



## THE EAST HAMPTON STAR

SHINES FOR ALL

June 14, 2007



photo: Carissa Katz

*"People find us very welcoming, very comforting."*

- Patient Navigator Heather Matthews

### From the Chairman



Duncan Darrow  
Chairman of the Board  
Fighting Chance

This newsletter accompanies our annual appeal, because we know this is the time of year many of you consider making -- or renewing -- donations to favorite charities.

Over the past five years, we have learned that donors like to see some kind of independent assessment of the charities they support.

For this reason, we are reproducing recent articles about Fighting Chance from three local newspapers. Each, I'm proud to say, paints a picture of an organization that is both highly professional and warmly embraced by the community it serves.

## Giving a Fighting Chance

BY CARISSA KATZ

When Duncan Darrow founded Fighting Chance five years ago, his goal was to help people with cancer navigate the confusing mass of information they faced after a diagnosis. Since then, Fighting Chance has matured into an organization that not only explains the resources available to people with cancer, but is itself a resource.

With a staff of three and new, larger offices that opened earlier this year on Hampton Road in Sag Harbor, Fighting Chance is able to offer people with cancer and their families some of the services it felt were missing elsewhere, including professional counseling. With more space, it can also accommodate support group meetings, a lending library of cancer literature, and a room where individuals, couples, or families can watch DVDs about the diseases they are dealing with.

"People find it very welcoming, very comforting," said Heather Matthews, the group's cancer information specialist. "We can hold families now; before, a couple would come in and one would have to leave."

Fighting Chance will give tours of its offices, at 112 Hampton Street, after a benefit ribbon-cutting ceremony on Saturday at 3 p.m. Visitors will be welcomed with cocktails and hors d'oeuvres. Tickets are \$50, or \$250 for benefactors.

Fighting Chance started out as a sort of clearinghouse for cancer-related information. Its first major effort was to compile a booklet it called "Coping With Cancer on the East End: A Practical Resource Guide." Packed with frequently asked questions and answers, names and phone numbers, and advice, it was "the yellow pages for all of the cancer care resources relevant to people on the East End," Mr. Darrow said. Having been through his mother's cancer diagnosis and treatment, Mr. Darrow knew how difficult it could be to track down pertinent information in the midst of all the tests and visits to the doctor. The latest edition should be out this week.

The booklet was meant to make the battle a little easier. Gathering the information also helped Fighting Chance see the gaps in the cancer care system. Bit by bit, Fighting Chance expanded its scope in an attempt to fill some of those gaps. Its first year, it hired Jessica Berlin as its director of Internet outreach. Ms. Berlin, who earned her master's in social work from Columbia Uni-

versity, introduced e-counseling to Fighting Chance's Web site, [www.fightingchance.org](http://www.fightingchance.org). "That led to an explosion of our Web site," Mr. Darrow said. "We routinely get, per month, 5,000 visitors." Ms. Berlin answers e-mails from local visitors to the Web site and refers others to appropriate resources in their communities.

In 2005, the organization hired Karrie Zampini Robinson, an oncology social worker who had been at Memorial Sloan-Kettering Cancer Center for 16 years. Finding her, Mr. Darrow said, "was really a miracle."

Ms. Robinson's experience allowed Fighting Chance to begin offering professional one-on-one and group counseling to people with cancer. "It was the first Fighting Chance program of our own to fill a gap," Mr. Darrow said. Ms. Robinson is available for counseling four days a week. She has set up support groups at Southampton Hospital and now can do the same at Fighting Chance's larger offices on Hampton Street.

The same year, the group began searching for a full-time secretary, but found much more than that in Ms. Matthews. She had also worked at Sloan-Kettering and had staffed the East Coast phone bank for the National Cancer Institute for two years.

In addition to the counseling and resource services Fighting Chance provides at its offices, the organization also sponsors an annual symposium on cancer called "A Day of Hope." The third symposium is planned for this fall.

"We've learned a Fighting Chance way of treatment," Mr. Darrow said. "Your day at Fighting Chance now is almost like a spa experience. You come in and tell us what type of cancer you have and we'll show you a tape on a 32-inch TV. You can watch it in a room alone or with family or friends. That gives you a basic understanding of your disease. Then you spend about an hour with Karrie." People can get help dealing with their insurance companies and, if they cannot afford medications, are given the "compassionate care" numbers at pharmaceutical companies.

"People are pretty scared when they come in here, so we try to make them feel warm and soothed," Ms. Matthews said last week. "People use us at different stages in their illness. It depends on the person and what they need. We just try to make ourselves available."

"The charge for all of that is zero dollars," Mr. Darrow said.



photo: John Bayles

THE TEAM: Karrie Robinson, Duncan Darrow and Heather Matthews

# 5 Years of Giving A Fighting Chance

BY JOHN BAYLES

FIGHTING CHANCE has moved from a tiny space behind the Kramoris Gallery to a traditional, beautiful Sag Harbor home on the corner of Jermain Avenue and Route 114. They may have a swank new place, but they're not letting it go to their heads. Their mission remains the same — to provide help to those who need it most.

Fighting Chance was founded five years ago by Duncan Darrow and on Saturday, they will hold a ribbon cutting ceremony for their

new offices. Fighting Chance is growing into a non-profit that Darrow hopes will one day be synonymous with his hometown.

The name came from a prayer. In 2001 Darrow's mother was diagnosed with lung cancer.

"My brother and I ran around for five months trying to deal with the logistics," said Darrow. "Frankly I was pissed off."

"Dear God, all we're asking for is a fighting chance. That was my prayer every night," said Darrow.

Fighting Chance began as a

small group of Darrow's friends, some of whom were cancer survivors, who gathered to brainstorm on ways they might be able to help cancer patients. Today Fighting Chance can proudly say that in five years they have helped approximately 2,000 cancer patients and caregivers, they have distributed over 10,000 resource guides and have over 5,000 visitors a month to their website.

"The guide is organized in order of how the disease attacks you," said Darrow, who explains that the initial idea to provide patients with a resource kit "snowballed" into the resource guide. "The table of contents is the arc of the disease."

They have updated the guide four years in a row. It contains useful resources such as transportation options to and from hospitals, information on available clinical trials for new cancer drugs and a list of pharmacies that take Medicare, have home delivery and speak Spanish. Many such resources can be found online, but a guide with all the resources in one place had never existed.

Director of Clinical Programs at Fighting Chance Karrie Zampini Robinson pointed out another benefit of the resource guide.

"A lot of older people don't go online," said Robinson. "The guide is good for them."

"We basically started as a clearing house," said Darrow. "Then one day I looked up and this little foundation had a Sloan Kettering Counselor and a National Cancer Institute Patient Navigator."

Patient Navigator Heather Matthews joined Fighting Chance in 2005 from the National Cancer Institute where she was trained as a cancer information specialist. Robinson also had 16 years of counseling care and oncology social work experience at Sloan Kettering. Darrow said without them Fighting Chance would not be what it is today.

"Cancer patient navigation will evolve into the next health care specialty," said Darrow.

The typical patient shows up at Fighting Chance's front door usually within 48 hours of diagnosis.

"They come in and we sit them down in the living room," said Darrow. "We show them a half hour video on their disease."

Robinson said the video might be the first time the patient really "heard about their cancer."

When the doctor tells you," said Robinson, "you're in shock and you're not really listening."

From the living room the patient is led into the cancer library where a "wall of hope" has been constructed showing the 10 best clinical trials currently underway in the country.

"A lot of people let go in this room," said Darrow. "They cry a lot."

The library also has cancer literature in Spanish. Darrow pointed out that a patient might spend an entire day trying to locate a guide for lung cancer in Spanish. Fighting Chance has taken this into account and has a number of guides in Spanish in their library.

The foundation has acknowledged certain facts: cancer isn't going any-

*"...one day I looked up and this little foundation had a Sloan Kettering Counselor and a National Cancer Institute Patient Navigator."*

- DUNCAN DARROW

where, hospitals are doing less and less for the patients, hospitals only treat the tumor.

At Fighting Chance, Robinson and Matthews treat the patient, the "whole patient," and the family.

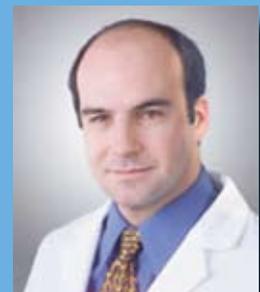
In the next five years Darrow hopes to see their model catch on in other communities. More importantly Darrow hopes they "continue to service an underserved community — his hometown."

*"their mission remains the same . . ."*

*. . . to provide help to those who need it most."*

## Physician at Memorial Sloan-Kettering joins Board of Fighting Chance

Dr. Bach is a pulmonologist/intensivist with expertise in quality of care and epidemiologic research methods. He has conducted research on racial disparities in the treatment and outcome of lung cancer patients, on the relationship between hospital volume and survival for lung-cancer surgery, and has participated in evidence-based guideline development for the care of lung cancer and COPD.



Peter B. Bach, MD, MAPP

# Benefit Celebration For 'Fighting Chance'

Cancer support organization in its 5th year

By Oliver Peterson

On Saturday, the Sag Harbor organization Fighting Chance will host a dinner and auction to celebrate five years of helping East End cancer patients and caregivers while asking for nothing in return.

The nonprofit organization was founded in 2002 by Duncan N. Darrow and has since grown to be a major resource, helping the scores of people affected by cancer, including the sick and those who love them, find the care and services they need.

Mr. Darrow, a New York attorney, came up with the idea for Fighting Chance when his mother, Charlotte, died in June 2001 after being diagnosed five months earlier with lung cancer.

"What struck me was the lack of supportive resources for caregivers," Mr. Darrow said, noting that they must contend with a bewildering array of new issues and navigate through an overwhelming quagmire of information, often without guidance, while at the same time suffering from grief and emotional stress.

"When she died, I wanted to do something for the next guy," Mr. Darrow said of his mother's role in the creation of Fighting Chance.

His original intention was to simply collect and distribute information—a model that still stands today, though significantly expanded. "We started out as a clearinghouse," Mr. Darrow said, explaining that he achieved a bird's-eye view of cancer care on the East End, he saw gaps, and Fighting Chance created programs to fill them.

In May of this year Fighting Chance moved from its 200-square-foot office behind the Romany Kramoris Gallery on Main Street in Sag Harbor, to a breezy

sunlit house on the corner of Jermain Avenue and Route 114. Visitors have access to counseling, support groups, a library of books and materials on all types of cancer, and a staff member ready to offer help.

In 2004, after years of work, Fighting Chance released "Coping with Cancer on the East End: A Practical Resource Guide." The guide takes cancer patients and caregivers through the arc of the disease, beginning with information on doctors, education and resources about cancer, to second opinions, physical therapy, and then on to spiritual support and eventually hospice care. The guide has been updated each year since 2004, and Fighting Chance says it has distributed more than 10,000 copies.

Mr. Darrow said one of the not-for-profit's new additions is a "sports bar TV" for the group counseling room, where visitors can watch DVDs explaining their particular cancer. "Once a doctor tells you you have cancer, you shut down and don't remember anything," Mr. Darrow said, explaining that patients rarely retain the details about their disease following the devastating news.

The first social worker on staff, Jessica Berlin, started in 2003, and in 2005 Fighting Chance hired social worker Karrie Robinson and Heather Matthews, its resident "Patient Navigator." Ms. Matthews was born and raised in Montauk, worked at Memorial Sloan Kettering Cancer Center's hematology division, then trained as a "cancer information specialist" at the National Cancer Institute, where she worked for two years. Eventually, Ms. Matthews returned to the East End and took the job at Fighting Chance, where she helps patients and caregivers determine what



# The Southampton Press

AUGUST 23, 2007

they need and how to get it.

"I love being in my own community," she said, but admitted that while rewarding, working with sick people that she knows and loves is not easy. One of Ms. Matthews's duties that can give an extra boost of hope to patients and their families is leading them to clinical trials applicable to their illness.

A new feature of the Fighting Chance office is Mr. Darrow's "Wall of Hope," where booklets on numerous clinical trials from prominent cancer hospitals and pharmaceutical companies are available to peruse. Information about the trials are also available via the internet through FightingChance.org, the well organized and comprehensive website detailing everything from the story of the inception of Fighting Chance, to links for other cancer resources and on-line contact and counseling run by Ms. Berlin, who responds to inquiries from visitors to the site when she's not counseling sick children at Mount Sinai Hospital in New York.

Ms. Matthews said Fighting Chance has been busy, which is unfortunate but encouraging, because people are taking advantage of the free services.

Fighting Chance is supported by hundreds of donors and has a budget of \$300,000 each year, which is detailed in an annual report complete with financial results prepared by an outside accounting firm.

On Saturday, August 25, Fighting Chance will host its dinner and silent auction at the home of Rick and Sue Davies in East Hampton to celebrate the fifth anniversary of the organization and

raise money for its expanding list of services and resources.

On November 10, the annual "Day of Hope" conference comes back to Bay Street Theatre in Sag Harbor, where Fighting Chance creates a forum for cancer patients, caregivers and survivors to gather and share support and hopeful stories, while also learning more about the disease. This year's keynote speaker will be Sloan-Kettering top lung cancer specialist, Dr. Mark Kris, who will provide information about advancements in his field of specialty.

At the end of the Day of Hope, patients and their loved ones write down what hope means to them and the words are added to the annual "Book of Hope," a moving collection of thoughts and affirmations distributed at no cost by Fighting Chance.

Mr. Darrow said the Day of Hope has had wonderful results, and related a story in which a girl shared that she was recently diagnosed with pancreatic cancer and her fear that it was a death sentence. Before long a survivor of her disease comforted her with his miraculous story, they bonded with a tearful hug and the girl left Bay Street Theatre with the hope she had lost.

"Those are the moments you feel like you're accomplishing something," Mr. Darrow said.

*Fighting Chance is located at 112 Hampton Street in Sag Harbor and has one-on-one and group counseling available to anyone, free of charge. Call 725-4646 or visit FightingChance.org for more information.*



Fifth Anniversary of Fighting Chance and the Ribbon Cutting Ceremony of the new offices at 112 Hampton Street in Sag Harbor.

## Fighting Chance Anniversary

FIGHTING CHANCE, a cancer counseling and resource center serving the East End, celebrated its fifth anniversary and the opening of its new Sag Harbor offices on June 16 with a ribbon cutting ceremony and cocktail party.



### FIGHTIN' FOLKS

- ◀ 1 > HC&G's Eileen Ekstract with Fighting Chance founder Duncan Darrow.
- ◀ 2 > Carol Mason with director of clinical programs Karrie Zampini-Robinson and Joanne Nardo-MacDowell.
- ◀ 3 > Patient navigator Heather Matthews and Duncan Darrow.
- ◀ 4 > Olivia Sterns.
- ◀ 5 > Katrina Miller and Eleanor Miller.
- ◀ 6 > Deborah Kalas.
- ◀ 7 > Director of Internet outreach Jessica Berlin.



PHOTOGRAPHS BY RICHARD LEWIS

## Karrie's Corner

... tips and coping strategies  
from our  
Director of Clinical Programs

## When the diagnosis is cancer

Most people are on unfamiliar terrain when diagnosed with cancer. Part of the initial challenge for the patient and family is to become familiar with a new language and begin to get a greater sense of control over healthcare needs.

At diagnosis, the following questions will help the patient and family begin to take control;

1. What type of cancer do I have?
2. What stage or grade is my cancer and what does this mean regarding the course of my illness?
3. What are my surgery and/or treatment options?
4. What do you recommend and why?
5. Should I be considering other treatment options?
6. Are there side effects from the treatment?
7. What about recovery after surgery and treatment?
8. Are there long-term or late effects from treatment?
9. Is follow-up care necessary following surgery or treatment?
10. Are there clinical trials that are appropriate for me?

Being able to make informed and educated decisions about the course of medical care is the beginning of the cancer patient's journey. Asking knowledgeable questions allows the doctor to further elaborate and explain about the course of illness and treatment. To familiarize oneself with this new environment is the beginning of empowerment and feeling in control. This information is adapted from the website of the American Society of Clinical Oncology, PLWC guide.

Karrie Zampini Robinson, LCSW



photo: CB Grubb

Karrie Zampini Robinson, LCSW  
Director of Clinical Programs,  
Fighting Chance

NEW  
in '07

## Cancer Patient Transportation Services

- To be sure you get to the doctor on time -

Lack of transportation can become an emergency issue for cancer patients who can't afford to miss potentially life-saving therapy sessions.

Breast cancer patients, for example, can require 30 consecutive days (excluding weekends) of radiation treatments. For some on the East End of Long Island, the nearest radiation oncologist is 50 miles away. Round-trip, that's 100 miles of driving.

But some days you could be too ill or fatigued to drive yourself to the doctor -- and your friends may all be working. Or, say your only car breaks down. How are you going to get to the doctor on time?

Now there is a simple answer: just call Fighting Chance at 631.725.4646. Thanks to the generosity of one of the leading car services in the Hamptons, their cars can now take our patients to emergency doctor appointments - using their reliable professional drivers. And like everything we do at Fighting Chance, the service is **free of charge**.

Made possible by a generous grant from Richard Perlman & Ellen Hansen and  
The Perlman Family Foundation.

Fighting Chance is a 501©(3) organization, and all contributions are fully tax-deductible. Checks can be made payable to Fighting Chance and sent to us at P.O. Box 1358, Sag Harbor, New York, 11963. Donations can also be made via credit card either on our website ([www.fightingchance.org](http://www.fightingchance.org)) or by calling our office at (631) 725-4646.