



“Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship”

Meeting: Tuesday September 19, 2017 3:30pm – 5:30pm
451 Junction Road
UW West Clinic Room 1287
Enter the clinic... proceed left past the vending area... turn left again and conf. room 1287 is the last one on the left.

Information: Jayne Schwartz 608- 244-2120 schwartzdon@sbcglobal.net Madison Multiple Myeloma Support Group website madisonmultiplemyeloma.org

Mailing Address: Wisconsin Multiple Myeloma Support Group
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More Information:
International Myeloma Foundation (IMF) Phone: 800 - 452 - 2873 Email: TheIMF@myeloma.org Website: www.myeloma.org
Multiple Myeloma Research Foundation (MMRF) 203 - 972 - 1250 Email: info@themmrf.org www.multiplemyeloma.org

Upcoming meeting speaker:

Dr Natalie Callander will be our October meeting speaker. She will be here at 4:30pm.
Sent an inquiry to the UW Pain Clinic for Dr Peggy Kim to join us soon.

Our September meeting does not have a scheduled speaker

A big **Thank You** to Ruth McNeill and Barb McGill (Don) for their generous contribution to our support group. It is appreciated and will go towards the mailing and printing expenses.

Two great conferences are coming soon!

LLS Blood Cancer Conference Saturday, September 23, 2017 and The Multiple Myeloma Patient and Caregiver Symposium Saturday, November 18, 2017. Information included. Mark your calendars to attend both! Register now. Conferences are free to all attendees.

For information about the Fall sessions of the Livestrong program...Contact Sharon Baldwin at the number below.
Lussier Family West YMCA 5515 Medical Circle Madison, WI 53719 [Sharon Baldwin](mailto:SharonBaldwin) at 608 906 8815

The next Trillium presentation will be November 9, 2017 at the WIMR (Wisconsin Institute of Medical Research). This research area is just adjacent to the Carbone Cancer center. More information to follow as the date gets closer. Mark your calendars now!

Our thoughts and prayers are with Texas and Florida as they endure the storms and make plans for recovery. So, it is not unexpected that our group member, Mary has some valuable information for all of us.

“I just went to the FEMA site below. There is a planning tool, a checklist, suggestions on communication with family and several other things I might not have thought of in a crisis. Let’s be prepared. It probably won’t be a hurricane, but it could be something else.” Click on ready.gov/prepare to see what you need to do. Thanks Mary!

(This article has been shortened to fit in the newsletter.)

Multiple Myeloma 2017 Update – Why Do People Beat the Average Myeloma Life Expectancy Prognosis? Or How To Improve Your Multiple Myeloma Survival Rate!



By [Gary Petersen](#) [Life With Multiple Myeloma](#)

The pace of change and progress for myeloma has become exponential. This is a very good thing! We have had 4 drugs approved for myeloma since 2015 (two are new classes of drugs).

In this period, myeloma approvals have been 13 times greater than the average cancer. I can only say thank you to the researchers, drug companies, myeloma specialists, clinical trial patients, and advocates for such an outstanding achievement. In addition, the pipeline is packed with new drugs, CAR T, checkpoint inhibitors, MIL's and initiatives to treat as early as practical. As a patient advocate I find it nearly impossible to keep up with the avalanche of new data. I cannot see how anyone but a skilled myeloma specialist can keep up to date with this rapid pace of change.

In the last two years, the average life expectancy has gone from 4 years to 5.5 years, according to The SEER (Surveillance, Epidemiology, and End Results) data for multiple myeloma published in April of 2017 by the National Cancer Institute. This is outstanding progress in that life expectancy had been stagnant at 4 years for 5 consecutive years. Some patients beat the odds and live 10 to 20 years or more. I believe there are three critical components to beating the odds: Part one is early diagnosis and treatment before end organ damage. Part two is disease dependent, or the hand that you were dealt. Part three is related to the level of care that is available to you.

Part 1 – Early Diagnosis and Treatment If you are lucky enough to have a general practitioner who picks up high protein in the blood and finds the disease early while it is smoldering, or stage one, you have won the Myeloma Lottery. Life expectancy of stage one disease is 3 times greater than if you have been found in stage three. Treatment guidelines were published in November of 2014 with the express purpose of finding and treating the disease before it has progressed and causes end organ failure.

If you are one of the lucky ones who are found in the early stages of active myeloma or smoldering myeloma, you will have the luxury of time to understand the treatment options, find a [myeloma specialist here](#) (a must) and plan to confront your disease before permanent end organ damage. Just as a note, the country of Iceland is testing all of its adult population over 40 to screen for MGUS, Smoldering, and active myeloma. They call it iStopMM, a clinical trial supported by the IMF (International Myeloma Foundation).

Part 2 – Disease Dependent Some people are just plain lucky and are given a form of myeloma that is not that aggressive. In other words they have myeloma, but it happens to be smoldering myeloma. This form of the disease can be present in the patient but not show any outward symptoms. It can remain in this mode for 5, 10, or even 20 years.

The age of the patient is very important, in that you are 2 times more likely to survive if you were diagnosed at 49 years of age or less. The average age of the typical myeloma patient is 70.

Some people may have an active disease but do not have any of the negative prognostic indicators. These indicators include, but are not limited to, deletion of chromosome 17p and translocation of 4;14 or 14;16 or 14;20. Your myeloma specialist will run the FISH test or other genetic tests like GEP (gene expression profiling) to determine if you have any of these negative prognostic indicators. If you are considered high risk (15% of patients), the life expectancy is less than half of the current average, or just 2 years.

The sensitivity of the disease to treatment is also important. My myeloma seemed to be very sensitive to the combination of Cytoxan, Thalomid and Dexamethasone, a treatment that put me into remission very quickly. Some people might have the same experience with Revlimid, Velcade, or Dex, or any combination of these drugs. If the disease comes back, as it often does, the re-application of the same regimen may continue to work for years. I know one patient who has taken Thalomid for years as his only treatment and remains in remission.

Part 3 – Quality of Care There are some elements that you may or may not have much control over, the first of which is the availability of insurance. If you do not have insurance or have no access to care, the average life expectancy is less than one year. However, Medicare has a Compassionate Allowance Program where you can be approved in less than two weeks if you go to your local office and can show that you will not live without care. To see the program [CLICK HERE](#). The Affordable Care Act may provide an option for the 15%, who are not insured, and Medicare, Medicaid, and drug company assistance programs are also available. In addition, there are other programs which can provide assistance listed on the bottom of the home page, to view [CLICK HERE](#).

Multiple Myeloma is a rare blood cancer; so many hematologist/oncologists may not see one patient in a year. As a result not all oncologists or hematologists are the same. However, some are very skilled and experienced with Multiple Myeloma and have treated many myeloma patients. The data shows these myeloma specialists provide an average life expectancy of 10+ years or more, compared to the average which is at 5.5 years.

For a listing of specialists [CLICK HERE](#) or for a more extensive list without survival history [CLICK HERE](#).

Myeloma specialists have access to drugs that other oncologists do not. Because they are the thought leaders, they are involved in clinical trials, and can obtain some drugs through other programs that lesser known oncologists do not have access to. Worse yet, oncologists who are not myeloma specialists may not even know that some of these drugs even exist. For example, some of the well-connected specialists have access to drugs or treatments like CAR T, MILs, Venetoclax or Selinexor, which are not approved treatments. But these experts can get approval for initial therapy through clinical trials or other programs. Or some specialists can use drugs that are only approved for relapse or secondary therapy options (Daratumumab, Ixazomib, Krypolis and Pomalyst), and obtain approval to use them for newly diagnosed patients. They also have access to the best clinical trials like KRDD (Krypolis, Revlimid, Darzalex, & dexamethasone) for first line therapy which provides a response in 100 percent of patients. When you run out of options with the currently approved drugs, they can provide access to those that have done great in clinical trial, but are not currently available to the general public. Because you need a significant infrastructure to conduct clinical trials at your facility and they cost the facility \$15,000 per patient, few local oncologists have access to clinical trials. Sometimes it is who you know!

Myeloma patients seldom die from myeloma, they die from the complications from myeloma. The number one complication is pneumonia, and others include infections, kidney failure, anemia, etc. This, therefore, brings me to the realization that supportive care for the treatment of the many complications of this disease may just be as important as the cancer treatment itself. Or a great Defense (supportive care) is as important as the Offense (cancer therapy). MD Anderson and Mayo Clinic emphasize supportive care in their programs, UAMS actually has a Director of Supportive Care in their myeloma program, and Dr. Elias Anaissie, the Director of the Myeloma Program at the University of Cincinnati Cancer Center, has an extensive background in supportive care. Dr. Anaissie has published a well written example of an exceptional supportive care model.

I also think the quality of care that you receive can be affected by the knowledge of the patient, and this can be obtained by doing your research on finding the best approaches to care by looking at the work of the best myeloma specialists on-line, and by going to great sites as listed in the Resource Section of www.myelomasurvival.com. Joining a support group will provide more great information to improve your life expectancy. I have found that the average life expectancy of most of these support groups far out-performs the average. Knowledge is power!

IMF Info Line – If you or someone you care for has myeloma, you have questions. Probably, lots of them. You can search the Internet all you want, but other than asking your doctor, there is no better way to get your questions answered than to call the IMF Info Line. Missy, Judy and Paul know their stuff and they want to share what they know with you. Just ask anyone who has called the IMF Info Line. Patients or caregivers are welcome to contact the Info Line staffed by trained specialists at 800-452-CURE (800-452-2873). The Info Line is staffed between 9am and 4pm Pacific Time, 11am to 6pm Central time or infoline@myeloma.org.

The Trillium Fund was established by our founding support group members to facilitate Multiple Myeloma research here in Madison at the Wisconsin Institute of Medical Research. If you or your family wish to donate or send a memorial to this program, checks can be made payable to the “UW Foundation – Trillium Fund”.

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