SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.

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President's Message

By Lois Dickerman PhD

As President's Messages go, this is a very personal one. As I write this, we are no longer dealing with esophageal cancer as the primary focus and driving energy affecting every aspect of our private lives.

Recently my husband Dick marked his third year of survival and 18 months free of all remnants of Stage IVB esophageal adenocarcinoma that had infiltrated his lungs, lymph nodes and liver. He is alive because we sought experimental treatments and told his physicians that we knew his odds for survival were grim. We pleaded that we wanted to try anything, no matter how improbable the likelihood for success.

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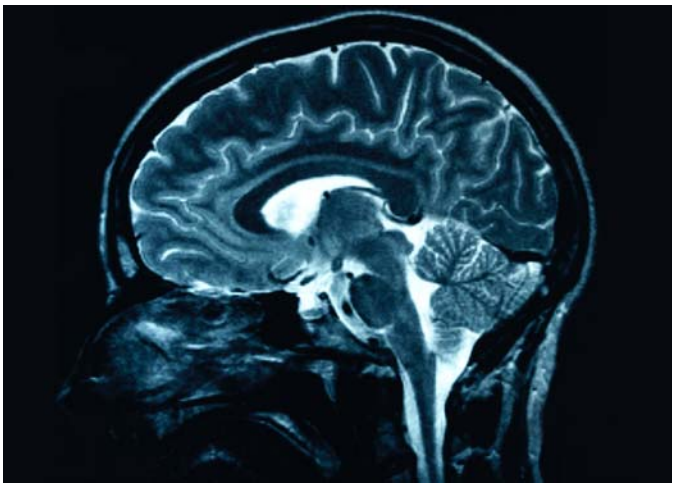
All In Your Head?

By Roger Tunsley

You know the feeling. You can't concentrate like you did. You're forgetting words that used to come easily to mind. You misplace your keys, your comb, your coffee. You tell yourself "Well, you're not getting any younger. You've got to expect these things." In the back of your mind lurks the question "Is it Alzheimer's?" You've had cancer. Can life be so cruel as to visit you with another dread disease?



For many of us who have been through the poison, burn, and cut treatments that attend cancer, there could be another reason for the mists that swirl in the mind – chemo brain.

Most people that have had chemotherapy have experienced to some degree the various unpleasant and debilitating side effects that go along with it.

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And that is exactly what we did, using two different experimental treatments. The physicians gave us no guarantees or even hope that these treatments might work, but they gave us a chance to try. Even now, they admit that they thought that survival of more than a few months was extremely unlikely and that Dick amazed them with his unexpected inner strength and determination.

Our choice to fight aggressively may not be the best choice for many patients, and Dick and I fully recognize this. However, Dick did not feel sick when diagnosed. He was active, exercised regularly since coronary artery bypass surgery four years earlier and still could swallow normally. He and I were both enjoying our retirement to the fullest, having just returned two weeks before he was diagnosed from a trip to Machu Picchu, the Amazon, and Galapagos Islands. Neither of us was willing to admit that his life span was limited to three months, the verdict of the first oncologist we consulted.

There are many esophageal cancer patients that seek only one opinion, and abide by the verdict of a single physician. Many oncologists currently in practice may or may not have had much experience with esophageal cancer, for it is still rare, although the fastest increasing cancer in the US. Our advice, borne out by our experience, is always to seek a second or even third opinion, no matter how bleak the first may be. We believe it is wise to seek information at a large cancer facility with teaching, research and clinical expertise. Esophageal cancer is so unusual that the average oncologist at smaller facilities may have encountered EC in only a few situations over the course of years of training and oncology practice. Oncologists may be speaking the truth as they learned it, that Stage IVB EC is incurable as cancers go. But Dick is the living proof that times and experiences are changing, and this rarest of cancers is no longer a death sentence.

We view life in a new way now, not with urgency, but with a belief that we must live in the present. We must take time to enjoy that sunset over the mountains that we can see from our living room. We must take that trip that we always wanted to experience or view the sight that we always thought we had years to see. We must take time to see our grandchildren who don't live nearby, and watch them change by months, not years. We can also simply be content to sit quietly near one another, reading our favorite books, and appreciate with true depth of feeling the comfort and warmth of each other's presence. Every day is a precious gift and the greatest blessing that esophageal cancer has given to us is the realization of that concept in every fiber of our beings. –*E*–

Changes to the ECAA Officers and Board

Since the last edition of the newsletter, two members of the board have stepped down – Sunny Nagel and Sean Waldron. Sean was just taking up the position of ECAA Treasurer when his personal circumstances changed. Bob Ginsberg has volunteered to take up the role of Treasurer in Sean's stead. The board sends both Sunny and Sean grateful thanks for their service to EC awareness and wishes them good luck for the future. –*E*–

Chemo Brain – from page 1

Nausea, hair loss, and fatigue are well known and accepted complaints from these treatments. But all too often, patients complain also of a mental fog that slowly settles around them. A slowing of the senses, of memory, of attention.

These effects are often present during the therapy itself, but often the effects last for some years after treatment has ended. "I've spoken to patients who were formerly lawyers and had to completely change their strategy for preparing for trial," says psychologist and chemo brain researcher Lynne Wagner, PhD, an assistant professor in the department of psychiatry and behavioral sciences at Northwestern University Medical School.

"People with 'chemo brain' often can't focus, remember things or multitask the way they did before chemotherapy," explained Dr. Daniel Silverman, head of neuronuclear imaging and associate professor of molecular and medical pharmacology at the David Geffen School of Medicine at UCLA who has carried out a study into the phenomenon[1]. "Our study demonstrates for the first time that patients suffering from these cognitive symptoms have specific alterations in brain metabolism."

Silverman and his colleagues used positron emission tomography (PET) to scan the brains of 21 women who had undergone surgery to remove breast tumors five to ten years earlier. Sixteen of them had been treated with chemotherapy regimens near the time of their surgeries to reduce the risk of cancer recurrence.

The team compared PET images evaluating the chemotherapy patients' brain function to PET scans from five breast-cancer patients who underwent surgery only, and 13 control subjects who did not have breast cancer or chemotherapy. As the women performed a series of short-term memory exercises, the UCLA team measured blood flow to their brains. The researchers also ran a scan of the patients' resting brain metabolism after the women finished the exercises.

The researchers found important differences between the groups. The women who had received chemotherapy had greater blood flow to certain areas of their brain during the memory tasks (indicating these areas were working harder), compared to the women who had not had chemotherapy. And the chemotherapy group had a lower resting metabolism in these areas of the brain than the other groups.

"The same area of the brain that was most different when performing the tasks was the area that had the most decrease in metabolism in the women who had the most severe symptoms [of chemo brain]," Silverman explained. "What that in effect says is happening is that… their brains have to work harder to perform the same tasks."

This study was very small and couldn't prove definitively that chemotherapy harms certain brain functions. But Silverman said it is a necessary first step to additional research on the subject. This small study doesn't prove chemotherapy actually causes forgetfulness. Depression can also cause mild memory loss.

Silverman is beginning a larger study to measure breast cancer patients' brain function before treatment as well as after to see what effect chemotherapy has. This study may help doctors understand if specific drugs are causing the problem and what the mechanisms of drug interactions with the brain may be. Those findings could help not only breast cancer patients, but any patient who gets chemotherapy. Breast cancer patients are usually the ones studied in chemo brain research because so many of them get chemotherapy and live long healthy lives afterward.

Dr. Tim Ahles, one of the first American scientists to study cognitive side effects, also agrees that studies have been too small and lacked adequate baseline data to isolate a cause.

"So many factors affect cognitive function, and the kinds of cognitive problems associated with cancer treatment can be caused by many other things than chemotherapy," said Ahles, the director of neurocognitive research at Memorial Sloan-Kettering Cancer Center in New York.

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Chemotherapy for Esophageal Cancer

By Mark Huberman M.D.

Chemotherapy plays an important and evolving role in the treatment of esophageal cancer. Studies of chemotherapy in esophageal cancer indicate similar results for both common types, adenocarcinoma and squamous (or epidermoid) carcinoma, so this article includes both types as esophageal cancer.

Chemotherapy is a broad term that includes many different drugs that are most often administered in combination of two or three at a time. In locally advanced (stages 2, 3, or 4A) esophageal cancer, chemotherapy may be used before surgery (neoadjuvant), often with radiation therapy, and sometimes after surgery. For stage 4 disease that has spread more widely, chemotherapy is the usual treatment.

Chemotherapy is systemic treatment; it pervades the whole body to attack cells that have spread beyond the reach of surgery or radiation therapy. When used prior to surgery it helps to shrink the local tumor, particularly when given with radiation where the drugs make the cancer cells more sensitive to the killing powers of the x-ray particles. If given after surgery, it attacks any microscopic cells that may have already left the primary area. Although some controversy exists, most oncologists believe that using chemotherapy along with radiation and surgery improves cure rate although much work still needs to be done. When the cancer has already spread and surgery is not useful, chemotherapy is used to relieve symptoms and prolong life.

Esophageal cancer patients are often confused by the different drugs and combinations used. There is no currently agreed upon “single best” chemotherapy for esophageal cancer but a number of effective single medicines that can be combined with one or two others effectively. Among the effective drugs are cisplatinum, 5 fluorouracil(5FU), an oral 5FU called capecitabine or Xeloda, docetaxel or Taxotere, paclitaxel or Taxol, irinotecan or CPT11, epirubicin, oxaliplatin, and lecovorin, a folic-acid-like vitamin sometimes given with 5FU. Cisplatin and 5FU are commonly given along with radiation as pre-operative treatment. For metastatic disease, docetaxel may be added to these two drugs with some added efficacy, but with more side effects. Cisplatin and irinotecan is another common combination. There are other useful combinations as well. Your oncologist will recommend which one he or she feels is best for you. This recommendation is based on a number of factors including safety if it is to be given with radiation, other medical problems that may make certain drugs more dangerous, and a general sense of what will be the most effective, best tolerated regimen for a given patient. Newer approaches are evaluating adding medicines like bevacizumab, an anti-blood vessel medicine, and agents that target cancer cell signaling pathways like Erlotinib or Tarceva and Cetuximab. The future looks hopeful that these newer drugs will improve our treatments. –*E*–

Mark Huberman is an Assistant Professor in the Department of Medicine at Harvard Medical School, and is on the staff of the Division of Hematology/Oncology at Beth Israel Deaconess Medical Center in Boston, MA.

Chemo Brain – from page 3

The new interest in chemo brain is, in effect, a testimony to enormous strides in the field of cancer treatment as a whole. Patients who once would have died now live long enough to have cognitive side effects, just as survivors of childhood leukemia did many years ago, forcing new treatment protocols to avoid learning disabilities.

In a paper in the *Journal of Biology* in November 2006, scientists found that even low levels of chemotherapy can kill brain cells. The study showed that cancer drugs were even more toxic to healthy cells than to malignant ones, says Mark Noble, a professor at the University of Rochester Medical Center.

Noble tested three common chemo drugs — cisplatin, cytarabine and carmustine — on rats and in human cells in lab dishes. Chemo killed 40% to 80% of cancer cells, but 70% to 100% of healthy brain cells. Some of the normal cells continued to die for several weeks after treatment, according to the study, funded by the National Institutes of Health and the James P. Wilmot Foundation.

Significantly, chemo killed not just rapidly dividing cells — the typical target of cancer therapy — but brain cells that weren't reproducing, including those responsible for creating the insulation around nerve cells, Noble says. This insulation is important because it helps nerve signals travel quickly.

The benefits of chemotherapy outweigh the potential risks for most people, since any memory and thinking problems appear to be subtle, the researchers write. Studies such as this should help inform people of the potential risks involved, however, for those deciding which treatment route to take. –*E*–

[1] "Altered frontocortical, cerebellar, and basal ganglia activity in adjuvant-treated breast cancer survivors 5-10 years after chemotherapy." Published online Oct. 5, 2006, in *Breast Cancer Research and Treatment*. First author: Daniel H.S. Silverman, MD, PhD, University of California, Los Angeles.

Barrett's Study Collaboration

Investigators who have studied Barrett's esophagus and esophageal cancer for many years continue their investigation on the genetics of these diseases. The group includes the Cleveland Clinic, Northeastern Ohio University College of Medicine, University Hospitals of Cleveland, and the Fred Hutchinson Cancer Research Center. Creighton University will be joining the collaborative network in the very near future. The researchers at the Cleveland Clinic and University Hospitals of Cleveland who are members of the Case Comprehensive Cancer Center are now performing the research jointly as part of one team.

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Barrett's – from page 5

What Is Barrett's Esophagus?

Barrett's esophagus is a change in the cells lining the esophagus, or swallowing tube, which is a forerunner of esophageal cancer. Patients with Barrett's have a 30 - 125 fold increased risk of developing esophageal cancer. Barrett's is closely linked with longstanding heartburn or GERD. About 10% of patients with longstanding GERD will develop Barrett's esophagus. Research by these investigators and others has shown that relatives of individuals with Barrett's esophagus and esophageal cancer have a higher rate of GERD and Barrett's. People who have had GERD symptoms for more than 5 years may be at risk for Barrett's esophagus and should discuss the possibility with their doctor. Symptoms include burning pain behind the breastbone, regurgitation, pain and difficulty swallowing. Some have only mild symptoms, or no symptoms.

Update on Research

Consortium (FEBC) investigators have shown that Barrett's esophagus and a certain type of cancer occur commonly in certain families. This type of cancer, classified as esophageal adenocarcinoma, is one the most rapidly increasing cancers in the U.S. It most commonly affects white men but can occur in all women and all races. Researchers think that this rapid rise may partially be related to an increase in the number of overweight people in the country. In research published in the journal CEBP, FBEC investigators found that approcimately one in ten individuals with Barrett's esophagus or esophageal cancer have another family member who is affected.

The researchers have identified over 100 families affected with Barrett's esophagus and esophageal adenocarcinoma, a specific type of cancer. The researchers feel that family members may also have higher rates of other cancers such as colon cancer and breast cancer.

Ongoing FBE Research

To identify the genes that cause Barrett's esophagus and cancer, the researchers continue to recruit patients for their studies. Investigators are continuing research sponsored by grants from the National Institutes of Health (NIH). Patients with Barrett's esophagus or esophageal cancer complete a questionnaire detailing GERD symptoms and family history. Relatives of those already involved in the study are also contacted to complete questionnaires and undergo screening. Using a very thin scope, they examine the esophagus to check for Barrett's! Blood samples from families with two or more affected members are being collected and now stored at the Rutgers University Cell and DNA Repository, which is supported by NIH. This repository will eventually help researchers from all over the country understand the genetic basis for these diseases.

For any questions, call Wendy Brock, RN at University Hospitals of Cleveland at 216-844-3853 or Mary Oldenburgh, RN at (216) 444-8562.

Barrett's On Line

For more information about Barrett's esophagus and esophageal cancer, the following web sites may be helpful:

www.Niddk.nih.gov www.chd.org www.cancer.org –*E*–

An Example To Us All

By Roger Tunsley

In May 2007, at just 36 years of age, Chris Hendrickson was diagnosed with esophageal cancer. He underwent surgery in June of this year, and is currently undergoing chemotherapy and radiation.

Chris' stepson Sean Federwitz , a senior at Del Oro High School in Loomis, CA, decided to do his senior project to raise funds to benefit the ECAA. In November, Sean arranged to hold a spaghetti dinner in the local Lion's Club hall. The Lions donated the hall and helped Sean to set everything up and to clean up afterwards, and local businesses donated the food and raffle prizes.

The evening was a great success. About 80 people attended the dinner itself, including four other EC survivors, and donations were also received from people that did not attend. Sean's efforts resulted in the grand sum of $2535 being raised, $500 of which was from the ECAA. Sean has chosen to donate all the money raised from the evening to the University of California Davis Cancer Center where Chris is being treated.

Chris Hendrickson talks about EC

Sean Federwitz introduces Chris

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Example – from page 7

That is an impressive enough story on its own, but it doesn't begin to describe the talents and tenacity of this very impressive young man.

Sean is also a mostly deaf person. From birth, he has only had hearing in one ear. However, he has continued to lose hearing in the other, so presently he is completely deaf in one ear and has a 65% hearing loss in the other ear. He is in a deaf and hard of hearing program at Del Oro High School, where he uses an interpreter for all his classes. He has had many years of speech and language therapy and he is proficient in American Sign Language. He studied at home with his mom, Mary Hendrickson, until he reached seventh grade when he became profoundly deaf and she was unable to continue. Sean is currently in a Regional Occupational Program to be an auto mechanic.

He has also been heavily involved in scouting for some time. He has completed many of the training programs and attended an out -of-state summer camp each year. He did his Eagle Scout project for the local school for handicapped children.

Sean is an inspiration to us all. Not just another caring and thoughtful teenager, he shows us that disability need be no barrier to success.

You can read more about Sean and his family in Mary's web site www.sheepshepherdess.com. If his story has inspired you, he is happy to still accept donations to the U.C Davis Cancer Center.

Call Sean on (916) 663-2510

–*E*–

ICU – The Early Daze

By Pat Davis

The main thing I remember about ICU is dozing in my bed; sleeping off and on and watching the staff move go about their tasks. Soon I became aware of something suspicious. They were going in and out of the same room across the hall for no apparent reason. It was obvious that they were planning to euthanize that patient so he could be reborn into a better life. I felt only slightly anxious though; I knew my nurse would watch out for me. I did ask him to pull the curtain around my bed. That way none of them would know I'd been a witness.

When I was much better and almost ready to move out of ICU, I complained to the charge nurse that she was impeding my progress because I should have been eating frequent small meals instead of the "nothing by mouth" regimen I had been on. (Of course I still had not taken a swallow test.) At this point she asked me if I'd ever heard of "ICU psychosis." and instantly I realized what had been happening. The aftermath of anesthesia, current painkillers, stress, and weakness had created a rich fantasy life, source of lively discussion and much laughter among my friends and family.

Another memory, from my first night on a regular ward is something I have not shared before. In the late-night-early morning hours, a nurse named Christine spent most of her time with me. She helped untangle the tangled tubes, straightened my tangled sheets, brought sponges for my dry mouth - and most importantly she said to me "I have seen lots of these surgeries and I'm convinced you are going to be all right."

I doubted that she had seen lots of transhiatal esophagectomies, but I chose to believe her. The next night she helped me lurch around the corridor on my first walk and again assured me that I would be fine. I looked for her each night after that but never saw her again. She might have been an angel

There are other memories of those eight days, but these illustrate what I have come to believe. First, take humor and hope and happiness wherever you can find them, even wearing hospital gowns and imagining plots for horror movies. The life we have is this one, not any other Second - and this is for friends and caregivers and reinforced by my experiences as a chaplain - affirm the living wholesome spirit of the person. Look into them and see who they are; not a disease but the person you love. Let them know they needn't be afraid. They are who they are and will not crumble. –$\mathcal{E}$–

Help Us to Raise the Awareness of EC

The ECAA is a small non-profit organization dedicated to raising the awareness of esophageal cancer in the general public and the medical professions. If you would like to help us in that effort, please consider becoming a member of the organization. Anyone with an interest, either as a patient or a caregiver, is welcome to join. Yearly subscriptions are just $25 for an individual membership and $30 for a family membership. The ECAA is a 501C3 organization.

Contact Pat Caldwell at pcaldwell@ecaware.org

"This is one of those new miracle drugs.
If you can afford it, it's a miracle."

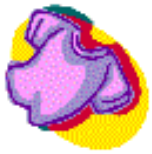
Please consider a donation to the ECAA

The ECAA is a small organization and depends upon donations and merchandise sales for all income.
We have no paid staff; we are an all-volunteer organization.
You can be sure that every penny donated will go towards helping us raise the awareness of esophageal cancer in the general public and the medical profession.

Help somebody. Donate to the ECAA.

Go to www.ecaware.org

ECAA STUFF



Spread the word about EC. We have merchandise that you can wear that will help to raise awareness of this disease. T-shirts, polo shirts and caps all display the swallow logo. Wrist bands are in the association colors of gold and blue and are impressed with "Be EC Aware".

For details, see the ECAA web site on www.ecaware.org, or contact Pat Caldwell at pcaldwell@ecaware.org

Important note: Articles published in this newsletter are from many sources and cover a wide range of topics. They are published for the benefit of our readers, but they do not necessarily represent the views of the Esophageal Cancer Awareness Association.