

## **SSBP Newsletter – September 2003**

### **Annual Review**

The SSBP continues to thrive with another successful and productive year. Our membership continues to increase with members from a wide range of diverse disciplines. During the year, Professor Tony Holland stood down as Treasurer and Committee member after many years of dedicated service. We shall certainly miss Tony's reassuring presence although he will continue to remain an active member of the Society. The mantle of responsibility for shepherding the Society's finances has passed to the capable shoulders of Professor Chris Oliver. In addition, we welcome two new committee members, Dr Petrus deVries and Dr Marc Woodbury-Smith. Many of you will remember that Marc was previously awarded the SSBP Research Award to work at the Johns Hopkins University School of Medicine.

### **7th Scientific Symposium: "Re-thinking the Brain", November 2-4th, 2002, Whistler, Canada**

The Society held its 7th Scientific Symposium in the world-famous ski resort of Whistler, British Columbia, Canada. The meeting was one of our best meetings yet and was well attended with a particularly strong presence from North America. The organisational skills of Roger Freeman in co-ordinating the meeting have now become legendary within the Society and if he is not careful, he will be asked to assist in the organisation of all future meetings! The keynote addresses included a wonderfully enlightening talk by Professor Kathleen Sulik, University of North Carolina, Chapel Hill on "Hindbrain development: Clues to the genesis of autism spectrum disorders". In addition, there were equally inspiring talks from Professor Jennifer Karrer, University of Kansas, "Cognitive neuroscience contributions to phenotypic patterns in brain development and function during infancy" and Professor Suzanne Lewis, University of BC, "New approaches to phenotype-genotype relationships in autism spectrum disorders". In addition, there were two panels on controversial topics in behavioural phenotype research; "Standardizing behavioural assessment: Advances and problems", given by Professors Elizabeth Dykens, UCLA, and Maryke Groenveld, University of BC and "How scientific is physical measurement in behavioural phenotypes?" given by Professors Judith Allanson (University of Ottawa), Sterling Clarren (University of Washington, Seattle), Judith Hall (UBC) and John Graham (UCLA). These panels led to much audience participation and were a very welcome new development to the scientific programme. In a further development, we were treated to a fascinating talk and slide show from Professor Judith Hall, UBC on "What do Northwest native peoples have to teach us about our syndromes of interest?" during the conference dinner.

In November 2003, the Society's 10th Annual Scientific Meeting will be held in Newcastle upon Tyne, UK. The conference is being organised by Professor Gregory O'Brien, former Honorary Secretary of the Society. One of the highlights of this meeting will be the Conference Dinner which will be held at Alnwick Castle, star of many films including "Hogwarts" of Harry Potter fame. So, contact Robbie Fountain now to reserve your place! See you in Newcastle.

Professor Kieran Murphy,  
Honorary Secretary



[From right to left:] Leopold Curfs, Pat Howlin, Tony Holland, Cathy DeAngelis [Jim Harris' wife and Editor, JAMA and other AMA journals], and (your editor) Roger Freeman, at the Whistler meeting



Paul and Randi Hagerman, and Alex von Gontard at Whistler



Judy Hall's after dinner talk on the relationship between Northwest coast aboriginal art and legends and behavioural phenotypes was elegant and a big hit

[All photos courtesy of Jim Harris]

## **Treasurer's Report**

Having taken over from Professor Tony Holland at the last AGM as Treasurer for the Society, this is my first report on the Society's financial position. I am grateful to Tony for his diligence in record keeping and thank him on behalf of the Society for his work as Treasurer. I am also mightily relieved that Robbie Fountain, who works with Tony at Cambridge, will continue to support the Treasurer. Her efficiency and good humour make the task easier. I am grateful to

her for her contribution to this report and thankful for her organisational skills.

A review of last year's accounts (year ending 31st August 2002) showed that the Society's expenditure had exceeded income by some £3000. This was caused by the Venice meeting not being able to raise the sponsorship hoped for and the Oxford meeting being hit by reduced delegate number after September 11 and the associated problems with travel. To avoid a recurrence of this shortfall, at the AGM (2001) it was proposed that membership fees should be raised by £5.00 (from £25.00 to £30.00). A second proposal was tabled from the floor suggesting an increase to £40.00 per year, given that much of this fee will be refunded to members if they choose to attend the Annual Conference. The proposal was endorsed by the meeting with a proviso that should financial difficulties preclude membership then an application could be made to the Treasurer for a reduction in fee.

Our membership is rising steadily and now stands at around 125 individual members with 10 groups affiliated to the Society. I would ask all members of the Society to encourage junior members of staff, postgraduate students and others to consider membership. Membership is the financial lifeblood of the Society and the higher the membership numbers, the greater the assured annual income to pay for the day-to-day cost of running the Society. I would also ask members who live in the UK and pay tax to use their Gift Aid form. Completing these forms has already allowed us to claim back some £300-£400 from the Inland Revenue and we shall continue to claim on a yearly basis. I have always said that the Inland Revenue is generous and long may it continue.

An increase in administrative work, in particular making claims to the Inland Revenue and other duties, has meant that the Society has asked Robbie Fountain to take on additional hours and we must, of course, continue to find funds for the salary. Thus, at a recent committee meeting, salary funding for 3 extra hours/week (making a total of 10 hours/week) was agreed. Given the efficiency of the SSBP office I am sure you will agree that this is good value for money.

The very successful meeting hosted by Roger Freeman (with the assistance of Patrick MacLeod) in Whistler in Canada in 2002, gave the Society a welcome income of just over £2700. The Society is grateful to them both for the interesting and informative meeting and for the financial success which has promoted financial stability for the Society. Planning for this year's meeting, hosted by Greg O'Brien in Newcastle, is progressing well. We hope that the focus on Autism and Asperger's syndrome will attract a large number of delegates and Greg has so far been successful in raising sponsorship for the meeting. We look forward to a stimulating meeting and a financial success.

The current financial stability of the Society means that we are able to offer bursaries/studentships to members of the Society wishing to attend the Newcastle meeting and we again offer the Research Fund of up to £2,000 for small research projects or "pump priming money". The Research Fund is available only to SSBP members and information can be found on the Web site ([www.ssbp.co.uk](http://www.ssbp.co.uk)).

The Society continues to grow at a steady pace but we must ensure that we are not stretched beyond our resources. We must encourage others to join us in the Society to expand the understanding of behavioural phenotypes and disseminate research findings and their clinical implications.

Chris Oliver  
Treasurer, SSBP

### **Newcastle Meeting details:**



### **Focus on Autism and the Broader Behavioural Phenotype**

The 10th Annual Scientific meeting will be at the Gosforth Park Marriott Hotel, Newcastle upon Tyne, UK, November 20-21, 2003, with the conference dinner taking place at Alnwick Castle.

#### **Keynote Speakers include:**

Uta Frith: Autism: a historical case study

Pat Howlin: Changing the future for people with autism

Elaine Perry: Cholinergic systems in autism

Also: Tom Berney, Patrick Bolton, Randi Hagerman, Tony Holland, Anne le Couteur and Helen McConnachie

Contact the Society's Office or check on the Web site for further information.

### **Advance Notice for the SSBP 2004 International Meeting**

The Society is in the early stages of organising its next International meeting in Barcelona, Spain. The proposed dates are the 11th and 12th November 2004. The venue will be the Hotel Gran Via; some limited accommodation will be available at the venue. Barcelona has many hotels and a list will be provided to those wishing to attend. The social programme will include a tour of Casa Batlló. The dinner will be held at 7 Portes (the oldest restaurant in Barcelona).



### **Conference or membership information**

Anyone requiring further information regarding any meeting or about the membership of the SSBP should contact:

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## **Gift Aid**

The Society is very grateful to all the UK members who have completed their Gift Aid forms and returned them to the SSBP Office. We have currently received just under £400 from the UK Inland Revenue. If you have yet received a form and would like one to help the Society's funds please contact Robbie at the SSBP Office.

It is hoped that similar schemes will become available for members in other countries in due course and information will be circulated to members.

## **Annual Fees**

Paying your fees regularly and on time saves the Society time and postage costs and Robbie would like to remind everyone who has not yet paid their 2003 fees that they are now due.

## **Recruitment**

One of the main ways the SSBP has of funding its day-to-day running costs is the Annual Fees paid by members of the Society. These fees help with the cost of office administration, advertising our meetings and paying for the up keep of the web site.

Another way of increasing both out funds and the Society's membership is to suggest to colleagues that they might like to join the Society. It is advantageous to the Society for there to be a wide-spread membership both geographically and in terms of areas of interest. We currently have members who are psychiatrists, psychologists, geneticists and paediatricians. A few members come from therapy services and some from educational backgrounds. Anyone who works clinically with those with Behavioural Phenotypes or their carers and families, or who carries out research in this field is able to apply for membership.

## **The Society's Web Site**

Information about all the Society's activities and membership can be found on the web site: [www.ssbp.co.uk](http://www.ssbp.co.uk)

The Society has some links posted on the web site but is always interested in providing links to other helpful sites. If you know of or run another site that you think might be of interest to SSBP members and colleagues, do please contact Robbie at the SSBP Office.

## **Syndrome Sheets**

The Society tries to provide up-to-date information on many syndromes. Many of these sheets are commissioned from those presenting data on studies at our various meetings. If you feel that there are syndromes not included on our site that should be, please, again, contact Robbie. Also, we would be very pleased to hear from anyone willing to up-date sheets.

## News from Members

This is only a very partial list, since many members are on holidays, but in future it may be expanded.

**Annapia Verri** (C. Mondino Institute Pavia, Italy) presented a paper "Quality of life in developmental disabilities " at the workshop "Quality of life for disabled persons and their families" held in Rome on November 22, 2002. She is a member of the International Society for Quality of Life Studies (ISQOLS) and of the International Well Being Group, founded by Prof Robert Cummins (Deakin University, Melbourne), and is its principal researcher for Italy. Annapia is currently completing a three-year clinico-biological study on the pattern of aging in Down syndrome. The results of this research will be presented at the 4th European Congress "Mental Health and Mental Retardation: A Lifespan Multidisciplinary Approach", to be held in Rome on September 17-20, 2003.

**Kieran O'Malley** (U Washington) tells of his 3 recent publications, two of which are relevant to genetic factors in fetal response to alcohol exposure: O'Malley KD & Storoz L. Fetal alcohol spectrum disorder and ADHD: diagnostic implications and therapeutic consequences. Expert Review of Neurotherapeutics 2003; 3(4): 477-489, on-line at [www.future-drugs.com](http://www.future-drugs.com) and O'Malley K & Streissguth A. Clinical intervention and support for children aged zero to five years with Fetal Alcohol Spectrum Disorder and their parents/ caregivers. In: RE Tremblay, RG Barr, RDeV Peters (eds.) Encyclopedia on Early Childhood Development, 2003, 1-9, on-line at [www.excellence-earlychildhood.ca](http://www.excellence-earlychildhood.ca)

**Roger Freeman** (UBC, Vancouver, your editor) has been active this year in starting a small study of joint-cracking, a repetitive pattern about which little is known (yet there is a widespread belief that it damages joints). At one end of the spectrum of behaviour it may be normal or beneficial for joints, and at the other (the urge to do it to an extreme point of pain, and in a "just right" and patterned or ritualistic manner) it might be related to obsessive-compulsive behaviours, Stereotypic Movement Disorder and/or impulsive or self-regulating behaviours such as skin-picking and trichotillomania. The ability to obtain the desired sensation must also depend upon individual differences in joint structure. An unexpected observation when assessing the 2 known (and unrelated) cases of female Duchenne muscular dystrophy (not manifesting carriers – each has skewed X-inactivation and one has a transposition) was co-occurrence with significant chronic motor tics. Whether this is merely a rare coincidence is as yet unknown. (Similar observations by other members would be welcome.)

**Stewart Einfeld** reports from Oceania: "We are continuing a number of behavioural phenotype studies. We have surveyed our Prader Willi Syndrome cohort, identified originally from genetics clinics. The lifetime incidence of psychosis in this group is about 16% - a high level but possibly less than others have found. In another study we are developing an intervention program for anxiety problems in people with Williams syndrome. We have received a grant from the National Institutes of Health (US) for the data analysis of our longitudinal cohort study, the Australian Child-to-Adult Development Study now in its 13th year. The cohort includes subgroups of individuals with PWS, WS, Frax and DS, and an autism cohort. As foreshadowed at the excellent Whistler meeting, we are planning for a possible meeting of SSBP in Australia."

**Judith Allanson** (keynote speaker, 2002) reports that the Second Edition of her well-received book "Management of Genetic Syndromes" co-edited with Suzanne Cassidy (Wiley-Liss, 2001) is in preparation, due out (she hopes) in about a year, with a greatly expanded set of syndromes.

**John Graham** (keynote speaker, 2002) reports that they are making progress on characterizing what have been called autistic features in CHARGE Association or syndrome; at least some of them seem to be behaviours associated with deaf-blindness or "multi-

sensory impairment.” He attended the recent international meeting in Chicago, where Tim Hartshorne, a speaker at our Whistler meeting, presented further results from his large database.

**Chris Oliver reports:**

In June this year a book on self-injurious behaviour in Cornelia de Lange syndrome was published, a guide for carers and professionals obtainable from the Cornelia de Lange Foundation (UK and Ireland) or downloaded from their website as a PDF file ([www.cdls.org.uk](http://www.cdls.org.uk)). The full reference is: Oliver C, Moss J, Petty J, Arron K, Sloneem, J & Hall S (2003). Self-injurious behaviour in Cornelia de Lange syndrome: A guide for parents and carers. Trident: Coventry.

## **Announcement**

Rett Syndrome Association UK  
Family Weekend  
10 to 12 October 2003  
Hilton Hotel, Collingtree, Northampton

The Rett Syndrome Association UK (RSAUK) is holding its 19th Annual Family Weekend. The weekend is aimed at families and carers of people with Rett syndrome as well as professionals with an interest in the disorder. There will be a number of speakers addressing some of the health and social issues surrounding the condition, for example, physiotherapy demonstrations, housing options and the effects of diagnosis. The keynote speaker will be Professor John Christodoulou, Director of the Western Sydney Genetics Program. He will be looking at research into links between mutations of the MECP2 gene and the characteristics, functioning and health of people with Rett syndrome.

Cost varies according to length of stay (max. £180 per adult). This event is free for people with Rett syndrome.

For more information please visit the RSAUK website: [www.rettsyndrome.org.uk](http://www.rettsyndrome.org.uk) email the office [info@rettsyndrome.org.uk](mailto:info@rettsyndrome.org.uk) or call 0044 (0)870 770 3266.

## **Final Comment**

As this goes to press, I have just attended the 24th Annual David W. Smith Workshop on Malformations and Morphogenesis, in Vancouver. Those who attended the Whistler meeting will recognize the following names of those present: Judith Hall, Judith Allanson, Patrick MacLeod, John Graham, Cynthia Forster-Gibson, Suzanne Lewis, Kathy Sulik, members from Leopold Curfs' group, and Brian Lowry and Margot Van Allen. What seems especially relevant to SSBP is the high level of interest in behavioural phenotypes, even at a meeting devoted to malformations.

From the Editor

If you have any comments about or contributions to the Newsletter, please contact me by e-mail: [rfreeman@cw.bc.ca](mailto:rfreeman@cw.bc.ca)

Roger Freeman