



TRANSFUSIONS IN MDS, & USE OF APPS TECHNOLOGY & IRON CHELATION SUPPORT GROUP MEETING

Patient-to-patient support for those affected by the
Myelodysplastic Syndromes

All MDS patients, their relatives and friends are welcome to join

2020 MEETING:

**Topic: Part 1: Transfusions in MDS and use of apps Technology
Part 2: Iron Chelation**

Date: 6th August 2020

Time: 3pm – 5 pm

Venue: Virtual Zoom Call



Register in advance for this meeting by clicking on link below:

<https://us02web.zoom.us/meeting/register/tZEtf-igrD4iHt2PhYF5eLnBpntiXvEw5tFS>

After registering, you will receive a confirmation email containing information about joining the meeting.

For further information, please contact us using any of the details below

MDS UK Main Office

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0207 733 7558

AGENDA

Dr Simon Stanworth - will review of recent evidence and recommendations to optimise transfusion practice in MDS and describe some of the next steps for research. He will also discuss ways to monitor activities and outcomes for use of transfusions in MDS. In addition, we will also explore the use of smartwatches and activity devices, in relation to monitoring energy and activity levels.

Professor Bowen - will explain how we have gathered the evidence that supports iron removal (chelation) in some patients with MDS who need regular blood transfusions, and provide some insight about how we are trying to learn more. He will explain which drugs are used for iron removal and their benefits and side effects.

Discussion questions - for during the meeting:

- 1.** Does your doctor decide when to give you a blood transfusion based only on the level of haemoglobin in your blood, or on how you are feeling, or both?
- 2.** Do you think that your blood transfusions give you a sufficient boost, and last long enough to keep you as active as you think that you could be?
- 3.** Has your doctor discussed removing iron if you have had more than 20-25 units of blood transfused (note that iron removal may not be appropriate for all MDS patients in this context)? Prof Bowen will discuss this.