

International Gaucher Alliance

Fair Processing Notice



1. Scope

This notice applies to all data subjects whose data is processed by International Gaucher Alliance.

2. Responsibilities

The Governance Committee (“GC”) is responsible for ensuring that all potential data subjects have sight of this notice prior to the collection and/or processing of their personal data by International Gaucher Alliance.

All employees of International Gaucher Alliance who interact with data subjects are also required to ensure that this notice is brought to the attention of all data subjects, securing their consent for the processing of their personal data.

3. Fair Processing Notice

International Gaucher Alliance will use the personal data collected from you for the following purposes:

Members: sending information; raising awareness; events. Humanitarian Aid: sharing patient information to advocate on your behalf

You hereby confirm that you are consenting to International Gaucher Alliance’s use of your personal data for the aforementioned purposes(s) and are granting International Gaucher Alliance permission to carry out those actions and/activities.

You may withdraw your consent at any time by reading our Right to Withdraw Consent Procedure 92017-1

4. What is Personal Data?

The EU’s General Data Protection Regulation (“GDPR”) defines “personal data” as:

“any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person”.

The GDPR classifies certain data as belonging to “special categories”, as follows:

- Racial origin;
- Ethnic origin;
- Political opinions;
- Religious beliefs;
- Membership to a trade-union;
- Genetic data;
- Biometric data;
- Health data;
- Data concerning a natural person's sex life;
- Sexual orientation; and
- Other.

The GDPR requires that consent is provided by the data subject for all types of personal data, including those pertaining to the special categories set out above and otherwise. Consent must be explicitly provided.

When International Gaucher Alliance requests sensitive data from data subjects, it is required to confirm why the information is required and how it will be used.

5. Why does International Gaucher Alliance need to collect and store personal data?

International Gaucher Alliance is committed to ensuring that all personal information collected and processed is appropriate for the stated purpose(s) and shall not constitute an invasion of your privacy. We may share your personal data with third party service providers who are contracted by us and we shall ensure that they will hold your personal data securely and shall use it only in order to fulfill the service for which they are contracted. When there is no longer a service need, or the contract comes to an end, the third party will dispose of all personal data according to our procedures. We will never share your personal data with third parties until we have received your consent, unless we are required do so by law.

6. How International Gaucher Alliance uses your information

International Gaucher Alliance will process your data (i.e. collect, store and use) according to the requirements of the GDPR at all times and shall endeavor to keep your personal data up-to-date, ensuring its accuracy and will not keep it for longer than it is required. In some situations, there are set legal requirements for the length of time that International Gaucher Alliance will retain your personal data but usually International Gaucher Alliance will use its discretion, ensuring that personal data is not kept outside of our usual business requirements.

We shall never be intrusive or invasive of your personal privacy and shall not ask you to provide data that is irrelevant or unnecessary and we will enact strict measures and processes to ensure that the risk of unauthorised access or disclosure of your personal data is minimised as much as possible.

We will only use your personal data for the following purposes:

Members: receive news; raising awareness; information about events; information on research projects; take part in research projects. Humanitarian Aid: to advocate on your behalf.

7. Document owner

The Data processor is the owner of this policy document and must ensure that it is periodically reviewed according to the review requirements contained herein.

The latest version of this policy document dated 01/05/2018 is available to all employees of International Gaucher Alliance on the corporate intranet.

This policy document was approved by International Gaucher Alliance's Board of Directors and is issued by the Chief Executive Officer ("CEO") on a version-controlled basis.

Name of CEO: Tanya Collin-Histed

Date: 01/05/2018

Change history record

Issue	Description of Change	Approval	Date of Issue
1	Change of name from EGA to IGA	N/A	16/10/18
2	N/A	N/A	N/A
3	N/A	N/A	N/A