

**EAHAD-EHC Joint Statement on:
Promoting central role of haemophilia comprehensive care centres
in the treatment of haemophilia and rare bleeding disorders using
novel non-replacement therapies**

For the past three decades, haemophilia A and B patients have been treated using FVIII and FIX replacement concentrates. These therapies are well known to clinicians and patients.

A promising new era has now begun in the treatment of haemophilia and rare bleeding disorders. A series of novel, non-replacement therapies are becoming available, which may significantly impact the clinical care and quality of life of patients.

The European Association for Haemophilia and Allied Disorders (EAHAD) and the European Haemophilia Consortium (EHC) welcome all novel therapies that have a meaningful impact on patients' treatment, care and quality of life.

These novel treatments work in a completely different manner in the body than standard factor replacement concentrates, acting on blood coagulation either by mimicking the function of FVIII or by rebalancing the coagulation process. It is therefore important that both patients and clinicians are well educated about these novel therapies and well informed about their management.

To ensure the optimal introduction, use and monitoring of these therapies, given their completely different and complex modes of action, EAHAD and the EHC jointly call for all novel therapies to be prescribed, managed and monitored exclusively by haemophilia comprehensive care centres. These centres should have medical specialists in haemophilia care who are well informed about these novel agents and who can be contacted on a 24-hour/7-days/week basis and have access to a specialist haemostasis laboratory.

EAHAD and the EHC also recommend that all patients being treated with any of these novel therapies carry an identity card indicating the type of drug they are being treated with, the treatment regimen, the haemophilia comprehensive care centre where their treatment is being overseen, and a telephone number where specialist care can be reached 24 hours a day, 7 days a week.

Any adverse events should be managed in collaboration with a haemophilia comprehensive care centre, be well documented and be reported to an adverse event reporting scheme.

It is the responsibility of all healthcare stakeholders to ensure the prescription, management and monitoring of novel non-replacement treatments by haemophilia comprehensive care centres, at least initially, to ensure the optimal safe introduction and use of these innovative and complex new treatments. An active continuous education programme discussing these new drugs should be introduced for patients and other healthcare professionals.