NMCCA

New Mexico Cancer Care Alliance

Fall 2009

Community Newsletter

Genetics & Cancer

Lori Ballinger, MS, CGC

How do they really relate?

Lori Ballinger, MS, CGC
Senior Genetic Counselor, UNM Cancer Center

All cancers are caused by genetic changes (mutations). These changes can cause cells to grow abnormally and develop into cancer. Mutations can be caused by exposures (chemicals, sunburns or from smoking, as examples), or they can be inherited. Mutations can also occur when a mistake happens during normal cell division, and these mistakes happen more often with age. Inherited cancers are caused by changes in genes that help to control cell growth, and these changes can be passed from parents to some of their children.

Most cancers are not inherited, but the evaluation of family history is always important. If a person does have an inherited cancer, there can be risks for other cancers, and the information can also impact the health of other family members.

Cancers that are inherited are more likely to develop at a younger than average age. For instance, a man with colon cancer diagnosed at age 34 is more likely to have an inherited cancer than someone diagnosed with the same type of cancer at age 75. Families in which there are two or more people with the same cancer are also more likely to have an inherited cancer. Some cancers are also related to one another, like breast and ovarian cancers, or colon and uterine cancers. Therefore, families with multiple cancers, especially those diagnosed at an early age, should be evaluated for a possible inherited syndrome.

Every person inherits two copies of each gene, one from each parent. If the gene inherited from one parent has a mutation, then the person is at increased risk for cancers. It does not mean that person will develop cancer, because a second mutation must happen in the gene inherited from the other parent (through exposures or mistakes in cell division). Sometimes these changes do not happen, and although a person has inherited a susceptibility to cancer, it may never develop. When a mutation is inherited and therefore in every cell, the likelihood a cell will become cancerous is increased, and why most inherited cancer happens at younger than average age.

For some families, the mutation that has caused the cancers in the family can be identified by genetic testing, which usually involves taking a blood sample. If genetic testing shows a mutation, other family members can be tested to see if they are also at higher risk for cancers. If a mutation is found, relatives without that mutation are not at a higher risk for developing cancer than someone in the general population.

One example is breast cancer, which is the most common cancer in women. Approximately 10% of women who have breast cancer have an inherited form of the disease. Women who have genetic mutations that cause cancer are more likely to be young at diagnosis, and/or have family history of breast or ovarian cancer. Mutations in genes called BRCA1

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Genetics & Cancer

How do they really relate?

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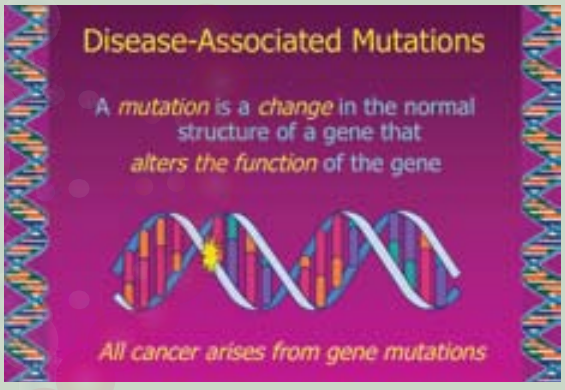


and BRCA2 are the most common cause of inherited breast cancers. If a woman has a mutation in one of these genes, she is at higher risk for a second primary (new) breast cancer. She also is at higher risk for cancer of the ovaries. (People with BRCA mutations are at slightly higher risk for other cancers, such as prostate cancer and pancreatic cancer.) For some women, having information about whether or not they have a mutation changes the type of treatment they choose. They may also need additional screening for other cancers. Not all inherited breast cancer is associated with BRCA1 or BRCA2, so a careful examination of the family history is important in deciding if this test is appropriate.

Another common cancer is colon cancer. Again, about 10% of colon cancer is inherited. There are many inherited colon cancer syndromes that have been identified. Lynch syndrome is the most common, and it involves multiple types of cancer. Families affected by Lynch syndrome often have more than one member with colon cancer (often diagnosed before age 50), or family members with cancer of the uterus, stomach, pancreas, or ovaries. Women who have Lynch syndrome may be diagnosed with uterine cancer in their late thirties or early forties, rather than in their sixties, which is the usual age for this diagnosis.

Some inherited colon cancers occur in families who have a tendency to develop multiple colon growths, known as polyps. Colon polyps are often precancerous growths. A person with colon cancer should ask other family members if they have ever been diagnosed with colon polyps, as well as cancer, as this information is important in making a correct genetic diagnosis.

Not every family with an inherited cancer syndrome has a mutation in known genes, so we know that we need to keep looking for new genes. UNM Cancer Center is participating in a research study with the Cancer Genetics Network to collect DNA from individuals who appear to have an inherited cancer, but do not have mutations in genes that we know are associated with inherited cancer syndromes. This research is important so that someday, all families who are at risk can be identified and measures can be taken to reduce the risk of developing cancers.

For more information on Cancer Genetics Research Studies, Contact Julie Baum, Research Coordinator 505-272-1422 or Jbaum@salud.unm.edu

Update on the City of Hope Protocol 96144

Molecular Genetics Studies of Cancer Patients and Their Relatives

By Paul Duncan, MD Hematology Oncology Associates

The City of Hope (COH) Protocol 96144 became an NMCCA protocol in late 2007. From inception there have been 70 individuals and family members who have consented through Hematology-Oncology Associates (HOA).

A new study initiative has been added to COH 96144 which will assist in our understanding BRCA mutations in our Hispanic women. BRCA mutations are abnormalities in DNA, inherited by both men and women, which predispose women to an increased risk of both breast and ovarian cancer over their lifetime. There are important strategies which we can use to reduce a woman's risk of breast and ovarian cancer if a BRCA mutation is identified in a family.

The main purpose of this study is to investigate the BRCA1 185delAG mutation in our New Mexican Hispanic women with breast and ovarian cancer. This particular mutation is thought to have been introduced into New Mexico in the 16th and 17th century and appears to be more common in women with breast or ovarian cancer who identify themselves as descendents of New Mexican Colonial Hispanics.[1]

We would like to learn more about the different types of BRCA1 and BRCA2 mutations seen in the Hispanic populations in the United States. It is possible there are only a limited number of mutations seen commonly and if so a BRCA "screening panel" might be developed which could reduce the cost to find such high risk families.

Eligibility:

Any Latina patient presenting to clinic with a personal or family history of breast and/or ovarian cancer (if bi-racial, cancer must be on the Hispanic side)

Patients must be consented to participate in a research registry (either COH 96144 or other research registry that allows sample and data sharing)

If NMCCA clinicians have Latina women in their practice that are eligible for this protocol or if further information is needed please contact Drs Duncan or Lin at 938-5858 or pauld@hoanm.com or jamesl@hoanm.com.

[1]PRDuncan, *Identification of the BRCA1 Mutant Allele in New Mexico Hispanic Families with Hereditary Breast and Ovarian Cancer,* Proc Am Soc Clin Oncology 23:858s, 2005.

It's All About the People

Maxine Anderson, the mother

In 1990, at the age of 38, I was diagnosed with stage 2 breast cancer. It was completely out of the blue—I had a toddler and a 3 year old and very little history of breast cancer in my family. At the time of my diagnosis, breast cancer was thought to be passed on through the mother and my mother was fine! I had a paternal cousin who had died of breast cancer at 29 but my oncologist assured me that she was just a "fluke" in my history and had nothing to do with my cancer. I had six months of chemotherapy and a mastectomy.

Thirteen years later, a routine mammogram found calcifications on my other breast. The biopsy confirmed that that breast had DCIS, not really cancer but possibly a precursor. Although my oncologist felt that my history didn't look suspicious, she recommended that I talk to a genetic counselor. This doctor made arrangements for me to see Lori Ballinger, the genetic counselor in the UNM Cancer Research and Treatment Center. I got a tremendous amount of information from Lori about my possible risks and decided to have the genetic test. It turned out that I was positive for a BRCA1 mutation. This discovery had a rather large effect on both me and my family.

Laura and Maxine

Once I had results, I was immediately scheduled for a prophylactic hysterectomy and removal of my ovaries. I had been in menopause for years due to chemotherapy and had no idea that I could be facing a very real risk of ovarian cancer. Having my ovaries removed was a "no brainer" for me. I then had to contact all of my cousins as by now it was very likely that the mutation carrier in my family was my dad, because of my cousin's early diagnosis. Since he had no sisters, breast cancer had not shown up in his family until she was diagnosed. His mother also lived well into her 80s, cancer free. Many of my cousins were tested and all tested negative. My dad did not want to be tested and has since died of colon cancer. My son wanted to be tested at 21 and was negative. My daughter, who at 21 is in college and just starting her adult life, has opted to wait. The fact that she has a 50/50 chance of inheriting this mutation is devastating. You see, by the time I was tested, I had already had breast cancer and beat it. Looking at it from my daughter's perspective is very different. I now know many "previvors" (women who are positive for a BRCA mutation but have not had cancer) who have to make the difficult decision to either do intense surveillance (alternating mammograms and breast MRIs every 6 months) or having prophylactic mastectomies and/or oophorectomies. I hate it that my daughter may have to make such a decision .

The last five years have been quite a journey. This is not the path I would have ever expected my life to take. But I have to say, being able to share my story and showing that there is life on the other side, makes it a lot easier to take.

One of the best pieces of information which I got from Lori was a brochure for an online support group called FORCE. This is a website which was developed to provide support to women (and men!) who are affected by genetic breast and ovarian cancers.

Laura Anderson, the daughter

I was in middle school by the time my mom was diagnosed with breast cancer for a second time. Though I grew up knowing she had it when I was a toddler, I was too young to remember her initial diagnosis and treatment. Not long after, my mom received genetic counseling and testing, which came back positive for a BRCA1 mutation. This changed everything. Though before I had simply been an observer at the age of 21, trying to be supportive of my mom's decisions, now I was, in a way, thrust into the middle of it. The fact that my mother has the gene means that there's a 50/50 chance that I, too, am a carrier. I don't think the implications of this diagnosis hit me until early this summer.

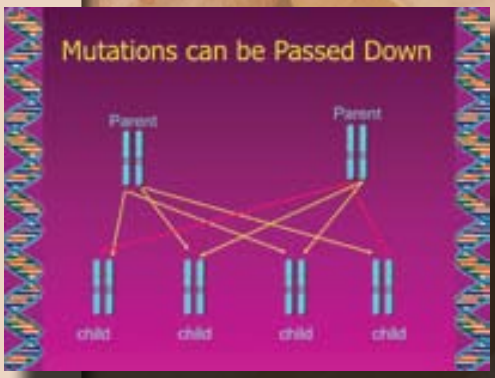
My mom and I attended the annual Joining FORCEs Against Genetic Breast Cancer conference in Orlando, FL, in May this summer. There, I was really exposed to other young women my age, grappling with the same decisions that I am trying to make. This was both heartening and terrifying. In one seminar session, I sat next to a 22-year-old who had recently tested positive for a gene mutation and was preparing to have a prophylactic double mastectomy. I cried for an hour for this girl, for all previvors who are forced to make these types of decisions, and for my own body. But after seeing my mom and all she has been through, I realized that these women who have had to battle breast cancer are still just as beautiful and, likely, a heck of a lot stronger than someone who has not.

So though I have not decided to get tested quite yet, I know it will happen soon. I also know that whatever my diagnosis, that breast cancer will not triumph over me because I have seen it be beaten, and I know that the human body is a resilient thing and that, no matter what parts could go missing in the future, we are all beautiful.

It's All About the People

Lou Sanchez Wilburn

My encounters with cancer have been too many -- three, at ages 27, 47, and 49. The second was a breast cancer treated with lumpectomy and radiation, the third was a second primary breast cancer treated with a bilateral mastectomy, TRAM Flap reconstruction, and chemotherapy. Pathology reports from both occurrences found the cells to be aggressive and triple-negative. At the suggestion of my oncologist, Dr. Mitch Binder from the Cancer Center at Presbyterian, I agreed to be tested for a genetic mutation. The results were positive for BRCA1 frameshift mutation 187delAG. It is interesting to note that my ancestors were Spanish colonists who settled in Northern New Mexico and lived there for many generations. The deletion I carry, 187delAG, is also the one commonly associated with Ashkenazi Jewish families. Following the genetic testing, I decided to have a bilateral salpingo-oophorectomy and complete hysterectomy to help prevent ovarian cancer. Due to previous research efforts, I had these life-saving options available to me. Due to research resulting in the availability of BRCA1 testing, my doctors and I are able to institute surveillance efforts to hopefully lead to early diagnosis should cancer return.



The three experiences with cancer, the surgeries, the treatments, the positive BRCA1 results, and the 50-50 risk to my children and my family now, and for generations to come have proven to be a very heavy psychological and emotional burden to carry. Lingering psychosocial issues continue to be an ongoing challenge. As an NCI CARRA advocate, my participation in Cancer Center renewal grants and various other types of grant applications have exposed me to the world of cancer research. Always, I leave these meetings impressed at the dedication and hard work put forth by scientists in the quest to end the suffering caused by cancer. I also leave with a heightened sense of hope.

Mary Gutierrez Breast Cancer Survivor

There is a definite history of cancer in my family. I am a survivor of breast cancer, I have a daughter who is also a survivor and I had a sister who lost her battle with breast cancer. Because of this history, my doctors recommended that I take a genetic test to determine whether there was additional risk of cancer to me and other members of my family.

The BRCA test (pronounced “brack-uh”) is a type of genetic test that’s offered to women who have an apparent higher risk of breast and ovarian cancer based on personal or family history. There are three possible outcomes from this test - positive, negative and inconclusive. A positive test result means that there is a higher likelihood of developing breast cancer or ovarian cancer. A negative test result means that no BRCA gene was found and sometimes the test results are inconclusive. In my case, the result of the BRCA test was negative.

While a negative test result did not make sense to me (given my family history), it helped me to learn more about genetic testing and cancer. Specifically, that the women in my family may still be at higher risk of getting cancer compared to the general population even though I had a negative test result. I have come to accept this result and more importantly, I believe that genetic testing is a valid and important test for women who want to learn more about the risk of cancer for themselves and their family members.

I compare my genetic testing experience to getting a mammogram. We know that not all mammograms detect cancer every time, but that doesn’t mean that women should stop getting mammograms! We should all do everything we can to learn about cancer, detect it early or prevent it altogether.

NMCCA Staff Member Wins The Komen Central NM Race for the Cure One Mile Run

Vicki Witte, Clinical Trails Assistant at NMCCA, won the 1 Mile Run with a time of 6:55 minutes. Vicki is an avid runner and has competed in several half and full marathons national and internationally.

Congratulations Vicki!

The Central New Mexico Affiliate of Susan G. Komen for the Cure becomes an NMCCA Affiliate

It all began with a sister's promise to build an organization to end breast cancer. Like so many others, Nancy Brinker's life was forever changed by her sister's battle against breast cancer. Susan Goodman Komen died at the age of 36. Founded in her memory in 1982, the Susan G. Komen Breast Cancer Foundation was born out of a sister's love and a solemn promise to do something to stop breast cancer from taking more lives. Within four years of Suzy's death, Nancy faced her own battle with breast cancer, and now she is a survivor!

Susan G. Komen for the Cure® began as a simple promise between two sisters. Twenty-six years later, the Foundation has more than 125 Affiliates in the United States and three other countries. More than 75,000 volunteers – many touched by their own or a loved one's fight with breast cancer – help raise awareness and funds in the fight against the disease and lead local efforts to improve breast health services and programs in their area.

The Central New Mexico Affiliate of Susan G. Komen for the Cure was founded in 1999. Through events like the Komen Central New Mexico Race for the Cure, they have invested over $1M in local breast health and breast cancer awareness projects in Sandoval, Santa Fe, Bernalillo, Los Alamos, Valencia and Torrance counties. Up to 75 percent of net proceeds generated by the Komen Central New Mexico Affiliate stay in New Mexico. The remaining income goes to the National Susan G. Komen Award and Research Grant program for energizing science to find the cures.

Susan G. Komen for the Cure looks forward to partnering with NMCCA to bring hope and help to New Mexicans.

The office is at 8200 Mountain Rd in Albuquerque. The staff of two can be reached at 505-265-4649 or through the web site www.komencnm.org.

Local Coffee Shops Support Cancer Research

During the month of October, area coffee shops will be using special NMCCA "Research Cures Cancer" coffee sleeves to increase public awareness of cancer clinical trials. NMCCA provides local access to the most up-to-date cancer research for New Mexico cancer patients through cancer clinical trials.

Thanks to the sponsorship of NMCCA's participants, The Cancer Center at Presbyterian, CHRISTUS St. Vincent Regional Medical Center, Hematology-Oncology Associates, Lovelace, Memorial Medical Center, New Mexico Cancer Care Associates, New Mexico Department of Health, Radiation Oncology Associates, P.A., and UNM Cancer Center, and the enthusiasm of the following coffee shops 62,400 coffee sleeves will be distributed in New Mexico.

Show your support by patronizing these businesses.

Albuquerque Coffee Shops:

Napoli Coffee
2839 Carlisle Blvd. NE

Java Joe's
906 Park Ave SW

Saxbys Coffee
8810 Holly Avenue NE

Perk Up Espresso Coffee
9111 Eagle Ranch Rd. NW

3rd Alarm Coffee
6510 Paradise Blvd.NW

Café Giuseppe Espresso
3222 Silver Ave. SE

Service League Espresso Café's
at UNM Hospitals

Santa Fe Coffee Shops:

Plaza Bakery-Haagen Dazs
56 E. San Francisco St.

CRISTUS St. Vincent Coffee Cart
455 St. Michael's Drive

The Koffee Klatch, Medical-Dental Center
465 St. Michael's Drive

Las Cruces Coffee Shops:

Milagro Coffee Y Espresso
1733 University

October is Breast Cancer Awareness Month

Purchase NM Breast Cancer License Plates to "Drive" Out Cancer

The Breast Cancer Awareness plate is available to any motor vehicle owner. $25.00 of the $37.00 fee collected for each Breast Cancer Awareness plate is transferred to the New Mexico Department of Health for the purpose of funding breast cancer screening, outreach and education.

Sponsored by Senator Gay G. Kernan • http://www.dmv.org/nm-new-mexico/license-plates.php

NMCCA HIGHLIGHTS
The Breast Care Center at Lovelace Women's Hospital

The two greatest risk factors for breast cancer are being a woman and getting older. You may have heard about other risk factors, such as having someone in your family with breast cancer or having an inherited breast cancer gene mutation. The truth is the majority of women with breast cancer do not have these or other risk factors – their only risks are being a woman and getting older.[1]

The earlier breast cancer is found, the better the chances that treatment will work. At the Breast Care Center at Lovelace Women's Hospital, our goal is to find breast cancer before symptoms occur. Services at the Breast Care Center were recently expanded because we know that early detection tests for breast cancer can save many thousands of lives each year.[2] If breast cancer is found and diagnosed while still confined to the breast, the 5-year survival rate is more than 90 percent.[3]

While doctors search for better ways to fight breast cancer, there are currently three methods to detecting breast cancer early:

- **Mammogram:** Women age 40 and older should have a screening mammogram every year. While mammograms can miss some cancers, they are still a very good way to find breast cancer.
- **Clinical Breast Exam:** Beginning at age 20 women should have a breast exam by a health expert yearly.
- **Breast Self-Exam:** All women should do monthly self-exams to familiarize themselves with what is normal for their breasts. Although most breast lumps are not cancerous, a breast lump may be the only physical sign of breast cancer.

Remember that early detection is the best protection against breast cancer. At the Breast Care Center at Lovelace Women's Hospital, we are making it easier than ever for women to do just that. We are introducing a rapid response service so patients can find out the results of their mammograms, clinical breast exam and lifetime breast cancer risk assessment within 24 hours. In the event a patient needs additional tests, the Breast Care Center will also let the patient know within 24 hours.

In the next few months, the Breast Care Center will also be sending out two mobile mammography vans that will provide digital screening mammograms and educational services to communities and businesses around New Mexico.

While mammograms are a vital screening tool for breast cancer, we realize that it can be an uncomfortable experience. That is why the Breast Care Center has the only Mammography Department in Albuquerque to provide patients with a MammoPad during their screening. The MammoPad is a soft, warm breast cushion that is used during a mammogram to help patients relax which can often result in better images.

With these new resources, we hope that more New Mexico women will get screened for breast cancer. With our team of physicians including breast surgeons, radiation oncologists, medical oncologists, pathologists, diagnostic radiologists, reconstructive surgeons and a breast care navigator, we will guide each patient through every step of their treatment plan.

For information on how to schedule a mammogram, a clinical breast exam, to learn how to do a breast self-exam or for general breast health information and resources please contact the Breast Care Center at Lovelace Women's Hospital at 505-727-6900.

[1]Susan G. Komen for the Cure. Breast Health Learn the Facts. 2008. [2]www.cancer.org/docroot/CRI/content/CRI 22 3X How Is Breast Cancer Found
[3]American Cancer Society's Cancer Facts & Figures 2009-08-19

NMCCA Affiliate, People Living Through Cancer, Announces Charter with The Wellness Community

people living through cancer
the wellness community
Putting lives together.

People Living Through Cancer (PLTC) unites with The Wellness Community® (TWC) to become TWC's newest center, located in Albuquerque, New Mexico. More than 8,200 New Mexicans are expected to be diagnosed with cancer in 2009, and The Wellness Community – New Mexico will continue to provide support, education and hope to people living with cancer and their loved ones in this region of the United States.

The Wellness Community's programs are offered free of charge for people affected by cancer to learn vital skills that enable them to regain control, reduce isolation and restore hope, regardless of the stage of their disease. TWC provides these services at nearly 100 locations worldwide and online at www.thewellnesscommunity.org. The Wellness Community – NM will continue to be recognized as a source of innovation and inspiration for psychosocial programs, services and research within the oncology community, as well as throughout the communities of New Mexico. TWC – NM will also continue to maintain the largest collection of cancer-related information for patients and their families at the lending library where there are books for every member of the family.

"We are delighted to enhance our position as the source of hope for people living with cancer in New Mexico," said Bernadette J. Lujan, Executive Director. "TWC has an international reputation for being at the forefront of psychosocial services for survivors and caregivers which allows us to offer exceptional care to survivors in our state."

To participate in support groups or any of our other programs visit www.pltc.org or call 505 242-3263 to register.

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 ☐ $_____

I authorize the New Mexico Cancer Care Alliance to charge my gift to:

☐ VISA ☐ MasterCard

☐ American Express

Account #: _____

Expiration date: _____

Signature: _____

Name as it appears on card: _____

_____

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Combined Federal Campaign

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.

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.

Contact Debbie Putt at dputt@nmcca.org
Or write to: NMCCA, 801 University Blvd. SE, Suite 102, Albuquerque, NM 87106.

Don't Miss Out!

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

email Debbie Putt at dputt@nmcca.org
or register on-line at www.nmcca.org

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

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Any submissions can be sent to Debbie Putt, Communications and Outreach Manager
dputt@nmcca.org • Phone 505 272-7819 • Fax 505 272-7799

Editor: Debbie Putt
Medical Editors: Dennie Jones, MD & Claire Verschraegen, MD
Graphic Designer: Kathy Montoya, Montoya Creative

Recipe for Constipation

Mushroom Barley Soup

1 teaspoon minced garlic
1 onion, chopped
2 carrots, chopped
½ pound sliced mushrooms
1 cup shiitake mushrooms, sliced
1 (8-ounce) can tomato sauce
8 cups beef or vegetable broth
¾ cup medium pearl barley
Salt and pepper to taste

In a large pot, sauté the garlic, onion, carrot, and mushrooms until tender. Add tomato sauce and broth. Bring to a boil and add barley. Reduce heat, cover and cook for 1 hour or until barley is done. Makes 8 servings

Recipe for Sore Mouth or Throat

Creamed Double Potatoes

1 ¾ pounds baking potatoes
1 ¾ pounds sweet potatoes
3 tablespoons margarine
1/3 cup skim milk
2 tablespoons honey

In a large pot, boil both potatoes for 40 minutes or until tender. Peel potatoes and place in mixing bowl with the margarine, blend until smooth. Gradually add milk and honey, mix until creamy.

Source: Eating Well Through Cancer, Easy Recipes & Recommendations During & After Treatment, Holly Clegg & Gerald Miletello, M.D.

New Mexico Cancer Care Alliance

801 University Blvd., SE
Suite 102
Albuquerque, NM 87106