



NEWSLETTER

Society for the Study of Behavioural Phenotypes

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ANNUAL REVIEW

The SSBP has had another successful and productive year. After 9 years of service on the Committee, Dr Jeremy Turk stood down as a Committee member but will continue to remain an active member of the Society.

In November 2003, the Society's 10th Annual Scientific Meeting was held in Newcastle upon Tyne, UK. The theme of the conference focused on autism and the broader behavioural phenotype and was expertly organised by Professor Greg O'Brien, former Honorary Secretary of the Society.

The keynote addresses included a wonderful historical review of autism by Professor Uta Frith (University College London) and overviews of the genetics of autism (Professor Patrick Bolton, Institute of Psychiatry, London) and cholinergic systems in autism (Dr Elaine Perry,

Newcastle General Hospital). Other keynote lectures included the diagnosis and assessment of autism by Dr Anne le Couteur (Fleming Nuffield Unit, Newcastle), a very enjoyable and technophilic talk on early intervention by Dr Helen McConnachie (University of Newcastle), changing the future for people with autism by Professor Pat Howlin (St George's, London), co-morbid disorder in Asperger college students (Dr Tom Berney, Prudhoe Hospital, Northumberland), and conclusions of a Department of Health report on the needs of people with Asperger syndrome (Professor Tony Holland, Cambridge). Finally, we were treated to an overview of phenotyping at the MIND Institute by Professor Randi Hagerman (MIND Institute, UC Davis), complete with slides of their beautiful new building. It was difficult not to be envious of such a wonderful facility!

In addition to Greg's obvious administrative skills in organising the meeting, we were also treated to a previously undiscovered skill as tour guide. While en route to the Conference Dinner at Alnwick Castle, of Harry Potter fame and ancestral home of the Duke of Northumberland, we were treated to a lively history of Northumberland that considerably shortened the journey time. Although the Duke and his family were in residence, we were privileged to be offered a personal tour of Alnwick and had a wonderful time exploring the stately rooms.

Although acknowledged a great success, a shadow was cast over the conference by the sad death of Les Fountain, Robbie's husband. In his memory, the SSBP has decided to award the Les Fountain Travel Bursary to attend the International meeting to be held in Barcelona, November 11-12th 2004.

Professor Kieran Murphy
Honorary Secretary

Some photos from Newcastle, most courtesy of Jim Harris:



Gene Fisch's table; Martin Bax, elegant as ever, in right foreground



Barbara O'Brien, Leopold Curfs, Pat Howlin, and Greg O'Brien



Randi Hagerman, Jeremy Turk, and Pat Howlin



The group on Hadrian's Wall, including Jim Harris, front left, and Kieran Murphy, right



Greg O'Brien holds forth



Pat Howlin giving a talk

Treasurer's Report

Our accounts are soon to be audited and the current position is rather different from this time last year. At the time of writing we have about £7,500 in our accounts (£760 deposit account and £6,870 current account); this is significantly lower than the total of £17,000 that we had last year. There are 2 reasons: (1) the substantial fluctuation in the balance that occurs throughout the year due to conference-related income and outgoings (we are slightly behind on income for this year's conference); (2) a delayed invoice from the University of Cambridge for salary and office costs. These factors, in combination with the addition of VAT for the

salary and office costs, have led to a depletion of our reserves and have also highlighted how dependent the Society is on income from conferences for recurrent annual costs. This dependency is unwise. The proportion of total turnover that is conference-related is very high. Consequently, if there is very low attendance we are vulnerable financially. This can happen. To continue to be so reliant on conferences as a stable income source is not a sustainable position; we must change the pattern this year to ensure that predictable costs are met by regular income. The easiest way to do this is to increase the membership. If each member recruits one new member the Society is immediately on a firm financial footing. I would urge each member to actively recruit and support the application of one new member this year. This would change our position quickly. The committee have also proposed a number of additional options that we shall put to the membership by way of a survey. The results of this survey will be used to develop proposals to be put at the AGM in Barcelona. Your response to the survey will help the committee put together workable options. *I hope you can find time to respond.* As ever, I extend my thanks to Robbie Fountain for her tireless support and attention to detail over the last year when these sorts of financial concerns are put into perspective by events that touch us all. It is a privilege for the Society to be able to offer travel bursaries for conference attendance in fond memory of Les Fountain.

Chris Oliver, SSBP Treasurer

Barcelona Meeting details:

Fragile X Syndrome – from Genes to Behaviour

The 8th International Symposium will be held at the Hotel Gran Via, Barcelona, Spain, November 11-12, 2004, with the conference dinner taking place at Magnum of the 7 Portes group, one of the most renowned restaurants in Barcelona.

The meeting will be followed by the International Fragile X meeting.

The conference is being organised by Dr Josep Artigas, Dr Carme Brun, Professor Randi Hagerman and myself, and promises to live up to the standards of previous meetings years. One of the highlights of this meeting will be the Conference Dinner! So, register for the meeting now to avoid disappointment!

See you in Barcelona!

Professor Kieran Murphy
Honorary Secretary

Keynote Speakers include:

Dr Xavier Estivill, Spain:
“Dissection of behaviour in murine models”

Professor Jean-Pierre Fryns, Belgium:
“The Fragile X syndrome and X-linked mental retardation: 25 years later”

Professor Paul Hagerman, USA:
“Fragile X: molecular insights into clinical involvement”

Dr Isabel Tejada, Spain:
“Genetic cause of mental retardation: the state of the art”

Professor Anita Thapar, UK:
“Advances in the genetics of Attention-Deficit/Hyperactivity Disorder”

Dr Jeremy Turk, UK:
“Fragile X syndrome: a longitudinal developmental perspective”

Anyone wishing further information or wishing to register should contact the SSBP Office or register on-line at www.ssbp.co.uk

Advance Notice for the SSBP 2005 International Meeting

The Society is now organising its next International meeting in Cairns, Australia. The dates are the 5th to 7th October 2005. The venue will be The Novotel Palm Cove, near Cairns. Our host will be Stewart Einfeld, with colleagues from both Australia and around the world assisting him in the organisation.



The hotel has 2 bars and 2 restaurants for those of you wishing to relax and several swimming pools, squash court, gym and a golf course for those feeling more energetic. It is

also set in beautiful tropical surroundings. The hotel has a tour desk to help you plan any post-conference activities.

Further information will be posted on the SSBP web site as it becomes available.

Conference or membership information

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

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The Les Fountain Travel Bursary

Many of you will know of the sad death of Les Fountain, Robbie's husband, in November 2003. In recognition of the important contribution that both Robbie and Les made to the Society, the SSBP has decided to award the Les Fountain Travel Bursary to attend the 8th International Symposium in Barcelona.

We are pleased to say that one bursary has been awarded for the Barcelona meeting to Katy Berg, a Ph.D student at the School of Psychology, University of Birmingham in the UK.

Behavioural Phenotype Journal

For some time we have been discussing the possibility of producing our own bi-annual journal with scientific papers on behavioural phenotypes. At the 2003 AGM, the membership voted to support such an endeavour and Dr Martin Bax has kindly agreed to undertake exploratory discussions with a number of publishing houses.

Gift Aid

The Society is again very grateful to all the UK members who have donated to the Society via their Gift Aid forms. We have currently received just over £636 from the UK Inland Revenue. If you have not 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 2004 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 our funds and the Society's membership is to suggest to colleagues that they might like to join the Society.

The Society's Web Site

Information about all of the Society's activities and membership can be found on the Web site:

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 the SSBP's 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 their studies at our various meetings. The Society would like to thank all those who have contributed to this year's meeting by providing a syndrome sheet. If you feel that there are still 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 syndrome sheets on a regular basis.

News from Members

Marc Woodbury-Smith (now an SSBP Board member) received a Travel Award from the SSBP to study at Johns Hopkins. He writes from Yale University Child Study Center:

"In March 2002, as a result of a generous travel grant awarded to me by the SSBP, I was fortunate in being given the opportunity to travel to Baltimore and be trained in the use of the Pragmatic Rating Scale (PRS) by Rebecca Landa, an eminent scientist in the field of autism research. This scale, developed by Dr. Landa, is one of only a few established methods to measure pragmatic language impairments, which are recognized as core clinical difficulties among people with higher functioning autistic spectrum disorders. As a result of the training I received I was subsequently able to conduct a small research study to investigate pragmatic language in adults with high-functioning ASDs (presented at the SSBP conference in Newcastle in 2003). This study, conducted whilst I was working at Cambridge University, investigated patterns of pragmatic and para-pragmatic language difficulties in a sample of adults (18+) with ASDs diagnosed according to ICD-10 criteria (N=18). A non-ASD comparison group (N=18) was recruited to allow specific hypotheses to be tested regarding pragmatic impairments in people with ASDs. In brief, the study found individuals with ASDs displayed impaired pragmatic language across the domains of discourse, presupposition and communicative intentions, and impaired para-pragmatics compared to the control group with 78% being given an overall rating of impaired pragmatic language ability. I am grateful to the SSBP for its support and hope to expand on this pilot study and use the PRS to address other research questions regarding communicative impairments in higher-functioning people with ASDs."

I have received a very interesting 5-page summary (with 12 references) of the recent work of **Randi** and **Paul Hagerman** on Fragile X-associated tremor/ataxia syndrome (FXTAS), which is unfortunately too long to include here. Some of this work was presented at the Whistler meeting in 2002. But Randi has also provided a narrative of the evolution of the concepts on which the research was based and how it was facilitated by patients and families, as well as by the many other disciplines with which they collaborate. Anyone who wishes to receive an e-mail copy can contact me for it.

I have also made an attempt to survey the recent literature for references to the publications of our members. The result was many pages of citations and abstracts. As readers can imagine, our members have indeed produced a substantial and interesting body of research. However, if this feature is desired by the members, I think we should ask *all* members for their past year's references, rather than leaving it to me to do the searching (some members may not wish to have their publications included). Comments and opinions about this idea will be gratefully entertained.

Roger Freeman (UBC, Vancouver, your editor) summarizes: (1) I have been active this year in completing a follow-up study of Stereotypic Movement Disorder without self-injurious behaviour in 15 children (this typically enduring pattern has its onset in the first or second year of life, and is often confused with autistic stereotypies). About a quarter develop Tourette syndrome later in childhood. (2) A multi-site

study of coprophenomena (coprolalia and copropraxia), especially in relation to other types of repetitive behaviour is under way, utilizing 19 sites of our international TIC Database Consortium. (3) A research grant from the US Association of University Disability Centers to the University of Washington will use our Children's Hospital clinic as the second site for a 2-year study of quality of life in pure and comorbid Tourette syndrome.

From the Editor

If you have any helpful comments about — or contributions to — our Newsletter, please contact me, preferably by e-mail at: rfreeman@cw.bc.ca

I need your help to increase interest for our members. Unfortunately I received nothing from a similar appeal last year!

Roger Freeman