Lung Cancer Alliance Times

Winter 2008

UP TO DATE INFORMATION ON LUNG CANCER

# Profile of Board Chairman Rear Admiral Phil Coady, USN (Ret.)

Rear Admiral Phil Coady has served as the Chairman of LCA's Board of Directors for the past year. Phil is a native Bostonian and a graduate from Tufts University where he studied economics. A career Navy man, Phil spent much of his life at sea where he commanded a destroyer, a cruiser, the Missouri Battleship Battle Group and the KITTY HAWK Carrier Battle Group. Phil has no medical background and no family tie to lung cancer. An avid hiker and rower, and life long non-smoker, he never imagined himself as someone at risk for this disease.

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Upon retiring from the Navy in 1995, Phil took over the Navy Mutual Aid Association, a non-profit veterans benefit association and mutual life insurance entity. Phil noted that a seemingly large number of Navy veterans had lung cancer listed as the cause of death. Shipboard service in the Navy, especially during the years that Phil served, routinely involved exposure to asbestos, second hand smoke and other service related sources of possible carcinogenic exposure. Additionally, many veterans, like Phil, were exposed to Agent Orange during their service in Vietnam.

**An avid hiker and rower, and life long non-smoker, he never imagined himself as someone at risk for this disease.**

In 2005, during a routine CT scan, doctors detected a 5 cm lump in Phil's left lung. When a biopsy proved positive for non small cell lung cancer, he immediately underwent surgery to remove the affected lobe and commenced adjuvant chemotherapy to reduce the likelihood of recurrence. Despite these precautions, the cancer recurred in late 2005 with metastases to his bones. Fortunately, doctors have been able to prescribe chemotherapy that has been largely successful in slowing the advance of the disease for the past two years.

Rear Admiral Phil Coady, USN (Ret.)

The rude shock of this unexpected diagnosis spurred Phil to investigate the disease, its treatment and the status of efforts to find a cure. He was stunned to learn that the disease received only a tiny fraction of the research funding that less lethal cancers received. He

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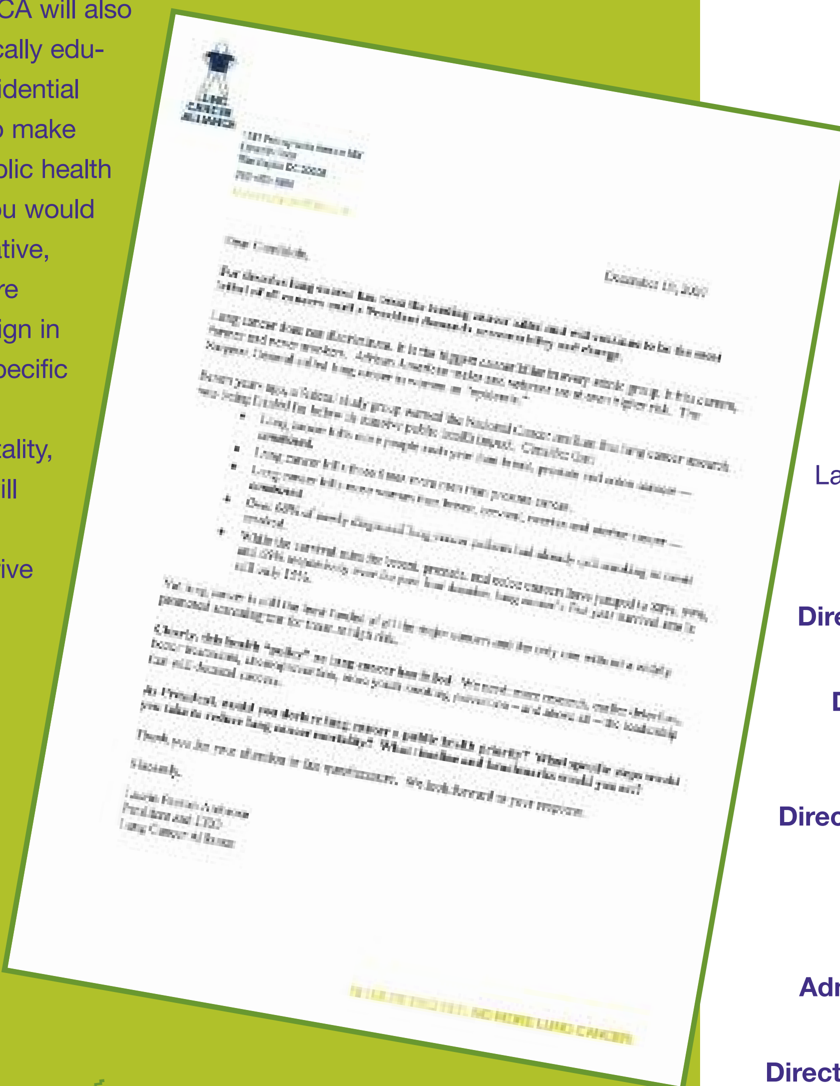
## Attention All NSCLC Surgical Patients

(See article on page 8)

**Dear Friends,**

Happy New Year! It is hard to imagine that LCA is beginning its fourth year. Looking back it is amazing to see how much we have achieved in such a short period of time. Why? Because of all of you! Your passion, courage, dedication, and commitment to challenging the status quo and demanding that lung cancer no longer be stigmatized and neglected is making a difference. We will build on this strong foundation moving forward in 2008. I am proud to say that our movement is here to stay.

No doubt 2008 will be even more exciting and purposeful. Why? The presidential campaign. Just as we have done on the federal and state levels, LCA will also consider ways to strategically educate our prospective Presidential candidates on the need to make lung cancer a national public health priority. Thus, I thought you would like to see LCA's first initiative, a Presidential questionnaire submitted to each campaign in December, asking what specific steps each would take to reduce lung cancer's mortality, if elected President. We will post these responses on our website when they arrive and continue to keep you apprised of additional developments on this and many other fronts as we fight to achieve greater compassion and research support for the lung cancer community. Again, let's make 2008 count even more! Thank you for all you do.



Sincerely,

Laurie Fenton Ambrose

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# Lung Cancer: How We Got Here and Where We Are Going

by guest columnist Fred Grannis, M.D.

It is an honor to have been asked to write this inaugural "Report from the Front" for the LCA Times. I would love to be able to present you with an upbeat, optimistic report, but to do so would be a disservice to the truth and to lung cancer patients. The stark reality is that, in the 36 years since I began to learn how to treat lung cancer as a junior surgical resident at the Mayo Clinic, the same time when President Richard Nixon declared "War on Cancer" in 1971, we have made very little progress in reducing lung cancer deaths. I have spent these intervening decades as a foot-soldier in that war, and have been privileged to take part in or observe many major victories against cancers of the breast, colon, cervix and prostate. But sadly, during that same period of time, 5-year survival in lung cancer patients has risen only from 12 to 15 percent. It is my carefully measured opinion that this can only be characterized as a shameful and disastrous failure on the part of our social, political and medical institutions.

If we are ever to make progress in the treatment of lung cancer, we must be brutally honest and forthright in examining the reasons for this dismal failure.

## Why have we failed?

First and foremost, the overwhelming share of the blame for 160,000 lung cancer deaths each year must be attributed to the high-level executives of the tobacco industry and the lawyers, lobbyists and scientists who serve them. These amoral individuals have clearly understood for more than five decades that their products kill. Regardless, they have made every effort to lie to the public and to subvert legal and political processes so that they could continue to profit from the sale of their lethal products.

Elected officials could act forcefully and effectively to prevent future lung cancers in a single legislative session, but for fifty years, with few exceptions, they have abjectly failed to make any meaningful effort to control the behavior of the tobacco industry and the sale of their products. Votes against tobacco control policies are directly related to tobacco industry campaign contributions. Meanwhile money from Big Tobacco continues to pour into campaign coffers and the influence of this largesse reaches to the highest levels of government.

**But there is new hope. Recent findings in the field of lung cancer screening signal a long-awaited breakthrough in the war against lung cancer.**

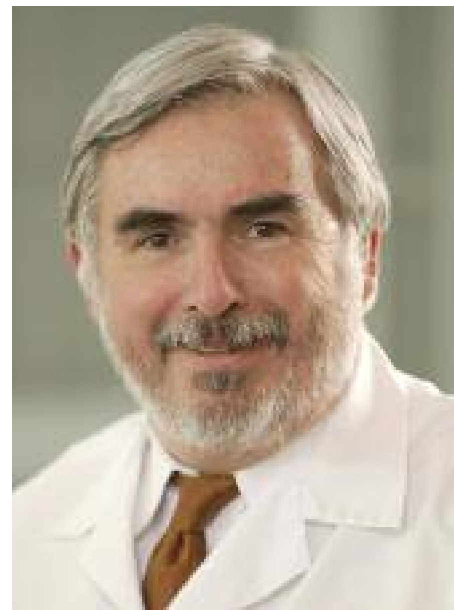
Similarly, the courts are culpable. Appellate judges who hold the commercial rights of corporations more important than the health and lives of citizens consistently gut public health legislation and overturn punitive judgments against tobacco companies.

The National Institutes of Health (NIH) and the National Cancer Institute (NCI) have allocated research funding for this leading cancer killer at absurdly low levels, relative to the number of deaths.

NCI scientists and leaders have also blindly focused on a strategy that allows symptomatic late-stage lung cancer to develop before applying expensive, toxic and largely ineffective treatment, rather than trying to detect lung cancer in early stages where treatment is far more effective. All of this, despite the striking improvements in survival of solid organ tumors based upon early detection by screening; breast cancer by mammography, cervical cancer by Pap smear, prostate cancer by PSA testing, and colon cancer by endoscopy.

While the tobacco industry spends fifteen billion dollars per year to entice our children to smoke, we spend one thirtieth as much to teach them not to.

Medical societies share the blame. Although lung cancer is a preventable disease, thoracic surgeons and oncologists have done little to foster prevention. The



Frederic W. Grannis, Jr., MD, FCCP, Chief of Thoracic Surgery, City of Hope National Medical Center

recent Lung Cancer Guideline from the American College of Chest Physicians offers almost no guidance in tobacco control or smoking cessation policy.

Many physicians fail to advise or assist their patients to quit smoking. Federal, state and private health care providers have only very recently begun to grudgingly pay for smoking cessation interventions and drugs.

Although chemotherapeutic pharmaceuticals offer short-term improvement in survival and quality of life, these treatments come at an enormous cost and cure few.

But there is new hope. Recent findings in the field of lung cancer screening signal a long-awaited breakthrough in the war against lung cancer. Although the Mayo Lung Trial of thirty years ago showed a three-fold survival improvement in lung cancers detected by chest x-ray screening, this promising approach was ignored by NCI investigators and attributed to improbable hypothetical biases. Thirty years later, in October 2006, the International Early

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# Veterans and Lung Cancer

Active-duty military personnel and veterans may be at higher risk for lung cancer, regardless of smoking status.

Some veterans have unique health risks and service-connected illnesses that are often overlooked by medical professionals. The long-term health effects of many biological, chemical, and nuclear warfare agents are still largely unknown but we do know exposure to the following compounds may increase lung cancer risk:

- **Sulfur mustard** (more commonly known as "mustard gas"), used in chemical warfare as early as World War I and as recently as the Iran-Iraq War (1980-88).
- **"Agent Orange"** and other herbicides containing dioxin used in Korea and Vietnam as well as on military bases in the United States.

**LCA joins a diverse group of healthcare professionals, advocates, and business interests in the newly formed Veteran's Health Care Council. One goal of the Council is to inform and educate veterans, their families, and clinicians about service-related health issues.**

- **Battlefield combustion products** (heaters, cook stoves, exhaust fumes, oil-well fires). **Depleted uranium** found in weapons systems and a known by-product of uranium enrichment.
- **Asbestos**, particularly for shipyard workers and those below ship deck and in submarines.

Your military history should be included as part of any detailed medical history taken by your doctor. If you are a veteran, tell your doctor about your military service, including where and when you served.

In addition to the lung cancer risk factors listed above, veterans may be at increased risk for other disorders as a result of service and combat related exposures and experiences. For more information on risk assessment contact the Department of Veterans Affairs' Special Issues Helpline at 800-749-8387. If you served during a specific conflict, you can also contact Korean War Veterans Association at www.kwva.org or 863-859-1384, Vietnam Veterans of America www.vva.org or 800-882-1316 and the Veterans of Modern Warfare www.modernveterans.com or 888-445-9891. ■

# LCA Welcomes Newest Staffer, Will Furtado

Will Furtado has joined LCA as our Administrative Assistant. He will be maintaining the day to day functions of the entire office while being the primary support for Director of Development, Emily Eyres. In addition, he will be providing back up on advocacy and public relations initiatives.

Prior to coming to LCA, Will spent two years in DC working with high school students from across the US, Europe, and Caribbean to promote youth civic participation, advocacy, and political involvement.

A native of Charleston, SC, Will moved to Washington, D.C. immediately after graduating from Duke University in 2005. His interest in LCA's mission is personal as he has lost his aunt and a close friend to lung cancer. LCA is proud to welcome Will to our team! ■

Will Furtado

## LCA Support Services

**Lung Cancer Information Line:**
800-298-2436
A credible source for information about all things lung cancer.

**LCA Survivors Community:**
http://lungcancer.clinicahealth.com
An online support community for lung cancer survivors and caregivers.

**Clinical Trials Matching Service:**
800-698-0931
A pre-screening and referral service that identifies clinical trial options.

**Phone Buddy Program:**
800-298-2436
A peer to peer telephone support network for people with lung cancer and their caregivers.

## Profile of Rear Admiral Phil Coady

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was outraged to discover that the stigma associated with smoking was used as an excuse by many foundations to put their research dollars elsewhere. And he was especially bothered to learn that few cancer research dollars spent by the Veterans Administration and the U.S. Department of Defense were directed at lung cancer, even though it is the largest cause of cancer deaths among Veterans. As a survivor of this disease, Phil felt a solemn obligation to help turn these circumstances around.

**"LCA . . . is the voice for all those affected by the leading cancer killer."**

Through the late Dave Grant, another veteran, lung cancer activist and co-founder of the LCA Survivors Community, Phil learned of LCA and immediately identified with the goals of the organization. He initially volunteered to work with Veterans groups to rally support for lung cancer research and early detection. As Phil learned more about LCA and its programs, he resigned positions he held on the USO and other Boards, so he could concentrate on the work of this organization.

He embraces the goal of educating the American public and policy makers to the fact that "no one deserves lung cancer." As he says "LCA is more that just another group seeking funding and support for some niche concern. It is the voice for all those affected by the leading cancer killer. LCA's efforts in advancing public policy and awareness of the disease may be the most important advocacy work being conducted in Washington and in the states. The case for more money and more attention to lung cancer is compelling. Working together, under the LCA banner, we can help bring that case to the American people and their representatives in government." ■

# Phone Buddy Volunteer John Grzesiak

John Grzesiak was diagnosed with Stage IIb, non-small cell lung cancer in 1999. He had surgery to remove his left lung, followed by radiation and chemotherapy. He is now cancer free.

John Grzesiak, a Phone Buddy since 2004, with Doug, his first match.

### How did you become involved in the Phone Buddy Program?

While waiting in my oncologist's office, I came across an issue of LCA's newsletter containing an article describing the program. I was impressed by the responsibilities given the Phone Buddy volunteers and made up my mind almost immediately to join.

### What is your favorite memory as a Phone Buddy?

My favorite memory includes both joy and sorrow. My first match was to Doug from New Jersey. We talked monthly for over two years and in the fall of 2006, we finally met. Our afternoon get-together was, by far, one of my most rewarding experiences. Doug lost his fight with lung cancer shortly after we met but I will never forget the joys I experienced with my first Phone Buddy and good friend.

### What has been the greatest benefit from your participation in the Phone Buddy Program?

When I was first diagnosed, being unable to converse with someone who personally experienced the physical and emotional implications of the disease, made my early days very frustrating. As a Phone Buddy, I do my utmost to help others avoid those frustrations. Talking with someone who has been there makes a real difference. In a word, **helping** is the most beneficial to me.

### What important message do you want to convey to lung cancer patients?

Always do your utmost to maintain a positive attitude. There will be times when the future is uncertain but in the final analysis only one person can effectively weather the storm and that person is you — the lung cancer survivor.

### What would you say to someone interested in volunteering to become a Phone Buddy?

Volunteering in the Phone Buddy Program is an extremely rewarding experience. You have the opportunity to share valuable life experiences, to listen and to support those who need help in their fight against lung cancer. Most importantly, as a Phone Buddy, you have the opportunity to make a difference — don't hesitate, take advantage of the opportunity! ■

**For more information about the Phone Buddy Program or to volunteer, please contact us at 800-298-2436 or by e-mail to volunteer@lungcanceralliance.org** ■

# The HealthWell Foundation's Non-small Cell Lung Cancer Fund

### What is the *Healthwell Foundation*?

The *Healthwell Foundation* is an independent, non-profit organization that provides financial assistance to underinsured patients living with chronic or life-threatening diseases, including non-small cell lung cancer. Since 2003, HealthWell has helped over 40,000 patients in over 20 disease areas pay for their medical treatments.

### How can the *Healthwell Foundation* help?

HealthWell helps eligible patients pay for out-of-pocket medical expenses, including prescription drug coinsurance, copayments, and deductibles.

If you or a loved one have been diagnosed with non-small cell lung cancer and prescribed a medication but are unable to afford the copayment required, HealthWell may be able to help.

### How does the *Healthwell Foundation* work?

Individuals who are covered by private insurance, employer-sponsored plans, Medicare, or Medicaid may be eligible. The *HealthWell Foundation* takes into account an individual's financial, medical, and insurance situation when determining eligibility. Healthwell will provide you with a medical form for your physician to complete. Proof of income will also be required.

Once approved, patients receive assistance for a 12 month period. In most cases, HealthWell can provide payments directly to your pharmacy or physician. When necessary, the Foundation can reimburse patients directly for expenses they pay themselves.

### How is the *Healthwell Foundation* funded?

The *HealthWell Foundation* receives funding and support from a wide range of sources including corporations, individual donors, and other foundations.

### How do I find out if I'm eligible?

It's easy! If you have internet access, visit www.healthwellfoundation.org for more information and to fill out an application. You can also call Healthwell toll-free at 1-800-675-8416 or e-mail info@healthwellfoundation.org ■

## Lung Cancer: How We Got Here and Where We Are Going

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Lung Cancer Action Program (I-ELCAP) research study results were published in the New England Journal of Medicine. 80% of patients with lung cancer diagnosed in a multi-institutional, protocol-based, computer tomographic (CT) screening trial survive ten years. Furthermore, individuals whose cancers were found in stage I and treated surgically had 92% 10-year survival. When these extraordinary figures are compared with the survival of 15% experienced by lung cancer patients in the United States today, it is hard to understand why any intelligent person would not immediately proclaim victory in the war against cancer, and begin to urge smokers and ex-smokers who are at high risk for lung cancer to be screened. No such thing has happened. Instead, epidemiologists have urged people at risk not to go for lung cancer screening. These authors, many of whom have received paychecks or grants from groups which might be asked to pay for such screening, including tobacco companies, the Centers for Medicare and Medicaid Services, medical insurers and managed care providers, have mounted an aggressive public campaign against implementation of lung cancer screening. They postulate a number of absurd theoretical objections to lung cancer screening. For example, a recent article in the Archives of Internal Medicine seriously suggests that the 80% ten-year survival seen in the I-ELCAP study can be explained away by the possibility that 80% of the lung cancers detected in that study might have been "non-lethal" in nature. This obstructionism is both medically and fiscally irresponsible. Detection of lung cancer in early stage will save both lives and healthcare dollars.

To conclude, despite the present doleful statistics, we now know that we can begin to reduce the death toll of lung cancer in 2008, by implementation of effective tobacco control public policy, by provision of smoking cessation interventions and by providing high risk patients with access to protocol-based, CT screening at centers of excellence. When these policies are implemented, we will begin to see a rapid reduction in lung cancer suffering and death. In the meantime, we need to more adequately support research into palliative and hopefully curative treatment of advanced stage lung cancer. ■

# Representative Donna M. Christensen

Fighting lung cancer is definitely a priority for communities of color since it is the biggest cancer killer of African Americans, both men and women, across our country. I am particularly sensitive to this issue as I have lost dear friends and family members to its devastation. As a family physician and the chair of the Congressional Black Caucus's (CBC) Health Braintrust it is an imperative to increase awareness and to provide the legislative support that will help to eliminate this killer which causes more deaths annually than breast, prostate and colon cancers combined. Clearly there is not enough research in this area, an issue that the CBC is committed to change. I was proud to join Representative Lois Capps (D-CA) in sponsoring House Resolution 335 which declares lung cancer a public health priority and calls for a coordinated effort to reduce lung cancer mortality by 50% by 2015. A similar resolution has been introduced in the Senate by Senators Hillary Clinton (D-NY) and Chuck Hagel (R-NE). Both the House and the Senate resolutions were passed unanimously this year, signaling that the Congress is aware of the seriousness of this disease and is willing to do the research and awareness building necessary to address it head on. ■

Representative Donna M. Christensen (D-VI)

# Representative Frank A. LoBiondo

Representative Frank A. LoBiondo (R-NJ)

As many of us know too well, lung cancer remains the leading cause of cancer death for both men and women in the United States. And, like countless Americans and many of you, my family has been directly affected by this devastating disease.

Nearly one year ago, my father-in-law, Joseph E. Ercole, passed away after battling lung cancer. After more than two years of back pain, shortness of breath and examinations by six different doctors, the correct diagnosis of non-small cell adenocarcinoma stage III-b was made. For the next nine months, my wife Tina watched as her father underwent the all too familiar characteristics of two rounds of chemotherapy: extreme exhaustion, fatigue and discomfort until he passed away.

This is only one of countless stories of lives that could have been changed with more advanced lung cancer detection and treatments. More than 164,000 Americans died of lung cancer in 2006. Even as lung cancer remains one of America's biggest killers, lung cancer research is the least funded of the major cancers. Likewise, the 5-year survival rates have risen significantly for breast, prostate and colon cancer while gains for lung cancer's 5-year survival rate remain at tragic levels.

I, along with Lois Capps (D-CA) and 15 of our colleagues in Congress, recently called upon the Secretary of the Department of Health & Human Services to make a commitment to increase funding for lung cancer research. Along with Lung Cancer Alliance, we are pushing for additional federal funding for lung cancer research, ensuring that the disease receives the support and resources it demands. We believe a coordinated and comprehensive effort must be pursued to reduce the mortality rate of lung cancer by fifty perfect by 2015. Researchers have achieved great successes in many areas, raising the hopes of countless families in the process. With adequate support, there is no reason to believe that progress can't also be made on lung cancer. ■

# Potential NSCLC Vaccine Needs Patients for Phase 3 Trial

A preventative vaccine for cancer, like those that have proven so effective for polio, small pox and other once major killers, is still a long way off. That is because cancer tumors are very complex and contain cells derived from the body's own cells that trick the immune system into ignoring them.

But a therapeutic vaccine—one that would bolster the immune system to attack cancer cells with a specific antigen on its surface is now in trials. This type of vaccine is called an Antigen Specific Cancer Immunotherapeutic (ASCI) and GlaxoSmithKline is developing one that would target an antigen called MAGE-A3 which is found in about a third of Non-Small Cell Lung Cancer (NSCLC) tumors.

The treatment would be given AFTER surgery to help prevent NSCLC from growing back. It has already shown promise in safety (Phase 1) and small scale (Phase 2) trials. Now, 2770 patients are needed to test the therapy in a large scale Phase 3 trial, the final step before asking the Food and Drug Administration for approval.

Recruiting this many patients will be very challenging. For that reason, and because this is the first ASCI vaccine ever developed for NSCLC, and because of the potential of such a treatment in reducing recurrence, LCA is bringing this trial to the immediate attention of all our stakeholders: patients, family, friends, caretakers and doctors.

So **attention stage IB, II and IIIA patients** who have just had surgery or who are about to have surgery. Talk with your doctor about having a small sample from your tissue specimen sent in for analysis, which GlaxoSmithKline will have done at no charge to you or your doctor.

If the analysis indicates that MAGE-A3 is present in your tumor cells, then—and only then—do you and your doctor decide whether you want to go into the vaccine trial or not.

Here's the math: To meet the target number of 2770 patients in the treatment trial, about 15,000 surgical patients must send in their samples just to find out if their tumors have MAGE-A3. So please consider this. For further information contact asci@gskbio.com ■

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