

# COVID-19 and Duchenne and Becker muscular dystrophy

*Transcript of WDO webinar, Saturday March 14 – 4pm CET*

This webinar was created to facilitate the questions to clinicians on the current Coronavirus outbreak and how this might affect the Duchenne and Becker muscular dystrophy community. We have collected the frequently asked questions and have clustered them. Then we asked DMD experts to provide their input.

The webinar is hosted by Elizabeth Vroom (chair) and Suzie-Ann Bakker (communications coordinator) from the World Duchenne Organization. The clinicians who provided input are Prof. Dr. Eugenio Mercuri, Prof. Dr. Francesco Muntoni, Prof. Dr. Jonathan Finder and Prof. Dr. Nathalie Goemans.

Patient organisations are free to translate the webinar in your own language, and share the materials as much as possible. Please note that this is a general guideline and a lot depends on the current situation in your country. In any doubts, contact your clinician. For more specific information about the topics you can watch the [webinar recording here](#), or scroll down to read the full transcript.

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## Summary

With the knowledge of Saturday March 14, we can make the following suggestions and considerations. These are general and a lot depends on the current situation in your country. In case of any doubt, contact your clinician.

**As insight may develop over the coming days and weeks, WDO will provide a weekly webinar update and will continue to update the live feed on changes.**

1. There are no confirmed cases yet of DMD/BMD with COVID-19.
2. People with Duchenne/Becker seem not to have a higher chance of catching the virus.
3. Being on (non-invasive) ventilation or using a cough assist does not affect chances of catching the virus.
4. Handwashing with water and soap is most important for everybody (patients and carers). Cleaning surfaces, door handles and touch screens is also an important measure
5. Stay at home as much as possible and encourage others to do the same #Home4Duchenne #Home4Becker
6. Postpone non-urgent hospital visits, or resort to telephone consultations instead.
7. In countries where schools are still open, it is advised to keep children on (daily) steroids at home, as well as children who are respiratory compromised.
8. Using steroids at the dose given in Duchenne is not considered a problem. Do not stop taking steroids as this will initially put the patient at a higher risk.
9. Do not make any changes in your medication regimen, unless your clinicians advise so. This is also advised for ACE-inhibitors.
10. It could be wise to order a supply of the medicines you are taking for an extra month or 2 in case of shortage.
11. In general, patients with respiratory insufficiency should have been immunised for whooping cough and pneumococcal infections. However, this will give no protection against catching COVID-19.
12. No specific foods or vitamins are said to help against any virus. Children should generally often eat fruit and vegetables in order to get their vitamins and minerals.
13. Duchenne and Becker patients will be at a higher risk if they catch the virus, as it can cause viral pneumonia, and pneumonia is always a risk for respiratory failure in this population.
14. Cardiac disease is a risk factor, so for the Duchenne and Becker patients with heart failure there is a higher risk of being severely impacted by a COVID-19 infection.
15. We cannot stress enough the rules of common sense and hygiene, applicable to the general population and even more important for the helpers and caregivers

## COVID-19 in general and in relation to DMD/BMD

Covid is a respiratory virus that can be spread by little droplets or aerosols when you are coughing and sneezing. The virus can survive for hours on hard surfaces, so you actually don't have to see the person who is symptomatic and spreading. Especially the older population above 60 and vulnerable people are at risk.

On Wednesday March 11, the World Health Organization officially declared the outbreak a pandemic, meaning that this disease affects the whole world. If you want to learn more about the virus in terms of how it started, and what the big flu pandemic of 1918 has taught us when it comes to trying to suppress further dissemination of a virus, we highly recommend the Stanford webinar called ['Coronavirus for non-virologists'](#).

We'd like to stress the importance that there is no such thing yet as a DMD/BMD Coronavirus expert. We are not aware of any cases of people affected with DMD/BMD who have been infected by the Coronavirus in China or Italy yet. Therefore, it's difficult to know how this affects Duchenne and Becker muscular dystrophy.

We have asked DMD experts to give their thoughts on some main topics. These should not be mistaken for guidelines; their answers reflect what we currently know. Each country, and sometimes even hospital, has different policies and rules, and we must respect and follow them.

## Q&A to clinicians

The clinicians that have provided input are:

- Prof. Dr. Eugenio Mercuri, paediatric neurologist
- Prof. Dr. Francesco Muntoni, paediatric neurologist
- Prof. Dr. Nathalie Goemans, paediatrician, child neurologist
- Prof. Dr. Jonathan Finder, paediatric pulmonologist

### Minimising chances of infection

Should I take my son out of school? If yes, how long for? How do I know when it's safe for him to go back?

*Prof. Dr. Eugenio Mercuri*

Keeping your child at home depends on what's going on in the country. Children are less likely to become infected, it is said to be 2 to 3 percent. Many children can be contagious as they often show few symptoms, so the risk of being infected at school is high. In isolated cases this is not a big deal, but even a few cases in the country not going to school could reduce the spread of the virus. No general rule can be applied, it needs to be tailored to an individual and the country he lives in.

*Prof. Dr. Francesco Muntoni*

In general, children have a very very low chance of catching the virus, although it's never zero. Paradoxically, the risk for their grandparents is much larger. It depends on the country and where it is in terms of the curve whether to keep your children at home or not. If your child is not at immediate risk, I would not suggest keeping them from schools. Of course, this changes when the level of Coronavirus diffusion goes up. It's better to keep children away from their grandparents.

*Prof. Dr. Jonathan Finder*

I think personally you should. Right now, we do not know much about whether the virus can affect muscle but if you consider how influenza can harm our boys and lead to loss of muscle function and to pneumonia, I would avoid any exposures. Schools are closing here in the USA.

*Prof. Dr. Nathalie Goemans*

Worldwide, children seem less affected than adults and elderly, however to be on the safe side, in Belgium we gave advice at the beginning of the week for all neuromuscular patients with restricted respiratory function and for all DMD boys on steroids to stay at home from school. Yesterday, this rule came anyway from our federal agency for all schoolchildren and students, which made it even easier for us. Additional measures have to be tailored to the individuals, taking into consideration their fragility and risk profile, their environment.

Does being on a plane give us a higher risk of catching the virus?

*Prof. Dr. Jonathan Finder*

Absolutely, any close exposures such as occur on an airplane will increase risk. Would I cancel a holiday? Yes, but I hope by May or June we can return to normal. But there is no telling how long this will last.

*Prof. Dr. Nathalie Goemans*

All travel for leisure should temporarily be cancelled, to limit personal risk and to limit spreading. It is not so much the air in the airplane, which is supposed to be filtered, but the fact of being close one to another for a longer time, such as also other events, concert hall, ...; the contact in the airport with the hand- and door rails one touches, the lavatories, ... However, no one can tell for how long, this depends on the curve of infection in the population, which may differ from country to country.

How to follow instructions if resources (hand gels, masks, pneumovax jabs) are limited?

*Prof. Dr. Eugenio Mercuri*

Of course, washing hands and cleaning surfaces should be done. Soap and water don't cost much and are most efficient. Washing is the best way to fight infection. Avoid contamination with the virus and wipe off surfaces.

*Prof. Dr. Jonathan Finder*

The best way to protect your sons is avoid crowds and careful hand washing with soap and water.

*Prof. Dr. Nathalie Goemans*

We cannot stress enough the rules of common sense and hygiene, applicable to the general population and even more important for the helpers and caregivers

*Elizabeth Vroom*

Next to washing your hands often, it's necessary to clean surfaces, door handles and touch screens regularly.

## Boosting my (son's) immune system

Could probiotics or extra supplementation with Vitamin D and Vitamin C help?

*Prof. Dr. Eugenio Mercuri*

Healthy food with vitamins and minerals helps in general terms. No specific vitamins are said to help against any virus. Children should often eat fruit and vegetables for vitamins.

*Prof. Dr. Jonathan Finder*

No, unfortunately. There is no superfood or vitamin to boost the immune system, contrary to all these nonsense advertisements I have seen online.

*Prof. Dr. Nathalie Goemans*

No scientific evidence for “immune boost” with vitamins, etc. again, common sense, healthy food, hand hygiene, social distance, avoiding contact with sick people and washing, washing and washing again.. will have more impact. (of note : washing hands thoroughly with water and soap is better than hand sanitizers – alcohol content of those should at least be  $> 70^\circ$  , which is not the case for most sanitizers, giving a false sense of security)

When infected, will it take DMD/BMD patients longer to fight it off?

*Prof. Dr. Francesco Muntoni*

When affected, DMD patients will develop a severe disease that is not different from the general population.

*Prof. Dr. Jonathan Finder*

We have no information about this. Presuming that steroids are being used, it is likely that the illness will be a bit harder to fight, since steroids are mildly immunosuppressant. This is NOT to say that one should stop steroids: DO NOT STOP STEROIDS, as this is dangerous, and riskier than the possible risks of COVID-19.

*Prof. Dr. Nathalie Goemans*

Yes, it is known that a severe case of COVID-19 can cause permanent damage to the lungs. On a positive note: although steroids are known to reduce immunity, it might well be that steroids could have a protective role in the pathophysiology ( cytokine-storm) of severe ARDS in COVID 19. But we don't know yet

What impact does steroid use have on the immune system? Should we stop using steroids?

*Prof. Dr. Francesco Muntoni*

Risk benefit is what should dictate everything we do in our daily activities. Stopping steroids is detrimental since it's not possible to stop abruptly. There are problems related to stopping steroids abruptly. If children get sick while reducing, and for several months after stopping steroids, they are less likely to fight off a virus and might well require stress-dosing.

*Prof. Dr. Eugenio Mercuri*

Steroids impact the immune response but in a mild way, especially in older children who receive a relative lower dose. We all agree we should not stop steroids. In practical terms we can say very young children are rarely affected, so we are mainly concerned with older boys. However, by the time they are in late teens or 20s they have much lower doses, so there is less risk of being seriously immunosuppressed.

*Prof. Dr. Jonathan Finder*

Steroids are a mild immunosuppressant and reduce the activity of lymphocytes, and these are the cells that help fight off viruses.

## Do people with DMD/BMD have a higher chance of catching the virus?

*Prof. Dr. Eugenio Mercuri*

Usually, people with Duchenne do not go out so much in winter or visit crowded places. So it's not as easy for the virus to spread to them. There is no evidence from China or Italy that a child with a disability is affected differently. Our hospital is monitoring a group of other disabilities, and there is no evidence that either children or teenagers are more affected if they have a disability or are on ventilation. If you respect the hygiene rules and avoid crowded places, chances of infection are lower.

*Prof. Dr. Jonathan Finder*

No, and possibly they have a lower risk given that they are less likely to be touching door knobs and handles and shaking hands and the like. Those in schools or just out and about have the same risk from respiratory droplets.

## Are DMD/BMD patients a high-risk or vulnerable group and more likely to die?

*Prof. Dr. Jonathan Finder*

They are at a higher risk to be sure, as the illness is a viral pneumonia, and having pneumonia is a risk for respiratory failure in this population. But as for "more likely to die" I would say NO as these patients are younger and for the most part do not have underlying lung disease. Those with chronic lung disease are the highest risk group, along with the elderly. On the other hand, cardiac disease is a risk factor too, and there is a great deal of cardiac disease in the DMD population. Thus, I do have concerns about the risk of COVID-19 infection for those patients with heart failure.

## Are ACE inhibitors a potential risk factor? Should we stop taking them?

*Prof. Dr. Jonathan Finder*

See below for more on this subject (short answer: no information to allow an accurate answer) but one should NOT discontinue use.





## POSITION STATEMENT OF THE ESC COUNCIL ON HYPERTENSION ON ACE-INHIBITORS AND ANGIOTENSIN RECEPTOR BLOCKERS



Based on initial reports from China, and subsequent evidence that arterial hypertension may be associated with increased risk of mortality in hospitalized COVID-19 infected subjects, hypotheses have been put forward to suggest a potential adverse effects of angiotensin converting enzyme inhibitors (ACE-i) or Angiotensin Receptor Blockers (ARBs). It has been suggested, especially on social media sites, that these commonly used drugs may increase both the risk of infection and the severity of SARS-CoV2. The concern arises from the observation that, similar to the coronavirus causing SARS, the COVID-19 virus binds to a specific enzyme called ACE2 to infect cells, and ACE2 levels are increased following treatment with ACE-i and ARBs.

Because of the social media-related amplification, patients taking these drugs for their high blood pressure and their doctors have become increasingly concerned, and, in some cases, have stopped taking their ACE-i or ARB medications. This speculation about the safety of ACE-i or ARB treatment in relation to COVID-19 does not have a sound scientific basis or evidence to support it. Indeed, there is evidence from studies in animals suggesting that these medications might be rather protective against serious lung complications in patients with COVID-19 infection, but to date there is no data in humans.

The Council on Hypertension of the European Society of Cardiology wish to highlight the lack of any evidence supporting harmful effect of ACE-i and ARB in the context of the pandemic COVID-19 outbreak.

The Council on Hypertension strongly recommend that physicians and patients should continue treatment with their usual anti-hypertensive therapy because there is no clinical or scientific evidence to suggest that treatment with ACE-i or ARBs should be discontinued because of the Covid-19 infection.

Prof. Giovanni de Simone,  
Chair, ESC Council on Hypertension  
On behalf of the Nucleus Members

## COVID-19 and ventilation

Should I get a cough assist even if my son doesn't really need it yet?

*Prof. Dr. Jonathan Finder*

COVID-19 causes viral pneumonia, and so does not produce much in the way of secretions that need clearance. In general, the CoughAssist is not helpful if you don't need it. If you think your son has a weak cough then by all means get one, as there is a risk of secondary bacterial pneumonia. Having a viral pneumonia will make one's lungs stiffer and harder to inflate, so a person with a weak diaphragm is at risk for developing respiratory failure.

*Prof. Dr. Francesco Muntoni*

If you have a severe problem, the cough assist might not help. COVID is a different type of pneumonia where fluid accumulates. It's a dry cough. A cough assist might help if people get additional bacterial pneumonia.

Are patients on ventilation less likely to contract the virus?

*Prof. Dr. Jonathan Finder*

This makes sense, and will probably prove to be the case. But hand sanitation is still really important. Those who cannot feed themselves, for example, are at risk for exposure from any virus on the hands of the caregiver.



## How efficient are the bacteria filters on non-invasive ventilators?

*Prof. Dr. Jonathan Finder*

They are fine for respiratory droplets.

*Pulmonologists UZ Leuven*

Invasive ventilation is not a “closed” system, otherwise there would be rebreathing with hypercapnia in the circulation. The ventilator uses ambient air. Bacteria filters on non-invasive ventilators are less efficient for viruses as viruses are much smaller.

## Could the Coronavirus cause long term damage to lungs?

*Prof. Dr. Jonathan Finder*

No information on long-term follow-up as this is a new virus. But based on our experience with similar infections this seems unlikely.

## COVID-19 and medicine shortage

### Could there be a shortage of medicine due to COVID-19?

*Prof. Dr. Francesco Muntoni*

There might be a chance that pharmacies face difficulties with stocking up, so I recommend stocking up on medications. You have to become familiar with stress doses of steroids.

*Prof. Dr. Jonathan Finder*

Unlikely to be any shortages of the kinds of medications used by DMD patients, but one cannot predict. I think it’s a good plan to get an extra month’s supply of medicine: in case one finds oneself quarantined and unable to leave home to pick up refills.

*Prof. Dr. Nathalie Goemans*

I cannot comment on the possible shortage of medication, this is also different from one country to another, however shortage of masks is an issue In Belgium, that is why we have strict rules about the use of these masks.

## Effect of COVID-19 on hospitals and hospital visits?

### Could it be that patients with Duchenne could be refused treatment?

*Prof. Dr. Jonathan Finder*

It seems unlikely that a patient with Duchenne could be refused treatment, when doctors have a policy of choosing to treat patients that are most likely to survive. But at the same time, I would avoid taking anyone to hospital without a high suspicion for COVID-19 or unless the patient is having difficulty breathing.

## Could routine/check-up hospital appointments be cancelled?

*Prof. Dr. Francesco Muntoni*

If your country is early in the disease spreading curve, an early hospital visit might be useful since now hospitals have space. We advise to postpone hospital visits and resort to telephone consultation. If the situation is abrupt and critical, you have to go. Hospitals might not be a big deal in case of infection hazard, but getting there might be a problem (due to public transportation being of high risk). In young adults with respiratory insufficiency or cardiac problems, chances of serious threats are higher.

*Prof. Dr. Jonathan Finder*

If there are no new concerns, I would reschedule elective visits to avoid risk of exposure.

*Prof. Dr. Nathalie Goemans*

It seems wise to delay any non-urgent visit to hospital in the upcoming weeks.

## Possible treatments or medications

Are there any medications we could take, or could using ACE inhibitors offer patients additional protection?

*Prof. Dr. Eugenio Mercuri*

We all agree to not change anything in the case of ACE inhibitors. There is a letter written by the Italian Hypertension Society that reflects that there is no evidence for stopping ACE inhibitors. You don't stop something that you know is beneficial for people with DMD. If there is a serious concern, you will absolutely hear from us.

*Prof. Dr. Jonathan Finder*

No, unless you get sick and might need extra (stress-dose) steroids, but this would be as per your doctor. We have simply too little information about the possible relationship between the ACE2 receptor and ACE-inhibitor to draw any conclusions. There is no proof yet that the use of ACE inhibitors worsens (or helps with) coronavirus infection.

*Prof. Dr. Nathalie Goemans*

Definitely no reason to change medications such as ACE inhibitors and steroids

## What about whooping cough and other vaccines?

*Prof. Dr. Jonathan Finder*

This is an unrelated infection; I have no reason to believe that this vaccine would benefit anyone with or protect anyone from COVID-19 infection.

## What about vaccinations?

Is it important to be vaccinated against pneumococcus?

*Prof. Dr. Francesco Muntoni*

It is important to get all vaccinations, since you don't want to be affected by both COVID-19 and another virus at the same time. Whooping cough is not mandatory but recommended to have all vaccinations to protect your health.

*Prof. Dr. Jonathan Finder*

In general this has been recommended but specifically in this scenario it provides no protection against COVID-19, and going to a medical facility for vaccination right now increases risk for exposure.

*Prof. Dr. Nathalie Goemans*

We cannot stress enough that containing this epidemic is everyone's responsibility, we should all temporarily restrict our contacts and stay at home, as much as possible adhering to strict measures of hygiene.

## What can we do as patient organisations?

- Avoid fake news in your community
- Share this webinar and report with your families and clinicians
- Spread the best information you can get
- Respect local authorities and guidelines
- Follow-up WDO webinar on more specific questions

## What can we do as the World Duchenne Organization?

- Recording will be available for dissemination soon
- Report to be translated and shared with families and clinicians
- WDO Live feed: [COVID-19 and Duchenne/Becker](#)
- Weekly follow-up webinar to update the community (next date: March 21, 4pm CET)
- Support everyone where we can!

## Show your solidarity!

Providing medical and clinical information is much needed in these complicated times. Beside this, we also need to think of the community. We have to show our strength. This is why we have created a social campaign to connect with everyone. Staying at home in some countries is obligatory (Italy, Spain). For our boys, staying at home is important. Involve civil society and let them know how best practices are important for people with rare and serious diseases.

Hold together and connect online in this way. Share this info with your family, and share photos with #Home4Duchenne or #Home4Becker. Once done, a video will be created from all the contributions.