

# PROJECT ON DEATH IN AMERICA

## Soros 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 Soros Social Work Leadership Awards for the Project on Death in America. Questions, comments and ideas should be addressed to:*

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#### IN THE SPOTLIGHT: Social Work Leader, Terry Altilio

*“Launching a Listserv in Palliative and End-of-Life Care”*

Terry Altilio, ACSW, has just launched the first listserv for social workers in palliative and end-of-life care. The Social Work Network in Palliative and End of Life Care is a professional listserv sponsored by the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center and is supported by a grant from the Project Death in America, with technical support provided by the Association for Cancer Online Resources, Inc.

The purpose of the listserv is to connect social workers with similar interests who work in areas such as geriatrics, HIV, hospice, nephrology, oncology, and pediatrics. The goal is to enhance communication, networking, and collaboration regarding clinical, education, research, policy, and professional issues. As the listserv develops, Terry plans to identify areas of commonality and unmet needs among social workers practicing in palliative and end of life care.

One benefit of the listserv is its potential to serve as a distribution network for resources, including lists of practitioners for referral, teaching, and joint project development. One resource, that has been distributed through the listserv is the "Caregiver Resource Directory," which helps professionals respond to the educational and emotional concerns of family caregivers coping with pain and palliative care issues. The directory is a user-friendly, comprehensive collection of key resources, fact sheets, and information for caregivers.

As the coordinator of the listserv, Terry will work with Wendy Walters, ACSW, of Odyssey Hospice in Alabama and Shirley Otis-Green, LCSW, of City of Hope in California to develop the list and make it responsive to the needs of participants by developing resources, advocating for legislative policy and increasing communication. If you would like to join the listserv, please send an e-mail to [LISTSERV@LISTSERV.ACOR.ORG](mailto:LISTSERV@LISTSERV.ACOR.ORG) and type SUBSCRIBE SW-PALL-EOL and your first and last name.



## ***Awards, Grants and Presentations***

**Gary Stein, MSW, JD**, has received grants from The Prudential and the Purdue Frederick Company to support an End-of-Life Conference March 8-11, 2001. The conference, titled “Living Well at the End of Life: An Interdisciplinary Intensive Course for Students in the Health Professions”, will be held in Princeton, New Jersey.

**Susan Blacker, LCSW-C**, was a panelist during the Palliative Care Fall Forum 2000 hosted by the Center to Advance Palliative Care in Washington, DC (December 3-5). The panel discussed "Staffing the Palliative Care Service: Recruiting an Interdisciplinary Care Team." Her co-presenters were Marie Whedon, RN, and Christina Puchalski, MD.

**Liz Mayfield Arnold, MSW, PhD**, presented a paper during a meeting of the North Carolina Public Health Social Workers Association on December 1 in Raleigh, NC. Her topic was “Values, Roles, and Expectations:

## ***Conferences***

**Gary Stein, MSW, JD**, Director of New Jersey Health Decisions/New Jersey Comfort Care Coalition, participated in a two-day continuing education conference for physicians titled “Education for Physicians on End-of-Life Care.” The conference was held October 27-28, 2000, at the New Jersey Hospital Association. It was co-sponsored by the Medical Society of New Jersey, the Academy of Medicine of New Jersey, and the Hospice and Palliative Care Association of New Jersey.

**Gary Stein, MSW, JD**, also piloted a two-day conference for students in the health professions. The conference, entitled “Living Well at the End of Life: An Interdisciplinary Intensive Course for Students in the Health Professions” was held on two Saturdays (November 11 and 18) and was sponsored in conjunction with the University of Medicine and Dentistry of New Jersey, Rutgers College of Nursing, Rutgers School of Social Work, Drew Theological School and Kean University Department of Social Work.

The Society for Social Work Research will hold its annual conference from January 19 to 22, 2001, in Atlanta, GA. **Social Work Leaders** will hold a breakfast with the Hartford Scholars and will conduct a special-interest group session at the conference. In addition, **Social Work Leaders Iris Cohen and Elizabeth Mayfield Arnold** will present papers during the conference.

**SAVE THE DATE!!!  
March 9-10, 2001**

**“Living Well at the End of Life: Expanding Our Vision”  
Princeton Marriott Forrester Village**

**Speakers Include:** Frank Ferris, Ann Berger, Grace Christ, Sean Morrison, Peter Selwyn, Patricia Murphy, Paul Brenner, Ken Doka, Richard Payne and William Isele

## New in Print and Media

### In Journals:

**Sormanti, M., & Kayser, K. (2000). *Partner support and relationship changes during life-threatening illness: Women's perspectives.* *Journal of Psychosocial Oncology*, 18(3).**

In this study, Mary and Karen found that the type of support the partner provides as well as the mutuality of the relationship contribute positively to women's coping. Thus, the mutuality of women's primary partnered relationships should be assessed routinely, and psychosocial interventions should sensitize couples to the benefits of enhanced mutuality during the illness experience.

### In Journals (by Faculty Scholars):

**Wolfe J, Klar N, Grier HE, Duncan J, Salem-Schatz S, Emanuel EJ, Weeks JC. "Understanding of Prognosis Among Parents of Children Who Died of Cancer: Impact on Treatment Goals and Integration of Palliative Care." *JAMA*. 2000; 284: 2469-75.**

This paper by Faculty Scholar Joanne Wolfe, M.D. and colleagues, sought to evaluate parental understanding of prognosis in children who die of cancer and to assess the association of this factor with treatment goals and the palliative care received by the children. The group found that a considerable delay exists in parental recognition that children have no realistic chance for cure, however, if this prognosis is recognized earlier by both physician and parents there was a stronger emphasis on treatment directed at lessening suffering and greater integration of palliative care.

<http://jama.ama-assn.org/issues/v284n19/abs/joc00623.html>

**Rebagliato M, Cuttini M, Broggin L, Berbig I, der Vonderweid U, Hansen G, Kaminski M, Kollee, LAA, Kucinskis A, Lenoir S, Levin A, Persson J, Reid M, Saracci R. "Neonatal End-of-Life Decision Making: Physicians' Attitudes and Relationship With Self-reported Practices in 10 European Countries." *JAMA*. 2000; 284: 2451-9**

This survey was conducted during 1996-1997 in 10 European countries to explore the variability of neonatal physicians' attitudes and the relationship between such attitudes and self-reported practice of end-of-life decisions. Results showed that physicians with beliefs valuing quality of life were more likely to report having set limits to intensive neonatal interventions in cases of poor neurological prognosis than physicians with beliefs valuing sanctity of life at any cost. Religious background, professional experience and country were the most significant factors.

<http://jama.ama-assn.org/issues/v284n19/abs/joc01341.html>

**Emanuel EJ, Fairclough DL, Emanuel LL. "Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide Among Terminally Ill Patients and Their Caregivers." *JAMA*. 2000; 284: 2460-8**

Dr. Emanuel and colleagues studied the attitudes of terminally ill patients toward euthanasia and PAS, and whether these patients seriously considered euthanasia and PAS for themselves. It was found that a small proportion of patients surveyed seriously considered euthanasia or PAS for themselves, and over half of patients opting for PAS changed their minds after a few months.

<http://jama.ama-assn.org/issues/v284n19/abs/joc01512.html>

## ***Job Openings and Fellowship Opportunities***

**JOHNSON & JOHNSON COMMUNITY HEALTH CARE PROGRAM GRANTS:** These grants provide funding for nonprofit community/public health organizations that propose creative and effective ways of promoting access to health care for medically underserved people in selected areas. Apply by Jan 15. Contact Tina Rasheed, e-mail: [rasheet@msm.edu](mailto:rasheet@msm.edu). <http://www.msm.edu/Johnson&Johnson/johnson.html>.

**JOB OPENING:** The Cleveland Clinic Cancer Center is developing mentoring program that will match longer term cancer survivors with newly diagnosed patients. Although an MSW is preferred, an MSN with counseling or volunteer experience would be good too. Very high profile. If you know people you can recommend for this position, please send their names to Grace Christ at [ghc1@columbia.edu](mailto:ghc1@columbia.edu).

### **NEW APPLICATION DEADLINE FOR SOROS AWARDS March 15, 2001**

The Project on Death in America just finished accepting applications for the third cohort for the Social Work Leadership Awards. The support of existing cohorts was invaluable in identifying and working with potential applicants. PDIA is now accepting applications for the fourth cohort. Please forward the names of potential applicants to Grace Christ at [ghc1@columbia.edu](mailto:ghc1@columbia.edu).

## ***Grant Resources on the Web for End-of-Life Care***

### **AARP Andrus Foundation - [www.andrus.org](http://www.andrus.org)**

During the past 30 years, the Foundation has supported more than 630 research projects with grants totaling over \$35 million. The AARP Andrus Foundation emphasizes the "practical over the theoretical--meeting the real needs of older persons in their everyday lives." Currently, the Foundation targets research funds in two areas: financial security and the ability to live with chronic health conditions. Under the latter category, the Foundation supports projects that measure the impact of chronic diseases, the effects of multiple chronic conditions, psychosocial coping skills the elderly use to adapt to chronic illness, how chronically ill older adults maintain reciprocal relations with others in their social world, and how psychosocial factors affect quality of life for older people with multiple chronic conditions.

### **Archstone Foundation - [www.archstone.org](http://www.archstone.org)**

The mission of the Archstone Foundation is to contribute toward the preparation of society in meeting the needs of an aging population. Resources are used to promote the health and well-being of the elderly, and to help all generations plan for the aging process.

### **Fannie E. Rippel Foundation - <http://fdncenter.org/grantmaker/rippel/interest.html>**

The primary mission of the Foundation is to fund initiatives that address the issues affecting elderly women, further current understanding or treatment of cancer, further current understanding or treatment of heart disease, and provide facilities and equipment for hospitals.

It is also interested in projects that incorporate one or more of the following components, effective strategies to reach under-served rural and urban populations, issues related to women's health and the health issues affecting elderly women, prevention and strategies to change the behavior of populations including research and access to preventive care, and humanistic medicine and mind-body-spirit connections including the importance of belief, support, communications, and relationships on the healing process.

**Terry Altilio, ACSW**

Department 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, EdD, MSW**

Smith College School for Social Work

**Susan Blacker, MSW, LCSW-C**

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

**Iris Cohen, MSW, LCSW-C**

Beth Israel Deaconess Medical Center

**Barbara Dane, PhD**

Ehrenkranz School of Social Work at NYU

**Norma del Rio, MSW**

Institute for Multicultural Research and Social  
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**Jim Keresztury, LCSW, MSW, MBA**

Center for Health Ethics and Law  
West Virginia Initiative to Improve End-of-  
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**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**

Greater Rochester Collaborative MSW Program  
Nazareth College

**Katherine Walsh-Burke, PhD, MSW**

Springfield College of Social Work

## **Grant Resources on the Web for End-of-Life Care (continued)**

### **Community-State Partnership to Improve End-of-Life Care Midwest Bioethics Center - [www.midbio.org](http://www.midbio.org)**

Provides grants to support statewide coalitions composed of citizens, health care professionals, educators and policymakers that identify problems, make recommendations and build public support for practical policies, regulations and guidelines to improve care of the dying. Publishes State Initiatives in End-of-Life Care.

### **Promoting Excellence in End-of-Life Care - [www.promotingexcellence.org](http://www.promotingexcellence.org)**

Manages 22 grant-funded projects designed to demonstrate excellence in end-of-life care in diverse institutional settings. The project is a National Program Office of the Robert Wood Johnson Foundation.

### **The Fan Fox & Leslie R. Samuels Foundation - [www.samuels.org](http://www.samuels.org)**

Aging issues and end-of-life care are "high" priorities for the Foundation. The Foundation has funded projects examining family perspectives on end-of-life care; Frances Schervier Home and Hospital's ethics network for long-term care institutions; Friends and Relatives of the Institutionalized Aged's Eldercare in the 90s; a handbook for caregiving relatives, a study to determine the relationship between cost and quality in nursing homes, and an ethnographic study of the Dorot Volunteer program in New York City.

### **The Greenwall Foundation - [www.greenwall.org/](http://www.greenwall.org/)**

Half of The Greenwall Foundation's funding is allocated to bioethics. Of this, a significant portion is dedicated to "ethical issues that pertain to end of life," a "crucial" concern. Recent grants have supported Choice in Dying's "Integrating Education About Care of the Dying into Existing Medical School Programs" project and a University of Chicago Initiative on Alzheimer's disease, as well as its "Survey of End-of-Life Practices."

### **The Nathan Cummings Foundation - Health Programs - [www.ncf.org/programs\\_health.html](http://www.ncf.org/programs_health.html)**

The Foundation is committed to improving the quality of life at its beginning and at its end by supporting humane patient-centered care that provides comfort and caring, as well as cure. It is concerned about patient/provider communication, patient empowerment, and the importance of family and community in nurturing new life and in facing death. They also have a deep concern about the radical disparities that characterize our current health care system, particularly the inadequate attention paid to the health needs of poor people.

*For other resources on grants and awards please check these additional sites:*

Last Acts - <http://www.lastacts.org>

Center to Advance Palliative Care - [www.capcmssm.org/links.html](http://www.capcmssm.org/links.html)

Project on Death in America Links - [www.soros.org/death/links.htm](http://www.soros.org/death/links.htm)

The Foundation Center - <http://fdncenter.org/index.html>