



# **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 19<sup>th</sup> October 2022)  
Mrs Kelsey Doran (newly elected 19<sup>th</sup> 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 31<sup>st</sup> 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 1<sup>ST</sup> January 2022 to 31 December 2022**

<b>RECEIPTS</b>	£
Fundraising events	5, 291
Gifts and donations	5, 305
Restricted fund donation	0
Gift Aid claims	1,093
Interest received	156
<b>Total receipts</b>	<b>11,845</b>
<b>PAYMENTS</b>	
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
<b>Total payments</b>	<b>46 135</b>
<b>Surplus (deficit) of receipts over payments</b>	<b>(£34 290)</b>

## BARTH SYNDROME UK

### Statement of Assets and Liabilities as at 31 December 2022

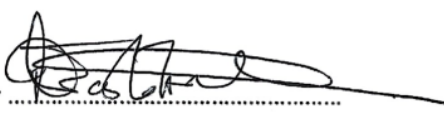
#### Assets

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	<b>41 681</b>

#### Liabilities

None

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

Mr Ralph Easterbrook  
Chairperson