

Integrating Oral Health for People with Bleeding Disorders into Rare Disease Policy

The European Haemophilia Consortium (EHC) calls on European and national policymakers to recognise oral health as a fundamental component of comprehensive care for people living with bleeding disorders.

For people with bleeding disorders, oral health is not merely an aesthetic issue. It is a matter of safety, prevention, and overall quality of life. Untreated dental conditions can result in pain, infection, emergency interventions, and potentially serious bleeding complications. Despite this, oral health remains insufficiently integrated into rare disease policy frameworks across Europe.

As revealed during interviews with the community, people with bleeding disorders continue to encounter barriers in accessing routine dental care. These barriers include refusal of treatment by professionals unfamiliar with their condition and preventable bleeding complications linked to inadequate preparation or insufficient collaboration with haemophilia treatment centres.

As the European Union (EU) advances its work on rare diseases through strengthened European cooperation, including the European Reference Networks (ERNs) and the EU4Health programme, oral health must be explicitly recognised within these frameworks as part of comprehensive and integrated care pathways.

The EHC calls for:

1. Integration of Oral Health into Rare Disease Plans

Oral health must be formally embedded within national Rare Disease Plans and reflected in EU rare disease policy initiatives, ensuring preventive dentistry, early intervention, and safe dental care are recognised as core elements of bleeding disorders management.

2. Stronger Multidisciplinary Care

Structured referral pathways and closer collaboration between Haemophilia Treatment Centres, Centres of Expertise within the ERNs, and dental services are essential. Coordinated care models should ensure timely access to appropriately trained dental professionals and shared clinical protocols for invasive procedures.

3. Investment in Research and Education

Targeted research funding under EU and national health programmes, the development of evidence-based clinical guidelines, and strengthened professional education are needed to equip healthcare providers with the knowledge and confidence to deliver safe oral care to people with bleeding disorders.

We urge EU institutions, national authorities, healthcare professionals, and patient organisations to work together to close the oral health gap in bleeding disorder care. By embedding oral health into Rare Disease Plans and EU health initiatives, fostering multidisciplinary collaboration, and investing in research and education, we can ensure that no person with a bleeding disorder is left without access to safe, timely, and equitable dental care.