



MetabERN Recommendations for all Rare Inherited Metabolic Diseases patients and caregivers about treatment adherence during the COVID-19 emergency

The COVID-19 pandemic is testing the resilience of robust health systems around the world. This may be impacting you in many different ways, such as creating additional anxiety or exacerbating other medical or therapy issues related to your Inherited Metabolic Diseases (IMD). In this difficult period MetabERN underlines the critical importance of sustaining efforts to prevent, diagnose and treat Inherited Metabolic Diseases (IMDs) assuring the continuation of the quality of care provided to you.

To help the entire metabolic community we have developed some recommendations that aim to support all IMDs patients and caregivers during the COVID-19 emergency.

FEAR OF BEING INFECTED WITH THE VIRUS both during the journey to hospital centres for your therapy/rehabilitation programmes and during the therapy/rehabilitation procedure itself

It is normal that you fear the possibility of contracting this potentially harmful infection that is spreading fast and for which there is currently no vaccine or preventative treatment. But you should carefully consider the real risk of suspending, even if for short periods, a therapy/rehabilitation that has proven to be effective at managing your disease and which has improved your quality of life, preventing you, for e.g, from acute and/or severe damage.

RECOMMENDATION

Do not act out of fear: wherever possible continue your therapy/rehabilitation during the COVID-19 emergency or, if this is not possible, simply follow the indications provided by your Referral Center. Be sure, however, to use all the necessary precautions and safeguards to prevent contagion both before, during and after the therapy and contain the infection following all the procedures recommended by national and international health bodies.

In any case remember to go to the hospital for a visit only if you have a scheduled and confirmed appointment or if it is really needed.

QUESTION: What can I do in case of strict travelling restrictions?

In case of strict travelling restrictions we recommend you to consult your local healthcare providers first in order to arrange with him pre-traveling on-line consultation of tertiary center or certification/authorization to go in the indicated referral center.

RECOMMENDATION

MetabERN recommends the use of Videoconferences as a replacement for many of the face to face meetings and invites the metabolic community to extend the use of these tools to allow patients to be in close contact with the specialized centers, to meet their doctor/physiotherapist, to get their questions answered.

QUESTION: What can I do if it is not possible to get the therapy safely at the hospital centre due to the lack of effective measures or precautions to prevent contagion? And what if the centre is not able to guarantee the administration of the therapy?

MetabERN suggests, that - whenever possible - you should be directed to home therapy. Of course this is subject to authorisation by the reference centre and according to the national rules.

Make sure to contact your hospital centre or metabolic expert for council and/or your national authority (in your country a helpline may be available).

MetabERN recommends that the Reference Centre should provide the therapy details and the protocol for each patient and monitor its proper execution.

QUESTION: What if I get the COVID-19 infection? What shall I do?

In the case of COVID-19 infection get immediately in touch with your Reference Centre. They are responsible for giving you medical advice, namely about the advisability of continuing or suspending therapy.

FINAL RECOMMENDATION

MetabERN urges you NOT to interrupt or postponed your therapy unless it has been directly recommended by your metabolic expert or become inaccessible/unavailable due to the current strain put on health services by the COVID-19 pandemic.

Be aware that you are an active agent in your in care! **But you are not alone - If you have doubts about your IMD treatment during this trouble times, make sure to contact your metabolic experts/centres or local health authorities. Keep alert, well-informed and safe.**

Please follow carefully the instruction of your National Recommendations.