# Children's civil liability actions regarding parental germinal gene-editing decisions

#### Ekain Payán Ellacuria\*

ABSTRACT: Advances in reprogenetic tools have completely changed parents' previously passive role in deciding what characteristics their children will have, giving rise to significant bioethical and legal implications. They now have genetic information which they can use in their reproductive decision-making to avoid serious disease in their children. Thus, children might bring claims against their parents, not only for their actions but also for their omissions. Therefore, this paper discusses whether parental freedom jeopardizes the rights of children and future generations. It discusses various conflicting and introduces the current legal discourse around the feasibility of CRISPR-Cas9 lawsuits.

KEYWORDS: Germline gene-editing, non-directive counselling, procreative autonomy, procreative beneficence, serious disease

SUMMARY: 1. Introduction – 2. Prospective parents' reproductive rights and responsibilities – 3. Civil liability actions: Wrongful birth and wrongful life – 4. The legal issue: Claims of prenatal damage for germline gene-editing – 5. Final remarks.

## 1. Introduction

hroughout human history, humans have desired to acquire new capabilities<sup>1</sup> but often lacked the ability to do so. In ancient times, it was believed that newborns received particular characteristics because of God's will, so parents had no choice but to submit to what was a genetic health lottery<sup>2</sup> and accept their children as they were. However, assisted reproductive technologies (ART) have opened up the possibility of artificial reproduction, which grants couples new rights and freedoms. Thus, if one of partner is unable to procreate, such as someone suffering from infertility, it is possible to use donated sperm or eggs, surrogate gestation, adopt, and conduct preimplantation genetic diagnosis (PGD) or prenatal diagnosis (PD) and select the desired embryos, allowing people to select for healthier biological offspring. However, gene therapy is the only method for correcting rare and incurable inherited disorders in both the unborn and

<sup>&</sup>lt;sup>2</sup> M. SANDEL, *The case against perfection*, Boston, 2004, 145.



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<sup>&</sup>lt;sup>1</sup> N. BOSTROM, *A history of transhumanism thought*, in *Journal of Evolution and Technology*, 14, 1, April 2005, 1.

subsequent generations.<sup>3</sup> Consequently, it seems inevitable that gene-editing will be used in the near future.<sup>4</sup>

A milestone in human reproduction occurred in late 2018 with the birth of the first two genetically edited human beings.<sup>5</sup> The purpose of this editing was not to cure an illness but rather to increase their resistance to acquiring human immunodeficiency virus (HIV) because their father was HIV-positive. This change can cause unforeseen and harmful lifelong consequences for children, such as off-target effects or mosaicism. He Jiankiu announced that he will monitor the children throughout their lives. However, the editing of their genes may have violated their fundamental rights, so the parents may bring a claim against the doctor for failing to secure properly informed consent<sup>6</sup> and advising them to receive genetic counselling before they agreed to the editing. When they reach the appropriate age, the children themselves may sue healthcare personnel if their parents have not done so on their behalf already or may even sue their own parents for causing them injury by their choice to have their genes edited.

The latter situation has already occurred for other families and, although the literature has addressed the bioethical implications of gene-editing,<sup>7</sup> it has not sufficiently examined compensatory liability for damages to human embryos. The goal of this paper is to identify parents' reproductive rights and responsibilities and what legal actions children can take against their parents and healthcare personnel for gene-editing under the current legal framework and precedents. It also addresses a double dilemma by focusing on the rights and guiding principles for how to treat children.

## 2. Prospective parents' reproductive rights and responsibilities

The right to procreate is not established per se by law. Nevertheless, it can be inferred from some international treaties that are binding on the signatory states. For example, the *Convention for the Protection of Human Rights and Fundamental Freedoms* (1950) Art. 3 prohibits inhuman and degrading treatment, Art. 8.1 recognizes the right to respect family life, and Art. 12 grants the right to start a family. The *International Covenant on Civil and Political Rights* (1966) Art. 23.2 grants the right to start a family. Therefore, the right to start a family implicitly protects procreative and childrearing rights. Thus, the freedom to decide whether to have children or not<sup>8</sup> can only be limited



<sup>&</sup>lt;sup>3</sup> R. ANDORNO, A.E. YAMIN, *The right to design babies? Human rights and bioethics,* in *OpenGlobalRights,* January 2019, accessible on <u>https://www.openglobalrights.org/the-right-to-design-babies-human-rights-and-bioethics/,</u> (last visited 15/04/2021).

<sup>&</sup>lt;sup>4</sup> J.A. DOUDNA, *The promise and challenge of therapeutic genome editing*, in *Nature*, 578, February 2020, 229.

<sup>&</sup>lt;sup>5</sup> M. MARCHIONE, *Chinese researcher claims first gene-edited babies,* in *Associated Press,* November 2018, accessible on <u>https://apnews.com/4997bb7aa36c45449b488e19ac83e86d</u>, (last visited 15/04/2021).

<sup>&</sup>lt;sup>6</sup> P. SANTILLÁN-DOHERTI, P. GRETHER-GONZÁLEZ, M.J. MEDINA-ARELLANO, S. CHAN, R. TAPIA-IBARGÜENGOITIA, I. BRENA-SESMA, et. al., *Considerations on genetic engineering: regarding the birth of twins subjected to gene edition,* in *Gaceta Médica de México*, 156, 2020, 54-55.

<sup>&</sup>lt;sup>7</sup> D. ARCHARD, P. DABROCK, J.-F. DELFRAISSY, *Human-genome editing: ethics councils call to governments worldwide,* in *Nature*, 579, March 2020, 29.

<sup>&</sup>lt;sup>8</sup> J.A. ROBERTSON, *Procreative Liberty and the Control of Conception. Pregnancy, and Childbirth*, in *Virginia Law Review*, 69, 3, 1983, 406.

by public authorities in justified and exceptional circumstances, which include when such freedom would harm third-party interests.<sup>9</sup> In addition, reproductive freedom is linked to the guarantees of individual autonomy and free development of the personality by the 1948 *Universal Declaration of Human Rights* Arts. 26.2 and 29.1 (UDHR), personal identity by the 1997 *European Convention on Human* Rights and Biomedicine Art. 1 (ECHRB), human dignity by the UDHR Art. 1 and the 2000 *Charter of Fundamental Rights of the European Union*, and well-being,<sup>10</sup> all of which have inspired several democratic constitutions. The volume and importance given to related guarantees are the reasons why reproductive liberty is commonly considered a subjective right.<sup>11</sup>

However, this freedom is not absolute. For example, parents have a duty to take care of their children and provide them with food, education, and healthcare, duties which remain throughout their minority and beyond if their children are unable to provide this for themselves because they are disabled when they reach the age of majority. Arts. 1 and 6 of the 1997 Educational, Scientific and Cultural Organization's (UNESCO) Declaration on the Responsibilities of the Present Generations Towards Future Generations hold that people have responsibilities towards future generations, so they must respect the human genome as part of respecting human dignity and human rights. This legal good was further enshrined in the 2005 UNESCO Universal Declaration on Bioethics and Human Rights Art. 16 which addresses the impact of life sciences on future generations. However, despite the other articles mentioned above, some argue that Art. 16 this is a staging of the sanctification of the heritage of humankind because germline gene-editing (GGE) is constantly changing and so would not introduce any novelty into the gene pool.<sup>12</sup> Furthermore, ECHRB Art. 2 gives puts the interests and welfare of individuals over those of society and science. Thus, according to some interpretations, the responsibility towards future generations<sup>13</sup> and the requirement to protect human dignity<sup>14</sup> would require that action be taken to change children's genes in a way that would make them healthier.

Be that as it may, parents make decisions for their children before they are born and until they reach the age of majority during which time the children are deemed to be incapable of giving informed consent to medical procedures,<sup>15</sup> giving parents both rights and obligations.

<sup>&</sup>lt;sup>15</sup> T. ISHII, I. DE MIGUEL BERIAIN, Safety of germline genome editing for genetically-related "future" children as perceived by parents, in The CRISPR Journal, 2, 6, 2019, 371.



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<sup>&</sup>lt;sup>9</sup> G. CAVALIERE, The problem with reproductive freedom. Procreation beyond procreators' interests, in Medicine, Health Care and Philosophy, 23, 2020, 132.

<sup>&</sup>lt;sup>10</sup> J.A. ROBERTSON, *Children of choice: Freedom and the new reproductive technologies,* Princeton, 1994, 24.

<sup>&</sup>lt;sup>11</sup> I. ALKORTA IDIAKEZ, *Nuevos límites del derecho a procrear*, in *Derecho privado y Constitución*, 20, 2006, 13.

<sup>&</sup>lt;sup>12</sup> A.L.V. HAMMERSTEIN, M. EGGEL, N. BILLER-ANDORNO, *Is selecting better than modifying? An investigation of arguments against germline gene-editing as compared to preimplantation genetic diagnosis, in BMC Medical Ethics,* 20, 83, 2019, 4.

<sup>&</sup>lt;sup>13</sup> I. DE MIGUEL BERIAIN, J. ALMQVIST, *Ethical questions in gene therapy*, in J. FAINTUCH, S. FAINTUCH (eds.), *Precision Medicine for Investigators, Practitioners and Providers*, San Diego, 2020, 526.

<sup>&</sup>lt;sup>14</sup> I. DE MIGUEL BERIAIN, B. SANZ, Human dignity and gene-editing: Additional support for Raposo's arguments, in *Bioethical Inquiry*, 17, 2, 2020, 167.

## 3. Civil liability actions: Wrongful birth and wrongful life

The obligation to compensate victims of medical malfeasance may arise for contractual reasons or from non-contractual reasons, such as negligence. However, both types of reasons must involve the performance of an unlawful act, omission, fault, or negligence that caused damage.<sup>16</sup> Private law claims can be supported by several allegations, such as wrongful conception, wrongful birth, wrongful life, and wrongful death, but birth and life actions will be briefly explained below because of their repeated application and relation to factual assumptions.

Both parents jointly or the mother solely can bring a claim for wrongful birth against obstetricians who do not propose appropriate diagnostic tests or detect foetal aberrations, depriving them of the opportunity to legally terminate their pregnancy. The damages of such claims may include the costs of raising the child, costs of providing extra care that certain children might require, and non-material losses.<sup>17</sup> Furthermore, the child or their representatives, such as their parents or legal guardians, can bring wrongful life claims against physicians who allowed them to be born to a life of suffering that caused them to have preferred to have not been born.

The main differences between wrongful birth and wrongful life claims are who brings them and their legal bases, even though parents often bring both of them.<sup>18</sup> Another difference is that wrongful birth claims are generally admitted while wrongful life claims are generally denied.<sup>19</sup> The main reason that the rights to health and human dignity are considered fundamental in most Western countries is because of the assumed legal, ethical, and social obligations to protect life. The assumption is that the lives of those suffering from pathologies are no less valuable than those that are not. Another reason that they refuse is that not doing so could lead to defensive medicine.<sup>20</sup> Regardless of the reason, the strength of this assumption differs by country and there are a few jurisdictions that do recognize a child's difficulties in life as grounds for bringing a legal claim (e.g., the Netherlands: Dutch Supreme Court, 18 March 2005, *Kelly case*;<sup>21</sup> California, USA: *Curlender v. Bio-Science Laboratories* (1980),<sup>22</sup> *Turpin v. Sortini* (1982);<sup>23</sup> Washington, USA: *Haberson v. Parke-Davis* (1983);<sup>24</sup> New Jersey,

<sup>21</sup> HR 18 March 2005, 2006 Nederlandse Jurisprudentie 606 nt JBMV (Kelly).



<sup>&</sup>lt;sup>16</sup> A. EMALDI CIRIÓN, *El consejo genético y sus implicaciones jurídicas*, Bilbao-Granada, 2001, 261-264.

<sup>&</sup>lt;sup>17</sup> A. VICANDI MARTÍNEZ, El concepto de wrongful birth y su inherente problemática. Una polémica del pasado y del presente, in Revista de Derecho, Empresa y Sociedad (REDS), 3, 2013, 50-54.

<sup>&</sup>lt;sup>18</sup> A. EMALDI CIRIÓN, *op. cit.*, 239.

<sup>&</sup>lt;sup>19</sup> A. MACÍA MORILLO, Una visión general de las acciones de responsabilidad por "wrongful birth" y "wrongful life" y de su tratamiento en nuestro ordenamiento jurídico, in Anuario de la Facultad de Derecho de la Universidad Autónoma de Madrid (AFDUAM), 10, 2006, 90.

<sup>&</sup>lt;sup>20</sup> I. GIESEN, Of wrongful birth, wrongful life, comparative law and the politics of tort law systems, Tydskrif vir Heedendaagse Romeins-Hollandse Reg, 72, 2009, 267; C. M. ROMEO CASABONA, A. PERIN (eds.), Derecho y medicina defensiva: legitimidad y límites de la intervención penal, Bilbao-Granada, 2020, 1-24.

<sup>&</sup>lt;sup>22</sup> Curlender v. Bio-Science Laboratories, 106 Cal. App. 3d 811,165 Cal. Rptr. 477, hearing denied, No. 2 Civ. 58192 Div. 1 (Cal. September 4, 1980).

<sup>&</sup>lt;sup>23</sup> *Turpin v. Sortini*, 119 Cal. App. 3d 690,174 Cal. Rptr. 128, 1981, rev'd, May 3, 1982, No. S.F. 24319.

<sup>&</sup>lt;sup>24</sup> Haberson v. Parke-Davis, 98 Wash. 2d 460, 656 P.2d 483, January 6, 1983.

USA: *Prokanic v. Cillo* (1984))<sup>25</sup>. Many jurisdictions have unclear legislation, including Belgium, Japan, and Spain,<sup>26</sup> although in Spain, wrongful life is contrary to the legal order.<sup>27</sup>

Given this legal background, children with congenital diseases may sue not only the medical personnel involved in their being born but also their parents who decide to continue with their birth knowing that they have a congenital disease or who reject embryonic treatment that could cure congenital diseases. In this context, the next section will discuss how GGE may change the concept of parental responsibility as it has been understood so far, leading to the occurrence of situations unanticipated by the law.

## 4. The legal issue: Claims of prenatal damage for germline gene-editing

At first glance, GGE would seem to be prohibited. The *Charter of Fundamental Rights of the European Union* Art. 3.2 bans eugenic practices, so given that GGE edits genes, some could see it as a slippery slope to eugenics.<sup>28</sup> However, some argue that what separates it from eugenics, which was characterized by bad science, state intervention, and discrimination, is knowledge, a lack of coercion, and a therapeutic intent.<sup>29</sup>

Furthermore, Art. 13 of the ECHRB requires that parents not intend to modify the genes of their offspring, *Directive 98/44/EC* on the legal protection of biotechnological inventions Art. 6.2.b prohibits the alteration of germline genetic identities, and *EU Regulation No. 536/2014* on clinical trials on medicinal products for human use Art. 90. However, these statutes mention genomes and germlines, which are different, so they may permit GGE.<sup>30</sup>

Furthermore, a global ban on GGE could infringe children's fundamental right to health in terms of equitable access to health benefits guaranteed by ECHRB Art. 3, the right to benefit from biological and medical progress guaranteed by UDHR Art. 27.1 and UNESCO's *Universal Declaration on the Human Genome and Human Rights* (UDHGHR) Art. 12.a, and the freedom of research guaranteed by UNESCO's UDHGHR Art. 12.b and ECHRB Art. 15, among others.

Another reason that gene-editing is feasible is that there are rules that expressly establish the individual right to claim compensation for undue damage. In this regard, UNESCO's UDHGHR Art. 8 states that "Every individual shall have the right, according to international and national law, to just reparation for any damage sustained as a direct and determining result of an intervention affecting

<sup>&</sup>lt;sup>30</sup> I. DE MIGUEL BERIAIN, E. ARMAZA, A. DUARDO SÁNCHEZ, *Human germline editing is not prohibited by the Oviedo Convention: An argument, in Medical Law International,* 19, 2-3, 2019, 227-228.



<sup>&</sup>lt;sup>25</sup> *Prokanic v. Cillo*, 97 N.J. 339, 478 A.2d 755, August 1, 1984.

<sup>&</sup>lt;sup>26</sup> P. FRATI, V. FINESCHI, M. DI SANZO, R. LA RUSSA, M. SCOPETTI, F. M. SEVERI, et. al., *Preimplantation and prenatal diagnosis, wrongful birth and wrongful life: A global view of bioethical and legal controversies,* in *Human Reproduction* Update, 23, 3, 2017, 346-348.

<sup>&</sup>lt;sup>27</sup> J. M<sup>a</sup> FUGARDO ESTIVILL, *Procreación humana y acciones de responsabilidad*, Barcelona, 2018, 158.

<sup>&</sup>lt;sup>28</sup> I. BROWN, *The new eugenics and human progress,* in *Journal of Policy and Practice in Intellectual Disabilities,* 16, 2, 2019, 137-140.

<sup>&</sup>lt;sup>29</sup> G. CAVALIERE, Looking into the shadow: The eugenics argument in debates on reproductive technologies and practices, in Monash Bioethics Review, 36, 1-4, 2018, 14.

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his or her genome".<sup>31</sup> Likewise, ECHRB Art. 24 states "The person who has suffered undue damage resulting from an intervention is entitled to fair compensation according to the conditions and procedures prescribed by law".<sup>32</sup>

Given that the ban on GGE may not be absolute and there are statutes in place providing for financial compensation for the damage caused by its application, the next step is to determine whether children can bring actions for wrongful life against their parents and healthcare providers. As a preliminary premise for making this determination, it must be assumed that parents are not obliged to know the risk of transmitting a hereditary condition to their children, so they should not be held liable for negligence if they unknowingly do so. Even if they are aware of such risk, they should not be forced to genetically modify their children as they may not want to do so for moral or religious reasons. Compelling them to do so would violate their fundamental right to religious freedom as guaranteed by the UDHR Art. 18 and would make such genetic treatment more similar to eugenics. An economic argument can also be made for not compelling people to edit their children's genes. There will be people who may want to edit their children's genes, but will not be able to afford to do so, despite how relatively inexpensive clustered regularly interspaced short palindromic repeats (CRISPR-Cas9) procedures will likely become. To try to compel them to do so could constitute discrimination under UDHR Arts. 2 and 7 and ECHRB Art. 11 unless the cost of such procedures was borne by the national health system, something that is impossible in countries without such systems. However, it is a different matter if both parents freely and voluntarily decide to use GGE. Assuming that GGE is effective and safe, children and even grandchildren might be able to bring civil claims against their families. One is positive and would be brought by children whose genes were edited against their will. The other is negative and would be brought when parents resorted to ART but not GGE.

The first type of claim calls into question the identity of the unborn and brings up the non-identity problem,<sup>33</sup> which entails the risk of giving birth to different individuals. However, some disagree because the embryo already has an identity by the time its genes are modified,<sup>34</sup> so illnesses, like Alzheimer's, are a part of that identity. Another argument against editing the genes of embryos is that it violates the child's right to autonomy as an adult.<sup>35</sup> Be that as it may, it seems ethically permissible for parents to use GGE to prevent serious diseases in their children, especially monogenic

<sup>&</sup>lt;sup>31</sup> United Nations Educational, Scientific and Cultural Organization, Universal Declaration on the Human Genome and Human Rights. Adopted by the General Conference of the United Nations Educational, Scientific and Cultural Organization at its twenty-ninth session on 11 November 1997; endorsed by General Assembly 53/152 accessible resolution of 9 December 1998, November 1997, on https://www.ohchr.org/EN/ProfessionalInterest/Pages/HumanGenomeAndHumanRights.aspx, (last visited 15/04/2021).

<sup>&</sup>lt;sup>32</sup> Council of Europe, *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, April 1997, accessible on <u>https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164</u>, (last visited 15/04/2021).* 

<sup>&</sup>lt;sup>33</sup> D. PARFIT, *Reasons and Persons*, Oxford, 1987, 371-372.

<sup>&</sup>lt;sup>34</sup> A. OMERBASIC, Genome Editing, Non-Identity and the Notion of Harm, in M. BRAUN, H. SCHICKL, P. DABROCK (eds.), Between Moral Hazard and Legal Uncertainty. Ethical, Legal and Societal Challenges of Human Genome Editing, Wiesbaden, 2018, 73-74.

<sup>&</sup>lt;sup>35</sup> J. FEINBERG, *Freedom and Fulfilment: Philosophical Essays*, New Jersey, 1992, 76-97.

ones, such as Tay-Sachs, Huntington's, or cystic fibrosis.<sup>36</sup> This type of use has legal endorsement in the 1989 *Convention on the Rights of the Child* Art. 3, which stipulates that the best interests of the child must be pursued, and Art. 24, which stipulates that children have the right to the highest attainable standard of health both before and after birth. The latter right is also safeguarded by the 1966 *International Covenant on Economic, Social and Cultural Rights* Art. 12. Both of these rights are supported by the principle of procreative beneficence, which holds that parents have a moral obligation to make choices such that their children will have the best possible life, given that there is a considerable consensus on how illnesses affect expected well-being.<sup>37</sup> However, some hold that quality of life is a product of physical health as well as relationships, social inclusion, material well-being, and being able to exercise rights.<sup>38</sup> The sum of these elements in a person's life are what produces overall higher levels of happiness<sup>39</sup> and what ensures the diversity and equality of all humans.

In light of all of these facts and arguments, the children whose genes were edited may have reasonable grounds to sue their parents. Although their parents had their genes edited to reduce the chances that they would get HIV, HIV infection is no longer lethal and children had not yet actually been infected by it. Therefore, they were unnecessarily exposed to risk despite having safer alternatives, such as treatment with antiretroviral therapies, condom use, or sperm washing. However, the admissibility of this claim will depend on whether the parents gave informed consent to the procedure and received genetic counselling. If they did not, their consent would be invalid, so the doctor and his team would be liable to the children.

A second situation would be if the parents used an ART, such as PGD, instead of GGE and *in vitro* fertilization (IVF).<sup>40</sup> Even though some commentators have argued that both techniques achieve the same results, they are not equivalent. PGD examines embryos for genetic mutations and only healthy ones are transferred to the uterus. Defective embryos are discarded or used for research purposes. Scientists often defend PGD over other practices because of its safety, although it may not be fully effective when both parents have the same recessive monogenic disorder.<sup>41</sup> However, some people may highly value the embryos for ideological or religious reasons and<sup>42</sup> so refuse to deliberately lose

<sup>&</sup>lt;sup>42</sup> M. WALKER, *Eugenic selection benefits embryos,* in *Bioethics,* 28, 5, 2014, 215.



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<sup>&</sup>lt;sup>36</sup> GERMAN ETHICS COUNCIL, *Intervening in the Human Germline*, May 2019, 26, accessible on <u>https://www.ethikrat.org/fileadmin/Publikationen/Stellungnahmen/englisch/opinion-intervening-in-the-</u>

human-germline-summary.pdf, (last visited 15/04/2021); NATIONAL ACADEMY OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, THE ROYAL SOCIETY, *Heritable Human Genome Editing*, Washington, D. C., September 2020, 96-104.

<sup>&</sup>lt;sup>37</sup> J. SAVULESCU, G. KAHANE, *The Moral obligation to create children with the best chance of the best life*, in *Bioethics*, 23, 5, June 2009, 279.

<sup>&</sup>lt;sup>38</sup> J. REINDERS, T. STAINTON, T.R. PARMENTER, *The quiet progress of the new eugenics. Ending the lives of persons with intellectual and developmental disabilities for reasons of presumed poor quality of life, in Journal of Policy and Practice in Intellectual Disabilities,* 16, 2, 2019, 101.

<sup>&</sup>lt;sup>39</sup> I. BROWN, R.I. BROWN, A. SCHIPPERS, A quality of life perspective on the new eugenics, in Journal of Policy and Practice in Intellectual Disabilities, 16, 2, 2019, 123.

<sup>&</sup>lt;sup>40</sup> M. VIOTTI, A. R. VICTOR, D. K. GRIFFIN, J. S. GROOB, A. J. BRAKE, C. G. ZOUYES, et. al., *Estimating demand for germline genome editing: An in vitro fertilization clinic perspective,* in *The CRISPR Journal,* 2, 5, 2019, 304.

<sup>&</sup>lt;sup>41</sup> R. RANISCH, Germline genome editing versus preimplantation genetic diagnosis: Is there a case in favour of germline interventions?, in Bioethics, 34, 1, 2020, 63.

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them.<sup>43</sup> Also, PGD after IVF requires mothers to undergo ovarian stimulation and invasive punctures to introduce the embryos into their wombs.<sup>44</sup> This process is more stressful and painful than the process that men undergo that requires them to abstain from sex for three days and provide a sperm donation through a mostly quick and painless process. Thus, PGD after IVF further burdens mothers in ways that it does not burden fathers. On the other hand, GGE can accurately and easily give health to a person who will one day exist. Also, GGE has no reproductive effects, unlike somatic geneediting, which is applied to a patient's own cells, and prevents future diseases from arising, unlike PGD.<sup>45</sup> Moreover, over time researchers are likely to develop more control over and knowledge about CRISPR-Cas9 by improving techniques, such as prime editing<sup>46</sup> and chimeric antigen receptor T-cell therapies.<sup>47</sup>

In this case, the child would have the right to an open future but their best interests in terms of health would not be served and their right to enjoy the highest attainable standard of health would be violated. As mentioned above, human dignity and the rights of future generations can be used as arguments both for and against gene-editing, so the way that they are used depends on each individual and how they view the issue.

#### 5. Final remarks

This paper discussed one of the edges of GGE. At present, this debate is currently moot given the state of technological development, but if GGE becomes safe and not subject to legal issues,<sup>48</sup> many more people would likely use it to treat their unborn children's diseases because it is easier and more effective to do so early in a person's life. However, GGE recipients may sue their parents for having edited their genes. Parents may mount the defences that such editing was therapeutic, its benefits outweighed its risks, and, under most legal regimes, parents are not liable for medical procedures which they consented for their children to undergo.<sup>49</sup> A good policy reason for exempting parents from liability for editing their children's genes is that they may opt to not reveal such editing if it would expose them to litigation.<sup>50</sup>



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<sup>&</sup>lt;sup>43</sup> A. NORDBERG, T. MINSSEN, O. FEENEY, I. DE MIGUEL BERIAIN, L. GALVAGNI, K. WARTIOVAARA, *Regulating germline editing in assisted reproductive technology: An EU cross-disciplinary perspective*, in *Bioethics*, 34, 1, 2020, 18.

<sup>&</sup>lt;sup>44</sup> F. SIMONSTEIN, *Gene-editing, enhancing and women's role,* in *Science and Engineering Ethics,* 25, 4, 2019, 1011.

<sup>&</sup>lt;sup>45</sup> N. KOFLER, K. L. KRASCHEL, *Treatment of heritable diseases using CRISPR: Hopes, fears, and reality,* in *Seminars in Perinatology*, 42, 8, 2018, 515-516.

<sup>&</sup>lt;sup>46</sup> A.V. ANZALONE, P.B. RANDOLPH, J.R. DAVIS, A.A. SOUSA, L. W. KOBLAN, J. M. LEVY, et. al., *Search-and-replace genome editing without double-strand breaks or donor DNA*, in *Nature*, 576, 2019, 149-157.

<sup>&</sup>lt;sup>47</sup> J.R. HAMILTON, J.A. DOUDNA, *Knocking out barriers to engineered cell activity*, in *Science*, 367, 6481, 2020, 976-977.

<sup>&</sup>lt;sup>48</sup> I. DE MIGUEL BERIAIN, C.M. ROMEO CASABONA, *The regulation of human germline genome modification in Spain,* in A. BOGGIO, C.P.R. ROMANO, J. ALMQVIST (eds.), *Human Germline Genome Modification and the Right to Science. A Comparative Study of National Law and Policies,* Cambridge, 2020, 379.

<sup>&</sup>lt;sup>49</sup> D. KREKORA-ZAJĄC, Civil liability for damages related to germline and embryo editing against the legal admissibility of gene-editing, in Palgrave Communications, 6, 30, 2020, 6.

<sup>&</sup>lt;sup>50</sup> T. ISHII, I. DE MIGUEL BERIAIN, *op. cit.*, 374.

From the opposite perspective, children can take legal action against their parents for not editing their genes to help them avoid certain diseases. Nevertheless, some claim that no one has the right to be born healthy even if they could have been.<sup>51</sup> However, these people may change their minds as gene-editing technology develops and gene-editing is done to protect children's rights to life and good health.

For that to ever happen, all civil liability must disappear because it remains the main obstacle preventing gene-editing from becoming more common,<sup>52</sup> particularly with regard to the causal relationship between the transmission of a disease and the damage it causes.<sup>53</sup> The latter excludes situations in which someone may be disadvantaged, but not sufficiently so to create civil liability.

Opening the door even slightly to GGE may lead to an increase in litigation by children against their parents and healthcare providers, a scenario in which this contribution tries to deepen by setting out the various fatherly and filial rights and duties involved in order to provide guidance and legal certainty for lawyers.

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<sup>51</sup> B.M. KNOPPERS, E. KLEIDERMAN, Heritable genome editing: Who speaks for "future" children?, in The CRISPR Journal, 2, 5, 2019, 289.
<sup>52</sup> A. EMALDI CIRIÓN, op. cit., 261-264.

<sup>53</sup> J. Mª FUGARDO ESTIVILL, op. cit., 216.

