



NEWSLETTER

Society for the Study of Behavioural Phenotypes

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ANNUAL REVIEW

The SSBP has had another successful and productive year. Our membership continues to increase with members joining from a wide range of complementary disciplines. At the recent AGM in Oxford, in recognition of the tremendous support and encouragement given to the Society over the years, Professor Tom Oppe became the Society's Life President and Dr Martin Bax became the newly appointed President.

Opposite:

Tom and Margaret Oppe receiving gifts from the Society at the meeting in Eynsham Hall



Research

Research continues to be an integral and essential part of the SSBP. In view of this, the Society now makes available up to £2000 to fund travel and other costs to support research.

At the recent AGM in Oxford, a Research Award of £700 was presented to Dr Marc Woodbury-Smith, SSBP Member at Cambridge University, to enable him to travel to the USA to receive training in assessments of adults with social and communication disorders. Specifically, he will work with Dr Rebecca Landa at the Johns Hopkins University School of Medicine and will receive training to allow him to measure pragmatic aspects of language in affected adults. This is the first Research Award of this type made by the Society but it is hoped that further awards will be made on an annual basis.

9th Annual Scientific Meeting : “From Bench to Behaviour” November 15-16th 2001 Oxford, UK

In November 2001, the Society's 9th Annual Scientific Meeting took place in the beautiful surroundings of Eynsham Hall, North Leigh, Oxford. The meeting was well attended and Society was delighted to be able to welcome delegates

from all over Europe, the USA and UK.

The theme of the meeting, "Behavioural Phenotypes - From Bench to Behaviour" was designed to appeal to the wide diversity of disciplines that make up the membership of the SSBP. There were five major sections of the programme 1) The neurobiology of behavioural phenotypes 2) Tuberous sclerosis 3) Attention deficit and hyperactivity disorder 4) Behavioural interventions in genetic disorders and 5) Fragile X syndrome. There were a number of outstanding Keynote Lectures including "Imprinted genes, brain and behaviour" by Dr Anthony Isles, Babraham Institute, Cambridge; "Neuroimaging of behavioural phenotypes" by Professor Declan Murphy, Institute of Psychiatry, London; "Psychiatric aspects of Tuberous Sclerosis" by Dr Patrick Bolton, University of Cambridge; "Neurobiology of the Tuberous Sclerosis Complex" by Dr Peter Crino, University of Pennsylvania; "ADHD and the expression of genetic risk" by Professor Eric Taylor, Institute of Psychiatry, London and "Behavioural interventions in genetic disorders" by Professor Chris Oliver, University of Birmingham.

Although there were some technical difficulties with the audio-visual equipment, both presenters and members of the audience

responded in a tolerant and good-humoured manner and disruption of the presentations was reduced to a minimum. The diverse programme was enhanced by the warm welcome given to everyone by staff at Eysham Hall. At the Conference dinner, a presentation was made to Professor Tom Oppe in recognition of his tremendous support for the Society over the years as President.

The meeting was generously sponsored by the Tuberous Sclerosis Association and the Society would like to thank the Association for its assistance in organising the meeting.



Above:

Martin Bax, the Society's new President

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

In November 2002, the Society's 7th International Symposium will be held in Whistler, Canada. The conference is being organised by Dr Roger Freeman, and his local group, as well as Dr Alexander von Gontard and Leopold Curfs from the European arm of the Committee and promises to live up to the standards of previous years.

See you in Whistler.

Professor Kieran C Murphy
Honorary Secretary

Treasurer's Report

This last year, as with the year before, has been more problematic for the Society from the point of view of its financial affairs. It has proved more difficult to be able to ensure a healthy return from the conferences and thus to ensure sufficient money to continue to support the running of the Society over the year.

In my report to last year's AGM I expressed concern about our ability to meet financial commitments and with this in mind it was agreed to raise the yearly membership fees from £25 to £40. This was the first significant raise for some period of time and has gone some considerable way to ensuring that we can cover our day-to-day costs without becoming reliant on the Conferences.

The last Conference was held in Oxford in conjunction with the Tuberous Sclerosis Association. I am extremely grateful to the TSA for their generous support for this meeting. For a number of reasons however, we made a loss of just over £2000 on the meeting. This was partly due to some cancellations because of September 11th but it also reflected the fact that the attendance was not as great as in the past. However, the content of the meeting was excellent and I am sure we have contributed to maintain the high academic standards that we have set ourselves to achieve. If we consider the amount of loss at the Conference most of it can be accounted for by our continuing commitment to offer bursaries together with some smaller costs that cover Committee room hire for the Committee meeting prior to the main meeting. If those costs are removed then the Conference nearly broke even. We have been

able to make some recovery with regards to the financial state and at the time of preparing this report the balance of our accounts was approximately £8000.

We have committed ourselves to a further meeting in North America this year and this has required deposits to be paid. However, the organiser of the Conference, Roger Freeman has so far been successful with sponsorship and we hope that this will continue. I think it is important to stress that whilst we have remained in a reasonable financial state our reserves are small and therefore any loss at a meeting has a disproportionate effect on the Society. We need to continue to be vigilant.

At present we have suspended the offer of Conference Fellowships for this year's meeting although we hope to be able to raise money from a private source that will allow us to reinstate this. At present we do not feel able to cover the cost of these Fellowships from our own resources.

I would like to again express my thanks to Robbie Patterson for the considerable support in the administration of the Society in preparing the accounts. I would also like to thank Mr Robert Clotney, the Society's Auditor.

Tony Holland
Honorary Treasurer

Mediaeval People

Some years ago, when my husband was dying, I had to go to England on business. I stayed with a friend, who at that time was Church Warden for St Mary's, Shenley*. On Sunday morning I went to Matins. The last hymn of the service happened to be the one that was sung at my wedding. A man with Downs Syndrome was in the pew in front of me. He wasn't singing, he was looking around. He looked at me, saw the tears in my eyes, and stretched out a hand to me. That gift of compassion was a very real strength to me in the difficult days that followed.

After the SSBP conference last week, I went to stay with my friend again. On Saturday morning she asked if I would like to see the renovations that had been done at the Church and as I often remember the Church and it's congregation with affection, I was very pleased to go with her. As we stood gazing at the mediaeval window, the early morning sun lit small carvings of faces and I was fascinated by the character the stonemason had managed to capture. These were surely a husband and wife known to the sculptor and those with coronets, were they a Lord and Lady, King and Queen, or were they his

neighbours? I decided to take a walk all round the Church and take a really good look at the carvings. And that's when I found them, one with Downs Syndrome and one with Fragile-X. As these carvings were not up with the gargoyles, but beside a window like the other portrait sculptures, the people portrayed may have been cherished members of the community. Hundreds of years of weathering have damaged the carvings a little but the physical phenotypes are still clear.

Margaret Collins
20th November 2001

* Shenley Church End is where the hero of the Enigma was billeted.

Obituary

It was with great sadness that we learned of Margaret's death on 25th April 2002. We extend our deepest sympathy to her family, friends and colleagues. Margaret supported the SSBP as a member and was a regular delegate at our meetings. Her contribution to the Society and her work in this field will be greatly missed.

The Behavioural Phenotype in Velo-Cardio-Facial Syndrome (del22q11): from infancy to adolescence, 2001, 148pp., Ann Swillen ISBN 90-806302-1-7

The subject of this thesis is the delineation of the behavioural phenotype in the Velo-Cardio-Facial Syndrome (VCFS), from infancy to adolescence.

A behavioural phenotype is a behavioural pattern-including cognitive processes and social interaction style that is consistently associated with, and specific to, a syndrome which has a chromosomal or a genetic aetiology.

The VCFS is caused by a sub-microscopic deletion in the long arm of chromosome 22 band q11 [del(22q11)}. The del22q11 is much more frequent than previously recognised and, with an estimated incidence of 1/4000 to 1/5000, it is the most frequent microdeletion syndrome. The main clinical features of this condition are velo-pharyngeal insufficiency (VPI), congenital heart defects, and a characteristic facies.

Developmental delay/learning difficulties and behavioural problems are also consistent features of VCFS (del22q11). This thesis includes a series of studies on the cognitive and behavioural spectrum of young children and adolescents with

VCFS. The overall aim of these cognitive and behavioural studies is to contribute to a more accurate characterisation/delineation of the cognitive development and behaviour in children and adolescents with VCFS (del22q11). All subjects were recruited from the multidisciplinary VCFS-clinic at the University Hospital Gasthuisberg and the Centre for Human Genetics Leuven.

Guidelines for education and guidance of children and adolescents with VCFS and future directions for research are also discussed .

Conference or membership information

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

*Robbie Patterson,
Administrative Secretary,
SSBP Office, Douglas House,
18b Trumpington Road, Cambridge
CB2 2AH, U.K.*

Tel: +44 (0)1223 746100

Fax: +44 (0)1223 746122

Email: SSBPROBBIE@AOL.COM

SSBP Annual Fees

Robbie would like to thank all members who have paid their annual fees so promptly this year and remind anyone who has not

paid yet, that their fees are now seriously overdue.

Gift Aid

The Society would like to be able to boost its funds a little by collecting the tax back from the Inland Revenue on the annual fees paid by its members. We will therefore be sending all UK tax paying members a form to complete and return which will give the Society the authority to do this. It means that we can claim back £8.00 for every £40.00 annual fee you pay. With over 50 UK members we can claim over £400 per year. Every bit of funding helps!!

From the Editor

If you have any comments about or contributions to the Newsletter please contact Susan Eckhardt on email: Eckhardt@gtonline.net

The Society's Web Site

Information about all the Society's activities can be found on the web site

WWW.SSBP.CO.UK

The Society has some links posted on the web site but are always interested in providing links to other helpful site. 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 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.