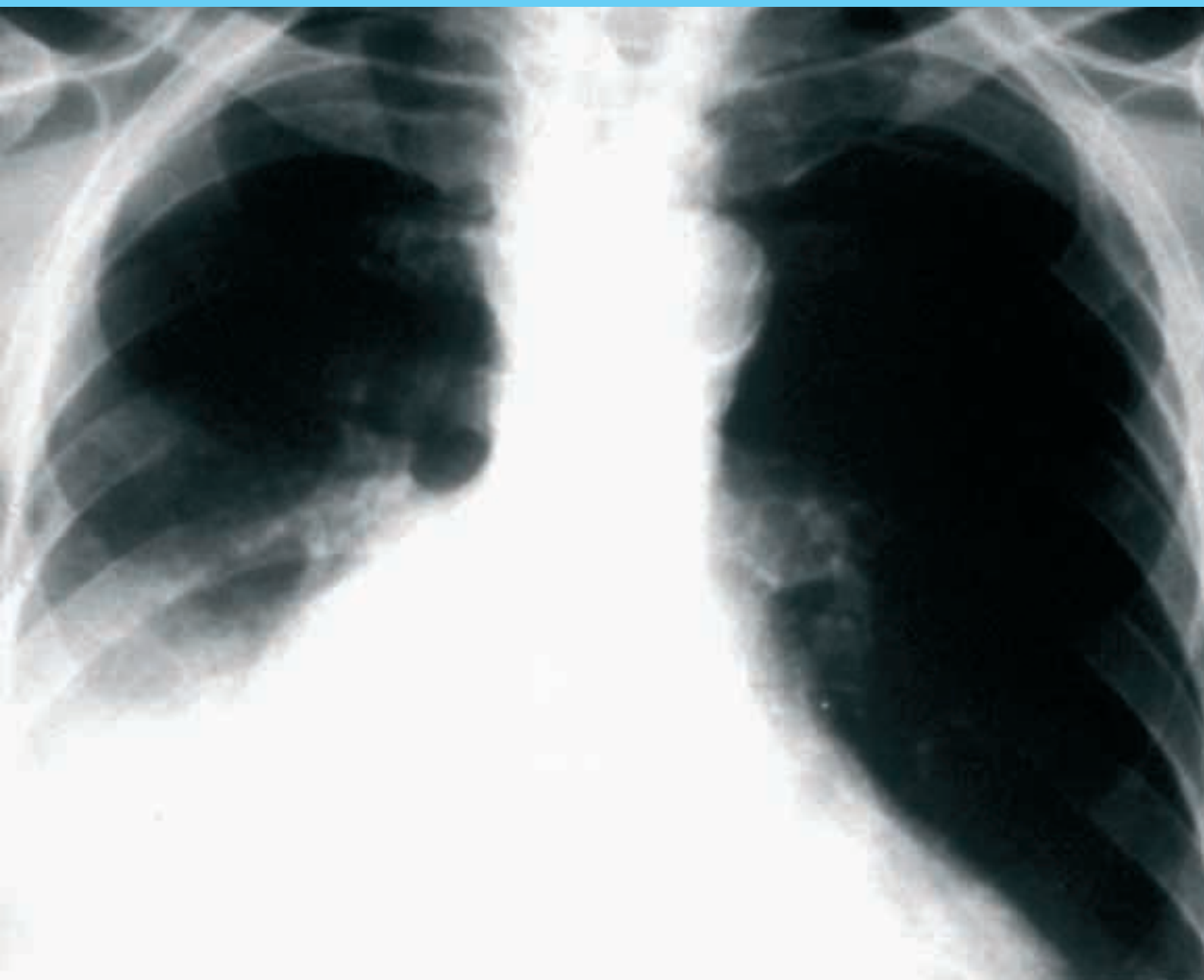


Lung Report III

– Casting a shadow over the nation's health



BRITISH LUNG
FOUNDATION

Contents

	Page
Biographies	4-5
Lifestyle and your lungs Dr Mark Britton, Consultant Physician, Ashford and St Peter's Hospitals, Chertsey	6-9
Asthma Dr Robert Angus, Lead Asthma Clinician, Aintree Chest Clinic	10-12
COPD Professor Peter Calverley, Consultant Physician and Professor of Respiratory Medicine, University Hospital Aintree	13-15
Lung Cancer Professor Stephen Spiro, Head of Respiratory Medicine, University College London Hospital	16-18
Respiratory Diseases in Young Children Dr Warren Lenney, Consultant Respiratory Paediatrician, University Hospital of North Staffordshire	19-21
Lung Infections Dr John Macfarlane and Dr Wei Shen Lim, Consultant Physicians, Nottingham City Hospital	22-25
Tuberculosis Dr John Moore-Gillon, Consultant Physician, St Bartholomew's and Royal London Hospitals	26-29
Mesothelioma Dr Mark Britton, Consultant Physician, Ashford and St Peter's Hospitals, Chertsey	30-32
Ambulatory Oxygen Professor Wisia Wedzicha, Professor of Respiratory Medicine, St Bartholomew's Hospital and London Medical School	33-35
Snoring and Sleep Apnoea Professor Neil J Douglas, Professor of Respiratory and Sleep Medicine, University of Edinburgh	36-38
Rarer Lung Diseases Dr Peter Cole, Professor of Respiratory Medicine, and Dr Athol Wells, Consultant Physician, Royal Brompton Hospital	39-42
The Role of Research Professor Moira Whyte, Professor of Respiratory Medicine, University of Sheffield	43-44
Conclusion Dame Helena Shovelton, Chief Executive, British Lung Foundation	45-46
About the British Lung Foundation	47

Foreword

AstraZeneca is proud to support the British Lung Foundation in the publication of Lung Report III. As one of the UK's leading pharmaceutical companies, AstraZeneca is focused on discovering new medicines that are designed to improve the health and quality of life of patients - medicines that are innovative and offer added benefits such as greater effectiveness or reduced side effects.

AstraZeneca is fully committed to making a real difference to the lives of patients with lung disease, particularly asthma, COPD and lung cancer. We believe that the treatment of lung disease should be given high priority by the government and the NHS.

The British Lung Foundation is the only UK charity that tackles all aspects of lung disease, which on average affect at least one member of every family. In sponsoring Lung Report III we hope to aid the British Lung Foundation in its work of disseminating information, supporting patients' needs and raising awareness of the need for new research into lung disease.

Rob Wood

Marketing Director
AstraZeneca UK

AstraZeneca 

Biographies

Dr Mark Britton was appointed Chairman of the British Lung Foundation (BLF) in September 1999. He is a Consultant Physician with an interest in Chest Diseases at Ashford and St Peter's Hospitals, Chertsey, and a previous Medical Director of the Trust. Dr Britton holds Honorary Senior Lecturer appointments at St George's Hospital and Imperial College, London. His research has been in the management and treatment of asthma and COPD, especially the clinical benefit of long-acting beta2-agonists. In addition he has had a long-standing interest in occupational lung disease, especially asbestos-related diseases including mesothelioma. He has been medico-legal adviser to the Treasury Solicitors and advises the Department of Trade and Industry as a member of the Medical Reference Panel for Coalminers, and has recently been appointed a member of the Industrial Injuries Advisory Council.

Dr Robert Angus began his training at Glasgow University initially in general internal and respiratory medicine in hospitals before completing his training in Liverpool. He has held a British Lung Foundation Research Fellowship and in addition has spent a period of attachment to academic intensive care units in London and Chicago. He was appointed to Aintree Chest Centre in January 1996. In addition to a general respiratory practice he was Medical Director of the hospital high dependency unit (HDU), which he helped constitute and establish. He is Lead Clinician for asthma in Aintree Chest Centre. He has also developed, in conjunction with the local community trust, a home care scheme (ACTRITE) for COPD. He is chairman of the education charity the Respiratory Education Resource Centres (RERC), based in Liverpool.

Professor Peter Calverley, an Edinburgh graduate, is Consultant Physician and Professor of Respiratory Medicine at University Hospital Aintree in Liverpool. He has been Chairman of the Scientific Committee and Executive Member of the BTS as well as Associate Editor of *Thorax* and Chairman of the British Lung Foundation Scientific Committee. He is an executive member of the Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD) and Chair of the GOLD Dissemination Committee.

Professor Stephen Spiro is Head of Department of Respiratory Medicine and Consultant Physician at University College London Hospital (UCLH). He has held the latter position since 1977 and formerly was Consultant Physician at the Royal Brompton Hospital from 1977 to 1994. He is also a former Editor of *Thorax* and a founder member of the European Respiratory Society, where he was President in 1996-7. He is President Elect for the British Thoracic Society 2003 and will hold the position of President in 2004. He has published more than 300 peer review articles, chapters, reviews, and books. Professor Spiro is also Chair of the London Lung Cancer Group, and a national clinical trials organisation for the management of lung cancer.

Dr Warren Lenney is Consultant Respiratory Paediatrician at the University Hospital of North Staffordshire and Associate Medical Director for Research and Development. He has been involved in paediatric asthma research for 30 years and has lectured and published widely on asthma and other respiratory diseases in children. He is Chair of the BLF's Information and Publications' Committee and represents the British Paediatric Respiratory Society on a number of British Thoracic Society committees. He is Editor-in-Chief of the *Paediatric Respiratory Reviews* journal.

Dr John Macfarlane is a Consultant Physician at Nottingham City Hospital and has had a long term research interest in the broad areas of the diagnosis, investigation and management of respiratory infections and pneumonia both in the community and in the hospital setting. He has lectured and published widely in this area and several of his research studies have been supported by research grants from the British Lung Foundation. He is Chairman of the BTS pneumonia guidelines' committee and also coordinated the committee producing the BTS/BIS SARS management guidelines.

Dr Wei Shen Lim has worked in the United Kingdom and Singapore. He trained in respiratory medicine in Nottingham and is now Consultant Physician at Nottingham City Hospital. His research interest is in respiratory infections particularly pneumonia. He is involved in the development of clinical guidelines for the management of pneumonia.

Dr John Moore-Gillon is a lung specialist working at St Bart's and the Royal London Hospitals. He is head of the Tuberculosis Service in Tower Hamlets, in London's East End, where TB rates are amongst the highest in Europe. He has written, lectured, and broadcast widely on the problems of TB in Britain and elsewhere. Dr Moore-Gillon has been involved with the BLF for over 15 years. He was its Chairman from 1994 to 1999, and succeeded Professor Malcolm Green as President in 2001.

Professor Wisia Wedzicha qualified from Oxford University and St Bartholomew's Hospital. She was appointed as a consultant at the London Chest Hospital in 1988 and then was appointed as Professor of Respiratory Medicine at Barts and the London Medical School in 2000. Her interests are in home oxygen therapy, COPD and exacerbations and ventilatory support. She was involved in writing a report on Domiciliary Oxygen Services and is the Chair of the British Thoracic Society Working Group on Oxygen Therapy. She is also the Editor in Chief of the respiratory journal *Thorax*.

Professor Neil J Douglas is Professor of Respiratory & Sleep Medicine at the University of Edinburgh, Director of the Scottish National Sleep Centre and Vice-President of the Royal College of Physicians of Edinburgh. His research interest focus is on the causation, consequences and treatment of sleep apnoea. He is a member of the Editorial Boards of the *American Journal of Respiratory and Critical Care Medicine*, *Sleep*, *Sleep Medicine* and *Sleep Medicine Reviews*.

Dr Peter Cole originally qualified at Charing Cross Hospital, then trained in Immunology at Middlesex Hospital, and in Infectious Diseases at the MRC Clinical Research Centre, Northwick Park. He entered Respiratory Medicine as Senior Lecturer at the National Heart & Lung Institute, Royal Brompton Hospital in 1974, where he set up the Host Defence Unit researching microbial pathogenesis and host responses in chronic airway infection. He was appointed Professor of Respiratory Medicine there in 1987.

Dr Athol Wells is a consultant respiratory physician in the Interstitial Lung Disease unit, at the Royal Brompton Hospital. He travelled from New Zealand in order to pursue his career in this field in a leading world centre. He works closely with a number of colleagues who are world leaders in the field (with expertise in CT interpretation, biopsy interpretation and clinical assessment, in scarring disorders of the lungs). He is the author or co-author of approximately 150 journal articles, review articles, editorials and book chapters.

Professor Moira Whyte has recently become Chairman of the British Lung Foundation's Scientific Committee. She is Professor of Respiratory Medicine and Head of the Academic Unit of Respiratory Medicine at the University of Sheffield and Honorary Consultant Physician, Sheffield Teaching Hospitals Trust. She trained at the Hammersmith Hospital/Royal Free Postgraduate Medical School and also at the Imperial Cancer Research Fund and the University of Nottingham.

Dame Helena Shovelton is Chief Executive of the British Lung Foundation. She combines this with her other responsibilities as member of the Competition Commission and Director of the Energy Saving Trust. She was previously Chair of the Audit Commission having been a Commissioner since 1995. She has been a member of the Better Regulation Task Force, Deputy Chairman of the Local Government Commission for England and a member of the Banking Code Standards Board. She chaired the National Association of Citizens Advice Bureaux from 1994 to 1999, has an MBA and is a Companion of the Chartered Management Institute.

Lifestyle and your lungs

By Dr Mark Britton

Everyday we expose our lungs to dangerous elements - we may live on a road with heavy traffic; we may smoke or spend time in a smoky atmosphere, such as a pub; we may work in a dusty environment or with chemicals, or with materials such as coal, MDF or asbestos. The lungs are the most fragile organ in the body and it is vital that we protect them whenever possible, otherwise debilitating conditions such as asthma, chronic obstructive pulmonary disease (COPD), lung fibrosis, lung cancer or mesothelioma can develop.

Smoking

Each year 120,000 people die as a direct result of smoking. Stopping smoking is the main way to give protection to the lungs. Some people find it harder than others to stop, but there are NHS smoking cessation programmes, which, working alongside Nicotine Replacement Therapy, make quitting an easier process. Just over a quarter of the UK population smoke and a similar number are ex-smokers.

The benefits to the lungs of stopping smoking are immediate - within 24 hours, the lungs start to clear themselves of mucus; within 72 hours the cough and breathing have begun to ease; and after 10 smoke free years, the risk of developing lung cancer is half that of a smoker. The only way to really protect yourself from the damaging properties of cigarettes is not to smoke. If you do smoke - stop, and more importantly for our children the message is - don't start.

Passive Smoking

Passive smoking - inhaling other people's second-hand smoke - also poses a risk to the lungs of people of all ages. In the UK it is estimated that 17,000 under five-year-olds are hospitalized each year as a result of passive smoking, and that 1,000 people die every year from exposure to other people's tobacco smoke. More and more places are not allowing smoking. Many restaurants, cinemas, transport infrastructures including most airlines, the Tube, and offices are smoke free. In some cities in America, state legislation has totally banned smoking in all bars and restaurants.

Until similar legislation is introduced in the UK, people can protect themselves to some extent from passive smoking by not sharing confined spaces, such as cars, homes or offices with a smoker, and by sitting in non-smoking areas in pubs and restaurants where possible. A non-smoker, living or working in a very

smoky environment over a prolonged period is a third more likely to develop lung cancer than a non-smoker who does not live or work with a smoker. Non-smokers should also support their friends and family who do smoke by encouraging them to give up, and continuing that support once they have stopped.

Cannabis

A new smoking danger was highlighted by the British Lung Foundation's report *Cannabis: A Smoking Gun?* published in 2002 - the respiratory risk caused by smoking cannabis. For the first time, a research review showed that people who smoked pure cannabis were putting their lungs at risk - cannabis is up to 50 per cent more carcinogenic (cancer causing) than cigarettes. Just three cannabis joints a day can lead to acute and chronic bronchitis and cause the same damage to the linings of the airways as 20 cigarettes. Ironically, many people smoke cannabis in the

belief that it is a 'safe' alternative and horrifyingly it has been estimated that almost a third of 15 year-olds used cannabis in 2002.

Further research by the British Lung Foundation in 2003 indicated that much more needs to be done to educate people on the risks of smoking cannabis - almost half of all adults who were asked if they thought cannabis was as dangerous as tobacco replied that it was not. In addition to this, research in 2002 by Life Education Centres found that 79 per cent of children believed cannabis was 'safe'. Only two per cent of children correctly understood that there were related health risks associated with smoking the drug.

The British Lung Foundation fears that this ignorance in children and adults will lead to an increase in the numbers of people with respiratory conditions, including

lung cancer and COPD in years to come as continual cannabis abuse takes its toll on the user's lungs.

The only way to protect your lungs from the damage of cannabis is not to smoke it. Whilst research is yet to be done on any passive smoking links with cannabis, it would be wise not to be in close proximity to people smoking cannabis for prolonged periods, especially in poorly ventilated spaces.

Alcohol and other drugs

Alcohol and most recreational drugs ultimately sedate and when taken to excess can result in loss of the cough reflex and aspiration. If associated with vomiting, the aspiration can lead to pneumonia and possibly lung abscess formation leading to long-term lung damage. Long-term misuse can also lead to impairment of the immune system

and result in increased susceptibility to respiratory infections, especially tuberculosis.

Air Pollution **Outdoor pollution**

Outdoor pollution from dust, traffic fumes and factory or power station smoke all pollute our skies and can damage our lungs when inhaled. It is estimated that up to 24,000 people die prematurely each year as a result of pollution, and those particularly at risk include people with a pre-existing lung condition, children and the elderly. One piece of research also suggested that lung cancer could be attributed to air pollution.

Dangerous pollutants mainly come from the smoke emissions from motor vehicles, especially those with diesel engines. These include smoke particles, especially the smaller particles (PM10s),



Much more needs to be done to educate people on the risks of smoking cannabis

which travel deeper into the lungs, sulphur dioxide, nitrogen dioxide, ozone, carbon monoxide, lead and acid air.

Another mode of transport which carries the risk of air pollution is London's Underground system. In October 2001, scientists from University College London warned that air quality in carriages and at stations was up to 73 times worse than at street level. Their research also found that travelling for 20 minutes on the Northern line through central London had the same effect on the lungs as smoking a cigarette.

You can protect your lungs by limiting your exposure to these harmful pollutants for the least amount of time possible. If you have to be exposed to traffic fumes, for example if you are a cyclist or courier - wear a mask.

Indoor air pollution

Similarly, some lung irritants pollute our workplaces and homes and can be harmful when they are in confined spaces. These include tobacco smoke, animal fur and dusts, mould, mildew and bacteria, house dust mites, cooking and heating appliances and asbestos. Other dangerous substances include formaldehyde gas, toxic chemicals present in some household cleaning products, paints, solvents and pesticides, and radon gas which can be released from certain types of rock and seep into the house in specific areas of the UK.

Adding insulation and double glazing in an effort to save on energy costs can trap contaminants inside the home. Adverse health effects caused by indoor air pollution are often referred to as 'sick building syndrome'.

You can protect your lungs by not allowing anyone to smoke in your home, not keeping pets

indoors, ensuring all rooms are ventilated, washing bedding frequently, hoovering thoroughly, avoiding the use of aerosols and using non-toxic products. Also make sure that all wood and coal burning stoves are properly installed, and chimneys inspected regularly for soot build-up. Specialist help can be sought for dealing with formaldehyde gas, gas or propane appliances, radon gas and asbestos.

Exercise

Exercise can help keep the lungs healthy by improving the capacity of the lungs, which improves one's overall well-being. However, some people may develop exercise-induced asthma, which means they become wheezy and breathless when they exercise. There is no reason why this condition should limit physical activity or achievement, but it will require proper asthma treatment. This is highlighted by the achievements of a world class athlete, the runner Paula Radcliffe, who has exercise-induced asthma.

Swimming has always been thought of as being a good sport for people with chest disease. However recent research has suggested that the increase in asthma may be due to exposure to chemicals released as a result of chlorine mixing with sweat or urine.

You can protect your lungs by not jogging in high-density traffic areas, and by exercising to increase your fitness levels and thus avoiding being overweight. Chemicals other than chlorine are now being used to keep swimming pools clean and hygienic.

Diet

We know that what we eat and drink can affect our health - and this includes our lungs. Some researchers have found a

connection between the diet of a pregnant woman and her baby's chances of developing wheezing, allergy and asthma. A maternal diet low in vitamins gives the baby little protection against sensitisation to allergens, a frequent cause of lung problems. Research in Scotland and Saudi Arabia showed a similar link between asthma and a low-vitamin diet.

Obesity, which stems from a combination of poor diet and lack of exercise, causes people to become more breathless in everyday activities like walking, running to catch a bus or going up stairs. Increased weight increases the energy and oxygen required to carry out these activities, as well as limiting the ability of the lungs to expand resulting in an increase in the work of breathing. Excess weight also results in poor lung expansion and poor lung clearance leading to atelectasis (postural lung collapse) at the bases of the lungs, resulting in the lungs being less effective. One condition where the impact of obesity is even more clear-cut is sleep apnoea, described in detail by Professor Neil Douglas later in this report.

You can protect your lungs by eating sensibly, monitoring your weight and ensuring you take regular exercise, even if it is only a brisk walk for 20 minutes.

Travel

Going on holiday abroad can sometimes put the traveller at risk of certain respiratory conditions.

Infectious diseases have always been a risk for the traveller. A new respiratory disease called SARS (Severe Acute Respiratory Syndrome) infected more than 8,500 people worldwide in 2003 and led to 800 deaths in just a few weeks. The condition was initially seen in China, but spread rapidly to

Singapore, Hong Kong, Taiwan and Canada as a result of the frequency and ease of air travel.

Tuberculosis can be contracted by visits abroad to developing countries, particularly Asia, South America and Africa. Travellers should ensure where possible that they have received the BCG vaccination either as a baby or during secondary school.

Deep vein thrombosis (DVT) from long haul travel occurs when a blood clot develops in the legs as a result of inactivity, and dehydration, exacerbated by alcohol consumption. The clot may then travel to the lungs - this is a pulmonary embolism. Small clots may cause no symptoms at all, possibly just some pleuritic chest pain, medium ones result in sudden breathlessness, and sometimes the clot is sufficiently large to obstruct the lung circulation, leading to collapse or even sudden death without warning.

You can protect your lungs when travelling by following the advice of the Foreign Office about any outbreaks of respiratory conditions such as SARS. DVT can be prevented by staying active when on a flight by walking about, moving your feet when seated, drinking plenty of water, and wearing special support socks which encourage circulation in the legs.

Conclusion

Lifestyle changes can protect the lungs from various insults, which can lead to serious debilitating or even fatal lung disease. Making the effort to make these changes is a small price to pay to avoid severe breathlessness resulting in isolation and a marked reduction in quality of life in the latter years. Protect your lungs.

Research:

Lifestyle has a big impact not only on health in general but also on lung health in particular. Smoking, exercise and diet are all factors that play a role in determining lung health and the Foundation has invested about £2 million looking into the various issues.

Professor William MacNee at the University of Edinburgh and his team have undertaken a number of studies investigating the effect of cigarette smoking on lung health. Their work focused on oxidative and antioxidative imbalances in the lungs of smokers and has resulted in the identification of a cellular component responsible for the regulation of the destructive process caused by smoke particles.

A study led by Dr Sally Singh from Glenfield Hospital in Leicester on lung disease and exercise has found that a four week programme of pulmonary rehabilitation was just as effective as a seven week programme. This means that significantly more people could benefit from this form of rehabilitation whilst at the same time saving the NHS valuable resources.

A nutritional study, carried out by Professor John Britton at Nottingham City Hospital and his team, found that asthmatics have higher levels of fatty acids in their diet which are thought to contribute to their asthma. Further research is now necessary to establish whether dietary changes could be beneficial to people living with asthma.

Sources include BBC, Action on Smoking and Health, Foreign Office, GLA

Asthma

By Dr Robert Angus

Asthma is the major long-term respiratory disorder in the UK. About 3.7 million adults and 1.4 million children are currently receiving treatment for asthma.

What is asthma?

Asthma is a chronic condition which primarily affects the air passages in the lungs and at present there is no cure. Classic symptoms include breathlessness, tightness in the chest, cough and wheezing. The airways in the lung are characterised by inflammation and increased irritability. These two features lead to airway narrowing which in turn causes many of the symptoms of asthma. This happens in a variable fashion but may be worsened by triggers such as infection, exercise and allergens. Although inflammation may reverse spontaneously or in response to treatment, sometimes episodes can be severe, known as an asthma attack and may require an increase in treatment and emergency healthcare.

How big is the problem?

With so many sufferers, asthma poses a major problem to patients, the healthcare system and the country as a whole.

The burden on patients is very real. Several carefully performed studies have shown that asthma has a major impact on many individuals; 71 per cent of patients experienced symptoms at least once a week and 42 per cent had symptoms every day or on most days. 42 per cent reported that asthma affects everyday life in terms of the things they can and cannot do and 33 per cent

reported that their sleep had been affected by their asthma. What is more, one quarter had sought emergency help for their asthma in the previous year.

The work-load for primary care is substantial and a study of GP consultations in 2000 showed that there were 3,864,921 consultations for asthma; 29 per cent of these were in patients under 14 years of age, indicating a disproportionate attendance in this group. There are still a large number of hospital admissions due to asthma with 73,929 in 1999 - 46 per cent of which were children. Patients who experience these asthma attacks present a particular challenge as their asthma is often more difficult to control, with those who require emergency care costing three times more than that of a patient with "stable" asthma (£381 against £108 respectively). In fact, half of all the asthma healthcare costs occur from one fifth to one quarter of patients who experience attacks in a year. Strategies optimising prescribing, adherence to treatment and teaching patients how to respond to attacks by offering personal action plans may have a significant impact on this.

Healthcare costs are only part of the total cost of asthma in the UK with the remaining costs borne by society. It is estimated that the total costs of this disease are in the region of £2,237 million. Lost

productivity accounts for £1,226 million, with direct costs to the NHS of around £850 million and to the then Department of Social Security of £161 million.

Are we seeing progress?

The last 10 years have seen some progress at a time of high prevalence in the UK. Hospitalisation rates in the under 14 age group fell between 1990 and 2000, reversing the decade on decade rise between 1960-1990. Overall deaths have also declined over the past decade although 1,500 people still die from asthma each year, including 25 children and 500 adults under 65 years of age.

What is the health care system's response to asthma?

The United Kingdom has a higher asthma burden than many other countries. For example, in the International Study of Asthma and Allergies in Childhood the UK had the highest incidence of severe wheeze at 14.1 per cent of the childhood population in comparison to 4.8 per cent in Sweden. The UK was one of the first countries to develop treatment guidelines and 2003 saw the publication of the first British evidence-based guidelines produced by the British Thoracic Society (BTS) and Scottish Intercollegiate Guidelines Network (SIGN).



We need more research to understand the basic mechanisms behind asthma

Within the field of pharmacological management the pharmaceutical industry has developed a range of therapies which can significantly improve asthma control and allow most patients to carry out their everyday activities without interference from their symptoms. Treatments are largely based around bronchodilator and inhaled steroid inhalers as well as anti-leukotrienes. Advances in combination treatments may reduce the number of inhalers a patient requires. Treatment success largely rests with patient adherence to therapies. Future new treatments such as the novel anti-IgE therapy are also likely to offer improved asthma control in selected patients.

Although targets for care have been included in the 2003 GP contract, it is perhaps disappointing that there has been no specific and comprehensive Department of Health initiative aimed at tackling a problem which affects so many despite treatment for mild to moderate asthma being effective.

Why is there no cure?

Our understanding of the mechanisms underlying asthma such

as the cells, chemical signalling, changes of structure in the airway and genetics has greatly increased. However at present we still do not fully understand why asthma inflammation is triggered and persists. We also do not completely understand the irritability of the airway smooth muscle. So, although treatments can reduce inflammation, hyper-responsiveness and airway narrowing, patients remain susceptible to the condition as we cannot remove or switch off these components of the disease. With the exception of occupational asthma, where early removal or avoidance of the agent triggering asthma can prevent the establishment of the disease, treatments are aimed at effectively controlling the disease in the individual and minimising its impact.

Goals

Goals for asthma care have been suggested by the Global Initiative for Asthma (GINA). These include;

- minimal (ideally no) chronic symptoms including nocturnal symptoms
- minimal (infrequent) episodes
- no emergency visits
- minimal (ideally no) need for as-needed rescue treatment
- no limitations on activities, including exercise
- medicine should cause no adverse effects
- lung function (peak flow) should be optimised with minimal variation

Against these goals the UK has some way to go before it can be said that asthma has been conquered. Towards this aim the 2003 evidence based BTS/SIGN asthma guidelines have particularly emphasised the need to educate and equip patients to manage their own asthma through the use of Personalised Asthma Action Plans. These plans help patients to recognise symptoms, adjust their treatment and seek emergency care if necessary.

What action is needed?

Asthma remains a major problem and if the situation is to be improved, it is vital that there is progress in both the research field and in our delivery of care.

Research needs

1. Further research is required to understand the basic mechanisms underlying asthma so that strategies for prevention and better treatments can be developed. This research will require cooperation from basic scientists as well as clinicians and patients.
2. Asthma remains a disproportionate burden in children particularly in very young children under the age of two. The diagnosis remains a challenge - there are no reliable tests for this age group.
3. In adults there are a group of treatment resistant asthmatics who remain problematic.



Service needs

1. Comprehensive services for asthma care do not exist and these need to be developed. In 2003 the Respiratory Alliance produced a guide to commissioning services called "Bridging the Gap". Healthcare purchasers should be encouraged to embrace the principles outlined.
2. Guidelines emphasise the importance and effectiveness of Personalised Asthma Action Plans (PAAPs) yet the last major survey in the UK suggested only three per cent of patients had written self-management plans. All healthcare professionals involved in asthma care need to be equipped to educate patients appropriately. It is important that PAAPs are coupled with appropriate pharmacological treatments and sufficient patient education to ensure that they are effective.
3. Although evidence based guidelines exist for asthma care, these remain voluntary. Future guidelines would benefit from official support.

Case Study:

**Kate Hunter,
30 from North London:**

"I was diagnosed with asthma when I was seven years old, after experiencing some breathlessness. As I was diagnosed at such a young age, I really adapted quite quickly to living with my asthma, and have learned how to manage it.

I take a preventer inhaler every day, and also have a reliever inhaler with me all the time in case I have some wheezing. I also monitor my own peak flow at home, and have the flu jab every autumn.

My asthma has never stopped me doing anything - I recently did a 35 mile bike ride - but I do need to be sensible. I have learned that certain foods can trigger an asthma attack, and that very smoky atmospheres, like pubs, exacerbate my asthma. I also find when I am on holiday in humid places it is harder to breathe, and I can't use a sauna or steam room.

I do make sure I exercise regularly and since childhood have found swimming very beneficial - it expands my lung capacity and makes breathing easier.

As well as my cycling I also do Pilates, which makes you concentrate on your breathing. I have an active social life - I like going to the cinema with friends, shopping, going to the pub and going to a club with my boyfriend - and I work full time managing a conference centre. I live life to the full - I'll not let my asthma stop me having fun!"

Research:

The Foundation has spent more than £5 million on over 100 projects investigating different aspects of asthma. The research undertaken spans basic research including investigations into the role of specific cells and signalling molecules causing the characteristic symptoms of asthma and possible therapeutic treatment using gene transfer. On the other side of the research spectrum, the BLF has funded clinical investigations, such as those carried out by Professor Peter Barnes and his team at the National Heart and Lung Institute in London. This concentrated on the levels of nitric oxide in the breath of people living with asthma and COPD. It found, for the first time, a simple non-invasive way to measure the severity of lung inflammation. This test can monitor the success of treatments such as steroids and antibiotics.

Research has also been done on asthma management. A study lead by Dr Hilary Pinnock from the Whitstable Health Centre in Kent compared the use of telephone consultations with face-to-face consultations for reviewing the health of adult asthmatics. The project showed that telephone reviews are an effective and safe alternative to face-to-face consultations in addition to being almost twice as quick. This indicates a possibly more efficient way of providing care for asthmatics which would also be more cost-effective to the NHS.

Sources include National Asthma Campaign, BTS/SIGN Asthma Guidelines

COPD

By Professor Peter Calverley

Most people with COPD attribute their symptoms to 'smoker's cough' and do not seek medical help until it is too late for appropriate treatment.

What is COPD?

Chronic obstructive pulmonary disease (COPD) is a common disorder in which lung damage over a long period of time impairs the flow of air in and out of the lungs and causes breathlessness.

Two related processes - chronic bronchitis and emphysema - cause COPD. Both are closely related to cigarette smoking. Chronic bronchitis is characterised by recurrent cough and production of sputum, due to an abnormal increase in the number of mucus-producing glands in the large airways. By contrast, the hallmark of emphysema is progressive destruction of the alveoli, the gas exchanging air sacs in the lungs.

COPD progresses slowly and sufferers do not normally seek medical attention until their disease is quite advanced. Although smokers in their late 20s may have early COPD, they often attribute symptoms to 'smoker's cough' and modify their daily activity to avoid exercise which provokes breathlessness. By the time they seek help, it may be too late for appropriate treatment. A huge awareness campaign for young smokers is therefore vital to stop this occurring.

How common is COPD?

Figures estimate that about 1.5 per cent of the population have been

diagnosed with COPD - a total of 900,000 people. This rises to two per cent in men aged 45 to 65 and seven per cent in men over 75. Men are more likely than women to have COPD, although the gap is closing. However, the real picture is probably much worse. Studies indicate that as few as one sufferer in four with COPD is recognised.

What are the problems for people with COPD?

The overall quality of life for people with advanced COPD is about four times worse than for people with severe asthma when the two are being assessed using similar quality of life questionnaires.

The problems of restricted mobility are compounded by social isolation and poor self-esteem. A Breathe Easy survey found that 90 per cent of COPD patients were unable to participate in socially important activities such as gardening or going dancing, two-thirds were unable to take a holiday because of their disease and one-third had socially disabling breathlessness.

Britain has one of the highest death rates from COPD in the European Union. In 1994, COPD accounted for more than five per cent of all male and three per cent of all female deaths. More recent figures show that about 27,000 people die of COPD and allied conditions each year.

What is the cost of COPD?

In an average UK health district serving 250,000 people, there will be 14,200 GP consultations every year for COPD. Hospitalisations with this disease have increased by 50 per cent between 1991-2000. Hospital costs due to COPD in 2001-2002 amounted to £587 million in the UK. More than five times the number of bed days are spent due to COPD compared with asthma (see figure 3). An audit of hospital admissions in Merseyside showed that 12.5 per cent of patients admitted as emergencies had COPD.

It is estimated that COPD causes at least 20.4 million lost working days among men and 3.5 million days among women every year: more than any other respiratory condition.

What advances have been made in research?

- Studies of birth records dating back to the 1930s have suggested that infant nutrition and birth weight may be important factors that 'pre-programme' an individual to be susceptible to the effects of cigarette smoke; this may explain why only one in four smokers develop COPD.
- British Lung Foundation sponsored research has shown

Relative impact of asthma and COPD on average UK health district

	Hospital admissions	Inpatient bed days	General practice consultations
Chronic bronchitis, emphysema and COPD	680	9,600	14,200
Asthma	410	1,800	11,900

Figure 3- Reproduced by permission of the British Medical Journal

how smoking causes white blood cells to migrate into the lungs where they may cause damage.

- We now understand that emphysema results from excess amounts of protein-destroying enzymes released by cigarette smoke that destroy the lungs. Other oxidizing chemicals in cigarettes may accelerate this damage. The role of environmental pollution in amplifying this response is being studied in another BLF funded project.
- Patients with COPD are no longer thought of as 'burnt-out' cases. Inflammation damaging the lung persists, even when they stop smoking. Understanding why this occurs is vital if we are to help these patients in future. Treatment with inhaled corticosteroids does not modify the progress of disease but does reduce the number of exacerbations, a process currently being investigated by BLF sponsored research.
- Research funded by the BLF has contributed enormously to our current understanding of exacerbations of COPD, how long they last and how they are caused.

What are the priority areas for research in the 21st century?

In the long run the most effective treatment will be to limit cigarette smoking. However, so many people have been damaged by cigarettes that, even if they disappeared tomorrow, there would still be a major need for research. In fact

smoking is not decreasing in dramatic amounts - 10 million people in the UK still smoke with as many as 450 children taking up the habit every day. There are five key areas:

1. Defining the size of the problem

Community-based studies are needed to determine the number of people with COPD and precisely how they are affected. We need more information about the economic consequences in order to persuade health purchasers and government to provide appropriate care for this neglected group of patients. Studies are needed to improve the detection of COPD in the community. More research is needed into pollution and COPD.

2. Understanding the mechanisms of diseases

Both oxidants in tobacco smoke and enzymes released by activated white blood cells contribute to COPD: studies are needed to help determine the relative importance of these factors and show whether the damage is continuous or episodic. New non-invasive markers of disease activity have been developed but we urgently need to understand which ones predict disease progression and whether they can identify patients particularly prone to exacerbation. Using these tests should allow us to speed up the rate of development of new treatments for COPD.

Laboratory research on how air pollutants such as ozone and

nitrogen oxides interact with models of COPD will provide important information relevant to air quality legislation.

We also need to understand which cells and indicators contribute most to disease progression and what the key steps are in this process. The British Lung Foundation is currently funding projects on this topic.

3. Improvements in treatment and disease management

Pharmacological treatment options have expanded in recent years and significant improvements in quality of life and exacerbation control can now be achieved with inhaled corticosteroids/long acting beta agonist combinations and tiotropium. Severe COPD patients in particular have benefited from recent advances.

The role of many new treatments needs to be evaluated including: the value of alpha-1-antitrypsin therapy in those who lack this enzyme, the role of new anti-inflammatory and antioxidant treatment, and the potential value of modifying white blood cell behaviour to reduce lung damage.

Further research is needed in the following areas:

- We need to develop better methods of optimising treatment in individual patients and predicting the magnitude of benefit from current inhaled treatments.
- The treatment of breathlessness improves exercise tolerance and quality of life but we need to

understand which factors are important in the individual patient and develop ways of identifying these. Quality of Life questionnaires need to be simplified to make them more useful to the patient. The British Lung Foundation has already funded a project looking at whether assisting breathing by a special machine during exercise can improve the patient's ability to undertake everyday activities.

- Lung rehabilitation programmes are growing in popularity but we need to understand which elements are key to their success, how they can be most readily implemented and how best to maintain the improvements they produce.
- Using a special ventilator has been shown by BLF research to improve the levels of oxygen in the blood but which patients should receive this treatment needs to be properly determined.

4. Use of healthcare resources

Primary Care teams need access to more information about the best ways in which COPD can be managed and recognised. The development of evidence-based therapies is central to the British Lung Foundation's activities in this area as is the encouragement of patient involvement in service planning. The availability of hospital-at-home services and the most effective way to implement them, is an important goal. BLF campaigning has led to the provision of portable oxygen in the community but the best way to assess patients for this treatment needs to be carefully studied.

5. Disease management

Understanding the causes of exacerbations of COPD and specifically whether continuing respiratory infection should be identified and eradicated is an important task for the coming years.

Case study:

Janice Matthews, 51 from Cheshire

Janice Matthews aged 51, from Warrington, was diagnosed with COPD in the late 1980s. She is an ex-smoker who smoked around 20 cigarettes a day and has appeared in a 'Don't Give Up Giving Up' television advertising campaign, that encourages smokers to get support by calling the NHS Smoking Helpline.

She says, "I started smoking at 12 because everyone was doing it. My children used to beg me to quit, but cigarettes were a drug that ruled me. But now I don't have any control over my life. They say life begins at 40, but mine just went into a downhill spiral. I can't even talk or walk without oxygen."

COPD has had a huge impact on Janice's personal and family life. She now travels in a wheelchair and uses 24 hour oxygen.

"When I finally gave up smoking, I was annoyed how easy I found it - the patches did it for me in the end. I wished I'd stopped smoking a lot sooner, but I kept saying 'I'll give up next month'. I'd say to anyone still smoking - just get the help you need and stop now."

Research:

Over the years the BLF has funded almost 60 projects totaling £3.7 million on research into COPD. BLF researchers have made significant contributions to the understanding of the disease and are, in some research areas, regarded as world leaders. Investigations carried out by a team led by Professor Wisia Wedzicha from St Bartholomew's Hospital in London for instance, have highlighted the importance of viral infections in causing the characteristic COPD flare-ups (exacerbations) as well as associating exacerbations with heart disease. Recent research by this team has identified that CT scans on COPD patients showed that a larger than expected number of people additionally suffered from bronchiectasis which directly influences the severity of their flare-ups. This could have direct repercussions on the type of treatment and monitoring these patients should receive.

A variety of projects have also been carried out on pulmonary rehabilitation. For instance, BLF funded research led by Dr Anita Simonds at King's College Hospital in London which has found that using a new type of ventilator can significantly increase the exercise tolerance of people living with COPD. The ventilator has made it possible for people to exercise on a treadmill or exercise bike much more intensively

Sources include LAIA, Action on Smoking and Health, NHS

Lung Cancer

By Professor Stephen Spiro

Lung cancer kills more men than any other cancer in the Western World and is almost equal in the number of deaths in women as from breast cancer. In fact, in some parts of Scotland and North East England, lung cancer deaths have overtaken those of breast cancer as many of the people who get lung cancer in a year in the UK will die of it - the average survival is only about nine months. Only 10 per cent of patients with this disease have a sufficiently localised presentation of the tumour to allow its surgical removal.

Lung cancer comprises two main types. Small cell lung cancer is entirely smoking related, very aggressive and hardly ever operable but responsive to cytotoxic (cell-damaging) anticancer chemotherapy. Although many people will respond to chemotherapy and, in appropriate cases, subsequent radiotherapy, the disease returns in most cases and only five to 10 per cent of patients will be cured.

Non-small cell lung cancer comprises of squamous, adeno and large cell types. Squamous and large cell cancer are almost entirely smoking related whilst adenocarcinoma is the only cell type that develops in non-smokers. Altogether, 90 per cent of lung cancers occur in people who smoke.

Who still smokes?

Smoking rates have fallen very slowly over the last ten years and, currently, 28 per cent of adult men and women are smokers. There is a slow but sustained rise in those smoking before their mid-20s and more young

women than young men smoke. The recent decline in smoking which has been clearly seen in men has not been so marked in women and, indeed, the trend to decreasing cigarette consumption in women appears to have reversed recently. Smoking is increasing alarmingly among children: up to 45 per cent of children under the age of 16 have smoked at some time and approximately 20 per cent claim to be regular smokers. Parental influence is very important in this area.



More young women smoke than young men

What are the symptoms of lung cancer?

Symptoms can arise from the lung itself due to the tumour ulcerating one of the large central breathing airways. The symptoms produced will include a cough or change of cough in those people who already have chronic bronchitis, coughing up of blood (haemoptysis), wheezing, chest infections and pneumonia. If the tumour affects the tissues of the lung itself, pneumonia is more common as is the development of fluid around the lung (pleural effusion). Central chest pain of an aching nature is reported in up to 40 per cent of cases.

If the tumour spreads from the lung to the centre of the chest (the mediastinum), symptoms can include hoarseness due to entrapment of the nerve to the left vocal cord where the nerve enters the chest. Engorgement of the draining veins from the head, neck and upper body (superior vena cava) causes facial swelling and swelling of the upper arms and

torso due to superior vena caval obstruction. Enlarging glands around the main airways in the mediastinum can compress the oesophagus and cause difficulty in swallowing. Other symptoms may be due to direct involvement by the tumour on the pericardium which lines the heart and entrapment of the nerves to the diaphragm, causing breathlessness.

Symptoms can also occur due to the tumour spreading outside the thorax into other parts of the body, such as the brain, the bones and the liver. Lung cancer, therefore, causes many symptoms and there are even additional symptoms due to hormones produced by the primary tumour itself.

Who are at risk?

Clearly, the risk for developing lung cancer is among the smokers. Once somebody has smoked the equivalent of 20 cigarettes a day for 20 years, their chances of getting lung cancer rises with the number of cigarettes smoked per day and the number of years of smoking. 20 cigarettes a day for 40 years gives a 55-fold increase in the risk of developing lung cancer compared to the non-smoker. Because of the slow growing nature of lung cancer, one cannot be certain that a patient will not develop the disease, having quit smoking, until approximately 12 years have passed. The earlier individuals quit, therefore, the better their chances of avoiding this disease.

Treatment

The treatment that offers the biggest chance of cure is lung surgery. Removal of a lobe of the lung or the whole lung (pneumonectomy) depends on the situation of the tumour and whether it has spread to lymph nodes that drain the lung. In large surgical units, approximately 30 per

cent of all patients who are offered a curative resection will ultimately be shown five years following their surgery to be cured.

Unfortunately, many of the tests used to identify the spread of a lung tumour and its seedlings are not sensitive enough to show seedlings until they are of a quite substantial size. Therefore, patients will go to surgery with undetected seedlings in their body which ultimately may cause their death.

The staging of lung cancer could be greatly improved with the advent of positron emission tomography (PET) scanning. This scan uses a glucose radio-isotope which is injected into the body and the individual is then scanned some hours later. The glucose used in PET scanning is taken up by living tumour tissue and will highlight tumour islands that are greater than 8mm in diameter. This living investigation is far more accurate than CT scanning and bone scanning and may seem as if it will improve the chances of identifying disease in patients going to surgery where the disease had not been detected by currently available tests. Whilst in the United States, there are already 700 PET scanners with this number likely to increase by 80 per cent in the next three years, the UK has just six PET scanners, only three of which are available to the NHS. A huge amount of effort needs to be made to get PET scanning accepted as a technique for the staging of lung and other cancers.

Chemotherapy and radiotherapy

For small cell lung cancer, chemotherapy is the treatment of choice for all presentations. Approximately half the patients will have a substantial response and another third a lesser response. Although only a small number of

patients will be cured, their improvement in quality of life and symptoms makes chemotherapy well worthwhile.

In non-small cell lung cancer, chemotherapy for advanced disease also improves quality of life, although does not sustain life for longer than, on average, three to four months, compared to not giving chemotherapy. Chemotherapy is also likely to be a useful additive to the role of radiotherapy which, until recently, has been the treatment of choice for disease that is too advanced for surgical removal but still confined and localised within the chest.

What advances have been made over the last decade?

Apart from PET scanning, there is considerable interest in looking at biological growth modifying agents. These are agents that will affect the structure upon which cancer grows, for example, blood vessel formation (angiogenesis) and blocking receptor sites for key substances vital to the growth of tumours. Studies are underway investigating these substances worldwide and three such studies started in the UK in 2003.

The organisation of cancer care through cancer networks, cancer units and multidisciplinary teams now allows every patient suspected of lung cancer to be seen by a chest physician within two weeks and diagnosed within a further two to four weeks. Every case of cancer is now discussed in a multidisciplinary team format including a respiratory physician, a medical and a clinical oncologist, a surgeon, a radiologist, a pathologist and a lung cancer specialist nurse. This allows optimal discussion of the best way to treat the patient and also allows the patient to meet his/her carers and treaters within a single clinical environment.

Each NHS Trust now has specialised smoking cessation clinics which play a key role in trying to prevent the continuation of cigarette use.

What are the priorities for research?

1. Prevention

Efforts continue to identify genetic risk factors for the development of lung cancer so that high risk groups might be identified and selected for special efforts at smoking cessation and prevention.

2. Screening for lung cancer

There is considerable interest in whether screening using CT scanning might be better than the disappointing results of the 1950s and 1960s, using six monthly or annual chest x-rays for smoking volunteers. Pilot studies are in progress in many parts of the world looking at whether spiral CT scanning identifies cancers in high risk populations at a much earlier stage than a chest x-ray would. The hypothesis being that, if the cancers are caught at an earlier stage and are removed by surgery, this may cure more people compared to the way cancers present to their doctors when symptoms have already become established. Large randomised controlled trials will be needed to assess the benefit of CT scanning as a screening tool in lung cancer and the answer will not be known for a decade.

3. Treatment studies remain essential and these need to be large scale studies which will determine whether the addition of one treatment to another established treatment advances the survivorship of patients with lung cancer and also improve their quality of life.

These studies include;

- The addition of chemotherapy to patients before or after surgery.

- The addition of chemotherapy to radical radiotherapy given either concurrently with or before the radiotherapy.
- The addition of biological growth modifiers to patients with advanced disease undergoing cytotoxic chemotherapy.
- The use of biological growth modifiers on their own in patients whose disease is too advanced or the patient too ill to tolerate cytotoxic chemotherapy.

Lung cancer remains one of the most under-funded and under-researched important diseases in the world. In the UK, only three per cent of research monies going to cancer go to lung cancer. This is an area that needs urgent attention and support.

Case study:

Gavin Wells, 43 from Leicestershire

"I am 43 years old and live in Leicestershire with my partner and children. I earn my living as a rigger and build stages for the theatre and music industry as well as shows for corporate events and festivals.

I am an ex-smoker and I smoked for the best part of 20 years. Ironically, I had managed to quit smoking 5 weeks before I was diagnosed with lung cancer.

My diagnosis followed a car accident in August 2002. I had no symptoms at all so I was lucky to be diagnosed very early. I ended up having emergency surgery - a lobectomy on my left lung. If they hadn't caught the cancer in the early stages I dread to think what might have happened.

I am currently in good health and require no pain relief although there is some residual pain from surgery. I am on the

whole recovering well and I do not require any oxygen.

Overcoming the psychological effects of a cancer diagnosis for me and my partner and children has been tough. Thankfully we are a strong family and understand the healing process of such trauma. Some days are good and some are bad."

Research:

Recent NCRI figures show that research into lung cancer is one of the most under-funded cancers. Lung cancer results in the largest number of deaths from cancer in the UK. As a result the BLF made lung cancer a particular research priority.

Ongoing research led by Dr Tariq Sethi at the University of Edinburgh Medical School examines the interaction between lung cancer cells and cells of the immune system. There has not been a lot of previous research in this area in the past and BLF funded researchers are one of the few groups in the world to look at this.

Another group of researchers headed by Dr Kenneth O'Byrne at the Leicester Royal Infirmary is looking at whether the presence of a specific cellular receptor molecule (called the epidermal growth factor receptor) that is present in 50 to 70 per cent of all non-small cell lung cancers can predict which patients will benefit most from a new type of lung cancer treatment which focuses on drugs that prevent the activity of this receptor molecule.

Respiratory Diseases in Young Children

By Dr Warren Lenney

The large airways are formed by the 16th week of pregnancy but development of other parts of the lung continues up to our eighth birthday. Although the lungs are then mature, they continue to grow in line with the rest of the body until our late teens.

Respiratory diseases are very common in babies and infants long before the lungs are mature, with 20,000 babies alone being admitted to hospital in the winter months each year with respiratory syncytial virus. Not only do respiratory diseases cause symptoms, serious illnesses and worry parents, they may cause damage to the developing lungs which is permanent and may be the main reason why many respiratory illnesses occur in adult life.

Important numbers

- One in four admissions to children's wards in the UK is because of a respiratory disease.
- One in seven children in the UK has a doctor-diagnosis of asthma.
- One in five children seen in the out-patient clinic has a respiratory illness as the main medical problem.
- Over 50 per cent of adults with chronic asthma have their asthma origins early in childhood.
- Tobacco-related symptoms account for a huge number of respiratory illnesses. This is the single most important environmental factor affecting respiratory diseases in both children and adults.

Lung diseases in babies What are the main breathing problems facing babies?

1. Babies born before they are fully mature may have breathing difficulties requiring additional oxygen and may need help in breathing by the use of a mechanical ventilator.
2. The most immature babies may need this help for many weeks or months and may require additional oxygen even after they have been discharged.
3. These immature babies, especially those requiring additional oxygen for long periods of time, have poor immune systems and are therefore less able to fight off infections.

4. Viral and bacterial infections are more common in the very young and the very immature.

5. One of the most frequent and severe infections seen in these young babies is Respiratory Syncytial Virus (RSV) chest infection.

Respiratory Syncytial Virus Chest Infections

1. 20,000 babies are admitted to hospital in England and Wales every year between November and March because of RSV chest infections.
2. Premature babies requiring prolonged additional oxygen support are more likely to catch RSV and 20 per cent of them are likely to need hospital admission.



In the last 20 years, the care of premature babies has improved greatly



Asthma is one of the most common medical reasons that children are admitted to hospital.

3. After discharge from hospital 40 per cent of babies admitted with RSV chest infections will have recurrent and repeated respiratory symptoms over the next four years.

4. There is intense debate about whether RSV infection increases the likelihood of children developing asthma or indeed chronic obstructive airway disease in adults.

The overall picture

Over the last two decades, the care of premature babies has improved greatly because of our increased understanding of the underlying problems. However, this has resulted in the survival of much more immature babies and it is now more likely that babies born at 24 weeks gestation will survive compared with those born 10 or 20 years ago. These babies are more prone to catching infections such as RSV or pneumonia as well as other viral and bacterial infections.

The way forward

We need to continue to increase our understanding of the problems faced by babies being born very early. We also need to increase our understanding of how to prevent these babies from catching serious and damaging viral and bacterial

infections. Research programmes are exploring the potential of active immunisations against viral infections and some of these are very encouraging.

Passive immunisation can be given to high-risk infants as a series of five monthly immunisations to prevent RSV infection. It appears that giving this immunisation can reduce the hospitalisation rate of preterm babies with chronic lung disease by a five-fold factor during the RSV season.

Asthma

Asthma remains one of the most common medical reasons for admission to hospital in both adults and children. The admission numbers are now falling and overall deaths are fewer than previously. It is very important, however, to continue to understand why the prevalence of the disease seems to be still rising and if there are any environmental and other measures we should consider if we are to improve patient care in the short-term and disease outcome in the long-term. Among the issues to be decided is how we can best apply the new BTS/SIGN Asthma Guidelines to ensure that patients benefit.

Genetics and the environment **Cystic fibrosis**

When the cystic fibrosis gene was discovered in 1989 it was thought it would not take long to find a cure for the disease. Since then we have come to realise that there are hundreds of different gene abnormalities and, even in patients with the most common gene abnormality there is a very wide variation in outcome.

The treatment of cystic fibrosis has greatly improved in recent years and usually includes physiotherapy and exercise alongside traditional drugs and supplements. This

improvement in treatment has increased the length of time that people with CF live - in 1969 half of all people with CF lived only until the age of 14. By 1996, 50 per cent of CF patients were seeing their 31st birthday - a huge improvement.

Asthma

From time to time various reports suggest that a new gene has been discovered which is very important in allergic diseases such as asthma. We now know that asthma is not a disease caused by a single gene defect but the outcomes for asthma may well be improved if we understand more clearly how one gene interacts with another and how different genes may interact with the environment.

Where are we in our understanding of respiratory diseases in children in the UK?

- Bacterial infections are usually fully treatable with antibiotics, with most babies and children making a full recovery.
- With the exception of the influenza virus we have little ability to prevent respiratory viral infections with an active immunisation programme.
- Passive immunisation for RSV is available (palivizumab) for high-risk infants but this treatment is very expensive.
- More very small immature babies are surviving but they have high risks of developing chest infections with consequently increased hospital re-admission rates.
- Asthma management and outcomes are improving but the overall prevalence of asthma is rising.
- The outlook for cystic fibrosis is much better than 30 years ago but it is still a fatal disease causing much suffering and anguish.
- In the community and in hospitals

in the UK, respiratory illnesses are the commonest medical problems seen in children of all ages.

Children versus Adults

Although the majority of respiratory illnesses in adults originate early in childhood, research over the decades has concentrated on the adult population. This has been because of ethical considerations, practical issues and financial constraints. None of these concerns really hold up to scrutiny and if we are to understand better the natural progression of disease and the disease process we need to increase our research efforts in children, particularly in the very young.

The British Lung Foundation is committed to doing this and in recent years has encouraged an increased submission of paediatric research projects for funding. Research is expensive and time consuming but the management of respiratory diseases is also expensive.

Areas of interest for future respiratory research in children

- We now realise that 'asthma' covers a spectrum of diseases each of which probably responds in a different way to different treatments. We need to know more about the basic pathologies and underlying mechanisms so that appropriate treatments can be developed.
- Viral infections cause children to wheeze. What is the mechanism responsible for this? Why are some children affected and others are not?
- How can we make an impact on smoking habits within the UK? How are we to reduce mothers smoking during pregnancy and children breathing in environmental tobacco smoke?
- By understanding the effects of insults to the lung in early

childhood can we reduce chronic lung disease in adults?

Case Study

Iona Ramsey, 4 from Glasgow

Iona's mum Julie said: "My daughter Iona was born prematurely at 26 weeks, weighing 11lb 12oz at birth. She underwent a heart ligation operation at four weeks and spent the first five months of her life in hospital. She was ventilated for six weeks and was eventually discharged weighing 5lbs.

Iona depended on home oxygen for two years. As a parent you always fear - what happens if she stops breathing? How will I know if she requires more oxygen than normal? Will we be able to deal with the equipment?

We left hospital with a condenser machine and two large cylinders of oxygen to replenish her portable cylinder. Loaded under the stairs were cylinders, nasal prongs & leads, her oxygen supply volume gauges and all her other paraphernalia. It didn't take long for the family to become familiar with Iona's requirements.

Outings could only be as long as her portable cylinder would allow. We always had to think ahead of any parties and social outings, to ensure that Iona would not come into contact with a smoky atmosphere or sick children.

As Iona became more mobile, she was restricted to the length of the oxygen lead. She was forever pulling the prongs from her nose and on more than one occasion an oxygen cylinder would be knocked over and the noise of hissing oxygen would echo through the house!

Iona has wonderful determination. Her life started out a complete uphill battle and she conquered every challenge put her way."

Research:

Over £1 million has gone into research investigating lung disease in young children and babies. An award went to Dr Tony Postle and his team in 1998 to investigate the role of various components of the thin film lining the surface of the lung's air sacs (surfactant) in the immune regulation of children to respiratory infections such as those caused by the respiratory syncytial virus. The team found that some surfactant components are destroyed in these children and that their deficiency may contribute to the severity of the disease.

Another BLF funded project undertaken by Professor George Davey Smith and his team at the University of Bristol investigated whether the size of a baby at birth had any impact on lung disease in adulthood. Their research showed that children who remain underweight and those who have chest infections in their early years tend to have worse lung health as adults.

Lung function measurements in pre-school children were refined by Professor Janet Stocks and her team at the Great Ormond Street Children's Hospital in a non-invasive method to measure the extent of small airway disease in children with cystic fibrosis called the multiple breathe washout technique. This technology has the potential of picking up lung disease in its early stages for all children so relevant treatment can be initiated early on.

Lung Infections

By Dr John Macfarlane and
Dr Wei Shen Lim

What is meant by a lung infection?

The terms lung infection, chest infection or lower respiratory tract infection (LRTI), cover a variety of different chest infections. These infections constitute a spectrum ranging from bronchitis, which is an infection of the larger airways (bronchial tubes carrying air in and out of the lungs), to pneumonia, which is generally a more serious infection and involves the lower parts of the lungs and the lung tissue responsible for transferring oxygen to the blood.

Most cases of lung infection start outside hospital and are termed 'community acquired' whereas those that arise in patients who are in hospital are termed 'hospital acquired'.

Certain lung infections such as Legionnaires' Disease attract widespread media attention, often because of the public health implications related to the spread of infection. The dramatic increase in travel and tourism has also served to heighten awareness of types of pneumonia previously restricted to specific geographical locations, such as the pneumonic plague in India in 1994 and Ebola virus in Zaire in 1995.

In the last decade, pneumonias caused by new types of viruses have been described, such as hantavirus in South Western USA in 1993 and avian influenza virus in Hong Kong in 1997. More recently and dramatically, the effects of the

Severe Acute Respiratory Syndrome (SARS) caused by SARS-coronavirus have been felt worldwide. Having emerged in Southern China in November 2002, by May 2003, 29 countries in five continents had reported cases, underlining the effect of air travel on the spread of infection.

Who is at risk of lung infections?

The risk of acquiring a lung infection is broadly related to age and general health. Healthy people may be affected although very young children, older persons and people with co-existing medical problems are generally at higher risk of infection.

Each year about four per cent in the community experience a lower respiratory tract infection (LRTI). In the elderly this figure rises to 10 per cent. Between five and 10 per cent of patients with LRTI will have

pneumonia if a chest x-ray is obtained. Only about 20 per cent of adults with community acquired pneumonia will need hospital admission.

In developing countries, LRTIs including pneumonia are one of the commonest acute illnesses seen and are the most common form of death in children under five, killing 4.3 million children worldwide in 1991 alone.

In people with impaired immune systems, such as those with AIDS, receiving chemotherapy for cancers, or following organ transplants, pneumonias are not only more common, but can also be caused by a wide range of micro-organisms which rarely cause disease in healthy people. Smoking is a big risk factor.

Hospital acquired pneumonia is the third most common infection acquired in hospitals and is potentially the most serious.

The risk of hospital acquired pneumonia is related not only to the patient's condition but also the medical condition that first resulted in hospital admission and its severity. Following an operation, around one to two per cent of patients develop pneumonia. Procedures that result in a breach of a person's normal defences against infection, such as the placement of an endotracheal tube (a plastic tube that passes from the mouth into the lungs) to allow mechanical ventilation of a critically ill patient, further increase the risk of infection. Thus, of patients admitted to intensive care units, up to one in four may develop pneumonia.

What symptoms can be expected?

In patients with a lower respiratory tract infection, the most common respiratory symptom is a cough. This is productive in nature in 30 - 50 per cent of patients depending on the type of infection. Discoloured (green or yellow) sputum is associated with infection. Patients who are more severely ill may also complain of breathlessness particularly on exertion and pleurisy type pain (a sharp pain made worse on deep breathing or coughing).

General symptoms of infection include fever, tiredness and lethargy. Mental confusion and disorientation are features of severe disease.

The elderly may not present with typical symptoms. There may be an absence of fever and mental confusion is common, affecting up to 30 per cent of elderly patients. Such atypical presentation may cause difficulty and delay in diagnosis.

In SARS, fever is characteristically high (38°C) and is the initial recognisable symptom. Respiratory symptoms occur two to three days later and may be accompanied by generalised muscle ache.

Progression from mild to extreme breathlessness can be rapid.

The length of time it takes for the symptoms to go away is dependent on multiple factors including previous health status of the patient, age, type of infection and severity of infection. In otherwise healthy patients with acute bronchitis, 85 per cent can expect to be back at work within two weeks.

Patients with community acquired pneumonia can expect symptoms to begin to clear on average three days following the start of appropriate treatment. In a major British study of community acquired pneumonia, the average length of hospital stay was 11 days and a quarter of sufferers had still not returned to their normal activities six weeks after leaving hospital.

What treatments are available?

An accurate assessment of the severity of disease is important in determining the type of treatment needed and whether the patient requires hospital admission. Patients with mild LRTIs may not need antibiotics and can often be treated at home by the general practitioner. Bed rest and plenty of fluids are important, as is patient education.

In community acquired pneumonia, one international collaborative study found that nearly 40 per cent of patients had non-severe disease. These patients would receive antibiotics and may be suitable for treatment at home by the general practitioner. In one Canadian study, patients with non-severe disease were successfully managed at home with daily follow up by a dedicated specialist nurse. Patients with moderately severe and severe disease usually need hospital care.

Penicillin-based antibiotics are still effective in many community acquired infections. Newer antibiotics are available for use in lung infections which persist despite initial antibiotics or in patients with difficult-to-treat infections, including patients with hospital acquired pneumonia.

Anti-viral agents, such as the new neuraminidase inhibitors, reduce the duration of symptoms of influenza but only if given within 48 hours of the onset of illness.

In patients severely ill with SARS the use of steroids reduces fever. However, at the time of writing, no agent has been definitely shown to be effective against the virus.

What progress has been made?

- Patients are more aware of the side effects of the widespread overuse of antibiotics, and the down sides of expecting their GP to prescribe antibiotics for minor chesty coughs which are often self limiting. The community has hence become less dependent on wanting antibiotics when not judged clinically necessary by their doctor.
- Research funded by the BLF has shown that informing patients about the long natural history of cough after LRTI (bronchial hyperreactivity) can reduce their need to request unnecessary antibiotics.
- Considerable advances have been made in developing guidelines and protocols for assessing severity in patients with community acquired pneumonia and targeting treatment according to disease severity.
- A new generation of quinolone antibiotics have been developed and offer the potential for a single agent effective against all the common micro-organisms associated with community acquired LRTIs.

- Neuraminidase inhibitors have been shown to be effective in preventing and treating influenza.
- Numerous studies have examined the role and contribution of newly described organisms which cause pneumonia, such as Chlamydia pneumoniae.
- New rapid and easy-to-use diagnostic tests have been developed that allow the detection of micro-organisms such as Streptococcus pneumoniae (the commonest cause of community acquired pneumonia) within 15 minutes. Such tests offer the possibility of 'bedside' or 'near patient' diagnosis and hence more focused antibiotic treatment from the very start.
- A new level of international collaboration between agencies, laboratories, scientists and scientific journals has been shown to be possible in tackling specific problems such as SARS. This has resulted in rapid advances in our understanding of SARS through the identification of the SARS-coronavirus, development of confirmatory diagnostic tests and sharing of clinical and infection control experiences across the world.

What progress needs to be made?

Community acquired LRTI:

1. Develop alternate strategies for the management of symptoms of LRTI, where antibiotics are thought necessary by the patient but not by their doctor.
2. Assess the place of the neuraminidase inhibitors for the early treatment of acute respiratory infections.

Community

acquired pneumonia:

1. Determine whether severity-based guidelines for the management of community acquired pneumonia are effective in terms of clinical outcome measures (such as hospital admission rates, death rates and length of hospital stay) and cost-effectiveness.
2. Develop 'hospital-at-home' strategies to manage patients with non-severe disease.
3. Develop focused and cost-effective antibiotic strategies based on the use of rapid bedside diagnostic kits.
4. Development of effective vaccines against the common pathogens, especially pneumococcal infection.

Hospital acquired pneumonia:

1. Develop strategies to prevent hospital acquired and post-operative pneumonia. These include tackling the increasing and major problem of antibiotic resistance of common bacteria, such as staphylococci and enterobacteria, in the hospital environment.
2. Improve diagnostic techniques for detecting pneumonia in patients who are being mechanically ventilated on intensive care units.
3. Assess the importance of the micro-organisms involved in pneumonia occurring in hospitalised patients who are prone to aspiration (such as the elderly and stroke patients).

Anti-microbial agents

1. Set up surveillance studies and identify factors related to increasing antibiotic resistance of the microbes (micro-organisms) causing pneumonia both in the community and in the hospital.
2. Develop effective anti-viral agents. More lung infections are being recognised as caused by viruses but currently there are few useful anti-viral agents available.

Prevention:

1. Assess the role of pneumococcal conjugate vaccines in adults, particularly the elderly who are most at risk of pneumonia.
2. Assess the importance of diet and nutrition in preventing lung infection.
3. Determine the role of molecular and genetic factors in the susceptibility to lung infections.

Health policy:

1. Demonstrate the significance of respiratory infections on the population and health services in order to win clinical and research interest in this area. The impressive advances in the understanding of SARS is an example of what can now be done when resources and will are turned to a problem. Many 'older' problems remain unattended.
2. Work in co-operation with government agencies and other professional groups in forming policy for issues such as vaccination, antibiotics and the monitoring of antibiotic resistance.

Sources include BTS, WHO, JAMA

Case study:

A male patient, 76 from Nottinghamshire:

"It was winter and I'd had a temperature for seven days and was coughing up green, 'mucky' sputum. I felt quite feverish, but I thought I must have caught a bad case of the flu.

I went to see my GP when I started getting very breathless and developed a pain in the right side of the chest, which got worse when I was breathing. My GP quickly established that I had a respiratory infection and referred me to hospital where an x-ray confirmed pneumonia on the right side of my chest.

I was in hospital for the next five days and was treated with oxygen, plenty of fluids, pain killers, regular paracetamol and antibiotics. My pain started to get better within 24 hours and my fever stopped after three days.

When I was discharged my cough and breathlessness were better but hadn't completely gone away. It took five weeks for me to fully recover at home. During that time I managed to quit smoking as I know that it is a big risk factor and I certainly didn't want to catch pneumonia again.

I now regularly have the flu vaccine to help protect me against colds and further pneumonia infections. I was very relieved when a follow-up x-ray showed that the pneumonia had totally cleared."

Research:

Almost £3 million has been spent on investigating lung infections in both adults and children. A grant was awarded to Dr John Macfarlane at Nottingham City Hospital in 1999 to investigate whether verbal advice and a patient information leaflet could reduce inappropriate use of antibiotics in people consulting their GP with acute lower respiratory tract illness. The study found that the demand and use of antibiotics was indeed significantly reduced and could, if distributed as a standard, lead to 750,000 fewer courses of antibiotics prescribed in the UK each year.

A significant contribution to molecular research on lung infection was made by Professor Jonathan Lamb and his team at the University of Edinburgh. Professor Lamb held the BLF/Glaxo Wellcome Chair in Respiratory Medicine from 1997-2003. His work focused on signalling systems involved in the body's natural fight against foreign bodies and has led to well over 50 publications in international journals.

Research into the immune effects of cytomegalovirus, the most common viral infection in transplant patients was carried out by Dr Ron Scott and his colleagues at the Freeman Hospital in Newcastle-upon-Tyne. The team found an immune reaction to the virus which causes life-threatening pneumonia. This means that predictions can now be made on the outcome of the disease in patients most at risk.

Tuberculosis

By Dr John Moore-Gillon

Tuberculosis (TB) is a disease which should no longer exist - yet a third of the earth's population are infected with the TB bacterium, millions of people die each year, and TB cases in London have doubled in the past decade. In the field of health and disease, it would be hard to find a more dramatic example of missed opportunities than that of TB.

How do people catch TB and become ill?

TB is an infection caused by the bacterium mycobacterium tuberculosis. In the past, TB sometimes was caught by drinking milk from cows infected with TB, but this is now very uncommon. Much more often, TB is caught when an individual breathes in bacteria which have been coughed up and expelled into the air by somebody with active TB in their lungs. Since the lungs are the route by which TB bacteria get into the body, the lungs are the commonest site to suffer from TB, but as well as infection in the lungs the disease can spread to infect any part of the body - most commonly the lymph nodes ("glands"), bones, kidneys and brain.

At the time of the initial infection of the lungs, most people have only a mild illness which can go completely unnoticed. Only about one in 10 recently infected people go on at this stage to have a more severe illness. In the remainder, the infected focus in the lungs heals up, often leaving a small scar which can be seen on a chest x-ray. The TB bacterium is, however, very unusual and can stay dormant in the lungs for months, years and even decades. This means that individuals infected with TB, even

though they are completely well, are sitting on a potential time bomb - for the whole of the rest of their lives they are at risk of reactivation of these dormant bacteria.

When somebody becomes ill with TB, it can be impossible to tell whether they have an infection which has been caught recently - in the last few weeks or months - or whether they are suffering as a result of the reactivation of bacteria which have been dormant since an infection which took place in earlier life. Often, it is reasonable to make assumptions. A child with TB whose mother also has TB has probably caught the infection recently. An elderly person who becomes ill, but who has no known recent contact with TB, may well have reactivation of the illness which they originally caught as a child, perhaps 50 or more years ago.

What determines whether or not somebody becomes ill with TB?

The answer lies in the balance that is struck between the TB bacterium's power to divide and multiply, and the power of the body's immune system to keep it under control. Any reduction in the

body's immunity will make it more likely that a person who has just been infected with TB will become ill at that stage, rather than fighting off the infection and just being left with a healed scar in the lungs. In the same way, if somebody has been infected in the past and has dormant bacteria in the lungs then these may become active if anything impairs their immunity - and the person then becomes ill with TB.

What are the factors which can result in reduced immunity?

The one that springs most easily to mind is HIV infection leading to AIDS, but there are many others. The very young and the very elderly have less efficient immune systems. Many diseases - but especially diabetes, kidney failure, leukaemia and other forms of cancer - will reduce immunity. So will treatments with certain drugs, like anti-cancer chemotherapy and steroids, although inhaled steroids used to treat asthma are completely safe in this regard. Perhaps most important of all on a global scale are the factors of nutrition and general health. People who are poorly nourished are at extra risk, so they will find it harder to fight

off a recent TB infection, and those with dormant disease are at high risk of reactivation of their bacteria.

Absolutely anybody can catch TB and become ill with it, but all the way through recorded history there have been some groups who have been more at risk than others. Poorer people are more likely to be badly nourished and have general ill-health. If they are newly infected with TB they are more likely to become ill with it (and infectious to others) rather than fight off the infection. Similarly, such people with old, dormant infection are more likely to have a reactivation of their disease, and thus pose an infection risk to others as well as being ill themselves. Poorer people are more likely to live in overcrowded conditions, increasing the risk of transmission of infection. Finally, they are less likely to have ready access to good healthcare - and the longer somebody with TB remains untreated, the longer they are infectious to others. It becomes obvious that the circumstances associated with poverty are potent factors in increasing the rates of TB. Add in to the equation the fact that HIV rates are at their highest in the poorest parts of the world, and the scene is set for what the World Health Organisation, referring to TB, has called "a global health emergency".

The symptoms of TB

TB starts as a lung disease, and remains a lung disease for most people, so the commonest symptoms are those related to the lungs. A troublesome cough is characteristic, with the production of sputum (phlegm) which can be bloodstained. In the later stages, breathlessness can occur as the structure of the lungs becomes progressively damaged. An intermittently high temperature, general tiredness, weight loss and

sweats (especially at night) are very common.

If TB has spread to other parts of the body, then the localised symptoms and signs may be different: persistently swollen glands, especially in the neck; backache and other bony pains; urinary symptoms; headaches and neck stiffness. The generalised symptoms of fever, tiredness, weight loss and sweats are also usually present. If untreated, people with TB die from failure of the affected organs, usually after months or years of progressive weakness and wasting away. The old term for TB - "consumption" - well illustrates the way in which the disease "eats away" at the sufferer; who becomes skeletally thin before finally succumbing.

What is happening to rates of TB?

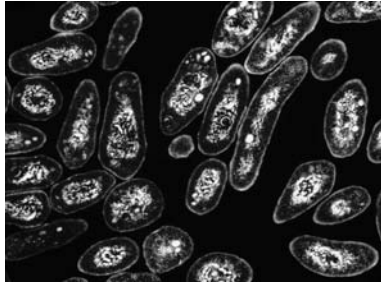
TB rates in developed countries began to fall long before vaccination (BCG) and antituberculous drugs became available in the late 1940s and 1950s. They fell simply because of improving living conditions, as well as a growing awareness of the value of reducing transmission of infection by isolating TB sufferers from those as yet uninfected. The greatest fall, of course, did come after drugs were introduced, and in Britain, as in other developed countries, TB rates fell steadily until the mid 1980s.

But what is going on now? The number of cases of TB is going up - both worldwide and in Britain. There are now about 7,000 new cases of TB in Britain every year. Our largest cities, and in particular London, have seen marked rises: rates have doubled in London as a whole in the past 12 years - and more than that in some districts of the capital, where rates are now the highest in Europe. Lung specialists who were told when

they were training in the 1970s and even the early 1980s that TB would be eradicated by the end of the 20th century are now finding that TB is literally an everyday part of their work. Tuberculosis bacteria resistant to at least one first-line TB drug make up nearly 10 per cent of cases. The feared multi-drug resistant tuberculosis (MDR-TB) is still relatively uncommon in the UK, with 50 to 60 new cases a year (the great majority in London). This may seem a small number, but the average cost of treating such individuals is in excess of £70,000 each, and again these cases are largely concentrated in London. London has more cases of TB - drug sensitive and drug resistant - than any other European city, and even when allowance is made for the size of London it is still almost at the top of the list for TB rates.

What has gone wrong?

If one word had to be chosen to sum up the problem it would be "complacency". It was simply assumed that, with the development of drugs to treat TB, the problem was solved. TB was consigned to the past in the minds of most people including, tragically, those making decisions about spending on TB research and TB control programmes. The world famous British Medical Research Council TB Unit had discovered the ways in which TB drugs needed to be used in combination - and for how long they needed to be used - and this research is still the basis for TB treatment throughout the world today. The unit was closed down in the 1970s and not replaced. Expenditure on new ways of preventing, diagnosing and treating TB stopped almost completely, in Britain and elsewhere. In the USA, laboratories stopped carrying out routine drug sensitivity testing to save money. Lung specialists with TB



The TB bacterium can stay dormant in the lungs for decades

experience retired and were replaced by doctors specialising in other areas of medicine.

Add to these factors the problems of growing political instability around the world, mass movement of populations on a scale not seen since the aftermath of World War Two, and the onset of the AIDS pandemic and the stage was set for an explosion in the number of TB cases around the world. And so it has proved - not just in old-style TB hotspots like the Indian sub-continent and sub-Saharan Africa but also in new and perhaps unexpected places. Alarm bells began to ring in the late 1980s when it was noted that TB rates in some boroughs of New York were higher than those in Nicaragua. Worse, the rates of multi-drug resistant TB in New York were very high - but unnoticed until then simply because drug sensitivity testing of TB cases had been stopped. The demise of the old Soviet empire in eastern Europe and Asia brought other problems. With economic chaos and a breakdown in healthcare systems, supplies of TB drugs could no longer be guaranteed. Infectious cases went untreated and when drugs were available the supplies were irregular and in the wrong combinations. The untreated cases spread disease, and irregular and inadequate treatment produces drug resistant strains - including multidrug resistant ones. Eastern Europe now has the highest MDRTB rates in the world.

So why do we have problems even in relatively wealthy countries like the UK?

The phrase "global village" may be a cliché but it could have been designed for TB, an infectious disease which knows no international boundaries. In the 21st century, great cities are a mirror of the world as a whole. But there is an additional problem: TB is perceived as being a disease of the past, and cases can go undiagnosed for a long while, infecting others as time goes by. Further, we have all come to expect a "quick fix" to medical problems: how many people complete even a seven day course of antibiotics for a routine infection? It is all too tempting to stop when one feels well again. The course of treatment for TB is long and complicated and most people with TB need constant support and help through the treatment period: stopping too early, missing some doses, and taking some drugs but not others is a recipe for relapse of the disease and creates the risk of drug resistance developing.

What needs to be done?

Education, research and investment are the key words:

- First, there is a pressing need for education about TB - and that means healthcare professionals as well as the public in general. An awareness of the common symptoms of TB means that members of the public can seek medical advice, and be checked for TB, earlier rather than later, thus reducing the chances of infecting others before treatment starts. Similarly, healthcare professionals like doctors and nurses need to be aware that TB has never gone away and, sadly, is very much on its way back. Many years ago, when TB was common, everybody had a very high index

of suspicion for TB. Nowadays, patients sometimes seek medical advice repeatedly before the diagnosis is finally made. The British Lung Foundation has information leaflets for people with TB and their families, and for those who just wish to know a little more about the disease.

- Medical research is crucial. We are still diagnosing TB by much the same methods as were being used 40 years ago. We are still treating TB with the same drugs as 30 years ago. We refer to modern TB treatment as "short-course chemotherapy" - but that is by comparison with the standard one and a half years treatment of the 1950s. Treating TB still needs three or (usually) four drugs for two months, followed by another four months treatment with two of these drugs. Research is needed to discover new, effective and safe drugs - and ones that are cheap enough to be used in the developing world. The BLF is committed to TB research, and has already invested in discovering new ways of identifying the presence of TB bacteria and of determining more quickly whether they are drug resistant.
- Finally, investment in resources. That means people who are trained in detecting TB, experts in managing the drug treatment, and specialist nurses to support patients with TB through their long course of treatment. This is something beyond the resources of a charity like the BLF - but what we can do is make sure that those who do allocate the resources understand just how pressing the need is.

The three key areas, above, are targets at which prosperous countries like the United Kingdom can aim. But far more needs to be done, at a more basic level, in

poorer countries. In the July 2000 G8 Summit Conference in Japan, the leaders of the world's richest nations declared TB and AIDS to be priorities which none could ignore. So what could and should be done, to prevent political statements from turning out to be just the usual empty rhetoric?

In developing countries, non-governmental organisations (NGOs) and aid agencies are doing their best to help the local system, but are working on a shoestring. Given their limited resources, they have to concentrate on "hot spots" of TB. But the hottest spots for TB of all - war zones - are exactly where it is most difficult to have a reliable long-term programme. Government aid - from those that can afford it - will help the NGOs and aid agencies work in those places that can't afford it, but ensuring that there is the local political will to make the aid as effective as possible is more difficult to achieve. The Governments of richer countries need to be persuaded that such aid and investment is not just altruism and philanthropy: in the medium to longer term it will result in falling TB rates in the rich countries as well.

Global political stability and a cure for AIDS are probably necessary for the complete eradication of TB - tough targets, and almost certainly unachievable. Even without them, though, we can again turn the tide against TB if there is the political will backed up with real money going into education, research and training personnel. These are decisions for politicians, and it may well be that the long-term future of TB in the world lies more in their hands than in those of doctors and nurses.

Case Study:

Lillian Snowden, 56, from West London

"I've got no idea how I was infected with TB. My son originally fell ill with TB in 1999. He was successfully treated with antibiotics and I had tests including an x-ray to make sure that I was ok. During this x-ray they found a shadow on my lung but all the TB tests proved negative.

Two years later I became ill and started losing weight. I became so anaemic that I had to have a blood transfusion but no one seemed to know exactly what was wrong with me. I was checked for colon cancer and I really started to worry.

About six months later a CT scan confirmed that I had TB. The symptoms hadn't been at all obvious as I already had a smokers cough and was getting hot flushes at night due to the menopause.

Both my lungs were severely infected and I was kept in isolation for eight weeks, which was horrible. Initially they told me I'd be in isolation for two weeks but my body kept rejecting drugs and food and I wasn't getting any better.

After a while I had a 'Hickman line' inserted into my neck that I took my medication through and I slowly started feeling better.

After I was released from hospital I had to keep the Hickman line in for a further five months and a nurse visited me at home daily to administer treatment. I felt quite reclusive after being in hospital for so long and it took me a long time before I felt comfortable going out in public by myself again.

I'm cross that it took so long for me to be diagnosed. Beating TB was a hard battle and took

away eight months of my life but at least I'm here to tell my story."

Research:

The British Lung Foundation has invested £1 million into TB research. With BLF funding, a team of researchers led by Dr Rory Shaw from St. Mary's Hospital in London was able to develop a way to reduce the diagnosis time for multi drug resistant TB from eight-10 weeks to just three-four days. They used a technique called the polymerase chain reaction which analyses the reaction of the TB-causing bacteria's genes to rifampicin, the most powerful TB drug used (in the mid 90s). As a direct consequence of this research, the technique is now widely used in UK hospitals.

A number of grants have looked at how the body's defence mechanisms react to being infected by the TB bacteria. In doing so, specific signalling pathways have been analysed. A grant awarded to Professor Graham Rook at the Royal Free and University Hospital Medical School in London is investigating the body's immune responses further. It aims to set up methods that will allow the use of patient's blood to identify the specific components in the TB bacteria that cause an unwanted immune response. Eventually, this could lead to the development of new vaccines based on these components which could prevent and treat TB.

Sources include: BTS, Department of Health, WHO

Mesothelioma

By Dr Mark Britton

Mesothelioma is one of the most difficult diseases that doctors, patients and their families have to face. It is almost always caused by a significant inhalation of asbestos fibre many years before symptoms develop.

What is mesothelioma?

A mesothelioma is a malignant tumour that arises within the mesothelium, a thin membrane that lines the chest (pleura) and the abdomen (peritoneum) and surrounds the lung or the bowel respectively. The pleural mesothelioma is much more common, and its rising incidence is causing concern.

The link with asbestos

Wagner et al. first described the condition of malignant mesothelioma and its association with asbestos in 1960. By 1960, the production and use of all forms of asbestos had increased worldwide and continued to grow for at least 15 more years. This has been paralleled, after a 30 to 40 year lag, by the widespread occurrence of cases of mesothelioma. It was not until the mid 1970's that the dangers of asbestos became universally recognised and action such as the phasing out of the use of asbestos within industry began to be taken. The Health and Safety Regulations were updated and more rigorously applied.

A history of occupational exposure to asbestos can be obtained in about 90 per cent of cases. The other causes of the disease are not fully understood. Neither smoking nor exposure to

more modern fire-resistant materials such as fibreglass is thought to increase the risk of developing mesothelioma.

Types of Asbestos

All types of asbestos can cause mesothelioma. Amphibole fibres such as crocidolite (blue asbestos) and amosite (brown asbestos) are known to be the most potent causes. A recent WHO review concluded that chrysotile (white asbestos) does impose an increased risk of mesothelioma in a dose dependant manner. Tremolite, another type of fibre previously not thought to give rise to an increased risk, has recently received more attention and may be more relevant. Length and width of the fibres are important characteristics, but so too are chemical and other factors, especially those that affect the persistence of the fibres in the tissues.

Incidence

The incidence of mesothelioma in the United Kingdom has been increasing rapidly over the last few years. The most recent figures show that 1,595 people died from mesothelioma in 1999 compared with 895 deaths a decade earlier. Studies clearly shown that the rise in cases of malignant mesothelioma mirrors the rise in the asbestos

imports into the UK 50 years previously. As the imports did not begin to fall until 1980, it is predicted that the rise in cases will continue with a peak of annual male mesothelioma deaths in the year 2020 of between 2,700 and 3,300 deaths.

Who is at risk?

Initially mesothelioma was seen principally in ladders, thermal insulation engineers, shipyard workers, and asbestos manufacturing workers and women who assembled gas masks during the war. In people heavily exposed to asbestos early and throughout their working life in these occupations more than one in 10 have died from mesothelioma. However, analysis of the occupations recorded on death certificates from recent deaths indicate that building workers, especially plumbers and gas fitters, carpenters and electricians are now the largest high risk occupational groups, although the incidence rate in these groups is much lower.

Mesothelioma from para-occupational exposure has long been recognised - for example, women who have laundered their husband's overalls. More recently a few cases of mesothelioma arising from non-industrial environmental contact have been reported, such



Carpenters are among the professions at risk of mesothelioma.

as people who, as children, lived and played in the vicinity of asbestos factories.

Diagnosis

- A detailed occupational history is essential.
- Clinical presentation is usually breathlessness due to a pleural effusion or chest pain.
- Chest X-ray suggestive with pleural effusion and/or a knobbly pleural tumour especially if supported by positive occupational history.
- CT scanning plays a key role in both diagnosis and staging, and with taking a CT guided biopsy.
- Thoracoscopy desirable
 - to obtain tissue for diagnosis if initial cytology or pleural biopsy negative

- to assess suitability for radical surgery
- allows talc pleurodesis if former not possible

Pathology

There are three main pathological types of mesothelioma: epithelioid, sarcomatoid (fibrous), and biphasic (mixed). The epithelioid is the most common and is easily confused with adenocarcinoma. Special stains should be used to help differentiate between the two. Pathological confirmation of diagnosis is recommended as it helps guide treatment plans, and can be a guide to prognosis.

Treatment options

After staging, the following treatment options need to be considered:

- Radical surgery
- Management of pleural effusions
- Radiotherapy
- Chemotherapy
- Best supportive care including active symptom control (ASC) for pain and breathlessness and palliative care

What advances have been made over the last decade?

- Very little progress has been made over the last decade with limited evidence based research on which to base guidelines. Until the last few years there had been a nihilistic approach to therapy.
- However clinical trials conducted in the UK using the following regimens:

- 1) Mitomycin C, vinblastine and cisplatin (MVP)
- 2) Navelbine (N)

have raised some hope. Trials in the USA using Pemetrexed (an antifolate/antimetabolite) in combination with cisplatin or carboplatin have also shown encouraging activity in phase I and phase II trials.

- Multimodality regimens involving radical surgery with radiation, chemotherapy or immunotherapy delivered regionally or systemically have emerged from the States, rekindling interest in radical surgery in the United Kingdom in patients with Stage I Epithelioid tumours.

Present studies

MSO I

This first randomised controlled trial is being carried out in the UK with the aim of recruiting 840 people and comparing active symptom control (ASC) with ASC plus N (outlined above) with ASC plus MVP (outlined above), was started in 2002.

MARS

This study is in the process of being set up to look at mesothelioma and radical surgery.

New approaches to research and treatment

- Various types of gene therapy have been proposed, with the introduction of genes to make tumour cells more susceptible to antiviral agents or to stimulate natural defence mechanisms
- Photodynamic therapy, which employs a red laser light to activate drugs which have a cytotoxic effect
- Various types of immunotherapy have been tried including intrapleural and systemic interleukin 2 and interferon
- Further studies looking at new combinations of chemotherapy and new treatments will be necessary, as well as a full evaluation of the role of PET scanning in the diagnosis and staging of mesothelioma.
- Additional work is required to establish the other causes of mesothelioma, as well as establishing the exact properties of the asbestos fibre that gives rise to its carcinogenicity.

Conclusion

It is over 40 years since the risks of mesothelioma were described by Wagner. In the intervening years both epidemiological and toxicological knowledge have increased enormously, but delay in action has resulted in a legacy of rising mesothelioma rates for at least the next twenty years. This increases the urgency to find more effective ways of managing patients who, through no fault of their own, will develop this dreadful condition.

Case study:

Mick Knighton, 60 from Tyne and Wear

Chris Knighton's husband Mick Knighton died from mesothelioma in March 2001. Mick had been exposed to asbestos while working for the Royal Navy. Chris, aged 55 from Wallsend, has set up a fund in her husband's memory to raise £100,000 for mesothelioma research which will be awarded to British Lung Foundation scientists.

She said: "My husband had his mesothelioma diagnosed 30 years after leaving the Navy. He died seven months after being diagnosed aged 60.

"We went on holiday in June 2000 and when we came home he had breathing problems. At first we thought he had a bad cold but when we went to the hospital we were told he had the cancer, which nobody seemed to know anything about."

"We are sure Mick got his illness from his days working in the Royal Navy where asbestos was used a lot. The hard thing is that it lay dormant for years and then all of a sudden it struck him and he had only months to live.

"I want to inform more people about the disease, it seems to be the 'unknown' cancer that creates little interest or research funding. There are thousands suffering from mesothelioma now and the number will increase dramatically over the next 20 years unless an effective treatment can be found."

Research:

Virtually unknown before the 1950s, mesothelioma is an aggressive form of lung cancer which is resistant to several current therapies. The British Lung Foundation is therefore keen to support research into finding new types of possible treatment. A grant was awarded to Dr Zsusanna Tabi at Velindre Hospital in Cardiff to investigate the body's natural defense system in order to investigate whether it can provide protection against the tumour itself and a tumour-inducing virus called the SV40 virus which is found in 60-80 per cent of people living with mesothelioma.

Previous research undertaken by Dr Stephen Mutsaers and his team at University College London has focused on interactions between cancer cells and structural molecules which support lung tissue and are found in the medium surrounding the cells. Tumour cells are partly responsible for producing these structural molecules in order to aid their own growth. The researcher focused on the production of these molecules and found that they could successfully block the process by replacing one of the key building stones with another one. The researchers were thus able to inhibit tumour growth. However, more research is still necessary in this area and the researchers are continuing in their efforts.

Ambulatory Oxygen

By Professor Wisia Wedzicha

Long term oxygen therapy (LTOT) is one of the most important therapies for patients with chronic obstructive pulmonary disease (COPD) as it is one of the few interventions to date that can improve mortality in COPD. The two major trials of LTOT took place over 20 years ago and showed that around 15 hours of oxygen therapy at home was required to reduce mortality. However an interesting finding in these studies was that the outlook was better in the US study, especially in patients given ambulatory oxygen therapy in addition to their stationary supply of home oxygen. The term ambulatory oxygen therapy refers to the use of oxygen outside the home, while the patient is mobile. In addition to COPD, ambulatory oxygen therapy can also benefit other patients with disabling lung diseases such as patients with pulmonary fibrosis and cystic fibrosis. Ambulatory oxygen can be particularly beneficial to children with chronic lung disease as it enables them to go to school on a regular basis and maintains their quality of life.

Some patients use oxygen only on a short term basis (short burst oxygen therapy) for example for five minutes before or after exercise to relieve breathlessness though there is little evidence to date for such use and this article is limited to the use of oxygen during ambulation.

Why is ambulatory oxygen useful?

Patients with chronic lung disease show increased falls in oxygen levels when they exercise - for example walking or going up the stairs - though these falls are variable

between patients. There is evidence that using oxygen therapy during exercise can prevent these falls and also improve symptoms of breathlessness and increase exercise capacity. Breathlessness is a very prominent symptom of chronic lung disease and is one of the major factors causing disability, preventing the patient from performing many activities of daily living.

However there is relatively little information on the longer term benefits of using oxygen during exercise though one would expect that quality of life would be significantly improved as patients

will be able to leave the home more independently. Supplemental oxygen therapy has a number of other effects in that psychological function improves, especially with reduction of anxiety and depression; conditions that are common in COPD patients.

Which patients are suitable for ambulatory oxygen?

Any patient with home LTOT is potentially a candidate for ambulatory oxygen therapy, as long as they have the ability to leave the house or need a portable oxygen

source to go out into their garden etc. The criteria of mobility is an important one as the provision of ambulatory oxygen is currently relatively expensive. Some patients especially those with pulmonary fibrosis may show marked oxygen desaturation on exercise and these patients will benefit particularly from the treatment. An assessment is required for any patient which requires a simple walking test on and off oxygen. This test is usually performed in a hospital out-patient setting. The objective of the test is to confirm that the patient has exercise hypoxia, to assess how much oxygen (in the form of the flow rate) is required to correct the fall in oxygen level and also to assess the nature of the delivery device for ambulatory oxygen.

Some patients who are not on LTOT may also benefit from ambulatory oxygen and this is the group of patients that have oxygen desaturation on exercise. Thus patients with COPD or pulmonary fibrosis who have levels of arterial oxygen above the limit for prescription of LTOT may benefit if an assessment shows a fall in oxygen on exercise and improvement with oxygen therapy. However further research is required to study the advantages of ambulatory oxygen in this patient group in the longer term.

How is ambulatory oxygen provision organised?

Patients requiring LTOT are currently provided in the UK with an oxygen concentrator - a machine that can extract oxygen from the air. This is provided on a rental basis, funded completely by the Department of Health and installed by a contractor that is appointed on a regional basis. The electricity used for the oxygen concentrator is also reimbursed. In contrast at present

we have no formal system for the provision of ambulatory oxygen therapy and the method of prescription and assessment is dependent on local practice mainly in hospitals. Portable oxygen cylinders are either provided by hospitals or purchased by the patient and the cylinders that are used for refilling are prescribed by general practitioners and supplied by pharmacists. However the Department of Health has recently announced the commitment to provide a comprehensive service for the provision of ambulatory oxygen by 2005 and this will involve a contractor providing all the oxygen modalities - both oxygen concentrators and the most appropriate ambulatory oxygen device for the particular patient. This new system will require a careful patient assessment and details of the process are being currently evaluated.

What equipment is available for ambulatory oxygen delivery?

At present the availability of equipment in the UK for ambulatory oxygen delivery is limited, though with the welcome announcement from the Department of Health about changes to the system, it is hoped that a wider range of equipment will be available for patients in the future.

Currently patients in the UK use small portable oxygen cylinders for ambulatory use that have a capacity of only about 250 litres. These will last for relatively a short time, if the patients use a flow rate of two litres per minute and even shorter if they need to use a higher flow rate. These small cylinders need to be refilled from larger F - sized cylinders (capacity about 1360 litres) and these cylinders have to be prescribed by general practitioners. Patients need to be

educated how to refill these small cylinders and some find this difficult. An alternative method is that cylinders can be provided for ambulatory use that are not refilled, though these tend to be heavier than the small refillable ones and require regular delivery. The weight of equipment is an important issue in compliance with the therapy and it is hoped that lighter equipment will be available in the future.

In order to lengthen the time that oxygen is available from a portable cylinder, an oxygen conserving device can be used. This device saves oxygen by controlling its delivery only when a user breathes in, unlike regular cylinders where oxygen is provided also during expiration but not required. It is anticipated with the new service developments announced that these type of devices will be widely available. A drawback of their use is that they do add weight to the cylinders and thus lightweight equipment needs to be developed.

Another form of ambulatory oxygen is liquid oxygen which is provided in portable flasks. The advantage of liquid oxygen for portable use is that one of these flasks may contain enough oxygen for the patient to use for about six to eight hours, thus allowing them to go out of the house for a longer time, for example to go to work or school. However the liquid oxygen flasks also need to be refilled on a regular basis from a larger tank that is delivered to the home. As liquid oxygen evaporates, the larger tank needs to be refilled on a regular basis and this is costly. Therefore liquid oxygen is the delivery method of choice only where a longer period of ambulatory oxygen is required. At present in the UK, liquid oxygen for ambulatory use is only available on a private basis or by special arrangement but the new changes



By 2005, there will be comprehensive provision of ambulatory oxygen

in service delivery will include liquid oxygen provision.

Other devices for ambulatory oxygen provision have included transtracheal systems where a catheter is placed directly into the trachea. The advantage is this saves oxygen but these catheters are associated with complications and are currently rarely used. With the provision of improved oxygen delivery such as the use of liquid oxygen, there will be less need for such devices.

Some patients who are housebound and unable to leave the house unaided may request an oxygen source when they are taken out to visit relatives or go for hospital visits. These patients will need a supply of portable oxygen though only on an infrequent basis, while other patients who are still working will require a longer ambulatory oxygen source. Thus the delivery method has to be appropriate to the individual patient's requirement and this emphasises the importance of careful assessment by suitably trained staff.

The future

After many years of difficulty in the UK with the provision of ambulatory oxygen for patients with chronic lung disease, recent announcements show the Department of Health's

commitment to improving this much needed and awaited service. However some of the delivery methods are costly and the appropriate delivery method needs to be provided for the patient depending on their ability to leave the home. Patients will need careful instruction about the use of ambulatory oxygen in order to optimise compliance. More research is required on the effects of ambulatory oxygen and which patient groups show benefit. With the exciting service developments, we will be in a good position to improve the quality of life of these patients with chronic disabling lung disease. The future is now optimistic!

Case study:

Pauline Adams, 42 from Edinburgh

Pauline Adams is a charismatic, 42 year old former nurse and mother of one who lives with the genetic lung condition Alpha -1 Anti-Tripsin deficiency (AIAD).

Pauline lives in Edinburgh, Scotland. She is largely confined to a wheelchair and is reliant on oxygen 24 hours day.

Pauline said: "I was devastated when I was diagnosed and told there was no cure and that my only hope is a lung transplant. I had to give up my career, which was terrible. I went from overnight being a nurse to a patient, which was very hard."

"My oxygen tank weighs more than two stone, so it's impossible for me to carry it around. The only way I can leave the house is by using ambulatory oxygen, but that doesn't come on the Scottish drug tariff.

"I've been campaigning to highlight this issue with Scottish ministers, and the feedback I've had is positive. It would make a

huge difference to people in my situation if this oxygen was available.

"It's very depressing to think that you can't even visit the corner shop for fear of running out of oxygen. Holidays and even short trips are totally out of the question for me."

Research:

The British Lung Foundation funds research not only into laboratory, clinical or epidemiological disease areas but also into issues that can impact the lives of people living with lung disease today. One of these projects was an evaluation of the effectiveness of Respiratory Nurse Specialist's education of people living with COPD on long term oxygen therapy and their carers in relation to improved compliance and quality of life. This research was undertaken by Mrs Angela Crewes from the Yeovil District Hospital in Somerset and found that it was indeed beneficial for people to receive additional education and home support.

Another study was conducted by Professor Wisia Wedzicha and her team from the London Chest Hospital on the use of nasal pressure support ventilation for COPD sufferers on long term oxygen therapy. They found that this supplementary measure improved not only the quality of life of these individuals but also improved the concentrations of gas in their blood and quality of sleep experienced.

Sources include: RCP

Sleep Apnoea and Snoring

By Professor Neil J Douglas

The sleep apnoea/hypopnoea syndrome is one of the most common medical conditions discovered in the last 50 years. It causes sleepiness, impaired work performance and raised blood pressure in one in 50 adults and results in them having a seven-fold increased risk of road accidents when driving. Major strides have been made in our understanding and treatment of this condition in the last few years but further research is also required into its prevention, diagnosis and treatment.

What is the sleep apnoea/hypopnoea syndrome?

An apnoea is a breathing pause and hypopnoea is a marked reduction in breathing. These result from marked narrowing or blockage of the throat during sleep. When one is awake, throat muscles contract to keep the throat open when breathing in. Sleep relaxes all muscles and thus there is a tendency for the throat to narrow when air is sucked in. If the throat narrows to a slit, then disturbed flow produces the vibration and noise of snoring. This itself is not medically harmful but if the throat narrows further to block or very nearly block then the individual fights for breath until they wake themselves up. This is so brief that it is normally not recalled in the morning but is sufficient to activate the throat muscles again. The subject takes in a few deep breaths and then falls rapidly back to sleep and so the throat muscles relax again, the throat may block and further brief awakenings ensue. This recurrent cycle of blockage, waking, sleep, blockage, waking,

sleep, may happen up to once or twice per minute all night. The many hundreds of awakenings per night shatter sleep quality and are the main cause of the daytime sleepiness - the major symptom of the sleep apnoea/hypopnoea syndrome.

How common is it?

The sleep apnoea/hypopnoea syndrome occurs in approximately two per cent of adults, being slightly more common in men than women. The referral rates to sleep specialists for this condition are still rising very markedly but it is estimated that only around one in 10 patients with the syndrome have so far been diagnosed and treated, with the rate of treatment lower in the UK than most other developed countries.

Consequences of the sleep apnoea/hypopnoea syndrome

Daytime sleepiness is the major problem for most patients with the syndrome. This may seriously impair their ability to do their job effectively and also usually results in

them being so sleepy in the evening that their social and family life are significantly disadvantaged. Patients often fall asleep uncontrollably in unusual situations such as chairing meetings, talking to colleagues, working at computers or operating machinery. The sleepiness is usually worst in monotonous situations. The combination of work and social problems contributes to these patients having significantly impaired quality of life and often depression.

Driving

Several studies over the last decade have confirmed that patients with the sleep apnoea/hypopnoea syndrome have a high rate of road accidents. This can be caused either by falling asleep at the wheel or by inattention and delayed reactions due to sleepiness. The consensus from many studies is that they have a seven-fold risk of road accidents compared to normal drivers. It is thus important to identify and treat these individuals, as rapidly as possible, as the accidents may involve not only the sufferer but also innocent road users.

Hypertension

A variety of studies from North America and Europe over the last three years have proved that the sleep apnoea/hypopnoea syndrome is associated with high blood pressure. This is thought to be due to both the drops in oxygen level and the awakenings with each breathing pause which are associated with a marked elevation in blood pressure. These blood pressure surges, occurring many hundreds of times every night over years or even decades, result in sustained hypertension. This almost certainly results in an increased risk of heart attack and stroke in sleep apnoea patients.

Treatment

The syndrome can be very effectively treated by a combination of weight loss, avoiding evening alcohol and continuous positive airway pressure therapy - a machine which blows a gentle stream of air in through the nose to keep the throat open during sleep. Some patients also benefit from dental devices to keep the lower jaw forward during sleep.

The cost of the sleep apnoea/hypopnoea syndrome

Economic cost

As yet, there have been no comprehensive estimates of the financial burden of the sleep apnoea/hypopnoea syndrome. The major cost is almost certainly due to a combination of some sufferers being totally unable to work and most performing sub-optimally in their employment. In addition, there is the health burden due to numerous consultations and prescriptions for most individuals attending their family practitioner with what is often wrongly perceived as non-specific symptoms. Most doctors still do not have a high index of suspicion for the

sleep apnoea/hypopnoea syndrome and it is common for patients to see many doctors with many differing complaints before the diagnosis is made. In addition, there are the large health service related costs of hypertension, myocardial infarction and stroke.

The other main economic burden relates to road accidents. Patients with the sleep apnoea/hypopnoea syndrome are seven times more likely to have road accidents and sleep related accidents carry a higher mortality and morbidity than average. As the financial burden of a fatal road accident is £1.2 million, these costs are very significant, particularly when set against the cost of about £250 to treat the syndrome.

Social cost

The sleep apnoea/hypopnoea syndrome imposes major social problems on the patient and their partner. Not only does the patient feel too sleepy in the evening to participate fully in family life or to go out, but also they are loud snorers with restless nocturnal sleep who tend to make their partner's life a misery overnight as well. The snoring also often imposes restrictions on their choice of holiday and employment because sharing rooms, or even being in the next door room to others can cause considerable embarrassment and annoyance. The inability to drive more than a short distance without falling asleep may also contribute to social isolation.

Advances in the last five years

There have been two major areas of advance in the last five years. The first is the definite confirmation that the sleep apnoea/hypopnoea syndrome is associated with hypertension. Two recent studies from Britain have shown that

treating patients with the syndrome with continuous positive airway pressure therapy (CPAP) significantly reduces their blood pressure. The second recent advance is confirmation from randomised placebo controlled trials that treating patients with the sleep apnoea/hypopnoea syndrome with CPAP therapy results in improvement in their symptoms, sleepiness, cognitive function, intelligence quotient, quality of life, mood and driving abilities. Many of these studies were funded by the British Lung Foundation. These have been useful in persuading health authorities to increase funding for the treatment of this condition and form the basis of the recently published SIGN/BTS (Scottish Intercollegiate Guidelines Network/British Thoracic Society) evidence based guidelines on the management of the sleep apnoea/hypopnoea syndrome.

Priorities for research

Among the important unanswered questions are:-

1. Why do people get the sleep apnoea/hypopnoea syndrome?

The factors known to predispose to sleep apnoea are obesity - although 50 per cent of patients are not obese - and a family history of the condition. Detailed genetic studies are required to determine whether there are genetic predispositions to facial structure or fat deposition in the neck which predisposes to the development of the syndrome. We also need research into why snoring and sleep apnoea peak in middle age and why they are more common in men.

2. Consequences of the syndrome

Britain has contributed more to research in this area than any other country but further funding is desperately needed to determine



About one in ten sleep apnoea/hypopnoea patients get treated

precisely the medical and economic consequences of the syndrome. Children who snore or have sleep apnoea do poorly at school, but the extent and significance of this needs to be established. There are still no definitive data that either heart attacks or strokes are definitely more common in adult patients with the sleep apnoea/ hypopnoea syndrome. A cost/benefit analysis of the diagnosis and treatment of sleep apnoea is urgently required to determine the priority that should be given to diagnosing and treating this condition.

3. Diagnosis

Simpler and cheaper diagnosis needs to be developed. Systems need to be developed with sensors which can be applied reliably by the patients for use in their own bed at home and as yet no such systems exist.

4. Treatment

CPAP remains the cornerstone of therapy but is relatively obtrusive if extremely effective. Patients would much prefer to take a simple tablet and a priority area for research must be to develop an effective medication. This is most likely to be developed either from a better understanding of the genetic basis of sleep apnoea or from a study of the neurochemical mechanisms controlling sleep and upper airway muscle function and thus both must be priority areas for research.

Conclusion

The sleep apnoea/hypopnoea syndrome is a very common disorder with major consequences for many Britons. The British Lung Foundation is the only specialist charity funding research into this important condition in the UK and the British Lung Foundation's contributions have already made significant contributions towards the understanding and treatment of this condition.

Case study:

Jasmine Smith, 45 from Staffordshire

"I'm 45 years old and live in Staffordshire. I have two lung conditions - brittle asthma and sleep apnoea. I didn't realise I had sleep apnoea at first, I had always put my broken sleeping patterns down to my asthma.

The condition means that I am often tired and lethargic in the day due to lack of sleep. You don't realise that you've stopped breathing in your sleep until you wake up suddenly. Obviously a good night's sleep makes you feel better, so lack of sleep aggravates my asthma.

From time to time I use a C - Pac machine (mini ventilator) to help me sleep. You have to wear head gear to use this machine so although it helps you sleep more easily the head gear is quite obstructive! The machine also makes a lot of noise which can disturb your partner's sleep so it's a double edged sword!

I know this condition can really disrupt some people's lives, they wake every few minutes throughout the night and it jeopardises their careers and relationships. But luckily for me the condition has become more manageable over the years, especially now since I now wear a trachea and use 24 hour oxygen."

Research:

The British Lung Foundation has funded a variety of projects into obstructive sleep apnoea. For instance, Dr John Stradling from Churchill Hospital in Oxford was awarded a grant in 1998 to clarify the severity of driving impairment in people suffering from obstructive sleep apnoea and to see if treatment by nasal continuous positive airway pressure could help. The researchers found that the driving skills of people with sleep apnoea were markedly reduced compared to a control group but that this could be improved by treatment with nasal continuous positive airway pressure. Professor Neil Douglas and his team at the Scottish National Sleep Laboratory in Edinburgh have been at the forefront of refining this form of treatment and comparing it with other types of treatment, backed by BLF funding.

Another study carried out by Dr Stradling on sleep apnoea in childhood found that there is a relationship between children suffering from sleep disordered breathing and daytime problems such as hyperactivity. Relief of the sleep disorder by removal of the tonsils was found to improve children's behaviour.

Research on babies suffering from bronchiolitis and who have disturbed sleep patterns was carried out by Dr Anne Thomson at the Radcliffe Infirmary in Oxford. Her research found that babies breathe more easily if they sleep on their front.

Rarer Lung Diseases

By Dr Peter Cole and Dr Athol Wells

Bronchiectasis

What Is It?

Bronchiectasis is an inflammatory disease of the bronchial airways in which there is destruction of the elastic tissue resulting in damaged, dilated airways which cannot clear away secretions as they normally do by the mucociliary clearance (MCC) system.

What Causes It?

If live bacteria persist within the airways because MCC is impaired, bronchiectasis develops in those airways. It is therefore the final common pathway of a number of causal conditions which have in common impaired clearance of bacteria, sometimes as a remote sequela to the initial insult. Such causes include inhalation of a foreign body that is not removed, genetic diseases such as cystic fibrosis (CF) and primary ciliary dyskinesia (PCD) that impair the mucus or ciliary components of MCC, and post-infective complications such as childhood whooping cough and pneumonia, deficiency of immunity to infection (especially antibody deficiency). But a number of patients have bronchiectasis where the history and investigation fail to reveal the cause (idiopathic).

How Common Is It?

It was common prior to the advent of antibiotics, and of vaccines to prevent childhood infections such as whooping cough. Now it is impossible to be sure of the prevalence of bronchiectasis because a CT scan is required to be sure that it is present or absent. That is an investigation that cannot

be employed in a population study because it involves exposure to ionising radiation. However, it is thought to be less common than the five cases in 10,000 that is commonly quoted as the cut off for a rare or orphan disease.

What Are The Patients' Problems With It?

The major problem for the patients is often undue fatigue which they commonly do not mention to their doctor, normally for fear of being labelled a malingerer. This ruins their quality of life, affecting performance of their job, stability of their marriage and enjoyment of their social life.

But the more objective symptoms are a cough, usually productive of purulent sputum often with breathlessness due to airflow obstruction and, sometimes, recurrent coughing of blood (haemoptysis). Recurrent acute airway infections are a big problem and may be associated with rhino-sinusitis. In some forms of the condition fertility may be impaired (eg. in CF and PCD).

What Are The Doctors' Problems With It?

First, the doctor must suspect the diagnosis and differentiate it from tobacco smoke-associated chronic bronchitis (most patients with bronchiectasis have never smoked or are ex-smokers). Diagnosis requires a CT scan of the lungs because a simple chest x-ray is often insufficiently sensitive to detect it.

Then the doctor needs to determine the cause, if this is possible, as some causes require

treatment of the underlying condition as well as of the resultant bronchiectasis.

Both of these diagnostic exercises usually require referral of the patient to a specialist with experience of managing this condition and with recourse to the special techniques required for its investigation.

What Are The Patients' Expectations?

A patient with bronchiectasis reasonably expects:

1. the GP to suspect bronchiectasis
2. to be referred to a specialist centre for diagnosis & planning treatment
3. to require not only diagnosis of the bronchiectasis but also determination of the cause
4. to be recognised as frequently suffering from undue fatigue as the main symptom.
5. to be taught by an expert chest physiotherapist to carry out regular, self-administered, gravity-assisted postural physiotherapy using the forced expiratory technique
6. to be given a suitable (adequate dose & duration) course of a satisfactory antibiotic to hold at home and use at the first sign of an infective exacerbation of the condition.

How Far Has Research Helped Patients And Doctors?

Over the last 10 years research has increased the profile of bronchiectasis and brought it to the attention of primary and secondary care, thereby increasing diagnosis of the condition.

Diagnostic techniques have improved and the diagnosis is now established by a painless method compared with previous bronchographic techniques. Determination of the cause of bronchiectasis has improved so that a cause is found in about 60-70 per cent of cases. Techniques for measuring MCC have improved, and for measuring the relative contributions to it of ciliary beating & mucus transportability.

Nevertheless, treatment still relies principally on physiotherapy and antibiotics as it has done for many years.

What Are The Research Priorities In The Future?

Research needs:

1. to target the relative contribution of genes and environment to the development of bronchiectasis
2. to develop non-antibiotic therapy designed to protect the bronchial wall against bacteria- & host-mediated damage (cytoprotection)
3. to improve the movement of mucus on cilia, ie. improve MCC (mucokinesis), and
4. to limit the damaging component of the inflammatory response (immunomodulation).

It is important to improve the patients' quality of life so the cause of the undue fatigue needs to be elicited.

Sarcoidosis

What is it?

The term sarcoidosis refers to a disease in which immune cells (that normally play a key role in defending the body against infection and foreign substances) accumulate in tissue in aggregates called "granulomas" and cause illness in their own right. The disorder often begins with acute symptoms, with fever, severe tiredness, joint aches

and, sometimes, drenching sweats at night, eye irritation and subcutaneous lumps (especially in the lower legs). Generally, the problem diminishes with time, and in many cases, it will resolve completely over six to 12 months, never to return. This form of sarcoidosis is quite a common illness in young adults, and it is likely that it often occurs without the diagnosis being made (as the symptoms are similar to those of infection).

The more serious form of sarcoidosis, occurring in a minority of patients, takes the form of persistent illness. Sometimes, the disease "burns out" over three or four years, and treatment can be withdrawn. However, in other unfortunate individuals the disease remains active indefinitely. Sarcoidosis can involve many different parts of the body in different sufferers of the disease, but in long-term disease the most common affected site is the lung. However, it is not unusual for the disease to involve two or more sites simultaneously (such as the lungs, skin and liver). Because any part of the body can be affected, it is useful for sarcoidosis sufferers to discuss any new unexplained symptom with their doctor as soon as possible, even if it seems unlikely that a new problem is related to sarcoidosis.

When abnormalities in tissue consist of aggregates of immune cells, it is usually possible to suppress the process with treatment, so that the abnormalities reverse completely. However, irreversible tissue scarring often occurs in those with prolonged disease, and when this is severe or rapidly progressive, the illness should be regarded as serious. As a general principle, treatment is required in sarcoidosis for two broad reasons. In a minority, there is serious organ involvement (e.g. lungs, heart, central nervous system,

liver, kidneys) or another dangerous complication (e.g. abnormally high blood calcium levels); in all these scenarios, there is a significant risk of reduced life expectancy if treatment is not introduced. In another large group, ongoing disease activity is not intrinsically dangerous but may be disabling because of a major or even devastating reduction in quality of life. Intractable fatigue is probably the most common disabling symptom in sarcoidosis, but quality of life may be unacceptably reduced due to loss of appetite and weight loss, fevers with drenching sweats, joint pain, muscle pain, nasal congestion, eye irritation and skin involvement.

How is it treated?

Steroids are generally used as first line treatment. It is essential that the benefits from treatment are weighed up against possible side-effects, before therapies are started. The most efficient way to ensure that the total steroid dose is as low as possible is to use a high dose to begin with, in order to take control of the disease. Once this is achieved, it is usual to reduce the dose reasonably rapidly to a relatively "civilised" dose (e.g. prednisolone 10mg a day). It takes longer to establish the minimum dose that meets an individual's needs, and attempts should be made to withdraw steroids altogether from time to time. However, it should be stressed that a daily dose of prednisolone of, for example, 7.5mg daily does not produce the steroid treatment horror stories known to most people. Side effects at this dose are generally minor and very effective and simple protective treatment against bone thinning is now available.

When disease is dangerous, a doctor has a duty to persuade someone with sarcoidosis, often

against their wishes, that treatment is needed. However, when the basic problem is loss of quality of life, only the sufferer has a true sense of the severity of the problem. In that situation, the challenge is to make sure that the patient has a true sense of the risks of treatment, in order to make a balanced decision on whether the potential benefit of treatment justifies its disadvantages. In this difficult situation, it is often a good idea to try a short course of treatment, to determine whether quality of life is transformed for the better, without any evidence of a treatment-related problem.

What research is being done?

Recent and future research in sarcoidosis has centred upon trying to understand better the way in which the disease develops, in order to find new and more effective therapies. Thus, a good deal of research is being devoted to identifying genetically inherited risk factors for developing the disease, and also to studying important molecules that cause disease to worsen. Based upon this research, a number of new treatments are being developed and some of these will be studied in humans in the near future.

Fibrosing alveolitis

What is it?

This umbrella term is used to describe a group of disorders in which there is significant scarring of the lungs without an obvious cause, or an underlying illness (such as sarcoidosis). These disorders are grouped together because when a sufferer first seeks medical advice, there are certain features that are similar for all lung scarring conditions, including the presence of scarring on a chest x-ray, breathlessness (sometimes with

cough) and crackling sounds in the lungs (heard with a stethoscope). Thus, "fibrosing alveolitis" is a term describing a particular clinical syndrome, that may result from a number of underlying conditions. Fibrosing alveolitis occurs in both sexes and is more common in males and those over 60 years of age, but can occur in all adult age groups. It is more common in current or former smokers but also occurs in those who have never smoked.

It is essential that further investigation be performed as soon as fibrosing alveolitis is detected, because the long-term outlook is critically dependent upon the nature of the underlying disease. Sometimes, a condition is uncovered with a good long-term outlook, although prolonged treatment may be required. Occasionally, tests reveal the fact that there must be a hidden cause in the environment, and this can sometimes be vital, as removal of the cause may bring a halt to worsening of the disease. The essential initial test is a CT scan, and it is often possible to be fairly certain about the underlying condition, just from CT appearances, blood test results and other features of the illness. However, sometimes more strenuous investigation is needed. This includes a bronchoscopy (in which a small tube is passed down the air-passages, in order to determine the activity of the disease process) and, sometimes, a minor operation in order to obtain a sample of tissue to examine under a microscope (a "surgical lung biopsy").

Unfortunately, the most common underlying condition is a disease known as "idiopathic pulmonary fibrosis" (IPF). This disorder tends to worsen steadily with time, in spite of treatment, although it is sometimes possible to

slow the disease process down. On average, in large groups of sufferers the average survival is three to four years. However, this "average" can sometimes be highly misleading, as the disease sometimes moves rapidly, but sometimes progresses rather slowly. The rate of worsening over, for example, three to six months in an individual is a much more reliable indicator of what will happen to that person in future.

How is it treated?

Treatment decisions are often difficult and it is absolutely essential that a person with fibrosing alveolitis is completely aware of what is being attempted. In some underlying disorders, there is an element of reversible disease and there may be a real improvement with treatment. In that case, high dose treatment is often required; it should always be understood that the hope of an improvement needs to be set against a greater risk of side-effects. However, in IPF and in some other conditions, the underlying condition has pure scar tissue with no reversible inflammation. In that case, treatment is given to try to prevent the development of more scar tissue, and as long-term therapy is required, it is terribly important to find a civilised treatment that causes as few problems as possible. It is sometimes necessary to "shop around" to find drugs that suit an individual; in effect, this may mean trying two or three drugs in succession, if side-effects start to occur. It is usual to take steroids in low doses and an immunosuppressive agent.

Occasionally lung transplantation should be considered, but it should be stressed that this is a rare situation. There is a desperate shortage of organs, and, in addition, the surgery itself is terribly arduous, with a death rate of 30 per cent in the next year.

Transplantation should not be considered unless there is a realistic hope of being able to cope with the procedure (i.e. no other major diseases present, the person is young enough to survive the operation) and the disease is very advanced and resistant to treatment. However, occasionally transplantation is a realistic option and discussion of the possibility is often a very good thing, even if the answer is disappointing.

What research is being done?

Recent research in fibrosing alveolitis has centred upon identifying more accurately, by the use of CT scans and other tests, which particular underlying condition an individual is suffering from. In the past, a surgical biopsy has often been needed for this purpose but recent research has established that the information previously obtained by biopsy can now often be gleaned from more "civilised" tests. Thus, it is increasingly possible, as never before, to make reasonably accurate predictions as to how a disease is likely to behave in an individual patient.

A second highly exciting area of new research growth is the development of a number of drugs that may, for the first time in medical history, bring about a reduction in scar tissue. It has always been accepted, from the time of the ancient Greeks, that scar tissue ("fibrosis") can be removed by drug therapy. However, there may be light at the end of the tunnel. Studies in the laboratory and in animals have suggested that several new treatments may actually bring about resolution of the scarring process. A number of trials of new drugs are now underway, or about to begin. Suffice to say that an unequivocally positive result in any of these studies will amount to a major breakthrough in this difficult disease.

Case study:

Carole Walker, 46 from Kent:

"I was diagnosed with bronchiectasis when I was six months old so I don't remember life before it. They think I might have contracted it either from whooping cough, or maybe from the afterbirth.

Since I was 21, I have had to go to the Royal Brompton Hospital twice a year to see my consultant, but I have also managed to lead a relatively normal life. I think I cope very well with my condition, and since I was diagnosed I've got married and had two children, and have just become a grandmother, so I am busy helping out with the new baby.

I also work full time as a secretary at a busy school, but bronchiectasis does leave me very tired. I usually go to sleep by about 9pm but I rarely have to take time off work and I have learnt to pace myself.

I have to do physiotherapy on myself, called postural drainage, each day when I get in from work to clear my bronchial tubes which is hard work but makes my breathing much easier. Until I was about nine my mum used to tickle me to do the postural drainage - being tickled simply makes me cough like mad!

Bronchiectasis has never stopped me doing anything in life - ironically I was at my fittest and healthiest during my two pregnancies. I do exercise, but gently - I walk on a treadmill and play tennis. I find it a very frustrating condition as I know I could do so much more if I didn't have bronchiectasis - and also very embarrassing - when I cough in public and it dislodges phlegm people wrongly assume I am a heavy smoker rather than realizing I have an illness."

Research:

The British Lung Foundation is the only UK organisation that funds research into all lung diseases. With well over 40 diseases, there are a large number of rarer, so called 'orphan' diseases such as fibrosing alveolitis. The BLF has spent over £1 million on research into fibrosis, or scarring of the lung. Professor John Britton and his team from City Hospital in Nottingham were awarded a grant to investigate whether there is a relationship between exposure to metal dust and development of fibrosing alveolitis. They found that there was indeed a direct link between the extent and duration of exposure to metal dust and death by lung fibrosis.

In many cases, lung transplantation is the only option of successfully treating people with advanced lung diseases such as cystic fibrosis, emphysema, pulmonary fibrosis, alpha-1-antitrypsin deficiency and pulmonary hypertension. Unfortunately many lung transplant recipients are eventually affected by a slow deterioration of lung function, which may be caused by a poorly controlled immune response. To improve the chances of successful lung transplantation, Dr Paul Corris from the Freeman Hospital in Newcastle-upon-Tyne studied a simple breathing test designed to pick up the earliest signs that the body is starting to reject an implanted lung. He discovered that patients beginning to develop chronic rejection breathe out higher levels of nitric oxide gas.

The Role of Research

By Professor Moira Whyte

Research is essential for answering fundamental questions in lung disease. Much of the research effort within the NHS aims to improve the delivery of existing treatments, while the pharmaceutical industry develops new drugs to modify disease processes, often with great success. Such approaches, together with research funded by charities like the BLF, will benefit individuals who currently have lung disease but will not discover the causes of disease and thus will not be truly “curative”. Curative treatments will most likely come from research into what gives rise to important lung diseases such as lung cancer and COPD, often called “basic research” because it aims to understand the fundamentals of disease.

Why is it important to fund research into lung disease?

Lung diseases are major killers in our society.

- COPD kills 51 men per 100,000 of the population each year and has been predicted to become the third leading cause of death worldwide by 2020.
- Lung cancer now kills more men than any other cancer in the UK and as many women who die of breast cancer are now dying of lung cancer. Its incidence is expected to rise even further over the next 20 years, with an increasing number of cases unrelated to smoking. Despite multiple trials of new chemotherapy and radiotherapy treatment regimens, the two-year survival rate is less than five per

cent and this figure has remained virtually unchanged over the last 30 years.

- Asthma affects 12 per cent of the adult population, costs the NHS £850 million each year and continues to kill significant numbers of people.

Yet, for all these conditions, the processes that give rise to disease are poorly understood. Only by identification of the key molecules involved in initiating and perpetuating these diseases can we hope to design the new treatments that are so urgently needed. In addition, although curing disease is crucially important, there is important research needed in disease prevention and in finding new treatments to help people currently living with lung disease.

How are we doing at present?

Lung disease is a very poor relation in terms of research funding. Nine per cent of total NHS resources are expended on lung diseases but, despite this, funding of respiratory research is disproportionately low in relation to the impact of lung disease on our society. A report in 2002, by City University, London for the Department of Health, looked at the research output of respiratory medicine in 15 different countries. The UK performed relatively well in terms of research publications, but 39 per cent of these had no specific funding support. Funding support for research was notably weak in areas such as lung cancer, COPD and pneumonia. Lung cancer receives a much smaller share of cancer

research funding than other cancers, such as leukaemia and breast cancer. These differences have important consequences for our ability to improve the prospects of our current and future patients with lung disease.

Why is lung research under-funded in the UK?

There are a number of possible reasons why lung disease is relatively under-supported. Many lung patients are old and in poor health and thus less able to participate actively in "pressure group" type campaigning. Moreover, many people believe that smoking cessation will abolish lung disease. Even for those lung diseases that are smoking-related, such as lung cancer and COPD, this will not help the patients currently affected, where research can make real improvements in quality of life and symptomatic treatment. Lung diseases like COPD and lung cancer are often viewed, even by academics and funding agencies, as "intractable problems", but there are now a number of novel therapeutic approaches for both these conditions and the BLF has been able to provide research funding in these areas.

Flagship research in lung disease sponsored by the BLF

Dr Tariq Sethi (University of Edinburgh) researches into small cell lung cancer, a particularly aggressive form of lung cancer. It is believed that cancer cells can evade the immune system and lung cancer patients show abnormalities in immune responses which correlate with poor survival. Augmentation of the immune system may provide a novel treatment for this disease.

Dr. Sethi has shown that there is an exciting interaction between small cell lung cancer cells and lymphocytes, involving signalling via a molecule called Notch. This results in the failure of the body's defences, such that cells of the immune system rather than killing cancer cells make them more dangerous (resistant to chemotherapy). In addition, the cancer cells themselves suppress the activity of immune cells. Understanding the mechanisms involved may lead to identification of novel therapies to restore the immunological defences against cancer cells.

The year 2002 saw the award of the first British Lung Foundation/Allen & Hanburys Research Fellowship in COPD and Airways Disease to Dr Lynne Bingle (University of Sheffield). Dr Bingle is studying a novel family of proteins known as PLUNC which may play a role in our host response to bacterial infection, since PLUNCs are structurally related to proteins critical to the host response to bacteria. PLUNC proteins are predominantly expressed in the airways and molecular analysis has shown they are among the most rapidly evolving proteins in mammals, a characteristic of proteins attempting to "outflank" pathogenic organisms. Understanding the role of this novel family of mediators in normal and diseased lungs will increase understanding of anti-bacterial defences in the lung.

Other awards in 2002 included grants to Professor Duncan Geddes and Dr Tudor Toma (Royal Brompton Hospital) for a new bronchoscopic technique to achieve lung volume reduction in patients with severe emphysema and to Dr Jeremy Brown and

Professor Gordon Dougan (Imperial College) for research into new vaccines for pneumococcal pneumonia, the commonest form of the condition.

Conclusion

Lung disease places a major burden upon individuals, their families and friends and the NHS and research into the causes of lung disease is urgently needed. The British Lung Foundation aims to expand and enhance research into lung disease, both by providing direct support for research, in the form of research grants, and by raising awareness of the importance of lung research to the Government and other grant giving bodies.

Conclusion

By Dame Helena Shovelton

In writing this conclusion to *Lung Report III* I am struck by how much and how little has changed since we produced *Lung Report II* in 2000. In that report we highlighted the facts about lung disease and the toll it takes on the National Health Service and on patients. Little has changed in this regard. In setting out the figures below it is possible to see that, if anything, some matters have got worse. But if we start with the good news...

Improvements:

- Announcement by the Government in response to pressure from the BLF and the BTS of the need for improvement in provision of oxygen therapy from 2005 in England.
- The creation of a National Service Framework for Older People including COPD which should result in the improvement of treatment for COPD patients from 2004/5.
- The creation of the National Patients' Collaboration which will use COPD as one of two conditions to concentrate on with 20 Primary Care Trusts during 2004/5. This programme has the potential to be rolled out to all PCTs following this initial programme.
- An increased provision of Pulmonary Rehabilitation for patients in the UK compared with 1999.

Decline in Services

Due to the introduction of National Service Frameworks diseases that are not covered are

being left behind. Since there is no overall NSF for lung disease, this means that for the millions of people with lung disease that are not covered by an NSF their treatment is seen as less important by the Government than other illnesses. For patients and doctors this is debilitating and depressing.

Numbers being admitted to hospital are still extremely high and have not diminished since *Lung Report II*. The overall cost to the NHS of these admissions is £1.08 billion.

The number of days lost to work of lung disease has not decreased over the last three years and remains at 25.28 million. The cost of this to the country as a whole is £1.5 billion.

The number of GP visits associated with lung disease is over 1.4 million per week and therefore costs the NHS £20.86 million a week.

The amount of money spent on research into the various lung diseases has gone down since 1999. The Medical Research Council only spends 3.8 per cent

of their gross expenditure on respiratory research.

Of all the monies spent on cancer research only three per cent is spent on lung cancer when over 35,000 people die each year from the disease.

More cases of mesothelioma are being recorded each year and approximately 1,500 deaths are now occurring annually from this asbestos-related disease.

The treatment of lung cancer in the UK puts us at the bottom of the European league of lung cancer morbidity.

One can see from this list that if you have a lung disease you are unlikely to be thought a priority. People will not even notice you have an illness as frequently the level of disability is so great that people are housebound. Four years has been taken over the oxygen review and a further 18 months is needed to work out how to make the changes agreed to. During this time those in need of long term oxygen therapy have been forced to stay at home for much of their lives or pay considerable sums of

money for the privilege of gaining truly ambulatory oxygen to enable them to move outside the home. Is it possible to imagine that people needing wheelchairs would have been forced to wait six years for the Government to decide to provide chairs on the NHS?

The BLF wants a better deal for people living with lung disease - mainly:

- Good implementation of the new oxygen policy. We have asked to be on the working party looking at this issue.
- Pulmonary rehabilitation as part of a NHS funded embedded service

for all those who would benefit from it - currently 900,000 people have COPD but only 1.1 per cent of them have access to pulmonary rehabilitation.

- A considerable improvement in the provision of monies for research into lung disease to help make the sort of progress that has been possible in other illnesses.
- Greater understanding of the need for early diagnosis and treatment in lung cancer to improve survival rates.

We are attempting in *Lung Report III* to provide you with a picture of lung disease as it is today in the UK. Since devolution it is difficult to compare all the figures with those of many years ago without amalgamating figures from Scotland, Wales, Northern Ireland and England. We know the picture differs in each country and we will be producing separate figures for each one over the years ahead.

We want people to know about the picture today and how it affects people living with lung disease - there are plenty of them - over eight million at the last count.

About the British Lung Foundation

The British Lung Foundation (BLF) is the only charity in the UK working to help people with all lung diseases. The BLF supports patients through the Breathe Easy Club network, and produces information including leaflets and booklets and disseminates it through many sources including its website.

The charity also finds solutions to lung disease by funding world class medical research.

In addition the BLF works to give the 8 million people with lung disease a voice through raising public awareness and campaigning, as well as lobbying Government.

The views expressed in this publication are not necessarily those of AstraZeneca.



**BRITISH LUNG
FOUNDATION**

*Supported by an
educational grant from*

AstraZeneca 

www.lunguk.org

Registered charity: 326730

ISBN 0 9527472 0 0