New Mexico Spring 2011 Cancer Care Alliance

COMMUNITY NEWSLETTER



Stefan Korec, M.D., Otero Oncology, P.C., Alamogordo

New Mexico Cancer Care Alliance Brings Clinical Trials to Southern New Mexico

The NMCCA has had a goal to expand access to clinical trials beyond the central Rio Grande Corridor for the past 2 years. Recently the Senior Leaders of NMCCA met with Stefan Korec, M.D. from Otero Oncology, P.C. in Alamogordo to discuss access to clinical trials in Southern New Mexico. It is with great excitement that NMCCA announces the addition of Otero Oncology P.C. to our network of research treatment centers. The commitment of Stefan Korec, M.D. to provide clinical trials to

his patients is commendable. NMCCA believes that all New Mexicans should receive the best cancer treatments. By the addition of Otero Oncology, P.C., access to new experimental research treatments, without the expense of leaving their communities, will become available to cancer patients in Alamogordo. Additionally, having family, friends and loved ones nearby during treatment greatly benefits patients. NMCCA will continue to work with the physicians in Southern New Mexico to include more communities in

New Mexico Passes Bill to Encourage Rural Oncologists to Conduct Cancer Research



Senator Timothy Z. Jennings

Due to the commitment and dedication of Senator Timothy Jennings, who sponsored Senate Bill 282, the "Tax Liability Credit for Certain Physicians" passed legislation in the New Mexico

2011 Regular Session. Senate Bill 282 provides a credit against personal income tax liabilities for physicians offering cancer treatment clinical trials in rural New

Mexico. The purpose of the cancer clinical trial tax credit is to encourage physicians in New Mexico to participate as clinical trial investigators. The tax credit will assist physicians in rural New Mexico to help establish the infrastructure in their office to participate as clinical trial investigators. The tax credit will be allowed for three years, beginning January 1, 2012, and ending on December 31, 2014. It is hoped that during this 3 year period the infrastructure can be established and a sustainable clinical trials program can be developed by the fourth year. An oncologist who is a physician licensed pursuant to the Medical Practice Act and

whose practice is located in rural New Mexico may claim, and the department may allow, a tax credit of \$1,000 for each patient participating in a cancer clinical trial under the taxpayer's supervision for a maximum credit allowed for all cancer clinical trials conducted by that taxpayer during the taxable year of \$4,000. Physicians who believe they are eligible for this tax credit should contact their tax consultant.

Senate Bill 282 is a significant accomplishment that will allow rural New Mexicans access to the same cancer treatments statewide.

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Understanding Clinical Trial Barriers

Clinical trials are research studies that involve people. These studies test new ways to prevent, detect, diagnose, or treat diseases. People who take part in cancer clinical trials have an opportunity to contribute to scientists' knowledge about cancer and to help in the development of improved cancer treatments. They also receive state-of-the-art care from cancer experts.

Potential benefits include

- health care provided by leading physicians in the field of cancer research
- access to new drugs and interventions before they are widely available
- close monitoring of your health care and any side effects
- · a more active role in your own health care
- if the approach being studied is found to be helpful, you may be among the first to benefit
- an opportunity to make a valuable contribution to cancer research

Potential risks include

- new drugs and procedures may have side effects or risks unknown to the doctors
- new drugs and procedures may be ineffective, or less effective, than current approaches
- even if a new approach has benefits, it may not work for you

Cancer clinical trials have brought enormous advances in the areas of cancer prevention, treatment and diagnosis. However, less than 5 percent of adults diagnosed with cancer each year will get treated through enrollment in a clinical trial. With broader enrollment, the effort to find new and better ways to treat and prevent cancer might be swifter.

It is important to understand the reasons why so few adults with cancer participate in clinical trials. A few are listed here.

Many people with cancer, or those at high risk for developing cancer, are:

- unaware of the option of participating in clinical trials
- unwilling to go against physician's advice or direction
- fearful, distrusting, or suspicious of research (Placebo, "guinea pig")
- · unaware of clinical trials
- concerned about potential costs of trials
- facing personal or practical obstacles
- language and/or literacy barriers may make it difficult for some people to understand and consider participating in clinical trials
- cultural or ethnic backgrounds may include values and beliefs that are very different from Western Medicine
- many people may face additional problems accessing clinical trials
- long-standing fear, apprehension, and skepticism in minority populations about medical research due to real abuses that have happened in the past (e.g., the legacy of the Tuskegee syphilis study)

Many doctors are:

- unaware of clinical trials
- unwilling to "lose control" of patient's care
- under the impression that standard therapy is best

New Mexico Cancer Care Alliance wants to help ease some of these barriers and inform the community about clinical trials through our HERO Educational Program. HERO is an acronym for Helping to Enhance Research in Oncology and was established to provide information to the public and medical staff about clinical trials. Our HERO education program focuses on raising the public's awareness and educating them about cancer clinical trials, what they are and are not, the possible benefits of participation, the mechanisms in place for patient safety, encouraging people to take an active role in their health care options, and recognizing cancer clinical trial participants. Through the HERO education program New Mexicans will have the knowledge to make informed decisions if they or a loved one are faced with a cancer diagnosis. They will have an understanding of clinical trials, how research is conducted in New Mexico. what clinical trials are available in New Mexico, and how research may lead to better cancer treatments. We need to test the best cancer prevention, detection, and treatment ideas in the shortest time possible, and this can only happen if more people participate in clinical trials.

Selected portions reprinted from "Cancer Clinical Trials: A Resource Guide for Outreach, Education, and Advocacy" National Cancer Institute.

http://www.cancer.gov/clinicaltrials/resources/outreach-education-advocacy

Prostate Cancer Support Association of NM Becomes an Affiliate

Prostate Cancer Support
Association of New Mexico was
founded in 1991 by Rae Shipp at his kitchen
table when he realized that he and other
men needed help with making decisions
about prostate cancer. From that start until
today, we have been providing education
and information to assist men and their
families in making informed decisions about
treatment and care. Other services that
we offer are bimonthly meetings, buddy
care, speakers' bureau, newsletter, Native

American outreach, lending library, and one-on-one counseling. Our services reach out to all New Mexican men.

We have also participated with the Prostate Cancer Research Program Summer Review Committee (PCRP) within the Congressionally Directed Medical Research Programs which is a part of Department of Defense U.S. Army Medical Research and Materiel over the past 3 years. We also had a representative participating in

the Oncologic Drugs Advisory Committee (ODAC) in the Center for Drug Evaluation and Research (CDER).

We are now proud to be a part of the New Mexico Cancer Care Alliance. We are looking forward to working together, sharing our information and supporting clinical research for prostate cancer in Albuquerque and the rest of New Mexico.

Joe Nai, Executive Director

Local Oncologists Bring Research Highlights to Albuquerque

The American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians who treat people with cancer. ASCO holds an annual meeting where oncology health care professionals gather to discuss the latest in cancer care. Thousands of scientific abstracts are released at this forum and the latest findings from cancer clinical trials are presented. NMCCA held its first annual advancement in research presented at the ASCO 2010 meeting. Local oncologists from New Mexico presented highlights from the ASCO Meeting to over 80 oncology health professionals from around the state. Some of the findings that were presented at the New Mexico Highlights included:

Breast Cancer

Older Women with Early Breast Cancer May Not Need Radiation Therapy

Research shows that some women age 70 or older with early-stage breast cancer may not need radiation therapy after lumpectomy if they receive tamoxifen (Nolvadex).

Removing More Lymph Nodes May Not Increase Survival for Women With **Breast Cancer**

Recent findings suggest that women with cancer in their sentinel lymph node and had additional underarm nodes removed did not live longer than women who had no additional lymph nodes removed.

Melanoma

Drug Improves Survival for Patients With Advanced Melanoma

Researchers found that patients with

advanced melanoma lived four months longer when they received the drug ipilimumab compared to patients who did not receive this drug.

Lymphoma

Maintenance Therapy with Rituximab Reduces Risk of Lymphoma Recurrence Research shows that patients with follicular lymphoma who received the drug rituximab (Rituxan) for two years as maintenance therapy were less likely to have return of cancer after treatment.

Non-Small Cell Lung Cancer New Drug Helps Manage Advanced Non-Small Cell Lung Cancer for Some **Patients**

Researchers found that crizotinib, a new drug, helped shrink the tumor in a small subset of patients with advanced lung cancer who have a specific genetic disposition.

Selenium Doesn't Prevent a Second Tumor for Patients with Non-Small Cell **Lung Cancer**

Several studies that look specifically at giving selenium to prevent cancer have not shown that it can prevent cancer.

Colon

Cetuximab Does Not Increase Survival for Some People With Operated Colon Cancer

A clinical trial showed that patients with stage III colon cancer and a normal KRAS gene who received the drug cetuximab (Erbitux) and standard chemotherapy did not live longer than patients who received only standard chemotherapy. In addition, patients who received cetuximab had more side effects. However, cetuximab remains helpful in patients with metastases.

Prostate

Combining Hormone and Radiation Therapies May Help Some with Prostate Cancer Live Longer

New research shows that men with locally advanced or high-risk prostate cancer who received hormone therapy combined with radiation therapy lived longer and were less likely to die from prostate cancer.

Head and Neck

Human Papillomavirus (HPV) Associated with Improved Response and Survival in Oropharyngeal Cancer.

The same virus that causes cervical cancer. HPV, is responsible for the current epidemic of oropharyngeal cancer. An analysis of banked tumors from two head and neck cancer radiation studies showed that HPV is responsible for an increasing proportion of oropharyngeal squamous cell carcinoma (cancer of the tonsil or base of tongue). HPV is associated with younger age, better performance status, smaller tumor size, and less tobacco exposure compared to head and neck cancer caused by tobacco and alcohol exposure. HPV positivity predicts improved response and survival.

Please note that although the above information is recent findings from research, each patient needs to consult with their personal physician to discuss their best treatment options.

Selected portions reprinted from ASCO Cancer Advances, ASCO Annual 2010 Meeting.

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, P.O. Box 4428, Albuquerque, NM 87196

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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6TH ANNUAL HERO RECOGNITION BREAKFAST RECOGNIZES CANCER PATIENTS

HERO is an acronym for "Helping to Enhance Research in Oncology (SM)" and NMCCA believes any person who participates in a cancer clinical trial is a HERO. These HEROs show courage by volunteering for a new experimental treatment that may offer hope and improvements in treatments for future generations.

On March 24, 2011, New Mexico Cancer Care Alliance honored these HEROs by hosting a recognition breakfast for patients that have participated on a cancer clinical trial. NMCCA recognized and thanked these cancer patients and their families for their participation. The keynote speaker, Selinza Mitchell, provided inspiration and hope through her "Fingerprints of a Survivor" tribute to these HEROs.

The breakfast also provided an opportunity to raise awareness of the importance of clinical trials to cancer research and advancing treatments, and the important role the HEROs play in advancing the treatment of cancer.



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Sarcoma?"Wait, what do I have?"

Unfortunately most patients confronted with this diagnosis have never heard of it before. While almost 200,000 women are diagnosed with breast cancer annually, sarcomas make up less than 1% of adult tumors. In fact, only 12,000 cases of sarcoma are diagnosed annually in the United States. Sarcomas are cancerous tumors that occur in tissues connecting or lining other structures or organs of the body, such as muscles, bones, fat, or tendons. There are over 50 different types. They can arise in the bone (osteosarcoma (bone), Ewing sarcoma (bone), chondrosarcoma (cartilage)) or in the soft tissues (rhabdomyosarcoma (muscle), liposarcoma (fat), leiomyosarcoma (smooth muscles),



Claire Verschraegen, M.D. University of New Mexico Cancer Center



Sujana Movva, M.D. University of New Mexico Cancer Center Fellow

angiosarcoma (vessels), and peripheral nerve sheath tumors (nerves)), and are generally named based on the adult tissue they resemble. Some sarcomas are more common in children and teenagers, such as osteosarcoma and Ewing sarcoma. The most common types of sarcoma in adults include gastrointestinal stromal tumors (GIST) - a sarcoma which arises usually in the wall of the bowel - and leiomyosarcomas or liposarcomas. The majority of these tumors occur in the extremities, but they can also occur in the abdominal cavity and more rarely in the chest, or in the head and neck region. The reason why some people develop sarcomas and some don't is still unclear. Risk factors include a rare genetic propensity, or exposure to certain chemicals or radiation. In most sarcoma, a chromosome anomaly is found, also called a translocation. This DNA rearrangement is the source of abnormal proteins that drives the cancer to grow.

Soft tissue sarcomas often present as a lump or mass in the extremities. If they occur in the abdomen they may cause pain and change in bowel or bladder function as they tend to compress rather than invade surrounding organs as they grow. If your doctor suspects that you have a sarcoma, you will be sent for a biopsy in order to prove the diagnosis, and to find out what type of sarcoma you have. You will also likely have imaging such as x-rays, computerized tomography (CT) scans, magnetic resonance imaging (MRI), or positron emission tomography (PET) scans to help stage your tumor. Staging refers to determining how extensively the tumor has spread in your body.

There are over 50 different types of sarcomas, making it difficult to establish uniform treatment guidelines. Important prognostic factors are grade (the degree of malignancy), type of sarcoma, stage (extent of disease) and location. Patients who present with a small, low grade tumor can usually be managed with surgical treatment alone. These patients are often considered curable. Patients with large or high grade tumors, require a multidisciplinary approach involving surgeons, medical oncologists, and radiation oncologists. These patients may require radiation and/or chemotherapy before or after surgery to help decrease the size of the tumor or to decrease the likelihood of the cancer returning. When disease has spread elsewhere in the body (metastasized) or has returned, chemotherapy is generally the preferred treatment. The most common site for a sarcoma to metastasize to is the lungs. Chemotherapy for sarcoma is usually given intravenously and either as an inpatient or outpatient. Survival in this group of patients is poor, approximately one year, and has not changed significantly in the last two decades. Therefore it is imperative that clinical trial funding and participation continues.

Some sarcomas have unique genetic changes that not only help identify them, but may have implications for treatment. These genetic changes produce abnormal proteins that drive cancer growth. There are now some specific drugs targeting these abnormal proteins. An example of this is the use of imatinib (Gleevec®), which is administered by mouth, in the treatment of GIST. These tumors arise in the wall of the gut - in the interstitial cell of Cajal- and are resistant to classical chemotherapy. A series of discoveries showing that mutations in a gene called c-KIT are responsible for the majority of GIST, and that imatinib is a small molecular inhibitor of KIT, have radically changed the treatment of these tumors and offered a dramatic improvement in survival for these patients. Unfortunately, for most sarcomas, there is no available targeted drug, even when the cancer driving protein is known.

Three new therapies that are showing promise in sarcoma are trabectedin,

Sarcoma? "Wait, what do I have?" continued from page 5

palifosfamide, and ridaforolimus. All 3 drugs have been or are in testing phases through the New Mexico Cancer Care Alliance (NMCCA). Palifosfamide is a sister drug of the traditional chemotherapy agent, ifosfamide, widely used for the treatment of sarcoma. In a recent clinical trial, palifosfamide was shown to have good clinical activity in patients with metastatic sarcoma, without the traditional side effects of ifosfamide such as bloody urine, confusion, and kidney complications. Another chemotherapy agent trabectedin (Yondelis®) is approved in Europe for the treatment of sarcoma in the metastatic setting after failure of first line chemotherapy. This is a marine-derived cancer agent. There is data to suggest that this drug is especially active in patients with liposarcomas and leiomyosarcomas, once again demonstrating that not all sarcomas are the same. Ridaforolimus is a biological treatment that inhibits a cellular mechanism called m-TOR. This drug was tested as a maintenance treatment for patients with advanced sarcoma. The final results of the study are not yet available, but preliminary data have been encouraging. In the future,

each sarcoma will have a specific treatment strategy, which should hopefully improve the prognosis and outcome of the disease.

Advice for Patients

- 1. Know exactly what type of sarcoma you have. This may require additional testing.
- 2. Consider enrollment in a clinical trial as this is the only way to help find a cure for sarcoma.
- 3. Consider treatment by a physician with expertise in this rare disease.

Patient Resources:

- 1. Sarcoma Foundation of America: www.curesarcoma.org
- 2. SARC: Sarcoma Alliance Collaboration: Research through http://www.sarctrials.org/public/pag1.
- National Cancer Institute Clinical Trials: http://www.cancer.gov/clinicaltrials
- For questions about clinical trials at the NMCCA, please visit: www.nmcca.org

Paddle for the Cure Crew

On July 10th, 2010 the 2nd Annual Paddle for the Cure tour of Elephant Butte Lake occurred. This year saw an increase in the number of paddle boats and donations (\$1600 last year increased to \$1860 this year). Fun was had by everyone as the 3 ½ hour tour took participants from Rock Canyon Marina north to the Dam Marina where a barbecue occurred on a small armada of boats. This year's donations were given by... Premier Towing, Bob Jones State Farm Ins. Hansen & Prezzano

2nd Annual Paddle for the **Cure is a Great** Success!

Builders, Cre8play LLC, Business Environments, Brett & Cassie Boning, PlaySafe LLC, Starnes Family, DeFillippo Family, Madrid Family, Sanchez Family, Jason Coulthurst, Terry & Mary Boning, Playwell Group, Deborah & Erik Bose, Goldberg Family, Venetia Fazio, Jo & Cameron Cunningham. Natalie Garza, Kris & Shanna Platow. A special thanks to Sew Special and Dam Site Resort for the donation of paddle boats.

The 3rd Annual Paddle for the Cure is scheduled for July 9th, 2011. Challenge vourself, help raise money for cancer research, and have fun at next year's event by calling Cassie Boning at 505-410-1197.

Advanced Sarcoma Protocols Available Through NMCCA

A Randomized, Multicenter, Phase III. Trial of Trabectedin (Yondelis®) versus Doxorubicin-based Chemotherapy as First-Line Therapy in Patients with Translocation-Related Sarcomas (TRS)

Phase I/II Study of Irinotecan and Temsirolimus in Patients with Refractory Sarcomas

A Phase III Multicenter, International. Randomized, Double-blind, Placebocontrolled Study of Doxorubicin plus Palifosfamide-tris vs. Doxorubicin plus Placebo in Patients with Front-line Metastatic Soft Tissue Sarcoma: the PICASSO III Study

NMCCA Welcomes New Board Members and Participants

NMCCA Board of Directors

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NMCCA looks forward to working with these new participants and board members and to the expertise they bring to the organization

CLINICAL TRIALS: Something to Consider

By George Edwards

Last winter started out like most winters. I travel a lot for my work as a professional geologist. As a result, occasionally I get a chest cold from breathing the same air as my fellow passengers on the airplane. In January 2010, I had a cold that wasn't getting better, so I went to a local clinic.

They diagnosed me as having bronchitis and prescribed antibiotics. By March, I still felt sick and saw my primary care physician. She did an exam and noted that there was little airflow in my lower left lung. Her thought was that because of my work, I was exposed to "valley fever" (coccidioidomycosis), which is endemic in Arizona and common in other parts of the southwest United States.

Laboratory tests showed that I didn't have valley fever. X-rays showed a mass in my lung. The initial radiology reports interpreted that mass as an infection and recommended draining through my chest. Not liking medical procedures, that wasn't something that I wanted to hear.

The mass in my lung was biopsied and the pathology report concluded that I had a rare type of cancer called synovial sarcoma. A quick look on the Internet suggested that the survival rates were low and there were limited treatment options. Treatment options included surgery, radiation, and standard chemotherapy drugs. Things just looked worse every day. I gave up looking on the Internet, as it was just too depressing.

At my first visit with my oncologist at the University of New Mexico Cancer Center, we agreed that aggressive treatment was necessary for my aggressive disease. Things started to look a lot better when my oncologist told me that a clinical trial for a drug that would treat my rare disease was starting that very day!

As geologists, we are trained to evaluate situations that have little data available, and

draw conclusions from what information we have. This turned out to be a valuable skill for deciding whether to sign up for the clinical trial. I went back on the Internet at the UNM Library and found that the clinical trial drug was being used in many parts of the world, except for the United States.

> The medical journal papers that I read concluded that the trial drug was more effective that the "standard" treatment for synovial sarcoma. I felt that this was my first and best chance to treat my cancer.

However, the requirements to take part in the clinical trial were stringent.



George continues his daily chores while on a clinical trial.

Patients couldn't have been previously treated for cancer, nor could they have any secondary cancers. Even if I was accepted into the clinical trial, there was a 50% chance of getting the study drug because patients were randomly assigned to one "arm" (medicinal jargon for group). The other option was to get the standard chemotherapy. At that point, 50% seemed like pretty good odds! I spent many days at the hospital getting blood tests, heart function tests, CT scans, PET scans, and a MRI scan. The test results were favorable and I crossed my fingers and waited to hear if I was accepted into the clinical trial.

Good news! I was accepted into the clinical trial and even better, was assigned to the study drug arm. In my case, I knew which drug I was getting because they were administered differently with the study drug infused over 24 hours and the standard drug infused over 48 hours. The clinical trial also requires weekly blood tests, doctor visits after each round of chemotherapy, and CT scans after every two rounds of chemotherapy. This didn't seem like a lot of extra work compared to not being in a clinical trial.

I am still getting chemotherapy as part of the clinical trial, so it will be a while before we know if the study drug was effective. Nevertheless, I think it was the right decision in my case. But would it be the right decision for someone else? I think it depends on the type of cancer and the type of trial.

If I had a common type of cancer that had a good treatment success with existing drugs, I would be less likely to enroll in a clinical trial than compared with a cancer that had poor treatment success. Also, the clinical trial design would matter. In my case, both drugs were known, which was a positive consideration. If the trial were "blinded" (the study participants do not know which treatment was given), I'd be less likely to participate.

Another consideration is our social responsibility to help science find new drugs. "Pay it forward," if you will. Think about all the drugs that we commonly use. Somebody had to participate in clinical trials before those drugs were legally available in the U.S. For example, as a child in the 1960s I had asthma and had to go to the emergency room for an epinephrine shot every time I had an asthma attack. That treatment continued until the 1980s when inhalers became widely available.

We are fortunate to have research trials being conducted in New Mexico and not having to go out of state. Also, the Internet can be a great resource for doing research on the trials, compared with the "old days" where I would drive for more than an hour to get to the UNM Library with a pocket full of quarters to photocopy articles. To find out more about clinical trials, ask your oncologist or visit http://www.clinicaltrials. gov.

In closing, I'd recommend seriously considering participating in a clinical trial if offered by your oncologist. Your choice is going to depend on what type of cancer you have and the type of clinical trial offered. It takes courage to participate in clinical trials, but they can be a gift worth considering.

2010 NMCCA Annual Meeting

New Mexico Cancer Care Alliance held its eighth annual meeting on October 14, 2010 that brought together many of NMCCA's participants and affiliates. NMCCA has had an exciting year. The NMCCA sites accrued 542 patients onto cancer trials last year. This

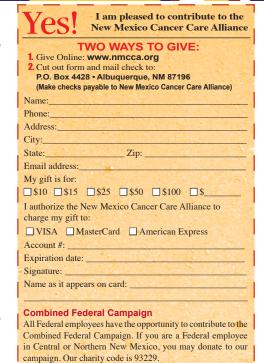


NMCCA STAFF
From left to right:

Martha Howell, Linda Kondziolka, Andrea Yost, Meghan Solwick, Kathy Anderson, Tammy Seaman, Ruby Allen, and Debbie Putt brings the total of patients helped by NMCCA since inception in the fall of 2003 to over 1494.

The Cancer Center at Presbyterian and New Mexico Cancer Care Associates were presented with special awards for the community sites with the most MBCCOP accruals. UNM Cancer Center was recognized as the NMCCA site with the most accruals. Dr. Claire Verschraegen with the UNM Cancer Center received the award for enrolling the most patients on clinical trials. The community site physician with the most accruals was Dr. Karen LoRusso, oncologist with New Mexico Cancer Care Associates located in Santa Fe.

This past year, NMCCA successfully added affiliate participants Ovarian Cancer Together from Los Alamos, NM and the Prostate Cancer Support Association of New Mexico.



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.



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