FAQS from Dr. DeZern's webinar

The UK MDS Support Group mentions a study with a combination of Vitamin C and azacitidine. Do you see this combination being studied in the US?
Yes, this is being studies in the US as well, specifically in TET2 mutated patients as there has been data to suggest Vitamin C will have a role in that disease biology.

Currently doing Vidaza (azacitidine) treatment for 18 months and having transfusions every 4 to 6 weeks. How do you decide what trial is good for you?
Lots of factors go into choice of trial (eligibility, disease biology/mutations, number of healthcare interactions and geography). Makes sense to sit with your physician (or an additional consultation at a trial center) to balance all of these for the individual.

Having MDS, should I be concerned getting my Covid Vaccination?
We do not honestly know as MDS patients were not included in the studies but based on all the information we have to date; we think it should be OK for the majority of patients.

Do you often see fibrosis in the lungs, given that it's recently been shown that erythropoiesis takes place there also? My dad has been receiving steroid treatments for blood in the sputum coming from his lungs for about 2 years now but as it is Fibrotic, I was wondering if that's due to MDS?
Hard to know without a few more specifics but there are conditions in an individual patient that could predispose to both MDS and lung fibrosis such as short telomers.

As a two-year MDS patient with mild symptoms currently living in Chicago, I am trying to learn if I will likely have serious troubles when we move to Sante Fe, New Mexico related to the high altitude.
This would be related to your degree of anemia as the hemoglobin level can be affected by altitude, but that acclimation takes some time and if the MDS is advancing, the acclimation may not be as feasible for the bone marrow so transfusions may be needed more, or in the short term, depending on the clinical scenario.

Were there presentations on progress treating GVHD in post-BMT patients?
Yes, several with some new approaches and drugs available.

How is oral azacitidine different from IV azacitidine? Oral azacitidine with a distinct pharmacokinetic and pharmacodynamic profile from injectable AZA; the two are not bioequivalent.
There are articles that show how that was determined - Garcia-Manero et al. J Clin Oncol. 2011;29(18):2521–7. 2. Laille et al. PLoS One. 2015;10(8):e0135520.

I understand that MDS does not respond well to alternative/complimentary therapies. Are you aware of any studies or new information in regard to any current research in this area?
There is some data with use of Vitamin C specifically in TET2 mutated patients. There are also studies of quality of life related to transfusion threshold.

What is current cure rate of high risk MDS patients who received allogeneic transplant?

There are many metrics that go into this type of rate such as type of transplant, type of donor, disease control at time of transplant, chimerism post-transplant, so it is a bit challenging to give one number.

Why won't hematologists treat my anemia (Hgb 11.6 at last CBC)? One would only administer Aranesp when my Hgb was under 12 and would not consider G-CSF because it might cause bone pain. The other would not consider either treatment and suggested that an Hgb of 11 was really good. I have MDS/RARS presumably from benzene contamination.

Those are standard parameters for treating anemia in RARS. We do not usually treat to a normal Hgb and there is package guidance on the Aranesp label as such, because these drugs do have side effects and thus, we only use them to avoid transfusions and allow good hemoglobin (if not perfect).

Can a compromised bone marrow result in monoclonal gammopathy (M-protein)?

M protein could be the start of a plasma cell dyscrasia in the bone marrow and this can often be associated with increased age and see in patients who also have MDS.