

Scottish Association for Sleep Apnoea

AGM & Conference – 10th October 2009

King Robert Hotel, Stirling

Chairman – Colin Tyler, welcomed members.

Apologies were given for members not receiving minutes of 2008 AGM but it was felt too risky using postal service due to impending strike action.

We had been unable to obtain a representative from ERI – Sleep Lab.

Mark Lincoln (SASA Website consultant) had been asked to prepare a presentation which would look at how SASA is presently run and what the members felt they would like to see in the future. Prior to Mark giving his presentation it was felt that we should discover members views first.

Members were split into three groups with Colin Tyler, Scott Elliot and Mark Lincoln acting as facilitators.

Items to be discussed –

1. What is SASA doing right?
2. What can SASA do better?
3. What do the members want from SASA?

Mark Lincoln would correlate the results of these discussions and results would be published.

Some of the points raised were - How could we raise awareness – leaflets/posters.
How can we encourage sleep clinics to notify newly diagnosed patients of the existence of SASA.

There followed an open discussion dealing primarily with communication. Most people are aware of the modern technology but not all are able to use it to its fullest.

During this discussion Mr Harry Purser (Head of Health Intelligence – NHS Lothian Board) introduced himself to the conference. He was attending as an aide to his mother who suffers from sleep apnoea. He felt in the absence of medical staff from Edinburgh Sleep Clinic he could bring to the conference the position the NHS now finds itself in and put forward some new ideas to SASA.

Due to issues with patient confidentiality it is difficult for NHS staff to act as an advocate for voluntary organisations.

A reduction in junior doctor training places has meant nurses having to be trained as advanced practitioners thus reducing their ability to give more personal attention.

Devolution of NHS funding has also meant that funding for Sleep Labs. has reduced ability to expand the service in line with increase in sufferers.

Mr Purser suggested the following actions –

1. Form formal liaisons with sleep labs to ensure patients freshly diagnosed are made aware of groups that can offer support.
This can be done using leaflets / posters / questionnaires.
Production of leaflets need not be a burden on our resources. Investigate the possibility of using the likes of Edinburgh and/or Glasgow Universities where students on art courses could produce designs as part of the course work.
2. Support must also be offered to patients' families and associates to make them aware of problems they may encounter and where possible provide solutions.
3. In the past one of our aims has been to try and stimulate research.
This is a minority condition and therefore there is a small market for further development.
He suggested that we investigate applying to colleges (e.g., Imperial College, London) particularly students on Innovation Design Engineering Courses to come up with a machine that would have minimum noise level (possibly silent) and a mask which had minimal facial impact.
We could then look at other things where we could target our resources.
4. We should continue to lobby MSP's to ensure GP's could provide prescriptions for spares for CPAP machines etc. At present NHS budgets are cash limited whereas GP budgets are not cash limited.
At present however GP's would not be able to supply equipment, as it does not appear in the 'Green' book, which limits what they are able to prescribe.
5. Make better use of website and newsletters and get them more widely distributed.

A member of the conference reminded us that Strathclyde University – Bio-engineering Department had done research on Sleep Apnoea. A PhD student had been funded to carry out research on why people were failing to continue treatment. Perhaps we could approach them to fund another student to carry out further research.

Mark Lincoln then gave his presentation.

SASA must move into the 21st Century and make greater use of the Internet and Websites.

The way forward was to –

- Listen to the views of members.
- Offer support to sufferers and their partners.
- Make greater use of technology. SASA has been a paper-based organisation for too long. Need to change – make use of website to distribute newsletters etc. This would enable members to receive very up to date information. Make use of social network sites e.g. Facebook.

SASA membership continues to drop yet diagnosis continues to grow.

Local groups, where they exist are failing to recruit new members.

Improvement in communication so that members are more aware of what is being done rather than them merely having a perception of what is happening.

Improve services to membership.

We must act when patients are referred and follow their progress by ensuring they have access to the right GP's and subsequently ENT doctors.

We would need to recruit volunteers to man clinics to personally deliver our message.

Build better relationships with professional bodies.

In summary Mark highlighted what he regarded as our priorities –

- Change the way we do things
- Improve communications
- Provide up to date information.

Further questions / comments were then invited from members.

There were some concerns voiced with regard to exposure to too much Internet usage. Mark suggested we would have to set up a monitoring group to ensure only relevant information was put on our sites.

Further use of free bulletin software was proposed which could be used as a social network through our website.

Make use of Community Television slots.

Jean Gall was then invited to give an update on the progress of SASA's petition to the Scottish Parliament.

She felt that it was a good time to remind members of the content of the petition.

“Mrs Jean Gall on behalf of SASA calls on the Scottish parliament to urge the Scottish Executive to increase awareness, promote proper diagnosis and treatment, and provide sufficient resources to tackle the health problems associated with obstructive sleep apnoea including undertaking a review of funding for sleep centres, particularly the Sleep Centres in Edinburgh and Glasgow.”

Jean explained that although members are allowed to attend meetings of the Public Petitions Committee (PPC) they are not allowed to speak.

However SASA is grateful to Christine Grahame (MSP – SNP – South of Scotland). Although not on the committee she can attend and speak by invitation of the Chairman of the PPC.

As far as the PPC is concerned this petition is now a closed book but has now been passed to the Health Committee of which Christine Grahame is convener.

At this point the Chairman – Colin Tyler, addressed the conference. He felt many of the points raised had already been discussed at length and had nothing to add.

Minutes of AGM 2008.

Colin admitted there were a number of typo and spelling mistakes and these would be rectified.

Minutes therefore accepted – proposed – David France – seconded – Alex Munro-Wallace.

Secretary's Report – Report attached.

Treasurer's Report - given by outgoing Treasurer Donald Swanson – Report attached.

At the end of the Treasurers report the Chairman presented Donald with a gift to express SASA's gratitude for the work he has carried out. It is worth noting that Donald is not a sleep apnoea sufferer but he has worked tirelessly for the association.

Membership Secretary's Report – Report attached.

Trustees Report – Report attached

Election of Office Bearers

Colin Tyler declared he was not prepared to stand for re-election despite having received a number of votes requesting he stay in office.

Colin was requested to remain as Chairman until election of new Chairperson.

Conference was asked to put forward nominations for the position.

Mark Lincoln proposed Jean Gall, which was seconded by Joan Tyler.

There being no other nominations -

Jean Gall accepted nomination expressing that she would stand for one term only (3years).

Jean thanked conference for having the confidence to vote her in for another term. Jean thanked Colin for the 2¹/₂ years service given to SASA over what has been a difficult period.

Other office bearers to continue with their 3 years service, other than John Paul.

John Paul has declared he is willing to continue as membership secretary.

John Paul was nominated by Ray Walker – there being no other nominees John Paul would continue in this post.

Nomination of Trustees

Jean Gall explained that there had been changes regarding trusteeship over the past few years and suggested we need to take legal advice before we proceed with any action.

The Management Committee can be classified as trustees but we need to have this verified.

Trustees in post are –

Dr Tom McKay – David France – Joan Tyler.

David France has expressed a desire to stand down and he was thanked for the work he had carried out.

Nomination for other trustees should be left until we receive clarification of legal requirements.

Co-opted members remain as - Mike Wilson - Newsletter Editor

Mark Lincoln – Webmaster

Mark was thanked for his work on the website and was especially thanked for the presentation he gave at conference this year.

Mike Wilson has reiterated his request that without input from members he cannot produce a worthwhile newsletter out of thin air.

He requires stories not necessarily related to sleep apnoea – jokes – cartoons – pictures – reports or anything anyone feels like sharing with members of the association.

It was suggested that each newsletter should include the advice given of the requirement to notify the DVLA when diagnosed with sleep apnoea.

A section should be created for sufferers and their partner's questions.

Chair to invite DVLA Senior Medical Officer to the next conference.

Local contacts to be asked if they will continue or if required look for replacements as it is felt it is important to maintain this method of contact especially in remote areas.

Secretary to write to contacts.

A raffle had been arranged and a total of £54 was raised – Well done! Thanks for your support.

Date and Venue of the next AGM

It is hoped to invite MSP Christine Graham to next conference therefore date would have to suit her diary.

Vote taken as to whether conference should be held in autumn or earlier in the year.

Majority voted for the autumn.

Management Committee to propose a date as soon as possible to ensure we give plenty of warning to all concerned.

It was proposed to look at venues in other parts of Scotland, bearing in mind ease of access.

Jean Gall closed the conference giving thanks to all who attended and thanking them for voting her into office.