

Sylvia von Mackensen

Sylvia von Mackensen is a senior scientist at the Department of Medical Psychology at the University Medical Centre in Hamburg, Germany since 2003.

She received her diploma in Psychology in 1994 from the Catholic University of Eichstätt, Germany, and performed her PhD at the Department of Medical Psychology at the Ludwig-Maximilian University of Munich. She was a visiting scientist at the Haemophilia and Thrombosis Centre in Milan, Italy from 2007-2010. She has done her post-doctoral thesis "Patient-Reported Outcomes in Haemophilia" at the University Medical Centre of Hamburg-Eppendorf, Germany in 2017.

She is working since 1999 in the field of haemophilia. Her main research interest is focussed on patient-reported outcomes (PRO) related to people with bleeding disorders, especially with haemophilia. She developed several disease-specific PRO measures for the assessment of health-related quality of life, treatment satisfaction, physical functioning and caregiver burden in patients with bleeding disorders such as haemophilia, ITP and VWD. Other fields of interests are urinary tract infections, hereditary angioedema, cleft-lip-palate, myelodysplastic syndrome, thalassemia, multiple sclerosis, and diabetes.

Sylvia von Mackensen was a member of the Psychosocial Committee of the World Federation of Hemophilia (WFH) from 2004-2020.

She is currently a lecturer in Medical Psychology at the Universities of Hamburg and Munich in Germany. She has lectured also at the Department of Medical Psychology at the Universities of Göttingen and Homburg/Saar (Germany) and at the International Haemophilia Course in Malmö, Sweden.

She has published about 100 papers in peer-reviewed professional national and international journals and has more than 400 presentations at national and international conferences.

She is an associate editor of the journal *Haemophilia* and a member of the editorial board of *The Journal of Haemophilia Practice*.