

The Wythenshawe ILD Virtual Support Group meeting was held on 14/5/21.  
There were over 40 patients and relatives on the meeting.

### **Survey**

Katie thanked you all for responding to our survey about the virtual support group meetings, we had 60 responses which is fantastic. The information will be presented at a respiratory nursing event.

### **APF webinars**

We asked who had attended the 1<sup>st</sup> Action for Pulmonary Fibrosis webinar talk that took place earlier this week. Feedback for the group was positive. We have added the link below if anyone else would like to sign up for the rest of the talks, Action for PF are putting the talks onto their website for any that you miss

<https://www.actionpf.org/news/talking-pf-free-zoom-sessions-about-life-lungs-and-staying-strong>

Steve from Bolton PF support group added that he will be adding the talks to the Bolton PF support group you tube channel.

Bolton Group YouTube Channel Link as below

<https://www.youtube.com/channel/UCGCwmS1DnDrIQUu3wzOj1w>

### **Our topic today is Coming Out of Lockdown**

Dr Chaudhuri attended to answer your questions and provide a general overview of our thoughts as a team

There is a planned lifting of lockdown in June however this may change according to government guidance. We wanted to highlight that covid has not gone and we would strongly encourage the continued use of face coverings for the rest of this year at least. Keep you distance and minimise contacts with people you don't know, continue to use alcohol gel and regular hand washing. You are still vulnerable, so we ask you to be cautious and careful. We know that patients have not had as many chest infections and viruses this year as people have been so careful.

Q- What is the plan for people on immunosuppression regarding the vaccine?

A- We know that people on these drugs were excluded from the clinical trials. We know that for the vaccine to mount a response it relies on an immune system and the concern is that people on immunosuppression may not respond and get immunity. We will only really know when we start to slowly lift out of lockdown and some people who take immunosuppression catch covid . We suggest that this group continue to wear face coverings, wash hands, use alcohol gel, avoid crowded areas. One of the group advised us that some areas were offering family members the vaccine.

Q- Is it a risk to go swimming?

A- There is no evidence that you can catch COVID from swimming, however the risk is being close to others. Make sure you know that the pool and environment have ventilation, make sure you are happy with the changing facilities, prepare beforehand. All venues need to show they are COVID secure. 1 member of the group has been swimming and found it very beneficial but advised be mindful in the changing areas. The safest way to exercise is still outdoors or in your own home. Dr Chaudhuri shared the below website for fact or fiction information.

<https://www.who.int/southeastasia/outbreaks-and-emergencies/novel-coronavirus-2019/fact-or-fiction>

Q- Meetings face to face- when can they start?

A- Government guidance says yes however consider that community spaces will have a capacity limit, think about wearing face coverings. Consider that venues are used by other groups too. Everything will need a thorough clean before and after. Some groups felt there is a lot to consider and my look at this again in October November time, the ILD team agree and are happy to guide but think its important to see what happens over the next few months as we reopen and re evaluate at the end of August.

Q- What do we think about overseas travel?

A- There are not many countries on the green list therefore travel will be limited, we suggest staying cautious this year

Q- What about holidays in this country?

A- Staycations are fine, self-catering ok, consider calling ahead and letting them know you are vulnerable. For these places to open they are covid secure. Consider taking some wipes to clean once you arrive.

One of the group stayed in a cottage in Wales recently and wanted to let everyone know that he felt very safe

Hotels- are covid secure but there will be more people around- be vigilant use alcohol gel in communal areas, avoid communal areas when they are busy. Being vaccinated will decrease your chance of severe disease.

Q- Can we meet family and have a hug?

A- We suggest you can meet family outside but avoid hugging. We can't protect you from everything.

Everyone needs to make their own individual risk assessment even when people have had vaccinations, negative lateral flow tests that does not guarantee they have not got or picked up covid.

We don't know whether we will be able to say it's completely safe.

Q – We look after our grandchild once a week can we do that safely?

A- Look at the risk versus the benefits; children are a risk as they pick up viruses at school and sports clubs etc, they could potentially pass it on to you. Covid is only not spreading now as we are in lockdown. It is good to see them outdoors, remember handwashing alcohol gel and distance.

Q- Face masks are difficult to tolerate- are face shields as effective.

A- not as effective as there are gaps at the side, but they could be used as an alternative

Q- I live in Bolton have you any additional advice?

A- Be more careful going out and careful mixing even after the easing of restrictions.

Q- Mycophenolate- how long would you take it before seeing an improvement?

A- The aim of it is to keep you stable, you may not feel any better taking it. We will be pleased if you remain stable and your lung function tests do too. We would consider that successful treatment.

Q- What sunscreen can be used with oxygen?

A-This related to some of the medication that we use which can cause photosensitivity. Most sunscreens are oil based but when you use oxygen, we recommend that you use water-based sunscreen instead. This is because oil and oxygen bring two flammable substances together, we discussed that we don't recommend the use of Vaseline for a sore nose, a water-based gel is preferable.

One of the groups added that Neutrogena Hydro Boost Moisturising Water Gel Sunscreen Factor 50 is good.

Q- Blood tests frequency on mycophenolate has gone from monthly to 3 monthly is this OK?

A- Once stable blood tests can be carried out 3 monthly, this can continue if bloods remain stable.