

Touchpoints

A newsletter of the Kenneth B. Schwartz Center

*Dedicated to
strengthening the
relationship between
patients and
caregivers*

“We’re not done caring yet,”: A model bereavement program

As a clinical nurse caring for patients on a neurology unit at Beth Israel-Deaconess Medical Center (BIDMC) in Boston, Pat Folcarelli, RN, had the experience of caring for many patients who died in the hospital setting. Following such a death, caregivers often met with a flurry of activity, but as soon as the body of the patient was removed from the hospital room, the bed was cleaned and another patient admitted in rapid sequence. Ms. Folcarelli found that, as a caregiver, there was simply not enough time to process the experience of caring for patients who had died in her care, nor

was it easy to find time to reach out even in small ways to the families who grieved. By the same token, families often missed the ongoing relationship with caregivers following the loss of a loved one.

“At most hospitals in this country, when someone dies, staff consider their job to be over,” Lachlan Forrow, MD, Co-Director of Palliative Care Programs at BIDMC, notes. “But for almost every patient who dies, there are family members who still need our caring afterwards.” To address this perceived gap, Dr. Forrow and other members of the palliative care team, *(Continued on Page 2)*

Please plan to attend the Schwartz Center’s sixth annual dinner on October 24, 2001, at the Westin Hotel. This year’s dinner is chaired by Charles Baker, president and CEO, Harvard Pilgrim Health Care; Harris Berman, MD, CEO, Tufts Health Plan; James Hooley, president and CEO, Neighborhood Health Plan; and William Van Faasen, president and CEO, Blue Cross Blue Shield of MA. Richie Havens will perform.



From left, Cynthia Phelan, RN; Lachlan Forrow, MD; Jessica Seabury; Rabbi Terry R. Bard, DD; Elizabeth Amis; Erik Charlson; Iris Cohen, LICSW; Sharon Bober, PhD; and Patricia Folcarelli, RN.

— A model bereavement program

(Continued from Page 1)
along with Pat Folcarelli, RN, and the hospital's Learning Center, approached the Schwartz Center with a grant proposal. They sought funding to explore the possibility of a model bereavement program at the hospital, a program that would set a few basic standards of caring for and supporting the families of patients who died,

emphasizing simple approaches that any hospital and its caregivers could use.

Dr. Forrow and his team had previously arranged two focus groups of families who had experienced the death of a loved one at BIDMC. These groups had been organized to better assess the needs of the families of dying patients, and they reported that almost all family members emphasized

how valuable and important it would be to receive even small gestures of support from the hospital caregiver team after their loved one's death. They also revealed that almost none of them had received such support.

With the support of a Schwartz Center grant, Dr. Forrow and colleagues designed and implemented a model bereavement program at the hospital.

Every family now receives a personalized letter within two months of their loved one's death, expressing sympathy and notifying them of available support sessions. These sessions include a monthly drop-in bereavement group, where families of patients who died at the medical center can attend a free session facilitated by members of the Bereavement Team and share their experience with others undergoing loss. The Schwartz Center grant also enabled Sharon Bober, PhD, Department of Psychiatry, to create and lead a more structured bereavement support group, meeting once a week for eight to ten weeks, for those individuals needing more active and ongoing support. These groups have been warmly received, and, as one participant remarked, "I thought the leadership [of the sessions] was effective and the people were extremely supportive and caring."

Yet the model hospital bereavement program designed at BIDMC seeks to do more than provide support for families alone. It aims to help caregivers address the difficult problems involved in caring for dying patients, and to provide mutual support for both caregivers and families following the death of a loved one.

To that end, the program has compiled extensive resource packets with literature on bereavement, fliers about bereavement support groups and community resources for families, and a simple card that individual staff can sign and send to families to express their sympathy. The bereavement materials in the resource packets are available to all staff at the medical center, and are easily accessible on each unit.

The bereavement program also now sponsors a monthly "Case Conference

on Death, Dying, and Bereavement," a forum where nurses, doctors, social workers and other clinicians share their experiences, thoughts, and feelings about caring for patients who die. Each conference features a specific case with discussion by involved staff about the challenges they faced in caring for the patient and family, with the goal of catalyzing ongoing discussions that will lead to improvements both in clinical care and professional support and renewal.

With the help of the Schwartz Center, the team of clinicians and researchers at Beth Israel-Deaconess has developed a bereavement program that lets family members of dying patients know they are not alone, while

giving clinical staff a forum to share their thoughts and concerns about caring for patients at the end of life. As a result of these efforts, the Palliative Care and Bereavement Teams were recently recognized by the medical center, receiving this year's "Excellence in Patient-Centered Care Award."

"When I'm sitting with family members of a patient who's dying," Dr. Forrow says, "it's wonderful to be able to say we want to help not only the patient but also the family in any way we can, and that they will be getting a letter from our office with more information soon after their loved one passes away. Even after someone dies, it means a lot to show their family that we're not done caring yet."

On June 5 the Schwartz Center and the Four Seasons Hotel hosted a reception attended by 60 supporters and friends. A brief program included an update on center activities as well as comments from Lidia Schapira, MD, Beth Israel Deaconess Medical Center, on the educational videotape she and her patient Julie Goldman created with their grant from the center.



Dinner 2001 chairs and Schwartz Center Board members Charles Baker, president/CEO, Harvard Pilgrim Health Care (far left), and Jim Hooley, president/CEO, Neighborhood Health Plan (far right), with Board chair Andrew Dreyfus and grant recipient Lidia Schapira, MD, Beth Israel Deaconess Medical Center



Board member Thomas Lynch, MD, with Barbara Green and daughter Deb Green



Kim Andrews, Amgen, Inc., (left), with Board member Carol Wells-Federman, MSN, MEd



Physician leaders of Schwartz Center Rounds at their respective hospitals (from left to right): Jon DuBois, MD, Emerson Hospital; Joel Schwartz, MD, North Shore Medical Center; and Board member Thomas Lynch, MD, Massachusetts General Hospital



Physician leader of Schwartz Center Rounds at UMass Memorial Healthcare, Brownell Wheeler, MD, (left), and at Brigham & Women's Hospital, Lynn Peterson, MD

WORKING WITH CLINICIANS TO IMPROVE COMMUNICATION WITH PATIENTS

IN APRIL, the Schwartz Center invited Terry Stein, MD, director, Clinician-Patient Communication, The Kaiser Permanente Medical Group, to lead a workshop to help clinicians relate more meaningfully to their patients. Entitled "Talk is (Not) Cheap", the workshop drew approximately 70 clinicians from all over the state. A nationally known expert on clinician-patient relationships, Stein presented data showing what patients most want from their relationship with their clinicians and outlined the positive impact on patient health outcomes. Joining the Schwartz Center in sponsoring the forum/workshop were the Harvard Risk Management Foundation and Massachusetts General Hospital.

In addition, the Schwartz Center, with Stein as a special guest, convened a dinner discussion with physician leadership from CareGroup Healthcare System and Partners HealthCare System focusing on how to enhance the way physicians talk with and show empathy for their patients.

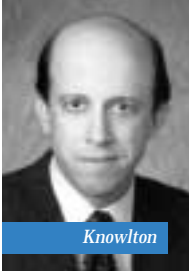
The Schwartz Center thanks Amgen for its support in making the Terry Stein visit possible.

"Getting the Most Out of the Clinical Encounter: The Four Habits Model" By Richard M. Frankel, PhD, and Terry Stein, MD. *The Permanente Journal*, Fall 1999, Vol. 3, No. 3. Excerpt:

- Invest in the beginning
- Elicit the patient's experience/involvement in decision making
- Demonstrate empathy
- Invest in the end

WHAT'S HAPPENING

William Knowlton, Esq., head of Ropes and Gray's Health Care Department, and **Becky Ruhmann Levin**, president/CEO of Levin and



Knowlton

Company, have joined the Schwartz Center's Board of Directors ... At the **Massachusetts Society of Clinical Oncologists'** annual dinner on November 14, the Schwartz Center will receive the **2001 Sullivan Award** for its work in

improving health care. Board member **Ned Cassem, MD**, is the guest speaker at the dinner ... In June the *Boston Business Journal* ran a flattering executive profile about the

multi-faceted career of Board member **Mike Astrue, Esq.**, general counsel at Transkaryotic Therapies, Inc. ... The *Newton Tab* ran a story on Board president **Ellen Cohen** who was honored for her work with the



Levin

Schwartz Center at the Wellness Community's annual dinner in May ... The February issue of *Boston Magazine* rated Boston's top doctors for women. Two Schwartz Center Board members, **Paula Johnson, MD**, Cardiology, and **Dr. Cassem**, Psychiatry, were included in their respective specialties ... WBZ-TV did a two-part series on Faith and Healing which included a piece on the **Schwartz**

Center's fellowship in pastoral care ... The educational videotape "**One Story, Two Voices**" featuring a moving dialogue about the relationship between oncologist **Lidia Schapira, MD**, and her patient **Julie Goldman** is available with an accompanying study guide by calling the Schwartz Center. With support from the center, the video was recently sent to every medical school in the country.

RECENT SCHWARTZ CENTER GRANTS

The Schwartz Center has recently given grants to the following organizations for projects that further the center's mission:

Bayer Institute for Health Care Communication, Milford, CT — to conduct interactive workshops in New York City hospitals to help cancer clinicians talk with patients when treatment fails;

Baystate Medical Center, Dialysis Bereavement Research Project, Springfield, MA — a two-year grant to develop a model bereavement program for families and professional caregivers of long-term dialysis patients;

Benedictine Health Foundation, Kingston, NY — to improve communication between professional and family caregivers;

Boston Medical Center, Boston, MA — to teach internal medicine residents how to care for culturally diverse patients;

Children's Hospital, Seattle, WA — to study whether parental feedback helps pediatric anesthesiologists communicate better with children and families;

Greater Brockton Parish Health Consortium, Brockton, MA — to expand a parish nursing program where volunteer nurses minister to the health needs of congregants;

Health Law Advocates (HLA), Boston, MA — to train faith-based health workers to help patients understand health care programs available to the poor and underserved;

Pastoral Care Fellowships — renewal of the Schwartz Center Pastoral Care Fellowship where clinicians (up to 12 over the next two years) learn how to meet the spiritual needs of patients and families;

Smith College School for Social Work, Northampton, MA — to support a Post Masters Certificate Program in End-of-Life Care for clinical social workers; and

Tufts University Family Practice Residency, Malden, MA — to support a curriculum to train family medicine residents in the effective use of family counseling/therapy in an outpatient health center.

For your convenience, we have enclosed an envelope should you wish to make a donation to the Schwartz Center.
Thank you for your support.

Touchpoints

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