



# NEWSLETTER

## "Amazing" new website is now on-line

S.A.S.A.'s brand new website is now on-line, and chairman Mike Wilson has hailed this exciting development as "amazing."

The Committee approved the setting up of a new website last year, and a project team ~ comprising Lesley Bagnall, Tom Irvine, Murray Phillips, Christina France and Mark Lincoln ~ was formed on October 30.

After much research, the team identified a cost of £1,000 upwards to set up the site using professional designers. At the same time, they found plenty of evidence that there was modern, low-cost software available that would provide a fully functioning website for a charity such as ours.

As a way of moving the project forward it was proposed at a meeting on January 10 that the sub-committee invest in a low-cost website that could be up and running very quickly, while also pursuing a fully functional higher-cost option over a longer period of time.

This strategy was approved by the full committee, and Lesley Bagnall approached Kathy Curran, a recent recruit to the ranks of S.A.S.A., who had been experimenting with a trial site. Kathy was happy to press on with what she had started, even although she had never attempted such an undertaking. However, with help from her son Rick and members of the project team, she started work in earnest on the do-it-yourself site.

As a result of Kathy's sterling efforts, combined with guidance resulting from continuous meetings (mostly using Skype) of the site sub-committee, the website is now fully functional.

Just over four months have elapsed since the formation of the site sub-committee, so it is no surprise the outcome has been described by S.A.S.A. chairman Mike Wilson as "amazing". He commented, "What a remarkable find Kathy Curran is ~ and she is a new member, too! Kathy and the team have put together a site that fits the bill so well, and in such a short time.

"The changes I have wanted to see for so long are happening right here and now. Congratulations to all involved, and a big thank-you to all."

The new site's easy-to-read and well-laid-out pages are full of extremely useful information. Anyone who has Sleep Apnoea will find up-to-date hints on how to deal with problems such as those relating to face masks and machines. In addition, the pages highlight news of the latest developments in technology designed to make coping with C.P.A.P. therapy easier to live with.

To view the fruits of the team's efforts log on to: [www.scottishsleepapnoea.co.uk](http://www.scottishsleepapnoea.co.uk)

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## CHANGES OPEN THE WAY TO A BETTER SERVICE, SAYS CHAIRMAN

THE CHAIRMAN, Mike Wilson, reported at S.A.S.A.'s Annual General Meeting, held at West Park Conference Centre, Dundee, on 21st September, 2013, on his first full year in charge. In his opening remarks, he said he had seen a change in the committee both in numbers (e.g. local representatives) and in attitudes.

There was a more upbeat mood amongst committee members in attempting to achieve S.A.S.A.'s aims and he was hopeful this progressive attitude could be maintained and the members would see an improvement in the service being offered.

The Chairman emphasised that communications play a key part in the organisation's efficiency and pointed out it would be beneficial if those with internet access ensured the committee had an up-to date list of email addresses by contacting the membership secretary.

He also said there was a need to submit items to the Newsletter Editor. Without input there could be very little output.

Commenting further on information, the Chairman reported that, due to closer contacts being developed with S.A.T.A., (Sleep Apnoea Trust Association), our equivalent organisation in England, S.A.S.A. had been given access to publications and information which was proving very useful.

In introducing new members of the committee who also act as Local Area Representatives, the Chairman noted that Lesley Bagnall, the Tayside and Dundee representative, had been extremely active, holding local meetings, awareness days in hospitals and had been the association's main link with S.A.T.A.

The Chairman was also pleased to report that local representatives had been able to reconnect S.A.S.A. with local N.H.S. Sleep Centres and an exchange of information was being developed. The committee would welcome assistance from members in this exchange.

The meeting was also told that the British Lung Foundation had been running a project for the past two years raising the awareness of sleep apnoea. They had been very proactive in engaging with Sleep Centres and politicians north and south of the Border. They had produced a lot of literature on the subject, much of which was on their website – <http://www.blf.org.uk/Region/Scotland>

Turning to levels of S.A.S.A. membership, the Chairman said numbers have been in decline for too long. Efforts would be made to encourage members to make contact with other sufferers to promote the association and thus increase the membership.

Having stressed that one of S.A.S.A.'s core objectives was to promote further research into diagnosis and treatment of Sleep Apnoea, the Chairman stressed that he was conscious of money held by the association which he felt should be invested in suitable areas.

In concluding his report, the Chairman thanked the Committee "Team" who had helped make a greater impact over the past 12 months.



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## **DON'T SUFFER IN SILENCE!**

If you feel you are not reaping the benefits of CPAP/ BiPAP, and are having the recommended 7-9 hours sleep of course, don't keep on suffering in silence! There can be many reasons for still feeling tired, such as diabetes, underactive thyroid, anaemia, anxiety/depression, coeliacs disease etc. so it's worth having some blood tests done.

Many GP's insist on yearly checks for diabetes and hypothyroidism due to the big link with sleep apnoea. You need to know that your CPAP therapy is working for you if you're still struggling. In addition, pressures sometimes need altering due things like weight gain/loss and hormone changes.

There are also lots of medications that can make sleep apnoea worse ~ see [www.diseasesandconditions.net/sleep\\_disorders.html](http://www.diseasesandconditions.net/sleep_disorders.html) Some sleep apnoea sufferers who struggled with CPAP therapy have had to change sleep clinics to get the treatment they desperately needed.

It is also on record that a patient who was struggling with their CPAP therapy had their machine taken off them.

Fortunately they sought a second opinion and they are now on very successful therapy with another clinic.

The bottom line is: if your treatment isn't working for you don't feel helpless and don't give up! insist you have your treatment reviewed. And if that doesn't work, be prepared to change your medical advisers. It can be done!



## Treading a finer line on “The Patient Pathway”

Having attended the British Sleep Society Anniversary Meeting in Edinburgh, SASA were invited by Judy Harris, OSA Project Manager at British Lung Foundation, to attend the Foundations OSA conference in Blackpool at the Hilton Hotel on Saturday 1st February 2014. Ray Walker and Lesley Bagnall took up the offer to attend.

The main topic of the Conference was looking at a number of ways in which ‘The Patient Pathway’ was being dealt with in different areas of the country. Clinicians from a wide area were in attendance including Scotland.

The first speaker was Professor John Stradling, Professor of Respiratory Medicine, Oxford University, who has strong links with SATA.

He talked about the need to improve / increase the involvement of GP’s particularly concerning the screening for OSA. A simplified method has been trialled using what is referred to as OSA – 50:

O – Waist size      S – Snoring      A – Stops Breathing  
50 – patients over 50

With training it should be possible for Sleep Studies to be carried out in Primary Care facilities or even by Community Pharmacists. This would also improve monitoring after a patient has been diagnosed with OSA.

The next speaker was Maxine Hardinge, Consultant at Oxford University Hospital.

One of the reasons why patients have difficulty with CPAP treatment is the length of time taken at Sleep Clinics in explaining to the patients what is involved.

It was suggested that the introduction of what was called a ‘One Stop Shop’ be introduced whereby patients would have the opportunity to absorb the information more clearly. This could be operated by adequately trained non medical personnel and possibly eliminate false diagnosis.

Next speaker was John O’Reilly, Consultant in sleep and respiratory medicine – University Hospital Aintree. His topic was mainly targeted at the medical professionals and dealt with how they should go about developing Business Cases to improve and further develop Sleep Clinics.

Those of us who were diagnosed at the old Edinburgh Royal Infirmary would have been aware of the struggle Professor Sir Neil Douglas had in maintaining the Sleep Clinic in Edinburgh. The move to the new facility assisted in them being able to set up the Department for Sleep Medicine as it now stands.

Business Cases do not guarantee success often it is down to luck, similar to the Edinburgh situation.

The next topic was about the management of OSA and why ongoing support is important. Ray and Lesley think this is a topic many members of SASA would acknowledge. There were a number of speakers who addressed this.

This is an area that is being investigated within Scotland to possibly tag on to a service being offered to home users of Oxygen supplies.

## Event of the Year

PLEASE PUT THIS DATE IN  
YOUR DIARY:

**Stirling**  
**Saturday 20th Sept. 2014**  
**9.30am-4.00pm**  
**SASA Conference & AGM**

The Golden Lion Hotel,  
8/10 King Street,  
Stirling, FK8 1BD,  
Further details will follow

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## CONTACTS

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Modern technology is obviously the main area where this can be improved, however this in itself poses the problem that remote monitoring can be achieved quite easily but having staff available to assess the information is a concern.

Following a break, the Conference delegates broke up into 4 groups to continue ‘The Patient Pathway’ discussion.

This was followed by a session looking at OSA minimum standards. This was led by representatives from England, Scotland, Northern Ireland and Wales.

Finally the conference closed with a panel of experts who put forward suggestions as to how to ensure OSA is made a priority within the NHS.

This is one area where the BLF have made great strides in raising awareness with Governments as well as the General Public.

## TIPS FOR USING YOUR EQUIPMENT



### ***CPAP/APAP/BIPAP Tolerance Problems***

A lot of people find it hard to tolerate their equipment at first, so it's a good idea to set it up during the day whilst relaxing, such as watching tv, to practice using it, rather than waiting for bedtime when you have no other distractions. If you need daytime naps, use it during these too for shorter periods. Practice wearing the mask only, without attaching it to the CPAP, to get used to it.

Remember most people take at least 2 weeks to get accustomed to using their masks and machines (some a lot longer), so you are not alone in this.

#### **Mask Leaks**

A good mask seal is essential for successful treatment. There are several reasons why your mask may be losing its seal so here are some causes and fixes:-

- Ensure it is correctly fitted, especially if you are using an APAP (where the pressure raises automatically when apnoeas are detected). When fitting the mask, lay down and have the mask loosely attached to your face. Set the CPAP/APAP on the highest setting it has been set for you, and whilst the air is blowing, fasten the straps, just enough to create a seal, making sure it's not too tight.
- Daily cleaning the mask seal is so important, as facial oils left on it will cause mask leaks. Contrary to even manufacturers' advice, cleaning the masks in household detergents is not adequate, as the extra conditioners eventually build up a film on the mask seal. Using CPAP Mask Wipes and Sprays is recommended. Vinegar diluted in water is also good.
- Have you got the correct size of mask? Ordering a mask online without having tried it on is risky. Trying on a mask in an upright position without the CPAP air blowing isn't ideal, so ask your clinicians if you can try the mask in a prone position attached to a machine.
- Another problem which causes mask leaks is the hose dragging on the mask. Try to get the hose elevated above your head (which is also vital if using a humidifier to prevent 'rainout').

#### ***Dry Mouth***

A CPAP Humidifier normally helps with this, but if you still have a dry mouth, keep a bottle of water by your bed (saves spilling a glass of water near your machine) and take just enough water to wet your mouth, as drinking can cause you to inhale any liquid (or food) if taken too close to your sleep time.

#### ***Mask Marks***

Assuming you have tried everything to avoid getting marks in the first place (like not over-tightening your straps and using mask strap covers). If you still have marks on your face do not be too concerned. After removing your mask the marks will be quite noticeable, but the majority of them will diminish fairly quickly, depending on your age and skin's elasticity. For any remaining marks, rub your skin with your fingers in circular movements to increase the blood flow and stretch the marked skin. Splash your face with cool water and pat dry with a towel. It is also a good idea to moisturise your skin.

*We would like to thank Kath Hope for the above tips from her website: [hope2sleep.co.uk](http://hope2sleep.co.uk)*

## **DRIVER FATIGUE AND ROAD ACCIDENTS**

Driver fatigue is a serious problem resulting in many thousands of road accidents each year. It is not possible to calculate the exact number of sleep related accidents but research shows that driver fatigue may be a contributory factor in up to 20% of road accidents, and up to one quarter of fatal and serious accidents.

These types of crashes are about 50% more likely to result in death or serious injury as they tend to be high speed impacts because a driver who has fallen asleep cannot brake or swerve to avoid or reduce the impact.

Sleepiness reduces reaction time (a critical element of safe driving). It also reduces vigilance, alertness and concentration so that the ability to perform attention-based activities (such as driving) is impaired. The speed at which information is processed is also reduced by sleepiness. The quality of decision-making may also be affected.

It is clear that drivers are aware when they are feeling sleepy, and so make a conscious decision about whether to continue driving or to stop for a rest. It may be that those who persist in driving underestimate the risk of actually falling asleep while driving. Or it may be that some drivers choose to ignore the risks (in the way that drink drivers do).

Crashes caused by tired drivers are most likely to happen:

- on long journeys on monotonous roads, such as motorways. \* between 2am and 6am
- between 2pm and 4pm (especially after eating, or taking even one alcoholic drink)
- after having less sleep than normal \* after drinking alcohol \* if taking medicines that cause drowsiness
- after long working hours or on journeys home after long shifts, especially night shifts.

