



Easy read
booklet

About Bardet-Biedl Syndrome



Who we are and what we do



We are **Bardet-Biedl Syndrome UK**. Bardet-Biedl Syndrome will be called **BBS** for short in the rest of this booklet.



We are the only charity in the UK helping people who have BBS, their families and carers.



We make booklets, newsletters and have a yearly meeting about BBS. We have events telling people about BBS and bringing people with BBS together.



This booklet tells you about BBS. We hope it answers some of your questions.

About BBS



BBS is an **inherited disorder** that a small number of babies are born with.



An **inherited disorder** is a health problem you are born with and will have your whole life.



Families from any background can be affected by an inherited disorder.



You can't catch BBS and people with BBS can't grow out of it.



Inherited disorders are passed from parents to children through **genes**.



Genes are inside of us and make us who we are and what we look like. We are made up of genes from our parents.



Parents who are related are more likely to have a child with BBS. This is because their genes are similar.



People can have a test to find out if they have BBS genes.

Symptoms of BBS



There are lots of **symptoms** of BBS. A **symptom** is a health problem caused by BBS.



Not everyone with BBS will have the same symptoms.



Symptoms can be mild or severe.



BBS is different for everyone.

Sight loss



BBS can cause sight loss called **Rod-Cone Dystrophy**.



BBS sight loss usually starts in childhood with **night blindness**. This means it is harder to see in the dark.



Night blindness is usually followed by a slow loss of vision which can take many years.



There are organisations that can help you if you have sight loss. We give contact information later on in this booklet.

Obesity



Obesity is when you are overweight.



Lots of people with BBS have obesity.



Obesity can cause other problems like diabetes and heart disease.



Eating healthy food and being active helps stop obesity.



Dietitians can help you if you are obese. **Dietitians** tell people how to eat well.

Kidney problems



Your kidneys are the organs in your body that make **urine**. **Urine** is your pee.



BBS can affect your kidneys in a few ways. Serious kidney problems don't happen very often.



If you don't have serious kidney problems before you are 20 years old, it is unlikely you will have them when you are older.



It takes a long time for the kidneys to stop working. So there will be time to prepare.

Learning problems



Learning problems are when people find it hard to learn new things.



Lots of people with BBS have learning problems.



People with BBS can find it hard to control their **emotions**. **Emotions** are feelings.



People with BBS can have problems with **depression**. **Depression** is when you feel worried and sad.



Your doctor can help you with these problems.

Speech problems



Some children with BBS have speech problems and take a long time to learn to talk.



A **speech and language therapist** can help with speech problems.

Extra fingers or toes



Some children with BBS are born with extra fingers or toes which can be removed in hospital.

Other problems



BBS can affect other parts of the body.

Treatments for BBS



There is no cure right now for BBS. This means doctors can't yet make it go away.



Doctors are trying to find new and better ways to help people with BBS.



There are 4 special NHS clinics in London and Birmingham to help people with BBS.



At **BBS UK**, we work with the NHS to help people with BBS. We can help you make an appointment with one of the special NHS clinics.

Contact us



If you would like more information about BBS please get in touch.



Send an email to us at
admin@bbsuk.org.uk



You can read more on our website
www.bbsuk.org.uk

Find us on Facebook, Twitter and YouTube.



Twitter **[@lmbbs1](https://twitter.com/lmbbs1)**

Facebook **www.facebook.com/bardetbiedlsyndromeuk**

Other organisations that can help



Here are other organisations that can help you with BBS.

R N I B

See differently

RNIB

They help with sight loss.

www.rnib.org.uk

0303 123 9999



Guide Dogs

They help with sight loss.

www.guidedogs.org.uk

0118 983 5555



VICTA

They help with sight loss.

www.victa.org.uk

01908 240831



Look

They help with sight loss.

www.look-uk.org

07464 351 958



Sense

They help with sight and hearing loss.

www.sense.org.uk

0300 330 9250



National Kidney Federation

They help with kidney problems.

www.kidney.org.uk

0800 169 09 36



The National Autistic Society

They help with autism.

www.autism.org.uk

0808 800 4104



Diabetes UK

They help with diabetes.

www.diabetes.org.uk

0345 123 2399



Supported by



www.breaking-down-barriers.org.uk

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