Alpha-1 UK Support Group Newsletter

Issue 17
Autumn 2018

Welcome....

...to our Autumn 2018 Newsletter

A massive thank you to all our members for their loyalty and support over the years and a very special welcome to all our new members - we hope you enjoy being part of our group!

We would like to thank everyone who has contributed to this issue of our annual Newsletter. We hope you find this Newsletter informative and are inspired by the members stories' and the examples of fundraising for our group. This Newsletter also pays tribute to our dear friends who passed away in the last year, and who we remember with deep affection and respect.

In This Issue

21 years Alpha-1 UK Support Group - coming of age

by the Trustees

This year is our group's 21th anniversary – we have finally grown up!

At last year's annual meeting, and in anticipation of this momentous anniversary, we decided it was time to give the charity a new, more modern and 'grown-up' look. Thanks to the generous support from a seasoned branding expert, we have developed two alternative new logos and styles for the charity. We will put both options to the vote with our members before the end of this year. Over the next 12 months, our website and all digital and print materials will be redeveloped in the new design. Next year, our Newsletter will also receive a complete makeover.

The Alpha-1 UK Support Group has also had a very busy year in many other respects. We have worked tirelessly to ensure that the charity has a voice in all initiatives and decisions directly or indirectly affecting the lives of Alphas and their families. Our trustees have represented the UK Alpha-1 patient community's interests at many national, European and global meetings, conferences and research initiatives, including NICE committees, Alpha-1 Global, the European Respiratory Conference, the European Conference on Rare Diseases, the European Reference Network LUNG, the European Alpha-1 Research Collaboration, the World Orphan Drug Congress, and many more. The articles on pages 2 and 8 provide a flavour of what our trustees got involved in on and behind the scenes.

In the last year, our group has continued to grow; today our registered membership is over 600 patients and supporters from the UK, and our Facebook community has over 3,000 members from all over the world. Facebook has become the main communication platforms for Alpha-1 patients, families and supporters in the UK.

Sadly, we have also lost treasured members who will be deeply missed and who will stay in our hearts and memories. We celebrate their lives and remember them and their loved ones in the obituaries.

21 years Alpha-1 UK Support Group—coming of age
(continued)

We are lucky to always have had keen fundraisers amongst our members and supporters: on average, more than thirty events are being held for our charity's benefit every year. Thanks to many dedicated fundraisers, we again managed to achieve a good income over the last year. Some members embarked on amazing challenges and literally went the extra mile to raise funds for the charity – you can read some of their inspiring stories in this Newsletter. We are very proud of them and their determined passion!

Additional income is generated by generous donations from members and supporters and, occasionally, grants from pharmaceutical companies. Another valuable gift we receive is the time that members and supporters commit to the charity, without which we would not be able to operate.

We would like to thank all of our members, donors, fundraisers and sponsors for their incredible and continuing support, and we welcome new members and new readers.

Please contact us if you wish to become a trustee or want to support the charity in other ways.

Board of Trustees, Alpha-1 UK Support Group

A brief update on augmentation therapy and potential new treatments for Alpha-1 currently in development
by Dr Sandra Nestler-Parr, Trustee

Since the last research update in our 2017 Newsletter, promising advances have been made in the development of potential new treatments for Alpha-1 and in our longstanding quest to get access to alpha-1 antitrypsin (AAT) intravenous augmentation therapy in the NHS.

At the beginning of this year, NICE commenced the formal evaluation of the clinical effectiveness and cost-effectiveness ("value for money") of Respreeza®, CSL Behring's intravenous AAT augmentation therapy product for the treatment of Alpha-1 associated emphysema, which received a drug license by the European Medicines Agency (EMA) in 2015. The NICE appraisal process is aimed at forming an independent, evidence-based opinion on whether or not a new treatment should be made available and paid for by the NHS. As part of the NICE appraisal of any new treatment, the drug manufacturer, expert Alpha-1 clinicians, professional organisations and patient groups are invited to participate in the NICE process and to share their knowledge, experiences and opinion of the condition and the new drug aimed at treating the condition. As such, our charity developed and submitted a patient group submission for the NICE appraisal of Respreeza® and, in August, participated in a large meeting in Manchester where the pros and cons of Respreeza® were discussed in the context of all submitted data. At the time of writing this Newsletter, NICE's draft recommendation in relation to the use of Respreeza® in the NHS has not yet been published.

Following last year's setback, Kamada is in advanced discussion with the U.S. Food and Drug Administration (FDA), the regulatory authority that issues licenses for new medical treatments in the U.S, in order to conduct a Phase 3 pivotal clinical trial of inhaled AAT for the treatment of AATD-associated lung disease. This demonstrates Kamada's continuing commitment to bring their inhaled AAT product to market.

Arrowhead Pharmaceuticals and Alnylam Phamaceuticals are two U.S. biotech firms that, several years ago, embarked on developing a new type of drug, called RNAi therapy, for the treatment of Alpha-1 liver disease. These novel RNAi therapies are aimed at reducing the production of mutant AAT protein in the liver (such as the Z or S forms), thereby potentially halting the progression of liver disease and allowing the liver tissue to regenerate and repair. Last year, in short succession, both companies announced delays in their respective clinical development programmes of their RNAi drug candidates for Alpha-1.

We are delighted that Arrowhead announced in August this year that it has completed its Phase 1 clinical study of the company's second-generation RNAi treatment for Alpha-1. The company appears to be back on track with the drug candidate's development.

A brief update on augmentation therapy and potential new treatments for Alpha-1 currently in development
(continued)

To our knowledge, Alnylam has terminated the Phase 1/2 trial of their RNAi candidate for Alpha-1 earlier this year due to unexpected toxicology findings in some study subjects.

We are pleased to announce a new company has entered the Alpha-1 space – Mereo BioPharma, a London-based, fairly young specialty biopharma company. One of Mereo's assets is a drug candidate with the potential to inhibit neutrophil elastase activity in Alpha-1 patients and prevent further damage to patients' lungs. A Phase 2 clinical trial of this potential treatment is in development.

Since last year's announcement that Apic Bio Inc., a U.S. based pre-clinical stage biotech company that develops gene therapies for a range of diseases, had achieved a pre-clinical proof of concept for its lead gene therapy product for the treatment of Alpha-1, we have no update.

Please visit our website www.alpha1.org.uk for updates on clinical trials for potential treatments for Alpha-1 in the UK and for information on how you could be considered for participation in such a trial.

How to get involved and stay informed?

Join the Alpha-1 UK Support Group. Joining the support group is easy. Just visit our website: www.alpha1.org.uk, click the "Join Here" button and follow the "Email Forum" directions. There is also a link to our closed Facebook group, which we invite you to join.

- By joining our group, you will be able to connect with a large community of Alpha-1 patients, their families and carers.
- You can exchange and discuss your experiences with AATD and get advice and support from other members.
- We will keep you informed of the latest news and all relevant information about Alpha-1, including new clinical trials and how you could get considered to participate in them.
- We will regularly offer lifestyle tips to help you to keep fit and active.

If you don't have access to the Internet, then you can contact us directly at the address on the back page of this Newsletter. We can then arrange to send you an information pack and our annual Newsletter.

Perhaps you could help raise funds to enable us to continue our work? Whether small or large, all donations will be put to good use, providing information, equipment and support to the UK Alpha-1 patient community. In addition, we aim to promote awareness and understanding of AATD and related diseases in the medical community.

Details of how to donate, or how to find us on *JustGiving*, can be found on page 32 of this Newsletter, or visit our website www.alpha1.org.uk.

It is also possible to raise funds without any cost to yourself, by using the *Easyfundraising* or *AmazonSmile* websites to do your online shopping, or the *Easysearch* website for your internet searches. Again, further information can be found on page 31 of this Newsletter, or please visit our website and follow the directions on the homepage to sign up to either of these free services.

The members of our charity face many issues that impact on the quality of their lives and the lives of their families. Alpha-1 UK Support Group is committed to addressing these issues, improving access and equality in access to adequate clinical expertise and effective treatments and to bringing about a well informed and responsive community. We have been supporting Alpha-1 patients for over twenty years and we are backed by the UK's leading experts and researchers in the field of AATD.

For more information about the Alpha-1 UK Support Group, or to help us with our work then please visit our website: www.alpha1.org.uk

Could you be an Alpha?

A guide to alpha1-antitrypsin deficiency for patients and their families

Could your lung or liver problems be caused by a hereditary condition called alpha1-antitrypsin deficiency?

Alpha-1 antitrypsin deficiency is a hereditary condition, which may lead to lung or liver problems that can significantly affect your health. For the sake of convenience, the condition is often called 'Alpha-1' or 'AATD' and patients sometimes refer to themselves as 'Alphas'.

In the earliest stages of AATD, people are commonly diagnosed as having asthma or COPD and may be treated for these conditions for many years before the correct diagnosis is made. However, it is important to know you are an 'Alpha' as early as possible so that you can take steps to protect yourself and to get treatment from an expert in AATD.

Alpha-1 antitrypsin (AAT) is a protein that is produced in the liver and, in healthy people, it is released into the blood circulation so that it can protect the body, from the damaging effects of inflammation. The protein that is produced by Alphas does not function properly and gets trapped in the liver. This can cause damage to the liver and, because the protein can't reach the circulation, the lungs lack the protection they need from the damaging effects of pollutants (particularly cigarette smoke) and infections.

Although the lungs and, to a lesser extent, the liver are the most commonly affected organs in AATD, there are some rarer complications that can lead to problems with the skin, kidneys and pancreas.

Being an Alpha means that you have inherited a tendency to develop these problems, so it is important to know what this means for you and for your family.

How does AATD affect the lungs?

It is important for the body to have a defence system against attack from pollutants and infections but these defence systems can also cause damage to bodily tissues through inflammation. Under normal circumstances, this 'collateral damage' is kept in check by AAT. However, in Alphas, the function and the amount of available AAT is reduced, with the result that the unchecked inflammation can cause serious structural damage to tissues. The lungs are especially prone to this process, so that regular exposure to pollutants such as cigarette smoke, may lead to a type of emphysema that is more severe in Alphas who lack the level of protection from AAT than is seen in people with normal AAT.

What are the symptoms of AATD-related lung disease?

The earliest symptoms of lung disease are often quite minor, even when the lungs may already have been significantly damaged. Cough, wheeze or breathlessness when undertaking physical activity are the commonest symptoms but may be mistakenly put down to things like lack of fitness or incorrect diagnoses such as asthma or COPD.

What is emphysema?

Emphysema is a lung disease caused by loss of tissue at the ends of the airway branches at the site where the lungs take up oxygen into the bloodstream. The loss of tissue causes the lung structure to change in a way that makes the airways floppy and collapsible, and the lung's microscopic blood vessels disappear. Breathing tests show that lung function is adversely affected by these changes and deteriorates over time. Over the course of many years, cumulative tissue damage can lead to the lungs being unable to maintain their function even under circumstances of maximum supportive treatment.

How does AATD affect the liver?

Although the AAT protein that Alphas produce gets stuck and tends to accumulate in the liver, this does not usually cause many health problems.

In some patients, however, this causes damage to the liver which can lead to liver disease.

At birth, the build-up of AAT in the liver of Alphas can lead to yellow jaundice and, rarely, severe inflammation in the liver. It is not well understood why only some babies with AATD experience these problems. In later life, a minority of Alphas may experience symptoms of liver disease that arise from liver damage, such as the 'scarring' process known as cirrhosis.

Could you be an Alpha?
(continued)

When should AATD be suspected?

- When there is a family history of lung or liver disease
- When symptoms of asthma are present that do not fully respond to treatment (e.g. breathlessness, wheeze, cough and phlegm)
- When a diagnosis of COPD was made in early adulthood
- When unexplained lung or liver problems occur
- When breathing tests show that lung function deteriorates rapidly
- When liver function tests are abnormal

Who should be tested?

Organisations, such as the World Health Organisation (WHO), have made recommendations on testing for AATD. In general, testing is recommended in:

- Everyone with emphysema, chronic obstructive pulmonary disease (COPD), or chronic bronchitis
- People with bronchiectasis
- Newborns, children and adults with unexplained liver disease
- People with a family history of liver disease
- Blood relatives of a person diagnosed with Alpha-1
- Anyone with panniculitis, a skin disease

How is AATD testing done?

Testing for AATD is fairly simple and quick. It is usually done with a blood test. However, because AATD is an inherited condition, patients should always speak to their GP or their hospital doctor about the possibility of genetic testing for AATD if they think they may need it.

Genetic testing should not be undertaken lightly, as it is important to consider all implications of having a test for a genetic disease: some people may, for example, experience difficulties in finding or renewing insurance cover (for travel, private health or other insurances) after having had a genetic test, irrespective of the test outcome.

Best practice therefore includes obtaining a referral from a GP, or specialist doctor if applicable, for genetic testing to be carried out. If your doctor thinks genetic testing for AATD may be appropriate, they should usually refer you for genetic counselling as well. It takes time and specialist expertise to be able to provide patients with an understandable and accurate explanation of the reasons for testing and the potential meaning of abnormal results, and the time to discuss this is *before* the genetic test for AATD is performed; this is called 'pre-genetic test counselling'.

Once the test results come back, it is possible to give more precise information about what the test result means, and this explanation may need to include the findings of other tests such as breathing tests and scans; this is called 'post-genetic test counselling'. The terms 'pre-genetic test counselling' and 'post-genetic test counselling' apply to genetic testing in general, not just to AATD testing.

For more information about testing for AATD, please refer to the relevant article in our 2017 Newsletter, also available at www.alpha1.org.uk.

What do the test results mean?

Genes contain instructions that tell our cells to make molecules called proteins, and we all have two copies for each gene – one from each parent. The AAT gene contains the code for the AAT protein. Each person has two copies of the AAT gene, one inherited from their father and the other from their mother. There are approximately 100 variations of the AAT gene, with the Z or S versions being most common abnormal variants. It is generally the case that both inherited copies of the AAT gene have to be an abnormal variant in order to cause a significant risk to health.

AATD can be inherited from Alphas (people with two abnormal AAT genes) or 'carriers' (people with one normal and one abnormal AAT gene). The figure below shows what could happen for the children of parents who are both carriers (genotype MZ); when both inherited genes are M, this results in normal AAT protein levels but when both genes are Z, the level of AAT is low to undetectable.

There are many combinations of different AAT genes, but the commonest 'genotypes' are as follows:

Normal (MM)

- Does not have the disorder; does not carry any abnormal AAT genes.

Could you be an Alpha?
(continued)

Carrier (MZ)

- Mild to moderate AAT Deficiency — may get disease symptoms and does carry an abnormal AAT gene.

Carrier (MS)

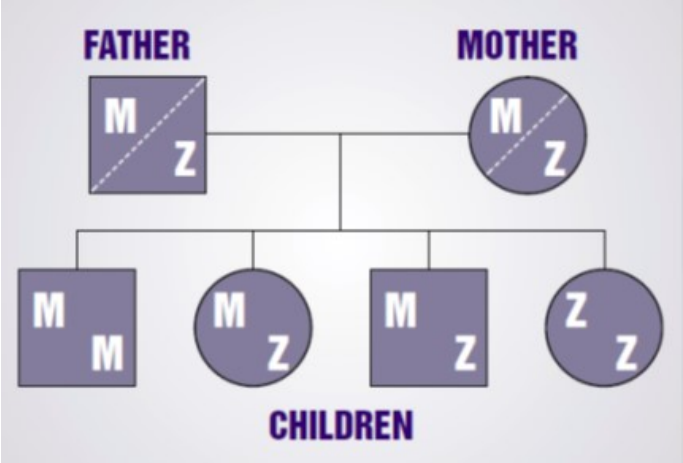
- It is unclear whether there is a risk for getting disease symptoms but does carry an abnormal AAT gene (most studies do not show an increased risk for disease).

Alpha-1 (SZ) or (ZZ)

- Moderate (SZ) to severe (ZZ) deficiency — could get disease and does carry two abnormal AAT genes.

Alpha-1 (SS)

- It is unclear whether there is a risk for getting disease symptoms but does carry two abnormal AAT genes (most studies do not show an increased risk for disease).



What does it mean to be a 'carrier'?

Carriers of AATD have one abnormal AAT gene and one normal gene, so that they have less functional AAT in the blood circulation than 'normal' people, but usually enough to prevent serious problems.

Being a carrier for AATD is not uncommon, and the vast majority of carriers are completely unaware that they have an abnormal gene and do not experience any AATD-related illness. However, carriers who have smoking-related COPD may be slightly more affected than patients with COPD who have two 'normal' AAT genes. It is therefore important for carriers to look after themselves and to avoid smoking or inhaling other pollutants. It is also sensible to avoid alcohol in order to minimise damage to the liver.

If I have AATD, how might this affect my children?

If you have AATD (two abnormal gene variants), it means that both of your AAT genes are faulty and that your children will inherit one of these. Your children will then be 'carriers' of this faulty gene. If your partner also has a faulty gene, there is then a chance of your children inheriting two faulty genes, i.e. one from you and one from your partner, that *could* lead to severe AATD. This is the reason why many partners of Alphas choose to have a genetic blood test themselves, to find out if they may also have a faulty gene.

If your child has inherited two abnormal AAT genes, this might lead to various lung and liver problems (as well as other rarer conditions), although it is impossible to predict whether, when and how your child's health might be affected by AATD. There are many Alphas with two faulty AATD genes who never experience serious health problems throughout their lives. In addition, the influence of the environment and personal habits, such as smoking and drinking, play major roles in determining whether and to what extent an individual person might experience ill-health, if at all. It is therefore important to receive genetic counselling and correct guidance and clinical advice in order to fully understand the implications of getting your child tested for AATD and the potential risks that AATD poses for their health.

How is AATD treated?

Symptoms are treatable using inhaled medications developed for use in asthma and COPD but these are not believed to significantly affect the underlying damage to the lungs. There are now many different types of inhalers and many different drugs for inhalation. The choice of what is best for individual patients depends on many factors, including personal preference for ease of use. Chest infections are thought to worsen lung damage and so it is always important to get these treated promptly, usually with antibiotics and oral steroids. Also, vaccinations against 'flu' (every year) and pneumonia (every five years) should not be forgotten because they reduce the chances and the severity of

Could you be an Alpha?
(continued)

chest infections. Your GP's surgery should arrange for these to be performed.

Replacement of the missing AAT protein is the logical treatment for AATD and is currently available as an intravenous preparation ('augmentation therapy') in some countries, including the US, Germany and Spain. Although an intravenous augmentation therapy product (Respreeza®) was licensed for use in the UK in 2015, it is currently not available on the NHS. NICE, the National Institute for Health and Care Excellence, is currently evaluating the effectiveness and the cost-effectiveness of Respreeza® and, in 2019, NICE will issue a recommendation for or against the use of Respreeza® in the NHS. The Alpha-1 UK Support Group has been involved and has been representing the Alpha-1 patient voice in this NICE evaluation process.

A number of new treatment approaches to treatment are currently under investigation but, unfortunately, there are still no specific treatments for AATD available in the UK. For more information about ongoing research into AATD, please refer to our research updates in this and previous issues of our annual Newsletter, available online at www.alpha1.org.uk.

What does a diagnosis of AATD mean for my future health?

A diagnosis of AATD can be unexpected and feel like a shock. For some people, the discovery of AATD may be by chance and not combined with any health-related problems. For other Alphas, it may come as a relief at the end of a frustrating journey of unexplained symptoms, worsening health and consultations with many different doctors, to finally obtain a clear diagnosis. The variability of the condition across patients means that your own experience is likely to be individual to you. However, what all Alphas have in common is the opportunity to take steps to avoid lifestyles that are known to pose a risk.

Even if you have developed symptoms, appropriate medication, treatments, exercise, and lifestyle choices can go a long way toward ensuring you live a long and happy life. Seeking care from an AATD expert will provide you with accurate information about AATD, about your own health, the best treatments and how to take good care of yourself.

What options are available to me?

It will help you if you develop an effective relationship with your family doctor and your consultants. However, it is important to recognise that AATD is just one amongst thousands of rare diseases, and most GPs and many specialists may not have much first-hand knowledge of the condition.

Expert knowledge and experience in the optimal management of AATD is therefore limited to a handful of clinical experts in the UK. You could ask your GP to refer you to one of the expert centres for AATD in the UK: Cambridge, Coventry, Birmingham and London. Several satellite clinics in the South and the North are currently being established.

Contact information about existing centres and regular updates from existing and new centres are available on our website.

In addition, you can take a number of steps to help yourself:

- ✓ Create an exercise programme (under medical supervision)
- ✓ Create a nutrition programme (under medical supervision)
- ✓ Think about your health behaviour and life style (smoking, alcohol use and excess weight)
- ✓ Avoid risk factors:
  - Stop smoking and avoid second-hand smoke as much as possible
  - Avoid being around dust and fumes
- ✓ Discuss with your doctor who in your family should be informed and encourage anyone who might be affected to speak to their doctor about getting tested for AATD

Researchers around the world are studying Alpha-1 and learning more all the time. Visit the Alpha-1 UK Support Group website regularly for the latest news and advice on managing your Alpha-1.

You can find us at: www.alpha1.org.uk

Annual Update From Alpha-1 Global

Like every year, we would like to share news from our fellow Alphas around the world. Most national or regional Alpha-1 patient groups are members of Alpha-1 Global. Their mission is to develop a collaborative global network of Alpha-1 patient leaders, physicians and researchers, to increase awareness, detection, and access to care for Alphas around the world. To that end, the strategic objectives of Alpha-1 Global are to:

1. Facilitate effective stakeholder collaboration
2. Raise Alpha-1 awareness globally
3. Support the launch and strengthening of Alpha-1 organisations
4. Promote early diagnosis and optimal access to care

Global Community and Physician & Researcher eNews

Alpha-1 Global continues to facilitate streamlined communication between patient groups, physicians and researchers in an effort to better serve the global Alpha-1 community. The Global Community eNews and Physicians & Researcher eNews are bi-monthly publications made available through Social Media and distributed by other Alpha-1 Associations as well.

Alpha-1 Advocacy Pathway

Alpha-1 Global has developed an interactive platform which will assist individuals through the process of understanding advocacy and provide the tools needed to become a dedicated Alpha-1 Advocate. The Alpha-1 Advocacy Pathway is available on the Alpha-1 Global website at http://alpha-1global.org/en/ and offers engaging training modules for five avenues of advocacy involvement:

- Self Advocate
- Social Media Advocate
- Community Advocate
- Policy/Legislative Advocate
- Patient Organisation Leader/Advocate

The Alpha-1 Advocacy Pathway was introduced in a Social Media campaign where Alpha-1 patient leaders from 10 countries were introduced as local advocates in their country. The pathway continues to be updated with links to newly developed materials that are offered as resources for patient advocacy.

Included in the Alpha-1 Advocacy Pathway is a start-up manual for new Alpha-1 Support Group leaders. The document outlines a plan containing best practices and resources related to Alpha-1, assisting aspiring patients to become effective support group leaders.

Regional Update: Europe

Alpha-1 EU Policy Recommendations

Alpha-1 Global contracted Rohde Public Policy Group (RPP) in Brussels in 2016-2017 to work with an Expert Group of patients, researchers and physicians to update the Policy Recommendations on Alpha-1 (originally developed in 2011). The new document entitled "*Time To Get Better*" was created as a current and comprehensive tool for advocacy on an EU and national level. The Policy Recommendations were officially launched in the European Parliament on 22nd March 2017. In the winter of 2017-2018, Alpha-1 Global coordinated the translation of the document into nine languages. After final review by medical representatives, the design of each booklet was completed by Alpha-1 Global staff. The Policy Recommendations are currently available online in ten different languages at http://alpha-1global.org/en/alpha1recommendations/. Five hundred printed copies in the following eight languages were distributed: Danish, Dutch, French, German, Italian, Romanian, Spanish, and Swedish.

Training Webinar and Checklist

In January 2018, RPP conducted a training webinar in preparation for the distribution of the Policy Recommendations. The user's guide (*5 Steps to Boost Alpha-1 Awareness in Your Country*) was created as a

working document to assist Alpha-1 leaders to outline the most effective advocacy goals and distribution plan for the Expert Recommendations document for their country. The webinar provided guidance for effective engagement with policy makers and increasing Alpha-1 awareness among healthcare providers.

Patient leaders exchanged experiences and ideas about the use of the document in their countries during Awareness Day events, and a survey conducted over the summer will provide an overview of the initiatives undertaken in each country so far and inform the next steps of ongoing advocacy initiatives at national levels.

EU Alpha-1 Awareness Day: European Health Made National

EU Parliament Meeting – Brussels, Belgium

25th April 2018 marked the first European Alpha-1 Awareness Day, dedicated to providing better understanding of the condition. To kick off the Awareness Day, a special meeting at the European Parliament, hosted by MEP Marek Plura from Poland, took place on the previous day. Alpha-1 patient leaders from ten countries attended the meeting. Seven of them presented the situation of access to care and treatment in their country including specific asks for policy makers. A full meeting report is available at the Alpha-1 Global website at http://alpha-1global.org/eu-alpha-1-awareness-day-25-april-2018/.

Roundtable on Alpha-1 Antitrypsin Deficiency

On 25th April, an EU Roundtable discussion in Brussels was organised to facilitate dialogue between specialists and patient representatives on how to share best practices in the diagnosis and care of alpha-1 antitrypsin deficiency and encourage collaboration between patients and caregivers at an EU and national level.

Presentations on alpha-1 antitrypsin deficiency, the use of the Expert Recommendations, and European Reference Networks (ERNs) including ERN-LUNG and ERN-rare LIVER were given. Afterwards, discussions took place regarding suggestions for increased awareness and education among physicians, and how to most effectively integrate Alpha-1 into the ERN-LUNG and ERN-rare LIVER structures. A full meeting report can be found on the Alpha-1 Global website at http://alpha-1global.org/eu-alpha-1-awareness-day-25-april-2018/.

Social Media Campaign

Facebook Banners were created in seven languages, outlining specific awareness messages for use in national Social Media efforts in the following countries: Belgium, Denmark, France, Italy, Netherlands, Poland, Spain, and Sweden.

Additionally, six Members of the European Parliament volunteered to create an awareness video in their own language: Finland, Netherlands, Poland, Spain, Italy and the UK (http://alpha-1global.org/en/alpha1recommendations/mep-support-videos/). They committed to improving the situation of alpha-1 antitrypsin deficiency in their respective countries, aiming to grow support, awareness and collaboration among national policy makers.

European Reference Networks for Rare and Complex Diseases

European Reference Networks (ERNs) are networks connecting healthcare providers across Europe through a virtual platform. The network aims to improve the diagnosis and management of complex or rare diseases and conditions that require specialist clinical expertise, highly specialised treatment and a concentration of expert knowledge and resources.

Alpha-1 Global is taking an active role in this initiative and is represented in ERN-LUNG by our group's chair Karen O'Hara who provides informed patient leadership in this forum. The aim is to create a communication structure via Alpha-1 Global that ensures that the voice of all EU Alpha-1 leaders is effectively represented at the ERN-LUNG.

A close working relationship with the patient representatives' coordinator of ERN-rare LIVER has also been established, in preparation for more streamlined activities to take place in 2019.

European Alpha-1 Registries Collaboration

Alpha-1 Global will be represented on the Steering Committee of the newly established European Alpha-1 Registries Collaboration (EARCO), to provide patient focused input into research and clinical priorities. EARCO will work closely with ERN-LUNG to avoid duplication between the two projects. Again, our Karen O'Hara is the Alpha-1 Global patient representative in this forum and has been involved in developing a strategic plan over the summer of 2018. One of the activities of this collaboration will be to develop a survey for patients and clinicians to determine research priorities. The first Steering Committee meeting took place on 3-4th July 2018 in Barcelona, Spain, and a follow-up meeting took place during the European Respiratory Society Congress in Paris, France, in mid-September.

Global connection and networking

Our quarterly Alpha-1 Leadership video conference continues to be a good networking tool between leaders and an important opportunity for face-to-face peer connections. Each participant provides a country update, which often stimulates new discussions, as leaders consider how an initiative that has become a success story in one country could be implemented in another. The video conference has proven to provide a format that is engaging and encouraging, especially for leaders of smaller associations. Alpha-1 Global also maintains a closed Facebook Group consisting of 42 leaders, to provide ongoing updates and encourage networking and communication.

Participants vary per call. This meeting included representatives from Austria, New Zealand, Norway, Denmark, South Africa, Belgium, the UK, Lebanon, Germany and Romania.

2017-2018 Master Calendar

Alpha-1 Global's annual calendar of events reflects participation in relevant meetings, ensuring best community representation. The 2017-2018 master calendar required coordination between a myriad of meetings and events, including: patient association meetings, meetings of the European Respiratory Society (ERS), European Lung Foundation (ELF), European Reference Networks (ERNs), European Alpha-1 Registries Collaboration (EARCO), European Rare Disease Network (Eurordis), Platform of Plasma Users (PLUS), International Plasma Protein Congress (IPPC) and the Latin America Thoracic Society (ALAT).

ELF Patient Meeting during ERS 2017

In the autumn 2017, Alpha-1 Global participated in the following patient meetings:

- Alpha-1 Norway annual meeting, including the Oslo Marathon (3 km)

- Alpha-1 Ireland annual meeting
- Alpha-1 Canada annual meeting
- The Romanian Lung Society annual meeting in Oradea, Romania (including a patient meeting)

Romanian Lung Society meeting in Oradea

7th Alpha-1 Patient Congress

The next bi-annual Global Patient Congress will take place on 5-6th April 2019 at the Sheraton Hotel in Dubrovnik, Croatia. Patient leaders, patients, physicians and scientists from around the world will come together to discuss the latest developments in patient advocacy, clinical care and Alpha-1 research. The International Research Conference on Alpha-1 Antitrypsin will take place at the same venue on 3-4th April 2019, immediately prior to the Patient Congress.

www.alpha-1global.org

London Marathon 2018

By Emma Hunt

When my brother Paul was on a ventilator in ITU after a particularly violent exacerbation, I decided that I would push my lungs to their limit. Because I could, and he couldn't. And so it was, way back in January 2012, that I ran my first mile since I'd left London in 1984, aged 13!

It hurt. A lot.

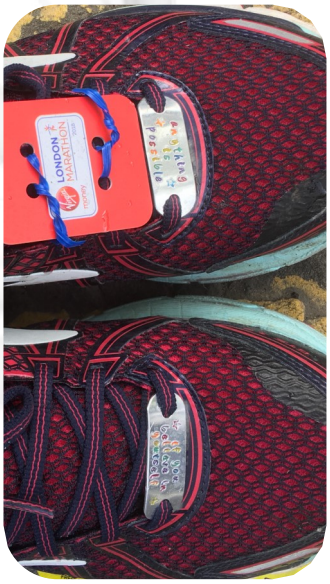
But I knew that what I was feeling was only a small percentage of the battle my mum had been through some 15 years earlier, and that my brother was suffering. I vowed to look after myself as best I could, so I could get the very best amount of time with my children. It was only a few months later that I had to sit down and tell Paul's children that he was dying, and that they should start to prepare themselves for the worst.

Since Paul's death, I've run more and more. I've found it to be a great way to clear my head when things get on top of me. I feel closer to him somehow when I concentrate on my breathing. I started running because of him, and I continue to run in memory of him. Over the past three years, I've raised money for the Alpha-1 UK Support Group in his memory through fundraising for various events, including two half marathons, and I entered the Virgin Money London Marathon ballot three times. I've always wanted to run the London Marathon, since the early 90s, but at over 16 stone, an ex-smoker, and a fairly consistent drinker, it was not looking like it would ever happen.

Still, I hung on in there and decided to chase that dream.

It was in May 2017 while I was submitting my annually unsuccessful ballot entry, that I realised there was a Charity Ballot, as well as an individual ballot, and mentioned this to Karen O'Hara, the chair of the Alpha-1 UK Support Group. I 'suggested' that the charity could apply to gain a place and give it to someone who would run and fundraise for the charity! The charity's application was successful, and people were given the opportunity to submit an application to the charity and bid for the place. I applied with a pledged target of £3000, and the rest, as they say, is history! When Karen called me to inform me that I had been chosen by the trustees to run for the charity, I cried. I was so happy, nervous, excited, terrified and overwhelmed - all at the same time!

I had been so hopeful to get the place, I had started my training several weeks before it was awarded to me! I had suffered with a nasty hip injury (bursitis and tendonitis) whilst running the Windsor Half Marathon in September 2016. Unable to walk properly or turn over in bed for a few weeks, I spent most of early 2017 trying to lose weight, giving up alcohol and rehabilitating myself through some extensive physio and hard work. By the time I felt healthy, fit and trim enough to start running again, I had lost almost four stone. But along with that weight, I had also lost my fitness and condition, and so decided to go right back to basics and downloaded the NHS 'One You Couch to 5k (C25K)' app.



C25K works by providing guidance, a training programme and encouragement whilst one trains three times a week. It breaks the sessions down into easy and manageable run-walk-run intervals until you can run solidly for 30 mins at the end of nine weeks. It is aimed at anyone who is a couch potato, has never exercised or run before, (although for anyone reading this who might be considering it, if you have any health concerns you should talk to your medical professional first!) and for slow, steady recovery from injury. My C25K course also happened to coincide with the lovely Keith White, a fellow Alpha who had a double lung transplant in 2015, doing the same programme and we were on the same weeks, encouraging each other to progress to the next session. I say encouraging, but in all honesty, you just can't beat a bit of friendly competition! As part of the C25K app, one can opt to have a celebrity talk through what to do and when – I chose Sarah Millican, and Keith chose Jo Whiley.

As a relatively healthy 47-year old woman, I had to give this my all and raise as much as I could for the group, and I was determined to do just that. Having lost my grandfather, three uncles, Mum and Paul, I also knew that if Alpha-1 was going to get me, it would be fairly soon and I probably wouldn't get another chance to run the London Marathon.

My training continued over the winter, and by Christmas I was regularly running 3-4 miles three times a week, despite having broken the second toe on my right foot only a few weeks in to this basic conditioning training! In

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the New Year, I downloaded a 16-week training programme and got on with the task in hand. Training runs got harder, they got longer, going out was more about willpower and determination than fitness, mornings were dark, evenings were dark, the woods where I trained were muddy and difficult terrain, the weather was cold and dreary. The only good thing about the training was that I could eat more food to give me the energy I needed! By mid-February I had hit the relative safety of the halfway point at 13.1 miles, but having only run Half Marathon distance before, I knew that from then on I was heading into the unknown.

My husband Jim and I had booked in to do a half-marathon event as part of my training. This was held at Dorney Lake (where the Olympic rowing events took place in 2012) on St Patrick's Day. I was up to being able to run about 15-16 miles at this point, and I chose that particular event as it fell on a drop-back week, it was flat and fast, and I would hopefully get a good time to boost my confidence before going in to the longer runs over the next few weeks. However, the Gods conspired against us and the weather was atrocious. The snow was driving sideways, the sting on the left of my face was harsh as I ran one way, then as I crossed the lake and ran up the other bank, the right side of my face got the battering. Jim ran off at his own pace, leaving me to struggle round 4.5 laps of the lake. I had never felt so unprepared for anything in my life (except perhaps childbirth, but that's another tale!)

On my third lap, I was contemplating dropping out of the London Marathon project as I was so hopelessly pathetic at running a half marathon, when I passed a fellow runner sitting on the floor, clutching his leg. I was way behind my target time and decided that there was no point pushing on and I couldn't just run past this runner on the floor. I stopped to help and found out he was on his last lap. He had lost a considerable amount of weight whilst training, and this was his first ever running event. He was an airline pilot, close to the end of his career, and this was on his retirement bucket list. As part of the challenge, he had secured some amazing sponsorship from the airline and his colleagues to give him an impetus to do the event and he was distraught that he was going to have to pull out. I sat down next to him, we chatted, and I told him that if he was prepared to get up and take a chance, I would help him finish. I stood him up and got him to put his arm around my shoulders. We started to hobble off towards the finishing line with him hopping on his good leg or just barely putting weight on his bad leg. As we reached a race marshal, he joined us and we both held up the runner as he limped his way around the last few hundred metres of the course. The medics were aware of his plight by this stage, but he refused their help as he was so desperate to make it round without medical intervention.

As we made our way towards the finishing line, he wanted to go over the line on his own, so I wished him well and set off on my last lap. Whilst completing it, I thought long and hard about what I wanted to achieve from doing London Marathon. I thought about Mum and Paul and all the other Alphas I have known through the Alpha-1 UK Support Group that had lost their battle. It became clear that it was not about being the best, or the fastest, or the most helpful, or even just completing a marathon. It was about raising awareness for all Alphas. In my fundraising efforts, I was pushing the cause rather than the challenge and it was a defining moment for me to realise that.

As I crossed the finishing line, I realised I was starting to feel a little excited about what I was achieving.

I couldn't find my pilot friend anywhere at the finish, so I spoke to the medics. I was told he had a suspected ruptured achilles tendon, but that he was likely to race again, thanks to the support I had provided so he could get round. If he had tried to finish the race unaided (which he was determined to do at one point) he would have done so much damage to his achilles tendon that he would never have run again.

The lesson I learned that day was that we all have our different reasons for doing these incredible challenges. But they are all personal. Some like the physical challenge, some the mental battle. My pilot friend wanted to raise money for children who were taking their last holiday, yet for him, it was so personal, he wasn't willing to accept help when he needed it. His need to complete the distance on his own two feet meant he wouldn't let us help him over the line. He had to do that on his own.

And he did!

I went home, feeling more prepared for the actual event I had been working towards, the London Marathon, which was only five weeks away.

The following week was Paul's anniversary – 22nd March – four years since his passing. I marked the date

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by holding a large fundraising event at my local coffee shop. I held a massive raffle and the prizes were amazing! I secured an interior design session worth £200, jewellery, high street vouchers, art work, restaurant meals, beauty treatments, children's attraction tickets, and signed cookery books and merchandise from Tom Kerridge (a local star!). Local people baked and donated cakes, I had begged local businesses to supply prizes for the raffle, I had engaged friends to sell tickets, and I hosted an amazing afternoon, raising over £1000 in two hours, in ticket sales and donations for coffee and cake. With online donations and sponsorship, I was well on my way to reaching my target of £3000 for the group!

My last long run was scheduled for Easter weekend. I was aiming to run 21 miles and I had set myself a target time. The morning of the run, I put my running kit on, loaded up my backpack with jelly babies, water and other fuel, and set off at 9.30 am. I wanted to be back by 2.30 pm – 4.5 to 5 hours – in order to be on track for my original forecast of a sub-6-hour marathon. The weather registered an 8.7 on the miserable scale, with heavy drizzle from the moment I left home until the moment I got back. I'd stopped for a toilet break and to get more water, I sat and had a lunch break and I kept telling myself that I would still make it back within my anticipated target. But I was out of the house nearly 6 hours and was absolutely soaked to the skin. I laid in the bath for over an hour before I felt like I had warmed up and I was completely drained of all energy and felt 'done'.

The following few days, I started to come down with something. I had a heavy chest and was really concerned that I was going to be too ill to run the race. I had some antibiotics from the doctor, who advised me not to run, but of course I chose not to listen. The week leading up to the marathon, I was still very unwell, and it was touch and go whether I would be able to race. It was clear to everyone looking in that I had 'left my race in training' (a phrase used by runners who give everything in their last training run and leave nothing in the tank for race day) and that my London dream was over.

But I'm not a quitter.

I was convinced that this was the start of my deterioration with Alpha-1. I was convinced that I would be too ill for 2019 and that deferral of my running the marathon was not an option. I was convinced I had to run. It was now, or never.

So, I dosed myself up, packed my kit bag, got on a train and went to collect my runners pack for the London Marathon. I found the whole experience overwhelming (not helped by the illness) and burst into tears when I held my race number in my hands. I walked miles across the capital that day, and picked up blisters so severe, that I couldn't wear any shoes that evening. I hadn't had ONE blister in all the months of training. And now, the eve of the race, not only did I feel dreadful, but I had ruined my feet with less than 24 hours to go.

I met my friend Jacqui who was also running the next day, raising money for St John's Ambulance. We were staying in a hotel on Tower Bridge and walking from the tube to the hotel made me emotional again, knowing I would be running over this landmark around the halfway point. We had already made a pact that if either of us felt unable to keep up the pace, then the other one must go on ahead. We both had our own challenges and expectations, and I was very conscious that I wasn't well, and I didn't want to undermine Jacqui's experience and potentially jeopardise our friendship. We ate loads of pasta and bread (carb-loading is a real thing!) and tried to sleep through the excitement and giggles!

Getting ready the next morning, the race day, we packed our bum-bags with Vaseline and aloe vera gel, normal plasters and blister ones, packets of jelly babies and Soreen malt loaf, Voltarol gel and paracetamol, phone chargers and emergency money, and once we were in our gear, we set off in a taxi to Greenwich.

The weather was glorious, and it was clear that, despite training in sub-zero temperatures, we would have to

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race in bright sunshine and 25-degree heat! This was going to compromise my fuelling and hydration and I was starting to feel the nerves set in.

Eventually, we were corralled into our holding pens before the official start. We had been promised by the organisers to get over the start line by 10.30 am, but in reality it was 10.50 am before we were finally on our way. There was an 8-hour cut-off to complete the distance and get a medal, but this was not from the time you crossed the line, but from the time the Elite started (10 am). This meant we now only had 7 hours to finish and collect a medal. The course would be dismantled as the field progressed along the route.

We had both 'sold' miles to people in memory of loved ones lost, or suffering, and at each mile marker I took a photo and posted to Facebook who I was running for and why. It helped focus my mind when the going got tough, allowing everyone to see how I was getting on and feel like they were a part of the experience. I cannot thank everyone enough for their overwhelming encouragement all day. Along with my family, Facebook was my sanity that day.

My first mile was for Mum.

We met up with Jim, Kate and Annie at mile 4, and again just before mile 6. They would pop up around the course several times, keeping me stocked up with fuel and encouragement. As we started to approach Cutty Sark, Jacqui and I split up and I was to face the next 20 miles on my own. Water had run out for us back markers because the earlier runners had used the bottles to douse themselves in the heat, I was struggling to breathe and couldn't run solidly, I felt like this was the most ridiculous challenge I had ever set myself, and I decided to drop back the pace to a slower run-walk-run approach. I always knew I would get around. I had my support crew. And I had my memories of Mum and Paul. But I also knew that with the increasing heat and difficult conditions, I would need to review my race plan.

Failure wasn't an option.

As I got to Tower Bridge, I met up with Jim's brother Will, his wife Sarah and their girls Hannah and Lottie. The 'sweeper car' was behind me dismantling the course and my morale was very low. But seeing them cheering me on was amazing and gave me a boost to climb up over the bridge and back down the other side.

Mile	Name
1	Geraldine Smoker (MUM)
2	Friends
3	John Mugford
4	Sandy Benning
5	Paul Harding Snr
6	Jane Nicholls
7	Dippy Denize
8	Freddie Butler
9	Aissa Shaw
10	Jane Hill
11	George Smith
12	Annie
13	Laurence Field
14	Veronica Wood
15	Kate Hunt
16	Linda Cooke
17	Max & Erin (Paul's grandchildren)
18	Jim
19	Helen Chaldecott & Run Mummy Run cheer team
20	Jennifer
21	All alphas across the world
22	Helen
23	Martin Cooper
24	Keith White
25	Karen O'Hara
26	Paul Smoker (BROTHER)

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(continued)

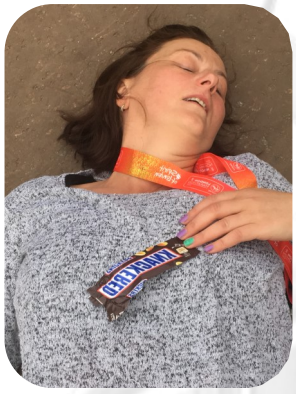
A little further on, I saw David Hill whose son had already completed the course and we had a chat about Jane and the group, and I carried on. I was beginning to realise just what I was achieving for myself and all Alphas in the group. I was pushing myself ever harder, through different challenges, to reach the very best me I could be. It wasn't always easy, but I had to survive that training run, that mile, that hill, and get on to the next step of the challenge. Rather like the battle of Alphas – trying to get through each challenge of getting out of bed, walking to the bathroom, cooking a meal, to get through yet another difficult day.

Eventually I was forced on to the pavement with the straggling spectators and managed to forge my way through to Westminster. There were few marshals, no water stations, and I was convinced I wouldn't get a medal. I think it was at mile 23 the course seemed to restart, and along the Embankment there were still hundreds of people shouting my name as I walked, ran and stumbled through the pain of my blisters and sheer exhaustion. That crowd were amazing and so uplifting.

Just before I reached Big Ben, I couldn't breathe in. I didn't feel any panic though. I remembered all the pursed lip breathing and managed to exhale as much air as I could. I was then able to breathe in and I carried on with the race! In my mind, this confirmed my fears that Alpha-1 was coming to get me and cemented my decision to run and not defer.

Eventually, after 7 hours and 25 minutes I crossed the finishing line. And despite the cut-off, the team had stayed on and there was a medal for me!! I sat down and sobbed and sobbed.

It was over. It was done. I was a marathoner!



London 2018 was officially the hottest London Marathon on record. Everyone's times were slower than they had trained for. Lots of people were disappointed. And when I went back to the doctor a week later, I was told that I had run the whole 26.2 miles with pneumonia!

By running London Marathon I raised £6,600 for the group, making my personal fundraising total for the group up to over £9,000 since Paul died in April 2014.

But in some respects, I was incredibly disappointed. I was so much slower than my target of 6 hours, and it's taken me months to realise that, what I achieved, was incredible. I have raised awareness for Alpha-1 and the charity, I've raised an amazing sum of money, I completed the training and raced through some extreme and adverse conditions.

But I've already applied again in the ballot.

Me and London…. we have unfinished business!!!

Member Stories - Our journey, his journey, my journey

by Rachael Silver

I 'found' Ian online on 'Plenty of Fish' just over 3 years ago! On our first date, he told me that he had a life-limiting condition called alpha-1 antitrypsin deficiency, and if it put me off him, then he would understand. He had taken me to an Italian restaurant and we'd talked and talked. He was charming and gentlemanly, and I was intrigued. I had no idea what this condition was or how it might affect our future, but that night I felt a comfortable connection with this man, although I wasn't sure what it was!

That first night, I thought it might be romantic to walk the short way to Swanage Quay 'to watch the twinkly lights'. Ian tried to explain to me that it wouldn't be possible, so we drove there in his car. Ian, at that time, had not long moved from a house to a ground floor flat, and was living with his two grown-up sons. To cut a long story short, it wasn't long before I moved in with them. As time progressed, it became more obvious that Ian's health was continuously declining. He couldn't even walk to the toilet without getting seriously out of breath. He now had to use an oxygen concentrator to do even the simplest everyday tasks.

Top picture—pre transplant
Bottom picture—post transplant

A fellow Alpha told us about a clinical trial being carried out at Southampton Hospital, where coils are fitted inside the lungs to open up the tubes; ironically, Ian's lungs were deemed too damaged for him to qualify for this trial. Ian was then referred by his consultant at Bournemouth Hospital to Harefield, the famous heart and lung transplant hospital in Middlesex. He went through the many tests, physical and psychological, before he was finally accepted onto the transplant list. Just before this, Ian had been through a five week long chest infection. This was a really frustrating time because we were informed that, if offered a new set of lungs, Harefield wouldn't be able to proceed if Ian had any trace of infection. I was very much involved in the process from the beginning, and right at the start I knew that I was going to be an integral part of Ian's recovery. However, while Harefield prepared both of us well for this life changing experience, I don't think anything can prepare you 100% for the reality of what was to follow. Ian's consultant told us that there was a very small window of opportunity for them to do the double lung transplant for Ian, then 46 years old. It wasn't until after the transplant that we were told that he probably wouldn't have survived that winter without it. Either that, or I just didn't want to accept defeat; Ian had to remind me of this after the op.

After all the tests, discussions, consultations and meeting the teams at Harefield, we were sent home to begin the waiting game. This was a very difficult time; Ian coped much better than I did. I'll never forget the first call we got. It was 3 am in the morning and, although we were told not to rush, we started to panic. The adrenalin started pumping. Ian's hospital bag was already packed, and it wasn't long before we began the 2-hour journey to Harefield. When we got there, we were met by a transplant coordinator who explained what would happen in the next few hours. They reminded us that, at any time and for many different reasons, the process could be deemed a false alarm and we would be sent home again. Ian was given a room and actually went back to sleep! Don't ask me how but I sat up till morning, wide awake. A nurse came and told Ian to shave himself then have a medical scrub shower, to prepare for surgery. He had finished this when the coordinator stopped us with the bad news that the donor basically hadn't died quickly enough and their lungs were not viable. It's horrible to think that this person's family had still lost them but now couldn't even donate their organs to at least give their loss some meaning. I could never imagine what it is like to have to decide to let a loved one go and agree to organ donation.

Obviously disappointed but totally prepared, Ian and I quickly accepted the situation - almost treating it like a rehearsal run. We returned home and got on with life as best we could.

Member Stories - Our journey, his journey, my journey
(continued)

Two weeks later, six weeks after originally being put onto the transplant list, Ian received his second call at 8 pm. I wasn't at home so he rang me. 'You're joking!' was my response. 'Please be careful driving home.' Ian pleaded. I still don't know how I managed it but I did get home safely, and we were soon on our way back to Harefield. It seemed a little easier than the first time as we sort of knew what to expect. We arrived at around 11.30 pm on 14th September 2017. We went through the necessary procedures only to be told that a suspicious lump had been found on the donor lungs and, of course, this had to be tested. After a few more hours of waiting through the night, the lungs were given the 'allclear', and we were told that the operation was on! Again, Ian had managed to sleep for a few hours but I hadn't. When Ian was ready, I was able to walk down to the entrance of the theatre, where we said 'See you later.' and I had to let him go. I had total faith in the medical teams that were looking after Ian. I didn't really have a choice. It was two days after Ian's 47th birthday!!!

I didn't plan it but I found myself in the multi-faith prayer room. No-one else was there and I was a bit disappointed that there were no Hebrew prayer books for me to hold onto. I did have a quick word with 'the man upstairs' to look after Ian for us. I don't know why but I had brought my new digital camera so spent the next couple of hours wandering the grounds of the hospital taking pictures of trees, flowers, anything to distract me from the fact that my partner was having his lungs replaced at that very time. Later on, I checked into the room I had booked at Parkwood - the relatives' accommodation of the hospital - to try and get some sleep. I had been awake for the last 28 hours, but I still couldn't sleep. I had been told that the operation would take five to eight hours. By 5 pm, I still hadn't heard anything. I couldn't wait any longer so rang the number that I had been given. I was told that Ian was already in ITU (Intensive Therapy Unit) and I would be able to come and see him after the nurses had settled him in. I had been told to prepare myself for the sight of him - unconscious, with the breathing tube, and connected up to many machines - so it wasn't so shocking. His face was already pinker than it was before the operation, which was a comfort, but he did look frail and helpless. The nurse was there, constantly monitoring him, administering the drugs that he needed. It was awe-inspiring how these professionals working in shifts were constantly meeting all of Ian's needs. The consultant would come round daily to check on him but it was the nurses' and support staff's care that was most reassuring amongst the bleeping flashing machines.

After 48 hours, I was told that they would attempt to wake Ian up. This must have been one of the lowest points as Ian wasn't ready to wake up. He opened his eyes but there was no response. The nurses encouraged me to talk to him, stroke him, anything to try and stimulate him - but to no avail. This was devastating and I almost convinced myself that he wouldn't wake up at all. After 72 hours they tried again; this time he responded by nodding his head. He couldn't talk as he still had the breathing tube in, but I talked to him and he nodded or shook his head. I cried. This was the moment when I hoped everything would be ok. Eventually the tube was removed, which is when I told him that the Alpha-1 UK Support Group had offered to pay for my accommodation for a few days so I could spend time with him. His first words were 'Unreal'!

We both started to learn that, although this was going to be a new lease of life for both of us, it was going to be a long hard slog. In ITU, Ian had to be put onto a bedpan. He had lost so much weight being ill, and now his body became even thinner, using every ounce of energy for recovery. Whilst asleep he'd been tube-fed, so at first he had to start with soft food as he might have been sick. It was weird because he never ate yogurts or ice cream before the operation but got a taste for them in hospital. Ian is one of these really annoying people who can take or leave eating so he had to really up his calorie intake to aid his recovery. As he was attached to so many tubes

and monitors, he had to drink through a straw. Then, as he was lying in bed, his wrists and ankles started to swell uncomfortably so he had to try to keep them moving. All this time, because of the wonders of Facebook, I was able to multi-message family and friends to let them know how we were both doing. I was surprised when people were asking me if I was ok. 'I'm ok', I heard myself replying. With hindsight, I think I was running on autopilot.

After another couple of days, Ian was deemed fit enough to be moved to the recovery unit in Rowan Ward. He was given a room right behind the nurses' station, a nice bright room, although it was very warm. Ian started to eat a more varied diet and be more alert even though he was still on morphine. There were building works at the hospital so Ian had to have an anti-fungal inhaler, which was disgusting. But he took it, as well as all the other drugs he had to take. Why wouldn't you???!!! After a week, he still hadn't managed to walk; this was a big concern to me. I thought that if he didn't push himself to try and walk that he would take longer to recover. Ironically, he did have a go on the exercise bike a couple of times. Everything else was going to plan, so he was moved in order that the latest transplantee could have the room. His new room was darker with a not so nice view of the building works. Ian had been taking a maintenance dose of anti-depressant ever since we met. However, his mood plummeted to a panic attack. I still don't know to this day what happened. Maybe he just found it too overwhelming. His appetite wasn't great, and that weekend staffing levels in the ward were definitely short. I took Ian's Nan to visit him and what we found wasn't pleasant. His bedding was dirty and hadn't been changed. He hadn't been given a wash so his Nan and I set to sorting him and the bed out as best we could. We felt that he had been abandoned a little and I'll never forget how Ian whispered weakly to me 'Take me home babe.' I felt so upset and helpless. It was really hard to leave that day but at least we could stay for a few hours till he had calmed down.

During the next five weeks, mainly at weekends when I wasn't working, I travelled back and forth to visit Ian. I'd bring him clean washing, spend time talking and encourage him to do his physio. Towards the end of his first stay in hospital he was even allowed out for a couple of hours for lunch, which was nice. It was weird not having to think about needing to park right next to where we were going. Ian could already walk further than he could before the transplant although he still had to take it easy.

Another low point was during a visit from Ian's Mum. She bought presents for him and it was nice because we didn't see her often as she lived so far away from us. However, the five chest drains that he had were very painful. I started to ask Ian a lot of questions about something the doctors had said to him earlier in the week. I wanted to understand but didn't. It was a weekend so the regular doctors were not around for me to ask them directly. Ian couldn't handle all my questions so he snapped at me. This was very unlike him. Usually he is so calm and collected. This was the first time he had snapped at me and I had to leave the room. I suppose that, finally, all of the stress and worry had caught up with me. Not long after that I was so glad to be able to talk to the counsellor at Harefield, about all my fears and worries and the long recovery ahead of Ian. The teams at Harefield really do have every eventuality covered, not only for the patient but for the family too.

Finally, after five weeks, all the staff at Harefield said Ian was fit enough to come home, although he still had a long way to go. I suddenly felt a panic - I knew I had to scrub the flat from top to bottom as he now had a compromised immune system due to the anti-rejection drugs that he had to take to stay alive. It didn't actually take me as long as I thought it would. The day came when I could pick him up. He was discharged with enough drugs to last him for a month or so - two very big carrier bags full. He strapped himself in the back of his car with a pillow between himself and the seat belt, to protect his sensitive scar.

One of my worries for Ian's recovery was our dog Yaffa. She was only just over a year old and quite an excitable puppy. Whilst Ian was in hospital, I had trained her to sleep in her own bed in our bedroom; previously she had always slept at the end of our bed. Another thing I feared was that Yaffa could lick Ian's face. I was even concerned that Ian wouldn't be able to pet her because of his depressed immune system. I needn't have worried because although young, she is quite a clean dog, able to groom herself. She even became less excitable around Ian. It was as if she knew that she had to be gentler around her daddy who she had truly missed for the last five weeks.

Two months after the operation, a bubble appeared along the clam shaped scar across Ian's chest. At that time, he was down to monthly clinic visits to Harefield, for check-ups and consultations. He felt fine in himself; his

Member Stories - Our journey, his journey, my journey
(continued)

temperature wasn't raised and we weren't overly concerned. He couldn't help squeezing the bubble. He cleaned it up and stuck a plaster over it. However, at the next clinic visit, he was told that he would not be able to go home and he was admitted. To this day, we still don't know how it had happened but apparently he had developed an infection in his scar. Though this complication is quite common he couldn't leave hospital until it was under control. Immediately, he was prescribed intravenous antibiotics, administered via a line in his arm. A pump was fitted on his scar, which would suck out the infection 24/7. Unfortunately, as building works were still going on at the hospital, he had to go back on the dreaded anti-fungal nebuliser. It was really frustrating because he didn't feel ill but he couldn't come home. After 17 days, he was taught how to self-administer the antibiotic via the line in his arm and sent home, still with the pump attached to his scar. He was told to come to clinic weekly for the foreseeable future. Again, it was very frustrating for Ian because he had to carry this pump around and sleep with it beside the bed. It was quite similar to how things were when he had to carry the oxygen concentrator around with him, just so he could breathe! In total, he had to have the pump and administer the antibiotic for four months until he was infection-free, and then he was able to go back to monthly clinic visits.

Now Ian is still only 10 months into his recovery from his double lung transplantation. We are both so grateful for his gift of life. I dread to think what could have happened if he hadn't received the transplant when he did! If he wants to send a letter of thanks to the donor's family he can contact the transplant coordinator at Harefield. The donor's family has to agree to receive a letter from Ian but as of yet, he isn't quite at that stage.

Although lung transplantation is not a cure for Alpha-1, Ian can now walk with me and the dog, sometimes for an hour or more. He can go to exercise classes and lead a more active life. He can't eat runny eggs, rare steak, certain fruits, or swim in a pool or the sea.....yet. But as I often remind him, he can breathe. Although not over, it certainly has been the start of an incredible journey towards what's hopefully a new lease of life!!!!!!

Rachael, Ian and Yaffa after walking to the top of Hengistbury Head. We walked 8km that day!

Member Stories - Africa 2017—Jensen and Ruth Kay
by Ruth Kay

Our Alpha journey

Background

When Jensen was born, I promised that I would love him forever, that we would have a life of adventures. I couldn't believe that I had been given a son. When Jensen was 2.5 years old, after many hospitals stays and chest infections and purpuras, Jensen was finally diagnosed with Alpha-1. As a family, we were shocked. Our son, our first boy (3 older sisters) was so very poorly but still utterly amazing. As Jensen got better and fitter, I always kept my promise that I would never treat him as an 'ill' child, and life was still going to be an amazing adventure, nothing was impossible.

Khaya - Home

I am a music teacher by profession, but I also do quite a lot of charity work. In 2015, my niece Jess and I went out to work in Africa for a while on a project called Khaya Centre that we have been fundraising to help build since 2012.

The Khaya Centre is situated in Lehae just outside Johannesburg in South Africa. The Centre has been constructed from old unused shipping containers and has become the heart of the 4000 NGO (not for profit) township. The word 'KHAYA' literally means 'home', and for hundreds of people living in the township of

Member Stories - Africa 2017—Jensen and Ruth Kay
(*continued)*

Lehae the Khaya Centre is a place they call home. It is their lifeline - the place they find support, care, education, food, training, love, community and so much more.

The Khaya Centre aims to develop and equip the community of Lehae to better the lives of individuals dealing with issues resulting from HIV/AIDS. The Centre runs a feeding programme through which thousands of people are given food each day, a free pre-school for children who otherwise wouldn't get the chance of education, counselling services, an after-school's programme, medical services, victim support and many more life changing projects.

Khaya also has a daily programme offering food, safety and assistance to orphans and vulnerable young people. To me, Lehae was a strange place when I first arrived. As a 40+ mum/step-mum to five children, I am very used to big families. However, there are very few people of my age there. Many of my age group have either just walked away from their families or have passed away due to HIV/Aids virus. Many of the houses in the township are child-lead households with up to sixteen young people living in a one-roomed house. There are also many houses that are led by elderly grandparents. I really struggled with the thought of my children having to run a house and fend for themselves. When I left South Africa in 2015, I left feeling very challenged by the experience.

2016 – A new project came up

A new project came up in South Africa, near the Kaya Centre, in 2016. It was to refurbish a derelict community centre and an old block of offices which would become classrooms, install a shipping container which would become the kitchen and offices, and refurbish the toilet block. This project has the capacity to supply pre-school education for up to sixty 2-6 year olds, and be a safe place for more than one hundred children and teenagers to play, learn and receive food after school. Khaya Le Themba (Home of Hope) was born.

Jensen, now a teenager, had not accompanied me on the previous trip in 2015. However, he decided it was time for an adventure and asked if he could fundraise to join me on the 2017 trip to South Africa. Thankfully, on my previous visit I was taken to see the local hospitals and medical facilities and had investigated the price of getting health insurance in South Africa!

I had promised Jensen a life of adventures no matter what, so planning for the trip commenced. Along the way we were joined by my niece Jess (again), my nephew Ben, and 19 other young people from Bolton.

On 25th August at 4 am, we all met in our hoodies and left on our 24-hour journey via Dubai to South Africa.

When we arrived at Khaya, the atmosphere was amazing, with an air of hope for change. All 26 of our build party camped out in the Khaya Centre, using the classrooms as our base. We had one toilet block and one shower to use between all 26 of us, and there was no internet, no TV, just fun, friendship, and a couple of packs of cards.

Week 1

The day after we arrived we went straight to work. We had been advised that a local building company would support us and provide materials to advance the project. However, due to a misunderstanding and corruption, the contractors pulled out on the first day and took all the materials with them. We transferred to plan B – 26 young and young-at-heart people set to make the project happen, come what may. We had the site cleared of all debris and dug up tree stumps. Underneath the rubbish we found a HUGE family of rats! However, we also discovered a beautiful pathway that led around the derelict site. In the madness of the day, this was a beautiful find.

The first week of the build was hard manual labour. We didn't have many tools, but we did have gloves, paint brushes, wheel barrows, a few spades and 26 willing hearts and pairs of hands. On site, we had one 'long drop' hole for a toilet and no running water. First things first … we needed water. During the day, in the hot sun,

Member Stories - Africa 2017—Jensen and Ruth Kay
(*continued)*

we stripped out and cleaned the derelict building. The team that pulled the short straw took on the job of the toilet block, rerouting drains and industrial cleaning to see if we could reuse any of the equipment.

How to measure a hole without a tape measure!

Despite the lack of tools, not a single person stopped working and much fun was had, with smiles all around.

When we arrived back at the Khaya Centre in the evenings, we were met by the local young people who use the centre for after school activities and clubs. Our young people couldn't wait to get back to their new friends and chat in broken English and Afrikaans about their days; about how similar and different their lives were. Jensen would often be the last man in the shower to wash off the dirt from a day of labour.

On Sunday, our only day of rest, we went to the Lion Zoo to see the local animals in their natural habitat, and we sat with some baby lions!

Week 2

Our jobs for the second week were painting, painting and a little bit of fence panelling - a hectic week. We had finished most of the building work apart from the kitchen and toilets. But this week was only a 3-day working week as we had to finish on Wednesday. On Thursday we were hoping to open the school, and the local community officials checked the work we had completed. Then we needed to pack to get our flights home again on Friday.

So started the massive painting project, painting the inside and outside of the school. We wanted the school to look colourful and inspirational so painted murals all the way round the school, inside and out. We even gave each classroom a theme of its own. I, of course, did a music room.

On our last day, we stayed on site very late, with many mad dashes to the local shops for extra bits of paint and toys for opening day.

On 31st August 2017, Khaya Le Themba, Home of Help, opened. Many people from the community attended the opening ceremony, there was music and we painted the faces of all the children. On opening day, 62 students signed up to start the school year on the following Monday!

Rebuilding the school changed the heart of the community. The school has since been transferred to the community alongside Khaya, and is going from strength to strength.

Jensen Kay, my PiZZ, my super Jensen, my very own super hero, contributed to this wonderful achievement that changes the lives and future of many deprived children in South Africa. Nothing is impossible, and nothing can ever stop him on this amazing adventure called life.

Watch out for the next thrilling instalment of the Adventures of Jensen – it's already in preparation and will be in Patagonia, South America, with Marjorie Hayward (AKA Nanny Noodle).

In Memory of Wendy Anne Arnold

Memories of my time with a Nightingale, by Robin Kelly

19th December 1958 – 28th February 2018

Wendy and my paths collided 13 years ago (2005) in a folk club when we were both at a very low point in our lives. We started singing a few songs together, or I might accompany her on guitar or just listen to her singing acapella. I particularly remember her haunting rendition of 'The Harp Song of the Dane Women' - originally a poem by Rudyard Kipling.

Robin and Wendy

Folk clubs seem to be a magnet for damaged souls, and Sam and Sandy who run the Woolston and Bursledon Folk Club took us under their broad wings. We discovered that not only were our musical interests the same, but we had the same love of nature. So Wendy spent a great amount of time on my 'little piece of England'. There, Wendy developed another of her passions - photography - and if I mislaid her, I would usually find her crouched over some tiny flower taking shots of a bee collecting nectar.

Our passion for music continued, and once we had purchased an electric mobility scooter which could be put in the car, we were able to travel around England to all sorts of venues to see our favourite performers. We even pushed the boat out and hired a very nice camper van to travel up to Shrewsbury for the annual folk festival.

In 2009 (after a trial run of a long weekend on the Basingstoke Canal) we bought a share in a narrowboat. For Wendy this was heaven and she loved the tranquillity and solitude of being moored up somewhere in the middle of nowhere, perhaps sat in a field next to the towpath watching clouds, sunsets and passing rabbits and deer who didn't seem at all bothered by our presence. This venture was so successful that we bought another share in the same syndicate which gave us 8 weeks a year on the boat. The electric scooter meant that we could travel further away from the canal and our diary entries (in the ship's log) about the adventures of 'the packhorse' have become legendary!

Wendy was a very capable helmsman and would normally take the boat in and out of the locks whilst I opened, closed, drained and filled them. If we were tackling a flight of double locks with another boat we would rope the boats together and the crews would set alternate locks whilst Wendy sailed serenely through them. And she did it always with that smile.

I have many pictures of a Falcon Experience day when we flew falcons and other birds of prey. Every picture of Wendy has that 'signature' smile - no requirement for Photoshop at all.

After Wendy's son, Lewis, died in a terrible motorbike accident in 2015, it became impossible for her to stay in the rented flat they had shared since 2008 and so we set about finding somewhere else for her to rent. The following year Wendy moved into a delightful 1960's bungalow in a quiet cul-de-sac. Wendy adored it. I find it astonishingly unfair that she had so little time to enjoy it.

We never really consciously thought about her being 'terminally ill'. We lived each day to the full and were always planning exciting things to do together (although simply holding her hand, sat on the sofa in the evening, was just the best for me). Wendy's sudden, unexpected parting was totally unfair.

Life dealt Wendy a bad hand of cards but I never heard her complain or whinge about her situation. She just carried on caring about others and smiling. Wendy was a lady who had had 'muck' piled on her through all her life and had smiled through it all. That smile is the one thing that everyone remembers about her - but I have more - I have her heart and I have her soul and I will carry them safely until I find her again.

Poetry Please

by Joe Lyons

Our dear friend Joe sadly passed away on 3rd February 2018.

Joe, and his wife Carol, have been long standing and active members of our Charity for many years.

Joe always had a passion for poetry and regularly entertained our members with his latest compositions. Poetry Please became a regular feature in our Newsletter and below we share a poem he wrote which was read by his daughter at the Service of Celebration in his memory.

RIP Joe, our very own sonneteer.

Fade Away

When the time had come to pass this way
I had made my mind up what I would like to say
It should have been glorious, vaguely victorious
Instead of just fading right away

Next time we meet, will my head be held high?
Will my hopes and aspirations soar and fly
I just can't imagine, now my thoughts are flagging
Will it now just all fade away like a load I'm dragging?

We all think we know just what to say
When the time comes to just fade away
As long as you've enjoyed the journey; taken pleasure for a while
Leave people and places; with memories that make them smile
That is all you can ask in this world today
Before the time comes for you to just fade away

Poetry Please

In memory of Joe Lyons and Barbara Owen

A Poem by Barbara Owen

I have friends I love so much
Always there with a loving touch
They comfort me when I'm not well
And laugh and cry at things I tell

Most of them I've never met
A circumstance I do regret
From near and far away they write
To say don't give in—keep up the fight

These friends of mine they are the most
Unlike some that live so close
So now I'm telling this to you
It's my Alpha Facebook friends so true

So my love to all of you out there
Thanks for being you

Poetry Please

In memory of Joe Lyons and Barbara Owen

A Poem by Ronnie Owen

Across these clear blue waters
On love we sailed through life
In our little boat the “BAR-RON”
Just Ronnie and his wife

The Gentle wind that filled it’s sails
Made our journey such a bliss
We’d sail away for hours and hours
On just a cuddle and a kiss

I never thought the day would come
Where we would be apart
Now my Barbie’s gone forever
Leaving me a broken heart

The gentle breeze that filled the sails
Has disappeared—so sad
My boat is now called only “RON”
I’m so alone and sad

In Memoriam

All Alpha friends that we have lost have left their mark on our lives, and it was a privilege to have known them.

Reflections *by Joe Lyons*

For the people who've gone before us, your fight was not in vain
Our thoughts and prayers are with you, we tried to ease your pain
We know you were the bravest, the best that you could be
And even then you smoothed a path for someone just like me

In life we all need heroes who would fight and be strong
You are all classed amongst them, even though you've gone
In our thoughts you're always there, we'd think of what you'd do
Even when life is a struggle we strive to be as good as you

Life takes so many heroes before we can get it right
Our thoughts are always with them throughout the day and night
So pause just for a moment let your mind free to take stock
Be thankful in that moment remembering what you've got

Paulette Robinson
19 November 2017

Steve Hundtofte
13 December 2017

John Castle
10 January 2018

Jenny Clarke
22 January 2018

Joe Lyons
3 February 2018

Wendy Arnold
28 February 2018

Theresa Patel
3 May 2018

Brian Grimes
6 May 2018

Bernadette Priest
12 May 2018

Robert Paul Gaylor
5 July 2018

Philip Gorvin
20 July 2018

Barbara Owen
4 August 2018

Fundraising and Awareness

A Big Thank You to everyone involved in fundraising activities and for donations to the group. This year supporters have been active as ever - running marathons, baking cakes and hosting coffee mornings and gala days, organising awareness stands, donating in memory of loved ones and special occasions, making regular donations, holding raffles, hosting singing and dancing events, and many other fundraising activities.

Through your activities we are able to continue funding our programmes of providing support and education for patients, families, carers and friends who are affected directly or indirectly by Alpha-1 Antitrypsin Deficiency. We aim to do this by:

- growing a social network for patients,
- providing discussion groups focusing on how better to cope with their condition aiming towards improving quality of life,
- advancing education, understanding and awareness of the condition, in particular among medical professionals, including information relating to genetic implications, treatment, and lifestyle choices, and
- supporting research and campaigning for better access to treatment for Alpha-1 patients.

We know there is so much more we can and need to do to promote better knowledge and understanding of Alpha-1 Antitrypsin Deficiency but we are limited by the funds we receive, so your support is valued and very much appreciated.

Cabaresque Charity Events
The Buff Club, Glasgow
Saturday 19th May 2018

The group, was formed and is run by Johnston B, a singer song writer, and his wife Misty Vie, a dancer, burlesque and fire performer who was recently diagnosed with alpha-1.

Cabaraesque XIII hosted an exciting and entertaining evening of burlesque, cabaret, belly dance and music from some of Scotland's finest performers along with a raffle and sweet treats!

Fay Whittaker and Graham Dalton attended the evening and talked about life living with alpha-1.

Alpha-1 Warriors
Land's End to John O'Groats
Saturday 11th August 2018

Paul & Becca Seager had a vision for the alpha-1 community to set off from Land's End and reach John O'Groats, covering 874 miles, in under 24 hours.

Paul and his friends set off at midnight to walk the gruelling 52.5 miles of Hadrian's Wall in Cumbria.

Mark, Veronica & Chloe Acland and Jan Carley walked along Felixtowe sea front.

Others recorded their walking distances at conferences, walking their dogs, walking at work or went for a run.

Together our members and their friends and family achieved a staggering 1,102 miles together, smashing our target.

Thank you to everyone who helped to make this event a huge success.

Every penny raised for this event, and more, will be donated for research with the aim to improve the lives of those affected by alpha-1.

Fundraising and Awareness

Jacqui Quinn, Bush Hill Park Bowls Tennis & Social Club, Gala Day August 2017

Sue Iliffe held a coffee morning to raise funds and awareness in September 2017

Rachael Silver entered the Salty Sea Dog Long Swim

Tanya Jones gave up gin and fizz for Dry January … cheers!

Steven & Vicky Fox set the target to lose 5 stone in 15 weeks. Well done and thanks to you both.

Nicky Lynch held a Christmas Raffle for friends and family

Fay Whittaker and Ina Smith at Kirkcaldy Victoria Hospital raising awareness and collecting donations

Rachael Silver entered the Bad Cow Frolic fun run from Corfe Castle, Yaffa, her dog, also joined in the fun too.

Maggie Sceal and her COPD friends are all members of the Breathless Choir and they kindly raised funds for our Charity.

Donations

Anonymous	In lieu of Christmas presents
Anonymous	Funds raised from family get together
A F Gowans	In lieu of Christmas Cards
Bucks Masonic CPSA	Emma Hunt's London Marathon 2018
Diane and Mick Stobart	Monthly donations
Susan Turner	In lieu of selling crochet blanket
Berenice White	Monthly donations

Donations in Memory

Anonymous	In memory of Eric Adams
Anonymous	In memory of Tony Creasey
Anonymous	In memory of Gerald Whybrow
Michael S Clarke	In memory of Jennifer Clarke
Mrs C M Crew	In memory of Lilian Weller
Mr Millar & Mrs Davies	In Memory of Jennifer Clarke
Friends & Family	In memory of Wendy Arnold
Friends & Family	In Memory of Philip Gorvin
Friends & Family	In memory of Brian Trevellyon Grimes
Friends & Family	In memory of Steven Hundtofte
Friends & Family	In memory of Joe Lyons
PR & N Gilbert	In memory of Wendy Arnold
Mr FT & Mrs RM Jones	In memory of Brian Trevellyon Grimes
Rebekah Lilley/Overton	In memory of Ray Overton

Raising Funds - How You Can Help

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 the condition throughout the medical profession, support research and campaign for better services and treatment for Alpha-1 patients in the UK. **Please visit our Website for more information: www.alpha1.org.uk**

JustGiving™

You will raise more for Alpha-1 UK Support Group on **JustGiving**. It's easy (and completely free) to set up a fundraising page for your favourite charity. It only takes 60 seconds to get up and running.

You can write out your personal fundraising story, add photos and even video and colour to your page. Best of all, it's all incredibly simple to do giving you the best tools to make it easy to ask friends to sponsor you.

If you are a UK tax payer our charity can also claim back via Gift Aid the basic rate tax already paid on donations by the donor. This means we can claim back from the government on your behalf 25p for every £1 donated, boosting the value of the donation by a quarter.

You can also use your mobile to send a donation. Text "ALPH10 £amount to donate" to 70070 to donate to Alpha-1 UK Support Group.

JustTextGiving is powered by Vodafone.

justtextgiving.com

easyfundraising.org.uk

easyfundraising.org.uk is a great way to raise money for our charity just by shopping online.

1. Start at easyfundraising

Go to easyfundraising.org.uk

2. Search for a Cause

Enter ***alpha1 uk yahoo support group***

3. Choose Support This Cause

Create your account with Facebook or an email address

4. Get the easyfundraising Donation Reminder

You can skip steps 1 and 2 with the easyfundraising Donation Reminder. Just click the Reminder when you shop to receive any eligible donations. You'll never forget a free donation again!

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You shop. Amazon gives.

Join Amazon Smile and raise funds for us every time you shop on Amazon.

https://smile.amazon.co.uk/ch/1146330-0

easysearch.org.uk

easysearch.org.uk is a free search engine that enables you to raise funds for the good cause of your choice whenever you search the Web. It costs nothing - **easysearch** is completely free.

How does it work?

If **easysearch** is used as the search engine for a web search, **easysearch** will donate half a penny to the Alpha-1 UK Support Group for every search you make. This is an easy way to raise money, so please use easysearch.

Expedia.co.uk · TESCO direct · The National Lottery · GAP · Argos · Boots · ebay · LOVEFILM.com · DELL · amazon.co.uk · GROUPON · LAKELAND · John Lewis · Toys R Us · Viking · Boden · DEBENHAMS

Alpha-1 UK Support Group Merchandise

On our website we have a selection of Alpha-1 merchandise available for purchase, including T-Shirts, wristbands, trolley key rings, badges and Christmas cards.

Alpha-1 information packs, booklets and posters are also available at no cost.
Please e-mail us with your full name and address at:

info@alpha1.org.uk

We are happy to supply our materials to healthcare professionals.

CHRISTMAS CARDS for 2018

Here is our 2018 selection of Christmas Cards. Please order either in our online Shop: alpha1.org.uk or by email: info@alpha1.org.uk The cost is £3.75 for a pack of 10 (140mm/5" square).

Snow Santa

Gold Tree

Twelve Days of Christmas

Santa's Reindeer

Star Christmas Wishes

Trustees & Committee

Karen O'Hara
Chairman
Trustee,
Treasurer

Bev Burroughs
Trustee,
Admin Support

Jemma Coad
Trustee,
Fundraising
Awareness
Co-ordinator
Parent
Support

Dr Sandra Nestler-Parr
Trustee,
Strategy and
External
Relations

Tanya Jones
Trustee,
Data Proection
Officer

Mel Brolly
Fundraising
Awareness
Co-ordinator

Graham Dalton
Scottish
Representative

Fay Whittaker
Scottish
Representative

Patrons

Professor Robert A Stockley

Professor of Medicine at University Hospital Birmingham, Director of Lung Immunobiochemical Research Laboratory

Professor William MacNee

Consultant Physician, Emeritus Professor of Respiratory Medicine University of Edinburgh, Royal Infirmary of Edinburgh

Supporters

ADAPT

Alpha 1 Alliance

The InterNet Factory

CSL Behring
Biotherapies for Life™

British Lung Foundation

ALPHA-1 CANADA

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Boehringer Ingelheim

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ALPHA-1 FOUNDATION
Research for a Cure

BRITISH LIVER TRUST

Chiesi

KAMADA
High Quality Pharmaceuticals

Children's Liver Disease Foundation
fighting childhood liver disease

Supporting alphas, their families, carers and friends since 1997

Alpha-1 UK Support Group
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Worcestershire
WR9 8NT

We are a registered Charity

England and Wales (1146330)

Scotland (SC043177)

www.alpha1.org.uk

info@alpha1.org.uk

Who are we?

The Alpha-1 UK Support Group is a not for profit organisation and registered charity founded in 1997 by those diagnosed with the genetic condition Alpha-1 Antitrypsin Deficiency who are dedicated to help, advise and support fellow sufferers, their families, carers and friends.

What are our objectives?

To relieve the needs of individuals suffering from the genetic condition Alpha-1 Antitrypsin Deficiency (AATD), their families, carers and friends, in particular, but not exclusively by:

a) Providing advice, support and equipment with a view to improve the quality of life of those suffering with AATD, their families, carers and friends;

b) Advancing awareness and knowledge of AATD, in particular among affected patients and medical professions and healthcare provider organisations;

c) Fostering improvements in access and equality of access to clinical expertise and optimal disease management and treatments for AATD;

d) Supporting initiatives aimed at development, introduction and widespread adoption of novel therapies for AATD, including research.

e) Working collaboratively with our members and relevant external individuals, groups of individuals, organisations and institutions in order to achieve a) - d).

What is Alpha-1 Antitrypsin Deficiency?

Alpha-1 Antitrypsin Deficiency also known as Alpha-1, A1AD or AATD is an inherited, genetic condition that is passed on from generation to generation. As the name suggests it is a deficiency of Alpha-1 antitrypsin (AAT) in the bloodstream. AAT is an enzyme produced in the liver to help protect the tissues of the body during infections. The low level of AAT in the blood occurs because the AAT is abnormal and cannot be released from the liver at the normal rate. This leads to a build up of abnormal AAT in the liver that can cause liver disease and a decrease of AAT in the blood can lead to lung disease.

Find us on Facebook
alpha1uksupportgroup

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Alpha1UKSupport

Notes

www.alpha1.org.uk

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