FAQS from Dr. Madanat's Webinar

What would be the first treatment option for MDS patients with low platelet counts (15-20)?
Options depend on the exact clinical scenario, MDS risk category, bone marrow blasts and cellularity. Options may include antithymocyte globulin or hypomethylating agent therapy.

Any opinion about long-term use of hydroxychloroquine and MDS? (I've had refractory anemia for last 40 yrs. and have been taking plaquenil the last 21 yrs.)
There is a small report of 4 patients developing secondary MDS after hydroxychloroquine therapy (https://doi.org/10.1182/blood.V108.11.4829.4829).

Do different MDS centers specialize in particular types of MDS?
Not to my knowledge, although certain research laboratory scientists at each center may focus their research efforts on studying specific subtypes.

Dr. Madanat, have you had experience using Imetelstat in MDS patients without ring sideroblasts? Does it reduce the bad clonal cells?
I would refer you to this publication with the early experience of using Imetelstat in MDS (https://ascopubs.org/doi/full/10.1200/JCO.20.01895?af=R). The biomarker assay does indicate certain effects on the mutant malignant clone; however, the confirmatory randomized clinical trial is still accruing patients and we do not have the results at this time.

I'm from Holland and recently diagnosed with MDS with multilineage dysplasia (MDS-MLD), EB1-2, with 9-10% blasts. My blood counts are normal, except for leukopenia. MDS diagnosis came after cryglobuline type 1 was discovered in my blood. Is there a known relation between MDS and cryglobuline? I am 60 years old on watch and wait.
There is a clear association between immune mediated conditions and MDS. I hope you continue to feel well.

I am low risk, currently getting 2 units of red blood cells every 4 weeks. Is this beyond the transfusion threshold and should I consider hypomethylating agents or clinical trials?
That is about 1 unit every 2 weeks which is about the time that you can consider starting therapy to become independent of transfusion support in order to improve symptoms and quality of life.

What is the relationship between MDS treatment and the heart?
It really depends on the therapy. Hypomethylating agent therapy such as azacitidine or decitabine has a low risk of heart toxicities such as atrial fibrillation (<5%), cardiac failure (<5%), chest wall pain (5%), congestive cardiomyopathy (<5%), hypertension (9%), hypotension (7%), orthostatic hypotension (<5%).

What type of autoimmune diseases are associated with MDS?

Most common are hypothyroidism, idiopathic thrombocytopenic purpura, rheumatoid arthritis, psoriasis (there is a study that has a more detailed breakdown in ~1400 patients with MDS, https://pubmed.ncbi.nlm.nih.gov/26875020/).

What is the trigger point in disease progression to consider a a stem cell transplant?

This depends on multiple factors including the disease risk, patient's comorbidities, available therapy options and patient's preference. A consultation with a transplant physician is always favored to learn about the process.