

MM Fighters! Support Group Meeting
June 26, 2021
Virtual Meeting

For the first time in a while, we had a duet of presenters, with Dr. Avasare from OHSU and Dr. Kwok from SCCA/UW discussing Myeloma and the Kidneys. In an easy to understand and very informative talk, Dr. Avasare explained the importance of the kidney and various difficulties patients can run into while Dr. Kwok complimented her presentation with explanations of how Myeloma and its many treatments can impact our kidneys.

Thought For The Month

While facing the many challenges that Myeloma throws at us, many of us are sidetracked from the path we originally set out on. But these challenges also provide each of us with a new opportunity, for

Life isn't about finding yourself. Life is about creating yourself.

Speaker

Dr. Avasare and Dr. Kwok covered a lot of ground during their presentation, starting with what the kidneys are and their function in the human body.

DAMAGE

Kidneys can often be damaged, especially during the course of treatment for Myeloma, which can lead to the build up of fluids in the kidneys and the body. **GRF** (Glomerular Filtration Rate) is used as a measurement of what percentage of the kidney is functioning.

- There are several different ways to calculate this, with the results often varying.
- Dr. Avasare believes the most accurate calculator can be found at the National Kidney Foundation, which can be found at https://www.kidney.org/professionals/KDOQI/gfr_calculator
- Normal level of function is around 90% (see chart in slides)
- CKD stands for Chronic Kidney Disease.

It is estimated that 50% of Myeloma patients suffer from some level of kidney damage.

- Fortunately, early detection and treatment can often reverse most of the damage.
- One sign of damage is foam in your urine, which is “thick bubbles that do not dissipate over time”, indicating excess protein.

TESTS

There are several tests to examine the health of your kidneys, and below are what you should focus on:

- GFR, Serum Creatinine, Urea Nitrogen – Be sure to focus on trends over time, not a single result, which is only a “snapshot”
- Urine tests
 - o Blood and protein are key to look at
 - o Albumin is one protein, only one detected in the dipstick test
 - o 24 hour urine collection examines a wider range of proteins, for example light chains
 - o Random urine collection – needs to be collected at the same time each day

WHAT CAUSES KIDNEY DAMAGE IN MM

There are several slides covering damage cause by Multiple Myeloma

- Damage occurs in two areas, the glomerulus (the filters (red)) as well as the tubules (yellow)
- Light chains can block the tubules, which causes swelling
- Light chains can also cause amyloid, which blocks the glomerulus and causes Albumin to leak out.
- Also high blood calcium and low fluid levels

To combat bone loss with biphosphonates, Zometa is preferred over Xgeva in most cases

- If Xgeva needs to be stopped, you must take a “tail medication”, such as Zometa... should not stop “cold turkey” or bones could revert to former state of damage.

TREATMENTS

Treating Myeloma also often helps the kidneys

- 60% of patients have decreased light chains, which can severely damage kidneys
- CyBor-D (Cyclophosphamide/Velcade/Dex) in many instances helps get patients off dialysis – up to 60% of patients
- Plasma exchange – takes light chains out of blood and return blood components
 - o Regular dialysis not good at removing light chains
 - o High cut off dialysis (not often used in US) is more effective
- Helpful chart outlines possible kidney toxicity of various MM drugs
 - o If a certain drug is appropriate to use, the patient should not avoid these drugs if there is a possibility of kidney damage
 - Defeating the Myeloma is the main focus
 - You should be monitored closely and steps taken if problems arise
 - Most damage can be reversed if detected and treated early
- Stem Cell Transplants have been associated with kidney damage

- Using lower doses of Melphalan helps decrease the risk
- Up to 1/3 patients that have severe kidney damage at the time of SCT experience improved functions afterwards

FINAL SLIDES

- Keys to prevention of kidney damage
- Good diets to benefit the kidneys
- Questions to ask your medical team
- Helpful Links

Dr. Avasare's slides are attached to the email.

Patient Roundtable

Jaw necrosis has returned, unfortunately. Jon's dentist discovered some exposed bone on his jaw. Looking into treatments from an oral surgeon

- Not sure if this was Zometa related
- Jean once had necrosis of the pallet – her dentist once worked at SCCA, very experienced in handling ONJ – Dr. Chen Inspired Dentistry in Renton
- Richard forwarded an article on ONJ to the group
- Be sure to go to the dentist regularly!

Two new members, Malia and Gary, introduced themselves

Covid vaccines and the production of anti-bodies was a hot topic

- One member got a third vaccine (JNJ this time) and finally had some antibodies produced
- Others had antibodies after two shots, but all at low levels
- Anyone can go to LabCorp to get an antibody test – \$42 for a test

Is anyone taking Carfilzomib (with no dex) and having side effects?

- We have discussed Carfilzomib and dex with side effects, but this is the first time this challenge came up

The Defeat Myeloma Walk/Run, a virtual event this year, was held on Sunday. A huge success with many members joining the effort!

- Nancy, Michele and Barbara started fund raising for the first time, raising between \$2,000 and \$6,00 each – Fantastic start!
- Other “veteran” members created teams again this year – Judy, Sarah, Mark, Jeff, Chris, Mike and the Defeat Myeloma Committee members
- A number of MM Fighters contributed to The MM Fighters Team or to other teams

Thank you all who contributed to supporting research into Defeating Myeloma!
Over \$100,000 raised this year!

There is still time to donate! For more information visit www.defeatmyeloma.org.

Next MM Fighters! Meeting:

Saturday, July 24th, 2021 – 10Am – Noon – Josh Epworth - SCCA – Understanding Myeloma Tests – Virtual Meeting

Saturday, August 28th, 2021 – 10 AM – Non – Tony and Sibel Blau – What does the progress in Covid-19 pandemic mean for Multiple Myeloma patients? – Virtual Meeting

October 9th, 2021 – IMF Regional Workshop for Washington State – details will follow!