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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 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. [On Route 114] the professionals shared one office and the library was in that office. We wanted the professionals to have their own offices.

We wanted a long 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 "Is there a person 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 was don't talk about it. Slowly but surely people started talking about their diagnosis because it became more curable. The second movement was called cancer patient navigation. This idea was part of the emotional distress of the disease and all of the logistical issues around it. We became like a concierge and came to the fore because the health care system became so confusing. People didn't know how to cut the red tape. We hired our first navigator in 2004. The guide has been edited every year. The third sort of trend in this area was 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 materials for patients simplify cancer.

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 are stage two or 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 people aren't wealthy. They are working families and this thing was like an atom bomb in what was already a difficult and challenging life. It has gotten worse with the recession.

One there was a total void [of organizations like Fighting Chance]. Secondly, this staff we have is terrifically talented. Our counselor was at Memorial Sloan-Kettering cancer center for 15 years. Our navigator spent 30 years as an academician. We really worked hard to reach out to the medical community. We have three doctors on the board. We have really tried to build bridges of awareness to the medical community and a lot of them know about us. And the staff has worked hard. The board has worked hard and our track record ... I defy you to find someone who has complained.

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.