Second International MHE Research Conference Held in Houston, TX Nov 2005

The Third International Conference will be held in Orlando, Florida. July 8-11, 2009
Co-organized by Yu Yamaguchi, M.D., Ph.D. Dominique Stickens, Ph.D. & Sarah Ziegler

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The MHE Research Foundation

Wings of HOPE as we REACH for the CURE to Multiple Hereditary Exostoses
www.MHEResearchFoundation.org

The MHE Research Foundation is a nonprofit 501(c)(3) organization for the support of researchers, families & physicians dealing with (MHE) Multiple Hereditary Exostoses (MO) Multiple Osteochondroma a rare genetic bone disease.

The MHE Research Foundation five point mission is to REACH, advance and support the following.

RESEARCH, to help researchers one day find a treatment / cure for MHE. Our foundation works hand in hand with researchers from around the world on this mission.

EDUCATION, to provide clinical information, guides to help benefit both families and physicians.

ADVOCACY, bring awareness about this disease in all areas throughout the world.

CLINICAL, to help provide resources to families enabling them to find the medical care they need.

HOPE, is that the research being conducted on MHE, the informational resources will bring a better quality of life to the families affected by this disease.

Our website includes comprehensive sections related to all research being conducted, a wide range of both Research & Orthopaedic Conferences. Organizing these International Conferences, brings together researchers and physicians from various disciplines, in order to have established an entire community devoted to the better understanding and the future discovers of treatments for Multiple Hereditary Exostoses. We offer numerous clinical informational guides, video presentations, resources including doctor directories and emotional support to families living with MHE.

There is no treatment for MHE / MO / HME the only current options are surgery and pain management.

Our organization is involved in studies with many institutions, including the University of Houston Medical School, University of California San Diego, The Children's Hospital of Philadelphia, The Burnham Institute, La Jolla, California, University Hospital of Antwerp, Belgium, Rizzoli Orthopaedic Institute, Bologna Italy and others.

WHAT IS MULTIPLE HEREDITARY EXOSTOSES?

Multiple Hereditary Exostoses "MHE" is also often referred to as Hereditary Multiple Exostoses "HME" Multiple Osteochondroma "MO" is the preferred term used by the World Health Organization (WHO). MHE / MO / HME is a genetic bone disorder in which many benign cartilage-capped bone tumors develop.

These bone tumors grow outward from the metaphyses of long bones, growth plates of long bones or from the surface of flat bones throughout the body. There is an increased risk of developing chondro- sarcoma. (Life time risk of 2%-5% reported).

MHE / MO / HME is an autosomal dominant disorder. This means that a patient diagnosed with MHE / MO / MHE has a 50% chance of transmitting the disorder to his / her children. This is equal for both male and female patients. Normally this disorder does not skip a generation.

MHE / MO / HME manifested by multiple Exostoses / Osteochondromas frequently associated with characteristic progressive skeletal deformities. Exostoses / Osteochondromas can cause numerous problems including: entrapment; impingement; compression of nerves; blood vessels; tendons; muscles.

Skeletal deformity often accrues with the loss of range of motion; short stature; limb length discrepancy; scoliosis; spinal cord compression; early onset arthritis; chronic pain and fatigue. The severity of this disease varies widely. Some patients may have as few as six tumors, but most patients develop many more and the numbers of tumors can run into the hundreds.

It is not uncommon for MHE / MO / HME patients to undergo numerous surgical procedures throughout their lives to remove painful or deforming Exostoses / Osteochondromas and or to correct limb length discrepancies and improve range of motion. Limb length correction involves gradual correction using an External Fixator (pictured on the right hand side) or insertion of one or two metal staples on the medial side (inside) of the growth plate.

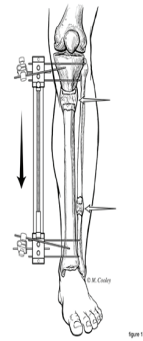

Figure 18 A monolateral external fixator with pins to affix the bones to the fixator.

Most individuals with MHE / MO / HME have a parent who also has the condition, however, approximately 10% of individuals with MHE / MO / HME have the condition as a result of a spontaneous mutation are thus the first person in their family to be affected.

There are two known Genes that cause this disease EXT1 located on chromosome 8q23-q24 and EXT2 located on chromosome 11p11-p12. In 10 to 20% of the patients, no mutation is found. At present, the outcome of genetic testing has no effect on determining orthopaedic care, but genetic testing does give more options in making choices concerning reproduction.

A genetic counselor can offer genetic testing to those families, and once the disease-causing mutation has been identified.

Prenatal diagnostics can be offered through chorionic villus sampling (CVS) at 10-12 weeks gestation or amniocentesis at 15-18 weeks gestation as well as (PGD) Preimplantation diagnostics. (PGD) is a test that screens for genetic mutations among embryos created during invitro fertilization.