

# Newsletter

# Alpha1 Awareness

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## A Word from the Chairman

The Letter printed in Nature on the 12<sup>th</sup> of October has created a real buzz in the Alpha world. The title, *Targeted gene correction of a1-antitrypsin deficiency in induced pluripotent stem cells*, gives little indication of the significance of the research work being reported. For the first time scientists have corrected the main alpha1 mutation (PiZ) in stem cells and then derived liver cells from them and these produce AAT with the correct structure and function. Previously attempts to cut and splice bits of genes have resulted in unwanted changes in addition to the desired ones. The latest work is important because it opens up the possibility of creating functioning liver cells from a sample of skin or blood. The Z mutation can be corrected and, because the genetic material would come from the person being treated, there is no rejection of foreign tissue. Professor David Lomas, our patron and one of the members of the research team, hinted at these developments at last year's European Alpha Congress in London. He also said that it may be a few years before a safe and practicable treatment became available. It may be a long road to travel but on the 12<sup>th</sup> of October a very significant milestone was passed.

The Alpha 1 Awareness charity is moving forward on a number of fronts. Patients talking to patients is one way to support Alphas and later in this newsletter there is an item on the latest Informal Lunch in Milton Keynes.

Another way to help patients is press our politicians and decision makers to improve our healthcare services. This is yet another long road but a significant step was taken on the 4th October 2011 when an expert working session on Alpha-1 antitrypsin deficiency was held in the European Parliament in Brussels. The objective of the meeting was to identify the issues facing Alpha-1 patients and prepare concrete recommendations that will help the European Institutions and Member States in identifying the best way forward to address these. The meeting was chaired by Carl Schlyter MEP (Sweden) who has an interest in better information being made available to patients. The importance of the report is that it is a set of recommendations, supported by experts in the field and Members of the European Parliament, in a form that links to the stated principles of the European Union. The report is 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.

**Alan Heywood-Jones**

## ERS Congress 2011

*In September the Alfa Europe Federation, was invited to have a stand at the ERS Congress. Our Chairman, Alan Heywood-Jones, attended in his role as AEF President. Dawn accompanied her husband Alan to help man the AEF Stand at the Congress, this gave Dawn the opportunity to get Alpha 1 Awareness UK's name recognised in the European Respiratory world. Here is Alan's report of the ERS*

The European Respiratory Society's annual congress (24-28 Sept) in Amsterdam was a very large event. There were more than 500 lectures, demonstrations, symposia, award ceremonies, and so on. A very large hall was given over to pharmaceutical companies to display the latest drugs, machines and services for respiratory physicians and other healthcare workers. A small section was reserved for patient organisations to demonstrate the work they do. Sixteen organisations were invited and from the UK there was the British Lung Foundation and the June Hancock Mesothelioma Research Fund. Dawn and I manned the Alfa Europe Federation stand. Apart from promoting the Federation and Alpha 1 Awareness we found time to meet up with our patron Professor Sabina Janciauskiene, Professor Rob Stockley, Doctor Sandra Nestler-Parr and John Walsh – CEO of the American Alpha 1 Foundation and a good friend to our charity.

The European Respiratory Society works very closely with the European Lung Foundation. The Congress included a number of events organised by the ELF. The meeting of the Patient Advisory Committee was particularly interesting in that plans were discussed for the Patient Ambassador Programme, World Spirometry day 2012 and the upcoming ERS task forces. The Ambassador Programme is to give patients' representatives the tools to put forward accurately the patients' needs and concerns to healthcare professionals. Patient involvement in all healthcare services, from research project to bedside care, is a major element of all European health and consumer legislation. This ethos has spread across the World – a medical researcher applying for a grant is quite likely to be told 'no patient involvement – no money.' The ELF hopes to make a more detailed announcement in the near future.

**Alan Heywood-Jones**

## Onwards but mainly Upwards

In the late Sixties Sherry Arnstein published *A Ladder of Citizen Participation*. In this paper she addressed the question of whether or not citizen participation is citizen power. Her answer was that the two are just different terms for the same thing. To analyse the level of participation she visualised an eight rung ladder; each rung being having a defined level of 'participation' (see Box)



Though rooted in the social turmoil and political debates of the Sixties, Arnstein's ladder has had a major influence on social policy. Recently the imagery of the ladder and many of the terms used are being applied to patient involvement in health care, health planning and even medical research. At the European Respiratory Society Congress more than one presentation showed a ladder with the higher rungs indicating more patient involvement in health issues. Often there are fewer rungs and the terms are adapted to the needs of today but the imagery is powerful and shows the upwards path that many organisations, the European Lung Foundation being one,

are attempting to follow.

A few years ago a patient would expect his or her doctor to state what the problem was and then proceed to treat it in the best way possible according to the best standards of the day. As patients became more knowledgeable about their bodies, their health and their rights, treatments were proposed but then only went ahead when accepted. This concept of informed consent was a major step up the ladder. Other changes, such as the patient's right to select his or her doctor also became more common in many countries (Countries, such as the USA, with a predominantly private health system already had this freedom because the patient is the paying customer.)

Further steps in consultation often involve patients' representatives – patients' organisations, health charities and people elected to health management boards. When these representatives have equal power to influence the outcome on all issues then we move up a rung to 'joint control'. Because medical issues can be complex and the words used outside normal experience it may be necessary to train the representatives. We do not want to be blinded by medical science, accountants' terminology, political jargon, etc. This is why the European Lung Foundation is introducing the Patient Ambassador Programme to give patients, or their representatives, the ability to meet and discuss health issues with the people running the system.

Beyond consultation is control, or at least control in equal partnership with the other stakeholders. Finally, there is commissioning medical research and services. At this highest level of participation is the American Alpha One Foundation which is the largest funder of research into alpha-1 antitrypsin deficiency. Here, a patient organisation is deciding what research is to be funded, how it is to be conducted (within the standard ethical rules), how patients are to be used (if clinical trials are involved) and how the results are to be used for the benefit of patients. This is an aspiration for many patient organisations. **Alan Heywood-Jones**

Sherry R. Arnstein, former Executive Director of the American Association of Colleges of Osteopathic Medicine, died at home in Washington D.C. in 1997 after losing her fight with breast cancer. The ideas she promoted live on.

#### **Arnstein's Ladder**

**1 Manipulation and 2 Therapy.** Both are non participative. The aim is to cure or educate the participants. The proposed plan is best and the job of participation is to achieve public support by public relations.

**3 Informing.** A most important first step to legitimate participation. But too frequently the emphasis is on a one way flow of information. No channel for feedback.

**4 Consultation.** Again a legitimate step attitude surveys, neighbourhood meetings and public enquiries. But Arnstein still feels this is just a window dressing ritual.

**5 Placation.** For example, co-option of hand-picked 'worthies' onto committees. It allows citizens to advise or plan ad infinitum but retains for power holders the right to judge the legitimacy or feasibility of the advice.

**6 Partnership.** Power is in fact redistributed through negotiation between citizens and power holders. Planning and decision-making responsibilities are shared e.g. through joint committees.

**7 Delegated power.** Citizens holding a clear majority of seats on committees with delegated powers to make decisions. Public now has the power to assure accountability of the programme to them.

**8 Citizen Control.** Have-nots handle the entire job of planning, policy making and managing a programme e.g. neighbourhood corporation with no intermediaries between it and the source of funds.

## Informal Lunches

### North Wales

Sadly due to lack of support the Lunch in North Wales had to be cancelled, this was a big disappointment to us all.

### Milton Keynes

The 15<sup>th</sup> October saw Dawn and myself welcome a group of around 20 ( members, spouses & children ) to the Mercure Parkside Hotel, Milton Keynes. It was great to meet up with old friends and meet people who we only new via email or letter, at last we could faces to names.

There was no lack of conversation, as everyone introduced themselves to each other, over coffee. Charlotte Price bought her 4 youngsters along to meet us, , the 3 younger children, were soon settled with paper crayons and stickers, Ryan the oldest of the 4 settled with his games, while the adults chatted away. As always seems to happen on these occasions everyone seemed to learn something from someone else and a huge array of topics were discussed, including, o2 suppliers, concentrators for travelling, insurance for Alphas, drugs trials and of course the main topic was the news that had been made public a couple of days before about the research at Cambridge. Lunch was one of the best we have had at any of our events and before we ate Dawn & I decided we would order a drink so that we could toast the news of the research, which is such a huge step toward the cure and gives hope to all Alphas. After the toast we gave the 3 younger children their Alpha Teddies ( one of our traditions for younger children at our meetings ) Ryan was not left out, he had an Amazon Gift Voucher After lunch, it being such a glorious warm sunny day, everyone went outside

and enjoyed the lovely peaceful countryside in which the Hotel was set, either walking round or just sitting and you've guessed it, chat !!!

After a last cup of tea people headed off and Dawn and myself retired to the village pub for a little drink !!

We were pleased to welcome John Mugford from the Alpha UK Support Group, who called in to say "Hello" as he lives just a few minutes away from where we were holding the lunch. Dawn had a long chat with him and it was good to shake hands and agree that the two groups work together on the Named Patient Programme.

Thank you to everyone who came along to the day and made it a very enjoyable occasion



Chatting over coffee



Ready for lunch



Adam, Thomas & Paige with their Teddies



## News in Brief

### Great News

Everyone in the Alpha world was given a terrific boost on 13<sup>th</sup> October, when our patron, Prof David Lomas, was heard on the Radio 4 Today programme, talking about the great breakthrough he and his research team at Cambridge, have made in their research into the Alpha gene ( see A Word from the Chairman ).

Prof Lomas has offered to talk about his research to UK Alphas at a meeting, this we hope we can arrange, however since the news broke as you can imagine Prof Lomas is in great demand and has a very busy schedule, we also will have to bear in mind that winter is fast approaching and winter weather is not good for Alphas. We at Alpha 1 Awareness UK, will do our utmost to organise an opportunity to invite you all along to hear Prof Lomas in the coming weeks/months, rest assured as soon as we have managed to arrange something you will be the first to know, in the meantime we will keep you up to date with any further news on the research. **Lin Daniels**

### Annual General Meeting

Members had notice was sent out to them about our AGM on 5<sup>th</sup> November. I have had a few voting slips returned, if you haven't returned yours yet, please we do need them before Saturday 5<sup>th</sup> November, you can post them or email them to me asap. Also if anyone is planning to attend the meeting, please can you let me know. Many thanks  
**Lin Daniels**

### Fundraising News

#### Christmas cards

We are once more selling Christmas Cards and a new supply of small notelets, to raise money. You should have all received order forms for the cards I have begun to receive orders already, incase you have not received an order form or have mislaid it, a new form is with this Newsletter.

We have increased the price to £3.50 per pack of 10 cards, which, I hope you will agree, is still excellent value. The notelets are unchanged at £1 per pack of 4 cards. **Lin Daniels**.

### Can You Help ?

I have had an idea to raise some money for the Charity, but to achieve it I need your help. All you need to do is send me yours or your family's favourite recipes, I will then bring them together into a small recipe book, so either post or email your recipes to me. I look forward to receiving them. Thank you  
**Lin Daniels**

### Wristbands, lanyards and sweatshirts

We have wristbands and lanyards, with our Charity name on them. We also have some very nice burgundy sweatshirts, with our Charity logo and name embroidered on them.

Wristbands £1 each  
Lanyards £2 each  
Sweatshirt £12 each  
sizes small, medium, large, extra large



Wristband £1



Lanyard £2



Sweatshirt £12

If you are interested in buying any of the above, please drop me a line to the PO Box addressor email me at [secretary@alpha1awareness.org.uk](mailto:secretary@alpha1awareness.org.uk)

### **Kayakers & Cyclists**

We were delighted to receive £1,700 from the team of and kayakers & cyclists who in March did their fundraising event by setting off from Hatherleigh, Devon kayaking along the River Lew into the Torridge and cycling following the river route to all end up in

### **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.

**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.**

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### **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.

Bideford. Well done and many thanks to you all

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If you or one of your family can raise funds for us we would love to hear from you, it doesn't have to be anything energetic, you could organise a Quiz Night or a Coffee Morning, sponsor the children in your family to do a sponsored silence, there are many little ways you can help

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 everytime you search a webpage you raise money for the Charity.

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

visit our website : [www.alpha1awareness.org.uk](http://www.alpha1awareness.org.uk)

This is our last Newsletter of 2011 so we would like to be the first send you festive greetings.....



Wishing you and all your family and friends

A Very Happy Christmas

&

A Healthy, Happy & Peaceful 2012

