



AZMN News

Arizona Myeloma Network
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Vol. 2, No. 5 ■ November/December 2008

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The Newsletter for People Interested in Multiple Myeloma

WISHING YOU ALL A HAPPY AND HEALTHY NEW YEAR!

From the President ... Barbara Kavanagh

2008 has been an amazing year for AzMN! So many important new Partnerships, Projects, and People have become part of our Arizona Myeloma Network. Our 2nd Living with Myeloma conference at the Scottsdale Conference Center brought together over 100 myeloma patients, families, researchers, and healthcare professionals, as well as new sponsors from Foundations, pharmaceuticals, and local businesses. We also held the 1st AzMN/Ft. Defiance Cancer Awareness and Advocacy Conference for the Navajo Nation, October 11th, 2008, with over 260 people attending from Arizona, Utah, and New Mexico. We collaborated with a wide range of cancer resources and organizations, including the Leukemia Lymphoma Society, TGEN, Mayo Clinic, Scottsdale Healthcare, the John Wayne Cancer Foundation, the Southwest American Indian Collaborative, and many others.



It has been a year of increased Awareness about myeloma. We were featured in the Arizona Republic, the Glendale News, the Navajo Times, and the Phoenix Business Journal. We received calls and emails from dozens of patients and family members throughout Arizona and other parts of the U.S. to learn more about AzMN. Our annual Dbacks Baseball Game and Charity Corner, was fun and another chance to share information about myeloma. We also participated in the AZ Cancer Coalition Advocacy Conference in Phoenix and in Tucson in November.

Thanks to all of you in this Holiday Season. Though we are all facing many challenges, I know that we will be strong and support one another as we have always done. And, if you can contribute 'time' as a volunteer or make a donation of any amount, we would be very grateful.

Best wishes!
Barbara



www.azmyelomanetwork.org/donation.html



4th Annual AzMN 2008 Charity Golf Tournament November 7th Is Best Ever!

Tournament Sponsor, the Black Bear Diners of Arizona, raised over \$6,000 from their October 14th Spaghetti Supper in all 6 restaurants and the Black Bear Raffle for the month of October. They also brought dozens of golfers and prizes to help make this year's tournament our largest and most profitable fund raising event in 4 years.

We had 135 golfers, 'diners', sponsors, and friends of AzMN participate. We were so pleased to have Mike, Lewis, and other new myeloma patients and friends of AzMN join us, as well as Ted, who recently celebrated his 1st year since his transplant by playing golf with his 4some. They are all winners!

Special thanks to Bruce Jacobs, our friend and celebrity host from KFYL, who auctioned himself 'off' to 3 golfers for a total of \$1750!

We had a great team of golf committee volunteers this year and you can 'meet' them on our website as well as view the photos by our volunteer photographer, Luis Alfonso, who will print your photos and donate 25% to AzMN. He also can provide you with wonderful Holiday and Special Occasion photos at a special rate. See our website for details.

Also, our thanks to Ron Baker, our golf event manager, who led our AzMN team.

Special thanks to our sponsors: **Tournament Sponsor:** Black Bear Diners, **Platinum Sponsors:** Arizona Orthopedic & Fracture Surgeons and Bowne Company, **Gold Sponsor:** Farmer Brothers, **Golf Prize Sponsor:** Black Bear Diners, **Drink Cart Sponsor:** Arrowhead Community Bank, **Goody Bag Sponsor:** Delta Dental of Arizona Foundation, **Lunch Sponsor:** Credit Union West, **Hole Sign Sponsor:** Bell Signs, **Program Sponsor:** UPS Store 5320.

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Uncle Sal's Restaurant
UPS Store 5320
Van's Chevrolet



Black Bear Diner Team



Bruce Jacobs Celebrity Team

Ask the Doctor

Dr. Joseph Mikhael newly associated with Mayo Clinic, has graciously offered to provide an informative column for our bi-monthly newsletter and will respond confidentially, to your questions to him via email.

Participating in Clinical Trials



Your physician may ask you to consider participating in a clinical trial for treatment of your myeloma. This can often be confusing to patients as they may have unrealistic expectations of the trial, or may also feel like a “guinea pig” for medical research. Very often it is the only way to have access to newer drugs that can benefit your condition and additionally provide critical information to help others. However, they do come with potential risks, so it is important to be fully informed about a trial so that you can make the best decision for you. This brief article is meant to introduce you to the concept of clinical trials and key things to know when potentially participating.

Types of Clinical Trials

In essence, clinical trials are biomedical or health-related research studies in human beings that follow a pre-defined protocol. I will focus on “treatment” trials. Trials tend to be conducted in phases:

In Phase I trials, researchers test an experimental drug or treatment in a small group of people (20-80) for the first time to evaluate its safety, determine a safe dosage range, and identify side effects.

In Phase II trials, the experimental study drug or treatment is given to a larger group of people (100-300) to see if it is effective and to further evaluate its safety.

In Phase III trials, the experimental study drug or treatment is given to large groups of people (1,000-3,000) to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the experimental drug or treatment to be used safely.

In Phase IV trials, post marketing studies delineate additional information including the drug's risks, benefits, and optimal use.

Why me?

Clinical trials define very clearly who is “eligible” for a trial based on the patient and the disease they have (inclusion and exclusion criteria). If you are eligible, there are many potential benefits and risks:

Benefits

Clinical trials that are well-designed and well-executed are the best approach for eligible participants to:

- Play an active role in their own health care.
- Gain access to new research treatments before they are widely available.
- Obtain expert medical care at leading health care facilities during the trial.

Risks

There are risks to clinical trials.

- There may be unpleasant, serious or even life-threatening side effects to experimental treatment.
- The experimental treatment may not be effective for the participant.
- The protocol may require more of their time and attention than would a non-protocol treatment, including trips to the study site, more treatments, hospital stays or complex dosage requirements.

Ask the Doctor (continued)

It is critical, therefore, that you discuss in detail with your physician what are the likely benefits and risks of the trial you may be start.

Be Informed

You will not be started on a clinical trial without written “informed consent” – this means that you must be well informed about the trial and choose to be on it. You can always withdraw by your choice – or at times you are withdrawn due to lack of effect or side effects.

Your Safety is Important

All clinical trials in the US must be reviewed by an Institutional Review Board, and all drugs used must be approved by the FDA. Furthermore, with so much medical research, only the most promising new agents are being used, especially in multiple myeloma.

Conclusion

Much more can be said about clinical trials, but it is important to remember that they have so contributed to the improvement in prognosis for patients in multiple myeloma. The future is brighter in myeloma than it has ever been, as there are an unprecedented number of clinical trials available to patients. Find out if there is one for you!

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Arizona Myeloma Network

You are cordially invited

to join us for the

3rd Annual

Living with Myeloma Conference

SAVE THIS DATE!

Saturday, March 28, 2009

8:30 a.m. - 4:30 p.m.

Scottsdale Conference Center

7700 E McCormick Pkwy

Scottsdale, AZ 85258

480-991-9000

Speakers include: Dr. John Carpten, keynote speaker on the TGEN Research and outreach to the underserved; Dr. Joseph Mikhael, Mayo on new developments in Myeloma Research, American Society of Hematology Report; other myeloma specialists from Huntsman Cancer Institute, Cancer Treatment Centers of America, Banner/City of Hope, and other myeloma and cancer leaders from Arizona, Utah, Nevada and other Southwestern and Western States. The Conference is now Regional, will offer CEU's, and is open to all patients and families, friends, caregivers, cancer researchers, and community physicians and healthcare professionals.

More information will be available soon.

Continental breakfast and a hot lunch will be provided.
Registration will be available online after January 1, 2009
You may also visit our web site at <http://www.azmyelomanetwork.org>.

AzMN is a nonprofit charity organization that conducts Outreach Events and Educational Programs for Arizona Myeloma cancer patients, their families and caregivers, with special consideration for the underserved African American, Asian/Pacific, Hispanic American and Native American.

Barbara Kavanagh, Founder, President
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