



# bbsuk

Bardet-Biedl Syndrome UK

## Who we are and how we can help!



REGISTERED CHARITY 1181244

# Who we are

**Bardet-Biedl Syndrome UK** is a voluntary organisation, primarily supporting those with Bardet-Biedl Syndrome, their families and/or carers.

We do this through the provision of support, information and advocacy services, activities and events, including:

- Weekend family conference and conference report
- Social weekends
- Family activity weekends
- Young people's forum
- Adults' focus group
- Information leaflets
- Newsletters
- Telephone and email support
- Website ([www.bbsuk.org.uk](http://www.bbsuk.org.uk))

In addition, the Charity aims to support those professionals who may have an interest in Bardet-Biedl Syndrome.



**The information and support made us feel we were not alone.**



**After the shock of the diagnosis, it was a relief to find someone to talk to who knew how we felt.**



**YouTube**

# What is BBS?

**Bardet-Biedl Syndrome is a rare, recessively inherited disorder** which affects approximately 1 in 100,000 babies born.

**The main symptoms of this complex condition are:**

- Visual impairment, often leading to blindness
- Extra fingers and/or toes
- Obesity
- Developmental delay
- Speech and co-ordination difficulties
- Learning difficulties
- Kidney abnormalities
- Other health problems may occur

Not all of the features are always present in those diagnosed as having BBS, and each one can vary in severity and appearance.



# Annual family conference

**Every year we hold our weekend family conference** offering a unique opportunity for those with Bardet-Biedl Syndrome, their families and/or carers to meet and stay at a hotel centrally located in the UK.

The Saturday offers a full programme of eminent speakers, experts in their field, and relevant to Bardet-Biedl Syndrome. This is an excellent opportunity for those with the Syndrome, and their families, to gain information and support. The children and young adults also enjoy a fun packed weekend.



**The whole conference weekend has been very instructive and we have gained a lot of knowledge relating to the condition, thank you for a wonderful weekend, it has been brilliant.**



**Knowing that lots of research about BBS is going on has given me a little hope for the future. Thank you to you all for making our experience so special.**

# Friends of BBS UK

**Friends of BBS UK is a fundraising initiative,** giving those who wish to regularly support the Charity, the means to do so.

**You can become a Friend of BBS UK in the following ways:**

- Take a collection box
- Organise a fundraising event
- Set-up a Regular Payment
- Combination of the above

If you would like more information about becoming a Friend of BBS UK or would like support with fundraising, please email **fundraising@bbsuk.org.uk** or telephone **07512 198484**.

If you would like to make a Regular Payment to BBS UK, please complete the form overleaf and return to **Kevin Sales, BBS UK, 1 Blackthorn Avenue, Southborough, Tunbridge Wells, Kent TN4 9YA**.

## **Gift Aid Declaration**

By choosing to Gift Aid your donations, Her Majesty's Revenue and Customs (HMRC) will add an extra 25p to every £1 you give to BBS UK. Making a Gift Aid declaration is quick and easy – all it takes is a simple tick.

I want to Gift Aid my donation of

£  and any donations I make in the future or have made in the past 4 years. 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.

# Standing Order Form

**I would like to become a Friend of BBS UK and make the following regular payments:**

Please pay the sum of £

Amount in words

To: **Bardet-Biedl Syndrome UK, Friends Account**  
Account No: **00906387** Sort Code: **201997**

With effect from  
and monthly thereafter.

Please complete the following in block capitals

**Name**

**Address**

**Postcode**

**Telephone**

**Email**

**Name of Bank**

**Address of Bank**

**Postcode**

**Account No**

**Sort Code**

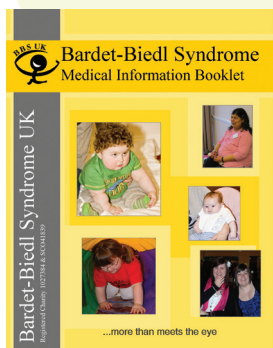
Reference (Surname/Initial)

Signed

Date

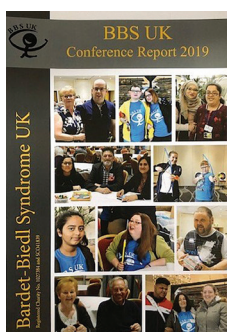


# Information



## Leaflets available

- Medical Information Booklet
- My Life, My Future! (A young person's guide to living their life with BBS)
- Information Booklet for Schools (Summer 2020)
- Introducing BBS (Summer 2020)



## Also available

- Newsletters
- Conference Report

# Fundraising



BBS UK relies entirely on the generosity of members and Friends, donations, grants and sponsorship from individuals and companies. Information about fundraising for the Charity or becoming a Friend of BBS UK and other fundraising schemes can be found on our website.

**For all our contact details and more  
please visit our website  
[www.bbsuk.org.uk](http://www.bbsuk.org.uk)**

  
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