

## Judging Bioethics and Human Rights

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### I INTRODUCTION

Bioethics is, without doubt, the premier mode of governing the biomedical and human life sciences and their technologies: sciences that “have ethics”<sup>1</sup> are widely lauded as good sciences – the epitome of responsible research and innovation. But international human rights law and practice also has something to say about science and technology, and about bioethics. There is, for instance, a European Convention on Human Rights and Biomedicine, which has a preamble invoking “the need for international cooperation so that all humanity may enjoy the benefits of biology and medicine,” as well as a range of protocols on matters such as biomedical research, human cloning, and genetic testing.<sup>2</sup> There is also a Universal Declaration on Bioethics and Human Rights,<sup>3</sup> which is part of a series of UNESCO initiatives on science, technology, and rights.<sup>4</sup> And recently, the UN Special Rapporteur on cultural rights expressed the view that it is “essential” for the ethics codes of professional scientific organizations to be “explicitly informed by human rights.”<sup>5</sup>

<sup>1</sup> C. Thompson, *Good Science: The Ethical Choreography of Stem Cell Research* (Cambridge, MA: MIT Press, 2013), p. 25.

<sup>2</sup> Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Convention on Human Rights and Biomedicine, as amended) (Oviedo Convention), opened for signature April 4, 1997, entered in force January 12, 1999, ETS 164, Art. 28.

<sup>3</sup> UNESCO Universal Declaration on Bioethics and Human Rights (adopted by acclamation on October 19, 2005, by the General Conference). For commentary, see, e.g., H. A. M. J. ten Have and M. S. Jean (eds.), *The UNESCO Universal Declaration on Bioethics and Human Rights* (Paris: UNESCO, 2009).

<sup>4</sup> See, e.g., UNESCO International Declaration on Human Genetic Data (adopted by acclamation on October 16, 2003, by the General Conference); Universal Declaration on the Human Genome and Human Rights (adopted by acclamation on November 11, 1997, by the General Conference, and endorsed by the UN General Assembly in 1998).

<sup>5</sup> *Report of the Special Rapporteur in the Field of Cultural Rights, Farida Shaheed*, ¶ 53, U.N. Doc. A/HRC/20/26 (May 14, 2012).

For me, the coexistence of bioethics and international human rights law and practice in governing the biomedical and life sciences and their technologies gives rise to two questions. First, how do bioethics and bioethicists see human rights in general, and international human rights law in particular? Second, how do human rights, and international human rights lawyers in particular, see bioethics? These questions, to be clear, are not about turf war or about acclaiming interdisciplinarity. They are about starting over, about engaging in fresh conversation between fields that have a history of shared interests but little in the way of mutual understanding.

Fresh conversation is made easier by fresh content. In this chapter, I suggest international human rights case law as a source of such content. I see its appeal as twofold. First, human rights case law focuses us on what “is,” obliging us to look at how the legal and the ethical are figured in judicial practice. Second, it is less likely to alienate than either philosophy, on the one hand, or stronger forms of legalism, on the other.

To develop these claims, I focus on an institution that has been described as “the conscience of Europe,”<sup>6</sup> the European Court of Human Rights. This court hears allegations of violations of the European Convention on Human Rights (ECHR), the “jewel in the crown” of international human rights law.<sup>7</sup> Its decisions bind contracting states, and its views tend to be cited both by other international human rights courts and quasi-courts and by national courts within and beyond Europe. It operates with a doctrine of deference to state decision-making in certain circumstances, which can irritate some who are purist about human rights, but appeals to others as an appropriate way to recognize that universal values are instantiated in specific local contexts.

Taking my lead from bioethics’ longstanding interest in both the start of life and biotechnology, I examine the court’s case law on assisted reproductive technologies (ARTs)<sup>8</sup> – a total of six cases, four of which include a judgment from the Grand Chamber of the court. The cases range across the technologies of assisted insemination (AI), *in vitro* fertilization (IVF), and pre-implantation genetic diagnosis (PGD),<sup>9</sup> and they focus primarily on limits and prohibitions on access to ARTs.

<sup>6</sup> Council of Europe, *The Conscience of Europe: 50 Years of the European Court of Human Rights* (London: Third Millennium Publishing, 2010).

<sup>7</sup> Convention for Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended), adopted November 4, 1950, entered into force September 3, 1953, ETS 5.

<sup>8</sup> For a science and technology studies reading of several of these cases, see T. Murphy and G. Ó Cuinn, “Taking Technology Seriously: STS as a Human Rights Method,” in M. Flear et al. (eds.), *European Law and New Health Technologies* (Oxford: Oxford University Press, 2013), pp. 285–308.

<sup>9</sup> AI is the process whereby sperm from a partner or a donor is placed inside a woman’s uterus; IVF is the process of fertilizing an egg, or eggs, outside the human body; PGD is a process used alongside IVF, whereby diagnostic testing is performed on an embryo to determine if it has inherited a serious genetic condition.

In *Evans v. United Kingdom*, the first of the cases, the applicant sought access to embryos that were her only chance of having a child to whom she would be genetically related.<sup>10</sup> The embryos had been created using her eggs and the sperm of her then-fiancé before she underwent treatment for ovarian cancer. When the couple separated, he withdrew permission for use or continued storage of the embryos, and under the law in the United Kingdom, this meant the embryos would have to be destroyed. The next case, *Dickson v. United Kingdom*, involved a married male prisoner serving a life term and his female partner, who challenged a refusal to allow them to access AI, which was their only option if they were to try for a genetically related child.<sup>11</sup> Next, in *S.H. and Others v. Austria*, two married heterosexual couples challenged a legislative ban on IVF with donor gametes.<sup>12</sup> In *Costa and Pavan v. Italy*, a married heterosexual couple who carried a serious inheritable genetic condition challenged a blanket ban on PGD.<sup>13</sup> In *Knecht v. Romania*, a woman complained *inter alia* of the refusal by medical authorities to allow her to transfer her embryos from the location where they were being stored to a clinic of her choice.<sup>14</sup> Finally, in the most recent case, *Parrillo v. Italy*, a woman who no longer wanted to use IVF embryos for reproductive purposes following the unexpected death of her male partner brought a challenge to a legislative ban on donating embryos to scientific research.<sup>15</sup>

So what am I aiming to do by looking at these six cases? Overall, the chapter is more exploratory and exhortatory than normative, which makes it unusual as a piece of legal scholarship. I am stepping back from what the law “ought to be” in order to encourage the fresh conversation that I want to see take place between bioethics and international human rights law and practice. To be openly and actively normative could encourage hubris – a sense that international human rights law and practice “does it better” than bioethics. It would almost certainly encourage allegations of hubris – a sense that international human rights lawyers think they and their field are the best. As we shall see, the relationships between bioethicists and international human rights lawyers are complicated enough; to focus on what a human rights-based approach to ART “ought to be” would only add to the trouble and hinder conversation.

I use the ART cases to address two questions. First, does the European Court of Human Rights have a view on how bioethics relates to international human rights law? Second, do the cases offer food for thought, not just for human rights lawyers,

<sup>10</sup> *Evans v. United Kingdom*, Eur. Ct. H.R., App. No. 6339/05 (Grand Chamber, April 10, 2007).

<sup>11</sup> *Dickson v. United Kingdom*, Eur. Ct. H.R., App. No. 44362/04 (Grand Chamber, December 4, 2007).

<sup>12</sup> *S.H. and Others v. Austria*, Eur. Ct. H.R., App. No. 57813/00 (Grand Chamber, November 3, 2011).

<sup>13</sup> *Costa and Pavan v. Italy*, Eur. Ct. H.R., App. No. 54270/10 (August 28, 2012).

<sup>14</sup> *Knecht v. Romania*, Eur. Ct. H.R., App. No. 10048/10 (October 2, 2012).

<sup>15</sup> *Parrillo v. Italy*, Eur. Ct. H.R., App. No. 464470/11 (Grand Chamber, August 27, 2015).

but for bioethicists too? Above all, do they incite us to think about the place of international human rights law in the space of bioethics, and the place of bioethics in the space of international human rights law?<sup>16</sup> These latter questions can, of course, be addressed in other ways as well. For instance, as Lea Shaver demonstrates in Chapter 2, we could concentrate on the right to science, framing any problematic application of technology as an “experiment” and foregrounding ways in which particular bioethics principles could be incorporated into human rights law and practice, and technological design and implementation, in order to prevent or mitigate harm.

This chapter, by contrast, begins by offering a short account of interactions to date between bioethics and international human rights law and practice. It describes the lack of interest displayed by the latter, and the harsh, persistent complaints concerning human rights that come from the former. The next sections offer an introduction to the ART cases. They explore the court’s descriptions of the technologies involved and the issues to be addressed. They also examine the court’s account of good lawmaking in this field (including how it sees its own role). I also consider the extent to which the court has broached the relationship between the legal and the bioethical. The last section provides a conclusion.

## II ENTWINING AND ESTRANGING: A SHORT HISTORY OF THE RELATIONSHIP BETWEEN BIOETHICS AND INTERNATIONAL HUMAN RIGHTS LAW AND PRACTICE

In this section, I sketch how bioethics and international human rights law and practice view each other, and how they are viewed by critics. I want, in particular, to look at how the two domains have both entwined and estranged. To do this, I begin with bioethics, the word itself coming from two Greek words, *bios* (life) and *ethos* (values or morality), and used today in multiple registers. It is difficult to parse these registers, so my plan is to focus on the principal ones – namely, bioethics as an intellectual field and as a governance practice.<sup>17</sup>

I know that immediately some will insist that bioethics is not a field, but a discipline or set of disciplines, an expert domain, or a topic. I am no expert, but I suspect that diverse national histories and diverse priorities for the future of bioethics make it important to accommodate a range of terms. However, because I need to move forward, my hope is that even if the idea of bioethics as a field is controversial, there will be common ground on the following: first, bioethics has an interdisciplinary character; second, philosophy, law, and medicine have been key contributors to that

<sup>16</sup> Adapted from S. S. Silbey and P. Ewick, “The Architecture of Authority: The Place of Law in the Space of Science,” in A. Sarat, L. Douglas, and M. Umphrey (eds.), *The Place of Law* (Ann Arbor: University of Michigan Press, 2003), pp. 75–108.

<sup>17</sup> See the incisive account in J. Montgomery, “Bioethics as a Governance Practice” (2016) 24 *Health Care Analysis* 3–23.

interdisciplinary character; third, bioethics has had a longstanding focus on patients and research participants; and fourth, more recently, it has been focusing on technology, in particular technologies of human reproduction and enhancement.<sup>18</sup>

As to the second register, which I have labeled “bioethics as a governance practice,” here too it might be best to acknowledge that contemporary bioethics hosts a range of such practices,<sup>19</sup> including the ethics committees of hospitals and research institutions. But my particular interest is “public ethics,”<sup>20</sup> by which I mean the practices of political or advisory bodies on bioethics. These bodies may be appointed by one state acting alone or by a group of states; they can also be independent of the state. The United Kingdom’s Nuffield Council on Bioethics is one example of the sort of body I have in mind; the Council of Europe’s Committee on Bioethics is another. Other examples include the Deutscher Ethikrat (Germany’s National Ethics Council), the US Presidential Commission for the Study of Bioethical Issues, the Comitato Nazionale per la Bioetica (Italy’s National Bioethics Committee), UNESCO’s International Bioethics Committee, and the European Commission’s European Group on Ethics in Science and New Technologies.<sup>21</sup>

Interestingly, what I have just said about bioethics could also be said of international human rights law and practice. The latter, in other words, is both an intellectual field and a range of governance practices, with mechanisms and institutions ranging from courts and quasi-courts to the UN Special Procedures.<sup>22</sup> There are other parallels, too. There is, for instance, a range of resonant preoccupations, including “the vulnerable human subject,” dignity, autonomy, and relatedly the requirement for informed consent prior to treatment. There are also stories of shared origins. Typically, this includes the Doctors’ Trial in Nuremberg in the aftermath of World War II, but there are also country-specific accounts that emphasize particular braidings of bioethics and rights; in the United States, for instance, some commentators point to the significance of the civil rights era for both fields.<sup>23</sup>

<sup>18</sup> For a sense of the field, see, e.g., H. Kuhse and P. Singer (eds.), *Bioethics: An Anthology* (Oxford: Blackwell, 1999); B. Steinbock (ed.), *The Oxford Handbook of Bioethics* (Oxford: Oxford University Press, 2007). Both public and global health have become prominent in recent years, and climate change is the focus of at least one recent book: C. C. Macpherson (ed.), *Bioethical Insights into Values and Policy: Climate Change and Health* (Basel: Springer, 2016).

<sup>19</sup> See Montgomery, “Bioethics as a Governance Practice.”

<sup>20</sup> See J. Montgomery, “Reflections on the Nature of Public Ethics” (2013) 22 *Cambridge Quarterly of Healthcare Ethics* 9–21 (contrasting ethical deliberation in the academy with its counterpart in the public domain).

<sup>21</sup> For a more complete list, it would be important to add the ad hoc groupings that tend to be convened in the wake of scandal or of growing public concern about a specific aspect of medicine, science, or technology.

<sup>22</sup> See generally A. Nolan, R. Freedman, and T. Murphy (eds.), *The UN Special Procedures System* (Antwerp: Brill, 2017).

<sup>23</sup> See, e.g., D. J. Rothman, “The Origins and Consequences of Patient Autonomy: A 25 Year Retrospective” (2001) 9 *Health Care Analysis* 255–64.

In a further parallel, both bioethics and international human rights law and practice seem rife with insider and outsider criticism. The critics of international human rights law and practice typically denounce it as both hegemonic and replete with out-of-date and inappropriate ideas and techniques. Meanwhile, the critics of bioethics accuse it of becoming “institutionalized ethics,” both too focused on conforming to standardized rules and regulations (and too keen to wrap diverse settings and states in a timeless, placeless, one-size-fits-all “global bioethics”) and too quick to endorse and promote technology’s promised utopias.<sup>24</sup>

What’s more, bioethics and international human rights law and practice have faced some similar criticisms. In particular, each has been accused of neglecting lived experience and structural injustice, and of overemphasizing freedom, autonomy, and consent and, more broadly, principles-based reasoning.<sup>25</sup> Typically, the most trenchant critics of each field are blunt about what needs to happen: bioethics (and, equally, international human rights law and practice) should “get out of the way.” For some of these critics, “progress” is the preferred guide; for others, it is “justice.” To be fair, though, whether we are talking about bioethics or international human rights law and practice, a majority of critics argue for reform and reorientation rather than abandonment.

Parallels are, however, just part of the story; there is considerable contrast too. Thus, bioethicists have spent far more time criticizing and engaging with international human rights law and practice than vice versa.<sup>26</sup> And bioethicists, not surprisingly, are far more skeptical of law than their international human rights counterparts. There are plenty of bioethicists who are also highly skeptical of human rights. More broadly, as the American Association for the Advancement of Science has observed: “Human rights *per se* are often viewed as irrelevant to the practice of ethics.”<sup>27</sup> Why is that?

The lack of a convincing theory of human rights is the biggest stumbling block. It has become a particular irritant in the context of the international right to health, where bioethicists and philosophers line up to insist that neither law nor legal scholarship offers a way to make sense of this right in the context of limited resources.<sup>28</sup> Other stumbling blocks to bioethical engagement with rights include

<sup>24</sup> See, e.g., C. A. Heimer and J. Petty, “Bureaucratic Ethics: IRBs and the Legal Regulation of Human Subjects Research” (2010) 6 *Annual Review of Law and Social Science* 601–26.

<sup>25</sup> See, e.g., P. Farmer and N. G. Campos, “New Malaise: Bioethics and Human Rights in the Global Era” (2004) 32 *Journal of Law, Medicine and Ethics* 243–51.

<sup>26</sup> For a concise, engaging account of responses to the UNESCO Declaration on Bioethics and Human Rights, see R. Ashcroft, “The Troubled Relationship between Bioethics and Human Rights,” in M. D. A. Freeman (ed.), *Law and Bioethics* (Oxford: Oxford University Press, 2008), pp. 31–51.

<sup>27</sup> American Association for the Advancement of Science, Science and Human Rights Coalition, *Intersections of Science, Ethics and Human Rights: The Question of Human Subjects Protection: Report of the Science Ethics and Human Rights Working Group* (February 2012) p. 2.

<sup>28</sup> See, e.g., J. P. Ruger, *Health and Social Justice* (Oxford: Oxford University Press, 2010).

the advocacy and activist orientation of international human rights law and practice, and its substantial focus on the state. There are also some bioethicists who would take the “human” out of human rights, either because they prefer to focus on “persons,” or because they see human rights as an obstacle to enhancement technology’s promise of “post-humans.”<sup>29</sup> Others, focused on the doctor–patient relationship, believe that human rights law risks denuding medical ethics of its capacity to be the “soul of medicine.”<sup>30</sup>

Thus, despite the fact that bioethics has engaged with rights-based approaches in the process of broadening its own interests from the doctor–patient relationship and questions concerning new technologies, there is an overall sense that bioethicists do not see human rights as a legitimate form of analysis and reasoning. There is a sense, too, that for those who play a formal part in public ethics, consensus might be hard to achieve if all parties were to come to the table claiming “their rights.”

Another clear contrast is that philosophy is central to bioethics, whereas it is less common and less valued in international human rights law and practice. Equally, by contrast with bioethics, international human rights law and practice has had low levels of interest in ART.<sup>31</sup> As far as technology is concerned, advocates of human rights have tended to engage with information and communication technology (including how it can be used to expose human rights violations), and with the uptake of technology in the criminal justice sphere. And as regards reproduction, the central foci of international human rights advocacy have been safe motherhood, forced sterilization, and the vast unmet need for access to modern contraception and associated information and services.<sup>32</sup>

“Safe motherhood” requires engagement with abortion, but as the term itself indicates, the emphasis has been on unsafe abortion as a major public health concern, rather than competing rights claims. States have been encouraged to decriminalize abortion and to guarantee access to quality post-abortion care in order to reduce the high levels of maternal mortality and morbidity that stem from unsafe abortion. Rights arguments have been put aside in order to avoid conflict and dissent

<sup>29</sup> See, e.g., J. Harris, “Taking the Human out of Human Rights” (2011) 20 *Cambridge Quarterly of Healthcare Ethics* 9–20.

<sup>30</sup> See, e.g., J. Montgomery, “Law and the Demoralisation of Medicine” (2006) 26 *Legal Studies* 185–210.

<sup>31</sup> If we take case law as a measure of interest, apart from the six ECHR cases, there is just one further case: *Artavia Murillo et al. (“In Vitro Fertilization”) v. Costa Rica*, Judgement, Inter-Am. Ct. H.R. (ser. C) No. 257 (November 28, 2012), a decision of the Inter-American Court in which Costa Rica’s complete ban on IVF was held to be contrary to the American Convention on Human Rights.

<sup>32</sup> A shift may be under way. See UN Committee on Economic, Social and Cultural Rights, *General Comment no. 22 on the Right to Sexual and Reproductive Health (art. 12)*, U.N. Doc. E/C.12/GC/22, ¶ 21 (May 2, 2016) (“The failure or refusal to incorporate technological advances and innovations in the provision of sexual and reproductive health services, such as medication for abortion, assisted reproductive technologies and advances in the treatment of HIV and AIDS, jeopardizes the quality of care.”).

that could stall state action and leave pregnant women at risk of injury and death. Relatedly, when asked to adjudicate upon state practice with respect to abortion, international courts (including the European Court of Human Rights) have avoided definitive statements on the status of the fetus. Their principal focus has been whether states, where abortion is lawful in at least some circumstances, have taken steps to ensure that abortion on these grounds is available in practice.<sup>33</sup>

### III A POOR PERCH? INTRODUCING THE ART CASES FROM THE EUROPEAN COURT OF HUMAN RIGHTS

The aim of this section, and the two that follow, is to explore the extent to which the six ART cases from the European Court of Human Rights can open up conversation between bioethicists and international human rights lawyers. The conversation could simply be about the regulation of ART, or it could be about the broader question of the optimum relationship between the legal and the ethical in regulation of the life sciences and their technologies – in particular, the relationship between human rights-based approaches to science and sciences that “have ethics.”

On first reading, the cases lack promise in that none of them makes explicit reference to bioethics.<sup>34</sup> There is also little by way of general comment on ART and human rights, and the technological dimensions of assisted reproduction seem to be under the radar too. Thus, IVF is described as a “fast-moving” technology, “subject to particularly dynamic development in science.” And its use is said to raise “sensitive moral and ethical issues.”<sup>35</sup> Overall, however, the cases lack the level of engagement one finds in cases from other fields of technology, notably *S and Marper v. United Kingdom*, in which the court issued a warning that any uptake of technologies in the criminal justice sphere must not “unacceptably weaken” the right to respect for private life, family, home, and correspondence in Article 8 of the ECHR.<sup>36</sup>

The judges also seem to be inconsistent in how they understand the technology involved, with some evidence that different labels align with different levels of scrutiny of state practice. In *S.H.*, which involved an unsuccessful challenge to

<sup>33</sup> See, e.g., *Karen Noelia Llantoy Huamán v. Peru*, U.N. Doc. CCPR/C/85/D/1153/2003 (Nov. 22, 2005); *Tysiąc v. Poland*, Eur. Ct. H.R., App. No. 5410/03 (March 20, 2007); *R.R. v. Poland*, Eur. Ct. H.R., App. No. 27617/04 (May 26, 2011).

<sup>34</sup> Interestingly, the court’s research division produced a report that collects and classifies what it describes as the court’s bioethics cases. See Research Division, “Bioethics and the case-law of the Court” (2009, updated 2012), [www.coe.int/t/dg3/healthbioethic/texts\\_and\\_documents/Bioethics\\_and\\_caselaw\\_Court\\_EN.pdf](http://www.coe.int/t/dg3/healthbioethic/texts_and_documents/Bioethics_and_caselaw_Court_EN.pdf).

<sup>35</sup> See, e.g., *Evans*, ¶ 81; *Parrillo*, ¶¶ 169, 174.

<sup>36</sup> *S and Marper v. United Kingdom*, Eur. Ct. H.R., App. Nos. 30562/04 and 30566/04 (Grand Chamber, December 4, 2008) ¶ 112; see also T. Murphy and G. Ó Cuinn, “Works in Progress: New Technologies and the European Court of Human Rights” (2010) 10 *Human Rights Law Review* 601–38.

Austria's ban on IVF using donor gametes, the joint dissenting opinion spoke exclusively of "medically assisted procreation,"<sup>37</sup> thereby framing ART as medical, not technological, and as an ordinary, understandable way of "assisting nature." The majority, by contrast, used the phrase "artificial procreation," taking its lead from the title of the law in the respondent state.

Overall, the cases display little depth or range. They indicate that the right to respect for private life encompasses the right to respect for the decision to become or not to become a parent, including in the genetic sense.<sup>38</sup> The right of a couple to conceive a child and to make use of medically assisted reproduction for that purpose is protected as an "expression of private and family life."<sup>39</sup> But this barely scratches the surface of the issues that arise. Relatedly, there is no sense of engagement across "different worlds of lived experience" of ART – engagement of the sort that is standard in fields like anthropology and sociology.<sup>40</sup> The court, of course, does not review legislation or practice in the abstract; it focuses on examining the issues raised by the case before it.<sup>41</sup> Nonetheless, there is a sense of missing context and problematic assumptions.

In *S.H.*, for instance, the majority spent a good part of its judgment looking at claims made by the respondent state as to the risks of permitting IVF with donor eggs. But then, with no discussion of whether the context was the same or not, it took its reasoning on this matter and applied it to donor sperm.

Similarly, in *Evans*, in which the applicant unsuccessfully sought access to six embryos that were her only chance of having a child to whom she would be genetically related, the court made no reference to the differing levels of sophistication of egg and sperm freezing – even though the opportunity to freeze eggs, rather than embryos created with her then-fiancé's sperm, would have avoided the difficulties that followed when their relationship broke down and he withdrew his consent to the storage or use of the embryos. The *Evans* court also made no reference to the requirement in domestic law (since amended) that treatment providers take account of the child's "need for a father," a requirement that could well have blocked the applicant's access to treatment if she had asked to use donor sperm to fertilize her eggs, rather than the sperm of her then-fiancé.

<sup>37</sup> *S.H. and Others*, joint dissenting opinion of Judges Tulkens, Hirvelä, Lazarova Trajkovska, and Tsotsoria.

<sup>38</sup> See, e.g., *Evans*, ¶ 71.

<sup>39</sup> *S.H. and Others*, ¶ 82; *Dickson*, ¶ 66.

<sup>40</sup> See, e.g., C. Thompson, *Making Parents: The Ontological Choreography of Reproductive Technologies* (Cambridge, MA: MIT Press, 2005); S. Franklin and C. Roberts, *Born and Made: An Ethnography of Preimplantation Genetic Diagnosis* (Princeton, NJ: Princeton University Press, 2006); S. Franklin and M. C. Inhorn (eds.), "Symposium: IVF – Global Histories" (2016) 2 *Reproductive Biomedicine & Society Online* 1–136. From a legal perspective, see K. Löhmus, *Caring Autonomy: European Human Rights Law and the Challenge of Individualism* (Cambridge: Cambridge University Press, 2015).

<sup>41</sup> See, e.g., *S.H. and Others*, ¶ 92; *Knecht*, ¶ 59.

The more recent decisions are just as frustrating. In *Costa and Pavan*, the applicants, who were carriers of cystic fibrosis, succeeded in their challenge to Italy's blanket ban on PGD. Crucial to the court's decision was the fact that Italian law was inconsistent: the law banned PGD (which allows the identification of genetic abnormalities in embryos created via IVF), but allowed abortion on grounds of fetal malformation. Under Italian law, in other words, the applicants could commence a pregnancy, take a prenatal genetic test, and request an abortion if the test suggested a malformation, but they could not have their embryos screened prior to implantation. For the court, it was entirely wrong that the applicants were put in such a position.

It is, I think, easy to empathize with the court on this, but where I have less empathy is the court's limited engagement with PGD. The court focused exclusively on the inconsistency of Italian law, making no real comment on PGD from a rights perspective. It did note that the applicants had not complained of a violation of a "right to have a healthy child." The applicants were, it said, relying on a more "confined" right, namely, "the possibility of using ART and subsequently PGD for the purposes of conceiving a child unaffected by cystic fibrosis, a genetic disease of which they are healthy carriers."<sup>42</sup> It also referred to the applicants' "desire" to conceive a child unaffected by cystic fibrosis, and to use ART and PGD to this end, as a "choice" that was "a form of expression of their private and family life" and thus within the scope of Article 8 of the ECHR.<sup>43</sup>

This leaves open many questions regarding both discrimination and choice. On different facts, would the court see PGD not as an ART but as a "selective reproductive technology"; i.e., a technology that is not only about overcoming infertility, but also "used to prevent or allow the birth of certain kinds of children"?<sup>44</sup> Evidence suggests that, in places, PGD is being used to select against sex and against disabilities, which compounds powerful prior practices of discrimination. The question that arises is: What would be a human rights-based approach to PGD?

PGD, and ART more broadly, also raise questions concerning choice and its companion, informed consent. How, for instance, would the European Court of Human Rights respond to ethnographic evidence that reproductive responsibility, rather than reproductive choice, can weigh heavily on would-be parents, leading some (who have given consent in the manner expected and promoted by international human rights law) to say they felt they had "no choice" but to use PGD?<sup>45</sup>

<sup>42</sup> *Costa and Pavan*, ¶ 53–54 (emphasis added).

<sup>43</sup> *Ibid.*, ¶ 57 (emphasis added).

<sup>44</sup> T. M. Gammeltoft and A. Wahlberg, "Selective Reproductive Technologies" (2014) 43 *Annual Review of Anthropology* 201–16 at 201.

<sup>45</sup> Franklin and Roberts, *Born and Made*; see generally I. Karpin and K. Savell, *Perfecting Pregnancy: Law, Disability, and the Future of Reproduction* (New York: Cambridge University Press, 2012); R. Mykitiuk and I. Karpin, "Fit or Fitting In: Deciding against Normal When Reproducing the Future" (2017) 31 *Continuum* 341–51.

These would-be parents seem to be reporting obligations, not options. Evidence also suggests that prenatal diagnostic tests are often undertaken without full knowledge of their implications and, above all, in the hope of reassurance, which leaves would-be parents ill-equipped for the “choices” that follow. Reading between the lines, it is clear that the court in *Costa and Pavan* saw the applicants as responsible would-be parents and Italian law as deeply irresponsible. That analysis, however, offers no guidance as to what would count as a human rights-based approach to technologies that encourage would-be parents to keep trying for a child and also offer increasing options for identifying, and eliminating, unwanted traits in any future children.

There are two other points. The first concerns what counts as an ART case; the second concerns the court’s position on the status of the human embryo. Those who follow the court’s case law may ask why my list of ART cases does not include decisions such as *Mennesson v. France*,<sup>46</sup> *Foulon and Bouvet v. France*,<sup>47</sup> and *Paradiso and Campanelli v. Italy*,<sup>48</sup> each of which involved a surrogate pregnancy facilitated by IVF. The question, in other words, is: Where does technology-enabled surrogacy fit in the court’s ART frame? My answer is that we need to wait and see, as the most recent decision, *Paradiso and Campanelli*, signals that several members of the court are deeply opposed to surrogacy and keen to limit the scope of Article 8 of the ECHR in this context.

The court’s focus in the surrogacy cases is narrow: it is looking only at the post-birth context, in particular at the steps that can legitimately be taken when a child has been born following an overseas surrogacy arrangement and the contracting state believes there has been a contravention of its domestic law.<sup>49</sup> But this did not constrain the four concurring judges in *Paradiso and Campanelli*, who expressed regret that the court had not taken a clear stance against surrogacy. Surrogacy, according to these judges, treats people “not as ends in themselves, but as means to satisfy the desires of other persons.” And, whether it is remunerated or not, “[it] is incompatible with human dignity. It constitutes degrading treatment, not only for the child but also for the surrogate mother.” It is, the judges conclude, incompatible with the values underlying the Convention.<sup>50</sup> This is a very strong stance. It does not, to be clear, represent the decision of the court. The decision does not rule on the compatibility of surrogacy with the Convention. It simply says that surrogacy

<sup>46</sup> *Mennesson v. France*, Eur. Ct. H.R., App. No. 65192/11 (June 26, 2014); see also *Labassee v. France*, Eur. Ct. H.R., App. No. 65941/11 (June 26, 2014).

<sup>47</sup> *Foulon and Bouvet v. France*, Eur. Ct. H.R., App. Nos. 9063/14 and 10410/14 (July 21, 2016).

<sup>48</sup> *Paradiso and Campanelli v. Italy*, Eur. Ct. H.R., App. No. 25358/12 (Grand Chamber, January 24, 2017).

<sup>49</sup> For a broader international human rights perspective on surrogacy, see J. Tobin, “To Prohibit or Permit: What Is the (Human) Rights Response to the Practice of International Commercial Surrogacy?” (2014) 63 *International and Comparative Law Quarterly* 317–52.

<sup>50</sup> *Paradiso and Campanelli*, concurring opinion of Judges De Gaetano, Pinto de Albuquerque, Wojtyczek, and Dedov, ¶ 7; see also the separate concurring opinion of Judge Dedov.

raises “sensitive ethical questions” on which there is no consensus amongst contracting states.<sup>51</sup> Hence my claim that we need to wait and see.

As to the status of the human embryo, by and large the court has sought to stay away from this issue, emphasizing that it is the state, not the court, that is the key decision-maker. But several of the ART cases suggest that this might not hold going forward. More importantly, the court could find itself in a tangle as it tries to steer clear of the question of personhood and when the right to life, protected in Article 2 of the ECHR, begins (which it sees as a question for states),<sup>52</sup> while also protecting women’s rights under the Convention and developing Article 8’s qualified right to respect for private and family life. The developing idea of human dignity could play a part too, given that the court has said that “the potentiality of [the embryo/fetus] and its capacity to become a person . . . require protection in the name of human dignity, without making it a ‘person’ with the ‘right to life’ for the purposes of Article 2.”<sup>53</sup>

In *Evans*, the court stated that “the embryos created by the applicant and [her ex-fiancé] [did] not have a right to life within the meaning of Article 2 of the Convention,”<sup>54</sup> a position described, in extreme terms, by a concurring judge in a later case as “the *Evans* anti-life principle.”<sup>55</sup> Then, in *Costa and Pavan*, the court said that “the concept of ‘child’ cannot be put in the same category as that of ‘embryo’,”<sup>56</sup> while also seeming to indicate that the status of the embryo falls within Article 8(2) of the ECHR, under which infringement of the right to respect for private and family life may be justified if necessary in a democratic society to protect the “rights and freedoms of others.”<sup>57</sup>

Most recently, in *Parrillo*, the majority made a range of similarly difficult-to-reconcile statements. On the one hand, and perhaps in line with *Costa and Pavan*, they framed the applicant’s embryos as “others”; on the other hand, they went on to say that they were not determining whether “others” extends to embryos.<sup>58</sup> In another difficult-to-interpret position, the majority said that “the embryos contain the genetic material of [the applicant] and accordingly represent a constituent part

<sup>51</sup> *Paradiso and Campanelli*, ¶ 203.

<sup>52</sup> See, e.g., *Vo v. France*, Eur. Ct. H.R., App. No. 53924/00 (Grand Chamber, July 8, 2004) at ¶¶ 82, 85. Art. 2 provides, *inter alia*, that “Everyone’s right to life shall be protected by law.” In *X v. United Kingdom*, No. 8416/79, Commission decision of May 13, 1980, Decisions and Reports (DR) 19, p. 244, the former Commission ruled out recognition of an absolute right to life of the fetus under art. 2 (at p. 252, ¶ 19).

<sup>53</sup> *Vo v. France*, ¶ 84. Immediately prior to this, the court noted that although there is no European consensus on the status of the embryo and/or fetus, “they are beginning to receive some protection in the light of scientific progress and the potential consequences of research into genetic engineering, medically assisted procreation or embryo experimentation.”

<sup>54</sup> *Evans*, ¶ 56.

<sup>55</sup> *Parrillo*, concurring opinion of Judge Pinto de Albuquerque, ¶ 31.

<sup>56</sup> *Costa and Pavan*, ¶ 62.

<sup>57</sup> *Ibid.*, ¶ 59 (emphasis added).

<sup>58</sup> *Parrillo*, ¶ 167; see also *Costa and Pavan*, ¶ 59.

of [her] genetic material and biological identity,” but also said that the applicant’s relationship with her embryos did “not concern a particularly important aspect of [her] existence and identity.”<sup>59</sup> It is hard to know why the majority made these clumsy statements. It seems the judges wanted to emphasize the importance of genetic material, while also ensuring that because the case was about the use of human embryos, the final decision would rest with the state, not the court.

*Parrillo* also featured a claim by the applicant to a property right over her embryos under Article 1 of the EHCR’s Protocol 1. This was dismissed with little consideration. The majority concluded on the point by noting that because Article 1 of Protocol 1 has an “economic and pecuniary scope,” human embryos cannot be reduced to “‘possessions’ within the meaning of that provision.”<sup>60</sup> The majority also noted that Article 2 was not at issue in the case, which meant that “the sensitive and controversial question of when human life begins”<sup>61</sup> did not have to be examined.

#### IV THE ETHICS OF THE MARGIN: HOW HAS THE COURT USED THE DOCTRINE OF THE MARGIN OF APPRECIATION IN ITS ART CASES?

The court’s particular identity is part of the reason it holds back from definitive statements on the status of the embryo and fetus: it is a supranational human rights institution, not a domestic one. To reflect this, the court has crafted what is called the doctrine of the margin of appreciation. The doctrine allows the court to control the amount of discretion it is willing to give to the contracting state against which a complaint of a rights violation has been levelled. Where the court declares that the margin should be wide, it takes a step back – in essence, positioning itself as the “international judge,” less well-placed than national authorities to be the central decision-maker on the issue at stake.<sup>62</sup>

For some, the granting of a wide margin of appreciation is a sign that the court is too keen to constrain itself and too quick to shelter the Convention from the dynamic or evolutive style of interpretation that could, they say, secure its status as a living instrument. Others take a different view: for them, the legitimacy problem stems from cases in which the court limited the margin accorded to the respondent state. These cases, they complain, are evidence of an international court acting like a

<sup>59</sup> *Parrillo*, ¶¶ 158 and 174, respectively.

<sup>60</sup> *Ibid.* See also the concurring opinion of Judge Pinto de Albuquerque at n. 32, describing the applicant’s property claim as inconsistent with her right-to-private-life claim.

<sup>61</sup> *Ibid.*, ¶ 215.

<sup>62</sup> See, e.g., *Evans*, ¶ 78 (recalling the words of Lord Bingham in the UK case *Quintavalle*: “Where . . . there is no consensus within the member States of the Council of Europe either as to the relative importance of the interest at stake or as to how best to protect it, the margin will be wider. This is particularly so where the case raises complex issues and choices of social strategy: the authorities’ direct knowledge of their society and its needs means that they are in principle better placed than the international judge to appreciate what is in the public interest.”); see also *Knecht*, ¶ 59.

constitutional court and involving itself in issues that are none of its business, issues that ought to be determined at the national level.<sup>63</sup>

For my purposes, the obvious question is: What would bioethicists think of the doctrine and its use-in-practice by the court? I anticipate strong views, given the debate about relativism versus universalism in bioethics. Four of the ART cases, *Evans, S.H. and Others*, *Knecht*, and *Parrillo*, involved the granting of a wide margin of appreciation to the states concerned. It appears there were two principal reasons for this: first, what the court saw as the absence of consensus within the member states of the Council of Europe on the issues raised (“either as to the relative importance of the interest at stake or as to the best means of protecting it”<sup>64</sup>), and second, and relatedly, the presence of “sensitive moral or ethical issues.”<sup>65</sup> In *Evans*, the court provided a third reason for greater deference: “There will usually be a wide margin of appreciation accorded if the State is required to strike a balance between competing private and public interests or Convention rights.”<sup>66</sup>

*Dickson*, by contrast, is a reminder that the court will restrict the margin accorded to a state “where a particularly important facet of an individual’s existence or identity is at stake.”<sup>67</sup> In *Dickson*, in which a prisoner and his wife successfully challenged the process by which they were refused access to AI facilities, the court indicated that “the choice to become a genetic parent” is one such facet of an individual’s existence and identity.<sup>68</sup>

In *S.H. and Others*, however, this was not enough to assist the applicants; their challenge to Austria’s ban on using donor gametes for IVF was rejected by the court. In rejecting their challenge, the court mentioned, *inter alia*, their option to seek assisted reproduction abroad and have parenthood recognized at home.<sup>69</sup> Relatedly, in *Parrillo*, having described the applicant’s cryopreserved embryos as a “constituent part of [her] identity,” a majority of the court later justified the granting of a wide margin of appreciation in part by drawing a distinction between the case before it and cases concerning “prospective parenthood.” The majority’s position was that

<sup>63</sup> For discussion, see M. K. Land, “Justice as Legitimacy in the European Court of Human Rights,” in H. Cohen et al. (eds.), *Legitimacy and International Courts* (New York: Cambridge University Press, forthcoming); A. Legg, *The Margin of Appreciation in International Human Rights Law: Deference and Proportionality* (Oxford: Oxford University Press, 2012); G. Letsas, “The ECHR as a Living Instrument: Its Meaning and Legitimacy,” in A. Føllesdal, B. Peters, and G. Ulfstein (eds.), *Constituting Europe: The European Court of Human Rights in a National, European and Global Context* (Cambridge: Cambridge University Press, 2013), pp. 106–41.

<sup>64</sup> *Parrillo*, ¶ 169.

<sup>65</sup> *Evans*, ¶ 81 (noting also that these issues arise “against a background of fast moving medical and scientific developments”); see also *S.H. and Others*, ¶ 94; *Knecht*, ¶ 59; *Parrillo*, ¶¶ 169, 174.

<sup>66</sup> *Evans*, ¶ 77.

<sup>67</sup> *Ibid.*

<sup>68</sup> *Dickson*, ¶ 78.

<sup>69</sup> See below text at nn. 90–93.

although the right to donate embryos to scientific research was “important,” it was not “one of the core rights attracting the protection of Article 8 of the Convention as it does not concern a particularly important aspect of the applicant’s existence and identity.”<sup>70</sup>

When the court grants a wide margin of appreciation, it does not abdicate all power and responsibility to the respondent state. As the court explained in *Costa and Pavan*, “the solutions reached by the legislature are not beyond the scrutiny of the Court.”<sup>71</sup> In conducting this scrutiny, the court tends to focus on the lawmaking process and whether the impugned law strikes a “fair balance” between all competing private and public interests.<sup>72</sup>

But the judges do not always agree on what is required, and there have been strongly worded dissenting opinions that accuse the majority of using the margin of appreciation in a formal or mechanical way – i.e., granting deference but without the companion scrutiny that would weigh the state’s arguments, evidence, and expertise. In *Evans*, for instance, the joint dissenting opinion cautioned that the doctrine must not be used by the court “as a merely pragmatic substitute for a thought-out approach to the problem of proper scope of review.”<sup>73</sup> Furthermore, none of the ART cases provides an explanation of the category of “sensitive moral and ethical issues” that will trigger a wide margin of appreciation. This leaves a range of questions. How does the court see the relationship between “moral” issues and “ethical” ones – are the terms synonymous? What is the significance of the adjective “sensitive” (or “delicate,” another qualifier used by the court)? And in what circumstances is there “acute sensitivity” or “profound moral views” (both of which were used by the court to justify a wide margin of appreciation in *A, B and C v. Ireland*, which involved a challenge to a restrictive abortion law)?<sup>74</sup>

Those interested in debates concerning universalism versus relativism will want to pay particular attention to the “European consensus,” another determining factor with respect to the degree of deference the court is willing to accord to contracting states. The “emerging European consensus” is more interesting still. It featured in *S.H. and Others*, in which the court made reference to “a clear trend in the legislation of the Contracting States towards allowing gamete donation for the purpose of *in vitro* fertilisation.”<sup>75</sup> Ultimately, the trend was not used by the court to limit the wide margin of appreciation granted to the respondent state; it was not based on “settled and long-standing principles established in the law of the member

<sup>70</sup> *Parrillo*, ¶ 174; see also the concurring opinion of Judge Pinto de Albuquerque, ¶ 34.

<sup>71</sup> *Costa and Pavan*, ¶ 68; see also *S.H. and Others*, ¶ 97.

<sup>72</sup> See, e.g., *S.H. and Others*, ¶ 100.

<sup>73</sup> *Evans*, joint dissenting opinion, ¶ 12; see also *Paradiso and Campanelli*, concurring opinion of Judge Dedov: “For the first time when ruling in favour of the respondent State the Court has placed greater emphasis on values than on the formal margin of appreciation.”

<sup>74</sup> *A, B and C v. Ireland*, Eur. Ct. H.R., App. No. 25579/05 (Grand Chamber, December 16, 2010).

<sup>75</sup> *S.H. and Others*, ¶ 96.

States,” but rather reflected “a stage of development within a particularly dynamic field of law.”<sup>76</sup> Nonetheless, the idea of the emerging consensus as a signaling tool – a shot across the (state) bow, a sign that the future could be different – is intriguing.

One final point about the emerging consensus and its counterpart, the European consensus: both concentrate the court’s attention on collectives. Notice that this also can be said of the court’s increasing reference to international instruments (which may not have been ratified by all contracting states) and to the evolution of societal thinking. So my question would be: How is this attention to collectives seen by those who criticize international human rights law and practice for being obsessed with the individual and the universal and with crude, decontextualized norms? Bioethicists feature heavily among those critics, so this would be one obvious opportunity for fresh content to stimulate fresh conversation.

#### V LAW’S CAPACITIES: DOES THE COURT HAVE FAITH IN LAW AND LAWMAKING ON ART?

I turn finally to the question of whether the court has expressed a view on what counts as good law and good lawmaking in the field of ART. As I see it, any such views would contribute to my hoped-for conversation between bioethicists and international human rights lawyers.<sup>77</sup> For instance, does the court share bioethicists’ enthusiasm for processes or procedures of decision-making? Equally, does it share the view of some bioethicists that law is a way of capping off bioethical consensus, a way of “putting [bioethics’] words and ideas into practice”?<sup>78</sup> Or does it, by contrast, prefer the negative view offered by others, that law generally gets in the way of both scientific progress and decent ethical argument?<sup>79</sup> Relatedly, does the court itself see law expansively, or is there a closing down of law’s forms and capacities – a sense that in the end, law talk is about bans, moratoria, and limits of other sorts? Finally, to what extent does the court endorse the popular view that while law might be “marching alongside” medicine, science, and technology, it is “always in the rear and limping a little”?<sup>80</sup>

The ART cases do not provide much explicit detail on the court’s views about what counts as good law and good lawmaking in the field of ART. In part the reason for this is that the wide margin of appreciation granted in four of the cases extends, in principle, “both to the State’s decision whether or not to enact legislation

<sup>76</sup> *Ibid.*

<sup>77</sup> *See also Vo*, concurring opinion of Judge Costa, joined by Judge Traja.

<sup>78</sup> C. E. Schneider, “Bioethics in the Language of Law” (1994) 24 *The Hastings Center Report* 16–22 at 16–17.

<sup>79</sup> For discussion in the context of the cloning report produced by President George W. Bush’s Council on Bioethics, see J. Lezaun, “Self-Contained Bioethics and the Politics of Legal Prohibition” (2008) 4 *Law, Culture and Humanities* 323–38.

<sup>80</sup> *Mount Isa Mines Ltd v. Pusey* (1970) 125 CLR 383, at 395.

governing the use of IVF treatment and, having intervened, to the detailed rules it lays down in order to achieve a balance between competing public and private interests.<sup>81</sup> Still, there are some pointers. In *Evans*, the court encouraged contracting states to take steps to recognize that embryo-freezing produces “an essential difference between IVF and fertilisation through sexual intercourse”: “the possibility of allowing a lapse of time, which may be substantial, to intervene between the creation of the embryo and its implantation in the uterus.” In light of this, the court advised states to devise legal schemes that take the possibility of delay into account. Such schemes were, it said, “legitimate – and indeed desirable.”<sup>82</sup>

Second, in both *Evans* and *S.H. and Others*, the court made clear that even when important private life interests are engaged, it is open to legislators to adopt “rules of an absolute nature” – “[rules] which serve to promote legal certainty.”<sup>83</sup> Put differently, legislators do not have to provide for “the weighing of competing interests in the circumstances of each individual case.”<sup>84</sup> But this is not a free pass for legislators. For instance, in *S.H. and Others*, having noted that “concerns based on moral considerations or on social acceptability must be taken seriously in a sensitive domain like artificial procreation,” the court went on to insist that such concerns “are not in themselves sufficient reasons for a complete ban on a specific artificial procreation technique such as ovum donation.”<sup>85</sup> The court then reminded contracting states that, even where a wide margin of appreciation is granted, the impugned domestic legal framework “must be shaped in a coherent manner which allows the different legitimate interests involved to be adequately taken into account.”<sup>86</sup>

But what is not clear from *S.H. and Others*, or from the ART cases as a whole, is what these different legitimate interests are. There are, at best, some pointers. Thus, in *Evans*, in determining whether the competing private and public interests had been weighed in a way that achieved fair balance, the majority emphasized two particular public interests: first, that the impugned provisions of the UK’s ART law upheld the principle of the primacy of consent, and second, that their “bright-line,” no-exceptions approach promoted legal clarity and certainty.<sup>87</sup> On the private interests side, the majority focused on the right to be, or not to be, a parent,

<sup>81</sup> See, e.g., *Evans*, ¶ 82; *S.H. and Others*, ¶ 100.

<sup>82</sup> *Evans*, ¶ 84.

<sup>83</sup> *Ibid.* ¶ 89; *S.H. and Others*, ¶ 110.

<sup>84</sup> *S.H. and Others*, ¶ 110.

<sup>85</sup> *Ibid.* ¶ 100.

<sup>86</sup> *Ibid.* See also *Dickson*, in which the court determined that the applicants’ interest in becoming genetic parents had not been given due weight; the relevant policy on prisoner access to assisted insemination imposed an undue “exceptionality” burden on the applicants; there was no evidence that the minister responsible weighed different legitimate interests, or assessed proportionality in fixing the policy; and because the policy was not part of primary legislation, the legislature also had not engaged in weighting or assessment.

<sup>87</sup> *Evans*, ¶ 89.

including in the genetic sense. In *Parrillo*, the majority noted that the drafting process of Italy's ban on donating human embryos to scientific research had taken account of both "the State's interest in protecting the embryo" and the private interest in exercising the right to individual self-determination "in the form of donating [one's] embryos to research."<sup>88</sup> In *S.H. and Others*, which upheld Austria's ban on donor gametes in IVF, the majority referred to the need to take account of "human dignity, the well-being of children thus conceived and the prevention of negative repercussions or potential misuse."<sup>89</sup> They also noted that there was "no prohibition under [the law] on going abroad to seek treatment of infertility"<sup>90</sup> and having the resulting maternity and paternity recognized upon returning to Austria.

Frustratingly, the majority made no attempt to engage with the particular challenges of cross-border reproduction. The joint dissenting opinion did engage to a degree,<sup>91</sup> and some of the potential challenges were raised by one of the interveners. The latter saw what it described as "procreative tourism" as a "negative side-effect of the ban" – one that left "couples seeking infertility treatment abroad . . . exposed to the risk of low quality standards and of suffering from considerable financial and emotional stress."<sup>92</sup> No one, however, mentioned the impact on donors in the state visited by the couple (including the risk of exploitation), or the potential costs to the health service in the home state. Equally, no one mentioned how would-be parents viewed treatment abroad, or whether they cared about recognition of legal parentage.<sup>93</sup> And no one mentioned the difficulties that might be faced by a donor-conceived child seeking information about his or her genetic origin.

More positively, the ART cases as a whole are clear about the court's enthusiasm for process. The court encourages states to be proactive: In upholding Austria's ban on IVF with donor gametes in *S.H. and Others*, the court emphasized that "this area, in which the law appears to be continuously evolving and which is subject to a particularly dynamic development in science and law, needs to be kept under review by the Contracting States."<sup>94</sup> But the court also observed that it was "understandable that the States find it necessary to act with particular caution in the field of artificial procreation"<sup>95</sup> and applauded Austria for an approach that was "careful and cautious."<sup>96</sup> Similarly, in *Evans*, the United Kingdom's ART law was described as "the

<sup>88</sup> *Parrillo*, ¶ 188.

<sup>89</sup> *S.H. and Others*, ¶ 113.

<sup>90</sup> *Ibid.*, ¶ 114.

<sup>91</sup> *S.H. and Others*, joint dissenting opinion of Judges Tulkens, Hirvelä, Lazarova Trajkovska, and Tsotsoria, ¶ 13.

<sup>92</sup> *S.H. and Others*, ¶ 74.

<sup>93</sup> For discussion, see E. Jackson et al., "Learning from Cross-Border Reproduction" (2017) 25 *Medical Law Review* 23–46.

<sup>94</sup> *S.H. and Others*, ¶ 118.

<sup>95</sup> *Ibid.*, ¶ 103.

<sup>96</sup> *Ibid.*, ¶ 114. For a bioethical view on the case, see, e.g., W. V. Hoof and G. Pennings, "The Consequences of *S.H. and Others v. Austria* for Legislation on Gamete Donation in Europe:

culmination of an exceptionally detailed examination of the social, ethical and legal implications of developments in the field of human fertilisation and embryology, and the fruit of much reflection, consultation and debate.”<sup>97</sup> Most recently, in *Parrillo*, the court highlighted the drafting process behind Italy’s ban on donating to scientific research human embryos that had been created for the purpose of medically assisted reproduction.<sup>98</sup>

This procedural lens is not without difficulties. In *Parrillo*, the court turned to the drafting process of the impugned law, having said it was about to examine whether a fair balance had been struck between the competing public and private interests at stake. In what followed, however, it focused exclusively on the formalities of the legislative process; there was, in other words, no engagement with the substantive arguments that had emerged during that process. *Parrillo* also raises questions about why, precisely, the court is relying on legislative process. Is it to determine the breadth of the margin of appreciation? Is it an element of a broader proportionality analysis, or is it simply a poor substitute for that analysis?<sup>99</sup> The dissenting opinion of Judge Sajó in *Parrillo* takes a much more probing stance on both the legislative process and the impugned law itself, which suggests that the court’s judges do not have an agreed stance on my questions.

There is a sense from some of the ART cases that, unlike some bioethicists and much of the media, the court has faith in law’s capacity to handle the challenges of a rapidly evolving set of technologies like ART. We should, of course, expect a court to have faith in law, so what is interesting is the detail. In *S.H. and Others*, the court seemed to suggest that law could handle what Austria described as the risks of “harm to women” arising from egg donation (in particular, the risk of exploitation of donors). In this regard, it drew attention to the success of adoption law, though it accepted that “the splitting of motherhood between a genetic mother and the one carrying the child differs significantly from adoptive parent-child relations and has added a new aspect to this issue.”<sup>100</sup>

There have also been indications of what irks the court in the context of law, law-making, and application of law – of what it sees as falling short of democratic legitimacy. In *Knecht v. Romania*, although the court dismissed the complaint, it took the time to describe the Romanian regulator’s attitude as “obstructive and oscillatory.”<sup>101</sup> In *Costa and Pavan*, it was the incoherence of Italian law that irked the court. The applicants, a married couple carrying cystic fibrosis, had been barred

An Ethical Analysis of the European Court of Human Rights Judgments” (2012) 25 *Reproductive BioMedicine Online* 665–69.

<sup>97</sup> *Evans*, ¶ 86.

<sup>98</sup> *Parrillo*, ¶¶ 184–88.

<sup>99</sup> See generally M. Saul, “The European Court of Human Rights’ Margin of Appreciation and Processes of National Parliaments” (2015) 15 *Human Rights Law Review* 745–74.

<sup>100</sup> *S.H. and Others*, ¶ 105.

<sup>101</sup> *Knecht*, ¶ 60.

from using IVF and PGD to screen their embryos so that only healthy ones could be implanted. Were they to conceive, however, the law permitted them to terminate the pregnancy on the grounds of fetal genetic condition. This, the court said, “caused a state of anguish for the applicants,”<sup>102</sup> and, as noted earlier, it went on to hold that Italy’s ban on IVF with PGD constituted a disproportionate interference with the applicants’ right to respect for private and family life.

## VI CONCLUSION

In drawing to a close, two points stand out from my review of the court’s ART cases. First, the court invokes “the ethical” but largely leaves us guessing about what would constitute a human rights-based approach to the relationship between “the legal” and “the bioethical.” Second, and relatedly, the court leaves us guessing as to what would constitute a human rights-based approach to ART.

These gaps are problematic. Rights holders and duty bearers would benefit from clarity on what is a legal responsibility and what is a moral or an ethical one. But I suggest we see the gaps as productive, too. They allow us to think about the scope and content of rights and responsibilities in the ART field, without stalling on what is legal and what is ethical. More broadly, they demonstrate that international human rights case law is a starting point for discussion, not a full stop – that it is much more contested than the stereotypes of freedoms, entitlements, and duties suggest, much more provisional than the word “law” indicates, and much more interwoven with the domestic than the word “international” implies.<sup>103</sup>

I am not saying that there is no need to grasp what is, or could be, unique to human rights law, just that it would be useful to approach that question in new ways. With that in mind, and focusing on the contribution that international human rights law and practice could make to “good science,” this chapter has explored whether the ART case law of the European Court of Human Rights could generate fresh conversation between human rights lawyers and bioethicists. My conclusion is that it could.

The ART cases, as we have seen, do not set down what “ought to be.” They flag the centrality of the right to respect for private life, which covers the decision to become or not to become a parent, including in the genetic sense, and to use medically assisted procreation to that end. In a less-developed manner, the cases flag the relevance of other Convention rights (notably the rights to life and to respect for family life), the Convention’s guarantee of nondiscrimination,<sup>104</sup> and the state’s

<sup>102</sup> *Costa and Pavan*, ¶ 66.

<sup>103</sup> See C. McCrudden, “The Pluralism of Human Rights Adjudication,” in L. Lazarus, C. McCrudden, and N. Bowles (eds.), *Reasoning Rights: Comparative Judicial Engagement* (Oxford: Hart Publishing, 2014), pp. 3–27.

<sup>104</sup> Article 14’s nondiscrimination guarantee is “parasitic,” i.e., it only prohibits discrimination in the enjoyment of other Convention rights. Recently, however, the European Court of Human

interest in protecting “the rights and freedoms of others.” Considerable ebb and flow should be expected as the court and states continue to grapple with the balance between these rights and interests.

The court’s particular identity as a supranational human rights court is flagged by the cases, too. ART is presented as a field that raises “sensitive moral and ethical issues,” which is one of the triggers for a wide margin of appreciation. But a wide margin is not a free pass, nor is it guaranteed. It can be limited by a European consensus (and potentially by an emerging one as well<sup>105</sup>). It can also be limited where a particularly important aspect of an individual’s existence or identity is at stake, which includes the right to respect for the decision to be or not to be a parent in the genetic sense. And even where a wide margin is seen as apt, the court has the power to scrutinize the democratic legitimacy of the impugned domestic measure. Each of these elements offers scope for study and, of course, for different views.

There are other potentially interesting elements that I have not addressed, such as: Did the gender of the judge count in any of the court’s ART cases?<sup>106</sup> In *S.H. and Others*, four women judges authored the biting dissent,<sup>107</sup> which suggests this question merits further study. Equally, how many of the court’s ART cases have featured third-party interventions, and is there a pattern in terms of who is intervening, in what types of cases, and with what sorts of claims?

Case selection is relevant too. For instance, would this chapter have read differently if I had framed the court’s ART cases as part of medical jurisprudence,<sup>108</sup> reproductive rights jurisprudence,<sup>109</sup> the jurisprudence of pregnancy,<sup>110</sup> or even a jurisprudence of kinship? And what would have emerged if I had looked at all of the court’s bioethical cases, which address issues including consent to medical examination and treatment, abortion, and assisted suicide? Equally, what would have

Rights has been developing this right by reference to views on substantive equality from other courts and in scholarship; see S. Fredman, “Emerging from the Shadows: Substantive Equality and Article 14 of the European Convention on Human Rights” (2016) 16 *Human Rights Law Review* 273–301.

<sup>105</sup> See *Goodwin v. United Kingdom*, Eur. Ct. H.R., App. No. 28957/95 (Grand Chamber, July 11, 2002).

<sup>106</sup> See S. H. Vauchez, “More Women – But Which Women? The Rule and the Politics of Gender Balance at the European Court of Human Rights” (2015) 26 *European Journal of International Law* 195–221.

<sup>107</sup> *S.H. and Others*, joint dissenting opinion of Judges Tulkens, Hirvelä, Lazarova Trajkovska, and Tsotsoria. Women judges were part of the majority opinion, but the dissent was authored exclusively by women.

<sup>108</sup> See J. Harrington, *Towards a Rhetoric of Medical Law* (London: Routledge, 2016).

<sup>109</sup> See L. Oja and A. E. Yamin, “‘Woman’ in the European Human Rights System: How Is the Reproductive Rights Jurisprudence of the European Court of Human Rights Constructing Narratives of Women’s Citizenship?” (2016) 32 *Columbia Journal of Gender and Law* 62–95.

<sup>110</sup> See, e.g., M. Ford, “*Evans v. United Kingdom*: What Implications for the Jurisprudence of Pregnancy?” (2008) 8 *Human Rights Law Review* 171–84.

emerged if either a particular concept (say, dignity or autonomy<sup>111</sup>) or a particular practice (say, cross-border care or informed consent) had been the focal point? And, changing tack again, what would we have seen if we had looked at all of the court's technology cases? In particular, do we expect the question of ethics to feature in the court's cases on other technologies, and if not, why not?

These, I suggest, are just some of the questions that arise. Moreover, if the aim is to delineate the relationship between the legal and the bioethical, and relatedly to capture what is distinctive about the authority of international human rights law, it will be important to locate the European Court of Human Rights within a broader frame. That frame should include not just other human rights actors, both domestic and international, but also other "palaces of hope"<sup>112</sup> from the field of international law that play a part in the regulation of the life sciences and their technologies. And finally, because human rights practice is not exclusive to legal actors, we should also be exploring how national bioethics bodies (such as those mentioned earlier in this chapter) and professional scientific organizations view the bioethics–human rights relationship. These explorations are not standard fare. They could, however, engage bioethicists and international human rights lawyers in ways that are important and overdue. And over time, they could contribute to "good science" as well.

<sup>111</sup> See, e.g., Löhmus, *Caring Autonomy*; J.-P. Costa, "European Dignity and the European Court of Human Rights," in C. McCrudden (ed.), *Understanding Human Dignity* (Oxford: Oxford University Press, 2013), pp. 393–402; C. McCrudden, "Human Dignity and Judicial Interpretation" (2008) 19 *European Journal of International Law* 655–724.

<sup>112</sup> R. Niezen and M. Sapiñoli (eds.), *Palaces of Hope: The Anthropology of Global Organizations* (New York: Cambridge University Press, 2017).