

**The University of New Mexico Health Sciences Center
Consent to be Contacted for Future Research**

What is the purpose of this consent? The doctors in the Neurology Clinic at UNMHSC are doing research that is designed to lead to better treatments and understanding for the types of medical problems experienced people with oculopharyngeal muscular dystrophy (OPMD). They want to know if you wish to learn more about their research studies or if you may wish to participate in any of the studies that may be appropriate for individuals with OPMD. By signing this form, you will allow qualified professional people on the staff in this clinic to contact you in the future to ask if you want to participate in any studies. You have no obligation to actually participate in any study.

What happens if I sign this form? If you sign this form, you are giving consent for information to be taken from your UNM medical records if available. This list includes information about your diagnosis, your name, date of birth, gender and contact information. This information will be kept indefinitely, unless you withdraw your permission. If a study on your condition needs subjects, you may be contacted to ask if you want to participate. You do not have to participate. You may withdraw permission to be contacted at any time by contacting the research coordinator, nurse, or physician.

What happens if I do not sign this form? Declining to participate will have no influence on your present or future status as a patient in this clinic. You will receive the same care as any other patient seen in this clinic. There will be no penalty or loss of benefits to which you are otherwise entitled.

Are there any risks to my signing this form? Participation in research may involve some loss of privacy. However, your records will be handled as confidentially as possible. Access will be limited to the data manager and the doctor organizing the study and will require a password. No information will be used for research without additional permission. Your contact information will not be shared with anyone outside this clinic.

Are there any financial considerations? There will be no cost or payment to you if you sign this form.

What if I decide later that I do not want to be included in this study? If at any time in the future you would like us to withdraw your information from this registry, please contact us at 505-272-3194. At your request we will securely delete any information you have provided us and unlist you from the registry. This registry is completely voluntary. If you decide you do not want to be in this registry, it will not impact your care at the UNM Neurology Clinic in any way.

What do I do if I have questions, now or later? If you have questions now, you should ask the person obtaining your consent. If you have questions in the future, you may contact Dr. Krzesniak-Swinarska and/or his/her research coordinator at 505-272-3342.

If you have any questions or concerns about your rights as a volunteer in this research, contact staff in the University of New Mexico Health Sciences (UNMHSC) Human Research Review Committee (HRRC) between the business hours of 8AM and 5PM, Mountain Standard Time (MST), Monday-Friday at 505-272-1129.

**HIPAA AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR PROTECTED HEALTH
INFORMATION (PHI).**

As part of this study, we will be collecting health information about you and sharing it with others. This information is “protected” because it is identifiable or “linked” to you.

Protected Health Information (PHI)

By signing this Consent Document, as described in this consent form, you are allowing the investigators and other authorized personnel to use your protected health information for the purposes of this study. This information includes your name, contact information, diagnosis of disease, and whether or not you have had genetic testing completed to confirm the diagnosis.

In addition to researchers and staff at UNMHS and other groups listed in this form, there is a chance that your health information may be shared (re-disclosed) outside of the research study and no longer be protected by federal privacy laws. Examples of this include health oversight activities and public health measures, safety, monitors, other sites in the study, companies that sponsor this study, government agencies such as Food and Drug Administration (FDA).

Right to Withdraw Your Authorization

Your authorization for the use and disclosure of your health information for this study shall not expire unless you cancel this authorization. This is because the information used and created during the study may be analyzed for many years and it is not possible to know when this will be complete. Your health information will be used or disclosed as long as it is needed for this study. However, you may withdraw your authorization at any time provided you notify the UNM investigators in writing. To do this, please send letter notifying them of your withdrawal to:

Dr. Monika Krzesniak-Swinarska
MSC 10 5620
1 University of New Mexico
Albuquerque New Mexico 87131

Please be aware that the research team will not be required to destroy or retrieve any of your health information that has already been used or shared before the date that your withdrawal is received.

The researchers agree to only share your health information with the people listed in this document. Should your health information be released to anyone that is not regulated by the privacy law, your health information may be shared with others without your permission; however, the use of your health information would still be regulated by applicable federal and state laws. You may not be allowed to participate in the research study if you do not sign this form. If you decide not to sign this form it will not affect you:

- Current or future healthcare at the University of New Mexico;
- Current or future payments to the University of New Mexico;
- Ability to enroll in any health plans (if applicable); or
- Eligibility for benefits (if applicable).

After signing the form, you can change your mind and NOT let the researcher(s) collect or release your information (revoke the Authorization). If you revoke the authorization:

- You will send a written letter to MSC 10 5620, 1 University of New Mexico, Albuquerque New Mexico, 87131 to inform Dr Monika Krzesniak-Swinarska of your decision.
- Researchers may use and release your information already collected for her research study.

If you have not already received a copy of the Privacy Notice, you may request one. If you have any questions about your privacy rights, you should contact the University of New Mexico Health Sciences Privacy Officer between the business hours of 8am and 5pm Mountain Standard Time, Monday-Friday at (505) 272-1493.

By submitting your information in this registration form you are providing consent to be part of this registry which includes permission to contact you about research studies for which you may qualify. By providing consent you are under no obligation to participate in future studies. If at any time you wish to no longer have your information included in this study, you can contact our study team at 505-272-3342 or the Neurology Clinic at 505-272-3160.