FOR OUR SUPPORT GROUP MEMBERS  
LIVING WITH MULTIPLE MYELOMA (MM)

NEWLY DIAGNOSED MEMBERS

If you are like most of us, your diagnosis of MM came as a shock. Although at this time it is incurable, our goal is to manage our MM and develop the mindset that MM is a serious, chronic, but treatable disease. There are many treatments now available for MM that mean we can look ahead with hope. Educating ourselves about the disease and seeking the encouragement of others willing to share their knowledge and experience is important in our support group.

As a newly diagnosed member, we suggest that you consider:

- Your primary hematologist/oncologist is the key to your success, and as such, you’ll want him/her to be knowledgeable about MM. Since MM originates in the blood, it’s important that she/he has hematological training. Don’t be shy about asking how many MM patients he/she is currently treating, how many in the last five years, and what has been their outcome. If you don’t feel comfortable with your oncologist’s MM experience, consider finding another one. After all, it’s your life and you want to have a relationship with this doctor for many, many years.
- Ask your hematologist what MM blood and genetic tests were done and their significance in terms of the stage and prognosis of your cancer. These tests are very important in making decisions about treatment options.
- Get copies of all your labs and maybe even develop a spreadsheet of your results (one of our members has a template that you might like to use). Be especially certain to track blood counts (red, white, platelets), kidney & liver functions, as well as your MM markers (IgG, IgA, kappa/lambda chains, plasma %, m-spike). This may be a great task for your caregiver and keeps them involved.
- Many doctors make dictations of your visit. Ask to be copied and mailed these dictations.
• Don’t be shy about asking for a second opinion from a recognized specialist in MM, even if it requires travel on your part. Some of our members see MM specialists at UCSF or Stanford 2-4 times a year but receive care from a local hematologist.

• You’ll have many questions for your doctor. Write them down ahead of time to make sure they are asked, starting with the most critical questions first. Take time to understand and write down the answers. Better yet, take an audio recorder and/or your caregiver to your appointments.

These are just some ideas that may work for you. Our monthly meetings are a great place to learn more and compare notes with others. The important thing is that you become educated about MM to receive the best treatment possible.

**FOR EXPERIENCED PATIENTS**

Because of the nature of MM, most people will have to try different treatments at some point. The Sacramento Valley MM Support Group can provide practical advice or information about treatment options. In addition, our members provide a sense of camaraderie with others who understand first-hand what you are going through, both physically and emotionally. Our members gain comfort and feel less lonely by attending meetings regularly.

Our group has several members who have successfully fought Myeloma for over 10 years.