

Zoom Support Group Meeting Notes 16th November 2020

Update from Wythenshawe:

- Some services at the hospitals have closed (such as some surgery), due to bed and staffing pressures, but the ILD service remains open, with most consultant clinics being performed by phone, with some virtual clinics. The nursing team are offering a mix of phone and virtual appointments
- Wythenshawe are continuing to monitor people who are suffering with “long covid”, with regular scans to check for any development of fibrosis in the lungs
- Lung function is still running at a low capacity, which is causing delays, so we are still unable to get as many lung functions as we would like, although our patients do get prioritised
- It is safe to attend hospital for tests such as lung function and bloods. We will not ask you to come in unnecessarily. We need regular blood tests from you if you take antifibrotics and may ask you to come to Wythenshawe for these, as some GPs are now unable to support us in this

Research in ILD

- MABEL is a trial to test the effectiveness of morphine as a treatment for cough. It is placebo controlled, meaning some participants will not get the drug
- The ATLAS study, which tested inhaled pirfenidone, showed some success, but the study needs to be repeated on a larger scale, across multiple centres, before we can fully interpret the results
- There was mention of a trial in the USA of nebulised nintedanib but we do not currently have this trial in the UK, and we will not know if this is effective until we get the trial results. Nebulised medication is inhaled rather than swallowed, so in theory, taking a medication this way should reduce side effects
- The GALECTIC study is looking at a new treatment for fibrosis and participants can also be on their regular dose of pirfenidone or nintedanib during this trial
- The TRAIL trial, which tested pirfenidone for rheumatoid arthritis related ILD, was stopped by the drug company during covid and unfortunately, we are unlikely to see any reports of significant results from this study
- If you are interested in joining any research study, please email ILDresearch@mft.nhs.uk with your details, including your hospital or NHS number
- We would never stop “standard of care” treatment, (medications that are already approved for your condition) to start a trial medication

Mould and humidity

- We had some questions about humidifiers, dehumidifiers and air purifiers. We discussed how generally, people find damp conditions can affect their lungs more, and that anecdotally, dehumidifiers can be beneficial
- Dehumidifiers are generally safe to use, providing they are cleaned and emptied regularly
- There is no evidence to say air purifiers help the lungs, although some group members feel they benefit from theirs. It is important that air purifiers are cleaned regularly, and the right products are used with them, to prevent injury to the lungs
- There is no evidence to suggest avoiding damp woodland areas, as levels of fungal spores in any outdoor conditions are likely to be low
- Bread yeast is unlikely to affect the lungs as it is swallowed rather than inhaled

Lung transplant

- There are certain criteria that need to be met before a referral to transplant is made. These include age, other diagnoses and overall health. Please ask your specialist if this has not been discussed with you before
- Lung transplantation is a last resort treatment, and not a cure. It replaces a progressive disease with a chronic disease which requires lifelong management

General questions about health

- We discussed green tea as an article had been sent to us which said it may help with scarring. There is no evidence for this, but it is generally assumed that green tea is beneficial to health
- We talked about how we want people to continue to exercise outdoors where they feel safe and able to, as it is beneficial for their lungs as well as their mental health
- There was a question about a recent discovery of a new salivary gland, and whether this might contribute to common issues such as blocked nose, rhinitis etc. We will have to wait for further research before this question can be answered

Covid vaccine

- There are over 200 vaccine trials globally currently
- Although we do not have specific details about the vaccine, we expect it to not interfere with other medications, as that is the case for vaccines in general
- We have no information on who will be vaccinated first, but we hope the extremely vulnerable group would be considered a priority
- Our general advice will be to get the vaccine, as the risk of side effects is likely to be low

Antifibrotics

- One group member asked how do we know if nintedanib is working for them. We consider lung function tests to be the best indicator of how well someone is doing on treatment, although we also assess the change in symptoms such as breathlessness and cough. The aim of treatment with nintedanib or pirfenidone is to slow the progression of disease, so we will always expect to see a decline over time. If we see a big decline, we may talk to you about switching treatment, if that option is available to you
- Nintedanib has been approved for use in progressive fibrotic ILDs (it was previously only approved for use in IPF). It has been licensed for this use in Europe, but we are still waiting for the license in the UK
- Dr Chaudhuri discussed how patient groups can be very powerful when they lobby for change, and patient voices will help to get the NICE criteria for prescribing antifibrotics changed to help a larger group of people with IPF. She mentioned writing to your MP about the issue and contacting Action for Pulmonary Fibrosis

Dental work and surgery

- We do not routinely recommend preventative or “prophylactic” antibiotics for dental work, even for people on immunosuppression and antifibrotics
- Remember that nintedanib can delay wound healing, so if you are on this drug and have any surgery planned, let us know and we will usually recommend stopping for a period before and after your surgery

Bolton

- Steve Milward of the Bolton Pulmonary Fibrosis Support Group shared the news that Bolton Hospital has given the go ahead to develop a satellite service which will provide IPF care closer to home for patients in Bolton. Well done Steve for your tireless work and we look forward to supporting the development of this service

Cough

- Cough is a symptom of lung fibrosis and can be difficult to treat, hence the trials for cough treatment that we are running
- Treatments may include oramorph, indigestion relief and stopping or swapping other medications which may contribute to cough