A controversy is unfolding over the report that Burlington Northern Railway has been using genetic tests on workers who complain of carpal tunnel syndrome. It’s not exactly clear why they would test, but the contention has landed them in court and raised the specter of how genetic testing might be used in the workplace and what, if anything, should be done about it.

The details of the case remain fuzzy, but reports contend that the railroad told workers who reported carpal tunnel syndrome that they needed to give blood for some testing. The railroad, for its part, has stated that it requested the blood to determine whether the reported injury was work related or the result of some genetic predisposition, and to make working conditions safer. But workers complain that they’re being tested without consent, to free the company of responsibility for work-related injury.

What are the issues when employers want to perform genetic tests on workers?

There are many reasons why employers might want to use genetic tests on workers—some to protect the company, but others in the interest of both employers and workers. Testing workers in advance of their hiring or before they are exposed to a toxic environment in the workplace could provide health information for their own protection and help employers make workplace conditions safer. But such testing could also be used to reduce companies’ liability for harm to workers, in at least two ways. By testing workers in advance, employers

From sacred quest to medical miracle to philosophical touchstone to the ultimate secret weapon, the rhetoric would have it that to know the human genome is to know everything about humans.

This great power is both exciting and unnerving. Yet it is precisely this power which must be questioned: merely calling the genome “the key to human life” does not make it so. Gilbert rhapsodized that soon “one would be able to pull a CD out of one’s pocket and say ‘Here is a human being; it’s me!’” While genes do matter, physiologically and functionally (although precisely how they matter is open to debate), just because they are necessary to human life does not mean genes are equal to human life. The issue for the non-scientist, then, is to decide: what do genes mean? If AGTC are clearly part of the what makes us human beings, then how do they affect who we are as human beings?
Evolution theorist Richard Dawkins has written that whatever species arise from a particular quantity and ordering of genes are fundamentally incidental: the point of genes is to replicate more genes, and all creatures are simply vessels through which this process of replication may take place. Yet even the reductionist Dawkins does not conclude from this that all of human social life must be organized according to the dictates of biology; in fact, he argues that one may use biological information precisely to subvert it. Genes may be “selfish”, Dawkins points out, but that does not mean that people have to be selfish: we can cooperate—if we choose to do so.

What, then, do we choose to do with our genes? Some have chosen to buy and sell them, in the form of eggs and sperm. An ad which ran in the Minnesota Daily last summer offered $80,000 for the donated eggs of a tall, white, smart, young, genetically sound woman (with extra money for someone who is “especially gifted in athletics, science/mathematics, or music”). In this case, a number of related meanings have been assigned to genes: First, they are commodities, to be bought and sold (never mind the so-called “donation”). Second, genes are biological raw material, from which are generated specific physical and intellectual attributes. Third, they are more than biological material, they are prophetic material, signs of the life to come. One is led to believe that not only are there different genes, there are better and worse genes, which more than anything affect who a person becomes. Why else would someone bid $80K to try to buy those good genes?

“Good genes” may also take on another meaning. Consider the arguments of philosopher George Schedler. Writing on the feasibility of children born with defects to sue their mothers for “wrongful life”, he argues that “as long as society views defective children as not completely whole, judges will naturally view them as deserving of compensation.” James Watson has similarly argued that “The truly relevant question for most families is whether an obvious good to them will come from having a child with a major handicap… seeing the bright side of being handicapped is like praising the virtues of extreme poverty.” And former Science editor Daniel Koshland has argued that genetically-involved illnesses such as bipolar disorder, Alzheimer’s disease, schizophrenia, and heart disease “are at the root of many current societal problems.” None of these gentlemen are so blunt as to state that good genes make a good person, but it is clearly implied that bad genes lead to bad lives.

These determinations of worth, however, are made not by genes, but by human beings who contain genes. Watson asks if an obvious good will come from introducing a handicapped child into the family, dismissing those who might answer “yes.” In so doing, Watson cuts off any chance for a conversation on what constitutes a good life. And that conversation is the province of citizens, not genomes; the question of the good life is one to be mulled through reason and reflection, not “solved” by genetic engineering.

The sequencing of the human genome is a marvelous technical triumph, exposing the bits that play crucial roles in our structure and functioning as physical beings. But while humans may be genetic creatures, we are not only genetic creatures; we are still able to think for ourselves, and to decide who we are and how we will live.

References
Profile

Terri Peterson, PhD

Terri Peterson, PhD is a 2000-2001 postdoctoral fellow at the Center for Bioethics. Dr. Peterson has relocated herself from the field of political science to that of bioethics, both literally and figuratively. Prior to her fellowship at the Center, Dr. Peterson received her BA in Political Science and International Relations at the University of Wisconsin, Madison, and her PhD in Political Science from the University of Minnesota, where she specialized in contemporary political theory. During and immediately following her graduate career, she taught courses in political theory and political analysis. Her general areas of interest concern the socio-political implications of bio-technology, especially genetic and reproductive technologies, and taking part in the development of a critical bioethics. While at the Center, Dr. Peterson has been working on revisions of her dissertation, *What Is Human: Considerations of a Genetic Definition of Human Beings*, in preparation for publication. Concurrently, she is working to develop the concept of "bio-existentialism" as an integrated approach to the challenges biological research presents to the American polity. She has also written on the work of Hannah Arendt and what her thought could add to the field of bioethics.

The post-doctoral fellowship at the Center has freed her from teaching responsibilities for the year, but she has taken the opportunity to lecture in a number of University classes, as well as for community groups. The topics of these presentations have involved the history of the genetic research and the Human Genome Project, and the social and political significance of genetic research, with an emphasis on the implications of genetic testing. Dr. Peterson hopes to continue working and writing in bioethics as a political theorist.

Center News

**AWARDS**

The Center for Bioethics recently received one of four grants awarded by the University’s new Consortium on Law and Values in Health, Environment & the Life Sciences. The project, “End of Life Care for the Medically Underserved: The Homeless and the Homebound,” will support co-investigators Dr. Edward Ratner, Dr. John Song, and Dianne Bartels to perform pilot interviews in the community to determine barriers in accessing health care among the homeless and the homebound who are seriously ill. This project is one part of a larger research agenda Drs. Ratner and Song are pursuing.

**FACULTY & ASSOCIATES**

Jeffrey Kahn, PhD, MPH, has been appointed to the Association of American Medical Colleges (AAMC) Task Force on Conflicts of Interest. The Task Force is charged with formulating new principles and guidance to address both individual and institutional financial conflicts of interest in research involving human subjects. It is chaired by Dr. William Danforth, chancellor emeritus of Washington University.

Debra DeBruin, PhD, has been appointed as Project Director for the Robert H. Levi Leadership Symposium being held on June 1-2, 2001 in Elkridge, MD. This year’s topic is the “Ethics of Medicare Reform.” For more information on this project, contact the Center for Bioethics.

David Mayo, PhD, was awarded a single semester leave from the University of Minnesota, Duluth, to examine objections to physician aid-in-dying brought by the disability community.

Steven Miles, MD, received the Distinguished Service Award from the ASBH for leadership in the American Association of Bioethics and for working to form the ASBH with Stuart Youngher (Society for Health and Human Values) and Robert Arnold (Society for Bioethics Consultation).

**VISITING FACULTY**

Sumiko Takanami, PhD, RN, Associate Professor in the Nursing Department at Hokkaido University in Japan will be a visiting faculty at the Center for Bioethics through June 2001. The focus of Professor Takanami’s research will be on informed consent and patients’ rights.
can warn them of some pre-existing sensitivity or pre-disposition to a risk in the work environment. It would then be up to workers to decide whether to work in such an environment—a shift in responsibility from the employer to the worker. By testing workers after they are injured, employers could argue that workers were genetically pre-disposed to the injury rather than the workplace or its conditions being responsible, again resulting in a shift of liability.

The problems with workplace genetic testing aren’t isolated to who benefits from its use. The real concern involves what might happen to the information such testing creates. What sorts of decisions will be made based on the information and who will have access to it? Employers may try to make hiring and firing decisions based on the genetic risks of workers. In shades of an Orwellian novel, groups of potential workers with particular genetic profiles could be excluded from entire areas of employment and selected for others. In more concrete terms, workers’ benefits could be limited based on a range of genetically pre-existing conditions.

Because we have so little sense of how genetic testing might be used in the workplace, we must bend over backward to create protections. At the very least, basic ethical principles requiring worker consent to testing must be strictly enforced. But we must go further—governments must step up, starting with the federal government. Regulations to protect workers, such as the Americans with Disabilities Act (ADA) and occupational safety rules, must be clarified to determine whether they apply to workplace use of genetic testing and its results. The most obvious solution is for the government to make rules about how and when employers may use genetic information, if at all. The Clinton administration proposed model legislation on the subject and congressional legislation was even considered, but neither effort yielded results. Whatever the answers, it is certain that as more tests are developed from the genetic revolution, more employers will be tempted to use them. Can they afford not to? Can we afford to let them? We can’t wait much longer to work out the answers—it might be railway workers today but it could easily be the rest of us tomorrow.

A version of this article appeared in an “Ethics Matters” column on CNN Interactive (www.cnn.com/health).

Center for Bioethics Seminars

APR 11
*Kristin Shrader-Frechette, PhD, Department of Philosophy and Department of Biological Sciences University of Notre Dame
(cosponsored with the Faegre & Benson Lecture Series)

APR 12
Tod Chambers, PhD, Ethics & Humanities Program, Department of Medicine, Northwestern University
(cosponsored with the CHIP lecture series)

APR 16
David Healy, MD, North Wales, Department of Psychological Medicine, University of Wales

MAY 4
Eric Meslin, PhD, National Bioethics Advisory Commission

Lectures will be held at 12:15 p.m. (except where noted * 11:30 a.m.) on the University of Minnesota campus. Locations and titles of talks to be announced. Please contact the Center for Bioethics or see our website.

Ethical Decisions About Environmental Risks: Balancing Facts and Values Symposium Series

Sponsored by the Center for Environmental & Health Policy and the Center for Bioethics

APR 20
Douglas MacLean, PhD, US Naval Academy
Location: 11-157 Phillips Wagensteen Building
University of Minnesota campus

MAY 3
Strachan Donnelley, PhD, The Hastings Center
Location: 2-260 Moos Tower
University of Minnesota campus

MAY 24
Virginia Ashby Sharpe, PhD, The Hastings Center
Location: 2-101 Basic Sciences and Engineering Building, University of Minnesota campus

Lectures will be held at 12:30 p.m. on the University of Minnesota campus. Titles of talks to be announced. Please contact the Center for Bioethics or see our website.
**PHYSICIAN ASSISTED DYING**

**Assessing the State of the Debate**

Conference – Minneapolis, Minnesota – April 27 & 28, 2001

**This conference** will examine the state of the debate about physician aid in dying (PAD), against the backdrop of the most current legal and political developments. Nationally known experts in medicine, bioethics, law, and public policy will offer their diverse perspectives about the role of PAD in end of life care.

**This conference** will foster dialogue and debate among conference participants and faculty who hold diverse perspectives about the ethics of physician assisted dying in end of life care.

**Objectives**

At the completion of the conference, participants will be able to:

- Describe the status of federal and state laws related to physician-assisted dying.
- Understand the impact of the Oregon Death with Dignity Law on patients and the practice of health care professionals.
- Consider ethical obligations for their own and other professional roles in relation to dying people.
- Articulate at least two philosophical positions related to developing policies about physician-assisted dying.
- Appreciate the historical and political context in the United States, and consider what might be the future of physician-assisted dying.

**Program**

Friday, April 27, 8:00 a.m. to 4:30 p.m.

**Session 1**

Starting on the Same Page: An overview of the status of national and state legislation about physician aid in dying – Alan Meisel, JD; Susan M. Wolf, JD

**Session 2**

Impact of the Oregon Death with Dignity Law – Linda Ganzini, MD

**Session 3**

Clinical Perspectives – Moderator: Ronald Cranford, MD
Speakers: Timothy Quill, MD; Kathy Faber-Langendoen, MD; Constance Holden, RN, MSN; Edward Ratner, MD

Saturday, April 28, 9:00 a.m. to 12:45 p.m.

**Session 1**

Seeing Physician Assisted Dying in a Cultural Context: Two Views – David Mayo, PhD; Steven Miles, MD

**Session 2**

Political and Historical Context: What’s the Likely Future of Physician Assisted Dying? – David Garrow, PhD

For registration or additional information, contact the Center for Bioethics or visit our website at [www.bioethics.umn.edu](http://www.bioethics.umn.edu)
Calendar of Events

**APR 5**
Ariana Marzetti, MD, will speak on "Is an Aging Workforce a Problem? Or an Asset?" at the Outreach Program, University of Minnesota–Crookston, Crookston, MN.
For information, call 218-281-8680.

**APR 6**
Jeffrey Kahn, PhD, MPH, will speak on "Ethics of Pre-implantation Genetic Diagnosis and Creating Stem Cell Donors," at HealthPartners Institute for Medical Education, Minneapolis, MN.
For information, call 952-883-6221.

**APR 10-14**
Muriel Bebeau, PhD, is an invited respondent for the Division I Vice Presidential Address "Teaching and Learning Professional Care," at the Annual Meeting of the American Educational Research Association, Seattle, WA. For more information, call 202-223-9485 or visit website: www.aera.net.

**APR 11**
The Florene Schorske Wald Palliative Care/Hospice Lectureship, "Improving Care for Children Near the End of Life," co-sponsored by the University of Minnesota School of Nursing, the Katharine J. Densford International Center for Nursing Leadership, the Center for Spirituality and Healing, and the Center for Bioethics. 4 pm at the Radisson Hotel Metrodome, 615 Washington Avenue SE, Minneapolis, MN.
For more information, call 612-624-9440.

**APR 12**
Dianne Bartels, RN, MA, Bonnie LeRoy, MS, and Mark Hughes, PhD, MD, will speak on "Made to Order Baby-The Genetic Testing of Embryos: How Will It Impact Our Future?" sponsored by the Minnesota Association for Human Genetics.
For information, call 612-625-0425.

**APR 14**
Jeffrey Kahn, PhD, MPH, will speak on "Bioethics in the 21st Century," at the Committee on Institutional Cooperation (CIC) Academic Leadership Program, University of Iowa, Iowa City, IA. For information, call 517-353-4851.

**APR 24**
Steven Miles, MD, will speak on "Politics of Aging," for the Minneapolis Jewish Federation, Women's Division, Power and Politics Study Series, Minneapolis, MN. For information, call 952-935-5739.

**APR 27 & 28**
Physician Assisted Dying: Assessing the State of the Debate conference in Minneapolis, MN.
See page 5 for details.

**APR 30-MAY 1**
Steven Miles, MD, will speak on "Geriatrics for the Primary Care Provider: A Clinical Perspective-A Personal Approach," at the Geriatric Research, Education, and Clinical Center (GRECC)/Department of Veterans Affairs, Minneapolis, MN.
For information, call 612-725-2051.

**MAY 3-5**
Steven Miles, MD, will speak on "Drug Lords: The Politics of Medication Coverage in the US," at the American Philosophical Association Central Meeting, Minneapolis, MN. For information, call 704-687-3542.

**MAY 4**
Carl Elliott, MD, PhD, will speak on "A New Way to Be Mad! The Case of Self-Demand Amputation," for the Psychiatry Grand Rounds, Wake Forest University, Winston-Salem, NC. For information, call 336-716-4551.

**MAY 29-JUN 2**
Jeffrey Kahn, PhD, MPH, will be on the faculty at the Ethics and Biotechnology Summer Institute Conference, sponsored by Iowa State University, Ames, IA. For information, call 515-294-0054.

**JUN 11-15 & AUG 6-10**
The University of Washington, Department of Medical History & Ethics, will hold its Summer Continuing Education Courses in Bioethics. For more information, call 206-616-1864, or e-mail: mbarnard@u.washington.edu.

**JUN 23**
Steven Miles, MD, will speak on "End of Life Care: Why Fundamental Reform of Clinical Practice and Public Policy is So Hard," at the American Academy of Hospice and Palliative Medicine (AAHPM), Glenview, IL. For information, call 847-375-4712.

**JUL 25-27**
The Royal College of Nursing, Australia, is hosting a multidisciplinary International Health Ethics Conference. For information, e-mail: ulies@rcn.org.au/web site: www.rcn.org.au.

**JUL 30**
Faculty Publications

**BOOKS**

**ARTICLES**

Center Publications

**READING PACKETS**
Center packets contain an overview of legal and ethical issues, key articles, and a bibliography.

- **No. 1:** Organ Transplantation (August 1997)
- **No. 2:** Withholding or Withdrawing Artificial Nutrition and Hydration (July 1997)
- **No. 3:** Termination of Treatment of Adults (September 1997)
- **No. 5:** Distributing Limited Health Care Resources (April 1997)
- **No. 6:** Resuscitation Decisions (June 1997)
- **No. 7:** The Determination of Death (May 1997)
- **No. 8:** New Frontiers in Genetic Testing and Screening (August 1999)

**MANAGED CARE AND END-OF-LIFE CARE PACKETS**
A Center program addressing ethical issues in managed care has led to the publication of annotated bibliographies on end-of-life care.

- Ethical Issues in Managed Care (1997) — articles addressing ethical issues in managed care.

Reading packets are available for $5 each. All orders must be prepaid. To order reading packets or reports, make checks payable and mail to:

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Visit the Center’s Resource Center at N504 Boynton, 410 Church Street SE, Minneapolis, MN; online at www.bioethics.umn.edu; or contact Gay Moldow, RN, MSW, Resource Center Director, 612-624-7137, or e-mail: moldoo004@tc.umn.edu.
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