



SLEEP MATTERS

ISSUE NO: 33

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(NB. Queries concerning membership, SATAday etc. should be addressed to the membership secretary (Ms Heather Holt) at the address below and not to the Editor of Sleep Matters).

SATAday

The Sleep Apnoea Trust
Association
Annual Conference and AGM

5th November 2005

**Tingewick Hall, The Academic Centre, John
Radcliffe Hospital,
Headington, Oxford**

**Registration starts at 10 am, and coffee will be served from
10.30 am**

Members please book your tickets as soon as you get your invitation. If you are not a member, please contact Heather Holt on 0845 60 60 685.

***Please do not turn up on the day without a ticket, as we
are always fully booked.***

A small note for those attending SATAday

- Please come prepared with your latest tips for coping with CPAP & Sleep Apnoea. There will be **prize** for the best tip
- If you have problems with **insurance**, because you are a sleep apnoea sufferer, please come prepared to raise them at the meeting

The Sleep Apnoea Trust

Registered charity no 1056963

The Sleep Apnoea Trust exists to improve the lives of sleep apnoea patients, their partners and their families and is managed entirely by unpaid volunteers.

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IS SLEEP APNOEA INHERITED?

Prof J Stradling

Whether there is an inherited component to sleep apnoea is an intriguing question. Reports of families where several individuals were affected appeared many years ago, and research work has been done in this area as a result. Indeed the Oxford Sleep Unit has several father and son CPAP users as well as brother and brother pairs.

The problem of course is separating out an inherited, genetic, component carried in the genes from a common environmental factor – like too much good food! It gets even more complicated given that there are genetic and environmental components to factors such as body weight. We know that body weight, lower facial shape, how breathing is controlled, and perhaps individual differences in the ease with which one can be disturbed from sleep, all determine whether one gets sleep apnoea or not, so there could be many genetic factors involved.

Another area of interest related to inherited tendencies to sleep apnoea relates to cot death, or 'sudden infant death syndrome' (SIDS) as it is now often called. Again there are reports in the literature of SIDS victims in families where one of the parents has sleep apnoea: but

does this occur more often than by chance alone?

There are several ways to investigate if genes matter in OSA. First there are family studies looking for a pattern that would suggest inheritance, and then seeing if particular genetic markers 'travel with' the sleep apnoea. Studies of twins are particularly powerful for this approach. You do not have to know what the gene might do to cause sleep apnoea, and if so-called 'linkage' is found then a hunt for what the gene might do has to follow. Alternatively you can select a known gene that might be related to sleep apnoea and see if it is more common in people with sleep apnoea. However this requires the researchers to guess what genes might be involved and if they do not think of the right one, the research is doomed to failure.

So, what does the evidence actually suggest? Some years ago, Neil Douglas's group in Edinburgh looked for undiagnosed sleep apnoea in family members of patients with known sleep apnoea to see if it was more common than in a matched control group. They found that it was, and that there tended to be a slightly more set back lower jaw in these families. This suggested that the inherited component might be the size and shape of the lower jaw – facial shape is known to have inherited components (remember the Hapsburg chin from your school days?). They then

went on to study whether this might also relate to the occurrence of cot deaths. They did not find a higher level of undiagnosed sleep apnoea in parents of SIDS children compared to controls, although there were some minor differences in overnight oxygen levels of questionable significance, so at the moment there is no good evidence of a link to SIDS here.

Susan Redline's group in the US have taken the blunderbuss approach and looked for any possible linkage between any part of the genetic code and sleep apnoea. Her results were controversial, but there was an area on the gene that 'travelled' with sleep apnoea. However the association was very poor by modern genetic standards and there was no suggestion as to what this area of the gene might be coding for in the body.

More recent, larger, family studies have tried to look for family trends in sleep apnoea. For example, Adrian Williams in London looked at 1,937 pairs of twins to see if sleep apnoea was more common between monozygotic twins (i.e. came from the same egg so genetically identical) compared to dizygotic twins (i.e. came from different eggs and therefore only half their genes in common, as with brothers and sisters). Using complex mathematics they estimated that about half the sleep apnoea risk was due to inheritance and half due to environ-

mental factors. Donald Bliwise in the US did a similar study in 122 older twin pairs and came up with a lower percentage for inheritability of about 35%.

So, in conclusion, what does the world of sleep apnoea think about the inheritability of sleep apnoea? Most believe that there is clearly an inherited component and this accords with our clinical experience of many families with more than one member affected. It may be that lower facial shape is the key factor, i.e. a relatively undersized or set back lower jaw that reduces the air space behind the tongue. Are there other factors, might a tendency to put on weight in the neck, rather than elsewhere, be important? At a simple practical level, if one family member has sleep apnoea then there should be a raised awareness of the possibility that someone else in the family might have it too. Many of our patients do in fact get recognised for exactly this reason – "my brother was diagnosed with sleep apnoea last year and I began to realise I had exactly the same symptoms".

OUR LETTER CAMPAIGN A Success Story

Thanks to all of you who wrote to your Member of Parliament and to NICE, following the appeal last month.

The text of the reply from NICE, which is printed

next to this column, shows that we are definitely making our point to the Government Authorities who will take a decision in the Autumn, on whether CPAP treatment should be referred to NICE for a technology appraisal.

A successful appraisal would make it compulsory for health authorities to provide adequate treatment for Sleep Apnoea in their area. I have also seen lots of letters from MPs who are putting pressure on the Department of Health to make a referral.

Well done! We now have to wait with baited breath until a decision is made sometime in the Autumn.


Frank Govan

**Merchandise Stall
- SATADay 2005.
Heather Holt**

We have a new range of Christmas cards this year and will be selling off the 'older' stock at greatly reduced prices. (We have especially large numbers of the 'Tree of Peace' cards). Order now - we can do very good deals on bulk orders. If you send out cards as part of your business (or just have a lot of friends) this could be the opportunity for you.

I have lots of new goodies to tempt you with at SATADay this year so please remember to bring your cheque books/cash.

I have had to recruit new helpers for the stall this



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6 September 2005

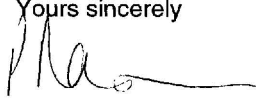
Dear Mr Govern

I have received a large number of letters, many, I believe, from members of your organisation, telling me of their experiences of using Continuous Positive Airway Pressure (CPAP) devices to manage their sleep apnoea, or of their desire to receive treatment. My understanding (although, if this is not the case, please let me know) is that these letters are part of a campaign coordinated by the Sleep Apnoea Trust to persuade NICE to look at this treatment.

Topics are referred to NICE by the Secretary of State for Health, in line with the national priorities established for the NHS. Once a topic has been referred, the development of the subsequent advice is entirely the responsibility of NICE. In this case, and as we have stated in our replies to your members, NICE and the Department of Health are currently considering, as part of the topic selection process, whether we should evaluate CPAP and issue guidance on it. We anticipate a decision in the Autumn, following which, if we are asked to consider it, an announcement will be made in the form of a press release from the Department of Health.

You might wish to circulate this information to your members.

Yours sincerely



Andrew Dillon
Chief Executive

year as my partner in crime Brian has gone off to be Chairman!

Please feel free to contact me either via email sata.admin@tiscali.co.uk or on 0845 606 0685. Looking forward to meeting up with you all at the conference.

OSA and travel

The article on OSA and travel in the last issue of Sleep Matters generated a large number of queries.

As a result of this - and of the large numbers of requests for information helpful to the traveller received by clinics and the help line volunteers - SATA is working on a booklet about travel and OSA .

Please contact us with any information or anecdotes that you may have encountered and solutions that you have found whilst travelling as an OSA sufferer. These

will be most gratefully received and will help to ensure that we produce a publication that truly meets your needs.

The best route of contact is by email to drtimhealing@hotmail.com or by phone, fax or letter to:

Dr Tim Healing, 8 St Mary's Road, Oxford, OX4 1PX. Tel/Fax: 01865 723961

(P.S. Don't expect a quick reply - I'm travelling!)

The Sleep Apnoea Trust Association

The Committee

Role	Name	Tel no.
Chairman	Frank Govan	01494 439719
Vice Chair- man	Brian Spires	01628 522116
Secretary	Denise Roberts	01865 225236
Treasurer	Wilma Govan	01494 439719
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Membership Secretary	Heather Holt	0845 6060685
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	Luke Wright	01865 343710
	Bill Johnston	01844 290060
	Terry Gasking	01296 748412
	Ian Richens	01451 870044
	Paul Jackson	01280 841338
Knud Rogilds Website supervisor		

The following Local Support Groups are affiliated to the Sleep Apnoea Trust.

Bristol Sleep Unit Patients Association	01934 862502
Humber Sleep Apnoea Support Group (email: sleep@hull24.com)	07957 618855
Plymouth Sleep Apnoea Support Group	01752 763865
SEESAW-(Southend)	01702 292507
SESAME (Bexhill,E.Sussex)	01424 845874
Welsh Sleep Apnoea Society www.welshsas.org	01633 774087

Help-lines (It helps to talk)

If you are worried about Sleep Apnoea, having difficulty in coming to grips with CPAP treatment, or just need a bit of practical advice, ring one of our helplines. It does not matter whether you are a member of the Trust or not.

You will get friendly and confidential advice. Each volunteer has a file of useful information and a wealth of personal experience. We do not provide medical advice. If you suspect that you may be suffering from Sleep Apnoea please consult your own GP, who will be able to refer you to a specialist sleep clinic.

The Help Line Volunteers

Area	Name	Tel no.
Bucks	Robert Horne	01908 643689
	Richard Yates	01494 863294
Cheshire/ Greater Man- chester	Frank Bennett** Edna Bennett*	0161 882 9058
Devon	Eileen Pearson	01803 834150
East Sussex	David Stephens	01424 845874
Lancashire	Peter Silvester	01524 771415
London	Thomas Pendred	0207 837 0327
London	Claire Mitchell*	0208 992 9920
Northants	Aileen Keith	01536 269375
Oxon	Barry Davies	01295 780291
	Sheelin de Freyne*	01235 847231
	Bill Ferriday	01865 880100
	Elsbeth Ferriday*	01865 880100
	Michael Storm	01869 243724
	Pat Watson*	01491 832089
	Simon Watson	01491 832089
Luke Wright	01865 343710	
Somerset	John Patrick	01225 317786
Surrey	Ken Pullen	0208 7158119
Wales	Hugh Roberts	01639 892977
W Midlands	Barry Pettitt	01675 463712
	Colin Short	0121 742 6256
Wilts	Tim Webber	01985 217113
Worcs	Phil Lawrence**	01527 459621

* Partners ** Nocturnal hypoventilation