

ELF Patient Organisation Networking Day:

Susanne Shanks: Q&A follow up

From Ian:

Q: Differences in COVID-19 policy/messaging in separate UK nations has certainly been a huge challenge for us at Asthma UK and British Lung Foundation. Has this experience been different in "single-nations" or have there been regional differences or challenges with people living on the borders of several nations? Is there anything you would like to share re. how you have dealt well with regional/national differences in policy/messaging and how to do a good job at keeping people affected lung conditions well-informed and well-supported?

A: Thank you for the question/ comment – the first part is an interesting thought, on which I can only partly comment based on my own experience of being a German living in the UK; I am certainly comparing quite closely what is happening in Germany with developments in the UK, which was especially useful in the early stages of the Covid-Pandemic spreading because Germany was a few weeks ahead of the UK. Reading about developments in Britain in the German press, is also an interesting experience because while it is lacking some of the insight one automatically has by living in the UK, commenting from a distance allows a different focus that opens new perspectives. Noticeable differences like the much higher mortality rate in the UK, would be interesting to be followed up by experts in relation to Health care systems/ political structures/ demographics and other factors.

For the second part of the question: one important aim of our Support Group is to help patients to be informed – originally that was in regard to PCD and how to access medical help. With the establishment of PCD services in England, there are now guidelines that both patients and health professionals can call upon and that are available for those patients in other parts of the UK that lack specialist centres. The nature of rare conditions makes it often necessary to work closely with other conditions and therefore PCD patients are often seen by other respiratory experts, like CF clinics, non-CF Bronchiectasis clinics, general respiratory wards. During the current Covid-19-pandemic we have been posting official clinical advice from PCD centres, the Royal College of Paediatrics, but also from the ERS. Through our social media links, we post information with relevance to lung health that comes from reputable sources and comments are being monitored by committee members. There used to be an online forum – ‘Health Unlocked’ to swap more personal medical experiences and seek advice, which was monitored by committee members, but a recently formed Facebook group, which is independent of the Support group, seems to be a more straight forward form of communication that is not regulated by the restraints of being a charitable organisation and official guidelines.

From Patricia:

Q: Suzanne also raised an issue I am interested in. She spoke about official guidance and then "unofficial" guidance on Facebook etc. We have found in Australia that the government advice was very general and not specific to patient groups. Does Susanne see a role for patient groups in communicating specific information to patient cohorts with

particular needs? How would that align with the Govt advice, in a manner not to undermine the general messaging.

A: This question/ comment goes to the centre of some of the discussions we have had recently in our group – on the one hand we see the group as a means of informing patients in an impartial manner, on the other it is a chance to react to developments, give people a platform to express their views. When we have our annual PCD days, there is a chance to exchange information directly, of course, this had to be online this year, but a few more virtual sessions mean that patients/ carers/ professionals can interact. We are also very active in the Rare Disease community and other, larger bodies like Genetic Alliance, ELF of course, BLF etc. and try and use these opportunities to direct our concerns and comments to professionals, who can then feed it back to the appropriate bodies, e.g. there was a Cross party meeting on Rare Genetic and Undiagnosed Conditions on the topic of Shielding that was attended by Professor Jason Leitch, National Clinical Director of the Scottish Government, and we were able to participate in this and to engage with him beforehand and during the meeting by posting questions.

In the initial stages of the developing Covid-19 situation, we also contacted PCD specialists directly in order to receive more guiding, which we then consequently posted on our website/ FB-page and now the communication seems to be working well between specialist PCD centres and our group in order to inform patients about current developments.