

Translation from "Il Sole24Ore", Sunday March 22, 2009

Charles Sabine, NBC War Correspondent

FROM THE BATTLEFRONT OF HUNTINGTON'S DISEASE

As the roman winter of 2005 turned to spring, i found myself caught, most evenings, in the rain showers falling on the vatican. Pope John Paul II's body was finally giving way to time, disease, and an assassins bullet. As a journalist, I had seen first hand the end of communism in his homeland, and inhaled the incense of his last pilgrimage to the holy land. But despite this affinity, I was not truly focused on his health, but on my own. For I was about to take a test which would determine the course of my life.

I have spent more than half of my life working for NBC news, mostly in places where the dangers of religious dogma are written in blood. Recently, Baghdad, where I learnt that good health can never be taken for granted. That was the lesson my *family* learnt, in january 1994. From that moment, every day would be coloured by that revelation.

My father was suffering from Huntingtons disease – a condition I had never heard of. It was, I was told, incurable – untreatable and genetic. I had a 50/50 chance of developing the disease myself, in the next ten to fifteen years. The independence I had spent so long cultivating, fell away like a silk cape from my shoulders, leaving me with a vulnerablity and fragility I had not known in adult life.

The problem with trying to *describe* HD, is that you run out of superlatives. Is the worst the loss of dignity for a once proud man to watch friends wince as his body and mind become twisted? As his heart lets out a silent cry for help? No. I know for certain my father would have willingly suffered all of that a hundredfold, if he could have been spared the worst pain by far. Which was to knowingly pass that nightmare on to his sons. My brother john is five years older than me. He joined one of the most prestigious law firms in Britain. Now, before meeting his neurologist, he practices walking in a straight line because he knows she will ask him to do it, and it is very difficult for him.

No-one should think that research into diseases like that which has struck my family is not relevant to them. The families whose lives are destroyed by dementia, represent a community hidden by its own shame and made transparent by a vacuum of self esteem – but a community far larger than people realise. By the middle of the century, some experts predict half the population of Europe will have some form of dementia when they die.

Twenty five years of watching men kill each other has taught me that societies lose their moral compass - their social equilibrium - when you take away from them; dignity and hope. Yes, those with dementia suffer a vacuum of dignity. But do they have hope? Well, we are at a *potentially* pivotal moment in medical history. It is possible that Huntington, for example, holds the answers to many questions of the future for everyone. If other diseases could also be predicted through genetic mutations, symptoms would only be treated as a last resort. Stem cell research, also, is at the threshold of untold promise – a fact recognised by the new us administration, which wants to repeal archaic legislation. So what stands in the way in Europe? Well, two strands that usually inter weave into a tapestry that shrouds vision – fear, and lack of communication.

Charles Darwin was dismissed by the Church as a heretic when his *Origin of the species* was published 150 years ago. But as Darwin himself said: "Ignorance more frequently begets confidence than does knowledge." The Vatican derided him for 'insulting the dignity of the human species.' The same Church that stayed silent on the issue of slavery— an issue he spent his life trying to end, as a *real* crime against human dignity. Now, the Church fears stem cell research. I've learned to recognise fear.

In march 1996, in the last days of the war in Yugoslavia, I was captured with a camera crew by a renegade platoon of mujahadeen guerillas. As the sun set, and the mujahadeen began a call to prayer, they fired a salvo of missiles at the serbian lines that were two miles to the north. I was by the door of our armoured car and could see the blood splattered wall where 2 overseas development workers had been blindfolded and shot the day before. The young fighter who had held an AK 47 to my chest for the last five hours, took the pin out of a grenade which he then held to my head while he closed his eyes and prayed to Allah. *That* is an experience of real fear. But not that moment, nor any other I have experienced, instills more terror than Huntington's disease.

In the end, though, I did return from Rome to take that test, and discovered that the disease that took my father and is now taking my brother, *will* take me, as well. Not an hour passes, when I don't picture how my quality of life will drain away, or wonder whether I will be able to dance with my baby daughter on her 16th birthday. Every day, thousands of sufferers slip into the cauldron of despair where they have lost hope that research might bear fruit in time for them.

Do not underestimate what the work of scientists means to the millions around the world who suffer from these diseases, and the even greater number who care for them, as we scour the newspapers and internet for any fragment of news from their laboratories. In a world of total darkness, the very faintest glimmer of light, emboldens the human spirit to go on. Following the invasion of Iraq in 2003, I went to find out what had happened to the country's mentally ill, during the war. In the country's only asylum, the doors had been stolen by looters and most of the male inmates simply walked out. The remaining women had no water or medication, and many were raped by the looters. All the staff had fled, save one. A nurse called Leyla, who disguised herself in an inmates uniform and risked all, to stay and look after the women who otherwise would surely have perished. My first reaction, was to think that the words 'god-forsaken' could never have been more apt.

But on reflection, I realised that in fact someone's god could not have been more manifested than in the power of human courage and simple love and goodness that nurse showed. It is in the darkest moments that the greatest qualities of the human spirit shine, and in doing so, they give us all hope.

It is in the nature of humanity to care for the infirm and strive to make them better. No single body has the right to impede that instinct. Huntington has had the power to challenge the human spirit. But it has lost that battle, because the very best of humanity surrounds it. Any organisation that stands in its way will have its conscience to reckon with. And I pray for its members sake, that neither they, nor anyone in their family, suffers from one of the diseases whose treatment they impede. It's within the reach of today's scientists to change what is perceived as unchangeable, because the human spirit is capable of anything.

In 1991, after the gulf war that did *not* remove Saddam, I went to the Iranian border with Iraq, after rumours that Kurdish refugees were spilling across it. What we found was a sea of humanity pouring over the mountains. A million people – mostly women and children - running from Saddams chemical attacks in the north of Iraq. It was winter - bitterly cold, and the sights would never have been believed had there not been a cameraman with me to record them. But the image inprinted in my mind till the day I die, was one particular girl of about 12. She was clambering over the rocks, focused on survival. On her back, was her younger sister, three years old, unconcious and barely alive. She had carried that child almost ninety miles.

We are capable of far more than you can ever believe, and a better world really is within reach. It may be too late for me, but on behalf of todays children and those who have not been born – I say; it is our collective moral responsibility, to give the millions who have until now, made up a lost European community, dignity and hope.