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# **NewScientist**



# New Scientist and Greenpeace Science Debates

Science, technology and our future: the big questions

The Search for perfection

30<sup>th</sup> April 2002

### **Question and Answer Session**

**Guy Herbert:** I'm not terribly relevant. The question that I have which was glanced at by Tom Shakespeare but not really addressed by anybody else is the fact that we live in a complicated and messy world and nobody mentioned the one word that I was expecting to hear tonight or alluded to the concept which is described as trade off. There's been a hidden assumption in all this discussion that you can fix one thing while leaving others unchanged and I would like the panel to comment on that.

Chair: Do you want anybody in particular to comment on that?

**Guy Herbert:** I'd like to hear anything they have to say.

Chair: Okay it is a trade off. Donald.

**Donald Bruce:** I mentioned about the anabolic steroids example. I think it is quite a good example of that where somebody has tried to go for one particular thing and it's thrown other systems of the body out. Now is that a justified trade off? Well maybe if that's what you're interested in and getting that medal and if it was of course within the rules then you maybe thought it was worthwhile. 30 years back would it still seem as good? You know when you are now suffering resulting from that. I doubt it.

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**Chair:** Kathy, you talked about some physical characteristics that would involve trade off – the big bum would be an advantage in Brazil, maybe less an example to Western Europe.

Kathy Phillips: Actually it wasn't me that said that. It was Donald that said it.

**Chair:** Oh Donald. Yes he went on quite a lot about that didn't he. Very revealing Donald. Kathy.

**Kathy Phillips:** I did mention that I didn't think that if you, the Barbie doll, ultimately would be satisfied with perfection if she or he ever acquired it because as you get older or as time change or as times pass, whatever you tried to achieve or whatever procedure in my world you went through, would not be enough and so there would be an addictive quality to what happened next. The trade off would be that you became addicted to trying to make everything better.

#### Chair: Tom.

**Tom Shakespeare:** Yes, I mean I think this is a very important point. I mean I inherited a number of things from my father – my name, my gene transposition and my suit among other things. My partner said it was actually quite fashionable which is great. I will give you the name of the tailor but he is dead because it was made in 1950. I think if you were to look at me and say look, and I don't think John would do this, but say look you know it's really terrible to have aconaplasia. I would say that well actually I've also got quite a good brain, extraordinary socio-economic privilege, listen mate I support a really good football team. These are in a sense trade offs and I think the problem comes when we see, particularly on disability, you do what a friend of mine calls and I don't know if this is the term selecticute. It's a Greek term for when you see a part, not the whole.

So my gene transposition is only a tiny part of the whole personality Tom Shakespeare, as it is of all of you. What other traits do you have and you all have recessive genes. You have 100 mutations in your genome. They are only part of your picture. The problem is that a lot of the time we can't look beyond people's impairments or whatever else it is to see whether there are other characteristics of which we are most active people.

I think the other thing is about ... really the question is about genetics and about pleiotropy and about how all our 31,000 genes are having multiple effect and so forth and so on. But of course evolution teaches us we are adaptive – but to environments. So in one environment,

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a particular gene or other characteristic would be advantageous and in another environment it will be a deep draw back. Not just large posteriors in certain cultures and not others but you know genes for Cystic Fibrosis or Malaria. If you have a single copy in certain parts of the world that's a real adaptive advantage. Here if you have two copies or anywhere if you have two copies it's a real problem and I think that you have to have this contextual view and not just to look at the idea or the issue in abstract.

#### Chair: Okay. John.

**John Harris:** Well when I had surgery early this year for one of my inherited defects I was making purely a trade off calculation as to whether it would be advantageous or not. Because I had that defect, among many others, I also, like Tom wouldn't be here 150 years to the future world but I think that would be worth trying to achieve. But I assure you that wouldn't bother me because it's 150 years hence.

But when we're talking about choosing between say embryos or genetic changes in the embryo, the issue of trade off doesn't arise because you're not creating an embryo with this new feature that otherwise exactly as it is because it isn't anything yet. So there's no way of actually talking about trade offs when we make changes in the embryo or when we select between embryos. Except in the last case which Tom put and that is where a trait let us say like Cystic Fibrosis confers supposedly an advantage in resistance to Malaria. Now that is a trade off, but it is a very, very, very difficult one. I think the question one has to ask there is are we going to condemn people to Cystic Fibrosis or thalassemia whatever it is for the sake of keeping that advantage?

It seems to me that the right course there is to pursue Malaria by other means. We have anti-malarial drugs. We have ways of clearing malarial swamps. We ought if we can to eliminate those terrible genetic problems, which cause really miserable disease and pursue Malaria by other means. We shouldn't condemn people to continue to suffer those diseases for the advantages that they supposedly could have.

Chair: Okay. Colin. I think that was your name? Are you satisfied?

Guy Herbert: Guy Herbert.

Chair: Guy I apologise.

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**Guy Herbert:** Yes. Everybody has addressed it all. Most people have addressed it on an individual level but there is also a trade off on a group level and Tom Shakespeare again was alluding to unpredicted social effects. An interesting example, I don't want to go on because people have got other things to say. But an interesting effect is what if sex selection becomes common in society where boys are vastly valued over girls? You get a lot of boys, very few girls. The society that has those values unbreeds itself out of existence.

**Chair:** Can I just say on sex selection because I think our last speaker mentioned a couple who were trying to have a girl suddenly following the death of their daughter. I think I'm right in saying that that never actually came to the HFEA. So the HFEA did not make a ruling on that. We are however having a public consultation on sex selection this summer. So watch our web site on that one.

Now you had a question.

**Brown:** Tom I think made some very good points. Why would it necessarily follow that one would need to regulate because what we've heard, the descriptions we've heard are people who are neurotic, obsessive. I heard him describe many people in their 30s who if they found a boyfriend might calm down a bit. We're talking about people all who have very particular tragic circumstances. So why would we want to organise our society around those peculiarities? Surely we would find it much better really to make the kind of convincing argument that people are able to make in a forum like this and ridicule people who become obsessed with inconsequential things like how they look to a point of their lips are expanding across their faces. Surely that would be a much more effective route than to regulate something which is ultimately a decision that parents have to make.

Chair: Okay, we can ridicule people out of hang-ups. Tom.

**Tom Shakespeare:** Oh to live in that world. I think that's, with respect, naïve. We could tell people you should really wear a seatbelt. It would really help you and you shouldn't drive too fast because it's not a rational thing and it might hurt somebody else. But we live in societies which make compromises and put laws in place to stop people harming themselves or harming others. That's the first point.

The second point is, and I am sorry to read over your shoulder John, but John has written in his notes on my talk patronising spokespeople come up with this pressure and in a sort of way it is. John Harris: I would never have said that out loud.

**Tom Shakespeare:** That was the drift in the question and I think what is an individual ranged against the power of multinational corporations, the media, Hollywood and all the other forces in society which are telling us to do things. Now you know we could be the most robust character alive but it's pretty hard to stand against that and I think we should help people stand against that by regulating not obsessively or in a nanny way, but in order to establish a better world for everyone.

Chair: Okay. I'm going to move onto another question.

**Amit :** We study mostly human problems or questions. But which ones are we talking about? Man in his best or in natural world that includes worms, ants, flies and everything.

Chair: Not sure I quite understood your question.

**Amid :** Which world are we talking about? Man in his best in human world or a world with every living being including worms, flies, cats, dogs?

Chair: Okay. Does anyone want to comment on that? Donald. Tom and then John.

**Tom Shakespeare:** Darwin is very interested in worms of course because he speculated the hidden work of landscape change didn't he. I think that the ecosystem has evolved. I think also human societies are complex ecologies and I think if we try to achieve perfection on either I don't think I really trust either genetic engineers or social engineers to get it right. I think that we keep that as a margin. That's good but having big game plans to make things better scares the hell out of me.

Chair: Donald do you want to go next.

**Donald Bruce:** There is a very important issue about taking not only our own evolution but the evolution of the world into our own hands. We can't know whether it's safe to leave it as it as unless we can foresee the future. Evolution has done a mixed job for us. In some things it's splendid. All the splendid people in this room. But we have terrible diseases. We have terrible famine. We have terrible a whole range of things. Evolution is a very mixed blessing. I'm not saying, Amit, with how the world is now, that I don't think it can be made better. It's of course risky to try to make it better. But we can't know whether that's more risky than leaving it as it is unless we know how things will be in the future and we don't

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know that. So we actually have no rational basis either to leave things as they are or to make changes. Whichever you advocte, there is obviously no rational basis for it. The only thing we can I think do is to try make, as we have always done in the past, small piecemeal changes for the better as we see it, i.e. to try to eliminate diseases. To try to eliminate famine. To try to purify the drinking water and so on and to hope that it won't have a disastrous effect on all of the collateral things, on all of the side effects which could be subject of the first questions.

**Chair:** I mean it seems to me there is a scale issue here. Yes, there is a lot of cosmetic surgery but there was only actually, what was it, 20,000 cosmetic operations and there are 59 million of us and I think so far through IVF, 40,000 babies have been born through IVF. You know so compared with the number of people here I don't think we're talking about massive evolutionary change. However you wanted to say something about this one.

**John Harris:** Just that the idea of trying to make small changes and hoping for the best, I don't think is a very good way of trying to use technology. I think one has to have a degree of foresight as far as you can go. The problem with things like global warming, the ozone hole, in total is all the effects that you thought were perfectly okay in the short-term or perhaps in more scale ends up by being vastly greater than it ought to have been. Also gradual small steps often delude you. It's a little bit like what we did before. Unless you stand back and have some moral framework against which to assess each small step otherwise you end up by getting to a place where you really had no intention of getting.

**Tony Gilliland, Institute of Ideas:** Two brief questions. Is the search for perfection a loaded term and aren't we really talking about the struggle individually and collectively to improve and transform our lives? Shouldn't that be what we are debating about, how to do that.

Secondly, the very controversial example that I'm surprised hasn't been raised already of the American, the two women who deliberately attempted and successfully achieved giving birth between them, if you understand what I mean, to their child. Which raises an interesting difficulty between John's arguments and Tom's because John said about believing individual human dignity and not regulating procreation which I believe, I'm strongly in that sentiment, but Tom then said well then is it a sin to have a disabled child. My question would then be well how can we resolve that contradiction because whilst I wouldn't regulate, surely society

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should take a moral position? Surely people should have a reaction to this example and it does seem to me wrong to deliberately bring into the world somebody disabled.

**Chair:** Right. Of course it's a loaded term. This is organised by Greenpeace and New Scientist. They wanted to get people here. Now can you keep your answers very, very brief? Is it a loaded term and is it okay, what was your reaction to choosing the best baby? Who wants to go first? Very, very short answers please.

**John Harris:** I would agree with the speaker. I think it is one thing to have a family who are best parents and I think it's quite different again to the same issue of us saying about what child actually is best child. It's very difficult to say given we have this particular condition ourselves, we would like our child to have the same condition because the child isn't there to answer the question. I think I would agree with the speaker.

Chair: Okay. You say no. Kathy.

**Kathy Phillips:** I think it was a very odd judgement to make of the parents to think that the child would want to be deaf. But there shouldn't be legislation against that. I mean it's weird but they did it.

Chair: They don't like it but you think they should be able to do it? Tom.

**Tom Shakespeare:** I think there are broader implications. I think a lot of the media coverage of that case was horrifyingly anti-deaf and really very shocking. The lesbian issue is irrelevant to the case. The case is should disabled people be able to have children in the knowledge that there is a high likelihood that that child will be disabled like them. I had two children knowing that there was a 50% chance that they were disabled. So logically some of the coverage of that case was suggesting that people like me shouldn't have kids. I know John wouldn't suggest that because he said that people who don't have a choice are allowed to have kids even if they turn out to be disabled. I think the underlying interesting question is the one that the gentlemen raises, you know if choice, patient autonomy is your watchword and people come to you with some pretty curious choices, then what are you going to say. I think it's very interesting the case of implanting embryos. If I go with my, she isn't, but if I go with my partner to an IVF session and say I want pre-implantation genetic diagnosis, to avoid a terminal outcome because if you get the genes from both parents that foetus dies. But I don't want you to put in the average height baby I want you to put in the impaired baby. Then that's a similar sort of case.

about that." But they tell us that they are acting in a case of choice, parental choice, guided by parental choice.

So I think the rhetoric around these types of autonomy actually get to you in some of these problematic areas.

**Chair:** I don't think we'll make you have donated gametes Tom you'll be pleased to hear. John.

John Harris: I mean I agree with the tone of your question. I think you identified the question correctly. In the deafness case, or in the case of any deliberate choice to have, to produce a child with disability you have to ask the question let's take deafness because it's the clear case. Is it harmful to be deaf or not? If it's genuinely not a bad thing to be deaf then there couldn't be anything wrong with a deaf or a hearing child. If it's genuinely morally indifferent then if parents decided having looked at their new-born, oh it's hearing what a pity. That's definite. That will be real choice. There would be no reason for them not to make that decision. I don't believe anybody thinks that that is a neutral choice. That shows us that we don't think it is a matter of moral indifference whether a child is deaf or not. We think it's a bad thing. We think it matters and if we think it matters, then it would be wrong deliberately to choose to have a deaf child. But I would, because I believe in reproductive freedom, I would nonetheless uphold the parents' right to make the selective choice that they have made. Not to deafen the child, but to make the selective choice that they made, but I certainly wouldn't protect them from criticism. I think they should be put under the light. I think they are doing something wicked and I think a decent person should tell them that that's what they're doing.

**Chair:** Interesting. Can we have a show of hands? Who thought that that couple were right to want to have their baby.

**Donald Bruce:** Can I clarify, is this probability or certainty? I.e. are they choosing a known outcome or is this to be the likelihood.

Female Speaker: To increase the probability?

**Chair:** Yes. To increase the probability of having. It was okay. Very few people think that it was okay to do that. Okay. Substantial minority. Very substantial.

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**Anthony Ferguson:** I've got no particular personal involvement in any of this. It seems to me that the emphasis from the speakers has been on the individual search for perfection. Is there any particular reason for that? In another time I think we might have been discussing the state search for improvement in its population.

Chair: Okay, the eugenic question Donald.

**Donald Bruce:** The problem with eugenics is it doesn't actually work.

Chair: But that's the only problem with eugenics?

**Donald Bruce:** The problem with the rhetoric of eugenics is you're not talking about the assumption that you will do something across the whole population. You only do it for some bits of it. The question is always which bits and who has got the right to decide and I get very, very worried about who is actually controlling those decisions. So I'm very, very wary about the use of eugenics as a rhetoric and even more so about the actual practices that will be implied.

Chair: Kathy, eugenics.

**Kathy Phillips:** I completely agree with Donald about that. I don't know how you could justify after the experiments in Germany.

**Tom Shakespeare:** I think the state does have that responsibility to improve the quality of the population which is why I support good maternity care, excellent NHS well funded and well structured, free education for all which actually values them and helps children grow until they are flourishing. That is the cost-effective humane and egalitarian way to improve the quality of the population and unfortunately we live in an individualistic age that even those choices are increasing less to individuals to make arrangements for themselves. I think you know the genetic ... you know if I wanted to improve my kids, the genetic route is not the efficient route. The efficient route is the environment and we can contribute to those as individual or as a society.

Chair: Would you make pregnant women eat healthily?

**Tom Shakespeare:** I would strongly counsel them to take folic acid and to stop smoking or so forth.

**Chair:** Shouldn't they already be doing that?

**Tom Shakespeare:** Absolutely and so they should. I wouldn't sit with them with a gun and say stop smoking...

Chair: Eat those vegetables.

John Harris: I agree with every word that Tom said that it does seem to amount to reduced tolerance or dessertaty. You say there's no difference in acts and omission, well I disagree with you on that. However on the ... I don't like to hear state policies about anything in terms of you know being described as eugenics. Any attempt to improve the health of an individual is eugenics. The Oxford Dictionary defines eugenic as the attempt to have a fine healthy child. I think under that description we should all be eugenicists. I am very hostile to the idea that eugenics was a bad word. We need to distinguish individual eugenic choices which are free and unfettered and people may make them or not as they please. That they are not coerced. That people might have a bit of strong will but that's what we try to do with education. In this country at least we try to create independent strong willed people who can resist pressures of all sorts.

If you leave it to individual choice, the choices are likely to be as diverse as the people. I'm in favour of individual choice. I'm in favour of diversity. I'm against state imposition of any of these decisions. I am against the medical profession imposing these decisions on us. I'm in favour of diversity but I think the best guarantee of diversity is to maximise the realm of individual choice because that is the only way you can be sure that you will not get a uniform solution. Go into a classroom and see what the kids are wearing. How diverse is that? Fashion, they told you what to wear and you sign up to it.

Chair: Anthony where were you? You asked the question.

**Anthony Ferguson:** Just an open question. I was interested because it did strike me that there was emphasis on always the personal.

**Chair:** Okay. Now I haven't had any questions from the gallery and I promised two people up there. Who was the first one?

**James McGuire:** We've got one issue absolutely brilliant but you touched about evolution. I think it really applies to beyond today and towards tomorrow. If we take perfection as a

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genetic template of what we say humanity today and then imply that that's perfect and we've got it for the future, are we not sending humanity on a cul-de-sac and a biological cul-de-sac and we're missing tricks and evolution we can't set in just evolution. We could be cutting off the next generation of humanity in ways that we can't begin to imagine.

**Chair:** Okay because we are going to get it wrong. We're going to get it wrong. So James' argument is the environment will bite back.

**Donald Bruce:** Evolution has almost stopped. If you believe in evolution the only way you're going to get it going on is if we take it into our own hands. That's the reality because people live to reproduction age by and large now. So if you really want, I'm not particularly in favour of continued evolution, but if you think it's a good thing then you've got to do it for yourselves because nature isn't going to go on doing it for you.

**Tom Shakespeare:** The fact that evolution has stopped is news to the Tuberculosis bacterium for a start. Of course I agree, but the world is going to change in ways we cannot predict and also who would you trust to design these people? Who would you trust to make these decisions? Politicians, doctors, philosophers, sociologists, fashion gurus. I don't think that we can really agree on what is best.

**Chair:** Well I was head for the select committee last week it was the view of one of the MPs that parliament should be making those decisions. MPs were the people who would make the best judgement. Kathy.

**Kathy Phillips:** The idea that politicians can decide on the aesthetics of the future population is really terrifying.

**Chair:** Put them on the editorial board of Vogue. Donald.

**Donald Bruce:** The conclusion from a researcher a few weeks ago was that genetic evolution in humans has more or less stopped and he backed it up with some pretty impressive data. So I think there was some data based behind that if I understand it correctly. But I would be concerned that we need to work rather hard at accepting each other as we are now much more than worrying about what we are trying to design for the future.

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**Tom Shakespeare:** What do they think the long-term future holds for us? Will our desire for perfection drive us into a society completely obsessed with physical perfection as we come to terms with our "flaws?

**Kathy Phillips:** Well I hate to say this but I am afraid I don't think we will stop worrying. I think it maybe 20,000 now, but I think the statistics are going to rise hugely. I think the mass population are going to want to perfect themselves.

**Chair:** The picture you drew which is a kind of modernisation of physical image so that everybody eventually wants to conform to a very narrow kind of range. In the end that's going to get boring isn't it because people will want to be more different?

Kathy Phillips: Yes. Lots of Lara Croft.

Chair: Lots of Lara Croft. Bit boring. Tom.

**Tom Shakespeare:** I think the other day I said it's dangerous to predict anything, particularly the future. But in these cases I am merely referring to a manual of futurology which - clearly with people of my generation is 2000AD, the comic books. In a future where a bachelor guy who made his living from selling designer blemishes because everybody looks so perfect, they want to stand out and look different. I think that there might be a backlash against conformity one day.

**John Harris:** I think it's got to do with the success culture. I was very struck in the States at a conference 10 years or so ago about how far it was almost as an offence not to succeed.

The other things like how people look - I have absolutely no appetite for it. I think it's almost misconceived and frankly stupid. But what does matter is making improvements in health and well being and that increasingly we can do and I think that increasingly we should do and if that does the search for perfection, well I'm for it.

**Chair:** But who is going to tell us how to achieve health and well being – doctors, complementary medicine.

**John Harris:** Well longer lived, less pain. All the simple things that we all understand. I don't think it is very problematic really.

**Chair:** Okay a lot of men have asked questions so I'm going to gender select now. If you would like to ask your question.

**Female Speaker:** I don't think I should identify myself because I'm probably the only hairdresser here. I was interested to know the search for perfection into the choice of one's career because panelbeaters, cabinetmakers and hairdressers are obviously not very often found here and it was viewed as quite a good laugh. I wondered if the search for perfection includes that choice as well?

**Chair:** Would it include that choice? John.

**Female Speaker:** It is acceptable to have a son or a daughter who chooses to be a panelbeater or a hairdresser.

John Harris: Absolutely.

Chair: Does anyone not think it is acceptable?

**Tom Shakespeare:** I don't see why anybody would need a hairdresser personally.

Chair: I see he's quite a bit around the back. See what you can do. Yes.

**Female Speaker:** I'm a gardener so I can be under the same umbrella. But my question is surely we are all missing the point. Surely what we actually want for our children is happiness and how dare we define it by them being more musical or blues eyed or brown haired or whatever. Surely all we actually want is happiness and that's one thing that we all seem to strive for and I don't think that can come?

**Chair:** Okay. I think that's an important point. One of the things what it has been a great privilege to do in the last few weeks is with some patients agreement to sit through some PGD consultations between patients and clinicians. It is absolutely clear to me that the reason why parents want PGD is precisely the point you're talking about because they want to avoid pain and unhappiness. John.

**John Harris:** We may not know what makes us happy but we sure as hell know what makes human beings unhappy and it is just the things that were mentioned. It is pain. It is foreshortened life. It is disease. It is the inability through disease or injury to do the things

that we want to do and while we can't guarantee that if we fix those people will be happy, it sure as hell removes a lot of the common causes of misery.

**Tom Shakespeare:** See I think I'm happy as Charlie. That's the curious thing. Lots of my disabled friends, and that lady who spoke from the front row, that I'm willing to bet a majority of them also agree with me yes in fact I'm very happy. Why do we want to change them? I think what makes people unhappy...

John Harris: Don't want to change them. I want to change...

**Tom Shakespeare:** You and more people like that thought because you see that means unhappiness and I think the equation of disability with unhappiness is not right. There are some very serious genetic conditions, diseases, disorders which make life very difficult I will accept that. But a lot of them, there's a variety of lives which you could call disabilities is not about suffering and misery. The real suffering and misery in the world comes from poverty and war, malnutrition and neglect. None of those are genetically caused. All of those are within our hands to chance and we should be prioritising that. Only 1% of all births is affected by disability but a staggering proportion of statistics, I don't have them now, of people are born into poverty. We can change that.

**Vicky Raymond:** Is there a problem with a concentration on eliminating disability and diseases that it means that we don't concentrate on improving the quality of life of the people who are born with disabilities or who become disabled for whatever reasons from trauma. For example I was born with a condition which was only medically treatable in the late 1950s and early 1960s. But it was another 20 years before any real clinical surgical improvement which really improved my quality of life. There's been really no radical change. I'm perfectly happy with my life. but I would say that I think the concentration because my condition is now eliminated by abortion, that that has meant that there is now people see it as not important to improve my quality of life in other ways in terms of the environment. But also medically and surgically.

Chair: Okay thank you. That's a very good point.

**Donald Bruce:** The resources put in to some of the areas that we've been talking about might very well be better put into exactly what you described.

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**Chair:** Do you think its an either or? Do you think that there is a direct relationship between those two and that we would put the resources in?

Vicky Raymond: Yes I think it is.

**Donald Bruce:** But just imagine if you're a medical student now what would you opt for a career in? You wouldn't opt for a career in dealing with Spina Bifida would you or whatever the case might be? Or Downs Syndrome, the complications of Downs Syndrome. It wouldn't be a good career move to go into that. Probably quite a good career move to go into genetics or geriatrics.

Chair: Cosmetic surgery.

Donald Bruce: Or cosmetic surgery.

**Simone:** I know people who have had cosmetic surgery on things like their belly buttons to convert them from an inner belly button to an outer belly button. Insignificant things like that. Where do you think these insecurities stem from at such a young age?

**Chair:** Kathy I think that one falls to you.

**Kathy Phillips:** Well sadly the media, you know the acceptance that being rich and famous and beautiful is going to give you a happier life. It's a theory that seems to proliferate and it's affecting young children and presumably their parents are affected to because they allow them or encourage them or let them, it doesn't satisfy them these small and insignificant things.

**Chair:** Who would be, in terms of the media, who do you think are the most influential? Is it Vogue or is it Sugar or one of the things that my kids read?

**Kathy Phillips:** I think particularly irresponsible media. I mean I think there are lots of magazines that particularly concentrate on celebrities. That's the gossip reporting so-called famous people and you know lots of photographs. You know virtualists and I think there are all sorts of parts of the press are irresponsible.

**Chair:** Yes. Well there's already a huge amount of people making a lot of money reversing tattoos because of you know tattoos being such a fashionable thing for young people. young people.

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**Tom Shakespeare:** I think we should have a campaign for successful ugly people as role models and I think we should recruit like on a Popstars-type programme some really quite unfortunate looking people. You know improve their confidence and all their skills, market them, give them give good jobs and then in the future people will go hey I could be like Robbie Williams or whoever it might be. Ugly and successful.

Chair: Okay well that's one for New Scientist and Greenpeace to take up next.

**Joseph Beartow:** I was just wondering how the panel would compare the right of the parent to make a genetic choice with the rights of the parent to make other choices throughout the life of the child such as what food to give them and how to discipline them, that kind of thing?

**Chair:** Good question. So for the people that don't think you should be giving parents these rights, how does that compare with onerous parental responsibilities in other areas? Tom.

**Tom Shakespeare:** I think that, and this is sort of crude, I thought it was very hypothetical when we were doing that generic selection. But I think that largely anyway, that, and I don't want to say this, but I think that our genetic inheritance is less malleable than our environmental influences. So you know we can send somebody to the most reactionary private school in the country, but they might still come out a Bolshevik or whatever else might be the case. Whereas I worry about hard wiring as Donald said. Hard wiring attitudes or their personalities. I just think that's going too far. I think almost everybody in this room at some point judged their parents. I think I'll make that predictive statement. There are some people where parents breeding a child will wish they hadn't, right? Now it is really badly luck as Phillip Larking said. If we're going to give parents the choice of actually choosing or whatever other characteristic, then I think wrong for life. We've not done anything like that. litigation for years.

**Donald Bruce:** The Welcome Trust had a play which is called The Gift which they were running several years ago in this they had genetic selection in America in the future where you could select utmost ability. It was in the context of a genetic disease in the family but also when the relevant choice was made, positive selection was made. So switch forward 20 years to the young American is now in the national basketball squad and happened to find in his father's desk the paper work that led to him being the way he was. In the play he said "this ability if only it was mine, but it's what you forced me to have". I thought it was a very interesting thing. I mean I don't know whether people would react that way or the other way.

I just thought those are the sort of things you're playing with. So it's actually our abilities were programmed rather than learnt.

**Jeremy Webb, Editor New Scientist:** Tom I'd like to ask you is there no condition or trait genetically you'd agree with screening out and do you agree with the status quo as it is now or do you want to take it back to the time before genetic screening?

**Tom Shakespeare:** I don't think anything that I said was about preventing people using genetic screening. I actually am not so dissimilar to John. I think people should have choices. I don't want the list of things for which you can have screening to be extended. So I suppose I think we're probably just about as far as I would want to see us go. I don't agree with sex selection. I do agree that people should have the right, unless there is actually minimal genetic screening, currently. It is considerable prenatal screening. But there's minimal genetic screening because it's just too complicated and expensive. I agree that people should have the right to have amniocentesis or to have serum screening today, yes I do. I want them to know though from as it were families who have lived the experience, what it's like to have Downs. I want them to have a balanced picture of Downs. I don't want them to be supported by the state if they choose to have a Downs child so that the health and education is there for that child. All of those things but, yes, of course I want them to have that choice. I just don't want to live in a free market reproductive dystopia of the kind that some writers, not John, but some writers have predicted.

**John Harris:** Could I just say despite Tom's best endeavours to encourage me to get rid of him I think ... I'm not recommending just getting, I'm about trying to eliminate diseases or disability. I would make children healthy if I could and if that meant that people like me would not exist in the next generation that would be fine with me too. There are many conditions that affect me which means that I probably will not live as long as I would wish. If I could enable my child to live as long as I would wish, i.e. well into its 90s, I'm very unlikely to get there, I would do that. That doesn't mean that I have a bad life. That doesn't mean that I despise myself. That doesn't mean that I think I'm fair game for anybody. It means that I want to give opportunities to the next generation that I won't be able to enjoy. But it's not about eliminating the disease or the disabled. It's about maximising the opportunity and the health of future generations.

**Donald Bruce:** I think I would say that ... no I think I will leave it.

Title

Chair: Kathy do you want to come in on this? No. Okay.

**David King, Co-ordinator of Human Genetics Alert:** We're a national pressure group that works on human genetic issues. My question for the panel is about human nature. Do you believe that there exists something called human nature that you know that we would jeopardise by genetically selecting our children and indeed genetically engineering them?

**Donald Bruce:** It is a question endlessly debated by philosophers of what is human nature. New Scientist last week or the week before had an article about Dalai Lama on precisely this question. His answer was this is a kind of holistic thing that all the discussions about human nature being tied to rationality or any other particular feature you may care to think of, have missed the point. It's the whole thing and you cannot define it because it is the whole thing and I would say logically, we are the last people who could actually define what we are. The only person who could do it is God. But we can't actually work out what human nature is. But I think there is such a thing as it because I'm a Christian and I do think about it. Very quickly, I don't think there is such a thing as human nature but if we were all in millenniums to come to evolve into a completely different species that was healthy and longer lived and I hope happier than us. But if it was not human I wouldn't regret our passing one jot. I don't believe in artificially keeping species going with museum pieces. If we can evolve into a species that will be healthier and happier I would not think there would be one trouble lost to the world.

**Tom Shakespeare:** I think we are healthier and happier. Sorry, we are healthier and longer-lived than we were one, two, three centuries ago. I don't think there is actually any evidence that we are any happier and some evidence that we're actually getting more miserable instead.

Chair: There's quite a lot I mean evidence on that yes.

**Female Speaker:** My brother has a learning difficulty and some people would say that therefore he's disadvantaged. But I'm constantly amazed at how he can take a problem and look at it from a very different angle to the way other people would and I think that every individual has a very unique talent. Don't you think John in your perfect society of 150 years time this society is going to be somewhat deprived or incomplete because of the unique talents that people who might be disabled have?

#### Title

John Harris: We will be like Posh and Becks. I think I will say first, I think diversity would be there but it would be different and I think talents would be there but they would be different. I think the question you have to ask is would it be perfect, and then this is the point that Tom made right at the beginning when he talked about the grit in the oyster. If the grit in the oyster is such a good thing, would we contemplate deliberately putting that grit there for the good that it does? If the answer is yes, if you think it would be worth creating somebody with learning disabilities just so that you could have those unique talents, then, and if that's the sensible judgement and it might be, then you're right. But if that's not a sensible judgement, if it will be better if people didn't have that particular disability we will find other ways to be original and unique. But that's not for you, or I or Tom or anybody who now exists is any less valuable for having the disabilities that we all have.

**Chair:** So that's what it's like doing philosophy at Manchester. Can you ask a very quick question because I want time to co-ordinate here?

**Rupert Bailey:** A very quick question about regulation which I think is partially to you Suzi as well really. To sum it up for me I think there is a big industry here. It's one that Kathy tells us we can get addicted to and therefore we can be exploited by. The question is really how effective will our systems of regulation be in a global market place in the future around these industries?

**Chair:** Okay. I certainly can't answer for cosmetic surgery and I have absolutely no idea how that is regulated from what Kathy said. It suggested that there was actually very little regulation. In our field we are well ahead of other countries in the world and coming to this as a newcomer it is very clear to me that we are massively advantaged here because we did some pretty hard thinking and some very good public policy planning a bit more than 10 years ago. Now the system we set up is criticised by some people for being too conservative both in terms of what we allow clinicians and patients to agree to and also in terms of research. But I think that it is right that we are cautious here. For instance it is hugely useful when journalists phone up and ask inevitable questions about human reproductive cloning to be able to say that is against the law. It is positively against the law in the United Kingdom. Long prison sentence and in many other countries and most other countries regulators can't say that.

#### Title

**John Harris:** I've done a lot of work in the European context and a lot of countries are pretty envious of the UK having the HFEA, the Act and also the excellent regulation in general, there are faults sure, but I think that's a very good imitation.

**Katherine Watling - Future Physical:** I am an artist and researcher. What I wanted to ask really was: should the question that was spoken here not be the search for perfection, but the search for balance? I'd like to get some response from that.

**Chair:** Interesting question. It's a question of balance Tom. It's not a question of search for perfection.

**Tom Shakespeare:** Yes I mean you know as Aristotle said a lot of sensible things. He said somewhere that short people can be neat and well proportioned but they can never be beautiful which of course I would say it is the perception issue. But he said also that when faced with two extremes you should take the medium and I think that the balance is what we should be trying to achieve. I think HFEA generally speaking has done that which is why I applaud it. You know we had a sort of nightmare vision on the one hand of people who think the whole genetic world is completely nasty, evil and then we have a libertarian vision of all the utopia and hyperbole about genetics on the other. I think most of us are down the centre. The happy medium. I'm all for that.

Chair: Okay. Kathy.

**Kathy Phillips:** Definitely in moderation, but would I felt confident that we are going to achieve it.

**Donald Bruce:** Most of living entails all sorts of trade offs as John said. Was it John or Tom earlier on? I think the whole question of how you cope with all distinctions of life are usually found apart somewhere in the middle.

John Harris: I don't want to just be moderately healthy.

**Chair:** Okay. Look I'm sorry it's 9.30 and I am going to have to wind up. There's clearly a lot more to be said about what we've been talking about and I am very sorry to think that we didn't most questions answered.

Can I ask you first of all to thank our speakers? You've been an extremely good audience underlines what I think which is that these issues need to be talked about more and more

#### Title

and that's part of what I want to see HFEA to be doing. Can I thank Greenpeace and New Scientist for putting this debate on. Thank all of you for taking the trouble to come out this evening. Look forward the edited version on the Greenpeace web site and also thank through you Gail, the Royal Institution for putting this on tonight. Thank you.

Debate ends