The Brave New World of Cancer and Genetics

Dr. Kenneth Offit Speaks at CST's Annual Luncheon

Kenneth Offit, MD, Chief of the Clinical Genetics Service at Memorial Sloan-Kettering Cancer Center, focused on the interrelationship of cancer and genetics in his presentation to a packed house at the 13th annual Gayle K. Lee Women's Health Awareness Luncheon on October 12th at the Westchester Country Club. Dr. Offit emphasized the importance of family history as a risk factor for specific cancers, including breast, colon and prostate. He described family history as “the greatest prognostic and preventive tool” available to guide people as they consider what types of cancer screening and preventive action they should take.

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The Touch of Cancer by Jolita L. Haigis

This article was adapted from a presentation that Ms. Haigis made at a National Cancer Survivors Day celebration in 2009.

When I reflect on my experience with cancer, I am still overwhelmed by the many different ways I was touched by the disease. It was just four years ago, Thanksgiving weekend 2007, that I found a large and painful lump that had certainly not been there even the day before. I could not stop touching it. I waited for days for it to go away, tried hard not to touch the lump, but as it grew and the pain increased, I realized that I needed a doctor's expert touch, skilled fingers to touch it and tell me what it was. That first set of fingers touching my neck was followed by many countless other touches.

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Greetings from the Executive Director

To screen or not to screen, that is the question. Every day, there is another article about the advantages and disadvantages of availing oneself of the many tests to screen for cancer. In a recent article in The New York Times, Jane Brody, the Personal Health Columnist (and the speaker at CST’s 2008 Women’s Health Awareness Luncheon) describes the controversy “raging” over the PSA blood test which screens for prostate cancer (November 15, 2011, p. D 7). An article in Medscape discusses new guidelines from the National Comprehensive Cancer Network that recommend screening by low-dose computed tomography, a type of CT scan, for people at high risk of lung cancer—that is, adults 55-74 years old with a history of smoking one pack or more per day for 30 years, even if they stopped smoking within the past 15 years (http://www.medscape.com/viewarticle/753575).

An article in the October 30, 2011 edition of The New York Times entitled, “Considering When It Might Be Best Not to Know About Cancer,” offers an excellent overview of the screening debate. The article focuses on the shift in attitude among some researchers and health care professionals from “test for everything” to “less is better” in the way of screening. The article cites studies that demonstrate more precisely the harm of screening. For example, recent clinical trials of prostate cancer screening found that screening “…often leads to what can be disabling treatments for men whose cancer otherwise would never have harmed them” (p.21).

On the other hand, often cancer screening can be beneficial as a way for people to protect themselves against the disease. More importantly, it is essential to be informed so that your doctor and you can develop the appropriate screening strategies. You can call Cancer Support Team at 914-777-2777 to discuss options related to cancer screening. The American Cancer Society’s website, www.cancer.org or the Mayo Clinic’s website, www.mayoclinic.org, are useful sources of information on the benefits and risks of screening tests.

Cancer Support Team is looking for volunteers to drive patients to chemotherapy and radiation therapy appointments. If you can help once a week, or once every few weeks, we would appreciate hearing from you. We will provide orientation to our program. Please call the CST office at 777-2777 if you are interested in becoming a volunteer driver.
Save the Dates for these Swim Events in Westchester:

- July 15: Chappaqua Swim & Tennis
- July 21: Orienta
- July 28: LI Sound Open Water Swim

There will also be swim events at Saxon Woods Pool, NYAC, Coveleigh Club, Lake Isle, Lakeside Field Club in North Salem and Germonds of Rockland County—the dates for these events to be determined.

Please update our Mailing and Email Lists...

We like to keep our supporters up-to-date on CST happenings and at the same time be cost-effective. Please let us know of a change of address or if you no longer wish to receive the newsletter. We can save on postage and paper by emailing you notices of upcoming events and programs. Call us at 914-777-2777 or send your email address to us at cst@cancersupportteam.org.

Team CST Dives Right In!

 Raises $18,000 for Swim Across America

On the rainy summer evening of July 8, 2011, Team CST participants braved the inclement weather to swim at the New York Athletic Club pool in Pelham to raise funds in support of Swim Across America of Long Island Sound (SAALIS). SAALIS is in its 19th year of raising funds for cancer research and services, and Cancer Support Team is a very grateful beneficiary of its successful fundraising efforts.

The Team included Maya Collins, age ten, who, along with her grandmother, Rosalie Matsuoka, and uncle, Robert Matsuoka, successfully completed the swimming event as a way to support the free services that CST offers. CST nurse and Team CST captain, Katie Shields described the atmosphere that evening: “On our third Team CST swim, there was great excitement, boundless energy and a feeling of togetherness and purpose!” Heartfelt thanks to Maya, Rosalie and Robert as well as Team CST’s other members including: Katie Briggs, Judith Dobrof, Eliza Hannigan, Ken Harris, Betty Kelly, Ruth Lowy, Julie Meade, Tommy Meade, Susan Pollack, Andrew Porter, Carla Volpe Porter and Katie Shields. In 2011, SAALIS raised $1.2 million for cancer prevention, research and treatment.

We hope that you will join us. Swim, volunteer or donate to Team CST or other teams by logging on to SAA’s website www.swimacrossamerica.org/long_island or by calling 914-632-3236.

Visit our website at www.cancersupportteam.org
Touch of Cancer
(con’t from page 1)

I was touched by doctors, nurses, technicians, surgeons and then I was touched by the definitive diagnosis of Diffuse Large B and T cell Non-Hodgkin’s Lymphoma.

Once that diagnostic touch had occurred, the real work began. The expert, caring and continuous touch of my wonderful first oncologist, Dr. Della Makower, to whom I had given no choice but the obliteration of this disease. The touch of the medical assistants and their needles as they took my blood over and over and over. The amazing multitude of touches I received in the chemotherapy infusion room at the Westchester Institute for Treatment of Cancer and Blood Disorders. I remember the touch of the oncology nurses with their toxic, but magical chemotherapies.

And then there is the unearthly sensation of touching your head and feeling your hair slip off between your fingers. It is a touch that is almost impossible to describe, one that you hope to cope with, gracefully and peacefully. You often touch your incredibly sensitive, vulnerable, and bare, yet beautiful head.

The side effects of steroids cause you to feel agitated and think that if anything, anyone touches you, you’ll scream. But what you really yearn for underneath this electricity, is for someone to hold you, to touch you gently and patiently, to tell you even without words that you don’t need to be scared and that you are not alone.

And that brings me to the most important touch—the touch of friendship, of family, of love and of the invaluable cancer-related personnel—like Cancer Support Team. I was touched when my friends would take care of my daughter without my asking, when they would use their vacation days to drive me to chemo and unselfishly insist on spending the entire day with me while I was receiving treatment and when they chipped in to generously help us financially through those trying times. How touched I was by their caring and generosity as they cooked for my daughter Liana and me daily for over half-a-year. How touched I was by my brave little girl, who never stopped believing in me and that everything would be okay. And lastly, how very touched I was when my elderly parents came up from Florida to stay with us for many months, to take care of us both, because I could no longer do it alone.

I am blessed to be a cancer survivor and now try to be strong, hopeful, resilient, faithful and willing to be touched by love. I gratefully accept and embrace the touch of support.

New Staff at CST

Cancer Support Team welcomes Sharon Lavery and Lourdes Parra to its staff. Ms. Lavery, RN, BSN, has many years of nursing experience working in hospitals and community settings. Most recently, she was a public health nurse at Dominican Sisters Family Health Service. Ms. Lavery was the 2005 recipient of the Caring Award from the Home Care Association of New York State. She has a BS in Nursing from Pace University and is a graduate of a professional language institute in Guatemala.

Ms. Parra, CST’s case manager, has a BS degree in Social Work and French from The College of New Rochelle. Previously, Ms. Parra was a Bilingual Parent Coordinator for the Even Starr Family Health Literacy Partnership and a Home Visitor and Teacher in a Head Start program. In addition, she is an ESL and computer teacher for Southern Westchester BOCES.

Memorial Donations
The families of the following people have designated CST for memorial donations:

- Jules Bemporad
- Michael Bollella
- Joan DeLevie
- William Kempkes
- Andrew Libo
- Terence Martin
- Christy Padin
- Bololo Rojas
- Carla Ruys
- Patricia Smalley
- James Dawson Wallace, Jr.

For more information about CST Services call 914•777•2777
take. (See companion article, “Greetings from the Executive Director” on pg. 2)

Dr. Offit’s research has focused on genetic factors that cause an increased susceptibility to cancer. He noted that early cancer surveillance and “preemptive action,” including the removal of healthy organs before the cancer strikes, are tools that can be used in efforts to control the incidence of the disease. However, Dr. Offit also recognized the controversies presently surrounding cancer screening as questions arise about the high rate of “false positives,” that is, tests that falsely indicate the possibility of cancer when, in fact, none exists. He also expressed concern that, through genetic screening, one might find out “a whole lot of stuff that we don’t want to know.” On the other hand, according to Dr. Offit, people may find some of the outcomes of genetic screening helpful when it leads to a proactive approach to one’s health maintenance regimen.

More positively, Dr. Offit described the present state of genetic screening as a “bold leap” that allows for a more personalized look at family history which can then guide the decisions that one makes about employing certain cancer screening tests—and determining what to do with the results. According to Dr. Offit, this “brave new world” of genetic testing is a major step in controlling the incidence of cancer as individuals have more of the information they need to make informed choices about cancer screening and prevention.

At the 13th Annual Gayle K. Lee Women’s Health Awareness Luncheon in October: CST staff member, Lourdes Parra (r.) at the resource table with Carol Headley (l.) and Mary Lee Berridge.
Ask the Team...

In this column, we pose questions to our staff. All of our readers are invited to call us with a question or email us at jdobrof@cancersupportteam.org.

Q: My sister has just been diagnosed with cancer. How can I help her during her treatment?

A: Patty Vaughn, RN, CST nurse, responds:

When you know that a family member or friend has cancer, usually your first wish is to give comfort and assistance. However, despite your best intentions, it is sometimes difficult to find the right words or know how to best help a loved one. Patients have told us that while most people are very supportive, some have done or said things that have been unintentionally intrusive, distressing or just plain unhelpful.

Here are some suggestions on ways to help:

Educate yourself about the cancer and treatment. This can give you a better understanding of what she will be experiencing.

“What can I do for you?” is not as helpful as “I’m available every Monday and Wednesday to drive you to your treatments.” Offer practical and specific ways you can assist her, like cooking, laundry, cleaning, errands, babysitting, emailing updates for her, etc.

Patients can often be inundated with unsolicited and confusing advice, books, articles, suggestions and stories. Offer to do research for her, but support and respect the decisions she has struggled hard to make and that she believes are best for her now.

Staying in contact with short visits, phone calls and cards are the best ways to express your love and support. However, let your sister know you understand that the side effects from treatment might make it difficult and burdensome for her to reciprocate and you do not expect this from her.

Be sensitive to her changing needs. There are times she might want to forget about cancer and spend a day doing “normal” things. When she does want to talk, she is looking for a compassionate listener, not necessarily a problem solver. If she expresses anxiety over an upcoming treatment, don’t dismiss the feeling by responding, “You’ve got to stay positive” or “Everything is going to be OK.”

Here are other statements that some people have told us they do not appreciate hearing: “You look wonderful—you don’t look sick.” “But you look great without hair.” “I understand what you’re going through.” “Were you a smoker?”

The following are helpful books on this topic:

Help Me Live: 20 Things People With Cancer Want You To Know, by Lori Hope.

Cancer Support Team’s Barbara Melamed Memorial Library has these books, along with many other resources focused on a variety of cancer issues. Please stop by to check them out.

Remember, your sister will be looking to you for support and affirmation and you can best provide it if you are mindful of ways to express concern and caring.

Spring Luncheon Honors Volunteers

Peter Rico, Regina King and Wendy McManus at CST’s volunteer luncheon in June, 2011. We are indebted to our volunteers for their dedication to CST and the people we serve.

Preparation of this newsletter was donated by Sandy Dewey/DeweyInk.
CST Makes a Difference!

A CST nurse first met Mrs. J. in July, 2010 when the patient was diagnosed with metastatic lung cancer. Mrs. J., a woman in her 50’s, had financial needs because of her illness and side effects from an aggressive regimen of chemotherapy, preventing her from working as a daycare provider for young children. Mrs. J. lived alone in a small apartment on the fourth floor of a walk-up building. She was facing eviction due to her difficulty paying the rent. She was anxious about the physical and financial toll that the treatment was having on her.

Mrs. J. received help from CST’s case manager who advocated with the landlord to suspend the eviction process. She also provided Mrs. J. with a grant from CST’s financial assistance program to help her with her living expenses.

Equally as important, through frequent home visits, the CST nurse helped Mrs. J. manage the side effects of her ongoing chemotherapy treatments. She also provided Mrs. J. with a Chemo Comfort kit which contains many items to help people receiving chemotherapy. Mrs. J. especially remarked that the kit’s journal encouraged her to write about her experience and this helped her to cope with the treatment.

For those affected by cancer, CST makes a difference!

CST offers free, ongoing support groups for women with breast or ovarian cancer.
- explore ways of coping with the diagnosis and subsequent treatments
- receive and provide encouragement and support

Call our office at 777-2777 for more information.

Chemo Kits

Chemo Comfort kits help to make the chemo-therapy experience easier by giving people the tools to cope with the day to day needs from the outset of treatment. Kits provide cancer patients with products that help with nausea, mouth sores and hair loss, among other side effects. For more information or to order a kit, log onto www.chemocomfort.org. CST thanks the Junior League on the Sound for its support, enabling us to continue to provide our patients with Chemo Comfort kits.

Please join us on Friday, January 27th at 2 p.m. for an Expressive Beading Workshop led by CST nurse, Patty Vaughn. Please let us know if you are interested in attending this event. Call our office at 777-2777 if you would like to learn more about this program.
Celebrating 34 years of service: 1978 – 2012

****Save the Date****
April 19, 2012
The New York Botanical Garden

Cancer Support Team’s Benefit Gala
“An Enchanted Evening in the Garden”

For more information and underwriting opportunities, please call the office at 914-777-2777 or email jdobrof@cancersupportteam.org.

Did you know?

Your tax-deductible donation helps us provide the following:

$1000 provides nearly 30 hours of nursing care for someone who is homebound.
$500 pays for four days of home health aide services for a frail older adult.
$250 covers 5 counseling sessions for a child whose parent has cancer.
$150 supplies 5 cab rides to life-saving treatment.
$50 pays for childcare so that a parent can see the doctor.