# Congress Interview

We had the pleasure of speaking with Ana Boban, President of the European Association for Haemophilia and Allied Disorders (EAHAD) and Head of the Haemophilia Centre at the University Hospital Centre Zagreb, Croatia. In this interview, she shares her vision for EAHAD's 2026–2028 term, discussing priorities such as harmonising care across Europe, advancing research and education in inherited bleeding disorders, and supporting clinicians and patients in an evolving therapeutic.

**Featuring:** Ana Boban

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President, European Association for Haemophilia and Allied Disorders (EAHAD); Head of the Haemophilia Centre, University Hospital Centre Zagreb, Croatia

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## EAHAD 2026–2028: Vision and Priorities

**Q1 What is your overarching vision for the European Association for Haemophilia and Allied Disorders (EAHAD) during your 2026–2028 term, and what are the key priorities you hope to achieve?**

The goals have always been the same, with core EAHAD activities focused on advancing care for patients with inherited bleeding disorders; first haemophilia, but also von Willebrand disease (VWD) and other rare bleeding disorders. Although the name of the organisation stresses haemophilia, we are also taking care of the entire community of inherited bleeding disorders. All our steps, research, education, and congresses aim to increase the quality of care for patients.

However, if I had to choose one outcome or one goal, it would be trying to harmonise care across all European countries. Obviously, that is not an easy task, due to the huge differences between countries in economic status, culture, geography, education, availability of drugs, and organisation of healthcare systems. Taking all that together, it is a difficult task, but as a European organisation, we are at least trying to achieve equity, so that all patients have access to both diagnosis and treatment.

On the other hand, although EAHAD is a European organisation, it has a global impact on the haemophilia community. This year's congress attracted delegates and speakers from almost 80 countries all over the world, and the results of the major clinical outcomes and studies were presented.

**Q2 How do you plan to build on the successes of previous leadership while addressing the evolving challenges in haemophilia and allied disorders?**

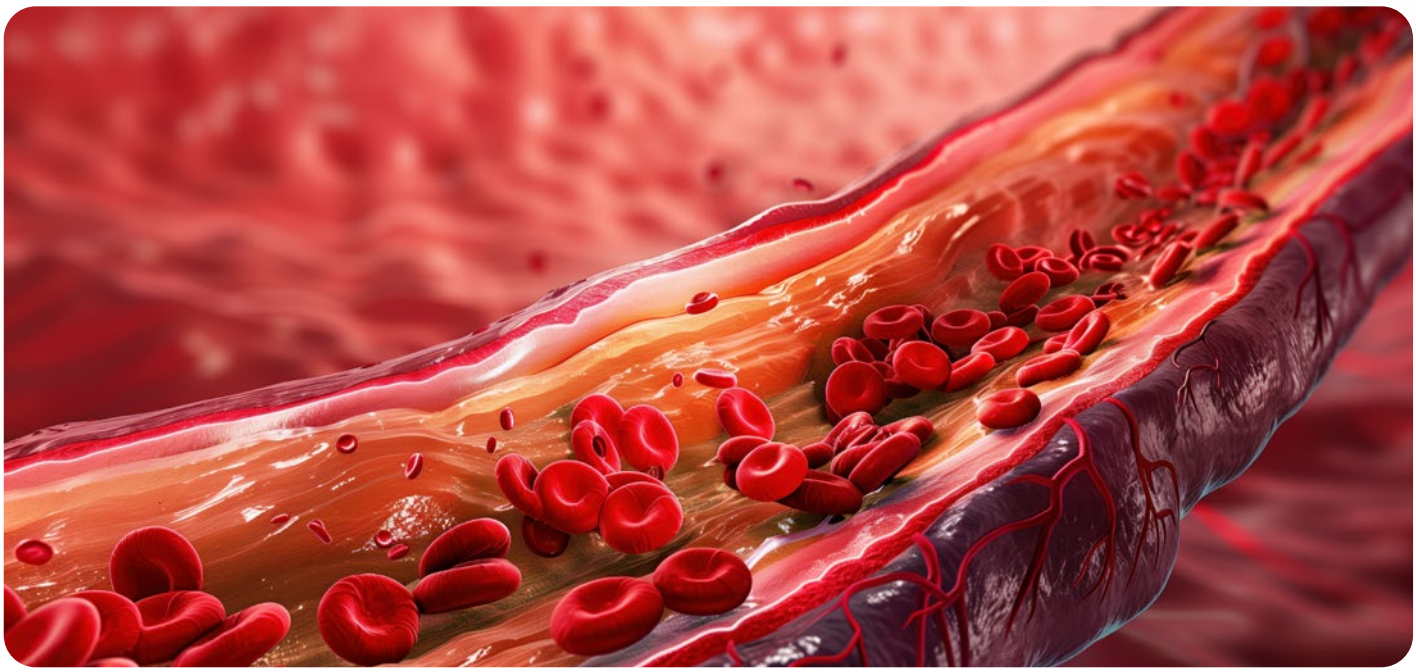
The projects EAHAD is running are usually long-term ones. The term of the president lasts 2 years, but I was serving as Vice President for 2 years, and will be serving as Past President for 2 years. Therefore, it is a period of 6 years where one can develop a programme, and commonly the new leadership continues the work and builds on it.

The EAHAD is running a number of projects, some on the level of the Executive Committee, some on the level of the working groups. We have several working groups focusing on the treatment of haemophilia, but also other aspects of management of haemophilia and other inherited bleeding disorders. We have a working group on Glanzmann thrombasthenia, on very rare bleeding disorders, and now we have established the group for VWD. The groups have been very active, which is also seen in the Congress presentations, published data, and statement papers.

When I joined EAHAD, I started a working group on the new accreditation process of haemophilia centres. Almost 200 haemophilia centres in Europe are certified by EAHAD, and are designated as haemophilia treatment centres or comprehensive care centres. The first goal of the working group was to update the guidelines for certification, so they reflect the advancements in treatment and the current management of patients with haemophilia, including gene therapy. Now, we are proposing a new protocol for the auditing of haemophilia centres. The pilot project is finished, and we are deciding how to move forward. Our goal is to have at least one EAHAD-accredited haemophilia centre in every European country, and active EAHAD members from all European countries. With that, we will have a much clearer picture of what is missing and what is needed, in terms of organisation, education and research, and finally, how we can help local countries achieve the standards for high-quality haemophilia centres.

**Q3 Are there specific areas within clinical practice, research, or education where you see the greatest opportunity for impact during your presidency?**

I think we are living in exciting times for haemophilia and other inherited bleeding disorders. A number of new molecules have entered the therapeutic field of haemophilia, and now we have to understand how to use them. Non-factor treatment, subcutaneous treatment, gene therapy: these drugs have different mechanisms of action, a different impact on haemostasis, and a different treatment burden, and therefore the treatment decisions are becoming increasingly complex. There are still unknowns regarding the efficacy and toxicity of these new treatment options, and we need to collect more data from patients treated outside of clinical trials. EAHAD has an important role in collecting these data. The



European Haemophilia Surveillance System (EUHASS) is monitoring the safety of treatments for people with inherited bleeding disorders in Europe.

The treatment for haemophilia is personalised. There are number of treatment options, and we need to learn how to use new drugs, and find the best option for every patient based on the disease type, bleeding phenotype, comorbidities, and lifestyle.

EAHAD has an important role in dissemination of knowledge, education, research, and collection of safety data on current treatments. Another important role of EAHAD is to increase awareness and support the research in other bleeding disorders. Usually, when addressing inherited bleeding disorders, the focus is on haemophilia. Even the name of the centres for inherited bleeding disorders is haemophilia centres. The patients with other inherited bleeding disorders were not so much in focus for a while, and research in the area was sparse. It can be challenging to do research in rare diseases and, moreover, rare bleeding disorders are often underdiagnosed.

I believe that we need to raise awareness about rare inherited bleeding disorders among physicians and the general population, to enhance timely diagnosis and start adequate treatment, in order to prevent complications.

**Q4 Looking back at this year's EAHAD Congress, what sessions or highlights stood out to you as particularly impactful?**

I believe we had a great Congress this year. We had an interesting programme, and we tackled different aspects of inherited bleeding disorders.

As I mentioned earlier, we are also trying to address the rare and extremely rare bleeding disorders. We had an interesting presentation from the working group on Glanzmann thrombasthenia. Glanzmann's National History Study (GNHS) was presented, with the aim of understanding the diversity in the clinical presentation of the disease. Then we focused on the women and girls with bleeding disorders, including Glanzmann's and VWD, and the management of pregnancy.

We then introduced a bit of basic sciences, with an interesting presentation on the molecular mechanism of angiodysplasia, a complication of VWD. VGA039, a new targeting molecule for VWD, was presented, and demonstrated possibility of prophylaxis of bleeds in patients with VWD through a subcutaneous drug, which is an unmet need in this group of patients. We often compare treatment possibilities in haemophilia and VWD, and at the moment, haemophilia research has progressed much further than VWD.

In the field of haemophilia, we heard interesting data from the PedNet group about the occurrence of inhibitors in previously untreated patients. To follow up on gene therapy, we had a discussion on side effects, dominantly liver health, and a demonstration of the 5-year results of the HOPE trial. Moreover, 9-year follow-up results from one of the first gene therapies for haemophilia

## The Haemophilia Landscape in Europe

**Q5 From your perspective, how would you describe the current landscape of haemophilia and rare bleeding disorders in Europe today?**

The treatment landscape has evolved significantly during the last couple of years. New molecules have improved the outcome of prophylaxis, not only by reducing the number of bleeds, but also by allowing patients more freedom and increased physical activities without increasing the risk of bleeding. Therefore, the aim of treatment is not only zero bleeds in patients who are sedentary, but also for those who are physically active, especially the young people who are starting prophylaxis at an early age. Moreover, the new treatment

has significantly alleviated the treatment burden, as the drugs are administrated subcutaneously or intravenously once weekly. This is even more true with gene therapy.

Gene therapy can achieve stable levels of Factor VIII or Factor IX after a single intravenous injection. The majority of patients treated with gene therapy have been free from regular prophylaxis. Results are a bit more favourable in the treatment of haemophilia B; it seems that Factor IX is much more easily incorporated in the liver, and the patients can achieve long-term stable levels of the factor.

Regarding other diseases, for example VWD, there has been a lot of discussion on how to increase awareness of the disease, to achieve timely diagnosis, as a large number of patients are still unrecognised and undiagnosed. The current treatment possibilities include supportive treatment and concentrates of VWF; however, the prophylactic treatment has not been established as in haemophilia. More studies and clinical experiences are needed in this area. We hope that the future treatment of VWD will include molecules that can be applied subcutaneously and, maybe in the future, gene therapy, although it is a bit more complicated than the gene therapy for haemophilia.

On the other hand, we are still missing specific treatment for a number of rare and extremely rare coagulation disorders. For the majority of these patients, we can manage bleeding in surgery or trauma; however, the treatments are not convenient for standard prophylaxis. Several molecules are in research for treatment of rare bleeding disorders, like Glanzmann thrombasthenia, and we hope that we will have these molecules in clinical practice soon.

**Q6 Which recent scientific or therapeutic advances do you believe are most influencing clinical care?**

I think that the possibility of subcutaneous treatment with good efficacy but reduced treatment burden is something that changed the haemophilia treatment landscape. Also, modified recombinant FVIII and FIX that require less injections, but offer better protection from bleeds have allowed the patients more freedom and increased quality of life. With the new options for prophylaxis, which are efficacious but with less rigid treatment burden, we need to redefine the outcome measures. Annual bleeding rate of zero is commonly achieved, and we need to find new, more precise outcomes and measures of the efficacy of the treatment. Now, we are focusing on more subtle changes, like micro bleeds, minimal joint damage evaluated by ultrasound and MRI, quality of life, and liver health (that has been introduced and pushed a little bit more due to gene therapy).

Following that, coming back to the accreditation programme for haemophilia centres, I believe that these changes also have an implication for the organisation of the haemophilia centres, and that the centres have to adapt to new needs and even introduce new members to the multidisciplinary teams.

**Q7 Where do you see the greatest unmet needs for patients and healthcare professionals, and how can EAHAD address these during your term?**

Despite significant progress in treatment possibilities for patients with inherited bleeding disorders, there are still unmet needs. For one, there are patients with haemophilia who don't have adequate prophylaxis. There are patients with haemophilia B and inhibitors, who didn't have prophylaxis until recently. Now, a new drug has been approved by the EMA for the treatment of patients with haemophilia B and inhibitors, but it is still not available in all European countries.

Also, as I mentioned before, a number of patients with inherited bleeding disorders other than haemophilia have no available prophylaxis, or no possibility for convenient long-term prophylaxis.

The patients with haemophilia who were born before the start of the regular prophylaxis of haemophilia suffered numerous joint bleeds, and have developed chronic arthropathy, disability, and chronic pain. These are the issues that we have to address and follow up in the future.

## Innovation and the Future of Care

**Q8 How can young clinicians and researchers be best supported to contribute to this evolving field?**

EAHAD recognises the need for supporting young scientists and clinicians and attracting them to the field of bleeding disorders. This is not easy, as young physicians have so many possibilities in so many different aspects of medicine. We believe they are not only the future, but the present of the Society. They are coming from the universities open minded, full of knowledge and enthusiasm, and have a lots of ideas on how to enhance the diagnosis, treatment, and management of bleeding disorders.

EAHAD offers several opportunities for young physicians: travel grants, to be able to travel to another country and spend some time in other centres; and research

grants, which every year become more and more competitive. From this year, we have a new session during our Congress that is dedicated to investigators in scientific research, and it was established with the aim of allowing young scientists to present their work. We are also inviting young scientists to come and present their work as a poster presentation. This year, we had the largest number of poster presentations. Each year, the best posters are rewarded. I believe it is important to show the young people that we care about their work, and to encourage them to persevere in their research.

**Q9 Looking beyond 2028, what long-term achievements would you like EAHAD and the broader haemophilia community to have realised in the next 5–10 years?**

It's not easy to answer this question, but, with the speed of progress that we are currently seeing in the management of haemophilia, I think that in 10 years we can achieve perfect prophylaxis, so that all patients with the severe disease/severe bleeding phenotype will have prophylaxis that is highly efficacious, but without any side effects and without high treatment burden. Gene therapy is starting to develop really quickly. There are a number of different gene therapy studies currently underway, Phase II and Phase III, on gene editing and new vectors. I believe that in 10 years, gene therapy will be present in clinical practice in Europe. New molecules that are mimicking FVIII activity are in development, also in a form of tablet for oral treatment.

You asked me, 'What's the role of EAHAD here?'. I think that EAHAD, as a global haemophilia conference, has an important role in leading this development, to support research and, more importantly, disseminate knowledge and education; start discussions, interactions, and the exchange of ideas between physicians; and not just demonstrate results, but stimulate dialog between different stakeholders involved in managing patients with bleeding disorders.

**Q10 Finally, a question we like to ask all our guests: if you had three magic wishes for the field of haemophilia and allied disorders, what would they be?**

First, I would say that we need timely diagnosis for all patients with inherited bleeding disorders. Second, post-diagnosis, before severe bleeding happens, we need to introduce a drug that has good efficacy, with low treatment burden and no side effects. Third, I wish that this would be possible for all patients, not just in Europe, but for all those around the world. In Europe, we are discussing annual bleeding rates of zero/one, or one/two injections a week, but unfortunately, the vast majority of the world does not have any treatment at all.

> **EAHAD has an important role in dissemination of knowledge, education, research, and collection of safety data on current treatments**