



## Tuberous Sclerosis Association

*"To promote awareness, research and the best management of Tuberous Sclerosis Complex, and support all affected individuals and families"*

TSA  
PO Box 8001  
Derby  
DE1 0YA

tel: 01332 290734  
e: [development-support@tuberous-sclerosis.org](mailto:development-support@tuberous-sclerosis.org)

Dear Member,

### **Annual Conference and AGM – Saturday 12<sup>th</sup> November 2011**

We would like to invite you to our Annual Conference and Annual General Meeting which is to be held at the Hilton Birmingham Bromsgrove Hotel, Bromsgrove, West Midlands.

As always, we listened to your feedback last year in planning what promises to be a fabulous day at this time of really exciting advancement in the field of TSC research – and in the life of the TSA itself.

The TSA International Conference in Belfast will have taken place just a few weeks previously and Jane Cox, our own Head of Research, will be giving us feedback. Additionally Jane and Dr Chris Kingswood, Trustee and Professional Adviser for the TSA, will be informing us about the latest drug treatments, with results from the various trials which are under way and yielding such promising outcomes.

Nicola Hartley from The Princess Royal Trust for Carers will be helping those of us who have a caring role for our family member(s), be they adult or child, with useful direction and guidance regarding carers' rights.

Dr Petrus de Vries, Consultant in Developmental Psychiatry, and well known to many of us for his interest in, and research contributions to, the field of TSC, will be giving us some practical solutions to some of the behavioural and learning aspects which impact on the lives of those affected by TSC.

And we will have news about the appointment of a Chief Executive Officer - what a day!

You will be warmly welcomed, whether a new member or an "established" member of the TSA – we would love to see you.

TSA literature, sales tables of fund raising goods and the national raffle draw will also be part of our full day.

... and of course, there will be the opportunity to meet and chat with staff and trustees, to catch up with old friends and make new ones!

The Mobile Crèche company will be assisting us again this year. These are trained staff, experienced in special needs, who have developed a programme of activities for the day which is tailored accordingly, with both creche facilities for younger children and the 'clubhouse' for older children and young people.

[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

The Mobile Crèche company are happy for parents to contact them directly to answer any questions on 0800 4580 187 or see [www.mobilecreche.biz](http://www.mobilecreche.biz) - The last date for booking a place in the crèche is **Saturday 22<sup>nd</sup> October**. Book your place(s) direct with the Mobile Crèche company on 0800 458 0187 or email [julie@mobilecreche.biz](mailto:julie@mobilecreche.biz)

The hotel has a swimming pool and we are invited to make use of it during “Splash Hour” on the Sunday morning between 9.30 – 11.00h.

We have reserved a number of rooms, including family rooms, for those wishing to stay overnight and the quoted cost is £58 per adult per night, which is for dinner, bed and breakfast based on 2 people sharing a standard double room.

Children's breakfast costs: no charge for children age 10 and under sharing parents' room; £7 for children age 11 – 18.

Children's evening meal costs: no charge for children age 10 and under sharing parents' room; £10 for children age 11 – 15; £16 age 16 and over.

Please book directly with the hotel, quoting ‘Tuberous Sclerosis’ or GTSAA, and *we advise that you book early*.

The **cost for the conference** is greatly subsidised by the TSA to £15 per adult, including lunch and refreshment breaks, with no charge for children under the age of 16 (including participating in the creche or club house.) Please ensure that your membership is up to date prior to booking - we always welcome new members who wish to attend. Membership forms can be obtained from Chris Johnson, 01332 290734 or downloaded at [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

Please contact Chris Johnson, Support Services Coordinator, in confidence, to discuss any special requirements or any difficulties with the conference venue, programme or cost.

We look forward to meeting you.

Philip Goldenberg  
Chair



**Annual Family Conference and AGM  
Saturday 12<sup>th</sup> November 2011**

Hilton Birmingham Bromsgrove  
Birmingham Road, Bromsgrove B61 0JB  
tel: 0121 447 7888  
[www.hilton.co.uk/birminghambromsgrove](http://www.hilton.co.uk/birminghambromsgrove)

**Programme**

- 09.00-10.00 Coffee and Registration (crèche and clubhouse open at 09.30)
- 10.00-10.45 **Annual General Meeting** (Treasurer / Deputy Treasurer)
- 10.45-11.15 **Research Round Up** (Belfast feedback: Jane Cox)
- 11.15-12.15 **Carers Rights**  
Nicola Hartley, Development Manager Midlands & East, The Princess Royal Trust for Carers
- 12.15-13.30 Lunch
- 13.30-14.30 **Latest Drug Treatments & TSC**  
Dr Chris Kingswood / Jane Cox, Tuberous Sclerosis Association
- 14.30-15.30 **Practical solutions to Problematic Problems**  
Dr Petrus de Vries, Consultant in Developmental Neuropsychiatry
- 15.30-16.00 Break
- 16.00-16.45 **Appeals, Cheque Presentations & National Raffle Draw** (Anne Carter)
- 16.45-17.15 **Final Remarks** and close of meeting (President / Chair)
- 17.30 Crèche and clubhouse close



**AGM and Annual Conference Booking Form – 12<sup>th</sup> November 2011**

Hilton Birmingham Bromsgrove, Birmingham Road, Bromsgrove B61 0JB  
Tel: Reservations: 0121 447 7888  
www.hilton.co.uk/birminghambromsgrove

**Please return your booking form by Saturday 22<sup>nd</sup> October.**

**Conference Cost £15.00 per adult, children up to 15 years free.**

Names	Vegetarian <input checked="" type="checkbox"/>	age (if child)	Crèche <input checked="" type="checkbox"/> 0 – 7yrs old	Clubhouse <input checked="" type="checkbox"/> 8yrs upwards
1. ....	<input type="checkbox"/>	.....	<input type="checkbox"/>	<input type="checkbox"/>
2. ....	<input type="checkbox"/>	.....	<input type="checkbox"/>	<input type="checkbox"/>
3. ....	<input type="checkbox"/>	.....	<input type="checkbox"/>	<input type="checkbox"/>
4. ....	<input type="checkbox"/>	.....	<input type="checkbox"/>	<input type="checkbox"/>
5. ....	<input type="checkbox"/>	.....	<input type="checkbox"/>	<input type="checkbox"/>

Address, including postcode: .....

.....

Telephone (please include dialing code): .....

Email address: .....

Any dietary or other requirements? .....

Is this your first time at any TSA Event?	YES / NO
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Please return your **completed form with your payment** (cheques payable to the TSA) by Saturday **22<sup>nd</sup> October** to:  
Chris Johnson, Support Services Co-ordinator  
TSA  
PO Box 8001  
Derby DE1 0YA

Any queries please phone or email Chris on 01332 290734 or [development-support@tuberous-sclerosis.org](mailto:development-support@tuberous-sclerosis.org)

If you wish to book the Crèche/Clubhouse, **please book direct with the Mobile Creche** on 0800 458 0187 or email [julie@mobilecreche.biz](mailto:julie@mobilecreche.biz) who will email you a booking form. The FINAL date for these bookings is also Saturday **22<sup>nd</sup> October**.

If you are staying overnight please book your **accommodation directly with the hotel** on 0121 447 7888 or email [www.hilton.co.uk/birminghambromsgrove](http://www.hilton.co.uk/birminghambromsgrove) as soon as possible because there are a limited number of rooms (ref: 'Tuberous Sclerosis' or GTSAA). This will ensure you will get your reduced rates as quoted in the enclosed letter.