



## Health Care Reform & Cancer Treatment

No matter what your opinion on the new Health Care Reform, knowledge about the changes may be important to a cancer patient. Changes include:

- No lifetime \$ caps
- Tightly restricted annual \$ limits
- In all new plans, preventive coverage is guaranteed which includes no out-of-pocket expenses for proven screenings
- Can no longer drop patients from coverage when they get sick
- Dependent children can remain on policy until age 26
- Children up to age 19 with pre-existing conditions, such as cancer, cannot be denied coverage

The specifics of what benefits insurers must cover is still in question. Some groups are pushing for restrictions on the number of visits covered in certain situations to keep premiums affordable. Representatives of ACS think this is a bad idea and could hinder treatment for cancer patients. Other changes include:

- Requiring coverage of standard care provided as part of clinical trials
- Establishment and funding of the Patient Centered Outcomes Research Institute focused on comparative effectiveness research
- Establishment of the Cures Acceleration Network to foster rapid translation of basic research to the bedside for treatment.
- Starting in 2011 most insurance companies must spend 80 -85 % of premium dollars on medical care & health care quality improvement, rather than on administrative costs.

## Get Ready - MAY 14<sup>TH</sup>! 2011 STAN WONG 5K FOR CANCER

Mark your calendars for Saturday **MAY 14, 2011!** We hope to see you with your walking/running shoes on ready to join in our fight against cancer.



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## Serving Up Hope

### SWF Board Members & Volunteers Serve up Funds, Food & Hope.

On Nov 14, 2010 representatives from the Stan Wong Foundation visited the American Cancer Society's Hope Lodge in New York city to host a special dinner for their guests, and to present a check for \$2,400. These funds help the Hodge Lodge continue to provide valuable services to cancer patients. Since the Hope Lodge opened its doors in November of 2007, it has provided free lodging and support services to over 4,600 guests while they receive treatment at local medical facilities like Sloan-Kettering. 60 of those guest, 30 patients and their caregivers, have been from local towns in Eastern Suffolk county. Many of these patients have stayed multiple times. Staff members told us of one patient from East Quogue that has been going back and forth since the opening in November of 2007.

During our visit, we had an opportunity to meet many of the guests that your dollars are helping. All the guests were so grateful for the delicious meal that our volunteers cooked up, as well as the financial support that we were providing to this place that many of them felt was a

home when they need it the most. One guest even graced us with his beautiful piano playing during dinner.

Although many of the guests had touching and wonderful stories, there was one guest in particular whose story touched us the most. For privacy, we'll call her Allison. She was staying at the Hope Lodge with her sister while she took part in a clinical trial for an amazing new drug called PLX4032, which treats advanced melanoma in patients with a BRAF gene mutation. Allison had been through many surgeries, and what seemed to be an endless list of other treatments at the University of Pennsylvania. Although this was quite a drive from where she lived, in a small town in rural Pennsylvania, the doctors there seemed to have exhausted their options for treating Allison. The doctors had been hopeful they halted the cancer several times in the past, only to find out later that it had metastasized to yet another part of her body. The cancer had started with a small spot on her left leg, then showed up later in her right leg, her liver, her lungs and her brain. By chance, what

seemed to be bad news when the doctors informed her the treatment they were giving her had not worked, actually turned out to be a blessing because it allowed her to qualify to take part in the clinical trial for PLX4032. She is one of only 32 patients who were able to take part in this Phase 1 clinical trial. She's been traveling approximately 4 hours from her home once of every 3 weeks for the past several months. She stays at the Hope Lodge for 2-3 days and then is able to return home. When she started the trial she had approximately 40 cancerous lesions in her lungs. After only a few weeks on the treatment, they were all gone.

Allison's story is one of many. She is still here today because of the services provided by the Hope Lodge and because the medical advances that are made possible through clinical trials. Without the services provided by the Hope Lodge, researchers may not be able to find enough qualified patients who are able to take part in these life saving research studies. By supporting the Hope Lodge we are not only helping those who stay there, but we are helping find a cure as well.

# Your Dollars at Work

## Clinical Trials

### ARE THEY RIGHT FOR YOU?

Many cancer patients view cancer clinical trials as a last resort in their treatment regime. However, clinical trials often offer the most cutting edge and advanced treatment available. However, patients often avoid clinical trials because of common misconceptions about the safety of clinical trials, the sometimes complex process of finding the right clinical trial, insurance coverage limitations on clinical trial treatments or simply because their doctors don't discuss it as a treatment option. Only about 3% of adult cancer patients participate in clinical trials, but without clinical trials cancer detection and treatment could not improve. The limited number of participants in clinical trials is a "major impediment for making progress in cancer treatment."

There are 3 Phases of clinical trials. All patients are carefully monitored in all phases and care is adjusted accordingly. Phase 1 enrolls a small number of patients to determine the best delivery method, frequency & dosage for minimal side effects. Phase II examines safety and effectiveness of a treatment while Phase III compares a treatment to the current standard of care. No patients are ever given placebos, or sugar pills in place of the standard care.

Doctors may not discuss clinical trials with their patients because they may be unaware of the latest trials available or because having a patient enrolled in a clinical trial creates more work and possibly higher costs of treatment for them. So don't depend on your doctor to find out if a clinical trial is right for you. Here are some web sites where you can find out more and search for a trial that may be right for you or your loved one.

- [www.cancertrials.org](http://www.cancertrials.org)
- [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)



*Miriam Gillies - 4th year volunteer & Cancer Survivor*

## Research Leading to More Personal & Effective Treatments

### Tumor Genotyping

Some of the most dramatic advances in cancer treatments are being made by targeting a tumor's specific characteristics. For the past few years cancer research had been focusing much attention on identifying specific genetic markers on certain tumors that determine the way they survive and grow. This is called tumor genotyping. Once a tumor's genotype has been identified, treatment can be customized to best attack the mechanisms that allow the tumors to survive and thrive, therefore killing or greatly reducing the cancer. Unfortunately, insurance frequently fails to cover the costs of genotyping.

In 2010 advances in the development of drugs that can effectively attack tumors of specific genotypes were significant. Two notable advances took place in cancers that have in the past proven very difficult to treat. The 5 year survival rate for Stage IV malignant melanoma is only 15-20%. But the development of a new drug called PLX4032 is offering hope to malignant melanoma patients with the BRAF gene mutation. Approximately 50% of malignant melanoma patients have the BRAF gene mutation and melanoma is one of the fastest growing populations of cancer patients. In the phase 1 trial

of PLX4032, 81% of those with the BRAF mutation had their tumors either completely or partially regress. Another significant development of 2010 took place in the treatment of non-small cell lung cancer. An orally administered drug called Crizotinib showed such promising

results in a Phase 1 trial that it is being fast-tracked by the FDA to a Phase III trial. A gene mutation called ALK is present in 20% of non-small cell lung cancer patients, that's approximately 11,000 people in the US alone. The ALK gene mutation also tends to be found in the tumors of young, non-smokers. In the phase I trial of Crizotinib, 90% of the

patients with the ALK gene mutation saw their tumors stabilize or shrink. Len Lichtenfeld, Deputy Chief Medical Officer of ACS says of Crizotinib, "This really has the potential to be a game changer for a select group of patients with a disease that is very difficult to treat."

### Other Advances in 2010

Some other notable advances include a Phase III trial that showed a combination drug called Folfirinix significantly increased survival in Stage IV pancreatic cancer patients. Another study found that adding the drug Bevacizumab to the standard chemotherapy drug treatment for ovarian cancer helped women live significantly longer without disease progression.

***"This really has the potential to be a game changer..."***

Research on breast cancer revealed this year that shorter courses of radiation are just as effective of preventing

reoccurrence of early stage breast cancer, that removing fewer lymph nodes during surgery does not impede survival and that a chemotherapy agent derived from a marine sponge helped patients with recurrent or metastatic breast cancer live longer.

These are just some of the advances that cancer research funding like ours has made possible in 2010.

## Prevention Corner

### 'Real' Men Get Check-Ups

"Study after study has shown that men are more reluctant to face up to worrisome symptoms or go to the doctor for checkups," says Dr. Timothy Johnson, ABCNEWS' medical editor. This is likely the reason why men have higher death rates from all 10 top causes of death as compared to women. Many of us have heard or experienced tragic stories about how men we know and love put off going to get checked out by a doctor and pay for it with their lives. It doesn't have to be this way! We know that early diagnosis improves survival rates dramatically in all types of cancers. So how do we motivate men to go see the doctor? Experts say an effective approach is to appeal to their sense of duty & responsibility. They can't be a provider & protector if they are not here. So everyone, including all you men, get check-ups regularly!

## Top Runners

It's time to start training!! Whether you plan on walking or running this year, science has repeatedly proven that exercise lowers your risk of cancer. So get moving, maybe you can even catch our top runners.

**TOP MALE OVERALL**  
**• TAYLOR MUCARIA 18:06**

**TOP FEMALE OVERALL**  
**• ELIZABETH ANDERSON 20:59**

**14 & UNDER AGE GROUP**  
 • (M) GREGORY HORBATIUK 24:53  
 • (F) GEORGIE NICHOLIS 23:41

**15-19 AGE GROUP**  
 • (M) COREY ZITZNIKI 19:49  
 • (F) AMBER SELIG 24:52

**20-29 AGE GROUP**  
 • (M) CHRISTOPHER STAFFORD 20:10  
 • (F) VERONICA WELSH 23:37

**30-39 AGE GROUP**  
 • (M) BRIAN TRENTOWSKI 18:30  
 • (F) KELLY TRICK-OLPHIE 22:24

**40-49 AGE GROUP**  
 • (M) CHARLES RUSSO 21:20  
 • (F) DEBRA BEATTIE 22:09

**50-59 AGE GROUP**  
 • (M) LARRY COSTANTINO 20:34  
 • (F) JEAN NESBITT 25:43

**60 & OVER AGE GROUP**  
 • (M) RICHARD KORTH 35:44  
 • (F) MAGGIE BLOOMFIELD 34:57

## Honor Roll Fundraisers/Donors

Our most heartfelt thank you goes out to all of you, but we'd like to extend a special thanks to those who went above & beyond in their fundraising efforts.

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**Top Fundraiser Jeff Pinkosh • Kids Fun Run Winners • Overall Winners Taylor Mucaria & Elizabeth Anderson**

## Volunteer Spotlight

The mission of the Stan Wong Foundation could not be achieved without our volunteers. This past year we had 52 volunteers working hard to put on a great event for race day. In addition, the Board of Directors put in many hours well before to race day to prepare for a successful event. Thanks to all our volunteers and Board Members.

We'd like to give a special thanks to Lucille Varanelli for volunteering to take a leadership role for our Auction & to Karen Fellows for cooking and helping us serve a wonderful dinner to the Hope Lodge guests. Karen is also a cancer survivor. Finally, a very special thanks to the East Moriches Community Ambulance, the Newport Beach Property Owners Assoc. & the 7<sup>th</sup> Precinct.

## Fundraising Results

The 2010 Stan Wong 5K for Cancer raised a total of \$14,382. In total since the first Stan Wong 5K for Cancer in 2007 we've raised just over \$40,000. With your help the Stan Wong Foundation can continue to raise more money to support cancer research. Step by step, this gets us closer to finding a cure. Our fundraising goal for this year is \$20,000. It is only with your help that we can reach this goal. **Here's what you can do:**

- Participate or volunteer in the 2011 Stan Wong 5K for Cancer and bring all your friends!
- Prior to race day, obtain sponsors to increase the funds you raise for the Stan Wong Foundation's fight against cancer.
- Volunteer to help us obtain business sponsors in the months prior to the race.

To volunteer or for more information Contact Lisa Serrell at : [lserrell@stanwongfoundation.org](mailto:lserrell@stanwongfoundation.org) OR call (631) 445-4600.

## Stan Wong Foundation Board of Directors



From LEFT to RIGHT: (President) Lisa Serrell, (Secretary) Dena Aponte, (Vice President) Edward Wong, Yuifun Chen-Hope Lodge Staff Member (not a Board member), (Treasurer) Marcelle Wong & Board Members Melissa Kanas, Trudi Norton, Denis Yuen

BOARD MEMBERS NOT PRESENT: Deirdre Parsons & Diane Nicholson

## Resources

- HEALTH CARE REFORM:** • <http://www.acscan.org/content/wp-content/uploads/2010/09/HowtheACAisHelpingPeople.pdf>  
 • [http://journals.lww.com/journalppo/Fulltext/2010/11000/The\\_Anticipated\\_and\\_Unintended\\_Consequences\\_of\\_the\\_10.aspx](http://journals.lww.com/journalppo/Fulltext/2010/11000/The_Anticipated_and_Unintended_Consequences_of_the_10.aspx)
- RESEARCH:** • <http://www.cancer.org/Research/ResearchAccomplishments/major-developments-in-cancer-research-2008>  
 • <http://www.unitingagainstlungcancer.org/research/ResearchPerspectives/Pao>  
 • <http://abcnews.go.com/Health/story?id=116898&page=2>
- PREVENTION CORNER:** • <http://www.canaryfoundation.org/docs/PressKit/EarlyDetectionFactSheet09.pdf>  
 • <http://www.cancertrialshelp.org/>  
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