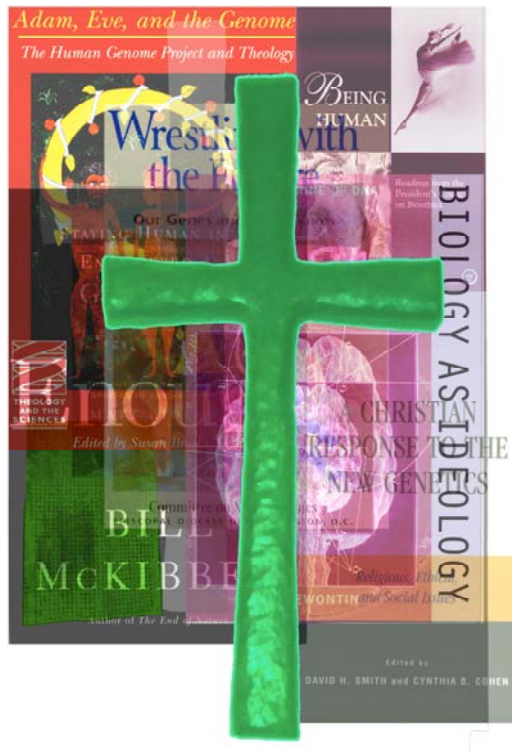


National Council of Churches USA

**FEARFULLY AND WONDERFULLY MADE:
A POLICY ON
HUMAN BIOTECHNOLOGIES**



**ADOPTED NOVEMBER 8, 2006
ORLANDO, FLORIDA**

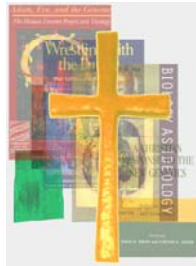


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“FEARFULLY AND WONDERFULLY MADE”*

Background and Overview

In 2000, the National Council of Churches, celebrating its 50 years of service and witness, set in motion a review of its own foundational policy statements. Some policy statements (e.g., “The Recognition of Mainland China”) were retired due to world events and the passage of time. Others have been updated to make current their insights and teachings. In reviewing the 1986 Policy “Genetic Science for Human Benefit” it was recognized that this very limited policy statement was inadequate to guide the work and witness of the Council and its member communions in the burgeoning field of biotechnologies. The 2000 General Assembly therefore established a feasibility committee to carefully review the existing policy and recommend an appropriate approach to policy development in the area of human biotechnology. That committee, reporting in 2002, recommended that a Human Biotechnology Policy Development Committee be established to address the human applications of biotechnologies. This policy statement builds upon the values and insights of the 1986 policy statement but by mandate does not address the agricultural applications of biotechnologies; therefore, this policy statement is adopted in addition to the 1986 “Genetic Science for Human Benefit” statement.

When we consider the moral and ethical dimensions of the human applications of current biotechnologies, we need to have an accurate understanding of the science on which they are based. Moral and ethical considerations also require an understanding of the social and regulatory contexts in which such biotechnologies and their human applications are emerging and developing. The complexity of the science, in addition to the complexity inherent in the diversity of our theological perspectives, and questions about how innovations will evolve into the future, created a need for us to provide preliminary material of both a theological and scientific nature. In order to provide the NCC General Assembly with the necessary background to assess, amend and adopt this proposed policy statement a companion study document entitled, “Equipping the Saints in an Age of Human Biotechnologies: A Study Document in Support of Fearfully and Wonderfully Made” has been prepared.

At the first reading of this policy statement at the 2005 General Assembly, the member communions asked that the study guide be formatted as a curriculum for use in congregations, seminaries, and other educational settings. This curriculum is now available under the title “Fearfully and Wonderfully Made: A Curriculum & Study Guide Document on Biotechnology”. Electronic editions of all these materials may also be obtained at www.nccusa.org/biotechnology

* Biblical excerpts are from the New Revised Standard Version, published by the National Council of the Churches of Christ in the USA.

The recommendations at the conclusion of this policy statement are addressed to the National Council of Churches USA, its member communions, and their constituent parts. It is anticipated that resolutions that apply the content of this policy statement to specific social, political, legislative or civil rights matters within our society will be brought to the General Assembly and/or Governing Board in years to come. By such resolutions, the churches may together bear witness to their beliefs in an age of emerging technologies.

“Injustice anywhere is a threat to justice everywhere.”¹

The Policy Development Committee responsible for the development of this Policy Statement has worked over the course of three years. Listening attentively to the concerns, suggestions for clarity and comments of the 2005 General Assembly, the Committee revised the text in response to what we heard. The most substantial change is the inclusion of section III D, “New Genetics or Old Eugenics?” which gives clearer expression of the ways in which emerging biotechnologies may exacerbate inequities and tensions of race and class, and even foster new forms of human conflict.

Ours has been a singular privilege over three years to prepare this policy statement, study guide, curriculum and related materials. We are grateful to the General Assembly of the National Council of the Churches of Christ in the USA for its adoption of “Fearfully and Wonderfully Made: A Policy Statement on Human Biotechnologies” at its General Assembly, on November 8, 2006.

In Faith,

The Policy Development Committee on Human Biotechnologies

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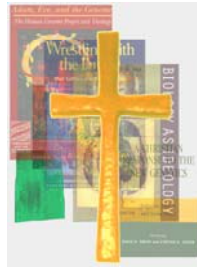
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I. Our Theological Self-Understanding

The Psalmist’s words “fearfully and wonderfully made,” from Psalm 139/138,* verse 14, reflect our awe and gratitude to the Holy One whose hidden purposes are partly revealed in our incarnate selves. The Psalmist speaks personally: “I praise You, for I am fearfully and wonderfully made,” and turns both outward to the whole world of wonders and inward to unformed parts “knit together in my mother’s womb.” It is our Creator God who does the knitting through human procreation; our genes and genesis are written in a book of infinite wisdom; the darkness of ignorance and despair is illuminated by the Divine Presence who knows and loves us no matter who we are.

The member communions of the National Council of Churches join their voices together precisely to help put ethical as well as theological concerns to the fore. Our approach must be one of reverence, humility, and deliberation, aware that scientific and social revolutions go hand in hand, and that our ecumenical witness must point to cultural as well as to natural wonders in the balance. We resist scientific reductionism and religious fundamentalism, each absolutist in its own way.

Our humility must extend as well to our own limited knowledge of God’s infinite design. Human frailties have allowed us too often to define too readily what constitutes “normal” or “whole” or “able-bodied” life. In so doing we relegate many of our sisters and brothers to the status of “other,” seeing only their differences, which we call “disabilities,” rather than seeing them as those who manifest, like us, the *imago dei* (Image of God).

We recognize that no single policy statement can express the fullness of the perceptions of our member communions, each with its own emphases and commitments to the Lord of Life. It is in the spirit of ecumenical reflection, however, to seek to include as many insights as possible, and thus we welcome discussion and response from within the churches and outside them. At the same time, new advances in biotechnologies are coming daily, often from the hands of enormously powerful commercial interests. It is not our duty to obstruct genuine progress in science, but it *is* our duty to recommend such measures as would help ensure that scientific advances progress ethically and equitably.

* This Psalm is number 138 according to the *Septuagint*.

FEARFULLY AND WONDERFULLY MADE

37 Scientific progress must, in our view, also be situated in a context of democratic
38 governance, where distorting inequities—notable in the U.S. health-care system—
39 can be addressed. The National Council of Churches is committed to the pursuit
40 of justice in church and society, racial justice, justice for women, environmental
41 justice, responses to the urban crisis, and the elimination of poverty. Without an
42 awareness of current injustices in our culture and others, any advance in
43 therapeutic (much less reproductive) biotechnologies threatens to enlarge current
44 social divisions and create new ones.

45
46 The potential impact of biotechnology on people with disabilities raises profound
47 philosophical and theological questions. Many people living with disabilities have
48 meaningful, productive lives, and would state that the major suffering in their
49 lives comes from the environment and social context: it is the physical, attitudinal,
50 and social barriers that limit them much more than their disability. Disability is
51 increasingly understood as contextual, and as simply one part, not the whole, of a
52 person's identity. As such, disability raises questions about what it means to be
53 human: whether disability is seen as defect, disease, or simply a difference in the
54 diversity of humankind; what does it mean to be a community that welcomes and
55 supports everyone. Because “disability” can so easily, and frequently, be where
56 we encounter the human capacity to make “one of us” into “the other,” it calls for
57 deep commitment to include the voices and perspectives of people with
58 disabilities and their families in the dialogue and decisions about the use of
59 biotechnology in personal, clinical, social, and political contexts.

60
61 Human history is a long testimony to our ability to draw distinctions between
62 races, tribes, clans, languages, and cultures that obscure the unity given in our
63 common heritage as the children of God. The advent of powerful new
64 biotechnologies holds both potential for overcoming such divisions, and potential
65 to deepen the rifts in human community. The Church must now join with all
66 persons of goodwill to seek the human application of those technologies that
67 strengthen both individuals and societies to better live the lives for which they
68 were created.

69
70 Beyond affirming our irreplaceable value, God's purposes are reflected in
71 our callings: each of us is qualified to serve God and our fellow human
72 beings in a unique way. All our God-given abilities were built into us to
73 equip us for a particular share of the world's work. This sense of vocation
74 includes our using these abilities for the welfare of the whole—our
75 individual value is related to our common good. Each of us has a call to
76 serve that is as unique as our fingerprints.

77 Thus, in our biblical understanding, our highest dignity as human beings is
78 not individuality in a personal sense. It is rather the paradox of sharing
79 with all humans that we are each uniquely created in the image of God:
80 “So God created humankind in his image, in the image of God he created
81 them; male and female he created them” (Genesis 1:27). The belief that
82 every person, no matter what race, nationality, gender, disability, or
83 “genetic makeup” embodies the image of God is a profound declaration of
84 the goodness God intends for all creation.

85

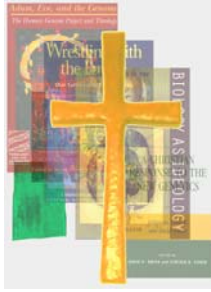
86 Psalm 8 presents the scope of these divine blessings in words that echo
87 Genesis:

88

89 **When I look at your heavens, the work of your fingers,**
90 **the moon and the stars that you have established;**
91 **what are human beings that you are mindful of them,**
92 **mortals that you care for them?**
93 **Yet you have made them a little lower than God,**
94 **and crowned them with glory and honor.**
95 **You have given them dominion over the works of your hands;**
96 **you have put all things under their feet,**
97 **all sheep and oxen, and also the beasts of the field,**
98 **the birds of the air, and the fish of the sea,**
99 **whatever passes along the paths of the seas. (NRSV 8:3-8)**

100

101 This work of applied ethics depends upon a high vision of the Church’s
102 calling. We join together as communions and individual believers to
103 advocate for the fullest potential life for those now living and generations
104 to come. We seek to be the extension of the Incarnation, the Body of
105 Christ, the one, holy, catholic, and apostolic church. In communion with
106 that body, beyond all divisions, we seek the restoration of all human
107 beings to the glorious state and destiny for which our loving God
108 continues to create us.



109 **II. The Church's Calling**

110

111 **A) Faith and Science**

112 Our world is the creation of the One God in Trinity. We come to realize this
113 through the revelation of Jesus Christ as recorded in Scripture and the Holy
114 Tradition of the Church. We investigate our world through the gifts that God has
115 given us to use in our stewardship of creation, culminating in our ability to use
116 technology and develop scientific inquiry.

117

118 Science is the discipline through which we explore God's creation. It comprises
119 sets of rules and methodologies that we use to measure and describe the material
120 world around us in as objective a manner as possible. This is contrasted but not
121 opposed to theology, the discipline through which we learn more about God and
122 divine things. The two look in different directions but are reaching for the same
123 goal, the Truth about God's creation.

124

125 Everyone is called to be a theologian because everyone is called to a life of
126 prayer. Through that prayer, grace, and subsequent spiritual advancement, the
127 theologian may come to know God as infinite and yet personal. Even then, the
128 theologian must stand in awe of the mystery of God and recognize that the Holy
129 One is unknowable, except through revelation and encounter. Those who have a
130 vocation in science will also struggle to know as much as possible about their
131 chosen field of study. They, too, must realize that they also stand before a
132 mystery, and that no one can ever know everything about God's creation.

133

134 From our Christian point of view, science is understood to be the exploration of
135 the created world, the measure and analysis of the material world in as wide a
136 framework as possible. Inasmuch as we are responsible for tending God's
137 creation, scientific endeavor is proper for a Christian because one should know as
138 much as one can about what one is responsible for. Problems arise when the
139 results of scientific investigations are misinterpreted or misused. For example, the
140 Human Genome Project that mapped the human genome gave us our first accurate
141 blueprint of human genetic structure. This is useful science; however, in its
142 experimental application it holds the capacity for both benefit and harm.

143

144 At the same time, we must recognize that theology looks to science to best
145 explain the created world. St. Basil of Caesarea used the science of his day to
146 explain God's creative work in his *Hexaemeron* (six days of creation). It would be
147 a grave mistake, however, if twenty-first-century theologians used the same

148 Aristotelian science that Basil used in the fourth century. The theological truths
 149 may be the same, but the understanding of the world has certainly changed. The
 150 Church historically responded to challenges by using new language and new ideas
 151 to more fully explain the truth. We must rise to contemporary challenges using the
 152 best tools and insights available, including those of modern science.
 153

154 When we recognize that science is a proper vocation, the question becomes:
 155 “Within what limits are these particular scientific vocations to be exercised?” Our
 156 answers must grow out of our belief in the sovereignty of God and a recognition
 157 that the exploitation of science to divide the human community is, by its very
 158 nature, sinful. Biotechnologies, like all human endeavors, stand under the
 159 judgment of God. From our faith perspective we seek then to raise questions on
 160 behalf of human well-being as we approach biotechnologies with the potential
 161 they bring for human advancement.
 162

163 **B) Biotechnology and Ethics**

164 As people of faith and stewards of God’s creation, we affirm the faithfulness of
 165 God present in human life as help and salvation, healing and wholeness. We
 166 approach the ethical questions raised by the application of new and emerging
 167 biotechnologies with the affirmation that theology informs every part of our life.
 168 All areas of life belong to God. Theological ethics undergird all that we say and
 169 do. This policy statement of the National Council of Churches is intended to help
 170 its member communions and others to understand God’s purpose in these new and
 171 emerging biotechnologies, make God’s will manifest in our common life, and find
 172 a common voice to herald God’s Good News in a faithful, responsible and just
 173 way.
 174

175 *We are faithful.* How Christians and churches make ethical assessments reflects
 176 who we are as a people and what the Church is called to be, believe, think, and do
 177 in the world. Our understanding of God shapes our moral life. What we believe
 178 about God, the cosmos, and ourselves raises profound moral questions about life
 179 and death and directs us from belief to values to concrete imperatives for action.
 180 Our ethical responses emerge from our shared life rooted in the Biblical vision of
 181 shalom – that is, the Peaceable Kingdom that God wills for creation. God’s justice
 182 is revealed in the prophets and fulfilled in Christ’s call to compassionate ministry.
 183 In short, how we deal with genetic issues impacts our life together and our life for
 184 others—our very faithfulness as Church is at stake in this strange new world.
 185

186 *We are responsible.* As member churches, we bear witness to what God intended
 187 the Church and the world to be. We share a sense of urgency that all will share the
 188 fruits of the new and emerging biotechnologies. In our stewardship of the
 189 creation, we lift high the concept of the common good—that we live in a covenant
 190 community with responsibility for one another. We face the sad fact today that
 191 receiving the material benefits of progress in biotechnology may well depend on
 192 family or societal income and may not be equally accessible to all in our global
 193 context. The persistence of poverty in the midst of great scientific advances is an

194 issue of basic justice and should deeply challenge both Church and society to
195 ensure the safety of individuals and a high quality of life for all.

196
197 *We seek justice.* Concern for the common good is both manifested in the life of
198 each community and advocated for all people. Members and churches witness to
199 God who is present in human life as help and salvation, healing and wholeness, by
200 taking on the task of safeguarding and furthering justice and peace. Having
201 knowledge of both the perils and possibilities of the new and emerging
202 biotechnologies, wonder and diversity must be held in an appreciative balance—
203 with a clear moral mandate and obligation toward, and for, the vulnerable.

204

205 **C) Pastoral Care**

206 As people of faith wrestle with the theological implications of genetics and
207 biotechnologies, we become even more aware of the issues raised about God’s
208 presence in creation, God’s will for creation, and our human responsibility as
209 faithful stewards of the gift of life and creation. People of faith have traditionally
210 turned to their communities of faith in matters of life and death.

211

212 The pastoral role as an expression of God’s presence and interpreter of belief and
213 communal understanding becomes even more important as the possibilities raised
214 by biotechnologies increase the number of decisions and turning points in life. It
215 is at those points where, with the Spirit’s help, matters of faith, hope, life and
216 death are encountered and interpreted. The challenge for pastors and lay
217 counselors is to be equipped with sufficient understanding and insight to help
218 individuals, couples and families address the profound issues that arise at the
219 intersection of faith and science. Such issues of genetic risk are often avoided by
220 both clergy and health-care professionals because of the complexity and power
221 inherent in these matters.

222

223 Individuals and families are faced with ever-increasing possibilities to shape life
224 through the use of biotechnologies. This challenges pastors to adapt traditional
225 roles and skills to a growing variety of places and times where people struggle
226 with the questions of faith that may arise, or with how to apply their own faith and
227 belief to the decisions they face. Those roles include, but are not limited to:

228

- 229 • pastoral presence at times of decision and crisis, including: marriage when
230 issues of genetics arise; decisions about pregnancy and the implications of
231 testing; guilt or blame in relation to those decisions; response to the birth of a
232 child with a genetic condition; the onset of a genetic disease; end-of-life issues
233 related to terminal care;
- 234 • pastoral assistance in determining new forms of family and selfhood in
235 relation to new forms of conception and medical treatment as individuals and
236 families struggle to understand the personal, spiritual, and theological
237 questions that are raised;
- 238 • pastoral advocacy in assisting individuals and families to acquire needed
239 services or supports, or serving as an interpreter and bridge between the

240 worlds of families, faith, and health care. That bridging role can be
241 accomplished in two ways: helping families to understand the language and
242 perspective of health-care professionals; and, helping health-care
243 professionals to understand the questions and feelings of families, particularly
244 in relation to issues of faith;

- 245 • pastoral support through a community of faith that can be called and
246 empowered to support individuals and families at times of decision, loss, and
247 need. The pastoral role of equipping and empowering a community of faith
248 can be both proactive, through preaching and education, and reactive, in
249 response to particular individuals and families. Chaplains, genetic counselors,
250 and even hospital ethics committees can become part of the larger equipment
251 of the community of faith.

252
253 The pastoral role and challenge is thus both large and complex. It is also
254 paradoxical, for it calls upon clergy to know enough about the world of genetics
255 and biotechnology to be alert and proactive, but also humble enough to know
256 what they do not know. The same is true for health-care professionals, who are
257 called to know enough about the spiritual and religious implications of their work
258 to be helpful, but also to recognize the complexity and diversity of religious
259 practices and understandings. With humility and mutual respect we look forward
260 to more appreciative collaboration and more effective support between clergy and
261 health professionals.



262 **III. Key Challenges for Church Engagement**

263
264 The terminology associated with human biotechnology is large and complex, and
265 the issues arising are many and serious. But with respect to these issues, the crux
266 of the matter lies deep within us all. Biotechnology can often lead human beings
267 to see other human beings not as beloved creatures of God whom God delights in
268 just as we are, but as instruments on which to work our will. This crux of the
269 matter therefore seeks to change grace to law, creatures to would-be Creators who
270 decline to seek God's will, considering their own will a worthy substitute.

271
272 Of the many matters we could have chosen, we selected five areas that have been
273 the subject of much current debate. We hold up these five key challenges in light
274 of our understanding of the central theological and ethical challenges of emerging
275 biotechnologies:

- 276 A) Stem cell research
- 277 B) Disabilities
- 278 C) Conduct of the biotechnology industry
- 279 D) New genetics or old eugenics?
- 280 E) Concern for the fabric of the commonweal

281
282 **A) Stem Cell Research**

283 Perhaps no area related to human applications of biotechnologies is more divisive
284 within the Christian community at present than the matter of stem cell research.
285 The divisiveness of this issue mirrors the strong opposing ethical views that
286 characterize the abortion debate in the United States, and within and among our
287 churches. The National Council of Churches, more than two decades ago,
288 determined that the hope of achieving consensus on the issue of abortion was not
289 possible, and hence the member communions resolved to forego an ecumenical
290 statement on the issue. While consensus was elusive for us, we believed we could
291 make an important contribution to the broader debate as each tradition and
292 perspective offered its insights and the theological and ethical thinking that
293 undergirds their respective conclusions.

294
295 While there are other morally problematic genetic technologies, notably
296 reproductive cloning and germ line therapy, these are not yet so controversial.
297 Proponents of reproductive cloning have yet to suggest any significant need for,
298 or benefit from, pursuing such technology, while the dangers are almost
299 incalculable. For example, the experimentation necessary to produce healthy live

300 cloned animals involved hundreds to thousands of initial “errors,” a process that
 301 would be blatantly immoral in humans. Effective germ line therapy could offer
 302 tremendous potential for eliminating genetic disease, but it would raise difficult
 303 distinctions about “normal” human conditions that could support discrimination
 304 against people with disabilities. But the human community has some time to
 305 reflect on this conundrum. Inaccuracies in somatic gene therapy have resulted in
 306 activating dangerous nearby genes and lead U.S. regulators to temporarily
 307 suspend all human gene therapy using viral vectors. As a result, the case for germ
 308 line therapy, which would affect not only those presently treated but all their
 309 descendants as well, has become even more difficult to make.

310

Embryonic Stem Cell Research

311 As with the abortion debate, much of the stem cell debate turns on the differing
 312 views we hold on the moral status of human embryos. Some have argued that
 313 from the moment of conception (however this is understood), it is a human entity
 314 and therefore irreducibly valuable, and the destruction of a human embryo at any
 315 stage of development is morally repugnant. On the other side of this question,
 316 others have argued that an embryo does not obtain full moral status until it
 317 reaches a more advanced stage of development.

318

319
 320 In the United States, federally funded research is limited to embryonic stem cell
 321 lines that were already in use prior to August 9, 2001. This federal ban does not
 322 limit private or state funding for research to create or use new human embryonic
 323 stem cell lines, nor does it affect research in other countries. The current federal
 324 restrictions have created a vacuum that has prompted some state governments to
 325 provide funding that is not available federally in order to compete with other
 326 states for highly skilled researchers and to encourage high-tech industry. The net
 327 result is a race to provide the most conducive environment for this emerging
 328 industry, and the tendency in the absence of federal regulation is for state
 329 governments to compete to be the least restrictive of business conduct. The best
 330 interests of the commonweal may not be well served in such a climate of
 331 competition.

332

333 The value of embryonic stem cell research to medical science and
 334 experimentation may yet prove disappointing to those who are hopeful that
 335 embryonic stem cells can uniquely unlock dramatic advances such as possible
 336 cures and/or treatments for diabetes, Parkinson’s disease, and organ failure.
 337 Researchers maintain that treatments to alleviate suffering and perhaps even effect
 338 cures can be learned by studying human embryonic stem cells. We are not able to
 339 judge whether these claims are well founded or overstated.

340

341 The churches of the National Council of Churches support the pursuit of medical
 342 research that may result in alleviating human suffering, and even possible cures,
 343 but hold differing strong opinions about the morality of human embryonic stem
 344 cell research. As a result of a lack of clear consensus, the National Council of
 345 Churches neither endorses nor condemns experimentation on human embryos,

346 and takes no position on the use of human embryonic stem cells for research
347 purposes. Research using human embryonic stem cells is now underway despite
348 moral, religious, ethical, and cultural objections of various groups.

349
350 We are, however, in agreement in our recognition of the irreducible sanctity of
351 human life, as well as the intrinsic moral and ethical good inherent in efforts to
352 reduce human suffering through medical science. We support medical research
353 utilizing alternative means of scientific research toward these ends. Our support
354 for alternative sources of stem cells does not prejudice the question of whether the
355 above-mentioned means are acceptable or not.

356
357 We also note suggestions within the scientific community, and specifically from
358 the President's Council on Bioethics, that alternatives may exist that may obviate
359 the sacrifice of human embryos, including but not necessarily limited to:
360

- 361 • human stem cell research using spontaneously aborted fetuses;
- 362 • stem cells taken from adult subjects;
- 363 • stem cells taken from umbilical cord blood;
- 364 • adult cells manipulated chemically or by other means and reverted to stem
365 cells.

366
367 Though of profound consequence, the theological and ethical divisions on this
368 matter that emerge from our various traditions are deep and insurmountable. On
369 these matters we will speak, each as required by conscience. We are however able
370 to identify several points of commonality, especially in the context of a highly
371 unregulated social context. Together, we:

- 372 1. strongly support legislation that would prohibit the sale or purchase of
373 human embryos;
- 374 2. oppose transferring genes from other species into human beings and
375 transferring human genes into other species as a source of tissue or
376 organs. We also oppose experimentation that might lead to an
377 intermediary human/animal species. However, we do not oppose transfer
378 of human genes that allow progress in human medical research. If such
379 research in the future demonstrates a unique benefit to human health, we
380 strongly favor a thorough public debate, including input from religious
381 leaders, which leads to the formulation of an informed consensus and
382 governmental regulation;
- 383 3. call on all private and public institutions that carry out experiments with
384 stem cells to establish publicly available guidelines, and to provide
385 rigorously independent public oversight in the absence of governmental
386 oversight;
- 387 4. while acknowledging that some of our members object strongly to
388 experimentation with human embryonic stem cells, we nevertheless
389 recognize the persistence of the practice, and therefore call for a clear,
390 comprehensive system of national and international regulatory oversight
and accountability, including provisions that take into account moral,

- 391 ethical, cultural and religious sensitivities, including clear limits on the
 392 stage to which experimental organisms are allowed to develop;
 393 5. support regulatory schema that represent the values of a broad community
 394 of stakeholders, including persons who may benefit from the medical
 395 progress made possible by the research in question; young persons who
 396 will live with the consequences of this research; as well as members of
 397 marginalized communities who have traditionally been underrepresented
 398 in decision-making processes; and persons representing the broad range
 399 of religious backgrounds in our society.
 400

401 **B) Perception of Disability**

402 The promise and danger of biotechnology is perhaps nowhere more obvious than
 403 the ways in which it affects people with disabilities and their families. There is no
 404 one “disability” perspective on the use of biotechnology. People with disabilities
 405 and their families are first of all people, with different values, theologies, and
 406 understandings about the purpose of life and God’s call to care for one another.
 407 The use of tools and processes declared to be neutral and value free, and designed
 408 to relieve suffering, holds great promise when they can support the lives of people
 409 with disabilities or alleviate unnecessary pain or suffering. But biotechnology
 410 becomes profoundly disquieting to many with disabilities when disabling
 411 conditions or predictions are equated with lifelong suffering, imperfection, or
 412 disease. When those personal and social values are combined with the power of
 413 technology to prevent the birth of a child with a disability or defect, the possibility
 414 of a new eugenics fueled by social values, market forces, and personal choice,
 415 rather than official policy, becomes quite real.
 416

417 Our reflection causes us to challenge the assumptions that everything needs to be
 418 “fixed” or “improved,” that we know how best to do this, and that just because
 419 something can be done means it ought to be done. Science cannot save us from
 420 finitude. The presupposition for life and appreciation of the whole human person
 421 as an entity argue for society to offer no disincentives to reproduction by and of
 422 persons with disabilities, in the absence of deliberate cruelty and undue hardship.
 423

424 Among the principles that have been identified by those with disabilities that
 425 ought to guide application of biotechnologies are the following, which we affirm:

- 426 1. The use of new human genetic discoveries, techniques and practices
 427 should be strictly regulated to avoid discrimination and protect fully,
 428 and in all circumstances, the human rights of people with disabilities.
- 429 2. Genetic counseling that is nondirective and rights-based should be
 430 widely available and should reflect the real experience of disability.
- 431 3. Parents should not be formally or informally pressured by medical,
 432 insurance or governmental policy to take prenatal tests or undergo
 433 “therapeutic” terminations.
- 434 4. Organizations of people with disabilities must be represented on all
 435 advisory and regulatory bodies dealing with human genetics.
- 436 5. The human rights of people with disabilities who are unable to consent
 437 are not to be violated through medical interventions.

438 **C) Conduct of the Biotechnology Industry**

439 Recent decades have seen the unprecedented growth and development of
440 biotechnology companies. Large amounts of venture capital are daily invested in
441 biotechnology pharmaceutical startups and other means of merchandizing
442 scientific advance. Without the business dimensions of the industry few
443 breakthroughs in science would ever find expression in therapeutic settings. Yet,
444 the rapid advance in science coupled with a vigorous and well-financed corporate
445 infrastructure has outstripped governmental capacity for adequate regulation.

446
447 Our North American context provides challenges, both cultural and socio-
448 economic, that threaten our identity as Christians and believers. Potent forces are
449 at play that compete to shape Christian identity and faithfulness. On the cultural
450 side, the danger of materialism is a denial of the social mandate of our faith rooted
451 in God’s gracious and generous love for all of God’s children. Our materialistic
452 culture leads to consumerism, which fosters a primary understanding of ourselves
453 as that of “buyers,” and distorts our vision so that we consume to fill our
454 emptiness, and to obscure our powerlessness and despair. In addition, unhealthy
455 exaggerated concepts of self-reliance, independence and personal privacy labeled
456 as individualism stand in opposition to biblical concepts of covenant community,
457 responsibility for one another, and care for the neighbor/stranger. Finally,
458 hedonism and its pursuit of pleasure as the sole purpose of life follows
459 individualism’s focus on personal fulfillment and jeopardizes the stewardship of
460 resources for the good of all of God’s children.

461
462 Socio-economic forces are at play as well. The United States and the Church exist
463 in a global context that demands a global analysis with a commitment for
464 equitable allocation of medical resources and funding for research. In a world of
465 poverty, wars, and hunger, a wise balancing and use of limited resources for the
466 basic necessities of life must temper our advancement of research and
467 consumption of newly available biotechnologies. Our identity as a people and our
468 faithfulness as Church must be conserved and lived with integrity.

469
470 With a commitment to view with thanksgiving the true advances made possible
471 through emerging technologies we, nonetheless, seek a more stable, accountable
472 regulatory environment in the interest of humanity and human community. Any
473 such regulatory infrastructure will address the policy issues related to:

- 474 1. **Access**--Public policies must be constructed in ways that maximize
475 access to beneficial technologies. Instituting such provisions may have
476 implications for public health policies, insurance regulation, and/or
477 allocation of research grants. Specifically of concern are the poor, those
478 lacking health-care coverage, and those who suffer from rare diseases.
- 479 2. **Privacy**--Genetic information is a deeply personal possession.
480 Individuals and groups have the right to keep private such information.
481 Public policies must be fashioned to prevent pressures from governmental
482 agencies, insurers or employers from compelling the release of such
483 information.

- 484 3. **Informed Consent**--The inherent complexity of genetics and of
485 biotechnologies provides special challenges in assuring informed consent.
486 Protocols and practices regarding informed consent must be developed to
487 address the needs of those who must make decisions about genetic testing
488 or treatments, whatever their education or background.
- 489 4. **Adequate Regulation**--Mechanisms must be developed to assess the
490 capacity of the biotechnology industry to self-regulate. Inconsistencies in
491 state regulations must be evaluated as to the risk to the consumer. An
492 international forum must be developed for assessing the inequities and
493 risks arising from the lack of global regulation. In particular, steps to limit
494 the practice of “eugenic tourism” must be pursued.
- 495 5. **Patenting**--In light of the realities of biotechnological advances, some
496 re-assessment on the part of all stakeholders of the patenting laws is
497 recommended. Agreed-upon means of assessing the consequences of
498 present intellectual property and patent laws for those suffering with
499 disease, as well as from the perspective of those seeking scientific
500 advance, must be developed. Patenting of life forms and genetic materials
501 gained from populations not fully informed of their potential use provide
502 two examples of areas of advocacy needed in the legal field.

503

504 All these questions and others require adequate national and international
505 debate. Such a discussion must include stakeholders as well as stockholders.
506 All of us, and future generations to come, are stakeholders in the codes of
507 conduct and regulatory environments that serve as the context for the
508 biotechnology industry. We salute those within the industry who have sought
509 to broaden the scope of those who participate in these discussions, but so
510 important a part of our societal life cannot be left to chance and goodwill.
511 Governmental leadership will be required to foster and sustain such a
512 conversation and churches have a substantive role to play in these
513 formulations.

514

515 **D) New Genetics or Old Eugenics?**

516 Among the most disturbing implications of the emerging biotechnologies are
517 the various potential applications that are likely to provoke or exacerbate
518 social tension and injustice. Race is a social construct, not a scientific one, yet
519 in our nation a long and sad history has attended, and continues to attend,
520 matters of race. While some of these concerns are addressed above in relation
521 to access, privacy and informed consent, greater focus is warranted both by
522 the particularity of our racial history and our ongoing struggle with racial
523 injustice. Therefore, we are attempting to bridge the divide between racial
524 injustice and genetics/biotechnology. As the member communions of the
525 National Council of Churches, we seek to speak with one voice and lift up the
526 following concerns as a point of departure for continued dialogue.

527 Among our chief concerns are:

- 528 1 The quest for human “enhancement” suggested by the burgeoning
529 cosmetic medicine industry may find powerful new possibilities in the
530 genetic modification of specific human features or characteristics, with
531 the effect that those with unfashionable traits are looked upon as
532 deficient or inferior.
- 533 2 Health disparities between racial and ethnic groups that already offend
534 moral sensibilities may be broadened by new technologies unless we
535 keep them lifted up before society.
- 536 3 Unless adequate privacy safeguards are developed and maintained,
537 individuals and whole groups of persons with a specific genetic marker
538 may face discrimination in employment, education, or insurance,
539 introducing another form of destructive social stratification. Moreover,
540 genetic screenings portend to become coercive if required for
541 employment, education or insurance coverage.
- 542 4 Those frustrated by what they view as ineffective social programs to
543 address drug abuse, violence and other social afflictions may, in an
544 unregulated environment, resort to ill-advised attempts to genetically
545 manipulate target populations.

546

547 Along with consideration of racial and ethnic bias the issue of social class and
548 economic location must be considered. Emerging biotechnologies could become a
549 forceful means of social division with the poor, or near poor, denied the health
550 benefits such technologies may offer others with greater financial means.

551

552 As in the case of disability, bias based on race, ethnicity and class have
553 historically been compounded within American society in ways that thwart
554 democracy and scandalize Christian morality. Left unchecked and unregulated
555 even the bright promise of biotechnologies could be dimmed by their application
556 in ways that foment human misery and social injustice. Such a bleak outcome
557 would lead us as a human race not into an age of new genetics but a return toward
558 a lamentable past of old eugenics.

559

560 The societal fabric can be rent or more closely woven by the ways in which our
561 societies meet the challenge of emerging biotechnologies. We believe that it is our
562 Christian duty to address these issues on behalf of the least, lost and marginalized
563 of our world.

564

565 **E) The Fabric of the Commonweal and the Future**

566 With gratitude, we affirm that creation holds the resources necessary for abundant
567 life and God intends the fullness of life for all. The present recommendations
568 concerning such matters as stem cell research, equal access to gene therapies,
569 patenting, and regulation have been developed recognizing that the economic and
570 social results of the new and emerging biotechnologies must serve the common

- 571 good. As these issues all have theological or pastoral implications, a rich
572 opportunity challenges us as the National Council of Churches. We:
- 573 1. Call on the churches to bring together the two strains of the ecumenical
574 vine we have not always joined together: the practice of the Church and
575 advocacy within our society.
 - 576 2. Challenge the notion that scientific and technological experts, politicians,
577 lawyers, lobbyists, and government officials ought to control the
578 discussion simply by virtue of their expertise. It will take all of our virtue
579 and expertise. To be a responsible Church, members must be fully
580 informed, equipped, and empowered to serve the common good.
 - 581 3. Lift a vision of partnership with regard to the development and control of
582 these powerful new tools, and believe that work for the common good
583 extends partnership.
584

585 To center ourselves anew in Jesus Christ is the great challenge emerging
586 biotechnologies present us as they offer to redefine the human. To map the values
587 of our faith is to recognize again that the human and incarnate Jesus is the one
588 who calls us to work for justice, to be a community, and to serve each other as the
589 body of Christ. In the presence of new technological advance we seek the
590 venerable values of equity, justice and fair play as the hallmarks of the
591 commonweal.
592

593 The emerging era of biotechnological discovery that now seems poised to usher in
594 a revolution in human medical innovation will no doubt also inspire the Church to
595 articulate new understandings of what it means to be human, God's own, and
596 stewards of God's creation. We have detailed here some of the most significant
597 social justice, regulatory and economic concerns that now, or soon will, confront
598 the Church as it struggles to engage the implications of human biotechnologies for
599 human life, morality and ethics, and social benefit. Some issues we have raised do
600 not lend themselves, at the present time, to specific recommendations. Time may
601 call on us to respond as the unknown future unfolds and the Church is moved to
602 respond to new challenges. In seeking to remain faithful to our charge as
603 Christians, the recommendations that follow reflect a response to the issues
604 detailed above, and also recommendations that represent positions that reflect a
605 broader elaboration of our commonly held Christian values. Collectively these
606 recommendations reflect what we believe it means to be prophetic and stand for
607 social and economic equity, the common good, and mindfulness of the needs of
608 the least among us in light of emerging biotechnological innovations.
609

610 We conclude then as we began; in awe and gratitude to the Holy One we join our
611 voices to that of the Psalmist, acknowledging that humanity is "fearfully and
612 wonderfully made." To honor the created nature of our being we offer then
613 recommendations to be embraced by the National Council of Churches that
614 together we might serve in faithfulness in embracing both the promise and
615 challenge of human biotechnologies.



616 **IV. Recommendations**

617
618 **THE NATIONAL COUNCIL OF THE CHURCHES OF CHRIST IN THE**
619 **USA GENERAL ASSEMBLY resolves:**

- 620 1. Provide an ongoing venue for member communions to discern together their
621 faithful response to the challenges presented by current advances in
622 biotechnologies. Together we will:
- 623 a. Call upon the Justice and Advocacy Commission of the National
624 Council of Churches to oversee and give leadership to the
625 Council's on-going efforts in the area of biotechnologies.
 - 626 b. Call upon the Washington Office of the National Council of
627 Churches to work in conjunction with the Washington Inter-
628 religious Staff Committee (WISC) to monitor legislative
629 developments regarding biotechnology and, as appropriate,
630 communicate the perspective of this policy statement to
631 policymakers, and as needed alert the member communions to
632 occasions requiring advocacy efforts.
 - 633 c. Be in close communication with ecumenical and interfaith
634 agencies in the states to learn of developments in biotechnology on
635 the state, local and regional levels, and to support their advocacy
636 efforts.
 - 637 d. Call upon the Office of the General Secretary and the International
638 Affairs Office to work in conjunction with other agencies on an
639 international basis, specifically the World Council of Churches,
640 Regional Ecumenical Organizations, and the world Christian
641 communions (Lutheran World Federation, World Alliance of
642 Reformed Churches, etc.) to support mutually agreed-upon points
643 of advocacy.
- 644 2. Provide an ongoing ecumenical voice informing church members and the
645 wider society of benefits and risks to the common good in the face of
646 emerging technologies.
- 647 3. Serve, along with other advocates, including those of faith groups that are
648 not members of the NCC, as an ongoing voice for the establishment of a
649 federal commission comprised of representative stakeholders from diverse
650 segments of the society, to foster a national inquiry and debate productive
651 ultimately of action to create:
- 652 a. a means for coherent federal regulatory authority and oversight
653 responsibility adequate to meet the challenges of advances in
654 human biotechnologies; and,

- 655 b. a process within the public domain for ongoing discourse
656 regarding the ethical, legal and social implications of
657 biotechnologies and the formulation of legislative
658 recommendations adequate to safeguard the individual and the
659 society while enabling research to proceed.
- 660 4. Work with other agencies to explore the potential for United Nations
661 actions and international treaty agreement provisions that may enhance
662 and extend the benefits of medical biotechnology for all persons and
663 minimize the potential risks to humanity.
- 664 5. Work within the NCC, seminaries, and pastoral care and counseling
665 networks to develop an Internet-based network of resources for ministry
666 that relates to pastoral concerns surrounding biotechnological issues,
667 including genetic screening and testing. This could include referral
668 resources for clergy who are working with individuals and families,
669 educational resources, training opportunities, etc.
- 670

671 **The National Council of Churches calls upon its member**
672 **communions to:**

- 673 1. Commend this policy statement for study and implementation to their
674 respective judicatories, pastors, congregations, and members.
- 675 2. Study biotechnology issues each in light of its own theology, engaging
676 its own membership in this inquiry.
- 677 3. Identify scientists within our member communions as valuable
678 interpreters of the scientific enterprise, guides to the wonders and beauty
679 of God’s creation, and aids in our understanding of genetics and its
680 associated technologies.
- 681 4. Identify clergy and lay members who are health-care professionals,
682 geneticists and molecular biologists, genetic counselors, and members of
683 families with experience in health-care matters, and recruit them as
684 resources for clergy and congregations who are facing biotechnology
685 issues, particularly as the Church encounters these issues on an
686 increasingly frequent and ongoing basis.
- 687 5. Develop worship materials that address the emerging needs created by
688 the new biotechnologies and the issues they present, including:
- 689 a. Prayers and liturgical materials that provide solace and comfort to
690 those who struggle with loss and distress related to genes, inherited
691 conditions, parenting and the issues raised by genetic screening
692 and testing, and other related pastoral concerns.
- 693 b. Prayers and liturgical materials that are appropriate for an evolving
694 self-understanding of our biological lives, life cycle, and occasions
695 of transition or decision.
- 696 c. Prayers of petition related to aspirations pertaining to genetic
697 testing and screening, and medical treatments with
698 genetic/intergenerational implications.
- 699 d. Prayers for scientists, both petitions for their blessing and for their
700 personal use in devotions.

- 701 6. Work to use existing mechanisms to keep clergy current with the impact
702 of these technologies on the life of parishioners and churches.

703

704 **The National Council of Churches calls upon congregations of our**
705 **member communions to:**

- 706 1. Provide study opportunities for congregation members to become
707 acquainted with issues related to biotechnologies, making use of the gifts
708 of scientists, genetic counselors, physicians, people with disabilities and
709 others that can help Christians understand, and respond to, these issues.
710 2. Support in prayer the efforts of the ecumenical community to seek the
711 well-being of both individuals and the commonweal through advocacy
712 for reform of the regulatory environment and broad national debate of
713 biotechnological issues.
714 3. Make available this policy statement and related documents from their
715 own traditions and denominations that offer insight and counsel on these
716 matters.
717 4. Offer support and nurture to congregational members struggling with
718 ethical decision making, recognizing and being sensitive to privacy
719 concerns as well as the sense of confusion, hope and despair that may be
720 commingled in such decisions.

721

722 **Parish priests, pastors, and others serving congregations are**
723 **encouraged to:**

- 724 Recognize that genetics and bioengineering raise a number of pastoral and
725 theological questions with which they, as clergy, are frequently and traditionally
726 involved. Those include:
727 1. An understanding of the value and worth of every person and the
728 pastoral roles in developing an appreciative stance toward the gift of life,
729 in all its diversity, and in shaping our identity as both individuals and as
730 a people of faith.
731 2. An understanding of free will, and the call to use our knowledge and
732 ability in faithful ways as stewards of life and creation;
733 3. Understandings of suffering and loss, and the grieving processes, rituals,
734 and traditions that have long sustained individuals, families, and
735 communities.
736 4. The pastoral role as representative of God in life and death situations
737 where people often feel anger, abandonment, and/or hope about God's
738 role as either cause and/or solution.

739 **The National Council of Churches calls upon the theological**
740 **seminaries of member communions and others engaged in**
741 **theological education to:**

- 742 1. Provide instruction to those preparing for church vocations regarding
743 ethical considerations raised by current biotechnologies, including their
744 implications for both individuals and society, and to provide ongoing
745 engagement of emerging questions prompted by current and future
746 research.
- 747 2. Expand opportunities for continuing education for clergy and health-care
748 professionals who are interested in developing expertise in addressing the
749 spiritual, theological, pastoral, and ethical dimensions of bioengineering
750 capabilities.
- 751 3. Provide instruction about the impact of biotechnological advances on
752 society and the Church and their ethical implications for pastors in
753 engaging individuals and society.
- 754 4. Identify scientists within our member communions as a valuable
755 interpretive and analytic resource to the Church.
- 756 5. Work toward creation of a national center on theology and genetics based
757 within an appropriate research and training center that would coordinate
758 its development, bring resources together, work as a collaborative pastoral
759 voice in the wider social dialogue about genetic and biotechnological
760 issues, and sponsor both research and training that will empower clergy,
761 congregations, scientists, and families as they seek to respond as people of
762 faith to these new frontiers of human identity, scientific research, human
763 technology, and theological understanding.

764
765 **The National Council of Churches calls on medical practitioners,**
766 **health-care professionals, and researchers to:**

- 767 1. Remain in ongoing dialogue with persons of broad religious backgrounds
768 about the impact of emerging biotechnologies and their impact on
769 religious sensibilities.
- 770 2. Recognize that the powerful technologies under their charge can be used
771 for evil as well as good, and that decisions made in laboratories about how
772 to use human genes can affect all humanity, both for good and for ill.
- 773 3. Update and revise guidelines pertaining to informed consent as
774 appropriate to advances in research, clinical trials, and clinical practice,
775 and in accordance with the highest standards.
- 776 4. Formulate plain-language standards for these technologies, so that as
777 broad a public as possible is included as a partner in this science.





"Fearfully and Wonderfully Made: A Policy on Human Biotechnologies"
can be accessed at: www.nccusa.org/biotechnology

Additional printed copies can be ordered by calling (888) 870-3325