FAQS from Dr. Wilde's Webinar

If the bone marrow is producing immature red blood cells does the hemoglobin content get counted in a Complete Blood Count (CBC) even though the hemoglobin does not reach organs and muscle? The CBC calculates hemoglobin based on the red blood cells that are circulating in the body (both mature and immature). It does not measure immature red blood cells that are still in the bone marrow.

What EPO drug do you use for treating MDS-RS and do you combine it with any other drug such as Aranesp + Neupogen? There are multiple brands of EPO that can be used. Aranesp is one of them. Others include Epogen, Procrit, and Retacrit. They all work the same, but the dosing can be different. Any of these can be combined with Neupogen (or another WBC growth factor drug).

Is Aranesp an EPO medication? Yes, Aranesp is the brand name for darbepoietin, which is an EPO medication.

How low can hemoglobin be allowed to go in a patient? If patient has fluid overload can hemoglobin be allowed to go down to 6 or 5 or even lower? Hemoglobin can be safely allowed to go below 7, even into the 5 and 6 range. Some people are very symptomatic when their hemoglobin is low, but others are not. If fluid overload is a problem with transfusions, there are other ways to manage it as well. I may give a water pill like lasix with the transfusion, give a half unit of blood, or transfuse very slowly to help with the fluid overload issues.

I have had problems with high iron levels (over 2000). This is now managed with Exjade (4x360mg daily). The iron levels are almost down to normal levels (under 500). I have developed problems with my heart due to iron build up. Will the iron slowly reduce in my heart if the blood levels are kept low? Exjade can help to remove some iron deposition from the heart, but the process is slow. The iron can also cause damage to the heat muscle that may not be reversible even with iron removal. Continuing to keep your iron levels low will help to prevent further damage, though, so it is important.

I am a low-risk RARS patient 10 years from diagnosis having tried everything including EPO and Vidaza with no success. I am now transfusion dependent and in the last few months, I have been neutropenic and thrombocytopenic. Once there is pancytopenia, what is the rate of marrow deterioration? Any time there is a change in blood counts I recommend having a new biopsy done for re-staging. This will help your doctor understand if your MDS is changing or progressing and will provide them with important information about your prognosis.

Is there nutritional supplements or foods that help the transfusion reach higher numbers or stay effective longer? Iron, vitamin B12, and folate are the building blocks of red blood cells. As long as you have adequate levels of them, you have what you need. There are unfortunately no other supplements or foods that can help.

During your presentation on blood transfusions, the topic of iron overload came up. I had a bone marrow transplant and due to excessive iron overload, I am having monthly phlebotomies. What is a

reasonable ferritin level to achieve from phlebotomies? It is generally reasonable to aim for a ferritin less than 500.

My husband is a 73 y.o. black male diagnosed with MDS in 2016. A year later, he went on dialysis. He was on Vidaza for 18 months and did not like side effects. He is now transfusion dependent. Palliative care includes weekly platelet transfusions on Tuesdays. If his hemoglobin is below 8, he gets red blood cell transfusions on Thursdays. What does he need to do in maintaining a good quality of life? It sounds to me like your husband has been through a lot and is being well cared for. Making sure that he gets transfusions and dialysis are the most important things he can do to maintain his quality of life.

I have a question regarding transfusion support. I'm currently on Procrit for my MDS with an IPSS-R score of 1. I've had four weekly doses of Procrit and my hemoglobin remains in the 8 g/dL range. Besides transfusions are there any other options that I have to raise my HGB level? Does the fact that the Procrit doesn't seem to work indicate anything regarding disease outcome? Sometimes it takes a little while for Procrit to work so give it some time. The most common reason that it is not effective is that your body is already making enough EPO on its own and there is a limit to how much your bone marrow can be stimulated by it. Next steps for treatment, if necessary, may include adding another growth factor medicine or changing treatments altogether.

I am a newly diagnosed MDS-RS patient. I have read the different side effects of most of the chemo drugs which include diarrhea and/or constipation. Having asymptomatic Crohn's disease which has been quiescent for many years, will my Crohn's be affected or restarted with these treatments? Each medication has a unique side effect profile, however, most treatments for low risk MDS are very well tolerated and have minimal GI side effects. I have cared for many patients with MDS and inflammatory bowel disease and have been able to manage quite well with symptom support. I would suggest that your MDS doctor and Crohn's doctor work together to keep you feeling well.