

Alpha-1 UK Support Group

Supporting Alphas and their families



SUMMER 2009 NEWSLETTER ISSUE 2



Chris Torrance
Group Owner



John Doyle
Treasurer



John Mugford
Moderator / Webmaster



Bob Oliver
Moderator



Linda Cooke
Liaison Officer

Hello everyone and welcome to this our second issue of the Alpha1 UK Support Group Newsletter

As many of you know there has been some exciting news for a couple of members since our last edition. Kelvin Buck (moley) was listed for a lung transplant at the end of November 2008 , he had his first call nine days later but sadly when he was five minutes from arriving at Newcastle hospital as sometimes is the case he was told it wasn't going to happen and had to return back home. Kelvin then spent the next few months in and out of hospital and was very poorly, during some of this time his name was temporarily removed from the waiting list. Thankfully once Kelvin was better he was listed again and the most fantastic news came through that Kelvin had received a double lung transplant on April 21st 2009.

Good news then followed for another member, yours truly Linda Cooke. I was told I would be accepted for a transplant on the 15th April 2009 and finally after waiting for the results of some blood tests on the 24th April my name was finally put on the waiting list....less than two weeks later on the 3rd of May I got my call from Papworth hospital and in the early hours of Monday morning the 4th May I received a double lung transplant. Both Kelvin and I are making a great recovery and realise how lucky we have been and will be eternally grateful to our donors and their families for these most precious gifts.

SUPPORT GROUP MEETING SEPTEMBER 12th 2009

Please don't forget the support group meeting; it's not far off now. There are still places left and rooms at the Hotel .This years' meeting is to be held in Plymouth hosted by John Doyle on Saturday September 12th 2009.. If you haven't already got your name down and would like to be there please contact John at [jedoyale@blueyonder.co.uk](mailto:jedoyle@blueyonder.co.uk) .

The Venue is at The Astor Hotel 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.

John Doyle can arrange accommodation for those members wishing to stay over at the hotel

John can also be contacted if you wish to purchase a bonus ball number or Alpha 1 tee-shirts and sweatshirts and also for the hire of our Portable concentrator. and Oximeter [jedoyale@blueyonder.co.uk](mailto:jedoyle@blueyonder.co.uk) . Christmas cards are also available to buy and will be on sale at Plymouth.



SUMMER CRUSH

Created by Ivan Romano, Fifth Floor
Harvey Nichols Cocktail Bar
4 chunks of watermelon
1 peach, skinned and pureed
60ml apple juice
10ml lime juice

Muddle (mash) the watermelon and peach puree together, place in a cocktail shaker with some crushed ice and the juices. Shake well and strain into a tall glass. If you don't have a cocktail shaker then simply blend all the ingredients and strain into the glass with a sieve.

Looking after your lungs in hot weather

People with respiratory disease should be particularly vigilant in hot weather as the heat may aggravate existing conditions.

Below are some tips to help you keep cool:

1. Avoid going outside during the hottest times of day 12-2pm
2. Avoid excessive physical activity, or do it in the cooler ends of the day.
3. Keep the windows closed while the room is cooler than it is outside. If safe, open windows at night when the air is cooler.
4. Have cool baths or showers, and splash yourself with cool water.
5. Drink water or fruit juice regularly (avoid alcohol, tea or coffee).
6. Wear loose, cool clothing and a hat if you go outdoors and remember to take any medication that you might need with you.
7. Avoid areas of high pollution – sunlight can react with pollutants to form especially harmful substances such as ozone and oxides of nitrogen
8. You can check pollution levels in your area by ringing 0800 556677 (for free) or on Teletext (page 156)
9. Make sure you drink plenty of water
10. If you suffer from hay fever during the summer months check the pollen count.

If you are worried, you can call NHS direct on 0845 4647 or the British Lung Foundation's helpline on 08458 50 50 20.

"Each morning when I open my eyes I say to myself: I, not events, have the power to make me happy or unhappy today. I can choose which it shall be. Yesterday is dead, tomorrow hasn't arrived yet. I have just one day, today, and I'm going to be happy in it."

-- Groucho Marx

A New study has discovered that boiling carrots before slicing them increase anti-cancer properties up to 25 percent.

According to the Newcastle University,



If you want to keep your eyes vision clear for many years eat fatty fish twice a week. According to a new study eating fish keeps you away from eye disease. If you eat fish like Salmon and Tuna it helps prevent a devastating eye disease, the age related Muscular degeneration. This is the main cause behind blindness in people

ADAPT REPORT/ PRESENTATION BIRMINGHAM

23/4/09 BY JOHN DOYLE

At around 1.20pm Prof. Stockley started the ball rolling by telling us how the number of patients had grown from around 124 in 1996 to 898 by February of this Year; then he spoke of the Exactle repair investigation meeting saying how it had been a negative study. He mentioned that a new trial (Eclipse) was to be held shortly and was looking for volunteers from the 'Alpha' community, also for non 'Alphas' for benchmarks. Dr. Deepak Subramanian took the floor and discussed PET scans (Positron Emitting Tomography). PET Scans are mainly used for cancer patients but are going to be extended in use to cover people with COPD, possibly 'Alphas', the procedure involves having a radioactive dye injection, prior to being scanned for around an hour, this method gives good definition 3D images.

Dr Helen Ward then spoke about 'Flights and oxygen use', stressing the need to book your oxygen well in advance, also pointing out the need / criteria for a fit to fly test. She also mentioned that some airlines charge for oxygen whilst others are free. There a few airlines that won't allow the use of oxygen at all, so you do need to check with the airline for the full conditions before booking a flight.

It was now my time to take the platform. with my PowerPoint presentation, on behalf of our 'group' .I showed how we had progressed through the years, from a membership of just 6 in 1997 to our current level of around 137. I spoke of our aims, hopes and achievements in a mission statement. I covered the 'new look' website, concentrator hire, the latest newsletter and our annual get together in September. I followed this with a more personal presentation 'From childhood to Transplant and beyond', giving a brief synopsis of my life as an 'alpha'. A thoroughly good time was had by all