

# Newsletter

# Alpha1 Awareness

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July 2011

## A Word from the Chairman

For many parts of Britain Summer is coming early this year. The apple harvest is already weeks ahead of that in a typical year. While nature hurries along human activities are slow to mature. The modernisation, called by some the dismantling, of the NHS has been returned to the drawing board. In Europe, the summer recess will delay the Commission's statement on certain medicinal products and clinical trials. The integration of Talecris into Grifols is transforming both but the process is slow and cautious. At least we always knew that the Named Patient Programme would take time to put in place so our expectations for this are not dampened.

In the meantime, enjoy what promises to be a glorious Summer!

*Alan Heywood-Jones*

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There are now 2 ways to chat to other Alphas online:

The Alpha 1 Awareness UK Forum - to join go to  
<http://techno.demon.co.uk/a1aforum/index.php>

There is also our Facebook Page - search for "Alpha 1 Awareness UK" and request to join, it is a closed group

## Information Day in Scotland 11<sup>th</sup> June 2011

For our Information Day this year we went North of the Border, to Erskine Bridge, nr Glasgow, Scotland. We welcomed around 28 people, a mixture of Alphas and their carers/spouses, many of whom had traveled up to Scotland from England. We had received many enquiries from Alphas in Scotland, prior to the day following our adverts in local newspapers but not all who made enquiries attended, which was disappointing and frustrating, to know there were more Alphas in the locality who chose not to attend. However it was lovely to meet 4 week old baby Lily, with her mummy and daddy, who was so very good, as was baby Cai, who was introduced to us by his parents, Claire and Byron, last year in London when he was 3 weeks old, both of these babies are PiMZ. We were also delighted to meet Rebecca, whose parents Rachel and Oliver were also in London last year, Rebecca is a lively 2 year old PiZZ, who played happily at the back of the room during the day. As has become our tradition we gave Lily and Rebecca a teddy each, Cai had had one last year in London.

Our Chairman, Alan Heywood-Jones, welcomed everyone he also welcomed our speakers for the day, Alan explained that the format of the day would be slightly different to our previous Info days, as we were handing the whole afternoon session over to Dr Mohit Jain and Dr Sandra Nestler-Parr, from Talecris\*, who were going to explain about the Named Patient Programme, they were hoping to run in the UK for Augmentation Therapy

Before handing over to our first speaker of the day, Prof Sabina Janciauskiene, Alan had an important announcement to make, concerning our Charity.

It was with pleasure that Alpha 1 Awareness UK Charity was able to announce, that Prof David Lomas and Prof Sabina Janciauskiene had agreed to be our Patrons.

The business of the day began with Prof Sabina, talking about her recent research in the field of Alpha1, she spoke of the positive benefits to Alpha sufferers of augmentation therapy, she also spoke about how as more is known about Alpha 1, the more there is evidence to link it with other conditions e.g. diabetes, ulcerative colitis, as ever Prof Sabina, was enthusiastic about her research and was happy to answer questions from those present.

The next speaker was Carolyn Bell a Specialist Physiotherapist in Pulmonary Rehab, Monklands Hospital, in Airdrie. Although Carolyn admitted she had never had an Alpha sufferer on one of her PR courses, she had learnt a lot about the condition, since being asked to come along to give her presentation, however pulmonary rehab is exactly the same for Alpha sufferers as it is for anyone else with other ongoing respiratory conditions. Carolyn is passionate about pulmonary rehab and I hope her enthusiasm will encourage the Alphas who were at the Info Day, to ask to be referred to courses in their own areas, as the exercises do help manage the condition.

Natalie Frankish was our final morning speaker, telling us of the work of Genetic Alliance UK, formally Genetic Interest Group ( GIG ). The aim of the organisation is to provide an umbrella organization for genetic conditions and help raise the profile of some of the lesser known conditions, such as Alpha 1, one of the things they have fought for is better insurance deals for people who suffer from genetic conditions, as we have mentioned in a previous newsletter. Natalie brought along information leaflets for people to take away and these were very soon snapped up.

We broke for an excellent buffet lunch, which gave people the opportunity to chat with other Alphas, as well as our speakers, who were all very happy to answer any questions individuals wished to ask.

The afternoon session was given over to our guests from Talecris and Norman Evans, who is a retired Consultant

Pharmacist, now a senior lecturer at Imperial College, London, who had been invited by Talecris to talk about the named patient system for drugs in the UK. ( a full report on the afternoon session is given at the end of this article ).

The afternoon session prompted a lot of questions and discussions from those present, unfortunately we did not have time to round the day off completely because of the very lively debate that ensued and our use of the room until 5pm. We were very sorry to have to cut the afternoon short at 5pm, because the hotel needed the room for another function, we offered to continue the discussions in the bar, but many people had to get away, as some had very long drives home, however the few people who were staying did continue the discussion in the bar

*\* Talecris are part of the Grifols Group*

**Talecris Presentation for Named Patient Programme**  
**Alpha 1 Awareness UK Info Day Glasgow 11<sup>th</sup> June 2011**  
**( Talecris are part of the Grifols Group )**

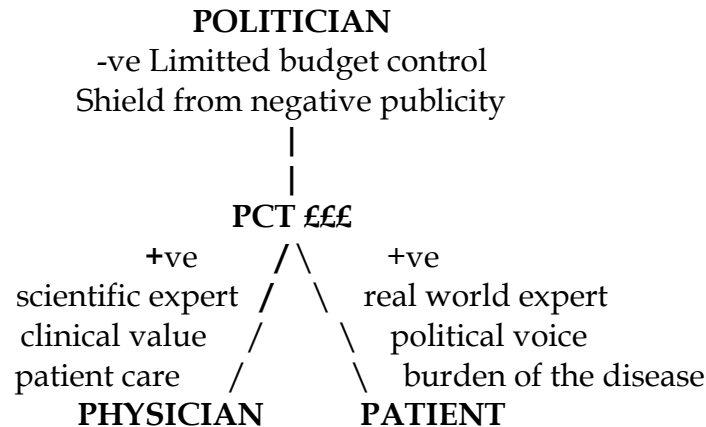
The following is a brief overview of the presentations about augmentation therapy and Individual Funding requests based on a named patient basis

**Dr Mohit Jain - Head of Market Access & Reimbursement, Talecris Biotherapeutics, part of the Grifols Group**

Dr Jain introduced the Named Patient Programme for augmentation therapy in the UK for Alpha 1 Antitrypsin Deficiency sufferers in the UK.

- Moving forward to provide access to therapy in the UK
- Giving a commitment to providing support to Alpha sufferers in the UK in their fight to access augmentation therapy
- Augmentation therapy is licenced in many European countries, Germany, France, Italy, Spain, Belgium, Austria, Sweden, Norway, Finland, Ireland, Portugal, Netherlands, Greece & Poland.

- For historic reasons, Talecris has made no application for a licence at the time when licence applications were made for other EU countries- historically the UK commissioning bodies, considered the clinical evidence, showing benefit of this therapy as weak. Now more clinical evidence to support therapy, therefore increasing the chance to obtain a marketing licence and therefore provide access to treatment.
- Clinicians have an important voice in the UK and need to support patient requests for access to treatment if they feel the patient is likely to benefit from therapy. This has to be assessed on a case-by-case basis



Alphas are able to help PCTs make Health Service decisions.

#### WHY

- in order to get the best care, access to therapies and treatments e.g. augmentation therapy.
- they can help shape the service provision e.g. home infusions, screening etc
- overcome hurdles in accessing the best care
- need registration approval - MHRA, SMC
- prove cost effectiveness - SMC, NICE, AWMSG and local PCT funding

#### HOW

- try to understand the NHS, their issues and expectations
- build relationships with all involved stakeholders & listen
- compile evidence to support why there is a need for added care for Alphas
- support access through relationships, evidence and experience.

This is the beginning of the process of augmentation therapy for UK Alphas, which will take time

## Dr Sandra Nestler-Parr - Health Liaison Lead UK, Talecris Biotherapeutics, part of the Grifols Group

Dr Nestler-Parr, explained she intended to look at

- Augmentation therapy & how it can help Alphas
- What Alpha 1 Antitrypsin Deficiency is
- PiZZs are helped most by augmentation therapy

Lung disease is the most common manifestation of AATD in adults.

Adults who suffer from emphysema, have too much of the bad protein, neutrophil elastase and have reduced or no protection to fight the bad protein because of the lack of AAT, the good protein

Augmentation therapy addresses the imbalance of AAT and neutrophil elastase in Alpha sufferers, by increasing the AAT levels in the bloodstream to above the protective threshold.

What is Augmentation Therapy ? - Augmentation therapy is produced from purified human plasma, it takes 9 months to produce it from donor plasma and is given as a weekly infusion.

It is the only available treatment which has shown in clinical trials a strong trend towards slowing the progression of emphysema in Alpha sufferers.

There is evidence that augmentation therapy does work for sufferers of AATD.

20 years ago a licence was given for augmentation therapy, on the basis that it was shown that it raises the AAT levels in PiZZ Alphas above what is considered the "protective threshold"

4000 + patients are currently receiving augmentation therapy worldwide.

The combined results of 2 clinical trials indicated that AAT replacement ( augmentation ) therapy reduces the loss of lung tissue in those receiving it, compared to those receiving no treatment.

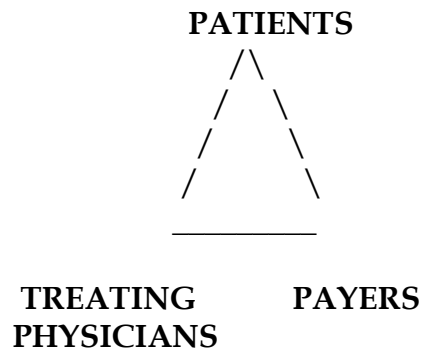
Two further, more recent trials, have supported the results of the original trials.

A large patient registry study in the USA has shown that patients who received no AAT treatment have higher mortality rates.

There are 2000 patients on therapy in the USA, the research there has shown a higher mortality rate in Alphas not receiving therapy.

## Named Patient Programme

- This programme will provide controlled access to augmentation therapy that is approved in other European Countries.
- The physician has to request funding from the local PCT on behalf of a specific named patient
- Programme requires a common understanding of all parties



### What can Alphas do to support the programme

- Raise awareness for the disease and the available treatment
- Advocacy – routed in the burden of the disease
- Empowerment – patient can request to be assessed clinically by the physician, with a view to be considered for treatment if the physician thinks this could be beneficial

### What is Talecris role ?

- To provide balanced information to all involved parties
- Support and communicate with interested parties
- Arrange for product availability in the UK

### What is the process to get access under the Named Patient Programme ?

1<sup>st</sup> step: Clinical assessment of patient by treating physician

2<sup>nd</sup> step: If physician feels that patient could benefit from therapy, physician can recommend treatment and make an application for a special Funding Request to local Commissioning body to get approval for reimbursement for therapy. If physician wants to learn more about the disease Alpha 1, available augmentation therapy or the clinical evidence of augmentation therapy, they should contact a patient organisation, that can provide some of this and point the physician in the right direction for more information.

Remember that it is not possible for a patient to demand therapy directly from their physician, hospital or local PCT. It is important to recognise that the ultimate decision for an application for funding on a named patient basis rests with the treating physician.

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**The final speaker for the afternoon was**

**Norman Evans - Consultant Pharmacist**

**Clinical Senior Lecturer,**

**Dept of Primary Care & Public Health,**

**Imperial College,**

**London**

NHS provides funding for drugs in

- PCTs
- Drugs - primary & secondary care
- Medicine management - formularies, guidelines NICE etc.
- Exceptional circumstances
- Individual funding requests
- Appeals process, lobbying

The UK spends less per head on health care than any other country in Europe, except for Poland

PCTs have statutory duties to

- Promote the health of the population
- Promote a comprehensive health service
- Establish priorities
- Allocate resources
- Blanket bans are unreasonable
- Should not exceed financial allocation

Named Patient Usage i.e. unlicensed or off label drugs can be made available when

- No alternative licensed medicine is suitable for the patients needs
- Use of the drug would serve the patients needs
- There is sufficient evidence or experience to show safety and efficacy
- The physician has expertise
- The physician takes responsibility for prescribing the drug and for the care, monitoring and follow up of the patient
- A register is kept of the medicines, their use and the reasons for their use
- A register of use must be established

Augmentation therapy works, Alphas should have access to it. The cost of augmentation therapy is less than that of many already licenced drugs for other conditions e.g some cancer drugs.

The treatment is licenced in the USA and it is possible using the same arguments for treatment, for reciprocal arrangements to be made here in the UK  
Individual Funding Requests ( IFR ) are possible.

The process for Named Patient Funding, in the MHRA guidelines is\*

1. Clinical assessment of patient drives physician to consider unlicensed treatment options
2. Physician applies to local decision committee for exceptional cases ( “special funding request”)
3. Exceptional Cases Body in PCT/Hospital Trust makes decision
4. If positive – drug is purchased under MHRA’s “The supply of unlicensed relevant medicinal products for individual patients” process
5. If negative – appeal process

\*<http://www.mhra.gov.uk/home/groups/is-lic/documents/publication/con007547.pdf>

Important points to consider with the Named Patient Process

- The process is complex
- Patients suffering with a severe disease and have no other alternative treatment options
- Not suitable for large patient numbers
- Gives the NHS experience of the use of an unlicensed medication
- Patients should be realistic in their expectations of funding success

Role of the NHS in the process

- To give patients sufficient information on treatment, side effects etc, , in order that they can make an informed choice
- To inform patients of the reasons for prescribing
- Report any adverse events to the MHRA, CSM
- Drugs should only be introduced following the approval of the relevant commissioners, unless there are very exceptional circumstances
- Funding : National or Regional Specialist Commissioning Group

My thanks to Dr Mohit Jain and Dr Sandra Nestler-Parr for their help in compiling this report

Lin Daniels  
Secretary  
Alpha 1 Awareness UK

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## **The History of the Named Patient Programme**

In early 2008 some of our members wrote to MPs, MSPs and MEPs requesting clarification of the rules for access and reimbursement. More than thirty letters were sent and about half elicited replies. Many of the responses referred back to the NHS guidelines and some referred to off-licence treatments as a possibility. Following this exercise the charity board decided to tackle the problem of no

treatment in the UK on two fronts. Changes in European legislation influence the direction that the NHS takes and lobbying in Brussels is clearly one way of modernising the UK health system. Unfortunately, this is a very slow process and so a shorter term objective was set of having a few alpha patients receiving replacement therapy on a named patient basis.



Later in 2008 two of the charity trustees met representatives of Talecris in Birmingham to discuss the matter and to find out more about how drugs are licensed. Further meetings that year and in 2009 did not advance the cause; CSL Behring made an abortive attempt to buy Talecris and the EXACTLE trial was due to be published and it was thought that this may have changed medical opinion in favour of replacement therapy.

At the Fourth Alfa European Federation Congress, 2010, the climate had changed. The CSL Behring takeover had been stopped by the American Securities and Exchange Commission, the EXACTLE trial had been published but, as yet, with little impact on clinicians and more than the usual number of staffers from the Talecris headquarters in North Carolina could be found in the European offices in Frankfurt. The clear intention was to increase the sales of Prolastin in those European countries with limited access to treatment. Prolastin is licensed in a number of countries but for a number of reasons patients do not receive it. The problem was compounded in the UK in that the product was not even licensed. Unsurprisingly, the staff of Talecris started to concentrate on improving access to treatment in Sweden, Belgium and others.

Undeterred by this new direction which still left the UK out in the cold, one charity trustee, Dawn Heywood-Jones, continued with the campaign for replacement therapy on a named patient basis. Named patient basis prescribing is a scheme which allows a doctor to prescribe an unlicensed drug to a particular 'named patient'. It is only an option for drugs whose manufacturer is prepared to release it on this basis, and has to be arranged by the doctor on an individual basis.

The outcome of meetings in Birmingham, Cologne, Vienna and a number of times

in Alicante have resulted in Talecris committing to release Prolastin in the UK. In the words of Dr Mohit Jain: [the programme] will provide controlled access to this therapy, which is approved in other EU countries, in response to a request by physicians on behalf of specific, or 'named', patients before alpha-1 antitrypsin medicines are licensed in the UK.

*The programme will take time to put in place in the UK.* One complicating factor is the recent takeover of Talecris by the Spanish pharmaceutical company, Grifols. The integration of the two companies will take time and may slow down the programme a little. Notwithstanding this, the direction has been set and the outcome is assured.

The Board of Alpha 1 Awareness UK would like to thank Dawn for her determination and persistence in persuading a producer of alpha1 antitrypsin to come to the assistance of UK alphas.

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The system to license products in Europe follows three different mechanisms:

- the company submits a licence application to the regulatory body of one European country and receives a licence in only this country.
- the company uses a national licence and applies in a number of additional countries with the assessment report of the regulatory body of this country. This procedure is the so called Mutual Recognition Procedure (MRP). After the initial 90 days process, every participating country approves the National licence on its own and without a predefined timeline. This is the procedure which was used to licence Prolastin in Europe

- the company applies centrally to the European Medicines Agency and receives licences in all EU countries at the same time.

The procedure 2 and 3 are independent of each other.

Talecris used the national licence in Germany as the reference for the licences in several other countries. One of these so called concerned member states was Spain therefore Germany and Spain both

received a licence following the MRP procedure which was finished in March 2006.

After a pre-discussion with the Medicines and Healthcare products Regulatory Agency (MHRP) who license drugs in the UK, Talecris took the decision not to include the UK as part of the MRP procedure

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## Patients In NICE Seminar 23-06-2011

Formal Title. *The use of unlicensed and off-label treatments where licensed alternatives exist – what is the impact on patient safety and long-term innovation?*

The co-sponsors of the seminar, the RNIB, are concerned about the Lucentis / Avastin debate and the choices available to their members. The issues raised in this debate have implications for drug manufactures, NICE, MHRA, doctors and patients.

### Terminology

When a drug has not received a licence it is said to be **unlicensed** – this does not mean that it has not been tested for safety and efficacy nor is it licensed in another country.

Drugs are licensed to treat specific conditions (diseases, illnesses). Sometimes it is found that a licensed drug is effective for a different condition. When it is used in for this different condition it is said to be used **off-label**.

### The Debate

The drug Lucentis made by Novartis is licensed for ARMD, a common form of age-related vision loss. A much cheaper drug, Avastin, is licensed for other conditions but it has been found to effective for the treatment AMRD.

The debate is about (i) the relative safety of Avastin as compared to Lucentis and (ii) about the relative costs between the two treatments.

**Doctor Heah** from Bayer gave a talk on *Drug development – from conception to delivery*.

The average process takes ten years. In this time about 10,000 candidate molecules are assessed and their characteristics mapped against known biological pathways and known activities. The ten thousand are down to about five when human tests start and these concentrate on safety activity and efficacy. The Doctor's figures on cost were hotly challenged by health technology experts in the audience.

Doctor Heah did not mention the slightly different process used for biologics (medicinal products such as a vaccines, blood or blood components) which obviously are of concern to Alphas but nevertheless her talk was informative.

**Doctor June Raine** from the MHRA talked about *Obtaining approval – the regulatory environment*.

Doctor Raine gave a standard presentation on the role of the MHRA but she did concentrate on the post approval stage and pharmacovigilance (the detection, assessment, understanding and prevention of adverse effects, particularly long term and short term side effects).

European directives and regulations also have changed the regulatory environment especially in the areas of (i) public health and (ii) access to health care and free trade.

Doctor Raine then talked about the European Medicines Agency and its co-ordinating and supervisory role. She thought that it would be at least a decade before most drugs will be authorised by a central European body. [The next section on the internal structure of the MHRA is not reproduced here.]

Off-label prescribing is very common in paediatric care. The drug trials are conducted on adults and approved in this basis. Rarely are trials conducted on children and so reduced adult doses are used but these are not tested to the same level. Doctor Raine said that the Adverse Drug Reaction rules for the off-label prescriber are stricter than usual but she did not elaborate on this point.

The doctor could not recall any cases where a clinician has been disciplined for off-label prescribing.

**Michael Keegan** gave an exposition of the ethical stance of the General Medical Council.

These guidelines produced by the GMC do not cover specific medicines nor do they give clinical or legal advice. They concentrate solely on the ethical issues – probably the best known is patient confidentiality

The doctor's first duty is to the patient and when it comes to an actual intervention "*cost alone cannot be the determining factor*".

For off-label and unlicensed products there are three consideration for the doctor

- Is there a licensed product that meets the patient's needs?
- Am I satisfied that there is sufficient evidence that it will be effective? (For rare conditions it is sufficient that a number of eminent colleagues are convinced – it doesn't have to be a multinational trial with clear statistically significant results.)
- Can I take responsibility for the outcome?

On this last point, all the medical doctors in the room claimed that they do this every time they see a patient no matter the licence status of what is prescribed – so no change there.

The next two presentations came from **Tim Cave** of Novartis and **Professor James Raftery** from the Health Technology Assessment unit of Southampton University.

This became a joint knockabout session with one side trying to justify the high cost of a particular drug and the other championing a cheaper, but off-label, alternative. Great fun!

One of the many facts that came out was that NICE and the MHRA who are supposed to work closely together and share data do not always do so.

**Greg Fell**, a Commissioner for the NHS Bradford and Airedale PCT addressed the practical application of regulations and guidelines.

Most of the presentation was devoted to a list of ethical problems regarding the provision of services with a limited budget. Greg Fell had few answers. He explained that the available money was divided into treatment areas (heart, ophthalmology, etc) and it was up to the providers of the medical services to optimise use within these areas.

We then were shown a long list of high and low cost treatments. Social cost is rarely taken into account even though social issues can affect treatment availability. For, instance there is social and medical pressure to treat 23 week babies but the failure rate and the social support for damaged bodies (and families) is not evaluated.

The issues that a commissioner has to consider (apart from the prime directive stay in budget) are: benefits, safety (both of the medicine and the supply chain), ethics, finance and the interests of patients versus taxpayers. In all of this, it appears that off-label prescribing is in fact quite common.

Finally, patient access schemes don't work. (These schemes put a cap on treatment costs when the course lasts longer than expected - the pharmaceutical company provides the drug freely when the treatment drags on.) The reason is that the PCTs do not have the infrastructure to monitor and claim back the money - so they continue paying for the medicine at the standard tariff.

Where does NICE fit into the debate about off-label and unlicensed treatments

**Peter Littlejohns**, the director of NICE, arrived just before his presentation was scheduled. He had three slides which he admitted had nothing to say and he then continued by saying nothing.

Amid general muttering that he was very discourteous to the attendees then received a good mauling by Doctor George Meakin from the Action for Sick Children.

The seminar concluded with an open discussion on **The role of patient organisations - how do we act in the best interest of patients?**

The general consensus was that some PCTs permit off-label use simply on the grounds of cost and comparable medical efficacy. It would seem that PCT commissioners, doctors and patients are not overly concerned about the off-label status of drugs. The regulators have not yet made up their minds in the issue and the patient organisations simply want a signal when the issue will be resolved.

AHJ & DHJ

A fuller report is available to members of the charity on request.

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## News in Brief

### **Visit to Paediatric Liver Unit, Kings College Hospital, London**

As you will be aware Emma Dent ran in this year's London Marathon and raise a staggering £5320 for Alpha 1 Awareness, we were overwhelmed with this money. Emma who is an Alpha herself, also has a young son Oliver who is a PiZZ alpha, he is treated at Kings, under Dr Dino Hadzic, at the children's liver unit. We therefore felt it appropriate to give Dr Hadzic £1000 for his ongoing research into the effects of Alpha 1 on the liver of PiZZ children.

While Alan and Dawn Heywood-Jones were in London for the PIN meeting, they arranged to meet with Dr Hadzic, at the Hospital and present him with the cheque personally. Here is what Dawn wrote about the visit.

*The highlight of the few days that we spent in London was the visit to Kings College Hospital.*

*There were no alpha children in the hospital on the day we were there. Doctor Dino Hadzic was kind enough to spend time with us and he personally escorted us around the Children's Unit.*

*We were taken to all the departments concerned with children's liver. There were two very young babies in the intensive care unit. One of these patients was from Saudi and was being treated privately. This demonstrates the international reputation of King's.*

*I presented our cheque to the Doctor Tushar Vince and her two nurses: they just said WOW look at that! Dino just smiled and said how much we support them. They asked why we were working in the charity, and I said I was a grown up Alpha. They said they had never met one of them.*

*We went to the day ward and spoke to the sister in charge. Then we went to the ordinary ward and the attached parents' room. The kitchen section of the room even had a dishwasher.. We were shown the playroom where the children are not allowed to run around, Dino said it was better to sit them in front of a screen with lots of games. There was also a schoolroom for the older children. The saddest room was for intensive care of older children. In this ward there was a very sick young boy: Dino did not speak about him.*

*It felt warm in all the rooms and they were homely, caring and friendly. The Variety Club, Sunshine Club and Toni and Guy, the hair people, all sponsor a huge amount of money to the unit. Dino asked where our money was from and we told him about Emma Dent and the London Marathon, he said "Ah, Oliver's Mum". We spoke about the little chap from Portugal, who is one of our members, Dino knew his name and said he would be seeing him in July. He is such a wonderful Doctor. I told him about the births of Amber, Eddie and Lily, I said he must have done something right in London, at the European Congress last year. He looked shocked and said, well no, not me but perhaps my presentation at the congress helped parents if they were thinking about another baby,.*

*Dawn Heywood-Jones*



Dr Dino Hadzic, Dawn & Dr Tushar Vince

Emma was delighted that we made a donation to Kings College Hospital; here was her response, when we told her

*"I can't tell you how happy that makes me. I know that spreading the word about the condition is really important, but money spent on research does seem so vital. Kings have been amazing with Oliver and I am in awe of the work they do there, so that's wonderful."* Emma Dent.

## Ultra Marathon

Once more this year Matt Rowley is running in the Ultra Marathon and a half marathon, in his email to me recently Matt wrote *"I'm running the Grimsthorpe Ultra, 70 mile marathon again, followed by a half marathon the next day"* The runs will be on the 12<sup>th</sup>-14<sup>th</sup> August. Matt has a Justgiving page if anyone would like to sponsor him.

We wish Matt the very best of luck and look forward to hearing how he gets on.

## Christmas cards

We will once again be selling Christmas Cards and a new supply of small notelets, to raise money. The delivery of the cards, from the publishing company will be here at the end of August, I will send out order forms at the beginning of September. We have increased the price to £3.50 per pack of 10 cards, which, I hope you will agree, is still excellent value. The notelets are unchanged at £1 per pack of 4 cards. *Lin Daniels.*

## Wristbands, lanyards and sweatshirts

We now have wristbands and lanyards, with our Charity name on them. We also have some very nice burgundy sweatshirts, with our Charity logo and name embroidered on them.

Wristbands £1 each

Lanyards £2 each

Sweatshirt £12 each sizes small, medium, large, extra large



Wristband £1



Lanyard £2



Sweatshirt £12

If you are interested in buying any of the above, please drop me a line to the PO Box address at the end of the Newsletter, or email me at [secretary@alpha1awareness.org.uk](mailto:secretary@alpha1awareness.org.uk)

*Lin Daniels*

## Transplant Diary

Unfortunately we will not have Rob's transplant diary, the last time we heard from him, he had had 5 calls from the transplant unit, but they were all false alarms. We hope that Rob gets a positive call very soon.

## Congratulations

Since our last Newsletter we have heard news of some new arrivals and we send congratulations on the safe arrival of

Lily a daughter for Dave Pennick and his partner Amy

Eddie a son for Neil & Lorna Jackson and a brother for Sam

Amber a daughter for Emma & Alan Wooler and a sister for Tyler

Felicity a daughter for Mikaela Charles & her husband

## Fundraising News

Thanks to Kristy Haddock and her family who organized a raffle and a Ready Steady Cook Challenge in May and raised £1693.98

## Information Books

One of our members has recently been in touch with me to request some of our information booklets, the respiratory nurse at the clinic the member attends, has offered to do a display in the clinic waiting room, using the information booklets we have produced, to raise awareness of Alpha 1. The same member has suggested I send him some booklets every 6 months and he will make sure there are always some in the clinic waiting room

This set me thinking, could you talk to your local health centre or hospital clinic and ask them to do a display or have some of our booklets on display in the waiting room. If your health centre or clinic agree, I am happy to post off booklets to you or directly to your health centre or clinic or if you would just like some for yourself or your family members, email me at [secretary@alpha1awareness.org.uk](mailto:secretary@alpha1awareness.org.uk), or write to me at the PO Box address at the end of this Newsletter.

Our full range of information books is :

Newly Diagnosed

Your Child's Liver - a guide for parents of an Alpha child

Living with Alpha - a life style guide for Alpha sufferers

Diagnosis & Treatment - a guide for medical professionals

A1toZZ a book explaining Alpha 1 for young children

We also have 2 flyers FIND A1 an initiative for patients and medical professionals  
Alpha 1 Awareness UK a general information flyer, which can be put in waiting rooms, libraries, pharmacists etc.

In the next 2 or 3 weeks we will be adding two more publications, to our list,

a flyer FIND A1 Children to complement the FIND A1 flyer and a book aimed at older children, about Alpha 1, this will be useful not only for children who are suffering with Alpha 1, but also for children who have a parent, grandparent or family member with Alpha 1.

Lin Daniels

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## Shop Online and Raise Funds

Don't forget when shopping online to register with [easyfundraising.org.uk](http://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.

Please share with us any plans you have for raising funds, be it a special birthday or anniversary, a coffee morning with your friends, a Quiz Night, getting the children to do a sponsored silence, we would love to hear. Thank you

If you wish to contribute in any way to future editions of the Newsletter, please contact at the address below.

### *Alpha 1 Awareness UK*

Raising Awareness of Alpha 1 Antitrypsin Deficiency in the UK

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visit our website : [www.alpha1awareness.org.uk](http://www.alpha1awareness.org.uk)