Second International MHE Conference
Held in Houston, TX Nov 2005

The Third International Conference will be held in San Diego, CA. July 2009
Co-organized by Yu Yamaguchi, M.D., Ph.D. Dominique Stickens, Ph.D. & Sarah Ziegler

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www.MHEResearchFoundation.org
The MHE Research Foundation is a 501 (c) (3) nonprofit Foundation.
The Multiple Hereditary Exostoses 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 Research being conducted, MHE / MO / HME Conferences, Orthopaedics, Genetics and Chronic pain. Research is one of our organizations main focuses. There is no treatment for MHE 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.

Organizing International Conferences, these conferences bring together researchers from various disciplines, in order to establish a research, clinical community devoted to the understanding and future discoveries of treatments for Multiple Hereditary Exostoses.

**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 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.

There is an increased risk of developing chondro-sarcoma. (Life time risk of 2%-5% reported).

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.

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 in reproduction.

A genetic counselor can offer genetic testing to those families, 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 16-18 weeks gestation.

As can Preimplantation diagnostics (PGD) is a test that screens for genetic mutations among embryos created during invitro fertilization.