

alpha-1

uk support group

supporting alphas
and their families

Newsletter

Issue 8
Summer 2011



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Welcome to the Alpha-1 uk Support group Summer 2011 Newsletter



RAFFLE AND AUCTION

If you are coming to the meeting could we please ask you to bring any unwanted gifts that you may have for our raffle and any items that you think might be suitable for Auctioning, by our very own Auctioneer Mr Stephen Mayhew...who always makes the Auctions such enormous fun
Also if you have any unwanted Books or CD's and DVD's we can sell those too and raise a few more pennies for the group funds.
Thank you .

ANNUAL GROUP MEETING IN YORK

This years annual meeting is to be held at the Burn Hall Hotel in York www.burn-hall.co.uk. on Saturday 10th of September 2011.

Many members make a weekend of it and will be arriving on Friday the 9th until Sunday 11th
Our meetings are always a lively and fun weekend.
We do have a few spare places so if anyone would like to join us please contact Chris Torrance at :-
chris.torrance@ntlworld.com who can give prices and room availability.

This year we are very pleased to announce we will have in attendance our Patron ,Professor Robert Stockley from ADAPT at Queen Elizabeth Hospital in Birmingham the UK's largest research centre for Alpha 1 Antitrypsin Deficiency and also we have Dr Sandra Nestler-Parr from Grifols (Talecris) ...who will be there to answer questions on the "Named patient" programme for Prolastin.

Those members who are unable to attend the meeting will be given the chance to put forward to the committee any questions they would like us to ask either of our guests on their behalf.

Encouraging Outlook for Augmentation therapy (Prolastin) in the UK

In June the committee meet with Dr Sandra Nestler-Parr and Mohit Jain from Grifols (Talecris)

We all found the meeting very informative and it gives up hope here in the UK that perhaps one day we will receive the much needed therapy we all need.

Grifols (Talecris) have committed to putting a framework in place in the UK very soon to provide information and educate consultants/ specialists regarding the administration, clinical efficacy and outcome of augmentation therapy which is hoped will support patient applications under the “Named patient Basis” , a practise that is recognised internationally and has been widely used in the UK for some years.

Further information will be available at our annual meeting in York on September 10th where a Grifols (Talecris) representative will be attending.

Thank you

A big thank you to Member Jan Carley’s Mum , Margaret who generously opened a Justgiving fund raising page in honour of her 80th birthday and raised over £250 by asking for donations for Alpha -1 uk Support group instead of giftswe hope you had a wonderful birthday Margaret.

Thank you to Kyle , John and Mary Doyle’s Grandson who stepped into the breach to run in the Plymouth Half Marathon earlier this year and with a Justgiving page raised almost £100...well done Kyle.

Thank you also to all members who make donations in many other ways on behalf of Alpha-1 uk .

If anyone else feels they are able to do something to raise some money for the support group a Justgiving page is very easy to open.

Or maybe you could hold a coffee morning ,quiz night, car boot or jumble sale....the ideas are endless and yours.

Here are some other ways to raise funds:- easyfundraising.org.uk, easysearch.org.uk
And eBay for charity.

You can also follow us on Twitter and Face book.

Promotional Gifts

This year we are happy to announce we have purchased some promotional gifts which have our group LOGO on them and they will be for sale from the September 2011 meeting onwards.

These are, Cotton shopping bags, Trolley key rings, Pedometers, Mouse mats, China mugs, Calendars and for 2011 newly designed Christmas Cards.

Those members who are unable to attend the meeting will still be able to purchase these items plus PPplease contact any committee member or mail

infoalpha1uk@googlemail.com

Prices are as follows :-

Cotton Shopping Bags £2.99 each

Pedometer..£2.50 each

Trolley Token Key Ring.£2,50 each

Calendars..£5 each

Christmas Cards £4 per pack of 10

Mugs £ 3.50 each

Mouse Mats £ 2.50 each



Start your Day with a Kiss !

It is said that kissing lowers levels of the stress hormone Cortisol and can put you in a good mood and lift your spirits for the day ...so pucker up guys and gals and get smooching !

POWER CHAIR

We are pleased to announce that the group power chair has now found a new home and is on permanent loan to one of our members.

Publications

We currently have two publications which along with other PDF files and posters are available for download from our website www.alpha1.org.uk

We would be happy to post out any of these brochures and posters should you wish to hand them out to your GP's ,consultants and local hospitals to help further spread the awareness of Alpha 1

Please contact any committee member or mail

infoalpha1uk@googlemail.com



Congratulations

Many congratulations to two of our members who have both had double lung transplants this year.

We wish them many many years of continued good health.

“Summertime” by Joe Lyons

Ice cream cones spill over top
Cold drinks alongside lollipops
Sun cream smothered on deep red skin
Ooohs and aghs as it sinks in

A hint of sunshine is all it takes
Flask of tea or coffee, we quickly make
Sandwiches packed more in haste
Brollies standing by in case

Water splashing time to swim
Cries of joy while diving in
Moment’s later rain it pours
Bodies rush to get indoors

So fickle our seasons from spring to fall
Mixed blessings weather never suiting all
Doesn’t matter, if it rain or shines
It always makes a special summertime

Top Ten Healthiest Vegetables

Our Mums always told us vegetables were good for us but did you know a recent study has looked at the vitamin, mineral and fibre content of foods together with their antioxidants and phytochemicals.

The top ten Vegetables found were :-

- 1) Watercress and kale
- 2) Bok choy
- 3) Spinach
- 4) Broccoli
- 5) Chinese cabbage
- 6) Brussels sprouts
- 7) Swiss chard
- 8) Rocket
- 9) Radishes
- 10) Bean sprouts

IN MEMORIUM

It was with deep regret we announced the passing of John Doyle , Francesca Johnson and Marion Rose earlier this year Our thoughts and prayers were with their family’s at such a sad time

Also our condolences are sent to those members who have lost a parent, close family members and friends this year.

May they all Rest in Peace
“One journey ends and another begins”