Newsletter of the Cardiac & Respiratory Support Service AUTUMN 2016

Chest Heart & Stroke Scotland

TAKE A BREATH

Inhaled Salt Therapy

IPF Awareness Week

New Grampian Support Group

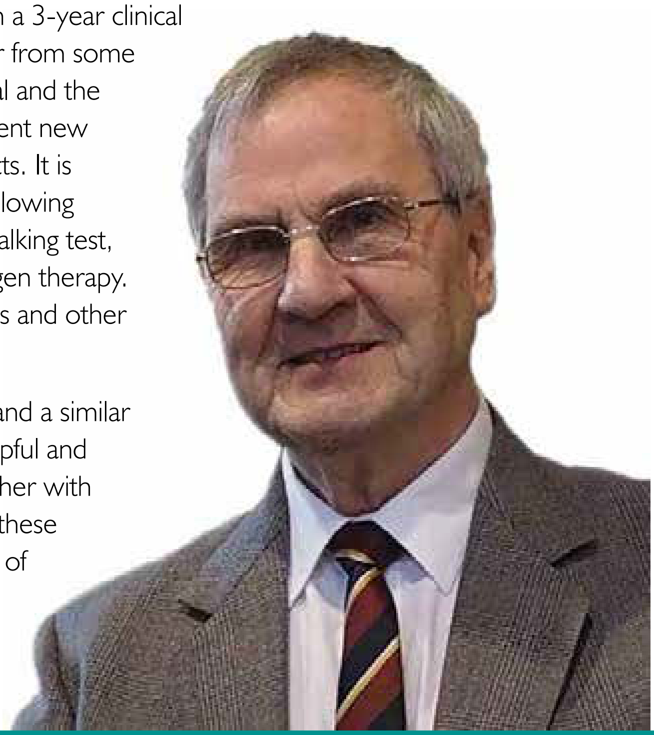
Jim's story of living with IPF

This edition we hear from Jim Hoseason who has been kind enough to share his story of living with Idiopathic Pulmonary Fibrosis (IPF) with us all. See page 3 for more information about this condition. If you would also like to share your experiences please just get in touch, see page 2 for details on how to get in touch.

I first noticed breathing problems as far back as the 1970s. As a keen gardener I frequently had to stop digging to relieve mild breathing discomfort, fortunately this did not require any medical intervention then. I'd been a smoker since the 1960s and believe I aggravated the problem by inhaling fine oak dust while regularly sawing oak barrel staves, I stopped smoking around 1979.

I tolerated the slowly increasing discomfort until 2006 when I consulted my GP. Following a CT scan, IPF was diagnosed and I was referred to Aberdeen Royal Infirmary Chest Clinic where I received regular check-ups and unsuccessful drug intervention. I volunteered to take part in a 3-year clinical trial for a new drug in 2011. Unfortunately I began to suffer from some side effects which meant that I was withdrawn from the trial and the drug. However, a few weeks later I was prescribed a different new drug, which I am still taking with no significant adverse effects. It is my perception that my breathing condition deteriorated following withdrawal from the first medication. During a 6-minute walking test, my oxygen levels dropped, so I was prescribed home oxygen therapy. I use this during times of real discomfort – walking outdoors and other mildly strenuous activities.

I attend the Grampian Pulmonary Fibrosis Support Group and a similar group at Forres Health Centre. I am finding these most helpful and reassuring. The sharing of information and problems, together with the social interaction is most beneficial. Through attending these groups, I hope awareness and understanding can be raised of this less well known chronic lung condition.



More details of the Grampian Pulmonary Fibrosis Group can be found on page 4.

Inhaled Salt Therapy

Should you take it's claims with a pinch?

Recently, people have been asking about the benefits of whether inhaled salt treatments are useful to help relieve the symptoms of COPD or other long-term chest conditions. Here are some answers to your questions…

Is inhaled salt therapy useful? Salt can have a role to play in helping to clear mucus from your chest and it is found in saline nebulisers, provided by healthcare professionals.

How does the salt work? It helps to break down the stickiness of mucus and makes it thinner, so that it is easier to cough out.

Can inhaling salt solution be dangerous? In special circumstances higher concentrations of salt can be used in nebulisers. However, there is a risk that this stronger solution will irritate your airways and cause wheeziness to develop. For this reason, a stronger solution should only be given with medical supervision.

Will the salt treatments that are advertised work for me? The commercial salt therapies that are advertised claim that the quality of the air inhaled will have similar benefits as these medical saline treatments. The websites and adverts do not appear to mention the actual level of salt concentration, so it is impossible to know if these claims are achievable. Most of the benefits that people hear about are usually anecdotal, with no clear evidence to support the claims made. It is worth bearing in mind that some of these are very expensive treatments and are being run by private companies, whose main goal is to make a profit.

What is best for me? Before you spend any money, ask your doctor or nurse about the device or therapy you are considering. They will be able to give you more personalised advice. Similar devices may even be available on prescription from your own health team, free of charge.

You can call the CHSS Adviceline Nurses for more information. Telephone 0808 801 0899, free from landlines and mobiles.

AUTUMN QUIZ

Famous Faces – Who was associated with the following? Answers on page 4.

1. **A cigar?**
2. **A glass slipper?**
3. **A coat of many colours?**
4. **An apple and a snake?**
5. **A flood?**
6. **A magic lamp?**
7. **A long sleep?**
8. **A trumpet and a hanky?**
9. **A spider's web?**
10. **Her lamp?**

Have your say…

Do you have any new information about services in your area, an interesting story or a helpful hint to share with people affected by chronic lung disease? Then please let us know so that we can share it with others. We'd love to hear from you:

Contact us by e-mail on respiratoryservices@chss.org.uk
Or call us on 0131 225 6963

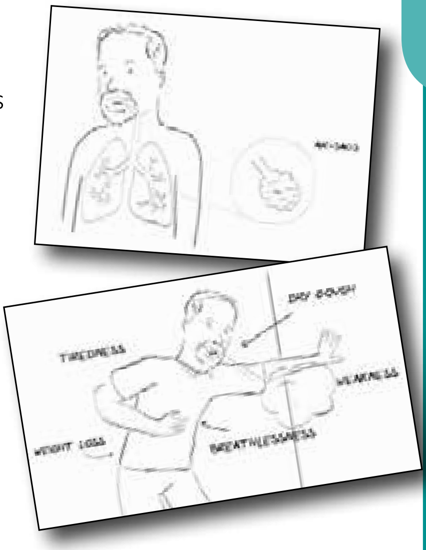
We look forward to hearing your news!

IPF AWARENESS WEEK

The **17th to the 25th September 2016** was IPF World Awareness week. Idiopathic Pulmonary Fibrosis is a less well known long term lung condition. The word 'idiopathic' means that the cause for the condition is unknown, 'pulmonary' means lungs and 'fibrosis' means scarring. Idiopathic Pulmonary Fibrosis is a an advancing, scarring lung condition, the cause of which is not known.

The theme for the awareness raising week is "Breath of Hope" and CHSS will be supporting this campaign to help make more people aware of this debilitating lung condition. Look out for images of people blowing bubbles!

In time for IPF Awareness Week CHSS has updated it's IPF booklet which gives more detailed information on this condition, we are also introducing a new Health Sketch information video which gives a short, animated, explanation of IPF.



Details of both of these resources can be found on the CHSS website – visit www.chss.org.uk for more details.

CHEST-A-MINUTE

How important is it to stay active?

It is really important to help keep your body in working order and can help control your breathing. It can improve your mood and possibly your social life. If you do not stay active your body becomes weaker and less able – if you don't use it you lose it!

How much activity should I do?

We should all try to be more active for **150 minutes each week**. That's the same as 30 minutes each day. This could be 2 walks that last 15 mins or 3 lots of activity for only 10 minutes each.

You should still be able to talk while you are being active and feel in control of your breathing.

Won't it make my breathing worse?

If you make sure that you begin gently and when you are feeling well, repeated activity will help **improve your breathing** and help you to control feelings of breathlessness. Do not start to increase your activity levels if you are feeling less well than usual.

Where can I go for help to get started?

It needn't cost you money to be more active, simply walking more, either inside or outside, will help. If you prefer to have company then ask at your local community centre or try the ALISS website www.aliss.org for information about local exercise groups. If you think you need more help then ask your nurse or GP about attending your local pulmonary rehabilitation classes.

‘LUNG AT HEART’ FUNDING SUCCESS

This edition, Pat Henderson, the chairperson of CHSS’s affiliated group in Nairn, shares her group’s recent success in acquiring additional funds.

‘Lung at Heart’ is a support group for people who live with a variety of chest conditions, heart failure or stroke. We are affiliated to Chest Heart & Stroke Scotland and meet weekly in Nairn Community Centre. Each week we have a gentle exercise session, a chat & a cuppa. We were formed nearly three years ago but have been struggling to maintain our membership numbers.

Being a small group means that it can be a struggle to cover our regular costs. To help with this we hold regular raffles, which mostly keep us afloat.

This year we had the chance to attract new membership. Local councillors introduced an awards system for local groups. Residents of Nairn and Nairnshire voted for the most worthy recipients. ‘Lung at Heart’ submitted a bid for around £600 to cover advertising and other promotions to attract new members. We were fortunate to be one of the chosen groups. One of the grant conditions was that it was not to be used for on-going expenses.

At the same time I was told about potential funds available through a Self- Management Grant provided by the Third Sector Interface. This was for a much larger amount and I saw it as an opportunity to help develop the group’s resources further.

- I applied for funds to hire the local community bus to bring members to our group meetings in Nairn, as the public transport links in the local area are poor. There were also some people who struggled to use public transport, so I included the cost of taxis in the grant application.


‘Lung at Heart group members enjoying some of the new equipment purchased with the funds’

- Members asked about the possibility of having some additional equipment for the exercise sessions, so I added the cost of some seated cycles and free weights.
- As a final thrust at promoting our group, I added the cost of creating a website for ‘Lung at Heart’. We were fortunate enough to be given the full amount, a total sum of £2891.95

It wasn’t a particularly easy task applying for funding and public funds need to be accounted for. However, if we are successful in raising our membership numbers and our profile, then the group should be assured of a long and healthy future.

HOW TO REGISTER Don’t want to miss the next issue of Take a Breath? You can sign up to receive an e-mail alert that will let you know that the next issue is available, and a link to take you straight there!

Visit: www.chss.org.uk/takeabreath-highland for more information

ANSWERS 1. Winston Churchill 2. Cinderella 3. Joseph 4. Eve 5. Noah 6. Aladdin 7. Rip van Winkle 8. Louis Armstrong 9. Robert the Bruce 10. Florence Nightingale