

# Cancer Caregiver News

by Arizona Myeloma Network®, AzMN

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a 501c3 Cancer Charity

Awareness. Advocacy. Education.

## A note from the Founder...

Dear Friends:

I want to wish you all a Happy Valentines Day! Personally, I think this Holiday should be a full month. A time for all of us to show our love and appreciation for our family and friends. For those of us who are 'living with cancer', it is a time to celebrate the cancer patient we care for and for them to show their love and appreciation for us-the Cancer CareGiver!

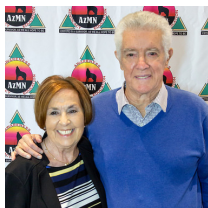
My New Year started off with a 'bang'! January 4th, I 'missed' two steps in my house and broke toes on my left foot. I also hit my face and got myself a dark purple 'black eye'. I know all of the scary statistics about people who fall or have accidents in their own homes. But, I was lucky, Jack was home and got me to a doctor who prescribed a 'big, heavy boot', a cane, and told me to keep my foot elevated, rest, and no driving! I wore the boot for 4 miserable weeks, and Jack became the CareGiver and I became the patient. It was a learning experience for both of us and I know that similar situations have happened to other caregivers. The change in our 'roles' and schedules was frustrating, and often stressful. My husband became the 'chauffeur', 'take out' manager since he doesn't cook...and other mundane but necessary tasks. I am not a 'patient' patient and know that I wasn't as calm and easy going as he is. Fortunately for our relationship, I am now wearing a smaller, equally unattractive orthopedic shoe and have more freedom and mobility. Lucky for my mental health and my husband's too! he was kind and helpful but clearly, uncomfortable and overwhelmed with these new responsibilities.

During my 'down time', I wrote my February blog for AARP, see the link below. I shared the lessons 'I learned' about how to 'ask' for help and also that men 'caregiver' in some different ways. I also developed this topic into another seminar for our Cancer Caregivers Education Programs, CCEP® series.

Sadly, we also had to make a sad decision. We don't have the funds for our annual Living with Myeloma Conference®. The grants applications we submitted were disappointing and our donations and sponsorships for 2018 did not give us enough budget to plan another event. As I mentioned in our December 2018 issue, we produced 3 major conferences and hosted over 500 cancer patients and families at our free educational events. We are proud of our record and our now seeking new partnerships so that we can work with other cancer groups and organizations to continue our innovative programs both for Myeloma and for All Cancer Caregivers. We will be posting information on our website and social media about opportunities for individuals, community organizations, businesses, and cancer research and treatment institutions can collaborate with us on a 'fee for service' basis. We still have so much to share and 'do'.

We are now back in my 'home office'- the kitchen, with a small, but dedicated parttime staff working 'virtually'. We started AzMN 14 years ago with even fewer resources, knowledge, or experience and know that we can continue to meet our charity mission: Awareness, Education, and Advocacy for all cancers and for those who are underserved and often alone.

Warm regards and see you all soon!  
Barbara and Jack Kavanagh  
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## Guest Column

### The Benefits of Seeking an Expert Opinion in Myeloma

Joseph Mikhael, MD, MEd, FRCPC

Chief Medical Officer, International Myeloma Foundation

Hematologist, HonorHealth Research Institute

Professor, Translational Genomics Research Institute



Multiple myeloma is an awful disease to face, but thankfully there are an increasing number of resources available to patients and caregivers as you can see from this newsletter! One of the potential resources available is seeking a consultation with an expert in the field to partner with your current medical team. There are approximately 250 myeloma experts worldwide. In addition to these, there are many centers of excellence that provide outstanding care to their patients and the oncology community.

This specialization in myeloma is critical as oncology becomes such a massive field. Literally every week new drugs and approaches are developed and approved for cancer patients. With this increasing complexity, especially in a rare disease like myeloma (accounts for only 1-2% of all cancers) having experts is critical. The relationship you have with your physician and health team is vital - but often it can be enhanced by a consultation with a myeloma expert.

This kind of advice is equally true for other forms of cancer - you are entitled to ask your oncologist/hematologist for a referral to a specialist for a consultation or '2nd opinion'.

Here are some reasons why this approach may be of help to you:

1. Cutting edge results - there is an incredible amount of information to take in about all the recent clinical trials and studies in oncology and a myeloma expert will be up to date on the latest in myeloma
2. Collaboration with your team - a second opinion is not expressing a lack of confidence in your physician or their team; the expert consultation is to facilitate and enhance your care. The consultant should have open and honest communication with you and your team. I have particularly found this partnership to be most valuable for both patients and their providers.
3. Education - this is an opportunity to take time to more deeply educate you and your caregivers about this complex disease. Education is empowerment.
4. Practical advice about current therapies - I have often found the most beneficial feature of being a consultant is giving practical tips about dosing of drugs, measuring the disease and a host of other issues that heavily impact a patient's care and their wellbeing.
5. Reassurance - often the consultation is a reassurance of the great care one is already receiving - this peace of mind if critical in one's health.
6. Establishing contact - a consultation will have an immediate benefit, but can also allow for ongoing contact in the event that things become more challenging and more urgent advice is required.
7. Access to clinical trials - there are an incredible number of exciting new drugs and approaches in myeloma and having access to these may have a profound impact on your myeloma and life.

If you would like more details about a consultation or information about clinical trials, you can reach me at the HonorHealth Research Institute where I now see patients one day a week: Intake office 480 323 1339 or [hri.intake@honorhealth.com](mailto:hri.intake@honorhealth.com).

February Blog:  
<https://states.aarp.org/cancer-caregiving-journey-loving-care-is-the-greatest-valentine-gift/>

# Exciting and Upcoming News!

Exciting news is that I have been asked to write a book about my 27 years of 'Living with Myeloma, a CareGivers Journey'. Though the book reflects Jack's and my experience since his diagnosis in April, 1991, it will have important information and resources for other myeloma patients and families, as well as our innovative cancer caregivers' programs for All cancers.

We currently have grants from Sanofi and Janssen to begin my book, and welcome additional grants, sponsorships, and donations.

I will tell you more about my book in our next newsletter, in early April, and let you know how you can participate!

We are developing a survey for cancer caregivers to help us learn more about how we can not only improve the quality of life for patients but also for their caregivers and families.

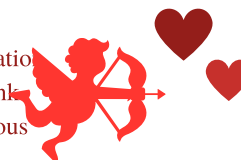
Please come out and visit us at the "Living with Cancer Patient Symposium" hosted by the Mayo Clinic on Saturday, February 23, 2019 from 7:15 am - 3:45 pm at the JW Marriott Phoenix Desert Ridge Resort & Spa, 5350 East Marriott Drive, Phoenix, AZ 85054. We will have an exhibit table at this event and would love to see you there!



Barbara and Jack Kavanagh, Founders of the Arizona Myeloma Network were featured in the article, "Arizona Myeloma Network, Thrive and Survive" in the January 2019 issue of Life Around the Lakes Magazine as a community non-profit making a difference!



In the loving spirit of the Valentine holiday we invite you to make a charitable donation in honor of a loved one or shop for your 'Valentine' by using our Amazon Smile Link when ordering your gifts! Go to [www.tiny.cc/Donate2AzMN](http://www.tiny.cc/Donate2AzMN) to submit your generous donation.



Myeloma Support Group - February 7, 2019

It was so special attending the Phoenix Myeloma Support Group at the Cancer Caregivers Community last week. Jack and I got to say 'hello' to our longtime friend and Founder of this wonderful group, Brenda Gregory. And, also greet another great friend of AzMN, and the staff leader, Suzanne Hyde.

Many of you know her from our Myeloma Conferences and also our Cancer Caregivers Seminars.

We brought with us to the meeting, a woman who's husband had just been diagnosed with myeloma and that we had met through a mutual friend.

She found it so helpful and hopeful!

If you would like to attend the support group, you can contact Brenda at: [Bgregory43@yahoo.com](mailto:Bgregory43@yahoo.com)

She can provide more details about the meeting and will add you to her email list for important myeloma updates.

Congratulations Brenda on your 20 plus years of 'living with myeloma' and for your personal support to Jack and I over the past 14 years!

Watch this informative video here ----> <https://www.facebook.com/SPELLCHECKSHOW/videos/302694903898438/>