

## **March 2024 – February 2025**

March 2024	Annual General Meeting
Periodically	Advocacy Workshops with THS UK
Periodically	Financial Strategy Workshops with THS UK
April 2024	WHD Celebration
April 2024	Global NMO Training – James Gauci
April 2024	WFH GA in Madrid – Alex Gatt and James Gauci
April 2024	EHC Catch Up – James Gauci
May 2024	Kurzita Jiem
June 2024	EHC Leadership Conference – Iliana Chatzifragkou
July 2024	UK Youth Camp 2024 – Jacqueline Cilia, Ivan Cilia and Jake Cilia
September 2024	Fundraising Event: Gozo – Malta Swim
September 2024	Self-Advocacy Symposium
September 2024	Launch of PROBE Questionnaire
October 2024	EHC Congress in Sofia – James Gauci
November 2024	EHC ERIN Summit 2024 in Croatia – Jacqueline Cilia, Ivan Cilia and Jake Cilia
December 2024	Twinning Project Action Planning for Year 2
January 2025	EHC Catch Up – James Gauci
February 2025	Haemophilia Treatment Options & Shared Decision Making Conference in Lisbon – Jacqueline Cilia

### **March 2023 – April 2024**

March 2023	Annual General Meeting and Election of new Executive Committee
April 2023	World Haemophilia Day Campaign
May 2023	CHI-MA-HAEM-NET project
June 2023	Meeting with Minister for Health
July 2023	WFH Twinning Program – Assessment Visit to Malta
September 2023	WFH Annual Meeting of the GA
September 2023	EHC Catch-Up
October 2023	EHC Congress in Zagreb – Iliana Chatzifragkou
December 2023	Christmas Outreach Event
December 2023	WFH Twinning Program – Successful Application
January 2024	WFH Twinning Program – Action Planning for Year 1

### **March 2022 – April 2023**

April 2022	Youth Leadership Workshop
April 2022	World Haemophilia Day Celebrations
April 2022	Article on MBDS in Online Journal of Haemophilia and Medicine
April 2022	WFH Meeting on Standards for NMO Capacity Development
May 2022	Meeting with Directorate of Pharmaceutical Affairs
May 2022	Attendance at WFH Annual Meeting
October 2022	Attendance at EHC Congress
October 2022	WFH Self-Assessment Visit
November 2022	Appointment of Ms Iliana Chatzifragkou as Social Media Officer
December 2022	Attendance at European Rare and Inhibitor Network Summit – Jacqueline Cilia, Ivan Cilia and Jake Cilia
December 2022	Christmas Dinner
January 2023	Development of Strategic Plan and Key Values
January 2023	EHC Meeting on Treatment Updates
February 2023	EHC Community Call: Launch of Organisational Health Programme
February 2023	Receipt of Educational Grant from Drugsales Ltd.
February 2023	Submission of Letter on Improved Treatments from EHC to Authorities
March 2023	WFH Meeting on Twinning Program
March 2023	Launch of 'Awareness on Bleeding Disorders' Videoclip
March 2023	Overview of Medical Therapy in Haemophilia
March 2023	Workshop on Physiotherapy in Bleeding Disorders
Periodically	Translation and Publication of 'Haemophilia in Pictures'

### **March 2021 – April 2022**

March 2021	Annual General Meeting and Election of New Executive Committee
April 2021	WHD Celebrations
July 2021	EHC Webinar on Key Concepts and Principles of Care for BD
July 2021	Online Workshop for Physiotherapists
September 2021	WFH Global Policy and Access Summit
October 2021	EHC Membership
November 2021	NMO Meeting with EHC
December 2021	Teambuilding and social event
February 2022	Publication of 'Haemophilia in Pictures' in Maltese Volume 1
March 2022	Application for EHC Activity Grant for WHD
Periodically	Distribution of educative material
Periodically	Social media updates

## **March 2020 – April 2021**

March 2020	Annual General Meeting and Updated Action Plan for 2020-2021
March 2020	Publication of COVID-19 Advice Memo for Patient with Bleeding Disorders – Prof Alex Gatt
April 2020	Confirmation from WFH that the MBDS has met the eligibility requirement to be an Associate NMO
May 2020	Attendance at WFH Virtual Summit
May 2020	Attendance at EHC Women & Bleeding Disorders Conference
October 2020	MBDS becomes an Associate Member of the WFH
October 2020	Attendance at WFH GA
October 2020	Publication of Adverts on Facebook to increase membership
November 2020	Introductory Meeting with WFH – open to all members
November 2020	MBDS applies for WFH Activity grant on ‘Increasing Awareness about Bleeding Disorders’
November 2020	Article on MBDS in Haemophilia World Online  <a href="https://news.wfh.org/malta-bleeding-disorders-society-becomes-an-associate-national-member-organization/">https://news.wfh.org/malta-bleeding-disorders-society-becomes-an-associate-national-member-organization/</a>
November 2020	Presentation at European Advocacy Webinar
November 2020	Campaign on Primary Identification of BD – First Project <ul style="list-style-type: none"><li>- Adaption of leaflets created by Swedish Haemophilia Society</li><li>- Versions in Maltese and in English</li><li>- Versions addressed to health professionals and general public</li><li>- Online dissemination</li></ul>
December 2020	Meeting with WFH President, VP NMO & CEO
January 2021	Contribution to WFH Covid-19 Relief Fund
January 2021	Publication of COVID-19 Vaccine Advice Memo for Patient with Bleeding Disorders – Prof Alex Gatt
February 2021	WFH NMO Consultation Meeting on Strategic Plan

Periodically	<p>Distribution of educative material</p> <ul style="list-style-type: none"><li>- Link to HaemoAction Online Games</li><li>- Guidance regarding COVID-19 vaccination for people with BD</li></ul>
Periodically	Social media updates

## March 2019 – April 2020

March 2019	Foundation of MBDS and appointment of Executive Committee
June 2019	Official launch and Educative event <ul style="list-style-type: none"> <li>▪ MBDS Set Up – Dr James Gauci</li> <li>▪ Joining International Committees – Mr Jo Eerens</li> <li>▪ Overview of Treatments of Haemophilia Discussion – Prof Makris</li> <li>▪ Discussion – Members</li> </ul>
July 2019	Development of Action Plan for 2019-2020

1	Application for Status as a Voluntary Organisation
2	Launch of MBDS with educative information for patients and families
3	Press Release re set up of MBDS
4	Media interviews re set up of MBDS
5	Creation of social media platforms
6	Creation of e-newsletter
7	Distribution of educative / informative pamphlets
8	Fundraising campaigns and workshops
9	Representation on an international level
10	Subscription to EHC mailing list
11	Becoming a national member organisation of WFH and EHC
12	Establishing a National Bleeding Disorders Patient Registry
13	Working to ensure Ensuring Mater Dei Hospital is a comprehensive care centre (CCC)

July 2019	Application and acceptance for Status as Voluntary Organisation
July 2019	Press release re set up of MBDS
September 2019	Creation of social media platforms
September 2019	Publication of MBDS e-newsletter – first issue
October 2019	Newsbook interview re set up of MBDS
October 2019	Attendance at EHC Congress in Skopje and Subscription to EHC mailing list – Dr James Gauci
November 2019	Attendance at Yearly Inhibitors Summit in Ireland – Jacqueline Cilia, Ivan Cilia and Jake Cilia
November 2019	Attendance at WFH 7 <sup>th</sup> Youth Leadership Conference in Amsterdam – Chanel Cassar

November 2019	Meeting with Ms Michelle Muscat, founder of Marigold Foundation and president of National Alliance for Rare Diseases Support <ul style="list-style-type: none"> <li>▪ Overview of aims of MBDS</li> <li>▪ Discussion re importance of National Patient Registry</li> <li>▪ Use of Meeting Place in Marsa</li> <li>▪ Involvement in Tendering process for procurement of medicines and updating of the Formulary for free medicines</li> <li>▪ Discussion re finances for specific projects</li> </ul>
November 2019	WFH accreditation visit by Mr Alan Weill (CEO) + Mr Julian Tsolov (European Manager) <ul style="list-style-type: none"> <li>▪ Haemophilia and Allied Bleeding Disorders in Malta – Prof A Gatt</li> <li>▪ MBDS Structure, History, Members and Aims – Dr James Gauci</li> <li>▪ WFH Overview + Accreditation process – Mr Alain Weill</li> <li>▪ Open discussion – Members</li> <li>▪ Visit of Hemophilia Treatment Center and Laboratory – Members</li> </ul> <p>Following this visit, we were informed the WFH Accreditation Committee confirmed that Malta Bleeding Disorders Society has met the eligibility requirement to be an Associate NMO and the Board of Directors have also recommended Malta Bleeding Disorders Society to be accredited as an Associate NMO at the WFH General Assembly. Accreditation of NMOs needs to be confirmed by voting members at the General Assembly of the WFH, based on the recommendation of the Accreditation Committee and approval of the Board.</p>
November 2019	Application for and acceptance as Member of the National Alliance for Rare Diseases Support
December 2019	Appointment of Ms Chanel Cassar as Awareness Campaign Co-Ordinator
December 2019	Educative event – What is the fuss about bleeding disorders? <ul style="list-style-type: none"> <li>▪ Introduction – Prof Alexander Gatt</li> <li>▪ Patient Empowerment – Ms Chanel Cassar</li> <li>▪ New treatments in Haemophilia – Prof Albert Farrugia</li> <li>▪ Discussion – Members</li> </ul>
January 2020	Publication of MBDS e-newsletter – second issue
February 2020	Attendance at Rare Diseases Day, organised by the National Alliance for Rare Diseases Support – Prof A Gatt, Dr James Gauci
Periodically	Distribution of educative material