



Society for Research into Hydrocephalus and Spina Bifida FALL NEWSLETTER 2017

President's Message

First my confessions: I freely admit to relaxing somewhat after the annual meeting in St. Louis and take full responsibility for the tardiness of this newsletter. But I am back on track, still “high” from what most attendees have acclaimed to be an excellent meeting, and looking forward to getting on with the Society's business.

In brief (because our Honorary Secretary Andy Wynd will provide more details later), although attendance was lower than previous annual meetings, I think the consensus was that the quality of the meeting in St. Louis was excellent. Many people found the topics and invited speakers very informative and inspiring, and the presentations by young investigators, including an impressive number of first-timers, were all regarded as some of the best we have seen. Certainly an advantage was gained by combining with the International Children's Continence Society, led admirably by Paul Austin, so the focus on both transition of care in spina bifida and hydrocephalus as well as fetal treatments for myelomeningocele was very beneficial. Our pre-meetings on Experimental Hydrocephalus and Clinical Cases attracted more attendees than ever before, and they provided an excellent kick-off to the regular meeting. Likewise, the competition for our prizes reached new heights, and Sven Mattsson's Casey Holter Lecture was outstanding.

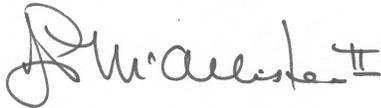
I am very pleased to announce that during the Annual General Meeting (AGM) Professor John D. Pickard, MD, FRCS FMedSci was confirmed by unanimous vote to be our next President-elect. As most of you know, Professor Pickard built and maintained one of the most respected academic neurosurgery programs in the world in the Department of Clinical Neurosciences of the University of Cambridge. He has made countless improvements in the care of patients with hydrocephalus and is currently Professor Emeritus in the Department of Neurosurgery at the University of Cambridge (details can be found at [https://ipfs.io/ipfs/QmXoypizjW3WknFiJnKLwHCnL72vedxjQkDDP1mXWo6uco/wiki/John_Pickard_\(professor\).html](https://ipfs.io/ipfs/QmXoypizjW3WknFiJnKLwHCnL72vedxjQkDDP1mXWo6uco/wiki/John_Pickard_(professor).html)). I have admired Professor Pickard for many years and I am thrilled that he will be our next President.

Finally, I want to summarize some very important changes that the Executive Committee (EC) has made regarding our annual meeting. After 6 months of careful deliberation, the EC voted (9 for, 2 against) to forego a full 3½ day scientific conference in 2018. This decision was strongly influenced by the declining attendance at previous meetings and the financial burden imposed. We were invited to join with the Hydrocephalus Society (formerly the International Society for Hydrocephalus and Cerebrospinal Fluid Disorders, ISHCSF) at their meeting in Bologna, Italy October 19-22, 2018. We even solicited the opinions of SRHSB members via an online poll, and followed the wishes of our membership. Nevertheless, we are required by our bylaws to hold an AGM every year, so we are planning on a **FREE** 1-day symposium in Bristol, UK, hosted generously by Ian Pople. The date has been set for Thursday **28th June 2018**, and will include time for the AGM and an optional evening

dinner. Ian has located a lecture theatre seating 140 at the Bristol Maternity Hospital near the University and Children's Hospital, which we can use at no charge all day. The tentative themes for the symposium are "Towards Guidelines for the Management of Spinal Lipomas and Complex Dysraphism" or "Recent Advances in *in-utero* Spina Bifida Repair". We will ask local speakers and members to give brief talks at no cost.

Last but certainly not least, since this 'Fall' newsletter has progressed into more Winter weather, I want to wish all of you a wonderful holiday and a healthy New Year.

Most sincerely,



James P. (Pat) McAllister, PhD
President of the Society for Research into Hydrocephalus and Spina Bifida

Honorary Secretary

In many ways the 2017 SRHSB Conference was a unique and memorable occasion. For the first time in its history, SRHSB joined forces with the ICCS (International Children's Continence Society) to host a joint conference. Over 100 delegates met in the Eric P Newman Educational Centre at the University of Washington School of Medicine in St Louis to focus attention on Research and clinical aspects of Hydrocephalus and Spina Bifida as well as having opportunities to spread our horizons into the Bowel and Bladder aspects of the condition and beginning to understand more clearly the impact of these conditions on the patient journey.

The conference began formally on Wednesday morning with ICCS workshops on Urodynamics and Bowel Management and parallel sessions in the afternoon from both societies with our traditional focus within the SRHSB on Experimental Hydrocephalus and Clinical cases both of which were well attended and ably chaired by Hazel Jones, Ian Pople and Dave Nash respectively.

A warm welcome to the USA and the joint conference was given at the Welcome reception in the evening by the Co-hosts of the Conference, Paul Austin and Pat McAllister supported by Dave Limbrick and Tryggve Neveus.

Thursday's sessions focussed on the Special Symposium for the Society on "Transition of Care in Spina Bifida" where we welcomed Daniel Wood from University College London and Sharon Levy from the University of Edinburgh who spoke on Past Treatment and Long Term Care and Scaffolding the Future: Transition in Action.

Parallel Sessions began once more with the ICCS Special Lecture on Molecular Insights into Chronic and Recurrent Bladder Infections by Thomas J Hannan from the Washington School of Medicine. SRHSB extended their Transitions of Care Symposium by welcoming Olivia Maccoux who spoke on her condition and experience of her patient journey over the years. Further presentations were delivered

on Transition and the Report of the Hydrocephalus Association Summit on Transitional Care and Neurosurgical Comparisons between Children and Adults with Hydrocephalus.

SRHSB's AGM concluded the formalities for the morning session and delegates then spent a relaxing and thoroughly enjoyable visit to the Missouri Botanical Gardens. The evening concluded with the joint ICCS- SRHSB Conference Dinner at The Bauernhof at Grant's Farm. A spectacular evening where delegates enjoyed an informal evening of exceptional food, wines and beers and entertainment in abundant supply.

Friday's sessional commenced with a special lecture from Gerald Tuite from St Petersburg, USA on Evaluation and Management of Tethered Chord Syndrome in Occult Spinal Dysraphism followed by Fetal in-utero repair of myelomeningocele in the post-MOMS Trial Era by Samer Elbabaa from St Louis University School of Medicine. Parallel sessions commenced again in the afternoon with the SRHSB programme focussing on Spina Bifida and Hydrocephalus and enabling the first group of successful abstracts to be delivered by their chosen presenters.

Saturday morning allowed SRHSB delegates to hear a number of abstracts on Experimental Hydrocephalus followed by the Casey Holter Lecture from Sven Mattson who delivered a heartfelt lecture on "Born with Spina Bifida – a Life to Live". This was followed by the Guthkelch Award Finalist Presentations, which were delivered, to a consistently high standard again this year. The final session focussed around Clinical Hydrocephalus and Biomedical engineering.

The Conference concluded with the award of Prizes in the various categories and a huge debt of gratitude to the local organising committee headed by our own SRHSB President Pat, for a truly memorable conference in the USA.

Andy Wynd
SRHSB Honorary Secretary

Publications Secretary

Dear friends and members of the SRHSB,

Firstly I would like to thank everybody on behalf of the whole EC for contributing to our 61st Annual. In spite of some concerns about possible travelling issues and the rather long distance especially for our European members, we are very happy about the large number of high quality abstracts we received.

I am also pleased to let you know that we received a great number of excellent papers and applications for our young scientist award: The Norman and Margaret Guthkelch Award. During our last Executive Meeting videoconference, we discussed every abstract thoroughly and we managed to put together a very acceptable program for our meeting.

We are very pleased to announce that the following traditional prizes of the Society were awarded:

Norman and Margaret Guthkelch Prize

Thanks to the generous donation by Dr. and Mrs. Guthkelch, this prestigious award of 1500 GBP is 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 following finalists to present their research:

- **Joel Haakon Borgstedt-Bakke**. Center for Experimental Neuroscience–Spine, Department of Neurosurgery, Aarhus University Hospital, Aarhus, Denmark. *“The incidence and effect of tethered cord release for tethered cord syndrome in myelomeningocele patients - population based study”*.
- **Katherine Belfield**, Sajitha Kalith, Richard Parkinson, and Roger Bayston. Biomaterials-Related Infection Group, School of Medicine, and the University of Nottingham, Nottingham, UK. *“Bacterial attachment to urinary catheters: how does this affect symptom presentation?”*.
- **Maria Garcia-Bonilla**. Department of Cell Biology, Genetics, and Physiology, University of Malaga, Malaga, Spain. *“Effect of bone marrow-derived mesenchymal stem cells on congenital hydrocephalus in the hyh mouse”*.
- **Sulmaz Zahedi**. Department of Neurosurgery, Wayne State University, Detroit, MI, USA. *“Micro-fabricated arachnoid granulations for treating hydrocephalus”*.

All of the presentations were excellent and worthy of this award. After quantitative scoring by the judging committee, we are proud to report that **Sulmaz Zahedi** was the winner of the 2017 Guthkelch Prize!

President’s Prize

Maria Garcia-Bonilla from the Department of Cell Biology, Genetics, and Physiology, University of Malaga, Malaga, Spain for *“Effect of bone marrow-derived mesenchymal stem cells on congenital hydrocephalus in the hyh mouse”*.

Best Oral Presentation on a Clinical Topic

Pei-Yi Lin, with collaborators Jason Sutin², Katherine Suen², Katherine Hagan¹, Andrea Medina², Fang-Yu Cheng¹, Rutvi Vyas², Parisa Farzam¹, Peter Ssenyonga³, Edith Mbabazi³, Francesca Yi², Sarah Blackwell², Maria Angela Franceschini¹, P. Ellen Grant², and Benjamin Warf^{2,4} from ¹ Athinoula A. Martinos Center for Biomedical Imaging, Massachusetts General Hospital / Harvard Medical School, Charlestown, MA02129, USA, ² Fetal-Neonatal Neuroimaging and Developmental Science Center, Boston Children’s Hospital/ Harvard Medical School, MA02115, USA, ³ CURE Children’s Hospital of Uganda, Mbale, Uganda,

⁴ Departments of Neurosurgery and Global Health and Social Medicine, Boston Children's Hospital and Harvard Medical School, MA02115, USA for *“Novel optical diagnostic for infant hydrocephalus in both the developed and developing world”*.

Best Oral Presentation on a Basic Science Topic

Yun C. Yung, with collaborators_Kyoko Noguchi, Whitney McDonald, and Jerold Chun from Sanford Burnham Prebys Medical Discovery Institute, La Jolla, CA, USA for *“Blood-derived lysophosphatidic*

acid signaling alters mitotic spindle orientation and subsequent cell fates of neuroprogenitor cells in post-hemorrhagic hydrocephalus”.

Poster Prize

Pat McAllister¹, with collaborators Esteban M. Rodriguez², Marie Monserrat Guerra², Leandro Castaneyra-Ruiz¹, Antonio J. Jimenez³, Dolores Dominguez-Pinos³, Deborah Sival⁴, Wilfred den Dunnen⁴, Diego M. Morales¹, Robert E. Schmidt⁵, David D. Limbrick, Jr.^{1,6} from ¹ Department of Neurosurgery, Washington University School of Medicine, St. Louis, Missouri, 63110, USA, ² Instituto de Anatomía, Histología y Patología, Facultad de Medicina, Universidad Austral de Chile, Valdivia, Chile, ³ Departamento de Biología Celular, Genética y Fisiología Facultad de Ciencias, Universidad de Malaga, Malaga, Spain, and Instituto de Investigación Biomédica (IBIMA), Malaga, Spain, ⁴ Departments of Pediatrics, Pathology and Medical Biology, University Medical Center Groningen, University of Groningen, Groningen, Netherlands
⁵ Department of Pathology and Immunology, Washington University School of Medicine, St. Louis, Missouri, USA, ⁶ Department of Pediatrics, Washington University School of Medicine, Missouri, 63110, USA for “*Ventricular zone disruption in human neonates with intraventricular hemorrhage*”.

Dr. Marcus Pauly
SRHSB Honorary Publication Secretary

Membership

Dave Nash has compiled the following data from our web page and data lists. The following numbers include members who are current with dues paid and those listed as members but overdue with membership payments.

We list 104 members but only 46 who are current with dues payment. That means 58 are overdue.

This does not include the Honorary Members, of which there are 14, including William Arnold who passed away in July of 2017.

	Total	Current/Paid	Overdue/Not Paid
UK	40	16	24
USA	21	13	8
Spain	6	3	3
Canada	5	2	3
Germany	5	3	2
Sweden	5	3	2
Ireland	3	2	1
India	2	0	2
Estonia	2	0	2
Norway	1	1	0
Nigeria	1	0	1
Austria	1	0	1
Australia	1	0	1
Denmark	1	1	0
Netherlands	1	0	1
Chile	1	1	0
Ethiopia	1	0	1
Japan	1	1	0
Costa Rica	1	0	1
Switzerland	1	0	1
Tanzania	1	0	1
Saudi Arabia	1	0	1
Russia	1	0	1
Pakistan	1	0	1

I hope this information is helpful. I did send a reminder out in the Spring to pay dues. The dues are not annual so they expire on the anniversary date of when they were paid.

Dave Nash
Membership Secretary

Website Update <https://www.srhsb.com>

Carolyn Harris has worked especially hard to construct an effective website for very little cost. We are always open to constructive comments and suggestions for improvements to the website, so please let us know what you think by visiting the "contact" page or by emailing Carolyn at caharris@med.wayne.edu.

You can still pay membership dues through the website via PayPal, credit card, or debit card. Options for payment include a recurring or one-time payment schedule for one or more years. We know how important it is to keep your information private, and we have worked with PayPal to acquire an https secure certificate. Importantly, recurring payments made on the old website have been discontinued; therefore you must pay through the new site. The new mail service option through the site will keep you updated on when future payments will be processed (if recurring) or when they are due again (if you made a one-time payment).

At the same time membership payments are made, it is very important to **create a NEW name and password** the first time you login so you can have access to the Members Only pages. This is done *separately* from the payment, and needs to be done only *once*. If your dues are current, you will be granted member-only access to the new site.

Obituary

We are deeply saddened by news of the passing of Dr. William (Bill) Arnold. Bill was great friend of the SRHSB for more than 35 years, having the distinction of being the first Canadian member, and he will be missed greatly. Doug Cochrane has provided the following memoriam:

Dr. William Arnold (July 10 1929 – July 20 2017)

Bill was a first class pediatrician, deeply committed to the care of his patients and families. He graduated from the University of British Columbia medical school in 1955, and completed a rotating internship in London, Ontario before practicing as a family doctor in Prince Rupert from 1957 to 1965. He then completed his pediatric residency training at the Columbia Presbyterian Medical Center in New York City from 1965 to 1968 before returning to join Drs. Robert Maclean and Jack Whitelaw in general pediatric practice in Vancouver. Inspired by what he had seen in New York, he established the first Canadian multidisciplinary spina bifida clinic in Vancouver and then served as medical director for 30 years. He was the first Canadian member of the Society for Research in Spina Bifida and Hydrocephalus, and in the 1980's Bill and David Shurtleff from Washington State worked together to establish an international myelomeningocele registry in Canada. This work contributed greatly to the academic contribution of the Society, which made important contributions to the infants and children affected by neural tube defects. Bill will be remembered for his regular attendance at the Society's annual meetings and his contributions to both the academic and social aspects of this Society.





Bill was appointed as the first head of the division of General Pediatrics at UBC, a role he filled for 10 years. He was devoted throughout his career to the care and treatment of children with neural tube defects, and worked tirelessly on their behalf. In this role he was instrumental in fostering and nourishing the professional development of many students, residents, nurses and allied health colleagues from a variety of health disciplines. He also served as president of the Vancouver Medical Association and the BCCH medical staff. He was tirelessly devoted to teaching, and was a Clinical Professor of Pediatrics at UBC.

Following his retirement from active clinical practice Bill led efforts to establish a spina bifida clinic in Guatemala, making numerous volunteer trips to that Central American country with his devoted wife Myrtle. He also continued his role on the Boards of research and review committees of the Spina Bifida and Hydrocephalus Association of BC and Canada and remained an active member over the years. Sir William Osler said that “The good physician treats the disease; the great physician treats the patient who has the disease”. Bill was a truly great physician, always committed to the patient and their family.

There have been so many of us who have benefitted from Bill’s care but it is the infants, children and adults with spina bifida to whom he was especially committed. He was a clinical pioneer and the father of spinal bifida care in Canada, and the memory of his many contributions will be cherished. There will be a celebration of Bill’s life in the end of September.

Paul Thiessen

Doug Cochrane, Chair & Provincial Patient Safety & Quality Officer
Beverly Irwin, BSN, RN Nurse Clinician in the Spinal Cord Program

Closing

As always, please do not hesitate to contact any of the EC members if you have any questions, comments or news, and stay tuned for updates on the symposium and AGM in Bristol.