Vol 6
Issue 24
October
2019

Norfolk & Norwich Pulmonary Fibrosis Support Group

Autumn Meeting – 19th October 2019

I'm sure I don't know where the months go! We are definitely into Autumn now and this meeting brings us towards the end of the 6th year that the NNUH pulmonary fibrosis support group has been running. The group aims to provide a place for people with a diagnosis of lung fibrosis and those close to them to find information and support, both from our speakers at each meeting but, perhaps more importantly, from each other. It can be really helpful just to chat to others who really know what it is like living with similar symptoms and may well have some useful tips for dealing with them.

As we head towards shorter days and colder weather, it is worth thinking about getting a bit prepared for the winter months. If you haven't already, contact your surgery for your annual flu jab. You can't get flu from the vaccination and if you pick up flu over the winter, you could become very unwell. It is also worth having the pneumococcal vaccination – this is a one-off jab that protects you from a bacterial infection that can cause pneumonia.

Winter can be a difficult season for people with breathing problems but there are some steps you can take to help stay well. Make sure you keep warm – several thin layers are warmer than a few thick ones and even indoors, keep enough layers on to stay warm. If you are not able to be very active, you may feel the cold more and it can be difficult to get warm again if you have got a bit cold. Check your central heating is working well, perhaps think about getting it serviced before the weather really turns. Avoid going out if it is very cold, unless you have to – this might be the time to take family and friends up on offers of help with shopping etc. And if you do need to go out, try wearing a scarf that you can pull up over your nose and mouth to warm the air a little as you breathe in and shoes with a good grip, especially if the paths are likely to be slippery.

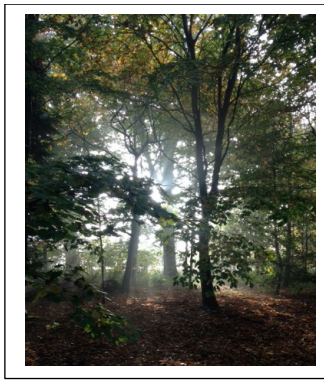
Make sure you have regular hot meals and drinks throughout the day; keep a supply of ready meals or pre-prepared food in the freezer, so that you can easily make a hot dinner if you can't get out or don't feel your best.

Try to keep away from people with colds and flu if you can and if you do pick up a cold, get plenty of rest, make sure you drink enough fluids and eat small frequent snacks and meals if you can't face a big meal. If you start coughing up more phlegm, especially if it changes to a darker yellow or green and you feel more breathless and unwell, seek advice from your GP promptly as you may need some antibiotics. Frequent handwashing helps to get rid of any bugs you may have picked up.

Make sure you have renewed your regular prescriptions so that you don't run out of medication and if you are prone to chest infections, it might be worth talking to your doctor about whether you could have a course of 'standby' antibiotics at home.

Stay well and warm. Best wishes for the end of the year, see you in 2020!

Best wishes, Sandra



Professor Andrew Wilson

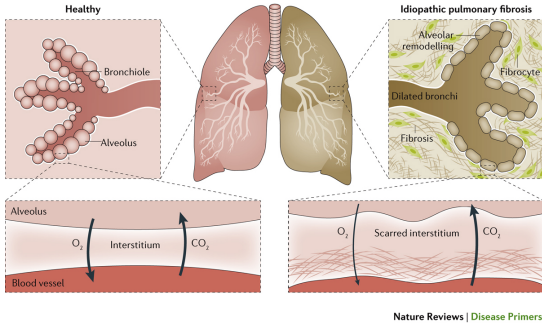
Consultant Respiratory Physician, NNUH

Research in Norwich – an update

We were pleased to welcome Professor Andrew Wilson to our Autumn meeting. Professor Wilson is a respiratory consultant at the Norfolk & Norwich Hospital (many of you will have met him in the outpatient clinics) with specialist interests in Interstitial Lung Disease (ILD) and asthma and also leads respiratory research in the School of Medicine at UEA.

He started by thanking the members of the support group, and the wider group of patients with pulmonary fibrosis, for being such willing participants in research studies, which has enabled Norwich to become an important player in the IPF research world and also to undertake studies in various other areas of ILD.

The function of the lungs is to allow oxygen to be transferred from the air that we breathe into our blood, to be transported to cells all around the body. This happens through a network of tiny airways (the 'tubes' in the lungs) which end in the alveoli, or air sacs. These have very fine walls and are surrounded by tiny blood vessels, into which the oxygen is absorbed, so that it can be carried through the arteries to the tissues and organs, so that they can work properly. The area around these air sacs and blood vessels is called the 'interstitium' and the ILDs are conditions where this gap is affected. If the gap is filled with cells from inflammation, fluid or abnormal scarring it will affect the normal function of the lungs causing symptoms, typically breathlessness and cough.



Martinez, F. J. *et al.* (2017)
Idiopathic pulmonary fibrosis
Nat. Rev. Dis. Primers doi:10.1038/nrdp.2017.74

It is estimated that there are over 200 different ILDs, classified according to whether we know the cause (things like asbestosis, silicosis and farmers lung) or 'idiopathic' which simply means we don't know the cause. The ILDs also include conditions like sarcoidosis, auto-immune conditions (such as rheumatoid arthritis) and some other very rare conditions, which can result in fibrosis in the lungs.

Undertaking research is a long and expensive process. In order to apply for funding for a study, researchers have to show that there is a question, or problem, that needs to be investigated and answered. They also have to prove that it is actually possible to complete the study – that enough people will agree to take part and that they will be able to continue to the end of the study. This often requires a small initial study, called a feasibility study, before a larger study can be conducted.

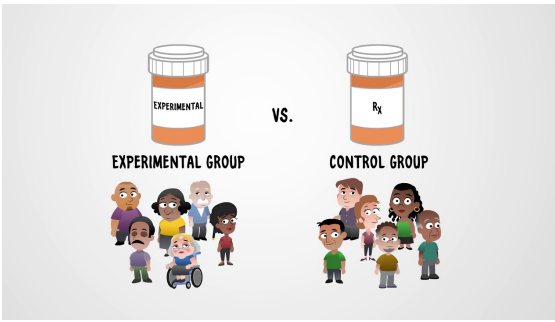
The Norwich ILD research programme has focused on 3 different areas:

FaST-MP (the Fatigue in Sarcoidosis, Treatment with Methylphenidate study):

Fatigue, or extreme tiredness, is a common problem for people with long term conditions. When people with sarcoidosis were asked about fatigue, more than 50% described moderate or severe fatigue, enough of a problem to interfere significantly in their ability to cope with daily life. This was far more than in others without sarcoidosis – known as 'controls' in research terms.

This feasibility study, undertaken by Dr Chris Atkins, used a questionnaire about tiredness to work out what effect a drug called Methylphenidate (also known as Ritalin) could have. Ritalin is a stimulant, which has been around since the 1950's; a bit like caffeine only stronger. 5mg of Ritalin is about the same as 100mg of caffeine, or about 3 strong cups of coffee. Dr Atkins was interested in working out whether it was possible to conduct a study to test whether giving Ritalin to people with sarcoidosis-related fatigue symptoms, could reduce the level of tiredness they suffered day to day.

The study was a Randomised Controlled Trial (RCT), which means it tested Ritalin against a placebo (or dummy drug). The 2 drugs are made to look exactly the same so that neither the researchers or the patients taking them would know whether they were taking the Ritalin, to get a true result of the effect of the drug rather than the effect of taking part in a study, which we know can in itself be beneficial.



Almost 400 patients with sarcoidosis were identified and screened to take part. Of those, 23 were recruited to the study, with half receiving Ritalin and half receiving the dummy drug. The study was successful in proving that people could be recruited and no-one had to drop out, so Ritalin was tolerated well. Although, people have previously reported feeling better on Ritalin, there was no measurable difference between the two groups, probably because the numbers in each group were small. It is hoped to do a larger study to find out whether this drug actually could help symptoms of fatigue.

Quality of life in IPF questionnaire study:

There are many different questionnaires which try to measure quality of life in different ways. It is thought that a standardized questionnaire is the best way to find out whether treatments are helpful. You will know that the measurements of your breathing tests (lung function) often does not match how you feel, or how much your breathing problems are affecting your quality of life, and this is recognized by doctors and nurses.

This study aimed to try to work out which was the best questionnaire to use in pulmonary fibrosis to measure whether a change after a treatment is meaningful; participants completed several different questionnaires on 5 separate occasions, and the responses were compared. Those of you who took part in this study may remember completing lots of questionnaires, some of them very long!

The study recruited 250 with IPF from 7 centres across the UK. Professor Wilson and the Norwich team led the study and Norwich was the biggest recruiter so thanks to all of you who took part!
The outcome was that most of the quality of life scores worked quite well but that the shorter, simpler questionnaires were better as they were much easier to use.

EME-TIPAC

The Efficacy and Mechanism Evaluation of Treating Idiopathic Pulmonary Fibrosis with the addition of Co-trimoxazole

Infection in IPF studies:

The third big area of research Professor Wilson has been involved in is trying to understand the role of infection in pulmonary fibrosis.

For many years, doctors and researchers have thought preventing or treating infection might be important in fibrosis. Chest infections seemed to be quite common and, along with other respiratory conditions, the winter can be difficult with more bugs around and more deaths over the winter months.

However, it was difficult to prove that there were bugs present in the lungs of people with PF. Sputum specimens sent for culture often don't grow anything and it wasn't clear if that was because there are no bugs there or just that they don't grow once they are not in the lungs. Now, by putting a camera into the lungs (a bronchoscopy) and taking washings of the cells in the lungs, researchers have identified that the lungs contain the DNA of bacterial as well as human cells. DNA contains the genetic code or 'signature' of an organism; by looking at this genetic information it could be seen that there are a lot of bacteria DNA in the lungs of people with PF. They also found that those with the highest amounts of bacteria died sooner, so it was suspected that preventing infection might be important.

About 20 years ago, a pilot RCT study tested an antibiotic called Co-trimoxazole (which kills lots of common bugs) against a placebo in 20 patients with IPF. People were able to cope with the side effects and, at the end of the study, those receiving the antibiotic seemed to have done better, so it was agreed that a bigger trial was needed to investigate further.

In 2013, Professor Wilson's Norwich team published the results of a larger RCT, which recruited 181 people with IPF, from across the UK, half given Co-trimoxazole and half given a placebo drug. Neither the patients nor researchers knew what they were taking until the end of the study and measurements were made of breathing tests, questionnaires, walking distance and side effects. The antibiotic group did better, with less chest infections, and it seemed that the antibiotics might be able to improve survival.

A further study began in 2015 to try to answer that question, this time recruiting over 330 people from 43 NHS Trusts throughout the UK (about 1 in 5 of all hospitals), again with Norwich leading the study and with the highest number recruited – many of you will have taken part, so thanks and well done to you all. As with the 2013 study, information about breathing tests, quality of life, hospital admissions and deaths were recorded and participants randomised to treatment (with the antibiotic Co-trimoxazole) or control (placebo) groups. Recruitment finished in May 2018, with a further 18 months to complete the follow up and analyse all the data.

The results are only just out and, disappointingly, this time there was no difference between the group given the antibiotic and the group given the dummy drug. One of the challenges of undertaking research in the clinical setting is that it takes such a long time to design a study, get agreement for it to be funded, recruit, follow up and analyse all the data. The "Co-trimoxazole Story" began almost 20 years ago and since then, we have seen big changes in the treatments recommended for IPF. We used to give drugs to suppress the immune system (including steroid tablets) but we now know they are not helpful in IPF (they may help some other interstitial lung diseases) and that they can increase the risk of infection. We have two anti-fibrotic treatments now, Pirfenidone and Nintedanib, which weren't available in the UK before 2013. However, even a negative study, when the treatment doesn't have the hoped for, adds to our knowledge and is of value. We still don't understand exactly what the role of infection is in IPF, but it seems unlikely that taking long term antibiotics alters the course of the disease. If you get signs of chest infection, with increased breathlessness, cough and sputum, then treatment with a short course of antibiotics is, of course, still recommended.

So…time to look to the next study that Professor Wilson and his team will be doing. This time, they are joining with researchers from across the UK and further afield, to investigate a question we have talked about before – does giving daily antacid tablets (drugs like Lansoprazole) to people with IPF slow disease progression? Watch this space for more details soon!

If you would like to take part, in this or any other suitable studies, do get in touch with Professor Wilson and the research team on 01603 289876. They would be happy to hear from you. Further information is available via the National Institute for Health Research (NIHR) website on all UK clinical trials.

Would you like to help train future doctors?

Norwich Medical School welcomes patient volunteers to help UEA medical students learn how to undertake consultations and physical examination. There are 3 respiratory sessions a year, plus sessions for the students' exams, led by NNUH respiratory consultants, so the UEA try to keep a pool of people they can call on. The students learn important skills, including listening to chest sounds, detecting subtle signs from clinical examination and taking a good medical history.

The sessions take place at the Bob Champion Research & Education Building and last up to 3 hours. Volunteers are offered reserved parking close to the building. You get reimbursed for your travel costs and are offered tea/coffee and biscuits. to add to their pool of people they can call. Those of you who have helped in the past always tell me it is an enjoyable experience and it is enormously valuable for our 'doctors of the future'.

If you are interested, do chat to your consultant or give Sandra a call, or you can contact Caroline Coombs, Medical School Administrator, direct on 01603 286618 or via email caroline.coombs@nnuh.nhs.uk

West Norfolk & North Cambs
Pulmonary Fibrosis Coffee Group Meeting

The West Norfolk & North Cambridgeshire Pulmonary Fibrosis Coffee Group are having a Christmas special meeting, with cream tea, at 3pm on Thursday 12th December at Dobbies, Tesco, Hardwick, Kings Lynn. If you would like to join them, let Mick Donoghue know so that he can make sure there are enough scones to go round!

Mick's contact details are tel: 01945 880576 or email at mickdonoghue@yahoo.com.

Dates for your 2020 diaries and calendars!

Anyone living with pulmonary fibrosis, of any kind, patients or those living with someone with the condition, is welcome to our meetings. Come and chat to others who know what it is like, share experiences and ideas, and enjoy an afternoon out. Web are a friendly group, no charge to attend and plenty of parking at the venue.

Winter meeting Saturday 11th January

Sandra Olive, Consultant Nurse, Respiratory Medicine, NNUH

Pulmonary Fibrosis? What's gone wrong and what can help.

Understanding what is happening in your lungs can make the symptoms more manageable.
Find out why pulmonary fibrosis causes breathlessness and what has been shown to help.

~

Spring meeting Saturday 28th March

NNUH Pulmonary Rehabilitation team

Keeping Active – Pulmonary Rehabilitation and more!

Keeping active is important for all of us, including when you are living with a long-term lung condition.
Find out why muscle fitness matters, how PR helps and how to get on a PR programme.

~

Summer meeting Saturday 27th June

Louise Bailey, Senior Lung Physiologist, Respiratory Medicine, NNUH

Breathing tests – why we do them and what they tell us.

Many people feel anxious about a visit to the lung function lab to do the breathing tests.
Louise will explain what we are measuring and why the tests are important

~

Autumn meeting Saturday 26th September

World Pulmonary Fibrosis month – raising funds and awareness

Let's get the Norwich group on the 'world fibrosis' map!
Debra Chand, APF Fundraising lead will be joining us. Details of activity nearer the time.

~

Winter meeting Saturday 12th December

Speaker and topic to be confirmed

All meetings at the Willow Centre, Cringleford, from 2-4pm.

World Pulmonary Fibrosis Month September 2019

September was World Pulmonary Fibrosis Awareness month, with 15th-22nd September World IPF week, when individuals and their families and friends are encouraged to raise funds and awareness. This year APF's campaign was "Listen to our Lungs" to spread the word about the importance of listening to the chest carefully if someone goes to the doctor with cough and breathlessness and to recognize the typical 'Velcro crackles' that can be heard when someone has pulmonary fibrosis. Across the country, people ran, cycled, jumped and held cake sales and coffee mornings in support of APF.

Mick Donoghue sent us this report of the challenge he set himself, walking the coastal path from Hunstanton to Wells!

Walking for APF

My IPF (Idiopathic Pulmonary Fibrosis) causes me the usual symptoms of breathlessness, tired muscles and inability to tackle hills and slopes. But I can still walk, albeit slowly and in stages, in the beautiful Norfolk scenery and this seemed the best way of setting a motivating challenge for myself while also raising much needed funds for the charity Action for Pulmonary Fibrosis. So, in World Pulmonary Fibrosis week, I decided to walk from Hunstanton to Wells-next-the-Sea.

I started from Hunstanton Lighthouse, with Wendy Dickinson from APF to see me off. And yes! I completed just over 10km, passing Holme and ending near The Orange Tree, in Thornham. Weather very good, tide was out and views great. Rhubarb & Ginger Icecream at Holme Dunes' Café was excellent and reviving. Towards the end I flagged a bit but once home, a glass, or two, of fermented grape juice worked wonders.

Second day was less pleasant as I had forgotten how long it can now take to recover from exertion, and my arthritic joints were complaining! Also, the stretch through Titchwell is away from the sea and alongside the road, less pleasant. A stop for coffee at Briarfields helped me reach Brancaster and then Brancaster Staithe, another 9km achieved.

Day off on Monday as Kay (porter, motivator, caterer and occasional photographer) had an appointment, and weather was a bit wet.

Third day, good weather although windy, and reached Burnham Overy Staithe via Deepdale after another 9 km. Main problem was that most of it was along the top of the sea wall and there was nowhere to sit and rest. Pretty tired at times but Kay kept me going, as usual. Weather holding up, keeping dry. Another day off tomorrow, as I have to lead one of my Easy Health Walks in Kings Lynn. A little emotional about several anonymous donations that have come in. Very humbling.

Next was Burnham Overy Staithe to Holkham. Bit of an error to spend so much time in the dunes rather than on the beach. They go up and down, in and out, adding to the effort required. As other IPF sufferers will know, the downs do NOT compensate for the ups! Finally, getting from Holkham bay to the road (and bus) along Lady Anne Drive is lengthy, about a kilometre, so another 9km day.

Final day was just from Holkham to Wells. Should have been a short one, through woods then the beach, but as I had parked near The Crown, at the far end of Buttlands we just reached 9km yet again. This brought the walk total to 46km in 5 stages. Wow! For me, now, that is an achievement. Difficult at times but helped by good weather, urgings from Kay and the thought of the donations received. As I write, the total is £961; could it reach £1,000? Would be great.

It's not too late to donate, if you've yet to do so. Just go to:
www.justgiving.com/fundraising/michael-donoghue5
Many thanks again to all who have given.

Mick Donoghue Sept 2019

Huge congratulations to Mick for this fantastic achievement – latest total donations amount to £1047.23!

Group News

The Norfolk & Norwich Pulmonary Fibrosis Support Group has been meeting quarterly for almost 6 years now, with, on average, upwards of 60 people at each meeting. We also have over 150 members on our regular mailing list. If you are one of the people who finds getting to the meetings difficult, I hope that the newsletter provides you with some useful information and helps you to feel part of the group.

If you have picked up the newsletter in the respiratory clinic waiting room and would like to be added to the mailing list, please complete a membership reply form or get in touch with one of the respiratory nurses.

If you have an email address, you can receive the quarterly newsletter and other mailings by email, which saves some postage. However, if you would prefer a paper copy, please do let me know and I will make sure one comes to you in the post. I will keep your name on our mailing list unless you let me know that you wish to be taken off it. Everyone is welcome to attend the meetings and to bring someone along with you if you wish. If you are coming alone, please don't worry - we are a friendly group and there are always people to chat to.

There were almost 70 people at our October meeting and it was a pleasure to welcome several new members. Thanks go to David and Jenny from Breathe Easy Norwich for helping with the raffle and to Kate, Alison and Annie for the refreshments.

Anyone who wishes to be more actively involved at the meetings, please do let us know either before or on the day. If there are particular topics or speakers you would like to hear at future meetings, I welcome your ideas – this is your opportunity to find out and share information. I try to bring a selection of information leaflets to each meeting, do help yourselves and have a look at the charity websites for much more information.

Group Funds

As of 30th September, the support group fund balance is £5745.34. This includes very generous donations in memory of Mr Russell Pike totalling £400.03 and Mr Russell Warne totalling £1780.00. These donations have enabled the PF group to purchase furniture for the quiet room in the Respiratory Outpatients Department which we hope will be completed for use very soon.

We have £104.36 in petty cash at present, including £85.75 from the raffle and donations at the October meeting. The annual costs of running the group come to around £450 in total for the meetings, which includes the venue and refreshments for 60-70 people per meeting, and around £400 for the costs of producing this newsletter. More than half of those on the mailing list receive the newsletter electronically, which saves some printing costs but I know for some people a printed copy is preferable and I feel it is money well spent to share the news from the group with those not able to get to the meetings. I hope you all agree!

We have also been able to continue to provide handheld fans for group members and those attending the ILD clinics, at a cost of around £350 over the last year. Thanks for the generosity of members and their families for the support and donations which enable us to make a little difference to those living with pulmonary fibrosis.

Any donations can be made payable to the Pulmonary Fibrosis Support Group Fund 052, c/o Sandra Olive, Nurse Consultant, Dept of Respiratory Medicine, NNUH, NR4 7UY.

Your committee

Professor Andrew Wilson, Honorary President
Sandra Olive, Chair/Editor
John Stroud, Treasurer

Useful Information Sources

Websites:
There is a lot of information on the internet – some reliable and helpful, some less so, and it can be difficult to know what you should believe. The following are reliable sources and have lots of useful information and resources. Do ask if you read anything that needs clarifying.

www.actionforpulmonaryfibrosis.org
www.pulmonaryfibrosistrust.org
www.blf.org.uk (British Lung Foundation)
www.europeanlung.org/en (European Lung Foundation)
www.sarcoidosisuk.org (UK Sarcoidosis Charity)
www.angliaasbestos.co.uk (support groups for those living with asbestos related disease, run by solicitors specialising in asbestos claims)
www.breathingmatters.co.uk
www.pulmonaryfibrosis.org (US Pulmonary Fibrosis Foundation)

Action for Pulmonary Fibrosis: Advice Line 01223 785725
Aims to give a voice, at national level, to those affected by pulmonary fibrosis to influence policy, research and education. Raising awareness and supporting individuals through PF specific support groups, information and advice.

Pulmonary Fibrosis Trust: Advice Line 01543 442191
Aims to provide personal practical, emotional and financial support to those affected by pulmonary fibrosis. Can help with stairlifts, mobility scooters, oxygen away from home and more.

British Lung Foundation: Helpline 03000 030 555
Information and support for people living with or affected by any lung disease. Oversee a network of UK Breathe Easy Support Groups. Provide wide range of information on website and in leaflet/booklet form.

Breathe Easy Norwich *(contact Paula Browne, Respiratory Nurse Specialist – 01603 289779)*
Monthly meeting: First Tuesday of each month, from 2-4pm, function room at St Faiths Community Centre, Horsham St Faiths, NR10 3LF. Free to attend, no need to book, all very welcome. Bi-monthly newsletter.

Singing for Breathing
Informal singing group with Breathe Easy Norwich. Second and last Friday of each month at the Willow Centre, Willowcroft Way, Cringleford, NR4 7JJ, 1.00pm for 1.30pm start.

Respiratory Nursing Team, NNUH

Sandra Olive, Nurse Consultant, Respiratory Medicine – 01603 289654
Oxygen/Pulmonary Rehabilitation Specialist Nurses – 01603 289779

We have a team of specialist respiratory nurses who you may meet at Pulmonary Rehabilitation, in the hospital wards or outpatient clinics, or in the home oxygen service. We are based in the Department of Respiratory Medicine, Level 3 East, NNUH, NR4 7UY. You can contact us for non-urgent advice and any of the team will do their best to find the answers to your queries. Please bear in mind that the telephone lines usually go to an answerphone or secretary so please leave your name, some general information about your query and a contact number and we will get back to you, usually within 48 hours.