



PF NEWS

*May 2014 Issue 4
For families affected by
pulmonary fibrosis*

In this issue:

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Support for Carers

The New Brunel Building

- Where to find Respiratory Outpatients and the Lung Function Unit.

News, Updates and Information



Living with Pulmonary Fibrosis

Welcome to the fourth edition of PF News.

The Bristol Support Group celebrated its first birthday in February. I'm sure all those who come along to the meetings will wish to thank Heather Lamb and all the staff who work in respiratory health who give up their own time to come along and support us.

We are always pleased to see new faces at the meetings and the talk by Rachel Gunary on living with PF was aimed not only at people newly diagnosed with the illness, but also provided food for thought for those already coping day to day.

Support for carers was a theme for the April meeting. Gill Deacon of the Carers Association gave advice about the support that is available to carers and our own Jeanne Cawley addressed the meeting to sound out support for a carers group specifically for those affected by PF. Later in this issue Jan Jenkin writes about reduced or even free entry for carers at local theatres.

The new Brunel building will be up and running by the time you are reading this and there is information in this newsletter about where to find the new respiratory outpatients and lung function unit.

If you have any topics you would like to see discussed at future meetings, or have advice or tips for other PF sufferers – or their carers and families – please do contact me or Heather.

Gail

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Front Cover

They made it! Congratulations to the BRAM Team.

REPORTS FROM MEETINGS

12 February 2014 – Bristol PF Support Group

Living with Pulmonary Fibrosis.

A talk by Rachel Gunary, Head of Psychology Service

Many people with pulmonary fibrosis experience a number of lifestyle changes – adapting and adjusting to changes in health in order to live as normally as possible, even though some day to day aspects have changed.

Rachel asked about how individuals felt when they received their diagnosis – feelings of confusion, the need for information to try to understand what does this mean for me? It can be a confusing time for individuals not helped by the jargon that comes with PF! Family dynamics, some individuals felt their families became overprotective, some not so due to lack of understanding of the condition.

The frustration of perhaps not being able to do the things that had always in the past been able to do. Some individuals have experienced feelings of anxiety and felt lower in mood at times due to the uncertainty of their condition and expectations of the future. The frustration that comes along with having to plan activities and lack of spontaneity of just doing as had been able to in the past. However many of our group did not experience these negative feelings and report being upbeat and positive despite their condition!

People with lung disease often limit exercise to avoid breathlessness. As a consequence inactivity weakens the muscles and they become less efficient which can make basic daily activity, such as washing and dressing, more difficult. Staying in shape can help minimise this. There is good evidence that pulmonary rehabilitation - a programme of physical activity, in combination with education, improves the quality of lives of patients with lung diseases. This has usually been provided in the hospital setting, although increasingly it is being offered in the community. It allows you to meet other people who have similar symptoms and lung diseases, and gives you an opportunity to learn more about your illness and ways of coping with it. A team of staff (including physiotherapists, doctors, nurses, psychologists and dietitians etc) provides pulmonary rehabilitation. Ask to be referred if you have not yet been offered this.

In addition rethinking the way you do things may make the task easier, more efficient, use less energy and reduce the resultant feeling of breathlessness. Indeed some tasks may not be necessary at all! These changes are commonly grouped under headings known as the 5 P's : Prioritising; Planning; Pacing; Positioning and Permission to do things differently or not at all. Pacing, planning, and prioritising are good coping strategies in dealing with tasks in a manageable way.

It's important to balance fatigue and rest, but what about those times when you must be doing something? Devise a plan for how to accomplish certain tasks. Plan for all that needs to be done. Prioritize the list and what needs to be done first. Pace yourself as you go through your prioritized list. The trick is to be organized and deal with tasks in manageable chunks. The result is that you may find you have more energy to accomplish daily tasks and you are less short of breath. Don't forget to schedule time for yourself. Time for something you enjoy for yourself, whether it be listening to music, reading etc and reap the benefits.

Learn and practice relaxation techniques. When you are physically and emotionally relaxed, you avoid excessive oxygen consumption caused by tension of overworked muscles. Additionally, learning relaxation techniques can help you manage the panic that may accompany shortness of breath in some individuals.

Eating smaller, more frequent meals may prevent stomach fullness that can make it harder to breathe. If you need help with your diet, ask your doctor to arrange for a dietician to work with you.

Getting at least eight hours of quality rest every night can boost your immune system and sense of well-being. There are well known sleep tips – go to bed at the same time each night, get up at the same time each day, establish a ritual so that your body will recognize it's time to sleep. Remember to wind down at the end of the day and avoid caffeine before bedtime which is a stimulant.

Remember - keep a positive attitude. Keep time to spend with those who are important to you and continue to do the things you enjoy.

Respiratory Patient Information leaflets can be viewed at:

<http://www.nbt.nhs.uk/our-services/a-z-services/respiratory-medicine/respiratory-patient-information-leaflets>

Research in Pulmonary Fibrosis

At Southmead hospital we have a very active respiratory research team. **Debbie Warbrick**, Senior Research Nurse came to speak to us about research and give us an overview of current studies and what opportunities there are to get involved.

Clinical research is really important; it's the way in which we improve treatments in the NHS. It determines the safety and effectiveness of medications, devices, diagnostic products and treatment regimens intended for use with patients.

Why we do clinical research in PF...

- How and why Pulmonary fibrosis develops
- Genetic and environmental factors that may play a role
- The success of education programs and health services programs to improve pulmonary fibrosis management
- Possible avenues to prevent the disease

- What new products and medications are most beneficial

What are the benefits of getting involved....

- Access to treatments not readily available
- Improve knowledge of condition
- Improved sense of well-being and quality of life
- The possibility to try treatments years before they are readily available
- To receive high quality healthcare
- Active role in healthcare
- Results from the study will help other in the future

Current research opportunities at Southmead hospital....

We currently have 9 studies running at Southmead for IPF.

3 are not accepting new patients

3 are observational studies

3 are drug trials

Our observational studies include:

PASSPORT - A post authorisation safety study of Pirfenidone

IPF PROM - Patient reported outcome measures in idiopathic pulmonary fibrosis study

PROFILE - Prospective study of fibrosis in the lung end points study

Our interventional studies include:

PANORAMA

A phase 2, randomised, placebo-controlled study to assess efficacy and safety of NAC when given with background treatment of Pirfenidone.

RAINIER

A phase 2 study, randomised, placebo controlled study to assess the efficacy and safety of Simtuzumab in IPF

RIFF

A phase 2 study, placebo-controlled study to assess the safety and efficacy of Lebrikizumab in IPF

Quite often Professor Millar, Dr Adamali, Debbie or a member of the research team may approach you during your clinic visit, if they think you may be suitable for a study, to ask you if you would like to have some information to take away and read.

However If you would like to find out more information about any of our research or how you can get involved then do contact Debbie and the team, who will be very happy to have a chat. Contact details are:

[Debbie Warbrick, Respiratory Research Unit, Clinical Research Centre, Southmead Hospital, 0117 424 8114](#)

Bristol to Amsterdam Charity Cycle Ride

Debbie and several of her colleagues from the Respiratory Research Unit have been just a bit busy cycling 500 miles to Amsterdam to raise money for Shine Together. The money raised will be divided between four good causes, these include:

Avon Mesothelioma Foundation
Action Pulmonary fibrosis
North Bristol Pulmonary Fibrosis fund
North Bristol Lung Cancer fund

Donations can be made on the Justgiving website:

<http://www.justgiving.com/rru>

The Challenge

“The challenge is to cycle from Bristol to Amsterdam, which is just over 500miles We will be leaving Southmead Hospital, Bristol at 8-8.30am on Monday 28 April. Our first 3 days will be spent cycling to Dover (this is the part I’m not looking forward to- especially the ‘undulating’ English countryside!)



Nick, Oli, Debbie, Natalie and Naomi

The remaining 2.5 days will be spent cycling through France, Belgium and Netherlands. We are planning on arriving in central Amsterdam at the I AM AMSTERDAM sign in Museumplein Square at around 12ish on Saturday 3 May. “ Debs

STOP PRESS! total raised so far is £3,660.00. Our thanks and congratulations go to Debs and her colleagues for their amazing challenge.

9 April 2014 – Bristol PF Support Group

Heather Lamb opened the meeting and welcomed many new faces. She introduced Gill Deacon from the Carers Association.

Support for Carers

A talk by Gill Deacon.

Gill opened her talk by asking what is a carer? It is someone who is unpaid and who cares for someone who cannot manage alone. It covers all illnesses and conditions and ages.

She then went on to outline the wide range of support and services that the Carers Association can provide:

As well as providing general leaflets and services, the Association also provides a telephone advice and information line.

Carers Line 0117 965 2200

Email: carersline@carerssupportcentre.org.uk

Carers line opening times:

Mon – Thurs 10am – 1pm and 2pm – 4pm

Fri 10am – 1pm

A newsletter 'Carers News' is produced three times a year. Carers can register by telephone using the advice line. The newsletter is available electronically or by post.

There are carers support groups which provide a safe, confidential place to meet with other carers to share information and give support to each other.

Emergency Card Scheme. If a carer has an accident or is taken seriously ill, the card will ensure that the person they care for continues to receive the support they need.

Carers Assessments. The Carers Association can help with getting an assessment. This allows Carers to get help and support for themselves and the person they care for from social services.

The Association can also provide: **Training courses** to help carers cope on a day to day basis; **Carer holidays** – breaks for carers in modern holiday caravans in Torbay and the Cotswolds. www.carersholidays.org.uk; **Breaks for carers**. Providing a companion for the person looked after so that carers can take a regular break. (There is a charge for this service to cover costs.); **Counselling service**. Allowing carers to discuss difficult issues in confidence. (There is a charge for this service.)

The Association can also help with referrals to companies or organisations that can help with adaptations to the home.

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PF Carers Group

Jeanne Crawley asked if anyone would be interested in setting up a group specifically for carers of people with PF. Jeanne has been looking for a suitable group to join, but has been unable to find one that addresses the particular needs of those living with a PF sufferer. Jeanne suggested that the group could meet alternate months. She has already received some interest and she can be contacted at: Diapason8@talktalk.net

The break for tea and biscuits gave members the opportunity to chat and mingle. The very large turnout at this meeting certainly gave the room a real buzz. The **raffle** was, as ever, well supported with a good set of prizes – all donated. Thanks as always to those who contribute.

Heather reminded everyone that the **Bring and Buy** stall also needs contributions. We are saving towards an oxymeter for earlobe pulse monitoring to be used by the Respiratory Unit. So far we have raised £97.35. Please remember any contributions that remain unsold must be taken home again as there is nowhere to store them the hall.

Singing Group

Ruth told the meeting about a singing group she has joined. It is only for those living within South Gloucestershire since it is partly funded by the council. It meets weekly and no experience is needed. There is a good mix of ages and between 6 - 16 people turn up regularly. Ruth says that singing with friends provides respite from a carer role and is also 'a really good laugh'.

There is a £2 fee and tea and coffee are provided for a very reasonable 30p!

If you are interested please contact Indigo on 07592 016878.

Disability Band Reduction

It may be possible to get a reduction of one Band of Council Tax, for example from Band D down to Band C, if one room of your home has been adapted to cater for your needs or is used to store medical equipment, such as an oxygen concentrator or oxygen bottles.

Unfortunately a concentrator in the hallway, bathroom or kitchen cannot be counted. It must be a room in the house you would otherwise use for other activities.

Heather gave out application forms at the meeting. They are also available from your local council.

Bristol Lions

Heather introduced Keith Akerman from the Bristol Lions, which is the largest charity trust in the UK. The Lions collect money for local charities.

Keith told the meeting about a hugely successful project - the Message In A Bottle campaign. For the elderly or the vulnerable living alone it is important that in an emergency in the home the rescue and medical services can quickly establish personal health details. Plastic bottles containing these details are kept in the fridge and a sticker at the front door will immediately enable the details to be found.

This is potentially life saving. Bottles were available to anyone who wanted them at the meeting.

They can also be obtained direct from the Lions at:

<http://www.bristolbrunellions.org.uk/contact/>
or by phone on 0845 8335849

Keith ended his talk by presenting Heather with a cheque, on behalf of the Bristol Lions, for £50 to help our group. Our thanks go to the Lions for their generous support.



Keith Akerman presenting Heather Lamb with a cheque from the Bristol Lions.

Brunel Building

Heather gave an update on the move to the new Brunel Building.

Respiratory outpatients is on Level One (entrance floor). On arrival you will need to use the 'Self Check-In' kiosk within the main entrance. You will be able to record that you have arrived for your appointment and obtain directions to the clinic. Respiratory outpatients is just on your right, through Gate 12 in the Green Zone. You will need to check in with reception at the gate.

Lung Function tests will also be undertaken in the same area.
Telephone: 0117 4145400
Email: jason.viner@nbt.nhs.uk

Respiratory inpatients are situated on Level 4, Gate 27B.

There will be lots of volunteers on hand to show patients and visitors where to go when the new building opens. Volunteers will be wearing special sweatshirts, so they will be easy to spot.

The following is taken from the Southmead Hospital Bristol web site:

“All outpatient clinics will be on Level 1, leading off from the atrium and on the same level as the main entrance. This means patients won't have to go far within the building to reach their clinic. They will use the check-in bays and wait in the designated areas in the atrium, where there will also be a public café. There are 5 reception desks in the atrium for all outpatient clinics and the teams will be located in fixed areas, so that patients will become familiar with where they need to go for follow-up appointments. This also allows us to base staff in areas according to their speciality to make sure that the speciality knowledge is maintained.”

Parking will largely remain in the existing Beaufort Multi Storey Car Park for the time being. There is a small amount of on street Pay and Display parking available, A shuttle bus service is available from the Beaufort Multi Storey Car Park to the main entrance of the Brunel building which runs approximately every 10 minutes from 8am until 8pm. The bus stop can be found by the main pedestrian entrance to the car park.

Car parking is managed by OCS. If you are having problems finding a parking space call them on 0117 323 5023; they may be able to help with finding a parking place.

Remember, if you have a blue disabled badge you can use the disabled parking spaces provided free of charge. If there are no disabled bays available, you may park in any other space within a public car park free of charge as long as a blue badge is displayed.

A full set of floor plans for the new building can be viewed at:
<http://www.nbt.nhs.uk/services-floorplans-0>

Bonus for Carers...

On a recent visit to the Colston Hall Booking office accompanied by Mike my husband with oxygen in tow, I was asked if I was a carer and then told to my surprise I didn't have to pay for my ticket. I thought then I would check other venues in our area just out of interest:-

Bristol Old Vic Theatre: Complimentary tickets for carer

The Hippodrome: Discount on tickets depending on show

Theatre Royal Bath: Wheelchair user £10 and carer's ticket half price

The National Trust also has discount membership, not sure about other venues but it is worth asking before purchasing tickets.

Jan Jenkin



Has anyone else come across any discounts or special offers? Please contact the editor and we'll make sure they are included in a future edition of the newsletter.

PF in the News

"A campaign is to be launched this year to raise awareness of a relatively unknown but deadly lung disease, which is estimated to claim as many as 5,000 lives a year in the UK.

Zahida Aslam, whose father, Mohammed Aslam Butt, died from IPF in June last year, less than four years after being diagnosed, will sit on the charity's new advisory committee on the disease. She said her family felt powerless and alone after his diagnosis at the age of 73.

Zahida is setting up an IPF charity to increase awareness among the public and politicians, and raise funds for research. Dr Toby Maher, consultant respiratory physician at London's Royal Brompton hospital, said: "There's been a real increase in the number of incidences of IPF over the last 20 years or so.

Maher believes IPF has failed to receive more attention in the past because lung diseases are associated with smoking and, until recently, the prognosis for IPF sufferers was seen as hopeless. Last year, Pirfenidone, which helps slow the irreversible damage to the lungs, became the first IPF drug to be recommended by the National Institute for Health and Care Excellence, the public body that chooses which drugs can be used by the NHS. Other clinical trials are under way."

From the Guardian

Puzzles

One

Over the last few hundred years there have been thousands of reported incidents of horses jumping over towers and landing on clergy and small men, forcing their removal.

These incidents are well documented and there is great evidence that they all happened.

How can this be explained?

Two

Three people check into a hotel.

They pay £30 to the manager and go to their room.

The manager suddenly remembers that the room rate is £25 and gives £5 to the bellboy to return to the people.

On the way to the room the bellboy reasons that £5 would be difficult to share among three people so he pockets £2 and gives £1 to each person.

Now each person paid £10 and got back £1.

So they paid £9 each, totalling £27. The bellboy has £2, totalling £29.

Where is the missing £1?

HELP!

I have quite a large **garden** and find keeping it under control is increasingly difficult. I get lots of pleasure from it and luckily I'm not fussy about a few exuberant areas. My husband cuts the grass and does any hole digging, but he isn't a gardener!

Does anyone have any useful tips or experience of gardening with PF or shortness of breath?

Gail



If to have something you'd like help with, let us know. There must be a wealth of experience out there that others could find of use and comfort.

If you'd like to write an article that you think might be of interest to readers of PF news we'd love to hear from you.

gailwmills@aol.com

Answers to puzzles

Puzzle One - In a game of chess! This occurs when a knight, which looks like a horse, takes a bishop or a pawn.

Puzzle Two - We have to be careful what we are adding together.

Originally, they paid £30, they each received back £1, they now have only paid £27.

Of this £27, £25 went to the manager for the room and £2 went to the bellboy.

A man goes to see the doctor. He has a carrot in his right ear, a banana in his left ear and a cucumber up his nose. 'What's the matter with me?' he asks the doctor. The doctor replies, 'You're not eating properly.'

Joke

*Why are Pirates Pirates?
Because they Arrrrr*

Useful Contacts

Heather Lamb, Respiratory Nurse Specialist

Heather.lamb@nbt.nhs.uk

0117 4147762

Lloyd Mayers,
Respiratory Pharmacist

0117 4142263

A more comprehensive contacts list will be provided when the move to the Brunel building is complete

Next Meeting

Our next meeting is on

Wednesday 11 June 2014

Future meetings, always on a Wednesday from 1 – 3pm are on: June 11, Aug 13, Oct 8, Dec 10 2014

The Bristol PF Support Group meets every two months at:

New Brunswick Church,
Wigton Crescent
Southmead
Bristol, BS10 6DY