

Newsletter 01 / 2023

INFORMATION from the BOARD

Organization of the Board – New assignments

Vice President – Nicolas von der Weid
Chair SHN Award – Pierre Fontana
Delegate SOHC committee – Lukas Graf

Upcoming Vacancy:

Wolfgang Korte would like to resign as **auditor of the SHN book keeping**. Alice Trincherio (Zürich, Adults) is willing to join Reta Malär in this job.

- Interested persons send an e-mail to the SHN office before 30 September 2023. In case of >1 applicant, we will organize a doodle poll.

Website:

The data protection requirements were updated to comply with the new law, which came into effect on 1 September 2023.

Members

SHN has 82 members in good standing.

- Please send updates and any change of e-mail address, phone number, etc. to the SHN office
- SHG-ASH-ASE has decided to go on with printing HCC and HTC information in their bulletin.

The SHN office provides SHG-ASH-ASE twice a year (September & March) with the actual information available at the SHN office. HCC and HTC make sure, that their information available at SHN office is correct!

SHN NEWS

SHN Research Award 2023

The SHN board extends to you all an invitation to apply for the 2023 subsidy of the SHN Research Award (amount 20'000.-). We are looking forward to interesting projects in the field of inherited bleeding disorders.

Application should be sent to the SHN office before 10 October 2023 23:59 CET. The Award is presented during the SOHC Congress in Basel (22.-24.11.2023). Further information can be found in the attached flyer as well as on the SHN and SGH SSH websites.

UPCOMING EVENTS

Swiss Oncology and Hematology Congress (SOHC),
Basel, 22 – 24 November 2023

Abstract submission deadline: 1 October 23:59 CET

- Our logo is on the website – SHN Board has now a member in the Committee, the position is held by Lukas Graf.

GTH 2024 – 68th Annual Meeting of the Society of Thrombosis and Haemostasis Research

Vienna, 28 February – 1 March 2024

Abstract submission deadline: 13 October 23:59 CET

Lecture: “Sozialrechtliches in der Hämophilie”

UniversitätsSpital Zürich, 21 September, 16h00-17h00, Meeting room KUE F4, followed by an Apéro.

SHG-ASH-ASE Gaming Event in Bern

21 October 2023, 11h00-17h00,

For adolescents and young adults (from age 12);
Flyer attached – we ask you to help with recruiting young people to become interested in the patient organization SHG-ASH-ASE.

UPDATES from WORKING GROUPS and on PROJECTS

Working group Gene therapy

The working group Gene therapy (Chair: Johanna Kremer Hovinga) meets virtually and had its first meeting in May. The next meeting is planned in October; the date will be announced on the web site. New members welcome.

A strong link with the *GTH AG Gentherapie* has been established, Johanna is a member of the GTH Gene Therapy Registry Steering Committee, that will work with the GENTS – Gene therapy software for hemophilia (have a look here: [GENTS | gents-haemophilia.com](https://gents-haemophilia.com)). This software is also suitable for the daily work in HUB and SPOKE centers. Alice Trincherio (Zürich, Adults) and Eugenia Buguzzi (Bellinzona, Adults) and Pierre Fontana will check for developments in Italy, France and Belgium, respectively.

The first gene therapy for hemophilia to come to Switzerland is HEMGENIX® (Hemophilia B, CSL-Behring). We have heard that CSL Behring is developing an innovative reimbursement scheme in cooperation with relevant health insurance companies.

- We ask HCC and HTC heads to give us an idea on the number of patients with severe or moderate hemophilia A and hemophilia B interested in genethrapy. Please send the number to the SHN office before 15 October 2023
- For hemophilia B patients, please also send the **name of health care insurances** involved to allow these companies to collaborate with CSL-Behring on developing a widely accepted reimbursement scheme.

Update Rare Diseases Network – KOSEK application

KOSEK National Coordination rare diseases mission: *The overall goal is to improve health care for affected people. Kosek's general approach to do so is to enable stakeholders and networks to cooperate within a national com-munity for the sake of affected people.*

End of January 2023 we have submitted our application for recognition as Network for Rare Coagulation Disorders with all SHN affiliated centers listed.

Simultaneously, GE, BS, BE and ZH submitted own dossiers for recognition as reference centers. On 9 August 2023, we have received a letter, that KOSEK had evaluated our network. For remaining questions and information on next steps, a virtual meeting will be organized by KOSEK between September and November 2023.

More details on KOSEK can be found here: [kosek - Nationale Koordination Seltene Krankheiten \(kosekschweiz.ch\)](https://kosek.ch) and information on the application and recognition process under "VERSORGUNG".

E-Diary (SmartMedication)

E-diaries used to document health related data and treatments are subject to the EU Regulations on Medical Device (MDR and IVDR) that Switzerland has adopted.

Our E-diary, Smart Medication App has turned 10 recently, and is in need of modernization. Together with the acquisition of the now necessary MDR certificates, smart medication eHealth Solutions GmbH foresees costs of at least two Mio Euro, costs and risks the company (a spin-off of the University of Mainz) is not able to take.

A collaboration with Florio GmbH, a SOBI subsidiary has been started and it is planned that successively and until mid-2025 at the latest all patient who want to carry on with an e-diary can switch to FLORIO app (more information here <https://florio.com/>).

FLORIO has received the necessary Class IIa MDR certificate in June 2023. A full separation from SOBI was required (Florio GmbH is now an independent SOBI subsidiary). During the next months, FLORIO will be updated to cover all hemophilia products, including Emicizumab. Direct transmission of data to WAPPS HEMO is no longer required and FLORIO is offered free of charge (as was SmartMedication).

- Patients who want to keep an e-dairy carry on until asked within the SmartMedication App whether they would like to join FLORIO or not – patients have to confirm several times (inadvertent switches are impossible).
- Transfer of old SmartMedication data is possible – patients again are asked to confirm this step.
- Patients starting on an e-dairy should be offered FLORIO.
- Sites can contact SOBI personnel for help.

KOSEK

