

## A word from the chairman

This year at the European Respiratory Society Congress there were a number of presentations given by patients or representatives from patient organisations. This is an important advance in having the patient's voice heard in medical circles where decisions about treatment and research are made. The members of the Patients Advisory Committee hope that at next year's Congress in Munich there will be even more active participation by patients in matters that crucially affect their lives. We have to share these presentations with other rare lung diseases but it is clear that progress is being made.

One of the many sessions at the Congress devoted to alpha-1 antitrypsin deficiency was one celebrating the 50th anniversary of its first description. One of the speakers was Professor Sabina Janciauskiene who spoke about the research that led up to discovery of AATD in 1963. Her presentation was almost identical to the one she gave at our Info Day meeting in May. Other speakers included Professor Stockley and Doctor Sandhaus from the United States.

The pharmaceutical company Grifolls used the event to announce the development of a new, quick way of detecting the presence of the Z form of antitrypsin in a single drop of blood. The research work done by Professor Janciauskiene was used to develop the testing device. This device does not distinguish between carriers of the Z gene or full Alphas with two Z genes but it is an important extra tool in shortening the time that many Alphas have to wait to get a proper diagnosis. It is hoped that the device will be available in a number of European countries in 2014. See the news item below.

*Alan Heywood-Jones*

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### Rapid Testing for the Z Allele

The AlphaKit® Quickscreen device was unveiled at the European Respiratory Society 2013 Congress in Barcelona. The testing device was developed by scientists working for Grifols.

The device is a quick way for physicians and healthcare providers to screen patients with COPD for Alpha-1. The Quickscreen requires a few drops of blood to detect the presence of the Z protein that is responsible for most severe Alpha-1 cases. The result is available within 15 minutes. It is anticipated that the kit will be available in several European countries in 2014.

Diagnosis is crucial. Individuals suffering from AAT deficiency often develop COPD, leading to disability and premature death. AAT deficiency is estimated to affect over 100,000 people in Europe alone, although greater than 90% of individuals remain undiagnosed.

"The good news is that for most patients, AAT deficiency can quickly be ruled out during a medical exam – and it only needs to be done once in a patient's life. If a patient tests positive, they are either a carrier of this genetic condition or are at risk of developing AAT deficiency emphysema," says Prof. Claus Vogelmeier, Professor of Internal and Respiratory Medicine at the Hospital of the Universities of Giessen and Marburg, Germany. "Thus, we can proceed with a full diagnostic test to make the definitive diagnosis as we've always done and, if appropriate, begin augmentation therapy."

Grifols anticipates that the QuickScreen will lead to improved patient outcomes by reducing the time and number of physicians it takes to make an accurate and timely diagnosis.

"It typically takes seven years and more than four physicians before the AAT deficiency diagnosis is made," says Dr Marc Miravittles, Chest Physician and Senior Researcher, Department of Pulmonology at the Hospital Vall d'Hebron, Barcelona, Spain. "By this point, the patients are symptomatic, and it is apparent that they may not have normal or usual COPD." Dr Miravittles' figures are typical for most Western countries and are probably appropriate for the UK.

Our patron, Professor Sabina Janciauskiene, was instrumental in developing the biochemistry behind this new, rapid and cheap way of diagnosing the presence of the Z allele.

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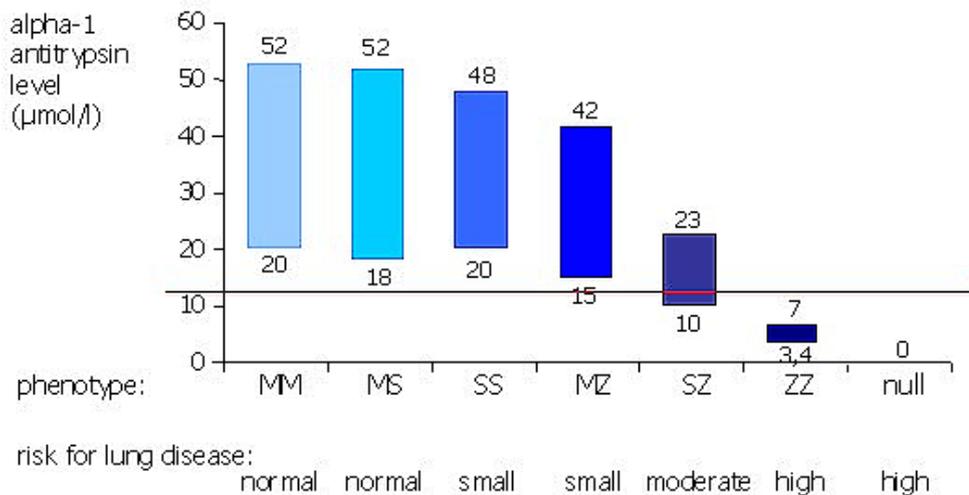
### **My Alpha-1 Antitrypsin is Low**

The hereditary condition alpha-1 antitrypsin deficiency gets this name because the amount of alpha-1 antitrypsin carried in the blood stream is insufficient to protect the lungs from other substances that the body produces naturally to defend itself against infections and other forms of irritant.

So why is the level of antitrypsin low when the programme of how to make normal antitrypsin (called M) changes to one that produces slightly different antitrypsin (called Z, S and so on)? The general answer is that the antitrypsin produced in the liver does not have the correct shape and it clumps together. In this form it cannot escape from the liver and make its way via the bloodstream to the lungs where it is needed. Some does make its way out but not very much and not enough to protect the lungs properly. Fortunately we all inherit two copies of the genetic programme to make antitrypsin, one from each of our parents. If one of these copies is normal (M) and one abnormal (Z, S, etc) then just about enough antitrypsin is produced to protect the lungs. But if two abnormal copies are present then the level of antitrypsin is very low and the lungs, without adequate protection, suffer permanent damage after infections and harm caused by cigarette smoke amongst other things.

This means that simply measuring the level of alpha-1 antitrypsin in the blood stream is a way of finding out if there is something abnormal. Unfortunately, the level of antitrypsin is quite variable and so deciding what is a 'deficiency' is not straightforward. However, measuring the antitrypsin level is still a good indication that more complicated tests may be needed to positively know if the patient is an Alpha.

Here is a graph showing the most common combinations of mutations and the levels of antitrypsin that may be expected.



The numbers in the diagram are generally accepted as typical but they are guidelines only. Some laboratories always seem to test high and some low. The red line is widely accepted as showing the level below which the lungs are not adequately protected.

There are two scales commonly used:

1. micromoles per litre —  $\mu\text{mol/L}$  (used in medical research papers and in America)
2. milligrams per decilitre —  $\text{mg/dL}$  (used in many countries of Europe but there is some variation in this such as grams per litre).

If you are given an antitrypsin level in milligrams per decilitre then multiply by 0.184 to get the level in micromoles per litre. To go from micromoles per litre to milligrams per decilitre then divide by 0.184 (or multiply by 5.34 which amounts is the same thing).

If you are given a level in grams per litre, such as 0.6 g/L then convert to milligrams (times by 1000) giving 600 milligrams per litre, then convert to deciliters (divide by 10) giving or 60 milligrams per decilitre. Multiplying by 0.184 gives the results in micromoles per litre. This is a fraction over 11  $\mu\text{mol/L}$  – just below the red line. This could point to SZ or, just possibly, MZ. This could be resolved by further tests.

Your doctor or specialist consultant will be able to explain all of the above to you and explain what tests are performed and why.

## WHAT IS MEANT BY THE TERM “ALPHA-1 CARRIER, MZ or MS ALPHA”?

An Alpha-1 Carrier is a person who has one normal alpha-1 gene (M) and one defective Alpha-1 gene (usually S or Z). Being a carrier is very common. Most Alpha-1 Carriers are MS or MZ. Carriers may have lower blood levels of Alpha-1 Antitrypsin protein, but their levels are rarely as low as those of people with Alpha-1.

## **CHILDREN OF ALPHA-1 CARRIERS**

Alpha-1 Carriers may pass their defective Alpha-1 gene to their children.

- If a carrier (MZ) has a child or children with a person who has normal Alpha-1 genes (MM), each child has one chance in two (50% risk) of being an Alpha-1 Carrier (MZ). There is no risk that any of the children will have the condition.
- If a carrier (MZ) has children with another carrier (MZ), each child has one chance in two (50% risk) of being an Alpha-1 Carrier. Each child also has one chance in four (25% risk) of having Alpha-1 (ZZ) and one chance in four of having normal Alpha-1 genes (MM).

## **HOW CAN BEING AN ALPHA-1 CARRIER AFFECT YOUR LUNGS ?**

Alpha-1 Carriers usually have only a slight risk of developing a disease related to Alpha-1. The main type of carrier linked to increased risk for lung diseases has MZ genes. Currently, there is no known risk for lung diseases for MS carriers.

**LUNG DISEASE:** The risk for emphysema may be greater for MZ carriers. This increased risk, however, is very small unless the carrier is a smoker or exposed to high levels of air pollution. The risk of having Chronic Obstructive Pulmonary Disease (COPD) is higher among MZ carriers who have relatives with COPD. This suggests that the COPD in these families may be due to other genetic factors. There is no scientific evidence that MS carriers are at risk for lung disease.

## **LUNG SYMPTOMS THAT MIGHT BE LINKED TO BEING AN ALPHA-1 CARRIER**

- Shortness of breath
- Wheezing
- Chronic cough and sputum (phlegm) production (chronic bronchitis)
- Recurring chest colds
- Decreased exercise tolerance
- Non-responsive asthma or year-round allergies
- Bronchiectasis

## **HOW CAN BEING AN ALPHA-1 CARRIER AFFECT YOUR LIVER?**

Alpha-1 Carriers usually have only a slight risk of developing a disease related to Alpha-1. The main type of carrier linked to increased risk for liver diseases has MZ genes. Currently, there is no known risk for liver diseases for MS carriers.

**LIVER DISEASE:** The risk of chronic liver disease in Alpha-1 Carriers is much less than that for people with Alpha-1. Research suggests that chronic liver disease might appear in MZ carriers only when the liver has been damaged first by something else, such as a virus, chemicals including alcohol or being overweight. There is no scientific evidence that MS carriers are at risk for liver disease.

**LIVER SYMPTOMS THAT MAY BE RELATED TO CARRIER STATUS**

- Eyes and skin turning yellow (jaundice)
- Swelling of the abdomen (ascites)
- Vomiting blood or passing blood in the stool
- Unexplained liver problems or elevated liver enzymes

**HOW CAN CARRIERS PREVENT OR REDUCE THEIR RISK OF GETTING DISEASES LINKED TO ALPHA-1?**

MZ carriers have only a slightly increased risk for the lung or liver diseases seen in people with Alpha-1. You may prevent or reduce the risks by making changes to your lifestyle, such as:

- Do not smoke and avoid second-hand smoke.
- Avoid repeated exposure to dust, fumes or gases.
- Quit or cut back on drinking alcohol.
- Do regular exercise
- Get vaccinated against hepatitis A and B.

If the Carrier has children who are also Carriers, the children should be informed about their genetic status. The importance of a healthy lifestyle should be emphasized from an early age.

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**A Penny for your thoughts**

The 2012-213 accounts for AAW were published at the AGM held in Bristol, August 28th 2013. There was very generous support from GRIFOLS and PRO-ACT. In addition the fantastic gifts, donations and sponsorship monies from our friends and supporters were noted with pleasure. The creation of our online shop, through the efforts and hard work of Alan and Emma Wooler, will certainly increase our revenue from the sale of a wide range of goods: sweatshirts, shopping bags, trolley keys and Christmas cards.

The expenditure on the information days and meetings in various parts of the country was good value. The availability of our information booklets continues to raise awareness about the condition. AAW made a number of donations to research projects both at Cambridge University and at King's College, London. As always we are indebted to the help and expertise of our officers and Trustees. The interest on our savings was £2.01 and such a small sum makes you think.

*Jeff Darkins, Treasurer AAW*

## Online Shop

On the 8th August we were proud to announce the arrival of 2 new products, the Jute shopping bags in small and medium.

Jute shopping bags not only holds your items securely but also won't fall under the pressure like most plastic or even some cotton bags. Jute is better for the environment than plastic bags that take years to rot away, or cotton bags that are bleached and dyed so have a very high water and Co2 footprint. Jute is natural and left in a natural state, created by hand to make sure of perfection and built to last with an expected 3+ years life they are also ethically produced.

Come along to our online shop to see the new bags as well as our other items that we have for sale. All the profits from the shop go directly to our charity to help support us and the products help bring awareness, so please help spread the word and bring awareness by taking a look at our shop [www.alpha1shop.org.uk](http://www.alpha1shop.org.uk)

*Alan Wooler*

## AGM

Is it because I am getting older, but our AGM, seems to come around faster each year ? Our AGM for this year was held at the end of August, once again, as we looked back we saw what another successful year we had, a good Information Day, where we focused on the 50<sup>th</sup> Anniversary of the discovery of Alpha 1, welcomed a good selection of speakers, including our 2 patrons and our great friend from the USA, John Walsh, along with many of you, our

Being the AGM, we had to elect Trustees and Officers. All Trustees and Officers agreed to stand for re-election for the coming year and all were

[ Note: an order form for Christmas cards is enclosed with this Newsletter, you can still order your cards as you have in previous years, if you prefer and wish to see our other merchandise then you can order through the website]

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## Parent Chat

An email was sent out for the new Parent Chat last month. Please check your inbox and junk mail for it as it appears it might have been lost in the electrical world of sending!

Parent Chat is for all parents of children (any age) to chat and share their experiences about Alpha and just the joy and stress of being parents.

I would love to hear from you and get this group up and running so please email me on: [ParentChat@Alpha1Awareness.org.uk](mailto:ParentChat@Alpha1Awareness.org.uk)

*Emma Wooler*

members, it was good to see old friends and welcome new ones who had only spoken to on line. There was lots of fundraising on our behalf (see reports later) during the year, for that we are extremely grateful to all those who worked hard in so many different ways to raise funds and of course ever event held helps to raise awareness of Alpha 1.

The Charity could not run without the hard work of all members of our Board and it is their hard work that helps our Charity go from strength to strength, so it is a big thank you to them.

voted back into their positions, which are as follows

- **Alan Heywood-Jones**  
Chairman and Trustee
- **Lin Daniels**  
Secretary and Trustee
- **Dawn Heywood-Jones**  
Special Projects and Trustee
- **Jeff Darkins**  
Treasurer
- **Meryl Darkins**  
Membership Secretary
- **Neil Jackson**  
Communications & I.T.Coordinator
- **Emma Wooler**  
Parents Support

- **Alan Wooler**  
Merchandising Manager
- **Andi Osborn**  
Board Member
- **Jackie Osborn**  
Board Member

We also looked at events for next year, look out for news of an Informal Lunch in Bristol in April and an Information Day in the Birmingham area hopefully in May, more details in our next Newsletter

## NEWS IN BRIEF

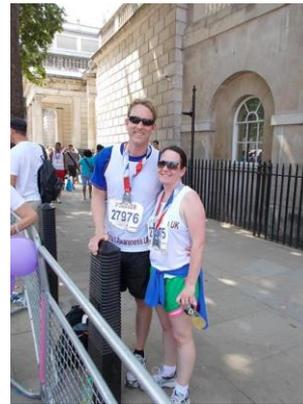
The last 3 months have been a busy time for Alpha 1 Awareness UK, with various events taking place, read on to hear more about Alpha 1 Awareness, on it's travels !!

**British 10 K Run** as many of you will recall the weather was extremely hot at the beginning of July and it was in those very high temperatures that the British 10K Run took place, 7.30 am on the morning of the run saw our intrepid 5 runners (unfortunately one of our runners had to drop out in the week prior to the race on medical grounds, but she still came along to cheer on our runners), head off from the Embankment to the Guards Club in Picadilly, already the day was hotter than a normal summers day and temperatures continued soaring. In the meantime I headed off towards Westminster with my niece, L.J., where we planned to meet up with Norah and Bob Oliver and their family, so that we could cheer our runners on, Norah & Bob's daughter Lisa and son-in-law Dave were 2 of our runners. By the time we all met up, it was still only 8.30am, the race was not due to start until 9.30am, so we were not

expecting to see our runners until around 11am, but with lots of chat and good company the time soon went by and armed with balloons we cheered our 5 runners on, as they bravely ran passed us, they were all hot and very tired, but by the time they reached us, they knew the finish line on Whitehall was not too far away. I understand from my son, Keith, that as he approached the finish line, the cheers from the crowds were amazing and really gave him a lift, in fact Keith said he sprinted to the finish line ! Sadly our runners all did different times and so all 5 never did manage to meet up. It was a great day and all 5 of our runners did a brilliant job, considering the high temperatures and the fact that some of them had injuries, so we send them all a big, big thank you for taking part and raising money for Alpha 1 Awareness, your efforts were great and we really do appreciate your support.



Keith Daniels, James Lanceley, Vicki Cornell



Lisa & Dave Johnson

So if you or a family are inspired to take part in next year's run, which will be a very special one, with lots of things happening to mark the 100th anniversary of the outbreak of World War 1

*Lin Daniels*

### **1-2-3 off we go again: The British 10k London race, July 13th 2014.**

The great efforts of each runner has been admired and the sponsorship money raised by taking part in the race has been greatly appreciated. If anyone would like to run and raise funds for AAW please

contact the Treasurer for the necessary entry form. ([jeff@alpha1awareness.org.uk](mailto:jeff@alpha1awareness.org.uk)) The information packs, sponsorship forms and Alpha running vest will be forwarded to each runner once their details are registered with the organising team. This will usually start early in the new year, 2014 The 10k London race has been a great success to AAW in raising awareness of the condition and in collecting funds. There are only 6 places available with our debenture so let me know if you are interested.

*Jeff Darkins, Treasurer AAW*

**Alpha 1 Alliance Petition** On Tuesday 30<sup>th</sup> July 2 of our members, Meryl Darkins and Neil Jackson, travelled to London, to join 2 representatives of the UK Support Group and Dr Ravi Mahadeva, as representatives the Alpha-1 Alliance, to delivered the campaign's e-petition to Number 10 Downing Street. The e-petition, which closed with 2,389 signatures, calls on the Government to nationally commission a highly specialised service for Alpha-1 within the NHS so

that patients can access specialised support and treatment, including augmentation therapy.

Dr Mahadeva, Alpha-1 specialist and Chair of the Alpha-1 Alliance said "I'm delighted at the level of support our e-petition received. By taking this petition to Downing Street and presenting it for the Prime Minister to see, we're making sure that politicians at the very highest level are aware of our campaign and the need to commission new NHS services for Alpha-1."



Meryl Darkins, Neil Jackson, Dr Ravi Mahadeva, Evie & her Mum, Steven Leadbetter in Downing Street to hand in the petition

## South West Charity Kayak Challenge

this was a huge event this summer for Alpha 1 Awareness UK. Jeff & Meryl Darkins went to Bude for the start of the Challenge and Lin Daniels went to Exeter for the Finish, during the 2 weeks the kayakers were paddling their 300 mile trip around the glorious South West Coastline of Devon & Cornwall, we all followed them avidly via satellite tracking on the internet.

### The Start - I do like to be beside the seaside

*Jeff and Meryl Darkins, our treasurer and membership secretary, went to Bude to support the 2013 Kayak Challenge. A team of kayakers had chosen Alpha 1 Awareness as one of their charities in this sponsored event.*

The group of kayakers led by Chris Brown-Marin, Matt Retter, Steve Carter and Chris Lake, they had once again chosen Alpha 1 Awareness UK as one of their chosen charities for this sponsored event. Chris Brown-Brown is himself an Alpha and last year had been elected as a Lung Champion by the British Lung Foundation. These aquatic adventurers began their trip at Bude, Cornwall and would complete the 300 hundred miles voyage around the coast 14 days later in Exeter.

The journey for the kayakers began on 10th August. The team was escorted by members of

Bude's kayak club, as far as Boscastle and the small fleet of kayaks looked impressive as they posed for photographs. The journey was to be tracked by high technology in the form of a heli-camera which flies and can hover overhead.

Friends and family members of the sponsored team were there to wave the group off. The opportunity to make the public aware of AAW was seized upon by the membership secretary. She had pitched the pop-up banner for Alpha 1 Awareness on the beach and she had inflated numerous balloons bearing our logo. These were given to families to tie on the wind-breaks. Leaflets and contact details for the charity were accepted by everyone who was approached. Donations were voluntarily given by many.

The kayakers were heading for Boscastle for their lunch-time break. This narrow, steep sided harbour again provided another opportunity for spreading the message to the public about Alpha 1. Meryl was sure-footed as any mountain goat as she carried the leaflets and collecting tin among the holiday-makers perched on the high cliffs above the entrance to Boscastle harbour. Again the response was one of genuine interest about the work of the charity as well as admiration for those

taking part in the kayak challenge.

Childhood memories are often evoked whenever you visit the seaside. The shrieks of delight as youngsters splash in the breaking waves are heard. There was a family cricket match taking place on Bude's beach as well as the sight of several kite-flyers and sand-castle builders. It was partly these activities together with a brave attempt to swim in the large sea-pool which made our visit to Bude enjoyable. However the tremendous effort of the



The start of the Kayak Challenge, 4 Paddlers + their trainer, with members of Bude Kayak Club

**The Finish – Exeter Safe and Sound** It was great to be able to meet with the Kayakers and their back up team, on Friday evening 23<sup>rd</sup> August, when we went out for a meal, prior to the final paddle into Exeter. They are 4 brilliant guys, who have shared an amazing experience, which challenged each of them in different ways. Saturday was a brilliant day and the look of sheer joy and delight as they finally reached the end was a great moment and was greeted by cheers from all on the Waterfront outside the Port Royal in Exeter. They were very pleased with the support they have received from Alpha 1 Awareness, appreciated all the messages on Facebook etc and were grateful to our presence at both the start and the finish of the Challenge.

It was lovely to see John and Joy Hehir, who are members who live in Exeter. They were delighted to see the guys come into Exeter and John in

kayak team in the 2013 Kayak Challenge for AAW was an inspiration and pleasure. I really do like to be beside the seaside. Congratulations to the team for their hard work which has provided publicity and funding for AAW.

It was lovely that one of our members Elaine Cartwright, who lives near Bude was able to meet up with Jeff and Meryl at Bude beach

*Jeff Darkins*

particular, who is an Alpha, was thrilled to meet Chris Brown-Martin and gave him a huge hug of congratulations.

All in all a great day, what an adventure for these 4 inspiring chaps, normal life will seem very boring after this adventure.....how will they top it, I wonder ? I spoke to lots of people about Alpha and handed out information booklets and just generally joined in the celebrations. The 4 “paddlers” are intrepid guys, who love a challenge and have been an inspiration to everyone who has heard about the Challenge, in particular, Chris Brown-Martin, whose courage as an Alpha himself has given all our members, who have followed their trip, a great deal of pleasure, hope and determination to not let Alpha beat you.



They did it, Chris Brown-Martin, Steve Carter, Chris Lake, Matt Retter, behind them is their instructor Rob , without whose guidance the guys would not have been able to complete this great Trip, sadly he could only join them at the start and finish.

Although obviously the 4 guys were the focus of attention, we must not forget their fabulous land back up team, who drove Camper vans, van and trailer with spare kayaks and all the camping gear, around the lanes of Cornwall and Devon. Steve's wife and 3 children were in one camper van and joined in the whole adventure, the children keeping everyone's spirits up, helping with the gear and the boats and even joined in the final paddle into Exeter, Chris Brown-Martin's partner was also a driver, as was Chris Lake's girlfriend and Matt's parents, Lyn Whitworth also joined them for one week, a great experience for all of

them and a huge thank you to them, the Challenge could not have gone ahead without this great back up team.

It goes without saying that a great big THANK YOU goes to all 4 of the paddlers, who gave up 2 weeks of their holidays to help raise awareness of Alpha 1 and raise money for Alpha 1 Awareness along with the very worthy other Charities, Devon Air Ambulance, Cornwall Air Ambulance and Surf LifeSavers. You are great guys and your efforts are admired and very much appreciated.

*Lin Daniels*

**Health Fair Winchester ATR** – August saw me heading off for the Army Training Regiment in Winchester, to a Health Fair, another brilliant opportunity to spread the word about Alpha , both among the young recruits and the staff, military and civilian, also the others who have stands at the Fair, the Naval nurses had already been told about Alpha 1, by the Medical Sergeant, Vicki Cornell, who always makes sure all new staff in the

Medical Centre are informed about Alpha, Medics from other Units and interestingly this time, 2 military personnel who work in the Military equivalent of the Environmental Health Dept.

It is all about spreading the word and getting Alpha known about.

*Lin Daniels*

**Informal Lunch Bodmin** – the day after our AGM, Dawn Heywood-Jones and I headed down to Bodmin in Cornwall, which was being held at the Westberry Hotel in the centre of the town. It was a lovely day and we were delighted to be joined by 11 people, some of who are members and were known to us, some although they are members, we had not met before. As ever there was lots of chat and laughter as everyone shared stories and chatted generally about Alpha. The buffet lunch provided by the Hotel was as good as Dawn and I remembered it, from our previous visit, there was more than we could eat so everyone went away with “doggy bags” of goodies.

It was lovely to see everyone in Bodmin and hope they all found it useful to meet up with other Alphas, we do have a lot of Alphas in Cornwall, so if they wanted to meet up a little local group, I feel sure there is someone down there who would co-ordinate this, just drop me a line or an email.

**Kernow Huffa Puffa's** - this is an support, exercise and social group for people with chest problems, organised and run by Trish Ashe, herself an Alpha, the Group meet every Thursday 10am-12noon, at Mabe Community Hall, Cunningham Park, Mabe, Cornwall, if you are interested in joining this group, you can contact Trish, her phone number is 01326 375238.

**Great River Race** - Alpha-1 Awareness is supporting the Great River Race. Two teams of rowers competing in the event will be wearing our livery to raise awareness of the genetic condition. The six-oar boats are Thames Waterman's Cutters most of which are owned by City Livery Companies. The two boats are the Master Glazier, since the boat has been on the

Thames it has always been rowed by an all-female crew – known as the Glaziers Girls The Glaziers Company provide support at all events. The Worshipful Company of Glaziers and Painters of Glass is one of the historic Livery Companies of the City of London. The second boat is the Trinity Tide. She is a modern day Thames Waterman Cutter boat which is used to represent Trinity House on the river Thames. She is designed based on drawings of boats used by watermen in the 1700's.

The race on the River Thames is the The UK Traditional Boat Championship and takes place over 21 Miles from London Docklands to Ham in Surrey.

The Great River Race, London's River Marathon, is a spectacular boat race up the River Thames that attracts over 300 crews from all over the globe and appeals to every level of competitor from those who enjoy fun, fancy dress and charity stunts, to serious sportsmen and women who like to win.

I was joined by one of our members Sonja Vetter, her son and his friend, the River Bank, at the finish line, where I had a spot was crowded with people, particularly as the boats began to arrive. The finish cannon was fired by Baroness Tanni Grey-Thompson, I was privileged to meet this amazing para-olympian and she was lovely, after firing the cannon, she stayed around to meet some of the boat crews and chat with them.

Unfortunately because of the sea of people and the organised chaos of 300 boats and crew arriving, I was unable to meet up with the Glazier and Trinity Tide Teams, to thank them personally for their support.

As a Charity we were thrilled to be supported by these 2 crews and thank them very much for their support



Glaziers with Dame Tanni Grey-Thompson



Trinity Tide Crew



Dame Tanni fires the Finish Cannon

**Consulting Room's Coast to Coast Cycle Ride across Ireland** - over the weekend of the 7<sup>th</sup>-8<sup>th</sup> September, a team of cyclists from the Consulting Room, decided as they were in Ireland for a Conference, they would do a sponsored cycle ride, coast to coast, so they set off from Galway heading for Dublin, they completed the 173 mile

trip over the two days and still went to their Conference the following day. We are extremely grateful to the team from the Consulting Room and also to Lorna Jackson, who suggested they money for Alpha 1 Awareness, so thank you to you all.



The Consulting Room Cycle team

**Charity Football Match** – on Sunday 29<sup>th</sup> September a Charity football match was held, by the Aztec Hotel in Bristol, as part of their

fundraising in support of our Charity, I am told it was a good day, but as yet I do not know how much money has been raised.

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## Will you support us ?

### Online shopping and searches

There are lots of ways you can support us, to help us support you, it is easy to use **easysearch** as your search engine on your computer, and every search you do raises money, just go to

<http://alpha1awarenessuk.easysearch.org.uk/>

Also **easyfundraising** is a way of raising money when you shop online, just go to

<http://www.easyfundraising.org.uk/causes/alpha1awarenessuk>

It will not cost you any more money on your purchases and many of the big companies are signed up to the scheme, Amazon, Tesco, M&S, John Lewis, Argos, the list is endless, so with Christmas approaching and no doubt many of you shopping online, sign up to Easyfundraising and as you buy your gifts, give a gift that costs you nothing to your Charity at the same time.

If you are shopping online then do not forget to visit our online shop, you might find something there that would solve that difficult present problem, go to [www.alpha1shop.org.uk](http://www.alpha1shop.org.uk).

### Christmas Cards

Once again this year we have a selection of Christmas Cards available, an order form is enclosed with the Newsletter, you can order them direct as you have in the past by returning your order form to me at the addresss given or if you prefer you can order from our online shop, the choice is yours

### Other ways of Support

Hold a coffee morning, invite a few friends around for coffee, cake and a chat.

Encourage the children to have sponsored silences, car washing, toy clear out, help organise a garage sale, the list is endless

Maybe someone in your family would like to take part in next year's 10K run in London or maybe register for another of the runs held locally up and down the country.

Whatever you decide to do, please let us know, we can provide you with booklets etc to support your event

Would you like to contact us? Maybe you would like to be in touch with other Alphas, request some more of our Information Packs to hand out to your Health Centre or Hospital Clinic, there are several ways you can be in touch with us and others.

**Facebook Group-** We have a friendly chatty Facebook Group, which is completely private and can only be seen by members

<http://facebook.com/groups/alpha1awarenessuk> and hit the 'Join' button

**Page-** This page is different from the private Facebook Group - whereas the Group is for members-only discussions (Alphas helping Alphas), the Page is for promotion of the Charity's activities, and highlighting those fabulous people who fundraise for us, and is your 'one-stop-shop' for all sorts of Alpha1 news that we've managed to dig up from all around the world, as soon as it breaks.

<http://facebook.com/alpha1awarenessuk>

**Twitter** For those of you who follow Twitter, you can follow our news on

<http://twitter.com/alpha1uk>

**Forum** Although it is not used so much now, our Forum is still running, so if you are not a fan of Facebook, but still want to chat to other Alphas, go to our Forum and request to join. I know that quite a few of you have joined and never contributed to the chat, so it would be good to see you on there, if you have a problem with your log in please contact us.

You will find the Forum on <http://techno.demon.co.uk/a1aforum>

**Website** Go to our website for more information and you will also be able to submit a contact from via the site.

**Email** You can email me direct at [secretary@alpha1awareness.org.uk](mailto:secretary@alpha1awareness.org.uk) or alternatively email [info@alpha1awareness.org.uk](mailto:info@alpha1awareness.org.uk)

**Post** and finally there is the more traditional letter post, just write to :

**Alpha 1 Awareness**

**PO Box 2866**

**Eastville**

**Bristol BS5 5EE**

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

*A Very Happy Christmas*

*&*

*A Peaceful and Healthy 2014*

