

## President's Winter Newsletter 2018

It is an honour and a pleasure to have been elected as your President for the next 3 years. With your support, I aim to continue the excellent work carried out under Pat McAllister's leadership. He has done a great job in guiding the SRHSB through some challenging times whilst inspiring and mentoring the next generation of researchers.

Sadly, we have to record the passing of two of our Past Presidents and Honorary Members during 2018. Both Professor Edward Guiney (Dublin) and Mr Ram Kalbag (Newcastle) made major contributions to the SRHSB and to the care of those who live with the consequences of hydrocephalus and spina bifida.

The SRHSB is blessed with a collegiate Executive Committee whose individual members bear their responsibilities with good humour. On your behalf, both Pat and I would like to thank those members whose terms of office draw to a close. Andy Wynd took up the burdens of Secretary when, unfortunately, Reinhold Cremer had to step down through ill health. Marcus Pauly has been our effective Publication Secretary and I am very grateful that Antonio Jimenez has agreed to take on the role. I would like to pay particular tribute to Carolyn Harris who, in addition to being our North American Corresponding Member, took over from Waheed Ashraf the thankless task of further reconstructing our website in 2016 (see below). Also, many thanks to Maria Cartmill for her sage advice as she leaves the Executive but not the SRHSB.

### Past President's Message

It is with fond memories and life-long friendships that I pass the Presidency of the SRHSB to Professor John Pickard. In 1985, as a young investigator looking for a scientific home, I was drawn immediately to the high quality of this Society and especially the emphasis on personal relationships amongst the many dedicated members. I have been particularly fortunate to keep close ties with my "home" Society, even surviving the constructive reprimand by Carys Bannister during one of my talks for not knowing that the rat does not have a foramen of Magendi, and it has been a high point of my career to serve as your President for the past 3 years.

My most sincere wish for all past, current, and future members of the SRHSB is that this Society will continue for at least another 62 years, and in doing so to preserve and amplify the core values of good science, collegiality, friendship, and an unwavering commitment to both spina bifida and hydrocephalus. Sometimes I think we lose sight of that unique combination, but we are the only society in the world that endeavours to pursue these two devastating disorders as RELATED *neural tube defects*. In an era of perseverative focus on "speciality", I am proud to say that this is one of the key features that attracted me to the SRHSB, and there is no question that I have become a better investigator as a result of the education and insights I have received from this unique approach to spina bifida and hydrocephalus. There have even been times when I've been tempted, when asked "what do you study?", to say "Hydro-bifida"! So in the most sincere way, I want to say "thank you" to the legacy of SRHSB leadership and dedicated investigators who have pioneered this perspective; please continue the pursuit of this unique goal!"

Finally, as a “people person”, I want you all to know that my small contributions to this Society have been on the strong shoulders of so many dear friends and admired scientists. I hope you all know who you are, because I don’t have time to mention everyone (and since my 4-year old granddaughter has already diagnosed me with “memory loss” I am sure I will leave out some important people). There is no doubt in my mind that the ongoing superb leadership of the Executive Committee, especially John, Andy, Ian, Carolyn, Jaleel, Jo, Leandro, and Antonio, will move us in the right directions.

Last but certainly not least, please know that I am definitely not “retiring” from the SRHSB. There are far too many exciting personal and scientific experiences awaiting all of us, and I am really looking forward to seeing you all in the Canary Islands. Who knows, Leandro may even get me to kite surf!

Respectfully and Affectionately to all,  
Pat

### **Bristol 2018**

Undoubtedly, the highlight of 2018 has been the ‘Update on Perinatal Hydrocephalus and Spina Bifida’ meeting organised by our Treasurer Ian Pople in Bristol. The presentations were excellent and, for those unable to attend, many of the talks can be viewed for the next few months on Talking Slides ([srhsb.talkingslideshd.com](http://srhsb.talkingslideshd.com) code:srhsb2806). Remarkably, there was no registration fee and the delightful dinner was free – a ground breaking exemplar going forward for future organisers of SRHSB meetings!

### **La Laguna June 26<sup>th</sup>-29<sup>th</sup> 2019**

Plans are well advanced for our next meeting in La Laguna – all the details are on the SRHSB website. Dr Leandro Castaneyra-Ruiz, Postdoctoral Research Associate at Washington University in St. Louis, and his father, Professor Agustin Castaneyra-Perdomo, the Dean of the Faculty of Health Sciences, University of La Laguna, are being very creative with the organisation of the meeting and its social programme whilst keeping costs down. The quality of the science is now up to you. Please submit your abstracts as soon as possible (deadline February 15<sup>th</sup> 2019) so that they can be reviewed and acceptance notices sent out before March 15<sup>th</sup> 2019.

### **The Website**

Amongst her many other responsibilities, Carolyn has redesigned our website to create an attractive, modern public face for the SRHSB. However, more work needs to be done to render it more user friendly in terms of ease of updating its content. It would be unfair to ask Carolyn to take on this further work so we have engaged, at no cost to the SRHSB, a web designer, Talissa Gasser, to take advantage of advances in web design. I am very grateful to Carolyn who has agreed to continue in a consultative role during this transition phase. We will be asking for your suggestions and contributions for new content early in 2019.

### **Governance – your homework for the festive season**

You will all be aware that all organisations including Charities worldwide must, as a matter of urgency, reflect on their governance structures and policies. Given the complexities and

pitfalls, I would recommend that our revised Constitution and governance policies fall within a single jurisdiction, namely that of the UK. Andy has previously circulated the two attached documents that were briefly discussed in Bristol at the AGM and are on the website.

As Andy writes, the new regulations will

- ensure that the Society becomes compliant with best practice within the charity sector
- will create a more flexible and responsive Board of Trustees (the Executive Committee)
- will allow flexibility within the Executive Committee to create short life working groups (for instance the Local Organising Committee for the Annual Congress), and
- will allow the Executive Committee to identify individual trustees to assume specific responsibility for key tasks, both regular and occasional (for instance the current posts of Membership Secretary, Publications Secretary etc would fall into this new category.)

Please read these documents carefully over the festive season and let Andy have your detailed responses over the next few weeks so that the new Constitution may be drafted in final form by the Executive prior to presentation at the Society AGM in La Laguna in June 2019.

### **Quo vadis?**

Ever since its inception, the SRHSB has sought to 'advance education and to promote research into hydrocephalus and spina bifida and for this purpose only to bring together workers in different fields who have a common interest in hydrocephalus and spina bifida so that they may be aided in their joint endeavour to prevent, cure or alleviate these conditions'. Many members of the SRHSB have expressed their willingness to engage with updating this mission and to embrace new disciplines that have an essential role in advancing research and education. The few pioneering multidisciplinary clinics that exist are under real threat. In 2019, we need to develop ways of being more inclusive of those who are at risk of or live with the consequences of spina bifida and hydrocephalus so that they may bring their unique perspective and powers of advocacy to our research and education initiatives ([www.invo.org.uk](http://www.invo.org.uk)). We all need to contribute to refreshing and renewing the SRSHB through listening, innovating and delivering.

With all best wishes for the festive season and looking forward to meeting you all in La Laguna,

John

Professor (emeritus) John Pickard