

Newsletter

Alpha Awareness

Vol 4
Issue 1
Jan 2012

A Word from the Chairman

Winter is the time for Alphas to hibernate. When the air is cold and damp it can be a trying experience to leave the comfort of home. Even when out and about many of the people we meet have seasonal coughs and sniffles – an inconvenience for the healthy but a real danger for those with reduced lung function. Therefore, it is not surprising that across Europe the Alpha groups are quiet – though no doubt they are preparing for events to be held in warmer weather.

In Spring we may expect the report from the expert working session on Alpha-1 antitrypsin deficiency held last October in the European Parliament in Brussels. The meeting identified the issues facing Alpha-1 patients and prepared concrete recommendations to help the European Institutions and Member States to determine the best way forward. The report will be a tool to raise awareness with politicians. We hope that the recommendations will eventually trickle down to Member States' health services such as the NHS.

The integration of Talecris with Grifols is taking time and very few statements are coming from Grifols as to the shape, aims and policy of the new enlarged company. Victor Grifols, chairman and CEO of the company, was recently selected as *Business Leader of the Year 2011* by the Spain-US Chamber of Commerce. We hope that he will lead the company to a charitable view of the associations that represent the patients who use its medicinal products.

At least, Grifols has continued to support the plan to assist UK GPs and consultant clinicians with informed medical opinion in the value of augmentation therapy for lung affected Alphas. From this data the doctors can then support requests for treatment with medical products not yet licensed in the UK – the so-called Named Patient Programme. We hope to hear more on the progress of this initiative. . .

. . . when Summer comes.

Alan Heywood-Jones

Bronchiectasis

Alpha-1 antitrypsin deficiency is a condition that can lead to many complications and just one of these is bronchiectasis.

Bronchiectasis is the destruction and widening of the large airways of the lung. It is in the same group of obstructive lung diseases as emphysema, bronchitis, asthma, and cystic fibrosis. The lung disease usually results from an infection or other condition that injures the walls of the airways. The injury to the walls is the start of a cycle in which the airways slowly lose their ability to clear out mucus. The mucus builds up and creates an environment where bacteria can grow. This leads to repeated lung infections. Each infection, which can be quite serious, then causes more damage to the airways.

With the passage of time, the walls of the airways become stretched, slack and scarred. Being out-of-condition, they cannot move air in and out. This can affect the amount of oxygen that reaches the bodies organs. If the organs are starved of oxygen then the results can be serious illnesses.

Bronchiectasis can affect just one section of the lungs or many sections of both lungs. It usually begins in childhood but symptoms usually only appear months or years after the start of repeated lung infections. Apart from bronchiectasis caused by infection or routinely breathing in food particles while eating, there may be congenital factors involved. The most common of these is cystic fibrosis - CF is the cause of about a third of all bronchiectasis cases in the United States.

Alphas have been found to be particularly susceptible to bronchiectasis but the reasons for this are not known. As with many complaints that may be associated with AATD, the number of patients in study groups is often quite low and researchers do not confirm that there is a definite link.

Symptoms include a chronic cough with large amounts of sputum being produced, a cough that is worsened by lying on one side, SOB worsened by exercise, weight loss, fatigue and wheezing.

Diagnosis techniques include a chest x-ray, CT scan, a sputum culture or a blood test. When listening to the chest with a stethoscope, the physician may hear wheezing sounds or small cracking sounds. Of all these tests, CT scanning remains the most reliable tool.

Treatment is aimed at controlling infections and bronchial secretions, relieving airway obstruction, and preventing complications. Regular, daily drainage to remove bronchial secretions is a routine part of treatment. A respiratory therapist can show the patient coughing exercises that will help. Medicines such as antibiotics, bronchodilators, and expectorants are often prescribed for infections.

Like AATD, bronchiectasis cannot be cured but with the appropriate care most people who have it can enjoy a good quality of life.

If you have any concerns about your health or if your condition changes for the worse then consult your GP or specialist immediately.

The World Health Organization (WHO) recommends that all adults should be tested for alpha-1 antitrypsin deficiency if they present with the following problems; COPD, asthma, and others not listed here. Given this and the possible, but unproven, link between alpha-1 antitrypsin deficiency and bronchiectasis, it is surprising that the *British Thoracic Society guideline for non-CF bronchiectasis* includes the following:

“Routine screening for a1-antitrypsin deficiency is not required unless the radiological investigations suggest basal emphysema.”

Alan Heywood-Jones

News in Brief

Annual General Meeting

At the AGM in November 2011, all board members and trustees were re-elected to post, with one change Jeff Darkins was elected as Treasurer, we thank Jeff for taking on the job. As many of you are aware we have been without a treasurer for some time, which has meant I have been doing the job alongside my job as secretary, so it is good that I can now relinquish this role and thank Jeff very much indeed

Lin Daniels

The Charity Board

Alan Heywood-Jones	Chairman and Trustee	
Lin Daniels	Secretary and Trustee	
Jeff Darkins	Treasurer and Event Support	
Dawn Heywood-Jones	Special Projects and Trustee	
Meryl Darkins	Membership Secretary	
Neil Jackson	Forum Co-ordinator	Ex officio

Other News

During November Jeff Darkins attended a day course, offered free to treasurers and/or trustees, about managing the finances of a Charity. Lin Daniels attended a 2 day conference looking at fundraising for small Charities, once again this was offered to small charities free of charge, this is the second course

LAD/AAW Newsletter
Jan 2012

looking at fundraising that Lin attended, last year, more details further on.

News from the Kayakers

Chris Martin-Brown, who organised the kayak trip and cycle ride to raise funds for Alpha 1 Awareness UK, in the spring of 2011, has contacted us

again this year to say he is planning another kayak adventure this year, unlike last year it will not be a day long event, it will take place over 14 days, with Chris and others, kayaking from Bideford in North Devon around the Devon and Cornwall coast to Exmouth and on to Exeter, where they hope they will be met by the cycling team who hopefully will cycle from Okehampton to Exeter. This is an amazing plan, we are very grateful to Chris and his friends and look forward to hearing how their plans and training progress in the coming months.

Health Fair ATR Winchester

I was pleased to be invited to attend the Health Fair at the Army Training Regiment in Winchester, at the beginning of January. This once again gave me an opportunity to go out and

talk to young people in particular, about Alpha 1, it was a successful day. At the end of the day Sgt Vicki Cornell, who had organised the day, presented me with £224, money that had been raised through the day, by raffling a stunt car day and also asking the recruits to "beast their PTI", in other words, pay £1 to see the Physical Training Instructors do all the press ups, sit ups, squat thrusts etc that the PTIs normally hand out to the youngsters to do. The money was a complete surprise, I was very touched that they should raise such a good sum of money for the Charity, considering the majority of those attending the Health Fair, were trainee recruits aged around 17/18 years of age. Our thanks go to them all.

Lin Daniels



Could you, a member of your family or a friend raise money for Alpha 1 Awareness UK in the British 10K London Run on Sunday 8th July 2012? We have been offered 6 places for this year, also for 2013 and 2014. We know we have quite a few runners in our membership so we would love to hear from you.

The British 10K London Run is the UK's most prestigious and sought-after 10km road race which is staged on the world's greatest route through the heart of central London. 25,000 runners fill the streets of the nation's capital and get the unique chance to run past many of the country's greatest landmarks including Big Ben, The London Eye, St Paul's Cathedral, Trafalgar Square and Westminster Abbey. Abilities range from charity fundraisers and recreational runners right through to Olympic champions!

The 2012 event is staged just 19 days before the start of the Olympic Games and the excitement and buzz within London at this time should make for a truly special occasion and the best British 10k London Run in its 12 year history.

<http://www.thebritish10klondon.co.uk>

If you would like to take up one of the 6 places in the 10K run, please contact Lin Daniels, at secretary@alpha1awareness.org.uk or by writing to Lin at Alpha 1, PO Box 2866, Eastville, Bristol BS5 5EE. We need to know as soon as possible

LAD/AAW Newsletter
Jan 2012

if you, a family member or friend wish to take up one of the places, so please will you make contact by the 29th February, we will notify you at the beginning of March to confirm your place and send you sponsor forms also details of how you can set up a Justgiving page if that is an easier way for you to raise sponsorship.

This should be great event, with London looking it's very best following the Queen's Jubilee Celebrations in June and the start of the Olympics in July and it gives us a chance to really get Alpha 1 noticed.

Fundraising

During 2011, I attended 2 different day conferences, both on the subject of fundraising for small charities. In the current economic climate all charities are finding raising funds a challenge and we at Alpha 1 Awareness are no different.

Some examples of fundraising that were suggested, discussed or had been used successfully by other charities included

- Marathon runners are a very common way to raise funds; also people doing treks, either in the UK or abroad.
- Corporate sponsorship - approaching companies, with whom members of the Charity have connection with, either themselves directly or through members of their family or friends - becoming a company's Charity of the Year
- Setting up of direct debit giving
- Approaching businesses for donation of goods or services which can be used in raffles or prize draws.
- Sponsorship in kind from companies, to provide services i.e. printing, stationery, postage, web hosting and design.
- Nowadays the internet provides a very good tool for fundraising, AAW already uses Justgiving.

- Social Media e.g. Twitter & Facebook. Twitter campaigns in particular have proven very successful when Charities have specific projects they need funds for.
- Lottery funding

On top of these ideas which are all looking at raising larger sums of money, all the Charities recognised the importance of fundraising by their members, who organise small fundraising events with their families and friends, e.g. coffee mornings, bake sales, car boot sales, garage sales, garden parties, supper parties, balloon races, BBQs, quiz nights the list is endless, there are all kinds of ideas people can come up with. There are things like sponsored silences, bedroom tidying, car washing that children or grandchildren can do

Both conferences were quite intense and I was on information overload, but I did come away with a much better idea of how we need to "up our ante" if we are going to survive the current economic downturn.

One thing that was very clear, ALL fundraising how ever large or small, also helps to raise public awareness of the Charity and the cause it supports, in our case it is a chance to raise more public awareness of Alpha 1 Antitrypsin Deficiency.

Lin Daniels

Can You Help ?

The Charity Board has decided that we would like to invite 2 or 3 members to liaise with each other, come up with ideas that can be rolled out to the other members and co-ordinate fundraising for us. You do not need to live close to each other, as much can be done via email or even Skype, which I know many people now use. This is an opportunity for you to help your Charity.

If you would like to become involved with a fundraising sub-group please contact Lin Daniels, either by email or post.

Thanks

Thank you to both of these young couples, who both have Alpha children, for all the support they continue to do to support the Charity. Kerry and Brian Cooper once again took a selection of our Charity's Christmas cards along with some of our wristbands to sell in the Post Office which they run in Cumbria. Alan Wooler has been in touch to say that the company he works for was looking for a Charity to support for 2012, Alan put Alpha 1 Awareness UK

forward, he was successful and so AAW have their first corporate sponsor for this year. Alan and his wife Emma, have a son who suffers with Alpha 1 and they have both been brilliant at raising money for the Charity. Living in a small Derbyshire town where Emma works in the local school, Emma and Alan have put the Charity collecting tins in all the local shops and Emma encouraged the school to raise money by holding events, Alan also asked a friend to design labels for our collecting tins and Alan has produced lovely labels for the tins, all properly printed.

Recipe Book

You may remember in our last Newsletter I asked for recipes, in order that I could compile a small recipe book. Sadly I only received recipes from one person, this was very disappointing, so unless I receive any further contributions in the next month, I will be abandoning the whole idea.

Lin Daniels

International Rare Disease Day - 29th February

The European Organisation for Rare Diseases (EURORDIS) has developed this information pack to help you plan and implement your own awareness-raising campaign on or around the last day of February every year.

As a member of the European Organisation for Rare Diseases (EURODIS), Rare Disease UK (RDUK), of which Alpha 1 Awareness UK is a member, have notified us of International Rare Disease Day

The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

The campaign targets primarily the general public but it is also designed for patients and patient representatives, as well as politicians, public authorities, policy-makers, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.

Since Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008, more than 1000 events have taken place throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage.

The political momentum resulting from the Day has also served for advocacy purposes. It has notably contributed to the advancement of national plans and policies for rare diseases in a number of countries.

Even though the campaign started as a European event, it has progressively become a world event, with the US joining in 2009 and patient organisations in 56 other countries participating in 2011. We hope many more will join in 2012. Our objective is for the WHO to recognise the last day of February as the official Rare Disease Day.

Stephen Nut the Executive Officer from RDUK says;

Unlike in previous years we will not be holding parliamentary receptions to mark Rare Disease Day this year (our reasons for this were outlined in our last newsletter [available here](#)). This does not mean that we won't be working hard to raise awareness of rare diseases and we are delighted that a number of our members have organised events and other activities.

We are hopeful that the consultation on the UK plan for rare diseases will be ready to launch on Rare Disease Day. This will provide an excellent springboard to raise awareness of the plan. We will stay in contact with the health departments in England, Scotland, Wales and Northern Ireland and fingers' crossed we will be able to bring you more news on this shortly.

Like last year, there will also be a pull out supplement about Rare Disease Day in the Independent newspaper, so if you would like copies to distribute, please let us know how many so we can arrange for them to be delivered to you in time for the 29th Feb.

Also, if you are holding events, remember to take photos so I can include them on our website and newsletter.

stephen@raredisease.org.uk 020 7704 3141

Best wishes,
Stephen Nutt
Executive Officer

For more information go to www.rarediseaseday.org
Raising awareness of rare diseases with local or national politicians is not an easy task for individual patients or their families, but it is possible to spread the word amongst friends and neighbours. Why not hold an Alpha 1 Coffee Morning, Bake Sale or a Quiz Night on 29th February. Little by little we can raise awareness that there are many rare diseases out there - Alpha 1 Antitrypsin Deficiency is one of them. You can download posters from the RDUK website for Rare Disease UK

If you would like a supply of our information booklets and leaflets, please contact Lin Daniels at secretary@alpha1awareness.org.uk or write to her at the PO Box address at the end of this Newsletter.

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.

Alpha 1 Awareness UK

Contact us at:

Alpha 1

PO Box 2866

Eastville

Bristol BS5 5EE

Email: secretary@alpha1awareness.org.uk

www.alpha1awareness.org.uk