July 2009

Dear Colleague:
This past year was distinguished by our extensive engagement of the public in ethics and values conversations on policies that affect the health of Minnesotans. The Center received two public engagement contracts from the Minnesota Department of Health, both of which were funded by the US Centers of Disease Control and Prevention. We led two large community forums to gauge Minnesotans’ thinking about rationing and their readiness to assume a public health perspective in a severe pandemic. Of course, the emergence of H1N1 novel influenza lent an immediacy and poignancy to these public discussions that we never anticipated!

Our second contract expanded the Minnesota Pandemic Ethics Project to allow us, in collaboration with the University of Minnesota Center for Bioethics, to facilitate several small group discussions across the state on how best to ration health resources, a process that is now underway. In planning and conducting these projects, the Center has expanded existing partnerships and forged new relationships with local public health agencies, health care providers, emergency planners and community organizations. Collaborating to elicit the values that should shape health policy is a hallmark of the Center’s work.

I look forward with excitement to celebrating the Center’s 15th anniversary in the coming year, and to participating with our talented and committed staff in pursuing unfolding, fascinating questions of health care ethics. I gratefully acknowledge the support of our Sponsors: Fairview Health Services, HealthEast Care System, and the Sisters of St. Joseph of Carondelet, St. Paul Province. The Center’s achievements are deeply grounded in our Sponsors’ enthusiastic support and valuing of our work.

Sincerely,

Karen G. Gervais, PhD
Director
Minnesota Center for Health Care Ethics

Vision: to foster community-wide solutions to ethical and policy quandaries in health care through collaborations of scholars, providers, health plans, advocates, spiritual leaders and policymakers.

Since its founding in 1994, the Minnesota Center for Health Care Ethics has advanced ethically informed health care decision-making, providing our Sponsors and the community with ethics leadership, service, education, research and scholarship.

This year we moved to our new home at the Carondelet Center, a Beaux Art landmark on the St. Paul campus of the Sisters of St. Joseph of Carondelet. Our neighbors include board members Mary Heinen, CSJ, PhD, and Karen Hilgers, CSJ, PhD, LP, along with the staff of St. Mary’s Clinics, the region's largest network of free clinics. We enjoy the gracious company and lovely space!

This year the Sponsors decided to incorporate the Center as an independent, tax-exempt charitable organization and bring its fiscal and human resources management in-house. This was our last year to contract with St. Olaf College for fiscal and human resources managerial services. We are grateful for the many contributions St. Olaf College has made to the Center’s flourishing over the last several years.
Service to Sponsors

The Minnesota Center for Health Care Ethics is sponsored by Fairview Health Services, HealthEast Care System and the Sisters of St. Joseph of Carondelet, St. Paul Province. The Center prioritizes its work with its Sponsors, engaging in educational, policy development and consultation activities on many critical issues in organizational, clinical, health policy, public health and research ethics. Staff members serve on numerous standing ethics committees; institutional review boards; and ad hoc committees on charity care, conflicts of interest, homecare, and emergency and pandemic preparedness. We consult at the bedside to help patients, families and health care professionals navigate complicated health care decision-making with compassion, professionalism and cultural sensitivity. We work creatively, developing role-play exercises to help train ethics committees. We engage issues of great societal import, from aging, dementia and health care at end-of-life to disaster preparedness. Together with our Sponsors, we are striving to develop an ethically justified approach to steward limited financial resources and compassionately extend charity care.

Highlights from this year follow.

Organizational ethics
- Financial aid and charity care obligations of non-profit health systems
- Relationships between health care providers and pharmaceutical and medical device companies
- Pandemic and disaster ethics issues in health systems, free clinics and faith communities
- Developing and implementing an organizational ethics consultation model

Clinical ethics
- Organ donation after cardiac death
- Surrogate decision-making, including decision-making for medical orphans, un-befriended patients and persons with dementia
- Advance care planning, do-not-resuscitate orders, end-of-life care, and palliative care
- Resolving conflicts among patients, families and care providers
  - Cross-cultural ethical conflicts
  - Medical futility
Community Service and Collaboration

We embrace collaboration as one of our central methods to conduct our work. Since its founding, the Center has worked with and in communities. We partner with hospitals, clinics, academic institutions, professional organizations, government agencies, private industry, and civic and community groups. We engage professionals from diverse disciplines as well as the general public. Our work extends beyond the confines of the state and region to national and international spheres of influence. In the last year the Center worked with health care providers ranging from the Mayo Clinic to HealthFinders (a free clinic south of the Twin Cities) and West Side Community Health Services, the metropolitan area’s largest community clinic organization.

Staff served on data safety and adverse events monitoring committees for several multi-center clinical trials. We served as peer reviewers for prestigious publications like Movement Disorders and Pediatrics. Much of the Center’s collaborative work this year grew out of the Minnesota Pandemic Ethics Project, leading to opportunities to work with the Institute of Medicine, American State and Territorial Health Officials, University of Minnesota Center for Disease Research and Policy, National Association of County and City Health Officials, and the US Centers for Disease Control and Prevention. Our expertise has been sought by the United Kingdom Department of Health’s Committee on Ethical Aspects of Pandemic Influenza, Harvard University, Johns Hopkins University, the University of Pittsburgh and Moravian College.

Key Areas of Research and Scholarship

Our research and scholarship, as well as much of our service with Sponsors and community members, center on five major themes, with activities often overlapping so that one activity efficiently addresses more than one project area. Here are some highlights of our work in these five key areas.
Disaster and public health ethics

This year marked an important expansion of the Minnesota Pandemic Ethics Project begun in 2007. The project is funded by the Minnesota Department of Health (MDH) and US Centers for Disease Control and Prevention (CDC). Most but not all of the project is conducted in collaboration with the University of Minnesota Center for Bioethics (UMCB). In phase one we convened a broad-based community panel to recommend ethical frameworks for rationing scarce health-related resources during a severe influenza pandemic. Several expert work groups and an implementation protocol committee advised the panel.

In January 2009, we publicly released the panel’s preliminary recommendations and began an extensive public engagement campaign. The Minnesota Department of Health convened a media event to draw attention to the campaign, issuing a news release and leading a press conference with the participation of the Center and UMCB. Media coverage was extensive, leading to stories statewide in print and on television and radio. Among the highlights were lengthy stories in the two metro daily papers, Star Tribune and St Paul Pioneer Press, an appearance by the Center’s spokesperson on public television’s Almanac, and an hour of Minnesota Public Radio’s Mid-Morning program devoted to an interview of the state’s epidemiologist, Dr. Ruth Lynfield and representatives from the Center and UMCB.

The efforts to secure media coverage paid off in public attention to the project. The panel’s preliminary recommendations were posted online for public comment, along with a companion report on implementation issues. MDH and the project team were thrilled with the number of comments received, six times the number the federal government received in response to national guidance for antiviral allocation. Though the comment period has closed, the reports can be viewed at www.ahc.umn.edu/mnpanflu.
Immediately following January’s media event, the Center turned to planning and implementing two large community forums in greater Minnesota. Last year at MDH’s request the Center drafted a competitive grant application to the CDC to secure funding for the community forums. This year we learned that the application had been successful, and Minnesota joined the ranks of five other states in obtaining CDC funds for pandemic-related public engagement projects. MDH retained the Center to lead the project.

Working closely with MDH, which was the principal investigator for the CDC-funded events, the Center convened one public forum in Owatonna and the other in Duluth. These Minnesota Pandemic Ethics Community Forums were opportunities for the general public to consider particularly controversial aspects of the preliminary rationing guidance and offer suggestions for improvement. 107 people attended the Owatonna forum and another 94 participated in Duluth, not counting the 36 presenters, facilitators, notetakers and support staff needed for each. Facilitators and notetakers were recruited from local public health, health care, emergency planning and college partners in northeastern and southern Minnesota. MDH leadership prioritized both day-long events. Dr. Lynfield in Owatonna and MDH Commissioner, Dr. Sanne Magnan, in Duluth, presented background on pandemic influenza. Both participated fully and fielded questions throughout the day.

Both events were publicized heavily both before and after the forums. Advance publicity, together with extensive word-of-mouth recruitment by local partners, resulted in achieving our recruitment goals for both forums. Media in both markets also covered the events themselves. The Duluth forum received particularly extensive coverage on the day of the event, with stories on every local television outlet as well as the local newspaper. This was no doubt due in large part to the primacy of the spring’s outbreak of novel influenza H1N1 virus. The forum was held on Saturday of the week in which the World Health Organization raised the pandemic

| “This is one of the best-planned events in the realm of emergency planning that I’ve attended. It challenged my thinking and values. The overriding comment I kept hearing was that people were so grateful to have had this opportunity to give input. It was just a knock-out program.” |
| Elizabeth Auppl, President |
| Steele County Community Awareness and Emergency Response |
| Speaking about the Minnesota Pandemic Ethics Community Forum in Owatonna |
threat from level three to level five. The event was deemed critically important by our state and local public health partners.

Planning is now underway for the last phase of the public engagement work: small group engagements designed to delve more deeply into questions of controversy raised by the panel and community forum participants.

The Center’s leadership in pandemic and disaster ethics is evidenced by numerous invitations to participate in federal pandemic planning projects and to present at national and international conferences. The long list includes:

- participation in an invitation-only CDC-convened public engagement workshop
- presentation to and participation in an invitation-only national Summit of the States on ethical issues in pandemic planning
- service on an Institute of Medicine committee concerning implementation of antiviral medication strategies in an influenza pandemic
- multiple presentations at the annual meetings of the American Society for Bioethics and Humanities and American Public Health Association
- participation in an invitation-only Town Hall session on pandemic influenza and community resilience sponsored by the American Public Health Association
- service on an Association of State and Territorial Health Officials work group on at-risk populations’ needs during an influenza pandemic
- invited presentation and facilitation at a conference on ethical and legal issues in pandemic planning and response co-sponsored by the Harvard University School of Public Health, Johns Hopkins University and the Massachusetts Department of Public Health
- contribution to the 1st Workshop on Ethical Issues in Europe on National Preparedness for Pandemic Influenza: From Principles to Policy Conference.

We also helped lead workshops on pandemic ethics for the Veterans Administration and University of Minnesota School of Public Health’s Center for Public Health Preparedness.

The following publications by Center staff on the topic of pandemic ethics appeared this year:


The Center looks forward to the successful completion of the ground-breaking Minnesota Pandemic Ethics Project in the coming fiscal year.

**Health policy**

In early 2009, the Center began collaborating with several community partners, including the Justice Office of the Sisters of St. Joseph of Carondelet, St. Olaf College, St. Catherine University and St. Mary’s Clinics to create a sustainable system for directly engaging Minnesotans on the values that should guide healthcare reform. Pairs of social justice and healthcare workers who have committed to leading engagements in their own communities will be trained by professional facilitators in both faith-based and secular dialogues to assist the public in articulating their values and goals for the future of our healthcare system. The public engagement training workshops will be offered in partnership with colleagues from the Center for Health Care Reform of the Sisters of St. Joseph of Orange, California, who will conduct public engagement train-the-trainer programs. We anticipate that those trained through this program will directly engage a remarkable number of 5,000 Minnesotans in healthcare reform in the first year. Training events are scheduled for October 16-18, 2009.

**Emerging technologies**


Center staff also co-authored Deep Brain Stimulation for Disorders of Mood, Behavior and Thought: Scientific and Ethical Issues, in press with *Archives of General Psychiatry*.

Scholarly presentations included “Ethical Issues in Device Research” at St. Cloud State University.

**Diverse cultural and faith perspectives**

Our book, *Healing by Heart: Clinical and Ethical Case Stories of Hmong Families and Western Providers*—the product of a multi-stakeholder collaborative project that includes contributions by 37 multidisciplinary and multi-ethnic contributors—continues to sell and be used as a teaching tool in a variety of settings throughout the country. Staff members are sought after to present insights on cross-cultural health issues to classrooms and other audiences throughout the region.

A proposal to present cross-cultural health care ethics and the *Healing by Heart* model was accepted by the Conference of the European Association of Centres of Medical Ethics. Here at home, staff used the *Healing by Heart* model as a centerpiece for a half-day workshop it led at the Sixth National Conference on Quality Health Care for Culturally Diverse Populations in Minneapolis. Similar presentations were made to audiences at William Mitchell College of Law and St. Olaf College.
End-of-life decision-making
End-of-life decision-making continued to be the subject of many of our consultations, education and policy development activities with Sponsors. Working with Wisdom Ways, staff developed a lecture series on *Living with Dying: Creating Opportunities at the End of Life*. As an outgrowth of our efforts within our sponsoring organizations, we have presented on the ethical complexities of organ donation after cardiac death and on a decision-making model for persons with advancing dementia.

Future
We will continue serving our Sponsors on emerging issues in clinical, organizational, health policy, public health and research ethics, carrying on our tradition of providing high-quality services at an excellent value. We will continue to build partnerships in our pursuit of ethical solutions to quandaries in health care ethics that call for community-wide collaboration. Building on successes of past years, we shall use Sponsors’ interests and needs as our springboard to developing community-wide ethics projects of significance to all health system stakeholders.

Personnel
With a mix of full-time professionals, Center associates and independent contractors, the Center’s team represents many disciplines and areas of excellence, including philosophy, health care ethics, health policy, public health, epidemiology, law, theology and faith, and pediatric neurology. Sponsors have benefited from the added expertise of our grant-funded staff, particularly in the area of organizational ethics, health policy and public health.
Karen G. Gervais, PhD, Director of the Minnesota Center for Health Care Ethics, received her BA from Oberlin College, and her doctorate in philosophy from the University of Minnesota. Formerly a philosophy professor, in 1989 she transitioned her career into the field of health care ethics. She served as Center Associate of the Center for Biomedical Ethics at the University of Minnesota, Coordinator of the Minnesota Network for Institutional Ethics Committees, Winifred and Atherton Bean Visiting Chair of Science, Technology, and Society at Carleton College, Visiting Distinguished Professor of Law and Liberal Studies at Hamline University, and Visiting Associate Professor of Philosophy at St. Olaf College. Dr. Gervais’ scholarly interests include clinical and organizational ethics and health policy, public health ethics, access to health care, resource allocation, community benefit responsibilities of non-profit health care organizations, ethically informed decision-making for persons with dementia, clinical conflicts of interest, and the definition of death. She has served as ethics and policy consultant for the Institute of Medicine, Office of Technology Assessment, Minnesota Council of Health Plans, Minnesota Medical Association, Hennepin Medical Society, Minnesota Department of Human Services, Minnesota Department of Health, Minnesota Attorney General’s Office, Science Museum of Minnesota, American Association of Health Plans, National Council of State Boards of Nursing and the National Marrow Donor Program. She also served as an ethics advisor to the Minnesota Commission on End-of-Life Care and is a member of the Minnesota Department of Health’s Task Force on Health and Bioterrorism. In 1987...
Dr. Gervais published *Redefining Death* (Yale University Press) and in 1999 co-edited *Ethical Challenges in Managed Care: A Casebook* (Georgetown University Press). She has published in the *Hastings Center Report, American Journal of Bioethics, IRB, The American Journal of Managed Care, Medical Humanities Review, Minnesota Medicine,* and contributed articles to several edited works, including the *Encyclopedia of Bioethics.*

**Dorothy E. Vawter, PhD,** is Associate Director of the Minnesota Center for Health Care Ethics and lead ethics consultant for Fairview Health Services. She was the principal investigator of an NIH funded project on ethical and policy issues in the study, use and financing of deep brain stimulation for Parkinson’s disease. She is co-directing a community-wide project (supported by the Minnesota Department of Health) on rationing health care resources in a severe pandemic and is the lead author of “Allocating Pandemic Influenza Vaccines in Minnesota: Recommendations of the Pandemic Influenza Ethics Work Group,” *Vaccine* (2007) 25:6522–6536. Directing the Minnesota Center’s work on cross-cultural health care ethics, Vawter is co-editor of the award winning book *Healing by Heart: Clinical and Ethical Case Stories of Hmong Families and Western Providers.* Other scholarly work is published in the *New England Journal of Medicine, Hastings Center Report, The Journal of Clinical Ethics, The American Journal of Bioethics, IRB, Transfusion, Cell Transplantation, The American Journal of Managed Care,* and *Minnesota Medicine.*

Dr. Vawter completed her doctoral studies in philosophy at Georgetown University and the Kennedy Institute of Ethics. In addition to holding appointments at several medical schools, she served on the staff of three federal advisory boards charged with developing policy recommendations for the protection of human subjects: the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research; the Ethics Advisory Board; and the President’s Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research. Her research interests include cross-cultural health care ethics, research with human subjects—with special attention to surgical research, disaster ethics, professional integrity, medical futility and end-of-life decision-making, organizational ethics, and organ/tissue donation and transplantation.
J. Eline (Ellie) Garrett, JD, is Assistant Director for Health Policy and Public Health. Her most recent publications include the co-authored articles, “Allocating Pandemic Influenza Vaccines in Minnesota: Recommendations of the Pandemic Influenza Ethics Work Group,” Vaccine (2007) 25:6522–6536, and “Health Care Workers’ Willingness to Work in a Pandemic,” American Journal of Bioethics 2008; 8:8:21. She was lead author on “Ethical Considerations in Pandemic Influenza Planning,” Minnesota Medicine (April 2008) 37–39. Ms. Garrett is one of the leaders of the Minnesota Pandemic Ethics Project, currently underway. She has nearly 20 years’ experience in health policy, managed care and insurance and is past president of the Minnesota Public Health Association. In 2004 she was awarded the Albert Justus Chesley award for distinguished service in the field of public health in Minnesota. Prior to joining the Center, she served as the Minnesota Council of Health Plans’ Director of Operations and Community Affairs for six years. Her interests include organizational ethics and the intersection of public health and health care. Ms. Garrett was educated at the University of Minnesota Law School.

Julia J. Anderson, RN BSN, Office Manager and Special Projects

Angela M. Morley, JD, Research Assistant and Assistant Office Manager

Center Associates and Independent Contractors

- Kathleen A. Culhane-Pera, MD, MA, Center Associate for Diversity Studies. Ramsey Family and Community Medicine Residency and West Side Community Health Center.
- Elizabeth Gilles, MD, Center Associate for Neurology and Pediatrics. Pediatric Neurology, Children’s Hospitals and Clinics, Minnesota
- Alan J. Hagstrom, DMin, Center Associate for Faith and Health. United Methodist Church, Wisconsin Conference
- Ruth Mickelsen, JD, MPH, Center Associate for Health Law and Public Health
- Angela Witt Prehn, PhD, Center Associate for Epidemiology and Public Health
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