

Declan Noone is the President of the European Haemophilia Consortium (EHC), he was elected in 2019. Mr Noone has extensive experience as a patient advocate at the national, European and international level. For eight years, he worked with the Irish Haemophilia Society (IHS) as Data and Public Policy Specialist. His main responsibilities included membership of the national tender board for the purchase of products for the treatment of haemophilia and other related conditions. He also worked on the area of hepatitis C and access to treatments. Before being elected President, he worked with the EHC as Project consultant on the PARTNERS Programme, an initiative to raise access to treatment in countries with a low standard of treatment. During his time with EHC he also coordinated projects on data collection and novel therapies.

Declan was also a member of the Board of Directors of the World Federation of Hemophilia and a member of its Educational Materials, Data and Demographics and Safety and Supply Committees.

He has co-authored several papers on the quality of life in people with haemophilia, access to haemophilia care in Europe and WFH and EHC Monographs. Most recently, he published the results of a survey on the evolution of haemophilia treatment and care in Europe between 2009 and 2019.