Minutes of the
Annual General Meeting of the SRHSB in Stirling
Friday, July 1st 2016 13.15 - 14.00

University of Stirling (congress venue at the Stirling Court Hotel)

Present members: Pat McAllister (President) Reinhold Cremer (Hon Sec), Ian Pople (Hon Treasurer), Marcus Pauly, Helen Williams (Publ Secr), Waheed Ashraf (Webmaster), Carole Sobkowiak (Folic Acid Spokesperson), David Nash (Membership Secretary), Jaleel Miyan, Carolyn Harris, Jo Glazier, Maria Cartmill, Montserrat Guerra, Andrew Wynd, Mark Hamilton, Mami Yamasaki, Hazel Jones, Ann Wing, Gillian Yaz, Roger Bayston, Sven Mattson, Gunilla Glad-Mattson, Jack Fletcher, Ann Paal, Ampar Cuxar, Takayuki Inagaki, Doug Cochrane, Eric Ballantine, Mykel Rasmussen, Naiia Naz, Margo Whitford, Ewen Mackinnon, Jon Selby, Rosemary Ellis, Vita Stagno, Agustini Castaneyro-Perdono, Emilia Carmona, Katrin Rabiei, Luña Pappa, Jothy Kandasamy, Roger Strachan.

Apologies: Alfred Aschoff, Liza Ramos, Richard Morgan, Esteban Rodriguez, Peter White

Minutes

1. Approval of the Minutes of the last AGM in Malaga 2015,
   a. matters arising from the minutes: A questionnaire about questions, complaints and tasks of the Executive Committee will be sent out to the members together with the Autumn newsletter.

2. Membership changes
   - 14 new ordinary members: see Membership Sec. list below: All new members approved unanimously.
   - no formal resignations submitted
   - deaths: Former President Moyna Gilbertson

3. Reports
   - President Pat McAllister expressed his sincere gratitude for being elected to the Presidency of the SRHSB and offered his sympathies for the passing of Moyna Gilbertson. He thanked Margareta Dahl
for her prior service as President, emphasizing the impact of her personal enthusiasm and especially her leadership in organizing the 2014 Annual Meeting in Uppsala, Sweden. He also thanked Andy Wynd and the local organizing committee for putting together a superb meeting in Stirling this year.

- He reminded everyone that when he was a younger scientist he was immediately drawn to the SRHSB because of the welcoming nature of the membership as well as the high scientific standards of the Society, and part of his mission as new President is to maintain those principles and attitudes. While reminding members of all the benefits of the Society, he also mentioned the challenges that face us, namely declining membership and attendance at the annual conference. Nevertheless, he is confident that with an improved website, a strong effort to recruit and maintain younger investigators and care-givers, and continuation of high scientific standards the Society will grow. He stressed that the SRHSB not only has a strong history, but it is the only international society that combines the fields of spina bifida and hydrocephalus, an effort that is most appropriate given the considerable overlap of the two disorders. The SRHSB is also one of the few Societies that includes members from all aspects of clinical care and research.
- He welcomes feedback as he begins his new position and is always open to suggestions.

- **Hon Secretary** Reinhold Cremer would like to have more feedback from the membership and more involvement from each member.

- **Hon Treasurer** Ian Pople: Three bursaries were granted in 2016. Roger Bayston commented, that the Society would need to ensure compliance with the Charity Commission which required full accounts to be available at the AGM.

- To give a detailed overview of all financial affairs, the Hon. Treasurer’s report will be attached to the minutes and will be sent round with the invitation to the next AGM.

- **Publication Secretaries** (Marcus Pauly and Helen Williams): Abstracts are published on the website (member’s area) and will be published in the electronic version of the Scottish Medical Journal (August 2016), if the authors agreed to the publication.

- **Membership Secretary** (David Nash)

- “We have 14 new members going back to the Malaga meeting. I’ve listed the new members, the date that each joined and their membership category. We had 8 new Ordinary members and 5 student members and one senior member join.

- According to the website data on June 15th, we have 62 active ordinary members, 10 senior members and 7 student members
which I assume means paid up subscription. There are 15 inactive members listed which I assume means that their subscriptions haven’t been registered as paid. In addition we have 17 Honorary members. I think this is the largest number of new members we’ve had since I have been Membership Secretary.

- Increasing the membership numbers will continue to depend on not only putting together high quality meetings but also getting the word out to those specifically interested research related to hydrocephalus and spina bifida. We have primarily relied on our web site and encouraging and invited colleagues. Perhaps we need to look at other options of advertising our meeting on other professional web sites.

- **New members:**
  - Laurence Watkins 06/21/16 Ordinary member
  - Elizabeth Fox 05/13/16 Senior member
  - David Bailey 03/16/16 Ordinary member
  - Ramin Eskandari 03/03/16 Ordinary member
  - Birgit Cremer 01/17/16 Ordinary member
  - Vita Stagno 11/20/16 Ordinary member
  - Lauren Bushell-Thompson 10/16/15 Student member
  - Helen Sims-Williams 09/28/15 Ordinary member
  - Anne Molloy 07/24/15 Ordinary member
  - Liina Pappa 07/12/15 Student member
  - Dominic Acri 07/10/15 Student member
  - Samed Talibi 06/30/15 Student member
  - Trudi Edginton 06/30/15 Ordinary member
  - Anuriti Aojula 06/29/15 Student member

**Folic Acid Spokesperson** (Carole Sobkowiak):

„In November 2015 the *BMJ* published an Editorial entitled “Folic acid fortification for Europe” urging the EU to take a further look at the issue. To date no European country has fortified although Scotland is considering it.

The US has now allowed corn masa flour to be fortified with folic acid which will particularly benefit the Hispanic communities.

We have been privileged to have Professor Andy Copp at our meeting this year when he presented his findings of the PONTI Study [Prevention of Neural Tube Defects by Inositol] which has been published in the *British Journal of Nutrition*. This has shown that the combination of folic acid with inositol has further reduced the incidence of NTD’s. Further studies are required.
Researchers from Johns Hopkins Bloomberg School of Public Health, in Baltimore have said that there is a link between high folate levels and autistic spectrum disorders. There is concern because the study was not peer reviewed at the time of the announcement. In view of this I contacted Professor Elisabeth Fernell at the Gillberg Neuropsychiatry Centre in Gothenberg, Sweden. Elizabeth has presented to this Society on hydrocephalus in the past and has an excellent knowledge about autism. Since then, Jaleel Miyan from Manchester and Sven Mattsson from Sweden have agreed to co-operate with Elisabeth.

Although much has been said over the years about prevention, whether this is through preconceptual supplementation or with the fortification of flour I would like to encourage our members and colleagues to continue the search for the cause of NTD’s.

I am now standing down as Folic Acid Spokesperson and wish my successor Jaleel Miyan well.

Thank you for all the wonderful support that you have given me."

4. Executive Committee changes:
   a. Andy Wynd proposed as Honorary Secretary elect by Helen Williams and Hazel Jones: approved unanimously. Reinhold Cremer will introduce Andy Wynd during the next year until he will stand down in 2017.
   b. Jaleel Miyan is elected as Folic Acid spokesperson, approved unanimously (proposers Jo Glazier and Helen Williams).
   c. Doug Cochrane is approved unanimously as new ordinary member following Jaleel Miyan (proposer Helen Williams, Reinhold Cremer).
   d. Leandro Castaneyra Ruizd following Montserrat Guerra as ordinary member approved unanimously (proposer Helen Williams, Reinhold Cremer)
   e. Helen Williams steps down as Publication Secretary.

5. Stirling update (Andy Wynd): number of attendees: 64 + 14 accompanying persons

6. 2017 Meeting in Saint Louis/USA (Host: Pat McAllister) from June 21st to 24th as a conjoined meeting with International Childrens Continence Society (local organizer: Paul Austin, Secretary of the ICCS).
The Friday will be organized as combined meeting, premeetings and Thursday program including Society’s outing as usual.

7. **Cooperation with other Societies/future meetings:** For 2018 initial negotiations about a cojoined meeting with the ISHCSF have been made. Pat McAllister and Hazel Jones are engaged in liaison positions in the Board and the Executive Committee of the two Societies. Both Boards are currently trying to define conditions for a cojoined meeting.

8. **Website improvement:** The current website hosted by Bluestation is not fulfilling the expectations of the Society. Options for an improvement will be explored. Till now there is no refunding of the costs of the website by donations or sponsorship, which were promised before the launching of the website. A linkage to social media (Facebook etc.) seems mandatory (Waheed Ashraf). Roger Strachan commented that connections to the Society via an App for mobile phones could attract younger members.

9. **New/other business:**
   From 10 applicants for the Guthkelch Award 6 presenters were chosen by the Executive Committee.
   Roger Strachan also suggested that a „life membership“ may be worth consideration at some future stage.

Reinhold Cremer
Honorary Secretary