case, however, made a compelling argument to move ahead with the cord-blood transplant.

**Ethics and students**

“Ethical questions are often more complicated than they look at first,” says Debra DeBruin, who teaches bioethics to public health students. DeBruin’s students have diverse interests, so she offers a broad array of topics. “We look at issues such as tobacco, international health, access to health care, public health genetics, and topics in research ethics—just to name a few. Then, together, we examine their ethical components,” she says. “I’ve found that the more voices you hear at the table, the better.” DeBruin ensures the tone of the debates remain respectful, allowing different viewpoints to be expressed. “Students often say that the study of bioethics has broadened their view of the world.”

DeBruin’s teaching assistant, graduate student Susan Parry, agrees. A Ph.D. candidate in philosophy, she initially was interested in informed consent but has since broadened her study to include how patient desires shape the practice of medicine. Some Lyme disease advocacy groups, for example, have lobbied state medical boards and legislators for specific treatment protocols, despite objections from researchers and clinicians that the protocols are scientifically unjustified. “This raises a broader question,” she says: “How does that change the patient-physician relationship?”

**Future of ethics**

The Center for Bioethics will celebrate its 20th anniversary in May with a symposium on the “Future of the Field.” As apt today as it was then is one of the center’s first research projects, “Do we need a new ethic for health care in a changing health care environment?”

Says Kahn: “The range of issues we face in bioethics continues to grow, from the ongoing issues of social justice and allocation of scarce health care resources to new and cutting edge issues in biotechnology. As the world becomes a more complicated place, the ethical issues get more plentiful and sometimes more complicated. We’ll continue to work with our colleagues around the University, the country, and the world as they confront both more traditional issues of bioethics as well as ethical issues in biosecurity research, genetically modified organisms, and other areas we couldn’t have foreseen when the Center for Bioethics was founded 20 years ago.”

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For health information from the University of Minnesota, see the Health Talk & You Web page, www.healthtalkandyou.com.
For more information on health sciences education at the University, go to the AHC Office of Education web page, www.ahceducation.umn.edu.
Life may be prolonged by innovations in medicine and health care, improved life support, and discoveries in genetics or stem cells. Yet these advances also raise many questions—questions that go beyond what is merely medically possible to broader, societal implications.

“Medical research often poses as many questions as provides answers,” says Jeffrey Kahn, director of the University’s Center for Bioethics. Who decides if and when life support can be withdrawn from a terminally ill patient? As genetic testing becomes more advanced, how will this information be used and who will monitor that use? Should an embryo, prior to implantation, be genetically screened to be a matching donor for a critically ill sibling?

For 20 years, the University’s Center for Bioethics has been at the forefront in addressing these questions and shaping clinical and health care policy. Established in 1985 as one of the country’s first multi-disciplinary bioethics centers, its work encompasses areas of health, law,
and ethics. Bioethics faculty at the University collaborate with scientists conducting research, legal experts examining health law, public health educators developing health policy, and health care providers facing complex patient care issues. “Bioethics as a field came out of other disciplines, such as philosophy, law, and medicine,” says Kahn, “so as a rule, we are used to examining issues across a wide range of perspectives.”

Arthur Caplan, the center’s first permanent director and a leading expert in bioethics, recalls that transplantation was among the pressing issues at the time of founding. Organs such as the heart and kidneys had been harvested upon death for transplantation. In the 1980s, however, the question became: could you use living donors as a source for organs? Says Caplan: “We had to ask ourselves, was it ethical to hurt someone, to make someone [the living donor] worse off, in order to make someone else better?”

Researchers and surgeons at the University, leaders in transplantation for more than 30 years, worked together on ethics and clinical practice to arrive at some guidelines. “The closer the emotional relationship, the more living donation was considered acceptable,” Caplan says. “It was generally agreed that relatives should be allowed to make this sacrifice.” Other considerations around living donors included prohibiting the sale of organs, screening donors for psychiatric stability, and protecting potential donors who do not wish to donate—all new concerns that came out of medical advances in organ transplantation.

Caplan wanted to ensure there was open dialogue around the complex issues the center was addressing. It’s important to ask questions, he says, in exploring implications to patients, to health care providers, and to society.

**Ethics and care**

In 1980, while chief resident at Hennepin County Medical Center, Steven Miles with his colleagues Ronald Cranford and Alvin Schultz authored the first Do-Not-Resuscitate (DNR) order. Although there were resuscitation guidelines in use, says Miles, “the radical idea behind the HCMC DNR policy was that it asserted the decision belonged to the patient.”

Several years later, Miles and Tim Crimmins drafted the nation’s first “portable advanced directive” system for resuscitation, allowing transfer of a DNR order. Before this, it wasn’t certain a DNR order kept on file at the nursing home would be honored if a patient’s heart failed on the way to the hospital, says Miles.

Miles also investigated the harm caused by restraints and bedrails in nursing homes, which led to a radical reduction in their use. He also has worked on developing better ways to offer palliative and end-of-life care.

Fellow bioethics faculty Dianne Bartels has been involved in end-of-life issues since her days as a nurse in the 1960s. She knows that patient care affects more than the patient. “Particularly in end-of-life cases, the family is the patient, too,” she says. Over the years, she has seen a change in the way health care providers and families deal with end-of-life care. “In the 1980s, when physicians were intervening to prolong patient life with life support, families began to assert their loved ones’ right to die,” she says. “The patients’ families were saying, ‘This is enough.’”

Now she is seeing more cases in which health care professionals question treatments as not necessarily
beneficial or medically appropriate to the patient. “Sometimes, however, the family is not willing to stop treatment,” says Bartels, who sits on a hospital bioethics committee. These reasons may include lack of trust in the medical system, experiences where family members have already survived against great odds, and communication challenges between families and health team members.

“We need to be better at fostering family discussion on end-of-life options before a crisis arises,” says Bartels. She recommends drawing up a living will as part of that process.

John Song also explores end-of-life care, focusing on homeless persons. “Their concerns are not traditionally counted for in end-of-life literature,” says Song. “I want to understand their perspective: what do homeless people worry about, what concerns do they have?” Song’s study found that “they worry whether they will die alone, without being memorialized in some way and being forgotten, and wonder what will happen to their bodies when they die. They’re also concerned they will not receive desired or required health care because of their homelessness. Many indicated that they would prefer not to have their biological family contacted at their deaths and identified non-related others as ‘family’ to be contacted.”

Song hopes to translate these findings into better health-care interventions for a vulnerable population. “As part of this ongoing research, we held a unique and successful conference bringing together homeless persons, homeless service providers, and health care providers to identify interventions based on our research to improve dying among homeless populations.”

Ethics and research

“In part, technology has driven bioethics debate and research,” says Kahn. The Human Genome Project completed its initial rough draft in 2003. The vast information it offers on health, disease, and behavior, he says, also poses potential risks in terms of issues such as infringement of individual privacy. Personal information from genetic testing could lead to problems obtaining life and disability insurance, or even employment.

Stem cell research also poses ethics questions. “As the University’s research on stem cells advances, so do the ethical challenges,” says John Wagner, scientific director of Clinical Research of the Blood and Marrow Transplant Program and Stem Cell Institute. “Access to experienced faculty at the center with wide-ranging expertise is critical to our mission. Of course we want to move novel stem cell therapies forward as quickly as possible, but only doing so in a thoughtful and ethical manner.” Many ethical questions can be anticipated and discussed well in advance but others must be dealt with as they arise. “Our research here has the attention of the world and we must set the highest standards,” says Wagner.

Kahn worked with Wagner on a landmark case in 2000, in which a six-year-old girl with a fatal genetic disease, Fanconi anemia, was treated with the umbilical cord blood stem cells of her brother. Prior to coming to the University of Minnesota, the brother was identified as a match through an in vitro method known as preimplantation genetic diagnosis. Even before the fertilized egg was implanted in the mother’s womb, the parents knew the baby could have a chance to help their daughter. This raised a host of ethical and policy issues, including concerns over parents “creating” one child for the purpose of saving another. The specific issues in the Molly Nash case are explored in the pages that follow.