

The Puffin' Appeal

Caring for children with breathing disorders

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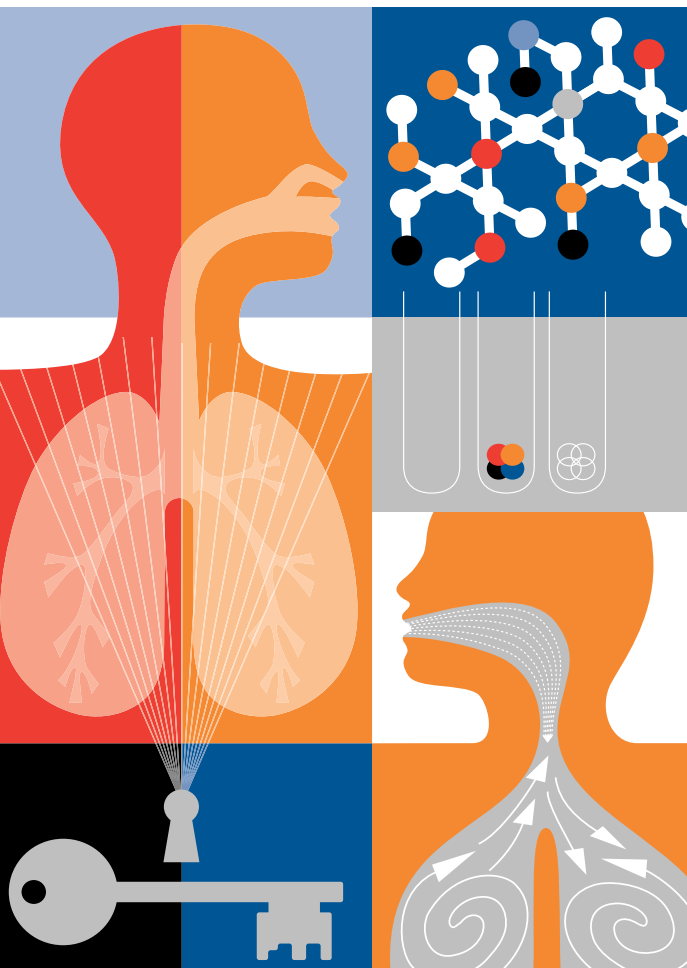
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www.puffinappeal.com



We can go without water for days and without food for even longer, but without air we will die in a matter of minutes. So imagine how terrifying it is for a child who must battle for breath. The fact is that such breathing disorders account for nearly half of all acute admissions of children to hospital in the North of England.



What is the Puffin Appeal?

The Puffin Appeal has been set up by Dr Spencer to create a world-class childhood respiratory unit in the North of England and to care for youngsters with cystic fibrosis (CF), asthma and other lung diseases.

Dr David Spencer, Dr Chris O'Brien and Dr Mike McKean have spent many years caring for young patients at Newcastle's Royal Victoria Infirmary, Freeman and General Hospitals. They are all specialists in complex childhood breathing disorders, into which they also carry out research.

This pioneering work has improved the lives of many youngsters but they recognise there is still an enormous opportunity to improve upon the quality of life of these children and help each one live as full a life as possible.

A great deal of research is still needed to help us understand lung diseases in children. With your help we can conduct this research into respiratory diseases which will help to make a real difference in the day-to-day lives of young patients.

Each year many children from as far away as Carlisle, Cleveland, Scotland and Ireland travel to Newcastle for specialist care. This demand from desperately ill children has stretched current resources to the limit.

When admitted for diagnosis and treatment, young patients and their families can face further upheaval due to childhood services being divided between the three hospitals. This can affect patient care, as patients may have to move between units for investigation and treatment causing delays and distress for the children and their families.

Together we can give all children with respiratory conditions the chance to live full lives.

Demi and Raegan

Demi and Raegan both suffer from cystic fibrosis, an inherited disease in which the lungs and digestive system become clogged with mucus, making it difficult to breathe and to digest food.

Although the outlook for patients has improved dramatically in recent years, it is still a very serious condition and most patients will have a shorter than average life expectancy. The UK average life expectancy is currently only 31 years.

For at least two weeks every three months, this sister and brother from Blyth in Northumberland, receive antibiotics through an intravenous line to fight off chest infections. They have to go to the clinic every few weeks and also need to be admitted to Newcastle's Royal Victoria Infirmary for more intensive treatment several times each year.

These young children must also undergo a daily regime of physiotherapy and breathing exercises, eat a special diet and take many medications to help them digest their food to remain reasonably healthy.

According to their mother Margy:

"They are generally happy kids who get on with life. Demi gets a lot more out of breath and needs a lot more treatment than Raegan who has too much energy and you wouldn't think he had anything wrong with him if he didn't keep getting chest infections.

Of course they get fed up sometimes. In the summer holidays if they have the lines in for the intravenous antibiotics, they say, Why can't we go swimming? Why can't we go out like other people and ride our bikes round the park?"

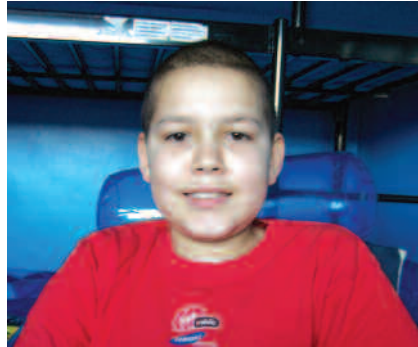
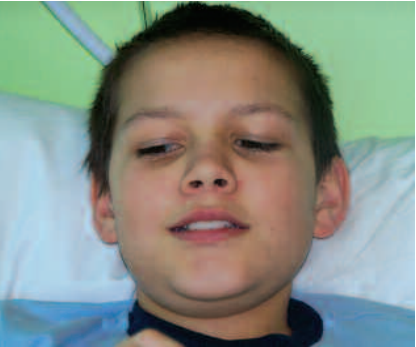
Demi and Raegan together at home – doing what they like to do

Demi and Raegan are just two of the young patients that the Puffin Appeal hopes to help.

Cystic fibrosis is the most common life threatening inherited disease in the UK, affecting one in every 2,500 births.



A great deal of research is still needed to help us understand lung diseases in children.



Clockwise from top left: Phillip recovering, well at home and ill in hospital



Phillip

Phillip, from Chester-le-Street, was a normal, healthy young boy, who didn't even go down with a cold, until he was about seven, when he began to suffer from what was thought to be asthma.

From that point, his condition deteriorated steadily and no drugs or treatments seemed to do much good. Physical exercise became increasingly difficult; he was dropped from the school football team and even began to struggle to walk up a hill.

His mum Christine recalls: **"We just didn't know what was wrong. We knew something wasn't right but we just could not understand it and he couldn't understand why he couldn't do the things his friends could do."**

Two years ago he was diagnosed with obliterative bronchiolitis, a rare form of lung damage, resulting from a virus which Phillip probably contracted in infancy. This severely damaged his lungs.

Two years ago, Phillip's lung capacity dropped to 10% of what it should have been, he was assessed for a double lung transplant and he decided he wanted to go ahead.

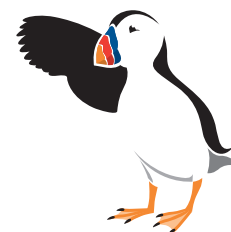
"He wanted to go through with it," says Christine. **"All he wanted was to be as normal as possible."**

Phillip had the operation at the end of 2006 at Newcastle's Freeman Hospital, and his lung capacity is now normal.

"I can hardly put into words what I feel," says Christine. **"Until his operation, we had adapted to his situation, as he had adapted to it, accepting his limitations."**

Now, it's as if he had been given a life, where previously he just had an existence. He can smile now, whereas before he couldn't because it took so much oxygen and he would have a coughing fit.

I'll never be able to thank Dr Spencer and the rest of the team enough. Without them, Phillip wouldn't be here. I remember that when David first diagnosed Phillip, he said he wished he could wave a magic wand and make everything all right. Well, I wish now I could just wave a magic wand and make everything all right for the Puffin Appeal."



David



Globally, respiratory infection is easily the biggest single killer of children, with over two million children dying from pneumonia each year.

Ann believes it was a mother's instinct that rang alarm bells over her eldest son's condition.

David was not getting over a virus that had hit the two other members of the family. In fact, he seemed to be taking a distinct turn for the worse.

Eventually, Ann, who lives in Thornley, took David to the Community Hospital in Peterlee, where he was diagnosed with a collapsed lung and referred to the University Hospital of North Durham, which in turn transferred him to the Freeman in Newcastle.

David had a severe pneumonia, which resulted in a complication whereby pus accumulated in his thoracic cavity. In the words of Ann: **"He was a very sick little boy."**

Within a few hours of his arrival, a team at the Freeman had operated and David was recovering in intensive care. After a week he was sent home with the expectation that he would gradually improve. Ann still felt something was wrong. **"I remember thinking to myself, I'm sure he's only breathing on one side, or am I only imagining it?"**

After a phone call to the Freeman, David was taken back into hospital, where it was confirmed that his lung had collapsed again and was

sticking to the front of his chest. A series of difficult operations followed over the next 4 months, which resulted in David having his lung re-inflated. When he got home, he faced a battle to recover his health and strength.

"We were told his lung was badly scarred and that he would always have some problems," says Ann. **"However, his right lung already has much more function than we were expecting. He is doing fantastically, he has put all his weight back on and he is allowed to do PE again at school."**

Ann has no doubt that he is doing so well thanks to the expert treatment David received. **"The care he received was absolutely fantastic. The doctors, surgeons and staff on the ward were excellent. There are some very sick children in there and these families are going through a very distressing time, but the staff do everything to make them better."**

It's not a depressing place, it's upbeat and if the Puffin Appeal can make any improvements then it deserves huge support. I can't stress how important the medical staff and their work is. If it wasn't for them, I don't think I'd have a little boy now."

David at home recovering



We will be building a radical new approach to how we work to provide an improved healing environment for our patients.

What we can do together.



Impression of the exterior of the new build at the Royal Victoria Infirmary site.



Impression of the interior of the new build at the Royal Victoria Infirmary site.

Most children's medical services in Newcastle will be brought together on the Royal Victoria Infirmary site by 2010 in a new building paid for by the NHS. Within that facility, space has been set aside for a Children's Respiratory Unit.

Here the **Puffin Appeal**, in partnership with the NHS, aims to:

- **Provide spacious, modern wards and treatment rooms**
- **Carry out more research into the treatment and cure of lung diseases**
- **Deliver world-class care for all our patients**
- **Establish an academic department for paediatric respiratory research in Newcastle**

How can you help?

Where will your money go and how we fund the fight against respiratory problems?

This is about more than bricks and mortar. We will be building a radical new approach to how we work to provide an improved, flexible service and comfortable, healing environment for our patients and their families.

To make these crucial improvements we need your help to raise £2million to provide essential equipment including:

- **A seminar room for teaching and learning, including video conferencing facilities to ensure medical professionals remain at the forefront in their field**
- **A dedicated children's sleep laboratory which assesses a child's breathing patterns whilst sleeping to provide a vital insight into the causes of lung abnormalities and to aid diagnosis**
- **A children's lung function laboratory and exercise testing equipment - crucial in assessing how the lungs work, aiding diagnosis, research and treatment.**



Respiratory diseases cause 13% of all deaths in the UK, but receive less than 3% of research funding.

Now's the time!

Most lung disease in adults has its origins in childhood. If we can improve the health of children's lungs, we will prevent lung damage in adults and improve the health of the whole population.

Childhood lung diseases are increasing in the United Kingdom leading to an urgent need to address resources for treatment and research. In the long term, research is the key to understanding and therefore preventing the development of lung abnormalities.

There has never been a better time to position Newcastle at the forefront of medical research in this field. With an established team of experts and new facilities, and, thanks to NHS investment, we're well on the way to realising this goal.

Newcastle is a major heart and lung transplant centre and one of only two supraregional centres dealing with severe immunodeficiency and infectious diseases in children within the UK.

It is not frequently realised that children with these many other serious illnesses frequently develop significant chest problems and then need specialised help from the Children's Respiratory Team.

It is only by providing comprehensive facilities that more children with serious and complex medical problems will survive these conditions with healthy lungs.



Asthma is the most common chronic disease in children.

The North of England has the highest reported rates of childhood asthma in the world.

Developing research.

Respiratory Paediatrics in Newcastle is now in a position to move from being a clinical service to that of a combined clinical and academic unit. The new build on the RVI site represents an ideal opportunity to develop this service.

The Puffin Appeal Trustees have recently approached Newcastle University to support the academic development of this service.

The aim is to support the establishment of an academic department of respiratory paediatrics, to be led by a new Professor.

It is proposed that the emphasis of this new department will be within the field of the acute and chronic effects of infection on the lungs, as this will allow development of pre-existing interests and facilitate further collaborations with the paediatric immunology and infectious disease unit.

£1,250,000.

A flexible seminar room for teaching and learning.

A state of the art seminar room, fully equipped with the latest technology will allow the multidisciplinary team to discuss the needs of complex patients, take part in discussions with colleagues in other centres and countries, thus allowing them to present, discuss, train and disseminate their knowledge quickly and effectively.

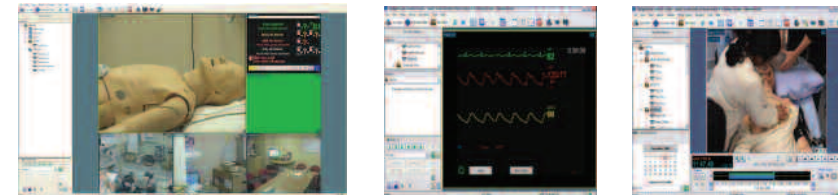
The latest video-conferencing technology will allow exchange of information between units whether in the same city, or indeed other parts of the world with digital technology giving superb definition on High Definition screens.

Two displays will allow participants to share data while viewing each other and when "offline" will give great presentation facilities to users of the meeting room.

£35,000.



A state of the art seminar room, fully equipped with the latest technology



High Definition videoconferencing solutions



The North of England has only limited specialised facilities for the management of children with sleep and breathing disorders.

A dedicated children's sleep laboratory.



Polysomnograph system

This system allows various measurements including breathing patterns, brain waves and blood levels of oxygen and carbon dioxide to be recorded, analysed and stored in a computer to diagnose breathing problems.

£ 30,000

Volusense

This is brand new technology which represents a significant step forward in research by allowing measurements of the lungs to be recorded without disturbing the infant.

This is because the infant wears a special magnetic jacket which transmits the abnormalities to the computer. This set-up avoids any instruments or catheters being applied to the face which is unpleasant for infants and young children.

£ 30,000

Embletta Home polysomnography recording system

For more simple recordings a home system is an advantage which means that the patient does not have to be admitted to hospital to be monitored.

£ 10,000 per unit

NIPPY BIPAP ventilators / flow drivers and masks and long life batteries

These ventilators allow provision of positive pressure ventilation and continuous positive airway pressure (CPAP) in patients who need help with breathing. We always need a supply of these on the ward for acute patients.

£ 26,000 per unit

TOSCA transcutaneous carbon dioxide and oxygen saturation monitors

These allow blood gas levels of carbon dioxide and oxygen to be recorded. These monitors are considerably more accurate and less prone to error than previous models.

We frequently use these at home and on the wards for overnight recording and consequently multiple units are required. Download cables and a computer are required for analysing and storing of data.

£ 24,000 per unit



The North of England is the only region in the UK without dedicated facilities for the performance of lung function measurements in children.

A children's lung function laboratory.



The Jaeger master screen baby body box

Small babies who have severe lung disease are often extremely difficult to manage. Many of them are preterm who have survived being born very early and have required a great deal of intensive care therapy in hospital.

One of the great challenges is to maintain their health as they go home and continue to grow. At present we are limited to listening to the chest with a stethoscope. This master screen baby body equipment will allow us to measure lung function, assess the growth of lungs and response to different treatment.

This sophisticated technology will allow us to analyse the volume in each breath taken. The infant wears a special jacket which allows us to measure how well the infant can breathe without any stress to the patient.

£60,000

Multiple Washout System

This brand new technology allows measurement of the lung clearance index (LCI). An incredibly sensitive measure of lung function which will be invaluable for the long term monitoring of sick children.

£100,000

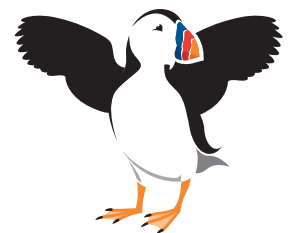
The Jaeger master screen paediatric lung function equipment

One of our major challenges is working out whether young wheezy children really have asthma or not. In older children and adults it is possible to use a small hand held device to measure lung function, but these instruments are not reliable in young children.

The Jaeger master screen paediatric technology will allow us to measure lung function from birth. It gives a computerised read-out which will allow us to assess how well a child has blown into a machine and it has incentive devices to encourage them along.

It will allow us to measure lung volume and the speed at which they can breathe out. It will also allow us to assess response to some of the asthma therapies and will greatly enhance the care we offer young children with lung disease.

£62,000



A children's lung function laboratory.

It is now common for babies born more than three months prematurely to survive, but many of these babies are left with significant chronic lung disease.

The Jaeger Aerosol Provocation System

In our older children it is sometimes very difficult to assess whether asthma is the underlying cause of their chronic cough or exercise induced breathlessness.

Simple lung function when measured in the clinic environment is often normal but we find it difficult to assess the child when their symptoms are intermittent and occur only under certain circumstances.

Provocation tests allow us to assess how the airways respond under different circumstances. Inhaling certain drugs and chemicals is known to induce wheezing. Asthmatic people wheeze far more easily than the average population.

The Jaeger system is the latest technology to allow us to perform aerosol provocation tests in a very safe manner. This will enable us to confidently assess our older children when we are trying to prove the diagnosis of asthma.

£ 13,000

The Analytix nitric oxide exhaled breath analysis

This system will allow us to analyse exhaled nitric oxide. A gas that is produced in increased amounts due to inflammation in the airways in exhaled breath to a higher level.

Effective treatment of the asthmatic inflammation will see reduction in the exhaled breath levels. It is extremely difficult to perform sophisticated lung function measurements in young pre-school children and this system allows us to assess inflammation levels and response to treatment without having to use sedation.

There is now evidence to suggest that this analysis improves diagnosis and allows the safe adjustment of therapy such as inhaled corticosteroids in young asthmatic children.

£ 20,000

Laptop computers for Paediatric Respiratory Nurse Specialists

Currently our nurse specialists use spirometers to measure lung function and then print out the results. To improve the quality of care we deliver, we want to monitor lung function each time we review the patient and compare the results on a computer. This will put us at the forefront of new therapeutic trials and provide long-term benefits for our patients.

£1,000 each unit



Yes! I want to help



Donations Form

giftaid it

Using Gift Aid means that for every £100 you give (at the standard rate of income tax), the Puffin Appeal will receive £128.20; helping your donation go further. Imagine what a difference that could make and it doesn't cost you a thing.

To donate to the Puffin Appeal simply complete this form and send it along with your donation to:-
The Puffin Appeal, No. 7 Beaufront Castle, Hexham, Northumberland NE46 4LT

Yes, I want to increase the value of my donation at no extra cost. I would like to make a donation to The Puffin Appeal using Gift Aid.

My Details

Title: _____ First Name: _____ Surname: _____

Address: _____

Postcode: _____

Email: _____

We would like to keep you informed about our projects and activities. However, if you would rather not receive information, please tick this box

I confirm that I would like to Gift Aid the enclosed donation of £ to the Puffin Appeal **Registered Charity No.1084369**.

- I confirm that I pay UK tax of an amount equal to or greater than the amount of tax at the 22% charity rate that the Puffin Appeal can recover on this donation.
- I would like to Gift Aid all donations I've made to the Puffin Appeal since 6 April 2000 and all donations in the future until I notify you otherwise.

(If you are a Higher Rate Tax Payer, we suggest that you may care to keep a record or copy of this form as, by its submission to HMRC through your Tax year end Self Assessment Tax Return, you can reduce your Higher Rate Tax liability for the year by 23.07p for every £1 of your donation.)

Signed: _____ Date: _____

For official use only: PAD Ref. No.

Yes! I want to help



Direct Debit Form

Instruction to your Bank or Building Society to pay by Direct Debit

Please allow one month between signing the form and the date of first payment.

giftaid it

Using Gift Aid means that for every £100 you give (at the standard rate of income tax), the Puffin Appeal will receive £128.20; helping your donation go further. Imagine what a difference that could make and it doesn't cost you a thing.

Yes, I want to increase the value of my donation at no extra cost. I want to start making a regular gift of £ a month until further notice to the Puffin Appeal.

Registered Charity No. 1084369

Name(s) of Account holders:

Bank/Building Society Account No.:

Branch Sort Code:

Name and full address of your Bank or Building Society

The Manager: _____ Bank/Building Society: _____

Address: _____

Postcode: _____

Signed: _____ Date: _____

E mail: _____

We would like to keep you informed about our projects and activities. However, if you would rather not receive information, please tick this box

Please tick here if you would the Puffin Appeal to reclaim the tax you have paid on any donations you have paid since 6th April 2000 and any future donation you make.



Please pay the Puffin Appeal Direct Debits from the Account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee.

I understand that this instruction may remain with the Puffin appeal and if so, details will be passed to my Bank/Building society.

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