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MITOCHONDRIA REPLACEMENT TO AVOID MATERNAL TRANSMISSION OF MITOCHONDRIAL DISEASE

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Is germ-line gene therapy acceptable in order to avoid maternal transmission of mitochondrial disease? Yes, says the UK's Nuffield Council on Bioethics (NCB) in its report *Novel Techniques for the Prevention of Mitochondrial DNA Disorders: An Ethical Review*, published in June 2012. In September 2012, the UK's Human Fertilisation and Embryology Authority (HFEA) launched a public consultation on the same issue. Four different germ-line therapy techniques had been proposed by the NCB; the HFEA sought the public's views on two of these: pronuclear transfer and maternal spindle transfer.

The focus of the ongoing ethical discussion reflected in the HFEA consultation is not the risks that might be attached to these procedures, but inter-generational relationships and attitudes toward the child-to-be. The question here is whether these kinds of techniques respect nascent human life and welcome the child-to-be as our neighbor. In order to assist us in thinking about this question from a Christian perspective, I shall sketch the techniques under consideration and, in light of a Christian understanding of human dignity and the value of human life, formulate three principles in terms of which to evaluate mitochondria replacement techniques.

The Four Techniques

Three of the techniques, namely pronuclear transfer, maternal spindle transfer, and blastomere nuclear transfer, lead to the creation of embryos free of faulty mitochondria. The fourth technique, mitochondrial transfer, involves adding healthy mitochondria to an egg before it is fertilized.

Mitochondrial disease can be serious and even fatal. So ways of avoiding maternal transmission of such disease would be welcome—but not, of course, at any price. What, then, is the price of the techniques under consideration?

Pronuclear transfer and maternal spindle transfer both involve cell nuclear transfer. They are in this respect similar to the cloning technique used to create Dolly the sheep in 1996. In the case of pronuclear transfer two IVF embryos are created. One is the embryo of the intending mother with mitochondrial disease and her partner. This embryo has faulty mitochondria. The other is created from a healthy donor's egg and sperm, usually from the intending mother's partner. The donor's embryo is enucleated—the two pronuclei (genetic material from both the egg and the sperm, which has not yet merged at this stage) of the cell are removed. And then the two pronuclei of the intending mother's IVF embryo are transferred to the donor's IVF embryo. The result is a reconstructed embryo containing the pronuclear DNA of the intending parents and healthy mitochondria contributed by the donor.

The technique, then, involves the sacrifice of at least one embryo—the donor's—and arguably two embryos depending on how one parses the identity conditions of the reconstituted embryo with that of the intending mother's embryo. It results in a reconstructed embryo with contributions from two genetic mothers: the intending mother and the egg donor; the intending mother and father provide the "combi-embryo's" pronuclear DNA, while the egg donor provides healthy mitochondrial genes.

Maternal spindle transfer likewise requires an egg donor free of mitochondrial disease. The spindle of chromosomes (in effect, the cell nucleus) from a healthy, unfertilized donor egg is removed and replaced by the spindle of chromosomes from the egg of the intending mother, a woman suffering from mitochondrial disease. The result of maternal spindle transfer, then, is a "combi-egg" with the intending mother's chromosomes and healthy mitochondrial genes. This healthy egg can then be fertilized in vitro, thus allowing the woman with mitochondrial disease to have a baby free of the disease.

No embryo is destroyed in the process, but—again depending on how one parses the identity conditions—at least one egg (the donor's) is destroyed, and arguably two. The resulting embryo has two genetic mothers, as its nuclear DNA comes from the intending mother and the mitochondrial DNA from the egg donor.

The two other techniques discussed by the Nuffield Council,

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from the director's desk

BY PAIGE COMSTOCK CUNNINGHAM, JD, MA
EXECUTIVE DIRECTOR

Michael Sleasman laid the *Chicago Tribune* on my desk. Yes, the print version. Who would have thought that one newspaper section could provide so much fodder for bioethical discussion? Join me as I "read" the paper and informally reflect. (And please overlook all the quote marks—annoying to read, but necessary for accuracy.)

The front page story—above the fold—was headlined: "Couple Battle over Frozen Embryos." Caption under photo accompanying story: "A devastating cancer diagnosis for Jacob Szafranski's girlfriend of five months led the couple to deposit genetic material for future children."[1] Five months into a romantic relationship, the reporters write, Jacob and his girlfriend Karla decided to use his sperm and her eggs to create embryos prior to Karla's undergoing chemotherapy which could make her infertile. Three embryos were created; the couple broke up; Karla was indeed infertile and wanted the embryos; Jacob refused.

The gametes—sperm and eggs—were labeled "genetic material" several times in the article. That was a new term for me. I think a cheek swab or donated blood could also appropriately be labeled "genetic material." This latest permutation of language minimizes the significance of what the couple was doing and the physical processes involved in retrieving her eggs and his sperm. The embryos were variously called "fertilized eggs" and "pre-embryos." The scientific term for a fertilized egg is "zygote." Zygotes created via IVF *may* be frozen for later use, but it is more common—and better practice—to freeze them at the blastocyst stage. Would a little fact-checking be in order?

Karla argued for the right to have "her biological child" and to "control the destiny of the embryos." Jason argued that "forced procreation" would violate his constitutional right and jeopardize his future prospects of having "a child of my own." (He speculated that his prospective girlfriend would reject a man who had an unknown child with another woman, "neither of which I have ever loved.") After so many years of legal cases that focus heavily on a woman's reproductive autonomy, it is curious to read of a man using the same language.

Nowhere in the story did I see any hint of concern for the best interests of the children. That's not surprising, since the relationship was not built on mutual self-giving and the marital promise of lifetime commitment. The sacrificial love of parent for child was completely absent from the contract language regarding disposition of the embryos that was the basis of the legal dispute.

At the bottom of page one was a story about Walgreens's new approach to healthcare coverage for its employees, intended to give the workers greater flexibility and control in selecting an appropriate plan for their needs.[2] Walgreens is moving their health coverage for employees from self-insurance to a private exchange. It is more evidence of the scramble to understand and comply with the ongoing rollout of the Affordable Care Act.

A report toward the end of the section described a study highlighting the wide disparities in access to healthcare for those living in poverty. "These variations in insurance coverage in many cases are mirrored by disparities in access to care, quality of care and even health outcomes."[3] This is a major concern of public health, and another reason why we need to advance Christian scholarship and reflection in this area.

Ah, some good news. Adjacent to the disparities report was a new study about childhood obesity. It seems to be leveling off, with "big gains" (by which the author means less obesity) in some areas.[4]

The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University.

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Exercise and consumption of fruits and vegetables are up; TV watching and consumption of sugary drinks are down. Although cautious, the authors of the study note that, "It may be that current public health efforts are succeeding." As a Christian, I am grateful for food pantries, school lunchrooms, community gardens, and other ventures that expand access to otherwise unaffordable or unavailable fresh fruit and vegetables.

Judaism is reviewing the use of technology on the Sabbath and in services.[5] Does using an iPad in the service violate the commandment against working on the Sabbath? Ultra-Orthodox, Orthodox, Reform, and Conservative rabbis each answer differently. This reminded me of my *Everyday Bioethics* commentary, "A Technology Sabbath," where I wrestled with the tendency of new technologies to control us, rather than the other way around. For all of us, these evolving technologies present continually perplexing ethical challenges.

In just one section of the newspaper, I found a handful of bioethical connections, each worth its own essay. The next time you read a print newspaper or journal, take the time to read critically and notice how bioethics seems to be always and everywhere in the news.

1 Bonnie Miller Rubin and Angie Leventis Lourgos, "Couple Battle over Frozen Embryos," *Chicago Tribune,* September 18, 2013.

2 Peter Frost, "Walgreen Shifts Approach to Worker Health Coverage," *Chicago Tribune*, September 18, 2013.

3 Noam M. Levy, "Study: 'Two Americas' in Health Care for Poor," *Chicago Tribune*, September 18, 2013.

4 Melissa Healy, "Study See[sic] Signs U.S. Teens Adopting Healthier Habits," *Chicago Tribune*, September 18, 2013.

5 Michelle Boorstein, "Honor the Sabbath, Switch Off the iPad?" *Chicago Tribune,* September 18, 2013.

MITOCHONDRIA - CONTINUED FROM PAGE 1

but not by the HFEA, are blastomere nuclear transfer and cytoplasmic transfer. In the case of blastomere nuclear transfer an egg from the intending mother is fertilized with sperm from her partner. At day five after fertilization, when the embryo has turned into a multi-celled blastocyst, a number of its cells, called blastomeres, are removed. The nucleus of each of these blastomeres is extracted and transferred into enucleated eggs from a donor free of mitochondrial disease. This results in embryos with the intending parents' nuclear DNA and healthy mitochondria from the donor eggs.

Again, the embryos have two genetic mothers. The father of the embryo—or embryos—is the intending mother's partner. And, as in the case of pronuclear transfer, the technique involves embryo destruction. The many donor eggs are destroyed, and arguably, the intending mother's original IVF embryo is as well.

In cytoplasmic transfer, the least manipulative of the four techniques, cytoplasm from a healthy donor egg is injected into an egg of the intending mother, the woman with mitochondrial disease. The result is an egg with both healthy and unhealthy mitochondria. The technique has been used to rejuvenate eggs of women with problems conceiving. But it would appear that it does not always yield germline changes in resulting offspring.[1] This technique might therefore be of little use in avoiding maternal transfer of mitochondrial disease. Furthermore, the NCB reports that cytoplasmic transfer "has been largely discredited in the scientific community because of safety concerns."[2] So let us say no more about this technique.

Three Christian Guidelines

In the light of Christian understanding of human dignity and the value of human life, I shall outline three principles which might guide us when evaluating pronuclear, maternal spindle, and blastomere nuclear transfer.[3]

We must not treat the child, born or unborn, as if he/she were a mere commodity of only instrumental value to us.

For Christians, every human life is of intrinsic value and so deserves respect and protection. An embryo, like any human being, is a participant in human nature and thus in the image of God, which ensures that she, too, possesses such value. Neither pronuclear transfer nor blastomere nuclear transfer reflects these attitudes towards the human embryo. This is obvious in the case of those embryos that are destroyed. They are treated in a purely instrumental way and seen as no more than raw material to be broken up in order to fabricate the desired products. Nor are the reconstructed embryos treated as human beings possessing intrinsic value. In the case of both pronuclear transfer and blastomere nuclear transfer, the resulting aggregate embryos—and hence the children-to-be—are assembled according to design as manufactured items. They too, then, are treated instrumentally, as are all artifacts (things produced or crafted by human endeavor).

Maternal spindle transfer involves egg destruction and aggregation rather than embryo destruction and aggregation. Nonetheless, the resulting embryo free of disease is an artifact; instead of being received as a gift with intrinsic value, it has been fabricated according to specifications dictated by its perceived purpose.

CONTINUED FROM PREVIOUS PAGE

So, not only does the technique reflect instrumental attitudes towards the eggs destroyed, but it also involves an instrumental attitude towards the child-to-be: the child comes into existence in accordance with humanly-established parameters in order to satisfy a certain standard.

There is also the question of egg donation. All three techniques involve egg donation, and, as Oliver O'Donovan noted in his book *Begotten or Made?* to participate in engendering a child for the sole purpose of allocating "one's parental relation to another . . . implicitly converts the child from a person to a commodity."[4] Whether or not money is involved in the transaction, the child or child-to-be is effectively treated as a possession, not as a person with intrinsic value.

Treat the child as a neighbor and give her an unconditional welcome as a gift from God.

Jesus taught us to recognize and welcome children as our neighbors (Mt 19:13-13; Mk 10:13-16; Lk 18:15-17); this means, among other things, that children possess independent status as "fully-fledged" human persons with inherent integrity, or completeness. But to come into being as a manufactured entity by aggregation and egg donation in order to satisfy a humanly-established standard is depersonalizing. It is, again, to enter the world as an artifact. As regards pronuclear and blastomere nuclear transfer, both the embryos produced (the children–to-be) and the sacrificed embryos are treated as mere inanimate biological material subject to manipulation. To treat the human embryo and child-to-be this way is to demonstrate a materialistic understanding of human life. On a Christian understanding, human life transcends the material from the moment of conception. It comes from God. It is created in the image of God. And it is meant to return to God. The human birth, life, and death of Jesus bear witness to this.

In the case of both pronuclear transfer and blastomere nuclear transfer, the end-product of the technique is a "collage" assembled from pieces of previously complete embryos. And in both cases the child-to-be is fabricated with a view to meeting a certain standard. These techniques pursue established parameters of health at the expense of nascent human life. This is not to accept the child-to-be as an intrinsically valuable gift and as it is, with inherent integrity. Neither technique is compatible with the requirement to treat the child as neighbor and as a gift from God, to give him or her an unconditional welcome. Rather, both pursue health at the expense depersonalizing the child.

Nor does the use of maternal spindle transfer satisfy the principle under consideration. This technique involves creating an egg by assembly of genetic material from different eggs, for the purpose of causing that egg to become an embryo created according to humanly-established specifications. Once again, the child-to-be is not treated as a neighbor and gift, and it is not given an unconditional welcome as such.

We should not seek to assume the role of God vis-à-vis our children, but we should serve and love them as servants of God.

A parent, scientist, medical technician, etc. who sees an embryo primarily as mere, or little more than, biological material might well feel he has a right and perhaps even a duty to manipulate this material in order to create a healthy child.

On a Christian understanding, however, there is no such right and no such duty. Christian belief entails humility. As Christians we recognize that there are limits not only to what we can do, but to what we should do as well. Our recognition of the embryo, foetus, and child as our neighbor is incompatible with treating nascent human life as disposable material to mold to our understanding of what a human should be like. Healing a child who is here, whom we regard as a fully-fledged person possessing independent integrity as such, is one thing; making one to specification is another. To do the latter is not to serve our neighbors as servants of the God who is both our and their creator; it is to assume creative power over them ourselves.

In Sum

To manufacture children-to-be by techniques like pronuclear, blastomere nuclear, and maternal spindle transfer is not to welcome and accept children with neighbourly love. When we adopt a perspective in which the costs associated with such techniques are justified for the sake of children-to-be's conformance to humanly-established standards of health, we fail to regard human persons as such, with all the diversity that entails. We impoverish our society by making it less welcoming of difference and diversity. Before employing the kinds of technology spoken of here, we should ask ourselves if a society characterized by such failure is where we wish our children to live.

1 Nuffield Council on Bioethics, "Novel Techniques for the Prevention of Mitochondrial DNA Disorders: An Ethical Review," (June, 2012), 38, http://www.nuffieldbioethics.org/sites/default/files/Novel_techniques_for_the_prevention_of_mitochondrial_DNA_disorders_compressed.pdf (accessed on August 14, 2013).

2. Ibid, 38

3 For an earlier discussion of how to evaluate germline interventions from a Christian perspective and the formulation of three guidelines that might be helpful in this respect, see my article: Agneta Sutton, "Germ-Line Gene Therapy Could Prove a Two-Edged Tool," *Christian Bioethics* 18, no. 2 (2012): 145-155.

I have been following Neil Messer's example of seeking to establish some principles in the light of which to evaluate different practices. See, Neil Messer, *Respecting Life: Theology and Bioethics* (London: SCM Press, 2011).

4 Oliver O'Donovan, *Begotten or Made? Human Procreation and Medical Technique* (Oxford: Oxford University Press, 1984), 37.

ACADEMY OF FELLOWS CONSULTATION "RECOMMENDATIONS ON THE ETHICS AND THEOLOGY OF SYNTHETIC GAMETES"

The following recommendations were developed by the Fellows and guest speakers who participated in the Center's November 2012 Consultation. This statement does not necessarily reflect the views of individual members of the Center's Academy of Fellows or that of CBHD, but is offered as helpful guidance to initiate further discussion on this emerging topic. We invite you to respond to their recommendations.

Preamble

The members of the CBHD Academy of Fellows Consultation on synthetic gametes and embryos,

Conscious of the accelerating developments in the synthesis of artificial gametes and embryos;
Convinced of the need to recognise the importance of protecting the inherent dignity of human persons;
Affirming that progress in biology and medicine should always serve human good and not violate the inherent dignity of human persons;
Recognising the importance of promoting a public debate on the questions posed by the synthesis of gametes and embryos as well as the responses to be given thereto;
Reminding all members of society of their rights and responsibilities;
Noting that most couples seek to have children of their own;
Recognising the intense suffering and distress that may arise when a couple cannot have children of their own;
Aware of the traditional[1] Christian belief that procreation should only take place in the context of the exclusive embodied relationship of love between a man and a woman bound to each other by marriage;
Conscious that procreation is not a virtual process but takes place in the context of embodied whole persons.

Noting that a child should represent the unconditional, exclusive and embodied love of his or her parents made flesh;
Mindful that sperm and eggs are parts of the human bodies from which they originated.

Aware that human sperm cells and eggs have no inherent moral value on their own.

Recognising that, in procreation, the entirety of each human sperm cell represents and reveals the whole man from whom it was produced and the entirety of each human egg represents and reveals the whole woman from whom it was produced;
Bearing in mind the traditional Christian prohibition on the use of donor sperm or eggs in procreation and their inability to represent either of the persons in the embodied and exclusive marital love of a couple.

Noting that (1) synthetic eggs obtained from maternal spindle transfer, (2) synthetic sperm cells obtained from women and (3) synthetic eggs obtained from men, no longer represent the whole individuals from whom they were produced;
Mindful of the psychological and social risks that may arise in a child who is uncertain of his or her identity through assisted reproduction;
Recognising that every child should always be unconditionally welcomed into existence;
Conscious that eugenic practices, defined as strategies or decisions aimed at affecting, in a manner which is considered to be positive, the genetic heritage of a child, a community or humanity in general, undermine the equal, inalienable and inherent dignity of human persons.

Recognizing that maternal spindle transfer, pronuclear transfer, cytoplasmic transfer, and blastomere nuclear transfer can all be characterised as eugenic procedures.

Aware of the substantial biological risks that exist from the use of synthetic gametes and embryos;
Conscious of the traditional Christian prohibition on the bringing into existence of human embryos for research and any intentional destruction of human embryos.

Have agreed as follows:

Eugenic interventions seeking to introduce any modification in the genome of any descendants, in particular genetic modifications of sperm and egg cells for fertilisation, should not be used in reproduction.

The use of gametes in reproduction in which modifications have been undertaken undermining their representation of the prospective parents should not take place.

Maternal Spindle Transfer should not be used in reproduction.

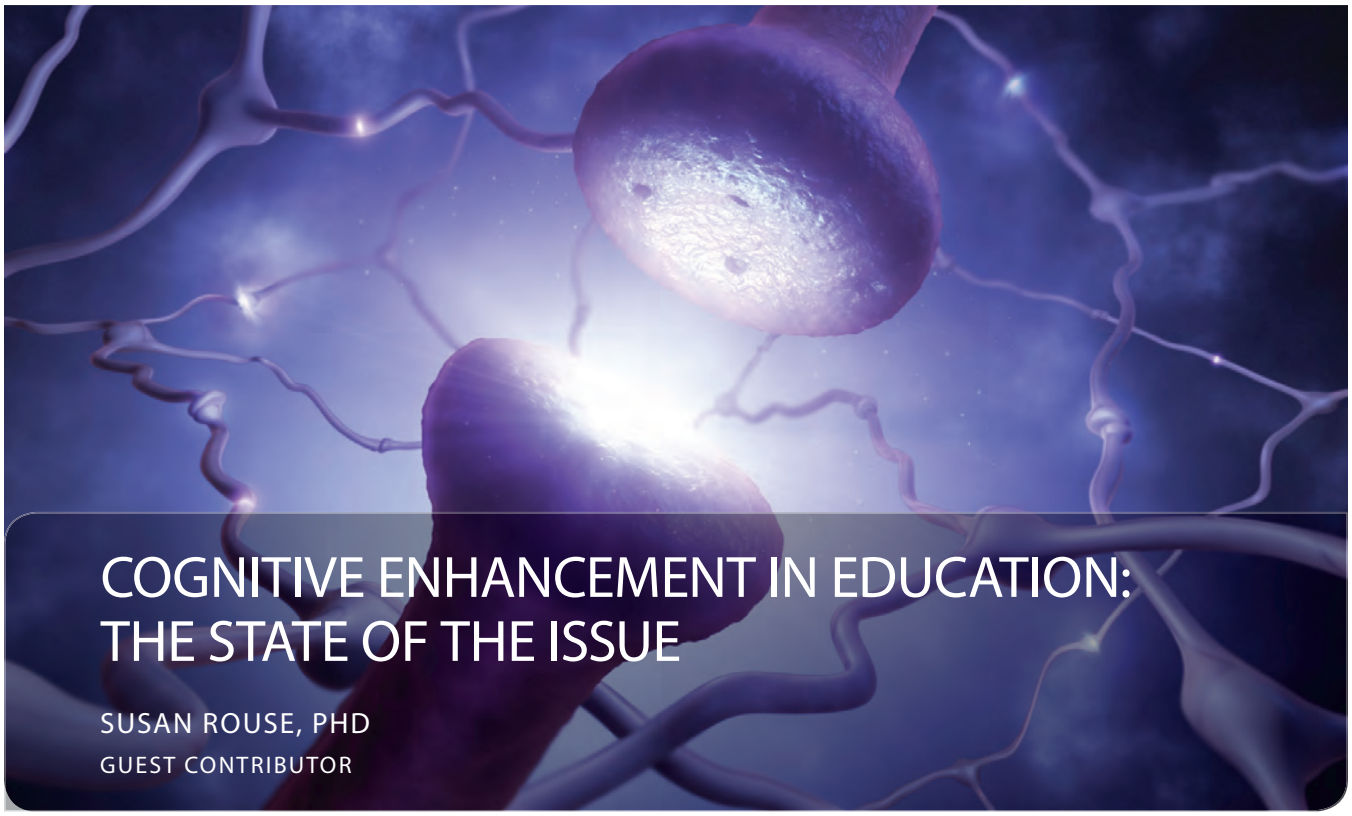
Pronuclear Transfer should not be used in reproduction.

Cytoplasmic Transfer should not be used in reproduction.

Blastomere Nuclear Transfer should not be used in reproduction.

Research on alternative ethical procedures that address mitochondrial disorders and infertility should continue to be supported.

1 Reference to 'traditional' in these recommendations reflects the historic theological position of the Christian church.



COGNITIVE ENHANCEMENT IN EDUCATION: THE STATE OF THE ISSUE

SUSAN ROUSE, PHD
GUEST CONTRIBUTOR

It is in our nature as humans to want to improve ourselves. We strive, both individually and corporately, to know more and accomplish more than those who came before us. Perhaps the most notable of such attempts to better ourselves is the effort we invest in pursuing knowledge through education. Education is so important to our culture that every state funds public education through high school. Clearly, we value the pursuit of knowledge in an effort to enhance our intellect.

What we value, we often want to improve. For this reason, the pursuit of intellectual or cognitive enhancement is not a new concept; indeed, the entirety of the teaching profession is aimed at the cognitive improvement of students. But we do not stop with cognitive enhancement via education. The cultural importance of maximizing cognitive skill and ability has also led us to medicalize intelligence, such that those with lower intelligence or substandard cognitive skills are diagnosed with medical conditions calling for medical intervention. So, pharmacological agents have been developed to bring those with cognitive performance classified as "dysfunctional" within the "normal" range. Drugs like methylphenidate (Ritalin© being the most recognized brand name) help those with attention deficits regain focus; modafinal (Provigil©) stabilizes wakefulness and vigilance in those who suffer from narcolepsy; and rivastigmine (Exelon©) slows memory loss in those suffering from dementia. However, as a consequence of the mechanism of action of these drugs and the wide range of functionality among individuals, these drugs can augment cognition even in individuals who do not meet the diagnostic requirements for a particular disorder. Therefore, the possible means for cognitive enhancement have moved beyond merely education and training into the realm of pharmaceuticals.

The response to this burgeoning frontier in cognitive enhancement has been mixed. Some view pharmacological cognitive enhancement as a new opportunity to raise the average in human achievement, while others fear that this is the first step down a slippery slope that ends in the degradation of human nature and human dignity. Still others question whether the use of such drugs for enhancement outside of therapeutics is even happening enough for us to bother addressing it, either ethically or practically, through public policy. In this essay, we will explore some of the distinctively ethical issues that arise in connection with cognitive enhancing drugs (viz. assessment of safety, justice/fairness, and concerns related to human nature and dignity). Then, in a future issue of *Dignitas*, we will return to this topic to explore some important empirical data and its implications for public policy.

Much of the ethical discussion and empirical research surrounding the issue of cognitive enhancement has focused on cognitive enhancement in college students; of the cognitive enhancing drugs available on the prescription market, those most accessible to college students are attention-enhancing drugs such as methylphenidate and mixed amphetamine salts. Therefore, for our purposes here we will focus on this student population and these drugs.

The Ethics of Enhancement: What Are the Issues and Is It a Problem?

Leon Kass and the President's Council on Bioethics, in analyzing the goals and ethics of human enhancement, acknowledge that "it is not difficult to appreciate, at least at first glance, the attractiveness of the goods being contemplated." [1] Performing at our best, serving one another, and improving our world through quality work in our careers and the development of new technologies are all worthy pursuits. Yet the worth of a goal is not determined exclusively by the end-product of its fulfillment. This point emerges as the thesis of the PCOB's treatise on human enhancement: The human experience is more about the sum of process and relationship than about their outcome.[2] This perspective highlights the emerging ethical dilemmas inherent in pharmacological cognitive enhancement. How does using drugs to enhance our human executive function, which oversees other cognitive processes such as attention and memory, affect our personal and social development? And, at a broader and more philosophical level, what implications might it have for what it means to live as a human person?

Is It Safe?

While opinions vary widely regarding most of the ethical issues that arise in connection with pharmacological cognitive enhancement, one concern reflected nearly universally in the literature is safety. All seem to agree that, first and foremost, drugs that are marketed for any reason, whether therapy or enhancement, should have a positive benefits-to-risk ratio.[3] This is particularly true for a drug that is taken electively, for a reason other than therapeutics. Risk/benefit analysis is difficult in such cases, because the definitions of acceptable risks and reasonable benefits become murky. For example, when risk/benefit analysis is conducted for a drug prescribed in the context of an illness or disorder, the benefits are couched in terms of relieving symptoms, normalizing function, and reducing morbidity. In the case of drugs used for enhancement beyond normal function (those that do not actually reduce morbidity in any significant way), what should be deemed an acceptable level of augmentation of function?[4] Moreover, if risks are defined as deleterious or unpleasant side effects that might be viewed as less deleterious than the untreated symptoms of the disorder, should any side effect or potential health risk engendered by pharmacological cognitive enhancers be acceptable for someone already capable of normal cognition, since such side effects could endanger her or his current "good" health?[5]

Perhaps a good starting place for a risk/benefit analysis of a nootropic (mind enhancing) drug is evaluation of claims that the drug can offer true enhancement of mental or cognitive functions. In the case of methylphenidate, empirical and anecdotal evidence suggests that the enhancement potential is real, but not consistent across individuals or cognitive tasks. Outram[6] reviews a number of studies that provide evidence for cognitive stimulants' improving working memory and executive function on novel tasks in normal adults. However, these studies also indicate that methylphenidate and related stimulants have little effect on concentration and attention in healthy subjects. Moreover, they provide evidence for a drug-induced impairment of previously learned tasks.[7] Anecdotally, on the other hand, college students who have taken methylphenidate without a prescription report that it helped them be attentive, stay awake, retain information and resist distraction during studying.[8] These students also report that methylphenidate has other positive, unintended side effects, like promoting weight loss and increased sociability.[9]

In light of their potential benefits, the risks of cognitive stimulants merit careful consideration. Methylphenidate and amphetamines function to increase attention by enhancing dopamine release in the brain. This effect is not selective, and while increasing dopamine in the prefrontal cortex augments attention, increasing dopamine in the reward pathway (mesolimbic dopamine pathway) results in euphoria. For this reason, methylphenidate, like any psychoactive drug that enhances dopamine in the mesolimbic dopamine pathway, is potentially addictive.[10] Additionally, methylphenidate and related drugs have been shown to reduce appetite[11] and cause sleep disturbances, and may also augment mental illness and be related to cardiovascular problems.[12] Moreover, many ethicists have expressed concern over broader, long-term changes in cognition that could result from the regular use of these drugs. Changes in cognitive style and long-term retention of information, premature cognitive decline, and inability to forget painful or irrelevant information are all potential side effects of these drugs.[13]

> ***"...the medicalization of cognitive ability has created a situation in which more and more people will perceive a "need" for cognitive stimulants..."***

The unequivocal conclusion from the "safety" discussion has been a call for further research and policy safeguards related to pharmacological cognitive enhancers. Even Greely, an outspoken proponent of cognitive enhancement, advocates focused research to elucidate both the efficacy of these drugs and their potential negative side effects.[14] Moreover, Schermer et al. call for consideration of the impact of medicalization on our risk/benefit analysis of cognitive enhancing drugs.[15] They argue that the medicalization of cognitive ability has created a situation in which more and more people will perceive a "need" for cognitive stimulants, thus, potentially impairing their ability to make informed and rational decisions about whether the risks associated with the drugs are worth taking. As a result, the responsibility for individual risk/benefit assessment lies with the

prescribing physician.[16] Bostrom and Roache echo this observation and add that the current "disease-focused model" is inadequate for addressing safety in the context of enhancement.[17] These authors all recognize that an acceptable benefit/risk assessment for a drug used as therapy may be deemed unacceptable when applied to a drug used for enhancement.[18] For this reason, Bostrom and Roache call for a new set of policy guidelines and approval processes for pharmaceutical companies to follow when seeking to market a drug for enhancement.[19]

Is Cognitive Enhancement Fair?

The safety issue and related call for more research on the enhancement efficacy of nootropic drugs may be a moot point if society agrees that the use of cognitive enhancers is simply not fair. The fairness discussion surrounding cognitive enhancement focuses on whether or not such drugs confer an unfair advantage on those who use them. Assessment along these lines has been useful in evaluating the appropriateness of performance-enhancing drugs in sports. Clearly, athletes who use performance-enhancing drugs have a competitive advantage over those who do not. This is significant because competition is the basis of sport. There is a winner and there is a loser, and performance-enhancing drugs increase one's chance of becoming the winner. Bostrom and Sandberg call this type of advantage a positional good.[20] The value of a positional good lies in the fact that others do not have it. While it is clear that performance-enhancing drug use in sports is a positional good, whether or not cognitive-enhancing drug use yields positional goods is hotly debated. Bostrom and Sandberg argue that cognitive abilities are not simple positional goods because they are intrinsically desirable.[21] Goodman offers a similar argument by assessing the benefits of cognitive performance as a non-zero sum activity. As opposed to zero-sum activities that have a clear winner and a clear loser, non-zero sum activities do not have a fixed number of winners and losers. Goodman, like Bostrom and Sandberg, argues that enhancement constitutes cheating only when a binding set of rules exists that aims to provide equal opportunity for winning to all participants.[22] However, cognitive performance and education, he argues, seldom fall within these parameters. Therefore, if cognitive enhancers are used to give an individual an advantage in, say, a competitive exam or a class graded on a curve, then one could consider their use cheating in that situation. But if pursuit of education and cognitive improvement is something that individuals do simply to improve themselves, then it is not a mere positional good, but a non-zero sum activity in which all individuals who cognitively enhance could benefit.[23] Therefore, according to this argument, using pharmacological cognitive enhancements is not cheating, or at least not always.

Moreover, many argue that viewing the use of cognitive-enhancing drugs in education as a form of cheating implies that educational opportunities are equal in the absence of pharmacological cognitive enhancement. In reality, a multitude of unequally distributed educational advantage opportunities exist. Access to good nutrition, tutoring, computer technology and other resources give some students, but not all, educational advantages every day.[24] Nevertheless, Cakic expresses concern that the use of cognitive enhancing drugs in education serves to make an already uneven playing field even more uneven, favoring the wealthy who have the resources to procure such drugs.[25] For Cakic, this serves only as a cautionary note and is not a strong enough concern to motivate prohibition.

However, the issue of fairness takes on another dimension when we consider the impact of cognitive enhancement on the whole of society as opposed to an individual or small groups of individuals. If the use of cognitive enhancers in education confers even a non-zero sum advantage, then individuals may come to interpret this advantage as necessary for success. On a social level, widespread use of cognitive enhancers could raise the "average" cognitive ability in a particular population. The danger in this scenario would be that individuals in that population may feel pressured or coerced into using cognitive enhancing drugs in order to "measure up." Cakic discusses the "Red Queen principle" in which "an individual must continue developing in order to maintain their fitness relative to others with whom they are competing."[26] The Red Queen principle as it relates to cognitive enhancement implies that if drugs such as methylphenidate substantially increase productivity, then individuals may feel pressured to use these drugs to "keep up" with their enhanced colleagues. Farah et al. envision a scenario where explicit coercion forces those who do not want to use cognitive enhancing drugs to do so anyway to keep their jobs or stay in school.[27] Greeley et al. acknowledge this possibility and seem to echo this concern, except in situations where the individual's performance impacts the health and well-being of others. For example, they seem to advocate universal use of cognitive enhancers for military and medical personnel.[28] Yet, respect for autonomy seems to tip the balance in this analysis toward a disdain for coercion, even if that coercion is implicit. Farah recognizes that "[c]learly coercion is not a good thing."[29] Yet, she goes on to assert that "it would seem at least as much of an infringement on personal freedom

"the use of cognitive enhancing drugs in education serves to make an already uneven playing field even more uneven, favoring the wealthy who have the resources to procure such drugs.

to restrict access to safe enhancements for the sake of avoiding indirect coercion of individuals who do not wish to partake."[30] The same regard for fairness that leads us to disapprove of coercion evokes our desire for equal access. Of course one could make the same argument for education as well. If we would not restrict access to education because it creates an environment in which there is pressure to be educated, on what basis should we differentiate this situation from that of pharmacological cognitive enhancement?

Can It Be Fairly Accessible to All?

So, in addition to worrying that those who do not want to partake in pharmaceutical cognitive enhancement might feel pressured to do so, some fear that individuals who do want to use cognitive enhancers will not have access to them. Discussions related to this aspect of fairness center around the almost certain notion that if drugs like methylphenidate were to become legalized for use in cognitive enhancement, they would be expensive and would likely not be covered by medical insurance. For this reason, a concern arises that only the wealthy would have access to these drugs, thus allowing the already troubling gap between the well-educated rich and the less-educated poor to become yet wider.[31] Moreover, it is unlikely that the drugs would ever be offered over-the-counter, so access would be restricted to those with the "high social capital and good information" to communicate effectively with a prescribing physician.[32] Overall, this perpetuates the success of those who know how to self-advocate and can afford the drugs and the detriment of those who lack such hallmarks of privilege.

Bostrom and Sandberg, however, make the point that the mere availability of cognitive enhancers could potentially begin to close the gap between the cognitively gifted and the cognitively disadvantaged. They point out that studies support the notion that drugs like methylphenidate have a more pronounced effect on those at the low end of the cognitive ability spectrum.[33] As a result, they call for a more nuanced analysis of the distribution issue, as they see equal distribution of cognitive enhancing drugs as analogous to access to public libraries and free education. Greeley likewise quips that "[o]ne could mitigate . . . inequality by giving every exam-taker free access to cognitive enhancements, as some schools provide computers during exam week to all students. This would help level the playing field."[34] But proposed solutions calling for monitored, equal distribution of such drugs to entire student bodies are widely regarded as unrealistic, and so are not the focus of most ethical analysis of the subject.[35]

Once again, though, some writers who acknowledge the potential for distributive injustice characterize it as an inevitable fact of life, pointing out that inequality is already a pervasive element of education. Unequal access to expensive, high-quality schools, computer technology, tutoring services, good nutrition, etc. currently contributes to an undeniable "opportunity gap" in education. As a result, some authors conclude that while this scenario is not ideal, it has never been sufficient grounds for prohibiting access to a resource.[36]

> ***What is good about human life, and how does pharmacological cognitive enhancement contribute to that?***

The way in which these different ethical dimensions weave together is important to recognize. If cognitive enhancing drugs are not safe or do not offer sufficient cognitive improvement to offset their risks (if any level of benefit is capable of doing so at all), then objecting to unequal distribution would be, in Leon Kass's estimation, like exclaiming, "The food is contaminated, but why are my portions so small?"[37] However, the safety issue also points to another perspective on the issue of distributive justice. Currently, we do not fully understand the range of side effects and long-term effects that drugs like methylphenidate have on individuals with normal cognitive function; the only way to assess the safety of these drugs is through research. But pharmaceutical research that would elucidate any negative effects of these drugs requires three things: Medical resources, money, and human subjects. Each of these raises issues of justice. William Cheshire and Ben Mitchell both argue that if drugs like methylphenidate became widely available for enhancement purposes, valuable medical resources such as physician and nurse time, drug availability, and testing to monitor side effects would be diverted from the truly sick.[38] Is it ethical to divert research dollars that could be invested in curing disease to the investigation of side effects of cognitive enhancers? Schermer et al. note that "it is not clear at all that investing money, time and expertise in developing cognitive enhancers would make more people better off."[39] Additionally, concerns arise as to which population of individuals would likely be the subjects of such research. It is reasonable to imagine that the poor or cognitively disadvantaged might become likely candidates. Scenarios like this are uncomfortably similar to unjust human research studies of the past, such as the Tuskegee syphilis experiments, against the recurrence of which society is morally responsible to guard.

So, the wheel of ethical analysis continues to spin. However, means-oriented questions of safety, fairness and distributive justice are all issues that can be addressed and even potentially resolved if our society agrees that pharmacological cognitive enhancement is a good idea in the first place – a goal worthy of our pursuit. This consideration points to perhaps the deepest of all of the ethical questions surrounding cognitive enhancement: how this practice would

affect human dignity and human nature.

Does It Threaten Human Dignity or the Basic Nature of Humanity?

The central ethical question regarding the use of cognitive enhancers relates to the underlying goal of enhancement, the betterment of human life. To evaluate if such drugs will indeed "enhance" our lives, we must first explore "what conception of a good life is behind the claims that radical enhancements would make human life better."[40] What is good about human life, and how does pharmacological cognitive enhancement contribute to that? The pursuit of the good life is inextricably linked to human enterprise, the living out of our human nature. Our unique human nature affords our species a level of dignity and respect that deserves defending. This is the heart of bioethics as it applies to humans, or at least it should be. In order to determine if a new technology or movement is ethical or unethical, a primary question should always be whether it will compromise human nature and whether it will promote or demean human dignity. While concrete definitions of human nature and human dignity are elusive, many (particularly those who defend human enhancement) posit that our unique human nature is tied to our intelligence and the autonomy that is born out of that intelligence.[41] It may seem logical to conclude that if intelligence is the core of human nature then it is characteristics such as intelligence and autonomy that confer dignity on human beings. However, such a view of human nature and how it relates to human dignity is grossly oversimplified and blurs important distinctions. Furthermore, it degrades the value of humans who are not autonomous (children and those with severe mental illness), as well as those with lower cognitive ability. Rather than attempting to tie human dignity to a single characteristic like this, therefore, it seems better to tie it simply to being human—that is, to human nature itself.[42] It is with this in mind, then, that we will consider just what are the ramifications of cognitive enhancing drugs for human nature and human dignity?

Some advocates of human enhancement see cognitive enhancement as an advancement in human evolution that will ultimately elevate humanity beyond the confines of our current biology.[43] Such proponents see this as an enhancement of human nature. The scientists and ethicists who most strongly advocate the use of cognitive enhancing drugs by the general public usually see their use as generating positive results for all of society.[44] Greeley and Cakic see these drugs as morally equivalent to education, exercise, and good nutrition, all of which have been shown to have profound cognitive benefits and have been instrumental in shaping human intelligence and innovation. Enhancement proponents Bostrom and Ord look to eliminate opposition to enhancement technologies on a philosophical level by arguing that those who resist human enhancement are succumbing to status quo bias.[45] They claim that simply defending our current best cognitive function as "normal" is invalid and advocate cognitive enhancers as a means to establish a new "normal" level of cognition and intelligence by which to define human nature. Indeed, advocates of cognitive enhancement seem almost universally to agree that cognitive enhancement will positively affect human nature by advancing average cognitive capability and intelligence.[46]

> ***"we can cure a lot with a pill, but not the hellish hangover our society will get if it overdoses on magic ones attempting to cure the human condition."***

Though none of these proponents explicitly address the concept of human dignity, the idea of raising the bar of "normal" human nature as they suggest has profound implications for how we view those who fall below that bar (either by stage of development or by ability level). Many who are concerned about the implications of human enhancement in general fear that cognitive enhancers are simply the first step on a slippery slope that ultimately leads to an undue focus on human intelligence and academic or otherwise intellectual accomplishment. They worry that this will result in the degradation of human dignity.[47] These fears manifest themselves in two main areas. The first is the potential devaluing of the mentally handicapped. If human nature is tied to intelligence and a human life is therefore valued by the measure of cognitive ability, then what is to become of those that are so far below "normal" that they cannot become "enhanced"? These individuals already suffer discrimination as a minority in utilitarian analysis, but their status runs the risk of plummeting if society over-emphasizes the importance of cognitive ability and performance. This has the potential to augment the already growing eugenic attitude toward pre-implantation genetic analysis and the use of genetic engineering to eliminate all manner of disease, even cognitive disability.

The second manifestation of the fear that cognitive enhancement may compromise human dignity is concern that the use of drugs such as methylphenidate to increase productivity will augment society's obsession with success as the ultimate human goal. This obsession devalues the process of accomplishing things via hard work and overcoming adversity as integral to the human enterprise.[48] For example, one study has shown that while methylphenidate works to increase focus, it does so at the cost of creativity.[49] This trade-off if properly understood might demonstrate a clear social preference. Schermer argues that there is something intrinsically valuable in the pursuit of education, that the acts of studying and learning are what make us better people, not simply what we end up knowing.[50] The PCOB invests considerable effort arguing this point. They quote Carl Elliot's testimony to the council in which he said,

[T]he very changes that some people may think of as unqualified 'enhancements' (i.e., becoming more attentive and mindful) are not quite as

unqualified as they may initially think; . . . these enhancements may well be changes critical to a person's identity, a person's sense of who he or she is.[51]

The PCOB goes on to make the point that the use of cognitive enhancing drugs removes the ability for us to accurately assess our own performance, as their use results in the separation of achievement from the art of achieving.[52] They illustrate this point by saying,

we admire…those who overcome obstacles and struggle to try to achieve excellence... This matter of character—the merit of disciplined and dedicated striving—is surely pertinent. For character is not only the source of our deeds, but also their product. As we have already noted, healthy people whose disruptive behavior is "remedied" by pacifying drugs rather than by their own efforts are not learning self-control; if anything, they may be learning to think it unnecessary.[53]

Using strong imagery to echo this concern, Barbara Amiel colorfully states, "we can cure a lot with a pill, but not the hellish hangover our society will get if it overdoses on magic ones attempting to cure the human condition."[54] These are salient points. All of us can relate to the satisfaction of looking back on our own perseverance in a difficult task, and many of us would probably agree that the sense of accomplishment is less about the outcome and more about the obstacles we overcame to facilitate that outcome. The notion that hard work and the process of accomplishing are intrinsically worthwhile, intrinsically good, is deeply rooted in our common cultural perspective about the world and ourselves.

It seems inevitable, therefore, that beliefs regarding the potential effects of pharmacological cognitive enhancement on the human experience should draw the dividing line between those who desire to allow broader use of these drugs and those who desire to prohibit their use for enhancement purposes. In another installment of this discussion, which will appear in a future issue of *Dignitas*, we will explore a range of empirical data regarding evaluations of and dispositions toward cognitive enhancing drugs among particularly salient populations, as well as the implications of this data for appropriate approaches to cognitive enhancement in public policy.

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HEALTH AND HUMAN FLOURISHING

JENNIFER MCVEY, MDIV
EVENT & EDUCATION MANAGER

The Center for Bioethics & Human Dignity celebrated its 20th annual summer conference, *Health and Human Flourishing*, July 18-20, 2013. After twenty years of bioethical reflection, it was time to revisit our notions of what health is, how ideas of health have shifted in our current society, and how those shifts have altered our understanding and experience of what it means to flourish. Christian theological reflection and tradition offer a rich understanding of what it means to flourish. But how does that contribution bear on our current ethos and praxis?

The Center presented an impeccable line-up of plenary speakers. Francis Cardinal George, OMI; Bart Cusveller, PhD; Allen Verhey, PhD; and William B. Hurlbut, MD, helped attendees navigate the ethical, theological, and practical considerations related to our individual health, our family, and society. Cheyn Onarecker, MD; Jane Hall, RN; Joyce Shelton, PhD; William Struthers, PhD; and Katherine McReynolds, PhD, participated in a symposium addressing some of the practical implications of what it means to flourish through the lenses of physical health, patient care, scientific research, mental health, and disability.

So how does our health relate to overall human flourishing? Do our preconceived notions of health sometimes prevent us from realizing a certain level of flourishing? Or is it our preconceived notion of what it means to flourish that hinders its realization in our lives?

The use of medicine and technology has moved beyond repairing injury and healing disease to pursuits that have the potential to improve human capacities and "correct" conditions that were once considered normal life experience. Not all human problems are medical problems. As the philosophy of health changes, we risk marginalizing those who fall beyond the shrinking boundaries of the "healthy" category and further maligning those who suffer from disease and disability. In framing the discussion, Paige C. Cunningham, JD, executive director of the Center, observed, "We are

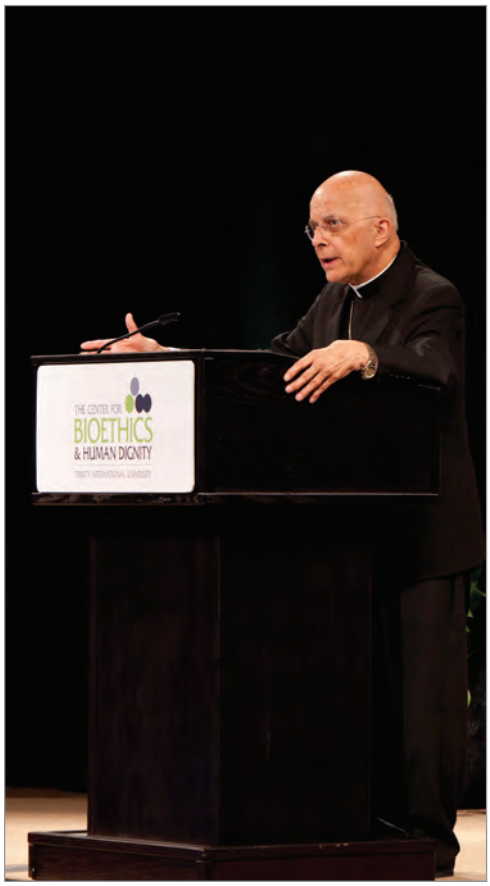
Top-left: Paige Cunningham gives opening remarks at CBHD's 20th anniversary dinner. Bottom-left: A place setting at the dinner. Right: Helen Alvare, JD, delivers the keynote address at the dinner.

intended by God to flourish not in spite of, but in and through our vulnerability, our suffering, our illnesses . . . we are more genuinely free when we accept our limitations, when we accept our dependence on others, when we accept help."

Our plenary speakers and symposium reminded us that not all who are experiencing physical and mental health are flourishing, and not all who suffer from disease and disability are languishing. Indeed, we often find that those who are suffering have a level of peace and gratefulness for the gifts of this life that enable them to flourish uncommonly well. Dr. Allen Verhey, professor of Christian ethics at Duke Divinity School, emphasized that health can become an idol, and that in this cult of health "Hospitals and exercise facilities are the temples, and doctors and dieticians are the priests." Christian tradition recognizes health as a good, but not the greatest good. If there is no one-to-one correlation between health and human flourishing, how then do we enact the latter? According to Dr. Verhey, it is through doxological gratitude, responding to God's grace and goodness, joyful hopefulness in our telos, knowing the Spirit is drawing all things toward God's good future, and affective appreciation—loving both God and neighbor—that we realize our flourishing.

Community, life lived in relationship with others and with God, establishing the common good, holistic peace, living in appreciation of God's good gifts in our lives, advancing human endeavors and science without sacrificing life—these are some of the things our speakers reminded us that embody human flourishing in this life. As we continue to think deeply about what it means to be healthy and look toward God, the author and perfecter of our faith, may we begin to flourish more fully.

Our conference was a reminder that the work of the Center is as pertinent now as upon its founding twenty years ago. There is still a palpable need for bioethical reflection from a Judeo-Christian Hippocratic tradition as medical and technological advances continue to raise questions. This journey will continue through our 21st annual summer conference, *Bioethics in Transition*, June 19-21, 2014. Please note that the date has changed! We will hear from Gilbert Meilaender, PhD; Henk ten Have, PhD; Jeffery Bishop, MD, PhD; Lisa Anderson-Shaw, DPH, MA, MSN; and Richard Doerflinger, MA. This promises to be another excellent conference. Hope to see you there!



Left: Francis Cardinal George delivers his plenary address at CBHD's 20th Anniversary Conference, Health & Human Flourishing. Top-right: A workshop during CBHD's summer conference. Bottom-right: Exhibit hall at CBHD's 20th Summer Conference.

TOP BIOETHICS STORIES: JUNE – AUGUST 2013

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

"DSM-5 Finally Debuts, Markedly Changed from Earlier Editions" by Christine S. Moyer *American Medical News*, June 3, 2013

> Nearly two decades after work began on the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, the manual is ready for use by physicians. The long-awaited print version was released May 17 during the American Psychiatric Association's annual meeting in San Francisco. DSM-5 will be available online later this year. (http://tinyurl.com/mtbpkpk)

Last spring there was much debate over how the *DSM-5* would portray mental illness. *The Diagnostic and Statistical Manual of Mental Disorders* has long been the standard for diagnosing mental illness; its recent edition, however, has garnered criticism for making the boundaries of mental illness too all-encompassing. This could lead to healthy people being treated, or even medicated, for problems that are not clinical mental illnesses. Part of the revision process of the *DSM-5* involved soliciting online commentary from medical health professionals.

"Judge Moves Sarah Murnaghan onto Adult Lung List" *BBC,* June 6, 2013

> A US federal judge has allowed a severely-ill 10-year-old girl a prime spot on the list to receive an adult lung transplant, despite her young age. (http://tinyurl.com/mx7vnve)

"Sarah Murnaghan Had Two Lung Transplants, One Failed" by Sydney Lupkin, *ABC News,* June 28, 2013

> The 10-year-old girl whose parents successfully fought a rule preventing her from qualifying for adult lungs didn't have just one lung transplant from an adult donor this month. She had two. (http://tinyurl.com/q4tmsfs)

Sarah Murnaghan was dying of lung failure due to cystic fibrosis. She was on the pediatric donor list. Her mother, however, petitioned to receive an exception to the Under-12 Rule, which generally requires that adult lungs be offered to adult patients in a region before being offered to children who would otherwise be higher on the transplant list. A federal judge allowed for her to receive adult lungs, and later the Organ Procurement and Transplantation Network (OPTN) created a mechanism for exceptions to the Under-12 Rule to be made on a case-by-case basis. The initial transplant failed, necessitating a second.

"US Supreme Court Says Human DNA Cannot Be Patented" *BBC*, June 13, 2013

> Human genes may not be patented, but artificially copied DNA can be claimed as intellectual property, the US Supreme Court has ruled unanimously. The court quashed patents held by a Utah-based firm on two genes linked to breast and ovarian cancer. The opinion said DNA came from nature and was not eligible for patenting. (http://tinyurl.com/kqvx6jq)

Myriad genetics has been involved in a three-year court battle over patent rights for genes isolated using its techniques. Specifically, the case centered upon two genes, BRCA1 and BRCA2, known to be markers for breast and ovarian cancer. The U. S. Supreme Court decided that Myriad cannot patent these genes because they occur in nature. If a company makes a synthetic gene in the lab, however, then it is eligible to patent that gene.

"Administration Issues Final Rules on Contraception Coverage and Religious Organizations" *Department of Health and Human Services*, June 28, 2013

> Today, the Obama administration issued final rules that balance the goal of providing women with coverage for recommended preventive care – including contraceptive services prescribed by a health care provider – with no cost-sharing, with the goal of respecting the concerns of non-profit religious organizations that object to contraceptive coverage. The final rules reflect public feedback received in response to the Notice of Proposed Rulemaking issued in February 2013. (http://tinyurl.com/od8fy6d)

The Obama administration announced a compromise allowing for certain religious organizations to be exempt from providing coverage for contraception. Contraception coverage for the employees of such organizations will be provided separately to women on their health plans at no purported cost to the organizations.

"Japan Approves World's First iPS Stemcell [sic] Clinical Trial" by Kyoko Hasegawa, *AFP,* June 27, 2013

> Japan has given the green light to the world's first clinical trial using stem cells harvested from a patient's own body, officials said Thursday, testing a treatment that may offer hope to millions of people robbed of their sight. (http://tinyurl.com/pq74bon)

Researchers in Japan received approval to proceed with a clinical trial using induced pluripotent stem cells (iPSCs) made from the patient's own skin cells. The trial will involve harvesting skin cells, converting them into iPSCs, and developing the latter into retinal cells. The trial participants all have age-related macular degeneration; they will receive the newly formed retinal cells, and researchers will determine whether this procedure improves the patients' vision. This will be the world's first clinical trial using iPSCs.

"Miniature Human Liver Grown in Mice" by Monya Baker, *Nature,* July 3, 2013

> Transplanting tiny 'liver buds' constructed from human stem

> cells restores liver function in mice, researchers have found. Although preliminary, the results offer a potential path towards developing treatments for the thousands of patients awaiting liver transplants every year. (http://tinyurl.com/mv6jch5)

Researchers were able to use a combination of induced pluripotent stem cells (iPSCs) coaxed into becoming liver cells, umbilical cord blood cells, and mesenchymal stem cells to make small liver "buds." The buds were transferred into mice that had liver failure, where they took on certain liver functions that kept the mice alive. Furthermore, the liver buds continued to grow within the mice. This experiment received quite a bit of press because of its potential as an eventual source of human organs.

"IVF Baby Born Using Revolutionary Genetic-Screening Technique" by Ian Sample, *The Guardian*, July 7, 2013

> The first IVF baby to be screened using a procedure that can read every letter of the human genome has been born in the US. Connor Levy was born on 18 May after a Philadelphia couple had cells from their IVF embryos sent to specialists in Oxford, who checked them for genetic abnormalities. The process helped doctors at the couple's fertility clinic in the US select embryos with the right number of chromosomes. (http://tinyurl.com/n6hyyua)

Using a new genome sequencing technique, "next-generation sequencing," scientists were able to sequence an embryo's entire genome quickly and relatively cheaply. While the doctors in this case were looking only at the number of chromosomes in the embryonic cells, they could have looked at the embryo's entire genetic sequence, if needed. As Dagan Wells, the fertility specialist who directed the screening, points out, this technique "can't make embryos better . . . but it can guide us to the best ones."

"Gene Therapy Trial 'Cures Children'" by James Gallagher, *BBC*, July 11, 2013

> A disease which robs children of the ability to walk and talk has been cured by pioneering gene therapy to correct errors in their DNA, say doctors. The study, in the journal Science, showed the three patients were now going to school. A second study published at the same time has shown a similar therapy reversing a severe genetic disease affecting the immune system. (http://tinyurl.com/oxnwfwz)

Gene therapy, much like stem cell research today, was hailed in the 1980s and 1990s as the next great medical breakthrough. But it has not cured the numerous diseases people had hoped it would. The tragic story of Jesse Gelsinger, who died from gene therapy, also set research back. Now two trials, one involving patients with metachromatic leukodystrophy and the other Wiskott-Aldrich syndrome, have proven successful. In both trials the children's bone marrow stem cells were removed, infected with viruses carrying DNA without the offending mutation, and then returned to the patient's body.

"Neuroscience: Solving the Brain" by Allison Abbott, *Nature*, July 17, 2013

> . . . on 2 April, Obama announced a US $100-million initial investment to launch the BRAIN Initiative, a research effort expected to eventually cost perhaps ten times that amount. The European Commission has equal ambitions. On 28 January, it announced that it would launch the flagship Human Brain Project with a 2013 budget of €54 million (US $69 million), and contribute to its projected billion-euro funding over the next ten years. (http://tinyurl.com/l52sbqb)

Both the U.S. and Europe have their minds set on mapping the human brain in an effort to better understand how its intricate neural connections work. The hope is that, by mapping the complex architecture of the brain, we can better understand the internal mechanisms and, perhaps, gain insight into mental illness, Alzheimer's, and other neurological diseases.

"Scott Simon: 48 Hours with Dying Mom Sad and 'Exhilarating'" by Susan Donaldson James, *ABC News,* July 31, 2013

> Radio host Scott Simon never intended to tweet his mother's final hours to 1.2 million followers, but her dying moments were among the most emotional in his public life. (http://tinyurl.com/k7tbhf5)

The ubiquity of social media brings up questions about privacy. Our privacy laws do not seem to extend to social media (several difficult cases regarding privacy issues have arisen recently), and our social norms about privacy do not seem to apply stably in that arena either. One of the most high-profile of recent stories, which garnered the attention of many bioethicists, was that of Scott Simon tweeting about the death of his mother.

"Famous HeLa Cells Get Genetic Close-Up, and New Data-Sharing Rules" by John Bohannon, *Science Insider,* August 7, 2013

> Five months after it was hastily removed from the Internet in the face of harsh criticism, the genome of the widely used HeLa cell line is back online today. Not only that, but it is also now sequenced at the highest level of resolution yet for a cancer research cell line. But scientists who want to use those data must now ask for permission from a committee that includes descendants of the woman whose cells were taken—without her consent—62 years ago. (http://tinyurl.com/kqtt4yb)

The Immortal Life of Henrietta Lacks, by Rebecca Skloot, brought to light an egregious case of researchers ignoring informed consent rules and disregarding genetic privacy. HeLa cells have been used in research for decades, but were initially harvested and grown without obtaining consent from Ms. Lacks or her family. In response to numerous complaints about the HeLa cells' genetic sequence being posted online, the NIH made new rules requiring scientists to obtain permission to use HeLa cells.

updates & activities

ONLINE RESOURCES

During the past months, we have been busy uploading a variety of audio and video resources. Recent updates include archived episodes of the *Everyday Bioethics Audio Commentary*, available at everydaybioethics.org. Additionally we have uploaded a number of videos from 2012-2013 events to our YouTube channel. These include videos from the November 2012 Academy of Fellows Consultation on the "Ethics and Theology of Synthetic Gametes" and the March 2013 launch event of Her Dignity Network.

EVENTS

Managing an Unexpected Prenatal Diagnosis: Critical Considerations for Counselors, Clinicians, and Friends

CBHD co-sponsored a one-day conference on prenatal diagnosis in July with The Jerome Lejeune Foundation, USA, Family Research Council, and Medical Students for Life. Sessions included presentations by David Prentice, PhD; Peter Smith, MD, MA; Mark Leach, JD, MA; Byron Calhoun, MD, FACOG, FACS; and Donna Harrison, MD. Topics ranged from an update on the accuracy and availability of prenatal testing methods, the relationship between prenatal diagnosis and termination, legislative and policy initiatives regarding prenatal testing and counseling, research into therapeutic treatments for genetic or congenital disabilities, as well as a session directed to communicating an unexpected prenatal diagnosis. Video of the sessions is available at cbhd.org and our YouTube channel.

MEDIA RESOURCES

CBHD.org on Twitter: @bioethicscenter

Bioethics.com on Twitter: @bioethicsdotcom

The Bioethics Podcast at thebioethicspodcast.com

Facebook Cause at causes.com/cbhd

Facebook Page at facebook.com/bioethicscenter

Linked-In Group at linkd.in/thecbhd

YouTube at youtube.com/bioethicscenter

The Christian BioWiki christianbiowiki.org

STAFF

PAIGE CUNNINGHAM, JD

- Was interviewed about vocational stewardship by a class of nine DMin students from Covenant Theological Seminary.
- Delivered opening session, "Framing the Discussion" at our 20th Annual Summer Conference in July.
- Taught the Intensive Institute Bioethics Course in July.
- Spoke at the TEDS/Trinity Graduate School chapel in September on "Indwelt by the Spirit."

MICHAEL SLEASMAN, PHD

- Delivered final session, "Reframing the Discussion" at our 20th Annual Summer Conference in July.
- Taught the Advanced Institute Bioethics Course, and guest lectures in the Intensive Institute and Basic Bioethics for Professionals courses in July.

RESEARCH LIBRARY UPDATE

During the late summer and early fall, CBHD received two generous donations of resources to our collections. CBHD advisory board member Scott Daniels, PhD, donated publications and supporting documents from early U.S. Presidential bioethics commission to our Presidential Commission Collection. The second generous donation was to the Edmund D. Pellegrino Special Collection in Medical Ethics and Philosophy from the late Dr. Pellegrino's family. These resources from Dr. Pellegrino's personal library include an impressive spectrum of topics, including some of his early research notebooks and numerous materials in medical ethics, Roman Catholic moral theology, and the virtue tradition among others.

ON THE CBHD BOOKSHELF

ARTICLES OF NOTE: **For those interested in knowing what books and articles the Center staff have been reading and thought worth highlighting.**

****Note that the resource includes material by members of the Center's Academy of Fellows.**

Association for Molecular Pathology v. Myriad Genetics, No. 12-398, slip op. (U.S. June 13, 2013).

**Hodges, Kevin, and Daniel Sulmasy. "Moral Status, Justice, and the Common Morality: Challenges for the Principlist Account of Moral Change." *Kennedy Institute of Ethics Journal* 23, no. 3 (2013): 275-296.

**Hurlbut, William. "St. Francis, Christian Love, and the Biotechnological Future." *The New Atlantis* 38 (Winter/Spring 2013): 92-99.

Shih, Jerry, Dean Krusienski, and Jonathan Wolpaw. "Brain-Computer Interfaces in Medicine." *Mayo Clinic Proceedings* 87, no. 3 (2012): 268-279.

**Sulmasy, Dan. "The Good Doctor." *The New Atlantis* 39 (Summer 2013): 51-55

Swekoski, Don, and Deborah Barnbaum. "The Gambler's Fallacy, the Therapeutic Misconception, and Unrealistic Optimism." *IRB: Ethics & Human Research* 35, no. 2 (2013):1-6.

Toll, Elizabeth. "The Cost of Technology." *The Journal of the American Medical Association* 307, no. 23 (2012): 2497-2498.

Tomlinson, Tom. "Respecting Donors to Biobank Research." *Hastings Center Report* 43, no. 1 (2013): 41-47.

VanDrunen, David. "Natural Law in Noahic Accent: A Covenantal Conception of Natural Law Drawn from Genesis 9." *Journal of the Society of Christian Ethics* 30, no. 2 (2010): 131:149.

Wellmon, Chad. "Why Google Isn't Making Us Stupid . . . or Smart." *The Hedgehog Review* 14, no. 1 (2012): 66-80.

Witherspoon Council on Ethics and the Integrity of Science. "The Stem Cell Debates: Lessons for Science and Politics." *The New Atlantis* 34 (Winter 2012): 5-146.

Zubrin, Robert. "The Population Control Holocaust." *The New Atlantis* 35 (Spring 2012): 33-54.

COMING SOON: AN UPDATE ON ADVANCE DIRECTIVES