

FAQS from Dr. O'Connell's webinar

Is there an average length of time that the Revlimid is shown to work for the 5Q Del MDS Patients? **About 2/3 of patients were still transfusion independent at 1 year, this response can last for several years.**

Do you see any effect of warfarin on low risk mds treated with Aranesp? **No but it's a blood thinner so if the platelets are low it can exacerbate bleeding.**

Are there any forms of MDS considered to be an auto immune disorder? **No but there are autoimmune causes of other low blood count problems.**

I am taking Venclexta daily with decitabine infusion once every 6-8 weeks. My bone marrow test results reveal zero blasts. Is my explained treatment the correct course? **That's a treatment for AML (still not FDA approved for MDS but tested and seems promising in clinical trials) and if blasts are zero that usually means it's working!**

My husband was diagnosed w/ LR MDS one year ago. He has been getting transfusions every 4 - 6 weeks. If he begins taking Procrit, is there no going back to transfusions? **No transfusions are always an option for patients and may be given for several years. Could be his EPO level is >500 and therefore the doctor felt Procrit wouldn't be effective.**

On luspatercept now, 3rd shot given yesterday. Is there a limit amount of shots before it shows improvement in hemoglobin, and is there a certain amount of shots before they say it's not working, and it's stopped? **Good question, I didn't participate in the clinical trials, but it looks like an effect was usually seen after the 2nd dose and if not, the dose was increased.**

I have been on Vidaza for 15 months with great results. However, I have Sweets Syndrome and Vidaza didnt help with Sweets. I have tried all the other medications associated with efficacy of that condition like: Dapsone, Potassium Oxide, Methotrexare and Colchine which have not worked for me only Prednisone has helped. What do you suggest? **Probably consultation with a good dermatologist, but unfortunately sometimes the sweets doesn't resolve with improvement in the MDS and ongoing topical or Sweet's directed therapies are necessary.**

I have intermediate MDS and have been receiving blood transfusions since 2007 and now it is usually 2 units every two weeks. In the absence of a drug, what is the long term prognosis by doing this? My blood tests have been very stable and my iron levels, liver, and heart, are monitored closely. Bone marrow transplant, at this point in time, is very risky for me. **You've made it a long time and the IPSS isn't a dynamic one meaning we can't really apply it to different time points in the disease, so it's difficult to say for sure. Myeloid mutation testing can help sometimes to see if new mutations are developing which may "speed up" the pace of the disease.**