

Information for all patients with rare liver diseases (and, in case of children, their parents)

Corona is not only dominating the media, Corona is increasingly in the mind of many of you worrying about vulnerability as a liver disease patient. Therefore, I would like to provide some information and guidance for the coming weeks and months.

I am writing to you not only as coordinator of the ERN RARE LIVER, but also as a specialist both in Hepatology and in infectious diseases. The scientific community knows very little about this disease; how should it with a new virus and a new disease? Nonetheless, we now have some experience on which we can base some important advice.

First and foremost:

Continue taking your immunosuppressive drugs in unchanged doses!

As a liver disease patient, do not reduce your treatment and do not change the dose. Right now it is clearly much more dangerous to reduce your treatment than to continue it unchanged. A flare of autoimmune liver disease, or a rejection episode of your transplant, is much more dangerous!

Yes, there is danger, but the danger is much smaller than one would think from watching the news, and in particular, it is much smaller to you liver disease patients, and patients taking immunosuppression, than one would think. Why can I say this? Because by now we have some data, mainly from China and from Italy, but also from other places, that give us genuine encouragement and reassurance. These data suggest that:

- **The mortality rate is much lower than reported, because there are far more additional undiagnosed cases than those in the official figures,**
- **The risk that in particular, children and young adults would suffer a severe disease when infected is very low indeed, and**
- **The risk for patients receiving immunosuppression and for liver transplant recipients does not seem to be increased.**

Who is in real danger of this new virus?

- The elderly, especially elderly men
- Patients with chronic airway disease, such as asthmatics
- And probably diabetics

If you belong to one of these risk groups and/or are elderly (older than 70), then you should be extra careful, you should strictly avoid contact with anybody who has symptoms of a respiratory infection, you should reduce your direct social contact, you should avoid direct physical contact, you should wash your hands whenever you have been in public places and

touched things that others have recently touched before you. And, of course, please follow the rules and recommendations in your country and region, as these may differ locally depending on the local epidemiological situation, which changes sometimes quite rapidly.

What do we know?

This new virus, called SARS-CoV2, because it is a variant of the SARS virus, is new, but not entirely new. Other Corona viruses have been around us for many years, usually causing mild respiratory infections, but both SARS and the MERS virus (Middle Eastern Respiratory Syndrome virus) have caused severe outbreaks in past years. Why is there this enormous worry and activity because of the new virus? Two key reasons:

- We know very little about this new virus, as mentioned, how should we with a new virus; how should anyone?
- There is probably no immunity to this virus in the community, because it is new

It is this latter point which explains why the virus can spread around the world and it makes it so difficult to slow the spread, and probably impossible to stop the spread. Most experts now agree that the virus is here to stay, and if we manage to slow the spread, it will still remain in the community, and can come back again and again. We may be wrong, and we might achieve disappearance, as was apparently achieved with SARS, but this is unlikely. Therefore, we all, you all, need to know how to deal with this new situation.

How can you protect yourself?

Indeed, it is clearly much more dangerous now to reduce your treatment, than to continue it unchanged. A flare of autoimmune liver disease, or a rejection episode of your transplant, is much more likely to result in severe disease or even death, than this new virus. So, please, please continue your drugs! Indeed, it might even be that disease course in patients on immunosuppression could be milder because of the drugs, but that at this stage is more speculation than facts, and we need to stay with the facts!! There is yet one additional point: a flare of the disease or a rejection episode in itself is an additional health risk making you more vulnerable – so please avoid this.

What else can you do to protect yourself? Many patients are asking about ways to strengthen their immune system, about vitamins, zinc, herbal drugs etc. I am afraid none of this will work. However, a healthy lifestyle is now at least as important as it is at other times: try to get some fresh air and some exercise every day – even quarantined persons can go for a walk, they just need to avoid close contact with others. Eat regularly, with the usual recommendations for a mixed and varied healthy diet – and try to not always think about this virus and this risk, but live your life, despite the many restrictions. For most of you, the risk from this virus is indeed very, very small – and most of you engage regularly in other behaviour which is much more risky.

Yours

Ansgar W. Lohse
Coordinator of the ERN RARE LIVER