DENTAL RESEARCH STUDY - Multiple Osteochondroma Dental Questionnaire Initiative of the MHE Research Foundation

Multiple Osteochondromas (MO) previously known as Multiple Hereditary Exostoses (MHE) or Hereditary Multiple Exostoses (HME) is relatively rare disorder associated with formation of bone outgrowths at multiple sites in the skeleton. The presence of dental problems has been communicated to us by some MO patients, but as far as we know, there are no medical data published that would confirm this observation. As problems with teeth might severely affect not only the self esteem but also general health, hence we recognize that dental health in MO patients needs to be investigated.

With the support and collaboration of <u>Pancras Hogendoorn, M.D., Ph.D.</u> and <u>Malgorzata Wiweger, Ph.D</u>. from the Leiden University Medical Center(LUMC) The Netherlands a questionnaire has been designed that could be answered without need of seeing any dentist or other medical professionals. We hope that this survey will contribute to better understanding of the MO disorder and improve the quality of care given to MO patients.

All Support groups and individuals who suffer from MO are invited to participate in this study by answering the questionnaire. In order to reach as many MO patients as possible and still be able to manage the project researchers from LUMC decided to place an on-line survey on the MHE Research Foundation website located on an encrypted secure webpage. All responses will be collected by Mrs. Sarah Ziegler (Vice President of the MHE Research Foundation, National Director of Research & Coordinator of Clinical Information, Executive Director of the National MHE Research Registry), encoded in order to keep anonymity /confidentiality of the respondents and forwarded to the team of researchers at the LUMC for analyses. The research team aims to make the results publicly available in a form of an article published in a scientific journal, so basic researchers; medical professionals and people affected by MO will be able to read the results. Please follow this link to fill out the questionnaire: <a href="http://mheresearchfoundation.org/mherf\_dental\_questionnaire.html">http://mheresearchfoundation.org/mherf\_dental\_questionnaire.html</a>.

As a quick reference a picture of the teeth has been placed here.

