

MHE/HME/MO AND HOW IT MAKES US “VULNERABLE”

Multiple Hereditary Exostoses is an incurable genetic condition. Because it is widely misunderstood, some are unaware it is a pre-existing condition that weakens the immune system and leaves patients more susceptible for viruses and infections-here's why;

1 OUR BODY AND IMMUNE SYSTEM IS UNDER CONSTANT STRESS

The constant pain that MHE puts on our body causes the body to be under constant stress and release cortisol. Having too much cortisol opens the door to for more inflammation. Stress also decreases the production of lymphocytes, which are the white blood cells that fight off infection.

Long term stress on the body can also cause cardiovascular problems such as fast heart rate and leave you with a higher risk for gastric ulcers, cancers, Type 2 Diabetes and mental decline over time.

2 MHE WARRIORS LIVE WITH CHRONIC INFLAMMATION

Our bodies are always inflamed in some way; the bone tumors cause inflammation locally in the areas where there are tumors but also throughout the entire body through cortisol production. Bursitis and cysts can also form due to the inflammation around tumors. Many MHE warriors also live with Early-Onset Arthritis, Fibromyalgia, IBS, Asthma and more. Chronic inflammation leads to the development and progression of conditions like these and weaken the immune system, leaving one more susceptible to viruses.

3 BONE TUMORS CAN AFFECT BEYOND THE BONE

Tumors are extra bone that should not be there and depending on where they are located, they can cause a bigger problem. Some tumors may compress and/or pinch nerves, tendons, and blood vessels and cause problems with movement and circulation. Heart problems like tachycardia and blood vessel aneurysms can occur from having bone tumors. The substantial pain and interference with circulation can cause the immune system to weaken, leaving one more susceptible to viruses.

4 MHE IS MORE THAN JUST A BONE DISORDER

In 2006, it was concluded that MHE patients have defective heparan sulfate proteoglycan biosynthesis (HSPG). HSPGs dominate extracellular interactions the same way nucleic acids dominate the nucleus. Polysaccharides control the communication between cells and also controls what goes in and out of the cells. This means MHE patients have a heparan sulfate deficiency that affects the entire body. Heparan Sulfate is essential to many healthy organs, and we don't know how our deficiency affects ours.

5 HEPARAN SULFATE IS ESSENTIAL FOR HEALTHY LUNGS

Heparan Sulfate is critical for pulmonary homeostasis, maintaining parenchymal structure and facilitating cellular signaling that is needed for lung development and function. The defect in the Heparan Sulfate associated with the MHE Genetic Mutation EXT1/EXT2 changes the cellular structure of the lungs in MHE patients. It is not known yet how MHE lungs differ from normal ones it as more research is needed. It is known that asthma can be co-morbid with MHE.

6 MHE PATIENTS HAVE REPORTED SYMPTOMS TIED TO HS DEFICIENCY

Severe fatigue, unusual drug reactions, higher prevalence to scarring and atrophic scarring, severe gastric issues, Cyclic Vomiting Syndrome, Kidney Stones and other Bladder problems, Neurological disorders like Migraines and Autism, Vertigo and hyperacusis, Lung issues, extremely painful menstruation/endometriosis, slow wound healing, inflammation, and Fronto Temporal Dementia are all related to the lack of HS and are experienced by many MHE patients in various ways.

7 MORE RESEARCH IS CURRENTLY BEING DONE ON HEPARAN SULFATE

Dr. Yamaguchi, a MHE expert and researcher, conducted an informal survey and realized MHE patients have other systemic symptoms that tend to be ignored frequently in a clinical aspect. Dr. Yamaguchi believes these symptoms can be explained by the heparan sulfate deficiency MHE patients have. R.A.R.E. has reached out to Dr. Yamaguchi and other heparan sulfate researchers to stay up to date on the latest cutting edge research.

8 BE YOUR OWN ADVOCATE!

We are here to help keep you safe, supported, and informed, but remember, you know your body the best! Stay in contact with your team of doctors and specialists who understand your MHE and tell your doctors every problem you have, even if you think it's not important. Join our R.A.R.E. Community to be a part of a safe and all inclusive platform that promotes open communication with other MHE and rare disease warriors from around the globe who are there to support and empower each other. Always ask other MHE warrior what their experiences are to learn more about how others are affected, and always do your own research. Doctors and experts do not know everything all the time.

