

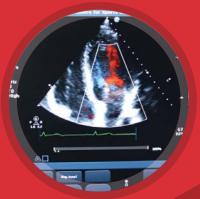
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CRY

General Election Manifesto 2015









Offering help and support to affected families

@CRY_UK /CardiacRiskintheYoung www.c-r-y.org.uk Young sudden cardiac death is one of the most common causes of death in young people.

The CRY Manifesto brings together our key campaigns, including; improving awareness in the general public and within the medical community, providing appropriate support and expert pathology, improving early diagnosis through screening, improved management of young people identified with cardiac conditions, and greater research into young sudden death.

The changes we ask for will:

- reduce the number of young sudden deaths in the UK (currently at least 600 every year)
- help thousands of people each year who are affected by the tragedy of a young sudden cardiac death in their family

We call for the government to establish a national strategy for the prevention of young sudden cardiac death

This strategy will ensure action to increase:

- awareness of medical practitioners and those at risk
- support after a young sudden death, including expert cardiac pathology
- screening for young people to identify cardiac conditions
- research to inform policy and practice

The national strategy will synchronise UK policies and lead to a dramatic reduction in young sudden cardiac deaths in the UK.

It is because of our bereaved families and the tens of thousands of people who have had their lives devastated by young sudden deaths that ministers must understand, accept and support CRY's aims, and relish what could be achieved with that support.

Cardiac Risk in the Young (CRY)

CRY is non-profit UK charity established to:

- · save young lives
- · help those affected

CRY are preventing young sudden cardiac deaths through awareness, support, screening and research.

CRY represents the thousands of families whose apparently fit and healthy children, partners and parents have died suddenly from undiagnosed cardiac conditions.

Because of CRY, these individual tragedies have a collective voice, articulated in a call to action.

Through awareness, support and screening many deaths can be prevented, and research into these conditions will be the key to providing the knowledge crucial to saving these young lives.

CRY families, and their communities, have created something incredible.

Through their tragedy they have provided the opportunity for others to be tested.

Through their tragedy they have provided the opportunity for research.

To do nothing is not an option for the thousands of people affected and the thousands still to be affected by an unnecessary death in their family.

The cost of suffering is hard to quantify. Consequently, the full impact of a young sudden cardiac death has not been properly understood.

Most of those affected will never have heard about CRY. Some will have previously dismissed the stories as being sensationalised – too unbelievable to be true. It is almost impossible to believe that a fit and healthy young person can die instantly, with no apparent reason.

awareness...

of medical practitioners and those at risk

Over the past 20 years there have been thousands of families throughout the UK that have suffered the tragedy of young sudden cardiac death. In the majority of cases these deaths are caused by inherited conditions, meaning other family members are at risk of harbouring the same potentially fatal condition. It is essential that both the public and medical practitioners are aware of how crucial it is to refer family members to experts for further testing.

Through raising awareness of these conditions, the public, medical and sporting communities will be alerted to the symptoms that can lead to a young sudden cardiac death, as well as the potential risks that these conditions carry for an asymptomatic population.

- The public will be aware of courses of action that can minimise their risk, including the choice to be screened at one of CRY's screening clinics.
- The medical community will be aware of specialist cardiac services available, including the CRY Centre for Inherited Cardiovascular Conditions, to aid diagnosis, as well as how to best manage patients.
- The sporting community will be aware of the specialist cardiac services available at the CRY Centre for Sports Cardiology, as well as the importance of screening athletes.
- Members of Parilament must be aware of the latest research so they can inform government policy.

Early, accurate diagnosis saves young lives.

Awareness not only helps to identify those at risk, but also ensures correct clinical practice when treating a young person with an inherited cardiac condition.



medical practitioners

- know the signs and symptoms to look out for to correctly refer symptomatic patients;
 - chest pain (exercise related)
 - fainting / syncope (as recommended by NSF CHD Chapter 8* and NICE TLoC guidelines**)
 - palpitations
 - dizziness
 - breathlessness
- know the referral pathways for families after a young sudden death;
 - NSF CHD Chapter 8* identifies the importance of specialist referral after a young sudden death
- have the resources available to help them support families;
 - www.c-r-y.org.uk/gp information for general practitioners
- know where to refer young people who want testing;
 - www.testmyheart.org.uk free cardiac screening
 - young people without symptoms or family history requesting cardiac testing can be screened at no personal cost through CRY's screening programme.

coroners

- know the service provided by the CRY Centre for Cardiac Pathology, which;

 - identifies the correct cardiology referral pathway for first degree relatives
 - offers a two week service (prior to this service families could wait up to 2 years to learn the cause of death)
 - $\,{}^{\circ}\,$ is fully funded by CRY

Members of Parliament

- know young sudden cardiac death is one of the most common causes of death in young people (aged 35 and under)
- know young sudden cardiac deaths are preventable and the conditions are treatable if diagnosed
- recognise that current health policies are contradictory, confusing medical communities and the general public

^{*} National Service Framework for Coronary Heart Disease, Chapter Eight: Arrhythmias and Sudden Cardiac Death

^{**} National Institute for Health and Care Excellence: Transient Loss of Consciousness

support...

after a young sudden death, including expert cardiac pathology

CRY offers support to affected families following their bereavement through a unique programme which trains volunteers who have been affected by young sudden cardiac death to help the recently bereaved come to terms with their tragedies.

Clinical support is equally important. CRY provides expert advice from the first contact; from helping the bereaved understand the cause of death, through to explaining the importance of risk assessment for other family members. The clinical support services CRY funds are embedded within the NHS at the CRY Centres for Inherited Cardiovascular Disease and Sports Cardiology and the CRY Centre for Cardiac Pathology at St George's Hospital in London.

The emotional impact of the sudden, seemingly inexplicable death of a young person on their family cannot be underestimated and adequate bereavement support must be made available.

Clinical support is required to first identify the cause of the death and expert fast-track cardiac pathology is essential – specialist cardiac referral is crucial for all first degree blood relatives after a young sudden cardiac death to identify any other family members who are at risk.



bereaved families

- are given the cause of death through expert cardiac pathology, which is essential to;
 - help the family grieve
 - identify whether the fatal condition was genetic
 - initiate specialist cardiac referral for family members
 - enable access to bereavement support
- have the right to a specialist cardiac referral;
 - to be seen quickly after the GP referral
 - to be seen as a family unit when requested
 - to have all necessary tests and, when possible, diagnosis at one appointment
- are made aware of the bereavement support services that are available
 - www.c-r-y.org.uk/gp information for general practitioners

the goverment

· does more to support essential services after a young sudden cardiac death



screening...

for young people to identify cardiac conditions

For over 20 years CRY has been screening young people aged 14 to 35. The programme developed by CRY has created the opportunity to save the young lives of those at risk that are asymptomatic, and appear to be "fit and healthy". The programme is available to schools, sports clubs, universities and local communities throughout the UK. The service is for boys and girls, Olympic gold medalists and local schoolchildren alike.

Since CRY was founded in 1995, CRY families have supported the screening of over 70,000 young people.

In 2015, over 20,000 young people will be tested and the programme is growing year on year in response to public demand.

Current screening policy is directed by the UK National Screening Committee (UK NSC) and contradicts the recommendations of the Department of Health and the National Institute for Health and Care Excellence (NICE). Consistency between the UK NSC, Department of Health and NICE is essential to avoid the confusion of the general public, policy makers and health system stakeholders. The government must be more effective in bringing the national screening position forward; in line with other countries and modern practices.

Screening to identify young people at risk is cost-effective when conducted correctly – the conditions can be treated, securing a future for those identified. All young people should have the choice to be tested.

In the future all young people will have their hearts checked, but how many young lives will be lost while we wait?



cardiac screening

- identifies young people who are at risk (1 in 300 people have a potentially life-threatening condition)
- reduces cardiac problems in later life (1 in 100 people tested are identified with cardiac conditions that cause problems in later life)
- prevents up to 90% of young sudden cardiac deaths (currently at least 600 deaths every year in the UK)
- informs important research that will drive up standards for the care of young people



research...

to inform policy and practice

CRY's screening programme is not just a service provision; it is also a research programme. CRY's research is applied, turning today's questions into tomorrow's policies. CRY's research programme, lead by Professor Sanjay Sharma since 1996,has developed the blueprint for the cardiac assessment of young individuals throughout the world, culminating in many revisions to international screening policies.

CRY funds medical research through research grants. These grants cover a broad spectrum; from fast-track screening to pathology after a death. The grants also help to provide specialist knowledge of inherited cardiovascular conditions and sports cardiology. The field-gathered data from CRY's screening programme is analysed and reported in peer reviewed journals, developing the international understanding of these conditions.

When CRY was founded in 1995, it was believed that one young person died every week from an undiagnosed cardiac condition. Through ongoing research we now know that at least 12 young people, aged 35 and under, die every week from an undiagnosed cardiac condition.

CRY have funded 14 research fellows and are currently funding a further 9 fellows. Each year this network of trained doctors grows and each year we move closer to the time when there will be an infrastructure of experts in the UK, making a national screening programme viable.

Medical research is essential to drive up standards of clinical care.

Research is fundamental to improving policy and practice.

Inaction is unacceptable when the price paid is so very high.



more research is conducted, improving our understanding of;

- the prevalence of young sudden cardiac death
- how to reduce young sudden cardiac deaths
- · how to reduce false positives in screening
- the role of genetic testing in identifying "at risk" groups
- the role of different diagnostic tests
- the impact of exercise on the heart
- ethnic and gender differences in cardiac conditions in young people
- · acquired cardiac conditions
- · environmental and lifestyle triggers for cardiac arrests in young people
- the prevention of serious cardiac conditions in the fourth decade of life through the early identification and treatment

CRY's research programme gives us unique access to general populationbased data, enabling comparisons between athletes, ethnicities and gender. Through a better understanding of what is normal for young people we can better identify and treat those at greatest risk.



SUPPORT after a young sudden death, including expert cardiac pathology

Young sudden cardiac death (YSCD) is often the first symptom of a condition and specialist pathology is required to identify the disease and bring the genetic implications of a potentially inherited disorder to the attention of relatives.

The coroner's mandate has traditionally been to exclude foul play and this role has only recently been extended to investigating the cause of all sudden deaths. Unless an expert pathologist with experience of conditions causing YSCD performs the post-mortem examination, conditions predisposing to fatal cardiac arrhythmias and YSCD (such as long QT syndrome) can be difficult to identify. In these circumstances the cause of death may be "unascertained" or attributed to "natural causes", thereby producing a falsely low estimate of the incidence of YSCD.

CRY Centre for Cardiac Pathology (CRY CCP)

The CRY Centre for Cardiac Pathology (CRY CCP) was launched in 2008. It is an international cardiac referral centre and was established with donations in memory of Howard and Sebastian English.

The service is led by expert cardiac pathologist Professor Mary Sheppard, with a team of staff funded by CRY. When a cause of death is "unascertained" and the deceased was aged 35 or under, the centre will provide a free, fast-track cardiac diagnostic service.

The examination and report from the centre will usually be completed within two weeks. When pathology is not referred to this centre it can take up to two years for an expert investigation to be conducted. Professor
Sheppard has
conducted over
1,400 examinations
since the launch of
the CRY CCP, helping
hundreds of families
to understand the
cause of death

CRY Centre for Inherited Cardiovascular Conditions and Sports Cardiology at St George's Healthcare NHS Foundation Trust

CRY's consultant cardiologist, Professor Sanjay Sharma, is Professor of Inherited Cardiovascular Conditions and Sports Cardiology at St George's Hospital in London.

In 1995 St George's was the first hospital in the UK to develop a family cardiac screening clinic. CRY's donation of an echocardiogram machine established a specialist clinic in young sudden cardiac death and meant that – for the first time – families could be screened together after their tragedy.

The CRY Centre for Inherited Cardiovascular Conditions and Sports Cardiology at St George's combines three essential features of CRY's mission to eliminate young

sudden cardiac death; offering services for affected families, young symptomatic individuals and athletes. The centre enables bereaved families to be tested for potentially life-threatening cardiac problems after the sudden death of a family member; have all tests conducted on the same day; to be seen as a family unit; and often to be seen within just a few weeks of the GP referral.

CRY funds the cardiac machinery, physiologist, cardiac nurse and eight research fellowship grants to support these services.

Supporting families after a tragedy

CRY's bereavement support programme has been developed to help families cope with their grief following the shocking sudden death of an apparently fit and healthy young child, sibling, partner, relative or friend. CRY provides emotional support through a network of volunteers who have themselves suffered the sudden death of a child, sibling or partner in this way. These volunteers have achieved British Association of Counselling (BAC) accreditation with Skills and Theory certification, following two years' training, so that they can help others come to terms with their tragedies.

Hundreds of people have contacted CRY wondering if there are others that they could talk to who have suffered similarly. No matter how much professional support is offered (either medical or therapeutic), sometimes just talking to someone who has been through such an experience helps the most.

CRY's national bereavement support days are held for people who would like to meet others in the same position and understand more about how to adjust to the sudden death of a young person from an undiagnosed heart condition. People travel from all over the country to attend these support days. They are specifically for bereaved mums, dads, siblings and partners after a young sudden cardiac death. Each of these days addresses a different aspect of grief. The tragedy affects every member of the family but each person will feel their loss in a different way.

CRY has created a library of "Grief Booklets" specifically addressing the different aspects of grief for mums, dads, siblings and partners. These booklets are available free on request from the CRY office.

Supporting those diagnosed – myheart Network

CRY's *my*heart Network provides help, support and information to young people who are coping with the diagnosis of a heart condition. CRY's *my*heart Network holds regular meetings so members can meet others in the same position as themselves, and discuss their experiences and medical concerns in an informal but supportive environment. An expert cardiologist and a counsellor are present at every meeting.

SCreening for young people to identify cardiac conditions

In 80% of cases of young sudden cardiac death (YSCD) there are no prior symptoms of a heart defect. CRY believes the frequency of YSCD can be dramatically reduced by making heart screening available to all young people between the ages of 14 and 35.

Systematic screening programmes are needed to establish the prevalence of cardiac conditions in the young. The aim of a screening programme is to detect a condition, or the risk factors of a condition. Once detected, preventative or therapeutic interventions can be implemented and the disease can be treated while it is less advanced. In the case of cardiac conditions, the aim is to put in place treatments and lifestyle changes that will minimise the risk of a sudden cardiac death. These preventative actions may include medications, surgery or lifestyle changes. Often specific medications or drugs will need to be avoided. In some cases the condition can be cured with the risk of sudden cardiac death entirely removed.

A simple way to diagnose most cardiac abnormalities is a quick, painless and non-invasive test called an electrocardiogram (ECG) which records the electrical activity of the heart. If a more detailed image is required, an ultrasound scan of the heart – called an echocardiogram – can be taken. Any person between the ages of 14 and 35 can book a place at a CRY screening event through www.testmyheart.org.

www.tes

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Athletic and occupational cardiac screening

There are now many career paths and professions that either mandate or recommend cardiac screening, such as in the fields of professional sport, aviation and the military. The US is setting its own standards in professional sport with governing bodies like the NBA and NFL and many universities requiring all their athletes to be screened. However, there are also strong critics of cardiac screening programmes in the US; the American Heart Association (AHA) has rejected the European Society of Cardiology (ESC) guidelines that recommend ECG testing prior to competitive sports participation.

In the UK, screening is required or recommended in most professional sports. Increasingly, European countries are developing similar policies to those in Italy, expecting their athletes to be tested prior to participation. When screening is mandated or recommended as part of a career pathway it is essential to identify

those at risk at an early stage, before personal and financial commitments are made towards career goals. Consequently, awareness of the importance of screening from a young age (post puberty) is important.

Sport is still immersed in the screening debate, with differing opinions between the European and American perspectives. However it is important to recognize that most young sudden cardiac deaths do not occur in sport. 80% of SADS (sudden arrhythmic death syndrome) deaths occur at home and the essential message to promulgate is that screening must be extended beyond sport and into local communities.

General population cardiac screening

In a society where disease prevention is becoming increasingly important, young people should have the opportunity to be tested. Annually, thousands of people in the UK will be personally affected by young sudden deaths and may require reassurance. Proactive testing is usually the only way a person can learn if they are at risk of sudden death. When screening is not provided – or even discouraged (as is the current case) – our society is being condemned to accept that every year a significant group of young people will die of these conditions.

The most recent UK National Screening Committee (UK NSC) review does little to advocate progress. They state, "The conditions that lead to sudden cardiac death are poorly understood and there is no evidence to guide clinicians regarding treatment or lifestyle advice when such a problem is found in a family member or when detected at a screening examination." The false premise and misleading conclusions of their report are a cause for great concern; they depict the field of inherited cardiac diseases and sports cardiology as void of any evidence to guide the investigation and management of individuals suspected to have or diagnosed with conditions associated with YSCD.

Their position is in conflict with Chapter Eight of the National Service Framework for Coronary Heart Disease, aimed at facilitating early identification of individuals at risk of YSCD: "Quality Requirement Three" states; "When sudden cardiac death occurs, NHS services have systems in place to identify family members at risk and provide personally tailored, sensitive and expert support, diagnosis, treatment, information and advice to close relatives... Sudden cardiac death in younger people is often indicative of inherited cardiac disease. There is real potential to prevent further tragedies by the appropriate care of family members in these cases."

Furthermore, the UK NSC is dismissive of the testing process; "There have been no assessments of the accuracy of these tests", "what is happening is that the tests are being used to pick up people with conditions that might lead to SCD." In fact, the ECG is a simple, safe and validated test as required by the World Health Organization (WHO) and UK NSC criteria. Moreover, the ECG has been studied extensively as a screening tool, particularly in the UK, for young individuals of different genders, ethnicities, levels of exercise and sporting disciplines. The

position of the UK NSC directly contradicts the National Institute for Health and Care Excellence (NICE) guidelines for transient loss of consciousness, which state that; "A 12 lead ECG is an important initial diagnostic test for identifying the likely cause of transient loss of consciousness in some people, and especially in predicting adverse events (for example, ECG abnormalities that are 'red flag' signs or symptoms may suggest structural heart disease or potential for arrhythmic syncope)."

It is important to acknowledge that screening to reduce

YSCD is a challenge, looking for more than one condition, some of which are fairly novel and lack evidence based management. However, it is unacceptable for policy to fall back on the lack of randomised controlled trials (RTCs) as the basis for insufficient evidence. In principle RCTs are the ideal standard in research to inform policy and practice. However, the ideal standard is not always achievable in many aspects of science (and life, in general). It would be technically and ethically challenging to perform a large scale randomised controlled study, particularly in light of the results of the 2006 Corrado et al. study (1) and the

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many studies relating to the effective management of individuals identified with an inherited cardiac disease.

As part of evaluating any screening programme it is first essential to understand point one of the UK NSC Programme Appraisal Criteria: "The condition should be an important health problem". For this there must be an accurate appraisal of the incidence of young sudden death. The latest screening report makes no reference to the data published by CRY (Papadakis et al. (2)) that informs CRY's "12 a week" figure. This is the most important data published to date on understanding the incidence of young sudden cardiac deaths in the UK.

The current UK national policy is based on a gross underestimation of the incidence of YSCD, the tests used the identify people at risk, and the management strategies to reduce risks. Current policy is failing to prevent young sudden cardiac deaths in the UK.

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research to inform policy and practice

The data derived from the CRY screening program has dramatically improved our understanding of electrocardiogram (ECG) patterns commonly present in young individuals and how these can vary for individuals of different ethnic backgrounds, genders, ages, sizes, levels of athletic activity and sporting disciplines.

Establishing what constitutes a normal pattern is crucial in order to accurately differentiate between traits attributed to the individual's demographics and characteristics that may represent underlying cardiac pathology and should trigger further clinical evaluation. By devising clear, demographic-specific criteria CRY have reduced the false positive rate of the 12-lead ECG and utilise

it as a useful screening tool in the context of a diverse,

young population in the UK.

The quality and novelty of the data acquired from the CRY screening programme is underscored by the number of peer-reviewed publications it has informed, as well as the incorporation of our conclusions into guidelines relating to the interpretation of the 12-lead ECG from international scientific bodies such as the European Society of Cardiology and expert consensus panels such as the

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By

"Seattle Criteria". Based on the CRY screening programme, the investigators have:

- 1. Reported the distribution of the corrected QT interval (QTc) in young athletes and the prevalence of prolonged QT interval, which may raise suspicion of long QT syndrome. (3)
- 2. Defined the effect of age on the 12-lead ECG. In this manuscript the author outlines what constitutes a normal ECG for an adolescent and how it should be interpreted in the context of preparticipation screening. (4)
- 3. Defined the effect of black ethnicity on the 12-lead ECG. The investigators identified ECG patterns that are highly suggestive of quiescent cardiomyopathy in white athletes but are a normal ethnic variant in individuals of African/Afro-Caribbean descent. (5–7)
- 4. Assessed the prevalence and significance of voltage ECG criteria for right ventricular hypertrophy (RVH), commonly considered to represent cardiac disease. This manuscript highlighted the relatively high prevalence of RVH on the ECG of young individuals and its poor predictive value for underlying cardiac pathology. (8)

5. Re-evaluated ECG indices, which by convention were considered to represent signs of cardiac disease, but our screening experience demonstrated were likely to be innocent bystanders. (9)

Based on our research we have been able to define structural adaptations in young athletic individuals. This is imperative to support an ECG screening programme given that echocardiography is commonly the first investigation performed in individuals who exhibit an abnormal 12-lead ECG. The investigators have:

- 1. Defined the physiological upper limits of the left atrial and ventricular size in young athletes, which are utilised to distinguish physiological adaptation to exercise versus heart disease. (10,11)
- 2. Addressed the effect of ethnicity in structural adaptation to exercise, and demonstrated that black athletes exhibit significantly more left ventricular hypertrophy, which is pivotal in order to ensure that no athlete with an abnormal ECG is falsely labelled with underlying cardiomyopathy based on imaging criteria derived from white athletes. (12,13)
- 3. Described the novel concept of increased myocardial trabeculations, which if misinterpreted can lead to a false diagnosis of left ventricular non-compaction, a fairly novel cardiomyopathy. (14)

CRY's preliminary screening results in 2008 (15) demonstrated that the 12-lead ECG was able to identify young individuals with cardiac disease. Nine out of 2,750 (0.3%) young individuals were diagnosed with a condition predisposing to sudden cardiac death. All diagnoses were based on an abnormal ECG, as all individuals were asymptomatic with no significant family history. In order, however, to assess the value of the 12-lead ECG as a screening tool for identifying young, apparently healthy individuals with cardiac disease, the investigators evaluated the ability of the ECG to identify cardiac disease but also, very importantly, the ability of a normal ECG to exclude cardiac disease and offer reassurance. In a recent study published in the journal Circulation (16) it was demonstrated that by refining the ECG criteria utilised during screening it was possible to improve the ECG's specificity without compromising its sensitivity. The results suggested that the ECG sensitivity remained close to 100% (with a negative predictive value of 100%) for major cardiac abnormalities while the specificity improved from 40% to 84% in black athletes and from 74% to 94% in white athletes.

During this research CRY have identified and treated a considerable number of individuals who harboured previously quiescent conditions predisposing to sudden cardiac death. Of 29,506 individuals (mean age 19.6 years, 68% male, 94% Caucasian) who recently underwent cardiovascular evaluation through CRY, 26,486 (89.8%) were cleared of cardiovascular disease on initial evaluation. A further 2,182 (7.4%) individuals were cleared after a transthoracic echocardiogram on-site. A recommendation for secondary evaluation on the basis of suspicion or diagnosis of

a cardiac condition was made in 838 (2.8%) individuals. Of these 838 individuals, 76 were given a definitive cardiac diagnosis. Interestingly, our results indicate that the prevalence of hypertrophic cardiomyopathy (HCM), which published literature suggested a prevalence of 1 in 500 individuals, may be lower than 1 in 3,500 in certain groups such as adolescents and young athletes. (17)

CRY's research demonstrates that ECG screening is feasible and the 12-lead ECG is a useful tool in identifying young, apparently healthy individuals with cardiac disease. It also demonstrates that symptoms and family history alone are a poor discriminator of pathology.

It is self-evident, based on the wealth of publications referenced above, that CRY's screening programme has contributed a considerable amount of knowledge to the international scientific arena.

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