



# IHO Update

*Bi-weekly News for Hospice Professionals in Iowa*

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**November 18, 2005**

## **IHO Fall Conference Draws Record Crowd**

Great keynotes from William Colby and Joy Johnson highlighted this year's IHO Fall Conference held this week in Ames. William Colby, the attorney representing Nancy Cruzan's family, provided an insider's view of the events behind this highly public legal battle and the tolls it took on the Cruzan family. Joy Johnson, co-founder of the Centering Corporation, provided a delightful closing keynote. With lots of humor, she shared her personal story of how she responded to her cancer diagnosis and subsequent treatment. Dillon Woods, president of the Living With Quality Foundation, provided the opening keynote and also entertainment for the 64 volunteers recognized in the Honored Volunteer Ceremony. Twenty-five breakout sessions over the two days rounded out the conference.

Pre-conference registration was nearly 590 – almost 50 registrations higher than last year. At press time, the final attendance figures were not yet available.

Be sure to mark your calendars for next year's IHO Fall Conference, which is set for November 15-16, 2006 at the Scheman Building in Ames.

A special thank you to members of the IHO Education Committee for all of their hard work to make the conferences such a success. Committee members include:

- Norene Bauman, Community Hospice, Lake City
- Dee Bryant, Mercy Hospice, Johnston
- Joel Fry, Hospice of Central Iowa, West Des Moines, *Co-Chair*
- Jennifer Gustafson, CCMH-Home Care/Hospice, Atlantic
- Rosy Harrington, Hospice of Central Iowa, West Des Moines
- Norma Haskins, Hospice of Central Iowa, Des Moines
- Dee Hiveley, Iowa Hospice, Johnston
- Margo Nixon, Hospice of Siouxland, Sioux City
- Tana Olson, Hospice of North Iowa, Mason City
- Kristin Paris, Hospice of Monroe County, Albia
- Nadine Schlien, Hospice of Fort Dodge, *Co-Chair*
- Denise Sheston, Mercy Hospice-Centerville

## **Special Thanks to Conference Exhibitors and Sponsors**

There were a record number of exhibitors at this year's IHO Fall Conference. Firms are beginning to realize that this is THE conference to exhibit at to meet Iowa hospices. Exhibitors this year included:

- Care Initiatives

- Hammer Medical Supply
- Health Enterprises of Iowa
- Hospice of Central Iowa
- Hospice of the Florida Suncoast
- Hospice Pharmacia
- HospiScript Services
- Iowa Lion's Eye Bank
- Mills and Murphy Software Systems, Inc.
- Option Care
- UniMed II
- Wellmark, Inc.
- Xap Interactive, Inc.

In addition to the exhibitors, the following organizations also provided support to this year's meeting:

- HPC Foundation for Hospice Care, Council Bluffs office, awarded a \$1500 grant to the conference.
- Hospice of Central Iowa in West Des Moines provided the flowers for the volunteers recognized in the IHO Honored Volunteer Ceremony.
- Iowa Hospice in Johnston provided the \$500 honorarium for the closing keynote.

### **State Says Reciprocity Agreement May Be Needed**

Martha Coleman from the Iowa Department of Inspections and Appeals (DIA) provided a regulatory update at this week's IHO Fall Conference. During her presentation, Coleman mentioned that federal law requires states to have a reciprocity agreement to provide hospice services under the Medicare program to patients in another state. Iowa currently has reciprocity agreements for home health but not hospice.

Coleman stated that the states in Iowa's Medicare region (Iowa, Missouri, Kansas, Nebraska) have begun to discuss establishing an agreement, but the issue has been tabled. Coleman had few details on this issue but told IHO that hospices should not change their practices until they receive more information from DIA.

IHO will be working on this issue with both state and federal contacts and will keep hospices informed of any developments. Once again, until hospices receive explicit written notification from DIA, IHO does not recommend any change of practices concerning hospices serving out-of-state patients. Questions can be directed to Becky Anthony ([anthonyb@ihaonline.org](mailto:anthonyb@ihaonline.org)) or Shannon Strickler ([stricklers@ihaonline.org](mailto:stricklers@ihaonline.org)) at IHO.

### **New Hospice Data Set Released; Iowa Data Provided at IHO Workshop**

NHPCO, in collaboration with state hospice organizations, has just released results from its 2004 National Data Set (NDS). In being one of the few databases that captures information on all hospice patients regardless of payer source, the NDS provides truly meaningful data and information for hospice professionals. Martha Tecca, president of Perforum, reviewed

the data collected from Iowa hospices at the workshop on quality and data she led November 14 in Ames. The summary data she provided is attached to this week's *IHO Update*. IHO will review feedback from the workshop and also explore future efforts with Perforum to increase the number of IHO members completing the NDS.

Below are some highlights pulled from the 2004 survey:

- The number of hospice programs nationwide continues to increase – from one program in 1974, to 2,312 in 1994, to 3,650 in 2004.
- Nonprofit programs continue to dominate the field at 63 percent (vs. 67 percent in 2003). “For-profit” programs increased to 31 percent and “government-run” programs increased to 6 percent.
- As of 2004, hospice has broken the 1 million-patient barrier – more than doubling the number served in only eight years.
- In 2004, 6.2 percent of hospice patients were of Hispanic or Latino origin (vs. just 4.3 percent in 2003) while 6.4 percent of patients identified themselves as “multiracial” (vs. 4.6 percent in 2003).
- Cancer diagnoses accounted for 46 percent of hospice admissions in 2004.
- Nearly two-thirds of hospice patients are 75 years of age or older (vs. 63 percent in 2003). About 1 percent are 35 years or younger, and 57 percent are female.
- Average length of stay in 2004 was 57 days (up by two days compared to 2003). The median length of service, a more accurate gauge in understanding the experience of typical hospice patients, remained at 22 days.
- About 35 percent of hospice patients died in seven days or less (vs. 36.9 percent in 2003) while 9 percent died in 180 days or less (vs. 7 percent in 2003).

### **Study Shows Physicians Not Getting End-of-Life Training**

A study in the current issue of the *Journal of Palliative Medicine* found that less than half of the medical residency programs in the state of Michigan offered any formal training in end-of-life care and that less than one-third of the programs provided any training in hospice care. Yet despite the apparent lack of training, the researchers report that most of the program directors rated their program's end-of-life training as adequate or excellent. This contrast led the authors to predict a slow pace for any end-of-life curriculum enhancements.

The study was conducted by researchers from the Michigan State University (MSU), including former Michigan Hospice and Palliative Care Organization board member Karen Ogle, M.D. “There have been slight improvements. But the bad news is we are not making huge strides in how we're training these new doctors,” said Dr. Ogle. “It's grossly inadequate.”

It's extremely important that this type of training be provided at this point in the medical resident's career, said Clayton Thomason, MSU assistant professor in the Department of Family Practice and Center for Ethics and Humanities in the Life Sciences and paper co-author. "This is when they are really creating their identity as a physician," he said. "This is when they develop their philosophy of care. If doctors go through this type of training, they'll practice differently."

Ogle said many residency directors are reluctant to teach new doctors how to bring about a "good death" in their patients. "There is a common theme that medicine has become too cure-focused or over-technologically focused," she said. "Death is still viewed as a medical failure."

There are a number of solutions to this issue, Dr. Ogle and Thomason said, starting with the physicians and other health care providers themselves through accreditation and examination.

"We like to say 'if you test it, they will come,'" Dr. Ogle said. "If questions about palliative care and hospice are on a licensure exam, people will take notice."

## **Center Holds Congressional Briefing on End-of-Life Care**

In an on-line news feature story on its Web site ([www.thehastingscenter.org](http://www.thehastingscenter.org)), the Hastings Center announced the release of the conclusions of its recent research project on end-of-life care. The report was shared at a Congressional briefing on November 10. "The project described the progress made in the past decade on improving end-of-life care and identified challenges that remain." The study presented ideas for a "new strategy to improve care of the dying." The goal is to build a better system of care. What is needed, according to the story, is a "shift from treating the patient in isolation to embracing the collective needs of patient and family."

The report, "Improving End of Life Care: Why Has It Been So Difficult?," which was released as a supplement to the November-December issue of *The Hastings Center Report*, is the result of an invitation to end-of-life experts to "explore the significance of changes in end-of-life care." The supplement consists of 10 essays, on subjects such as public policy and disability rights. Each essay is written "to consider what we believe to be true about end-of-life care, to consider what is actually true, and to envision a different approach to concerns such as personal autonomy, advance directives, disability rights, and the legal system."

The executive summary says that what is needed "is a new paradigm for improving end-of-life decision-making and care delivery that puts less emphasis on the specific medical decisions concerning the individual dying patient and instead fosters shared decision-making and communication among patients and loved ones." In the future, the authors say, "the emphasis should be on promoting a system of care that offers much better coordination of services, treatment planning, and continuity of care and that sets parameters for better family dynamics and decision-making around end-of-life issues."

The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute founded in 1969 to explore fundamental and emerging questions in health care, biotechnology, and the environment.

## **Oregon Creates EOL Resource Guide for Seniors**

Oregon's Governor's Commission on Senior Services (GCSS) has issued a new report, *Being Prepared: A Resource Guide for End-of-Life Decisions and Planning*. Available from the GCSS Web site ([www.oregon.gov/DHS/spd/adv/gcss/home.shtml#reports](http://www.oregon.gov/DHS/spd/adv/gcss/home.shtml#reports)), the report is designed to help people think through their wishes about end-of-life and communicate those wishes to their families.

The booklet, designed as a workbook, includes sections on how to talk with family, information about personal finances, providing adequate health information (including advance directives), information on burials, cremations and funerals, and additional resources.

The booklet also suggests keeping a "list of lists," with all the information that someone would need to handle a deceased person's affairs. Items such as passwords, charge accounts and credit card numbers, outstanding loans and leases, all pertinent ID and PIN numbers, all financial accounts, the location of all important papers, tax information, location and identity of all needed keys, items loaned to or borrowed from other people, utilities and tradespeople to notify of the death, and others should be included.

## **Agency Offers Post-Diagnosis Help on Web Site**

The federal Agency for Healthcare Research and Quality is offering "Next Steps After Your Diagnosis," a patient advocacy Web site with general advice on what to do after being diagnosed with a serious illness. It offers general advice for people with almost any disease or condition, and includes tips to help users learn more about specific problems and how it can be treated. The information is presented in a simple way to help users scan the material and read only what they need when they need it. Organizations, publications, and other resources are included for reference and more detailed information.

The Web site, located at [www.ahrq.gov/consumer/diaginfo.htm](http://www.ahrq.gov/consumer/diaginfo.htm), is constructed around five basic steps for users:

- **Step 1: Take the time you need.** Do not rush important decisions about your health. In most cases, you will have time to carefully examine your options and decide what is best for you.
- **Step 2: Get the support you need.** Look for support from family and friends, people who are going through the same thing you are, and those who have "been there." They can help you cope with your situation and make informed decisions.

- **Step 3: Talk with your doctor.** Good communication with your doctor can help you feel more satisfied with the care you receive. Research shows it can even have a positive effect on things such as symptoms and pain. Getting a “second opinion” may help you feel more confident about your care.
- **Step 4: Seek out information.** When learning about your health problem and its treatment, look for information that is based on a careful review of the latest scientific findings published in medical journals.
- **Step 5: Decide on a treatment plan.** Work with your doctor to decide on a treatment plan that best meets your needs.

## Pain Notes

- According to a research letter published in *The Journal of Pain and Symptom Management*, “thousands of armed robberies and thefts from pharmacies, manufacturers and distributors result in millions of dosages of opioid pain medications being diverted into the illicit market.” The letter, “Drug Crime is a Source of Abused Pain Medications in the United States,” is available at the University of Wisconsin’s Pain & Policy Studies Group Web site, [www.medsch.wisc.edu/painpolicy/publicat/05jpsm/05jpsm.pdf](http://www.medsch.wisc.edu/painpolicy/publicat/05jpsm/05jpsm.pdf). (*PPSG Website*)
- Pain Therapeutics has granted King Pharmaceuticals the right to market an abuse-resistant form of OxyContin’s active ingredient, oxycodone. Remoxy is “encased in a sticky, highly viscous material that resists crushing, snorting, injecting or dissolving in alcohol.” If a planned January final-stage clinical trial is successful, Pain Therapeutics and King will file for FDA approval of Remoxy in 2007. (*The New York Times*, 11/10)

## Hospice Notes

- The Hospice of the Florida Suncoast has made a shift toward social, or “viral,” marketing. Michael Bell, vice-president of development and community relations, says the hospice asked, “Who are those that influence, either directly or indirectly, access to hospice care in our community? And let that drive our marketing plan.” (*Hospice Letter*, 11/2005)
- Caring Connections, NHPCO’s consumer engagement initiative, held a national forum on November 10 to “explore ways that national organizations can help their constituencies continue conversations about end-of-life issues.” Speakers included NHPCO’s J. Donald Schumacher, attorney William Colby, Dr. Carlos Gomez of Capital Hospice, nurse Rebecca McDonald of The Hospice of the Florida Suncoast, and Newsweek contributing editor Eleanor Clift. (*NHPCO Press Release*, 11/10)
- The VA’s National Center for Post Traumatic Stress Disorder (PTSD) says that the nation’s 3.6 million WWII veterans may be “especially vulnerable” to PTSD. That is why organizations like Nebraska Hospice and Palliative Care Association and the Department of Veterans Affairs want to educate caregivers, hospice providers and others about how to recognize the syndrome in the elderly. More public awareness is needed, since most veterans are treated in private facilities rather than in VA medical centers. (*AP*, 11/10)

- The Virginia Initiative for Palliative Care, a joint project of Virginia Commonwealth University Massey Cancer Center and Capital Hospice of Fairfax, will “provide free, highly individualized training to doctors, nurses, chaplains, social workers and other professionals who seek tangible ways to improve patient care.” Virginia residents should contact Carrie Cybulski at ccybulski@vcu.edu, or call her at 804-628-1819. (*VCU Massey Cancer Center Press Release, 11/1*)
- The Hospice of Southwest Florida plans to celebrate its 25th anniversary and raise money by placing 70 large fiberglass clowns, sponsored by businesses and painted by artists, around Sarasota. Hospice leaders and the city council were enthusiastic about the idea, but opponents said that the clowns would “cheapen a city that bills itself as the ‘cultural coast.’” Not only that, people who suffer coulrophobia have e-mailed city commissioners about their abnormal fear of clowns. The hospice will proceed with its plans, with one stipulation – no scary clowns. (*AP, 11/6*)

## **Enclosure**

2004 NHPCO National Data Set-Iowa State Summary Report