



www.mheresearchfoundation.org

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**MHE RESEARCH FOUNDATION / THE NATIONAL MHE RESEARCH
REGISTRY
CERTIFICATE OF COOPERATION**

The MHE Research Foundation will receive a copy of all IRB project paper before it is submitted for review by the Human Subjects Committee.

When the project is accepted by the Board of Director, the researcher will agree to the following conditions:

1. The researcher will not release any personal identification information about anyone who is participating in their research as a result of their registration in The National MHE Research Registry.
2. The researcher will not distribute any blood, tissue, cell lines, or any patient medical information derived from Registry families to any other investigator if they are accompanied by any personal identification information. If a researcher does wish to distribute such samples with personal identification information, neither the samples nor information may be sent until the recipient researcher has obtained informed consent from each individual involved and the MHE Research Foundation is notified of request.
3. The researcher will provide The MHE Research Foundation and its National MHE Research Registry with a summary, in lay language, of the progress of the project at least once every 12 months. This information will be used to inform the registrants of The National MHE Registry of the research activities currently ongoing. This information will be put up on the MHE Research Foundations website and may be published as part of informational materials. If the researcher feels the information is confidential or contains pulmonary results and does not wish to make it public at that time, their wishes will be honored.

4. The Research Foundation and website www.mheresearchfoundation.org and The National MHE Research Registry will be acknowledged in any publication or presentation of data derived from our member participation.

5. The Researcher will agree, if he/she collaborates with another researcher on this project now or in the future they will inform the collaborators about the MHE Research Foundation participation in this project and will notify the MHE Research Foundation of the collaboration.

I, WIM WUYTS (principal investigator) agree to comply with the above conditions regarding any research which utilizes patients which were identified due to their membership in The National MHE Research Registry of the MHE Research Foundation. I also certify that all associate investigators will honor this agreement.

Principal investigator

Signature: [Signature]

Date: 14 dec 2006

Witness: _____

Date: _____

All submissions must be sent in quadruplicate to:
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