

FEARFULLY AND WONDERFULLY MADE:



A POLICY ON HUMAN BIOTECHNOLOGIES

National Council of Churches USA

NOTES AND QUESTIONS

**NCC POLICY STATEMENT:
HUMAN BIOTECHNOLOGIES POLICY DEVELOPMENT COMMITTEE
“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 Communion in the burgeoning field of biotechnologies. The 2000 General Assembly therefore established a Feasibility Committee to review and recommend an appropriate approach to policy development in the area of biotechnology. That Committee, reporting in 2002, recommended that a Human Biotechnology Policy Development Committee be established to develop a new Policy Statement addressing 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 offered 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. 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” has been prepared. There we have provided an outline of current technologies, meant as a starting place for serious study by individuals and church groups who want to contribute meaningfully to biotechnology discussions. Following its theological, ethical, and biological statements, the study document reviews the insufficient, and inept levels of regulation and non-regulation in many countries of the world, and at various governmental levels within the United States. Consideration of the study document will provide important information that supports the conclusions and directions of this policy statement.

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

This document, the proposed policy statement proper, begins with a theological discussion of our anthropology or self-understanding particularly in regard to biotechnologies which now hold potential for altering ourselves and those for generations to come. A second major section discusses the nature of the Church's calling especially in relation to faith and science, biotechnology and ethics, and pastoral care. A third section describes what we take to be the key challenges for Church engagement. These challenges we describe in relation to: human embryonic stem cell research, perception of disabilities, conduct of the biotechnology industry, and the fabric of the commonweal. The fourth and final section offers recommendations for consideration and implementation by the General Assembly.

In submitting this document for consideration and a first reading, it is our prayerful hope that this draft provides a useful basis for ecumenical encounter and discernment. For the moment our time of speaking is at a conclusion and we shall, for now, listen to the insights of others as churches and individuals respond. What we hear will, of course provide the basis of changes we will make in anticipation of a final reading and adoption in 2006.

We are grateful for the opportunity to have served the ecumenical community in this way and offer for your reflection our proposed policy statement, "Fearfully and Wonderfully Made."

In Faith,

The Policy Development Committee on Human Biotechnologies

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I. Our Theological Self-Understanding

The Communion joined in this policy statement on human biotechnologies take its title from Psalm 139/138*, verse 14, to 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 churches are united in opposing cloning for human reproduction, and in wanting safeguards for “regenerative” medicine. This policy statement is meant as a guide for our members and as a witness to our values in a complex and fast-moving debate.

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 be glib about 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, reflections of the *imago dei*.

We recognize that no single policy statement can express the fullness of the perceptions of our member communions, each with their 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, advances in biotechnologies are coming by the day, often in hands of

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

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39 enormously powerful commercial interests. It is not our duty ever to obstruct
40 genuine progress in science, but it is our duty to recommend what measures we
41 see that would help that progress be genuine.
42 Scientific progress must, in our view, also be situated in a context of democratic
43 governance, where distorting inequities—notable in the US healthcare system—
44 can be addressed. The National Council of Churches is committed to the pursuit
45 of justice in church and society, including the elimination of poverty, racial
46 justice, justice for women, environmental justice, and responses to the urban
47 crisis. Without an awareness of current injustices in our culture and others, any
48 advance in therapeutic (much less reproductive) biotechnologies threatens to
49 enlarge current social divisions and create new ones.

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

66
67 Human history is a long testimony to our ability to draw distinctions between
68 race, tribe, clan, language, and culture that obscure our unity given in our
69 common heritage as the children of God. The advent of powerful new
70 biotechnologies holds both potential for overcoming such divisions, and a like
71 potential to deepen the rifts in human community. The Church must now join
72 with all persons of goodwill to seek the human application of those technologies
73 that strengthen both individuals and societies to better live the lives for which
74 they were created.

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

84 Thus, in our biblical understanding, our highest dignity as human beings is
85 not individuality in an individualistic sense. It is rather something we all
86 share, being created in the image of God: "So God created humankind in
87 his image, in the image of God he created them; male and female he
88 created them" (Genesis 1:27). The belief that every person, no matter what
89 race, nationality, gender, disability, or "genetic makeup" embodies the
90 image of God is a profound declaration of the goodness God intends for
91 all creation.

92

93 Psalm 8 presents the scope of these divine blessings in words that echo
94 Genesis:

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

106

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



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

116

117 **Faith and Science**

118 Science is “a branch of knowledge or study dealing with a body of facts or truths
119 systematically arranged and showing the operation of general laws.” Given this
120 definition, theology is a science, the science of divine things or religious truth.
121 Theology systematizes and interprets elements from scripture, tradition, worship
122 life and reason itself. What we call science today, however, has come to be
123 limited to the natural.

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 mystery
132 and that no one will 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 used unscientifically. For
140 example, the Human Genome Project that mapped the human genome gave us our
141 first accurate blueprint of human genetic structure. This is useful science,
142 however, in its experimental application phases it holds the capacity for both
143 benefit and harm.

144

145 At the same time, we must recognize that theology looks to science to best
146 explain the created world. St. Basil of Caesarea used the science of his day to
147 explain God's creative work in his *Hexaemeron* (six days of creation). It would be
148 a grave mistake, however, if twenty-first century theologians used the same
149 Aristotelian science that Basil used in the fourth century. The theological truths
150 may be the same, but the understanding of the world has certainly changed. The
151 Church historically responded to challenges by using new language and new ideas
152 to more fully explain the truth. We must rise to contemporary challenges using the
153 best tools and insights available, including those of modern science.

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

162

163 **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 undergirds 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 seek to understand God’s purpose in these
171 new and emerging biotechnologies, make God’s will manifest in our common
172 life, and find a common voice to herald God’s Good News in a faithful,
173 responsible and just way.

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

196 We seek justice. Concern for the common good is both made manifest in the life
197 of each community and advocated for all people. Members and churches witness
198 to God who is present in human life as help and salvation, healing and wholeness,
199 by taking on the task of safeguarding and furthering justice and peace. Having

200 knowledge of both the perils and possibilities of the new and emerging
201 biotechnologies, wonder and diversity must be held in an appreciative balance—
202 with a clear moral mandate and obligation toward, and for, the vulnerable.

203

204 **Pastoral Care**

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

210

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

221

222 As individuals and families are faced with ever-increasing possibilities to shape
223 life through use of genetics and biotechnologies, pastors are called to adapt
224 traditional roles and skills to a growing variety of places and times where people
225 might struggle with the questions of faith that may arise, or with how to apply
226 their own faith and belief to the decisions they face. Those roles include, but are
227 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 a birth of a
232 child with a genetic condition, support at the times of onset of a genetic
233 disease, and end of life issues 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 the role of assisting individuals and families to acquire
239 needed services or supports, or serving as an interpreter and bridge between
240 the worlds of families, faith, and healthcare. That bridging role can be two
241 ways, helping families to understand the language and perspective of health
242 care professionals and, vice versa, helping health care professionals to
243 understand the questions and feelings of families, particularly in relation to
244 their issues of faith.

- 245 • Pastoral supports 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 roles of preaching and education, and reactive,
249 in response to particular individuals and families. Chaplains, genetic
250 counselors, and even hospital ethics committees can become part of the larger
251 equipment 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 don't 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. Human beings see other human beings not as
267 beloved creatures of God whom God delights in just as we are, but as instruments
268 on which to work our will. The crux of the matter changes grace to law, creatures
269 to would-be creators, fallen humans who decline to seek God’s will, considering
270 their own will a worthy substitute.

271

272 Of the many matters we could have chosen, we selected four areas that have been
273 the subject of much current debate. We hold up these four key challenges in light
274 of our understanding of the crux of the matter: stem cell research, disabilities, the
275 conduct of the biotechnology industry, concern for the fabric of the commonweal.

276

277 **Stem Cell Research**

278 Perhaps no area related to human applications of biotechnologies is more divisive
279 within the Christian community at present than the matter of stem cell research.

280 The divisiveness of this issue mirrors the strong opposing ethical views that
281 characterize the abortion debate in the United States, and within and among our
282 churches. The National Council of Churches, more than two decades ago,
283 determined that the hope of achieving consensus on the issue of abortion was not
284 possible and hence the member communions resolved to forego an ecumenical
285 statement on the issue. While consensus was elusive for us, we believed we could
286 make an important contribution to the broader debate as each tradition and
287 perspective offered its insights and the theological and ethical thinking that
288 undergirds their respective conclusions.

289

290 While there are other morally problematic genetic technologies, notably
291 reproductive cloning and germ line therapy, these are not yet so controversial.
292 Proponents of reproductive cloning have yet to suggest any significant need for,
293 or benefit from, pursuing such technology, while the dangers are almost
294 incalculable. For example, the experimentation necessary to produce healthy live
295 cloned animals involved disposing of hundreds to thousands of initial “errors,” a
296 process that would be blatantly immoral in humans. Effective germ line therapy
297 could offer tremendous potential for eliminating genetic disease, but it would
298 raise difficult distinctions about “normal” human conditions that could support
299 discrimination against the disabled. But the human community has some time to

300 reflect on this conundrum. Since targeting inaccuracies in somatic gene therapy
301 have resulted in activating dangerous nearby genes, leading to the U.S.
302 suspending all human gene therapy using viral vectors, the case for germ line
303 therapy, which would affect not only those presently treated but all their
304 descendants as well, has become even more remote.
305

306 **Embryonic Stem Cell Research**

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

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

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

336 The churches of the National Council of Churches support the pursuit of medical
337 research that may result in alleviating human suffering, and even possible cures,
338 but hold differing strong opinions about the morality of human embryonic stem
339 cell research. As a result of a lack of clear consensus, the National Council of
340 Churches neither endorses nor condemns experimentation on human embryos,
341 and takes no position on the use of human embryonic stem cells for research
342 purposes. Research using human embryonic stem cells is now under way despite
343 moral, religious, ethical, and cultural objections of various groups.

344 We are, however, in agreement in our recognition of the irreducible sanctity of
345 human life, as well as the intrinsic moral and ethical good inherent in efforts to

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346 reduce human suffering through medical science. We support medical research
347 utilizing alternative means of scientific research toward these ends. Our support
348 for alternative sources of stem cells does not prejudice the question of whether the
349 above-mentioned means are acceptable or not.

350
351 We also note suggestions within the scientific community, and specifically from
352 the President's Council on Bioethics, that alternatives may exist that may obviate
353 the sacrifice of human embryos, including but not necessarily limited to:

- 354 • Human stem cell research made possible using spontaneously aborted
355 fetuses.
- 356 • Stem cells taken from adult subjects.
- 357 • Stem cells taken from umbilical cord blood.
- 358 • Embryonic stem cells from other species.
- 359 • Adult cells manipulated chemically or by other means and reverted to
360 stem cells.

361
362 Though of profound consequence, the theological and ethical divisions on this
363 matter that emerge from our various traditions are deep and insurmountable. On
364 these matters we will speak, each as required by conscience. We are however
365 able to identify several points of commonality on which we speak together,
366 especially in the context of a highly unregulated social context. Together, we:

- 367
368 • strongly support legislation that would prohibit the sale or purchase of human
369 embryos;
- 370 • oppose the creation of chimeras, or any experimentation that might lead to an
371 intermediary human/animal species. Should future scientific investigation into
372 minimal gene transfers between species result in clear evidence of realizable
373 medical benefits, we strongly favor a thorough public debate, including input
374 from religious leaders, which leads to formulation of an informed consensus
375 and governmental regulation;
- 376 • call on all private and public institutions that carry out experiments with stem
377 cells to establish publicly available guidelines, and to provide rigorously
378 independent public oversight in the absence of governmental oversight;
- 379 • while acknowledging that some of our members object strongly to
380 experimentation with human embryonic stem cells, we nevertheless recognize
381 the persistence of the practice; and, therefore call for a clear, comprehensive
382 system of national and international regulatory oversight and accountability,
383 including provisions that take into account moral, ethical, cultural and
384 religious sensitivities, including clear limits on the stage to which
385 experimental organisms are allowed to develop;
- 386 • support regulatory schema that represent the values of a broad community of
387 stakeholders, including persons who may benefit from the medical progress
388 made possible by the research in question, young persons who will live with
389 the consequences of this research, as well as members of marginalized
390 communities who have traditionally been under-represented in decision-

391 making processes, and persons representing the broad range of religious
392 backgrounds in our society.

393

394 **Perception of Disability**

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

409

410 Our reflection causes us to challenge the assumptions that everything needs to be
411 “fixed” or “improved” and that we know how best to do this; and that just because
412 something can be done does not mean it ought to be done. Science cannot save us
413 from finitude. The pre-supposition for life and appreciation of the whole human
414 person as an entity argue for society to offer no disincentives to reproduction by
415 and of persons with disabilities, in the absence of deliberate cruelty and undue
416 hardship.

417

418 Among the principles that have been identified by those with disabilities which
419 ought to guide application of biotechnologies, and which we affirm are:

- 420 a) The use of new human genetic discoveries, techniques and practices are
421 strictly regulated to avoid discrimination and protect fully, and in all
422 circumstances, the human rights of disabled people,
423 b) Genetic counseling that is non-directive, rights based, widely and freely
424 available and reflects the real experience of disability,
425 c) Parents are not formally or informally pressured by medical, insurance or
426 governmental policy to take prenatal tests or undergo “therapeutic”
427 terminations,
428 d) Organizations of disabled people must be represented on all advisory and
429 regulatory bodies dealing with human genetics,
430 e) The human rights of disabled people who are unable to consent are not
431 violated through medical interventions.

432

433 **Conduct of the Biotechnology Industry**

434 Recent decades have seen the unprecedented growth and development of
435 biotechnology companies. Large amounts of venture capital are daily invested in
436 biotechnology pharmaceutical start-ups and other forms of merchandizing

437 scientific advance. Without the business dimensions of the industry few
438 breakthroughs in science would ever find expression in therapeutic settings. Yet,
439 the rapid advance in science coupled with a vigorous and well-financed corporate
440 infrastructure has outstripped governmental capacity for adequate regulation.

441
442 Our North American context provides challenges, both cultural and socio-
443 economic, that threaten our identity as Christians and believers. Potent forces are
444 at play that competes to shape Christian identity and faithfulness. On the cultural
445 side, the danger of materialism is a denial of the social mandate of our faith rooted
446 in God's gracious and generous love for all of God's children. Our materialistic
447 culture leads to consumerism, which fosters a primary understanding of ourselves
448 as that of "buyers", and distorts our vision so that we consume to fill our
449 emptiness, and obscure our powerlessness and despair. In addition, unhealthy
450 exaggerated concepts of self-reliance, independence and personal privacy labeled
451 as individualism stand in opposition to biblical concepts of covenant community,
452 responsibility for one another, and care for the neighbor/stranger. Finally,
453 hedonism and its pursuit of pleasure as the sole purpose of life follows
454 individualism's focus on personal fulfillment and jeopardizes the stewardship of
455 resources for the good of all of God's children.

456
457 Socio-economic forces are at play as well. The United States and the Church
458 exist in a global context that demands a global analysis with a commitment for
459 equitable allocation of medical resources and funding for research. In a world of
460 poverty, wars, and hunger, a wise balancing and use of limited resources for basic
461 necessities of life must temper our advancement of research and consumption of
462 newly available biotechnologies. Our identity as a people and our faithfulness as a
463 church must be conserved and lived with integrity.

464
465 With a commitment to view with thanksgiving the true advances made possible
466 through emerging technologies we, nonetheless, seek a more stable, accountable
467 regulatory environment in the interest of humanity and human community. Any
468 such regulatory infrastructure will address the policy issues related to:

- 469 A. **Access**--Public policies must be constructed in ways that maximize
470 access to beneficial technologies. Instituting such provisions may have
471 implications for public health policies, insurance regulation, and/or
472 allocation of research grants. Specifically of concern are the poor, those
473 lacking health care coverage, and those who suffer from rare diseases.
- 474 B. **Privacy**--Genetic information is a deeply personal possession.
475 Individuals and groups have the right to keep private such information.
476 Public policies must be fashioned to prevent pressures from governmental
477 agencies, insurers or employers from compelling the release of such
478 information.
- 479 C. **Informed Consent**--The inherent complexity of genetics and of
480 biotechnologies provides special challenges in assuring informed consent.
481 Protocols and practices regarding informed consent must be developed to

482 address the needs of those who must make decisions about genetic testing
483 or treatments, whatever their education or background.

484 D. **Adequate Regulation**--Mechanisms must be developed to assess the
485 capacity of the biotechnology industry to self-regulate. Inconsistencies in
486 state regulations must be evaluated as to the risk to the consumer. An
487 international forum must be developed for assessing the inequities and
488 risks arising from the lack of global regulation. In particular, steps to limit
489 the practice of "eugenic tourism" must be pursued.

490 E. **Patenting**--In light of the realities of biotechnological advances, some
491 re-assessment on the part of all stake holders of the patenting laws is
492 recommended. Agreed upon means of assessing the consequences of
493 present intellectual property and patent laws for those suffering with
494 disease as well as from the perspective of those seeking scientific advance,
495 must be developed. Patenting of life forms and genetic materials gained
496 from populations not fully informed of their potential use, provide two
497 examples of areas of advocacy needed in the legal field.

498
499 All these questions and more require adequate national (and perhaps international)
500 debate. Such a discussion must include stakeholders as well as stockholders. All
501 of us, and future generations to come are stakeholders in the codes of conduct and
502 regulatory environments that serve as the context for the biotechnology industry.
503 We salute those within the industry who have sought to broaden the scope of
504 those who participate in these discussions. But so important a part of our societal
505 life cannot be left to chance and goodwill. Governmental leadership will be
506 required to foster and sustain such a conversation and churches have a substantive
507 role to play in these formulations.

508

509 **The Fabric of the Commonweal and the Future**

510 With gratitude, we affirm that creation holds the resources necessary for abundant
511 life and God intends the fullness of life for all. The present recommendations
512 concerning such matters as stem cell research, equal access to gene therapies,
513 patenting, and regulation have been developed recognizing that the economic and
514 social results of the new and emerging biotechnologies must be judged to serve
515 the common good. As these issues all have theological or pastoral implications, a
516 rich opportunity challenges us as the National Council of Churches. Both at the
517 same time and on the same issue we:

- 518 • Call on the churches to bring together the two strains of the
519 ecumenical vine we have not always joined together: the practice of
520 the church and advocacy within our society.
- 521 • Challenge the notion that scientific and technological experts control
522 the discussion simply by virtue of their expertise. It will take all of our
523 virtue and expertise. To be a responsible church, members must be
524 fully informed, equipped, and empowered to serve the common good.
- 525 • Lift a vision of partnership with regard to the development and control
526 of these powerful new tools and believe that work for the common
527 good extends partnership.

FEARFULLY AND WONDERFULLY MADE

- 528 • To center ourselves anew in Jesus Christ is the great challenge
529 emerging biotechnologies present as they offer to redefine the human.
530 To map the values of our faith is to recognize again that the human and
531 incarnate Jesus is the one who calls us to work for justice, to be a
532 community, and to serve each other as the body of Christ. In the
533 presence of new technological advance we seek the venerable values
534 of equity, justice and fair play as the hallmarks of the commonweal.
535

536 The emerging era of biotechnological discovery that now seems poised to usher a
537 revolution in human medical innovation, will no doubt also inspire the Church to
538 articulate new understandings of what it means to be human, God's own, and
539 stewards of God's creation. We have detailed here some of the most significant
540 social justice, regulatory and economic concerns that now, or soon will, confront
541 the Church as it struggles to engage the implications of human biotechnologies for
542 human life, morality and ethics, and social benefit. Some issues we have raised
543 do not lend themselves, at the present time, to specific recommendations. Time
544 may call on us to respond as the unknown future unfolds and the Church is moved
545 to respond to new challenges. In seeking to remain faithful to our charge as
546 Christians, the Recommendations that follow reflect a response to the issues
547 detailed above, as well as recommendations that represent positions that reflect a
548 broader elaboration of our commonly held Christian values. Collectively these
549 recommendations reflect what we believe it means to be prophetic and stand for
550 social and economic equity, the common good, and mindfulness of the needs of
551 the least among us in light of emerging biotechnological innovations.
552 We conclude then as we began; in awe and gratitude to the Holy One we join our
553 voices to that of the Psalmist acknowledging that humanity is "fearfully and
554 wonderfully made." To honor the created nature of our being we offer then
555 recommendations to be embraced by the National Council of Churches that
556 together we might serve in faithfulness in embracing both the promise and
557 challenge of human biotechnologies.



558 **III. Recommendations**

559
560 *The following recommendations are broadly drawn so that this policy statement*
561 *may serve the Council as a foundational document for several years even within*
562 *the context of a highly dynamic biotechnology industry. The emphasis of these*
563 *recommendations is on enabling the communions and ecumenical bodies to*
564 *prepare and participate in shaping much needed material for debate about human*
565 *applications of biotechnologies.*
566

567
568 **THE NATIONAL COUNCIL OF THE CHURCHES OF CHRIST IN THE**
569 **USA GENERAL ASSEMBLY Resolves to:**

- 570 1. Provide an ongoing venue for member communions to discern together their
571 faithful response to the challenges presented by current advances in
572 biotechnologies. Together we will,
573 a. Call upon the Justice and Advocacy Commission of the National
574 Council of Churches to oversee and give leadership to the
575 Council's on-going efforts in the area of biotechnologies
576 b. Call upon the Washington Office of the National Council of
577 Churches to work in conjunction with the Washington Interfaith
578 Staff Committee (WISC) to monitor legislative developments
579 regarding biotechnology and, as appropriate, communicate the
580 perspective of this policy statement to policymakers, and as needed
581 alert the member communions to occasions requiring advocacy
582 efforts.
583 c. Be in close communication with ecumenical and interfaith
584 agencies in the states to learn of developments in biotechnology on
585 the state, local and regional levels and to support their advocacy
586 efforts.
587 2. Provide an on-going ecumenical voice informing church members and the
588 wider society of benefits and risks to the common good in the face of
589 emerging technologies.
590 3. Serve, along with other advocates, including those of faith groups outside
591 of NCC membership, as an ongoing voice for the establishment of a
592 federal commission comprised of representative stakeholders from diverse
593 segments of the society, to foster a national inquiry and debate productive
594 ultimately of action to create:

- 595 a. A means for coherent federal regulatory authority and oversight
596 responsibility adequate to meet the challenges of advances in
597 human biotechnologies, and,
598 b. A process within the public domain for ongoing discourse
599 regarding the ethical, legal and social implications of
600 biotechnologies and formulation of legislative recommendations
601 adequate to safeguard the individual and the society while enabling
602 research to proceed.
- 603 4. Work in conjunction with other agencies on an international basis such as
604 the World Council of Churches, regional ecumenical organizations, and
605 the world Christian communions (Lutheran World Federation, World
606 Alliance of Reformed Churches, etc.) to support mutually agreed-upon
607 points of advocacy such as seeking a global ban on reproductive human
608 cloning, and germline modification (inheritable genetic modification), and,
609 a. Develop an ongoing mechanism to periodically review, monitor,
610 and identify mutually held concerns in the field of biotechnology.
611 b. Give particular attention to the economic implications and to areas
612 of inadequate regulation, as they may develop in the future.
613
- 614 5. Work with other agencies to explore the potential for United Nations
615 actions and international treaty agreement provisions which may enhance
616 and extend the benefits of medical biotechnology for all persons and
617 minimize the potential risks to humanity.
618
- 619 6. Work within the NCC, seminaries, and pastoral care and counseling
620 networks to develop an Internet-based network of resources for ministry
621 that relates to pastoral concerns surrounding biotechnological issues,
622 including genetic screening and testing. This could include referral
623 resources for clergy who are working with individuals and families,
624 educational resources, training opportunities, etc.
625

626 **The National Council of Churches Calls Upon its Member**
627 **Communities to:**

- 628 1. Commend this policy statement for study and implementation to their
629 respective judicatories, pastors, congregations, and members.
630 2. Study biotechnology issues each in light of its own theology engaging its
631 own membership in this inquiry.
632 3. Identify scientists within our member communions as valuable
633 interpreters of the scientific enterprise, guides to the wonders and beauty
634 of God's creation, and aids in our understanding of genetics and its
635 associated technologies.
636 4. Identify clergy and lay members of our communions who are health care
637 professionals, geneticists and molecular biologists, genetic counselors,
638 and members of families with experience in health care matters, and
639 recruit them as resources for clergy and congregations who are facing

- 640 biotechnology issues, particularly as the Church begins to encounter
641 these issues on a frequent and ongoing basis.
- 642 5. Develop worship materials that address the emerging needs created by
643 the new biotechnologies and the issues they present, including:
- 644 a. Prayers and liturgical materials that provide solace and comfort to
645 those who struggle with loss and distress related to genes, inherited
646 conditions, parenting and the issues raised by genetic screening
647 and testing, and other related pastoral concerns.
- 648 b. Prayers and liturgical materials that are appropriate for an evolving
649 self-understanding of our biological lives, life cycle, and occasions
650 of transition and/or decision.
- 651 c. Prayers of petition related to aspirations pertaining to genetic
652 testing and screening, and medical treatments with
653 genetic/intergenerational implications.
- 654 d. Prayers for scientists, both petitions for their blessing, and for their
655 personal use in devotions.
- 656 6. Work to use existing mechanisms to keep clergy current with the impact
657 of these technologies on the life of parishioners and church.
658

659 **The National Council of Churches calls upon congregations of our**
660 **Member Communions to:**

- 661 1. Provide study opportunities for congregation members to become
662 acquainted with issues related to biotechnologies, making use of the gifts
663 of scientists, genetic counselors, physicians, members of the disabled
664 community and others that can help Christians understand, and respond
665 to, these issues.
- 666 2. Support in prayer the efforts of the ecumenical community to seek the
667 well being of both individuals and the commonweal through advocacy
668 for reform of the regulatory environment and broad national debate of
669 biotechnological issues.
- 670 3. Make available this policy statement and related documents from their
671 own traditions and denominations which offer insight and counsel on
672 these matters.
- 673 4. Offer support and nurture to congregational members struggling with
674 ethical decision-making, recognizing and being sensitive to privacy
675 concerns as well as the sense of confusion, hope and despair which may
676 be commingled in such decisions.

677 **Parish Priests, pastors, and others serving congregations are**
678 **encouraged to:**

679 Recognize that genetics and bioengineering raise a number of pastoral and
680 theological questions with which they, as clergy, are frequently and traditionally
681 involved. Those include:

- 682 1. An understanding of the value and worth of every person and the
683 pastoral roles in developing an appreciative stance toward the gift of life,
684 in all its diversity, and in shaping our identity as both individuals and as
685 a people of faith.
- 686 2. An understanding of free will, and the call to use our knowledge and
687 ability in faithful ways as stewards of life and creation;
- 688 3. Understandings of suffering and loss, and the grieving processes, rituals,
689 and traditions that have long sustained individuals, families, and
690 communities.
- 691 4. The pastoral role as representative of God, in life and death situations
692 where people often feel anger, abandonment, and/or hope about God's
693 role as either cause and/or solution.

694
695 **The National Council of Churches calls upon the theological**
696 **seminaries of member communions and others engaged in**
697 **theological education to:**

- 698 1. Provide instruction to those preparing for church vocations regarding
699 ethical considerations raised by current biotechnologies, including their
700 implications for both individuals and society, and providing ongoing
701 engagement of emerging questions prompted by current and future
702 research.
- 703 2. Expand opportunities for continuing education for clergy and health care
704 professionals who are interested in developing expertise in addressing the
705 spiritual, theological, pastoral, and ethical dimensions of bioengineering
706 capabilities.
- 707 3. Provide instruction about the impact of biotechnological advances on
708 society and the church and their ethical implications for pastors in
709 engaging individuals and society.
- 710 4. Identify scientists within our member communions as a valuable
711 interpretive and analytic resource to the Church.
- 712 5. Work toward creation of a national center on theology and genetics based
713 within an appropriate research and training center that would coordinate
714 its development, bring resources together, work as a collaborative pastoral
715 voice in the wider social dialogue about genetic and biotechnological
716 issues, and sponsor both research and training that will empower clergy,
717 congregations, scientists, and families as they seek to respond as people of
718 faith to these new frontiers of human identity, scientific research, human
719 technology, and theological understanding.

- 720 **The National Council of Churches calls on medical practitioners,**
721 **health care professionals, and researchers to:**
- 722 1. Remain in ongoing dialog with persons of broad religious backgrounds
723 about the impact of emerging biotechnologies and their impact on
724 religious sensibilities.
 - 725 2. Recognize that the powerful technologies under their charge can be used
726 for evil as well as good, and that decisions made in laboratories about how
727 to use human genes can affect all humanity, both for good and for ill.
 - 728 3. Update and revise guidelines pertaining to informed consent as
729 appropriate to advances in research, clinical trials, and clinical practice,
730 and in accordance with the highest standards.
 - 731 4. Formulate plain-language standards for these technologies, so that as
732 broad a public as possible is included as a partner in this science.



National Council of Churches USA