

Touchpoints

A newsletter of the Kenneth B. Schwartz Center

*Strengthening the
relationship between
patients and
caregivers*

STEPPING OUTSIDE OF THE CLASSROOM AND INTO PATIENTS' LIVES

PAIRS program connects medical students with Alzheimer's patients

Medical student Gabriel Merlin's "buddy," Barbara Abrahams, often forgets the names of her four children, but she has no problem recalling the password that opens her locked garage. Over the past year, she has become increasingly nonverbal, but will break out into song, when prompted by a movie she's watching.

"A lot of people see this disease as black and white," said Merlin, a first-year medical student at Boston University School of Medicine (BUSM). "Yes, it's very debilitating, but you are always catching glimpses of hope. Patients are capable of a lot, especially in the early stages. It's important for people to remember this."

Educating future doctors

Insights like these are one of the goals of the two-year-old PAIRS Program (Partnering in Alzheimer's Instruction Research Study), which is based at the Boston University Alzheimer's Disease Center (BU ADC) and supported in part by a grant from the Schwartz Center. This year, Merlin and 14 other first-year BU medical students

(continued on page 2)

SAVE THE DATE

Celebration of Women in Health Care

May 20, 5-7:30pm

Schwartz Center Annual Dinner

November 19, 5-9:30pm

See page 9 for details



Fifteen first-year BU medical students participate in the PAIRS program, a buddy program for students and Alzheimer's patients.

—Stepping outside of the classroom and into patients' lives

are partnering with early stage Alzheimer's patients, many of whom receive their care from BU ADC clinicians or participate in BU ADC research studies. The pairs typically spend about four hours a month together, watching movies, going out for meals, taking walks, or just hanging out playing board games or talking.

The students also meet monthly – without their buddies – for an educational luncheon directed by the PAIRS Program faculty and staff, where experts talk about topics like evolving Alzheimer's therapies or the neuropathology underlying language deterioration. Some of the luncheons have no formal speakers and are simply a time for students to debrief from their encounters, discussing situations like what to do when a patient who lives alone is no longer taking good care of herself. Students also take pre- and post-program assessments of their knowledge of and attitudes toward patients with Alzheimer's disease; keep a journal about their visits; and write a reflective essay about the program's influence on their medical training at the end of the year.

Students get no academic credit for participating in the PAIRS Program, just a fascinating out-of-the-classroom glimpse of how one devastating neurological disease impacts the lives of patients and their families.

"The program has several goals," said director Angela Jefferson, PhD, a neuropsychologist and clinical researcher at BU. "First and foremost, we want this to be educational for the students.

Many of them have never interacted with a person with Alzheimer's disease, so it helps them obtain knowledge about the disease and develop an appreciation for what these patients and their families go through outside the medical examination room."

The experience also helps students build good communication skills through their interactions with their buddies, whose own conversational abilities may be starting to dwindle, according to Jefferson. "And these communication skills are applicable to any future clinical experience they will have working with older adults," she said.

Students get no academic credit for participating in the PAIRS Program, just a fascinating out-of-the-classroom glimpse of how one devastating neurological disease impacts the lives of patients and their families.

"We know the Schwartz Center is committed to improving patient-caregiver communication across the healthcare system, so we're very pleased that the Center saw our program as a good investment toward that goal," she said.

"It was a good experience, learning how to connect with someone with cognitive difficulties," said Dan Kirshenbaum, a second-year medical student at BUSM and Barbara Abrahams' buddy last year. "You learn things like when to pursue a question and when to know that the person can't answer what you're asking. There were situations where the conver-

sation would come to a standstill. You learn to be comfortable with the silence."

The BU program is modeled after a similar educational program developed a decade ago at Northwestern University Feinberg School of Medicine by Darby Morhardt, MSW. It was conceived after an Alzheimer's patient at Northwestern's Cognitive Neurology and Alzheimer's Disease Center, who happened to be a physician, expressed frustration to his own doctor that he could no longer pursue his life's work. His doctor believed that his experience with Alzheimer's would prove instructive to medical students.

The patients in the BU ADC PAIRS program range in age from 53 to 84, and most are in the earliest stage of Alzheimer's disease, which is important because they are able to reflect on the cognitive and functional changes occurring and articulate these changes to their student buddies. Patients are encouraged to re-enroll in the program year after year, as long as their disease has not progressed too quickly.

Benefiting patients and families

While the primary purpose of the PAIRS Program is to enrich the education of future doctors, the program is just as beneficial to patients and their families. The patients have the opportunity to mentor and influence future doctors, by spending time with them doing the things the patients enjoy the most.

"It's something mom really looks forward to," says Linda Abrahams, a lawyer who cares for her 78-year-old mother Barbara at home in Natick. "If I say to her 'buddy Gabi or buddy Dan is coming to take you out,' she lights up like a Christmas tree. She's all smiles and happy. My mom doesn't remember people she's known most of her life, but



(left) First-year medical student Gabi Merlin and his buddy Barbara Abrahams



(right) First-year medical student Fonda Chan with her buddy Stephen Morse

she immediately recognizes both Dan and Gabi." And for caregivers like Linda, the time her mother spends with her buddy is a welcome respite.

Making the match

The program staff tries hard to pair patients and students with similar interests and backgrounds, also taking into account that ineffable quality – chemistry. Abrahams said the program's matchmaking skills as far as her mother is concerned have been superb. At the fall gathering where the patients and families meet the students, she felt a little sorry for Gabi, as many

of the other patients were still able to communicate clearly and did not seem diminished by the disease. "When mom went to the ladies room, I told Gabi I felt bad because my mom is not very verbal any more," said Abrahams. "He told me, 'I'm the luckiest person in the room because I'm going to have to learn how to communicate nonverbally.' And they do have this real connection that's nonverbal."

Some of the student-patient relationships have blossomed into much more than monthly meetings, according to Jefferson. When one current student went to his buddy's

home for the first time, he was amused to find last year's student buddy visiting. One patient invited her buddy to go dancing with her. Others have asked their student buddies to Passover Seder and Thanksgiving dinner. One patient kept insisting his student buddy meet his eligible granddaughter.

Has the program been a success? Jefferson said that anecdotally, and based on the students' reflective essays, the first year of the program was tremendously beneficial for both the students and their buddies. However, the attitude and knowledge data collected so far is based on a small number of students, preventing statistical analyses. Jefferson has approval from BU's institutional review board to forward students' journals, essays and assessments to Northwestern for analysis. She hopes that within a couple of years there will be enough data to draw quantitative conclusions about the program's success.

But from Jefferson's perspective, there is no greater endorsement of the program than the fact that three out of the seven students participating in the program last year went on to do neuroscience and Alzheimer's-related research over the summer.

For more information on the PAIRS Program, contact Angela Jefferson at angelaj@bu.edu or 617-414-1193.

Medical Student Jami Johnsen reflects on her PAIRS experience

Editor's note: The following is an excerpt from student Jami Johnsen's essay. The patient's name has been changed to protect his confidentiality.

During my monthly visits with my buddy, I got a glimpse of how difficult it is to be a caregiver for someone with Alzheimer's disease. We frequently had the same conversation multiple times during the course of a visit. While it is easy to be patient when it is only for a few hours, I can imagine the immense frustration of dealing with it on a regular basis. There was one particular moment where the impact of AD on someone's life became clear to me. During our December visit, I asked Alan how his Thanksgiving had been. He looked at me, somewhat confused, and asked if Thanksgiving had already happened this year. I had just returned from spending the holiday with my family, a trip that gave me the emotional boost to finish my first semester of medical school. It was distressing to think that he could not even remember if the holiday had occurred, especially when my own holiday had given me so much joy.

I was also fortunate that his wife, Helen, was willing to candidly discuss just how difficult it can be to watch someone you love forget so much. I admired her attitude towards the situation; she was determined to make the best of it. They joined a dual support group for people with AD and their caregivers. She incorporated ideas from the group into their daily lives. For example, in their kitchen, they have a whiteboard where she writes the date, the weather and the day's activities. They are also actively participating in research so that others don't have to go through what they are going through.

Annual dinner celebrates past and present compassionate caregivers

She was willing to cross that professional rubicon – to reach out and talk about my fear of dying or even worse, my fear of not living out my life...and she took the risk of talking about her own father's recent bout with cancer... the rule books, I'm sure, frown upon such intimate engagement between caregiver and patient. Maybe it's time to rewrite them.

—Ken Schwartz talking about his nurse, Mimi Bartholomay, from “A Patient’s Story,” *Boston Globe Magazine*, July, 1995

Echoing Ken Schwartz’s words, Schwartz Center Board Chair Peter Biagetti got to the heart of what the evening was about, honoring, as he said, “those who have set about rewriting... the ‘rule book’ on the healing power of compassion.” This past November, in addition to honoring the 2008 Schwartz Center Compassionate Caregiver Award winner and four finalists, attendees were also treated to a look back at the 10-year history of the award. The nine previous winners and this year’s awardee, Cynthia French, NP, were feted in a special anniversary book that profiled each one. A video, “Portraits in Compassion,” focused on 2001 winner Ann-Marie Thomas, MD, and 2004 winner Helen Mullen, RN.

One of the people interviewed in the video, Anna Ling Pierce, took to the stage afterward and spoke about her daughter Ali’s relationship with Helen Mullen more than a decade ago, when Ali was 12 years old and battling liver cancer. “Ali was afraid of needles,” said Pierce. “When it was time to start a procedure, she would say ‘OK,’ then quickly say ‘wait.’ And Helen would wait. Ali would say ‘OK, go ahead,’ then again, ‘wait.’ Sometimes this would go on for 20 minutes. Even though Helen had other patients to treat, she never lost patience with Ali’s apprehension.”

At the end of her very moving speech, Pierce asked attendees to consider making a donation to the Schwartz Center in recognition of a compassionate caregiver, who would be notified of the honor. Approximately 600 attendees responded, raising \$82,000 for the Center, an amount that has been matched by Board President Ellen Cohen (See p. 8).

The dinner, attended by more than 1,600 people, raised a robust \$1.2 million for the Schwartz Center. Executive Director Julie Rosen spoke about the programs that those donations support, including Schwartz Center Rounds, which now take place in 165 facilities in 30 states, drawing in some 40,000 clinicians each year.

Dinner chair Joe Mullany had the privilege of introducing Schwartz Center Compassionate Caregiver Awardee Cynthia French, a nurse practitioner at UMass Memorial Medical Center, whom he described as “the person who will bring a nourishing snack to the worried daughter of a patient in the emergency room; deliver 50 roses to a colleague going through a difficult time on her 50th birthday; and sit with patients and their families as death draws near.” (See p. 6)

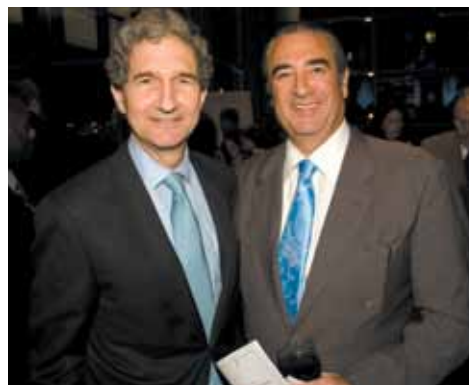
The Schwartz Center is deeply indebted to dinner chairs Bill and Deb Knowlton, Joe and Cori Mullany, Daniel and Diane Shimkus, and Tom and Sally Simons for making the 13th annual dinner such a tremendous success.



Schwartz Center Leadership Council member Tom Grape, Debbie McAneny, and Fred Pratt, all of Benchmark Assisted Living



Paula DiMartino and Schwartz Center Board member Charlie Baker, both from Harvard Pilgrim Health Care, and Leanne Berge, Network Health



Cameron Kerry, Mintz Levin, and Richard Glovsky, Prince Lobel Glovsky & Tye

All photo captions are left to right.



1. Guests browse the silent auction items.

All photo captions are left to right.

2. Past winners of the Schwartz Center Compassionate Caregiver Award: Scott Pomeroy, MD, PhD, Children's Hospital Boston; Ann-Marie Thomas, MD, Spaulding Rehabilitation Center; Judith Best-Lavigniac, MS, APN-BC, CNS, Highpoint Treatment Center; Burton J. Polansky, MD, Signature Healthcare Brockton Hospital; Paula Rauch, MD, Massachusetts General Hospital; Barbara Moscovitz, MSW, LICSW, Massachusetts General Hospital; Helen Mullen, RN, UMass Memorial Medical Center; Cynthia French, MS, NP, UMass Memorial Medical Center; and Cleopatra P. Ferrao, MS, FNP, Boston Medical Center

3. Jeff Kang, MD, CIGNA Healthcare; Schwartz Center Board member Andrew Dreyfus, Blue Cross Blue Shield of MA; and Richard Soloman, MD, CIGNA Healthcare

4. Ralph DiPisa, Phillips, DiPisa and Schwartz Center Leadership Council; Schwartz Center Board Chair Peter Biagetti, Mintz Levin; Schwartz Center Board member Lynn Wiatrowski, Bank of America; and Dan Phillips, Phillips, DiPisa



Rev. Judy Swahnberg, Schwartz Center Board; David Reif, AstraZeneca; and Dinner Chair Joe Mullany, Vanguard Health Systems



Mike Astrue, Social Security Commissioner, and Dinner Chair and Schwartz Center Board member Bill Knowlton, Ropes & Gray



Helene Solomon, Solomon & McCowan; Deborah Enos, Neighborhood Health Plan; and Steven Aubrey, Dovetail Health

Cynthia French, NP, MS, receives Schwartz Center Compassionate Caregiver Award

Cynthia French remembers the moment she realized she was taking care of people, not illnesses. She was a 19-year-old RN, and had just finished her shift at the hospital.

“[He was a] quiet gentleman who often came to our ICU because he could not catch his breath, even though he was only in his 40s,” she told a rapt audience, after accepting the Schwartz Center Compassionate Caregiver Award. “On my way home I happened to see him struggling on the sidewalk outside a local convenience store, his oxygen tank and two young children in tow. I remember thinking, ‘He is someone’s dad!’... How could I not get involved?”

Cynthia has spent the last 35 years getting involved, not only as a superb and compassionate clinician but also as a highly effective advocate.

“She has been an angel to her patients, especially those who were progressively paralyzed by amyotrophic lateral sclerosis (ALS), or Lou Gehrig’s disease,” said Dinner Chair Joe Mullany, before giving Cindy the award. “She would visit them at home when they could no longer travel to her clinic; teach overwhelmed families how to care for them; and always advocate for more services for her patients.”

Again and again Cindy has recognized when patient needs are not being met, then worked with kindred spirits to change things. For example, when she and her long time mentor, Richard Irwin, MD, realized that their pulmonary patients with ALS were having trouble managing multiple appointments at different locations, they created a virtual ALS center, offering multidisciplinary care in one location.



Dinner chair Joe Mullany presents the Schwartz Center Compassionate Caregiver Award to Cynthia French, MS, NP, UMass Memorial Medical Center.

Cindy shared another patient story, one about “Emma,” a young woman with lung disease who was developmentally disabled and terrified of anyone in a white coat. Cindy disarmed her from the moment she met her, ignoring the conventional wisdom to not get emotionally involved.

“I took an exam glove, blew it up like a balloon, drew in eyes and a mouth and in a minute’s time I was holding a chicken, complete with a comb on top of its head. The chicken and I went into the room to welcome our new friend Emma. Together we shared her delight and her fear quickly dissipated... She visited our clinic many times thereafter and I always made sure to have a small gift and a big hug ready for her.”

As Joe Mullany put it: “Through gestures large and small, Cindy shows how much she cares about her patients, their families and her colleagues.”

Schwartz Center Compassionate Caregiver Award nominations are open

Nominations are now open for the 2009 Schwartz Center Compassionate Caregiver Award. The award recognizes a caregiver (or team of caregivers) who demonstrate extraordinary compassion in caring for patients. Anyone (patients, families and/or other caregivers) can nominate a professional caregiver practicing in Massachusetts. The deadline is **April 17, 2009**.

The Schwartz Center gratefully acknowledges **AstraZeneca**, a leading international pharmaceutical company, for supporting the award.

For more information or to access the online application form, visit www.theschwartzcenter.org or call 617-726-0512.

Schwartz Center fetes compassionate caregivers

The Kenneth B. Schwartz Center established the annual Compassionate Caregiver Award in 1999 and this year celebrated its 10th anniversary. The award recognizes Massachusetts caregivers who display extraordinary compassion in their daily work. The award is made possible with the generous support of AstraZeneca, a leading international pharmaceutical company.

The Schwartz Center received 112 nominations in 2008, a record number. The 2008 Compassionate Caregivers Award finalists include:

Marcela del Carmen, MD *Massachusetts General Hospital*

"She is brilliant, yet humble; highly educated, yet down to earth," is the way a colleague describes Marcela del Carmen, MD, a gynecologic surgeon. Marcela will hold the hand of the fearful and cry with a woman when the news is bad. She opens her heart to patients and promises they will never be alone on their journey. "Dr. del Carmen does not impose herself...she is your partner, your ally in this battle for your life," said a patient.

A native of Nicaragua, Marcela holds a weekly clinic for Latina women and has made many trips to Nicaragua, providing state-of-the-art surgical care for the underserved. Her research currently focuses on Latinas' barriers to health care access. When Spanish-speaking patients first meet her, "the look of relief in their eyes when they realize their surgeon is able to talk to them in their own language is priceless," commented a colleague.

Avra Goldman, MD *Boston Medical Center*

It may be the Statue of Liberty that summons the "tired, the poor, the huddled masses yearning to breathe free," but it's Avra Goldman, MD, who tenderly cares for them. Her patients hail from all over the world and are often quite sick, with multiple chronic illnesses. Some are political refugees who have fled abuse and torture in their native countries. As the medical director of Boston Medical Center's Family Medicine Clinic, Avra is their lifeline.

She'll make room in her overbooked schedule for those who trust only her. And she connects deeply with her

patients. "Dr. Goldman always knows what is going on medically with me, but more importantly, she understands what is going on spiritually and emotionally on my journey," said one patient with AIDS.

Avra not only has a busy clinical practice but also does volunteer medical work in the southern African country of Lesotho; mentors medical students and residents; and runs her department's home visit program.

Rabbi Sara Paasche-Orlow *Hebrew SeniorLife/Hebrew Rehabilitation Center*

"Transformational" is the word used over and over by admirers to describe what Rabbi Sara Paasche-Orlow has done in her four short years at Hebrew SeniorLife. As director of chaplaincy services, Rabbi Sara creates and oversees religious programming; conducts regular Torah study sessions and "conversations with the Rabbi"; and somehow finds the time to attend to the spiritual and religious needs of individual patients, families and staff.

She has also created a clinical pastoral care program to increase the number of spiritual caregivers; devised ways to embrace the Russian residents with tenuous connections to their Jewish roots; and worked hard to create an atmosphere of inclusion: Passover's ritual meal – the Seder – now includes gospel songs of freedom so staff feel included.

Families tell of their agitated loved ones dying peacefully after a

visit from Rabbi Sara and of her gift of connecting with the most difficult or confused patients. Every encounter with her is a lesson in how to treat all human beings with dignity.

Maripat Toye, RN, MS *Baystate Medical Center*

As the program manager of her hospital's pediatric/perinatal/adolescent HIV/AIDS program, Maripat Toye is a problem solver, a surrogate mother, a clinician, a social director and so much more. "Maripat uses her role as a nurse and program manager to make a population of patients, often feared or forgotten, to feel as though they are as important as any VIP," said a colleague.

On their birthdays, the youngest patients receive birthday cards in the mail and their special day is celebrated during clinic visits with crowns, glitter, cakes and gifts. For patients who have lost their parents, Maripat keeps files with their pictures and accomplishments, so they know someone is keeping track, lovingly. And her reach goes far beyond western Massachusetts: her expertise has taken her to Africa, India and Vietnam, where she has led HIV/AIDS trainings.

"Patients know they have a special medical home with Maripat," said a colleague, "often more stable than any home they've ever had."

Development Matters

Honoring a caregiver with a gift to the Schwartz Center



Alison Jaffe

Alison Jaffe's connection to the Schwartz Center grew from the friendship between her son, Jacob, and Ken Schwartz's son, Ben, in pre-school. Over the years, she became an admirer and supporter of the Center, always buying a table at the annual dinner and inviting friends to share the inspirational evening with her and her husband, Dan.

But the importance of the Center's work never hit her on such a personal level until March 10, 2008, when she was diagnosed with colon cancer. "I've always been grateful and respectful of my caregivers," said Jaffe. "But once you are diagnosed with a life-threatening illness, suddenly your relationship with them takes on much greater significance. Compassion and good communication become critical. I am so lucky to have two doctors who personify compassionate care."

So at the 13th annual dinner, when the Schwartz Center offered attendees the opportunity to make a donation in honor of their own compassionate caregiver, Jaffe didn't have to think twice. She recognized Robert Mayer, MD, her

Dana-Farber oncologist, and the fellow who worked with him during her treatment, Andrea Myers, MD.

"I thought this was such a great idea because there are never enough ways to let people know how grateful you are," said Jaffe, who celebrated the end of her chemotherapy treatment in October with a thank you brunch for 85 people who had supported her throughout her ordeal. The gathering included a bulb planting ritual in her Newton yard to celebrate the gift of life. Mayer was out of town, but Myers attended with her husband and baby. Jaffe said it was only natural that she would invite the pair, who helped see her through some very dark days. "They were both so available and we made a connection that was much more than a medical connection," she said.

The doctors also reached out to her teenage children. Mayer invited them to come in to talk with him and Myers and then tour the infusion area with them. They both took him up on the offer and Jaffe fondly recalls her daughter, Kayla, and Mayer, having a good laugh over Jaffe's propensity for planning and organizing everything.

When a post-treatment colonoscopy revealed a polyp, Mayer called Jaffe on a Sunday morning to tell her the results were negative so she wouldn't worry a moment longer than necessary. Over the months, she and Mayer talked a lot about their families; Jaffe brought in books for his grandchildren. Mayer kept track of the comings and goings of her kids.

Jaffe said that she and Myers

shared a similarly warm connection. The young oncologist would call her at the end of each week during her treatments to check in and see how she was feeling and to ask whether she had any questions or concerns. At Jaffe's appointments, Myers would always remember the small details of her life. She was especially good at helping her figure out how to maintain her workout schedule—a routine that was healing to Jaffe on many levels—despite the rigors of chemo. "She was always supportive and understanding," said Jaffe.

Myers said that when she learned that Jaffe had honored her with the Schwartz Center donation, she was very touched. "Cancer is a life-altering event and maintaining the tasks of everyday life can be overwhelming for patients," said Myers. "It is really special when a patient finds the time and energy to express gratitude to the healthcare team."

Corporate and Foundation Grants

The Schwartz Center gratefully acknowledges the following funders which have recently awarded grants to support its work:

Abraxis BioOncology

\$25,000 for Schwartz Center Rounds

AstraZeneca

\$60,000 to support the Compassionate Caregiver Award program 2009

Bank of America

\$10,000 for general support

Millennium Pharmaceuticals

\$75,000 for Schwartz Center Rounds

Joshua Boger, PhD, discusses the importance of compassionate care at business breakfast



Josh Boger, PhD, Vertex Pharmaceuticals, addresses 50 business professionals at corporate breakfast.

The Schwartz Center's **VIP Business Breakfast**, sponsored and hosted by Taj Boston last September, continues to be a successful event. More than 50 business professionals, representing a wide range of health professions, pharmaceutical companies and corporations, gathered for a morning of networking and conversation about compassionate health care.

The Schwartz Center was honored to have Joshua Boger, PhD, president and CEO of Vertex Pharmaceuticals, as the featured speaker. Boger shared a story about the development of a drug for cystic fibrosis and how many of the employees at Vertex got involved in some way, even those who were not officially working on the project. He explained that Vertex employees were compelled by the prospect of helping CF patients live longer and healthier lives. Many employees got to know a particular patient and were deeply affected when he passed away. Boger's presentation beautifully illustrated the notion that many people in the healthcare field are motivated by compassion for others even if they do not provide direct care for patients.

SAVE THESE DATES

Celebration of Women in Health Care

Date: Wednesday, May 20, 5-7:30pm
 Location: Tufts Health Plan
 705 Mount Auburn Street, Watertown

To attend or for more information, please call 617-724-4746 or email schwartzcenterevents@partners.org

Schwartz Center 14th Annual Dinner

Date: Thursday, November 19, 5-9:30 pm
 Location: Boston Convention and Exhibition Center
 415 Summer Street, Boston

Dinner Chairs: John Albert, Regional President
 Kindred Healthcare

Richard Kobus, Senior Principal
 Tsoi/Kobus & Associates

James Roosevelt, Jr.
 President and CEO, Tufts Health Plan;
 Schwartz Center Board member

The evening includes a silent auction, video presentation and announcement of the recipient of The Schwartz Center Compassionate Caregiver Award.

Please call 617-724-4746 or email schwartzcenterevents@partners.org for more information.

A special thank you to the major supporters of the 2008 Annual Dinner

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 Harvard Pilgrim Health Care
 Partners HealthCare System, Inc.
 Ropes & Gray
 Tufts Health Plan
 Vanguard Health Systems

TO MAKE A GIFT

For your convenience, we have enclosed an envelope should you wish to make a donation to the Schwartz Center. You may also donate by credit card via www.theschwartzcenter.org. Thank you for your support!

Schwartz Center Speaker Series

Exploring end of life communication

Good communication skills to help patients and family members cope with end of life issues are in increasing demand. The Schwartz Center hosted its second Speaker Series dedicated to this topic in Boston on September 25, 2008, co-sponsored by CRICO/RMF, the Massachusetts Medical Society and Beacon Hospice. More than 100 health care professionals participated in an interactive discussion on “Compassionate and Effective Communication at End of Life: Overcoming the Barriers.” The forum began with five panelists sharing different scenarios, highlighting examples of effective communication or situations where advance directives would have been beneficial. The panelists were: **Susan Block, MD**, chair, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute and Brigham and Women’s Hospital, and professor, Harvard Medical

School; **Lois Green, MPA**, cancer patient, Board chair, Better Ending Partnership and director, Geriatric Clerkship, UMass Medical School; **Barbara Moscovitz, MSW, LICSW**, Massachusetts General Hospital Geriatric Medicine Unit, and Schwartz Center Compassionate Caregiver Awardee in 2007; **Christine Rachwal, RN, MS**, educator, Neonatal Intensive Care Unit, Children’s Hospital Boston; **Sheila Trugman, MD**, medical director, Jewish HealthCare Center and Jewish Home Hospice, and assistant professor, UMass Medical School. **Lynn Nicholas, FACHE**, president and CEO, Massachusetts Hospital Association, skillfully facilitated the evening.

The discussion that followed the panel presentations was interactive and educational. “The presentations were heartfelt and compelling,” one participant stated. Another participant shared an idea for replacing the

“DNR” (Do Not Resuscitate) order; she proposed the use of a novel “AND” order – “Allow Natural Death.”

The evaluations of the program were overwhelmingly positive, the biggest drawback being that there was not enough time for further discussion. The majority of the participants felt the program objectives were met and the diversity of the cases presented was excellent. Many attendees noted the power of including the patient perspective.

Overall, the participants gained a better appreciation for the importance of talking about end of life situations and advance directives with patients and their families early on in their care. The program reinforced the need for clinicians to listen to patients and families and the importance of being empathic and supportive as patients approach end of life.

Forum on compassionate care for patients with Amyotrophic Lateral Sclerosis (ALS)

The Schwartz Center and Massachusetts General Hospital’s ALS Clinic held an interactive facilitated discussion, “**A Positive Outlook on Negative News: Promoting Compassionate Care for Patients with ALS**,” on January 15, 2009 in Charlestown, Massachusetts. More than 80 multidisciplinary caregivers from the region were present, including physicians, nurses, occupational therapists, hospice professionals and home health aides.

Three professional caregivers from MGH shared their perspectives on the challenges and rewards of caring for patients with ALS. The panelists were: **Merit Cudkovicz, MD, MSc**, director, Neurology Clinical Trials Unit and ALS Clinic, and associate professor of Neurology, Harvard Medical School; **Matt Bellanich, NP**, ALS clinic coordinator; and **Darlene Electa**

Pulley, program manager, Clinical Trials Unit. The evening was facilitated by **Lawrence Kron, PhD**, former co-director, Center for Coping with Chronic Illness, and a psychologist in private practice. The conversation broadened to engage the audience in a discussion about how to remain compassionate and positive with ALS patients and their families. This was the first multidisciplinary forum for caregivers of ALS patients to gather together to validate, support and learn from each other.

Much of the discussion focused on how caregivers for patients with ALS continually need to address challenging issues, such as what and *how much* life support their patient will want as the debilitating illness progresses. Many caregivers struggle with the timing of such difficult conversations. One caregiver shared a concern about one of her patients: “I’m seeing her

experience more losses... and I’m afraid that the conversation won’t come up until it’s too late.” The panelists validated and discussed her concern. As in most situations, caregivers need to take cues from patients and their family members.

A common theme emerged throughout the discussion. Many of the caregivers noted that the rewards far outweighed any of the challenges they face in caring for patients with ALS. The evening ended on a positive note, as many of the providers left the forum feeling appreciative of having the opportunity to support one another in their daily work.

Schwartz Center Board member **Ruth Kilduff** and her husband, **Jay Carrigan**, provided support for this annual educational forum in memory of Cristian Minard, a close friend who succumbed to ALS.

Our Health Care World



Like many of you, I have been overwhelmed by the number of emails and letters from not-for-profit organizations trying to garner support during these troubling economic times. These communications and requests for money are understandable and predictable as most of these organizations are experiencing a decline in their endowments and donations. The economy has challenged the Schwartz Center in similar and different ways, directly related to our mission.

Immense cost pressures on the U.S. healthcare system means fewer clinicians to provide care, more caregiver stress and less time with patients, all of which put a strain on compassionate, patient-centered care. We are getting an increasing number of calls from the organizations we fund who are deeply worried about the ability of their clinicians to provide compassionate health care during this time of crisis. In other words, our mission could be in jeopardy.

We cannot allow fear of this economy to change our goals or aspirations. Here at the Schwartz Center, we are mindful of the financial difficulties but are forging ahead with exciting plans to ensure that the healthcare system becomes more humane. Schwartz Center Rounds, our largest and most far reaching program, gives multidisciplinary caregivers the opportunity to discuss difficult emotional and social issues that arise in caring for patients; it has expanded to 165 sites in 30 states with more than 40,000 clinicians per year participating. We are adding approximately 35 new sites per year in this country and I am excited that two hospitals in the United Kingdom will pilot the Rounds in 2009 (see p. 12). Our programs have a multiplier effect: each clinician that we train cares for thousands of patients over his/her career in a more compassionate, humanistic way. We also continue to support a number of exciting pilot programs through our grants in the areas of cultural competency, end of life care and spirituality— all focused on improving communication between patients and clinicians.

We are a great investment for you, our donors, as we operate with a small staff and a lot of *pro-bono* help. We are extremely lucky in that a number of organizations provide generous in-kind support to us, including Massachusetts General Hospital and Mintz, Levin, Cohn, Ferris, Glovsky and Popeo, PC, and others who help us with many of our administrative, infrastructure, legal and other expenses. Most of our events are generously underwritten by hosts, including Goulston and Storrs, Tufts Health Plan and the Taj Boston. Unlike almost every other not-for-profit, that means that the donations we receive go directly to pay for our programs and staff.

This year, we have started a wonderful new program to honor compassionate caregivers. If you would like to make a donation in honor of a special clinician to support the work of the Center, please fill out the enclosed donation envelope. We will send your caregiver a certificate of appreciation on your behalf.

I thank you all for your continued support during these financially challenging times and promise to continue working to fulfill Ken's vision of a more humane healthcare system.

Sincerely yours,

Julie A. Rosen
Julie Rosen
Executive Director

Touchpoints

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WHAT'S HAPPENING

Massachusetts Coalition of Nurse Practitioners (MCNP) News, the Worcester Telegram & Gazette, Boston.com, the Massachusetts Hospital Association newsletter, CHEST Physician newsletter, and the American Thoracic Society newsletter, each published an article recognizing **Cynthia French, NP, UMass Memorial Medical Center**, as the 2008 Schwartz Center **Compassionate Caregiver Awardee**... *BBC News* featured a story called "Hospitals are medical factories" which mentions the Schwartz Center's new international program with Point of Care (POC) to pilot **Schwartz Center Rounds** at two hospitals in the **United Kingdom** (see story below)... *Nurse.com* featured an article about the Schwartz Center Rounds at **Overlook Hospital** in Summit, NJ... An article entitled, "The Talking Cure: Schwartz Center Rounds Foster Compassion and Collaboration" was published in a recent issue of the *Journal of Cancer Education*. The article highlights the impact that Schwartz Center Rounds has on hospitals... *The Boston Globe* published an **editorial** called, "Physician, heal thy heart," focusing on the importance of the Schwartz Center promoting emotional connections between the clinician and the patient... Three **Schwartz Center Board members** were recently honored. **The Arthritis Foundation** honored **Charles Baker**, Harvard Pilgrim Health Care, with a Lifetime Achievement Award. **Thomas Lynch, MD**, Massachusetts General Hospital, was honored at the **American Lung Association of Massachusetts'** first annual dinner. **Beverly Armstrong**, Paratek Pharmaceuticals, was named one of *Boston Business Journal's* "40 Under 40," a leader to be watched in her field... **Andrea Cohen**, *HouseWorks*, and

Schwartz Center Leadership Council member, was awarded the **Pinnacle Award for Achievement in Entrepreneurship** at the **15th Annual Pinnacle Awards** sponsored by the Greater Boston Chamber of Commerce... **Jon DuBois, MD**, Leadership Council member and Rounds physician leader at **Emerson Hospital** in Concord, MA, and Schwartz Center Assistant Program Director, **Pamela Mann, MSSA**, presented at the **American Society for Healthcare Risk Management (ASHRM) Annual Conference** in Boston, MA. Their presentation was called *Strengthening the Patient-Caregiver Relationship While Reducing Risk*... **DuBois** also made a presentation on the Schwartz Center Rounds at the **22nd Annual Gravens Conference on the Physical and Developmental Environment of the High Risk Infant** in Clearwater Beach, FL... **Beth Lown, MD**, Board member and Rounds physician leader at **Mount Auburn Hospital** in Cambridge, MA, presented at the **American Academy on Communication in Healthcare (AACH) Research and Teaching Forum** in Madison, WI. Her presentation focused on the findings of the Schwartz Center Rounds evaluation. **Maysel Kemp White, PhD**, a Schwartz Center consultant, joined **Pamela Mann** at AACH to present *The Patient Voice for Compassionate Care: Schwartz Center Dialogues*... **Theresa Raphael-Grimm, PhD, CNS**, Rounds facilitator at **University of North Carolina at Chapel Hill**, spoke at the **30th Annual International Association for Human Caring Conference** about fostering compassionate care through the Schwartz Center Rounds.

Schwartz Center Rounds go international

The Schwartz Center and The Point of Care program at The King's Fund, a non-profit organization in the United Kingdom, have created an exciting partnership to pilot the Schwartz Center Rounds in two hospitals in England. The Point of Care's mission is to improve the patient experience in hospitals and promote compassionate care. It recently issued a report stating that current efforts do not do enough "to transform hospital culture or support staff to provide compassionate care." The Point of Care's research identified two practical initiatives that have real potential to create sustainable change – one of them was the Schwartz Center Rounds.

The Rounds, the Schwartz Center's signature program, give caregivers from multiple disciplines a safe, comfortable forum to discuss difficult emotional and social issues that arise in patient care. An evaluation of the Rounds showed multiple benefits, including that they help caregivers learn from and support each other. The Rounds now take place at 165 sites in 30 states. The POC pilot will be the first time the Rounds take place in another country.

Representatives from The Point of Care and the Royal Free Hampstead NHS Trust, one of the hospitals that plans to start Rounds, came to Boston in October to see Rounds at Emerson and Massachusetts General hospitals and to meet with Rounds leaders, facilitators, Board members and staff. They plan another visit this spring. In the meantime, discussions between the Center and The Point of Care continue as to how the Rounds might need to be adapted to succeed in the U.K. healthcare system and how to best evaluate them.

See future issues of *Touchpoints* to see how this exciting new venture unfolds.