

# SURVIVORSHIP MIDWEST STYLE

BY SANDRA CARBONE

Cancer survivorship as a distinct phase of the continuum of care has drawn much public attention since the Institute of Medicine's 2005 landmark report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, which motivated cancer centers of all types to establish survivorship programs.

Multidisciplinary, integrative care has always been at the center of services at Indiana University Health Goshen Center for Cancer Care. Formed in 1999 to serve the residents of Northern Indiana, Goshen Center for Cancer Care offers medical, surgical, radiation, and naturopathic oncology, onsite diagnostics, and supportive care services, including dietitians and complementary therapy all in one building. Approximately 1,200 new patient consultations are provided annually. Treatment planning for cancer patients is patient centered and begins at weekly prospective planning conferences where all members of the team participate.

## Program Development

With the cancer center's history of dedication to innovative, patient-centered care, development of a cancer survivorship program was a natural next step. In spring 2008 at the annual cancer survivor celebration, Joseph Gagliardi, senior vice president, announced that the cancer center would be developing a survivorship program and invited former and current patients to contribute ideas for what the new program would offer. By August 2008, a survivorship coordinator was hired to begin the process of developing the survivorship program. Funding for the survivorship program was included in the cancer center's Integrative Care budget.

Focus groups followed, composed of 55 cancer patients and family members. The groups produced a wealth of ideas that provided the basis for the new program. Some focus group members offered to serve as volunteer members of the Coordinating Committee to help guide program development. By January 2009, the first survivorship newsletter, "The Link for Hope," was published. The name for the newsletter, developed by Coordinating Committee members, was seen as a statement on survivorship—that linking survivors together gave them hope for the future.

"The Link for Hope" includes cancer-related information from the cancer center's medical oncologists, naturopathic physicians, dietitians, and mind-body counselors. Each issue also includes a story of hope, written by a survivor who shares how he or she has adjusted to the "new normal." The newsletter also connects patients to survivor resources such as *CANCERcare*® Connect workshops, Relay for Life events, Look Good—Feel Better classes, and other health-related opportunities. "The Link for Hope" is now mailed bi-monthly to more than 3,000 homes, and is distributed electronically to network members and 1,400 IU Health Goshen colleagues.

## Outreach Efforts

In January 2009, the cancer center hosted a *Join the Network Night*, an opportunity for survivors and family members to share a meal and learn more about healthy living. Response to the first event was encouraging, with over 120 attendees.

Social gatherings are an important part of the Survivor Network, offering opportunities for new patients and long-term survivors to meet and share experiences. *Join the Network Night* was held again in 2010 and effectively helped build membership and increase visibility for the new survivorship program. Both events offered attendees an opportunity to hear the latest in cancer advances from a cancer center oncologist. A December holiday celebration was established in 2009 and continues. This annual event features a survivor speaker, catered lunch, musical entertainment, and a survivor ornament to celebrate survivorship. All events are



The Survivor Network often hosts displays with cancer education materials at Goshen Center for Cancer Care-related events. Pictured at the annual Run for Research event is Cancer Survivorship Coordinator Sandra Carbone (left) with Emmy Conley, member of the Survivor Network Coordinating Committee.

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provided free of charge to an audience of 150 survivors and family members.

Providing education and information was a top priority for the new survivor program. In 2009 a local attorney presented at a *Lunch & Learn* to educate survivors about the Americans with Disabilities Act and the employment rights of cancer survivors. Attendees received copies of the booklet, “Working It Out,” by Barbara Hoffman, JD, available from the National Coalition for Cancer Survivorship. The survivorship program distributes no cost educational materials from the American Cancer Society, the Leukemia & Lymphoma Society, the National Coalition for Cancer Survivorship (Cancer Survival Toolbox), and the National Cancer Institute.

In 2010 the Network continued to connect survivors to education and resources through the addition of a survivor-specific website: [www.goshensurvivors.org](http://www.goshensurvivors.org). This site allows

the Network to provide up-to-date news, education, and information that can be accessed at the survivor’s convenience—anywhere, anytime. The site had nearly 1,200 site visits in the first six months it was operational.

### Beyond Support Groups

In the focus groups, patients had requested a mechanism to provide encouragement and support for one another in a format outside of the support groups offered by the cancer center’s counselors. Two strategies were developed to meet this request:

- Creation of a structure and guidelines for off-site, informal self-help friendship groups
- Development of a Survivor Buddy program, for one-to-one support.

**At Goshen Center for Cancer Care, patients are considered survivors from the moment of diagnosis, and the survivorship coordinator is available to all patients beginning with their first visit to the center. New patients typically receive a personal welcome from the survivorship coordinator and are introduced to the integrative care model, as well as offered information about support services and the opportunity to have a Survivor Buddy. Interested patients can join the Goshen Cancer Survivor Network, which has enrolled more than 1,700 patients to date. HIPAA issues were addressed by including a *Join the Survivor Network* enrollment form in all new patient paperwork packets.**



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**A collaborative effort with the Leukemia & Lymphoma Society has recently been established to provide an educational seminar and dinner in 2012 at no cost for hematology patients in Northern Indiana. Grace Suh, MD, medical oncologist at Goshen Center for Cancer Care will present the educational program designed to promote understanding of hematologic cancers.**

One-on-one support is available through the Survivor Buddy program. Cancer Survivorship Coordinator Sandra Carbone (left) with volunteer "Buddy" Nancy Leichty.



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The first friendship group was *Mujeres De Esperanza*, for Spanish-speaking female cancer survivors. The Survivor Buddy program began in April 2009, and was offered to new cancer patients at the cancer center. The Survivor Buddy program expanded on a previous program, which provided support to patients through contact with another patient with similar treatment experiences.

There are now two additional friendship groups: *PINK-Positive Influence N Knowledge* for women breast cancer survivors, and *CanSurvivors*, a group of retirees with winter homes in Estero, Fla. All three friendship groups were started by IU Health Goshen Center for Cancer Care patients who wanted to encourage other cancer survivors. The Survivor Buddy program has been successful with 30 trained survivors providing encouragement and support to 82 new patients.

### **Beyond Treatment**

Another important initiative of the new Network was the development of treatment summaries and survivor care plans for patients completing treatment. A team from Goshen Center for Cancer Care attended the 2009 final conference of the NCI-funded national project, *Survivorship Education for Quality Cancer Care*, conducted by City of Hope National Medical Center in Duarte, Calif. The team consisted of the new survivorship coordinator and a RN, OCN. The team returned with formal goals to advance the cancer center's new survivorship program, including:


- Establishing a treatment summary and survivor care plan
- Recruiting a physician champion to endorse the survivorship program
- Educating cancer center colleagues about survivorship issues.

A team of colleagues and cancer center physicians formed a process improvement group to determine how to move forward with the provision of treatment summaries and

survivorship care plans. After nine months of planning, two pilots were launched, one for medical oncology patients and one for radiation oncology patients. Survivors were scheduled with a nurse practitioner for a follow-up visit. Copies of the treatment summary and care plan were given to the patient and also sent to the patient's primary care physician. Patients were also given the NCI booklet, "Facing Forward: Life After Cancer Treatment." The pilots were completed in 2011 and are now being transitioned to a new electronic medical record (EMR) system, which will dramatically reduce the time required to create the documents.

Two continuing education classes focused on cancer survivorship issues were provided to nurses and other health system colleagues, and an online class is available for all health system colleagues.

A program to provide supplements recommended by the cancer center's naturopathic oncologists at no cost to new patients with limited income, was established in October 2010, with the creation of the Patient Supplement Fund. Original funds to start the program came from family and friends of loved ones who did not survive their cancer battles. Since then, the fund has received donations from the Goshen Hospital Auxiliary, local civic organizations, businesses, Network members, and others. Currently, the fund has more than \$15,000 available to benefit patients, and an active fundraising effort is being conducted by the Network Coordinating Committee.

To learn more about the IU Health Goshen Cancer Survivor Network, visit: [www.goshensurvivors.org](http://www.goshensurvivors.org) or call 866.775.4673. 

—Sandra Carbone is cancer survivorship coordinator with Indiana University Health Goshen Center for Cancer Care, Goshen, Ind. She was a team participant at the 2009 final conference of the NCI-funded national project Survivorship Education for Quality Cancer Care, which was conducted by City of Hope National Medical Center, Duarte, Calif.