



“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 October 21, 2014 3:30 – 5:30 PM**
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

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

More Information:

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

Upcoming event!

We have a date for the Trillium presentation! Thursday November 20th from noon to 2:00pm with a tour of the labs at the Wisconsin Institutes for Medical Research (WIMR) after the presentation. Maureen Dembski, our coordinator is working with Dr Natalie Callander and her researchers on the agenda and room reservations. Lunch will be provided and the presentation is free. Your invitation is attached. RSVP and mark your calendars now. This event will take the place of our normally scheduled meeting Tuesday November 18th. **There will be no regular meeting November 18th.**

Upcoming meeting speakers

Dr Natalie Callander will be speaking at our October meeting. She will be joining us at 4:30pm.

Our condolences...

It is with great sadness that I report the passing of our group member, Sandra Lee Courter. Sandy passed away on Wednesday, October 8, 2014. She was diagnosed December 2009 and joined our group March 2012. Sandy kept a detailed blog of her life after diagnosis and during treatment. From those entries, you learned that she had a deep faith in god and clearly loved her family. We will miss her. Our sympathies to her family.

If you were not able to join the Living Well with Myeloma Teleconference on **Understanding your Immune System and Lab Values in Myeloma**, there is a replay and you will be able to access the slides and hear the teleconference at labvalues.myeloma.org

Preclinical Study Offers Hope Against Hair Loss During Chemotherapy

Madison, Wisconsin - The same drug that keeps the dentist's Novocain right where it's injected soon could help cancer patients keep their hair.

A new University of Wisconsin-Madison study outlines a new strategy using a vasoconstrictor (a drug that narrows blood vessels) to save the hair follicles of patients who undergo chemotherapy and radiation. By constricting blood flow to an area of skin, a simple topical application can mitigate the effects of radiation and small-molecule drugs.

Chemotherapy drugs have been developed to attack rapidly dividing cancer cells, but they attack healthy cells that divide rapidly, too. Hair follicle cells are some of the fastest-dividing cells in the body, which is why many chemotherapy patients lose their hair.

But by temporarily constricting the blood vessels that sit a millimeter under the skin, hair follicles can be spared from the effects of chemotherapy, according to the study published in the [International Journal of Cancer](#). The vasoconstrictor additive in your dentist's Novocain constricts blood vessels to keep the numbing agent localized, providing some relief from the dental work while keeping your whole face from going numb.

"That's essentially what's happening here; we're keeping chemotherapy drugs away from the outer skin and hair follicles where the vasoconstrictor has been topically applied," said [William Fahl](#), professor of oncology at the School of Medicine and Public Health and member of the UW Carbone Cancer Center.

Fahl was testing other topically applied drugs that could provide protection against radiation, mixed with vasoconstrictors to provide localized protection. In control studies without the protective drug, he observed the protective effect from the vasoconstrictor alone.

"Preventing alopecia (hair loss) is a big deal," said Fahl. "When you walk through the cancer clinic here at the UW, the single largest poster on the first floor shows women what they're going to look like after chemotherapy so they can emotionally prepare themselves. There is a store downstairs that sells hats, wigs, et cetera, specifically for patients suffering from treatment-related hair loss. What if we as an institution didn't have to do that? I'd like to see that happen. My responsibility as a scientist is to make sure that this technology succeeds and solves these terrible problems."

In an unrelated study, alopecia was ranked second among unwanted side effects by patients. First was the perceived effect on the family or partner. Another unrelated study cited alopecia as the worst anticipated side effect by 58 percent of women preparing for chemotherapy.

The same technology has already successfully made it through several clinical trials in treating radiation dermatitis, (radiation burn) and will be tested soon for oral mucositis.

Fahl and colleagues have completed three clinical trials at the UW using the vasoconstrictor. The next scheduled trial is a study to determine that the vasoconstrictor is safe and is effective in suppressing oral mucositis in bone-marrow transplant patients receiving cytoxan and total body irradiation. An additional study is being planned for alopecia.

According to Fahl, the greatest roadblock now in getting this technology to the market is funding the necessary trials to demonstrate safety and efficacy.

Lately there has been a lot of conversation in our group discussions about getting a second opinion at diagnosis and when Myeloma relapses. Here is an article that I found.

[Why Variability in Cancer Care Recommendations Means You Should Consider Second Opinions](#)

Huffington Post 07/24/2014

We know there is a surge of interest in using electronic health records to help you get better health care, and also to help healthcare administrators evaluate decisions and outcomes of patients. The [federal government](#) will be using [Big Data](#) (accumulation of electronic records) to look for best ways of treating patients and how research advances are being implemented in practice. In cancer care, the American Society of Clinical Oncology (ASCO) will be using electronic records to identify successful approaches to medical care.

In most situations with individual patients, these NCCN guidelines can be used to develop the treatment plan that surgeons, radiation oncologists and medical oncologists follow so that every patient receives care that makes use of the most recent advances. Meticulously, NCCN committees review important new advances and rapidly update the guidelines. Nationally, when patients are discussed at hospital tumor board discussions, physicians often refer to the guidelines. Beyond cancer, [guidelines also exist for nearly every disease](#), many developed by specialty physician organizations.

But how well do oncologists follow these NCCN cancer care guidelines? A [recent study](#) looked at variability in our best cancer centers' compliance with published guidelines for cancer care. Over 25,000 patient records from NCCN institutions were evaluated for deviations from their own published NCCN guidelines.

The results were surprising. Poor compliance (over 10 percent deviations from the guidelines) occurred in 20 percent of all NCCN cancer centers. By disease, poor compliance with the guidelines were found in 41 percent of lymphoma decisions, 21 percent of breast cancer decisions, 15 percent of lung cancer decisions, and 12 percent of colorectal cancer decisions. Choice of chemotherapy represented 37 percent of the poor compliance data, and not following recommendations for diagnostic procedures represented 46 percent. More shocking was that some individual institutions had 60 percent to 80 percent noncompliance rates for decisions in breast cancer patients.

This shows patients that there can be great variability in physician recommendations for care of cancer; even at our nation's best cancer centers.

And this data in cancer is not alone. Other data in care of [diabetes](#) or care of [heart disease](#) also show some [variable physician compliance](#) that can threaten how well you might do if you have one of these conditions.

What are Dr. Cary's tips for you based on this new information?

- Be sure you have health insurance that allows you to get second opinions in case you should develop a life-threatening illness.
- When a test indicates you have a serious disease, be certain you ask for a second opinion. If it is a scan or X-ray or a biopsy, ask your physician to have the scans or biopsy reviewed by another radiologist or pathologist to be certain of the diagnosis.
- Once you are certain of the diagnosis and have a recommended treatment plan, ask for a second opinion at a center that specializes in your condition to see if there is any difference in recommendations. And if there is, ask for a third opinion to be sure you have the highest chance at cure with least side effects. Remember, Fran Drescher needed seven second opinions to get the right diagnosis of her uterine cancer and through her courage in seeking this additional advice, she survived and is cured (see her book [Surviving American Medicine](#) for Fran's story and for details on how and where to get second opinions).
- Use the internet to find guidelines for your illness. Then make a list of questions about how the guidelines apply to you and get clear answers from your doctor if there are any deviations between guideline recommendations and what your doctor has suggested. In cancer, use the [NCCN guidelines](#), plus also information from the [American Society of Clinical Oncology](#) and the [American Cancer Society](#).

The recent surprising information indicates there is sometimes poor compliance with standards of care. Make sure your care is following the best guidelines, or if your doctor is not following best guidelines, that the doctor has a good explanation of why you actually need something different. Good patients (and their families) get good information which gets good care which gets the very best outcomes. And often, good patients need to get second opinions.

Of special interest in the CURE magazine (Fall 2014)...

“Cancer 911”, an article about when to go to the ER. Highlights which symptoms call for immediate action and which can be safely ignored. Also within that article, they speak to what information is critical for ER doctors to know about your cancer and treatments. Another strong reason to complete the Emergency Medical Summary included in the August Myeloma newsletter. This summary was created by our group member, Mary Levin and has been shown to be very valuable in those emergency situations where time is critical and complete information is needed.

Another article of interest was the “Out of Control, Overbearing caregivers can undermine patient recovery”. Caregiving is a difficult balancing act. Article was informative.

If you get a chance to read the Forbes magazine (September 29, 2014 edition), check out the article on Dr Patrick Soon-Shiong. I was in awe of what this doctor has accomplished. A patch that patients can wear at home that monitors heart, pulse and blood pressure and that data is monitored by a control center of doctors that monitor hundreds of patients. A pill bottle that lights up when you are scheduled to take your medicine and sends a message to your doctor when you opening the cap. There were many other items too numerous to mention in this newsletter. This doctor is making progress with a company that would connect all the data about a patient in the hospital, and combine it with genetic information on a level nobody else is imagining.

LLS Myeloma Survivorship Conference slides now available. Access the LLS website and click on the September Myeloma conference agenda tab. Slides are there from Dr Pasquini, Dr Natalie Callander, Dr Ann Maquire and Dr Hari. There are also slides from Dean Gruber and David Straseski’s session on Access, Affordability and Understanding Treatment Costs.

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. Debbie, 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 info@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”.

Send to: Maureen Dembski, Director of Development

UW Carbone Cancer Center

University of Wisconsin Foundation

1848 University Avenue

Madison, WI 53726

maureen.dembski@supportuw.org