

Newsletter 03 / March 2025

➤ J. Kremer Hovinga on behalf of the SHN Board

SHN Presidential Report for 2024

INFORMATION from the BOARD

In 2024, we had four SHN Board Meetings – in January, April, August and November.

Following the last GA and the revision of the SHN bylaws, we welcomed **Gabriel Lottaz**, delegated by the Swiss Hemophilia Society, and representatives of the Hemophilia Nurses, **Esther Latenser** (St. Gallen, adults) and **Sara Mettler** (Zürich, adults) – they work in job sharing, as new SHN board members

For Nicolas von der Weid (Basel, pediatrics) and Lukas Graf (St. Gallen, adults) their 2nd three-year term in the SHN Board ends at the General Assembly and they will step down. Also at the GA, the first three-year term of Manuela Albisetti (Zürich, pediatrics) and Johanna Kremer Hovinga (Bern, adults) ends. While Manuela has decided to leave the SHN Board to focus on her GTH presidency, Johanna stands for re-election as SHN president.

Lukas Graf is the SHN Board delegate to the SOHC organizing committee (taking place in November in Basel). The SHN Board has decided that Lukas remains in the SOHC organizing committee in 2025 and will work closely with the next SHN Board member taking this job.

INFORMATION from the SHN Office

Our office manager, Marie Beurret married and became Marie Stutz. At the end of 2024, she and her husband welcomed their first child, a boy named Mathis Pierre. **Congratulations!** During Marie Stutz' maternity leave, **Marina Nadig** supports us.

Members

- At the end of 2024, we had 80 members in good standing.
- Please send updates and any change of e-mail address, phone number, etc. to the SHN office.
- SHG-ASH-ASE goes on with printing HCCC and HTC information on the last page of their bulletin! The SHN office provides the available and hopefully up-to-date information to the SHG-ASH-ASE office in **September & March**.

SHN NEWS

Cooperation SHG-ASH-ASE & SHN

The collaboration contract between SHG-ASH-ASE & SHN was revised, adopted by both boards and then signed by the two presidents.

In addition, we have developed a SOP with binding division of tasks for mutual events, like the Herbsttagung, Journée romande, etc.

KOSEK

On 27 January 2025, the Swiss Hemophilia Network was recognized by KOSEK as Network for Rare Coagulation Disorders (this includes *rare hemorrhagic disorder* as well as *rare thrombotic disease of hematologic origin*, r both hereditary and acquired (Classification level: Group of disorders, ORPHA Code: 98429). Also in January 25, HCCC Inselspital Bern received the recognition as reference center for rare coagulation disorders. The evaluation of the hemophilia centers of Geneva, Basel and Zürich is underway (Phase 3 of the application process), and should be completed during the summer. This 2-2.5 year process comes thus soon to a successful end.



Given the important roles assigned to HTC and HCCC as well as to SHN by the FOPH by restricting the prescription of new treatments (i.e. Emicizumab and Concizumab) as well as for the organization and the access to gene therapy, the recognition by KOSEK provides SHN and its affiliated HTC and HCCC the necessary authorization to stand the ground.

Gene therapy

The working group Gene therapy or Gene Therapy Expert Board, chaired by Johanna Kremer Hovinga, and representation from all Swiss HTC and HCCC met 4x during the past 12 months. The FOPH, CSL-Behring and health insurances have agreed on a price-model for HEMGENIX® (gene therapy for hemophilia B), which on the SL since 01.01.2025. Gene therapy is paid in installments when certain milestones are reached. The number of tranches and the size of the individual tranches are not disclosed (confidentiality agreement between authorities, CSL-Behring and health insurances). Inselspital Bern is the designated HUB where the gene therapy is given, while all other Swiss HCCC and HCT act as spoke centers, taking care of patients before and after administration of gene therapy. A positive recommendation of the SHN Gene Therapy Expert Board is necessary to apply for the assumption of costs. So far, four patients have been presented to this board, two have been approved, and the decision for two other patients was deferred until further evaluation. The application for assumption of costs for the first patient has been submitted to the patient's health insurance in February.

Swiss Hemophilia Registry (SHR)

In September, we entered in a contract with **Elsbeth Müller** who acts again as SHR monitor. Monitoring makes good progress. Sites may delegate data entry to Elsbeth – in such cases, the compensation foreseen (CHF 60.- for inclusion and baseline; CHF 30.- for every follow-up year) will be used to pay for Elsbeth's extra time. We plan to have a second monitor, **Sara Mettler** (Zürich, adults), to help and as back up. Negotiations with Sara and Elsbeth are underway.

In 2025, the SHR is already 10 years underway, thus re-approval by ethics is necessary. We plan to submit the necessary amendment, including the PI change (from **Manuela Albisetti** (Zürich, pediatrics) to **Mattia Rizzi** (Lausanne, pediatrics), to the ethics committee in Lausanne in the course of this year.

Under the lead of **Alessandra Bosch** (Zürich, pediatrics) and Manuela Albisetti an **abstract on the SHR** (entitled: *The Great Return: Rebuilding and Advancing the Swiss Hemophilia Registry*) was presented during the poster session on 20 February at the GTH 2025 in Lausanne (PW-07-06). Alessandra presents the essentials also in the Public Part of the SHN General Assembly 2025.

SHN Research Award 2024

Marissa Schraner, PhD, a post-doc in the DBMR Blood Cluster, University of Bern submitted the winning application. She present her project, entitled "*Longitudinal Epitope Mapping of inhibitory Alloantibodies against factor IX in a Hemophilia B patient*" in the Public Part of the SHN General Assembly in March 2025.

SHN Research Award 2025 Announcement

SHN hopes to hand out an SHN Research Award again this year – provided we can raise the necessary funds. Submission deadline will be **10 October 2025 23:59 CET**. **Pierre Fontana** (Geneva, adults), the Award Chair and the SHN Office will communicate details by e-mail and on the SHN- and SGH-SSH websites later this year.

Military service and Hemophilia & allied disorders

There are many questions around the "fitness for service" in the army for persons diagnosed with hemophilia or allied disorders. **Janice Delfosse** (Bern, adults) organized a meeting on 6 December 2024 with the Oberfeldarzt Divisionär Stettbacher and members of SHG-ASH-ASE and SHN. The position of SHG-ASH-ASE and SHN that there should be a clear and transparent standard for Switzerland was well taken. Divisionär Stettbacher and his legal advisor are developing a position paper before the end of Q1/2025 that will be distributed via the SHG-ASH-ASE and SHN websites and e-mail to all Swiss HTC and HCCC.

S2k AWMF Guideline Diagnosis and S2k AWMF Guideline Treatment of Thrombocytopathies (TROMB-Kid plus)

SHN was invited to participate in the revision of the S2k Guideline (in German). Our representations in the project were **Markus Schmutge** (Zürich, pediatrics), who had already contributed to the generation of the first guideline, and **Lorenzo Alberio** (Lausanne, adults).

SUCCESSFUL past EVENTS

Pediatric GTH 2024 (pgth2024.de)

Luzern, 14 – 16 October 24; Messe Luzern

Lead: **Freimut Schilling**

GTH 2025 (www.gth2025.com)

Lausanne, 18 – 21 February 2025

Lead: **Manuela Albisetti** and **Lorenzo Alberio**

We thank the congress presidents and their teams for the excellent meetings.

Thrombosis and Hemostasis Switzerland excelled!

FACTOR CONSUMPTION in 2024

1.) Factor consumption / capita

(Resident population of Switzerland Q3/24: 9'027'859)

	Total (U)	FVIII (U)	FIX (U)	Non-F (mg)
2004	4.01	3.36	0.64	-
2009	4.59	3.84	0.7	-
2014	6.85	5.83	0.95	-
2019	8.09	7.33	0.76	0.00
2024	6.50	5.58	1.12	0.08

2.) Type of factor used

	Factor VIII			Factor IX		
	pd (%)	rSHL (%)	rEHL (%)	pd (%)	rSHL (%)	rEHL (%)
2004	40.6	59.4	-	93.3	6.7	-
2009	23.4	76.6	-	90	10	-
2014	18	82	-	74.9	25.1	-
2019	4.5	35.2	60.3	10.3	10.2	79.5
2024	3.11	18.83	78.07	3.49	8.2	88.31

3.) Absolute factor used in 2024:

- total: 58'710'000 Units
- FVIII: 48'578'500 Units
- FIX: 10'131'500 Units
- Emicizumab: 697'230 mg
- Concizumab: 14'000 mg