

30th December 2013

The Rt. Hon Mr. Jeremy Hunt MP Secretary of State for Health Department of Health Richmond House 79 Whitehall London W1A 2NS

Dear Mr. Hunt,

## University Hospitals Birmingham NHS Foundation Trust (Queen Elizabeth Hospital in Birmingham)

The tale I have to tell is a harrowing one. We have never met, nor are we ever likely to meet and you may want to have a strong drink while you read my letter, for it is long and weary, and you will think it a familiar story for, undoubtedly, where we have suffered, many others have too and they are sure to have crossed your paths, directly or indirectly. You will wonder what it is I want from you, but you have already given to me, and now I want for others what you generously gave to my husband and me. My blood still runs cold at the thought of the cruelty, the inhumanity, the torture.

My husband's name is well with the Were I a betting person, I would place a bet that his name means nothing to you, that it has already been forgotten and that's alright. You did what was necessary then, and there is no need to remember his name. My husband's name was made known to you by our Member of Parliament, the Rt. Hon. Mr. who had written to you, seeking assistance to facilitate treatment for my husband's condition. to you because he felt our suffering and the urgency of our situation when he received my correspondence, and he cared enough to act. It was not a politically motivated act as he could have mobilized the media and used our circumstances in his own interests, had he wanted to; it was an act of pure benevolence. I did, on occasion, outline our story via correspondence to the media merely because of desperation but, truthfully, we are private people with no interest in making our lives public and, while I was unhappy and disappointed then, that the media appeared to have no interest, I am thankful that the outcome now has meant we are able to retain our privacy. Indeed, this letter is not for public disclosure. The gravity of our situation was not lost on and his urgent actions were what I would have expected from the consultants responsible for my husband's care. Sadly, that gravity and urgency were lost on them, and their actions paved the way for my husband's death, a death that would have been certain, had I not been in their way.

has had a severely deprived background but managed to complete both a Bachelor's and a Master's degree and had even commenced the path for his doctorate. Throughout all of this, he has suffered with epilepsy, with some level of control over his condition. After suffering from epilepsy for many years, condition steadily worsened and eventually became uncontrollable in 2012 to the point where, at his worst, he would suffer between 25 to 30 seizures in one

morning. He had no quality of life as his debilitating condition meant he became a vegetable who could only move from the bed to the sofa. He had to be surrounded by soft furnishings. He was house-bound and bed-ridden. If he ate, he would have a seizure, if he slept, he would suffer multiple seizures; if he peed, he would have a seizure, if he walked, he would have a seizure. Never a night would pass without interruption caused by seizures/fits. What bliss it is to sleep peacefully, not so for my husband; his waking hours, like his sleeping hours were nightmarish.

The severity and debilitating nature of his condition resulted in his constant attempts to take his life and, when he finally succeeded in overdosing, his life was spared only because I woke in time to find him. The night he overdosed, he had been discharged from New Cross Hospital the day before, having suffered some 70 seizures in that week. I had to watch over him 24 hours every day to prevent him from taking his life, to the point where I became ill. Time and time again, I begged, pleaded with his medical consultants to have him hospitalised and his condition thoroughly investigated. Time and time again, my pleas were rejected and my husband made to feel he was wrong for asking for treatment, for asking for some stability to his condition, for thinking about taking his life, a life which was agonizing and unbearable. Time and time again we went to A&E, only for him to be sent home. Time and time again, brief hospital admissions resulted in him being sent home without his condition properly investigated and treated.

Our army personnel will tell you what it is like to have a grenade explode and seeing their colleagues die in front of them or themselves being involved in an explosion. Seizures are electrical currents in your brain. My husband can tell you what it feels like to have his brain in a state of consistent explosion, because that is precisely how his seizures felt to him – like grenades going off in his head repeatedly, non-stop, over and over and over. (I use the past tense 'felt' and hope this will always remain so, because of his brain operations, as will become clear later in my letter).

I hope you can imagine what this suffering is like. I recall reading an article where you mentioned that 'cruelty became the norm in the NHS'. How true, yet even that statement fails to capture the brutality and viciousness of what we (and, undoubtedly, many others) have had to endure. Medical practitioners no longer seem to have a 'duty of care'. The licences with which they practice are questionable and, while I do not follow many James Bond movies, there is one Bond film with the word 'licence' in it, which seems appropriate in my husband's case and, as more stories become known, also appears applicable in the case of numerous others. This should not be the nature of the licences of practitioners of medicine. A medical licence is an amazing tool and a privilege and should be treated as such but, for some, it is a powerful and deadly weapon.

There is nothing I can write that can encapsulate our pain, that can capture the harm to my husband, his prolonged suffering, the inhumanity meted out to him in a country that pretends to focus on human rights. I hope the day will come when, like the Nelson Mandela and Doreen Lawrences of this world, I will be able to forgive; however, I do not have their mobility and perhaps never will. Walsall Manor Hospital, the Royal Wolverhampton New Cross Hospital, Birmingham & Solihull Mental Health NHS Foundation Trust Hospital, can never make amends for their role in the torture of my husband. How majestic they sound, the Manor, the Royal hospitals, a Foundation Trust, what does all this mean, what trust do they hold; how truly cringeworthy and revolting they are. We trusted them with care. They failed and I to question their right to treat people. Yes, there were staff who treated my husband with respect and dignity and I will always be grateful to them; and yes, there were staff who fed and watered me when my husband overdosed, and I refused to leave his side, and I will never forget their kindness. I cannot forget cruelty; those who inflict cruelty on others must be avoided. Equally, I do not forget

kindness. I am not the most palatable with words, especially in liaunting, distressing and traumatic circumstances as we were in. Where others can disguise hostility with politeness, I cannot. I can attempt diplomacy and do manage it sometimes, but not in situations such as this. I honour and respect those like Mr. Mandela for it is people such as him I derive strength from; however, his conciliatory personality was more godlike than human and I do not believe I can manage that, but am thankful for his greater inner strength in empowering people like me.

Foundation Trust -Queen Elizabeth Hospital (QE), where I had to struggle to have my husband admitted. How we eventually managed to have my husband admitted to the QE is another tale which I will spare you at the moment, for it is not a pleasant tale and the bile still rises in my stomach at what we endured. Truthfully, the QE should never be mentioned in the same breath as those others mentioned above, but since they feature prominently in our experience, it is necessary to do so. It was the QE which detected the abnormality in my husband's brain, after three other nospitals failed to do so, including Walsall Manor Hospital and New Cross Wolvernampton Hospital. This was not an acquired abnormality or injury. My husband was born with this abnormality and, had it not been for the QE, I would have been visiting him at the cemetery instead of watching him recuperating at home, after his recent discharge from hospital. I would have been placing flowers atop his grave instead of helping him regain his mobility and independence after the two brain operations performed by the caring, expert hands of Dr. Chelvarajah, Consultant Neurosurgeon at the QE to eliminate his seizures.

I have acquired such a distrust and distaste for the medical fraternity that I find it onerous to interact with them at any level and, while the treatment by all staff at the QE was not at the desired quality, the fact of the matter is that this is the one hospital which thoroughly investigated my husband's condition, identified the problem and acted to attempt to cure him. They succeeded where others failed. They cared when others did not. They acted when others merely pacified and filled us with platitudes. I was not surprised when I learned of the Christina Edkins/Phillip Simelane case. Like Mr. Simelane's mother, I too repeatedly requested hospitalisation for my husband. Mr. Simelane was being treated by Birmingham and Solihull Mental Health NHS Foundation Trust. I do not know if his mother's repeated requests were made to that Foundation Trust hospital, but I know my requests were, and they repeatedly rejected my requests. I have always suspected that, if my husband suffered the way he did, there were others in the same and even worse situations; we just did not know their stories but they do exist. It is only when a case like this becomes public, the seriousness of the neglect becomes evident. My husband too, would have lost his life and not just lost his life, but would have taken it, had it not been for my suicide watch over him. 27 7 No.

In our time of crisis, our General Practitioners, Health Centre in were precisely who we needed and I am still overwhelmed by their care and interest in our welfare and well-being. They set a standard we had not experienced before. It could not have been easy for them, particularly with the volume of patients they have to deal with, but they actually appeared to place value on us as human beings and treated our situation with immediacy, assurance and, most importantly with great responsibility and undeviating support. There are many on whom great responsibility is thrust or who choose to undertake this colossal duty. are two such practitioners and they met the burden of our illness with true commitment. Our previous GP was useless. Then there was live to the way husband's Social Worker at whose quick assessment of the urgency of the situation was backed by her immense and unwavering efforts to secure medical and care services for The Home Treatment Team of the also features prominently in monitoring my husband and I can recall one fateful

day that the rushed to our home. That day saved my husband's life and my life. On another day, it was a life and my life. I mention the Home Treatment Team since the last also has a Crisis Team which I have been at odds with for failures on their part, but that hospital's Home Treatment Team has credibility and merit and deserves recognition, for they work under severe strain and cutbacks. That I have mentioned only two of their team members does not mean the others from the Home Treatment Team are not worthy of mention for they all are, and though we suffered at the hands of their crisis team, I have made my peace with them through their actions afterwards to correct the situation. My sincere thanks to the last team at the last the least hough the end, the last to save my husband's life.

Yet, the support we had paled in comparison to the insurmountable support we did <u>not</u> have. We were consistently met by blockades to have my husband hospitalised and treated. Vital funding was secured for my husband's treatment because of my relentless efforts and Minister was eventual crucial and compelling input. Thank you very much Mr. Thank you was much Mr. Thank you was much Mr. Thank you Mr. Hunt for responding to the request from our Member of Parliament.

When my husband was eventually transferred from New Cross Hospital in Wolverhampton to the QE, it was not because the consultants cared but because our tale was coming to an end that would have been brutal and, as harsh as the medical fraternity had been to us, that was how harsh I was with them. I was tired of feeling that we needed to bow down to them and kiss their feet with their godlike egos because they felt themselves to be saviours of mankind, only for them to shoo us away, while they gave themselves self-congratulatory pats on their own shoulders. As I have said, the story of transfer is another tale which I will spare you, but transferred he was, finally, to the only hospital which mattered, the QE, and to new consultants who would transform the next chapter of our lives.

On admission to the QE, it was Dr. Additional who first supported my husband's long-held theory that there was a connection between his seizures and the numbness in his left arm, despite years of his theory being undermined by other medical practitioners. (In fact, Dr. Additional) had been the only GP to refer my husband to have his arm investigated when a brought it to his attention.) We now know that my husband was correct, as the area of his brain from which his seizures emanated did, in fact, overlap with his motor cortex affecting his left side. When Dr. Was absent, Dr. The provided full care and support. Both worked with Dr. Though we never met Dr. The provided full care and 'duty of care' we experienced under the care of both Dr. Manual and Dr. The are still deeply felt by us and we are grateful that Dr. The facilitated us.

My husband's care was taken over by Lead Epileptologist and head of the Neurology Department, Dr. 1997. Who was more than ably assisted by 1997. He was our bedrock. He is and always will be that one person whom I believe embodies all the virtues of a physician. I had reached out to Dr. 1997. In desperation, before I met him. Thankfully, he came through for us when he did. And now we get to what I need from you, for it is the QE and his neurology department that need your vital support to continue to provide treatment to people who require it. They don't need miniscule funding Mr. Hunt; they need real funding, funding which matters, that will provide short and long-term research, treatment, and pioneering medicine and care. They need funding and that means you, your department and any other Secretary of State for Health. Not one person from the QE has asked me to do anything on their behalf, but I am driven to do so because of the savagery we experienced within the NHS on a whole, and the humanity of the QE

in contrast. In the drive to focus on human rights around the world, let us not forget the human rights of those in the United Kingdom for my husband was treated like a prisoner of war in a Nazi camp. His suffering was unbearable, and the weight of what we went through, you will never understand.

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I know my letter is lengthy; I am not seeking publicity and do not wish for our lives or my letter to be made public. I would not want to meet you or anyone from your team as we are private beople and it is only my husband's condition which has led me to write to you because of what we have endured. I am writing to you because I want you to understand how some of us have to live, what we have been subjected to, and that there are many others who need this help and may never get it. It scares me that there are others re-living our lives. It frightens me that there are many more Philip Simelane who are not being treated because enough people do not care. My husband was labelled a mental case, even told by one paramedic who came out to the house, that his seizures were in his mind. He had short admissions at Hospital, which is a mental health hospital although he did not suffer from a mental health condition; it was our circumstances which caused this. Birmingham and Solihull Mental Health Foundation NHS Trust facilitated this label and caused this to happen. They were brutal in their dismissive nature of his condition and his treatment. They could not even get his diagnosis correct, despite their supposed expertise. Before his lengthy admission and treatment at the QE, my husband had been advised by that mental health foundation trust that was treating him, that he had pseudo-seizures and required intensive psychotherapy. Mr. Hunt, there was no psychotherapist in the world who was going to cure him of the structural abnormality that was in his brain for all who actually cared to see. psychotherapy session would have removed the lesion. There was only one cure and the brilliant Dr. Ramesh Chelvarajah, Consultant Neurosurgeon at the QE attended to that with his capable team. Seems to me that there are mental labels being attached to people simply to keep some in high-paying jobs. 

When I was fighting for my husband's life and called those particular consultants for help because my husband was intent on taking his life, instead of trying to help my husband, they threatened me as if I actually cared about what would happen to me. I could be charged for giving my husband his medication, I was told. I knew that but why wasn't the response "let's get him into hospital asap" instead of using me to continue to hold my husband hostage to the wretchedness that was his life, a wretchedness facilitated by them. We husband was languishing in pain; he was in torture and I still blame myself for prolonging his suffering because I believed he would get help. Had I not made the stand to get him into the QE when I did, he would have been dead. I was prepared for my husband to die that die, for his anguish was substantial, and I too prepared to end my life, end it all, for those who were supposed to care existed only in theory. Like I said, I am not the most palatable with words, especially in such circumstances as we were in. Those who had a duty of care towards my husband would have had him in a cemetery. They had him languishing for months. If Nelson Mandela could stand up to his oppressors, I could stand up against ours and, had my husband taken his life. I too would have taken mine. I want you or the next State Minister of Health and all others who undertake the nature of healthcare in the United Kingdom, to know the reality of our lives, to understand our trauma and to put in place funding for the Queen Elizabeth Hospital where they appear to genuinely want to treat people, to find solutions, to give people back their lives. I also want you to implement measures to prevent those from practicing who should not be, for it is not a pleasant thing to seriously jeopardize people's Hives. The outcome has proven evident so many times. How the family of Christina Edkins must mourn for they will never ever get her back. How Mr. Simelane's mother must mourn for the son she has lost and for his slaying of another, not because he was a truly violent person, but because he suffered a serious illness without getting appropriate medical treatment for which she begged, pleaded.

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We eventually got the treatment but it still pains me that I contributed to my husband's suffering. Please bear in mind that, when I speak about the cruelty, I am speaking about other consultants who are not connected to the Queen Elizabeth Hospital. Prior to his admission at the QE, the care of (my husband) was with others outside of the QE. My husband's care was with Birmingham and Solihull Mental Health Foundation NHS Trust. Once was admitted to the QE in June of this year (2013), that was when we saw the real professionals at work. These were Dr. Ramesh Chelvarajah, Dr. Dougall McCorry, Dr. Tom Hayton, Dr. Andy Hawkins, Dr. Sharon Muzerengi, Dr. Tom Baldwin, Dr. Daniel (Dan) Bailey, Dr. Andy Hawkins, Dr. Colin Shirley, Mrs. Satinder Bhath and her Clinical Physiologist team comprising of Shakil Qabil and David (Dave) Rollings. Dave always spared the time to talk to us; his interest in his work was refreshing and captivating. He does research each week at the University of Birmingham, which translates to medical knowledge, care and value to the QE. I have also mentioned the very patient and thoughtful Dr. Andy Hawkins, Consultant Clinical Neuropsychologist, where insufficient funding means that he cannot dedicate more time at the QE; that's woefully inadequate Mr. Hunt.

I have mentioned these key persons but they had a team working with them and I thank every single one of them and ask Dame Moore, the Chief Executive of the QE, to whom a copy of this letter is being sent, to extend our thanks. I have no problem in them receiving a copy of my letter but it is <u>not</u> otherwise intended for public disclosure. Saying thank you seems so inadequate. What they have done is accomplish a feat that appeared to be beyond the scope of others in the medical field. It is no small accomplishment, yet funding had ceased for the operation my husband required. Why? Why do this to people? Why leave people to suffer in this way? Why take away something that is vital to people and leave them to die because there is no other way out? Why? Why are those to whom we expect to care for us so distant, indifferent, unfeeling, merciless? Why take a global stance against suffering worldwide and ignore those at home.

I still become overwhelmed when I think of Dr. Chelvarajah, humble, nice, confident but completely lacking in arrogance. He performed two main brain surgeries on the intra-cranial EEG and the second operation to remove the electrodes as well as the lesion. I watched incredulously, hope mixed with despair, as Dr. Chelvarajah conducted his meticulous investigations, managing his team with tenacity and assurance. I had faith in them but amidst that faith was fear; the QE was where needed to be; that he was finally there was a relief but the outcome was still uncertain.

Dr. Chelvarajah had informed us that, due to the locality of the abnormality around the motor cortex and cognitive area of brain, it was likely that ability to communicate would be affected. He could also suffer partial or full paralysis of his left side, if the lesion/abnormality was removed. How would you feel if your partner or child had to go through this, or your mom, dad, sister, brother, a good friend? There could be no partial removal of the lesion; it had to be removed in its entirety for chance of seizure freedom. It was a painful moment but we had no choice, for chand no life, and Dr. Chelvarajah and his team worked relentlessly to explore the possibilities of surgery before taking the plunge. Through their careful and thorough exploration, Dr. Chelvarajah concluded that the abnormality could be fully removed with having full mobility, with the exception of his left arm/hand. This, again, was a painful moment; it was bittersweet but again, had no life so we had no choice, and there were gains, as we had moved from a position of partial or full left-sided paralysis to losing the use of one limb (the left arm/hand). We all want it all, but life doesn't play fair and the hopelessness of the previous hospitals and medical doctors had been replaced by what was to become the miracle of the QE.

The risks were great; could end up losing his life but we had a chance where none had existed before. And guess what Mr. Hunt, funding for this type of procedure had stopped . . . .

My husband had two brain surgeries in August 2013, a fortnight apart, his intra-cranial EEG on Friday, 9th August 2013 and the removal of the electrodes and abnormality on 23rd August 2013. Though not due at work, Dr. Chelvarajah came to see the following his second surgery the day before. He saw the disappointment we felt at the immobility on the left side and knew that we felt he had let us down when we realised there was paralysis as a result of the surgery. We did feel crushed but we also realised it was very early days and the merit of what he had done would become evident as the weeks passed, as regained some strength on his left side and has continued to be seizure-free. We hope this continues. My husband is now able to walk for short distances with a walking stick but requires a wheelchair for longer distances. Where there had been no movement in his left arm and hand, he now has very slight flexion in his fingers and can manage the occasional fold of his elbow, though this takes gargantuan effort on his part. Dr. Chelvarajah had not let us down; he and his team had given the life back.

Dr. Dan Bailey too, who was also not due at work that Saturday, also came to check on and became concerned when he learned that I had spent the night sitting/sleeping downstairs in the reception area at the hospital because I could/would not walk away from the hospital and leave my husband. Dr. Bailey understood what the nursing staff did not; that even when they turned me away. I would not go; he understood that when one has gone through what we had, one could not simply walk away. He may not have known all the details but he understood a lot. Maltreatment and negligence had made me distrustful of medical staff and, despite the interest and care of the specialist medical team, my husband had suffered at the hands of some of the nursing staff at the OE, so I would see my husband through to the end, no matter what hurdles were placed in my way. I had this fear of leaving and returning to find my husband dead. It has happened to others at so many hospitals and, considering the negligence we had suffered from the medical fraternity as a whole up to this point, it was not inconceivable. I think, in his unassuming manner, Dr. Bailey understood this and addressed it with ease; no fuss. Just as importantly, whatever the nursing team at the QE did wrong, most of the doctors acted immediately to correct. I can recall only one incident when Dr. Chelvarajah was absent and I reported an unacceptable issue regarding my husband's medication to the consultant who was covering for Dr. Chelvarajah. His response was not satisfactory. I reported the issue to Dr. Hayton the following day, when I next saw him. Dr. Hayton immediately rectified the situation with ease; no fuss.

As for Dr. the had seen almost every single day since he became main doctor; it didn't matter which ward was on or whether Dr. that had just moments to spare, Dr. the was always there, always. Every day was another day of further disempowerment for my husband; Dr. took on the responsibility to re-empower to get through each day to help make it to the end. I didn't always see him but I saw a lot of him. It was enough that he was there for the Anyone who was there for the was also there for me. Was an emergency case, suffering from a debilitating condition where his brain felt like it was consistently being fried. When he was admitted to the QE, he wanted to live but had had long lost the will to do so. One could not continue to exist with such a condition. Every day of investigation meant another day of suffering for him, as the doctors sought to fully get to the bottom of his condition. Each day of their investigations (and a thorough investigation it was), meant another round of seizures and another day and night of torment for him and he did not want this; it was unbearable, excruciating afflicted days and nights. Dr. The second to relieve his pain and reject his medical discharge because the discharge meant certainty of death. When Dr. took over, his precision in his care, in his personal monitoring of the and administering medical aid was

flawless. We need more like him. What I also discovered was that he was this way with all his patients. This one doctor was more doctor than many combined. I recall mentioning to Dr. that it was a good thing we saw so much of Dr. as we saw so little of him (Dr. Dr. Dr. Dr. response was that it was precisely because we saw that much of Dr. why we didn't need to see him – pretty good deduction. The QE is like an institution full of the matching intellect of Sherlock Holmes. They have the brains and they actually care; they just need you and any other Secretary of State in charge of Health to make sure they go the funds to do what they are indeed gifted to do, and are, additionally, keen, responsive and inspired to do.

I write to you because, no matter how light-hearted aspects of my letter sound, my heart is still full of pain for what we endured. I mention these persons because I want you to understand the brutish cruelty we experienced on the one hand, and the immense kindness, support and medical care from those at Hospital, Drs. knowledgeable and expert care by the highly competent team at the Queen Elizabeth Hospital. The QE was where my husband needed to be. There is relief that we have pulled through and we are hopeful that my husband will continue to be seizure-free because of the essential operation/treatment these integral physicians performed. Mr. Hunt, as the man who currently filtimately governs the NHS, you can act to prevent this inhumanity and to ensure that others like my husband benefit from the treatment they require. You can act to prevent deaths such as Christina Edkins by ensuring people like Phillip Simelane are not sidelined, and you can reduce suicidal attempts by those who feel there is no other way out because, not only do their conditions make them dehumanised, but so too do those who are entrusted with their medical treatment. Any life-changing, soul-destroying situation makes one reflective and I reflect on my own situation and my own education, which is similar to my husband's. We, like many others, left university filled with hope, dreams and plans. Much of this will not be realised but, if all it has led to is this moment where we are in a position to advocate to prevent mass deaths within the NHS, then perhaps it has led to some good. I have cried for too long because the NHS held my husband hostage. My tears could have filled rivers, canals and many reservoirs that have run dry, but I've stopped crying now. I hope to never be in this position again. Now, I am reclaiming our lives and, in doing so, I hope to be able to assist others who have no voice and no one to speak and fight on their behalf, to reclaim their lives. I do so by appealing to you.

In our time of crisis, the Home Treatment Team at Hospital, Drs. How and Hospital entered our lives in a meaningful way. As things worsened, the QE became that elusive important element. Never before have I seen such passion, interest, compassion, sincerity and empathy as my husband and I experienced at the QE. There were imperfections and I would like to think the Chief Executive of the QE will address these, which I will outline in my letter to that hospital in due course. Importantly, this hospital needs funding Mr. Hunt. They need it to help them to progress their work in an area which is deficient in expertise and care. Your funding is a lifeline to others in similar circumstances. Their neurology unit doesn't just need funding to exist; they need to expand; they need to be able to conduct research and engineer and perfect treatment in this area. Bear them in mind. Bear in mind those indispensable social workers and key staff such as those who are part of the Home Treatment Team at Hospital. Bear general practitioners such as our GPs in mind, who act with integrity for their patients' welfare. When all was focused on my husband, our GPs focused not only on him, but also on me. If How were to live, I had to live. My physical and mental needs fell into their hands, which they are still crucial in managing to this day.

At some point, you will take on another role and you will forget my husband and me, and that is fine; you've probably already fallen asleep after my first few pages. You never need to remember us, just so long as you always remember that the conduct and scale of the reprehensible

You do no need to respond to my letter Mr. Hunt but I do hope you manage to get through it and that you take immediate action necessary to prevent current and future harm. Delay means death.

Best regards.

Yours truly,

Copied to: