

Gateway to Hope

St. Louis plastic surgeon creates ‘clinic without walls’ to help breast cancer patients from diagnosis through reconstruction – for free

BY JIM LEONARDO

If ASPS Member Surgeon David Caplin, MD, St. Louis, Mo., were able to reverse time, he says he would go back to 2006 and find Suzanne, the breast cancer victim who felt she couldn't meet the expense of a double-mastectomy because it would disrupt her family's income flow and place additional burdens upon her children. It was a choice born of self-sacrifice that ultimately ended her life.

"Suzanne was in her early 30s, with two small children and a disabled husband," Dr. Caplin recalls. "She was the sole breadwinner in the family but had no insurance, so when she found a lump in her breast she ignored it for two years – because she knew that even if she had a mammogram, she couldn't afford any subsequent medical care. I had been treating her husband when I learned this, but by that time she was quite sick."

Suzanne died not much longer after that, leaving behind her husband, who was unable to work, and two small children. Her death, however, drove Dr. Caplin to form Gateway to Hope, a St. Louis-based "clinic without walls" to help uninsured or underinsured women receive complimentary, comprehensive treatment for breast cancer through donated medical services and other assistance, such as transportation, food and child care.

"That's when I decided we were going to do something about this," he says. "I thought that it was simply impossible for someone like Suzanne to fall through the cracks in our health care system. But the reality is, she did – and other women just like her still do."

The National Cancer Institute estimates that approximately 180,000 new cases of breast cancer are diagnosed each year. According to ASPS procedural statistics, there were approximately 57,000 breast reconstruction procedures performed in 2007 – a 93 percent increase since 1992.

Arranging help

Shortly after Suzanne's death, Dr. Caplin began asking medical professionals throughout the greater St. Louis area to donate their services to financially struggling breast cancer patients. The impressive response allowed Gateway to Hope to take root – and the organization is helping an ever-growing number of breast cancer patients.

"Without Gateway to Hope, I would be financially destroyed," says Roberta Losciuto, Affton, Mo., who underwent a double mastectomy in 2005, followed by breast reconstruction and related aesthetic procedures.

"I would have gone ahead with the mastectomy to save my life, of course, but I also would have undergone breast reconstruction to save my self-esteem and that connection to womanhood," Losciuto says. "But I probably would have needed to declare bankruptcy to pay the bills – bills that Gateway to Hope ensured wouldn't come."

ASPS Member Surgeon and Gateway to Hope volunteer Patricia McGuire,

MD, St. Louis, recalls the joy she saw in a 50-year-old woman, Cretia, who received help from the organization after having lived without breast reconstruction for 10 years.

"Cretia, her mother and one of her daughters were in a holding area just before her surgery, and they all were crying – they never thought the day would come," says Dr. McGuire, who shares a practice with Dr. Caplin and Melvin Maclin, MD – another Gateway volunteer – at Parkcrest Plastic Surgery.

"Cretia said something that stuck with me," Dr. McGuire adds. "She told me, 'I'll be able to date again.' That's something I had never thought about regarding women who undergo mastectomies but haven't undergone reconstruction. She also told me that she already felt whole – though I had only finished the first stage of her treatment. She loved the fact that she could get up in the morning and not automatically think about the fact that she had both breasts removed."

Modest beginnings

Dr. Caplin says the high cost of breast cancer-related procedures had Gateway to Hope organizers originally expecting to be able to help a modest number of patients in the program's inaugural year.

"Our original goal was to treat 12 breast cancer patients per year – in addition to providing mammograms, imaging, lab work and other nonsurgical services," he says. "The [per-patient] cost of comprehensive care can easily range from \$100,000-\$200,000."

Dr. Caplin located surgery centers, laboratories and hospitals willing to donate facilities and services because their administrators felt Gateway to Hope's efforts were an important service to a part of the community that even charity hospitals couldn't accommodate, he says.

"My first call was to Marlys Schuh, MD, an oncologic surgeon who agreed to co-found the organization and helped recruit her partners to perform mastectomies," he says. "Each of my three partners was also willing to take on three or four new reconstructive surgery patients."

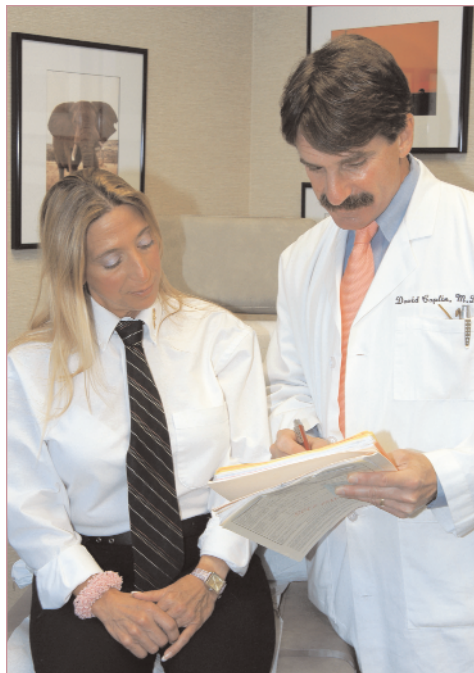
They went on to find additional oncologists and radiation therapists to take on one or two new patients per year, and as the need increased, the organization's recruitment efforts widened.

"This has ended up being much more successful than any of us had anticipated," Dr. Caplin adds. "We've branched out to include oncologists, oncology nurses, support staff, chemotherapy regimens, radiation therapy, all forms of radiologic imaging and a host of other services. We even provide hysterectomies and oophorectomies when appropriate for some of our breast cancer patients."

And Dr. Caplin says the Gateway to Hope system for ensuring that patients aren't billed for any service is simple: "They have 'Gateway to Hope' stamped on their charts, so they're never charged."

Making an impression

The need to catch breast cancer patients who fall through the holes in the health care system – whether the victims of insurance coverage gaps or financial burden – is an unfortunate reality of today's insurance and economic landscape, Dr. Caplin notes.



Gateway to Hope founder David Caplin, MD, consults with a patient.

“We’re on track this year to treat approximately 40 patients,” he says. “Unfortunately, that’s a reflection of the fact that the current health care system simply doesn’t work for many patients. One of the problems in St. Louis is that we have wonderful university-affiliated programs, but most of these require patients to pay for their care on a sliding scale basis – and a lot of the patients we see can’t afford to pay *anything*.”

Steven Kronowitz, MD, associate professor of plastic surgery and program leader for the Komen Breast Fellowship for Plastic Surgery at the M.D. Anderson Cancer Center in Houston, says that patients who are unable to afford post-mastectomy breast reconstruction are all too common and praises Gateway to Hope as one of the best programs he’s encountered for meeting the needs of a forgotten population.

“This is truly a remarkable achievement,” Dr. Kronowitz says. “This model could stand to measure against some of the great cancer centers in the nation, as a program that delivers a very high level of all-encompassing patient care – it’s not just focused on removal of the tumor or the reconstruction.

“It’s also a great humanitarian effort that serves the ‘in-between’ population, which has no money to pay for their care even though they may be working or (insufficiently) covered by Medicaid, as well as care for their family members,” he adds. “It’s an ideal model.”

Dr. Kronowitz says that while insurers and the government agree on the need for mastectomy, where subsequent breast reconstruction is concerned, there is no single, guiding principle to ensure coverage for all.

“We need to continue to push at the federal and state levels to ensure this ‘in-between’ patient population is covered in some way,” he says. “The Gateway to Hope effort is very important and serves a great purpose, but insurers and government shouldn’t become complacent when they hear about efforts such as this; they are not off the hook regarding their responsibility to provide reconstruction services to breast cancer patients. Breast reconstruction after mastectomy is not a privilege – it’s a human right.”

“These women have no other option,” Dr. McGuire adds. “As plastic surgeons, this is something we can do to help. In many ways, Gateway to Hope provides services more effectively than the government.”

Proactive care

To date, Dr. Caplin says Gateway to Hope has treated breast cancer patients from as young as 23 to women in their mid-60s – just shy of the Medicare range. In order to determine need, the organization’s staff members “means-test” potential patients in the same fashion as hospitals and clinics.

“Patients provide formal documentation of income and assets, and need to fall between 200-350 percent of the federal poverty guidelines – which indicates to us that they make enough to be ineligible for Medicaid or state-funded programs (such as Missouri’s Show Me Healthy Women program), but not enough to pay for insurance,” Dr. Caplin says.

He says a typical Gateway to Hope patient is well-educated and works full-time, but her job doesn’t offer health insurance – or pay enough for her to afford it.

“We also have a number of patients who’ve had mastectomies that were never reconstructed because they couldn’t afford it or insurance wouldn’t cover it,” Dr. Caplin says. “Some women have had insurance but recently lost it. But to be a patient here, these women don’t need to be indigent or unemployed; they only have to have the financial need.”

Gateway also has helped women find the disease before it became manifest, as well as advised them on courses of action when cancer seemed to be looming.

“If we find patients who we think that, based on their family history or genetics, are at risk, we can offer genetic screening at no charge,” Dr. Caplin says. “Then we look to their family to see if there are other members who should be screened. Although the original idea was to treat breast cancer patients, we’re now treating patients who have genetic mutations that put them at high risk for breast cancer, and we’re performing prophylactic mastectomies and breast reconstructions on them as well.

“We sent a 23-year-old – whose 19-year-old sister was being treated for metastatic breast cancer – for an MRI and mammogram, which unfortunately revealed a very large tumor in one breast,” he adds. “We started her on a course of chemotherapy, she underwent bilateral mastectomies, radiation therapy and chemotherapy, and she will be reconstructed at the appropriate time. All of her care was provided by Gateway to Hope – because she didn’t make nearly enough money to pay that from her own pocket.”

Another patient who received a free ticket to a Gateway fund-raising event became engaged in conversation with a volunteer who eventually learned that the woman needed free care. “This patient mentioned that she had been in the middle of chemotherapy when her husband divorced her, taking her health insurance with him when he left,” Dr. Caplin recalls. “The next week we brought her into the organization and finished her treatment. There are a lot of great stories.”

Start your own effort

Dr. Caplin says one of his long-term goals is the formation of similar Gateway-type armies throughout the nation, so that no woman anywhere is without help in a time of desperate need.

“All a plastic surgeon needs to bring this to his or her city is a general surgeon who’s willing to perform the mastectomy and a surgery center that’s willing to donate the facilities,” he says. “The breast implant companies have been very generous, too.”

Gateway to Hope is a 501(c)3 charitable organization, which allows for certain tax exemptions for corporate and individual donors. “Gaining this designation was one of the more involved parts of the effort,” Dr. Caplin says. “The thought of trying to achieve this might be a sticking point for others, but we’ve done the hard work; we can let others know how to get the designation for charitable-medical work. We can show them how to create the infrastructure, and we will gladly share all protocols and documents. It’s very easy to begin this effort on a small scale.

“If others choose to carry this as far as we have, our staff would work with them and the process would be quite easy,” Dr. Caplin adds. “For instance, we have a simple protocol that allows us to locate and recruit physicians in St. Louis. Everything can be replicated in other communities.”

“All ASPS members should consider joining an effort like this,” Dr. Kronowitz says. “Dr. Caplin can help them build such an effort in their city or town. As he says, the hard work has been done for them.”

The unfortunate reality is that great programs often spring from tragedy, but Dr. Caplin says that Suzanne – the woman who’s cancer was never addressed – might be pleased that she has saved other lives.

“My sense is that she would be thrilled to know that there was a safety net in place for women in her position,” Dr. Caplin says. “I also think she might be heartbroken to know that she might have been cured and enjoyed a long life with her family, had the organization

been in place a few years earlier. But her misfortune may have helped lead to a solution for others facing similar challenges – I think she would be very happy to know that.” **PSM**

Reprinted from the Oct./Nov. 2008 issue of:



AMERICAN SOCIETY OF
PLASTIC SURGEONS