MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk

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31/7/13

Re:Response to ACD:Myelodysplastic syndrome (deletion 5q) - lenalidomide [ID480]

Hi [redacted],

I just wanted to confirm that I agree with Rodney's comments. I must admit that as a patient the meeting and also the resulting document there were aspects of this process that I found very technical and sometimes difficult to understand at times due to the medical terminology etc. I am also a little frustrated as a patient that this process seems to be based purely on one study whereas there must be a lot more information available on the benefits of this drug.

I know that Rodney has commented on section 4.14 but I also wanted to add a comment. This paragraph states that there was "no observed gain in survival with lenolidamide in the MDS-004 study". I know that for me personally this drug has definitely slowed down the progression of my disease, which in a younger patient is vitally important. It will therefore definitely contribute to a much greater gain for my survival rate as it currently staves off the need for other more risky treatments such as bone marrow transplants etc.. Therefore this is why I think just relying on one study doesn't show the whole picture.

Regards
Fiona

Fiona Pirilla