

alpha-1

uk support group

supporting alphas, their families, carers and friends

Newsletter
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John Mugford
Chairman
Trustee
Webmaster



Christine Torrance
Vice Chairman
Treasurer/Trustee
Yahoo Group Owner



Linda Cooke
Liaison Officer
Trustee



Bev Burroughs
Trustee
Admin Support



Ray Overton
Trustee
Admin Support



Karen North
Secretary
Trustee
Project Co-ordinator



Joe Lyons
Admin Support



Sioned Lewis
Admin Support

A very Happy New Year to you all and a big welcome to our new members and to this our 11th newsletter.



2012 Annual Meeting in Wales

The September 2012 Group get together in Bridgend in Wales was a huge success . We were so happy to see many members make the journey and especially pleased to have one of our overseas members the lovely Jenni Nankervis and her husband Bill join us for the weekend all the way over from Australia it was great to finally get to meet them.

As many members know our meetings are essentially social occasions rather than formal affairs. This year it was lovely to have some of our members bring their young children to join us , they were a delight and very well behaved.

Everyone enjoyed a lovely buffet lunch and during the afternoon we had presentations from Dr Nichole Sinden and Dr Jennie Gane from ADAPT and Jamie Holyer Managing Director of Advocate Policy & Public Affairs Consulting Ltd and there was the opportunity for members to ask questions .

The rest of the afternoon was taken up with general fun, chat plus our auction and raffle. We raised a fantastic sum of £807.41.

Our thanks to Committee member Sioned Lewis who very kindly made some delicious Welsh cakes and thanks also to her lovely young daughter Ffion who dressed in full Welsh costume and took them around the room to sell them to raise much needed group funds.

We all met up again in the evening for dinner, followed by a DJ and Karaoke which the children loved.

Our grateful thanks to Jackie Davies for all her hard work in arranging the meeting .

2013 The 50th Anniversary of the Discovery of Alpha-1 Antitrypsin Deficiency

Alpha-1-antitrypsin deficiency (AAT) was first reported in 1963 by Carl-Bertil Laurell and Sten Eriksson who discovered a link between low plasma serum levels of AAT and symptoms of pulmonary emphysema. Since this discovery an understanding of the biochemical mechanisms and genetic abnormalities involved has developed and AAT is now thought to be one of the most common hereditary disorders worldwide, comparable in frequency to cystic fibrosis.

By 1969 an association with liver disease had been discovered in the US, and patients in both Europe and North America began to be identified with the condition.

To celebrate this 50th anniversary events are being held in the UK and worldwide, details of which will be available soon on our website www.alpha1.org.uk

A Healthcare Professional's Guide to Alpha-1 Antitrypsin Deficiency

The Alpha-1 UK Support Group has been commissioned by Healthcare Professionals in the UK to design and produce a new Guide to educate doctors, nurses, and patients about AAT deficiency and the resources available. Special thanks to the Alpha-1 Foundation and to our Vice Chairman Chris Torrance who spent many hours designing this fantastic guide. Available to view at our website: <http://www.alpha1.org.uk/publications.html> The Printed version is now available .

Alpha 1 Support Group Goodies Shop

On our website we have a list of Alpha-1 products to purchase, these items are available to buy by post.

They include :- Christmas cards , pedometers , shopping trolley key rings, Alpha 1 support group badges , shopping bags and Mugs .

Our 2013 calendar is currently on special offer at a bargain price of £3.99 plus p&p.



Double Lung Transplant

Wonderful news regarding Alpha 1 member Jill Mayers who recently received a life saving double lung transplant at Wythenshawe hospital.

Jill had a bit of a bumpy ride but we are pleased to announce she is now well again and back home with her family and living her new life. She thanks everyone for their , prayers , cards and kind best wishes.

Our thoughts and grateful thanks as always are with the Donor and their brave family without whom this gift of life for Jill would not have been possible .

Alpha-1 Alliance Campaign Update

E-PETITION PLEASE SIGN / Alpha-1 Alliance (UK) launches e-petition to the Department of Health calling on the Government to nationally commission a specialised service for Alpha-1 so that patients can get the vital treatment and support they need.

The Alpha-1 Alliance's campaign for a nationally commissioned specialised service for Alpha-1 antitrypsin deficiency, including access to augmentation therapy, is now well under way.

The Alpha-1 Alliance brings together key Alpha-1 patient groups and clinicians to campaign for better services and treatment for Alpha-1 patients.

The Alliance includes the Alpha-1 UK Support Group, Alpha-1 Awareness UK and Alpha-1 Advocacy and Action and is chaired by Dr Ravi Mahadeva, representing the clinical community.

The Alliance is in the process of securing meetings with key officials at the Department of Health as well as meeting with Members of Parliament to raise awareness of the needs of Alpha-1 patients. We've also just launched an online petition to the Department of Health calling on the Government to nationally commission a specialised service for Alpha-1 so that patients can get the vital treatment and support they need. It's really important that we get as many signatures as possible to demonstrate the strength of feeling about the need for specialised Alpha-1 services and we need your help to make this happen.

Please show your support for the campaign by signing our e-petition, then spread the word by forwarding the petition to friends, family and work colleagues. Don't forget to post the petition on Facebook and Twitter too, if you use them. We currently need to reach 5,000 signatures in order to make it into the top 10 petitions to the Department of Health, and if we can get 100,000 signatures the petition has the chance to be debated in Parliament.

You have to be a British Citizen or normally live in the UK in order to be able to sign the petition. So, British Citizens living abroad would be able to sign the petition and it would count (which is why the petition provides a 'Country' drop down menu).

To sign Petition:- Go to
<http://epetitions.direct.gov.uk/petitions/39732>

New Committee Faces

You will have noticed a new line up in the photos of committee members on this Winter Newsletter
A big welcome to Alpha 1 members Sioned Lewis from Wales and Joe Lyons from Nottingham.
We all look forward to working with them.
If anyone else feels they have something to offer and would like to join the committee please contact John Mugford or indeed any other committee member.

In Memorium

With deep regret we announced in August that Alpha 1 member , Alistair Hunter from Scotland had sadly passed away .
Our deepest condolences, thoughts and prayers were sent to Alistair's family

Fundraising for our Group.

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

Becky Dore – Completed the Kenilworth Half Marathon 2012 on 02/09/2012 Total raised £850

Marianne Mullen - Completed a Marathon swim over the summer months (26 miles in total) Total raised £530

Gillian Duffy - Gave up chocolate for 200 days. Total raised £161

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.

50th Anniversary 2013 Alpha 1 support group meeting .

It has already been mentioned that 2013 is the 50th anniversary of the discovery of Alpha-1 Antitrypsin Deficiency so we want to celebrate the 2013 Group meeting in style and we have already started making plans to make this event very special.

We are delighted to announce that our Patron Professor Stockley from ADAPT in Birmingham will be joining us and hopefully some other names will be added to the line up as the year progresses

The date for the meeting has already been finalised, Member Al Holmes offered to find a venue in the Midlands region and member Jackie Davies offered to re-book the hotel we used in Wales in 2012 ...this was put to members for a vote and we congratulate Jackie on winning and our commiserations to Al but our thanks for offering ...maybe next year Al ! So there it is, this years meeting is to be held at The Heronston Hotel and Leisure Club in Bridgend in Wales www.bestwestern.co.uk/Heronston_Hotel on Saturday 14th September 2013...as we always say it is a day meeting but many members make a weekend of it and come Friday through to Sunday morning. So put that date in your diary and keep an eye on our website for updates and events that will be happening that weekend.

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