



Society for Research into Hydrocephalus and Spina Bifida

NEW YEAR/WINTER NEWSLETTER 2017

President's Message

My etiquette advisors tell me that it is acceptable to send "Happy New Year" wishes right up until the end of January; obviously we have missed that deadline, and I apologize, but I hope you will still take to heart my wishes for a healthy and happy 2017.

As Andy Wynd, Antonio Jimenez, Margareta Dahl, and all the former hosts of the Annual Meeting know so well, I have been very busy planning the meeting in St. Louis June 21-24, 2017. Many details have been included in the update below, but suffice it to say that I think this will be a very exciting conference for several reasons. We have combined our presentations and social events with the International Children's Continence Society (ICCS); led by Paul Austin, whom we met for the first time in Uppsala, this is a dynamic group that shares many of our interests in spina bifida. To my knowledge this is the first time we have conducted such a conjoint meeting, and as I hope you can tell by the preliminary program I think it will definitely broaden our horizons. In addition, we will again include a Special Symposium; the first two were quite well-received and I think the topic "Transition of Care in Hydrocephalus and Spina Bifida" will be very educational. Our three speakers, Michael A. Williams, a very academic and well-known neurologist from the University of Washington in Seattle, Sharon Levy, Programme (please note the correct spelling) Director of Nursing Studies at the University of Edinburgh, and Mark G. Luciano, Professor of Neurosurgery and Director of the Cerebral Fluid Center at the Johns Hopkins School of Medicine, will present a comprehensive and challenging overview of the clinical transition for young adults. I anticipate some enthusiastic discussions in the extra time provided. During the conjoined session with ICCS on Friday, we will also benefit from the extensive neurosurgical experience of Samer Elbabaa, currently the Department Chair and Director of Pediatric Neurosurgery at St. Louis University School of Medicine, during his invited lecture on "Fetal In-Utero Repair of Myelomeningocele in The Post-MOMS Trial Era". Our good fortunes will continue with Dan Wood's invited lecture; many of you probably know him from his extraordinary work in the Department of Maternal and Fetal Medicine at University College, London. Finally, we are attempting to make the entire conference experience more casual, especially by having our Retreat (with all the ICCS members) at the Missouri Botanical Gardens.

While I am excited about our upcoming Annual Meeting, I – along with many of our members – am saddened by the passing of Gillian Hunt at 94 years young. She has many long-time friends in the Society and she will be greatly missed. Please see the personal messages and the wonderful article published in *BMJ Careers* at the end of this newsletter. As a basic scientist, I must say that in reading the article I got a chuckle out of Jill's thought "What's statistics got to do with it?"; and at my age of 69 I can definitely relate to her statement that "If you are 70 years old and not part of a team, it is difficult to get funding". It's amazing that she never took a salary!

Most sincerely,

A handwritten signature in dark ink, appearing to read "D. Williams II". The signature is written in a cursive, somewhat stylized script.

The 61st Annual Meeting in St. Louis, Missouri, USA June 21-24, 2017

Plans for this conference are coming together well, especially with the help of Paul Austin, Dave Limbrick and Emily Brown. Emily is the lead organizer for RX Worldwide Meetings, with whom we have contracted to manage the meeting. Recently RX Worldwide launched a website, concurrent with ours, and you can find many details, including registration information, at <http://www.cvent.com/events/iccs-and-srhsb-joint-conference/fees-c3a5754d5e6c4ee4a85a7e0cdf03a498.aspx>

Abstract and Guthkelch Award Submissions will still be managed through the SRHSB website (<http://www.srhsb.com/stlouisabstracts> and <https://www.srhsb.com/guthkelchsubmission>) and reviewed by the SRHSB Executive Committee (EC). The deadline for both of these submissions is still **February 15, 2017** at 24:00 Eastern Standard Time (06:00 GMT). Please be sure to check your theme preference to help us merge our presentations with those of the ICCS. The EC will review all abstracts and Guthkelch Award applications at the board meeting on March 4, and we will notify everyone a few days afterwards. We have already received about 12 abstracts from a variety of investigators, including those from Scotland via Portland, Maine USA, Cincinnati, Ohio, USA and (of course) St. Louis, Missouri, USA.

The Preliminary Program is outlined below. Here's a general chronological overview with my biased comments:

- Once again we will have the popular **Pre-meeting sessions** on Wednesday, June 21. Please contact Hazel Jones (hazelcjones@btinternet.com), Marcus Pauly (pauly-castro@web.de) and Roger Bayston (Roger.Bayston@nottingham.ac.uk) for information about the Experimental Hydrocephalus and Clinical Case Presentations sessions, respectively.
- The **Welcome Reception** will be combined with the ICCS members on Wednesday evening, June 21.
- The **Special Symposium** on "Transition of Care in Hydrocephalus and Spina Bifida" and the presentations from the **Guthkelch Award finalists** will take place Thursday morning, June 22. Our speakers are some of the best in the world. Michael A. Williams from the University of Washington in Seattle is one of the most active and influential voices on this topic and former President and cofounder of the International Society for Hydrocephalus and Cerebrospinal Fluid Disorders (ISHCSF). Sharon Levy from the University of Edinburgh will share his insights in transition of care for spina bifida, based on his collaborations with Spina Bifida Hydrocephalus Scotland. Finally, Mark Luciano, who has attended our previous meetings and now directs the Cerebral Fluid Center at the Johns Hopkins School of Medicine, will present his broad experience treating both children and adults with hydrocephalus.
- Our **Society Outing** will be held Thursday after at the beautiful Missouri Botanical Gardens; the members of the ICCS will join us and I'm excited to show them our friendship and collegiality at this traditional event.
- We will break somewhat from tradition by having our **Conference Dinner** after the Retreat. The decision to do this was based partly on our attempts to minimize costs but also to maintain a more casual atmosphere for the entire meeting. Therefore, cocktails and dinner will be held at The Bauernhof at Grant's Farm. This "farmstead" was built in 1913 and it surrounds a beautiful courtyard typical of a 19th century Bavarian farm, complete with stables, a carriage house (with the Busch family's world-renowned carriage collection), and offices and quarters for those who lived and worked there. The food and drinks are wonderful, and we will have plenty of time for toasts, Guthkelch Award announcements, and of course an entertainment surprise you won't want to miss!

- An **Invited Lecture** on "Fetal In-Utero Repair of Myelomeningocele in The Post-MOMS Trial Era" will be given on Friday by Samer Elbabaa, who maintains one of the top 3 busiest (by patient volume) practices in fetal surgery in North America.
- Most of our spina bifida related presentations will be given on Friday, when we share a full day **conjoined with the ICCS** talks and panel discussions.

SRHSB-ICCS Preliminary Program

Wednesday, June 21, 2016

- 08:00 – 20:00 Registration – Eric. P. Newman Educational Center (EPNEC) lobby
- 08:00 - 12:30 ICCS Board Meeting w/ lunch – BJC Institute of Health 11th floor Conference Room A/B (available 8:00-12:00 only), with box lunch
- 09:30 – 12:30 SRHSB Executive Committee meeting – BJC Institute of Health 9th floor Conference Room, with box lunch
- 13:00 – 17:00 ICCS Workshops – EPNEC or Farrell Teaching and Learning Center 2nd floor classrooms
1. Urodynamics I
 2. Urodynamics 2
 2. Bladder Management Program (Clean intermittent catheterization)
 3. Bowel Management Program
- 13:00 – 17:00 SRHSB Pre-meeting Sessions – BJC Institute of Health:
1. Experimental Hydrocephalus – 8th floor Conf Room A/B
 2. Clinical Cases – 10th floor Conf Room A/B
- 18:00 – 20:00 Welcome Reception for all ICCS-SRHSB registrants (includes Welcoming Presentations by Paul Austin, Pat McAllister, Dave Limbrick – EPNEC lobby)

Thursday, June 22, 2016

- 08:00 – 18:00 Registration - EPNEC lobby

ICCS Program - EPNEC Large Auditorium

- 08:00 – 10:00 Bladder 1 - Overactive Bladder (OAB) & Lower Urinary Tract Symptoms (LUTS)
- 10:00 – 10:20 Refreshment Break, Exhibitors and Poster Viewing – EPNEC
- 10:20 – 11:00 Panel Session 1 – OAB & LUTS
- 11:00 – 12:00 Bladder 2 – Bladder Dysfunction
- 12:00 – 13:30 Lunch

SRHSB Program – EPNEC Seminar B

- 08:00 – 10:15 SRHSB Special Symposium on “Transition of Care in Hydrocephalus and Spina Bifida”
- 08:00 – 08:05 Introduction: David D. Limbrick, MD, PhD, moderator
- 08:05 – 08:30 Michael A. Williams, MD; Department of Neurology, University of Washington, Seattle, WA, USA
- 08:30 – 09:00 Sharon Levy, Programme Director of Nursing Studies, University of Edinburgh, Edinburgh, Scotland
- 09:00 – 09:30 Mark Luciano, MD, PhD; Johns Hopkins Hospital,

Baltimore, USA

09:30 – 10:00 General Discussion and Questions
10:00 – 10:30 Refreshment Break, Exhibitors and Poster Viewing – EPNEC
10:30 – 12:00 SRHSB Guthkelch Award Finalist Presentations (n=4 or 5) – 10 minutes + 5 minute Questions and Discussion for each
12:00 – 13:15 SRHSB Annual General Meeting with lunch – EPNEC Seminar B

ICCS-SRHSB Retreat – Missouri Botanical Gardens and the The Bauernhof at Grant’s Farm

14:30 Buses depart from EPNEC (or Parkway Hotel) for the Missouri Botanical Gardens for tours & strolls
17:30 Buses depart the Missouri Botanical Gardens for Grant’s Farm
18:00 – 21:00 Cocktails & Dinner – The Bauernhof at Grant’s Farm
21:00 Buses return to hotels

Friday, June 23, 2016

08:00 – 18:00 Registration

ICCS-SRHSB Joint Program - EPNEC Large Auditorium

08:00 – 08:15 Welcoming for the Joint Session
08:15 – 09:15 Panel Session 3 – Transitional Care
09:15 – 10:15 Free Papers 5 – Transitional Care
10:15 – 10:45 Refreshment Break, Exhibitors and Poster Viewing – EPNEC
10:45 – 11:30 Kelm Hjalmas Lecture – Daniel N. Wood, MD; Department of Maternal and Fetal Medicine, University College London, London, UK
11:30 – 12:30 Free Papers 6
12:30 – 13:30 Lunch
13:30 – 14:30 Free Papers 7 – Bladder 3, NGB
14:30 – 15:30 SRHSB Special Lecture: “Fetal Treatments of Neural Tube Defects”, Samer Elbabaa, MD; Department of Neurological Surgery, St. Louis University School of Medicine, St. Louis, MO, USA
15:30 – 16:00 Refreshment Break and Poster Viewing
16:00 – 17:00 Basic Science

Saturday, June 24, 2016

08:00 – 13:00 Registration
09:00 – 17:00 ICCS Presentations – TBA by Paul Austin
09:00 – 12:30 SRHSB Presentations - Hydrocephalus
12:30 – 13:00 SRHSB award presentations and closing remarks

Registration will be processed through RX Worldwide. The early-bird deadline for a discount will be **May 15, 2017**; of course, members in good-standing will also be given a discount, so please renew your membership (see details below under Our New Website).

Continuing Medical Education (CME) credits will be provided on an individual basis. In spite of all our inquiries we discovered that administration of CME credits would be very expensive (\$12,000!) if they were made available to all attendees. Therefore, we are asking those people who need CME credits to pay a small fee (\$90 or \$180 for 10 or 20 hours, respectively) for this service.

Accommodations have been arranged with discounts at several hotels within walking distance (no more than 10 minutes) of the conference venue (the Eric P. Newman Educational Center, EPNEC). In addition, a limited number of low cost rooms (about \$60/night single occupancy) will be available at the School of Medicine's Olin Dormitory. A larger quantity of dormitory rooms will also be available on the undergraduate Danforth Campus, which is just 3 miles and 1 Metro stop (3 minute ride) away. We are still working out the details of these accommodations, but these modern facilities can house up to 50 people in a combination of singles and doubles. The double and single rates per night will be \$34.50 and \$38.50, respectively, with a one-time linen package of \$15.00 per person. There is also the option for guests to use meal points at the local cafeteria.

Local Transportation from the St. Louis Lambert Airport and all around the city is very convenient. As detailed on the RX Worldwide site, a taxi from the airport to our local hotels is about \$45 but the Metro train is only about \$2.50. Uber cars are about half the price of a taxi, e.g. \$22 to the airport, but please keep in mind that only the most expensive type of Uber cars are allowed to *pick up* at the airport, and they will cost about \$60. I highly recommend the Metro train service, especially because there is a stop (Central West End) just 50 meters from the conference venue!

Accompany Persons will be offered a program of their own for selected excursions. We are still working out the details of these half-day trips but I'm sure they will be attractive. Some of the major attractions are:

- Gateway Arch and Jefferson National Expansion Memorial (https://en.wikipedia.org/wiki/Gateway_Arch)
- St. Louis Art Museum (<http://www.slam.org>)
- Forest Park – a 5-minute walk from the hotels and conference venue with 1,300 acres, including the St. Louis Zoo, (<https://www.stlouis-mo.gov/government/departments/parks/parks/Forest-Park.cfm>)
- Busch Stadium, home of the St. Louis Cardinals professional baseball team – if you haven't seen American baseball this is *The Place* to start; Cardinals' fans expect their team to win the championship *every year!* (<http://stlouis.cardinals.mlb.com/stl/ballpark/index.jsp>)
- Budweiser (Anheuser-Busch) Brewery (<http://www.anheuser-busch.com>)
- National Blues Museum (<https://www.nationalbluesmuseum.org>)
- Missouri Botanical Gardens (<http://www.missouribotanicalgarden.org>)
- City Museum (<http://www.citymuseum.org>)
- Central West End restaurants and nightlife – there are many excellent international restaurants and pubs within a 10-minute walk from our hotels and conference venue (https://www.tripadvisor.com/Restaurants-g44881-zfn8585-Saint_Louis_Missouri.html)

Our New Website

We are pleased to announce the launch of our new website (<https://www.srhsb.com>) effective November 1, 2016. Our goal with the new website was to provide our visitors, and especially our SRHSB members, an easier way to learn generally about SRHSB, our events, and our history. The new website is interactive and gives the executive board control to fix errors and create live updates. One key advantage of the new site is the lack of third-party vendor control for even small modifications. We now have nearly full control to manipulate the design and content. Please let the executive board members know if there is something you'd like modified. Depending on the size of the modification, we can make efficient changes, bring it to a vote through the EC, or create a survey on the site in which all SRHSB members could vote. Please let us know what you think by visiting the "contact"

page or by emailing Waheed Ashraf (waheed.ashraf@nottingham.ac.uk) or Carolyn Harris (caharris@med.wayne.edu).

Another very important benefit is that we are saving more than 2400 GBP (nearly \$3000 USD) in annual hosting fees by developing and maintaining our own website. Please congratulate Carolyn Harris and Waheed Ashraf on their tremendous accomplishment.

Amongst new features, the website contains Members Only pages, an Executive Committee dashboard, clear and updated details on the upcoming meeting, a highlighted member of the month (congratulations this month go to Roger Bayston!), and a donation page. We will constantly be updating the site and will soon have integrated social media buttons, a cleaner mobile interface, and the ability to take or generate member surveys so every voice of our membership is heard.

We continue to provide the capability to pay dues through the website, which can be done through PayPal, credit card, or debit card. Options for payment include a recurring or one-time payment schedule for one or more years. We especially strive to keep your information private and work exclusively through PayPal and an https secure certificate. Importantly, as we onboard our new system, we ask you to pay attention to emails from our Membership Secretary, Dave Nash. Dave will be contacting you once your current dues are set to expire to make a payment. Recurring payments made on the old website will be discontinued, and 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 as payments are made, it is very important to **create a name and password** in order to receive 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.

Finally, since you are or have been active paying members of the society, you have been grandfathered into the newsletter system. Please let us know if you'd like to opt out of future notifications. If you'd like to continue to receive news emails from SRHSB, please add us to your safe senders list.

We hope you find the new website with a fresh look with easy to access information.

Obituaries

We are all saddened to report the death of Dr. Gillian M Hunt MD, Honorary Member of the SRHSB, past Executive Committee Member and winner of the Casey Holter prize, on November 8, 2016 at the age of 94. We thank Roger Bayston and Jill's daughter, Pippa Oakeshott, for reminding us that "Gillian was active in studying a complete, unselected cohort of 117 people born with open spina bifida for over 50 years. She produced much valuable work helping to inform us of the value of sensory level at birth to predict survival, walking, continence and urological related death. She also described long-term quality of life issues and how achievement was related to the need for a CSF shunt. I think this was the longest unbroken cohort study carried out. She was a general practitioner in Cambridge and she had a wide knowledge and experience of spina bifida."

There will be a memorial service for Jill at St Mark's Church, Barton Road, Cambridge at 1500 on April 23, 2017.

A more detailed and personal eulogy will follow shortly. In the meantime, please read the wonderful article that follows on Jill, published by BMJ Careers and kindly provided by Jill's children, Pippa Oakeshott, Joanna Poulton, Sally Poulton and Chris Poulton. In a recent email Pippa also added:

“The SRHSB meant such a lot to our mother and was a huge stimulation for her research. She, Dad and I enjoyed your many friendly and interesting conferences. You and ASBAH also provided funds for her research. We have just completed the 50 year follow up of Mum's cohort. When we were ringing up the remaining 37 still alive this summer Mum said it was like having a party with old friends.”

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 more updates on the Annual Meeting.



Gillian Hunt studied medicine at Girton College Cambridge and the West London Hospital during the second world war. She curtailed a transatlantic career in academic paediatrics to marry Christopher Poulton, assistant director of the Medical Research Council's Applied Psychology Unit in Cambridge. She worked as a part time general practitioner in Cambridgeshire while bringing up four children, three of whom became medical practitioners. Since 1970 she has been studying a cohort of 117 consecutive children born with open spina bifida.

Receiving an MD at 90: an interview with Gillian Hunt

Born in 1922, when few women had careers, Gillian Hunt received an MD for her research in November 2012 at the same ceremony as her youngest daughter, Alison Poulton, received her MD. Her granddaughter **Rosalind McLean** spoke to her about her experiences.

How did a governess educated 18 year old decide she wanted to become a medic?

My older sister was a prewar debutante, but the social implications of that kind of life didn't appeal to me at all. Also, I was very interested in the subjects that one would study in order to become a doctor, like observing animals. One night in 1940 after listening to a prom on the radio we heard bombs start to drop round us. We got up and found an incendiary bomb in the stable yard, two craters in the garden, and an unexploded bomb, which later went off in a wheat field. Having missed the bombs, I thought God had saved me for something and decided I wanted to be a doctor.

What was your experience of being a female medical student in 1941?

I studied medicine at Girton College Cambridge, although women could not be members of Cambridge University at that time. We went to lectures where 90% of the medical students were male, and they would make comments when the women entered. Lecturers would address us as "gentlemen." The men wore gowns but we were not entitled to. However, I felt so privileged to be a student at Cambridge that it did not worry me in the least. Like many others, I chose to complete the preclinical course in two years rather than three because of the

We went to lectures where 90% of the medical students were male, and they would make comments when the women entered

war. When I applied to do the clinical course at Guy's, where my father had been a physician, the response from the dean of medicine was, "Women medical students? Over my dead body."

What do you remember about wartime hospitals in and around London?

They were very short handed. As a medical student I found myself also acting as a hospital porter, fire watcher, or x ray or pathology technician in the casualty department. And when you were over halfway to being qualified, if they were short of doctors, you did hospital locums, which was excellent experience for me, but not necessarily so for the patients.

How did you combine the roles of mother and medic in the 1950s?

Most women gave up their careers on marrying and having a family, but mine became a mix of part time appointments, mainly in general practice, as they fitted in with my family life. My husband, Christopher, encouraged me to continue working. Together we investigated fatigue in junior hospital doctors and showed that sleep deprivation of three or more

hours affected performance. This underpinned subsequent national guidelines. He also taught me early on that if you do research you must get the statistics right. At the time I thought, "What's statistics got to do with it?"

In 1970 you were asked to be the independent observer for an ongoing study started in 1963 of children treated for open spina bifida. What did you find out?

Instead of dying in infancy, these children's lives had been saved by closing their backs and inserting a cerebrospinal fluid shunt for hydrocephalus if needed. I found that the neurological deficit in terms of sensory level recorded by a neurosurgeon in infancy related to mobility, intelligence, continence, overall disability, and death from renal failure. I later discovered that adults with spina bifida with the best outcomes, who are incredibly courageous in dealing with all their enormous problems, tended to be the ones who didn't need a shunt or didn't need to have their shunt revised. Episodes of severe or prolonged symptomatic shunt insufficiency could be followed by loss of motivation or blindness.

Why did it take you 40 years to receive your MD?

It needed a long follow-up to investigate expectation of life in spina bifida and the late onset of numerous complications that had

never previously been recorded, including increasing dependency. I was awarded my MD for a lifetime of "published works," including five *BMJ* papers, rather than a piece of work, as would be the case with a PhD.

What troubles did you have doing your research?

If you are 70 years old and not part of a team, it is difficult to get funding. I did get small grants towards costs from the hospital and a spina bifida charity [the Newlife Foundation], but I was never paid a salary. However, as it was the only complete cohort of people with spina bifida followed up from birth, I thought the research was so important I couldn't stop.

How does it feel to have your MD?

It's very satisfying. It's nice when you've had disappointments and people not being interested in or ignoring your crucial findings. Every little encouragement becomes rather important.

Were you happy to be receiving it alongside your 55 year old daughter?

Absolutely! It's rather like being beaten at tennis by your child. You're really rather pleased that they are good enough to do that. Competing interests: None declared.

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