Fighting Chance Opens New Sag Harbor Office on Oct. 2nd

Ribbon-Cutting Brigade Has 20 Survivors

Special Thanks to Tiffany & Co. Loaves & Fishes and Round Swamp Farm for their Generous Contributions to our Summer Gala 2010. We raised over $125,000.
A Conversation with Duncan Darrow

The founder and chairman of the Fighting Chance board, sits down with the Sag Harbor Express to talk about his organization’s most recent move, what makes his organization successful and the importance of community participation in cancer testing initiatives.

Why did Fighting Chance move and what was the organization looking for from a new space?

This is our third space. The first was a little garage in the back of Romany Kramoris. It was a great place to start. But there were logistical issues. The patient navigator couldn’t be in the room when the counselor was there with a patient. At the next spot on Route 114 we had room for the counselor and the navigator and that was a breakthrough for patients. Most patients see us right after their diagnosis, usually within 48 hours. They are in a state of shock and emotional distress. They leave with our guide and work from that guide in terms of developing coping strategies.

We moved here to Bay Street because we used to cram our support groups into the counselor’s office, which only sat five to six people. We have much bigger support groups now and we needed a bigger room. The second thing that we felt very strongly that we wanted was to have a cancer patient library. There is so much duplication and venting on the Internet. If you aren’t experienced and you don’t know where you are going, you come across things that aren’t very helpful. In our patient library we have edited out all the junk. What you are seeing here is the best of the Internet.

We also wanted a long-term lease. Most non-profits out here aspire to be like the Peconic Land Trust or ARF [Animal Rescue Fund of the Hamptons, Inc] who both have their own buildings. We had a chance to get a 10-year lease [with this building]. I said to the board that this is sort of like buying a building. With not-for-profits you have long range dreams and part of our dream was to stabilize our office situation.

We wanted to stay in Sag Harbor. People identified us with Sag Harbor. Our first board meeting was at Cormaria. A lot of board members are in Sag Harbor.

In 2002, why did you start Fighting Chance?

It came out of my experience as a caregiver to a cancer patient, which was my mother who was diagnosed with stage four lung cancer at Southampton Hospital. She lived 100 days. After the diagnosis, I spent 100 days trying to figure out all the logistical things and there were absolutely no resources. I remember walking out of Southampton Hospital thinking “Isn’t there someone around here I can talk to?”

Now when you leave Southampton Hospital they give you our “Coping with Cancer on the East End” guide. All the stuff that bewilders you about second opinions, hospitals and insurances, is explained.

There has probably been three movements within the field of oncology that we have been part of in a significant way. The first movement -- which went on for decades, was “let’s not talk about it.” Having cancer was as bleak a diagnosis as having AIDS. Slowly but surely people started talking about their cancer diagnosis because it became more curable. The second movement was called “cancer patient navigation” -- which is about helping patients with the logistical issues raised by a cancer diagnosis. We became like a concierge and came to the fore because the healthcare system can be so confusing. People didn’t know how to cut the red tape. We hired our first navigator in 2004 and our where-to-find-it Resource Guide was first published the same year and has been fine-tuned and improved upon every year since then. The third sort of trend is the “cancer patient literacy” movement. I have spent a lot of time with cancer patients and I have never heard anyone say, “Doctor could you explain that more technically?” The way we educate cancer patients really needs to be simplified.

When you considered that the rates of survivability seem to correlate with how easy it is to test for a specific type of cancer, like breast cancer compared to lung cancer, as shown in Fighting Chance’s handbook “Cancer Simplified,” do you think a key to fighting cancer is finding simpler ways to detect certain cancers?

For some cancers the detection has to get better. The community has to be more insistent about testing and people have to get it into their head to get tested. We need to make testing available and publicize it, and adopt it as part of our lifestyle sort of in the same way you know what your cholesterol level is.

This is a rural area and we have rural cancer care. It goes back to the pervasiveness of early detection. When was the last time you saw a mobile mammogram trailer or an ad in the paper to have your colonoscopy? Even if you saw it, you would have to drive 25 miles to get tested. Out here early detection is not as pervasive as in many other environments and as a consequence most patients we see at Fighting Chance come to us with their cancer already advanced meaning stage two or stage three, or sometimes four. It’s almost never stage one.

You’ve pointed out that of the 1,000 East End residents who are annually diagnosed with cancer roughly 400 of them call Fighting Chance within the first 48 hours of their diagnosis. Why do you think Fighting Chance has become one of the first calls these patients make?

Mostly these patients aren’t wealthy. They are working families and a cancer diagnosis is like an atom bomb in what was already a difficult and challenging life. It has gotten worse with the recession. Also there was a total void, until a few years ago, of organizations like Fighting Chance. In addition, we have a terrifically talented staff. Our Senior Oncology Social Worker was at Memorial Sloan-Kettering Cancer Center for 15 years. Another counselor spent 30 years as an academician in a medical center setting. We have really tried to build bridges of awareness to the local medical community and a lot of them know about us.

Why was it important to you to establish Fighting Chance in Sag Harbor?

I have lived here for 30 years and I have a lot of affection for Sag Harbor. I think in these small communities people take care of one another. I think that is part of the history and culture of Sag Harbor. We sort of belonged here. I think Sag Harbor is one of those villages where people spend a little more time taking care of one another.

Fighting Chance will hold a ribbon cutting celebration at their new location at 34 Bay Street from noon to 12:30 p.m. on Saturday, October 2.
1,000 to 1,500 people each year are diagnosed with some kind of cancer on the East End. Of those, 350 end up dying in hospice care within that year, according to Duncan Darrow, the founder and chairman of Fighting Chance in Sag Harbor.

The diagnosis, as one patient described it, “is like being struck by lightning.” Mr. Darrow said he envisioned the service organization as a resource to answer the questions patients have within 48 hours of being told of their disease, and to let them know what services are available in an area somewhat remote from specialty health care.

He started the organization in a garage in 2002 after seeing the struggles his mother went through during treatment on the East End. He began with a vision for a guide to services, and as the years have passed he has continued with symposiums, Web site development, psychological support, targeted informational materials, and even practical support such as cleaning services and transportation.

And now the group has a bright and cozy new headquarters on Bay Street in Sag Harbor, with a library, conference area, and private meeting rooms all designed to be warm and welcoming to patients and caregivers dealing with trauma. A sold-out benefit for the group will be held on Saturday at the Wolffert Estate Vineyard in Saggaponack.

A large portion of those diagnosed with cancer on the South Fork find their way to Fighting Chance, where they are given free counseling and a variety of information targeted to their disease and appropriate to their willingness and ability to absorb that information.

The oncology social workers include Karrie Robinson, who came out of retirement from Memorial Sloan-Kettering Cancer Center to help the organization as director of clinical programs, William De Scipio, a clinical psychologist, and Margaret Bromberg, an oncology social worker.

With few cancer specialists serving the area, the group strives to step in and help with questions regarding the illness and the effects of treatment, as well as holistic approaches to well-being. It is not linked with any of the East End hospitals, but Ms. Robinson said they have an informal relationship with them. “We know when one of our patients leaves the hospital” after treatment, for example, or when they go back in for more.

Hearing the concerns of patients firsthand has given the group a unique role in advocacy and in meeting needs such as patient literacy. Fighting Chance has joined an effort to change the way doctors speak to be more intelligible to those outside the field. Having three oncologists on its board makes these discussions easier to have.

On its own, it has devised a flip-chart booklet called “Cancer Simplified,” which provides a 15-minute education in the basic biology of the illness, the cost of treatment, the types of treatment and the aftereffects, services available, questions to ask, and how to navigate it all. It is one of the first things given to Fighting Chance patients.
East Hampton Volunteer Ocean Rescue Squad

&

Swim Across America

... a new partnership for raising funds to fight cancer.

July 2010

The 1st Annual Hamptons Swim raises $100,000 for Fighting Chance and other cancer care facilities . . . over 125 swimmers
Behind every successful party is someone with boundless warmth and hospitality who seems to orchestrate the entire event and makes everyone feel at home. Sue Davies has graciously played that starring roll for Fighting Chance, serving as Chairwoman for our Summer Galas for the last five years -- including the 2010 Gala at Wolffer Vineyards with a record breaking attendance of 180 guests. Sue joined our Board in 2003.

Her enormous contributions to Fighting Chance and, by extension, to improving the quality of care for cancer patients on the East End -- earned Sue our Medal of Honor in 2006. It is a recognition bestowed on only a handful of individuals during our eight year history.

“Cocktails for 180? Coming right up!”

Duncan Darrow
Chairman of Fighting Chance