Zakim Center reflects commitment to providing comprehensive cancer care

With the snip of a red satin ribbon, Lenny Zakim’s dream of enhancing patient care at Dana-Farber became a reality last month. Family, friends, and supporters of the late DF CI patient officially opened the Leonard P. Zakim Center for Integrated Therapies during a stirring Nov. 27 ceremony at the Institute. The center, which provides clinical services such as acupuncture, nutritional counseling, and music therapy, rose out of Zakim’s heartfelt belief that cancer patients should be active participants in their own care. Its mission includes providing education and conducting research to determine the efficacy of specific complementary approaches. Based in the Shields Warren lobby, the center hired its first staff member – Project Coordinator Anne Doherty – last year.

“Lenny’s legacy continues and even grows,” Ken Anderson, M.D., Zakim’s physician at Dana-Farber, told a standing-room crowd at the ribbon-cutting. “Lenny’s mission in life was to make this world a better place. This center named in his honor assures us that Dana-Farber will forever be a better place for both patients and caregivers.”

An outspoken advocate for the availability of complementary therapies to Dana-Farber patients, Zakim utilized a variety of these therapies – including massage, meditation, acupuncture, and music therapy – during his five-year battle with multiple myeloma. After his death in December 1999, a contingent of supporters on the Institutes Complementary Therapies Task Force continued his efforts and ultimately helped establish the center.

New grant supports multi-pronged research into childhood leukemia

In a demonstration of the galloping pace of research into acute lymphoblastic leukemia (ALL) in children, a grant that was funded from 1985 to 2000 for $5.6 million and encompassed three research projects has been renewed for the next five years – at more than $15.6 million and including seven projects.

The funding, contained in a “program project grant” from the National Cancer Institute (NCI), supports the study of genes and cell processes that in some cases were unknown when the research was first funded in 1995, according to the grants principal investigator, Chief of Staff Stephen Sallan, M.D.

As Sallan points out, laboratory research from the first grant has already ripened into novel therapies that are now being tested in patients.

“The projects within this grant cover some of the most exciting areas of research into ALL, the most common malignancy in children,” Sallan says. “Although we’ve made vast improvements in our ability to treat this disease – more than 80 percent of all children are now cured – we need to get cure rates even higher and reduce the toxic side effects of current treatments.”

ALL strikes about 1,500 children a year in the United States. It’s a disease in which the bone marrow loses the ability to produce enough red and white blood cells and platelets, causing patients to have fever, fatigue, aching joints, and persistent infections.

Staff rally around colleagues after tragic fires with expressions of support and contributions

After a pair of devastating fires during Thanksgiving week left two Dana-Farber staff members homeless and claimed the life of one employees young son, co-workers quickly rallied with financial and other assistance.

On Saturday, Nov. 25, Andre Davis of Accounts Payable lost his 4-year-old son, Andre Jr., and “Little Dreds” 10-year-old cousin, Charles Wilborn, in a fire that also razed his brand-new Mattapan house. The blaze, reportedly caused by a space heater left too close to combustible material, injured Davis’ foster mother, Mattie Williams, and three other family members.

Just a few days earlier, on Nov. 21, a fire had demolished the Roslindale home of Cable Cafeteria Cashier Andrea Nei – leaving Nei, her husband, and three other family members.

Renovations to increase patient privacy, comfort

Greater privacy for patients and their families, individual workstations for nurses and clinic facilitators, more beds for patients receiving chemotherapy infusions, and a more comfortable, better-organized environment for everyone. All are in sight, thanks to a major renovation project planned for the infusion and exam areas of Dana 1 and 10.

The renovations, slated to begin this week and continue for about 10 months, will yield a new layout and decor for the Dana 1 infusion area and more infusion space on Dana 10 East. The aim is to make these areas more functional and attractive, improve patient flow, and create personal work spaces for staff, according to Elizabeth “Libby” Tracey, R.N., Ph.D., AOCN, director of Adult Ambulatory Nursing, who served on a committee that spent nearly half a year planning the changes.

“As our patient volume has increased, the infusion areas on Dana 1 and Dana 10 East have become increasingly difficult places for staff to work and patients to receive treatment,” she says. “A group of nurses, doctors, DF CI building staff, patients, and families has worked with an architectural firm to

Dana-Farber investigator presents end-of-life findings at national press briefing

In the weeks after the presidential election turned the country on its ear, it sometimes seemed there wasn’t a journalist in Washington, D.C., not writing about voting issues.

On Nov. 14, however, nearly 40 top health and science reporters filled a room at the National Press Club in Washington to hear some of the country’s leading experts on end-of-life issues.

Joanne Wolfe, M.D., M.P.H., medical director of the Pediatric Advanced Care Team at Dana-Farber and Children’s Hospital Boston, was one of four investigators participating in the three-hour press briefing, sponsored by the Journal of the American Medical Association (JAMA) to coincide with articles on the subject in the Nov. 15 issue of JAMA.

Wolfe presented findings from a study done at the Institute and Children’s that showed there is considerable delay among parents in recognizing when children with advanced cancer have no realistic chance of cure, and that this lag leads to later integration of palliative care and treatment to lessen suffering.

“Caregivers and parents are appropriately committed to curing children with cancer,” says Wolfe, lead author of the study. “Unfortunately, not all children will survive, so it’s important that we provide appropriate palliative care when treating the underlying disease.”

see Zakim, page 4

see Renovation, page 3

see Wolfe, page 4
Donor Recruiter Lou Goldberg is helping of seven Harvard-affiliated institutions involved in infusion of new leadership on the ECR, a body which reflects, in part, his belief in the need for a regular parts of the college.

Presented at a recent meeting of the college's Society of Physician Assistants.

He is being succeeded as committee chair by of the Dana-Farber/Harvard Cancer Center (DF/HCC).

The committee to focus on his duties as deputy director Massachusetts College of Pharmacy and Health Sciences (MCPHS) has yielded

A new partnership between the Kraft Family Blood Donor Center and the Massachusetts College of Pharmacy and Health Sciences (MCPHS) has yielded many new platelet donors, including some who have already donated twice.

The college invited the center to display at its Oct. 13 health fair, and Donor Recruiter Lou Goldberg and DFCI volunteer and platelet donor Joe Blundo presented at a recent meeting of the college's Society of Physician Assistants.

Giving platelets is now recognized as a regular activity of the society, and President Wendy Olson has offered to help the Kraft Center reach out to other parts of the college.

"The response has been outstanding," says Goldberg, himself a veteran platelet donor. "More than 40 potential new donors have signed up to date, and several students have already become repeat donors."

The Massachusetts College of Pharmacy and Health Sciences offers a master of science degree in physician assistant studies.

Physician assistants generally provide about 80 percent of the services typically given in a primary-care practice. Although they have been part of the health-care system since the 1960s, patients still commonly wonder what they do.

"Their lack of recognition is not unlike the lack of public awareness around platelet donation," notes Goldberg. "The MCPHS physician assistant program and the Kraft Family Blood Donor Center can help spread the word together."

Having completed his five-year term as chair of the Institute's Executive Committee for Research (ECR), David Livingston, M.D., has stepped down from the committee to focus on his duties as deputy director of the Dana-Farber/Harvard Cancer Center (DF/HCC). He is being succeeded as committee chair by Stanley Korsmeyer, M.D., of Cancer Immunology and AIDS.

Livingston said his decision is his alone and reflects, in part, his belief in the need for a regular infusion of new leadership on the ECR, a body which helps set policies and priorities for research at the Institute. He added that the DF/HCC -- a consortium of seven Harvard-affiliated institutions involved in cancer research -- is "an increasingly active and growing enterprise," requiring more and more of his time.

Amy Sullivan, Ed.D., of Adult Oncology has received an award from the 2000 Harvard Medical School Fund for Women's Health. The fund provides grants of up to $45,000 to HMS faculty to initiate collaborative research projects or education programs in any area of women's health.

Sullivan was recognized for her project, "Who Cares for Women at the End of Life?: The Nature and Effects of Caregiving Relationships for Older Women with Life-Threatening Illness."

"Because of women's longer life expectancy, older women tend to be at greater risk than men of living alone, being poor, and having multiple chronic illnesses," says Sullivan. "We want to know who is caring for older women with advanced illnesses, what caregiving responsibilities women themselves have, and how these relationships affect the quality of their lives and the choices they can make about their medical and end-of-life care."

She adds, "My colleagues and I -- Susan Block and Laurie Rosenblatt at Dana-Farber, and Sharon Steinberg and Antoniette Peters at Harvard Pilgrim Health Care -- hope that understanding issues specific to women will help us develop programs and processes that better meet their needs."

The HMS Center of Excellence in Women's Health Research Committee awarded 11 grants this year, up from eight last year. Dana-Farber provides funding for these awards, along with Harvard Medical School, CareGroup, Partners HealthCare System, and the Joslin Diabetes Center. This year's grants support collaborations by 40 faculty members, 75 percent of whom are women. They represent HMS and six affiliated institutions.

Winners announced for the 2000 Partners In Excellence Awards

Two awards were presented at a recent meeting of the college's Society of Physician Assistants.

Generous donors, employees, and others who contribute to Dana-Farber receive the Partners In Excellence Award. This year's recipients were:

• Jane Russell,olonist and RN, Dedication to Care• Lori Buswell, Involvement in the local community• Sylvia Bartel, Good Neighbor• Kelly Barnes, Supportive teammate and friend• Robert Levy, Senior Writer

Inside the Institute is published semimonthly for staff members and friends of Dana-Farber Cancer Institute. The next issue is scheduled for Tuesday, Dec. 29.

Story ideas and "News of Note" items are welcome and may be sent to Debra Ruder or Saul Wisnia at 375 Longwood Ave., Room 654, Boston, MA 02215, or call (617) 632-4090 or fax to (617) 632-5530. The Institute's Web site is at http://www.dana-farber.org. The intranet is at https://intranet.kdfs.harvard.edu.

Inside the Institute is printed on recycled paper.

The Institute recently celebrated Health Information and Technology Week to recognize the contributions of staff members in Information Services, Medical Records, and other areas that manage health information. As part of the Nov 5-11 observance, the Information Services Department held community-building activities, including a luncheon around the theme of “making a difference with health information.” It also posted computer-user tips of the day around the Institute and displayed photos of department teams and members outside the cafeteria.

Meanwhile, members of the Health Information Services Department – which includes Medical Transcription Services and other areas – enjoyed visits from two members of the senior leadership: Chief Operations Officer Jim Conway and Lawrence Shulman, M.D., vice chair for Clinical Services in Adult Oncology. Conway described how he launched his career in health administration filing X-rays at Children's Hospital, while Shulman acknowledged the growth of the organization and its impact on health information staff.

Professionals in the health information and technology field count among their goals: developing computer-based patient record systems, managing data quality, preventing fraud and abuse, and maintaining the security of information.

"So many of our staff work behind the scenes, running the computer rooms, managing our large databases, or keeping the network up and running," says Director of Clinical Information Systems Judith Remz. "We take pride in that work and are thankful for their contributions, as well as to look externally and provide some helpful hints to our user community."
Area child-care center opens with fanfare and finger paint

It was, in many ways, a typical day-care center morning. Preschoolers stacked blocks and dipped pumpkin pieces in finger paint. A group of toddlers clapped hands and sang "The Itsy Bitsy Spider" in the activity room. Parents peeled off their young-

sters' coats, kissed cheeks, and left for work.

But Monday, Nov. 27, also was an unusual day at the Bright Horizons Family Center at Landmark. That's because it marked the dedication of the brand-new center serving Dana-Farber, Brigham and Women's Hospital, Children's Hospital, and Harvard Medical School.

Representatives from the four Longwood Medical Area institutions gathered at the 140-space facility in the Landmark Center, located at the inter-

section of Brookline Avenue and Park Drive, to celebrate the long-awaited occasion. Dana-Farber has reserved 34 slots at the site across the age range of three months to 5-6 years.

"This is an extraordinary resource for the staff of our institutions," said Jim Conway, DFCl chief operations officer and chair of the MASCO Operations Committee, before cutting the ribbon - actually a strip of paper with kids' handprints - with oversized scissors.

The center grew out of meetings and focus groups in recent years that underscored the need for work-family enhancements in the Longwood area. The project was spearheaded by a committee led by MASCO (Medical Academic and Scientific Com-

munity Organization) which included Emily Barclay and Peggy Malumphy of Dana-

Farber's Human Resources Department.

Originally scheduled to open this past summer, the child-development center could not do so until fire officials deemed other parts of the building safe. Staff and children were placed at other Bright Horizons pro-

grams around Boston until the Landmark locale was okayed for business on Oct. 23.

Everyone praised the parents for their patience and flexibility during these delays.

"Our staff were amazing," said center Director Laura Batagowski. "They rode the 'T' and carpooled to the other sites, and they got to see how other centers operate. Now we're just waiting for more kids; another round is coming on Dec. 1."

Bright Horizons Chief Executive Officer Roger Brown, who co-founded the organization in 1986 with his wife, Linda Mason, said the new facility is good for area institutions, parents, and - most importantly - children. Studies have shown that high-quality child care can be "transformational" for children, he noted. "Our key challenge is to work every day to meet people's needs."

MASCO President Rick Shea said he was pleased with the partnership that MASCO had developed with Bright Horizons Family Solutions, which operates 12 centers in Greater Boston. "We at MASCO take the long view, and we're very happy about what this means for the future."

Renovation continued from page 1

design spaces that will serve every-

body better."

The changes on Dana 1 will cover everything from the location of infusion beds and chairs to the types of lighting, flooring, and interior design elements the area will have. Under the plan, nurses will have their own workstations with computers, in addition to a remod-

eled and relocated central nursing station. Clinic facilitators also will have individual workstations so they can meet with patients one-on-one. Neither group currently has this type of private work space.

The plan also places infusion beds for patients with more severe conditions in one group of rooms and infusion chairs in another area. Currently, beds and chairs are intermingled, which can complicate patient management.

Other improvements include a larger room for phlebotomy (blood drawing) and a private room for registration.

Architects have planned for a series of strategically located closets and storage areas so carts and equipment can be tucked away where they won't interfere with traffic and work flow, says lead architect Sherri Rullen of Miller Dyer Spears of Boston.

Particular attention has been given to the lighting, colors, and fabrics of the renovated clinic. Rullen adds: Slight lines will be improved and glass shielding employed in certain areas to provide a greater sense of privacy.

"The Dana 1 infusion unit will have the feeling of being less of a clinic and more of a comfort area for patients receiving chemotherapy or blood products," Libby Tracey explains.

On Dana 10 East, the construction work will enlarge the infusion area to accommodate an additional seven chairs and add a pharmacy and workstation for the unit's nurses.

To inconvenience patients as little as possible, construction will proceed in

stages. The Dana 1 infusion area will be divided temporarily - with half under construction, and half open to patients. To accommodate the patients dis-

placed from Dana 1, a temporary infusion area is being constructed on Dana 10.

Patient and family input

The renovations come as a response to com-

ments from patients and staff and a study by members of the Adult Patient and Family Advisory Council. The council, which aims to enhance cancer care at DFCI and Brigham and Women's Hospital, has been exploring ways of reducing waiting times in the Institutes clinics. It recom-

mended a redesign of the Dana 1 infusion area as one way to address that problem.

"The current layout doesn't support a good flow of patients," says council Co-Chair Joe Nies, who served on the committee studying waiting times. "We felt improvements could be made in a variety of areas."

A committee of council members, doctors, nurses, and facilitators met with architects to formulate the current plans.

"The changes we've planned will go a long way toward improving patient flow, giving patients and family members more privacy, and helping care-

givers be more productive and effective," says Henry King of the Patient and Family Advisory Council. "There will be some inconvenience while construc-

tion is under way, but the end result will be a better experience for patients and Institute staff."

Elevator is off limits

Because of the renovations to the infusion space on Dana 10, the Institute is restricting one elevator for construction use. In the rear lobby, elevator 8 - with stops up to Dana 12 only - will be out of regular service through the project.

Inside the Institute December 5, 2000
Zakim continued from page 1

Among the task force members were Cynthia Medeiros, LICSW, director of Patient and Family Support Services at Dana-Farber and administrative director of the Zakim Center, who organized the ribbon-cutting event.

“Lenny had a dream to bring complementary therapies into the daily lives of cancer patients,” said Medeiros. “He lived his dreams and never wavered from them.”

“Dana-Farber is building another bridge to progress in comprehensive cancer care.”
— David Rosenthal, M.D.

Wolfe continued from page 1

In the study, Wolfe’s team interviewed 103 parents of children who died of cancer between 1990 and 1997, surveyed each child's primary oncologist, and reviewed the child's medical charts. They asked, among other questions, when parents and physicians became aware that a child had no realistic chance for cure; what factors were associated with parents and physicians acknowledging around the same time that the child was terminally ill; and whether understanding the child’s prognosis altered the parents’ treatment goals.

The authors discovered that, on average, physicians saw that a child had no realistic chance for cure around 100 days earlier than the child's parents. When both parent and physician recognized the child’s prognosis more than 50 days before death, there was a stronger emphasis on treatment aimed at easing the child's suffering.

“We found that high-quality palliative care is more likely when both physicians and parents recognize the child’s prognosis,” says senior author Jane Weeks, M.D., M.Sc., of Population Sciences and Adult Oncology. “This highlights the importance of honest, effective communication between caregivers and families of seriously ill children.”

Forming a PACT

When asked how they first became aware that their child had no realistic chance for cure, only 49 percent of parents reported that this realization grew out of a discussion with the medical team; 30 percent claimed it came from a perceived change in the way their child looked or acted, and 9 percent stated that it came from a feeling or dream.

Based on early data from this study, Wolfe had led a 1997 effort at Dana-Farber and Children's to establish a pediatric palliative care service, the Pediatric Advanced Care Team (PACT). This multidisciplinary group advises caregivers of children with advanced disease about ways to manage symptoms and improve quality of life. Members of PACT also help coordinate care in the inpatient, outpatient, and home-care settings, lead teaching sessions, and are developing new ways to improve communication among physicians, patients, and their families.

The study data bear out what we were seeing anecdotally and inspired us to create PACT,” explains Wolfe. “Our team consists of caregivers from many different disciplines committed to maximizing comfort in children with life-threatening illness and to providing support and information to families. PACT helps us step back, regroup, and refocus on the families’ and patients’ overall care experience.”

In addition to Wolfe, former Dana-Farber oncologist Ezekiel Emanuel, M.D., Ph.D., of the National Institutes of Health, Timothy Quill, M.D., of the University of Rochester School of Medicine, and Karen Steinhauser, Ph.D., of the Duke University Medical Center, also presented at the JAMA event.

The press briefing was held to highlight JAMA’s theme issue on end-of-life research. Journal editor Catherine DeAngelis, M.D., said so-called “theme issues” generate a 50-percent to 100-percent increase in the number of papers submitted for consideration to the journal. “Considering we can only publish about 400 articles per year, we know we’re turning away some good papers,” she said. “But we know we are publishing the truly top studies.”
First ‘Lenny Lecture’ focuses on the science of complementary therapies

Of the many maladies for which people seek unconventional treatments, one exceeds all others in terms of patient interest and dollars spent: cancer. To help scientists around the country sort out whether complementary therapies are beneficial or bogus, the government has established the National Center for Complementary and Alternative Medicine (NCCAM) at the National Institutes of Health.

On Nov. 16, the center’s director, Stephen Straus, M.D., delivered the first annual “Lenny Lecture at Dana-Farber, an event named after Leonard Zakim, a former DFCI patient who spearheaded efforts to make alternative therapies and their study available at the Institute.

The use of complementary therapies in the United States is vast and growing. Straus told the audience of staff and patients gathered in Smith 308/9. An estimated 40 percent of Americans have already used such methods, which include everything from acupuncture to herbal remedies to meditation, and have spent some $27 billion on them. Tellingly, 60 percent of alternative therapy users don’t disclose such use to their physicians.

Removing the aura of intrigue and subjectivity from such therapies and grounding their use, or disuse, in hard science is the goal of the NCCAM, Straus said. Created last year, the center funds research on techniques ranging from oriental medicine and homeopathy to dance and art therapy, chiropractic and massage, Qigong, and therapeutic touch.

Straus presented data showing that, despite Western medicine’s traditional scorn for such therapies, some of them may well be effective. He cited a study that found the herbal remedy St. John’s Wort to be as effective as a placebo. Patients may object to enrolling in clinical studies where they are randomly assigned to use an alternative therapy or a placebo.

“People often come into such trials with firmly held beliefs about the effectiveness of complementary therapies,” Straus remarked. Other difficulties are a lack of understanding of how alternative treatments work on a molecular or cellular level, the complexity of methods such as Reiki touch therapy or meditation, and the ethics of withholding proven, standard care from patients to study unproven alternatives.

Lastly is the issue of product standardization: the manufacture and labeling of alternative therapies such as herbs is not regulated by the government, unlike the strict oversight given to conventional medications. “The standards for some of these products are less than for a head of lettuce,” Straus said. “When you buy something that says ‘lettuce’ on the wrapper, you know you’re getting lettuce. With alternative medicine compounds, there’s no requirement that what’s inside the package is the same as what’s on the label.”

He added that such obstacles are surmountable, but they require creativity. Projects currently funded by the NCCAM include research into the use of shark cartilage against cancer and the use of a complex diet regimen against advanced prostate cancer. The office seeks to invest in areas of greatest public need, in therapies that are particularly controversial, and in treatments that have reached a level of maturity, Straus said.

“‘There’s only one ‘good’ medicine,” he concluded. “That is the medicine for some of these products are less than for a head of lettuce,” Straus said. “When you buy something that says ‘lettuce’ on the wrapper, you know you’re getting lettuce. With alternative medicine compounds, there’s no requirement that what’s inside the package is the same as what’s on the label.”

Happening

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<th>Event</th>
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<tbody>
<tr>
<td>Seminars in Oncology</td>
<td>Tuesday, Dec. 5</td>
<td>4 p.m.</td>
<td>Smith Family Room (D1620)</td>
<td>Matthews Mann, Ph.D.; Professor, University of Southern Denmark</td>
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<td>“Novel Proteomic Methods to Map Protein-Protein Interactions and Signaling Pathways” Tue., Dec. 12, 4 p.m. Jimmy Fund Auditorium</td>
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<td>Friends of Dana-Farber Holiday Concerts</td>
<td>Friday, Dec. 15</td>
<td>noon to 1 p.m.</td>
<td>Dana lobby</td>
<td>Ellen Farber Schmidt and daughter singing</td>
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<td>John Rosenblatt Holiday Party</td>
<td>Monday, Dec. 18</td>
<td>2:30 p.m. to 4:0 p.m. Dana lobby</td>
<td>Dana lobby</td>
<td>All are invited to enjoy refreshments and music, courtesy of Miriam “Mimi” Rosenblatt, who hosts the annual party to thank staff for the care her late husband received at the Institute.</td>
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First ‘Lenny Lecture’ focuses on the science of complementary therapies

An estimated 40 percent of Americans have already used complementary therapies.

— Stephen Straus, M.D.

Europe that found St. John’s Wort reduces the blood levels of drugs used to treat AIDS, rendering them less effective.

“If one is to presume that alternative therapies have some pharmacological benefits, it would be irresponsible not to investigate whether such treatments also can have unintended, harmful consequences,” Straus said. By funding research into complementary approaches, the national center hopes to disentangle tantalizing, if unproven, claims from proven facts.

Murphys continue Yule tradition

The Murphys are well known each holiday season in their hometown of Randolph: they are the “Christmas tree family.” Each year for the past three decades with their tree sales.

The Murphys – Dan Sr., Priscilla, and Dan Jr., with help from others – do this part of an extended thank you to Dana-Farber. Thirty-one years ago, the Murphys were asked to help out with the Dana-Farber annual party to thank staff for the care that her late husband received at the Institute.

The Murphys have been saying “thanks” to Dana-Farber for three decades with their tree sales.

There are other obstacles as well. Patients may object to enrolling in clinical studies where they are randomly assigned to use an alternative therapy or a placebo.

“The plural of ‘anecdote’ is not ‘evidence,’” Straus said, suggesting that no number of personal stories about unorthodox treatments can compensate for rigorous scientific testing. “Anecdotes are hypotheses; they’re inspiring. But in the domain of public health, one attempts to build on evidence.”

Research challenges

To support the testing of alternative therapies, the NCCAM provides funding in four strategic areas: research, training investigators, expanding outreach, and facilitating the integration of proven therapies into standard practice.

Straus noted that the study of complementary approaches poses challenges not faced in conventional medical science, where research typically proceeds from the study of molecules to animals to humans. "With alternative medicines, we’re dealing with treatments that are already being used by people,” he said.

There are other obstacles as well. Patien
President’s Forum addresses staff members’ questions and concerns

Will there be more space for research? When will the order-entry system be upgraded? What will the human genome project mean for us?

These were some of the questions posed by staff members during a President’s Forum on Oct. 31 in the Smith Family Room. Held quarterly, the forums allow a wide group of staff — usually about 50 people — from throughout the Institute to pose questions to senior leadership.

This President’s Forum marked the first for Dana-Farber’s new president, Edward J. Benz Jr., M.D. He was joined by Patricia Reid Ponte, R.N., D.N.Sc. (director of Nursing and Patient Care Services), Faye Austin, Ph.D. (director for Research), Jim Conway (chief operations officer), and Dorothy Puffy (chief financial officer).

What follows is a summary of some of the questions asked during the two-hour session.

Space Concerns

Q: How will Dana-Farber balance the need to grow physically — especially in the area of animal resources — with the desire to contain its growth?

A: The space issue has become more urgent in recent months because of some new research grants that will demand additional staff. At the same time, more laboratories will be using animals as the field of genomics grows. We may have to reclaim some space now leased to the Harvard community, and we expect to add new construction at some point. A master space plan will likely be developed within two years.

Patient Safety

Q: What’s the status of improvements to our medication order-entry systems?

A: Patient safety is job No. 1 at Dana-Farber. We are playing a major role in the project to bring the next level of clinical order-entry system to Massachusetts General Hospital, Brigham and Women’s Hospital, and Dana-Farber. We have been assured that the late spring implementation of that system at DFCI will not be delayed, despite a lag at MGH. The pediatric chemotherapy safety system is expected to go online in February. We generate monthly reports on safety and promptly investigate any concerns expressed by clinicians. Connecting the Pharmacy and order-entry system is a priority.

Social Work Support

Q: Nurses would like more social work support for outpatients, as our social workers are often busy addressing inpatient needs. Can this be done?

A: This clinical service is currently being reviewed by DFCI and BWH, and changes are expected to be announced within the next two months.

Patient Volume

Q: Will clinic hours be expanded to meet patient demand?

A: The Institute is now renovating and enlarging some existing facilities, and it will likely extend its hours for direct clinical care and ancillary services such as radiology. We need to make sure space is being used as efficiently as possible and consider work/life issues for staff in these decisions.

Fire continued from page 1

their four children homeless. The cause of this fire had not been determined at press time.

As soon as word spread about the Mattapan tragedy on the Monday after Thanksgiving, contributions for Davis began flowing into the Accounts Payable office at 1309 Beacon St. and the Cashier’s Office in the Dana lobby. A former temporary employee who was hired full-time last December, Davis stayed with friends during the week after the fire.

“He’s devastated, of course, but he’s held up very well,” says Lydia Rojas, Davis’ supervisor. “His only son was a huge part of his life, and they were very tight. As soon as word spread about the Mattapan fire, people came running off the street and dropped anything they had to do just to lend a helping hand.”

Filling the jar

The support for Nei has also been extraordinary. Now in her eighth year at Dana-Farber and one of four full-time cashiers in the cafeteria, Nei is known for her warmth and this past spring was nominated for the Rowlee Award for Staff Excellence. On Tuesday, Nov. 21, she was working her normal shift when her husband, Izaque Romain, rushed in to tell her their house was on fire. By 5 p.m. that evening, the family’s possessions were gone.

While the couple and their children (ranging in age from 10 to 15) relocated to a Holiday Inn for the next couple of weeks, a glass jar labeled “Andrea Nei Relief Fund” was placed in the entrance way to the cafeteria and money started pouring in. By late last week, cash donations for Nei’s family had reached $12,000, and additional offers of food, toys, school supplies, and other items had been made. Staff were invited to donate clothes and shoes, and any items not needed by the family will go to the Red Cross.

“People keep calling, and it means so much to me,” Nei said last week. “When Darrell first told me how many people were worried about me, then gave me all the money, I didn’t know what to say. My thanks go out to everybody.”

Information Services

Q: What progress is being made to find a successor to Ben Bembenek, former chief information officer (CIO)?

A: Three people are managing the clinical, research, and financial administration systems right now, and Partners HealthCare System CIO John Glaser is devoting significant attention to Dana-Farber. We have hired a search firm to help determine which skills are most important in our chief information officer, and a search committee is being formed. Many resumes have come in for the job.

Documentation

Q: How will DFCI ensure that clinical staff can adequately fill out the paperwork needed by insurance companies?

A: The Institute has focused much attention on this issue in recent years. There are ongoing efforts to keep clinical staff current about changing third-party reimbursement requirements. We are also looking for ways to make the process less time-consuming for clinicians by exploring the use of electronic tools (like Palm Pilot technology) to reduce paperwork.

Intranet

Q: Will there be more training and support for the intranet?

A: Yes, the Communications Department is now looking for a coordinator to work with departments to build their sites and help staff members take advantage of the system. The goal is to make the intranet more user-friendly.

Translational Research

Q: How long does it take to bring research to bear on treatment?

A: This is a special time in science. A lot of knowledge is converging to help us understand better how cells function on a genetic level, how certain molecular pathways lead to cancer, and how to target drugs against particular tumors. But the technology is expensive and requires space, so resources and collaboration are critical. There’s a roughly 10-year lag between laboratory discoveries and their application to patients. Organizations that can demonstrate bench-to-bedside outcomes will be better positioned to attract patients and research grants.

Genetics

Q: Will the human genome project mean that future newborns will receive their genetic blueprints?

A: Not likely. But the information will help scientists examine genes that put people at higher risk for cancer and probe genetic differences among tumors so that treatments — and possibly prevention methods — can be developed. The field raises many ethical questions; Dana-Farber has an ethics committee and will soon appoint a clinician/researcher to be our official ethicist.

Staff members interested in attending a future President’s Forum may e-mail Emily Barclay in Human Resources.
The seven projects in the new grant tackle ALL from a variety of angles—from explorations into the basic genetics of the disease to new techniques for diagnosing and treating it.

**Long-term survivors**

The first project springs from a 1996 discovery by Dana-Farber researchers and colleagues at Brigham and Women’s Hospital and Children’s Hospital. The scientists found that of the children whose leukemia cells expressed the TEL/AML1 gene, more than 90 percent were long-term survivors. The finding may mean that patients with the gene can be treated differently than those without it. The current study, led by Gary Gilliland, M.D., of Brigham and Women’s and Stuart Orkin, M.D., the new chair of Pediatric Oncology at Dana-Farber, will attempt to find out.

**Focus on infants**

The second study examines the genetics of leukemia in infants. Although overall cure rates for pediatric ALL now exceed 80 percent, the rate among infants is closer to 50 percent. Infants often respond well to an initial round of chemotherapy, but, for unknown reasons, about half die of a recurrence within a year. Researchers led by Stanley Korsmeyer, M.D., of Cancer Immunology and AIDS and Scott Armstrong, M.D., Ph.D., of Pediatric Oncology are probing the genes involved in the natural process of cell death. They’re exploring whether these genes undergo a change from the time ALL is first diagnosed in infants to the time it recurs. Their work may disclose why many infants become resistant to the chemotherapy that initially pushes the disease into remission. The research may be applicable to many other types of cancer, such as ovarian cancer, in which chemotherapy loses its potency after a time.

**T cell disease**

The third focuses on a particularly aggressive type of leukemia known as T cell ALL. Researchers led by Thomas Look, M.D., of Pediatric Oncology are comparing the genes involved in T cell ALL to those involved in standard ALL. The genes under study won’t come from pediatric patients, however, but from zebra fish. Look will be working with Leonard Zon, M.D., of Children’s Hospital, who pioneered the use of zebra fish in genetic research. In previous studies, Look has shown that T cell ALL patients who express a certain gene have a cure rate of 70 percent, compared with a 20-30 percent cure rate in patients without the gene.

**Genetic snapshots**

The fourth study, led by Todd Golub, M.D., of Pediatric Oncology, will complement the first three projects and expand their scope. Using microarray technology, which produces a “snapshot” of the activity of thousands of genes within a cell, Golub and his colleagues will analyze genetic patterns in different types of ALL. They’ll compare the patterns in T cell ALL with those in standard ALL, pediatric ALL with adult ALL, and infant ALL with standard ALL. Where differences in genetic activity are found, researchers will have promising targets for new therapies.

**More sensitive tests**

The fifth seeks to improve doctors’ ability to detect leukemia cells lurking in patients who otherwise test as being disease-free. Current exams that look for leukemic cells in the bone marrow and blood aren’t always sensitive enough to pick up “minimal residual disease,” the few remaining leukemia cells that may mount a comeback of the illness. In previous research, John Gribben, M.D., Ph.D., of Adult Oncology made clones (or copies) of leukemia cells from children diagnosed with ALL, then used these clones to create tailor-made probes for detecting leukemia after treatment. Gribben and his colleagues found that such probes were just as successful in finding leukemia cells in patients’ blood as in bone marrow. The new study will build on these findings.

**Alerting the immune system**

The sixth project seeks to overcome one of the most frustrating aspects of ALL: the ability of ALL cells to become “invisible” to the body’s immune system, which would otherwise attack and destroy them. Scientists at DFCI have found that ALL cells not only fold in on themselves, hiding the surface proteins that would betray them to the immune system, but also are able to shut down the immune cells around them. To re-alert the immune system to ALL cells’ presence, Lee Nadler, M.D., and Angelo Cardoso, M.D., Ph.D., of Adult Oncology plan to apply a technique originally developed in the laboratory. Known as adaptive immunity, the method involves “training” immune cells to recognize a patient’s leukemia cells, then duplicating the immune cells hundreds of thousands of times and injecting them into patients. Nadler and Cardoso also will work with Eva Guinan, M.D., and Nicholas Haining B.M., B.CH., of Pediatric Oncology on a tumor vaccine against ALL. Both the vaccine and adaptive immunity techniques will be tested in adult as well as pediatric patients.

**Raising cure rates**

The seventh investigation, led by Sallan, involves clinical trials aimed at trying to increase five-year cure rates for the disease beyond the current level of 83 percent. The project will focus on finding more effective drugs or drug combinations.

Projects of this scope generally require large-scale NCI funding, Sallan notes. But when discoveries are made independently of NCI grants, it is funds from private donors such as those raised by the Friends of Dana-Farber Cancer Institute—that enable scientists to refine their work to the point where it is fundable by the NCI.

“TNCI support, supported established research projects,” Sallan notes, “but seed money from individual donors is crucial in the earliest stages of scientific discovery.”

In addition to the seven projects described above, the grant will fund the research support services of biostatisticians who help investigators design studies and analyze their results.

**Blum Center offers support with backpacks and fanny packs**

Thanks to the generosity of several corporate and individual contributors, the Blum Patient and Family Resource Center can now lend support to children who have parents with cancer.

Attractive navy blue backpacks, stuffed with little toys such as bouncy balls, rubber stamps, and cuddly stuffed animals, are given out to boys and girls between the ages of 4 and 12 whose parents are in treatment. Teenagers receive navy blue fanny packs, also filled with age-appropriate items such as rulers and sunglasses.

Donations from Stop & Shop and Ortho-Bio Tech have made these giveaways possible.

During the past few months, more than 75 backpacks and fanny packs have been given to children with parents in treatment for cancer. Each pack contains jokes written by kids and a suggestion sheet with tips such as: “Be a cook. A parent will enjoy a bowl of JELL-O or a glass of gingerale, knowing it was prepared by you.”

Accompanying the packs are materials to help parents discuss cancer diagnosis and treatment with their children, as well as resources such as Web sites for families dealing with the disease. Also included is a video by Cancervive, entitled “Kids Tell Kids,” in which youths of various ages talk about what it’s like to have parents with cancer.

Blum Resource Center volunteers have noted that families have been surprised, thrilled, and grateful to receive these items.
Diane Cotting believes two things saved her life after she was diagnosed with breast cancer last year: Dana-Farber and the sport of rowing. Now that she's in remission and back on the water, Cotting is striving to raise awareness of the disease and help other women get through its physical and emotional challenges.

The 50-year-old Bostonian received local and national media attention in October, when she formed a team for the Head of the Charles Regatta consisting of eight rowers and a coxswain who were all breast cancer survivors. Naming their boat “One in Nine” – for the number of women who will develop breast cancer at some point in their lifetimes – Cotting's all-female, pink-uniformed squad competed in the masters eights division and was the inspirational story of the event.

What the television cameras captured that weekend, however, was only a small part of Cotting's tale. After being diagnosed in April 1999, she endured four lumpectomies, a mastectomy, lung surgery, and numerous other procedures during the next several months. She missed an entire season with the Style Driven Rowing Club on which she competed and feared she would never be able to participate in the sport again. When she did make it back this past spring, she had a new appreciation for both the fellowship she found rowing and for her caregivers at Dana-Farber and Brigham and Women's Hospital.

“I always had a goal to get back out there rowing,” says Cotting, a 5-foot-1, late-blooming athlete with an infectious smile and iron will. “My Style Driven teammates kept me posted on what they were up to, and that pushed me to do things in terms of rehab that I wouldn't normally do by myself. At the same time, while I was undergoing my treatment, the doctors, nurses, and everybody from the parking attendants on down at Dana-Farber and the Brigham made me feel like I was the only patient they had. My husband, Norm, was also with me through it all. It was clear I didn't have a team just on the water.”

Weekend warrior
Cotting was introduced to her passion in 1994, when a friend suggested a class at the Community Rowing Club in Brighton as a way to lose a few pounds. She grew to love the sport, especially after attending Olympian Holly Metcalf’s annual “Row As One” camp for women the following summer. “It was the most unbelievable experience of my life,” recalls Cotting. “I had grown up in an era when girls were not encouraged to play sports or be part of teams. Now here I was being respected and encouraged as an athlete. It was an invigorating week.”

Upon returning from camp, Cotting and a group of other middle-aged women formed the Style Driven team. They hired Metcalf – a 1984 gold medallist and Providence native – as their coach, and soon this diverse squad of teachers, lawyers, and other professionals was competing locally and nationally. Cotting, who runs her own business designing employee benefits programs, gladly worked early-morning practices and weekend regattas into her schedule.

Four years later, in the spring of 1999, Cotting felt a lump in her breast during her monthly self-examination. When tests confirmed it was cancer, teammates steered her to Dana-Farber’s Gillette Center for Women’s Cancers. Surgical oncologist Carolyn Kaelin, M.D., and medical oncologist Ursula Matulonis, M.D., oversaw her care there, with Charles Herreuter, M.D., of BWH performing her plastic surgery. Her doctors and husband weren’t the only ones on call during this period. Rowing friends would appear at the Gillette Center just when Cotting needed a shoulder to cry on, and one even got recertified as a nurse so she could help. In a display of solidarity, teammates sent a photograph of themselves standing by the dock, holding a sign that read “Reserved for Diane Cotting.” As soon as her physicians allowed her, she was back preparing for the 2000 season.

During her cancer treatment, Cotting’s teammates made sure she knew her spot on the “Style Driven” squad was safe. (Photo courtesy of Diane Cotting)

According to Matulonis, Cotting’s belief that “rowing helped save my life” was not so far-fetched. “Those who are in better shape physically and emotionally tend to do better in chemotherapy,” says Matulonis. “Studies have shown that exercise during chemotherapy does lessen side effects. For post-menopausal women, keeping lean and trim lessens the chance of developing another breast cancer. Extra fat cells make estrogen, and high estrogen levels in the blood have been associated with a high risk.”

Psychiatrist Laurie Rosenblatt, M.D., of Adult Psychosocial Oncology says there are also documented mood benefits to physical conditioning that can help with a patients recovery. “Cancer is a disease of multiple losses, be it the loss of hair, a breast, or your sense of physical integrity,” she explains. “People feel they have been thrown into this battle, and conditioning is one way of getting their lives back.”

Rosenblatt warns, however, that recovering patients often have less “reserve energy” than before their cancer treatment – and should act accordingly. Another major risk for breast cancer patients is lymphedema, a swelling in the arm caused by excessive fluid build-up after lymph nodes in the underarm are removed or treated with radiation. Lymphedema is thought to be spurred on by repetitive, unremitting rowing. So Kaelin recommends patients consult with their physicians before attempting sports such as rowing.

“Exercise is beneficial, but it needs to be individualized for each patient,” says Kaelin. “If a patient wants to get back to the form of conditioning she did before, she needs to tailor that exercise program to minimize the chances of lymphedema. Once you get lymphedema, you always have it.”

Finding inner strength
She knows the risks and respects her doctors, but Cotting says nothing was going to keep her from rowing. She feels so strongly about the sport's role in her recovery that she felt compelled to find survivors from across the country to fill her “One in Nine” boat for the Head of the Charles regatta, which took place during Breast Cancer Awareness Month. Team members came from as far away as California and included one woman who had suffered a recurrence two weeks before the event. The group so inspired other competitors that just before their race, they were surrounded by 20 other boats and given an ovation. “I think they did it on purpose,” Cotting jokes. “They made us cry, then left us in the dust.”

Cotting is now back with the Style Driven team, whose members are under-going yearly mammograms and monthly self-examinations. And she is working with her coach, Holly Metcalf, and trainer, Abigail Peck, to develop a post-operative program for breast cancer patients that includes conditioning with rowing machines and a rowing camp where survivors can forge friendships through teamwork.

“We want to give women in recovery an opportunity to rebuild their bodies, learn to trust their bodies again, and work with the inner strength they have found from battling this disease,” explains Cotting, who wears a diamond-studded breast earring as a reminder of her ordeal. “After they leave the hospital and finish physical therapy, we want to help them get back to their regular lives stronger than ever.”

Text by Saul Wisnia

Diane Cotting (third from bottom) and her “One in Nine” crew compete in the Head of the Charles regatta on Oct. 22. All nine are breast cancer survivors. (Boston Globe photo by John Bohm)