

Newsletter

Alpha1 Awareness

Vol 1
Issue 2
March 2009

A Word from the Chairman

Near the end of last year we planned to hold an Information Day in Spring or early Summer 2009. In order to contact Alphas who may wish to attend these meetings we placed adverts in local papers inviting them to contact us. More people than we anticipated wrote or emailed and so now we plan to have two Information Days. More details on this can be found in this newsletter in the item from our Secretary.

Another momentous event is that Alpha1 Awareness UK has received sponsorship from the pharmaceutical company Talecris to distribute **AlphaKits®** to those members, associate members and their families who have not yet been tested. Initially the kits will be given to people with a close family member who is known to be an Alpha.

There will be no charge for the kit or the test, either to the person or their GP. Full details will be given out on our Information Days. If you feel that you may benefit from this service please contact us.

The **Newly Diagnosed?** leaflet has been favourable received by many Alphas, nurses and physicians. The second leaflet in the series of four, **Your Child's Liver**, is currently being checked by doctors for medical accuracy and it should be available soon.

Finally, I would like to add that we have made a donation to the research programme hoping to find a cure for Alpha1 being conducted at Addenbrookes Hospital under the direction of Professor Lomas.

Alan Heywood-Jones

AlphaKit is a registered mark of Talecris Biotherapeutics GmbH

Do you belong to a Breathe Easy Group, a LEEP Group, or a Pulmonary Rehab Group, we would love to hear about it, share your stories with us, tell them about us if there are other Alphas in your group.

Remember anyone can become a member of the Charity they do not have to be an Alpha, they can be a family member, a friend, they can even be from the medical profession, if they are sympathetic to our aims, they can join us, it doesn't cost anything to be a member, you can find a membership form on our website.

www.alpha1awareness.org.uk

News in Brief

Marathon Runners 2009

As we reported in our December Newsletter, Garry Stone from North Wales, is running in the London Marathon, in memory of his father who died last year from Liver related Alpha 1.

In February of this year we were contacted by Phil Sharpe, from Derbyshire, who lost his wife 6 years ago to Alpha. Phil is running in the Paris Marathon on the 5th April and also in the Derby 10k run 2 weeks later, the money he raises from his runs he will be donating to the Alpha 1 Awareness Charity.

We would like to wish both Garry and Phil all the very best of luck. Both of them will be wearing running vests with Alpha 1 Awareness UK and their names on, so if you see any footage of the runs on the TV look out for them.

To support Garry or Phil go to:

www.Justgiving.com/garrystone

www.Justgiving.com/philipsharpe

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

Christmas Cards

Our Christmas Cards were very popular, we were pleased with how well they sold. In fact we are already looking at ordering this years designs, we also plan to have some Everyday Notelets, both we hope to have on sale at our Information Days.

Social Evening

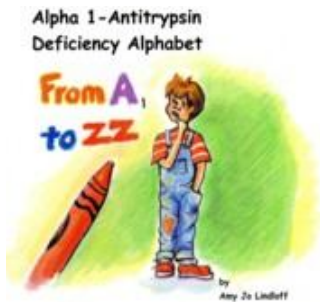
Garry Stone's late father ran a Social Club in North Wales, the Entertainments Manager there has been in touch with the Artist who perform there and a Charity Night is being held there on the 16th April, with all proceeds coming to the Charity. We hope to be able to send a member of the Charity Board along to the evening.

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

European Conference in Vienna

Now that the UK is a member of the Alpha Europe Federation, two people have been invited to the Conference in Vienna, at the end of June, look out for a report on the Conference in our next Newsletter.

Alpha Children



If you have an Alpha child between the ages of four and eight then you may find the booklet *Alpha 1-Antitrypsin Deficiency Alphabet From A₁ to ZZ* a great help in explaining the condition to them. Despite the long title the booklet is easy to read and quite upbeat. It may also be helpful to non-Alpha children in explaining the illnesses of their older relatives. Contact Lin for a copy.

Over the last year we have heard of several babies and children being diagnosed with Alpha 1, parents of these children are obviously distressed, confused and concerned for their children when they are told of the diagnosis. To help parents to understand more about Alpha 1 and to have contact with other parents and families

in a similar position, we have set up a Parents Forum, it is possible to contact the forum via our website or by writing to the Parents Forum via the PO Box number, we have also set up a Facebook Group for parents and young people, this is a closed group and is administered by one of our board members, who is in contact with a number of parents and is keen to get the group chatting on Facebook to share any worries and problems they may have. It is so important for these parents and young people to know they are not alone.

There is an excellent article on our website, under “Alpha Children”, written by a young woman, who was diagnosed as a child with Alpha 1, as was her sister, who had to have a liver transplant as a child. This is a story of encouragement and hope for all parents of Alpha children, as both these young women lead near normal adult lives (for those of you receiving this through the post we are attaching a copy of the article).

We also hope to have our new information booklet written for parents of Alpha children, available very soon, if you would like copies of this booklet and are not coming to our Information Day in June, please email info@alpha1awareness.org.uk and we will send you a copy in the post as soon as they are available

Membership and Contacts

Our membership over the last few months has grown, people are finding our website and sending in the contact form. We are reaching a large number of people who are keen to find out more information about Alpha 1, either because they themselves or members of their family have been diagnosed with the condition.

In February we decided to put some small adverts into local newspapers, to begin with we have covered the South Coast and the West Country from Gloucestershire to Cornwall, we wanted to contact Alpha sufferers and their families, also we wanted to see if there would be support if we held an Information Day. We selected a specific area, because we were not sure how successful this campaign would be, also we had to be mindful of cost.

We have been amazed at the response we have had, from parents whose children have Alpha to adults from families where 2 or 3 members are affected, many have not been given information about Alpha 1 and do not know where to turn, because their doctors and medical professionals do not know about the condition. Following on from this we are pleased to say that we have secured funding to hold 2 Information Days this year, one in June and one in September which will also be our AGM as well as an Information Day (see information at the end of this Newsletter to book for the June Day) this is a big challenge for us but we have seen that there is a great need for these days and we are looking forward to meeting many of you at one or both of the days. We are busy working on a programme of interesting and varied speakers and this will be circulated when we confirm your booking, we will also put the programme on our website.

Stem Cell Research

A programme to generate patient specific stem cells for research into liver disease has recently started at Addenbrookes under the direction of Dr Tamir Rashid, Dr Graeme Alexander and Prof. David Lomas.

The following is extracted from their published aims.

The study is organised and funded by the Cambridge Institute of Medical Research, along with the Department of Hepatology at Addenbrooke's Hospital and the Wellcome Trust. It has been reviewed by the Hertfordshire Research Ethics Committee.

The purpose of the study is to create pluripotent stem cells from patients at the Laboratory of Regenerative Medicine, Cambridge University. You may have read or heard about these special, valuable cells. Pluripotent stem cells are "master cells" that can form any type of cell found in the body. Pluripotent stem cells come from at least two sources. One type of pluripotent stem cell, called an embryonic stem cell, is taken from early human embryos, when the embryo consists of between 8 and 200 cells. Another type of pluripotent stem cell is made by inserting genes into cells taken directly from your body. This procedure is called "direct reprogramming" and it creates a type of cell called an "induced" pluripotent stem cell.

Embryonic stem cells and induced pluripotent stem cells can be grown in Petri dishes in the laboratory forever. It is hoped that scientists can learn how to make pluripotent stem cells become specific human tissues, like blood, skin, liver and heart muscle. Researchers at Addenbrookes and other researchers want to make stem cells from patients with diseases to study the harmful effects of disease on tissue formation and investigate the possibility of overcoming these in order to provide new cures for disease. Pluripotent stem cells can also be used to test the helpful or the harmful effects of drugs on the diseased cells.

In this study, the researchers did NOT wish to use embryonic stem cells but instead used a very tiny number of cells taken from patients known to suffer from liver disease. They wanted to take these cells and place them in a Petri dish with genes and/or chemicals to "reprogram" them into pluripotent stem cells. The goal of their methods is to "reprogram" a specialized cell in the body (skin, blood, stomach, liver, etc) into a pluripotent stem cell.

In this study the researchers asked each patient to allow a doctor to take some cells from his/her body to use as donor cells for making stem cells. The doctor performed a skin biopsy and collect 2 tablespoons of blood. Scientists would use cells grown in a dish from the skin biopsy and specialized cells from the blood samples as the "somatic donor cell" in stem cell experiments.

This research study is aimed at advancing knowledge only, and will not result in any direct medical benefit to specific patients.

The participants in this study gave a tiny sample of skin known as a "skin or skin-punch biopsy". The sample is only a few millimeters long, takes only a few seconds to obtain and was done at the same time as a routine patient appointment. In addition a routine blood sample was taken. After the biopsy and blood sample there was no further participation in this study.

Once obtained the skin sample was taken to the Laboratory of Regenerative Medicine, Cambridge University and processed as outlined above. The induced pluripotent or stem like cell lines that are generated will be used to study the causes of and investigate new therapies for liver diseases.

There are many researchers around the world who are also trying to find cures to these diseases and in order to try to reach the answers in the fastest possible way, the regulatory authorities governing this type of research have suggested that all scientists share resources such as cell lines (www.isscr.org).

As a consequence, if a reputable investigator from another country requests a sample of the cell lines that have been generated in Cambridge, the researchers would consider the application sympathetically provided that the intended use is analogous and complimentary to the original research objective and falls within the limits of the resource transfer agreement proposed by the international regulators. If they do not feel that their intended use for the cell lines is appropriate then they reserve the right not to send out the lines.

EXACTLE Trial

As of now there is still no further news on the EXACTLE Trial, the finding of the trial into the use of Prolastin, was published in a medical journal at the beginning of this year, it is hoped it will progress to the next stage, that of bringing the study to the attention of NICE (National Institute for Clinical Excellence) which is the licensing body for prescription drugs in the UK.

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

We would like to invite you to our first Alpha 1 Awareness UK Information Day, it will be held on Saturday 6th June, 10.30am – 5.30pm at

Aztec Hotel & Spa
Aztec West
Almondsbury
Bristol BS32 4TS

Tel 01454 201090

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.

The Aztec has given us a reduced room rate of £96 per room per night, with breakfast, unfortunately we are unable to pay for your hotel accommodation, but if you wish to stay overnight you can contact the hotel yourself, when you make your booking say that you are there for the Alpha 1 Awareness Day and you will be charged the reduced rate. If you need a disabled room you will need to ask for this when you book. If you wish to eat before you leave on the Saturday there is an a la Carte restaurant or in a separate building adjacent to the Hotel is a place call "The Lodge in the Park" where they offer pizzas and pasta dishes etc at very reasonable cost.

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

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 Aztec Hotel is situated just off Junction 16 of the M5 motorway, taking the A38 towards Bristol, you go right at the first roundabout and follow the signs, a map will be included in your booking confirmation for the day.

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

Don't forget if you can't manage our Bristol Information Day in June we are holding another day on Saturday 5th September at the Concorde Club, Eastleigh near Southampton, so make a note in your diary now. More information about that day in our July Newsletter

Alpha 1 Awareness UK

Registered Charity Number: 1125467

**INFORMATION DAY 6TH JUNE 2009
AT AZTEC HOTEL AND SPA, AZTEC WEST, BRISTOL BS32 4TS**

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