

# SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association



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## President's Message

By Amy Schoener



This is truly an exciting time for the ECAA.

In August, the Board of Directors held officer elections. I am extremely honored to be serving as your President for this term. I hope

that you will join me in welcoming our new Vice President, Ann Novogradec, returning Treasurer, Bob Ginsberg, and Secretary, as well as merchandise manager, Dana Lilienthal. As you will see in the

following pages, we also welcomed the addition of three new Board members; Michele Reiland, Dr. Michael Rothwell, and returning member Roger Tunsley, each who bring with them a strong personal passion for our cause and valuable skills.

One of the first challenges that we faced was refreshing our place in the EC Community, and so we began by drilling down our mission statement to be more specific and more powerful.

We have accepted this new mission statement for the ECAA:

We are a grassroots, not-for-profit organization that is dedicated to providing outreach for esophageal cancer patients, caregivers, and survivors. We strive to increase public awareness of this disease and to provide education and information in a supportive environment.

Impassioned with a renewed sense of urgency, we as a group have made a commitment to grow our organization into the pre-eminent patient advocacy group for the EC community by DOING more than we have been able to before for the EC cause and doing it more productively than we have in the past.

While we are excited, we are also aware that there are many organizational challenges ahead of us. As a small organization, which started only seven years ago, we have made leaps and bounds each year, but we still have work to do. Our team has spent the last two months building the foundational stepping-stones that are necessary for us to succeed in our goals, streamlining simple administrative processes and developing more structure for our team.

We have initiated the revamp of our website, with hopes of providing a more user-friendly experience for our visitors. We are reviewing fundraising initiatives to help in our growing goals, and we are currently reviewing

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## American Cancer Society Launches More Birthdays Mobile App



**ATLANTA 2009/11/30** – American Cancer Society, the Official Sponsor of Birthdays, today announced the launch of a new, free mobile application available for the iPhone and iPod Touch that brings its More Birthdays movement to life and makes it easier for mobile users to never forget the most important birthdays in their lives. The app, created by Welikesmall, is the first mobile application of its kind to offer interactive birthday cake animation and the ability to track friends' birthdays, send customized greetings, make a donation and even join the Society's movement to create a world with less cancer and more birthdays.

The new More Birthdays app allows mobile users to:

- Link-up with contact lists and Facebook to track friends' birthdays and receive and customize alerts for upcoming birthdays
- Customize a birthday cake greeting with personalized text to send to friends on their birthday;
- Donate to the American Cancer Society
- Have fun with an interactive birthday cake animation by choosing from different cakes. Users can blow out the candles and receive audio celebratory response
- Learn more about and join the American Cancer Society's More Birthdays movement.

"The American Cancer Society More Birthdays app is a powerful new social utility bringing people together to remember and celebrate birthdays as an important milestone in our lives," said Scott Bennett, national vice president of marketing, American Cancer Society. "This app gives mobile users a fun and easy way to learn more about and support the Society's movement to save lives and create a world with less cancer and more birthdays."

The application is now available for download from the iPhone App Store and a demonstration of the application is available on the American Cancer Society's YouTube channel.

The American Cancer Society invites people to join the movement to create a world with less cancer and more birthdays by visiting [morebirthdays.com](http://morebirthdays.com) where they can join the movement for more birthdays, download a healthy "how to" birthday kit and send e-cards to friends and family. People can also spread the word on Facebook or by visiting [OfficialBirthdayBlog.com](http://OfficialBirthdayBlog.com). –E–

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*President's Message – from page 1*

the opportunity of a large annual summit for the EC community.

We recognize that a board of nine cannot do this alone. We are thankful for our members, for the contributions that come from across the world, and for those who offer their time and support. We need more help to achieve our goals, and I hope that those of you who are willing and able will reach out. With so many projects on the horizon, there will be many roles to fill within the ECAA.

I look forward to updating you on our progress each quarter.

*Note: I want to personally thank our Past President, Lois Dickerman, for all of her hard work over the past 18 months. If not for the dedication that she and her husband, Dick, gave to our organization, we would not be armed to move forward in the way that we are. –E–*

## New Board Members



### **Dana Lilienthal**

My dad, David Davis, was diagnosed with Stage 3 esophageal adenocarcinoma in October 2008 at the age of 64. As is the case with many EC patients, he had no symptoms until he experienced difficulty swallowing. My family and I were completely shocked at his diagnosis and the frightening fact that this cancer had been developing over a number of years with no obvious signs. He underwent an esophagectomy in March 2009 and rebounded wonderfully. Having believed he could now enjoy a new lease on life, we were shocked once again in late July when we learned that the cancer had spread. After a courageous fight, my dad lost his battle with EC in December.

I became involved with ECAA as a way to honor my parents, especially my dad. I believe it is imperative that we create awareness of this often silent, but deadly, disease. I look forward to working with our members to make that happen. –E–



### **Roger Tunsley**

I am an almost four-year survivor of Stage 3 EC. A previous ECAA board member, I have recently taken early retirement from my job as an engineering project manager for a manufacturing company and I'm now working relaxed hours as a freelance writer and business communications software developer.

With more time on my hands, I have rejoined the board. I have a special interest in promoting membership and establishing member groups and activities to help support and inform patients, caregivers, and survivors. –E–

*More Birthdays – from page 2*

## About the American Cancer Society

The American Cancer Society combines an unyielding passion with nearly a century of experience to save lives and end suffering from cancer. As a global grassroots force of more than three million volunteers, we fight for every birthday threatened by every cancer in every community. We save lives by helping people stay well by preventing cancer or detecting it early; helping people get well by being there for them during and after a cancer diagnosis; by finding cures through investment in groundbreaking discovery; and by fighting back by rallying lawmakers to pass laws to defeat cancer and by rallying communities worldwide to join the fight. As the nation's largest non-governmental investor in cancer research, contributing about \$3.4 billion, we turn what we know about cancer into what we do. As a result, more than 11 million people in America who have had cancer and countless more who have avoided it will be celebrating birthdays this year. To learn more about us or to get help, call us anytime, day or night, at 1-800-227-2345 or visit [cancer.org](http://cancer.org). -E-

*Becky Erwin*

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## What Can I Do To Help?

The ECAA is a small organization that depends on membership fees, donations, and merchandise sales for all its income.

We have no paid staff. We are an all-volunteer organization.

So what can you do to help?

- Join us – Life membership is just \$25 for a single member and \$30 for a couple.
- Purchase our merchandise. We have pins, shirts, caps, and wristbands that will help you to raise awareness of this disease in the community.
- Donate in someone's memory or in support of someone in treatment.
- Volunteer your time and energy to help us increase membership, form support groups, pass out information on EC, and reach out to patients and caregivers.

Go to [www.ecaware.org](http://www.ecaware.org)

# Hammers, Needles, and Androgynes

*By Roger Tunsley*

I'm sitting in a seedy waiting room in a seedy office building in a seedy part of Chinatown. A bookcase next to me contains copies of pamphlets in English and Chinese advertising "The Lotus Path to Enlightenment," and small yellow books entitled "Introduction to Acupuncture." There are faded charts on the wall of faceless and sexless human figures, covered in lines and dots like a subway map of some human-shaped city. I'm not sure I want to be here, but she—who-must-be-obeyed has spoken. "Just give it a try," she said. "It can't hurt."

I had been diagnosed with esophageal cancer. There were no particular complications involved. I was, at 58, young enough to undergo a full treatment regime of radiation, chemotherapy, and surgery. The cancer was advanced, but not enough to preclude surgery. All was well in the world of western medicine.

However, along with the diagnosis came a flood of unsolicited well-intentioned advice from friends, many of whom have friends that know someone that was cured of cancer through a macrobiotic diet, meditation, prayer, exercise, and so on. SWMBO wanted me to try anything to get rid of the beast – shark cartilage, essence of bull testicle, powdered snow frog placenta – anything. She became convinced about the curative benefit of acupuncture. A male friend of ours had a very severe case of colon cancer and was undergoing both western medicine and acupuncture. He was in long-term remission, his wife was convinced that the acupuncture had a lot to do with it, and she convinced SWMBO. She described the acupuncturist in breathless excitement. "He's world-famous," she said. "He's just wonderful. He's been featured on TV."

Ever willing to do my bride's bidding, off I went. The acupuncturist – I'll call him Jim – was, like his office, entirely unprepossessing and untidy. Faded polyester shirt with a crumpled collar, trousers worn thin at the knees and hems, scuffed shoes. He could easily have taken the place of one of the down-and-outs on the street outside. I had been expecting a movie star. World famous? Hmm.

Tim greeted me warmly and asked me why I was there. "I've been diagnosed with ca..." Instantly he told me that he could cure me. Not help me, but cure me. "I've cured all kinds of cancer. Lung, liver, bone, brain." He went on to tell me how he could basically cure anything – headache, heartache, and hemorrhoids. But that was not all. If I signed up for one of his seminars, I could learn to do all this myself in ten weeks. OK, I admit, I should have left then and there. But I'm not an absolute skeptic regarding acupuncture; I have read enough articles to be cautiously optimistic that it is at least beneficial in various ways.

So, open minded as I am, off I went into the treatment room. I lay on my stomach; he placed several needles in my legs, back, scalp, and ears, and left me to relax in the dark. There was no pain at all from the needles, and I spent a calm thoughtful interlude. After thirty minutes he came back, gently removed the needles, and proceeded to try to kill me with his bare hands. This was thinly disguised as a massage, but he was actually trying to force his hands into my body. I believe he wanted to reach in and rip the tumor out. I was yelling out in pain, but he just muttered about the good he was doing me. I was just about to grasp him warmly by the tender parts when he stopped. I thanked him for his attention and left. I didn't feel any different. Yes I did, I felt bruised and relieved it was over.

OK, I confess, I'm an idiot. At SWMBO's bidding, I went back for another go a week later. Call me any names you like, I've called myself the same already. I turned up very early for the appointment and so had to wait some time for my punishment. There were a couple of staff members there and two other customers waiting

*Hammers* – from page 5

with me, an older lady and gentleman. We all sat there quietly. After a while, another young western lady came in and sat in a customer chair. She seemed to know the staff members quite well and I assumed she was a long term customer. Out of the blue, the older lady customer asked Jim if he could do anything about her husband's knees, which were very painful and swollen. Without a word, he took a small silver hammer down from a hook, and picked up a small 8-inch model of a naked man covered in the acupuncture subway map.

Jim hands the hammer and the androgyne to the young newcomer without a word. She begins to tap the model with the little hammer. She taps it up and down the spine, then on each knee in turn. I was just dumbfounded. I looked around at everyone else and they were all completely relaxed and chatting away about various things – Jim kept telling us every minute or so that he had a customer with esophageal, lung, liver, and kidney tumors and he had cured him. The tapping continued for 5 minutes before I exploded.

“What are you doing?” I cried. I believe I really did cry out I was so pent up.

Young newcomer looked at me as if I was a child. “I'm helping the man's knees.”

“How?”

“I'm sending him healing energy.”

“How do you know he's getting it? You might miss and the energy gets me instead or goes whizzing out of the window and heals the knees of some poor unsuspecting passer-by.”

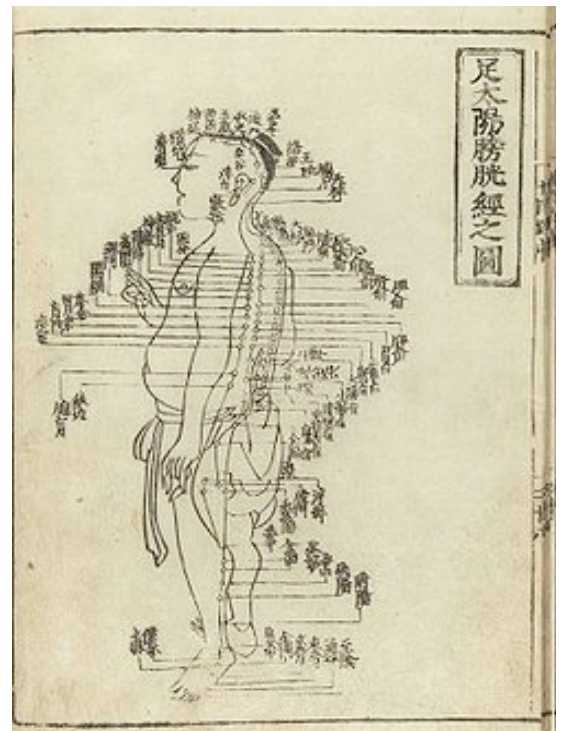
“Because I'm thinking about him”.

She then asked the guy how his knees felt. “They feel funny,” he said, “all tingly.” Hmm.

At this point, I was led into the treatment room. Once more with the “I can cure anything” stories while the needles are inserted. This time, as he was unable to penetrate my skin during the first session, he sent an evil henchman to do the massage. An Egyptian guy called Igor (probably) with no neck and huge hairy hands who had obviously done the ten week

seminar and was now a world famous acupuncturist, able to cure all ills. He was twice as strong and twice as determined to inflict pain. When he squeezed my neck, I felt he was actually trying to pop my head off my shoulders.

I've had enough. I'm not going back. However, I've been to another acupuncturist since. She's charming, she's calming, she makes no claims apart from being able to help the body's healing processes, and she's incredibly attractive. Now we're talking. This is the acupuncture for me. I'm not sure SWMBO's so happy with this new turn of events though. –E–



# Volunteering Your Time

*By Roger Tunsley*

Do you remember your reaction when you were first diagnosed with cancer? I do to this day. I felt emotionally alone and physically scared. I had never heard of esophageal cancer. I started to investigate it on the Internet and the lonely and scared feelings increased in intensity as I absorbed the statistics.

The start of treatment is a strange time. You don't know what to expect, your life becomes a string of new experiences. I soon found myself standing at the entrance to the chemotherapy ward with my wife by my side. I looked at the rows of blue plastic recliner chairs, most of them occupied. Fluid bags on metal poles, tubes and needles in arms and chests, televisions playing to themselves while the occupants slept or chatted to their family members. There was a gentle murmur of voices and the odd laugh. I think I expected despair but this was not a sad place.

My nurse, expecting me, came over with a broad smile and took over my life. She led me to a chair and settled me in, and explained carefully what she was about to do and made small talk in the intervals between information. I took in hardly any of it. I was in new experience overload. Once I was plugged in and as settled as I could be, she left us alone while she dealt with another patient.

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*“Hello, I haven't seen you before. Is this your first time?”*

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My wife and I made small talk as well but we had little to say as we both took in the sights and sounds of the ward. Suddenly, a voice.

“Hello, I haven't seen you before. Is this your first time?”

I looked up to see a gray haired gentleman with

a rumpled shirt and a big smile pushing a small cart filled with fruit, snacks, and sodas.

“My name's George” he said, walking in and holding out his hand. “Can I get you anything? A snack or a drink?”

“No thanks. Are you on the staff?” I said, a little puzzled by his age and his appearance.

“Well, sort of. I'm a volunteer.”

We chatted together for a few minutes, and then he continued his round with the trolley. Ten minutes later he turned up again with two ladies, also volunteers, to introduce me as the new guy.

“We're all survivors,” said George with a wide grin. “I'm a colon, Beth's a breast, and Debby's a kidney. Between us and the other volunteers, we're trying to make a body.”

George, Beth, Debby, and many others that I met while moving through treatments helped to make the whole process less scary and more human. They were all survivors of chemotherapy and other treatments at the hospital, and had decided to give back some of their extended life by helping to care for others. They served lunches, snacks, drinks, coffee, but most importantly they were there to talk to. They had time. They had been there, seen it, and done that. Never inquisitive about your own issues, but ready to share their experiences, offer non-medical advice, and, above all, always ready to listen.

I'm now an almost four-year survivor. Every week I travel to the hospital, put on my ID card with its yellow “Volunteer” lanyard, and push the cart. I hand out lunches, snacks, drinks, and I'm ready to listen. I've met several EC patients who were scared and really happy to have me share my story. I know

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*Volunteering – from page 7*

the value that can bring.

Beth Israel Deaconess Medical Center in Boston has an exceptionally strong volunteer program. The program on the chemo ward, called the “patient to patient” program, is just one of a wide range of opportunities to help patients and their families to move into and through the medical processes. There are many other programs as well; emergency room and intensive care liaison volunteers help and support family members when someone is admitted to the ER or into ICU, volunteers help with patient rehabilitation support, and so on.

Your local hospital may well have a volunteer program that you can join. If they don’t, ask if you can help anyway.

Give something back; it makes you feel good. –E–

## Prescription Costs Can Make You Sick!

*By Bob Ginsberg*

John was tired and dismayed. He was undergoing chemotherapy for esophageal cancer and he wasn’t sleeping well due to the drugs he was taking. John’s doctor had written him a prescription for a sleeping aid, but when John dropped the prescription off at his local drug store he found out that they would cost far more than he could afford. So now he was likely to lie awake worrying about the costs.

His wife Emily, never one to take “No” for an answer, went on the Internet to explore options. She found that there were several drug discount cards available that would give John a significant discount on his purchase. Emily also contacted the manufacturer of the drug. She was surprised to discover that the company had a special needs program for people like John and could provide the medication at a reduced price.

Are you having trouble paying your drug bills? Are you losing insurance? Are you in the “donut hole”? Here are some tips from my personal experience.

- Perform an Internet search for “discount drug cards” with your zip code. You should see a large listing of cards. Some can be printed out immediately, while others will be mailed. Even if you have insurance, you should still compare prices with the drug cards. They may be less expensive.
- Find out who makes the drugs that you are taking. Contact the company and ask about any drug assistance programs that may be available.
- Ask your physician if there are alternate medications or a generic form of your current medication that can be prescribed.
- Call around the various pharmacies. Prices can vary widely between different pharmacies for the same medication.

## EC Chat

*By Mickey Love*

You may be interested to know that there is an online chat group for EC patients, caregivers, and survivors. It is not affiliated with the EC-Group or the ECAA, though most of our attendees do come from the EC-Group. Some of us are long-term survivors and, by sharing our experiences, we try to make life a little easier for people new to the EC struggle.

We have never restricted what anyone shares. So many different topics are discussed and all are so willing to share – the good and 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, then that becomes paramount.

**The group meets on-line on Sundays and Wednesdays at 8:00 PM ET** and everyone is more than welcome to attend. You can access the group through <http://ngc1514.com/chat>. You just type a username that others will see, and then click the Connect button.

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](mailto:mlove33567@aol.com) or Eric Greene, at [eric@ngc1514.com](mailto:eric@ngc1514.com) if you have any questions. –E–

## The NCI Clinical Trial Search Tool

*By Roger Tunsley*

Many hospitals and research institutes run clinical trials of drugs, drug protocols, surgical techniques, medical devices, and so on. More than 8000 clinical trials are currently listed in the National Cancer Institute's database as accepting participants. If you are interested in looking into whether there are any trials in which you could participate, the NCI has a database search tool that can help you to investigate.

To access the search tool, go to <http://www.cancer.gov/search/SearchClinicalTrials.aspx>. The page that displays, headed "Search for Clinical Trials", is divided into various sections that will help you to focus your search.

Here are some tips to help you get the best results from your search.

- The more choices you make using this tool, the fewer trials will be displayed in the search results. For example, if you search for phase 2 trials related to stage 3 esophageal cancer, within 50 miles of your home, related to a specific chemotherapy drug, you are likely to receive few, if any results. Conversely, if your search focus is more general, and you select only esophageal cancer to search, then you will receive many results of trials all over the world, for all stages of EC, related to all types of clinical trial, and so on. Try to focus on trials with conditions that are valid to you.

*Prescriptions – from page 8*

- Warehouse clubs, such as Costco or Sam's club, often offer some of the best prices. You don't need to be a member to use the pharmacy. Just tell the greeter you are there to get a prescription. They are obligated to fill your prescription at the same price that they charge their members.
- Contact the American Cancer Society and see if they can assist in finding out more about these programs.

John is now sleeping well and experiencing significant savings on all of his medicines. –E–

## Help Us to Raise the Awareness of EC

The ECAA is a small non-profit organization dedicated to providing outreach for esophageal cancer patients, caregivers, and survivors. We strive to increase public awareness of this disease and to provide education and information in a supportive environment. If you would like to help us in that effort, please consider becoming a member of the organization. Anyone with an interest is welcome to join. Lifetime membership is just \$25 for an individual and \$30 for a couple. The ECAA is a 501C3 organization.

Contact Roger Tunsley at [rtunsley@ecaware.org](mailto:rtunsley@ecaware.org) or 1-800-601-1063.

### 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



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. Wristbands 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](http://www.ecaware.org), or contact Dana Lilienthal at [dlilienthal@ecaware.org](mailto:dlilienthal@ecaware.org) or 1-800-601-0163.

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.

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*Trials – from page 9*

- The drop-down list of diseases that you can pick from is long. To quickly find esophageal cancer in the list, type “es” and the list will automatically highlight esophageal cancer. Press the **Enter** or **Return** key to select it.
- Take care when specifying the stage of your cancer if it has not yet been fully confirmed by your physician.
- You do not have to enter information in every section of the tool. For example, if you don’t select any options in the **Trial/Treatment Type** section, then you will get results for all trial and treatment types.
- If you need an explanation of the purpose or use of any of the sections, click the little question mark button at the right of the section. A screen will open to explain more about the use of that section.
- There are also help links on the left side of the search screen that offer excellent advice and reference information about clinical trials.
- When looking at the results of your search, it is easy to be overwhelmed by the details and the language that you see. You can choose to display the results in “patient-friendly” language. If you look at the top of the results page, you will see a box headed **View Content for:** If you click the button marked **Patients**, the results display in more friendly language.
- If you have either too many or too few results you can either refine your current search or start over completely, using the buttons marked **REFINE SEARCH** or **START OVER** on the Results screen.
- Make sure to discuss clinical trials fully with your physicians. Don’t forget that these are trials of new drugs or new protocols or new devices. This means that the trial participants are being used as experimental subjects.
- Finally, be aware many clinical trials in the USA have critics. Because pharmaceutical companies sponsor many trials, there are often allegations of bias in reporting the results of trials. Marcia Angell, a previous editor of the *New England Journal of Medicine*, is a particular critic of these sponsored trials.

Many patients and caregivers are interested in how clinical trials may be able to help them. Make sure that you become an educated consumer in this area. Learn about clinical trials and their stages, and discuss any finding with your physician.

Better yet, if your physician considers that clinical trials may be helpful to you, then ask for help with your search. –E–



# Membership Application

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:

Esophageal Cancer Awareness Association, P.O. Box 55071 #15530, Boston MA 02205-5071

## Personal Details

Name (Last, First): \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

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) \_\_\_\_\_

## Interested in Volunteering?

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