

## COMMENTARY: UNCERTAINTY IN THE ART AND SCIENCE OF MEDICINE AND BIOTECHNOLOGY

SUSAN HAACK, MD, MDIV

GUEST CONTRIBUTOR

*“Medicine is a science of uncertainty and an art of probability.”<sup>1</sup>*

**I**t has been said that nothing is certain but death and taxes, yet how often do we neglect that truism when confronted with medical or bioethical decisions? Our lives are shrouded in uncertainty, colored not merely in black and white (which we find much more palatable) but in many shades of gray. In both medicine and technology, this fact is largely underappreciated and its consequences disregarded as the promise of technology is promoted while its perils and uncertainty are ignored.

Science does not leap ahead as rapidly as we would prefer; new developments happen slowly, prolonging uncertainty, and uncertainty does not make for a good news story. Researchers, public relations departments, and the media are all a bit to blame for hyping the hope suggested in the results of the research studies while ignoring the fact of uncertainty.<sup>2</sup>

The certainty of uncertainty became clear to me recently as I cradled the head of my beloved black lab in my lap. Everything was shrouded in uncertainty, including her age. While we had her for 8 years, she was an abandoned “rescue,” age unknown. The last year had been difficult for her as she began accumulating a long list of diagnoses. I knew that she was declining yet that did not make a sudden change in status any less of a surprise. Hadn’t we just been on a road trip with her days before? Now she could barely stand, much less walk, had a high fever and her liver enzymes were 10 times normal. What was the etiology? With a sullen face, the veterinarian said, “Probably a malignancy.” She looked so peaceful lying on my lap, but would she respond to conservative treatment? Would she live until we returned from a brief trip? As I contemplated the decision before me with regard to my dog, I could not help but wonder with horror how anyone could make such decisions in the midst of uncertainty for another human being.

Despite the advances in scientific knowledge and technology

and the claims of “evidenced-based” or “precision” medicine, uncertainty and ambiguity are inherent in and pervade all aspects of contemporary medical care from diagnosis to therapy and prognosis. Technological advances have changed the content of medical uncertainty and altered its contours, but uncertainty has not been eliminated.<sup>3</sup> The proclamation that medicine is a science neglects the fact that medicine is also an art—a moral art—dependent not simply on scientific data but on human judgment regarding the good of the person who has presented for care. This is no less true of biotechnology whose development is grounded in science, but whose application is also a moral art. Uncertainty is located in the amalgam of the unreliability of human knowledge, the fallibility of human judgment, and the complexity and contingencies of the human person.

The unreliability of our knowledge is a fact. More than three decades in the medical profession regularly demonstrated to me the inadequacy of medical “evidence” as new research often contradicted the previous prevailing scientific facts. Examples abound: whether it is the relationship of butter, salt, and red wine to health or of childhood exposure to nuts and the subsequent development of peanut allergy, the pendulum too often swings from one extreme to the other and back again as a result of new studies or the reinterpretation of old ones.

While scientific studies provide data, that data requires interpretation to be useful; and interpretation is a matter of human judgment which is subject to bias, thus adding another layer of fallibility to diagnostic and therapeutic uncertainty. Clinically, uncertainty is often cloaked in the phrase “cannot rule out . . .” that regularly accompanies the results of medical imaging and pathological diagnoses. In other words, “the data fit this diagnosis but we can’t be sure that it isn’t consistent with this alternative diagnosis.” So the worst-case scenario must always be ruled out first, requiring more invasive testing to confirm or negate that diagnosis in an attempt to arrive at greater clarity. Interpretive uncertainty, therefore, adds another layer of ambiguity.

Susan Haack, “Commentary: Uncertainty in the Art and Science of Medicine and Biotechnology,” *Dignitas* 24, no. 3 (2017): 1–2.

## "COMMENTARY: UNCERTAINTY IN THE ART AND SCIENCE..." FROM PAGE 1

In the era of highly technological laboratory and imaging studies, we have forgotten that a diagnosis originally began as a “differential diagnosis”—a list of possible diagnoses that were more or less consistent with the signs, symptoms, and laboratory values that had been obtained. Arriving at a more precise diagnosis involved a process of elimination, an acknowledgement of the complexity and uniqueness of the human individual who could not be counted on to respond as predicted to a particular disease process.

Besides diagnostic uncertainty, there is therapeutic uncertainty. Human beings are highly integrated organisms—bio-psycho-social beings—who function as complex wholes. A change in one system has a ripple effect—if not a cascading one—on other systems within the being. Even with a relatively certain diagnosis, the response to therapy is highly contingent upon the individual, their particular manifestation of disease, and the bodily environment in which it exists. Comorbidities—the individual’s accompanying health issues and diagnoses—also impact the response of the individual to any particular therapy. Therapeutic efficacy has been improved for some illnesses by the recent introduction of molecular studies (given the deceptive pseudonym of “personalized” medicine) that determine the responsiveness of a particular tumor or disease to a specific drug. But uncertainty remains, for what the testing does not indicate is the response of the patient to the therapeutic modality. Will the treatment adversely impact the other organ systems? Will the patient be able to tolerate the side effects, or will the “cure” be worse than the disease?

The uncertainty inherent in both diagnosis and therapy is compounded in prognosis, which is contingent upon diagnostic fallibilities, therapeutic ambiguities, and individual idiosyncrasies. Prognostic algorithms, developed from patient populations, are frequently consulted; but such algorithms perform best across patient populations, a fact that is generally neglected when interacting with the individual patient. Flesh and bones do not fit into our templates and algorithm boxes no matter how hard we try to force them to do so.

Finally, for the Christian there is the issue of spiritual uncertainty. Even though the goal—our final destiny—is known and assured in Christ, and despite the fact that Jesus is Himself the “Way” to that goal, “ground fog” often obscures our immediate next steps. Scripture does not give us specific guidelines for addressing the medical and bioethical problems we face today, only God-honoring principles that again are subject to human interpretation. Furthermore, as sinful human beings, even our prayerful decisions are not free from contamination by our own selfish desires and will. Can we ever be certain that what we have decided is God’s will? Despite our best discerning efforts, our decisions often do not work out as we had planned or hoped. It is as if we acted in ignorance. Yet God repeatedly uses the ignorant actions of His children to advance His purposes and plans for their lives and for His Kingdom (i.e. Acts 3:17–18). For the will of God is hidden in a Being whose thoughts are not our thoughts nor are His ways our ways (Isaiah 55:8). This does not abdicate us of our responsibility for seeking God’s will, but by His grace absolves us of guilt when we are faced with making decisions in the midst of human fallibility, ignorance, and uncertainty.

Uncertainty is a pervasive fact of life as well as of medicine and biotechnology. An acknowledgment of the many facets of uncertainty that surround our medical and bioethical decision-making should ease the anxiety-laden task of making the “right” decision and enable us to hold lightly and humbly to what we know in light of the “more” that we do not know. ●●●

1 William Osler, Robert Bennett Bean, and William Bennett Bean, *Aphorisms from His Bedside Teachings and Writings* (Springfield, IL: Thomas, 1961), 125.

2 Julie Beck, “Of all the Categories of Fake News Health News is the Worst,” *The Atlantic*, June 25, 2017, [https://www.theatlantic.com/health/archive/2017/06/of-all-the-categories-of-fake-news-health-news-is-the-worst/531540/?utm\\_source=twb](https://www.theatlantic.com/health/archive/2017/06/of-all-the-categories-of-fake-news-health-news-is-the-worst/531540/?utm_source=twb) (accessed June 28, 2017).

3 Tham Soon Kit and Choi Kwok Pui, *Uncertainty of Medicine*, Proceedings from the 14<sup>th</sup> National Undergraduate Research Opportunities Programme Congress, February 18, 2009, National University of Singapore, [http://www.nus.edu.sg/nurop/2009/FoS/14th%20NUROP%20Congress\\_FoS/Statistics/Tham%20Soon%20Kit\\_U042324M.pdf](http://www.nus.edu.sg/nurop/2009/FoS/14th%20NUROP%20Congress_FoS/Statistics/Tham%20Soon%20Kit_U042324M.pdf) (accessed June 2, 2017).



**Editor’s Note:** It was with great sadness that we learned that Dr. Susan Haack was taken home to be with the Lord in late December. Dr. Haack was a long-time friend of the Center, frequent paper presenter at our annual summer conference, and regular author for the Center’s various publications. In addition to her distinguished professional career in obstetric medicine, she was a former MDiv intern for the Center and later an Associate Fellow of CBHD’s Academy of Fellows. Susan’s infectious intellectual curiosity and passion for theology will be deeply missed.

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

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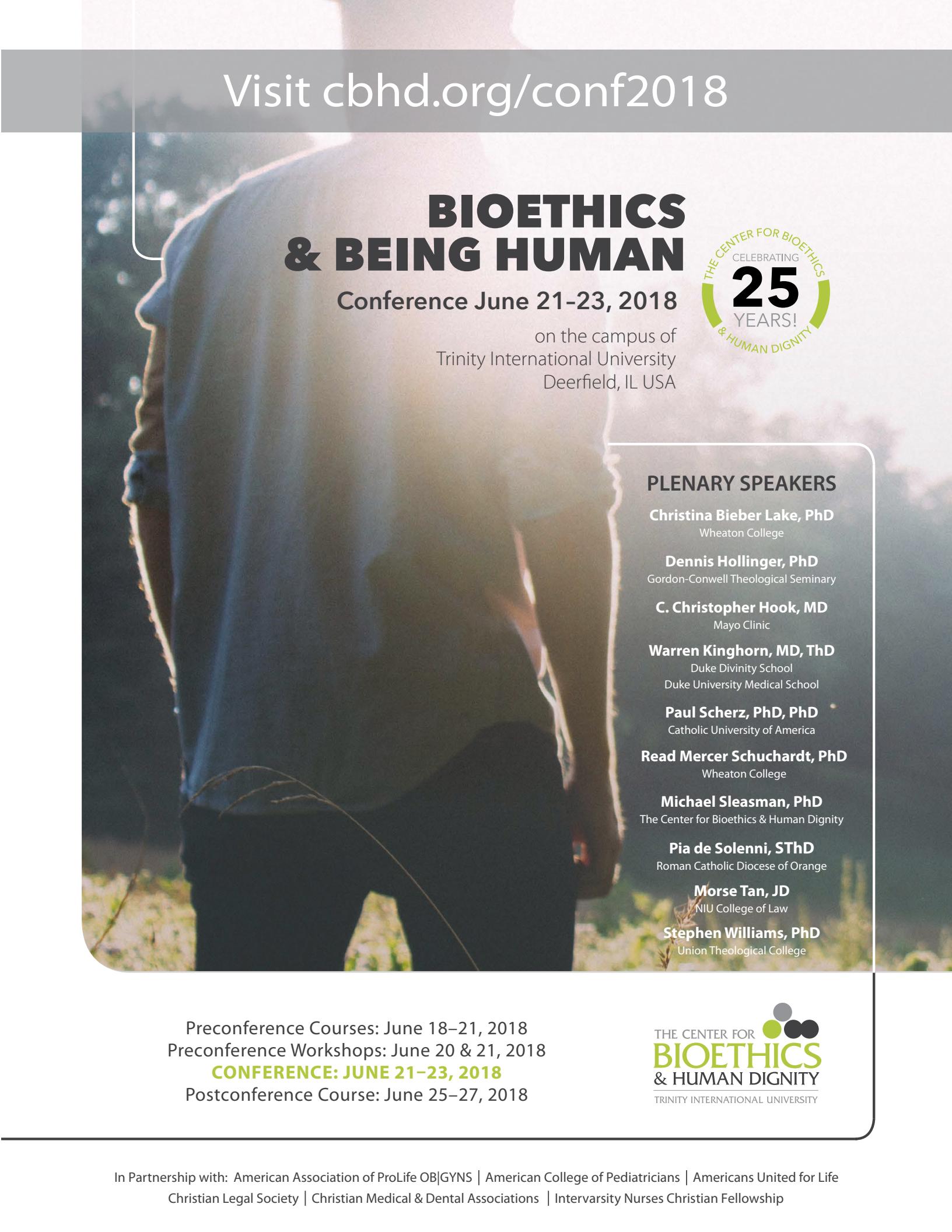
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# ETHICAL CONSIDERATIONS IN POTENTIAL TREATMENT FOR DOWN SYNDROME

TIM MROWIEC, MA

GUEST CONTRIBUTOR



**D**own syndrome is a common chromosomal abnormality caused by trisomy (an extra copy) of chromosome 21 and affecting 1 in 600 live births.<sup>1</sup> Individuals with Down syndrome (DS) suffer from cognitive impairments and face a higher risk of heart defects, hematopoietic diseases, and early-onset Alzheimer's disease.<sup>2</sup> Potential treatments of DS have proven elusive thus far due to the number of genes affected by trisomy 21 and the phenotypic variety among the affected individuals.<sup>3</sup> These medical issues combined with a lack of treatment options have tragic consequences. Maternal serum screening, a relatively common procedure, can detect 90% of fetuses with DS by 11–13 weeks,<sup>4</sup> which has resulted in between 70% and 90% of these pregnancies being terminated.<sup>5</sup>

Though the abortion rate remains very high, people with DS are generally treated with respect and have access to many vocational and educational opportunities.<sup>6</sup> Moreover, despite these medical issues, individuals with DS generally have a high quality of life in Western societies. In the absence of genetic treatment or presumptive cures, significant efforts have been made in providing resources to assist DS individuals for functioning in society with their untreated disabilities, which have proven largely successful.

It is surely a paradox that contemporary

society sees fit to terminate the majority of the DS population in utero while holding survivors in relatively positive regard. This article explores whether it is in the best interests of persons with trisomy 21 to pursue treatment, in light of this paradoxical and complex relationship. Particular areas of interest are whether improved physical health and intellectual capacity necessarily entail improved quality of life, and whether the best interests of current and future generations may conflict.

## Current Research and Potential Treatment Options

Research published in 2013 established, in principle, possible *in vitro* dosage compensation treatments to treat trisomy 21, that is, silencing of the extra copy of chromosome 21.<sup>7</sup> The strategy is analogous to X chromosome silencing in mammalian females by its use of the X-inactivation gene (*XIST*). Though this work is significant and could be a first step toward major therapeutic breakthroughs, it remains to be seen what actually will be feasible in the future. It would be premature to imagine the third copy of chromosome 21 being effectively “switched off” by an injection of *XIST*. And even if that were possible, many developmental events affected by the trisomy would have already occurred, such as a heart defect or the distinctive epicanthic folds. What appears to be more

likely are new opportunities to research the particular cellular pathologies of trisomy 21 and thereby develop individual postnatal treatments for certain symptoms and comorbid conditions, such as the higher risk for leukemia found in people with DS.<sup>8</sup>

Regardless, many years of further research and testing remain before any kind of treatment might become available. And, until such progress is made, the physical side effects and risks of the treatment will remain unknown. However, the ethical ramifications of potential scenarios must be considered now—*before* treatment becomes available—so that a sound ethical understanding can inform the choices of therapy options.

In order to explore these future potentialities, the “treatment” referenced in this paper will indicate a hypothetical, relatively low-risk therapy that becomes readily available to the DS population,<sup>9</sup> and which addresses both the physical and intellectual handicaps implicated by the syndrome. Whether the treatment would entail one, all-inclusive *XIST* transgene regimen or a series of individual protocols will not be considered here, though that could become ethically relevant.<sup>10</sup> Future treatment options could potentially be administered early in embryonic development (such as in an *in vitro* fertilization setting), but this paper will only explore the issues of treating individuals who have already manifested symptoms of DS.

An important aspect of this hypothetical scenario is that most of the symptoms of DS are affected at some point during treatment, including both intellectual and physical components. If this is not the case, then treatment for DS is not being considered, but rather isolated cases of developmental delays, heart defects, Alzheimer's disease, etc. This distinction of intent to treat Down syndrome proper is what makes community-level considerations relevant, as the design of the therapy carries with it certain social messages

"quality of life." It is assumed that if the treatment does not improve the quality of life for individuals with DS then there is no legitimate rationale to support it. This assumption raises a significant issue regarding the notion of "quality of life." Care must be taken both to not impose an external conception of quality of life onto persons with trisomy 21 without considering their opinions, and to counteract the current inconsistency in how a diagnosis of DS is discussed.

in society. Intellectual capacity could increase and thereby open new job opportunities and more options for independent living. Reduced risk for hematopoietic disorders and Alzheimer's disease is of course of great benefit. These are noble goals and ones that undoubtedly reflect the aspirations of many within the DS community. However, this may come at a great cost to the community and deprive treated individuals of previously available support structures. The special education, job training, and health-care resources currently available were designed with the strengths and weaknesses of untreated Down syndrome in mind, and it might be unfeasible to continually adapt them to the changing circumstances of a "mid-treatment" DS community in transition. The DS population includes a wide spectrum of functional levels and abilities, and assessing disability is already sufficiently difficult given issues of cultural contextualization in addition to phenotypic and personal variability.<sup>14</sup> As this diverse group of individuals responds to treatment with different rates of progress, the resultant "mid-treatment" and "post-treatment" states could be even more complex and diversified. The worst case scenario is a sort of Balkanization, wherein a diverse but well-understood disability is superseded by a wider spectrum of previously unpredictable disability states, making access to resources and support more difficult for individuals with DS, despite whatever benefits treatments may bring.

*...the ethical ramifications of potential scenarios must be considered now—before treatment becomes available—so that a sound ethical understanding can inform the choices of therapy options.*

that impact more than just the individual patient in question. This holds true even if some of the treatments developed find application outside of the DS population (for example, other trisomies such as Patau syndrome or Edwards syndrome could be better understood by further *XIST*-based research). Therefore, the purpose of this article is to explore whether pursuing treatment for DS would be in the best interests of those who have the trisomy in light of potential community-level concerns and social messages. A thorough discussion of disability ethics, identity, and the goals of medicine is warranted before making definitive conclusions on the issue of treatment for DS. However, the limited scope of this paper does not permit the kind of investigation necessary to do those topics justice. Thus, the goal here is to discuss the kind of questions that potential treatment for DS brings to light, and submit this preliminary work for evaluation in the existing conversations on disability, identity, and medicine.

#### Ethical Implications and Social Messages

Perhaps the most obvious first question to address in determining the best interests of the DS population concerns

As previously mentioned, the conflict between the high abortion rate and celebration of living persons with DS represents seemingly contradictory views on quality of life. On one hand, the cultural message appears to be that a DS life is not worth giving birth to, while paradoxically holding that same DS life is worth supporting outside the womb. Because of the availability of prenatal screening and elective abortion, what was once considered something left up to fate—the birth of a child with a disability—is now discussed as if it were choice, a burden that the parents are bringing into the world.<sup>11</sup> As early as 1986, Stanley Hauerwas warned of the collateral damage which is done when campaigning for prenatal screening under the guise of a compassionate desire to limit suffering. How can one express a strong desire to see a disability disappear without doing so at the expense of the people who currently have that disability? Hauerwas cautioned that "disease descriptions and remedies are relative to a society's values and needs"<sup>12</sup> and seemingly limited resources could be more the result of a "lack of moral will and imagination"<sup>13</sup> than actual scarcity.

If treatment is successful, individuals with Down syndrome stand to gain many new advantages for functioning

This scenario of fracturing support structures and loss of common resources is, admittedly, subject to a number of variables and is unlikely to be unsalvageable. Special education experts and social workers are already well versed in assessing individual needs. However, the emotional and cultural consequences of a fracturing community are worthy of serious consideration. How would one evaluate what is in the best interests of a DS patient if he or she were to gain increased intellectual capacity and physical health, but simultaneously would lose access to valuable social and educational resources, and perhaps

a sense of belonging? When a disability presents itself, the choice is whether "to change biology, psychology or society."<sup>15</sup> Julian Savulescu argues that sometimes changing society may be the most logical option when addressing issues that involve existing people so that personal identity is not altered. However, he also sees treating an individual with DS who has more severe cognitive impairments as the potential replacement of a non-person with a new, unimpaired person.<sup>16</sup> Savulescu's notion of procreative beneficence calls for a rational consideration of the "benefits and risks, the opportunity costs and the context" and calls for us to "make an active choice which reason supports."<sup>17</sup> For him, such a deliberation will cause us "to select the best children, those with the least disabilities."<sup>18</sup> While raising important questions of the preservation personal identity at the expense of changing society, the view of personhood suggested is more malleable than a Christian perspective can allow.<sup>19</sup>

However, sound theology does not automatically answer existential anxiety about a *sense* of identity. Individuals with Down syndrome benefit greatly from interaction with peers of similar functioning level, and separation from their community can have serious effects on their wellbeing.<sup>20</sup> Might the replacement of a common sense of identity within the DS community with progressively splintering subgroups erode important emotional support structures for individuals with DS? The untreated DS population has also produced a number of outstanding role models for individuals with various disabilities to look up to, and this valuable position could be challenged by a new emphasis on seeking treatment as the appropriate end for people who have DS. This must be carefully nuanced, however. There is no shame in seeking therapeutic interventions, and taking reasonable steps to avoid leukemia is certainly prudent healthcare. But treatment that specifically targets Down syndrome as a collective entity carries with it important social messages.

Furthermore, the notion of treatment

being able to improve the capabilities of the affected individuals may place a much larger burden for success in societal functioning than the treatment can actually provide. Regardless of the accuracy and realism of the information presented by medical personnel or researchers, an expectation may develop that accommodations to mid-treatment or post-treatment individuals are no longer necessary. This could lead to unreasonably high standards in the workforce and the

develops if the presence of untreated DS in the population is greatly diminished. If pursuing treatment remains cheaper and more accessible than supporting a child with untreated DS, then one can expect as a reasonable consequence that there will be fewer people living with untreated DS. In addition, if abortion is also cheaper and more accessible than treatment, one can anticipate even fewer people with Down syndrome being present in the population. Such realities may

*...sound theology does not automatically answer existential anxiety about a sense of identity.*

education system that outpace the actual improvements experienced by patients. Even if the assumption is granted that the treatment will become predictable over time and the functioning level of these theoretical subpopulations will stabilize—and furthermore that society learns how to support mid-treatment and post-treatment individuals—a period of instability and readjustment may leave a lasting de-incentive to work with individuals who have disabilities which are eligible for such therapies. Disability advocacy groups have had a profound impact on the United States, but not without obstacles and some mixed success.<sup>21</sup> The Americans with Disabilities Act is a significant accomplishment for protecting opportunities for persons with Down syndrome, but future interpretation of certain key phrases in the law could be unfavorable. For example, accommodating any significant changes in a mid-treatment state could constitute an "undue hardship" for an employer. The ADA protects the disability status of an individual regardless of the mitigating effect of any "learned behavioral and adaptive neurological modifications."<sup>22</sup> Is it conceivable given these developments that future trisomy therapy options may be redefined as too radical to merit such protection?

Within a perspective that desires to avoid elective abortion, a potential concern

lead an expectant mother considering abortion for her child with DS to believe there are limited opportunities for people with untreated DS to live fulfilling lives, due to the absence of such examples, thus creating a vicious cycle of more abortions and fewer persons with Down syndrome.

Lastly, the DS population may have an advantage in that most of the individuals with the syndrome are easily recognizable by their physical appearance. While this also enables quicker discriminatory judgments, this has the unexpected effect of potentially benefitting the DS community. So long as a positive public perception of DS individuals exists, their recognizable appearance can elicit a quicker response of affording extra patience and courtesy to the affected individuals. This is an advantage that people with other disabilities—for example, people on the autism spectrum—generally do not have. Should treatment for trisomy 21 become a reality, physical features will already be determined despite whatever malleable aspects are improved. This could turn the recognizable appearance into a liability, whereby a pursuit of additional opportunities and integration is hampered by a physically distinctive post-treatment state. The potential benefit of cosmetic surgery for people with DS was briefly but intensely debated in the 1980s, and such arguments may make an unwelcome and dehumanizing return.<sup>23</sup>

The advantages that individuals with DS might gain from the treatment, however, are very significant. Though a rocky transition period may result in special education schools and job programs losing some effectiveness, improved functioning levels of DS individuals could compensate for diminishing external support. An equally resilient “post-treatment” DS community could emerge as well to fill any gaps that have been left behind by obsolete support structures. Furthermore, the future individuals affected by DS must be considered as an issue of intergenerational justice.<sup>24</sup> There is no guarantee that the generally favorable perception and level of accommodation that currently exists will continue, as that depends on cultural, social, and legal factors that cannot be controlled. The situation faced by future generations of DS individuals may be inhospitable and unaccommodating, and securing therapeutic options may become necessary for their functioning in society. Essentially, the current generation of people with DS may have a much more favorable position from which to weigh its options regarding treatment than future generations, as the two scenarios may be vastly different.

## Conclusion

In summary, there is reason for concern regarding the loss of current opportunities during “mid-treatment” states, a fragmentation of “subpopulations” that respond to therapy in different ways, and exaggerated expectations from society for “post-treatment” persons with DS. Perhaps it would not be in the best interests of the current generation of people with DS to seek treatment for their trisomy, given the inferior quality of life that could result. However, future generations of persons with trisomy 21 cannot depend on the current advantages that are open to the DS population, and so it is in their best interest to have treatment options available. Thus, pursuing the best interests of future generations of people with DS may fall to the current generation in seeking out treatment options now, so they remain available in the future when the need could be greater.

In order to synthesize these two goals and serve the entire DS community—current and future—special precautions should be taken. For example, safeguards that deserve further thought are legal protections for persons undergoing treatment, supportive measures not being conditioned on receipt of treatment, and educating the public to avoid overzealous expectations. Regardless, it is still far too early to tell what promise *XIST*-based research holds or what therapies may be available in the future for people with trisomy 21, or what insights and precautions may come from further work in disability ethics. Nevertheless, before treatments become available, it is necessary to evaluate what social messages such treatment would convey and how the concerns of the DS community can be incorporated into therapeutic decision-making, so that people with Down syndrome may pursue their best interests with adequate protection and respect for their dignity. ●●

*Handicapped, and the Church* (Notre Dame, IN: University of Notre Dame Press, 1986), 161.

13 *Ibid.*, 163.

14 Paula Sotnik and Mary Ann Jezewski, “Culture and the Disability Services,” in *Culture and Disability: Providing Culturally Competent Services*, ed. John Stone (Thousand Oaks, CA: Sage Publications, 2005), 28–35.

15 Julian Savulescu, “Procreative Beneficence: Reasons to Not Have Disabled Children,” in *The Sorting Society*, ed. Loane Skene and Janna Thompson (New York: Cambridge University Press, 2008), 61–62.

16 *Ibid.*

17 *Ibid.*, 66.

18 *Ibid.*

19 John Kilner, for instance, has rebutted misunderstandings that the *imago Dei* is lost or damaged in persons with disabilities, and challenged the belief that changes to any particular attributes or functional level could threaten the status of human dignity for an individual. John Kilner, *Dignity and Destiny* (Grand Rapids: Erdmans, 2015), 18–21, 101, 327–329.

20 Dennis McGuire and Brian Chicoine, *Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges* (Bethesda, MA: Woodbine House, 2006), 35–36.

21 Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality* (Washington, D.C.: Georgetown University Press, 2003), 70–74.

22 Americans with Disabilities Act of 1990, Pub. L. 101–336, 104 Stat. 328, 108<sup>th</sup> Congress, 2<sup>nd</sup> session (26 July 1990), <https://www.ada.gov/pubs/adastatute08.htm> (accessed June 14, 2017).

23 Yong, *Theology and Down Syndrome*, 67–68.

24 Janna Thompson, “Genetic Technology and Intergenerational Justice,” in *The Sorting Society*, ed. Loane Skene and Janna Thompson (New York: Cambridge University Press, 2008), 85–87.

- 1 Jun Jiang et al., “Translation Dosage Compensation to Trisomy 21,” *Nature* 500, no. 7462 (2013): 296.
- 2 *Ibid.*
- 3 While technical distinctions may exist in certain professional contexts, “treatment” and “therapy” will be used interchangeably.
- 4 Agnes Bankier and David Cram, “Genetic Testing, an Informed Choice,” in *The Sorting Society: The Ethics of Genetic Screening and Therapy*, ed. Loane Skene and Janna Thompson (New York: Cambridge University Press, 2008), 8–9.
- 5 Amos Young, *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, TX: Baylor University Press, 2007), 64.
- 6 *Ibid.*, 67.
- 7 Jiang et al., “Translational Dosage Compensation to Trisomy 21,” 296
- 8 Ed Yong, “Shutting Down the Extra Chromosome in Down’s Syndrome Cells,” *National Geographic*, July 17, 2013, <http://phenomena.nationalgeographic.com/2013/07/17/how-to-shut-down-the-extra-chromosome-in-downs-syndrome/> (accessed June 14, 2017).
- 9 A treatment only accessible to a small percentage of the population with DS would still warrant ethical consideration, but would not raise the specific questions this paper aims to address.
- 10 For example, if a treatment is started that increases the intellectual abilities of a DS patient who develops the capacity to offer informed consent without a proxy as a result of the treatment, and subsequently declines consent for the remainder of the treatment regimen.
- 11 Michael J. Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Cambridge, MA: Belknap Press, 2007), 88–89.
- 12 Stanley Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally*

# 24<sup>TH</sup> ANNUAL SUMMER CONFERENCE RECAP: GENETIC & REPRODUCTIVE TECHNOLOGIES

LINDSAY CALLAWAY, MA

GUEST CONTRIBUTOR

## When the Unthinkable Has Become Conceivable

In the wake of progressively increasing uses of human gene editing, Dr. David Baltimore addressed an international summit in December 2015, stating, “the unthinkable has become conceivable and today we sense we are close to being able to alter human heredity.”<sup>1</sup> Gametes can be extracted from their hosts and conception achieved *ex utero*. Mitochondrial disease can now be circumvented using nucleus transfer, leaving resultant embryos with DNA from three different parents. CRISPR-Cas9 laudably promises the eradication of disease but opens doors to other, more disturbing, forms of genetic modification, perhaps permanently altering the human germ line. Scenarios once unthinkable, relegated to the pages of science fiction and dystopian literature, have become a haunting foretelling of the landscape of contemporary reproductive and genetic technologies and other reproto genetic technologies appearing on the near horizon.

Emerging from CBHD’s 2017 summer conference, “Genetic & Reproductive Technologies,” was a profound sense that science and technological advancement do not emerge in a social vacuum. Assumptions pertaining to human origin, identity, and destiny inevitably inform the process of scientific exploration and the direction of biotechnological advancement. As the conference provided an opportunity to evaluate reproductive and genetic technologies for their potential—and potentially devastating—impact, it became clear that bioethical deliberation has a rightful claim and an important stake in shaping

not only moral and technological imagination, but also the future of humanity itself.

## Who am I? What am I? Whence did I come?

In the first plenary address, C. Ben Mitchell, PhD, focused on the looming reality and implications of extra-uterine fetal development. In a thought experiment, Mitchell took a cue from Haldane and Huxley, imagining a world in the not too distant future where ectogenesis is routine and traditional pregnancy a thing of the past. His characters boast of having chosen the most exclusive company, with expensive services that allowed them to determine the gender, biological traits, and personality of the fetus gestating within the sterile confines of a synthetic womb.

Moving into cautionary critique, he asked whether we could have persons without pregnancy. Oliver O’Donovan, in his monograph *Begotten or Made* (from which Mitchell borrowed the title of his address), opens with this claim, “What we ‘make’... is alien from our humanity. In that it has a human maker, it has come to existence as a human project, its being at the disposal of mankind.”<sup>2</sup> If we rob a human being of their begottenness, an existence that emerges from the mutual I-Thou relationship, O’Donovan argues that the resulting child represents the embodiment of individual human will and volition, rendering the child’s identity and very being at the disposal of the person who determined it.

Similarly, Calum MacKellar, PhD, in his discussion about artificial sperm and

eggs emphasized that knowing from whom and whence we come is fundamental to shaping both individual and corporate identity. If interdependent existences are what create bonds of mutual belonging, how will artificial gametes comprised of several donors, or created from pluripotent stem cells, affect the bonds of mutuality at the core of our identity? MacKellar appealed to the perplexing lament of Dr. Frankenstein’s monster, “I was dependent on none and related to none. The path of my departure was free and there was none to lament my annihilation. . . . Who was I? What was I? Whence did I come?”<sup>3</sup>

At the root of the monster’s identity crisis is his composite existence lacking the correspondence that comes from being made from representative wholes. “Origins,” MacKellar stated, “are stronger than genetics.”<sup>4</sup> Tampering with the representative nature of the sperm and egg union tampers with the very nature of being that enables one to self-identify and belong to the world. Getting genetics “right” does not guarantee that life will find meaning if it is stripped of its corresponding identity and origin.

## Shaping the Moral and Technological Imagination

Issues associated with genetic discrimination are not limited to the existential or ontological, however. Discussing prenatal screening and testing, David Prentice, PhD, described how life-determining decisions are being made based on the results of routine genetic screening. Prenatal screening is a non-invasive routine test assessing risk that has become conflated with the results of a diagnosis, where it is determined whether the individual is an actual carrier. While the results of screening and diagnosis can be helpful for parental education and

planning, the pattern of use has increasingly resulted in abortive decisions based on genetic risk rather than a true diagnosis.

Citing a UK sampling, Prentice reported that every individual studied chose to abort a fetus based on the results of a disappointing prenatal screening, having not distinguished between risk and condition. The moral landscape has shifted

selective reduction, and other procedures. Gilbert Meilaender summarizes, “we share together the dignity of being human. We are therefore not at each other’s disposal, not fit subjects for ‘quality control’ by one another.”<sup>8</sup> Considering “the quality of our children” creates a world where the erasure of a mutual human dignity leads to value judgments based on two things of the same worth.

the unthinkable has already become conceivable.”

Hurlbut’s focus on the trajectory of scientific exploration and Prentice’s appeals to the genetic ramifications for future generations evoke another analogy from O’Donovan: “We live not at the seed-time but at the harvest of the modern age, when we have the privilege of seeing what is its true character more clearly than those who have gone before us. And we have to think of the next seedtime, if one is given to us, and ask what we shall sow.”<sup>10</sup>

Ours is an unprecedent moment in which advancements in science and technology are able to leave a permanent legacy for our offspring. What standards and qualities do we presume to impose upon succeeding generations?

to allow life-determining, society-shifting decisions based on chance and not on actuality. As the lines between risk and diagnosis blur, Prentice described it as a lethal discrimination occurring under the guise of duty and socio-economic responsibility, and “when you start to choose which kinds of people should exist based on genetics, you have eugenics.”<sup>5</sup>

Therefore it is clear that humanity’s stake in genetic and reproductive technology is not only rooted in the ethics of the procedures themselves, but the underlying assumptions that inform their pursuit and application. The eugenic sympathies of Dr. Robert Edwards, the father of IVF, informed an imagination that prized product over persons, and commodity over community.<sup>6</sup> “Soon it will be a sin of parents to have a child that carries the heavy burden of genetic disease,” Edwards said, “We are entering a world where we have to consider the quality of our children.”<sup>7</sup>

Dr. Edwards’s belief that the human gene pool should be manipulated and improved reveals that an attitude of quality control has seeped into the assumptions behind pre-implantation genetic diagnosis, prenatal screening and testing,

Understanding how Edwards’s moral imagination shaped his scientific research, we must ask ourselves, “how can we govern and shape the next generation of science and technological innovation?” The current moral trajectory informing the use of genetic and reproductive technologies is quickly moving beyond treatment or cure to enhancement or elimination. For example Iceland recently boasted of its eradication of Down Syndrome, but this is not the elimination of Trisomy 21, but of persons who possess the genetic anomaly. This moral trajectory changes what it means to be human.

J. Benjamin Hurlbut, PhD, called for greater ethical accountability in the process of scientific aspiration, rather than reactive responses to technical application: “Governing the future well requires that we understand the trajectory we’re on.”<sup>9</sup> The future of Christian bioethics does not lie in a defensive posture that shakes its fist at every new technology presented to society. Our role instead ought to be proactive, making a timely contribution in light of the high stakes and the need for clear theological insights, before a technology is adopted, because too often the “public is only invited to evaluate the end product, when

### Messy and Inconvenient

Finally, it is suitable to ask what role the church should play in governing the future and shaping the moral and technological imagination, especially for believers who are contributing to scientific research, doctors and clinicians who are faced with their application, and for those who are the intended beneficiaries.

Revisiting Mitchell’s opening thought experiment, his characters portrayed an apparent evangelical commitment to sexual purity and pro-family ideals while simultaneously lacking critical theological engagement with the procedures to which they consented, theological anthropology, and the sacrificial call of Christ. When discussing the archaic practice of pregnancy, one of his characters remarked, “It seems so messy and inconvenient.”<sup>12</sup> Mitchell aptly included the church’s lagging response in his thought experiment, not necessarily because the church is unaware of the issues, but because the body of Christ is often ill equipped to critically evaluate the implications of the procedures



Left to Right: Scott Rae, PhD; C. Ben Mitchell, PhD

themselves and identify the theological assumptions communicated through their use.

The church's response (or lack thereof) highlights the distinct role of organizations like CBHD that recognize the dangers of the church's silence on matters of bioethics and seek to bring scientific and theological clarity to these complex issues in service of the church. This commitment was highlighted in the final colloquium session, which was dedicated to an ecumenical dialogue on reproductive technologies between representatives of the three great Christian traditions. While varying in approach and theological commitments, each panelist represented both an aptitude in their field of study (ranging from canon law and ethics to molecular biology) and a high level of theological engagement from within their ecclesial tradition on matters of bioethics.

The predominant mood was one of general agreement and amiable clarification from the panel. With thoughtful prohibition characterizing the Catholic approach, the Protestant and Orthodox traditions both granted modest permission in their assessments of reproductive technologies, appealing to theological principles such as virtue, stewardship, and *oikonomia* (household management). The panel unequivocally agreed, however, that engaging theologically on matters of reproductive technology was undeniably pastoral in nature.

Scott B. Rae, PhD, commented that his interaction with laypeople whose attitude

often communicated "don't bother me with the ethics."<sup>13</sup> Gayle E. Woloschak, PhD, observed that people simply did not think to get counsel from the church on scientific matters, harkening to Hurlbut's session that addressed how systems of governance assign authority based on who they judge to know what is best.<sup>14</sup> This mind-set assumes that since clergy are neither scientists nor doctors, one need not bother consulting theology on matters of biology. Marie Hilliard, JCL, PhD, RN, called it "a teaching problem,"<sup>15</sup> sensing that as the church becomes increasingly aware and educated on the intricate details of reproductive technology, and the ensuing theological and ethical implications, the gap between clergy and laity must be addressed and narrowed.

Ministering through infertility is inextricably linked with people. Navigating the heartache is "messy and inconvenient" for the church, but must be taken seriously as a matter of witness. The biblical narrative informs and addresses the fundamental questions of human origin, identity, and destiny. It grounds human dignity in our identification with the Creator, not our genetics. The church has a stake in matters of genetic and reproductive technologies and the colloquium stressed the imperative to prepare and equip the Christian mind in shaping moral imagination to influence and evaluate the future of scientific advancement and technological application.

The summer conference may have left attendees asking more questions than answering them. Yet, as the unthinkable increasingly becomes conceivable, we were encouraged to start asking the right kind of questions. What are the underlying assumptions that will drive the future of technological advancement? What priorities and practices will guide moral and scientific deliberation? What genetic legacy will we leave future generations? As we explored important assumptions and implications in genetic and reproductive technologies, many of the inquiries boiled down to the question, "what does it mean to be human?" Therefore, next

year's 25<sup>th</sup> annual conference, "Bioethics and Being Human," is a natural next step for examining science and technology and the underlying metaphysics and ontology that inform what it means to be human. ●●●

- 1 The Economist, "Time to Think Carefully," *The Economist*, December 3, 2015, <https://www.economist.com/news/science-and-technology/21679434-international-summit-discusses-use-gene-editing-time-think-carefully> (accessed October 12, 2017). J. Benjamin Hurlbut referred to Dr. Baltimore's speech in "Governing Human Embryo Research at the Nexus of Gene Editing & Developmental Biology" (plenary address, The Center for Bioethics & Human Dignity's 2017 Annual Conference, "Genetic & Reproductive Technologies," Deerfield, IL, June 24, 2017).
- 2 Oliver O'Donovan, *Begotten or Made?* (New York: Oxford University Press, 1984), 1.
- 3 Mary W. Shelley, *Frankenstein* (Boston: Sever, Francis & Co., 1869), 101.
- 4 Calum MacKellar, "Artificial Sperm and Eggs" (plenary address, The Center for Bioethics & Human Dignity's 2017 Annual Conference, "Genetic & Reproductive Technologies," Deerfield, IL, June 23, 2017).
- 5 Ibid.
- 6 C. Ben Mitchell, "Begotten or Made?" (plenary address, The Center for Bioethics & Human Dignity's 2017 Annual Conference, "Genetic & Reproductive Technologies," Deerfield, IL, June 22, 2017).
- 7 Osagie K. Obasogie, "Commentary: The Eugenics Legacy of the Nobelist Who Fathered IVF," *Scientific American*, October 4, 2013, <https://www.scientificamerican.com/article/eugenics-legacy-nobel-ivf/> (accessed October 12, 2017).
- 8 Gilbert Meilaender, *Neither Beast Nor God: The Dignity of the Human Person* (New York: Encounter Books, 2009), 34–35.
- 9 Hurlbut, "Governing Human Embryo Research."
- 10 O'Donovan, *Begotten or Made?*, 12.
- 11 David Prentice, "Prenatal Screening and Testing" (plenary address, The Center for Bioethics & Human Dignity's 2017 Annual Conference, "Genetic & Reproductive Technologies," Deerfield, IL, June 23, 2017).
- 12 C. Ben Mitchell, "Begotten or Made."
- 13 Scott B. Rae, "Protestant, Catholic, & Orthodox Approaches to Reproductive Technologies" (colloquium, The Center for Bioethics & Human Dignity's 2017 Annual Conference, "Genetic & Reproductive Technologies," Deerfield, IL, June 24, 2017).
- 14 Hurlbut, "Governing Human Embryo Research."
- 15 Marie Hilliard, "Protestant, Catholic, & Orthodox Approaches to Reproductive Technologies" (colloquium, The Center for Bioethics & Human Dignity's 2017 Annual Conference, "Genetic & Reproductive Technologies," Deerfield, IL, June 24, 2017).

## 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 research@cbhd.org.

## BIOETHICS AT THE BOX OFFICE:



*Allegiant* (2016, PG-13 for intense violence and action, thematic elements, and some partial nudity). *Designer Babies, Disaster Ethics, Emerging Technology, Eugenics, Genetic Engineering, Human Enhancement, Neuroethics, Research Ethics*.



*The Circle* (2017, PG-13 for a sexual situation, brief strong language, and some thematic elements including drug use). *Privacy, Technology & Society*.



*Equals* (2015, PG-13 for thematic content, sensuality, partial nudity, and disturbing images). *Eugenics, Genetic Engineering, Human Enhancement, Neuroethics, Reproductive Ethics*



*Insurgent* (2015, PG-13 for intense violence and action throughout, some sensuality, thematic elements, and brief language). *Neuroethics, Research Ethics*.



*Jupiter Ascending* (2015, PG-13 for some violence, sequences of sci-fi action, some suggestive content, and partial nudity). *Genetics, Radical Life Extension, Regenerative Medicine*.

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STUDENTS

# BOOK NOTE: *THE IMAGE OF GOD, PERSONHOOD AND THE EMBRYO*

CALUM MACKELLAR, PHD  
CBHD FELLOW

One of the reasons I was encouraged to write *The Image of God, Personhood and the Embryo* was because a specific and detailed examination of how the image of God may be reflected in the embryo seemed to be missing from the accumulated heritage of Christian study.<sup>1</sup>

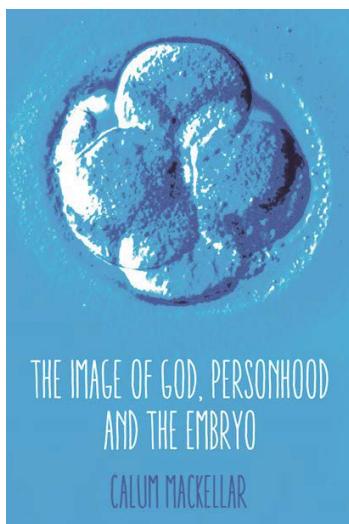
A lot had been written, previously, concerning the moral status of the human embryo. Over the past centuries, even more had been published concerning the image of God in humankind. Surprisingly, however, the combination of these two themes had not resulted in any significant volume of literature. From a theological perspective, this was interesting since any discussion relating to the moral status of human embryos cannot be dissociated from a consideration of the image of God that gives true value and meaning to all persons. In this regard, the Church of England ethicist Brendan McCarthy indicates:

This concept of the dignity and status of humans being fundamentally determined by the image of God is an important one in our attempt to evaluate the human embryo. If it can be demonstrated that the image is to be found in the human embryo, then any destruction of it or experimentation on it ought to be opposed.<sup>2</sup>

There is, therefore, a real need for clear understanding about the manner in which entirely human, and partially human, embryos may be considered as reflecting the image of God. This is especially the case when new utilitarian demands relating to the “special moral status” of the human embryo are continually putting pressure on this status to be reconsidered and questioned.

For example, in 1984, Lady Mary Warnock (one of the main architects of the UK embryology legislation) commented, in her report that led to the UK *Human Fertilisation and Embryology Act* of 1990, that the embryo “ought to have a special status”<sup>3</sup> under UK law. Later, in December 2002, her position had changed significantly, indicating instead:

I regret that in the original report that led up to the 1990 legislation we used words such as ‘respect for the embryo’... I think that what we meant by the rather foolish expression ‘respect’ was that the early embryo should never be used frivolously for research purposes.<sup>4</sup>



*The Image of God, Personhood and the Embryo*,  
Calum MacKellar, SCM Press, 2017

She added, “you cannot respectfully pour something down the sink—which is the fate of the embryo after it has been used for research, or if it is not going to be used for research or for anything else.”<sup>5</sup>

This example demonstrates how an entity, which was understood as having a special status in the 1980s, is no longer considered to have such a status and, in

fact, is seen to have lost all moral status. From this perspective, it is apparently only the biomedical research (and not the embryo) that should now be respected in the UK.

So how can the image of God be seen to be reflected in a very small human being who does not even have a brain or any developed organs?

To begin with, it must be recognized that the topic of the image of God being reflected in the human embryo and its associated moral status will inevitably be sensitive and controversial, including amongst the Christian theological community. Indeed, this may be one of the reasons why it has been somewhat put aside or even avoided. It may even be suggested that, because of the discomfort associated with any appropriate discussions relating to the moral status of embryos, this subject matter may have become somewhat taboo, including in local church situations.

This may have happened in order to show appropriate compassion and sensitivity towards those affected by the very difficult experiences of infertility, miscarriage, and abortion, with all the significant suffering generally associated with such occurrences. But, this may also mean that many parishioners are being singularly deprived of any Christian guidance about how to consider and regard the human embryo, a situation which may have been compounded by pastors themselves feeling (1) unqualified from a theological and scientific perspective to address such a subject, or (2) unprepared to speak to their congregations on a deeply moral issue out of an understandable fear of causing deep upset to, or even alienating, some church members. Regrettably, this silence may at the same time have led many Christians

to resemble the Israelites in the time of the Judges where “everyone did as they saw fit” (Judges 17:6, NIV).

John Kilner argues that the silence and inaction of most churches in this arena is distressing.<sup>6</sup> Similarly, Charles Colson and Nigel Cameron expressed concern that our churches are “sleeping through another moral catastrophe” for which they “are ill-prepared.”<sup>7</sup>

Thus, there was a need for a thoughtful new study to be presented based on serious theological analysis and the very rich arguments from different Christian denominations on the concept of the image of God in the embryo. It was in this context that *The Image of God, Personhood and the Embryo* was written, with the intention to produce a resource that could be used by all the different stakeholders in helping this important conversation move forward in a constructive manner while being informed by the latest scientific results.

The work begins with the recognition that the image of God can only be better defined but never completely understood since it reflects something of the mystery of God. From this perspective, however, it is possible to examine prevalent arguments about the nature of the image of God or more specifically what it means for humans to be created in the image of God.

The main discussion then gets underway by exploring substantive aspects and the way the image of God may be reflected in *Homo sapiens* from the standpoint of physical human nature or substance. Functional aspects and the capacity of human beings to do or be are examined in the next chapter, followed by a survey of the relational aspects and the way these enable loving relationships to exist giving value and meaning.

Throughout I explore how the image of God and the associated notion of personhood might be applied to the arguments concerning the moral status of the embryo. But these perspectives are shown to be insufficient, on their own, to adequately discuss whether the image of

God can be recognised in human embryos.

To address this problem, it was important to investigate two relatively new angles in relation to the embryo: the creation of humankind by God (which I examine in chapter 4) and the incarnation of the Word of God (chapter 5), and how both inform the image of God and personhood. As such, I argue that these could be far more useful and relevant when seeking to discuss and understand the true value and worth of human embryos.

Of course, it will never be possible to scientifically prove that the image of God is reflected in the human embryo. Indeed, it is only because of the Christian faith in God that a belief in the image of God in persons is possible which then enables a belief in the image of God in embryonic persons.

Nevertheless, this does not mean that deliberately destroying an embryo with its mysterious image of God is no unimportant matter. This is because, as Kilner explains: “Destroying someone in God’s image, in light of God’s connection with humanity, is tantamount to attacking God personally.”<sup>8</sup>

The deep commitment of love that God has given through creating humanity in his image, might suggest that he has opened himself up to a kind of vulnerability with this image.<sup>9</sup> This may be one of the reasons why this image has come under so much attack in both history and modern society.

In 2012 Lord Alton (a member of the UK House of Lords) indicated that the destruction of human embryos—human persons made in the image of God—had reached an “industrial” scale in “casual indifference.”<sup>10</sup> If human embryos may be considered to reflect the image of God, as I suggest in this book, and they are deliberately being destroyed by society, then this may be just another front of the war against God in the context of his creation. But, it is also a front in which Christians should engage with God’s help, love, compassion, and wisdom.

This means the worldwide Christian church should be profoundly challenged by the millions of human embryos that are being destroyed without the expression of any significant protest or compassion. In this respect, it should be remembered that one of the moral measures of the Christian church is how it considers the smallest, weakest and most helpless individuals with the most vulnerable claims of personhood reflecting the image of God. ●●●

1 Portions of this essay have been adapted from the “Preface” of Calum MacKellar, *The Image of God, Personhood and the Embryo* (London: SCM Press, 2017), vii–xi.

2 Brendan McCarthy, *Fertility & Faith* (Leicester: InterVarsity Press, 1997), 126–127.

3 Report of the Committee of Inquiry into Human Fertilisation and Embryology (London: Her Majesty’s Stationery Office, 1984), 63.

4 House of Lords Hansard, Volume 641 Part 14, Column 1327, 5 December 2002.

5 Ibid.

6 John Kilner, *Dignity and Destiny: Humanity in the Image of God* (Grand Rapids: Eerdmans, 2015), 327.

7 Charles Colson and Nigel Cameron, eds., *Human Dignity in the Biotech Century: A Christian Vision for Public Policy* (Downers Grove, IL: InterVarsity Press, 2004), 20–21.

8 Kilner, *Dignity and Destiny*, 319.

9 William Channing, “Spiritual Freedom,” in, *The Works of William E. Channing*, vol. 4, (Boston, MA: James Monroe, 1841), 76, referenced in Kilner, *Dignity and Destiny*, 117.

10 Andrew Hough, “1.7 Million Human Embryos Created for IVF Thrown Away,” *The Telegraph*, December 31, 2012, <http://www.telegraph.co.uk/news/health/news/9772233/1.7-million-human-embryos-created-for-IVF-thrown-away.html> (accessed June 30, 2017).

## TOP BIOETHICS NEWS STORIES: JUNE 2017–AUGUST 2017

BY HEATHER ZEIGER, MS, MA

RESEARCH ANALYST

**“New Concerns Raised Over Value of Genome-Wide Disease Studies”** by Ewen Callaway, *Nature*, June 15, 2017

Compare the genomes of enough people with and without a disease, and genetic variants linked to the malady should pop out. So runs the philosophy behind genome-wide association studies (GWAS), which researchers have used for more than a decade to find genetic ties to diseases such as schizophrenia and rheumatoid arthritis. But a provocative analysis now calls the future of that strategy into question . . . . (<https://tinyurl.com/y725fuum>)

Several news stories this past summer drew attention to potential limitations of genetic sequencing, such as the problems with genome-wide disease studies addressed by this *Nature* article. These studies compare thousands of genomes with a particular disease to genomes without, with the assumption that variances are likely associated with the disease. However, scientists found that many of these variants do not have biological relevance or that several thousand variants may play a role in a particular disease, but none play a large enough role for targeted therapies.

**“Wealth and Poverty Propping Up Pakistan’s Illegal Kidney Trade”** by AFP, *Al Arabiya.net*, June 27, 2017

When Pakistani authorities burst into a makeshift hospital in Lahore this year, doctors were caught midway through two illegal kidney transplants, the local donors and Omani clients still unconscious on the tables. The doctors were allowed to finish the operation then arrested . . . . (<https://tinyurl.com/y924q66q>)

**“Medical Staff Involved in Organ Trafficking Arrested in Egypt”** by Ashraf Abdel-Hamid, *Al Arabiya.net*, August 23, 2017

Egyptian authorities announced on Tuesday evening [August 22<sup>nd</sup>] the capture of a gang of medical staff for trafficking human organs in the area of Abu Nomros in Giza, southern Egypt. The authorities arrested 16 people involved in the case, reported Al Arabiya. (<https://tinyurl.com/yccgqy8x>)

Illegal organ trading has been an ongoing problem in Pakistan, where enforcing rules against organ trafficking is difficult. This past summer, however, successful reports of stifling traffic rings in Pakistan and Egypt demonstrate that efforts are underway to curb the practice. Additionally, China has shown some progress in banning the procurement of organs from executed prisoners.

**“Court Rules Hospital Can Withdraw Life Support for Sick Baby Charlie Gard”** by Susan Scutti, CNN, June 30, 2017

The European Court of Human Rights ruled Tuesday a hospital can discontinue life support to a baby suffering from a rare genetic disease. Born in August, Charlie Gard has a rare genetic disorder known as mitochondrial DNA depletion syndrome. (<https://tinyurl.com/yay2snyu>)

**“Charlie Gard Parents Announce the Death of ‘Beautiful Boy’”** BBC, July 28, 2017

Charlie Gard, the baby at the centre of a legal row over his treatment, has died, a family spokesman has confirmed. The 11-month-old was

moved to a hospice following a High Court ruling. (<https://tinyurl.com/y825xx3t>)

The Charlie Gard case garnered international attention largely because of a social media campaign to save his life, and resulted in conflicting assessments among those in prolife advocacy and Christian bioethics. After going through several appeals through the British court system, the European Court of Human Rights determined that the hospital could discontinue life support for 11-month-old Charlie Gard. His parents, Chris Gard and Connie Yates, wanted to transport him to the U.S. for experimental treatment that had never been tried on his specific disorder. While Charlie had a slim chance at survival even with the experimental treatment, some ethicists question whether the hospital and the court stepped over the line by overriding the parents' authority to make decisions for their child. Some raised questions regarding the nature of the U.S. researcher's consult and recommendation for this experimental treatment. Still others argued that the parents were not making a decision that was in Charlie's best interests.

**“At ClinicalTrials.Gov Untested Stem Cell Clinics Advertise for Free!”** by Megan Molteni, *Wired*, July 19, 2017

Usually people pay money for medicine *after* there's proof it works. In the last few years, some of these stem cell clinicians have begun posting large-scale studies on a government-run website called ClinicalTrials.gov, even though they're often not up to medical research standards or even in compliance with federal regulations. This allows them to masquerade

their pay-to-participate studies as legit science. (<https://tinyurl.com/y8obpdm8>)

Many companies are trying to profit from stem-cell “therapies” that have not been tested for safety or efficacy (NPR, <https://tinyurl.com/ydblzx6a>). Because many of these therapies use the patients’ own stem cells, some companies have sought to work around certain FDA regulations and were even using ClinicalTrials.gov as a way to advertise for their procedures. In response to reports of injury and mistreatment, the FDA has started sending warnings and confiscating dangerous materials from questionable stem cell clinics.

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**“CRISPR Fixes Disease Gene in Viable Human Embryos”** by Heidi Ledford, *Nature*, August 2, 2017

An international team of researchers has used CRISPR–Cas9 gene editing—a technique that allows scientists to make precise changes to genomes with relative ease—to correct a disease-causing mutation in dozens of viable human embryos. The study represents a significant improvement in efficiency and accuracy over previous efforts. (<https://tinyurl.com/y9fmpgcs>)

CRISPR-Cas9 is a robust gene editing tool that has reenergized the field of genetic engineering. This summer researchers in the U.S. used CRISPR to edit the gene for hypertrophic cardiomyopathy in a human embryo. Shoukhrat Mitalipov’s group found no evidence for off-target cuts, and of 58 embryos (all were destroyed), only one was a mosaic where different cells within the embryo contain different genetic sequences. Experts caution that just because Mitalipov’s group did not find off-target cuts, does not mean that they are not there.

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**“What Kind of Society Do You Want to Live in?: Inside The Country Where Down Syndrome Is Disappearing”** by Julian Quinones and Arijeta Lajka, *CBS News*, August 14, 2017

With the rise of prenatal screening tests across Europe and the United States, the number of babies born with Down syndrome has significantly decreased, but few countries have come as close to eradicating Down syndrome births as Iceland. Since prenatal screening tests were introduced in Iceland in the early 2000s, the vast majority of women—close to 100 percent—who received a positive test for Down syndrome terminated their pregnancy. (<https://tinyurl.com/y8snacge>)

While it is well-known in bioethics circles that the vast majority of babies found to have Down syndrome (DS) and other genetic disorders through pre-natal screening are often aborted, Iceland made headlines by claiming to be almost Down syndrome free. Most women in Iceland choose pre-natal screening, and most abort if the baby is found to have DS. However, the tests do not always catch chromosomal abnormalities, so every year about two babies are born with DS in Iceland. Many condemn this as modern-day eugenics, while other countries, such as China, have greatly increased their use of pre-implantation genetic diagnosis for the purpose of eliminating embryos with unwanted genetics.

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**“More Than 500,000 Infected with Cholera in Yemen”** by Donald G. McNeil, Jr., *The New York Times*, August 14, 2017

More than 500,000 Yemenis have been infected with cholera this year, and nearly 2,000 have died, the World Health Organization said Monday [August 14<sup>th</sup>]. Cholera is endemic in Yemen . . . . Civil war and bombing by neighboring Saudi Arabia have crippled much of the

country’s water-distribution system, destroyed hospitals and forced vast numbers of people to flee their homes. (<https://tinyurl.com/yam-jpza7>)

Deemed the worst cholera outbreak in the world by the WHO, the most recent numbers indicate that there are actually 750,000 suspected cases of cholera, more than half of whom are children. The Red Cross predicts that there will be one million cases of cholera in Yemen by the end of the year.

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**“Storm Flooding Engulfs MD Anderson Cancer Center, Canceling Treatments for Days”** by Casey Ross and Kate Sheridan, *STAT News*, August 29, 2017

Tropical Storm Harvey has flooded the roads in and around MD Anderson’s primary Houston hospital, leaving one of the world’s foremost cancer centers unable to see patients for appointments or previously scheduled treatments until Thursday [August 31<sup>st</sup>] at the earliest. (<https://tinyurl.com/yba088ms>)

Hurricane Harvey, a massive hurricane whose impact spanned the length of the Texas coast, caused devastating floods and damage to downtown Houston and its surrounding areas. Houston has one of the nation’s largest medical districts, including the MD Anderson Cancer Center. Several hospitals were stranded in rising floodwaters without access to food and supplies for their patients. Many patients were unable to get to the hospital for planned treatments or emergencies. The flooding caused other public health concerns including risk of bacterial infection.

Visit Bioethics.com, a public service provided by CBHD where you can follow stories like these as they happen.

# updates & activities

## CBHD RESEARCH LIBRARY

In the late summer, Susan Haack, MD, MDiv, donated over 300 books to the CBHD Research Library. We are grateful for Susan's generosity and the addition of volumes in bioethics, theology, and philosophy. To learn more about how to donate resources to our Research Library email us at [research@cbhd.org](mailto:research@cbhd.org).

## RESOURCE KITS FOR INTERNATIONAL LIBRARIES

Did you know that CBHD has provided library kits of Christian bioethics books and resources to university and seminary libraries and medical institutions around the world free of charge as part of our International Bioethics Scholars Program? Representing nearly the nearly 25 years of Christian bioethical reflection, resources include books and booklets produced by the Center, as well as several by our friends and close affiliates. With nearly two dozen kits sent to recipients on five continents over the past few years, the Center continues to seek ways to expand this initiative. To recommend an institution or request a kit for your institution, please contact us at [research@cbhd.org](mailto:research@cbhd.org).

## MEDIA RESOURCES

-  CBHD.org on Twitter: @bioethicscenter
-  Bioethics.com on Twitter: @bioethicsdotcom
-  Everydaybioethics.org on Twitter: @edbioethics
-  *The Bioethics Podcast* at [thebioethicspodcast.com](http://thebioethicspodcast.com)
-  Facebook page at [facebook.com/bioethicscenter](https://facebook.com/bioethicscenter)
-  LinkedIn page at [linked.in/thecbhd](https://linked.in/thecbhd)
-  YouTube channel at [youtube.com/bioethicscenter](https://youtube.com/bioethicscenter)
-  The Christian BioWiki [christianbiowiki.org](https://christianbiowiki.org)

## STAFF

### PAIGE CUNNINGHAM, JD, PHD

- In June, taught the Intensive Bioethics Summer Institute.
- In July, discussed ethical issues surrounding the Charlie Gard case on "Chris Fabry Live" (Moody Radio).
- In August, discussed ethical issues regarding the successful editing of the genes of an embryo through CRISPR to eliminate a heart condition on "Let's Talk with Mark Elfstrand" and in a World Radio interview.

### MICHAEL SLEASMAN, PHD

- In June, taught the Advanced Bioethics Summer Institute, and guest-lectured in several other bioethics courses leading up to CBHD's summer conference.
- Presented "Analyzing Attitudes and Use of Cognitive Enhancement among Christian College Students: A Preliminary Study" as a parallel paper presentation at CBHD's summer conference.

### MICHAEL COX, PHD (CAND.)

- Presented "From Life-Ethic to Bioethics: A Paradigmatic Approach to Deuteronomy"

as a parallel paper presentation at CBHD's summer conference.

### HEATHER ZEIGER, MA

- Presented "Media Coverage of the Zika Virus: The Ethics of Reporting on Diseases" as a parallel paper presentation at CBHD's summer conference.
- In August published "Silicon Valley's Creepy Obsession with Longevity" on MercatorNet.
- In August, published an update on haploid stem cells on Bioethics.com.

### BRYAN JUST

- Presented "The Ante-Nicene Fathers on Abortion: Contrasts to the Prevailing Greek, Roman, and Jewish Cultures" as a parallel paper presentation at CBHD's summer conference.

### LINDSAY CALLAWAY, MA

- Presented "Are Reproductive Technologies Good for Women? Insights from Feminist Theological Anthropology" as a parallel paper presentation at CBHD's summer conference.

## ON THE CBHD BOOKSHELF

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

On the Bookshelf:

- Bennett, Gaymon. *Technicians of Human Dignity: Bodies, Souls, and the Making of Intrinsic Worth*. (Fordham University Press, 2015).
- Buxhoeveden, Daniel, and Gayle Woloschak, eds. *Science and the Eastern Orthodox Church*. (Routledge, 2016).
- Cahill, Lisa, and Margaret Farley, eds. *Embodiment, Morality, and Medicine*. (Kluwer Academic Publishers, 1995).
- Cameron, Nigel M. de S. *Will Robots Take Your Job? A Plea for Consensus*. (Polity, 2017).
- Copan, Paul, Tremper Longman, Christopher Reese, and Michael Strauss, eds. *Dictionary of Christianity and Science: The Definitive Reference for the Intersection of Christian Faith and Contemporary Science*. (Zondervan, 2017).
- Dyer, John. *From the Garden to the City: The Redeeming and Corrupting Power of Technology*. (Kregel, 2011).
- Goldberg, Ken, ed. *The Robot in the Garden: Telerobotics and Telepresence in the Age of the Internet*. (MIT Press, 2001).
- Goodman, Kenneth. *Ethics, Medicine, and Information Technology: Intelligent Machines and the Transformation of Health Care*. (Cambridge University Press, 2015).
- Gordijn, Bert. *Medical Utopias: Ethical Reflections about Emerging Medical Technologies*. (Peeters, 2005).
- Hauskeller, Michael, Thomas Philbeck, and Curtis Carbonell, eds. *The Palgrave Handbook of Posthumanism in Film and Television*. (Palgrave Macmillan, 2015).
- Hayler, Matt. *Challenging the Phenomena of Technology: Embodiment, Expertise, and Evolved Knowledge*. (Palgrave Macmillan, 2015).
- Hayles, N. Katherine. *How We Think: Digital Media and Contemporary Technogenesis*. (University of Chicago Press, 2012).
- Hurlbut, J. Benjamin. *Experiments in Democracy: Human Embryo Research and the Politics of Bioethics*. (Columbia University Press, 2017).

## COMING SOON: CONTEMPORARY ISSUES IN REPRODUCTIVE TECHNOLOGY