ARTP SLEEP

S-News

Dreaming of a better night's sleep

Volume 3, Issue 1 Spring 2012

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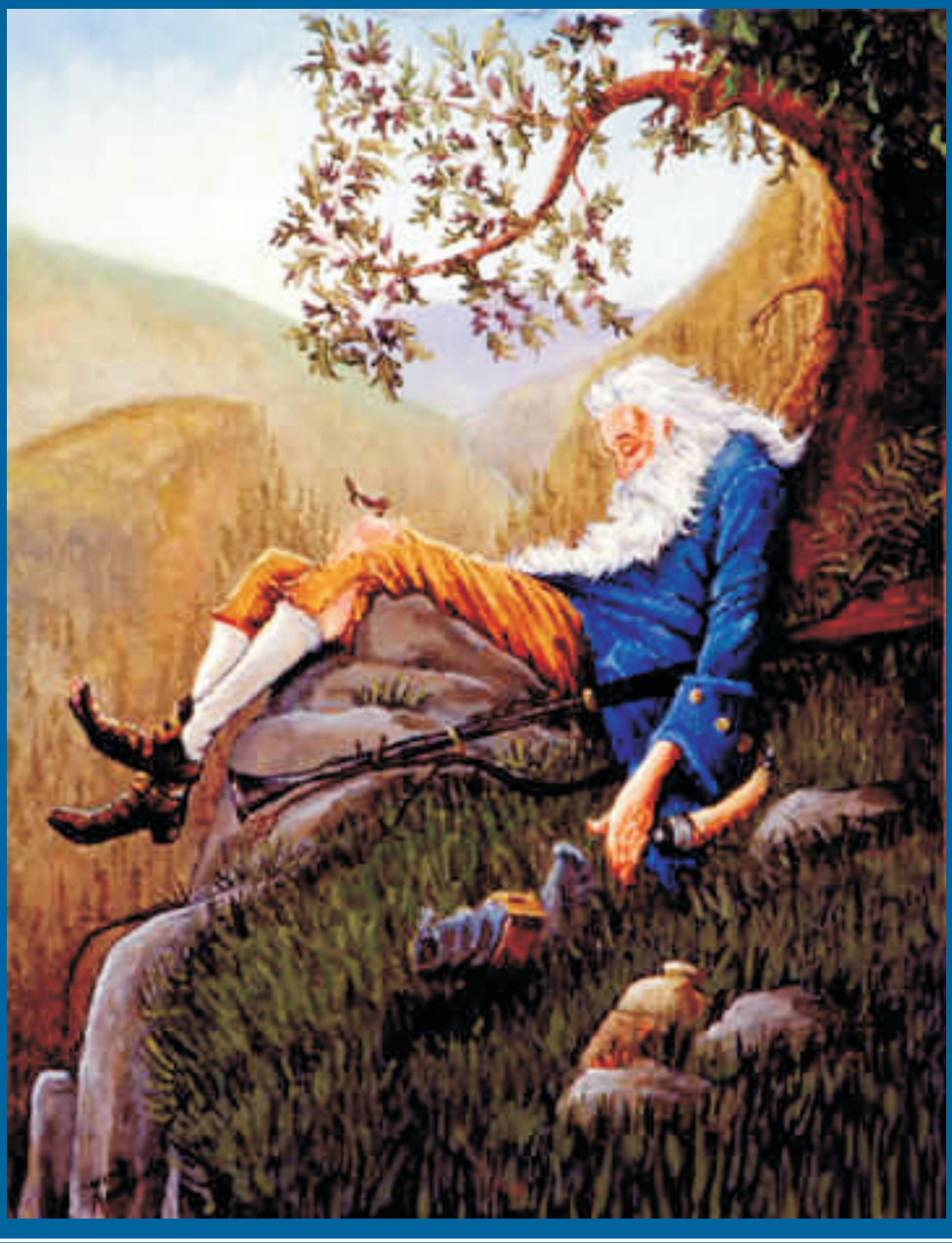

ARTP SLEEP is a subsidiary of the Association for Respiratory Technology and Physiology

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Resmed

Welcome

Welcome to the latest edition of S-news. Exciting times are afoot with Jubilee celebrations and the London Olympics making many manufactures quick to highlight their products as British with the Union Jack prominent on packaging. A number of CPAP mask manufacturers have now brought out "female" ranges in very "feminine" pink and lilac colours and it is almost surprising that they haven't jumped on the Union Jack band wagon in order to increase UK sales. Whilst I'm all for improving sizing to be more fitting to feminine or masculine face and head shapes I'm not convinced that a pink rather than blue or black headgear is going to improve patient compliance. After all this is something they wear in bed not out to parties.

In this edition you can read the first of hopefully a series of articles of some of the less well known sleep disorders. In this case Kleine Levin Syndrome, a disorder of exessive sleep which also renders sufferers to exhibit toddler-like tantrums, over eating and even excessive sexual behaviour. This was really interesting to research and writing an article for S-News is a great way to learn something new (hint, hint). We also have updates from ERS and from the BLF OSA awareness campaign. Enjoy the issue.

Sleep People - Joy Crosby
Staff nurse-Sleep & Ventilation Unit, Oxford

My name is Joy Crosby and I am a Staff Nurse on the Sleep and Ventilation Unit in Oxford, a post which I will be leaving at the end of June after 25 years!

I thought this would be an ideal time to record my time in the job.

I originally started back in 1984 working for John Stradling as a Research Nurse along with 2 research registrars, a very small team which has grown over the years to a much larger team running a clinical unit, with over 7500 patients on CPAP and 350 on non-invasive ventilation, and a research unit.

I had no experience of what Obstructive Sleep Apnoea was, and John tells me the only reason I got the job in the first place was because our birthdays are on the same date! I undertook my nurse training in Oxford in 1979, and after qualifying, worked in neurology. The advert for the job sounded very interesting. It was very much learning on the job, and the main project I worked on was an epidemiological study looking at the incidence of OSA in the male population. I visited 900 men between the ages of 35 and 65 in their homes over a 4 year period, no mean feat I can tell you! It was a slightly tricky beginning, with my first subject refusing to take part in the study when I arrived at his house having arranged the visit by phone! But generally after that, the people who volunteered to be part of the study were very helpful and interesting!

After taking maternity leave, I worked on other research projects involving OSA and blood pressure, and then actually managed to leave the sleep unit for a couple of years after having my second child! But the lure of sleep medicine was too strong, and I returned in 1995 on a part-time basis to work on more research projects!

In 2002, I moved to the clinical side of the unit, and became part of the nursing team setting up patients on CPAP and running clinics. Gradually I

Dates for your Diary

APSS Sleep 2012
9-13 June 2012
Boston, USA

ERS
1-5 September 2012
Vienna Austria

21st Congress of the European Sleep Research Society
4-8 September 2012
Paris, France

International Sleep Medicine Course
23-27 September 2012

"Sleeping Beauty syndrome"

became involved in setting up patients on NIV as well, and my hours of work gradually crept up as my children got older and became more independent. Over the years the unit has become larger and much busier, and my experience has grown and grown.

And now I find myself, moving to pastures new down in Devon and leaving behind all those years and all the wonderful colleagues I have worked with for a whole new life.

Kleine-Levin Syndrome

by Vicky Cooper

Kleine-Levin syndrome, otherwise known as sleeping beauty disorder is a rare neurological condition which is characterised by recurrent episodes of hypersomnia and various degrees of behaviour and cognitive disturbances, such as child like tantrums, compulsive eating behaviour, hypersexuality in males, depressive mood, lethargy and apathy. The condition predominantly affects males in their second decade, but can affect either gender and in a literature review of 186 cases[1] subjects were aged between 4 and 82 years, with an average age of 23 years.

The recurrent episodes can last from 2.5 to 80 days at a time (mean 12±9 days), with periods of 0.5 to 72 months (mean 6±10 months) in between. In between episodes subjects can be perfectly healthy, with no behavioural or cognitive dysfunction. The symptoms can the reappear with very little warning. The condition is considered "cured" if subjects have gone more than 6 years between episodes. The duration of the condition has been reported from 0.5 to 41 years (median 8 years), with episodes tending to decrease in frequency, duration and intensity (less pronounced hypersomnia) prior to termination of the condition[1].

The cause of Kleine-Levin syndrome is not known. Some researchers believe there may be a hereditary predisposition, whilst others believe it may be the result of an auto-immune disorder[2]. There have also been reports of it being triggered by upper respiratory tract infections[3] with many reports of flu-like symptoms preceding an episode.

The diagnosis of Kleine-Levin syndrome is difficult and is a diagnosis of exclusion. All diagnostic test results on KLS patients to date, including brain imagery, EEG, serum virus titres, and CSF examination, have been normal[2]. A long list of other conditions which can mimic the symptoms need to be excluded. For example, for the symptom of hypersomnia, sleep disorders and endocrinology disorders such as diabetes and hypothyroidism need to be ruled out. The somnolence and hyperphagia mimic severe depression. There can also be a high energy level manic episode leading patients to be misdiagnosed with bipolar disorder. Other conditions such as Multiple Sclerosis also need to be excluded.

Hypersomnolence is the key symptom to this disorder and is mandatory for the diagnosis. Sleep duration has been reported from 12 to 24 hours a day (mean 18±2 hours)[1]. The urge to sleep is so overwhelming that there are reports of cases of people sleeping under porches, teenagers leaving the classroom and lying down to sleep in the corridor and others found asleep on the pavement[1]. Some can lose days or even months, having no recollection of the episode[4]. After the hypersomnolence there may be rebound insomnia. There have been no reported cases of cataplexy or sleep paralysis.

The **Sleep Apnoea Trust** have changed their address and phone number:

PO box 60
Chinnon
OX39 4XE

Tel: 0845 0380060

For further information Click Here

Treatment of this disorder tends to focus on treating the hypersomnolence and there has been some success with amphetamines and Modafinil[1]. Due to its similarities to Bipolar disorder Lithium has also been used to treat Kleine-Levin syndrome.

Living with Kleine-Levin syndrome may be difficult. A large number of patients report depression during one or more episodes. The effects of excessive sleeping, eating and possibly sexual behavior can be very debilitating. During episodes it is impossible to go to work or school, making it difficult to maintain a normal job or education, and in some cases criminal charges have resulted from unrestrained sexual behavior. Periodic binges associated with the episode can lead to weight gain, and Kleine-Levin syndrome patients often exhibit an above-average BMI. However, the literature does not report obesity as a sign. There may also be a psychosocial stigma due to the unusual activities during an episode which are not understood by others. Many patients report embarrassing episodes before Kleine-Levin syndrome was diagnosed.

The effects of excessive sleeping, eating and possibly sexual behaviour can be very debilitating.

In many cases, the disorder disappears as mysteriously as it appears; often when patients reach their twenties. Of the patients that have been studied, more than 90% will outgrow Kleine-Levin syndrome symptoms and even those who have some degree of it left after ten years, it is usually much, much milder[6].

References:

1. **Arnulf** I, Zeitzer JM, File J, Farber N, Mignot E. (2005) **Kleine-Levin syndrome: a systematic review of 186 cases in the literature**. *Brain* **128(Pt 12):**2763-76.

2. **Kleine-Levin syndrome - Center for Narcolepsy - Stanford University School of Medicine**

3. Huang YS, Guilleminault C, Lin KL, Hwang FM, Liu FY, Kung YP. (2012) **Relationship between Kleine-Levin syndrome and upper respiratory infection in Taiwan**. *Sleep* **35(1):**123-9.

4. **BBC Article The teenager who sleeps for 10 days. 8 December 2010**

5. F. Muratori, N. Bertini, G. Masi. (2002) Efficacy of lithium treatment in Kleine-Levin syndrome. *Eur Psychiatry* ***17*****(4):** 232-233.

6. **Kleine-Levin syndrome - Wikipedia**

ERS News

Brendan Cooper

ERS / ESRS Joint Meeting Berlin

The second international conference organised by the European Respiratory Society (ERS) and the European Sleep Research Society (ESRS)

11-13 APRIL 2013 BERLIN

The Sleep and Breathing conference is the largest pan-European meeting of its type and the only meeting offering an integrated approach to the investigation and treatment of sleep disorders. This will be the second Sleep and Breathing conference after the successful inaugural meeting in Prague. The conference is aimed at all medical professionals with an interest in respiratory sleep disorders and other related dyssomnias.

In Berlin 2013, the focus remains predominantly on sleep breathing disorders but the programme will extend to cover sleep-related areas of paediatrics,

ERS congress, Vienna 1-5 September

ARTP bursaries available

obesity, cardiovascular disorders, diabetes, psychology, psychiatry and neurology. ARTP SLEEP plans to offer 2 £1000 bursaries for this conference – details to be sent out soon!

ERS Product of Outstanding Interest 2012

This year at the ERS Congress in Vienna, 1st - 5th September 2012, there will be a session on innovation around the most promising new device in the clinical arena as nominated by each Assembly within ERS. This is based on an idea by ARTP for Manufacturer of the year, but is meant to highlight new innovation rather than excellent service. It is likely that several sleep related devices will be mentioned in the session with a winner being announced at the conference.

Of course the ERS Congress is full of great sessions on Sleep with a leaning towards sleep disordered breathing, and ARTP is likely to offer bursaries for this conference as well. Keep an eye out on the website!

ERS Sleep Task Force

Finally, the ERS Sleep Apnoea task Force is working with sleep organisations throughout Europe to develop a harmonised training in sleep medicine for physicians, nurses, technologists and healthcare scientists so we can train our sleep staff to an international standard. ARTP SLEEP are fully supportive of this initiative and Dr Brendan Cooper has been invited to be a member of the task Force. As head of ERS Assembly 9 (Allied Respiratory Professionals) he as pushed for specific modules that "non-doctors" can take to gain qualifications in sleep medicine.

Sleep in the News

43 % of 500 members of the British Airline Pilots Association admitted to having fallen asleep in the cockpit.

Apparently it is a myth that we should sleep in one 8 hour stretch. Up until the late 17th century there are many references to the first and second sleep, whereby a first sleep began about two hours after dusk, followed by a waking period of one to two hours and then a second sleep. References to these two sleeps started to disappear during the late 17th century around the same time as the introduction of street lighting. Prior to this time the night was a place populated by people of disrepute, criminals, prostitutes and drunks. However, socialising during the night became more common place (following the reformation) and the trend towards consolidating sleep into one block became the norm. The night became fashionable and lying in bed was considered a waste of time.

Something to consider when planning your next holiday or business trip abroad. A survey of 500 members of the British Airline Pilots Association found that 43% of them admitted they had fallen asleep in the cockpit.

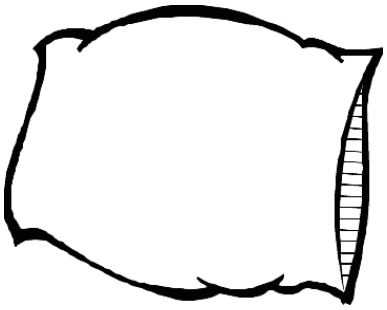
Shift workers who get too little sleep at the wrong time of day are at risk of type 2 diabetes and obesity according to researchers. An experimental study which controlled bedtimes and meal times of 21 healthy subject found that changes to normal sleep patterns caused disruption to blood sugar control. Some participants even showed early signs of diabetes within weeks of the trial. Part of the study involved extending the day to 28 hours simulating a full-time flyer that is constantly jet lagged. Blood sugars were higher after meals and also during fasting times.

Insulin levels were also found to be lower.

Just to prove that motorway signs can be right, a lorry driver was fined for dozing at the wheel and driving into the "Tiredness Can Kill- Take a Break" sign in Dumfries and Galloway.

Pillow Talk

manufacturer's news, new equipment and a bit of gossip!



Philips Respironics is pleased to introduce our new Account Manager for the North West region, Wendy Snelling. Wendy has worked either in or with the NHS for 27 years, most of that time nursing in a variety of clinical settings. Wendy has a passion for chronic disease management and has had the opportunity to develop respiratory and diabetes services during her time as a primary care nurse. The latter part of Wendy's nursing career was spent as a diabetes nurse specialist, where she first developed an interest in sleep apnoea. The NHS has undergone many changes over the years, working in the commercial environment has enabled Wendy to support clinicians to meet these changes in a variety of ways. Improving patient care and health outcomes continues to be her motivator . There are more changes, and certainly challenges ahead for the NHS, but Wendy is keen to look more innovatively at how some of these challenges can be overcome. For now she is settling in well, getting to know everyone in her area and already making a difference.

Philips Respironics announce the launch of TrueBlue – the first blue gel nasal mask with Auto Seal technology."TrueBlue brings together our best technologies in one mask. Designed to push the limits of performance and fit, this mask sets the gold standard for a good night's sleep. The TrueBlue gel nasal mask with Auto Seal is designed to deliver a higher degree of comfort, stability, and freedom of movement with minimal adjustments. This intuitive gel mask is designed for quicker set-ups and fittings, fewer callbacks, and easier lab titrations. With TrueBlue, you can deliver a more complete sleep solution. Why settle for anything less?"

It is with regret that ResMed announce the departure of Stuart Whiteley effective 16th March. "Stuart joined us 13 months ago and quickly introduced himself to his customers as an outgoing, helpful and willing territory manager. Stuart is going to take some time out to travel through SE Asia and then, after driving through Oz, will land up in Sydney to resettle in his native Australia sometime around August. His Mum might be delighted, but it is our loss!"

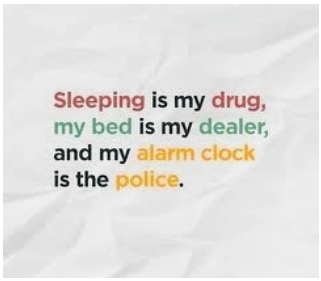
"Replacing Stuart I am pleased to announce the appointment of John Mitchell who joins us on 10th April. John has 20 years sales experience in the building, veterinary and healthcare industries and comes to us after 12 months with Great Nordic Otometrics, selling audiology and balance medical devices into the NHS and private health care sector and, before that with Bard (Verathon Medical) for five years selling ultrasound and video laryngoscopy products, where he has enjoyed much success.

John also served in the Royal Navy, notably HMS Ark Royal, serving in the first Gulf war and finding time along the way to raise funds for Help for Heroes and other related charities.

Respironics welcome Wendy Snelling and ResMed welcome John Mitchell into the fold

Sleep Facts:

The record for the longest period without sleep is 18 days, 21 hours, 40 minutes during a rocking chair marathon. The record holder reported hallucinations, paranoia, blurred vision, slurred speech and memory and concentration lapses.



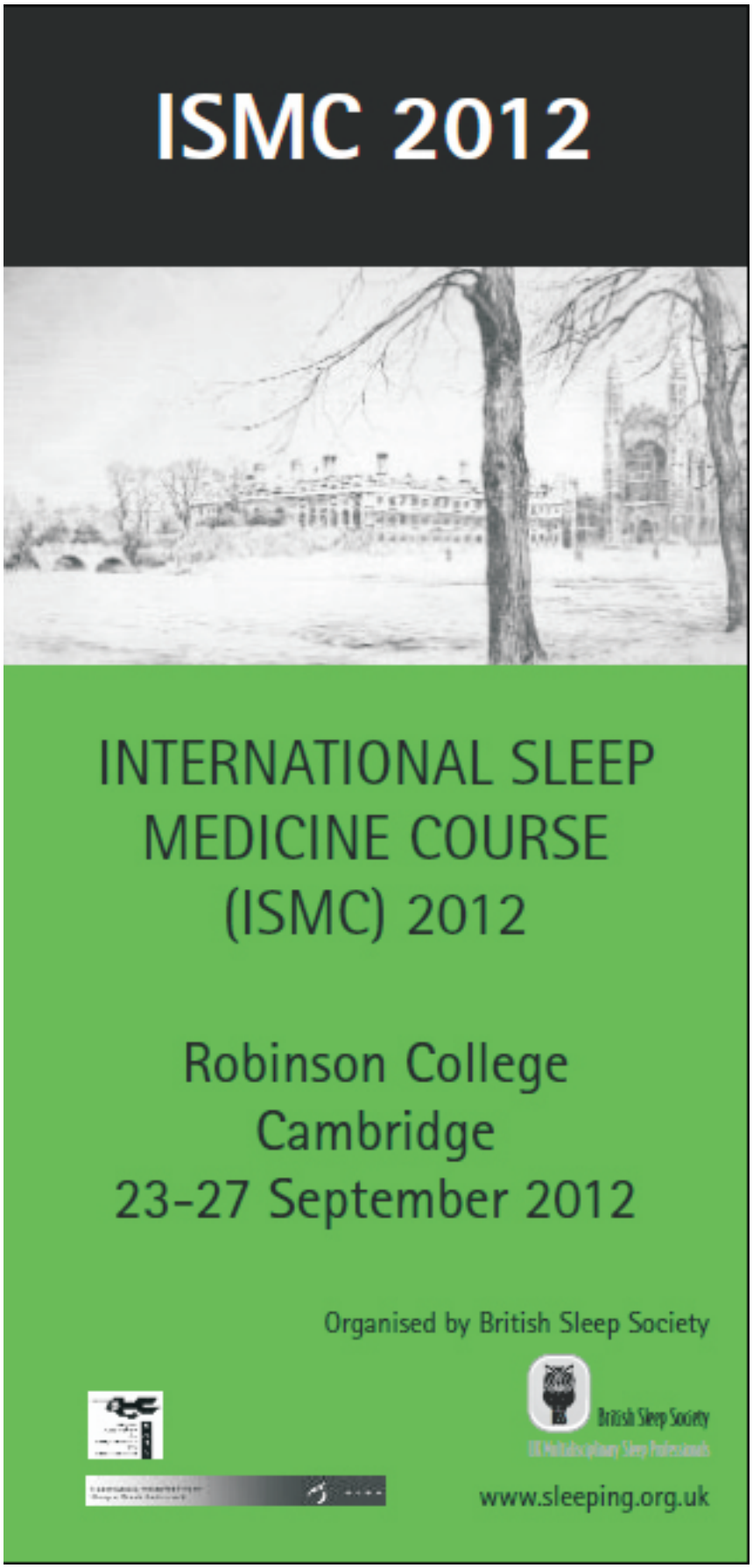
John will inherit Stuart's telephone number and will be contactable with effect 10th April. Please join me in wishing Stuart and John every success."

ARTP Sleep Track at the annual conference

This year's sleep track started with a question and answer workshop on mask issues. This generated interesting discussion and also highlighted some of the widely varying practices between different trusts. This was followed by a session on managing the non-OSA excessively sleepy patient. Firstly Dr Ian Smith of Papworth Hospital, Cambridge gave us an insight on diagnosing and managing idiopathic hypersomnolence and how this compares to narcolepsy. We then heard from Dr Manny Bagary, consultant Neuropsychiatrist in Birmingham about diagnosing and managing depression in the context of a sleep clinic. In the afternoon Professor Mary Morrell of Imperial College, London, spoke about managing OSAHS in the elderly. We learned that we should not apply the same criteria for diagnosing and managing elderly patients as we do for younger patients with OSAHS.

This years Sleep manufacturer's award went to ResMed UK, scoring 75.3 out of 85.

Upcoming International Sleep Courses



For further information visit the BSS website

The 2nd Sleep and Breathing Conference 11-13 April 2013 Intercontinental Hotel, Berlin, Germany

"The Sleep and Breathing conference is the largest pan-European meeting of its type and the only meeting offering an integrated approach to the investigation and treatment of sleep disorders. Register for the second Sleep and Breathing conference and join thousands of other medical professionals with an interest in respiratory sleep disorders and other related dyssomnias. In Berlin 2013, the focus remains predominantly on sleep breathing disorders but our programme will extend to cover sleep-related areas of paediatrics, obesity, cardiovascular disorders, diabetes, psychology, psychiatry and neurology."

For further information visit http://www.sleepandbreathing.org/

BLF OSA Awareness Campaign Update

Here is an update of the progress we've made in achieving each of the project's four overarching goals since our last newsletter in November 2011, as well as the project's priorities as it enters its second year.
For all the details visit our project update page on the BLF website here .

Progress towards four main goals since November

1. Promote OSA as a strategic priority for the BLF and Department of Health

- The Project Manager continued to visit sleep clinics and hold key meetings with sleep medicine professionals. This will be crucial in influencing change at the Department of Health.
- Ten BLF reports have been created, which will shape the BLF's OSA charter and campaigning priorities.

2. Help increase awareness of OSA among the public and professionals

Public:

- A major success in this period was coverage on *BBC Breakfast News*. This led to more than 20,000 hits on the OSA pages of the BLF website within a few days.
- The *Daily Telegraph* uploaded our video showing a man having an apnoea on their website, and it received 22,000 plays in a week. Other media successes included a Radio 5 live interview with a patient, an article in *Women's Fitness* magazine and an article in the Association of Respiratory Nurse Specialists' newsletter.

Professionals:

- The new *'top tips for GPs'* web page was sent to all members of the Primary Care Respiratory Society by the Department of Health.
- We have now reached more than 2,000 health care professionals through a number of different activities.

3. Help find undiagnosed people

- The NHS Choices website now has a link to the BLF's OSA pages from its OSA section.
- More than 20,000 people have completed the Epworth Sleepiness Scale on the BLF website.

4. Help improve OSA services

- Interviews with more than 20 health care professionals and 30 patients have been collated and will inform year two priorities and the OSA charter.
- The BLF in Northern Ireland has jointly planned and run a pilot OSA support group for diagnosed patients.
- The BLF has supported the developement of standards for sleep services in Scotland and Northern Ireland.

Activities planned for the next three months

- The BLF OSA charter will be launched. This will be a key part of our campaign and we want to ensure it has optimum impact to help improve awareness, find undiagnosed people and improve services.
- The new BLF health information leaflet on OSA will be printed after consultation with patients and health care professionals.

Priorities for year two (February 2012 to January 2013)

- Development of a BLF OSA patient information pack, which will be available to sleep clinics to give out to patients.

BLF Helpline - 08458 50 50 20
Confidential advice and support for anyone affected by lung disease.
Helpline open Monday to Friday, 10am to 6pm. Calls charged at local rate.

New OSA leaflet available

- Reporting on the mapping of current services, including identifying areas where there are gaps in provision.
- Launch of awareness campaigns in targeted areas.
- The OSA patient survey will question a large number of people with OSA about their condition and the services they have received.

BLF research grants

Please see our website if you are interested in applying for a research grant.

BLF membership

If you are new to working in partnership with the BLF, we would like to encourage you to become a member - have a look at our membership page for more information.

Judy Harris
OSA Project Manager
Judy.harris@blf-uk.org

Would you like to feature as next month's sleep person, or would you like to publish a short article?

Please submit all articles to s-news@artp.org.uk

Printed in the United Kingdom