

# Cancer Was the Easy Part

by Bill Dupes

Monte Gardner is a self-possessed young man, mature beyond his 18 years. He was born under the sign of Libra (the Scales), which is appropriate, given his even-tempered nature. Ironically, the same scales also represent a balance of fairness in the law, which is further emphasized by the figure of “Blind Justice” holding them. Monte and his parents are currently seeking ways to open the eyes of justice to tip the scales in favor of future amputees. He sums up the experience in a few simple words: “The cancer was the easy part.”

On April 27, 1999, only a few days after moving from Fairfax, Virginia to Round Hill, Virginia, to break ground on their new house that she and her husband, Bob, had designed, Lorna Gardner received a call from Monte’s school. She was told that Monte had fallen and broken his left leg while playing kickball. With boxes of unpacked belongings still scattered throughout their rental home, Monte and his family were soon forced to deal with a far more serious problem.

The x-rays of his broken leg revealed an egg-sized tumor in his femur (thigh bone). Following a battery of tests, he was diagnosed with osteosarcoma – bone cancer. Monte had never really noticed any significant pain before, although in looking back, he now realizes that the occasional minor aches and pains he’d chalked up to the usual scrapes from playing ice hockey were probably early warning signs of the tumor growing within his leg.



The timing of Monte’s diagnosis, coupled with the construction of the family’s new house, inspired Bob, Monte’s father, to modify its design by widening the doorways and putting a full bathroom on the ground floor in case Monte became wheelchair-bound and needed to live on one level. Although their house has no ramps, it is designed so that they could easily be added, if necessary.

Monte began a series of chemotherapy treatments, five rounds before his first surgery on his 13th birthday in October 1999, followed by seven more rounds. He suffered the usual side-effects of chemotherapy, such as hair loss, insomnia, aching bone pain, and nausea, losing 19 pounds in only two weeks. Unfortunately, these problems were further complicated by Monte’s numerous drug allergies, particularly to narcotics. The medical

team worked around these obstacles by trial and error.

Monte received his first allograft (donor organs, tissue or bone) during the first operation to replace the diseased portion of his femur with bone taken from a deceased donor and reinforced with a titanium rod. Approximately 500,000 allografts per year are conducted in neurological and orthopedic surgeries, and, in theory, the human body seems to accept and heal more readily around these tissue transplants than around mechanical devices. In Monte’s case, however, the allograft “literally dissolved” and failed 15 months later.

Between April and June 2001, he had four more surgeries to clean up the infection that occurred at the site of the allograft. This time, his entire knee and all but 7 inches of his femur were replaced with an endoprosthesis, titanium femur and a cobalt chrome knee with a tibial stem. After causing considerable hip pain, this implant also failed in January 2003. Amputation seemed to be the only option left.

Monte’s surgeon, who had performed the previous operations, advised repairing the device and having a below-knee amputation. Frustrated with their surgeon and other local doctors, the Gardners were left searching for any other available options. Although all of the tissue between Monte’s thigh and just below his knee had been mutilated from multiple

surgeries, his leg from his calf down was still untouched and in beautiful condition, and his foot functioned normally. Even though Monte now had a 6-inch difference in the length of his legs and wore a platform shoe that weighed 4.5 pounds, the family refused to consider amputation of his foot.

Through a referral from Lorna's mother-in-law, a retired nurse, a new option was found: rotationplasty.

Rotationplasty is a reconstructive surgical procedure in which a damaged or diseased portion of the femur is removed and the middle and lower portion of the tibia and the foot are turned in a half-circle and reattached so that the ankle joint then functions as a knee. The foot, now turned backward, slides into the socket of a below-knee prosthesis. Rotationplasty is particularly well-suited for children because it enables better function than amputation. It also allows the child's leg to continue to grow.

The Gardners traveled to Savannah, Georgia, to consult a prosthetist who had undergone a rotationplasty nearly 18 years earlier. The family came away from their visit completely impressed and encouraged by his attitude and his ability to live a normal, active life. As they launched a new effort to find a qualified surgeon to perform the procedure, all roads led to a surgeon at Mount Sinai Hospital in New York. He had been in the field longer and had performed the procedure on more patients than anyone else – including, coincidentally, the prosthetist they had consulted.

Lorna's insurance provider typically only approved doctors in the Tri-State area (Maryland, Virginia and Washington, DC). At the Gardner's request, the insurance company provided the names of surgeons who could perform the surgery. Some of the surgeons on the list also recommended the surgeon at Mount Sinai as the most qualified to perform the procedure.

The insurance provider verbally agreed to work with Mt. Sinai and their team "in network" to pursue the surgery, Lorna says. However, on October 14, 2003, the

day before Monte's scheduled surgery, Lorna received a call advising her that the coverage for the proposed surgery had been revoked, she says. But she was determined to pursue her son's best chance for a normal life and to save his foot. The family went forward with the surgery as planned.

What was supposed to be a four-hour surgery stretched into nearly 11 hours due to complications posed by the scar tissue from the five previous surgeries. Other than that obstacle, the procedure went perfectly; Monte left the hospital five days later and was back in school in three weeks. Eight weeks after the surgery, Monte received his first prosthesis, which he has worn ever since.

The insurance company also subsequently reduced the coverage of Monte's prosthesis, Lorna says. Fortunately, Monte's parents were able to work out payment arrangements for the hospital charges as well as the prosthesis. But, in Lorna's words, "We had to rob Monte's college fund to do it."

The most frustratingly ironic part of it all, Lorna says, was that the insurance company approved five surgeries that did not prove to be effective but refused to pay "in network" for the single procedure that has given Monte his life (and his leg) back.

The entire ordeal was very difficult for Monte and put him in an awkward position; he couldn't help feeling guilty about the financial pressures that his situation was creating for the family. But his parents didn't want Monte to be left "out of the loop." They felt that shielding him from such issues would not help him learn to make informed decisions on his own. As his mother explains, "It wasn't enough that he beat the cancer and overcame many other obstacles; that's why 'the cancer was the easy part!'"

Today, Monte lives a very normal life again; he is cancer-free and extremely mobile! He golfs with his younger brother and dad, swims, surfs, fishes, and has a lovely girlfriend. He is an active member of the American Cancer Society's "Relay for Life" and has been its commencement



speaker and Western Loudoun liaison for six years. He is also a member of the Amputee Coalition of America and shares his experiences with others, speaking to support groups to promote the advantages of rotationplasty and to share life as an amputee. He is starting college this fall, planning a double major in kinesiology and biomechanics, preferably at the University of Tennessee, Knoxville. Ultimately, he hopes to establish a career as a certified prosthetist and orthotist.

With the help of a close family friend, Lorna and Monte are developing a Web site and brochures. The Gardners want to share their experiences to help any other families who find themselves in a similar situation. Lorna has also hired an attorney to continue to appeal the insurance company's decision. But she doesn't intend to stop there. She is determined to take the fight to the next level and bring the issue to the attention of the Virginia state legislature.

"This isn't just about Monte anymore," Lorna says. "I want to help in any way I can to change the current laws for a better future for all prosthetic wearers." ❖

*For more information about rotationplasty, see "Know Your Options":*

*[www.amputee-coalition.org/inmotion/mar\\_apr\\_05/rotationplasty.html](http://www.amputee-coalition.org/inmotion/mar_apr_05/rotationplasty.html)*