

EAHAD Joint Health in Inherited Bleeding Disorders Working Group

Terms of Reference

1. Purpose and goals

The purpose of the Joint Health in Inherited Bleeding Disorders Working Group is to improve the management of joint health in patients with inherited bleeding disorders, such as haemophilia, through evidence-based research, standardization of care, and educational initiatives. The Working Group will focus on improving early diagnosis of joint issues, improving management based on current best evidence and enhancing overall quality of life.

The goals of the Working Group are:

- **Establish standardized ultrasound biomarkers** for identifying subclinical bleeding, synovitis, and osteochondral damage in patients with haemophilia.
- **Collaborate with international and national scientific societies** to establish a standardized language for the diagnosis and management of joint health using ultrasound.
- **Promote education and training** by developing and implementing courses on joint health assessment for healthcare providers in European Haemophilia Treatment Centres (HTCs).
- **Define research priorities** in the field of joint health in inherited bleeding disorders to focus on clinically relevant and patient-centered projects.

2. Membership

- The Working Group will include between ten (10) to fourteen (14) members, including experts in haemophilia, joint health, imaging, musculoskeletal ultrasound.
- They will include a range of professionals, including medical, as well as nursing colleagues and physiotherapists and other experts as required.
- Members may be invited based on expertise in haemophilia care, joint health, and imaging.
- The Chair will be appointed by the EAHAD Executive Committee.
- At least one EAHAD Executive Committee member will be included as a member of the Working Group.
- Additional co-opted members with specific expertise may be invited to participate in relevant projects as needed.

3. Duration of the mandate

- The Working Group will have a fixed term mandate of two (2) years. After that period, the mandate term will be re-evaluated by the Executive Committee, based on goals, objectives, and deliverables.

4. Frequency of Meetings

- Maximum of five (5) meetings per year. The meetings will be in-person or virtual.
- In-person meetings should, when possible, be organised to coincide with other meetings (e.g. the annual congress)

- All Working Group members are required to actively participate in the work of the Working Group
- At least one staff representative from the EAHAD Office will attend the meetings and help with the preparatory work, the minutes and reporting.

5. Funding

- Meetings and support by the EAHAD Office will be funded by EAHAD with possible external support according to the EAHAD Sponsorship Policy.
- The annual budget is 10,000 EUR.
- The funding will cover in-person meetings, teleconferences, publication fees, IT support, etc.

6. Reporting requirements

- The Working Group will produce reports outlining its progress on agreed objectives. The reports will be submitted to the Executive Committee. A summary will be included in the EAHAD annual report.
- Minutes will be drafted and distributed to Working Group members after the meeting date.

7. Dissemination activities

- The Working Group will support the dissemination of its activities by providing content to the EAHAD staff to share on the EAHAD website and social media channels
- Publications and presentations by the Working Group are encouraged
- Any publications should acknowledge the Working Group and all its members

8. Review of the terms of reference

- The Working Group will review the terms of reference every two (2) years

October 2024