Newsletter Issue 24
June 2020

Contents

1. Message from the Chair

Welcome to the June 2020 EUMDS newsletter

The human world, and especially the world of older persons, is going through dramatic changes and challenges. It is clear that all of us involved in the EUMDS registry - patients and caregivers, research nurses, data managers, research staff and physicians - are affected by the consequences of the COVID-19 pandemic.

- Patients do not dare to leave home and avoid visits to hospitals and other health facilities.

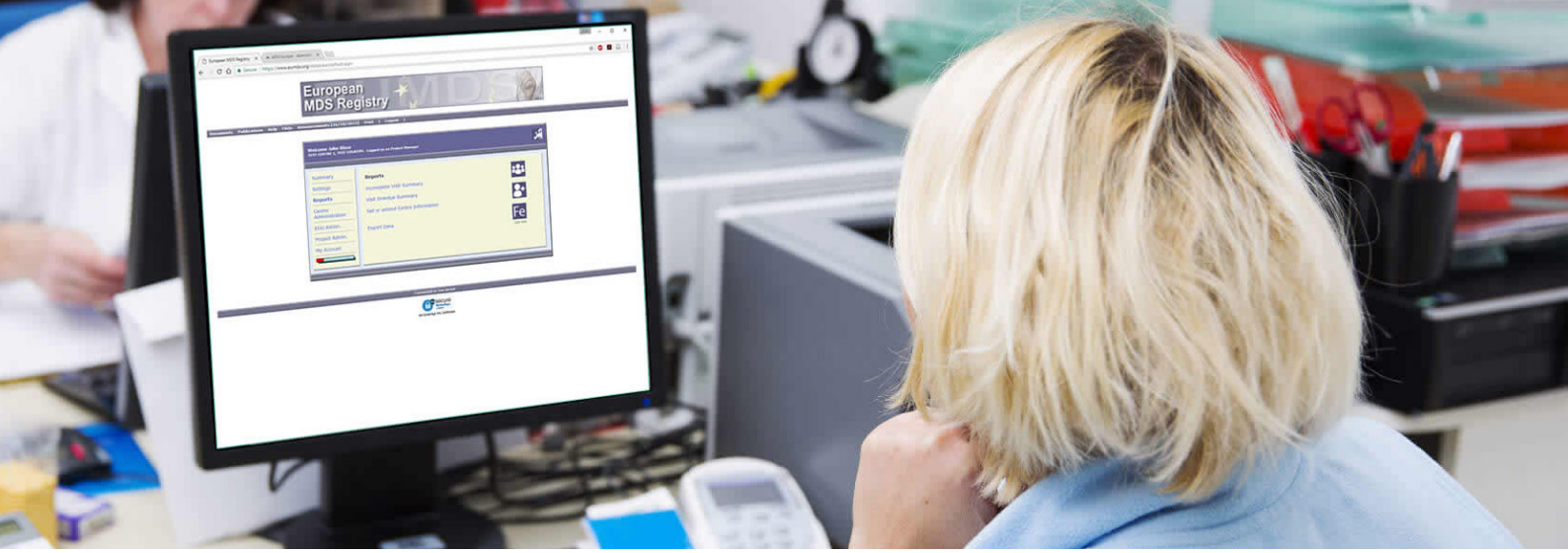
- Clinical research activities have been limited or put on hold in many hospitals so clinical staff could commit their efforts to the increased demand for clinical care. New inclusions of patients in the EUMDS Registry this year (76 as of 1 June) do not seem dramatically low, however this number has dropped heavily during the second quarter of this year. To get more insight in the consequences of the pandemic on MDS care, we would like to monitor all new patients during the COVID-19 pandemic, also those patients who have died prematurely during the first 6 months after diagnosis. We will put together a proposal in July how to address and to study these issues properly.

- Our annual meeting in Mannheim has been skipped due to travel restrictions, but we plan a dedicated video meeting in September. Details will follow before the end of August.

The good news is that our team managed to submit a new grant application for Horizon 2020 "Digital transformation of real-world datasets to improve understanding and management of chronic anaemia and the associated complex chronic conditions in older persons (DI-CAP)". We will hear before the end of October 2020 the outcome of this application.

We are pleased that we can continue the EUMDS Registry beyond 2020 and looking forward to continue the success of the EUMDS Registry together.

Theo de Witte
Coordinator, EUMDS Steering Committee



2. Updated EUMDS website

We recently launched the updated EUMDS website. Featuring a refreshed visual design that automatically adapts to the screen size on any device. The new site also includes a comprehensive list of EUMDS-related publications, abstracts and other publications and for the first time also lay summaries).

Access to the database is still via the website, but you are now able to login using the link at the top right. This will also give you access to 'Study information', 'Documents', 'Announcements' and 'FAQs' - these links will appear in the left-hand navigation menu.

In the Documents section, you have access to the Progress and Interim reports. The Interim report March 2020 provides an extensive overview of the data available in the Registry.

If you experience any difficulties using the new website or if you have any feedback, please get in touch (enquiries@eumds.org).

3. New grant application

The quantity and quality of the EUMDS Registry data are becoming more and more relevant. This is reflected by the rapidly increasing number of presentations and publications by our consortium. In addition, the research projects TRIAGE-MDS, MDS-RIGHT and HTx contribute substantially to our ongoing and planned studies.

Activities of TRIAGE-MDS are being continued and extended as part of the MDS-RIGHT. HTx has just started in 2019 and the first 2 studies have been identified recently, including a study on iron chelators. Work is progressing well, and also MDS-RIGHT will be completed this year.

To gain additional funding for our research activities, a new grant application to the Horizon 2020 program has recently been submitted (Di-CAP). This project will focus on chronic anemia and the associated complex chronic conditions (CCC) in older persons, addressing the interaction between individual CCC, the potential contribution of multiple shared pathogenic mechanisms, and shared therapeutic effects and the gap between RWD and RCT data.

This project will provide improved understanding of pivotal molecular, inflammatory, and immune mechanisms playing a role in progression of the MDS clone as well as non-resilient aging and contribute to more effective and repurposed interventions. Quite a few of the recently developed sub studies will contribute to our knowledge in this field and will support our chance to a successful grant application.

Typical examples of these new studies are: Cardiovascular Biomarkers in Lower-risk MDS, the impact of anti-depressive drugs (serotonin antagonists) on outcome of MDS, the role of metformin on progression of MDS, and the role of hypomethylating agents on auto-immune diseases.

4. MDS-RIGHT progress

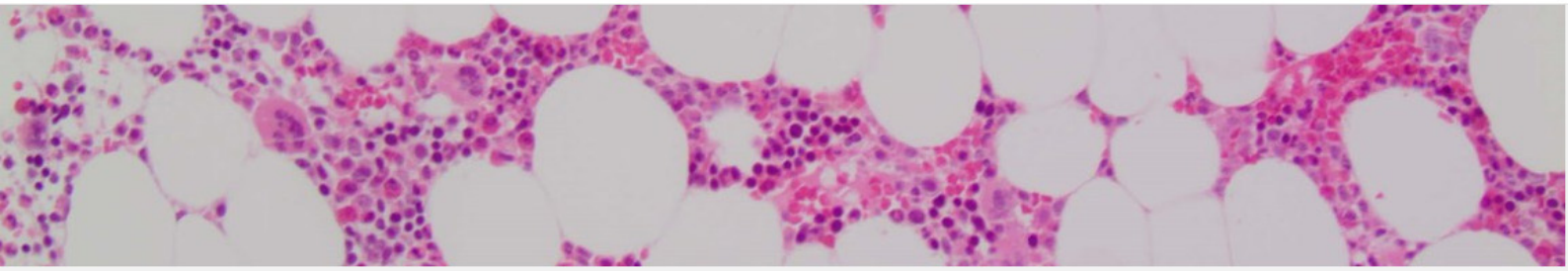
The third period activities of the MDS-RIGHT have been completed successfully, thanks to a productive scientific meeting at the Steigenberger airport hotel at October 2019 and the input of all participants, relentlessly stimulated by Corine van Marrewijk.

The MDS-RIGHT participants are working to achieve its final goal. The official completion of the project was scheduled at the end of April 2020, however, due to the COVID-19 challenges and restriction, it was necessary to request a prolongation of MDS-RIGHT for another 6 months until the end of October 2020. This extension will allow us to complete several studies, especially the studies integrating the molecular and clinical data collected and harmonised in the TRIAGE and MDS-RIGHT project. These studies are ongoing on an integrated dataset of more than 1000 patients.

The HRQoL group showed a new core outcome set with predictors for low quality of life (HRQoL). This information will be integrated with the biological (molecular) subtypes to aid the development of new clinical guidelines and cost-effective analysis.

The burden of MDS on HRQoL has been assessed by comparing HRQoL within participants of the LifeLines cohort and the EUMDS Registry. This study shows a clear MDS-specific impact on quality of life independent of red blood cell transfusions and anaemia (manuscript in preparation).

MDS-RIGHT has successfully translated the existing European MDS guideline (Malcovati et al. Blood 2013) into an interactive online guideline (see next item). All results of the MDS-RIGHT project will be integrated.



Patient management

This is a recently developed section of the website; as such, we welcome comments from our users on content, design and functionality. If you have any

5. Interactive MDS online guidelines

The MDS-RIGHT interactive online guidelines are open to anyone (https://mds-europe.eu/management).

The guidelines use the same system for evidence and recommendation level as other published guidelines. The advantage of the online format is that information about new evidence and recently approved treatments can be made available to caregivers and patients without the usual route of publication in a scientific journal. However, it is essential that everything that is added to or removed from the guidelines undergo consensus decision in the guideline committee.

There are many benefits to interactive online guidelines for patient management, the most important being that we are able to provide all physicians in Europe, specialists in haematology as well as internist and doctors in training, a handy tool for gaining access to how MDS patients are diagnosed, how prognosis is established, and how treatment is chosen based on this work-up. In other words, the online guidelines serve to elevate the median and lower level for correct management, rather than to educate MDS specialists.

The guidelines are written in a concise and well-structed format, with clear bullets. We have good experience from the Nordic MDS Group with the Nordic guidelines and many patients actually print out and bring them to their doctor and ask for further information.

6. Publications

Four manuscripts of EUMDS sub studies or collaborative studies have been submitted to peer-reviewed journals:

- Hoeks M, Bagguley T, van Marrewijk C, Smith A, Bowen D, Culligan D, Macheta M, Symeonidis A, Garelius HKG, Spanoudakis M, Langemeijer S, Roelofs R, Wiegerinck E, Tatic A, Killick S, Panagiotidis P, Stanca O, Hellström-Lindberg E, Čermák J, van der Klauw M, Wouters H, van Kraaij M, Blijlevens N, Swinkels DW, de Witte T, on behalf of the EUMDS Registry Participants. **Toxic iron species and oxidative stress in lower-risk myelodysplastic syndrome patients: course of disease and effects on outcome.**
  [Submitted: Leukemia]

- de Witte T, Malcovati L, Fenaux P, Bowen D, Symeonidis A, Mittelman M, Stauder R, Sanz G, Čermák J, Langemeijer S, Hellström-Lindberg E, Germing U, Holm MS, Mądry K, Tatic A, Almeida AM, Savic A, Mandac Rogulj I, Itzykson R, Hoeks M, Garelius HG, Culligan D, Kotsianidis I, Ades L, van de Loosdrecht AA, van Marrewijk C, Yu G, Crouch S, Smith A. **Novel dynamic outcome indicators and clinical endpoints in MDS developed during the first 10 years of the EUMDS Registry: the MDS-RIGHT project perspective.**
  [Submitted: Haematologica]

- Oster HS, Crouch S, Smith A, Yu G, Abu Shrkihe B, Baruch S, Kolomansky A, Ben-Ezra J, Naor S, Fenaux P, Symeonidis A, Stauder R, Čermák J, Sanz G, Hellström-Lindberg E, Malcovati L, Langemeijer S, Germing U, Holm MS, Mądry K, Guerci-Bresler A, Culligan D, Sanhes L, Mills J, Kotsianidis I, van Marrewijk C, Bowen D, de Witte T, Mittelman M. **Clinical and Lab Parameters may rule out and assist in the Diagnosis of MDS.**
  [Submitted: Leukemia]

- Stojkov K, Silzle T, Stussi G, Schwappach D, Bernhard J, Bowen D, Čermák J, Dinmohamed AG, Eeltink C, Eggmann S, Fenaux P, Germing U, Haschke M, Hellström-Lindberg E, Heger M, van de Loosdrecht AA, Passweg J, Pfeilstöcker M, Platzbecker U, Malcovati L, Almeida AM, Mittelman M, Morgenthaler C, Steensma D, Santini V, Stauder R, Symeonidis A, Schär S, Maddox C, de Witte T, Bohlius J, Bonadies N, the Swiss MDS Study Group, the Swiss Group of Clinical Cancer Research (SAKK). **Guideline-Based Indicators for Adult Patients with Myelodysplastic Syndromes.**
  [Submitted: Blood Advances]

6. Meeting calendar

Due to the COVID-19 pandemic, the MDS-RIGHT GA & EUMDS SC meeting (Mannheim 2020) and the Second stakeholder meeting have been postponed.

New dates will be set as soon as the situation has sufficiently stabilized and allows us to meet again.

EUMDS REGISTRY

with thanks to our patrons

NOVARTIS

PLATINUM PATRON
from 2007

AMGEN

SILVER PATRON
from 2017

Celgene

SILVER PATRON
from 2019

janssen
PHARMACEUTICAL COMPANIES OF Johnson&Johnson

SILVER PATRON
from 2020

MDS EUROPE
mds-europe.eu

all the MDS-related information you need, in one place