



Cancer Caregiver News

by Arizona Myeloma Network®, AzMN

Issue: Spring 2019

Awareness. Education. Advocacy.

Cancer CareGiversAz®
Educating Cancer CareGivers for their wellbeing & improved patient outcomes



A note from the Founder...

Dear Friends:

I hope that you are enjoying our 'brief' but lovely Spring weather! Jack and I celebrated our 'joint' Easter and Passover Holiday with me in my Easter Bonnet. And my favorite spring flowers, tulips...memories of Holland.

Taking 'time out' to enjoy your family time and your own interests and hobbies are an important part of coping with cancer. Many patients and families spend much of their life and 'time' at doctor's appointments. Or 'waiting' for results on labs, exams, and trying to balance their needs, their children, filling in insurance forms, and job demands. In the months of May and June, there will be 'graduations', possibly weddings, and plans for summer vacations. And, of course, baseball games, which are Jack's favorites! We hope that you will be sharing some of these happy occasions or just create your own Celebrations or 'Staycations'. Arizona has lovely lakes and mountains as well as a Waterpark and Aquarium.

In our newsletter, we are focusing on information and resources that can 'help' you with cancer questions and issues. Our Spring Newsletter Welcomes Dr. Sumit Madan to our 'Guest Column' and to Arizona! We are featuring a summary of his recent presentation at the Phoenix Myeloma Support group.

Our Fall issue will feature a cancer caregiver's 'story'. We invite you to send us your story of how you, the 'CareGiver' has coped with your loved one's cancer diagnosis and treatment. Our limit is 500 words. All your stories are important to us, so even if your story isn't selected for the Fall newsletter, your story may be included in my Book and/or on our website. Please also include a photo of you, your family and/or your pet!

We are also posting on our website and in our newsletter, our donation link and additional opportunities to participate and support 'our' Book: "Living with Myeloma, a CareGivers Journey®". A Guide for all cancer patients, families, and healthcare professionals.

Read about the latest myeloma clinical trials in the March 2019 Conquer Magazine Article featuring Barbara Kavanagh, representing myeloma patients and caregivers at:

https://azmyelomanetwork.org/wp-content/uploads/2019/05/Conquer-Magazine_022519.pdf

Looking forward to hearing from you all and wishing you a pleasant Spring and Summer season.

And, be sure to visit our Amazon Smile link to do your Father's Day and other special occasion shopping.

<http://smile.amazon.com/ch/32-0169742>

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You shop. Amazon gives.

Fondly,
Barbara and Jack Kavanagh



AzMN's May/June AARP Blog:
<https://states.aarp.org/colorado/cancer-caregiving-journey-living-with-myeloma-a-caregivers-journey>

Multiple Myeloma: Addressing the Right Questions with Your Oncologist

Guest Column



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Multiple myeloma is a cancer of plasma cells, a type of white blood cells that reside in the bone marrow. Patients with myeloma may experience one or more of the following: anemia, bone disease/bone pain, kidney problems, elevated calcium levels. Often, myeloma may present itself with fatigue, generalized weakness, bone pain, spontaneous or non-traumatic fractures, recurrent infections. In the US, more than 30,000 new cases of myeloma are diagnosed each year, and approximately 180,000 patients are living with this condition. Although, there is no cure for multiple myeloma, with proper treatment and supportive care, patients can go into remission for prolonged periods and enjoy a good quality of life.

You can feel empowered and improve your outcomes by learning more about myeloma. Here are some questions you should ask your oncologist:

1. How many patients with myeloma do you treat each year?

Myeloma is a rare cancer. General oncologists may only see a few patients. It's best to seek a myeloma specialist.

2. What is my stage at diagnosis?

Knowing your risk profile will identify your treatment options and outcomes.

3. How will you follow my disease for response or for disease recurrence?

Specialized measurements taken of blood and urine proteins track the progress and recurrence of the disease.

4. What therapy/treatment plan should I follow?

Although treatment options must be individualized, the treatment considered for most patients involves 3 drug regimens.

5. Am I a candidate for a stem cell transplant? Why or why not?

Statistically, only about 30% of myeloma patients undergo this procedure. Eligibility varies. Referral to a transplant center should be considered for all patients with myeloma.

6. Am I on the appropriate drugs for management of bone disease and other supportive care medications?

Bone strengthening agents should be considered for all myeloma patients.

7. What is the planned next line of treatment when the patient relapses?

Since there are a number of options approved to treat recurrent disease, talking with your myeloma specialist will help determine the best approach.

8. Should "I" participate in a clinical trial for myeloma patients?

At any stage of myeloma, a clinical trial can be a high-quality treatment option.

Recent strides in diagnostics, treatments and research offer reason for encouragement. There is no right or wrong time to ask for a second opinion – you can ask for advice at any point. If you would like an expert opinion on your myeloma or more information on a clinical trial, you can reach me at the contact information listed at the top of this article.

Read the entire article and the full text of Dr. Madan's responses at:
https://cancercaregiversaz.com/wp-content/uploads/2019/05/Sumit-Madan-MD_Guest-Column_May-2019.pdf

A Busy Spring for AzMN Out in the Community!



AzMN Board Members and honored Attendees at the AzMN Celebration Reception - April 17, 2019

Thank you to Perkins Coie Law Offices for hosting the Celebration of our 28th Anniversary of Jack's diagnosis and our marriage. Thank you to the AzMN Board and other guests for their attendance at this event. Special thanks to Kurt Riske and Los Sombreros restaurant for catering. Also, our appreciation to Chris Libby with N2Publishing for featuring AzMN & Cancer CareGivers AZ in the June 2019 issue of Life Around the Lakes Magazine. The article can be read on our website: www.azmyelomanetwork.org



Mayo Clinic Symposium for Cancer Patients and their loved ones, Feb. 23, 2019
Derrick Hall (D-Backs), Amy (wife), co-founders of www.pro-state.org
Barbara & Jack (AzMN)



Congressman Andy Biggs (AZ), Barb & Jack, Michael Foley (AzMN Board), and Paul Layeux (AzMN Board), Meeting legislators to bring awareness to our cause and the plight of the cancer caregiver, Feb 29, 2019



Barbara and Tammy McLeod, CEO of Flinn Foundation, discussing efforts to assist cancer patients and caregivers at the Bioscience Roadmap Luncheon, April 4, 2019
Barbara serves on Flinn's Entrepreneurship Committee



Rebecca Pierson, Community Relations & Public Affairs Manager Translational Genomics Research Institute (TGen) and hostess of the May 22, 2019 meeting



Special thanks to TGen for hosting our AzMN Planning and Collaborative Meeting on behalf of cancer patients and caregivers. Thank you to the attendees & our faculty.



Jonathan Keats, Ph.D. Assistant Professor & Director of Bioinformatics Translational Genomics Research Institute (TGen) shared some of the newest myeloma clinical trials with us.



Joan Koerber-Walker, CEO of AzBio, presented at the AzMN Planning and Collaborative Meeting, hosted by TGen. Joan and AzBio have been longtime partners with AzMN.

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