



Society for Research into Hydrocephalus and Spina Bifida SPRING NEWSLETTER 2017

President's Message

I hope everyone is enjoying Spring as much as I, although I know that those of you in the southern hemisphere may not be so fortunate. Part of my enthusiasm comes from seeing the venue for our annual meeting in St. Louis come to life. Just outside the conference center the cherry trees are in full bloom and the ducks have returned to the pool in the courtyard.

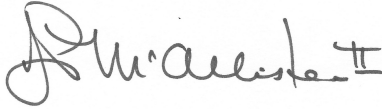
The conference itself is also in full bloom. We are still tweaking the schedule but you can see in the Preliminary Program below that practically everything has been arranged. I am particularly excited about our Special Symposia (please note that the "Transition of Care" theme has been divided into "Spina Bifida" and "Hydrocephalus" components to maximize participation from the members of the International Children's Continence Society, ICCS), our Special Lectures and the presentation of the Casey Holter Lecture by our friend Sven Mattson. I am sure that all of these presentations will be very educational and inspiring, especially the personal story of Olivia Maccoux, an amazing young woman who has experienced first hand the rigors of transition of care with well over 100 shunt revisions. Once again, I am very thankful to Norman and Margaret Guthkelch for sponsoring the annual prize in their names. I am pleased to announce that Joel Haakon Borgstedt-Bakke, Katherine Belfield, Maria Garcia-Bonilla, and Sulmaz Zahedi are the finalists for this prize.

As you know, for the first time this will be a joint meeting with the ICCS. Paul Austin has done a remarkable job of putting together one of the most comprehensive programs I have ever seen, with expert speakers from all over the world and stimulating panel discussions. All of the ICCS sessions are open to SRHSB attendees, and I'm sure you will find them very rewarding. In order to accommodate most of the 65 abstracts from ICCS members, Dr. Austin needed to shorten those oral presentations to 4 or 6 minutes followed by time for discussion. Initially we tried to merge the SRHSB spina bifida-related oral presentations with those of the ICCS for the Friday program, but unfortunately the constraints on time created an inequity between our spina bifida and hydrocephalus presentations. Therefore, we created a short separate session on Friday afternoon to give everyone equal time.

Of course, logistics and costs are always an issue with international meetings, so please take advantage of the **Early Registration deadline of May 15, 2017**. Registration can be completed easily on the website for the joint meeting at <http://www.cvent.com/events/iccs-and-srhsb-joint-conference/event-summary-c3a5754d5e6c4ee4a85a7e0cdf03a498.aspx>. In addition, please note that relatively low-cost housing is available in dormitories on the Washington University campus; these are located very close to the public transportation Metro station and thus just 10 minutes away from the conference venue. Finally, while browsing airfares online I've discovered that airfares from many locations in Europe are relatively inexpensive these days, so I hope you will take advantage of those fares as well.

Last but certainly not least, in continuing the Springtime theme I must emphasize the beauty of the Missouri Botanical Gardens where we will have our annual retreat with all the members of the ICCS. It is truly an enchanting place and one of the most respected botanical gardens in the world. I am sure you will enjoy continuing the casual theme of this meeting in these gardens.

Most sincerely,



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

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 Meeting which will be held in St. Louis, Missouri, USA from June 21-24 2017. 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. This year the meeting will be held as a joint meeting with the ICCS (International Children's Continence Society), which made it even more challenging, but also inspiring.

Continuing our SRHSB tradition we will also have a Clinical Case Session and an Experimental Hydrocephalus Session on Wednesday June 21 from 13:00 until 17:00 as pre-meeting sessions. Those two events attract more and more people every single year. Every participant in the past has appreciated the great opportunity to intensely discuss clinical cases or the latest achievements in experimental hydrocephalus. So please feel free to send your Clinical Cases to Roger Bayston (Roger.Bayston@nottingham.ac.uk) and Marcus Pauly (pauly-castro@web.de). The Experimental Hydrocephalus meeting will be organized by Hazel Jones and invitations will be sent out shortly.

Meet us in St. Louis!

Best wishes

Dr. Marcus Pauly

SRHSB Publication Secretary

Preliminary Program

Joint Congress of the International Children's Continence Society (ICCS) and The Society For Research Into Hydrocephalus And Spina Bifida (SRHSB)

June 21-24, 2017
Washington University School of Medicine
St. Louis, Missouri, USA

Locations:

Eric. P. Newman Educational Center (EPNEC)
BJC Institute of Health (BJCIH)
Farrell Teaching and Learning Center (FTLC)

Tuesday, June 20, 2017

12:00 – 17:00 ICCS Board Meeting with lunch –BJCIH 7th Floor Conference Room A/B

Wednesday, June 21, 2016

07:00 – 20:00 Registration – EPNEC lobby

08:00 - 12:00 ICCS Workshops

1. *Urodynamics I* – EPNEC Great Room

Co-Directors: Paul Austin and Mario De Gennaro

8:00 - 8:05 Welcome/Introduction - Paul Austin

8:05 – 8:45 Vision & Explanation of the Instruments – Christian Sager

8:45 – 9:25 Non-invasive urodynamics Uroflowmetry - Israel Franco

9:25 – 10:10 Urodynamics – Stephen Yang

10:10 - 10:40 Break

10:40 – 11:15 Videourodynamics – Mario De Gennaro

11:15 – 11:55 Pelvic floor Urotherapy – Anka Nieuwhof-Leppink

11:55 - 12:00 Wrap-up Remarks – Paul Austin

2. *Bladder Management Program (CIC)* – FTLC 2nd floor classroom

Course Director: Konstatinos Kamperis

8:00 - 8:05 Welcome/Introduction – Konstatinos Kamperis

8:05 – 8:45 Standard Urotherapy and Role of Pelvic Floor Therapy– Anka Nieuwhof-Leppink

8:45 – 9:25 Role of CIC and update on navigating catheter type and regimens – Ann Raes

9:25 – 10:10 Co-morbid psychological conditions with bladder dysfunction – Alexander von Gontard

10:10 - 10:40 Break

10:40 – 11:15 TENS neuromodulation & bladder dysfunction – Ubirajaro Barroso, Jr.

11:15 – 11:55 Implantable sacral neuromodulation for refractory bladder dysfunction – Seth Alpert

Wednesday, June 21, 2016 (continued)

11:55 - 12:00 Wrap-up Remarks – Konstatinos Kamperis

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

1. ***Urodynamics 2*** - EPNEC Great Room
13:00 – 17:00 Hands-on with Dry Lab Urodynamic Equipment – All Faculty
2. ***Bowel Management Program*** – FTLC 2nd floor classroom
13:00 - 13:05 Welcome/Introduction – Charlotte Siggaard Rittig
13:05 – 13:45 Role of Fiber and laxatives in managing bowel dysfunction – Charlotte Siggaard Rittig
13:45 – 14:25 Enema irrigations in Non –neurogenic bowel - Cecilie Voldum Siggaard
14:25 – 15:10 Enema irrigations in Neurogenic bowel – Eliane Fonseca
15:10 - 15:40 Break
15:40 – 16:15 Co-morbid conditions with bowel dysfunction – Anne Wright
16:15 – 16:55 Role of neuromodulation with refractory bowel dysfunction – Seth Alpert
16:55 - 17:00 Wrap-up Remarks – Charlotte Siggaard Rittig

13:00 – 17:00 SRHSB Pre-meeting Sessions

1. ***Experimental Hydrocephalus*** – BJCIH 8th floor Conf. Room A/B
Director: Hazel Jones
2. ***Clinical Cases*** – BJCIH 10th floor Conf. Room A/B
Co-Directors: Marcus Pauly, Roger Bayston, Mark Luciano, Marion (Jack) Walker

18:00 – 20:00 **Welcome Reception** for all ICCS-SRHSB registrants – EPNEC lobby
Welcoming Presentations by Paul Austin, Pat McAllister, Dave Limbrick & Tryggve Neveus

Thursday, June 22, 2016

08:00 – 13:30 Registration - EPNEC lobby

ICCS-SRHSB Program - EPNEC Auditorium

- 08:00 – 09:30 **Special Symposium Part A: "Transition of Care in Spina Bifida"**
- 08:00 – 08:15 Introduction: Tryggve Neveus, MD; Paul Austin, MD, moderator
- 08:15 – 08:45 **Kelm Hjalmas Lecture** – "Back to the Future - Past Treatment and Long Term Care", Daniel N. Wood, PhD, FRCS(Urology); Consultant in Adolescent and Reconstructive Urology, University College London Hospitals, London, UK

08:45 – 09:15 **Special Lecture** - "Scaffolding the Future: Transition in Action", Sharon Levy, Programme Director of Nursing Studies, University of Edinburgh, Edinburgh, Scotland
 09:15 – 09:30 Discussion
 09:30 – 10:00 Break - Exhibitors and Poster Viewing – EPNEC lobby

ICCS Program - EPNEC Auditorium

10:00 – 10:45 **Special Lecture** – Molecular Insights Toward Chronic Cystitis – Scott Hultgren, PhD, Helen L. Stoever Professor of Molecular Microbiology Director of the Center for Women’s Infectious Disease Research at Washington University School of Medicine
 10:45 – 12:15 **Bladder I Session** - (Basic science and epidemiology)
 12:15 – 12:45 ICCS General Assembly Meeting with Lunch
 12:15 – 13:30 Lunch

SRHSB Program – EPNEC Seminar B

10:30 – 10:15 **Special Symposium Part B: “Transition of Care in Hydrocephalus”**
 10:30 – 10:35 Introduction: Pat McAllister, PhD, moderator
 10:35 – 10:50 “A Patient’s View of Transition of Care”, Olivia Maccoux, Hydrocephalus Association and Augsburg College, Minneapolis, MN, USA
 10:50 – 11:20 “Transition is But the First Step in a Journey of 1000 Miles. Report of the Hydrocephalus Association Summit on Transitional Care”, Michael A. Williams, MD; Department of Neurology, University of Washington, Seattle, WA, USA
 11:20 – 11:50 “Neurosurgical Comparisons between Children and Adults with Hydrocephalus”, Mark Luciano, MD, PhD; Johns Hopkins Hospital, Baltimore, USA
 11:50 – 12:20 General Discussion and Questions
 12:20 – 13:30 SRHSB Annual General Meeting with lunch – EPNEC Seminar B

ICCS-SRHSB Retreat– Missouri Botanical Gardens

14:30 Buses depart from EPNEC for the Missouri Botanical Gardens for tours & strolls
 17:30 Buses depart the Missouri Botanical Gardens to return to hotels

ICCS-SRHSB Conference Dinner – The Bauernhof at Grant’s Farm

18:30 Buses depart hotels for Grant’s Farm
 19:00 – 20:00 Beer & Wine Reception – The Bauernhof courtyard and grounds at Grant’s Farm
 20:00 – 21:00 Dinner and Entertainment – The Todd Hill quintet
 22:00 Buses return to hotels

Friday, June 23, 2016

08:00 – 18:00 Registration

ICCS-SRHSB Joint Program - EPNEC Large Auditorium

08:00 – 10:15 **Special Lectures:** David D. Limbrick, MD, PhD, moderator

08:00 – 08:45 “TBA occult tethered cord syndrome consensus and BBD+UTI”,
Gerald Tuite, MD

08:45 – 09:30 “Fetal In-Utero Repair of Myelomeningocele in The Post-MOMS
Trial Era”, Samer Elbabaa, MD; Department of Neurological
Surgery, St. Louis University School of Medicine, St. Louis, MO, USA

09:30 – 09:55 General Discussion and Questions

09:55 – 10:25 Break - Exhibitors and Poster Viewing – EPNEC Lobby

10:25 – 11:00 Panel Session 2 – Transitional Care
Dan Wood, Rosalia Misseri, Gino Vricella

11:00 – 11:45 **Transitional Care Session**

11:45 – 12:30 **Bladder II Session – (pathogenesis and evaluation)**

12:30 – 13:30 Lunch – EPNEC Great Room

13:30 – 14:30 **Neurogenic bladder Session**

14:45 – 15:30 **Special Lecture:** “Implications of the Gut Microbiome” - Jeffrey
Gordon, MD, Dr. Robert J. Glaser Distinguished University
Professor, Director of the Center for Genome Sciences and Systems
Biology, Washington University School of Medicine

15:30 – 16:00 Break - Exhibitors and Poster Viewing – EPNEC Lobby

16:00 – 17:00 **Bowel dysfunction (BBD) Session**

SRHSB Program – EPNEC Seminar A

16:00 – 16:50 **Spina Bifida & Hydrocephalus Session**

16:00 S1(018): Charlotte Rosenkrantz-Bodin – incidence & outcome of
spina bifida in Denmark

16:10 S2(019): Natalie Sanford – mobile application for SB transition of
care

16:20 S3(020): Sharon Levy – emotional touch points to collect data

16:30 S4(021): Jeff Blount – neurosurgical practice preferences in SB

16:40 S5(016): Llina Pappa – Exome analysis case report

Saturday, June 24, 2016

08:00 – 13:00 Registration

ICCS Program - EPNEC Auditorium

08:00 – 08:45 Panel Session 4 - Alternative therapies for Bladder Dysfunction
Seth Alpert MD, (interstim); Ubirajaro Barroso, Jr, MD (TENS) and
Israel Franco MD (Botox)

08:45 – 09:10 **Special Lecture:** “Current Update on the Pharmacology of the
Bladder” – Anne Wright MD, Evelina London Children’s Hospital, St
Thomas’ Hospital, London, UK

- 09:10 – 10:00 **Bladder III Session – (treatment)**
 10:00 – 10:30 Break - Exhibitors and Poster Viewing – EPNEC Lobby
 10:30 – 11:30 Panel Session 5 - New Aspects of Enuresis Care and Research
 Soren Rittig – Role of genetics and enuresis
 Kostas Komparis – Optimization of desmopressin response
 Ann Raes – Role of sleep and enuresis
 Tryggve Neveus – Therapeutic approach in Non-monosymptomatic enuresis.
- 12:30 – 13:30 Lunch
 13:30 – 14:45 **Nocturnal enuresis Session**
 14:45 – 15:15 Announcement of 2018 ICCS Meeting and Adjournment – EPNEC Auditorium

SRHSB Program – EPNEC Seminar B

- 08:00 – 09:50 **Hydrocephalus 1 – Experimental Hydrocephalus**
 08:00 H1(O10): Zakia Abdelhamed – defective motile cilia neonatal mouse hydrocephalus
 08:10 H2(O1): Yun Yung – neuroprogenitor cells in post-hemorrhagic Hydrocephalus (PHH)
 08:20 H3(O2): Leandro Castaneyra Ruiz – PHH
 08:30 H4(O3): Leandro Castaneyra Ruiz – PHH
 08:40 H5(O4): Patricia Paez-Gonzalez – treating ventricular wall damage
 08:50 H6(O5): Pat McAllister – gyrencephalic model of PHH
 09:00 H7(O6): Antonio Jimenez – NG2 cells in congenital hydrocephalus
 09:10 H8(O7): Agustin Castaneyra-Perdomo – choroid plexus in SH rats
 09:20 H9(O8): Shawn Vuong – choroid plexus gene expression in mouse model
 09:30 H10(O9): June Goto – genetic characterization of new mouse model
 09:40 H11(O14): Jenna Koschnitzky - HANDS
- 09:50 – 10:20 **Casey Holter Lecture** – “Born with Spina Bifida – a Life to Live”, Sven Mattson, MD, PhD, Department of Pediatrics at the University Hospital of Linköping, Sweden
- 10:20 – 10:50 Break - Exhibitors and Poster Viewing – EPNEC Lobby
 10:50 – 11:50 **SRHSB Guthkelch Award Finalist Presentations**
 10:50 G1: Joel Haakon Borgstedt-Bakke – tethered cord in myelomeningocele
 11:05 G2: Katherine Belfield - Bacterial colonization of urinary catheters: how does this affect symptom presentation?
 11:20 G3: Maria Garcia-Bonilla – stem cells in congenital hydrocephalus
 11:35 G4: Sulmaz Zahedi - Micro-fabricated arachnoid granulations for treating hydrocephalus
- 11:50 – 12:45 Lunch
 12:45 – 13:35 **Hydrocephalus 2 – Clinical Hydrocephalus & Biomedical Engineering**
 12:45 H15(O12): Pei-Yi Lin – optical diagnosis in the developing world
 12:55 H16(O13): Brandon Baksh – CSF in infection in PHH

13:05 H17(O15): Ian Pople – DRIFT in PHH
13:15 H19(O17): Margareta Dahl – precocious puberty in hydrocephalus
13:25 H20(O11): Sulmaz Zahedi – heat shrink tubing for shunts
13:35 – 13:45 Welcome to the 2018 Annual Meeting
13:45 – 14:00 SRHSB award presentations and closing remarks
14:00 Adjourn
14:30 – 16:00 SRHSB Executive Committee meeting

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 \$60-74/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. 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. \$25 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. We highly recommend the Metro train service, especially because there is a stop (Central West End) just 50 meters from the conference venue!

Accompanying 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>)
- Cathedral Basilica of St. Louis (<http://cathedralstl.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

Have you visited our new website (<https://www.srhsb.com>)? We are always open to constructive comments and suggestions for improvements so please feel free to 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).

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, 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.

Obituary – Jill Hunt

We were delighted that a number of SRHSB members were able to attend Jill Hunt's Memorial Service in Cambridge on Sunday 23 April. The following are Rosemary Ellis' reflection's on the day.

"It was a lovely Spring Cambridge day, bluebells and wisteria just in bloom round the Church. There must have been about 200 people at the service - Jill's large family counted for a lot of them!

The service was beautifully done with lots of input from the family. Whoever would have known that they had their own Madrigal Choir?? And a son-in-law with a splendid baritone voice who sang a Handel aria accompanied by organ and trumpet? Not to mention Jill's granddaughter who designs lingerie and who took her granny to her fashion shows!

Ewan McKinnon was there and Gill Yaz, who was representing SHINE. Pippa Oakeshott [Jill's daughter] was delighted to see people from organisations that Jill had been part of - said she didn't expect that anyone would have the time to attend! There were 2 sets of parents of the "children" from the Cambridge cohort and lots of friends and old colleagues from Cambridge.

Pippa said that she has sent off the paper reporting the 50 year outcome of the cohort to a couple of journals, and is hoping that one will accept it. I don't know if anyone is going to continue Jill's work. It would be a real pity if it wasn't taken on by someone: organisations like SHINE are finding that the membership in the 45+ age group with spina bifida is bigger than ever as so many are now surviving, but, of course, no-one really knows what will happen to them in the future.

It was a joyful day. As one of Jill's daughters said "Mum would have loved this. And will be fed up to have missed it"!!

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 final updates on the Annual Meeting.