

HEART SCREENING **for 14-35 year olds**

What you need to know



Who should read this leaflet?

- Anyone between the ages of 14-35.
- Anyone exhibiting symptoms as listed on page 5.
- Anyone with a family history of conditions.
- Parents.
- Teachers.
- Sports coaches.
- Sports governing bodies.
- School nurses.

What is the aim of this leaflet?

This leaflet provides information about cardiac screening. It aims to help you make an informed choice about whether to have your heart tested.

What is the purpose of cardiac screening?

Sometimes an individual may have a cardiac abnormality without having any symptoms. Screening with an ECG is aimed at identifying people with conditions such as cardiomyopathies or electrical faults of the heart.

Is cardiac screening important?

- The European Society of Cardiology (ESC, 2005) and International Olympic Committee (IOC, 2009) recommend cardiac screening with an ECG for any young person taking part in competitive sport.
- In countries such as Italy screening participants in representative sports is mandatory. (Corrado *et al*, 1998)
- In some professions cardiac testing is also mandatory. FIFA and UEFA regulations mean that from August 2008, every player in the first squad at a football club that participates in International competitions must have a minimum of one electrocardiogram (ECG) test and one echocardiogram (ECHO) test in their personal medical records. The Premier League also now undertakes bi-annual cardiac testing for all professional players.
- There is a simple way to diagnose most cardiac abnormalities.
- Although government statistics are not available, cardiac experts believe that at least 12 young people die each week in the UK from undiagnosed cardiac conditions (Papadakis *et al.*, 2009).
- About 1 in 300 people have a potentially serious condition that will require lifestyle modification, treatment or surgery (Wilson *et al.*, 2007).

Is screening just for athletes?

At CRY, we offer all young individuals (14-35) the opportunity to be screened. The screening programme is not just for people who play sport.

Cardiac incidents can take place at any time. They are not limited to high level sport, they may occur just jogging across the park or when asleep at night.

So any young individual may attend a screening, whether they are top sportsmen or perform minimal exercise.

What is the procedure at a CRY screening?

Prior to your arrival, you will need to fill in a personal and family history medical questionnaire and sign a consent form. A screening administrator will measure your height and your weight.

The basic test is an electrocardiogram (ECG) which is a simple, non-invasive and painless test that examines the electrical activity within your heart. The ECG involves lying down quietly and it takes 5-10 minutes only. Small stickers are placed at strategic points on your chest, arms and legs. Flexible leads (known as electrodes) that extend from the ECG machine are then attached to these stickers. The electrical rhythm of your heart is recorded and printed out. This part of the process only takes 2-3 minutes to perform.

After the ECG has taken place it is reviewed by a doctor who is an expert in these conditions. The doctor reviews each individual in conjunction with the personal and family history questionnaire.

About 5% - 10% of individuals will require an additional test following the ECG, which is usually an echocardiogram (ECHO). An ECHO is very similar to the ultrasound scan that is used for a pregnant woman to check the health of her baby. In cardiac screening, an ECHO will measure dimensions of the heart and the flow of blood in and out of the heart.



Does it hurt?

Both the ECG and ECHO are painless, non-invasive procedures.

Do I need to prepare anything prior to my appointment?

You should rest for at least 30 minutes prior to your ECG appointment.

If you have been sent a personal and family history medical questionnaire and consent form you can fill this out to bring it with you.

Young people wishing to be tested, who are under the age of 16, must seek written permission from a parent or guardian.



Do I need someone with me?

If you wish, a friend or chaperone can accompany you during the procedures. We strongly recommend that a parent or guardian is present when the person being tested is under 16.

Do I have to undress?

To conduct the tests, the physiologist will have to access your bare chest. If you are female you will be required to either remove or loosen your bra. Female physiologists will be used where possible.

Is there always a female present?

There is always at least one female ECG physiologist present.

When do I get my results and what do they mean?

You will be notified on the day by our doctor if you have a normal ECG and ECHO.

In the majority of cases, individuals will receive a letter stating that no abnormality has been identified. However, sometimes individuals will be invited to attend an appropriate hospital for further cardiac testing.

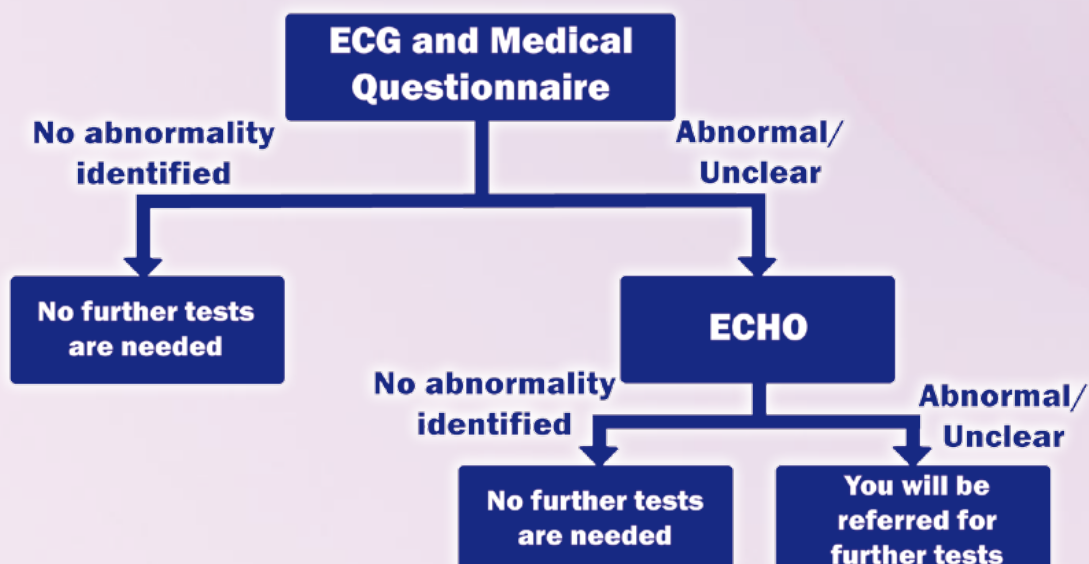
About 5% - 10% of individuals will require an ECHO on the day, but only 2% of individuals are usually referred for further tests. There are a number of reasons why an ECHO is felt to be of benefit. The ECG readings MAY indicate an athlete's heart (where the heart muscle is naturally enlarged due to lots of physical activity) or it may suggest a heart muscle problem (cardiomyopathy). In order to rule out a cardiac abnormality, a further testing may be required.

In the small percentage of cases where results appear abnormal, individuals will require follow up tests to further evaluate cardiac health. CRY aims to notify you (or your parents if you are under 16) and your GP within 4 working weeks of the screening.

What if there is an abnormality?

About 2% of people have abnormalities that need to be checked out. The majority of these are not a problem. About 1% of cases require ongoing monitoring; some conditions are not life-threatening but may require some minor lifestyle modification. Up to 1 in 300 people will have a potentially serious condition that will require ongoing lifestyle modification, treatment or surgery.

Additional tests, such as a Holter monitor (a 24 or 48 hour ECG) and/or exercise stress test may also be required. It is important to realise that a further review does not necessarily mean you have a cardiac condition. However, further information is required to give a full diagnostic evaluation.



What will happen if I am found to have a condition?

It would depend on the condition. Although most of the conditions are not 'curable' they are all treatable and treatments range from lifestyle adaptations to drug therapy or, in some cases, surgery.

How reliable is cardiac screening?

The majority of cardiac abnormalities that are most likely to affect young people will be identified. However, some conditions will not be identified. These will include coronary artery anomalies.

What symptoms should I look out for?

If, having been screened by CRY where no abnormality was identified, you develop symptoms or a first-degree blood relative is diagnosed as having an inherited cardiac condition, you should contact your GP for further evaluation. If the GP does not view it as urgent, CRY offers a further screening at the next available event.

Symptoms include:

- Chest pain during exertion
- Breathlessness
- Palpitations
- Dizziness
- Fainting

What happens to my results?

The information from the tests is strictly confidential and will not be disclosed to anyone other than yourself (or your guardian if you are younger than 16 years), your GP and others who are directly involved within your care, e.g. other consultant cardiologists.

CRY's screening programme is about identifying people at risk. However, it is also about building our understanding of these conditions. Every person we test will not only receive advice from a leading world expert in these cardiac conditions affecting young people but also they will make a real contribution to our understanding of these conditions in the future. The information from these tests will be held on a database at CRY, assuming consent has been given, and may be used anonymously for research purposes.

CRY's screening research programme is overseen by Professor Sanjay Sharma. Sanjay is Professor of Inherited Cardiovascular Disease and Sports Cardiology at St George's University of London, and Medical Director of the Virgin London Marathon. In 2008 he was voted, as the only British Representative, onto the European Association for Cardiovascular Prevention and Rehabilitation (EACPR) Sports Cardiology Section Nucleus, an elite committee tackling the complex issues of sports cardiology.



Do I need to be re-tested?

In the majority of individuals a one off screening will suffice in the context of no symptoms or family history. Further screenings may be recommended:

1. by the relevant sporting federation, in individuals who participate in high level, competitive sports
2. for individuals who develop new symptoms or a family history of an inherited cardiac disease
3. for young individuals, going through adolescence, whose ECG is considered to represent a juvenile pattern (i.e. pre-puberty ECG).

Points to consider

Before deciding whether or not you want to take part in the CRY cardiac screening programme, you may like to consider some of the benefits and disadvantages, and think about what is important to you.

- Undetected heart conditions affect about 1 in 300 people. Our tests are able to detect the majority of cardiac abnormalities most likely to affect young people.
- In the event that a cardiac abnormality is diagnosed you must be aware that this may affect certain mortgage applications, particular types of life insurance and it may also affect some careers.
- Cardiac screening is about probability, and decreasing your risk of suffering a sudden death. The ECG will significantly reduce your risks. This is why European Society of Cardiology and International Olympic Committee guidelines recommend having an ECG before participating in competitive sport.
- After initial screening the doctor may ask for further testing.
- A normal ECG does not predict cardiac health in the long-term and individuals who develop symptoms that cause concern should seek medical advice from their GP.
- After reading this you may decide not to have your heart screened. At CRY we believe what is most important is that you obtain all the information you need to make an informed decision.

Booking a screening:

CRY holds both public and private screenings and will test individuals from the age of 14 to 35. CRY holds regular screening clinics throughout the UK. There are also mobile screenings, family memorial fund screenings in local communities, school screenings and services for elite athletes.

Those people who require a follow up test (ECHO), due to having an abnormal ECG, will be able to have this test done on the same day. A doctor specialising in cardiac conditions that can affect young people will attend the screening event. In most cases, the doctor will discuss the result with the person on the day, but will also confirm this in writing within 4 weeks.

Public screenings:

All appointments can be booked online. Usually these events are fully funded, however sometimes there is a subsidised fee of £35. To see a list of dates and locations of upcoming screenings visit www.c-r-y.org.uk/ecg.htm

Private screenings:

CRY will test up to 120 people a day. If you are interested in organising a private screening for your group, school, club etc. please contact the CRY Screening Administrator on **01737 363 222**.

Information and support:

For more information on CRY or to watch a short film of David Walliams being tested, visit www.c-r-y.org.uk



If you have any questions about screening, visit www.testmyheart.org/QnA.aspx



Who to contact:

If you have further questions, go to www.testmyheart.org for frequently asked questions or call CRY on **01737 363 222**.

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Professor Sanjay Sharma,

Professor of Inherited Cardiovascular Disease and Sports Cardiology, St. George's Hospital, London

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Philips, a world leader in medical technologies, is working with CRY to support the pioneering subsidised heart testing the charity offers to all young people aged between 14 and 35.

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Mair Shepherd

What is CRY?

Cardiac Risk in the Young (CRY) is a national charity that raises awareness of potentially life-threatening cardiac abnormalities in young people and promotes screening.

Some of the sporting bodies that CRY carries out screening for include:

Premiership Football Clubs and Football League Clubs

Great Britain & Northern Ireland Olympic Athletes

England Rugby Union and Premiership Rugby Union Clubs

Great Britain Rugby League and Super League Clubs

Lawn Tennis Association

County Cricket Clubs

CRY has a comprehensive resource network for affected individuals and family members that includes counselling and personal advice. The charity offers support to families who have experienced the tragic death of a young individual due to a cardiac condition. CRY facilitates screening of all first-degree relatives of the deceased in highly specialised clinics, in an attempt to prevent further potentially avoidable tragedies.

CRY actively promotes research in the field of inherited cardiac diseases, sudden cardiac death, screening and sports cardiology in an attempt to advance our understanding of conditions predisposing to sudden cardiac death and prevent further tragedies. CRY sponsors competitive research grants for outstanding individuals who wish to specialise in this field and has contributed to numerous abstract presentations in national and international medical conferences as well as publications in distinguished journals. For further information visit www.c-r-y.org.uk/research.htm

If you would like to help support CRY, visit www.c-r-y.org.uk to see how you can help.

Further free copies of this leaflet are available from:

Cardiac Risk in the Young

Unit 7 Epsom Downs Metro Centre

Waterfield

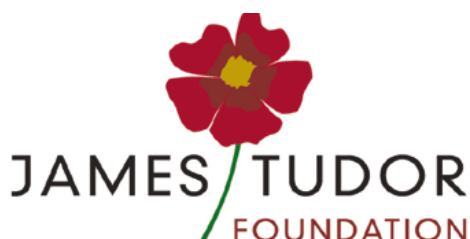
Tadworth

Surrey

KT20 5LR

They can also be downloaded from www.c-r-y.org.uk/ecg.htm

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www.c-r-y.org.uk
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