

INTERVIEW WITH PROF. ERIC LEGIUS

COVID-19 and NF

Questions & Answers

Professor Eric Legius is Head of the Centre for Human Genetics at the University Hospital Leuven. He was trained as a paediatrician and has been working in the field of human genetics since 1988. He received his PhD in 1994 on neurofibromatosis type 1. His studies are mainly focused on neurofibromatosis type 1 and related conditions.

Q1. ARE THOSE WITH NEUROFIBROMATOSIS TYPE 1 (NF1), NEUROFIBROMATOSIS TYPE 2 (NF2), AND SCHWANNOMATOSIS AT GREATER RISK OF COVID-19?

A. No they are not at any extra risk of getting the virus or complications of the virus due to the conditions themselves.

Most people will have minor symptoms comparable to regular flu. A small proportion of those who get COVID-19 will get severe symptoms and end up in intensive care and a small proportion of these will die.

HOWEVER, COVID-19 is VERY contagious so large numbers will be affected. So even if the percentage of those who will die is low that still means a lot of people. This is the problem as hospitals cannot deal with the number of patients needed in intensive care at the same time. There is a limited amount of intensive care beds on top of the normal non-COVID-19 admissions.

Even if children are affected – there is a high chance that the symptoms will be that of the common cold or flu and will not need any hospital admissions.

EXCEPTIONS

Those on chemotherapy but no more than those without NF1, NF2 or Schwannomatosis.

A small proportion of adults with NF1 who smoke develop an interstitial lung disease that is related to smoking and NF1. They may have a higher risk of developing COVID-19 and more complicated symptoms. STOP SMOKING!

Q2. ARE THOSE WITH HIGH BLOOD PRESSURE AT INCREASED RISK OF GETTING THE VIRUS AND COMPLICATIONS?

COVID-19 affects those in the older age bracket and many of those in this age bracket have high blood pressure and other conditions so it's more complicated to be sure. In a young person whose hypertension is managed and controlled with drugs they are not at increased risk. Also, those on ACE inhibitors (to lower blood pressure) are as far as we know not at increased risk.

Q3. I UNDERSTAND THE MAIN COMPLICATIONS OF COVID-19 IS THAT IT AFFECTS THE LUNGS.

The main problem with COVID-19 is that many people get pneumonia, which causes collateral damage to lungs. A small percentage of people will have their heart affected by the virus causing myocarditis. This is difficult to treat but these are exceptions. There is no reason to believe that getting the virus will affect the growth of neurofibromas.

Q4. ARE NF1 PATIENTS WHO HAVE PLEXIFORM NEUROFIBROMAS LOCATED CLOSE TO THE LUNGS OR AIRWAYS UNDER INCREASED RISK?

In any critical condition that affects breathing this will not help the situation but having these plexiform neurofibromas in these areas is more mechanical and does not increase the risk of getting the virus.

Q5. PRESCRIBED DRUGS AND COVID-19.

There is no evidence at the moment that any drugs, including anti-asthma drugs (Montelukast, Seretide), thyroid, steroids, or epilepsy treatment and hormone drugs have an impact on the pathway of COVID-19; however, those patients on chemotherapy for cancer and benign tumours should contact their oncologists and ask whether specific measures are needed. This includes MEK inhibitors, but this is precautionary as there is no evidence either way.

Q6. SHOULD WE TAKE IBUPROFEN?

Although no research has been done, advice is to take paracetamol instead. Paracetamol has an effect on pain and fever, while Ibuprofen and Aspirin and some other drugs from that same group also have an effect on inflammation. Because Ibuprofen works on a different level, it has potentially more side effects than paracetamol.

Q7. WHAT CAN BE DONE TO HELP WITH THE SOCIAL SIDE OF AUTISM OR ANXIETY DISORDERS AND HELP TO COPE WITH ISOLATION?

Internet! Organisations should help to keep people in contact via online groups, Zoom, Facebook, Skype etc

Q8. EVERY EU COUNTRY HAS DIFFERENCES IN DEALING WITH COVID-19. WHAT ARE YOUR VIEWS ON HOW WE SHOULD BEHAVE?

A. Yes, every country is dealing with this in a different way. However, the goal now is to slow down the spread of the virus so that not everyone becomes ill at the same time, which will put a strain on the healthcare systems, therefore people will not get the correct care.

We do not know why some people die of COVID-19, it seems that their body reacts strangely to the virus and no medical treatment can help. Therefore, there are cases of some young healthy people dying from it even with treatment and we do not know why. My personal feeling is that it's in the genetic makeup, some genetic predisposition, but this is hypothetical.

DRUGS

There are clinical trials to help make the symptoms milder or last a shorter amount of time. Antiviral drugs will be used but we are not sure of their efficiency and this still does not stop people from dying. We have flu vaccinations but each year thousands die of flu – we can't prevent people dying from flu, but we can reduce it with a vaccine, which is the plan for COVID-19.

MASKS

In Italy they have started to use surgical masks whenever anyone must leave the house, but in most other country's masks are not enforced for the following reasons.

1. They are impossible to get.
2. They can only be used once – so millions will be needed.

At the same time, masks can reduce the risk of infection and any mask is better than nothing. It is also important to respect at least the 1.5m social distance to protect yourself.

TESTING

The approach seems to vary from country to country.

There is a global shortage of tests so getting hold of them is very difficult. Some countries filter who will get a test, i.e. health workers.

It's obviously easier in some countries to work towards testing everyone but it depends on the population. Iceland has 300,000 whilst Belgium has 11 million, and the numbers make it impossible to test everyone in a few months.

There are also rapid tests that try to detect the virus in the mucus with an antibody but they are not as accurate as those that detect the viral RNA.

As more tests become available, more tests can be done.

Q9. HOW LONG SHOULD WE DELAY OUR REGULAR CHECK- UP?

Neurofibromas and schwannomas are slow growing so a delay of a few months will not matter. However, do ensure with your medical provider that you will get your routine follow-up, even if it's a few months later. Do not delay it by a further year or two. If you are due a scan or just finished chemotherapy, contact your medical provider and they can inform you when they need to see you and if it can or can't wait.

Q10. HOW EFFECTIVE ARE CHLOROQUINE AND AZITHROMYCIN FOR PROTECTION AGAINST COVID-19?

We just don't know. If they do have an affect its relatively minor, but that's better than nothing. It's very much in demand now so it's not easy to source. Basically, there is a world shortage of everything we need to fight this virus.

Q11. HOW DO WE PREVENT FAKE NEWS FROM SPREADING?

Take advice from official guidelines published by competent healthcare authorities!

STAY HOME
WASH HANDS
KEEP YOUR SOCIAL DISTANCE
ASSUME YOU ARE INFECTED
PROTECT OTHERS
STAY SAFE!