



British Heart
Foundation

LIFE WITH INHERITED ABNORMAL HEART RHYTHMS

I'm training to be
a children's nurse

I want to help
people like me

I'm looking towards
my future

I live with an
inherited heart
condition

SHANNON'S STORY,
PAGE 36

**FIGHT
FOR EVERY
HEARTBEAT**

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In association with



**Cardiac
Risk in the
Young**





This booklet is not a substitute for the advice your doctor or cardiologist (heart specialist) may give you based on his or her knowledge of your condition, but it should help you to understand what they tell you.

The illustrations used in this booklet are artistic impressions and are not intended to accurately depict the medical material that they represent.

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Published by Cardiac Risk
 in the Young (CRY) and the
 British Heart Foundation.

INTRODUCTION	02
UNDERSTANDING YOUR HEART	05
The normal heart	06
Types of inherited abnormal heart rhythm	08
INHERITED ABNORMAL HEART RHYTHMS	11
Long QT syndrome (LQTS)	14
Brugada syndrome	20
Catecholaminergic polymorphic ventricular tachycardia (CPVT)	22
Progressive cardiac conduction defect (PCCD)	23
Short QT syndrome (SQTS)	24
Familial atrial fibrillation	24
TESTING AND YOUR FAMILY	25
Implications of a diagnosis of an inherited abnormal heart rhythm for a family	28
Assessment at a clinic for inherited heart conditions	29
EVERYDAY LIFE	35
General lifestyle advice	38
Medicines and drugs to avoid	39
TECHNICAL TERMS	47
MORE INFORMATION	51
INDEX	53

You may be reading this booklet because you've been diagnosed with an **inherited abnormal heart rhythm**. Or maybe someone else in your family has been diagnosed with an abnormal heart rhythm, and your doctor has suggested that you should have some tests to find out if you've inherited the same condition.

An abnormal heart rhythm – known as an arrhythmia – is when your heart is beating too fast, too slow, or with an irregular pattern. Some arrhythmias can be inherited, which means they're passed on through families. They can affect one or several members of the same family and can be life-threatening and cause sudden death. This is why it's important that families who are affected receive an accurate assessment, diagnosis, treatment and support from specialists in a clinic for inherited heart conditions.

This booklet:

- describes how the normal heart works
- explains what can go wrong with your heart when you have an inherited abnormal heart rhythm
- explains why it's important that close blood relatives of someone who has been diagnosed with certain abnormal heart rhythms should have an assessment to find out if they have inherited the same condition
- describes the tests your doctor may ask you and your close family to have
- offers advice on how to live a healthy lifestyle if you are found to have an inherited abnormal heart rhythm.

We explain the medical and technical terms as we go along but, if you find a word you don't understand, look it up in the list of Technical terms on page 47.

We hope that this booklet will help you to understand your condition and to come to terms with what it means for your close family. If you need further support or information, see page 51.

UNDERSTANDING YOUR HEART

THE NORMAL HEART

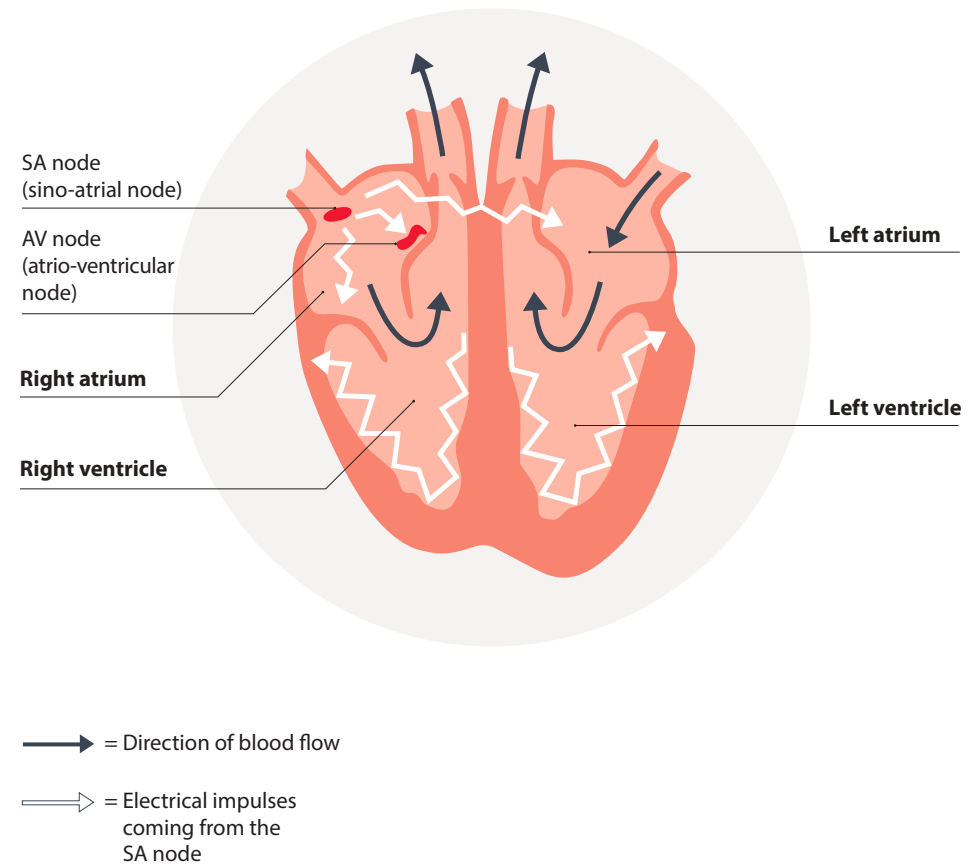
The heart is a specialised muscle that contracts regularly and continually, pumping blood around your body. The pumping action of your heart is caused by a flow of electricity through the heart that repeats itself in a cycle. If this electrical activity is disrupted – for example, by an **arrhythmia** – it can affect your heart’s ability to pump properly.

How the heart functions electrically

- Your heart has four chambers – two at the top (the atria) and two at the bottom (the ventricles).
- The normal trigger for your heart to contract starts in the heart’s natural pacemaker, the SA node (sino-atrial node), which is in the right atrium (see the diagram on page 07).
- The SA node sends out regular electrical impulses, which make the atria contract and pump blood into the ventricles.

- The electrical impulses then pass to the ventricles through a form of ‘junction box’ called the AV node (atrio-ventricular node). This causes the ventricles to contract and pump blood out of your heart.
- The blood from the right ventricle goes through the pulmonary artery to your lungs, and the blood from the left ventricle goes through the aorta and then around your body.

The speed of your heart’s pacemaker and the force of the pumping action of the ventricles are also controlled by nerves that regulate your heart by releasing certain chemicals that circulate in your blood. For example, adrenaline increases your heart rate and the volume of blood pumped out of your heart.



TYPES OF INHERITED ABNORMAL HEART RHYTHM

Some abnormal heart rhythms are caused by a group of uncommon conditions known as ion channelopathies. These conditions can cause life-threatening disturbances in your heart's electrical system, known as arrhythmias.

Ion channelopathies affect the electrical functioning of your heart. There are several different types of ion channelopathies including:

- Long QT syndrome (LQTS)
- Brugada syndrome
- Catecholaminergic polymorphic ventricular tachycardia (CPVT)
- Progressive cardiac conduction defect (PCCD)
- Short QT syndrome (SQTS)
- Familial atrial fibrillation.

We describe each of these on pages 11-24.

Other conditions where an ion channelopathy may be found include:

- Idiopathic ventricular fibrillation (IVF)
- Early repolarisation syndrome (ERS).

For more information on diagnosing conditions like these, see pages 25-34.

If you've been diagnosed with an ion channelopathy you'll need to have a specialist assessment so that your doctor can treat your condition appropriately. This is very important, as if left untreated, ion channelopathies can increase your risk of sudden death.

It can be difficult for you and your family to come to terms with the need to have an assessment and to deal with the results. For information on where to get emotional support in coping with any aspect of the diagnosis and assessment see page 51-52.

What causes an ion channelopathy?

Ion channelopathies are caused by abnormalities in an individual's genetic make-up. Each one of us has our own genetic information that makes us unique. Your genes make you who you are, for example what colour your hair is, your blood type and your gender. This genetic information is held in your DNA, in the cells of your body. Your genetic information acts as a code that allows a system of proteins to be created. This tells all of the cells in your body what their function should be.

If there's a mistake in one of these codes, your cells may not work as they should do. These mistakes are known as **gene mutations** or **gene faults**.

Certain gene mutations will cause an ion channelopathy. They are usually inherited from your parents, although they can occur for the first time in a family. If they occur for the first time in a single family member they are described as 'sporadic'. In some cases, a person may inherit a gene mutation, but not show any symptoms of the genetic condition. However, these people are still able to pass the gene mutation on to their children and are known as 'carriers' of the condition.

Some mutations affect certain genes that are responsible for the production of 'ion channels' in your heart.

- An ion is a chemical substance – such as sodium or potassium – that carries an electrical charge and forms the basis of the movement of electricity through your heart muscle.
- An ion channel is a gateway that allows ions to pass in and out of your cells.

For example, a potassium channel is an ion channel that allows potassium ions to pass in and out of your cells.

In your heart, the movement of ions in and out of heart muscle cells controls the heart's electrical impulses. This allows you to produce a heartbeat.

- Heart muscle cells are activated by the flow of ions in a process known as **depolarisation**. This allows them to contract and produce a heartbeat.
- A later flow of ions allows heart muscle cells to return to rest after contraction, through a process known as **repolarisation**. This gets your heart ready for another heartbeat.

Conditions that can occur as a result of an ion channelopathy

If the ion channels in your heart don't behave normally, you're at risk of developing dangerous arrhythmias which can lead to blackouts, cardiac arrest and in some cases sudden death.

An ion channelopathy can increase the risk of developing ventricular arrhythmias that affect the ventricles, the lower pumping chambers of the heart. The two main types of ventricular arrhythmias are ventricular tachycardia and ventricular fibrillation.

Ventricular tachycardia – or VT for short – occurs when the electrical signals in the ventricles become disorganised and take over the heartbeat independently from the SA node. This leads to a rapid heartbeat. VT can cause blood pressure to fall to a dangerously low level, and lead to a cardiac arrest.

Ventricular fibrillation – or VF for short – is a fast heart rhythm which causes your heart to ‘fibrillate’, or quiver, instead of pumping blood around your body. This is a cardiac arrest.

While ion channelopathies cause electrical disturbances in the heart, the structure of the heart remains normal. This means they can’t be detected after someone has died (post-mortem). If someone dies suddenly, and no other cause can be found, this is termed **Sudden Arrhythmic Death Syndrome (SADS)**. Ion channelopathies are thought to be the cause of around four in every ten cases of SADS. For more information see page 51 and the BHF booklet *Sudden Arrhythmic Death Syndrome*.

INHERITED ABNORMAL HEART RHYTHMS

KELLEY'S STORY

I was diagnosed with long QT syndrome as a child, but I didn't let it beat me. Growing up, I rode horses and went swimming. But after I left school I started to have blackouts and I had to have an ICD fitted.

I tested positive for two gene mutations for long QT syndrome, so when I became pregnant I knew my son Jayson could have inherited the condition. Jayson was four days late and I had an emergency C-section when his heart rate dropped.

They put me to sleep and when I came round, they took me to see him. He was amazing.

Jayson had an ECG the day he was born. I was told he had long QT syndrome when he was just one day old. He started medication straight away. It was terrifying finding out he had the condition, but I like to get on with life – I'd like Jayson to pick up on that and learn not to let his condition stop him doing what he loves.

I'm a busy mum

My condition
doesn't stop me

It won't stop
my son either

I live with an
inherited heart
condition



LONG QT SYNDROME (LQTS)

LQTS is the most common and best understood type of ion channelopathy.

- It occurs in as many as one in 2,000 people.
- For seven in every ten people with LQTS, the ion channels involved have been identified.
- In most cases, two potassium channels that regulate the movement of potassium ions from the inside to the outside of cells are affected.
- In a smaller proportion of people with LQTS, sodium or calcium channels are affected.

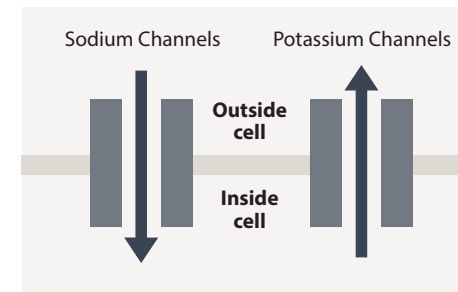
In people with potassium channel-related LQTS the ion channels do not behave as efficiently as normal. They let potassium ions out of the cell too slowly. If the sodium channel is affected, too many sodium ions are allowed into the cell (see the LQTS diagram on the next page). This results in an electrical disturbance in the cells of your heart called 'prolonged repolarisation' (see page 09). This means that the heart cells in your ventricles take longer to recharge after each heartbeat.

This can sometimes be seen on an electrocardiogram (ECG) recording as a lengthening of a part of the heartbeat cycle known as the **QT interval**. This is where the name long QT syndrome comes from. For more information on having an ECG test, see page 30.

The diagrams below show the flow of potassium and sodium ions in and out of the heart's cells. The thick arrow represents too much flow. The thin arrow represents a reduced flow.

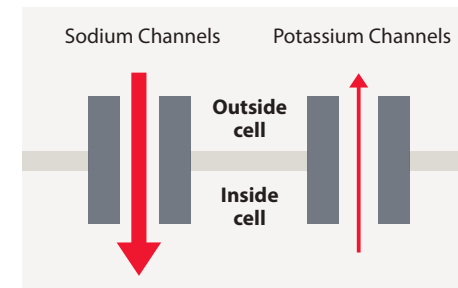
Normal heart

In a normal heart, potassium flows out of the cell to repolarise the heart (see page 09), and sodium flows into the cells to activate the heart.



LQTS

In people with LQTS, the flow of potassium is usually reduced. In some people with LQTS, the flow of sodium may be increased.



What are the different types of LQTS?

There are currently 13 known types of LQTS. The type of LQTS you have depends on which gene mutations you inherit and whether you inherit a gene mutation from one or both of your parents.

The most common type of LQTS is known as Romano-Ward syndrome. Rarer forms of LQTS include:

- Andersen’s syndrome
- Timothy syndrome
- Jervell and Lange-Nielsen (JLN) syndrome.

Each type is associated with different ion channels abnormalities, which are shown in the table below.

Type of LQTS	Ion channels affected		
	Potassium channels	Sodium channels	Calcium channels
Romano-Ward syndrome	X	X	X
Andersen’s syndrome	X		
Jervell and Lange-Nielsen (JLN) syndrome	X		
Timothy syndrome			X

What are the symptoms of LQTS?

LQTS varies greatly in severity. Symptoms vary according to:

- the ion channel involved
- whether you’re male or female
- your age
- the length of the QT interval on your ECG.

Males are more likely to have symptoms before puberty, while females are more likely to have them in adolescence and early adulthood. Relatives from the same family who have inherited the same mutation may have very different experiences. For example, you may have:

- a normal QT interval and not have any symptoms
- a very abnormal QT interval but no symptoms
- a very abnormal QT interval and have many episodes of arrhythmia that put you at risk.

The most common symptom of LQTS is blackouts, caused by an arrhythmia. Sometimes palpitations due to extra or ectopic heartbeats can be a problem. Some types of LQTS are associated with sudden death related to exercise, when

a person is asleep or when the person has been startled or awoken suddenly (sudden arousal).

If you have Andersen’s syndrome you may also have muscle weakness or minor abnormalities of the skull, chin, fingers and toes. Children with Timothy syndrome usually have many other problems that are present from birth and make it easier to diagnose the condition. People with JLN syndrome also have hearing loss from birth.

How is LQTS diagnosed?

Diagnosis involves having an ECG (see page 30). Sometimes experts can tell which ion channel has been affected just by looking at your ECG recording. Unfortunately, diagnosis can be very difficult and many people with the condition will have a normal ECG. Repeated ECGs, exercise tests, 24–48 hour Holter monitoring and adrenaline testing may be needed before any hint of the condition is seen. Even then there may be no clear sign of the condition. We describe all these tests on pages 30–34.

Genetic testing can sometimes identify carriers of LQTS (see page 34). However, three in every ten people diagnosed with LQTS do not have gene mutations known to be associated with LQTS.

Many families who do have a gene mutation appear to have a specific change in their DNA code which is not found in other families. This change is known as a 'private' mutation. This can make it difficult to decide whether a gene mutation is causing the disease or not. Things are further complicated by the fact that people with the same mutation can be affected by the condition differently, with varying degrees in severity. All of this can make it difficult for doctors to decide on the best way to treat people with LQTS. That is why it's recommended that you get an expert medical opinion from a clinic that specialises in inherited heart conditions.

How is LQTS treated?

The treatment you'll need depends on your risk of sudden death. People at the greatest risk of sudden death are those with one or more of the following features:

- a previous cardiac arrest
- blackouts
- a very long QT interval on the ECG
- young adult women
- certain gene mutations
- having more than one gene mutation.

Children who are most at risk tend to be young boys before puberty, and girls who are passing into puberty.

Medicines

The first line of treatment is with medication. The most commonly used medicines are beta-blockers. These block the effects of adrenaline and associated natural chemicals in your body that make your heart pump harder and faster. They therefore also block the effects of exercise on your heart. They are effective in the most common forms of LQTS, as they reduce your symptoms and most importantly your risk of sudden death.

Recent advances in anti-arrhythmic medicines may provide new treatment options. These medicines block the disturbances in your heart rhythm that can cause sudden death. However, the long-term benefits of these treatments are unknown. Potassium supplements may also be prescribed by your doctor and have been successful in some cases.

Cardiac devices

If you're at high risk of sudden death (for example if you have already had a cardiac arrest) or if medication has failed to control your symptoms, your doctor may advise you to have a pacemaker or an implantable cardioverter defibrillator (ICD) fitted, as well as taking your medicine.

A pacemaker and an ICD consist of:

- a small metal box called a pulse generator, containing a battery

- one, two or three electrical leads known as electrodes that deliver electrical impulses to the heart muscle.

Pacemaker

A pacemaker can prevent your heart from beating too slowly by 'pacing' your heart to make your heart rate faster. A pacemaker works by:

- monitoring and storing information about your heart rhythm and heart rate
- sending electrical impulses to your heart that stimulate it to contract. This helps to control your heart rate and stop any excessive slowing of your heart that could trigger an arrhythmia.

Most pacemakers are set to work on demand – they monitor your heart and only deliver an electrical impulse if your heart has missed a beat, or if it's beating too slowly. Some pacemakers send out impulses all of the time and are known as fixed rate pacemakers.

A pacemaker is usually implanted just under your left collarbone. This procedure usually takes about an hour and is normally done with a local anaesthetic and mild sedation. The pacemaker battery usually lasts between six and ten years (and sometimes even longer), but you should have regular check-ups.

For more information on pacemakers, see our booklet *Pacemakers*. To order our booklets see More information on page 51.

ICD

An ICD monitors your heart rhythm through electrodes placed into your heart. If it detects a dangerous arrhythmia it can deliver a small electrical shock to restore your heart's normal rhythm. This is called shock therapy. An ICD can deliver the following treatments:

- sending electrical impulses to your heart that stimulates it to contract (in the same way as a pacemaker)
- cardioversion – one or more small electric shocks to restore your heart's normal rhythm
- defibrillation – one or more larger electric shocks to get your heart back into a normal rhythm.

An ICD is slightly larger than a pacemaker and may be positioned above or under the chest wall muscle below your left collar bone. The procedure may take between one to three hours. Most people have a local anaesthetic and mild sedation, but some may have a full (general) anaesthetic. The ICD battery lasts between four and eight years, but you should have regular check-ups.

A new type of ICD called a subcutaneous ICD – or S-ICD for short – is more suitable for some people. An S-ICD works in the same way as an ICD, but there are no leads inserted into the heart. Instead, a lead is inserted just under the skin of your chest (on the outside of your ribcage). The metal box is usually placed below your left armpit.

For more on ICDs, see our booklet *Implantable cardioverter defibrillators (ICDs)*. To order our booklets see [More information on page 51](#).

Surgery

Another option is to perform surgery to disrupt the nerves that release adrenaline and related chemicals into your heart. This is known as cervical sympathectomy or cardiac denervation. It involves operating on the left side of your neck and blocking or removing the nerves.

Advice on physical activity for people with LQTS

If you have LQTS, your doctor will advise you to avoid excessive exercise or strenuous athletic activities. See [General lifestyle advice](#), on page 38.

BRUGADA SYNDROME

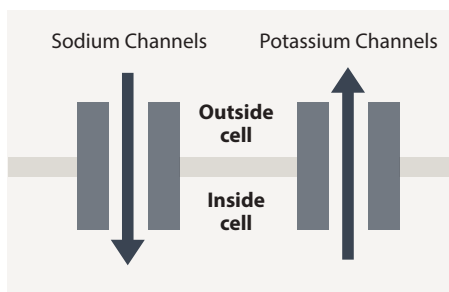
Brugada syndrome affects mainly young and middle-aged adult men. It is not a common condition in the western world, but seems to be much more common in South East Asia.

For one in every five people with Brugada syndrome, a sodium channel is affected by a gene mutation. This causes the channel to restrict the movement of sodium ions into the cell (see the Brugada syndrome diagram on the next page).

These diagrams show the flow of potassium and sodium ions in and out of the heart's cells. The thin arrow represents a reduced flow.

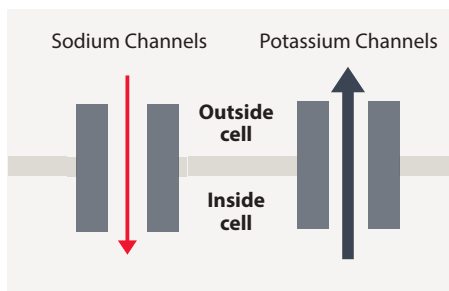
Normal heart

In a normal heart, potassium flows out of the cell to repolarise the heart (see page 09), and sodium flows into the cells to activate the heart.



Brugada syndrome or PCCD

In people with Brugada syndrome or PCCD (see page 23), the flow of sodium into the heart cells is reduced.



What are the symptoms of Brugada syndrome?

Some people with Brugada syndrome have no symptoms at all. Others may have palpitations, blackouts or even a sudden cardiac arrest (which can lead to sudden death).

How is Brugada syndrome diagnosed?

Diagnosis involves having an ECG (see page 30). The changes characteristic of Brugada syndrome may appear on your ECG continuously or come and go, or they may not show at all. Having a fever can sometimes unmask your ECG changes. In some cases, changes on the ECG may only be seen if the ECG leads that are normally placed over the middle of the chest (known as V1 and V2) are placed higher up on the chest wall (known as the high V1 and V2 leads).

If your ECG appears normal, a provocation test can be used to make the ECG changes associated with Brugada syndrome visible (see page 32). During the test, you'll receive an injection of a small amount of an anti-arrhythmic medicine while having an ECG. The medicines most commonly used for this are ajmaline and flecainide. However, ECG changes may still not be seen and you may need to have further tests.

Genetic testing is not very useful for diagnosing Brugada syndrome, because gene mutations are found in only a small proportion of people known to have the syndrome.

How is Brugada syndrome treated?

There is a risk of sudden death for people with Brugada syndrome, which is greatest in adult males and most often happens during sleep or when resting. It's therefore common practice for people at high risk of sudden death to have an ICD fitted. For more information on ICDs, see page 19. Medication to treat Brugada syndrome may be possible in the future, thanks to promising research on two drugs, quinidine and hydroquinidine. However, these drugs are not licensed for use in the UK.

If you have an abnormal ECG but don't have any symptoms, it can be very difficult to determine your risk of sudden death and decide what treatment you should have. An EPS (electrophysiological study) may help your doctors decide whether you need an ICD or not. Research suggests that people who have a normal ECG and no symptoms should be safe without having any treatment. It is unusual for children to be at high risk.

If you're a carrier and you get a fever or high temperature, you should take paracetamol or ibuprofen to help lower it. This is because having a fever seems to increase your risk of developing an arrhythmia. If the fever persists you may need further treatment and close monitoring in hospital until it settles.

CATECHOLAMINERGIC POLYMORPHIC VENTRICULAR TACHYCARDIA (CPVT)

CPVT is a rare condition which causes a particular type of arrhythmia – known as ventricular tachycardia (see page 10). It is found mainly in children and young people, and has been associated with gene mutations in two genes. These genes make proteins known as:

- the human ryanodine receptor (a calcium ion channel)
- calsequestrin (a protein that interacts with the channel).

These proteins help to regulate the level of calcium inside your cells. If they don't work correctly, the level of calcium inside your cells becomes too high, resulting in ventricular tachycardia.

What are the symptoms of CPVT?

Some people with CPVT have no symptoms at all. Others may have palpitations or blackouts. In some cases, sudden death may occur when the person is exerting themselves or suffering emotional stress.

The condition can affect children and seems to cause more blackouts in males than in females.

How is CPVT diagnosed?

If you experience symptoms, your doctor will refer you to a specialist who will do an exercise test and possibly an adrenaline test. These tests use an ECG that records your heart's electrical rhythm whilst you are exercising or receiving a slow adrenaline injection (see provocation tests on page 32).

Genetic testing is also useful if a member of your family has been found to carry a gene mutation and is showing the signs of the condition. This can identify members of the same family that carry the same gene mutation and are at risk of developing CPVT.

How is CPVT treated?

Your doctor will advise you to take beta-blockers (a type of medicine) and to restrict the amount of exercise you do. This combination greatly improves the outlook for people with CPVT. Sometimes another medicine called flecainide is useful if beta-blockers cannot control your arrhythmia.

If you're at high risk of sudden death, you may need to have an ICD fitted (for more on ICDs, see page 19). You may also be considered for surgery to disrupt the nerves that release adrenaline and related chemicals into your heart. This is known as cervical sympathectomy or cardiac denervation. It involves operating on the left side of the neck and blocking or removing the nerves.

PROGRESSIVE CARDIAC CONDUCTION DEFECT (PCCD)

PCCD – also known as Lev-Lenègre's syndrome - is a rare condition. In people with PCCD, the heart's electrical impulses pass through the heart very slowly and over time this can lead to heart block. Heart block is a failure of the heart's electrical impulses to conduct properly from the top chambers – the atria – to the bottom chambers – the ventricles. The severity of the condition and its associated risk can vary.

PCCD can also cause other types of arrhythmias, including:

- slow heart rhythms (bradycardias)
- fast heart rhythms (tachycardias).

In some people, PCCD has been associated with sodium channel mutations that cause changes in ion channel behaviour similar to those found in people with Brugada syndrome (see the diagram on page 21).

What are the symptoms of PCCD?

Some people with PCCD have no symptoms at all. Others may have episodes of dizziness or blackouts, and sudden death may also occur.

How is PCCD diagnosed?

Arrhythmias characteristic of PCCD may be detected either on a standard ECG or with 24-hour Holter monitoring. An electrophysiological study (EPS) may also help your doctor make a diagnosis. (We describe all these tests on pages 25-34.)

If a sodium channel mutation is identified in affected members of a family, genetic testing may also be used to find the same gene mutation in other close blood relatives.

How is PCCD treated?

If you have PCCD, you will need to have a pacemaker fitted in order to stop your heart rate from dropping too low. However, this does not prevent your heart from beating too quickly, so you may also need to take anti-arrhythmic medicines. Some people may need to have an ICD fitted. (For more information on pacemakers and ICDs, see page 19.) Medication alone does not appear to help.

SHORT QT SYNDROME (SQTS)

This is a very rare condition where the QT interval is shorter than normal (see page 14 for information on the QT interval). SQTS may cause dangerous arrhythmias and even sudden death. As in LQTS, potassium channels are affected, but with SQTS too much potassium is allowed to flow out of the cells. If you have SQTS, your doctor may prescribe you the anti-arrhythmic medicine quinidine to treat your condition. Some people may also need to have an ICD fitted. For more on ICDs, see page 19.

FAMILIAL ATRIAL FIBRILLATION

Atrial fibrillation is the most common type of arrhythmia in the general population. In a small number of people, atrial fibrillation is inherited and happens at a much younger age than usual. This is called familial atrial fibrillation. In people with familial atrial fibrillation, gene mutations can be found in:

- potassium ion channel genes that can cause too much potassium to flow out of the cells
- sodium channel genes that can reduce the flow of sodium into the cells.

For more information on atrial fibrillation, see the BHF booklet *Atrial fibrillation*.

TESTING AND YOUR FAMILY

I've got a great set of friends

It helps to have someone to talk to

My condition won't stop me

I live with an inherited heart condition



KEVIN'S STORY

The first sign of my heart condition was when I collapsed. I'd been having headaches and had a high temperature, so I went to see my doctor. I think I was in the waiting room when I blacked out, but I woke up in the back of an ambulance. I had an ECG test and was kept in hospital overnight for monitoring before being sent home.

A short time later, I was asked to make an appointment with the hospital cardiac team.

The cardiologist asked me a lot of questions, especially about my blackouts. They told me that my ECG test showed that I had a genetic condition called Brugada syndrome.

I felt like my world had been blown apart and for the first year, Brugada syndrome dominated my life. But I got a lot of support from my family and friends and I became stronger. I don't think about my condition nearly as much now, and I'm still moving forward.

IMPLICATIONS OF A DIAGNOSIS OF AN INHERITED ABNORMAL HEART RHYTHM FOR A FAMILY

If you're a close blood relative of a person who has been diagnosed with an ion channelopathy, it's highly recommended that you have an assessment at a specialist clinic for inherited heart conditions to find out if you have inherited the same medical condition. On pages 29-34 we describe all the tests that you may be offered as part of the assessment.

If you're deciding whether to go for an assessment or not and need more information, or if you don't know where to go for the assessment, call the **BHF Genetic Information Service** on **0300 456 8383**.

What if you're diagnosed with an inherited heart condition?

If you've been diagnosed with one of the conditions described in this booklet, you should have regular follow-ups – whether you decide to receive treatment or not – unless your doctor believes

that you are at very low risk. The people at highest risk are those who have symptoms, or have already had a cardiac arrest, or have significant abnormalities on their ECG.

What if you show no signs of an inherited heart condition?

In families where someone has been diagnosed with an ion channelopathy and the remaining family members are tested, about one in every four families show no sign of an inherited heart condition. This can be due to two reasons:

The person diagnosed may not have inherited any abnormality from their parents. Either that person was the first to develop a gene mutation in the family (and therefore their children are the only relatives who are at risk),

or

Some family members may have a gene mutation but show no signs of any disease. It's impossible to give 100% reassurance that a relative is not a carrier, except in cases where genetic testing has shown that a specific gene mutation causing a condition is not shared by other family members. However, people who don't have any symptoms or signs are at low risk of sudden death.

ECG changes can become more obvious with age in children (especially during puberty) and young adults. Unless a genetic test has ruled out the possibility of having an inherited heart condition, it's important that children and young people are tested again when they're older to ensure they're not affected.

If you develop new symptoms (for example blackouts or seizures) this could be a sign of an underlying condition, even if it has not been detected before. You'll need to be re-checked immediately at your nearest accident and emergency department and must let your GP and cardiologist know so that urgent follow-up can be arranged.

If a recognised gene mutation is found in a member of your family and you don't have the same gene mutation, you can be assured that you are not affected by the same condition.

ASSESSMENT AT A CLINIC FOR INHERITED HEART CONDITIONS

Below we describe what happens when someone has an assessment at a clinic for inherited heart conditions.

Medical history

It's vital that a clear medical history of you and your family is established. Your doctor will want to know:

- if any medical conditions affect you or your family, including your parents and possibly your grandparents
- if you've ever had symptoms such as blackouts, palpitations or seizures
- if there have been any sudden deaths in your family, including any cot deaths.

Medical examination and tests

Many people with an ion channelopathy don't have any visible physical signs of their condition. In a medical examination, your doctor will:

- listen to your heart and lungs with a stethoscope
- take your blood pressure
- do an ECG to check your heart's rhythm and rate.

Your doctor will also suggest that you have some of the tests we describe below.

NON-INVASIVE Tests marked with this symbol are 'non-invasive', which means that the test does not involve penetrating the skin or body.

ECG **NON-INVASIVE****Also called an electrocardiogram**

This is the most basic test. Small sticky patches called electrodes are put onto your chest, and sometimes your arms and legs. These are connected by wires to an ECG recording machine. This picks up the electrical activity that makes your heart beat. If the first ECG does not show any abnormalities it can be repeated later.

Signal-averaged ECG **NON-INVASIVE**

This is an ECG that adds together the electrical readings from at least 250 heartbeats so that any very subtle variations can be seen – for example, if the electrical impulses in the heart are being conducted more slowly. It is useful for diagnosing Brugada syndrome.

Exercise test **NON-INVASIVE****Also called a stress test**

This test is the same as the ECG described above, but is recorded before, during and after a period of time spent exercising on a treadmill or an exercise bike. This allows the doctor to examine any changes in the electrical patterns that occur with exercise, and analyse any abnormalities. This test is particularly useful in detecting some of the features that are characteristic of LQTS or CPVT.

Cardiopulmonary exercise**test** **NON-INVASIVE**

This test analyses the efficiency of your heart muscle by measuring the amounts of oxygen your body uses during exercise. You will be asked to breathe into special equipment while you're exercising. If the efficiency of your heart is low, this may suggest that you have cardiomyopathy (a disease of the heart muscle).

Holter monitoring **NON-INVASIVE****Also called ambulatory ECG**

This test involves using a small digital device that you wear on a belt round your waist. Four or six ECG leads from the device are taped to your chest. The device records the electrical activity of your heart for 24 to 48 hours, or for up to seven days. The doctor can then analyse the electrical activity and rhythm of your heart to find out if you have any arrhythmias, for example, the arrhythmias typical of LQTS and CPVT.

Cardiomemo and cardiac event recorders **NON-INVASIVE**

These are more sophisticated versions of the 24-hour Holter monitoring test described above. Whenever you have an episode of symptoms, you can activate the device to record your heart's rhythm. The advantage of the cardiomemo is that it doesn't have any leads, so you can just place it on your chest when you get symptoms.

Implantable loop recorder**Also called an ILR**

When it's difficult to assess or record a symptom because it only happens infrequently – as with blackouts – an implantable loop recorder (or ILR for short) can be used. The device, which is the size of a packet of chewing gum or smaller, is placed under the skin at your left shoulder. You'll need to go into hospital as a day case to have this done. A small cut about 2cm long (just less than one inch) is made and the device is inserted. The device monitors your heart's rhythm and can record any abnormal events that it's programmed to detect. If anything happens, you just place a special small box on the surface of your skin over the ILR. You can then activate the device by pressing a button on the box, which makes the ILR record the preceding few minutes of your heart's activity. The device can then be 'interrogated' by a computer at the hospital and your doctor can examine the recording. The device can remain in place for up to three years if necessary.

Provocation tests**Also called ajmaline, flecainide or adrenaline tests**

You may be asked to have an ajmaline or flecainide test if your doctor suspects Brugada syndrome or an adrenaline test if your doctor suspects CPVT or LQTS. During these tests, you'll have an ECG whilst being given an injection of ajmaline or flecainide (anti-arrhythmic medicines) or adrenaline. These medicines can unmask ECG changes associated with some ion channelopathies.

A fine plastic tube is inserted into a vein in your arm. The medicine is injected through the tube for about five to ten minutes and you will be monitored for 20 minutes or a few hours afterwards, depending on the medicine used.

However, there is a risk, as one in every 200 Brugada syndrome carriers or their immediate blood relatives have a potentially life-threatening arrhythmia during the injection. The test is therefore always performed with appropriate facilities to protect patients from this risk. Ajmaline is preferable to flecainide as it remains in the body for a shorter period of time.

Echocardiogram NON-INVASIVE**Also called an echo**

This test uses ultrasound waves to look at the structures of your heart. It's useful for people whose ECG shows changes that could be caused by a heart condition that has damaged your heart – for example, a previous heart attack that you may not have even been aware of. An echocardiogram can also detect other types of structural heart disease such as cardiomyopathy and mitral valve prolapse.

Cardiac magnetic resonance scan**Also called an MRI scan**

This is a special kind of scan used to examine the structure of your heart and the nature of its muscle. At the start of the test you may need to have a special dye (contrast medium) injected into a vein in your arm. A magnetic resonance scanner will then create intense fluctuating magnetic fields around your body while you're inside the scanner. This generates the signals that make up the pictures produced. It may be useful for detecting the presence of fat and scarring in the heart muscle that is associated with cardiomyopathies.

Coronary angiogram and electrophysiological study (EPS)

Depending on the results of the tests described above, your doctor may suggest that you have other tests such as a coronary angiogram or an electrophysiological study (EPS).

A **coronary angiogram** involves having a local anaesthetic in your wrist or groin, where a catheter (a thin flexible tube) will be passed into your artery. Using an X-ray machine, the catheter will be directed through your blood vessels and into your heart. A special dye will then be passed through the catheter and a series of X-rays taken. This can show up any narrowed areas or blockages in your arteries that could be caused by coronary heart disease, which can sometimes produce similar ECG changes as those seen in Brugada syndrome or LQTS.

An **EPS (electrophysiological study)** uses the same technique to place electrical leads inside your heart. These leads analyse your heart's electrical activity and can help trigger an arrhythmia. This test may be useful in diagnosing PCCD, and for deciding what treatment to give people with Brugada syndrome.

Tilt-table test

If you get episodes of dizziness or blackouts, your doctor may recommend that you have a tilt-table test to find out if this is caused by:

- common conditions – such as vasovagal syncope (see page 50) – which tend to affect young women and girls but have a very low risk of causing sudden death
- one of the ion channelopathies mentioned in this booklet.

This test can bring on your symptoms under controlled conditions to help your doctor make a diagnosis.

In this test, a fine plastic tube is inserted into a vein at the front of your elbow. This is in case your doctor needs to give you any medicines during the test. You will lie flat on a special table, while your blood pressure and ECG are monitored. The head of the table is then raised to an angle of 60 to 90 degrees and monitoring is continued. If nothing happens, a medicine called GTN is sprayed under your tongue. This will make your heart rate a little faster and your blood pressure a little lower to help reproduce your symptoms. You'll continue to be monitored and after another 10 to 15 minutes, the table will be returned to the flat position. The whole test takes around 45 minutes.

If your blood pressure falls at the same time as you suffer your usual symptoms, this means that you have vasovagal syncope or a related condition.

Genetic testing

In most of the ion channelopathies, mutations of specific genes have been detected and are thought to cause a specific disease. Identifying one of these gene mutations in someone who has been diagnosed with an arrhythmia can help diagnose an ion channelopathy. However, as we don't know all of the genes and mutations involved in each condition, genetic testing does not always help. For example, only seven in every ten people known to have LQTS have mutations of identified genes.

EVERYDAY LIFE

SHANNON'S STORY

I was diagnosed with CPVT two months before my 15th birthday.

I'd been having seizures since I was nine and was told I had epilepsy, but my symptoms started to get worse. I went for some tests and had a resting ECG and a 24-hour ECG, but they didn't show anything unusual. It was only when I had an exercise test that the problem with my heart was picked up.

I was given information about CPVT and was told to restrict exercise. Giving up sport was one of the hardest things for

me. I used to be a competitive gymnast and dancer, and I loved all sports at school from netball to rugby. Overnight all that was gone.

But I'm not alone. My whole family was tested to see if they had CPVT and my dad tested positive. He's basically on the same treatment plan as me and takes the same medication.

Having a heart condition is always in the back of my mind – but I'm in control of my condition now. I'm a teenager, not a heart condition.

I'm training to be a children's nurse

I want to help people like me

I'm looking towards my future

I live with an inherited heart condition



GENERAL LIFESTYLE ADVICE

Exercise

For many people with an arrhythmia, exercise can trigger your symptoms. Competitive sports and high intensity activities will often need to be avoided, but normal exercise regimes are usually recommended as part of a healthy lifestyle. Getting individual exercise advice that is specific to you and your condition is important, especially for young people that may need help in understanding their physical limitations and how to engage in safe exercise.

While you should avoid high intensity activities, you should also be conscious of any symptoms during rest and at night, as deaths due to ion channelopathies such as Brugada syndrome and sodium channel LQTS can also occur at night and during sleep. If you have one of these conditions, your doctor can advise you what to do if anything happens, and may encourage you to buy a home defibrillator. (If someone has a cardiac arrest, this machine may be able to return the heart to a normal rhythm by delivering an electrical shock through the chest wall.)

Vomiting and diarrhoea

In people with long QT syndrome or Brugada syndrome, a drop in the levels of potassium in the blood can cause a serious deterioration in the person's condition. Any prolonged vomiting or diarrhoea (lasting more than a day) can cause a significant loss of potassium in the blood – a condition called hypokalaemia. If this happens, it's important that you get rehydrated, using a salt and sugar preparation such as Dioralyte. (You can buy this at your local pharmacy, or you may be able to get a prescription for it from your doctor). If vomiting prevents you taking this, you should go to hospital to receive appropriate fluids through a drip. It's best to get your GP to arrange this, but if this is not possible you should go to your nearest accident and emergency department.

MEDICINES AND DRUGS TO AVOID

Anyone with a condition affecting the heart that can cause sudden death needs to take extra care with medicines. All medicines, both those prescribed by your doctor and any you buy over the counter, must be checked by your GP or cardiologist as some can increase the risk of life-threatening heart rhythms.

Medicines which people with long QT syndrome should avoid

For people with long QT syndrome, there are specific medicines that can have a serious effect by further prolonging the QT interval. We give a list of these medicines below. This list includes medicines that can stimulate and irritate the heart. This list may not be complete so, before taking any new medicine, check with your GP or cardiologist that they're suitable for you.

* = Medicines which have been unlicensed, withdrawn or suspended in the UK market.

Drug group	Avoid completely	Close monitoring and professional supervision required if medicine is absolutely necessary
Anti-anginals and vasodilators	bepidil* lidoflazine* prenylamine* terodiline*	ardenafil
Anti-arrhythmics Class I	ajmaline* dihydroquinidine* disopyramide procainamide quinidine*	cibenzoline* flecainide mexiletine pirmenol* propafenone

Drug group	Avoid completely	Close monitoring and professional supervision required if medicine is absolutely necessary
Anti-arrhythmics Class III	almokalant* amiodarone azimilide* dofetilide* dronedarone* d-sotalol* ersentilide* ibutilide* nifekalant* sematilide* sotalol terikalant*	
Anti-cancer	arsenic trioxide	geldanamycin* octreotide sunitib tacrolimus tamoxifen
Anti-histamines	astemizole* terfenadine*	diphenhydramine ebastine*
Anti-hypertensives	indapamide	isradipine moexipril/ hydrochlorthiazide nicardipine
Anti-microbials Macrolides	clarithromycin erythromycin spiramycin	azithromycin roxithromycin* telithromycin
Fluoroquinolones	moxifloxacin sparfloxacin*	gatifloxacin* gemifloxacin* grepafloxacin* levofloxacin ofloxacin

Drug group	Avoid completely	Close monitoring and professional supervision required if medicine is absolutely necessary
Anti-fungals	chloroquine halofantrine* pentamidine	fluconazole itraconazole ketoconazole voriconazole
Anti-malarials	chloroquine halofantrine* pentamidine	quinine
Others		amantadine cotrimoxazole foscarnet trimethoprim sulfa
Psychiatric Phenothiazines	chlorpromazine thioridazine*	fluphenazine prochlorperazine trifluoperazine
Serotonin reuptake inhibitors		citalopram fluoxetine paroxetine sertraline venlafaxine zimidine*
Tricyclic anti-depressants		amitriptyline amoxapine* clomipramine desipramine* doxepin imipramine nortriptyline protriptyline* trazodone trimipramine

Drug group	Avoid completely	Close monitoring and professional supervision required if medicine is absolutely necessary
Others	droperidol* haloperidol sertindole	clozapine lithium maprotiline mesoridazine pimozide quetiapine risperidone ziprasidone
Serotonin agonists and antagonists	cisapride* dolasetron ketanserin*	granisetron ondansetron
Other medicines to avoid	domperidone levomethadyl* methadone probutol	alfuzosin amantadine chloral hydrate clobutinol* felbamate* fosphenytoin galantamine organophosphates* perflutren lipid microspheres (echocardiographic contrast) solifenacin tizanidine vasopressin

Stimulants

Some cold remedies contain some of the following medicines and drugs, which should also be avoided, so it's important always to check the label:

- adrenaline (epinephrine)
- cocaine
- dobutamine
- dopamine
- ephedrine
- fenfluramine
- isoprenaline (isoproterenol)
- metaproterenol
- midodrine
- norepinephrine (noradrenaline)
- phentermine
- phenylpropanolamine
- pseudoephedrine
- ritodrine
- salbutamol (albuterol)
- salmeterol
- sibutramine
- terbutaline.

For the latest information on medicines and drugs for people with LQTS to avoid, visit www.qt drugs.org

Medicines which people with Brugada syndrome should avoid

In people with Brugada syndrome, a number of medicines may make the condition worse. For example, certain anti-arrhythmics, all beta-blockers and some anti-depressants are known to increase the risk of symptoms.

Below is a list of the medicines that people with Brugada syndrome should avoid. Always check new medicine with your GP or cardiologist before you take it, as this list cannot be guaranteed to be complete.

Drug group	Medicines to avoid
Alpha adrenergic agonists	methoxamine noradrenaline
Anti-arrhythmics Class 1	All to be avoided including: ajmaline cibenzoline disopyramide flecainide pilsicainide procainamide propafenone
Anti-depressants Tetracyclic anti-depressants	maprotiline
Tricyclic anti-depressants	All to be avoided, including: amitriptyline clomipramine desipramine nortriptyline
Beta-blockers	All to be avoided, especially propranolol
Calcium channel blockers	diltiazem nifedipine verapamil

Drug group	Medicines to avoid
Ergot alkaloids	ergonovine
First-generation anti-histamines	dimenhydrinate
Local anaesthetics	bupivacaine
Nitrates	isosorbide dinitrate nitroglycerine
Opioid analgesics	propoxyphene
Parasympathetic agonists	acetylcholine
Phenothiazine	cyamemazine perphenazine
Potassium channel activators	pinacidil
Selective serotonin reuptake inhibitors	fluoxetine
Other medicines and drugs to avoid	alcohol intoxication cocaine lithium propofol

For the latest information on medicines and drugs for people with Brugada syndrome to avoid, visit www.brugadadrugs.org

D**Defibrillator**

A device that can be used if a person has a cardiac arrest. It may be able to return the heart to a normal rhythm by delivering an electrical 'shock' through the chest wall.

DNA

The genetic code from which proteins 'the building blocks of life' are made. We all receive a copy of half of each of our parents' DNA when the egg and sperm meet to conceive a new human being.

E**Ectopic beat**

An early (premature) or extra heartbeat which can occur, disrupting your heart's normal rhythm. The majority of people who have ectopic beats are unaware of them.

G**Gene**

A segment of DNA responsible for the production of a specific substance such as a protein, which in turn is essential for a particular characteristic or function in your body.

H**Heart block**

When the electrical impulses sent by the atria to the ventricles are delayed or are blocked.

Holter monitoring

A 24-hour recording of an electrocardiogram (ECG).

I**Implantable cardioverter defibrillator (ICD)**

A metal electronic device similar to a pacemaker. It is implanted under the chest wall muscle below your left shoulder. It can regulate the rhythm of your heartbeat and, if a dangerous arrhythmia occurs, it can deliver an electrical shock to your heart to restore the normal heart rhythm.

Ion

A chemical substance (such as sodium or potassium) that carries an electrical charge and forms the basis of the movement of electricity through your heart muscle.

Ion channel

The route that ions take in and out of your heart muscle cells to allow movement of electricity.

Ion channelopathy

A condition caused when ion channels in the cells of your heart do not work properly. They can affect the electrical functioning of your heart and may be life-threatening if not treated.

M**Mitral valve**

The valve on the left side of your heart, between the atrium and ventricle.

Mitral valve prolapse

When a mitral valve is floppy and leaks.

Mutation

A mutation or 'mistake' in the DNA code that causes its eventual product (usually a protein) to function abnormally, which in turn is responsible for a disease.

P**Pacemaker**

An electronic device which takes over the role of your heart's natural pacemaker and regulates the rhythm of your heartbeat. It is usually implanted just under your left collarbone.

Q**QT interval**

A lengthening of the time period of a particular part of your heartbeat cycle, as seen on an ECG.

S**Sino-atrial node**

The heart's natural pacemaker.

Sudden Arrhythmic Death Syndrome (SADS)

A death is described as sudden when it occurs unexpectedly, spontaneously and/or even dramatically. Some deaths will be unwitnessed or occur during sleep, while others occur during or immediately after exercise (exercise-related sudden death).

Syndrome

A collection of medical features of an illness that make it a distinctive condition.

T**Tachycardia**

A fast heart rate.

V**Vasovagal syncope**

A disorder of the nerves supplying the blood vessels and heart that can result in dizzy episodes, blackouts and fainting. This is due to a sudden drop in blood pressure and heart rate, which means less blood is able to reach the brain. It is usually harmless, although blackouts may place the person in dangerous situations. Treatment can involve medicines and/or a pacemaker.

Ventricles

The two bottom chambers of your heart.

Ventricular

From, or belonging to, the ventricle.

MORE INFORMATION

For information on your nearest clinic for inherited heart conditions

BHF Genetic Information Service (GIS)

Greater London House
180 Hampstead Road
London NW1 7AW

Phone: 0300 456 8383

Website: bhf.org.uk

The BHF GIS can provide you with information and support if someone in your family has been diagnosed with, or has died from, a suspected inherited heart condition. This includes supporting you and your family by helping you get an expert assessment in a specialist clinic that deals with inherited heart conditions.

To find out more about our work on inherited heart conditions and the research we fund, visit bhf.org.uk/research

BHF publications

The following booklets will give you more information on making changes to your lifestyle and reducing your risk of diseases of the heart and circulation.

Implantable cardioverter

defibrillators (ICDs) (HIS19)

ICD – your quick guide (G967)

Living with a pacemaker(HIS15)

Pacemaker – your quick guide (G968)

Losing someone to heart disease (G419)

Sudden arrhythmic death syndrome (M111A)

Heart rhythms (HIS14)

Medicines for my heart (HIS17)

Tests for heart conditions (HIS9)

Atrial fibrillation (HIS24)

Atrial fibrillation – your quick guide (G963)

To order any of these booklets:

- call the BHF Orderline on 0300 200 2222, or
- email orderline@bhf.org.uk, or
- visit bhf.org.uk/publications

Our resources and services are free of charge, but we rely on donations to continue our vital work. If you'd like to make a donation, please call our donation hotline on **0300 330 3322** or visit our website at bhf.org.uk/donate

FOR MORE SUPPORT ON COPING AS A FAMILY WITH AN INHERITED ABNORMAL HEART RHYTHM

Cardiac Risk in the Young – CRY

1140B The Axis Centre
Cleeve Road
Leatherhead KT22 7RD

Phone: 01737 363222

Email: cry@c-r-y.org.uk

Websites:

www.c-r-y.org.uk
www.sads.org.uk

CRY offers help, support and counselling to families where there has been a sudden cardiac death of an apparently fit and healthy young person.

Cardiac Risk in the Young *myheart* Network

CRY's *myheart* network offers help, support and information to young people who are coping with a diagnosis of a heart condition.

Website: www.myheart.org.uk

Contact details as above.

INDEX

A

activity 20, 23, 38
Andersen's syndrome 16, 17
angiogram 33
assessment for inherited cardiac conditions 08, 28, 29
AV node 06, 07

B

Brugada syndrome 20, 21, 22, 27, 44

C

calcium channel 14, 16, 22
cardiac event recorder 31
cardiac magnetic resonance scan 32
cardiomemo 31
cardiomyopathy 30, 32
cardiopulmonary test 30
catecholaminergic polymorphic ventricular tachycardia 22, 23, 36
channelopathy 08, 09, 28
clinic for inherited cardiac conditions 28, 29, 51
coronary angiogram 33
cot death 29
CPVT 22, 23, 36

D

defibrillator 18, 20, 38
diagnosis 28

E

ECG 30
echocardiogram 32
ectopic beat 17
electrophysiological study 33
EPS 33
exercise 20, 23, 38
exercise test 30

F

Familial atrial fibrillation 24
family 08, 09, 25, 28, 29

G

genetic testing 28, 29, 34

H

hypokalaemia 38

I

ICD 18, 19, 20
ILR 31
implantable cardioverter defibrillator 18, 19, 20
implantable loop recorder 31
ion channel 08, 09

J

Jervell and Lange-Nielsen (JLN) syndrome 16, 17

L

lifestyle advice 38
long QT syndrome 12, 14-20, 38, 39
LQTS 12, 14-20, 38, 39

M

magnetic resonance scan 32
medicines 18, 39, 44
medicines to avoid 39, 44
mitral valve prolapse 32
MRI scan 32
mutation 09, 28, 29, 34

N

normal heart 06, 07

P

pacemaker 18, 19
PCCD 21, 23, 24
potassium channel 09, 14, 15, 16, 21
private mutations 18
Progressive cardiac conduction defect 21, 23, 24
provocation test 32

Q

QT interval 14, 17, 39

R

Romano-Ward syndrome 16, 17

S

SA node [06, 07](#)

SADS [10, 52](#)

sodium channel [15, 21](#)

structural heart disease [32](#)

Sudden Arrhythmic Death Syndrome [10, 52](#)

surgery [20, 23, 52](#)

symptoms [17, 21, 23, 24, 28, 29](#)

T

tilt-table test [33](#)

Timothy syndrome [16, 17](#)

treatment [08, 18, 22, 23, 24, 28](#)

About the British Heart Foundation

The British Heart Foundation is the nation's heart charity, saving lives through pioneering research, patient care and vital information.

What you can do for us

We rely on donations to continue our vital work. If you would like to make a donation to the British Heart Foundation, please call our donation hotline on **0300 330 3322**, visit **bhf.org.uk/donate**, or post it to us at the address below. Thank you for supporting our fight.

There are lots of other ways that you can help us. Go online at **bhf.org.uk** to find out how.

Have your say

We would welcome your comments to help us produce the best information for you. Why not let us know what you think? Contact us through our website at **bhf.org.uk/contact** or write to us at the address below.

British Heart Foundation

Greater London House
180 Hampstead Road
London NW1 7AW
bhf.org.uk

Heart Helpline

0300 330 3311

(a similar cost to 01 and 02 numbers)

For information and support on anything heart-related.

Genetic Information Service

0300 456 8383

(a similar cost to 01 and 02 numbers)

For information and support on inherited heart conditions.

About Cardiac Risk in the Young

Cardiac Risk in the Young is a charity that:

- Aims to reduce the frequency of young sudden cardiac death by working with cardiologists and family doctors to establish good practice and appropriate screening facilities to promote and protect the cardiac health of our young.
- Offers bereavement support to those who have suffered a loss, through a network of affected families and counselling.
- Offers support to those young people diagnosed with cardiac conditions.
- Publishes and distributes medical information written by leading cardiologists for the general public.
- Promotes and develops heart screening programmes and funds medical research.
- Funds fast track services at the CRY Centres for Sports Cardiology, Cardiac Pathology and Inherited Cardiovascular Conditions at leading London hospitals.

Cardiac Risk in the Young

1140B The Axis Centre
Cleeve Road
Leatherhead KT22 7RD
www.c-r-y.org.uk



**British Heart
Foundation**



At the British Heart Foundation, we've pioneered research that's transformed the lives of people living with heart and circulatory conditions. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

Cardiac Risk in the Young supports young people diagnosed with potentially life-threatening cardiac conditions. We promote and develop heart screening programmes and fund medical research to help reduce the risk of young sudden death.

But so many people still need our help.

Join the British Heart Foundation and Cardiac Risk in the Young in our fight for every heartbeat in the UK. Every pound raised helps to make a difference to people's lives.