# FIGHTING CHANCE

Resource Directory for Cancer Patients on the East End of Long Island

www.fightingchance.org
Sag Harbor Office: 631.725.4646
Southampton Office: 631.638.7400

#### Welcome

Over 15 years ago my mother, who lived in Sag Harbor, was diagnosed with lung cancer. She lived for another 100 days.

We desperately searched for someone to patiently educate us about cancer so that we could make well-informed de-



**Duncan Darrow** Founder & Chairman

cisions concerning treatment options.

We also needed an expert to help navigate the healthcare system which was overwhelming us with red tape. And we needed professional counselors who could help us overcome the feelings of hyper-anxiety. Back then there was no place to go.

Now there is: Fighting Chance

### Accreditation





In 1951 the American Medical Association established the "Joint Commission" as a non-profit that would audit healthcare facilities once every 3 years and "accredit" them if they met the highest standards of patient care.

Fighting Chance is the only cancer counseling center in the United States to have sought and obtain such accreditation, a process which included a 3 day on site visit to interview staff and review all office procedures.

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Group Counseling Room at our Sag Harbor office



Our the new office at The Phillips Family Cancer Center in Southampton



Fighting Chance is America's oldest and largest free Cancer Counseling Center which operates on a regional basis and is accredited by the Joint Commission.

In our case the regional focus is the East End of Long Island.

Fighting Chance has two offices: our office in Sag Harbor (at #34 Bay Street) which we have occupied for a decade, and a second office opened in early 2019 within the Phillips Family Cancer Center in Southampton

Both offices are staffed by highly credentialed professionals including: oncology social workers, clinical psychologists, and certified cancer patient navigators. All of their counseling services, and all other support we provide, is free-of-charge.

Our counselors typically meet with a cancer patient once a week for two months. The main concern is helping patients cope with two overwhelming fears and manage the stress and hyper-anxiety those fears produce..

First of all, many patients view a cancer diagnosis as a death sentence. They are afraid they are going to die, afraid the dying process will be painful and afraid that their family unit will be disrupted.

Second, patients are fearful of battling cancer. They realize it is a journey, but one into the unknown. In these cases, part of our job at Fighting Chance, is to explain the journey, step-by-step, so patients feel there will be very little which is unexpected. They take comfort in the fact that we have navigated cancer journeys for over 2,000 patients during the past 18 years.

#### Portfolio of Services (Free)

Counseling for **Navigators for the** Psychological & **Cancer Journey Emotional Dis-**& Cutting Red tress Tape Free Transportation to Doctor Offices on **Education (Patient** The East End Guides & Website) & Free Jitney Tickets and Free Weekly to NYC Yoga Hospital **Appointments** 

- Counseling. This is a service in greatest demand and most patients like to see their counselor once a week for two months and call them once a day.
- Navigators. They remain by the patient's side every day of the cancer journey to be sure there's nothing unexpected.
- Patient Guide. Every patient receives a copy of both our Guides. The "Red Guide" is a list of cancer care resources on the East End, and the "Blue Guide" takes the patient, step-by-step, through the cancer journey.
- Free Transportation. Going to a doctor's appointment on the East End? Our volunteer drivers will get you there. Need to see a specialist in New York City? We have free Jitney tickets for you.

### Chapter 1

## Cancer Centers & Research Hubs for East End Residents



A "Cancer Center" refers to a facility where every therapeutic option is "under one roof" or literally a block or two away. Also, within the facility or nearby, is counseling for psychological stress and the equipment needed for diagnostic tests. Those test include: a CT Scan, MRI, Pet Scan and a Biopsy. For those on the East End there are two such facilities -- one in Southampton and the other in Port Jefferson.

### Phillips Family Cancer Center | Southampton | 740 County Rd 39A 631 638 7400

This \$25M facility with 15,000 sq. ft. opened in early 2019 and offers exceptionally sophisticated radiation oncology (with a linear accelerator) and clinical oncology with treatments ranging from chemo to immuno-oncology. The Center also has a Fighting Chance office whose counselors can treat patients suffering from acute psychological stress.

The Center is affiliated with Stony Brook Southampton Hospital and, just a few blocks away, patients can find diagnostic testing. Surgical oncology also is based at the hospital with notable excellence in breast cancer surgery.



The Center's patients have access to the cutting edge cancer care protocols being pioneered The MART, part of the Stony Brook Healthcare Complex in Port Jeff.

### Stony Brook's New Cancer Center & MART Facility

Port Jefferson | 3 Edmund Pelligrino Rd 631 638 1000

In November 2018, Stony Brook vacated its cancer center which it had occupied for a couple of decades.



Stony Brook's old cancer center vacated in late 2018

As a replacement, Stony Brook has built an entirely new cancer center that is an integral part of the 10-story medical building that was occupied in late 2018 and is known as The Medical and Research Translation Facility or MART.

The Most significant feature of MART is that it permits the treatment of cancer patients to take place side-by-side with scientists engaged in cancer drug discovery. For example, the MART has 25 cancer biology-oriented labs, a 30-station infusion center for chemo and 30 additional rooms for other cancer treatments



Stony Brook's new cancer center & MART facility

For those who require inpatient treatment, the MART exists adjacent to a new 10-story Hospital Tower. The entire complex cost \$475 million. The combination of The MART and the new Hospital Tower makes Stony Brook cancer care unrivaled on Long Island and within a peer group of the finest cancer centers in the country.

# Chapter 2 Hospitals

### East End Hospitals & Other Cancer Care Resources

#### Stony Brook Southampton Hospital Southampton | 240 Meeting House Lane 631 726 8200

This is the most significant hospital on the East End of Long Island. It was founded in the early 1900s, has 125 beds and several parts of the facility have been modernized in recent years. These include: The Ellen Hermanson Breast Center; The Gruss Heart & Stroke Center; The Paulson Emergency Room Facility and The Ed & Phyllis Davis Wellness Center.

The crown jewel of this modernization campaign is, of course, the \$25 million Phillips Family Cancer Center.



- Q. During a cancer patient's last two weeks of life, how many times do they go to a hospital emergency room?
- **A.** Every other day -- in other words 7 times during a two week period.

### The Ellen Hermanson Breast Center Southampton | 240 Meeting House Lane 631 726 8466

Constructed in 2009 – largely with proceeds from the Ellen's Run Charity – this Center is a separate wing of the Southampton Hospital facility. Among its distinctive features is a surgeon specializing in resection of breast tumors and mastectomies. There also is a dedicated pathologist, a navigator, and state-of-the-art imaging for mammograms.

NY Cancer & Blood Specialists (NYCBS) Southampton | 640 County Rd 39 Riverhead | 750 Old County Rd 631 751 3000

New York Cancer & Blood Specialists (NYCBS) is one of the nation's leading oncology practices providing state-of-the-art cancer care. Their community cancer centers offer an array of integrated cancer services, including medical oncology, hematology, radiation oncology, diagnostic imaging, and comprehensive support services.

NYCBS offers cutting-edge medical technology and equipment, a full-service research department, 60+ clinical trials with the latest cancer therapeutics, and an onsite laboratory and pharmacy, with locations throughout New York State, including Riverhead and Southampton, so patients on the East End have access to world-class cancer and blood disorder care all under one roof and close to home.



### The Comprehensive Cancer Centers of New York City

#### About the "CCCs"

In the United States there are 50 Comprehensive Cancer Centers or "CCCs." That is a designation awarded by the National Cancer Institute which has provided almost all federal funding for the war on cancer since 1971.

Being awarded CCC status means that a facility not only offers exceptional treatment for cancer patients, but also runs a robust cancer research operation and serves as a main site for conducting clinical trials of promising new cancer drugs.

Also, the vast majority of grants made by the NCI are channelled to scientists working at CCC-based laboratories. Over the last 50 years all NCI grants have totalled over \$150 billion.

Patients who choose to be treated at a CCC often do so for the piece of mind of knowing that the CCC physicians should be up to speed on the latest cancer treatment advances.

On the other hand, CCC facilities are very large and patients sometimes complain that the atmosphere is impersonal and that their doctor lacks a bedside manner.

There are three CCCs in New York City and each of them has treated many East End cancer patients over the years.

#### Memorial Sloan Kettering Cancer Center New York City | 1275 York Avenue 212 639 7230

MSK is the largest healthcare facility in the US that is exclusively focused on cancer. It has almost 1,000 physicians treating cancer patients and another 1,000 scientists engaged in cancer research. It ranks #2 in the US for cancer treatment capabilities just behind MD Anderson in Houston. It also has a midtown satellite on Lexington Ave. at 53rd Street, and another one in Commack Long Island.

### New York - Presbyterian University Hospital of Columbia & Cornell

> Herbert Irving CCC at Columbia New York City | 168th St. & Broadway 212 305 2500

> Meyer Cancer Center at Weill Cornell New York City | 1300 York Avenue 646 962 6132

There are two world-class cancer centers that both operate under the New York-Presbyterian Hospital umbrella.

The Columbia CCC is unique because it is an integral part of one of the world's largest university complexes. This permits the doctors and scientist to draw upon a vast pool of intellectual capital.

The Weill Cornell campus is noteworthy for its recent commitment to develop a sizeable cancer research capability, now housed in part of a new 20 story Manhattan skyscraper.

#### Mt. Sinai Comprehensive Cancer Center New York City | 1176 Fifth Avenue 212 241 6756

The Sinai complex received its CCC status in 2015 and is widely viewed as an up-and-coming facility for both treatment and research, including, importantly, the Dubin Breast Center. Overall, the Sinai umbrella extends over a dozen hospitals within the NYC-Metro area.

### **Chapter 4**



### Top Oncologists Available to East End Cancer Patients

Because the Phillips Center in Southampton is affiliated with the Stony Brook Cancer Center in Port Jefferson, it is likely that many of the physicians in Port Jefferson will spend considerable time in Southampton, or be readily accessible to patients who initially visit the Phillips Cancer Center.

When accessing an oncologist in Port Jefferson be mindful that its cancer center oncologists serve on one of 12 "Interdisciplinary Teams" -- each focused on one of the organs where cancer is most prevalent.

In most cases the **Team Leaders** (described below) have been recognized as among the "Top 1%" of US physicians according to the definitive guide known as <u>Castle Connolly</u>.

#### Lung

#### Thomas Bilfinger, MD

He specializes in micro-surgery techniques that can remove early stage tumors in the lung.

He is the author of over 200 scholarly articles and NY Magazine ranks him as among the top 2% of physicians in the MY Metro Area.

#### Prostate/Urologic

### Wayne Waltzer, MD

He has been a urologist for over 40 years and is one of Long Island's most experienced practitioners in the area of treatment options for prostate cancer; he also has gained recognition for pioneering work in kidney transplants.

#### Breast

#### Brian O'Hea, MD

He specializes in complex breast cancer surgery and also heads up the Carol M. Baldwin Breast Cancer Care Center at Stony Brook.

Dr. O'Hea has been ranked among the "Top 1%" of US doctors, year after year by Castle Connolly.

#### Colon & Upper GI

#### Aaron Sasson, MD

He is the author of over 100 scholarly articles and is ranked among the "Top 1%"" of US doctors by Castle-Connolly.

Dr. Sasson is a surgeon and specializes in cancer of the upper gastrointestinal tract including: liver, pancreas and stomach. He also is Chief of all surgical oncology at Stony Brook

#### **Head & Neck**

#### Ghassson Samara, MD

He has been a practicing physician for 30 years and may be best known for pioneering robotic-assisted surgery for patients with ear, eye, nose or throat conditions.

#### **Pediatric Oncology**

Laura Hogan, MD

Dr. Hogan serves as Team Leader for the Pediatric Oncology unit and has been practicing medicine for 15 years.

#### **Gynecologic**

William Burke, MD

He has been practicing for 23 years and has specialized in complex gynecologic surgeries.

He received his medical training at Columbia, followed by a fellowship at Michigan.

#### Melanoma

Tara Huston, MD

Dr. Huston leads the melanoma team after her education at Harvard College and obtaining her medical degree at Stony Brook.

### Hematology

Michael Schuster, MD

He has led the building of Stem Cell Transplant ("SCT") programs at Stony Brook and at two other prominent medical centers prior to joining Stony Brook a decade ago.

SCT procedures are highly complex, and can produce remarkable cancer remission; Dr. Schuster has facilitated several thousand such operations during his 25-year career.

#### Radiation Oncology

Samuel Ryu, MD

Dr. Ryu has a worldwide reputation for his pioneering work in several areas of radiation oncology, including stereotactic radiosurgery, which utilizes externally generated ionizing radiation to inactivate or eradicate defined targets in the head or spine without the need to make an incision



### Important Non-Oncology Physicians on the East End

### The Cancer Patient's Medical Support Team

### > Role of the Primary Care Physician

Not every physician on the medical support team for a cancer patient is an oncologist. For example, the patient's primary care doctor -- sometimes known as the" family doctor" -- is almost always on the team, in part because they are most familiar with the patient's long-term medical history which will become relevant in many decisions about cancer treatment options.

### > Role of Non-Oncology Specialists

Another member of the medical team often is a physician knowledgeable about the organ in which the malignant tumor is located, or to which it is adjacent.

For example: a gynecologist would be an important part of the team treating a female with cancer of the uterus or cervix. As another example a gastroenterologist might well have detected the patient's cancer, if it was in organs including the pancreas, liver, or colon and their insight could be invaluable in deciding on a surgical solution.

### >Changing the Team's Composition

Sometimes a patient has an emergency procedure for their cancer -- for example, to remove a tumor-related blockage in the colon -- but they do not have a relationship with a non-oncology specialist familiar with the organ under focus.

In those cases East End cancer patients will have to find a non-oncology specialist and hence many of them are listed in the pages that follow.

### Meeting House Lane Medical Practice - New Umbrella Organization for East End Physicians

In 2009 Southampton Hospital organized over 20 East End doctors -- all of whom had admitting privileges at the Hospital -- into a new healthcare consortium known as "Meeting House Lane."

Today, the vast majority of doctors on the East End practice under the Meeting House Lane umbrella. These doctors all have affiliations with Southampton Hospital and are now located in a strategic pattern so that there are doctor offices in virtually every village and hamlet on the East End.

Meeting House Lane is also set up to insure that the doctors within its organization encompass an exceptionally broad range of specialization.

The physicians listed below, who are part of the Meeting House Lane practice have that status denoted with an asterisk (\*).

### Dr. Alex Aponte\* Westhampton Beach I 147 Beech Rd. Suite A 631 288 7746

Dr. Aponte, a specialist in Family Medicine, is one of the few members of the Meeting House Lane group whose practice is based in Westhampton, it also is noteworthy that he serves as Medical Director of the Davis Wellness Institute at Southampton Hospital.

### **Dr. Louise Collins\* East Hampton** I 200 Pantigo Place 631 329 6500

Dr. Collins specializes in gynecology and obstetrics and has been in practice for almost 20 years. She received her medical degree from Georgetown University School of Medicine.\*

#### Dr. Charles DeFraia\* Amagansett I 518 Montauk Highway 631 267 5373

A specialist in Internal Medicine who also supervises and teaches medical students and residents at Southampton Hospital.

### **Dr. George Dempsey East Hampton I** 200 Pantigo Place 631 324 9200

Dr. Dempsey specializes in Family Medicine and is based in the facility established by the East Hampton Healthcare Foundation. He attended the Mayo Medical School and went on to a residency and subsequent fellowship at the Department of Family Medicine, State University of New York. He has been in practice for over 27 years.

#### Dr. Michael Genereux\* Montauk I 679 Montauk Hwy 631 668 3705

Dr. Genereux has a Family Medicine practice and is the only member of the Meeting House Lane group whose office is based in Montauk.

### Dr. Ralph Gibson East Hampton I 200 Pantigo Place

631 324 4700

Dr. Gibson is a highly regarded internist who spends part of his time practicing in East Hampton, at the Health-care Foundation, and also sees patients in New York where he has an affiliation with Lenox Hill Hospital. His medical degree is from Weill Cornell and he has served important community boards.

### Hamptons OB/GYN Southampton I 595 Hampton Road

631 283 0918

A practice group of six physicians, this is the dominant OB/GYN practice group on the East End and has additional offices in Hampton Bays, Riverhead and Westhampton Beach.

#### Dr. N. Patrick Hennessey Wainscott I 386 Montauk Hwy, NY

631 537 6020

Dr. Hennessey has a unique dermatology practice because he has an office in Wainscott as well as a practice in New York City where he is on the staff of the NYU Langone Medical Center. He completed his medical internship at the University of Michigan Hospital and his residency was at Harvard.

#### Dr. Cynthia Ickes Greenport I 74825 Main Rd

631 477 1720

Dr. Ickes specializes in Internal Medicine and is one of the few physicians with a long-time presence on the North Fork; she is affiliated with Eastern Long Island Hospital.

### **Dr. Peter Keit Shelter Island I** 44 South Ferry Road

631 749 3149

Dr. Keit specializes in Family Medicine and is one of the few doctors with a full-time practice on Shelter Island; he is affiliated with Eastern Long Island Hospital and Winthrop Hospital.

### Dr. William Blake Kerr\* Wainscott I 83 Wainscott NW Rd.

631 537 1892

A native of East Hampton, Dr. Kerr went away for college to Dartmouth but returned to practice medicine on the East End some 25 years ago. He practices out of the Wainscott Walk-in Clinic and advance appointments generally are not necessary. A beloved figure on the East End

### Dr. John Oppenheimer\* Sag Harbor I 60 Bay Street

631 725 4600

Specializes in Internal and Geriatrics Medicine, and received his medical degree from Tulane and has been in practice for more than 20 years.

### Chapter 6



### **Transportation Assistance**

### **Three Transportation Challenges**

- 1. From Patient's Home to East End Doctor . . . problems arise when there is only one car in the family and the patient's spouse has taken it to work. Need a ride to the doctor? Just call Fighting Chance and a member of our volunteer drivers corps will pick you up and drive you home. Call 631.725.4646.
- 2. Going to New York City for Specialized Treatment Sometimes patients need to get to an urban cancer center in Manhattan and plan to take the Hampton Jitney. But Jitney tickets -- for the patient and a caregiver on a round trip basis -- cost over \$120. Is there any charity that can help defray that cost?



Thanks to the generosity of the Hampton Jitney and donations from Fighting Chance supporters, you can get **free** Jitney tickets to/from Manhattan if you are travelling there for specialized cancer treatment.

Tickets must be picked up, in person, at the Fighting Chance office in Sag Harbor. Call 631.725.4646 to let them know you are coming. If you are not seeing a counselor, we ask that you spend a few moments speaking with them.

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### Thank You Notes from Patients Receiving Free Transportation

Dear Fighting Chance,

There were times I just could not get my wife to Riverhead for radiation, but your volunteer drivers came through. Such wonderful folks.

Thanks for all, Stan

To the Staff at Fighting Chance,

When I was connected to a volunteer driver they picked me up exactly on time and took me from Sag Harbor to Stony Brook. We became quite friendly and this volunteer helped me again and again. By now I consider her a true friend.

Fondly Cheryl

To My New Friends at Fighting Chance . . .

There were a number of times when I called Fighting Chance, to request bus tickets to our hospital in New York City. They were always helpful. It is not just about bus tickets. When I would visit the FC office to pick up tickets, a counselor would take the opportunity to warmly invite me to talk, from the heart.

Dave

Dear Kind Souls,

Thank you so much for your Jitney tickets that enabled me and my husband to travel for free to a hospital in NYC.

This is a tremendous help to me in getting the cancer treatment I need without worrying about the cost. Your endless support, care and generosity will always be appreciated.

Sincerely, Rosemarie

### **Chapter 7**



### Urgent Care & Ambulance Services

Because of the strength and toxicity of cancer treatments – such as chemo and radiation – many patients will find themselves visiting the emergency room on multiple occasions. Some of the symptoms that require urgent care include: dehydration, uncontrollable vomiting, difficulty breathing, and pain.

When patients face these issues, on the East End, they have the option of getting to an "urgent care" facility on their own or calling an ambulance, in which case they will be taken to the emergency room of the nearest hospital.

### Jenny & John Paulson Emergency Department Southampton Hospital | 240 Meeting House Lane 631 726 8420

Thanks to a \$5 million gift from the Paulson Family, the hospital's emergency room was completely renovated in 2012 and is now state-of-the-art and staffed by Emergency Medicine Specialists. It is open 24/7 every day and handles cases from Montauk to Westhampton.

### Emergency Medicine at ELIH Eastern Long Island Hospital/Greenport

201 Manor Place

Another recently renovated urgent care facility that serves the needs of the North Fork.

# PBMC Health Emergency Peconic Bay Medical Center/Riverhead | 1300 Roanoke Ave 631 548 6000

PBMC has recently integrated emergency medicine specialists from Northwell to lead the staffing of its emergency room. Also notable as having a State certified "stroke treatment center."

### East Hampton Urgent Care East Hampton | 470 Pantigo Road

631 329 5900

Hours: 9 am to 5 pm, seven days a week. Affiliated with the Meeting House Lane Medical practice of Southampton Hospital and one of the best urgent care centers on the East End.

#### Wainscott Walk-In Medical Care Wainscott | 83 Wainscott Road 631 537 1892

Technically a family medicine practice, headed up by Blake Kerr, MD; but because no appointments are required, it often functions as an emergency care center.

#### East Hampton Healthcare Foundation East Hampton | 200 Pantigo Road 631 324 8943

Technically a center for family medicine practice and some part-time specialists, but capable of handling emergency medical issues.

### Stat Health Cutchogue | 32645 Main Road

631 734 5505

About the only emergency walk-in clinic on the North Shore. Part of a chain of clinics on Long Island, and staffed with Emergency Medicine Physicians.

### Need an Ambulance . . . Always Call 911

If a cancer patient is considering calling an ambulance on the East End, they should be mindful that almost every village has its own ambulance service.

Between Montauk and Sag Harbor, however, there is a single "911 Dispatching Service," which happens to be based in the East Hampton Firehouse. For villages within Southampton Town, there is a similar Dispatching Service.

Also be aware that if an ambulance is summoned, a police squad car will also be dispatched and, in many cases, the police arrive slightly before the ambulance service.

### When Cancer Patients

**Need a Pharmacy** 

The most common forms of therapeutics, used in treating cancer patients, are not obtained like typical prescription drugs picked up a pharmacy.

For example, all forms of chemo therapy agents are shipped directly to a clinical oncologist and patients receive them at the doctor's office in a "chemo infusion suite."

Radiation is another very common and effective form of treatment and that is delivered in the clinic of a radiation oncologist and requires no drugs at all.

The most common drugs prescribed for cancer patients -- which they do pick up at a pharmacy -- are those that blunt the distressing side effects of treatments like chemo therapy or symptoms of the cancer disease.

These drugs could include anti-nausea treatments, pain medications, drugs to relieve hyper-anxiety, sleeping aids and remedies for constipation.

In the list that follows, we have tried to include one major pharmacy located in each of the main villages and hamlets of the East End.

Rite Aid Drug Store
Bridgehampton I Bridgehampton Commons
631 537 0235

CVS Pharmacy East Hampton I 38 Pantigo Road 631 324 8587

White's Pharmacy East Hampton | 81 Main Street 631 324 0082

#### Rite Aid Drug Store Bridgehampton I Bridgehampton Commons 631 537 0235

CVS Pharmacy East Hampton I 38 Pantigo Road 631 324 8587

White's Pharmacy East Hampton | 81 Main Street 631 324 0082

Center Island Pharmacy Hampton Bays I 254 West Montauk Highway 631 728 3300

**Rite Aid Hampton Bays I** 22 East Montauk Highway 631 728 2566

White's Pharmacy Montauk I 95 On The Plaza 631 668 2994

Barth's Drug Store Riverhead I 32 East Main Street 631 727 2125

Shelter Island Heights Pharmacy Shelter Island I 19 Grand Avenue 631 749 0445

Sag Harbor Pharmacy Sag Harbor I 120 Main Street 631 725 0074

Corwith Pharmacy Southampton I 56 Hampton Road 631 283 0001

Rite Aid Westhampton Beach I 161 Main Street 631 288 5845



### Wellness, Yoga & Exercise

**JUST MOVE.** While most cancer patients know that some form of exercise is helpful they often worry about exactly what type would be best . . . and sometimes end up doing nothing. Just move. Any type of movement is beneficial.



"Movement can help increase health and mental resilience in the midst of the trauma of cancer."



### Phyllis & Ed Davis Wellness Institute at Stony Brook Southampton Hospital Southampton | 240 Meeting House Lane 631 726 8800

This is a facility that embraces the simple principle "Just Move" because there are a multitude of classes and exercise venues within this new addition to the hospital facility.



"A recent study of patients with breast cancer found that women who exercised for two and a half hours per week after they had been diagnosed had a **67 percent lower risk** of death compared with patients who did no exercise."

#### Yoga Shanti Sag Harbor | 33 Bridge Street 631 725 6424

Run by Rodney Yee and Colleen Saidman -- both among the leading yoga teachers -- the facility is located in its own building just behind



Sag Harbor's Main Street. Yoga classes there are free, for cancer patients, on Tuesdays and Thursdays, thanks to the generosity of Rodney and Colleen.



### Ananda Yoga Wellness Center Southampton I 39 Windmill Lane

(631) 204-1219

Founded in 2001, this is one of the oldest y and most highly regarded yoga centers on the East End. It is operated by the husband and wife team of Mary Angela Buffo and Dr. Andrew Cohen, D.C., a chiropractor whose practice is located in the same office space. In late 2016 they began providing free-of-charge yoga sessions to cancer patients of Fighting Chance.

### **East End Acupuncture**

East Hampton I 43 Pantigo Rd.

(631) 329-5292

This facility opened over 20 years ago and is run by Julie Sigler-Baum and her daughter Carol Sigler, who have impressive professional credentials; quite possibly the "gold standard venue" for East End Acupuncture.

### Without an Oncology Emphasis

### Knowledge About Cancer . . . Why is it Useful to a Licensed Clinical Social Worker?

At Fighting Chance our counselors are known as "Oncology Social Workers." That means they have an in-depth understanding of how a cancer diagnosis traumatizes the patients and useful techniques for minimizing that trauma.

On the East End there are a few other LCSWs -- and they are listed below. But none of these LCSWs concentrate exclusively on treating patients traumatized by cancer. Instead, these social workers, for the most part, are helping patients cope with emotional distress which has other origins -- such as alcohol, marital issues and domestic violence.

Susan S. Griffin, L.C.S.W. Sag Harbor I 110 Jermain Avenue 631 725 2978

Karen Melnick-Nadell,LCSW East Hampton I 12 Will Curl Highway 631 324 0714

Randy Meadoff, LCSW East Hampton I 10 Sylvie Lane 631 926 2211

Edyle O'Brien, L.C.S.W. East Hampton 631 329 0520



### When Cancer Patients Benefit from Physical Therapy

During the course of primary therapy, a cancer patient has minimal need for a physical therapist. But, cancer treatment is a grueling experience and physical therapy can be very useful within the post treatment setting. Here are a few examples:

- > Lymphedema: This condition results from the removal of lymph nodes, most often as part of treating a patient with breast cancer. The consequence is a degradation in lymphatic drainage and that can be partly remedied through a form of physical therapy known as "lymphatic massage."
- > Cancer-Related Fatigue or "CRF." This is one of the most common and enduring side-effects of chemo and radiation and is best combated through a program of aerobic training and strength conditioning, both of which can be guided by physical therapy.
- > Pain. Both during treatment and post-treatment, a cancer patient can experience pain of considerable intensity and frequency. Treatment strategies -- many of which are well known to the physical therapist -- include: massage, as well as, muscle stretching and extension.
- > Peripheral Neuropathy. This is an abnormal nerve function that can be experienced as numbness and tingling at nerve endings. Various exercises focused on the local of the tingling sensation can be beneficial and is an area where physical therapists have expertise.



Hamptons Physical Therapy Sag Harbor I 34 Bay Street #206 631 919 5189

**Eastern LI Hospital - Physical Therapy Ctr. Southold I** 46520 North Road
631 765 9389

Southampton Hosp. - Phys.Therapy Ctr. Southampton I 240 Meeting House Lane 631 726 8520

Hampton Physical Therapy Hampton Bays I 188 West Montauk Highway 631 728 6377

Manual Sports Therapy Sag Harbor I 60 Bay Street 631 725 4450

East End Physical Therapy East Hampton I 300 Pantigo Road 631 329 1828

Peconic Bay Physical Therapy Center Riverhead I 64 Commerce Drive 631 727 9654

Sandra Perry Physical Therapy Group Southold I 57190 Main Road 631 765 3620

Southampton Sports Rehabilitation West Westhampton Beach | 147 Beach Road 631 288 7767

### A Caregiver's Dilemma-The Home Bound Cancer Patient

Sometimes a patient with cancer finds that their illness does not get better . . . it gets worse, and they become home bound.

Now the caregiver -- such as the patient's spouse -- is going to need help attending to basic patient needs such as bathing and food preparation.

Initially a "home health aide" may be hired to come in every afternoon for three hours. But before long, in many cases, home health aides are necessary "around the clock." And the costs can skyrocket. Are those costs covered by Medicare? Here's the answer from the AARP's website:



www.aarp.org 888,687.2277

HEALTH / AARP'S MEDICARE QUESTION AND ANSWER TOOL

Does Medicare cover home health services?

Medicare home health care is a valuable benefit that provides a range of skilled nursing services, therapy, medical supplies and medical social services to you in your own home. Medicare covers all these services in full by paying a home health agency to provide them for up to 60 days at a time. But to get this coverage, you must meet all the conditions:

You must be home bound — that is, unable to leave home without considerable effort, unaided or at all.

A doctor must certify that you need one or more specified professional services — skilled nursing, physical or occupational therapy, or speech pathology.

You must be under a plan of care established and regularly reviewed by a doctor.

The home health agency caring for you must be approved by Medicare.

### **Chapter 12**



### **Help-At-Home**

### **Categories of Help-At-Home Assistance**

In New York it is important to understand the distinction between the different forms of help-at-home that would be sought by the cancer patient or by family members on their behalf.

- > First there are "Home Health Agencies" which administer skilled licensed nursing services, within a patient's home, under a physician's orders. These operations require extensive New York State licensing, and usually require Medicaid and Medicare certification as well. On the East End there are also a handful of licensed nurses who operate as solo practitioners but specialize in making in-home visitations.
- > Second, there are "Home Health Care" businesses which also require State licensing but do not generally require Medicare and Medicaid certifications. This type of business provides in-home aids who assist with all sorts of tasks around the home, as well as the patient's hygiene, but they are not nurses and are not to be involved with any aspect of medical treatment.
- > In addition, there are some individuals engaged in the assisted living business who have ignored licensing requirements or are conducting business even though their license application to the State has not been granted due to extensive bureaucratic delays.
- > Finally, there are free-lancers who provide dedicated and valuable assistance with the chores of daily living but they are not licensed and have no intention of getting licensed. This type of worker is increasingly commonplace in the so-called "gig economy."
- > Because aides from the Home Health Care business are less expensive than those from Home Health agencies, it is assistance from the Home Health Care groups that is most sought after. But, most of these groups are based in Western Suffolk County and there are only a handful with offices located on the East End; they are noted below.

### Tender Loving Care Agency East Moriches I 250 Montauk Hwy.

631 803 0988

This business is run by Mary Bricker and has submitted its application for New York State licensing as a Home Health Care Agency; the license is expected but has not been granted due to bureaucratic delays. Mary overseas a team of 10 aides and she is a much beloved figure in the East End healthcare community because of her rapid response in providing assisted living that is requested on am emergency basis.

### Shene Nursing Services Wainscott I 419 Montauk Hwy.

(631) 324 9555

This business is part of a regional complex whose offices provide both the skilled nursing services of a Home Health Agency and the assisted living services of a Home Health Care business. Although its office is in Wainscott, Shene can provide staff on an at-home basis across all East End Communities.

### Baylin Home Care Southampton I 80 White Street

631 283 3033

A fixture in Southampton for many years, Baylin provides nonmedical staff for in-home assisted living. And, the Baylin business is fully licensed for that service.

#### Peconic Bay Home Health Services Riverhead I 1300 Roanoke Avenue 888 865 2903

This agency is based within the Peconic Bay Medical Center complex and is fully licensed to provide Home Health Care services and does so across the East End Communities. Although the more specialized in-home nursing services are not a core business, the agency can provide this assistance if requested.



### **Hospice Options** & Calvary Hospital

**East End Hospice - In Home Services** Westhampton I 481 Westhampton Riverhead Rd. 631 288 8400

This is an extremely well run facility with top notch patient care. The majority of patients are cared for within their home. Patients are only eligible if they have less than 6 months to live, and agree that no more curative medicine will be administered. The Hospice service is free and, indeed, essentially subsidized by the government.

### **East End Hospice - The Kanas Center** Quoque I #1 Meeting House Road

631 288 2100

Opened in early 2016, and known as the Kanas Center, this facility has 8 private rooms fully equipped to manage the complex needs of the critically ill -- an option akin to what is sometimes called "in hospital hospice." There's 24 hour visitation and the facility is widely viewed as on of the "crown jewels" of the East End healthcare system.



Exterior of the Kanas

'/isitor's Lounge

Patient Bedroom



### "Respite Stays" - Relief for Caregivers

To provide these caregivers with some temporary relief, East End Hospice has arrangements for a "Respite Stay." This means that the patient will be transferred for up to five days to the Kanas Center or, if it is full, to the overflow beds at Southampton Hospital.

At the end of the Respite Stay, the patient returns home and the caregivers, hopefully, are refreshed from a brief break in their patient care responsibility.

To make arrangements for a Respite Stay the patient or a family member should call the central office of East End Hospice 631 288 8400).

#### Calvary Hospital Bronx, NY I 1740 East Chester Rd. 718 518 2000

This is. within the East Coast rethe only fully aion. accredited acute care specialty hospital exclusively providina and other palliative end-of-life care for cancer patients with late-stage disease.



It has 225 beds but the average length of stay for a patient is only a few days so accommodations usually can be arranged on short notice. This option is especially important when a cancer patient has "vital signs" sufficiently robust to disqualify them from further in-hospital care, and yet is near death and suffering from a range of painful symptoms. Some form of insurance (private or governmental) covers virtually all patient care at Calvary.



### **Useful Websites**

### What Makes an Website Useful for Cancer Patients?

There are hundredss of websites that discuss cancer in one way or another. After almost 20 years as a cancer counseling service, those who run Fighting Chance have formulated opinions about the most useful websites for a patient. They are listed below.

The American Cancer Society has many resources that help support people with cancer and their loved ones. And best of all, our help is free. We can connect you with these resources, whether you are a cancer patient, caregiver of a person with cancer, community leader or volunteer, health care professional, or someone who wants to know about programs and services. We can also help you find other free or low-cost resources available in your area.

#### SEARCH FOR PROGRAMS IN YOUR AREA





www.cancer.org 800.227.2345

#### National Cancer Information Center (NCIC)

The National Cancer Information Center provides information and support to those facing cancer 24 hours a day, 365 days a year. Trained cancer information specialists are available via phone, or live chat, providing accurate, up to date cancer information to patients, family members, and caregivers and connecting them with valuable services and resources in their communities.

The American Cancer Society -- or "ACS" -- was founded in 1915 and raises \$1Billion per year, most of which goes to fund cancer research.

But the ACS also has patient support services and the most useful, by far, is the hub of "cancer information specialists" who speak to hundreds of patients each day via a telephone hotline. They are not physicians, but they are highly trained and have a wealth of information.



www.cancer.gov 800.422.6737 The National Cancer Institute -- or "NCI" -- has spent \$150 billion in the last few decades funding research aimed at conquering cancer. But its website also has one of the most informative summaries about cancer and different tumor types.

About Cancer		Find a Cancer Type	
What is Cancer	>	Breast Cancer	>
Causes & Prevention	>	Childhood Cancers	>
Diagnosis & Staging	>	Colorectal Cancer	>
Prognosis	>	Leukemia	>
Cancer Treatment	>	Lung Cancer	>
Cancer Treatment Side Effects	>	Lymphoma	>
Find a Clinical Trial	>	Metastatic Cancer	>
Cancer Statistics	>	Pancreatic Cancer	>
Coping with Cancer	>	Prostate Cancer	>
Learn more about cancer	•	View all cancer types	•



www.cancercare.org 800.813.4673

Cancercare is a non-profit that has been in business for 75 years. The "Crown Jewel" of its many supportive services are one-hour talks by a panel of experts who have an uncanny ability to simplify some of the more complex issues that patients face during the cancer journey

#### Connect Education Workshops

Leading experts in oncology provide up-to-date information in one-hour educational cancer workshops over the telephone or online.

ClinicalTrials.gov

301.496.4000

On any given day there are over 1,000 clinical trials being conducted in the United States -- that are testing, on humans, promising new anticancer drugs.

The government has a website -- www.clinicaltrials.gov -- which makes it quite easy for a patient to locate a trial that may be appropriate. Simply enter your name, type of cancer, hometown and how far you are willing to travel to participate in the trial. (15 miles, 100 miles, etc.). If a trial is open and recruiting you will receive a message that looks like this:

Status	Study Title							
Recruiting	Durvalumab (MEDI4736) With or Without SBRT in Clinical Stage I, II and IIIA Non-small Cell Lung Cancer							
	Conditions	Interventions	Locations					
		Drug: Durvalumab     Other: Durvalumab plus SBRT	Weill Cornell Medicine     New York, New York,     United States					

#### **Other Useful Websites**

### National Brain Tumor Foundation www.braintumor.org

### Susan G. Komen for the Cure www.komen.org

### Colon Cancer Alliance www.ccalliance.org

### National Ovarian Cancer Coalition www.ovarian.org

### The Kidney Cancer Association www.kidneycancer.org

### Leukemia and Lymphoma Society www.leukemia-lymphmaorg

### Multiple Myeloma Research Foundation www.themmrf.org

### **Lung Cancer Research Foundation**www.lungcancerresearchfoundation.org

### **Lustgarten Foundation** (for pancreatic cancer) *www.lustgarten.org*

### **Prostate Cancer Foundation** *www.pcf.org*

### **The Melanoma Research Foundation** *www.melanoma.org*

#### **Author's Notes**

This pamphlet is known around the Fighting Chance office as the "Orange Guide." It has a companion which is known as the "Blue Guide." If you are someone coping with cancer on the East End of Long Island, I suggest you read both guides because they are intended to be complimentary.

This Blue Guide is entitled, "The Cancer Journey: Step-by-Step." It reflects 18 years of accumulated wisdom, on the part of myself and our staff, regarding precisely how the "cancer journey" unfolds and ways to avoid unexpected surprises.

Meanwhile, The Orange Guide is a where-to-find-it resource directory that puts empowering and actionable information into the hands of cancer patients searching for ways to cope with the disease..

The first time Fighting Chance prepared a guide for cancer patients was in 2003 -- about a year after our charity started. Since then the guide has been revised on several occasions as we have accumulated evermore wisdom about the disease through counseling over 2,500 cancer patients.

As the author of the very first guide in 2003, and subsequent revisions, and as the author of both the Orange Guide and Blue Guide, I am deeply indebted to C.B. Grubb, a gifted graphic artist. I have spent hundreds of hours at Charlie's elbow, in his Bridgehampton studio, and these guides would not have been possible without his dedicated collaboration.

Sag Harbor, NY March 1, 2019 **Duncan N. Darrrow** *Principal Author and Founder & Chairman of Fighting Chance* 

www.fightingchance.org



### GET A NAVIGATOR. FREE CALL FIGHTING CHANCE

SAG HARBOR OFFICE #34 Bay St, Suite 201



631,725,4646

#### SOUTHAMPTON OFFICE Phillips Family Cancer Center 740 County Rd 39A

631,638,7400





**Free Cancer Counseling**