HemoNED
Dutch Hemophilia Registry

Dutch Hemophilia Registry

Annual Report 2025

HemoNED Foundation
June 2026

www.hemoned.nl/en

Contents

Introduction

This annual report describes data from the Dutch Hemophilia Registry ('HemoNED Registry') and the VastePrik digital infusion log for home treatment available on 31 December 2025.

HemoNED Foundation

The HemoNED Registry & VastePrik are managed by the HemoNED Foundation.

The aim of the HemoNED Foundation is described as follows:
"The Foundation aims to maintain a national register of people with hemophilia and related disorders, including data about their disease, treatment and complications, to conduct scientific research, to provide reports and to deliver education, thereby to contribute to an improvement of the quality of care."

The HemoNED Steering Committee, consisting of representatives from all the Dutch Hemophilia Treatment Centers (HTCs), the NVHP for everyone with a congenital bleeding disorder and the Dutch Hemophilia Nurses Society (NVHV), is responsible for assessing and approving the annual reports and data applications. The procedure for submitting a data request is available on the HemoNED website Data application HemoNED.

Dutch Hemophilia Registry

The Dutch Hemophilia Registry was established in 2017 as a joint initiative from the Dutch Hemophilia Treaters Society (NVHB), the NVHP and the NVHV. For rare diseases like hemophilia, for which there is an effective but expensive treatment, a national hemophilia registry is an important tool for monitoring treatment and improving quality of care. The HemoNED Registry collects information on diagnosis, treatment and treatment outcomes of people with hemophilia or related disorders in the Netherlands. Anonymized registry data are used for overview reports, scientific research and efficacy and safety studies of drugs. Most data are entered manually by healthcare professionals. In addition, some information is provided through automated data linkages from Electronic Health Records of the HTCs. The registry includes validation checks to safeguard data quality. In 2025, additional emphasis was placed on data quality, including updating inhibitor status and reviewing and updating treatment plans.

VastePrik

The digital infusion log VastePrik was launched in 2018 both as an app and a web application. Participants can record their home treatment, including infusions and bleeding episodes. VastePrik is mainly used by participants on prophylactic treatment. Through a secure online environment, healthcare professionals can review these data and use them to support treatment evaluation. In consultation with the patient, entries can be amended or supplemented when needed.
In 2025, preparations started for an update of VastePrik, with a focus on improved usability and maintainability. Continued attention was also given to the importance of complete recording, including bleeding episodes treated in hospital.

Inclusion

All national certified HTCs routinely invite eligible participants for the HemoNED Registry:

- Amsterdam UMC location AMC
- Erasmus MC Rotterdam
- LUMC Leiden & HagaZiekenhuis The Hague
- HTC NEM: Radboudumc Nijmegen & MUMC Maastricht & MMC Veldhoven/Eindhoven
- UMC Groningen
- UMC Utrecht (Van Creveld Clinic)

People with one of the following diagnoses are eligible to participate in the HemoNED Registry:

- Hemophilia A or B, including women with factor levels ≤ 40%
- Carriers with hemophilia A or B: coagulation factor levels > 40%
- Von Willebrand disease, VWFag and/or VWFact and/or VWFrcf and/or FVIII levels ≤ 30%, and/or dependent on clotting factor concentrates
- Rare factor deficiencies and platelet disorders, prophylactic treatment and/or dependent on clotting factor concentrates or platelet transfusion during surgery or after trauma
- Acquired clotting factor disorders

Adverse events

Adverse events and complications are recorded in the HemoNED Registry by all Hemophilia Treatment Centres.
HemoNED provides quarterly overviews to the NVHB, the HTCs, the European Haemophilia Safety Surveillance (EUHASS) and yearly to the Netherlands Pharmacovigilance Centre Lareb.

Data analysis

The HemoNED project office analyzed the 2025 data on behalf of the Steering Committee. The statistical software SPSS was used to perform descriptive statistical analyses to analyze and describe the data.
The HemoNED Foundation ensures that only anonymised data are presented. To prevent indirect identifiability, cells with values below 5 are shown as less than 5 or are aggregated with other (sub)categories where necessary.
Because this is a topical issue, this report includes additional attention to changes in the treatment of hemophilia A. Other relevant topics may be addressed in future reports.

Publications

In 2025, HemoNED again contributed to international data collections, including the World Federation of Hemophilia Annual Global Survey in collaboration with NVHP. Annual Global Survey – WFH - World Federation of Hemophilia

Organisation

Board members HemoNED Foundation in 2025:

- **Chair: Dr. Samantha Gouw,** Pediatric hematologist Amsterdam UMC Hemophilia Treatment Center
- **Secretary: Stephan Meijer,** Delegate of the patient organisation NVHP for everyone with a congenital bleeding disorder
- **Treasurer: Prof. Dr. Karina Meijer,** Internist-hematologist, UMC Groningen Hemophilia Treatment Center

The following representatives were part of the HemoNED Steering Committee in 2025:

- **Dr. Samantha Gouw,** chair Steering Committee, Amsterdam UMC Hemophilia Treatment Center
- **Dr. Corien Eckhardt,** Van Creveld Clinic UMC Utrecht
- **Prof. Dr. Marieke Kruip,** Erasmus MC Rotterdam Hemophilia Treatment Center
- **Dr. Britta Laros-van Gorkom,** Hemophilia Treatment Center Radboudumc Nijmegen, MUMC+ Maastricht & MMC Eindhoven/Veldhoven
- **Drs. Marjet Stein-Wit,** UMC Groningen Hemophilia Treatment Center
- **Dr. Paul den Exter,** Hemophilia Treatment Center LUMC Leiden & HagaZiekenhuis The Hague
- **Dr. Ilmar Kruis,** Patient organisation NVHP for everyone with a congenital bleeding disorder
- **Marlène Beijlevelt, MSc,** Dutch organization for people with hemophilia or an inherited bleeding disorder Dutch Hemophilia Nurses Society (NVHV)

In 2025, the HemoNED project office consisted of:

- **Caroline van Veen, MSc,** Project coordinator HemoNED
- **Liesbeth Taal, MSc,** Data manager HemoNED

In 2025, a service agreement was also concluded with an external Data Protection Officer for 3 hours per month, in connection with additional assessment under the Dutch Quality Registries in Healthcare Act.

Results Dutch Hemophilia Registry

General

Figure 1a Number of unique participants in HemoNED registry by gender

Total participants

Total completed 3270 (100%)

Gender

Man 2264 (69%)

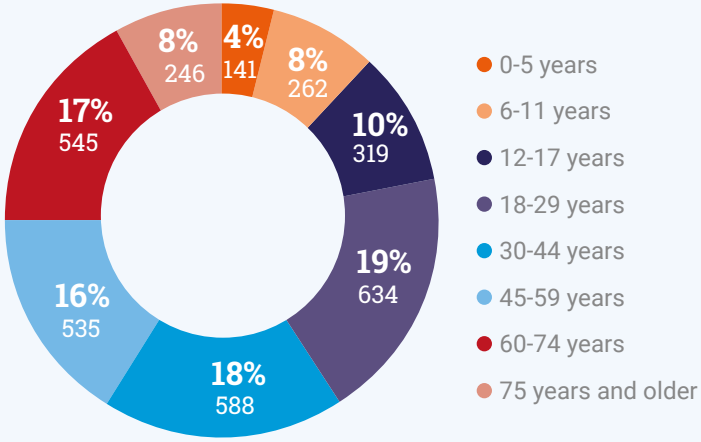
Woman 1006 (31%)

General

Figure 1b Number of unique participants in the HemoNED registry by age and diagnosis

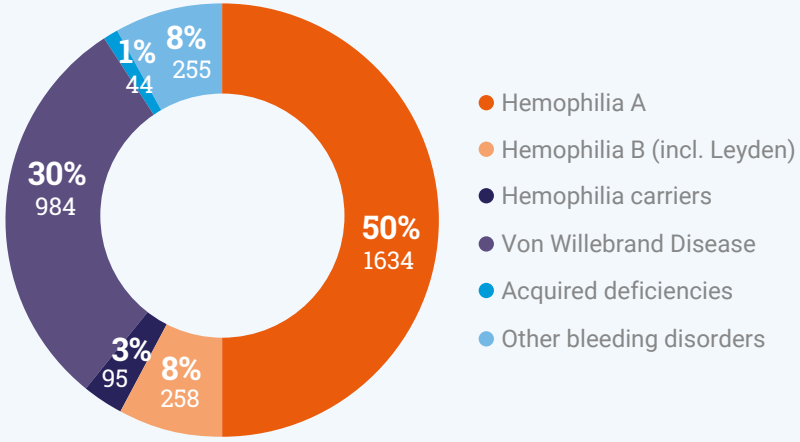
Age

Total completed **3270** (100%)



Diagnosis

Total completed **3270** (100%)



General

Figure 2a Number of participants included in the HemoNED registry until December 2025

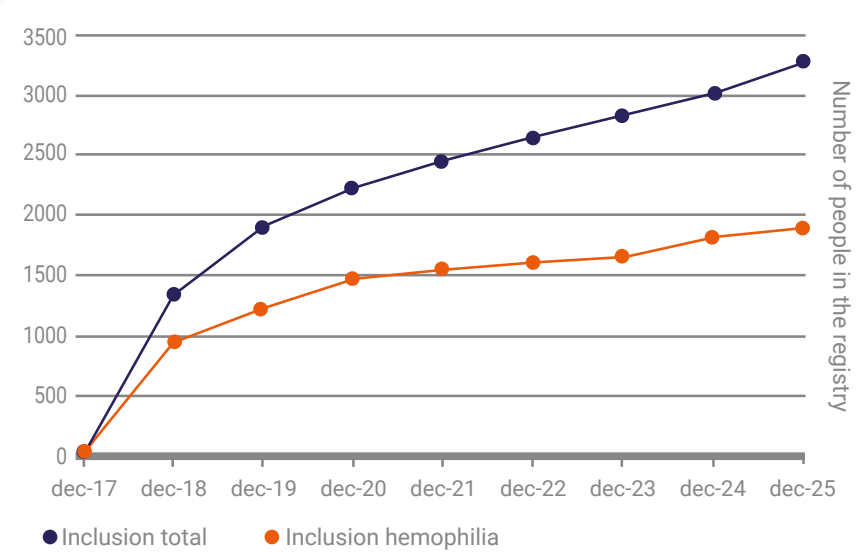
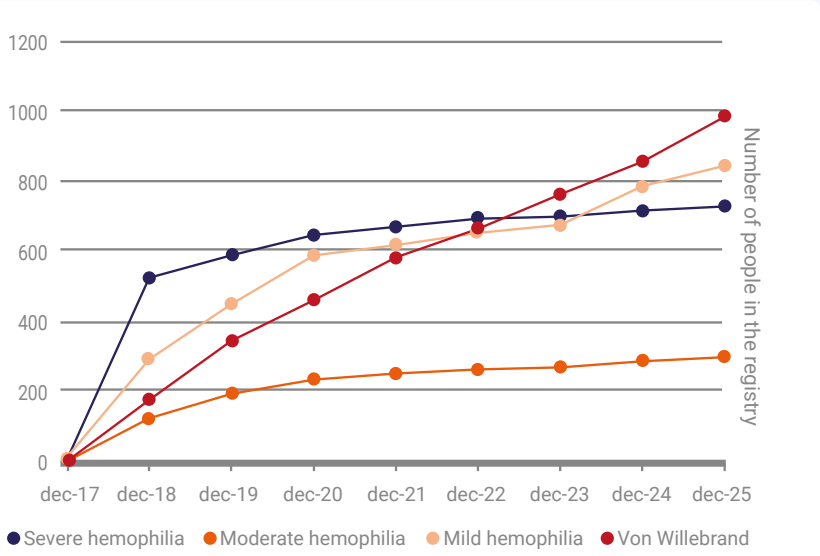


Figure 2b Number of participants with severe, moderate and mild hemophilia and Von Willebrand Disease included in HemoNED until December 2025



Mortality

2018-2024: 107 participants died

2025: 22 participants died

The data from these participants are excluded in this report

Hemophilia

Diagnosis and demographic data

Table 1 Number of participants in the HemoNED registry with diagnosis Hemophilia

Diagnosis	Number	%
Hemophilia A	**1634***	**100**
Severe	632	39
Moderate	256	16
Mild	746	46

Diagnosis	Number	%
Hemophilia B	**258****	**100**
Severe	93	36
Moderate	40	16
Mild	97	38
Leyden	28	11

Diagnosis	Number	%
Hemophilia Carriers	**95**	**100**
Hemophilia A	72	76
Hemophilia B	22	23
Missing	1	1

* 1512 men, 122 women
** 224 men, 34 women

Hemophilia

Figure 3a Participants with Hemophilia A by severity

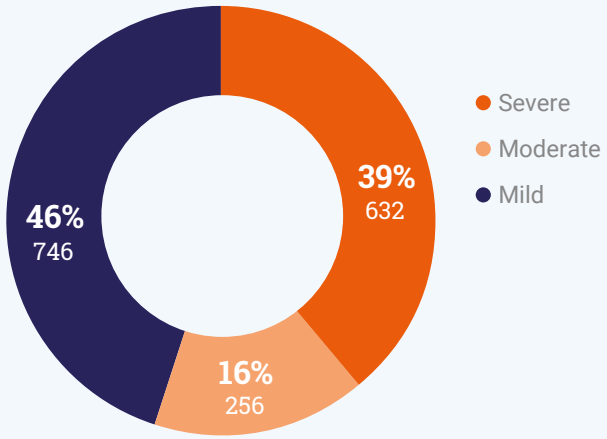
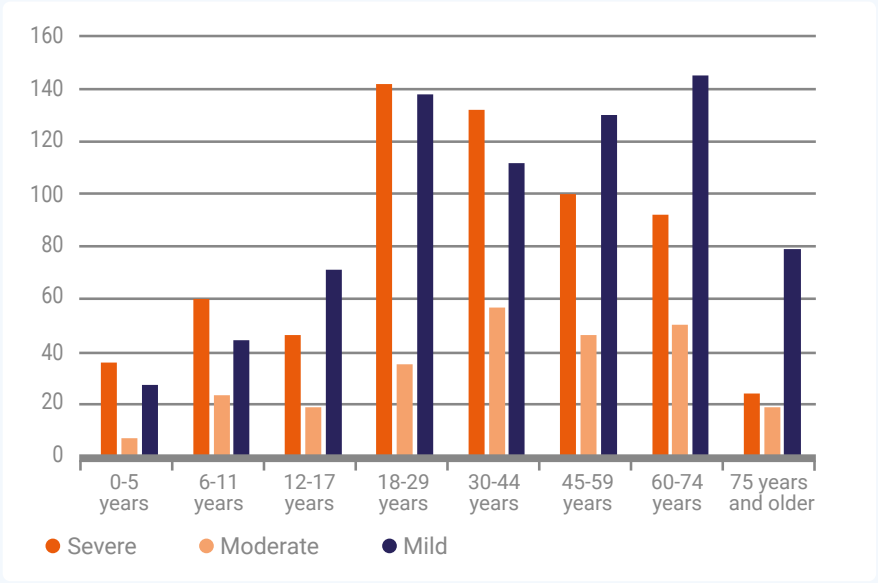


Figure 3b Participants with Hemophilia A by age and severity



Hemophilia

Figure 4a Participants with Hemophilia B by severity

Hemophilia B

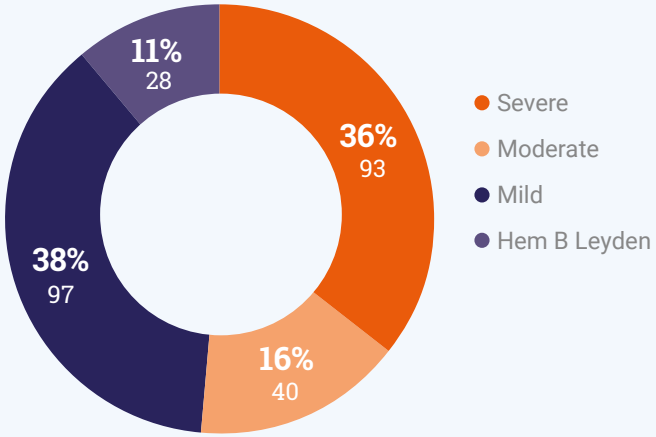
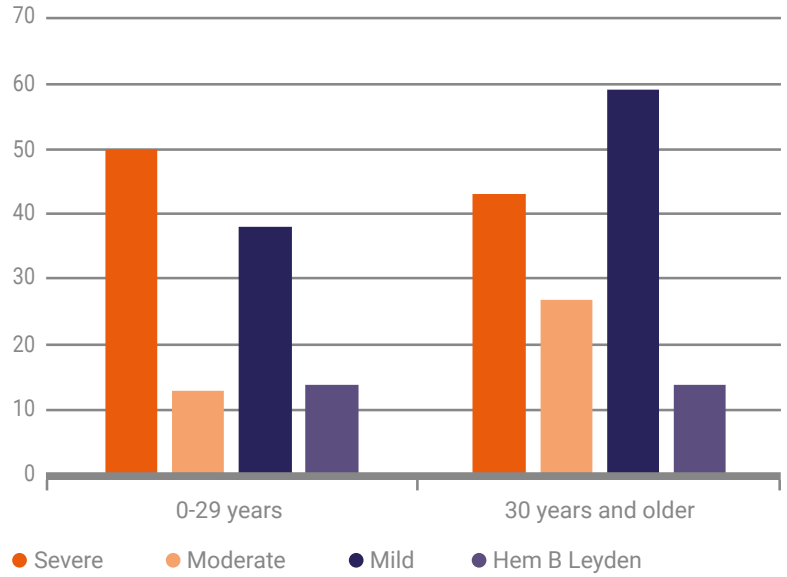


Figure 4b Participants with Hemophilia B by age and severity

Age and severity Hemophilia B



Hemophilia

Viral infections

Table 2 Number of participants, born before 1992, with diagnosis Hemophilia that suffer(ed) from a blood-borne viral infection

Viral infection	Number	%
Total participants with hemophilia born before 1992	**1062**	
Not completed	**33**	
Total completed	**1029**	**100**
Unknown*	92	9
No	514	50
Yes**	423	41

Viral infection	Number	%
HIV infection	**30**	

Viral infection	Number	%
Hepatitis B infection	**103**	

Viral infection	Number	%
Hepatitis C infection	**387**	**100**
Successfully treated	295	76
Spontaneously cleared	47	12
Still infected	26	7
Unknown	19	5

* Classified by a health care provider as 'Unknown'
** Participants may have or have had more than one infection

Inhibitors

Table 3 Inhibitor status of participants with diagnosis Hemophilia A or B

Inhibitors and Hemophilia A	Number	%
Total completed*	**1591**	**100**
Never	1374	86
Current or past inhibitor	194	12
Unknown**	23	1

Inhibitors and Hemophilia B	Number	%
Total completed***	**224**	**100**
Never	211	94
Current or past inhibitor	5	2
Unknown**	8	4

* Data available for 1591 of 1634 participants with Hemophilia A
** Classified by a health care provider as 'Unknown'
*** Data available for 224 of 230 participants with Hemophilia B

Hemophilia

Treatment

Table 4 Number of participants with diagnosis Hemophilia A or B on prophylactic treatment

Hemophilia A	Number completed	Number on prophylaxis	% on prophylaxis
Total	**1617**	**709**	**44**
Severe	630	614	97
Moderate	255	82	32
Mild	732	13	2

Hemophilia B	Number completed	Number on prophylaxis	% on prophylaxis
Total	**230**	**99**	**43**
Severe	93	81	87
Moderate	40	17	43
Mild	97	1	1
Leyden	28	0	0

A few participants with severe Hemophilia B have undergone gene therapy treatment in the past.
These remain classified as ‘severe’.

Hemophilia

Table 5 All prescribed treatment products for participants with diagnosis Hemophilia A or B

Hemophilia A*	Number
Total completed	**2358 (for 1617 participants)**
Product A	895
Product B	508
Product C	311
Product D***	257
Product E	178
Product F	52
Product G	42
Product H	41
Product I	18
Product J	17
Product K	12
Other products**	27

Hemophilia B	Number
Total completed	**260 (for 258 participants)**
Product A	94
Product B	88
Product C	64
Product D	10
Other products**	4

For some of the participants more than one product was prescribed

* For 17 participants with Hemophilia A the treatment plan is missing

** Number of prescriptions too small (<10)

*** Incomplete registration

Hemophilia

Table 6 Number of participants with diagnosis Hemophilia A or B by type of product*

Hemophilia A	Number	%	Number on prophylaxis	%
Total completed	**1617**	**100**	**709**	**100**
Standard Half Life	921	57	100	14
Extended Half life	106	7	82	12
Non Replacement Therapy	508	31	508	72
Bypassing Agents	33	2	0	0
Plasma derived	14	1	1	0
Study drug	18	1	18	3
Only Desmopressin	17	1	0	0
Other	0	0	0	0

Hemophilia B	Number	%	0	0
Total completed	**258**	**100**	**99**	**100**
Standard Half Life	152	59	11	11
Extended Half life	104	40	86	87
Other	2	1	2	2

* If more than one product was prescribed to a participant, the main product is shown.

Figure 5 Number of persons with Hemophilia A on prophylactic treatment, by type of prescribed product since 2020

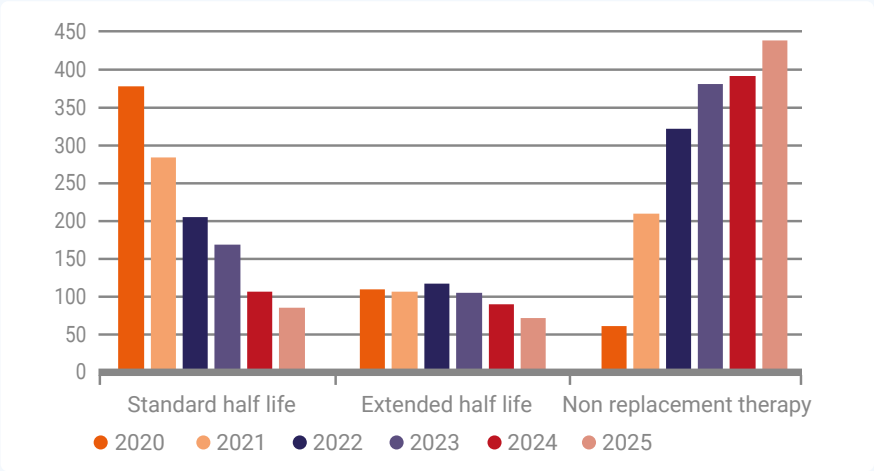
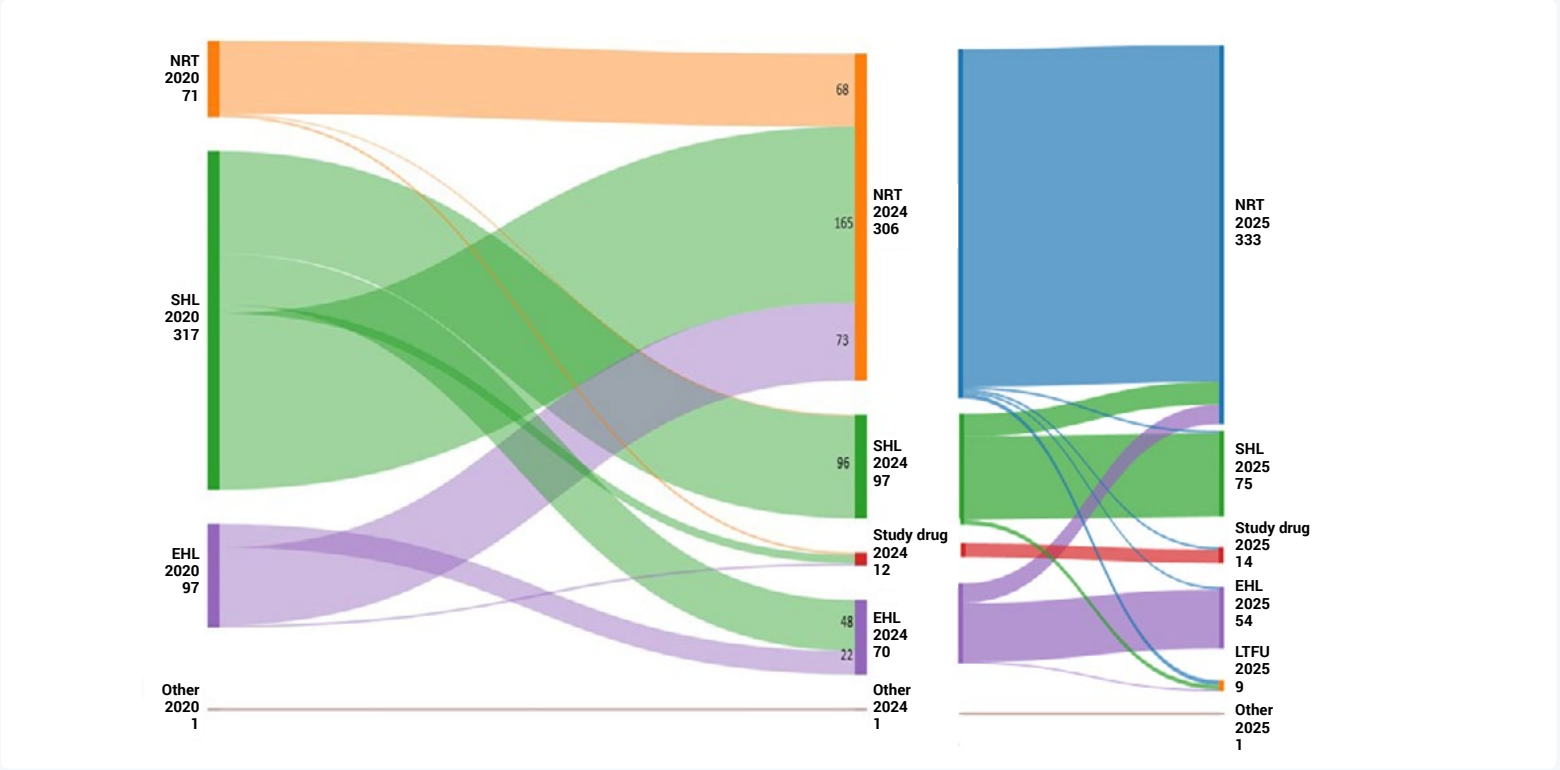


Table 7 Reason to start with Non Replacement therapy

Reason to start Non Replacement therapy	Number	%
Total completed	**499**	**100**
Recurring bleeds despite regular prophylaxis	105	21
Venous access problems	78	16
Inhibitor with bleeding tendency	41	8
Not being able to administer regular prophylaxis	20	4
Very active life (sports, travelling)	19	4
Preference of both patient and physician, non-specific	236	47

Hemophilia

Figure 6a and 6b Sankey diagrams of the (change in) treatment according to product type for persons with severe hemophilia A on prophylactic treatment, in the years 2020, 2024 and 2025 (Selection: participants included in HemoNED before 2021, severe hemophilia on prophylactic treatment, known treatment plan (N=486 in 2024, N=477 in 2025)). LTFU=Lost to follow up, mainly due to death



The Sankey diagrams show the product use for a closed cohort. The treatment of persons with severe hemophilia A, included in HemoNED after the year 2020, is not visible.

In the year 2025 21 persons with severe hemophilia A were included. Of these participants, 20 have a known treatment plan: 18 receive prophylactic treatment of whom 15 NRT.

Hemophilia

Figure 7 Prophylactic treatment of severe hemophilia A with NRT, EHL or SHL products for different age categories in 2025 (N=597).

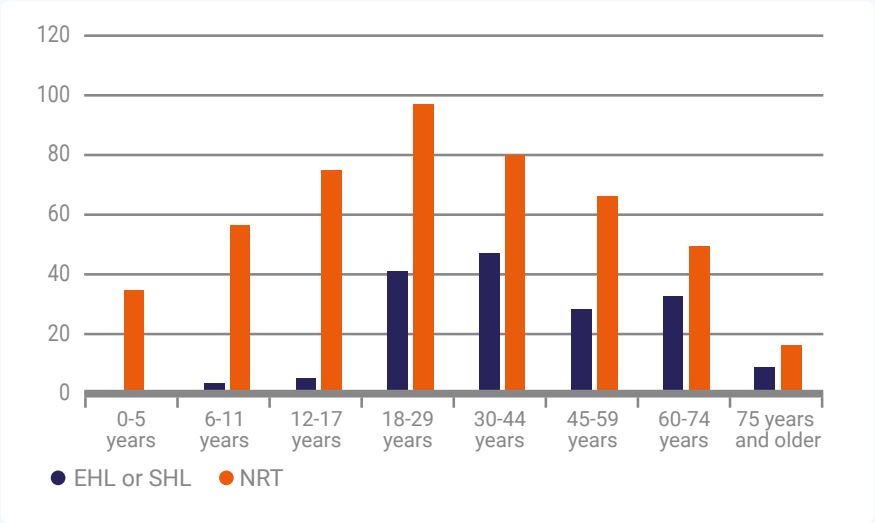
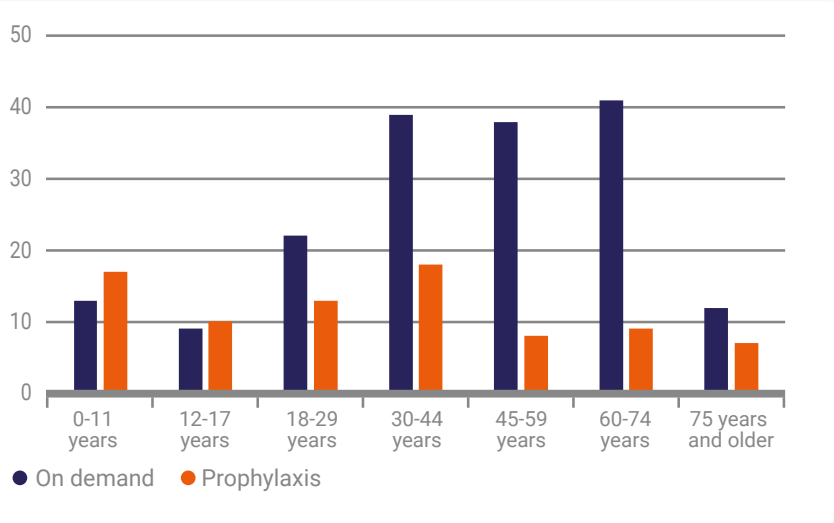


Figure 8 Treatment of moderate hemophilia A for different age categories in 2025 (N=255).



More than 75% of people with moderate hemophilia A on prophylaxis receive NRT.

Hemophilia

Table 8 Prophylactic treatment of participants with moderate hemophilia A in 2024 and 2025

Product type	2024 (N=72)	2025 (N=82)
Non Replacement Therapy	27	64
Standard Half Life	26	11
Extended Half Life	18	6
Other	<5	<5

The percentage of persons with moderate hemophilia A on prophylactic treatment, has risen slightly in recent years.
2023: 25%, 2024: 29% and in 2025: 32%.
There has been a significant change in the prescribed product: as of the end of 2024, NRT has been included in the basic health insurance package.

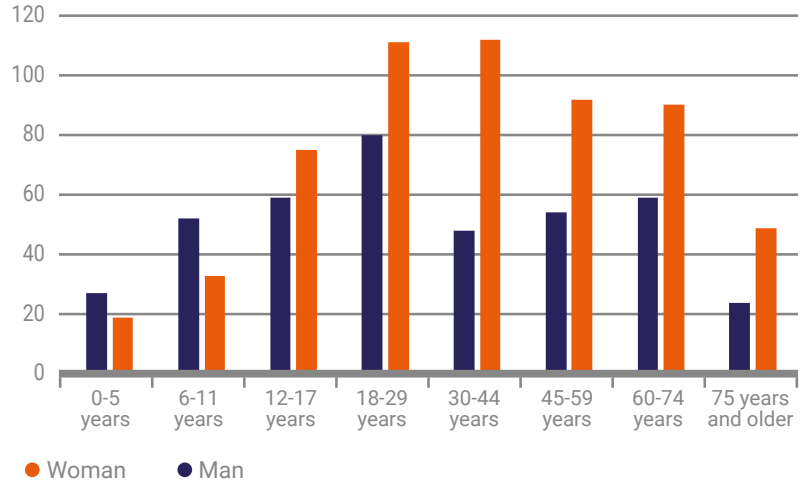
Von Willebrand Disease

Diagnosis and demographic data

Table 9 Number of participants with diagnosis Von Willebrand Disease

Diagnosis	Number	%
Von Willebrand Disease	**984**	**100**
Type 1	566	58
Type 2, no subtype	18	2
Type 2A	153	16
Type 2B	69	7
Type 2M	76	8
Type 2N	25	3
Type 3	40	4
Other/type unknown	37	4

Figure 9 Participants with Von Willebrand disease by age and gender



Von Willebrand Disease

Inhibitors

Table 10 Inhibitor status of participants with diagnosis Von Willebrand Disease

Inhibitors and Von Willebrand Disease	Number	%
Total completed	**712***	**100**
Never	522	73
Current or past inhibitor	<10	
Unknown**	186	26

* Data available for 712 of 984 participants with Von Willebrand Disease
** Classified by a health care provider as 'Unknown'

Treatment

Table 11 All prescribed treatment products for participants with diagnosis Von Willebrand Disease

Products and Von Willebrand Disease	Number
Total completed	**1234 (for 947 participants)***
Product A	657
Product B	336
Product C	195
Product D	24
Other products**	22

* For 37 participants the treatment plan is missing; for some of the participants more than one treatment product was prescribed
** Number of prescriptions too small (<10)

Table 12 Prescribed products for participants with Von Willebrand Disease on prophylaxis

Products and Von Willebrand Disease	Number
Total completed	**42**
Product A	27
Product B	12
Other products*	<10

* Number of prescriptions too small

Other bleeding disorders

Table 13 Number of participants in HemoNED registry with other bleeding disorders

	Number	%
Other bleeding disorder	**299**	**100**
Factor VII deficiency	42	14
Factor XI deficiency	32	11
Glanzmann's disease	24	8
Acquired Hemophilia A	33	11
Afibrinogenemia/hypofibrinogenemia/ hypodysfibrinogenemia/dysfibrinogenemia	25	8
Storage Pool Disease	31	10
Factor XIII deficiency	14	5
Factor V deficiency	10	3
Other bleeding disorders	88	29
Various other platelet disorders	58	
Rare factor deficiencies	11	
Other acquired bleeding disorders	11	
Other bleeding disorder or disorder not specified	8	

Other platelet disorders include Gray platelet syndrome, Bernard-Soulier syndrome, May-Hegglin syndrome.
Rare factor deficiencies include Factor II deficiency, combined Factor V and Factor VIII deficiency, Factor X deficiency.
Other bleeding disorders include alpha-2-antiplasmin deficiency.

Adverse events

Table 14 EUHASS adverse events and complications reported in HemoNED registry

Adverse events and complications	Number
Reported with event date in 2025	**39**
Mortality	24
Malignancy	6
Inhibitor	3
Allergic or other acute event	1
Thrombosis	4
Other	1

Reports from HemoNED participants and non-participants (these are reported anonymously).
Of the 39 reported events, 6 were from non-participants.

Side effects, including the occurrence of thrombosis, are also closely monitored in connection with new medication.

33 persons with acquired Hemophilia A were reported to HemoNED in 2025.
For some of these persons, informed consent for full registration in HemoNED was obtained.

Results VastePrik

Diagnosis and demographic data

Table 15 Diagnosis of VastePrik users (usage ≥1) in 2025

Diagnosis	Number of VastePrik users	%	Number of VastePrik users on prophylactic treatment	Number of HemoNED Registry participants on prophylactic treatment
Total	**527**	**100**	**478**	**878**
Hemophilia A	**432**	**82**	**399**	**709**
Severe	345		340	614
Moderate	74		55	82
Mild	13		<5	13
Hemophilia B	**52**	**10**	**48**	**99**
Severe	44		42	81
Moderate	7		6	17
Mild	<5		0	<5
Von Willebrand Disease	**23**	**4**	**17**	**42**
Type 3	12		10	22
Other types	11		7	20
Other bleeding disorders	**20**	**4**	**14**	**28**
Factor XIII deficiency	8		8	13
Factor VII deficiency	<5		<5	<5
Afibrinogenemia or hypofibrinogenemia	7		<5	7
Other	<5		<5	5

Diagnosis and demographic data

Figure 10 Age distribution of the VastePrik users on prophylactic treatment (n=478) and registry participants on prophylactic treatment (n=878) in 2025

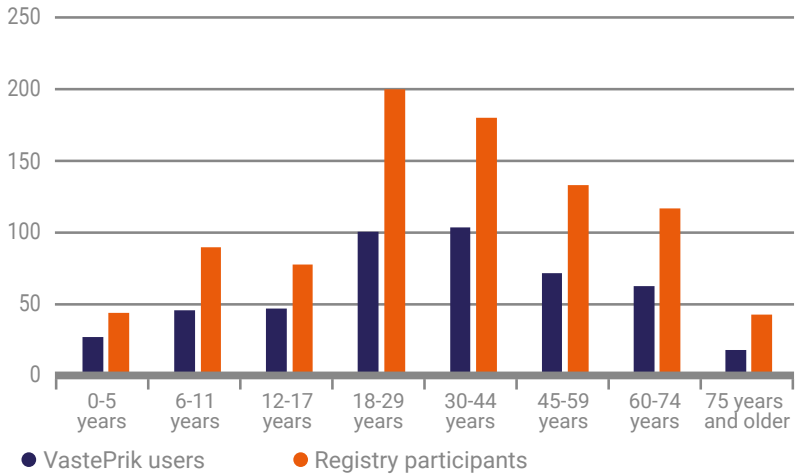
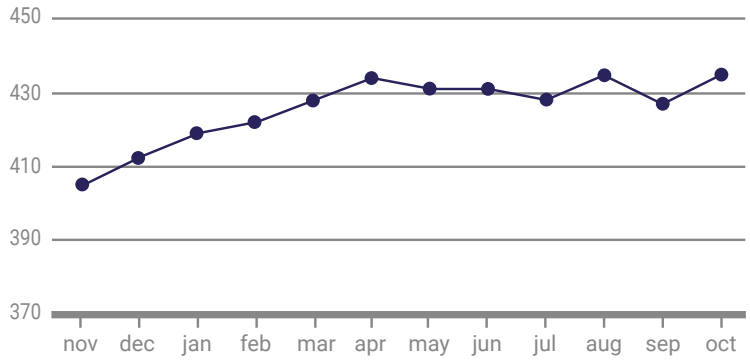


Figure 11 Number of unique VastePrik users each month 2024-2025



Infusions and bleeds

(self-report of the VastePrik users)

Table 16 Number of infusions by reason reported in VastePrik (November 2024 - October 2025, 1 year)

Reason infusion	Number of infusions	%
Prophylaxis*	20435	90
Precaution (risky activities)	494	2
(Directly following a) Bleed**	905	4
Aftercare (after a bleed or surgery)	883	4
Total	**22717**	**100**

* Prophylaxis reported by 490 of 527 VastePrik users
** Bleeds reported by 245 of 527 VastePrik users
Joint bleeds reported by 163 of 527 VastePrik users

Table 17 Type of bleeds reported

Type	Number of bleeds	%
Joint	444	49
Muscle	156	17
Subcutaneous	57	6
Mucous membranes	42	5
Other	206	23
Total	**905**	**100**

Table 18 Location of joint bleeds

Location	Number of bleeds	%
Ankle	121	27
Elbow	111	25
Knee	93	21
Shoulder	31	7
Hip	12	3
Wrist	25	6
Other	51	11
Total	**444**	**100**

Infusions and bleeds

Table 19 Bleed severity

Severity	Number of bleeds	%
Mild	246	27
Moderate	489	54
Severe	141	16
Missing	29	3
Total	**905**	**100**

Table 20 Cause of bleeds

Cause	Number of bleeds	%
Spontaneous	284	31
Overexertion	234	26
Accident, trauma	245	27
Postoperative	6	1
Other or missing	136	15
Total	**905**	**100**

Table 21 Severity of joint bleeds

Severity	Number of bleeds	%
Mild	123	28
Moderate	256	58
Severe	63	14
Missing	2	0
Total	**444**	**100**

Table 22 Cause of joint bleeds

Cause	Number of bleeds	%
Spontaneous	155	35
Overexertion	160	36
Accident, trauma	100	22
Postoperative	0	0
Other or missing	29	7
Total	**444**	**100**

Infusions and bleeds

Table 23 Reported bleeds in VastePrik (November 2024 – October 2025, 1 year) by users with hemophilia (selection: regular VastePrik users, mean registration of ≥ 1 prophylaxis infusion each month, N=297: 262 hemophilia A, 35 hemophilia B)

	Number of participants without bleeds	Number of participants with bleeds	Number of bleeds	A(J)BR*		Model based A(J)BR***
				Median (IQR)**	Range	Median (95% CI)****
All bleeds	155 (52%)	142 (48%)	506	0 (0-2)	0-22	1.7 (1.4 -2.1)
Joint bleeds	195 (66%)	102 (34%)	285	0 (0-1)	0-14	1.0 (0.8-1.2)

* Annualized (Joint) Bleeding Rate = median number of (joint) bleeds per person per year
** Interquartile range
*** Negative binomial regression
**** Confidence Interval

Infusions and bleeds

Table 24 Reported bleeds in VastePrik (November 2024 – October 2025 (1 year) by different groups of regular VastePrik users (regular use is defined as registration of ≥ 1 prophylaxis infusion/month)

		Number of VastePrik users without bleeds	Number of VastePrik users with bleeds	Number of bleeds	A(J)BR		Model based A(J)BR
					Median (IQR)	Range	Median (95% CI)
Hemophilia A (N=262)	All bleeds	140 (53%)	122 (47%)	453	0 (0-2)	0-22	1.7 (1.4-2.2)
	Joint bleeds	173 (66%)	89 (34%)	264	0 (0-1)	0-14	1.0 (0.8-1.3)
Hemophilia B (N=35)	All bleeds	15 (43%)	20 (57%)	53	1 (0-3)	0-7	1.5 (1.0-2.3)
	Joint bleeds	22 (63%)	13 (37%)	21	0 (0-1)	0-4	0.6 (0.3-1.0)
Severe Hemophilia A (N=233)	All bleeds	130 (56%)	103 (44%)	338	0 (0-2)	0-18	1.5 (1.1-1.8)
	Joint bleeds	157 (67%)	76 (33%)	209	0 (0-1)	0-13	0.9 (0.7-1.2)
Non-severe Hemophilia A (N=29)	All bleeds	10 (34%)	19 (66%)	115	2 (0-4)	0-22	4.0 (2.3-6.9)
	Joint bleeds	16 (55%)	13 (45%)	55	0 (0-3)	0-14	1.9 (0.9-3.8)
Hemophilia A < 18 yr (N=57)	All bleeds	36 (63%)	21 (37%)	52	0 (0-1)	0-7	0.9 (0.6-1.5)
	Joint bleeds	45 (79%)	12 (21%)	28	0 (0-0)	0-4	0.5 (0.2-1.0)
Hemophilia A ≥ 18 yr (N=205)	All bleeds	104 (51%)	101 (49%)	401	0 (0-2)	0-22	2.0 (1.5-2.5)
	Joint bleeds	128 (62%)	77 (38%)	236	0 (0-1)	0-14	1.2 (0.9-1.5)
Hemophilia A only NRT one year (N=182)	All bleeds	116 (64%)	66 (36%)	210	0 (0-1)	0-14	1.2 (0.8-1.6)
	Joint bleeds	137 (75%)	45 (25%)	123	0 (0-0.3)	0-13	0.7 (0.5-1.0)
Hemophilia A only SHL/EHL one year (N=40)	All bleeds	14 (35%)	26 (65%)	75	1 (0-2)	0-12	1.9 (1.3-2.8)
	Joint bleeds	18 (45%)	22 (55%)	47	1 (0-2)	0-11	1.2 (0.8-1.8)

Infusions and bleeds

Table 25 Most recently used prophylaxis product by VastePrik users with Hemophilia

	Number of users	%
Hemophilia A	**370**	**100**
Product a	290	78
Product b	34	9
Product c	22	6
Product d	10	3
Other products*	14	4

	Number of users	%
Hemophilia B	**45**	**100**
Product a	36	80
Other products*	9	20

* Number of users too small (< 10)

Table 26 Most recently used prophylaxis product by VastePrik users with Hemophilia, by type of product

	Number of users	%
Hemophilia A	**370**	**100**
Standard Half Life	40	11
Extended Half Life	36	10
Non Replacement Therapy	290	78
Other products	4	1

	Number of users	%
Hemophilia B	**45**	**100**
Standard Half Life	4	9
Extended Half Life	41	91

Back to contents

Support

HemoNED received a grant/research support from the following sponsors in 2025:

- CSL Behring B.V.
- Novo Nordisk B.V.
- Pfizer B.V.
- Roche Nederland B.V.
- Swedish Orphan Biovitrum BVBA/SPRL
- CAF-DCF

Contact

HemoNED Foundation
p/a LUMC, Staff Thrombosis and Hemostasis
Albinusdreef 2
2333 ZA Leiden
The Netherlands
E-mail: info@hemoned.nl
Website: https://hemoned.nl/en