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THE FACES OF FINDING STRENGTH

Barrington photographer Susan McConnell and writer Mary Klest have teamed up once again, this time creating the *Finding Strength* photo narrative exhibit to honor those facing cancer. The exhibit will be displayed at the Barrington Area Arts Council Gallery at the Garlands in Barrington from May 4 through June 30. Here, Mary Klest writes about what she learned through her work on the project.

WRITTEN BY MARY KLEST / PHOTOGRAPHY BY SUSAN MCCONNELL

Photographer Susan McConnell and I approached the subject of cancer the way most people do: we were scared. We were unsure how our inquiry would be received, afraid we might not say the right thing or do something wrong. But our fears dissipated while listening to people talk with grace about the most difficult moments of their lives. “You have cancer,” they were told. From that minute forward, they became cancer survivors.

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INSPIRED by the dignity, creative energy, and will of people facing cancer, Susan initiated the *Finding Strength* exhibit as a way to honor her mother, who died from the disease. “She and I experienced the daily opportunity of learning and fighting to live one more day,” she says. “My mother was a fine example of strength, and I bring to this exhibit my own strength that I inherited from her.”

According to the American Cancer Society, nine million people are living with cancer today, with the disease affecting one in every three families. To tell these stories, Susan and I approached Wellness Place, a cancer resource center in Palatine that provides free services to cancer survivors, their families, and caregivers (see page XX). Jack Wood, the organization’s president, and Simone Wheeler, the director of development, gave us the go-ahead to create the exhibit. Clinicians Kathy Scortino and Kathy Hill introduced us to people willing to share their stories. We set out to learn who they are and how they cope.

From the start, we imagined a stylized exhibit presented in a way unfamiliar to most people in this area. Using a full-field camera, Susan bathes her subjects in natural light. She located one of the country’s premiere printers to produce her images using the French giclee method. Hand-torn edges frame the photographs with narratives repeating the irregular edges on handmade fine-art paper.

For several months, we talked with and photographed survivors and their families. Every survivor with whom I spoke admitted to being scared. These survivors are strangers to each other, connected only by the services provided through Wellness Place. We assumed they were fragile. Some were and some were not. We found their strength coming from a multitude of sources, including faith in God, family and friends, humor, and gratitude. Family members are a great source of strength for some and noticeably absent for others.

We learned that the worst thing anyone can do is take over a cancer survivor’s life. “They need to make their own decisions about treatment and care,” says Scortino, who leads the Finding Your Way group at Wellness Place.

Scortino tells participants, “Have faith in yourself and the people you are connected with.” Building an “angel team” of caring, supportive people helps. Unfortunately, many survivors say their list of friends dwindles after being diagnosed. So they find networks, research the possibilities, and often attend support groups.

Each person in our exhibit travels his or her own journey, but they are not alone. They reach out. They find help with treatment decisions, learn about the effects of treatment, cope with the side effects, and talk with others.

These are their stories.

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CAROL VENTURA

CAROL VENTURA, WHO WAS diagnosed with breast cancer in January 2004, says, “I had back surgery several years ago that required being restrained in a body cast. It was difficult, but cancer is something else. It threatens your life.” Carol’s ability to look back at the camera prompted Susan to make her portrait the exhibit’s signature photograph. “You can’t tell someone to do what she did during our photo shoot,” says Susan “It is something from within her that shows.” At Carol’s home, candles flicker while music plays softly. I ask, “Do you have a boyfriend?” She tells me: “No, a woman is invisible after 65.”



CATHY GORDON

Breast cancer survivor Cathy Gordon and her husband, Mike, enjoy a good laugh and the routines of life. Mike quips, “I’m getting my arms around this illness one finger at a time.” One of their exhibit photos shows Mike sitting alone at the kitchen table. What we know is that he is looking at Cathy. We see she is a well-loved woman. A conversation between the two also appears in the exhibit.



JEAN HOHOL

Jean Hohol’s colon ruptured a few months after she retired as a financial planner. She says the gravity of the disease affects everyone: “It’s too painful for them.” Relying on humor to bridge the gap, she says: “I was an hour from death but didn’t have enough sense to die.” Jean’s expressions change rapidly. Teardrops signal pain, joy, and release. While talking with her, we witness the rollercoaster ride survivors face day to day, or hour by hour, waiting for news from a doctor.



CHARLIE STEPHENS

Charlie Stephens says prayer brought him through his first hours as a cancer survivor. He began his cancer journey alone, counting out his losses. After 15 years of facilitating weekly support groups, he says, “I am grateful for being in community with others on this journey.”



STEVE HOOCZKO

While Steve Hooczko was working as an engineering manager at Motorola, he was diagnosed with non-Hodgkins lymphoma. He shakes his head when remembering what well-intentioned people said to him, such as, “God doesn’t give you anything you can’t handle.” He entered a clinical trial and received a stem-cell transplant. His wife, Ginnie, supported his decision. In the exhibit, his hands gesture as if he is speaking in sign language. As an outspoken advocate for cancer research and fundraising, he has learned new ways of expressing what is in his heart.

Helping Children Cope with a Cancer Diagnosis

Child psychologist Liz Bolash serves as the child and family program coordinator at Wellness Place. While every family circumstance is unique, in this question-and-answer session, she shares her insight on why communication is important during a health crisis.

Are there any myths about cancer you would like to dispel?

The idea that children should be protected from a family member's cancer. You cannot protect them. You can help them cope.

Can you share a story of parents telling their children that one of them has cancer?

I can describe a typical situation. A mother tearfully explains that her husband has been diagnosed with cancer. Their kids, ages eight and six, know Dad has not been feeling well. Through her tears, the mother reports her husband is scheduled to begin chemotherapy next week. They have not [yet] said anything to the kids so as not to upset them.

What would you counsel them to do?

I try to help parents come up with words that are both comfortable for them and developmentally appropriate for their children. Kids often overhear things. It's better to give them information directly than leave them to make assumptions on their own. Kids' imaginations can often make out things to be worse than they actually are (even in cases where the reality is pretty bad).

I believe it's important to use the word "cancer." Children often overhear adults using this word but may not know what it means. In the case mentioned above, the parents might say: "The doctors have found out why Dad hasn't been feeling well. It's because he has an illness called cancer." It's important to tell kids cancer is not contagious and nothing they did could cause Dad to get cancer.

Do you need to tell kids everything?

I recommend being honest with kids above all else, but limit the details to what they need to know. For example, I think it's important to introduce words that may be unfamiliar, such as "oncologist," "surgery," "chemotherapy," or "radiation." If they ask specific questions, answer them as directly as you can. If you don't know an answer, tell them you don't know, and that you will do your best to find out (and then follow through).

Honesty is particularly important if tough questions come up. Often, children ask if their parent is going to die. An honest reply might be: "Sometimes people do die from cancer, but not everyone—lots and lots

of people get better. Dad's doctors are working very hard to help him get better." Then give examples of all the things the doctors are doing to help Dad get well, such as surgery and chemotherapy.

What about the different stages of treatment?

In the above case, Mom can say that chemotherapy is a type of medicine to treat cancer and that it is stronger than any medicine Dad has taken before. She can continue, "Because this medicine is so strong, it could make Dad feel sick at times. This type of medicine also makes some people's hair fall out." Kids can have a variety of responses to this. For some, it's cool to see Dad in a hat, for others it may be scary to see Dad looking so different. It helps to stress all the things about Dad that will stay the same even if he looks different.

Most children are concerned about how their parent's cancer will affect them. So this should be an important part of the discussion. Let kids know what will be the same and what will be different in their day-to-day lives. I recommend trying to keep things as normal as possible. However, some things will be different. I talk about what the "Dad jobs" are around the house, and who will be taking care of those things if Dad is unable to do them. Kids come up with a list of what their parent does, such as: "He walks me to school, he takes out the garbage, and he picks me up from dance class." They will be less anxious if parents tell them in advance how those logistics are being handled.

Are there things you warn parents not to do?

Yes. I tell them not to make promises they cannot keep. If you say you're going to pick Johnny up after soccer practice, be there on time. While this is good advice all the time, it is especially relevant during the cancer experience, when kids' sense of security may be shaken. They need to know they can trust you when they are worried, and trust is built on kept promises.

Also, do not feel that you always have to protect children from worried or sad feelings. It is better for kids to see you model good coping skills than for them to think you never feel that way. It shows kids that it is okay to feel sad or worried and that there are ways to get through it.

How do families benefit from this approach?

If given developmentally appropriate information and support, children will learn positive ways to cope. In the example above, Mom and Dad were able to sit down with the kids and give them some basic information about what to expect in the coming months and answer their kids' questions. As the days and weeks go by, the kids may have different questions. The family is able to talk openly about changes as they occur because they set the tone early on for open, honest communication.



DEBBIE GREENE

Debbie Greene was the first person we spoke with. At age 35, she was diagnosed with an aggressive form of breast cancer. Her struggle with cancer lasted five years, a time when she would see her one-year-old baby become a six-year-old schoolgirl. Debbie knows while talking with us that she will not live to see the exhibit, but she gladly participates.

Each time I visit her she is surrounded by family members. Her sister-in-law tells me the family is following her lead. Debbie invited them to attend sessions at Wellness Place to help them cope. Her husband Stuart, daughter Molly, sister Chris, and parents did so. Debbie’s mother called the sessions “a pressure release.”

While creating Debbie’s images, Susan observed, “She was aware this would be her last portrait. She wanted it to be beautiful. She brought her jewelry and asked my opinion on which to wear. With the camera between us, she then asked, ‘May we use these [photographs] at my service?’” In the most prominent photograph we selected for the exhibit, Debbie’s arms gently cross her chest in a hug, holding on. She loves her life.

On August 14 of last year, during one of our visits with Debbie, she is wearing a pretty, red and pink poppy-print dress. Sitting on a couch with her extended family circled in the living room of her house, she listens to Liz Bolash, the child and family coordinator at Wellness Place, give them suggestions on how to talk with Molly after her mom is gone. After that, she recounts with me moments of her life with cancer. She talked with her sister Chris for a long while after I left. The next morning Debbie died peacefully while sleeping, beside her husband, Stu, who adored her.

LAURA KRAUSE

All of the participants mention spirituality as a source of strength, but Laura Krause put it in writing. Diagnosed with breast cancer in 2000, she writes eloquently about her faith in God. She is trying to stay strong for her family—a husband and two children—yet she believes her life rests in God’s hands.

Editor’s Note: The Finding Strength exhibit will be on display at the Barrington Area Arts Council Gallery at the Garlands from May 4 until June 30. Viewers will be invited to sign their names on a scroll and also list those they know who are living with cancer. The scroll will serve as a visual reminder of all those hoping for a cure. On June 9, the exhibit will travel to the annual Wellness Place Auxiliary Gala in Barrington Hills. Current sponsors of the Finding Strength exhibit include: Pat and Vince Foglia of Barrington; Harris Barrington; Gay and Paul Daniel of North Barrington; Alexian Brothers Hospital Network; Advocate Good Shepherd Hospital; QSN Industries; Joan and Robert Clifford of Inverness; Myrna and Stu Porter of Barrington; Midwest Bank; Barrington Area Arts Council; Illinois Arts Council; and media sponsor QUINTESSENTIAL BARRINGTON. For more information and a schedule of venues hosting the exhibit, please visit www.findingstrength.org.

- BY STEFANIE BRUNNER -

Wellness Place: A Haven for People Facing Cancer

During the seven years of its existence, Wellness Place, a Palatine nonprofit cancer resource center, has seen thousands of people pass through its doors: cancer survivors, their families and friends seeking information and support; volunteers giving time and energy; and donors supporting the mission. Services, offered at no cost to participants, range from one-on-one, cancer-related counseling and child and family programs provided by licensed professionals to presentations led by experts in nutrition, stress prevention, and cancer-specific education. In an average month, more than 80 people new to Wellness Place reach out for services and information. Yet a formidable challenge persists—to ensure that all those living with cancer in the resource center’s 60-community service area are aware that Wellness Place is here for them.

Kristin, who is 42 and a melanoma survivor, learned of Wellness Place through her acupuncturist Dr. Hong Luo, who operates AcuCare Clinic, a private practice in Rolling Meadows [patients’ last names are not used to protect her privacy]. She soon took advantage of the many resources provided by Wellness Place, including expert-led presentations, meditation, guided imagery, journaling, massage, T’ai Chi Chih, yoga, and the lending library.

“I’m so thankful I found out about Wellness Place when I did,” she says. “You think that you pretty much know what’s going to happen next week. I felt a large lump in the center of my back, and in the span of four days I had a biopsy and surgery. I had to make a lot of decisions very quickly. I didn’t have time to think, to feel. How was my soul going to adapt? And, I realize it could happen again.”

A full-time corporate strategy consultant in mergers and acquisitions, Kristin’s work environment can be highly charged. “I look at my life differently now,” she says. “At Wellness Place, I learned breathing techniques to help me relax before my surgery, and I use the same methods to stay calm when tempers flare on the job.”

After the whirlwind diagnosis and surgery, Kristin’s doctor had good news. They had successfully removed all of the melanoma. “Even though the cancer had been cut out, there was still my spiritual side that needed to heal,” she recalls. “Guided imagery and the meditative exercises inherent in T’ai Chi Chih helped me connect to the messages that this cancer had for me.”

A few short months after her surgery, Kristin, who also has a family, found time in her busy schedule to volunteer at Belongings, a Barrington donation and consignment shop that benefits Wellness Place. She says, “It’s my way of supporting the organization that has helped me in so many ways.”

Dr. Luo is among several medical professionals who recognize the tremendous benefits of Wellness Place services and who routinely refer

those recovering from cancer. Dr. Michael Kinney, director of the Center for Advanced Breast Care in Arlington Heights and a regular Wellness Place speaker, is another. “I’m grateful to Wellness Place for providing a supportive haven to my patients and their loved ones, who are seeking renewed strength while facing cancer,” he says.

Barb, another Wellness Place devotee, heard about Wellness Place in a more roundabout way. Her discharge nurse told her about Cancer Wellness Center in Northbrook. In October of 2000, she was diagnosed at age 48 with cancer of the common bile duct. Barb was told treatment would involve a pancreatoduodenectomy surgery (whipple procedure) followed by six weeks of radiation and chemotherapy. “They told me it would be at least a year before I would feel back to normal,” she says. Eventually Barb was able to eat without pain and nausea, but she hasn’t returned to “normal” or her former way of living.

At the time, Wellness Place had just opened and was not well known. But Barb was a resident of Palatine, and as soon as she heard about the center’s opening, she began attending support groups. “Just being in the company of others going through similar experiences relieved my stress,” she says. “The Wellness Place lending library was a great resource for me. I read everything I could get my hands on.”

She continues, “My cancer experience not only changed my eating habits, but also modified how I think about life. Pre-cancer, my husband and I didn’t take many trips. As soon as I felt well enough, we were off to the British Virgin Islands. I said to my husband, ‘If we don’t do this now, when will we?’”

Barb believes there is no such thing as a free lunch. In 2001, she volunteered to organize the Wellness Place library that had been so helpful to her, and today she also helps out with Belongings. She feels compelled to spread the word to anyone in need of cancer support. She frequently hands out cards listing all the cancer support centers that make up the Cancer Health Alliance, which includes Wellness Place as well as the Cancer Wellness Center in Northbrook, Wellness House in Hinsdale, and the Cancer Support Center in Homewood.

Wellness Place is located in Willamsburg Village at the intersection of Euclid Avenue and Roselle Road in Palatine. The center encourages those interested in learning more about programs and services to stop in Monday, Wednesday, and Thursday from 9 a.m. to 5 p.m.; Tuesday from 9 a.m. to 9 p.m.; or Friday from 9 a.m. to 3 p.m. A 30-minute orientation and tour is held each Wednesday at 6 p.m.

Stefanie Brunner is director of public relations for Wellness Place. For more information about Wellness Place and other members of the Cancer Health Alliance visit www.wellnessplace.org or www.cancerhealthalliance.com.