



## **ESTABLISHING FUTURISTIC RIGHTS - LESSONS FROM THE CURRENT EXAMPLE OF REGULATIONS GOVERNING GENOME EDITING**

David Wood, Chair of London Futurists and  
Principal, Delta Wisdom, London

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I'm going to talk about the kinds of arguments we need to make if we want to establish futuristic rights. I'll try to draw lessons from some examples of arguments and discussions about establishing rights in other fields. In particular, I'm going to look at some things that have been happening in the last few weeks, which are arguments and discussions about genomic editing, such as CRISPR<sup>1</sup> editing, in which people would have more rights over what kind of children they might bring into the world, and also rights over their own body in ways that haven't been possible before.

I was at a conference in London yesterday of several hundred people, in which many of the leading protagonists of genomic editing were discussing their experiences and what they had achieved. I think there are useful things to come from this.

I am a technologist; I spent twenty-five years developing technology for mobile software, mobile computers and smart phones. I have great confidence that exponential technologies (nanotech, biotech, infotech and so on) are the main driver for human enhancement. However, I am not a technological determinist. I believe that the whole process is strongly influenced by lots of non-technical things, including the expectations that the market brings, the way that subsidies are applied, the ways incentives operate, and regulations and the law. In turn, all of these factors are heavily influenced by politics.

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<sup>1</sup> CRISPR - an acronym for Clustered Regularly Interspaced Short Palindromic Repeats; For more details, see for example the book "A Crack in Creation: Gene Editing and the Unthinkable Power to Control Evolution" by CRISPR pioneer Jennifer Doudna

The story of my own evolution over the last few years is a little bit similar to Zoltan Itsvan<sup>2</sup> in that both Zoltan and I have come to appreciate that if we really want to change the world and let technology do its very best for humanity, we need to get involved in the political process too. There are often good reasons why politics impinges on the development and deployment of technology. We futurists and transhumanists need to intelligently and wisely engage in that discussion.

Let's look at some examples of where technologists have *failed* to engage properly in such discussions and have got themselves into trouble. One example is with genetically modified organisms (GMOs). Especially in Europe, the positive argument for GMOs was not well communicated – in Europe, most governments have rules in place that prevent the proper use of these organisms in ways that would produce much better, healthier foods and so forth. That's one example where people have been adversely influenced by graphical pictures and other distortions, in which the argument is, "oh this is dangerous and therefore, we must stay away from it".

Another example in which the argument has not been properly won and in which non-technical matters tend to dominate the debate is over the future of another kind of enhancement, in which we might power some of society with nuclear energy. Just as with GMOs, there are some significant objective arguments

that deserve to be heard, but lots of what is discussed in the general public is much more emotive and is a distortion of what is actually happening. To mention just one point, few people realise that the Three-Mile Island nuclear accident, which received a storm of publicity, has actually had apparently no effect on cancer rates in the surrounding area.

### Technologies with adverse social reaction



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Credit: Windows Mobile <sup>TM</sup>. 2010. Microsoft Corporation.

<sup>2</sup> Zoltan Itsvan - Founder of the Transhumanist Party, a legally recognized and PR-minded political effort that calls attention to what tomorrow's mainstreaming of today's rapidly developing technology could mean for human life. Retrieved from <http://www.zoltanitsvan.com/TranshumanistParty.html>

Another example in which social discussion and public opinion strongly influenced how well technologies were accepted and adopted comes from my own background in the mobile computing and smart phone industry. Microsoft failed, time and again, to gain much traction or engagement from many of the phone manufacturers, not because of technical reasons, but because these companies were fearful of what that big, powerful company had done in PCs - dominating that industry and extending standards in self-centered ways. That's why companies were afraid to give Microsoft too much influence over the mobile phone space. Microsoft is still, to an extent, locked out, even after all that time.

I'm also glad how governments of the world said to Microsoft, "we are going to apply some regulation over what you do, so that when you roll out new versions of your operating systems, Windows, you will not bundle the web browser, Internet Explorer (IE), so tightly to it that other browsers have no chance." That was a great example of a regulation working positively.

Another example in which regulation can work positively is in the emerging field of drones (self-flying vehicles). Many of us are technological fans of the idea of what drones might be able to deliver, but drones are also dangerous. Here's an example of last year in which a father was showing off a drone to his child, and he didn't pay attention to the fact that it strayed too close toward the path of a major airline with a resulting incident risk rating of A (serious risk of collision). There are some needs for regulations there.



Credit: <http://www.theguardian.com/world/2014/dec/07/drone-near-miss-passenger-plane-heathrow>

We could talk briefly about one other example in which a company, 23andme, has some very interesting technology – technology to help people understand their genetic makeup more fully - but that company has run into lots of regulatory hurdles, especially in America. The Food and Drug Administration (FDA) took issue with some of the

advice that 23andme was providing, and shut down some of the services that 23andme wanted to offer. It's not clear exactly what the correct apportionment of blame is in this case, but from my own experience working with regulators, I will not accept that they are all narrow-minded conservatives opposed to innovation. On the contrary, there are many regulators who would love to see innovation, but they are also fearful about adverse side effects of modern technology. My conclusion from this is that companies such as 23andme need to become better at engaging with the regulators.

I've discussed all of this to set the tone to shift to the field of genetic editing. It all starts at the beginning as it were, in the 1970s, back when I was a student, back when there was a huge public discussion about test-tube babies. Test-tube babies were, for a long time, extremely controversial within the general public. I remember many religious people saying that this idea was an abomination. Here's an excerpt from someone who believed they were channeling 'Our Lady' in 1978 who said,

"It is an abomination in the eyes of God for man in his arrogance ... to create the living being. What he is creating is a soulless monster...!"

## Changing mindsets



"It is an **abomination** in the eyes of God for man in his **arrogance** and pride to seek to create the living being. What he is creating is a **soulless monster**, a being of destruction for all that it will meet. I say 'it', for it is not truly a human being but a 'thing'!"

– Our Lady, July 25, 1978

Opposition from politicians too

And from fellow scientists

Request for funding was denied by the UK's Medical Research Council

Credit: [https://web.archive.org/web/20160701094432/http://www.heaven-speaks.com/bayside\\_test\\_tube\\_babies.html](https://web.archive.org/web/20160701094432/http://www.heaven-speaks.com/bayside_test_tube_babies.html)

Credit: <http://www.newscientist.com/article/dn19537-test-tube-baby-pioneer-wins-medicine-nobel.html>

As a variant of that argument, people worried that test-tube scientists might manage to create something that looked human, but something fundamental would be missing. It wasn't just the religious people who were opposed to the scientists 'playing God' as it was termed; politicians at the time were also fearful of it, partly because they were respecting their religious constituency, and partly because they were influenced by another prevailing social opinion, namely the fear of overpopulation. Many of the politicians therefore said, "we've got enough people on this planet; we should not be spending lots of money to find yet more ways to add more people, like in-vitro

fertilization for infertile couples.” In fact, many of their fellow scientists and other doctors were hostile to the works of the two scientists, Dr. Patrick Steptoe<sup>3</sup> and Robert Edwards<sup>4</sup>, who performed this original work. Many of the women who were original test subjects suffered tremendous pain, due to hormonal ups and downs. Public funding for these scientists was denied, so the research was funded solely by private individual donors. It was tough work, but it all changed just a few weeks after the denouncement from the Virgin Mary, as it were, when ‘Super Babe’ arrived, as proclaimed by one of the London newspapers of the time. Louise Brown, the world’s first test-tube baby, born in the United Kingdom, appeared extremely normal. She was a charming, lovely, cute child. As people looked at her, and at all the other test-tube babies who were increasingly born, they could not discern any lack of soul; they could not discern any lack of humanity. Although some opposition remained, the public mood thankfully changed, remarkably quickly.

Looking at this positive example, we may be tempted to think we just need some heroic scientists to pioneer the way, and then eventually the public opinion will change automatically. However, in general, things are more complicated. Let’s move on and look at a few other examples.

More recently, there’s been a lot of discussion about another form of genetic editing. In this case, it is to fix a particular type of disease, which is often passed on in families; it is called Mitochondrial Disease. Consider the case of a woman, many of whose siblings had died at an early age. Two children from her first husband also died at an early age, and the third was very ill – all due to this inherited Mitochondrial Disease. The woman then divorced her first husband and married a second time. Three of her five children from that marriage died at an early age and the two others were very sickly. This story was told in recent debates in Britain by one of the doctors who had been looking after this family for many decades. The story doesn’t end there. The woman was so desperate to have a ‘normal’ child she had another partner and sadly, that child died early as well. A few years later she tried again with another partner. Unfortunately, that child also died.



(25 July 1978). Front page, *London Evening News*.

I mention all of this because this human story of grief from a genetically inherited disease was one of the factors that made many of the politicians in Britain, in a recent vote in the House of Commons<sup>5</sup> and then in the House of Lords<sup>6</sup>, say, “we should be

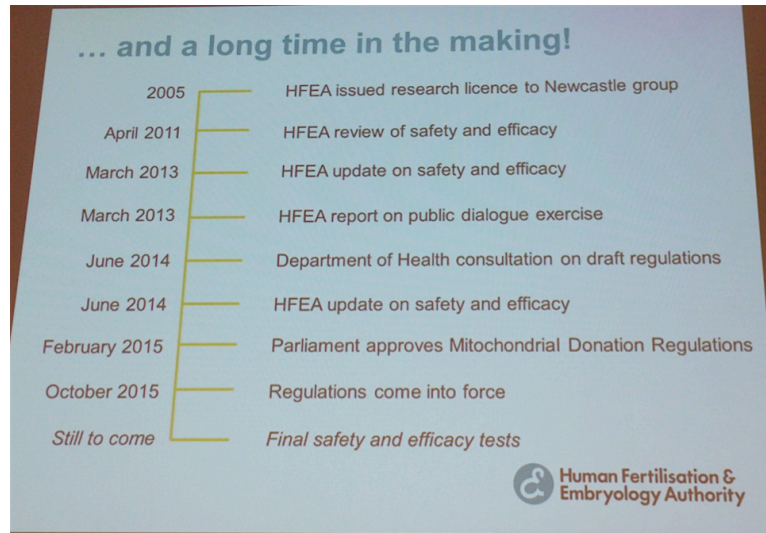
<sup>3</sup> Dr. Patrick Steptoe – [A] British obstetrician and gynecologist Patrick Steptoe (1913-1988), gained international acclaim when years of hard work resulted in the birth of the world's first "test tube baby." Retrieved from <http://biography.yourdictionary.com/patrick-steptoe#ozAZmv21A5zrTycm.99>

<sup>4</sup> Robert Edwards – [A] Cambridge University physiologist [who] developed a technique for fertilizing human eggs in the laboratory, in an effort to help women with defective fallopian tubes become pregnant. Read more at <http://biography.yourdictionary.com/patrick-steptoe#ozAZmv21A5zrTycm.99>

<sup>5</sup> House of Commons - The UK public elects 650 Members of Parliament (MPs) to represent their interests and concerns in the House of Commons. Retrieved from <http://www.parliament.uk/business/commons/>



open-minded about this”. They opened their minds to the idea of allowing what’s now known (a bit misleadingly) as 3-parent children, in which the mitochondrial DNA (in the main part of the egg as opposed to the nucleus) can be changed, incorporating material provided by another mother. The main part of the DNA, the nucleus, comes from the original, natural mother, but the mitochondrial DNA comes from the second mother.



Initially, many people, particularly people with a Catholic background, were horrified at this possibility. But over a long period of time - and you can see it on this chart – minds changed. Back in 2005, a group in Newcastle in the north of England started doing research work under license from the Human Fertilisation Embryology Authority (HFEA)<sup>7</sup>. Over more than ten years, numerous trials took place, and various possible regulations and standards were discussed governing when and when not these therapies might be applied. Eventually, there was a debate in February 2016 in the Houses of Parliament, and Britain became the first country in the world to legalise this treatment.

As I said, I attended a conference on this topic in London yesterday. I think many of the recommendations from this conference apply to other fields in which we transhumanists and other technology enthusiasts would like to get public support for some of the things we want to do. First of all, there is value in slow moving bureaucratic bodies such as the United Kingdom HFEA, because when conservative critics say, “oh we’re rushing into this, we’re on a slippery slope”, people are able to reply, “nothing of the kind”. Bureaucratic processes are in place to guard against misuse – use outside what’s already been approved. Second, there’s great value in preparing the ground, airing the issues well in advance and getting the general public used to the idea. Third, there is also great value in seeking to clearly separate science questions and value questions. It’s

<sup>6</sup> House of Lords - There are about 780 members of the House of Lords; not voted in by the public. Retrieved from <http://www.bbc.co.uk/newsround/18005165>

<sup>7</sup> Human Fertilisation Embryology Authority - <http://www.hfea.gov.uk/>

often the case that when people say, “the science isn’t clear here” – that what they actually mean is, how science is affected by their values is not clear. It is much more important to be able to state clearly what the science makes possible, and then have a separate debate about our values in reaction to that. Fourth, it’s important to emphasise the benefits as well as the risks, so when people exclaim, “There are risks with this technology”, we can point to the strong benefits including human benefits, speaking to the heart as well as the head.

Speakers at the meeting also spoke in favour of engaging bishops. Indeed the House of Lords in Britain has a number of bishops sitting in it for historical reasons. There was some fear that these bishops would disrupt and vote against the proposal. But after gene-editing supporters took the time to explain to many of them what the science was, it turned out that many of the bishops were swayed by their humanitarian instincts, rather than conservative theological instincts.

I move on to the most recent discussion about the phenomenon, which is using CRISPR, a different mechanism to edit embryonic genes, possibly even pre-embryo. There was a debate in Washington DC over the last few weeks on CRISPR. Perhaps the most impactful part of that debate was from Sarah Gray of the American Association of Tissue Banks, when speaking to the panel of scientists from the floor while choking back tears. She spoke of how her son suffered before dying six days after he was born from a genetic disorder. This was a different type of genetic disorder, one that couldn’t be fixed by mitochondrial offering. “If you have the knowledge and skill to fix these diseases”, Gray said, “then frigging do it!”

There was an article in Britain’s Daily Telegraph<sup>8</sup> on December 9, 2015, quoting Britain’s Chief Science Officer, who reports to British Government about science issues. He is quoted as saying; “Britain should lead way on genetically engineered babies.” What he basically said is that Britain is good at the science and good at putting in place regulatory frameworks, which can give the general public confidence with how the science is used. Public debate takes time – it’s important to walk it through. It’s important to challenge some people’s naivety, in things like the Precautionary Principle<sup>9</sup>. The Precautionary Principle essentially says, “let’s avoid anything that involves risk.” The answer to that is that doing nothing has lots of risks; doing nothing involves accepting the risk of disease and people who are otherwise going to be afflicted.

Of course, we transhumanists want to go beyond just offering repairs and cures for which the public reaction is often, “yes, I guess that’s right”; we want to move to a phase when we can get public support for enhancement, and this is where the futuristic element comes in. Related issues were also briefly discussed at the conference in London. Some speakers said, actually it’s not a diametrical opposition – cures *versus*

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<sup>8</sup> Knopton, S. (9 Dec 15). Britain should lead way on genetically engineered babies, says Chief Scientific Adviser. *The Telegraph*. <https://www.telegraph.co.uk/news/science/science-news/12042178/Britain-should-lead-way-on-genetically-engineered-babies-says-Chief-Scientific-Adviser.html>

<sup>9</sup> Precautionary Principle – [A] major principle of international environmental law and is extended to other areas and jurisdictions. Retrieved from [http://www.newworldencyclopedia.org/entry/Precautionary\\_principle](http://www.newworldencyclopedia.org/entry/Precautionary_principle)

enhancement; there is actually a continuum. There are various ways in which we can enhance people to make them less likely to have diseases. For example, vaccination is in many ways an enhancement because, in mass quantities, it makes people less likely to be afflicted by diseases, which previously were very prevalent. We can go further and point out that surgeons would be less likely to err if they had steadier hands and had more self control, ate more healthily, had better memory and keener thinking. Such enhancements will help their patients to avoid sickness and illness. That's another argument where some enhancements will enable people to live healthier lives.

The final stage of this argument is to recognise that what's natural is often flawed and that 'humanity+' can be decisively better. The enjoyment provided by 'super babe' Louise Brown is a foretaste of the joy and fulfillment that futuristic 'super people' can enable. The kinds of arguments we must take the time to develop and engage the public include steps like showing that these future 'humanity+' people will be attractive rather than weird, and that transhumanism upholds and elevates what's best about humanity. Emphatically, there's nothing anti-human about transhumanism. We're not setting ourselves up as somehow being separate, divisive or antagonistic; rather we're welcoming and inclusive. We're not promising a Utopia in which things are already final; rather we're talking about an extropian journey. We're not talking about an irreversible change in which, after we perform an experiment there's no going back; rather, as far as possible, and with genetic editing this is the case, we can reverse what we're doing. Rather than talking about a brave new world which people fear, we must be able to find ways in which people can see this as a wonderful, new world.

These are my basic lessons from my observations of the public discussion about support for futuristic technologies. I look forward to us improving some of our advocacy further, so we can quickly build wider support for virtual super intelligences and our own evolution.

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