

WORLD DUCHENNE ORGANIZATION

DMD/BMD AND COVID-19



March 14, 2020

AGENDA

DMD/BMD CONSIDERATIONS WITH COVID-19

16:00 Welcome and introduction, *Elizabeth Vroom*

16:05 About COVID-19, *Suzie-Ann Bakker*

16:10 Questions to clinicians

Prof. Dr. Eugenio Mercuri (online)

Prof. Dr. Nathalie Goemans (online)

Prof. Dr. Jonathan Finder (in writing)

Prof. Dr. Francesco Muntoni (in writing)

16:40 Questions and discussion, moderator *Elizabeth Vroom*

16:45 Show your solidarity, *Nicoletta Madia*

17:00 Conclusion & wrap-up, *Nicoletta Madia*

UPDATE ON THE SITUATION

WHAT WE KNOW ABOUT COVID-19

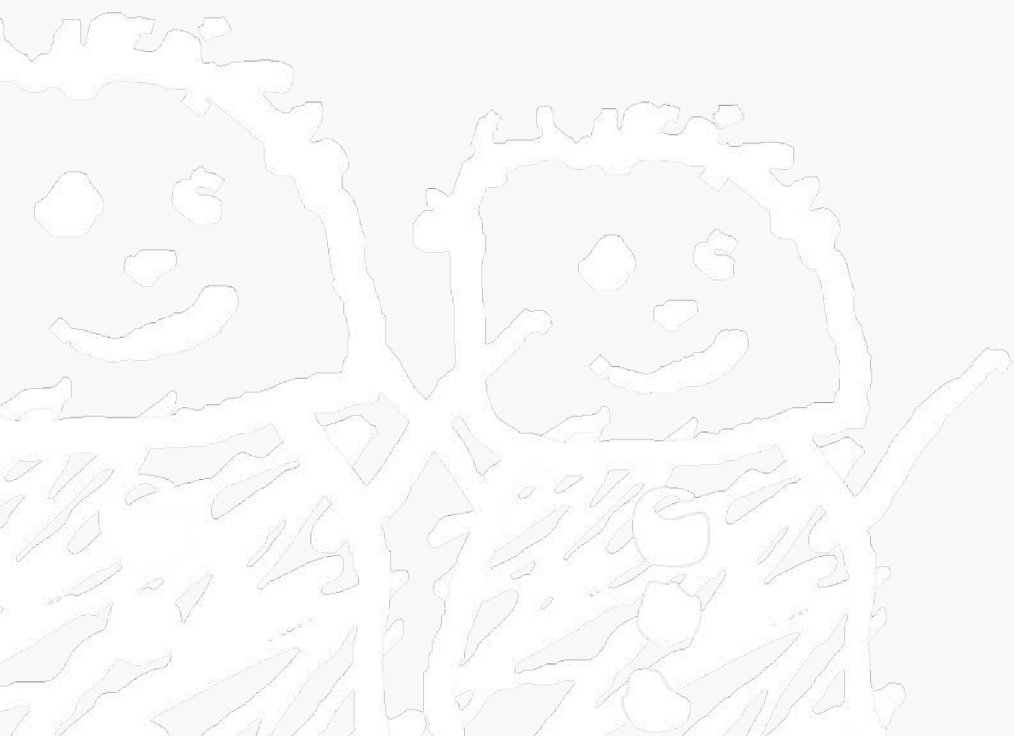


COVID-19 CORONAVIRUS

GENERAL INFORMATION

- It's a respiratory virus that can be spread by aerosols: little droplets when you cough or sneeze.
- Symptoms are coughing, having fever, shortness of breath and difficulty breathing.
- The virus can survive for hours on hard surfaces, so you don't have to see the person who is symptomatic and spreading.
- Highest risk are the older population above 60 and vulnerable people.
- This Wednesday, the WHO officially declared COVID-19 a pandemic.

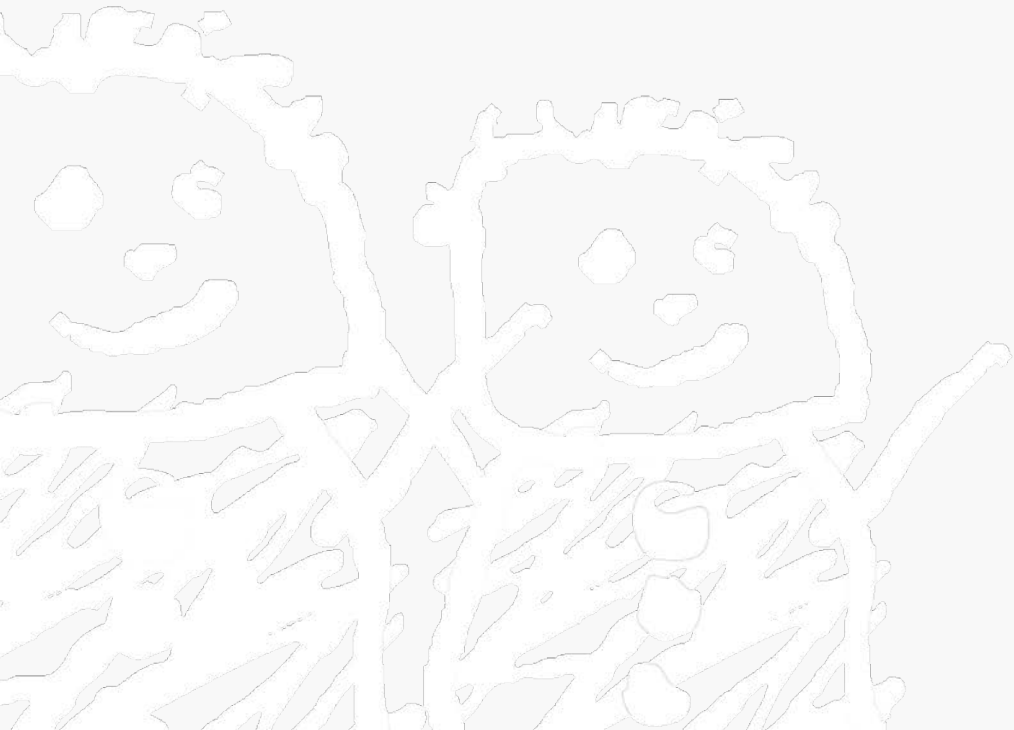
Stanford University School of Medicine
[Webinar 'Coronavirus for non-virologists'](#)



COVID-19 CORONAVIRUS

AND DMD/BMD

- There is no expertise about Duchenne / Becker muscular dystrophy and the coronavirus as we don't know any DMD/BMD patient affected by it
- We have asked DMD experts to give a reaction to the questions of our families
- Situation and national rules will be different in all countries



BIG QUESTIONS

QUESTIONS TO CLINICIANS



DUCHENNE & BECKER AND COVID-19: WE ASKED QUESTIONS TO CLINICIANS



Prof. Dr. Eugenio Mercuri
Paediatric neurologist



Prof. Dr. Nathalie Goemans
Paediatrician, child neurologist



Prof. Dr. Jonathan Finder
Paediatric pulmonologist



Prof. Dr. Francesco Muntoni
Paediatric neurologist

WHAT CAN WE DO BEST FOR OUR BOYS AND MEN?

- What are the best ways of minimising chances of infection?
- How can I boost my (son's) immune system?
- What is the risk with people with Duchenne/Becker?
- How does COVID-19 interfere with ventilation?
- Will COVID-19 cause a shortage of medicine?
- What is the effect of COVID-19 on hospitals and hospital visits?
- Are there possible treatments or medications?

SHOULD I TAKE MY SON FROM SCHOOL?

“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. Jonathan Finder

“Worldwide, children seem less affected than adults and elderly however to be on the safe side, in Belgium we gave the advice at the beginning of the week for all neuromuscular patients with restricted respiratory function and for all **DMD under 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.” – Prof. Dr. Nathalie Goemans

“We do not know for how long this makes sense, and for pragmatic reasons in Belgium we included the duration of Easter Holiday, so this means till the 19th of April. In the meanwhile there will be a better view on the evolution of the spreading. We have to bear in mind that these measures from our regulators are driven by aspects of public health, trying to contain/dilute the spreading of the virus. **Additional measures have to be tailored to the individuals** taking into consideration their fragility and risk profile, their environment.” – Prof. Dr. Nathalie Goemans

IS BEING ON A PLANE A HIGH RISK TO CATCH THE VIRUS?

“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. Jonathan Finder

“Yes, I think **all travelling 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 to one another for a longer time than at other events, e.g. concert halls ..; contact at 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.” – Prof. Dr. Nathalie Goemans

HOW TO FOLLOW INSTRUCTIONS IF RESOURCES ARE SCARCE?

“The best way to protect your sons is avoidance of crowds and careful **hand washing with soap and water.**” – Prof. Dr. Jonathan Finder

“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.**” – Prof. Dr. Nathalie Goemans

“Next to washing your hands often, it’s necessary to **clean surfaces,** door handles and touch screens regularly.” – Elizabeth Vroom

COULD SUPPLEMENTING WITH VITAMIN C/D OR PROBIOTICS HELP?

“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. Jonathan Finder

“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 of most sanitizers, giving a false sense of security)” – Prof. Dr. Nathalie Goemans

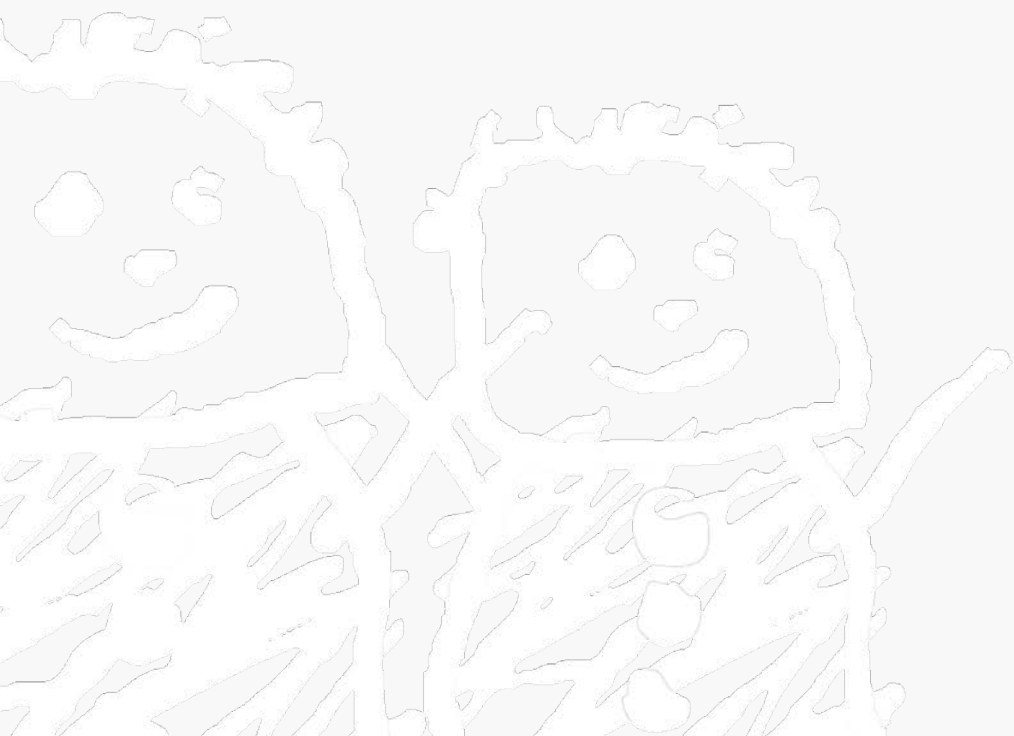
WHEN INFECTED, WILL IT TAKE THEM LONGER TO FIGHT IT OFF?

“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. Jonathan Finder

“Yes, it is known that a **severe course 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.” – Prof. Dr. Nathalie Goemans

WHAT IMPACTS DO STEROIDS HAVE ON THE IMMUNE SYSTEM?

“Steroids are a **mild immunosuppressant** and reduce the activity of lymphocytes, and these are the cells that help fight off viruses.” – Prof. Dr. Jonathan Finder



DO PEOPLE DMD/BMD PATIENTS HAVE A HIGHER CHANCE OF CATCHING THE VIRUS?

“No, and **possibly they have a lower risk** given that they are less likely to be touching door knobs and handles and shake hands and the like. Those in schools or just out and about have the same risk from respiratory droplets.” – Prof. Dr. Jonathan Finder

“We cannot stress enough that containing this epidemic is everyone’s responsibility, we should all **temporarily restrict our contacts** and stay as much as possible at home, respecting strict measures of hygiene.” – Prof. Dr. Nathalie Goemans

ARE THEY AT HIGH-RISK OR 'VULNERABLE PEOPLE' MOST LIKELY TO DIE?

“They are 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**, 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.” – Prof. Dr. Jonathan Finder

ARE ACE INHIBITORS A POTENTIAL RISK FACTOR? SHOULD WE STOP TAKING THEM?

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

[Position Statement of the ESC Council on Hypertension on ACE-Inhibitors and Angiotensin Receptor Blockers](#)

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

SHOULD I GET A COUGH ASSIST EVEN IF HE DOESN'T NEED IT YET?

“COVID-19 causes a 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 the risk for a secondary bacterial pneumonia. Having a viral pneumonia will make one's lungs stiffer and harder to inflate, so a person with weak diaphragm is at risk for developing respiratory failure.” – Prof. Dr. Jonathan Finder

ARE PATIENTS ON INVASIVE VENTILATION LESS LIKELY TO CONTRACT THE VIRUS?

“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.**” – Prof. Dr. Jonathan Finder

“No, this is not a “closed” system, otherwise there would be rebreathing with hypercapnia in the circulation. The ventilator uses ambient air.” – Pulmonologists UZ Leuven

“Bacteria filters on non-invasive ventilators are less efficient for viruses as viruses are much smaller” – Pulmonologists UZ Leuven

“There is **no information on whether the coronavirus causes long term damage to lungs**, or on any long-term follow-up as this is a new virus. But based on our experience with similar infections this seems unlikely.” – Prof. Dr. Jonathan Finder

COULD THERE BE A SHORTAGE OF MEDICINE DUE TO COVID-19?

“Unlikely to be any shortages of the kinds of medications used by DMD patients, but one cannot predict.” – Prof. Dr. Jonathan Finder

“I cannot comment on 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.” – Prof. Dr. Nathalie Goemans

“I think that 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. Jonathan Finder

WHAT IS THE EFFECT OF COVID-19 ON HOSPITALS AND HOSPITAL VISITS?

“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.” – Prof. Dr. Jonathan Finder

“I think that if there are no new concerns I would **reschedule elective visits** to avoid risk of exposure.” – Prof. Dr. Jonathan Finder.

“It seems wise to delay any non-urgent visit to hospital in the upcoming weeks” – Prof. Dr. Nathalie Goemans

ARE THERE ANY ADDITIONAL MEDICATIONS WE COULD TAKE?

“No, unless you get sick and **might need extra (stress-dose)** steroid, but this would be as per your doctor.” – Prof. Dr. Jonathan Finder

“Definitely **no reason to change medications** such as ACE inhibitors and steroids” – Prof. Dr. Nathalie Goemans

“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. Jonathan Finder

WHAT ABOUT WHOOPING COUGH VACCINE? DOES THIS MAKE SENSE?

“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.” – Prof. Dr. Jonathan Finder

“This obviously does not protect against Corona, However it is a general rule that patients with respiratory insufficiency should have been immunized for whooping cough and pneumococcal. If this has not been done, it could be administered now, as a general measure, however protection will only occur after 4-6 weeks.” – Pulmonologists UZ Leuven

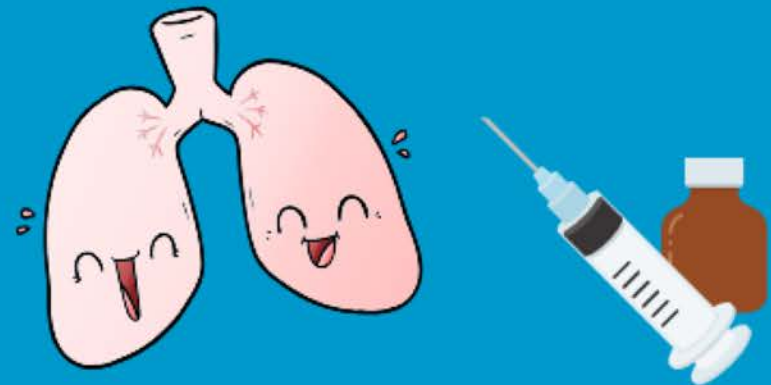
“In general it has been recommended to be vaccinated against pneumococcus, but specifically in this scenario there is **no protection from COVID-19**, and going to a medical facility for vaccination right now increases risk for exposure.” – Prof. Dr. Jonathan Finder

No. Vaccines against pneumonia, such as pneumococcal vaccine and Haemophilus influenza type B (Hib) vaccine, do not provide protection against the new coronavirus.

The virus is so new and different that it needs its own vaccine. Researchers are trying to develop a vaccine against 2019-nCoV, and WHO is supporting their efforts.

Although these vaccines are not effective against 2019-nCoV, vaccination against respiratory illnesses is highly recommended to protect your health.

Do vaccines against pneumonia protect you against the new coronavirus?



#2019nCoV

MODERATOR: ELIZABETH VROOM

DISCUSSION



WE ARE IN THIS TOGETHER

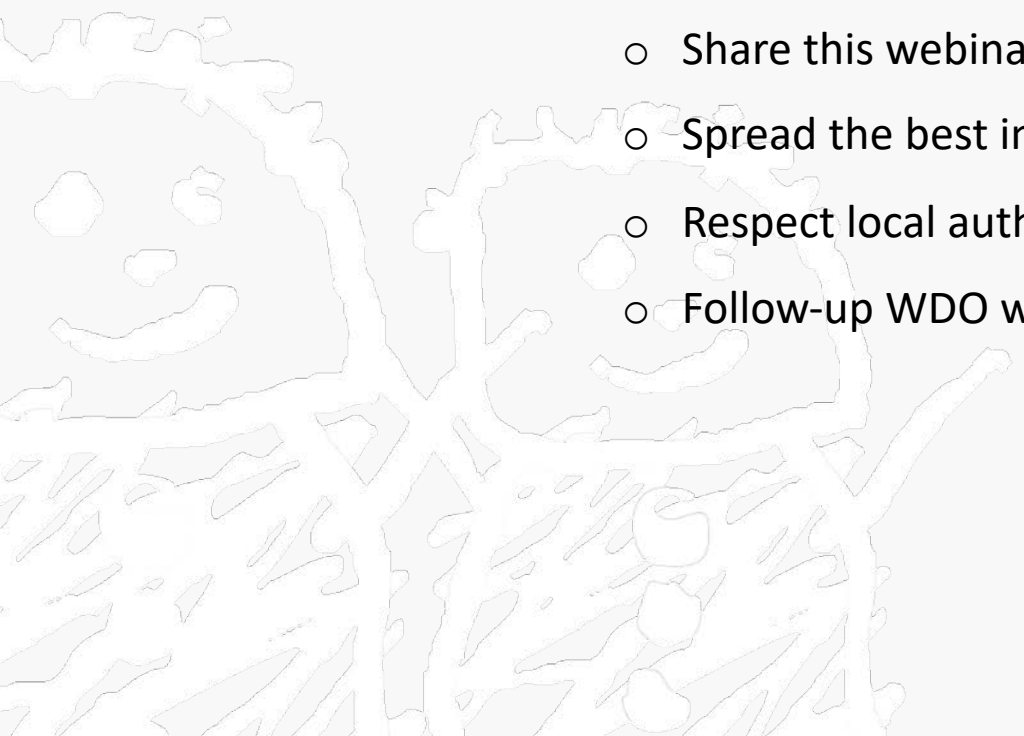
WHAT CAN WE DO AS DUCHENNE AND BECKER PATIENT ORGANISATIONS?



WHAT CAN WE DO AS DMD/BMD PO'S?

ACTIONS FOR 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 WDO DO FOR DMD/BMD PO'S?

ACTIONS FROM WDO

- Recording made 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

#HOME4DUCHENNE
#HOME4BECKER

WHAT IT IS

Social campaign of the global Duchenne Community

OBJECTIVES

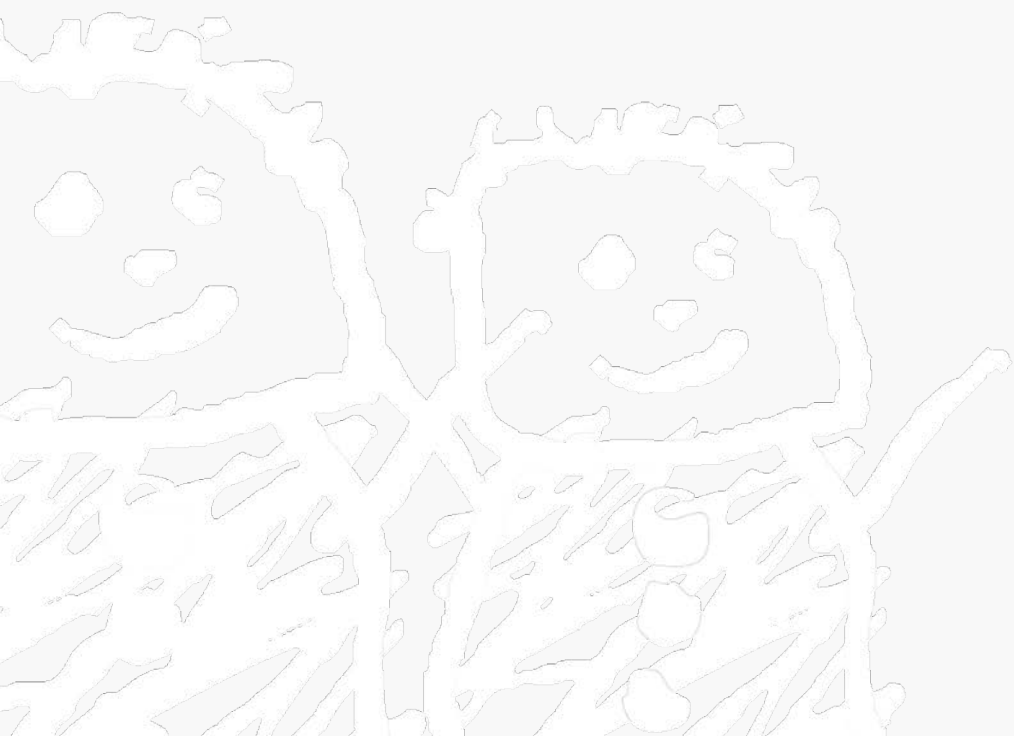
1. Involve the civil society on how best practices are important for everyone and essential for people with serious diseases like DMD
2. Create a stronger community during this difficult moment: we are all together

WHAT TO DO

Every family can share a photo of them at home with the #

WHEN

From tomorrow on photos will be shared on WDO pages and included in a final video



**WDO WILL HELP AND
LET'S HELP EACH OTHER!**

For questions please contact

nicoletta.madia@worldduchenne.org

suzieann.bakker@worldduchenne.org