NMCCA
New Mexico Cancer Care Alliance
Spring 2012
COMMUNITY NEWSLETTER

An Epidemic in Throat Cancer is Caused by Human Papillomavirus

By Julie Bauman, M.D., Assistant Professor, Medical Oncology, University of New Mexico Cancer Center

Rates of oropharyngeal cancer are rapidly rising, and this newly described epidemic is caused by human papillomavirus (HPV), the same virus that causes cervical cancer in women. The oropharynx is the back of the throat, chiefly the tonsil and the base of the tongue. Recently, researchers demonstrated that the proportion of oropharyngeal cancers that are infected and driven by HPV has increased markedly since 1980. During the 1980s, approximately 16 percent of oropharyngeal tumors tested positive for HPV, while in the 2000s the HPV-positive proportion rose to more than 70 percent!

Cancer of the oropharynx has two main causes: 1) HPV, which is linked to sexual transmission, and 2) the classic risk factors of tobacco and alcohol exposure. As the use of tobacco decreases nationally, tobacco-related cancers have fallen off. This is true for lung cancer, as well as all non-oropharyngeal sites of the mouth and throat, such as the front of the tongue or the voice box. However, oropharyngeal cancer is unique due to the newly recognized association with HPV. HPV-positive oropharyngeal l cancer occurs more commonly in males, and at a younger age than tobacco-related cancer.

Almost all cases of HPV-positive oropharyngeal cancer are caused by one type of HPV, HPV 16. This suggests a potential role for the HPV vaccine in the prevention of oropharyngeal cancer in both men and women, because HPV 16 is a target for both HPV vaccines approved by the FDA to prevent cervical cancer. Cervarix is approved in girls age 9-26, while Gardasil is approved in both boys and girls age 9-26. Although there is scientific reason to hope available vaccines could prevent oropharyngeal cancer, there is a compelling need for research to test whether the vaccines prevent oral infection with HPV. Unfortunately, the vaccines cannot treat an established cancer; the vaccines prevent infection by blocking the initial entry of the virus into the cell.

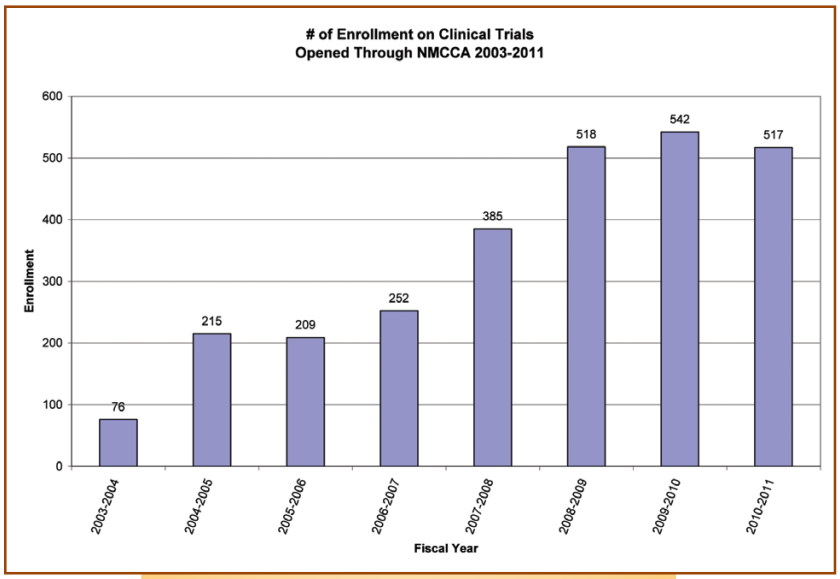
Fortunately, HPV-related oropharyngeal cancer is more responsive to treatment than tobacco-related cancer. However, treatment remains very arduous, generally consisting of radiation to the back of the throat delivered simultaneously with intravenous chemotherapy. Side effects of chemoradiation are harsh, including malnutrition, pain, and voice changes. Because of the promising survival for HPV-related disease, a national priority is the reduction of toxicity from treatment while preserving excellent survival rates. Clinical trials are now being conducted specifically in patients with HPV-positive disease in order to define the optimal treatment while decreasing side effects.

As seen in the rest of the United States, the incidence of oropharyngeal cancer is increasing in New Mexico. This increase is measurable in our three dominant populations, including Hispanics, non-Hispanic whites and Southwestern Native Americans. The New Mexico Cancer Care Alliance is participating actively in the first national trials testing treatment strategies for patients with HPV-positive oropharyngeal cancer. We just completed clinical trial ECOG 1308, which tested lower dose radiotherapy in patients with HPV-positive disease after a complete response to upfront chemotherapy. Now, our new clinical trial RTOG 1016 will compare the current standard of care, chemoradiotherapy with cisplatin, to bioradiotherapy with cetuximab.

INSIDE AT A GLANCE

New Mexico Cancer Care Alliance Celebrates 10 Year Anniversary

February 18, 2012 was the **10th anniversary** of New Mexico Cancer Care Alliance offering cancer clinical trials to New Mexicans. It is through the continued hard work and dedication of everyone involved in the NMCCA network, that we continue to advance the global knowledge of cancer research through local participation in cancer clinical trials.



The NMCCA's mission is to provide local access to innovative clinical trials for the prevention, screening, diagnosing and treatment of cancer through a statewide partnership. NMCCA provides educational opportunities and raises awareness of the role clinical trials in allowing patients to receive cancer care in their own communities. Over the past 10 years, NMCCA has grown into a network of more than 90 physicians who work in private practice and in the major healthcare institutions in central, southern and northern New Mexico. The individual participants of the NMCCA network collaborate to find the most efficient and effective ways to bring the most promising cancer treatments available through cancer clinical trials to New Mexicans. NMCCA is the result of a small group of dedicated cancer physicians in Albuquerque who were concerned by the fact that the newest experimental cancer treatments generally were only available through clinical trials conducted outside the state. They saw firsthand that the economic and emotional cost of travel kept New Mexico cancer patients from participating in these programs.

These physicians and their institutions became the founding participants of NMCCA.

The Founding Institutional Participants are:

- Lovelace Health Systems and St. Joseph Healthcare
- New Mexico Veterans Affairs Health Care Systems
- Presbyterian Healthcare Services
- University of New Mexico Cancer Research & Treatment Center

The community physician practices that were Founding Participants are:

Private Practices:

- William Abbott, M.D.
- Susan Seedman, M.D.
- Linda Ann Smith, M.D.

Albuquerque Urologic Associates

Hematology Oncology Associates

New Mexico Colon & Rectal Surgery Associates

New Mexico Ear, Nose, Throat Specialist, P.C.

New Mexico Oncology Hematology Consultants (No longer participating)

Radiation Oncology Associates (No longer participating)

Southwest Gynecologic Oncology Associates

NMCCA's goals are to increase the quality of cancer care in New Mexico, bring new knowledge to the field of oncology by opening cancer clinical trials offered by government agencies, physician initiated, and pharmaceutical sponsors, make it easier for cancer patients to participate in a clinical trial, and ensure access for all New Mexicans to the best cancer therapies offered through clinical trials.

In 2003, NMCCA hired its first two staff members and opened its office, developed the Medical Scientific Review Committee meetings to review and open new trials, and enrolled 76 patients that year. Today NMCCA has 9 staff members and enrolled nearly 3,000 patients since 2003.

Each year NMCCA recognizes and honors cancer patients who have participated on a cancer clinical trial through our HERO (Helping to Enhance Research in Oncology) Educational Program. This year promises to be better than ever with the additional celebration of our 10 year anniversary. On May 3, 2012, our 7th Annual HERO Recognition Program and 10th Anniversary Celebration will be held at the National Hispanic Cultural Center.

Cancer patients that participated on a clinical trial and a family member or friend are invited to attend the 7th Annual HERO Recognition Program and 10 Year Anniversary Celebration.

Kay Kerbyson

The Irresistible Resolve to Control Life with Cancer

January 2012, Los Alamos Monitor

I feel one coming on, oh heck I feel a lot coming on. Oh no, I don't want to do it but I can't control the temptation. Yikes, here they come….. my New Year's Resolutions.

Ok, here goes. I resolve to grow my hair back in a month, my eyebrows in a week. I resolve to banish cancer from my body forever, and stop my husband nagging me. Oh hang on, but I have no control over any of those things, especially the last one! Umm. What on earth am I going to do?

Seems silly doesn't it to try and control that which we have no power over, like our own health, but it's often a reflex reaction when you're diagnosed with cancer. You feel there must be some way that you can solve this. But at some point you realize that life is going to take you where it wants, regardless. Sometimes, the fact that we have no control over the big things in our life, transforms into a need to find things we can control – all the petty stuff: like which way up wine glasses are put in a cupboard; or how the dishwasher is loaded. But at the end of the day, do you really want to be putting all your energy into controlling stuff that, in the big scale of things, doesn't really matter?

It's not unusual for survivors, or their loved ones, to fall into the 'sweat the small stuff' trap, because when you can't control whether you're going to live or die, lose or hold your loved ones forever, it's easy to channel your focus into the petty, the inconsequential, the 'nagfest'. We forget that there are plenty of meaningful ways to take back control.

So, my resolution this year? Well, to just go back to the old standards I guess, like eating right, getting fit and losing some weight. My resolutions don't usually last very long, but this year I had a brain wave. Doing all these things is going to give me the best chance of keeping my cancer away. Making sure that I'm as healthy as can be, and my immune system is fighting fit, will help my own body keep any abnormal cells in check. Huh! So maybe I do have some control after all.

What I've realized is, that I must accept the things that I can't change, like the way the dishwasher's been stacked for the last 20 years, and instead have the courage to change the things I know I can. But the true key to control, is having the wisdom to know the difference. I can control my attitude. I can manage how I look after my own body, and I definitely have power over the way I treat other people. So I have the resolve to control this New Year, but now I'm channeling it in the right direction.

Kay Kerbyson is an Associate of the Los Alamos Council on Cancer, and Founder/President of Ovarian Cancer Together Inc.

Resources, support and education materials, for those effected by cancer, can be found at www.losalamoscounciloncancer.org and www.ovariancancertogether.org Kay can be contacted at KayatLACC@live.com or at Kay@ovariancancertogether.org

Sharing Your Thoughts

Have you participated in a clinical trial?
Would you like to share a few words about your experience?

If so, we'd love to include your thoughts in our newsletters, email: info@nmcca.org or write to: NMCCA, P.O. Box 4428, Albuquerque, NM 87196

Don't Miss Out!

Sign up to Receive the *NMCCA Community Newsletter* Today!

email info@nmcca.org
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Electronic versions of NMCCA newsletters available at www.nmcca.org/whatsnew/newsletters.htm

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2010-2011
New Mexico Cancer Care Alliance Annual Report

7/1/2010 to 6/30/2011

The NMCCA sites accrued 517 patients onto cancer trials last year. This brings the total number of patients helped by NMCCA since inception in the fall of 2003 to nearly 3,000 patients.

Special recognition to the University of New Mexico Cancer Center who was the NMCCA site with the most accruals and to Southwest Gynecologic Oncology Associates for the community site with the most NCI accruals. Claire Verschraegen, M.D. formerly with the UNM Cancer Center enrolled the most patients on clinical trials and Paul Duncan, M.D., Hematology Oncology Associates, enrolled the most patients at a community site.

Southwest Gynecologic Oncology Associates
Francisco Ampuero, M.D.; Bernice Fernandez; Karen Finkelstein, M.D.; and Ruby Draper

NMCCA Welcomes New Participants

The New Mexico Cancer Care Alliance, Board of Directors appointed Elizabeth McGuire, M.D., Section Chief from the Veterans Administration Medical Center, Lovie Bey, M.D. from Hematology Oncology Associates, Mitchell Binder, M.D. from The Cancer Center at Presbyterian, and Cherie Hayostek, from Memorial Medical Center-Cancer Center, Las Cruces as new board members.

Additionally, Prostate Cancer Support Association of New Mexico was approved as an Affiliate Participant. Affiliate Participants are groups involved with cancer treatment, research, support and education.

Chest Medicine of New Mexico:
Jeffrey Dorf, M.D.

Hematology Oncology Associates:
Steven Schechterman, M.D.

Lovelace Women's Hospital:
E. Diane Bowers, M.D.

Memorial Medical Center-Cancer Center, Las Cruces:
Cherie Hayostek, M.D. and Robert Francis, M.D.

New Mexico Veterans Administration Medical Center:
James Lin, M.D.

Otero Oncology, PC, Alamogordo: Stefan Korec, M.D.

Presbyterian Healthcare Services:
Lisa Balduf, M.D., Stephanie Fine, M.D., Kevin Hudenko, M.D. and Kimberly A. Vanderveen,M.D., Kenneth Smith, M.D., M. Anas Tarajki, M.D.

Presbyterian Plains Regional, Clovis:
C. Arnold Curry, M.D., Manuel Macapinlac, M.D.

Private Practice: Mark Thomas, M.D.

University of New Mexico Cancer Center:
Sagus Sampath, M.D., Itzhak Nir, M.D., Stephen Lu, M.D., Katherine Morris, M.D., C. Etta Tabe,M.D., Ibrahim Ahmed, M.D., Elizabeth McGuire, M.D., Dulcinea Quintana, M.D., and Esme Finlay, M.D.

HPV 16 was my Diagnosis

By Ronald Cossey

In late October of 2010, I noticed a small lump on the left side of my neck. I had just returned from a trip to Africa so I thought perhaps I had picked up some type of infection while there. I lost my tonsils when I was four, (Mom had them yanked as a preventive measure) so I was unsure what this lump might be.

I made an appointment with my Primary Care Physician and through the usual referral process ended up in the office of a specialist. The Ears, Nose and Throat doctor performed a fine needle aspiration during his exam and ordered a round of antibiotics for me to start taking. Two days later he called and said to forget the antibiotics and to come to his office ASAP. The fluid he had drawn from the mass in my neck had malignant cells. The mass was soon surgically removed and sent off to Pathology. The Thanksgiving holidays were a time of travel with family and friends with the underlying thought and concern of what might be.

I was referred to the University of New Mexico Cancer Center and Dr. Julie Bauman, Oncologist. We met in early December and got things started with a PET scan. The Christmas Holidays were rapidly approaching and I was trying to keep my mind clear and enjoy the holidays with the family.

In early January I met Dr. Garth Olson, ENT with UNM Hospital. He had the results of the PET scan and the pathology report.

The reports confirmed the initial diagnosis of cancer in the throat. Dr. Olson felt the next step was to take additional biopsies from three different areas inside my throat near the base of my tongue. This procedure was to hopefully pinpoint the source of the cancer. The results of the biopsies would be presented in my follow-up meeting with Dr. Bauman the following week.

Squamous Cell Carcinoma caused by human papillomavirus, HPV 16, was my

Dr. Julie Bauman & patient Ronald Cossey

diagnosis, a virus I encountered silently many years ago. The options were:

1.) surgery to remove approximately 1/3 of the base of my tongue in the left side of my throat, or 2.) chemotherapy and radiation. Dr Bauman explained that even with surgery I would need chemo and radiation so I quickly ruled out the surgery to remove part of my tongue, opting to try the chemotherapy and radiation first. During this visit Dr. Bauman told me about a new clinical trial to study a different treatment for HPV throat cancer. She asked me if I was interested in participating, assuming I qualified for the clinical trial. Having retired from a biomedical research organization with a division that conducted clinical trials, I was familiar with the importance of clinical trails and their potential benefits. I knew that I might benefit from a new treatment and I knew that others would benefit from the results of the trial. Being a part of the trial was a quick and exciting decision for me, that is, if I were accepted. The acceptance part took more time as biopsies had to be sent off to a different lab for analysis and additional confirmation of the HPV. Dr. Bauman reviewed my case with the doctors at UNMCC. This review and biopsy results were just what I needed to join the trial. According to Dr. Bauman and Radiation Oncologist Dr. Sampath, the standard procedure for treatment of this type of cancer involved lots of radiation aimed directly at the affected area of the neck. The new trial would use less radiation and in my thinking, less radiation is hopefully "more better."

Scans, blood draws and paperwork started the process and I received my first chemotherapy treatment in early March. Having been a runner for many years I entered this process in decent physical condition. I told Dr. Bauman I had plans to run a marathon in early May and asked if she thought that was a good idea. I figured I could keep running through the entire process. She looked at me very sincerely and told me this would be the hardest marathon I would ever run. After the chemo started I quickly realized I had to give up any idea of serious running. The chemotherapy and radiation were very energy draining and I was lucky if I felt like going for a walk, much less a run. Energy conservation became a priority as eating grew more and more difficult. I lost 25 pounds during the treatment. Although the chemo/radiation treatments are now over, the healing is a slow process and I am constantly reminded to be patient and let my body do the work. Follow up scans have shown no signs of the cancer.

I feel that I have been very blessed by being a part of a clinical trial. I will continue to be a part of this clinical trial as the monitoring of my condition will continue for several years. The drugs and medications currently available are a result of participation in clinical trials. Do all trials immediately result in new and better mediations? Of course not, but the knowledge gained in these trials provides the path for future trials and hopefully the eventual elimination of illness and disease. If given the chance to participate in a clinical trial I hope that everyone will seriously weigh the benefits of helping themselves and others.

Shortages of Essential Chemotherapy Drugs

Hospitals and outpatient centers across the country are facing a shortage of essential chemotherapy drugs. Several commonly used generic chemotherapy drugs used to treat cancer are currently in short supply. Most of the drugs involved are in a category known as sterile injectables and are the drugs that have been used for years to treat cancer. Across the country many physicians are struggling to treat their patients because of the unavailability of drugs. The shortage is causing concerns about safety, cost, and availability of lifesaving treatments, and is causing physicians to delay treatments, substitute drugs, and force some patients to travel to a less convenient treatment center. This shortage is not only affecting patients currently receiving treatment, but is having a negative impact on current and future cancer clinical trials. Researchers struggle to keep clinical trials on track. Clinical trials often use the generic drugs that have been in short demand as either a control or in combination with experimental drugs. Often these trials are being delayed or suspended and not allowing new patients to enroll on them, as a clinical trial does not allow for a substitution of a drug. Treatment delays are critical to a cancer patient and could limit their chances for a cure or remission of their disease. Suspending these trials due to drug shortages will delay obtaining the results from these trials which could affect the availability of new therapies in the future.

Shortages of both hospital medications and prescriptions filled at community pharmacies can be caused by a variety of problems along the drug supply change, including:

- Production and quality issues
- Supplies of raw materials
- Companies that cease making a drug that has become less profitable
- Drug companies are consolidating
- Drug makers are not required by law to alert the FDA when they expect a shortage
- Hospitals throughout the nation are hoarding or stockpiling drugs making the situation worse
- Medicare reimbursement rate is the average sales price of the drug plus a 6% markup to cover practice cost. Often the reimbursement rate is less than the cost of the drug administration causing oncologists to switch to brand-name drugs instead of the cheaper generic drugs. Thus, causing less demand to make the generic drugs.

Shortages change from day-to-day and come without prior notice. One day there's plenty of drug, the next there's a shortage.

In New Mexico our physicians are faced with this drug shortage. Dr. Karen Finkelstein, Southwest Gynecologic Oncology Associates and NMCCA Board member was recently asked how this crisis has affected her outpatient practice.

Did you experience drug shortages in your practice?

Unfortunately yes. Since early June 2011 we have experienced shortages of taxol, one of the leading drugs in the treatment of ovarian, endometrial, and cervical cancers, as well as liposomal doxorubicin, one of the leading drugs in the treatment of recurrent ovarian and endometrial cancers.

How has this affected your ability to offer the best treatments?

We were able to obtain supply to get through the summer, but as of the end of August 2011, most patients requiring taxol were switched to a "sister taxane" taxotere per guidelines from our National Society of Gynecologic Oncologists. Now we are able to obtain taxol in limited quantities and so those patients that we feel might do better on taxol are able to be started on it. Liposomal doxorubicin is still not available for any new patients to be started on it. Patients that were on it prior to the shortage, however, have been able to continue on their infusions through a program called "Doxil Cares" that allows for preferential shipment of this drug for these patients.

How has this affected your ability to offer clinical trials?

Due to the shortages we were unable to enroll patients in the majority of our clinical trials from September through November. Thankfully we are now able to obtain taxol in limited quantities and are able to enroll patients on trials involving taxol at this time. Patients that were on a trial using taxol during the shortage were allowed to be switched to taxotere per protocol guidelines if the drug was not available. Unfortunately with liposomal doxorubicin, we are still unable to enroll any patients on trials involving doxil due to the lack of supply.

What changes did you have to make within your practice to handle the drug shortages and not impact care?

Our staff and chemotherapy nurses have been extremely diligent in calling the various companies and vendors on a daily basis to ensure drug availability for our patients. We have had to obtain drugs from alternate vendors than usual due to the shortage, patients have had to call to verify that drug is available prior to coming in for their infusion. Thankfully, now that the taxol

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Shortages of Essential Chemotherapy Drugs

Continued from page 6

supply is slowly trickling in, this is much less of a problem for taxol. For doxil, we had to go through a submission and approval process with the Doxil Cares program for each and every patient and then still hound the program to process their application efficiently to guarantee drug availability in a timely manner.

What should patients do?

Patients need to understand that this is not a local problem, but a national problem that needs to be addressed at the highest levels of government. I encourage them to contact their representatives and demand that drug shortages be addressed efficiently and thoroughly so that drugs can be readily available for those that need them. Also, I encourage each patient to have an open dialogue with their treating physician about the options of treatment so that they are not potentially started on a drug whose supply is unstable if there is a good alternative.

Drug shortage article references:

The National Coalition for Cancer Research. *Testimony of the National Coalition for Cancer Research House Committee on Energy and Commerce Health Subcommittee Hearing: "Examining the Increase in Drug Shortages."* September 23, 2011

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SAVE THE DATE

May 3, 2012

New Mexico Cancer Care Alliance

Be Our Guest

at the

HERO Recognition and 10 Year Anniversary Celebration

Honoring Cancer Patients Participating on Clinical Trials

You are our HERO!

Patient and one guest will receive complimentary tickets.

The New Mexico Cancer Care Alliance invites you to join us for our 7th Annual HERO (Helping to Enhance Research in Oncology) Recognition Program on May 3, 2012. This year, in addition to recognizing the individuals who have participated in clinical trials, the NMCCA will be celebrating its 10th Anniversary.

May 3, 2012

National Hispanic Cultural Center
1701 4th Street SW • Albuquerque, NM 87102
Grand Hall in the Pete V. Domenici Education Center

Registration and Tour of the Art Museum: 5:00-6:00pm

Program: 6:15 pm -7:30 pm *Heavy Hors D'oeuvres will be served*

Keynote Speaker:

Amy Dee-Kristensen, ***You, the Everyday Hero***

Amy is a dynamic speaker with an extraordinary life story and a marvelously candid ability to touch people's hearts and souls. She has been a professional speaker for 20 years and her presentations stem from practical and proven truths.

You, the Everyday Hero, can find marvelous moments every single day!

Worta McCaskill-Stevens, M.D. from the National Institute of Health will be invited to speak about the transformation of the national clinical trial program and the role organizations like NMCCA will play in moving these changes forward (pending confirmation).

Ribbon Colors and their Meaning

Yes!

I am pleased to contribute to the New Mexico Cancer Care Alliance

TWO WAYS TO GIVE:

1. Give Online: **www.nmcca.org**
2. Cut out form and mail check to:
   P.O. Box 4428 • Albuquerque, NM 87196
   (Make checks payable to New Mexico Cancer Care Alliance)

Name:_____

Phone:_____

Address:_____

City:_____

State:_____ Zip: _____

Email address:_____

My gift is for:

☐$10 ☐$15 ☐$25 ☐$50 ☐$100 ☐$_____

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All Federal employees have the opportunity to contribute to the Combined Federal Campaign. If you are a Federal employee in Central or Northern New Mexico, you may donate to our campaign. Our charity code is 93229.

United Way Donor Option Plan

During your company's United Way campaign drive, you can specify your donation be given to New Mexico Cancer Care Alliance. For questions, call United Way at 505-247-3671.

New Mexico
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