Third International MHE Research Conference Held in Philadelphia, PA Nov. 1,-Nov. 4, 2012

The Fifth International MHE Research Conference Will be held on Oct. 29,-Oct. 31, 2015

Co-organized by Jeff Esko, 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

The MHE Research Foundation is a nonprofit 501(c) (3) organization dedicated to the support of Researchers, Physicians & Families dealing with Multiple Hereditary Exostoses Syndrome (MHE) Multiple Osteochondroma Syndrome (MO) a rare genetic bone disease.

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

RESEARCH: to assist and support researchers in order to one day discover a treatment / cure for MHE. Our foundation works hand in hand with researchers and physicians from around the world in this mission.

EDUCATION: to provide vital clinical informational guides & accompanying video benefiting both families and physicians.

ADVOCACY: bring awareness about this disease throughout the world.

CLINICAL: to provide resources directly to families enabling them to locate the medical care they require.

HOPE: the research being conducted on MHE/MO/HME & the informational resources will bring a better quality of life to the families affected by this disease around the world.

WHAT IS MULTIPLE HEREDITARY EXOSTOSES?

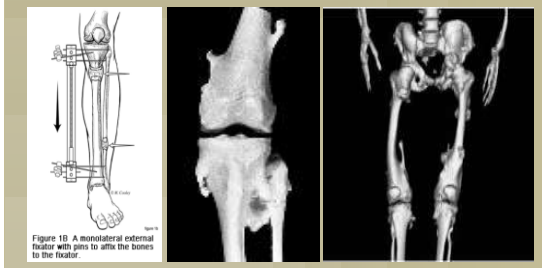
Multiple Hereditary Exostoses Syndrome "MHE" is also often referred to as Hereditary Multiple Exostoses "HME" Multiple Osteochondroma "MO" is the preferred term used by the World Health Organization (WHO). MHE/MO/HME is a genetic bone disorder in which benign cartilage-capped bone tumors develop, affecting 1/50,000 people

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 a increased risk of developing chondro-sarcoma. (Life time risk of 2%-5% reported). MHE/MO/HME is an autosomal dominant disorder. This means a patient diagnosed 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.

This rare genetic bone disorder manifested by Multiple Exostoses / Osteochondromas frequently being associated with characteristic progressive skeletal deformities. Osteochondromas / Exostoses can cause numerous problems including: entrapment compression and impingement of blood vessels, tendons, nerves and 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 two 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 or insertion of one or more metal staples or 8 plates on the medial side (inside) of the growth plate.



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

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) Pre-implantation diagnostics. (PGD) is a test that screens for genetic mutations among embryos created during invitro fertilization.

Our website

Offers comprehensive sections related to all research being conducted around the world; numerous educational clinical informational guides, video presentations and resources including doctor directories and emotional support to families living with MHE/MO/HME. Our Foundation has educational display's at a wide range of both Orthopaedic & Research Conferences. We organize the MHE Research Conferences bringing together researchers and physicians from various disciplines, in order to have established an entire community devoted to the better understanding and the future discoveries of treatments and the ultimate CURE. Our organization is involved in studies with many institutions, including The University of Houston, The Burnham Institute, LaJolla, CA; University of California San Diego CA; The Children's Hospital of Philadelphia Orthopaedic Dept. and in conjunction with the Translational Research Program in Pediatric Orthopaedics; The Children's Hospital Los Angeles CA; University Hospital of Antwerp, Belgium; Rizzoli Orthopaedic Institute among others.