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CRISPR UPDATE: CONSIDERATIONS FOR A RAPIDLY EVOLVING AND TRANSFORMATIVE TECHNOLOGY

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Earlier this year, only a few months after the Chinese stunned the world by announcing that they had edited genes in human embryos,[1] the British Human Fertilisation & Embryology Authority (HFEA) gave researchers in the U.K. permission to conduct similar experiments with human embryos who have been abandoned at local fertility clinics.[2] This research—made possible by a technological revolution in DNA editing called CRISPR/Cas9—is controversial not only because of the moral status of the embryos involved but also because of the potential for permanent changes to be introduced into the human gene pool by means of germline intervention, and fears of the further commodification of human life in the form of designer babies.

For decades, researchers have been introducing changes into the DNA of model organisms in order to better understand the function of those particular stretches of DNA and the role different genes play in the progression of disease. Some scientists have tried to use similar techniques in humans to correct diseases known to be caused by a single DNA mutation, but gene therapy based on these older technologies has proven extremely difficult to use safely in human patients. In fact, after almost 25 years of research and development, the Food and Drug Administration (FDA) has yet to approve any gene therapy product for sale in the U.S. These older gene editing technologies are also labor intensive, expensive, and inefficient.

The new CRISPR/Cas9 system, an adaptation of an elegant, naturally occurring gene splicing mechanism, offers several advantages over its predecessors. The CRISPR/Cas9 system was originally identified as a tool that bacteria use for defending themselves against infection caused by foreign DNA found in small, virus-like pathogens. The system contains a "homing mechanism" which is able to locate and bind to a very specific sequence of DNA and a pair of "molecular scissors" which cut the target DNA at a precise location within that sequence. Scientists have transformed this naturally occurring tool into a "find and replace" system that can edit DNA sequences efficiently and specifically. Depending on whether the goal is to obliterate gene function or introduce specific changes in the DNA sequence, different modifications of the CRISPR/Cas9 system are used. The system has worked in almost every organism tested, including organisms previously resistant to more traditional forms of DNA manipulation.

Transformative Technology with Far-Reaching Applications

The applications of this technological revolution are profound. Yogurt producers are interested in using the system as originally designed, to protect their bacteria from infections that can ruin large batches of yogurt.[3] Several agribusinesses are interested in using CRISPR/Cas9 to create genetically modified livestock and crops.[4] In 2015, Cibus became the first company to bring a genome-edited product (herbicide-resistant Canola) to the market in the U.S.[5] These products are distinct from GMO (genetically modified organisms) food because CRISPR-modified organisms do not contain foreign DNA or "transgenes." The U.S. Department of Agriculture (USDA) has already ruled that organisms modified with prior generation editing techniques do not require special approval (as traditional GMO agriculture does) because they do not involve the use of "plant pests" to introduce changes to the plant's DNA.[6]

As a laboratory tool, CRISPR/Cas9 is opening new ways for scientists to model human disease and develop potential treatment options. In 2014, scientists used CRISPR to precisely target two genes in cynomolgus monkeys (a variety of macaque), the first time researchers were able to selectively disrupt genes in primates.[7] Scientists have shown that a mutation associated with tyrosinemia, a human metabolic disease, could be corrected in an adult mouse using CRISPR/Cas9 to "fix" the mutation.[8]

Some researchers are exploring the use of CRISPR/Cas9 to create gene-drives. With the use of this technology, scientists could eradicate vector-borne diseases such as yellow fever, malaria, or Zika by engineering disease-free mosquitoes specially designed to take over the entire mosquito population in a few generations.[9] While the elimination of these diseases could have an enormous public health benefit, critics have urged caution, since the release of these organisms could have unintended ecological consequences, as there is no way to control the genetic

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from the director's desk

BY PAIGE C. CUNNINGHAM, JD
EXECUTIVE DIRECTOR

"*Do you think any business or clinic should sell fetal tissue for a profit?*" With that question, Rep. Marsha Blackburn, chair of the Select Investigative Panel on Infant Lives, opened a hearing on bioethics and fetal tissue research on March 2nd. I was an invited witness, along with Kevin Donovan, MD (Pellegrino Center for Clinical Bioethics at Georgetown); Patrick Lee, PhD (Center for Bioethics at Franciscan University of Steubenville); and Kathleen Schmainda, PhD (Medical College of Wisconsin). More about that in a moment.

If you have followed CBHD since our beginning, you may remember that in the early years, the Center was more active in public policy, testifying, issuing press releases, and commenting on the developments of the day. Over the past decade, and with a smaller staff, we chose to concentrate our emphasis on scholarly engagement of bioethical issues, continuing to strengthen the reputation and credibility of CBHD as a place of "rigorous research, theological and conceptual analysis, and charitable critique."

One of the most visible results has been the formation of the Academy of Fellows about seven years ago. The Academy has coalesced into a group of Christians committed to advancing scholarship and encouraging one another in their pursuits. As one Fellow recently wrote me, "The combination of solid scholarly work in bioethics with personal faith and love for the Lord *(scientia et pietatis)* in a group the size of the Academy, is rare!"

Listening in on the Academy consultations is a blessing to me, as well as a stimulus to deeper thinking about a broad range of bioethical concerns. You will note that our Academy of Fellows recently met in February and that one of our Fellows, Bart Cusveller, is a contributor in this issue. The formation and maintenance of the Academy has been supported by a generous grant, now expiring. We are praying that others will see the value of this unique initiative, and take up the challenge to make future consultations a reality.

I have been reflecting on our commitment to academic rigor in light of my recent trip to Capitol Hill. My participation and written testimony reflect the level of scholarship that has become the hallmark of CBHD.[1] Rather than concentrating on sound bites, which is what I was accustomed to in my years in the pro-life movement, the focus of my written testimony was on providing careful research and analysis of the current state of human fetal tissue research and its ethical landmines. In my shorter oral testimony, I aimed to engage the listening audience. We think this approach combines the best of our early years of public engagement with our commitment to continuing to raise the bar on academic excellence.

My testimony addressed three main points:

1. *Respect the fetus.* The fetus is a human being who is entitled to the protections of modern guidelines for medical research, and the foundational principle of respect for persons should apply to unborn children without distinction.

2. *You cannot take a life, then give away the body.* Participants in elective abortion, including the mother, are morally disqualified from consenting to donating the body, organs, or tissue of the now-dead fetus for research purposes.

3. *There are proven, more ethical alternatives.* Thousands of studies using ethically derived cells are showing promising successes.

The stated purpose of the hearing was to educate and inform on the bioethical issues of fetal tissue. Nonetheless, some chose to focus questions on Planned Parenthood and the undercover videos that exposed their connections with fetal tissue brokers, as well as researchers' awareness about the source of

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the tissues they used. Lawrence Goldstein, PhD (University of California, San Diego School of Medicine), a minority witness who uses fetal tissue in his research, admitted he had "no idea" where the tissue came from or what it cost.[2]

Certain representatives, however, were more interested in complaining about subpoenas, eliciting yes/no answers to complex ethical questions, making comparisons with the Red Scare and the 1692 Salem witch trials, and generally describing the investigation into fetal tissue research as a "proxy attack" on "safe abortion in this country." One of their more astonishing claims was that if one did not participate in fetal tissue research, they had no grounds on which to speak. According to this logic, only plagiarists have the right to critique stealing someone else's research, to put it mildly.

One participant mistakenly claimed that fetal tissue research has already saved the lives and health of "millions," and was necessary for future life-saving cures. Setting aside the back and forth on whether aborted fetuses were necessary for vaccines, Dr. Goldstein admitted that "I'm not aware of any [cures for disease] that have been definitely solved using fetal tissue, although arguably the development of treatments for HIV depended upon humanized mice." Meanwhile, the march for ethically-derived therapies and cures goes inexorably on. It might take longer, but we will not have to apologize for exploiting abortion.

I was grateful to represent the Center and Trinity International University at the hearing. I realize the distance traveled since I crafted sound bites and rapid responses for journalists, more than a decade ago at Americans United for Life. All these things have their place. But my place now is in the often hidden world of "rigorous research, theological and conceptual analysis, and charitable critique."

1 The testimony is posted at https://cbhd.org/testimony-bioethics-and-fetal-tissue.

2 The congressional hearing (two panels of two hours each) is posted at http://www.c-span.org/video/?405854-1/hearing-fetal-tissue-research.

drift of the engineered mosquitoes once released into the wild.

One of the key reasons that the CRISPR/Cas9 system has generated so much enthusiasm is its potential for use in human gene therapy protocols. CRISPR/Cas9 could be used to correct mutations in human adult stem cells or induced pluripotent stem (iPS) cells. These edited cells could then be transplanted back into the patient to treat diseases. In basic laboratory experiments, scientists have already used CRISPR/Cas9 to excise HIV from the DNA of human cells and to correct a mutation that causes a blood disorder called Fanconi's anemia in iPS cells that are then differentiated into hematopoietic (blood) stem cells.[10] Although this has not yet been tested in human patients, these now-healthy stem cells could in theory be transplanted back into a human patient to reconstitute a healthy blood cell population. Researchers are exploring a similar technique to re-engineer patients' blood cells to become HIV-resistant.[11]

Germline Intervention & Potential Implications

Although much work remains to translate these promising results into safe and effective human therapies, these techniques have not generated ethical controversy because they manipulate the DNA of somatic cells rather than germline cells or embryos. Somatic cells include all of the cells in our bodies that are not involved in reproduction. Genetically modifying somatic cells will not affect the human gene pool because the edited DNA cannot be passed onto the patient's children.

The opposite is true of germline cells—the egg and sperm cells that become future human beings. Changes made to these cells (or to embryos created in vitro) will be passed to almost every cell of the next generation and can be inherited by future generations. Since the early days of modern genetic engineering, when researchers first discovered how to cut and splice DNA, researchers maintained that permanently altering the human gene pool was a bright line that should not be crossed.[12] The American Medical Association, for example, currently maintains that, "The fundamental difference between germ line therapy and somatic cell therapy is that germ line therapy affects the welfare of subsequent generations and may be associated with increased risk and the potential for unpredictable and irreversible results. Because of the far-reaching implications of germ line therapy, it is appropriate to limit genetic intervention to somatic cells at this time."[13] But this opinion was written in 1996, before modern DNA editing technologies were on the horizon. Now what was previously unimaginable—and therefore easy to oppose—is now possible.

Since the early days of modern genetic engineering, when researchers first discovered how to cut and splice DNA, researchers maintained that permanently altering the human gene pool was a bright line that should not be crossed.

In April of 2015, Chinese researchers reported that they had "successfully" used CRISPR/Cas9 to edit a mutation known to cause β-thalessemia (a serious blood disease) in human IVF embryos.[14] Although only 4 of the 86 embryos that were injected with the CRISPR-Cas9 system were shown to contain the corrected DNA sequence, this study demonstrated the technique's feasibility. Now, scientists can tweak and refine the technique in the pursuit of therapies for previously intractable diseases and to understand the very first steps in human development.

While most voiced some level of concern, the reaction of the scientific community was mixed. Harvard Professor David Sinclair told *Technology Review* that "[p]eople would look back at this moment in time and recognize it as a new chapter in 'how humans control their bodies'… because it would let parents determine 'when and how they have children and how healthy those children are actually going to be.'"[15] Edward Lanphier, biotech CEO and Chairman of the Alliance for Regenerative Medicine, voiced a different perspective, saying, "Many oppose germline modification on the grounds that permitting even unambiguously therapeutic interventions could start us down a path towards non-therapeutic genetic enhancement. We share these concerns."[16] And CRISPR pioneer Jennifer Doudna said, "It cuts to the core of who we are as people, and it makes you ask if humans should be exercising that kind of power."[17] This ambivalence among key figures in the biomedical research community is notable since they each support the use of discarded IVF embryos for the purpose of embryonic stem cell research.

Knowing that the Chinese results were forthcoming, Doudna and other prominent scientists and bioethicists convened a meeting to discuss what the collective response of the scientific community in the U.S. should be. Many of those present signed a document calling for a moratorium on the creation of genetically modified children but endorsing research on human embryos, reminiscent of a similar agreement forged when recombinant DNA technology first emerged.[18] Uncomfortable with the prospect of designer babies, these researchers nonetheless are interested in the potential of CRISPR/Cas9 to cure genetic diseases and unravel early human development.

Like the U.S., the U.K. had a similar and even more binding moratorium on germline genetic engineering. Recently, however, the HFEA reversed course and granted a license for a team of scientists to use CRISPR/Cas9 to genetically modify healthy human embryos discarded from fertility clinics under the condition that these embryos be destroyed and never implanted into a woman's uterus.[19] Kathy

Niakan and her team want to modify genes involved in the earliest stages of human development to learn exactly how these complex processes are regulated in the hopes of better understanding the causes of infertility.

Ethical Concerns for Germline Interventions

As excitement and momentum about the promise of germline genetic engineering builds, we must of course pause and ask: is it prudent, and is it ethical? The short answer is no. In addition to the serious safety concerns raised by germline genetic modification, there are several arguments against the use of CRISPR/Cas9 in human embryos and human germline cells.

First, germline genetic engineering violates the autonomy of future generations because it is impossible to obtain their consent for the genetic manipulation they will inherit. Bioethicists from widely divergent ethical and philosophical traditions have agreed on the importance of informed consent in human biomedical research. This principle guards against the commodification of other human beings in the quest for scientific progress. Demanding that future generations serve our ends—however noble they may be—crosses this line.

Second, although our methods of manipulating and sequencing DNA have progressed rapidly, our understanding of exactly how genotype (the precise DNA sequence of a gene) relates to phenotype (the characteristics that we can observe or measure) remains primitive. When sequence variations are observed, scientists struggle to determine which are simply part of "normal" variation within our species and which are implicated in disease. Most mutant genes implicated in human disease do not cause disease in every patient that carries that mutation. For reasons scientists are only beginning to unravel, "penetrance"—the extent to which a given phenotype is consistent with a given genotype—is highly variable due to environmental factors, other interacting genes, and cellular factors that interact with DNA. In recent years, what was thought to be "junk" DNA is now known to play a role when certain genes are active or inactive. Gleaning meaningful information from the massive amounts of DNA sequence data that have been collected requires sophisticated algorithms that push the limits of current computing power. Furthermore, our ability to meaningfully sort out sequence data is limited by the fact that our databases of DNA sequences lack ethnic diversity. Additional complications arise because in some cases, mutations which cause disease in one context confer health advantages in other contexts. The classic example is the gene for sickle cell anemia. Two mutant copies of the sickle cell gene cause disease, but one copy confers resistance to malaria. Taken together, this means that there may be unintended consequences of changing the sequence

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of a gene. This is a risk that might be worth taking for an individual patient who is not going to pass that change onto his or her children. It would be cavalier to begin making such changes in germline DNA that will permanently alter the human gene pool.

Third, germline genetic engineering takes us into the murky water of how imprecise definitions of "disease" and "harm" can be. In the field of plastic surgery, for example, therapy and enhancement can be difficult to distinguish. If we begin to allow parents to correct "bad" mutations in their embryos, drawing such distinctions will be even more problematic. Culturally, there is already disagreement—particularly among affected individuals—about whether being deaf or dwarf is truly a disability. What is a liability in some communities is an asset in others. Whatever we might think about physical enhancement, adults who want to "improve" themselves through plastic surgery or other means are making an individual decision about their own body. Children whose genomes are edited as embryos have no such choice. As others have extensively argued, allowing parents to choose the characteristics of their children implicitly commodifies children and subverts their dignity.

Furthermore, germline genetic engineering, even if made widely available in the developed world, will exacerbate preexisting global socioeconomic inequities. The developed world would not only be healthier in terms of nutrition and decreased risk from pathogen-based disease, but would also be on the path to becoming genetically superior, in an exponential fashion. Similarly, the dignity of disabled individuals will be put at additional risk. As some Japanese researchers recently argued, "If childbirth with a genetic disease no longer occurs in a country due to the extensive practice of the preventive medicine [that is, germline genetic modification], it might impact the rights of the disabled with the genetic disease, intentionally or unintentionally assuming a posture against the existing patients who deserve respect, dignity, and support."[20]

Fifth, although the most commonly stated reason for pursuing germline genetic engineering is of course the possibility of easing human suffering and even curing disease, in most cases, germline genetic engineering is not medically necessary. For many diseases, although this has only been shown in principle for a few, therapy could in theory be accomplished by reprogramming cells from affected tissues into iPS cells, making the necessary correction in the DNA of those cells, and directing the cells to develop back into the tissue-type of choice. For diseases not amenable to this approach, as MIT biologist Eric Lander argued, "Genome editing would require making IVF embryos, using preimplantation genetic diagnosis (PGD) to identify those that would have the disease, repairing the gene, and implanting the embryo. Yet it

> ***…in most cases, germline genetic engineering is not medically necessary.***

would be easier and safer simply to use PGD to identify and implant the embryos that aren't at risk."[21]

This brings us to a more fundamental moral concern about germline gene editing. Whether the actual correction is made in egg or sperm cells or in the early embryo itself, germline genetic engineering—like human cloning—requires the special creation of IVF embryos and then necessitates the destruction of those in which the editing was ineffective or those which are simply not needed. Treating human embryos as products to be made and discarded is an assault on human dignity.

In spite of these serious ethical concerns, Congress has never banned germline genetic engineering, although the federal prohibition on the use of federal funding for research in which human embryos are harmed or destroyed (the Dickey-Wicker amendment) remains in place.[22] National Institutes of Health (NIH) director Francis Collins said, "NIH will not fund any use of gene-editing technologies in human embryos. The concept of altering the human germline in embryos for clinical purposes has been debated over many years from many different perspectives, and has been viewed almost universally as a line that should not be crossed."[23] Last year, the Obama administration said that "altering the human germline for clinical purposes is a line that should not be crossed at this time,"[24] leaving the door open for germline gene-editing for research purposes. The regulation of germline gene-editing for clinical use falls under the jurisdiction of the FDA, even in its investigational stages, but gene-editing research designed to answer basic questions about human development or infertility does not.[25] Congress added new restrictions late last year prohibiting the FDA from reviewing applications for new therapies "in which a human embryo is intentionally created or modified to include a heritable genetic modification,"[26] which effectively prohibits any clinical therapies based on germline genetic engineering from being developed in the U.S., along with other techniques that create heritable changes (like mitochondrial transfer, or "3-parent babies"). This language, like the Dickey-Wicker amendment, must be renewed annually.

Mutual Concerns

Unlike the debate about embryonic stem cell research, which was quickly recast into the familiar lines of the abortion debate, the controversy surrounding germline genetic engineering raises an additional set of questions that trouble many scientists who are not pro-life. This ambivalence amongst the scientific community may result in a surprising degree of "self-policing." Last year, *Technology Review* reported that Nessan Bermingham, CEO of Intellia Therapeutics, "a Boston startup that raised $15 million last year to develop CRISPR into gene therapy treatments for adults or children. . . says germline engineering 'is not on our commercial radar,' and he suggests that his company could use its patents to prevent anyone from commercializing it."[27]

> ***Does science enable human flourishing or human mastery?***

The Age-Old Quest for Mastery over Nature

As the writer of Ecclesiastes said, there is, indeed, nothing new under the sun. Modern genetic engineering is at its essence merely one of latest frontiers in a centuries-old quest to gain mastery over nature itself. Although the techniques were unavailable at the time, Sir Francis Bacon, who many consider to be the father of the scientific method, envisioned a utopia brought about by scientific discovery in which:

> We have also parks and enclosures of all sorts of beasts and birds which we use not only for view or rareness, but likewise for dissections and trials; that thereby we may take light what may be wrought upon the body of man. . . . By art likewise, we make them greater or taller than their kind is; and contrariwise dwarf them, and stay their growth: we make them more fruitful and bearing than their kind is; and contrariwise barren and not generative. Also we make them differ in colour, shape, activity, many ways. We find means to make commixtures and copulations of different kinds; which have produced many new kinds, and them not barren, as the general opinion is. … Neither do we this by chance, but we know beforehand, of what matter and commixture what kind of those creatures will arise.[28]

Over 200 years later, Mendel began to lay the modern scientific foundation for genetic engineering. Since its inception, scientists, ethicists, and concerned citizens have been wrestling with whether genetic engineering constitutes "playing God." Modern debates about embryonic stem cell research, cloning, three-parent babies, genetically modified food, and synthetic biology expose fundamental philosophical differences among us about what it means to be human and the very purpose of scientific discovery. In the West, the stage for this debate was set during the Enlightenment. Are we the masters of our own destiny? Or are we image-bearing creatures in the service of a more glorious King? Does science enable human flourishing or human mastery?

These historical details are not an entertaining side-bar to the CRISPR/Cas9 story. Rather, the philosophical traditions we have inherited bear directly on the trajectory of this and other current bioethical debates. Recognizing these historical influences can help us move beyond polarizing rhetoric and instead marshal arguments that resonate in our current cultural context. The ambivalence many scientists feel about human germline engineering may reflect a fundamental sense that there is more to being human than they are able to articulate. Shared values of human flourishing, equity, and justice may give us tools to

"CRISPR Update" continued from page 7

use in the public square to persuade others in our pluralistic society that permanently modifying the human genome is not in the interest of our common good.

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QUESTIONS?

Would you like to offer comments or responses to articles and commentaries that appear in *Dignitas*? As we strive to publish material that highlights cutting-edge bioethical reflection from a distinctly Christian perspective, we acknowledge that in many areas there are genuine disagreements about bioethical conclusions. To demonstrate that bioethics is a conversation, we invite you to send your thoughtful reflections to us at info@cbhd.org with a reference to the original piece that appeared in *Dignitas*. Our hope is to inspire charitable dialogue among our readers and those who contribute material to this publication.

OF CODES AND CONSCIENCE: REFLECTIONS ON NURSING ETHICS IN THE NETHERLANDS

BART CUSVELLER, PHD
CBHD FELLOW

About a year ago (January 2015), I had the privilege to co-author and present the first national professional code of ethics for nurses and other care workers in The Netherlands to the Chief Nursing Officer, Marieke Schuurmans, PhD.[1] For our small country this occasion was of some historical significance, but perhaps there is something to be learned for other countries as well. What follows are a few comments to contextualize the discussions, and the resolution of several key issues.

Historical Aspects

To understand the significance of this national professional code, some background information is necessary. The way the Dutch organized their society in the twentieth century gave it a matrix-like structure. On the horizontal rows, so to speak, there were societal and cultural groups, organizations, and institutions—like unions, sports clubs, schools, political parties, healthcare facilities, media networks, and so on. In the vertical columns the Dutch very consciously located their ideological and religious traditions with fault lines between the organizations on the horizontal rows. The daily realities of family life, work and leisure were thus characterized by this *modus vivendi* for a religiously and ideologically pluralist society. To illustrate, children from a Reformed denomination would have typically attended a Reformed school and Reformed sports clubs (no matches on Sunday), and their parents would have typically read a Reformed journal and voted for a Reformed party in elections. An example of the fault lines can be seen in a comparison with Roman Catholic families whose sports leagues did play matches on Sunday. Typically, interaction between the ideological and religious groups (e.g., between Roman Catholics, liberal democrats, or Socialists) was very limited, in some cases even non-existent.

Accordingly, when nurses started to vie for professional and academic recognition (roughly after the Second World War), a plethora of nursing associations emerged. Not only did these emerge along the ideological and religious fault lines, but also according to sectors of health care. Thus there were Protestant, Catholic, (and other) associations for community nursing, operating theatre nurses, pediatric nurses, and so on.

This is a remarkable contrast to nearby countries such as Great Britain and the Scandinavian countries where a single national body existed to advocate the interests of nurses! Because of these national bodies, at least some nationwide impact was possible on education, quality of care, working conditions, and, significantly, the formulation of ethical codes. Also, these national bodies were in the center of things when the nursing profession began formulating their professional codes of ethics. Such codes were first formulated in the early 1950s with the International Council of Nurses (ICN, 1953), the global association for Roman Catholic nurses, CICIAMS (1953), and the American Nurses Association (1950) setting the example. After three decades or so, evolving from the ICN code, Scandinavian countries, Canada, and the United Kingdom followed suit. Interestingly, the contents of these codes have been influenced not only by the Hippocratic medical code, but also by the pledge or set of moral principles formulated by nursing pioneer Florence Nightingale (around 1875). In turn, she was inspired by her training from Lutheran pastor Theodor Fliedner's school for deaconesses in Kaiserswerth, Germany.

> ***...it was not until 2006 that the main nursing associations sat at one table for their first—and failed—attempt at a unified ethics code for Dutch nurses.***

CONTINUED ON PAGE 11

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Workshop led by Ferdinand D. Yates, MD
& Elizabeth Hensley, MD

Preconference workshop descriptions are available at cbhd.org/conf2016/workshops

Toward a Unified Code

At this point it should be clear why a national code of ethics for nurses in The Netherlands was something of a historic event. Some of the largest of these nursing associations had taken it upon themselves to formulate codes of ethics for their own membership. In the 1970s, five such codes were known for nurses alone! Moreover, a few smaller associations for Christian nurses jointly published a Christian code of professional ethics for nurses (1995), in part to take a stand against inflated patient autonomy. Needless to say, nothing close to a consensus on nursing codes existed in the Dutch nursing profession as a whole. (As an aside, the medical profession in The Netherlands has long been a 'glitch in the matrix,' so to speak: it has had a unified, royal society and a single ethics code since the mid-nineteenth century). And although the matrix-like structure of Dutch society has been eroding rapidly since the end of the twentieth century, it was not until 2006 that the main nursing associations sat at one table for their first—and failed—attempt at a unified ethics code for Dutch nurses.

For a society as diverse as The Netherlands is today, it is remarkable for organizations with such deep-running, traditional differences to cooperate, much less reach a consensus on something as fundamental and value-laden as an ethics code—especially without financial or other external motivators. These historical developments highlight just how significant it was that the main nursing bodies were able to cooperate, but furthermore that the associations for Christian nurses with their Hippocratic ethical convictions also decided to participate in the conversation. This meant they were willing to consider giving up their Christian code of ethics, provided the new code would reflect ethical positions they could accept as well. In my personal opinion it was nothing short of a blessing that this is exactly what happened: important principles from the Christian code of ethics became part of the consensus document. This is especially important when it comes to the position of nurses with conscientious objections to specific interventions or procedures, particularly any cooperation in abortion and euthanasia—a point to which I will return shortly.

Basic Principles

By and large, the new code is in line with the ICN code, with its sections on the nurse's relationship to practice, to the patient, to those she works with, and to society. Likewise, with respect to its basic principles it conforms to the international code, with a proviso or two for new developments such as self-employed nursing and responsibilities for quality care. Three of those basic principles are worth mentioning before we address conscientious objections, as they were very much on the agenda for Christian nurses.

> ***…in a context where patients are often on the vulnerable end of the power balance, it is not superfluous to remind professionals of their commitment to ground their moral decision-making on the purpose of the nursing profession: to foster the patient's flourishing, not as a means to something else, but an intrinsically valuable end in itself.***

To begin with, as in the international codes, the very first clause of the code is a 'non self-serving clause': the good of nursing care is pursued in the interest of the patient (not in the interest of the team, the nurse, the family, or anyone else). This may seem obvious, but in a context

From left: Marieke Schuurmans, PhD, a nurse participant, and Bart Cusveller, PhD at a meeting to develop the first national professional code of ethics for nurses in the Netherlands.

where patients are often on the vulnerable end of the power balance, it is not superfluous to remind professionals of their commitment to ground their moral decision-making on the purpose of the nursing profession: to foster the patient's flourishing, not as a means to something else, but an intrinsically valuable end in itself. In Christian language, the nursing profession came into existence to serve the lives and health of those who cannot serve themselves—as Christ served us.[2]

Second is the 'non-discrimination clause,' which is also found in most nursing codes. Again, this is not an exclusive claim from the Christian code of nursing ethics, but it is, nonetheless, an important principle from a Christian perspective. If charity is worth anything, then it is not restricted to one's own clan or tribe, as in ancient societies,[3] but is extended to friend and foe alike. So even when nurses are confronted with a patient who lives a life they see as hopeless, unhealthy, or even sinful, it is not their place to judge and withhold care. Perhaps it is precisely such a patient (like the paralytic who had lived near the Bethesda baths for thirty-eight years) who most needs a nurse to really see him or her?

A third clause that became part of the new code for nurses in The Netherlands is the 'non-abandonment clause.' This, like the previous clauses, is not an exclusively Christian principle, but it stands out because it relates to the 'conscientious objections clause' to which we shall return shortly. It is significant because when a nurse has conscientious objections to a given intervention, her objections are limited only to those interventions and not to everything else that her care for that patient demands. Note that this requires a good deal of discernment and self-control, particularly when the objections create emotional turmoil. Thus, when a nurse is asked to participate in a procedure she thinks is wrong, say, preparing a patient for an abortion, she has both a right to refuse to participate in this preparation but also a duty to care for that patient in all other respects, such as hygiene and nutrition, and not abandon her.

> ***…even if the objection is based on a religious or other personal conviction, the code challenges the objector not to opt out by default but to present it as a professional objection and remain part of the discussion…***

This, lastly, brings us to the clause on conscientious objection itself. It was here that something crucial was at stake for the Christian nurses associations. In the diversity of codes between the nursing associations, the right to refuse cooperation in objectionable procedures was not controversial as such. It is also included in health law and collective labor agreements in healthcare. How to couch the principle in an acceptable way to all parties, however, was an entirely different matter. A key difference existed between the Christian code of 1995 and some of the other codes. The Christian code stated that a nurse who refuses to participate in some procedure for conscientious reasons relinquishes her responsibilities to her superior (and provides her reasons for doing so). The superior can then consider how to proceed. This is in contrast to the code from nurses' unions AbvaKabo-FNV and CNV Publieke Zaak (1996, 2006), which states that a nurse with conscientious objections must relinquish her responsibilities to a colleague.[4] Their reason for this phrase ("relinquish . . . to a colleague") is the non-abandonment clause, which makes sense. But from the perspective of the objector this is unacceptable as it comes down to asking somebody else to do something the objector herself thinks is wrong. It comes down to saying, for instance, "I will not be involved in this euthanasia procedure, for I believe killing someone is wrong, but you go ahead." (In addition, in this formulation the nurse does not have to voice her objections to her superior, who could possibly intervene.[5])

For these reasons, therefore, it was important to get the final text for this issue right. In the end, we reached the consensus that the clause should read in the more principled way (relinquishing responsibility to her superior). The only exception is when there is no (acting) superior, in which case one would need to call upon a colleague or to resolve the conflict in some other way (while continuing to observe the non-abandonment clause). One could say that, even if the objection is based on a religious or other personal conviction, the code challenges the objector not to opt out by default but to present it as a professional objection and remain part of the discussion: "This is bad care. How can we improve it?" This, again, calls for discernment and other competencies to participate in 'ethics conversations.'[6] And such conversations about values are perhaps the way a professional code of ethics is supposed to work in the first place.

1 *Beroepscode van Verpleegkundigen en Verzorgenden*, Vereniging van Verpleegkundigen en Verzorgenden, 2015.

2 See also my "In Defence of Selflessness: A Philosophical Analysis of a Central Virtue in Professional Caring Practices," *Ethics & Medicine* 27, no. 3 (2011): 147–154.

3 While it was not a point of discussion in these meetings, it is well documented in the literature on the history of caring professions that in pre-Christian societies one usually did not care for the infirm outside of their own household. It was the Christian traditon in Europe that established hospitals with care for the stranger.

4 *Beroepscode Verpleging en Verzorging,* AbvaKabo-FNV & CNV Publieke Zaak, 1996 (revised, 2006).

5 I thank Dignitas editor Michael Cox for bringing this point to my attention.

6 See also my "Nurses Serving on Ethics Committees: A Qualitative Exploration of a Competency Profile," *Nursing Ethics* 19, no. 3 (2012): 431–442.

BIOENGAGEMENT:

The promise and perils of advances in technology, science, and medicine have long been fertile fodder for creative works in literature and cinema. Consequently, a variety of resources exist exploring the realm of medical humanities as well as those providing in-depth analysis of a given cultural medium or particular artifact. This column seeks to offer a more expansive listing of contemporary expressions of bioethical issues in the popular media (fiction, film, and television)—with minimal commentary—to encompass a wider spectrum of popular culture. It will be of value to educators and others for conversations in the classroom, over a cup of coffee, at a book club, or around the dinner table. Readers are cautioned that these resources represent a wide spectrum of genres and content, and may not be appropriate for all audiences. For more comprehensive databases of the various cultural media, please visit our website at cbhd.org/resources/reviews. If you have a suggestion for us to include in the future, send us a note at msleasman@cbhd.org.

BIOFICTION:

Margaret Atwood, ***The Heart Goes Last*** (Nan A. Talese, 2015). *Autonomy, Free Will, Human-Robot Interactions, Neuroethics, Organ Trafficking, Robot Ethics.*

William Gibson, ***The Peripheral*** (Berkley, 2015). *Nanotechnology, Robotics, Telepresence, 3D Printing.*

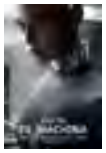
Lois Lowry, ***Gathering Blue*** (Houghton Mifflin, 2000). *Infanticide, Disability.*

Lois Lowry, ***Son*** (Houghton Mifflin, 2012). *Surrogacy.*

Kass Morgan, *The 100 Series*
The 100 (Little, Brown, and Co., 2013)
Day 21 (Little, Brown, and Co., 2014)
Euthanasia, Research Ethics.

Several centuries after nuclear war has ravaged the planet, the human race is surviving on an aging orbital colony. With resources scarce, the governing council decides to send a group of 100 teenage criminals to Earth to investigate whether radiation has dissipated enough for the earth to again be habitable. The 100 work to rebuild some semblance of society in a radically new environment, meanwhile several of their leaders struggle to come to grips with their past. After a series of mysterious murders, the 100 come to the startling realization that they are not the only survivors on the planet.

BIOETHICS AT THE BOX OFFICE:



Ex Machina (2015, R for graphic nudity, language, sexual references and some violence). *AI, Personhood, Robot Ethics.*

Lucy (2014, R for strong violence, disturbing images, and sexuality). *Human Enhancement, Neuroethics, Transhumanism/Posthumanism.*

Terminator Genisys (2015, PG-13 for intense sequences of sci-fi violence and gunplay throughout, partial nudity and brief strong language). *AI, Personhood, Robotics.*

Age of Adaline (2015, PG-13 for a suggestive comment) *Life Extension.*

Self/less (2015, PG-13 for sequences of violence, some sexuality, and language). *Life Extension Research, Neuroethics, Transhumanism.*

TOP BIOETHICS NEWS STORIES: DECEMBER 2015 – FEBRUARY 2016

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

"**In Syria, Health Care Workers Are the Heroes—and the Targets**" by Maanvi Singh, *NPR*, December 1, 2015

> Since the conflict in Syria began in 2011, nearly 700 medical workers have been killed and more than 300 facilities have been hit with missile strikes and bombs, according to the advocacy group Physicians for Human Rights. In an article last month in the New England Journal of Medicine, American doctors said that their counterparts in Syria need help: The disruption of health services has become a weapon of war that the Syrian government is using against those opposed to President Bashar Assad. (http://tinyurl.com/ptvv926)

In war-torn Syria, hundreds of doctors are being killed, medical facilities are being targeted by air strikes, and supplies are dwindling. More than half of the Syrian population is displaced, causing a refugee crisis throughout Europe. Those that have remained in the warzone are in need of the medical facilities available, but many doctors are fleeing for their lives. Targeting medical facilities and doctors goes against the rules of engagement as outlined in the Geneva Conventions.

"**India Scales Back 'Rent-a-Womb' Services**" by Shashank Bengali, *Los Angeles Times*, January 25, 2016

> Chasing dreams of financial independence, thousands of poor Indian women have found work as surrogate mothers, helping to turn this country into a favored destination for foreign couples who can't become pregnant on their own. Now India's government is taking the first significant steps to rein in commercial surrogacy, citing fears that the women are being exploited by a mushrooming industry that pays them a fraction of what surrogates earn in the West. (http://tinyurl.com/h6gqcfp)

"**Surrogate Carrying Triplets Sues to Stop Forced Abortion**" by Carl Campanile, *New York Post*, January 4, 2016

> A surrogate mom who refuses to abort one of the triplets she's carrying because the father only wants two of the kids filed a lawsuit Monday claiming that California's surrogacy law is unconstitutional. (http://tinyurl.com/jarul5l)

Two stories this quarter have shed light on the darker side of gestational surrogacy. On the international front, India, a go-to hot spot for foreigners looking for a gestational surrogate, has tightened its rules on surrogacy for fear that poor Indian women are being exploited. In the U.S., Melissa Cook made headlines when she refused to abort one of the triplets that she was carrying for a single father. She had offered to adopt the unwanted child, but the father refused, saying he wanted her to abort it and that she was in violation of her contract. Later reports revealed that the father, at first, wanted to abort all three babies because he could not afford the hospital fees.

"**Bitter Fight over CRISPR Patent Heats Up**" by Heidi Ledford, *Nature*, January 12, 2016

> A versatile technique for editing genomes has been called the biggest technology advance since the polymerase chain reaction (PCR), and the US Patent and Trademark Office (USPTO) is set to determine who will reap the rewards. On 11 January, the USPTO granted a request to review a key patent awarded for the technique, known as CRISPR–Cas9. The outcome of the ensuing proceedings, called a patent interference, could be worth millions to the research institutions that are at war over the relevant patents. It might also influence who is allowed to use the technology—and under what terms. (http://tinyurl.com/zt6wjpk)

Since the initial publications of the CRISPR/Cas9 system in 2012, hundreds of papers have reported experiments using the robust gene-editing technology. Its ability to cut-and-paste gene sequences in multiple locations means that the patent could be worth millions of dollars to the institution that filed the patent. However, there is an ongoing legal dispute over who should be the proper holder of the patent rights between Jennifer Doudna of the University of California, Berkeley and Emmanuelle Charpentier, now at the Max Planck Institute for Infection Biology on the one hand or Feng Zhang at the Broad Institute and Massachusetts Institute of Technology. As of this writing, the dispute remains unresolved.

"**UK Scientists Gain License to Edit Genes in Human Embryos**" by Ewen Callaway, *Nature*, February 1, 2016

> Scientists in London have been granted permission to edit the genomes of human embryos for research,

UK fertility regulators announced. The 1 February approval by the UK Human Fertilisation and Embryology Authority (HFEA) represents the world's first endorsement of such research by a national regulatory authority. (http://tinyurl.com/hl2box2)

HFEA approved the use of the gene editing technology CRISPR/Cas9 in healthy human embryos for research purposes. As part of the stipulations for approval, the embryos must be destroyed after seven days. Researchers hope to use this technique to understand early development and infertility. This comes after a U.S. summit determined that it would be "irresponsible" at this time to alter the genomes of human embryos or gametes to produce a baby.

"**For Boys Only? Panel Endorses Mitochondrial Therapy, but Says Start with Male Embryos**" by Gretchen Vogel, *Science*, February 3, 2016

An experimental assisted reproduction technique that could allow some families to avoid having children with certain types of heritable disease should be allowed to go forward in the United States, provided it proceeds slowly and cautiously. That is the conclusion of a report released today [February 3rd] from a panel organized by the U.S. National Academies of Sciences, Engineering, and Medicine (NAS), which assesses the ethics questions surrounding the controversial technique called mitochondrial DNA replacement therapy. (http://tinyurl.com/gn8hrb7)

A U.S. ethics panel says that mitochondrial replacement therapy—also referred to as mitochondrial donation or transfer and popularly dubbed "three-parent embryos,"—should be approved by the Food and Drug Administration for women who do not want to pass on the risk of mitochondrial disease to their children. The research cannot occur during this fiscal year, however, due to the 2016 congressional bill banning the use of government funds for experiments that genetically alter human embryos. Interestingly, the panel recommends using the technique on male embryos only, so as to avoid the potential of hereditary concerns commonly raised for germline gene interventions. Additional concerns have been raised by some that the shift away from technical terms such as 'maternal spindle transfer' or 'pronuclear transfer' in favor of terms such as 'mitochondrial donation or transfer' minimizes the risks and significance of the procedures.

"**200 Million Girls and Women Living with FGM: UNICEF**" *Medical Xpress*, February 5, 2016

At least 200 million girls and women worldwide have been subjected to female genital mutilation with half of those living in Egypt, Ethiopia and Indonesia, according to the UN children's agency. Somalia, Guinea and Djibouti continue to show the highest prevalence of FGM globally, but the overall rate in some 30 countries has dropped, said a UNICEF report released ahead of International Day of Zero Tolerance for FGM, on Saturday. (http://tinyurl.com/jfn8upl)

"**Female Genital 'Nicks' Should Be Legal: Gynecologists**" by Emma Batha, *Reuters*, February 22, 2016

Countries that have banned female genital mutilation (FGM) should allow less invasive practices such as small surgical nicks to girls' genitalia as a compromise, two American gynecologists said on Monday. (http://tinyurl.com/zortpd5)

A controversial proposal by two American gynecologists writing in the *Journal of Medical Ethics* has made headlines for suggesting a compromise to female genital mutilation. FGM is recognized by many as a violation of human dignity, and the UN hopes to completely eliminate the practice by 2030. The authors of the article suggest allowing for small nicks on the clitoris as a compromise. They also suggest changing the name to "female genital alteration" to avoid "demonizing important cultural practices."

"**Assisted Suicide Study Questions its Use for Mentally Ill**" by Benedict Carey, *New York Times*, February 10, 2016

A new study of doctor-assisted death for people with mental disorders raises questions about the practice, finding that in more than half of approved cases, people declined treatment that could have helped, and that many cited loneliness as an important reason for wanting to die. The study of cases in the Netherlands should raise concerns for other countries debating where to draw the line when it comes to people's right to die, experts said. (http://tinyurl.com/z7r6yo2)

A study of assisted suicide cases in The Netherlands showed that, of the people who elected to have physician-assisted suicide for mental health reasons, more than half declined treatment that could have helped. Many patients received approval from doctors that they had only seen once, sometimes going to a mobile "end-of-life clinic" funded by a local euthanasia advocacy group. Notably, the majority of the mental health cases were women, and loneliness was a common theme. This has implications for places such as Canada, where physician-assisted suicide was recently legalized, and the various U.S. states where physician-assisted suicide is either legal or is being debated in the state legislature.

For the latest bioethics news updates, events, and relevant journal articles visit bioethics.com.

ACADEMY OF FELLOWS CONSULTATION

In early February, the Center hosted our 5th Academy of Fellows Consultation on the theme of "Hope and Christian Bioethics." Presentations by two leading biblical scholars (Willem VanGemeren, PhD, and Grant Osborne, PhD) discussed the Old and New Testaments, examining the topics of hope, ethics, and suffering. These foundational sessions were followed by presentations by CBHD staff and fellows exploring the relationship between hope and bioethics. Video of the presentations will be available on the Center's YouTube channel in the coming weeks.

SPECIAL REPORT ON POLST

As a supplement to the Winter 2015 issue of *Dignitas*, CBHD published a special report, *Examining POLST*, edited by Michael Sleasman and Michael Cox. This resource includes lead essays by Edward Grant, JD, and Lisa Anderson-Shaw, DPH, MA, MSN, with invited responses by Christian Brugger, DPhil; Mary Harned, JD; Robert D. Orr, MD; and a co-authored response by Patrick Smith, PhD, and Carol Powers, JD. As a reminder, an electronic version of this resource is publicly available online at cbhd.org/POLST.

MEDIA RESOURCES

CBHD.org on Twitter: @bioethicscenter

Bioethics.com on Twitter: @bioethicsdotcom

The Bioethics Podcast at thebioethicspodcast.com

Facebook page at facebook.com/bioethicscenter

LinkedIn page at linkedin.com/company/the-center-for-bioethics-and-human-dignity

YouTube at youtube.com/bioethicscenter

The Christian BioWiki christianbiowiki.org

STAFF

PAIGE CUNNINGHAM, JD

- Contributed a piece on "The Great Cloning Debate" for her "Biohazards" column in the Winter 2015 issue of *Salvo*.
- Was interviewed by "LIFE Matters TV" providing a basic introduction to bioethical questions. The episode aired 7 times in December.
- In January, spoke at the Evangelicals for Life Conference in Washington D.C. as part of a panel on fetal tissue research.
- Participated as a guest commentator discussing sex selective abortion for an early February episode of *VernacularPodcast.com*.
- Was profiled in a front-page *Washington Post* story on the pro-woman, pro-life strategy in late February.
- Was interviewed on "Brian and Kathleen Mornings" (Moody Radio, Cleveland) on three occasions discussing gestational surrogacy and triplets, IVF and the increase in twins, and compensation caps for egg donors.

MICHAEL SLEASMAN, PHD

- In January, published an entry on "Robots" in the online version of the *Encyclopedia of Global Bioethics* edited by Henk ten Have (Springer, forthcoming).
- Presented a paper on "Eschatological Hope and Human Flourishing: Beyond Utopias and Bare Life" in early February at the 2016 CBHD Academy of Fellows Consultation.
- Co-authored the introduction and served as co-editor with Michael Cox for CBHD's special report on *Examining POLST*.

MICHAEL COX, MA

- Presented lectures on "The Role of Technology in Christian Formation" and "Human Futures" in December for a course on *Foundations of Christian Thinking and Living* at TIU.
- Facilitated the late January Theological Bioethics Roundtable Discussion of Pope Francis' encyclical *Laudito Si'*.
- Co-authored the introduction and served as co-editor with Michael Sleasman for CBHD's special report on *Examining POLST*.

HEATHER ZEIGER, MA

- Published "When Baby-Making Takes Three: You, Me, and She," in Volume 39 (1) of *Christian Research Journal,* featuring interviews with Paige Cunningham and CBHD Fellow C. Ben Mitchell.
- Continues to offer freelance pieces for *phys.org* and *Salvo* magazine's blog.

ON THE CBHD BOOKSHELF

For those interested in knowing what books and articles the Center staff have been reading and thought worth highlighting. **Notes that the resource includes material by members of the Center's Academy of Fellows.

Articles of Note:

Galvin, Robert. "How Employers Are Responding to the ACA." *New England Journal of Medicine* 374, no. 7 (2015): 604–606 .

Hudson, Kathy, and Francis Collins. "Bringing the Common Rule into the 21st Century." *New England Journal of Medicine* 373, no. 24 (2015): 2293–2296.

Lynch, Holly, Barbara Bierer, and I. Glenn Cohen. "Confronting Biospecimen Exceptionalism in Proposed Revisions to the Common Rule." *Hastings Center Report* 46, no. 1 (2016): 4–5.

**MacKellar, Calum. "Representative Aspects of Some Synthetic Gametes." *The New Bioethics* 21, no. 2 (2015): 105–116.

Madueme, Hans. "Adam and Eve: An Evangelical Impasse?—A Review Essay." *Christian Scholars Review* 45, no. 2 (2016): 165–183.

Mills, M. Anthony. "Is Pope Francis Anti-Modern?" *The New Atlantis* 47 (Fall 2015): 45–55.

Porter, Michael, Stefan Larsson, and Thomas Lee. "Standardizing Patient Outcomes Measurement." *New England Journal of Medicine* 374, no. 6 (2016): 504–506.

Ruger, Jennifer Prah, Theodore Ruger, and George Annas. "The Elusive Right to Health Care under U.S. Law." *New England Journal of Medicine* 372, no. 26 (2015): 2558–2563.

Sacks, Chana, and Celestine Warren. "Foreseeable Risks? Informed Consent for Studies within the Standard of Care." *New England Journal of Medicine* 372, no. 4 (2015): 306–307.

Salladay, Susan. "Moral Distress: New Way of Looking at an Old Problem?" *Journal of Christian Nursing* 32, no. 3 (2015): 147.

Saloner, Brendan, Lindsay Sabik, and Benjamin Sommers. "Pinching the Poor? Medicaid Cost Sharing under the ACA." *New England Journal of Medicine* 370, no. 13 (2014): 1177–1180.

COMING SOON: FETAL TISSUE RESEARCH SPECIAL REPORT