The Summer 2002 Bioethics Examiner submission deadline is Wednesday, June 5. 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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Autonomy: Cutting the Gordian Knot

By N. Yasemin Oguz, MD, PhD

One of the most significant achievements of modern Western medicine in the second half of the 20th century is introduction of the discourse on professional values into the daily life of health care professionals. This development has had its impact on other countries, which adopt modern Western medicine as well (Asai; Tharien). Professionals have adopted both Western technologies and values. For some of these countries, adopting the universe of values that are structured according to the conceptual framework of the Western culture is not as easy as adopting the technological developments (Wang and Marsh; Harrison et al). In this article, autonomy, one of the most problematic concepts for Eastern societies, will be discussed with special reference to Turkey, which has its own characteristics among other Eastern cultures.

At the very beginning of this discussion, it is wise to identify two major problems that emerge while writing this kind of article. First, one of these problems is the illusion caused by dividing the cultural geography of the world into two as West and East. There is a vast spectrum of Eastern cultures, which are fundamentally different from each other; and there is more than one Western culture as well. The reductionist approach to the cultural geography of the world is an obstacle for understanding the contemporary era. The second problem is the impact of the relationship of the individuals who constitute the Western and Eastern societies with their own

From the Director...

The Questionable Future of Unregulated Reproduction

By Jeffrey Kahn, PhD, MPH

The American Society for Reproductive Medicine, the major professional society for the specialty, recently issued a ruling that recommends restricting use of a technique that can test the gender of embryos and therefore select the gender of future children.

The ruling is a revision of an earlier position suggesting that using gender genetic testing on embryos would be acceptable. That position raised serious ethical concerns, however, both because it seemed to endorse the practice of choosing embryos for no other reason than their gender, and because it would entail first making embryos, and then choosing some but discarding others—again based solely on their gender. The new ruling states that “the need for gender variety in a family does not at this time justify the use” of genetic testing of embryos.

Will this ruling prevent people from seeking to implant only male or female embryos? Should there be rules about how far reproductive technologies should be allowed to go, and if so, who should make and enforce them?

Continued on Page 2
Autonomy is one of the most interesting concepts to come out of this imported package, and it is the most frequently addressed concept in the studies of biomedical ethics in Turkey. Cultures. Undoubtedly this relationship largely shapes their value judgments. Generally there is a failure to understand that every Muslim does not reflect his religious beliefs in his values and daily life in the same way. Every Catholic does not think about euthanasia as the Pope does, and every Turk is not the epitome of hospitality. This fact is usually ignored, and consequently individual versions of value judgments are sacrificed for a generalization that leads to absurdity (Evanoff). What I have to say about the problems in applying autonomy in the everyday practice of medicine in Turkey is applicable to the other Eastern cultures only to a certain extent.

The formal study of biomedical ethics began at the end of the 1970s in Turkey (Ors et al). Most of the early references originated from Anglo-Saxon literature (Oguz). During the period of the Ottoman Empire (1299-1920), every effort towards modernization received its concepts, knowledge, and technology from Europe, and medicine was no exception to this (Unat). According to this well established tradition, the academicians in our present age do not feel uncomfortable about the establishment of this new area of study by importing the Western values and principles as a whole. Autonomy is one of the most interesting concepts to come in this imported package, and it is the most frequently addressed concept in the studies of biomedical ethics in Turkey.

At the beginning of the studies on autonomy, the academicians themselves had difficulty in fully understanding the concept, foreseeing its applications in the practice, and appreciating the overall consequences for medicine. While these difficulties still exist, it was generally accepted that autonomy as a concept is the basic element of Western biomedical ethics and that many aspects of Western medical practice originated from this concept (Oguz and Arda). Without autonomy, it would not be possible to decode Western bioethical discourse (Beauchamp and Childress). Naturally, the next step was to introduce this concept to the other health professionals, adopting the procedures stemming from this concept and getting a step closer to modern Western medicine. Many serious problems have arisen during this phase however. First of all, the health professional who is willing to respect the patient’s autonomy in his daily practice would likely not find an autonomous individual in the Western sense of the term (Ersoy et al). The phrase “a health professional who is willing to respect autonomy” can sound very strange to Western ears; but in Turkey most of the patients have no request for respect of their autonomy. In fact, they do not have any opinion about the meaning of autonomy in the Western sense at all. “Respect for autonomy” is a duty of health professionals that exists only in their universe of values and is partially created by ethicists.

Informed consent, as a procedure, is one of the most concrete appearances of the respect for autonomy in the practice of medicine (Faden and Beauchamp). When this procedure was introduced in Turkey, many additional problems arose. One of the most difficult problems was the unwillingness of individuals to participate in the process as an “autonomous unit.” In Turkish society, the smallest unit that can function as an autonomous entity is the family. It is necessary to understand family as a larger unit than is usually conceptualized in Western societies. Nuclear family is a phenomenon that is limited to a few large cities in Turkey. A Turkish family generally consists of grandparents and other blood relatives. Even some very close friends who are not bound to the family with blood relations can be treated as family members. The family does not act alone in the decision-making process (Oguz). Other people that are known to the family, such as friends and relatives who have experienced the same situation, and social and religious leaders, also act as the decision-makers. Whatever the dimensions of the decision-making unit, the most interesting feature of the social construct of the Turkish society is the undetermined nature of the individual boundaries and the complexity of interpersonal relationships. The crucial point for the health professional is that the individual expects the health professional to involve the entire culturally structured decision-making unit in the decision-making process (Oguz). Health professionals are unfamiliar with the concept of autonomy as well, and the Western definition of autonomy does not
Yasemin Oguz is spending the 2001-02 academic year as a Postdoctoral Fellow at the University of Minnesota Center for Bioethics. She graduated from the Ankara University Faculty of Medicine and received her PhD in Medical Ethics and Medical History from the Institute of Medical Sciences at the same university. She has been teaching medical ethics and medical history at the Ankara University Faculty of Medicine Department of Deontology (Medical Ethics) since 1995. She taught ethics courses for medical students, nursing students, and students of allied health sciences. She designed the first course on the ethics of architecture in Turkey in collaboration with Haluk Zelef who is an architect and a lecturer at the Middle East Technical University Faculty of Architecture.

Professor Oguz is currently chair, as well as a founding member of the Turkish Philosophical Association’s Unit of Bioethics. She is also one of the founding members of the Turkish Bioethics Association and the Ankara Chamber of Physicians’ Unit of Medical Ethics. She serves as a member of the Research Ethics Committees for Ankara University’s Faculty of Medicine and Faculty of Dentistry. She is also on the Ethics Committee of The Union of the Chambers of Engineers and Architects of Turkey.

Her areas of interest are meta-ethics, applied ethics education, research ethics, psychiatric ethics, and euthanasia. Her approach is mainly cross-cultural and she devotes most of her work to cultural differences in understanding and reasoning of ethical issues. Her current research is on the project entitled, “Assessing the Comprehension Level of Human Research Subjects.” She is also working on identifying the differences between the pedagogical techniques such as seminar sessions, and using drama and class lectures in medical ethics education.

**Selected Publications:**

**Book Chapters**


Oguz N. Tip Metodolojisi (Tip Etkinligi ve Oteki İnsan Etkinlikleri Arasindaki Yeri) [The Methodology of Medicine: Medical Practice and Its Place Amongst Other Human Activities]. In Arda B, Oguz N, Sahinoglu-Pelin S (eds.) *Deontoloji (Deontology).* Ankara, Turkey: Ankara University Faculty of Medicine, 1999.


**Articles**


Several authors have suggested that autonomy may not work as a primary guiding principle in health care across all cultures (Oguz; Wang). Indeed, professionals who see clients with genetic concerns in the US often report ethical challenges that are a product of differing cultural expectations (McCarthy Veach). Family members who make hierarchical decisions or who choose to ignore their genetic predispositions, for instance, create ethical dilemmas for the practitioners who have different expectations. Professional education programs are attempting to address increasing diversity in health care settings through a myriad of educational efforts.

Diversity is not, however, the only reason we ought to re-examine our autonomy-based cultural assumptions. Another reason is that patients and families are not really separate entities. Nowhere is this more evident than in genetic health care. As we develop powerful genetic technologies to predict susceptibilities to diseases, we are also producing more evidence that an individual focus is too narrow a lens through which to view the complexities of modern health care.

Genetics and families are inextricably intertwined. Genetic testing can directly reveal information about our ancestors, about the health of other family members, and of future generations. Many of us predict our future health risks by reflecting on our family histories. Families share both facts and myths about their inheritance and about their health. Some families “pre-select” the individual who is expected to develop a family illness like breast cancer or Huntington disease (Kessler; Bloch). They are surprised when genetic tests reveal the fact that a family member other than the one selected actually has, or will have, the familial genetic condition. Disclosures that challenge our expectations have the power to transform family beliefs, family roles, and family relationships.

Family considerations also raise questions about whether professionals must always maintain confidentiality of medical information. When a patient chooses to withhold relevant genetic information because he or she is estranged from other family members, practitioners face a dilemma. Agreeing to maintain confidentiality could have serious health consequences for another family member. At a policy level, such questions raise concern about whether professional responsibility extends beyond the person who is the identified patient. Even when family members are present, some professionals struggle to determine how to honor autonomy with the presence of “hordes” of family members in a genetic informational session (Bartels). They describe elegant strategies for deciding who might really represent the patient’s position. They seldom ask, however, whether enhancing autonomy should be a primary goal in a complex decision-making process.

Over the last 30 years, the field of bioethics has had a profound influence on strengthening the role of individuals in health care decision-making. We have come a long way from the days of professional paternalism, when we believed that doctors and other authority figures knew what was best for us. Most of us now believe that patients ought to decide what is the best course of action for them. Unfortunately, we now also know that respecting patient autonomy is just a starting point for addressing the complex challenges in today’s health care system.

So, how do we go about developing a more expansive vision for ethical approaches to family health care? First, we might develop more multidisciplinary approaches to health care decisions since no single discipline has sufficient knowledge to address the complexity of today’s clinical and policy questions. Secondly, it may be time for those of us socialized in Western values to explore clinical and policy concerns with people who see the world through other lenses. As we shed our blinders and see more possibilities a new vision may emerge.

References
Bartels D. Families, Genetics and Health Care: Ethical Challenges for Practitioners, submitted.
Dianne Bartels, RN, MA, PhD, the Center’s Associate Director, completed a doctoral program in the University of Minnesota’s graduate program in Family Social Science in December 2001. Participating in that program afforded an opportunity to focus on issues that families face when they confront health challenges. Two areas of particular interest are genetic health care and end of life care.

A Josiah Macy, Jr. Foundation grant supported research on ethical challenges that primary health care professionals face when they see patients and families with genetic concerns. The end result of that four year project is a website that offers continuing education credits free of charge to health care practitioners interested in the clinical, ethical, and professional challenges in genetic health care (see website at www.cmeprograms.umn.edu/bestpractice). Dr. Bartels and her colleagues, Bonnie LeRoy and Pat McCarthy Veach, prepared several manuscripts describing various aspects of their research (listed below).

Participating as the Center’s representative to the Minnesota Commission on End of Life Care in 2001-02 provided what Bartels calls a “wonderful opportunity to address barriers on end of life care at a policy level.” A report of the Commission’s findings is available at www.minnesotapartnership.org.

Selected Publications

**BOOK CHAPTERS**

**ARTICLES**


Center News

**FACULTY HONORS**
Raymond DeVries, PhD, will spend six weeks at the University of Maastricht (the Netherlands) this spring. Hosted by the Faculty of Health Sciences and Medicine with funds from the Council for the International Exchange of Scholars, he will be consulting on their research program in ethics. While in the Netherlands, Professor DeVries will spend time studying “medisch-ethische toetsingscommissies” (METCs), the Dutch equivalent of institutional review boards (IRBs), and has been invited to serve as “opponent” in the dissertation defense of Piia Jallinoja at the University of Helsinki (Finland). Jallinoja is a sociologist; her dissertation is, “Genetics, Negotiated Ethics and the Ambiguities of Moral Choices.”
The world of reproductive medicine is almost totally self-regulated. There are almost no federal rules about what can and can’t be done in making and testing embryos for reproductive purposes. Reproductive technologies are constrained only by scientific limits and what patients are willing to pay for. As repeated news about new technology indicates, along with recent articles in the medical literature about increased health risks for children conceived through assisted reproductive technologies, physicians and patients are willing to push the envelope.

So are voluntary restrictions enough? While it would be nice to hope so, given the market-driven nature of reproductive medicine, it will only take a single clinic offering an unproven or ethically questionable technology for other clinics to follow suit as a matter of economic competition. The problem is that if the profession won’t regulate itself, there are plenty others ready to step in and regulate it for them, including federal and state governments.

The main impetus isn’t the prospect of gender selection, although that will add fuel to the fire, but the controversy surrounding embryonic stem cell research. The connection is that embryos for stem cell research come primarily from fertility clinics. So the controversy over government funding of embryonic stem cell research quickly reaches into the unregulated domain of reproductive medicine. The government is now reviewing the authority of the Food and Drug Administration (FDA) to oversee and control reproductive medicine. If the FDA doesn’t have authority, Congress can intervene and pass legislation controlling reproductive technologies. This started last summer when the House of Representatives passed legislation that bans all applications of human cloning—both research and reproductive—with stiff penalties for violators. The Senate has yet to act, but passing a similar bill to the House would be an ill-advised rush to policy-making.

There is no doubt that rules for reproductive medicine are a must, with the only serious question being what they should look like and where they should come from. Until then, the key will be self-control by medical professionals in order to buy enough time for well-reasoned policies. Unfettered technology will force the hand of lawmakers, making them choose between a brave new world and overbroad government regulation. Neither is a good option for today’s patients or tomorrow’s children.

A version of this article appeared in Dr. Kahn’s column, “Ethics Matters” which appears bi-weekly on CNN.com
June 21 & 22, 2002
“African Genealogy & Genetics: Looking Back to Move Forward”
McNamara Alumni Center, University of Minnesota Twin Cities Campus

This conference is a first time ever gathering of African-American scholars, community members, and religious leaders in a dialogue on the importance and implications of using genetic technologies and genealogical methods to reconstruct an African identity.

National speakers include:

- Attum Azzahir
- Rose Brewer, PhD
- Annette Dula, PhD
- Troy Duster, PhD
- Joseph Graves, Jr, PhD
- Samuel Myers, PhD
- Gwendolyn Midlo Hall, PhD
- Ricky Kittles, PhD
- John Powell
- Charmaine Royal, PhD
- Marian Gray Secundy, PhD

Continuing education credits are available. For program details, registration, and lodging information, contact the Center for Bioethics at 612-624-9484 or visit the Center’s website at www.bioethics.umn.edu.

Sponsors and funders – Center for Bioethics, University of Minnesota; Powderhorn/Phillips Cultural Wellness Center; Insight News; Community Action of Minneapolis; Department of Continuing Medical Education, University of Minnesota; National Institutes of Health; Allina Foundation; The Minneapolis Foundation; and the Greenwall Foundation.

July 14-17, 2002
“Exploring Ethics and Public Health: An Intensive Workshop”
Rutgers Bay Lake Lodge, Deerwood, MN

The University of Minnesota Center for Bioethics and The Hastings Center will host a summer intensive workshop on ethics and public health. This workshop will provide an opportunity for intensive study and discussion of approaches and frameworks for a range of ethical issues in public health, including: Responses to Bioterrorism; Infectious Disease Control; Genetics–Screening Programs and Individual Testing; Public Health Research and Practice–Domestic and International Settings; and Teaching Ethics and Public Health. Ten nationally recognized faculty will lecture and lead small group discussions with a select group of attendees. Space is limited.

The workshop is co-sponsored by the Association of Schools of Public Health and the University of Minnesota School of Public Health. For more information, contact the Center for Bioethics or visit the website at: www.bioethics.umn.edu.
provide a solution for handling this situation (Beauchamp and Childress). Therefore, comprehending how the son of an elder aunt can become the primary decision-maker for a young girl when the method of anesthesia is in question, requires a cultural and social understanding and recognition. In the beginning, most of the biomedical ethicists in Turkey, including the author, thought that this issue was directly related to the level of development and were convinced that their function should be enhancing this development of individual autonomy through education (Oguz). On this view, individual boundaries of Turkish people will become clearer after adequate education, and they will become autonomous in the Western sense of the term (Ersoy et al). This perspective is based on an assumption that the result of social development of all human beings will necessarily end up with the characteristics of the people from the West. This view is changing with a growing recognition that uncertainty about the individual boundaries has more fundamental origins that stem from the conceptualization of the universe: life, community, and human. The differences in conceptualization are so fundamental that people who exist in this cultural environment will have a very different decision-making process than people from the West when they reach a further level of development (Oguz). So the task for biomedical ethicists is to create or discover a method to honor this “collective autonomy” (which seems to be a misleading term) (Wang and Marsh). This perspective and the task of creating a new method originating from it, do not belong solely to the professionals who have difficulties with the concept of individual autonomy because of cultural differences.

Another problem with autonomy originates from the specific nature of the relationship between the decision-making unit and the health care professional. Turkish society is paternalistic, where vertical hierarchy is the main structure, and authority is a determining factor in interpersonal relationships (Wang and Marsh; Guvenc). The traces of this deeply historical structure can be observed in every kind of social relationship, and the relationships in health care are no exception. The health care professional serves as an authority figure in society, due to his special knowledge. This is in accordance with the overall structure and expectations of the society. A non-directive approach from the health professional is perceived as incompetence or hesitation by the patients and the families, which causes great anxiety (Oguz). Therefore a completely objective, non-directive, informative approach usually worries those involved in decision-making. This anxiety is communicated in various different ways, which are culturally structured; one can understand them only if he is familiar with the widely used communication patterns of a given society. Two of the most common responses to a non-directive attitude in Turkey would be either waiting silently without leaving the area, which will make the health care professional feel that he needs to say something more to finish the communication; or directly saying, “you know best, because you are the professional” (Oguz). There are other patterns of communication that can affect the decision-making process. For instance in Turkish tradition, it is not socially acceptable to talk to an authoritative figure unless asked by him. An unfamiliar observer of this pattern can read this silence as a lack of objection, which would be a mistake (Oguz). Another important cultural pattern of communication is the sensitivity to hiding disagreements in the family from outsiders. This behavior is also common in Arabic and Iranian cultures. An unfamiliar or ignorant observer can interpret this way of communication as a consensus amongst family members and can wrongly assume that the person who voices the decision is the representative of the family (Oguz). The Western model of family meetings is useless and misleading in this situation. At the point of decision, the family needs to be left alone to discuss in privacy, preferably in their own environment. It is apparent from these general examples that culturally structured communication patterns and decision-making processes are important features in bioethical analysis.

As a result, while individual autonomy can be perceived as a key concept for some cultures and some areas of medical practice, it is not so for some other cultures and some specific areas of medicine. Thus it cannot be a universal principle (Beauchamp and Childress). Modifying the methods of obtaining informed consent
or the composition and content of consent forms will not be adequate to overcome this problem in a culture where the notion of autonomy does not exist at all. The problem cannot be solved either by education or by making a more flexible definition of autonomy as a concept. A solution such as accepting the decision-making unit as a changeable, autonomous entity will not work, because autonomy as a concept is tightly bound to individuality (Beauchamp and Childress). Reviewing the concept of autonomy and its applicability from an intercultural perspective and rethinking its universality seem to be necessary.

References


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Oguz N. Hasta haklari alanindaki gelismeler ve degisen degerler. (Developments in the patients’ rights and the changing values). *Turkiye Klinikleri Tibbi Etik Dergisi (Turkish Journal of Medical Ethics)* 1997;5(2):50-55.


Calendar of Events

**APR 13, 25 & MAY 2,9**
“The Heart of Healing: Palliative Care and the Arts.” A series of continuing education opportunities offered by the Palliative Care Initiative of the College of St. Catherine and Fairview Health Services. For information, call 651-690-8830.

**APR 20**
Jeffrey Kahn, PhD, MPH, will speak on “Little Cells, Big Issues: The Ethics of Stem Cell Research” for the Twin Cities Eye Meeting in Minneapolis, MN. For information, call 612-625-4400.

**APR 24**
Dianne Bartels, RN, MA, PhD, will speak on “Genetic and Reproductive Decisions: A Look at Ethical and Pastoral Challenges” for the United Theological Seminary of the Twin Cities, New Brighton, MN. For information, call 612-633-4311.

**APR 26**
Carl Elliott, MD, PhD, will speak on “Genetic Ancestry Tracing and the Little Races of the South” at a conference, “Engineering Good and Engineering People: Ethics and the Biotech Revolution” at the California State Polytechnic University, Pomona, CA. For information, email: dturner@scupomona.edu.

**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, Chicago, IL. For information, call 773-702-2313.

**MAY 3**
Jeffrey Kahn, PhD, MPH, will participate in a panel on “Identifying and Managing Conflicts of Interest in Clinical Research” at a national conference, “Promoting Integrity in Clinical Research” in Cleveland, OH. Sponsored by the Cleveland Clinic Foundation and the DHHS Office of Research Integrity. For information, call 216-444-8720.

**MAY 12**
Debra DeBruin, PhD, will speak on “Distributing Limited Health Care Resources” at St. Michael’s Church, Roseville, MN. For information, call 651-631-1510.

**MAY 15**
Jeffrey Kahn, PhD, MPH, will speak on “Little Cells, Big Issues: The Ethics of Stem Cell Research” for Medical Alley, Minneapolis, MN. For information, call 612-598-2168.

**MAY 19-21**
“Foods for Health,” a national conference sponsored by the National Agricultural Biotechnology Council (NABC), will be hosted by the University of Minnesota in Minneapolis, MN. Program details and registration information are available at www.coaes.umn.edu/nabc2002.

**MAY 29**
Debra DeBruin, PhD, will speak on “Ethical Issues in Women’s Health Research” at the Graduate Women in Science Lecture, University of Minnesota, Minneapolis, MN. For information, e-mail: mija0002@umn.edu.

**JUN 3-8**
“8th Annual Training-of-Trainees Conference on Teaching Survival Skills,” a conference sponsored by the University of Pittsburgh Skills and Ethics Program, funded by NIH. For information, call 412-624-7098 or visit website: www.pitt.edu/~survival~.

**JUN 4**
Jeffrey Kahn, PhD, MPH, will participate in a panel on “Identifying and Managing Conflicts of Interest in Clinical Research” at a national conference, “Promoting Integrity in Clinical Research” in Cleveland, OH. Sponsored by the Cleveland Clinic Foundation and the DHHS Office of Research Integrity. For information, call 216-444-8720.

**JUN 14-17**
“Exploring Ethics and Public Health: An Intensive Workshop,” sponsored by the University of Minnesota Center for Bioethics and The Hastings Center. See information on p. 7 in this issue of the *Examiner.*

**JUL 27**
Muriel Bebeau, PhD, will speak on “Can Ethics Be Taught: A Look at the Evidence” for the Georgia Dental Association, Amelia Island, FL. For information, visit website: www.gadental.org.
Recent Faculty Publications

BOOK CHAPTERS


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)

ANNOTATED BIBLIOGRAPHY

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, make checks payable and mail to:

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- Current and past issues of the *Bioethics Examiner* and CNN.com *Ethics Matters* columns
- Annual Reports
- Reading Packets
- Upcoming events and announcements
- Minnesota Network for Healthcare Ethics Committees (MNHEC)
- Links to other bioethics resources