

**P-05-870 Let's Get Every Young Heart Screened (Age 10-35), Correspondence  
– Petitioner to Committee, 31.05.19**



**WELSH HEARTS**  
**CALONNAU CYMRU**  
THE HEART CHARITY FOR WALES  
ELUSENY GALON DROS CYMRU

**Date 31/5/19**

**REFERENCE PETITION P-05-870**

**LET'S GET EVERY YOUNG HEART SCREENED (age 10 -35)**

**For submission for discussion by the Committee  
at the meeting to be held on Tuesday 11<sup>th</sup> June 2019**

In response to Mr Gethin's letter dated 16<sup>th</sup> May 2019, it is with astonishment that we view his generalisations, when there is clear evidence to contradict his comments.

To state that it is harmful to detect cardiac risk factors, which in his words 'would **never** otherwise develop into a serious condition or complication', are both outdated and thus ill informed and insensitive comments.

With our first hand knowledge of cardiac wards in hospital, it has been seen to be the case that so-called 'minor' cardiac issues, have developed into problems that have needed addressing.

He then makes a contradictory comment to his earlier remark, stating that 'receiving a low risk result does not prevent the person from developing the condition at a later date'. Exactly as we state in our previous comment, so isn't it better to 'know' and get any issue checked out further? From firsthand experience, we can assure that it is.

Mr Gethin's comment about 'false negatives' not guaranteeing protection, is an aspect of screening that has been shown to have been improved massively in recent years and is now negligible, compared to the number of detected, previously undiagnosed cardiac issues, in both athletes, recreational participants and non-athletes, enabling further investigation and treatment as required, saving lives.

Quote taken from article by Dr Harshil Dhutia

A large proportion of sudden cardiac death in young individuals and athletes occurs during rest with sudden arrhythmic death syndrome being recognised as the leading cause. The international recommendations for ECG interpretation have reduced the false-positive ECG rate to 3%.

Reference from CRY article

**1. Previous studies (September 2016) showed that current screening protocols significantly reduced the level of “false positives” (often used by Government advisors as an argument against screening) from 21.8% to 4.3%.**

Mr Gethin then goes on to state that the National Screening Committee have considered heart screening for 12-39yr olds, to prevent SCD (Sudden Cardiac Death) and he adds that ‘population screening programmes should only be offered where there is robust, high quality evidence that screening will do more good than harm’. The report from the committee is outdated (30<sup>th</sup> July 2015), with quality of interpretation of readings having been shown to have significantly improved in recent years. Their recommendation was ‘against screening for risk of sudden cardiac death’ citing it as ‘rare’ and the risks ‘tiny’. Recent evidence noted herewith, shows otherwise.

In response - The most persuasive evidence supporting the theory that early identification of disease through ECG screening saves lives comes from a large prospective Italian study of 42,386 competitive athletes aged 12–35 years. The study demonstrated that since heart screening was brought in, a reduction in the incidence of SCD from 3.6/100,000 person-years to 0.4/100,000 person-years, representing a 90% reduction in mortality. The predominant reason for this reduction was a decrease in SCD due to cardiomyopathy.

Mr Gethin comments that high risk families should be screened.

High risk family members such as SCD relatives are given help, advice and mostly screened, but this cascade screening is after the fact a lot of the time.

He states that it would be irresponsible to provide a screening programme against the advice of the experts and which evidence does not support.

There are plenty of other experts, including BMJ, Cardiologists, Cardiac researchers, medical and cardiac institutes who would disagree, also up to date data and sports associations, all supporting the rolling out a heart screening program for all young people.

This petition is addressing the issue of all the young people who have undiagnosed heart issues and often are asymptomatic until the worst happens.

Out of date information and lack of direct knowledge or involvement, used as the argument against rolling out a screening campaign for all young people across Wales is nothing short of extraordinary.

Below is evidence (just a couple of the many) showing clearly how such a campaign could very well have saved these young lives, by the very fact that **YOUNG LIVES HAVE AND ARE BEING SAVED BY THE HEART SCREENING SESSIONS CONDUCTED BY WELSH HEARTS.**

### CASE STUDY 1

(quote from WalesOnline)

A devastated mother in Wales, found her teenage daughter collapsed in the bath after her heart suddenly stopped, an inquest has heard. Fit and healthy Amber Rummels, 18, was found under the water with the taps still running at her family home. An inquest heard her mum Anita Lewis, 44, pulled Amber out of the bath and carried out CPR (cardiopulmonary resuscitation). Paramedics managed to get Amber's heart started but she died four days later in hospital. Medics believe waitress Amber died of sudden arrhythmic death syndrome - a cause of unexpected deaths in young people.

### CASE STUDY 2

(quote from WalesOnline)

Nothing showed how important it may be to get your heart tested than the tragic events immediately following last year's Cardiff Half Marathon.

Ben McDonald, 25, from the Vale of Glamorgan, and dad-of-one, Dean Fletcher, 32, from Exeter, both suffered **cardiac arrests** after crossing the finish line on October 7.

Ben had been described as a "very fit and healthy young man" with no past medical history.

A post-mortem report found that his heart was normal and the cause of death given was Sudden Arrhythmic Death Syndrome (SADS).

Ben's tragedy also highlights and adds to the substantial evidence to support sport preparticipation screening of all athletes, which in turn should include recreational sports participants and ultimately, all young people, saving lives in Wales.

### What is Sudden Death Syndrome?

Every year in the UK at least 620 young people aged 35 or under die suddenly from an undiagnosed cardiac condition. Sudden death syndrome (SDS) is an umbrella term used for the many different causes of cardiac arrest in young people. In about 1 in every 20 cases of sudden cardiac death and up to 1 in 5 young sudden cardiac deaths, no definite cause of death can be found, even after drugs have been excluded and an expert cardiac pathologist has examined the heart for structural abnormalities. The conditions responsible for SDS cause a cardiac arrest by bringing on a ventricular arrhythmia, even though the person has no disease affecting the structure of the heart.

One of the ways we could prevent some of these tragic deaths is by screening young people, particularly those involved in heavy exercise.

**HEART SCREENING** finds so many undiagnosed, potentially life limiting cardiac problems or issues that need addressing further in hospital. It maybe something that just needs keeping a regular check on, spanning up to someone requiring major surgery, as has happened at screenings held by Welsh Hearts.

### **Welsh Sports Association Joins Forces with Welsh Hearts to Raise Heart Health Awareness Through Screening**

Hidden heart conditions can pose a real risk for participants in sport and physical activity, so the issue of heart screening is of huge importance to the members of the Welsh Sports Association. We are therefore delighted to be supporting the charity Welsh Hearts in their initiative to ensure heart screening for 8-45 year-olds is readily available across Wales.

**In conclusion, Welsh Hearts believe there is a strong argument for a working committee to be set up, with up to date contributions and evidence from an extensive pool of resources, experts and service providers and then a comprehensive assessment can be made, on**

**all aspects of hearts screening in young people, to potentially identify undiagnosed heart issues, that can in turn be addressed, with the strong possibility of saving more young lives across Wales, with a view to ultimately rolling out the heart screening programme across Wales, called for in this petition .**