

Petitioner submission of 5 June 2023

PE1911/MM: Review of Human Tissue (Scotland) Act 2006 as it relates to post-mortems

Further to the recent committee meetings, I would like to express my heartfelt gratitude for the overwhelming support I have received from both the public and Members of the Scottish Parliament regarding my petition. The outpouring of compassion and understanding has been overwhelming, and it underscores the significance of the concerns I am raising.

In early 2020 when trying to retrieve the samples of my son the Procurator Fiscal suggested I may think about counselling! It is mainly due to their archaic practices that I have extremely horrific nightmares and anxiety. Of course, my son's death has impacted me but it's what happened following his death that really traumatised me. The people responsible for inflicting this trauma having the audacity to suggest that I seek counselling left me with a profound sense of betrayal and disbelief. The last evidence session was a breath of fresh air to learn that other regions have better practices. This feeling is shared by many families who have endured similar ordeals and highlights the urgent need for change.

I expected a view and grant post-mortem for Richard. I did not know the invasiveness of a full post-mortem with the removal of the brain, throat and tongue. The recent evidence session showed how the current Scottish system lacks empathy, accountability, and respect for the deceased. Richard Stark's Law is about ensuring that future generations are spared the anguish and distress we have endured. The evidence session in May really affirmed the devastating impact of Scottish post-mortems being performed without due consideration of the deceased's medical history or the wishes of the family.

We heard compelling evidence that other parts of the UK and across the globe adopt practices, such as digital scanners, that prioritise the emotional well-being of families to limit & avoid invasive post-mortems. Scotland must follow suit for many reasons, but one which I will note again is to alleviate the burden on pathologists, allowing them to focus on the living and reducing the financial strain on our healthcare system. I believe that you should not go out of this world scarred and with pieces missing, not without consent. I cannot believe what my family have gone

through. Pathologists are seemingly exempt from the legal consequences of causing bodily harm.

We are a very quiet living family, Richard was in the garden the night before he suddenly died. There was medical history where a seizure had been considered – this living medical evidence was ignored, my son had attended A&E and a seizure was considered. We heard at the May evidence session that England takes a different approach and does consider medical history. Richard's cause of death was pieced together by me and I had a subsequent fight to have his death certificate changed. It was only after a charity named SUDEP Action who are experts in seizures and gave their own professional opinion, that a pathologist then changed from "Unascertained" to Suspected Seizure/Cardiac Arrhythmia – cause uncertain". I was advised in a report from a neurologist received this morning that Richard died of a seizure, after looking at a recording. I expect the pathologist to change his DC to seizure only, the pathologist had refused to look at the recording. They told me that their decision was final and could not be changed under any circumstances. They swiftly changed their mind when challenged by other experts in this field. The pathologist advised me that they do not welcome external pressure but did make the change grudgingly. The certificate is still incorrect, as arrhythmia was not supported in tests, the pathologist refused to look at a recording of Richard having a seizure. Pathologists and officials must comprehend the lasting impact and trauma they inflict on families when there are alternate practices available to them.

We are advised to protect our identity, yet current laws are allowing tissue samples to be retained without consent, **DNA of a family**. In my opinion, this represents an abuse of rights and privacy of the grieving families.

I have read stories from across the world on tissue-sample retention and DNA. It is disheartening to witness the lack of protection, essentially equating to the theft of a family's DNA.

Part of Richard Stark's Law is to ensure it becomes a standard procedure to offer tissues samples to the next of kin. We heard in May's evidence session that this happens in England and I know it happens in Ireland and Wales too. It is unacceptable that these samples are retained without consent in Scotland. Furthermore, I am deeply concerned about the storage and use of retained samples. Scotland's capacity to store these samples raises questions regarding their whereabouts and potential uses. It is crucial to ensure transparency in

this regard and prevent any misuse or unauthorised access to deeply personal genetics.

I look forward to the outcome of the evidence session attended by the Lord Advocate and the subsequent steps taken to review and reform the existing laws and guidance.

Scotland is a beacon of human rights and individual choice. Introducing Richard Stark's Law with an opt-out system, akin to the organ donation system, would empower individuals and families to make decisions about post-mortem procedures, respecting personal autonomy and preserving the dignity of the deceased.

Scotland should be leading the way. We have a bill coming forward that will discuss assisted dying, all people want is **choice**. I don't have words strong enough to express my feelings as I write this. I will never forgive those who did this to my son, my son would have had less damage to his body if he had been attacked by a dog. I firmly believe you should go out of this world the way you came in.

The current law and procedures fail to **prioritise human rights and the right to choose**, leaving families like mine feeling abandoned and disempowered. Richard was such a gentle and sensitive boy, I am hoping he leaves a legacy behind.

Be part of that legacy. Future generations can be spared the suffering of my family. Please enact the necessary reforms to protect the human rights and choices of all individuals involved.