



**UNITED
MITOCHONDRIAL
DISEASE
FOUNDATION®**

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**HBOT
UMDF NEWSLETTER
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The UMDF member services department receives many requests for information on the utilization of Hyperbaric Oxygen Therapy (HBOT) for the treatment of various mitochondrial diseases.

While there is much discussion and controversy about the benefits of this treatment, unfortunately the evidence of these benefits has been largely anecdotal or issued by a biased source.

The value of HBOT therapy as a treatment for mitochondrial disorders was posed to our Scientific and Medical Advisory Board, and it was their unanimous opinion that, at this time, until there is clear, clinical evidence to support the benefits, they cannot endorse or recommend HBOT therapy as a treatment for mitochondrial disorders.

Mitochondrial disease is not as rare as once thought. It is now conservatively estimated that one in 4,000 persons will develop some form of mitochondrial disease in their lifetime, with some researchers suggesting an occurrence rate as high as one in 2,000. Half of these will develop the disease in childhood. There is no cure or treatment for mitochondrial disease, and the impact upon the patient ranges from mild symptoms to death.

UMDF realizes that research is the key to saving the lives of those afflicted with mitochondrial disease. The disease is under recognized and complex, affecting multiple organ systems at any age of the patient. Mitochondrial dysfunction also mimics or is the cause of other common diseases such as Parkinson's, Alzheimer's, diabetes and more. Its complex array of symptoms and multiple modes of inheritance make mitochondrial disease difficult to diagnose and currently very difficult to treat.

With this in mind, UMDF has instituted a peer review research grant program that has, to date, funded more than \$4 million of mitochondrial disease research. No research funded thus far has included or involved hyperbaric oxygen therapy, and to the best of our knowledge, there has never been a controlled trial for the use of hyperbaric oxygen in the treatment of mitochondrial disorders with human subjects.

The issue with patients who have electron transport chain disorders is an inability to reduce molecular oxygen, which we breathe, into water, which we excrete, because of a block in complex IV or proximal and distal subunits. For the purpose of energy production, it is contra-intuitive to believe that putting more oxygen into this system would be helpful. Hence, hyperbaric oxygen would not push energy production, unless the problem with the mitochondrial disorder was caused by an oxygen binding issue with complex IV, which has not been described.

Excessive oxygen results in free radical production, and because there is adequate proof that excessive free radical production results in further damage to the mitochondria in many mitochondrial disorders and mitochondrial models, the use of hyperbaric oxygen poses a relative risk.

There is an inherent danger in any single case report demonstrating a treatment benefit in a patient. Please consider the following:

- There are hundreds of mitochondrial disorders, and successful treatment of one disorder will not translate into successful treatment of others.
- With case reports, especially those where the report is based on retrospective views of function without objective measurements, there is potential bias on both the parents' and physicians' parts.
- If there is a conflict of interest, especially a financial conflict of interest, it should be mentioned one way or another in a report. In the case of hyperbaric therapies, the physician that makes the report may be an owner or part owner of the hyperbaric facility or benefit in some other financial way. If a conflict exists, it should be stated. If a conflict does not exist, it should be stated.

- The issues we have seen are based on newspaper reports, not reports in peer-reviewed journals.
- There is a problem with proof of principle. The science of mitochondrial disorders, as we understand them, is that patients would worsen with extra oxygen.
- If the single patient does have a mitochondrial disorder AND truly gets better with hyperbaric oxygen, there may be other factors that could explain the improvement.

UMDF strongly suggests that you seek the advice of a physician with clinical experience in the treatments of mitochondrial disease and who is familiar with your affected family member's medical history before considering any treatment regime.

UMDF, with the limited scientific information available for review, cannot at this time endorse the use of hyperbaric oxygen therapy (HBOT) for the treatment of mitochondrial disease.