 Total £	2020 Total £
RECEIPTS			
Fundraising events		13,783	20,727
Gifts and donations		13,241	10,296
Gift Aid claims		3,855	2,271
Interest received		128	644
Total receipts		31,007	33,938
PAYMENTS			
Fundraising expenses		216	359
Science and medicine		22,177	5,720
Family support and education		1,439	966
Accountant		175	-
Bank service charges		182	86
Awareness		3	68
Subscriptions		76	-
Administration/Office		146	16
Insurance		96	
Computer expenses		196	243
Salary expenses		20,134	19,635
Total payments		44,840	27,093
Surplus (deficit) of receipts over payments		**(13,833)**	**6,845**
Balance brought forward at 1 January 2021		89,990	83,145
		£76,157	**£89,990**

BARTH SYNDROME UK

Statement of Assets and Liabilities at 31 December 2021

Assets

The charity has the following bank and cash balances:

	2021	2020
	£	£
Current account (CAF)	2,095	1,942
Savings account (CAF)	24,062	38,048
Restricted account (for reserves)	50,000	50,000
	£76,157	**£89,990**

Liabilities

None

Approved by the trustees on 4 February 2022
and signed on their behalf by

Mrs Cheryl Parish
Chairperson

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

I report to the trustees on my examination of the accounts of the charity for the year ending 31 December 2021.

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 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.

Jason Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 7 February 2022