

PROJECT ON DEATH IN AMERICA SOCIAL WORK LEADERSHIP AWARDS *Monthly Newsletter*

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"Promoting Social Work Leadership in Care of the Dying and the Bereaved"

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This monthly newsletter is produced as part of the Social Work Leadership Awards for the Project on Death in America. Questions, comments and ideas should be submitted to:

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IN THE SPOTLIGHT

Social Work Leader, Jim Keresztury

"Changing Policy and Practice in End of Life Care in West Virginia"

Jim Keresztury, Project Director of the West Virginia Initiative to Improve End of Life Care, recently coordinated the 2000 West Virginia Summit on End of Life Care. More than 230 West Virginians attended, including physicians, lawyers, nurses, clergy, social workers, and health care consumers. Two announcements made at the Summit highlighted the success that the Initiative has had in influencing the policy and practice of end of life care in West Virginia.

Joan E. Ohl, Cabinet Secretary for the West Virginia Department of Health and Human Services, announced that she will include funding to start a West Virginia Center for Palliative Care and Hospice in next year's budget. The Center would continue and expand on the work of the West Virginia Initiative.

◆ Charlene Farrell, President of the West Virginia Hospice Council, announced that efforts by the West Virginia Initiative have been successful in making hospice available to the West Virginia nursing home residents by adjusting the case-mix formula used by Medicaid. The adjustment removed a disincentive that existed for nursing homes to contract with hospices for the care of their dying residents. As a consequence, more dying nursing home residents will receive hospice care throughout the state.

◆ Members of the West Virginia Initiative, which receives funding from PDIA and the Robert Wood Johnson Foundation, have spent the last year advocating for these kinds of policy changes, which can improve access to end-of-life care. One of their first projects was to identify weaknesses in end-of-life decision-making laws and educate the Legislature about ways to strengthen the law. As a result, the last legislative session passed the new West Virginia Health Care Decisions Act, which ensures a patient's right to self-determination in health care decisions.

If you want to know more about the work of Jim Keresztury and the Initiative, please visit their website at www.wvinitiative.org.

"I am encouraged that state government is recognizing the importance of quality cost-effective end-of-life care for West Virginians. It's not only the right thing to do, but it will result in substantial savings for West Virginia's Medicaid program. We are optimistic that the state legislature will agree and include the Center as part of next year's budget package."

-Jim Keresztury, Social Work Leader

Social Work Leaders Awards, Grants and Presentations

Susan Taylor-Brown, PhD, recently received a grant to create a Consortium to Provide Experiential and Recreational Services for HIV Affected and Infected Youth in Western Upstate New York. This project is funded by the Abandoned Infants Assistance Program, Children's Bureau, HHS. The grant is funded for 4 years beginning September 2000.

Norma del Rio, MSW, has received three grants this summer for a project she founded in 1997, Access to End of Life Care. The grants are from the Van Loben Sels Foundation ; the Evelyn and Walter Haas, Jr. Fund ; and the Friedman Family Fund. Norma also serves as co-chair of the board and chair of the curriculum task force for Access to End of Life Care. Access conducts educational outreach in underserved communities and trains Bay Area health care and social service providers in multicultural elements of end-of-life care.

Gary Stein, MSW, JD, received two grants in Summer 2000 to support his ongoing work with the New Jersey Comfort Care Coalition and New Jersey Health Decisions. The State of New Jersey awarded a 2-year grant to promote the policy and practice environment for end-of-life care in New Jersey. The Johnson and Johnson Foundation also awarded a 1-year grant to support New Jersey Health Decisions.

Mary Sormanti, PhD, is co-investigator for a 3-year grant (2000 - 2003) from the National Institutes of Health for a study titled "Partner Abuse and HIV in Women Receiving Emergency Care." The study will explore the relationship dynamics and sequences of events that culminate in the co-occurrence of partner violence between intimate partners and sexual and drug-related HIV risk behaviors among women; examine longitudinally the prevalence and incidence of partner violence; and elucidate the temporal relationships between violence and HIV risk among women. The study aims to increase understanding of the relationship between partner violence and HIV risk behavior and may inform assessment, referral, and treatment protocols used by Emergency Department staff to meet the diverse needs of women at risk.

Katherine Walsh Burke, PhD, MSW, was awarded a HELP grant in September 2000 from the Northeast Regional American Cancer Society to develop "Adventure Based" programs for cancer survivors and caregivers. The project will also examine the impact of this intervention method and train graduate students in its use.

John Linder, MSW, developed the overall curriculum and presented two seminars for the Roxane Palliative Scholars course. This course is hosted by UC Davis and brings together health professionals from around the country for two days of intensive training and one day of field experience in end-of-life care. This curriculum, described in the Fall 1999 Journal of Cancer Education, offers diverse, interdisciplinary training to health professionals to sharpen their skills in the delivery of palliative care.

Grace Christ, DSW, was invited to speak at the New York University School of Medicine for the Department of Pediatric Grand Rounds on October 6, 2000. She gave a presentation on "Children's Grief: A Developmental Perspective".

Terry Altilio, ACSW, was an invited speaker at the following conferences:

August 2000, Buena Vista, FL - The Annual Conference of the Florida Society of Oncology Social Workers on "Pain Management: Assessment and Intervention for Social Workers."

June 2000, Tampa Bay, FL - Berlex Laboratories sponsored a conference for physicians on Advances in Treatment for Bone Pain Due to Cancer. The title of her presentation was "Psychological Aspects of Pain Management."

April 2000, St. Louis, MO - The annual meeting of the American Society of Pain Management Nurses. She spoke on "Assessing and Managing the Psychological Needs of Pain Patients."

Conferences

Jim Keresztury, MSW, MBA, of the West Virginia Initiative to Improve End-of-Life-Care recently organized two conferences for Social Workers and Allied Health Care Professionals in West Virginia. These conferences were a collaboration between the Robert C. Byrd Health Science Center and the West Virginia School of Social Work and Public Administration at the Eberly College of Arts and Sciences. These meetings were very successful with over 120 social workers attending from throughout the state. The first conference, on September 29, featured a presentation by Matt Loscalzo, MSW, on "Psychological Distress in End-of-Life Care." Loscalzo is Director of Patient and Family Services and Co-Director of the Center for Cancer Pain Research at The John Hopkins Oncology Center. The second conference, held on October 6, featured a presentation by **Leadership Program Director Grace Christ, DSW**, on "Healing Children's Grief: A Developmental Perspective." Dr. Christ is Associate Professor at the Columbia University School of Social Work.

Five Social Work Leaders presented at the annual meeting of the Association of Oncology Social Work in April 2000. This year's meeting in Vancouver was held in partnership with the Canadian Association for Psychosocial Oncology and the American Society for Psychobehavioral Oncology. Presentations by the leaders were as follows:

Susan Blacker, MSW, ILCSW-C, "Palliative Care and Hospice: Shared Traditions and Evolving Futures."

Grace Christ, DSW, "Children's Grief: A Developmental Perspective."

Terry Altilio, ACSW, "Advanced Topics in Palliative Care and Symptom Management."

Iris Cohen, MSW, LICSW, "In Sickness and In Health: How Do We Know Which is Which?"

"Preaching What We Practice: Psychosocial Care of BMT Patients and Families."

Katherine Walsh Burke, PhD, MSW, "Cancer Survivor Toolbox"

Norma del Rio, ACSW, of San Francisco State University helped to organize an ACCESS sponsored educational forum in February 2000 on "ACCESS to End of Life Care: Serving our Diverse Community." **PDIA Faculty Scholar La Vera Crawley, MD**, was the keynote speaker for the event.

UPCOMING CONFERENCE

“Social Work and End of Life Care Symposium: Clinical Practice in Palliative Care”

November 10 and 11, 2000

Baltimore, Maryland

**The Johns Hopkins Oncology Center’s Continuing Education Program in
Psychosocial Cancer Care**

(Program Director: *Social Work Leader, Susan Blacker, LCSW-C*)

Developed with support from: The Project on Death in America Social Work Leadership Development Award

In Association with: The National Association of Social Workers - Maryland Chapter and The Maryland Society for Clinical Social Work

***** Patricia Prem, MSW, and PDIA Board Member will be presenting at this conference on the creation of the Soros Social Work Leadership Development Awards Program and discuss new directions in Social Work and Palliative Care. *****

Leadership Initiatives

Social Work Leaders

Terry Altilio, ACSW

Dept. of Pain Medicine and Palliative Care
Beth Israel Health Care System

Elizabeth Mayfield Arnold, MSW, PhD

Graduate School of Social Work
University of North Carolina, Chapel Hill

Joan Berzoff, MSW, EdD

Smith College School for Social Work

Susan Blacker, MSW, LCSW-C

The Johns Hopkins Oncology Center

Iris Cohen, MSW, LICSW

Beth Israel Deaconess Medical Center

Barbara Dane, PhD

Program in Advanced Clinical Social Work
Ehrenkranz School of Social Work at NYU

Norma del Rio, MSW

Institute for Multicultural Research and Social
Work Practice - San Francisco State University

Jim Keresztury, LCSW, MSW, MBA

West Virginia Initiative to Improve End of Life
Care

John F. Linder, LCSW

UC Davis Cancer Center

Margo Okazawa-Rey, EdD

Institute for Multicultural Research and Social
Work Practice - San Francisco State University

W. June Simmons, MSW

Partners in Care Foundation

Mary Sormanti, PhD

Columbia University School of Social Work

Gary L. Stein, MSW, JD

New Jersey Health Decisions

Susan Taylor-Brown, PhD, MPH, ACSW

Greater Rochester Collaborative MSW Program
Nazareth College

Katherine Walsh-Burke, PhD, MSW

Springfield College School of Social Work

Jim Keresztury, MSW, MBA, as launched a number of collaborative initiatives in the humanities to draw attention to end-of-life care issues. He recently acted as a consultant to the Old Brick Playhouse, a theater group, to produce a puppet video related to death, dying, and loss to encourage elementary school children to discuss issues related to end-of-life care. Jim has received funds from The Claude Worthington Benedum Foundation to make the video available to schools throughout the state. The West Virginia Initiative to Improve End-of-Life Care, of which Jim Keresztury is Project Director, is also working with West Virginia Writers, Inc., to sponsor an essay competition for high school students on the topic "Reflections on Personal Loss and Grief." This fall, the Initiative also set up reading groups throughout the state on the topic of end-of-life care.

John Linder, LCSW, of the UC Davis Cancer Center under a contract with the California Department of Corrections, provides an educational program for physicians, staff (medical, administrative, and custodial) and inmates at the California Medical Facility at Vacaville, which houses the hospice facility for state-incarcerated terminally ill felons. A group of about 40 inmate volunteers provides services to fellow inmates during their time in hospice, and these volunteers sit round-the-clock vigil when a hospice patient is dying. This work will be featured in a series on prison hospices that John is developing for upcoming publication in the Journal of Palliative Medicine.

Susan Taylor-Brown, PhD, of the Nazareth College has established a National Advisory Board of leading experts for her project on Enhancing the Care of Families Living With HIV/AIDS. Along with parents, adolescents, and caregiver members, the Board includes Dr. Lori Wiener of the National Institute of Health; Dr. Vincent Lynch of Boston College; Dr. Susan McFeaters of the University of Maryland; Dr. Barbara Draimin of NYU; Peter Lesko, CSW, of Benjamin Rush Psychiatric Hospital; Robyn Jones, MSW, of Family and Children's Services in Baltimore; Max Yurenda, Director of Double "H"; Margarita Suarez, Director of Virginia Satir's Avanta Network; and Evelyn Blackburn, ACSW.

Susan Blacker, MSW, LCSW-C, of the Johns Hopkins Oncology Center represented social work at the June 30, 2000, meeting of the Last Acts Institutional Innovations Task Force. She provided feedback on the document "Precepts to Practice." This Task Force is headed by Joe Fins, Judy Peres, and Don Schumacher.

New In Print and Media

In Journals:

Walsh-Burke, K. "Matching Bereavement Services to Level of Need." *The Hospice Journal*, **15** (1), 2000.

The establishment of hospices in the U.S. has resulted in an increase in bereavement services available to clients experiencing loss. Many of these services, such as educational and peer support groups, are provided without screening or assessment of risk for complicated bereavement in the individuals who use those groups. While acceptance of uncomplicated bereavement is important, assessment for complicated bereavement also is important to ensure that appropriate services are offered to those at risk for problems of adjustment. This article by **Katherine Walsh-Burke, PhD, MSW**, reviews the literature on risk criteria for complicated bereavement and proposes a method for both assessing risk and matching service to level of need on the basis of these criteria.

Sormanti, M., & Kayser, K. "Partner Support and Relationship Change During Life-Threatening Illness: Women's Perspectives." *Journal of Psychosocial Oncology*, **18** (3), 2000.

Mary Sormanti, PhD., co-authored this article which examines the role of the primary partnered relationship as a factor in women's adjustment to cancer. The study addressed the following questions: How do women with cancer perceive the effect of their illnesses on their primary partnered relationships? What types of support do women receive from their partners during the illness experience, and is this support adequate? What is the relationship between mutuality of the primary partnered relationship and support provided by the partner? Results indicated that the type of support provided by the partner as well as the level of relationship mutuality contribute positively to women's coping.

Altilio, T. "Building a Pain Management Program: Background and Basics." *Oncology Times Supplement on Oncology Pain Management*, **14**(5), 1999.

An institutional commitment to managing pain effectively is best achieved through interdisciplinary assessment and intervention. **Terry Altilio, ACSW**, outlines the basic elements of an institution-wide pain management program and specific institutional activities in which oncologists should participate.

Christ, G. "The Impact of Development on Children's Mourning", *Cancer Practice*, **8**(2), 2000.

This first attempt to find a way to separate children into developmentally more homogeneous subgroups for analysis led to the clarification of patterns of mourning behaviors. The increased precision of findings, such as how development affects children's mourning and the related parental support they need, can lead to the creation of more specific and effective interventions.

IMPORTANT NEW RESOURCE SUPPORTED BY PDIA **Grief at School: A Guide for Teachers and Counselors**

This book is a resource for educators faced with growing numbers of grieving children in an increasingly loss-ridden and violent world. It is intended to supplement the schools' existing systems for dealing with immediate crises.

For more information, contact:

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phone -202/223-0204 fax - 202/223/0208
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www.americanhospice.org

New In Print and Media, continued

In the Media:

Gary Stein, MSW, JD, designed a survey on New Jersey residents' attitudes on end-of-life care that was subsequently conducted by the Star Ledger/Eagleton-Rutgers poll. The results of this survey were published in diverse New Jersey newspapers in July 2000. Two of the newspapers that published the report were the *New Jersey Sunday Star-Ledger* and the *Jersey Journal*.

Interviews with **Social Work Leadership Program Director, Grace Christ, DSW**, were featured in:

United States: *The New York Times* and the *Science/Health Times* (3/28/00). "When A Patient Dies: New Findings on How Children Cope with Death," by E. Goode.

Chile: *La Tercera - Ciencia y Salud* (4/2/2000). "Revelan Impacto del Duelo en Ninos," by D. Rozowsky & N. Niranda.

Germany: *Hamburger Abendblatt* and *Journal-Wissen* (6/24-25, 2000). "Kinder Trauern Anders," by S.Friedhoss.

Switzerland: *Facts* (5/18/2000). "Wege aus dem Schmerz," by S. Friedhoff.

Grace Christ's book, *Healing Children's Grief*, was featured on two major healthcare web sites:

Dr. Everett Koops's web site in the Parenting and Children's Health section: "Helping Children Cope With Grief." (7/23/00 - 8/6/00), by B. Gilbert.

Robert Wood Johnson Foundation's web site, *Last Acts*, featured the book on its home page (8/22/00) and recommended it as an "invaluable" resource for professionals. *Last Acts'* Electronic Newsletter also featured the book in a top story, "Dispelling Myths About Children and Grief," by L. Schmidt.

Job Openings, Fellowships and Grants

IMPORTANT UPCOMING DEADLINE: NOVEMBER 15

**Applications for the 3rd Round Cohort for PDIA's Social Work Leadership Awards due
November 15**

Please distribute this announcement widely.

For more information or for application materials: www.soros.org/death

AMERICAN CANCER SOCIETY 2001 POST-MASTER'S TRAINING GRANTS IN CLINICAL ONCOLOGY SOCIAL WORK

New Grant Policies and Application materials for the Society's Post-Master's Training Grants in Clinical Oncology Social Work are available at: www.cancer.org. The new deadline for submission is November 15, 2000. Applications will be accepted from schools of social work or medical institutions capable of training individuals to conduct research related to the psychosocial needs of persons with cancer and their families. The trainee must be MSW-prepared and a doctoral candidate at the start of funding.

Questions may be directed to the Program Director, Virginia (Ginger) Krawiec, MPA, at 404-329-7612, email: gkrawiec@cancer.org.