

# EHC NOW!



## Looking forward to the EHC Conference

*Interviews taken by Laura Savini, EHC Public Policy Officer*

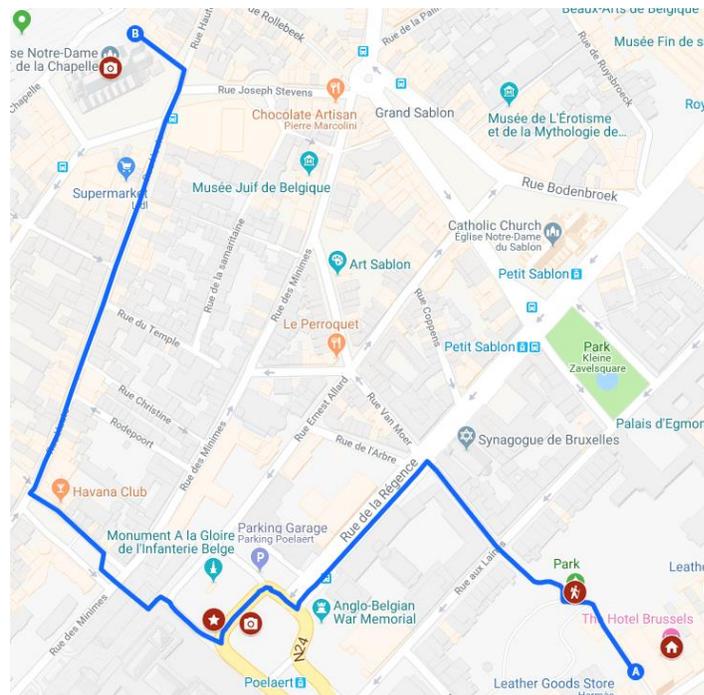


With only a couple of days left to the European Haemophilia Consortium (EHC) Conference (#EHC2018) we thought it would be appropriate to give you, dear readers, a glimpse of what you can expect from this year's event. To do so, we turned to the EHC staff and asked them to tell us what they are especially looking forward to as well as any tips that they may want to share with our readers on how to make the most of their stay in Brussels and their attendance at the EHC Conference.

### Saskia Pfyffer, EHC Office Assistant

*What are you most looking forward to in the next EHC Conference?*

For this year's edition, I am particularly excited about **the EHC stand**. In fact, we have come a long way in terms of stands and with each event it is getting better and better! This year the EHC stand will be divided into three sections: one for EHC activities, one for the Inhibitor Working Group (IWG) and one for the Women and Bleeding Disorders (WBD) Committee. Although the IWG and WBD Committee are two of our 'newest' groups (established in 2017 and 2018 respectively) they are also two of our most active groups and have already been developing a wealth of activities. I really invite everyone to come by and talk to these groups. In particular for representatives of our National Member



*Map of Brussels showing the Marolles area nearby the conference venue*

Organisations (NMOs) it would be interesting for them to come by and see how they can get involved or bring back some of their activities to their countries. As for the part of the stand focusing on EHC activities, I do not want to spoil much but we are already thinking of our 30<sup>th</sup> anniversary celebration, which will take place next year and we have developed something special, so come by and help us in preparing the festivities!

*What would you advise our delegates to do in Brussels during their free time?*

I really like **the Marolles area**. It is an area located walking distance from the Conference venue, filled with flea markets, antique shops, vintage clothing shops and lots of small cafés and restaurants. It's really great to take a stroll around on a Sunday.



### Kristine Jansone, EHC Community Programme Officer

*What are you most looking forward to in the next EHC Conference?*

On Thursday, the day before the start of the Conference, we will be holding our second **pre-conference inhibitor workshop**, during which we will be discussing how NMOs can be more inclusive of people with inhibitors in their national activities. This workshop has doubled in attendance since last year and I am really looking forward to energising discussions and fresh ideas!

*What would you advise our delegates to do in Brussels during their free time?*

To complement Saskia's suggestion above (to visit the Marolles), I would say that it's really worth going there via **Place Poelarts** where the imposing building of the Justice Palace is located. From there you'll have a great viewpoint of Brussels. This is particularly nice at sunset, so if you're looking for a place to walk in between sessions and dinner, I would totally recommend to go and check it out. From there you can take an elevator to the lower part of the city, the neighbourhood of the Marolles.

### Declan Noone, EHC PARTNERS Consultant



*What are you most looking forward to in the next EHC Conference?*

For me the **Saturday night dinner and dance** is the best part of the Conference. I love watching the switch from serious dedicated work by clinicians, patients and NMOs taking the time to enjoy each other's company. It is these connections and interactions that have built the strength and unity in this community over the last 30 years.

*What would you advise our delegates to do in Brussels during their free time?*

I do not live in Brussels and every time I visit I am in and out of the city in a day, but if our delegates want to experience something typical, I would recommend to **taste one of the many beers that Belgium has to offer**. In particular, I would recommend to try a Kwak beer in its specific beer glass. Just make sure to not wear your best clothes because it can get messy!



### Fiona Brennan, EHC Community Programme Officer



*What are you most looking forward to in the next EHC Conference?*

Personally I have been very much involved in the preparation of the **Youth Debate Symposium** taking place on Friday at 16.30 hrs. I love to see how our youth volunteers grow from attending their first EHC event, which often is the Youth Leadership Workshop, to this moment. It is quite intimidating to debate against some of the most prominent clinicians and patient leaders in the haemophilia community but, so far, all of them have stood up to the challenge and I am sure that this year's participants will do an equally fantastic job!

*What would you advise our delegates to do in Brussels during their free time?*

I am also not based in Brussels but from my many visits, I found out that Brussels is in fact a very green city with many parks. I would highly recommend to take a stroll in one of Brussels' many park and in particular in **Parc d'Egmond**, which is adjacent to the Conference venue. It's a small park featuring a lovely café where our delegates will be able to stretch their legs and – hopefully – enjoy some sunshine!



### Jo Eerens, EHC Membership Officer

*What are you most looking forward to in the next EHC Conference?*

As membership officer, I am really looking forward to **meeting with all of our members**, in particular those that do not have the opportunity to attend other EHC events. The Conference is always a great time to catch up and learn what our members are busy with in their own countries.

*What would you advise our delegates to do in Brussels during their free time?*

If you are visiting the Marolles, I would recommend to stop by **Kapellekerk (église de la Chapelle)** where Bruegel the elder (a famous Flemish painter) is buried. This year marks Bruegel's 500th anniversary and to celebrate, many exhibitions and events are taking place around Belgium and in Europe. Currently there is a small exhibition of Bruegel in the church itself where characters from his paintings have been placed all around the church.



*Statue of Bruegel the elder outside Kapellekerk*

### Laura Savini, EHC Public Policy Officer

*What are you most looking forward to in the next EHC Conference?*



I think this year's **session on gene therapy** will be very exciting (Sunday at 12.00 hrs). This is, in particular, as many of the gene therapy trials are entering phase II or III and will start recruiting patients in Europe. I believe it is extremely important that our members are aware and informed of this revolutionary medical technology and I am delighted that we will have a patient describing his experience going through the treatment.

*What would you advise our delegates to do in Brussels during their free time?*

Although you may think this is a bit cheesy, I personally think that no visit to Brussels is complete without some **culinary experience!** Brussels has an impressive selection of restaurants and if you've never had it, I think you should try the classic dish of mussels with chips and beer! Many restaurants in the downtown area will feature this dish, I would say that Chez Léon in the city centre is a landmark for this particular dish.

### Amanda Bok, EHC CEO

*What are you most looking forward to in the next EHC Conference?*

Everything! Absolutely everything! I'm also looking forward to events just starting already - we've been preparing for so long and it's the busiest Conference we've ever organised! But since you insist, I might give some special mentions. In addition to the usual programme and everything the others have mentioned, we also have our **#thisway awareness-raising bike ride** tomorrow, in which half the team and myself will participate - I can't wait! It builds on the fantastic Dutch Bloodrelatives initiative from 2016 and includes some of the original cyclists! I'm so impressed in particular with Minette van der Ven and Evelyn Grimberg who will start cycling in The Netherlands, meet us in Leuven, and then join our Leuven-Brussels #thisway bike ride





Brussels city map featuring some of Amanda's recommendations

to the Conference. The other thing happening this weekend, behind the scenes, is that we have two separate film crews on site who will be filming, respectively, an **educational patient-focused series on gene therapy and a documentary about women and bleeding disorders**. But really, I'm looking forward to everything and everyone. It's a great community - and a great team - and I'm looking forward to coming all together again this weekend.

I'm one of those rare people that is really in love with this city. I recommend two things. For those who want to stay near the hotel, I highly recommend strolling behind the hotel between **Petit and Grand Sablon** all the way to the **Royal Palace**. In between you'll find lots of cafés, restaurants, art galleries and museums! There is a new exhibit that I really want to go to called **'Beyond Klimt' at the Bozar**, includes works by Josef Capek, Egon Schiele, Oskar Kokoschka, László Moholy-Nagy and 75 other artists. I'm a big fan of Kokoschka myself! And as our Conference dinner will take place at the Bozar, people will already know how to find it! For others who would rather leave the touristic area and go 'slightly' further, I recommend **Place St Boniface** (still within walking distance!) where my favourite Brussels bar/brasserie, [Ultime Atome](#), serves a great selection of Belgian beers!

*What would you advise our delegates to do in Brussels during their free time?*

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*Thanks to all EHC staff for their recommendations. We are excited to meet and welcome all delegates in a few days!*

For more information about the EHC Conference visit <http://conference.ehc.eu>

For recommendations on things to do in Brussels go to <https://visit.brussels/en>