



White House Cottage
The Cathedral Green
Ar Lan Yr Afon
Llandaff, Cardiff
CF5 2EB

30th August 2023

The Deputy Clerk
Petitions Committee
Welsh Parliament

Dear Deputy Clerk

Thank you for the Welsh Government's consideration of our *Petitions' Committee regarding the availability of Heartscreening for all 11 to 35 year-olds in Wales who represent their school or county in sport.*

We thank Eluned Morgan MS, Minister for Health and Social Services, for her comments on this petition. We would, however, respectfully challenge the Minister's annotations and conclusions, as follows:

As the Minister rightly commences by saying, population screening programmes do indeed save lives through early risk identification but then refers to the UK National Screening Committee's findings that screening programmes may also do harm by identifying risk factors that would never otherwise develop into a serious condition or complication. However, I would argue this statement and refer to the findings in the New England Medical Journal which, in summary, states:

Of 269 sudden deaths in young people, 49 occurred in competitive athletes. The most common causes of sudden death in athletes were arrhythmogenic right ventricular cardiomyopathy (22.4 percent), coronary atherosclerosis (18.4 percent), and anomalous origin of a coronary artery (12.2 percent). Hypertrophic cardiomyopathy caused only 1 sudden death among the athletes (2.0 percent) but caused 16 sudden deaths in the non athletes (7.3 percent). Hypertrophic cardiomyopathy was detected in 22 athletes (0.07 percent) at pre-participation screening and accounted for 3.5 percent of the cardiovascular reasons for disqualification. The results show that hypertrophic cardiomyopathy was an uncommon cause of death in these young competitive athletes and suggest that the identification and

disqualification of affected athletes at screening before participation in competitive sports may have prevented sudden death.

Also, it is important to note that heart screening has been compulsory in all teenagers and adults competing in athletic sports in Italy since 1982. Many other European countries offer similar cardiac screening programmes including France, Greece, Spain, Luxembourg, Sweden, Norway, Germany and Poland. Professional bodies such as FIFA and the International Olympic Committee recommend cardiac screening for all their sportsmen and women. The American Heart Association and European Society of Cardiology have prepared guidelines to facilitate this.

We acknowledge the reference to the National Screening Committee work. However, their most recent relevant review was mainly a literature review and was looking at the whole population cohort of 12-39 yr olds. As most of the literature it reviewed, in fact, looked at athletes, the NSC had concerns about the applicability of the data to the asymptomatic general population of that group, hence the inability to recommend screening at general population level.

What the review did report as a result of this was the documented differences between the hearts of athletes and non-athlete; differences in ECG patterns between athletes and non-athletes, such as that a higher proportion of athletes show ECG changes such as T-wave inversion and early repolarisation, whilst a higher proportion of non-athletes have a long corrected QT interval. This, we argue, means that the recommendation for no-screening for this age group at population level cannot be simply read across to be pertinent to this smaller cohort of athletes.

Based on our current ECG heart-screening sessions, we found that 1 in 4 screenings revealed the need for further investigation with an Echo Cardiogram. Even accepting a percentage of false positives, we consider these odds too high to ignore. While there will be a period of anxiety between initial screening and a clean bill of health for some, the reassurance is worth that. We do not accept the argument that they may develop a condition later and, therefore, are falsely reassured. If anything, the screening may be an opportunity to educate and inform of long-term risks to further minimise the current fatality statistics which, at present, are growing when we look at the population overall. **Conversely, where a risk is identified, the individual and their family have the opportunity to consider how to manage it. The Minister's assertion that there is no agreed treatment and, therefore, there is effectively no point in finding out, is rather worrying.**

We concede that this targeted screening does not offer a solution to the incidence of false negatives. However, the issue identified by NSC across almost all studies was the lack of follow-up in individuals who were categorised as screen-test negative, and that itself undermines the usefulness of the NSC review. It confirms that an "assumption was seemingly made that these individuals did not have a disease that may cause Sudden Cardiac Arrest. As such, for these studies, there was no method to determine if these individuals actually had the target condition, although it is acknowledged that the detailed follow-up of screen-test negative individuals is challenging due to the range of tests required to exclude all conditions

that may cause sudden cardiac death. For the majority of studies, this lack of follow-up precluded calculation of key outcomes, namely sensitivity, specificity, and negative predictive value. A systematic review, which reported data from 47.137 athletes across 15 studies was included. However, examination of the primary studies included in the systematic review indicate that these studies were at high risk of bias due to inadequate follow-up of screen-negative individuals. On this basis, data from the systematic review must be interpreted with caution.”

As this effectively admits that the review does not help in terms of reliable evidence in support of the Welsh Government’s present position on this, **we suggest that a way forward would be to acquire its own Wales-specific evidence.** This could be done by commissioning a longitudinal study on the back of an appropriate period of screening of sportspeople in the cohort referred to in the petition.

3This would give the opportunity to track young sportspeople’s incidence of (a) false positive and false negative test results; (b) physiological changes which would produce positive results mean that they had to change behaviour to manage risk and, possibly, prompt screening for family members.

We would like to take the opportunity of informing the Welsh Government that Calon Heart Screening & Defibrillators is very proud to have recently launched a mobile Heartscreening initiative, supported with funding from Loteri Cymru, which we are taking around the whole of Wales. **To date, we have screened the hearts of nearly 15,000 people, distributed 29,000 defibrillators and trained nearly 95,000 people in CPR and defibrillator use.** We are a small, hard-working and dedicated Cardiff-based charity, surviving solely by fundraising. We receive no Welsh Government financial support whatsoever. We understand the financial implications of initiating a heart health programme of this sort but we ask that this measured against loss of life, families without loved ones and an ever-growing heart health pandemic. We would say it becomes immeasurable. We are doing our bit to combat the aforementioned tragedies and we merely ask our ministers to do the same.

We thank the Welsh Government for recognising the importance of defibrillators and for addressing this potentially life-saving issue.

We respectfully request that the Welsh Parliament considers the foregoing and ask that our Petition is favourably accepted and implemented.

Yours sincerely

Sharon Owen

**Sharon Owen
Charity and Fundraising Director
Calon Heart Screening & Defibrillators**