

## International Schwannomatosis Database Letter of Intent

A major obstacle to the advancement of translational and clinical research is locating enough patients to collect meaningful data. In order to support the development and successful execution of research studies, we have created the **International Schwannomatosis Database (ISD)**. The mission of the database is to collect and organize information on all schwannomatosis patients, such as their symptoms, and their management and medication, and whether biological specimens are available for research. The database houses information about individuals who consent to be enrolled that can assist in identifying the number and location of appropriate candidates for a particular study, all of whom have agreed to be contacted about participating in future studies.

The ISD allows clinicians as well as basic science and translational research to identify patients eligible for various research studies, facilitating collaboration among researchers and institutions. The ISD model is set up so those enrolling patients are under control of how their data is used. Researchers proposing studies in the field of schwannomatosis can submit a letter of intent to the ISD Steering Committee describing their proposed research and inquire about the number of patients meeting basic eligibility criteria for their research study.

The ISD Central Study Office performs Quality Assurance checks of all data in the ISD. The central study office keeps the database current with the clinical criteria for schwannomatosis diagnoses.

In order to apply to use data maintained in the ISD, please submit a Letter of Intent (LOI) to the ISD Steering Committee for review. The LOI should provide a **ONE PAGE** overview of the proposed research.

### **The LOI should contain the following information:**

1. A brief summary of the research project
2. Description of patient population that will be recruited for this study
3. A list of specific aims and brief description of research design
4. Significance of the proposed project in advancing the field of schwannomatosis research
5. Complete contact information for the PI
  - a. Phone numbers, address, fax number, email.

Please include the following attachments to your LOI:

1. Biographical sketch of PI (NIH format preferred)

Please submit the LOI and Biographical sketch to the ISD Steering Committee for review by emailing your documents to:

Shawanna Jackson  
ISD Project Manager  
Email: [isdteam2015@icloud.com](mailto:isdteam2015@icloud.com)

You will receive an email confirmation that your LOI has been received. Review of the LOI will occur within 1 week of submission. You will receive a response by email. If your LOI is approved, you will receive preliminary information from the ISD on the patient population of interest for your study. The ISD will also facilitate connections between you and the PIs at the sites where these patients are enrolled.