

EHC NOW!



AFH Congress 2018: Innovating for a better future

Interview with Olivia Romero-Lux, member of the French Haemophilia Association (AFH) and EHC Steering Committee, by Raia Mihaylova, EHC Communications Officer



Innovations or revolution? That was the guiding question of the French Haemophilia Association's (AFH) 45th National Congress, which took place from June 2nd-3rd in Nancy, France. The 350 participants – patients and health care professionals – tackled this question in relation to novel haemophilia therapies coming to the market and how they will revolutionise health care. Extended half-life treatments, non-factor replacements and the anticipation of gene therapy are changing the daily lives of patients and the AFH is preparing their community through education, workshops and exchange of experience.

“Change” echoed throughout the whole event, as the Association welcomed a new President and CEO – Nicolas Giraud and Fabrice Pilorgé, respectively.

Olivia Romero-Lux, member of the AFH and EHC Steering Committee, attended the Congress and shares what stood out to her from the weekend.

There was a lot of information presented at the Congress, did anything surprise you? What is your take-home message?

It was not really a surprise but definitely the confirmation that the AFH needs to train patients in light of upcoming new products that do not have the same mechanism of action as the existing ones. The hope is high but we need to be prepared and to be able to understand the benefits and risks of each treatment solution.

You were one of the speakers at the event, can you briefly summarise some key points of your presentation?



I moderated a workshop on Europe and disparities in access to treatment. Amanda Bok, CEO of the EHC, and Philippe de Moerloose, former EAHAD President, attended and made high-level presentations on the European Principles of Care, comprehensive care and on [PARTNERS programme](#) developed by the EHC for the 14 less-privileged European countries we serve, in terms of access to treatment. I think it was an eye-opener for the participants and I'd like to thank Amanda and Philippe for giving such interesting and in-depth presentations on how patient representatives and health care professionals can collaborate towards the better interest of our community.



Presentations aside, what is your top highlight from the weekend?

The French Society has undergone a huge revolution under Thomas Sannié's presidency but it was probably time to change our leadership to build on the momentum and write a new page in our history. Now, a new President has been elected - Nicolas Giraud - and we are very proud to have a person with von Willebrand Disease (vWD) to lead our Society. This is definitely a sign that things are changing and that our community takes into account all inherited rare

bleeding disorders, not just haemophilia, even if haemophilia is in our DNA.

As you mentioned, there were a lot of emotions throughout the event – Thomas Sannié, President of the AFH for the last six years, is stepping down. You have worked closely with him on numerous occasions, what is your 'goodbye' message to him?

When I started as a volunteer in 2000, Thomas was probably the first person I met and it was love at first sight for me 😊 The man was a visionary, I could tell. I'm so honoured to have collaborated with Thomas and I've grown so much thanks to him. And funnily enough, I was elected to the Board of the French Society last Saturday and I'll be in charge of International Actions, where Thomas will still support our work by leading the Afath* program, our development plan to accompany French-speaking African countries. So, I'll get to keep working with him in the years to come...

There was a quote on Twitter in response to the Congress that the AFH will have to be innovative in the near future about their role as a patient organisation. How do you see its role, will it change in the next 5-10 years?

I think the AFH has to support our community in two ways. First, we need to educate and train our members in order for them to be in control of their care. New molecules, new treatments, new protocols are on their way and this is a complete gamechanger. We also need to pave the way for those who are

**Franco-African Alliance for the Treatment of Haemophilia (Afath). Learn more at <https://afh.asso.fr/2015/01/30/afath-premiere-plateforme-web-animee-par-patients-et-professionnels-de-sante-afrique/>*

expecting therapeutic solutions for VWD, or other bleeding disorders where solutions are still too scarce. Second, we need to build our capacities in public health and data collection as budget constraints are going to be a major element in reimbursement and market authorisation. We need to be able to elaborate more fine-tuned advocacy tools to prove our case when the time comes to assess new medicines, especially where business models do not yet exist, like for gene therapy. Those are very exciting times for the community and the AFH definitely has to be innovative to make sure we stay focused on what is relevant for us.

The EHC congratulates Nicolas Giraud and Fabrice Pilorgé and wishes them success in their new roles as President and CEO, respectively, of the AFH.



Tweets from the Congress
[#CNAFH2018](#)



MissLondres @MissLondres · Jun 3

@CNAFH2018 the new president of the #AFH_Officiel Nicolas Giraud closes the National Congress and introduces the new office



Gaetan DUPORT @Gaetan_Duport · Jun 3

In innovation we can all work together on an equal basis. Knowledge of the patient = knowledge of the pros #afh #CNAFH2018



Cébé Denim @cebe_tweet · Jun 2

Will gene therapy kill the hemophilia game? You believe it! 🙌 @CN2018AFH #AFH_Officiel

