Action for Pulmonary Fibrosis

Supported by British Lung Foundation

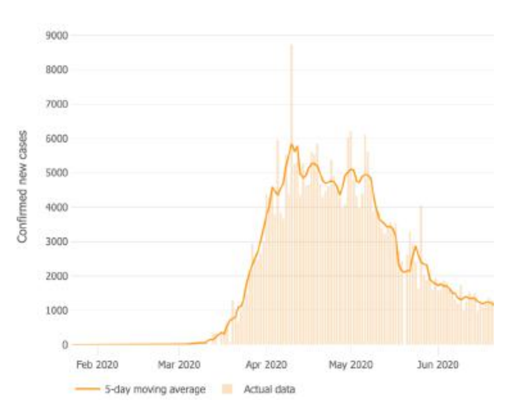
Vol 7
Issue 29
June 2020

Norfolk & Norwich
Pulmonary Fibrosis Support Group

June 2020 newsletter

Almost 4 months into the Covid-19 pandemic, our daily lives are still significantly affected by this new disease and, although the Government is gradually lifting some of the restrictions, it seems unlikely that things will go ‘back to normal’ in the near future.

The John Hopkins University in Baltimore, USA has been collecting and tracking global data throughout the pandemic, which is published daily on their website. The red areas on this map show the areas affected by Covid-19 outbreaks – as of 27th June 188 countries have reported a total of 9,985,425 confirmed cases.



In some countries, the number of cases each day is still rising; this does not seem to be the case in the UK but the virus is still around, with almost 1000 new cases reported on 27th June.

For those of you who have been ‘shielding’, this means that the risk of coming into contact with someone with the virus is considerably lower than at the peak in April but, unfortunately, if you were unlucky enough to pick it up you could still become more unwell because of your existing health problems. From 6th August the Govt advise that you can meet up to 6 people from other households but must follow strictly the 2-metre social distancing rules and should continue to take extra care after touching surfaces (especially commonly touched areas like door handles etc), avoid touching your face and wash your hands frequently. Provided that there is not a rise in cases, it looks as though official shielding will be paused from 1st August. Strict social distancing outside of your household or ‘social bubble’ should still be observed but you will be able to go out to work if you can’t work from home (provided your workplace can ensure a ‘Covid-safe’ environment), to places of worship, to buy food and to exercise. Although the formal Govt support will end, NHS and council support for those most in need will continue and I understand the supermarkets will continue to offer priority delivery slots.

I know many of you that have been so careful to stay at home are feeling quite apprehensive about going out into public places again, which is a common and completely understandable reaction. My advice would be to take things gradually, pick places you feel comfortable with and where you can be in the open air, if you can, as the risk of infection outside is much lower. It feels a little like we are all holding our breath to see what happens next and, of course, it is possible that the advice will change if we see a rise in infection rates again. But let’s hope that isn’t the case and that the recovery can continue.

Best wishes, Sandra

Our first Zoom Group 'Meeting' – 27 June 2020

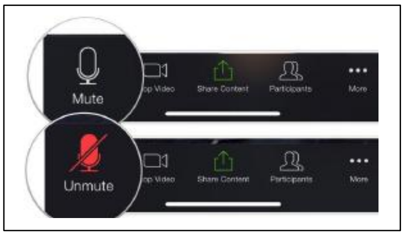
As you all know, we are unable to meet as a group as we have in the past for the time being and, until we are have a bit more guidance or assurance that it is as safe as it can be, I think that will remain the case.

But we know how important this contact is for many of you and perhaps now more than ever. I mentioned in the last newsletter that many different social groups and activities have been happening 'virtually' over the lockdown period – from exercise classes to choirs, book clubs and religious services. You name it, it is probably happening somewhere via the internet!

So, at the end of June, we had our first support group meeting via an app called Zoom. With the exception of me somehow managing to set up two 'meetings' and then joining the wrong one myself (I am learning this too!) it seemed to work well. An email comes to you with a link that you click on – this takes you to the Zoom page and a 'window' that asks if you want to join the meeting. If you join with your computer video and audio, we can all see and hear you.

It should be fairly simple and, in my experience, you don't seem to always need to download the Zoom app just to join a meeting but you may find it helpful to have a look at some of the 'how to Zoom' advice on YouTube which talk you through connecting. Kate, Respiratory Nurse from Outpatients, found this https://support.zoom.us/hc/en-us/articles/201362193 which is from the company, or there are lots of others that are made by people like you and me learning to use it!

For everyone's security, there is a 'waiting room' feature, which means that when you connect, the system will tell you that you are in a waiting room and then the meeting organiser brings you into the meeting from the waiting room.



We were a small group, pictured above, but we managed to chat for over an hour and it was good to have some contact. You can only hear one person speaking at a time and if there is noise in the background it can make it difficult for others to hear but if you click on the mute symbol at the bottom of the screen, unless you are speaking, it seemed to work quite well.

For some that joined the group, it was much easier than coming to Norwich and the general consensus was that we should keep having virtual meetings, perhaps in addition to our quarterly face to face meetings when we can resume those. Most people wanted to meet a little more often so I will try to plan a diary of Zoom meetings every 6 weeks or so.

There were a number of things that came up that I am sure many of you have been thinking about. I know lots of people have been concerned about what is happening with outpatient appointments. In the past, we have tried to see you regularly and I know we have talked in the past about why we put you through so many breathing tests and trips to the hospital. We are having to think a bit differently now – we can't go back to a crowded waiting room and long waits for x-ray, breathing tests and your clinic appointment all on the same day as that would mean too many people in one area for too long, possibly increasing the risk for everyone. The lung function tests themselves are a particular problem as they are classed as an 'aerosol generating procedure' which means that because you are asked to blow out hard from a big breath in, in theory if you had the virus you could breathe out droplets containing the virus into the air. As a result, the lung function lab team can only see one patient at a time for breathing tests now, have to wear full protective equipment to do the tests and have to clean the room thoroughly between patients. At the moment, they can only do about ¼ of the tests they used to do so we can only ask for breathing tests where we think they are essential.

You may be pleased to know that we are questioning ourselves hard before we ask for tests – if they are going to provide us with useful information that will help us make decisions about your diagnosis and treatment then they are very useful but if they are not going to change what we are doing for you then, perhaps, they are not as necessary as we have thought in the past. If you do need to have breathing tests, you will probably be asked to come at a set time for the tests and, usually, be able to leave again straight afterwards, with a telephone or video consultation soon afterwards. Where we think more regular monitoring of breathing tests would be helpful, we might, in the future, be able to send a small handheld device to you with instructions so that you could do some of the blowing tests at home. We can't do that at the moment, but it is something we are thinking about.

The tests we do, once we have established your diagnosis, are only part of making a judgement about whether things are keeping steady or getting worse. Many of you will know that, sometimes, you tell us you feel a bit worse but the breathing tests haven't changed much and this is because the changes in the lungs can be very small and may not be picked up on the breathing tests until there has been quite a bit of change. We have always also relied on how your symptoms are effecting you and what you can do day to day and, for the most part, we are likely to be asking you to monitor this to help us decide when we do need to see you face to face or when some more tests would be useful.

Usually, the most bothersome symptoms are cough and breathlessness, so it might be helpful to try to have a 'measure' in mind that you can check yourself against, so that you can tell if things have changed, for example:

1. Breathlessness:
   - When do you notice it? Has it changed?
   - What can you do before you have to stop and get your puff? You might think about how many minutes it takes you to walk a set distance, have you had to slow down, do you have to stop sooner than you used to? If you have stairs, can you go up and down them in one go, or do you have to stop half way? Can you do the stairs several times before you are puffed? How long does it take you to recover?
   - What about day to day tasks – showering, dressing, carrying things, bending forward?
2. Cough:
   - Do you have a cough?
   - Is it better/the same/worse than before?
   - Is it a dry cough or do you cough up phlegm? What colour is your phlegm usually?
3. Other symptoms:
   - Is your appetite alright? Have you lost or gained weight?
   - Are you sleeping ok?
   - Do you feel worried or down in the dumps?

The other thing we usually do at the hospital appointment, and of course can't do over the telephone, is check your oxygen levels. You can buy a small device, called a pulse oximeter, for around £20 from chemists or the internet which may be useful to see whether your oxygen levels are changing. The device clips on your finger and gives you a reading of your heart rate in 'beats per minute' (BPM) and your oxygen levels as a percentage.

Some tips for getting an accurate reading:

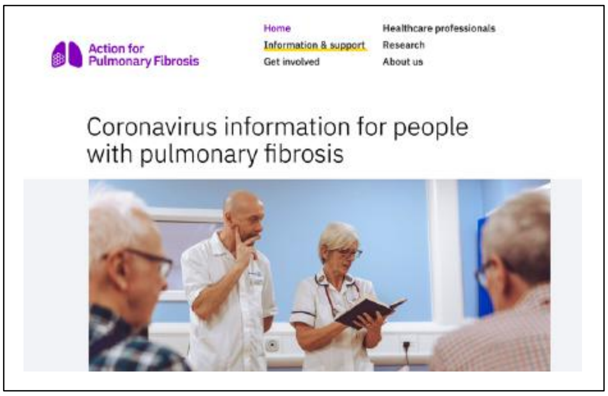
- Make sure your hand is warm
- Avoid nail varnish and false nails, as they interfere with the light signal
- Rest the hand gently so that it is not moving and wait for a couple of minutes to let the readings settle
- Once you know what your level is at rest, it can be useful to check your readings moving around over a set distance so you can judge if there is a change over time.

If you do decide to get a pulse oximeter, please don't feel tied to it! The numbers are just numbers – we generally start thinking about whether oxygen might be helpful if your resting levels are less than 92% but if you feel ok when you are walking, even if they drop a bit lower, how you feel is probably the best guide.

What advice is out there?

There is lots of information available and the lung charity websites are a good place to start. Action for Pulmonary Fibrosis have given their website a 'facelift' and have lots of advice both related to Covid but also many other things that may of use and interest. Similarly, the British Lung Foundation and the European Lung Foundation both produce a range of information leaflets and advice sheets on every aspect of living with breathlessness.

One aspect of health that has been in the news a lot lately is the impact of the lockdown period on our mental health and sense of wellbeing. For many people this has been a real challenge, with social contacts reduced and the prolonged period of isolation, to say nothing of the understandable anxiety about catching the virus. If you do find you are feeling low in mood, tearful, irritable, lethargic, or any other new symptoms, do talk to your doctor about it or contact the Wellbeing Service – you can refer yourself and they can offer a range of different ways of supporting you.



Coronavirus information for people with pulmonary fibrosis

Mental wellbeing and lung health

If you live with a lung condition, you might be more likely to experience problems with your mental health in addition to your physical symptoms. This factsheet explains how to look after your mental wellbeing, what mental health conditions you might experience, and where to find support if you are not feeling well.

What is mental wellbeing?

Mental wellbeing is a term used to describe how you are feeling and how you cope

You can contact the Norfolk & Suffolk Wellbeing Service on their telephone helpline 0300 123 1503, available 8am to 8pm or they accept online referrals via their website https://www.wellbeingnands.co.uk

We all need to remember it is ok to admit that we are 'not ok' sometimes and just talking to someone else can make a world of difference.

The best place to look for the most up to date government advice on the changing rules and regulations is the Coronavirus page on the government website www.gov.uk/coronavirus

On 14th July the Health and Social Care Secretary, Matt Hancock, announced that from 24th July face coverings will be mandatory in shops and supermarkets as well as public transport and healthcare settings. The reasoning behind this is not so much that a face covering protects the wearer but rather that if we all wear face coverings in those more enclosed, more crowded environments that if we cough, any droplets we cough up will be caught by the face covering and avoid infecting others if we are, unknowingly, carrying the virus. A face covering does not have to be a mask, although many people are choosing to wear masks, it could be a scarf or anything else that covers your nose and mouth. Whilst the government has made face coverings in these settings a legal requirement, they have also allowed for certain categories to be exempt from the ruling – in particular, young children or people with health conditions that would cause distress through having their face covered.

The British Lung Foundation have some very helpful advice on their website – they suggest trying a face covering at home first to see if you feel comfortable. It can take a little while to get used to, so you could try wearing one for short periods around the house to give yourself time to adjust to the feeling. It might be worth trying different types – there are lots of suggestions from bandanas, to head scarves, home-made versions from everything from t-shirts and socks to very fancy cloth ones if you have someone handy with a sewing machine in the family. And of course, a vast array of masks of varying fabrics and designs are being manufactured now and available to purchase, some of them being designer items and outrageously expensive! But if you can't manage a face covering the BLF have links to the main public transport operators' advice and a graphic that you can download to your phone or print off to carry with you.

From our members...

Lorraine and Ray have been sending me regular photos to enjoy at a 'tea-break' throughout the last few months – hope you enjoy them too...

A Poem for Now – sent by Janet, something to make you smile!

This was written by a 75-year-old woman on lockdown in a retirement village in Auckland. Nothing much else to do right now so might as well write a poem!

I'm normally a social girl
I love to meet my mates
But lately with the virus here
We can't go out the gates.

You see, we are the 'oldies' now
We need to stay inside
If they haven't seen us for a while
They'll think we've upped and died.

They'll never know the things we did
Before we got this old
There wasn't any Facebook
So not everything was told.

We may seem sweet old ladies
Who would never be uncouth
But we grew up in the 60s -
If you only knew the truth!

There was sex & drugs & rock 'n roll
The pill and miniskirts
We smoked, we drank, we partied
And were quite outrageous flirts.

Then we settled down, got married
And turned into someone's mum,
Somebody's wife, then nana,
Who on earth did we become?

We didn't mind the change of pace
Because our lives were full
But to bury us before we're dead
Is like a red rag to a bull!

So here you find me stuck inside
For 4 weeks, maybe more
I finally found myself again
Then I had to close the door!

It didn't really bother me
I'd while away the hour
I'd bake for all the family
But I've got no bloody flour!

Now Netflix is just wonderful
I like a gutsy thriller
I'm swooning over Idris
Or some random sexy killer.

At least I've got a stash of booze
For when I'm being idle
There's wine and whiskey, even gin
If I'm feeling suicidal!

So let's all drink to lockdown
To recovery and health
And hope this bloody virus
Doesn't decimate our wealth.

We'll all get through the crisis
And be back to join our mates
Just hoping I'm not far too wide
To fit through the flaming gates!

ReSPECT – what is it all about?

Some of you may have heard of the ReSPECT document – it stands for Recommended Summary Plan for Emergency Care and Treatment and has been introduced widely across the country, including in this region since March this year, to help people to create a personalized record of their wishes as a guide, or recommendation, for clinical teams regarding what care you would like in an emergency situation, if you were too unwell to express those wishes for yourself.

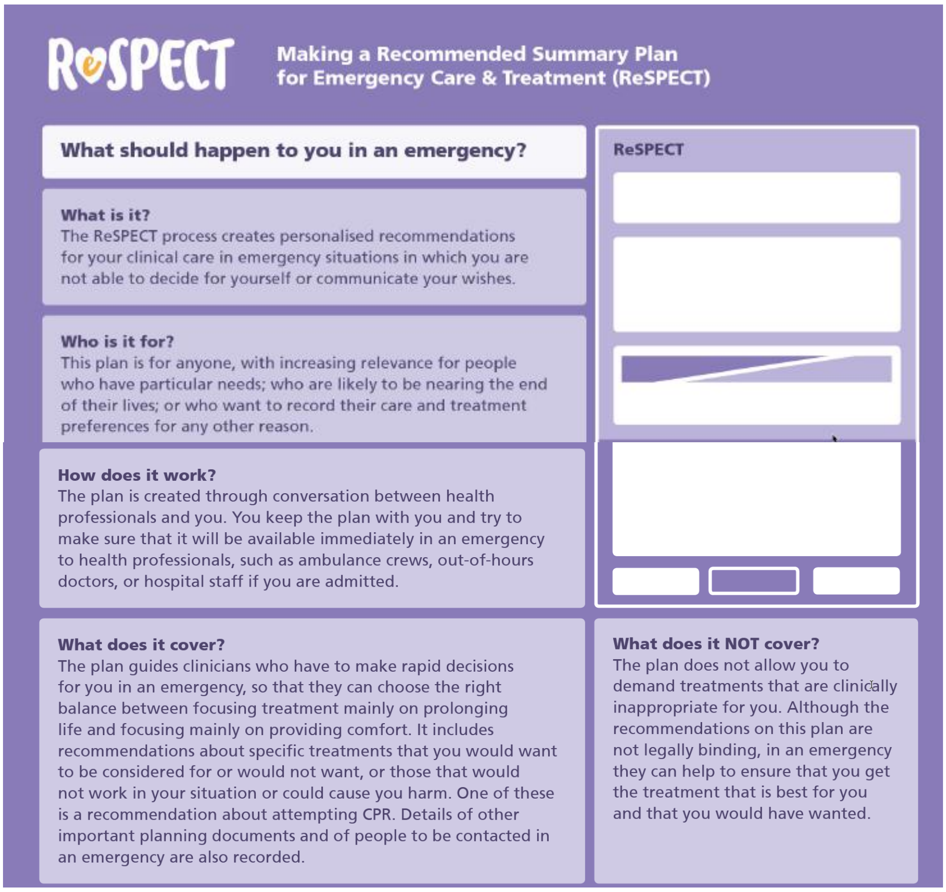
None of us really like to think about that situation but we probably all should, particularly if we have strong views about what we would or would not want. We tend to assume that our loved ones 'know what we want' but actually, even if we think we have discussed our wishes with our nearest relatives, when it comes to it they may feel unable to follow that in the stress of an emergency situation. All too often we see people admitted to hospital who have very clearly stated before that they really don't want to come into hospital again; the natural reaction if someone has become very unwell is to call a doctor or an ambulance and if nothing is documented to the contrary, they are obliged to follow their usual protocols in what they believe to be the patient's best interests, which may mean an ambulance trip to hospital, and tests or treatment that the person may not have wanted, even if there is not an obvious reversible illness.

The ReSPECT plan gives you a chance to think about what you do and don't want, talk to your family about it and, importantly, get your wishes documented. It is not a prediction of impending doom and it does not stop clinical teams offering you treatment that they think you may benefit from. Neither does it allow you to demand treatments that would not be offered for your illness. But it does allow you to feel reassured that, in the case that you are unable to tell the clinical team yourself, your wishes will be taken into account. It is important to know this is not just about whether CPR should be attempted – in fact that is really a very small part of the plan and there are many other aspects related to your wishes regarding comfort or willingness to risk harm from emergency treatments.

It is likely that a doctor will ask you about your preferences if you are admitted to hospital very unwell, in case you get worse and can't tell them what you want. If you have been in hospital, your GP or hospital team may suggest a ReSPECT form, in case you become very unwell again and if you have a condition we can't cure, which is getting worse, completing one may be suggested.

We know these conversations are difficult and, ideally, you need time to think about it, which is why the ReSPECT form is intended as a means of 'planning ahead'. Most people say they feel better to have the chance to talk about what is often on their minds anyway.

If you wish to know more, contact your GP, community or hospital team – they can send you more information and arrange a time to chat through with you what your preferences might be.



ReSPECT

Making a Recommended Summary Plan for Emergency Care & Treatment (ReSPECT)

What should happen to you in an emergency?

What is it?
The ReSPECT process creates personalised recommendations for your clinical care in emergency situations in which you are not able to decide for yourself or communicate your wishes.

Who is it for?
This plan is for anyone, with increasing relevance for people who have particular needs; who are likely to be nearing the end of their lives; or who want to record their care and treatment preferences for any other reason.

How does it work?
The plan is created through conversation between health professionals and you. You keep the plan with you and try to make sure that it will be available immediately in an emergency to health professionals, such as ambulance crews, out-of-hours doctors, or hospital staff if you are admitted.

What does it cover?
The plan guides clinicians who have to make rapid decisions for you in an emergency, so that they can choose the right balance between focusing treatment mainly on prolonging life and focusing mainly on providing comfort. It includes recommendations about specific treatments that you would want to be considered for or would not want, or those that would not work in your situation or could cause you harm. One of these is a recommendation about attempting CPR. Details of other important planning documents and of people to be contacted in an emergency are also recorded.

What does it NOT cover?
The plan does not allow you to demand treatments that are clinically inappropriate for you. Although the recommendations on this plan are not legally binding, in an emergency they can help to ensure that you get the treatment that is best for you and that you would have wanted.

Update on the NNUH ILD Service

I am conscious that as we are doing more remote consultations, it can be difficult speaking to someone you have never met face to face. Many of you will have met Consultant Physicians, Professor Wilson or Dr Kamath or me (Sandra, Consultant Nurse). In March we were delighted to welcome Dr Atkins to the Consultant medical team – he has worked with us before and we know he will be a real asset to the ILD Service.

Katy and Natasha are part of the lung function team and spoke to many of you during the early part of the lockdown. I don't have photographs of all of the secretarial team – many of you will have spoken to my secretary Jo, Dr Kamath's secretaries Jo and Sarah or the two Christines who work with Professor Wilson and Dr Atkins.

Maggie is our multidisciplinary team (MDT) meeting coordinator and makes sure that the recommendations of the meeting are documented and followed up.

We would be lost without our admin team – they keep us organised, type the hundreds of letters we produce and answer lots of phone calls. Please be patient with them, they always do their best to help where they can but cannot answer clinical queries or magic up appointments when our waiting lists have got a bit behind.

Revised Diary 2020

It seems unlikely that we will be able to meet in person for our usual group meetings any time soon. Whilst I think most would agree that this would be preferable, it would be difficult for us to have so many people in a room in the way that we usually do, so we have agreed to continue to hold meetings via Zoom for now, a little more frequently and at a slightly later time of day. For the moment, I won't plan particular topics – given the change and uncertainty at the moment, we thought a question and answer session might be best, so bring your questions, share your experiences and, for those of you who can't connect via Zoom, send your questions to me so that I can include them in the discussion and in the next newsletter.

The only exception is the September meeting – September is Pulmonary Fibrosis Awareness month and we had planned to have a fund-raising event and make some noise about pulmonary fibrosis. Debra Chand, National Support Manager from APF, is still hoping to join us to tell us about the work the charity is doing to raise the profile and needs of people living with pulmonary fibrosis. Perhaps you, or your family and friends, could have your own fund-raising effort and we could share your story? Do we have our own 'Capt Tom Moore' who is up for a challenge? What about a theme? Perhaps 'Go Purple' and wear something in APF colours? APF have ideas and fund-raising packs – if you contact them, they will be happy to send you details. We could have a gallery of photos to publicise pulmonary fibrosis, our group and the national cause! You could share your story with your MP or the charities (APF or BLF)? They are always looking for stories to illustrate life with pulmonary fibrosis and would be glad to hear from you.

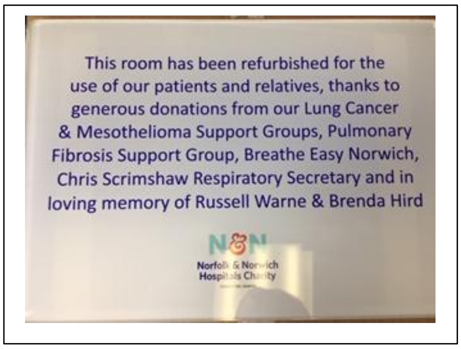
Dates for Zoom meetings for your diaries and calendars – I will send out email invites nearer the time:

Saturday 8th August 3.30-4.30
Saturday 26th September 3.30-4.30
Saturday 7th November 3.30-4.30
Saturday 19th December 3.30-4.30

Group News

Our support group membership has grown to almost 200 over the last few months, with about 2/3 on email contact. At our usual meetings we typically had 60-70 people attend, both patients and 'other halves' or friends. So, I know there are many people on the mailing list who receive the newsletter but may not be able to make it to the meetings or 'group things' are just not for them (this is fine! Groups are not everyone's cup of tea!). I hope you all find something of interest or useful in the newsletters and feel part of the PF group. Your name will remain on the mailing list unless you let me know that you wish to be taken off it.

The newsletter has been our biggest recurring expenditure over the last few months, although as many of you receive it via email that significantly reduces our costs. As we are not meeting in person we are not paying the room hire costs, of course, but we are also not having our raffle which pretty much covered the room and refreshments each quarter! We are very grateful though to the kindness and generosity of family and friends who think of us and make donations in memory of loved ones. Thanks to these donations we were able to make a generous contribution to the creation of our Outpatient Dept Family Room, which is still in use if a little less frequently at the moment. We have recently received further donations of over £330 in memory of Mr Raymond Boyce and £80 from Mrs Fairweather, who made and sold face masks and some plants for donations. I am really grateful to you all for your continued support – our fund stands at a healthy £2,792.55 as of 30/6/20, which means we are able to continue to support people even if it is a little more remote for now.


This room has been refurbished for the
use of our patients and relatives, thanks to
generous donations from our Lung Cancer
& Mesothelioma Support Groups, Pulmonary
Fibrosis Support Group, Breathe Easy Norwich,
Chris Scrimshaw Respiratory Secretary and in
loving memory of Russell Warne & Brenda Hird

N&N
Norfolk & Norwich
Hospitals Charity

Action for Pulmonary Fibrosis – news from Regional meeting:
APF continue to reach out to try to understand how the charity can best support those living with fibrosis, both patients and carers. A carers' focus group in June identified a need for information and support at the point of diagnosis and a desire for better awareness of the condition amongst health professionals and earlier information from respiratory teams about support groups. The NNUH ILD team are conscious of this already and would like to provide a 'pack' of information to be given at diagnosis.
APF are developing their Support Line, manned by trained and supported volunteers, which aims to provide a listening ear. It complements rather than replaces their clinical support line, where queries are answered by a trained ILD nurse specialist. If anyone is interested in joining the team of volunteers do contact APF or let me know and I can pass your details on.

Useful information

Websites:
The lung charities have some helpful information and resources; general information regarding living with lung conditions but also, at the moment, information about Coronavirus (Covid-19). Most also have helplines for further information and advice.

www.actionpf.org Action for Pulmonary Fibrosis **Advice Line 01223 785725**

www.pulmonaryfibrosistrust.org Pulmonary Fibrosis Trust **Advice Line 01543 442191**

www.blf.org.uk (British Lung Foundation) **Helpline 03000 030 555**
www.europeanlung.org/en (European Lung Foundation)

www.sarcoidosisuk.org (UK Sarcoidosis Charity)

www.nnuh-pf-supportgroup.org – our support group website (includes useful links, copies of previous newsetters and other useful content developed by our webmaster Mick Donoghue)

Local contacts:

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