HemoNED
Dutch Hemophilia Registry

Dutch Hemophilia Registry

Annual Report 2024

HemoNED Foundation
May 2025

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 2024.

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 set up a nationwide registry of people with hemophilia and related disorders including data about their disease, treatment andcomplications, to perform scientific research, to publish reports and to provide education to contribute to an improvement of the quality of care."
The Steering Committee of HemoNED, 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 data applications can be found 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 about the diagnosis, treatment and treatment outcomes of people with hemophilia or related disorders in the Netherlands. The anonymized registry data are used for overview reports, scientific research and efficacy and safety studies of drugs. Health care providers manually complete the registry with relevant medical information and part of the registry is automatically filled with data from Electronic Health Records of the HTCs. The registry database has built-in validation checks to ensure quality of data. In 2024, haemophilia carriers with low factor values (factor level <=0.40 IU/ml) were being reclassified to hemophilia.

VastePrik

The digital infusion log VastePrik was launched in 2018 both as an app for smartphones and a web page. Participants can register their home treatment (infusions and possible bleeds). VastePrik is mainly used by participants on prophylaxis. The health care provider also has access to the VastePrik data and overview reports of his/her patient through a secured online web page, to evaluate and adjust home treatment if necessary. In agreement with the patient, health care providers can add or change infusions or bleeds in VastePrik. In 2024, patients were made aware of the importance of also registering treated bleeds in the hospital in VastePrik.

Inclusion

All national certified HTCs routinely invite possible 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 will be eligible to participate in the HemoNED Registry:

- Hemophilia A or B
- Carriers with hemophilia A or B: coagulation factor levels > 0.4 IU/ml or unknown
- 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 infusion with thrombocytes at surgery/trauma
- Acquired clotting factor disorders

Adverse events

All HTCs enter adverse events and complications for people with bleeding disorders in the HemoNED Registry. Quarterly, HemoNED provides an overview of reported events 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 2024 data on behalf of the Steering Committee. The statistical software SPSS was used to perform describing statistical analyses to analyze and describe the data. The HemoNED foundation ensures that all information provided for research and publication is fully anonymized. To further prevent indirect traceability this annual report presents, wherever possible, cells with values lower than 10 as '<10' or values have been aggregated with other (sub)categories.

Publications

HemoNED provided in 2024 numbers for the Annual Global Survey 2023 of the World Federation of Hemophilia in collaboration with NVHP. Annual Global Survey -WFH -World Federation of Hemophilia.

Organisation

Board members HemoNED Foundation in 2024:

- **Chair: Dr. S.C. (Samantha) Gouw,** Pediatric hematologist Amsterdam UMC Hemophilia Treatment Center
- **Secretary: Dr. M.H.E. (Mariëtte) Driessens,** Delegate of the patient organisation NVHP for everyone with a congenital bleeding disorder
- **Treasurer: Prof. Dr. K. (Karina) Meijer,** Internist-hematologist, UMC Groningen Hemophilia Treatment Center

The following representatives were part of the HemoNED Steering Committee in 2024:

- **Dr. S.C. (Samantha) Gouw,** chair Steering Committee, Amsterdam UMC Hemophilia Treatment Center
- **Dr. K. (Kathelijn) Fischer,** Van Creveld Clinic UMC Utrecht (till half of 2024)
- **Dr. C.L. (Corien) Eckhardt,** Van Creveld Clinic UMC Utrecht (from half of 2024)
- **Dr. M.J.H.A. (Marieke) Kruip,** Erasmus MC Rotterdam Hemophilia Treatment Center
- **Dr. B.A.P. (Britta) Laros-van Gorkom,** Hemophilia Treatment Center Radboudumc Nijmegen, MUMC+ Maastricht & MMC Eindhoven/ Veldhoven
- **Dr. M.A. (Marjet) Stein-Wit,** UMC Groningen Hemophilia Treatment Center
- **Dr. P.L. (Paul) den Exter,** Hemophilia Treatment Center LUMC Leiden & HagaZiekenhuis The Hague
- **S.L.A. (Stephan) Meijer,** Patient organisation NVHP for everyone with a congenital bleeding disorder
- **M. (Marlène) Beijlevelt,** MSc, Dutch organization for people with hemophilia or an inherited bleeding disorder Dutch Hemophilia Nurses Society (NVHV)

The HemoNED Project Office in 2024:

- **C.M.E. (Caroline) van Veen,** MSc, Project coordinator HemoNED
- **E.M. (Liesbeth) Taal,** MSc, Data manager HemoNED

Results Dutch Hemophilia Registry

General

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

Total participants

Total completed **3008** (100%)

Gender

Man **2144** (71%)

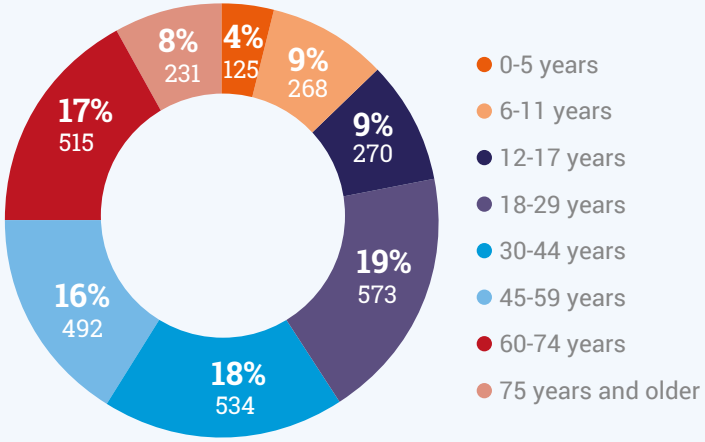
Woman **864** (29%)

General

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

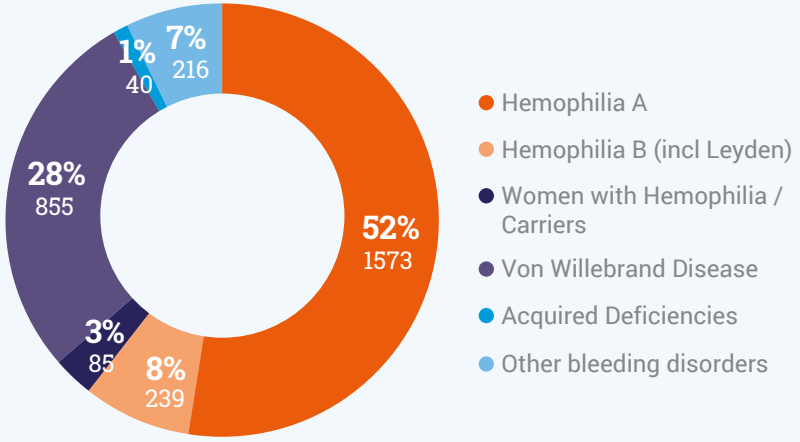
Age

Total completed **3008** (100%)



Diagnosis

Total completed **3008** (100%)



General

Figure 2a Number of participants included in the HemoNED registry until 31 December 2024

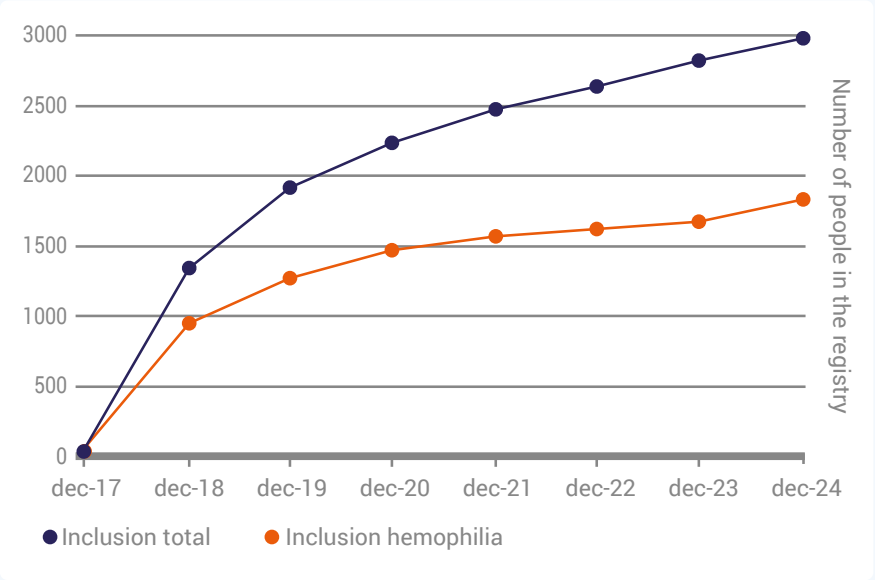
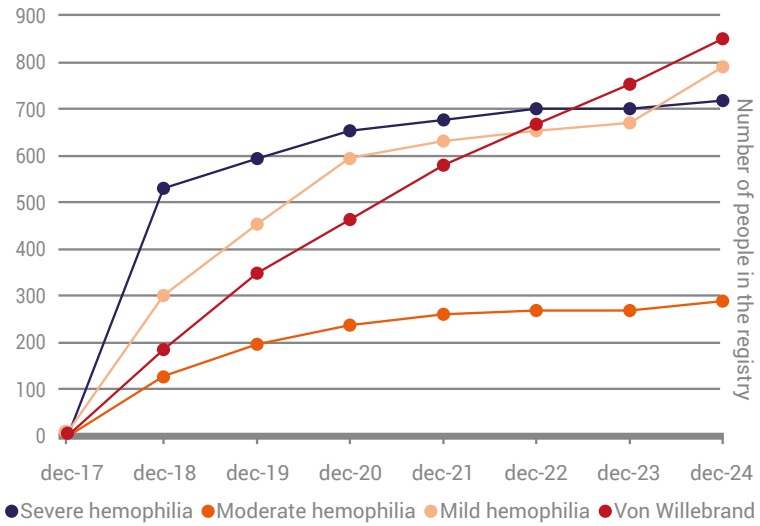


Figure 2b Number of participants with severe, moderate and mild hemophilia and Von Willebrand disease included in HemoNED until 31 December 2024



Mortality

2018-2023: 90 participants died. The data of these participants are excluded.

2024: 17 participants died. The data of these participants are included in this report.

Hemophilia

Diagnosis and demographic data

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

Diagnosis	Number	%
Hemophilia A	**1573***	**100**
Severe	623	39
Moderate	248	16
Mild	702	45

Diagnosis	Number	%
Hemophilia B	**239****	**100**
Severe	93	39
Moderate	37	15
Mild	86	36
Leyden	23	10

Diagnosis	Number	%
Hemophilia Carriers	**85**	**100**
Hemophilia A	62	73
Hemophilia B	22	26
Missing	1	1

* 1475 men, 98 women
** 206 men, 33 women

Hemophilia

Figure 3a Participants with Hemophilia A by severity

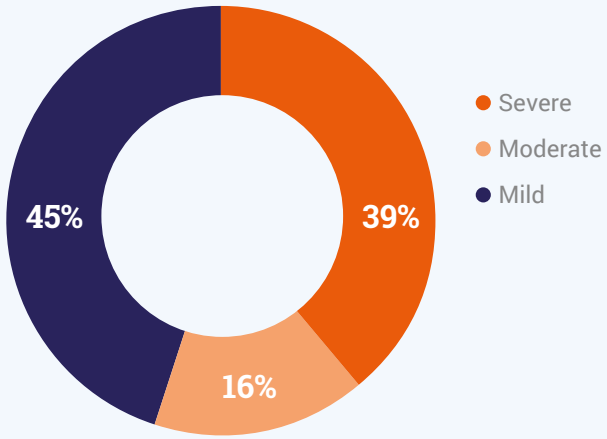
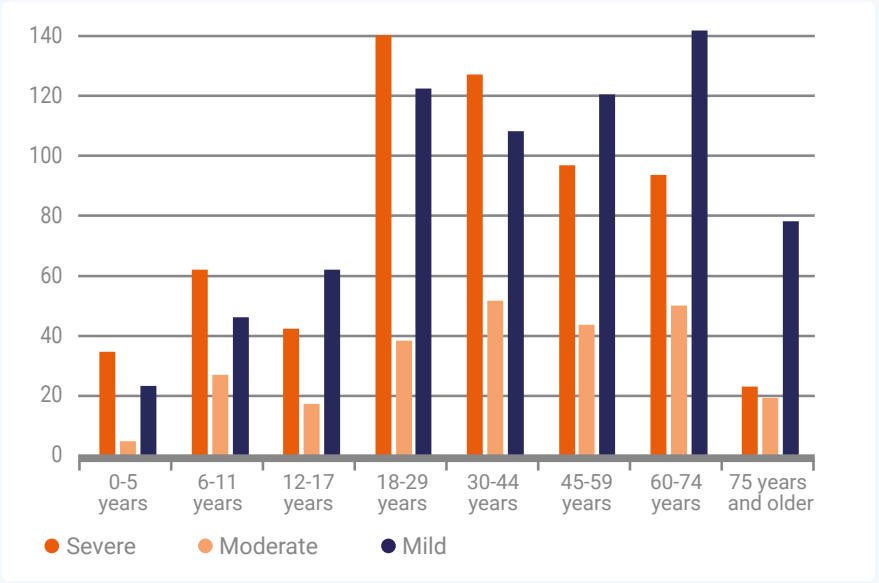


Figure 3b Participants with Hemophilia A by age and severity



Hemophilia

Figure 4a Participants with Hemophilia B by severity

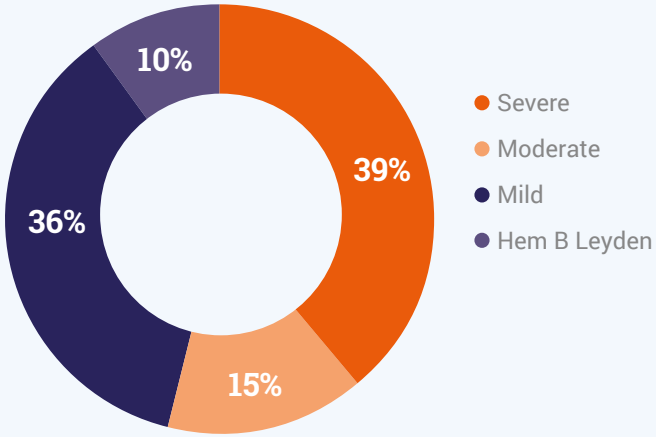
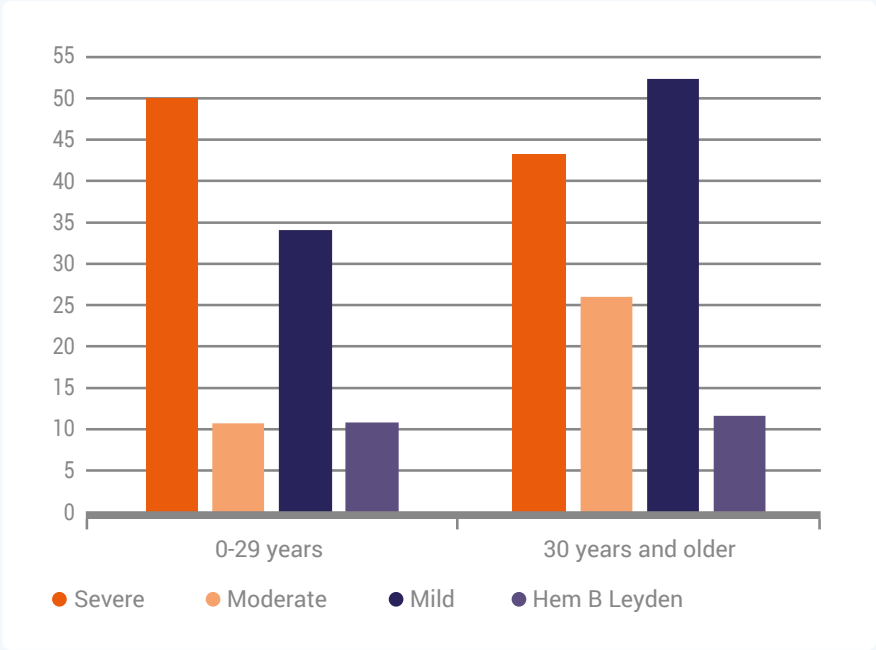


Figure 4b Participants with Hemophilia B by age and severity



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	**1023**	
Not completed	**23**	
Total completed	**1000**	**100**
Unknown*	87	9
No	485	48
Yes**	428	43

Viral infection	Number	%
HIV infection	**30**	

Viral infection	Number	%
Hepatitis B infection	**105**	

Viral infection	Number	%
Hepatitis C infection	**390**	**100**
Successfully treated	296	76
Spontaneously cleared	49	13
Still infected	26	7
Unknown	19	5

* Classified by a health care provider as 'Unknown'
** Participants may (have) suffer(ed) from more than one infection

Inhibitors

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

Inhibitors and Hemophilia A	Number	%
Total completed*	**1525**	**100**
Never	1294	85
Current or past inhibitor	193	13
Unknown**	38	2

Inhibitors and Hemophilia B	Number	%
Total completed***	**210**	**100**
Never	199	95
Current or past inhibitor	5	2
Unknown**	6	3

* Data available for 1525 of 1573 participants with Hemophilia A
** Classified by a health care provider as 'Unknown'
*** Data available for 210 of the 216 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	**1560**	**685**	**44**
Severe	622	602	97
Moderate	246	72	29
Mild	692	11	2

Hemophilia B	Number completed	Number on prophylaxis	% on prophylaxis
Total	**215**	**94**	**44**
Severe	93	76	82
Moderate	37	16	43
Mild	85	2	2

Hemophilia

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

Hemophilia A*	Number
Total completed	**2184 (for 1560 participants)***
Product A	853
Product B	423
Product C	316
Product D	221
Product E	181
Product F	74
Product G	39
Product H	16
Product I	14
Product J	13
Product K	10
Other products**	24

Hemophilia B	Number
Total completed	**239 (for 238 participants)***
Product A	101
Product B	94
Product C	34
Other products**	10

* For 13 participants with Hemophilia A and 1 participant with Hemophilia B the treatment plan is missing. For some of the participants more than one treatment product was prescribed.

** Number of prescriptions too small (< 10).

Hemophilia

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

Hemophilia A	Number	%	Number on prophylaxis	%
Total completed	**1560**	**100**	**685**	**100**
Standard Half Life	944	60	138	20
Extended Half life	121	8	108	16
Non Replacement Therapy	423	27	423	62
Bypassing Agents	32	2	0	0
Plasma derived	15	1	2	0
Study drug	14	0	14	2
Only Desmopressin	11	1	0	0
Other	0	0	0	0

Hemophilia B	Number	%	Number on prophylaxis	%
Total completed	**239**	**100**	**94**	**100**
Standard Half Life	135	57	10	11
Extended Half life	102	43	83	88
Other	2		1	1

* 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

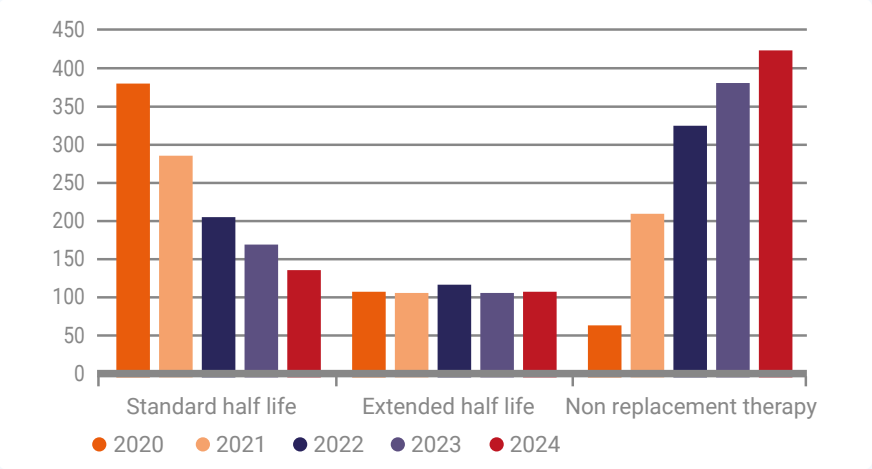
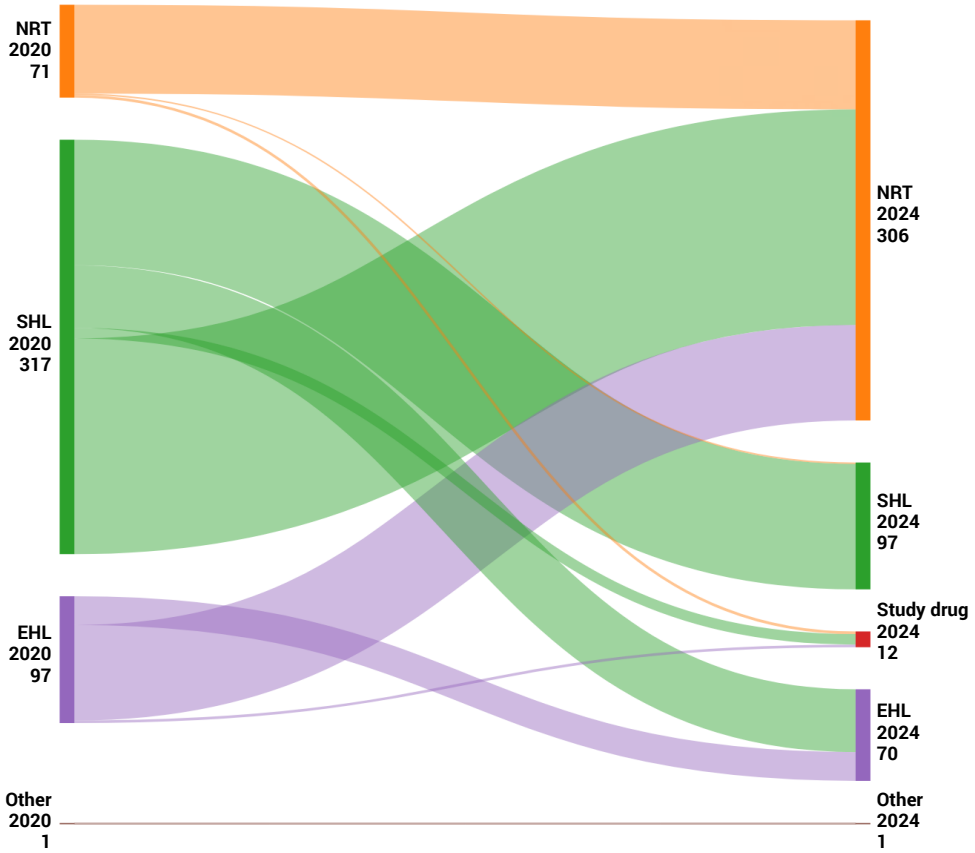


Table 7 Reason to start with Non Replacement therapy

Reason to start Non Replacement therapy	Number	%
Total completed	**430**	**100**
Preference of both patient and physician, non-specific	192	45
Recurring bleeds despite regular prophylaxis	97	23
Venous access problems	69	16
Inhibitor with bleeding tendency	37	9
Not being able to administer regular prophylaxis	19	4
Very active life (sports, travelling)	16	4

Hemophilia

Figure 6 Sankey diagram of the (change in) treatment according to product type for persons with severe hemophilia A on prophylactic treatment, in the years 2020 and 2024 (Selection: participants included in HemoNED before 2021, severe hemophilia on prophylactic treatment, known treatment plan (N=486)).



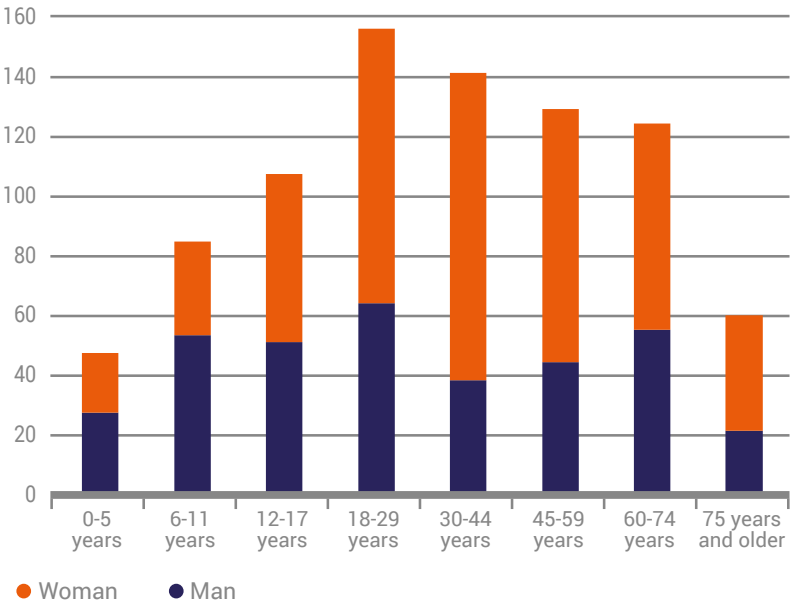
Von Willebrand Disease

Diagnosis and demographic data

Table 8 Number of participants with diagnosis Von Willebrand disease

Diagnosis	Number	%
Von Willebrand disease	**855**	**100**
Type 1	485	57
Type 2, no subtype	14	2
Type 2A	127	15
Type 2B	68	8
Type 2M	61	7
Type 2N	21	2
Type 3	37	4
Other/type unknown	42	5

Figure 7 Participants with Von Willebrand disease by age and gender



Von Willebrand Disease

Inhibitors

Table 9 Inhibitor status of participants with diagnosis Von Willebrand disease

Inhibitors and Von Willebrand	Number	%
Total completed	**586***	**100**
Never	422	72
Current or past inhibitor	<10	0
Unknown**	162	28

* Data available for 586 of 855 participants with Von Willebrand disease

** Classified by a health care provider as 'Unknown'

Treatment

Table 10 All prescribed treatment products for participants with diagnosis Von Willebrand disease

Products and Von Willebrand	Number
Total completed	**1052 (for 798 participants)***
Product A	573
Product B	286
Product C	153
Product D	22
Other products**	18

* For 57 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 11 Prescribed products for participants with Von Willebrand disease on prophylaxis

Products and Von Willebrand disease	Number
Total completed	**32**
Product A	21
Product B*	<10
Product C*	<10

* Number of prescriptions too small (<10).

Other bleeding disorders

Table 12 Number of participants in HemoNED registry with other bleeding disorders

Diagnosis	Number	%
Other bleeding disorder	**256**	**100**
Factor VII deficiency	35	14
Factor XI deficiency	28	11
Glanzmann's disease	22	9
Acquired Hemophilia A	30	12
Afibrinogenemia/hypofibrinogenemia/ hypodysfibrinogenemia/dysfibrinogenemia	18	7
Storage Pool Disease	25	10
Factor XIII deficiency	14	5
Factor V deficiency	10	4
Other bleeding disorders	74	29
Various other platelet disorders	48	
Rare factor deficiencies	10	
Other acquired bleeding disorders	10	
Other bleeding disorder or disorder not specified	6	

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 13 Adverse events and complications reported in HemoNED registry

Adverse events and complications	Number
Reported with event date in 2024*	**48**
Mortality	27
Malignancy	9
Inhibitor	4
Allergic or other acute event	0
Thrombosis	8
Other	0

* Reports from HemoNED participants and non-participants (these are reported anonymously).

In 2024 37 persons with acquired Hemophilia A are reported in HemoNED. From a few persons with this diagnosis informed consent was asked and obtained for full registration in the HemoNED registry. These are also included in table 12.

Results VastePrik

Diagnosis and demographic data

Table 14 Diagnosis of VastePrik users (usage ≥1) in 2024

Diagnosis	Number	%
Total	**514**	**100**
Hemophilia A	**421**	**82**
Severe	342	
Moderate	67	
Mild	12	
Hemophilia B	**53**	**10**
Severe	44	
Moderate	<10	
Mild	<10	
Von Willebrand Disease	**23**	**5**
Type 3	11	
Other types/unknown	12	
Other bleeding disorders	**17**	**3**
Factor XIII deficiency	<10	
Factor VII deficiency	<10	
Afibrinogenemia or hypofibrinogenemia	<10	
Other	<10	

Diagnosis and demographic data

Figure 8 Age distribution of VastePrik users N=514 in 2024

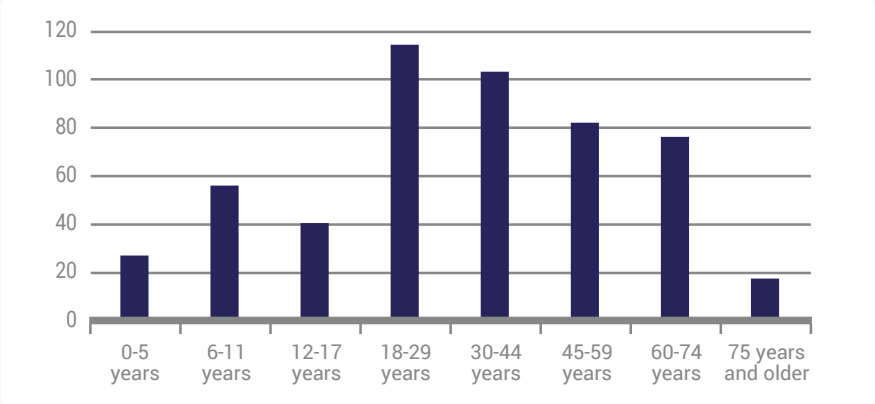
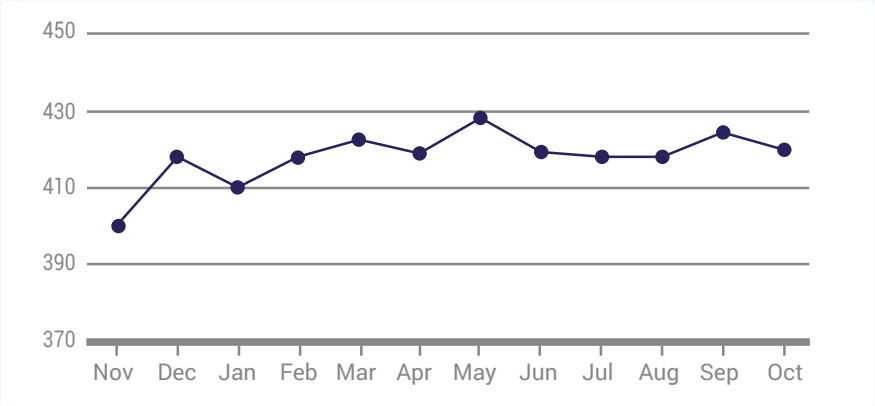


Figure 9 Number of unique VastePrik users each month 2023-2024



Infusions and bleeds

(self-report of the VastePrik users)

Table 15 Number of infusions by reason reported in VastePrik (November 2023 - October 2024, 1 year)

Reason infusion	Number of infusions	%
Prophylaxis*	22669	90
Precaution (risky activities)	550	2
(Directly following a) Bleed**	1013	4
Aftercare (after a bleed or surgery)	1018	4
Total	**25250**	**100**

* Prophylaxis reported by 468 of 514 VastePrik users
** Bleeds reported by 274 of 514 VastePrik users
Joint bleeds reported by 162 of 514 VastePrik users

Table 16 Type of bleeds reported

Type	Number of bleeds	%
Joint	471	46
Muscle	225	22
Subcutaneous	76	8
Mucous membranes	52	5
Other	189	19
Total	**1013**	**100**

Table 17 Location of joint bleeds

Location	Number of bleeds	%
Ankle	137	29
Elbow	120	25
Knee	88	19
Shoulder	31	7
Hip	17	4
Wrist	18	4
Other	60	13
Total	**471**	**100**

Table 18 Bleed severity

Severity	Number of bleeds	%
Low	346	34
Moderate	498	49
High	132	13
Missing	37	4
Total	**1013**	**100**

Table 19 Cause of bleeds

Cause	Number of bleeds	%
Spontaneously	276	27
Overload	280	28
Accident, trauma	294	29
Postoperative	6	1
Other or missing	157	16
Total	**1013**	**100**

Table 20 Severity of joint bleeds

Severity	Number of bleeds	%
Mild	155	33
Moderate	249	53
Severe	64	14
Missing	3	1
Total	**471**	**100**

Table 21 Cause of joint bleeds

Cause	Number of bleeds	%
Spontaneous	160	34
Overload	168	36
Accident, trauma	102	22
Postoperative	0	0
Other or missing	41	9
Total	**471**	**100**

Table 22 Reported bleeds in VastePrik (November 2023 - October 2024, 1 year) by users with hemophilia (selection: regular VastePrik users, mean registration of ≥ 1 prophylaxis infusion each month, N=303; 271 hemophilia A, 32 hemophilia B)

	Number of participants without bleeds	Number of participants with bleeds	Number of bleeds	A(J)BR*	
				median (IQR)**	range
All bleeds	141 (46%)	162 (54%)	535	1 (0-2)	0-29
Joint Bleeds	203 (67%)	100 (33%)	279	0 (0-1)	0-13

* Annualized (Joint) Bleeding Rate = median number of (joint) bleeds per person per year
** Interquartile range

Table 23 Most recently used prophylaxis product by VastePrik users with Hemophilia

	Number of users	%
Hemophilia A	**382**	**100**
Product a	258	68
Product b	47	12
Product c	40	10
Product d	22	6
Product e	13	3
Other products*	2	1

	Number of users	%
Hemophilia B	**49**	**100**
Product a	41	84
Other products*	8	16

* Number of users too small (<10)

Table 24 Most recently used prophylaxis product by VastePrik users with Hemophilia, by type of product

	Number of users	%
Hemophilia A	**382**	**100**
Standard Half Life	60	16
Extended Half Life	62	16
Non Replacement Therapy	258	68
Bypassing Agents	2	1

	Number of users	%
Hemophilia B	**49**	**100**
Standard Half Life	4	8
Extended Half Life	45	92

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Support

HemoNED received a grant/research support from the following sponsors in 2024:

- CSL Behring B.V.
- Novo Nordisk B.V.
- Octapharma Benelux N.V.
- Pfizer B.V.
- Roche Nederland B.V.
- Swedish Orphan Biovitrum BVBA/SPRL

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