



SOCIETY FOR RESEARCH INTO HYDROCEPHALUS AND SPINA BIFIDA

AUTUMN NEWSLETTER 2016

President's Message

I suspect that many of you are still happily reminiscing about the wonderful meeting we just had in Stirling, Scotland. Without doubt Andy Wynd was the *Perfect Host*, the science maintained the high quality we have come to expect, and the evening at Stirling Castle was absolutely amazing – one of the best experiences we have ever had! So let's all take a moment to thank Andy and his Organizing Committee for a job extremely well done.

Since the Stirling meeting, I had the distinct pleasure – with Carolyn Harris – to be invited to the 101st Birthday Party for Norman Guthkelch. As you know, Norman has made significant contributions to the SRHSB over many years and recently has funded a prestigious annual prize for our younger investigators in his name and that of his wife, Margaret. Sadly, Norman passed away last July, but his family and friends wanted to celebrate his life with a 'Thank You' party. As you might imagine, this event was very emotional but also extremely uplifting. It brought together many of Norman's personal friends, family, and especially an inspirational group of families that Norman supported when they were falsely accused of "shaken baby" involvement. Even in the last few years of his life he was actively helping people! Carolyn and I were welcomed warmly, and I was allowed to read portions (about half) of Roger Bayston's message (see the full transcript below) and make a few comments and thank you's of my own. Many people went out of their way to thank us for attending and we heard many emotional personal stories from grateful patients and families. I am deeply honoured that we were allowed to express our gratitude on behalf of the SRHSB. I want to thank Roger Bayston for his moving eulogy and for all his efforts to have UK newspapers and a prominent medical journal publish his memorial to Norman.

Finally, I am reminded daily that our 61st Annual Meeting is fast approaching. It will be held June 21-24, 2017 in St. Louis, Missouri, USA, and I will be co-hosting this meeting with Drs. Paul Austin and Dave Limbrick. Dave is my close colleague and Chief of Pediatric Neurosurgery at the Washington University School of Medicine (WUSM) and the St. Louis Children's Hospital. Paul is a Professor of Urologic Surgery at WUSM and Secretary of the International Children's Continence Society (ICCS; <http://i-c-c-s.org>); some of you may remember Paul's attendance at our 2014 meeting in Uppsala, Sweden. We are all excited about trying something new this time – a conjoined meeting with another Society that overlaps with our mission. The ICCS is a very active group with an international membership 2-3 times our size. Because the ICCS shares our interest in spina bifida, we plan on having a full day, Friday June 23, for combined presentations by members of both Societies. That will leave Thursday and Saturday mornings, June 22 and 24, respectively, for a focus on hydrocephalus. We will definitely preserve our tradition of The Outing, and we are planning special sessions on in utero treatments and transition of care. We are all enthusiastic about the prospects of making new acquaintances and broadening our scientific horizons, but I must warn you that, primarily because of the complexities inherent in organizing a larger joint meeting, the abstract submission deadline will probably be a little earlier than usual, most likely in early January 2017.

I'm sure you will enjoy this Newsletter that Reinhold Cremer and our new Secretary-elect, Andy Wynd, have put together, and I am really looking forward to seeing you all in St. Louis.

Kindest Regards to All,

Professor Pat McAllister
President, SRHSB

Report of the 60th Annual Meeting in Stirling, Scotland, 2016

SRHSB 60th Anniversary Annual Meeting and Conference Stirling Scotland 2016

Over 70 delegates gathered at the University of Stirling, Stirling Court Hotel to celebrate the 60th Anniversary of the Society.

SBH Scotland (the only charity in Scotland supporting children Young People and Adults with Spina Bifida and/or Hydrocephalus) hosted the event to celebrate their 50th anniversary and also acted as major sponsor of the conference.

The customary pre meetings on Experimental Hydrocephalus and Clinical Cases on the Wednesday afternoon allowed delegates the opportunity to focus on their respective interests in two parallel group sessions.

The Welcome Reception was hosted by SBH Scotland at their purpose built Centre named after Prof Dan Young (who was an eminent paediatric surgeon who introduced shunting to neonates in the early 1970's in Glasgow. Dan also chaired the Local Organising Committee for SRHSB when they hosted the SRHSB Conference when it last visited Scotland in 1993.)

The 2016 Conference was formally opened by Dan's Daughter, Dr Rhoda Abel, a local medical general practitioner.

The Conference kicked off with a special symposium on the Genetics of Hydrocephalus and Spina Bifida with one of our guest speakers Prof Andrew Copp speaking on the Genetic Requirements for fusion of the neural folds as the neural tube closes. Executive committee member, Jo Glazier stepped in at the 11th hour (due to cancellation of one of our speakers) to deliver a presentation on Maternal embryo folate transport – a role for the yolk sac?

Prof Copp also presented a paper on Inositol for prevention of NTD's – The PONTI pilot randomised control trial.

The afternoon Session began with the Society Official Photograph and excursion and chartered cruise on Loch Lomond.

Friday's full sessions began with our first Special Lecture from Mark Hamilton on the Role of Endoscopic Third Ventriculostomy in the Adult Hydrocephalus Patient.

Later that morning presentations were made by the Guthkelch Award Finalists followed by the Society's AGM.

The Afternoon session focussed on Hydrocephalus: Experimental and Clinical Aspects which was followed by our 2nd Special Lecture from Roger Bayston on the Zika Virus and Microcephaly: Influence of External Infectious Agents of the Fetus.

The formal sessions concluded with Poster Presentations and two historical reflections on the Society over the years, given by our activist Ewen McKinnon and the West of Scotland's Contribution to Spina Bifida.

The Society's Annual Gala Dinner was hosted at Stirling Castle where delegates were able to capture a little of the host country's history and hospitality.

The conference formally concluded on Saturday morning with presentations on Urology and Psychology and announcements of Prize winners. This was followed by a warm invitation to the Conference in 2017 in St Louis hosted by our President Pat McAllister.

Formal feedback and results of the conference evaluation can be obtained from andy.wynd@sbhscotland.org.uk



The following traditional prizes of the Society were awarded:

-Gutkelch Award 2016:

The Norman and Margaret Guthkelch Prize was given to a young investigator. Thanks to the generous donation by Dr. and Mrs. Guthkelch, this prestigious award of 1500 GBP will be given annually to a student in training or an early career investigator who is conducting high quality research in the area of hydrocephalus and neural tube defects, including spina bifida. This award builds on the legacy of Professor Guthkelch who was the first Paediatric Neurosurgeon in Great Britain, and one of the first to recognise and describe retino-dural hemorrhage with non-accidental head injury. A special session allowed the finalists to present their research.

Kailyn A. Bradley, from Icahn School of Medicine at Mount Sinai New York, NY, USA for her speech entitled: **Corpus callosum structure and auditory interhemispheric transfer in spina bifida myelomeningocele**

President's Prize:

Maryoris Jara from Valdivia, Chile for her speech entitled: **Subcommissural organ (SCO) encapsulated cells to promote neurogenesis in hydrocephalic HTx rats**

Best Oral Presentation on a Clinical Topic:

Katrin Rabiei from Sahlgrenska University Hospital, Göteborg, Sweden (**No title to be published**)

Best Oral Presentation on a Basic Science Topic:

Leandro Castañeyra-Ruiz from Universidad de La Laguna, Tenerife, Islas Canarias, Spain for his speech entitled: **Aquaporin-1 expression in human choroid plexus development and its variation in Arnold Chiari type I and lissencephaly pathologies**

Poster Prize:

Julie B. Berge from TRS Resource Center for Rare Disorders Oslo, Norway for her poster presentation entitled: **Enhanced attentional performance following paediatric goal management training in children with spina bifida: A pilot study.**

The Society wants to thank Andy Wynd and the local organizing committee for the excellent meeting in Stirling:

Members of the Local Organizing Committee:

- Mr Andrew Wynd MBE MIOd, CEO Spina Bifida Hydrocephalus Scotland
- Dr Margo Whiteford, Consultant Geneticist
- Mr Eric Ballantyne, Consultant Neurosurgeon
- Miss Carole Sobkowiak, Former President SRHSB
- Prof Robert Carachi, Paediatric Surgeon
- Jothy Kandasamy, Consultant Neurosurgeon
- Roddy O'Kane, Consultant Neurosurgeon
- Chris Driver, Consultant Paediatric Surgeon (Urology)

Obituaries

Moyna Gilbertson

Moyna was the Chief Executive of ASBAH , now known as Shine, and was awarded the Queen's Honour of OBE [Order of the British Empire]for her services to that Charity. She was also made a Fellow of the Chartered Society of Physiotherapy in 1996. This Fellowship does not require taking an exam but is awarded as a result of recommendation by peer evaluation.

I knew Moyna when she was at the Great Hospital for Sick Children in London at a time when I was at the Sheffield Children's Hospital where the pioneer surgery was taking place on early closure of MM with Bob Zachary paediatric surgeon and when John Sharrard pioneered so many procedures as orthopaedic surgeon. In the wings there was John Lorber who contested the ethics of early closure. Moyna and I both knew our dear friend John Holter.

These were wonderful heady days.

There will be a memorial service for Moyna as follows:

Sunday 11 September: 2-00 pm at the Chapel , Christ's Hospital, Horsham, West Sussex, RH13 0YP

Christ's Hospital is nothing to do with medicine but is a famous Independent Public School founded in 1552 by King Edward VI and the current Patron is our Majesty Queen Elizabeth. Moyna had bought a flat in the grounds there after leaving London and was a Director of some of their Trusts.

Carole Sobkowiak

Arthur Norman Guthkelch 1915-2016

We were all saddened by the news that Norman had passed away in Toledo in July this year, a few weeks before his 101st birthday. Norman's name has become known in the Society for Research into Hydrocephalus and Spina Bifida through his characteristic generosity in endowing a prize for young researchers, in memory of his wife Margaret.

Norman had a very interesting, long life. His interest in biology began when he was six years old and he lamented not being able to help an injured bird in the garden. His mother suggested that he might focus his attention on humans, and he determined to become a doctor. Later he studied Classics at school because his teachers refused to let him study science, though the school did support his medical studies at the University of Oxford, on condition that he did not get married. Norman won a scholarship in Classics to Balliol College, Oxford and immediately switched to Medicine. From then on, he benefitted by being taught by world-famous tutors. After a year as laboratory assistant to (later Sir) Solly Zuckerman, Norman gained a further scholarship that allowed him to do clinical work at Manchester Royal Infirmary, where he met his "master", Sir Geoffrey Jefferson, a renowned neurosurgeon and the first UK professor of neurosurgery. After publishing two case reports in the British Medical Journal and passing his Fellowship of the Royal College of Surgeons examination, he was appointed to the post of Chief Surgical Resident in Manchester. However, the war intervened and Norman was appointed by the army to lead one of two neurosurgical units. Again, he learned from capable colleagues and found time to publish. On return to civilian life his previous mentor, Jefferson, was influential in having Norman appointed to the Children's Hospital in Manchester as the first paediatric neurosurgeon in UK. He was then to find that there was no provision for a salary, and he agreed to accept the post as "Honorary" (a situation that I too encountered 25 years ago when I moved to Nottingham!). Norman then set about improving

the rather neglected field of paediatric neurosurgery. He was particularly interested in subdural haematoma in children, and published a paper in 1953 in which he described surgical treatment of what was then a not uncommon condition. Guthkelch's studies and clinical experience in paediatric subdural haematoma led him to form the opinion that many cases were the result of shaking of the baby by the parents, an accepted practice at the time to quieten "fractious" children. This later led him into conflict with colleagues and authorities in UK and USA, and he was a key figure in several high-profile court cases where a parent was accused of criminal assault. One of Norman's great disappointments was that the UK employment system made retirement mandatory on reaching the age of 65 and he was not ready for this. He therefore secured, with the help of Tony Raimondi, a professorial appointment at Pittsburgh Children's Hospital where he practised for many years until he and Margaret, his wife, decided to retire to Tucson, where Norman took on a temporary appointment at the university. After his wife passed away, Norman moved to Chicago and continued to publish, co-authoring a paper in 2013.

Norman's other great neurosurgical interest was in hydrocephalus and spina bifida. Though in the 1950's and 1960's a common condition, little could be done for those children affected until the first practical shunting devices became available due to the groundbreaking developments of John Holter and Robert Pudenz. This led to a rekindling of medical and surgical attention for the two associated conditions, and in 1957 the Society for Research into Hydrocephalus and Spina Bifida was created at a meeting at Great Ormond Street Children's Hospital in London. Guthkelch's name appears as a signatory in the minutes of that inaugural meeting, and he remained an influential figure in the field for many years, becoming President of the Society in 1958. He also served as Publications Secretary, and was awarded the Society's Casey Holter Lectureship for his work on visual evoked potentials in hydrocephalus. Norman hosted the 2nd Annual Scientific meeting of the Society in Manchester in 1958 and the 14th during his period at Hull Royal Infirmary in 1971, and he was a regular attendee at the Society's meetings where I first met him in the 1970's. I was greatly impressed by his breadth of knowledge and his willingness to question the established views of his colleagues. He questioned current opinion on the status of the spinal cord in spina bifida and wrote extensively on such topics. He and I remained in touch from time to time, and in 2014 he suggested to me that he might like to donate a considerable sum to the Society in memory of his wife Margaret. This was duly arranged and the Society now awards the Norman and Margaret Guthkelch prize for innovative significant research in the fields of spina bifida and / or hydrocephalus. The first recipient of the prize, Dr Carolyn Harris, visited Norman and became a good friend to him in his last years. Norman was a polymath. Despite his shunning of Classics at school, he spent some time translating the New Testament from the Greek, and he was a prolific photographer of birds. His insight was enormously valuable both in the neurosurgery and neurophysiology of hydrocephalus and spina bifida and in his interest in shaken baby syndrome, on which he continued to publish until shortly before his death.

Norman lived a long life that, from an early age, he had decided to apply to improving the lot of sick children and their families. He will be remembered with great affection as a wise, courageous friend and professional. He was fond of quoting his mentor Sir Geoffrey Jefferson: "It has all been the greatest fun."

In the words of Leonard Cohen, "It's time that we began to laugh and cry and cry and laugh about it all again."

Roger Bayston

Members of the Executive Committee since the last AGM 2016

President:
Pat McAllister

Membership Secretary
David Nash

Folic Acid Spokesperson
Jaleel Miyan

Honorary Secretary
Reinhold Cremer

Publication Secretary
Marcus Pauly

USA Corresponding Member
Carolyn Harris

Honorary Secretary elect
Andy Wynd

Webmaster
Waheed Ashraf

Co-opted Member
Jocelyn (Jo) Glazier

Honorary Treasurer
Ian Pople

Ordinary Members
Doug Cochrane
Maria Cartmill
Leandro Castaneya Ruiz

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Next dates:

Next Executive Committee Meeting: September 10th 2016, 2 pm to 6 pm GMT as telephone or video conference (separate invitation will follow)

Next Annual Meeting in Saint Louis, USA, during the 61th Annual Meeting 2017



Reinhold Cremer
Honorary Secretary