Dana-Farber prepares to act on issues raised during the staff opinion survey

With results in hand from the staff opinion survey conducted this past September, Institute leaders are now taking steps to address areas of concern raised during the process.

Over the next few months, Dana-Farber will begin planning improvement activities around Institute-wide and departmental issues identified during the survey. Among these are pay and performance recognition, communication and collaboration across departments, and the satisfaction of certain groups within the DFCI community.

"The learning coming out of the survey is extremely important," says Chief Operations Officer Jim Conway. "People are proud to work here, and their general satisfaction is well above the national norm. But staff have to feel better about our pay system and other areas that surfaced in the process. It's very clear we have a lot of work to do."

Nearly 1,000 staff members from throughout DFCI filled out the questionnaire, which was administered by Baird/Melnick Associates of Chicago. The turnout was somewhat below average, and consultant John Baird, Ph.D., speculated that some staff declined because they were too busy or felt the endeavor wouldn't lead to change.

In December, staff received in the mail a letter from Institute President Edward J. Benz Jr., M.D., and an overview of the findings; in January, results of the DFCI community.

Study finds long-term effects of chemotherapy on fertility

In a study reflecting the growing interest in the long-term effects of cancer treatment, researchers at Dana-Farber’s David B. Perini, Jr. Quality of Life Clinic and Children’s Hospital have found that boys treated with high doses of a common chemotherapy agent are likely to experience irreversible fertility problems as adults.

The study, published in the Feb. 1 issue of the journal Cancer, involved 17 adult males who, as children, had been treated with chemotherapy drugs known as alkylating agents for a variety of sarcomas – cancers of the bone, cartilage, or certain muscles. The drugs are known to produce fertility declines in adult cancer patients, but their long-term effect on children had not been well studied previously.

The researchers, led by Lisa Diller, M.D., medical director of the Perini Clinic, found that 10 of the 17 study participants (60 percent of the group) had no sperm production, five (or 29 percent) had reduced sperm production, and only two (or 12 percent) had normal sperm counts. The two with normal sperm counts had received the lowest doses of the chemotherapy drugs.

All the patients who had been treated prior to puberty had abnormalities in their semen, a finding that contradicts doctors’ long-held belief that exposure to these drugs before puberty was safe for the male reproductive organs.

"The results indicate that exposure to alkylating agents prior to puberty is not protective, and that the risk of infertility increases with higher doses of the therapy," Diller says. "It's important that parents of young patients be informed about the potential for long-term side effects on fertility."

Alkylating agents work by destroying fast-dividing cells in the body. These include cancer cells, as well as hair cells, cells in the digestive tract, and cells in the testicles that produce sperm. Because the sperm-producing cells in children have not begun to function as in adults, it is possible for children to have irreversible fertility problems.

"We also hope this research leads to better treatment options for our male patients," Diller says.

Annual Walk team enables DFCI researchers to probe the rare histiocytosis disease

Seven-year-old Alexander Mufson may be the youngest captain in the history of the Boston Marathon® Jimmy Fund Walk, but he’s also one of the best. The youngsters “Team Histo” has raised more than $530,000 over the past four years and was the Walk’s top fundraising team last year, garnering $183,000.

Not surprisingly, it is Alexander’s mom who has been the real force behind this tremendous effort. A full-time mother of two boys and a former volunteer with Dana-Farber’s Blum Resource Center, Dorie Mufson spends several months each year crafting inspiring letters to sponsors and
Some new ingredients will soon be added to the Institute’s food services operation. After 18 years at Dana-Farber, Sodexho/Marriott has prevailed in a competitive bidding process for DFCI’s food services contract. But it has promised to invest more than $50,000 to upgrade the cafeteria and its other services, such as room service, vending, and catering.

Last year, the Institute put its food service (Dietary) contract out for bid for the first time in several years. Although pleased with the existing service, the leadership felt it was important to investigate other vendors to determine whether the Sodexho/Marriott contract was price-competitive, according to Director of Operations James A. Wall Sr.

A Food Service Contract Evaluation Committee was formed to help with the selection process; it included Wall, Anne Chiavacci, Louise Forrest Bowes, William Lowe, Steven Connolly, Libby Tracey, William Corbett, and Janice Simmons.

At Dana-Farber, Sodexho/Marriott serves roughly 250,000 meals a year in the Austin and Marcia Cable Dining Hall, at catered events, and to patients receiving treatment and their families. Its operation here represents one of the largest outpatient food services in the area. The company also manages the vending machines around the Institute, whose revenues go to the Jimmy Fund.

Committee members were pleased with many aspects of Sodexho/Marriott services. The vendor labels, dates, and rotates all food products, values customer concerns. New self-service equipment, such as a heated pizza display, will also be installed.

Sodexho/Marriott intends to continue its collaboration with Institute dietitians. “We have partnered with Dana-Farber to complement its mission,” explains Swift. “This includes having a menu with many cancer-fighting foods. We can also provide a breakdown of ingredients in the meals.”

In an effort to improve catering efficiency, Sodexho/Marriott plans to purchase 200 sets of china, thus eliminating rental costs for many events. It also intends to use DFCI Online, the Institute’s intranet, to better publicize its services and menu.

To foster further confidence, Sodexho/Marriott will put 10 percent of its fee into a “quality assurance fund.” Every quarter, the food service committee will decide whether the company is doing a satisfactory job, and the funds will either be released or retained.

“We’re very pleased that we are continuing our relationship with Sodexho/Marriott,” says Wall. “The company’s commitment to excellence reflects Dana-Farber’s dedication to excellence in research and patient care, and we look forward to working together into the future.”

NEWS OF NOTE

Dianne McKay, M.D., of Pediatric Oncology leads one of five research teams in the United States receiving grant awards from the Roche Organ Transplantation Research Foundation this year. The grants, which total approximately $1 million, support investigators working to advance the science of solid organ transplantation. The winning teams were selected from a field of 134 grants submitted by researchers around the world. The title of McKay’s project is “Alterations in IL-2R signaling induced by anti-IL-2R antibodies.”

Anti-IL-2R antibodies provide an important new addition to the treatments available to prevent rejection of solid organ transplants. McKay’s work is focused on understanding how these antibodies affect the biochemical signaling within immune system cells, called lymphocytes, that cause rejection. Her work will provide insight into the mechanisms of rejection and its prevention.

One of Dana-Farber’s newest staff members is Li Cal, M.D., Ph.D., an information service manager in the Research Computing Department. He joins a staff of five experts who maintain the computing environment that supports research.

“We assist the researchers with all their hardware and software needs,” explains Cal. “The genomic analyses that researchers conduct here generate a huge amount of data. That data doesn’t make sense if you don’t know how to analyze it, so I try to evaluate, select, and develop the needed software tools and biological databases. This will help scientists understand molecular bases that affect human health and disease.”

Cal began working at DFCI on Dec. 18 after completing his postdoctoral training in Connie Czechek’s genetics lab at Harvard Medical School. His work covers wide aspects of biological computing, including bioinformatics, UNIX system administration, and Web development.

He earned a medical degree at Yichun Medical School in his native China and arrived in the United States in July 1991, attending Rutgers University as well as the University of Medicine and Dentistry of New Jersey’s Robert Wood Johnson Medical School.

Although the complex nature of his work required him to “dive right in,” Cal is still getting familiar with DFCI and the projects that research groups are working on. “This an exciting and challenging job for me,” he reflects, “because it allows me to combine my interests and background in both biology and computers.”

Colleagues bid farewell last week to Michael Buckley, administrator for Nursing and Patient Care Services, and praised his love of family, politics, and Dana-Farber. Chief Operations Officer Jim Conway, for one, noted how Buckley “glowed” when speaking about the Boston Marathon® Jimmy Fund Walk and its Team Dana-Farber, which Buckley led for each of his three years here.

Buckley, who is leaving DFCI to pursue broader opportunities, thanked assistant Sandy Johnson and others for their generosity. “I have felt enormously fortunate to be part of your great team,” he told a group of well-wishers on Jan. 29. “You have enriched me as a professional, and you’ve enriched my family.”

Lisa S. Schwartz
Inside the Institute
Mayer research receives boost from national colorectal cancer alliance

Research by Robert J. Mayer, M.D., director of the Center for Gastrointestinal Oncology and vice chair for Academic Affairs in Adult Oncology, recently received a boost — thanks to about $216,000 in support from the National Colorectal Cancer Research Alliance (NCCRA).

The NCCRA is a charity organization launched last year by NBC television Today show co-anchor Katie Couric, cancer fundraiser Lilly Tartikoff, and the Entertainment Industry Foundation in an effort to increase awareness, encourage preventive testing, and raise funds for physician-scientists engaged in promising colorectal research.

One of eight physicians on the alliance’s medical advisory board, Mayer is designing studies focused on discovering causes and preventing the development of colorectal cancer. Additional funding from the NCCRA is anticipated later this year and next year on the basis of these efforts, to help Mayer and his colleagues continue their investigations.

Since its launch, the alliance has garnered $11 million in gifts and pledges for colorectal cancer research and awareness. Mayer and his fellow investigators on the NCCRA board are encouraged to seek out other physician-scientists engaged in promising research for future alliance support.

“We are going to take this great responsibility very seriously,” says Mayer. “The NCCRA has made a commitment to make colorectal cancer screening accessible and to publicize its importance. The alliance hopes to change the insurance coverage rules for everyone who is appropriate for screening and to make that testing as effective as possible. And, at the same time, it is funding our basic research into what causes this disease.”

Says Couric, whose husband, Jay Monahan, died of colon cancer in 1998, “I am thrilled to be able to make this extraordinary contribution to these dedicated scientists. We have spent the past nine months working on fundraising and awareness efforts. Now our scientists will use the fruits of our labor to research better treatments and, I believe, ultimately find a cure for colon cancer.”

According to the American Cancer Society, colorectal cancer is the second-leading cause of cancer deaths in the United States. An estimated 130,200 new cases were reported nationwide during 2000, and 56,000 people died from the disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening. Men and women are equally at risk of dying from colorectal disease. It is more than 90 percent curable, however, if detected early through regular screening.

For more information on the National Colorectal Cancer Research Alliance, call (800) 872-3000 or visit the alliance’s Web site at www.nccra.org.

Lance Armstrong Foundation supports Dana-Farber research on survivorship

World champion cyclist Lance Armstrong is helping Dana-Farber investigators develop methods to improve care for cancer survivors.

Since forming a foundation just a few months after his own diagnosis with cancer in 1996, Armstrong has helped make a difference in the lives of many others who are fighting the disease and its aftereffects.

Now, the Lance Armstrong Foundation has awarded Christopher Recklitis, Ph.D., of Pediatric Oncology and Craig Earle, M.D., of Adult Oncology nearly $250,000 to support their research on behalf of childhood cancer survivors.

Recklitis, chair psychologist at Dana-Farber’s David B. Perini, Jr. Quality of Life Clinic, is slated to receive $150,000 over the next three years to develop a standardized screening program to identify survivors who suffer from learning disabilities, anxiety, depression, and other psychological long-term effects of cancer treatment.

When Recklitis began his work at the clinic in 1998, there were no standardized methods to determine the specific psychological needs of survivors. So he developed a clinical assessment program of his own. With the Lance Armstrong grant, he aims to improve his screening method to make it shorter, more accurate, and applicable to wider audiences.

“I am pleased with the screening we have here,” says Recklitis. “But it won’t be a major contribution to the field unless we can take our homegrown program and expand it into something that can be used at other places, such as clinics that do not have the psychosocial staff that we do.”

Earle, meanwhile, will use his $95,000 award (given over two years) to learn whether cancer survivors receive adequate care for their non-cancer health needs.

By studying the interactions between colorectal cancer survivors and the health-care system, Earle hopes to determine if survivors use routine preventive medical services such as flu shots, breast screenings, and cholesterol monitoring more or less than individuals with no history of cancer.

Earle says the findings will help providers develop guidelines for the appropriate clinical care of patients with prior cancer diagnoses and contribute to better comprehensive long-term health care for survivors.

Prep school’s hockey tourney nets Jimmy Fund contribution

Students who take part in the annual St. Sebastian’s School Jimmy Fund Hockey Tournament have at least two goals: to score often and raise money for Dana-Farber.

Held this past Labor Day weekend, the latest tournament helped generate $7,500 for the Jimmy Fund and brought to $40,000 the total amount raised for the cause by the college preparatory school for boys in Needham.

Punctuating the 2000 event was a moving ceremony featuring honorary master of ceremonies Bobby Cintolo, a St. Sebastian’s student who was diagnosed with a brain tumor last April, underwent treatment at Dana-Farber, and is now cancer-free. At the event, Cintolo presented the championship trophy to Brett Hayes, last year’s honorary emcee and a leukemia survivor.

“We look forward to continuing our efforts to raise money for the Jimmy Fund,” Tournament Director Jack Doherty wrote to Jimmy Fund Chairman Mike Andrews. “It has been a very rewarding and gratifying experience for all of us at St. Sebastian. We hope that in some small way the St. Sebastian’s School Jimmy Fund Hockey Tournament will help contribute towards future success stories.”

Chris Recklitis, Ph.D.

Craig Earle, M.D.

Robert Mayer, M.D. (Steve Gilbert photo)

Chris Recklitis, Ph.D.

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Chris Recklitis, Ph.D.

Craig Earle, M.D.

Robert Mayer, M.D. (Steve Gilbert photo)
Histiocytosis continued from page 1

David G. Nathan, M.D., saluted and serenaded at appreciation dinner

In an evening filled with surprises for the guest of honor, Dana-Farber President Emeritus David G. Nathan, M.D., was lauded for his five years of Institute leadership during a dinner at the Museum of Fine Arts on Jan. 23.

Some 200 people, including family members and DFCl staff, trustees, and friends attended the festivities, where they dined while enjoying live operatic arias. One selection came from a trio of musicians that Nathan, now the Robert A. Stranahan Distinguished Professor of Pediatrics, didn't know would be performing: daughter Deborah Nathan Charness on flute; son-in-law Michael Charness, M.D., Ph.D., on piano; and David Fisher, M.D., Ph.D., of Pediatric Oncology playing cello.

After current DFCl President Edward J. Benz Jr., M.D., spoke of the pride and challenge he felt in succeeding Nathan, another surprise attendee “roasted” the guest of honor: Professor Sir David Weatherall, FRS, Emeritus Regius Professor of Medicine at the University of Oxford, and one of Nathan’s closest friends in medicine.

The night concluded when Benz and Board of Trustees Chairman Gary Cytrynbaum delighted Nathan, an avid sailor, with an oil lamp for his sailboat. It bears the inscription: “Presented with heartfelt gratitude to David G. Nathan, M.D., for his tireless service as President of Dana-Farber Cancer Institute.”

As a gesture of thanks, Board of Trustees Chairman Gary Cytrynbaum (left) presented Nathan with an oil lamp for his sailboat. (Steve Gilbert photo)

Histioctosis

maintaining detailed spreadsheets of the team’s fundraising progress. She even produced a glossy newsletter last year from her family’s Sharon home to keep walkers and supporters updated on new developments. Under her leadership, the team has grown from 24 members in its first year to 50 members – many of them Pacesetters (walkers who collect $500 or more apiece) – in 2000.

Yet, it’s clear that her oldest son is the inspiration behind it all. In February 1997, just before his fourth birthday, Alexander was diagnosed with histiocytosis, a rare disease that affects an estimated one in 200,000 people each year in the U.S. These patients have too many histiocytes, a form of white blood cell that multiplies widely and can attack any part of the body, including bones, liver, lungs, skin, and lymph nodes. Similar in some ways to cancer, histiocytosis is treated with radiation and chemotherapy.

Because histiocytosis is an “orphan” disease affecting few people each year, it has not been a priority for federal funding. As a result, there has been little research into the causes and treatment of the disorder. That is, until the Mufsons got involved.

“IT’s logical that federal funding is allocated to fight the more common diseases,” reasons Mufson. “It makes complete sense to focus on problems that affect more people. But when it’s your child who has that rare disease, you can’t just sit back and accept it. You’ve got to do something.”

So, Dorie and her husband, Michael, formed Team Histic Just in time for the 1997 Walk. As nearly $86,000 in proceeds from the event poured in, the Mufsons met with DFCl Chief of Staff Stephen Sallan, M.D., Barrett Rollins, M.D., Ph.D., of Adult Oncology, and Kim Nichols, M.D., formerly of Pediatric Oncology, to assemble a research and clinical care team to tackle histiocytosis.

The research program, one of the first of its kind in the Northeast, aims to improve understanding of the causes of histiocytosis and to design improved treatments for children and young adults with this disorder.

“When it’s your child who has that rare disease, you can’t just sit back. You’ve got to do something.”

— Dorie Mufson

“Without Team Histio’s generous contribution, we could only work on this problem in our spare hours,” says Rollins. “Their support has allowed me to devote a significant amount of my time to this area of research, as well as hire a postdoctoral fellow (Marcia Fournier, Ph.D.) to focus on it full-time.”

Rollins adds that the research they are now able to conduct on histiocytosis may lead to discoveries about cancer as well as other diseases – which could produce more opportunities for federal funding in the future.

Histiocytosis care at Dana-Farber, led by Sarah Alexander, M.D., of Pediatric Oncology, is coordinated between the Jimmy Fund Clinic and Children’s Hospital. Approximately 10 to 20 new patients come for treatment or consultation each year. Several of them and their families are members of Team Histio.

Meanwhile, Alexander Mufson’s disease has been in remission since September 1997, and he’s been able to do the three-mile Patient/Family Walk for the past two years. As two of the team’s top fundraisers, he and his 5-year-old brother, Wyatt, received a standing ovation at the Walk’s Pacesetter Reception last June.

“We have been so blessed that he hasn’t had a recurrence,” says Dorie Mufson. “But what we do know about this disease is that it’s chronic, it waxes and wanes, and it could come back at any time. So, until there’s a cure, we’ll continue to be involved.”

Perini continued from page 1

hadn’t been known whether chemotherapy would impair their future fertility. Pediatric oncologists at Dana-Farber and Children’s plan several avenues of research in an effort to reduce the chances that patients will experience abnormal sperm counts later in life. Among them are using lower doses of alkylating agents and using other chemotherapy agents that have fewer side effects on fertility. For patients who have already reached puberty, banking sperm before treatment may offer a chance to father children biologically later in life, researchers say.

“We continue to search for ways to use current therapies to minimize side effects,” says the study’s lead author, Lisa Kenney, M.D., M.P.H., of Pediatric Oncology. “The more we learn about the long-term ramifications of cancer treatments from past patients, the better we can manage patients today.”

Also contributing to the study were Mark Lauer, M.D., of Children’s and Brigham and Women’s Hospital; Frederick Grant, M.D., of Children’s; and Holcombe Grier, M.D., of Dana-Farber and Children’s.

Pictured at right, Lisa Kenney, M.D., M.P.H., of Pediatric Oncology, is lead author of the study on long-term effects of chemotherapy given to boys with sarcomas. (Steve Gilbert photo)
Conway reviews Institute’s ‘journey’ of quality improvement

The tragic overdoses of two breast cancer patients at Dana-Farber in 1994 made the Institute “Exhibit A” in discussions of medication errors at hospitals around the country. Today, DFCI is known as a leader in the effort to reduce such errors and respond appropriately when they occur.

How the Institute made the journey from cautionary example to admired exemplar – and how it continues to work to reduce clinical errors – was the topic of a talk by Chief Operations Officer Jim Conway on Jan. 18. Delivered in Smith 304 to a group of about 25 staff members, the presentation was the first in a series on patient safety scheduled for the next few months.

The lunchtime events are modified versions of talks that Institute leaders have given to health-care management groups around the country. Delivering them to Dana-Farber staff is a way of “celebrating what we’ve achieved as an organization,” Conway said, but also serves as a reality check against “romanticizing” those accomplishments to outside groups.

Conway began his Jan. 18 discussion by recalling that when he interviewed for his current position, shortly after the overdoses became public, he was impressed by the approach that Institute leaders intended to take toward the problem. “They made clear that they wanted to use this terrible tragedy to move the Institute to a very different place,” Conway said. “In three years, they wanted Dana-Farber to be viewed as a leader in quality improvement.”

That is precisely what happened: a subscription to people throughout Dana-Farber who subjected every aspect of clinical care to intense scrutiny and identified ways of making improvements, Conway noted.

In many respects, the approach taken by Dana-Farber was atypical, he continued. “Elsewhere in the country, people tend to respond to a crisis of this kind by getting into the bunkers and lying low. But it’s been proven over and again that this doesn’t work. What works is to be open about the problems and use what you’ve learned to make improvements.”

Conway noted that error reduction should be part of the intrinsic culture of health-care institutions, not something that springs into action solely in response to a mishap. As evidence, he cited Dana-Farber’s ongoing quality improvement program for all its operations.

The next presentations in the patient safety series are scheduled for Feb. 15, March 15, and May 17 at noon. Please contact Leigh Holden in Human Resources for more information.

Survey continued from page 1

were presented to managers, supervisors, and the Executive Committee of the Board of Trustees.

This month, reports about individual departments are being distributed to the respective department heads, and the Joint Quality Improvement and Risk Management Committee also plans to discuss the data that has emerged. (The survey was conducted anonymously, and to ensure that individual staffers cannot be identified in the analysis, Baird/Melnick has broken down the information into groups of 10 people and larger.)

Next steps

Looking ahead, members of the Executive Management Group (EMG) will take a three-pronged approach to address major concerns highlighted in the process, according to Director of Quality Improvement Charley Borden – whose department led the survey project with Human Resources.

Institute-wide initiatives will be undertaken with the active involvement of staff members, although those details have not yet been worked out. Departments and work groups, meanwhile, will be encouraged to hold discussions to “dig deeper into the results, identify projects, and then launch them,” Borden says.

The third prong involves “easy fix” items, and Human Resources and Quality Improvement are looking for ways to accommodate those suggestions.

Of those who filled out the questionnaire, 68 percent said they were extremely or generally satisfied with their work life at Dana-Farber. Another 8 percent said they were slightly satisfied, and the rest were either neutral or dissatisfied. Only 1 percent marked “extremely dissatisfied,” versus the national norm of 5 percent for comparable institutions (research and outpatient health-care organizations).

Those results are especially gratifying when one considers that competitive and financial pressures have driven down employee satisfaction in the health-care industry nationally over the past 15 years, according to Baird, whose company surveys hundreds of health-care institutions a year. Among those areas receiving positive ratings at Dana-Farber were executive leadership, supervisors, patient care and research, benefits, communications about the organization, and the DFIC culture and climate.

Most staff who filled out the survey said they like their colleagues and are pleased they chose to work here. Items that drew negative scores included salaries and performance recognition, communication and collaboration across departments, workloads, decisions about promotions and transfers, and workspace.

The results reveal lower DFIC satisfaction among several groups of employees, and there will be follow-up to better understand and act on concerns aired by those groups, Borden notes.

Leaders believe the survey showed how well the staff and Institute have withstood the changes and challenges of the past five years, and they believe the improvements resulting from this process will help strengthen DFICs position for the future.

“The survey results are very encouraging overall, but they are also a clear call for action to do even better,” states Benz. “There is a universally felt need for us to do better at communicating across our academic and administrative units and to find even better ways to recognize outstanding performance. We regard these results as our guide to make Dana-Farber the very best place in which to work.”

Chief Operations Officer Jim Conway has traveled around the country describing Dana-Farber’s successful efforts to enhance clinical safety. (Gina Lelanscher photo)
A tribute to Einar ‘Jimmy’ Gustafson 1935-2001

Whether transporting bicycles across the state in his 18-wheeler during the Pan-Massachusetts Challenge, joining Jimmy Fund Clinic patients for the last three miles of the Boston Marathon® Jimmy Fund Walk, or simply greeting people with a warm word and handshake at numerous other Institute-related events, Carl Einar Gustafson seemed always to be spreading a message of triumph and hope to Dana-Farber patients, staff, and friends.

It was less than three years ago that this gentle, 6-foot-5 giant from New Sweden, Maine, emerged after a half century of anonymity as the original “Jimmy” who inspired the Jimmy Fund’s creation in 1948. In that short period of time, however, Gustafson made a tremendous impact. From the moment he was “discovered” until he died at age 65 on Jan. 21 following a stroke, he gave selflessly to the organization that had saved his life years ago. In doing so, he helped many others face their own disease with courage and confidence.

“My favorite part of coming forward has been going to the Jimmy Fund Clinic and seeing the kids,” Gustafson said in 1998. Fifty years earlier, as a 12-year-old, he had been treated for what is now known as non-Hodgkin’s lymphoma by Institute Founder Sidney Farber, M.D. “The kids are all so young, they don’t think about what’s happening to them or what made their treatments possible. They just want to go home, like I did.

“You know, I’ll do anything to help the Jimmy Fund,” continued Gustafson. “This year, I’ve met people who ride their bikes all over Massachusetts, walk a marathon, golf – you name it – all to raise money to beat this darn disease. If they can devote that much of their time and effort, then I figure I can, too.”

Thank you, Einar, for doing just that – and so much more.

“Einar Gustafson’s story is the story of our nation’s war on cancer, and over the past five decades, tens of thousands of people have rallied against cancer in his name.”

- President Edward J. Benz Jr., M.D.

“If we had tried to create a grown-up ‘Jimmy,’ we couldn’t have come up with a better one than the real one, Einar. He was absolutely genuine – a completely kind, gentle, and generous man.”

- Jimmy Fund Chairman Mike Andrews

In July 1999, two of the Jimmy Fund’s most valuable players – Gustafson (far left) and Boston Red Sox baseball legend Ted Williams (center) – had a historic meeting in the Jimmy Fund Clinic and reached out to fans of all ages.
“Jimmy” connected with people of all ages and backgrounds. At his 1998 “Welcome Back” celebration, he greeted pediatric patients (above) and, at right, then-DFCI President David G. Nathan, M.D. (far right), and Jimmy Fund Chairman Mike Andrews.

During the two-and-a-half years between his “rediscovery” and his death, Gustafson was an integral part of many Dana-Farber events. Above, he led the Patient and Family Walk contingent during the 1998 Boston Marathon (right) and Jimmy Fund Chairman Mike Andrews.

“Carl Einar Gustafson, a.k.a. ‘Jimmy,’ leaves his wife, three children, six grandchildren, and a legacy of hope for millions.”

- Dan Shaughnessy, Boston Globe
consultation service for both inpatient and outpatient care.

“Dana-Farber and Brigham and Women’s are fortunate to have in place a wealth of expertise relating to pain and palliative care,” says Abrahm, a hematologist/oncologist who joined the Institute in January after 20 years at the University of Pennsylvania Health System.

There, in addition to leading a pain and symptom management consultation service for patients undergoing anti-tumor therapy, she developed a disease-management program for patients at the end of life. She also served as medical director and director of education and research for a university-owned hospice center.

“This new program will build on the pain-management and palliative care services already being provided here,” explains Abrahm, whose book, A Physician’s Guide to Pain and Symptom Management in Cancer Patients, was published last year by Johns Hopkins University Press. “Our goal is to enable Dana-Farber patients to have the best possible quality of life as they go through treatment or approach the end of their lives—wherever they happen to be: in a hospital inpatient unit, an outpatient setting, at home, or in a hospice.”

Allied experts

The new program’s team will be available to advise physicians or other caregivers who have questions or concerns about pain or palliative care issues in individual patients.

“Pain management continued from page 1

“The team will be available to consult on many kinds of physical problems or other sources of distress,” Abrahm says. “Patients may have uncontrolled cough or nausea or troubling combinations of psychological, social, or spiritual issues.” In addition to Abrahm, Maureen Lynch, M.S., R.N., CS, AOCN, CHPN, and Mary Jane Ott, M.N., M.A., RNCS, serve as core members of the group, along with psychiatrists, chaplains, social workers, clinical pharmacists, and anesthesia pain management specialists.

“By having experts in each of these fields, we’ll be able to ensure that every patient and family receives the best palliative care,” Abrahm remarks. “We’ll also be equipped to teach the various components of palliative care both to interested staff members and to other care providers.”

“Our goal is to enable patients to have the best possible quality of life as they go through treatment or approach the end of their lives.” — Janet Abrahm, M.D.

The team will also include a community coordinator—a nurse who helps the primary oncology team keep in contact with patients who are being cared for at home by family or with assistance from an agency. And the program members will work closely with the Institute’s palliative care resources nurses, who are based in most disease centers.

“Our aim is to provide support for the primary oncology teams, particularly in difficult or complex cases,” adds Abrahm.

Outpatients can also have appointments in the Pain and Palliative Medicine clinic on Friday mornings. In addition to team members listed above, patients in the clinic will also have access to consultations with Nathaniel Katz, M.D., a neurologist who is an attending physician at Brigham and Women’s Pain Management Center and director of the Pain Clinical Trials Center.

Materials are being prepared describing the new program and listing the phone and pager numbers of team members.

Research and education

Abrahm, who has written extensively on palliative care issues, said she was attracted to Dana-Farber and its affiliates. “Research studies will help us expand the knowledge base in this field,” says Susan Block, M.D., chief of Adult Psychosocial Oncology at Dana-Farber, who has been instrumental in creating the new program. Current projects include a study of caregiving relationships and end-of-life care, and a new model for educating physicians in palliative care.

The Pain and Palliative Care Program will be allied with the Harvard Medical School Center for Palliative Care, which has developed a variety of training programs for clinicians, nurses, medical students, and others.

“Janet [Abrahm] is a truly superb leader who is about to work with patients and educating our staff,” Block says. “Palliative care addresses the sources of suffering that many people are most afraid of. Through this program, we can provide crucial support for patients and families as they go through this profound human crisis.”