

**Third International
MHE Research Conference
Was held in Boston, MA
Oct. 30, - Nov. 1, 2009**



**The Forth International
MHE Research Conference
Will be held in Philadelphia, PA
on Nov. 3, - Nov. 6, 2009
Co-organized by
Maurizio Pacifici, 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
Multiple Osteochondroma
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 support researchers
in order to one day discover a treatment /
cure for MHE. Our foundation works hand
in hand with researchers from around the
world on this mission.

EDUCATION, to provide vital clinical
information and guides benefiting 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 locate the medical
care they require.

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 offers comprehensive sections related to all research being conducted; numerous clinical informational guides, video presentations and resources including doctor directories and emotional support to families living with MHE / MO / HME. A wide range of both Orthopaedic & Research Conferences, by organizing these International Conferences they bring 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 for Multiple Hereditary Exostoses.

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 Thomas Jefferson University College of Medicine Philadelphia, The Burnham Institute, La Jolla, California, University of California San Diego, University of Houston Medical School, The Children's Hospital of Philadelphia, Children's Hospital Los Angeles, CA 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 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 / HME 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 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 (pictured on the right hand side) or insertion of one or two metal staples on the medial side (inside) of the growth plate.

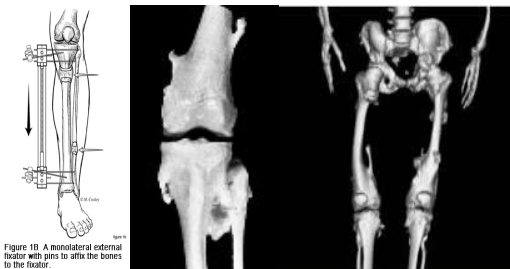


Figure 10. A monodirectional external fixator with pins to affix the bones to the fixator.

There is also a risk of abnormal scarring with keloid formation following surgery for excision of exostoses / osteochondromas.

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.