

Database

Information and consent notice

Dear patients and parents,

In the context of the neuromuscular disease which affects you or your child, your physician envisages an evaluation of your motor capabilities by a test which measures motor function (MFM).

The transmission of the results of this MFM to a database will make it possible for us to better understand the functional effects of neuromuscular diseases and to appreciate the usefulness of this test for each disease. This database has been developed by the genetics laboratory of Professor Mireille Claustres at Montpellier and is coordinated by Dr. Carole Berard of the Hospices civils de Lyon (HCL). Its production has been financed by AFM (Association Francaise contre les Myopathies).

The database includes clinical information (diagnosis, medical history, severity of the muscular effects), as well as your present, past and future results on the MFM. Analysis of the scores will help us gain a better understanding of the progression of your disease.

In the context of this database in which your physician and your physical therapist have suggested your participation, a computerized analysis of your personal data (or that of your child) will be developed. Medical data which concern you (or your child) may be transmitted to persons or associations for scientific study after verification and approval by the pilot committee * of the MFM. This data will be identified by a code number, the first three letters of your family name and the first two letters of your given name (or those of your child).

In conformity with the dispositions of the (French?) law relative to informatics, data files and liberties, you have the right of access and rectification. You also have the right to oppose transmission of this data without effect on the treatment that you (or your child) is currently receiving.

You may access the ensemble of data which concern you in application of the provisions of article L 1111-7 of the Public Health Code through your physician or any physician of your choice.

For the MFM Study Group and the MM Pilot committee,
Dr. Carole Berard

*The Pilot Committee for the MFM includes: two physicians from the Hospices Civils de Lyon, the Directors of the Scientific Council and Medical Actions Departments of AFM, the Director of the Institut de Myologie, the curator of the database, a representative of the genetics laboratory of Montpellier, two physicians from pluridisciplinary consultations for children and adults, two elected physicians and two physical therapists elected from the users of the MFM study group.



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Date:.....

I agree that the medical records/data which concern me (or my child) which are collected during the MFM testing session may be used in the context of computerized analysis for the MFM database. I have been informed that the data collected will remain strictly confidential and they may only be consulted by scientists or physicians duly appointed by the MFM Pilot Committee.

Family name and given name of the person (adult or child) to be tested:

..... Signature

Family name and given name of the legal representative for the child (mother, father, legal guardian)

..... Signature:

Family name and given name of third party of the legal representative is not present:

..... Signature:

Title:..... Signature:

Family name and given name of the physician who prescribed the MFM:

..... Signature :