



THE UNIVERSITY OF NEW MEXICO
HEALTH SCIENCES CENTER

Department of Neurology
MSC10 5620
1 University of New Mexico
Albuquerque, NM 87131-0001
Phone: (505) 272-3342
Fax: (505) 272-6692

Dear Registry Applicant,

Thank you for your interest in the **Oculopharyngeal Muscular Dystrophy Registry**. The Registry was established by the University of New Mexico to link researchers who are studying this rare disease. At this time, we are registering individuals with OPMD, as well as unaffected family members. Therefore, we invite you to encourage other family members to apply.

In this packet, you will find the forms necessary to apply to the OPMD Registry. To apply, please complete the following steps:

1. There are two identical *Consent Forms*. Please read and sign one of these forms. The **entire copy** of the signed *Consent Form* must be returned to us in order for us to review your information. The second *Consent Form* is for your files.
2. Please complete the *OPMD Registry Questionnaire* and return it to us.
3. Please complete the *Authorization for Release of Medical Information* form and return it to us. This form gives us your permission to communicate directly with your physician and to request your medical records.

For your convenience, we have enclosed a postage paid envelope (if you do not have one, please call or email us). Please place all signed forms into this envelope and return the packet to us. Once all of your information is received, it will be reviewed carefully. You may receive a phone call or letter from one of the study coordinators to clarify information.

If you have any questions as you complete this process, please do not hesitate to contact us:

OPMD Registry
Sarah Youssof, MD
MSC 10-5620
1 University of New Mexico
Albuquerque, New Mexico 87131
Phone: (505) 272-6354 Toll-Free: (855) 676-3721
Fax: (505) 272-6692
Email: opmd@salud.unm.edu
Website: <http://som.unm.edu/programs/opmd>

Please do not send personal health information by email, as it is not a secure way to send sensitive information. We suggest using email to ask questions about the study, to set up a phone appointment or in-person appointment, or to request a mailed registry enrollment packet.

We sincerely appreciate your willingness to participate in this important endeavor!

Sincerely,



Sarah Youssof, MD
Principal Investigator