

Newsletter

Alpha 1 Awareness

Vol 4
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July 2012

A Word from the Chairman

After a long period of cold and rain, summer seems to have arrived at last. Just as it is possible to enjoy spending time in the open air many of us will stay inside and sit watching television. London Olympics and Paralympics news is everywhere. Not surprisingly health issues are not being covered in the Press and information about the structures of the new NHS Commissioning Board is hard to find. We shall have to wait until Autumn to find out how the Patient and Public Engagement process will work in the specialised services being planned for rare diseases such as alpha-1 antitrypsin deficiency.

The formation of the Alpha-1 Alliance is a great advance in pressing for better treatment for Alphas. Alpha 1 Awareness UK is pleased to be a part of this with Dawn as our representative on their board. The chairman of the Alliance is Doctor Mahadeva. He is a consultant respiratory physician at Addenbrooke's Hospital in Cambridge. He is a colleague of Professor David Lomas and he has published a number of research papers jointly with our other patron, Professor Sabina Janciauskiene. He brings a wealth of experience and talent to the Alliance. We look forward to an update to inform us of the progress of the campaign and how we can get involved and support the activities.

In September I shall be attending the European Respiratory Society (ERS) Congress in Vienna as the representative of the Alpha Europe Federation. Dawn will also be in Vienna as a member of the patients' committee of the European Lung Foundation. This Foundation was created by the ERS in 2000 with the aim of bringing together patients, the public and respiratory professionals. The Congress is a great opportunity to discuss all things Alpha and to meet clinicians, researchers and policy makers.

Later in September, Dawn, Lin and I shall be going to the Annual Social Gathering of the Alpha-1 UK Support Group which is being held in Bridgend. I should like to thank their chairman, John Mugford, for inviting us to this event and we all look forward to catching up with old friends and meeting new friends in the expanding Alpha-1 UK community. In the meantime, enjoy London 2012.

Alan Heywood-Jones

Exacerbations

An exacerbation of COPD is a dramatic worsening of breathlessness, coughing and bringing up phlegm. GOLD, the experts who brought us the four level classification of COPD, have a formal definition, see the box at the end of this article. Unfortunately, there are many subjective elements to the definition and this makes it difficult to know exactly how common exacerbations are. Sometimes exacerbations are defined as being present when a patient is admitted to hospital because of an exacerbation.

When a patient has a suspected exacerbation there are diagnostic tests that may be used. These include checking the patient's history, a physical examination, spirometry, arterial blood gases or pulse oximetry and chest x-rays. However none of these is a definitive, confirmatory diagnostic test for an exacerbation of COPD. So what do doctors take into account? In addition to the shortness of breath, cough and phlegm mentioned above they consider how much normal daily activities are impaired. Then there are many secondary symptoms to think about - wheezing, tightness and pain in the chest, high pulse rate, rapid breathing, fatigue, sleeplessness, depression and confusion.

What causes them?

Five causes of exacerbations have been investigated by researchers: **bacterial infection, viral infection, air pollutants** (nitrogen dioxide, dust, sulphur dioxide and ozone), cold weather and the interruption of regular treatment.

How can we prevent them?

We can help ourselves by **keeping warm in cold weather, staying away from dusty atmospheres** and **avoiding people who may have colds** but for the rest we must turn to our medical advisers.

Influenza vaccinations are currently recommended in the care of people with COPD. These recommendations are based largely on evidence from observational studies with very few randomised controlled trials (RCTs) being reported. However, combining the results from a number of trials (so-called meta-analysis) indicates that these vaccines reduce exacerbations in COPD patients. There is a mild increase in short-term adverse effects with vaccination, but no evidence of an increase in early exacerbations.

Pneumococcal vaccine is recommended for everyone over the age of 65, adults with COPD and children or adults in a number of other special risk categories. Normally revaccination is performed after 5 years so the pain and soreness at the vaccination site experienced by about half the people is a small price to pay for the increased protection.

A study conducted in 1999 showed that daily **inhaled salmeterol** (Serevent) reduced the likelihood of exacerbations in COPD patients. **Inhaled ipratropium** (Atrovent, Apovent, Aerovent) was slightly less effective but better than a placebo. A second study in 2000 showed a similar reduction in exacerbations for patients taking **inhaled corticosteroids** (Seretide, Advair). More recently the TORCH study showed that all active treatments were significantly superior to placebo in decreasing the risk for exacerbations requiring steroids. Two randomised clinical trials have shown that **roflumilast** (Daxas, Daliresp) when taken with a LABA (see the box of Abbreviations) such as Serevent is more effective at reducing exacerbations than taking the LABA alone.

Other researchers have investigated the use of **antibiotics** to reduce the number of exacerbations. The PULSE Study Group found that moxifloxacin was effective. When a patient with an exacerbation is admitted into hospital it is important that antibiotic

treatment is started early. If the treatment starts after the second day it is more likely that mechanical ventilation may be needed and that the patient will be re-admitted within 30 days.

Pulmonary Rehabilitation (PR) also has its role to play. Researchers at King's College Hospital have shown that outpatient post-exacerbation pulmonary rehabilitation (PEPR) reduces subsequent hospital re-admissions. Even regular PR reduces the likelihood of the need for hospital admission.

Even after doing our best to prevent exacerbations they sometimes still happen so how are they treated?

Treatment

At the first signs of an exacerbation some COPD patients take antibiotics or steroids (GPs will prescribe a small store of these for suitable patients). If this is not appropriate or the symptoms get worse then a doctor will consider admitting the patient into hospital. The GOLD guidelines for this are any of:

- *Marked increase in intensity of symptoms, such as sudden development of shortness of breath when resting*
- *Severe underlying COPD*
- *Onset of new physical signs (e.g., turning blue, swelling of hands or feet)*
- *Failure of exacerbation to respond to initial medical management*
- *Significant other health problems*
- *Frequent exacerbations*
- *Newly occurring unstable heart rate*
- *Older age*
- *Insufficient home support*

The majority of patients taken into hospital for COPD exacerbation have very low levels of oxygen in the blood (hypoxaemia). This typically responds to treatment with low-flow oxygen (less than 4 litres/minute via nasal cannula).

Inside a hospital more tests can be made and it is possible to give stronger drugs and inhalers and constantly check on the patient's progress. Also there are specialists available to deal with other health problems that may be interfering with, or at least confusing, the symptoms of the exacerbation.

Alan Heywood-Jones

Definition of Exacerbation

“An event in the natural course of the disease characterised by a change in the patient's baseline dyspnoea, cough, and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication in a patient with underlying COPD.”

From the Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease, Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2009.

What the abbreviations mean

GOLD: Global Initiative for Chronic Obstructive Lung Disease

LABA: Long-Acting Beta-adrenoceptor Agonists such as salmeterol (Serevent) or the ultra-long-acting indacaterol (Onbrez)

PULSE: Not an acronym. Perhaps the PULSE Study Group wished to say that there were planned periods of non-treatment.

SABA: Short-Acting Beta2-adrenergic receptor Agonists such as salbutamol (Ventolin)

TORCH: TOwards a Revolution in COPD Health

UPLIFT: Understanding Potential Long-term Impacts on Function with Tiotropium.

Natural Cleaning products

Many Alphas have problems with using certain commercial cleaning products, we are grateful to Wendy Rogerson for sending this list of alternative cleaning products using things we all keep in our store cupboards

All purpose cleaner

For an all-purpose kitchen cleaner you can use on almost any work surface, mix up one part vinegar to one part water in a spray bottle. The vinegar works as a disinfectant, but should not be used on marble.

Floor cleaner

The faithful vinegar and water solution will do the trick for your floor tiles.

Lime-scale remover

Get rid of lime-scale build-up on the shower by removing the head and leaving it to soak in a half water half vinegar solution for a few hours. Rinse thoroughly afterwards if you don't want to smell like a chip shop the next time you take a dip.

Natural bleach

Mix up a paste of two parts bicarbonate of soda to one part lemon juice, allow it to work its magic for ten minutes or so before washing away. The lemon juice acts as a natural bleach as well as attacking the lime-scale with its acidity.

Furniture spray

Instead of using an aerosol furniture polish use beeswax or, alternatively, mix one cup of olive oil with half a cup of lemon juice in a spray bottle, shaking well before use.

Window cleaner

Banish the window spray and instead mix up one part vinegar to four parts water. Use a lint-free cloth to clean off any dirt and then polish off smears with scrunched-up newspaper or paper towel.

Make your glassware sparkle

Wash glasses in a plastic bowl in your sink with a little washing-up liquid. For the final rinse use warm water with a couple of drops of vinegar then gently buff dry with a cloth.

Removing washing machine mould

If your washing machine door seal has become black and mouldy douse a cloth in white vinegar and wipe over.

Use bicarbonate of soda

a) Make a thick paste with Bicarbonate of Soda, spread liberally on a cold oven that has been dampened with water first, leave for 2-3 hours. Then spray on white

vinegar and watch it fizz, leave for another couple of hours and wash away with warm water.

b) Mix with a little warm water to make a paste, and this will clean everything from fridges to ovens.

c) Try unblocking sinks by pouring down some bicarbonate of soda, followed by some clear vinegar. This solution should fizz and bubble up, and give your pipes a good cleaning out! Stops smells too.

Clean shelves in the dishwasher

Encrusted grime on oven shelves can be blitzed by running them through a hot wash in the dishwasher. Alternatively, line the bath with old towels to protect the finish, and then soak the shelves in biological soap powder. Scrub any remaining grime with a cream cleaner or abrasive pad. Biological soap powder also works for baked-on grease in grill pans or try soaking in vinegar overnight.

Shiny Silver (Solid silver ONLY)

To clean solid silver (not plated silver) line a plastic bowl with aluminium foil, shiny side up. Put a mug full of soda crystals in the bowl and add sufficient hot water to immerse. Put your rubber gloves on, drop in the silver items they will turn into a beautiful bright shade in a couple of minutes. Rinse under a warm tap until no soda remains on them. Buff to a high shine with a soft cloth.

Net Curtains

Clean your nets with denture cleaning tablets - dissolve 2-4 in a bowl of warm water and leave your curtain in the solution for half an hour - then wash as normal or just rinse and re-hang.

Fridge Seals

Use toothpaste and a toothbrush.

NEWS IN BRIEF

New Board Members

As many of you will be aware, there is lots of work goes on behind the scenes to keep the Charity running smoothly. For a long time we have had just 5

Board members, but this summer we decided that more help and skills were needed to keep things running smoothly. I am pleased to say that the Board numbers have been increased to

8 members, the new members and their jobs are :

Wendy Rogerson will be helping members with benefits claims and advice

Neil Jackson Neil has been an ex-officio member of our Board for the last 3 years, he set up our online Forum, his expertise and help has been invaluable. He has at long last joined us as a full Board member, where he will continue to moderate the Forum, help with any technology problems and work closely with Alan Heywood-Jones on the website.

Emma & Alan Wooler are parents of a young Alpha child, who have agreed to join the Board, to liaise and help other parents of Alpha children. They will be able to talk to new parents using their first hand knowledge and are also there help other parents.

We are extremely grateful to these people who have agreed to join us to help make the Charity stronger for all our members.

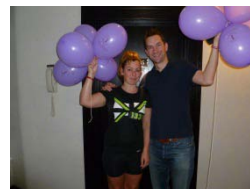
At this point I would also like to say thank you to Lorna, Neil's wife, who is a great newshound, searching out Alpha news items and links and bringing them to the attention of our Facebook Group and also our Forum.

Fundraising we have had several people fundraising for us just recently and a couple in the future, we are extremely grateful to them for the support they have given us, in this way. Nicola Winstanley, her sister & brother in law ran in the Midlands to raise money in memory of their father, Elaine Anderson who did a sponsored walk. Good luck to Jodie Sainsbury who is doing a sponsored zip wire challenge later in the year, Alan

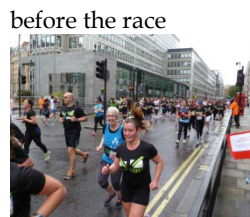
Wooler has decided to have his head shaved on his birthday in August and friends and colleagues are sponsoring him. Chris Brown-Martin and 2 friends who are planning a Kayak Challenge for next year

<http://www.southwestkayakcharitychallenge.co.uk/>

British 10K Run was held in London on 8th July we had secured 6 places in this run for Alpha 1 Awareness UK, we had 5 people take up the places, Phil Hale, Rich Baker, David Halfacree, Heidi Haden and Denis Horrellou. All the runners had a great day despite the now familiar summer downpour of rain and have raised a fantastic amount of money for the Charity. All the runners were given balloons with our Charity name on, for their supporters to have along the route (you can see Heidi with hers below)



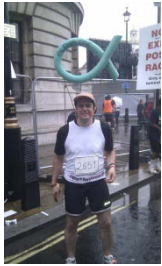
Heidi, with her husband



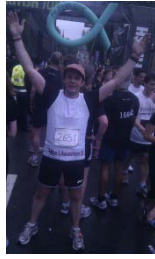
before the race

Heidi, pounding the streets of London during the race.

Thank you to them all for such a great effort, I have heard from them all and many of them are keen to take part again next year.



Before the race



Still standing at the end!!

Denis ran the whole race with a large Alpha symbol above his head

We do have 6 places again in next year's 10K run and it would be brilliant to have all places filled next year. 2 places have definitely been taken, so if you or any of your family members wish to take up a place, please contact us here at the Charity.

AGM the AGM this year is being held on the Friday 14th September, at the Vassall Centre in Bristol, further information and details of the AGM are included with this Newsletter. It would be good to see some of our members attending this meeting.

Christmas Cards sorry to mention the subject of Christmas, when we haven't had much summer, but I know many of you like to get your card shopping done early. You will find the order form for this year's cards, with this Newsletter.

T-shirts & Polo Shirts we have recently had some adult, t-shirts and polo shirts produced, we have a choice of black or white and the Charity logo is embroidered on them. The sizing is

small, medium, large & ex large, and the cost is £11 for polo shirt and £8-50 for t-shirt



polo shirts



t-shirts

We do also have sweat shirts available they are the same sizes as the above and cost £12 each



sweatshirt

Chat online to other Alphas

Remember if you want to chat to other Alphas and you have access to the internet, there are 2 ways you can do it. There is:

The Alpha 1 Awareness UK Forum - to join go to
<http://techno.demon.co.uk/a1aforum/index.php>



We also have a Facebook Page – If you are on Facebook, search for “Alpha 1 Awareness UK” we have our logo next to our name, click “request to join”, it is a closed group page so nothing on there is public, other than our Group description.

Shop Online and Raise Funds

Don't forget when shopping online to register with easyfundraising.org.uk and it won't cost you a penny more to shop and raise funds in this way. In fact you could even SAVE MONEY as many retailers give exclusive discounts, special offers and even 'e-vouchers' when you shop through the easyfundraising site.

Easyfundraising is a shopping directory featuring over 600 trusted online stores, including: Asda, Tesco, Argos, Amazon, the Body Shop, NEXT, Debenhams, John Lewis, Toys'R'Us, HMV, Virgin, iTunes, CD WOW, Marks and Spencer, Currys, Dixons, Staples, PLAY.COM, Pets at Home, Choices Direct, WH Smith, The AA, RAC, Direct Line, Churchill, The Carphone Warehouse, Ticketmaster and over 600 others...

Register for **Alpha 1 Awareness UK** and just by doing your shopping online you will be helping raise funds for the Charity.

Also you can set up www.easysearch.org.uk, as your search engine page and register Alpha 1 Awareness as your chosen cause then every time you search a webpage you raise money for the Charity.

We would love to hear from you, if you wish to contribute in any way to future editions of the Newsletter, please contact at the address below.

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