

Newsletter

Alpha1 Awareness

Vol 1
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July 2009

A Word from the Chairman

The Information Day held in Bristol on the 6th of June was well attended and well received. In total, 43 Alphas, carriers and carers came to the event. Apart from presentations on the work of Alpha1 Awareness and an open discussion session, we planned for four major talks. The first on the Clinical Manifestations of Alpha-1 Antitrypsin Deficiency (AATD) was given by Professor Sabina Janciauskiene of the University Hospital Malmö, Sweden. This was followed by a talk on respiratory rehabilitation by Susannah Barr, Respiratory Physiotherapist at the NHS LEEP programme in Bristol. After lunch the next talk was to have been on research in the field of Alpha1 Antitrypsin Deficiency. Sadly, Doctor Goptu from Birkbeck College, London was unable to attend because of a bereavement in his family. Professor Janciauskiene kindly offered to present some of the research and findings that she and others have been working on. Her enthusiasm for the subject was infectious and though much of what she said was highly technical, the questions from audience showed that they had gained much knowledge from her two talks. The final talk was given by Melissa Hillier who is an Assistant Director of the Genetic Interest Group. AATD is a genetic condition and the work of the Genetic Interest Group is important in promoting the interests of all similar conditions which often are rare and do not attract public attention and political support. In recognition of the city in which we were meeting, all our speakers were presented with an item of celebrated Bristol Blue glassware.

Following a break for tea, I spoke about the aims of the Alpha1 Awareness charity, what we wanted to do in the United Kingdom and, working with Alpha associations in Europe, what influence we wanted to gain in Brussels. My wife, Dawn, spoke about augmentation therapy, its obvious benefits and our hope that it will become available in the UK. The open forum started with a brief explanation of the AATD testing kits and the steps involved in using them. Twenty-three kits were given to attendees who were either uncertain of their own genotype or were concerned about their close family relatives. Finally we all discussed the problems of living with Alpha1 and how we can best help ourselves. One of our guests is an expert with computers and using them to create interactive forums. Shortly this will be operational so look for an announcement on our website.

I must thank Lin Daniels and my wife, Dawn, for the tremendous effort they put into organising this, our first and very successful InfoDay .

European Adventures

In May the German and Danish Alpha associations held a joint congress in Hamburg. This was the twentieth congress for the Germans and the fifth for the Danes. Dawn and I were invited to attend and listen to the presentations. The talks were in either German or Danish and there was a simultaneous translation service between these two languages. We had an interpreter assigned to translate into English. For presentations on patient care this was necessary, less so for the more scientific papers which are often published in English.

Our European associates are keen to pass on their experience of holding these events which do much to raise awareness of AATD in their own countries. The travel and accommodation costs did not come from the charity's funds.

In June, Lin and Dawn were delegates at the Fourth European Alpha1 Congress in Vienna. I also attended as a candidate. The Congress was preceded by the AGM of the Austrian Alpha1 Association and then by the AGM of Alfa Europe Federation. Alpha1 Awareness UK is one of the eleven member associations that constitute the Federation. Aside from the formal programme the congress was an opportunity to meet experts in Alpha1 research, advocacy of our cause to our European bureaucrats, and simply to find out how Alphas organise themselves both here and in the United States – John Walsh of the Alpha1 Foundation came from America.

There were two candidates for the post of president of the Federation. I was the one elected. Apart from the personal honour and the additional workload this should help put us on the map of Europe.

All accommodation and my travel costs came from personal and other sources.

Alan Heywood-Jones

WHAT IS MEANT BY THE TERM “ALPHA-1 CARRIER, MZ or MS ALPHA”?

An Alpha-1 Carrier is a person who has one normal alpha-1 gene (M) and one defective Alpha-1 gene (usually S or Z). Being a carrier is very common. Most Alpha-1 Carriers are MS or MZ. Carriers may have lower blood levels of Alpha-1 Antitrypsin protein, but their levels are rarely as low as those of people with Alpha-1.

CHILDREN OF ALPHA-1 CARRIERS

Alpha-1 Carriers may pass their defective Alpha-1 gene to their children.

- If a carrier (MZ) has a child or children with a person who has normal Alpha-1 genes (MM), each child has one chance in two (50% risk) of being an Alpha-1 Carrier (MZ). There is no risk that any of the children will have the condition.
- If a carrier (MZ) has children with another carrier (MZ), each child has one chance in two (50% risk) of being an Alpha-1 Carrier. Each child also has one chance in four (25% risk) of having Alpha-1 (ZZ) and one chance in four (25%) of having normal Alpha-1 genes (MM).

HOW CAN BEING AN ALPHA-1 CARRIER AFFECT YOUR LUNGS ?

Alpha-1 Carriers usually have only a slight risk of developing a disease related to Alpha-1. The main type of carrier linked to increased risk for lung diseases has MZ genes. Currently, there is no known risk for lung diseases for MS carriers.

LUNG DISEASE: The risk for emphysema may be greater for MZ carriers. This increased risk, however, is very small unless the carrier is a smoker or exposed to high levels of air pollution. The risk of having Chronic Obstructive Pulmonary Disease (COPD) is higher among MZ carriers who have relatives with COPD. This suggests that the COPD in these families may be due to other genetic factors. There is no scientific evidence that MS carriers are at risk for lung disease.

LUNG SYMPTOMS THAT MIGHT BE LINKED TO BEING AN ALPHA-1 CARRIER

- Shortness of breath
- Wheezing
- Chronic cough and sputum (phlegm) production (chronic bronchitis)
- Recurring chest colds
- Decreased exercise tolerance
- Non-responsive asthma or year-round allergies
- Bronchiectasis

HOW CAN BEING AN ALPHA-1 CARRIER AFFECT YOUR LIVER?

Alpha-1 Carriers usually have only a slight risk of developing a disease related to Alpha-1. The main type of carrier linked to increased risk for liver diseases has MZ genes. Currently, there is no known risk for liver diseases for MS carriers.

LIVER DISEASE: The risk of chronic liver disease in Alpha-1 Carriers is much less than that for people with Alpha-1. Research suggests that chronic liver disease might appear in MZ carriers only when the liver has been damaged first by something else, such as a virus, chemicals including alcohol or being overweight. There is no scientific evidence that MS carriers are at risk for liver disease.

LIVER SYMPTOMS THAT MAY BE RELATED TO CARRIER STATUS

- Eyes and skin turning yellow (jaundice)
- Swelling of the abdomen (ascites)
- Vomiting blood or passing blood in the stool
- Unexplained liver problems or elevated liver enzymes

HOW CAN CARRIERS PREVENT OR REDUCE THEIR RISK OF GETTING DISEASES LINKED TO ALPHA-1?

MZ carriers have only a slightly increased risk for the lung or liver diseases seen in people with Alpha-1. You may prevent or reduce the risks by making changes to your lifestyle, such as:

- Do not smoke and avoid second-hand smoke.
- Avoid repeated exposure to dust, fumes or gases.
- Quit or cut back on drinking alcohol.
- Do regular exercise
- Get vaccinated against hepatitis A and B.

If the Carrier has children who are also Carriers, the children should be informed about their genetic status. The importance of a healthy lifestyle should be emphasized from an early age.

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AN ALPHA CARRIERS PERSONAL EXPERIENCE

Remember that most Alpha carriers live a perfectly normal life with no affects of Alpha 1, it is just the occasional unlucky person who can have problems, as one of our members shares with us, in the brief piece below.

HD describes that although being born full term with a good birth weight, in 1947, she was a “failure to thrive baby”, suffering vomiting and jaundice, years of unexplained ill health, taking a variety of medication followed. After 2 pregnancies and more bouts of ill health, she decided to change her diet, cutting out gluten and subsequently all grain products and taking various vitamins and minerals, her life for a number of years became better. After about 8 years symptoms began to return, so HD went through a series of investigations, including Barium Enema, Colonoscopy, Gastroscopy and others, the only result from these tests was that there were raised liver blood tests and CRP (a sign of inflammation), an Ultrasound showed signs of a fatty liver, attributed to being overweight.

Becoming frustrated with 25 years of no diagnosis or explanation of her condition, despite consulting numerous consultants, including one for food allergies, HD applied for copies of her medical notes, at first she did not find anything in the notes that meant anything to her and they were subsequently put away in a draw. One day she decided to take a more thorough look at her notes, in doing so she noticed a low value for Alpha 1 Antitrypsin, not understanding what this meant she did some research and began to understand that this could be the key to her health problems, she also discovered that she had be genotyped as MZ bur no one had ever mentioned this fact to her, because it was not considered to be the reason for her health problems, although it was thought she may suffer liver problems.

Thankfully HD has never smoked and only drank a small amount of alcohol occasionally, but because of all her ongoing health problems from being a baby, she had taken a large amount of drugs, which may have affected her liver adversely.

After discovering about Alpha 1 she was seen at ADAPT in Birmingham, where the MZ diagnosis was confirmed, fortunately her husband was MM, so both daughters could only be MZ, the youngest is showing similar symptoms to her mother, but investigation has shown no diagnosis. A liver biopsy performed on HD in Birmingham found Alpha 1 inclusions, though fortunately no cirrhosis.

Now at the age of 62, other than being on some prescribed drugs, HD manages her condition herself with a diet low in fat and carbohydrate, with meat, fish, low fat dairy, eggs, fresh fruit and vegetables along with various dietary supplements and lives life to the full, travelling and working part time as a nurse.

She says “ despite my GP’s belief in the causes of my symptoms, after studying Alpha 1 and other people’s experiences I have no doubt it is the cause of the problems. My last liver function tests were normal, only the CRP was raised, but inflammation is part of Alpha 1”

With grateful thanks to Alpha 1 Awareness UK Member HD, for kindly providing us with the above insight into her life as an MZ Alpha

If you have story about Living with Alpha that you would like to share with us, in future Newsletters, please email or post it to us, we would love to hear your stories.

News in Brief

Alpha 1 Awareness Forum

As you will see from Alan's letter at the start of this edition, we have been very busy over the last 3 months, our Information Day in Bristol was a big success, one of the things that came out of the discussion at the end of the Day, was that Alphas and carers did feel isolated and would like a way to be able to talk to others in the same position. This was something that we in the Charity Board were also concerned about, but were not sure how we could tackle it, we had tried Facebook for Parents and Children and young people, but it didn't seem to get off the ground and sadly for personal reasons we lost our administrator of the Facebook Group..but what else was there ? Low and behold at our Information Day, we had a young man there, who was recently diagnosed, with the technical ability and know how, who offered to get a forum up and running on the Internet, he has created an excellent forum site for us and it "goes live" on Saturday 11th July. It is easy to use, you will need to register, one of the moderators (Dawn or Lin or Neil) will contact you when you first register, as the main discussion part of the Forum is not a public site it is only for those who register and login to use it. This is your chance to talk about your worries or concerns about Alpha 1 or just to find out about different aspects, other sufferers have a wealth of knowledge about Alpha 1 and if no one can answer you we will find someone who can.

We have lots of parents of Alpha children who have contacted us and we hope they will use this Forum, if we have enough of you join, we can maybe have a Parents and Children's section on the Forum.

So go to this link <http://techno.demon.co.uk/a1aforum/> after Saturday 11th July register and start chatting, it is a brilliant opportunity to get support and help, please give it a try. Our thanks to Neil for all his hard work in getting this Forum up and running for us and for coping with Dawn and myself (Lin) and our occasional lack of technical know how when we first began using the Forum !!!

Test Kits

This is our other big news, as we touched on it in our last Newsletter, thanks to the generous sponsorship of Talecris Biotherapeutics, we are able to offer AlphaKits® to people who have family members who need to be tested for Alpha 1. There is no charge to the patient or the GP for these Test Kits, they have full instructions for the GP as to how to carry out the test and we even put a stamp on the envelope to send the kit to the testing laboratory. If anyone one would like a Test Kit for their family members, please either email to secretary@alpha1awareness.org.uk or drop a line to the PO Box address at the end of this Newsletter

AlphaKits® is a registered mark of Talecris Biotherapeutics GmbH



Collage of photos from our Information Day June 2009

PHOTOS FROM INFORMATION DAY JUNE 2009



Two of our Alpha Babies with their Teddies from the Information Day June 2009

Marathon Runners 2009

As we reported in our last Newsletter, Garry Stone from North Wales, ran in the London Marathon, in memory of his father who died last year from Liver related Alpha 1 and has raised over £700 for Alpha 1 Awareness UK, which is absolutely brilliant, on top of this, as we also told you last time, Garry's late father ran a Social Club in North Wales, the Entertainments Manager has been in touch with the Artists who perform there and a Charity Night was held on the 16th April, with all proceeds coming to the Charity, but it doesn't stop there, the club decided to make AAW their Charity for the year during this year's summer season. All the money they have raised this year will presented to the Charity at a special evening on 3rd October. We are extremely grateful to Garry, his family and friends for supporting us in this way and send them our heartfelt thanks.

Phil Sharpe, from Derbyshire, who lost his wife 6 years ago to Alpha, ran in the Paris Marathon on the 5th April and also in the Derby 10k run 2 weeks later. Mant thanks to Phil for raising £375, from his runs, for Alpha 1 Awareness.

London Marathon 2011

Alpha 1 Awareness UK has been given a Silver Bond place in the 2011 London Marathon, we will be looking for someone to take up the place.

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** and just by doing your shopping online you will be helping raise funds for the Charity

Other Fundraising

We have had several other offers of fund raising, by people doing local marathons and having collecting tins in their shops, we will give you more news on these as the year goes on.

Christmas Cards & Everyday Notelets

Our Christmas Cards were very popular, last year and we are pleased to say we now have a selection available for this year, an order form is at the end of this Newsletter, I know it is early but we have already sold quite a few at our Information Day in Bristol, so to avoid disappointment get your orders in early.

We also have a selection of small everyday notelets, they are £1 for 4 cards, there are too many designs to send out, with this Newsletter but if anyone is interested if you email or drop me a line, I can let you have a copy of the designs to choose from, they are really useful little cards for birthday, get well, brief notes etc.

We are grateful for any fundraising that is done for the Charity and always like to hear from anyone who has ideas about how we can raise funds. Remember if you, one of your family or friends are having a Quiz Night, Skittles Evening, Coffee Morning, Sponsored Silence (one the children could maybe do!) etc, to support Alpha 1 Awareness we would love to hear from you

4th European Alpha 1 Congress

Vienna June 2009

Well it certainly doesn't feel like it is 12 months since I did a report from the European Alpha 1 Congress, but here we are again.

It certainly was a privilege to attend this year's Congress in Vienna, as it is the first year that the UK has attended as a full voting member of Alfa Europe Federation and this year we had 2 delegates, I was joined by Dawn Heywood-Jones, with Alan Heywood-Jones and Karen North there as observers.

The weekend began as soon as we arrived at Vienna Airport, where as Alan has said in his letter, we met with John Walsh, from the Alpha 1 Foundation in the USA, who had been invited to attend the Congress as an observer. It was good to have the chance to talk to John, about the work of our UK Charity and also the work of the US Foundation. The one new and the other older well established, but both working to the same end, supporting Alphas and their families, raising awareness and supporting research into Alpha 1.

The coming together of the 11 member countries of Alfa Europe Federation annually, gives all the individual country's associations a chance to share knowledge, ideas, concerns and encouragement in their fight to, raise awareness, support sufferers and research into Alpha 1. The Congress is always a lively and friendly meeting; it is amazing how Alpha 1 breaks down language barriers.

Dawn and I were, along with other delegates not to be able to go on the River Cruise on the Danube, because of flood conditions, but we returned to the Hotel and spent the afternoon, before the start of the Congress, meeting with other delegates, for me this was an opportunity to renew acquaintances made in Prague and Rome at previous Congresses.

The Congress began properly in the late afternoon of Friday 26th June 2009, with the AGM of Alfa Europe Federation. Before the meeting began we were warmly welcomed to Austria and in particular Vienna, by the newly elected chairman of the Austrian Patient Group, Walter Berger, who handed over to the Federation Treasurer for the more formal part of the meeting, which was to be chaired by Robert Strauch, a German lawyer, in line with the Federation's Statutes, parts of this meeting can be difficult to follow due to the legal aspects, but basically it is the financial reports, along with reports of the President and Vice President and the plans for the coming year, there was an attempt to disrupt the meeting by the Italian delegation, something that has, sadly, become a regular occurrence, at least in the 2 previous meetings I have attended, after a difficult few minutes things

settled down, although there was still lots of chatting from the Italians.

This year was slightly different, as before the Congress the President Larry Warren, had decided to retire his position, mid way through his term of office, this meant there was to be a Presidential election. Alan Heywood-Jones had been invited to stand prior to the meeting and Mario Cuiffini from Italy also put himself forward as a candidate. Both candidates had been asked to submit their applications a month before the meeting and the applications were circulated to member countries. Unfortunately one or two delegates had not seen the applications and the Czech delegate asked for the candidates to introduce themselves briefly to the meeting, this was not planned, however Mr Cuiffini was very quickly on his feet with a prepared "statement", Alan then gave a short unprepared speech. The voting for President went ahead undisturbed, France and Norway, who were not attending, had sent proxy votes and it was with delight that we realised Alan had been elected as President of the European Federation.

At this point I feel it is only right that I publicly congratulate Alan on his Presidency, it will be more work for him, but I am sure he is up to the task and will do a very good job, he has made it perfectly clear that his first loyalty is to his role as Chairman of Alpha 1 Awareness UK. This is a huge step for our UK Charity and it is an acclamation of the regard with which Alpha 1 Awareness UK is already held in Europe.

So the AGM came to an end and we all went for a convivial dinner and an early night to prepare for a long day of "Scientific Programme" which Saturday promised.

As ever Saturday's programme began very early, we expecting 8 presentations from various speakers.

The morning began with a brief presentation from Elisabeth Takehashi, from the European Alpha 1 Foundation, who gave a brief explanation of the work of the Foundation, she handed over to the first speaker of the day, Hon Prof Robert Schlogel, from the Austrian Ministry of Health, who welcomed Federation delegates and members of the Austrian Patient Group, he spoke, briefly about the occurrence of Alpha 1 per head of population in Austria and his role in the Ministry of Health.

The second speaker was Dr Karin Schmid-Scherzer, a pulmonologist who has treated Alpha 1 patients for many years and has, along with her colleagues, developed an extensive registry of lung affected Alphas in Austria. Dr Schmid-Scherzer began by saying how good it was to see so many people at the Congress and how pleased she was at the

growth of the Austrian Patient Group since it's formation in 2005. She spoke of the evolution of Alpha 1 over the last 30-50 years, the introduction of the use of Prolastin in Austria and German in 1989 and how in 2002 Prolastin became available on a prescription basis in Austria. Four Alpha Centres have been set up in Austria recently and the Wilhelminen Hospital in Vienna is one of the founding members.

The next speaker for us from the UK was a particularly interesting speaker, Prof Robert Stockley from ADAPT at the Queen Elizabeth Hospital in Birmingham. Prof Stockley spoke of the setting up of ADAPT in 1996. Prof then went on to talk about the EXACTLE Trial which was held in 3 centres, at ADAPT in the UK, in Denmark, and Sweden, Holland was unable to take part in the trial, he explained how the trial was conducted and how patients were monitored, with regular weekly injections of either Prolastin or placebo and regular CT scans. The trials have now closed and the data and results have been compiled and published. The results at first showed little difference between the patients on Prolastin or placebo, but after a year those on the placebo showed a more marked deterioration in their condition. The next trials will be of the inhaled therapy. In the questions and answers after his talk, Prof Stockley was unable to say when the UK would have Prolastin, despite the fact that parts of Europe and the USA have been receiving it for 20 years.

After coffee we settled back to hear Dr Till Voigtlander, who as well as working as a neurobiologist in the Vienna Medical School, is also the Coordinator for Orphanet in Austria and head of the newly established Subcommittee for Rare Diseases. He explained that Orphanet is an organisation for rare diseases, it 's Internet based information system, www.orphanet.net, gives an encyclopaedia on rare diseases and is in 5 languages. The services offered by Orphanet, included special clinics, laboratories, self help groups, research and a newsletter. It deals in all rare diseases, of which Alpha 1 is one; orphan diseases are rare diseases with no one to look after them because little is known about them.

The next presentation was of interest to those who travel and especially those who travel with oxygen. Dr Klaus Kenn spoke about how important mobility is to day to day life, travel and holidays, for some people they need o2 to help them live a good day to day life, others only need o2 when they travel, but whether you need o2 or not, as an Alpha there are things that need to be taken into consideration when making travel plans.

- Islands often do not have good medical care
- Altitude of over 1200ft is not recommended, mountain air is good but not high altitude
- With World Travel jet lag takes it's toll
- Check in advance the suitability of accommodation
- Are there health risks...injections needed in advance, are o2 supplies readily available
- Drink plenty of water
- Take medicines in hand luggage along with medical history, have enough medication

Dr Kenn then handed over to Ursula Krutt-Bockemuhl the Deputy Chair of the German Support Group for Long Term Oxygen Therapy and Editor of the periodical O2 Report,

who told us with good forward planning, travel can be enjoyable even when you have to travel with o2, it is important to

- Make sure you have good supply of o2
- Contact oxygen supplier for help with travel plans
- Take emergency number of your o2 supplier
- See your consultant for a "fit to fly", before travelling
- Always take your o2 passport

Travel concentrators are available, they are small easily carried and are very good but are expensive, it is possible to get small travel cylinders.

Always check with your airline before flying, some charge for flying with o2 other do not.

The Congress broke for lunch

Resuming after lunch we were told that our next planned speaker Dr Jan Stolk, was unfortunately ill, so we would proceed to the second speaker of the afternoon, Dr Klaus Pittschieler, who is a Medical Director of the Dept for Paediatric and Adolescent Medicine, at Bolzano Central Hospital and University Hospital, he is also a Professor at Innsbruck University Children's Hospital. In 20 years of neonatal screening, nearly 100,000 newborn babies have been tested and their development monitored in a special department. This testing has provided valuable data particularly in regard to unusual phenotypes, heterozygotes, with Alpha it can also identify rare strains i.e. M,Z,S,F,P. Identifying conditions early in life, aids better monitoring, treatment and life expectancy. It is better to treat in early stages, costs less for treatment.

Very few young lung Alphas, tend to be liver affected. It is possible to minimise the effect on the liver by taking Vitamin E and have infections for Hepatitis A&B, careful control of the weight is important as overweight people can suffer from liver problems, alcohol should be avoided and smoking within the whole family should be avoided.

Two mass screening programmes took place in Sweden between 1972-1974, but the screening only tested for Alpha 1 Liver not phenotyping, Dr Pittschieler's screening between 1986-2009 has tested for phenotype.

Alpha 1 is an illness caused by Caucasians and is one of the most severe genetic diseases.

The American Thoracic Society and the European Respiratory Society, say testing should only be performed where there is a family history of Alpha 1

World Health Organisation say COPD sufferers, both adult and adolescent should be screened

Mass neo natal screening is needed in the whole of Europe, to guarantee early detection of Alpha. Help may be needed from patient groups to get this screening performed as routine.

The afternoon moved quickly on and our speaker before we had a break was Dr Laura Fregonese, who is a clinical

immunologist and pulmonary physiologist specialising in rare lung diseases, she is also a member of AIR, the Alpha 1 International Registry.

AIR was set up in 1997 after WHO recommended that International Registries were set up for rare diseases.

AIR provides

- A database of all countries involved in working with Alpha patients
- Knowledge sharing,
- Good selection of data of clinical research
- Guidelines for good practice and management of Alpha 1
- A National reference centre for every country, it is accessible to GPs, hospitals and patient groups

Running the PAAIR (Patient Association & Alpha International Registry) Project, which is looking at different diagnosis and treatments of Alpha 1 patients, experts in the field of Alpha 1 are rare, patients can feel isolated and socially excluded. More help and patient input is needed with this project is needed.

A questionnaire has been organised to find out patient's experiences and expectations of Alpha 1 Antitrypsin Deficiency.

Before our final speaker we had a break for a welcome cup of tea and light refreshments.

The final speaker of the Congress was Dr George Lang, a surgeon at the Cardiothoracic Surgery Unit at the Vienna Medical School, a world leader in lung transplants.

The hospital in Vienna is one of the largest in Europe with over 8000 employees, it is a main centre for transplants, doing more transplants than any other hospital. It has an excellent success rate. Dr Lang is doing research into the recovery of the efficiency of transplanted lungs, which show a severe reduction in organ function during or after transplant.

Dr Lang talked about the procedure of transplantation and the care given to recipients of donor lungs.

Our Austrian hosts had presented each of the speakers throughout the day with Gifts from Vienna, but the final presentation to Dr Lang was perhaps the most special and poignant, it was made by Walter Berger, the Austrian President, who had himself 1 year ago had a lung transplant in Vienna, his surgeon was Dr Lang.

The Congress came to a close, with a sightseeing bus tour of the city of Vienna. Dinner that evening saw lots of chat and laughter, as those delegates who were still at the hotel, shared stories and ideas from each of their countries, a fitting end to a very successful Congress.

Once again, I am very grateful for the opportunity to have attended the European Congress on behalf of all UK Alphas and I know Dawn felt the same and so we both thank you for the opportunity.

As delegates Dawn and myself had our flights paid for by the Charity, our accommodation and other costs were met personally and from other sources.

Lin Daniels
July 2009

We would love to hear your views on our Newsletter, if there is anything you would like us to include please get in touch, our contact details can be found below.

Alpha 1 Awareness UK

Raising Awareness of Alpha 1 Antitrypsin
Deficiency in the UK

Contact us at : Alpha 1
PO Box 2866
Eastville
Bristol BS5 5EE

email : secretary@alpha1awareness.org.uk

visit our website : www.alpha1awareness.org.uk

Alpha 1 Awareness UK

Registered Charity Number: 1125467

Information Day September 5th 2009

We would like to invite you to our second Alpha 1 Awareness UK Information Day, it will be held on Saturday 5th September, 10.00am – 4pm at

Concorde Club
Stoneham Lane
Eastleigh
Hampshire SO50 9HQ TEL: 023 8061 3989

You will have the opportunity to hear experts give presentations about Alpha 1 and about living with and managing the condition; it will also give you the chance to meet with other Alpha sufferers.

The Day is open to Alpha sufferers, their families and interested medical professionals. There will be no charge for the Day, a buffet lunch, tea and coffee in the morning when you arrive and in the mid afternoon, will all be included.

The room we are hiring is a ground floor room with easy disabled and wheelchair access and the Hotel is giving us free parking all day on the Saturday.

If you wish to stay at the Concorde Club on either the Friday or the Saturday night, you can contact the Club yourself and book a room making sure you say you are there for the Alpha 1 Information Day, that way you will get the special rate that we have been given. We must point out that although there is no problem with children attending the Information Day, but if you wish to stay for the evening and have a meal, because Concorde is a Club, children are not allowed in the restaurant in the evening, they can of course use it for breakfast in the morning.

There are other hotels and B&Bs close by, if you do a search on the internet you will be able to find them, but we are sorry we are unable to vouch for any of them.

The Concorde Club is situated just off Junction 5 of the M27 motorway, taking the road towards Eastleigh and Chandlers Ford, a map will be included in your booking confirmation for the day.

You will be able to claim a contribution towards your travel costs on the day, so please keep receipts for trains, taxis etc

Please complete the attached form to book your place on our Information Day.

We look forward to meeting you on the 5th September and hope you find the day useful.

Alpha 1 Awareness UK

Registered Charity Number: 1125467

**INFORMATION DAY 5th SEPTEMBER 2009 AT
CONCORDE CLUB, STONEHAM LANE, EASTLEIGH,
HAMPSHIRE SO50 9HQ**

BOOKING FORM

NAME

ADDRESS

.....

.....**POSTCODE**.....

TEL

EMAIL

No. OF PEOPLE ATTENDING

NAMES OF THOSE ATTENDING

Please indicate who is an Alpha

.....

.....

.....

.....

HOW WILL YOU BE TRAVELLING ? **CAR**.....**TRAIN**..... (please indicate)

PLEASE GIVE ANY DIETARY REQUESTS

Please return your completed form to : **Mrs L Daniels**
 Alpha 1
 PO Box 2866
 Eastville
 Bristol BS5 5EE

If you cannot print this form, send me an email with your address and I will send you a paper copy of the form in the post

Alpha 1 Awareness UK

Registered Charity Number: 1125467

CHRISTMAS CARDS ORDER FORM 2009

Name.....

Address.....

Tel No.....

Cards are £3 per pack of 10 p&p will be £2 up to 2 packs; £4 for 3 or more packs

Design	Number of packs	Cost
K02 Adoration		
K03 Christmas		
K05 Holy City		
K06 Starry Night		
KK12 Santa		
K18 Star of Wonder		
K17 Winter Visitor		
Total Number of Packs		Add p&p
	TOTAL TO PAY	

Cheques can be made payable to **Alpha 1 Awareness UK**

Return your order form & payment to: **Alpha 1,
PO Box 2866,
Eastville,
BRISTOL BS5 5EE**

Alpha 1 Awareness UK

Registered Charity Number: 1125467

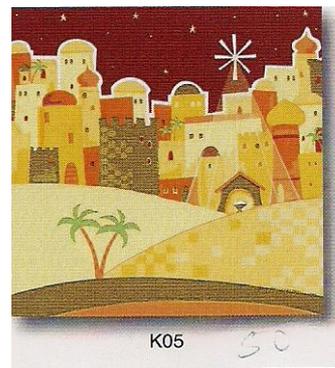
CHRISTMAS CARD DESIGNS 2009



ADORATION



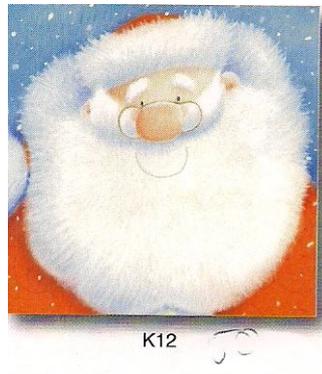
CHRISTMAS



HOLY CITY



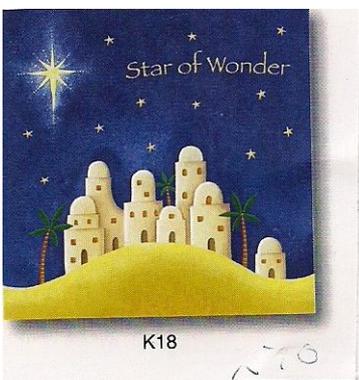
STARRY NIGHT



SANTA



WINTER VISITOR



STAR OF WONDER