

# Newsletter

# Alpha 1 Awareness

Vol 5  
Issue 2  
May 2013

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## A Word from the Chairman

For many years Andi and Jackie Osborn have come to our meetings and help raise money for the charity. It gave me great pleasure that now they have agreed to join the board of the charity. We value their opinions and practical help with the info Days. Those of you who attended the 50<sup>th</sup> Anniversary Info Day in Bristol will recall that Andi and Jackie manned the Alpha-1 Awareness Shop. Talking of which, we now have an Online Shop which sells a variety of products branded with our Alpha-1 logo – all to help with spreading awareness of the condition. I would like to thank Alan Wooler for all the work involved in creating the shop. Neil and Lorna Jackson are working very hard on promoting the items for sale in the shop using Facebook and Twitter. Thank you all.

On April 12<sup>th</sup> and 13<sup>th</sup> the Fourth International Alpha-1 Patient Congress was held in Barcelona. The guest of honour was Sten Eriksson who in 1963 was the co-discoverer with Carl-Bertil Laurell of AATD. Lin Daniels, Dawn Heywood-Jones and I attended the Congress representing our charity. Delegates from 23 countries discussed priorities for action. They considered awareness of Alpha-1 to be the most important need for the Alpha-1 communities in their countries. As well as finding out about the issues in our various countries we met many eminent researchers and clinicians including old friends who have spoken at our Info Days – Sabina Janciauskiene, Bibek Gooptu and Dino Hadzic.

Two presentations at the Congress were memorable. Professor Rob Stockley spoke about the value of computed tomography (CT) scans as a better measure of lung degradation than the usual lung function tests. We invited him to give the same presentation at our Bristol event. Professor Albert Farrugia from the Plasma Protein Therapeutics Association (the companies that make augmentation therapy products) spoke about Health Technology Assessment (can we afford to pay for treatment). His experience of justifying preventative treatment for haemophilia is being carried forward to studies on Alpha-1. Dawn and I have heard him many times before and his authority in this area is undoubted.

At our Info Day in Bristol Professor Lomas mentioned the new Alpha-1 Clinic at the Royal Free Hospital that he and his colleagues have established. The clinic is run by Dr John Hurst, Dr Bibek Gooptu and Professor Lomas. It is designed to cover all aspects of antitrypsin deficiency: a joint clinic run by hepatologists (liver doctors) and respiratory physicians. Individuals referred to the clinic will have blood tests, chest X-rays and lung function tests as well as liver scans. The clinic will also offer opportunities to take part in research studies aimed at understanding antitrypsin deficiency and developing a cure. This promises to become a real centre of expertise.

The results of the clinical trial sponsored by CSL Behring study have been announced. They show the efficacy of augmentation therapy in preventing the loss of lung tissue as measured by CT scan lung density at full inspiration (TLC), which is a more sensitive measure of disease progression than conventional parameters. This is the first prospective study to demonstrate the efficacy and safety of replacement therapy in a randomised, placebo-

controlled trial using this parameter. We hope that this scientific evidence helps us in our fight to have replacement therapy available in the UK.

Finally. The weather is not being kind to people with breathing difficulties. One day it is warm and sunny and the next cold, wet and blustery. Let us hope that May eventually follows the proverb for March and having come in like a lion goes out like a lamb. I wish you all a healthy and easy-breathing, somewhat delayed, Spring.

*Alan Heywood-Jones*

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## **Let's Clear the Air**

Poor air quality can be especially harmful to Alphas and other vulnerable groups such as children, the elderly, and those with heart or lung diseases.

For many years indoor air pollution received significantly less attention than outdoor air pollution. The latter often came from industrial processes and transport emissions – areas in which legislation and control are easy to implement. However, in recent years the dangers of exposure to indoor air pollution have become more apparent.

Some pollutants are found mainly indoors. These include tobacco smoke, radon (a radioactive gas formed in the soil), gases or particles from burning fuels, chemicals, and allergens (dust mites, pet dander, etc.). Others include carbon monoxide, nitrogen dioxides, particles, and volatile organic compounds and these can be found both outdoors and indoors.

Our legislators have already moved in on smoking in public places and all well-informed Alphas know to avoid tobacco smoke in their own or friends' houses. However this is only the start of the battle.

Many of us might spend up to 90 % of our day indoors – at home, work or school. The quality of the air we breathe indoors also has a direct impact on our health. It may come as a surprise that the air in an urban street with average traffic might actually be cleaner than the air in your living room. Studies indicate that some harmful air pollutants can exist in higher concentrations in indoor spaces than outdoors.

In 2007 researchers in Scotland found that fine particulate pollution levels were, on average, four times the maximum recommended by the U.S. Environmental Protection Agency. Much of this pollution came from second-hand smoke but both smokers and non-smokers were negatively affected. Interestingly, an analysis of the effect of indoor air quality on smokers versus non-smokers revealed that smokers suffered greater adverse effects than non-smokers. Earlier studies of indoor air quality had tended to exclude smokers, which may have resulted in an overall underestimate of the impact of indoor air quality on health status, as well as painting an unrealistic picture of the COPD patient population.

So what can we do? A good start is to use unscented products. Some perfumes and scents trigger COPD symptoms in some people. Choose cleaning products are fragrance-free and this may help avoid breathing difficulties. Staff working at the Alpha 1 Foundation offices are requested to use unscented shampoos, soaps and antiperspirants. Unfortunately, the use of strong scents seems to be a growing trend. Once the domain of women, fragrances are now worn by men and no respectable room is without its plug-in freshener.

We can keep our homes ventilated. Opening windows and doors when possible, running exhaust fans, and installing an air filters are great ways to ventilate our homes and reduce

the amount of allergens and irritants that are inside. We can stick to natural cleaning products – or at least stay away when bleach or ammonia is being used. The same goes for when the painters and decorators are in. And of course we can try to reduce dust. Dust mites are a nuisance, so keep carpets clean, regularly wash curtains, wipe down dust, and keep clutter to a minimum.

After doing all these virtuous things there are still unexpected pollutants that are difficult to avoid – someone leaving a candle to gutter out and die, a neighbour using too much lighter fuel to light a barbecue, a fuel spill on a service station forecourt, and many more.

The best advice would seem to be ‘stay vigilant’.

*AHJ*

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## 50<sup>th</sup> Anniversary Info Day

The Alpha-1 Awareness Meeting in Bristol held on the 11th May was attended by more than 70 people; Alphas, families and friends.

Since we were marking the 50<sup>th</sup> anniversary of the discovery of alpha-1 antitrypsin deficiency it was very appropriate to start the day with a talk by Professor Sabina Janciauskeine who worked in Malmö with the co-discoverer Carl-Bertil Laurell.



Professor Rob Stockley gave an impressive presentation which compared the progression of lung disease as measured by Lung Function Tests and Computerised Tomography (CT) scans. While the familiar breathing tests are relatively easy to conduct and the numbers are widely used as measures of COPD severity, they are poor indicators of what is happening within the lungs. From this it would seem that CT scans are the way forward and it will be interesting to see how the NHS use them for the medical management of alpha-1 antitrypsin deficient patients.



Heidi Haden spoke about the effect that her mother's Alpha condition had on the family and how Heidi determined to help our charity raise money. Heidi trained for many months and eventually ran in the 2013 London Marathon. Her story of persistence and determination was very personal and it showed that with the correct will the impossible can be made possible.



The head of the European Lung Foundation (ELF), Monica Fletcher, talked about the work of the Foundation and how it, along with the European Respiratory Society, is trying to educate medical professionals and patients about the many lung diseases.

The ELF has started a Patient Ambassador Programme which is an online learning course which aims to help patients speak to doctors, the media and politicians about their condition.



Professor David Lomas and Doctor Tamir Rashid gave a joint presentation on their researches and their two approaches to finding a cure – preventing the polymerisation of PiZ alpha-1 antitrypsin and correcting the genetic sequence which leads to the production of PiZ alpha-1 antitrypsin



*Prof Lomas*



*Dr Rashid*

In our Newsletter of March 2009 we reported the start of the programme to generate patient-specific stem cells for research into liver disease at Addenbrookes. At that time we reported that the study was aimed at advancing knowledge and it would not result in any direct medical benefit to specific patients. Such has been the progress in this field that things look slightly different now and both speakers received spontaneous applause as they announced their findings.

We were extremely pleased that John Walsh, the co-founder and CEO of the Alpha 1 Foundation made the long journey to the United Kingdom to talk about the American experience and how they use patient power to effect change – lessons that we can learn to advocate better treatment here.

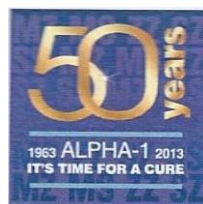


Of course, it being an anniversary, we also had a decorated cake and for the 13 children who attended the crèche there were presents which included Alphonse teddy bears for first timers.



*Claire McGown from CSL Behring cuts cake*

*We are grateful to CSL Behring for their support and thank them for the donation towards the Information Day, commemorating the 50<sup>th</sup> Anniversary of the discovery of Alpha 1, which we held on 11<sup>th</sup> May 2013*



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## **NEWS IN BRIEF**

### **Alpha-1 Clinic at the Royal Free**

A new Alpha-1 Clinic has been established at the Royal Free Hospital in North London. The clinic is run by Dr John Hurst, Dr Bibek Gooptu and Professor David Lomas and has been designed to cover all aspects of antitrypsin

deficiency. It is a joint clinic run by hepatologists (liver doctors) and respiratory physicians. Individuals referred to the clinic will have blood tests, chest X-rays and lung function tests as well as liver scans. The clinic will also offer opportunities to take part in research

studies aimed at understanding antitrypsin deficiency and developing a cure.

Referrals can be made to Dr Hurst at:  
The London Alpha-1-Antitrypsin Clinic  
Respiratory Medicine GF673  
Royal Free Hospital  
London  
NW3 2PF



### **Membership Matters**

Membership numbers continue to grow steadily, in fact, since I joined in 2009, we have seen a five-fold increase in membership to over 250. There is a steady increase of about two, per month, with an upsurge after any one of our events, like the recent successful 50th Anniversary Celebration. Our mission is to raise awareness of the condition, so, hopefully each of our members has a network of friends and family, who now know about the condition and about our work.

With the high cost of postage, we are fortunate that most members opt to receive their communication by email, However, I have one plea for any members who change their email address - please let us know your new address. Email addresses change much more often than postal addresses, which we would also want to keep up to date.

In the 50th Anniversary Celebration, some members indicated that they would like to get in touch with other alphas in their geographic area, for mutual support. This seems a very good idea for those who want it. We are looking at the best way of achieving this, while maintaining absolute confidentiality of your email addresses, and respecting the wishes of those who would not want to be part of such a scheme

Please keep up the good work of spreading the word about alpha 1 antitrypsin deficiency to your family, friends, GP, chest clinics and so on, and help us recruit more members, so that we become a stronger lobbying group

*Meryl Darkins*

### **Parent Support News.**

Having met some of the parents at the conference it came to light that many of us face the same issues with our alpha children. Sadly often we are left to wonder if this is just a quirk of our child. So I am proposing that we have a support group where we as parents can voice our concerns, issues, frustrations or just have a laugh. This will be an email group where we can all communicate and support each other when the need arises. It won't just be for our concerns but also where we can share some of the highlights and mile stones of our children. After all we like to know how the children are doing.

If you would like to join this group then please email me on [emma@alpha1awareness.org.uk](mailto:emma@alpha1awareness.org.uk) so I can add you onto the list.

I look forward to hearing from you and getting this group up and running!

*Emma Wooler*

### **New Shop**

The conference saw the new Alpha 1 Charity shop go live. It has taken a lot of work and there are still a few tweaks to be made but it is now fully up and running and waiting for you to visit and place an order.

We have a lot of fantastic items that are designed to raise awareness and money of course! On offer are new products to the charity from lapel badges, trolley coins, shopping bags and more. We also have the old favourites, Christmas cards, t-shirts, sweat shirts etc.



So pop along to the shop and take a look, you will find lots to buy! [www.alpha1shop.org.uk](http://www.alpha1shop.org.uk)



*Alan Wooler*

### **Facebook, Twitter & Forum**

It's been quite a busy few months for us on Facebook and Twitter, we're happy to say. We're lucky enough to have a growing band of people sharing all kinds of Alpha1 information on the private, members-only Facebook Group: helping each other out, asking and answering questions, or sometimes just supporting each other and being there. The Alpha1 Awareness Team try hard to keep up to date with breaking Alpha news and information - and you can always be sure that our well-connected members will pick up anything that they miss, and start a new discussion - which is exactly what our Facebook Group is for! If you're not already signed up, and you use Facebook at all, please pop along to <http://facebook.com/groups/alpha1awarenessuk> and hit the 'Join' button - we'd love to have you on board, and there will be plenty of stuff for you to read and comment about. We have new people joining all the time (most of whom are either Alphas, family-members or carers), so you'll not be the new kid on the block for too long, if that's the sort of thing that worries you! We're a happy bunch, and we play well with strangers! Our main, public Facebook Page (<http://facebook.com/alpha1awarenessuk>) is growing fast, in the short time that it's been online. This page is different from

the private Facebook Group - whereas the Group is for members-only discussions (Alphas helping Alphas), the Page is for promotion of the Charity's activities, and highlighting those fabulous people who fundraise for us, and is your 'one-stop-shop' for all sorts of Alpha1 news that we've managed to dig up from all around the world, as soon as it breaks. We've already breached the '100 Likes' target we had set at launch a few months ago, and this will help us raise in prominence on Facebook - and the more noticeable the page is, the more we're spreading awareness of Alpha1, which is of course our main aim! Now we're aiming to reach 500 Likes - so please remember to signal your appreciation for the charity by hitting the page's Like button, if you haven't already!

Over on Twitter

(<http://twitter.com/alpha1uk>) we've been trying hard to promote the new online shop, and we've had some retweets by other Twitter-users at home and abroad. We've also highlighted the Alpha 1 Alliance's E-petition several times, and drummed up a few more signatures for this crucially important campaign to get us antitrypsin replacement therapy in the UK under the new NHS arrangements. If you've not already signed it, please hurry along as soon as you can, because the closing date for signatures is 17th July 2013 - so there isn't long left! And if you have already signed it, please make sure you tell someone new about it - a friend, a family-member, someone at work... anybody! After the deadline, the petition will be presented to government and the NHS management, so you can see we need those extra signatures, fast! You'll find it

<http://epetitions.direct.gov.uk/petitions/39732>

Finally, our online Forum still continues to be used

(<http://techno.demon.co.uk/a1aforum>), but is fair to say that things have slowed down a little in recent months - due largely to the interest in Facebook. We

think it's fair to acknowledge that Facebook is a much more commonly-used arena for people to chat in, so most new discussions tend to arise there. However, we make an effort to copy across the more important items to the Forum, so that the users who prefer using Forums to Facebook, can still make their voices heard. We're working on ways to try and automate this process a little (for information that is not personally sensitive), so that the Forum doesn't lag behind Facebook too much, so watch this space.

We'd like thank all of our contributors and responders - on Facebook, Forum, and Twitter. Our online community is a vital link for us all to keep each other informed, to cheer us up when we are having a dark day, and to meet and make new friends who understand our special situation. Without them, there'd be no group, and nothing to talk about - so please keep the chats and the news coming!

*Neil & Lorna Jackson*

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## **Fundraising**

### **Proact Fund Raising**

When not busy being a dad or doing charity work I work for Proact. My CEO is a true family man and when he heard about my son he wanted to help. So for the last 2 years he has taken Alpha 1 Awareness on as one of two charities to raise money for. His support has been amazing and vital in helping raise money and awareness.

Last month 4 people did the Sheffield Half Marathon raising £330

Last week the whole company, customers and suppliers took to the field to play at the Chesterfield Football stadium and raised a total of £260



Proact Football game

In July some of my colleges will be doing the 3 peaks challenge they have so far raised £633.

Later this year there will be a Grand Charity Ball with a 3 course meal and silent auctions. It is a grand affair and raised an amazing amount of money last year. It was at this event last year that my speech touched the heart of one of Proact's external trainers and she is going to do Cheshire Triathlon and so far has raised an amazing £580.

I have been humbled by the support of my CEO and colleagues in helping me to raise money and awareness. They have raised a staggering amount of money and are still busy coming up with ideas to raise even more! I cannot thank them enough.

*Alan Wooler*

### **British 10K Run**

The British 10K run is taking place once again this year in London, it is being held on Sunday 14th July, we have 6 runners this year, running to raise money for Alpha 1 Awareness UK, who as I write are all busy training for the event. So on behalf of everyone at the Charity, we thank Lisa & Dave Johnson, L.J Cooper, Vicki Cornell, Keith Daniels & James Lanceley for their support and wish them luck for the run

### **Sponsored Slim**

Well done to Jackie Osborn on losing 2 stone and raising £200 for us, thank you Jackie.

## Other Fundraising Efforts

### South West Kayak Charity Challenge

4 kayakers are planning to sea kayak from Bude in Cornwall to Exeter, following the Northern coastline of Cornwall, around Lands End, along the South Coast of Cornwall and Devon ending in Exeter. Chris Brown-Martin, who is an Alpha, and some of his friends, did a kayak and cycle event in 2011 to raise money for Alpha 1 Awareness UK and Devon Air Ambulance, but he wanted to do more of a challenge.....

**The Challenge** ... in brief... 4 kayaks, 4 paddlers, 300miles of coastline (approx), 1 land support crew, 2 weeks...

**Who...** Chris Brown-Martin, Matt Retter, Chris Lake & Steve Carter.

**When...** August 2013 - aiming to finish in Exeter at the Quay on Bank Holiday Saturday (24th August)

**Why...** again, in brief, to support 4 charities - Devon Air Ambulance Trust, Cornwall Air Ambulance Trust, Surf Life Saving GB and **Alpha1 Awareness UK**.

If you are in the Devon or Cornwall area, in August between the 10<sup>th</sup> and 24<sup>th</sup> keep a look out around the coastal area, you never know you may well see these brilliant guys and their back up team, if you can be in Exeter on 24<sup>th</sup> August when they reach the end of their journey, please go along and give them a big, big, cheer.

Follow their story and their journey at [www.southwestkayakcharitychallenge.co.uk](http://www.southwestkayakcharitychallenge.co.uk). Thank you to all the team, we wish them all the luck in the world, fair weather and sunshine, but not too hot, stay safe.

**Great River Race** we are delighted that we have 2 boats in the Great River Race,

supporting Alpha 1 Awareness UK, it looks from the website as though it will be a great event, check out the website for yourself at [www.greatriverrace.co.uk](http://www.greatriverrace.co.uk), many of the boats taking part took part in the Jubilee River Pageant last year. Look out on our Facebook News Page and our website for more news as we get it and there will be photos in the September Newsletter.

**Great River Race is held in London every year on the River Thames The UK Traditional Boat Championship**

**21 Miles from London Docklands to Ham in Surrey  
Saturday 7th September 2013  
Starting Cannon - 11:40am**

**The Great River Race, London's River Marathon, is a spectacular boat race up the River Thames that attracts over 300 crews from all over the globe and appeals to every level of competitor from those who enjoy fun, fancy dress and charity stunts, to serious sportsmen and women who like to win. A great fun day out for competitors and spectators alike.**

**Brighton Marathon 2014** Chris Lyon, has a place in this marathon and is running to support Alpha 1 Awareness.

**Coffee Morning** Scott Barron and his partner Emma, whose little boy has Alpha 1 held a coffee morning at their local school and are planning another one for September.

It is wonderful that so many people wish to help us raise funds, which in turn goes towards us holding Information Days, Informal Lunch and Learns and producing information booklets that enable us to help you our members understand and learn more about Alpha 1. It is also helping us to raise much more awareness of Alpha 1.

A huge thank you, from everyone at Alpha 1 Awareness, to all those who are



so willing to help us in so many amazing ways.

We love to hear about ways in which you are supporting and helping us, so please drop us an email or a line in the post.

### **Many Happy Returns**

Alpha members raise funds in many different ways. Last year there were sponsored slims, kayak races, dances , cake sales as well as the 10k Diamond run held in London on July8th. ProAct is a company that has been particularly active and generous in their donations to us. The participants in these events usually chose JustGiving as a convenient and safe way of attracting their sponsors who can give their donations easily. The method enabled the charity to raise thousands of pounds. Money received in this manner is put to immediate good use. Information booklets and other material needed by members have been sent by post every month. The publications are needed by families as well as local doctors and clinics. Other expenditure included the information days like the recent 50 th celebration conference held in Bristol on May 11th.

A new venture has been the online shop which has a wide selection of goods which can be purchased via Paypal. Again the profits go to supporting the work of the charity as well as advertising Alpha 1 Awareness UK.

The charity has a debenture membership for the 10k London run. This year, 2013 there are six runners who have been training hard for the race on July 14th. They all need support and sponsorship . Last year the race was held on a significant birthday for the treasurer and I stood on the Chelsea embankment with my alpha balloons cheering the Alpha runners. I was content that the event would certainly bring many happy returns to Alpha's bank balance. Let's

repeat this achievement for the sake of alphas.

***Jeff Darkins***  
***Treasurer***

### **AGM**

An important date for your diary is the AGM, which this year is being held on Thursday 29<sup>th</sup> August, at 2pm at Vassall Centre Trust, Gill Avenue, Fishponds Bristol BS16 2QQ. Everyone welcome, tea and coffee and I expect cake will be available.

### **Informal Lunch & Learn**

Saturday 31<sup>st</sup> August at the Westberry Hotel, Bodmin, 11am-3pm. If you live in the Devon or Cornwall area, this a good opportunity to meet and chat with other Alphas and their families, share your experiences and any concerns you may have and also get to know people who live in your area. We have organised a buffet lunch for you, so that you can enjoy a relaxed time getting to know other Alphas and who knows maybe if there are people living close to you, you can maybe arrange to meet up occasionally over a cup of coffee.

So if you are feeling isolated and feel you are the only Alpha, come along, you will be surprised to find others in a similar situation.

There is no charge for the day and you can claim a contribution to your travel costs. It helps us to know how many people are likely to attend, as we need to order the food etc, so please if you would like to join us, fill in the attached booking form and return it no later than 31<sup>st</sup> July. We look forward to seeing you in Bodmin.

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## Alpha 1 Awareness Charity Board News

**Welcome.** We are very pleased to announce that Andi and Jackie Osborn have agreed to become members of the Charity Board, they have been very loyal supporters of the Charity, raising money for us and attending Information Days etc when there work commitments permitted, many of you will have met them at our Information Day in May, when they stepped in and manned the merchandise table for us. Welcome Andi and Jackie we all look forward to working with you.

**Wendy Rogerson.** It was with great sadness that we heard of the sudden death of Wendy in the early hours of Friday 1<sup>st</sup> March, Wendy had been in and out of hospital since last summer, fighting infection after infection. Shortly before being discharged from hospital for the last time, she had made the long journey to Newcastle to be assessed for a transplant, only to be told it would not be possible, a devastating blow for Wendy, her partner Sam and her family. Many of you will remember Wendy from the Forum and Facebook Group, where when she was well she chatted a lot, it was a lifeline to her, she could not get out without the help of her partner Sam and when he was at work, our online groups kept her going through the day, sadly latterly when she was not in hospital she found she could not even concentrate on her computer. Wendy was a great help with advice on benefits and making claims, she was a fount of knowledge and help several of our members to make successful claims for benefits, after previously being rejected.

Wendy was a great person, who cared a lot, her common sense and plain speaking, along with her knowledge of the benefit system are greatly missed on the Charity Board.

Our thoughts and love go to Sam, Wendy's partner, Barbara her Mum, her brothers David and Alan and her sister Karen, along with her nephews and nieces, along with our thanks for the donations in memory of Wendy.

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## 4<sup>th</sup> International Alpha 1 Patient Congress

The 4<sup>th</sup> International Alpha 1 Patient Congress was held in Barcelona on 11<sup>th</sup>-13<sup>th</sup> April, representatives from 24 countries around the world had come together for this important event, commemorating the 50<sup>th</sup> anniversary of the discovery of Alpha 1. The patient congress was running alongside on 11<sup>th</sup>-12<sup>th</sup> April was the 1<sup>st</sup> Biennial International Research Conference, which was attended by many leading specialists and researchers from many countries in Europe and North America. On the evening of the 11<sup>th</sup> April, attendees at both Conferences came together for a dinner hosted by Grifols Pharmaceuticals at their Headquarters on the outskirts of Barcelona, guest of honour at the dinner and the whole Conference was Sten Eriksson, who with Carl-Bertil Larell discovered Alpha 1 Antitrypsin Deficiency in 1963. The Patient Congress began properly on Friday 12<sup>th</sup> April, it was a varied and interesting programme, topics included looking at the discovery of Alpha 1, research progress, testing and diagnosis, augmentation therapy, management of Alpha1, lifestyle and diet. We in the UK are not on our own in the fight for replacement therapy, there are still many countries not in receipt of it, also a common theme is the lack of diagnosis and understanding by the medical profession and one thing that was very loud and clear from this Conference is the need for unity in the fight for better treatment, diagnosis and care for Alphas, around the world. As ever these Conferences, are a wonderful opportunity to meet with others from different countries and there is always plenty of time, to talk, to share experiences and information which is as valuable as listening

to all the presentations. Once again I myself feel very privileged to have attended the Conference, along with Dawn and Alan Heywood-Jones, as your representative on the International Alpha stage, thank you for the opportunity.

*Lin Daniels*

**A Warning Tale** from an ex pat Alpha living in New Zealand.

One morning after over sleeping, Val quickly used her inhaler before leaving for work, afterwards she said she felt as though something was stuck in her throat, she coughed & coughed all the way to work, which as she was driving was pretty stressful. When she arrived at work, having parked the car, in her words "she coughed her lungs up" & managed to clear her throat and there was something in her throat.....a spider who was still alive when she coughed it up !!!!!!!

A lesson to all, keep you cover firmly on your inhaler when you are not using it and always look before you use it.

*Retold with permission, from Val Orchard, of the New Zealand Alpha 1 Association.*

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**Newsletter Items** we would love to hear your stories and ideas for the Newsletter, please let us know by contacting Alpha 1 Awareness, contact details are at the end of this Newsletter

**And Finally** the next edition of our Newsletter will be at the end of September, as from now on we will be only publishing 3 issues per year, at the end of January, May and September.

**Important Reminder** if you change your postal address or email address, please let us know so that we can still be in touch with you and keep you up to date with news from the Alpha world.

## Shop Online and Raise Funds

Don't forget when shopping online to register with [easyfundraising.org.uk](http://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](http://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.

### *Alpha 1 Awareness UK*

*Contact us at:*

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*Eastville*

*Bristol BS5 5EE*

*Email: [secretary@alpha1awareness.org.uk](mailto:secretary@alpha1awareness.org.uk)*

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