



For internal use: Date application received _____

KBG Foundation Natural History Study Data Use Agreement

This application and agreement is for the express purpose of authorizing access to data maintained by the KBG Foundation Natural History Study (“Study”) and online patient registry, IRB # NB200071. Use of the data requires adherence to regulatory guidelines to protect the privacy of the patients, including, where applicable, Health Insurance Portability and Accountability Act (HIPAA) and the General Data Protection Regulation (GDPR) (EU) . The KBG Foundation **Statement of Informed Consent** becomes part of this agreement, as the researcher agrees to read and honor it.

For the purposes of this agreement, “requested data” refers to de-identified information obtained through the KBG Foundation Natural History Study hosted on the Matrix platform.

Data Request Application:

Applicant (Principal Investigator/Research Scientist requesting data)

- **Name:** _____
- **Email:** _____
- **Phone:** _____

Applicant’s organization: _____

Principal Investigator’s CV or Biosketch (Attach)

IRB/IACUC Approval # _____



Funding source for the research the requested data will support:

Date information is desired: _____

Describe the specific purpose for which the requested data will be used:

Include a brief lay summary of the hypothesis and nature of the Study for which you are requesting data. Include endpoints. (May attach additional page if needed)

Please itemize the survey(s) data you are requesting. The KBG Foundation Natural History Study is composed of surveys according to body systems, e.g. Neurological, Skeletal, Behavioral. Upon request, we can provide a full list of surveys available through the Study registry, which is maintained by Matrix.

Data Use Agreement

By signing this application, I certify that:

- I will receive the use of de-identified data requested of the KBG Foundation to the fullest extent the Foundation is capable of honoring my request.
- I understand the data will not include names of individuals or other information, such as dates of birth, that could reveal the identity of an individual patient.
- I will not use or allow to be used the data provided for any purpose other than that specifically set forth in this application. I will not alter or misrepresent data



provided by the KBG Foundation. The data may not be linked to any other database without the written permission from the Foundation.

- No attempt will be made to use the data to discover personal identifiers, and the data shall be treated as strictly confidential.
- All results of my research shall be restricted to aggregate data.
- No statement may be made indicating or suggesting that interpretations drawn from KBG Foundation Registry data are those of the KBG Foundation Registry and Natural History Study.
- If the provided data are used for research, a pre-print report of my research shall be furnished to KBG Foundation .
- The KBG Foundation will be credited in any research published as the source in regards to the data obtained through this request. I have reviewed the **Statement of Informed Consent form** required of Study Participants and understand and agree to uphold all expectations of privacy. I further acknowledge that the means to contact a specific person if desired is only possible through the KBG Foundation, which serves as the steward of the data.
- Co-authorship recognition may be requested based on any further involvement by the Foundation, its members or Participants.
- The information supplied on this application and all attachments is complete and correct, to the best of my knowledge.
- I acknowledge that upon approval, I will be granted use of data only, and that I do not own the data.

Applicant Signature: _____

Date: _____

**The KBG Foundation will make our best effort to fulfill the data request by the date desired, however depending on the nature, timing, and extent of the request, the final date for completing*



and sending the requested data to you may be subject to change and will be communicated with you via email.