

# Meeting with... the UK Haemophilia Society



Every quarter we dedicate an article to the presentation of a haemophilia society within the European Hemophilia Consortium (EHC). For this edition, Alain Weill, Vice-President of the AFH, responsible for European and International Affairs, put questions to Chris James, Chief Executive of the UK Haemophilia Society (UKHS).

**Alain Weill** *When was your Society founded?*

**Chris James** Our Society was founded in 1950. It is the only society in the United Kingdom for haemophiliacs, patients with von Willebrand disease and those with coagulation disorders. Today we have just over 4000 members.

**A. W.** *How is the UKHS organised?*

**C. J.** At the Society's headquarters we have nine permanent staff members, including two part-time employees, plus two volunteer workers who play a very important role. The Society is supported by a large number of volunteer workers throughout the country who are active in the sectors of communication and collecting funds. In addition to its headquarters, the UKHS has 16 regional committees in the United Kingdom.

**A. W.** *What are your sources of finance?*

**C. J.** Although a significant part of our budget comes from the pharmaceutical industry, we equally rely heavily on government grants and income from our foundation. We also receive donations from the general public...

**A. W.** *What treatments are prescribed to British patients?*

**C. J.** In our country, all haemophilia A and B patients have access to recombinant<sup>1</sup> Factor VIII and Factor IX products, even though plasma derivatives<sup>2</sup> are also available. Most young patients are today under prophylactic treatment<sup>3</sup>. It should be noted that this protocol is constantly increasing with the adult population.

**A. W.** *Do you have any therapeutic education programmes?*

**C. J.** Such programmes do exist but vary from one region to another. Our Society offers training programmes adapted to the young, the elderly, to women suffering from coagulation problems and to patients who have developed inhibitors.

**A. W.** *Do you have twinning or partnership programmes with societies from other countries?*

**C. J.** Thanks to the World Hemophilia Association, we have set up a twinning programme with Armenia. We have also developed special links with India which we are currently looking to extend.

**A. W.** *Try to imagine your Society in a few years' time. How do you think it might be different from today?*

**C. J.** I hope that in 10 years time we will have been able to have brought justice to those who have suffered from the contaminated blood scandal.

It is also important to reach our objective that haemophiliacs can freely choose their treatment. I would like that all those suffering from coagulation disorders may have access to the quality care they need.

Finally, I would like to see those in developing countries have the same level of care that we do in the United Kingdom so that they do not have to suffer the consequences of ill adapted treatments.

1•Recombinant products are anti-hemophilic drugs made from genetic engineering.

2•Plasma derivatives are anti-hemophilic drugs also called plasma products.

3•Prophylaxis is a therapeutic procedure aimed at, in the case of haemophilia, preventing hemorrhage accidents by regular and systematic injections of anti-hemophilic factors.