



“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 May 21, 2019 3:30pm – 5:30pm  
451 Junction Road  
Madison, WI  
UW West Clinic Room 1287

Enter the clinic... turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

Group Information:

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Madison Multiple Myeloma Support Group website  
[madisonmultiplemyeloma.org](http://madisonmultiplemyeloma.org)

Mailing Address: Wisconsin Multiple Myeloma Support Group  
3309 Chicago Avenue Madison, WI 53714-1815

Information Sources :

International Myeloma Foundation (IMF)  
Phone: 800 - 452 - 2873  
Email: [TheIMF@myeloma.org](mailto:TheIMF@myeloma.org)  
Website: [www.myeloma.org](http://www.myeloma.org)

Multiple Myeloma Research Foundation(MMRF)  
Phone: 203 - 972 - 1250  
Email: [info@themmrf.org](mailto:info@themmrf.org)  
Website: [www.multiplemyeloma.org](http://www.multiplemyeloma.org)

Upcoming Meeting Speakers... **Mark your calendars now!**

Erin Costanzo, PH. D. UW Cancer Psychology department will join us for the June meeting.

Kelley Sidorowicz, IMF Support Group Regional Director will be our featured speaker at the August meeting.

Our Myeloma Support Group will be recognizing a milestone 20yrs in September. No speaker is planned. Leaving the time open for us to celebrate!

Dr Natalie Callander will likely join us for the October meeting.

**Mark your calendars for the 3<sup>rd</sup> Annual Myeloma Patient and Caregiver Symposium** in Pewaukee, WI Saturday, September 28<sup>th</sup>. This is a great conference and you will not want to miss it. More info to follow.

**Ever wondered how your hospital stacks up against others? This was an interesting comparison.** [Medicare Hospital Compare Results](https://www.medicare.gov/hospitalcompare/results.html#dist=50&loc=53714&lat=43.099931&lng=-89.3084607&utm_campaign=20190313_gmd_cpt_gal&utm_content=english&utm_medium=email&utm_source=govdelivery) Compare Medicare and Medicaid-certified hospitals which meet your search criteria within your area.  
[https://www.medicare.gov/hospitalcompare/results.html#dist=50&loc=53714&lat=43.099931&lng=-89.3084607&utm\\_campaign=20190313\\_gmd\\_cpt\\_gal&utm\\_content=english&utm\\_medium=email&utm\\_source=govdelivery](https://www.medicare.gov/hospitalcompare/results.html#dist=50&loc=53714&lat=43.099931&lng=-89.3084607&utm_campaign=20190313_gmd_cpt_gal&utm_content=english&utm_medium=email&utm_source=govdelivery)

## **A Week in Review with Dr Durie.... May 02, 2019**

### **Dr Durie's take on "What does a cure really mean?"**

The outlook on response, remission and survival is already very bright for many patients diagnosed in 2019 and beyond. Over 90 percent of patients will respond well with initial therapy. First remission will be in the four-year range. And overall survival for good responding patients (VGPR or better) is more than eight years. Then there is the impact of new immunotherapy and additional novel approaches.

When does remission become cure?

Achieving minimal residual disease (MRD) negative is the subject of much discussion. Bone marrow samples that show zero out of a million myeloma cells remaining are predictive of long remission and very good survival. But what about cure? This is the next step in the research: If MRD negative persists at one year, this is excellent. If it persists at three and five years, even better. But this is not an absolute guarantee of permanent success, or the fabled cure.

It is important to take a step back and understand what we know about long survival in myeloma patients:

1. Excellent response, including MRD-negative status, is a definite indicator of best outcomes.
2. A study from the University of Heidelberg showed that half of patients who had survived 20 years and beyond had residual disease. But these patients were still in remission and doing well. They had achieved a new equilibrium. Their immune system could control residual myeloma and, thus, prevent relapse. This immune status is now the focus of intense study.
3. Some MRD-negative patients become MRD-positive with relapsing disease. This resistant disease pattern is the subject of intense study.
4. Long survival can occur with and without negative MRD status, and negative MRD status may not be permanent.

What is a useful definition of cure today?

A good way to define cure right now is when patients live with a good quality of life and succumb to something other than myeloma—such as old age, vascular disease, or other common illnesses of the elderly. By this definition we are well on the way to curing many myeloma patients, with the prospect of curing many more in the future.

It is worth noting that even with older therapies, long-term follow-up showed survival at 20 years as 14.36 percent, not zero. So, with our new Cure trials we are not starting at rock bottom.

## **June 15<sup>th</sup> Detroit, Michigan IMF Regional Community Workshop**

Event Date: Saturday, 06/15/2019    Registration: 8AM -9AM    Workshop: 9AM-3PM

Registration is FREE but seating is limited – Register now on the IMF website.

*Lunch and refreshments will be provided*

### Agenda

- Myeloma 101 / Basics plus
- Upfront treatment at diagnosis
- Relapse / Refractory
- Maintenance and Clinical trials
- Support care presented by a Nurse leadership board member

**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](mailto:infoline@myeloma.org).

### **New information!**

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” and sent to UW Carbone Cancer Center, University of Wisconsin Foundation, 1848 University Ave, Madison, WI 53726. Donations may also be made online at [www.supportuw.org/give](http://www.supportuw.org/give) (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call (608) 264-5437 or email [curecancer@supportuw.org](mailto:curecancer@supportuw.org).