

PV of the SGIEM General Assembly, 16th May 2019, 09:45-11:15

Location: Inselspital INO floor F, Seminar Room of the Institute of Pharmacology

1. **Welcome, additions to agenda** • Presentation of the program of the day, housekeeping information

No additions to agenda.

2. **Minutes of previous meeting / Matters arising from previous minutes**

The minutes of the previous meeting were accepted. No other matters were arising.

3. **Elections/Confirmation**

Vote counters: O. Hasselmann and C. Serratrice.

Revisors: M. Hochuli and A. Lämmle revised and approved the finances of the SGIEM of the year 2018. They would be willing to continue in their function and were confirmed unanimously by vote.

SGIEM representative for the Fachbeirat for *Paediatrica*: M. Gautschi proposed A. Lämmle for this position. He was confirmed with 19 votes, no abstentions or dissentient votes.

4. **SGIEM News** (M. Gautschi)

New SGIEM office in Bern: Ms. Tamara Tschannen is the new secretary in the SGIEM office. She is engaged to work at 20% for the SGIEM. It was necessary to change the email address of the SGIEM office, as the gmail address did not work well. The new email address is offered by the SGIEM homepage provider: info@inbornererrors.ch. The new SGIEM letterhead will be sent out to all members. A new bank account was opened for the SGIEM at the Raiffeisen Bank.

Metabolic pilot with kosek for Swiss Reference Centers/Networks Setup: The SGIEM was founded in 2004 and became an association in 2016. In the second half of the year 2017 the SGIEM was asked by the kosek ("Nationale Koordination Seltene Krankheiten") to be one of the two pilot projects (other: neuromuscular diseases) for the establishment of a national patient care network and reference center setup. The SGIEM accepted and in 2018 the Kerngruppe was constituted: M. Baumgartner, Zürich, E. Christ, Basel, M. Gautschi, Bern, C. Tran, Lausanne, T. Hundsberger, St. Gallen, I. Kern, Geneva, and D. Ballhausen, Lausanne. A kick-off meeting to

which all stakeholders were invited took place in Bern on the 7th March 2019. On this occasion the “new” SGIEM was constituted and mandated to build up the national patient care network. Documentation on the kick-off meeting was sent out to all SGIEM members. M. Gautschi explained the vision of the Kerngruppe for the network structure. Kosek will be the endorsement authority and the BAG will give a recommendation. The presented concept was accepted with 20 votes and 2 abstentions.

ASMM 2019 in Vienna & Future of ASMM / SGIEM Annual Meetings: The Austrian Swiss Metabolic Meeting (ASMM) 2019 took place on the 4th/5th April in Vienna. In the future there will only be every 2nd year a combined meeting with the Austrian group, which means that every 4th year there will be a meeting abroad. There were equal votes for the future Swiss meeting to take place in May 2020 (7 votes) or June 2020 (7 votes). A one-day meeting was preferred by the majority of the participants (22 votes with 7 abstentions). The next SGIEM meeting will probably take place in Bern in June 2020.

Sponsoring: Meeting on 21/Mar/2019 & new sponsoring concept: The number of sponsors went up from 6 to presently 10 sponsors. International companies have more and more regulations. The SGIEM will propose different sponsoring categories (like platin, gold, siver etc.). It needs to be defined what the sponsors will get back for their sponsoring. On the 6th March 2019, CHF 60'000.- of sponsoring by industry were obtained for the year 2019.

The new Website (I. Kern was absent)

The new SSIEM Website has finally been activated: <https://inbornerrors.ch/> - there is still considerable work to do and regular updating needs to be provided.

5. Finances 2018 / Budget 2019 (JM. Nuoffer)

The 2019 budget was not clear during the meeting and therefore no vote for the budget was carried out. The 2019 budget will be sent to all members with the minutes.

6. Reviser's Report (M. Hochuli, A. Lämmle): Both revisers confirmed that the finances the year 2018 of the SGIEM were correct.

7. Secretary's Report / Update on Membership (D. Ballhausen): The SGIEM has currently 68 members. 8 persons had asked to become new members of the SGIEM. One of them was Mrs. Hartmann from HTHC. The majority of the present SGIEM members recognized a conflict of interest for Mrs. Hartmann and therefore decided that she could not become a member of the SGIEM. With 1 abstention all other present SGIEM members voted against her acceptance as a SGIEM member. All other 7 persons (Dr Laura Roose, Unispital Zürich, Prof. Nicolas Regamy, Kinderspital Luzern, Dr. Thomas Schmitt-Mechelke, Kinderspital Luzern, Mrs Daniela Lampis, UKBB, Dr Sarah Sigrist, KS St. Gallen, Dr Tatiana Bremova-Ertl, Inselspital Bern, Dr. Maria

Peralta, CHUV Lausanne) were accepted unanimously as new SGIEM members. B. Thöny suggested that new members should disclose their financial support from industry when they ask for membership. As Mrs. Hartmann at this point had already participated in votes it was decided that the discussion on new members should be the first point in future SGIEM meetings.

8. Work groups

- **Rare Disease Registry (M. Baumgartner):** It seems that a budget will be given by the universities of Zurich and Bern and that this will enable the start of the project. This would allow applying in 2020 to the ministry of health for future financing.
- **Dietary products & KSME/GGML lists (BSV/BAG) (D. Ballhausen / Dieticians):** D. Moor (Zurich), C. Salvisberg (Bern) and D. Ballhausen (Lausanne) met Dr. Bailat and Mr. Honegger from the BSV on the 7th May 2019. The reimbursement system of drugs is currently under revision and will probably change in 2021. Dietary products will also be concerned by this revision. In the meantime there will be in general one update of the KSME list per year on the 1st January. Applications for new products have to be submitted by the producing companies latest until the 31st July. The SGIEM does currently not have any official role in this process and can only be informed about details of the process if the producing company demands this in their application letter.
- **Lab Analyses List/BAG (D. Mathis):** The BAG accepted the demanded changes on the Analysenliste. The notification for the changes is expected for the 1st January 2020.
- **Newborn Screening (M. Baumgartner):** The newborn screening center is currently facing severe technical problems secondary to an abrupt change of the provider of the measuring instruments (Perkin Elmer to Lab Systems). The problems result in significant delays of result generation. Dietary controls of diagnosed patients are the most severely affected with some results pending since 6 weeks. Lausanne and Bern complained about a lack of information on these problems and M. Baumgartner agreed that the flux of information was not optimal. M. Baumgartner expects the newborn screening program to go back to normal functioning in June 2019. D. Ballhausen asked if there was an increased number of false positive screening results for GA-I as Lausanne recently had two cases. M. Baumgartner replies that 5-6 false positive samples are expected per year and that the real numbers do not exceed these expectations.

9. Sub-groups

- **SALS (M. Rohrbach):** In December 2018 a lysosomal network meeting took place. In June 2022 the international MPS conference will take place in Lucerne and SALS will serve as the scientific committee for this big event. SALS and the adult group had a joint meeting in the

afternoon.

- **Adults** (C. Tran): The program for the afternoon meeting was announced.
- **Dieticians** (C. Salvisberg/D. Moor): There are new dietetic recommendations for pediatric patients suffering from galactosemia (will be joined to the minutes). The French translation is still missing. The Swiss patient organization might be asked again to help with the translation.
- **Bone and connective tissue group** (M. Rohrbach): The bone group will meet in June 2019 and still needs to formally decide to become a subgroup of the SGIEM.

10. Varia

• *Updates on current and planned studies:*

N-Acetyl-Leucine for LSD by IntraBio (T. Brémovà-Ertl): due to lack of time no further information on this topic was provided.

11. Next meeting

The SGIEM Meeting 2020 will take place in Bern probably in form of the 1st Swiss National MetabNet Meeting.