SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.

Volume Number July 2009

Presidents Message

By Lois Dickerman, PhD

As I sit here trying to think of profound, funny, interesting, or informative things to write for the Swallow Tales editorial, I am in creative paralysis. All I can think of at the moment is that we lost our son the end of May, and grief still overwhelms both my husband and me. Despite all of the turmoil, fear, anger, concern, despair and hopelessness that we first felt when Dick was diagnosed with Stage IVB esophageal cancer, those experiences did nothing to prepare us or to help us deal with the emotions that we are facing now.

Parents are not supposed to outlive their children and grandchildren are not supposed to be without a father. Our children are meant to follow us and tell their families of how we lived, what we did with our lives and what heritage we have given to the future. Our daughter can do that for her two children, but our daughter in law is left to deal with a mother with Alzheimer's disease that is living with her and three children, two of whom are minors. We plan to be there as much as we can for them, although we live more than 1000 miles away.

Basically, whether you are dealing with unexpected deaths in the family or incurable disease or any other overwhelming circumstance, there is only one choice…..to make it through, one day at a time. I am not good at this type of thinking, but Dick, my husband, is a master. All of the time he was in chemotherapy and his other treatments for esophageal cancer, he always said, "I can make it through today". He always said, "None of us know what will occur tomorrow. We must live in the present".

So, I am doing my best to follow Dick's example, to remember and cherish the days we had with our son, and to be there for our grandchildren as they move toward adulthood. But the ache will always remain for the little boy who loved cars and trucks and collected Matchbox cars and trucks. I can still see the two year old who took his cars to bed, instead of a teddy bear, and woke up each morning with imprints of wheels, bumpers and other parts on his face, arms and legs.

The Disparity In Cancer Research Funding

Cancer Is Down Overall, But Some Of The Fastest-Growing Types Are Getting The Least Attention

As reported on CBS Evening News

May 27, 2009 | by Jonathan LaPook

(**CBS**) In 2006, 560,000 Americans died of cancer, down 2 percent from the previous year. Cancer is on the decline in this country - down 19 percent among men between 1990 and 2005 and 11 percent among women between 1991 and 2005.

But those declines are concentrated among the cancers that receive the most research unding, while some of the fastest *growing* cancers are getting little publicity or funding, as **CBS News medical correspondent Dr. Jon LaPook** reports.

Amy Schoener loves her life as a new mother. But a year ago she took on another role when her father, Edward, was diagnosed with cancer of the esophagus.

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Inside this issue:

Talking with Kids about Cancer

by Michele Reiland

I would like to share with you our story and some information that I found helpful in talking with kids about cancer. My husband Keith & I met in college in 1987. We have been married 14 wonderful years and have three beautiful children ages 9, 7, 5 years. Keith works as a Manufacturing Manager at a local plastics company. I have chosen to be a stay at home Mom for a few years while our kids are young. Keith & I are volunteer to help out at the kids school, coach their softball & soccer teams, and even being a Girl Scout Leader. We were enjoying our family life together and had no worries.

One day, just before Thanksgiving, in November 2008, Keith started complaining of pain in his right side. At first, he thought he pulled a muscle. Keith (age 39) had always been health conscious and in good physical shape by running and lifting weights. After a few days, the pain got worse and he decided to go to the Emergency Room. This is when our nightmare began. We had an excellent Doctor in the emergency room who ordered an CT Scan. He told us that he saw spots on Keith's liver that looked like metastatic cancer. We were told to make an appointment with our family physician and schedule a liver biopsy right away. The liver biopsy was done on December 4, 2008. It confirmed our worse fears, a cancer diagnosis. It was metastatic adenocarcinoma that spread to Keith's liver. Doctors need to find the site of Keith's primary tumor. On December 19, 2008, we had a GI endoscope done. The Doctor found Keith's primary tumor at the GE Junction, the point where the esophagus and stomach connected. Unfortunately, Keith's cancer was stage IV. It had spread to the near by lymph nodes and liver. We were told that Keith had 10 -12 months to live. The cancer was too widespread to be a candidate for surgery or radiation. Our only option was palliative chemotherapy to reduce the side effects of cancer and prolong Keith's life for as long as possible. A diagnosis of esophageal cancer (EC) was a shock. Keith was young and did not meet any of the common risk factors of the disease (smoker, over weight, heavy drinker, chronic heart burn or acid reflux).

Cancer affects the entire family. Our children knew something was wrong. What and how much should we tell them. Here are some tips from www. cancercare.org that help us communicate with our children about Keith's cancer diagnosis. It also helps to take some time to prepare yourself and think about what you want to say.

Cancer affects the entire family.

- Give your children accurate, age appropriate information about cancer in a way they can understand. show or tell them where the cancer is in the body. This is a very difficult thing to do and there is no easy way of saying it. It is ok to get upset or cry. For example, I have an illness called cancer. Some cells , black spots, or bad guys in my body are growing too fast and are not supposed to be there. It is sore. It makes me sad to feel sick. I have to take strong medicine to try to get rid of it. The Doctor's will do their best to help me get better.

- Explain the treatment plan and how it will affect their lives. We told the kids that the chemotherapy might make Daddy feel sick, very tired, loose his hair, weight loss, etc. We explained his medical port, the home infusion pump, and how they would be used. We also tell them when we got to the hospital for treatments, tests, and appointments and why the babysitter will be coming.

- Answer your children's questions as simply and accurately as possible. it is ok to say, "I don't know."

- Reassure your children that they will still be loved and cared for, and who will look after them. Explain that they did not do anything to cause cancer and they can't catch cancer like they can a cold. Leave them with feelings of hope that the Doctors are doing their best to help and there will be both good days and bad days ahead.

- Let them know that they can turn to others for support. Your spouse, relatives, friends, clergy, teachers, coaches, etc. They can ask others questions and talk about their feelings.

- Allow your children to participate in your care. Give them age appropriate tasks like bringing you a glass of water or a blanket.

- Encourage your children to express their feelings. It is ok to feel sad or to try.

- To the extent possible, make communicating with your children a priority. They can over hear conversations or hear news from others. Listen to your children and help them feel comfortable. Show your children a lot of love and affection. Let them know that although things are different now, your love for them has not changed.

Finally, parents who are concerned with how their children are coping should talk to the child's pediatrician, teacher, school counselor/ psychologist, or the social services department of their local hospital where they are receiving treatment. Two good non - profit support groups for kids are:

1. KATS- Kids Adjusting Through Support. Help children and families cope with serious illness or loss. They also have summer camps available for kids & families.

The Disparity In Cancer Research Funding

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The least funded were cancers of the stomach ($1,168), lung $1,553), and esophagus ($1,542).

"When a doctor looks in your face and says, 'Your father has a year to live, and the treatment options are small,' and I'm not a doctor, and I'm not someone who can go out and research a cure personally, what can I do?" Schoener said.

What she does is spend all her spare time raising awareness of her father's disease, one of the country's fastest-growing and least funded cancers.

"Until we get some attention and some dollars for research, we're going to be exactly where we are now - it's going to keep growing," Schoener said..

A **CBS News** analysis of data released Wednesday by the American Cancer Society reveals a large disparity in funding for different types of cancer.

For every cancer death, the most federal research dollars were spent on cancer of the cervix ($18,870) and breast $14,095) and on Hodgkin lymphoma ($12,791). The least funded were cancers of the stomach ($1,168), lung $1,553), and esophagus ($1,542).

One reason for the disparity - some advocacy groups, like those for breast cancer, are more adept at raising awareness. And with awareness comes cash.

"It's clear that some of the gender related cancers are very effective in raising funding for research," said Dr. Raymond DuBois, provost at the M.D. Anderson Cancer Center.

Twenty-eight-year-old Andrew Lesser is feeling the effects of this inequity. He's battling esophageal cancer, which gets just a tiny slice of the cancer research pie.

"Certain ones get more attention, get more funding. They know more about them. This - it's still kind of an unknown," Lesser said.

Officials at the National Cancer Institute say they're not getting enough grant proposals for research into cancers of the esophagus, stomach, and pancreas.

Talking with Kids about Cancer

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2. Gilda's Club - offers support groups, workshops, lectures, social activities, and a special playroom and program for children with cancer or whose family member has been diagnosed with cancer.

Cancer affects the entire family. Children pick up on things very quickly. If they don't know what it is, they may imagine terrible things that are even scarier than a cancer diagnosis. Children react in different ways. Some act brave and take on more responsibility at home, some get angry and act out. Others become afraid and withdrawn from the parent who is sick. Finding a counselor or support group for children can give your child a safe place to work through complex emotions. We need to take steps to take care of ourselves & our families during this difficult time. You can still have a good quality of life with a cancer diagnosis. Live strong every day and laugh often.

Michele Reiland is the wife of Keith & Mother of three

Swallow Tales Needs Your Help.

Do you have a story you would like to tell?
Would you like to contribute an article to Swallow Tales?

Email your article to Robert Ginsberg at rginsberg@ecaware.org . We'll do our best to incorporate it in our next issue.

Remember, we cannot reproduce copyrighted material without

Know Your Rights

If you feel you are being singled out at your workplace because of a diagnosis of Esophageal Cancer you have certain rights under the law.

For more information about your rights visit the Job Accommodation Network (JAN) online atjan.wvu.edu , or call (800) 526-7234. The JAN provides free consulting services, including one-on-one consultation about job accommodation ideas and requesting accommodations. Here are some other resources:

- The National Disability Rights Network, a national network of legally based advocacy services for people with disabilities: napas.org or 202-408-9514.

- The Office of Disability Employment Policy at the Department of Labor: dol.gov /odep/ or 1-866-ODEP-DOL (633-7365).

- Does your employer need guidance in implementing the ADAAA's requirements? Steer them to the Employment and Disability Institute at Cornell University: ilr.cornell.edu /EDI/index.cfm or 607-255-7727.

NCI Cancer Bulletin

The Curious Rise of Esophageal Adenocarcinoma

An incidence chart of major cancers in the United States over the past three decades shows lines that are mostly flat or moderately sloped. But if the incidence of a relatively uncommon cancer, esophageal adenocarcinoma (EA), is added to the graph, the contrast is stark. After all, rarely do incidence rates of any disease, let alone a type of cancer, increase by 300 to 400 percent in 30 years.

Already infamous for being one of the most lethal types of cancer, these stunning gains in incidence have garnered EA a reputation as a looming threat.

“There are a lot of issues at play as to why those numbers have gone up,” says Dr. Nicholas Shaheen, director of the Center for Esophageal Diseases and Swallowing at the University of North Carolina at Chapel Hill. “But I am concerned because we haven’t been able to figure out what’s causing the increase.”

Epidemiologic studies have identified several factors that significantly increase EA risk, says Dr. Wong-Ho Chow, of the NCI Division of Cancer Epidemiology and Genetics. A 1999 case-control study conducted in Sweden, for instance, found that long-standing and severe reflux symptoms increased EA risk by more than 40-fold. When coupled with overweight or obesity, the risk increase jumped to more than 00-fold. Several studies have shown that smoking is also an important risk factor.

While these are risk factors for what is still a fairly rare cancer—approximately 7,000 new cases a year, mostly late-stage disease—it’s as if something has happened to unleash what was once nothing more than a medical anomaly.

“The only change in Western society that really mirrored this increase in incidence is the epidemic of obesity,” says Dr. Shaheen. “And that makes it the most logical candidate for why things are going the way they are. But we really don’t know that. It’s still just a theory at this point.”

According to Dr. Chow, for a significant portion of patients, EA is thought to begin with reflux, which causes acid from the stomach to spout up into the lower portion of the esophagus. The acid displaces cells that line the lower part of the esophagus—just above where it meets the stomach—with a different, potentially cancerous cell type in a condition known as Barrett’s esophagus.

People with Barrett’s esophagus have at least a 30- to 40-fold increased risk of developing EA compared with the general population; however, their overall risk is very low: 90 to 95 percent of patients will never develop the cancer.

“Why only a small percentage of Barrett’s continues to become cancer, and what makes some people progress and others not, we just don’t know yet,” Dr. Chow says.

Unfortunately, most people who develop EA don’t have symptoms until they already have late-stage disease, at which time the few available treatment options are not very successful. Even for patients who are amenable to treatment, 5-year survival ranges from just 5 to 30 percent.

A handful of investigators who have been involved in studies with Barrett’s patients are searching for molecular indicators that might predict the likelihood of somebody with chronic reflux or Barrett’s progressing to EA. At the University of Southern California/Norris Comprehensive Cancer Center, Dr. Peter W. Laird and colleagues are using a test called MethyLight to see if certain changes in the extent of DNA methylation—a way to activate or deactivate genes—can detect EA in its earliest stages or predict the likelihood of progression.

At Fred Hutchinson Cancer Research Center, Dr. Brian Reid, who heads the Center’s Barrett’s Esophagus Program, and colleagues are examining biopsy samples to determine whether mutations in two genes (p16 and p53), as well as abnormalities in the amount of DNA in a cell—that is, a condition called aneuploidy—are predictive of progression to EA.

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The Curious Rise of Esophageal Adenocarcinoma

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Because EA is still so rare, much of this work is really about surveillance, Dr. Reid notes.

"If we can reassure those people who are at low risk, and get high-risk people into appropriate surveillance or treatment options, it would be a big help," he says.

The only current option for screening of people with chronic reflux or surveillance of Barrett's is endoscopy, which involves inserting a long, flexible tube—fitted with a light and video camera on one end—through the mouth and down into the throat to examine and take biopsies from the esophagus and stomach.

But using endoscopy as an everyday screening tool for EA isn't prudent or really feasible, Dr. Shaheen argues. An estimated 40 percent of people have chronic heartburn, "and most will never go on to have Barrett's or certainly will never have cancer, so you'd literally be searching for a needle in a haystack," he says. "We do that in other areas of medicine, but we generally don't do it with a test that costs more than $,000."

Dr. William J. Blot, of the Vanderbilt-Ingram Cancer Center, is leading an effort that he hopes might help identify candidates for regular EA surveillance. Much like the Gail model, which assesses breast cancer risk, he and his colleagues are developing a model that takes into account all of a person's risk factors and stratifies them into a low- or high-risk category for developing EA over a subsequent 5-year period.

There is not nearly as much data on EA risk factors as there is for a far more common cancer such as breast cancer, Dr. Blot says, so the new model would be less precise than the Gail model. "But," he adds, "it's a start."

GETTING BIGGER NUMBERS

Much of the uncertainty surrounding EA can be directly attributed to the fact that it is rare.

To gather enough EA and Barrett's cases—and, more importantly, biological samples from those cases—to generate the statistical strength to provide a clearer picture of these diseases, NCI has formed a consortium of academic medical institutions and cancer centers that specialize in EA and Barrett's.

Called BEACON and currently chaired by Dr. Thomas Vaughan of the Fred Hutchinson Cancer Research Center, the consortium includes investigators who have conducted case-control studies of EA and Barrett's in the United States, Canada, Great Britain, Sweden, and Australia.

ECAA Board Positions Open

Many people, when first confronted with this disease, are surprised and often angry that there is little information about EC in the public eye. They struggle to find information. They need to talk face to face with people who have walked in their shoes. They cry out "Why isn't more done?"

Well, now is your opportunity to get involved and make a difference in people's lives.

The ECAA is looking for volunteer members to join the board. The role of board member is a voluntary unpaid position, and the main contribution that any board member can bring to the association is the commitment and drive to help us fulfill our aim of increasing the awareness of this dire disease.

We are particularly interested in filling the position of Membership Coordinator. The task of the membership coordinator is to establish a committee of members that can:

- Promote membership in the society.
- Help to organize state, regional, and city groups for local support, outreach, fundraising, and publicity of our cause.

This role is demanding. It requires personal drive and time commitment. You must be competent with electronic communications and with record-keeping using computer spreadsheet and word processor software. The ability to relate to patients, survivors, care-givers, and loved ones is of course crucial.

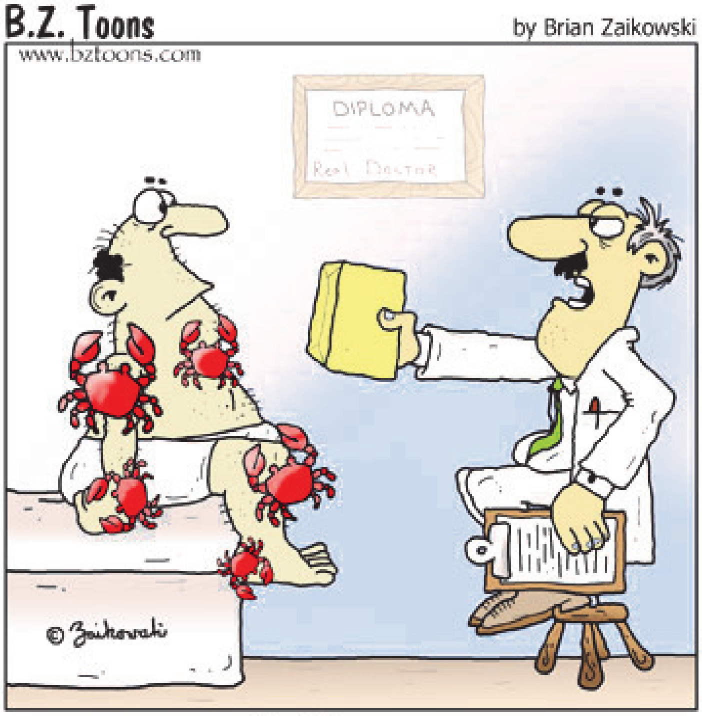
If you have been wondering what you can do to fight this disease, now is your opportunity.

PET Imaging May Help Guide Treatment of Esophageal and Gastric Cancers

According to the results of a study published in *Lancet Oncology*, use of positron emission tomography (PET) imaging to evaluate response to neoadjuvant (before surgery) chemotherapy may help guide treatment of patients with cancer of the lower part of the esophagus or the upper part of the stomach (adenocarcinoma of the esophagogastric junction).

For patients with operable, locally advanced adenocarcinoma of the lower esophagus, stomach, or esophagogastric junction (the area where the esophagus joins the stomach), a Phase III clinical trial indicated that chemotherapy before and after surgery may improve outcomes.[1] Not all patients respond to chemotherapy, however. Being able to identify early in the course of treatment those patients who are not responding to chemotherapy would allow these patients to stop chemotherapy early and proceed more quickly to surgery.

Positron emission tomography is an imaging technique that is sometimes used to help stage cancer. Prior to a PET scan, a substance containing a type of sugar attached to a radioactive isotope (a molecule that spontaneously emits radiation) is injected into the patient's vein. The cancer cells "take up" the sugar and attached isotope. The low energy radiation emitted by these cells helps physicians locate cancer.



Try this cream.

To evaluate the use of PET for assessing early response to neoadjuvant (before surgery) chemotherapy, researchers conducted a Phase II clinical trial among 110 patients with locally advanced adenocarcinoma of the lower esophagus or the upper part of the stomach.[2] Patients were assessed by PET prior to the start of neoadjuvant chemotherapy and after the first two weeks of neoadjuvant chemotherapy. A comparison of the two scans allowed physicians to assess which cancers were responding to chemotherapy.

Patients who responded to chemotherapy (as assessed by PET) continued on chemotherapy for a total of 12 weeks. Patients who did not respond to chemotherapy stopped chemotherapy after the first two weeks and proceeded directly to surgery.

- 49% of patients were classified as chemotherapy responders on the basis of their PET results.
- Median survival without cancer relapse was 29.7 months in the chemotherapy responders and 14.1 months in the chemotherapy nonresponders. The survival among the chemotherapy nonresponders was similar to the survival noted in a previous study in which nonresponders continued on chemotherapy; this suggests that stopping chemotherapy early in the nonresponders did not have an adverse effect on treatment outcomes.

The researchers conclude that use of PET to monitor chemotherapy response is feasible in patients with adenocarcinoma of the lower esophagus or upper stomach, and may allow for more individualized treatment. Early identification of patients who are not responding to chemotherapy may allow these patients to avoid unnecessary side effects and to consider other treatment options. The researchers note, however, that Phase III clinical trials will be necessary to further evaluate these issues.

References:

[1] Cunningham D, Allum W, Stenning S, et al. Perioperative Chemotherapy Versus Surgery Alone for Resectable Gastroesohpageal Cancer. *New England Journal of Medicine*. 2006 ; 355:11-20.

[2] Lordick F, Ott K, Krause B-J et al. PET to assess early metabolic response and to guide treatment of adenocarcinoma of the oesophagogastric junction: the MUNICON phase II trial. *Lancet Oncology*. 2007;8:797-805.

What Can You Do To Help?

The ECAA is a small organization and depends upon membership, donations and merchandise sales for all income.

We have no paid staff; we are an all-volunteer organization.
So what can you do?

- **Join us – only $25 for life membership.**
- **Purchase our pins, shirts, caps, and wristbands to help raise the awareness of this disease in our community.**
- **Donate in memory of someone, or in support of someone in treatment.**
- **Volunteer your time and energy to help us increase membership, form member groups, pass out information on EC, reach out to patients and caregivers..**

You can be sure that every penny donated goes toward raising the awareness of esophageal cancer in the general public and the medical profession.
Help somebody. Donate to the ECAA.
Go to www.ecaware.org

To join the ACOR EC-Group mailing list, send mail to
LISTSERV@LISTSERV.ACOR.ORG
with the command
SUBSCRIBE EC-GROUP

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.

Show your colors and spread the word with ECAA merchandise: caps, shirts, wrist-bands, pins and magnetic ribbons and bracelets.

Caps are off-white cotton with a navy blue bill. They sport the ECAA logo and the web site address.

Our polo shirts are white and embroidered with the ECAA logo on the left breast. They are a 50/50 cotton/polyester blend of 6.5 oz. material for long lasting good looks.

Our traditional t-shirts are pale blue with a large full-color ECAA logo on the front. The back has the message “ESOPHAGEAL CANCER – HARD TO SWALLOW” together with the association web address.

Wrist bands are silicone with one half blue and the other half yellow. They bear the ECAA web address and the slogan “Be EC Aware”.

The pin is a great accessory for your outfit - formal or informal. Attractive and bound to provoke interest and questions, the pin is $^7/_8$ in. square. Quality manufactured in the USA, it is imprinted with the ECAA initials and logo, and the phrase "Be EC Aware". The background color is periwinkle blue.

The magnetic ribbon is in the association colors of blue and gold. It sports the association web address and the swallow logo. It measures approximately 6 inches tall and 2 inches wide. It is almost guaranteed to create interest and conversation.

Lastly, the bracelets are crafted with care and love by one of our members. This beautiful bracelet with its multicolored beads will accentuate any outfit. Each bead color represents a different type of cancer, for example pink is for breast cancer, teal is ovarian, and so on. Each bracelet is finished with a charm and a sterling silver awareness ribbon.

Please note: The bracelets are made to order and will be shipped separately from any other items that you may order.

ECAA Polo Shirt

ECAA T-Shirt Front

ECAA T-Shirt Back

ECAA Cap

ECAA Wrist Band

ECAA Enamel Pin

ECAA Magnetic Ribbon

Cancer Awareness Bracelet

ECAA MERCHANDISE ORDER FORM

Polo Shirt $16.00 each	Youth L Qty	Youth XL Qty	Adult M Qty	Adult L Qty	Adult XL Qty	Adult XL Qty	Adult XXXL Qty	$
T-Shirt $12.50 each	Adult Small Qty	Adult Medium Qty	Adult Large Qty	Adult XL Qty	Adult XXL Qty			$
Cap	One size fits all - $8.00 each			Quantity				$
Wrist Band	One size fits all - $3.00 each			Quantity				$
Enamel Pin	One size fits all - $3.00 each			Quantity				$
Magnetic Ribbon	$3.00 - each			Quantity				$
Cancer Awareness Bracelet	One size fits all - $15.00 each			Quantity				$
Sub-Total								$
Shipping and handling $1for orders totaling up to $9.99, $4 for orders from $10 to $39.99, $6 for orders totaling $40 or more.								$
I would like to make al donation to the Esophageal Cancer Awareness Association.					☐ $25.00 ☐ $50.00	☐ $100.00 ☐ $250.00	☐ $500.00 ☐ Other	$
I would like to become a lifetime member of the Esophageal Cancer Awareness Association.						☐ Individual $25.00	☐ Family $30.00	$
Total								$

Ship my order to:

Name: ____

Street Address: ____

City: ______________________________ State: __________ Zip Code: __________-__________

Phone#: ______________________________ Fax# ______________________________

Email Address: ____

Please make your check payable to the Esophageal Cancer Awareness Association.

Mail your completed order form and payment to:
Dick Dickerman (Treasurer)
Esophageal Cancer Awareness Association
P.O. Box 55071, #15530
Boston, MA 02205-5071

You can also become a member, make a donation or order merchandise on our website at www.ecaware.org.

Thank you for supporting the Esophageal Cancer Awareness Association

Esophageal Cancer
Awareness Association

Membership Form

Thank you for your interest in membership of the Esophageal Cancer Awareness Association.

The ECAA depends on its active members to ensure our growth and to increase our ability to spread awareness of esophageal cancer to the general public and to the medical community.

ECAA life membership is $25.00 for a single membership or $30.00 for a couple (husband and wife, partnerships, patient and caregiver, and so on). This is tax-deductible.

Please send your details and a check for your membership to:

Dick Dickerman (ECAA Treasurer), P.O. Box 55071 #15530, Boston MA 02205-5071

Personal Details

Name (Last, First): ____

Address: ____

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Phone :__________________________(H) __________________________(M)

Email: ____

Interest (Optional)

- I am an esophageal cancer patient or survivor
- I am or was a caregiver to an esophageal cancer patient or survivor
- I am a medical professional
- Other (Please specify) ____________________________________

Volunteer Interest

- Form a local support or contact group
- Outreach to patients
- Distribute support materials at clinics and hospitals
- Membership campaigns
- Fundraising

ESOPHAGEAL CANCER CHAT AND SUPPORT

New people may be interested in knowing that there is another place for support for EC patients, caregivers, and survivors along with the ECAA and the EC-Group affiliated with ACOR. It is in no way affiliated with the EC-Group or the ECAA, though most of our attendees do come from the EC-Group.

We have a Chat Group that can be accessed through ngc1514.com/chat. **We meet on-line on Sundays and Wednesdays at 8:00 PM ET** and everyone is more than welcome to attend. Some of us are long-term survivors and by our continuing to share our experiences, we make it at least a little easier, especially for people new to the EC struggle.

You may be interested in knowing how the Chat Group came into being. Many years ago, Connie DeLury, a caregiver for her husband, Walt, asked if anyone would be interested in getting together online to chat. The answer was a resounding "yes" and the EC Online Chat Group was formed. Roger Thompson was the first Host, assisted, I believe by Bill (Guy) Churchill, also an EC survivor. As an aside, Guy still attends Chat when he can. By the time I, an EC survivor, arrived, Chat was well established.

When the site for Chat changed, Roger went on to other things, and Lenny Mandel (a caregiver) hosted. Again, another site was needed and the timing was not good for Lenny to look for a new site, so Eric Greene, an EC survivor, kindly offered us the use of Parachat, accessed through his website. It was then that I, along with Ike Eichelberger, former caregiver and Chris Slaughter, also a former caregiver, took over the hosting job. We launched the Invitation to Chat notifications and Chat Reminders. In time Chris went on to other things and Homer Lathrop, a survivor, joined Ike and me as co-hosts. Homer co-hosted until he was well enough to return to work and no longer had the time, but still attends Chat when he can.

Sadly, Ike passed away a little over a year ago, and now I, along with Eric Greene, host Chat.

It is our pleasure to be involved with Chat, where we have been fortunate in meeting some really wonderful people. Everyone is just so respectful of everyone else. Attendance varies from week to week. Those that attend on a fairly regular basis soon find that they have made new friends and have contact outside the Chat sessions. It is a more intimate setting than the ECG, and many have commented how comfortable they are in a smaller setting.

We have never restricted what anyone shares. So many different topics are discussed and all are just so willing to share, especially the good, and regrettably, the bad. There are times when EC is not even brought up and we talk about things going on in our lives and the lives of our loved ones. But, if anyone at any time wants to ask questions or share concerns about any aspect of their EC journey that becomes paramount.

We look forward to welcoming new people as well as the return of any patients,long-term survivors, or caregivers who want to update us on how things are going for them.

Feel free to contact me, Mickey Love, at mlove33567@aol.com or you can also contact Eric Greene, at eric@ngc1514.com if you have any questions.

NEW!

Stomach / Esophageal Cancer Support Group

Monthly Support Group Meetings at Sylvester Comprehensive Cancer Center

A Caring, Sharing and Educational support group for Stomach & Esophageal Cancer patients, their families and friends.

Support Group Meetings are 4th Thursday of every month 5:30p.m. to 7:00 p.m.

Upcoming session July 23, 2009
Speaker: Dr Bach Ardalan, Medical Oncology
Topic: Advanced Adenocarcinoma: Comparing Treatment Modalities UM, others US Centers and the U.K.

Where: Sylvester, 1475 NW 12 Avenue, Room 3408, Miami, FL 33136
Contact: Rosa Caiseda: 305-243-4193 or Joyce Rios: 305-243-9573

The Esophageal Cancer Awareness Association, Inc. (ECAA) is a volunteer-member-driven, not-for-profit; tax-exempt organization founded by esophageal cancer (EC) survivors, caregivers and patients in 2002. Our membership is open to all with an interest in raising awareness of this deadly disease.

We invite you to visit our web site (**www.EcAware.org**) or contact us by telephone, email or mail for
additional information on dealing with Esophageal Cancer.

We care and EC is survivable! Please join us in our efforts.

You can help us help others with a donation, merchandise purchase or membership.
See pages 8-10 for details

The ECAA is an IRS approved 501(c) (3) tax exempt organization

Donations are tax deductible to the extent as allowed by law.

Esophageal Cancer Awareness Association
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