

Newsletter

Alpha 1 Awareness

Vol 2
Issue 4
Oct-Nov 2010

A Word from the Chairman

Alpha 1 Awareness UK has now completed the second year as a registered charity. It has been a year of steady growth and consolidation.

Thanks to the hard work of the charity board and our members we have achieved many things:

- Hosting the Fifth European Alpha Congress in London.
- Three lunch-time meetings in Wales, Cornwall and the North-East of England.
- Production of the fourth in the series of guidance booklets. This one is written for medical professionals caring for Alphas.
- Publication of the book for children *From A1 to ZZ*. This was possible because of the assistance of the American Alpha-Kids organisation and the copyright holders of the text and graphics.
- Provision of a free AATD testing service thanks to the sponsorship of Talecris Biopharmaceuticals.
- Donations to the research work being done at King's College Hospital, London into Alpha children's liver problems.
- Spreading awareness of AATD with our display stands and booklets at Army health fairs.
- Trustees have participated in Alpha1 meetings in Gothenburg and Madrid. These have been at no cost to the charity.
- Registration as a cross-border charity with the Office of the Scottish Charity Regulator (OSCR).

Jeff Darkins joined the charity board in time to assist with the running of the European Alpha Congress in July. After the London Congress Jan Parle also joined the board. Jan's main concerns will be initiatives to raise funds.

At the AGM the existing three trustees, Lin Daniels, Dawn Heywood-Jones and myself were re-elected and we should like to thank all members who took part either in person or by proxy for their continuing support and confidence in the team. Also at the AGM Liz McKenna was elected as Honorary Treasurer. Liz is from Scotland and is a highly qualified accountant and we look forward with keen anticipation to her help and advice.

As I reported last year the system for allocating places in the London Marathon has changed – the old system was seen to be unfair towards small charities. Alpha1 Awareness has been awarded and paid the fee for a place in the 2011 marathon. The place has been offered to one of our members and I wish her good luck both in the race and in getting sponsors.

In the coming year we plan to continue the programme of regional Information Days. Alpha1 Awareness is sponsoring an initiative called FIND-A1, more details about this are in the article *Where are the Alphas?*. The charity board is looking at similar schemes for liver-affected children and COPD sufferers in general.

Alan Heywood-Jones



Fig. 1

Nebulisers are used for the treatment of COPD (including alpha1-type emphysema), asthma, cystic fibrosis and other respiratory diseases.

The aim is to get a medication, such as a bronchodilator, directly into the lungs where it can have an immediate medical beneficial effect. The most effective way of doing this is to create an aerosol which a mixture of gas and particles and breath this aerosol or mist into the lungs. The particles are droplets of liquid containing the medication and the smaller they are the faster they reach the parts of the lung where they have their effect.

Though not called a nebuliser the Metered Dose Inhaler, generally called a *puffer*, works in the same way. The MDI contains a small canister of harmless and eco-friendly gas that propels a fixed amount of the drug for each puff. Each dose is released by pressing the top of the canister. The inhaler is quick to use, small, and convenient to carry. To be effective it needs good co-ordination to press the canister, and breathe in at the same time.

Hospital nebulisers, and until recently, most home-use nebulisers, use compressed air or oxygen passing through a fine jet which breaks up the liquid medicine and creates the aerosol. When oxygen is not available or not needed for therapeutic reasons the compressed air comes from a pump driven by an electric motor. Figure 2 shows a typical mains-powered machine for home use – an Omron CX. These machines are simple to operate and the only maintenance other than the regular cleaning of the drug container and the mouthpiece or mask is the replacement of the air filter.



Fig. 2

A more portable nebuliser is the Freeway Lite II (Figure 2 centre). This machine may be operated from the mains, a car 12 volt connector or its own internal rechargeable battery.

The problems with compressed air nebulisers are (i) noise from the jet (ii) noise from the electric motor and, in the case of a portable machine, (iii) the weight of the motor, pump and battery.

Recently, small, dry cell operated nebulisers have become available and these use a different principle. An electronically controlled element is made to vibrate at ultrasonic frequencies. The element is in contact with the liquid medication and the vibration is sufficient to create a mist of air and very fine droplets. The latest machines have a vibrating element which is a mesh perforated with thousands of laser-drilled holes. These Vibrating Mesh Technology nebulisers produce a very small particle size in the aerosol and this is more efficient and can reduce the treatment time. Figure 1 and Figure 2 (left) shows an Omron NE-U22.

A different direction has been taken with the Respimat Soft Mist Inhaler which could be described as a hand-driven nebuliser. The user twists the device which winds up an internal spring. Pressing a button releases the

spring which then this squeezes a flexible container forcing the liquid out through two fine nozzles, thus forming a soft mist.

There are other aspects to using a nebuliser; ease of cleaning, mask or mouthpiece, vented or unvented, reservoir bag to hold the aerosol, etc. All of these things should be discussed with a medically trained person along with the recommended medication to put in the nebuliser.

Finally – Travelling with nebulisers

FAA and European regulations require that a bronchodilator inhaler is included in the aircraft emergency kit on aircraft registered in Europe or the USA.

The following is extracted from the British Thoracic Society’s guidelines on air travel.

For an acute exacerbation on board the patient’s own bronchodilator inhaler (or airline emergency kit inhaler if available) should be administered and the dose repeated until symptomatic relief is obtained. A bronchodilator administered via a spacer is as effective as a nebuliser.

Nebulisers are not included in the airline medical kit because the aircraft oxygen system cannot provide the high flow rates needed to ensure correct dose delivery, and compressor devices are heavy and bulky.

So if you need to use a nebuliser when flying and you don’t want to use a spacer and puffer then you’ll have to take your own. Most airlines permit use of the small dry cell battery operated nebulisers (except during takeoff and landing) but you should check in advance.

Where Are the Alphas?

Less than ten percent of alpha-1 antitrypsin deficient patients in the United Kingdom are aware of the causes of their condition. Many of the undiagnosed patients have been told that their complaint is asthma, bronchitis, bronchiectasis or some other pulmonary condition. These conditions may be present and may confuse the clinical picture making accurate diagnosis difficult. However, correct diagnosis is important in that it leads on to the most appropriate treatment.

The FIND-A1 project is designed to engage patients, doctors, nurses and other medical healthcare providers in the detection of the many alpha-1 antitrypsin deficient patients who are currently not diagnosed or who are diagnosed as having some other condition. Doctors will be more aware of the symptoms that indicate the presence of alpha-1 antitrypsin deficiency, patients will have the knowledge needed to change their lifestyle in order to live with the condition and society in general will know more about a much under-diagnosed rare disease.

To find out more about FIND-A1 go to website www.find-a1.org or e-mail info@find-a1.org

Over the next few weeks members will receive leaflets for their own use and spares to give to their health care professionals to raise awareness.

In producing this leaflet we have had the support of Professor Sabina Janciauskiene who some of you heard speak in Bristol and London.

In the New Year we hope to start a similar initiative for children suggested by a parent at the Newcastle Meeting – FIND-AlphaChildren.

Help us to help you.

NEWS IN BRIEF

Following on from the European Congress in London in July, we had a few weeks to gather out thoughts and look towards our next events, the Informal Lunch in Newcastle, the Balloon Race and the AGM.

Newcastle Lunch

Dawn & I were joined in Newcastle by Jan Parle, who had joined us on the Board, following the London Congress. Jan came along to see how we do our Informal Lunches. As we have found previously with these lunches, we meet with familiar faces and new ones also, so it was in Newcastle. There was lots of discussion and exchange of ideas and information, it was good to have the parents of 2 Alpha children there, we had met Kerry and Brian in London but in Newcastle we had the chance to meet their 3 lovely children, 2 of whom are Alphas, it was useful and enlightening to hear their experiences since their children have been diagnosed and it was through discussion with them that we had the idea to work on FIND-AlphaChildren, it was good to meet up with Ray and Suzanne again and to meet Suzanne's son, Aiden. By the end of our time together we had a new treasurer, Liz McKenna, Rob's wife, offered to take on the job. All in all Newcastle was a very good meeting and we sincerely hope that those members who joined us felt the same.

The Balloon Race

On 23rd October, I headed off on the early train for Bognor Regis, where Jan Parle had organised for us to release the helium filled balloons, which many of our members, their families and friends had purchased. We sold just under 500 balloons, it was disappointing not to have sold the 1000, but having seen the net full of 500 balloons and helped to anchor it down in the high winds, I don't know how we would have managed with 1000 balloons. Jan's family and friends did a great job, blowing up the balloons, attaching the return tags to them and making sure they did not blow away once the holding net was full. On the dot of 2pm, Jim Brooks, Bognor's Deputy Mayor, did a countdown and helped to release the balloons they soon blew

high in the sky and floated out across the Channel, heading in an Easterly direction.



Preparing for the start of the race



Releasing the balloons

Following the race, tags were returned from quite a number of balloons which were found along the East Sussex and Kent Coasts, however the winning balloon tag was returned from The Netherlands, which was brilliant to think one of the balloons travelled so far, mind it was very windy and the balloons went very high in the sky. The person whose balloon travelled the furthest was Andrew Osborn, who lives in Buckinghamshire, congratulations to him. Thank you to every one who purchased balloons and supported us.

AGM

The Charity's AGM was held on the 30th October in Bristol, the existing Trustees and Board members were voted back in for a further year, we were also very pleased to welcome 3 new Board members who have joined over the last year, Jeff Darkins, Meryl's husband, Jan Parle and in Newcastle we met Liz McKenna, wife of Alpha Rob, who agreed to join us on the Board.

I am pleased to say that at last we have a new treasurer, Liz McKenna was appointed to the post, after offering to take over the task. Liz is well qualified being a retired accountant, so we know our accounts are in safe hands and we thank her for taking on the role.

So it is welcome and thanks to all new Board members and thanks to the whole Board for their hard work and support during the last year and we look forward to moving on to the coming year with the new initiatives we have in the pipeline.

FIND-a1

This is a new initiative to raise awareness of Alpha 1 and encourage GP and hospital clinicians to begin looking to finding the many Alpha 1 sufferers who are yet to be diagnosed, because it is never thought about when they are faced with patients who suffer with COPD, Asthma, Chronic liver disease, Bronchiectasis, to name but a few conditions. Over the next few weeks we will be sending you some leaflets and asking you to take them to your GP, Health Centre, Respiratory Department, Respiratory Consultant etc.

Getting Information

Many hospitals now have a central information point we would ask please that you enquire if

Rob McKenna, joined the Charity back in the summer, he is on the Transplant list and has agreed to keep us in touch with how things progress for him in his waiting time, here is Rob's introduction.

My diary - *a bit about me. My name is Rob and I recently joined the Alpha 1 Group as I have been diagnosed with Alpha 1 Antitripsin for about 9 years . After a long process and many hospital visits I finally got placed on the active list this year and I am currently awaiting a double lung transplant which hopefully will be done at Freeman Hospital Newcastle. I have a great consultant Mr Dimitri.*

I came across the charity Apha 1 Awareness Uk through the internet engine and it has impressed me greatly. I went down to the meeting in Newcastle at the beginning of October and met some lovely people who have partners and children with the same condition as myself. I learned a lot about my condition and for the first time I felt I was not alone with my condition which boosted my self esteem.

At my local health centre I have been battling with my doctor to get emergency antibiotics as I had been suffering with the flu which in turn developed into a chest infection. The doctor for some unknown reason decided in his wisdom to stop giving me antibiotics. I had to threatened him that I would contact my consultant at Freeman Hospital to intervene. It was then he agreed to give me the course of antibiotic. My local doctor needs to read my notes!!!

your local hospital have information about Alpha 1, if they haven't will you please let our secretary, Lin Daniels, know and she will send out leaflets directly to the hospital.

For another project which it is hoped will be launched next year, we need the names and contact details of your GP and/or hospital Consultant, who manages your treatment for Alpha, this is an exciting project, about which you will hear more in the New Year, but to get it off the ground, we need this vital information from you ASAP, so please, email the details to dawn@alpha1awareness.org.uk, info@alpha1awareness.org.uk or write to our PO Box address, the address is at the end of this Newsletter.

2011 Marathon Runners

We are pleased to say that we have we have two runners signed up for Marathons so far in 2011, one, Tracy, in the Brighton Marathon in April and Emma in the London Marathon, this is the first time we have had a London Marathon place in our own charity's name.

Matt Rowley who did the Ultra Marathon in July of this year is also hoping to continue to run and race money on behalf of the Charity.

I have recently been trying get the charity's leaflets into my doctor's surgery as well as with my pulmonary rehab nurse. I have now succeeded in distributing the leaflets to assist in the awareness of the condition and to encourage people who have the condition to come forward and make themselves known to the charity.

On returning to Bristol airport from attending the Charity's AGM on Sunday Liz and I met a lovely lady from Cumbernauld who was in a wheelchair and she told us she was suffering from COPD and was finding it difficult to understand as she had always been a healthy person. Liz spoke to her about my condition and gave her a few leaflets to give to her doctor and asked her to make contact with her doctor for the Alpha test as she appeared to explain similar symptoms associated with Alpha 1. Her name is Mary Gilhooley and she gave us her telephone number. She was very pleased to meet us and she explained she felt very alone with her condition and was delighted to meet someone else who understood about lungs!

I have also started posting our Alpha website on Facebook and asked friends to pass this on to their friends too - again to spread the word. If you are on Facebook can you please do the same?

Dawn asked me to write this diary. I will keep you all updated on my progress. The AGM held in Bristol was very good and before I forget there is a great chip shop near Lins house.

Well that's all from me for now and I will try to post this on the forum .

Rob McKenna

Met Office service for health warnings

The following item is taken from the Met Office website:

<http://www.metoffice.gov.uk/health/public/healthy-outlook>

Healthy Outlook® COPD forecast alert service

Healthy Outlook® helps people with chronic obstructive pulmonary disease (COPD), including emphysema and chronic bronchitis, stay well throughout the year.

Supported by the NHS

Chronic obstructive pulmonary disease (COPD) is the collective name for a group of conditions, including chronic bronchitis and emphysema. Weather conditions can significantly increase the risk of ill health and hospital admissions for people who have COPD. In winter a combination of environmental factors including virus levels can make symptoms worse. In summer, extreme heat can also pose a threat.

The Met Office has created Healthy Outlook® to help people with COPD take control of their own health. We monitor environmental conditions and warn people when their health is likely to be affected, giving them the opportunity to take action to stay well.

How can you sign-up to the service?

Healthy Outlook® is delivered through local GP practices in areas where Primary Care Trusts have signed-up for the service. If you would like to receive Healthy Outlook® please contact your GP surgery to find out if it is offering the service.

How much does it cost?

Healthy Outlook® is paid for by Primary Care Trusts and, in some instances, GP practices. Individuals will not have to pay to receive the service.

Last Updated: 4 November 2010

Note from AAW not all GPs and PCTs subscribe to this service, but it has to be worth asking your GP.

IMPORTANT MESSAGE

To Everyone who has had a Test Kit. We have heard from the Test Laboratory in Dublin that they have some test results that they cannot return to GPs, because the GP has failed to fill in the correct return address. If you had a test kit from us for yourself or a family member and the GP has not received the results, please ask your GP to contact the Test Laboratory or our secretary, Lin Daniels.

It is important that these results are returned to the GP who sent them, not to do so is a waste of everyone's time and money.

Test results take around 6 weeks to be returned to your GP and remember it is necessary for you to return to your GP for the test results, they will not be sent to you.

We have also been told by the Test Laboratory that only 20% of the Test Kits we have sent out have been returned to the Laboratory, this means that some of you still have Test Kits lying around not yet taken to your GP for the test to be done.

Sadly if the Kits you receive are not used, our suppliers, who provide them to us at not cost to the Charity, will be unwilling to send us more supplies. So if you have a kit, please take it to your doctor and get the test done. Thank you

Christmas Cards

Christmas Cards are still available, an order form is with this Newsletter, to make sure you get your cards in time for Christmas, the last date for orders is Saturday 4th December 2010.

Don't forget our online forum, lets you chat to other Alphas, it can be found at <http://techno.demon.co.uk/a1aforum>, it would be great to see you there.



*With Best Wishes to All Members of Alpha 1 Awareness UK
For a Very Merry Christmas
&
A Happy & Healthy New Year
From*

The Board Members of Alpha 1 Awareness



If you wish to contribute in any way to future editions of the Newsletter, please contact at the address below.

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