



**Patient-centred Newsletter**  
**Issue 1 – Winter 2020**





# Welcome to your first patient-centred newsletter from the European MDS Registry!

## Introduction

With such a large patient community, we wish to share some of the outcomes of the EUMDS Registry with you. This will demonstrate how your participation is helping our understanding of MDS, and how you have contributed to improvements in the way that we look after patients with MDS.

You may or may not know it, but the EUMDS Registry comprises 17 countries, 16 in Europe plus Israel, and we aim to extend the number of participating countries in 2021. Since its inception in 2008 the registry has collected data from over 2800 patients! This data has been very helpful in contributing to research into MDS and has already changed the way we look after MDS patients. Read on to hear how you have played your part...

We also like to take the opportunity to inform you that we have added a section with layman summaries of publications by the EUMDS Registry (<https://eumds.org/publications/summaries>) on our website. Furthermore, we have developed the MDS Europe website (<https://mds-europe.eu/>) where you find MDS-related information for different countries in one place. We collaborate with the MDS-Hub (<https://mds-hub.com/>) which has been launched on December 4<sup>th</sup> 2020. The MDS-Hub has the mission to enhance the collective knowledge base in MDS through global multichannel dissemination of the most up-to-date evidence-based information in MDS and to help inform on disease management and treatment strategies.

## Outcome of the EUMDS Registry

The Registry has identified more efficient indicators of patient outcome, along with better methods to assess how well treatments are working.

*For example:*

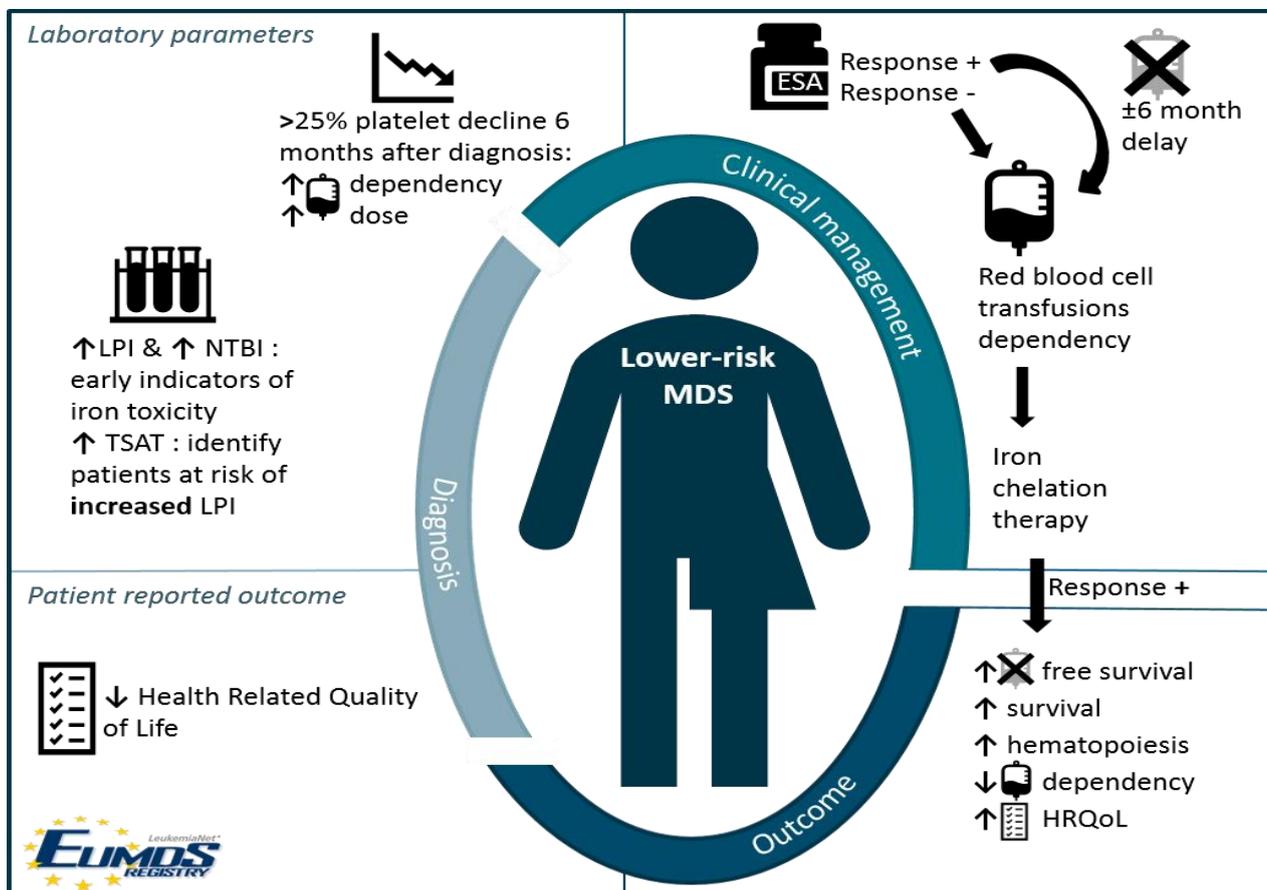
Using **drugs to reduce anaemia such as ESA** (erythropoiesis stimulating agents) is more effective when started *before* patients need regular blood transfusions (transfusion independence), than *after* they need regular transfusions to maintain a sufficient Haemoglobin level (transfusion dependency).

**Transfusion dependency** can lead to shorter survival, highlighting the need for research to improve this.

**Drop in platelet counts** shortly after diagnosis can be valuable as an indicator of prognosis. Combined with a need for regular blood transfusions, this drop in platelets can be used for early identification of a shorter survival projection. Clinical trials can be designed to address this.

**Questionnaires completed by patients** are important for understanding the effects of disease on individual well-being. By completing these questionnaires you have told us that Quality of Life in MDS patients is markedly reduced compared to the general population.

**Quality of Life questionnaires** also support the assessment of treatment effectiveness.



LPI– labile plasma iron; NTBI – non-transferrin bound iron; TSAT – transferrin saturation; HRQoL – Health Related Quality of Life



with thanks to all participants  
and our patrons



PLATINUM PATRON

from 2007



SILVER PATRON

from 2017



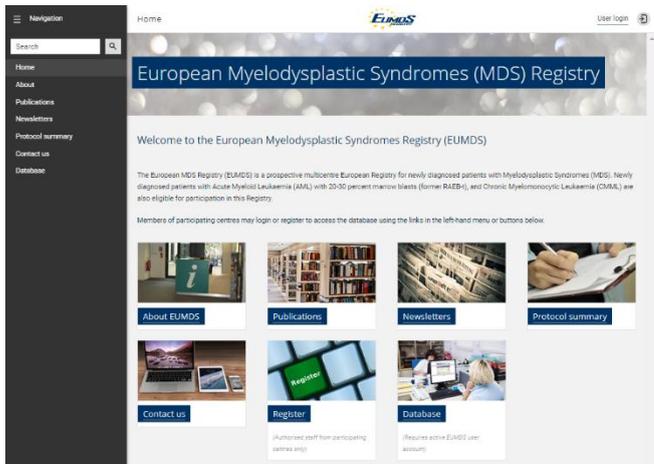
SILVER PATRON

from 2019



SILVER PATRON

from 2020



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