

## EHC News

### Comprehensive care in haemophilia: Physiotherapy and OB-GYN

*In this issue, we continue our series on comprehensive care in haemophilia by looking at physiotherapy and at specialised gynaecology and obstetrics for women with rare bleeding disorders and carriers. Laura Savini took advantage of the EHC Annual Conference (see page 13) to interview two medical specialists from each of these disciplines speaking during the event.*

#### Physiotherapy in the comprehensive care of haemophilia

*Dr Sébastien Lobet\* interviewed by Laura Savini\*\**

*Dr Sébastien Lobet works at the Cliniques Universitaires Saint Luc in Brussels, Belgium; alongside Prof Cédric Hermans, Vice-President of the European Association for Haemophilia and Allied Bleeding Disorders (EAHAD). Sébastien tells us more about being a physiotherapist and working with people with rare bleeding disorders.*

##### *On physiotherapy*

Physiotherapy is a technique to restore musculoskeletal health by giving back motion and muscle strength to patients. It is generally performed with hands although the physiotherapist can also use a medical device or a machine. People with haemophilia (and other rare bleeding disorders impacting joints) suffer from joint problems and muscle weakness and therefore it is important to use physiotherapy to restore their strength and mobility.

##### *On the role of the physiotherapist*

Sébastien currently has two jobs, he is both a physiotherapist and a researcher. As such, he fulfils four different tasks in the haemophilia centre where he works.

His first role is to be a treator for people with haemophilia, for example, Sébastien will provide care for

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*In Sébastien's opinion, the three main challenges in physiotherapy are the assessment of patients, proving physiotherapy cost-effectiveness and to recognise the specific competences of physiotherapists working with people with haemophilia.*

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people with haemophilia following orthopaedic surgery or following an acute bleed. Another one of Sébastien's responsibilities is to assess joint health in both children and adult patients. In children, his aim will be to preserve good joint status and to detect the first signs of arthropathy. In adults he will try to estimate whether joint health is improving or becoming impaired and try to correct this. Sébastien also manages the musculoskeletal condition of his patients. This requires, for example, working closely with other specialists such as haematologists, orthopaedic surgeons and the rehabilitation department. It is important for physiotherapists to ensure that specialists are well informed of the musculoskeletal condition of the patient.

Finally Sébastien also conducts clinical research in the field of biomechanics. His main research area at the moment is the development of new tools and methods to assess joint health more precisely and to understand the impact and consequences of joint arthropathy on an individual's gait and balance and on his or her ability to conduct daily activities. The research is conducted with both the Université Catholique de Louvain (UCL) and the Katholiek Universiteit Leuven (KUL) in Belgium. Although this research is designed for and carried out on people with haemophilia, it will be adaptable to patients

suffering from joint arthropathy resulting from other conditions such as osteoarthritis, juvenile idiopathic arthritis, rheumatoid arthritis and for people suffering from foot problems in diabetes.

#### *On working with other healthcare professionals*

Besides working closely with orthopaedic surgeons and haematologists as mentioned above, Sébastien also works closely with nurses and paediatricians. Moreover, Sébastien is in close contact with other physiotherapists who do not regularly treat people with haemophilia. Belgium has many good physiotherapists and patients are lucky enough that they can choose to see a physiotherapist that lives close by instead of travelling to the haemophilia centre for each consultation. Therefore, one of Sébastien's jobs is to be the liaison person between the centre and the physiotherapists who may have never seen a patient with haemophilia. Sébastien will explain haemophilia to these non-specialist physiotherapists and provide details on the orthopaedic treatment that the patient has received (e.g. a new prosthesis).

#### *On preventing joint problems*

The key element to preventing problems in joints is to have access to prophylactic treatment with coagulation factor concentrates. Sébastien notes great differences between his younger and older patients, with younger patients who have been on prophylaxis since birth having much better joint protection compared to older generations who had not received good treatment in their youth. Furthermore, when patients have access to prophylaxis, regular physical activity is recommended while for patients with limited access to treatment physical activity must be performed with caution as it may put them at risk for joint bleeds.

Another important problem that affects joints is obesity. This is not only because of the additional load put on the joints by extra weight but also because fat tissue acts as an endocrine organ releasing inflammation in the whole body. Therefore a big role of the physiotherapist is to educate both children and adults on the risks associated with obesity, to try to prevent obesity in both children and adults, and to reduce obesity in affected patients.

The last issue that impacts joint health is the willingness of people with haemophilia to take the time to care for themselves. In theory a person suffering from severe haemophilia should see a physiotherapist at least two to three times a week for preventive or curative physiotherapy sessions. Unfortunately, this is not always possible as people with haemophilia generally lead very busy lives. It is therefore important for the physiotherapist to talk to his patients and stress the importance of taking the time to do regular physiotherapy to preserve and improve joint health.

#### *On European professional collaboration*

Sébastien is a member of the Physiotherapists Committee of the European Association for Haemophilia and Allied Disorders (EAHAD), a European organisation representing healthcare professionals working in the area of haemophilia and other rare bleeding disorders. For Sébastien, it is important to have a platform for European collaboration to be able to exchange with peers who are faced with the same types of patients and issues in order to exchange and learn from one another.

The EAHAD physiotherapy group hopes, through joint collaboration, to improve its members' professional knowledge, to establish and improve physiotherapy guidelines, to develop a network for physiotherapists and to pinpoint the current status of physiotherapy practice in haemophilia care in Europe.



*Dr Sébastien Lobet is a physiotherapist specialised in working with people with haemophilia (photo courtesy of Sébastien Lobet)*

### *On the treatment landscape in Europe*

As Sébastien explained access to prophylaxis is not equal in all European countries and, while some regions benefit from good access, in others this is still lacking.

With regard to physiotherapy services, the level of access and the quality of these services throughout Europe remains a big question mark and this is one of the questions that will be explored by the EAHAD Physiotherapy Committee. Sébastien notes that sometimes even in a single country the services available to patients can vary hugely depending on whether the service is provided in a haemophilia centre or if the patient lives in a more remote area. Another thing that will be looked at by the EAHAD group is the level of training of physiotherapists in Europe, because this will also affect the role the physiotherapist play. For instance, it is likely that the higher the level of education of the physiotherapist, the easier the interactions with the medical team in the haemophilia treatment centre will be.

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### *On current and upcoming challenges in physiotherapy for haemophilia*

For Sébastien, there are three main challenges in physiotherapy. The first one is the assessment of patients. Thanks to prophylaxis there is a huge improvement in the musculoskeletal health of children and, therefore, it will become increasingly difficult to diagnose and assess arthropathy. For example, although the revision of the haemophilia joint health score (HJHS) has improved this working tool, it is still, in some instances, not sensitive enough to assess the onset of arthropathies. Sébastien also believes that more could be done to prevent joint bleeds.

The next challenge is that although physiotherapy is effective and efficient in patients with haemophilia, it is very difficult to scientifically prove its efficacy and efficiency. This is because physiotherapy encompasses many different techniques and it is sometimes difficult to isolate one technique to prove its effectiveness. Therefore, although not impossible, it is very difficult to conduct clinical trials to prove the efficiency of physiotherapy. In the last five to ten years there has been much research conducted in the field of osteoarthritis that proves the efficiency of manual therapy. According to Sébastien, haemophilia is simply a *super* osteoarthritis and therefore it could be easy to transfer this knowledge to the field of haemophilia. A challenge for the future would be to develop guidelines and to prove that physiotherapy in haemophilia is efficient and cost-effective compared to factor replacement. Furthermore, physiotherapy has no or very few side-effects. So in Sébastien's opinion it is very important to use this non-pharmacological method to improve and preserve joint health.

The last challenge is to recognise specific competences of physiotherapists in the haemophilia centre, which as he described encompass more than simply treating patients but also include the assessment of patients, liaising with other healthcare professionals and conducting research. For instance, specialisations for nurses who need specific competences already exist, as in the cases of haemophilia nurses or nurses specialised in diabetes. Sébastien believes that the same should be applied to physiotherapists and this will be one of the objectives of the EAHAD's Physiotherapy Committee.

### *On training for physiotherapists*

In Sébastien's opinion, in order to become a specialised physiotherapist for people with rare bleeding disorders and to work in a haemophilia centre, one needs to see a lot of patients. Therefore it is crucial

that each centre has one or two physiotherapists that solely take care of people with haemophilia. In many cases physiotherapists are attached to the rehabilitation department but in practice the best would be that the same physiotherapists would treat people with haemophilia because there is an important learning curve in dealing with people with haemophilia.

At the moment there is no specific physiotherapy training for haemophilia. However, this will change in January 2016 when he and a colleague will launch the HAE-MOTION-Training course for physiotherapists specialized in haemophilia care.

Physiotherapists looking to learn more about the EAHAD Physiotherapy Committee's work can send a message to [physio@eahad.org](mailto:physio@eahad.org)

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## Gynaecology and Obstetrics in the Comprehensive Care of Haemophilia

*Rezan Kadir\* interviewed by Laura Savini\*\**

*Dr Rezan Abdul-Kadir is a Consultant Gynaecologist with subspecialty in foetal medicine and a special interest in women with bleeding disorders working at the Royal Free Hospital in London, United Kingdom (UK). Rezan tells us more about her work caring for women with bleeding disorders and carriers.*

*About obstetrics and gynaecology*

Obstetrics and gynaecology are all about bleeding. Gynaecology is associated with bleeding, for example, through menstruation, and in obstetrics, a normal amount of bleeding occurs during delivery and miscarriages. If you have a bleeding disorder you are more likely to bleed in these instances and even women who are only affected by a mild bleeding disorder will suffer more during gynaecological events because their bleeding disorder will contribute to the bleeding.

*On the role of the obstetrician-gynaecologist (OB-GYN)*

Rezan's work is very diverse. She is trained as an OB-GYN but also works in the area of women and bleeding disorders and in this capacity she cares for all aspects of gynaecological and obstetric care for her patients. So for instance, when women come to her clinic, she will be able to take care of the prenatal diagnosis thanks to her specialisation in foetal medicine, she will also do gynaecological surgery, and thanks to her obstetrics specialisation, she will be able to look after her patients during delivery. Additionally, she works as a community gynaecologist and as such she is able to provide advice to women on issues such as contraception. Through all of these services, Rezan is able to provide a comprehensive care service to women, which is not always the case in other centres.

*On working with other healthcare professionals*

Rezan works closely with the nurses in her centre whom she sees as crucial in running the OB-GYN service. In particular, she works closely with a specialised haemophilia nurse who is key in running the women's service. Nurses are very important in establishing the first contact with the patient and assessing the patients' needs. Often the nurse will be able to sort out most of the problems by her himself, however whenever the problem is too complex, the nurse will bring it to Rezan's attention. The nurse is also key in the organisational aspects of the clinic and will liaise with other specialists such as the scanning technician, for example, to arrange prenatal diagnosis.