

# Alpha-1 UK Support Group

## Supporting Alphas and their families



SPRING 2009 NEWSLETTER ISSUE 1



Chris Torrance  
Group Owner



John Doyle  
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John Mugford  
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### **Support group meeting 2009** Hosted by John Doyle

This years' support group meeting is to be held in Plymouth on Saturday September 12th 2009. The meeting in York last year was a great success and it looks like 2009 is going to be another bumper year with many members attending. If you haven't already got your name down and would like to be there please contact John Doyle at [jedoyale@blueyonder.co.uk](mailto:jedoyle@blueyonder.co.uk) it's a great chance to put faces to names and have a good old natter. The day is very friendly and informal.....we would love to see you there.



Our Red Hatters in York 2008

The Venue is at The Astor Hotel [www.astorhotel.co.uk](http://www.astorhotel.co.uk)  
The cost of the buffet lunch is £12 per head which also includes a cream tea later in the afternoon. For members who would like to stay for the evening meal, the cost will be subsidised by group funds and will be £15 per head.

There is an Auction prize of one nights stay in the Bridal Suite, complete with Four Poster bed which has been very generously donated by the hotel management (to be taken another time subject to availability) Many members make a weekend of these meetings and will be staying at the hotel, at the time of printing there were a few rooms still available but they are going fast.

The hotel is oxygen user friendly so don't forget to contact your o2 supplier and GP in plenty of time to make sure you'll have an adequate supply.

### **Easy Fundraising**

Please don't forget to make any online purchases through the Easy fundraising website [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk)

A cash back donation will be made to the group of your choice so don't forget to enter Alpha-1 UK support group when you register....every little helps.

### **BONUS BALL**

There are still some bonus ball numbers available

Anyone wishing to purchase one please contact John Doyle at [jedoyale@blueyonder.co.uk](mailto:jedoyle@blueyonder.co.uk)

You might just win yourself £25 or more if it's a roll over !

### **New look Alpha-1 website**

Thank you to John Baxendale, his team at the Internet factory and John Mugford for designing and putting together our brand new look Alpha -1 website. Please note that the site is still under construction. However for a sneak preview please look at: - [www.alpha-1.org.uk](http://www.alpha-1.org.uk)

## **POWER BREATHE**

There has been some chat on the support group mail recently regarding the Power Breathe.

The Power Breathe is a small breathing instrument that when used on a regular basis the makers claim can help to exercise and strengthen the lungs. The Instrument can be purchased at many places including John Lewis stores, Argos and online at Amazon and e-bay. The cost can vary from £26-£35.

One of our group members has recently been able to get an NHS prescription for one so if you are interested, it's certainly worth asking about at your local doctors surgery.



## **PORTABLE CONCENTRATOR HIRE**

As you may all know this year Professor Stockley at Adapt very generously gave the Alpha -1 UK support group a donation of £3000.

On the groups behalf we have purchased a Portable Concentrator, an Invacare XP02 for members to hire for holidays abroad and in the UK. .

There will be a total charge of £35 for the concentrator, £20 to cover the cost of postage and packing and a £15 donation to cover the cost of hire and maintaining the machine... Insurance for the concentrator will need to be covered by members own home insurance.

We also have for hire a Pulse Oximeter which gives you an Oxygen saturation or "Sats" reading ( the amount of Oxygen in your blood )

Anyone interested in hiring either of these two items should write to John Doyle [jedoyle@blueyonder.co.uk](mailto:jedoyle@blueyonder.co.uk)

### **Eating and your Lungs**

Try to make sure you eat a healthy mix of grains, fruit, vegetables and lean meats.

Eating 3 big meals a day may prove difficult especially if you get breathless whilst eating or maybe you have a poor appetite, better then to try eating several smaller meals throughout the day.

Try not to drink just before or during a meal if you can help it, it will make you feel unnecessarily full. Mealtimes can become very stressful for you and your carers, so eat what you enjoy and take your time preparing and eating your meals.

## **ADAPT - Roche Repair Drug Trials Update**

by John Mugford

Preliminary results have now been received for trials recently conducted by ADAPT for a new drug that is thought to repair alveoli. The official statement from Roche is as follows: -

### **Safety**

5mg of the drug daily was generally well tolerated relative to placebo.

### **Efficacy**

In general the data analysis failed to show significant effect in the entire patient population who received 1 year of treatment with the drug. However, further analysis will be carried out that may identify a subgroup of patients who may benefit from receiving the drug.

The results together with that of an ongoing 2 year study in patients with smoking induced emphysema, that is not limited to alpha-1 antitrypsin deficiency, will give a clear idea whether the drug is beneficial for the treatment of emphysema.

### **Low fat Quick Vegetable Soup Serves 6**

1 Medium Potato	2 leeks thinly sliced
2 carrots thinly sliced	1 Onion finely chopped
2 Courgettes sliced	50gr Frozen Peas
1 Small tin of chopped tomatoes	1 Vegetable Stock cube
freshly ground black pepper	750ml of Water

- 1) Place Potatoes, leeks, carrots and onions in a pan with the water and stock cube, Bring to the boil and simmer for 20 minutes until the Vegetables are tender
- 2) To make a chunky soup, remove just a third of the Vegetables and whiz in a blender with half the tomatoes.
- 3) Then return to the pan with the rest of the vegetables and stock. Finally add the rest of the tomatoes and frozen peas, heat through thoroughly and serve.