



## LIVING INITIATIVES FOR END-OF-LIFE CARE

*Helping Kansans with advanced chronic and terminal illnesses  
live with dignity, comfort and peace*



# 2005 Annual Report

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In Wichita: 219-3059  
Pain Management Hotline: (913) 588-6392

# 2005 Public Policy Efforts



*John Carney, Chair of the LIFE Project Public Policy Task Group, takes questions during the September 29 Public Policy Forum in Topeka.*

Throughout the interim session, the LIFE Project continued to work with the Kansas Judicial Council in its goal to improve Kansas statutes related to the complex issues surrounding end-of-life care.

On September 29 the LIFE Project worked jointly with the Kansas Pain Initiative to sponsor an all-day public policy forum in Topeka for state leaders and public policy officials. State Representatives Bob Bethell and Nancy Kirk hosted the session and facilitated the question and answer portions. Participants included members of state medical and nursing licensing boards, state long-term care associations, hospital and hospice providers, state governmental

agencies, elected officials and other key stakeholders.

The morning session was set aside for focused attention and dialogue on pain management issues in our state.

Dr. Bob Twillman, Pain Management

Program Director at the University of Kansas Medical Center, and Co-Chair of the LIFE Project Pain Management Task Group, presented “Pain Management: Promising Practices and Frightening Fragmentation,” which outlined the barriers to pain management in Kansas and recommendations for improving access to good care. The American Alliance of Cancer Pain Initiatives has supported and funded this effort.

The afternoon session of the forum was dedicated to discussion on other critical issues facing Kansans with chronic and terminal illnesses, such as advance care planning, guardianship and nutrition and hydration. John Carney, VP of

Aging and End of Life at the Center for Practical Bioethics, Kansas City, Missouri, and Chair of the LIFE Project Public Policy Task Group, provided a thorough explanation in his presentation “Issues in the Provision of Nutrition and Hydration and Critical Issues in Guardianship and Advance Care Planning.” Thoughtful dialogue followed each session, with participants voicing concerns and suggestions for addressing many of the issues.

As a result of the information presented at this forum, the LIFE Project will draft a monograph for state policy leaders in early 2006. Tentatively titled, “Critical Issues in Care for Chronically and Terminally Ill Kansans,” this informative brief will be distributed to public policy leaders in 2006.



*Dr. Gary Dolittle presents "Giving Bad News" to a capacity crowd at the October 27 "Talking About Death Won't Kill You" event.*

# 2005 Professional Education Efforts

In 2005, the LIFE Project maximized the momentum focused on advance care planning. Stacie Ogborn conducted three intensive training sessions in Hays, Manhattan and Lawrence, using the Respecting Choices® curriculum. Through these workshops, 75 additional advance care planning facilitators were tooled and trained to continue the efforts to increase awareness about advance care planning and to engage Kansans in significant conversations regarding their wishes in healthcare as they near the end of life. These new facilitators came from various professions - nursing, social work, hospice, long-term care, hospital ethics, patient advocates and community and faith leaders.

Presentations on end-of-life issues were made throughout the year by Donna Bales, Stacie Ogborn and other LIFE Project leaders to various statewide organizations. Events included the annual training conference for the State of

Kansas Long-Term Care Ombudsman Volunteers, Older Kansans Information and Referral Services Association, Wichita State University College of Health Professions and the Midwest Regional Conference on End of Life Care. In addition, *Caring Community* and LIFE Project leaders conducted numerous presentations on the importance of advance care planning to churches and other community organizations across the state.

On October 27, the LIFE Project partnered with Kansas Health Ethics and Faith Home Health & Hospice of Wichita for a successful full-day conference at the Wichita Marriott entitled "Talking About Death Won't Kill You." The keynote address was provided by Virginia Morris, author of the book by the same title. The event was attended by 250 professionals, hospice workers, nursing and physician assistant students, as well as community leaders. Other presenters included Dr. Gary Doolittle, Dr. Steve Jeffers, Mary Lynn Burnett, and Jefri Leonardi.



Author Virginia Morris drew large crowds during a book signing session at the "Talking About Death Won't Kill You" conference on October 27.

On October 28, the LIFE Project hosted a half-day "Tools for Action" workshop for community leaders and consumer advocates. Stacie Ogborn introduced representatives from three *Caring Communities* who shared about successful endeavors in their communities. Projects highlighted included an end-of-life resource center at the Lawrence Public Library, an advance care planning refrigerator magnet project in Washington County, and a community-wide awareness campaign on advance directives in Barton County. Gwynn Sullivan, Consumer Program Specialist with the National Hospice & Palliative Care Organization presented information on NHPCO's consumer awareness campaign, "It's About How You LIVE," and Myra Christopher, President and CEO of the Center for Practical Bioethics, made the keynote address on the "Ethical Imperatives in Caring for the Voiceless and Vulnerable."



Participants at the August 4-5 Respecting Choices Advance Care Planning Course for Facilitators held in Hays conduct activities during a break-out session.

# 2005 Public Engagement Efforts



*A member of the Topeka Caring Community Council facilitates advance care planning with a participant during the "Let's Talk Turkey" senior fair held November 17.*

The LIFE Project *Caring Communities*, our community-based coalitions, continue to be engaged with citizens in 32 communities across Kansas. Many of these community activist groups used the national media attention on the Terri Schiavo case in Florida to bolster their efforts to increase awareness for advance care planning.

Additional resources were made available for coalition groups by the National Hospice and Palliative Care Organization via their

"LIVE" campaign and Caring Connections website in 2005, inspiring many community leaders to host senior fairs and community forums as a platform for discussing important end-of-life issues. Public events, such as Topeka's "Let's Talk Turkey" offered opportunities for citizens to have their questions answered, obtain advance directive documents and complete them with assistance from professionals.

In 2005, the LIFE Project teamed up with the Kansas Parish Nurse Ministry to find ways to better support their work with faith communities. The LIFE Project continues to plan strategically with these important healthcare professionals. The Kansas Parish Nurse Ministry program received funding from United Meth-

odist Health Ministry Fund in Hutchinson. This funding provides the organization time to develop sustainable funding and infrastructure.

The LIFE Project Consumer HelpLine and website remain valuable resources for patients and families needing assistance with a variety of end-of-life issues, including hospice, advance care planning and pain management. Kansans who are in pain are still able to obtain clinical advice and resources via the Pain Management Hotline.



*The Topeka Caring Community organized a pre-holiday community event on November 17 entitled, "Let's Talk Turkey" to provide information and awareness for consumers.*

## 2005 Statistical Highlights

- Over 35,000 pieces of educational resources on advance care planning and pain management were distributed to community leaders, individuals and organizations all across Kansas.

- There are now over 825 people who subscribe to our weekly *Newsflash* newsletter. Each edition of *LIFeline* is distributed to 920 people, and 475 community leaders receive our period *Caring Communities* "Note."



*Eighty participants attended the "Tools for Action" workshop for community leaders and consumer advocates at the Wichita Marriott on October 28*

- In 2005, the LIFE Project website was visited 33,855 times. The site is visited an average of 2,824 times each month, or 93 times a day. Consumer resource

materials were downloaded at record levels from the LIFE website in 2005, including our Durable Power of Attorney for Health Care forms, our most popular download, which showed a 300% increase over the previous year.

- The LIFE Project Consumer HelpLine continues to receive several calls each week from consumers needing hospice referral information and other resources. Advance care planning facilitation services are now available through the HelpLine.

# Champions for LIFE Gala

The 2<sup>nd</sup> Annual Champions for LIFE Gala was held on October 27 at the Wichita Marriott to honor eight Kansas leaders and one *Caring Community*, all of which are demonstrating excellence in palliative and end-of-life care. The 2005 Champions are advocates from all walks of life who share a passion and commitment to improve the quality of life for Kansans with advanced chronic and terminal illnesses. This diverse group of mentors consists of a physician, hospice directors, a pastoral care director, palliative care nurses, a health reporter and a community-based coalition. Their service and efforts inspire us to continue our work to support these

very vulnerable citizens and families.

2005 Champions for LIFE include Gary Doolittle, Diane Johnson, Sandy Kuhlman, Dorothy Kurtz, Teresa Sikes, Bryan Thompson, Tom Welk, JoVeta Wescott and the Jackson County *Caring Community*.

Sandy Kuhlman was honored as the recipient of the Emily Taylor Champion for LIFE Award. Emily Taylor's powerful leadership and exemplary work in helping create quality of life for citizens living near the end of life benefited



2005 Champion for LIFE winners, L-R, Bottom Row: Henriette Area, Esther Ideker, Sharon Bukacek, Cathleen Reed; Back Row: Donna Kuti, Zennie McClintock, Tom Welk, Dorothy Kurtz, Sandy Kuhlman, JoVeta Wescott, Bryan Thomson, Gary Dolittle, Teresa Sikes, Diane Johnson, Janet Blair-Carpenter

many Kansans. Emily, who died in 2004, understood and advocated for good pain management and advance care planning and offered a constant and visionary voice for excellence in care.

## LIFE Project Partners

### **Governmental Agencies:**

Kansas Association of Area Agencies on Aging  
 Kansas Board of Emergency Services  
 Kansas Department of Health & Environment  
 Kansas Department of Social & Rehabilitation Services  
 \* Kansas Department on Aging  
 \* Kansas Foundation for Medical Care, Inc.  
 Kansas Insurance Department  
 Kansas Office of the Attorney General  
 Kansas Office of the Governor  
 Kansas Office of the Long-Term Care Ombudsman  
 Kansas State Board of Healing Arts  
 Kansas State Board of Nursing  
 Kansas State Board of Pharmacy  
 Kansas State Library

### **Academic Institutions:**

Emporia State University  
 Johnson County Community College  
 Kansas State University, Extension – Research Services  
 Landon Center on Aging at University of Kansas  
 University of Kansas School of Medicine  
 University of Kansas School of Nursing  
 Wichita State University

### **Consumer Advocacy:**

AARP Kansas  
 Disability Rights Center of Kansas  
 Kansas Advocates for Better Care

### **Other Partners:**

\* American Alliance of Cancer Pain Initiatives  
 American Cancer Society - Heartland Division  
 The Center for Practical Bioethics  
 \* The Foundation for Hospice Care, Inc.  
 \* K.T. Wiedemann Foundation  
 Kansas Health Ethics  
 Kansas Health Institute  
 Kansas Humanities Council  
 Kansas League of Women Voters  
 \* Northwest Kansas Area Health Education Center  
 \* PhRMA  
 \* United Methodist Health Ministry Fund

### **Media Organizations:**

Kansas Association of Broadcasters  
 Kansas Press Association  
 Kansas Public Radio  
 Kansas Public Television - KPTS  
 Kansas Senior Press Services

### **Medical Providers:**

\* Faith Home Health Hospice  
 \* Harry Hynes Memorial Hospice  
 \* Hospice Services, Inc.  
 \* Kansas City Cancer Center  
 \* Lighthouse Hospice  
 Midland Hospice  
 Shawnee Mission Medical Center  
 \* South Wind Hospice  
 University of Kansas Medical Center  
 Via Christi Regional Medical Center  
 Wesley Medical Center

### **Professional Associations:**

\* Kansas Association for Family & Community Education  
 Kansas Association of Homes & Services for the Aging  
 Kansas Association of Osteopathic Medicine  
 Kansas Chapter, National Association of Social Workers  
 Kansas Funeral Directors & Embalmers Association  
 Kansas Health Care Association, Inc.  
 Kansas Home Care Association  
 \* Kansas Hospice and Palliative Care Organization  
 Kansas Hospital Association  
 Kansas Medical Society  
 Kansas Organization of Nurse Leaders  
 \* Kansas Pain Initiative  
 Kansas Pharmacists Association  
 Kansas State Nurses Association

### **Caring Communities:**

Clay Center, Dickinson County, Dodge City, Emporia, Garden City, Great Bend, Greenwood County, Hays, Hutchinson, \* Jackson County, Jefferson County, Junction City, Kansas City, Lawrence, Liberal, Manhattan, Morris County, Nemaha County, Northeast Kansas, Newton, Norton, Osborne County, Phillipsburg, Pittsburg, Pratt, Rush County, Salina, Shawnee Mission, Topeka, Wamego/Pottawatomie County, Washington County, Wichita

\* Denotes FRIENDS FOR LIFE Contributing Partners who have made direct financial contributions during 2005



# "Friends for LIFE" 2005

The LIFE Project expresses heartfelt thanks and appreciation for the generous contributions that enable and support our efforts.

## *Honoring our 2005 "Champions for LIFE"*

### Gary Doolittle

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Linda Hall, Kansas City, KS  
Sandy Kuhlman, Phillipsburg, KS  
Anita Macan, Kansas City, KS

### Jackson County Caring Community, Holton, KS

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Jackson County Caring Community, Holton, KS  
Jackson County Nursing Home, Holton, KS  
Mercer Funeral Home, Holton, KS

### Diane Johnson

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Michele Chandler, Pratt, KS  
South Wind Hospice, Pratt, KS  
Barbara Shinkle, Pratt, KS  
LethaMae "Pat" Gilham, Pratt, KS

### Sandy Kuhlman

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Kim Fair, Brookville, KS  
Hospice Services, Inc., Phillipsburg, KS  
Carole and Bob Hull, Newton, KS  
Kay and William "Buzz" Lohmiller, Ponca, AR  
Dianne Michaud, Clay Center, KS  
Carol Whitehair, Abilene, KS

### Dorothy Kurtz and Teresa Sikes

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Lawrence Memorial Hospital, Lawrence, KS  
Linda and Ted Upstill, Lawrence, KS  
Linda and Quentin Kurtz, Overland Park, KS

### Bryan Thompson

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Sandy Kuhlman, Phillipsburg, KS  
Lou and Ken Thompson, Bucklin, KS

### Tom Welk

Donna Bales, Wichita, KS  
Dianne and John Carney, Wichita, KS  
Lowell and Patresa Ebersole, Wichita, KS  
Ginger and Jim French, Wichita, KS  
Jerry Howell, Wichita, KS  
Sisters Adorers of the Blood of Christ, Wichita, KS  
Carol Moore, Hutchinson, KS  
Loretta Seidl, Topeka, KS  
Harry Hynes Memorial Hospice, Wichita, KS

### JoVeta Wescott

Joan Aldrich, Wichita, KS  
Elma Ash, Derby, KS  
Donna Bales, Wichita, KS  
Lynn Borchardt, Hutchinson, KS  
Dianne and John Carney, Wichita, KS  
Esther Ideker, Holton, KS  
Janet Cusick and Gary Jost, Wichita, KS  
Debbie and Ray Deutsch, Kansas City, MO  
Mallory and Louis Medvene, Wichita, KS  
Jette and Steen Mortensen, Wichita, KS  
Sister Josephine O'Gorman, Wichita, KS  
Andrea Romeiser, Bison, KS  
Grace Sadiq, Wichita, KS  
Dr. Jamie Spikes, Manhattan, KS  
Patti Wright, Wichita, KS  
Beth and Claudio Ferraro, Wichita, KS  
Martha McCabe, Wichita, KS  
Marilyn Peterson, Garden City, KS  
Faith and Bruce Roberts, Champaign, IL  
Virginia Elliot, Hutchinson, KS

## *In Memory or Honor of Others*

### In Memory of Melvin Kuhlman

Donna Bales, Wichita, KS  
Kay and William Lohmiller, Ponca, AR

### In Memory of Emily Taylor

Donna Bales, Wichita, KS  
Artie Shaw, Lawrence, KS  
Hilda Enoch, Lawrence, KS

### In Honor of Esther Ideker's 75th Birthday on June 19, 2005 and still working with a passion for end-of-life issues

Henriette Area, Holton, KS

### In Memory of Lola Olson

Jane Bemis, Daughter of Lola Olson, Great Bend, KS

### In Memory of Mark Morrison

Dr. Jamie Spikes

### In Memory of Esther and Jack Medvene and Almon and Alpha Pepper

Mallory and Louis Medvene

### In Memory of Rosalee Sanderson

Linda and Quentin Kurtz, Overland Park, KS

## *More "Friends for LIFE"*

Dianne and John Carney, Wichita, KS  
Carole and Bob Hull, Newton, KS  
Kay and William "Buzz" Lohmiller, Ponca, AR  
Errol and Suzanne Luginbill, Wichita, KS  
Genevieve McMahon, Lawrence, KS  
Theresa Meyer, Palmer, KS  
Loyette Olson, Winfield, KS  
Teresa and Greg Sanderson, Horton, KS  
Ted and Linda Upstill, Lawrence, KS

## *Organizations*

United Methodist Health Ministry Fund, Hutchinson, KS  
K.T. Wiedemann Foundation, Wichita, KS  
American Alliance of Cancer Pain Initiatives, Madison, WI  
Foundation for Hospice Care, Kansas City, MO  
Kansas Department on Aging, Topeka, KS  
Pharmaceutical Research and Manufacturers of America, Washington, DC  
Kansas City Cancer Center, Lenexa, KS  
Northwest Kansas Area Health Education Center, Hays, KS  
Lighthouse Hospice, Horton, KS  
Kansas Association for Family and Community Education, Canton, KS  
Midland Hospice, Topeka, KS