



Year in Review Center for Practical Bioethics 2005

Programs

Aging and End-of-Life

- With the Federation of State Medical Boards, we completed participation in five conferences across the country to advocate for better pain care.
- We continue to work with the State of Missouri to advance quality improvement strategies to better end-of-life care for nursing home residents; for the first time, through the Local Investment Commission, the Center has received funding from the State of Missouri to support its long-term care initiative with nursing homes.
 - Mediated case consultations
 - Co-sponsored two townhall meetings with the Missouri End-of-Life Coalition in Kansas City
 - Wrote a white paper for Missouri legislators proposing a legislative agenda based on townhall meeting input
 - Developed a policy guideline on “*Intimacy in the Nursing Home*”
- Conducted more than 100 Caring Conversations workshops for faith communities, civic organizations, and service groups serving more than 3500 people in the Kansas City area
- Provided consultation and training for Cleveland Clinic to develop a Caring Conversations initiative for their entire nursing staff.
- In the wake of the Terri Schiavo case the Center hosted seven special Caring Conversations workshops which were publicized on KCUR Radio and in the Kansas City Star. In addition the Center:
 - Responded to hundreds of phone calls from individuals seeking information on advance directives.
 - Delivered thousands of *Caring Conversations* documents through our website and by mail during two weeks in March prior to her death.
 - Responded to news media requests from dozens of media outlets, from CNN in London to Billings, Montana.
- Provided a communication packet including posters, brochures and other materials to 440 community and statewide end-of-life coalitions to promote September as Pain Awareness Month.

- Launched the Pediatric Palliative Care Project
 - Hosted a pediatric palliative care conference featuring Dr. Brian Carter, author of the Handbook on Pediatric Palliative Care. Dr. Carter also did grand rounds at both the University of Kansas Medical Center and Children's Mercy. Developed video describing this initiative.
 - Hosted Jennifer Stepanek who presented grand rounds at Children's Mercy Hospital
 - Researched and cross-walked national and international standards on palliative care
 - Formed an Advisory Council
 - Convened four task forces, including:
 - Consumer Resource Center
 - Professional Education and Support
 - Outside the Hospital DNAR
 - Quality Standards
 - Hosted a Fall community update for pediatric providers and children's advocates.

Clinical and Organizational Ethics

- Launched a research/policy initiative: *Medical Futility Guidelines*. Held 11 focus group sessions with community members representing diverse racial, ethnic and socio-economic populations
- Provided two training sessions for ethics committee members
- Provided technical assistance to local hospital ethics committees.
- Contracted with the St. Luke's bone marrow transplant team to provide ongoing ethics consultation services.

Health and Healthcare Disparities

- Launched a planning process with policy makers, patient advocates and other thought leaders to expand access to specialty medical services and hospital care to those currently served by our free health clinics. Called the *Medical Outreach Project*, this endeavor received funding from the Healthcare Foundation of Greater Kansas City and the Sunflower Foundation.
- With the National Center for Bioethics and Research at Tuskegee University, we are guest-editing a special issue of *Cambridge Quarterly* on health and healthcare disparities.

Life Science Research Ethics

- Hosted meeting of clergy to discuss early stem cell research and provided them with educational materials for their use.
- Held national roundtable in January.
- Published policy brief in March; mailed to 30,000 policymakers nationwide.
- Held a public forum on early stem cell research at Liberty Memorial
- Provided dozens of community education programs for churches, synagogues, civic and service clubs, hospital boards and others on the science and ethics of early stem cell research.

Lecture Series

- **Layton Gallery Showing** at Carter Art Center, Penn Valley Community College, March.
- **Robert Biblo Lecture**, Jennifer Stepanek (mother of Mattie Stapenek noted author and poet) spoke on pediatric palliative care, May
- **Flanigan Lecture**, Dr. Edmund Pellegrino (Chair of President Bush's Bioethics Council) spoke on medical futility, August
- **Cockefair Lecture**, Randy Cohen (New York Times ethics columnist) spoke about his book, The Good, The Bad & The Difference: How to Tell Right From Wrong in Everyday Situations, November

Public Outreach

- More than 75 presentations by Center leadership and associates throughout the year, including participation in a forum with the Center for American Progress and the International Joint Bioethics Congress in Sanliurfa, Turkey.
- *Approaching Futility in End of Life Care*, October 7 in collaboration with Shawnee Mission Medical Center and Nazarene Theological Seminary
- Collaborated with Johnson County Library and St. Luke's Hospital to conduct four seminars throughout the year on medical ethics topics.
- Cato Institute forum on pain policy, September

COMMUNICATIONS

Publications

- Launched *Practical Bioethics*, a new quarterly publication
- Published 2 issues of *State Initiatives to Improve End-of-Life Care*
- Established *Ethics E-Alert* weekly email.
- Established *Center Briefing* monthly email.
- Center staff published articles in outside peer reviewed journals

Website: developed and launched entirely new website (www.practicalbioethics.org)

News Media

- Contributed to more than 60 news media placements throughout the year, including in:
 - *USA Today*
 - *Washington Post*
 - *CNN*
 - *Frequently quoted in the Kansas City Star*
 - *Regular appearances on KCUR Radio talk shows hosted by Walt Bodine and Steve Kraske*

Awards

- Nathan Davis Award, American Medical Association. Center submitted successful nomination on behalf of Drew Edmondson, Oklahoma attorney general.

- Non Profit Professional of the Year Award, Myra Christopher, Kansas City Council on Philanthropy. Presentation of award May 13, 2006

RESOURCE DEVELOPMENT

Annual Dinner

- Raised \$215,000, a record for this event.
- Jennifer Stepanek, featured speaker launched pediatric palliative care project.
- Video developed for the dinner and for use to promote pediatric palliative care project.

Endowment/Francis Chair

- \$3 million gift announced in July
- Search committee established in August.
- Search committee identified first tier of candidates and began interview process.

Fundraising

- The Health Care Foundation of Greater Kansas City made a \$50,000 grant to support the Medical Outreach Project.
- The Sunflower Foundation awarded \$22,500 to the Center's Medical Outreach Project.
- The Cloud L. Cray Foundation approved funding for the Center's Science and Ethics Literacy Project. The Foundation will contribute \$50,000 a year for the next three years starting in 2005. The next phase of the project will focus on research involving human subjects with impaired cognitive capacity.
- Visits to national organizations for funding support, including:
 - National Committee for Quality Assurance
 - U.S. Health and Human Services Department
 - American Bar Association
 - Pew Charitable Trusts
 - National Association for Attorneys General
 - Greenwall Foundation
 - Commonwealth Fund
 - Open Society Institute
 - Johnson & Johnson
 - Pfizer
- Long term care contract with Local Investment Commission (LINC) and State of Missouri, \$75,000
- Funding for pediatric palliative care initiative include contributions from the following:
 - Ten Ten Foundation
 - Cerner Foundation
 - Mr. Irv Hockaday
 - Ronald McDonald Charities
 - Tom McDonnell (DST)
 - Hall Family Foundation
 - Speas Family Foundation

- Dunn Family Foundation
- Miller and Jeannett Nichols Foundation
- William and Marjorie Sirridge

Organizational Membership

- Redefined membership benefits and fee schedule
- Successfully marketed to 80 hospitals, nursing, homes, and others

Individual Membership

- Re-defined membership package and added benefits, including *Ethics E Alert* and a monthly *Center Briefing*
- Established a Young Professionals Membership Group