

Measuring Compliance with  
Breast Cancer Post-Therapy  
Surveillance | 34

Bridging the Gap from  
Inpatient to Outpatient  
Care | 42

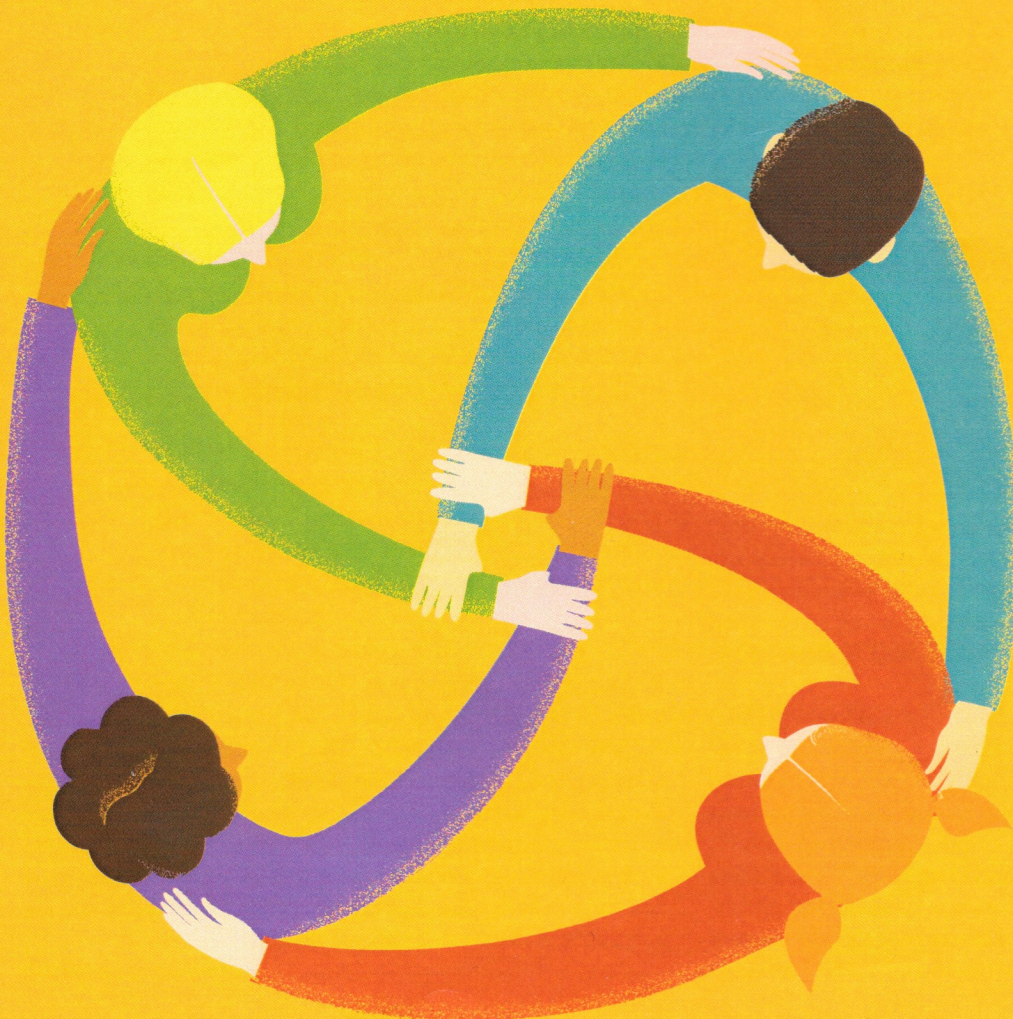
Exploring New Options for  
Prostate Cancer Detection &  
Diagnosis | 48

# ONCOLOGY ISSUES

This publication is a benefit of membership  
Association of Community Cancer Centers

November | December 2016

## Growing Supportive Care Services Through Philanthropy



## *A community comes together to meet the needs of its cancer patients*

**A**n estimated 14.5 million cancer survivors live in the U.S. today, and that number is expected to increase to 19 million by 2024.<sup>1</sup> Previously considered a death sentence, cancer is now viewed as a treatable, sometimes curable, cluster of diseases. Cancer is also regarded as a chronic illness, with greater emphasis on managing late effects and enhancing quality of life (QOL). Side effects from cancer—and cancer treatment—include physical, psychological, social, spiritual, and financial concerns, which have potential long-term impact on cancer patients and their families. As a consequence, cancer survivorship is now a public health issue.

Increasingly, cancer survivors are seeking guidance and support as they transition out of active treatment into ongoing surveillance and a return to “normal” life. These individuals seek services and tools to help them to adjust while maintaining wellness in the post-treatment phase of life.

In 2002 *CA: A Cancer Journal for Clinicians* reported that “increased use of outpatient services for cancer treatment, shortened hospital stays, longer survival, and the rise in the number of patients receiving home health services have created a greater need for assistance with regard to transportation, home medical care, activities of daily living, and out of pocket expenses.”<sup>2</sup> The authors went on to further describe that community-based and philanthropic organizations often provided cancer patients with essential services that were unavailable from traditional medical services.

---

The hospital foundation strategically cultivates relationships with generous donors to understand and be true to the donor’s interests and desires. To support these efforts, the hospital foundation develops “menus of giving” that suggest services donors can support.

---

### **A Changing Landscape**

Research suggests that as many as 90 percent of cancer patients use some form of integrative medicine compared to 40 percent of the general population.<sup>3</sup> Historically, cancer patients were often challenged to find these integrative services on their own; oncology providers were often unaware of the additional services pursued by their patients. It soon became clear to providers that they must find ways to bridge the gap between traditional medicine and the integrative medicine that patients desired.

*(continued on page 29)*



# PATIENT AND FAMILY SUPPORT SERVICES PROGRAM



## 2015-2016 Patient and Family Support Services Program Highlights

Launched in 2011, the OHSU Knight Cancer Institute's Patient and Family Support Services Program has grown and thrived because of generous gifts from many contributors. Under the leadership of Susan Hedlund, M.S.W., L.C.S.W., and with cumulative philanthropic support we have been able to sustain, expand and create a range of patient- and family-centered support and care programs. This past year, we:

- Launched drop-in stress management breath-by-breath class in addition to offering ongoing mindfulness based stress reduction classes. Mindfulness is a practice of moment-to-moment observation, and can be highly effective in helping bring calm and clarity to the pressures of daily life. This is a powerful adjunct to therapy or medical treatment, and has proven beneficial for health conditions such as cardiovascular disease and chronic pain disorders.
- Offered three popular yoga classes, including gentle yoga for women healing from cancer. Classes are taught by a nationally certified cancer yoga teacher.
- Expanded acupuncture services to Knight Community Hematology Oncology clinic in Beaverton.
- Created, under the leadership of social work team members Nancy Boyle and Keren McCord, a quarterly well-attended cancer survivorship series for patients with hematologic malignancies. Topics have included: dealing with cancer and treatment related fatigue, chemo brain, exercise.
- Collaborated with a program dietician to pilot healthy cooking classes for breast and gynecological cancer survivors.
- Moderated successful therapeutic writing groups for adult patients and added a new program specifically for adolescent and young adult oncology patients and survivors.
- Partnered with Children's Healing Art Project to provide inpatient art therapy to help patient and family members reduce stress, pain, isolation and anxiety.
- Continued to fund a massage therapy program for inpatient with plans to expand to offer massage in outpatient clinics.
- Provided nearly \$70,000 in emergency patient assistance to help with transportation, medication and lodging costs.
- Established the Jill Austin Cancer Pain Management Fund to support educational, research and care initiatives to help patients with cancer pain return to their highest level of functioning and to help them restore their quality of life.

(continued from page 27)

Recent trends in cancer care delivery also suggest there is increasing awareness of—and need for—services beyond those historically provided by cancer programs. This article describes the experience of one NCI-designated Cancer Center that has received extensive philanthropic funds to develop supportive care services for cancer patients.

### Our Story

Five years ago, the Knight Cancer Institute at Oregon Health & Sciences University (OHSU), Portland, Ore., created a department within the cancer center called Patient & Family Support Services. Recognizing the need to create services that supported patients and families through the continuum of treatment and into survivorship, the new program had the backing of hospital leadership, as well as the philanthropic support of the hospital's foundation.

Indeed, the hospital foundation provided essential early support into program development. For example, in 2010, when conversations began about the need for supportive care services beyond medical treatment, the foundation helped recruit leadership for this program, and promised to provide funding for half of this FTE position for the first three years. The hospital made a commitment to pick up the funding for that role after the first three years. Soon, patients, families, and cancer program staff began to ask how they could make donations specifically for patient support.

At that time, in addition to 5 social workers, we offered one yoga class, thanks to an estate gift that specifically acknowledged the benefit of yoga in cancer recovery. This program was continued largely through the support of an oncology nurse who also believed in the programs' benefits.

Fast forward to today, our cancer program has experienced unprecedented growth in recent years. Over the past five years we've developed a robust program of supportive care services, including 12 oncology social worker positions (10.7 FTEs) funded by the hospital—essentially doubling our social work staff.

### Expanding Our Services Through Philanthropy

The hospital foundation strategically cultivates relationships with generous donors to understand and be true to the donor's interests and desires. To support these efforts, the hospital foundation develops “menus of giving” that suggest services donors can support. Below are some of the supportive care services we've been able to fund through philanthropy.

**Emergency assistance fund.** Our oncology social workers assess all cancer patients for financial need and then recommend assistance based on this assessment. Each year patient need increases. (Of note, Oregon is primarily a rural state, and we are the only academic medical center in the state and the only cancer center with NCI-Cancer Program designation.)



High school senior Krysta Kilmer (left) raised funds for the Patient & Family Support Services program in honor of her mother and cancer survivor Mary Kilmer (right). The family benefited from the program when Mary traveled to the Knight Cancer Institute at Oregon Health & Sciences University from her home in Idaho for treatment and wanted to pay it forward. Accepting the generous donation is Nancy Boyle, LCSW.

One grateful patient asked her oncologist how she could help other patients. He directed her to the hospital foundation, and in 2011, the patient hosted the first of what has become an annual fundraiser. Hosted at the patient's catering business during the holidays, *Wine, Dine, and Be Merry* is now in its fourth year and is well-attended by hospital and cancer program staff, patients, families, and friends. Much of the funds raised at this annual event support a Patient & Family Emergency Assistance Fund. This fund has proved to be critical for serving some of our most vulnerable patients. This past year alone we provided approximately \$60,000 of emergency assistance to patients. Most assistance went towards providing housing and/or transportation to patients who would not have been able to access care.

Recently two other family foundations have offered generous philanthropic support to the emergency assistance fund. The Dominic Fouts Memorial Cancer Fund uses their gift to honor the brother of the foundation's administrator, who died of cancer at age 34. The Bess Spiva Timmons Foundation also supports this important fund.

**Integrative therapies.** Another OHSU patient, who had been a childhood cancer survivor, and was now being treated for CML as an adult, had a family foundation. He met with representatives from the hospital foundation and asked how they might partner together. He and his wife were specifically interested in the use of integrative therapies to accompany traditional medical treat-

(continued on page 31)



## A Special Report August 2016

### Fund Purpose and History

Established in October 2015, the Jill Austin Cancer Pain Management Fund provides vital support for educational, research and care initiatives to help patients so that they are able to return to their highest level of functioning and to help them restore their quality of life. Gifts to this fund make a huge difference in the lives of these patients and their loved ones.

### Your Support

Thank you for supporting the Jill Austin Cancer Pain Management at the OHSU Knight Cancer Institute. Nearly one-third of the patients treated for cancer experience pain, which may significantly alter their quality of life. Acute or chronic pain affects basic daily activities becoming a contributing factor to fatigue, depression and stress. The OHSU Knight Cancer Institute and the OHSU Comprehensive Pain Center are committed to making sure that all cancer patients who experience pain have access to resources and care to reduce their pain and return to their day-to-day activities. When pain is controlled people may eat and sleep better and participate in the daily activities that are meaningful to them. For

“Jill always gave to others and never asked anything in return. In this loving spirit we hope to help ease the pain of others. **Thank you for your support.**”

— *The Sorenson Family*

loved ones who support cancer patients during treatment this relief may provide an immeasurable sense of comfort. Your support is making it possible for OHSU to develop and implement strategies to specifically address care, education and research initiatives around cancer pain management.

It is important to OHSU and the Sorenson family that you know how your support is making a difference. Please read more about the impact your gifts are making.



**Jill Austin**

In memory of Jill, Richard Sorenson, her widower, created the Jill Austin Cancer Pain Management Fund to help others who suffer from debilitating pain. Jill was the life of the party, up for new adventures, and constantly playing and laughing with her grandchildren. She loved gardening, hosting big parties, being a wonderful mother, and a devoted friend to countless people. Before Jill lost her battle with cancer, the pain took away her amazing quality of life—it took her life before cancer did. This gift is to help patients and their loved ones become better equipped to conquer pain associated with their cancer.

— *The Sorenson Family*

(continued from page 29)

ment. Through the family foundation's gift, we were able to add two additional yoga classes and a program on *Mindfulness-Based Stress Reduction*.

**Massage and healing touch.** As Patient & Family Support Services continued to evolve, we found that financial gifts inspired other, larger gifts. Simply put: our cancer patients very much wanted to help other cancer patients. Two former patients—both with hematological malignancies treated with bone marrow transplantation—worked as national marketing representatives for Nike, the athletic company. They approached us and indicated that they were having an annual fundraiser, and wanted our cancer program to be the recipient of this benefit.

---

As Patient & Family Support Services grew, we wanted to be sure that the services we offered were in line with the needs of patients and loved ones. To do so, we conducted five focus groups with cancer survivors in 2014.

---

When talking with these former patients about what was important to them, one indicated that the only time she was touched “non-medically” during transplant was by the oncology massage volunteer.

The benefit raised \$85,000 for our cancer program, and we committed all funds to grow our cancer massage services. We now have five oncology-trained massage therapists who work part-time on our inpatient oncology units and in the outpatient oncology clinics. We also have a massage internship program for licensed massage therapists seeking to learn the specialized skills needed for working with an oncology population.

We have begun to evaluate the impact of massage for our oncology inpatients by administering a pre- and post-massage survey to measure the impact of massage on the patient experiences of anxiety, fatigue, and pain.

Last year, we provided 1,434 massages on our inpatient oncology units. The results have been impressive. Before implementing this service, 22 percent of patients reported high levels of anxiety; only 8 percent reported anxiety after. We saw similar improvements in pain scores: 22 percent of patients reported pain before massage services were added, and only 10 percent reported pain after implementing the massage program. We also realized an improvement in patient-reported fatigue, with 21 percent of patients reporting fatigue prior to these services, and

17 percent reporting fatigue after. Clearly the addition of massage services helped to reduce the distress of our cancer patients.

**Pain management.** Another donor gifted money and helped raise funds to support our Jill Austin Cancer Pain Management Fund, in the hope that cancer patients will not have to suffer as a result of cancer-related pain. To meet this need, the oncology program is partnering with the hospital's department of anesthesiology to develop a program to improve treatment of cancer-related pain and ensure patient access to these critical services. See box at left for more on this fund.

### Adding the Right Staff

Through philanthropy, the Patient & Family Support Services was able to hire its first acupuncturist. The hospital agreed to pay for the acupuncturist on a part-time basis until she was able to be largely self-supporting through billing. Cancer program staff navigated the acupuncturist through the credentialing process and set up billing mechanisms for her services. We hired a practitioner who had been an oncology nurse in our healthcare system prior to becoming a licensed acupuncturist and naturopath. This decision was critical because she understood cancer, cancer treatment, and the related side effects. While she is currently practicing as an acupuncturist, Patient & Family Support Services is exploring how we might add her naturopathic skills to our practice setting.

It has been important to recruit integrative medicine providers who are willing to collaborate with more traditional Western medicine practitioners. Thus, in the massage program, we set the bar high by requiring that the massage therapists had specific and in-depth training in cancer-specific massage techniques.

Our mindfulness-based stress reduction and yoga teacher has extensive experience working with cancer patients, offering trainings at Duke University, as well as having one of the first evidence-based NCI research studies on the efficacy of mindfulness-based intervention for cancer patients.

These staffing choices have been intentional, and have resulted in great acceptance and support of services that could potentially be perceived as “unconventional” by providers and staff.

### Identifying New Needs

As Patient & Family Support Services grew, we wanted to be sure that the services we offered were in line with the needs of patients and loved ones. To do so, we conducted five focus groups with cancer survivors in 2014. We also conducted a one-month survey of cancer survivors inquiring as to what services they most wanted to see added. The results from 374 patients surveyed identified these top three needs:

- Fitness classes: 18 percent
- Nutrition classes: 18 percent
- Traditional support groups: 12 percent.



Knight Cancer Institute's Patient & Family Support Services benefits greatly from the ongoing philanthropic support of its community. In 2010 and 2011 Patty Reed, owner and president of Patty Reed Designs, gave generously in support of breast cancer research and patient care. (Reed is pictured holding the check.)

Additional feedback from the focus groups reflected the desire for classes on chemotherapy-related cognitive changes, fatigue, stress management, and integrative medicine. All have been added as a result.

We have since added expressive arts to our service line offerings. Currently, we offer three writing groups: one for women with cancer, one for men with cancer, and one for adolescents and

young adults with cancer. All groups are led by trained writing facilitators. Our experience is that these groups are often attended by people who might not attend more traditional support groups.

- Patient & Family Support Services also supports:
- A large and active prostate cancer support group—11 years strong—and a support group for young adults with cancer
  - A healing arts program on the inpatient transplant unit

- Survivorship classes
- A “Cooking for Wellness” monthly pilot in conjunction with the Center for Women’s Health and the hospital’s Nutrition Department
- Classes on dealing with fatigue, chemo brain, and intimacy issues after cancer.

All services are offered free-of-charge with the exception of acupuncture, which is a fee-for-service offering, and the mindfulness-based stress reduction, which is offered at half the normal cost for the series.

### Sharing Lessons Learned

Hospital foundation leaders share that there is sometimes a misconception that “things just happen,” meaning supportive care services simply get created. The reality: it takes people who understand the needs and wishes of people with cancer, combined with the required resources, to create these services. It is simply not realistic to expect that all of these resources can come from within the hospital system itself, which is often managing multiple competing priorities.

Leveraging philanthropy to seed fund some of these supportive care programs helps lay the foundation for programs that ultimately become self-sustaining, as was the case for our acupuncturist. In other instances, the supportive care programs inspire ongoing and larger gifts. Family foundations, memorial gifts, and/or the desire to leave a legacy are all aspects of philanthropic support.

Another lesson we can pass on is the critical nature of relationship building. It has been essential for Patient & Family Support Services to maintain and proactively seek relationships with our donors on a personal level. We cannot emphasize enough that being “good stewards” to the donors’ intent is of utmost importance. Letting donors know how funds are received and used and how their gifts truly make a meaningful difference in the lives of patients is essential.

We make a concerted effort to let donors who cannot give large amounts know that every gift makes a difference. For example, a gift of \$25 immediately becomes a gas card to help a patient get to treatment.


An inspiring component of this evolution is how much our staff, who spend each day working with oncology patients and their loved ones, want to support Patient & Family Support Services. Staff attend our annual fundraiser—both as volunteers and donors—and are enthusiastic about their support. It is inspiring and humbling to see their efforts.

Staying current with what patients need and want is also important as cancer patients and survivors have a range of needs. Periodic focus groups and surveys help us keep our fingers on the pulse of those needs.

Relationships between Patient & Family Support Services and

key foundation directors are also essential. We offer education to members of the hospital foundation about our current offering of supportive care services; the foundation has found this ongoing education helpful to make solicitations. Patient & Family Support Services has also created print materials and reports to share with potential donors (see pages 28 and 30). Finally, sharing patient stories of how lives have been touched by these supportive care services is powerful. We keep our momentum going by being available to meet with donors, giving community presentations, and, most importantly, always expressing gratitude.

Most people with cancer and their loved ones tell us that it takes more than medicine to help them heal. The role of supportive care services cannot be underplayed, yet expecting our hospitals and health systems to pay for this support is unrealistic. We are so fortunate that donors in our community have stepped up to help, supporting our efforts to create a robust offering of supportive care services to our patients and their loved ones.

The most critical takeaway for cancer programs looking to leverage community philanthropy is this: prepare for it to be an ongoing endeavor. Fundraising is not a single event in time. Building on relationships with donors, measuring the impact on cancer patients, soliciting patient feedback, and letting donors know that their gifts indeed change lives is essential. 

*Susan Hedlund, MSW, LCSW is manager, Patient & Family Support Services, Oregon Health & Science University, Knight Cancer Institute, Portland, Ore.*

### References

1. Alfano CM, Rolland J. Recovery issues in cancer survivorship: a new challenge for supportive care. *Cancer J.* 2006;(12)5:432-443.
2. Shelby RA, et al. The role of community-based and philanthropic organizations in meeting cancer patient and caregiver needs. *CA Cancer J Clin.* 2002;52(4):229-246.
3. Yates JS, et al. Prevalence of complementary and alternative medicine use in cancer patients during treatment. *Support Care Cancer.* 2005;13(10):806-811.

