The Coalition for Quality at End of Life (CQEL), an organization dedicated to improving end-of-life care in the region by identifying and collaborating with key stakeholder groups, is now being convened by the Jewish Healthcare Foundation (JHF).

Comprised of leading health systems, providers, insurers, citizen groups, government agencies and an array of philanthropic, faith-based and other organizations, CQEL was being convened by the Institute to Enhance Palliative Care (IEPC). In July of this year, Dr. David Barnard stepped down as chair of CQEL and director of IEPC. At that time, CQEL’s steering committee asked that JHF assume the responsibility of convening the organization’s bi-monthly meetings.

“Dr. Barnard’s dedication and forward-thinking positioned CQEL as a thoughtful convener and leader on a host of end-of-life issues, including widespread availability of Physicians Orders for Life-Sustaining Treatment (POLST) and palliative care. Together, during his tenure, we raised awareness in the region, engaged the minority and disabled communities in the conversation about end-of-life and championed for better professional education around this topic,” says Nancy Zionts, JHF’s chief program officer. “The foundation is committed not only to maintaining but also building off of the momentum Dr. Barnard and CQEL have gained over these last six years.”

CQEL is the brainchild of five people with a passion to improve end-of-life care: Dr. Barnard; Ms. Zionts; Dr. Bob Arnold, a colleague of Dr. Barnard’s at IEPC; Dr. Judy Black, medical director of senior markets, Highmark; and Nicole Fowler, former administrator of IEPC. In April 2004, all five attended a meeting organized by Dr. Kenneth Melani, president and CEO of Highmark. During that meeting, Dr. Susan Tolle, who founded the Oregon Health & Science University Center for Ethics in Health Care, described how terminally ill patients and their families in Portland were being counseled on whether ICU stays and additional interventions were likely to be value-added for the patients. Dr. Arnold then presented local data on ICU utilization, access to palliative care and costs that were significantly higher than those in Portland.

“The five of us had already been discussing end-of-life issues over coffee on a regular basis. That meeting just sealed the deal,” says Dr. Barnard. “We shared a vision to improve end-of-life care. But we also recognized that we could not do the work alone; so we formed a steering committee and asked the IEPC to convene CQEL. The rest is history.”

Dr. Arnold, who has become a leading voice, both locally and nationally, on end-of-life issues, palliative care and medical ethics, will serve as interim director of the Institute to Enhance Palliative Care while a national search is conducted for his permanent replacement. In addition, CQEL members participated in a survey over the summer to evaluate the organization’s mission and goals. The results are now being used to establish an agenda and work plan for 2011.

“The changing landscape in health care has made this an exciting time for the end-of-life agenda in our region. Most health-related institutions, large and small, are embracing palliative care. Pennsylvania lawmakers are close to finalizing policy on POLST. Real change is on the horizon,” says Ms. Zionts. “JHF is excited to continue this journey with CQEL to redefine quality care for people with life-threatening illnesses by raising expectations and empowering our community to want and demand a different health care experience.”

JHF has collaborated with CQEL partners on several end-of-life initiatives including Closure, an educational, planning and outreach effort focused on end-of-life care. With the help of partners from CQEL, JHF has been able to convene a series of conversations in the Jewish
and African-American communities that delved into aspects of end-of-life and concluded with participants designing action plans for their own communities. Another series of Closure conversations will be launched in the Catholic community this winter through a partnership with the Catholic Diocese of Pittsburgh.

To help further engage and educate the community, CQEL has also launched www.compassionatecareforall.org, a website for anyone in southwestern Pennsylvania who has a serious life-threatening illness or cares for someone who is seriously ill. CQEL members wrote content, reviewed material and suggested topics for the website, which provides users with a comprehensive guide to understanding the myriad of decisions that must be made in planning for end-of-life.

Another cornerstone of CQEL’s mission is to focus attention on the regulatory and financial barriers to quality end-of-life care. To further that goal, CQEL members assisted State Representative Dan Frankel as he introduced a bill that will change policy to require that physicians complete 24 continuing education units in pediatric palliative care. A vote is pending.

A key 2011 initiative that CQEL will be involved with is a new one-hour documentary that will examine numerous medical, legal, cultural and religious implications surrounding end-of-life and palliative care. Produced by WQED-TV and funded by JHF, the documentary will premiere in 2011 and will be followed by live televised conversations.

“The goal of this documentary is to demystify many of the concepts and issues at end-of-life, and allow community members the chance to think about their own preferences and learn about opportunities to have their care and healing needs heard and respected,” says Ms. Zionts. “Our partners with CQEL will be critical in telling this story and engaging the community in conversation.”

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