

NATIONAL MHE RESEARCH REGISTRY REGISTRATION FORM

www.mheresearchfoundation.org

The National MHE Research Registry was formed to create a national listing of people diagnosed with Multiple Hereditary Exostoses (or other name used to describe this disorder) who are interested in participation in MHE / MO / HME research. Participation may take the form of answering questionnaires pertaining to the clinical manifestations of MHE / MO / HME and / or donating surgical specimens of exostoses and blood samples obtained during medically prescribed treatment, obtaining X-rays and medical records. I also understand my participation in any research will cost me nothing.

The registry serves to provide information on current research, details on what is involved in participation and both assistance and support to participating families throughout the entire research process. In order to be insured of informed consent, and to make sure that families have all of the necessary information needed to make the decision that will be right for them, the MHE Research Registry provides explanations in layman's terms.

Please mail this registry form to the following address.

The National MHE Research Registry
Sarah Ziegler, Executive Director of the National MHE Registry
Address: 149-34 16th Road, Whitestone, NY 11357

Toll Free: 1-877-486-1758

For information and inquiries regarding The National MHE Registry:

Email: sarahziegler@mheresearchfoundation.org

Note: In cases where multiple family members are to be included in the registry, please fill out a separate form for each individual.

Registrants Name:

Address:

Telephone number:

E-mail:

Registrants birth date:

Registrants age at the time of diagnoses:

Name given at time of diagnoses:

Name of treating physician:

Address:

Phone number:

I understand that participation in any research study will not affect my immediate healthcare; that participation is entirely voluntary; and that non-participation will not influence my medical treatment.

I also understand that by registering with the National MHE Research Registry. I am not obligated to become a member of any organization or support group, to participate in any research that is being conducted.

I understand that my personal information will remain with Sarah Ziegler and give her consent to release this information to Researchers or Clinicians conducting research and that this information will be located in a secure data base with no internet access.

I understand that the Researcher(s) or Clinicians will not release any personal identification information provided to them by the National MHE Registry. In the case of surgical specimens, samples will be analyzed in the laboratory by number only. Results of research studies will not be available to individual participants. However, results of these studies may be published in research journals that will be made available to the MHE Registry, healthcare providers, and participating families.

I have the right to withdraw my name from the registry at any time, upon written request sent by electronic or US Mail to: Sarah Ziegler, Executive Director, The National MHE Research Registry, 149-34 16th Road, Whitestone, NY 11357, email: sarahziegler@mheresearchfoundation.org

If this form is being submitted by someone other than the registrant (i.e., parent or guardian of a minor child) Please indicate your relationship to this registrant:

Registrants interest in research participation: Yes No

Print name:

Signature: _____

Date:

Each form Sarah Ziegler will assign an ID number to # _____

This PDF file may not be linked or attached to any website without written consent being obtained from Sarah Ziegler.