

EHC-NMO Organisational Health Programme

Rationale of the programme

- Tool to help the NMOs fulfil the statutory requirements (Article 5.3.) adopted in 2021;
- Tool to support an ongoing evaluation, growth and improvement of the NMOs and the EHC itself;
- Opportunity for self-reflection and place for improvement for the NMOs and EHC itself;
- A process with worldwide recognition to support the NMOs in more successful fundraising and advocacy;
- Long term incompliance and stagnation may lead to reviewing of the membership.



Implementation instruments

Principles of Good Organisational Health

Building blocks of a healthy organisation, extension of the paragraph 5.3. of the EHC statutes where the NMO obligations are outlined.

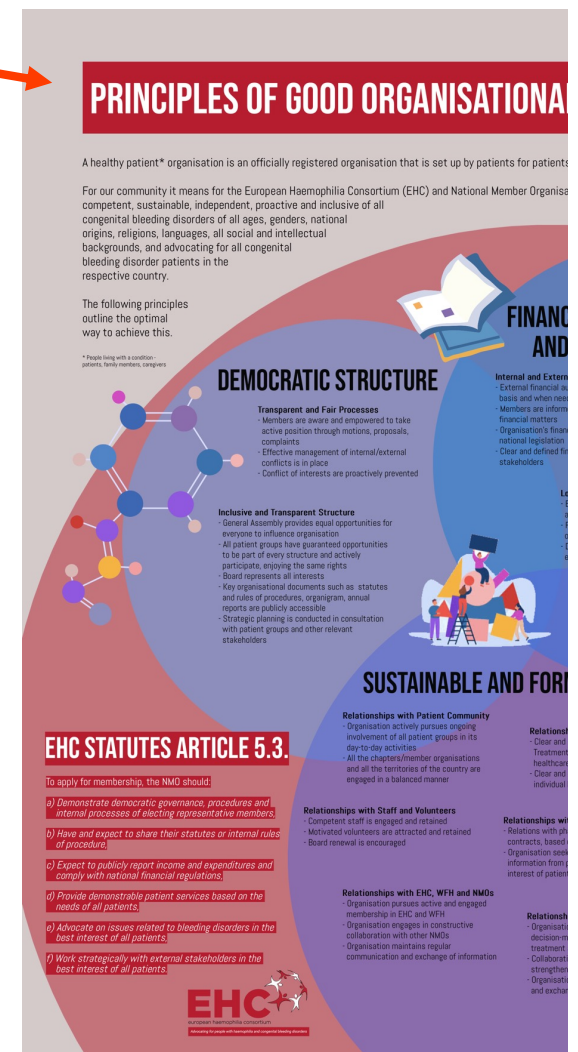
Assessment Tool

Assessment Tool that is developed for the WFH Capacity Development Program will be used also for the EHC OHP, focusing on aspects relevant for the OHP.



Toolkit for Good Organisational Health (to be produced during 2023)

Community recommendations and alternative practices which keep in mind the diversity of the EHC membership and will offer concrete tools and good practice examples to improve organisation's health under each OHP principle.

Will include NMO reports as good practice examples.



Process in 2023




February – June 2023: time to conduct the Assessment Interviews with the NMOs that are expected to report to the GA in 2024 (Groups 1-2-3). The actual schedule will be worked out in discussion with the individual NMOs.

ALL NMOs are invited to do the self-assessment.



EHC Leadership Conference 2023: An opportunity for exchange and update

Time will be set aside during the EHC Leadership Conference in June for the NMOs to have a structured exchange about the OHP process, seeking exchange of experiences and best practices.

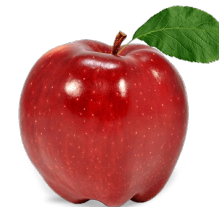


June – October 2023: continued work with the Assessment Panel to develop tailored action plans.



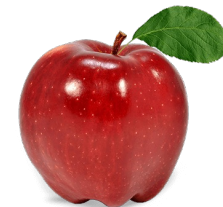
EHC GA 2023: An opportunity for exchange and update

Time will be set aside during/around the EHC GA in October for the NMOs to have a structured exchange about the OHP process, seeking exchange of experiences and best practices.



Results and reflections so far

- Assessment calls with **7 NMOs** carried out so far, 1 availed of the **interpretation offer**.
- If not full boards, then multiple board members always present at calls.
- Provides very **deep insight** and **better understanding** of the structure, functioning and work of the NMOs.
- NMOs report **the process itself to be beneficial** to them as offers time to analyse and reflect.
- Strengths and challenges are rather individual, but there are **trends to be observed**.
- More time consuming than anticipated 😊



EHC Youth Strategy

Preparing our NMOs for succession, autonomy & independence

Youth Leadership Workshop

Focuses on training and empowering young leaders to be strong and active voices in the community.

Leadership Conference

This conference brings together patients, leaders and staff to work in collaboration and share experiences



Youth Fellowship Programme – launched in 2019, focuses on cross national collaboration and helping youth become involved in the goals of both their NMOs and the EHC



EHC Conference

We encourage engagement from our youth at all EHC events but at EHC Conference they are invited to attend the full EHC Conference and are given the responsibility of defending a position publicly, alongside esteemed experts in our community having being provided with training and support by the EHC beforehand.



On a Pathway Towards Healthy Ageing

- Needs assessment survey in 2021
- Dedicated WHW in 2023
- Dedicated webinars in 2023:
February, April, September, November
- Community preview of the film at the LC 2023
- Film premiere and a Round Table of Stakeholders in December 2023

#ageinghealthy

On a Pathway Towards Healthy Ageing: **Possibilities for Support**

Thanks to the improvements in treatment today people with haemophilia and other rare bleeding disorders are living longer than ever. However, there are still challenges that need to be addressed. To understand what those challenges are and how to best address them, the EHC carried out a needs assessment survey* among the members of the bleeding disorders community.



* Survey was carried out in quarter 3 of 2021, **181** valid responses from **13** countries were received, representing men and women with a variety of bleeding disorders in the age range of **50-81** years.

#ageinghealthy

EHCUcate

- 3 new topics on Emicizumab are coming out shortly!
- 3 gene therapy topics to be released next.
- treatment content to be expanded to all treatment options including factor replacement therapies.





***360-degree patient education!
Coming out this year to help NMOs navigate through the complexity of topics.***

The EHC Academy is designed to include the following blocks:

- Treatment (EHCucate project and EHC New Treatment newsletter, treatment by cohort information).
- Legislation (EHC Public Policy Reviews).
- Access to treatment and care (Surveys, Health Economics Course).
- Advocacy materials (Principles of Care, handbooks, statements).

With the motto “Empowering the bleeding disorders community”, we aim to empower members of our community by providing them with unique high-quality knowledge and practical tools, scaling up their advocacy skills. Thus, making a step forward towards a better quality of life for patients in Europe.

THE REGISTRATION TO THE HEALTH ECONOMICS COURSE IS NOW OPEN!

FACE-TO-FACE: 15-18 JUNE
PENTA HOTEL BRUSSELS CITY CENTRE
BRUSSELS, BELGIUM

EHC LEADERSHIP CONFERENCE 2023

#thisway campaign

- Objectives: promote deep health, educate & inspire members of the community to make *sustainable* lifestyle changes
- Quarterly EHC staff physical activities (Tai Chi, hiking, cycling, etc.)
- #thisway walks/guided tours at EHC conferences
- Interviews, articles, videos, surveys, challenges, etc.



Ross' story

HOME • EHC NEWS • ROSS' STORY

In the framework of our #thisway campaign, the EHC interviewed **Ross Bennett (25)**, a patient with severe haemophilia B, who shared with us not only his struggles around sports but also how he overcame them, how he managed to stay physically active, despite all the injuries and bleeds he suffered throughout the years, and plenty of actionable steps you as a patient can take to improve your physical health.

We hope you find Ross' story inspirational and his tips helpful. If you have any questions or would like to get in touch with Ross, please do not hesitate to drop us an [email](#).

Ross Bennett (25), United Kingdom

"I was diagnosed with severe haemophilia B when I was 3.5 years old after I cut my tongue on a Coke can. It bled for a week, so my dad took me to the hospital, so I was diagnosed late, even though for years I had smaller bleeds and was constantly covered in bruises.

When I was 8, I had a major bleed in my right thigh and I spent 4 weeks in the hospital, and it took me 12 weeks to learn to walk again. It was also at that age I started prophylaxis, which wasn't widespread in the UK back then, and got serious with sports afterward, even though I had a lot of right thigh bleeds from 8 to 21 years old and right shoulder bleed at least 30-40 times, and other big injuries such as twisting ankles.

Despite my medical condition, I was active from the day I learned to walk. My parents would take my sister and I swimming at a very young age, and at age 7, I went to boarding school, and started doing sports daily: I played football, field hockey, and cricket, and I would run and cycle. In university, I played baseball at a high level.





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EHC LEADERSHIP CONFERENCE 2023

#thisway campaign - Every Step Counts

- Announcing: EHC community challenge
- In the fall, leading up to the EHC Conference (6-8 October)
- Work at your own pace, by yourself or with others
- Log your activities via MapMyRun 📱
- Win a gym goodie bag for your NMO

*Watch the EHC website & social media channels –
more information coming over the summer!*

Workout name

Start time Date *

HH:MM AM 🕒 06/01/2023 📅

Activity *

Select an activity type

- Football, Casual
- Gardening
- General Sports
- Golf
- Hang Gliding
- Horseback Riding
- Inline / Roller Hockey

Let the EHC support you!

- Use the EHC Activity Grants and Physical Activity Grants to implement your projects!
- Stay informed by signing up to receive the EHC monthly Newsletter – features updates from the EHC and NMOs, important news & dates!
- Make use of the EHC tools available – Novel Treatment Products Newsletter & Gene Therapy Guidebook!



Follow the EHC



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EHC LEADERSHIP CONFERENCE

2023



LET'S GROW TOGETHER!

FACE-TO-FACE: 15-18 JUNE
PENTA HOTEL BRUSSELS CITY CENTRE
BRUSSELS, BELGIUM

BIOMARIN
haemophilia

SANOFI GENZYME



sobi
rare strength