

# Family Services

## What happens when I contact the Trust?

Someone from the Family Services Team (named on this page) will respond as soon as possible.



Michaela Damir and Family

We understand what you are going through.



Sarah, Dave and Family

The Barth Syndrome Trust gives up-to-date information about the care of your son.

***Barth syndrome can be managed and we are here to help you do so.***



Annick and Grandson

Each of us has first hand experience of living with Barth syndrome.



Allanna and Family

We are only an e-mail or phone call away when you need us.



Julie and Family

## Barth Syndrome Trust

We offer

- Direct access to Barth syndrome medical experts
- Specialist multidisciplinary NHS-funded service
- International conference every two years arranged by the Barth Syndrome Foundation for families and medical experts from all over the world
- Regular opportunities for entire families to meet and share experiences
- Support network for grandparents
- Fact sheets, newsletters, case stories, information for doctors and other publications are available on request
- The opportunity to enrol into the Barth Registry and Repository to further research

**Call, email or write in strict confidence.  
No need to wait for test results.**

### Barth Syndrome Trust

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Romsey              info@barthsyndrome.org.uk  
SO51 5RG           www.barthsyndrome.org.uk  
United Kingdom

### Affiliated to :

Barth Syndrome Foundation      www.barthsyndrome.org

Barth Syndrome Trust Registered Charity No 1100835 (England & Wales)

## Barth syndrome?



**A genetic disorder that affects mostly boys with some or all of the following:**

- heart problems (cardiomyopathy)
- recurrent infections (neutropenia)
- muscle weakness / 'floppy baby'
- feeding problems
- fatigue
- growth delay / delayed milestones

Waiting for diagnosis?

Diagnosis just confirmed?

Want to talk?



*You'll find  
a warm welcome  
and the information  
you need*

www.barthsyndrome.org.uk  
Find us on facebook

## Think it might be Barth syndrome?

Free diagnostic testing available through the Bristol Royal Hospital for Children.

**Please contact us for more information**

info@barthsyndrome.org.uk

## Waiting for diagnosis? Just diagnosed?

We all remember this stage. The wish for a definite diagnosis and, at the same time, the fear of the diagnosis.

- Words like "cardiomyopathy" and "neutropenia" - What does it all mean?
- How do I manage the daily care of my son? What signs should I be looking for?
- Will he have a job and family of his own one day?
- Can we have more children?
- Could my other children be affected?

*\* All individual boys and men shown, and some in groups, have Barth syndrome*

## Is there hope after diagnosis? . . .



We are living proof that there is great hope.

In fact, an accurate diagnosis is a key milestone in your journey. And we are here to help you along the way.

We are parents of boys and men with Barth syndrome, supported by dedicated doctors, scientists and volunteers.



*"My son is 10 years old, and I promised him that we would do everything we could to find a treatment for him and all the other affected boys around the world.*

*I told him that all he needed to do was just get on with being a boy."*

*Michaela Damin,  
Chair & Founder BST*

This commitment is shared by parents worldwide and progress is being made in the treatment, understanding and search for a cure.



# Barth Syndrome Trust

## Information and support

We support families in the UK and the rest of Europe. Our 'boys' range in age from birth to men with their own children.

We keep in touch by phone and email. Families also share information and experiences with each other and expert doctors through a private email forum.

We are affiliated to the Barth Syndrome Foundation, and we work closely with them. All those affected by this rare disorder benefit from this international co-operation. Pooling our knowledge is vital in our quest for a cure.

We are unique in being able to offer you information based on over 12 years of research, experience and observations by scientists, doctors and parents.



Families, medical staff and helpers at a UK clinic

## Other languages

Information and support is available in Dutch, French, German, Italian, Portuguese and Spanish and other languages by arrangement.