

Newsletter

Alpha1 Awareness

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A Word from the Chairman

Fifty Years On. As a part of the events being staged to mark the fiftieth anniversary of the discovery of alpha-1 antitrypsin deficiency, Alpha-1 Awareness will be holding a "50 years of Alpha-1" Information Day on the 11th May 2013. The presentations will cover the discovery, progress over the years and prospects for treatments and cures. This is an ambitious programme but we have the support of key figures in alpha-1 research, clinical practice and patient organisations. The planned venue is the Aztec Hotel, Bristol. The event will be open to all Alphas, family and friends and medical people with an interest in the condition. A crèche will be available for those Alphas travelling with young families. Please note the date in your diaries. You will be sent the full programme later.

As part of the worldwide celebration of the work of Carl-Bertil Laurell and Sten Eriksson in 1963, we have created a website to record the major steps made over the past fifty years, events which are planned and the thoughts of people in the Alpha community of patients, clinicians and scientists. The website is being added to and is not yet visible to Google, Yahoo, etc. but you may go to it directly at www.50yearsofalpha1.org. Patients and their desires and needs are very important in today's health landscape. This is especially true of rare conditions. The more we do, the more we are recognised. From the website you can use the Contact Us page to ask your name to be put on the Patients Page. If you want to say more then please include your thoughts. If you just want to be there, simply write your name and Pi condition (PiZZ, PiMZ, and so on). If you have not already done so then please go to the HM Government e-petition website and sign your support for a nationally commissioned specialised for alpha-1 antitrypsin deficiency. The petition was created by Dr Ravi Mahadeva, chair of the Alpha-1 Alliance. Specialised medical services are for rare conditions and diseases that require expert and multidisciplinary care. To quote the petition "We strongly urge the Government to nationally commission a specialised service for Alpha-1, including access to augmentation therapy, so that Alpha-1 patients can get the vital treatment and support they need". You can do more. Talk to your friends and neighbours and ask them to sign the petition - there is strength in numbers!

Alan Heywood-Jones

News about Clinical Trials

European rules on how clinical trials are authorised and carried out are set to be rewritten over the coming months. Glenis Willmott, Leader of the European Parliamentary Labour Party and spokesperson for Labour MEPs on health, has been named as the rapporteur, or lead MEP, for the job. The lead committee for the Clinical Trials Regulation is Environment, Public Health and Food Safety (ENVI).

Ms Willmott has published a press release (www.gleniswillmott.eu/labour-mep-to-lead-on-clinical-trials-rethink/), stating that the new regulation is a great opportunity to create jobs in the United Kingdom and in the EU by improving the rules governing clinical trials. She furthermore emphasised the necessity of increasing the number of clinical trials in Europe by reducing the administrative burden particularly for multi-centre clinical trials and highlight that this will be a core issue to be tackled in her report. She furthermore mentioned the need for improvement, especially to make trials feasible for rare diseases which are dependent on multi-centre clinical trials. She also mentions that she expects better clinical trials rules to lead to an increasing number of treatments and to stimulate research not only in pharmaceutical companies but also by research charities and academic institutions.

The nomination of the Glenis Willmott is interesting news, given that she is known for her advocacy for rare diseases. For example, she has hosted several events concerned with primary immunodeficiencies in the European Parliament. Her statements in this press release and previous ones along with her previous engagements indicate that she will be changing clinical trial application in the favour of rare diseases, especially when it comes down to multicentre and cross-country clinical trials.

Ms Willmott is predominantly interested in patient's rights and patient safety.

Update from Alpha-1 Alliance UK

Patient Survey

Shortly the Alpha-1 Alliance UK will be inviting all Alphas to take part in an online Patient Survey. As soon as we know more we shall send you a link to the survey website. Please remember that everything we and the Alliance are doing is to help get the specialised centres that can look after your lungs and your liver. We cannot do this without your help. So please, fill in the survey when it becomes available.

E-petition

A few weeks ago, those of you with email addresses were sent an email about the e-petition, which the Alpha-1 Alliance UK has posted, asking you to sign it and also forward it to people in your email address book.

At the time of writing we have less than 600 signatures on the e-petition to Commission a Specialised Service for Alpha-1 antitrypsin deficiency. To be effective we need at least 5000 signatures. Go to <http://epetitions.direct.gov.uk/petitions/39732> to add your signature to the petition. Your family, friends, neighbours and work colleagues can also sign the petition and by doing so they will be helping you.

Dawn Heywood-Jones

Facebook and Twitter

 As well as our main charity website at www.alpha1awareness.org.uk, we now have a new Facebook Page at www.facebook.com/Alpha1AwarenessUK (you'll find quicklinks to this page from the top-right corner of our main website, if that's easier for you).

The new Alpha1Awareness UK Facebook Page is the public face of the charity on Facebook, and it will contain general news items about Alpha-1, our charity's activities in the UK and those of our members (particularly people who may fundraising for us; the new page will link to and promote their various Justgiving or Facebook pages especially). Anyone can post comments on the page but these are moderated, that is to say, they are checked as being consistent with the aims of the charity before they are publicly displayed.

This new Facebook Page is not the same as the 'closed' Facebook Group on which you may freely post comments on matters relating to Alpha-1 and how it affects your lives. You can find this Group on the slightly different link www.facebook.com/groups/Alpha1AwarenessUK (note the addition of the word 'groups' in the middle there). There are links to this Group from our new Facebook Page too, so you should be able to find it easily, even if typing in long links is not your thing. The Facebook Group is loosely restricted in terms of access – each new joiner is approved by one of the Charity's administrators, having checked that person's own Facebook page to see whether they have a logical reason to be a part of our Group - but bear in mind there is limited amount of checking we can do on Facebook, if a person is not already a charity-member. There are people on our Facebook Group who are members of other Alpha groups or charities both in the UK and around the world.

Online Forum

The original Alpha-1 Awareness Web Forum is still online at <http://techno.demon.co.uk/a1aforum> and the place where you may write freely in the knowledge that the only people who can read what you write are other members of the Alpha-1 Awareness UK charity or approved carers or medical professionals.

 We have now re-energised our Twitter account, which is @alpha1uk (see its website-page at www.twitter.com/alpha1uk). Follow this link to read the tweets about alpha-1antitrypsin deficiency, the charity and related health issues. We'll be using this medium for making contact with other groups and professionals and hopefully helping them to support our cause, as well as announcing timely news or providing links back to important features on our main website or Facebook Page.

We hope you'll join us in spreading the word online about Alpha 1 in the UK – and of course we hope to meet you in one of our various groups or forums, if you ever feel like a chat, or if you have questions on your condition, or want to meet others in the same boat.

Neil Jackson

A big thank you Neil and his wife Lorna for setting up the Facebook Page to raise the profile and post news of Alpha 1 Awareness UK news worldwide, they have also revived our Twitter account and apparently we have many followers now. All this is good for the Charity and the wider Alpha 1 community in the UK.

Lin Daniels

AGM

Our AGM this year was held on the 14th September, all Officers and members of the board had agreed to stand and were voted in for another year.

Officers and Board members are as follows:

Alan Heywood-Jones	Chairman & Trustee
Lin Daniels	Secretary & Trustee
Jeff Darkins	Treasurer
Dawn Heywood-Jones	Special Projects & Trustee
Meryl Darkins	Membership Secretary
Neil Jackson	I.T. & Communications
Wendy Rogerson	DLA & ESA advice
Emma Wooler	Parent Support
Alan Wooler	Parent Support

We are grateful to all our board members who give of their time and expertise so freely, also a huge thank you to Neil, who has finally become a full Board Member and to Wendy Rogerson, Emma and Alan Wooler who have all joined the Board in the last year and are willing to continue for a further year.

NEWS IN BRIEF

UK Alpha 1 Support Group Annual Meeting

On 15th September, myself, Dawn & Alan, Meryl & Jeff and Neil & Lorna (accompanied by their young sons Sam & Eddie, who were wonderfully behaved) attended the UK Support Group Annual meeting which was held in Bridgend. It was great to meet up with old friends, from the Support Group. After chat and catching up, there was a lovely buffet lunch, after lunch we heard a presentation given by Doctors Sinden and Gane from ADAPT and then a presentation from the Alpha-1Alliance UK, the afternoon rounded off with a raffle and auction. Dawn, Alan and myself stayed overnight, enabling us to join with others from the Support Group for a very enjoyable meal in the evening.

Thank you to John Mugford and the Committee for inviting us to the meeting, it was good to all be together, sharing friendship.

Fundraising

South West Kayak Challenge

The Challenge ... in brief... 4 kayaks, 4 paddlers, 300miles of coastline (approx.), 1 land support crew, 2 weeks...

Who... Chris Brown-Martin, Matt Retter, Chris Lake & Steve Carter.

When... August 2013 - starting in Bude finishing in Exeter at the Quay on Bank Holiday Saturday (24th August)

Why... again, in brief, to support 4 charities – Devon Air Ambulance Trust, Cornwall Air Ambulance Trust, Surf Life Saving GB and Alpha1 Awareness UK.

Written in brief like that it sounds easy doesn't it? But 'easy' is definitely not the word! They will face 2 weeks of navigating tides, rip currents, rocks, other boats, sharks (I kid you not – basking sharks have been spotted this year!), dolphins, weather (who knows what 2013 summer holds for us?!). 2 week *holiday*? No!

In 2011 Chris Brown-Martin organised a successful river kayak event, Matt taking part, (with a sponsored cycle running on Terra firma alongside) from Hatherleigh to Bideford, with a total of £4000 being raised. This event was in support of the Devon Air Ambulance Trust (DAAT), Alpha 1 Awareness and Cancer Research.

Chris would be the first to say that life is for living and he always lives life to the full, and more often than not, doing so at a fast and furious pace! Yet in 2008 a devastating fire changed things for Chris and he either had to make changes in his own life or face worsening health, and potential disability. The George Hotel burning to the ground 'saved' his life. Having always thought he was asthmatic the smoke inhalation caused more problems than expected, and a subsequent blood test confirmed that Chris has Alpha1 Antitrypsin Deficiency, a genetic condition potentially causing lung and liver conditions. A chest X-ray showed up the start of emphysemic changes.

So, at the age of 26 Chris was faced with life changing news – he was almost certainly facing deteriorating lung and liver function, disability and, potentially, premature death. So Chris chose life! Taking on board the diagnosis, which cannot be cured, he now looks after his health, his lungs, his liver, and at the same time is still able to enjoy life to the full – and still fast and furious at times!!

Life is still for living. And, as the fire 'saved' Chris's life, he wants to help save others – hence the Kayak Challenge for 2013

<http://www.southwestkayakcharitychallenge.co.uk/>



Zip Wire Challenge

On October 6th Jodie Sainsbury did a Zip Wire Challenge, at the Oval Cricket Ground, where the zip wire was set up from the highest stand, 75ft high and 500ft long. This is a great challenge for Jodie to have chosen to do and we can only admire and thank her. This is what Jodie wrote, when she told us of her intention to do the Zip Wire Challenge:

" I have applied to do a 500ft zip wire over the Kia Oval in London on Sat 6th October. My friend's little boy Tyler was diagnosed at 5 weeks old, and I know your charity did wonders for them, they've been through so much and I know nothing I could do would ease the pain for them, but giving something back to you for all your help I know would mean a lot to them! So this is for Tyler."

Tyler is Emma & Alan Wooler's young son, who is now 4 years old and Jodie was one of Emma's students, at the school Emma works at.

Corporate Sponsorship

As you may be aware this year Alpha 1 Awareness UK has been chosen as one of the Charities of the Year by Proact UK IT Ltd, in Chesterfield, Derbyshire. The company has done a lot to promote the Charity and raise money for us. A few weeks ago teams made up of Managers from the Company, took part in the Yorkshire 3 Peaks Challenge*, each

team supporting one of the Charities, being supported by the Company this year. The team who did the Challenge in support of Alpha 1 Awareness UK have raised £1688.63. As you can imagine, we are delighted to have this sum of money raised for the Charity and grateful thanks must go to all who took part.

**The Yorkshire Three Peaks Challenge takes in the peaks of Pen-y-ghent, Wharfedale and Ingleborough, usually in this order, and in under 12 hours. These peaks form part of the Pennine range, and encircle the head of the valley of the River Ribbles, in the Yorkshire Dales National Park. (from 3 Peaks Challenge website).*

10K Run 2013

In 2013 we once again have 6 places in the British 10K Run, which will be held in London on Sunday 14th July. Those who took part this year enjoyed the day, despite the rain, and raised an excellent sum of money for the Charity. If you or a family member would like to take one of the places please contact our Treasurer, Jeff Darkins, his email address is jj.darkins@btinternet.com or you can write to him at 17 Maesglas, Tredegar, Blaenau, Gwent NP22 3ET.

Can you help us raise some funds ?

We are always looking for ways to raise money, can you help us ? Could you, a member of your family or a friend hold a coffee morning, a quiz night, a cake sale ? Maybe your children or grandchildren could have a sponsored silence.

Anything you can do will help not only raise money for the Charity but help to raise the profile of Alpha 1, with in your community.

Promotional Merchandise

Alan Wooler has been working hard for the last few months to get a range of promotional

merchandise for the Charity, it is hoped that we will have these items, in the next few weeks, so keep a look out on the website, Facebook page and in our next Newsletter for more details.

Remember we do have our t-shirts, polo shirts, sweatshirts, wristbands and lanyards, which you can buy.

In the t-shirts and polo shirts we have a choice of black or white and the Charity logo is embroidered on them. The sizing is small, medium, large & ex large, and the cost is £11 for polo shirt and £8-50 for t-shirt



polo shirts



t-shirts

We do also have sweat shirts available they are the same sizes as the above and cost £12 each



Sweatshirt

We still have packs of our Christmas cards available an order form accompanies this Newsletter.

Look out for details in the New Year about our 50th Anniversary of Alpha 1 Celebration and make sure you have penciled the date in your diary. Saturday 11th May 2013

Shop Online and Raise Funds

Don't forget when shopping online to register with easyfundraising.org.uk and it won't cost you a penny more to shop and raise funds in this way. In fact you could even SAVE MONEY as many retailers give exclusive discounts, special offers and even 'e-vouchers' when you shop through the easyfundraising site. Easyfundraising is a shopping directory featuring over 600 trusted online stores, including: Asda, Tesco , Argos, Amazon, the Body Shop, NEXT, Debenhams, John Lewis, Toys'R'Us, HMV, Virgin, iTunes, CD WOW, Marks and Spencer, Currys, Dixons, Staples, PLAY.COM, Pets at Home, Choices Direct, WH Smith, The AA, RAC, Direct Line, Churchill, The Carphone Warehouse, Ticketmaster and over 600 others...

Register for Alpha 1 Awareness UK and just by doing your shopping online you will be helping raise funds for the Charity.

Also you can set up www.easysearch.org.uk, as your search engine page and register Alpha 1 Awareness as your chosen cause then every time you search a webpage you raise money for the Charity.

This Newsletter is for all our members, we would love to hear from you and would welcome contributions of articles, news, poems, photos etc from you, our members. If you have anything you would like to contribute to our Newsletter, please email it to secretary@alpha1awareness.org.uk or write to me Lin Daniels, at the address below

IF YOU HAVE CHANGED YOUR POSTAL ADDRESS OR EMAIL ADDRESS PLEASE REMEMBER TO NOTIFY ME, BY EMAIL OR POST.....Thankyou

*With very best wishes to all our
members and their families for*

*A Very Happy Christmas
&
A Peaceful and Healthy 2013*



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