

Message from the President - Barbara B. Kavanagh

It has been a busy and challenging few months since our 2nd Living with Myeloma Conference on March 29th. We have had so much interest in our work on behalf of myeloma patients and have been invited by a number of other cancer groups to 'share' our ideas and our programs. We would love to help all cancer patients, with additional programs and resources, but without funding, our small volunteer staff is 'stretched' and 'stressed'.

We need your help! The AzMN Diamondbacks Charity Baseball event on Labor Day, Monday, September 1st, is your chance to have a great afternoon and 'cheer' for the Dbacks and AzMN, and raise much needed \$\$ for AzMN.

We are fortunate to have the support of our 'Community Partners', the Black Bear Diners. They are selling baseball tickets at all of their restaurants. Or, you can contact AzMN for tickets (additional details on our website.) Please buy tickets for yourself, friends, family business associates, even if you aren't able to come to the game. Your donations of any amount really make a difference! As you will read in the 'patient' stories, AzMN is already providing a 'network' of resources and information that is much needed in Arizona. And, through the awards we are receiving, we are building greater understanding and more interest in myeloma research.

And, don't forget our 4th Annual AzMN charity Golf Tournament on Friday, November 7th. Sign up early and you are eligible for special prizes! We need golfers, sponsors, and volunteers. All golf and raffle prizes, Auction packages, and other donations are welcome. You can help make our golf event a success, and help us raise the funds we need to continue our important education, awareness, and advocacy programs.

Thanks and see you at the Ballgame! Barbara

Thanks to Black Bear Diners for your support!

Help Strike out Cancer!



The Diamondbacks' Charity Corner will feature Arizona Myeloma Network (AzMN) for the

St. Louis Cardinals' Game at Chase Field
 Labor Day, September 1, 2008 at 1:10pm

Join our Cancer Fighting Team and Cheer for
 AzMN and the Diamondbacks!



Game tickets are available for a suggested minimum
 \$10 donation for two tickets at any of the four Arizona

Black Bear Diner Locations

(Phoenix, Glendale, Gilbert or Goodyear) or call 623-388-6837

More information is also available at www.azmyelomanetwork.org

Details and Black Bear locations can be found on the Black Bear Diner website: www.blackbeardiner.com. Proceeds from the baseball tickets will fund free educational programs provided for myeloma patients and families.

4th Annual Charity Golf Tournament



You are also invited to participate in AzMN's 4th Annual Charity Golf Tournament on November 7, 2008, at Orange Tree Golf Course. Honorary Chairman will be Ray Romano and Celebrity Host will be Bruce Jacobs of KFYI Radio. Sponsorships and golf registrations are available on the AzMN web site: www.azmyelomanetwork.org or call Ron Baker - 623-266-2045 or Barbara Kavanagh - 623-388-6837.

You Can Help With the Golf Tournament!

We need the following:

- ✓ Volunteers
- ✓ Sponsors
- ✓ Golfers
- ✓ Raffle and Auction items

Donations (PayPal, credit card or check)

We are a 501(c)(3) nonprofit organization.



Jazz Benefit for Mike Howard

Mike and Debi Howard's Jazz Benefit at West Valley Museum, June 13th was a great success and raised money and awareness for myeloma and for Mike's myeloma treatment. Read their important story on our website.

AzMN IN THE NEWS!



Barbara Kavanagh is the Arizona Rural Health Association's "Distinguished Martha Ortiz Volunteer of Year." She accepted the award on August 5th, in Flagstaff. Fred Hubbard, Director of the Advisory Council of Indian Health Care, presented the award and was joined by T. Lon Owen, PhD,

Professor of Biological Sciences at Northern Arizona University.

Barbara Kavanagh is one of 31 finalists for the 12 Phoenix Business Journal's *Health Care Heroes for 2008*. She is one of two finalists in the category of Education. [Click here to see the article.](#)

Barbara and Jack Kavanagh were interviewed for an article in the Arizona Republic on June 20 in the Valley and State section. [Click here to see the picture and article.](#)

Ft. Defiance Cancer Conference

AzMN is proud to present the 1st Annual Ft. Defiance Navajo Cancer Awareness and Advocacy Conference on Saturday, October 11th, 2008 at the Navajo Museum, Window Rock, AZ. The AzMN/Ft. Defiance Cancer Awareness and Advocacy Conference is a collaboration of the Ft. Defiance Hospital staff and the Navajo community working with cancer patients and families, health care providers, cancer advocates, outreach workers, medical and nursing students, educators, researchers, Tribal officials, and others concerned about cancer at Ft. Defiance and the Navajo Nation.

If you are interested in helping or for more information, contact us at 623-388-6837. More details will be in our September newsletter.

Ask the Doctor

AzMN is pleased to welcome Dr. Joseph Mikhael to Arizona, and to our myeloma community. He has graciously offered to provide an informative column for our bi-monthly newsletter, and will respond confidentially, to your questions to him via email.



I have recently joined the Myeloma Team here at Mayo, as of February 2008. I was previously at the Princess Margaret Hospital in Toronto, Canada, where I had been a myeloma physician for 6 years. I attended Medical School at the University of Ottawa, completed my Internal Medicine residency in

Ottawa, then completed my Hematology training at the University of Toronto. I have a Masters Degree in Education, and a 2 year Multiple Myeloma Fellowship at the Princess Margaret Hospital, working closely with Dr. Keith Stewart.

At the completion of my Myeloma Fellowship, I became an attending physician working primarily in MGUS, Myeloma, Amyloidosis and Waldenstroms Macroglobulinemia. My research interests included relapsed myeloma, MGUS, amyloidosis and education.

I decided to join the group at Mayo for many reasons. Mayo is truly the world leader in Multiple Myeloma, and having the opportunity to work with that team is a privilege. The work at all three campuses of Mayo (Rochester, Scottsdale and Jacksonville) is respected world-wide. I was particularly interested in the group here in Arizona because I believe this program here is growing and has limitless potential (not to mention better weather than Minnesota!). I work very closely with Drs. Fonseca, Stewart and Bergsagel, both in patient care and research. I have the privilege of being the principal investigator on several trials, especially in relapsed myeloma.

I also have a role to play in education as the Vice Chair of Education for the Division of Hematology-Oncology. I direct the fellowship program for trainees in hematology-oncology and have a goal of expanding education in myeloma to physicians, other allied health staff, patients, and the community.

I am delighted to be here in Arizona working at the Mayo Clinic. I look forward to a close relationship with AzMN and the Myeloma community. I hope to be a resource to you, and look forward to working with you. I can be reached through AzMN, or directly by email: mikhael.joseph@mayo.edu.

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For a list of current clinical trials, see the AzMN web site: www.azmyelomanetwork.org

One Patient's Story ... by Mickey Gulli

My incredible husband, Nick, never complains. When asked, he is always "Fan-tastic!!!" So last November when he began complaining about significant pain in his right shoulder that began radiating down his arm, I knew that it was not something to be ignored.

Our first stop was to see a chiropractor. He had two manipulations and the pain escalated. Then we were off to see his primary care physician. X-rays indicated that it could be bursitis. The concern was that the discomfort was too intense to be bursitis. The next test was a dopler to check for a blood clot. For weeks the findings were inconclusive. After numerous blood tests, more X-rays and a PET scan the next step was for a CT scan.

I was alarmed when his doctor called personally just two hours after the CT. She began to explain the results and when she said the word cancer I could hear myself gasp. Nick had metastatic lesions on C5 and C6 of the upper spine and his spinal column was being compressed by a tumor. We were then scheduled to see a neurosurgeon. He would need to do surgery to remove the tumor and to replace the bones with plastic pieces similar to Lego's. Pathology determined the tumor to be a plasmacytoma and Nick was given a diagnosis of multiple myeloma. He would require radiation therapy to kill the remainder of the tumor cells.

At that point we met with an oncologist. Nick had a bone marrow biopsy that indicated there were 18% malignant plasma cells. The oncologist suggested a "wait and see" stance and set an appointment for us to return in three months. To us, even 1% sounded like too much. We opted for a second opinion. We met with another physician in the practice. This doctor diagnosed Nick with a rare and aggressive type of myeloma that comprised only 2% of all myeloma patients. She contacted the radiologist personally to discuss intensifying each radiation session to lessen the duration of treatments so that chemotherapy could begin as soon as possible.

As a manager of psychiatric offices for twenty years, I knew firsthand the benefit of counseling in a crisis. We were facing a medical crisis in our lives that I never imagined. Because we were going to Sun City daily for Nick's treatments, I called Banner Thunderbird Hospital which is close to our home, in the hopes of finding a support group for caregivers. I spoke with a social worker and she offered complimentary one on one sessions. The time we shared was extremely helpful to me.

We have learned a lot on this journey: you have to follow your gut feelings, even when they differ from a physician's recommendation; it is necessary to ask questions and repeat the questions if you don't understand the answer; there is a considerable amount of financial and emotional help in the community, the difficulty is knowing where it is and how to access it.

Editor's Note: *Victor Carrasco of LLS passed along this information for patients: To obtain an application for the Patient Financial Aid Program please call Victor Carrasco, Patient Services Manager at 602-788-8622 x13 or via email at victor.carrasco@lls.org. To obtain an application for more information on the Co-Pay Assistance Program, call the LLS Home Office at (877) 557-2672 or via email at copay@lls.org.*