

PE2067/J: Improve data on young people affected by conditions causing Sudden Cardiac Death

Petitioner written submission, 18 February 2025

I thank the Committee for this opportunity to add to the information heard last March and for this review relating to my petition.

I am unable to find evidence of the NSC review due in 2023/24. There appears to be universal agreement about a lack of clarity regarding the numbers of young people affected, and even after Jenni Minto, Minister for Public Health and Women's Health, contacted the NSC, they simply said "in due course". Considering the last review is now 6 years old, I believe their data and information is significantly outdated, and hope the Committee might be able to shed light on this situation. Their review appears overdue, and young people are still dying.

I welcome the response from NICCS, noting they agree that "more needs to be done". The importance of genetic testing is recognized, and my son David falls into the 15-20% diagnosed, as a group who would never have been identified, being asymptomatic and with no family history. However, this is only instigated after a death for relatives of the deceased. Perhaps if screening had been available, David might still be here. However, in the 3 years since he died, assuming 12 deaths weekly, 624 have died each year – over 1,800 young people lost and families devastated.

The response from CHSS is appreciated, and I am grateful for their work to support those suffering a cardiac arrest out of hospital, and provision of defibrillators. However, a defibrillator is "a treatment of last resort" (Dr Steve Cox, CRY CEO) and can still be fatal, even if the defibrillator gets them to hospital. Survival rates are increasing, but this is population wide, not specific to young people with no apparent underlying disease. CHSS noted from the previous NSC review that "further research is necessary" and support my petition. Analysis from Dr Steve Cox (CRY CEO) shows how difficult it is to accurately show the numbers affected by conditions causing SCD, and why a common language is needed in describing the number of deaths. I commend his analysis to this Committee.

I had a meeting last March with then First Minister Humza Yousaf, along with Health Secretary Neil Gray, Oliver Mundell MSP, and 2 cardiologists, I believe from Queen Elizabeth Hospital in Glasgow – all of whom were supportive of the aims of this petition to clarify the impact of SCD. The First Minister reassured me how seriously the Scottish Government takes the issue of SCD in the young, and agreed to discuss with the Chief Scientific Officer commissioning or supporting research into the impact of diseases leading to SCD in Scotland. I await news from Neil Gray MSP regarding this.

After meeting with the First Minister, I attended [a round-table meeting, "One Voice, Many Hearts", at Westminster, chaired by a parent who sadly lost her daughter last year](#), where published research was shared, discussions held about what effective preventative strategy might look like, and how to build a policy for a screening

programme. This involved MPs, cardiologists, associated professionals, bereaved families and survivors of diseases that cause SCD.

The impact of SCD on young people was again discussed only a few weeks ago at [a meeting reported in the press with the then Parliamentary Under-Secretary of State at the Department of Health and Social Care, Andrew Gwynne MP, also attended by Dr Steve Cox, Professor Mary Sheppard \(Director of Cardiovascular Pathology, CRY\), Professor Ann Mackie \(Director of Screening for Public Health England\) and a fellow CRY parent who lost her son to SCD some years ago](#). At this meeting, Professor Sheppard pointed out that 12 deaths a week is an outdated figure and shared that she receives at least 16 hearts a week for detailed post-mortem, knowing there are others she doesn't receive. If we inform our estimation on Professor Sheppard's baseline number, then we are losing 832 young people every year, and over 2,500 since my son has died. Professor Mackie simply expressed her sorrow at my friend's loss of her daughter, and remained steadfast in her opinion that losses of 12 a week are an overestimation, in spite of hearing clear evidence to the contrary from Professor Sheppard. It is disappointing that Public Health England and the UK National Screening Committee appear unwilling to adjust their positions in light of updated evidence being shared with them.

The same friend also attended a meeting at the Italian Embassy in London, coordinated by the same bereaved parent; to review the impact of their screening decisions and how it could inform changes in practice here in the UK. The meeting included the Italian Ambassador, the President of the International Federation of Sports Medicine, the President of both Italian and European Federation of Sports Medicine, the Cardiology President of the Royal Society of Medicine, as well as several prominent cardiology experts from institutions including St George's University Hospitals, Guy's and St Thomas' hospitals, and Cambridge University – who spoke about the Cambridge screening programme. The discussion covered aspects of how other countries manage this issue, what the UK needs in order to meaningfully reduce the incidence of young SCD, and how to get there. There is in Italy mandatory screening for all young people involved in organised sport (backed by research) including school groups who are not professional athletes, where the deaths from SCD have been reduced by almost 90%. While “mandatory” isn't what we advocate, this shows a need to consider some kind of voluntary screening for our population.

SCD has been highlighted so often, especially over the last year and there is data showing that screening saves hundreds of lives every year. I urge the Committee to push the Scottish Government to take the lead in securing new research regarding voluntary population screening to clarify the extent of SCD in Scotland's population, and the incidence of conditions that cause it, which impact on cardiac outcomes beyond the age of 35, without relying on the death of a young person to instigate screening of the surviving family.