Thank You

Donations

You can donate online at **www.barthsyndrome.org.uk**

or by cheque to:
Barth Syndrome UK, 20 Regal Drive, East Grinstead RH19 4SB

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Please consider helping us reclaim 25p tax on every £1 you donate.
Gift Aid Declaration for donations to Barth Syndrome UK:
I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

- **I would like to Gift Aid this donation of £** _____
- **I would like to Gift Aid all future donations until further notice**
- **I would like to Gift Aid all donations I've made during the current and previous 4 tax years**

Name _____

Full Home Address _____

_____

_____ Postcode _____

Signature _____ Date _____

Details will not be used for any reason other than to reclaim tax.
Please let us know if you
1. Would like to cancel this declaration
2. Change your name or home address.
3. No longer pay sufficient tax on your income and/or capital gains.

Your Invitation

We extend a warm invitation to you to join us, especially if you are a Barth syndrome family, doctor or other medical professional, a donor or a friend who wants to help.

Together we can:

- Save Lives
- Provide a Caring Community for Families
- Work towards Finding Treatments and a Cure

General Enquiries:
Barth Syndrome UK
1 The Vikings
Romsey
SO51 5RG
Phone: +44 (0)1794 518785
info@barthsyndrome.org.uk

All the activities of Barth Syndrome UK are made possible by fundraising by our members and friends. We urgently need donations in order to continue this vital work.

Barth Syndrome UK is registered as a charity in England and Wales no 1181830.
Barth Syndrome UK is affiliated to Barth Syndrome Foundation (BSF)

August 2019

Saving Lives through Education, Advances in Treatment and Finding a Cure for Barth Syndrome

Barth Syndrome UK

www.barthsyndrome.org.uk

Saving Lives through Education, Advances in Treatment and Finding a Cure for Barth Syndrome

Barth Syndrome

A rarely diagnosed life-threatening genetic disorder that usually affects boys. The main symptoms are:

- **Heart failure (Cardiomyopathy)**
- **Weak immune system (Neutropenia)**
- **Muscle weakness / General fatigue**
- **Feeding problems / Growth delay**

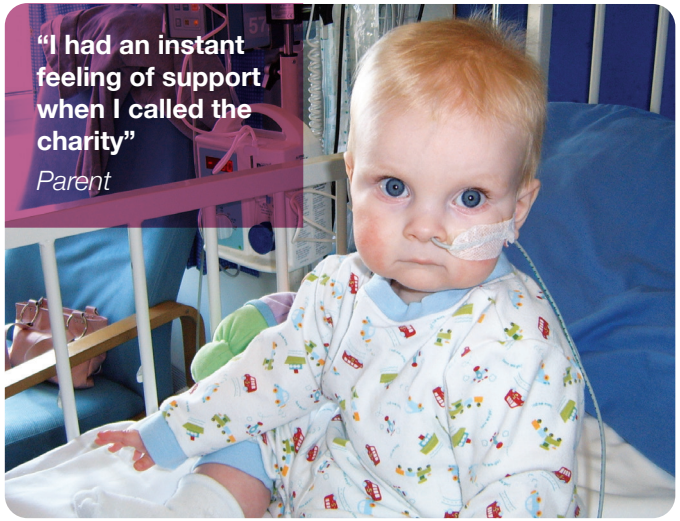
Why 'Barth'?

Barth syndrome was first described by Dr Peter Barth, a paediatric neurologist in The Netherlands. He observed a family with an extensive history of male infant mortality and started researching effects of the disorder.

Information is Vital

Before recent advances in the diagnosis of the syndrome, most babies did not survive.

Today, with improved diagnosis, treatment and management, the survival rate and future of these children is much brighter.



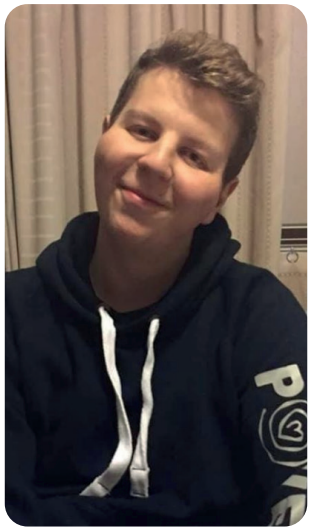
Living with Barth Syndrome

A Parent's Perspective

Parents of babies with Barth syndrome often realise something is wrong, but it can take some time before the condition is diagnosed and they are made aware of its seriousness. These can be difficult days for affected families.

After diagnosis parents have to become experts to care for their children. They need to talk to others who understand what they are going through.

Parents want to make informed decisions to help their children lead normal lives



Daily Vigilance

Living with Barth syndrome requires constant vigilance. Our children often face serious emergencies such as low blood sugar, heart failure, cardiac arrests or overwhelming infections. Careful hygiene and avoidance of germs are important. There are regular hospital visits and tests and a daily regimen of medication.

Muscle weakness and fatigue can affect simple everyday activities, such as writing, climbing stairs, playing and attending school.

Barth syndrome can place severe emotional and physical demands on families. The information and support available outside Barth Syndrome UK are very limited.

Barth Syndrome UK

We are part of a worldwide community helping families affected by Barth syndrome and working towards finding new treatments and a cure.

Early Diagnosis

We provide up to date information for the medical community and affected families and raise awareness of Barth syndrome to assist early diagnosis.

A Caring Community for Affected Families

Our telephone and email lifelines keep our families in daily contact with each other and with Barth specialists. We host Family Gatherings and help families with travel costs so that they can attend specialist clinics.

An end to isolation—
Families meet after a Bristol Clinic

Supporting Research

Together with BSF, Barth Syndrome UK funds research into treatments, causes and a cure. We host international conferences for doctors, scientists and families, collect patient information and facilitate the exchange of knowledge about Barth syndrome.

Barth Syndrome UK