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PRACTICING MEDICINE AND ETHICS

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CBHD FELLOW

My recent volume *Practicing Medicine and Ethics*[1] addresses a set of interconnected challenges that join together in the life and work of the health professional. These challenges pertain to patients in the dynamic of shared decision-making, to professionals themselves as they navigate the implications of conscientious practice, and to the wider community as professionals fulfill their social contract with society. This book offers a vision of healthcare that views medicine as a goal-oriented endeavor guided by both virtues and principles and reliant on the conscientious practice of the professional, especially when faced by the challenges of religious and philosophical pluralism. It culminates in an integrity-centered framework for practical wisdom in medicine that is intended to be clinically useful and theoretically transparent. In the following paragraphs I will summarize a number of the book's key concerns.

A Framework for Practical Wisdom

Within the tradition of virtue ethics tracing back to Aquinas and Aristotle, practical wisdom is the foremost of the cardinal virtues because it shows us how to respond realistically—in the sense of being true to reality—when faced with a decision. This virtue gives us the ability to know what ends (or goals) are worth pursuing and what means are most likely to achieve them. Practical wisdom can be seen as having five core elements:
(1) pursuit of worthwhile ends (goals) derived from a concept of human flourishing; (2) accurate perception of concrete circumstances detailing the specific practical situation; (3) commitment to moral virtues and principles that are interdependent and form an integrated moral framework; (4) deliberation that integrates ends (goals), concrete circumstances, and moral virtues and principles; and (5) motivation to act in order to achieve the conclusions reached by such deliberation.

These elements form a trajectory of moral decision-making that is guided by goals, responsive to empirical facts, directed by normative principles and virtues, organized through moral reasoning, and motivated by a desire to make actions consistent with beliefs.

Goals

Goals of care are, therefore, a vital part of practical wisdom in medicine. They provide clinically relevant objectives for the care of individual patients and usually involve one or more of the following: curing, living longer, improving function, being comfortable, achieving life goals, providing support for family, or clarifying the diagnosis or prognosis. Prioritizing goals of care helps patients, families, and clinicians articulate goal-oriented assessments and preferences that can guide shared decision-making and increase the likelihood that treatments will harmonize with patients' values and the reality of their medical conditions. Once clarified, goals of care allow decision-makers to discuss whether a possible intervention makes sense by asking, "Will this treatment help achieve the agreed-upon goal(s)?" If goals are ignored, medical decisions may be dictated by immediate circumstances or "usual" care, rather than by the unfolding clinical realities and longer-term goals that reflect a patient's enduring beliefs and values. Focusing on goals helps situate interventional options against a broader background of meaning and can counter the impression that a treatment may be advisable merely because it is available. Goals remind us to ask where we are going before we consider possible ways of getting there.

The importance of goal-oriented thinking is nowhere more apparent than in decision-making toward the end of life or in the management of chronic-progressive conditions (e.g., organ failure). It is therefore disappointing when instruments intended to facilitate decision-making under these circumstances focus primarily on interventions (e.g., cardiopulmonary resuscitation, artificially administered nutrition, intravenous fluids, or antibiotics), rather than on goals of care that would provide a basis to decide whether or not a given intervention makes sense in light of unfolding medical realities that often cannot be known very far in advance. Such intervention-oriented thinking is evident in Iowa's Physician Orders for Scope of Treatment form which, like others in the POLST (Physician Orders for Life-Sustaining Treatment) paradigm, focuses on interventions without also clarifying goals (except for the goal of comfort, which is offered as the option of "comfort measures only" in contrast to "limited additional interventions" or "full treatment"). While we must

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from the director’s desk

BY PAIGE C. CUNNINGHAM, JD

EXECUTIVE DIRECTOR

“John, we thought we could get rid of God and retain a value for human beings, but we found we couldn’t.” John Lennox, Professor of Mathematics at Oxford, made this comment at a conference I recently attended in Indonesia. Lennox referred to a Siberian academic acquaintance who was wrestling with the inability of post-Enlightenment Western thought to account for violence in the 20th century and beyond. The comment illuminates the dominant conclusions about the devaluation and appropriation of human embryos for research.

At the December 2015 conference in Indonesia on “Christian Responses to Global Health Issues,” I had the privilege of attending an event that was conceptualized and planned by someone else, something that many of our CBHD friends experience every June. This gave me the chance to give my full attention to the plenary speakers and presenters without all of the pressures of the behind-the-scenes responsibilities. There is a blessing in being an active listener, a student of the thoughts of others. Some of the ideas generated might be profound in their simplicity.

Dr. Ravi Zacharias, for example, tackled the tough questions of “unwanted children.” He admitted, “Not every child is wanted.” These lonely children may ask the questions we all should ask: *“Why am I? Why do I exist?”* And Zacharias’s life-giving answer: *“You exist because God wanted you to be.”*

Various speakers took up the themes of God’s love for human beings, Christian morality and truth, Christian responses to pain and suffering, and engagement with emerging technologies and treatment, which meshed with the challenges faced by doctors and nurses, but also the broader concerns of bioethics.

One of the four major sessions focused more narrowly on bioethics and technology—the session for which my paper proposal had been accepted. I presented on “Human Dignity and the ‘Child of Choice’: Technology, Human Procreation, and Christian Engagement.” (Yes, we, too, go through submitting proposals for professional conferences.) One doctor asked how I would apply my framework in his context. During the panel session, a bioethicist from Taiwan noted, *“This is the most inspiring conference I’ve ever attended. We should form an association of Christian ethicists.”*

So, why this narrative account of a conference?

Because as a participant, I was open to synthesizing new ideas, generating project possibilities through conversations with others, and learning about bioethical contextualization. One of the most intriguing ideas was the possibility of an international association of Christian bioethicists. One of the original visions I had when I joined the Center more than six years ago, was to form a global consortium of bioethicists and bioethics centers. We have been gradually moving toward that goal.

We initiated the Global Bioethics Education Initiative (GBEI) in 2009, and now eight scholars have spent one month with us. Our relationship with Dr. Jameela George, a 2009 recipient, generated a bioethics workshop in New Delhi in 2011 (co-taught by Dr. Dennis Sullivan and me). That, in turn, generated ideas for “training the trainers” via a Masters in Bioethics from Trinity Graduate School and the launch of a Christian bioethics center in India.

No one could have anticipated the fruitful outcome of our initial friendship with Dr. George. But, trusting in God, we took one step after another, working around detours along the way.

Acquaintances made at the Indonesia conference may one day lead to an international association of Christian bioethicists. Of course, we cannot see that clearly now. But by faith, we can move forward in developing friendships, providing resources, proactively refining ideas, and being available for the next opportunity.

Do you have an interest in global bioethics? Have you made a positive connection at one of our summer conferences? Please send me your story or comments at pcunningham@cbhd.org.

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

“Exploring the nexus of biomedicine, biotechnology, and our common humanity.”

Dignitas is the quarterly publication of the Center and is a vehicle for the scholarly discussion of bioethical issues from a Judeo-Christian Hippocratic worldview, updates in the fields of bioethics, medicine, and technology, and information regarding the Center’s ongoing activities.

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With this issue of *Dignitas*, you will see the fruit of another project, a special supplement on POLST (Physician Orders for Life-Sustaining Treatment). It is the result of numerous conversations, some of which took place at the 2014 conference on "Bioethics in Transition." Differing conclusions about POLST alerted us to the need for clarification. We invited a conversation among scholars of good will, who are committed to the Judeo-Christian Hippocratic tradition and respect for human dignity.

The supplement is a bonus for our members. I hope you find this to be a practical and valuable tool.

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"Practicing Medicine and Ethics" continued from page 1

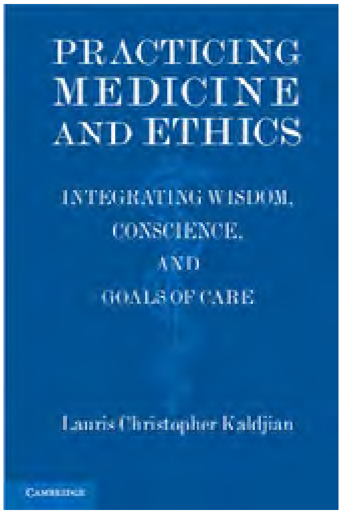
acknowledge that there comes a time in the course of a patient's illness when a decision to forgo life-sustaining interventions needs to be made, we should recognize that instruments codifying decision-making in terms of standardized interventional choices run the risk of doing a disservice if those choices are not guided by a patient's current goals of care and the specific details of his or her current medical condition.

> “*To care for patients wisely, clinicians need a wide range of knowledge…*

Perceiving Dimensions of Decision-Making

To care for patients wisely, clinicians need a wide range of knowledge that arises from direct interaction with patients; awareness of their individual psychological, social, and spiritual contexts; gathering of medical information; training in the diagnosis and treatment of diseases and disorders; and familiarity with the ways that healthcare can be delivered. In addition to understanding the patient's goals of care, clinicians need to incorporate two other dimensions into shared decision-making to insure an accurate perception of what a patient believes and values. One of these is probabilities. Patients need to decide how much value they attribute to different goals in light of the statistical probabilities attached to the means of achieving those goals (e.g., what is the likelihood that, if a patient suffers cardiac arrest in the hospital, the performance of cardiopulmonary resuscitation will lead to survival and good brain function). Discussing probabilities can be challenging, but medical practice requires knowledge of an ever-flowing stream of probabilities that are integral to evidence-based practice. Another dimension of the patient's reality is the willingness to endure suffering and bear the burdens of treatment, whether from physical or emotional pain, disability, dysfunction, social dislocation, rehabilitation, or financial or other hardships. A treatment may impose such a heavy burden that a patient is unwilling to accept it, even though in itself it might be seen as medically beneficial.

These three dimensions (goals, probabilities, and suffering) provide a realistic perception of patients as persons by knowing their personal, social, and medical details, their goals of care, the value they attach to outcome probabilities, and their willingness to bear the burdens that treatment entails. Some people might argue that another important dimension for clinicians to consider is financial cost. This dimension includes the financial burdens experienced by individual patients, but it is perhaps more frequently framed by professionals in terms of costs to society as a whole. In light of society's challenges in controlling healthcare costs, some suggest that physicians have a dual and simultaneous responsibility: to care for individual patients, one at a time, and to control healthcare costs through bedside rationing of healthcare. But we need to consider seriously what this suggestion implies and avoid placing on the shoulders of clinicians more than they can bear. Given the moral limitations physicians face as human beings in their ability to distribute healthcare services without favoring some patients and discriminating against others, it would not be realistic to expect them to micro-allocate resources fairly. Though overarching decisions in healthcare are necessary to control costs, they need to be made through democratic processes of deliberation and administration that allow for a division of labor between those responsible for fair allocation procedures and those responsible for direct patient care.



Principles, Virtues, and Consequences

Practical wisdom requires moral grounding so that the ends of decision-making, and the means to those ends, are guided and justified by identifiable moral standards that form a moral frame of reference. A normative ethical grounding of this kind can rely on virtue ethics, deontology, and limited consequentialism. Virtue-based and principle-based ethics enjoy a close and complementary relationship. As formal prescriptive norms, principles can be seen as having a certain objectivity that is external to the subjectivity of an individual's character. This objectivity can provide rational justification in ethical deliberation. By contrast, virtues can be seen as providing the internal drive and motivation for moral action that principles, as abstract norms, lack.

Unlike principles and virtues, consequentialism provides a certain flexibility that arises from calculations that calibrate the moral rightness of particular actions according to the assessed value of predicted outcomes. This flexibility may be perceived as a weakness or strength. In the practice of medicine, where ethical judgments routinely include assessments of likely outcomes, reasoning based on likely consequences is intuitive and necessary. Predicted outcomes regarding benefits and risks are essential to moral assessments and stand unavoidably alongside principles and virtues. However, it is one thing to take into consideration the anticipated balance of consequences, and another to adopt consequentialism formally as a guiding conceptual framework. (Formal approaches to consequentialism adopt a single principle that defines some uni-dimensional good—such as happiness, preference satisfaction, or financial cost—as the measure of right action.) Well known problems with consequentialism should not keep us from taking consequences seriously. And we should note that to the extent moral action aims at goals—as is the case with virtue ethics—it inherently takes the consequences of action seriously. Having said this, we should remain clear on the features of consequentialism that set it apart from other frameworks and remember that virtue ethics ascribes a moral significance to virtues that is morally independent of consequences.

> *On this account,* all *moral frameworks make claims that entail foundational beliefs about what is* ultimately real *and* ultimately good*—beliefs that in turn determine the values, commitments, and actions that characterize ethical decision-making.*

Reasoning, Moral Pluralism, and Foundational Beliefs

Moral reasoning faces special challenges in the setting of moral pluralism, a setting that deprives the health professions of a comprehensive moral consensus capable of specifying and prioritizing relevant virtues, principles, and consequences. The problem of pluralism cannot be resolved by supposing the existence of some morally neutral vantage point. Such a vantage point is unavailable. Ethical decision-making requires some sort of moral compass, whether provided by a developed moral framework or simply a statement of moral priorities. The need for such moral orientation raises questions about the foundational beliefs that justify and guide moral reasoning.

These foundational beliefs may be expressed in religious or philosophical terms, and given the debates that surround religion in western societies, it is important to clarify what religious beliefs should be taken to signify in the context of ethics. If we focus on the function of foundational beliefs in ethical reasoning, there is no compelling reason to draw a line of separation between religious and philosophical beliefs. This is the essential point John Reeder makes when he observes that the stereotypical division between religious and nonreligious moral traditions loses its relevance to ethics once it is recognized that all moral perspectives make claims about what is believed to be *good* in light of what is recognized as *real*.[2] On this account, *all* moral frameworks make claims that entail foundational beliefs about what is *ultimately real* and *ultimately good*—beliefs that in turn determine the values, commitments, and actions that characterize ethical decision-making. Foundational beliefs can therefore be religious or philosophical, and because all moral frameworks make fundamental claims about what is real and good, foundational beliefs are unavoidable in moral reasoning. And because these foundational beliefs represent the roots of our moral frameworks, they will inevitably have practical manifestations.

Integrity and Conscientious Practice

Integrity entails the imperative to live life with the goal of being at unity with oneself. The word integrity is instructive, as it brings to our minds the idea of integration and its relevance to the constellation of foundational beliefs, values, commitments, and actions that constitute our multifaceted moral lives. It refers to our need for personal wholeness and harmony and indicates the harm we experience when circumstances tempt or coerce us to live a double life by compartmentalizing our activities according to the different roles we play in different contexts.

The more one appreciates what integrity is, the more one sees that it is not helpful to speak about integrity without also speaking about ethics and moral reasoning. If we agree that integrity fundamentally involves moral reasoning and represents the culmination of one's best efforts in moral decision-making, there are important implications for medicine and medical ethics. One of these is that integrity cannot plausibly be categorized as merely a private moral concern. Rather, it needs to be seen as something that can facilitate genuine moral dialogue. For when they are communicated, the reasons and reasoning of one person's integrity become accessible to other persons and, thereby, part of shared moral deliberation.

This facilitation of dialogue is highly significant when one considers the mixture of privileges and responsibilities that flow within the so-called 'social contract' between health professionals and society. Within this relationship, society sometimes exercises its prerogatives in response to physician behaviors that disregard generally accepted features of a health professional's fiduciary responsibilities. This can be seen, for example, in federal and state regulatory responses to conflicts of interest arising from financial relationships between physicians and healthcare companies. But in other contexts—such as abortion, contraception, or physician-assisted suicide—some clinicians perceive the expectations of society as imposing inappropriate demands that contradict their primary moral commitments. In such cases, there is the prospect of deep tension between society's prerogative to impose its will on medicine and the medical professional's prerogative to practice medicine with integrity. Within a morally pluralistic society, such tension will be less likely to arise if there is ongoing dialogue and consensus about clinical practices that should be considered controversial and therefore accompanied by protections that accommodate the professional's freedom of conscience.

To mention conscience in a discussion of integrity reminds me to say that there are very good reasons to treat these two concepts as largely interchangeable. At

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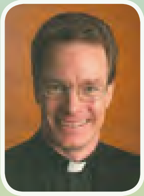
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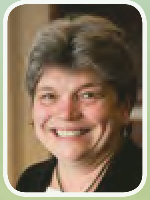
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times it is particularly helpful to use the language of conscience, such as when we are considering the *negative* work of conscience as expressed by *conscientious objection*. We should immediately note, however, that the reasons, feelings, and motivation that comprise conscience not only repel one away from morally objectionable actions, they also draw one toward morally desirable goals. Conscience therefore also does *positive* work, as expressed by *conscientious practice*, which captures the interdependence between a professional’s conscience and his or her motivation to serve patients. This motivation lies at the heart of an integrity-centered practice of medicine, and it warrants enduring respect and cultivation if health professionals are to be encouraged to integrate medicine and ethics in the care of their patients.

> ***The fallibility of conscience is a potent reason for believing that moral deliberation in medicine needs humility.***

Moral Dialogue

Practical wisdom in medicine depends on the moral beliefs and values that clinicians bring to their professional work. This dependence is most obvious in the need to decide which goals of care, virtues, and principles should serve as the guiding objectives and moral standards for patient care, and how these should be specified and prioritized in specific cases. The particular moral content that goes into a framework for practical wisdom will always require specification and affirmation by the individual using the framework. Once someone fills this or any other moral framework with particular moral content, he or she must reckon with the moral diversity of other persons involved. Engaging this diversity in western societies can test the consensus on which democracies rely to maintain shared commitments to moral expectations, policies, and laws. Though the practice of medicine enjoys a substantial degree of moral consensus around the general pursuit of health and healing, the challenges of moral pluralism are nevertheless real for healthcare professionals and, in some clinical contexts, can pose serious moral tensions and conflicts.

Given the dependence of practical wisdom on moral beliefs and values that are bound to be diverse in morally pluralistic societies, it is important to identify personal, professional, and social resources that can facilitate moral courage, shared decision-making, professional cooperation, and respectful social engagement and accommodation. There is reason to hope that such resources can be found when we pursue moral dialogue with moral imagination and humility. One of the reasons moral dialogue is of great importance arises from the fundamentally *dialogical* character of moral life that gives interpersonal moral dialogue a special relevance for moral identity.[3] On this view, as we communicate our beliefs and values to others in moral dialogues, we also increase our moral understanding of ourselves. Through dialogue, our moral identities are cultivated and sustained, and the act of articulating our beliefs and reasons strengthens our pursuit of the good that our beliefs and reasons represent. As clinicians articulate their reasons for pursuing a given course of action, their listeners are informed, their own reasons are opened to critical dialogue, and their own moral identities are strengthened.

Humility

A second reason for moral dialogue stems from the fallible nature of conscience (or integrity). If conscience is understood as involving practical moral reasoning, then it can err from mistakes in observation, interpretation of facts, or assessments of the moral values pertinent to those facts. Conscience can also be misled by self-deception and rationalization. Mistakes in moral reasoning, weaknesses in moral character, and self-deception explain why conscience should never be treated as if it were beyond dialogue and questioning, even if in the end it is respected as being finally authoritative for each individual. The fallibility of conscience is a potent reason for believing that moral deliberation in medicine needs humility.

Even when someone is compelled by conscience to stand firm in the strength of his or her moral convictions, humility encourages confidence without arrogance. Such humility is closely related to what some writers refer to as *moral imagination*—the ability to realize vividly the inner lives of those around us, to “be aware of others as persons, as important to themselves as we are to ourselves, and to have a lively and sympathetic representation in imagination of their interests and of the effects of our actions on their lives.”[4] Perhaps it would be appropriate to hear the need for moral imagination as a modern echo of the ancient call to love our neighbors as ourselves.

In Closing

Seen in its full light, practical wisdom in medicine invites us to move discussions about medical ethics well beyond the dilemma-filled enclosures of principle-based ethics or the narrow lanes of proceduralism. It encourages us to see ourselves in our ethical deliberations as persons for whom integrity matters—persons on a journey who need to make sense of individual actions not just one at a time, as isolated episodes, but also as part of an unfolding life story that defines who we are and who we have become.[5]

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[1] Lauris Kaldjian, *Practicing Medicine and Ethics: Integrating Wisdom, Conscience, and Goals of Care* (New York: Cambridge University Press, 2014).

[2] John P. Reeder, “What Is a Religious Ethic?” *Journal of Religious Ethics* 25, no. 3 (1997): 157–181.

[3] Charles Taylor, *The Ethics of Authenticity* (Cambridge, MA: Harvard University Press, 1991), 33–35.

[4] William Frankena, *Ethics* (Englewood Cliffs, NJ: Prentice Hall, 1973), 69.

[5] Alasdair MacIntyre, *After Virtue* (Notre Dame, IN: University of Notre Dame Press, 1984), 203.

BIG DATA IN MEDICINE

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

The Rise of Big Data in Research

At The Center for Bioethics & Human Dignity's 2015 summer conference, Dr. Jimmy Lin, founder and president of Rare Genomics Institute and director of Clinical Genomics at the National Institutes of Health National Cancer Institute, discussed how his group is helping to make genomics a clinical reality. Robert Stone, one of his first patients and now a teenager, has been confined to a wheelchair since he was one year old. His parents spent thousands of dollars trying to figure out why their healthy baby suddenly lost motor function. They eventually found Dr. Lin's group who connected the Stone family to Johns Hopkins and Baylor College of Medicine to get Stone's genome sequenced and analyzed by specialists. By comparing his genome to thousands of other genomes, they discovered that Stone has a mutation in the PRPKA gene, known as *Dystonia 16*. He is one of only nine patients in medical history to have this disease.[1] Now Dr. Lin's group is helping the Stone family to connect with specialists who work on therapies for genetic diseases.

> ***Big Data rightfully placed within the context of a research program can serve as a valuable tool in the scientist's toolbox.***

A more traditional route, in which a single doctor or institution had investigated Stone's case, would have left the family in the dark because they would not have had the data pool available to compare Robert Stone's genome to others. Companies like Rare Genomics take a Big Data approach to solving medical puzzles. This approach emphasizes large data sets, algorithm-based analytics, and collaboration. While collecting data, even large amounts of data, is not new, as David Bollier of the Aspen Institute points out, the growing scale, sophistication, and ubiquity of data-crunching to identify novel patterns of information and inference is new.[2] Now companies and research organizations can collect petabytes (=1,000,000 gigabytes or 1,000 terabytes) of data that can be sifted and analyzed with ever more sophisticated algorithms.

According to a recent *Nature* article, the Human Genome Project instigated this new approach as the first large-scale, government-funded Big Data endeavor, or what the article calls "consortium science."[3] At the time, their ambitious goal was to sequence all 3 billion base pairs of the human genome in hopes that this would provide clues to the genetic causes of certain diseases. In order to accomplish this, they had to work with a diverse team of researchers hailing from various fields. Their work was as much about creating the technology as collecting the data.

Today there are several Big Data projects that include initiatives such as the 1,000 Genomes Project, the Cancer Genome Atlas, the Human Microbiome Project, the U.S. Precision Medicine Initiative, and the U.S. BRAIN Initiative. All of these involve acquiring massive amounts of data, and, at times, developing the technology to store and analyze the data concurrent with its collection. Many of these projects hope to use these databases to identify diseases and develop therapies, just as Dr. Lin's did with the Stone case. They also hope to use the data for many other future studies.

Aside from consortium-based projects, electronic medical records (EMRs) are another area where Big Data is changing medicine. Sifting through EMRs has allowed researchers to re-purpose drugs. Furthermore, personal device trackers, like FitBit, provide daily health data to help with preventative medicine and tracking diseases. These innovative projects offer many benefits but they also raise bioethical concerns over privacy and informed consent.

How Is Big Data Being Used in Medicine?

Critics caution against an overly optimistic view of what Big Data can do. There is a cadre of people who believe large data sets coupled with sophisticated algorithms can replace clinical trials or the scientific method altogether.[4] This appears to overestimate what Big Data is capable of doing; however, Big Data rightfully placed within the context of a research program can serve as a valuable tool in the scientist's toolbox.

Dr. Peter Yu, president of the American Society of Cancer Oncology, has expressed optimism about what Big Data can do to help cancer research.[5] While clinical trials are still the "gold standard," Big Data can answer some questions by revealing correlations, saving researchers time and money. One example of this is in breast cancer research, where tumor databases such as The Cancer Genome Atlas or the METABRIC (Molecular Taxonomy of Breast Cancer International Consortium) help identify genetic biomarkers that distinguish one tumor from another. There are many types of breast cancers, and by treating the cancer based on the type of tumor rather than its location on the body, doctors have seen better overall results in treatment.[6]

Another way that researchers are making use of a Big Data approach in medicine is in drug development. Often it is prohibitively expensive to research and develop specialty drugs that would be used for only a small subset of the population. However, using electronic health records (EHRs) and data analytics, researchers can find correlations between a certain therapeutic effect and a drug that has already been FDA-approved for another purpose.

One of the first cases to use EHRs to find a secondary use of a drug was a 2014 study at Vanderbilt University on metformin and cancer. Doctors noticed a correlation between a decreased incidence of cancer and people who were taking metformin,

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a drug typically prescribed to regulate type 2 diabetes. An analytics study of EHRs found that diabetic patients on metformin had a 23% increased survival rate after being diagnosed with several types of site-specific cancers compared to the non-diabetic population.[7] This correlation was verified by comparing the Vanderbilt data to EHR data from the Mayo Clinic and by independent review by thoracic nurses who examined the charts to determine drug exposure. Additional analysis showed that, indeed, patients on metformin saw a decrease in mortality compared to both non-diabetic patients and diabetic patients that were not on metformin.

What Are the Ethical Concerns Associated with Big Data?

The Human Genome Project set aside funds to investigate the bioethical issues surrounding the project, but many consortium-based research projects do not have such programs, even though Big Data projects pose important bioethical questions when it comes to privacy and informed consent. While anonymizing genetic data was at one time a possibility, current technologies make it impossible to have truly anonymous data.[8] Furthermore, Big Data projects typically try to collect data that will have multiple uses, including future experiments that have not been thought of yet. Additionally, Big Data projects are collaborative, and, while sharing data helps with scientific discovery, it also means that data is accessible to more people, including hackers, and raises issues of data security.

In talking with Dr. Lin about how his group deals with the issue of privacy, he points out that there is always a balance between public interest and individual privacy. His group collaborates with research facilities around the world. One way that his group deals with privacy is to give patients complete control over their data, and to make them partners in the research process. The patient requests his or her data and provides it to the various care facilities and research institutions. This prevents institutional competition and data hoarding, and it lets the patient decide who receives their data.

For many patients who are uncomfortable with sharing their genomic data, Dr. Lin says it is often an issue of risk versus benefits. Patients who are already sick have less to lose, and are more willing to share their data. Healthy patients are the ones who are often hesitant to share their genetic data for fear that they will face discrimination either by insurance companies or by their employers. Notably, they fear many of the things against which GINA (The Genetic Information Nondiscrimination Act of 2008) was meant to protect.

> “*While anonymizing genetic data was at one time a possibility, current technologies make it impossible to have truly anonymous data.*

Medical data hacking is a growing problem. Any time data is shared over the Internet, it is at risk for hacking. Hospitals and insurance companies have been recent targets for hackers because medical data has a large black market value. Unlike credit card data, which is only good until the card is reported stolen, stolen medical data can be misused for much longer. It is often used for identity theft, obtaining expensive medical procedures without insurance, and for blackmail. This can go on for months until a patient realizes someone has stolen his or her data. One recent high-profile example of hacking involved Anthem, the company that owns Blue Cross Blue Shield. Last year they reported a hack that compromised 80 million customers' and employees' data. To put this in perspective, Anthem reports stopping about 200 hacking attempts per day.

The Common Rule and Informed Consent

Finally, Big Data research is running into problems with informed consent. The current policy in the United States for government-funded research involving human subjects, known as the Common Rule, does not require consent for secondary use of biological specimens, which is why it is currently being revised. Author Rebecca Skloot brought to light one of the most egregious cases of secondary biospecimen use without consent in her New York Times bestseller, *The Immortal Life of Henrietta Lacks*. In the case of Henrietta Lacks, doctors removed some cells from her cervical cancer biopsy and, after growing them in the lab, found that they were able to grow indefinitely. At the time, doctors were not required to obtain informed consent from Mrs. Lacks. But, as it turned out, these cells, known as HeLa cells, became one of the first immortal human cell lines and have been used in countless studies and publications since the 1950s.

Flash forward to the 2000s, when people are still using and sequencing HeLa cell for research purposes so they can compare their results to prior studies. HeLa cells are the only cell lines currently in use that are still identified by the patient's name, and with current technologies, people can find out genetic information regarding Mrs. Lacks' children and grandchildren. Her story is an important lesson because today there are many biospecimens that have been collected over the years without the patient knowing that his or her biomaterial will be used for research purposes. Even when certain genetic markers have been removed, the biospecimens can still be re-identified.

Many Big Data projects involve biobanking and collaboration across multiple institutions. The current wording in the Common Rule does not adequately address patients' concerns for consent and privacy. For this reason, the Common Rule is being updated to include consent for the collection and use of biospecimens for research purposes, and it includes changes to the institutional review process to accommodate research across multiple institutions.[9]

Big Data can serve as a powerful tool in the researcher's tool box to solve difficult puzzles like Robert Stone's mutation or determining why some breast cancers respond differently to treatment than others using large genomic databases. It can help drive down the cost of pharmaceutical research and development by investigating secondary uses of old medicine using millions of electronic medical records. But, just as scope and its accessibility are two of the major advantages to Big Data, they are also the two areas that are cause for concern for protecting patient privacy and informed consent.

1 Jimmy Lin, in discussion with the author, December 2015; Jimmy Lin, "Solving the Mystery of Rare Diseases with Technology and Crowdfunding," *TEDx-MidAtlantic*, Apr. 22, 2014, https://www.youtube.com/watch?v=evC3HGI-Lnc.

2 David Bollier, *The Promise and Peril of Big Data* (Queenstown, MD: Aspen Institute, 2010).

3 Eric D. Green, James D. Watson, and Francis S. Collins, "Human Genome Project: Twenty-Five Years of Big Biology," *Nature* 526, no. 7571 (2015), http://www.nature.com/news/human-genome-project-twenty-five-years-of-big-biology-1.18436.

4 Chris Anderson "The End of Theory: The Data Deluge Makes the Scientific Method Obsolete," *Wired*, June 23, 2008, http://www.wired.com/2008/06/pb-theory/.

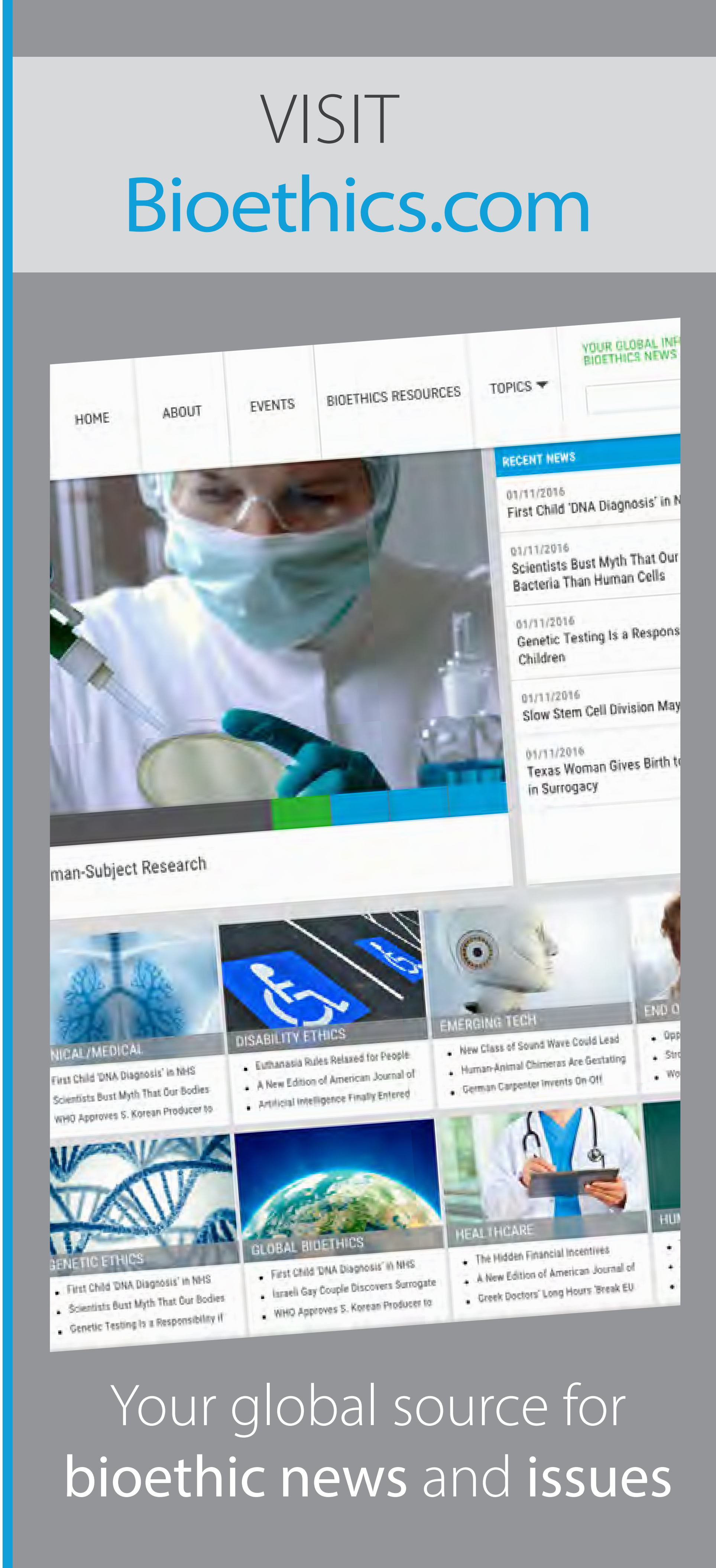
5 Gabriel Miller "ASCO President Peter Yu, MD, on Big Data, Big Themes for Upcoming Annual Meeting," *Medscape*, May 27, 2015, http://www.medscape.com/viewarticle/845246.

6 Jill U. Adams, "Genetics: Big Hopes for Big Data," *Nature* 527, no. 7578 (2015), http://www.nature.com/nature/journal/v527/n7578_supp/full/527S108a.html#close.

7 Hua Xu et al., "Validating Drug Repurposing Signals Using Electronic Health Records: A Case Study of Metformin Associated with Reduced Cancer Mortality," *Journal of the American Medical Informatics Association* 22, no. 1 (2014): 1–10, doi:10.1136/amiajnl-2014-002649.

8 Jennifer Cousin-Frankel, "Trust Me, I'm a Medical Researcher," *Science* 347, no. 6221 (2015), https://www.sciencemag.org/content/347/6221/501.summary?related-urls=yes&legid=sci;347/6221/501.

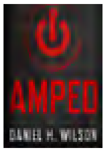
9 Christine Grady et al., "Broad Consent for Research with Biological Samples: Workshop Conclusions," *American Journal of Bioethics* 15, no. 9 (2015) 34–42, doi:10.1080/15265161.2015.1062162. The U.S. government has recently extended the comment period for the Common Rule: Notice of Proposed Rulemaking to January, 2016.



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.

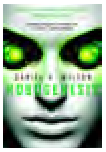
BIOFICTION:



Daniel Wilson,
Amped (Vintage, 2013).

Cognitive Enhancement, Neuroethics, Personhood, Posthuman.

The author of *Robopocalypse* returns with a sci-fi thriller from the not-too-distant future. The novel opens with a breaking decision from the U.S. Supreme Court: amplified human beings (amps) are no longer deemed a protected class of human beings. Their sheer existence, it is ruled, creates inequality with the general population. Immediately, hundreds of thousands who had received neuro-implants through government programs to address poverty and cognitive impairments are relegated to a persecuted underclass. Owen Grey, a history teacher, and recipient of an implant to control his epilepsy, finds himself at the center of a wide-ranging conspiracy with one faction seeking to inaugurate a posthuman future and another seeking to eliminate all humans that have been unnaturally enhanced. The novel explores the potential social and legal concerns at the limits of neuro-enhancement and the limits of human use of emerging technologies.



Daniel Wilson,
Robogenesis (Doubleday, 2014).

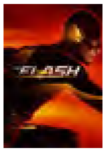
Artificial Intelligence, Cyborgs, Human Enhancement, Neuroethics, Personhood, Robotics, Posthuman/Transhumanism.

In this sequel to *Robopocalypse*, humanity is picking up the pieces in the wake of the robot/AI rebellion known as the New War that nearly destroyed the human race. Beyond the sheer devastation and loss, all types of atrocities are coming to light from the robotic augmentation experiments that the AI Archos R-14 directed during the New War. As humanity and the free-born robots that joined in their defense are reestablishing pockets of civilization, a new AI threat emerges desiring to conquer humanity and the world.

PRIMETIME BIOETHICS:

***Agents of Shield* (2013–).** *Human Enhancement, Neuroethics, Research Ethics.*

***Arrow* (2012–).** *Human Enhancement.*



***The Flash* (2014–).** *Human Enhancement.*

***Revolution* (2012–2014).** *Nanotechnology.*

***The 100* (2014–).** *Disaster Ethics, Genetic Engineering, Human Experimentation, Neuroethics, Research Ethics.*

THEOLOGICAL BIOETHICS ROUNDTABLE UPDATE:

MICHAEL COX, MA
RESEARCH ANALYST

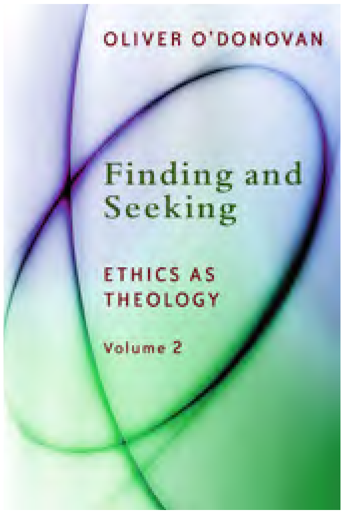
Each semester for the past several years the Center has hosted two Theological Bioethics Roundtable Discussions where graduate and doctoral students from Trinity Evangelical Divinity School and Trinity Graduate School join the Center's research staff and discuss a recent book that engages issues of theology, ethics, and/or bioethics. This semester, the gatherings focused discussion on Oliver O'Donovan's recent work *Finding and Seeking.*[1]

Finding and Seeking is the second in a projected three-volume series that explores "the foundations of ethics in theology."[2] In a recent interview, O'Donovan was asked to describe these three volumes in ten words or less, and suggested: 1) *Self, World and Time*: "And now these three remain"; 2) *Finding and Seeking*: "faith, hope and love"; and 3) *Entering into Rest*: "But the greatest of these is love."[3]

Finding and Seeking guides readers toward moral decision-making by means of the theological virtues, namely, faith, hope, and love. Each chapter unfolds lyrically, if informally. It would not be improper to call the argumentation 'beautiful'—especially by the standards of analytic theologians! At times this can be frustrating, leaving the reader longing for a chart, an outline, or even a thesis—but O'Donovan has employed this medium as his message. O'Donovan does not provide a guidebook, but sees himself as a guide on the path. As such he does not so much provide a description of the path itself but the beauty one sees while travelling the path.

Each chapter lays out vistas of virtue but also points to pitfalls of vice. For example, in the chapter "Hope and Anticipation," O'Donovan explores a particular "sin against time": Anxiety, which is "a failure to allow the promise of God's good future to illuminate the time given us now for action."[4] In the face of anxiety, Jesus offers a call "to set the unknown future of life and action in the light of God's promise. That is to say, it is a call to hope."[5]

O'Donovan's is not a bioethical study but a study of moral theology. He does not provide answers to ethical questions, much less bioethical ones. But this should not discount the book's value to bioethics. O'Donovan does not seek answers to questions, but rather to frame these questions between creation and consummation. He offers theological definitions, taxonomies of terms that must be understood to engage the relevant questions well. In so doing, he provides avenues for thinking theologically about moral decisions. Indeed, O'Donovan has offered just the kind of book that both appeals to Bible and theology students and can guide all of us toward thinking well as we approach bioethical issues. In this volume, O'Donovan does not provide answers to questions of *what* Christians should think regarding such issues as life, death, and defining 'human' in the face of posthuman futures. Instead, he provides answers to questions of *how* Christians should think about such issues. Walking the path well (i.e., finding and seeking) can be more important than arriving at the 'moral' destination.



For the Spring Semester, we will engage two shorter works, Pope Francis' recent encyclical, *Laudito Si'*, and Jean-Claude Larchet's *The Theology of Illness.*[6]

Additionally, we look forward to expanding the Roundtable discussions to engage even more aspiring pastors and scholars and providing them additional opportunities to connect their theological study to the bioethical issues of our time. We are working with several of this Fall's student participants to form an officially recognized student group and making plans to begin hosting a series of Bioethics Brown Bag lunches to discuss biblical and theological perspectives on bioethical issues.

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[1] Oliver O'Donovan, *Finding and Seeking: Ethics as Theology Volume 2* (Grand Rapids: Eerdmans, 2014).

[2] Oliver O'Donovan, "Five Questions with Oliver O'Donovan," *EerdWord*, March 17, 2015, http://eerdword.com/2015/03/17/five-questions-with-oliver-odonovan/.

[3] Ibid. Note that in the Fall of 2014 CBHD hosted Theological Bioethics Roundtables discussing O'Donovan's *Self, World, and Time: Ethics as Theology Volume 1* (Grand Rapids: Eerdmans, 2013). We look forward to discussing the third volume upon its release.

[4] O'Donovan, *Finding and Seeking*, 173.

[5] Ibid.

[6] Pope Francis, *Laudito Si' [Encyclical Letter on the Care of our Common Home]*, Vatican Website, June 18, 2015, http://w2.vatican.va/content/francesco/en/encyclicals/documents/papa-francesco_20150524_enciclica-laudato-si.html, and Jean-Claude Larchet, *The Theology of Illness* (Crestwood, NY: St. Vladimir's Seminary Press, 2002).

TOP BIOETHICS NEWS STORIES: SEPTEMBER – NOVEMBER 2015

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

"US Agencies Plan Research-Ethics Overhaul" by Heidi Ledford, *Nature*, September 3, 2015

> After years of uncertainty, the US government has revived an effort to update regulations that govern human-subjects research. The revision would be the most significant change to the rules since they were introduced in 1991. On 2 September, the US Department of Health and Human Services (HHS) announced a proposal to address concerns that have emerged since the regulations — known collectively as the 'Common Rule' — took effect more than two decades ago. (http://tinyurl.com/oeftvb9)

Some of the proposed changes to the Common Rule address the need for patient consent to use biomaterials for research purposes as newer technologies no longer make anonymizing biospecimens feasible. The changes would also address institutional review standards for collaborative research over multiple institutions. As of this writing the comment period on the proposed changes has been extended into January.

"States Move to Ban Aborted Fetal Tissue from Medical Research" by Kelley Vlahos and Fox News Team, *Fox News*, September 17, 2015

> Aggressive state efforts to ban the use of fetal tissue in research are alarming some scientists who say such measures will set back efforts to cure the world's deadliest diseases, including cancer, diabetes and Alzheimer's. But lawmakers in states like California and Wisconsin, which are deliberating whether to make their state laws even tougher than federal restrictions, say ending the practice of harvesting organs from aborted fetuses is a moral and ethical imperative. (http://tinyurl.com/hfcrogm)

"Research on Fetal Tissue Draws Renewed Political, Scientific Scrutiny" by Rob Stein, *NPR*, September 29, 2015

> Research involving fetal tissue has come under renewed public scrutiny recently because of a series of videos involving the Planned Parenthood Federation of America. The president of the organization, Cecile Richards, is slated to testify before a House committee Tuesday, even as some members of Congress try to cut off funding for Planned Parenthood, and some states try to restrict research involving fetal tissue. (http://tinyurl.com/hrxj29r)

The merits of fetal tissue research and whether it should be used in government-funded projects came to the forefront of political debate this past fall. Some states support restrictions while others fear that this will stymie research. This debate was prompted by a series of undercover videos revealing that Planned Parenthood, which receives government subsidies, also receives compensation for organs that some claim amounts to "selling organs" from aborted fetuses used for research purposes.

"The Drug with a 5,000 Percent Markup" by Julie Beck, *The Atlantic*, September 22, 2015

> The drug company Turing Pharmaceuticals is under fire after a New York Times article published Sunday detailing how it raised the price of a toxoplasmosis drug by more than 5,000 percent after acquiring the drug in August. One tablet of Daraprim used to cost $13.50; now, after its acquisition by Turing, it costs $750 per tablet. (http://tinyurl.com/p5mtlcn)

Rising drug prices have captured the news headlines lately. Turing Pharmaceuticals increased the price of Daraprim, a drug that treats taxoplasmosis, tounprecedented levels, resulting in a congressional investigation. However, drugs like Sovaldi, used to treat Hepatitis C and costs $84,000 for a full course of treatment, have also made the headlines leading to broader claims of industry abuse (http://tinyurl.com/q788kkc). Whether it is abuses by the industry or companies legitimately trying to recoup costs, high drug prices mean that insurance companies must limit who gets coverage for a drug. In the case of Sovaldi, for example, only people with liver failure qualify for coverage.

"After Struggling, Jerry Brown Makes Assisted Suicide Legal in California" by Patrick McGreevy, *Los Angeles Times*, October 5, 2015

> Caught between conflicting moral arguments, Gov. Jerry Brown, a former Jesuit seminary student, on Monday signed a measure allowing physicians to prescribe lethal doses of drugs to terminally ill patients who want to hasten their deaths. Approving the bill, whose opponents included the Catholic Church, appeared to be a gut-wrenching decision for the 77-year-old governor, who as a young man studied

> to enter the priesthood. (http://tinyurl.com/op8pfcs)

After failing in committee the first time the bill came before the California legislature, the End of Life Option Act passed the California legislature during a special session. Governor Brown eventually signed the bill that would allow physicians to prescribe a lethal dose of drugs to someone with a terminal illness. California joins Oregon, Vermont, and Washington with legislation that legalizes physician-assisted suicide.

"No Pig in a Poke" *The Economist*, October 17, 2015

> Until now, though, two technical problems have stood in the way of routinely transplanting animal organs into people. One is that the recipient's immune system must be persuaded to tolerate a big chunk of foreign tissue. The other is that swapping tissues between species risks swapping diseases, too. This second problem may soon be addressed, if George Church of the Harvard Medical School has his way. (http://tinyurl.com/p3m2j2x)

The waning field of xenotransplantation has been revitalized thanks to the gene editing technology of CRISPR/Cas9. Researchers are investigating if they can rid pigs of viral DNA using gene editing, bringing them one step closer to harvesting organs from pigs that could be used for transplantation in humans. Studies with baboons have shown some promise with one baboon living for over one hundred days with a transplanted kidney from a genetically modified pig.

"Reprogrammed Stem Cells Work as Well as Those from Embryos" by Mitch Leslie, *Science*, October 26, 2015

> Researchers who hope to use stem cells—the unspecialized cells that produce all of our tissues—to treat diseases face a dilemma. Stem cells from embryos (ES cells) could provide a wealth of new cells but spark ethical objections. Stem cells produced from adult cells (so-called induced pluripotent stem [iPS] cells) avoid the ethical difficulties, but some scientists have questioned whether they are as powerful as ES cells. A new study suggests that the two types of stem cells are equivalent and may help soothe worries about the capabilities of iPS cells. (http://tinyurl.com/psa6ck4)

Currently there are clinical trials for both ESCs and iPSCs, and scientists have been using adult stem cells to treat diseases for years. While iPSCs seemed to be a way to avoid the morally contentious destruction of embryos, some scientists questioned whether they were truly alternatives to the so-called "gold standard" of ESCs. This study, while not highly publicized, helps allay these concerns. As it turns out, the genetic differences between ESCs and iPSCs have more to do with genetic differences between the donors rather than differences in cell type.

"India to Ban Surrogacy Services to Foreigners through Supreme Court" by AFP, *Australian Broadcasting Corporation*, October 28, 2015

> India's government says it plans to ban surrogate services for foreigners wanting babies, a move likely to hit hard the booming and lucrative industry. Ranks of childless foreign couples have flocked to the country in recent years looking for a low-cost, legal and simple route to parenthood. (http://tinyurl.com/o2zbxgu)
>
> **"No Visa for Foreigners Planning Surrogacy in India"** by Rahul Tripathi, *Economic Times*, November 11, 2015
>
> In a setback to foreign nationals planning surrogacy in India, the union home ministry has instructed Indian missions and foreigners regional registration offices (FRRO) not to grant visa to couples intending to visit India for surrogacy. The move comes with health ministry also banning commercial surrogacy in India. (http://tinyurl.com/gl6rgye)

India had been the go-to destination for international commercial surrogacy, due to its few restrictions and lax laws. The health ministry recently moved to ban commercial surrogacy for people who are not from India and for unmarried couples, leaving many international couples and their unborn children in legal limbo. Thailand also recently banned commercial surrogacy and, in September, the Supreme Court of Nepal issued an order to stop commercial surrogacy services. More recently the European Parliament condemned surrogacy for exploiting vulnerable women.

"China's One-Child Policy to End" by Steven Jiang and Susannah Cullinane, *CNN*, October 30, 2015

> China will allow two children for every couple, the state-run Xinhua news agency reported Thursday, a move that would effectively dismantle the remnants of the country's one-child policy that had been eased in recent years. 'To promote a balanced growth of population, China will continue to uphold the basic national policy of population control and improve its strategy on population development,' Xinhua reported, citing a communique issued by the ruling Communist Party. (http://tinyurl.com/naes27h)

In an effort to counteract undesired effects of its social policy, China is lifting its one-child policy, but still maintaining control over how many children a couple can have. In some parts of China, the government resorted to coercive measures to ensure that couples comply with the one-child policy. However, thirty years of this policy has resulted in an imbalanced sex ratio and an aging population without the resources to care for them.

updates & activities

STRATEGIC PARTNERSHIPS

CBHD continues our ongoing partnership with the Christian Medical and Dental Assocations (CMDA) and their bioethics initiatives. In early November, the Center continued our annual tradition of hosting the Fall meeting of CMDA's ethics committee, which is chaired by CBHD Senior Fellow William P. Cheshire, Jr., MD.

SPECIAL SUPPLEMENT ON POLST

CBHD members are the first to receive access to our Special Supplement on POLST (Physician Orders for Life-Sustaining Treatment). The Supplement includes articles 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. It will be available publicly at cbhd.org/POLST.

STAFF

PAIGE CUNNINGHAM, JD

- Was interviewed by "Karl and June Mornings" (Moody radio) on three separate occasions to discuss euthanasia in Belgium, the use of animals to grow human organs, and the physician-assisted suicide law passed in California, a topic also discussed on "Let's Talk with Mark Elfstrand" (WYLL Chicago).
- Presented a workshop on the 25th Anniversary of the Americans with Disabilities Act and Prenatal Genetic Discrimination at the 2015 Christian Legal Society Conference.
- Participated in a panel discussion representing the bioethical perspective on "The Future of Marriage" with R.R. Reno (editor, *First Things*), Daniel J. Olsen, and Mike McDuffee at New Covenant Church in Naperville.
- Presented on the topic "Brave New World: Bioethics, Cloning, and GMO Humans" at the World Congress of Families IX in October. This was part of a panel session on "Choice and Consequences."
- Led an adult Sunday school class at The Orchard Church (Arlington Heights, IL) on fetal tissue research ethics in light of the Planned Parenthood controversy.
- Joined a panel for high school students on abortion at College Church (Wheaton, IL).

MICHAEL SLEASMAN, PHD

- Presented "Machine Morality: Considerations for the Robotic Revolution" for the Division of Science, Technology, and Health Department Chapel at Trinity International University.
- In October, represented CBHD at the annual meeting of the American Society for Bioethics and Humanities in Houston.
- In November, represented CBHD at the annual professional meetings of the Evangelical Theological Society and American Academy of Religion in Atlanta.

MICHAEL COX, MA

- In November, attended the annual meeting of the Evangelical Theological Society where he presented a paper entitled, "Cases of Sex Sin: An Exploration of Deuteronomy 22 and 1 Corinthians 5."
- Facilitated two theological bioethics roundtable discussions with graduate students and CBHD staff on Oliver O'Donovan's *Finding and Seeking* (Grand Rapids: Eerdmans, 2014).

MEDIA RESOURCES

CBHD.org on
Twitter: @bioethicscenter

Bioethics.com on
Twitter: @bioethicsdotcom

The Bioethics Podcast at
thebioethicspodcast.com

Facebook Page at
facebook.com/bioethicscenter

Linked-In Group at linkd.in/thecbhd

YouTube at
youtube.com/bioethicscenter

The Christian BioWiki
christianbiowiki.org

COMING SOON:
2015 ANNUAL REPORT

ON THE CBHD BOOKSHELF

For those interested in knowing what books and articles the Center staff have been reading and thought worth highlighting.

Articles of Note:

Green, Jeremy, and Elizabeth Watkins. "The Vernacular of Risk: Rethinking Direct-to-Consumer Advertising of Pharmaceuticals." *New England Journal of Medicine* 373, no. 12 (2015): 1087-1089.

Halpern, Scott. "Toward Evidence-Based End-of-Life Care." *New England Journal of Medicine* 373, no. 21 (2015): 2001-2003.

Mena, José Ulises. "A Prefertilization Mechanism of Action of Plan B: Assessing Effects on Postovulatory Ovum Transport." *The National Catholic Bioethics Quarterly* 14, no. 2 (2014): 235-244.

Mendola, Annette. "Undocumented and at the End of Life." *Narrative Inquiry in Bioethics* 4, no. 2 (2014): 179-184.

Mohaptra, Seema. "Using Egg Freezing to Extend the Biological Clock: Fertility Insurance or False Hope?" *Harvard Law & Policy Review* 8, no. 2 (2014): 381-441.

Phillips, Trisha. "Incentives to Participate in Research: Are Lotteries the Winning Ticket?" *IRB: Ethics & Human Research* 37, no. 2 (2015): 1-7.

Phimister, Elizabeth. "Curating the Way to Better Determinants of Genetic Risk." *New England Journal of Medicine* 372, no. 23 (2015): 2227-2228.

Raviele, Kathleen Mary. "Levonorgestrel in Cases of Rape: How Does It Work?" *The Linacre Quarterly* 81, no. 2 (2014): 117-129.

Ravitsky, Vardit. "Autonomous Choice and Right to Know One's Genetic Origins." *Hastings Center Report* 44, no. 2 (2014): 36-37.

Rehm, Heidi, Jonathan Berg, Lisa Brooks, Carlos Bustamante et al. "ClinGen: The Clinical Genome Resource." *New England Journal of Medicine* 372, no. 23 (2015): 2235-2242.

Rosenbaum, Lisa. "Transitional Chaos or Enduring Harm? The HER and the Disruption of Medicine." *New England Journal of Medicine* 373, no. 17 (2015): 1585-1588.

Rothwell, Erin, Karen Maschke, Jeffrey Botkin, Aaron Goldenberg, Thomas Murray, and Suzanne Rivera. "Biobanking Research and Human Subjects Protections: Perspectives of IRB Leaders." *IRB: Ethics & Human Research* 37, no. 2 (2015): 8-13.