

CARING FOR THOSE WITH BREAST CANCER

By Peggy McGuinness

The mission DONNA of the Foundation, according www.thedonnaFoundation.org is "to provide financial assistance and support to those living with breast cancer and to fund groundbreaking breast cancer research." Toward that end, the Foundation holds several events each year, including the DONNA Marathon Weekend, which is held the second weekend of February and reported to attract nearly 10,000 runners and supporters from all 50 states and more than 20 countries. 26.2 with DONNA, the weekend's main event, is, according to Amanda Napolitano, Executive Director, "the only marathon in the United States dedicated to breast cancer research, awareness, and care." And Ocean Blvd. Thinks Pink, a group of neighbors profiled in our feature story this month supports that race in a big way.

How the DONNA Foundation came to be, and the origins of Marathon Weekend, I've discovered, were actually the result of a kind of "Perfect Storm." Donna Deegan, a three-time breast cancer survivor, is the woman for whom the Foundation is named, and a very familiar face in the Jacksonville area. Many residents will recall that after Donna's first diagnosis, she shared very publicly about the disease and her treatment for it in her capacity as an on-air journalist with First Coast News. At that time, in the late 1990s, Donna's treatment consisted of a lumpectomy, chemotherapy, and radiation to address Triple Negative Breast Cancer. There was no medical follow-up protocol, so once treatment ended, the story ended.

Donna's attitude toward her diagnosis had been fairly matter of fact, according to Amanda, who was a fellow runner and friend of Donna's long before joining the Foundation. Amanda tells me that Donna had originally approached cancer as something that had to be dealt with and then put in the rear-view mirror, so she could get on with her life. And, for a period, that's the way it went. Until two years later when she learned the cancer was back.

A second cancer diagnosis in 2002 was a bit scarier than the first one. It was then that Donna fully realized the terrible impact cancer could have on her and her family. Although she had no desire to take herself and her viewers through another public journey of treatment, Donna felt the need to share her experiences in an online journal; or what we would call a blog today. Through this journal Donna shared what was happening to her and, in doing so, engaged with many other women whose lives and families had been altered by breast cancer. What became abundantly clear to Donna was that there were an awful lot of women out there not only dealing with cancer



and related treatments but "many of them literally had to choose between treatment and groceries," Amanda says. In many ways, the stress caused by the financial impact of cancer on their lives was as bad as the cancer itself. Donna decided she would "use her megaphone" again – this time to make a difference in the lives of other cancer patients.

Donna had a great job, good insurance, and two young children – Drew and Danielle - when she first learned she had cancer. She was lucky enough to have the support of her family and friends as well as her co-workers and employer, which made a tremendous difference in her recovery. But she learned by engaging with other women online that there is an alarming number of women facing cancer who have little or no emotional or financial support. Donna was compelled to help them and decided to start by selling "Run with Donna" tee shirts when she ran local road races. She would donate the money to women who needed help with all kinds of expenses as they dealt with cancer. Thus, the DONNA Foundation was initially established in 2003 to care for financial needs of women with breast cancer. Donna was again treated with chemotherapy and radiation, and life went on.

In the meantime, Amanda was leading some marathon training classes for the River Run Expo in Jacksonville under former US Olympian Jeff Galloway. Jeff, a lifetime runner, had been an All-American collegiate athlete and a member of the 1972 US Olympic Team. He is the Chief Executive Officer of Galloway Productions, which conducts a broad range of training programs and events, and he's written several books on marathon training. Jeff approached Donna and suggested they train a group of people to run a marathon while fundraising for the DONNA Foundation. Donna threw out the suggestion on the air, hoping to get at least ten people to take the challenge.

Donna recalls "Ultimately, more than 80 signed up, and they raised more than \$100K, which got me thinking." She did some research and realized there was no classic marathon distance race for breast cancer. So she approached her oncologist, Dr. Edith Perez with the idea to start one. "The plan," says Donna, was "to split the proceeds between The DONNA Foundation to help underserved women with breast cancer, and research that was near and dear to Dr. Perez."

This is where the perfect storm comes in, or the "trifecta," as Amanda puts it. When Donna Deegan, broadcast journalist, runner, and cancer patient, began to train with Jeff Galloway, well-known Olympian, marathon trainer, and writer and became inspired by Dr. Edith Perez, renowned cancer specialist and researcher, the DONNA Foundation really took off. The trio began work on a marathon to be held in February of 2008 that would be called "26.2 with Donna The National Marathon to Fight Breast Cancer,"

Fast forward to October of 2007, four months before the inaugural race was to occur. Donna, incredibly, received the crushing news that she had breast cancer again and that it had metastasized to her lung. Terrified now, she asked husband Tim to help her "learn how to live" within this new reality. She struggled with fear as she underwent treatment and surgery and sought peace and acceptance. She read a book entitled "Love is Letting Go of Fear", which Donna has compared to a "12-step program for fear addicts," and eventually made a conscious decision not to be fearful. She decided to focus on "love over fear," and through new eyes decided to change the name of the race from the National Marathon to Fight Breast Cancer to the National Marathon to Finish Breast Cancer, replacing "fight" with "finish."

When February came, Donna planned to run just a leg or two of the 26.2-mile race, relaying with others who would finish it for her. On race day, she stood with Dr. Perez watching the runners and spectators with growing excitement, and suddenly asked: "What would you think about me running the entire race?" Donna remembers Dr. Perez responded with, "I think if you feel well enough to do it, it could be the best thing for you." And so, Donna ran the entire marathon along with 7,000 other participants, and she's "never looked back," she says. Now 11 years later, Donna is cancer free and enjoying a new life focused on her Foundation work, health, and well-being.

Donna serves on the board of the Foundation along with seven other volunteer board members. They have a staff of five and are partnered with a non-profit service company which operates their "care line," staffed with case managers who guide cancer patients and their families. Amanda says that 60% of the people who contact them earn incomes under \$25K annually, so knowing what resources are available is paramount. The "care line" is staffed

with people who not only provide guidance but who can direct patients to specific resources and help them navigate through their particular circumstances.

The Foundation helps 550 families each year and for every dollar invested in the "care line," \$5 of debt relief is obtained for families living with breast cancer, up to \$500,000 annually. 32% of Donna families request assistance with insurance-related issues that impact their ability to receive care or manage monthly expense. 60% of Donna families seek help with everyday costs and debt relief as they live through treatments, surgery, and recovery. Since 2003, 11,000 families have had critical financial needs eased through the Foundation.

Since 2008 The DONNA Foundation has funded the Mayo Clinic Breast Cancer Translational Genomics Program, with more than 3 million dollars in race proceeds. The program, which was originated with the race, Donna says, "has resulted in a number of breakthroughs for researchers, including a new vaccine that's being trialed for triple negative breast cancer."







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