



# Choices & Hope

## *The Shoes that Saved My Life*

Fall/Winter 2010

*Hildy Grossman*



In the Fall of 2006, I bought a pair of green sandals with a cute kitten heel. I enjoyed the color and style and made sure they were comfortable, but it never occurred to me to examine the sole. Several days later I put them on and headed down my basement stairs. One step onto the threshold and out went my feet as though I'd stepped onto ice—one foot went back

and the other scraped the wall in front of me. Fortunately, the basement stairs are very narrow, and I was able to catch myself by grabbing both walls of the passageway.

Thus began an astonishing journey.

After my narrow escape, I felt fine, except for some discomfort in my left wrist, elbow and right ankle. I figured I should check myself out, primarily for the twinge in my left forearm. So, I began with a referral to see a hand surgeon who wanted to give me cortisone injections, but she wasn't sure what site to use. Next, another hand specialist who wasn't sure the problem had to do with my hand-- maybe it was tennis elbow? My referral was to a neurologist to confirm a diagnosis, but he only tested for my wrist and not my elbow. He concluded there was no nerve damage in my wrist and ordered an MRI to see if I had a pinched nerve in my back. The MRI came back. It showed no pinched nerve-- but it picked up two tiny spots in my right lung. My internist sent me for further tests and an eventual biopsy. The diagnosis: lung cancer!

Fortunately, my Internist sent me to a top-notch surgeon at Massachusetts General Hospital who scheduled my surgery for three weeks later. Because of my early diagnosis, he was able to remove just the two small tumors in two lobes and a small section of tissue around the sites. They were small, early stage, and contained—they hadn't spread. My oncologist felt I didn't need any further treatment as did her colleague. My internist reflected on all the events that led to this fortunate outcome and said to me, "Somebody up there really likes you!"

I went home from the hospital to recuperate.

Most people would say there's nothing fortunate about getting lung cancer. In fact, it was horrifying, shocking and upsetting to wrestle with the diagnosis and try to figure out

## November is Lung Cancer Awareness Month!

what it meant for my life and life expectancy. As I came to terms with it, I also found that the experience gave me a different level of awareness of how lucky I have been. My husband, Richard and daughter, Micaela went to all of my doctor's visits with me. My son, David and his wife, Amy arranged for food to be delivered. My daughters Claire and Robin came from San Jose and Chicago to nurse me in the hospital and when I came home. My dearest friends rallied to help me in every way possible, from researching the latest treatments and outcomes of lung cancer to bringing me dinner and keeping me company. Their extreme kindness made me vow to be a better friend to someone in need. So many people expressed concern, good wishes and a desire to be involved and updated about my recovery. I was so moved by how connected all of our lives are, even extending to good people we've never met.

All of us know someone who has had lung cancer. Most of us have stereotyped lung cancer: I know I have. It seemed like a disease reserved for elderly men who smoked for a lifetime. This isn't true. It can happen to any one of us. This disease touches all of our lives. It might be a member of your family, a friend or a neighbor. Perhaps you are a survivor. Or, perhaps it's someone you feel you know. Did you experience the same shock and unfairness I did when learning that Dana Reeves, a young non-smoker, died after years of heroically caring for her husband Christopher Reeves following his riding accident? Perhaps after inviting Peter Jennings into your home every evening to bring you the news, you too were surprised by his illness and death. Remember how charming and funny Suzanne Pleshette was on *The Bob Newhart Show*? For me, no one had a voice like Beverly Sills. All of these well-known celebrities suffered and died from lung cancer. That's why early detection is so important.

In the days after I came home from the hospital, I worked to get my strength back. I did laps around my bedroom for exercise. I used my recovery time to reflect on my life, on what was important and how to spend my time. I found inspiration through a book recommended to me by a tour guide, Tolga, whom I'd met while on vacation in Turkey. I emailed him

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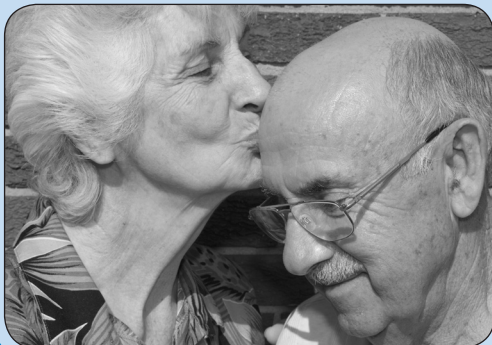
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**Mission:** The Caring Ambassadors Program mission is to help improve the lives of those affected by lung cancer through advocacy, information, and support.



# From the Program Director

*Dear All,*

The Caring Ambassadors Lung Cancer Program has been serving people living with lung cancer and their families since 1997. We continue to be dedicated to helping improve the lives of all those affected by the disease.

It is with great pleasure that CAP welcomes new board members Suzanne Hawkins and Mary Ellen Tong, we look forward to working together in furthering the mission of CAP.

This year we are hosting our 2nd Annual CAP Lung Cancer Benefit Bowl-A-Thon during November, Lung Cancer Awareness Month. The event last year greatly increased lung cancer awareness in our region. Help CAP raise funds to support our programs and services by visiting [www.firstgiving.com/caringambassadors](http://www.firstgiving.com/caringambassadors) and making a donation. If you live in the Vancouver, WA/Portland, OR set-up a team and join us for this fun evening at Big Al's. The Silent Auction includes the use of a vacation home in Vail, CO, jewelry, artwork, gift baskets, golf packages, sports memorabilia, and much more to bid on (don't forget to bring your checkbooks).

In June, I attended the American Society of Clinical Oncology (ASCO) meeting in Chicago. During the meeting I had the opportunity to attend lung cancer sessions (see article about the MAGRIT trial in this issue) and network with other lung cancer advocates and discuss ways we can all work together to change the course of this disease.

CAP Board Member, Roberta "Birdie" Urban was featured in an article, "One fight, many battles" by Erin Middlewood in the Columbian, Vancouver, WA. Birdie is a seven year lung cancer survivor and works tirelessly to raise awareness about lung cancer. Dr. Christopher Jackson, Birdie's surgeon, Dr. Charles Thomas and Dr. Alan Sandler of Oregon Health Sciences University (OHSU) were also featured. Both Dr. Thomas and Dr. Sandler are nationally recognized for their work in lung cancer. If you would like to read the article, visit <http://www.columbian.com/news/2010/jul/11/one-fight-many-battles-in-the-war-against-lung-can/>

Thank you to our contributors this month, Hildy Grossman, Brenda Wilcox, RN, and Mathew Ninan, MD, – together we are making a difference in the lives of all those affected by lung cancer.

Progress is happening in the lung cancer field and there is HOPE for those living with the disease.

With Best Wishes for Your Health,

*Cindy Langhorne*

Cindy Langhorne  
Program Director

**LungCancerCAP.org**

# Within CAP Lung Cancer

## Ways to Give!

NOVEMBER IS LUNG CANCER AWARENESS MONTH

More than 222,500 American men and women will be newly diagnosed with lung cancer this year and tragically, approximately 157,000 will die of the disease. November is Lung Cancer Awareness Month and we encourage you to join with us in our efforts to raise lung cancer awareness, compassion, and help reduce the stigma associated with the disease.

CAP Lung Cancer is honored to be serving the lung cancer community through advocacy, information and support. Each and every contribution is important to the organization – please make your donation today! We are genuinely grateful for your support.

Helping the Caring Ambassadors Lung Cancer Program is easier than ever. The CAP Lung Cancer Program has developed a special donation opportunity for you!

A CAP Celebration Gift celebrates milestones in a loved one's life — a birthday, anniversary, graduation, wedding, or another cause for celebration. A CAP Celebration Gift is also a meaningful way to pay tribute to those living with lung cancer as they mark personal milestones on their journey.

When you request a CAP Celebration Gift or CAP Gift in Memory online, we will send a personalized card to the person or family you are honoring to let them know of your gift. Your secure online donation will help the Caring Ambassadors Program continue our efforts to improve the lives of people affected by lung cancer.

*Make someone's day by sending them a  
Caring Ambassadors Card today!*

[LungCancerCAP.org](http://LungCancerCAP.org)

*Please help the Caring Ambassadors Lung Cancer Program continue serving the lung cancer community. As a public charity, we rely on your help and support to continue providing services to people living with lung cancer and their loved ones.*

### Caring Ambassadors Program Online

- *State of the art information about lung cancer diagnosis, treatment and supportive care*
  - *Choices & Hope newsletter*
  - *Weekly E-News*
- *Lung Cancer Medical Writers' Circle*
- *Monthly lung cancer literature review*
- *Pharmaceutical patient assistance programs*
  - *Lung cancer awareness activities*
  - *Community outreach and support*

Sign-Up at [LungCancerCAP.org](http://LungCancerCAP.org)



**Would you like to contribute to  
the Writers' Circle?**

**Email [Info@LungCancerCAP.org](mailto:Info@LungCancerCAP.org)**

*Together we are making a difference in the lives  
of people affected by lung cancer.*

# Caring Connections

## *Light in the Darkness: The Role of the Patient Navigator*

Brenda Wilcox, RN, BSN, OCN

With a word, "business as usual", is turned upside down and inside out. A cancer diagnosis can stop us in our tracks and life as we know it is suddenly altered, looking strange and uncertain. It is at this difficult time of crisis that the role of the patient navigator becomes a beacon of light to offer guidance on a path that is not always clear.

A patient navigator is typically a licensed trained medical professional, such as an oncology nurse or social worker, who possesses a thorough, in-depth understanding of the oncology health care system. The purpose of patient navigation is meant to optimize and streamline survivor care by coordinating therapies, helping individuals and families to understand the information they are given, as well as helping those they serve make sense of a complex medical system that often involves multiple disciplines. (Wilcox, B. 2009. "What Can A Patient Navigator Do For You?" *Coping Magazine*, September 2009.) Navigators provide information and education not only to those with a cancer diagnosis, but also to families and caregivers in order to assist them in understanding how best to offer support to their loved one. Navigators take whatever time is needed to spend with individuals who have received a cancer diagnosis, ensuring that their questions are answered and concerns addressed. With such a fast flood of information, processing and digestion can become extremely difficult, especially in time of crisis. Patients can experience a "virtual deafness" that couples with an inability to cope. The navigator is there to help tease through the information given to patients by their physicians and other members of the health care team. Navigators are never meant to intrude, but only to augment and reinforce the physician-driven plan of care that can become blurred to patients as they travel the road of survivorship. Empowering those diagnosed with knowledge and understanding helps to reduce anxiety as well as assists in maintaining control in a seemingly out of control situation. Serving as liaison and advocate, navigators enhance communication between members of the patient's health care team, (such as nurses, physicians, social workers, spiritual counselors, dieticians); in order to better provide optimal continuity of care. With just a phone call, the navigator is available to come along side those in need to offer support, guidance, and a listening ear throughout the entire cancer journey.

Once a cancer diagnosis has been made, the diagnosing physician contacts the patient navigator with the referral. The navigator then contacts the patient within twenty four hours and explains that she will be available to act as a "go to" resource for any and all questions and concerns that they may have

throughout the course of treatment. She then goes on to say that she will coordinate the planned oncology appointments and will meet them each time they come to the clinic. Navigator contact information is given, as well as a soft word of encouragement along with a pledge of the navigator's availability and support. Thus begins the timely relationship of navigator and survivor.

The following scenario illustrates utilization of the patient navigator. Ms. Smith has just been diagnosed with a small cell lung cancer by her pulmonologist. The physician explains to Ms. Smith that the next best step in caring for her is to see a medical oncologist, and also explains that she will receive a call from a patient navigator who will coordinate her cancer care and make her necessary appointments. The physician contacts the navigator, who in turn, phones Ms. Smith to coordinate and offer support. As the patient's records are obtained, the navigator checks to be sure that all needed diagnostic studies have been done prior to Mrs. Smith's first visit. Upon review, all studies have been done except for a brain scan which the navigator knows is necessary for Ms. Smith to have in order to rule out any evidence that the cancer from her lung has spread to her brain, as can be characteristic of the disease. After the medical oncologist's review of Ms. Smith's records, he orders a brain scan prior to her first visit. The navigator then phones Ms. Smith to explain the reason for the needed scan, reassuring her that although her physician does not suspect that the cancer has traveled to the brain, it is important to be sure, as the findings help drive the plan of care that her oncologist would recommend. She then coordinates the scan appointment with Ms. Smith's permission, and explains that the scan lasts about an hour, is quite noisy, (ear phones and music are used to help offset the noise), and that the area over the head is somewhat enclosed. The navigator also reassures her that if she is claustrophobic, sedation can be offered to help.

Upon Ms. Smith's first visit to the cancer center, she and her family are greeted by the navigator who gives them her contact information as well as a navigator brochure, and encourages the patient and her family to phone with any questions they might have after the visit. The navigator then speaks with the medical oncologist after his consultation with Ms. Smith to become aware of the proposed plan of care, and finds that the plan includes the initiation of chemotherapy. In caring for Ms. Smith, the navigator begins to prepare her for treatment by initiating chemotherapy education which includes the process of what to expect on the first day, expected side effects and how to manage them, as well

**No One Deserves Lung Cancer!**

## *Light in the Darkness (continued)*

as making sure that all of her questions are answered; all the while being sensitive to Ms. Smith’s needs and concerns. She also makes Ms. Smith aware that the likelihood of hair loss is great, and supplies her with wig shop information as well as making her aware of the “Look Good, Feel Better” program offered by the American Cancer Society at the cancer center free of charge. As treatment begins, the navigator continues to assess the ongoing needs of Ms. Smith and offers the services of the social worker, financial counselor, dietician, chaplain, psychological counselor, and support groups as deemed necessary. She also continues to relay pertinent information to Ms. Smith’s health care team on her behalf. With Ms. Smith’s permission, her family is encouraged to contact the navigator for information on how best to support her during her cancer journey. Throughout the course of Ms. Smith’s care, the navigator continues to meet with her during her clinic visits, offering words of reassurance and encouragement to call at any time, for any reason, and with any questions or concerns she might have.

Patient navigation, although defined specifically to meet the needs of the institution that it represents, is truly a role meant to optimize and streamline patient care across the cancer care continuum. Navigators seek to empower those they serve by offering education, resources, and an open line of continuous support; a light to offer calm guidance in the midst of the storm.



***Brenda Wilcox, RN, BSN, OCN** - Brenda is employed as an oncology nurse navigator at Duke Raleigh Cancer Center, an out-patient comprehensive cancer care facility on the campus of Duke Raleigh Hospital in Raleigh, NC, for the past five years.*

*With over 20 years of oncology nursing experience, she is a dedicated “voice” in the promotion of patient navigation as well as the patients and families that she serves.*

## *The Shoes that Saved My Life (Continued from page 1)*

about my lung cancer. He wrote back, quite unsentimentally, and said to read *The Alchemist*, a fable by Brazilian author Paulo Coelho. It’s a book about learning to read the omens strewn along life’s path, and, above all, following our dreams.

This wise guide said it was for me to make something of my experience. After I finished reading the book, I realized that the key point was about transforming commonplace events into something of value, making something of each and every experience. This message spurred me to think about how I could find a way to make something worthwhile and life affirming out of having had lung cancer, an experience that on the surface was of no value whatsoever.

The answer was Upstage Lung Cancer. We have now created a non-profit 501(c)3 organization whose mission is to raise awareness of the seriousness of lung cancer, the lack of public and private funding and the need for research, while raising funds for research into early detection and novel treatments.

We are using music and musical theater to accomplish this goal. I love the idea of using music because for me, a singer, it is all about breath, life and transcending time and place. To date we have had two house cabaret concerts in the Boston area. We are excited about this wonderful event that will have a short talk about this charming house, a brief talk by a Thoracic radiologist from the Brigham and Women’s Hospital and Dana Farber Cancer Institute, and a concert by The Follen Angels, cabaret/jazz group (that’s my group!). Last November we had our first annual major event at a Boston Theater called, “Life is a Cabaret”. We had four nationally known solo artists with a fabulous music director. We also had a Boston celebrity Arts and Entertainment journalist/TV personality, Joyce Kulhawik and we honored Jerry Remy, the Red Sox announcer who came forward to tell about his lung cancer. It was a magnificent evening, up spirited, received lots of press and TV coverage and was enjoyable to all. We are planning our second annual “Life is a Cabaret” this November. We’d love to hear from interested people.

## From the Experts

### The MAGRIT - (MAGE-A3 as Adjuvant Non-Small Cell Lung Cancer Immunotherapy) Lung Cancer Vaccine Trial

Mathew Ninan, MD, FACS, FRCS(C/Th), FETCS, MSCI  
Midsouth Regional Thoracic Center  
Memphis, Tennessee

After years of modest results, the use of vaccines (immunotherapy) to prevent the recurrence of lung cancer is making a comeback. We examine the role of a major clinical trial that is ongoing to prevent recurrence after surgery for lung cancer.

Surgery, especially minimally invasive ('key-hole') surgery, is an effective and safe treatment for patients with early stage lung cancer. However, between 20 to 30 percent of patients relapse in the first five years following surgical treatment alone in Stage 1 non-small cell lung cancer. In Stage 2, this percentage rises 40 to 50%. There have been many recent attempts to decrease this rate of relapse. Chemotherapy after surgery has been investigated thoroughly. Latest pooled data from the best studies have shown that chemotherapy after surgery improves survival approximately 4% more than surgery alone at five years. Because of these modest results, there has been at least one major study looking at targeted therapy using the drug erlotinib after surgery. Results of this trial are awaited. One other strategy would be to use vaccines (immunotherapy) against lung cancer.

Using the body's own immune system to fight cancer has long been considered a possible anti-cancer strategy. However vaccine therapy for cancer suffers from potential difficulties. One difficulty was that the vaccine should be targeted against the tumor alone, and not normal tissue. In other words, the genetic makeup of the tumor should contain specific targets that the vaccine would act against, leaving normal tissues unaffected.

In the early 1990s, researchers began to look more closely at the genetic makeup of cancers. It was noticed that many cancers contained a specific family of genes, named the 'cancer-testis antigens'. These genes were most pronounced in non-small cell lung cancer. One class of these genes was called the Melanoma Associated Antigen (MAGE). In the following years many teams investigated the details of the MAGE family. Amongst the many MAGE antigens found in lung cancer, the MAGE 3 antigen was considered a good target for development of a vaccine against the lung cancer that contained this particular antigen. However, only 30% of non-small cell lung cancers contained ('expressed', in medical parlance) the MAGE 3 antigen.

Scientists at GlaxoSmithKline, the pharmaceutical company, are developing a specific vaccine against the MAGE 3 expressing non-small cell lung cancer. The vaccine may induce specific white blood cells to attack the tumor. In addition, the vaccine contains a non-specific immune boosting mechanism that may enhance the effect of these specific white blood cells. Early studies of this vaccine in patients with non-small cell lung cancer were conducted which led to the establishment of a large clinical trial testing this vaccine (called the Phase III MAGRIT trial). Many centers around the world are participating in this trial. There are also smaller trials of various immunotherapy approaches going on at specific institutions in the U.S, however the MAGRIT Trial



**MATHEW NINAN, M.D., FACS., FRCS(C/Th)., FETCS., MSCI** - General Thoracic Surgeon, Midsouth Regional Thoracic Center, Memphis, TN; Clinical Associate Professor of Surgery, University Of Tennessee, Memphis, TN; Fellow, American College of Surgeons; Fellow, Royal College of Surgeons in Cardiothoracic Surgery; Fellow, European College of Thoracic and Cardiovascular Surgery - Dr. Ninan has 10 years of thoracic surgical practice in both academic and semi-academic settings in Tennessee. Dr. Ninan is a local P.I. for three international trials in thoracic oncology and is a consultant for improved accrual and surgical participation in clinical trials nationally. Dr. Ninan's clinical focus is on the use of robotic technology in thoracic surgery.

is the only vaccine trial for post-surgical patients being conducted worldwide at this time.

Patients are consented to participate in the trial following surgery. As a first step, the patient consents for the tumor that was removed at surgery to be tested for the MAGE 3 antigen. If their tumor contains the antigen it means two things – one, that the patients who are MAGE 3 positive do somewhat worse (in the long term) than people who are MAGE 3 negative and two, they are eligible for the trial. MAGE 3 positive patients are then randomized to receive the vaccine over a period of the next two years in 13 injections. The injection is given into the arm or thigh muscle, similar to a flu shot. The patients are randomized on a 2:1 ratio, meaning every 3rd patient receives a placebo and the other two patients receive the vaccine. This is done in a blinded fashion, meaning neither the research staff or the patient knows who is receiving the vaccine versus the placebo. I would encourage all patients who have surgery for lung cancer to discuss with their surgeon or oncologist for possible enrollment in the MAGRIT Trial.

CAP Lung Cancer has partnered with EmergingMed in the Lung Cancer Call to Action Campaign. To find out more about the MAGRIT trial call 1-800-698-0931.

Each time a person with lung cancer faces a treatment decision, it is important to explore all options, including clinical trials. Your participation is critical because advances in research, leading to cures, cannot happen without you.

Register with our service now to learn what clinical trials may be an option for your particular situation now and throughout your cancer journey. Call for a confidential conversation with one of our clinical trial specialists.





## Thank You to Our Sponsors



### Radiation Medicine at Knight Cancer Institute

Help CAP raise funds to support our programs and services by donating today. If you cannot attend the event you can participate as a "Phantom Bowler" and raise funds for the program by setting up your fundraising page at [www.firstgiving.com/caringambassadors.com](http://www.firstgiving.com/caringambassadors.com).

Together we are making a difference!



P.O. Box 1748  
Oregon City, OR 97045

*The goals of the CAP Lung Cancer Program are to:*

**Improve** the quality of life of people living with lung cancer and their families through information and support

**Provide** state-of-the-art information about lung cancer treatment options to patients and their families

**Increase** lung cancer awareness and advocate for increased prominence of lung cancer on local, state and national public health agendas

**Motivate** people and groups concerned about lung cancer to work together for the good of all persons affected by the disease

*Choices & Hope*

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PO Box 1748

Oregon City, OR 97045

Phone: 503-632-9032

Fax: 503-632-9038

[info@LungCancerCAP.org](mailto:info@LungCancerCAP.org)

[LungCancerCAP.org](http://LungCancerCAP.org)

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