MBDS

MALTA BLEEDING DISORDERS SOCIETY

NEWSLETTER

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WORLD FEDERATION OF HAEMOPHILIA VISIT

On Saturday 2nd November 2019, the MBDS was visited by the World Federation of Haemophilia (WFH). Alain Weill, WFH President, and Yulian Tsolov, WFH European Regional Manager attended Mater Dei Hospital, where they were received by the MBDS.

The visit started with an introductory presentation on the MBDS structure, statute, projects and action plan delivered by MBDS President Dr James Gauci. MBDS Medical Advisor Prof Alexander Gatt then delivered a presentation on the care and treatment for people with bleeding disorders in Malta.

Product availability was discussed, as well as the local multidisciplinary team and international collaborations involved in the care of people with bleeding disorders. The Malta Centre for Bleeding and Thrombotic Disorders at Mater Dei Hospital is listed on the European Association for Haemophilia and Allied Disorders (EAHAD) website as a certified European Haemophilia Treatment Centre (EHTC).

WFH President Mr Alain Weill gave an overview of the World Federation of Haemophilia and the accreditation process. The WFH priorities are to improve outreach and diagnosis of people with bleeding disorders, to increase sustainable access to safe therapies, and to increase access to adequate and affordable care. The MBDS intends to apply for WFH membership at the next WFH General Assembly in June 2020 in Kuala Lampur. This will be followed by an application to join the European Haemophilia Consortium. Benefits of joining the WFH include access to publications, and access to WFH healthcare programmes such as Global Alliance for Progress (GAP), International Haemophilia Treatment Centre Fellowships, and Twinning partnerships. Further benefits include participation in WFH congresses, and participation in skills training workshops.

Discussion was followed by a visit of the Coagulation and Haematology Laboratories and of the Haemophilia Treatment Center at Mater Dei Hospital.

WORLD FEDERATION OF HAEMOPHILIA VISIT

USEFUL LINKS

World Federation of Haemophilia website
www.wfh.org/en

WFH Global Alliance for Progress website:
www.wfh.org/en/our-work-reg-national/gap-program

WFH Annual Global Survey website:
www.wfh.org/en/our-work-research-data/annual-global-survey

WFH Educational Materials
www.wfh.org/en/resources-education/educational-materials

Travellers:
European Association for Haemophilia and Allied Disorders (EAHAD) certified centres map www.euhass.org/aspxpages/certcentres.aspx

Women of child-bearing age:
Self-administered Bleeding Assessment Tool (SELF-BAT)
www.letstalkperiod.ca/self-bat

CSL Behring
Biotherapies for Life™

MBDS EDUCATIONAL WORKSHOP

On Friday 27th December, the MBDS organised an educational workshop at the Salini Resort in Bahar ic-Caghaq. Grant for the event was supplied by CSL Behring. Ms Chanel Cassar delivered a presentation on Awareness Campaigns. She spoke about the importance of raising awareness on the symptoms and signs of bleeding disorders, both among healthcare professionals and non-healthcare professionals. The subject of bleeding disorders in women of child-bearing age was also discussed.

Our international guest speaker was Prof Albert Farrugia, Professor at the University of Western Australia, as well as Advisor for the European Haemophilia Consortium and for the Associazione Emofilici di Toscana. Prof Farrugia delved into the history of Haemophilia and the use of clotting factor concentrates. He then explained the new and emerging treatments in Haemophilia, by highlighting the mechanism of action, advantages and disadvantages of extended half-life agents, non-factor agents and gene therapy. The talk was followed by a discussion on the way forward for the MBDS as regards the application for the procurement of newer therapies in Malta.

MEETING WITH MARIGOLD FOUNDATION

The MBDS was received by Mrs Michelle Muscat, founder of The Marigold Foundation and President of the National Alliance for Rare Diseases Support, and Ms Josette Azzopardi, Secretary of the National Alliance for Rare Diseases Support, at Villa Francia in Lija on Wednesday 20th November 2019. The MBDS members outlined the aims of the society, and the results that MBDS has achieved so far. Several issues were discussed, including the importance of a registry of patients with bleeding disorders and the tendering process for the procurement of medicines.

The MBDS is now in contact with the managerial staff of The Meeting Place in Marsa, which is intended for voluntary organisations, in order to register to use such facilities. The MBDS has submitted its application to join the National Alliance for Rare Diseases Support.