

# SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.



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## Welcome

*By Roger Tunsley*

Hello and welcome to the first edition of *Swallow Tales*, the newsletter of the ECAA.

The board of the ECAA has recently been invigorated by the election of several new members and we are on a mission – to promote the awareness of esophageal cancer and to offer information to the membership. We have two main outlets for this information; the web site and the newsletter.

We have varying reactions when our disease is first diagnosed. Many of us crave information about the disease, its prognosis, treatments, side effects, statistics, and so on. Others avoid this information, preferring to be guided by their medical professionals or by their own feelings. There is, of course, no right answer for everyone.

We hope to be a useful source for information for those who want it. The board includes medical and scientific professionals who will do their best to ensure that the medical and technical articles are

## Managing Your Disease

*By Lois Dickerman*

One of the most difficult challenges that you and your family will ever experience is dealing with the overwhelming news that you have esophageal cancer. It is frightening beyond comprehension, confusing and inexplicable in terms of normal experiences, and just plain overwhelming. When Dick, my husband, was diagnosed in November, 2004, with esophageal adenocarcinoma, Stage IVb with metastases to lungs, lymph nodes and liver, we were totally devastated and confused. Yet we were somewhat better prepared than many

### Inside This Issue

### Page

Welcome	1
Managing Your Disease	1
President's Message	2
Introducing your Board of Directors	2
Trust Me	4
"Anatomy" of Cancer Surgery	4
"Googling" EC	6

sound. We will also try to ensure that the newsletter remains positive and as lighthearted as possible with personal stories and gentle humor. We'll congratulate survivors who make the magic five year mark and there will be some reflection as we memorialize our members who leave us.

This newsletter is for you, the members of the association. We welcome and encourage your input. Letters to the editor, suggestions for articles, comments, criticisms, and your personal stories are all welcome. Your personal stories can be terribly important to others. So please join in.–E–

families because we have backgrounds and training in science. Information and understanding are powerful tools, yet organization can be even more powerful. The following are some of the simple things that we did to cope with the mountain of new information and complications of daily life that a life-threatening disease can bring.

- Prepare yourself to ask questions and don't hesitate to ask as many questions as necessary to reach some degree of understanding. To ask effective questions,

*See Managing Your Disease on page 5*

## President's Message

*By Richard Stienmier*

This is a notable day in the progress of the ECAA. We have long talked about having a newsletter, and now have the opportunity and challenge to do so. My hope is that this periodical will be a useful and reliable source of information about esophageal carcinoma, in all its aspects – from research on causation to suggesting solutions to the mundane yet difficult everyday problems that a person with EC must confront.

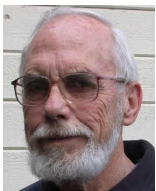
We face both new problems and new progress in the enigma of esophageal carcinoma. The meteoric rise of adenocarcinoma, coupled with the decrease in the incidence of squamous carcinoma will probably continue. Unfortunately, EC may stop being a “rare” tumor. Rapid advances are being made in the analysis of the genetic changes occurring in carcinoma cells that will

better enable us to categorize the exact nature of the disease each cancer patient has. This will soon allow for much more specific “Tailored for each cancer” treatment. The days of extremely toxic general cell poisons as cancer drugs may run their course, as well as the use of wide field radiation therapy. The questions as to which are the best operative approaches to removal of the primary tumor and nearby nodes may be solved. In the long run, treatment modalities will undoubtedly be found that allow us to hold the cancer cells in check, wherever they are, even if they cannot be all killed. Thus very long term palliation seems a valid expectation. The time will come when even those persons who have the great misfortune of having the initial diagnosis made after distant spread has

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*See President's Message on page 8*

## Introducing Your Board of Directors



**Richard Stienmier – President – [rstienmier@ecaware.org](mailto:rstienmier@ecaware.org) - Colorado**

I am a semi-retired MD, certified in anatomic, clinical and forensic pathology, and I served twenty years in the U S Army Medical Corps before starting my civilian career. I've worked as a physician for over forty five years. I developed esophageal adenocarcinoma in 2002, and I've had no recurrence since receiving chemo-radiation therapy and an esophagectomy. I have served as ECAA President since October 2006. My interests lie in assisting other esophageal carcinoma patients in finding the optimal treatment for their disease and helping their caregivers in providing support and care.



**Lois Dickerman – Vice President – [ldickerman@ecaware.org](mailto:ldickerman@ecaware.org) - Colorado**

I live in Estes Park, CO with my husband Richard. I am a retired associate professor in the departments of pediatrics and genetics at Case Western Reserve University. My passions are the outdoors and traveling, and my hobbies include painting, reading (especially mysteries), and gardening. Until Dick's EC diagnosis two years ago, we were volunteers at the greenhouse in Rocky Mountain National Park to cultivate native plants for restoration projects.

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*See Introducing the Board on page 3*

*Introducing the Board from page 2*



**Barb Price – Secretary/Treasurer – [bprice@ecaware.org](mailto:bprice@ecaware.org) - California**

I live in Ventura, CA, along with the rest of my family. I'm 52, the mother of one daughter and 1 grand daughter, the light of our lives! I work in medical sales for a provider of oxygen, durable medical equipment and enteral nutrition. My younger brother, Steve, was diagnosed with EC, at the age of 43, on Nov. 17, 2004, a day that we will never forget. Steve's job as a firefighter has exposed him to many unknown carcinogens. This is an area of interest to me as there are many instances of industrial causes of EC. Spreading the word about early detection of EC is also a focus and is desperately needed in this country. My own brother's situation is proof of this as he had been having problems swallowing his food for about 9 months prior to his endoscopy, which was only done at his insistence! I am glad to work with the ECAA to spread knowledge about this disease. Steve and I have met some extraordinary people on this journey and if we can help one other person, then it's worth it.



**Pat Caldwell – [pcaldwell@ecaware.org](mailto:pcaldwell@ecaware.org) – South Carolina**

I have been a nurse and nursing instructor for the past 25 years. I became very interested in learning everything I could about esophageal cancer when my husband, Dave, was diagnosed with the disease in April 2006. He fought the disease with all his strength until he died November 2006. We were married for 38 years. I want to help others learn as much as they can about the disease and caring for themselves or loved one. I live in South Carolina and enjoy the Carolina blue sky and the Gamecocks. I have three children who have graduated from college, married and are self-supporting. I have two grandchildren who are in Santa Fe, NM who I love to visit.



**Sean Waldron – [swaldron@ecaware.org](mailto:swaldron@ecaware.org) - Illinois**

I am one of the newest members of the Esophageal Cancer Awareness Association Board and could not be more honored to be a part of the group. In January of 2005 I lost my Dad to esophageal cancer. He had been diagnosed just two weeks prior. I wish that I would have had some of the information then that I have now and my goal is to help anyone that I can whether giving information or just listening. Thank you for your support of this group and good luck in your battles.



**Barby Woods – [bwoods@ecaware.org](mailto:bwoods@ecaware.org) – New Mexico**

As a teacher, I became acutely aware of the importance of knowledge when my husband, Bob, was diagnosed with EC. That is how I became familiar with the ECAA. We live in the sunny southwest, have one son who is about to graduate from college with a degree in anthropology and will be married for 25 years this October. I welcome any questions you may have. As it is often said, "been there, done that, got the t-shirt!" And we do have t-shirts for EC!!!

*Note: There are ten members of the board. Six of us have been introduced this month. The other four will appear in the next issue. If you need help, advice, or just to vent to someone, and you don't wish to use the EC-G list, you can email any one of us privately. -E-*

## Trust Me

*By Steve Preston*

In my 35 years of firefighting experience, many of them as an EMS [Emergency Medical Services] provider, and being a cancer survivor myself, it is safe to say that I have been to my fair share of hospitals. Certainly, as a provider, we are often asked by caregivers and family members "what do I bring" when heading to the hospital. Here are some helpful tips in what you may be involved with.

If you feel the need to call 911 because you or your loved one has a significant health issue, that's OK. Please don't feel guilty about doing so. And don't try to transport the patient in your own vehicle. TRUST ME...if it is "do-able" the paramedic in charge will be OK with that in most cases. But it should be their call. Ambulances today are set up as mini ER's so rest assured in that regard.

More than likely you will have somebody like myself

knocking on your door while you're still on the phone with 911. What you can do to help us help you is have a list of whatever medications (both prescription and over-the-counter) the patient is currently taking, a medical history past and present, list of allergies, and any papers such as a DNR (Do Not Resuscitate) that may be important and needed during transport or at the hospital. A list of medications is fine – physically bringing them is not necessary. All of this information is extremely important in the chain of events in getting your loved one or you to the hospital in a timely fashion.

Here is another tip. If you're the caregiver, try to drive yourself or have somebody drive you to the hospital in a private vehicle. The trap that people fall into is that they want to ride in an ambulance with their loved one. The problem is in getting back

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*See Trust Me on page 7*

## "Anatomy" of Cancer Surgery

*By Marc Siegal*

"Grey's Anatomy," Thursday, Jan. 11 and 18, 9 p.m

**The premise:** Intern George O'Malley (T.R. Knight) is worried because his father, Harold, having recently undergone a heart operation (aortic valve replacement), is now having an operation for esophageal cancer. The doctors don't know if the cancer has spread. Harold is told that the tumor won't be removed if it is too extensive. Harold tells the surgeon, Dr. Richard Webber (James Pickens Jr.), that he wants the cancer removed no matter what. The operation reveals metastases to the stomach, lymph nodes and liver. Webber follows the patient's wishes and performs an extensive operation. Postoperatively, Harold does poorly, requiring an emergency reintubation (insertion of a breathing tube), before going into kidney failure

and dying. George wrestles with the fact that his father might have lived longer without surgery.

**The medical questions:** Must a surgeon wait for the operation to know how far a cancer has spread? Is it reasonable to remove metastases as well as the primary tumor? Would a resident perform an emergency intubation? Would Harold have lived longer without surgery?

**The reality:** Though cancer spread cannot be predicted with total accuracy before surgery, in Harold O'Malley's case, the metastases were extensive and probably would have been found. A routine preoperative CT, MRI or PET scan would almost certainly have shown the lesion on the liver, and endoscopic ultrasound (often followed by a

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*See Anatomy on page 7*

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*Managing Your Disease – from page 1*

you may have to do some homework. Buy a medical dictionary and a simple human anatomy text. Paperbacks or used texts are adequate and economical. You will gain some vocabulary and you will be able to ask questions using appropriate words. You will be amazed at how medical professionals will respond to you when you make a real effort to communicate and to understand. Knowledge of what is happening in your body and what to expect will give you power and strength.

- Keep a daily log, especially while you are on chemotherapy. Write brief notes as to your energy levels, how you felt, when you had side effects like bad tastes or mouth sores, and when symptoms began to improve. After several treatments, you will know when some of the side effects lessened and when you will have improved appetite. You will learn how to pace yourself and conserve your energy. Dick always let me know when food started tasting better so I could start baking pies again.

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### Weight Loss Products



"I FOUND AN APPETITE SUPPRESSANT THAT REALLY WORKS. IT'S CALLED FOOD!"

- Organize every aspect of your medical history and treatments as efficiently as you can. Buy a three ring notebook and dividers. You will want to divide your medical information into easily accessible categories.
- Record the names, addresses, and contact numbers of all of your physicians, nurse practitioners, dieticians, pharmacists, and so on; the medical centers or hospital facilities where you are being treated, including those of your local medical facility if it is not the same (should an emergency arise); numbers of important departments like medical records room, radiology, radiation therapy, oncology therapy, and so on.

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*You will be amazed at how medical professionals will respond to you when you make a real effort to communicate and to understand.*

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- Develop a monthly calendar listing all appointments as they are made. Record the telephone number of the appointments desk or contact person.
- Have sections for copies of reports: laboratory results and blood tests, medical imaging reports such as interpretations of CT scans, and PET scans. It is easiest to arrange these in reverse order with the most recent first, as you accumulate more and more reports.
- List your current and past prescriptions since your diagnosis, when they were prescribed, by whom and for what problem. You may want to add summaries of side effects and potential risks of these medications for quick reference.
- Make a copy of your health care power of attorney, your living will and/or your advanced

## “Googling” EC

*By Roger Tunsley*

When I was first diagnosed with EC, I went home, as we all do, in some shock. My personality craves information about things relevant to me that I know nothing about, so I immediately sat down at the computer, cranked up Google, and started to search avidly. Of course, the shock increased as I began to read the stories, statistics, and details. However, the more I read, the more conflicting information I received. The statistics ranged wildly, as did the stories and the details. I quickly realized several things:

- You can't believe everything you read, especially on the web. Read critically.
- Statistics figures are heavily influenced by the date that they were published.
- Everyone's EC experiences are very different.

A couple of days later, on my first consultation with the surgeon who would eventually perform my esophagectomy, his first words were “Do not Google this disease”. He was concerned that the plethora of information and misinformation on the web would just be too depressing and confusing. “Too late” I said, but reassured him that I was a critical reader and could sort the wheat from the chaff.

By reading information critically, we are able to deduce many things. I knew the survival statistics were dire, but found that had been improving over the last few years. I found that many of the statistics published were very broad and did not take into account the age of the patient, the stage of the cancer, the availability of skilled medical practitioners and establishments, and so on. I learned about the various forms of treatment and the various types of surgery before I went for consultations with my various ologists. This helped

me enormously during my consultations with them and in making the decision as to which treatment protocol to follow. After talking to the various doctors, I could look them up on the web and find out where and how they trained, whether they had published any academic papers, what the survival record of their hospital was for the operation, and so on.

So how do we get information out of the internet? I will offer some tips using the Google search system, although the same basic techniques work also with others such as Yahoo, Ask, and so on.

To open Google, in your web browser, type [www.google.com](http://www.google.com). The home page opens with a text entry field for you to enter your search terms.

To perform a basic search, enter `esophageal cancer`. This search results in links to every article that has the words esophageal and cancer no matter where they are in the article.

To find pages that have the exact phrase esophageal cancer, enclose the search term in quotes - `“esophageal cancer”`.

To find synonyms for a term, use the `~` operator immediately in front of the term - `~food ~facts` will find information on nutrition, cooking information, and so on.

Here are some other search terms you may wish to use:

- `dumping syndrome tips`
- `hospital volume esophageal cancer survival`
- `esophagus cancer alternative medicine`

Good luck with your searching. -E-

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*Anatomy* – from page 4

diagnostic fiber optic scope placed into the chest or abdomen) has an accuracy rate of close to 90% in showing regional node involvement. For this reason, exploratory laparotomies are rarely done these days, and in most cases a treatment strategy can be considered before surgery.

Patients sometimes benefit from the removal of isolated metastases, but studies on esophageal cancer have shown that having several lymph nodes involved reduces overall five-year survival to less than 5% regardless of treatment (including chemotherapy).

A surgeon is unlikely to agree to perform an extensive tumor-removing operation just because the patient insists on it. But George's father probably would not have lived very long even without surgery, and in fact, chemotherapy after esophageal surgery has been shown to increase early mortality. Kidney failure is possible but is not a common result of this kind of tumor or surgery. Finally, a resident would be unlikely to insert a new tube without an anesthesiologist or an ear, nose and throat surgeon standing by. –E–

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*Dr. Marc Siegel is an internist and an associate professor of medicine at New York University's School of Medicine. He can be reached at [marc@doctorsiegel.com](mailto:marc@doctorsiegel.com).*

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*Trust Me* – from page 4

home again. It may seem funny but it actually happens quite a bit where the patient and caregiver have no way of getting home because they rode in on the ambulance.

Finally, limit the personal belongings of the patient that you bring to the hospital. Hospitals can be chaotic and, as much as we love to trust people, stuff does have a way of going missing. So limit jewelry, money or other valuables. But do bring insurance cards and the patient's list of doctors. That is very important. By doing a little bit of homework and having it in a readily available place, you can save at least some of the stress that goes with such an event. –E–

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*Managing Your Disease* – from page 5

directives. List family phone numbers, your attorneys, friends that you would want to notify immediately if problems arose, and other emergency numbers.

- A section for forms requesting medical information, reports, and physicians' consult notes, along with a pocket containing stamped, self addressed envelopes to your mailing address. You have the right to obtain all of these reports and your medical providers must abide by your requests by law. Take advantage of this.

If you wish to seek second opinions with regard to some proposed treatments, organizing your information in this way will save time. It is also highly encouraging to be able to see improvements in some of your tests over time and to follow the success of your treatments.

Keep this notebook with you at all times as you go to your various medical appointments and for any hospitalizations. This is particularly important if your care is coordinated between two facilities.

In part 2 of this article in the next edition of the newsletter, I have some further tips on medications, exercise, and keeping a positive attitude. –E–

*Presidents Message – from page 2*

occurred can fully expect that the disease can be checked, if not checkmated.

We recognize the extreme importance of having excellent medical advice and following it, yet there will always be questions that need further explanation and a place for giving suggestions to caregivers and patients that are based on our own sufferings, both physical and mental. We believe that you can never get too

much information about how to deal with this cancer that some have characterized as “The Beast”.

Until the bright promises of the future comes to pass, and even when they do, the shock of discovering a malignancy with such an evil reputation occurring in our own body or in one of our family members or friends will still have to be managed, and issues of support dealt with. To this end, we dedicate this newsletter. –E–

### Are you having difficulty with your medical expenses?

This organization may be able to help:

[www.patientadvocate.org](http://www.patientadvocate.org)

The Patient Advocate Foundation Group is a national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

Call 1-800-532-5274

# 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.com](http://www.ecaware.com), or contact Barb Price at [bprice@ecaware.org](mailto:bprice@ecaware.org) or 1-866-370-3222

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.

## 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 Barb Price at [bprice@ecaware.org](mailto:bprice@ecaware.org) or 1-866-370-3222