

Barth syndrome . . .

...a rarely diagnosed life-threatening genetic disorder that usually affects boys.

The main symptoms are:

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

Why 'Barth'?

Barth syndrome was first comprehensively 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 Barth syndrome, most boys did not survive.

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



"I had an instant feeling of support when I called the Barth Syndrome Trust"

Parent

Living with Barth syndrome

A parent's perspective

Parents of baby boys 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 boys. They need to talk to others who understand what they are going through.



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

Daily vigilance

Living with Barth syndrome requires constant vigilance. Our boys often face serious emergencies such as low blood sugar, heart failure, cardiac arrests or overwhelming infections. Extra careful hygiene and avoidance of germs are needed at all times. 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 BSF / BST are very limited.

Barth Syndrome Trust

(affiliated to Barth Syndrome Foundation)

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

Saving the lives of affected boys

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 annual Family Gatherings to coincide with the NHS Barth Syndrome Clinic in Bristol.



*An end to isolation—
Families meet after a Bristol Clinic*

Supporting research

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



Thank you for making a donation

Your donation will go towards our programmes to save the lives of boys with Barth syndrome, provide a caring community for affected families and support research. We spend a minimum on administration.

You can donate online - www.bmycharity.com

or by cheque to

Barth Syndrome Trust
20 Regal Drive, East Grinstead
West Sussex, RH19 4SB

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Please consider helping us reclaim tax you have paid.

Gift Aid Declaration:

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. Please tick all that apply:

- 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 _____

Address _____

Postcode _____

Signature _____ Date _____

Please notify the Barth Syndrome Trust 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.

Details will not be used for any reason other than to reclaim tax.

Names (only) of donors often appear in our newsletter. Please tick if you would prefer not to have your name printed.

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. Membership is free. Together we can:

- save the lives of boys with Barth syndrome
- provide a caring community for families
- work towards treatments and a cure

Please contact us to discuss anything in this leaflet or if you have any other questions.

General enquiries:

Barth Syndrome Trust
1 The Vikings
Romsey
SO51 5RG
United Kingdom

Phone: +44 (0)1794 518785
info@barthsyndrome.org.uk

Donations:

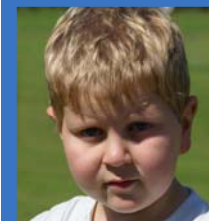
You can donate online - www.bmycharity.com

Please make out cheques to
Barth Syndrome Trust
and send to
20 Regal Drive, East Grinstead,
West Sussex, RH19 4SB, UK

The Barth Syndrome Trust is affiliated to
the Barth Syndrome Foundation
www.barthsyndrome.org

Other affiliates in France, Canada and South Africa

Barth Syndrome Trust is registered as a charity in
England and Wales No.1100835



Barth syndrome

Saving lives
through
education,
advances
in treatment
and
finding
a cure



**Barth Syndrome
Trust**

www.barthsyndrome.org.uk