side by side

In this issue:

A *Newsletter* by and for patients and families, published by the Adult and Pediatric Patient and Family Advisory Councils

Volunteers serve patients as active listeners

Volunteer Phyllis Shulman gets feedback from patient Claire Cuddy.

Dana-Farber's array of clinical and support services are united by an underlying philosophy: attention to what patients themselves bring to cancer treatment. Volunteers have always played an important role in contributing to this patient-centered approach to health care that ensures the highest level of quality and safety.

A good example is the Patient Relations Volunteer Program, established in 2001 in an effort to obtain feedback from adult patients through personal interaction.

Assisted by Volunteer Services, the program recently recruited several new volunteers to make weekly "rounds" in the infusion and waiting areas on Dana 1, 9, 10, and 11. The volunteers ask patients open-ended questions, ranging from "How are you doing today?" to the more direct, "What might we do to improve our services?"

Former patient and current volunteer Jessica Carnevale notes that patients often open up to volunteers who are familiar with the environment and can share information about accessing resources and services. "We have an insider's view of some of the frustrations," she says. "For example, if we learn that a patient prefers that an injection be given at 8:30 a.m. instead of the scheduled 11:30, we can ask the patient and family relations representative to talk with staff and see if this preference can be honored."

If patients are inclined to speak their minds, volunteers become "active listeners," giving them a chance to tell their story or express their needs. Any problems are immediately relayed to nurse managers or to patient and family relations for investigation and timely response.

Comments get results

"By proactively getting feedback, we help our staff understand the patient experience and can use these conversations to make improvements," says Janet Korman-Parra, patient relations representative. "This feedback is measured and analyzed

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Patients and families help plan ways to ease the transition to home care

When oncology patients are discharged from the hospital, their care may continue at home by a community health nurse. However, due to the specialized nature of cutting-edge cancer care and research, the type of care they receive at Dana-Farber, Brigham and Women's Hospital (BWH), and Children's Hospital Boston may not be the same at home. Community health nurses are trained to provide a range of care for patients with many different types of illnesses.

In recent discussions among members of the Patients as Educators Committee – which includes members of the Adult and Pediatric Patient and Family Advisory Councils and staff from Dana-Farber, BWH, and Children's – council members expressed the desire for home-health-care providers to receive more education about cancer. Among the important topics to be covered were types of cancer, chemotherapy and its side effects, radiation therapy, and accessing ports.

Patients and families say they appreciate being actively involved in their care at a hospital or health-care setting, and would like this to continue at home. In an effort to promote this role, the councils, the Patients as Educators Committee, the Care Coordination Department, and the Cancer Care Education Committee developed a one-day conference, "Adult and Pediatric Pain and Symptom Management." It is geared toward visiting nurse associations and home-health-care agencies that provide home care to patients of Dana-Farber, BWH, and Children's. It will take place on Sept. 17 at Best Western-The Inn at Longwood.

The conference is an opportunity for caregivers to receive specialized training and education in oncology and develop additional expertise. It will also allow Dana-Farber to build relationships with community health-care providers. Both councils are pleased to see this first-of-its-kind conference take place, and they appreciate Dana-Farber's commitment to extend the continuum of care to patients receiving treatment at home.

"We recognize the outstanding contribution to care that community health nurses make," says Diane Hanley, MS, of Nursing and Patient Care Services. "We also understand the challenges they face in caring for cancer patients at home. We look forward to building relationships through these kinds of forums."

– Cyndi MacKinlay

Spring 2003

DANA-FARBER
CANCER INSTITUTE

From the *Editors*

Advocacy comes in different shapes

On the brink of conflict during World War II, General George S. Patton wrote, "In 40 hours I shall be in battle, with little information, and on the spur of the moment will have to make the most momentous decisions. But I believe that one's spirit enlarges with responsibility and that, with God's help, I shall make them, and make them right."

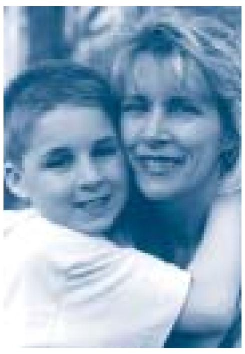
Making decisions about cancer care is often very different from other important life decisions that allow careful planning. No one prepares for cancer to take center stage. The suddenness of a cancer diagnosis quickly propels us into new and uncertain territory. While we often have time to carefully research the safety features of a new car, we may need to make life-altering decisions about cancer care in a matter of hours. Sometimes, lack of knowledge about our disease contributes as much to our fear as the cancer itself.


Barbara Holtz

Some of us may rely solely on the information provided by our caregivers, while others devour every bit of additional information on our disease. Wherever we fall on this scale, and however we choose to advocate, support can come in many different forms. You will find as much, or as little, information as you need in the Blum Resource Centers located within Dana-Farber, Brigham and Women's, and Children's hospitals. At the end of the day, however, some of the most meaningful support may come from conversations in a clinic waiting area or shared hospital room, with those who have walked in our shoes.

Reading the pages of this newsletter may be your first step towards advocacy. In advocating for yourself or your child on any level, you are actively participating in your treatment with your caregivers. This partnership promotes better communication, awareness, and safety.

Those who are new to *Side by Side* will learn how patients and family members serve on various committees around the Institute. A full-day conference on pain and symptom management for visiting nurse associations across Massachusetts came out of work done by patients and family members on the Patients as Educators Committee. A pilot adult greeter program allows new patients to receive a tour of Dana-Farber given by former patients who can share valuable "tips from trenches," such as where to find the best free coffee.


Cyndi MacKinlay with her son, Andrew

Reading the words of those who have traveled further along in their journey with cancer may offer the encouragement we need to face the next difficult day, the next chemo cycle, or the tears on our child's face. *In the Spotlight* profiles the strength of a family who has come through treatment and now offers support to other families. We have also included personal reflections written about living with cancer. Please let us know if you would like to share your story or writings.

Side by Side is written by and for patients and family members in this community that none of us asked to join. However, it is through our shared experiences that you discover you are not alone, and that however briefly, "Daylight will peep through a very small hole." (Japanese proverb)

– Your editors
Barbara Holtz and Cyndi MacKinlay

Volunteers *continued from page 1*

in such categories as communications, service, quality of care, billing, and the management of support services."

Suggestions are gained from pediatric patients and families in a similar fashion. Each month, a member of the Pediatric Patient and Family Advisory Council meets with patients and families in the Jimmy Fund Clinic to listen to their concerns and acquaint them with the work of the council. Important issues are communicated to the appropriate department and may also be brought to the council for discussion and action.

So far, there is a high volume of compliments for Dana-Farber staff and volunteers. Although patients continue to express concern about the amount of time they spend waiting for an appointment or infusion, Korman-Parra says that these complaints have decreased, due to efforts by many Institute departments and staff.

Mary Gershanoff, former patient and current volunteer, says "Patients appreciate our taking an active interest in them because it helps minimize stress and makes them feel connected to the general community. When we hear of their concerns and convey them to a ready resource, it ultimately results in improved communication between patient and care provider."

According to Barbara Bierer, MD, vice president for Patient Safety, "This method enhances patient safety because problems or complaints are quickly given to the appropriate Dana-Farber departments and addressed in a timely manner."

Thanks to information elicited by this cadre of volunteers, the Institute's facilities group repaired a pothole in the garage, close to the curb where patients enter and exit the building, helping them avoid a sudden fall or loss of footing. Push-button, handicap accessible doors were installed for patients needing easier access from the garage to elevator lobbies by the Dana 2 and 3 garage areas. Similar doors will soon be installed at the Shields Warren entrance, near the Longwood Galleria. Restroom doors on Shields Warren 1 now open more easily.

"When patients feel listened to as they await treatment, they have a general feeling of safety and well-being," Korman-Parra says. Among the compliments offered by patients, one said, "We've been to many hospitals, but we find we get far better treatment and attention here than at any other place. Dana-Farber provides excellent attention to detail."

– Barbara Holtz

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In the Spotlight

Life beyond cancer: One family's story of hope

On July 6, 2001, my wife Denyse and I received the terrible news that our 19-month-old daughter, Isabelle, had a malignant tumor that grew from her spine and was rapidly filling every available space in her abdomen. It was neuroblastoma, a cancer of the nervous tissue. We had come to Children's Hospital from our Cape Cod vacation so that Isabelle could undergo a routine medical procedure to find the cause for a urinary tract infection. We hoped to return to the Cape by midday to go sailing.

Never again will I take an afternoon of sailing, or the health of my children, for granted.

The previously invisible world of childhood cancer emerged for me as I walked the corridor to the oncology unit at Children's known as 7 West. I glanced at the cartoon characters painted on the walls and the photos of former patients, and without warning, I saw this new world.

Through the open door of a patient room, a little person was looking back at me with wide eyes made even larger by the absence of eyebrows and hair. I held on to words spoken earlier: Isabelle would receive the best and most compassionate medical care in the world. But no one could tell Denyse and me that she would be all right.

I will never forget those early days in the hospital, especially the compassion shown to us by veteran parents. While in the postoperative waiting area, a couple whose son was also in surgery overheard us say the word neuroblastoma. They seized the opportunity to introduce themselves, and then eased our greatest concern. They told us that the chemotherapy really worked for their son.

Next, the father of our hospital roommate brought me coffee and the morning newspaper before we had officially met. At that time, Isabelle would not sleep unless my wife or I lay in the crib with her, and this parent understood my dilemma. A few weeks later, we met the infamous "pasta lady" who shared the story of her daughter who was successfully treated for neuroblastoma seven years earlier. She returned every Sunday to provide food and hope to families on the oncology floors.

During her many months of treatment that included chemotherapy, radiation, surgery, and a stem cell transplant, Isabelle, our then 6-year-old son, Oliver, Denyse, and I gradually grew accustomed to hospital life. In time, Isabelle allowed Denyse and me to sleep outside her crib as long as we were always in sight. She collected kitchen condiments to decorate her food. She learned to change thermometer caps, start the blood pressure machine, and silence the infusion pump alarm. She renamed hospital gowns "on tops" as they were to be worn "on top" (and backwards) of her clothes.

When Isabelle was well enough, which was more often than not, she sang, danced, and stayed up way past her bedtime without consequence. She came to adore the nurses who encouraged her natural curiosity and playfulness, and her doctor who visited her every night to say good-bye before he left work.


Oliver, Denyse, Michael, and Isabelle Dodd

I will never forget the fear, and the long days stretched into long nights on 6 and 7 West. However, I will always hold close the memories of my family and me, hunkered down together, united in our common goal to preserve the spirit of life. We forgot the formerly all-consuming problems of ordinary living and learned to live one day, or sometimes just one moment at a time, trying to balance hope and helplessness in the face of a life-threatening illness. And we did not do it alone. We had the love and support of family, friends, hospital staff, and other families with whom we shared our accommodations and our lives.

– Michael Dodd

Michael and Denyse Dodd founded a program called "Hospital Campers," described below.

Hospital Campers program offers companionship to families of children with cancer

Through a program called Hospital Campers, held one Sunday each month, Michael and Denyse Dodd, their 8-year-old son, Oliver, and 3-year-old daughter, Isabelle, return to Children's Hospital to offer refreshments and hope to other families.

The Dodds founded the program in February 2002 after Isabelle finished treatment for neuroblastoma. Because Isabelle had required so many lengthy hospitalizations, including a month-long stay for a stem cell transplant, they eventually referred to those experiences as hospital camping. During this time they were touched by the support given by other families. Inspired by this kindness, they looked for a way that they, too, could have a positive impact on families when they need it most.

At "camp," newly diagnosed families have the chance to meet and talk with others who have ended treatment and can ask hopeful questions about reaching this milestone. "They are the light and hope at the end of the tunnel," says Kimberly Williams, who arrived cradling her 2-year-old son Jermel, who also has neuroblastoma and recently had surgery.

Inpatient families can drop by for a cup of coffee and may bring their child, who can try a craft project or join other activities. A recent gathering featured sock puppets. It is also a welcome break for parents during the weekend stays, which can seem longer without regular weekday activities.

"I remember how frightened I was when Isabelle was first diagnosed," says Denyse. "I will never forget the day I met Mary Russell in the 7 West hallway. Mary told me about her daughter, Catherine, who had received a double stem cell transplant six years earlier, and was doing fine. That gave me so much hope and strength. Today, one year after Isabelle's transplant, it is my privilege to be able to give that back."

Hospital Campers is supported by the Center for Families, the Betty Ann Blum and Marjorie Blum Pediatric Resource Room at Dana-Farber, and volunteer Paige Anderson. Meeting dates are posted on the floors of 6 and 7 West as well as in the Jimmy Fund Clinic. For more information, contact Christine Rich at the Center for Families at (617) 355-3994 or e-mail the Dodds at *hospital_campers@attbi.com.*

– Cyndi MacKinlay

Adult Patient and Family *Update*

Council News

We welcome **new members** to the Adult Patient and Family Advisory Council (APFAC): Donna Maria Cusson of Franklin, Baila Janock of Chestnut Hill, Debra Marks of Andover, and Scott Viera of Attleboro.

A pilot version of Dana-Farber's **Greeter Program,** created by the APFAC and jointly sponsored by Volunteer Services and the Dana 1 Gosman Clinic and Infusion Services group, was launched in April. The program is founded on the belief that first-time patient and family visitors greatly value a one-on-one, informative conversation with a knowledgeable volunteer who may ease their transition into the unknown territory of cancer treatment.

Volunteer greeters in the waiting areas create an opportunity for patients and families to feel welcome and to become acquainted with "who's who and what's where." While patients wait for their first medical exam or infusion session, greeters may share information about DFCI or answer practical questions about support services, cafeteria selections, or chapel services.

We helped the Friends Boutique select appropriate contents for the complimentary **Hope Bags** for female patients and **Andy Packs** for male patients. (See story on page 6.) Council members relied on their experience as cancer patients to plan for items that could offer comfort and practicality. We also helped the boutique identify resources such as vendors and funding.

We continue to visit with oncology inpatients on the 5th and 6th floors at Brigham and Women's Hospital (BWH). These weekly **rounds** enable patients to feel personally attended to, with face-to-face information exchange and conversation. Patients and family members (or partners) are excellent sources of information that the rounders relay to staff. This feedback is critical to quality of care.

In March and April, several members helped incoming patients fill out **wait-time surveys** in the Dana 1 clinical practice and infusion areas. The Institute conducts these surveys occasionally to identify the reasons that patients may have to wait, and to work on improvements.

Members of the adult council have arranged to publicize the resources available to cancer inpatients and their families on the closed-circuit television system at BWH. Inpatients can now access important resource information provided in bulletin board format on Channel 16, one of the patient education channels. The bulletin boards offer key information such as where to find resource rooms that offer support for the whole family, educational material for women and children with cancer, and how to make contact with someone who's been there through *One-to-One: The Cancer Connection.* Information on various cancer conditions and treatments can also be found on Channel 22, the Cancer Care Channel.

Resources

Feel free to stop in at the Blum Resource Center on Dana 1 to browse the following selection of websites offering patient assistance or information about advocacy organizations:

American Cancer Society:
www.cancer.org

American Society of Clinical Oncology (ASCO): *www.asco.org*

Angel Flight of New England:
www.angelflightne.org

Cancer Care:
www.cancercare.org

Compassion in Dying Federation:
www.compassionindying.org

FindCancerExperts.com:
www.findcancerexperts.com

Health Privacy Project:
www.healthprivacy.org

National Breast Cancer Coalition:
www.stopbreastcancer.org

National Cancer Institute (NCI):
www.nci.nih.gov

National Center for Complementary and Alternative Medicine (NCCAM):
www.nccam.nih.gov

National Coalition for Cancer Survivorship (NCCS):
www.cansearch.org

National Comprehensive Cancer Network (NCCN): *www.nccn.org*

New England Coalition for Cancer Survivorship: *www.neccs.org*

Patient-Centered Guides:
www.patientcenters.com

Patient Travel:
www.patienttravel.org

The Wellness Community:
www.wellnesscommunity.org

– Barbara Holtz

In memoriam: Sheila Cunningham (1926–2003)

Sheila Cunningham

Sheila Cunningham, who died Jan. 16 at Brigham and Women's Hospital with her family at her side, demonstrated her commitment to Dana-Farber by being an enthusiastic trustee, founding president of the Friends of Dana-Farber Cancer Institute, and member of the Adult Patient and Family Advisory Council.

A passionate council member, Sheila carried the message and ideals of patient advocacy throughout DFCI. She was committed to creating an ethnically diverse council and actively recruited candidates even in her last weeks. Similarly, she was a staunch supporter of the Institute's initiative to recruit women and minorities for participation in clinical trials. She helped plan the chapel on Dana 1 with its stained-glass windows, and selected art work to be hung in the clinics and on the treatment floors. She also collaborated with colleagues to improve waiting-area décor and create color schemes that would be soothing to patients.

"Parallel with her Council activity, Sheila was an advocate of the volunteer program at DFCI, often informing me of the important contributions volunteers provide to the recovery of cancer patients," says Thomas Edward, director of volunteers.

Ingersoll "Sandy" Cunningham, her husband of 56 years, joined in her volunteer activities. He cheered patients by delivering sandwiches and soft drinks at lunchtime in the infusion areas while his wife volunteered in the Friends' Gift Shop. "Sheila shared herself through her volunteer work, hospitality to out-of-town cancer patients, and devotion to family and friends," says Sandy, who still serves as a volunteer. "All who crossed her path admired her. Hers was surely a life worth living."

In addition to her husband, Sheila is survived by three brothers, five children, and 11 grandchildren.

– Barbara Holtz

Pediatric Patient and Family *Update*

Council News

Mary Rhude joined the Betty Ann Blum and Marjorie Blum Pediatric Resource Room as its new pediatric patient and family education specialist.

New patient and family education specialist Mary Rhude talks with Jimmy Fund patient Charlotte Karol, 8, and her father.

Mary, a child life specialist, comes from the Brigham and Women's Pediatric Radiation Therapy Department, so she may be a familiar face to some. Watch for many new activities and programs that Mary is working to develop. She will provide patients and families new to the Jimmy Fund Clinic with clinic tours and review patient resource information. Mary is also the new coordinator for all information about camps for children and teens with cancer. The Blum Pediatric Resource Room is located on Dana 3; phone is (617) 632-3900.

Children's Hospital Boston has added a **meditation room** for families looking for a quiet corner. Located on 8 East, this small and cozy room provides comfortable chairs where one or two people can sit quietly, read, or listen to relaxing music on a CD player. For more information, contact Summer Holubec in the Blum Resource room on 7 West at (617) 355-8079.

Jimmy Fund Clinic families who would like to venture outside the clinic can do so with a new **pager system.** The bright red, restaurant-style pagers allow families to travel a mile away or less. Ask your nurse or one of the facilitators for more information.

Calling all Teens: The American Cancer Society and Dana Farber Friend's Boutique is offering **"Look Good . . . Feel Better"** classes for young people. They provide tips on cosmetics, hairstyling during treatment, and appearance. For more information, stop by the Resource Room or call Julie Durmis in the Friends Boutique at (617) 632-2211.

The council congratulates former member Sarah Schulte and current member Lindsay Roache for their work on the Jimmy Fund Clinic **Teen Survey,** which received an honorable mention for team project at Dana-Farber's Quality Improvement Fair in March.

The Council is pleased to welcome its newest parent member, **Sheila Dollard** of Danvers.

Resources

Stop by the Blum Pediatric Resource Center on Dana 3 outside the Jimmy Fund Clinic or on 7 West at Children's Hospital to view the websites and books listed below.

This month's top book and website picks are: *Living With Childhood Cancer, A Practical Guide to Help Families Cope,* by Leigh Woznick and Carol Goodheart. "Provides precisely what the title promises. This is a wonderful book . . . full of real feeling and real stories from people dealing with childhood cancer."

— Mark Chesler, PhD, National Board Member, Candlelighters Childhood Cancer Foundation

Squirrel Tales: *www.squirreltales.com.* Started by a parent to empower and encourage parents, this site contains great resources, stories of hope, and practical tips. Visit the very funny "You know you are a parent of a child with cancer when …" Parents and patients have contributed more than 400 entries such as: "You know you are a parent of a child with cancer when you carry a tube of EMLA in your purse instead of lipstick." If you have an entry, stop by the Blum Resource Center on Dana 3 and share it with Mary Rhude to get a Jimmy Fund Clinic list going!

Books

Childhood Brain and Spinal Tumors by Tania Shiminski-Maher, Maria Sansalone, Patsy Cullen

What About Me? When Brothers and Sisters Get Sick by Allan Peterkin and Frances Middendorf

Websites

Childhood Cancer Awareness: *www.childhoodcancerawareness.org.* Order free childhood cancer awareness items including the gold ribbon. Also includes information on Childhood Cancer Awareness month (September) and other activities. You can also call 1(800) 458-6223.

Gold Ribbons for Childhood Cancer: *www.goldribbons.org.* Meet the mom who started it all in memory of her daughter, Kelsey.

Association of Cancer On-line Resources (ACOR): *www.acor.org.* Disease-specific resources and support for patients and families. Go to home page, then to disease menu.

College scholarships for survivors: *http://www.acor.org/ped-onc/scholarships/index.html*

Back to School Comments and Suggestions: *http://www.acor.org/ped-onc/survivors/index.html.* Parents comment on their child's return to school. Scroll down to Back to school, neurocognitive issues.

For teens

2bme: *www.2bme.org.* For teenagers between 13 and 16. Tips on hair loss, wigs, skin care, and appearance. Site is fun and colorful.

4Youth: *www.acor.org/4youth.html.* For young survivors 12-21 as well as for young people currently in treatment.

The Ulman Cancer Fund for Young Adults: *www.ulmanfund.org.* Learn about support groups, survivor's network, and scholarship opportunities.

Pediatric council thanks retiring co-chair

When Patricia "Pat" Dwyer, LICSW, retired from her position as associate director of the Pediatric Psychosocial Unit and stepped down from the Pediatric Patient and Family Advisory Council (PPFAC), patients, families and staff saw the light fade from a shining harbor. Pat worked for Dana-Farber for 10 years and brightened the lives of countless pediatric patients and their families. "The Jimmy Fund Clinic should have an entire staff of Pat Dwyers," said Wendy Pearson, a council member. The council bid farewell to Dwyer at its Feb. 25 meeting.

Pat Dwyer

In 1999, Pat and her former co-director Pam Hogen, PhD, helped found the PPFAC, which represents pediatric patients and family members treated in the Jimmy Fund Clinic and the oncology floors of Children's Hospital Boston.

"Pat continually impressed me with her professionalism, energy, commitment, and dedication to patient care,"' says Pam. "She brought laughter and a balanced perspective to every aspect of her job."

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Massage therapist joins Zakim Center

Attending to the whole person – not simply treating the disease – has been one of the underlying philosophies of the Leonard P. Zakim Center for Integrated Therapies. Recently, the Zakim Center announced that Maria Barbara ("Bambi") Mathay has joined the team as massage therapist.

"I always knew that I wanted to contribute to quality of life," says Mathay, who used massage and healing touch techniques to bring comfort and relaxation to her terminally ill father. "Touch is powerful, and all the more so when combined with love, compassion, and the full intention of 'being there' for someone."

The addition of massage extends the Zakim Center's range of clinical services, which include acupuncture, music therapy, nutritional counseling, Reiki, meditation training, and expressive arts therapy. Because the demand for integrated therapies has doubled in the past year, the Center now provides services four days a week in its suite of rooms on Dana 11 and in the Jimmy Fund Clinic.

Mathay graduated from the University of the Philippines Medical School and later received training at the Muscular Therapy Institute in Cambridge, Mass. She is a member of the American Massage Therapy Association and a number of other prominent organizations. In addition to serving the Dana-Farber community, she works part time at the North Shore Heart and Wellness Center (at Salem Hospital) and maintains a private practice. An experienced practitioner of Swedish massage techniques, she is trained in Reiki healing and cranio-sacral therapies, which she hopes to be able to incorporate into her practice here.

Coming to work at Dana-Farber's Zakim Center fulfills a personal and professional vision, Mathay says, whereby she can bridge the practice of conventional and alternative therapies. "I can apply my medical skills while providing a service that gives patients more choices in managing their care."

"We are excited to have Bambi on staff," says Cynthia Medeiros, LICSW, director of the Zakim Center. "Her skills and experience in massage therapy, combined with her extraordinary warmth and caring, are essential ingredients in providing patients with a sense of well-being. She helps to foster the mission of the Center – to provide interventions that help patients feel calm, relaxed, and more in control in the face of medical treatment that is often overwhelming."

One Zakim Center patient told Mathay, "Massage is a miracle that fell into my lap in the midst of cancer treatment and all that was happening to me." Another said, "I am so thankful to receive massage along with my regular, conventional treatment. It helps me cope with my illness."

For more information about the Zakim Center's complementary therapies or to schedule a massage appointment, please call (617) 632-3322.

– Barbara Holtz

Massage therapist Bambi Mathay helps patients relax.

About the Zakim Center

The establishment of the Zakim Center for Integrated Therapies in 2000 realized the vision and honored the memory of Leonard P. "Lenny" Zakim, a multiple myeloma patient and advocate for integrating complementary and alternative medicine with conventional care.

Friends Boutique provides complimentary gifts

The DFCI Friends Boutique is offering complimentary gifts for patients: Hope Bags for women and Andy Packs for men. Given free of charge as an added support to patients and their families who are navigating through the cancer experience, these gifts are available in the Friends Boutique on Dana 9 and in the Eleanor and Maxwell Blum Patient and Family Resource Center on Dana 1. In addition, they will be provided to oncology inpatients at Brigham and Women's Hospital. Pediatric gift bags are in the planning stages and will be announced when available.

Funding is provided by donations raised by Team Andy, the Friends Boutique, and the DFCI annual Boston Mararthon® Jimmy Fund Walk.

Hope Bags include:

- resource information for women;
- advice on coping with hair loss;
- a large cotton scarf, with tips on how to tie or knot it creatively;
- shampoo formulated for hair loss;
- a sink or bathtub drain filter / 'hair catcher';
- Coppertone SPF 30 sunscreen; and
- a relaxation CD.

Andy Packs include:

- resource information for men;
- advice on coping with hair loss;
- a Boston Red Sox baseball cap;
- Coppertone SPF 30 sunscreen
- a relaxation CD; and
- Estee Lauder's "Intuition" fragrance for men.

"Patients find these gifts encouraging as well as useful," says boutique Manager Julie Durmis. "Often, family members come to pick up the gifts and tell us how appreciative patients are. This is another example of how Dana-Farber makes every effort to care for the whole person instead of simply treating the disease."

For further information, or to ask about having these gifts mailed, please call (617) 632-2211.

– Barbara Holtz

Openings

It is a year ago that I was diagnosed with cancer.
Open up to love.

It is the second time I hear the words, “You have cancer.”
Open up to love.

I made it through the first time, do I have it in me to do a second?
Open up to love.

Once again, I tell my family and friends. This is the most painful.
Open up to love.

Once again, I feel the loneliness that only cancer brings.
Open up to love.

This can’t be happening. When am I going to wake up?
Open up to love.

Why? Did I do something wrong? Just tell me. I’ll change. I’ll do anything. I’ll be good.
Open up to love.

Don’t you know, I have a life to live?! I can’t be bothered with cancer!
Open up to love.

Get armed. Gather all the information.
Take charge.
Open up to love.
Open up to love.
Open up to love.

There is hope.
Opening to love.

There are people who want to help.
Opening to love.

I don’t have to go through this by myself.
Opening to love.

It is an opportunity to connect with others and to deepen in relationship.
Opening to love.

I discover strengths in myself that I didn’t know existed.
Opening to love.

I see sunsets. I hear birds. I smell trees.
Opening to love.

This is life, too. Live it to the fullest.
Opening to love.

Sometimes our hurts are the openings that allow the light to shine through,
To warm our hearts and to heal,
Even if there isn’t a cure.

Open up to love.

Keep opening.

Stay open.

LOVE

– Yasemin Turkman

Maybe One Day

Maybe one day a child diagnosed with cancer will know they will be cured.

Maybe one day when a child is diagnosed with cancer, his father will not break down and cry his heart out.

Maybe one day when a child is diagnosed with cancer, his mother will not feel the need to bargain with God so her child will live.

Maybe one day a child diagnosed with cancer will not lose years of his childhood battling for survival.

Maybe one day parents of a child with cancer will not have to hold their child down for painful procedures and listen to their screams.

Maybe one a day a child diagnosed with cancer will not have to ask: “Why do they need to hurt me to help me?”

Maybe one day a child diagnosed with cancer will not have to go to school without hair and worry that classmates will tease him.

Maybe one day a child diagnosed with cancer will not have to take medication that causes his coordination to leave him and to trip and fall, hurting him and his self esteem.

Maybe one day cancer therapy will not jeopardize the lives of our children.

Maybe one day a parent will never have to wonder what their child’s potential might have been.

Maybe one day we will never listen to another eulogy for a child who dies from cancer.

Maybe one day there will be no more cancer … Maybe one day.

Dedicated to “our small soldier, Andrew”
– Cyndi MacKinlay

Pat Dwyer retires

continued from page 5

Pat and Pam believed that the collective experiences of patients and families who have gone through treatment could be a way to improve programs in the future. They also recruited senior leaders to join the council. This collaboration of patients, parents, and staff brought about many initiatives, such as the Emergency Department “Fast Track,” improvements to the process by which patients and families end treatment; and the teen survey, the results of which led to changes to the teen wait area and will be included in the Jimmy Fund Clinic renovations.

Former Jimmy Fund Clinic patient Katie Egan, 14, who was diagnosed with Ewings sarcoma in 1998, says, “I have many good memories of Pat. She was easy going, a great listener, and made me feel so important. She knew just how I was feeling and how to comfort me.”

Pat received several appropriate gifts from fellow council members. One was a metronome to inspire her goal to play the piano during retirement. Council Co-Chair Nancy Stratton said, “We hope each time you sit down to play the piano, this gift will serve as a reminder of your gift to the Institute.”

The other was a life preserver, inscribed with her name and DFCI and presented by council member Gary Jernegan. “For so long, you have provided an anchor and a safe harbor to so many children and families,” he said. “Your ability to take hold of someone’s hand and steer them through turmoil is worth its weight in gold. There is no way for people like me to ever repay people like you. We can only try to give you back what you so willingly gave to us.”

– Cyndi MacKinlay

Free flights for patients, families

Patients and families who travel long distances to Dana-Farber can fly free of charge, thanks to Angel Flight Northeast, a nonprofit organization that utilizes private aircraft and volunteer pilots. With the motto “Getting there should never be an obstacle to getting better,” Angel Flight arranges flights throughout the United States and most of Canada. Patients who are unable to travel by car because of their medical condition, or who live in a remote area, may benefit from this and other services such as AirLifeLine. For more information on Angel Flight, please call (800) 549-9980, or visit the web site: *www.angelflightne.org.* AirLifeLine can be reached at (877) 247-5433 or at *www.airlifeline.org.*

side by side

Spring **2003**

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Comments may be sent to:

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call (617) 632-4319 (adult)
or (617) 632-6143 (pediatric)
e-mail *pfac@partners.org*
visit *www.dana-farber.org*,
Patient Care, Support Services section

Let us know if you'd like to be on our mailing list or if you'd like to be taken off.

If you are a patient or family member who would like to be involved in planning, decision making, and improvement efforts at Dana-Farber and its affiliates in cancer care, please consider joining one of the advisory councils.

Spring
2003

Speak Up Campaign can help patients become involved in their own care

In March 2002, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), together with the Centers for Medicare and Medicaid Services (CMS), launched a nationwide program to urge patients – together with their families and caregivers – to take a role in preventing health-care errors by becoming active, involved, and informed participants on the health-care team.

One year later, this program has borne fruit. Health-care organizations are now distributing printed materials for patient waiting areas, sponsoring local public service announcements, and sharing essential safety tips on closed-circuit patient education TV stations.

Highlighted recently during National Patient Safety Awareness Week, this campaign features brochures, posters, and buttons with the *Speak Up* message.

- **S**peak up if you have questions or concerns and if you don't understand, ask again. It's your body and you have a right to know.
- **P**ay attention to the care you are receiving. Make sure you're getting the right treatments and medications by the right health-care professionals. Don't assume anything.
- **E**ducate yourself about your diagnosis, medical tests you are undergoing, and your treatment plan.
- **A**sk a trusted family member or friend to be your advocate.
- **K**now what medications you take and why you take them. Medication errors are the most common health-care errors.
- **U**se a hospital, clinic, or other type of health-care organization that has undergone a rigorous on-site evaluation and has established, state-of-the-art quality and safety standards, such as those provided by JCAHO.
- **P**articipate in all decisions about your treatment. You are the center of the health-care team!

The campaign encourages patients be aware of safety issues and to "speak up" in order to avoid problems in advance.

Speak Up is a service mark of the Joint Commission on Accreditation of Healthcare Organizations. For more information, please visit the website: *www.jcaho.org.*

– Barbara Holtz

Side by Side Founder *Geri Malter*

The late Geri Malter

Each issue of the patient advocacy newsletter, *Side by Side*, is dedicated to the memory of Geraldine "Geri" Hass Malter (1945–2002). Geri was a founding member of Dana-Farber's Adult Patient and Family Advisory Council in 1998 and the visionary who created *Side by Side* and managed its quarterly publication from 1999 until her death in 2002.

"One might wonder why, after many years of treatment including surgery, chemotherapy, and radiation, I would want to continue my involvement in the cancer world during my times of wellness," Geri wrote in her first editorial. "Like other members of the council, I wanted to give back and perhaps help other cancer patients navigate smoothly along a very rough road."

As a teacher, creative thinker, and prolific writer, Geri's vision was that *Side by Side* would continue to be a premier publication for patient advocacy. This publication is her living legacy.