

**EuroBoneT consortium, a European Commission granted Network of
Excellence for studying the pathology and genetics of bone tumors
March 2007**

Identification and characterization of genes and molecular mechanisms causing multiple osteochondroma (MHE / MO / HME) and related bone disorders, Clinical and molecular study of factors implicated in Multiple Osteochondroma (MHE / MO / HME). It is only by the collection of large numbers of samples and data that major progress can be made in human study of MHE. Tumor samples are needed !, if you are under going surgery please let us know, The MHE Research Foundation and the Researchers working on this project would like your help.

Please consider participating in the project. It does not cost you any thing to participate.

This research project is not simply depending on samples & data from people with MHE / MO / HME that visit this website, this research project is obtaining samples & data directly from hospitals around the USA and multiple countries.

How ever you are a very important part of this approach and your help is greatly needed. There has been major problem in human studies up until now. This was mainly due to the low number of available samples in previous studies and the lack of a uniform phenotype scoring systems used. With the construction of this large MHE / MO / HME network these problems have been addressed and by pooling these samples (construction of a tissue bank) and data of MHE / MO / HME patients & uniform phenotype scoring system. These researchers are also in contact with researchers using animal models to study MHE / MO / HME, together we feel that even larger gains will be made in the future. Together this approach will help greatly in achieving a much better understand of MHE / MO / HME. Research can now move forward in a more comprehensive direction.

The MHE Research Foundation will be collaborating on this new research project with the following researchers listed below. These researchers are partners of the EuroBoneT consortium, a European Commission granted Network of Excellence for studying the pathology and genetics of bone tumors. The researchers heading up this project are being assisted by other researchers in this field. All study information is coded and personal identifiers are removed.

This foundation gives full detailed disclosure, including signed agreements between this foundation and researchers. We also give full back round information of these researchers. We believe you should know where and how this data is being used.

This foundation will never simply request for participation without full and detailed information.!

One question many people have is why Belgium, Italy and Netherlands? Because most labs do not invest in laborious and expensive techniques to identify mutations which are

not found by standard mutation analysis of EXT1 and EXT2. To identify a potential EXT1 or EXT2 mutation, negative patients are analyzed with the most sensitive techniques, including RNA and promotor analysis to identify intronic or regulatory mutation. The identification of mutations in regulatory regions may point to sequences crucial for proper EXT regulation and these sequences can be used as targets for the identification of proteins regulating EXT expression. Most research that has been done in humans used only two step approach, standard genetic testing and clinical information or standard genetic testing and the study of tumors. This research is using comprehensive genetic testing techniques, pathology, studying chondrocytes isolated from the exostoses and clinical information as well as the additional clues that come from animal models. Funding is also an issue, human genetics study into MHE / MO / HME is not being funded by the National Institute of Health, hence the vast amount of this type of research is not done in the United States.

Pancras C.W. Hogendoorn, MD, PhD years of experience in pathology and genetics of bone tumors has paid off! He's the leader of the [EuroBoneT consortium](#), a European Commission granted Network of Excellence for studying the pathology and genetics of bone tumors and the use of comprehensive genetic testing methods & techniques. Wim Wuyts , PH.D. has researched for years by comprehensively studying genetics in MHE / MO / HME and by using these state of the art genetic testing methods & techniques as well and was one of the first researchers to discover the first of the two genes that causes MHE / MO / HME. Luca Sangiorgi, M.D., PH.D. has also been using comprehensive genetic testing techniques in his research, the Rizzoli Orthopaedic Institute has a clinic set up for MHE / MO / HME. Dr. Sangiorgi is also Coordinator of the Italian Registry of Hereditary Multiple Exostoses as well.

All of these researchers sever as advisors to family support groups in there countries. Dr. Wuyts and Dr. Sangiorgi Scientific sever on the Scientific and Medical Board of this Foundation and we are working very very closely with Dr. Hogendoorn as well. Simply put! this is a DREAM TEAM conducting this research with state of the art testing methods & techniques when it goes to genetics and pathology in the world of MHE / MO / HME research!. MHE / MO / HME research deserves the best and does not have to settle for less. They all understand and are deeply concerned about quality of life issues people with MHE / MO / HME face every day, thus can incorporate this into research. The MHE Research Foundation is in a uniquely qualified position of be able to help bring research forward and address quality of life issues within research it self.

Working directly with researchers allows us to give insight into secondary symptoms that have been over looked in many clinical settings. As important if not more important having direct contact with so many people living with MHE / MO / HME enables us to help address quality of life issues in this research settings as well. This was clearly illustrated by Sarah Ziegler, MHE Research Foundation's National Director of Research in the presentation she gave at the Connective Tissue Oncology Society conference this past Nov held in Venice Italy.

This is a well balanced comprehensive research approach, this first of its kind. It is this

foundation's hope by giving detailed information about this research project and the How's and Why's that will lead people with MHE / MO / HME to want to participate in MHE / MO / HME Research. By bring both the MHE / MO / HME community and the Orthopaedic community together, the numbers of samples and data will add up and ultimately make this research bear more fruit in the future.

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