Thinking About Genetics in Everyday Life

By Karen-Sue Taussig, PhD

In the late 1980s the United States government committed to a major scientific initiative known as the Human Genome Project (HGP), earmarking $3 billion for an attempt to delineate the billions of base pairs making up the genetic material in human beings. One of the persistent promises made by the HGP’s proponents has been a revolution in medicine, including the ability to treat and/or cure a wide array of human afflictions. The constant popular and professional media barrage of genetic findings points not just to the rapid development of genetic knowledge but also to a public discourse in which genetic causality is increasingly used to explain human diversity and affliction. At the same time, a complex array of individuals, from bench scientists to clinicians, activists, lay people, and anthropologists work to question any too-easy biological reductionism about the power and meaning of genetics and genetic difference.

The recent unveiling of a complete “rough draft” sequence of the human genome in June 2000 came nearly simultaneously with publicity about the failure of virtually every gene therapy trial, including media coverage of the death of Jesse Gelsinger, a teenager who had volunteered to participate in a gene therapy trial at the University of Pennsylvania. Knowledge from the Human Genome Project has dramatically expanded the potential for genetic diagnosis, including prenatal diagnosis for a wide range of conditions, and has been employed to develop extraordinary interventions into biology, including reproductive technologies, cloning, and stem cell research. Nevertheless, there have been few, if any, clinically useful results so far coming from the vast amount of knowledge developed through this

From the Director...

On the Path to Cloning?

By Jeffrey Kahn, PhD, MPH

Cloning is making its way back into the news, with announcements by a Massachusetts biotechnology company, Advanced Cell Technology (ACT).

ACT claims it has created “normal” cows through cloning and is making public the results of its successful human embryo cloning effort—and the “recipe” for creating cloned embryos. The company says it created the clones for research into how it might produce stem cells for therapeutic purposes, and has no intention of allowing any of the embryos to be implanted into a woman’s womb to create a pregnancy.

But the announcement of a successfully cloned human embryo, even for research purposes, rekindles the fear that cloning identical copies of humans cannot be far off. The technical reality is still a distant prospect, but even early stage successes at cloning embryos is another step along the path. What are the appropriate limits on stem cell research and the application of cloning technologies?

ACT’s research focuses on so-called therapeutic cloning, where a cloned embryo is made using the DNA of a patient who could benefit from a stem cell transplant. The cloned embryo would then be allowed to divide only a few times, after which the embryonic stem cells would be collected and used to grow genetically-matched tissues or specific cell types needed to treat the same patient.

Cloning embryos for their stem cells is controversial for two reasons. For many people the intention for which embryos are created is critically important in thinking about the

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Continued on Page 6
Strokes, births, myocardial infarctions, deaths, burns, trauma, and cancer are part of daily experience in health care settings. For those who work in health care, these conditions are routine and expected. However, this is rarely the case for patients and their families. Instead, patients and families experience these events as crises; their lives are changed by them. History even becomes measured by the event: “it happened before (or after) Dad’s stroke.”

This difference in perspective marks a cultural gap between the providers and the recipients of health care. This gap is rooted in differences in experience, in roles, and often in values. As our society has come to emphasize the importance of autonomy in American health care ethics, the need to close this gap has become clear. In order to do this, the public needs to be better informed about their roles in health care decision making. Thus, the ECHO Project (Educating Community about Health Care Options) was founded in Duluth six years ago.

The ECHO Project works to educate the public about health care in several ways. The group originally evolved from membership of ethics committees in local hospitals, nursing homes, ambulance services, pharmacies, and consumers. It has focused its efforts on informing the public about health care issues and about their options in decision making, and on returning the public’s voice to health care providers and institutions.

Formally, the ECHO Project’s stated purpose is, “To promote care with dignity and reduce suffering and pain, and to become a community level resource regarding appropriate, ethical use of health care resources.” The objectives it pursues to achieve that purpose are: “1) developing guidelines for the use of intensive care and end of life issues; 2) providing common resources for health care settings and providers; and 3) being involved in community education.” These objectives are accomplished through multiple projects that involve community, institutional, and professional interactions.

Educating community members by raising awareness about health care options has been a primary focus over the past few years. This has been accomplished through facilitated discussions among groups about the roles that they may have as active participants in health care decision making.

To stimulate discussion in such groups, ECHO developed a video with three vignettes. Each vignette portrays a common medical experience (and a crisis for the patient and family); a clinical setting where a significant health care decision must be made; and ends without showing the decision the patient, family and providers make. It is then up to the audience to decide how they (individually) would proceed.

The first vignette portrays a couple who is about to deliver a 23 week pregnancy. The second shows a family that has learned their young adult son has suffered brain death. The third depicts a long term care setting where an elderly woman decides not to begin renal dialysis although it has been recommended by her physician.

In producing the vignettes, health care providers were invited to “play themselves” on the tape by doing and saying what they routinely do in similar everyday settings. The family members in the video were played by actors who were directed to improvise in response to the words and actions of these professionals with an overall goal of communicating the difficult dilemma faced by the family and providers.

Each time the video is presented, one of the three vignettes is viewed and discussed with the assistance of two trained ECHO facilitators. One person facilitates the discussion, and the other records the issues, topics, and questions raised by the participants. After two years’ of use in this format, the recorded comments have been analyzed using qualitative analysis techniques. The findings of the analysis have been returned to the ECHO subcommittee working in the area of community concerns. Through them, the findings have been presented to several groups of providers and professionals to encourage changes in institutional policies and procedures in response to public concerns.

For example, in response to the vignette about the pre-term delivery, the public identified their need for more information than was being offered, especially about the child’s potential morbidities and about potential expenses and costs of care. In response, the ECHO Pediatric Subcommittee has developed (with community obstetricians, pediatricians, and NICU physicians) guidelines for discussions with these families and
Faculty Profile
Barbara Elliott, PhD

**Barbara Elliott** is a Faculty Associate in the Center for Bioethics and Professor in the Department of Family Medicine in the School of Medicine, University of Minnesota, Duluth. She also has an appointment as an Adjunct Professor in the Department of Behavioral Sciences and serves as the Director of Clinical Research for the School of Medicine in Duluth. Her education includes degrees from the University of Minnesota, studies in Europe, a Visiting Scholar at the Hastings Center, and a Fellowship with the Kellogg National Leadership Program. Her PhD is in Medical and Family Sociology.

**Dr. Elliott’s research interests** focus on social justice issues in health care settings. Her funded projects often combine community development efforts with research. Currently most of her funded research involves adolescents’ access to health and care. Among them are projects working to reduce depression among adolescent girls (thus also reducing their use of alcohol, tobacco, other drugs, and delaying sexual activity); a demonstration project providing health, social welfare, and child care to teen-families (to keep them in school and develop employable skills); and a research project investigating the health care teens forgo in rural settings.

**Other areas of research** interest include access to care for those living with family violence, in rural settings, or as part of a minority ethnic group; with dementia, in poverty, and at life’s end. Each of these projects has been or is designed as a collaborative effort that involves the University with community and government agencies. Thus the services that are created as a part of the project can be continued after the research funding ends.

**In her teaching**, Professor Elliott is Course Director for the ethics curriculum in the School of Medicine, Duluth. She teaches an elective on family violence as a health issue, and teaches classes on international health and women’s health issues. She also serves as a Problem Based Learning (PBL) facilitator. In addition, she mentors medical students with their own research projects.

**Besides her teaching and research**, Dr. Elliott’s service includes writing a regular column on health issues for the Duluth News Tribune, serving as Examining Chaplain for ethics and moral theology for the Episcopal Diocese of Minnesota, and providing leadership for the ECHO Project (described elsewhere in this issue). In addition, she has been trained by the Red Cross in International Humanitarian Law and as an International Delegate.

**Dr. Elliott’s work** and efforts have been honored by several groups. She has been recognized by the Governor as one of Minnesota’s Marvelous Women of the Year (1995), and as an outstanding teacher by Family Medicine residents. In addition, she has received the President’s Award from the Minnesota Academy of Family Physicians, and the Stop The Violence Award from the Minnesota Medical Association.

**Selected Publications:**

**Book Chapter**

**Articles**
publicly funded project. This fact is, in tension, however, with a powerful belief among many, including physicians and researchers, that molecular medicine will take center stage in the near future.

As an anthropologist interested in scientific knowledge and practice in everyday life, I have been tracking the production, circulation, and use of genetic knowledge in the Netherlands and the United States since 1992. Here I want to reflect on some of the social implications of genetic knowledge at a moment in which it enables some choices while it constrains others. A discourse of “benefits and burdens,” “perils and possibilities,” and “danger and opportunity” surrounds contemporary discussions of genetic technologies and their presumed power to challenge the foundations of nature (Paul 1995; Strathern 1992). It is this complex interplay that makes it difficult to distinguish the benefits from the burdens in contemporary medical genetics.

Of course much of what I am concerned about is not new. Since Galton coined the term eugenics in 1883 to indicate an active interest in improving the human stock through a combination of encouraging and discouraging specific human matings, eugenics has had a place in medicine (cf. Kevles 1985; Paul 1995; Proctor 1988, 1995). Eugenics exploded as a world wide social movement during the 1920s and 30s with its greatest application in Nazi efforts to destroy lives they determined “not worth living” (Proctor 1988, 1995). As part of their post-World War II rejection of Nazi eugenics, geneticists around the world worked to delineate a scientific practice of human genetics that was distinct from eugenics (Keller 1992). Practitioners of this newer medical genetics, who are now concerned with using the powerful tools of molecular biology to uncover the basis of hereditary or congenital disease, view their field as having developed after a sharp break with prior genetic traditions. They denounce interventionist mating regulations and favor scientific scrutiny at the molecular level as a way to individualize medicine. Thus, what we are seeing today invokes not only older understandings of heredity or family predispositions but also holds out the promise of a new and precise linking of snippets of DNA and their mutations, made possible by molecular biology, to specific traits and characteristics in individuals.

Today genetic counseling and testing are predicated on a notion of “non-directive counseling,” based on the idea that providing individuals with knowledge about their health and reproductive risks will enable them to make informed decisions about such testing and their own reproduction. In her book on the social impact of amniocentesis, the anthropologist Rayna Rapp describes women and men facing the reproductive decisions enabled by amniocentesis “moral pioneers” (Rapp 1999). Indeed, many of us now increasingly face new kinds of questions about what makes an acceptable child and, therefore, what makes an acceptable human being. I have come to understand the complexity of these issues through my encounters with some of those who have the most at stake with regard to these issues: those living with genetic conditions and the researchers and clinicians with whom they interact over the course of their lives.

In 1993 John Wasmuth and his colleagues published an account of the discovery of FGFR3, the gene for achondroplasia, the most common form of heritable dwarfism, in the journal *Cell* (Shiang et al. 1994). This discovery made it a relatively simple matter to develop a prenatal test for achondroplasia. The eugenic potential of these developments are obvious and were not lost on the dwarf community. When I attended the national meetings of the Little People of America (LPA—the national lay-advocacy organization for people of short stature) in the summer of 1997, I learned that the organization’s best selling t-shirt was the one that had the words "Dwarf: Endangered Species" emblazoned across the front. Achondroplasia is a dominant condition inherited in a classic Mendelian pattern. Hence, it is extremely rare for two people of average stature to conceive a child with this condition, so it is not a condition for which a test has been routinized into prenatal testing. The condition is frequently mentioned, however, as one that could and would be included as prenatal genetic testing expands.

While those in the dwarf community that I encountered were keenly attuned to the eugenic potential of such testing, they themselves said they wanted the option to the test. One of the striking things about the LPA meetings was the extent to which dwarf children were celebrated. Given the inheritance
Karen-Sue Taussig, PhD, Faculty Associate, Center for Bioethics; Assistant Professor, Department of Anthropology; Department of Medicine, University of Minnesota Medical School.

Dr. Taussig's work has focused on the emergence, circulation, and meaning of new genetic knowledge in the United States and Europe. Her current project takes as its premise that we in the United States are in the midst of a profound world-view shift involving genetic causality and human affliction. By arguing that such a shift cannot just happen but must be attached to institutional, political, and economic changes, she is examining the diverse range of sites in which a wide array of individuals are engaged in teaching, learning, and experiencing genetics.

Selected Publications

BOOK CHAPTERS


ARTICLES
ethics of their use. For them, using embryos that were created in fertility clinics–originally intended for use in reproduction–is more acceptable than creating embryos expressly for the purpose of research. In this view, creating embryos expressly for research purposes does not treat them with adequate respect. But for others, the moral costs of creating early stage embryos exclusively for research purposes are outweighed by the promise of significant medical benefits.

While therapeutic cloning is morally very different from trying to create an identical copy of a human through reproductive cloning, the newly published techniques used to create the embryos would be exactly the same. But instead of collecting stem cells, doctors would place the cloned embryo in a woman’s uterus in the hope that it would result in a pregnancy and the birth of a cloned baby. For some, this implies that therapeutic cloning will inevitably lead to reproductive cloning.

If we believe that the benefits of therapeutic cloning outweigh its moral costs, how can we prevent the same technology being used to clone humans? . . .

The challenge for stem cell research policies is to create appropriate parameters to allow its benefits while preventing abuses or unethical applications.

**Center News**

**FACULTY & ASSOCIATES**

Jeffrey Kahn, PhD, MPH, has been appointed to the National Children’s Study Ethics Working Group.

Carl Elliott, MD, PhD, and Sharjeel Sabir, Research Assistant in the Center, have been awarded an NIH Minority supplement grant for Dr. Elliott’s ongoing project “Ethnicity, Citizenship, Family: Identity After the HGP” The major purpose of this project is to bring together scholars from science and medicine and those from the humanities and social sciences to think about the meaning of gene mapping for identity.

Joan Liaschenko, PhD, served as a consultant to the Committee to Advance Ethical Decision-Making in Community Healthcare, a joint initiative of the Toronto Community Care Access Center and Community Health Centres of Canada, funded by Human Resources Development, Canada.

Steven Miles, MD, has just returned from the Islamic Republic of Iran where he has been setting up programs to work with Afghan refugees. This work is the first connection between a US charity and Iran in many years.

**VISITING FACULTY**

Raymond DeVries, PhD, was awarded a Fulbright Senior Specialist award which allows him to work with colleagues studying research ethics at the University of Maastricht in the Netherlands for six weeks in Spring 2002.
Hold the Date – June 21 & 22, 2002
“African Genealogy & Genetics: Looking Backwards to Move Forward”

The University of Minnesota Center for Bioethics and the Powderhorn/Phillips Cultural Wellness Center will convene a national conference to discuss the reconstruction of African-American genealogies and ancestries that were disrupted and destroyed by the Trans-Atlantic slave trade. Speakers will include national and local experts on this work who are using traditional family trees and new genetic tracing to reconstruct family lineages. Civil rights leaders, scholars, and community members will discuss the merits, problems, and implications of this work. The conference is aimed at a diverse general audience. The conference will be held at the MacNamara Alumni Center, University of Minnesota, Minneapolis, MN.

For more information, contact the Center for Bioethics at 612-624-9440.

Announcing the Minnesota Network for Healthcare Ethics Committees

The Minnesota Network for Healthcare Ethics Committees (MNHEC) has been revitalized and officially launched on November 1, 2001. The University of Minnesota Center for Bioethics is the Network’s administrative home. MNHEC goals are to provide a forum for discussion of ethics committee activities through regular contact, both in-person and electronically via e-mail and listserv; to provide educational resources; and to aid in the development of new committees.

Initial efforts of the Network will focus on facilitating the sharing of knowledge among members as well as formal education. Activities include conferences and meetings; providing journal article reviews; recommending websites; answering queries regarding medical ethical issues; researching topics; collecting and distributing member institution policies; and developing statewide policies and procedures.

Network membership is available to all members of ethics committees in medical centers, long term care facilities, and individuals and institutions interested in medical ethics regardless of committee membership, throughout Minnesota and adjacent states. Current members represent institutions throughout Minnesota.

Meetings are held quarterly in Greater Minnesota and in the Twin Cities metro area. Meeting topics, dates, and times will be listed on the Center for Bioethics website, www.bioethics.umn.edu.

Please contact Gay Moldow, BSN, MSW, Network Coordinator, at 612-625-1610 or e-mail: moldo004@umn.edu, for information and membership in the Network.

Position Available
Post-Doctoral Fellowship

The Center for Bioethics at the University of Minnesota invites applications for a one year post-doctoral fellowship, available to begin in July 2002. The goal of the fellowship is to foster scholarship and career advancement in the field of bioethics. The award will be $27,000 plus health care coverage for the fellow and a partial subsidy for dependents. The fellow will be expected to commit at least 75% time to conduct his/her defined area of research. One or more Center faculty will be available to act as advisors. Research may be conceptual/philosophical, policy analysis, empirical or a combination of approaches.

Applications must be submitted by February 15, 2002. EO/AAE. For information and applications, contact the Center for Bioethics, at 612-624-9440, fax 612-624-9108, or e-mail: howar025@tc.umn.edu.
Barbara Elliott continued from Page 2

pattern of the condition, two dwarfs who seek to have their own biological children have a 25% chance of having a child of average stature, a 50% chance that one or the other of them will pass on the dwarfish gene, resulting in a dwarf child, and a 25% chance that they will both pass on the dwarfish gene. This latter possibility is described as "double dominant" and is always fatal. Thus, while every dwarf couple I met would have welcomed and celebrated the birth of a dwarf child, and some expressed a strong preference for such a child, the prenatal test for FGFR3 allows them to determine whether their fetus has the double dominant condition, enabling them to choose to terminate the pregnancy or to prepare to deliver a dying child.

Looking at how different people think about the genetic testing possibilities available to them illustrates that the definition of a healthy or acceptable person is not uniform. As the proliferation of molecular technologies expand the potential to narrow the notion of what makes an acceptable human being, it is important to enrich medical, lay, and scientific understandings of the diversity of lives worth living by critically examining such technologies in a broad social, philosophical, and historical context.

Karen-Sue Taussig continued from Page 4

brochures for pregnant mothers who are at risk of preterm labor. The committee is now investigating how discussions between providers and family members can be sensitized to the power dynamics of these interactions, to assure family/parent participation in the decision making.

Currently the ECHO Project also has a well developed initiative regarding the meaning and use of DNR/CPR orders in hospitals, and another that is designed to streamline communication when transporting and transferring patients between facilities. ECHO also serves as a resource for regional institutions about ethical issues emphasizing the voice of the community in ethical decision making. We anticipate developing other initiatives too, as time and funding permit.

Over the past six years, it has been interesting to watch the social and institutional changes that have resulted from ECHO efforts and which now provide the context for ECHO. There is now less distance between institutional ethics committees’ efforts and the ECHO Project’s focus. Both are invested in assuring that the public has better information and is prepared to participate in health care decision making.

Despite ECHO’s successes, many challenges remain. The institutions tend to be more interested in making information from the institution’s perspective available to potential patients. It remains important for the ECHO Project to listen to the public voice and represent it clearly to institutions and providers. If patient and family participation in decision making is to become meaningful, hearing the public expression of their needs and wishes while raising community awareness with information is essential.

References


Center for Bioethics Seminar Series

The Center for Bioethics presents the following seminars on the University of Minnesota campus. All lectures will be held from 12:15 - 1:30 pm, at a location to be announced. For more information, contact the Center.

JAN 11
“Naming Genes: Patenting and the Legal Construction of Authority over Human Genetic Material” by Jonathan Kahn, JD, PhD, Research Associate, Consortium on Law and Values in Health, Environment & the Life Sciences; Joint Degree Program in Law, Health & the Life Sciences; Center Associate, Center for Bioethics, University of Minnesota.

FEB 8
“Who Decides? The Compositions and Characteristics of Institutional Review Boards” by Raymond Devries, PhD, Visiting Faculty, Center for Bioethics, University of Minnesota, and Carl Forsberg, Science Department, Breck School Research Program.

MAR 8
“Do Patients Have a Clue? A Look at How to Improve Patients’ Health Care Decisions” by Peter Ubel, MD, Director, Program for Improving Health Care Decisions, Ann Arbor VAMC, and University of Michigan.

APR 12
“The Value of Life According to Islam” by Yasemin Oguz, MD, PhD, Post-Doctoral Fellow, Center for Bioethics, University of Minnesota.

MAY 10
“Health Care in Nazi Germany: Meanings and Morality” by Andre Mineau, PhD, Department of Religious Studies and Ethics, University of Quebec, Rimouski.

Save the Date

February 26, 2002

This day-long national conference will explore the legal, ethical, and clinical implications of pharmacogenomics. Sponsored by the Consortium on Law and Values in Health, Environment & the Life Sciences, the Joint Degree Program in Law, Health & the Life Sciences, the Center for Bioethics, College of Pharmacy, MD/PhD Program, and Department of Pharmacology, University of Minnesota. The conference will be held at Cowles Auditorium, Hubert H. Humphrey Center, University of Minnesota West Bank campus.

For more information, call 612-625-0055.
Calendar of Events

JAN 11
Steven Miles, MD, will speak on “Bedrails and Restraints: Emerging Data” at the VA Medical Center, Minneapolis, MN. For information, call 612-725-2000, ext. 3997.

JAN 18
Jeffrey Kahn, PhD, MPH, will speak on “Ethics, Stem Cells, and Genetic Technologies in the 21st Century” for the Minnesota Hospital and Healthcare Partnership Trustee Meeting, Plymouth, MN. For information, call 651-641-1121.

JAN 23
Steven Miles, MD, will speak on “Bedrails and Restraints” at the Sioux Valley Hospital Center for Ethics and Caring, Sioux Falls, SD. For information, call 605-333-6381.

FEB 4
Jeffrey Kahn, PhD, MPH, will speak on “Bioethics in the 21st Century” for the Rice Memorial Hospital Continuing Medical Education Seminar, Willmar, MN. For information, email: jhof@rice.willmar.mn.us

FEB 8

FEB 12
Jeffrey Kahn, PhD, MPH, will speak on “Ethical Issues in Cancer Clinical Trials” at the Metro Minnesota Chapter of the Oncology Nursing Society, location to be announced. For information, call 612-273-2946.

FEB 14-15
Jeffrey Kahn, PhD, MPH, will speak at Bioethics Update 2002 on “Commentary on the Works of Ruth Faden” at The State of Bioethics: Kennedy Institute of Ethics 30th Anniversary Conference, sponsored by the Kennedy Institute of Ethics, Georgetown University, Washington, DC. For information, call 202-687-8099.

FEB 28-MAR 1
Steven Miles, MD, will give two presentations for the Broward General Medical Center and the University of Miami Florida Bioethics Network, Ft. Lauderdale, FL. For information, call 954-355-5653.

MAR 12
Steven Miles, MD, will speak on “Soda Pop and Your Daughters’ Bones: Schools and Aging” at the Minneapolis Women’s Club, Minneapolis, MN. For information, call 651-430-2954.

APR 5-7
Jeffrey Kahn, PhD, MPH, will speak on “The Use of Stem Cells and Cloning in Medicine” for the Hennepin Medical Society Senior Physicians Association, Minneapolis, MN. For information, call 612-623-3030.

APR 19
Jeffrey Kahn, PhD, MPH, will speak on “Ethics and Stem Cell Research” for the Twin Cities Eye Meeting and Department of Ophthalmology, University of Minnesota, location to be announced. For information, call 612-625-4400.

APR 25-26
Carl Elliott, MD, PhD, will give a talk at the California State Polytechnic University, Pomona, Spring Ethics Conference, Pomona, CA. For information, call 612-624-9440.

APR 29
Jeffrey Kahn, PhD, MPH, will speak on “Is Payment for Organ Donation Ethical?” at the American Transplant Congress/Transplant 2002, in Washington, DC. For information, call 856-439-0880.

APR 29
Steven Miles, MD, will participate in a debate on “Ethics and Economics of Universal Health Care Coverage: Why Do We Care?” for the 2002 Robert Wood Johnson Clinical Scholars Program, Health Economics Symposium in Chicago, IL. For information, call 773-702-2313.

Elder Learning Institute Bioethics Series on the University of Minnesota Campus
Center faculty will participate in an eight week lecture series beginning March 28 - May 16, 2002. The series will address contemporary issues in bioethics. For more information, call 612-624-7847.
Recent Faculty Publications

**BOOKS**


**BOOK CHAPTERS**


**ARTICLES**


Ratner E. Role of Home Care in Long-Term Care. *Clinic in Family Practice* 2001;3(3):491-500.


**ANNOTATED BIBLIOGRAPHY**

Ethical Issues in Managed Care (1997) — articles addressing ethical issues in managed care.
The Spring 2002 Bioethics Examiner submission deadline is Wednesday, March 6. Submissions should be addressed to: Bioethics Examiner, Center for Bioethics, University of Minnesota, N504 Boynton, 410 Church Street SE, Minneapolis, MN 55455-0346. Telephone: 612-624-9440 Fax: 612-624-9108 E-mail: holmb006@umn.edu

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