

# **PE2067/K: Improve data on young people affected by conditions causing Sudden Cardiac Death**

## **Petitioner written submission, 25 February 2025**

With my second submission I would like to address the statements from the British Heart Foundation (BHF) and the UK National Screening Committee (NSC).

I am pleased to note the agreement from BHF regarding the uncertainty surrounding the incidence of Sudden Cardiac Death (SCD) and the conditions which can cause SCD.

I am heartened by BHF's commitment to raise the knowledge of CPR in the population at large, and the increase in the availability of defibrillators. We all know these together can, and do, save lives. However, the BHF report a survival from cardiac arrest as only 1 in 10, and these figures are for the population in general of all ages, many of whom have underlying conditions, and doesn't take into account the number of asymptomatic young people affected. If anything, this highlights the perspective that CPR and use of a defibrillator is still a treatment of last resort, and to prevent such a catastrophic situation we must intervene before this point.

The BHF submission clearly states "[r]esearch is vital to improving our understanding" and I welcome their offer of support in high-quality research to "better understand the prevalence of these conditions and how best to effectively screen for them on a whole population basis." This is precisely what my petition asks for – research with pre-agreed parameters and reporting of incidence of both prevalence of conditions and number of deaths, which is essential to avoid any ambiguity regarding the scope of these conditions.

There is already collaboration between BHF and CRY, which could form the basis of the pilot study research I am seeking.

I acknowledge the response from Professor Anne Mackie, on behalf of the UK NSC Secretariat, and recognise her conclusions from the 2019 review.

I am disappointed that the NSC now plan to review evidence relating to population screening for SCD in the next three years – after the 2019 review, it was clear that the next review would be expected in 2023/24, which has not yet happened, and now it will be up to a further three years before this will happen. How many young people will die because of such a delay? Perhaps if a review had been conducted when expected there would be recognition of the body of research that has been published since the last review, the increased effectiveness of the testing available and the progress in treatment pathways.

I am grateful the NSC will now consider targeted screening. This might provide an agreeable starting point for the conversation regarding development of a screening programme, I struggle with the idea of stratified screening for SCD. By its very nature, SCD is impacting young, generally fit and healthy people with no underlying cardiac concerns, and I fail to see how identifying their risk factors will ensure

screening is effective, as they are the very ones who don't have identified risk factors!

I am sure the physical exam of babies will improve detection of congenital heart disease, but as it was only introduced in 2014, there are many in the population who have not benefitted from this and remain asymptomatic while potentially at risk. Additionally, congenital heart disease is only one aspect of the conditions leading to SCD, and takes no account of the other causes including genetic conditions, or the impact of the number of people in the population who will die from the accumulated causes of SCD.

I believe that the pilot study I seek will provide critical evidence to present to the UK NSC whenever the next review happens, and with the backing promised from the Scottish Government and collaboration with all agencies offering support, will not only save the lives of young people in Scotland, but lead to a four nation approach towards the development of effective screening for Sudden Cardiac Death.