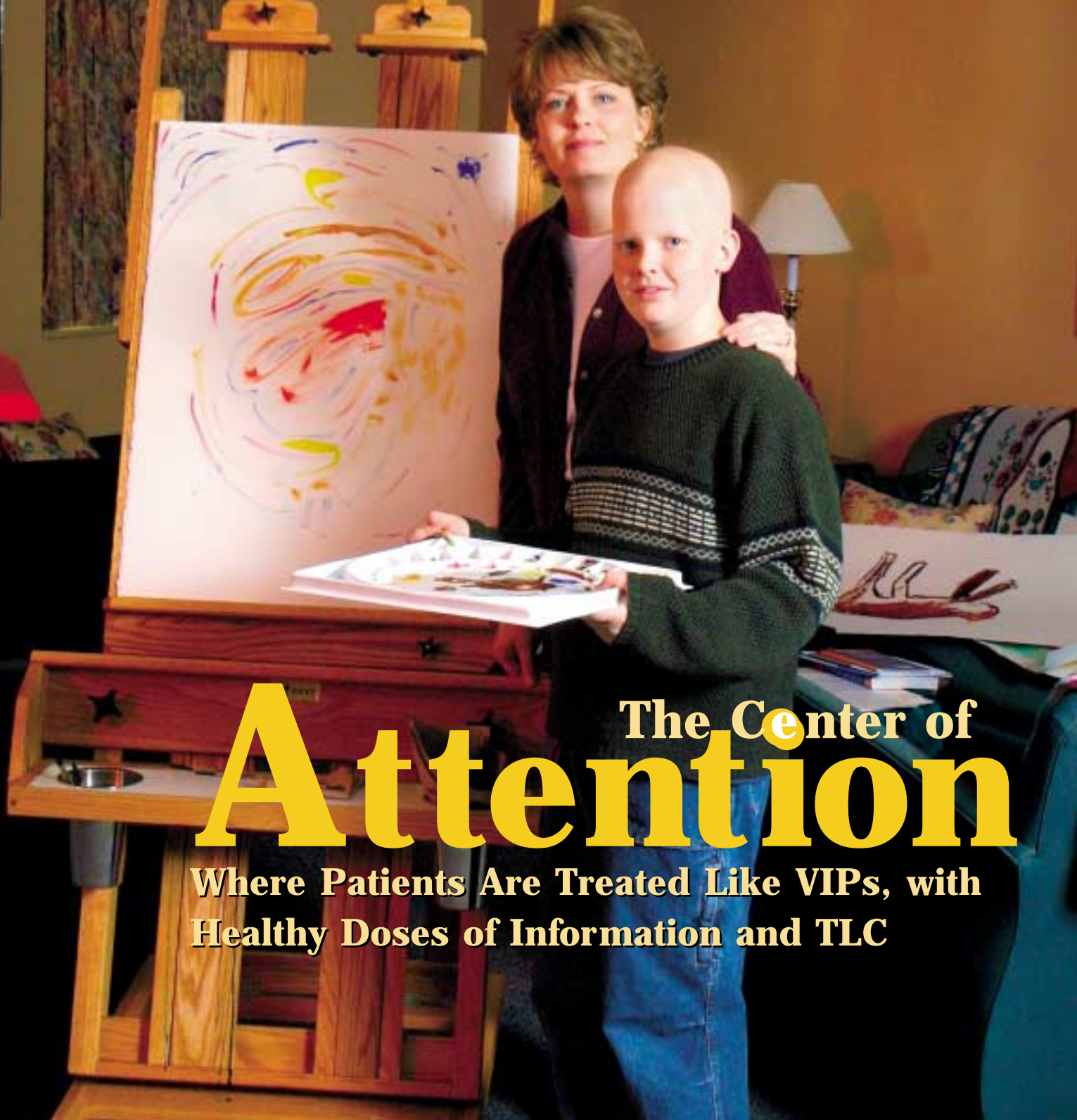


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The Center of **Attention**

Where Patients Are Treated Like VIPs, with
Healthy Doses of Information and TLC

C o v e r S t o r y

The Center of Attention

By Colleen M. Karuza

“Most of our first-timers come looking for answers, but they’ll often return for our special brand of TLC,” smiles Elaine Bauer, Manager of the Community Cancer Resource Center (CCRC) at Roswell Park Cancer Institute.

The CCRC, located on the second floor of the Hospital, was created to help visitors locate helpful, timely and accurate information on cancer. With a generous start-up donation of over \$100,000 from West-Herr Automotive Group, the CCRC opened in 1999.

Ms. Bauer says that there’s a good reason why the Center is called a *community* cancer resource. Anyone, including health care professionals and non-Roswell patients and their families, can take advantage of the many resources the CCRC provides.

Visitors can search the National Cancer Institute’s PDQ cancer information database for clinical trials; select cancer-related publications; borrow books and videos; browse the updated news bulletin boards; and find information on virtually any aspect of cancer screening, prevention, diagnosis, treatment and supportive care.

Looking for statistics on rare cancers such as ocular melanoma or thymic carcinoma? “If the disease exists, so does the information,” reassures Ms. Bauer, who pulls from her shelves unwieldy reference books such as **The Textbook of Uncommon Cancers** or **The Principles and Practices of Oncology** for visitors hungry for information. Want to know what a prostate or breast tumor feels like in its early stages? The Center has

“We don’t want to give anyone a mixed message or inadvertently promote questionable practices or therapies,” said Ms. Bauer.

Physicians and nurses tend to be the greatest sources of information for cancer patients and their families, but sometimes even the most compassionate, knowledgeable health care professional is not always able to answer questions or locate important resources that fall outside their realm of expertise. “We’re here to provide guidance on how to properly access, correctly interpret and effectively personalize the wealth of information that is available,” said Ms. Bauer. “We are not medical professionals, and don’t pretend to be.”

In a large room painted in a warm shade of “summer melon,” trained Cancer Information Specialists Jaina Ruffino and Diana Litzinger welcome a new batch of patients and their families – and a loyal band of repeat visitors – each day. Today, Pachelbel’s familiar *Canon in D* plays, almost inaudibly, in the background. Walk in, and the room instinctively feels like home, with soft lighting, pretty drapes, comfortable sofas and chairs, handmade quilts, plump pillows (some embroidered with the mantra “Nothing is Impossible”), curio cabinets, framed posters, and even a few computers.

“The computer area is a big draw for both first-time and repeat visitors,” notes Ms. Ruffino, pointing out three state-of-the-art computers, each at its own workstation. The computers have internet access, make fast connections, and are hooked to a color printer. The book, **Oncology and**

“Most of our first-timers come looking for answers, but they’ll often return for our special brand of TLC.”

“hands-on” palpation models donated by several pharmaceutical companies. Don’t know where the pancreas is located? The CCRC staff will give you a copy of **Gray’s Anatomy** to consult.

Each resource – whether a book, videotape or recommended website – is reviewed by RPCI’s physicians before it is shared with visitors.

*Cancer Information Specialist
Jaina Ruffino*





Hematology: Important Websites, is placed at each station for easy reference.

While most visitors typically “surf” for cancer information, some use the computers to do nothing more than check or send their emails. “We had one patient tell us that with email access, she only had to ‘tell her story once’ and copy it to a wide network of friends and family members. Multiple phone calls would have cost her dearly in long-distance bills,” says Ms. Litzinger. The staff often show patients and family members how to set up free email accounts with Yahoo. Software has also been purchased to design personalized greeting cards to send to loved ones.

Visitors who walk in wearing the face of confusion, frustration or fear (“We can sense those who are having an especially bad day,” said Ms. Bauer.) are handed complimentary CDs of classical music, pairs of “guardian angel” earrings or bottles of Keri Lotion to “smooth out the rough spots.” Hugs are just one of those special pick-me-ups that Ms. Bauer and her team distribute daily and in large doses. “We disarm visitors with genuine concern,” she says. “Nine times out of 10, the response is a smile.”

Center staff take seriously all visitors’ suggestions for improvements. Months back, a brightly colored “Suggestion Box” was placed on an end table; emptied daily, the box continues to offer up one creatively

constructive idea after another. “It was clear that patients and family members wanted more than just a resource library,” said the Center Manager.

Virtually overnight, the CCRC became all things to all customers. “Too many visitors told us that we needed more diversions. They’d write, ‘The room is pleasant, and the best information is here, but something’s missing,’” recalls Ms. Bauer. “Patients and families can quickly reach an information saturation point, and they want something besides cancer to fill their time.”

Center staff added games and puzzles to the room. Novels, the complete “Chicken Soup for the Soul” series, videotapes, including children’s

movies, a wide selection of books on tape and even personal headsets to patients who ask, were made available.

Today, an artist's easel and watercolor paints dominate one corner of the Center; a mini-golf course spans another. An exquisite chess set, with hand-carved Oriental figurines on an ornate mahogany playing board, is both used and admired by visitors. "The chess set seems to grab everyone's attention," said Ms. Bauer. "We've had strangers as well as large families come together in marathon chess matches."

For families, there are activities to keep even the youngest members occupied for an hour or two. "One woman came in for same-day surgery, and brought in her five children. Each child took turns painting pictures for mom, and by the time she was out of surgery, mom had five colorful pictures and five happy kids to take home with her," said Ms. Bauer.

Because many visitors find the CCRC to be an escape from the stressors of cancer, weekly programs, such as yoga and meditation classes, are pop-

ular and well-attended. For those seeking spiritual nourishment, prayer books and prayers on tapes, representing all religions, are available.

For those needing a cosmetic boost, the Center houses a Wig, Scarf and Hat Boutique, co-sponsored by the Bosom Buddies Support Group.

"The Boutique has been a work in progress," said Ms. Bauer, "a true labor of love. It began with women's wigs, but we gradually added men's hairpieces, children's wigs and multi-cultural wigs. The patients wanted scarves and so scarves in every color appeared. Our public wanted hats, and today, hats ranging from everyday caps to turbans to Sunday-best straw hats are available." High-colored lace dickeys that discreetly mask surgical neck scars are also available to women.

"We have had so many grateful patients who have found the Boutique by accident when they visit the Center. They can't believe that everything is free and of department-store quality, even though many items are handmade," said Ms. Bauer. "We're not beauticians, but we help patients



Proceeds from the Annual Rewards and Recognition Banquet, held by the northern district of H&R Block, Williamsville, NY, were donated to the CCRC. Michael Schill, District Manager; Lin Kucharski, Office Manager of the Williamsville Branch, and Jeff Phillips, Assistant District Manager, present a \$1,610 check to Elaine Bauer.

select and try on wigs, hats and scarves." She tells the story of one woman, who after her 'mini-makeover,' took one look in the mirror, burst into tears and called the staff angels. "The change in her self-image, and self-confidence, was amazing."

While Ms. Bauer believes that the CCRC makes a genuine difference in many lives, she says that the real "angels" are the donors. "We are run by donations and could not exist without them. Our visitors thank us, but we have to give most of the credit to a generous community, particularly companies such as West-Herr Automotive, that continue to support our efforts. There are also so many people who consistently make smaller donations of items such as books on tape, "hats of hope," embroidered pillows, seeds for planting, and so much more. These donations make all the difference."

The CCRC is open Monday through Friday, from 9 am to 5 pm. Weekend visits can be scheduled by appointment by calling 716-845-8659.

To support the work of the CCRC through a gift, please contact Linda A. Kahn at 716-845-7606.



Betty Bright admires the creative handiwork of son Zack, a Roswell Park patient.