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Karen North  
Secretary  
Project Co-ordinator

Hello and Welcome to this our Summer 2012 Newsletter...and a very special welcome to all our new members , we hope you enjoy being part of this group .



### Summer 2012 Annual Social Gathering

This years annual meeting is to be held at the Heronston Hotel and Leisure Club in Bridgend, Wales on Saturday 15th September.

Many members make a weekend of it, arriving on Friday 14th and staying until after breakfast on the Sunday 16th..its always a great opportunity to catch up with old friends and to put faces to names of those Alpha members and new friends we've yet to meet.

Everyone is assured of a warm welcome, it's always a fun weekend.

So far we have around 70 members , family and friends attending this year but there are still approximately ten rooms left vacant at the hotel , so if you're wondering if you'd like to join us and haven't got your name down yet then now is the time to contact Jackie Davies who is organising this years meeting...Jackie will be able to give you the details if you contact her on :-

[hotlipsjackie@hotmail.com](mailto:hotlipsjackie@hotmail.com)

There will be a buffet lunch and a presentation from Dr Sinden and Dr Gane from ADAPT in Birmingham with a question and answer session and also a presentation from Advocate Policy and Public Affairs Consulting Ltd followed by afternoon tea and a raffle and Auction, finishing around 5.30 pm to enable everyone time to get ready for the evening meal and later some fun with the resident DJ and Karaoke.

## **Alliance to campaign for better access to Alpha-1 treatment**

The Alpha-1 community has formed an unprecedented alliance to campaign for better access to treatment for Alpha-1 patients. The recently established **Alpha-1 Alliance** will be campaigning for a nationally commissioned specialised service for Alpha-1 and for more awareness of the unmet medical need of Alpha-1 patients.

The Alpha-1 Alliance brings together the key patient groups for Alpha-1 in the UK, including the Alpha-1 UK Support Group, Alpha-1 Awareness UK and Alpha-1 Advocacy & Action. The Chair of the Alliance will be Dr Ravi Mahadeva, Clinical Director in Respiratory Medicine at Addenbrookes Hospital, who will be representing the Alpha-1 clinical community.

The Alliance will offer a platform for patients and clinicians to work and campaign together. Dr Mahadeva said: *“For a long time patients, families and carers have been waiting for better access to Alpha-1 therapy. We therefore strongly support the campaign for a nationally commissioned specialised service for Alpha-1, as it will allow for a more holistic treatment approach and provide the necessary infrastructure for future research in the disease area.”*

As an initial part of the campaign, the Alliance will be meeting with key stakeholders to discuss the application process for a nationally commissioned specialised service and to raise the profile of Alpha-1 in Parliament. The Alpha-1 Alliance will provide regular updates to inform patients of the progress of the campaign and how they can get involved and support the activities.

Dawn Heywood-Jones, Trustee of Alpha-1 Awareness UK and member of the Alpha-1 Alliance, said: *“We are pleased that the Alpha-1 community has finally joined forces to campaign for the common goal of better access to Alpha-1 treatment. It is of great importance that we speak with one voice to make our concerns and medical needs heard in the public policy arena. A nationally commissioned specialised service will not only provide better therapy for patients but will also end the current postcode lottery in access to treatment.”*

Karen North, Project Co-ordinator at the Alpha-1 UK Support Group and member of the Alpha-1 Alliance, said: *“The policy structure for the commissioning of specialised services is currently in a state of flux. However, we look forward to engaging with the Government to discuss a common approach for improving services for Alpha-1 patients in the future.”*

Margaret Millar, representative of Alpha-1 Advocacy & Action and member of the Alpha-1 Alliance, said: *“We appreciate both other patient groups for all their hard work over the years and are happy to be part of this historic momentous occasion working together in an Alliance for better treatment and therapy for all Alpha-1 patients in the UK today.”*

## New Alpha-1 Liver Booklet “

A Guide to the assessment and management of A1AD related liver disease” is available on our website [www.alpha1.org.uk](http://www.alpha1.org.uk) the printed version will be available soon.

Special thanks to Chris Torrance for all her hard work in producing this guide.

## Donation to Children’s Liver Disease Foundation

We are pleased to announce that through the sales of last years calendar the Alpha-1 UK Support Group managed to raise the sum of £100 which has been donated to the Children's Liver Disease Foundation.

Thank you all for your support.

## Wake with a smile

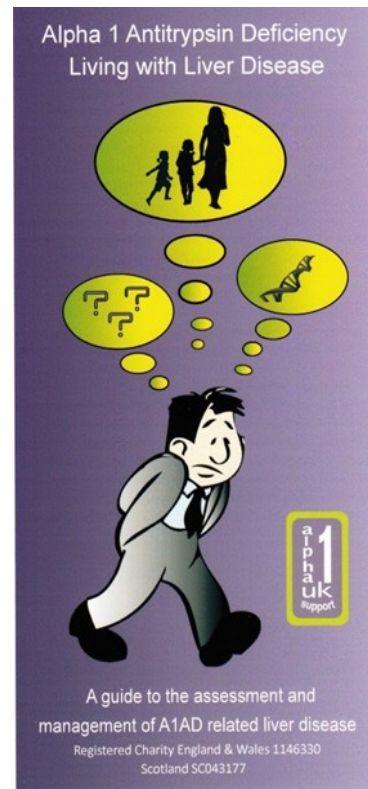
What person in their right mind wakes up laughing...but just think how good it would be to start your day that way.

**LIE ON YOUR BACK** with your eyes closed. Think back on a ridiculous thing you ( or someone else ) did that makes a hilarious story.

**REMEMBER A TIME** you laughed really hard. What happened to make you laugh so much? And who were you with?

**SEE IF YOU CAN** coax a chuckle out of your calamities. Learn to laugh at yourself and see if it can spill into your day.

Taken from “Five Good Minutes” by Dr Jeffrey Brontley



## Take time for Tea

You may have heard otherwise, but tea hydrates just as well as water. It may also protect you against heart disease and even cancer , according to research from Kings college, London. Three or more cups a day could also protect your teeth and strengthen your bones. The secret? Researchers think it could lie in antioxidant plant compounds that are found in black tea but also in white and green teas which help prevent cell damage.

Taken from “Woman and Home” FEEL GOOD YOU.

## Fundraising for Our Group

A big thank you to the following fundraisers using our JustGiving page:-

**Marianne Mullen** - Marathon swim over the summer months (26 miles in total).

£257 raised so far, please support Marianne by making a donation:-

<http://www.justgiving.com/MarianneMullen>

**Becky Dore** – Running Kenilworth Half Marathon 2012 on 02/09/2012.

£415 raised so far, please support Becky by making a donation:-

<http://www.justgiving.com/beckydore>

**Gillian Duffy** - giving up chocolate for 200 days.

£55 raised so far, please support Gillian by making a donation:-

<http://www.justgiving.com/Gillian-Duffy1>

Perhaps you could help raise funds to enable us to continue our work? Whether £5 or £500, all donations will be put to good use, providing information, equipment and support for all Alpha-1 patients. In addition, we aim to promote better awareness and understanding of A1AD related diseases throughout the medical profession and general public.

For details of how to donate, or how to find us on JustGiving please visit our Website <http://www.alpha1.org.uk/fundraising.html>

It is also possible to raise funds without any cost to yourself, by using Easyfundraising to do your online shopping, or the Easysearch for your internet searches. Again, please visit our website <http://www.alpha1.org.uk/fundraising.html> to sign up to either of these free services.

Thank you to everyone who has been involved in fundraising activities and donations for our group. We constantly have new targets to reach and new projects to fund, any financial help we receive is channelled into bringing practical help and advice to all our members, and the wider alpha community. Your kindness and the money donated will help us to do even more.

It is with great sadness that we announce that Liz Mckenna has resigned from her position as Treasurer and also as trustee of the Alpha-1 support group due to health reasons and Liz wants to spend more time with her husband Rob who has also been unwell.

I am sure you will join us in thanking Liz for everything she has done in supporting our group since taking on these responsibilities and we wish Liz and Rob the very best for the future .

Chris Torrance has agreed to take back the responsibility of Treasurer temporarily and we would like to take this opportunity to invite any of our members to join the Committee, which of course would go through the usual Electronic Poll Vote process for member approval . We specifically would like someone with an accounting background to take over the role of Treasurer although this is not essential, in addition to this help in other areas would also be appreciated.

If you would like a challenge and feel you have something to offer please contact John Mugford on [john.mugford@googlemail.com](mailto:john.mugford@googlemail.com)

**[www.alpha1.org.uk/shop](http://www.alpha1.org.uk/shop)**

On our website we have a list of Alpha-1 products to purchase, these items are available to buy by post or at the September 2012 Annual meeting. They include -:

Porcelain Mugs, Christmas Cards, Pedometers, Shopping Trolley Key rings, Alpha 1 Support Group Badges, and Shopping Bags.

The 2013 Calendar is at the printers as we write and it should be ready very soon. We would like to say a very big thank you to Alpha member Mike Daish and his friend Paul Ruddoch for their wonderful photographs.



**In Memoriam**

With deep regret we announced in January that Jim Livingstone from Scotland had sadly passed away .

Our deepest condolences, thoughts and prayers were sent to Jims family.

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