

# Genetics in Community: Understanding Difference for Growth and Development

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*An astounding paradox, today, the generation following Nazism is giving the world the tools of eugenics beyond the wildest Hitlerian dreams. It is as if the unthinkable of the generation of the fathers haunted the discoveries of the sons. Scientists of tomorrow will have a power that exceeds all the powers mown to mankind. that of mini Mating the genome. Who can say or sure that it will be used only for the avoidance of hereditary illnesses? (R.O. Mason and G.E. Tomlinson, p. 433, 1998).*

*The glory and challenge of being human is that we are called on 'to play God»: we are challenged to assist nature by being creative and by controlling our own lives and the happenings of the environment. If we are to fulfill our humanity, we must take an active role in sha to our own destiny, help others fulfill their destiny, and maintain the ecology of the universe (O'Rourke and Brodeur, p.96, 1989).*

**B**ringing these two contexts together helps us to realize that manipulating the genome in a worthwhile sense implies we are responsible for the destiny of ourselves and others. It also means that while fulfilling our responsibilities, limitations must truthfully be admitted. To a certain extent, admitting these limitations is quite simply asking the relevant ethical questions: If everything cannot be done, what goods or values are most important? What are our responsibilities to these goods and values in light of a diverse community?

## INTRODUCTION

In June of 2000, five years earlier than anticipated, the scientific community recontextualized these questions unlike ever before. Hailed as a modern-day Copernican Revolution,<sup>1</sup> the announcement that Human Genome Project (HGP) had neared 90% completion and below the estimated cost of nearly \$3 billion, elated a community ready to taut discoveries in human biology and processes that would one-day cure, not simply treat human pathologies.

In general, the announcements post HGP have attempted to deal with the multiple avenues related to prevention or treatment of disease and the improvement of human health and capabilities. Though many lie outside the scope of this brief work, pre-implantation somatic cell gene therapy (SCGT) offers a context in which to explore the dialogue between science and religion to serve as a clear example by which understanding difference can lead to a specific community's growth and development. The two communities this paper attempts to bring into dialogue are the scientific community and the Roman Catholic magisterium.

An essential understanding for this argument is that the use of genetic manipulation for the purposes of therapeutic intervention is inextricably tied to in-vitro fertilization (IVF) when that discussion involves intervention pre-implantation - as is the case for pre-implantation SCGT. The inability to pursue legitimate, therapeutic interventions based on the Roman Catholic magisterial prohibition of IVF warrants a critical evaluation of that position in light of the new therapeutic reality.

### SOMATIC CELL GENE THERAPY

Somatic cell gene therapy attempts to introduce genetic material into the patient's cells for a specified therapeutic goal. Current forms of therapy for many diseases remain ineffective and often precipitate morbidity or mortality (King, 1999; Friedmann, 2000; Jenks, 2000; Smith, 1999). The link between the genetic component of such diseases and the potential benefit offered by gene therapy provides the impetus to pursue safe and effective SCGT.<sup>2</sup> The benefits of this science may one day be used to treat Lesch-Nyhad syndrome, Duchenne muscular dystrophy, cystic fibrosis, familial hypercholesterolemia, and sickle cell anemia (Blaese, 1997; Goldberg, 1998; Barinaga, 1994; Kaji and Leiden, 2001; Mattei, 2001). The ethical foundation which grounds the goal of the science is the desire to relieve human suffering (Polvino and Anderson, 1996). SCGT in conjunction with the use of IVF technology may eventually allow the therapy to intervene at the earliest possible stage, thereby *preventing* human suffering (Sliver, 2000).

Many of the current protocol proposals are to undertake gene therapy *in utero*. As these proposals stir discussion and debate, evidence suggests that we are moving closer to genetic interventions prior to implantation. Arthur Caplan and James Wilson point out that «it only makes sense to try to intervene as early as possible to prevent or slow dysfunction and morbidity (Caplan and Wilson, p. 107, 2000).» What has been found in the literature most recently, separate from desires for early intervention, is that the fetus may be the best candidate for gene therapy (Zanjani and Anderson, 1999). Therefore, an obligation may exist to use IVF technology to maximize human flourishing allowing preventative intervention at the pre-implantation level. The goal of this project to address the degree to which that obligation exists.

### SOMATIC CELL GENE THERAPY WITHIN A THEOLOGICAL ANTHROPOLOGY

The American ethos, often disturbed by a discussion of genetics with its seemingly Frankensteinian connotation, often attempts to qualify its ethical evaluation of moral acts by how one's personal rights will be protected or violated. The only apparent communal context is a focus on whether embryos are

involved in the genetic research and to what extent we are responsible for their destruction or preservation. Though a very important topic, deserving far greater discussion still, the social issues, derivative of the HGP, are far broader than this rigidly finite context.

The Catholic social tradition teaches that anthropology is the interpretation of human existence (in its origin, nature and destiny) in light of revelation (Fiorenza and Galvin, 1991; Rahner, 1978). That said, given the articulation of a shared, foundational anthropology - envisioned in terms of self-awareness, freedom and transcendence - reveals a discontinuity when articulating the social tradition's fidelity to human flourishing. Namely, the magisterium, in its prohibition of IVF, desires to uphold a noble end - that of procreation directed toward child bearing. Likewise, pre-implantation SCGT desires to uphold a noble end - that of medical attention for healthy children. The commitment of the Catholic social tradition cannot both maintain fidelity to relieve human suffering and maintain fidelity to its prohibition of IVF.

This sets up a very odd ethical situation for pre-implantation SCGT.<sup>3</sup> In essence, where IVF is used for procreative purposes, the Magisterium's position against its use would produce a peculiar result where people could not acquire an essential good - that is, medical attention for healthy children. People would be morally obligated to use resources for tangential or nonessential ends. People lacking access to effective gene therapies will be forced to rely on less effective conventional therapies that, in many cases, somewhat address the symptoms of their ailments rather than cure. This becomes especially problematic for cases of Huntington's chorea, Cystic fibrosis, and Lesch-Nyhan syndrome, to name just a few, where human persons suffer greatly and there is no cure outside a pre-implantation genetic context (Verlinsky, et al., 2002; Gibbons, et al., 1995; Rubanyi, 2001; Sellers, et al., 2001).

Given the impasse Catholic social teaching finds itself at, the paramount question seems evident: can fidelity to relieve human suffering be maintained without undermining magisterial teaching? I believe the answer is a resounding yes. However, the use of doctrinal development will be essential for this task.

## **DOCTRINAL DEVELOPMENT OF THE MAGISTERIAL PROHIBITION OF IVF**

Lived realities provide the context for moral teachings to develop and change. The organic nature of magisterial teaching allows for such growth and development. As such, lived realities may create a context that was not envisioned by those who proclaim a specific teaching. Specific to this project, genomic contexts were unrealized when the magisterium constructed its moral prohibition of IVF in 1987 in a document entitled, «Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation.» As reason begins to extrapolate the teachings of this document in accordance with revelation and human experience, an appeal to doctrinal development with regard to pre-implantation somatic cell gene therapy is appropriate and necessary.

## **SELF-AWARENESS AND DOCTRINAL DEVELOPMENT**

In order for magisterial teaching to be meaningful for the Church, revelation must be interpreted (Dulles, 1987; Sullivan, 1983). This interpretation is performed on many levels from the authori-

tative figures of the Church hierarchy to the laypersons - all of which contain a deposit or consciousness of faith (Flannery, 1996). Contemporary discussions of ecclesial authority put forward that this «sense of the faithful» is one of the principal means for the precision of church authority. In this ecclesiology, all teaching authority is rooted in, and of service to the faith (Noonan, 1995).

Hence, each individual has an obligation to be aware of his or her duty to offer insights on matters concerning the Church as well as awareness of the insights themselves - most notably in matters of doctrine and theology (Noonan, 1999). Specific to pre-implantation SCGT, self-awareness demands persons understand the promise and limits of gene therapy - the case of Jesse Gelsinger highlights this prerogative.<sup>4</sup> Where individual self-awareness is limited, a demand on communal awareness is necessary to alleviate suffering where that suffering may limit one's ability to flourish.

A moral burden also falls upon the science of gene therapy in general. Acting as our redeemers from human suffering, scientists must never fall victim to placing the value of their discoveries above unnecessary harm to human persons. The manner in which science will act upon these insights necessitates freedom's assistance - specifically as this relates to pre-implantation SCGT.

### HUMAN FREEDOM AND DOCTRINAL DEVELOPMENT

A theological anthropology of freedom argues that one should not impose an unwarranted limit to another's freedom. Imposing such a limit would be counter-intuitive to the goal of human flourishing and disrupt human movement toward that telos. Needless suffering is such a limit. Needless suffering limits one's ability to fulfill individual and communal obligations to human flourishing. If these obligations cannot be fulfilled then one is not acting freely. It therefore follows that needless suffering, which is an unwarranted limit to self-awareness is also an unwarranted limit to freedom, and should not be imposed on anyone. That said, the wrong that exists in imposing needless suffering is this: where pre-implantation SCGT proposes a solution to relieve needless suffering, not to do so by allowing a deleterious genetic anomaly to manifest is a deprivation of freedom (Harris, 1998). Furthermore, to not do so would place gene therapy in the considerably odd context of deeming it worthwhile to preserve genetic anomalies in the event that some good might come of their existence at an unspecified point and with unpredictable benefit (p. 218).

John Harris, author of *Clones, Genes and Immortality* and ethical consultant to the European Union, European Parliament and the World Health Organization, argues that society has a negative obligation not to deliberately permit harmful situations to persist (p. 214). Where limits to freedom are left in place, the moral significance of not acting to remove such limits is equivalent to the moral significance of acting to inflict harm. When all efforts are made to remove unnecessary suffering and where existing limits to freedom do not fall prey to apathy, the exercise of freedom is necessarily aligned with the telos of human flourishing - thereby legitimizing the efforts of the genetic intervention. Thus, where human freedom is aligned with human flourishing the genetic therapeutic intervention is justifiable on the grounds that individual human freedom is preserved in its proper orientation.

## TRANSCENDENCE AND DOCTRINAL DEVELOPMENT

Genetics, within the context of an awareness and freedom of the *sensus fidelium* or sense of the faithful, has revealed a teleologic end of the marital act that was unforeseen in the original context of the Magisterium's prohibition on IVF - the assurance of a healthy child. Pre-implantation somatic cell gene therapy orients the *telos* of the therapy to relieve human suffering in order to fulfill the «co-operative» role of human flourishing. For pre-implantation somatic cell gene therapy, transcendence must work to parallel the teleology of human flourishing with that of the teleoogec vision of the *imago Dei* or image of God.

The power of socially developed criteria, aided by the awareness of a teleological vision and the freedom to exercise such a vision, discerns meaning for somatic cell gene therapy. As the therapy seeks to both relieve human suffering and promote human flourishing, the moral evaluation of the therapy rests in the ability of the individual, science and the community to continually evaluate the convergence of these two parallel teleologies. Somatic cell gene therapy that recognizes this parallel will work toward human flourishing while noting the necessary role of the therapy to «work out God's design.» This insight fulfills a *telos* much greater than the preservation of properties of the act itself in addition to reinforcing the Tradition's importance for the marital act. Thus, somatic cell gene therapy via IVF holds true to the moral wisdom gained from the Tradition's insight regarding preservation of the dignity of the marital act, while transcending the present *telos* to one of far greater concern for the Catholic Church - a healthy child (Haring, 1992; Noonan 1999).

## CONCLUSION

Application of an anthropology found in Catholic Social Teaching to pre-implantation SCGT unveils a new context for understanding the teleologic ends of IVF - the procreation of *healthy* children. Doctrinal development advocates for change on the prohibition of IVF for procreative purposes where the magisterial prohibition does not adequately consider this new context. The community, through continual evaluation of two converging teleologies - human flourishing and the *imago Dei*, determines the extent to which use of the therapy is considered legitimate. Based on this standard alone, one could still argue that SCGT is an effort to use genetic research to alter our destinies, moving us away from an understanding of a diverse community where a reduction of anomalies in the gene pool eliminates currently unrecognized but vital responses to a future Darwinian evolution. This position, however, necessarily implies that human suffering - genetic variety - is more beneficial than eradicating genetic anomalies - genetic similarity.

Avoiding the implications of genetic reductionism, adequately recognizing the genetic component of human identity does support a venerable claim of Catholic morality. Namely, in a society where basic needs and purposes are understood to be common to us all, a moral community should serve these needs in order to achieve those purposes that will truly develop the person and the community in tandem. A society that does so, recognizes that our basic human commonality is the only plausible foundation for acknowledging the role of the community in evaluating moral acts. As President Clinton noted in a White House address upon completion of the HGP, «in genetic terms all human persons are 99.9 percent the same. What that means is that modern science has confirmed what we first learned from ancient faiths. The most important fact of life on this earth is our common humanity (Cahill, 2000).»

The Human Genome Project is therefore not only a Copernican Revolution in science but in anthropology, bringing us together with the understanding that the genome symbolizes our unity in a very real and contemporary context. As Lisa Sowle Cahill argues, «If we can recognize the unity of all people ... then perhaps we have a chance to reap the benefits of genetic discovery, while avoiding the more pernicious abuses (Cahill, 2000).»

## NOTES

1. This is an application of the phrase used in reference to the concept of the pre-embryo, see: Mori (2000).

2. For a more elaborate discussion of this impetus as it specifically relates to reproductive issues of women, see: Mahowald (2000).

3. This work is based on the assumption that, at some point, science will note differentiation between somatic and germline cells prior to implantation. Pursuing this hypothetical removes distracting discussion surrounding eugenics while remaining faithful to the end goal, see: Glover (1999), Pernick (2000), and Caplan (2000). Furthermore, the argument remains relevant most specifically when considering genetic therapeutic interventions in the petri dish, separate from the use of IVF for procreative purposes, see: Rubanyi (2001).

4. Jesse Gelsinger died in 1999 of an immunological reaction to the viral vector that was used to deliver the gene therapy, see: Institute for Human Gene Therapy's Response to FDA (2002).

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***Back to current electronic table of contents***