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Studies in Christian Ethics 2009 22: 314

DOI: 10.1177/0953946809106235

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DANCING WITH MACROMOLECULES: ETHICAL TASKS AT THE DAWN OF MOLECULAR MEDICINE

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ABSTRACT

Rival paradigms of genetics suggest different perceptions of human life and, correspondingly, of the task of medicine. In dialogue with two paradigmatic heuristics of genetics, I will show that bioethics needs to articulate a narrative that encourages a renewed understanding of the complexity of the phenomena of human life to which molecular medicine must be open. These considerations will be put to the test by discussing the ethical implications of the recent developments in stem cell research and in personal genetics.

KEYWORDS

bioethics; genetic diseases; genetics; genome sequencing; molecular medicine; regenerative medicine; stem cell research

*At the Dawn of Molecular Medicine:
On the Ethical Implications of Dancing Macromolecules*

Responding to research into the molecular dimension of nature is like trying to hit a moving target. New techniques challenge ethics to remain up to date with science. In its December 2007 issue, the journal *Science* awarded two biotechnological developments the 'breakthrough of the year':¹

¹ See Donald Kennedy, 'Breakthrough of the Year', *Science* 318.5858 (21 December 2007), p. 1833.

- sequencing techniques that scan individual human genomes for variations that help to see how deletions and insertions in the DNA are linked to behavioural traits and diseases;
- reprogramming techniques that generate induced pluripotent stem cells (iPS cells) by a retrovirally-mediated introduction of transcription factors into adult human fibroblasts.

Both breakthrough techniques inspire visions of medical applications: Will it be possible to develop individual gene drugs, to cut out, switch off or exchange genes that are associated with certain diseases, or to enhance an individual's genome? Will it be possible to drink from the fountain of youth by means of a regenerative medicine that applies the genetically-induced capacity of adult cells to renew themselves and to differentiate into all cell types of the adult human body to the immunocompatible transplantation of organs and tissues.

These questions challenge our perceptions of diseases, of health and of medicine. Medicine will probably get a grip on facets of human life that have so far been beyond the range of human mastery. The visions of predictive and regenerative medicine promise new therapies for diseases and increased chances to govern and rationalize human life. At the same time, however, genetic research continues to bring to light complexities and dynamics of genetic and epigenetic processes that do not support the idea of easy solutions for medical applications.

Up to now, two rival paradigms of genetics have emerged. The mainstream view is that of genetic determinism that models the ontogenesis of an individual's organism as the linear, causal expression of a genetic programme. The competing paradigm sees the phenotype as the result of the interplay of genetic and epigenetic networks, in which genes are just one, albeit important, factor of many that gradually organize a phenotype.² Drawing on his analysis of hereditary diseases, Ulrich Wolf (Institute of Human Genetics and Anthropology, University of Freiburg, Germany) regards ontogenesis as

a succession of stages in which each particular stage requires the realization of the preceding one. The successive stages are the result of interactions between internal and external factors and conditions, and this process does not allow for the separation of a hereditary or environmental portion. In addition, it is almost impossible to define whether a particular component belongs to the hereditary or environmental complex: a gene finds itself in the environment of other genes that may interact, there a position effects and gradients of inactivation, the prospective fate of a differentiating cell depends

² See Ulrich Wolf, 'The Genetic Contribution to the Phenotype', *Human Genetics* 95.2 (1995), pp. 127–48.

upon its spatial position within the embryo or tissue, etc. The organism does not function like a computer running a program and producing results that are independent from any variables outside that program. Development is a historical process, and therefore, each developmental step is unique, as are other historical events.³

Wolf concludes that 'the realization of the phenotype is characterized by program-like, regulatory, stochastic, and historical processes that interact to form a network of relationships, rather than a linear succession of events. There is no fundamental design or program that is followed but rather the interactions taking place from the program'.⁴

This description of ontogenetic development contradicts the predominant paradigm of genetics as it can be found in the school books, and for which the phenotype is the expression of a blueprint that can be found in a single cell. Wolf's account is one among many re-conceptualizations of genetic theory that try to yield a dynamic and complex understanding of DNA and of ontogenesis. In 1985, Susan Oyama (now emerita from John Jay College of Criminal Justice, Psychology Department, City University of New York) developed a constructive interactionism paradigm of genetic development, suggesting that organisms like ours are the result of a 'choreography of ontogeny',⁵ a choreography in which every step of the dance between macromolecules and environment is a real, multifactorial move where every developmentally-relevant component matters.

There is an intense debate about alternative descriptions of ontogenesis that differ from the mainstream metaphor which regards it as the realization of a genetic masterplan.⁶ For ethics, there are extremely divergent moral and ethical implications⁷ to understanding ourselves as the products of determined genetic programmes or as the unique and unpredictable results of a dynamic, complex, multifaceted and communicative becoming.⁸ The impact of genetic theory on our self-understanding (and vice versa) cannot be underestimated, and is of

³ Wolf, 'The Genetic Contribution to the Phenotype', p. 128.

⁴ Ibid., p. 144.

⁵ Susan Oyama, *The Ontogeny of Information: Developmental Systems and Evolution* (2nd edn; Durham, NC: Duke University Press, 2000), p. 26.

⁶ For this debate see E. M. Neumann-Held and Christoph Rehmann-Sutter, *Genes in Development: Re-reading the Molecular Paradigm* (Durham, NC: Duke University Press, 2005).

⁷ Throughout this article, I use the (frequently contested) distinction between moral and ethical issues as applied by authors like Seyla Benhabib or Jürgen Habermas, which can be traced back to Kant. According to this use of terms, moral reflection aims at normative universality and entails the reflection on rules and norms while ethical reflection concentrates on life-forms, practices and habits.

⁸ For the ethical implications of the distinction between programme- and systems-theory of genetics, see Christoph Rehmann-Sutter, 'Gene, Körperlichkeit und Identität', in *Zwischen den Molekülen. Beiträge zur Philosophie der Genetik* (Tübingen: Francke Verlag, 2005), pp. 135–74.

paramount importance for our vision of molecular medicine.⁹ In a systems- or interaction-theory of ontogenesis, the idea of gene therapy, such as genetic surgery, which aims at cutting out genes that are associated with certain diseases, encounters difficulties that make its therapeutic feasibility questionable. In the light of the new semantic considerations, and of the latest results in biotechnological research, the development of molecular medicine will probably head in very different directions than have previously been imagined.

With regard to this situation, bioethics must perform a twofold task:

- The first task of bioethics is dialogue with science. This task is about binding ethical reflection to the results of research, in order not to anticipate scenarios that are unrealistic from the present point of view and to become and remain aware of those elements of nature that oppose their rationalization and with which we need to cooperate in order to find successful applications.
- The second task of bioethics is analysis of the social and anthropological implications of the metaphors and models of genetics. This task includes responding critically to the ways in which the insights of research in genetics and the imagination they evoke change our perception of ourselves, including our understanding of health, of diseases, and of how medicine needs to respond to this understanding.

With regard to the fact that research in genetics continues to affect and shape the perception of our lives, our bodies, our diseases and other cultural and social categories,¹⁰ ethics would be ill-advised to focus solely on normative questions that only respond to an ongoing process of research whose aims and responsibilities remain undebated, or to restrict the discussion to weighing the positive aspects of genetic research against its risks. We have already taken the risk, and we will continue to risk interventions into the communication that is happening between the molecules that we are made of, even if our knowledge of the grammar and the language that constitutes this molecular communication remains deficient for some time to come.¹¹

⁹ See Hans G. Ulrich, 'Embryonenforschung und Stammzellentherapie – Zu den Folgen für Menschenbild und Krankheitsverständnis', *epd-Dokumentation Bioethik und Gentechnik* 26 (Frankfurt 2001), pp. 31–39.

¹⁰ Paul Rabinow has used the term 'biosociality' in order to describe the growing reorganization of social life according to the genetic identity of persons; see 'Artificiality and Enlightenment: From Sociobiology to Biosociality', in *Essays on the Anthropology of Reason* (Princeton, NJ: Princeton University Press, 1996), pp. 91–111.

¹¹ Clinical applications of gene therapy, for example, remain subject to heavy public funding in many of the developed countries despite their complete failure until today.

The question is not only which developments in biotechnology should be allowed or forbidden, but also which views of human life are impacted by genetic metaphors and how these views shape the task of medicine.¹² The primary end of medicine cannot be the elimination of (genetic) diseases and of suffering, at least not without major shifts in the traditional medical ethos. According to this ethos, the prevention, amelioration or cure of diseases serves as a means for a higher end, namely to help people lead bearable lives. The crucial question is whether the application of molecular medicine can be understood in terms of therapeutic means to this end, or whether a programme paradigm of genetics suggests that the removal of disease-associated genes and thus the elimination of diseases is the primary end of medicine. Should the latter be the case, the medically-induced absence of disease and suffering would eventually define what could be called a bearable life. Medicine would create functionalistic parameters of such human life, instead of merely serving it.¹³

While bioethics today mostly takes an external, moralizing perspective on research, focusing on the risks of research, the consequences of applied research, and on the universal norms that should be applied,¹⁴ we need a debate on the underlying views of phenomena of human life such as diseases, suffering, aging and dying.¹⁵ Moral reflection cannot provide much guidance here.¹⁶ Modern moral discourse tends to concentrate on

¹² For a discussion on the relationship between cultural trends and the rise of medical techniques see Robert Song, *Human Genetics: Fabricating the Future* (London: Darton, Longman and Todd, 2002).

¹³ See Christoph Rehmann-Sutter, 'Politik der genetischen Identität. Gute und schlechte Gründe, auf Keimbahntherapie zu verzichten', in Christoph Rehmann-Sutter and Hansjakob Müller (eds.), *Ethik und Gentherapie. Zum praktischen Diskurs um die molekulare Medizin* (2nd edn; Tübingen: Francke, 2003), pp. 225–36.

¹⁴ See the extremely influential approach by Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (5th edn; Oxford: Oxford University Press, 2001).

¹⁵ For a strong answer to this, see Gerald P. McKenny, *To Relieve the Human Condition: Bioethics, Technology and the Body* (Albany, NY: State University of New York Press, 1997).

¹⁶ For this observation, see H. Tristram Engelhardt Jr., 'Germ-Line Genetic Engineering and Moral Diversity: Moral Controversies in a Post-Christian World', in Richard Sherlock and John D. Morrey (eds.), *Ethical Issues in Biotechnology* (Lanham, MD: Rowman & Littlefield, 2002), pp. 503–16. Significantly, Engelhardt's account of the history of thought on human nature goes as follows: 'Whether understood as the gift of God or merely the deliverance of spontaneous mutations, random selection, genetic drift, cosmic happenstance, and biochemical constraints, human nature has until now been regarded as placing constraints on human freedom' (507). This is of course not all there is to say about the traditional understandings of human nature that offer much more complex accounts of the relationship of human freedom to human nature. But it is enough for Engelhardt to miss the important differences in the moral implications of seeing human nature as a gift, or as something else. I comment on this detail because it is characteristic of a problem in the contemporary discourses on bioethics. They tend to ignore semantic details and their moral and ethical implications. There is a significant difference

the individual freedom from (human) nature. The moral philosophy both of Aristotle and of Kant has largely been limited to a discourse about the question of how to preserve the autonomy of practical reason. This discourse struggles to respond critically to the program paradigm of genetics, and to a biotechnology that regards 'human nature' as material that is to be formed and overcome by reason in its strive for freedom. From the point of view of a dualism of human spirit and the human body, ethics fails to see that the attempt to free ourselves from human nature by means of reason imprisons us in our own instrumental rationality and makes us just as unfree as 'nature' does.¹⁷ Instead, ethics needs to operate with an account of human life that is located at the junction of reason, self, body and the lifeworld, as has been described by phenomenology that bears affinities to the interactionism paradigm of genetics.¹⁸ To regard ourselves as beings who become selves as interactive and communicative bodies, not just as fixed, freestanding selves who happen to have bodies, means seeing the significance of experiences that contribute to our becoming. The propositional content of these experiences for each of us cannot be translated into universal moral norms, but this does not mean that they are no less urgent and compelling. Alternatives to a merely moral, universalistic discourse are called for by the results of biotechnological research itself, and by new paradigms in genetics that help to see the refractory and cooperative elements of the reality of human life. Of course this meets the interests of a theological ethics that tries to uphold the tension between the reality that we construct and the reality that we receive in the encounter with God's Word.

Apart from universalistic accounts, and without sinking into their abstractions and principles, we must focus on the question of how the perceptions of human life, of disease, of health, and of medicine are shaped by the results, models and metaphors of research in genetics.¹⁹ This implies the task of identifying and discussing the normative content which these

between regarding human nature as a gift, or as subject to God's creation, preservation and redemption – just as there are important differences between 'mutation', 'selection', 'drift' or 'happenstance'. The different models and metaphors stand for very different narratives with very different moral and ethical contents.

¹⁷ See exemplarily Jürgen Mittelstraß, *Leonardo-Welt: über Wissenschaft, Forschung und Verantwortung* (Frankfurt/Main: Suhrkamp, 1996). Mittelstraß develops an English version of his argument in Jürgen Mittelstraß, 'Science and the Environment: Challenges, Risks and the Future', *European Journal of Clinical Pharmacology* 38 (1990), pp. 1–4.

¹⁸ See Maurice Merleau-Ponty, *The Visible and the Invisible* (ed. Claude Lefort; Evanston, IL: Northwestern University Press, 1968), pp. 130ff. For the late Merleau-Ponty, our 'flesh' is the place at which our bodies and the world intertwine.

¹⁹ For an analysis of the semantics and central metaphors of biotechnological research, see E. F. Keller, *Refiguring Life: Metaphors of Twentieth-Century Biology* (New York: Columbia University Press, 1995).

perceptions and narratives yield. While the program-paradigm invokes a narrative which is compatible with the attempt to come to grips with life as thoroughly as possible, the interaction-paradigm invokes an undomesticated narrative which contradicts the attempt to force human nature under the rule of rationalization and to treat the human genome mechanically. From the point of view of the latter paradigm, attempts to change a genetic 'program' will probably fail, and biotechnology will need to cooperate with a body in its becoming.²⁰ Interventions by molecular medicine will have to join the dance of the molecules; they cannot simply change a molecular mechanism.

The distinction between the ethical implications of two different paradigms of genetics helps us to perceive significant differences within different kinds of biotechnology, that is, between a gene therapy that sets out to develop individual gene drugs, genetic surgery that intends to cut out disease-related genes, genetic enhancement that tries to improve an individual genome, and the new world of regenerative transplantation medicine. Biotechnology is diversified, leaving us to question which kind of molecular medicine shapes which kind of self-understanding. It is a realistic option that can be pursued at the expense of other medical techniques. The results of genetic research continue to add complex views of molecular interaction, and show that ethics needs to respond to accounts that show reality as both refractory in some fields and as cooperative in others.

This calls for a third task of bioethics: finding and exploring a narrative that may criticize or even contradict accounts of reality that only focus on the things that we produce as opposed to the things that we receive, or on claims that we can universally justify as opposed to claims that go back to experiences that are related to our becoming:

- The third task of bioethics is to renew our understanding and the direction of medical technology development by the articulation of refractory narratives and judgements on the reality of human life. This task entails stimulating and performing a public dialogue through which perceptions of ourselves may be articulated that resist and contradict the attempt to effect a complete rationalization of human life and that bring to bear the phenomena of human life in their full, refractory and hospitable complexity. We need to articulate how things appear to us and happen for us, how we receive things and cooperate with them, and how we become the human beings that we are through the network of suffering and shaping reality. This entails exploring

²⁰ See Lars Reuter, *Modern Biotechnology in Postmodern Times? A Reflection on European Policies and Human Agency* (Dordrecht: Kluwer Academic Publishers, 2003), pp. 82ff.

and communicating which judgements on the reality of human life exist in the life with God. In order to find out which direction we want new medical techniques to take, we need to debate our understanding of those elements and forms of our lives without which we cannot imagine a life that we would find bearable in the light of the promises that God has given to us.

This task of ethics requires a perception of reality that contradicts an affirmative, naturalistic or idealistic perception. In theological ethics, this has been reflected paradigmatically by Dietrich Bonhoeffer, for whom appropriateness, *Sachgemäßheit*, means to respond to 'nature' as the medium through which we encounter God's creative and preserving action, and which approaches us both as criticizing our own imaginations of its composition (e.g. the idea of creation orders, or of genetic determinism) and as inviting us to explore it in all its complexity and richness in order to gain a new understanding of creatureliness.²¹ *Sachgemäßheit* is Bonhoeffer's technical term for '*secundum naturam vivere*', the old principle of natural law ethics that Bonhoeffer reinterprets in terms of a dynamic understanding of nature as a means through which God addresses his creatures (over against a metaphysical interpretation of nature). To act *sachgemäß* means to live according to nature as it approaches us. The expectation of a living God who makes use of his creation adds an enormous dynamic to Bonhoeffer's account of nature, and can be regarded as one of the rare twentieth-century Protestant examples of *liber naturae* thinking.²² Bonhoeffer holds, as does any 'natural law' theory that ranges beyond naturalism and idealism, that to live in accordance with nature means to join a dance: to explore the steps that are required together with a partner, to be entangled in movement, and to respond to new situations that arise with every new step. This entails exploring the complex interrelation of the way things present themselves to us and the way we intentionally respond to them, including the attentiveness to what is heard through this complex relation. It involves entering an interdisciplinary dialogue in which we put the models, narratives and metaphors to the test which shape and orient our perceptions and receive consenting, differing and contradicting responses.

These more hermeneutic and heuristic tasks of bioethics need to be completed (at least) by a fourth task, which focuses on the issues of the sick, the suffering, the weak, the poor, the disabled and the old: in short, it is about care and justice in medicine as an integral part of the development

²¹ See Dietrich Bonhoeffer, *Ethik* (ed. Ilse Tödt, Heinz Eduard Tödt, Ernst Feil and Clifford Green; DBW 6; Gütersloh: Chr. Kaiser/Gütersloher Verlagshaus, 1998), pp. 269ff.

²² For a contemporary conversation with this tradition, see Oswald Bayer, *Schöpfung als Anrede: zu einer Hermeneutik der Schöpfung* (2nd edn; Tübingen: Mohr, 1990), pp. 9ff.

of new medical techniques.²³ In the developed countries, medicine has achieved a lot in the past 40 years, while many developing countries lack sufficient medical support and face enormous suffering that could be ameliorated with comparatively small efforts. For reasons of profitability, research is more likely to develop treatments only for rich people, such as the costly development of adipositas drugs at the expense of the development of vaccine research and other interventions against HIV, malaria and tuberculosis in developing countries.²⁴ Today, the systematic discrimination of the poor is found not only on a world-wide scale, but also within the national health care systems of developed countries, although with less atrocities:

- The fourth task of bioethics is being a voice for the disadvantaged and the poor, and insisting that every effort is needed to make an endurable life with enough medical treatment possible for all, not only for the rich. This entails opting for medicine that is good enough to ameliorate suffering and to cure diseases so as to make a health system possible in which nobody has to despair because he or she falls ill, grows old or needs care. Such a task should not be underestimated. It requires maximum exertion to create and maintain an endurable health care. Any public funding of the development of a cost-intensive molecular medicine needs to be vindicated against the backdrop of this very basic requirement.

In what follows, I will put these considerations on the ethical implications of the latest results in genetics to the test by turning towards the new reprogramming and sequencing techniques that are regarded as breakthroughs on the way towards a predictive and regenerative medicine.

Stem Cell Research: On Being Your Own Therapy

Ever since the cloning of Dolly the sheep in 1997, the miraculous capacity of the cytoplasm of mammalian oocytes has been subject to feverish research.²⁵ Obviously, there is a cocktail of factors found in mammalian oocytes with outstanding regenerative capacities. They can turn any adult cell into a

²³ See the discussion in Rosamond Rhodes, Margaret P. Battin and Anita Silvers (eds.), *Medicine and Social Justice: Essays on the Distribution of Health Care* (Oxford: Oxford University Press, 2002).

²⁴ See the website of the European and Developing countries clinical trials partnership (EDCTP) at <http://www.edctp.org>.

²⁵ Ian Wilmut et al., 'Viable Offspring Derived from Foetal and Adult Mammalian Cells', *Nature* 385 (1997), pp. 810–13.

quasi embryonic iPS cell. The prize-winning question is which factors are responsible for inducing pluripotency in adult cells.

In 2006, Shinya Yamanaka and Kazutoshi Takahashi (Department of Stem Cell Biology at Kyoto University) were among the first to isolate four pluripotency genes (Oct 3/4, Sox2, c-Myc and Klf4) and to demonstrate in mouse experiments that it is possible to induce pluripotent stem cells from adult fibroblasts by means of a retrovirus-mediated transfection of four defined factors that induce pluripotency.²⁶ That year, Rudolf Jaenisch's group (Whitehead Institute for Biomedical Research, MIT, Cambridge, USA) achieved similar results. At the invitation of Walter Doerfler (Institute for Virology at Erlangen, Germany), Jaenisch presented his results at a Symposium on 'Medicine at the Interface between Science and Ethics' at Weißenburg, Germany.²⁷ He began his presentation by showing a classic painting of the fountain of youth and by relating this picture to his research on the mechanisms of genomic reprogramming, on the capacity of ES cells for self-renewal, and on their ability to differentiate into all adult cell types. Like other scientists, Jaenisch points to the fact that research on pluripotency, self-renewal and reprogramming is essentially a modern sequel to the age-old quest for the fountain of youth. When Scottish researcher Ian Chambers managed to isolate another of the ES cell associated genes with reprogramming capacity, he named this factor NANOG, after the Tir nan Og legend, the myth of the Land of the Ever-Young, thereby indicating the mythological dimension of the results of his research.²⁸ NANOG helps to keep ES cells pluripotent, and it helps to generate iPS cells when transfected into adult fibroblasts by means of viral vectors.

In late 2007, Yamanaka's and Takahashi's group demonstrated that iPS cells can also be generated from adult human dermal fibroblasts with the same factors as the mouse iPS cells.²⁹ They stated that their research serves to circumvent both the ethical controversies involved in using human embryos for human ES cells, and the problem of creating patient- and disease-specific stem cell therapies without compromising the immune

²⁶ Kazutoshi Takahashi and Shinya Yamanaka, 'Induction of Pluripotent Stem Cells from Mouse Embryonic and Adult Fibroblast Cultures by Defined Factors', *Cell* 126 (25 August 2006), pp. 663–76.

²⁷ The proceedings of the symposium will be published soon under the title: 'Medicine at the Interface between Science and Ethics.'

²⁸ 'Cells of the Ever Young: Getting Closer to the Truth', *Science Daily* (2 June 2003), at <http://www.sciencedaily.com/releases/2003/06/030602024530.htm>.

²⁹ Kazutoshi Takahashi et al., 'Induction of Pluripotent Stem Cells from Adult Human Fibroblasts by Defined Factors', *Cell* 131 (30 November 2007), pp. 1–12.

³⁰ Ibid., p. 1. For shared concerns see James A. Thomson et al., 'Induced Pluripotent Stem Cell Lines Derived from Human Somatic Cells', *Science* 318.5858 (21 December 2007), pp. 1917–920 (1920).

system as is the problem of every mode of transplantation medicine.³⁰ Along with the transcription factors, however, the vector molecules also settled down arbitrarily in each host genome. In mice experiments, Takahashi and his group found that this random integration of retroviral material leads to an undesired activation and mutations of genes at the insertion sites that caused tumours in 20 per cent of all mice derived from iPS cells.³¹ These results show that iPS cells are real time bombs in terms of tumorigenesis. James A. Thomson (from the Genome Center of Wisconsin, Madison, USA) and his group experienced similar problems with mutations caused by viral integration even though they used a different reprogramming cocktail (OCT 4, SOX 2, NANOG, LIN 28).³² Hence, research groups in Japan and the USA are working towards ways to integrate transcription factors other than by retroviral transduction, in order to make iPS cells applicable for use in human therapies.

Reprogramming techniques promise to boost research in the field of regenerative medicine without the moral problem of producing and destroying human embryos to acquire ES cells for growing replacements for dysfunctional cells or organs. They allow for the production of cells with features almost identical to ES cells, such as the ability to differentiate into all cell types in the adult body.

News of the development of iPS cells has stirred up contemporary bioethical controversies, especially on the use of ES cells. Characteristically for the orthodox view of bioethics, these discourses have concentrated largely on moral, normative issues. They focus mainly on the question of the moral status of the embryo, and thus on the justification or prohibition of embryo-destructive research.³³ Is an embryo to be regarded as a human being or as a cell mass? While some claim that human life begins with the fusion of ovum and spermatozoon,³⁴ and that everybody who stems from human beings is a human person and must be regarded as such, however small he is,³⁵ others hold that human life begins with

³¹ Takahashi et al., 'Induction of Pluripotent Stem Cells', p. 8.

³² Thomson et al., 'Induced Pluripotent Stem Cell Lines', pp. 1917–920.

³³ For an overview of the German discussion see G. Damschen and D. Schönecker, *Der moralische Status menschlicher Embryonen. Pro und contra Spezies-, Kontinuums-, Identitäts- und Potentialitätsargument* (Berlin/New York: de Gruyter, 2003).

³⁴ See Rat der Evangelischen Kirche in Deutschland zur aktuellen bioethischen Debatte (ed.), *Der Schutz menschlicher Embryonen darf nicht eingeschränkt werden* (Hannover: Pressestelle der EKD, 22 May 2001) and Deutsche Bischofskonferenz zu Fragen von Gentechnik und Biomedizin (ed.), *Der Mensch: sein eigener Schöpfer?* (Bonn: Deutsche Bischofskonferenz, 2001).

³⁵ For this argument see Robert Spaemann, *Personen, Versuche über den Unterschied zwischen 'etwas' und 'jemand'* (Stuttgart: Klett-Cotta, 1996), p. 261 and Wolfgang Huber, *Der gemachte Mensch. Christlicher Glaube und Biotechnik* (Berlin: Wichern-Verlag, 2000), pp. 18ff. See also the jurisdiction of the German Constitutional Court: BVerfGE 88, 203 (252).

nidation,³⁶ or another identifiable stage of embryonic development,³⁷ so that it is morally acceptable to destroy embryos at an early stage of their development. Others regard the human embryo as a potential human being and therefore worthy of being protected, but have seen this claim outweighed by the possibilities of medical progress, the potential benefits to patients and the personal rights of parents.³⁸ The debate reveals that there is no cogent reason for any answer to the question at which point of their interaction the involved cells shall be regarded as a human being.³⁹ The question of the beginning of human life only makes sense in an in-vitro context when human embryos are already the direct objects of manual treatment, when their life depends on decision, and when their 'dignity' has become subject to attribution. This question presupposes a moral discourse that asks whether we should or should not destroy embryos. It does not ask whether such action belongs to us, whether it is appropriate to the objects of research, whether it is not simply justified but good for us, whether there are alternatives to research and whether we would agree to the vision that guides the use of stem cells. The moral discourse orbits around the 'potentiality' of an embryo to be one of us, but this metaphor only makes sense within a program theory of ontogenesis, for which the complex interactions and interrelations, and the environment (including ourselves), does not add to the becoming of the human being whose essence lies in its DNA. If the metaphysics of potentiality cannot be made evident, and it is quite hard to see a human being in cells in a Petri dish, the embryo has lost all the trumps. On account of a reductionistic genetic theory and a restricted focus on universalistic morality, the potentiality argument puts all its eggs in one basket.⁴⁰

The moral problem of killing embryos has not disappeared, although much intellectual energy has been invested in finding ways to eliminate it. Even the frequently-used distinction between human beings and

³⁶ See the recommendation of the 1984 report of the Committee of Inquiry into Human Fertilization and Embryology (Warnock Commission) and the British Human Fertilization and Embryology Act of 1990, §3.4.

³⁷ For a discussion on the basis of systems biology see P. Yeung, 'When Does Human Life Begin?', *Ethics & Medicine* 21.2 (2005), pp. 69–71.

³⁸ See, e.g., Nikolaus Knoepffler, 'Menschliche Embryonen und medizinethische Konfliktfälle', in N. Knoepffler and A. Haniel (eds.), *Menschenwürde und medizinethische Konfliktfälle* (Stuttgart/Leipzig: Hirzel, 2000), pp. 55–66 (65) and Hartmut Krefß, 'Präimplantationsdiagnostik im Rahmen genetischer Diagnostik – Zu den Auswirkungen auf medizinethische Normen und auf Elternschaft', *epd-Dokumentation Bioethik und Gentechnik* 26 (2001), pp. 23–30 (28).

³⁹ Yeung, 'When Does Human Life Begin?', p. 69.

⁴⁰ For this argument, see Christoph Rehmann-Sutter, 'Sind Zellen mögliche Menschen? Ethisch-anthropologische Implikationen der Schutz Begründung durch Totipotenz', in Uwe Gerber and Hubert Meisinger (eds.), *Das Gen als Maß aller Menschen? Menschenbilder im Zeitalter der Gene* (Frankfurt/Main: Peter Lang, 2004), pp. 191–211.

'something human' or 'human life' cannot convincingly answer the question of which parameters of 'human life' can be distinguished from a 'human being'. Embryos only become 'human life' in the sense of human 'material for research' if we turn them into such a thing.⁴¹ The pressing moral question of what could justify turning human offspring into material cannot be silenced. We can, of course, not pay attention to it. The most honest way to deal with this question is to acknowledge the moral norm that embryos should not be killed, but kill them anyway. There is no way to keep a morally clean slate, however good the reasons are for such actions.

What we need more urgently than speculation on the moral status of the embryo is a shift from a moral to an ethical discourse that casts light on the implications of ES cell or iPS cell research on our understanding of medicine, and of ourselves, including the life form of natality. There is more at stake than embryos when we talk about research on embryos. From the semantics of the 'embryo'-metaphor to the visions of the land of the Ever-Young, there is a broad range of such implications. That there are such things as 'embryos' that can be brought visibly to the fore has already changed our perception of natality, of the becoming of human beings, of children, and of all sorts of medical diagnoses. As the becoming of human beings is more and more rationalized, it appears as something that we have to come to grips with even in its earliest stages. Prenatal diagnostics link the 'embryo' and 'foetus' development with parental and medical responsibilities, options and decisions.⁴² The promise of regenerative, immunocompatible medicine that emphasizes research on the cloning of human embryos in order to isolate pluripotent cells challenges the limits of traditional therapy and draws funding resources from the development of other technologies.⁴³

However, news about the possibility of generating iPS cells that behave like ES cells hardly shifted the focus of discourse to social, ethical and hermeneutic issues related to regenerative medicine, instead raising hopes that issues with the controversial moral implications of embryo-destructive

⁴¹ See Hans G. Ulrich, *Wie Geschöpfe leben. Konturen evangelischer Ethik* (EThD 2; Münster: Lit, 2005), pp. 633ff. See also Hans G. Ulrich, 'Forschung für den Menschen – jenseits des Erlaubten?' in *Über die Grenzen von Wissenschaft und Forschung*, Erlanger Forschungen 28 (Erlangen: Universitätsverlag, 2005), pp. 37–61 (52ff). See also Hans G. Ulrich, 'Embryonenforschung und Stammzellentherapie – Zu den Folgen für Menschenbild und Krankheitsverständnis', *epd-Dokumentation Bioethik und Gentechnik* 26 (2001), pp. 31–39; see also Hans G. Ulrich, 'Leben als Humanum oder Leben aus dem Humanpool?', in V. Hörner und K. Patzer (eds.), *Optionen für eine Medizin der Zukunft? Präimplantationsdiagnostik und Stammzellforschung*, Speyrer Texte 6 (2001), pp. 66–87.

⁴² See Brian Brock and Stephanie Brock, 'Being Disabled in the New World of Genetic Testing: A Snapshot of Shifting Landscapes', in John Swinton and Brian Brock (eds.), *Theology, Disability and the New Genetics: Why Science Needs the Church* (London: T&T Clark, 2007), pp. 29–43.

⁴³ For this argument, see Hans Jonas, 'Wissenschaft und Forschungsfreiheit. Ist erlaubt, was machbar ist?', in H. Lenk (ed.), *Wissenschaft und Ethik* (Stuttgart: Reclam, 1991), pp. 193–214.

research could be solved in the long run. The question of just how far the dawn of a new regenerative medicine reaches into our lives and medical practices has so far not been sufficiently discussed in the public arenas of EU countries, which have focused instead on various legal solutions.⁴⁴ In Germany, the production of human iPS cells from adult fibroblasts made it right into the February 2008 parliamentary debates about a possible liberalization of the 'Act for the safeguarding of embryo protection in the context of the import and use of human embryonic stem cells' of 2002. This act prohibits research on ES cells with the exception of cell-lines that have been produced outside Germany and before 1 January 2002. German researchers are threatened with a prison sentence when using ES cells that are produced after that deadline.⁴⁵ The development of iPS cells was grist to the mill of those who opted against the liberalization of this Stem Cell Act. Annette Schavan, Federal Minister of Research and member of the central committee of German Catholics, immediately announced a funding initiative to sponsor research projects dedicated to the production of pluripotent and multipotent stem cells. For those who thought that these new techniques would render the use of left-over in-vitro-fertilized embryos or therapeutic cloning obsolete, it came as bad news that the techniques' development was only possible through basic research on cells that were derived from embryos. Such research is bound to continue if ever the production of new drugs, new disease models, and applications for transplantation medicine will succeed.⁴⁶

The debate is not likely to shift from moral issues to ethical questions, including the question of which kind of transplantation medicine is really needed in order to lead a bearable life. As the use of metaphors such as the Land of the Ever-Young indicates, research itself seems to be interested in expanding the possibilities of medicine to an extent where renewed human life itself becomes the resource for therapy. This is, of course, an extremely elegant vision for medicine. The new regenerative transplantation medicine does not just use drugs or alien donor organs, but the body of the patient himself. Human life switches from being the end to the means of therapy. The hope is that unlimited and immunocompatible regeneration resources will one day replace every possible organ and tissue in the human body. By comparison, the contemporary practice of treating chemotherapy patients with bone marrow stem cells looks like stone age medicine.

⁴⁴ European Consortium for Stem Cell Research (EuroStemCell): Regulations in EU Member States regarding hES cell research. Available online at: http://archive.eurostemcell.org/Documents/Outreach/stemcell_hesc_regulations_2007FEB.pdf

⁴⁵ Stem Cell Act, 28 June 2002, §13.

⁴⁶ See Jose Cibelli, 'Is Therapeutic Cloning Dead?' *Science* 318:5858 (21 December 2007), pp. 1879–80.

In this situation, we need a public debate on the direction that medical technology is taking, and how deeply this direction affects the phenomena and forms of human life that we would not so quickly give up. We need to shift the focus from speculation about the beginning of human life to asking how research has altered and will alter the way in which we conceive of ourselves. This entails a debate on the contours of human life to which Christians contribute what they learn and explore about life as creatures. Such a debate will necessarily be controversial. In the light of the controversial relationship between our shared understanding of human life and the narratives that we find indispensable to bring a renewed understanding of ourselves, this debate will have to orbit around the question of which kind of medicine we want. Does our understanding of medicine and of our life as it is interwoven with health and illness imply where to draw the line between therapy and renewal? Do we still think of medicine along the lines of this distinction? And where is the tipping point at which therapy, the healing of diseases and the soothing of pain turn into something else? Is our medicine geared towards enabling us to live a bearable life with our given bodies and their diseases and aging processes that will eventually lead to death, or does medicine aim at an unlimited replaceability of deficient organs? In terms of our self-understanding, we either understand ourselves as bodily selves, or as selves that have a body whose organs may be subject to replacement by new ones. What happens to us if we regard our bodies as the hardware of our lives, instead of trying to understand how our bodies are involved in everything we do, think and suffer?⁴⁷ What is at stake is our understanding of therapy, of health, disease and dying, and of their corresponding practices.

A public discourse on the new field of regenerative medicine made possible by stem cell research but which has not yet produced specific therapies seems to be of paramount importance now, especially since clinics for 'regenerative medicine' are being established that give hope to desperate patients for whom there is no therapy for the diseases they have. The objective of regenerating human life threatens to overshadow the urgent development of therapies from which people may benefit now. We need to discuss where the vision of the renewal of human life leads toward therapies, and where it obscures the therapeutic task of medicine. And we need to ask what it means for us, and for our children, that such medicine be gradually established.

The question remains, how much do we value our life to resist the desire to live longer? The lifeworldly practices and experiences from which this resistance may stem come to mind here, such as the practice of expecting

⁴⁷ See Bernhard Waldenfels, *Das leibliche Selbst. Vorlesungen zur Phänomenologie des Leibes* (ed. Regula Giuliani; (Frankfurt am Main: Suhrkamp, 2000), p. 12.

renewal of man from God, not from reprogrammed cells. Have we sufficiently understood what it means for us that our lives are primarily about generation, not about regeneration, and about passing on, not about prolongation? And do Christians sufficiently witness to these practices in the public debates? The debate that we would better lead is primarily about the hope that we have, and about the hope that we lack: it is only secondarily about embryos.

Personal Genetics: On Having a Disease Without Being Ill

The recently-developed sequencing techniques have opened up the new field of personal genomics, and a related field of molecular medicine: Gene therapy. They are likely to make the complete analysis of one's genome possible in the not too distant future, not only for rich people but also for many ordinary 'customers'. This will provide the knowledge of gene variants and alterations that predispose people to diseases like diabetes, arthritis, Alzheimer's, breast cancer, multiple sclerosis, and heart disease. It also bears the promise to make a new type of personalized medicine possible with new challenges to genetic counselling.⁴⁸ Such variations range from chromosomal abnormalities to monogenic diseases, polygenic diseases and imprinting defects.⁴⁹ However, even with a fully sequenced personal genome, we still lack sufficient knowledge of the complex genetic and epigenetic mechanisms that affect the relation of the genetic defect and its phenotypic expression. Mendelistic views on heredity and models of genetic programs merge to form unrealistic expectations on predictive medicine.⁵⁰ The results of research do not suggest that we may understand the genotype-phenotype relationship simply in terms of the determined expression of a program. As has been discussed above, the construction and function of organisms seems to be more of a step-by-step communication process between many factors, among which DNA sequences are of special importance for predispositions and the rise of causal relations.⁵¹

⁴⁸ See Elisabeth Pennisi, 'Breakthrough of the Year: Human Genetic Variation', *Science* 318.5858 (21 December 2007), pp. 1842–43.

⁴⁹ See Walter Doerfler, 'Conditio Humana as Viewed by a Geneticist', in John Swinton and Brian Brock (eds.), *Theology, Disability and the New Genetics: Why Science Needs the Church* (London: T&T Clark, 2007), pp. 115–31 (122ff).

⁵⁰ See Thomas Cremer, 'Good Genes and Bad Genes: The Dangerous Marriage of Old Mendelistic Views and New Predictive Medicine', in Walter Doerfler (ed.), *Medicine at the Interface between Science and Ethics: Proceedings of the Third Weissenburg Symposium* (forthcoming).

⁵¹ For a developmental systems perspective on gene functions, see H. Frederik Nijhout, 'The Ontogeny of Phenotypes', in Susan Oyama, Paul E. Griffiths and Russel D. Gray (eds.), *Cycles of Contingency: Developmental Systems and Evolution* (Cambridge, MA: MIT Press, 2001), pp. 129–40.

We still lack sufficient understanding of the genetic processes through which genetic 'diseases' become expressed as phenotypes that can be experienced as 'illness'. One of the primary ethical problems that result from this situation is that the talk about genetic 'diseases' for the time being does not indicate a specific course of curative or preventive action, such as gene 'therapy'.⁵² While public expectations have been shaped differently, the lack of sufficient understanding of the existing forms, features and of the molecular communication processes that form the foundation of our human life makes it impossible to induce changes on this very basic level of human life without running the risk of extremely undesirable effects of such applications, such as tumours. In the light of the complexity of the genetic processes, it even seems open to question whether the metaphor of 'disease' can be adequately applied to gene functions. In accordance with the multifactorial process of ontogenesis, we have to distinguish between the following set of 'genetic diseases': '1. chromosomal abnormalities; 2. monogenic diseases; 3. complex, multifactorial or polygenic diseases; 4. imprinting defects; 5. amplifications of trinucleotide repeats; 6. diseases caused by mutations in mitochondrial DNA.'⁵³ This means that future gene therapies have to respond to abnormalities, defects, amplifications, and mutations. If this family of genetic diseases cannot be defined as program defects, but have to be understood in relation to multifactorial determinants, the discourse on genetic diseases becomes even more complex.

First, it has to relate to the external criteria of medicine which defines diseases according to the results of research and to the experiences of physicians. Secondly, it has to relate to the internal criteria of the patient's own experience of illness. The vague knowledge of a genetic predisposition, for example, to an incurable disease, may throw a person into incongruent worries about an uncertain future, and it may induce all sorts of social, political and economic discrimination. Our understanding of disease (and of health) changes where a 'disease' is understood as a molecular malfunction separate from the experience of an actual 'illness'.⁵⁴ The number of healthy people who suffer from diseases by waiting for symptoms of illness will rise with every sequenced personal genome. Thirdly, talk of genetic diseases needs to answer to the social criteria for the typical functioning of an individual.⁵⁵ To become aware of a 'disease' is not based on the mere

⁵² See Sigrid Graumann, 'Die somatische Gentherapie in der Krise - kritische Fragen an ein experimentelles Therapiekonzept', in Christoph Rehmann-Sutter and Hansjakob Müller (eds.), *Ethik und Gentherapie* (Tübingen: Francke, 2nd edn, 2003), pp. 117–33.

⁵³ Doerfler, 'Conditio Humana as Viewed by a Geneticist', pp. 122ff.

⁵⁴ See D. Leder, 'Health and Disease: The Experience of Health and Illness', in W. T. Reich (ed.), *Encyclopedia of Bioethics* (New York: Macmillan/Simon & Schuster, 1995), pp. 1106–1113.

⁵⁵ See Ulrich H. J. Körtnner, *Unverfügbarkeit des Lebens? Grundfragen der Bioethik und der medizinischen Ethik* (Neukirchen-Vluyn: Neukirchener, 2001), pp. 38–39.

facticity of phenotypes, but on the culturally variant ways we have learned to see phenotypes as 'healthy' or as 'ill'. Phenotypic variations, and the experience of illness, may stimulate research in genetics, but in most cases the causal chain between the nucleotide sequence which is identified as abnormal and the phenotype is weak.

This raises tough questions for genetic counselling. The mere facticity of abnormalities in the nucleotide sequences does not provide a patient with knowledge of a determined fate that he or she faces, but only with developmental tendencies that depend on a whole range of unknown factors. This calls for intensive dialogue between physician and patient about the way to deal with slight and undetermined risks. However, public debate has mostly been concerned with the question of how to prevent the misuse of personal genetic data by employers and insurance companies. So far, the effect of personal genetic diagnosis on the relationship of patient and physician has mostly been discussed with regard to possible therapy services. What is at stake in genetic testing, however, is a relationship which includes intensive dialogue, consolation and care. The lack of gene therapies and the need for a physician who is able to accompany a patient, and free him or her from the fixation on a future that is filled with fear, go hand in hand. The physician who does genetic counselling must be both an interpreter of bodily developments and a manager of hope. The genetic counsellor should be able to articulate that the course of somebody's life is not at all prescribed or determined by his or her DNA sequences, but open to many contingent factors that give reason to hope. Genetic counselling implies pastoral care, whether the counsellor wants it to or not. The question is whether he or she is practising good or bad pastoral care.

However, the undifferentiated talk of genetic diseases has generated the view that medicine is able to create therapies and has assigned to physicians the role of mechanic.⁵⁶ At the same time, the complexities of ontogenetic development restrict the possibilities of modelling gene therapies, and the curriculum of medical training rarely includes ethics and counselling. Even for monogenic diseases, gene therapy cannot be modelled like a surgical intervention, but has to be designed to cooperate with multifactorial communication and interaction processes that guide the development of organisms from one step to the next. If the gene is an important indicator for steps in the ontogenetic development, but not the blueprint for a whole development program, it does not seem promising to

⁵⁶ See Brian Brock, Walter Doerfler and Hans G. Ulrich, 'Genetics, Conversation and Conversion: A Discourse at the Interface of Molecular Biology and Christian Ethics', in John Swinton and Brian Brock (eds.), *Theology, Disability and the New Genetics: Why Science Needs the Church* (London: T&T Clark, 2007), pp. 146–60 (149–50).

push the development of gene surgery that aims at cutting out, switching off or exchanging disease-related genes.

As for germ-line therapy, 'there is at present no reasonable chance to deliver genes to their correct position in the genome of an individual, any attempts to correct a genome in the germ-line would most certainly lead to failure and cause disaster'.⁵⁷ While the *nil nocere* principle of course remains undisputed, every effort has to be made to clarify how germ-line therapy relates to the concept of 'therapy'. Does it try to help human beings to bear their lives, or does it aim for the replacement of these lives with ideal visions? In any case, the amount of knowledge required by germ-line therapy does not only include the mechanics of gene delivery and the well-being of the patient who is immediately affected, but also all future generations. The knowledge we need for germ-line therapies should encompass the long-term effect of genetic manipulations on the evolution of our descendants. The disaster may occur when those who have caused it are long gone, when the manipulations have become technically irreversible and future generation will have to be scrapped.

Even if we could one day make sure that engineering the human germ-line would remain without undesired side-effects, we would still be left with the question of what we expect from a longer life that would be relatively free from suffering and diseases. Why function better and live longer? This question touches upon the source of our hopes. From whom do we expect the healing of humanity? Are we strong enough to at least leave this question open and limit medicine to the prevention or cure of the diseases of present patients which would already be a big enough task? In light of the disenchantment of the genes that is taking place in new models of genetics, the ethical question is not whether we are for or against gene therapy, but which kind of gene therapy is good enough for us so that the kind of human life that we experience becomes bearable and remains humane, not only for us but also for future generations. While germ-line therapy seems disqualified, the vision of a somatic gene therapy against cancer, for example, remains within the range of possible and desirable developments. Up to now, the immunological side-effects of the introduction of genes into tumour cells has not encouraged the application of such techniques, and calls instead for the improvement of chemotherapy and other alternatives.

With a view to these considerations, the pressing ethical questions that arise from the breakthroughs in biotechnology are not so much how to draw the line between the traditional tasks of medicine (therapy) and the 'enhancement' of human life. If enhancement was the aim of medicine, gene therapy would for the time being not be preferred over against

⁵⁷ Doerfler, 'Conditio Humana as Viewed by a Geneticist', p. 126.

hormone treatments or other pharmacological interventions. As H. Tristram Engelhardt Jr. has argued,⁵⁸ there is no way to draw the line between therapy and enhancement from a moral point of view. The argument of species-typical levels of species-typical functions that shall give culture-independent accounts of diseases that legitimately demand medical treatment as opposed to culturally variable and just desirable medical interventions is not very strong. What can be regarded as 'typical' for the human species is subject to change and cannot be regarded as universally normative.

There is no universal normativity to be found in our experiences of health, needs, diseases, illness, disabling conditions and suffering. Yet the task of ethics is not only to depict species-typical conditions, but also to explore how the perception and self-understanding of human beings change within different social, medical and other practices. This is where the controversial and pressing ethical questions concerning the development of molecular medicine arise. It makes a difference whether practices of medicine, of caring, therapy and healing, bind people to their pre-established schemes of perception of their lives and those of others, or whether they open up new perceptions, and a new awareness for different, alternative judgements on their and other people's lives. The ethical question is whether this freedom for a new judgement on human life in the complex tension of its givenness and need of formation is implied in the practices of medicine, or whether these practices just answer to any claim or need that is declared as normative. We are indeed free to re-evaluate which kind of medicine we want, and we should do so with regard to the question of what kind of understanding of the human being different medical practices will convey to ourselves and to others. The structures of these practices should not in principle prevent people from being guided from utopian notions and ideals into new judgements on the reality of their life. This is where theological ethics in particular asks how far our accounts of the reality of human life need to be countered and renewed by God's external judgement. The reality of human beings cannot simply be depicted, but needs to be articulated. The theological question is how the reality of human beings is named and discerned within the life with God, and in the encounter with his contradicting and creative Word.

This includes a debate on the role of suffering in our lives. Do we have to make every effort to eliminate suffering, or is it sufficient to ameliorate pain wherever it appears and becomes unbearable for somebody? In the light of universal moral norms, there is nothing wrong with the attempt to eliminate suffering by means of medicine, at least as long as other people do not suffer from it. The lottery of 'nature' has distributed suffering very

⁵⁸ See H. Tristram Engelhardt Jr., 'Germ-Line Genetic Engineering and Moral Diversity: Moral Controversies in a Post-Christian World', in Richard Sherlock and John D. Morrey (eds.), *Ethical Issues in Biotechnology* (Lanhan, MD: Rowman & Littlefield, 2002), pp. 503–16 (512ff).

unequally, just as any other phenomena. Some people have to suffer more than others, whether through weak health, bad looks or socio-economic disadvantages. Why not at least use genetic engineering to eliminate genome related injustice, and to enhance the equal distribution of chances?⁵⁹

A dialectical reading of the attempts to abolish such human phenomena reveals that they will not make us free but will most probably cause new suffering.⁶⁰ It is only the reflection on the actual experience of suffering, aging, disability and dying that makes us see that the attempt to eliminate them would not be morally justified, or dialectic, but that it would be intrinsically ambivalent. Any reduction of pain, be it through the withdrawal from life by the use of drugs, or through the distraction of increased activities, diminishes life, as Nietzsche has shown.⁶¹ This does not indicate an affirmative attitude towards suffering, but it means to question attempts to work towards a thorough rationalization of life that replaces passivity and suffering with activity and control.⁶² The primary task of medicine is therapy, 'service', including preventative action, healing and caring for people, not the genetic elimination of suffering. However, healing and caring may entail the elimination of certain diseases, such as by vaccination or by future gene 'therapies'. Yet to eliminate, repair or prevent diseases can only be the means and not the ends of medicine, if medicine is not to become totalitarian.⁶³ We should not do everything we can to eliminate suffering and disease because we have enough to do with the amelioration of suffering and the prevention and curing of disease for everybody. The problem of the development of high-end medicine like gene therapy is not that it changes the *conditio humana*, but that it threatens to draw both resources and attention from the job of physicians to care for the poor, the suffering and to prevent people from despairing on account of disease.

The dawning age of a personalized and regenerative medicine calls for a public debate on how these new techniques influence our self-understanding, our practices and our hopes. However, the debate still

⁵⁹ For this argument see the discussion in Timothy F. Murphy and Marc A. Lappé (eds.), *Justice and the Human Genome Project* (Berkeley, CA: University of California Press, 1994). See also Allan Buchanan, Dan Brock, Norman Daniels and Daniel Wikler (eds.), *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000).

⁶⁰ See Gerald P. McKenny, *To Relieve the Human Condition: Bioethics, Technology and the Body* (Albany, NY: State University of New York Press, 1997), p. 174.

⁶¹ See Nietzsche, *Beyond Good and Evil*, Part 7, Aph. 225.

⁶² For a Freudian and phenomenological discourse on the ambivalence of the mastery of pain see Bernhard Waldenfels, 'Das überwältigte Leiden', in *Der Stachel des Fremden* (3rd edn; Frankfurt am Main: Suhrkamp, 1998), pp. 120–34.

⁶³ For this argument see Christoph Rehmann-Sutter, 'DNA-Horoskope', in *Zwischen den Molekülen. Beiträge zur Philosophie der Genetik* (Tübingen: Francke Verlag, 2005), pp. 83–108 (105).

focuses mainly on normative questions: the debate about stem cell research concentrates on the moral status of the beginning human life, while the debate on the unveiling of the personal genome aims at regulatory means to prevent the misuse of genetic data. It is time for a shift in these debates.

The latest results of genetic research do not suggest that it will be promising for genetic intervention to be modelled according to the program paradigm of ontogenesis. In order to find therapies that do not harm but instead serve patients, molecular medicine will have to comply with more complex and dynamic conceptualizations of genetics. It will have to participate in an extremely interactive and vivid field of molecular and environmental communication if ever there shall be the prospect of developing new therapies. It will at the same time have to be sensitive to the field of social interaction and relationships, so that the development of new therapies does not broaden the divide between rich and poor patients. And it will have to live in accord with the medical ethos with its prerogative for care and cure, and its task to strive for a bearable life for everybody. This calls for the development of gene drugs more than for the development of gene surgery. The new medicine will have to cooperate with nature in its creatureliness, not to govern or oppose nature. There is only one who governs the world, even down to the microcosm of genetic and epigenetic interaction. This is the complex reality of human life to which medicine needs to respond when it starts dancing with macromolecules.