

Barth Syndrome UK Travel & Meal Expense Policy (Bristol Clinic)

Helping You Attend The Bristol Clinic

(Financial Assistance Available From Barth Syndrome UK)

Last Reviewed: **May 2026**

Introduction

Attending the Bristol Clinic is a great benefit for everyone directly or indirectly affected by Barth Syndrome. Affected individuals can be examined by world leading experts across a range of medical disciplines, who can also share their up-to-date knowledge of symptoms and the most effective treatments. Families can meet and learn from each other. Affected boys (and girls) can meet and make friends with others like them. Other family members, including siblings and other carers, can also benefit from attending through meeting others and gaining further insights into Barth Syndrome.

The clinic also helps these leading experts to gain greater understanding of the condition and collect relevant data. The more affected families from the British Isles who attend the clinic, the more diverse data can be collected to aid further research into treatments and ultimately a cure. The University Hospitals Bristol NHS Foundation Trust is a Centre of Excellence for Barth Syndrome.

Unfortunately, not everyone can easily afford the costs of attending the Bristol Clinic, especially when travelling long distances. This is where BS UK can help (subject to the availability of funds).

What you need to do

The following is intended to explain everything you need to know about the arrangements we have made about providing financial assistance and answer your questions. Please contact the Chief Executive of BS UK, if anything is unclear or you need further information.

Email michaela.damin@barthsyndrome.org.uk

We look forward to seeing you at the Bristol Clinic.

Who can ask for financial assistance?

Immediate family attending the clinic with their child/ren who have Barth Syndrome or any adult with Barth Syndrome who is attending on their own/with immediate family if they normally reside in the British Isles.

What is covered?

We will help to pay a portion of your travelling costs to attend the Bristol Clinic (subject to the availability of funds).

How much can I claim?

Barth Syndrome UK – Registered Charity No: 1181830

Travelling by car

We will refund you the cost of travelling the return distance from your home to the Royal Hospital for Children in Bristol/other designated clinic venue, based on a rate of 25 pence per mile.

If you share a car with another individual/s attending the clinic, please note that we can only make one reimbursement, i.e., we cannot reimburse each individual travelling in the vehicle.

If travelling by car, no receipts are needed.

Other means of transport

Regardless of which method of transport is chosen by the family (train, plane etc), we will only pay your actual costs to attend the Clinic or 25 pence per mile, **whichever amount is the lesser**.

Only one reimbursement can be made per family. Receipts are needed.

Example: a family of 4 (2 parents and 2 children with Barth Syndrome) travels from Scotland to the clinic by plane. The return distance from the family's home is 500 miles. BS UK will only pay a total maximum of £125 to this family (not £125 per individual) or the actual cost of the flights, whichever is the lesser amount.

What if I'm eligible to get assistance from other sources?

We will limit the help we provide if other means of financial support are available to you; for example, if in the UK you are on benefits and use the HTCS scheme (see below).

How do I apply?

Please contact the Charity after attendance at a clinic if you wish to claim the travel refund. A direct payment will be made into your bank account. This can only be done once the Charity has your bank details, contact details and any necessary receipts.

When is the refund of travel expenses made? ^[OBJ]

We will make refunds after the Bristol Clinic unless we have agreed alternative arrangements with you beforehand to make an advance payment before you travel. Payments from BS UK will be made in pounds sterling (GBP).

Important Notice

It is BS UK's intention to continue to help families attend a clinic annually – bi-annually where medically required - by subsidising part of your travel costs; however, we cannot guarantee that this will be ongoing. BS UK Trustees will periodically review the financial position of the charity and will decide if there are any necessary amendments. If this financial assistance has to be terminated, temporarily suspended or amended in any way, we will inform all existing family members who may be affected by this change, giving at least 90 calendar days' notice.

Further Information for United Kingdom Residents Receiving Treatment under the NHS

Financial help is available under the [Healthcare Travel Costs Scheme \(HTCS\)](#), to those patients who do not have a medical need for ambulance transport but who require assistance with their travel costs to obtain treatment under the NHS.

Travel expenses can be reimbursed through the NHS Hospital Travel Costs Scheme (HTCS). The HTCS can provide help to NHS patients, who do not have a medical need for ambulance transport, meet the costs of travelling to and from hospital, if they are in receipt of income support, income-based job seekers allowance, pension credits, tax credits, or hold a current entitlement certificate (either HC2 for full help or HC3 for partial help).

Entitlement is based upon a patient's social security status. Patients should be able to present the evidence of entitlement outlined above (e.g. Letter from DSS or exemption certificate).

The following is a link to further information regarding the Healthcare Travel Costs Scheme

<https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>

Meal Expense

From 21st June 2023, BS UK will offer families attending the Bristol clinic and staying overnight a meal allowance of up to £15.00 per person, subject to a maximum of £50.00 per family (subject to the availability of funds). This aims to cover expenses for an evening meal for the overnight stay of their visit. There will be no reimbursement for alcohol. Receipts must be kept and sent to BS UK before reimbursement can be arranged. Families are encouraged to apply for reimbursement ahead of the clinic visit if this is required and these cases will be agreed on an individual basis.

The board of the Charity retains the right to approve, taking individual circumstances into account, allowable expenses above and beyond the norm, to ensure that as many affected individuals as possible (and their families) are able to access our services and the appropriate medical treatment (subject to the availability of funds). As well as affected individuals, this will also help the Charity in fulfilling its mission and vision statements. In each case where the expenses claimed are or will be over and above the norm, the particular circumstances will be discussed by the Board, with the agreed outcome and reasoning recorded (redacting personal information).