Dr. Edward Libby – Q&A

- Regarding your advice on sports, with your concerns regarding the spine, would golf and bowling be sports you would suggest we eliminate?

    My advice is really without any good research to back it up so I want to be honest

    with you about it. My worrry with golf is the amount of  stress we put on the back

    with a really big swing like a tee off. Having said that I think its pretty safe unless you

    have a very bad back from myeloma and then you wont wat to play anyway. Bowling

    is a little different but if your back feeels well enough to try it and your myeloma doc

    doesn't prohibit it I think its OK.

- How do I know if I am high risk if I have a 17p deletion?

   Unfortunately everyone with a 17p deletion is considered high risk. But not everyone

   with a del 17p deletion  has myeloma that behaves badly. We all have patients with del

   17 whose myeloma has been average. In general though it is a poor prognostic

   finding.

- What are your thoughts on the safety of the Covid vaccine for MM patients?

   I understand that are several versions, one of which is “live”...     The vaccines should

   be safe. The current 2 vaccines Pfizer and Moderna are not live or inactivated. They

   use a different and brand new technique to induce immunity.. These are the ones

   patients are most likely to get. As far as I know none of the vaccinies in development

   in the are "live" or "inactivated".

- If a patient has MGUS or Smoldering MM, what are your recommendations regarding siblings and children and testing for MM?

  Generally no experts recommend that siblings parents or children be tested. In

  general myeloma in not considered a "familial" disease. But there are definitely rare

  familites in which the disease seems to be passed down. If someone was from a family

  in which multiple family members had had myeloma it would be resonable to screen

  1st degree realtives of the familiy member with myeloma. First defree would be

  parents, siblings and children not cousins etc. To screen for myeloma one could get a

  serum protein electrophoresis and serum free light chains at the age of 50 and then

  every 5-10 years. This is not a standard recommendation though. At this time there is

  no genetic testing avaialbe to look for a tendency to get myeloma.

- What areas of Myeloma knowledge are important in order to have treatment discussions with your oncologist?

  The most important thing to know is where you my stand e.g are you in a partial

   remission, very good partial remission, complete remission, stringent complete

   remission or MRD negative or positive. Thats alot to understand of course...to simplify

   it is adequate to know you are in a partial remission, very good partial remission ,

   complete remission or have progressive (relapsing) disease.I think it is very valuable

   for the patient or a family member or friend to understand these terms. They will tell

   you where you are in your journey with myeloma. It is also good to know if you have

   standard risk or high risk myeloma. Patients with high risk myeloma tend to have more

   aggressive myeloma that is harder to control.

- When, or how often, should a patient have a bone scan in order to check of lesions and bone damage?

  Some myeloma docs do one every year. I do not see a reason to do this in most

  patients whose myeloma is in excellent control e.g very good partial remission or

  complete remission.

- When Dr. Cowan spoke to us about trials, it seems that the results were measured in terms of ScR, CR, VGPR, etc.  Other trials have been using MRD. Is there a reason SCCA is not using the MRD criteria?

  As you have pointed out the different ways we define response to chemotherapy has

  become complicated in myeloma. The following terms are everything currently used:

  Progressive (relapsing) disease, stable partial remission, very good partial remission,

  complete remission, stringent complete remission and MRD negative or

  positive disease, Six different levels of response.

  MRD testing is not ready for prime

  time although it is available. There is insufficient research regarding what to do with

  the results. It requires a bone marrow biopsy which is uncomfortable and even

  miserable for some patients. Ideally the process of using  MRD testing is initiated with

  the first diagnostic bone marrow biopsy but the vast majority of oncologists around

  the country arent ordering it a diagnosis yet and that makes trying to do it several

  years later much harder. If we do use MRD testing should it be done every year ? every

  six months ? etc ? we just dont know. It is not thought that MRD testing would be done

  once and then never again. It essentially could be a more sophisticated way to

  measure the level of myeloma in the body along with the SPEP, free light chains, urine

 Bence Jones proteins, CT/PET scans etc.  The bottom line is that MRD testing is an

  important advance for myeloma but currently it is not applicable in the routine care of

  myeloma patients and no one knows how to apply it for routine care. MRD testing is

  standard in all research trials though.  Much more research will have to be done

  before we know how to incorporate MRD testing into the routine care of myeloma

  patients. MRD testing is available at the SCCA and we have used MRD testing in some

  patients at the SCCA. All patients on myeloma trials at the SCCA get MRD testing.