



EHC NOW!

Novel technologies in haemophilia care: EHC tried and tested methods to keep-up-to date with an evolving medical landscape

By Laura Savini, EHC Public Policy Officer

The New Year is traditionally a time for taking stock of the year that is past and looking ahead at a year full of promise and exciting opportunities. This is also applicable to the field of haemophilia care in which we are seeing, like never before, many new treatments being developed and in late clinical trial phases. Some of these treatments will most likely come to the European region in the next few years, so this is the time to really familiarise yourself with all these new technologies and closely follow what is going on in this field. Of course doing so can be sometimes time-consuming, daunting and often one does not know where to begin to look for information. So, look no further, in this edition of EHC Now! we give you our tried and tested tips on how to familiarise yourself with novel technologies and stay-up-to date with developments in haemophilia treatment.

First up, get yourself a copy of the EHC New Products Newsletter

The 'Novel treatments in haemophilia and other bleeding disorders: A period EHC review' is a newsletter issued by the EHC in which we provide you with extensive information on ALL novel technologies in development for the treatment of haemophilia but also other rare bleeding disorders. The first issue, published in May 2018, is [available on our website](#) and provides great detail on the modes of actions of these new technologies as well as information about the regulatory process to develop a new medicine.

The second edition of this review newsletter covering updates from May to December 2018 is currently being finalised and will be released shortly. It will not be as extensive as the first issue and will primarily give an update on advances in existing trials, medicines that have been licensed, clinical trials that have been started and ended. This newsletter also offers some points for reflection including, for example, the impact of gene therapy on patients in terms of how this will affect someone not only physically but also, for example, psychologically.

The next issue of the EHC New Products Newsletter will be out in the coming weeks.

Check out Medscape

In 2018 Medscape developed and launched together with several patient organisations including the European Haemophilia Consortium (EHC) a medical education programme on gene therapy in haemophilia. The programme is designed to educate healthcare professionals involved in haemophilia care such as haematologists and paediatricians to get up to speed with the latest developments in gene therapy in haemophilia. The training is free and counts towards continued medical education (CMEs) credits. This programme was supported by an educational grant from BioMarin. The EHC partnered on it together with the World Federation of Hemophilia (WFH) and the US National Hemophilia Foundation (NHF).

While that programme focuses primarily on healthcare providers, we believe that these educational videos are also interesting for patients with more advanced knowledge and understanding of gene therapy, as well as good tools for patients to take back to their healthcare providers nationally - so please help spread the word and the learning!

Find out more about [Medscape Gene Therapy education here](#). You will need to create an account to view the content but it's easy so don't let that stop you!

Get on to social media such as Facebook and Twitter

Perhaps you view social media as a black hole for free time and a means to procrastinate on important work, and you've made it your New Year's resolution to stop wasting time on your phone!

We couldn't agree more on the need to use social media in a smarter way and to try to minimise daily screen time. However, if consulted in moderation, social media can also offer timely and broad updates on medical advances in haemophilia care, so we recommend choosing whom to 'follow' wisely! And while we're dishing out unsolicited advice, we personally recommend to follow the [Facebook page of Haemophilia News](#). This page compiles haemophilia-related news from across the web and is updated almost daily. The page, which is managed by a patient, gives an overview of global news in haemophilia ranging from medical advances to changes within the pharmaceutical industry to curious facts about haemophilia and other rare bleeding disorders.

We also strongly advise anyone with an interest in haemophilia to start following [@ProfMakris](#) on Twitter. This is the Twitter handle of Prof Michael Makris, Professor of Haemostasis & Thrombosis at Sheffield University and a member of the EHC Medical and Advisory Group (MAG). The information provided in Prof Makris' Twitter feed does not solely relate to haemophilia (although the theme is predominant) but also looks at scientific and medical information related to thrombosis, general research and education.

Attend the EHC Conference.... and if you want to get down to the nitty gritty of novel technologies, join us for the EHC New Technologies Workshop

Now we're really getting ahead of ourselves, but in case you don't already know, the EHC organises a scientific conference each year during the first full weekend of October during which we provide a general update on scientific and medical advances in the field of rare bleeding disorders. This event is open to all and the [next edition](#) will be held on 4-6 October 2019 in Skopje, Macedonia. The official programme will be released shortly but we can tell you that it will certainly feature sessions on gene therapy, non-replacement therapies and extended half-life as well on their real world clinical use and future potential impacts.

Then, once you'll have attended the EHC Conference, you'll have gotten a taste of all the novelties and, we would imagine, that you would really want to get to the bottom of all of those technologies. That's what our 23-25 November 2019 workshop on New Technologies will be for! [This workshop](#) is only accessible to EHC patient members and designated healthcare providers and national authorities. It is comprised of two intense days of scientific presentations on novel therapies in haemophilia and other bleeding disorders, and their clinical use. The workshop however, also gives an opportunity to participants to have candid conversations and ask questions to world-leading experts on anything that may excite or concern them with regard to these new technologies. So if you are a curious patient, healthcare provider or national decision-maker, don't miss it!

The next Workshop on Novel Technologies in Haemophilia Care will be held in Athens, Greece.

We hope that this brief overview will help our readers to get started on learning more about advances in haemophilia therapies. For further information do not hesitate to get in touch with the EHC office.