Terms and Conditions for Investigators

The Global Dystonia Registry (GDR) is a self-reported registry of persons affected by all forms of dystonia. The GDR is owned and operated by the GDR Steering Committee. This registry compliments the current scope of research for the Dystonia Coalition, a National Institutes of Health supported clinical research effort.

TERMS AND CONDITIONS OF GRANTING ACCESS

1. Investigator agrees to acknowledge the GDR in any publications and public presentations that result from or utilize any findings from the use of the GDR.

2. Investigator agrees to provide an advance copy of any publication to the GDR Secretary at the address provided when approval is granted.

3. Investigator will comply with all applicable laws and regulations.

4. Investigator assures that IRB approval has been obtained and investigator will comply with all IRB and HIPPA requirements.

5. Investigator is responsible for all study expenses incurred while utilizing the GDR.

6. Investigator agrees to notify the GDR Secretary should they change institutions.

7. Investigator agrees to hold harmless the GDR Steering Committee, GDR Scientific Committee and all supporting organizations (officers, directors, employees and affiliates) from any and all liability, including any and all direct, indirect, incidental, special, consequential or exemplary damages, and any and all costs and/or expenses, direct or indirect, resulting from the research conducted through utilizing data from the registry.

8. Investigator will notify the GDR Secretary should the approved study be discontinued.

Please e-mail the completed form and all requested information to:
coordinator@globaldystoniaregistry.org

Request Form

To request access to the GDR, investigators are required to provide the following information that will be presented to the GDR Science Committee for review.

1. A summary of the study, not to exceed two pages, that includes the title of the study, major objectives of the study, the hypothesis of the study, study aims, the inclusion and exclusion data criteria, and experimental and analytical methods.
2. The IRB approval from the investigator's institution.
3. Informed consent, if applicable.
4. Biosketch of the Principle Investigator (NIH format).
5. Description of financial support for the study.
6. IRB approved advertisement for distribution use including the criteria for patients.

_____

Project Title

_____

Investigators Name

_____

Institution

_____

Mailing address

_____

City State Zip/Postal Code Country

_____

Phone Number Alternative Phone Number Fax Number

_____

Email

_____

Date