

Stem Cell Opponents? Give Me Your Best Shot

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<http://dx.doi.org/10.1016/j.stem.2012.07.011>

For generations, families like mine have had to suffer a total absence of treatments for the devastating effects of Huntington's disease (HD). But an unprecedented collaboration across scientific fields has now brought the first real hope of therapies in the future.

These approaches involve pluripotent stem cell technology on two fronts: ongoing work using human embryonic stem cell based transplantation is showing highly promising results, raising hopes that that these types of approaches could provide delay in disease onset and progression (e.g., [Ma et al., 2012](#)); and human iPSCs differentiated into neurons and other brain cells, used to study the disease, to confirm current HD cell therapies, for drug screens, and for, potentially, transplantation, are presenting evidence that they could lead to new therapeutic targets and drug candidates (e.g., [An et al., 2012](#); [The HD iPSC Consortium, 2012](#); [Perrier and Peschanski, 2012](#)). Other strategies involving different types of stem cells, particularly neural stem cells, or even activation of endogenous stem cells, have also been encouraging ([Benraiss and Goldman, 2011](#)).

But still dogma threatens these green shoots just as HD families have begun to dare to hope. Members of the European Parliament are under immense pressure from Catholic organizations to exclude embryonic stem cells from Horizon 2020, its program for research and innovation for the next 6 years. In addition to the disastrous effect of such a vote on direct funding, the pressure of the "anti" groups continues to cause wider fallout. Despite the targeting of embryonic stem cells, all stem cell research becomes tarred with the same brush, and opponents seem strangely happy to leave waters muddied. Investors, academic institutions, and other parliaments, preferring to stay away from contentious matters in times of recession, will often be more inclined to follow public opinion that they suspect may be flawed than attempt to reeducate.

The most effective argument of the opponents' lies not in any interpretation of religious texts, but in the *relativity* of medical research. *All medical advances are relative anyway; there will always be people made miserable by disease.* Scientific progress merely moves the goal posts of what those ailments are. Plague? Tuberculosis? HIV/AIDS? Multiple Sclerosis? Pick your century.

In short, opponents might argue, "Why not save resources for those we know we can help, and let God, or natural selection, sort the rest out, rather than chasing the unobtainable (and probably undesirable) dream of neverending life for the sake of scientists' egos?"

My reply to this "best shot" refers to a powerful human trait that I was privileged to witness in my career as a TV news correspondent, but which the opponents seem blind to: the instinctive desire and need for human beings to want to look after, or improve the health of, those who are sick.

If the Nazis had won the Second World War, I would very likely not be typing these words, because they advocated (and effectively practiced) euthanasia for people with my disease. A 1938 Nazi poster promoting the compulsory euthanasia program pictures a doctor standing next to a patient with HD, and the words, "This person suffering from hereditary defects costs the community 60,000 Reichsmark during his lifetime. Fellow Germans, that is your money, too."

But this eugenic interpretation of Darwin's theories would have depressed him greatly, because he was very clear on this issue: the "balance of dependency is part of our social axis," allowing the growth of the "instinct of sympathy," which he called "the noblest part of our nature" ([Darwin, 1871](#)).

HD has challenged the human spirit because it has sucked hope into a vortex. But it has never defeated that spirit, because the very best of humanity surrounds it. The tireless patience of the

caregivers, and the extraordinary devotion from the scientists and clinicians—these are the battlefields on which the greatest qualities of the human spirit shine brightest, and in doing so, give us *all* a reason to exist. The right to care for the infirm and strive to make them better is no less sacred than the right to bear children. No person, or organization, can keep any moral high ground if they stand in the way of those who might offer better quality of life.

I ask those who refer to a "monstrous attack on human rights" through stem cell research's "evil" endorsement of "Frankenstein" experiments ([O'Brien, 2008](#)) to have the courage of their convictions to discuss with *me* on a public platform what truly constitute relevant "human rights" and the "dignity of man" in this issue, someone who has seen his father's pride destroyed, and who not only faces an equally terrible future, but has to brace the next generation for the same fate too.

The act of witnessing more than a dozen wars, five revolutions, four earthquakes, and more suicide bombings than I can count has left me with a stark lesson about mankind: human beings lose their moral compass—their social equilibrium—when you take two things away from them: dignity and hope.

The vacuum of dignity wrought by HD upon my father was no more or less vividly exhibited than in any other sufferer of the disease. He was a once proud soldier who had to watch friends and family wince as his body and mind became twisted until unrecognizable; my mother broke both of her wrists lifting him out of baths, before he finally found death a blessed relief from a tube down his throat acting for his stomach.

And what about hope? Do we HD families have that?

The answer to that question lies in the hands of not only the researchers who are the custodians of new science, but also the legislatures, executives, and

churches that will dictate how our societies treat the infirm in the 21st century. Neither group should underestimate what research means to the families around the world who suffer from untreatable diseases, as we scour the media for any fragment of news from laboratories. In a world of total darkness, the very faintest glimmer of light emboldens the human spirit to go on.

We in the communities of families suffering so far untreatable diseases owe a debt of gratitude to all those who have had the courage to not bend in the face of dogma, and we appreciate that they

should feel very proud of pushing the frontiers of medical understanding. It may be too late for me, but on behalf of the next generation to face HD, those who have yet to be born, and those whose lot it shall be to care for them; I say: thank you.

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