

## **LIFE PROJECT PARTNERS ATTEND ATTORNEYS GENERAL LISTENING FORUM ON END-OF-LIFE CARE**

**Those who are concerned about the quality of end-of-life care have a new ally.** Each year, the President of the National Association of Attorneys General (NAAG) selects a topic to be the Association's Presidential Initiative, a special area of focus for attorneys general to spotlight and discuss. **Drew Edmondson, Attorney General of Oklahoma** and the current president of NAAG has, as HNN reported in the 9/3/02 edition, **chosen end-of-life care as his Presidential Initiative.**

**LIFE Project Partners were represented by participation from Donna Bales, the LIFE Project; Myra Christopher and Carolen Collins, Midwest Bioethics Center; Ardie Davis, the Kansas Department on Aging, Maren Turner and Ernest Kutzley from AARP-Kansas; Bill Colby, author, speaker and attorney; and Bob Twillman, Kansas Pain Initiative. "The forum," says Bales "provided a powerful exchange of needs, issues and, most importantly, possible solutions that can be found and supported by the work of America's Attorneys General."**

To engage attorneys general in addressing the legal and consumer rights issues related to care near the end of life, Edmondson has encouraged every attorney general to attend one of three listening forums that he will host during the next eight months. The first of these conferences was held in Overland Park, Kansas, on September 26. **Participants in the meeting came from 24 states and 15 state AG offices.** Kansas Attorney General Carla Stovall welcomed the Attorneys Generals and their staffs to Kansas and to the forum.

**The forum began with a keynote overview of end-of-life issues by Ira Byock, who presented "Dying in America: A Consumer Crisis and an Opportunity for Leadership." The remainder of the forum focused on three critical issues in end-of-life care: pain management, advance care planning and professional expertise.** The format for each of these topics featured a panel that included input from a consumer, from experts and from an attorney general's office.

During the course of the day, presentations were made by David Joranson, Pain and Policy Studies Group at the University of Wisconsin, Robert Williamson, US DEA, Assistant AG Jack Schwartz, Maryland, Chris Cruzan White, sister of Nancy Cruzan, Charles Sabatino, American Bar Association, Karen Kaplan, Partnership for Caring, LAST ACTS and Rallying Points, attorney Bill Colby, who represented Nancy Cruzan and her family, Assistant AG Maureen Glynn, Rhode Island, Betty Ferrell, City of Hope, **Myra Christopher, Midwest Bioethics Center,** and AG Drew Edmondson, Oklahoma. Two of the three consumers who offered testimony were from Kansas as well.

Numerous ideas for possible action by attorneys general were mentioned. These included suggestions that AGs can:

**\* Be sure that they, or a designated staff member, develop expertise in end-of-life issues.**

- \* **Join in endorsing other groups' joint guidelines for providing excellence in pain management and end-of-life care.**
- \* **Take any visible action to support good pain and symptom management.**
- \* **Help to communicate, publicize and promote guidelines that are adopted by licensing boards and others.**
- \* **Serve as sponsors for events that educate healthcare professionals and promote professional expertise in end-of-life issues.**
- \* **Educate consumers about their rights in expecting and receiving quality care at the end of life.**
- \* **Connect and collaborate with the state's experts in end-of-life issues.**
- \* **Address consumer rights issues related to end-of-life care.**
- \* **Promote and strengthen expectations that advance care directives be honored.**
- \* **Promote a balanced public policy that both values and promotes pain management and works toward prevention of drug diversion and abuse.**
- \* **Consider the impact of investigatory methods. In investigations, look for conformity to good clinical practice and not the amount or frequency of prescribing practices.**
- \* **Address the diversion and abuse of drugs in ways that do not interfere with good medical practice and patient care.**
- \* **Identify pain management as a regulatory obligation.**
- \* **Consider legislation or AG opinions that confirm consumers' rights to refuse/deny medical treatment and intervention.**

Edmondson shared his hope, as a public servant, to leave a legacy of protecting the vulnerable. Years ago, he said, when he began his public service as an AG, he thought of the vulnerable as those such as children and victims of domestic violence. But he didn't think of citizens near the end of life. Now he does, he says, and he wants all AGs to join him in better serving the needs of all Americans as they age and die.

At the end of the three forums, Edmondson intends to publish a book of the findings of the forums. He would like to see the book on the desk of every AG in the nation, to get the issue more clearly on their "radar screens," to have every AG as a messenger for this cause and to see this work as a focus on representing the vulnerable. **"My goal," says Edmondson, "is to encourage a positive public awareness and professional understanding of the developing role of attorneys general as change agents in this challenging endeavor."**

LIFE Project Partner, Midwest Bioethics Center, along with the Law Schools of the University of Kansas and the University of Missouri, hosted a reception and dinner on September 26. At the September 27 meeting, Myra Christopher, President/CEO of the Midwest Bioethics Center and Program Director of the Robert Wood Johnson Foundation Community-State Partnerships to Improve End-of-Life Care, addressed the Attorneys General. Christopher encouraged the AGs and their staffs to work with end-of-life coalitions, like the LIFE Project and to not underestimate the importance of adding their support and partnership to end-of-life care.

Additional listening forums are planned February 20-22, 2003, in San Diego and May 15-17, 2003, in Baltimore. For more information, contact Debbie Manson at 202-326-6053.